

Special Edition
**"Palliative Care and Oncology:
 Time for Increased Collaboration
 and Integration"**

Mini Review

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Special Edition 1

Article Ref. #: 1000PMHCOJSE1104

Article History

Received: March 6th, 2017

Accepted: April 25th, 2017

Published: April 25th, 2017

Citation

Mouhawej MC, Maalouf-Haddad N, Tohmé A. Cultural challenges in implementing palliative services in Lebanon. *Palliat Med Hosp Care Open J*. 2017; SE(1): S15-S18. doi: [10.17140/PMHCOJ-SE-1-104](https://doi.org/10.17140/PMHCOJ-SE-1-104)

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Cultural Challenges in Implementing Palliative Services in Lebanon

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ABSTRACT

Palliative Care (PC) is a relatively new discipline in Lebanon with some progress being made in recent years. Based on our clinical experience, we describe and discuss the cultural aspects of palliative care, the attitudes and the practice of physicians and nurses in PC, and the challenges to implement it in our country. In our society, death is a taboo subject that is rarely discussed, even with patients at the end-of-life. Under family pressure, physicians do not inform the patients about their diagnosis or prognosis. With the extraordinary progress of medicine, more deaths occur in institutions. These advances, in a context of repression of death, lead to over-medicalization of the end-of-life and to the exclusion of the dying person. Several trends in health care today decrease the chance of cancer patients to have 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. Most patient care in our country is disease oriented. Care is usually complex, and treatment involves many medical specialties with fragmentation and limited coordination of patient care. One approach is to transform the current disease-focused approach to a patient-centered philosophy. With the aging of our population and the increasing number of cancer patients in Lebanon, the need for PC teams and programs will also increase. The recognition of the specialty by the Ministry of Health and the adequate reimbursement for PC services will encourage physicians in training to consider careers in PC. Education of professionals in palliative care and clarification of the concept to the general public are also essential steps to improve PC.

KEY WORDS: Palliative care; End-of-life; Death; Patient-centered care; Supportive care; Cancer patients; Quality of life.

ABBREVIATIONS: PC: Palliative Care; WHO: World Health Organisation; QoL: Quality of Life.

CURRENT STATE OF PALLIATIVE CARE SERVICES IN LEBANON

Palliative Care (PC) has been defined by the World Health Organisation (WHO) as 'an approach that improves the quality of life (QoL) of patients and their families facing the problems associated with life-threatening illness. This is achieved through the prevention and relief of sufferings and early and precise identification, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems'.¹

By current estimates, Lebanon has an annual mortality rate of 4-5/1000, or over 22,000 deaths a year. There are more than 8000 new cases of cancer each year, and around 12,000 patients are in need of opiates. Sixty percent of patients need pain relief and PC but only 5 to 10% receive PC.²

Palliative care is new to health care in Lebanon. The concept was first introduced in 1995 at the WHO National Cancer Control Workshop and later at the Middle East Oncology Congress in 1999. These workshops helped launch the first efforts to establish PC services in the country.

On 2004, the Ministry of Public Health introduced a law confirming the patients' right to PC and informed consent and established on 2011 a National Palliative Care Committee,³ with the mandate of elaborating national plans for research, education, practice and policies related to PC. This Committee launched on October 2012 a national strategy to raise public awareness. It incorporated the standards for essential PC into the new hospital accreditation criteria to ensure that all hospitals in Lebanon are providing a minimum level of PC to their patients, recognized PC as a new specialty, introduced new narcotic drugs to the market and facilitated their renewal procedure.⁴

Many hospitals already have special pain clinics and some have recently introduced a consultant PC team; only 2 hospitals have inpatient PC unit.

Three years ago, we launched in our hospital, an interdisciplinary PC consultant team, consisting of a specialized physician in PC, a specialized nurse, a psychologist, a social worker and a priest and prepared for a PC unit with adequate ward 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 patient 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 (Table 1).⁵

We describe the 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 barriers to its development. We also propose some recommendations as to how to address the barriers to providing PC in our country in a culturally appropriate way.

CULTURAL ASPECTS OF PC IN OUR COUNTRY AND THE BARRIERS TO ITS DEVELOPMENT

In our society, death is a taboo subject that is rarely discussed 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.⁶ 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.

Patients and family members request sophisticated treatment to prolong life at any cost, even with great sufferings. They accept physical and psychological pain as a price to pay for an illusional prolongation of life upto the last moments.⁷ This new attitude has replaced the formally accepted and embedded social tradition of dying with dignity in the warmth of a family. Now-a-days our society prefers to die in hospitals surrounded by beeping and whistling machines. Also, uncovered financial costs, and insufficient specialized PC teams are important barriers to home support.

