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RESEARCH

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## Cuidados paliativos e bioética: estudo com enfermeiros assistenciais

Palliative care and bioethics: study with assistance nurses

Cuidados paliativos y bioética: estudio con enfermeros asistenciales

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### ABSTRACT

**Objective:** The objective was to investigate the ethical observances used by nurses assisting the patient without possibilities of cure. **Methods:** Exploratory research, qualitative in nature, performed with 28 nurses of a public hospital, located in the city of João Pessoa/PB. The data were collected through a questionnaire, from August to October 2012 and subjected to content analysis technique. **Results:** The categories identified were: Palliative Care: principles of Bioethics to the patient without possibilities of cure and privacy and professional secrecy under the palliative care. Such categories indicated that the professionals are valuing the principles of Bioethics, as well as the privacy and the professional secrecy, using them as a strategy to assist the care to the patient without possibilities of cure. **Conclusion:** This study is expected to subsidize new investigations, because they are still incipient the research addressing bioethics in patient assistance in palliative care.

**Descriptors:** Bioethics, Palliative Care, Nursing.

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## RESUMO

**Objetivo:** Objetivou-se investigar as observâncias éticas utilizadas pelos enfermeiros ao assistirem o paciente sem possibilidades de cura.

**Métodos:** Pesquisa exploratória, de natureza qualitativa, realizada com 28 enfermeiros de um hospital público, localizado na cidade de João Pessoa/PB. Os dados foram coletados por meio de questionário, de agosto a outubro de 2012 e submetidos à técnica de análise de conteúdo. **Resultados:** As categorias identificadas foram: Cuidados Paliativos: princípios da Bioética ao paciente sem possibilidades de cura e privacidade e sigilo profissional no âmbito dos Cuidados Paliativos. Tais categorias indicaram que os profissionais passam a valorizar os princípios da Bioética, assim como a privacidade e o sigilo profissional, utilizando-os como estratégia para auxiliar o cuidar ao paciente sem possibilidades de cura. **Conclusão:** Espera-se que este estudo subsidie novas investigações, pois ainda são incipientes as pesquisas que abordam a Bioética na assistência ao paciente sob Cuidados Paliativos.

**Descritores:** Bioética, Cuidados Paliativos, Enfermagem.

## RESUMEN

**Objetivo:** Este estudio tuvo como objetivo investigar las observancias éticas utilizadas por los enfermeros para ayudar al paciente sin posibilidad de cura. **Métodos:** Encuesta exploratoria, de naturaleza cualitativa, realizada con 28 enfermeros de un hospital público en la ciudad de João Pessoa/PB. Los datos fueron recolectados a través de un cuestionario, de agosto a octubre de 2012 y sometidos a la técnica de análisis de contenido.

**Resultados:** Las categorías identificadas fueron: Cuidados Paliativos: principios de Bioética al paciente sin posibilidad de cura y privacidad y secreto profesional en el ámbito de los Cuidados Paliativos. Estas categorías indican que los profesionales pasan a valorar los principios de la Bioética, así como la privacidad y el secreto profesional, usándolos como una estrategia para auxiliar a la atención de los pacientes sin posibilidad de cura. **Conclusión:** Se espera que este estudio pueda subsidiar nuevas investigaciones, pues aún son incipientes las encuestas que abordan la Bioética en la asistencia al paciente bajo Cuidados Paliativos.

**Descriptorios:** Bioética, Cuidados Paliativos, Enfermería.

## INTRODUCTION

Technological advances associated with medicine, with new equipment and techniques have enabled early diagnosis and treatment of numerous diseases and added the survival of patients with incurable diseases. If on the one hand, these advances have provided an improved quality of life, on the other, that longer survival results from unnecessary prolongation and unjustifiable treatment with the therapeutic obstinacy at any cost.<sup>1-2</sup> This exaggerated extension in lifespan has led to ethical discussions and the need for a new modality of care, the reason why Palliative Care emerged.

