THE SUFFERING AND PLEASURE OF NURSING STAFF RESULTING FROM CARE TO HIV/AIDS PATIENTS¹

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ABSTRACT

The objective of this article is the suffering and pleasure of nurses assisting patients with HIV/AIDS in the Unit for Infectious Diseases. The main objective is to describe and analyze the feelings of these nursing workers deriving from the assistance to patients with HIV/AIDS. The methodology applied consists of a qualitative approach, of descriptive and exploratory character. The data were obtained between May and August 2010, through semi-structure interview, and also analyzed by the Thematic Content Analysis techniques. It was found out that the psychic pain was due to the patients' process of death/dying, the stigma of the disease, the prejudice that both patients and professionals suffer as well as the fear those professionals feel of the occupational contamination. Their joy was connected to the feeling of being useful and the patients' acknowledgement to the quality of the given care. The experience of pain appeared in a stronger way than the feeling of pleasure. The following strategies are recommended, among others, to minimize the psych pain of the professional people: focus groups, laboral gymnastics, alternative therapies, more humanized laboral environment and permanent education of the professionals.

Keywords: Occupational health. Occupational nursing. Nursing care. HIV. Acquired Immunodeficiency Syndrome (AIDS).

INTRODUCTION

The present work aims to address the pain and the pleasure of the nursing workers arising from customer care with HIV/AIDS. This object has emerged as a clipping dissertation defended at the Faculty of Nursing of the University of the State of Rio de Janeiro (ENF/UERJ), in the year 2011⁽¹⁾.

The motivation to investigate nursing work with customers in the HIV/Aids situation and the health of workers began to observe empirically that this job was painful due to the multiplicity of care that these customers demanded, increasing the employment rate and the need for refined psychomotor skill. It alludes to issues of

death and dying around this backdrop of work, in addition to the stigma of the disease, which permeates the history of this pathology since its emergence.

In this sense, infers that Aids, more than a disease, is characterized as a deviant and perverse form of social discrimination, intrinsically linked to the universe of homosexuality, prostitution and betray, exposing the people to have more intimate, hidden through taboos that society doesn't want to explain and confront^(2,3).

On the issue of close coexistence with death and the dying process of assisted clientele, the disease is characterized by a high emotional burnout, because this employee feels powerless to deal with the possibility of

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death and finitude of human life⁽⁴⁾.

In addition, the nursing workers are afraid of contagion resulting from the possibility of accidents at work and of biological contamination⁽⁴⁾. From this perspective, accidents with biological material exposure affect emotionally the nursing worker, which corroborates the psychic suffering and illness⁽⁵⁾.

The nursing work has caused a great physical and psychological wear and tear to the workers on the basis of the hospital environment; it is often painful and unhealthy, not offering favorable conditions for health and job satisfaction, which makes the fourth nursing profession more stressful in public service⁽⁶⁾.

In addition, there is the precariousness of Brazilian public hospital environments, with qualitative and quantitative shortages of human and material resources. There is then, a variety of negative consequences for the subjective dimension of workers. Authors highlight the need of everyday adaptations and improvisations of materials and equipment, due to the lack of these inputs. In this sense, the worker presents psychophysical wear on the necessity of having constantly to create within an environment made precarious (7,8).

Another emotional wear and tear factor is the close involvement of the professional in the process of illness, pain and death of customers, beyond the suffering of the relatives. There are also issues relating to occupational hazards and accidents afflicting workers due to fear of contagion and the possibility of illness, for example, by contamination by hepatitis B and C and HIV, too^(9,10).

Aids is a disease defined as a disorder of cell-mediated immunity, caused by a virus of the subfamily Lentivirinae (family Retroviridae), characterized by opportunistic infections, neurological disorders and a variety of other syndromes. This disease, classified as chronic, has a generally slow evolution, and can take ten years between the contamination and the submission of clinical manifestations⁽¹¹⁾.

The contagion of HIV/Aids can give by the sperm, the vaginal secretion, breast milk, blood and its derivatives, through blood transfusions or needles and syringes contaminated with blood from infected people, through congenital or in other work-related circumstances. In this case, it

can be characterized as an occupational disease, if the causal link is established⁽¹²⁾.

