

ORIGINAL ARTICLE

QUALITY OF LIFE OF TRANSEXUAL WOMEN LIVING WITH HIV/AIDS*

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ABSTRACT

Objective: To understand the quality of life of transsexual women living with HIV/AIDS.

Methods: This was a qualitative, descriptive, exploratory study, carried out in 2017 with six transsexual women at a reference hospital for HIV/AIDS in Pernambuco, Brazil. The interviews were recorded and transcribed using the *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*, using the similitude analysis technique.

Results: The following classes emerged: "Vulnerability to HIV/AIDS and implications for coping"; and "HIV/AIDS treatment adherence and the programming context".

Final considerations: The condition of living with HIV/AIDS for transsexual women goes beyond the disease, involving intimate suffering in terms of social violence, denied human rights, and vulnerability, which limits their personal and social development and impacts the totality of human conditions to reach a high quality of life.

DESCRIPTORS: Nursing; Quality of life; HIV; Acquired Immunodeficiency Syndrome.


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QUALIDADE DE VIDA DE MULHERES TRANSEXUAIS COM HIV/AIDS

RESUMO

Objetivo: compreender a qualidade de vida de mulheres transexuais que vivem com HIV/AIDS.

Método: estudo qualitativo, descritivo, exploratório, realizado em 2017 com seis mulheres transexuais, em um hospital de referência para HIV/AIDS em Pernambuco, Brasil. Gravaram-se e se transcreveram as entrevistas com programa Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires, pela técnica da Análise de Similitude.

Resultados: obtiveram-se as classes: "Vulnerabilidade ao HIV/AIDS e as implicações para o enfrentamento"; "Adesão ao tratamento do HIV/AIDS e o contexto programático".

Considerações finais: considera-se que a condição de viver com o HIV/AIDS para as mulheres transexuais vai muito além da doença, envolve o sofrimento íntimo mediante a violência social, negação dos direitos humanos e vulnerabilidade, o que limita seu desenvolvimento pessoal e social e impacta no conjunto de condições humanas para o alcance da qualidade de vida.

DESCRIPTORIOS: Enfermagem; Qualidade de vida; HIV; Síndrome de Imunodeficiência Adquirida.

CALIDAD DE VIDA DE MUJERES TRANSEXUALES CON VIH/SIDA

RESUMEN:

Objetivo: Comprender la calidad de vida de mujeres transexuales portadoras de VIH/SIDA.

Métodos: Estudio cualitativo, descriptivo, exploratorio, realizado en 2017 con seis mujeres transexuales en hospital de referencia en VIH/SIDA de Pernambuco, Brasil. Se grabaron y transcribieron las entrevistas utilizando el programa Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires, aplicando la técnica de análisis de similitud.

Resultados: Se obtuvieron las clases: "Vulnerabilidad al VIH/SIDA e implicancias de su tratamiento"; "Adhesión al tratamiento del VIH/SIDA y el contexto programático".

Consideraciones finales: Se considera que, para las mujeres transexuales, ser portador de VIH/SIDA va mucho más allá de la enfermedad, involucra al sufrimiento íntimo a través de la violencia social, denegación de los derechos humanos y vulnerabilidad, limitando ello el desarrollo personal y social, e impactando en el conjunto de condiciones humanas para el alcance de la calidad de vida.

DESCRIPTORES: Enfermería; Calidad de Vida; VIH; Síndrome de Inmunodeficiencia Adquirida.

INTRODUCTION

An estimated 25 million people in the world are transgender⁽¹⁾. The term transgender refers to people who experience their personal sense of gender (gender identity) as different from their biological sex and the characteristics associated with it since birth. Gender identity is considered the actual experience of who one is, and is not the same as sexual orientation, which refers to the person to which there is attraction⁽¹⁻²⁾. Transsexual women are "those that transformed themselves into women for themselves and for society, despite being raised to be men because of the genitals with which they were born"^(3:372-373).

Transsexual women are among the most marginalized people in the world, being denied social rights such as access to health care, education and employment, in addition to presenting an average life expectancy of 35 years⁽⁴⁾. Within the context of social vulnerability, it is estimated that these individuals are 49 times more likely to be living with the human immunodeficiency virus (HIV) and falling ill from acquired immunodeficiency syndrome(AIDS)⁽⁵⁾.

