



Social support for the elderly with HIV/Aids: an integrative review

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Abstract

Objective: The present integrative literature review aimed to verify the scientific knowledge produced about social support for elderly persons with HIV/Aids. *Method:* A search was carried out in the Lilacs, Medline, Scopus and Web of Science databases for studies published in the last ten years. The final analysis consisted of seven articles. *Results:* It was found that social support is extremely important in the life of the elderly with HIV/Aids, and a real need for this support was identified. Such support can both contribute to quality of life in many ways, as well as impair the care of those who live with the disease, as the diagnosis, treatment and the entire stigma surrounding this chronic condition directly influence the type and quality of support provided. *Conclusion:* It is hoped that the results of this review will contribute to reflection on health practices for the elderly with HIV/Aids.

Keywords: Elderly.
Social Support. Acquired
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INTRODUCTION

The population aged 60 and over in Brazilian society is growing rapidly. At the same time, fast-moving advances in medicine and technology are allowing people to grow older in a healthier way, with a better quality of life. This includes prolonging sexual activity through facilitators of modern life, such as hormone replacement and impotence drugs. These facilitators help the elderly to rediscover experiences, including sexuality, making their lives more enjoyable yet more vulnerable, and requiring investment in prevention campaigns against sexually transmitted infections (STIs), especially AIDS¹.

The aging of the HIV epidemic has brought new challenges related to both diagnosis and the link between the elderly person and the proposed therapeutic approach, in the hope of achieving greater adherence to and connection with treatment, while not overlooking issues such as human rights, mutual respect and inclusion. The overall population is aging and the increase in HIV prevalence among the elderly is related to the fact that people can contract HIV at more advanced ages through unprotected sex, as well as the greater life expectancy of people who have been living with HIV since before the age of 60².

Recent data from the 2017 Epidemiological Bulletin on AIDS and STI from the Ministry of Health indicate that in 2016, when 1,294 HIV cases were registered, there was a 15.0% increase in the number of people aged over 60 with the virus in comparison with the previous year. In 2015, meanwhile, the numbers were 51.16% (1,125 people infected) higher than in 2014, when 856 people were diagnosed with the virus³.

Receiving a positive diagnosis of HIV represents a significant event, triggering reactions and a combination of negative feelings linked to ideas of death/finitude. It is a serious concern that greatly affects the physiological and psychological systems of both those with the disease and their families, who are directly involved in the care of the sufferer, whether through social, religious, ethical or moral impacts⁴.

In the 2015 study by Silva, the reactions of the elderly to a diagnosis of HIV positive involved fear of death and disability, and notably that the

diagnosis, which is considered shameful, would be revealed to family, friends and others from the patient's social network, causing embarrassment, rejection, discrimination and distancing from others. HIV-related stigma and prejudices have a number of negative consequences in the battle against AIDS, both for people living with HIV and for prevention strategies⁶.

HIV/AIDS in the elderly has effects that can lead to changes in their identities, experiences, and a remodeling of their being and situation in the world. AIDS-related prejudice is still with us, taking its toll on people living with HIV in terms of suffering, isolation and loneliness, notably because such discrimination often comes from relatives and those closest to the sufferer, restricting their support network, which has consequences for the positive coping with the disease⁷.

According to Silva⁸, social support networks are hierarchical groups of people who maintain links between one another, typically of relationships in which they give and receive support, and places that usually provide material help, services and information, such as allowing people to believe they are cared for, loved and valued in times of need and ensuring that they belong to a network of common and mutual relationships. Social support is important insofar as it corresponds to the needs experienced by the elderly themselves. Within this perspective, social support includes a broad network of emotional, informational and instrumental support.

Thus, the need for listening, attention, information and esteem is established as fundamental, influencing different attitudes towards HIV/AIDS, both in the diagnosis and during the course of the disease, depending on the social support received by the elderly. The aim of the present study was therefore to carry out an integrative review of literature, seeking scientific evidence about social support for the elderly living with HIV/AIDS.

