







## ONCOLOGY NURSING CARE IN A PALLIATIVE CARE HOSPITAL (2005-2006): A HISTORICAL-SOCIAL APPROACH\*

CUIDADO DE ENFERMAGEM ONCOLÓGICA EM UM HOSPITAL DE CUIDADOS PALIATIVOS (2005–2006): ABORDAGEM HISTÓRICO-SOCIAL\*

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-  Carolina Fraga Paiva<sup>1</sup>
-  Rosane Barreto Cardoso<sup>2</sup>
-  Tânia Cristina Franco Santos<sup>2</sup>
-  Camila Pureza Guimarães da Silva<sup>2</sup>
-  Patrícia dos Santos Augusto<sup>1</sup>
-  Antonio José de Almeida Filho<sup>2</sup>

<sup>1</sup>Universidade Federal do Rio de Janeiro – UFRJ. Escola de Enfermagem Anna Nery - EEAN, Departamento de Enfermagem Fundamental - DEF. Rio de Janeiro, RJ - Brazil.

<sup>2</sup>Universidade Federal do Rio de Janeiro – UFRJ. Escola de Enfermagem Anna Nery - EEAN, Professor(a) do Departamento de Enfermagem Fundamental - DEF. Rio de Janeiro, RJ - Brazil.

**Corresponding author:** Rosane Barreto Cardoso

**E-mail:** rosane.bcardoso@gmail.com

### Authors' contributions:

**Conceptualization:** Carolina F. Paiva, Antonio J. Almeida Filho; **Data Collection:** Carolina F. Paiva; **Investigation:** Carolina F. Paiva; **Methodology:** Carolina F. Paiva, Antonio J. Almeida Filho; **Project Management:** Carolina F. Paiva; **Resource Management:** Carolina F. Paiva; **Statistical Acquisition:** Carolina F. Paiva, Antonio J. Almeida Filho; **Supervision:** Carolina F. Paiva, Antonio J. Almeida Filho; **Validation:** Carolina F. Paiva, Antonio J. Almeida Filho; **Visualization:** Carolina F. Paiva, Antonio J. Almeida Filho, Rosane B. Cardoso, Tânia C. F. Santos, Camila P. G. Silva, Patrícia S. Augusto; **Writing – Original Draft Preparation:** Carolina F. Paiva; **Writing – Review and Editing:** Carolina F. Paiva, Antonio J. Almeida Filho, Rosane B. Cardoso, Tânia C. F. Santos, Camila P. G. Silva, Patrícia S. Augusto

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## ABSTRACT

**Objective:** to analyze the role of nurses in the planning and implementation of the Day Care - Espaço CuriosAção (Day Care - CuriosityFacility) project, in a referral hospital for cancer treatment in an oncological palliative care setting. **Method:** this is a qualitative study with a historical approach, whose direct sources were written documents and photos from the documentary archives of the Hospital do Câncer IV, in addition to oral testimonies. **Results:** the Day Care - Espaço CuriosAção project was a strategy employed with the aim of humanizing palliative care, where the nurses acted as leaders with specialist knowledge during the planning stages of the project, while structuring the space and conducting the pharmacological and non-pharmacological activities. This initiative had the support of the Humanization Group and a partnership was established between the institution's management and the Nursing Division to support these measures in line with the World Health Organization. Cicely Saunders' St. Christopher's Hospice in London was adopted as a reference. **Conclusion:** the nurses, who have an important wealth of scientific capital and are part of a professional support network, participated directly in the discussions and practices of planning and implementing the Day Care - Espaço CuriosAção project, based on the philosophy of palliative care and the meaning of hospice. In this initiative, they also consolidated and disseminated specialized scientific resources.

**Keywords:** Palliative Care; History of Nursing; Oncology Nursing; Quality Management; Pain Management; Nursing Care.

## RESUMO

**Objetivo:** analisar a atuação dos enfermeiros no planejamento e implantação do Projeto Day Care - Espaço CuriosAção em um hospital de referência para o tratamento de câncer, no contexto dos cuidados paliativos oncológicos. **Método:** Pesquisa qualitativa, de abordagem histórica, cujas fontes diretas foram documentos escritos e fotos do acervo documental do Hospital do Câncer IV, além de depoimentos orais. **Resultados:** o Day Care - Espaço CuriosAção foi uma estratégia empreendida com o objetivo de humanizar o cuidado paliativo, onde os enfermeiros atuaram como líderes detentores de conhecimento especializado durante as etapas de planejamento do projeto, na estruturação do espaço e na condução das atividades farmacológicas e não farmacológicas. Esse movimento contou com o apoio do Grupo de Humanização e com uma aliança estabelecida entre a direção e a Divisão de Enfermagem da instituição para sustentar tais ações em conformidade com a Organização Mundial de Saúde. Adotou-se como referência o St. Christopher's Hospice de Cicely Saunders, em Londres. **Conclusão:** Os enfermeiros, detentores de um importante volume de capital científico e inseridos em uma rede de apoio profissional, atuaram diretamente nas discussões e práticas do planejamento e implantação do Projeto Day Care - Espaço CuriosAção, fundamentados pela filosofia de cuidados paliativos e pelo significado de hospice. Nesse movimento, também consolidaram e difundiram capital científico especializado.

**Palavras-chave:** Cuidados Paliativos; História da Enfermagem; Enfermagem Oncológica; Gestão da Qualidade; Manejo da Dor; Cuidados de Enfermagem.

