

# END-OF-LIFE CARE

*“CURE SOMETIMES, RELIEVE OFTEN, AND COMFORT ALWAYS”*



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Arab region is largely lacking, and remains an area which is under-searched, worldwide.

While improving the quality of life has been a well accepted concept that informs and underpins public policy, “quality of death” is another matter (EIU, 2010). When the chance of cure becomes unlikely as death approaches, care is shifted to optimize quality of death and to minimize suffering. These efforts have become the basis of palliative care. Too often such care is simply not available. According to the Worldwide Palliative Care Alliance, while more than 100m people annually could benefit from palliative care, less than 8% of those in need access it. Few nations incorporate palliative care strategies into their overall healthcare policy, and training in palliative care is rarely included in healthcare education training curricula. Furthermore, the availability of painkilling drugs is inadequate across much of the world and institutions that specialize in giving palliative and end-of-life care are often not part of national healthcare systems (EIU, 2010). The result of this state of affairs is a surfeit of suffering, not just for the patients, but also for their families. End-of-life decisions are difficult to make and is influenced by several factors such as cultural characteristics, attitudes of families, background and experience of physicians, the nature of health care system, and legalities of the country.

Only recently has end-of-life care gained visibility among health professionals and started to capture the attention of the public health community. The American Medical Association and the Institute of Medicine have outlined goals for improved care at the end of life, and the Robert Wood Johnson Foundation has devoted millions of dollars to public education on the issue. The National Consensus Project for Quality Palliative Care in the US has brought together various organizations to create Clinical Practice Guidelines for Quality Palliative Care addressing practitioners, policy-makers and consumers. More recently, the Lebanese Medical Journal published in 2008 a special issue on “Pain Relief and Palliative Care in Lebanon” advocating for the promotion of high quality palliative care in the country (Issue 56). Also, the Economist Intelligence Unit surveyed several countries and ranked them according to quality and availa-

## POLICY BRIEF

### END-OF-LIFE CARE

Advancements in healthcare have been responsible for the most significant years-of-life gains. However, with aging come more life-threatening diseases and complex issues and that are harder to manage. Few countries across the world recognize late-life care in their healthcare and medical education policies. Drawing on experiences and research findings from Lebanon, this policy brief highlights the ethical, legal, medical and financial challenges facing healthcare systems, physicians, patients and families at the end of life.

### INTRODUCTION

In the 21<sup>st</sup> century, our expectations of life and death are different from those of a century ago (Rao et al., 2002). With aging, older people are at a higher risk of major degenerative diseases such as dementia, disabling stroke and frailty. Increasing longevity, aging populations and more prevalent life threatening conditions mean that the proportion of older people who remain free of health problems is shrinking. Given the unique challenges faced by the very old, it is surprising that information about the circumstances surrounding the end-of-life years of older people in the

bility of end-of-life care and services, devising a “Quality of Death” Index and raising pertinent issues in end-of-life care (EIU, 2010). In this brief, we highlight these issues within the context of the deliberations of the Roundtable Debate which was conducted in Lebanon in October, 2010.

**Palliative care** refers to a comprehensive approach that improves the quality of life of patients and their families facing 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.

**Hospice care** refers to care in specialist institutions, where attempts to cure the person’s illness are stopped. In North America, hospice care is generally interpreted to mean end-of-life care and may refer to care within the home.

**End-of-life care** is the term used to describe the support and medical care given to prevent or relieve suffering in as much as possible during the time surrounding death. End-of-life care includes palliative care but also refers to the broader social, legal and spiritual elements of care relevant to quality of death.

Sources: WHO, 2006 and EIU, 2010

## CULTURAL AND SPIRITUAL ISSUES IN END-OF-LIFE CARE

Religious norms, belief systems and socio-cultural values explain much of national and regional variations in public attitudes to death and awareness of end of life care (EIU, 2010). For example, strong taboos against talking about death exist in countries such as Japan, China and India, thus inhibiting open communication with the patient towards an appropriate treatment plan. In the US, appropriate end-of-life care is often tagged with an attitude of ‘cure at all cost’. Doctors’ own personal beliefs may also play a dominant role in medical practice. Doctors who describe themselves as non-religious are more likely than others to report having given continuous deep sedation medications, and to have discussed these decisions with patients and families (Seale, 2010). In Lebanon, interviews with a sample of physicians about reasons for not involving patients in end-of-life decisions revealed such responses as ‘the belief that the dis-

cussion would mean psychological trauma for the patient or respect for the will of the family which often refuses to involve the patient’ (Pochard et al 2005). Physicians with training in North America reported more willingness to initiate end-of-life decisions by themselves. In a country as Lebanon, with over 15 religious sects, end-of-life care requires knowledgeable and culturally sensitive clinicians to provide individualized care for culturally diverse patients and families (Gebara and Tashjian, 2006).

## THE LAW, ETHICS AND THE DECISION TO DIE

The nature of the health care system and legal structures in the country also have an impact on end-of-life decisions. Euthanasia (in which one party takes action to end the life of a patient, at the request of the latter) and assisted suicide (where one provides the means for patients to end their own lives) have been the subject of debates since several years (EIU, 2010). In several countries, demands for legalizing end-of-life decisions come largely from the public lobby, rather than the healthcare professionals (e.g., Pratchett, 2010). While living wills and do not resuscitate (DNR) documented directives entail a legal status, the difficulty remains for doctors to meet the wishes of a document that may have been written several years ago when the patient was in a very different mental and physical state (EIU, 2010).

“...provision of euthanasia and physician-assisted suicide should not be part of the responsibility of palliative care, and a distinction should be made between terminal or palliative sedation and administration of lethal drugs to patients with the intention of killing them.”

Ethics Task Force of the European Association for Palliative Care, 2003

Ethical considerations underlying end-of-life practices and the involvement of the patient, families and health care members are valued out differently among diverse cultures and various legal structures. Whereas physicians from the Middle East, including Lebanon, seem to consider, within the legal framework, that withdrawal and withholding of life-sustaining treatment are not ethically equivalent and are reluctant to withdraw therapies in critically ill patients, in most European and North American countries, decisions to withhold treatment are not distinguished from withdrawal



decisions. Despite this, European physicians report practicing withdrawing therapy less often than withholding (77% vs. 93%) (Vincent, 2001). Similar variations are noted in Lebanon among ICU patients, albeit at much lower rates (7% vs. 38%) (Yazigi et al., 2005). End-of-life decisions were reported to be made solely by the medical staff without participation of the nursing staff in a quarter of the ICU patients. Around one in five families were not involved in the decision-making process, and patient involvement was noted in only 2.3% of the cases. Furthermore, decisions were not documented in the patients' medical record in 23% of the cases (Yazigi et al., 2005). The lack of guidelines and official statements from Lebanese legal and scientific bodies partly explain the ethical dilemmas of the decision-making process in the country.

