Palliative care focuses on relieving suffering in patients with serious illness. Patients who receive palliative care have better control of distressing symptoms, are less likely to suffer from depression and have a better quality of life.

Although palliative care has become an integral component of health care systems in many developed countries, it has yet to be established in most developing countries. In Lebanon, Palliative care was only recently recognized as a specialty and there are not enough palliative care providers to cover the needs of the population. This article describes the opportunities and barriers to the development of palliative care in the Lebanese context.

Keywords: palliative care, Lebanon, health services

INTRODUCTION

Palliative care is a medical approach that focuses on the relief of suffering and improvement in the quality of life of people with serious illness. Palliative care does not seek to postpone or hasten the dying process but regards dying as a natural fact of life that must be managed with a focus on the comfort of those who are dying and their families [1].

Patients with serious illness who receive palliative care have improved quality of life compared to those who do not. They are less likely to suffer pain and other distressing symptoms and are less likely to have depression associated with their illness [2]. A recent study showed that patients who receive palliative care early in their illness live longer than those who do not [3]. Palliative care has also been shown to improve the experience of caregivers and reduce the costs of medical care towards the end of life [2]. This has been attributed to a decrease in unnecessary hospital admissions and in the use of expensive and often futile medical interventions that are common towards the end of life [4].

Approximately 77% of deaths in Lebanon are attributed to chronic diseases such as cardiovascular disease (45%) and cancer (10%) [5]. It is estimated that about 60% of the 25,000 people who die in Lebanon each year could benefit from palliative care [6]. Palliative care needs are only expected to increase as the population ages and the proportion of people living with chronic illness increases. Yet, the majority of people who could benefit from palliative care in Lebanon do not receive it [7]. Unfortunately, the medical community in Lebanon has yet to embrace the concept of palliative care. Palliative medicine was not recognized as a medical specialty until June 2013 and, until recently, there had not been any serious efforts to integrate it into the healthcare system [8].

In the late 1990s and early 2000s, the Lebanese Cancer Society organized a series of workshops on palliative care. These resulted in the establishment of a Pain Relief and Palliative Care Group (PR & PCG) within the Lebanese Cancer Society. The PR & PCG brought together individuals from various disciplines from all over the country who had an interest in the development of palliative care in Lebanon. Members of this group published recommendations for the development of palliative care in Lebanon in 2008 [7]. These included:

- Integration of palliative care into undergraduate medical curricula;
- Establishment of postgraduate training programs in palliative care for physicians and nurses;
- Development of an advocacy campaign to increase awareness about palliative care among policy makers, health care providers and the community;
- Revision of current regulations regarding prescription of opioid analgesics;
. Establishment of palliative care in hospitals as well as home care services;
. Initiation of multidisciplinary research on topics related to palliative care.

Since the publication of these recommendations, there has been little progress in Lebanon. Although some nursing schools have included palliative care in their curricula, palliative care has yet to be integrated into medical school curricula. There is also no postgraduate training in palliative care. Furthermore, even though a number of hospitals have been considering starting palliative care consultation services, the American University of Beirut Medical Center is the only hospital with an active palliative care consultation service. This service was launched only recently, in August 2013.

In May 2011, the Lebanese Ministry of Public Health announced the establishment of a National Committee for Pain and Palliative Care with a mandate to develop palliative care in Lebanon [9]. This committee has started actively working towards that end. As we move towards establishing palliative care, it is important to recognize the challenges that we face as well as the factors that would favor and facilitate the development of palliative care in the Lebanese setting.

This paper is a reflection on the challenges and issues associated with delivering palliative care in Lebanon based on my experience as a provider of palliative care in Beirut over the past five years.

PATIENT CHOICE, TRUTH-TELLING AND ADVANCE DIRECTIVES

Application of many of the concepts and practices of palliative care in Lebanon requires recognition and an understanding of the customs and norms particular to Lebanese culture. This applies particularly to the concept of truth-telling which is highly valued and an accepted part of medical practice in Western cultures but remains debatable as a practice in Lebanon [10-11].

