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## Cuidado paliativo ao cliente oncológico: percepções do acadêmico de enfermagem

Palliative care to cancer client: the nursing student's perception

Los cuidados paliativos al cliente oncológico: la percepción de los estudiantes de enfermería

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### ABSTRACT

**Objectives:** To identify the knowledge of nursing students in relation to palliative care and discuss the differential of this professional to the quality of care to the customer cancer at an advanced stage. **Method:** This is a descriptive study with qualitative approach. The study setting was a private university located in the city of Rio de Janeiro. The subjects were sixteen nursing students who were duly enrolled in the 9th and 10th periods, in the period of data collection. **Results:** Two emerged categories: Knowledge of academics about palliative care and the difficulties of dealing with death; and the Role of the Nurse in palliative care. **Conclusion:** We believe that good practice should be the result of dedication, the pursuit of scientific knowledge, and especially, the strengthening of the human being that exists in every professional. This feature is extremely important for the implementation of sentiment in care.

**Descriptors:** Palliative care, Medical oncology, Nursing care.

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## RESUMO

**Objetivos:** Identificar o saber dos acadêmicos de enfermagem com relação aos cuidados paliativos e discutir o diferencial deste profissional para a qualidade do cuidar ao cliente oncológico em estágio avançado. **Método:** Trata-se de um estudo descritivo com abordagem qualitativa. O cenário de estudo foi uma universidade privada localizada no Município do Rio de Janeiro. Os sujeitos foram dezesseis acadêmicos de Enfermagem, que estavam devidamente matriculados no 9º e 10º períodos, no período da coleta de dados. **Resultados:** Emergiram duas categorias: O conhecimento dos acadêmicos sobre o cuidado paliativo e a sua dificuldade em lidar com a morte; e o Papel do Enfermeiro no cuidado paliativo. **Conclusão:** Acreditamos que a boa prática deve ser resultado de muita dedicação, de busca por conhecimentos científicos, e principalmente, pelo fortalecimento do ser humano que existe em cada profissional. Essa característica é de extrema relevância para a aplicação do sentimento no cuidar.

**Descritores:** Cuidados paliativos, Oncologia, Cuidados de enfermagem.

## RESUMEN

**Objetivos:** Identificar el conocimiento de los estudiantes de enfermería en relación a los cuidados paliativos y discutir el diferencial de este profesional a la calidad de la atención al cliente cáncer en una etapa avanzada. **Método:** Se trata de un estudio descriptivo con enfoque cualitativo. El ámbito del estudio fue una universidad privada ubicada en la ciudad de Río de Janeiro. Los sujetos fueron dieciséis estudiantes de enfermería que fueron debidamente inscritos en los períodos 9 y 10, en el período de recopilación de datos. **Resultados:** Emergieron dos categorías: Conocimiento de académica sobre los cuidados paliativos y las dificultades de lidiar con la muerte; y el papel de la enfermera en los cuidados paliativos. **Conclusión:** Creemos que la buena práctica debe ser el resultado de la dedicación, la búsqueda del conocimiento científico, y sobre todo, el fortalecimiento del ser humano que existe en cada profesional. Esta característica es muy importante para la aplicación de los sentimientos en la atención.

**Descritores:** Cuidados paliativos, Oncología médica, Atención de enfermería.

## INTRODUCTION

The cancer in Brazil is currently the second cause of death per disease.<sup>1</sup> With the population aging this index may increase more and more,<sup>1</sup> because of it, it is necessary to think if the future nursing professionals are ready and capable of dealing with palliative care.

The term palliative care was defined in 1990 and updated in 2002 as the assistance provided by a multidisciplinary team, aiming the life quality of the patients and their familiars improvement, facing a disease that threats life through prevention and suffering relief, previous identification, perfect evaluation and treatment to pain and others physicals, socials, psychologicals and spirituals symptoms.<sup>2</sup>

Even being a multiprofessional assistance, the nursing team is the one that is involved in the daily care, facing complex and hard situations. In front of this situation, it is necessary a psychological evaluation and continued education, in order to turn the nursing even more capable of dealing with this client and the high and spread knowledge.

Currently, it is believed that there are about 40 palliative care units in Brazil distributed throughout the country, most acting only in outpatient clinics and home care.<sup>3</sup>

Brazil has advanced a lot in palliative care, however there are some gaps to be filled. Although there are some palliative care units, there are few compared to the need of the population.

