

Vulnerability, empowerment and knowledge: nurses' memories and representations concerning care

Vulnerabilidade, empoderamento e conhecimento: memórias e representações de enfermeiros acerca do cuidado

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Keywords

Health vulnerability; Nursing care; Acquired immunodeficiency syndrome, Education, nursing, continuing; Health care

Descritores

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Abstract

Objective: To analyze the interfaces among knowledge, vulnerability and empowerment present in memories and social representations regarding nursing care for people who live with HIV/Aids.

Methods: This was a qualitative research conducted with thirty nurses from a public hospital. The theoretical reference used was the processual approach of the Theory of Social Representations. The semi-structured interviews were transcribed and submitted to thematic content analysis, using the software NVivo 9.0.

Results: Vulnerability was expressed in the fear derived from feeling unprepared, professional insecurity and the lack of scientific information. Empowerment was personified in the search for scientific knowledge, in the acceptance of the nature of the work, and the time in professional practice.

Conclusion: Data indicated a complex set of interfaces and a process of naturalization of AIDS, conducted by nurses to adapt their practices to the historical transformations inherent to the syndrome.

Resumo

Objetivo: Analisar as interfaces entre conhecimento, vulnerabilidade e empoderamento presentes nas memórias e representações sociais acerca do cuidado de enfermagem a pessoas com HIV/Aids.

Métodos: Pesquisa qualitativa realizada com trinta enfermeiros de um hospital público. Adotou-se o referencial da abordagem processual da Teoria das Representações Sociais. As entrevistas semiestruturadas foram transcritas e submetidas à análise de conteúdo temática instrumentalizada pelo *software* Nvivo 9.0.

Resultados: A vulnerabilidade foi expressa no medo oriundo da sensação de despreparo, insegurança profissional e escassez de informações científicas. Já o empoderamento corporificou-se na busca por conhecimento científico, na aceitação da natureza do trabalho e no tempo de atuação profissional.

Conclusão: Os dados apontam para um conjunto de interfaces complexas e um processo de naturalização da AIDS realizado pelos enfermeiros para adaptar suas práticas às transformações históricas inerentes à síndrome.

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Introduction

Due to the emergence and progression of AIDS in the social significance, the science field devoted efforts in the search for its origin, explanations about its epidemiological behavior, definitions of groups or practices that could provide a higher risk for illness and, especially, the scope of possible therapeutic resources. The uncertainties that originated from the appearance of AIDS, particularly in the beginning of the 1980s, placed nurses in a delicate position within an atmosphere of tension, given the consideration on one side in which the profession's ethical postulates demanded provision of uninterrupted and quality care, and on the other side fear of the unknown and potentially fatal nature, could, at least in part, divide professionals and patients.

In consonance with polysemy, complexity and usability of the vulnerability concept by various areas of knowledge,⁽¹⁾ the healthcare field shows itself productive in the problematic and conceptual approach of the subject, since it is in the human essence, especially in its frailties, that the phenomenon of vulnerability settles. In the last years, conceptual prepositions of vulnerability have expressed facets that emphasize the social context of population groups,⁽²⁻⁶⁾ not considering their quantifiable aspects that could potentially produce the illness.

In this study, vulnerability is understood as a typically human dynamic and mutable state of fragility or of incapacity, owning different dimensions and the result of several factors and situations, intrinsic and extrinsic, for health system users or the professionals providing their care. This status drives them to formulate coping strategies, thus configuring their empowerment when confronting the experience of the health-disease-care processual interaction.⁽⁷⁾

The question that guides this research is: what is the role of knowledge in the configuration of vulnerability and empowerment present in memories and social representations, elaborated by nurses regarding nursing care for people

living with HIV/Aids? As a subject, the interfaces among knowledge, vulnerability and empowerment present in nurses' memories and social representations of nursing care for people who were carriers of HIV/Aids were defined. The aim of this study was to analyze the interfaces among knowledge, vulnerability and empowerment present in memories and social representations concerning nursing care for carriers of HIV/Aids created by nurses.

