WHAT DO NURSES DO FOR PATIENTS IN THE LAST DAYS OF LIFE?

KAJ DELEJO MEDICINSKE SESTRE PRI BOLNIKIH V ZADNJIH DNEH ŽIVLJENJA?

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ABSTRACT

Key words: nurses, palliative care, end-of-life
The article looks at the role of nursing in palliative care, which historically has been a central one. However, there are many elements of nursing care in the last days of patients’ life which are understudied. The starting point of the authors is therefore to present attempts to understand the complexities of end-of-life care. One of them is the OPCARE9 EU FP7 project, uniting researchers and clinicians from nine countries in Europe and beyond, and aimed at looking into what is going on in the last days of life of patients with cancer. The project joins expertise of nurses, physicians, sociologists and psychologists. One part of it is also looking into alleviating suffering by non-pharmacological interventions and the role of nurses.

IZVLEČEK

Ključne besede: medicinske sestre, paliativna oskrba, konec življenja

Introduction

Increasingly people are living longer and have a range of chronic and complex illnesses that are life limiting. At the end of life, a palliative approach has much to offer to dying people and their families. Nurses are the health care professionals most often providing care to them. Dying persons and their families have individual cultural beliefs and values, so culturally sensitive and holistic care that respects existential and religious beliefs is essential. A caring and supportive environment that acknowledges the inevitability of death and helps family members to accept and deal with loss and grieving is essential to good care. Advances in life-sustaining procedures and changes in societal values about quality of life have raised ethical
dilemmas in nursing. Many issues, such as withholding or withdrawing treatment, patient directives and choices or “living wills” and concerns for quality of life are important. The quality of care during the end stage of life greatly contributes to peaceful and dignified death and provides support to family members in dealing with their loss and grieving process (ICN, 2006).

Nurses should be prepared to offer compassionate and skilled care for dying patients and their families. The International Council of Nurses (ICN, 2006) views the nurse’s role as fundamental to a palliative approach that aims to reduce suffering and improve the quality of life for dying patients and their families through early assessment, identification and management of pain and physical, social, psychological, spiritual and cultural needs.

Nurses’ role in palliative care - overview of literature

Studies of nurses’ work with dying patients reveal that to a great part it is related to coordinating and collaborating on patient care plans, sharing, consulting and facilitating the work of other health care professionals/agencies, as well as negotiating the system on behalf of the patients and family. Another important part of nurses' work is responding to patients and families in crisis, being there, sitting with, listening to, fostering reconciliation, sharing the moment and secrets, and sharing nearing death mystical experiences. Nurses' work involves controlling pain and symptoms, teaching, helping and guiding patients and families in preparing for death, and letting go of the attachment to life as it has been. For an overview of these studies see (Rasmussen, Sandman 2000).

When comparing the work of hospice and oncological nurses (Rasmussen, Sandman 2000), it was found that nurses' direct care activities in a hospice as well as in an oncological unit were determined by institutional routines. This is not to say that nurses did not try to attend to patients' individual needs, rather that there were certain periods corresponding to shift exchanges, staff meetings, morning and evening care and meals that structured nurses involvement in direct care. Direct care activities consumed 37% of nurses' work at the hospice whereas it was much lower (21%) at the oncological unit.

Though nurses’ involvement in emotional labor is shown to be greatly influenced by organizational structures and encouragement by head nurses, it is also influenced by societal values. Studies reveal that both nurses (Rasmussen, Sandman and Norberg 1997) and patients (Milburn et al. 1995) describe emotional labor or caring as doing the 'little things'. Researchers have interpreted the expression “little things” as being associated with the stereotyping of care as women's natural work, which keeps it invisible, undervalued and not recognized as hard work requiring formally taught skills (Smith 1992; James 1992). Moreover, doing the 'little things', or nurses' emotional labor in in-patient settings, is tightly bound up with physical labor such as serving the patients' favorite hot drink (Rasmussen, Sandman and Norberg 1997), and manicuring their nails (Smith 1992). Thus it may be arbitrary to divide nurses' work into emotional and physical labor. Nonetheless, it must be of interest for nursing practice and education to gain a deeper understanding of the similarities and differences of the skills encompassed by nurses' emotional labor when carried out on its own and when integrated with physical labor.

