

Quality of Life According to The Viewpoint of Hiv/Aids Bearing People: Future Perspectives in Educational Practices

Qualidade de Vida sob a Ótica de Portadores de Hiv/Aids: Perspectivas Futuras nas Práticas Educativas

Calidad de Vida Bajo la Óptica de Portadores de Vih/Sida: Perspectivas Futuras en las Prácticas Educativas

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ABSTRACT

Objective: The study's purpose has been to describe the life quality of HIV/AIDS bearing people through their own perspective. **Methods:** It is a descriptive study with a qualitative approach. This research counted with the participation of 21 individuals enrolled in a municipality from the Paraná State. Data were analyzed by the content analysis method. **Results:** Two central points were identified, as follows: 1. Unveiling the knowledge about HIV/AIDS. The understanding vis-à-vis contamination, condom use, and virus detection time was considered satisfactory; some participants were unaware of gestational transmission and also neglected the use of condoms; 2. Recognizing the life quality determinants after the diagnosis. The participants have pointed out discomforts at the beginning of treatment, changes in routine, social and financial aspects, as well as discontentment in doing both physical and sexual activities. **Conclusion:** The individuals' perception concerning their quality of life are influenced by the biopsychosocial alterations and aggravating factors in their way of life, so it is important to improve the health professional planning towards the educational practices of those individuals.

Descriptors: Quality Of Life, Acquired Immunodeficiency Syndrome, Comprehensive Health Care.

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RESUMO

Objetivo: Descrever a percepção da qualidade de vida de indivíduos com HIV/AIDS. **Método:** Estudo descritivo com abordagem qualitativa. Participaram 21 indivíduos cadastrados em um município no Paraná. Os dados foram analisados pelo método da análise de conteúdo. **Resultados:** Identificou-se dois eixos: 1. Desvelando o conhecimento sobre HIV/AIDS. O conhecimento foi satisfatório sobre contágio, uso do preservativo e tempo de detecção do vírus; alguns desconheciam sobre transmissão gestacional e ignoravam a utilização do preservativo; 2. Reconhecendo os determinantes na qualidade de vida após o diagnóstico. Apontou desconfortos no início do tratamento, alterações na rotina, nos aspectos sociais, financeiros, e insatisfação com a prática de atividade física e sexual. **Conclusão:** As percepções da qualidade de vida destes indivíduos são influenciadas pelas alterações e agravantes biopsicossociais no modo de viver, por isso é importante o planejamento dos profissionais de saúde nas práticas educativas destes indivíduos.

Descritores: Qualidade de vida, Síndrome da imunodeficiência adquirida, Atenção integral a saúde.

RESUMEN

Objetivo: Describir la percepción de la calidad de vida de los individuos con VIH/SIDA. **Método:** Estudio descriptivo con enfoque cualitativo. Participaron 21 individuos registrados en un municipio de Paraná. Los datos fueron analizados por el método del análisis de contenido. **Resultados:** Se identificaron dos ejes: 1. Desvelando el conocimiento sobre VIH/ SIDA. El conocimiento fue satisfactorio sobre contagio, uso del preservativo y tiempo de detección del virus; algunos desconocían sobre transmisión gestacional e ignoraban la utilización del preservativo; 2. Reconociendo los determinantes en la calidad de vida después del diagnóstico. Se señalaron molestias al inicio del tratamiento, alteraciones en la rutina, en los aspectos sociales, financieros, e insatisfacción con la práctica de actividad física y sexual. **Conclusión:** Las percepciones de la calidad de vida de estos individuos son influenciadas por las alteraciones y agravantes biopsicosociales en el modo de vivir, por eso es importante la planificación de los profesionales de salud en las prácticas educativas de estos individuos.

Descriptores: Calidad de vida, Síndrome de inmunodeficiencia adquirida, Atención integral de salud.

