

Palliative care in highly complex oncology care: perceptions of nurses

Cuidados paliativos na assistência de alta complexidade em oncologia: percepção de enfermeiros
Cuidados paliativos en la atención oncológica de alta complejidad: la percepción de los enfermeros

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ABSTRACT

Objective: This study aimed to identify the difficulties faced up to provide care for people hospitalized in the context of palliative care in a High Complexity Oncology Care Center at Rio de Janeiro State according to Nurses' perception, and discuss strategies to better qualify nursing care in this context. **Methods:** This descriptive study used a qualitative approach. Institutional Review Board approval was obtained. We interviewed 13 Nurses, and applied the thematic analysis to the data. **Results:** Two categories emerged: daily life of Nurses in the presence of patients in palliative cancer care; and thinking about strategies to better qualify the nursing care. They highlighted the lack of knowledge in palliative care; the necessary creation of differentiated beds; and creation of institutional networks. **Conclusion:** The study alerts to the need for effective changes to assist these people, who depend on collective effort to qualify the practice and on further research.

Keywords: Palliative Care; Oncology Nursing; Hospital Care.

RESUMO

Objetivo: Identificar as dificuldades enfrentadas na prestação da assistência à pessoa hospitalizada no contexto dos cuidados paliativos em um Centro de Assistência de Alta Complexidade em Oncologia do estado do Rio de Janeiro, na percepção dos enfermeiros; e discutir estratégias para melhor qualificar a assistência de enfermagem nesse contexto. **Métodos:** Pesquisa descritiva, com abordagem qualitativa. Obteve aprovação do Comitê de Ética em Pesquisa da instituição. Foram entrevistadas 13 enfermeiras. Os dados foram submetidos à análise temática. **Resultados:** Emergiram duas categorias: O lidar cotidiano do enfermeiro na presença de pessoas hospitalizadas em cuidados paliativos oncológicos; e Pensando em estratégias para melhor qualificar a assistência de enfermagem. Destacam-se a falta de conhecimento em cuidados paliativos; a necessária criação de leitos diferenciados; e formação de redes institucionais. **Conclusão:** O estudo alerta sobre a necessidade de mudanças efetivas para atendimento dessas pessoas, que dependem de esforço coletivo para qualificar a prática e da realização de novas pesquisas.

Palavras-chave: Cuidados Paliativos; Enfermagem Oncológica; Assistência Hospitalar.

RESUMEN

Objetivo: Identificar las dificultades en la prestación de la asistencia a la persona hospitalizada en el contexto de los cuidados paliativos en un Centro de Asistencia de Alta Complejidad en Oncología del Estado de Rio de Janeiro, bajo la percepción del enfermero; y discutir estrategias para mejorar la atención de enfermería en este escenario. **Métodos:** Investigación descriptiva, con enfoque cualitativo. Fueron entrevistadas trece enfermeras y los datos analizados según el análisis temático. **Resultados:** Emergieron dos categorías: el cotidiano del enfermero en la presencia de personas hospitalizadas en cuidados oncológicos paliativos; y la proposición de estrategias para cualificar la asistencia de enfermería. Se destaca la falta de conocimiento en los cuidados paliativos; la necesaria creación de sectores diferenciados; y formación de redes institucionales. **Conclusión:** El estudio advierte sobre la necesidad de cambios efectivos para atender a los enfermos, lo que requiere esfuerzo colectivo para cualificar la práctica y nuevas investigaciones.

Palabras clave: Cuidados Paliativos; Enfermería Oncológica; Atención Hospitalaria.

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INTRODUCTION

The problem involving the deficiency in oncology teaching and palliative care in undergraduate health courses, including nursing, has been discussed in recent years due to the increasing number of new cancer cases; the high morbidity and mortality rates due to the disease, the consequent demand of the job market for qualified workforce; and the development of practices coherent with the principles of the Unified Health System (SUS) and public policies¹⁻³.

According to the estimates of the Brazilian National Cancer Institute (INCA) for 2014, approximately 576 thousand new cancer cases are expected, including the cases of non-melanoma skin cancer. As a chronic health condition, cancer has contributed to changes in the evolution of Brazilian mortality rates as, among these conditions, it represents the second cause of death due to a well-defined diseases, surpasses by cardiovascular illnesses only¹.

The late diagnosis of cancer hampers curative treatments, reducing the length of people's survival and quality of life. As the disease is incurable, care measures need to be implemented to maintain the comfort and quality of life, based on palliative care.