## RESUMEN

**Objetivo:** analizar la actuación de los enfermeros en la planificación e implementación del Proyecto Day Care - Espaço CuriosAção [Proyecto Day Care - Espacio de Curiosidad] en un hospital de referencia para el tratamiento del cáncer, en el contexto de los cuidados paliativos oncológicos. **Método:** investigación cualitativa, de enfoque histórico, cuyas fuentes directas utilizadas fueron documentos escritos y fotos del archivo documental del Hospital del Cáncer IV y testimonios orales. **Resultados:** el Proyecto Day Care - Espaço CuriosAção fue una estrategia emprendida con el objetivo de humanizar el cuidado paliativo, en la cual los enfermeros actuaron como líderes con conocimientos especializados durante las etapas de planificación del proyecto, en la estructuración del espacio, en la realización de actividades farmacológicas y no farmacológicas. Este movimiento contó con el apoyo del Grupo de Humanización y de una alianza establecida entre la dirección y la División de Enfermería de la institución, para respaldar dichas acciones de acuerdo con la Organización Mundial de la Salud; se adoptó como referencia el hospicio St. Christopher's de Cicely Saunders en Londres. **Conclusión:** los enfermeros, con un importante volumen de capital científico y en una red de apoyo profesional, participaron directamente en las discusiones y prácticas de planificación e implementación del Proyecto Day Care - Espaço CuriosAção, fundamentados en la filosofía de los cuidados paliativos y en el significado del hospicio. En este movimiento, también consolidaron y difundieron un capital científico especializado.

**Palabras clave:** Cuidados Paliativos; Historia de la Enfermería; Enfermería Oncológica; Gestión de la Calidad; Manejo del Dolor; Atención de Enfermería.

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## INTRODUCTION

The demand for palliative care is growing rapidly due to an aging population, an increase in chronic diseases, and the growing number of cancer cases worldwide<sup>(1)</sup>. Aging is a challenge for healthcare professionals and society as a whole, and it is vital to research ways of ensuring quality of life for those involved in this process<sup>(2)</sup>. Although science has advanced, longer life expectancy is not synonymous with better health, and chronic diseases can represent anguish and suffering for patients and their families<sup>(3)</sup>.

Cancer is the second leading cause of death in the Americas. Estimates of the global burden published by the International Agency for Research in Cancer (IARC) indicate that, by 2040, the number of new cancer cases is expected to increase to 30.2 million and that, by 2060, the need for cancer care is expected to double. Health management is therefore facing a significant challenge due to the demand for specific care for this population, which is increasing considerably, in addition to the lack of palliative care available<sup>(1,4)</sup>.

Cancer can cause intense physical, emotional, and social suffering<sup>(5)</sup>. It was in the 1950s that Cicely Saunders, a nurse, medical doctor, and social worker, became aware of the consequences of the disease and paved the way in structuring palliative care in England, founding St. Christopher's Hospice in 1967. In terms of professional practice, the hospice was one of the pioneers in recognizing pain management and symptom control as a priority. It also developed palliative care, teaching activities, and clinical research in this field<sup>(6)</sup>. In the 1980s, the practices led by Saunders were introduced in Brazil and, along with the scientific literature of the World Health Organization (WHO), there was then an increasing supply of services focused on comprehensive palliative care<sup>(7)</sup>.

The importance of developing and implementing policies focused on palliative care was noted in 2014 in the World Health Assembly Resolution on Palliative Care, which emphasized its strengthening as a component of comprehensive care throughout life. This was registered as a WHO public health model, which included ensuring comprehensive education on the subject; availability and accessibility of essential medication; funding and implementation of palliative care programs; as well as the existence of specific policies<sup>(8,9)</sup>.

In terms of approach, palliative care is promoted by a multidisciplinary team, centered on the patient and their family, with an emphasis on relieving the pain and suffering caused by serious conditions, and on physical, psychological, and social needs. Palliative care is useful

at all stages of the disease, at any time after diagnosis, but is generally most effective when initiated early, in combination with curative approaches<sup>(7)</sup>. According to this approach, treatment should be started early in the course of a life-threatening illness.

In its technical-scientific training, nursing holds care and its provision as the core object, with the aim of providing qualified, safe, and comprehensive care. Palliative cancer care also addresses the need for more humanized care, which considers biological and psychological aspects, as well as providing emotional support for patients and their families at all stages of the disease<sup>(8)</sup>.

Studies on the careers of nurses in specialized and reference centers, such as the Hospital do Câncer IV, a unit of the National Cancer Institute (INCA) and a reference for oncological palliative care in Brazil, help to highlight the role of nurses in this type of care, both from the societal perspective and within the multidisciplinary institutional framework<sup>(9,10)</sup>. Thus, studies on the progress of the profession expand, making it possible to highlight its leading role and contributing to the social recognition of nursing in the healthcare field.

In light of the above, this study poses the following question: how did nurses perform in the planning and implementation of a pioneering project at the Hospital do Câncer IV (HCIV/INCA) in the field of humanization, in the context of the Day Care - Espaço CuriosAção (Day Care - CuriosityFacility), in the face of new institutional challenges? The aim of the study is to analyze the role of nurses in the planning and implementation of the Day Care - Espaço CuriosAção project in a referral hospital for cancer treatment, in the context of palliative cancer care.