METHOD

The present study comprised an integrative review of literature, systematically gathering and synthesizing the results of research on a given topic,

allowing the incorporation of the evidence in clinical practice⁹. The study was carried out based on the following steps: 1) Definition of the theme and elaboration of the guiding question; 2) Selection of the electronic databases used in the research; 3) Establishing of inclusion and exclusion criteria; 4) Definition of descriptors; 5) Pre-selection of articles; 6) Evaluation of the articles that made up the sample; 7) Interpretation of results and 8) Presentation of the integrative review¹⁰.

The following guiding question was applied: what scientific evidence has been published in the last 10 years that addresses social support for the elderly with HIV/ AIDS? Articles were selected from four databases: Latin American and Caribbean Literature in Health Sciences (or LILACS), Medical Literature Analysis and Retrieval System Online (MEDLINE), SCOPUS and WEB OF SCIENCE. The articles were collected between May and June 2018. Descriptors in Portuguese and English were taken from the Health Sciences Descriptors (or DeCS) of the Virtual Health Library (HIV, AIDS, social support and the elderly) and the Medical Subject Headings (MeSH) of the National Library of Medicine (HIV, Acquired Immunodeficiency Syndrome, Social Support and Aged), combined with Boolean operators. In the LILACS search, the search key “HIV or AIDS and SOCIAL SUPPORT and THE ELDERLY” was used. In MEDLINE, SCOPUS and WEB OF SCIENCE the following combination was used: “HIV or ACQUIRED IMMUNODEFICIENCY SYNDROME and SOCIAL SUPPORT and AGED”.

The inclusion criteria were: complete articles available electronically in any language, published in the last 10 years and that cover the theme of social support in the elderly with HIV/AIDS. The exclusion criteria included review articles, dissertations, theses, letters to the editor, technical guidelines,

expert opinions and books. Repeated articles were considered only once.

Once selected, the articles were read and analyzed in an organized manner to evaluate the rigor and characteristics of each study, observing their methodological aspects, intervention or proposed care, result, conclusion and level of evidence. The instrument corresponded to the Hierarchical Classification of Evidence for the Evaluation of Studies, based on the categorization of the Agency for Healthcare Research and Quality (AHRQ), where the quality of evidence is classified into seven levels. According to the eligibility criteria, the levels of the Hierarchical Classification in the present study were: Scientific evidence from randomized controlled clinical trials, well-delineated clinical trials without randomization, cohort studies and well-delineated control cases and scientific evidence derived from descriptive or qualitative studies¹¹.

Figure 1 shows the distribution of articles found and selected based on the inclusion and exclusion criteria. The great majority of the excluded articles were removed due to the fact they did not approach the theme of social support in elderly people with HIV/AIDS, and when the theme of “social support” was addressed, it was in the pediatric or adolescent population.

RESULTS

After the exploratory reading of the 11 articles selected, seven articles were selected for inclusion in the integrative review, after which the hierarchical classification of the evidence for the evaluation of studies was performed, based on the AHRQ categorization.

The relevant information of the selected articles is described in Chart 1.