The World Health Organizations (WHO) defines palliative care as active and comprehensive care offered by a multidisciplinary health team, aimed at improving the quality of life of people and their relatives in view of a life-threatening disease, through the prevention and relief of suffering and pain, as well as of other physical, social, psychological and spiritual problems. The premise is that such care should start when the disease is diagnosed, so as to accompany curative therapeutic measures; and, when these measures fail, that palliative measures be implemented exclusively; and that care becomes the primary focus, to the detriment of cure³.

In view of the emerging need for investments in palliative care in Brazil, some movements that integrate health professionals, services and entities, like the Brazilian National Academy of Palliative Care for example, are seeking increasing visibility and political forces. These movements aim to contribute to: consolidate a public policy that specifically addresses palliative care; establish an integrated network so as to bind primary care to offer home care as the main care modality, as well as to create the supply of differentiated beds in the many general hospitals that attend to people with advanced cancer; produce access mechanisms to medication, material and services; and adapt the undergraduate and graduate curricula, including specific palliative care content, in undergraduate health education⁴.

In the political area, although it does not discuss a specific public policy, Ministry of Health Decree 876, launched in May

2013, guarantees access to palliative care to people diagnosed with cancer without indication of anti-tumor treatments⁵.

Based on this Decree, the States, the Federal District and Cities are responsible for organizing cancer care and define referral flows to provide care for patients with cancer. The care network in this specialty has been established in Decree 62, from March 2009, which mainly consists of: High-Complexity Oncology Care Services (UNACON), comprising hospitals with appropriate technical conditions, physical facilities, equipment and human resources for providing care based on the diagnosis and treatment of the most prevalent types of cancer in Brazil; and High-Complexity Oncology Care Centers (CACON), which are hospitals in conditions to diagnose and treat all kinds of cancer⁶. Nevertheless, the deficient supply of palliative oncology care at the services has been commonly evidenced, which are often only linked to the pain clinic in the outpatient contexts.

It can be affirmed that, nowadays, the extension of life to the detriment of its quality and the isolation in the hospital environment are factors that compromise the patients' dignity in their dying process, so that this experience is marked by suffering. In general, the services in Brazil are not prepared to offer care that guarantees good quality of death rates, making it fundamental to develop and improve palliative care programs⁷.

In view of this problem, based on the authors' practical experience at a teaching hospital accredited as a CACON, and considering that the nursing team is the most dedicated to care for patients and family members in the hospitalization context, as these professionals are present 24 hours per day, including at night, the study rests on the following guiding questions: What are the difficulties faced up to provide care for people hospitalized in the palliative care in the context of CACON, according to the nurses? What strategies can be implemented in view of these difficulties?

Thus, this study aimed to: identify the difficulties faced up to offer care for hospitalized patients in the palliative care context at a CACON at Rio de Janeiro State, according to Nurses; and to discuss strategies to better quality nursing care in that context.

The study is justified by the need to contribute to the discussion on palliative care, considering the emerging situation related to the epidemiology of cancer, as well as other chronic health conditions, and to the increase in the number of elderly in the population. Therefore, palliative care should be treated as a fundamental need, in defense of society⁸. Studies that aim to identify the difficulties faced in palliative care practice and that propose strategies to minimize them can contribute to the qualification of nursing care in oncology care and to the quality of life of patients and their family members.

METHOD

A descriptive research with a qualitative approach was undertaken. The qualitative approach was chosen as the main objective in this research was to obtain knowledge based on professionals' individual perceptions. Hence, the characteristics of the study object are subjective, involving the perceptions, opinions, beliefs and values the study participants attribute⁹.

The research was developed at a teaching hospital located in the city of Rio de Janeiro - Brazil. The institution is a highly representative CACON at offering care for patients with cancer.

The data were collected between December 2011 and April 2012 at two of the hospital's clinical infirmaries, with a varying availability of approximately 40 beds. The nursing team consists of 18 nurses who work in different work scales.

Thirteen nurses participated in the research, who complied with the following inclusion criteria: being formally employed at the institution and having worked at the clinical infirmary at the time of the data collection for more than six months. The five nurses who were on medical leave or holiday at the time of the data collection were excluded.

The data collection technique used was the semi-structured interview, guided by the script: What are the difficulties in faced with offering care for people with advanced cancer in the context of the CACON according to you? What strategies could be implemented to better qualify nursing care? In the course of the interview, the following variables were also investigated: sex, age, length time of work at the institution, year and place of graduation.