## METHOD

This historical study, with a qualitative approach, fits into the perspective of Present Day History and stems from a doctoral thesis. It emphasizes that "history is not only a study of the past, but also, with less depth and particular methods, a study of the present"<sup>(11-12:28)</sup>.

The study's direct historical sources were written documents, photos, and oral testimonies. The written documents, stored at HCIV/INCA, consisted of reports from the Nursing Division, meeting reports from the Nursing Division and the Board of Directors, and Technical Standards and care protocols, all of which were digitized and stored in folders identified by year, on a computer installed at the institution's service headquarters. The photographs used in the article were also part of the archive mentioned above, while the oral sources were produced through interviews with a semi-structured

script, conducted between August 2021 and August 2022. The indirect sources consisted of articles from scientific journals on the subject, which provided the basis for data analysis. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were followed.

The inclusion criteria for participants were the following: professionals who held management positions during the period under study, namely 2005 and 2006. An exploratory survey was conducted to identify those who met the criteria, followed by the referral of other participants (snowball sampling). Recruitment was carried out by e-mail and in person. During this period, eight participants met the criteria; of these, only one refused to participate for health-related reasons. As a result, seven people participated in the doctoral research and four were quoted in this article as they were related to the aim of this study. The location of the interviews was set by the participants, and they were audio-recorded, lasting an average of 236 minutes (approximately 4 hours). To identify the testimonies, the initial letter of the profession was used, followed by an Arabic number in sequential order: nurses (E1, E2, E3, E4, E5).

The study setting was the HCIV, which is INCA's exclusive reference unit for palliative cancer care, located in Rio de Janeiro city, in the state of Rio de Janeiro, Brazil. As such, this INCA unit was responsible for providing care in line with the national and international literature, as well as the regulations defined by the Institute and the Ministry of Health. It is also responsible for investing in research and professional training specializing in oncological palliative care at a national level.

The documentary corpus consisted of the following aspects: relevance, sufficiency, completeness, representativeness, homogeneity, and organization of the documents<sup>(11)</sup>. In order to analyze the documentary corpus, the written sources were catalogued considering the chronological sequence of the facts, followed by external and internal criticism, in order to ensure their authenticity, legitimacy, truthfulness, and reliability. Regarding the direct oral sources, the interviews were transcribed and later validated by the participants, which allowed the phenomenon to be highlighted. The reliability of the results was ensured by emphasizing the documentary corpus and not just isolated documents. The analysis was a scholarly and well-founded synthesis of the historical version presented.

The study followed the ethical precepts of Resolutions 466/12 and 510/16 of the National Health Council, and was approved by the Ethics Committee for Research with Human Beings of the participating institution. The

images were retrieved online and the identification of the people has been removed, respecting their image rights.

## RESULTS

Considering that palliative care represents a public health need that has been widely documented in scientific publications and WHO guidelines, the inclusion of these practices is a priority, as they adopt a holistic approach to providing care to patients with advanced cancer and their families. In line with these records and in pursuit of excellence in care, as per the Joint Commission International accreditation certification manual, the HCIV started planning strategies focused on humanization with the participation of nurse leaders, including the development of the "Day Care - Espaço CuriosAção" project. This project, based on Cicely Saunders' St. Christopher's Hospice model, was developed in Brazil, as described in the report below:

*The Day Care project consisted of a day dedicated to providing care to patients. [...] I introduced the idea for the St. Christopher's Project, in which both inpatients and those receiving home care could participate. When families needed to take care of things away from home, they could leave the patient with us to look after them and then pick them up again. [...] In England, it was quite easy because everything was so close by, but here in Brazil, it sometimes would take longer, although occasionally it would be possible. [...] Patients from the HCIII also started to come [...]. There was even a wedding of a patient from HCII inside the CuriosAção facility. [...] Initially, the idea was for patients to spend just one day there [...], but the Day Care eventually became a daily activity, as there were more activities and patients every day. [...]. (E1)*

When planning this strategy, the unit's nurse leaders recognized the importance of incorporating the *Day Care - Espaço CuriosAção* as part of nursing care. By constantly participating in the planning meetings held by the unit's director and the Nursing Division, these nurses expressed themselves assertively and contributed to the materialization of the proposals. One of the interviewees comments on this action:

*[...] The nursing team attended several meetings so that CuriosAção could be established at the HCIV. [...] We carried out extensive research into how it should work, what would be provided, [...] we imagined a place with lots of activities, which could offer maximum comfort for the soul and the body. [...] We thought about treatment and, at the same time, the well-being and happiness of patients, carrying out day-to-day activities within*



*the Day Care - Espaço CuriosAção facility. [...] Dr. Cláudia brought some ideas from Europe, [...] and some nurses actively participated in this project alongside her, because we had to lead the activities that would be carried out and, at the same time, provide care for the patients. [...] We had knowledge of palliative care. [...] It was a challenge to organize it in such a way that patients felt more at ease, had moments of distraction and felt good, for their own emotional well-being. [...] We also had to ensure the practical side of nursing care. [...] It was a unique space that made all the difference to these people's lives. [...] We did it in a way that it became a reference for other hospitals and professionals. [...]. (E4)*

During planning, the nurses held a significant leadership position within the group, discussing operational and care issues with authority, backed by their specialized knowledge. The following testimonies reflect this: ]

