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End-of-life Palliative Care: Lived Experiences and Beliefs of Healthcare Professionals with a Focused Ethnography Approach

Cuidados Paliativos al Final de la Vida: Experiencias Vividas y Creencias de los Profesionales de la Salud según la Etnografía Enfocada

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ABSTRACT

Introduction: this study explores the experiences and beliefs of healthcare professionals working in end-of-life palliative care in Catalonia, Spain. Recognizing the complex emotional, psychological, and ethical challenges they face, the research aims to deepen understanding of the facilitators and barriers within their clinical practices.

Objective: the aim of this research was to explore the lived experiences and beliefs of end-of-life palliative care professionals in a palliative care Unit in Catalunya, Spain.

Method: a qualitative approach was used, focusing on focused ethnography to capture the nuanced realities of healthcare dynamics in palliative care. Seven healthcare professionals (six nurses and one physician) from a public hospital's palliative care unit participated. Data were collected through in-depth interviews and analyzed via thematic coding to identify recurring themes and subthemes.

Results: analysis revealed two primary themes: "Beliefs associated with palliative care clinical practice" and "Lived experiences of working in palliative care." Each theme encompassed individual and interpersonal factors. Key facilitators included coping strategies and teamwork, while barriers involved emotional stress, proximity to death, and resource limitations.

Conclusion: the findings underscore the need for institutional support to address the psychological and practical challenges in palliative care. By acknowledging the multifaceted demands on these professionals, targeted interventions can enhance both professional resilience and patient care quality. Further, the study highlights the importance of comprehensive, empathetic training to improve the social visibility and understanding of the psychosocial aspects of end-of-life care.

Keywords: Terminal Care; Palliative Care; Health Personnel; Medical Ethics; Qualitative Research.

RESUMEN

Introducción: este estudio explora las experiencias y creencias de los profesionales de la salud que trabajan en cuidados paliativos al final de la vida en Cataluña, España. Reconociendo los complejos desafíos emocionales, psicológicos y éticos que enfrentan, la investigación busca profundizar en la comprensión de los facilitadores y las barreras dentro de sus prácticas clínicas.

Objetivo: el objetivo de esta investigación fue explorar las experiencias vividas y las creencias de los profesionales de los cuidados paliativos al final de la vida en una Unidad de Cuidados Paliativos en Cataluña, España.

Método: se utilizó un enfoque cualitativo, centrado en la etnografía enfocada para capturar las realidades

matizadas de las dinámicas de atención médica en cuidados paliativos. Participaron siete profesionales de la salud (seis enfermeras y un médico) de la unidad de cuidados paliativos de un hospital público. Los datos se recopilaron a través de entrevistas en profundidad y se analizaron mediante codificación temática para identificar temas y subtemas recurrentes.

Resultados: el análisis reveló dos temas principales: “Creencias asociadas a la práctica clínica de los cuidados paliativos” y “Experiencias vividas al trabajar en cuidados paliativos.” Cada tema abarcó factores individuales e interpersonales. Los principales facilitadores incluyeron estrategias de afrontamiento y trabajo en equipo, mientras que las barreras involucraron estrés emocional, cercanía a la muerte y limitaciones de recursos.

Conclusión: los hallazgos subrayan la necesidad de apoyo institucional para abordar los desafíos psicológicos y prácticos en los cuidados paliativos. Al reconocer las demandas multifacéticas sobre estos profesionales, las intervenciones específicas pueden mejorar tanto la resiliencia profesional como la calidad de la atención al paciente. Además, el estudio destaca la importancia de una formación integral y empática para mejorar la visibilidad social y la comprensión de los aspectos psicosociales de los cuidados al final de la vida.

Palabras clave: Cuidado Terminal; Cuidados Paliativos; Personal de Salud; Ética Médica; Investigación Cualitativa.