Another aspect to be considered is the need of technical and scientific knowledge that nursing workers need to take care of the patient with HIV/Aids. Among the causes of suffering of these professionals, are the secrecy about clients' diagnosis with Aids and personal identification with the suffering of people with Aids and their families⁽¹³⁾.

From this perspective, there are repercussions for workers working with this patients, such as isolation, fear and uncertainty about the future; anxiety and fear against the effects of their work on their personal relationships and family dynamics and professional; the difficulty of assisting these customers, when they run into a situation terminality, feeling powerless to deal with the suffering and death; and the high rate of absenteeism, physical and psychological, for suffer prejudices of co-workers, acquaintances and friends, as well as their families (2,4,14). So, in this context, the suffering potentiates and the chances of negative repercussions on the health-disease process increase exponentially.

Considering the working environment and the specificity of clients assisted it was chosen the following problem of research: what are the feelings that emerge in the nursing workers arising out of labor activity with customers diseased by HIV/Aids?

In order to respond to the research problem, it is aimed to describe and analyze the nursing workers' feelings arising from customer care with HIV/Aids.

METHODOLOGY

This research was qualitative in nature, descriptive and exploratory. The scenario chosen was the infirmary of Infectious and Contagious Diseases of a large university hospital of Rio de Janeiro.

The subjects were ten nursing technicians, two nursing assistants and a nurse. As a criterion for inclusion, the participants of this survey had to take care of patients with HIV/Aids for at least two years/Contagious Diseases Unit, besides availability to provide the information, as well as participate voluntarily in the study.

The data were collected through semi-structured interview and recorded in MP3-type equipment and after the permission of the participants, through informed consent; these data were treated through the technique of Thematic Analysis of Content. This analysis allows accessing to various contents, explicit or not. This is an investigative technique that, through an objective, systematic and quantitative description of the manifest content of communications, aims at the interpretation of these same communications⁽¹⁵⁾. The applicability of this technique did emerge the following categories of analysis: HIV/Aids – between the pain and the pleasure of taking care.

The project was submitted to the Committee of Ethics in Research (CEP) of the hospital where the survey was developed and approved under the protocol number 2597 - CAAE: 0026.0.228.000-10.

RESULTS AND DISCUSSION

The analysis of the information brought out a dialectical situation, which involved the feelings of pleasure and pain, of satisfaction and dissatisfaction, demonstrating that the professional practice in this context is complex and permeated by contradictions which affect positively or negatively on the health-disease process of the nursing workers.

HIV/AIDS AMONG THE SUFFERING AND PLEASURE OF CARING

The notion of pleasure is closely linked to the feeling of being healthy, feel useful and to be recognized, what takes place, the organization of work for the clients assisted and by families. Besides, the pleasure is also coupled by the professional identification with the task prescribed and actual activity⁽¹⁶⁾.

On the other hand, the feeling of pain emerges when the worker's capacity to deal with the adversities of the world of work and the characteristics of their task exceed their psychophysical resistance. In this sense, the work environment necessitates hospital nursing worker deal daily with human limitations, with the finitude of life, with the abandonment of the family and the humiliation because of

prejudices. All these experiences are linked to the feeling of suffering, making this worker more prone to emotional and mental diseases⁽¹⁷⁾. This suffering is evidenced through the following speeches:

We get penalized. We know that all are condemned to death. But when you think that the patient is so young, so cool. Even if it is a lady, a lord, but a child, anyway, we're sad. Then there's the family, move a little with the emotional side. One gets a little bit penalized. (E13)

Another issue that emerged in the lines of the subject was the fear of contracting the disease as a result of an accident at work, because Aids is a contagious disease, incurable and with high social stigma. This fear is featured in the following talks:

When handling the patient, I take all precautions to protect me. The puncturing, wear gloves; although the glove also is not safe because it can stick. Take all precautions. But, if it happens? I always use when I have to use. Insulations: use cloak, mask. In precaution of respiratory contact I use these materials. With direct customer care I use gloves. Always use protection when handling the patient. But I'm still scared. (E6)

Thus, in the unit of Infectious and Contagious Diseases, the work of nursing has a great psychic load due to fear of contamination because it is necessary to deal as a communicable disease and with the opportunistic infections that impose, including, the physical isolation of the customers. In addition, customer care with HIV/Aids implies the handling with armorpiercing and/or sharp materials, causing fear of contagion and making this extremely technical and impersonal care.