*[...] we held several meetings to discuss new ideas. [...] We would meet with the unit director and other groups to discuss the activities and how CuriosAção would work. [...] The nursing team was quite confident in saying what was adequate, as we had extensive experience and knowledge of palliative care. [...] We recorded the planning of recreational activities, along with care activities, such as certain times for medication and assessment of vital signs [...]. (E3)*

In this context, the progress from planning to implementation of the Day Care - Espaço CuriosAção imposed new leadership possibilities for nurses in an unprecedented field of activity at the HCIV. Meanwhile, it strengthened specialized oncology palliative care nursing in a pioneering INCA project at a national level. Corroborating this, a nurse assumed the position of head of the Day Care facility, which reflected the director's and other professionals' recognition of nursing competence. The following excerpt from the interview demonstrates this:

*[...] CuriosAção was led by a nurse who was always present, responsible, and led it competently [...] she had been working with palliative care for several years and was involved in numerous teaching activities at the HCIV [...] she studied, lectured, and participated in everything [...] nothing happened without her knowledge and authorization [...] she was a highly intelligent and strong woman [...] a professional we admired and regarded as a model.[...]. (E4)*

Regarding nursing care as part of the project team, the nurse's competences were planned through discussions, recorded in the meeting reports held throughout 2006 and documented in the INCA/HCIV Administrative

Standard on the Day Care - Espaço CuriosAção project. The discussions covered pharmacological and non-pharmacological therapies, in line with scientific publications and the unit's humanization strategies, with a focus on work processes and quality of health and life.

Therefore, regarding these competences, some of the assignments recorded in the Standard were: visiting patients who were in a clinical condition and wished to participate in the project; explaining to the patient the importance of the sector and of their participation; warmly welcoming patients and introducing them to other members of the team; providing nursing care during their stay at CuriosAção; participating in manual activities whenever possible; administering and/or supervising medications at the scheduled times; receiving and accommodating patients at scheduled meal times; providing or promoting rest for patients after lunch; encouraging patients to return to activities; recording the dynamics of the sector in a dedicated book; and contributing to group activities aimed at providing information to patients and their families/caregivers, when necessary.

Regarding the physical space where the project was established and the activities were carried out, the speech fragments show that the environment reproduced a domestic, welcoming, familiar, and cozy environment

*[...] it was as if it were their [the patients'] home [...] decorated and full of artwork that they produced [...] they made friends and danced with each other [...] they watched television and talked [...] the hours passed very quickly [...] meanwhile, I was doing my job as a nurse with the hospital's medications and protocols and at the same time caring for their souls [...] caring for the pain [...] of each one of them in the way they needed it [...]. (E3)*



Figure 1 - Part of the Day Care - Espaço CuriosAção facility. Rio de Janeiro/RJ, Brazil, 2024.

The nurses' specialized knowledge was strategically shared in order to offer palliative care in that welcoming space within the hospital environment. In addition to appropriating the new space to provide qualified care

practices, the nurses consolidated their position as a national reference group. The excerpt below is evidence of this

*That space was extremely important, [...] we worked on care and followed all the protocols, but we also focused on the patients' other needs. It was really important for their care and self-esteem. Can you imagine being locked up for days on end? [...] CuriosAção also worked on this part of self-esteem, there was a hairdresser there once a week to give them a haircut or an eyebrow job [...]. As well as working on this part of self-esteem, we did manual work together and made them feel useful [...], that was important [...] They felt capable [...] regardless of being debilitated, they were able to paint, do manual work, sew, be with other people, and look after themselves. [...] There was also the caregiver's part, which was very important [...], they knew that the patients were receiving care in that space, that they were going to take their medication, that they were going to be looked after when they needed it and, likewise, that their self-esteem was going to be boosted so that they knew how important they were in society, for their family, and for themselves. (E3)*

In this scenario of expanded and humanized nursing care, it was possible to identify humanized care practices, with non-pharmacological measures and an approach focused on relieving patients' pain and suffering, as described in the reports below:

*[...] they received all the care they needed [...] there were medications and so many other things we provided to take care of them [...], games, dances, parties, music, painting, drawings, and even letters [...]. They did so many activities that the day went by quickly [...], they were very close to us [...], they trusted us and felt welcome (E5).*



Figures 2 e 3 - The application of non-pharmacological measures in the facility. Rio de Janeiro/RJ, Brazil, 2024.

It is also worth noting the excerpt from the statement in which a participant integrates pharmacological guidelines, assessments, and practices into the care provided at the *Day Care - Espaço CuriosAção* facility, in line with

WHO publications and guidelines, with the aim of providing qualified, unique care.

*[...] all the medication protocols we were able to develop at CuriosAção were carried out [...] because that space transformed even the acceptance of medication [...]. There was a small room next door that we used to assess vital signs and even some admissions [...]. We held discussion groups on educational topics for those who went home with specific care, such as dressings, tracheostomized patients, those with a bladder tube or a fully implanted catheter [...]. I provided extensive guidance on home care when they were discharged from CuriosAção [...]. The way they received the instructions and booklets for home care was totally different [...]. (E4)*



Figures 4 e 5 - Medication protocol being carried out in the facility. Rio de Janeiro/RJ, Brazil, 2024.

