

PAIN RELIEF AND PALLIATIVE CARE IN LEBANON IMPLEMENTATION OF PALLIATIVE CARE IN LEBANON Past, Present, and Future

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PAIN RELIEF AND PALLIATIVE CARE GROUP

Daher M, Estephan E, Abu-Saad Huijer H, Naja Z. Implementation of palliative care in Lebanon : Past, present, and future. *J Med Liban* 2008 ; 56 (2) : 70-76.

ABSTRACT : The goal of palliative care (PC) is to relieve suffering. PC is an urgent humanitarian need worldwide for people with cancer and other chronic fatal diseases.

PC in Lebanon has made some important strides in the last decade but it is still in its infancy. More attention needs to be given in the near future to the implementation of the recommendations already listed by previous meetings and workshops. In order to do so, it is necessary to change the legislative system in Lebanon in order to recognize and to integrate this new discipline. Education and training of health professionals in PC should be provided by medical and nursing schools throughout the country. Postgraduate education in medicine and nursing and ensuing certification should be made available.

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 as important and essential to involve policy makers in the development of pain relief and PC services and clinics which 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.

In order to respond to the cancer priority needs in a community and make the best use of scarce resources, PC services should be strategically linked to cancer prevention, early detection and treatment services.

The time will come for Lebanon to form the National Council for Pain Relief and Palliative Care as an advocacy and coordination body for pain relief and PC in the near future. To that effect, we believe the future is near.

Daher M, Estephan E, Abu-Saad Huijer H, Naja Z. Mise en place des soins palliatifs au Liban : Passé, présent et avenir. *J Med Liban* 2008 ; 56 (2) : 70-76.

RÉSUMÉ : Le but des soins palliatifs (SP) est de diminuer la souffrance. Les SP constituent un besoin humanitaire urgent à l'échelle mondiale pour les patients cancéreux ou atteints de maladies chroniques incurables.

Malgré quelques progrès au cours des dernières décennies, les SP au Liban sont toujours au stade d'enfance. Une attention particulière devrait être donnée dans le proche avenir à l'application des recommandations déjà définies au cours des séminaires et ateliers de travail organisés dans le passé. Dans ce but, il est nécessaire de changer la législation actuelle en vue de reconnaître et d'intégrer cette nouvelle discipline. L'éducation et la formation pratique des professionnels de santé en SP devraient être pratiquées par les facultés de médecine et les écoles d'infirmières à l'échelle nationale. La formation postuniversitaire en médecine et soins infirmiers devrait être possible à travers des certificats de formation spécialisée.

Idéalement, les SP devraient débuter dès le diagnostic d'une maladie incurable, adaptant les besoins de plus en plus importants des patients cancéreux et de leurs familles au fur et à mesure que la maladie progresse vers le stade terminal, et assurer un soutien aux familles au cours de la période de deuil. Il est important, et même essentiel d'impliquer les décideurs dans le domaine de santé dans le développement de services de soins de la douleur et de SP. Des services de SP adaptés aux spécificités culturelles, sociales et économiques du Liban et impliquant les secteurs privé et public devraient être intégrés au système actuel de santé à tous les niveaux, spécialement dans les soins communautaires et à domicile.

En vue de répondre aux priorités de la prise en charge des cancers dans la communauté et de faire le meilleur usage possible des ressources limitées disponibles, les services de SP devraient être stratégiquement liés aux mesures de prévention, de diagnostic précoce et de traitement.

Nous espérons que dans un avenir que nous voulons proche sera constitué un Conseil National pour le contrôle de la douleur et des SP dont l'objectif principal sera de coordonner ces services à l'échelle nationale.

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INTRODUCTION
WHAT IS PALLIATIVE CARE ?

The goal of palliative care (PC) is to relieve suffering. The World Health Organization has defined PC as “the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of PC is achievement of the best quality of life for patients and their families...” [1].

A most recent status defines PC as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems – physical, psychosocial and spiritual.” [2]

PC should be applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy.

PC should also include the investigations needed to better understand and manage distressing clinical complications.

PC provides relief from pain and other distressing symptoms, integrates the psychological and spiritual aspects of patient care. It offers a support system to help

both patients and their families through counseling if indicated to cope during the patient’s illness in order to live as actively as possible until death. PC will certainly enhance quality of life ; thus, positively influence the course of illness.