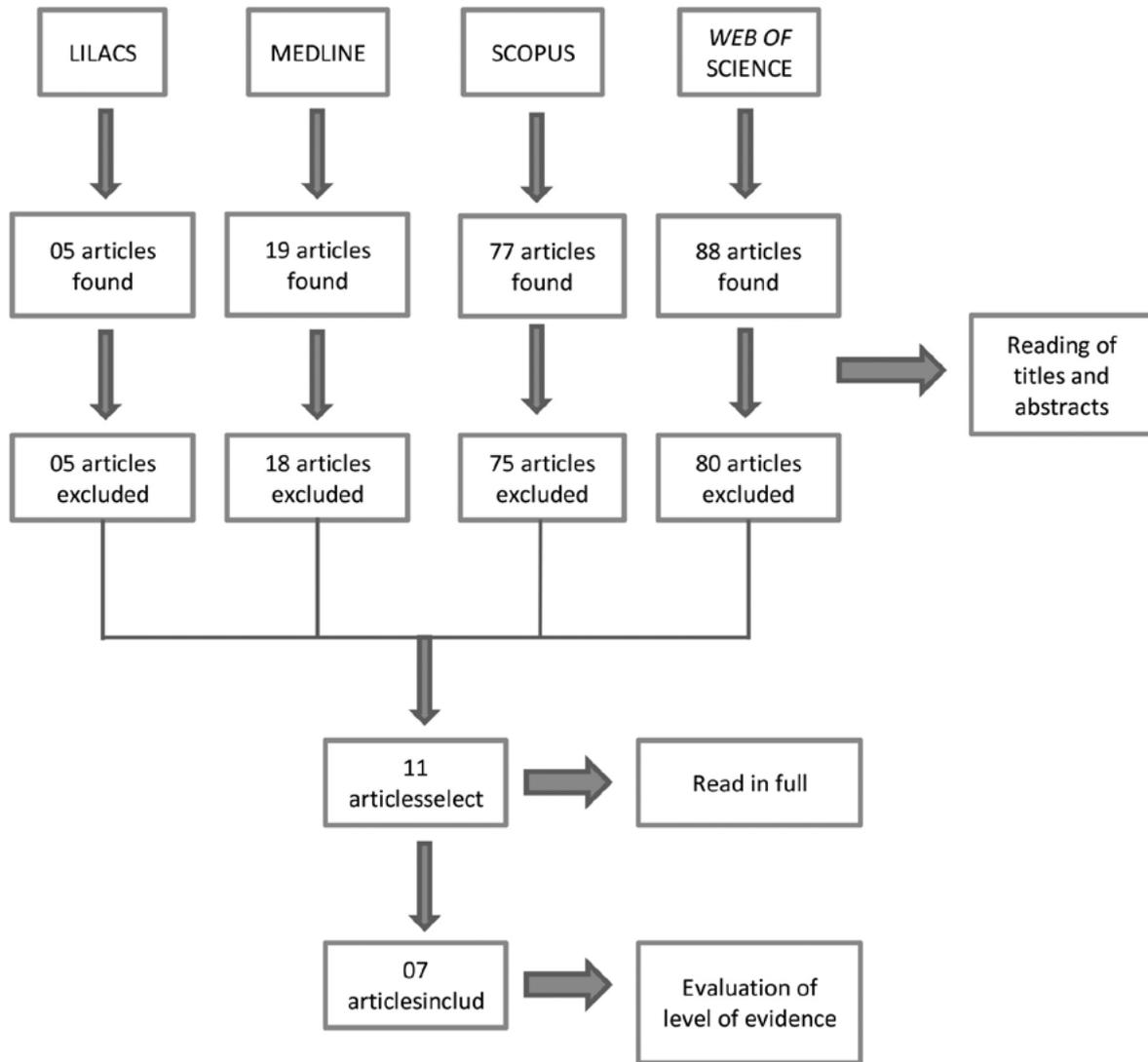


Figure 1. Diagram of articles found and selected from database search. Recife, Pernambuco, 2018.

Chart 1. Characteristics and presentation of synthesis of articles included in integrative review. Recife, Pernambuco, 2018.