#### Legal Considerations: the case of Lebanon

In February 2004, a law (No. 574) was instituted in Lebanon regarding 'Patients Rights and Informed Consent'. This law focuses on the right of the patient and family members to receive information, the necessity to secure informed consent to medical acts, and respect of privacy and confidentiality. While this law has been a breakthrough for medical practice in Lebanon, statements regarding end of life decisions are, however, sometimes contradicting (the physician has no right to cause willful death to the patient, but it will be advisable to abstain from resorting to technical means and from excessive use of medicaments to prolong the moribund to the end, in a way that keeps his dignity; Chapter 2, Article XXVII-10).

The Lebanese Penal Law (Article 552) states that, "shall be punished by detention for up to ten years the one who, in a feeling of compassion, would intentionally put a person to death at his/her insistent request." In spite of this a study conducted by Adib and colleagues (2003) exploring attitudes of judges regarding end-of-life issues reports that that 56% of judges hold an opinion different from article 552, and believes that physicians should be legally allowed to assist terminally ill patients, should those patients express a desire to do so. The study concluded that whereas, the increase in the proportion of health care workers trained abroad, mainly in the United States and Europe, and the enactment of Law No.574 have played a role in raising standards for end-of-life care in Lebanon, there remains a great need to increase public awareness regarding end-of-life matters and the development of appropriate national health policies.

## AVAILABILITY AND ACCESS TO END-OF-LIFE CARE: POLICY ISSUES

### *Availability and use of pain control medications*

Pain is the most frequently identified concern for severely ill patients and their physicians (Steinhauser, 2000). It remains underreported among older people, notably those with dementia and among the institutionalized. In order to draw attention to the need to monitor and treat pain adequately, the Lebanese Society for the Study of Pain, a chapter of the International Association for the Study of Pain (IASP) was founded in 1999, and a Pain Relief and Palliative Care Group was created under the auspices of the Lebanese Cancer Society in 2001 (Daher et al., 2008).

Access to pain control medications varies widely across the world, with only 20 countries accounting for 86% of the morphine consumed. In Lebanon, it is estimated that around 12-15,000 patients are in need of morphine, with the majority of patients facing poor drug availability (Huijjer and Daher, 2005; Daher et al., 2008). There are many reasons for the enormity of the gap between pain treatment needs and what is being delivered. One reason lies in the complex narcotics control regulations restricting the sale of morphine. Furthermore, lawsuits and medical investigations for over prescription involve enormous expense for doctors and influence much the medical pain management practices.

Palliative care is a human right and its provision the responsibility of every doctor:

"The obligation to respect and to protect the dignity of a terminally ill or dying person derives from the inviolability of human dignity in all stages of life. This respect and protection find their expression in the provision of an appropriate environment, enabling a human being to die with dignity".

Source: Council of Europe, 1999

### *Financing end-of-life care*

End-of-life care has considerable financial impact on the individual and the society alike. Governments are rarely the main sources of funding of end-of-life care, and this is partly due to the lack of recognition of end-of-life care

in their healthcare policies. Consequently, funding end-of-life care has relied heavily on charitable donations and philanthropic activity, with the patients and families having themselves to pay for most of the services. In the US, it is estimated that the costs of care associated with the last year of life accounts for around 30% of the overall Medicare budget (Lubitz & Riley, 1993), and this is likely to increase sharply in the near future, owing to the advent of new technologies and intense interventions to the aging population. Studies conducted in a range of settings provide evidence that palliative care, particularly if it were home-based, can be cheaper than traditional medical treatment, and can reduce costs associated with hospital treatment or emergency admissions (EIU, 2010; Liu et al., 2006).

### *Education and training*

Access to quality end-of-life palliative care depends on the availability of trained physicians and nurses, and better equipped volunteers and community workers (EIU, 2010). However, even in developed countries, training in end-of-life care remains insufficiently well established. According to the Association of American Medical Colleges, fewer than 40% of medical schools offer an elective course in palliative care, and even fewer have made such a course a requirement. The nursing curriculum is already overcrowded, making it particularly challenging to find room for the resource-intensive additional teaching models. Khoury (2008) and Naccache and colleagues (2008) note that, while the nursing curricula in Lebanon reflect some form of integrated concepts of palliative care and pain in the undergraduate training, only one medical school includes an eight-hour module in its undergraduate education. Nine motivated physicians and nurses, who had received a 2.5 days training course in 2001 in the US, currently provide the basis for potential trainers in the country. Naccache and colleagues (2008) call for the creation of a multidisciplinary multilevel (undergraduate education, residency programs and continuing medical education) Lebanese National College for Palliative Medicine in the country.

### *Capacity building for home-based care*

Hospice and palliative care is often thought of as being delivered from within an institution, as it was in the early days of the hospice movement in Britain. This remains the case in Lebanon. Most patients die in hospitals in spite of their desire to die at home, and this, in large, because reimbursement policies currently do not support care at home (Huijjer and



Daher, 2005). Considerable savings for the health care system could be realized if an effective coordinated home care system is in place (Daher et al, 2008). There is a potential for such technology as mobile phones and video chatting that help people connect with doctors to change this.

## THE WAY FORWARD

End-of-life care in Lebanon is still in its infancy, and studies in this area are still lacking. The cultural and religious diversity of the Lebanese society offers a particularly fruitful context for studies into such questions as the contextual and ethical considerations of end-of-life decisions.

The recommendations below are drawn from the deliberations and contributions made by a number of colleagues and scholars who participated in the CSA Roundtable Debate on "Late-life care" that was conducted in Beirut, Lebanon (Oct, 2010).

- **Pain control and availability of opioids:** The fact that opioids can only be prescribed by oncologists and only to patients who have a cancer diagnosis makes them inaccessible to people who suffer pain from other causes. The fact that professionals don't have access to immediate release oral morphine also makes it extremely difficult to titrate pain medications properly and quickly.



• **Advanced care planning:** Cultural, religious and legal barriers hinder tailoring care to the individual needs of our patients. Debates and the media are critical to changing public attitudes and act as a catalyst for viewing end-of-life care a process of shared decision making and communication that acknowledges the values and preferences of patients and their families.

• **Promotion and recognition of Palliative Medicine as a specialty:** This as an important step that would help us insure that palliative care services are *reimbursed* by insurance companies and public funds, and hence, encourage physicians to seek *education, training* and certification in palliative medicine. This would also impel us to integrate palliative care into medical and nursing school curricula in the future. Accreditation represents an obvious mechanism for improving the quality of end-of-life preparation.