With the extraordinary progress of medicine in our milieu, it is logical that more deaths occur in institutions. These advances, in a context of repression of death, lead to over-medicalization of the end-of-life and to the exclusion of dying person, especially when he perceives the gap between his worsening situation, and the promises held, thus creating an additional factor of anxiety.

The idea of a crisis of death was experienced in western societies in the 1970s. Thomas⁸ published in 1975 his book *Anthropologie de la mort*, in which he made a comparative research on the experience of death in the West and in Africa. Thomas opposes the good traditional African death, characterized by the acceptance and integration of the latter, the paternalism and securing of the dying person taken in charge by the group, to the

Table 1: Cultural Issues Specific to the Development of PC Services in Lebanon.

Cultural aspects of PC	Current attitudes and practice
- Death is a taboo subject.	- Professionals rarely approach death even with patients at the end-of-life.
- Truth will lead to grave and even lethal consequences for the patient.	- Paternalistic approach in care provision. Physicians often cannot inform the patients about their diagnosis or prognosis by resigning to the wishes of the family;
- Surrogate decision making is frequent.	- Exclusion of the dying person even from the important decisions concerning his life.
- PC is equated with failure of treatment.	- Late consultation of PC team and late referral of patients.
- Narcotic prescribing is equated to some patients or their families with the end-of-life.	- Narcotic prescribing necessitates often a long discussion.

repressed death of the Western industrialized world, lived in anguish, loneliness and denial.^{8,9}

Another aspect of PC in our country is reluctance to tell the truth which is a human right. In our country, physicians often cannot 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 Huijer's survey published in 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.⁵ 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 decision-making process. This need to move from the paternalistic approach in care provision to patient-centered care that promotes patient autonomy has also been reported in studies from other countries in the Mediterranean Basin.^{10,11} We should also notice that narcotic prescribing could be equated to some patients or their families with an end-of-life.

Several trends in health care today decrease the chance of cancer patients to have 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 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, focusing on specific treatments, delivered frequently by a multitude of poorly coordinating medical specialists. This results in a complex and fragmented medical management of patients. One approach is to transform the current disease focused approach to a patient-centered philosophy, where the needs and the goals of the patient and the patient's family become essential in planning patient 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 of the needs of the patients and of their families. Spiritual support, often neglected in the routine management, is an integral aspect of PC. It is essential in a "multi-confessional" country like Lebanon in order to insure community buy-in and collaboration.⁴

Another difficulty that we encountered during our practice is late consultation of the PC team and late referral of patients. This is not surprising in a private system where indi-

vidualistic culture predominates. Reasons for the late referrals also includes the fact that PC is equated with failure of treatment, making it difficult for patients, families, and medical staff to switch to a "non-treatment mode" and to give up the search for a cure. Even health professionals often have misconceptions about PC and consider it as terminal care or care applicable only to oncology patients. A change in health care to include PC early in the course of cancer, in parallel with conventional curative medicine, may 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 between physician, patient, and family. The better understanding of the mission of PC team by the patient and his family, and the understanding of its role in supporting and advising the initial medical teams in the management of patients is an important step to change this practice.

An additional challenge to implementation of PC 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.¹²

SUMMARY AND RECOMMENDATIONS

PC is a relatively new discipline in Lebanon. Although, progress has been made in recent years, only 5 to 10% of patients who need PC receive it. Most PC services are provided in large cities, leaving a large segment of the population without access to PC. Furthermore, over 50% of patients cannot afford PC services or medications.

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, the terminal phase of existence and death constitute a crisis that is poorly managed. The policy of non-informing the patient about his diagnosis must be contested and public education is necessary.

Introducing early PC for cancer or other life-threatening illnesses and recognizing PC as new medical specialty, may help accepting the actual situation of patients and reduce the taboo of death among people. PC can provide better QoL for the patients and their families by managing all the unpleasant symptoms.

Recommendations to improve PC in our country,

- Education of professionals in PC is urgently needed. Primary palliative care curriculum should be introduced into medical and nursing schools and primary care residency programs should be added to ensure that all primary care physicians can provide a basic level of palliative care to the community.

- Education and clarification of the concept of PC to the general public who needs to learn what palliative care entails and how palliative care teams operate in many general and specialist hospitals (media, press, leaflets, etc.).
- Adequate reimbursement for services is essential if palliative care programs are to be established. This will allow the expansion of palliative care services, and will also encourage physicians in training to consider careers in palliative care.
- Standards for Palliative Care Programs and Centers of Excellence in Palliative Care should be publicized to allow hospital administrators to work towards these goals. It is essential to create in-hospital 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 to create of specialized teams in this field, especially that patients often wish to be treated at home.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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