Authors/Year/ Local	Sampling	Database	Objectives and delineation of study	Principal Results/Conclusion
Okuno et al., 2014 ¹² /Brazil	201: -128 men -73 women Mean: 56 years	<i>Web of Science</i>	To evaluate the quality of life of the elderly with HIV / AIDS and to correlate it with the sociodemographic, economic and clinical variables presented. Epidemiological/ Cross-sectional/ Analytical	One of the domains with the lowest HAT-Qol scores was: concern for confidentiality, where there was a strong correlation between age and the stigma associated with the disease, referring to the devaluation, discrimination and judgment of the way of life and behavior of the elderly individual requiring social, family and professional support.
Okonkwo et al., 2016 ¹³ / Ireland	45: -35 men -11 women	<i>Scopus</i>	To determine the level of perceived social support among elderly people living with HIV and AIDS in Dublin Quantitative/ Cross-sectional	A little over half of the elderly participants scored poorly in perception of social support. Social support in the form of emotional and informational assistance provided through the appropriate channels has been shown to improve people's quality of life. However, more can be done by formulating strategies to encourage older people to participate more proactively in the community to which they belong through voluntary services that keep them physically and mentally active and more intrinsically involved with the community.
Warren- Jeanpiere et al., 2017 ¹⁴ /USA	23 women Mean: 57 years	<i>Web of Science</i>	To describe the perceptions of elderly African American women about aging and the chronicity of HIV and how this affects their social support needs Qualitative	In the analysis of the focus group, four central themes were perceived: "Life begins at 60", marking a positive change in the identity of the elderly, as they reached a point of acceptance in life, despite their HIV status. "Stop worrying about everyone else" shows the perception of the elderly is to desire the instrumental and emotional support that can facilitate self-empowerment and in turn improve the self-management of HIV. "Silence is killing us," indicates the need for emotional support of the elderly in order to resist the stigma of HIV. "I need something more," means that elderly women need ongoing emotional and instrumental support as they grow older with HIV.

to be continued

Continuation of Chart 1

Authors/Year/ Local	Sampling	Database	Objectives and delineation of study	Principal Results/Conclusion
Emlet et al.,2013 ¹⁵ /USA	226 men Mean: 62.9 years	<i>Web of Science</i>	To analyze risk and protection factors associated with physical and mental health-related quality of life among gay and bisexual people living with HIV.	Social support and self-efficacy were positively correlated with quality of life related to physical health, where they are factors of protection for quality of life related to physical and also mental health, where a significant result was obtained.
			Quantitative/ Cross-sectional	
Furlotte et al.,2017 ¹⁶ /Canada	11: -9 men - 11 women Mean: 60 years	<i>Web of Science</i>	To analyze how the elderly living with HIV describe their experiences in mental health	Engagement with social support is one of the strategies for achieving resilience, based on an individual approach. The elderly noted that the social support sought and received (family, peer group, spiritual) positively affected their quality of life and this search for social support helped to promote resilience. The elderly value the support of psychological services, showing the importance of formal social support for the elderly with HIV.
			Qualitative	
Johnson et al.,2009 ¹⁷ /USA	244: -173 men -71 women	<i>Medline</i>	Comparison of alternative models for adherence to antiretroviral drugs among the elderly living with HIV/ AIDS	Relationship of direct effect of social support with maladaptive coping and adherence to antiretroviral therapy. The study emphasizes the importance of social support in influencing behaviors and results for health, as well as the importance of intervention in groups to improve coping with the disease and in the relief of psychological suffering.
			Randomized Clinical Trial	
Daskalopoulou et al.,2017 ¹⁸ /UK	3258	<i>Scopus</i>	Evaluates whether the non-disclosure of HIV status is associated with psychological symptoms, adherence to antiretroviral therapy and viral load among people living with HIV in the UK.	The elderly had a higher prevalence of the non-disclosure of serological status in a social context, especially those with a long-term partner, when compared to other age groups and types of marital relationships. Elderly persons in a relationship were more likely to have low social support or to experience psychological symptoms.
			Multi-centric Clinical Trial	

The seven articles found were published between 2009 and 2017 (based on the inclusion criteria of publication in the previous 10 years). Two were published in European countries (the UK and Ireland), three in the USA, one in Canada and one in Brazil. One article was evaluated as evidence level II and six scored level VI.

Most of the findings came from cross-sectional and descriptive studies, with the direct observation of a planned number of people with HIV/AIDS in a single moment, preventing the long-term comparisons of the characteristics of the sample.

