BUILDING SUPPORT NETWORKS: THE ROLE OF THE FAMILY IN THE CARE OF PEOPLE LIVING WITH HIV

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Abstract: HIV/AIDS is more than a physical illness, affecting not only the body, but also the social, economic, mental life and quality of life of people who live with it. Over time, these people have shown a growing interest in not only prolonging life with treatment, but also in living well, adapting their health condition naturally to everyday life. The family plays a fundamental role in this health and illness process. Often, it is to the family that the individual turns for support when coping with the disease. Therefore, this study aimed to examine how family relationships influence people living with HIV/AIDS. To do this, we searched for information in databases such as SciELO and VHL, using keywords such as "Family", "HIV" and "Quality of Life", combined with the "AND" operator. After analyzing a series of criteria, we selected 10 relevant articles for our review. Thus, it was possible to realize that, although the family plays an important role in quality of life, it is just one of the many variables that influence the lives of people with HIV/AIDS. This influence can be positive or negative, depending on the nature of the relationship between the person and their family after the diagnosis.

Keywords: Family; HIV; Quality of life.

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INTRODUCTION

HIV, or Human Immunodeficiency Virus, can result in Acquired Immunodeficiency Syndrome (AIDS), as defined by the Joint United Nations Program on HIV/AIDS (UNAIDS). This chronic condition is not only restricted to the biological aspect, but also encompasses social, economic, mental health and quality of life (QoL) factors. Statistics reveal that by 2021, 38.4 million people were living with HIV.

Data from Agência Brasil indicate that, last year, 694 thousand people in Brazil had access to HIV treatment, which corresponds to 81% of the total positive diagnoses. Since 1996, Law No. 9,313 guarantees free and universal access to medicines for all users of the Unified Health System (SUS) proven to be infected.

In 2014, the Ministry of Health (MS) began the process of decentralizing the diagnosis and management of people living with HIV/AIDS (PLWHA) in Brazil. Previously focused on secondary care, this process was shared with Primary Health Care (PHC) units, integrating into the Family Health Strategy (ESF).

Despite technological advances and the increase in the life expectancy of PLWHA, challenges persist that perpetuate the vulnerabilities of this population. It is observed that PLWHA have shown greater concern about living well and naturalizing their daily lives, in addition to seeking effectiveness in treatment and prolonging life.

The Quality of Life (QOL) of these people is influenced by several aspects, including family relationships, spirituality and individual characteristics. The definition of QoL by the World Health Organization (WHO) considers individual perception in relation to culture, values, objectives and expectations. Identifying and modifying factors that influence QoL contributes to the well-being of these people.

A study conducted by Lenzi et al. (2018) highlighted the importance of social support in coping with HIV, influencing adherence to treatment and disease control. Another research carried out by Almeida-Cruz et al. (2021) examined the experience of young people after being diagnosed with HIV, showing that a good family relationship is associated with a feeling of happiness and positively influences QoL.

This study aims, therefore, to investigate the role of family support in the quality of life and adherence to treatment of individuals living with HIV/AIDS.

METHODOLOGY

This work consists of a bibliographical research with a strategic search for scientific articles. Initially, we carried out an exploratory search to assess the relevance of the topic, identifying references prior to the period defined for the strategic search and including them for convenience.

We searched for scientific articles indexed in the VHL and SciELO databases, using the descriptors obtained on the DeCS platform: "Family", "HIV" and "Quality of Life". We used the "AND" crossing method to combine the search terms, resulting in the sentences "Family AND HIV" and "Quality of Life AND HIV", during the period from 2018 to 2022. This allowed us to select articles that addressed the most updated on the topic in question.

The inclusion criteria adopted were: a) studies that investigated the relationship between family support and quality of life of people living with HIV/AIDS (PLWHA), b) articles published between 2018 and 2022, and c) national studies and in Portuguese. The exclusion criteria were: a) paid articles, b) lack of availability of the full text in the VHL and SciELO databases, and c) abstracts that were not related to the objectives of this study.

We carried out the survey in indexed databases using sentences as initial search criteria. We apply the filters provided by the databases themselves, such as year of publication, language and country, and select the works to read in full. We then reviewed the full text for careful selection according to the research objectives and methods. Works published in more than one database were considered only once in the final selection.

RESULTS AND DISCUSSION

Initially, we identified a total of 76 articles, which were subjected to the filters available in the databases, according to the inclusion and exclusion criteria defined for this research. After this process, we selected 10 articles for analysis. The detailed results are presented in Table 1.

Table 1: Classification of selected articles according to topics: Title, Objectives and Type of Study.

TITLE	GOALS	KIND OF STUDY
Structure of social networks of people living with HIV and AIDS	Analyze the structure of the social network of people living with HIV and AIDS .	Exploratory and descriptive research with a qualitative approach.
Perceptions about the quality of life of people living with HIV	Understand the meaning of quality of life attributed by people living with HIV.	Qualitative study carried out with people living with HIV.
Social representations of the quality of life of young people living with HIV	Analyze the social representations of quality of life for young people living with HIV.	Qualitative research.
Quality of life in individuals initiating antiretroviral therapy: a cohort study	To longitudinally evaluate changes in quality of life in people living with HIV starting antiretroviral therapy.	Prospective cohort study, monitoring people living with HIV, aged 18 or over, and starting antiretroviral therapy.
Social Support and HIV: Relationships Between Clinical, Sociodemographic Characteristics and Treatment Adherence	Investigate the relationship between social support, sociodemographic and clinical characteristics and adherence to ART.	Cross-sectional study.
Social representations of the quality of life of people living with HIV/AIDS	Analyze the social representations of the quality of life of people living with HIV/ AIDS .	Descriptive, exploratory study, with a qualitative approach
Caring for People Living with HIV/ AIDS in Primary Health Care: a new agenda for tackling vulnerabilities?	Analyze the implications of decentralizing assistance from PLWHA to PHC in the (re)production or reduction of vulnerabilities.	Focus groups with professionals, participant observation and semi-structured interviews were carried out.

