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Social representations of nurses about the decentralization process of HIV care: A structural approach

Representações sociais de enfermeiros acerca do processo de descentralização do atendimento ao HIV: abordagem estrutural

Representaciones sociales de enfermeros sobre el proceso de descentralización de la atención al VIH: un enfoque estructural

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ABSTRACT
Objective: to analyze nurses' social representations about HIV care in primary health care, using a structural approach. **Method:** descriptive, exploratory study, with a qualitative approach and structural character, with 160 nurses, from December 2019 to March 2020, in family health units in the city of Recife, Pernambuco, Brazil. Semi-structured interviews were carried out, using the Free Word Association Technique, and a sociodemographic questionnaire. Data were processed by the IRAMUTEQ software, anchored by the Theory of Social Representations. Research protocol approved by the Research Ethics Committee. **Results:** the stimulus to the inducing question originated 188 different words with a minimum frequency of five evocations and a maximum of 64. Terms associated with subjective factors are expressively observed. **Final considerations:** it was shown that the social representations related to HIV are relevant and diverse, related to the role of nurses in the care provided to people living with HIV.
Descriptors: Nurses; Primary Health Care; HIV; Health Knowledge, Attitudes, Practice; Social Representations.

RESUMO
Objetivo: analisar as representações sociais de enfermeiros sobre o atendimento ao HIV na atenção primária à saúde, por meio de uma abordagem estrutural. **Método:** estudo descritivo, exploratório, com abordagem qualitativa e caráter estrutural, com 160 enfermeiros, no período entre dezembro de 2019 a março de 2020, nas unidades de saúde da família do município de Recife, Pernambuco, Brasil. Realizaram-se entrevistas semiestruturadas, com a Técnica de Associação Livre de Palavras, e questionário sociodemográfico. Os dados foram processados pelo software IRAMUTEQ, sendo ancorados pela Teoria das Representações Sociais. Protocolo de pesquisa aprovado pelo Comitê de Ética em Pesquisa. **Resultados:** o estímulo à pergunta indutora originou 188 palavras diferentes com frequência mínima de cinco evocações e máxima de 64. Observa-se expressivamente termos associados a fatores subjetivos. **Considerações finais:** evidenciou-se que as representações sociais relacionadas ao HIV são relevantes e diversas, relacionadas com a atuação dos enfermeiros frente ao atendimento prestado às pessoas vivendo com HIV.
Descritores: Enfermeiros; Atenção Primária à Saúde; HIV; Conhecimentos, Atitudes e Prática em Saúde; Representações Sociais.

RESUMEN
Objetivo: analizar las representaciones sociales de los enfermeros sobre el cuidado del VIH en la atención primaria de salud, utilizando un enfoque estructural. **Método:** estudio descriptivo, exploratorio, con enfoque cualitativo y carácter estructural, con 160 enfermeros, de diciembre de 2019 a marzo de 2020, en las unidades de salud de la familia en la ciudad de Recife, Pernambuco, Brasil. Se realizaron entrevistas semiestructuradas, utilizando la Técnica de Asociación Libre de Palabras, y un cuestionario sociodemográfico. Los datos fueron procesados por el software IRAMUTEQ y están anclados en la Teoría de las Representaciones Sociales. El Comité de Ética en Investigación aprobó el protocolo de investigación. **Resultados:** el estímulo a la pregunta inductora originó 188 palabras diferentes con una frecuencia mínima de cinco evocaciones y máxima de 64. Se observan expresivamente términos asociados a factores subjetivos. **Consideraciones finales:** se demostró que las representaciones sociales relacionadas con el VIH son relevantes y diversas, relacionadas con el papel de las enfermeras en el cuidado prestado a las personas que viven con el VIH.
Descriptores: Enfermeros; Atención Primaria de Salud; VIH; Conocimientos, Actitudes y Práctica en Salud; Representaciones Sociales.

INTRODUCTION

The first measures for the decentralization process of Human Immunodeficiency Virus (HIV) care in Primary Healthcare (PHC) in Brazil took place in 2012 through Ordinance No. 77 of January 12, 2012, which instituted rapid testing for HIV and syphilis in prenatal care for pregnant women and their sexual partners within the scope of PHC. The Ministry of Health (MoH) proposed a change in the care model for People Living with HIV (PLHIV) in 2014, considering PHC as the gateway and originator of care with the aim of increasing accessibility to health services for these patients[1,2].

