

Strategies of assistance in the care of people with Immunodeficiency Syndrome Acquired

Estratégias de Assistência no Cuidado à Pessoa com Síndrome da Imunodeficiência Adquirida

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Abstract

This is an integrative review of the literature that aimed to unveil the scientific articles of the last 10 years concerning the care for adults diagnosed with Acquired Immunodeficiency Syndrome (AIDS). We analyzed 18 articles, from 2008 to 2017, collected in the databases SCIELO, LILACS and BDENF. The research was carried out in April 2017, where the articles were identified by their titles and abstracts, while the data extraction was performed by two reviewers. The data were then analyzed and categorized in a synoptic table. After the reading of the articles, two thematic categories were discussed: "strategies to assist people with HIV" and "difficulties faced by health professionals in the care of people living with AIDS" It is concluded that social stigma and prejudice against HIV positive people present difficulties in providing a whole and humanized care to people. It is perceived the need for actions such as permanent education in health services, which aim to make the professionals of the multiprofessional team aware of the need to get rid of judgments and negative attitudes when caring for the person living with this chronic disease, thus guaranteeing the respect, fairness and the provision of holistic assistance.

Keywords: Acquired Immunodeficiency Syndrome; Caution; Chronic disease; Health Team.

Resumo

Trata-se de uma revisão integrativa da literatura que objetivou desvelar a produção científica dos últimos 10 anos sobre a assistência ao adulto com Síndrome da Imunodeficiência Adquirida (AIDS). Analisou-se 18 artigos, entre os anos 2008 a 2017, coletados nas bases de dados SCIELO, LILACS e BDENF. A coleta foi realizada no mês de abril de 2017, onde os artigos foram identificados por leitura dos títulos e resumos, enquanto a extração dos dados foi realizada por dois revisores. Foi feita então a análise dos dados, que foram categorizados em quadro sinóptico. Após a leitura dos artigos, foram listados para serem discutidas duas categorias temáticas: "estratégias de assistência à pessoa com AIDS" e "dificuldades enfrentadas pelos profissionais de saúde no cuidado à pessoa com AIDS". Conclui-se que o estigma social e o preconceito frente ao HIV/AIDS apresentam-se como dificuldades na prestação do cuidado integral e humanizado a pessoas. Percebe-se a necessidade de ações, como por exemplo a educação permanente no serviço de saúde, que objetivem conscientizar os profissionais da equipe multiprofissional quanto ao desvencilhamento de julgamentos e de atitudes negativas ao cuidar da pessoa que vive com esta doença crônica, garantindo assim o respeito, equidade e a prestação de uma assistência holística.

Palavras-chave: Síndrome de Imunodeficiência Adquirida; Cuidado; Doença Crônica; Equipe de Saúde.



Introduction

Acquired Immunodeficiency Syndrome (AIDS) is characterized by a decrease in the CD4 + T cell count, below 350 cells mm / mm³, as a result of Human Immunodeficiency Virus (HIV) infection, causing opportunistic diseases and characteristic neoplasias (1-2).

In the perspective of chronic disease, AIDS person living with Acquired causes the Immunodeficiency Syndrome to change their daily routine, leading them to rethink their concept of self, as well as their vision on the society in which they are inserted. In addition, the use of daily medications and the lack of a known cure cause feelings of fear and hopelessness, which directly interferes with their decision to seek treatment and the improvement of their quality of life (3). In this way, people living with HIV / AIDS go through a process of discovery related to their own existence, generating a need to (re)transform themselves and get used to the new routine (4).

In addition to the chronic condition, AIDS brings prejudice and stigma, which causes the person to be marginalized by society in general, which imposes on them the fault for the transmission and spreading of the disease. Faced with this, HIV positive people choose to keep the diagnosis hidden, even from friends and family, in fear of going through social repression and having their bonds with these people weakened or even broken ⁽⁵⁾. Thus, health professionals should be attentive of the mental health of people living with AIDS, as they may be in psychological distress due to the different situations they face, which are mainly related to the fear of affective rejection, family and social ⁽⁶⁾.

Given the complexity of living with AIDS as regards to the chronic condition, use of medications, prejudice and social stigma, we must emphasize the importance of care for people living with HIV / AIDS that nursing, as a profession that aims to care for patients, should assist them in the process of coping with the disease. In this sense, the objective of the study was to unveil the

scientific production of the last 10 years on the assistance of the adult with Acquired Immunodeficiency Syndrome.

Method

It is an integrative review of the literature that has is characterized by bibliographical survey, carried out in a judicious way. This allows the organization of scientific knowledge, in addition to bringing the researcher closer to the research topic and its evolution over time ⁽⁷⁾. In this way, the integrative review is characterized by summarizing knowledge as well as its applicability in the practical setting ⁽⁸⁾.

