

Palliative Care Nursing in Jordan

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Abstract

Palliative care is progressively more existing and the importance of its role is increasingly acknowledged by many countries. This paper identifies and examines main stepladders taken by Jordan for the development of palliative care.

In palliative care, the primary goal is alleviating symptom distress resulting from multiple symptoms and enhancing quality of life for patients and their families. To meet patients' multiple needs, it is generally believed that the care should be holistic, multidisciplinary, and patient as well as family centred.

Countries should develop and implement educational programs for multidisciplinary healthcare providers so as to be able to enhance the quality of care provided to patients and families at all levels of care. Unfortunately, in Jordan, skill development among health care providers; few educational and training opportunities exist to this point; and specialty acknowledgement also has not yet occurred. Research capacity is also inadequate. Policy to develop, improve, and sustain palliative care is also lacking in Jordan. Palliative care in Jordan is evolving but has far to go. Adequate resources provision, educational programs, credentialed healthcare providers are crucial elements that palliative care in Jordan needs.

Keywords: Palliative care; Jordan; Nursing

About Jordan

Jordan is a small Arab country located in the Middle East that occupies an area of 89,000 km². It has an estimated population of about 6.5 million. In 2012, about 12.8% of Jordanians were under the age of 5 years, 37.3% were under the age of 15 years and 3.2% were above the age of 65 years [1]. Administratively, Jordan is divided into three regions (i.e. Central, North and South) and has 12 governorates.

The religion of Islam and the family structure are the most influential factors in shaping the Jordanians' beliefs. Islam is the religion of the majority of the population, thus, with concordance with the Islamic teachings most Jordanians believe that illness and wellness are God's will and religious practices (e.g., prayer, reading holy Quran) are widely used to help people cope with illness especially life threatening illnesses [2]. Decision making on health issues is considered a social process and many family members (e.g., spouse, children) could be involved in that process.

One of Muslims' beliefs is that healing comes from God; hence, Muslims have the obligation to search out and to receive the best of medical care and treatment leaving the final outcomes to God. Muslims acknowledge that death is an inevitable phase of a human being, and that human beings are guardians of their bodies.

Cancer statistics and cancer care in Jordan

Cancer is the second cause of death in Jordan (15%) after cardiovascular diseases (36%). According to the Jordan Cancer

Registry (JCR), trends of the past decade show that the incidence of cancer in Jordan is rapidly increasing [3]. For instance, the number of new cancer cases diagnosed among Jordanians increased from 3362 cases in 2000 to 4675 in 2011 (i.e. a 39% increasing rate) [3]. Of the total 4675 new cancer cases that were reported among Jordanians in the year of 2011, 2194 cases (46.9%) were males and 2481 cases (53.1%) were females. The majority of the new cases were invasive cancers (98.4%), 28.9% were localized cancers while 23.6% were advanced stage cancers with distant metastasis. Breast cancer is currently ranked first among both Jordanian males and females accounting for 20.4% of the new cases diagnosed in 2011 followed by colorectal cancer (10.9%) [3]. Jordanian cancer patients are treated at the expense of the government through King Hussein Cancer Center, university-affiliated hospitals, Royal Medical Services and Jordan Ministry of Health Hospitals.

In the late nineties, cancer care in Jordan has gone major improvements. The establishment of Jordan Cancer Registry (JCR) in 1996 made it possible to move from a hospital-based registry to a population-based cancer registry. JCR provides timely and accurate national cancer data that can be used for clinical and epidemiological research and for the planning and evaluation of health services. In 1997, the first and the only specialized cancer center in Jordan, King Hussein Cancer Center (KHCC) was established. KHCC is an independent, non-governmental, not-for-profit institution that it is accredited by the Joint Commission International. KHCC provides treatment for about 60% of cancer cases in Jordan in addition to patients from several Arab nationalities.

While cancer treatment modalities including surgery and chemotherapy are available in many public and private hospitals

besides KHCC, radiation therapy is available only at KHCC and Al-Basheer hospital. In addition, most of cancer treatment services are located in the central region of the country, specifically in the capital Amman. Supporting services such as support groups, psychological care services and palliative care are generally lacking except in KHCC [4]. Qualified physicians including medical, surgical and radiation oncologists, radiologists and pathologists are available across different public and private hospitals in addition to KHCC. But, there is a shortage of qualified oncology nurses and other supporting health care providers (e.g., social workers) [4].

Evolution of Palliative Care in Jordan

In the nineties, end of life care was provided by a single facility in Jordan which is AlMalath foundation in the capital Amman. Palliative care philosophy as defined by the WHO was introduced to cancer care in Jordan in year of 2001 with the launching of Jordan Palliative Care Initiative [5,6]. As a result of this initiative, the first palliative care unit was established in Jordan at King Hussein Cancer Center in 2004 [5,7]. The unit provides palliative care services through its interdisciplinary team to thousands of patients at KHCC, it provides inpatient, outpatient and also home care palliative care services [7]. Besides KHCC and AlMalath foundation, supportive care services are also provided at a Basheer hospital which is a public hospital governed by the Ministry of Health [8].