Thus understanding the portion of nurses' work that is spent in direct care and emotional labor is a complex exercise, and is influenced among other aspects by societal values, organizational structures, the unit's climate, goals and philosophy, the nurses' skills, education, dedication and patients' and families' needs and the length of stay.

The actual role and work of nurses when caring for the dying patients and their families may differ depending upon whether they have a supportive and coordinative function, as in a hospice home care setting, or are engaged in the day to day practical tasks of nursing care in
an inpatient hospice or acute care setting. It seems that at busy times, physical care takes priority over emotional care or caring behaviors, and that, under these circumstances, the nurses accept a common-sense understanding of 'work' as 'doing something', i.e., providing physical care. Other studies show that nurses routinize or hurry through their physical care which can, either in itself or through sheer demand, interfere with the nurses' emotional care. Still today, most nursing care interventions related to dying patients and their families are based on experience-based practice and to a minor extent upon evidence-based practice, a fact the European project “Optimal Palliative Care at the End of Life (OPCARE 9) is going to address.

**How to look systematically at what is going on in the last days of patients’ life?**

OPCARE 9 is a project that has been developed by 9 participant institutions in Europe and beyond, entitled “A European collaboration to optimize research and clinical care for cancer patients in the last days of life”. It is coordinated from the University of Liverpool, Marie Curie Palliative Care Institute and includes UK, Germany, The Netherlands, Italy, Sweden, Slovenia, Switzerland, Argentina and New Zealand.

Its aims are to optimise research and clinical care for cancer patients in the last days of life, where to optimise means to ‘make the most of’ existing knowledge and not undertake research. Last days of life is a very specific focus similar to that of the Liverpool Care Pathway for the Dying Patient (LCP).

Due to ethical, moral, practical difficulties of undertaking research in palliative care, an impoverished evidence base knowledge is available to solve dilemmas that palliative care experts face when helping their patients. An even greater challenge is to find knowledge about care in the last days of life. In addition, it is important to develop a more ‘global’ understanding about the best practice and not ‘reinventing the wheel’ in each country.

The project group has been performing a systematic review of the published and unpublished research of care in the last days of life, a Delphi method to explore ‘expert’ opinion regarding best practice in the last days of life and is having regular meetings to share, debate and gain consensus regarding emergent findings.

Primary expected outcomes are to review existing knowledge on signs and symptoms of approaching death, end-of-life decisions, complementary comfort care, psychological and psychosocial support for patients, relatives and caretakers and voluntary service.

So, at the end of the project we will have a comprehensive and systematically evaluated ‘state of the art’ on care in the last days of life, an outline of research protocols, a list of evaluated ‘technologies’ to provide practitioners with an up-to-date resource to underpin the delivery of care and/or the assessment of the quality of care, a list of evaluated European Quality Indicators against which to measure future care in the last days of life in each of the work packages, and recommendations for the further development of the LCP framework.

This will be of interest for patients and carers, clinicians, nurses, allied health professionals, health care organisations delivering and commissioning care in the last days of life, providers of education and training, researchers, national/international policy makers, European governments and European Commission.

The authors Pahor and Rasmussen are involved in the project related to complementary comfort care, especially by focusing upon non-pharmacological care-giving activities in the last days of life. Currently we are collecting non-pharmacological care-giving activities from all 9 participating countries, including Slovenia and Sweden and so far we have received information about 1000 care-giving activities. Some of them will be presented at the congress and discussed upon in the light of different cultural context.
Conclusion

Although the central role of nurses in the end-of-life care has been acknowledged and studied, there is still a lot that we don’t know about the layers of seemingly “simple” activities and their consequences in alleviating suffering and increasing comfort of dying patients.

References