The nurses stressed the importance of a broader approach to pain and suffering relief, going beyond pharmacological measures, in line with the principles of palliative care published by the WHO. One of the interviewees' comments on pain management as a priority in nursing care stands out:

*[...] They would arrive sad, in pain, and leave refreshed and pain-free [...], often the medication we administered was unable to relieve the pain as it was not a physical pain, but rather a mental pain or some form of anguish that they had and were unable to express [...], it was a priority for us that they left CuriosAção pain-free and with some joy. [...] the activities they did and the time they spent at CuriosAção were also a medication for the pain in their bodies and souls [...], I cared for them as a nurse and with kindness and they reciprocated with plenty of love and gratitude [...], we had a very trusting relationship [...]. (E4)*

While basing themselves on scientific literature and WHO and Ministry of Health guidelines to implement strategies in palliative care, they have also appropriated the space:

*[...] CuriosAção was created and transformed by nurses [...], I dedicated a lot of my professional and personal time too [...], I lived with these people constantly and knew all about their pain, sadness, longing, problems [...], the care provided was far beyond just medication [...]. (E5)*

In addition to constituting a new leadership field, representing the empowerment of nurses in this scenario, specialized knowledge was also consolidated and disseminated:

*[...] it became a place for the nursing field [...] we created a routine and there was a massive effort made by most nurses there to make it a place where we could offer much more than medication [...], it was where I felt safe to be a nurse [...], I applied all my professional knowledge and training [...], I also taught other professionals who were passing by about the importance of the place and the care we provided [...], the nursing team at the HCIV became even stronger with that place [...], countless professionals from other hospitals, students, and other nurses wanted to learn from us [...]. (E4)*

As recorded, the work of the HCIV nurse leaders in planning and implementing the *Day Care - Espaço CuriosAção* project resulted in the strengthening of humanized nursing care for oncology palliative care patients, their families, and all those involved in their care. Furthermore, the implementation of this strategy disseminated the importance of nurse leadership in this process and their position in the field.

## DISCUSSION

The unit's director, as part of the HCIV/INCA Humanization Project, planned actions focused on the humanization of healthcare, enabling the innovative *Day Care - Espaço CuriosAção* project to be carried out both within the unit and across the country. Palliative care planning should be based on the assessment of suffering - whether physical, psychological, social, or spiritual - that has not been adequately prevented or minimized, highlighting the essential role of nursing in overcoming the challenges posed by providing universal access to this care<sup>(13,14)</sup>. Human resources emerge as the most crucial component in healthcare organizations<sup>(15)</sup>.

Inspired by the principles of palliative care and the hospice concept, the nursing leaders at the HCIV were motivated to engage in the institutional planning of the *Day Care - Espaço CuriosAção* project. This engagement stemmed from their autonomy, specialized knowledge, and experience in the field. The aim was to adapt the

care practices observed by the unit's director at the Cicely Saunders hospice, considered a model and inspiration, to the Brazilian reality, focusing on the quality of the work processes and the health of those involved in the care. Leadership in nursing is vital for achieving positive results in healthcare<sup>(16)</sup>.

A nurse assumed leadership of the facility, aiming to develop a project that emphasized the importance of a welcoming, home-like environment, which would enable extended, humanized, and holistic care, in addition to the application of pharmacological measures. The nurses receive specific training in this model of person-centered and holistic care, which naturally aligns with the philosophy of palliative care.

In terms of ensuring qualified care, lead nurses are responsible for ensuring this, and therefore need to establish direct partnerships with patients and their families<sup>(17)</sup>. Thus, they are responsible for achieving excellence in care and adapting it to the individual needs of each human being.

In nursing, leadership is crucial for achieving significant results for health organizations, patients, and everyone else involved; it is intrinsically related to care actions and sets a model for the team. Such leadership, based on mutual trust, respect, fairness, and flexibility, favors team participation in decisions<sup>(18)</sup>. As a result, these leaders face a significant emotional burden in their roles, given their deep connection with the healthcare organization and the management of their teams.

Regarding professional nursing practice in palliative care, the Federal Nursing Council (COFEN), in Resolution Nº. 564/2017, outlines the responsibilities of nursing professionals in its article 48: "Providing nursing care to promote quality of life for people and their families in the process of being born, living, dying, and bereavement." - Sole paragraph. "In cases of serious, incurable, and terminal illnesses with an imminent risk of death, in agreement with the multi-professional team, all available palliative care should be offered to ensure physical, psychological, social, and spiritual comfort, respecting the person's wishes or those of their legal representative."<sup>(19)</sup>.

Backed by this resolution, the nursing competencies were discussed and implemented in line with the project's objectives and recorded in the INCA/HCIV Administrative Standard for the *Day Care - Espaço CuriosAção* project. The nurses carried out all activities, from actively searching for patients and their families in the wards, during all shifts, to planning, developing, and supervising pharmacological and non-pharmacological activities, as well as documenting the dynamics of the sector. Professional



leadership has a key role, directly impacting on outcomes in the work environment and on the well-being of professionals and patients<sup>(17)</sup>.

The project included bed-to-bed visits, allowing patients in suitable clinical condition to participate in group activities designed to promote socialization, bonding, pain care in all its dimensions, and new experiences during hospitalization in a familiar environment. By establishing a relationship with patients, nurses enable the discussion of sensitive issues and understand what the best time to end discussions is. This approach highlights the compassionate and artistic aspects of nursing, which are essential for the patient and the professional practice, and reinforces the perception that they are adding something extra to the patient and family care routine<sup>(20)</sup>.