Social vulnerability proposes a wider understanding of social problems which previously focused only on income or the possession of material goods. The vulnerability of transsexual women to HIV/AIDS can be considered a global public health problem. This epidemic affects especially transsexual women who work as sex professionals, due to the context of marginalization, transphobic violence and extreme social violence⁽⁵⁾.

It is worth emphasizing that in Brazil, the introduction of antiretroviral therapy, in 1996, contributed to reducing death by AIDS and consequently to the disease's chronicity. HIV/AIDS became more prevalent among lower-income populations, in women outside of the country's capital cities⁽⁶⁾. The course of this epidemic has been more directed at heterosexual, homosexual, bisexual and transsexual females, which characterizes the "feminization of AIDS"⁽⁷⁾.

In civil society, the condition of living with a chronic disease with heavy social stigma, anchored to the idea of blaming the lack of support from a social network, difficulties in accessing health care, especially to empower individuals to cope with social stigma, treatment and prognosis represent barriers to care that improve quality of life⁽⁸⁾.

Based on these aspects, this study is relevant to understand the quality of life of transsexual women living with HIV/AIDS.

METHOD

This was a descriptive and exploratory qualitative study. The study was carried out at a reference hospital for persons living with HIV/AIDS, located in the metropolitan region of Recife, in the state of Pernambuco, Brazil, with six young transsexual women. "Young" was defined according to the Ministry of Health and the World Health Organization (WHO) definition, between 15 and 24 years old⁽⁹⁾.

A convenience sample was used with youths older than 18 years old who self-identified as female, who had not undergone male-to-female transsexual surgery, heterosexual, HIV positive or receiving AIDS treatment, and who had casual sex partners. Individuals with hearing impairments were excluded, as the researcher did not know Brazilian Sign Language (Libras).

The subjects were approached by the multiprofessional health team, who were briefed on the objectives of the study and the data collection procedures. The professionals were then asked by the researchers to help recruit participants, according to their availability, with no changes to their work routine. The subjects were invited to participate in the hospital's waiting room and those who agreed were taken to a private room reserved by

the institution for individual interviews.

The data were gathered between April and June 2017, using data saturation as the criterion for ending data collection. Reaching saturation means deepening the investigation of the object of study, enabling the understanding of the meanings given to it⁽¹⁰⁾.

An interview script was used consisting of three guiding questions previously validated by experts, about living with HIV/AIDS. The interviews were recorded and lasted an average of one hour.

The corpus was analyzed using the lexical analysis technique, with the help of the *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRaMuTeQ) program, version 0.7, alpha 2. This program has been widely used in qualitative research, as it enables methodological rigor and allows for various types of analysis, based on statistical techniques, and for this reason, stands out as an important tool to help interpret the results⁽¹¹⁾.

The textual analysis of the data was conducted using similarity analysis, based on graph theory and that indicates connectivity among words. This analysis yielded a similarity tree guided by the hierarchy of the connections among terms and their surroundings for each class identified⁽¹¹⁾.

The present study abided by Resolution no. 466 of December 12, 2012, of the National Health Council of the Ministry of Health, which sets forth the guidelines and norms that regulate research with humans⁽¹²⁾. Data collection began after obtaining approval by the Research Ethics Committee of the Health Sciences Center of UFPE - CCS/UFPE, ruling no. 2.028.200.

RESULTS

Interviews were conducted with six transsexual women with a mean age of 21.6 years. The mean number of years in school was nine years and mean family income was up to three monthly minimum wages. The participants had received an HIV positive diagnosis between 14 and 19 years of age. Furthermore, of the six participants, four reported being sex professionals, one was a hairdresser and the other, a teaching assistant.

Figure 1 presents the analysis of the textual corpus, showing the interface of the similarity analysis with the identification of co-occurrences among the words used by the participants and the indications of connectivity among these same terms; this helped determine the daily problems that impact the quality of life of transsexual women living with HIV/AIDS.