PC focuses not only on cancer, but also on other life-threatening diseases. These conditions include HIV/AIDS, congestive heart failure, cerebrovascular disease, neurodegenerative disorders, chronic respiratory diseases and diseases of older people, among others [3].

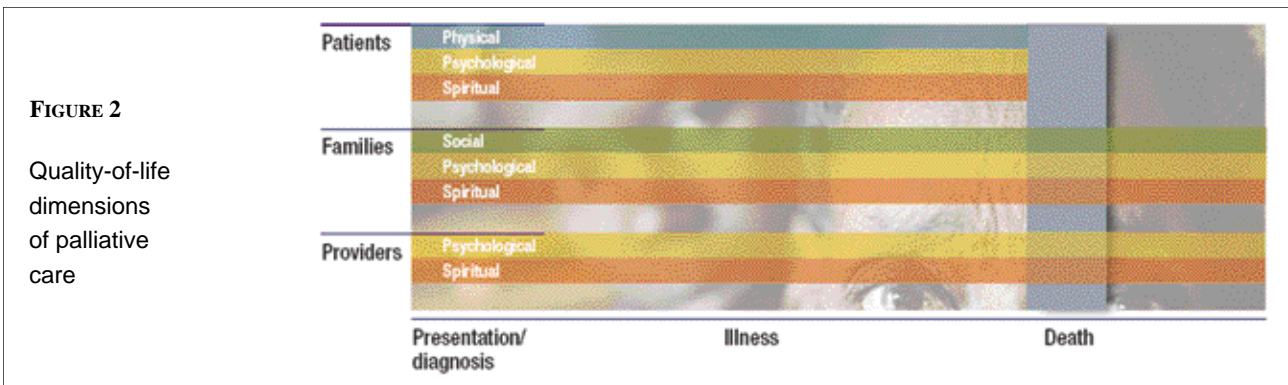
Implementation of PC is particularly crucial in terminal cancer patients who experience an advanced stage of the disease where curative treatment is no longer useful, the disease is assessed to be incurable and the patient’s condition is progressively deteriorating. PC should be developed with a public health approach that targets all age groups [3].

Figure 1 illustrates the continuum of care associated with curative and palliative care. Treatment intended to modify the disease decreases as illness progresses, while palliative care increases as the person reaches the end of life. Palliative care also provides support for the family during this entire period. After the patient dies, bereavement counseling for family and friends is important.

The quality-of-life dimensions of palliative care are illustrated in Figure 2.



SOURCE : Adapted from American Medical Association Institute for Medical Ethics (1999). *EPEC : Education for physicians on end-of-life care*. Chicago, IL, the Robert Wood Johnson Foundation.



SOURCE : WHO (2002a) National cancer control programme : Policies and managerial guidelines, 2nd ed. Geneva, World Health Organization.

Palliative care is concerned not only with all aspects of the patient's needs, but also with the needs of the family and of the healthcare providers.

IMPLEMENTATION OF PALLIATIVE CARE IN LEBANON THE PAST

In Lebanon, PC is unfortunately new to the healthcare field. The need for pain relief and PC was first identified as a priority in **1995** at the **WHO National Cancer Control Workshop** with leading nationals, supported by the Lebanese Ministry of Health and WHO where affordable solutions were recommended. This was the first attempt at raising awareness of health professionals and sensitizing the public to the need for PC services in Lebanon.

Then in **May 1999**, a special full day **Symposium on PC and Ethics** was held during the Middle East Oncology Congress (COMO IV) organized by the Lebanese Cancer Society [4-5]. This resulted in recommendations and plans for action submitted to the Ministry of Health and WHO mainly focusing on freedom from cancer pain as a human right by facilitating the restrictions imposed on morphine prescriptions.

Moreover, *undergraduate training of nurses and doctors* on pain relief and PC were assessed as an area of emphasis integrated in curricula. Drawbacks of *doctors' reimbursement*, lack of multidisciplinary clinics, and homecare development were the main discussed topics to develop.