INTRODUCTION

Human Immunodeficiency Virus (HIV) is a virus that attacks mainly the CD4+ T lymphocytes that are cells responsible for the organism defense. The contamination is mainly caused by unprotected sex, sharing contaminated syringes, during pregnancy and breastfeeding.¹

It is estimated that 36.7 million people are living with HIV worldwide.² In Brazil, 194,217 cases of HIV infection were reported in Brazil in the Sistema de Informações de Agravos de Notificação (SINAN) [Information System of Notification Aggravations] from 2007 to June 2017. Data indicate that, from 1980 to June 2017, 882,810 cases of Acquired Immunodeficiency Syndrome (AIDS) were identified in the country, characterizing an important challenge for the health sector, with an annual average of 40,000 new cases of AIDS in the last five years. From 2000 to June 2017, a total of 673,634 cases of AIDS were registered in the country, and 316,088 deaths were reported in the last three decades, with HIV/AIDS being the primary cause.³

Because of Antiretroviral Therapy (ART), HIV/AIDS has transformed from an acute and fatal disease to a chronic disease that has led to changes in the lives of infected individuals, increasing survival and adding new biopsychosocial challenges.⁴ Adherence to treatment has made it possible to increase survival, but it is recognized that not always a longer life is accompanied by quality.⁵

Quality of life is related to the individual's perception of their position in life, in relation to their goals, expectations, standards, and concerns, as well as the context of the culture and value system in which they live. Moreover, the fact that a person is infected with a chronic and incurable disease, and also living with the stigma and adverse effects that the drug therapy provides, especially in the first year of treatment,⁶ might cause negative repercussions for their quality of life, besides favoring the state of social, economic, physical and emotional vulnerability of this individual.

Based on the perception of these individuals and facing the challenges experienced in the practice of health services, it is evident the pertinent gap to effective strategies of promotion of the quality of life developed by the Nurses of Basic Attention. In this context, the research question is: What is the perception regarding the quality of life according to HIV/AIDS bearing people? Given the aforementioned, this study aimed to describe the life quality of HIV/AIDS bearing people through their own perspective.

METHODS

This is a descriptive study with a qualitative approach, which was performed with 21 (twenty-one) individuals bearing HIV/AIDS and being followed-up by the Sistema Integrado de Atendimento em Saúde (SINAS) [Integrated Health Care System] of a municipality in the Northwest region of the Paraná State.

The participants of the study were selected from the following eligibility criteria: individuals bearing HIV/AIDS, being followed-up by the SINAS and being over 18 years old.

Participants were invited to answer the following questions: What do you know about HIV/AIDS?; What factors influence your quality of life after the diagnosis?

Data collection took place over the period from August to September 2016, through an individual interview, recorded in audio format, with an average duration of 40 minutes, in a reserved room of the SINAS. Data collection occurred until the moment that new elements to subsidize the desired theorization (or possible in those circumstances) were no longer understood.

The interviews were transcribed in full and analyzed according to the methodological framework of content analysis, thematic modality,⁷ followed by the phases of pre-analysis, material exploration, results processing and interpretation. There were several readings for the corpus arrangement, mapping of common themes and systematic

reduction, which resulted in thematic axes, which will be illustrated by excerpts from the participants' speeches.

Ethical criteria involving human research were respected, according to the Resolution No. 466/12 from the National Health Council of the Ministry of Health, which refers to research involving human beings. Participants were clarified about the study objectives and signed the Informed Consent Form (ICF). This study was approved by the Research Ethics Committee with Human Beings from the Universidade Estadual de Maringá (UEM) under the Legal Opinion No. 1,714,951, in the year 2016. In order to guarantee the anonymity of the study participants, the subjects were identified with the notation "G" of "guest", followed by an Arabic number, defined according to the chronological order of the data collection.