This integrative review was built respecting six stages: identification of the theme and selection of the hypothesis or guiding question of the research; establishment of criteria for inclusion and exclusion of studies; definition of the information to be extracted from the selected studies; evaluation of studies included in the review; interpretation of the results and presentation of the review and synthesis of knowledge ⁽⁹⁾.

To this end, the following guiding question was elaborated: what has been written in the last ten years about the assistance of the adult with Acquired Immunodeficiency Syndrome? Included in the review were studies made with human beings, published in full between the years 2008 and 2017 in the English, Portuguese and Spanish languages, and that, regardless of the design, dealt with the main theme, being available in the databases: Scientific Electronic Library Online (SciELO), Latin American and Caribbean Literature on Health Sciences Information (LILACS) and Nursing Database (BDENF). We excluded studies, dissertations, monographies, literature reviews, case studies, catalogs and letters to the editor that did not answer the research question. The database was consulted during the month of April 2017.

The descriptors used for the formulation of the research strategy were: "Assistance" and "Acquired Immunodeficiency Syndrome", which



were previously consulted in the Descriptors in Health Sciences (DeCS). It should be noted that "AND" was used between the descriptors, as Boolean operator. During the data collection, topics considered significant were classified, such as: type of publication, methodology and sample, place and year of publication, results presented with emphasis in the Network of Care, difficulties / facilities in the care given to adults with Acquired Immunodeficiency Syndrome , as well as the professionals' feelings about the disease.

After combining the mentioned descriptors, and applying the defined criteria, a total of 16 articles emerged in the SciELO database. Of this total, 12 studies were excluded because the title did not address the proposed theme, one because it was literature review and one for not having been performed by health professionals. Thus, 2 articles were selected in this database to compose this study through the aforementioned database.

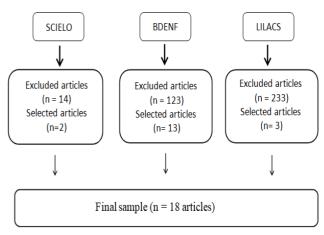
In the BDENF database, a total of 136 articles emerged. Of this total, 87 studies were excluded because the title did not address the proposed theme, 10 because they were literature reviews, one because it was also present in the other databases, one because it was an experience report and 17 after reading the abstract, since were performed with health professionals. Of these, a total of 20 studies remained for reading in full. After analyzing the texts, 7 studies were excluded, since the results presented did not answer the guiding question of this research. Thus, 13 articles were selected to compose this study.

In the LILACS database, a total of 236 articles emerged. Of this total, 195 studies were excluded because the title did not address the proposed theme, 10 because they were literature reviews, one because it was an experience report, 10 due to duplication with the other databases, and 8 for not being performed with health professionals. Of these, a total of 12 studies were left for reading in full. After the analysis of the texts, 9 studies were excluded, since the presented results did not answer the guiding question of this research. Thus,

3 articles were selected to compose this study.

In this way, 18 articles were selected to compose the sample, and a flow chart was elaborated to better understand the selection.

Flowchart 1. Search flow of articles selected for review. Pelotas, RS, Brazil, 2017.



Source: research data

Results

For a better understanding of the included studies, Tables 1 and 2 demonstrate the characterization of the studies included in this review. The language of the articles found was, for the most part, Portuguese. Most of the studies were carried out in Brazil, while one was carried out in Portugal. Most of the participants were nursing professionals, the others were performed with all professionals from the multiprofessional team.

Regarding the place of research, reference public hospitals for treatment of HIV / AIDS, Specialized Assistance Service ⁽⁴⁾, Basic Health Units (BHU) ⁽²⁾, Non-governmental institutions that provide assistance to people living with HIV ⁽¹⁾, Municipal Health Office ⁽¹⁾, Department of Infectious Diseases ⁽¹⁾, Outpatient Clinic for HIV / AIDS (1), Infectious Diseases Clinic and Specialized Assistance Service (1) , Center of Testing and Specialized Assistance Service (1) and home and



workplace of the interviewees (1).

Regarding the methodological approach, most of the studies analyzed used a qualitative approach, except two studies that used a quantitative approach. The data collection of the studies was done through a semi-structured interview (11), documentary analysis and oral history (1), open interview and direct observation using a field diary (1), open interview in depth (1), documentary analysis, field observation and semi-structured interview (1), oral history (1), standardized questionnaire (1) and previously structured forms (1).

