

Palliative Care and Psychosocial Communication in Honduras: Implementing Educational Programs for Oncology Clinicians

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Cancer and Palliative Care

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 number of cancer cases is projected to double in the next 20 to 40 years because of the population growth of low-and middle-income countries and the aging of these populations [2]. Globally, there is a projected increase in cancer is also due to modifiable risk factors (smoking, obesity, and sedentary life styles), limited access to screening and early detection, stigma associated with cancer diagnosis, limited access to services, poverty, and the on-going risk of infectious etiologies [2]. Some of the leading cancer diagnoses—lung, liver, breast, cervical, colorectal, and stomach - are the result of these modifiable risk factors [2,3].

Low and middle income countries (LMIC) often face a heavy cancer burden due to later stage of diagnosis, scarcity of diagnostic and treatment resources, and lack of trained oncology providers. In 2011, the World Health Organization (WHO), the United Nations (UN), and the Union for International Cancer Control held the first high-level meeting to discuss the growing burden of noncommunicable diseases, including cancer, in LMIC and developing countries 4. This meeting called for global partnerships between countries and organizations to enhance capacity and cancer care [4] with a goal of reducing cancer mortality by 25 % by 2025.

In 2014, the World Health Assembly passed a landmark resolution in 2014 (WHA67.19,) encouraging all member states to invest greater interest in palliative care [5]. The resolution noted that more than 40 million people worldwide have been identified as needing palliative care services and 80% of these live in LMIC. However, only 20 countries (8.5%) have integrated Palliative care into their health-care systems [2]. Similarly, the Institute of Medicine (IOM) has recommended international partnerships for developing and improving cancer care in low-income countries through twinning or other relationships [6]. Specific initiatives include education and training for all healthcare workers in palliative care. Also in 2014, WHO and the Worldwide Palliative Care Alliance (WPCA) published the Global Atlas of Palliative care at the End of Life to quantify the availability of and need for these services around the world [7]. The report identifies that the highest proportion of adults needing palliative care live in LMIC. Since nursing care including symptom management and psychosocial care are large components of palliative care, nurses should be included in education and training initiatives to improve palliative care.

Palliative Care in Low Resource Settings

It is clear that regardless of the purpose of a specific global program, the principles should include collaboration, curiosity, compassion, courage, creativity, and capacity building [8]. In general, the greatest impediment to improving healthcare in low-income countries is the ability to train and sustain an adequate workforce [9]. The global shortage of professionally trained healthcare personnel including nurses and the projected increase in cancer diagnoses requires developing strategies to train and educate professionals who will respond to this crisis [10] particularly the palliative care needs of the population. Global partnerships need to be collaborative and creative to increase training and build in-country capacity to provide palliative care services in LMIC.

Service Learning and Mission Work

In low-resource settings, volunteer healthcare providers historically have provided services during short-term, volunteer trips, efforts that often end with their departure. Health care providers may include doctors, nurses and students in the healthcare professions traveling to LMIC as part of academic, professional or faith-based organizations.. These programs, while helpful in the short term, often lack a long term plan to guide the efforts of volunteers and local partners in creating sustainable changes. In the last ten years, these models of mission and service learning work have shifted to include partnerships with in-country organizations and incorporated local healthcare providers to guide the development of culturally-appropriate programs and create sustainable improvements in health [11]. Nurses have a long history of participating in work in the global community as volunteers, educators and civil servants (Leffers). Leffers et al. described a partnering process is seen as essential before the development of outcomes such as improved health, continuing innovation and program activities and eventual host country ownership [12].

Nursing and Palliative Care

In October 2015, the International Society of Nurses in Cancer Care (ISNCC) released the Palliative Care Position Statement [13].

It described the key role of nurses in palliative care delivery around the world. The Statement notes that the goal of holistic nursing care is consistent with the goal of palliative care - to comprehensively address distress in the physical, psychological/emotional, social and spiritual domains. In fact, ISNCC advocates that all cancer nurses should receive palliative care training to develop their capabilities and effectively communicate, manage pain and other symptoms, care for the dying patient and their families, and identify when to refer patients with complex needs for specialty care [8].