Methods

The Theory of Social Representations was adopted as a theoretical-methodological path for this study, in its processual approach, developed from the Social Psychology perspective. The study sample was composed of 30 nurses who performed their work in the chosen scenario for the survey, a public hospital of Rio de Janeiro, a reference for the treatment of HIV/Aids and tuberculosis. The reason for this sample size was the consensus existent within the Theory of Social Representations, being the minimum quantity to recover social representations in a group.⁽⁷⁻⁹⁾ Professionals with less than six months of professional activity within the context of the chosen scenario were excluded. The reason for this was due to the time factor being configured as a determinant in the elaboration of social representations. No other attribute was considered to be a justifiable exclusion criteria.

The technique used for data collection was a sociodemographic questionnaire to characterize the subjects and interview. Data were collected between June and August of 2009. For technical analysis, an Analysis of Thematic Content was conducted after systematization⁽¹⁰⁾ and enabled by the software QSR NVivo 9.

This computerized tool is based on the principle of coding and storage of data in categories.⁽⁷⁾

The development of the study met all of the national and international ethics regulations for research involving humans.

Results

The subjects were mostly female (87%), belonging to the age group of 41 to 45 years (27%), Catholic (40%), had a partner (70%), with *lato sensu* graduate degrees (90%), 16 years or more of institutional practice (37%), and of working with HIV patients (30%), at care assistance work during the time of data collection (63%), and with access to scientific information (77%).

The results of analysis instrumented by NVivo 9 obtained 311 Node Classifications, distributed in 22 themes and related to 100% of the analyzed corpus. Vulnerability was elucidated by the subjects through deficiencies in their professional training for working with the patient with HIV/Aids. The themes linked to vulnerability had essentially negative content, which could be verified in the presence of fear, guided by the lack of preparation, insecurity and the theoretical insufficiency, simultaneous to the need for the constant provision of care. In their memories, when describing the start of work with carriers of HIV/Aids, nurses reported being scared due to the deficit of theoretical knowledge about the syndrome, which transformed it into an unknown entity.

"Because survival is a normal thing of the human being. We have fear of an unknown thing whose death is ugly. Until now there was not too much knowledge. So the feeling was fear". (E11)

"[...] I came to work in the AIDS unit and it was scary for a while. I was very scared. Also because we did not have any preparation. It was a thing unknown for us and even for the other professionals. To tell the truth, I was afraid of working with this type of patient". (E12)

It was noticed that lack of available scientific knowledge was present in the memories of nursing care elaborated by the subjects, who needed it for initiating their work with HIV/Aids. There was evidence that lack of scientific information maintained interfaces with nurses' vulnerability, since it placed them in a position of disadvantage, and they showed themselves to be scared and fearful, even though they were unable to demonstrate such feelings.

"I am a nurse, I am the head nurse. I can be dying of fear, but I cannot tell that I am afraid". (E10)

In the discursive excerpts listed below, it is possible to verify that the vulnerable state was expressed by the subjects through the permanence of insecurity provided by the deficit of theoretical knowledge concerning AIDS, its treatment, and nursing care for HIV-positive patients, despite its larger availability in scientific sources. In this way, nurses establish a self-criticism of their practice and their professional preparation.

"I do not know the theory. I do not know. How can I do it differently? I do not know. [...] For us this affects the care a little bit". (E3)

"[...] sometimes I feel insecure when handling certain situations, such as medications that I do not know well. We are very mechanical and sometimes I miss this [theoretical knowledge]". (E6)

"[...] my part is failure, I guess. I have an educational preparation that I think it should be enriched [...]". (E17)

Regarding the feeling of insecurity faced by the nurses, two facets could be identified. The first was related to its rise at the beginning of the syndrome, and the subsequent permanence in the healthcare assistance routine. The second was linked to its configuration as an obstacle to the completeness of care. Insecurity in this sense, according to the subjects themselves, provided greater mechanization of the procedures, low self-esteem and difficulty in delivering more qualified nursing care.

