HIV/AIDS care according to the perspective of healthcare providers

O CUIDADO A PESSOAS COM HIV/AIDS NA PERSPECTIVA DE PROFISSIONAIS DE SAÚDE

CUIDADO DE PERSONAS CON VIH/SIDA DESDE LA PERSPECTIVA DE PROFESIONALES DE LA SALUD

Carla Sofia de Oliveira Sousa¹, Alcione Leite da Silva²

ABSTRACT

The present study aimed to understand the care provided to patients with HIV/AIDS in Portugal according to the healthcare providers' perspective. Thompson's method of oral history was used in the study, which included 22 healthcare providers. The data were collected by means of semi-structured interviews and were analyzed from the narrative compilation perspective formulated by the author using QSR Nvivo software. The study complied with the ethical precepts for research. Care was analyzed according to three dimensions: cognitive, affective-relational, and technical--instrumental. The participants attributed particular relevance to the cognitive dimension in association with the moment when the diagnosis of HIV/AIDS was established, as well as throughout the course of disease. The affective-relational dimension was cross--sectional and considered to be valuable throughout the course of the disease from its diagnosis to the death of the patients with HIV/AIDS. The technical-instrumental dimension was more expressive in the advanced stages of the disease, in patients suffering from addiction and in terminal illness. As a function of the results, we can conclude that the three investigated dimensions are highly relevant for the care of patients with HIV/AIDS.

DESCRIPTORS

HIV Acquired immunodeficiency syndrome Health personnel Nursing care Qualitative research

RESUMO

Este estudo teve por objetivo compreender o cuidado as pessoas com HIV/aids, na perspectiva de profissionais de saúde, em Portugal. Foi desenvolvido através do método da história oral, de Thompson, com a participação de 22 profissionais de saúde. Os dados foram obtidos através de entrevista semiestruturada e analisados com base na perspectiva de coletânea de narrativas, propostas pelo autor com o apoio do programa QSR NVivo. Os aspectos éticos foram obedecidos ao longo do estudo. O cuidado foi agrupado em três dimensões: cognitiva, afetiva-relacional e técnico-instrumental. A dimensão cognitiva destacou-se no período da revelação do diagnóstico de HIV/aids e ao longo da evolução da doença. A dimensão afetivo--relacional foi transversal e valorizada em todo o processo, desde o diagnóstico até à morte das pessoas com HIV/aids. A dimensão técnico-instrumental foi mais expressiva na fase mais avançada da doença, em situação de dependência e de terminalidade. Diante do exposto, podemos concluir que estas três dimensões são fundamentais para o cuidado à pessoa com HIV/aids.

DESCRITORES

HIV Síndrome de imunodeficiência adquirida Pessoal de saúde Cuidados de enfermagem Pesquisa qualitativa

RESUMEN

Este estudio tuvo por objetivo comprender el cuidado de las personas con VIH/SIDA, desde la perspectiva de profesionales de la salud, en Portugal. Fue desarrollado basándose en el método de la historia oral de Thompson, con la participación de 22 profesionales de la salud. Los datos fueron obtenidos a través de la entrevista semiestructurada y analizados desde la perspectiva de agrupación de relatos, propuestas por el autor con el apoyo del programa QSR NVivo. Los aspectos éticos fueron seguidos durante todo el estudio. El cuidado fue agrupado en tres dimensiones: cognitiva, afectivo-relacional y técnico-instrumental. La dimensión cognitiva de cuidado se destacó en el momento de la revelación del diagnóstico de VIH/ SIDA y a lo largo de la evolución de la enfermedad. La dimensión afectivo-relacional fue transversal y valorada durante todo el proceso, desde el diagnóstico hasta la muerte de las personas con VIH/SIDA. La dimensión técnico-instrumental fue más expresiva en la etapa más avanzada de la enfermedad, en el momento terminal y de dependencia. Teniendo en cuenta lo anterior, se concluye que estas tres dimensiones son fundamentales para el cuidado de la persona con VIH/SIDA.

