

Palliative Care and Nursing: A Look Inside

Cuidados paliativos y enfermería:
una mirada hacia dentro

Cuidados paliativos e enfermagem:
um olhar para dentro

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According to the World Health Organization (WHO) (1)

[...] Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

In 2018, the International Association for Hospice and Palliative Care put forward a consensus-based definition of palliative care (PC) “palliative care is the active, holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. Its aims to improve the quality of life of patients, their families, and their caregivers” (2).

When it comes to PC, it is necessary to go back to the hospice movement in the 1970s, led by Cicely Saunders, a British professional who established the basic principles of what we know today as PC. Thanks to her vision as a nurse and training as a doctor and social worker, she was able to promote this movement (3).

From its origins, Saunders (4) emphasized the importance of eliminating terminal agitation and the fear of suffering from it by combining sound science and personal attention to detail. For her, the unit to be treated is the whole family—patient and caregiver-family—. She recommends sharing as much truth about the situation as possible, recognizes the importance of teamwork, and discloses her own experiences of loss and change. The PC approach is multi-professional and interdisciplinary in caring for people diagnosed with an advanced, incurable, progressive disease or in the end-of-life stage.

The main characteristic of PC is the comprehensive care provided, considering the physical, emotional, social, and spiritual aspects; that is, holistic, personalized, and continuous care. On the one hand, the patient’s autonomy and dignity are guiding factors in making therapeutic decisions in an environment of respect, comfort, support, and adequate communication. On the other hand, the family is considered the primary support nucleus for the patient, fundamentally during home care and assistance, for which they require guidance, help, and learning (5).

The PC nurse bases her care on compassion, concern, affection, commitment, sensitive response, active listening, therapeutic communication, the helping relationship, and the humanization of care. This care “is not directly observable and often not even perceived by the patient or family,” according to Collière (6) and Alberdi (7), and neither by the rest of the team’s professionals. This invisible dimension of care shapes the essence of PC assistance (8).

PC is becoming increasingly important in health systems. Therefore, there are international references and recommendations from the WHO/PAHO, strategies, a documented and argued knowledge field, and trained professionals. However, the public and professional debate have reached a consensus on the need to increase the training of professionals and extend the creation of specialized

units, support teams, home care programs, and, above all, regional and local programs that favor uniform and coordinated development and eliminate existing territorial inequalities. So, what is necessary to respond to this demand? What is our role as nurses?

The current scenario in which PC takes place encounters a misalignment in specific nursing training, and a lack of curricula and graduate training is evident. Although the bill “whereby palliative care education is consolidated” is in the approval process, a significant achievement, rigid and aligned work is required (9).

Training is needed that covers the wide range of knowledge and skills necessary for nurses to deal with the care situations of these patients. Knowing and conducting advance care planning (ACP) from individuality, continuity, flexibility, accessibility, polyvalence, and a multidisciplinary approach becomes a mainstay of this care (8,10).

Professional practice in PC must be considered in the framework of a conceptual model, the application of the scientific method, and the development of care plans under critical thinking, clinical judgment, decision-making, and problem-solving. At the same time, it is necessary to advance in reflective practices based on the best available scientific evidence that enables nurses to provide the best possible care to patients and their families.

Therefore, upon graduation, the challenge first is that professionals must have the training to carry out their care activity with patients with chronic, degenerative, advanced, or end-of-life diseases and their families. Study plans must integrate basic PC knowledge, skills, and abilities.

Secondly, continuous training must be guaranteed at those care levels in which these patients and their families are treated, which caters to professionals’ need to refresh their knowledge of specific topics.

Finally, the next level should be specific PC training for professionals who tend to reach an advanced graduate level. Currently, the offer of multidisciplinary and specific PC programs that nurses can access in the country is still insufficient. Thus, efforts must continue to encourage advanced training, recognition in the labor field, and the commitment of universities and health institutions to supporting this purpose.

The professional role within the care team should be clarified. Nursing skills in PC must be defined to provide advanced quality practice that ensures excellence in the care provided to patients and their families and defines the scope of action. Identifying skills will directly affect care and show the need for training, management, and research.

In conclusion, there is awareness of the care gap that can occur when the patient needs PC, particularly when they reach an advanced or end-of-life stage. Patients in this situation only have one

chance to die with dignity and for their families to be with them. It is an obligation, a responsibility, and a continuous challenge to assure patients that the best professionals will treat them. This is a great task; fortunately, more individuals are interested in broadening their PC knowledge, and more initiatives are being undertaken to contribute to this end.

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