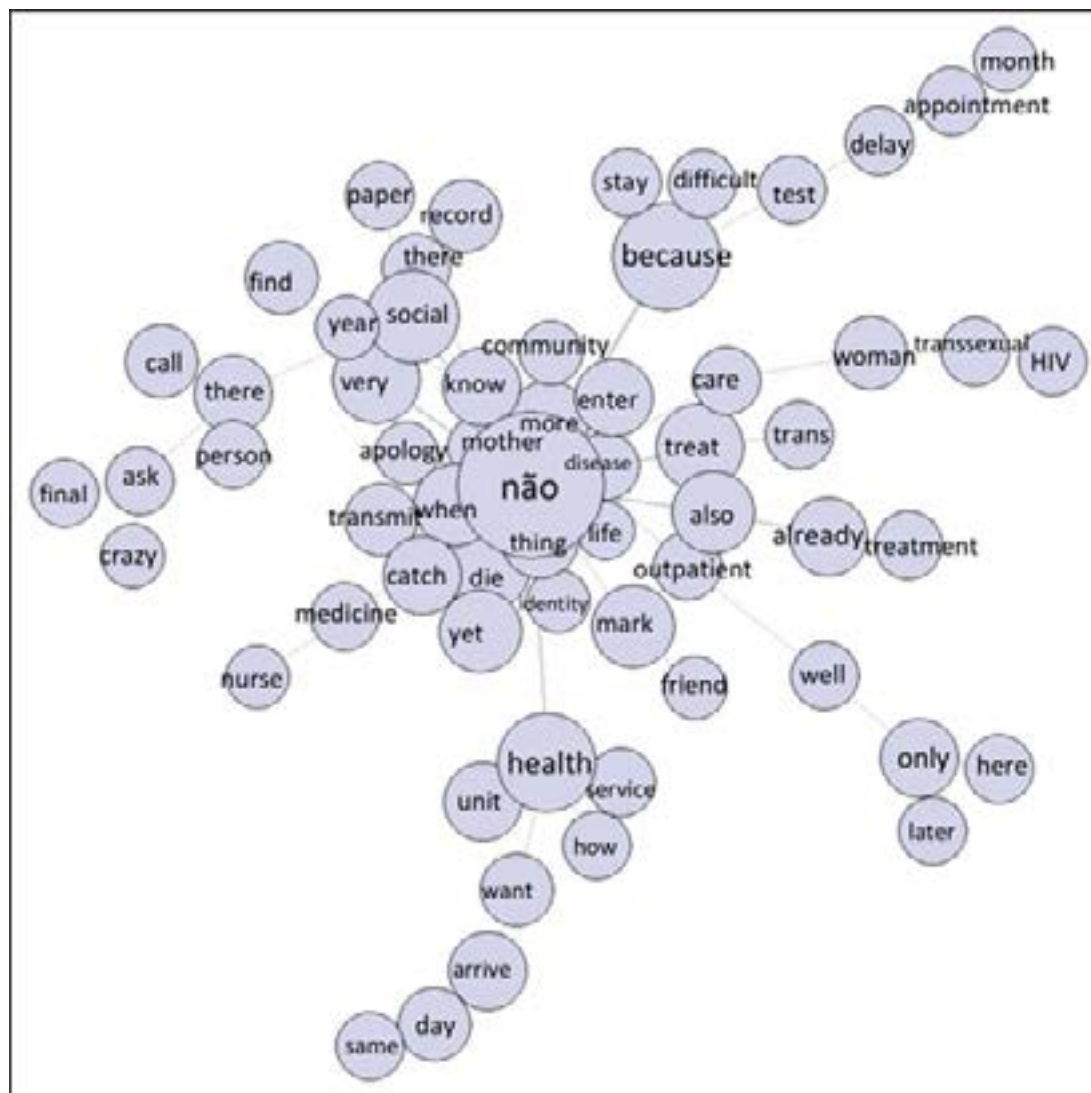


Figure 1 - Results of similarity analysis shown through a co-occurrence tree with words used by young transsexual women about daily life with HIV/AIDS. Recife, Pernambuco, Brazil, 2018

Vulnerability to HIV/AIDS and implications for coping

This tree revealed the daily lives of transsexual women living with HIV/AIDS. Given their social context, prostitution can become a means of survival that exposes them to situations of vulnerability and that is permeated by lack of dialogue when negotiating the use of condoms:

[...] I left home to become a prostitute and when I was 16 years old, I found out, it was the first HIV test I had, I did it with some friends just for the heck of it, to be sure, and at 16 years old I discovered I had HIV [...] (Respondent 06)

[...] They don't know I have HIV, none of them, when they ask me, I don't say. When a client performs oral sex on me, they don't usually use a condom, and I don't say anything because there is still great prejudice among the community [...] (Respondent 04)

The answers given by the participants showed how transsexual women were embraced by friends who are experiencing similar life stories, but the prejudice against HIV/AIDS restricted mutual support:

[...] There are few friends who stand with you and say: you have HIV, but you are my friend and will continue to be so. The girls joke about it, they are prejudiced...they say they've got the monster, or the Bug, that's normal among the trans community [...]. (Respondent 05)

The transsexual women coped with social prejudice on a daily basis, representations of abjection, and therefore, the unity of the transsexual community was an important coping mechanism:

[...] Society in general only looks at what you do wrong. When someone wants to beat one of us up, or something like that, when they want to beat one of us up in front of the others, or want to humiliate us, no trans women keeps quiet, it's the only time when we are truly united, with rare exceptions. (Respondent 05)

They also referred to the fragile/absent religious connection, but the maintenance of spirituality based on God:

[...] I never imaged I would get along so well with an Evangelical person, with a girl from the nursing staff, every time she's there I talk to her, I spend some time there and I found out recently that she is Evangelical, I went to take a Benzathine injection with her and she speaks about the word of God and everything. I've been to many churches, I think it's a joke, to be honest that's it, I believe in God (Respondent 05).

[...] I've been to the Evangelical church, Catholic church, but I also gave up [...] (Respondent 01)

The fragile social bonds and lack of knowledge contribute to the fragmentation of emotional and social support bonds.

[...] It was hard because my mother never accepted me, my father never accepted me, he always saw things that weren't there, said it was perversion [...] I'm more of a loner, I'm by myself, you know? [...]. (Respondent 06)

[...] I had to adapt to the disease, I had to learn about the disease and understand that it's not how the community conveys it, the community makes it out to be something it's not [...]. (Respondent 03)

HIV/AIDS treatment adherence and programmatic context

The second category presents the social and programmatic factors that interfere with adherence to antiretroviral therapy (ARVT) and consequently the quality of life of transsexual women. Denial of the disease delays the beginning of treatment.

[...] I began treatment when I was 23, I knew I had HIV since I was 16...I got tuberculosis, syphilis, I still have tuberculosis [...] (Respondent 06)

Treatment nonadherence is a potential risk for acquiring an opportunistic disease. Living with AIDS implies biopsychosocial limitations that greatly impact quality of life and alludes to the idea of death associated with hopelessness:

[...] Until I reached a stage where my syphilis really flared up, I didn't want to take the tests, I started to feel a lot of things...I got shingles [...]. (Respondent 05)

[...] Nowadays I'm afraid of having sex, even with a condom, I'm afraid because I've already been hospitalized [...] (Respondent 06)

[...] In the trans community, some prefer to get treatment and others prefer to die [...] (Respondent 05)

One of the respondents expressed knowledge about the importance of self-care for quality of life but reported lack of self-care among most transsexual women:

HIV prevention for me means that I am protecting myself from other diseases, protecting my partner from harm, seeking a higher-quality and longer life. Very few of them [transsexual women] take care of themselves, many of them have it, but they are not at all interested in

getting care, they don't get treatment, they don't want to be treated [...]. (Respondent 02)

The respondents mentioned weaknesses in the primary healthcare service that stem from lack of inclusion and harassment due to healthcare professionals not using their social names:

[...] At the health center I am still treated according to my biological sex...I think that is harassment, to be called by the name on my ID and not by my social name [...]. (Respondent 02)

[...] The health center for me is for people who don't have any disease, who don't have HIV or AIDS. So you have a cold, you go to the health center, you want a complete blood test, you go to the health center, but I don't have to because I get it all done here at this hospital. [...]. (Respondent 06)

DISCUSSION

In Brazil and in the world, the expression of HIV/AIDS in transsexual women is directly related to social vulnerability⁽⁵⁾. This and other studies have shown that the daily life of people living with HIV/AIDS is permeated by negative feelings of fear, stigma and risk of depression, which strongly impact their quality of life^(9,13-14). Social exclusion has been observed to be the main precursor for denial of the disease, social isolation and low treatment adherence⁽¹⁵⁾.