Palliative Care emerged as a philosophy of care, whose measures provide improved quality of life for patients and their families in coping process at the end of life, through early identification, prevention and suffering relief, evaluation and treatment of physical, psychosocial and spiritual problems.<sup>3</sup>

The philosophy of Palliative Care began in England in 1967, with the initiative of *Cicely Mary Stode Saunders* (social worker, nurse, and medical assistance) that spread this new way of caring for patients who experienced terminal illness and close to death. Such care aims to understand all the patient's needs (within the possible limits), considering the patient as a whole being.<sup>4</sup>

It is emphasized that the palliative word comes from the Latin *pallium*, meaning mantle. Such nomenclature denotes the fundamental idea of this philosophy: to protect, support, cover, shelter when the cure for a disease is no longer possible. Moreover, in Latin, *pallium* are garments worn by the Pope. Therefore, there is a strong connection of this historical term with the sacred and spirituality.<sup>5-6</sup>

Thus, Palliative Care make up an interdisciplinary field of total care, active and integral designed to improve the quality of life of the patient without possibility of cure and their families, through proper evaluation and adequate treatment for pain relief and the symptoms of the advanced stage of a disease, and provide psychosocial and spiritual support in all stages, from the diagnosis of an incurable disease to the family mourning period.<sup>7</sup>

In this sense, the nurse as a member of the interdisciplinary Palliative Care team plays a fundamental role in promoting care for the patient without the possibility of cure and should be supported by ethical principles. These principles underlie the practice of Palliative Care and value the autonomy of the patient as one of the basic points to the pursuit of excellence of care provided by Nursing.<sup>8</sup>

Thus, there is Bioethics, which denotes the ethics of life. The bios Greek root word means the development observed in the life sciences, such as ecology, biology, medicine, among others. Ethos seeks to bring to consider those involved in conflicts of life values.<sup>9</sup> Therefore, the definition of Bioethics embraces this process of confrontation between the biological facts and human values in making decisions involving the practical problems in different areas of life.

Therefore, it is observed that Bioethics is involved with the birth, living and dying, being essential to the practice of health professionals and is marked with four basic principles: beneficence, autonomy, justice and non-maleficence giving reasons to deal with new discoveries and their applications.<sup>10</sup> Thus, it is of fundamental importance that the nursing professional uses his knowledge of Bioethics to guide their professional practice.

Given the above, considering the relevance of the theme in the area and the smallest quantitative studies on Palliative Care in national literature, the interest in developing this study emerged, with the following question: what are the ethical observances adopted to promote Palliative Care directed to the patient without possibilities of cure? Thus, the study had as objective: to investigate the ethical observances used by nurses to assist the patient without the possibility of a cure.

## METHODS

This is an exploratory research, with a qualitative in nature. The research scenario consisted of inpatient units of a public hospital in the city of João Pessoa/PB, considered reference in this state. It is important to mention that this hospital is in the implementation phase of a Palliative Care unit, but the professionals have not received training on this practice.

The participants were 28 nursing assistants of the selected institution for the study, providing care directed to the patient without possibility of cure, selected by the following criteria: the professional acted for at least one year in that unit, were in professional activity during the data collection period and had availability and interest to participate in the survey, confirming their agreement with the signing of the consent term. Data collection took place during the period from August to October 2012.

To obtain the empirical material, a form of a pertinent question to the proposed objectives for the research was used: 1) What are the ethical observances you adopt to promote Palliative Care targeted to the patient without the possibility of cure? The nurses were contacted at the hospital and completed the forms on their premises, in place and time appropriate for professionals.

It should be noted that to maintain the anonymity of nurses enrolled in the study, the statements from the interviews were identified by the letter "E" followed by numbers from one to twenty-eight. For example, the first nurse interviewed was coded as follows: "E1"; the second professional, "E2" and so on.

The data obtained through the instruments proposed were qualitatively systematized by the content analysis proposed by Bardin<sup>11</sup>, defined as a set of communications analysis techniques to obtain, through systematic procedures and description of the objectives of message content, indicators that allow the inference knowledge relating to the conditions of production/reception of these messages.

In this study, this technique was carried out through the following steps: pre-analysis, which was to organize the data collected through the forms; material exploration, identifying the relevant points of each question with their respective converging points according to their common focus to then group them into categories and treat the results, when the inferences and interpretations were addressed.

It is noteworthy that the data collection procedure was initiated only after approval of the research project by the Research Ethics Committee, as CAAE 02685412.2.0000.5183. Thus, the study was conducted considering the 466/12<sup>12</sup> Resolution of the National Health Council, especially concerning standards and regulatory guidelines for research with human beings.