Changes in the daily lives of women living with HIV: outpatient analysis, Rj , Brazil	Investigate changes in daily life and analyze women ‘s coping after the diagnosis of HIV / AIDS and the introduction of Antiretroviral Therapy (ART).	Descriptive and prospective study of a qualitative nature .
Assessment of the quality of life of people living with HIV/AIDS: integrative review	Analyze studies relating to the assessment of the quality of life of people living with HIV in Brazil, through an integrative literature review.	Integrative review.
Social representation of the quality of life of young people living with HIV: a contribution to nursing	Analyze the social representations of quality of life for young people living with HIV.	Descriptive study, with a qualitative approach.

Source: Prepared by the authors.

Among the most frequently mentioned sources of support among PLHIV, family, friends and neighbors, churches and self-help groups stand out, with the first two being considered significant protective factors. In the partial or total absence of this emotional support,Dealing with stigma and prejudice may seem more challenging than facing the infection from a physical health perspective(Lenzi et al.,2018).

Andrade et al. (2021) evaluated the structure of the support network of PLWHA, divided between primary and secondary, and concluded that the family is at the center of the primary social network of the majority of patients analyzed in the study, that is, they constitute strong emotional bonds, which are expanded the greater the coexistence and help offered.

The concept of “family” has evolved over the years. Minuchin (1985) defines it as an organizational system, while Osório (2002) points out that it is a difficult expression to define due to the different structures it assumes. In contemporary society, affection has become the central element of the family, its purpose being to promote the full fulfillment of human beings and contribute to the well-being of all its members.

Regarding QoL, Almeida-Cruz et al. (2021) states that QoL for PLHIV is related to four thematic classes: the difficulties faced during treatment, coping with stigma and decreased self-esteem, living in expectation that something will happen, and being healthy. Such classes can have a positive or negative impact on patients' QOL depending on their experiences. The study can infer that hope and family support are positive factors for coping with the infection, since having a good family relationship is also related to the feeling of happiness.

The assessment of QoL must be carried out through an individual, multidimensional and subjective approach (Marques et al, 2020). After interviewing 24 young people living with HIV, followed in specialized services in Rio de Janeiro, Silva et al. (2021) describes the perception that HIV has an influence on social and family relationships, generating an impact on QoL. Some of the interviewees highlighted the importance of a good relationship with the family in coping with the infection with regard to post-diagnosis life.

Pimentel et al. (2020) analyzed family involvement with reducing prejudice and reducing stigma in relation to the disease in cases where there is a positive relationship. Similar result found by Souza et al. (2019) in their evaluation of women living with HIV in the city of Rio de Janeiro, who despite their fears, find a point of support in the family.

In contrast, they cite the fear of rejection and prejudice with the revelation of seropositivity, generating situations with a negative impact on QoL due to the absence and the need to maintain confidentiality about the diagnosis. It is reiterated the results found in the aforementioned studies that family relationships can be a complicating factor in the case of rejection of the disease, reducing QoL and worsening adherence to treatment due to discrimination and feelings of loneliness Pimentel et al. (2020).

Furthermore, they highlight the PHC service as a participant in the secondary social network of these patients, however, they conclude that they have a preference for secondary services due to specific care for the disease.

Still in relation to PHC, Damião et al. (2022) states that it represents a space for confronting vulnerabilities faced by PLWHA, as it recognizes individual needs, provides comprehensive care and facilitates the creation of bonds and adherence to treatment, however, this relationship can become weakened by fear of breach of confidentiality, which would end up increasing violence and consequently reducing the QoL of this population.

People living with HIV/AIDS (PLHA) face daily challenges related to their health condition, including stigmatization, low self-esteem and hope for a cure. Understanding how different factors affect the quality of life (QoL) of people with chronic diseases is essential. Studies have explored both the positive and negative aspects, which vary depending on the individuality of each individual and their social relationships. Therefore, it can be inferred, from the studies analyzed, that the family plays a fundamental role in the care of PLWHA, since they are affected by a chronic disease that, even today, is still surrounded by stigma and prejudice.

CONCLUSION

The family context plays a crucial role in the health and illness process. Often, it is in the family that the individual seeks support to face the illness process. Treatment of PLHIV, combined with family support, helps to alleviate symptoms and promote a better quality of life. This study sought to evaluate, through a narrative review of the literature, the relevance of family support in improving the quality of life (QoL) of people living with HIV/AIDS (PLWHA), a crucial aspect for effective management, understanding and care. of these patients. When analyzing scientific articles from the last five years, we observed that, although the family plays a significant role in QoL, it is just one of several variables that influence the QoL of PLWHA. This influence can be both positive and negative, depending on the quality of the relationship established between the family and the individual after the diagnosis is revealed.

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