It was found that fear was established as something constant in nurses' professional lives, correlated with unfamiliarity about HIV/Aids. Nurses attributed the lack of knowledge to a deficient educational preparation and to scarcity of available, reliable information about Aids. The first professional contact with a HIV-positive patient was reported as a traumatic event, in which little knowledge was accessible to guide action.

In the following section, discursive excerpts of nurses relative to empowerment, that is, about the feeling of having the resources necessary to minimize the vulnerable state throughout the care giving career of working with HIV/Aids patients, will be described.^(6,7) Among representational content that

pointed to a higher perceived status of empowerment were the valuing of: clinical practice, length of service, knowledge and information - such as its priority to ward off fear, the active search for more reliable scientific information than that which is broadcasted by media or that is not available in the hospital, promoters of skills and practical knowledge concerning HIV/Aids.

Nurses, despite being aggrieved by a deficit of information at the beginning of healthcare assistance activities in the HIV/Aids scenario, as discussed previously, moved to achieve an active search for knowledge. The knowledge seemed to be mediated by the interest awakened by the fragility of the patient under care. Therefore, nurses assigned positivity to knowledge, either because it strengthened their professional autonomy, enabled them to work with HIV/Aids patients, optimized the care provided, or dispelled their fear.

“After I started working then I began to be interested. Because it is a disease that depresses the patient a lot and he really needs us. Then I became more interested”. (E3)

“The more knowledge we have, the better will be the care provided. So this will reflect directly in the care. Who is not prepared, is not qualified”. (E14)

“What made me change was, over the years, various courses and lectures. That taboo of the beginning, that impact that I had in relationship to HIV / Aids over 15 years ago has been decreasing as the years pass, with the obtaining of information, training, services, lectures ... So I was relaxing. Relaxing not without being preventive, but of not staying with that fear that I had at the beginning”. (E19)

“You can only achieve space through knowledge, showing that you know”. (E11)

It is noted that in the memories created by the nurses, there was an overcoming of the tension in working with HIV/Aids by means of the knowledge obtained. In the nurses' words, the taboo, the impact, or even the fear were replaced by the know-how gathered from information obtained inside and outside of the hospital setting.

Knowledge was conceived as a propellant for autonomy, successful care and qualified practice.

Nurses valued the biomedical knowledge as guidance for health care practices in the context of Aids. In this sense, knowledge is novel and the representational content as a fundamental instrument to nursing practice, able to cope with the difficulties experienced by the patient and professional.

The transformational capacity of experience was voiced by professionals in the following passages.

“We ended up getting used to the situation and better accepting the work. Maybe it is precisely because of the cocktail, of the medication, and perhaps also, for knowing the disease, knowing what are the routes of contamination. Nowadays people work more calmly with HIV patients and the majority are more affectionate, giving more attention to the social side of the person, listening and talking”. (E8)

“In the course of time, about six months, it [AIDS] was being more clarified and the fear was disappearing. And then it became a normal thing to me. Even because I had a lot of affection for the patients, I was a friend for them and their families”. (E12)

“And then, after this contact, you see that things are not as bad as they look. We have to be careful, but they are people like us”. (E16)

“Nowadays I see a patient like any other. Like a diabetic patient, with hypertension or any chronic disease that is being well treated. There is no difference between one disease and another”. (E18)

As can be observed, for some subjects, that practice experience seems to be established as sovereign in the formulation of knowledge about HIV/Aids, that is, in turn, susceptible to confirmation, correction or refinement when further research for new knowledge will be performed.

Among the passages above, the role of affectivity is highlighted in the redefinition of nursing care, considering the influence of social interactions and of the bond between professional and family in the visualization of seropositive status more positively and, in addition, the comparison of AIDS with other chronic processes of illness.

This is based, among other things, on the survival rates afforded by pharmacological treatment and by the creation of public policies aimed at promoting the health of people living with HIV/Aids.