Despite the progress made in the treatment of HIV infection and Aids, providing improved quality and increased life expectancy, it is observed that the fear of contagion of Aids is still seen as a threat to the physical integrity of the human being, triggering mental operations dating back to stigmas and prejudices, making this confrontational and difficult health problems for workers have to deal with it (17).

The lines below exemplify the high emotional charge for which the nursing workers pass:

You're dealing with a patient off balance emotionally, by illness, fearful, very afraid. In addition to other diseases, so have patients here, rebels. (E4)

Other patients aren't even there. We had a patient here, old, because he was disgusted with the disease, already slashed employee, already slashed medical resident. (E5)

Living with the disease causes in nursing workers many feelings as: compassion, commitment, satisfaction, the suffering, the pain by stigmatization and prejudice. Thus, dealing with the stigma, discrimination, powerlessness, hopelessness, aggression, denial is impacting and requires special attention to such problems⁽³⁾.

The establishment of the diagnosis of HIV/Aids causes an impact on the whole family, generating a situation of difficult confrontation, which may be associated with the design of Aids as a disease of moral and social character, which involves two major taboos in Western society: sex and death.

Facing this, what subjects they observe and what bothers them is the rejection that customers suffer, so that many find themselves cut off from the family, the marital relationship, culminating with the occurrence of abandonment and social isolation.

A lot are dropped by the family, many are abandoned. Many or were orphans or the companion has passed away, has already left, his friends moved away, though mostly they contracted this disease. (E11)

In this perspective, the professional sees himself faced with the impotence to help this client in the recovery process. There is sometimes the refusal to treatment and the acceptance of associated morbidity, and this situation result in suffering and psychic wear.

Patients come here when they have relapses. Do not take the medication right. Then, care is difficult. It is exhausting for the team, for the patient and when the family is close, for them, too. (E2)

Identify the suffering and the sense of worthlessness or a task unfinished, due to lack of attendance to the completeness of the care ⁽³⁾. One realizes this situation by means of the following narrative:

The rule of patient that I left and came back the next shift, find it the same way. More than twenty

days in a coma, go back and find it still the same way. I wish the best for him. Wish I could do more. (E6)

It's pretty difficult. It is that desperate patient. Up, even by the look of the patient, people feel the desperation of patients. But, there is no more help; it is frustrating! (E8)

An important aspect for analysis was the recognition, by subject, the differences in working with HIV/Aids clients with respect to other diseases, leading to nursing professionals dealing with specific aspects such as fear of exposure to infection transmission; the fear that other clients, friends or relatives know that they possess a professional performance by the customers with Aids; and difficulties in working with specific subgroups, such as homosexuals, drug addicts, prostitutes, in which come into play prejudice about lifestyles. In addition to these questions, infers that the subjects reported that they are compelled to process a large amount of information, scientific or not, on HIV/Aids, which are true bombings of news and/or information, in which the despair of the client, the family and the team itself, in General, are unlikely to discriminate what's appropriate or not.

Exemplifies this analysis through the following lines:

I wanted to get out of the unit because of prejudices of the disease. I'm not here for 17 years because I wanted to stay. Many times I wanted to quit, but only comes out for barter. People don't want to come to the DIP. People say: I don't work there, has AIDS. Has HIV. Have opportunistic diseases. Nobody wants to be part of this group. This was and is very bad for me. (E7)

At the beginning I had a feeling a bit different compared to this customer base. Then, I got used to it. [...] We find people like us, with our bodies, with our guy; talkin, walking. However, are HIV positive. (E11)

Another factor faced by nursing in the context of professional customer service gotten sick by HIV/Aids and resulting in suffering is caused by physical efforts psychophysical resulting from the specificity of the work of the nursing process.

We enough with that amount of patients, and that sometimes I am very requested. So, you do

everything running. From the morning, when you start, with the care, food hygiene, medication. So, it's kind of hectic. Finish the day, very tired physically. (E7)

Have shifts that are too burdensome and, depending on the physical effort, a low back pain. Has everybody here shifts until time to go to the bathroom, eat something. It is to rest. We don't stop working all night. (E11)

It is evidenced as an indicator of reality exhausting and nursing workers suffered the fact of possessing double, sometimes triple employment.

