

Palliative nursing care in Spain

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This paper describes the practice of palliative nursing care in Spain. The management of palliative hospital and home care is presented. Nursing roles in the multidimensional aspects (physical, psychological, social, cultural and spiritual) of patient and family care are provided. Nursing participation in informing and counselling patients is evaluated, together with nursing cooperation in multidisciplinary work. Finally, this paper states the current lack of nursing education in palliative care and the recommendations for integrating palliative care into the nursing curriculum.

Keywords: palliative care, nursing care, Spain.

INTRODUCTION

The art and science of palliative care consists of living with hope and dying with dignity. Palliative care has been defined as an active treatment programme that has the purpose of maintaining or improving the life conditions of patients with incurable illnesses in the terminal phase of the disease (Astudillo *et al.* 1997). In general, the definitions of palliative care address multidimensional aspects (interpersonal, physical, psychological, social and spiritual) of patients and their families (Pickett *et al.* 1998). The primary objective of palliative care is to enhance the quality and the meaning of life and death (Zalot 1989). Palliative care offers many possibilities for the patients to reach a good control of the distressing symptoms and to support their families.

Patients in terminal phase are those who have been diagnosed with a progressive and incurable disease, with multiple complications, and who are likely to die in a period of time <6 months (Sociedad Española de Cuidados Paliativos 1993). Among the individuals assisted with palliative care are patients with cancer (the most prevalent), acquired immune deficiency syndrome (AIDS),

Alzheimer's syndrome, multiple sclerosis, cerebrovascular diseases, Parkinson's disease, irreversible coma, chronic obstructive pulmonary disease (COPD), renal or cardiac chronic insufficiency, and dementia.

Approximately one-third of the people in developed countries will pass through a long-term care facility before they die, and many who require palliative care will reside there during the final weeks or months of their lives. Spain is not an exception. In recent years, our country has developed new palliative care services with a multidisciplinary approach. Nursing has been involved in this process by providing supportive physical and psychotherapeutic measures that help to minimize distress, enhance feelings of control and improve quality of life.

Spain has a Social Health Care System which provides universal health care coverage. Palliative care is practised by Public Health Services in hospitals (53.3%) and in home care (46.6%) (Centeno & Arnillas 1998).

Palliative hospital care

Generally, patients are admitted for palliative hospital care if they meet the criteria of a expected survivorship period of less than 3 months. The average hospital stay for these patients is between 5 and 18 days. The palliative care units treat the following individuals: (1) patients who cannot be properly managed by home care, with rapid progression of their advanced disease, for pain control or

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other symptom control; (2) patients with health problems who need a temporary hospitalization owing to the psychological impact of the disease process or the fatigue of the family care takers or the home care support system; and (3) patients without relatives, living alone and without the possibility of being cared for at home.

Most of these units are open to family visits, allowing the relatives or significant others to stay at the bedside and provide rooms for them to sleep over. In some cases the patient is also allowed to go home for the weekend.

Palliative home care

Palliative home care is only partially covered by the Health Care System. Currently, this type of care is being developed and, in many cases, it is still the family who provides most of the care and who cover the expenses of the necessary equipment. Medication for home-care patients is covered 100% by the System.

Although most of the palliative home care is provided by Public Health Services, private foundations, such as the Spanish Cancer Society, co-ordinate some of those programmes. There are regional differences in the models of home care in Spain. In Catalonia, for instance, there are more than 70 PADES (Primary Care) (Bayés 1999), which are public health services that provide palliative home care with the following functions: control and follow-up of drug administration, providing personal and material resources, teaching family members and care-takers the basic skills for patient care, ensuring support for the patient and family, providing meetings with the patient, family and health professionals to prepare the treatment strategy, evaluate the need to hospitalize the patient in a palliative hospital unit, and provide emotional support to the family after the patient's death.

NURSING ROLE IN PALLIATIVE CARE

The modern hospice movement and more recently palliative care is becoming more bureaucratic and moving away from charismatic, charity-based and empathetic care (Aranda 1999). Empathy, a quality regarded as fundamental to nursing practice, is particularly important for the nurses undertaking the difficult responsibility of providing compassionate, holistic, patient-focused care of the terminally ill person.