In 2010, Jordan Palliative Care Society (JPCS) was established in order to raise awareness on palliative care in Jordan and to provide palliative care training and education. JPCS offers workshops and lectures on different aspects of palliative care including pain management, wound care, geriatric care, and stress and burnout management. JPCS organized the first international palliative care conference in November 2012 which was held in Amman. A hospice and palliative medicine fellowship program is offered by the palliative care department at KHCC.

Although pain and symptom management are generally available to Jordanian cancer patients across many university-affiliated hospitals, Royal Medical Services, Jordan Ministry of Health hospitals and several private hospitals, the palliative care unit at KHCC is the only specialized palliative care unit in the country that hosts an interdisciplinary team trained on palliative care.

Current Status of Palliative Care Nursing in Jordan

Palliative care nursing started in Jordan with the launching of Jordan Palliative Care Initiative in 2001 as nurses are recognized as vital members of any interprofessional palliative care team. Since then, Jordanian registered nurses (RNs) across different settings (e.g., KHCC, Ministry of Health and university affiliated hospitals) have been trained on palliative care both inside and outside Jordan (e.g., San Diego Hospice, USA) [6,9]. Many Jordanian nurses, both bedside nurses and faculty members, have also attended palliative care educational activities organized and funded by the Middle East Cancer Consortium (MECC) over the last 10 years.

In concordance with the WHO definition of palliative care, palliative nurses at KHCC provide nursing care to patients (e.g., symptom, pain and wound management) and their families (e.g., psychological support and information provision) with the aim of improving their quality of life and easing their suffering. Palliative care nurses at KHCC are working in the inpatient palliative care unit that mainly serves patients who are at-end-of life or in the outpatient

palliative care clinic. Some of these nurses (i.e. nurse coordinators) provide care to patients in other departments in the center who have symptoms that need consultation of the interdisciplinary palliative care team. All palliative care nurses at KHCC are registered nurses and several of them have a master's degree in palliative care nursing. Before being assigned to the palliative care unit, palliative care nurses at KHCC have to pass a 2-day palliative care nursing course that is accredited from the American Nurses Credentialing Center (ANCC). They have to renew their certificate annually through the Clinical Nurse Resource in the center.

Because of their advanced education and hence the high-quality care they provide Jordanian cancer patients, palliative care nurses at KHCC have succeeded in achieving a good status and they are recognized as a valuable asset to the success of the interdisciplinary palliative care team at the center [10]. In addition, other specialized nursing teams have been established at KHCC to provide palliative care to cancer patients including the Pain Nurse Team and the Home Care Team.

At other institutions that treat cancer patients but do not have specialized palliative care units or interdisciplinary palliative care teams (e.g., Ministry of Health hospitals, Royal Medical Services) there is no job description for the palliative care nurse. Although many nurses at some of these institutions have been trained on palliative nursing care, their roles are not formally activated as palliative care nurses. Palliative care/palliative care nursing is currently limited to cancer patients; it is not available to other medical conditions (e.g., dementia, congestive heart failure, or stroke).

With regard to education on palliative care, several public and private Jordanian universities are currently offering palliative care nursing courses as elective courses to their undergraduate nursing students. At other universities, palliative care is introduced to undergraduate nursing students through other courses such as fundamentals of nursing or medical-surgical nursing courses. At the graduate level, Jordan University (JU) offers a master degree in palliative care (i.e. clinical nurse specialist) and the German University in collaboration with JPCS offers a Diploma in palliative care. Additionally, most Jordanian healthcare professionals who had completed their post graduate education in Western countries are aware of the concepts of palliative and end of life care.

Barriers to Palliative Care Nursing in Jordan

Much have been achieved in Jordan in the field of palliative care nursing as alluded to in previous sections but the field is still in the infancy period and many challenges have to be tackled in order to develop and promote palliative care in general and palliative care nursing in particular at the national level. These barriers can be related to 1) policy and legislation, 2) clinical practice, 3) education, and 4) research.

Today, Jordan does not have a national palliative care policy [8]. Thus, with the exception of KHCC, palliative and home care services are not available at the national level leaving a large proportion of Jordanian cancer patients without access to palliative care. Overall, in the Jordanian health care system, the resources are focused more on cure and acute care as opposed to caring for patients who are dying and there is a negative attitude to caring for the dying patients and palliative care among both health care providers and the public [4]. Thus, palliative care nursing might not be an attractive specialty to a large number of nurses as opposed to other nursing specialties. On the

other hand, although palliative care nurses at KHCC have their own job description, they are not officially recognized by the regulating entities in the country such as Jordan Nursing Council or Jordan Nurses and Midwives Association as specialized palliative care nurses including those who have a master's degree in palliative care nursing.