I go home and take a shower and I'm still working at home, type: cooking, washing, passing. If you have to keep working, keep working. (E12)

Making an analysis of the profile of subjects with previous speech concerning numerous activities and roles, it is important to mention the issue of gender in the work of nursing, since this is a predominantly female profession, and the workers, in addition to having to take a formal position, still remain responsible for the education of children and household management, wearing even more nursing workers⁽⁶⁾.

The pleasure-pain is a subjective relationship of the worker with his work and is based on the design of the work place of realization, of identity, of appreciation and recognition and that the pursuit of pleasure is a constant for the workers in order to maintain their psychic balance. Thus, the recognition is the process of recovery from stress and suffering invested to carry out the work, which allows the subject to construction of their identity, namely the experience of pleasure and accomplishment of yourself, confidence, cooperation and solidarity⁽¹⁶⁾.

Although markedly greater feelings of grief, there are situations that generate pleasure to these workers, such as: the possibility of health recovery of these clients; recognition by clients/family for the work done; the constant learning; the feeling of being useful; and the appreciation of life.

For me is very gratifying. Not only rewarding, the work is so very enriching because I learn a lot. It gives me great pleasure. I also like helping patients and support the family. And like when they note that I care about them. (E4)

For that, despite working with a client surrounded by stigma, prejudice, with the constant concern of the risk of contamination by the HIV virus, one realizes that the important thing for this professional is the ability to be able to handle; it can be useful, to be constantly learning. So, it reinforces the premise to be valued by the object of his work is a possibility for the psychoactive socio-professional relations structuring. To feel valued, the worker considers work important for himself, for the institution and for society, creating a positive self-image⁽¹⁶⁾.

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FINAL CONSIDERATIONS

The current research shows that study participants present distress due to multiple factors related to the characteristic of the process of working with this clientele and the subjective issues of the workers themselves.

This nursing worker has high psychophysical risk, for experiencing daily the suffering of those who suffer this disease, since it is incurable and lethal, coupled with the fact that it is heavily stigmatized and surrounded by prejudices, because often the HIV-positive people are still being included in the social imaginary, in risk behavior groups responsible for the infection itself and by the spread of HIV/Aids. Therefore, it can be seen that the diagnosis of HIV represents much more than a fatal disease.

So, this situation requires a high psychic burden of nursing worker, due to the need for more rigorous secrecy, having to overcome his own fear and prejudice related to the disease, and has to dribble and/or create strategies to deal with the prejudice of professional colleagues and family, passing to be them discriminated and marginalized.

Added to these facts the absence of a cure for the disease, the high rate of infected people, the need to take care of customers of their age and social group, the possibility of having to deal with aggression and resentment of the customer and of the relatives and the ostracism that disease imposes and exposure to death. There is also the question of the danger of the self-contamination involving the biological risk and the risk of accidents with sharps contaminated.

It is evidenced, so, the feeling of fear of acquiring a disease as AIDS and being between life and death.

Despite the progress made in the treatment of HIV/Aids infection, the fear of contagion is still seen as a threat to the physical integrity of the human being. Thus, the nursing professional needs to be constantly seeking new knowledge about the technical and scientific advances to take care of this clientele, enabling continuously in order to understand since the causes, signs and symptoms until the warranty of the completeness of the care to clients with HIV/Aids.

However, some subjects were emphatic in declaring feeling pleasure, alluding good feelings when cared for and watched the improvement of the patient from the nursing action when they are recognized by the Chief or by customers due to the work that developed next to this clientele and when they feel useful. It was considered that such situations protected the subjectivity of these workers and helped don't get sick before an adverse context of caution.

Before what was analyzed, it is recommended to decrease the emotional charge of work, from help strategies for professionals, such as focus groups, workshops, gymnastics and complementary therapies (such as floral, Reike, acupuncture). These strategies are suggested because there are extension projects at the University which develop these alternatives, which can be quoted to the servers who work in

critical sectors like this. There needs to be awareness of managers, political will and stimulation of Labor Organization in order to adapt the framework of professionals according to the needs of the clientele, as well as to the supply of inputs needed the assistance of clientele and that workers have the opportunity to participate in these projects from qualitative and quantitative adequacy of personnel and material.

