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Representations and care practices of health professionals for people with HIV*

Representações e práticas de cuidado de profissionais de saúde às pessoas com HIV

Representaciones y prácticas de cuidado de profesionales sanitarios a las personas con VIH

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Rebeca Coelho de Moura Angelim[1]
Brígida Maria Gonçalves de Melo Brandão[1]
Sergio Corrêa Marques[2]
Denize Cristina de Oliveira[2]
Fátima Maria da Silva Abrão[1]

ABSTRACT

Objective: To analyze the social representations of health professionals regarding the care of people living with HIV. **Method:** A descriptive and exploratory study with a qualitative approach in light of the Theory of Social Representations, carried out with health professionals. The semi-structured interview technique was used, which was analyzed using the lexical content analysis technique. **Results**: Forty-six (46) professionals participated. The analyzed results reveal that the representations and care practices referred to by health professionals are technical, relational and organizational, ensuring the confidentiality of the diagnosis and taking care to develop embracement actions, provide guidance, clarification and emotional and psychological support, as well as being based on confidentiality, multi-professional care practice and addressing structural difficulties. **Conclusion**: It is important to encourage multiprofessional care for people living with HIV, so that professionals engage, develop critical thinking and are able to act in improving healthcare services.

DESCRIPTORS

HIV; Acquired Immunodeficiency Syndrome; Public Health Nursing; Professional Practice; Comprehensive Health Care.

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[1] Universidade de Pernambuco, Programa Associado de Pós-graduação em Enfermagem, Recife, PE, Brazil.

[2] Universidade do Estado do Rio de Janeiro, Programa de Pós-graduação em Enfermagem, Rio de Janeiro, RJ, Brazil.

Corresponding author:
Rebeca Coelho de Moura Angelim
Rua Arnóbio Marques, 310
CEP 50100-130 – Santo Amaro, Recife, PE, Brazil
rebecaangelim@hotmail.com

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INTRODUCTION

Following the establishment of the National Program on Sexually Transmitted Diseases (STD) and AIDS in 1986, the Acquired Immunodeficiency Syndrome (AIDS) epidemic obtained technical and financial support to combat discrimination and the rights of affected persons(1), with important implications for public policies and transformations in the healthcare practices of individuals living with the Human Immunodeficiency Virus (HIV)(2). This has favored occupying a potential leading position in HIV prevention programs and in the clinical management of patients by suitably trained health professionals(3).

This social scenario contributed to forming social representations and memories of health professionals about the various aspects of the AIDS context(2). Thus, it is of great value to construct such representations through theories which aim to explain a certain phenomenon from a collective perspective, such as the Theory of Social Representations, in order to understand the world(4), especially when it comes to the social phenomenon of AIDS and in view of the changes which occurred during the epidemic, both in relation to its expansion and the care provided by scientific advances.

The Theory of Social Representations was used as a theoretical reference due to the need to identify and understand the knowledge construction shared by health professionals about the Healthcare phenomenon as experienced by this social group. Thus, by implementing this theory it becomes possible to "understand human behavior in its cognitive, affective and social dimensions, thus contributing to interpreting the practices which surround the human being, serving as a foundation and instrument to direct and facilitate relations with the environment, people and the social world"(5).

Considering that the implications of HIV/AIDS on people living with the virus go beyond physical and biological involvement as they also affect the psychological, social and economic spheres, it is imperative that the multiprofessional team is prepared to provide qualified and humanized care to these individuals(6).

In addition, the care provided by health professionals working with people living with HIV (PLHIV) should be carried out in light of ethical behavior(7), and it is also important to incorporate efforts to avoid possible losses in follow-up and gaps in the provided care(8).

Thus, in considering the aforementioned issues, the following guiding questions were formed: What are the care practices performed by health professionals for PLHIV? What are the contents present in the social representations of care for PLHIV developed by health professionals? "The rationale lies in understanding the transformation of professional care practices that have been in place since the beginning of the HIV/AIDS epidemic to the present day"(9). Thus, this study aimed to analyze the social representations of health professionals regarding the care provided to people living with HIV.