Nurses provide palliative care in differing settings and with varying resources and training. [14] The list includes key psychological and emotional issues that should be assessed and addressed in palliative care: 1) assessment and treatment of psychological distress, 2) addressing the suffering of the relative or caregiver(s), and 3) assessment and treatment of depression and anxiety. There is evidence in the literature about training programs in the psychological and emotional issues in palliative care. In one study, Kubota et al. (2015) implemented a psycho-oncology training program for nurses to teach topics such as the normal reactions of patients, detecting and managing clinically significant distress, and assessing suicidal thoughts and depression using multiple teaching pedagogies [15]. The findings of this study demonstrated that nurses knowledge and confidence were increased with training. Pastrana, Wenk, De Lima (2015) used a workshop in another Latin America country, Colombia, to develop consensus-based palliative care competencies for undergraduate nurses and physicians [16]. The findings of this study described six categories of palliative care and included psychosocial and spiritual issues.

The ISNCC 2015 Palliative Care Statement reaffirms that the delivery of palliative care to cancer patients must be culturally sensitive and relevant to the country and context. Cancer nurses play a key role in attending to important cultural considerations, such as beliefs related to disease causation, stigma, diagnosis, treatment, side effects, end of life care and personal preferences [13]. In most cultures, decisions reflect the family values and the needs of the patient but specific values may be unique to the patient and family and cannot be assumed based on the culture or religious and spiritual beliefs. There must be a willingness on the part of the nurses and palliative care providers to create time for open, sensitive discussions about the patient's and family's needs and concerns, separate from routine physical care.

Psychosocial Communication in Palliative Care

Addressing psychosocial concerns is a core component of palliative care. The WHA resolution (WHA67.19) [5] recognized the ethical duty of healthcare providers to alleviate suffering, including suffering related to psychosocial issues, as foundational when providing palliative care. IAHPCC List of Essential Practices [14,15] includes key psychological and emotional issues that should be assessed and addressed in palliative care: 1) assessment and treatment of psychological distress, 2) addressing the suffering of the relative or caregiver(s), and 3) assessment and treatment of depression and anxiety.

Communication about psychosocial issues in palliative care may be difficult to begin for both patients and nurses. One question that has been used as a global entrée into these discussions is "What matters most to you?" [16,17] A program initiated for the Institute for Health Care Improvement started a program based on this one question to help begin these important discussions about psychosocial issues and, in the case of life-shortening illness, end-of-life preferences. The question serves as an opening to a conversation with patients and families to promote being "conversation ready" whether in the home, hospital or clinic.

In palliative care, specific communication issues arise when discussing psychosocial concerns with patients and families. Common psychosocial concerns include anxiety, uncertainty and fear, worries and depression, anticipatory grief and loss, family relationships, and existential concerns. Some of these conversations may be difficult for

nurses and evoke emotions in the nurse such as sadness that may limit the ability or willingness of the nurse to discuss sensitive issues with the patient and family. There is evidence in the literature that training programs in the psychological and emotional issues in palliative care can improve nursing knowledge and confidence in addressing these issues. In one study, Kubota et al. (2015) implemented a psycho-oncology training program for nurses to teach topics such as the normal reactions of patients, detecting and managing clinically significant distress, and assessing suicidal thoughts and depression using multiple teaching pedagogies [15]. The findings of this study demonstrated that nurses' knowledge and confidence increased with training.

Palliative Care in Latin America and Honduras

In Latin America, macro indicators were used to track palliative care development in Latin America [16]. The macro indicators identified the main barriers to the development of palliative care in four domains: policy, education, medication availability and implementation. Honduras ranked in the lowest group with Bolivia, Dominican Republic and Guatemala. Lack of policies about palliative care services such as lack of national standards and guidelines impede the development and implementation of palliative care [17]. In addition, the process for acquiring morphine and other opioids is limited due to paperwork and many levels of approval prior to giving a patient in pain a narcotic for relief of suffering.