• **Integration of palliative care into mainstream services:** Data suggest that palliative care decreases depression, improves quality of life and prolongs life when started soon after diagnosis and in conjunction with curative treatments. Early referral to palliative care can also reduce the cost of care among patients towards the end of life.

• **Palliative care need not mean institutional care:** Much palliative care can be, and is given at home. Community and home care can reduce costs associated with futile use of life-preserving medical technologies, hospital stays and emergency admissions. However, capacity building and training of caregivers is necessary to enable homecare with suitably high standards.

• **High-level policy recognition and support:** Integration of palliative care into national healthcare systems is vital. A clear national policy is needed. This does not only facilitate and legislate a patient's right to care, but also the necessary components of education, drug availability and allocation of budget.

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# PALLIATIVE CARE RESEARCH IN LEBANON: CURRENT SITUATION & FUTURE PLANS



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## INTRODUCTION

Palliative Care is 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 (World Health Organization, WHO 2006).

The World Health Organization (1990) and the Barcelona (1996) declarations both called for palliative care to be included in the health services of every country. They stipulated that

- Every patient with an active, progressive, and far-advanced illness has a right to palliative care.
- Every doctor and nurse has a responsibility to employ the principles of palliative care in the care of these patients.
- Successful palliative care requires a multidisciplinary team approach which includes physicians, nurses, social workers, physical therapists, occupational therapists, psychologists, pastoral/spiritual care and volunteers.

Unfortunately, many patients with advanced disease do not receive palliative care; some are referred too late in the course of their disease to benefit from treatment. The reasons for this may relate to the physician, the patient, or to social factors:

- Physicians may lack communication skills to address end-of-life issues; they may not believe in the value of palliative care; they may be afraid of losing control as well as income; and institutional standards for end-of-life care may be lacking.
- Patients may believe the prognosis to be better than what they are told; they may have unrealistic expectations of disease response; there may be patient-family disagreement about treatment options; and advance care planning may be lacking.
- A number of social and legislative factors could play a role such as lack of public education & awareness, high cost of treatments and medications, lack of physician reimbursement for palliative care services, and the current laws and regulations restricting or prohibiting the use of opioids.

## Palliative Care Services

Every country should be encouraged and enabled to develop its own model(s) of palliative care, taking advantage of the available experience and expertise and not copy models from affluent countries. The planning of any palliative care service requires a well-conducted needs assessment study which should address patients' needs, priorities, models of care, relationships with other agencies, discussions with strategic planners and other providers, local health professionals, community, local hospitals, & other palliative care services if they exist.

*Research in this field is crucial in helping each country*

*adopt a palliative care model adapted to its needs and population characteristics.*

## Education in Palliative Care

Palliative care workers often report that politicians, the press, fellow professionals, and even the public do not know much about palliative care. Politicians need to know that palliative care affects people they represent & it is an integral part of health care. Issues related to opioid availability are important issues in developing countries. The press needs to be kept well-informed; they can be the friends and allies of palliative care. They can help raise funds and public awareness & they offer a platform to deal with key issues such as resource allocation and opioid availability. Health Professionals have often misconceptions about palliative care; it is seen as terminal or geriatric care, or care of the incurable, & as being appropriate only to oncology patients. The general public and patients associate palliative care with care of the dying. They need to know what palliative care entails and how palliative care teams can operate in general and specialist hospitals.

*Research and audits can help to define the current situation in Lebanon and the needs for future development of education at all levels in palliative care.*

## Palliative Care Practice

Practice in palliative care is guided by the ethical principles of beneficence, non-maleficence, autonomy, and justice. Different aspects of ethics present themselves as dilemmas in the practice of palliative care and in particular when decisions are made regarding cardiopulmonary resuscitation, withdrawal of alimentation and hydration, & truth telling.

Pain is one of the most common symptoms in palliative care. The aim of palliative care is to allow patients to be pain-free and for their pain to be sufficiently controlled that it does not interfere with their ability to function or impact their quality of life. In palliative care, the treatment of pain needs to be part of a holistic and multidisciplinary approach to patient care. Pain can cause or aggravate problems related to other causes of suffering and the pain has to be controlled before other problems can be addressed and treated; it is not possible to have meaningful discussions about psychosocial concerns if a patient has uncontrolled pain.

Professional opiophobia constitutes the main reason why clinicians do not prescribe opioids to patients with acute/

chronic/cancer pain. The reasons why clinicians under-prescribe and nurses under-administer opioid drugs are: (1) belief that morphine hastens death, (2) fear of respiratory depression, (3) "morphine doesn't work", (4) morphine causes unacceptable side effects, and (5) fear of tolerance, physical and/or psychological dependence. Patient & family opiophobia is also common and is related to the fears of addiction and hastening death.

*Research in this field is essential for the development of evidence-based practice guidelines in palliative care which guide health care professionals in providing most effective care.*

## CURRENT RESEARCH IN LEBANON

Palliative care research is still in its infancy and needs to be further developed in Lebanon a number of studies have been conducted in Lebanon, the results of which are published in national and international journals and are summarized below.

In 2007, a needs assessment study was conducted by Abu-Saad Huijjer et al. (2007, 2008, and 2009) on knowledge, attitudes, and practices of nurses and physicians regarding PC in Lebanon. A total of 15 hospitals geographically spread in Lebanon and 3757 nurses and physicians were included in the study. Results showed that all nurses and physicians expressed the need for palliative care services and for continuing education programs in Lebanon. The majority of nurses and physicians believed terminally ill patients and their families should be informed of the diagnosis and prognosis; however only 19% percent of physicians routinely informed terminally ill patients about their diagnosis. The majority agreed that palliative care should have consultation services, inpatient units, and hospice programs and could be provided at home by ambulatory outpatient clinics, home care agencies, and hospice. The most frequently proposed model for delivering palliative care was 'creating a specialized PC unit within the hospital including a palliative care team', followed by hospice, and home care.

On the issue of truth telling and disclosure, Hamadeh and Adib (1998) found 47% of physicians working in Beirut disclosing the truth regarding cancer to their patients and 41% of the general public preferred to remain uninformed in case of terminal diagnoses (Adib and Hamadeh, 1999). The majority of medical students at AUB on the other hand believed in telling the truth (Hamadeh and Adib 2001). Yazigi et al. (2005) in a study on withholding and withdrawal

of life-sustaining treatment in a Lebanese intensive care unit reported that nursing staff was not involved in the decision making process of 26% of terminally ill patients and families were not involved in 21% of the cases. A significant percentage of nurses (17.8%) and physicians (8.6%) believed that patients do not have the right to choose 'do not resuscitate'. In a qualitative study on communication and truth telling among cancer patients, Doumit and Abu-Saad Huijjer (2008) highlighted the need to move from the paternalistic approach in care provision to patient-centered care that promotes patient autonomy. The patients in this study clearly accentuated their rights to be told the truth about their condition.

