Finalidades dos cuidados paliativos voltados para o paciente com hiv/aids: estudo com enfermeiros

Purposes of palliative care for the patient with hiv/aids: A study with nurses

Finalidad del tratamiento paliativo para el paciente con vih/sida: estudio con enfermeras

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ABSTRACT

Objective: investigating the understanding of clinical nurses about the goals of palliative care directed to patients with HIV/AIDS. Method: an exploratory study with a qualitative approach. The sample consisted of thirteen nurses. It was used an instrument containing relevant issues to the purposed; and the data were analyzed by Content Analysis Technique. The study was approved by the Research Ethics Committee of the Federal University of Paraíba, under the n. 04171512.7.0000.5183. Results: there was developed the following category: "Ends of palliative care: relief of pain and suffering and improving the quality of life of the patients and their families." Conclusion: it is hoped that this study will contribute to support further researches on the theme. Moreover, it should be mentioned that the research has some limitations such as the small number of participants, which prevents the generalization of the results. Descriptors: nursing, care, palliative care.

Abstract


RESUMO

Objetivo: investigar el conocimiento de las enfermeras clínicas sobre los objetivos de los cuidados paliativos dirigidos a los pacientes con HIV/AIDS. Método: un estudio exploratorio con abordaje cualitativo. La muestra está formada por trece enfermeras. Se utilizó un instrumento que contiene temas pertinentes para la finalidad propuesta, y los datos fueron analizados por la Técnica de Análisis de Contenido. El estudio fue aprobado por el Comité de Ética en Investigación, de la Universidad Federal de Paraíba, en el n. 04171512.7.0000.5183. Resultados: se ha desarrollado la siguiente categoría: "Objetivos de los cuidados paliativos: el alivio del dolor y el sufrimiento y la mejora de la calidad de vida de los pacientes y sus familias." Conclusión: se espera que este estudio pueda contribuir a apoyar las nuevas investigaciones sobre el tema. Por otra parte, se debe mencionar que la investigación tiene algunas limitaciones tales como el pequeño número de participantes, lo que impide la generalización de los resultados. Descriptores: enfermería, cuidado, cuidados paliativos.

RESUMEN

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The scientific-technical progress has contributed to the recovery and healing of seriously ill individuals. Else part, is increasing the number of people with chronic and debilitating diseases for which there are no more therapeutic possibilities of cure, and throughout the course of the disease have very specific limitations and weaknesses of physical, psychological, social and spiritual nature, which expose the individual and family to a situation of intense pain and suffering, such as HIV/AIDS, for example. Thus, the process of living is greatly prolonged.

HIV/AIDS is a serious disease, progressive, incurable and potentially cause life-threatening, even in the era of highly active antiretroviral therapy (HAART). Furthermore, patients with HIV/AIDS may also have significant comorbidities, such as viral hepatitis, tuberculosis, syphilis, anemia, depression, hypertension, drug allergies, kidney diseases, diabetes, among other. Therefore, it is essential to provide good quality life to the patient without therapeutic possibility of cure with palliative care, emphasizing an approach that fully meets their needs.

Palliative care is recommended because it contributes to the control of the physical, emotional, spiritual and social suffering of the patient and his family. Furthermore, it promotes the relief of pain and symptoms associated with the disease, since the beginning of its therapeutic. From this perspective; it aims to meet to the human understanding him as a holistic being, covering it in his biopsychosocial and spiritual dimensions.

In this light, this type of care emphasizes the importance of multidisciplinary and interdisciplinary approach to patient treatment outside the therapeutic healing resources, providing him a harmonious and convergent him and his family tour. The minimum palliative care team should be composed of physician, nurse, psychologist and social worker, plus the assistance of other professionals such as a physiotherapist, occupational therapist, pharmacist, dietitian, chaplain, dentist, audiologist, among others, which should be properly trained on the philosophy and practice of palliative care.

Nursing, as an integral part of palliative multidisciplinary team is essential for palliative care patients and their families, because the essence of their practice is the care, since it combines art and science to a care providing protection, comfort and support, the assumptions nursing and palliative. A study on knowledge and practice of palliative care, particularly in the area of nursing certifies that there are few researches on the subject. This fact points out the importance of further studies that may contribute to socialization of knowledge about the importance of the subject.