INTRODUCTION

End-of-life care requires professionals to address psychological, social, spiritual, and physical needs, with the meaningfulness of their work mitigating stress and enhancing vitality, personal growth, and job satisfaction.⁽¹⁾

In Catalunya, 60 % of oncologic and 30 % of non-oncologic diseases required palliative care support, with 60 % of 2019 deaths potentially needing specialized care. Among a population of 7,57 million, approximately 113 557 individuals had palliative needs (NECPAL+), including 15 141 terminally ill patients with a prognosis of under six months.⁽²⁾

Healthcare professionals often consider the complexity of the patient’s clinical condition for decision-making. Currently, palliative care training consistently includes competencies that enable such an approach.⁽³⁾

Healthcare professionals’ beliefs about dignity and care often emphasize preserving patients’ self-management and autonomy. While palliative care does not focus on curing diseases, it aims to alleviate suffering for both patients and their families. This includes addressing physical symptoms as well as emotional and spiritual needs, underscoring the importance of interprofessional collaboration and teamwork. Additionally, avoiding futile treatments and examinations is crucial to minimizing unnecessary suffering at the end of life.⁽⁵⁾

Research highlights that palliative care providers encounter diverse lived experiences in their practice. Bennardi et al. (2020) identified key barriers and facilitators, including awareness of palliative care, collaboration and communication among professionals, and attitudes and beliefs toward palliative care.⁽⁶⁾ Honest dialogue and attentive communication are reported as critical facilitators, enabling patient participation and aligning care trajectories with their preferences. Furthermore, openness to discussing death and alternative treatments fosters effective care planning, coordination, and informed decision-making regarding treatment options.⁽⁷⁾

Nevertheless, little is known about Catalunya-based professionals’ lived experiences and beliefs including specific individual, interpersonal and contextual factors. Based on the regional PC epidemiological data, Catalunya conveys a relevant context for this study, where evidence-based actions in the palliative care context are much needed.

METHOD

Study Design

This study employed a qualitative research approach, adhering to rigorous criteria of subjectivity, reflexivity, and social validity to ensure trustworthiness.⁽⁸⁾ Focused ethnography methods were used to analyze data,⁽⁹⁾ enabling an in-depth understanding of healthcare dynamics, including individual and group behaviors, care roles, and the psychosocial impacts of illness.⁽¹⁰⁾

Participants

A purposive sample of seven healthcare professionals (six female nurses and one male physician) holding diverse clinical practices within palliative care were included in this study. Participants were recruited from a Catalunya-based public health hospital with a palliative care unit. Their ages ranged from 27 to 62 years ($M = 47,7$; $SD = 10,1$); formal education ranged from 16 to 20 years ($M = 16,8$; $SD = 7,3$). All of them were bilingual in Catalan and Spanish and had been active in their current position for at least six years at the time of data collection. Time elapsed since they began working in healthcare ranged from 6 to 27 years ($Median = 15$; $SD = 1,5$).

Data analysis

The data analysis was conducted with the lead of one researcher, with a transcript. The other investigators cross-checked this work, making any needed changes and personal observations. Grounded theory methods were used for thematic analysis.^(11,12)

Open coding was used to conduct the analyses for each sentence. This enabled the development of codes aimed at covering the data thoroughly. The emerging codes were in vivo and included verbatim quotes from the participants.

Ethics Approval

The research project received the approval of the research ethics committee of the Faculty's Ethics Advisory Committee. Catholic University of Uruguay. According to Opinion No CAEFETS03/23.

RESULTS

Thematic analysis resulted in two emergent themes: Beliefs associated with palliative care clinical practice and Lived experiences of working in palliative care: perceived barriers and facilitators. These themes are composed by the following subthemes: Individual factors, Interpersonal factors, and Contextual factors (table1) with their associated codes.

