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ORIGINAL ARTICLE

THE DIMENSIONS OF NURSING CARE PROVIDED TO INDIVIDUALS LIVING WITH ACQUIRED IMMUNODEFICIENCY SYNDROME

AS DIMENSÕES DO CUIDADO DE ENFERMAGEM ÀS PESSOAS VIVENDO COM A SÍNDROME DE IMUNODEFICIÊNCIA ADQUIRIDA

LAS DIMENSIONES DEL CUIDADO DE ENFERMERÍA PARA PERSONAS VIVIENDO CON SÍNDROME DE INMUNODEFICIENCIA ADQUIRIDA

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ABSTRACT

Objective: to describe the dimensions of nursing care provided to individuals living with HIV/AIDS. ***Method:*** exploratory cross-sectional study with a quantitative approach conducted with nursing professionals in reference services for individuals living with HIV/AIDS in Manaus and Coari, State of Amazonas, Brazil. The data were collected through a structured instrument with 78 nursing professionals. The variables were descriptively analyzed according to their distribution characteristics in tables. ***Results:*** the results revealed important aspects of the dimensions of nursing care provided to individuals living with HIV/AIDS, among which stigma and fear of becoming infected stood out. ***Conclusion:*** these dimensions may become obstacles for effective care, especially in the dimensions of relational care. ***Descriptors:*** Acquired Immunodeficiency Syndrome; Nursing Care; Nursing.

RESUMO

Objetivo: descrever as dimensões do cuidado de enfermagem às pessoas vivendo com HIV/AIDS. ***Método:*** estudo exploratório, transversal, de abordagem quantitativa, desenvolvido com profissionais de enfermagem nos serviços de referência no atendimento às pessoas vivendo com HIV/AIDS, nas cidades de Manaus e Coari, AM. Os dados foram coletados por meio de instrumento estruturado com 78 profissionais de enfermagem. As variáveis foram analisadas de forma descritiva conforme suas características de distribuição a partir de tabelas. ***Resultados:*** os resultados mostraram aspectos importantes das dimensões do cuidado de enfermagem às pessoas vivendo com HIV/AIDS, dentre os quais se destacaram o estigma e o medo de se infectar. ***Conclusão:*** a presença destas dimensões pode se constituir em empecilho ao cuidado efetivo, especialmente nas dimensões do cuidado relacional. ***Descritores:*** Síndrome de Imunodeficiência Adquirida; Cuidados de Enfermagem; Enfermagem.

RESUMEN

Objetivo: describir las dimensiones del cuidado de enfermería para personas viviendo con VIH/SIDA. ***Método:*** estudio exploratorio transversal con enfoque cuantitativo desarrollado con profesionales de enfermería de servicios de referencia en el cuidado para personas viviendo con VIH/SIDA en las ciudades de Manaos y Coari, Estado de Amazonas, Brasil. Los datos fueron recogidos a través de un instrumento estructurado con 78 profesionales de enfermería. Las variables fueron analizadas descriptivamente según sus características de distribución en tablas. ***Resultados:*** los resultados mostraron aspectos importantes de las dimensiones del cuidado de enfermería para personas viviendo con VIH/SIDA, entre los cuales se destacaron el estigma y el temor de contraer la infección. ***Conclusión:*** la presencia de estas dimensiones puede convertirse en obstáculo para el cuidado efectivo, especialmente en las dimensiones de la atención relacional. ***Descriptores:*** Síndrome de Inmunodeficiencia Adquirida; Cuidado de Enfermería; Enfermería.

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INTRODUCTION

Nursing professionals should be prepared to perform their activities in the face of adversity and changes, such as the emergence of new diseases, new technologies. new ways of dealing with diseases, or understanding the needs of each patient. Among the changes in this context, the acquired immunodeficiency syndrome (AIDS) and human immunodeficiency virus (HIV) are characterized by a set of peculiarities relating to social behavior patterns. These behaviors are determined by the fact that this is an non-curable disease, with forms of transmission associated with sexuality and drug use, as well as poverty. These aspects are usually associated with the occurrence of the disease,[1] which led to profound social, political, economic, and health changes. As a result, there has been a growing concern about how healthcare should be structured in order to deal with this challenge.[2]

The relationships between nursing professionals and individuals living with HIV/AIDS have already been investigated. Studies on the social representations seek to understand the symbolic constructs of care from nursing professionals' perspective[3-6] and HIV-positive patients' expectations about nursing care.[7-8] In addition, the negative implications for HIV-positive adolescents,[9] the profile and behavioral aspects of HIV-positive individuals[10-13] and the operational aspects involved in care provided to individuals living with HIV/AIDS have been also investigated.[14-5]

However, there are unexplored aspects relating to nursing care provided to individuals living with HIV/AIDS, especially in the relationships developed in daily care provided by nursing professionals. Therefore, some nursing care dimensions were taken into consideration in the present study, which may contribute to the understanding of the care process. This way, the goal was to describe the dimensions of nursing care provided to individuals living with HIV/AIDS.

