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Palliative Care and Nursing in Palestine, 2015

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Abstract

As cancer is the second leading cause of death in Palestine (14.2%), and as it is diagnosed usually in the late stage, this makes its burden heavier on both patients and the healthcare system, and leads to poorer quality of life (QoL) of patients. This leads to great need initiate and implement palliative care (PC) to improve patients QoL. PC nursing is on the priority within such endeavors, which is still in its early development and needs national and international support.

On the clinical aspect, only one PC team, composed of a nurse and a social worker, is implementing PC consultations in Bethlehem, depending on minor support from local community. On the other hand, opioids are still under prescribed by limited number of physicians only, with no access of nurses to prescription or modification. Hospice service or nurses are not available yet in the country.

Knowledge of PC and its importance is limited among nurses, as well as other healthcare professionals, in Palestine. There is a new initiative to include PC education in the curriculum of undergraduate nurses in the governmental education in the ministry of health, but still no official programs in PC yet. Nevertheless, there are some workshops in PC conducted by the Middle East Cancer Consortium and AL-Sadeel Society. Even though, limited researches done in Palestine suggest a positive attitude of Palestinian nurses toward PC and willingness for its education.

Needs for development of PC include, after adopting supporting legislations and policies within the national system, proper PC training and certification, public awareness, and formation of PC teams. Future outlooks include initiating educational programs in palliative care nursing at the undergraduate and post graduate levels, integrating PC into the national health plans and education, valuing competent palliative care, and more national and international concerns and funds for those struggling to initiate PC in Palestine.

Keywords: Palliative care; Nursing; Palestine; Cancer; QoL; Education; Legislations; Integration

Introduction

Cancer is of the leading causes of death globally. It caused 8.2 million deaths in 2012, 30% of them are preventable [1]. Cancer is the second leading cause of death in Palestine, accounting for 14.2% (6,696 cases) of all deaths, reported new cases in 2014 were 2,294 in the West Bank (WB) of Palestine, with an incidence rate of 82.2 per 100,000 populations (MOH, 2015). Most of the cases are diagnosed at the end stage of the disease [2,3] this late diagnosis makes it difficult to treat and resource cancer care, and results in poor QoL of cancer patients in Palestine (measured global QoL was 42 on a scale of 100 [2], and high financial burden on the patients and the healthcare system; as much more resources are needed to deal with the advanced disease, especially in the absence of generalized palliative care (PC) decision making in the healthcare system in Palestine.

On the other hand, it is estimated that at least 100 million people would have improved QoL if today's knowledge of palliative care was accessible to everyone of the public worldwide [4], as well as that palliative care and pain control is considered as one of the human rights [5]. Moreover, and as cancer is the second leading cause of death in Palestine and in the region [6,7], this represents a significant need for palliative care service in the Middle East region, including Palestine [7]. The vision of the national health strategy for cancer is to have "Better quality of life for the Palestinian people through controlling cancer prevalence in Palestine", and it's fourth strategic objective considers palliative care, and specifically pain relief, as an "essential part of cancer control and can be provided relatively simply and inexpensively" and improves QoL [8].

Quality of life (QoL) for the cancer patients is a vital issue in the presence of this devastating condition that depletes all resources on both the individual and community level. Palliative care for cancer patients is the advanced and most up to date choice that should be provided for them. Unfortunately, palliative care is not integrated in the healthcare system in Palestine yet [2,7-9]. One study findings illustrated the main problems in the region in lack of fund or governmental support, and lack of awareness for need for such service among the public as well as the policy makers and professionals [7,10].

PC nursing is still underdeveloped in Palestine. There are only two PC nurses in Palestine trained officially and have certificates. However, there is a non-governmental organization in Bethlehem, AL-Sadeel Society for Palliative Care, who initiated in 2008 the first professional conference for palliative care in the country, which included nurses and other health professionals. This organization is the first and only

one so far in this field. It is run by specialized PC nurse and tries to spread awareness and knowledge, among healthcare providers and clients, about the importance of having palliative care service to be integrated within the healthcare system. These efforts are still in the beginnings and need a lot of support both on the national and international aspects [11].