Table 1. Themes & Subthemes

Beliefs associated with palliative care clinical practice		Lived experiences of working in palliative care: perceived barriers and facilitators	
Individual factors	Facilitators & Barriers - Beliefs regarding career-related decision. - Beliefs regarding adaptation process of care at the end-of-life. Barriers - Beliefs regarding risk factors of work in palliative care at the end-of-life. Facilitators - Beliefs associated with protective and valuable factors of work in palliative care at the end-of-life. - Beliefs regarding core competencies and skills required for working on palliative care at the end-of-life.	Individual factors	Facilitators - Coping strategies. - Strategies aimed at balancing emotional distance. - Health professionals' lived experiences regarding specific training on palliative care at end-of-life stage. Facilitators & Barriers - Professionals' experiences regarding activities undertaken within the palliative care unit. - Dying peacefully and a good death: perceived associated factors.
Interpersonal Factors	Facilitators - Beliefs regarding human dignity and autonomy. - Beliefs regarding ethical, empathic approach and respect. - Beliefs on key aspects of communication and communication and interaction with patients and their families.	Interpersonal Factors	Facilitators - Multidisciplinary and interdisciplinary approach. - Spiritual experiences in palliative care. Facilitators & Barriers - Coping and lived experiences associated with the proximity of death. - Experiencing and managing pain and suffering.

Beliefs associated with palliative care clinical practice

Individual factors

This subtheme embodies healthcare professionals' individual aspects, as they articulate both in the process and the outcomes. It is composed by the following categories:

Beliefs regarding career-related decision

Including intrinsic motivation; joy of caring for and helping others and assisting patients at end-of-life. Furthermore, healthcare professionals' family systems providing support emerged as psychological protective factors in this sample.

Beliefs regarding adaptation process of care at the end-of-life

Beliefs regarding adaptation process to care while working in end-of-life palliative care context, appeared to be related to high levels of psychological challenge. Participants believed they needed to adapt to a job that

is difficult, as it is being able to be of help.

Beliefs regarding risk factors of work in palliative care at the end-of-life

Work-related tiredness and chronic distress, as well as emotions associated with their work's psychological impact emerged as psychological risk factors.

Beliefs associated with protective and valuable factors of work in palliative care at the end-of-life

Beliefs associated with protective and valuable factors of work in palliative care involve prioritizing and appreciating the process and shared objective, which is greater than the individual one.

Beliefs regarding core competencies and skills required for working on palliative care at the end-of-life

Participant's perceptions indicate personal and professional experience as being key aspects that contribute to building resources, spiritual, moral or ethical education towards coping with end-of-life situations. Core competencies in palliative care convey holistic care, including comfort, medication and techniques, active listening skills and the ability to provide suffering patients and their families with sustained social and emotional support.

"I consider continuing education to be relevant and necessary, yet I believe one's attitudes, disposition, job-related lived experiences to be especially important...emotional support is provided to the patient and their family, utilizing a set of available resources, identifying problems, promoting continuing education, teamwork, including psychology and social work." [E1]

Interpersonal factors

This theme embodies healthcare professionals' interpersonal aspects and is composed of the following subthemes: Human dignity and autonomy; Ethical, empathic approach and respect; and Communication and interaction with patients and their families.

Beliefs regarding human dignity and autonomy

According to participants' narratives, the time a patient's family member dedicates to nursing has a positive impact on their competencies as caregivers and the quality of their care. Counting on a professional nurse and a main family member carer is positively evaluated.

Beliefs regarding ethical, empathic approach and respect

Participants' perceptions regarding the ethical and respectful approach is linked to emotional support and facilitating communication with the patients and their families. Dedicating time, facilitating the opportunity to vent emotions.

Beliefs on key aspects of communication and communication and interaction with patients and their families

A team-based approach through open information and communication starting at the diagnosis stage, enables the patient and their family to adapt while the processes unfold, even when these are highly dynamic.

"Tact is very important, I believe, and the gaze, the smile... is the key that opens everything. The person may have cognitive deterioration and still if you smile at them and meet their gaze, something comes out of there." [E7]

Lived experiences of working in palliative care: perceived barriers and facilitators

This theme conveys lived experiences of working in palliative care: perceived barriers and facilitators, and is composed by individual, interpersonal and contextual factors and the categories that emerged from them.

Individual factors

Coping strategies

Among facilitators of lived experiences in palliative care, professionals pointed out solution-focused strategies (i.e.: internal locus of control and problem-solving coping strategies) (e.g.: teaching nursing techniques); and emotion focused strategies (e.g.: using humor as a coping strategy).

Strategies aimed at balancing emotional distance

The strategies that professionals put in place to balance emotional distance acted as facilitators for sample participants.