The data were grouped into two categories: Palliative Care: Principles of Bioethics to the patient without the possibility of cure; Privacy and professional secrecy in the practice of Palliative Care to the patient without the possibility of a cure.

## RESULTS AND DISCUSSION

### Presentation of survey participants

The study sample consisted of 28 clinical nurses - Twenty-four females and four males. In nursing, the gender is evident, especially for its historical trajectory of being an eminently female profession. Although already noticed a movement about the insertion of man in the profession, the socio-demographic data of this survey also reveals the predominance of women in care practices<sup>13</sup>.

According to the Federal Council of Nursing<sup>14</sup> in Brazil, most nursing professionals - 87.24% - are women. Male correspond to 12.76%, which is why the survey sample, is predominantly female. The Northeast is the macro-region with the highest proportion of female nursing professionals, with 90.08%. In Paraíba, 91% are female, only 9% are represented by men.

As to age, it was found that five nurses have between 20 and 29 years old; 16 were from 30 to 39 years old; six between 40 and 49 years old; and one was more than 60 years old. It should be noted that the sum of the corresponding age groups of 20-29 and 30-39 years old had 21 subjects of the total sample. The results presented to confirm the COFEN<sup>14</sup> report data, in which the professional categories of nurse and nursing technician have the highest concentration of professionals in the age group of 26-35 years old.

Participants report having finished academic training between 1979 and 2010. It is noteworthy that the highest prevalence of educational institution was the Federal University of Paraíba (UFPB). As the titration, it was found that most of this study are inserted expert professionals (26), and two have graduated. It is important to note that four specialist nurses have postgraduate studies at Master's level. Most surveyed nurses stated perform their professional activities in Nursing in public health. The training ranged between two and 33 years and the time that exercises activity in the profession institution ranged between two and 31 years.

### Presentation of the empirical material of the study

The answers obtained from the proposed question allowed the construction of two categories presented below.

#### Category I – Palliative Care: Principles of Bioethics to the patient without possibility of cure

The principles of Bioethics are intrinsically linked to the practice of Palliative Care since this philosophy aims to rescue the ethical and human values, a scenario where the individual patient autonomy stands out as one of the core values within the practice. Thus, the nurse professional who spends more time with the patient should take the facilitator position promoting the patient's quality of life without

therapeutic possibilities based on the principles of Bioethics: the principle of autonomy, beneficence, of non-maleficence and justice.

Concerning the autonomy of the patient, they refer to the freedom of the individual, their domain, reflected in the ability of reason to check their interests to instances of human nature. Therefore, respect for autonomy implies that everyone has the right to dispose of their life in the way that best suits and may choose for their well-being and comfort in exhausting their forces at the time that their very existence becomes subjectively inadmissible.<sup>16</sup>

Based on this premise, it was observed that the professionals interviewed identified the principle of autonomy as a fundamental aspect of the practice of Palliative Care, as evidenced by the following reports:

*"It is very important to respect the wishes of the patient, their autonomy, trying to identify what the patient wants with the treatment, with that action that we execute [...]" (E2)*

*"I always respect the will of the patient and family; also avoid unnecessary care and respect the sleep schedule." (E4)*

*"[...] I always promote the patient's wishes, trying my best to prevent his suffering, respecting his will and thus providing dignity to him." (E5)*

*"I preserve his integrity [...] I try to meet the patient without discrimination of any kind, respect his autonomy within his context and so I provide dignity to him. [...]" (E13)*

*"I always promote nursing care by the will of the patient, family/companion who is present at the time." (E19)*

*"[...] I respect for patient autonomy and thus sought to restore his dignity." (E20)*

The exposed testimonies demonstrate that the enhancement of autonomy to provide dignified care to patients without therapeutic possibilities is valued. Thus, it was found that nurses consider the principle of autonomy as a fundamental instrument in the context of Palliative Care.