METHOD

This is an exploratory cross-sectional study with a quantitative approach. It was conducted in specialized care services and testing and counseling centers of Manaus and Coari, State of Amazonas, Brazil. Coari is located in the countryside of the state, in the central region, and is one of the richest municipalities in the northern Brazilian region, with an estimated population of 83,078 inhabitants in 2015.[16] This municipality has an institute for tropical medicine, characterized as a reference center for clinical research and healthcare in the Middle and Upper Solimões region. It has a specialized service and a testing and counseling center, in addition to other health services. Due to these characteristics, the municipality was included in the study in addition to the state capital, Manaus, which concentrates most of the reports and the largest monitoring network of individuals living with HIV/AIDS.

The participants of the study were nurses, nursing technicians, and nursing assistants that directly performed in the nursing care of the STD/AIDS Program at outpatient level. The recruitment of the participants took place in different work shifts and sectors at the site of study. We sought to include all the professionals working in the selected services.

For the collection of data, we used a structured instrument composed of closed questions relating to socio-professional characterization and dimensions of nursing care provided to individuals living with HIV/AIDS. The instrument of care dimensions was submitted to a jury of experts with an assessment form relating to the relevance of the items and their respective dimensions. This way, the items of the instrument were adjusted and it was applied after a pre-test and training of the research team.

We conducted interviews with the professionals in their own workplace from December 2012 to May 2013. The data were entered and analyzed in the SPSS 16.0 software (Statistical Package for the Social Sciences) for Windows.

We assessed four dimensions of nursing care distributed as follows: "Stigma in nursing care" with seven questions; "Relationships in nursing care (professional-patient)" with two questions; "Negative attitudes of individuals living with HIV/AIDS during nursing care" with three questions; and "Nursing professionals facing the possibility of personally living with HIV/AIDS (themselves, family members, or close friends)" with four questions. The dimensions of nursing care were assessed according to the percentage grouped into three categories. In the first category we included the answers "strongly disagree" or "disagree" and "never" or "rarely". The second category included the situation of neutrality with the answers "neither agree nor disagree" and "sometimes". Finally, the third category grouped the last two responses referring to "strongly agree" or "agree". The division of the dimensions was didactic, in which we heuristically sought to group the items

according to topics that could express the dimensions of care.

We analyzed the continuous variables according to their characteristics of distribution, average, and standard deviation. On the other hand, the categorical variables were analyzed by number and percentage, distributed according to professional categories or dimensions of care, identified from the final classification.

This study is part of a multicenter project entitled "The transformation of nursing healthcare in AIDS times: social representations and memories of nurses and health professionals in Brazil". The goal of that project was to capture the dimensions relating to social representations of care and AIDS at the national level. The goal of the present study was to determine the dimensions of nursing care in the Amazonian context.

The project of the present study was approved by the Ethics Research Committee, with certificate CAAE 06849812.8.0000.5020. An informed consent form was provided to all the participants and signing it was a condition for performing data collection.

RESULTS

During the study period we found 126 nursing professionals who provided care to individuals living with HIV/AIDS. It was not possible to collect data from 48 (38.1%) professionals, because 27 were not at the institution in all access attempts, and 21 refused to participate in the study. Of the remaining 78 participants, 30 (38.5%) professionals were nurses and 48 (61.5%) were nursing technicians and nursing assistants. Of these professionals, 65 (83.3%) were female, with an average age of 41.7 years (standard deviation = ±8.6), and these data were similar in all the professional categories.

Among the nurses, incomes ranged from R$ 5,000.00 to R$ 10,000.00, and the incomes of professionals with secondary education ranged from R$ 600.00 to R$ 4,500.00. There was a predominance of individuals from both professional categories aged from 40 to 49 years (47.4%). Most of them were not single (61.5%) and 76.7% of the nurses reported having completed graduate courses at specialization level. It is worth noting that 15 (31.3%) professionals who worked as nursing technicians and nursing assistants were graduated, and nine (18.7%) had completed graduate courses at specialization level. However, for the purposes of the present study, we considered the professionals who were working in the program, as shown in Table 1.

Table 1. Socioeconomic profile of the nursing professionals who provided care to individuals living with HIV/AIDS. Amazonas, 2013.