A **two-day workshop** organized by the Lebanese Cancer Society, and sponsored by the Lebanese Ministry of Health, WHO, and the Clinical Research Institute in Montreal, Canada, was held in **November 2000**. The principles and barriers for establishing pain relief and PC were discussed. Deans and directors of medical and nursing schools were convinced to introduce an undergraduate curriculum on pain and PC and to select fellows for overseas training who would eventually initiate PC services in Lebanon.

Fellows training, January 2001 • Immediately after the workshop, nine fellows were selected for the 2.5 days Education of Physicians on End-of-life Care (EPEC) "Become an EPEC Trainer" conference in the United States. This course covered the entire content of the EPEC & End-of-Life Nursing Education Consortium (ELNEC) curriculum including approaches to effective communication, negotiating goals of care, advance care planning, sudden illness, futility, requests to withhold or withdraw therapy, and physician-assisted suicide [6-7]. The management of physical symptoms (e.g., pain, shortness of breath, constipation, nausea, anxiety, depression, delirium) and care in the last hours of life was also discussed. The course also exposed the fellows to the different techniques they might use to teach EPEC more effectively in Lebanon.

After this EPEC conference, the fellows spent a week with bedside training under the auspices of the EPEC Team which included visits to various programs and practical experience in providing PC, especially in Chicago.

National Workshop, November 2001 • A further workshop was held in Beirut, to evaluate the results achieved

by the fellows since their return from the US, including the number of patients treated, the barriers encountered for implementing effective pain relief and PC, as well as progress made in integrating pain relief and PC in health professionals' curricula.

In **1999**, the **Lebanese Society for the Study of Pain (LSSP)**, a chapter of the International Association for the Study of Pain (IASP) was founded in Lebanon. LSSP is affiliated to the National Council for Scientific Research (CNRS). A successful first scientific meeting of LSSP was organized in February 2005 with the theme "Update on Pain Management in Lebanon".

A **Pain Relief and Palliative Care Group (PR & PCG)** was created under the auspices of the Lebanese Cancer Society in **2001** (Table I). The PR & PCG Group has since then sponsored two educational activities in 2003, and 2004; the first on Palliative Care in the Elderly, and the second on the role of Nurses in Palliative and Home Care. Two workshops were then organized in 2005 and 2006.

IMPLEMENTATION OF PALLIATIVE CARE IN LEBANON THE PRESENT: WHERE ARE WE NOW ? [4-5, 8]

Health Care System

The Lebanese Health Care System is primarily dominated by the private sector (hospitals, doctors and pharmacies). There are 7 medical universities and 9 nursing schools, around 120 medical oncologists, 15 radiotherapists. No expert in palliative medicine exists.

Severity of the problem

Assessing the number of people in need of cancer PC

It is estimated that 4,500,000 people are living in Lebanon. With a death rate of 4-5/1000, and over 22000 deaths a year, it is estimated that around 12000 patients are in need of morphine (60% needs pain relief and palliative care). The number of new cancer patients is estimated to be around 7500 yearly (NCR Report 2003). The great majority suffer needlessly, and do not get pain relief or PC.

Assessing cancer PC needs is in many ways equivalent to assessing an urgent humanitarian need to reduce unnecessary suffering of patients and their families.

As cancer is usually diagnosed in advanced stages, then it will be necessary to provide integrated PC services for the specialties concerned.

Health authorities

Lebanese health authorities do not recognize PC as a proper discipline; it is not included neither in the public nor in the private health systems. Yet they pay for futile interventions but they do not pay, or they do not pay enough, for PC. This situation jeopardizes the sustainability of activities, which are mostly run by volunteers, with resources from charities and nongovernmental organizations.

Opioid availability and accessibility

There is good availability of different opioids, but poor accessibility because of their high cost, lack of

TABLE I

PAIN RELIEF AND PALLIATIVE CARE GROUP (PR & PCG)

CREATED UNDER THE AUSPICES OF THE LEBANESE CANCER SOCIETY(LCS) TO PROMOTE PALLIATIVE CARE IN LEBANON AND TO ACT AS A FOCUS FOR ALL THOSE WHO WORK, OR HAVE AN INTEREST, IN THE FIELD OF PAIN & PALLIATIVE CARE

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
-

training among health personnel on how to prescribe and use opioids, and restrictive regulations [9].

