

Cultural challenges in implementing palliative services in emerging countries

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Abstract

Introduction: Palliative care (PC) has been defined by the World Health Organization (WHO) as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual [1].

Palliative care is a relatively new discipline in Lebanon although progress has been made in recent years. On 2004, the ministry of public health introduced palliative care as a patient right in an article of the law on patient rights and informed consent and established on 2011 a National Palliative Care Committee [2], with the mandate of elaborating national plans for research, education, practice and policy related to palliative care. This committee launched on October 2012 the national strategies and plans to raise public awareness: introduction of a primary palliative care curriculum into medical and nursing schools and primary care residency programs to ensure that all primary care physicians can provide a basic level of palliative care to the community; recognition of PC as a new specialty; incorporation the standards for essential palliative care into the new hospital accreditation criteria to ensure that all hospitals in Lebanon are providing a minimum level of palliative care to their patients; introduction of new narcotic drugs to the market and facilitating the procedure to renew them [3].

Many hospitals have already special pain clinic and some of them recently introduced a consultant PC team (mobile team) but only 2 has PC unit. In our hospital, we launched PC services with an interdisciplinary team 3 years ago, then prepared for a PC unit with adequate local and equipments. Attitudes and approaches to PC vary widely amongst religions and cultures. Decisions are influenced by the beliefs of the caregivers, patients and their families. Several studies stressed the importance of cultural issues when practicing PC. Concepts such as decision making, life support and advance directives, family involvement in the care, suffering and expression of pain, as well as religion and faith differ from one culture to another and play important roles in how end-of-life care is perceived [4].

We describe cultural aspects of PC in our country and discuss, based on our clinical experience, the attitudes and practice of physicians and nurses in PC and challenges to implementing PC in emerging countries.

Cultural aspects of PC in our country and current attitudes and practice: In our society, death remains a taboo subject that we try to hide from our reality and that is why we rarely approach it even with patients at the end of life. In a recent survey we conducted with university students to test the attitudes of our society towards death and the end of life, more than half of the students considered that our society refuses to face death and does not even allow us to choose the place to die [5]. Although 76% of these students say they would like to die at home, the majority of the patients in our country die in the hospital. The main barriers to home support are financial cost and insufficient specialized teams to manage these patients at home.

With the extraordinary progress of medicine in our milieu, it is logical that deaths predominate in institutions, and these advances, in a context of repression of death, lead to over-medicalization of the end of life. It leads also to the exclusion of the person who is dying, especially when she perceives the gap between the worsening of her situation and the speech held to her and this is a major anxiety factor. Truth is a right for every human being. In our country, physicians often can't inform the patients about their diagnosis or prognosis by resigning to the wishes of the family who consider that the truth will lead to grave and even lethal consequences for the patient. In Abu-Saad Huijjer's survey published on 2007, the majority of nurses and physicians reported that the patients should be informed of the diagnosis and prognosis; however, only 19% of physicians routinely inform terminally ill patients about their diagnosis [4]. These results are not surprising because in Lebanon, the family plays an important protective role in the life of individuals. However, with the advancement in education and technology, patients are becoming empowered and as such increasingly knowledgeable on diseases and treatment modalities, leading to their increased involvement in the disease-making process.

Challenges to implementing PC in our country: Several trends in health care today decrease the chance of cancer patients having access to palliative care. These range from limited availability of palliative care services to the philosophy of patient care that dominates our health care system. With the aging of our population and the increasing number of cancer patients in Lebanon, the need for teams and programs that provide PC services will also increase. The recognition of the specialty by the ministry of health and the adequate reimbursement for PC services later will encourage physicians in training to consider careers in PC. The expansion of the pool of PC providers is an essential step towards ensuring that PC services are available to anyone who may need them in the future. The role of nurses should also be recognized and rewarded appropriately.

Most patient care in our country is disease oriented, with a focus on the tumor, the treatment approach and specialty consultation by various medical disciplines. Care is usually complex and treatment involves many specialties with fragmentation of the individual patient's care and limited coordination of care across this many disciplines. One approach is to transform the current disease focused approach to a patient-centered philosophy, where the needs of the patient and patient and family goals become essential to planning the patient's care. The interdisciplinary

PC team should include at least a physician, a nurse, a mental health specialist, a social worker and a spiritual consultant to respond to all the needs of the patients and their families. Spiritual support is an integral aspect of PC and is often neglected in the routine management; or, this is essential in a multi-confessional country like Lebanon in order to insure community buy-in and collaboration [3].

Another difficulty that we encountered during our practice is late consultation of PC team and late referral of patients. This is not surprising in a private system where individualism culture predominates. Reason for the late referrals includes also patients, families, and medical staff difficulties switching to a non-treatment mode, inability to have the conversation about death with the patient and family, and reluctance of the patient and family to give up the search for a cure. A change in health care to include PC early in the course of cancer can begin to familiarize the family with PC services, start communication about death earlier in the course of treatment and provide an opportunity for a discussion of goals of care among physician, patient and family. We hope that this situation will change in the future with the better understanding of the mission of PC team by the patient and his family and by understanding his role in supporting and advising the initial teams in the management of these patients. An additional challenge to implementation of palliative care is the limited evidence for this specialty. Needed are studies that provide evidence to guide better decisions on symptom management, different health care models, decision-making approaches about treatment options, communication on sensitive topics such as death and support for family caregivers [6].

Summary

In order to provide the best possible care to patients and families in end-of-life situations, it is important to understand their cultural constructs as well as their individual preferences. In our society, there is a crisis in the face of dying and we have difficulty managing satisfactorily the terminal phase of existence. The policy of non-informing the patient about his diagnosis must be contested and public education is necessary.

In order to improve end-of-life care in our country, it is essential to create in hospitals PC services adapted to the cultural, social and economic specificities of our country, involving the private and public sectors.

It is also essential to improve the management of these patients at home and the creation of specialized teams in this field, especially that patients often express the choice for the home.

Biography:

Mouhawej Marie Claire studied at St Joseph University in Beirut. She is specialized in Palliative Care from Claude Bernard University in Lyon (France). She carries 30 years of multifaceted experience in managing and dealing with different population of patients. She is the co-founder of the first home hospice in Lebanon and she launched the palliative care program at Hotel Dieu de France (HDF) in Beirut and soon after the first palliative care unit in Lebanon. She is an often-invited speaker on Palliative Care issues in different settings: academic, serving centers and others. She frequently attended conferences as an invited member and sometimes as a presenter of specific topics in local, regional and European conferences. She is the member of the registered nurses order in Lebanon and member of the SFAP (Société Française d'accompagnement et de Soins Palliatif).