Professionals' experiences regarding activities undertaken within the palliative care unit

Among factors that influence both the job's dynamics and experience, participants reported on activities that facilitate or hinder actions within the unit. As a facilitator, they describe their job as an autonomous, patient centered one that is plastic regarding timing and planning. Internal locus of control regarding actions aimed at building a trust-based relationship (i.e., enabling the patient to vent emotions), as well as towards enhancing patients' quality of life were also reported by participants as facilitators. Among barriers, feeling sad for considering they have not attained the best care they possibly could provide by their standards and criteria, while they could have done better, emerged as noteworthy.

Interpersonal factors

Coping and lived experiences associated to the proximity of death

Shared work among team members leads to the identification of potentially shocking situations, and decisions are made to buffer and prevent the emotional impact associated with dealing with death. The healthcare team addresses the patients and their families through competencies that enable a comprehensive approach. These resources are made visible both on their technical competencies and through psychosocial skills such as empathy.

Multidisciplinary and interdisciplinary approach

The mastery of the competencies necessary for care during the process of dying, which are related with skills and training of different professionals, is reported by participants. The latter facilitates the understanding of diverse situations from different professional perspectives and points of view, which enables shared decision making.

"...that all the physical symptoms are compensated, controlled, that the patient does not experience extreme pain or suffocation, that he/she does not die with anguish. We have sufficient resources to be able to palliate, so we do it. We always do it through dialogue and direct participation, if the patient is capable, with the patient, following his indications, working on it beforehand." [E1]

Experiencing and managing pain and suffering

The participants report on their lived experiences with the patients' suffering. Death in solitude emerged as a negative indicator, which they manage by accompanying patients during the dying process.

"Total pain experience goes beyond the physical injury in an organ or tissue, no, no...it is more than that. Pain is also spiritual, psychological, emotional...Suffering is similar, I guess there is some connotation. Yes...when there is intense and total pain...there is suffering." [E7]

Spiritual experiences in palliative care

Spiritual accompaniment of the ill persons is reported as part of the nursing approach. The acceptance and understanding of the different lived experiences of individuals and families emerged as a relevant dispositional and purpose-related aspect. Serenity and acceptance of death was associated by study participants with patients perceiving external locus of control, as well as with that what had to be done, was done in the best possible way.

"Some individuals who are believers find benefits within the religious experience, or simply by thinking that they have gone through life and have done the best they could in the best possible way, that they have lived. They keep in mind their whole life story and the fact that that is as far as they have come and does not depend on them, and there is a certain sense of serenity and acceptance in that moment." [E2]

DISCUSSION

Beliefs associated with palliative care clinical practice

The present theme captures attitudes, beliefs, and expectations of healthcare professionals regarding palliative care clinical practice. Furthermore, it includes the participant's motivations for nursing chronically ill patients in advanced stages of the disease, organized into individual factors and interpersonal factors.

The study findings suggest that patients' need for care and wellbeing appeal to the palliative care staff both as healthcare professionals and as human beings when caring for patients and their families at the end-of-life. The latter motivates them to struggle to relieve and accompany suffering and enables them to understand that they can make a difference. Furthermore, experiencing the care of patients at the end-of-life as a meaningful calling and decision, and not just a mere job, and provides personal satisfaction.⁽¹³⁾

The perception of palliative care as a demanding, psychologically challenging career path emerges as

a psychological risk factor. Support networks between professionals emerged as a valuable resource. Self-care programs led by health professionals would grant participants the opportunity to evaluate their own professional expertise and experiential knowledge to form a broader understanding of their situation and educational needs.⁽¹⁴⁾

According to evidence, the coping process seems to be linked to the development of professional careers in palliative care. Research reports on stressors such as the difficulty of letting go of the emotional burden of working with dying patients and the emergence of emotions. These risk factors include fear of uncertainty and projection of one's own death. Sapeta et al. (2022) found frequent exposure to death, lack of time, and communication difficulties as negative factors.⁽¹³⁾ The lack of personnel constitutes a substantial problem that results in a heavy workload.⁽¹⁵⁾

The shared goal of engagement and willingness to help among participants emerges as an aspect that contributes to building shared meaning. Palliative care professionals are inclined to visualize their professional activity as a challenge and a path towards personal growth.⁽¹⁾

Promoting the patient's autonomy within a palliative care unit may be a misguided intention, since the loss of autonomy could be the main problem itself. In this sense, it is appropriate to propose a substitute-help relationship.⁽¹⁶⁾ Nevertheless, professional's views regarding dignity included aspects like autonomy and self-management. Health professionals also consider that the preservation of dignity at end-of-life includes the care provided by the family members.