Many physicians and caregivers continue to argue that giving patients bad news is detrimental to their well-being. Interestingly, I have found that, given the choice, a surprising number of patients will opt not to be told about their diagnosis or prognosis. Although most will not express it as eloquently as the patient did in the situation described below, many give clear indications that they do not want to be informed about their medical condition if the prognosis is poor or the diagnosis is life threatening.

"Please don't get American on me!"

NC was a 96-year-old woman with metastatic cancer. She was intelligent, educated and she remained very clear in her thinking and communication until the very last stages of her illness.

One afternoon in the hospital, after I had obtained new information about the progression of her disease, I met with her to discuss her expectations, answer her questions and get a better understanding of what her goals were in terms of her medical care. We had not discussed the extent of her disease or her prognosis, but she had a sense that she was at the terminal stages.

After examining her and a few minutes of a social conversation, I offered to answer her questions and provide any information that she wanted regarding her illness and management options. She interrupted my offer with: “Please don't get American on me! They like to talk about these things and lay everything out on the table. I don't want to talk about these things. I trust that you will make decisions that are in my best interest."

Providing care that is in line with the values and beliefs of patients is a central component of palliative care. As illness progresses, important choices often need to be made regarding testing and treatment. When the patient does not “like to talk about these things,” choices become increasingly more complex and the “best approach” becomes less clear as each potential intervention has associated risks and benefits. Patients and their families need to be properly educated and informed about their options. This enables them to make the best decisions regarding their healthcare. It also ensures that interventions and medical procedures that go against their values and goals are avoided.

Advance care planning is one way that individuals can communicate their wishes regarding medical interventions should they become seriously ill and incapable of expressing their choices in the future. Advance care planning allows patients to define the treatments they wish to receive and forgo medical interventions when care is considered futile. They also allow individuals to designate someone to make health care decisions on their behalf. Advance directives have been used in different forms in many Western countries. They are legally binding and health care providers are legally protected when they honor the decisions of their patients.

There are numerous barriers to setting advance health care related goals in the Lebanese setting. Discussion of death and dying remains a taboo and few people are able to have open discussions about these issues with their families. The belief that mention of something negative can induce it is commonly held. Many avoid the mention of death or avoid using words like cancer in the belief that mentioning them could invite them. However, even when people are able to have these discussions, there is no mechanism to document their choices in a legally binding manner. Families often find themselves in situations where they have to make serious decisions about medical care without prior discussion or planning. The fact that most patients have not discussed these issues with those around them makes it very difficult for health care providers to deliver appropriate care. As such, physicians often find themselves performing invasive procedures and aggressive interventions at the request of family members, which may not be wanted by the patient and are likely to be futile.

When patients have a prolonged serious medical ill-
ness, they usually have the benefit of time to contemplate and communicate their wishes regarding medical care to their families and physicians. However, physicians and family members often do not disclose a serious or potentially life-threatening diagnosis to patients in Lebanon [10-11]. Most cite a fear of causing depression and loss of hope by sharing such information. They argue that disclosure could have negative implications on mental health, quality of life, longevity and response to treatment.

The code of medical ethics does not require physicians to inform patients of their diagnosis and allows concealment if a physician deems it to be in the best interest of the patient. This common practice can work against the principle of informed choice. It allows physicians and family members to avoid disclosure of medical information by arguing that it could potentially harm the patient. Developing a medical approach and legal framework that ensures that patients who want to be informed about their illness and participate in medical decision-making have that option while the wishes of those who do not are respected will be a challenge.

THE HOUSEHOLD, FAMILY AND HOME-BASED CARE

Home-based care is an important component of palliative care. Several studies have demonstrated that patients with advanced illness prefer to receive their medical care at home. Given the choice, a majority of patients would prefer to die at home. In a study of cancer patients in Lebanon, Doumit et al. found that patients dislike hospital stays and feel “trapped” in the hospital environment [12]. Home-based care also reduces medical costs while increasing satisfaction with care [13].