To register the data collected in each interview, a digital recorder was used with the participants' agreement. Next, the interviews were transcribed and analyzed based on the thematic analysis method, which permits highlighting the participants' main perceptions according to the most frequent elements of the discourse. The themes can be characterized that originated the categories. Hence, in this method, the gross data based on empirical research were submitted to pre-analysis; exploration of the material; treatment of the results and interpretation⁹.

The participants' anonymity was preserved and the excerpts from their statements were identified using the letter "N" for nurse and an Arabic numeral, according to the chronological order of the interviews (E.g.: N1, N2, N3...).

The discussion of the data was based on the literature review and conceptual bases that discuss the theme, and also on the authors' critical view.

Approval for the research project was obtained from the Institutional Review Board, under protocol 942/11. The legal and ethical aspects of research involving human beings were respected, in compliance with National Health Council Resolution 466/2012.

RESULTS

Thirteen nurses participated in the research, all women. The most prevalent age range was between 20 and 30 years of age, corresponding to 42.8%. The length of work at the hospital ranged between two and 15 years, the most prevalent interval ranging between six months and five years, equaling 46%. All nurses mentioned experience in palliative oncology care at the infirmaries during that period.

As to the time since graduation, most participants reported having graduated more than 16 years earlier, i.e. 39%. In the remainder of the group, 23% of the nurses had graduated between six months and five years earlier; 23% between six and ten years; and 15% between 11 and 15 years. As to the institutions where they had graduated, the Universidade do Grande Rio, Universidade Federal do Rio de Janeiro, Universidade Federal do Estado do Rio de Janeiro and Universidade Estácio de Sá graduated two nurses each. The Universidade Gama Filho, Universidade Souza Marques, Universidade Federal do Piauí, Universidade do Estado do Rio de Janeiro and Faculdade de Enfermagem Luiza de Marillac contributed by graduating one nurse each.

Based on the analysis of the data, two categories were produced, which are: The nurse's daily practice in the presence of hospitalized patients in palliative oncology care; and Devising strategies to better qualify nursing care at a CACON.

The nurse's daily practice in the presence of hospitalized people in palliative oncology care

Among the difficulties the nurses mentioned, aspects stood out that were related to professional education, in view of the lack of preparation to cope with situations that reflect the complexity of the human being and the dying process, as well as with the lack of material and human resources, the absence of appropriate physical structure, so as to favor high quality, individualized and humanized care. According to their testimonies:

Here at the university hospital we face difficulties with human and material resources. One example: the amount of screens is insufficient to offer good care to all patients. And, often, at a certain ward, with this insufficient number of screens, what happens? We need screens for a bed bath and, at the same time, there's a terminal cancer patients, and both need the screens at the same time. What's gonna happen? We will prioritize the use of the screens for the bath because the patient will be exposed, undressed[...] (N3).

The professionals should be humane in their form of giving care [...] the majority does not offer the humanized care the medical clinical patients need, mainly in oncology. The care ends up not being as effective as it should be[...] (N7).

Concerning the health professionals' lack of preparation at the undergraduate level, particularly including the nurses, to deal with the advance of the disease and the consequent death and dying process, the following statement stands out:

As the hospital is not specialized in oncology, the fact that a patient is beyond the possibility of care is not characterized at any time, which interferes in the conducts. The professionals end up executing unnecessary invasive procedures because they do not know how to deal with this, and they think the family will require, or the teacher will require, the colleague will require, that that will be omission of help, when it actually is not [...] (N3).

The above testimony highlights another peculiarity of the context, being a university hospital and training area for undergraduate and graduate students in different health areas. For the physicians, specifically the medical residents, their turnover among the sectors can influence care provide to patients in palliative care, as the objective of the treatment is not distinguished in the history of most patients, creating possibilities for invasive conducts in view of possible clinical complications.

In nursing care management, the nurses also reveal difficulties to set care priorities, considering the variation in the profile of the people attended at the medical clinical, and in the treatment objectives, when they end up prioritizing cases in which cure is a possibility.

It is very complicated, because it's not a specific hospital for cancer patients here, there are people with several other diseases. So, it's complicated for you to deal with terminal cancer patients, at the same time as there's another patient in need of immediate care [...] (N1).

The lack of human resources in nursing, the absence of the multiprofesional team to attend to these people's needs, and of material resources, are difficulties that limit the practice. These shortages lead to an overload of administrative activities, distancing these nursing professionals from direct care provide to people.

Contact with the patient is very quick, being a medical clinic with many beds, we do not only provide care but also do the bureaucratic part [...]. Over here, unfortunately, the demand is very big for the nurses and, as there are few, it ends up putting a strain on everyone, so that we do not provide correct care (N5).