Discussion

Limitations of this study are related to the restricted number of subjects and investigation of a single scenario. Nevertheless the results have the potential to reveal contexts of fragility or strength perceived by nurses over the historicity of HIV/Aids, both mainstreamed by the influence of (mis)understanding of the syndrome and care for people living with HIV

When verbalizing their memories about nursing care in the context of AIDS, the nurses of this study drew a paradox between past and present, from a mental process of reinterpretation of events. This work has influenced the history of the group, subjectivity of its individuals, nature of the work environment, among other factors.

Empirical data revealed the multifactorial nature of the phenomenon of vulnerability and reaffirmed its inseparable presence in human life. For presenting a well branded representational field, positive or negative attitudes and a body of consolidated knowledge, vulnerability and empowerment present themselves as objects of representation, such as have been explored by other authors. Furthermore, this study reinforced the assumption that fragilities, which touch the human being, particularly the nurse when providing care to other human beings in vulnerable situations, were answered with attitudes, knowledge and practices whose goal was to move the subjects to a more favorable context, in which a greater degree of empowerment could be achieved.^(1-8,9,11-16)

Data highlight that knowledge maintains interfaces with vulnerability, with empowerment, with social representations of AIDS and of nursing care for patients with HIV. Even when dealing with distinct objects of representation, it is postulated that there was an intertwining of them, of complex configurations, and that it was susceptible to transformations consonant with interpersonal relationships among the social actors involved in daily healthcare and, more broadly, the geopolitical injunctions related to the AIDS phenomenon.⁽¹¹⁾

The nurses who faced numerous difficulties in structuring their practices against insufficient

sources of scientific knowledge, verbalized their vulnerability to a condition ruled by the fear they felt due to a sensation of professional unpreparedness, insecurity and the scarcity of information about AIDS and its forms of transmission and treatment. This data corroborates findings of other research.^(5-7,8) However, the time in professional practice in the HIV/Aids area, the growing interest in a disease process that generates dependency in multiple domains of the human being, and acquisition of scientific knowledge available to the subjects over the years, especially in the media and professional courses offered by the institution, contributed to acceptance by the nurses, of the activity of providing healthcare to patients who were HIV seropositive, which embodied the representational content about a more favorable state of empowerment. In this direction, the search for knowledge, the increased interest in AIDS, and time of practice in this context (most of the subjects had 16 or more years of experience) were elements present in the representational construction of subjects as opponents to the power of fear, based on uncertainty and imminence of the perceived risk of contamination.

It is emphasized that the knowledge, which mobilized subjects from a perceived vulnerable status to one of empowerment, was not necessarily linked only to scientific knowledge, given that professional practice of care was verbalized by the nurses as an important resource to coping with fear, unpreparedness and insecurity. For its simultaneously relational and biomedical construction, the professional practice of nurses is embodied by constructions arising both from the reified universe as much as the consensual, it appropriates the information available in daily life and in the interaction with people and articulates with the body of scientific knowledge to structure itself.

It is noteworthy that, unlike other more immediate forms of coping,^(7,16) those that were identified by this research developed gradually, in measure to the experiences, interpersonal relationships and symbolic exchanges of those who share in the environment of care. It is proposed