The ability to prioritize the nature of care according to the needs of the ill person is considered an ethical and respectful approach by health professionals. Addressing the latter, a recent study highlights the relevance of compassionate, supportive, kind, respectful, committed and competent professionals' care.⁽¹⁷⁾ Moreover, the importance of teaching active and empathic listening skills to ensure good care has been reported by hospice and palliative care volunteers.⁽¹⁸⁾

Among coping strategies, professionals describe solution-focused practices that make palliative care processes more flexible: symptom control, communication and adaptation of resources to the dynamics and requirements of the situation, including contextualized and timely entertainment / use of humor. Using humor as a coping strategy among palliative care professionals has been previously studied. Positive attitudes toward humor seem to alleviate the distress associated with end-of-life care.^(19,20) Furthermore, using humor as a coping mechanism has been associated with lower levels of distress and enhanced cheerfulness among palliative care professionals.⁽²⁰⁾ Research suggests that humor may play an important role in promoting wellbeing and preventing burnout and emotional exhaustion.⁽²¹⁾

Professionals describe their perceived difficulty with distancing themselves from the suffering. However, being more experienced and the possibility of venting emotions within the team facilitate coping. One way of coping and continuing to contribute as professionals is to be aware of one's emotions, spending time with friends, family and colleagues.⁽²²⁾ Furthermore, interventions aimed at enhancing stress management skills through training in adaptive coping strategies have also been found to reduce the risk of burnout among health professionals, hence contributing to developing resources towards balancing emotional distance.⁽²³⁾

Teamwork buffers the impact of complex situations related to coping with death. According to Hui et al. the interprofessional approach is especially suitable for addressing end-of-life care needs and reducing burnout.⁽²⁴⁾

Interprofessional approach with patients and families is grounded in the prior work, when possible, of considering their care preferences. Medical, nursing, psychological, social and occupational work, physical therapy, faith ministers, and other healthcare professionals bring their unique expertise to the care of people at the end-of-life. They collaborate cohesively towards palliative care goals in multidimensional interventions.⁽²⁵⁾

Spiritual experiences in palliative care

Accompanying the different human dimensions is the goal of nursing care. The final stage of life in people who in some ways have cultivated their spirituality is a serene one, both for professionals and for family members. The practice of religion may be a necessity at the end-of-life. This approach is consistent with the roles of the palliative care team members and is part of addressing multidimensional supportive care needs.⁽²⁵⁾ However, there are barriers for physicians to involve a spiritual caregiver.⁽²⁶⁾

CONCLUSION

This study provides invaluable insights into the critical role emotional intelligence (EI) plays in the adaptive coping strategies employed by nurses in intensive care units (ICUs). The findings underscore that EI is not only integral to managing stress but also to fostering resilience in the face of high-pressure environments where end-of-life care and decision-making often converge. The dual nature of stress as both a motivator and a challenge emerge prominently in the narratives of ICU nurses, highlighting the importance of targeted emotional and psychological support.

The evidence suggests that humor, as a coping mechanism, offers a dual benefit: it alleviates emotional

burden while strengthening interpersonal bonds within the healthcare team. Furthermore, EI facilitates a deeper connection with patients and families, enabling nurses to balance technical proficiency with empathic care. This balance is particularly vital in palliative contexts, where the emotional demands are heightened by the proximity to death and the complexity of ethical decision-making.

Institutional frameworks need to prioritize the integration of emotional intelligence training into nursing education and professional development programs. Additionally, fostering team-based support systems and regular debriefing sessions can mitigate burnout and enhance job satisfaction. By addressing these dimensions, healthcare organizations can empower nurses to sustain high standards of patient-centered care while preserving their well-being.

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