Table 1. Identification of the studies regarding type and level of evidence. Pelotas, RS, Brazil, 2017.

Study	Type of study	Evidence level
1 Health promotion actions in an outpatient clinic specialized in HIV / AIDS ⁽¹⁰⁾ .	Qualitative	Level VI
2 Potentials and weaknesses of the care network of people with HIV / AIDS.	Qualitative	Level VI
3 The dimensions of nursing care provided to individuals living with acquired immunodeficiency syndrome.	Quantitative	Level IV
4 Social representations of care provided to HIV seropositive patients.	Qualitative	Level IV.
5 Representations of primary care professionals about HIV / AIDS.	Qualitative	Level IV
6 Care for people with HIV / AIDS from the perspective of health professionals.	Qualitative	Level VI
7 Palliative care in HIV / AIDS patients: principles of bioethics adopted by nurses.	Qualitative	Level VI
8 Teamwork and interdisciplinarity: challenges for the accomplishment of integrality in outpatient care for people living with HIV / AIDS in Pernambuco.	Qualitative	Level IV
9 Dental care for HIV patients in the public health care (SUS) services in Fortaleza, Ceará.	Quantitative	Level IV
10 Nursing care in Ambulatory Service Specialized in HIV / AIDS.	Qualitative	Level VI
11 Perception of AIDS by health professionals who experienced the epidemic during the care provided to people with the disease, in Florianópolis (SC), Brazil.	Qualitative	Level VI
12 AIDS and the first responses to the epidemic: contributions from health professionals.	Qualitative	Level VI
13 Social representations of HIV / AIDS by health professionals in referral services.	Qualitative	Level VI
14 Vulnerability, empowerment and knowledge: memories and representations of nurses about care.	Qualitative	Level VI
15 Between suffering and pleasure: vulnerability to nurses in interpersonal relationships with patients with HIV / AIDS.	Qualitative	Level VI
16 Challenges and confrontations in care by nurses: a study of social representation.	Qualitative	Level VI
17 Social representations developed by nurses who care for people with HIV on their vulnerability.	Qualitative	Level IV
18 The quality of health care of HIV patients: opinions of health professionals.	Quantitative	Level IV

Source: research data.

Table 2. Characterization of studies regarding sample, language, place and year of publication. Pelotas, RS, Brazil, 2017.

Study	Sample	Language	Place	Year
1	Three doctors, two nurses, two psychologists and one odontologist.	Portuguese	Brazil	2011
2	Eight people with HIV / AIDS and their network of care, totaling eighteen participants. Among the members of the family care network are: mother, sister, brother and wife. The members of the institutional-professional healthcare network were represented by physicians, nursing staff and psychologists.	Portuguese	Brazil	2015
3	78 nurses.	English	Brazil	2016
4	20 nursing assistants and 20 nurses.	Portuguese	Brazil	2010
5	Seven nurses and five doctors.	Portuguese	Brazil	2009
6	11 nurses and 11 psychologists	Portuguese	Portugal	2013
7	Twelve nurses.	Portuguese	Brazil	2013
8	35 subjects: the managers of the SAE-VIH / Aids studied (03); 13 technicians, representatives of each professional category directly involved in the assistance and who are part of the minimum team proposed by the Department of STD, AIDS and Viral Hepatitis; the State Coordinator of the STD and AIDS Program and the Municipal Coordinator of the STD and AIDS Program of Recife; and 17 users linked to the units surveyed.	Portuguese	Brazil	2012
9	186 dental surgeons.	Portuguese	Brazil	2010
10	Ten nurses.	Portuguese	Brazil	2016
11	Four doctors, eight nurses, four nursing technicians, three nursing assistants, one dentist, one nutritionist, one social worker and one psychologist	Portuguese	Brazil	2014
12	Três enfermeiras e três médicos.	Portuguese	Brazil	2015
13	86 health professionals	Portuguese	Brazil	2014
14	30 nurses	Portuguese	Brazil	2014
15	30 nurses.	Portuguese	Brazil	2013
16	30 nurses.	English	Brazil	2014
17	30 nurses	Portuguese	Brazil	2014
18	34 health professionals.	Portuguese	Brazil	2016

Source: research data





Discussion

After reading the articles, the results that were most discussed in the research were listed to be discussed in two thematic categories: "Assistance strategies for people with Acquired Immunodeficiency Syndrome" and "Difficulties faced by health professionals in the care of people with Immunodeficiency Syndrome Acquired ".

Assistance strategies for people with Acquired Immunodeficiency Syndrome

When analyzing the researches, it was possible to observe a series of strategies used assist people Acquired to with **Immunodeficiency** Syndrome. these In strategies, health professionals need, when caring for people living with the disease, to provide a care that is equal to that provided to others, free from prejudice and stigma, guaranteeing the individual a holistic care based on their needs (10).