Regarding the physical space where these activities were carried out, the project was implemented in a facility with homely characteristics, including furniture and objects reminiscent of a house, ensuring that the provision of activities and care, including pharmacological and non-pharmacological measures, was carried out in a welcoming and innovative way in a hospital environment. This approach allowed the creation of a close bond between patient, family, and professionals, as well as promoting nursing care that contemplates a broader vision of the human being. It is imperative that health systems in every country incorporate comprehensive palliative care services, as their absence implies that health is not universally achieved<sup>(7)</sup>.

The reimagining of the hospital environment, exemplified by the Day Care - Espaço CuriosAção initiative, has shown the viability of establishing bonds and providing humanized, patient-centered care. Instead of a space of limitations and segregation, usually created by the division of beds, rooms, and floors, the hospital also became a place for symbolic interactions, welcoming, socializing, as well as physical and mental care between patients and nurses. This reimagined space offered nurses a leading role in the planning and execution of activities, allowing them to base their actions on the scientific knowledge of cancer palliative care, and thus achieve professional recognition in this field. This action reinforced their position of power within the unit, ensuring institutional and national recognition for qualified and humanized care in this form of assistance.

In this context, nurses have directed their practices towards pharmacological and non-pharmacological measures, with an emphasis on the holistic and humanized treatment of human beings, aligning their actions with international and national publications, as well as WHO

guidelines. Without the strategic optimization of the nursing workforce, universal and high-quality access to this care is unlikely<sup>(21)</sup>.

The nurses involved in this care use their knowledge and experience to discuss and exemplify best practices. By sharing this information and standing as references, they validate their confidence and ability to their colleagues, influencing the collective perception of quality and having a key role in team reflection and collaboration<sup>(22)</sup>.

In order to expand access to palliative care and develop projects in this field, the nursing workforce represents an essential and still underused resource that can be mobilized globally and at all stages of serious illnesses<sup>(23)</sup>. This workforce has the training, experience, and numbers to work effectively with interdisciplinary partners in health, politics, economics, and administration to collaboratively achieve universal access to care strategically<sup>(11,24)</sup>. After all, healthcare cannot exist without nurses<sup>(25)</sup>.

Regarding palliative nursing care at the HCIV, the nurses worked strategically and consciously. They are professionals qualified to manage oncological pain through pharmacological and non-pharmacological interventions, and they are closer to patients<sup>(26)</sup>. With the primary responsibility for pain management, they actively assess and intervene<sup>(27)</sup>, using both approaches in the assessment and management of pain<sup>(28)</sup>.

Cicely Saunders, who pioneered palliative care, defined the concept of Total Pain, stating that the physical component of pain can be altered by emotional, social, and spiritual factors. Physical and emotional pain leads to mood swings, loss of control over personal life, hopelessness, and the need to redefine oneself in relation to the world. Social pain comes with the fear of abandonment and isolation, loss of one's social role, communication difficulties, and economic losses. Spiritual pain is represented by hopelessness and the meaning and significance of life - it is the "pain of the soul"<sup>(29)</sup>, while social and spiritual pain contribute in a complex way to the patient's suffering. In addition to the physical pain and symptoms, there are adverse effects on mental health, including hopelessness, anxiety, anger, depression, fear, loss of control, and vulnerability.

The study participants reported using an expanded approach, based on scientific knowledge, which emphasizes the provision of nursing care focused on these aspects; promoting qualified pharmacological and non-pharmacological therapies, focused on pain relief and comfort. As defined, the absence of pain, worry, discomfort, and distress are key elements in holistic nursing care<sup>(30)</sup>.

The research results emphasize that, in addition to providing basic care, it is the role of nurses to offer personalized and special nursing care to each patient in order to increase their comfort. Meeting the comfort needs of cancer patients has a positive impact on adherence to treatment, satisfaction with the services provided, and quality of life<sup>(31,32)</sup>.

In light of the current scenario of population aging, the increase in chronic non-communicable diseases such as cancer, and the importance of palliative care, this study contributes to understanding nurses' experience in planning and implementing a pioneering palliative care project nationwide, emphasizing their protagonism and leadership, backed by robust scientific knowledge on the theme, in order to provide comprehensive, humanized, and qualified care.

This study paves the way for future research into palliative nursing care, both oncological and non-oncological, in various historical contexts. Palliative nursing care transcends oncological diagnoses, encompassing any condition that requires constant and continuous care, with an emphasis on chronic and degenerative diseases. The limitation of this study lies in the need to explore other historical sources and the possibility of expanding future studies, which could adjust this historical narrative

## CONCLUSION

This study highlighted the key role of nurses in planning and implementing the Day Care - Espaço Curioso project at the HCIV/INCA, highlighting the relevance of their professional skills in this process and consolidating their position as representatives of the authorized discourse in the field of palliative cancer care.

The unit dedicated exclusively to palliative care emerged as an important stage for the consolidation and dissemination of specialized nursing knowledge, emphasizing humanized, qualified, and holistic care. In order to align these practices with international and national scientific literature, as well as WHO guidelines, it was essential for the group to have not only specialized knowledge, but also scientific support and leadership to direct its expertise in this process. This was achieved through innovation and pioneering in the project's development.

