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EDITORIAL

Evolution of end-of-life care from the nursing perspective: training, research and professional commitment*

Evolución de los cuidados al final de la vida desde la perspectiva enfermera: formación, investigación y compromiso profesional

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There is no need to say that we all die, and talking about end-of-life care is neither new nor a novelty, although the recent pandemic has helped to raise its profile.

Patient end-of-life care and attention has been growing in importance for the last thirty years, since the 1990s. In fact, the journal *Enfermería Clínica* published two papers on the training that is necessary to help dying with dignity,[1] as well as to supply a guide on gaining the curriculum that covers appropriate death.[2] Times and nursing skills have progressed thanks to the formation of the European Higher Education Area (EHEA) and greater access to graduate nurse Master's Degree and Doctorate programmes. This has led to an exponential in the training given in Spanish universities,[3] strengthening the skills that nurses have to acquire to be able to offer quality care to their patients. This is not restricted to general care, as it also applies to care at the end of life.

Caring is above all an act in life that, as Collière[4] says, takes place ''within the context of the process of life and death that people and human groups (definitively, individuals) face every day in the development of their existence''. It relieves suffering and applies technical scientific advances supplied by professionals to accompany and attend individuals and their needs, in a specific context so that they are able to live their lives as ''present'' in their individuality, with dignity, free of pain and suffering in an optimum environment, placing them at the centre of their lives and at the end of the same.

In the last 20 years Spanish nursing has not only made progress at an academic level, as it has also undergone legal improvements in terms of how services are supplied in the National Health System, and most particularly in end-of-life care. The following documents stand out within this new legal and organizational framework:

- The National Plan for Palliative Care. Bases for its development in 2001.[5]
- Law 41/2002, of 14 November, the basic law regulating Patient Autonomy and Rights and Obligations in the field of clinical Information and Documentation.[6]
- Law 16/2003, of 28 May, on the Cohesion and Quality of the National Health System.[7]

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- Royal Decree 1030/2006, of 15 September, which establishes the portfolio of services of the National Health System and the procedure for updating the same.[8]
- Palliative Care Strategy of the National Health System, 2007.[9]
- Royal Decree 124/2007, of 2 February, which regulates the National Registry of Living Wills and the corresponding automated personal data file.[10]
- The Palliative Care strategy of the National Health System, 2010–2014 update.[11]
- Strategy for Managing Chronic Disease in the National Health System, *Sanidad 2012. Ministerio de Sanidad, Servicios Sociales e Igualdad.*[12]
- National Health System Cancer Strategy. Update approved by the Interterritorial Council of the National Health System, January 2021.[13]
- Organic Law 3/2021, of 24 March, which regulates euthanasia.[14]

This new reality, the progress in training, knowledge, research and the commitment of nurses to patient centred end-of-life care, leads us to question the care we now supply and should supply throughout life, the need to affirm others' lives, the suitability of care and respect for other people's decisions.

Nurses reflect as necessary on caring for people whose horizon is the search for a cure for their disease, maintaining their quality of life in the face of a progressing and incurable illness, which we usually describe as palliative care, or the possibility of a longed-for death when the criteria for euthanasia are met. In this context, and considering that euthanasia has now been legal for two years, although it is too soon for a full evaluation, the training of medical staff in this field could be reviewed. This is necessary to understand the reasons for their reluctance, and the points in favour of the law and against it could be debated and assessed, while we could also make progress in ensuring that it is applied in a uniform way throughout national territory, given that it is still applied differently in some autonomous communities. This would definitively ensure that healthcare professionals and users start to consider euthanasia as just one more option at the end of life.

Nurses are increasingly on the side of the most vulnerable people, those who suffer and die. Nurses fulfil the function of caring and witnessing other people's pain, being the voice of those who have no voice. Due to their skills and dedication, nurses are therefore said to be team leaders in the search for the necessary agreement within the same and with other healthcare teams, based on respect, protocol-governed care and rational decision-making. This route would benefit real interdisciplinary working, improving the lot of individuals and those close to them. It would guide us towards a shared framework that centres on the care we give, ethical aspects, working dynamics, emotional support, and the control of pain and symptoms as areas that are no less important in end-of-life care. The work by AECPAL (the Palliative Care Nursing Association) stands out here, as it defends the specific training of nurses in end-of-life care.

Similarly, the nurses Ruland and Moore[15] offer their mid-level ''theory of the peaceful end of life'', a simple and useful framework by which to understand and accompany those who are dying. The aim of care at the end of a life is not to optimize it by offering the best or most technologically advanced treatment, or any type of care that involves over-treatment, but rather to offer the best possible care involving a wise use of technology and measures which add to wellbeing, to increase quality of life and achieve a peaceful death. This theory sets certain specific limits in terms of time, the surroundings and the population of patients, and it was developed for use with adults in a terminal situation and their families, who are attended in an acute patient context. Although the concept of a peaceful end of life originated in a Norwegian context and may be questioned in other cultures, it has been used in practice and in research by nursing professionals in other contexts. The concepts and relationships involved find a response in many nurses, and it covers the many dimensions of end-of-life care exhaustively. The assessment criteria are associated with the five concepts that cover the technical aspect of care:

1 Use pharmacological and non-pharmacological interventions to relieve symptoms.
2 Communication for decision-making.
3 The psychological aspect for emotional support.
4 Dignity.
5 Respect the patient, treating them with dignity, empathy and respect.

On the other hand, good practice guides for end-of-life care have proliferated, seeking to transform care and broaden nurses' knowledge. Some of these guides are based on the results of multidisciplinary research. An example is the one issued by the Registered Nurses Association of Ontario (RNAO)[16] which uses the GRADE method (*Grading of Recommendations Assessment, Development, ad Evaluation*) and the CERQual method (*Confidence in the Evidence from Reviews of Qualitative Research*).

Of the new challenges in end-of-life care, advances in the law over the past decade have affected paediatric care. These advances have been recognised as rights by the WHO, UNESCO and the Council of Europe, and they should be taken into account to ensure a correct approach.

The immediate future will involve progressing in improving end-of-life care through education and the support of healthcare professionals, care-givers and those who are closest to the patients. Although this task is not free of problems, it is gratifying, and the aim is to strengthen the nurses who work of bring quality to the lives of the individuals they care for.

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