DESCRIPTORES

VIH

Síndrome de inmunodeficiencia adquirida Personal de salud Atención de enfermería Investigación cualitativa

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¹ Gerontologist. MA in Gerontology. Specialization in Family- and Community-Based Intervention. Aveiro, Portugal. carlasousa@ua.pt ² Nurse. PhD in Nursing. Guest Associated Professor, Department of Health Science, University of Aveiro. Aveiro, Portugal. alsilva@ua.pt



INTRODUCTION

In the third decade since the onset of the epidemics, the acquired immunodeficiency syndrome (AIDS) is a chronic, contagious, and debilitating disease, demanding a revamped healthcare structure. AIDS imposed a holistic approach towards the ill individual and compelled healthcare providers to address issues seldom taken into consideration hitherto, such as sexuality, difference, loss, and death. AIDS also brought affective and social issues to the foreground, making evident healthcare providers' lack of preparation and disorientation relative to the care of the affected individuals. The chronic nature of AIDS remains a challenge facing the healthcare services and professionals with regard to improving the quality of care.

Despite thirty years of experience in the care of individuals infected with the human immunodeficiency virus (HIV)/AIDS, there is a lack of studies on the perspective of the healthcare providers about HIV healthcare.

Available empirical evidence indicates the need for

professional training aimed at increasing healthcare providers' knowledge⁽¹⁾, enhancing their awareness of the disease and the affected individuals⁽¹⁻²⁾, and changing their attitudes. This evidence also demonstrates that because of the stigma and discrimination associated with this disease, AIDS continues to pose a major challenge to healthcare providers and society at large⁽³⁾. The studies on the care of individuals with AIDS

demonstrate that involved professionals

must learn how to cope with the feeling of

powerlessness triggered by terminal illness

and death^(2,4) by means of steady, although

sometimes painful, reflection on their limits as healthcare providers⁽²⁾. Professional experience leads the healthcare providers to gloss over the suffering caused by AIDS and to direct care and treatment efforts towards the most subjective aspects⁽⁵⁾. Other studies have identified the difficulties healthcare professionals have in dealing with drug users (3,6). According to the investigated professionals, such difficulties arise from the poor adherence to antiretroviral therapy of such patients and the fact that they exhibit undesirable behaviors, lack discipline, and cause countless problems for the healthcare services⁽⁶⁾. One study found that nurses from rural areas in the United States are concerned with the risk of contamination as an occupational hazard as well as with the potential threats posed by the patients' behavior to society at large⁽⁷⁾. Those nurses also believe that confidentiality with respect to HIV status and the implementation of proper precautions are important in the assistance of any patient with HIV/AIDS⁽⁷⁾.

We were not able to locate any published study addressing the cognitive, affective-relational, and technical-instrumental dimensions of care in the case of patients with HIV/AIDS, particularly in Portugal. For these reasons, the aim of the present study was to understand the care provided to patients with HIV/AIDS in Portugal according to the healthcare providers' perspective.

THEORETICAL FRAMEWORK

Currently, healthcare includes several dimensions designed to meet the needs of patients. In the present study, we chose to analyze three closely correlated dimensions⁽⁸⁾: the cognitive, affective-relational, and technical-instrumental dimensions.

The cognitive dimension relates to knowing knowledge, i.e., the scientific competency of healthcare providers that underlies their professional action. This dimension is of paramount importance in all areas of health interventions, including the promotion of health, the prevention of disease, diagnosis, and therapeutic decision-making, as well as in the recovery and rehabilitation of affected individuals. One of the healthcare providers' duties is to help people acquire the knowledge needed to make decisions and behavioral changes to improve their state of health and well-being.

For that purpose, healthcare providers must develop professional and personal competencies to orient, inform, support, and meet the needs of their care recipients.

The affective-relational dimension involves knowing how to be and results from interactions that allow the healthcare providers to express their subjectivity as related to their personal experience. The affective-relational dimension is concerned with how one manifests affection, is entirely present, and attributes value to other people⁽⁸⁾. Showing affection is typically considered a

modality of care that manifests in demonstrations of love, endearment, and friendship, which represent manners of paying attention to someone else and to what one is doing⁽⁸⁾. This dimension includes relationships based on mutual appreciation and trust, where responsibility, commitment, respect, and valorization of the other individuals are present⁽⁸⁾. Verbal and nonverbal communication plays a crucial role in this type of relationship because it facilitates positive actions/relationships/interactions between healthcare providers and care recipients⁽⁹⁾.

