### ANNALES

# UNIVERSITATIS MARIAE CURIE-SKŁODOWSKA LUBLIN — POLONIA

VOL. LVII, N 1, 60

SECTIO D

2002

Chair of Clinical Nursing, Medical University of Lublin Department of Oncology, Medical University of Lublin

## MAŁGORZATA E. KRASUSKA, ANDRZEJ STANISŁAWEK, MARIA MAZURKIEWICZ

Palliative care professional education in the new millennium: global perspectives – universal needs

Hospice and palliative care includes much more than an understanding of symptoms and their skilled relief. It is concerned with the whole person, part of the family network who share in all the emotional, social, and spiritual distress that accompany physical problems and the inexorable losses that make up the experience of mortal illness. Dame Cicely Saunders.

Facing the challenges of the new millennium, many professional organizations look for some international scheme toward building a learning and study curricula for all the professionals involved in the cancer care. "Palliative care is a broad band of care of indeterminate length which should start the moment the cancer is diagnosed or even before, when there is a gleam of apprehension in the patient's eye" says Ronald Fisher (5).

Discussion on the subject how the palliative care should fit into the professional education of the health professionals as well as the teaching of the public are essential for the quality care given to the dying people and their families in the global perspective.

Goals of the professional education in the area of palliative care should include the following: increase awareness of evidence-based, culturally sensitive symptom management as an important component of quality palliative care; increase professional and public knowledge related to the symptom management, need for better 'end of life care'; empower nurses, and demonstrate the value of the palliative care nurse in contributing to quality palliative/end-of-life care; translate research into practice, and create evidence-based practice guidelines; impact policy and regulating bodies related to the organization, and symptom management (pain).

The community is the first and the best source of resources for the organizing the relevant model of care. Looking in that direction, we should ask some questions: Can palliative care specialists come together, pool resources, and deliver a community-wide orientation course for those who are decision makers or those who are new in the field? Is there enough interest and desire to explore this opportunity? Can we actually develop

and implement such comprehensive educational program and, as a group and individually, benefit from the results? (12)

Many patients with advanced disease do not receive hospice care or fail to enter hospice programs until the last few days of life. Thus, the core principles of hospice care must be integrated into healthcare delivery systems, and comfort measures should command as much importance in the hospital settings as in the hospice setting (5, 9). Although complete relief of suffering is a major goal of cancer care, misperceptions about pain persist, and cancer pain continues to be inadequately treated. Regardless of the setting, patients with cancer deserve the highest form of pain control. Hence, the tenets of ethical comfort care must pervade all healthcare delivery systems, and leaders within these systems should facilitate the acquisition, as well as application, of appropriate pain management beliefs.

The importance of treating patients holistically and meeting patient's individual needs is underestimated. Patient and family centered care is a holistic approach that focuses on patient's goals and expectations (14).

All aspects of the disease trajectory, such as health, healing, treatment beliefs, impact of illness, role of emotions, personalities in health, spirituality, physicians/nurse/other specialist/patient communication, legal issues, managed care should be considered (3).

Family caregivers need to shoulder the task of caregiving that may interfere with their existing responsibilities and activities of daily living (1). The center for the comprehensive support which pulls together informational resources should be available in every local community. This should provide multiple types of information (including financial information) and service resources available to families. Trained personnel should help in finding a proper coping strategies for families whose member has cancer. The palliative care specialist's role as an advocate could be part of such an organization. It is important to create the world-wide interdisciplinary and multiprofessional network in order to have the direct contacts and access to the most relevant organizational and human resources as well as the current professional literature, knowledge, skills and research (8).

We should stress the cross-cultural approach of teaching the public "education for better death and dying" (9) and preparation of the people (local community) for an active participation in the structures of end of life care and taking the responsibility for the care.

It comes within the duties of those who are responsible for the professional teaching to prepare the guidelines for the professional caregivers serving for dying persons and their families, also in the form of a minimum program for their professionals education (7). Hospice program must provide care using an interdisciplinary team, which team provides a variety of services, including pain and symptom management, psychosocial support, spiritual support and bereavement services (6). The appropriate professional education improves symptom control and increased caregiver satisfaction included in the hospice program (11).

With the trends of early discharge from the hospitals and the promotion of home care, nurses are assuming a prominent role in working with family caregivers. They are excellent professionals skilled to create the teaching program for the patients, their families and caregivers which enable them to use the "time before death" not only to afirmate life and to maximize the quality of life, but to prepare them to the moment of dying and death as a very specific and unique experience in their spiritual life (13).

The transcultural model of teaching the children and adolescents: "education for death of human being" is the one whose goal is to incorporate the "need for a spiritual care for dying and death awareness among living" into the normal social life, to teach that subject during the basic schools.

Specialists may feel inadequate in their ability to meet the changing needs of terminally ill, especially, when they, too, share human experience of loss and grief that their patients face (10). Knowing what to do and what to say does not come from a "cookbook" approach, but rather from knowledge of the patient, the family, their experiences with cancer, and their needs while approaching death (15). It involves being fully present as a source of validation, education, comfort, and support during life's most painful transition (Bruera, 4). It means guiding others through a time of uncertainty and helping them to find meaning in still living, as well as in dying (10).