In a recent study conducted by Abu-Saad Huijjer et al. (2011, 2012) on the quality of life and symptom management of cancer patients in Lebanon, adult cancer patients reported a fair quality of life and social functioning with high prevalence of physical and psychological symptoms. Nausea and pain were the symptoms mostly treated. The most prevalent symptoms were feeling nervous, feeling sad, lack of energy, and pain; symptom management was in general inadequate. Higher physical and psychological symptoms were correlated with lower health status, quality of life, and functioning. Based on these results, providing adequate symptom management and social support to Lebanese cancer patients is highly recommended. A similar study has been conducted among pediatric cancer patients and is currently approaching completion. Similarly, the results of a study conducted by Ghosn et al. (2011) on the experiences of patients with advanced cancer in palliative care, showed that only 34% of patients were informed of the severity of their disease, 76% suffered from severe pain, and anxiety and depression were prevalent.

In a study conducted by Saad, Abu-Saad Huijjer et al. (2011) on the quality of palliative care services provided to pediatric cancer patients in Lebanon as perceived by bereaved parents, fatigue, anorexia and pain were found to be the most prevalent symptoms and edema the most distressing. Communication with the healthcare team and quality of care were rated by the majority of the bereaved parents as "very good" to "excellent". Parents suggested improving the organization of care, the communication, and the availability of human and material resources.

Studies addressing the lived experience of patients in palliative care (Doumit et al. 2007) highlighted the distress of patients from being dependent; their dislike for being pitied; concerns related to their families; their dislike of

hospital stays; their need to be productive; their fear of pain; and their need to communicate. Similarly, the results of Khoury et al. (2011) on the lived experience of parents of children in palliative care found living with the shock of the diagnosis and with uncertainty, changes in the family quality of living and family dynamics, sibling rivalry and changes in couples' relationships to be most distressing.

Finally, in a study (group project) conducted by Med IV students at the American University of Beirut (AUB) on the economy of terminal pain in Lebanon, three concerns were highlighted: 1) Lebanon has an inadequate geographical distribution of healthcare centers and access is difficult in rural areas; 2) the tedious & bureaucratic system of acquiring narcotics; and 3) limited availability of opioids on the Lebanese market.

## PROJECTED RESEARCH PRIORITIES FOR LEBANON

In order to set palliative care research priorities for Lebanon, a multidisciplinary research subcommittee of the National Task Force on Pain Relief and Palliative Care in Lebanon was appointed (see box 1 with names and mandate of the subcommittee) to discuss and make recommendations. After a thorough assessment of the current situation in Lebanon and benchmarking with other countries, the committee on research proposed a number of research priorities for Lebanon. These priorities are in general aligned with the research endeavors and priorities of a number of research-active countries in the field of palliative care. The priorities focused in the first place primarily on the knowledge, attitudes, and practices of health professionals and those of the public and on clinical, education, and public policy topics. The work of the Task Force is still ongoing and may result in modifications of the proposed priorities listed below. The proposed priorities are grouped under three main areas; public policy, education, and practice.

### A. Public Policy & Organization of Services

- Situation Analysis and needs assessment of palliative care services in Lebanon
- Attitudes of the public with regard to end-of-life care, early referral, and awareness
- Public policy on advanced directives and advanced care planning
- Situation analysis on legislation of withdrawal of life support measures
- Models of palliative care services

### B. Education

- Situation Analysis on palliative care educational programs in Lebanon
- Interprofessional palliative care education
- Pain assessment and management as core curriculum for undergraduate students

### C. Practice

- Pain and symptom management in cancer & non cancer patients, elderly and cognitively impaired
- Truth-telling and family values
- Attitudes towards opioid use and availability
- Chronic pain; prevalence and management
- Non-cancer palliative care needs

Box 1: Research Committee mandate and membership

#### Mandate of Research Committee

1. To develop national research priorities for the field of pain relief and palliative care that target gaps in treatment, knowledge transfer, education, & policy.
2. To recommend research methods to address the gaps in information related to pain relief and palliative care in Lebanon.

#### Membership:

Dr. Huda Abu-Saad Huijjer: Chairperson  
Dr. Georges Karam, Dr. Joseph Maarrawi, Dr. Salah Zeineddine, Dr. Husam Ghosn, & Dr. Mary Deeb

## CONCLUDING REMARKS

Research in the field of palliative care in Lebanon is gradually growing; it remains however in its infancy. Clinical practice in general is still based on experience and needs to become evidence-based, underscoring the importance of research in this field. Ethical and methodological issues are very common and need to be seriously considered when designing studies; the improvement of quality of life of patients should remain the primary endpoint of studies in palliative care.

Palliative care research needs proper funding; specific programs supporting research on a national level are needed. In order to improve palliative care research at the national level, research groups need to be established and given the responsibility and incentives to conduct collaborative research in Lebanon. For this reason, it is important to train a sufficient number of researchers in

palliative care research and to provide them with the support needed to work collaboratively.

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# PALLIATIVE CARE IN LEBANON: ACHIEVEMENTS & FUTURE STEPS



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Palliative care is a new concept in the Lebanese health care sector and it is mainly linked with cancer disease. A thorough literature search yielded to few articles on the topic in Lebanon. Moreover, it is worth noting that cancer in the Lebanese society is believed to be a protracted illness causing great disability and suffering that finally leads to a painful death. Myths and taboos concerning cancer have their expression such as “growth”, “lump” and “that disease” as alternatives. (1)

## ACHIEVEMENTS IN PAIN RELIEF AND PALLIATIVE CARE

Palliative care was first tackled in Lebanon in 1995 during a National Cancer Control Workshop with national health leaders and supported by the Ministry of Health and the WHO. The need for pain relief and palliative care (PC) was identified as a priority. Official morphine quota for Lebanon was 0.5 kg. Only 95 patients were registered to receive opioids. After this workshop, although the need for palliative care was emphasized, dispensing free cancer chemotherapeutic drugs was the only major outcome. (2)

Later, in May 1999, a special full-day symposium on Palliative Care and Ethics was organized by the Lebanese Cancer Society and sponsored by WHO. It became obvious that a positive conversion regarding palliative care

had happened over the past four years between these two workshops.