Taking into account the importance of professional nursing practice in palliative care and incipient quantitative studies of the national literature, this study intends to expand and disseminate knowledge about this issue directed to the patient with HIV/AIDS.
Through this perspective, the study was threading the following research question: What are the goals of palliative care targeted to patients with HIV/AIDS in view of clinical nurses? Thus, this study has the objective to investigate the understanding of clinical nurses about the goals of palliative care targeted to patients with HIV/AIDS.

**METHOD**

The proposed study is in an exploratory study with a qualitative approach, performed in a Clinical Infectious Diseases of a public hospital in the city of João Pessoa/Paraíba. The sample consisted of thirteen clinical nurses who were active in selected for the research and who agreed to participate in clinical research. The sample was obtained by accessibility. The inclusion criteria for the selection of the participants were the following: that the nurses acted on the unit selected for the study, which were active during the period of data collection, they were acting in assisting the patient with HIV/AIDS for over a year and had availability and interest in participating in the research.

To facilitate data collection, a questionnaire containing questions relating to the purpose of the study was used. Data were collected after all participants signed a consent form, preceded by an explanation of the purpose of the research and the procedure for data collection. The instrument was delivered respecting the workload of each nurse. For that, previously scheduled place, the day and time that were convenient to them and gathering.

It should be noted that to ensure the anonymity of study participants, they were identified by the letter E, followed by numbers from one to twelve. Accordingly, the nurse who responded to the first form has been encoded as E1, the second and E2, and so on.

The data collection was conducted during the month of June 2013; the empirical material was analyzed qualitatively using the Technique of Content Analysis proposed by Bardin. To operationalize this technique, we followed the recommended steps: Pre-analysis, in which documents are selected, and formulate hypotheses and research objectives; material exploration, when specific techniques are applied according to the objectives; treatment of results and interpretations.

The present study was examined and approved by the Ethics Research Committee of the Lauro Wanderley University Hospital, Federal University of Paraíba, with the number of CAAE 04171512.7.0000.5183. It is noteworthy, too, that the ethical aspects were considered in research involving humans, according to Resolution 466/2012 of the National Health Council, in force in the country in the period of the study, especially with regard to ethics, privacy and anonymity of the participants.
RESULTS AND DISCUSSION

Characterization of the participants

The study included thirteen clinical nurses, eleven of whom are female, and two males. This higher number of professional nursing females, according to the COFEN\(^1\), is justified by the fact that this population corresponds to 87.24% of nursing professionals in Brazil, while the male corresponds to only 12.76% of total of such professionals. It is noteworthy also that the Northeast is a macro-region that has the highest proportion of professional nursing females (90.08%), more specifically, Paraíba, with 91% of female sex workers, and 9% represented by men.

As regards the time of work in the institution, it was found that the majority provides service for over ten years, while carrying on their activities in selected for the study unit, assisting the patient with HIV/AIDS.

The analysis of empirical data obtained from the instrument proposed for the study, the category emerged as follows:

**Category - Ends of palliative care: alleviating pain and suffering and improve the quality of life of patients and their families**

The main goal of palliative care is to ensure a quality of life (QOL) improved the patient and his family, by means of essential components such as the relief of the signs and symptoms and the psychological, spiritual, emotional and social support throughout the course of disease, and death, extending the grieving stage. It should be emphasized that the search for good quality of life has been one of the cornerstones of palliative care, which lead to a significant and growing number of studies that address what would be quality of life in care at end of life.\(^{11\text{-}12}\)

From this perspective, nurses enrolled in the study express their understanding of the purpose of the practice of palliative care. Some emphasize that that type of care aims to improve the quality of life of patients without therapeutic possibilities of healing and terminally ill and their families, as illustrated by the following reports:

- \(\ldots\) Is an approach that seeks to improve the quality of life of patients \(\ldots\) for diseases that threaten life, relieving pain, suffering, \(\ldots\) (E1).
- Supportive care targeted to patients without healing tips with the intention of providing relief from suffering \(\ldots\) (E2).
- Palliative care are actions, procedures aimed at improving the quality of life of patients and their families \(\ldots\), provide relief from both physical and spiritual suffering. (E3)
- Care is relieving the suffering of the patient \(\ldots\) and improving the quality of life and even their families. (E5)
- Care provided to patients \(\ldots\), to improve the quality of life, \(\ldots\), even in a terminal. (E10)
- Constitutes assistance \(\ldots\) aiming to improve the quality of life of patients facing a life threatening illness (E12).
Every assistance [...] to treat, prevent or diminish physical pain, [...] care to benefit the patient and family, before an incurable disease [...] in order to improve the quality of life. (E13)

These excerpts are evidence that the respondents consider that the quality of life is essential for the promotion of palliative care focused on the patient and their family. Its goal is to improve the quality of life of patients without therapeutic possibilities of healing and terminal phase and their families, through humanization and applying ethical, epidemiological, and scientific and management principles in the treatment of information, education health care and administration.13

According to the World Health Organization, palliative care are presented as an approach that improves the quality of life of patients and families facing life-threatening diseases through early identification, assessment and treatment of pain and other problems, be they physical, psychological, social or spiritual order, especially when the disease is in an advanced stage and there is little likelihood of cure or even when facing end-stage disease, constituting a support system for the patient and family.14-15

Based on this understanding, it is undeniable the importance of quality of life as the central focus of the practice of palliative care. This shows that nurses’ understanding of the study of the purpose of palliative care is guided on which the WHO recommends. It is noteworthy that the concept of quality of life, in general, is taken as synonymous with health, life satisfaction, good living conditions, lifestyle, among others16. In this sense, it is the individual’s perception of their position in the cultural context and value system in which it is inserted.13

Study shows that quality of life is associated with a broad set of factors that include culture, education, transport, the environment, clothing, housing, beliefs, myths, values and health and not just limited the economic and political aspects, encompasses physical, psychological, social and spiritual aspects and provides the individual, in the last years of his life, a tendency to its overall assessment, in particular in the field of Health.17

In the context of palliative care, the human being is valued in its entirety, that is, a holistic view. So reach effectively, its fundamental purpose, which is to promote a better quality of life for the patient without therapeutic possibilities of healing and being terminally ill and their families.

The term holistic considers not only the physical, but also psychological, social and spiritual concerns of human existence.18 This view is highlighted by some professional participants of the research regarding the practice of palliative care, indicate the lines of some nurses enrolled in the study:

[...] Care are seeking to improve the quality of life of patients and their families [...] aimed at physical, social and spiritual well-being of these (E4)

[...] This type of care includes the patient [...] as a whole, for a better quality of life. (E6)

Care to improve the quality of life, [...] alleviate suffering, gives physical support, psycho social bio in its entirety interacting holistically [...] (E7)
Care is offered covering several areas, not only physical, but mental/emotional, social, spiritual, [...] across the stage the patient is. (E8)

The highlighted lines reflect that professionals understand that the practice of palliative care is guided by the holistic view of the human being, with the aim of promoting a better quality of life for patients and their families.

The concept of quality of life is extremely important for the patient and his family in the practice of palliative care, since this type of care seeking behaviors and measures that respect and understand the individual as a social being, the bearer of values, beliefs and individual needs.¹⁹

The patient and family need to be assisted in a holistic perspective, since the family is also considered a unit of care in the context of palliative care.²⁰ Therefore, the families also deserve comprehensive care, as often exceed their psychological needs the patient, mainly to the detriment of the diagnosis of incurable disease, as well as the impending death of their loved one.²¹ the family should be supported, especially when death becomes something concrete in the family by health professionals because people feel disoriented and surrounded by feelings of anguish and pain, facing the possibility of the absence of the loved one in the home.²¹ From this perspective, research claim that professionals working in palliative care should review their way of facing death, because this practice requires a new way of caring for the terminally ill human being as well as in promoting assistance to his family.²⁰,²²