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The HIV/AIDS kit for PHC was launched by the MoH in 2017. It presents a series of recommendations indicating an expansion of diagnosis, access to Antiretrovirals (ARVs) and risk stratification for asymptomatic and symptomatic patients, recommending that patients who are asymptomatic are attended by PHC with the immediate start of Antiretroviral Therapy (ART), request for TCD4 lymphocytes and Viral Load (VL) tests by the unit, carrying out the first post-diagnosis medical consultation with the Specialized Assistance Services (*Serviços de Assistência Especializada - SAE*) as a matrix service. The symptomatic, co-infected, pregnant women, children, or individuals with an indication of alternative schemes must be referred to the *SAE*[3].

The implementation of this care model for PLHIV aims to improve care continuity, promote the bond between professionals and patients, optimize interventions in education with the aim of promoting, preventing, diagnosing early and treating HIV/AIDS in a timely manner, in turn enabling better control of the disease development. This model contributes to expand diagnoses, adherence to therapy and suppress the viral load of PLHIV with a consequent suppression of the HIV/AIDS epidemic in the country[4].

However, there are also some negative points, mainly regarding: the risk of exposure and breach of confidentiality; still incomplete teams and staff turnover; test reliability; perception of work overload; expectation of lack and/or high demand for the test; counseling and communication of the diagnosis due to insecurity because of a lack of training; work process routines, lack of inputs and materials which affect the continuity of the service[5].

In this perspective, it is evident that the decentralization process of HIV care in PHC is still recent and incipient in Brazil, with greater emphasis on aspects related to rapid testing such as test reliability, counseling, and diagnosis communication, which is configured as a challenge within the services[6].

The work of the multidisciplinary team is highlighted for the viability of this process with the promotion of self-care for patients. The patient must understand and accept the prescription, and because it is a dynamic process, the health team is co-responsible for compliance. However, the subjective interpretation of the nurse's role in attending the demands of HIV infection is emphasized, since the role of nursing is inserted in user embracement, qualified listening, empathy and bonding[7].

Social representation is proposed as a practical knowledge modality which enables understanding aspects of everyday reality through symbolic sets based on communication and behavior between individuals. Thus, it composes a product of social interactions resulting from the dynamic process of identities. In this context, the Theory of Social Representations (TSR) is a relevant instrument which helps to access information, expressions and identifications that consider the sociocultural sphere, which goes beyond individual levels and reaches the social system[8,9].

In this line, representing the HIV epidemic and the various subjects involved in care is to imbue the way of acting and experiencing all the magnitude and challenges that surround PLHIV. The TSR considers the influence on human behavior and the dynamic and broad perspective that constitute the disease to a given social group[9].

Given this scenario and knowing social representations from the perspective of nurses who work in HIV care can contribute to understanding the perception of these professionals in the reorganization process of the healthcare model in PHC. An investigation of social representations makes it possible to understand the way in which individuals perceive everyday events through a system which interprets reality and guides the relationships of individuals with their environment, indicating common sense theories based on the knowledge experienced for their positions taken when faced with conflicting events[9-11].

Thus, the present study aims to analyze the social representations of nurses about HIV care in primary healthcare through a structural approach.

METHOD

This is a descriptive, exploratory study with a qualitative and structural approach based on the theoretical-methodological framework of the Theory of Social Representations proposed by a Frenchman named Jean-Claude Abric. Abric states that all social representation is organized around the central nucleus and the peripheral system. Thus, social representation is an organized and structured set of information, beliefs, opinions and attitudes[12]. The study was developed in the city of Recife, Pernambuco, Brazil, which consists of 131 Family Health Units (*Unidades de Saúde da Família - USF*) and has 326 nurses who work in the Family Health Teams (*Equipes de Saúde da Família - ESF*).

Next, we considered the number of *ESF* in the city of Recife, PE (N = 276), a prevalence estimative of 50% (unknown) and a confidence interval (CI) of 95% in order to calculate the sample size. After the calculation, the sample proportion was performed by calculating the proportional N and then the simple randomization of each stratum was performed by lot.

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From this perspective, a sample of 160 participants was selected by drawing lots from the *USF* distributed among the eight health districts of Recife, PE. The inclusion criteria were defined as: a) male and female nurses; b) linked to *ESF*; c) and with experience of at least one year in the *ESF*. The following were excluded from the sample: those who are on leave for any reason for a period of more than 90 days.

Data collection took place from December 2019 to March 2020 using an instrument for the free word association technique (FWAT), which presented the following inducing question: What are the five words that immediately come to your mind in relationship about care for PLHIV at the *USF*?