The results of the present study show that despite the advances in medication and universal access to them, which increases life expectancy, discussions about vulnerabilities, aspects that hinder effective health care and quality of life of transsexual women with HIV/AIDS, are undervalued within the scope of public health. The participants mentioned suffering from social prejudice that stems from their gender identity and the condition of living with HIV.

Comprehensive care as understood by the National Comprehensive Health Policy for LGBT consists of a set of actions that are sensitive to diversity, a relative axis for building cross-sectional and longitudinal strategies for coping with HIV/AIDS, tailored to the specificities of individuals and social groups for equal care^(7,16).

Knowledge about the disease is a determining factor for self-confidence and quality of life. Dealing with HIV/AIDS requires that people be empowered and develop coping strategies. The participants reported being accepted by friends, other transsexual women who face similar difficulties, but that the prejudice against HIV/AIDS still prevents dialogue and, consequently, mutual support.

There are no official strategies for promoting quality of life among transsexual women living with HIV/AIDS based on coping with their context of vulnerability. The Comprehensive Plan for Coping with the Feminization of AIDS and other STIs gives priority to the wide dissemination of prevention measures against HIV/AIDS and access to information that corroborates decision-making aligned with individual and social context, in order to reach a better quality of life^(7,17-18).

Another study about the quality of life of transsexual women showed that 51.4% suffered from depressive symptoms and 40.4%, from anxiety⁽¹⁹⁾. The psychosocial conditions of these individuals are that of elevated risk of suicide, drug use, history of sexual abuse, assaults, negligence, homelessness, and depression, which coexist with HIV/AIDS, which is called a syndemic⁽¹⁴⁾.

It is important to emphasize that prejudice in the care of thousands of people who begin their HIV/AIDS treatment is a reflection of biopolitics and inequality between those who have resources to afford health care and those who are condemned to clinical worsening

and side effects, representing a threat to and disregard for these people's lives⁽²⁰⁻²¹⁾. It is worth emphasizing the importance of the systematic pressure exerted by civil society organizations in the fight for rights that resulted in Ordinance 35/2016, which resulted in the inclusion of two new medications for initial treatment, which have fewer side effects and improve patient treatment adherence and quality of life⁽²²⁾.

Regarding contextual aspects, transsexual women in this study and another similar investigation found in prostitution a means of survival and socialization, especially those rejected by the family environment and social spaces, which exposes them to situations of vulnerability⁽²³⁾. Furthermore, living with a chronic disease that is anchored in social stigma, implies lack of community support, a daily life filled with fear, lack of dialogue and limited possibilities to negotiate the use of condoms with sex clients, as mentioned by the participants of the study.

Most transsexual women in this study worked with prostitution and frequently suffered from situations of exclusion and lack of emotional support. Relationships with their social networks (family, friends, church, work and health services) were fragile and sometimes permeated by the overlapping of prejudice relative to their gender identity and the fact that they are living with HIV/AIDS.

Emotional support is an extremely important strategy for individuals living with HI, as it improves self-esteem and encourages them to seek positive interactions in the community⁽²⁴⁾. However, among the participants of this study, the absence of social acceptance took place first in the nuclear family, due to the rejection of their gender identity. This rejection results in isolation, risk of depression and suicide. The participants also mentioned weakened religious bonds, but strong potential for spirituality that should be valued by health professionals that practice comprehensive care.

Within the healthcare environment, the persistence of the conservative, patriarchal and sexist approach extends to the binary biomedical care model, which is a potential risk to human rights. The difficulties in accessing and finding acceptance in primary healthcare services contribute to greater rates of treatment abandonment and lower quality of life⁽⁶⁾.