This holistic care includes physical, psychosocial, spiritual and cultural aspects in the interaction with the patient and his/her family (Gorchs *et al.* 1997). The nurse is the provider and the advocate of patient care. He/she must ensure optimal quality of life for the patient by

controlling treatments and working productively in a multidisciplinary team. Through accurate assessments and expertise in delivering treatments, nurses pursue optimal palliation of the physical symptoms of their patients. Apart from controlling physical symptoms, they may also prevent the possible complications associated with the disease process (e.g. decubitus ulcers, constipation and mouth sores).

Spirituality is one of the most important aspects nurses in Spain consider in palliative care, as it is a significant element in the lives of most Spaniards and plays a role in coping with crisis events associated with this type of care. Therefore, nurses respond to the spiritual dimension of the patient by learning and using appropriate assessments protocols and by including appropriate spiritual interventions in their care-plans. The mutual nurse-patient relationship should keep a balance between the respect for the patient's autonomy and the beneficent guidance of the nurse, while protecting the moral integrity of both.

Some of the most perplexing and troubling ethical issues in nursing care arise within the context of palliative care. Being prepared to deal with these ethical issues can foster patient and family well-being and protect the integrity of the nurse. For instance, anger, hostility and despair are the most common patterns in palliative patients. The despair or lack of hope seems to be related to social isolation. Nurses recognize that these psychological symptoms may often trigger thoughts of suicide, but they should also know that prompt treatment of pain and symptoms reduce this risk (Breitbart & Krivo 1998). Nursing work includes also economic aspects playing an active role in assessing and advocating cost-effective palliative interventions.

In addition to caring for the physical and psychological aspects of the patient, nurses assume also the role of being the liaison between the patient and his/her family and the health care team. The nurse helps the family understand the clinical complexities in care which occur in the physical and psychosocial domains. The nurses' role includes the facilitation and updating of information among health care team and care takers. In addition, the palliative care nurse endeavours to help patients and family members to cope, attain hope and anticipate their grief.

Besides assisting the patient and his family, nurses also support and teach volunteers in palliative care. They provide continuous care, social support and co-ordinate different palliative services. Volunteers are a key element to provide social companionship and contribute to the humanization of health care, because they provide friendship and understanding to patients and families.

Researching new ways to improve palliative care is another role nurses in Spain are assuming. For instance, one line of nursing research is the identification of the specific coping mechanisms that contribute to a patient's adaptation to end of life, psychological distress or death anxiety in the palliative setting (Zabalegui 1999a, b).

Nursing participation in informing and counselling patients

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The Código de Ética y Deontología Médica Española (Spanish Ethical Code 1990) establishes that the patient has the right to know his disease diagnosis and prognosis, and that the physician is the person who gives that information. The nurse is the health professional who spent most of the time by the patient's side and it is she/he who clarifies the information to the patient and family. In many cases the patient and its family ask the nurse about the disease and its progression.

Nurses cooperate with physicians in explaining the diagnosis and prognosis of the disease to the patients and their families, so they can make the necessary anticipatory arrangements. While medical schools focus on cure, rather than on death and dying, nursing schools include the care of the dying person as a fundamental professional role. Therefore, in many cases the nurse is the health care professional best qualified to inform the patient. Usually the information given by physicians is not well understood, while the information given by nurses may be more acceptable and understood.

Therefore, good communication between nurses and patients is a central aspect of palliative care. Nurses have knowledge, communications skills and the right relationship to be effective in informing and counselling patients in palliative care. Nursing interventions promote patient involvement in decision making. Nurses have an important role in assisting patients and their families in the treatment decision-making process in palliative care.

A study done in the hospitals of La Paz, Gregorio Marañón, and San Carlos (Madrid) evaluated patient information on the terminal phase of cancer. Two hundred and four participants including nurses, physicians, family members and patients were interviewed. The researcher (Poveda 1992) found that 66% of patients requested information about their prognosis; 73% of the family members believed that the patient should not be informed about the disease because he or she was not ready to get that information; and 63% believed that if they were the patient they should get the information themselves; 18% of the physicians did not inform the patient, 30% did inform the

patient and 52% informed the patient depending on the situation.