For this question, the five associations that came to the mind of the participants should be evoked considering what would be most important within the universe of the proposed theme in ascending order of importance. Based on this type of stimulus, it is possible to obtain aspects, opinions, experiences and thoughts of the participants[13].

The interviews took place individually on days and times previously scheduled by the researchers with the participants, conducted in a room indicated by the professionals to guarantee privacy and secrecy. Before starting the interviews, an Informed Consent Form (ICF) was presented, and data collection was performed after they signed two copies. The interviews lasted an average of 15 to 25 minutes each. Then the answers were stored using Microsoft Excel® software.

The *Interface de R pour les Analyzes Multidimensionnelles de Textes et de Questionnaires* (*IRAMUTEQ*®) v.0.7 alpha2 software program was used to assist in the analysis and processing of qualitative data. This program enables analyzing simple frequencies and multiple frequencies which identifies the main words that stood out in the frequency evocation order and the prototypical analysis, which is a simple technique and the main technique in the field of social representations based on the frequency and order of evocations. This is represented by a diagram which has four quadrants: central core, first periphery, second periphery and contrast zone, which correspond to the four dimensions of the social representation structure[14,15].

The mean order of evocations (MOE) is calculated by dividing the total sum of evocations of all words/phrases belonging to a category by the number of categories, and the mean of the mean order of evocations is obtained by dividing the sum of all MOE by the number of categories[16]. Thus, the TSR was considered according to the central core theory by the peripheral and central categories to subsidize the interpretative data analysis[12].

This study has preliminary data from the "Assessment of care for HIV/AIDS" (*Avaliação da assistência frente ao HIV/Aids*) project developed by the Study and Research Group on Infectious and Neglected Diseases at the University of Pernambuco. The study was approved by the Ethics Committee of the institution involved, and all ethical precepts established by Resolution 466/2012 of the National Health Council were attended during the development of the study.

RESULTS

The stimulus to the inducing question from applying the FWAT to the 160 nurses originated 188 different words with a minimum frequency of five evocations and a maximum of 64. A high multiple frequency of 64 evocations (8%) was identified for the term "embracement", followed by 41 for the term "treatment" (5%), and 35 for "guidance" (4%), which configures them as a probable central representation core of the investigated group. Thus, it was possible to build the Framework of Four Groups about the care of PLHIV in PHC, as shown in Figure 1.

The central core is the main element of social representations. From this perspective, the upper left quadrant represented by the central core suggests an integration with elements aimed at interpersonal relationships in therapeutic care, such as: "Embracement", "Guidance", "Prevention", "Confidenitality", and "Access", which are coexisting, configuring themselves as basic links which enable strengthening the bond between professionals and patients, and thus provide effectiveness in the care decentralization process for PLHIV in PHC.

In addition, in the primary periphery, terms such as "Treatment", "Follow-up", "Prejudice", "Support", "Care", "Referral", and "Medication" are evident. These terms are related to the central core, taking into account that one of the focuses of decentralization is to start immediate treatment, for which it is necessary to train these professionals to guide these patients and follow-up with the multidisciplinary team. Also, the referral should be emphasized, which must be carried out through shared care with the *SAE* as matrix services.

The secondary periphery brings together less frequent elements, but with potential significance to constitute the central core; these point to the existence of other relevant and diverse lines of thought, which in turn point to objective

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elements related to the treatment and to the context that encompasses the framework, so we can observe a great diversity of words.

Central core			**Primary periphery**		
Freq. >=13.7	**Freq.**	**Rang <2.96**	**Freq. >=13.7**	**Freq.**	**Rang <2.96**
Embracement	64	1	Treatment	41	3.1
Guidance	34	2.9	Follow-up	29	3.4
Prevention	24	2.8	Prejudice	28	3
Confidentiality	15	2.6	Support	26	3.3
Access	15	2.3	Care	22	3.3
			Referral	15	3.5
			Medication	14	3.8
Contrast zone			**Secondary periphery**		
Freq. >=13.7	**Freq.**	**Rang <2.96**	**Freq. >=13.7**	**Freq.**	**Rang <2.96**
Respect	13	1.9	Adherence	13	3.8
Empathy	12	2.6	Fear	12	3.7
Bonding	9	2.4	Examination	12	3.7
Humanization	7	2	Transmission	11	3.3
Rapid testing	7	2.7	Information	11	3.2
Training	6	2.7	Attention	9	3.3
Insecurity	6	2.7	Shame	9	3.1
Knowledge	5	2.8	Infrastructure	8	3.2
Listening	5	2	Condom	8	3.1
Trust	5	2.6	Neglect	7	4
			Responsibility	7	3.6
			Doubt	6	3.7
			Self-care	6	3
			Partners	6	3.7
			Death	6	4
			Protection	5	3.6
			Accpetance	5	3.4
			Family	5	4

FIGURE 1: Prototypical analysis of the social representation of care for people living with HIV from the perception of Primary Healthcare nurses. Recife, Pernambuco, Brazil, 2021.