Clinical Aspects

It was found that low level of pain control and palliative care, low level of staff training, and also low number and level of health facilities that care for cancer patients in Palestine are available; only three main centers in WB [12]. As well, there are no hospices or hospice care available for such patients.

Multi-disciplinary teams play an important role in addressing patients' needs early and providing them with advice for better access to the best benefits and least costs. A survey of the Middle Eastern countries showed that about 55% have PC consultation team or service [13]. To the best of our knowledge, there is one palliative care team working in Palestine. It adopted the consultative model of PC; it implements PC consultations for cancer patients, in the main governmental hospital for cancer care in the WB. This team is the team of the AL-Sadeel non-governmental organization, which is composed of a PC nurse and social worker, with occasional consultations from an oncologist, who has six months training in PC. Now, this team is providing PC consultations for patients and their families in the inpatient and outpatient departments in the hospital, as well as in the homes; with limited access due to lack of funds. AL-Sadeel society records of 2014 showed that the team provided services to a total number of 554 patients and 476 family caregivers; distributed as follows: 469 patients and 411 family caregivers at the hospital, 17 patients and 45 family caregivers at the home, and 68 patients and 20 family caregivers at the PC clinic in the society itself.

Nurses still do not have any privileges to order or modify any medications, especially pain medications such as Morphine, for patients. Opioid drugs are still prescribed only by limited number specialist physicians only. Nurses working with cancer patients, terminally ill patients, geriatric departments have no special training in end of life care or in PC. Moreover, Staff shortage in hospitals is also a serious problem. Nurses' accessibility to controlled drugs is constricted and complicated. Myths and misbelieves of nurses regarding side effects of opioids are also major obstacles [9].

Moreover, there are still no such services like hospice, geriatric homes, and home nursing. Even though, there is some unorganized and not official home care nursing services scattered in the centres of some urban areas in Palestine. These usually are run by individual nurses on bases of personal contact with some patients and their families undergoing hospitalization for chronic and terminal illness. There is one privately owned centre in the south and one in the middle of the WB that provide private home nursing care services for patients who can afford it by direct out-of-pocket expenditure.

Knowledge

There is limited knowledge of PC services and importance among the general nursing population in Palestine. A survey of the Middle Eastern countries showed that 86% of respondents wished to learn more about palliative care [13]. A small scale study in the northern part of the WB of Palestine showed that nurses had poor knowledge of PC [14]. Moreover, most health care providers in Palestine who work in cancer units need training and education concerning providing patients with palliative care [9]. These results emphasize the fact of poor knowledge of nurses in Palestine about PC modalities, as well as the disparate need for such service to be provided to patients with cancer and other chronic diseases.

Education and Training

To recognize the value of palliative care there is need for competent palliative care. This can be done through including palliative care requirements in the training programs of nurses, and through system redesigns that has palliative care as essential part of its standard cancer care. This will need, off course, necessary investments in resources; both human and logistic [15]. The tragedy is the non-availability of palliative care for most of the world's population [4], as it is the case for Palestine now.

Taking into consideration the current status of palliative care in the various countries in the Middle East, it seems that the most urgent task would be to focus on the education of professional staff members, physicians and nurses, in order to come up with a reliable, updated nucleus of experts who would be responsible for the development of modern palliative care teams. A third party such can facilitate the organization of such educational activities in the region. AL-Sadeel initial activities focused on education and training of physicians, nurses and the public (patients and their families) about basic principles of palliative care [16]. There is need for training of health professionals in palliative care, scientific workshops and conferences for professionals who are working in the field of cancer care, and to involve palliative care education within the curriculum of schools of health professions [9,11].