Among the 21 participants, 13 were female and 11 were self-declared white. The average age was 51 years old (minimum 28 and maximum 71 years old), 10 had companions, 5 (five) were single, 1 (one) divorced and the other 5 (five) widowers. Low schooling was prevalent among the participants, 1 (one) was illiterate and 12 had only elementary education.

The majority reported following a religion (13 Catholics, 6 (six) Evangelicals and 1 (one) Spiritists), and more than half (13) had their own house, with an average of three people in the family. In relation to monthly family income, 10 reported income from three to five minimum wages, 9 (nine) received up to two wages, 1 (one) with income from five to ten wages, and 1 (one) had no income.

The results of the qualitative analysis included two themes: Unveiling the knowledge about HIV/AIDS and Recognizing the life quality determinants after the diagnosis.

Unveiling the knowledge about HIV/AIDS

In this category, it is perceived that when questioned about the knowledge concerning the disease, individuals soon refer to the forms of infection:

[...] What I do know is that it is possible to be infected with HIV by having unprotected sex or by sharing syringes [...] (G1).

[...] it is not possible to donate blood because the virus can be transmitted by blood transfusion [...] (G8).

[...] I also know that the mother can transmit the virus to the baby, during pregnancy, during normal labor and breastfeeding [...] (G6).

and to risk behavior:

[...] if I had acted differently, I would not have been infected [...] (G14).

[...] before we did not think about what could happen, now I know that if I had been careful, I would not get AIDS [...] (G15).

Nevertheless, one of the interviewees was unaware of the transmission source:

I think the baby can be infected by the virus, when the mother shares the dishes and tableware with him/her [...] (G7).

Therefore, the use of condoms is emphasized as a protection priority, even if they have sex intercourse with other individuals who are also HIV positive:

[...] I learned that condoms should be used in all sexual interactions, even when partners are seropositive [...] (G2).

[...] I know that protection happens with the use of condoms, even with my old partner [...] (G5).

However, some of the participants mentioned that condom use is not necessary when the couple has HIV/AIDS, as shown in the following statements:

[...] I do not think there is a need for condom use if both have HIV [...] (G3).

[...] I do not think you need to use condoms if your partner also has AIDS [...] (G12).

Regarding the time that the AIDS virus takes to be detected in the body, the individuals in general demonstrated some doubt or even did not know to answer:

I think the virus can be detected after two months after infection. (G4).

[...] I do not know how long [...] (G6).

[...] I know that it takes time to appear in the examinations [...] (G10).

Recognizing the life quality determinants after the diagnosis

A limitation pointed out by the participants with regards to the daily practices were the discomforts caused by ART at the beginning of treatment:

Nowadays, I do not feel anything else, just at the beginning of the treatment, I had nightmares, diarrhea and a lot of headaches [...] (G13).

At first, when I heard about the diagnosis and started with the AIDS cocktail, I was very ill, I did not adapt to the medication [...] (G9).

Currently, I live better, I am more accustomed to everything, but when I started the treatment, it was difficult, because of the side effects of the remedies. (G5).

Nonetheless, some of the individuals reported not perceiving limitations in their routine and sexual life:

[...] my quality of life has not changed much; I live a normal life taking the medicines [...] (G21).

I do not feel that HIV today brings me limitations because I continue with my daily activities normally. (G9).

[...] I'm still working normally, I had problems at first, but now everything is fine [...] (G11).

[...] my sex life has not changed, my boyfriend knows I have HIV, but he does not like to use condoms, we live a normal life, as if the virus did not exist, he did not get it yet but does the tests every month [...] (G20).

[...] I have no problems with my partner, we use condoms without any problem [...] (G18).

[...] I go out, I go to parties and dances, not as much as I used to, but I have a lot of fun [...] (G4).

[...] now, I do not feel jeopardized in my life just about anything [...] (G8).

However, they emphasize the need for confidentiality regarding the diagnosis, in order to maintain those relationships:

[...] people are very discriminatory, I have friends who do not know that I have HIV because I know that if I tell them, they will not even come to my house to have a coffee [...] (G11).