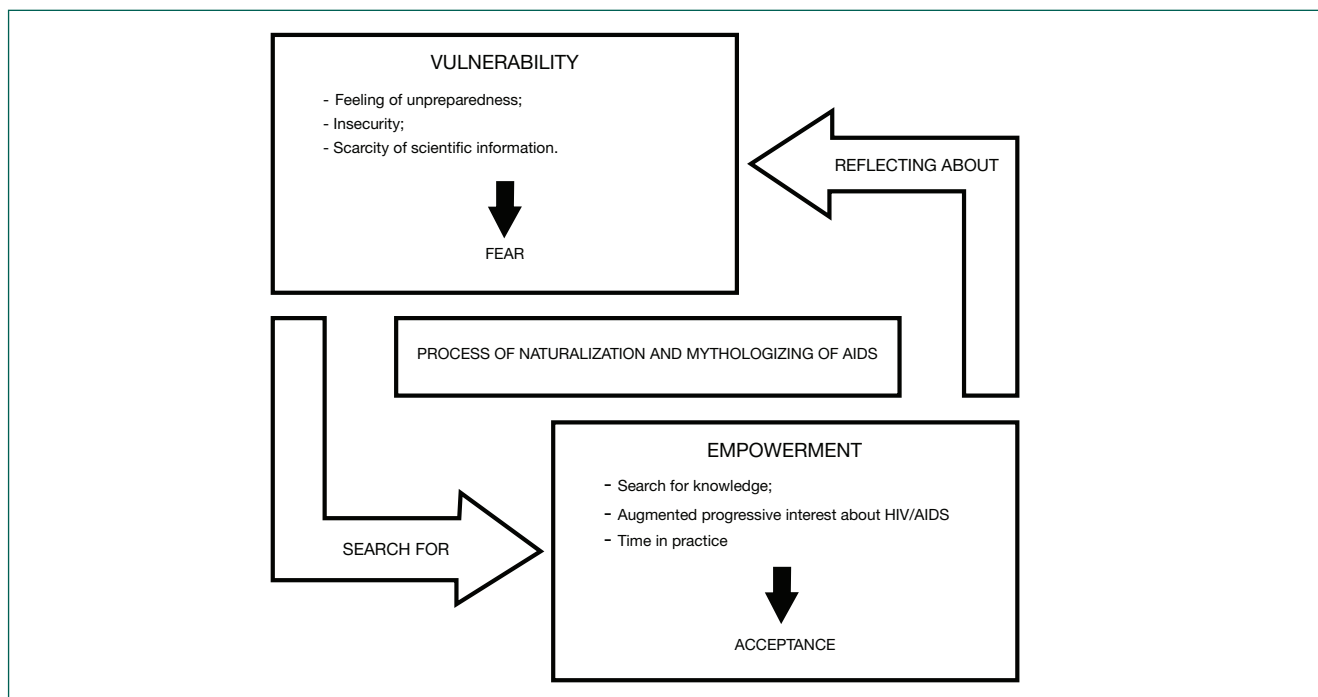


Figure 1. Illustration of the dynamics of vulnerability and empowerment in the nurses' memories and social representations regarding nursing care

that throughout this temporality, a process of naturalization of AIDS developed and was marked by its redefinition (Figure 1). In this sense, its acceptance and comparison with chronic diseases indicated a more positive attitude of the subjects. This possibility finds its mainstay in recently published research.⁽¹⁴⁾

This study points to pathways so that further research can investigate, under different conditions and in different contexts, the issue of vulnerability in nursing care and its reframing by nurses, patients and family.^(12,13) The influence of variables such as the role of leadership,^(14,15) the physical proximity to the diseased body and mind of the people living with AIDS, the educational function in a historical moment in which little technical and scientific knowledge was available about AIDS,⁽¹⁶⁾ and the relationship between vulnerability and possible expressions of spirituality/religiosity,⁽¹⁷⁾ appeared as variables that could be analyzed, associated with vulnerability and empowerment present in healthcare.

Empowerment, in turn, had as one of its pillars obtaining theoretical-practical information for the work in HIV/Aids.

Conclusion

The results indicates that the interfaces among knowledge (reified or consensual), vulnerability and empowerment of nurses were complex, and were present in memories and social representations created about nursing care for people with HIV/carriers of Aids. It is realized that the feeling of unpreparedness or lack of knowledge about AIDS, whether occurring at the beginning of the epidemic in the work setting or that which is still present in nurses' professional lives, shown as a fruitful terrain predisposed to the vulnerability of these people.

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Collaborations

Santos EI and Gomes AMT declare that they contributed to the development and performance of the project, analysis and interpretation of data, writing the article, the relevant critical review of the

intellectual content, and approval of final version to be published.

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