Compared to other Middle Eastern countries, Jordan has made important achievements in the availability and accessibility of opioids especially morphine [6,8] but constraints on opioids prescribing and interruption in its availability still exist [4,8].

The aim of palliative care as outlined by the WHO is to enhance the quality of life for both patients and their families. The patient family is not usually considered a target of medical or nursing care among health care providers in Jordan; family care needs of cancer patients are usually left unmet [11,12] which contradicts with the WHO definition of palliative care. Thus, to promote palliative care, there is a need for a cultural change that entails considering the family in the care provided to Jordanian patients.

Attitudes toward disclosure of cancer diagnosis and prognosis are changing in a positive direction among Jordanian cancer patients with the majority preferring to know whether the diagnosis is cancer and the stage of the disease [13]. But, truth concealment from cancer patients is still common in Jordan especially with elderly cancer patients. Thus, it would be difficult for palliative care nurses to provide quality care to a cancer patient who is not aware of his/her diagnosis and/or prognosis. Another challenge faced by palliative care nurses (i.e. those at KHCC) is the delay of referring patients to the palliative care because many physicians (e.g., oncologists) still equate palliative care with hospice care.

Education on palliative care nursing is improving in Jordan but further efforts are needed in this regard. Because of the absence of a national policy on palliative care, palliative care nursing is not included in the undergraduate or post-graduate curricula of many nursing schools in Jordan. Thus, recent research has shown that there is a lack of knowledge among Jordanian nurses regarding different palliative care dimensions. Jordanian nursing students and nurses working in public hospitals lack basic knowledge about palliative care including its philosophy and the difference between palliative and hospice care [14-16]. Lacking necessary knowledge regarding pain and pain management is one of the biggest barriers to effective cancer pain management among Jordanian nurses and many of these nurses hold negative attitudes toward pain medications especially opioids (e.g., fear of addiction and negative physiological effects) [17-19]. Jordanian nurses' knowledge about the pathophysiology, assessment and management of cancer symptoms (e.g., cancer-related fatigue) is also insufficient for effective symptom management to enhance patient quality of life [20].

Several years ago, nursing research in the area of palliative care did not exist in Jordan. Today, palliative care is one of the national nursing research priorities identified by Jordan Nursing Council and a few nursing researchers are focusing their programs of research on palliative care. However, research on this topic is limited. Most publications were focused on issues related to pain management (e.g., barriers to effective pain management) and a few focused on nurses' knowledge of and attitudes toward palliative care. None have addressed issues related to other symptoms (e.g., delirium, cachexia), psychosocial issues (e.g., depression, anxiety, and spirituality), social issues (e.g., social support, family issues), communication issues, staff

burnout, or grief and bereavement. Additionally, funding for research in general is limited in Jordan.

Possible Action Strategies

A national policy on palliative is urgently needed. Once this policy is formulated and implemented, several barriers to palliative care in general and palliative care nursing in particular would be resolved. Presence of this policy will ensure standardization of education on palliative care nursing, access to palliative care for the largest proportion of Jordanian cancer patients and their families (e.g., through establishment of palliative care services), sustainability in the availability of opioids and less restrictions on its prescription, adequate funding, and standardization of care (e.g., development of evidence-based standards and guidelines of care). Jordanian health care providers working in palliative care (e.g., the interdisciplinary team at KHCC, Jordan Palliative Care Society and the NGOs providing palliative care services) can negotiate with the government to develop and implement a national palliative care policy. They can lobby with political figures in the country (e.g., the Parliament) to advocate for the policy. They can also launch public information campaigns (e.g., mass media campaigns) to increase public awareness about palliative and end-of-life care and also gain support for the formulation of the national policy on palliative care.

Accreditation bodies such as the Higher Education Accreditation Commission should ask for palliative care nursing to be integrated into the undergraduate curricula in every nursing school either as an obligatory or elective course. Jordan Nursing Council has recently started the process of certifying and recognizing several nursing specialties. Palliative care nurses should seek certification from the council. Health care institutions should be made aware of this certification and thus encourage their palliative care nurses to be certified.

More nursing and interdisciplinary research is needed in the area of palliative care and new topics need to be addressed (e.g., social and psychological issues and the impact of nursing care on patient's outcomes). Faculty members for instance can encourage their graduate students to conduct research on palliative care. More funding for research on palliative care should be allocated by funding bodies such as the Jordanian Scientific Research Support Fund and deanships of scientific research in the universities.

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