

Perspectives on the Role of Nurses in Contemporary Palliative Care Practice: The Middle East as Example for the Developing World

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Abstract

Modern nursing ought to apply rigor and reliability to the human aspect of care. Basically, the goals of oncology and palliative care nursing have not changed; which are to alleviate suffering and comfort patients and their families deal with life-threatening illness. Yet, modern oncology and palliative care nursing should assume leadership roles in practice, education and research.

Hence, the modern nurse faces the dilemma of how to keep up with the accumulating new knowledge, whereas the individual patient and his family are kept as the focus. Patient-centred care has been and should always remain as the motto for nursing, whether it be in the hospital, community or at home. Further, honesty should remain as the cornerstone for nursing practice at all stages of the disease trajectory. Now, as before, palliative care nurses have the obligation to provide meaningful service and play a pivotal role in the multidisciplinary care for cancer patients and their families.

Keywords: Cancer; Nursing; Palliative Care; Service; Patient; Family

Introduction

Countries in the Middle East as other developing countries anticipate an exponential rise in the incidence of cancer in the coming 20 years, as the population ages; and consequently a tsunami of need for care is on the horizon. Many cancer patients will need quality palliative care throughout the disease trajectory. At the moment, most Middle Eastern countries have a very underdeveloped system of palliative care, so when the tsunami arrives, the health care systems will be unprepared. Despite the lack of attention in this area, positive developments have recently occurred in promotion of palliative care:

On May 23rd, 2014 the 67th World Health Assembly passed a landmark resolution in Geneva, Switzerland (#WHA67) that encourages all member states to take greater interest in palliative care, and calls among others to:

1. Support palliative care initiatives including education and training
2. Include palliative care as a part of integrated training for all healthcare workers who routinely work with people with serious illness.
3. Foster partnership between governments and civil society to increase access to palliative care.

Although this was a historic moment for palliative care, it was only the beginning for a combined effort nationally, regionally, and globally to ensure the resolution is put into practice, in order to reach the millions of cancer patients around the world. It is the challenge of international organizations to work together and use the existing

commitment, compassion and energy to relieve the suffering of patients and to make their life worth living.

Cancer is a leading cause of morbidity and mortality worldwide, with an estimated 14.1 million new cases and 8.2 million deaths in 2012 [1]. The mortality/morbidity ratio in the Middle East is, as in other less developed countries, 0.66; as compared to the world's 0.58, and to the US 0.38. As of today, only 20 countries (8.5%) have integrated palliative care adequately into their health-care system [2].

In daily oncology practice, quite often difficulty exists in predicting expected survival time, therefore physicians maintain aggressive treatment. The medical model reinforces the goal of cure, which also contributes to reluctance to engage in palliative care. Patients' and families' denial of terminal disease further compounds the problem [3].

In Western cultures, oncology nurses are frustrated when physicians fail to communicate the terminal nature of disease to patients and persist with aggressive care despite the inability to cure, while nurses have to manage the complex emotions and incomplete understanding of family members [3]. Moreover, Western culture, which relies on the individualistic approach, believes patients have the right to fully understand and accept that they are nearing the end of their life. This means that the start of optimal palliative care begins with open communication with patients about their prognosis. In the Middle East and in most developing countries the collective approach prevails, where physicians communicate first with a family member rather than with the patient himself/herself. The question that still exists refers to who should speak with patients and what messages are important to communicate? [3]. Many health care professionals also misunderstand the true definition of palliative care, thinking that it only applies to the end of life. The World Health Organization's definition is much broader, however, recognizing that palliative care occurs throughout a

disease trajectory to ameliorate physical, psychosocial, and spiritual suffering and improve quality of life.

Perspectives of Oncology and Palliative Care Nurses

Oncology and palliative care nurses serve as critical links between physicians on the one hand, and patients and families on the other. These specialty nurses have the expertise to understand both the complex medical needs of cancer patients and the diverse psychological and spiritual needs of patients throughout the care continuum and when nearing the end of life. Further, palliative care nurses aspire to give patients "a good death", in ways that respect dying patients' values, needs, and desires [3]. As relationships develop with each family, nurses must consequently determine how best to meet their needs in an individualized culturally and spiritually sensitive manner [4].

As has already been mentioned above; in palliative care, communication is the basis for inter-human connection. In cancer care, communication involves listening, sharing, soliciting information and conveying empathy. Carrying an open dialogue with patients and families, the palliative care nurse can assure a unique role of clarifying how family members interpret information shared with them; and to then inform the primary oncology team of any perceived misunderstanding.

In recent years, great advances have been achieved whereby palliative care nurses try to assure that difficult conversations remain compassionately and as much as possible patient-focused; whereas decisions reflect family values and the best interests of the patient. With that, part of the strategy of nursing care is to have the family identify the symptoms that are of most concern to them so that priority attention can be given to those [4].