New approach for caregivers as well as for patients is the one which requires health professionals to create and accept the new paradigm for "end of life care" with an emphasis on getting the spiritual benefit from that particular event (2). It also requires the tender loving care which shows that you can befriend cancer by letting love in, opening your heart, telling the truth, and asking for help. This is a thought-provoking attitude that shows that the responses we have toward events in our lives can help us as individuals by bringing out our creativeness and wisdom, whereas other responses lock us into seeing ourselves as victims.

In her paper presented at the 23<sup>rd</sup> Annual Congress of the Oncology Nursing Society in San Francisco, Jeannine M. Brant (3) pointed out that: "We need to continue to educate nurses in the art of palliative care, emphasizing holistic care that encompasses the mind, body and the spirit. Total suffering of a human being involves all three of these components, and end-of-life care must include the same. We can master the art. By learning from our mentors and by listening to the experts on suffering – the patients themselves. We can promote a dignified death by managing deleterious symptoms. We can instill hope that goes beyond the grave. We can make a difference in the lives of people dying of cancer. Furthermore, we can be the leaders in palliative care for those suffering and dying from other diseases. We, as oncology nurses, have a unique opportunity to chart the course of palliative care in the 21<sup>st</sup> century by refocusing attention on the naturalness of dying and challenging clinical research in the area of palliative care".

### REFERENCES

- 1. Ackworth A. et al.: Family therapy when one member is on the death bed. Journal of Family Therapy, 7, 379, 1985.
- 2. Bradshow A.: The spiritual dimension of hospice: The secularization of an ideal. Social Science Medicine, 43, 409, 1996.
- 3. Brant J. M.: The art of palliative care: Living with hope, dying with dignity. Oncology Nursing Forum, 25, 6, 995, 1998.
- Bruera E.: Research into symptoms other than pain. In: D. Doyle, G.W.C. Hanks,
  N. MacDonald (Eds.), Oxford Textbook of Palliative Medicine, 2<sup>nd</sup> ed. 179, Oxford University Press, New York 1998.
- 5. Fisher R.: Introduction: Palliative care a rediscovery. In: Penson J. et al. (eds.) Palliative care for people with cancer, 5, 1994.
- Grey A.: The spiritual component of palliative care. Palliative Medicine, 8, 215, 1994.
- 7. Hebanowski M.: Nauczanie medycyny paliatywnej i opieki terminalnej w kształceniu lekarzy medycyny rodzinnej. Medycyna po Dyplomie, 1, 16, 1993.
- 8. Koopmeiners L. et al.: How healthcare professionals contribute to hope in patients with cancer. Oncology Nursing Forum, 24, 1507, 1997.
- 9. Kübler-Ross E.: Death: The Final Stage of Growth, Simon & Shuster, New York 1975.
- 10. Maguire P. et al.: How to communicate with cancer patients. Part 2. Handling uncertainty: collusion and denial. British Medical Journal, 297, 972, 1988.
- 11. Penson J.: Teaching Bereavement Care. Bereavement Care, 9, 2, 22, 1990.
- 12. Portenoy R.: Hospice and palliative care: Program needs and academic issues. Oncology, 10, 1074, 1996.
- 13. Stoddard S.: The Hospice Movement: A Better Way of Caring for the Dying. Briarcliff Manor, Stein & Day, New York 1978.
- 14. Twycross R. G.: Quality before quantity a note for caution. Palliative Medicine, 1, 65, 1987.
- 15. Vachon M. L. S.: Psychosocial issues in palliative care: The patient, the family and the process and outcome of care. Journal of Pain and Symptom Management, 10, 142, 1995.

#### **SUMMARY**

In the 20th century, the palliative care is based mostly upon the Anglo-Saxon and Christian contemporary model of care. Is such a model sufficient and could be transformed to the places outside of Judeo-Christian based, west civilization? Is such a model transcultural and could be used for problems solving for those who are professionally involved in the end-of-life care? The universal needs of the dying human being and the family are seen by the authors in the global perspective, and that perspective is tailored as a base for the transcultural model of the education for the professionals within the palliative care.

Kształcenie profesjonalne w zakresie opieki paliatywnej: globalne perspektywy – uniwersalne potrzeby

Opieka paliatywna w XX wieku przybrała zdecydowanie anglosasko-chrześcijański charakter. Czy opieka nad będącym u schyłku życia przewlekle chorym i jego rodziną odzwierciedla w większości osiągnięcia zachodniej cywilizacji i kręgów judeochrześcijańskich, czy też w obliczu globalnej perspektywy może stanowić uniwersalny sposób na rozwiązanie wspólnych dla wszystkich ludzi problemów związanych ze śmiercią i umieraniem? Artykuł przedstawia możliwości kształcenia profesjonalnych przedstawicieli opieki paliatywnej w perspektywie międzynarodowej, z uwzględnieniem krajów rozwijających się, w taki sposób, ażeby sprostali oni również wyzwaniom innych religii oraz wyzwaniom transkulturowym.