METHOD

STUDY DESIGN

A descriptive, exploratory study of qualitative approach.

SCENARIO

This study was developed in seven health units, including six HIV/AIDS Specialized Care Services (*SAE – Serviços de Assistência Especializada*) and a Counseling and Testing Center (*CTA* – Centro de Aconselhamento e Testagem), which conduct activities related to the National STD/AIDS Program in the city of Recife, Pernambuco, Brazil.

STUDY POPULATION

Forty-six (46) health professionals working in HIV care teams participated in this study. The study group was formed by invitation to all professionals working in the existing services in the city of Recife, applying the inclusion and exclusion criteria and acceptance by the professionals to participate in the study. The inclusion criteria were: professionals of technical or higher level, who had performed professional activity in the health field from the beginning of the HIV/AIDS epidemic (1980s); being active in a SAE or CTA unit, and having developed actions in the National STD/AIDS Program for at least 6 months. Professionals who were on leave or vacations during the data collection period were excluded.

DATA COLLECTION

Data collection was carried out from February 2012 to February 2014 using a semi-structured interview technique guided by a thematic roadmap elaborated for exploring the social representations of HIV/AIDS and a description of the care practices developed since the beginning of the epidemic. The interviews had an average of 60 minutes in duration, and were recorded, transcribed and organized for data analysis. Participants were identified by the letter "I" (interviewed) and their respective number, followed by the professional category, thus preserving the anonymity of the subjects.

DATA ANALYSIS AND PROCESSING

The data analysis was performed using the lexical analysis technique assisted by the *Analyse Lexicale par Contexte d'un Ensemble de Segments de Texte* (*ALCESTE*) software version 4.10. It was possible to disclose care practices and representational contents about HIV/AIDS among health professionals through these analyzes.

The software generated five thematic classes, however only two classes were analyzed to meet the objective of this study.

ETHICAL ASPECTS

The research was approved by the Ethics and Research Committee of the Oswaldo Cruz University Hospital Complex and the Pernambuco University Cardiological Emergency Room (*HUOC/PROCAPE*), according to the opinion no. 2.623.235/18, respecting the recommendations of Resolution no. 466/12 of the National Health Council and the signing of the Free and Informed Consent Form by all study participants.

RESULTS

A total of 46 health professionals participated in the study. The participants were mostly female (76.1%), belonging to the age group of 41-50 years (39.1%), Catholic (43.5%), living with a partner (56, 5%), with *lato sensu* post-graduation (52.2%), with less than 5 years since graduating (45.7%).

Regarding their duration in the HIV/AIDS Program, 20 (43.5%) had been working for less than 5 years, 15 (32.6%) between 6 and 15 years, and 11 (23.9%) between 16 and 25 years. In relation to the time spent with people living with HIV, 17 (36.95%) professionals had been working for less than 5 years, 16 (34.8%) between 6 and 15 years, 11 (23.91%) between 16 and 25 years, and only two individuals had worked with people who were HIV positive for more than 26 years.

The following thematic categories were obtained from the identification process of the discursive contents: Care provided for individuals with HIV throughout the epidemic; and Following-up people living with HIV and the impact of the diagnosis. The following will present the discursive contents of each class.

CARE PROVIDED FOR INDIVIDUALS WITH HIV THROUGHOUT THE EPIDEMIC

In this category, the care provided by health professionals from the beginning of the epidemic in the services is addressed, as can be observed in the registry units:

There was a nursing consultation, delivery of material, adherence group (E31, nurse).

I checked the pressure, I showered and changed the patient's diaper, prepared the dressing, inserted a probe. All nursing care at that time was developed by us, the nursing assistants. Because at that time we had a nurse for the entire hospital (E13, nursing technician or assistant).

We have psychological follow-up, dental follow-up, gynecological follow-up and follow-up by the doctors, because here we have an infectious, rheumatologist, allergist, immunologist... (E34, psychologist).