[...] I see my limited practice, starting from the point where we have a limited structure, with a lack of material and human resources [...] we have several functions in our work schedule [...]. In addition, there is no multiprofessional team for palliative care here, to promote further comfort to these patients are their relatives (N7).

Devising strategies to better qualify nursing care at a CACON

This category presents the different strategies, based on the nurses' perception, to better qualify care provide in the context. The following stand out: team training through continuing education and in-service training; dissemination of care humanization policy; reduction of turnover and deployments among nursing team members; investment in the number of human resources; and existence of beds to specifically welcome palliative care patients.

You need to train the team to be able to provide appropriate care to this terminal cancer patient [...]. Training courses on palliative care could be promoted [...] (N7).

Among the questions related to personnel management, besides the strategies to reduce the employee turnover and deployments, as well as to invest in the number of nursing human resources, the nurses discussed the lack of attendance to their own needs, mainly those related to psychological support.

The team also needs enlargement, and should always be a team, without keeping on changing teams, we should stay in a single, unique team and stay with it for a long time [...] without a high turnover, so that we can keep up the work [...] (N5).

[...] having that psychology professional working with the team [...] because we are vulnerable, getting emotionally involved with this patient and relatives, so we'll need that too [...] (F7).

The need to create a supply of distinguished beds in general hospitals, which are part of the cancer care network, was largely ratified in the nurses' statements, as observed in the following statement.

[...] it would have to be a private room, a specific sector for the cancer patients and, in this situation, a sector for each type of care. I don't know if that would be utopic. But the ideal would be a specialized environment, a specific environment for palliative care [...] (N7).

DISCUSSION

Getting to know the nurses' reality in care provide to patients in palliative care in the context of a CACON is a relevant form of reflecting and seeking new routes to cope with the difficulties faced. Some empirical observations by the authors evidence that the theoretical and legal frameworks are not in line with the reality of the public health services, especially concerning oncology care, with a common lack of many resources. This research enhances that kind of observation.

Thus, the nurses' testimonies raised several critical points for discussion. When identifying the difficulties faced in this context, the nurses highlighted: the deficits in professional education, which does not prepare them to cope with the death and dying process. This problem is further aggravated as the institution is a teaching hospital, with a lack of human resources, material and basic infrastructure for care, including the inexistence of a multiprofessional team for palliative care; and the absence of differentiated beds for this client profile, as the current configuration of beds at the clinical infirmaries, being a general hospital, has contributed to the difficulty to set priorities in care, as well as to organize the care time at the bedside. This fact is also related to the lack of nursing human resources.

These difficulties lead to a discussion based on strategies that can better qualify nursing care in this context. The need to train the multiprofessional team is highlighted, mainly the nursing team, through continuing education, with a view to facilitating the performance of knowledge-based actions and preset institutional conducts¹⁰.

This strategies requires the constitution of a team with a background in palliative care, reflecting the need for combined actions, so that isolated movements or investments are not weakened and discontinued. The variation in the participants' level of experience and length of work at the institution, for example, demand that training be part of the nurses' routine, and that the didactics used take into account the novelty of the theme for many professionals, with possible practical examples through case studies.

As regards the humanization of care, it is highlighted that the dissemination of this praxis remains far beneath the necessary levels in many contexts. Dehumanized care is an existing reality at many health care services, including the hospital environment. It is highlighted that not following the precepts of palliative care and the accomplishment of futile and unnecessary treatments in this phase of the disease can be considered dehumanizing practices, as they contribute to the suffering of patients and relatives, as well as to the valuation of the physical aspects to the detriment of compliance with the needs that involve other dimensions of the human being in the dying process. Humanized care is a premise,

which should be disseminated among the peers, reflected in an action of respect for fellow citizens in any relationship, constructed based on communication and the help relation¹¹.

Hence, as the humanization concept entails solidarity and respect, patients beyond cure should have their autonomy and dignity preserved. It should be highlighted that, when the patients perceive humanized care, they can express their desires and feelings in the course of the finite process and can achieve a good death⁷.

The relationship among the professionals and the evidence of their own needs are also valued, mostly related to the psychological dimension, in view of the daily reality marked by the (un)certainly of death. The psychological support to cope with these situations has been appointed as an important strategy¹². General nursing team strategies involving other individual and group protection strategies are commonly observed, in view of the feeling of their own vulnerability. Hence, the use of screens to "isolate" people who are dying is highlighted. The discussion should be raised that the strategy of creating differentiated beds in the study context, if not combined with investments in qualified human resources, can contribute to this type of "isolation".