This study concluded that nurses are the health professionals that spend most of their time at the patients' bedside. During the final death process, the nurse is at the bedside in 76% of cases, the physician in 26% of the cases, family members in 31%, with only 7% dying alone.

Nursing cooperation in multidisciplinary work

Palliative care is in the process of dynamic change (Pickett *et al.* 1998). A team approach is required for holistic care which focuses on effective symptom control that requires coordinated and multidisciplinary efforts. The interdisciplinary palliative care team may include nurses, physicians, nurse aids, physical therapists, social workers, psychologists, occupational therapists, dieticians, priests and volunteers. In palliative care units, the specialists (medical oncologist, radio-oncologist and anaesthetist) provide expert assistance in both common or infrequent symptoms. The palliative team in home care consists of nurses and physicians, who, in some areas, work with the collaboration of social workers and volunteers. The patient's family is the main care-taker in this setting, always supported by the health team.

NURSING EDUCATION IN PALLIATIVE CARE

Increasing attention to palliative care education in Spain has created major opportunities for improving education about care at the end of life. In this context, University education programmes are being rigorously evaluated to identify the best educational practices. In order to improve nursing practice in this area, palliative care education is included in some diploma nursing curricula and also in post-graduate nursing education. In addition, palliative care nurses have a responsibility to update their own knowledge on end-of-life care.

Whereas nearly all nursing schools offer some formal teaching about end-of life care, there is evidence indicating that current diploma nursing training is inadequate (Caja 1999; Duran, 2000). The Spanish Government needs to officially recognize the baccalaureate programme as a professional nursing degree. Moreover, teaching about palliative care is received favourably by students, positively influencing students attitudes, and encouraging enhancement of their communication skills. Currently, curricular content in this area varies considerably among Spanish Universities. The major teaching format is the lecture, in optional or elective courses. Additionally, not all the students have some clinical experience in palliative care

when they graduate. Nationally, at the present time there is little attention to nursing home care practice.

Nursing palliative care providers need special education and training. At present, this is carried out in the format of courses for post-graduate education. In Spain, 80% of the nurses participate in continuous education programmes. Post-graduate courses on palliative care are still not accredited by the government. There is an emphasis on courses designed to improve nurses communication skills, pain management, loss and grief, drug therapies, and other topics. However, more emphasis needs to be placed on caring for patients in their home, shifting the focus from dying in the hospital to dying at home (Schachter & Coyle 1998).

One goal of these programmes is to improve nursing skills in psychosocial care. Participants are encouraged to reflect critically on their practice experience within a group setting. The focus of the group's discussion and reflection is to share incidents from clinical practice; each participant is given the opportunity to identify and describe an incident from their own professional practice.

In summary, there is an increasing interest in palliative care in Spain, as indicated by the increasing number of courses for graduate and post-graduate education. This is not only a local but an international trend, as it is reflected in the growing number of publications related to this topic in national and international journals. These articles are also sources of information to guide the practice of the carers. A MEDLINE search from 1980 through 1995 shows over 9000 citations on palliative care and related topics. From 1985 through 1996, 14 international journals have started the publication of articles on the topic of palliative care. However, this literature is in the English language. This language therefore still represents a barrier to the Spanish carers, who otherwise could benefit greatly from this scientific material.

RECOMMENDATIONS FOR FUTURE PALLIATIVE NURSING CARE IN SPAIN

Access to palliative care in Spain appears to increase with the integration of services into mainstream health funding. Several topics are of special relevance to the nursing profession in Spain in this area, so nurses can respond to the palliative care demands.

An ethical framework and guidelines for clinical decision making needs to be developed for the proper

management of these patients' difficult and diverse situations.

More research needs to be carried out in nursing decision making in palliative care, as it has been identified as an understudied area.

Cost-effective holistic care strategies need to be available to all patients and families at home or hospital care, incorporating an accepted change of focus by all members of the multidisciplinary team.

Nursing baccalaureate as a professional nursing education needs to be officially recognized by the Spanish government to include palliative care education.

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