This approach is based on the social stigma, which becomes a barrier that makes the access to the service harder, due to the lack of searching for assistance because of the fear of the prejudice they suffer on a daily basis ⁽¹¹⁾. That way, letting go of all judgements and negative actions becomes essential for health professionals, with the intention of reducing the impact of the disease on society and to bring the person closer to the service through a humane and integral treatment.

Therefore, a study shows that the inclusion of the theme in nursing schools is fundamental, based on the assumption that the professionals at some point will have to care for a person with AIDS. It focuses on the history of the disease and on the social impact. Furthermore, continued education is an

important care strategy, once it provides continuity and exchange of knowledge and experience between professionals, being the information subsequently used with the users in the form of health education (12).

At this juncture, a study (10) points out that health education is an essential tool for the care of people living with AIDS, since it has the role of informing the person about their social and welfare rights. In addition, it provides insight into the care of their health, changes in the daily routine and importance of adhering to treatment. Thus, this process empowers them and gives them greater control over their life, making them the protagonist of their care, in order to make them active in their care process Accordingly, another study (13) shows that health education promotes better acceptance of antiretroviral treatment and links health professionals and people living with HIV / AIDS, through guidelines that encourage fighting the disease.

Another form of assistance that was relevant was communication and active listening as potentialities in the care process of person living with the Acquired Immunodeficiency Syndrome. These provide the individual moments of guidance and conversation, as well as an opportunity to vent and alleviate their anxiety. Therefore, by giving a voice to HVI positive people, professionals provide a warm and comfortable environment to express their feelings and anguishes, and consequently strengthen the bond between both parties by showing interest and providing care in a comprehensive way, being wholly available (11).

The dialogue between the professional and the person living with AIDS is essential to encourage and stimulate continuity of



treatment, with the objective of improving the quality of life of the patient (14). On the other hand, another study (15) was analyzed that discusses the difficulties that the professionals face in approaching people to intervene and improvement in their habits, stimulate frustrating the professionals working in the service. It is important to emphasize the importance of helping the population to know and understand the relevance of adopting the protective practices of HIV infection (16) However, in order to achieve that, health professionals need to know the meaning that people who they intend to care for attribute as they contract the virus.

Another technique to be approached is the demonstration of affection that is pointed out as a way of sensitizing to the situation lived bν the person with Acquired Immunodeficiency Syndrome (17). Thus, by providing support and understanding for these people's experiences, the professional shows empathy, which helps them to provide care in a holistic way in moments of fragility. In addition, the establishment of trust gives the professional the opportunity to know and understand the patient's daily life, identifying their physical and psychosocial needs, as well as providing more effective care, according to their needs (17).

As far as communication is concerned, it should be emphasized that because it is a stigmatizing disease, the person living with HIV / AIDS has the right to keep the diagnosis confidential, and it is incumbent upon the professional not to disclose the diagnosis to other people participating in the network of this support, thus acting ethically in their professional practice (18). That way, professional ethics are essential in the care of HIV-positive people, in order to preserve their

rights and reduce the negative impacts of stigmatization of the disease in society, also helping improve their quality of life (19).

Teamwork is described as an important strategy in the care of people living with Acquired Immunodeficiency Syndrome, because it is through this that actions of planning, evaluation and interaction between the professionals of the multiprofessional team are developed, reflecting directly in the patient's care ⁽²⁰⁾. Thus, it is relevant to offer dental care in the integral care of these people, since oral maintenance has the capacity to directly influence the behavior of the disease, avoiding possible complications coming from it ⁽²¹⁾

In addition, a study (22) addresses the importance of bringing family members to care, as they become critical in actively participating the care process, facilitating encouraging treatment adherence, stimulating self-care. Finally, the importance of comprehensive and humanized care for people living with AIDS is recognized, and the constant training of health professionals is indispensable, in order to contribute to and guarantee the quality of the care provided through strategies that bring the patient closer to professionals, that guarantees respect, equity and the provision of humanized care, free from negative actions and prejudice.

Difficulties faced by health professionals in the care of people with Acquired Immunodeficiency Syndrome

The beginning of the Acquired Immunodeficiency Syndrome epidemic was historically marked by fear, allied with discrimination and stigmatization of the people diagnosed with the pathology. This is related to the fact that the disease initially mostly



affected homosexuals, injecting drug users and sex workers, as well as being an uncurable disease. As a result, many health professionals have refused to work in institutions that take care of these people, reinforcing prejudice and discrimination against them ⁽²³⁾. It is known that, historically, stigma and prejudice directly affected the care given to these people, because the professionals were pressured by the media that exploited the disease with sensationalist articles that reinforced intolerance and prejudice ⁽²⁴⁾.