Thus, the example of the priority use of the screen at the infirmary, in view of distinct needs, gives rise to the question: to what extent the care with the use of screens in this environment derives from the nurse's intention to preserve the dying patient's privacy, or from the unconscious need to cover up the reality in view of the difficulty to cope with death?

Assertions that professionals need skills and training to work in oncology and in palliative care are common in the literature. Nevertheless, attending to the professionals' own needs in view of complex realities remits to the fact that these are people taking care of people, making it important to articulate and integrate care for the self, the other and "for us"⁸.

The quality of the health team's care is related to appropriate personnel management, considering staff dimensioning and the characteristics of education, especially when the professionals are hired. Nevertheless, adapting the needs of the client profile to the ideal number of employees, mainly in the nursing team, which is the largest group, entails high costs for the hospitals¹³. Due to the lack of professionals, specifically nurses, the care burden becomes a predictable consequences and, due to their multiple tasks, they end up spending more time on administrative activities, most of which are their exclusive responsibility. These activities distance the nurses from direct care, due to the time their execution demands. This is yet another restrictive factor in care practice for palliative oncology patients¹⁴.

Peculiarities of the profile of palliative oncology patients should be taken into account, in view of the great instability of

their clinical condition, demanding that the nurses constantly reassess them, for example, to adapt the care plan according to the new or continuing needs. Also, the family members' care demand is highlighted, which needs to be attended to, as they get ill together with their loved ones in these experiences linked to the chronic health conditions. In general, the family members' needs are related to effective communication, which requires that the professionals have time and dedication to tighten the relationships based on empathy¹⁵.

Nursing care requires a comprehensive and humanized look from the professionals, with a view to comprehensive care provide, respecting the patients' biopsychosocial aspects and particularities, beyond the mere valuation of specific techniques and practices¹⁶. Nevertheless, appropriate work conditions are needed for the compliance with these demands to be feasible, instead of a utopia. This nursing care is executed in different contexts, including palliative care, in which these professionals participate actively, in hospital as well as in home care, due to their enhanced technical-scientific background, whose substance includes care for the other.

Nevertheless, to attend to the social needs and the roles of social and intellectual education of man, the curricular reform movements in health join several aspects in response to contemporary requirements, particularly interdisciplinary practice¹⁷⁻¹⁸. However, whether due to cultural influence or influence from the capitalist system, the curricula still lack opportunities to discuss oncology, and specifically palliative care.

The limitation in this study is based on the fact that the scenario was a single hospital in the cancer care network of the State of Rio de Janeiro. A broader view on the problem is needed though, so as to contribute to networking among the services. This expansion should involve other health professionals beyond the nursing team, including representatives from the administrative sphere.

The implications for practice point towards the implementation of measures that can qualify nursing care, involving care and administrative actions, particularly service organization, like in the example of the differentiated beds and in human resource management, considering service scales, training sessions and premises for hiring or other selection processes, in accordance with the clients' profile. These actions are articulated with a view to retroactive causes and effects and can lead to continuous improvements.

CONCLUSION

The research revealed that the nurses face great difficulties to attend to palliative care patients in the context of a CACON. The following difficulties are highlighted: the absence of differentiated

beds for this client profile; the deficiency in professional education, particularly the difficulty to cope with the theme death, as well as the influence of the curative model; lack of material and human resources, including the lack of a multidisciplinary team to attend to end-of-life needs; and humanized care.

These constraints can compromise the quality of care provide, leading to negative experiences during hospitalization.

In view of the difficulties faced, the nurses proposed strategies to better quality nursing care in the research context, particularly team training and ongoing education, disseminating the palliative care theme, in view of its insufficient discussion in undergraduate and graduate programs. In addition, the creation of differentiated beds is highlighted as a strategy, in line with the ideas disseminated in movements aimed at expanding the supply of palliative care in Brazil. Among other strategies discussed in the text, this strategy leads to more comprehensive themes, including the use of resources by the Unified Health System (SUS), the creation of public policies and networking.

It is also highlighted that, to achieve effective changes, the patients, professionals line with contemporary social needs, based on scientific knowledge, so as to guarantee efficiency, efficacy, safety and quality.

There are many challenges and, to overcome them, appropriate planning is needed, whether of institutional actions, within a micro-perspective, or of national actions, within a macro-perspective. The actions need to be determined in plan with short, medium and long-term targets, and representative leaderships need to be available in the country, including referral institutions in oncology care. Further research is needed to support these strategic plans and return reflections and discussions on successful or failed experiences to the practical sphere, contributing to the development of this activity area, which is considered as a new care mode.

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