I do not like to tell you that I have the disease, to protect my children from prejudice, to keep people away from them because of me [...] (G13).

I hid from my family that I had HIV for ten years, they only found out when I got sick. (G16).

I am afraid to tell others that I have HIV, afraid they will point me out and tell others, make fun of me [...] (G17).

[...] my son discovered that I was seropositive a few months ago, I was afraid that my daughter-in-law or my son would remove the grandchildren from me [...] (G19).

Others were dissatisfied in doing both physical and sexual activities:

Nowadays, I am somewhat sedentary, I only do house work. (G2).

[...] I used to play soccer during the weekend, now I cannot do nothing else [...] (G10).

[...] I cannot enjoy life as before, what has changed the most is the sex that is no longer the same [...] (G12).

[...] getting excited has been a problem because when we think about having a relationship it is a tense atmosphere, I am afraid of transmitting it to her [...] (G12).

Moreover, they have underlined their concern related to financial aspects:

[...] most of the time I am worried about the bills, afraid of shortage of money, but I think it is like this for every human being, not only for those who have HIV [...] (G13).

The female gender was more prevalent among HIV/AIDS patients participating in the study, which corroborates the profile of the epidemic in recent years, which was previously associated with specific groups, and after becoming a public health problem, presents new groups vulnerable to infection.⁸

The low educational level is a factor that negatively impacts the quality of life,⁹ because it influences the level of knowledge and hinders access to better working and health conditions. Furthermore, when combined with the poor quality of health services, they contribute to increasing the vulnerability of these individuals.^{8,9}

Considering the transmission of the virus by sources other than the sexual one, satisfactory knowledge of the interviewees was observed, although one of them (G7), still presents doubt about the transmission during the gestation. This result was changed after the diagnosis, whose individuals reported having more information in regards to the disease, diagnosis, treatment and living conditions. Thus, the importance of the service to invest in actions that favor individuals to know about the diagnosis, to identify from their specificities the factors that can influence the quality of life and finally to plan, jointly, professional and patient, the actions that to overcome new challenges.

It is also worth noting that the health education process

implemented in SINAS may have helped respondents' answers both to the forms of contamination and to the use of condoms, which recognized their importance as an effective way against HIV infection, a result that corroborates with other research.^{9,10} Yet, the G3 response underlines gaps in knowledge about condom use among seropositive partners, information that can subsidize discussion to improve the actions developed by the multiprofessional service team, especially in individual care.

It is observed that there is a lack of knowledge regarding the period of detection of the virus in the body, information commonly provided to the individual during counseling consultations prior to testing, as recommended by the protocol of the Brazilian Ministry of Health.¹ However, the need for information to be permanently discussed, with HIV/AIDS and the general population, and not just passed on, is now needed. Continuing education on HIV/AIDS reflects on the acquired knowledge, on the continuity of social life and on the adequate adherence to the treatment of all the information that permeates the state of health/illness, and consequently results in improving the quality of life.¹¹

The quality of life referred by the participants was determined by aspects related to the effects of treatment, routine, sexual life, social relations, physical activity practice, and the financial component.

The discomforts of ART at the beginning of treatment were referred to as negative determinants of quality of life, since they limit daily activities, according to the statements of G5, G9 and G13, since the quality of life of people living with HIV/AIDS can be influenced by adherence to ART, such as the absence of symptoms or the presence of undesirable effects of medication.¹¹

Faced with this, each adverse effect must be viewed with care and attention by the health professional, especially primary care, so that it is always an ally in coping with the disease.