	Professional category					
Profile of nursing professionals	**Nurse**		**Nursing assistant/technician**		**Total**	
	n = 30	%	n = 48	%	n = 78	%
Sex						
Male	6	20	7	14.6	13	16.7
Female	24	80	41	85.4	65	83.3
Age range (years)						
20 to 29	1	3.3	3	6.2	4	5.1
30 to 39	11	36.7	13	21.1	24	30.8
40 to 49	16	53.3	21	43.8	37	47.4
50 or over	2	6.7	11	22.9	13	16.7
Average age (SD)	40.8 (8)		42.3 (8.9)		41.7 (8.6)	
Individual income (minimum wage*)						
Up to 3	0	0	22	45.8	22	28.2
3.1 to 6	9	30	12	25	21	26.9
6.1 to 9	6	20	2	4.2	8	10.3
over 9	14	46.7	12	25	26	33.3
N/A	1	3.3	0	0	1	1.3
Family income in Brazilian Reais (SD)**	5,113.60 (2,170.60)		2,095.30 (1,136.60)		3,240.20 (2,170.70)	
Marital status						
Married	21	70	27	56.2	48	61.5
Single	9	30	21	43.8	30	38.5
Number of children						
1 to 2	19	63.3	20	41.7	39	50
3 or more	6	20	13	27.1	19	24.4
No children	5	16.7	15	31.2	20	25.6
Higher level of education						
Secondary education	0	0	24	50	24	30.8
Higher education	7	23.3	15	31.3	22	28.2
Post-graduation (specialization)	23	76.7	9	18.7	32	41

* Minimum wage in Brazilian Reais, June 2013 (R$ 678.00); **SD = standard deviation.

Table 2 presents the responses of the professionals according to the items and dimensions of care provided to individuals living with HIV/AIDS. With respect to the dimension called "stigma in nursing care", 45.4% of the professionals considered that there were differences in care provided to individuals with homosexual behavior. Likewise, 61.0% responded that risky behaviors resulted in HIV infection.

Regarding the dimension "professional-patient relationship", almost all of the professionals (90.9%) agreed that it was possible to create a relationship during nursing care, and 71.4% responded that care was made easier when there was a friendship bond between professionals and patients.

With respect to the dimension "negative attitudes of individuals living with HIV/AIDS during nursing care", 89.6% strongly agreed affirming that the lack or inconstant attendance at follow-up visits hindered the treatments in individuals living with HIV/AIDS.

Regarding the dimension in which we sought to identify how professionals facing the possibility of personally living with HIV/AIDS (themselves, family members, or close friends) would feel, the highest percentage of responses was "repeatedly/always" with 46.7% in the item related to whether nursing professionals had already planned to undergo tests to detect HIV infection. The items related to whether the professionals had already thought about being infected with HIV, or what it would be like to live as an HIV-positive individual, 59.7% and 64.9% of the answers were "never/rarely", respectively.

Table 2. Percentage of the nursing professionals' responses according to the items and dimensions of care provided to individuals living with HIV/AIDS. Amazonas, 2013.

Dimensions of care and their items	Strongly disagree/ disagree	Neither agree nor disagree	Strongly agree/agree
Stigma in nursing care			
In nursing care, HIV/AIDS-positive individuals are treated with prejudice.	63.6	11.7	24.7
AIDS is still considered a homosexuals' disease.	75.3	7.8	16.9
The are difficulties in care provided to HIV/AIDS-positive homosexuals.	58.4	14.3	27.3
Nursing professionals should provide special care to HIV/AIDS-positive individuals due to their health conditions.	48	10.4	41.6
There are differences in care provided to children, men and women with homosexual behavior.	42.9	11.7	45.4
Wearing two pairs of gloves to avoid needle-stick injuries.	62.3	10.4	27.3
The risk behavior of the patients led them to be infected with HIV.	20.8	18.2	61
Professional-patient relationship in care provided to individuals living with HIV/AIDS			
During care provided to patients, a friendship bond is created (patient-professional).	2.6	6.5	90.9
Nursing care becomes easier when a friendship bond is created (patient-professional).	16.9	11.7	71.4
Negative attitude of individuals living with HIV/AIDS during nursing care			
HIV/AIDS-positive individuals feel discriminated when they receive nursing care.	62.3	18.2	19.5
Lack or inconstant follow-up visits hinder care provided to HIV/AIDS-positive individuals.	6.5	3.9	89.6
HIV/AIDS-positive individuals have unsociable behavior toward the nursing team.	58.4	20.8	20.8
Nursing professionals facing the possibility of personally living with HIV/AIDS (themselves, family members, or friends) .			
	Never/rarely	**Sometimes**	**Usually/always**
Has already thought of undergoing the exam to detect HIV.	27.3	26	46.7
Has already thought of discovering whether he/she has been infected with HIV.	59.7	18.9	22.1
Has already thought about what it would be like to live as a HIV-positive individual.	64.9	26	9.1
Has already thought about what it would be like to have a family member or close friend infected with HIV.	49.3	33.8	16.9

*In the present study, stigma in HIV/AIDS was defined in accordance with the Joint United Nations Program on HIV/AIDS [UNAIDS] (2007), which considers a depreciation process and/or unequal and unfair treatment due to the condition of individuals who carry the virus that causes AIDS.