In addition, there are few professionals working in this area as well, there are professionals struggling with palliative care, by having to deal with finitude.

The motivation of this study arose from the possibility of providing those in need of palliative care, a differentiated care through a team that has the right profile for this type of work.

In this context, this study can provide information about the knowledge of the nursing academic and palliative care, allowing the spread and sedimentation of these for future nursing professionals.

## OBJECTIVES

- To identify the knowledge of nursing students with respect to palliative care;
- To discuss the differential of this professional to the quality of care to oncological customer at an advanced stage.

## Theoretical framework

Terminality life is conceptualized when all curative therapeutic resources are depleted and when there is no longer time nor the opportunity to do something. The individual becomes unrecoverable and walks to death, without being able to reverse this walk.<sup>4</sup>

The phase of human terminal illness makes the process of caring more complex, as the patient needs to be taken care of comprehensively considering both the disease and the degenerative process of his own age. The care to the terminally ill patient needs to be offered holistically, that is, recognizing the individual who is terminally ill as a whole being in need of assistance in their biopsychosociospiritual ball.<sup>5</sup>

The nursing team plays a fundamental role in palliative care: it is the team that, because of their work, it's in direct and deep contact with the population, either at health centers, hospitals or in the community, taking the opportunity to educate and inform the population about the palliative care.<sup>6</sup>

The actions of the nurse, in caring for terminal patients, is not easy and not an isolated activity, there is a need to deeply know the patient, valuing their symptoms, personal characteristics, culture and family, with the need of a multi-work, it can be developed in hospitals, helping the quality of life.<sup>7</sup>

Nursing professionals cited difficulties in relation to the suffering of these patients and feelings expressed by them, as revolt prospect of death, sense of helplessness in the face of disease, numerous hospitalizations, as well as unfavorable conditions of nursing practice, such as lack of time to provide

a good service, lack of staff and organization at work, as well as the excess of activities.<sup>8</sup>

## Emergence of palliative care

The concept of palliative care originated in the hospice movement, originated by Cicely Saunders. It spread around the world a new philosophy about caring, two key elements that preached the control of pain and other symptoms resulting from treatments performed in the advanced stage of disease. Caution should cover the psychological dimensions, social and spiritual needs of patients and families.<sup>9</sup>

Cicely Saunders was able to understand the care of the problem that was offered in hospitals for terminal patients. Still today, families and patients listen to doctors and health professionals the phrase “there is nothing else to do,” she always refuted “there is still much to do.”<sup>10</sup>

Currently, England is the country with the highest coverage of palliative care in the world, and palliative medicine recognized as a medical specialty since 1987 in that country. Second, it is cited Spain.<sup>11</sup>

In the United States (US), the hospice movement began in 1974 and, from there, there are several palliative care teams in the sport on a larger scale home care. Initially, doctors were not involved in home care, due to category resistance and the fact that this type of assistance is not covered by health insurance.<sup>11</sup>

In the 90s, there was the development of palliative care program in various locations: South Africa, Australia, Asia, Japan, Taiwan, China and South Korea. In South America, Palliative Care emerged in the 80s in Buenos Aires and Bogota.<sup>11</sup>

In Brazil, isolated initiatives and discussions regarding palliative care are found since the 70's. However, it was in the 90s that began to appear the first organized services, even on an experimental basis.<sup>10</sup>

Palliative care were included in 2002 in the Unified Health System (UHS),<sup>12</sup> it is indicated implement multidisciplinary teams to care for patients in pain and in need of palliative care.

With the founding of the National Academy of Palliative Care (PCNA) in 2005, palliative care in Brazil gave a huge institutional jump. From the advancement of professional regulation of the Brazilian palliative, was established quality criteria for palliative care services, there was precise definitions on the subject and took the discussion to the Ministry of Health, the Federal Council of Medicine and Brazilian Medical Association.<sup>10</sup>

The Ministry of Health has formally consolidated palliative care in the country's health system through Ordinances: GM/MS n° 1319 of July 23, 2002, 19/GM of January 3, 2002, n° 874 of May 16, 2013, among others.