Family ties remain strong in Lebanon and the extended family continues to play a prominent role in the lives of individuals. Family members often act as care providers to their sick relatives at home. It is rare to find a hospitalized patient in Lebanon without a family member at the bedside around the clock to support them and insure that their needs are met. People tend to take pride in the quality of care and degree of attention they provide to a family member who is sick. Placement of the elderly or the sick in nursing homes is still uncommon and is generally considered a form of abandonment.

Family members can be assisted in caring for the sick by paid caregivers. In Lebanon, these caregivers are often foreign unskilled workers who live in the family home and work as domestic servants providing housekeeping services. As the cost of hiring foreign domestic servants is low, a significant proportion of families opt for this option instead of placing the family member with a serious illness in a nursing home. When the need arises, domestic workers become caregivers to the sick or elderly in the family home. The ready involvement of family members in caring for the sick and the accessibility of paid caregivers at low cost make home-based care more feasible in the Lebanese setting. Family members and paid caregivers can be trained to assist patients with their basic needs, which can reduce the need for skilled nursing care.

In our experience, we have found that involving family members in the care of their loved ones has an added benefit to both the care recipient and the caregiver. When they are empowered to provide care to their family member, caregivers feel skilled and supported in providing this care. This increases their sense of control as the uncertainty and fear that often accompanies illness is reduced. We believe that allowing caregivers to play a positive role in the care of a sick family member can also ease their bereavement. Caregivers frequently tell us how comforted they are by the knowledge that they were able to support their loved one during the difficult phases of their illness.

PAIN MANAGEMENT AND OPIOID ANALGESICS

Pain is a frequent source of distress among patients with advanced illness and pain management is an essential component of palliative care. Opioid analgesics such as morphine are essential tools for the management of moderate to severe pain. Morphine is inexpensive and when used appropriately it is safe and very effective in controlling pain. Untreated pain continues to be a problem worldwide especially in developing countries [6]. In Lebanon, there are many barriers to adequate pain management and patients with serious illness continue to suffer needlessly.

The availability and accessibility of opioid analgesics is often restricted because of the potential for abuse of these medications. The International Narcotics Control Board (INCB) monitors and regulates the trade and use of opioids internationally. On the national level, control and monitoring is usually in the hands of ministries of health and law enforcement. These bodies attempt to strike a balance between ensuring the availability of opioids for medical use and restricting trafficking and illicit use.

Opioid consumption statistics are commonly used as indicators of opioid availability for pain management. Opioid consumption trends in Lebanon show an increase in per capita consumption over the past ten years, however rates remain well below what is expected for our population and significantly lower than the global mean [14].

In recent years, Lebanon has witnessed regulatory changes that have reduced the barriers to access to pain medication. Laws allowing physicians to prescribe higher doses for longer periods of time and simplifying the process of having prescriptions filled for patients and families have reduced the bureaucratic hurdles of obtaining opioids. Opioid analgesics are no longer restricted to patients with a documented diagnosis of cancer thus allowing patients with noncancer pain to be treated.

Despite these changes, we continue to face major barriers to prescribing. Prescription of opioid analgesics is restricted to oncologists and pain specialists – specialists who may not be accessible to patients for financial or geo-
graphical reasons. The opioids available on the Lebanese market are limited to long acting oral morphine, fentanyl patches and the injectable forms of both morphine and fentanyl. The lack of availability of other forms of opiates, specifically the immediate release oral forms of these medications, is a major barrier to proper pain management. Immediate release oral formulations are essential for the treatment of acute pain exacerbations and for titration of medications to insure adequate pain control. These have been recently approved by the Ministry of Public Health but are not yet available on the market.