The elements which have the least impact on the organization of the other structural zones are in the contrast zone. These elements are associated with the subjective side of the treatment and were evoked more frequently; respect, empathy and bonding were the most expressive, which points out the importance of going beyond the health-disease process and paying attention to the uniqueness of each individual.

In this sense, terms such as “Insecurity”, “Shame”, “Fear” and “Doubt” incorporate the affective dimension, while “Treatment”, “Referral”, “Medications”, “Condom” and “Responsibility” represent the information dimension. Also, it was possible to identify behaviors and attitudes incorporated by peripheral or contrasting elements, as well as “Empathy”, “Listening”, “Adherence” and “Acceptance”.

DISCUSSION

Starting from the free evocation of the words, it was possible to highlight the importance of embracing PLHIV for adequate connection to the continuous care sequence. In this sense, qualifying the care provided to these people is a measure to reduce inequities and should be a priority in the healthcare of this population. In view of the importance of nurses in PHC, it is necessary to train them so that they can support user-centered care.

Although some health promotion and HIV prevention actions are already widespread in PHC, a comprehensive diagnosis and follow-up of PLHIV is still something recent and little studied[6]. Although the *ESF* is composed of a multidisciplinary team, the nurse is a protagonist in consolidating public policies, as well as in the planning, organization and operation of health services[5].

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It appears that the nurse, through rapid HIV testing in the PHC, plays a very important role in the early diagnosis and implementation of reorganizing the recommended healthcare model[17].

The word "embracement" in the central core is found to be the most evoked by the interviewees. User embracement is one of the guidelines of the National Humanization Policy; it must be present and sustain the relationship between service-professional-patient. Through attentive listening, it is possible to provide the user with access and to build relationships based on trust, commitment and bond between the user and the health services[18].

It is noteworthy that the central core is composed of stable, consistent, permanent and resistant to change elements and are related to the collective memory of the representations. The central core performs two functions, namely: generating function in which it creates or transforms the meaning of other elements, giving value and meaning to the elements; and organizing function, since it determines the nature of the associations between the representation elements[19].

Along these lines, in order to establish acceptance for PLHIV, it is necessary to listen carefully to the patient's demands regarding their complaints, anxieties and fears, thereby enhancing clarification of their doubts and recognizing risk situations. Embracement must be present in all care relationships with the user, from their inclusion in the health service, as well as in recognizing their needs and weaknesses, facilitating access and treatment[20].

Right after the term "embracement", we have the terms "guidance" and "prevention" composing the central core. Thus, guidance and prevention maintain an essential relationship for HIV control. It is essential to increase the care qualification of PLHIV with the adoption of behavioral, biomedical and structural interventions, also called combined prevention, being guided as strategies. Such interventions should not only be aimed at individuals, but also at their social groups[21].

Examples of behavioral interventions are consistent condom use, testing for HIV and STIs, and harm reduction. The distribution of condoms, distribution of lubricating gels, testing for HIV and other STIs, Pre-exposure Prophylaxis (PrEP), Post-exposure Prophylaxis (PEP) and treatment of STIs are adopted as biomedical interventions. Finally, structural interventions are aimed at confronting racism, sexism, homophobia and promoting human rights through educational and awareness campaigns. However, continuing education is necessary for the nurse to be able to advise on the use and demonstrate the available measures[22].

The term "confidentiality" is also verified; it has an extremely important relationship with the term "embracement", since establishing "bond" and "trust" relationships between health professionals and users is expected.

However, it is observed in the literature that the breach of confidentiality is a major problem for decentralization, since "fear" and "insecurity" (terms present in the secondary periphery and contrast zone) in being attended to close to their homes are present in the reality of those living with HIV, being considered one of the main barriers for the decentralization of HIV care in PHC[6, 23,24].