Finally, the *technical-instrumental dimension* of care involves quality and competency in action as well as specialized technical interventions imbued by *knowing how to do*⁽⁸⁻⁹⁾. This dimension includes the technical-scientific knowledge and the skills required to act⁽⁸⁾.

METHOD

Verbal and nonverbal

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The present study was based on the qualitative paradigm and used Paul Thompson's⁽¹⁰⁾ oral history method by means of the narrative compilation perspective.



The settings selected for the present study were organizations/institutions that assist individuals with HIV/AIDS and that agreed to participate. Thus, seven nonprofit nongovernmental organizations (NGOs) from northern, central, and southern Portugal and one hospital in the north of the country were included. The included NGOs offer home support, perform activities targeting education on HIV/AIDS, and include centers for psychosocial assistance. The hospital, in turn, includes admission units as well as an outpatient clinic for patients with HIV/AIDS.

Among the healthcare professionals who were invited to participate, only nurses and psychologists tending to individuals with HIV/AIDS agreed to participate, and the sample was a convenience sample. The inclusion criteria were the following: healthcare professionals from both genders with at least one year of experience in the assistance of individuals with HIV/AIDS who agreed to participate in the study and signed an informed consent form.

The data were collected from December 2010 to April 2011 by means of semi-structured interviews⁽¹⁰⁾. The instrument that was employed had two separate sections; the first corresponded to the informants' characteristics, and the second included one single open-ended question: *Tell me about what caring for people with HIV /AIDS means to you?* The interviews were conducted in a reserved room at the participants' workplace, recorded using a digital voice recorder, and lasted 35 minutes on average.

Data analysis comprised three stages: organization and structuration, classification, and interpretation⁽¹⁰⁾. During the first stage, the data were transcribed, the interviews were read as one single unit, and reflection ensued. The interviews were listened to and read many times to ensure that the transcriptions were as trustworthy as possible and to allow for the analysis and organization of the most important ideas by approaching the dataset as a whole rather than in a fragmented manner.

During the second stage, the interviews were read many times to identify the internal coherence of each narrative as well as their main ideas, key-moments, and the participants' stance relative to the investigated subject. This procedure allowed the construction of empirical categories and their corresponding subcategories based on the three dimensions previously mentioned, which were transformed in theoretical analytical categories. Each category subsumed the parts of the interviews related to a definite subject. Also during the second stage, we performed a cross-sectional reading of the interviews per category and made the required revisions and alterations. Categorization was performed using software -QSR Nvivo 1.7 for qualitative analysis. The third stage comprised the interpretation of the categories as a function of the selected theoretical and empirical framework and the study aims.

The study was approved by the hospital ethics committee (reference 180-CES) according to the stipulations in

Decree-law No. 97/1995⁽¹¹⁾. All of the procedures in the study complied strictly with the ethical precepts, whereby the participants' anonymity and the confidentiality of the data were protected, and the volunteers were required to sign an informed consent form. Consistent with the assumption of anonymity, each participant was assigned a code, which consisted of a letter corresponding to their profession (N for nurses and P for psychologists), a letter for the type of institution (O for NGOs and H for the hospital), a letter for the gender (M for males and F for females), and a number corresponding to the successive order of the interviews.

The study rigor was ensured by applying the following standards: credibility (respect for the truth as known and expressed by the participants), confirmation (collection and validation of the primary data), meaning within context (two types of healthcare professionals acting in similar and/or different contexts), establishment of patterns (repeated experiences relative to the investigated subject), and data saturation (data were collected until no novel information was reported on the investigated subject)⁽¹²⁾.

RESULTS

A total of 22 volunteers participated in the present study, including 11 nurses (six males and five females) and 11 female psychologists. Among the nurses, seven worked at the NGOs, and four worked at the hospital. Among the psychologists, 10 worked at the NGOs, and one worked at the hospital. The participants' ages varied from 24 to 56 years old (33 years old on average), varying from 24 to 56 (mean=36) years old among the nurses and from 26 to 40 (mean=30) years old among the psychologists.

The participants' perspectives on care were analyzed based on their narratives according to the three above-mentioned dimensions, i.e., cognitive, affective-relational, and technical-instrumental. Although these dimensions are closely interrelated, they were presented separately.