Recommendations to the Ministry of Health, and a request to WHO for help and action, were agreed upon. The recommended points were as follows: 1) a clear national policy is needed to offer pain-free treatment; 2) an essential drug list, not only for cancer chemotherapy drugs, but also for pain and palliative care drugs should be established; 3) undergraduate training of nurses and doctors in palliative care is essential; 4) reimbursement of treating physicians for palliative care services should be sought; 5) a multidisciplinary approach to palliative care is a must; 6) strengthening home care and social assistance is essential; 7) provision of palliative care is a right for all patients suffering from a chronic and fatal disease (2,3).

### Aims and objectives are:

- Increase the awareness and promote the development and dissemination of palliative care at scientific, clinical and social levels
- Promote the implementation of existing knowledge, train those who at any level are involved with the care of patients with incurable and advanced disease and promote study and research
- Support and give patronage to scientific and educational events promoting the dissemination and development of palliative care
- Bring together those who study and practice the disciplines involved in the care of patients with advanced disease (doctors, nurses, social workers, psychologists, volunteers and others)
- Address the ethical problems associated with the care of terminally ill patients

Afterwards in 2000 the *Lebanese Pain and Palliative Care Initiative* was launched and started under the auspices of the Lebanese Cancer Society. (Table 1)). The members consisted of physicians of several specialties dealing with cancer, nurses, and other health professionals involved in PC. The purposes of this initiative were to: 1) educate physicians and nurses about palliative care and the concept of quality of life in that context; 2) to develop postgraduate training programs for physicians and nurses who wish to develop special expertise in palliative care; and 3) to introduce palliative care into medical and nursing curricula.

Two national workshops were conducted in 2000 and 2001 in order to discuss the principles for establishing good pain and palliative care and to identify potential barriers for implementation of palliative care. These workshops were sponsored by the Lebanese Minister of Health, the WHO, the Lebanese Cancer Society, and the Clinical Research Institute in Montreal, Canada. The principles for establishing pain relief and palliative care in Lebanon were reviewed, and barriers were identified. Examples of undergraduate curricula were provided. The deans and directors of nursing and medical schools were motivated to introduce an undergraduate curriculum in pain and palliative care and to select fellows for overseas education. (3)

Immediately after the 2000 workshop nine fellows from different universities were chosen to attend a two and a half day course provided by the Education for Physician on End-of-life Care (EPEC) in the US to become an EPEC trainer. This course covered the entire content of the EPEC curriculum. After the EPEC course, the fellows spent a week with bedside training under the auspice of the EPEC team to experience the practical approaches used to provide palliative care. (4)

A national conference was held in November 2001 to evaluate the results achieved by the fellows since their return from the training in the United States. Fellows reported the following educational activities: a 12-hour undergraduate curriculum was developed for medical students; a continuing education program was implemented for practicing nurses on pain and palliative care, courses on palliative care were implemented for nursing students.

A symposium with over 300 participants was held on pain and end-of-life care in April 2001; Several lectures were presented covering subjects such as breaking bad news, pain and palliative care for general practitioners, breathlessness, and gaps in end-of-life care.

There was a week-long national television series on pain relief and end-of-life care; tumor board meetings started to include palliative care in the management of patients; number of patients receiving opioids increased to 600, a nine-fold increase from 1995 to 2001, according to the Ministry of Public Health; Morphine quota increased to 4.5 kg

In 2003: Educational activity organized by the Pain and Palliative Care Group: Palliative Care in the Elderly

In 2004: Educational activity organized by the Pain and Palliative Care Group: Role of Nurses in Palliative Care and Home Care. And then several Symposia and Workshops organized by the PR& PC Group or supported by this Group were organized in different parts of the country (Tripoli, Saida, Jounieh, Byblos...) Some interesting articles based on study results were published in national and international journals (5,6,7,8). However, despite all efforts the subject of palliative care in Lebanon is still not approached scientifically. Research is lacking at all levels, and palliative care is delivered by non specialized physicians and registered nurses.

Although palliative care is still not officially institutionalized, patients are financially covered by private insurance companies and the ministry of health to receive palliative care in hospitals. Chemotherapeutic drugs are dispensed free of charge by the Ministry of Health.

Based on the National Cancer Registry (NCR) which was revived in 2003 as an information system designed for the collection, storage, management and analysis of data on cancer cases throughout Lebanon, the annual cancer incident caseload is estimated at about 7,555 new cases (Ministry of Public Health, WHO, & National Non-Communicable Diseases programme [NCDP], 2003). Official data about the number of cancer patients receiving palliative care in Lebanon are lacking; but we can estimate that with a death rate of 4-5/1000, and over 22000 deaths a year, around 12000 patients are in need of morphine (60% need pain relief and palliative care). Only 5-10% of patients who need PC receive it. Over 90% of all PC services are provided in large cities; Over 50% of patients cannot afford PC services or the medication;

Today, we can say that in the past decades, there have been significant advances in our understanding of the complexity of pain relief and palliative care and in our knowledge about the field. Significant developments have taken place



in education, practice, and research but a number of challenges remain which need to be addressed at the national level. At the professional level, challenges include a lack of knowledge and skills as well as inappropriate attitudes and behaviors among health professionals. Practice and system challenges include lack of resources, inadequate financial coverage, poor coordination of care, problems with drug availability and accessibility, and lack of legislation and recognition of the specialty areas. (9)

And finally, after so many efforts and advocacy from the PR&PC Group, the Ministry of Health took the initiative to create in May 2011 a **National Committee for Pain Relief and Palliative Care**, whose mandate is to elaborate a national plan to deliver change in pain relief and palliative care across the life span. This plan should focus on 4 broad areas: Education, Practice, Research, and Public Policy. The mandate to the National Committee for Pain Relief and Palliative Care (NCPR&PC) is defined as follows:

### 1- In Education

- To recommend a core curriculum to be used in the training of health care professionals with emphasis on knowledge, attitudes, and skill development.
- To recommend specialization trajectories of physicians and nurses in the field.
- To institute the importance of continuing professional education in the field as a requirement for recertification and licensure.
- To develop strategies for public education in the field.

### 2- In Practice

- To develop national standards and competencies for pain relief and palliative care.
- To develop strategies to engage professionals from different disciplines in the care process such as the use of multidisciplinary care pathways.
- To recommend models for service delivery such as home care and residential care and the use of palliative care



teams in hospitals.

- To develop mechanisms to empower the family and the patient to be actively involved in the care process emphasizing the importance of family and patient-centered care.

### 3- In Research

- To develop national research priorities for the field of pain relief and palliative care that target gaps in treatment, knowledge transfer, education, & policy.
- To recommend research methods to address the gaps in information related to pain relief and palliative care in Lebanon.