There is no official or evidence-based recommendations for what would be the best method or approach of training or education of palliative care in Palestine. But suggestions include integrating it in the curricula of undergraduates of medicine and nursing, special training courses for professionals working in the field, exchange programs with other countries that have palliative care service, and organizing scientific conferences and workshops for professionals on regular bases [11]. This should be arranged and supported by the government and the ministries of health and education, the local partners who work in the field of cancer care and education, and the international donors and supporters. All of that would be doable only when the issue of palliative care got the attention of the policy makers and achieve the success to be put on the priority agenda on the national and international aspects.

To the best of our knowledge, there is no any specialized educational or training program in palliative care in Palestine in nursing schools yet. Also, there are no specialty diplomas in the field of PC nursing. Moreover, no formal educational courses are available in this field so far for nurses working with cancer patients. Nevertheless, there are collaborative efforts between AL-Sadeel society and the health education directorate at the ministry of health (MOH) to integrate palliative care education at the undergraduate level for nurses. This would be the starting point of palliative care education in the country, and it will include primarily students of the governmental nursing education through the ministry of health.

This project is funded by the World Bank and implemented by the MOH in partnership with AL-Sadeel society and Augusta Victoria Hospital (AVH). It includes evaluation and restructuring of the curriculum of the bachelor in nursing, as well as training of junior

students. So far, about 120 undergraduates had training in PC in AVH and Beit Jala governmental hospital by AL-Sadeel PC team, in the preparatory phase of the project. Also, through this partnership three workshops in PC have been conducted for nursing students and teachers. Moreover, a training fellowship for faculty members from the MOH, AL-Sadeel, and AVH was done in King Hussein Cancer Centre in Jordan.

In addition to that, AL-Sadeel society has organized, in the last 2 years, two workshops in issues related to PC for nurses and other health professionals working in the MOH hospitals in WB. Also, AL-Sadeel is currently working on developing an online PC course in cooperation with MOH. This ten-module online course is based on the EPEC-O training curriculum, and it will be available for nurses and other healthcare providers in the MOH in September 2015.

The Middle East Cancer Consortium (MECC) has participated significantly in providing specialized and professional workshops in PC topics for nurses. Of these in 2014 was a training course for three days for nurses and other professionals in cooperation with AL-Quds University, and an international conference in PC for oncology in Turkey.

Despite all of that, still there are no programs, diplomas, or degrees in PC for nurses in Palestine.

Attitude

Nurses' attitude toward PC is somehow unclear due to limited number of studies about attitude of Palestinian nurses, and due to inadequate awareness and knowledge of them in the field. One study found that Palestinian nurses' attitude towards PC was moderate [14]. One small scale study of nurses' attitudes in three hospitals in the northern part of the WB found that they have a moderate or balanced attitude toward PC [14]. This is maybe due to lack of knowledge of PC amongst those nurses. Most nurses get terrified when they are asked to work at cancer units or even handle the cytotoxic drugs. In addition, nurses' attitude toward patient's perception of pain and disbelieve of the patients' complaint of pain is another obstacle. Moreover, pain management is not in the priority of the nurse schedule of work and daily duties and is not taken as a fifth vital sign [9].

Awareness campaigns in local community and through media toward the importance of palliative care for better QoL for cancer patients are needed [11]. Education should be on multiple levels including nurses and other healthcare providers, as well as societal and religious figures of the community to overcome any cultural or religious barriers, which may not necessarily to PC concepts, but to education in PC [16].

Research

Generally speaking, research is limited in Palestine in the field of PC and QoL of patients with cancer and other chronic and serious diseases. However, there were few researches done to study cancer patients and their suffering. There were two researches in 2011 on the bachelor level done by nursing students from Bethlehem University in cooperation and technical support from AL-Sadeel society. Also, another master level research of the QoL of cancer patients was supported by the society in 2013 in cooperation with AL-Quds University. As well, another one was done in 2014 by nursing students from AL-Najah University. Recently, a PhD research project is in progress in cooperation with Hebrew University that will focus on outcomes of PC services provided by the AL-Sadeel society.