DISCUSSION

Although few articles were found using the search key and eligibility criteria, some important points arose through the construction of this study, namely that great importance is attached to social support in the life of the elderly with HIV/AIDS, as well as the genuine need for such support and help.

The search for means of help or support is considered a natural reaction of human beings who are going through difficult situations under severe stress. In other words, there is a search for support networks, both formal and informal, aimed at coping with the changes generated after HIV diagnosis¹⁹.

Many studies of elderly persons living with HIV/AIDS highlight the fact that this population is at risk of a deterioration in their psychological and physical health when such social support from friends and family is inadequate^{12,17,20}.

In a study of individuals aged 50 or more living with HIV/AIDS²¹, it was found that such individuals are more likely to reside in nursing homes than those who do not have HIV/AIDS. The reasons that led to this difference in types of residence were the fact that those living with HIV/AIDS said that they were not able to rely on emotional and/or financial support from their relatives, with the implication that such a lack of support results in a decline in their physical and emotional health. The elderly tend to have a reduced network of social support and ways of dealing with psychological

and social stressors, resulting in a perception of lower social support.

A greater propensity of elderly persons without parents and/or who may have an older partner with declining health may suffer limitations in both the type and level of support available to them²². In the study by Okonkwo, Larkan and Galligan (2016) it was found that slightly more than half of the elderly participants had a low perception of social support. In the analysis of this study, emotional and informational support was found to improve the quality of life of these elderly people living with HIV/AIDS, when provided through the proper channels¹³.

HIV-related stigma and prejudice have a number of negative consequences for the fight against AIDS, both for people living with HIV and for prevention strategies⁶. In addition, the reality of being old and living with HIV/AIDS is often shocking, unthinkable and difficult to accept, since it contradicts the stereotypes specifically related to the elderly, which are mainly related to conceptions of asexuality at this time of life²³.

One of the studies that used the HIV/AIDS Quality of Life test (HAT-QoL)¹² (a specific instrument for evaluating the quality of life of individuals living with HIV/AIDS) supported this idea of the negative impact of socially constructed stigma and prejudice, as one of the domains assessed most negatively by these elderly people was "concern with confidentiality", which may be related to the stigma connected with the disease, leading to the devaluation, discrimination and judgment of the way of life and behavior of these elderly people living with HIV/AIDS.

All such biopsychosocial impacts means the elderly require social, family and professional support, as the discovery of the diagnosis can generate changes in several aspects of the life of these individuals. In relation to disclosing the news of a positive HIV diagnosis, many prefer to live in silence, for a variety of reasons: lack of a social support network or insufficiency thereof, fear of stigma, abuse based on stereotyped views of people living with HIV, loss of social support, breach of confidentiality and the desire not to burden family members with problems of health²⁴.

In the study aimed at analyzing whether non-disclosure of HIV status is associated with psychological symptoms, non-adherence to antiretroviral therapy and viral load among people living with HIV in the UK, the elderly were more likely to have low levels of social support or experience psychological symptoms, in addition to having a higher prevalence of non-disclosure in a social context and lacking a long-term partner, compared to other age groups¹⁸.

In addition, there is a possible association between HIV/AIDS in old age and a greater perception of the level of stigma among the elderly than among younger people. In a qualitative study²⁵ conducted with 63 African American, Latino and Caucasian elderly people with HIV, several barriers to social support were identified: age bias, family unavailability, non-disclosure of diagnosis, HIV stigma and concern about not becoming a burden. Despite these statements about the non-disclosure of HIV status, disclosure can also represent a strategy for providing social and psychological support to overcome a diagnosis which is in many ways more complex than other chronic conditions²⁶.

The elderly have formal and informal support needs. In the studies, informal support was the resource that is most received and perceived by the elderly (family, friends, neighbors and religious communities)^{27,28}.

However, one study shows that the elderly living with HIV/AIDS are more disconnected from informal sources of support, often leading to gaps in care, thus requiring support from health professionals, companies and formal integral care services²¹.

