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"Palliative Care and Oncology:
Time for Increased Collaboration
and Integration"

Mini Review

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Cultural Challenges in Implementing Palliative Programs in Emerging Countries

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ABSTRACT

Clinical approach of palliative care is beneficial during an individual's journey with illness, and can be utilized through many care settings by all members of the health care team. Many complex cultural issues can affect the patient and the families during the course of a life-threatening illness. Palliative care services in all countries need to be delivered in a way that meets the cultural and spiritual needs of its people.

KEY WORDS: Palliative care; End-of-life; Challenges; Culture; Patient; Family.

Insuring the availability of palliative care has become an increasingly important global health priority in recent years. As population age and the prevalence of chronic illnesses increases in emerging countries, as in all other countries worldwide, the need for palliative care has risen significantly. The World Health Organization (WHO) estimates that more than 40 million people require palliative care annually at the end-of-life.

One of the challenges of palliative care is to honour the personal wishes of culturally diverse patients while meeting universal medical relief standards. Palliative care begins with the understanding that every patient has his/her own story, relationships and culture, and is worthy of respect as a unique individual.

Culture refers to common elements or characteristics within one's sociological grouping. Different values, beliefs, behaviours, languages, rituals, customs or traditions, and accepted practices for living and dying, partnering, marriage, childbearing, parenting, and family communal life creates cultural groupings. Culture can include elements such as developmental stage of life, profession, and educational level, geographic region of the country, religion, spirituality, sexual orientation, political affiliation, gender, socioeconomic status, and more.

Palliative care is a relatively new concept in many countries in the developing world. Health professionals and whole populations are unaware of palliative care. Health care is not only providing cures, also improving the quality of life of patients and patient's families. Palliative care is applicable during the onset of life-threatening illness. A common misconception is that only terminal ill cancer patients are in need of palliative care. By contrast, the hospice and palliative care movement has been providing increasing awareness of various end-of-life issues. End-of-life care means more than treating physical symptoms – it extends to the psychosocial, existential, and spiritual aspects of the patient's needs, including developing trust in the substantial care of the patient and the family during this time. Numerous studies aimed to understand the relevance of culture to death and dying and found that communication was the greatest barrier between the health-care provider and the patient and family during end-of-life care.¹⁻³

Early discussion of prognosis and end-of-life care options were found to help and facilitate an earlier acceptance of palliative care.⁴ The desire to tell or know the truth about illness or death is clearly a Western cultural value. Every patient has the right to know about his/her ill-

ness for decision-making in end-of-life care. In some societies, however, talking about diagnosis, prognosis and death and dying is a taboo subject because it causes loss of hope and concern about reduced compliance with treatment.⁵⁻⁷ Not knowing the fact of the patient’s illness is a major challenge for an effective relationship between physician and patient and the administration of palliative care.⁸⁻¹¹

The family may expect information to be given to them first, so that they can make the best health-care decisions. Although collective decision-making is the norm in some societies, it often clashes with the value of autonomy and an individual’s right to make one’s own decisions about health and dying. Still, many cultures actively protect dying patients from knowing their prognosis.¹² Additionally, family members often do not want to be the ultimate decision-makers when death is inevitable. They may have the expectation that it is the physician’s role to decide on all health care and end-of-life care. These values can cause a treatment dilemma for the health-care provider whose focus is on getting the patient involved in palliative care. Patient beliefs and values should be respected in the decision-making process and in the case of the end-of-life issue even if the decisions differ from the family’s or the health-care professional’s views. While respecting cultural norms by providing patient autonomy, independent decision-making rights are also recognized.¹³

The belief system that makes the disease meaningful, and its symptoms, should be evaluated when the patients themselves are evaluated in accordance to varied cultures. Pain is a universal phenomenon, but culture can affect a person’s response to pain, both in the meaning and the expression of pain.¹⁴ Total pain is more than a response to a physical/biological injury. The basic principle in palliative care is to assess and relieve suffering not only from physical pain, but also from psychological, social and spiritual distress. Concealing pain may result in under-medicating pain symptoms.¹⁵ In some cultures, pain must be experienced as evidence of the body fighting to overcome disease. In

other cultures, pain is viewed as punishment.¹⁶ In some cases, it may be necessary to make changes according to pain assessment scales.^{17,18} Patients may be reluctant to take medication and analgesics for a number of reasons. Lack of knowledge and skill in pain assessment and treatment, unavailability of morphine, and fear of opioid addiction are some of the complex barriers in emerging countries.

Cultural factors shape patient’s preferences regarding decision-making, receiving bad news, and end-of-life care.¹⁹ Death is an inevitable outcome of every person’s life but each individual’s experience of death is unique. Treating patients at the final stages of their life is often stressful and sad for everyone involved—a situation that may be worsened when the health care professionals do not fully comprehend the nature of the patient’s beliefs. Some cultures have different attitudes toward reducing or ceasing artificial nutrition and fluids. Discussions about resuscitation and approaches to providing symptom control may also be dictated by an individual’s belief systems. Some cultural and religious groups may choose to prolong life despite a medical assessment of futility. At the end-of-life, palliative sedation can engender a merciful death when treatment resistant and highly distressing symptoms (e.g., pain, dyspnea and delirium) are present. However, loss of consciousness by sedation is unacceptable for the control of resistant symptoms in some cultures (Table 1).²⁰⁻²²

There is no one best way to deal with a life-threatening illness, yet cultural, religious and interpersonal approaches strongly affect an individual’s feelings. Individualized care is based on the fact that human responses to a similar situation vary significantly, and the recognition that only part of these variations, are predictable.

In anthropology today, culture is not viewed as homogenous or static. Culture is inseparable from economic, political, religious, psychological and biological conditions. Moreover,

Table 1: The Attitudes Towards Truth Telling in Different Country and Religious Beliefs on End-of-Life Management.

Country	Attitudes towards truth telling	Religious beliefs on end-of-life
Italy	Trend of partial and non-disclosure persists. ⁵	Christianity - Key belief is repentance and life after death.
Spain	Tradition of partial and non-disclosure. ⁵	If wanting to confess, strong religious justification for high-technology medicine to maintain consciousness until final anointing Those who have repented may recognise no need for aggressive interventions to postpone death. ²⁰
Turkey	Tradition of non-disclosure. ⁵	Islam - Decisions about aggressive invasive treatment to extend life are jointly made by all associated with the patient including religious leaders. Withdrawal of life-sustaining treatments, when considered futile, is seen as allowing death to take its natural course. ²¹
China	When fatal diagnosis or prognosis, physician informs family and hides it from patient. ⁷	Buddhism - There is no need to go to extreme lengths to provide treatment if little or no prospect of recovery. Some may be unwilling to take strong analgesics or sedatives. ²²

the presence of palliative care awareness in a community will also affect culture. To effectively integrate palliative care in emerging countries, appropriate national policies must provide for adequate opioids availability; the education of health-care workers and the general public; and a culturally appropriate implementation of palliative-care services at all levels of society.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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