Teams and programs

There is limited information on the number of teams or programs providing PC services, and the type of care they deliver. The programs differ according to their development : community- or hospital-based ; with one or more disciplines ; with mixed or exclusive home, out-patient or inpatient care.

National PC associations

There is only one Pain and PC Group. There is a need to create a national PC Association.

Education

Health professionals are increasingly interested in PC, and this interest is paralleled by increasing learning opportunities. However, less than 5% of those who deliver end-of-life care have received undergraduate PC education. Most have acquired knowledge and skills after graduation.

Research

Resources and expertise in research are scarce, so little research is carried out and it is of variable level.

Care

No data is available about how and where patients die, how many receive PC, and the characteristics of the caring process.

Coverage

The availability, accessibility and affordability of PC are inadequate. It is estimated that only 5-10% of patients who need PC receive it ; over 90% of all PC services are provided in large cities ; and over 50% of patients cannot afford the services or the medication.

Outcome

No assessment tool is available to determine the factors responsible to accomplish an effective PC.

**IMPLEMENTATION OF PALLIATIVE CARE IN LEBANON
THE FUTURE**

The next step is to consider what *could* be done, given limited resources and capacity, in order to answer the question : *Where do we want to be, and how to get there ?*

PC needs a holistic approach which emphasizes comprehensive knowledge and clinical skills as well as changes in attitudes and practices among healthcare professionals. These are essential for developing PC services in Lebanon.

Many efforts should be done in order to enhance the education, practice and research in PC [4-5].

Education

Undergraduate training • Until recently, little attention has been paid to the education and training of health professionals on pain and PC, examinations of doctors or nurses. However, within the last year, a 12-hour modular curriculum has been developed for undergraduate medical trainees, and the concepts of pain and palliative medicine have been integrated into the education of nurses at some faculties and schools of nursing.

It is recommended that PC should be integrated into the undergraduate training provided by all 7 medical university and 9 nursing schools in Lebanon. As well, questions related to pain management and PC to be integrated into all examinations of doctors and nurses.

Postgraduate training • Currently there is no post-graduate training in pain management or PC in Lebanon. To effectively manage the large number of patients in need of PC services, Lebanon should have adequate numbers of specialists in pain management and PC who in turn can support the primary care providers in the management of difficult and complex pain patients across Lebanon.

It is suggested that postgraduate training programs be developed for both doctors and nurses who wish to acquire special expertise in pain management and PC. Certification of healthcare workers in pain management and PC should be instituted.

Practice

Community providers • Only a few healthcare providers have adequate knowledge of pain management and PC, thus *WHO proposal to integrate pain and PC into the upcoming community health program should be strongly supported.*

Advocacy • Most people in Lebanon are unaware of the fact that simple and affordable methods exist to control major suffering caused by common diseases, particularly in the terminal phase of life. *It is recommended that an advocacy strategy be developed to increase the awareness of the general public, health policy makers, health professionals (e.g., doctors, nurses, pharmacists, social workers, etc.), religious leaders, and relevant non governmental organizations about pain management and PC.*

Pain management

Opioid availability • Immediate release oral morphine is not readily available in all pharmacies and parts of Lebanon. *It is recommended that slow and immediate release morphine should be made more readily obtainable in Lebanon.*

Prescribing/dispensing practices • At present morphine prescriptions can only be given to cancer patients by anesthesiologists or medical oncologists, and only after providing the pathology report, and a prescription signed by two doctors who provide their identity cards. No more than a 2-week supply can be prescribed at one time.

It is recommended that all licensed doctors be permitted to write morphine prescriptions for patients of any age, with any diagnosis, at any stage during the course of their illness when their pain cannot be managed otherwise. National laws and regulations should be changed to remove barriers to pain management, while still maintaining accountability.

Home care

At present, most patients die in hospitals in spite of their desire to die at home, because actual reimbursement policies currently do not support care at home. Considerable savings for the health care system could be realized if an effective coordinated home care system would be in place.

Hospital PC and home care units should be established as a nucleus for training and education in pain and PC and should work collaboratively with existing pain clinics and community services. The 3-generation family should be informed and educated about palliative and supportive care that they can provide.

Research

In order to develop PC services for children and adults in Lebanon, an inventory of needs of palliative care users and PC providers is of importance.