In addition, we propose improvements in the working environment making it more relaxing and pleasant to look at, with relaxing colors, ambient music; primarily, it is necessary to make a reform in the physical structure of this space.

Client care diseased with HIV/Aids requires nursing professional changes in the subjective behavior in relation to disease, to the prejudice and stigma surrounding this pathology in order to reduce and eliminate exclusion form in which the HIV virus was introduced into society and thus provide a better way to handle. From this perspective, are important steps to improve the training of nursing professionals, promoting courses in continuous update on the evolution of HIV/Aids, and to encourage and facilitate the qualification of nursing professionals in specialization courses, master's and doctoral degrees.

It is expected that more scientific studies can be conducted in future, so that they can learn in greater depth the issues involving the occupational health nursing in its subjectivity, in order to ensure a better quality of life for the professionals.

O SOFRIMENTO E O PRAZER DOS TRABALHADORES DE ENFERMAGEM NO CUIDADO AO CLIENTE COM HIV/AIDS

RESUMO

O objeto deste artigo são o sofrimento e o prazer dos trabalhadores de enfermagem decorrentes da assistência a clientes com HIV/AIDS na Unidade de Doença Infectocontagiosa. Como objetivo, deseja-se descrever e analisar os sentimentos dos trabalhadores de enfermagem decorrentes da assistência ao cliente com HIV/AIDS. A metodologia empregada é a abordagem qualitativa, de caráter descritivo e exploratório. Os dados foram obtidos entre maio e agosto de 2010, utilizando a entrevista semiestruturada, são analisados através da técnica de Análise Temática de Conteúdo. Constatou-se que o sofrimento psíquico advindo da vivência do processo de morte/morrer dos pacientes, do estigma da doença, da discriminação aos pacientes e aos profissionais e do medo que os profissionais têm da contaminação ocupacional. O prazer estava atrelado ao sentimento de utilidade e ao reconhecimento dos pacientes acerca da qualidade do cuidado. A vivência do sofrimento apareceu de forma mais contundente que o sentimento de prazer. Recomendam-se, entre outras, as seguintes estratégias para minimizar o sofrimento psíquico deste coletivo profissional: grupos de reflexão, ginástica laboral, terapias alternativas, ambiente laboral mais humanizado e capacitação permanente dos profissionais.

Palavras-chave: Saúde do trabalhador. Enfermagem do trabalho. Cuidados de Enfermagem; HIV. Síndrome da Imunodeficiência Adquirida (AIDS).

EL DOLOR Y EL PLACER DEL PERSONAL DE ENFERMERÍA EN LA ATENCIÓN AL PACIENTE CON EL VIH/SIDA

RESUMEN

El objeto de este artículo fue el sufrimiento y el placer de los trabajadores de enfermería decurrentes de la atención a pacientes con VIH/SIDA en la Unidad de Enfermedad Infecto-contagiosa. Tuvo como objetivo describir y analizar los sentimientos de los trabajadores de enfermería decurrentes de la atención a pacientes con VIH/SIDA. La metodología empleada fue el abordaje cualitativo, de carácter descriptivo y exploratorio. Los datos fueron obtenidos entre mayo y agosto de 2010 utilizando la entrevista semiestructurada y fueron analizados por medio de la técnica de Análisis Temático de Contenido. Se constató que el sufrimiento psíquico advino de la experiencia del proceso de muerte/morir de los pacientes, del estigma de la enfermedad, de la discriminación a los pacientes y a los profesionales y del miedo que los profesionales tienen de la contaminación ocupacional. El placer estaba relacionado al sentimiento de utilidad y al reconocimiento de los pacientes acerca de la calidad del cuidado. La experiencia del sufrimiento surgió de forma más contundente que el sentimiento de placer. Se recomiendan, entre otras, las siguientes estrategias para minimizar el sufrimiento psíquico de este colectivo profesional: grupos de reflexión, gimnasia laboral, terapias alternativas, ambiente laboral más humanizado y capacitación permanente de los profesionales.

Palabras clave: Salud del trabajador. Enfermería del trabajo. Cuidados de enfermería. VIH. Síndrome de la Inmunodeficiencia Adquirida (SIDA).

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