The dichotomy between "keeping alive" and "letting die" is observed with the provision of tests and universal access to antiretroviral medications, in contrast with the neglect of their context of vulnerability, which permeates social relationships, hindering the comprehensiveness of care. This context results in health actions that are disconnected from the specificities of individuals in order to quality of life⁽²⁵⁾. It is worth mentioning that one of the participants reported how her community of transsexual women neglected self-care; thus, health promotion efforts are pressing both for treatment adherence and to encourage self-care.

The participants of this study recognized the importance of knowledge about HIV/AIDS for overcoming social taboos. Thus, health professionals should develop health education actions based on topics of interest for transsexual individuals, especially for health promotion within the scope of primary care, in order to provide inclusive practices, using their social name and encouraging the strengthening of bonds with the Family Health Strategy.

Care actions aimed primarily at condom use during sexual intercourse do not encompass the actual demands for empowerment associated with relationships in the social, political and cultural context. This problem is compounded by insufficient availability of material resources, communication, schooling and programmatic efforts.

International health programs, in partnership with the World Health Organization (WHO), use health education as their main empowerment and coping strategy for HIV/AIDS. This process enables the construction of knowledge, based on a social, cultural, political and economic approach that reflects on the vulnerability of young transsexual women living with HIV/AIDS⁽²⁷⁾.

Within the programmatic aspect of health, care delivery is based on the stigma and prejudice present in the representations of professionals about the disease⁽²⁸⁻²⁹⁾. This appeared in the participants' interviews in situations such as violation of confidentiality and the unpreparedness of health professionals to meet their specific needs. These are barriers to building relationships between transsexual women and primary health care services, which implies fragmentation of longitudinal care, especially in terms of disease prevention and health promotion.

Coping with HIV/AIDS requires fighting against transphobia, empowering youths about gender identity, sexuality, transmission and criminalization, in alignment with human rights⁽²⁵⁾. Furthermore, it is also essential to expand access to serology tests, timely diagnosis and the rational use of antiretrovirals⁽²⁰⁾. Priority must be given to research production, policy implementation, and guidelines ratified by transsexual women's social movements, coupled with the wide dissemination of knowledge that includes HIV/AIDS prevention measures^(7,17-18).

Activism provides benefits to individuals who suffer from the stigma of HIV, because it allows for greater connection among individuals in similar situations and sense of life purpose and meaning. Forming social networks enables new ways of actively dealing with the various aspects of discrimination, resignifying life and a sense of purpose and power⁽³⁰⁾. The analysis of the present results indicates that achieving greater treatment adherence and life perspective among transsexual women requires coping actions that include their social support networks.

Moreover, the curricula of health programs should be planned to include issues relative to the LGBT community, such as through the use of case studies, blogs, magazines, discussion groups, research and group projects in a virtual classroom and learning and community spaces, to address themes relative to the history of gender identity, sexual health, and possible referrals so that the practice of future professionals may include sensitive care⁽²⁾.

A limitation of the present study is the fact that the participants were recruited at an HIV/AIDS reference service, and consequently, presented better health conditions. The results cannot be generalized to other spaces; however, they provide a wide-reaching understanding of the patients' quality of life, based on social and healthcare aspects that negatively impacted coping and comprehensive well-being.

FINAL CONSIDERATIONS

The daily life of transsexual women was permeated by lack of social support, leading to isolation, low treatment adherence, the emergence of opportunistic diseases, and the risk of depression, which limits their quality of life. The respondents referred to the following opportunistic diseases: shingles, syphilis and tuberculosis, which stemmed from lack of self-care and can be highly life-threatening. Maintaining life and obtaining well-being are intimately tied to coping with social abuse, managing emotional and sexual partnerships, and health promotion.

The main ideas pointed to the chronic nature of the disease, which is aggravated by the negative impacts of the precarious living and work conditions and lack of support, especially in the family and programmatic health dimensions, which result in lack of meaning in life, fear, and social isolation.

Multiprofessional health actions that empower individuals and encourage social activism are urgently needed. Furthermore, it is necessary to share care delivery among the health team, family and the target audience in order to provide comprehensive care for the specificities of transsexual women and to understand the social elements that comprise the daily lives of these individuals, to ensure human rights and quality of life.

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