Cognitive dimension of care

In most of the interviews (n=16, five NM, three NF, and eight P), the cognitive dimension was closely associated with health education and prevention campaigns. This dimension was considered most relevant at the time of diagnosis, which requires significant information on the HIV/AIDS health-disease process and its treatment and healthy lifestyles along the progression of disease. Health education manifested as the need to provide the care recipients orientation relative to the infection by HIV and AIDS. Topics such as transmission, reinfection, and treatment were mentioned, as some of the participants had little or no knowledge of them. The participants also considered it important to convey the idea that although there is no cure for AIDS, it can be treated. In addition, the volunteers observed that orientation to the medications is crucial, as well as, more particularly, orientation to the benefits of adhering to treatment and the consequences of



non-adherence. Other issues mentioned by the participants related to the progression of disease, the relevance of the use of condoms, and the need to elucidate the patients' doubts, concerns, and fears. The participants also indicated the need to dispel myths, prejudice, and misconceptions, to inquire on the patients' expectations, to deconstruct beliefs, and to adjust the information to the beliefs, culture, and educational level of the care recipients.

Now, we try to convey the idea that, indeed, there's no cure for this disease but that it can be treated, and if they follow the treatment in an assertive manner, they might live with the infection many years and with good quality of life (NHM2).

We have to try and convey the information in a way that fits the beliefs, culture, and the way people cope with the given information (POF1).

According to the psychologists, adherence to treatment and to the scheduled visits is linked to the trust the individuals with HIV/AIDS have in their healthcare providers, to the room granted to them, to the way one approaches information, and to familial support. The latter was considered important inasmuch as it provides support to the individuals with HIV/AIDS. The participants also observed that injectable drug users have more difficulty in complying with treatment, as their links to their families are usually severed and as they have become marginalized and lack well-defined goals in life.

It's different when they're in the family setting and understand that it's worth going on than when they have no reason to go on. As the men we have here have a history of drug addiction and gave up their families long ago, they have no reason to fight, and therefore, it's more difficult for them to adhere to treatment (POF6).

With respect to medication, the participants observed that vomiting and diarrhea are frequent occurrences at the onset of treatment. Those symptoms often lead the individuals to discontinue the treatment because as they do not feel that they are ill and they judge that they have nothing to lose. Thus, the participants believe that the side effects of the medications should be discussed with the patients together with the initial and long-term effects of treatment.

First, because the initial stage makes the individuals feel quite ill, a series of symptoms, vomiting and diarrhea. Quite often this makes them give up, and why? Because they aren't sick; they have a virus but aren't sick (NOM3).

It's important to orient them to the medications they have to use, both with respect to their initial effects and to the long-term ones and the consequences of stopping the medication (NOM4).

Health education must fit the characteristics and expectations of the patients with HIV/AIDS. That is, education must take their cognitive skills into consideration as well as their educational level, habits, age, gender, sexual orientation, race/ethnicity, religion, and social class, among other

traits. The population of people with HIV/AIDS is remarkably diversified. Consistently, the participants observed that at times, they need to educate the care recipients on even the most basic features, such as brushing the teeth, shopping, preparing meals, and cleaning the house. In the case of couples, orientation must take into account their HIV status, as the seroconcordant ones tend to believe they do not need protection. Such misguided ideas must be deconstructed, as the partners might be at different stages of progression or exhibit different viral strains. The participants considered this information important for the care recipients to become responsible for themselves and thus enhance their autonomy.

It's important to demystify the ideas they have, even in the case of two infected people, that is, a couple in which both partners are infected. They have to realize they might be at completely different stages of disease progression, or they might have completely different viral strains, and they can be coinfected by another disease the partner doesn't have and that thus becomes easier to transmit. These and many other issues should be discussed with them, but there's that lack of concern, before or after contagion (POF10).

The volunteers also take part in *prevention campaigns* involving the distribution of condoms and orientation, in places where youths and adolescents tend to gather, such as clubs, schools, and school parties. Occasionally, the participants give lectures at schools, where they talk about their personal experience.

With respect to the specific prevention campaigns, many of them are launched upon a school's request or under more concrete circumstances, for instance, when we take part in programs in which these topics are included (NOM1).