## Life quality

There are indications that the term first appeared in the medical literature in the 1930s, according to a survey of studies that were aimed at defining and that made reference to the evaluation of quality of life.<sup>13</sup>

The World Health Organization (WHO) defines quality of life as “the individual's perception of their position in life in the context of culture, value systems in which they live in relation to their goals, expectations, standards and concerns.”<sup>14</sup>

Brazil still needs to advance in specific measures to provide humane care for those who have no chance of healing through therapeutic intervention. According to 2010 study conducted by British consultancy Economist Intelligence Unit, with 40 countries on indicators of quality of life of patients who are about to die, Brazil is in 38th place, second only to India and Uganda. At the top of the ranking appears United Kingdom, followed by Australia.<sup>15</sup>

Palliative care is focused on the quality of life of the patient, always seeking the best for him to have a dignified and peaceful death without suffering. The nursing team plays an important role in the quality of life of these patients because we are the ones who are watching and looking after the patients 24 hours. The nurse must have technical and scientific knowledge to better care.

## METHODS

This is a descriptive study with qualitative approach. The study setting was a private university located in the city of Rio de Janeiro. The subjects were sixteen nursing students, of a total of 20, who were duly enrolled in the 9 and 10 periods, the period of data collection. Scholars who did not meet the inclusion criteria did not participate.

All ethical requirements proposed by Resolution no. 466/12 of the National Health Council were respected, was approved by the Research Ethics Committee of the University Veiga de Almeida, under n° 43266914.6.0000.5291. Data collection was carried out only after the issuance of this opinion and authorization of the institution. Participants signed a consent form clarified, protecting its autonomy and anonymity. The participants were identified by fictitious names.

The data collection period was from February to March 2015 and as data collection instrument was used semi-structured interview. The interviews were recorded and later transcribed. The data were subjected to content analysis<sup>16</sup> testimonies, followed by its systematization in themes and categories.

## RESULTS AND DISCUSSION

Sixteen undergraduate students of the nursing undergraduate course were interviewed, eight students from the ninth period and eight from the tenth period. All participants had developed a practical hospital activities or have had customer care small, medium, and high complexity. Data analysis led to the construction of two categories: Knowledge of academic about palliative care and their difficulty in dealing with death; and the role of nurses in palliative care.

### Knowledge of students on palliative care and the difficulties of dealing with death.

Death, decease, passing are synonyms used to refer to the irreversible process of cessation of biological activities necessary for characterization and lifetime maintenance on a system once classified as alive. After the death process, the system no longer lives; and is dead. The processes that follow to death (post-mortem) usually are the ones that lead to the breakdown of systems. Under specific environmental conditions, different processes may follow it, for example those leading to natural bodies mummification or fossilization.

According to the World Health Organization, palliative care is the comprehensive care offered to patients and families when facing a serious illness that threatens the continuity of life. The goal of palliative care is to provide effective treatment for the symptoms of discomfort that can accompany the patient, whether caused by disease or treatment. Unfortunately, in our culture, the term "palliative" brings an aspect of an inconsistent measure or worthless, making the acceptance of such care as essential in the life of a human suffering on an active and progressive disease that threatens the continuity of life. *Pallium* comes from Latin and means cloak blanket. Therefore, palliative care is the protection of care that improve the quality of life of patients, for caregivers to treat the suffering that illness can bring.

In the context of this research, we questioned the subjects about this theme through the following question: "How do you deal with death." From that question came the following statements:

*"I do not know because I never lived this situation."*  
(Carla)

*"[...] I do not know because I've never worked in the area, I believe that is part [...]"* (Thiago)

*"Currently still do not know, just living, but I believe that in time will be a common thing [...]"* (Enzo)

*"[...] I still have a vision of it, not experienced it yet, so I do not know how I would cope [...]"* (Michelle)

It can be noticed in the presented speeches that the academics, even at the end of the graduation course, are not prepared to deal with the death of a patient, even knowing that this will be part of their daily life, regardless of the sector that will work.

Nursing academics are not prepared to experience the death-dying process of their prospective clients because of the few opportunities to discuss such a subject at undergraduate level.<sup>17</sup>

If it is a question of death, it can be said that people die more in hospitals than at home, and no other health professional lives as close and often to death as the nurse, since he is the one who spends the most part of time with the hospitalized individual.<sup>18</sup>

Few academics who said they had experienced that moment of death, and even those who have reported having difficulties.