Another aspect worthy of highlight concerns the recognition of nurses involved in the study about the importance of the multidisciplinary team and multidisciplinary care for the practice of palliative care for patients and their families, with the aim of improving their quality of life. The following reports confirm this assertion:

[...] The care is provided by a multidisciplinary team, aiming to a better quality of life of patients [...] as well as of their families. (E9)

[...] Are multidisciplinary therapeutic approach in order [...] to improve the quality of life of the patient and family. (E11)
Assistance constitutes promoted a multidisciplinary team aiming to improve the quality of life of patients facing a life threatening illness. (E12)
Every multidisciplinary care, [...] aiming to improve the quality of life; treating, preventing or decreasing: physical, spiritual, psychology, etc. pain; evaluating and defining care benefiting patients and families facing the pathology. (E13)

The stories of these nurses betray how the involvement of the multidisciplinary team and multidisciplinary care as guiding principles in the practice of palliative care. Palliative care is practiced, according to his philosophy, by a multidisciplinary team, and the humanized care for patients and their families.²³ To form said staff should consider the needs of the patient in need of such assistance.²⁴
The palliative care team consists of physicians, nurses, pharmacists, physiotherapists, nutritionists, psychologists, social workers, art therapists, therapists breathing, holistic therapists, occupational therapists, recreationists therapists, music therapists and pastoral and spiritual caregivers (chaplaincy), educator, philosopher and specialist in Thanatology.25-26

The value of the multidisciplinary effort has as its fundamental principle the understanding that the patient has fully.27 Therefore; each team member should assist the patient according to their area of expertise. Moreover, the common goal is to ensure that different needs of the patient, family and staff can be recognized and met by joint actions of different natures.

As for multidisciplinary approach is greatly relevant to refer the patient and his family to the practice of palliative care, since professionals have specific skills, but attuned to each other.28 In practice of palliative care is essential to provide a multidisciplinary approach focused assistance to the quality of life of patients and their families in coping with diseases that endanger life.29

Another key aspect to be registered is related to interdisciplinary team working in palliative care. The interdisciplinarity appears as a reciprocal relationship between the different techniques of various interventions and professional interaction of this knowledge that, through direct and consensually written verbal communication, exposes their actions and promotes mutual cooperation.30 This provides a comprehensive and participatory assistance when it will take care of patients and their families with a view to complementarity of their actions.

In this exchange of knowledge, the inclusion of the results of various specialties is established, and this allows each professional to develop quality care for palliative care.31 The promotion of palliative care, both in hospitals and in residential, requires priority, interdisciplinary work, that stands for complementation of knowledge, sharing of responsibilities, tasks and care and denial of simple overlap between the areas involved. Furthermore, the perception of the multiple needs of the individual in palliative care and make sure that only one area do not provide the answers needed to grow and consolidate undeniable search for work effectively in an interdisciplinary team.32

In this approach, the practice of palliative care should be interdisciplinary. And for those actions are effective, interdisciplinarity should be articulated among practitioners, patients and their family; with common goals.33 Thus it is clear that the performance and integration of the interdisciplinary team are essential to devote such care to the patient and his family, with the aim of improving the quality of life for both.

**CONCLUSION**

The present study highlights that clinical nurses involved in research to understand the aims of palliative care for patients with HIV/AIDS seek to relieve pain and suffering and
improve the quality of life of patients and their families, with emphasis on the role of team multidisciplinary and interdisciplinary care. In the field of such assistance, the nurse plays a key role when interacting holistically to develop their practice guided by the completeness of actions that help the patient to understand the current situation in which it lies.

Research also indicates, through the accounts of participants in the study nurses, the importance of multidisciplinary and interdisciplinary team care within palliative care, since this is essential in the practice of care to improve the quality of life of patients with HIV/AIDS and their families.

Based on the foregoing, it is expected that this study will contribute to understanding the goals of palliative care targeted to patients with HIV/AIDS from the perspective of clinical nurses and subsidize further research on the theme. On the other hand, we should mention that the research presents a limitation of the small number of participants, which prevents generalization of results.

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