Mainly at school parties, and targeting the students; also at the events associated with the World AIDS Day, which target the overall population (POF6).

Affective-relational dimension of care

This dimension of care was detected in almost all of the participants (n=19, five NM, four NF, and 10 P) and was reported to manifest along the entire process of care, i.e., from diagnosis to death. The most valuable features of this dimension were as follows: respect, showing affection, attention, provide comfort, trust-based relationships, and communication.

Respect was mentioned as a way of showing appreciation to the individuals with HIV/AIDS, and its association with the various ages, races/ethnic groups, and religions was stressed. In addition, the participants also reported respecting the sexual practices and lifestyles of older adults.

We must respect the differences relative to religion, culture, and academic degree (...) There are also homosexual older adults, who must also be respected regarding their sexual practice and lifestyle (POF1).



Showing affection was characterized as a manifestation of sensitivity in the care of patients with HIV/AIDS, who as a rule are removed from their families and society at large. According to the participants, affection might eventually replace the family. That feeling also grounded the participants' disposition to help patients with HIV/AIDS and was also related to the themes provide support, understand the other, accept the other unconditionally, endearment, greet by kissing and hugging, be together and present one to the other, shake hands, and attribute value to other people.

I don't know if you've noticed, but they cling to us all the time, kiss us, hug us, want to talk to us (...) We're their family (...) When there's no family, we replace it (NOF2).

To me, care means helping other people give meaning to issues they find difficult to work out (...) To care is to help, to understand, to listen, to listen actively; it is to accept other people unconditionally (PHF1).

Attention was also mentioned by the participants within the context of the care recipients' specific needs and their availability to and interest in them. Attention must be directed to the physical, biological, psychological, and emotional needs as well as to the particularities associated with gender, age, and social class. Attention was also expressed as concern with other people, which the participants manifested by asking the care recipients how are you? or how do you feel? and by prioritizing the human being at the expense of social prejudice. Attention was hinted at in expressions such as make us available to other people, relate, and build a bridge.

Care means to pay attention and to make us available to other people. It's to look at other people trying to wear different glasses, or all types of glasses, rather than looking with my own eyes through my preconceptions. Because no matter how much I might fight them, I'll always have them, and they'll always keep on coming. It's like with anyone else, I try to identify them and then to make them vanish. Yet, to me, to care for people is to pay attention above all, to relate, to build a bridge (...) Each person is different; the same thing affects different people in different ways, and one should pay attention to the attention given to each particular individual (NOM3).

Another component of the affective-relational dimension related to the theme *providing comfort*. According to the participants, providing comfort to patients with HIV/AIDS involves caring for their environment, which must be quiet and pleasant. Comfort and privacy were also significant. Comfort bore close association with the basic needs and the psychological well-being of the care recipients, especially when they reached the more advances stages of disease.

Yes, it's also an important moment. This is the reason: no matter where they are, the place where they live, to try and provide them as much comfort and privacy as possible. Because they need to rest. That moment of quiet and peace is important (POF1).

Developing a *trust-based relationship* was considered essential to give support to people under vulnerable circumstances. Such a type of relationship also allows knowing, understanding, and accepting other people and facilitates change. However, trust-based relationships are not always easy to establish. For instance, trust-based relationships were reported as particularly difficult relative to injectable drug users. Professional secrecy is crucial for trust-based relationships because it is the component that allows for closeness to develop.

One of the earliest difficulties I encountered upon working with these patients had to do with the relationships [with drug addicts] (NHM1).

Professional secrecy is crucial in relationships; that is, people must feel that the privacy of what they share is guaranteed (POF1).

Relative to *communication*, nonverbal communication and active listening were identified as crucial. The participants observed that they must pay attention to nonverbal communication because people with HIV/AIDS often exhibit difficulty in making their needs known. Active listening was considered to represent a manifestation of interest and concern relative to the care recipients as well as a manner of being entirely present.

Therefore, here we have to be the mediators in this situation, and we have to pay more attention to the nonverbal communication than to the verbal communication, that is, the type that is more complex (NHF3).

This is why I say that internal availability is very important for authenticity within the relationship. Those people *ask a lot* silently; they need us to be available quite often, and we have to be truly able to be [available] (POF1).