Professionals report that care for PLHIV was and still is performed by several health professionals involving diverse activities. However, although the services are composed of a multiprofessional team, it is noticed that the way professionals interact with each other to discuss the cases presented in the services varies from service to service.

There is always a different update, in which as we have contact there is an opening to talk with doctors or with the nurse, so they always update us when they can, sit, talk (E37, nurse technician or assistant).

We work very articulate and together here. The team is closed, it is a closed sector, we do not have professional turnover, and there is an interaction precisely because of this (E44, nursing technician or assistant).

They were discussing that case and conducting it, I miss that here. Here, the model should really be a healthcare team in this sense, which is multiprofessional and because we have a nurse, a nutritionist, an infectologist, a gynecologist, a psychologist, a social worker, a nursing technician (...) (E43, social worker).

It is perceived that the care efficacy also depends on organizational and political factors. Therefore, they evaluate that when the demand for service is greater than the offer, the care becomes impaired, being necessary that the public power reassess the offered services.

I think the healthcare which we provide in light of the current knowledge, and what we can provide, I think it has to improve, the number of vacancies, beds, hospitals interested in working with HIV, number of health staff (E33, doctor).

We would like to have a better HIV-positive outpatient service because the outpatient clinic here is not multiprofessional, and that's lacking. Also the health team is again integrated with case study and lecture programs for these HIV positive patients, seeking to help their self-esteem and their insertion in society (...) (E28, nutritionist).

(...) we are not able to attend all those in the service, imagine if they were all. This was the main thing, if you want to maintain the care, the follow-up, that this HIV positive patient comes to the service, you have to have those who can provide care, it is not only the doctor, the nurse, the service adapts to the need. (E20, doctor).

There is concern about the self-esteem and social insertion of individuals living with HIV/AIDS and the need for a sufficient multiprofessional team to meet the full demand of patients, resulting in improved care.

FOLLOWING-UP PEOPLE LIVING WITH HIV AND THE IMPACT OF THE DIAGNOSIS

In aiming toward better understanding of this category, two thematic groups will be described below: HIV diagnosis and implications in social relations and care; and The dynamics of care in routine consultations.

The first thematic group portrays the issue of diagnosing HIV seropositivity, addressing the issue of health professionals' orientations and the family relationship. Regarding the family, the participants state that there is still a fear in some PLHIV in revealing their diagnosis to the people in their social life, especially to their relatives, as can be observed in the following statements:

Usually, when an HIV-positive patient comes in, I ask, "Do you want your companion to stay?" Because sometimes he wants to talk about something that he does not want his family to know, so usually they are accompanied by someone other than the HIV positive patient's family who they do not want to know (...) (E15, nurse).

The family does not know. So they come to us to say, "So-and-so cannot know, because my family will not like it", so we respect his wish (E37, nursing technician or assistant).

When it is an HIV positive patient who is open in relation to the family, he says: "In my family that person has knowledge, she will come to accompany me in the consultations" (E4, social worker).

They come with the family, and we're always around. We always see the family around and what they need, they ask (E10, nursing technician or assistant).

In this context, the issue of secrecy about HIV serology emerged in the interviews because it is an individual right and not only involves health professionals, but also family members and/or companions.

Inside the house, no one in his family knows about him, he comes and then sometimes we need to get in touch with the HIV positive patient, we never identify ourselves when we call the HIV positive patient (E15, nurse).

(...) if he doesn't want anyone to know, that right is preserved (E14, nursing technician or assistant).

Also in the scope of the HIV diagnosis, the professionals' concern about serological testing, providing embracement, pre-test counseling, diagnosis disclosure, post-test counseling, guidelines and information about the disease and the offered service were also perceived.

If the user arrives, they are well attended there at the reception, then they go to the counseling. The nursing assistant will attend them, will embrace the patient. After they go to my room, I'll do the blood test and they feel secure, they feel they're going to get a diagnosis, they need to trust the service (E14, nursing technician or assistant).