Although palliative care teams may not be readily available in every cancer centre, let alone in the community, nurses across practice levels are in ideal positions to provide basic palliative care services to cancer patients and their families; as nurses have the capacity to appraise the patient's physical discomfort level, presence of emotional pain, communication channels, and care settings [5].

Ethical and Moral Considerations

Oncology and palliative care nurses often encounter ethically difficult situations, and as a result more moral distress than other specialists [6].

Also, nurses spend more time with patients than other members of the care team, and therefore have a unique opportunity to know what's important to patients and to help them navigate decisions involved in their treatment [7]. Moreover, many times nurses are the first to know when patients and their families are ready to start a verbal dialogue. This is the time when nurses should act as the patient's advocate [7]. This is the reason why patients trust nurses to hear their concerns, and help them work through the many conflicting emotions and uncertainties in advanced illness [7]. An experienced nurse avoids a one-size-fits-all approach, but rather continues assessing the individual patient's condition throughout the illness trajectory [8].

Discussion

There is growing evidence supporting the contention that early palliative care referral improves quality of care and potentially

improves survival [9]. The American Society of Clinical Oncology (ASCO) has stated that quality cancer care "requires access to and the availability of state-of-the-art palliative cancer care rendered by skilled clinicians, buttressed when necessary by palliative care experts" [10]. Because a large part of the practice of palliative care includes symptom management, nurses assigned to palliative care should have at least primary - if not advanced level skills in this speciality [11]. These include management of pain, symptoms, anxiety and suffering [11]. Nurses, as pivotal members of the multidisciplinary palliative team, need to help overcome the perception of the cure/care dichotomy, and promote the realization that palliative care is essential throughout the continuum of care [12]. Yet, even with the growing recognition and acceptance of the nursing role and contributions of palliative care to patients, their families and caregivers themselves; there is an acute shortage of palliative care nurses in Western Countries and even more so in developing countries. One way to overcome this critical gap is through endorsing partnerships between international organizations. For example, the Oncology Nursing Society (ONS) in the United States has developed multiple educational tools for symptom management and nursing leadership, and has also formed international collaborations with the Middle East Cancer Consortium (MECC) to offer palliative care training courses for nurses in the Middle East [13]. The American Society of Clinical Oncology (ASCO) is also collaborating with MECC, in a new initiative to promote palliative care in the community. Such partnerships serve as catalysts for advancing national palliative care programs in individual countries, as well as regional research projects to further advance this clinical discipline globally [14]. We in the Middle East fully realize that our effort to integrate palliative care into mainstream oncology face numerous potential obstacles. These include the need for a cultural or paradigm shift and recognition of policy makers about the essentiality of such services at all healthcare levels- from the community to the cancer centres.

Conclusion

The human aspect of palliative care has advanced with respect to the quality of interactions with patients and families-some call it the art of nursing, which is the essence of nursing practice [15]. Hence, modern nursing ought to apply rigor and reliability to the human element of nurses' care. In the Middle East, like other low-income and middle-income countries, regulations hampering opioid accessibility combined with the scarcity of trained doctors and nurses, stymie delivery of pain treatment and palliative care [16,17]. MECC together with ONS has initiated training programs for nurses at all levels of the health-care system in the Middle East [18]. In 2015, oncology and palliative care nursing should be transformative in leadership, education, practice, and research; as the essentials of these kinds of care encompass the psychological support required to provide excellent care to patients and families from initial diagnosis through end of life [19]. In spite of the remarkable advances accomplished in recent years, the goals of oncology and palliative care nursing are the same: to help cancer patients and their families deal with life-altering disease and to reduce the burden of their journey [20]. The question that the modern nurse is facing: how to keep up with all the new knowledge, but at the same time keep the individual patient and family needs as the focus? [20] Conceptually, the nurse, as part of the professional community, should stick to the idea of patient-centred care in order to meet the patient where he or she is, whether that be hospital, clinic, nursing home, hospice or home [12]. Further, all of us managing cancer patients need to be honest about prognosis and treatment limitations,

because patients can make better decisions when they know what's going on- even if the reality is difficult to hear [6]. Nowadays, experienced nurses need to take reign of leadership roles in nursing practice, teaching, research and service [5]. Nursing research must also be a priority. ONS members have conducted a multitude of prospective descriptive studies, but now longitudinal and intervention research is needed to address deleterious symptoms, emotions, and grief and death-related fears at diagnosis and throughout the illness trajectory [5]; as it is essential for nurses to recognize patient and family experiences of illness, death and dying [4]. Now, as before, palliative care nurses have the obligation to provide meaningful service and play a pivotal role in the multidisciplinary care for cancer patients and their families.

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