Living with HIV/AIDS has repercussions in several domains of quality of life, requiring for its evaluation and intervention by the health professional, better knowledge and understanding of the different variables that negatively impact after the diagnosis. Although the participants reported non-recognition of routine changes with the disease, as represented in the statements of C9, C11, and C21, it was observed that for maintaining social relationships, keeping confidentiality about the diagnosis is then necessary. Therefore, the prejudice and stigma associated with AIDS are difficulties often encountered in trying to maintain normal life.¹²

In addition to prejudice, secrecy may also be related to the individual's association with the diagnosis of "terminal illness" or as a potential "death sentence" transmitter. Bearing this in mind, it is necessary to emphasize the importance of the multiprofessional support network to these individuals, in order to recognize the needs that

emerge from the diagnosis and that lead to the establishment of coping actions, considering that this is a chronic disease that entails numerous biopsychosocial consequences.¹³

Sexuality, on the other hand, is an aspect of life that is severely compromised by the impact of diagnosis, and by both emotional and social effects.¹³ Although most people living with HIV/AIDS face the fear of transmission to the partner and difficulty speaking on sexuality with health professionals, in some cases it was observed the maintenance of risk behaviors and denial of the disease, as indicated in the speech of G20. As a result, the nursing team plays an important role in the health team, and it is necessary to develop educational actions and interventions that promote the health and quality of life of people living with HIV/AIDS, including partners.

Another point that should also be considered in actions and educational interventions in the quality of life of people living with HIV/AIDS is the practice of physical activity, which when supervised can stimulate the immune system, increase disposition, self-esteem, stress relief, improvement of depression, control of comorbidities, among other health benefits,^{14,15} along with this the sexual relationship, which adds positively as part of personal satisfaction and partner.

Nevertheless, maintaining these practices can be a challenge for this population after the diagnosis, as shown in the G2, G10 and G12 lines, this can occur due to limiting reasons that the treatment itself imposes or even the way they experience the disease, accompanied by feelings like insecurity, fear, difficulties of establishing affective bonds and interferences in existing ones, also altering the standard of sexual life.^{16,17} So, in order to face these personal dissatisfactions and to motivate them of the positive additions that physical activity and the sexual relation can provide is an important task of health professionals.

Conclusively, when addressing the economic aspects, there was a certain apprehension in the speech of G13, which justifies a loss in the quality of life portrayed in the financial concerns that are probably related to the low income of the individuals who have the disease, which makes it difficult to pay bills on a day-to-day basis.¹⁷ Furthermore, one can consider the retirement of individuals from work and early retirement with low salary, since a study showed that when the individual stays in work activities, he presents a better quality of life, because work allows access to material conditions, the deviation of thought from negative issues of disease, the process of productive activity and the generation of the sense of usefulness.⁴

Hence, quality of life from the standpoint of HIV/AIDS can be a multidimensional concept that includes several questions about health conditions, lifestyle, personal satisfaction, social and sexual, financial, among others. It is conceptualized according to a system of values that change from person to person and represents the positive and/or negative sum of each person's feelings.¹⁸ And it is because of this character of vulnerability that these individuals

and society need public health policies that act on their sexual knowledge, attitudes and behaviors, from which health professionals, including nurses, can work with interventionist activities that motivate HIV/AIDS patients to take care of their living habits, reflecting a good quality of life.

The study had as limitation being related to a single SINAS, which assists a specific region of the Paraná State, thus provided a small number of participants. But, it was possible to recognize the relevance of the information obtained in the speeches, highlighting the continuity and professional appreciation in health education.

CONCLUSIONS

Overall, the perception regarding the quality of life according to the participants bearing HIV/AIDS was considered satisfactory. Although, it has been permeated by knowledge gaps, difficulties at the beginning of treatment with regards to side effects, the need for confidentiality concerning the diagnosis aiming to maintain social relations, concernment with financial issues, as well as discontentment in doing both physical and sexual activities.

Health professionals, particularly registered nurses, are qualified to provide health education. Nevertheless, it was observed a need for problem-solving strategies related to the knowledge, attitudes and sexual behaviors of HIV/AIDS bearing individuals, still to be included in care planning.

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