You are going to provide all this guidance, and it is an arduous job to explain it every time they come, they have a question, we explain things again, and so here is mainly the reception, the orientation of what the sector offers to the patients (E15, nurse).

Regarding the second thematic group, the participants approached routine medical appointments to following-up and evaluating the patient's clinical, emotional and psychological profile. It is observed in the speeches that it is a moment in which the professional provides their patient with greater comfort and seeks to establish a relationship of trust, so that they feel at ease to expose their difficulties and anxieties.

We inform about the diagnosis, we embrace what comes from the user, whatever comes from their feelings, discomfort, revolt, questions, sometimes a lot of feelings of guilt (E16, psychologist).

We assure the minimum so that they are able to perform the treatment. We've received many HIV positive people who stop taking the medication because they didn't have a way to get here, they didn't have transportation to get to the unit to get the medication, they couldn't come for a consultation (E7, social worker).

We are the HIV-positive facilitator. Sometimes they don't have a medical appointment, they need something from the doctor, so they come here, we kind of bridge them, sometimes they come here, they don't complain about anything, but we already plan and schedule them in the nursing consultation (E15, nurse).

For me treatment is this, it is the reception from the time that the person arrives with the test in hand, and there is the result, and it is embraced, and we try to do this reception in the best way possible, for me this is the treatment process (E13, social worker).

It is observed that the care provided by health professionals to PLHIV, whether at the time of diagnosis or in routine consultations, incorporates active listening, support and emotional support in addition to guidance, with a stimulus regarding relational care. In this context, we seek to provide a moment of comfort governed by a relationship of trust and secrecy, respected according to the wishes of the patient, also counting on the participation and support of friends and family, which are of great value in this adherence process to treatment. It is also observed that there is strong concern about treatment adherence in the context of care for PLHIV, especially with regard to drug therapy.

There is an increase in the care actions, mainly with the use of soft-hard and soft technologies, aimed at strengthening the relationship between the service's clientele and health professionals.

In their care practice, the professionals identify some difficulties in the visits, and they also observe those experienced by the patients in coping with the disease.

This demands healthcare, longer hours for you to be able to focus more on that HIV positive patient, so you can talk, sometimes guide them to a room to give a talk (E26, dentist).

As you know a first time nursing consultation is extensive. And, because of a lack of human resources, things don't get done, they are missing and we somehow make due (E31, nurse).

She needs cd4, viral load every 3 months, and how can she do it if the exam is every 2 months? (E33, doctor).

Once the diagnosis is confirmed, the patient still has an immense difficulty to be able to adjust the viral load, and the cd4 dosage. These results take 2 months or more to get ready. This can all be decisive. (E18, nursing technician or assistant).

But what I realize with the HIV positive patients coming in from another service is that they don't have cd4, viral load at the appropriate time (E33, doctor).

We need to have more time for them because they come in more distressed, they need to understand that they are there, that they have an illness and have to be treated like a diabetic who has an illness and has to be treated, like a hypertensive (E46, nutritionist).

They don't have time, people need to have more time in their offices to meet the human person who will enter your room (E1, social worker).

Of course we always ask for a room, and sometimes we don't have a room, there's always someone there. And sometimes they ask the person who's there to go because we are attending an HIV positive patient, and sometimes they can't. (E11, nurse).

Among the difficulties encountered, the structural and organizational characteristics of the services stand out, with physical areas lacking to meet the demand, difficulty in obtaining cd4 test results, limited consultation time and the need for technologies' improvement. The need to expand the team by hiring professionals qualified to work in these specialized services, planning and management was also observed.

DISCUSSION

Constituting a social representation of a particular object implies a process in which individuals or social groups feel uncomfortable or attracted by a social object or practices which are not considered familiar by the group, requiring an establishment of consensus about the object. The interpretation of an object must be measured as it emerges in the social sphere, thus facilitating the representational approach that characterizes it as unfamiliar(4).