### 4- In Public Policy

- To develop strategies that will ensure the availability, accessibility, & prescription rights of opiates.
- To recommend strategies that will ensure the practice of interdisciplinary palliative care teams in the care process.
- To recommend appropriate legislation for the regulation of pain relief and palliative care for adults and children in Lebanon.
- To recommend models for cost allocation and reimbursement for pain relief and palliative care services.
- To recommend the institution of pain relief and palliative care as integral parts of the health care system in Lebanon.

## FUTURE STEPS AND CONCLUSIONS

We can say that Palliative care in Lebanon has made some important strides in the last decade but it is still in its infancy, and urgent attention needs to be given to the implementation of the recommendations listed above,

The National Committee for Pain Relief and Palliative Care (NCPR&PC) has already started the work; intensive meetings including qualified persons from different disciplines allowed the elaboration of a situational analysis in each area, and a plan for the future. Practical steps were defined and an agenda for the next year is already proposed and approved by the policy makers.

Ideally, PC services should be provided from the time of diagnosis of life-threatening illness, adapting to the increasing needs of cancer patients and their families as the disease progresses into the terminal phase. They should also provide support to families in their bereavement.

It is important to change the legislative system in Lebanon to recognize and to integrate this discipline. Education,

training and postgraduate certification should be provided by all medical and nursing schools, and a close collaboration between medical and nursing associations will be needed to achieve this. It is also essential to involve policy-makers in the development of services and clinics that meet the needs of the population in Lebanon.

Effective PC services should be integrated into the existing health system at all levels of care, especially community and home-based care. They involve the public and the private sector and are adapted to the specific cultural, social and economic setting.

At the end of this review, two main conclusions can be cited:

- Provision of PC provides better outcomes than usual care and is cheaper on the health care system in the long run.
- Continuing education programs in PC are needed in Lebanon.

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# PALLIATIVE CARE IN LEBANON: BACKGROUND RECOMMENDATIONS FOR POLICY-MAKING



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## BACKGROUND

Escalating numbers of end-stage cancer and chronic diseases world-wide called for end-of-life (EOL) care as a public health priority. Palliative care (PC) is earmarked as the comprehensive compassionate care that comforts and supports families and individuals, who are living with, or are dying from a progressive life-threatening illness.

Declarations from Canada, Cape Town, the European Committee of Ministers, the International Working Group (European School of Oncology), Pope Benedick XVI, and Korea have all asserted that palliative care is a fundamental human right. (Brennan, May 2007, *Journal of Pain and Symptom Management* p.494)

World Health Organization (WHO) postulated three founding measures for Palliative Care as a public health approach:

- a government policy to integrate PC services into the national health-care system,
- an educational policy for health-care professionals, volunteers and the public, and
- a policy on opioids to relieve pain and psychological distress. (WHO, 1996 FINAL-PalliativeWHO.pdf\_Adobe Reader p6)

In Lebanon a decree was issued May 4, 2011 by Ministry

of Health (MOH) to endorse Palliative Care a public health concern. A National Palliative Care Committee was convened with four sub-committees on practice, education, research and policy-making. Represented on the national committee is a panel of PC experts i.e. physicians, nurses and public health professionals from academia, service and NGOs involved in home hospice care. Palliative Care i.e. quality end-of-life care challenges the taboo of death and dying in Lebanon and ultimately requires an all-encompassing intervention at policy-making level.

### 1. The National PC Sub-committee on Policy:

Since its inception the sub-committee met on regular/interim basis to advocate for a zero-tolerance policy for terminal illness and at end of life. Adapting the WHO tenets the subcommittee thoroughly evaluated the narcotic drug availability cycle in Lebanon. To better understand the narcotic supply, distribution, regulation, dispensing and costing multiple interview were conducted with experts from MOH, oncologist, and other stakeholders. The following were identified:

- Mechanisms of narcotic and psychotropic drugs dispensing procedures: Patient-related procedures were tracked and evaluated i.e. the narcotic initiation procedure at Ministry of Health (MOH) and purchasing procedure were thoroughly examined. It was seen as a laborious process for families but minimal changes were recommended to ease the process.
- Prescription mechanism used by physicians: prescribing opioids and other psychotropic drugs was evaluated. Mechanisms to optimize the use of narcotics for EOL patients; and to guard physicians against unnecessary legal scrutiny & criminalization, and narcotic-associated crimes were fully scrutinized.
- Impediments for the use of potent drugs in pain management were isolated: Physicians' exaggerated fears of morphine dependency syndrome and fear of losing their license were major obstacle in promoting a zero-tolerance

PC policy. Additionally, physicians' general orientation to treat the disease not pain constituted further impediment.

- The interplay between Ministry of Health and the International Control Narcotic Board (ICNB) is stated as crucial in updating the list of narcotic drugs (appendix below). To make the most potent drugs available on the market with multiple routes and doses, and at affordable prices was yet another challenge. Narcotic availability is essentially based on a demand and supply cycle. Only 23 pharmacies are licensed to dispense narcotics in Lebanon and they are not well geographically distributed. It was found out that lack of incentives, unnecessary scrutiny and criminalizing of unimportant and unintentional mistakes disenchanted and scared off pharmacies.
- It was stressed that the current focus is on a pain relief policy, yet policy-making process has to endorse all activities and recommendations made by sub-committees on practice, research, and education.

**2. Voices from the community:** Translating fundamental PC values into policy-making constructs in Lebanon explored how are agency, dignity, hope; solidarity and sustainability are constructed to ensure the rights of the dying and their families. What about pain management, communication, decision-making at EOL?

To shed the light on concerns of EOL patients and families, a focus group discussion was conducted in May 2012, by SANAD, an NGO for home hospice. Bereaved family members who were supported by SANAD for an average of six months were interviewed by an independent facilitator. Family members voiced their reflections and concerns as follows:

- The tension between cure and care burdened patients and their families at end-of-life e.g. (futility of treatment, financial strains, loss of patient's autonomy and decision-making power, lack of communication between some oncologists and families, total confusion due to lack of consensus between oncologist and surgeon, hospitals described as unfriendly environment for EOL patients and their families.
- Family care-givers bear the heaviest toll at EOL: All or most family members fell sick during the EOL phase. Even grand-children of EOL patients sustained significant delays in their growth and development milestones. Some care-givers were cancer patients themselves. Some care-givers were concerned about their own EOL especially in a multi-generational family with cancer. Other care-givers reported multi-tasks as a risk factor for depression, physical and emotional burnout, and loss of self

and depletion of financial resources.