Technical-instrumental dimension of care

The technical-instrumental dimension of care was mentioned by the entire subsample of nurses exclusively and was particularly relevant in the advanced stages of disease when the patients become more dependent on the care providers. The most remarkable features associated with this dimension were as follows: nutrition, bathing, dressing and undressing, providing comfort, changing dressings, inserting tubes, and administering medications. These technical aspects were mentioned by the nurses from both investigated settings and are important to meeting the needs of the individuals with HIV/AIDS. The topic nutrition included the need to adjust the diet to each individual and to meet their needs and preferences as much as possible, while taking their cultural mores and beliefs into consideration.

As healthcare providers, we also have to tend to the patients in advanced stages of disease. In those stages, one has to pay attention to the patients' comfort, hygiene, everything. They must feel comfortable. When there's a need, I feed them and I bathe them (NOF2).



The nurses who work in the hospital setting placed particular emphasis on the *blood collection* required for laboratory tests as well as on the gastric tube.

Often we believe that caring involves just bathing, just nutrition, just the gastric tube; it doesn't (...) Naturally, people show up when I'm going to collect a blood sample; there are techniques for all those kind of things (NHF3).

DISCUSSION

For the present sample of healthcare providers, the cognitive dimension of care was of paramount importance in both the actual care of patients with HIV/AIDS through actions related to health education as well as the prevention of transmission through the participation in campaigns. *Health education* manifested as the need to provide the care recipients orientation relative to contamination and reinfection by HIV, AIDS, and treatment. Furthermore, in the literature, this dimension is associated with orientation^(5,13) to enhance the adherence to treatment and the consequent improvement of the quality of life of individuals with HIV/AIDS⁽⁵⁾.

The interviewed healthcare providers considered it essential to provide orientation relative to the medications, their benefits, and the consequences of non-adherence to treatment based on the fact that AIDS is incurable. This type of orientation and follow-up was considered relevant as a function of the serious side effects of the medication, including nausea and vomiting, which often lead individuals with HIV/AIDS to discontinue treatment⁽¹⁴⁾. These findings have also been reported in the literature because the intermittent use of antiretroviral drugs correlates with the emergence of viral resistance⁽¹⁵⁾. The particular difficulty of drug addicts in complying with antiretroviral treatment reported in the present study is also consistent with the reports in the literature⁽⁶⁾.

The topic *prevention campaigns* was also detected in the present study, as well as in the literature, which stresses the fact that healthcare providers should not restrict their action to the divulgation of information because information alone does not lead to changes in attitudes or behaviors⁽¹⁶⁾.

The *affective-relational* topic was the care dimension to which the interviewed nurses and psychologists attributed the most value in the care of individuals with HIV/AIDS. *Respect* was understood as a way to manifest appreciation of the care recipients independent of their age, race/ethnicity, religion, and decisions made. In the literature, *respect* is associated with *beliefs and values, feelings,* and *abilities and limitations of the infected people*⁽¹³⁾.

The data collected in the present study relative to the topic *showing affection* are consistent with the literature. Studies conducted in Brazil on the care of individuals with HIV/AIDS identified *give support, understanding*⁽⁵⁾, *empathy*⁽⁴⁻⁵⁾, *show affection and kindness, be patient, exchange emotions and expectations, understand, give up prejudice and preconceived notions, share, hold hands, walk together*

in the quest for friendship and trust, smiling, and exchange warmth in the relationship with care recipients as further expressions of showing affection⁽¹³⁾. In addition, the participants in the present study also reported that affection is able to replace the care recipients' families, which agrees with the findings of other authors⁽¹⁾.

The disposition to help people with HIV/AIDS was also an expression of affection manifested by the participants and can be found in the literature as a human response to a call for help⁽¹⁷⁾. Such a response is actualized in the healthcare universe whenever its inhabitants are engaged, committed, feel co-responsible, and are present in a face-to-face relationship with each other⁽¹⁷⁾.