Research points out that human dignity is the true pillar through which emanate from the principles, especially autonomy, and that should be present, unequivocally, in all decisions and interventions.<sup>16</sup>

Authors support the above assertion mentioning that the Palliative Care is vulnerable. However, often conscious and oriented, giving him the right to make decisions related to his treatment and make sure he respects the principle of autonomy.<sup>17</sup>

Therefore, it is important to emphasize that nursing professionals should evaluate with him, the benefits and risks

of treatment and seek to promote the good for them, facts that constitute the principle of beneficence, as evidenced in the statements, as follows:

*"[...] I do good to him. I talk, and I try to know how is the treatment, so I work based on ethics." (E3)*

*"[...] I preserve his integrity, doing well for him during my care [...] within the context in which he is, promoting good in the care, always evaluating the risks and benefits of treatment." (E27)*

*"[...] Trying to do good is always very important, as it increases the bond with the patient and so I improve my assistance, promoting humanized care [...]" (E15)*

*"[...] I always try to do good to the patient, talk to him and try to know his troubles. Doing good is essential." (E16)*

It is evident from the above excerpts the concern of the interviewed nurses valuing the principle of beneficence with the patient under Palliative Care, thereby strengthening the link between professional and patient guided in a humanized and holistic care.

The principle of beneficence is based on the precept to do good and avoid bad things, maximizing the benefits and minimizing potential risks. It concerns the moral obligation to act on behalf of others, to make or promote the good, to prevent and eliminate bad things or harm requiring that important and legitimate interests of individual.<sup>18</sup>

Thus, this principle enables the nursing staff to maximize the benefits to the patient by promoting care in a holistic way that meets their physical, psychosocial and spiritual needs and seeks to minimize the damage resulting from the assistance to their health, especially in for technical procedures involving the care process. Thus, it becomes apparent that beneficence is the guiding principle of health care, and that goes beyond the technical care practice.<sup>19</sup>

In this sense, the bioethical principle of beneficence is not limited only to the technical aspects of the care process, but the appreciation of the human and ethical relationship between the health professional and the patient, considering him a being who feels, thinks, suffers and need to maintain a closer relationship with the professional.<sup>20</sup> Moreover, it is necessary to assess the risks of each clinical decision in the team with the patient and their families and provide them with the principle of non-maleficence. This principle was also highlighted by some nurses in the study, as shown by these reports:

*"I always try to challenge the team actions that do not lead to any benefit [...]" (E28)*

*“The quality of life of the patient without the possibility of cure should be the priority, but without compromising his classic treatment or interfere with it, always give priority to improving the quality of life.” (E6)*

*“Try not to bring any harm to the patient is very important for the assistance.” (E14)*

The fragments of the speeches of the nurses mentioned show that professionals also avoid causing possible damage to the patient's health in the context of Palliative Care, emphasizing the principle of non-maleficence.

The principle of non-maleficence is to prevent damage, and even if an act does not benefit, may be ethically positive since it does not cause harm.<sup>18</sup> A study of nurses who provide Palliative Care to patients with HIV/AIDS showed that such professionals value the principle of non-maleficence, to avoid misdeeds and provide humanized care, meeting the needs of patients, depriving for their protection during their hospitalization.<sup>19</sup>

Therefore, the professional must try and prevent the foreseeable damage. Therefore, it is not enough that he has good intentions, it is necessary to avoid any situation that denotes risks and determines whether the mode of action is not harming the patient without the possibility of cure or, in some way, there are risks. Thus, non-maleficence assures that they are alleviated or avoided harm to patients. To meet this principle, not just the health professional has good intentions not to harm the patient. It is necessary that in their care practice they seek to avoid predictable damage.<sup>18</sup>

Therefore, it is up to the multi-professional team, especially the nurse, because he is the professional who lives daily with the patient, reducing potential damage and maximize the benefits, also ensuring the resources available and ensuring a dignified care – the principle of justice.

Regarding the principle of justice, some nurses highlighted in their statements to the importance for the promotion of a fair and equitable assistance without discrimination of any kind, as the following reports:

*“[...] To try to give some dignity to the patient [...] with fair treatment to the individual, without discrimination.” (E24)*

*“Do not discriminate against the patient at any time, always seek to provide an equal service.” (E3)*

*“[...] It is very important for us nurses, strive for ensuring the rights of patients who have no more healing chance and thus providing a more dignified care.” (E12)*

In these reports, it is observed that the listed participants noted that the practice of Palliative Care should also be guided by the principle of justice.