It is recommended that multidisciplinary PC research which addresses needs assessment, symptom and pain management, models of PC service delivery, as well as ethical issues be encouraged and stimulated.

Define the target population for PC

The selection of the target population for a PC plan will depend on where the greatest numbers of patients (adults and children) are concentrated ; the urgent needs of those patients and of their family members and caregivers ; and the resources available.

The greatest needs for PC are generally among cancer patients presenting with advanced stages. However, available resources may not be sufficient to target this entire group. Faced with this dilemma, many countries when starting PC within a comprehensive cancer control plan may decide to initially focus on terminal cancer patients and their caregivers. This group has the most pressing needs. The majority of terminal cancer patients (over 80%) suffer from severe pain and other serious symptoms that require urgent relief. On a long-term basis, PC will be extended to non-cancer patients.

Assess feasibility of interventions

The feasibility of PC for a given population depends on the skills and infrastructure available, the knowledge and attitudes of the target population, and the motivation of the government and the care providers.

In order for a PC program to be fully effective, it should deliver good quality services for relief of pain and other symptoms, psychosocial and spiritual support, and bereavement care, equitably and for an indefinite duration to all members of the target population in need, including patients, family members and caregivers.

A good PC program encompassing interventions at all levels of care, with a particular focus on primary health-care services and home-based care, could eventually result in a reduction in hospitalization and the use of inappropriate expensive procedures.

Consider ethical issues [10]

Ethical and legal issues of a PC plan and program should stress the following ; first, allocation of adequate human and financial resources to PC ; second, integration of PC with curative care to ensure high-quality care, social, individual and professional obligations and responsibilities regarding the provision of care. Moreover, adopting different perceptions and attitudes in various cultural contexts concerning, for example, quality-of-life versus length-of-life goals, enduring or relieving pain, and the end of life.

In addition, autonomy of decision-making and valid informed consent of either the patient or legal guardian are essential.

Bridge the gaps in PC

It is important to evaluate the actions to bridge the gaps from the perspective of those who support and will eventually implement those actions, and from the perspective of any potential opponents. Identification of the key person with power to make the desired change should be contacted and convinced to do so.

Raise the necessary resources

To make sure that the necessary human and financial resources are available to implement the strategies and actions included in the PC plan,

The PC plan should be accompanied by a resource plan that outlines existing resources, needed resources and possible strategies for acquiring the needed resources from both governmental and nongovernmental sources.

Organize cancer PC services across all levels of care

All countries, rich or poor that implement PC with a public health approach need to integrate the services at all levels of care in order to ensure accessibility to the whole target population. Comprehensive PC includes management of pain and other symptoms, complications, psychosocial care for patients and caregivers, spiritual understanding and approaches for patients and caregivers.

The above services can be progressively extended across all levels of care. When organizing cancer PC services, it is important that cancer PC services should respond to the needs of patients and their families, and to the objectives and priorities of the cancer PC plan. In addition, the services should be accessible to a large majority of the target population, and should be delivered in an equitable manner across all levels of care, whether services are public or private.

It is estimated that over 80% of advanced cancer patients will benefit from relatively simple and low-cost interventions that can be integrated into primary healthcare and home-care services, through a community-based approach. Less than 20% of advanced cancer patients will require relatively specialized PC services that can be provided by PC units at district hospitals or at the tertiary level.

Adopt a team approach

Strong leadership and overall program management should ensure that local managers and healthcare providers work in multidisciplinary teams across the health system, and coordinate closely with community leaders and organizations involved in the program, in order to achieve a common goal. The composition of the PC team will vary depending on the objectives of the program, and the healthcare professionals available.

In general, PC requires a strong network of trained healthcare practitioners, community leaders, traditional healers, and family caregivers with specific roles and functions across the different levels of care and within the community.

Understand the role of healthcare providers and create PC teams

Healthcare providers involved in PC may include physicians, nurses, social workers, psychologists, spiritual counselors, volunteers, pharmacists and traditional healers [11-15]. Each can play a useful role :

Physicians play a crucial role in interdisciplinary PC. They must be competent in general medicine, competent in control of pain and other symptoms, and must also

be familiar with the principles of management of the patient's disease. Physicians working in PC may be responsible for assessment, supervision and management of many of the difficult treatment dilemmas. They may also be responsible for leading the interdisciplinary teams. They clearly play an important educational role as they discuss medical management decisions, are involved in research and the critical application of research findings as an integral part of their work.