DISCUSSION

We decided to primarily focus on the profile of nursing professionals who provided care to individuals with HIV/AIDS and, subsequently, discuss the issues relating to nursing care dimensions. The high percentage of women in the nursing staff of the services studied results from the historical distribution of the profession, which has been eminently feminine. Therefore, in line with the findings of another study,[17] most of the participants in the present study were women providing care to individuals living with HIV/AIDS.

Regarding personal incomes reported by the professionals under study, the standard deviation of the nurses' income approached the average income of nursing technicians and nursing assistants, indicating that some nurses, despite being hired as such, received equal wages than nursing technicians and nursing assistants. On the other hand, we observed that there were graduated nursing technicians who continued receiving technicians' wages due to their hiring model. Although it has not been the subject of investigation, it is considered that this wage and function discrepancy relating to professional training can generate dissatisfaction in the professionals and affect care provided to individuals living with HIV/AIDS.

Therefore, it should be noted that the search for additional training was remarkable, considering that most of the subjects surveyed had completed specialization courses. This fact can encourage institutional incentives for training and professional qualification, as well as the interest of the subjects to stay updated.

With respect to the dimensions of care provided to individuals living with HIV/AIDS, it is considered that several dimensions may possibly emerge at the same time. This makes it possible to think about the aspects involved in nursing care, which may result in progresses or show elements that can be worked out. The purpose would be establishing the best possible relational care and, as a consequence, make the actions of nursing professionals effective.

Stigma in nursing care is something difficult to be registered; however, it admittedly hinders healthcare, because it tends to distance individuals from services.[18] The stigma is still present, whether in the way of providing care, whether in the way of judging individuals living with HIV/AIDS. It is considered that this dimension can unveil the presence of negative perceptions of the professionals about the disease and also about the groups affected, bringing up the marks of a disease whose history regards homosexual behavior as an important risk factor for infection.[18] However, the configuration of the disease, as well as the knowledge of its physiopathogenesis and treatment, have changed and expanded quickly. This fact has been accompanied by social change and stigmatizing conceptions of the individuals and professionals affected.

The statement that risk behaviors had resulted in HIV infection brings up stigmatized judgments on the part of society and affirmed by the professionals, blaming the patients for being carriers of the virus. However, it is known that HIV infection is not only possible due to the so-called risk behavior—such as unprotected sex, or the use of injected drugs, among other forms—but to vertical transmission of the virus to children of infected mothers, which obviously does not denote a risky behavior on the part of the children. Therefore, it is important to reflect on pre-judgments that denote stigma, formed by negative symbolism present in the context of AIDS epidemic and experienced by these professionals.[18]

In this sense, stigma in nursing care provided to individuals living with HIV/AIDS can result in difficulties for the relationship with HIV-positive patients during healthcare.[19] This stigmatization may inhibit the demand for health services because of differences in treatment and after the serological condition is confirmed.[18] These facts give rise to the need of professional practices devoid of stigmatization that may prevent an understanding of the multiple demands imposed by AIDS. On the other hand, considering that the professionals are also social beings, it is necessary that they have critical awareness of their positioning, in order to reduce the impact of AIDS on their practices.

In this context, joint efforts are essential to invest in the training of nursing professionals, since, when graduated, it is most likely that they will have to provide care to HIV-positive patients without knowing the social implications of AIDS. Therefore, it is important that the educational curricula include courses that deal with issues relating to the history of AIDS epidemic and its social impact. Another important aspect with easy applicability is the implementation of continuing education, in order to enable the exchange of experiences between nursing professionals and between patients and professionals.

The creation of bonds by the professionals could be related to the professional experience obtained during the time that care has been provided to individuals living with HIV/AIDS. This fact could allow nursing professionals to have a greater understanding of the implications imposed by HIV/AIDS to the individuals affected and, consequently, the relationships would be facilitated. Another important aspect is the fact that most of the patients, because of the chronicity of HIV infection, visit health services for a long time and frequently, which might facilitate the bond between professionals and patients.