The principle of justice concerns the fair distribution of social benefits. It is noteworthy that the nurse establishes equity as a fundamental condition, which can be ratified as an ethical obligation to treat each according to what is morally right and proper.<sup>21</sup>

It should be noted that distributive justice should be in health care in general with the promotion of fair distribution of resources in society for those who need them, with the aim of safeguarding the fair distribution of resources and care through the impartiality and access to adequate and decent medical services.<sup>22</sup>

Given the above, it is observed that health professionals, especially nursing, using the principles of Bioethics as a care strategy, may assist the patient in coping with their disease process. Thus, it is evident that all the principles of Bioethics are of paramount importance to guide the practice of Palliative Care, as highlighted in the reports of the nurses of the proposed research.

## **Category II - Privacy and professional secrecy in the context of Palliative Care**

In health, the obligations of an ethical nature are intrinsically embedded in the daily lives of the professionals that comprise it. In this sense, ethics is embraced as a philosophical discipline that studies the moral systems created by men to understand well why the rules and its prohibitions, and explain its implications.<sup>23</sup>

On privacy and professional secrecy, it is worth noting that such aspects are inherent in the ethical principles, which raises a confidentiality setting. In this context, it is common and necessary for patients and their families to express personal information during treatment. Thus, all these data are part of the professional secrecy, as well as those acquired by other professionals, exams and physical and electronic records.<sup>24</sup>

Based on such understanding, it was observed that some of the interviewed nurses recognize the importance of privacy and professional secrecy in patient care without curing possibilities, as shown by these reports:

*“I never talk about the patient to other people of my living; I always keep confidentiality.” (E1)*

*“I seek to preserve patient information at the hospital.” (E18)*

*“[...] I keep secrecy about information and reserving it and ensuring the privacy during the performance of nursing care.” (E21)*

*“During my assistance, I preserve patient privacy and maintain the confidentiality of the information I know about him. [...] they are essential for the humanization of care.” (E17)*

*"I preserve patient information while maintaining his privacy and confidentiality." (E22)*

The parts of the testimonies show that study participants understand and value for nursing care, ethical aspects concerning the guarantee of privacy and confidentiality for the assistance.

The patient's privacy is a legal, ethical obligation to be respected in oral or written communications, not just in interactions held between the patient and the nursing staff, but with other workers who participate in the care, as well as their families. It is a professional duty of the nursing team to defend the patients at all times during care, ensuring their privacy, confidentiality and guard their autonomy, as predicted by the Code of Ethics of Nursing Professionals and the Charter of User Rights the Unified Health System.<sup>25-6</sup>

Thus, it is evident that the professional secrecy and the privacy of duty are very important in the behavior of nursing professionals, especially in caring for the patient without the possibility of cure.<sup>27</sup> Research<sup>28</sup> points out that the subjects have the natural potential of self-preservation and protection. In this conception, respect the other transcends the physical body care. Similarly, it involves the understanding of the individual in his multiple dimensions, which involves sensitivity, values, beliefs, relationships with God and the environment. Thus, acting properly in the protection of privacy and without therapeutic possibilities patients' rights constitutes into a virtue that can be achieved by acting guided by ethical principles.

Another study ensures that the knowledge and information about privacy and professional secrecy in nursing care of patients are important strategies for the humanization of health care services, explaining the importance as principles derived from autonomy, encompassing intimacy, private life and honor of the people, corroborating the testimony of the study participants.<sup>29</sup>

Given the above, it is evident understanding and appreciation of the professionals interviewed about privacy and professional secrecy in patient care without curing possibilities, being important issues to be discussed by nurses, especially in the management level of care and organization of the working processes of nursing teams.

## CONCLUSIONS

The study showed the participants nurses recognize the need to value the principles of Bioethics when assisting the patient in Palliative Care, and to preserve the privacy and professional secrecy for the assistance.

The category Palliative Care: principles of Bioethics to the patient without the possibility of cure revealed, from the reports, the use and recovery of Bioethics principles as a strategy in the care of terminally ill patients, showing that all

principles are of paramount importance to guide the practice of Palliative Care.

Regarding privacy category and professional secrecy in the context of Palliative Care, there was the appreciation of the participants interviewed about privacy and professional secrecy in the patient care in Palliative Care, revealing that these are important issues to be discussed in nursing.

Therefore, this research, little explored in Academy, raises new studies that will contribute to improving the quality of life of patients without therapeutic possibilities, by a practice based on ethical principles. It is worth noting that the study has some limitations, including the inability to generalize the results, because it is a qualitative research, with a reduced number of participants.

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