- Families experience with SANAD as home hospice: The competence and compassion of SANAD infused patients and their families with hope, that an EOL patient can still live free of pain, have meaning in life and stay connected with family till his last moments. The positive interplay between the physician and nurse was profiled as comforting and infusing families with confidence that their patient is receiving the best care. Family members strongly believe that their quality of life at EOL is ensured in the authentic presence of a competent and compassionate PC nurse who can communicate, guide, support and intervene at home. There was a loud outcry for a nurse case manager, emulating SANAD's model, to assist and support families immediately at the time of diagnoses with cancer/ end-stage disease.

- Pain management: family members struggled with the concept of pain relief. They received no support from most of the oncologists. There was fear by physicians and families alike to resort to morphine. There was no clear guidance that pain relief is a patient's right. Some oncologist rarely responded to family queries and fears. Before SANAD pitched in, families were left to experiment with pain-killers on their own. Families reported that SANAD brought them peace of mind. SANAD made a thorough assessment of patients and needs, prescribed pain-killers, followed up with MOH and made the drug readily available to the family at no cost. Pain-killers were administered and families were fully instructed what to expect, how to monitor for effective results and when to seek further help. All families reported full satisfaction with a pain-free end of life. Some families lost their patients before the morphine stock was over, and pharmacies refused to take back the intact leftover morphine stock.

- Truth telling: Families believe that truth telling should not be a mandate at EOL. While some are adamant about telling the truth to their EOL patients, others are totally against it for fear of further compromising a vulnerable patient. A lot of family conflicts emerged as family members struggled with the issue of truth telling.

- Family ties and resiliency: Some family members used their care-giving experience to engrave family values, "family lives for family". Some wives and husbands were highly committed and very instrumental in supporting their in-laws at all costs and with no reservations.

### 3. Policy Recommendations:

- The spectrum of PC has to cover all options: in-hospital PC unit, in-hospital PC beds, hospice and home hospice. PC service has to be integrated into the health care



system. Furthermore, hospice care should be allowed flexibility to operate as community centers and at home.

- Interdisciplinary PC team has to consist of PC physician and PC Nurse Case Manager as the core team. A support team may include psychologist/ psychiatrist, dietician, physical therapist and a religious figure etc. PC professionals have to be certified according to scope of practice.
- PC Practice is grounded in best practices and high standards of care to ensure good quality of life for individuals and their families, and a good death for patients.
- A PC zero tolerance policy for pain: use of pain-killers stepwise approach, use of potent drugs for uncontrolled pain (oral / SL/ patches /IM/ IV drip/ PCA), surgical interventions and other natural or alternate modalities have to be fully explored and evaluated.
- PC umbrella is all encompassing. It covers end-stage cancer and all other debilitating conditions and injuries of all age groups.
- PC public and private coverage are best provided as group insurances.
- Costing of PC is packaged either as basic or advanced care. All PC options (In hospital unit, in-hospital bed, hospice or home hospice etc) have to be clearly priced according to service, provision of advanced equipment and most importantly nursing coverage i.e. (part-time or full time basis).
- PC Nurse Case Manager fees have to be earmarked as authentic nursing functions not under hospital room / bed rate.
- PC policy that protects the rights of family care-givers has to ensure sustainability, solidarity and cost-containment at EOL care. This can be translated by providing an affordable (low cost) health monitoring and medical coverage for family care-givers during their caring period and thereafter.
- Promotion of all PC research, population-based, action-oriented research and qualitative research to integrate reflection, dialogue, collaboration, multiple actions and interpretations. Application of knowledge gained from palliative care research empowers end-of-life care and education and care. The loops can be closed between theory and practice with more home-grown research that is grounded in the voice of the community and the latest know-how.
- At the legal level, a PC policy has to advocate for restorative justice as it resolves conflicts and keeps families together.
- Promotion of NGOs that subsidizes PC care in the

community via fund-raising and volunteerism is of utmost importance. Different models should be promoted to suit different needs.

- All professional educational programs have to undergo curricular changes to become more sensitive and savvy in EOL care.
- Promoting awareness in the community will end the era of death. Major campaigns and different activities will help dispel myths and fallacies that are prevalent among health professional, policy-makers and the community.

Appendix -  
RECOMMENDED LIST FOR STRONG OPIOIDS

Strong Opioids/Morphine:

- Immediate release (IR):  
oral liquid, immediate release Oral liquid: 2 mg (as hydrochloride or sulfate)/ml.  
Tablet: 10 mg (as sulfate).  
Injection: 10 mg as (hydrochloride or sulfate) in 1 ml ampoule.
- Prolonged Release  
Tablet: 10 mg, 30 mg, 60 mg, 100mg, 200mg (as sulfate).  
Granule: to mix with water: 20 mg, 30 mg, 60 mg, 100 mg, 200 mg (morphine sulfate).

Fentanyl

Transmucosal lozenge: 200 mcg, 400 mcg, 600 mcg, 800 mcg, 1200 mcg, 1600 mcg (as citrate).  
Transdermal patch (extended release): 12.5 mcg/hr, 25 mcg/hr, 50 mcg/hr, 75 mcg/hr, 100 mcg/hr (as base).  
Injection: 50 mcg/ml in various vial sizes (as citrate).

Hydromorphone

Injection: 1 mg in 1 ml ampoule, 2 mg in 1 ml ampoule, 4 mg in 1 ml ampoule, 10 mg in 1 ml ampoule (as hydrochloride).  
Tablet: 2 mg, 4 mg, 8 mg (as hydrochloride).  
Oral liquid: 1 mg (as hydrochloride)/ml.

Methadone (WARNING: requires additional training for dosing)

Injection: 10 mg/ml in various vial sizes (as hydrochloride).  
Tablet: 5 mg, 10 mg, 40 mg (as hydrochloride).  
Oral liquid: 1 mg/ml, 2 mg/ml, 5 mg/ml (as hydrochloride).  
Oral concentrate: 10 mg/ml (as hydrochloride).

Oxycodone

Tablet: 5 mg, 10 mg, 15 mg, 20 mg, 30 mg (as hydrochloride).  
Tablet (modified release): 5 mg, 10 mg, 15 mg, 20 mg, 30 mg, 40 mg, 60 mg, 80 mg, 160 mg (as hydrochloride).  
Capsule: 5 mg, 10 mg, 20 mg (as hydrochloride).  
Oral liquid: 1 mg/ml (as hydrochloride).  
Concentrated oral liquid: 10 mg/ml, 20 mg/ml (as hydrochloride).

The use of Pethidine (Dolosal) is not recommended.