Few other unpublished researches was done by nursing students from several universities in Palestine were performed in cooperation with AL-Sadeel, as it is considered a scientific and clinical resource for researchers looking in this field in Palestine. The AL-Sadeel society plays a role in supporting and participating in research in the field of palliative care and QoL of cancer patients in Palestine [11].

Legislation

Nurses' accessibility to controlled drugs is constricted and complicated and is considered a major obstacle [9]. As well, there are no certificates in PC for nurses or accreditation for related training of education in the field. The MOH rules and regulations do not recognize PC, hospice care, or end-of-life care as a sub-specialty in nursing yet. The Worldwide Palliative Care Alliance recommends that governments must integrate palliative care into each country's health care system.

Needs

The main areas for attention in the scope of needs for development and initiation of palliative care services in Palestine, as well as it is same with other places, are professional training, public awareness, and integrating palliative care into the healthcare system and health education [7,9-11]. But unfortunately, the Middle East countries still lack governmental policies that recognize palliative care [16].

The healthcare organizations in the field of cancer care should promote education on pain management and ensure correction of wrong beliefs and myths, such as those related to pain management and addiction, should educate and train staff on issues related to palliative care, pain and symptom management, and communication skills, and should work on formation of multidisciplinary teams to care for cancer patients [11]. Promoting palliative care education and certification for physicians and nurses is crucial [13].

Oncology nurses at the Palestinian Authority face many challenges and obstacles in their practicing of pain management for the cancer patient. These challenges are classified under 3 main categories: rules and regulations, nurse-related practices, and patient and family beliefs [9]. Of the top barriers found in recent survey, to the provision of PC services in the Middle Eastern countries, is the need for staff training in the field, which include nurses specialization in PC [13].

Nurses effect in the process of pain management in local oncology department in the governmental hospital is limited to administering the ordered medications for the patient, as well; the high work load, the limited time available for assessment of patient needs and pain, and the lack of training and education in pain management and palliative care are of the main obstacles [9].

Future

The availability of good educational system in the nursing schools in Palestine is an opportunity. These universities, which already provide education in many nursing aspects, in collaboration with other available resources; such as hospitals, NGOs, and international supporters, are good candidates for hosting and initiating educational programs in palliative care nursing at the undergraduate and post graduate levels. Within this scope, there is a process in progress now in

Palestine, in collaboration between the only governmental nursing college (Ibn Sina College for Nursing and Midwifery) and the only palliative care provider [12], to integrate a palliative care education and competencies in the curriculum of the undergraduate nursing students. This, maybe, will be the start of a systematic approach toward building up the bases for palliative care education and service in the country.

Conclusion

The poorer QoL of Palestinian cancer patients, on comparison with other similar populations, might be due to the deteriorating socio-economic and political situation in the country, and/or lack of professional and specialized care to support cancer patients [2]. Also, the lack of secured funds for organizations working in the field, and no enough cancer care facilities are of the main factors in not having palliative care service in Palestine yet [11]. Barriers to PC are also the protective attitudes of the family of patient [9].

Moreover, the challenge of chronic diseases, including cancer, is not the only one. The national economy, strategic planning, health-care policy formulation, and national priority setting are affected by the prevailing geopolitical situation. The geographic and administrative fragmentations of Palestine, and the barriers to movement, are all having their damaging effects on the health care system abilities and deliverability. In addition to adding to the physical suffering of patients and the financial costs since they have to travel for treatment [17].

Within these endeavours, many strategies defined nationally and internationally to bridge in the gaps to implement palliative care programs and education. Of these; are integrating PC into the national health plans and education, education and training of nurses and other healthcare providers in PC, providing good nursing care including home-based nursing care, especially as most patients prefer to die at home and not able sometimes to afford coming to the hospital, and valuing competent palliative care, including palliative care requirements in the training programs of nurses and professionals [2,4,11,15,16,18,19].

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