The nurse is the team member who will typically have the greatest contact with the patient. This prolonged contact gives the nurse a unique opportunity to know the patient and the caregivers, to assess in depth what is happening and what is of importance to the patient, and to assist the patient to cope with the effects of advancing disease. The nurse's expertise in providing physical and emotional care to the patient, symptom management, patient and family education, and in organizing the patient's environment to minimize loss of control, is critical to PC.

Nurses are able to work closely with patients and families to make appropriate referrals to other disciplines and healthcare services. In some settings they play a role in providing public and volunteer education about PC.

Moreover, the role of **the social worker or psychologist** is to help the family and patient deal with the personal and social problems of illness and disability, as well as to provide support during the progression of the disease and the bereavement process if the patient is at the end of life.

The social worker's assessment helps define the patient's and family's needs from a psychosocial perspective, and helps anticipate problems within the family that may result from dysfunction and financial difficulties, particularly as the family begin planning for the future.

The spiritual counselor should be a skilled and non-judgmental listener, able to handle questions related to the meaning of life. Such questions invariably arise for patients and their families. The role of the spiritual counselor is often one of listening, to facilitate recollection of the past and growing readiness for what lies ahead. Spiritual counselors need to be trained in end-of-life care.

The role of the volunteer within the PC team will vary according to the setting. Volunteers are included in hospice and PC teams with the aim of assisting healthcare professionals to provide the optimal quality of life for patients and families. Volunteers come from all sectors of the community, and often provide a link between healthcare institutions and patients. Incorporating volunteers in a PC team brings in a dimension of community support and community expertise. With the appropriate training and support, volunteers can provide direct service to patients and families, help with administrative tasks, or even work as counselors.

The pharmacist ensures that patients and families have access to the essential drugs for PC. Morphine and other suitable medicines are necessary for PC. The pharmacist's expertise is also needed to support the healthcare team by providing information on drug doses, drug interactions, appropriate formulations, routes of administra-

tion, and alternative approaches.

A recent study was conducted by Huda Abu-Saad Huijjer et al. emphasizing on the need for developing PC services in Lebanon [16]. The provision of quality PC services requires however the education and training of health professionals in this field. PC needs to become an integral part of all nursing and medical school curricula as well as continuing nursing and medical education program offerings.

The development of this new field in Lebanon requires the commitment of governments and policy makers at all levels and as such the allocation of budget and other resources to make it happen. Other challenges facing this field include establishing practice guidelines and policies on end-of-life care such as advanced directives, breaking bad news, and withholding and withdrawing life sustaining treatments.

Further studies are needed in this area to clearly understand the problems encountered in the practice setting and to guide the adoption of a PC delivery model that is culturally sensitive and meets the needs of the Lebanese population.

CONCLUSION

PC is an urgent humanitarian need worldwide for people with cancer and other chronic fatal diseases. PC is particularly needed in places where a high proportion of patients present in advanced stages and there is little chance of cure [17].

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 necessary to change the legislative system in Lebanon in order to recognize and to integrate this new discipline. Education and training of health professionals in PC should be provided by medical and nursing schools throughout the country. Postgraduate education in medicine and nursing and ensuing certification should be made available. A close collaboration between medical and nursing associations to achieve this end will be needed and is highly recommended. It is as important and essential to involve policy makers in the development of pain relief and PC services and clinics which meet the needs of the population in Lebanon.

The coordination of PC services remains to be one of the most crucial aspects and one of paramount importance. As terminally ill patients and their families move between the different settings and healthcare agencies, they need the support and guidance of a healthcare professional familiar with their situation who can coordinate their care.

Effective PC services should be integrated into the existing health system at all levels of care, especially community- and home-based care. They should involve public and private sector and be adapted to the specific cultural, social and economic setting. In order to respond to the cancer priority needs in a community and make the best use of scarce resources, PC services should be strate-

gically linked to cancer prevention, early detection and treatment services for both adults and children.

The time will come for Lebanon to form the National Council for Pain Relief and PC as an advocacy and coordination body for pain relief and PC in the near future. To that effect, we believe the future is near.

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