The HIV/AIDS phenomenon has a representational evolution which has already been identified by some authors(2), and it is important to understand it under the psychosocial approach, since subjective content and constructions of collective knowledge are valued, taking into account the meanings that the actors give to their practice(10).

Thus, the first aspect of the social representation of care provided by health professionals evidences multiprofessional care practice, and an affective-relational dimension may be associated with this practice. This care carried out by professionals involves a technical dimension and a relational dimension, but there is also interaction and sharing of actions among professionals, so that care for the patient and the family occurs in a comprehensive way.

In this sense, studies reveal that the care meaning of PLHIV for health professionals is established within a social interaction process. Therefore, it is influenced by concepts, meanings and symbols that these professionals bring from their social context(11-12).

The identified representational content seems to be more associated to the diverse composition of the team than to the interaction and articulation among its members. In this respect, it is worth mentioning that it is important to encourage the articulation of actions among the team, enabling integration of professional knowledge in face of individual and collective needs.

In the care context for the person living with HIV, it is not only recommended to observe the physical or biological aspects present in the syndrome, since it is a condition that mobilizes and interferes in other spheres of daily life such as social, behavioral and spiritual aspects which affect their life balance(10).

Thus, the multiprofessional work must be supported by a practice in which professionals act together, aiming to attain comprehensive care of the clientele. To this end, it is suggested that support groups be formed to promote understanding between the health team and the system's users, leading them to general integration and enabling understanding of certain problems experienced by individuals(13). Moreover, demands on outpatient HIV services have increased due to antiretroviral therapy, probably due to the increase in the life expectancy of PLHIV, and it is necessary to promote planning in the provision of these services(14).

It is understood that the care process can be enhanced by a "therapeutic relationship governed by the trust and emotional support established by the professional, so as to act as support in the midst of conflicts experienced by the patient in the presence of seropositivity"(15).

Thus, knowing that the care process implies overcoming the technicist model, the social representations of care are complex, considering that these professionals deal with anxieties, fears and uncertainties that permeate the illness process(15).

Throughout the epidemic, it has become clear the attendance, care, caution and concern of professionals during their care for the PLHIV, demystifying the proximity of death and considering AIDS as a chronic condition which requires comprehensive and constant care. In this sense, international studies also reveal that HIV is being considered as chronic, evolving from a life-threatening infection to a manageable condition in the long term due to advances in medicine, radical changes in health and social assistance policies, and the impact of population aging, with early detection and referral to treatment being vital(16-17).

It is fundamental to realize the importance of managers to incorporate the use of hard and soft-hard technologies in the services in order to reduce their structural failures, such as a large number of patients, lack of management protocols, fragility in referral and counter-referral service and lack of professionals(18). Thus, to say that care represents "difficulty" means to express that the outcome of actions is not desirable or that care cannot be fully implemented due to inadequate public policies or structural problems such as lack of staff, inputs and work process organization. Such policies are normative, insofar as they reflect situations of a political and institutional nature in which the professionals do not have the power to interfere.

Therefore, it is necessary to offer a service with equitable access to healthcare using mainly light technologies which can contribute to recognizing an individually, socially and politically constructed health world in order to guarantee the service being acceptable in the HIV context(19). And so professionals need to incorporate light technology in the care of PLHIV, which refers to the relations of communication, bonding and embracement to provide care to the patient under a holistic and complex perspective, with a view to improve their quality of life, being attentive to the ethical and legal precepts, safeguarding information secrecy and respecting their dignity(20).

When it comes to the HIV diagnosis, it should be remembered that HIV seropositivity has been fraught with stigma and prejudices since the beginning of the epidemic, constituting some of the factors which allow concealment of diagnosis in the social sphere of the individual. Studies have shown that the fact that the disease constitutes a taboo for several social groups forces people to face psychosocial and emotional challenges which interfere in the disclosure and diagnosis acceptance process, thereby opting for confidentiality(21-23).