Attention was also an expression included in the affective-relational dimension, which the participants associated with the satisfaction of the care recipients' specific needs and their own availability for and interest in them. According to the participants' narratives, attention encompasses a full field extending from the detection of the physical, biological, psychological, and emotional needs of the care recipients to their singularities related to gender, age, and social class. Furthermore, the literature associates the notion of care with the attention paid to someone for the sake of his or her well-being⁽⁶⁾, support, and solidarity⁽⁵⁾. Therefore, according to the literature, caring for patients with HIV/AIDS demands that the care providers approach the recipients as human beings with specific needs who are fragile and deserving of respect and attention⁽¹⁸⁾.

According to the participants, providing comfort to people with HIV/AIDS also encompassed their environment, which must be quiet and pleasant. Comfort was also defined as having close ties with the basic needs and the psychological well-being of the care recipients in the advanced stages of disease. These findings are consistent with the literature, which emphasizes the fact that the treatment of terminal patients requires additional care and involves providing comfort, pursuing healthier lifestyles, stimulating the care recipients to fight for their lives, and being close to them⁽¹⁹⁾. At that stage of disease, comfort also includes helping the individuals and their relatives cope with disease, providing symptom relief, and allowing death to occur in a dignified and comfortable manner⁽¹⁹⁾.

Trust-based relationships proved to be of paramount importance for the participants to be able to provide support to individuals under vulnerable conditions. These relationships also allow the care providers to know, understand, and accept the recipients and to facilitate change. According to the literature, care is based on relationships involving appreciation and trust, which are expressed through the responsibility for, commitment to, respect towards, and valorization of the care recipients⁽⁸⁾.

The participants consider active listening a manifestation of their interest in and concern for the care recipients, as well as a manner of being entirely present to them. According to



the literature, communication is crucial in the care provider-recipient relationship and is consubstantial with *knowing how to listen, listening, understanding anguish and expectations,* and *reducing frustrations and fears*⁽¹³⁾. Verbal and/or nonverbal communication allows care providers and recipients to share feelings, emotions, perceptions, and values^(9,17). Communication is also important to encourage the patients with HIV/ AIDS in their fight against the disease and to enhance their adherence to treatment to improve their quality of life⁽³⁾.

The technical-instrumental dimension of care was exclusively mentioned by the subsample of nurses in the present study and was more significantly associated with the advanced stages of disease. More particularly, it was expressed as nutrition, bathing, dressing and undressing, providing comfort, changing dressings, tubes, and administering medications. The nurses from the hospital setting also emphasized the collection of blood samples for laboratory tests as well the care of the gastric tubes. These findings are supported by the literature, which associates the technical-instrumental dimension of care with specialized technical interventions imbued by the knowledge of how to perform such interventions⁽⁸⁻⁹⁾.

CONCLUSION

The aim of the present study was to address the care of patients with HIV/AIDS from the perspective of the healthcare providers in Portugal based on three dimensions of care: cognitive, affective-relational, and technical-instrumental. Only nurses and psychologists agreed to participate in the study. The cognitive dimension was identified by the participants as being particularly relevant at the time when the diagnosis of HIV/AIDS is first established

and communicated as well as throughout the course of disease and was associated with health education, disease prevention, and participation in prevention campaigns. The affective-relational dimension was cross-sectional and was attributed value throughout the process of caring for patients with HIV/AIDS. Respect, showing affection, attention, comfort, trust, and communication stood out among the expressions relative to this dimension. The technical-instrumental dimension was more significantly associated with the advanced stages of disease, patients suffering from addiction, and terminal illness. This dimension was expressed as procedures including providing comfort, changing dressings, inserting tubes, and collecting blood samples. The nurses' and psychologists' narratives tended to converge with respect to the cognitive and affective-relational dimensions of care, whereas only the nurses mentioned its technical-instrumental dimension. The nurses' expressions relative to the care dimensions did not differ as a function of gender. Based on the results, we can conclude that the three investigated dimensions of care are valuable for the participants and are an integral component of care for patients with HIV/AIDS.

The results of the present study are supported by the literature. With respect to study limitations, representatives of only two healthcare professions, i.e., nurses and psychologists, agreed to participate in our study. Due to the lack of studies in this field focusing on the three investigated dimensions of care, we recommend that further studies be conducted including other healthcare professions, different settings, and patients with HIV/AIDS. Thus, knowledge will increase, and we will be able to improve the quality of the care provided to patients with HIV/AIDS.