Currently, prejudice and stigma still represent barriers in the care service, as professionals bring the historical negative perceptions to the care, in the form of judgment and the blaming of people living with AIDS. This behavior results in the fragility of the bond established between both parties, negatively impacting the quality of the care provided ⁽¹²⁾. At this juncture, professionals still have negative feelings about caring for people living with Acquired Immunodeficiency Syndrome, since they fear being infected ⁽²⁵⁾.

According to one study (26), professionals feel vulnerable when caring for people living with the disease due to lack of knowledge and of information lack about Acquired Immunodeficiency Syndrome. Thus. thev classify the first contact with the user as a traumatizing event, since they did not have enough knowledge to base their practice on. Complementarily, professionals corroborate the lack of knowledge to base the care of people living with Acquired Immunodeficiency Syndrome, but report that the uncertainty motivates the search for information to base their practices and make them feel confident enough to care for these people (27).

Thus, the first contact of the professional with the seropositive patient represents a

turbulent moment because it is a chronic disease that is usually accompanied by the suffering experienced by the patient and his / her relatives (28). In this sense, care for people with HIV / AIDS becomes exhausting due to the physical and psychological demands of the disease, since it requires intensive and ongoing care of their physical and psychosocial wellbeing. The increase in demand, the reduced number of specialized professionals and the limited physical structure appear as fragilities the care of people with Acquired Immunodeficiency Syndrome. By acting in precarious conditions with an excessive number of patients, professionals become overwhelmed and discouraged, directly interfering with the quality of the care provided (11).

Another study (10) points out that the difficulties related to physical space and human resources have an impact on the implementation of care and health promotion. Thus, the lack of good infrastructure affects both the patients and professionals, since they feel uncomfortable in providing care in precarious conditions, making them vulnerable to situations of stress and work overload (29). A study with health professionals reinforced that they feel a dissatisfaction related to the work structure and work conditions when taking care of the person with AIDS. However, most believe that the quality of the assistance provided is adequate, being satisfied with the support provided by the service to these patients (30).

In this perspective, the shortage of professionals in the service makes it difficult to participate in collective actions, which weakens the work of the multiprofessional team. This way, the assistance provided is fragmented, since the team works in a dismantled way.



Such support is strongly influenced by the biomedical model which revolves around curative actions, interfering and making the integral attention to users more difficult ⁽²⁰⁾. There are also other difficulties that corroborate with the fragmentation and decentralization of the care provided, such as the discontinuity and lack of planning of the actions performed by the professionals of the team ⁽¹⁵⁾.

In addition, the professionals also point out difficulties in approaching seropositive people due to the fear of their reaction when receiving the diagnosis (27). Often, professionals are targets of physical and verbal assault resulting from the state of revolt of the person who just received the diagnosis, which places the professionals in a situation of vulnerability in the daily care of the people living with the disease. Consequently, it is necessary to increase the number of professionals in the nursing services in order to improve the care provided, since it would allow them to have more time to participate in team meetings, and care planning and performing.

Conclusion

When answering the guiding question, the present study identified some assistance strategies of health professionals in the care people with Acquired Immunodeficiency Syndrome, as well as the difficulties faced by them. The social stigma and prejudice against this chronic disease are presented as difficulties in the provision of an integral and humanized care to people who suffer from it. However, it has also been observed that there is prejudice on the part of health professionals who often do not have the qualification to meet this demand.

That way, one can notice the necessity of practical actions such as providing permanent education within health service. The objective is to bring awareness to the health team regarding the act of letting go of all judgement and negative behaviors when caring for HIV positive patients, thus guaranteeing a holistic assistance.

In addition, it's fundamental for the professionals who are acting in said service to work together in order to consolidate the care and make it integral. To this end, it's important to take actions that allow the exchange of knowledge between the members of the service in question, aiming to tackle the difficulties of the care of people who were diagnosed with AIDS, as well as allowing the planning and the continuity of the given assistance.

The study is limited by the lack of scientific articles about the subject. However, this research brings an important contribution for healthcare practitioners and academic training too. That way, they can ponder over the discrimination against seropositive people, given the fact that there is an invisibility that silences them. This reflection, in addition to the discriminatory process, adds knowledge especially regarding the issue of patient autonomy and its effective participation in care with a focus on prevention, implementing strategies to reduce stigma, creating care practices that can be (re) constructed in social and affective relations.

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