Therefore, maintaining this secrecy condition causes many patients to stop seeking care and follow-up in health services near their home or their city, since these services constitute a place of social interaction with people who are known, making access to health services difficult, and consequently leading to care discontinuity. It can be seen that the social representation about the HIV seropositivity diagnosis is permeated by secrecy and isolation of people with HIV, which may be associated with fear of prejudice and discriminatory attitudes of other individuals if their serological condition is revealed to people close to their life.

CONCLUSION

The present study has allowed us to infer that the contents of social representations for care are based on the care, management, political and social dimensions, prioritizing the use of soft technologies in detriment of hard and soft-hard technologies. The results demonstrate the importance of a skilled multiprofessional team, as well as the need for structural and organizational conditions to provide care to PLHIV in order to meet the different client care needs.

Regarding the diagnosis confidentiality by the professional, it is worth mentioning that it is a conduct determined by ethical issues, meaning that it is normative in nature, and not a personal decision. Concerning the reception, orientation and support actions, referred to as representational contents of care, it was found that they are functional in nature, since their contents are those referring to the direct action by the professionals on the demands and needs of the users, which in this study were effectively shown to be more affective, relational and orientation dimensions.

Thus, the results point to the importance of encouraging multiprofessional care for people living with HIV, in a way that professionals engage in the provided care and develop critical thinking so that they are able to identify failures and act on improving services, always striving for confidentiality, support and quality of care.

RESUMO

Objetivo: Analisar as representações sociais de profissionais de saúde acerca do cuidado de pessoas vivendo com HIV. **Método:** Estudo descritivo e exploratório, de abordagem qualitativa, à luz da Teoria das Representações Sociais, realizado com profissionais de saúde. Utilizou-se da técnica de entrevista semiestruturada, a qual foi analisada por meio da técnica de análise de conteúdo lexical. **Resultados**: Participaram 46 profissionais Os resultados analisados revelam que as representações e as práticas de cuidado referidas pelos profissionais de saúde são de ordem técnica, relacional e organizacional, assegurando o sigilo do diagnóstico e preocupando-se em desenvolver ações de acolhimento, fornecer orientações, esclarecimentos e apoio emocional e psicológico, além de se basear no sigilo, na prática assistencial de natureza multiprofissional e no enfrentamento das dificuldades estruturais. **Conclusão**: É importante estimular o cuidado multiprofissional às pessoas que vivem com HIV, de forma que os profissionais se engajem, desenvolvam pensamento crítico e sejam capazes de atuar na melhoria dos serviços.

DESCRITORES

HIV; Síndrome de Imunodeficiência Adquirida; Enfermagem em Saúde Pública; Prática Profissional; Assistência Integral à Saúde.

RESUMEN

Objetivo: Analizar las representaciones sociales de profesionales sanitarios acerca del cuidado a las personas que viven con el VIH. **Método**: Estudio descriptivo y exploratorio, de abordaje cualitativo, a la luz de la Teoría de las Representaciones Sociales, llevado a cabo con profesionales sanitarios. Se recogieron los datos mediante entrevista con guión semiestructurado, los que se analizaron según la Técnica de Análisis de Contenido. **Resultados**: Participaron 46 profesionales. Los resultados analizados desevelan que las representaciones y las prácticas de cuidado referidas por los profesionales sanitarios son de orden técnico, relacional y organizativo, asegurando el sigilo del diagnóstico y preocupándose por desarrollar acciones de acogida, proporcionar orientaciones, aclaraciones y apoyo emotivo y psicológico, además de basarse en el sigilo, la práctica asistencial de naturaleza multiprofesional y el enfrentamiento de las dificultades estructurales. **Conclusión**: Es importante estimular el cuidado multiprofesional a las personas que viven con VIH, de modo a que los profesionales se involucren, desarrollen pensamiento crítico y sean capaces de actuar en la mejoría de los servicios.

DESCRIPTORES

VIH; Síndrome de Inmunodeficiencia Adquirida; Enfermería en Salud Pública; Práctica Profesional; Atención Integral de Salud.

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