REFERENCES

- Salada ML, Matias LO. Os significados atribuídos ao cuidar de pacientes com AIDS. Rev Esc Enferm USP. 2000;34(1):1-8.
- Resuto TJ, Mendes SN, Oliveira MT, Lourenço EL. A assistência de enfermagem aos portadores de HIV/AIDS no vislumbrar da sua epidemia em Ribeirão Preto. Relato de experiência de uma equipe de enfermagem. Rev Esc Enferm USP. 2000;34(3):2333-9.
- 3. Formozo GA, Oliveira DC. Representações sociais do cuidado prestado aos pacientes soropositivos ao HIV. Rev Bras Enferm. 2010;63(2):230-7.
- Alves IC, Padilha MI, Mancia JR. A equipe de enfermagem e o exercício do cuidado a clientes portadores de HIV/AIDS. Rev Enferm UERJ. 2004;12(2):133-9.
- Ribeiro CG, Coutinho MP, Saldanha AA, Castanha AR. Profissionais que trabalham com AIDS e suas representações sociais sobre o atendimento e o tratamento. Estudos Psicol (Campinas). 2006;23(1):75-81.

- 6. Lima M, Costa JA, Figueiredo WS, Schraiber LB. Invisibilidade do uso de drogas e a assistência de profissionais dos serviços de AIDS. Rev Saúde Pública. 2007;41 Supl.2:6-13.
- Mullins IL. How caring for persons with HIV/AIDS affects rural nurses. Issues Ment Health Nurs. 2009;30(5):311-9.
- Silva AL. O cuidado no encontro de quem cuida e de quem é cuidado. In: Mercado FJ, Gastaldo D, Calderón C. Paradigmas y diseños de la investigación cualitativa en salud: una antologia iberoamericana. Mexico: Universidad de Guadalajara; 2002. p. 285-318.
- Baggio MA, Callegaro GD, Erdmann AL. Compreendendo as dimensões de cuidado em uma unidade de emergência hospitalar. Rev Bras Enferm. 2008;61(5):552-7.
- 10. Thompson P. A voz do passado: história oral. 2ª ed. Rio de Janeiro: Paz e Terra; 1992.
- 11. Portugal. Decreto-lei n. 97 de 10 de maio de 1995. Dispõe sobre as normas que regulam as comissões de ética para a saúde. Diário da República, Lisboa, 10 maio 1995. Série I, p. 3.



- 12. Leininger M. Evaluation criteria and critique of qualitative research studies. In: Morse JM. Critical issues in qualitative research methods. Thousand Oaks, California: Sage; 2008. p. 95-115.
- 13. Neves CL, Amorim WM, Moraes NA, Leite JL. Os cuidados de enfermagem ao cliente com HIV/AIDS em um hospital universitário na década de 1980. Rev Pesq Cuidado Fundam. 2009;1(2):299-316.
- 14. Cardoso AL, Silva N, Waidman MA, Marcon SS. Adesão e nãoadesão à terapia anti-retroviral: as duas faces de uma mesma vivência. Rev Bras Enferm. 2009;62(2):213-20.
- 15. Bonolo PF, Gomes RR, Guimarães MD. Adesão à terapia antiretroviral (HIV/Aids): fatores associados e medidas da adesão. Epidemiol Serv Saúde. 2007;16(4):261-78.

- 16. Monteiro MJ, Raposo JV. Reconhecer a problemática da infecção VIH/SIDA para agir. Rev Invest Enferm. 2007 Fev:4-23.
- 17. Schaurich D, Crossetti MG. O elemento dialógico no cuidado de enfermagem: um ensaio com base em Martin Buber. Esc Anna Nery Rev Enferm. 2008;12(3):544-48.
- 18. Luz PM, Miranda KC. As bases filosóficas e históricas do cuidado e a convocação de parceiros sexuais em HIV/ AIDS como forma de cuidar. Ciênc Saúde Coletiva. 2010;15 Supl.1:1143-8.
- Chaves I. SIDA e cuidados paliativos [Internet]. Lisboa: Centro Português de Investigação em História e Trabalho Social; 2012 [citado 2012 maio 17]. Disponível em: http://www.cpihts. com/PDF02/In%C3%AAs%20Chaves.pdf