It was concluded that the nurses assumed leadership roles, adopting effective strategies to overcome the challenges faced during the planning and launch of the project. This effort resulted in the significant consolidation of their positions within the facility, sparking an innovative transformation in line with the international standards

set by Cicely Saunders at St. Christopher's Hospice in England.

It is worth noting that the nurses' authority, strengthened by their considerable scientific knowledge, was vital in the development of the project at the healthcare unit, promoting humanized palliative cancer care in all dimensions of the human being. Therefore, the HCIV has become a valuable setting in the field of oncological palliative care for the consolidation and dissemination of specialized knowledge in terms of care, teaching, professional training, and national scientific production.

Finally, this study has the potential to disseminate knowledge on palliative cancer care, increasing nurses' awareness of their importance and responsibility as members of a multidisciplinary team. It is hoped that this work will expand their vision of humanized care, both for the patient and their family, even in the context of non-oncological diagnoses.

## REFERENCES

1. Strang P. Palliative Oncology And Palliative Care. *Mol Oncol*[Internet]. 2022[cited 2023 Nov 20];16(19):3399-409. Available from: <https://doi.org/10.1002/1878-0261.13278>
2. Derhun FM, Scolari GAS, Castro VC, Llobet MP, Salci MA, et al. A possibility for active aging: university activities for the elders. *Rev Gaúcha Enferm* [Internet]. 2022[cited 2023 Nov 20];43:e20200493. Available from: <https://doi.org/10.1590/1983-1447.2022.20200493.en>
3. Pinto KD, Souza CTV, Teixeira MLB, Gouvêa MIFS. Animal assisted intervention for oncology and palliative care patients: A systematic review. *Complement Ther Clin Pract*[Internet]. 2021[cited 2023 Nov 20];43:101347. Available from: <https://doi.org/10.1016/j.ctcp.2021.101347>
4. World Health Organization. International Agency for Research in Cancer (IARC). Estimated Number of new cases from 2020 to 2040, both sexes, age [0-85+]. Geneve: WHO; 2020 [cited 2023 nov. 21]. Available from: <https://gco.iarc.fr/tomorrow/en/dataviz/isotype>
5. Nogueira LA, Machado CAM, Marques ACB, Kalinke LP. Implications of financial toxicity in the lives of cancer patients: a reflection. *Rev Gaúcha Enferm*[Internet]. 2021[cited 2023 Nov 21];42:e20200095. Available from: <https://doi.org/10.1590/1983-1447.2021.20200095.en>
6. Clark D. Cicely Saunders: a life and legacy. Oxford: Oxford University Press; 2018.
7. World Health Organization. Global atlas of palliative care at the end of life (2<sup>nd</sup> edition). London: World Wide Palliative Care Alliance; 2020[cited 2023 Nov 22]. Available from: <https://thewhpcar.org/resources/global-atlas-of-palliative-care-2nd-ed-2020/>
8. Golmohammadi M, Ebadi A, Ashrafzadeh H, Rassouli M, Barasteh S. Factors related to advance directives completion among cancer patients: a systematic review. *BMC Palliat Care* [Internet]. 2024[cited 2023 Aug 22];23(1):3. Available from: doi: <https://doi.org/10.1186/s12904-023-01327-w>
9. Nascimento AAA, Azevedo VD de, Silva AF da, Godinho ML, Martins QCS, Santos VEP et al. Educational technologies used to teach self-management after hematopoietic stem cell transplantation: a scoping review. *Texto & Contexto Enferm* [Internet]. 2023