Government regulation is not the only barrier to adequate pain management. Physicians do not receive enough training in pain management during their medical education. Many physicians and nurses remain wary of using morphine for pain management. Health care providers often cite fear of addiction and respiratory depression as their main concerns about the utilization of morphine. Fortunately, neither is a true risk if morphine is used appropriately. The stigma of morphine also affects patients and their families who may resist initiating treatment with morphine due to concerns about addiction or side effects. Many also associate morphine with the terminal stages of illness. Patients and their family are resistant to receiving it because they perceive initiation of morphine as a sign that they are giving up. People will often say that a patient “has reached the morphine stage” which implies that the person is at the very final stages of life.

HEALTHCARE SYSTEM

Since palliative care was not a recognized specialty in Lebanon, palliative care services are not reimbursable by health insurance companies. This not only limits the availability of these services, it also discourages physicians and nurses from considering palliative care as a career option. As a result, there are currently no physicians who devote their practice exclusively to the provision of palliative care. The providers of palliative care currently are family physicians, geriatricians, oncologists or pain specialists who have an interest in addiction or palliative care and therefore dedicate part of their time to providing these services. The recent recognition of palliative care as a specialty should lead to coverage of palliative care services by insurance companies. This is an essential step towards making these services accessible to those who need them. This should include reimbursement of home-based services, which at this stage are not routinely covered by health insurance companies. This omission is especially counterintuitive since home-based services for the terminally ill are actually the most cost-effective and humane form of care available.

Western data shows that people would prefer to die at home. In the US, although 90% of people surveyed indicated that they would prefer to die at home the majority of people continue to die in hospitals. To date, no research has been conducted to establish either preferred or actual place of death in Lebanon. Whereas an unpublished thesis reports that 80% of deaths in Beirut occur in homes [15], a report on NCDs (noncommunicable diseases) states that a substantial number of deaths in Lebanon occur in hospitals [5].

CONCLUSIONS

Although efforts to develop palliative care in Lebanon have been underway since the early 1990s, until recently there had been little progress in the field. In a recent survey of physicians and nurses practicing in Lebanese hospitals nearly all respondents felt that palliative care services should be developed in the country [16]. The establishment of a National Committee for Pain and Palliative Care by the Ministry of Public Health is a clear sign that the Lebanese government is committed to the integration of palliative care into the healthcare system.

As we work to develop palliative care in Lebanon, the issues of disclosure and choice will need to be addressed. Laws that would allow advance directives to be used should be considered. It will be challenging to develop laws and policies that encourage autonomy and choice in a context where serious illness and death are rarely discussed. Patients may choose not to know their diagnosis or prognosis. Health care providers must be sensitive to this and respect that choice. Providers should be trained to read the signs that patients give them and assess the readiness of patients to discuss their medical conditions and their treatment options.

The social and family structure in Lebanon supports the provision of palliative care and specifically the development of home-based care. Home care frees hospital beds for patients who are more acutely ill and reduces costs to the healthcare system. Home-based care is much more feasible in this context where the extended family is present and involved and there is easy access to paid caregivers. However, once the burden of care is shifted from the medical system to family caregivers, palliative care providers should give special attention to training, supporting and empowering caregivers at home. Research to establish whether our observations about the benefits of empowering caregivers are true would be valuable. It would allow providers to consider family and caregiver involvement and empowerment part of their package of interventions.

Several countries have used hospital accreditation systems as a way to ensure the incorporation of palliative care services into their health systems. In the United States, the Joint Commission developed criteria for advanced certification in palliative care to recognize hospitals that provide quality palliative care services. The Lebanese government began the implementation of a new hospital accreditation system in 2002. The MOPH can accelerate the process of integrating palliative care into the healthcare system and ensure that patients have access to some level of palliative care when they are hospitalized by incorporating palliative care into the accreditation system.
There are several organizations that are actively working to support the development of palliative care internationally. Organizations like the US-based International Association of Hospice and Palliative Care or the UK-based Help the Hospices have a mandate to support organizations and governments in palliative care initiatives. The World Health Organization has designated six palliative care collaborating centers that support the development of palliative care programs around the world. These organizations can support Lebanon as it works to establish palliative care and build it into its healthcare system.

REFERENCES