In 2001, the Latin American Association of Palliative Care (ALCP) was formed to promote the development of palliative care in Latin America and the Caribbean (<http://cuidadospaliativos.org/home>). In 2012, the ALCP published the ALCP Atlas of Palliative Care to monitor the development of palliative care services in Latin America [18].

According to the macro indicators, Honduras ranked in the lowest group with Bolivia, Dominican Republic and Guatemala [18]. Honduras carries the burden of many low resource countries – few programs for screening, later stage diagnosis and greater symptom burden. According to the World Bank (2103), 58.8% of the population of Honduras lives below the poverty line [19]. While Honduras has a National Primary Care Program, only 60% of the population receive public health care services provided by the Secretary of Health (WHO, 2015). In Honduras, there are 7,400 new cases of cancer per year with the most frequent cancers being cervix uteri, stomach, liver, breast and prostate [20]. Cancer of the cervix uteri is the fourth most common cancer worldwide but the most frequently diagnosed cancer, regardless of gender, in Honduras, and the leading cause of cancer deaths among women [21]. According to the ALCP Atlas, Honduras ranked lowest in palliative care services/units/teams per one million inhabitants (0.24) with one team in the country, no hospice facilities, no faculty teaching palliative care in the medical schools, and no information about the numbers of nursing faculty [20]. There is one hospice unit in the country, the Palliative Care Unit at Emma Romero de Callejas Cancer Center in Tegucigalpa.

Palliative Care: Nursing Education in Honduras

Education and training in palliative care are needed for all health professionals. One of the macro indicators proposed by Pastrana et al. was the proportion of nursing and medical schools that include palliative care education in undergraduate programs. Unfortunately, there was no information available regarding the numbers of nurses or

nursing faculty for palliative care education in 2014 [20]. Given the need for palliative care including psychosocial care and symptom management, nurses require training in undergraduate education and practicing nurses need more advanced training [22,23].

In 2011 and 2012, the American Society of Clinical Oncology's International Cancer Corps (ASCO ICC) in partnership with Health Volunteers Overseas (HVO) created two teams to provide the first oncology nursing conferences in Honduras [24]. To develop the curriculum, the ICC team included symptom management, pain control, and psychosocial communication as key components of oncology nursing education for the first conference. After collecting feedback from the participants at the first conference, the team created a second conference to provide advanced content and topics identified by Honduran nurses as key to improving cancer care and palliative care in their country.

In 2015, ASCO ICC and HVO were asked to develop a team to provide an interprofessional palliative care conference in Honduras. A team of three oncology providers including two advanced practice nurses and one oncologist, created a four-day, interprofessional workshop to discuss the implementation of palliative care in Honduras. The workshop was held in the capital city, Tegucigalpa, and included doctors, nurses, psychologists, dieticians and community advocates. Interactive features included small group work on specific topics that have been identified as key issues including access to pain medications and psychosocial concerns of people facing a life potentially shortened by serious illness. Continuing partnerships between ASCO ICC and Honduras will develop and implement further programs to improve palliative care delivery and alleviate suffering for patients and families.

Conclusion

The important values of mutual respect and trust are essential at the macro and micro levels: 1) in creating global partnerships to improve palliative care, and 2) in developing relationships between palliative care providers and patients and their families. Nurses are the largest healthcare workforce in the world and the center of the health care team. They serve as patient advocates, providers of direct care, coordinators of palliative care and expert communicators. With undergraduate and continuing education, they provide palliative care that is patient-focused and family-centered. They establish trusting relationships based on the ethical tenets of respect for persons and beneficence while being compassionate and empathetic. They understand that families and cultures may have different values and beliefs that require awareness, understanding and respect. Nurses in palliative care need training in specific communication skills to address the special needs and psychosocial concerns of patients and families with serious illnesses including cancer. International partnerships provide opportunities for shared program development and training initiatives that improve palliative care and empower nurses to advocate for these services and resources for their patients. With on-going relationships, greater awareness and new policies regarding essential palliative care services, nurses can promote a world culture where palliative care is a right of every person.

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