In the study which sought to observe the social support needs of African-American women who were HIV-positive, the elderly individuals described a need for emotional support (talking to others, feeling close to others, pampering themselves), informational support (adverse effects of medication, family support group information, mental healthcare provider information) and instrumental support (transportation assistance, health insurance). One of the needs highlighted by the elderly women is the

desire to talk about their HIV-related and general concerns about life with other people who would act empathetically and not be judged¹⁴.

These elderly women described the need to express their concerns, thoughts and experiences about aging with HIV and seek advice from doctors, therapists, family members and friends living with HIV/AIDS¹⁴. These types of support which are described as necessary for the elderly should be provided continuously as these people age with the disease, making them a facilitator in building self-empowerment and the self-management of HIV¹⁴.

The participants found the search for informal social support more useful although, due to the simultaneous occurrence of HIV stigma and the aging process, these elderly persons tend to find it more difficult to seek social support from informal sources to assist them with the condition, compared with other chronic diseases¹⁴. Again the stigma acts as a barrier in the search for social support, especially from informal sources. The study by Poindexter and Shippy reached a similar conclusion, with African-American women living with HIV aged 50 to 83 years revealing that they did not consider their families to be a reliable source of social support²⁹.

This importance of social support in the lives of elderly people with HIV/AIDS and their need for such help and support is further emphasized with other studies selected in the review, where social support and self-efficacy were considered as protection factors for quality of life, mental health and physical health, contributing to the “cushioning” of life’s adverse events and contributing to better adaptability when faced with these changes¹⁵.

Social support is a protective factor in promoting resilience in old age, since many elderly people living with HIV experience uncertainties and stigmas that may contribute to mental suffering, requiring consistent and structured social support to be able to use resilience as a coping ability and an important pillar in the lives of these elderly people. It was also found that the social, family, peer group and spiritual support sought and received positively affected the quality of life of these elderly people, as well as promoting resilience¹⁶.

When inadequate, social support has been directly related to poor adaptive coping with the condition of HIV/AIDS. The negative affect of this social support completely mediated the associations between maladaptive coping and adherence to antiretroviral therapy, emphasizing the importance and necessity of social support in the influence of behaviors and results for health¹⁷. It is likely that improving coping, support and affection will positively influence the adherence of the elderly to the management of the disease³⁰.

Limitations of the present study include gaps in detailed theoretical information and explanations of fundamental concepts such as social support and help in most of the studies, and also the fact that social support was evaluated in most of the studies in a secondary form. The research included in this review was carried out in several socio-cultural contexts, which may lead to different results, and few longitudinal studies were found, with the cross-sectional approach most prevalent among the studies analyzed in the review.

CONCLUSION

The present integrative review identified far fewer studies than might have been expected considering the period investigated, the significance of this epidemic in the elderly population, and the importance of both formal and informal social support in the life of these elderly persons. There is therefore a shortage of scientific production on social support for the elderly in the context of HIV/AIDS, especially in terms of the primary analysis of social support in scientific research.

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Social support has been shown to play a role in contributing to the quality of life of the elderly living with HIV/AIDS, as well as having a negative effect when absent or inadequate, considering the burden of diagnosis and treatment and the stigma attached to the disease. Support becomes a strong ally throughout the process of dealing with the disease.

The elderly suffer a greater stigma in relation to HIV/AIDS than other age groups, and those living with HIV/AIDS among this population receive less social support, hindering care. Because of this stigma, many face the disease in a solitary manner, generating negative feelings throughout its course, thus reinforcing the need for informal social support from relatives, friends, as well as the formal support provided by professionals and reference services. This support can help to avoid negative consequences in terms of adherence to treatment, isolation and difficulties in seeking help when required.

Reactions to elderly persons with HIV from family members may be influenced by the meanings given to the disease by society, resulting in situations of discrimination and exclusion by the family group.

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