In line with the present study, another study conducted with hospitalized HIV-positive patients found that, despite discourses with prejudiced attitudes in nursing care, the creation of relationships and friendship had been an extremely important issue in the daily lives of the patients.[8] Other studies have pointed out that the creation of bonds during nursing care could strengthen the therapeutic relationship between professionals and patients, thus favoring the combat against HIV/AIDS.[15-20]

The high percentage of responses to the item referring to lack or inconstant follow-up visits — which hinders the treatment of individuals living with HIV/AIDS — in the dimension characterized by "negative attitude of individuals living with HIV/AIDS during nursing care" can unveil the concern of nursing professionals with respect to such circumstance. At the same time, due to these responses, it can be inferred that, possibly, they would had already observed similar situations. Even though this fact was not assessed in the present study, we question whether inconstant follow-up visits are

common in the services studied, in which case further investigation with this approach would be necessary in order to resolve this concern.

The high percentage of professionals who responded that they had already thought about undergoing the test for identification of HIV could be evidence of awareness about the possibility of infection and the need of being tested for HIV, since these professionals are exposed to needle-stick injures caused by potentially contaminated materials. On the one hand, this fact can be considered positive, on the other hand, if the professionals cannot cope with this concern, it might cause a negative impact on care provided, raising the fear of HIV infection. Consequently, there would be interference due to detachment from direct care provided to patients, thus hindering the professional-patient relationship. Moreover, many professionals stated that they had never thought about finding out whether they were infected with HIV and what it would be like to live as a carrier of the virus.

We considered that the answers expressed professionals' fear of living as carriers of the virus due to the daily coexistence with the implications imposed by HIV to the patients affected, such as prejudice, discrimination, and stigma.[21-22] However, other questions could be raised with respect to these two items discussed in this dimension. The first suggests that professionals can consider AIDS as someone else's disease, i.e., they disregard the possibility of being infected with the virus. The other hypothesis is that, perhaps, for not having HIV/AIDS cases related to their social conviviality, these professionals have a false sense of immunity.

Although the present study had limitations, we considered that nursing professionals' denial in participating in the study did not hamper the analysis. However, we interpreted that these refusals might hide the difficulties of the professionals in communicating the various aspects involved in providing care to individuals living with HIV/AIDS. Since the contractual situation was not obtained to better analyze the denials, it is suggested that further qualitative studies should be conducted in order to detect the phenomena that was not observed in the present study.

Another limiting aspect was that there is currently no validated instrument to assess the dimensions of care. For this reason, we used an instrument elaborated for our study as a first approach to the topic, in order to descriptively observe the various aspects of care. Therefore, although we did not have a validated instrument, we consider that the internal validity was not jeopardized. The present study has the potential to contribute to promoting a better understanding of care and the elements that hinder and interfere with it, including stigma, lack of bonds, and fear.

CONCLUSION

The findings revealed a predominance of female nursing professionals. The average age in the two professional categories was around 40 years old. There were high percentages of post-graduated nurses, with average family income of around five minimum wages.

The present study unveiled important aspects of the dimensions of nursing care provided to individuals living with HIV/AIDS. Among them, it is worth mentioning stigma and fear of being infected during care provision. These aspects refer to conditions found at the beginning of the AIDS epidemic, when there was little information about the disease. In this sense, these dimensions may hinder effective care, especially in the dimensions of relational care. In this respect, it is important to deepen the studies in order to understand the reasons for the persistence of dimensions that have negative aspects in relational care, such as stigma and pre-judgments. This way, it will be possible to deal with them so that care may be developed as a professional activity, in a relatively free manner for the professionals in their completeness.

On the other hand, the presence of professional-patient bond can be a facilitator of relational care. This way, it will be possible to provide humanized care, approaching the parties involved in care and, consequently, deconstructing the negative perceptions about HIV infection and their groups affected. However, the articulation on the part of managers of specialized services that provide care to individuals living with HIV/AIDS is necessary to minimize issues relating to nursing professionals' stigma and fear of being infected with HIV. This can be achieved through continuing education activities relating to infection issues. At the same time, activities can be developed to allow the exchange of experiences in a dialogical relationship addressing the disease and its implications in patients' lives. In this way, nursing professionals' awareness and interaction with patients will be promoted.

Nursing professionals should reflect on their practices, since they reveal their own manner of providing care and have to be changed, like the profile of AIDS epidemic that has changed over time. To that end, it is

also necessary that educational institutions improve themselves, so that new professionals can have a new perspective regarding the process of providing care to individuals living with HIV/AIDS.

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