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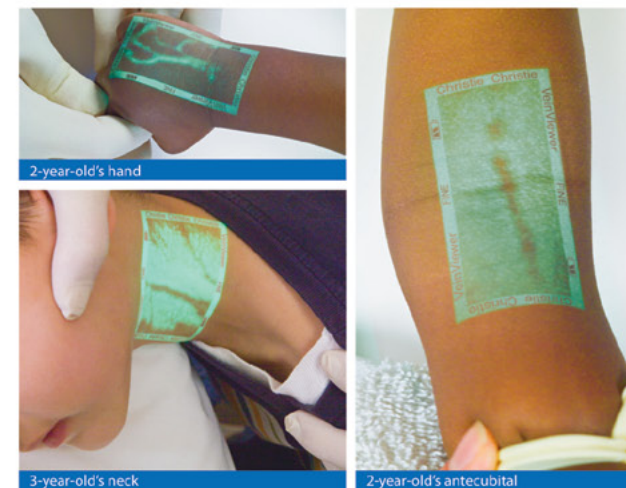
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# MANAGING SYMPTOMS IN PALLIATIVE CARE



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The goal of palliative medicine is to relieve suffering and improve the quality of life of patients living with life-threatening illness. Palliative care providers must attend to the psychosocial and spiritual needs of patients and their families. However, management of symptoms that cause physical distress is an essential first step towards relieving the suffering of patients with serious illness. Control of physical symptoms is at the core of Palliative Medicine. If these are not controlled, it can become impossible to avoid depression and anxiety, and the social and spiritual dimensions of illness become secondary to patients and their families.

Advanced illness is commonly associated with physical symptoms that can cause significant physical and mental distress. The most common symptoms include pain, dyspnea, fatigue, anorexia, constipation, nausea, vomiting, and insomnia. Once identified, these symptoms can often be managed effectively with relatively simple interventions. Appropriate management can dramatically improve the quality of life of patients and may even allow them to live normally despite their basic disease. Palliative care providers should be experts in the identification and management of symptoms associated with advanced illness.

## PAIN

Pain is one of the most commonly encountered symptoms in palliative care and is a frequent source of distress to patients. Fortunately, it can be managed cheaply and ef-

fectively if clinicians have access to the appropriate pain medications and the knowledge to use them safely. Opioid analgesics can be very effective in the treatment of moderate to severe pain, however, their availability and accessibility is often restricted due to their potential for abuse. In Lebanon, although recent regulatory changes have reduced the barriers to access to opioid analgesics, their use remains restricted. Prescribing of opioid analgesics is limited to oncologists and pain specialists. Geriatricians, family physicians and other specialists who may provide palliative care do not have the right to prescribe them. In cancer cases, they must rely on the patient's oncologist to prescribe opioids when needed. For non-cancer patients who are experiencing pain, the health care provider must resort to one of the few pain specialists in the country if opioid analgesics are required for pain management. This is an important barrier that discourages physicians from addressing the pain that their patients may be experiencing. In addition to the restrictions on prescribing, the formulations of opioids available on the Lebanese market are also limited. Immediate release oral morphine or other short acting opiates are essential for proper titration of analgesia and to ensure adequate pain management. Unfortunately, there are no immediate release opioid formulations on the Lebanese market. As a result, clinicians often resort to the inappropriate use of long acting oral formulations by asking patients to "crush" long acting morphine tablets to obtain an immediate analgesic effect.

In 2007, the International Association for Hospice and Palliative Care, in collaboration with experts in the field of palliative medicine, developed a list of essential medicines to be used in the palliative care setting. Of the 34 medications on the list, at least 4 are not available on the Lebanese market or are not accessible to patients receiving palliative care. These include immediate release morphine as well as methadone and oxycodone. The following statement comes as a bolded footnote to this list: "No government should approve modified release morphine, fentanyl or Oxycodone without also guaranteeing widely available normal release oral morphine." (IAHPC, 2007)

Long acting formulations of opiates are available in Leba-

non but are limited to morphine and fentanyl. Although in many situations, pain can be managed using one of these two formulations, there are cases in which alternative opioids are necessary for adequate pain management. Opioid rotation is a strategy that can be used to control pain when patients demonstrate poor response to a particular opioid or are experiencing side effects related to toxicity from it. With the limited options available on the Lebanese market, opioid rotation is not an option in the management of pain in our patients.

Methadone is a synthetic opioid that is most commonly recognized for its use as substitution therapy for patients with opiate addiction. It can also be used very effectively for the management of pain. Methadone was only recently approved for use in Lebanon but the indication for its use has been restricted to substitution therapy and the only physicians who can prescribe it are psychiatrists. As such Methadone is not accessible to providers of palliative care or pain specialists at this stage.

Per capita consumption of opioids in Lebanon has increased over the past 10 years. However, consumption remains much lower than expected for our population and significantly lower than the global mean. This is an indicator that pain is not being managed adequately in our setting. (PPSG, 2009)

## OTHER PRESCRIBING BARRIERS

### **1. Inconsistency in the availability of some medications:**

We have found that medications are not consistently available on the Lebanese market. Megestrol Acetate (Megace) can be very effective as an appetite stimulant in patients with anorexia and cachexia. Unfortunately, its availability on the market has been inconsistent. Patients often have to delay starting it or have to obtain it from abroad with the assistance of friends or relatives. It is especially distressing when patients have had good results with such treatments and they have to interrupt it because they can no longer find it on the Lebanese market.

**2. Lack of clarity in policies:** Midazolam can be very effective in management of delirium, anxiety and restlessness especially in the terminal phases of life. We have had very inconsistent responses from pharmacies regarding the dispensing of injectable Midazolam. While some have stated that they can be dispensed with a simple prescription in the name of the patient, others have refused to dispense it without special permission from the Ministry of Public Health.

**3. Simple formulations are not readily available:** Medications like Codeine and Diphenhydramine can be use-



ful in the palliative care setting. These medications are available in Lebanon but only in combination with other medications such as Paracetamol. This restricts our ability to use them in patients who are often already taking multiple medications and have several comorbidities.

**4. Restricted Prescribing:** Restricted prescribing is not only limited to opioid medications. Methylphenidate (Ritalin) is a psychostimulant that is most commonly used to treat Attention Deficit Disorder and related conditions. In most countries it is considered a controlled substance. Its use is monitored and regulated because it can potentially be abused as a recreational drug. Methylphenidate has many potential benefits in the palliative care. It has been used effectively to treat depression, improve cognitive function, and it can act synergistically with opioid analgesics to reduce pain (Rozans, 2002). However, prescription of methylphenidate remains restricted to psychiatrists and is not accessible to palliative care providers.

## CONCLUSION

Excellent management of symptoms is at the core of palliative care. In addition to proper training in palliative care, clinicians must have ready access to medications that will help them adequately control symptoms that can be important sources of distress for patients and their families.

## References

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