*"I've actually dealt, so it's something that ends up becoming commonplace, but it is not cool."* (Celia)

*"For me it's too bad, I still have difficulty dealing with death."* (Deborah)

This subject should be discussed and addressed during the academic period for future professional can be better prepared to deal with the process of death. Graduation gives more emphasis on nursing techniques and care for the physical body of the patient, leaving a gap with regard to psychological care that should be offered to patients and families. It is understood that to be a nurse taking care of terminal patients, as well as their families, is to experience daily such a challenge, to be present in the external subjective space and in the internal subjective space, that is, to be composed in the landscape of that patient and in the from your family.<sup>17</sup>

When asked about the knowledge of palliative care, the response was almost unanimous. They talked about comfort, quality of life and that palliative care is the care facing the terminally ill patient.

*"It is the care of terminally ill patients."* (Karla)

*"I know it is a method used to provide minimal comfort for the patient who is terminally ill..."* (Larissa)

*"Palliative care is when you give quality of life for the patient before death."* (Deborah)

*“For me, palliative care is to offer comfort to the terminally ill patient, to try as far as possible give a quality of life in the last moments to him...” (Talita)*

*“Palliative care it is to promote comfort to the patient when there is no chance of cure...” (Daniela)*

In the replies presented, we realized that academics, in general, know what palliative care is, but in none of the discourses the care of the family was considered.

When caring for a terminally ill patient, it is essential that nursing and all health staff assist the patient as a whole being, not forgetting those who are following the process of death. The psychological state of those around the patient reaches directly to him. In the process of the disease, family members play an important role, and their reactions contribute much to the proper reaction of the patient.<sup>19</sup> Therefore, caring for the family is fundamental. Palliative care consider the family a care unit that should also receive assistance throughout the follow-up of their patient and even after his death, the mourning period.<sup>3</sup>

Faced with this information, it is also necessary to discuss the profile of the nursing professional and his performance in the face of death situations. So we continue this discussion with the next category.

## **The role of nurses in palliative care**

Studies indicate that nursing professionals spend more time with patients at the end of life than any other health professional<sup>20</sup>. When asked about the role of the nurse, we realized that academics know the importance that have the face of this situation, even in the most succinct answers.

*“Comfort, make one pass the last few days in the best possible way, give affection, attention, try to perform some desire that this patient still has.” (Amanda)*

*“I believe that the nurse, because he is more with the patient than any other health professional, has a great obligation to be always at his disposal and always striving to obtain as much knowledge to perform good palliative care, as to understand the Patient side...” (Felipe)*

*“You respect the patient, respect the situation he is in, are always listening, giving word of support, both emotional and physical.” (Larissa)*

*“The nurse’s role is to promote the quality of life for that patient, giving comfort and helping understand the process of death, the stages, so that he can die quiet, with an acceptance of that disease.” (Daniela)*

*“For me is fundamental, it is the nurse who is providing care full time, 24 hours, in full and it can promote the best care in a humane way [...]” (Talita)*

Care in palliative nursing is to provide comfort, act and react appropriately against death situation with the patient, family and himself; is promoting the personal growth of the patient, family and yourself, to cherish suffering and achievements, empower others with their care and empower themselves for the care, it is to fight to preserve the physical, moral, emotional and spiritual, is connect and link up and help each other and themselves to find meaning in situations. Care in palliative nursing is to provide relief of symptoms, be flexible, have care goals, advocate for the patient and recognize it as a unique human being.<sup>20-21</sup>

Besides taking care of the patient and family, the nurse should not forget their team, they also need care, especially in the palliative care sector, it was pointed out by an academic in the interview.

*“In addition to coordinating all care, give the best care, you have to think that you will deal with a team that will be with unstable psychological, so beyond the care itself has to take care of the team...” (Enzo)*

For this, one must pay attention to its activities not only direct assistance to patients and families, as well as educational and guidance for your team. This approach can be accomplished via single or collective dialogues.

## **CONCLUSION**

The study makes it possible to highlight the importance of nurses in palliative care, but also the profile of this professional for proper and quality care to cancer patients in a hospital.

In view of the arguments presented it is noted the difficulty of academics to deal with death, a problem that is related to culture, as well as the absence of discussions on the subject during the academic period. Knowledge about palliative care goes beyond patient care that should extend to the family, and the influence of this to the patient. It also highlights the importance of nurses in palliative care sector, which is the professional most present throughout the process of death. And the profile of this professional in the view of scholars.

Thus, it is clear that there is much to in develop this theme. We believe that good practice should be the result of dedication, the pursuit of scientific knowledge, and especially the strengthening of the human being that exists in each professional. This feature is extremely important for the feeling of the application in the care of a being that evolved to death.

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