- [cited 2023 June 26];32:e20220170. Available from: <https://doi.org/10.1590/1980-265X-TCE-2022-0170en>
10. Mendes BV, Donato SCT, Silva TL, Penha RM, Jaman-Mewes P, Salvetti M de G. Spiritual well-being, symptoms and performance of patients under palliative care. *Rev Bras Enferm* [Internet]. 2023 [cited 2023 June 26];76(2):e20220007. Available from: <https://doi.org/10.1590/0034-7167-2022-0007>
  11. Barros JDA. A fonte histórica e seu lugar de produção. Petrópolis, RJ: Vozes; 2020.
  12. Delgado LAN, Ferreira MM. História do tempo presente. Rio de Janeiro: FGV; 2014.
  13. Carrasco JM, Inbadas H, Whitelaw A, Clark D. Early impact of the 2014 World Health Assembly Resolution Palliative Care: A Qualitative study using semi structured interviews with key experts. *J Palliat Med* [Internet]. 2021 [cited 2023 Nov 22];24(1):103-6. Available from: <https://doi.org/10.1089/jpm.2019.0384>
  14. Roth AR, Canedo AR. Introduction to hospice and palliative care. *Prim Care* [Internet]. 2019 [cited 2023 nov. 22];46(3):287-302. Available from: <https://doi.org/10.1016/j.pop.2019.04.001>
  15. Rosa WE. Integrating Palliative Care Into global health initiatives: opportunities and challenges. *J Hosp Palliat Nurs* [Internet]. 2018 [cited 2023 Nov 22];20:195-200. Available from: <https://doi.org/10.1097/njh.0000000000000415>
  16. Rosa WE, Krakauer EL, Farmer PE, Karanja V, Davis S, Crisp N, et al. The global nursing workforce: realising universal palliative care. *Lancet Glob Health* [Internet]. 2020 [cited 2023 nov. 22];8:e327-8. Available from: [https://doi.org/10.1016/s2214-109x\(19\)30554-6](https://doi.org/10.1016/s2214-109x(19)30554-6)
  17. Specchia ML, Cozzolino MR, Carini E, Di Pilla A, Galletti C, Ricciardi W, et al. Leadership styles and nurses' job satisfaction. Results of a systematic review. *Int J Environ Res Public Health* [Internet]. 2021 [cited 2023 Nov 23];18(4):1552. Available from: <https://doi.org/10.3390/ijerph18041552>
  18. Cummings GG, Lee S, Tate K, Penconek T, Micaroni SPM, Paananen T, et al. The essentials of nursing leadership: a systematic review of factors and educational interventions influencing nursing leadership. *Int J Nurs Stud* [Internet]. 2021 [cited 2023 Nov 23];115:103842. Available from: <https://doi.org/10.1016/j.ijnurstu.2020.103842>
  19. Schenker Y, Althouse AD, Rosenzweig M, White DB, Chu E, Smith KJ, et al. Effect of oncology nurse-led primary palliative care intervention on patients with advanced cancer: The CONNECT Cluster Randomized Clinical Trial. *JAMA Intern Med* [Internet]. 2021 [cited 2023 Nov 20];181(11):1451-60. Available from: <https://doi.org/10.1001/jamainternmed.2021.5185>
  20. Oliveira C, Santos LC, Andrade J, Domingos, Spiri WC. Leadership in the perspective of Family Health Strategy nurses. *Rev Gaúcha Enferm* [Internet]. 2020 [cited 2023 Nov 20];41(3):e20190106. Available from: <https://doi.org/10.1590/1983-1447.2020.20190106.en>
  21. Conselho Federal de Enfermagem (COFEN). Resolução COFEN Nº 564/2017. Aprova o novo Código de Ética dos Profissionais de Enfermagem. Brasília. Diário Oficial da União; 2017 [cited 2023 Nov 15]. Available from: <https://www.cofen.gov.br/resolucao-cofen-no-5642017/>.
  22. Mohammed S, Savage P, Kevork N, Swami N, Rodin G, Zimmermann C. "I'm going to push this door open. You Can close it": a qualitative study of the brokering work of oncology clinic nurses in introducing early palliative care. *Palliat Med* [Internet]. 2020 [cited 2023 Nov 20];34(2):209-18. Available from: <https://doi.org/10.1177/0269216319883980>
  23. Rosa WE, Campos AP, Abedini NC, Gray TF, Huijter HA, Bhadelia A, et al. Optimizing the global nursing workforce ensure universal palliative care access and alleviate serious health-related suffering worldwide. *J Pain Symptom Manage* [Internet]. 2022 [cited 2023 Nov 23];63(2):e224-36. Available from: <https://doi.org/10.1016/j.jpainsymman.2021.07.014>
  24. Johansen H, Helgesen AK. Palliative care in the community - the role of the resource nurse, a qualitative study. *BMC Palliat Care* [Internet]. 2021 [cited 2023 Nov 23];20(1):157. Available from: <https://doi.org/10.1186/s12904-021-00860-w>
  25. The Lancet. The status of nursing and midwifery in the world. *Lancet* [Internet]. 2020 [cited 2023 Nov 23];395(10231):1167. Available from: [https://doi.org/10.1016/S0140-6736\(20\)30821-7](https://doi.org/10.1016/S0140-6736(20)30821-7)
  26. Kang M, Seo M. Factors affecting nurses' performance of cancer pain management in a tertiary hospital. *J Hosp Palliat Care* [Internet]. 2022 [cited 2023 Nov 23];25(3):99-109. Available from: <https://doi.org/10.14475/jhpc.2022.25.3>
  27. Park CS, Park EJ. Identification of knowledge structure pain management nursing research applying text network analysis. *J Korean Acad Nurs* [Internet]. 2019 [cited 2023 Nov 23];49(5):538-49. Available from: <https://doi.org/10.4040/jkan.2019.49.5.538>
  28. Alsaman A, Mansour M, Almobarak F. Nurses' knowledge and attitudes regarding pain management: cross-sectional survey in the Eastern Province of Saudi Arabia. *Nurs Open* [Internet]. 2023 [cited 2023 Nov 23];10(8):5306-13. Available from: <https://doi.org/10.1002/nop2.1768>
  29. Saunders C, Sykes N. The Management of terminal malignant disease. Londres: Edward Arnold; 1993.
  30. Can A, Hintistan S. An assessment of the comfort level of cancer patients receiving Chemotherapy. *Bezmialem Science* [Internet]. 2021 [cited 2023 Nov 20];9:310-6. Available from: <https://doi.org/10.14235/bas.galenos.2020>
  31. Miao J, Liu M, Ma J, Wang H. Effectiveness of comfort nursing combined with continuous nursing on patients with colorectal cancer chemotherapy. *Evid Based Complement Alternat Med* [Internet]. 2022 [cited 2023 Nov 20];2022:9647325. Available from: <https://doi.org/10.1155/2022/9647325>
  32. Garralda E, Benítez E, Montero Á, Sánchez-Cárdenas M, Tripodoro V, Centeno C. Enhancing global development palliative care: insights from Country Experts on Atlantes Observatory's Role. *J Palliat Med* [Internet]. 2023 [cited 2023 Nov 24];26(12):1709-14. Available from: <https://doi.org/10.1089/jpm.2023.016>