The word "access" is observed in analyzing the central core. Rapid testing is evident, sometimes being responsible for the user's initial access to health services. A limitation in the offer of rapid testing and targeting only pregnant women can be noticed in studies[25,26].

Offering the rapid HIV test during family planning or early pregnancy has positive results in terms of controlling maternal infection and reducing mother-to-child transmission[27-29]. However, it is necessary to offer the rapid test to all those who seek service at the health unit with a view to early diagnosis, initiating treatment in a timely manner and expanding access[18,25,27].

Despite matrix support in healthcare production, it is shown to be a relevant element in the significant increase in the performance of effective communication, in carrying out the HIV test, in clinical follow-up and in risk assessment. Such care components have a greater chance of adequate interventions when there is guidance between professionals in a shared construction process of responsibilities[28].

The peripheral system of a social representation must be evaluated in an individualized and contextualized way, since they are associated with individual characteristics and the context in which the individual is inserted. The peripheral system is a very important element because it is possible to anchor new processes through its association with the central core, constituting an indicator of future modifications of the representation, since the representation is in effective transformation[29].

Thus, it is observed in the primary periphery that the most evoked terms were "treatment", "follow-up" and "support". In turn, it is evident that the treatment decentralization provides benefits in terms of care qualification, immediate initiation of ART, creating bonds with professionals, reduction in the number of doses, and easier schemes, which help facilitate treatment in PHC. However, the treatment must be shared with the *SAE*, with these matrix services being related to provide joint actions[30,31].

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For the secondary periphery, it is noted that the most evoked term was "Adherence", followed by "Fear" and "Examination". In addition, the most evoked terms in the contrast zone were "Respect", "Empathy" and "Bonding". In view of this, a relationship which occurs between these terms, the central core and the primary periphery is observed. Adherence is directly associated with access, treatment and follow-up, and fear is associated with prejudice and confidentiality. The exam is related to prevention, since early diagnosis can provide a greater chance of controlling the infection[32,33].

We observed that the term respect is associated with support, and it is also associated with prejudice, not only by users but also by professionals, which once again ends up interfering with the adherence rate to treatment in PHC. This in turn leads us to empathy related to care for PLHIV, who need emotional support during this moment which not only affects them physically, but also psychologically[34].

Finally, the bond is associated with monitoring PLHIV by health professionals, who need to establish a relationship of trust between patient and professional which is of fundamental importance for the adherence process. When dealing with several chronic diseases, trust in the health professional is associated with good adherence and represents a therapeutic tool. A relationship with the patient with empathy and good communication can favor adherence to treatment[35].

In short, it is observed how the association of the terms listed in the central core and the social representations have an impact on users being inserted in the routine of the services. Such fragility in user adherence to PHC may possibly be associated with the distancing inherent in the fear and insecurity of having their diagnoses exposed to the community group. Unfortunately, the stigmatization of individuals still occurs due to the personification of HIV for interpersonal relationships. In addition, the social representations linked to the diagnosis and treatment are understood from the evocations listed in the peripheral system, pointing out fear as a negative aspect and the support provided by the teams as a positive aspect.

Study limitations

The limitations of this study come from the fact that it was only developed with nursing professionals in the care of people with HIV/AIDS, which expresses a reality based on the subjectivity of a delimited group, making it impossible to generalize the data among other categories.

FINAL CONSIDERATIONS

The representations of nurses' perceptions about care for PLHIV in PHC by the present study revealed nuances constructed by the participants by facing their health context, as providers of care to patients with a chronic disease, which makes it possible to approach them as being co-responsible for adherence to the therapeutic course and nursing care.

It was verified from the results found that the terms and categories are related. It was evident that the terms "embracement", "guidance", "treatment", "monitoring", "respect", "empathy", "adherence" and "fear" were the most cited terms in their respective categories; however, it is clear that the first five terms are of paramount importance for the patient's bond with health services and are essential terms for the success of the decentralization process of HIV care in PHC.

It is clear that "fear" permeates those who live with HIV according to the professionals' perception, which can impact PHC care; thus, the need to reduce this feeling in these patients by strengthening the bond and trust between the professional-patient is emphasized.

From this perspective, problems are observed through a structural approach of social representations, allowing us to consider the various factors capable of influencing HIV care in PHC, and to understand the importance attributed to these factors and how much they impact decisions related to PHC care and to being attended in these services. In addition to being relevant, it appears that the social representations are diverse and are directly related to the professionals' way of acting/behaving regarding the care provided.

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