

# PALLIATIVE CARE IN LEBANON Where are we now? Where are we going?

## PALLIATIVE CARE RESEARCH IN LEBANON

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NATIONAL COMMITTEE FOR PALLIATIVE CARE

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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 [1].

According to the International Association for Hospice and Palliative Care (IAHPC, 2008), in developed and developing countries alike, people are living and dying with unrelieved pain, uncontrolled physical symptoms, unresolved psychosocial and spiritual problems, and in fear and loneliness which could be helped or prevented with palliative care. A number of professional, social and legislative factors could play a role such as lack of education among health professionals and the public, lack of palliative care services, and the current laws and regulations restricting or prohibiting the use of opioids [2].

The planning of any palliative care service requires a well-conducted needs assessment study which should address patients' needs, priorities, models of care, the health services available in hospitals and communities, as well as the cadre of specialized health professionals. Research is crucial in helping the country adopt a palliative care model adapted to its needs and population characteristics. Similarly, all physicians, nurses, and allied health professionals working in palliative care will need training. Routine professional education does not adequately equip them to offer the best standard of palliative care. Palliative care workers often report that politicians,

the press, fellow professionals, and even the public do not know much about palliative care. Research and audits can help to define the current situation and the needs for future development of education in palliative care. Practice in palliative care is guided by ethical principles which at times present themselves as dilemmas when decisions are made regarding cardiopulmonary resuscitation, withdrawal of alimentation and hydration, and truth telling and consideration of family values. The aim of palliative care is to allow patients to be pain-free and for their pain and other symptoms to be sufficiently controlled that they do not interfere with their ability to function or impact their quality of life. Research in this field is essential for the development of evidence-based practice guidelines which guide health care professionals in providing most effective care.

### CURRENT SITUATION 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, 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 Huijer *et al.* 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

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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 [3-5].

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 [6]. The majority of medical students at the American University of Beirut (AUB) on the other hand believed in telling the truth [7]. Yazigi and colleagues (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' [8]. In a qualitative study on communication and truth telling among cancer patients, Doumit and Abu-Saad Huijer (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 [9].

In a recent study conducted by Abu-Saad Huijer *et al.* 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 [10-11]. 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 [12].

A similar study by Abu-Saad Huijer *et al.* (2013) addressing quality of life and symptom experience among pediatric cancer patients found similar results. The participants reported acceptable health-related quality of life and normal daily functioning, however they experienced highly prevalent physical and psychological symptoms. Young children 7-12 years of age reported to suffer mostly from pain, lack of appetite and nausea; while adolescents 13-18 experienced lack of energy, irritability, and pain. The most treated symptoms that yielded the most success in symptom management were pain and nausea. On the other hand, the psychological symptoms despite being highly prevalent like feeling irritable, worrying,

feeling nervous and feeling sad were inadequately addressed by the healthcare team [13]. Interestingly, a new study by Abu-Saad Huijer *et al.* (2013) that addressed pediatric palliative care services as perceived by parents of children with cancer confirmed the latter findings. The study emphasized the need for comprehensive symptom assessment, and treating both the physical and psychological symptoms through different intervention strategies in order to decrease symptom burden and improve quality of life [14].

In a 2011 study conducted by Saad and colleagues 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. Communications 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 [15].

Studies addressing the lived experience of patients in palliative care 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 [16]. Similarly, the results of a qualitative study by Khoury *et al.* 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 [17].

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 and bureaucratic system of acquiring narcotics; and 3) limited availability of opioids on the Lebanese market.

In conjunction with some of the studies mentioned above, Abu-Saad Huijer *et al.* tested the psychometric properties of the translated Lebanese-Arabic version of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 (EORTC QLQ-C30) in a heterogeneous sample of Lebanese adult cancer patients. Six out of the nine subscales had Cronbach's alpha coefficients above 0.70. Multitrait scaling analysis showed that all item-scale correlation coefficients met the set standards of convergent (95.8%) and discriminant validity (79.7%). In inter-scale correlations, all conceptually related scales had correlation coefficients of greater than 0.40 with few exceptions. In known-groups comparison, the instrument differentiated significantly between some of the subscales with respect to education, employment, and age. Confirmatory factor analysis showed an almost good fit (GFI = 0.87) with respect to the data set used [18]. Currently, Abu-Saad

Huijjer *et al* are testing the reliability and validity of the Memorial Symptom Assessment Scale which is approaching completion.

#### DEVELOPING RESEARCH PRIORITIES

The development of research priorities in palliative care is deemed essential for the development of palliative care services in general. In reviewing the literature on this topic, a few examples were found which will help frame the development of research priorities in palliative care for Lebanon.

The United States national palliative care research center is focusing their research priorities on pain and symptom management, through exploring the impact of pain and other distressing symptoms on quality of life, independence, and functional performance, as well as developing interventions directed at their treatment in patients with advanced and chronic illness. In addition, the impact of improving communications between the patient, his/her family and health care providers is another research priority area. Finally, models and systems of care for patients living with advanced illness and their families are being studied and are considered a priority area for research [19-20].

The goals for the European palliative cultural research center focuses on clinical, translational and basic research studies addressing symptom control, assessment, classification and underlying mechanisms of common signs and symptoms that lead to patient suffering [21].

The American National Cancer Institute is focusing its palliative care research efforts on interventions aiming at improving the quality of life of patients and their families while facing problems secondary to life-threatening illness through early identification, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems [22-23]. Areas under study include: effective, practical interventions to prevent or manage cancer

and treatment-related symptoms and toxicities across the cancer care continuum, from diagnosis to end of life; care delivery systems for symptom management; effects of treatment on quality of life; techniques to maintain and restore physical and psychosocial functioning during treatment; and the impact of different care delivery sites, such as the home or a community-based setting, on patient and caregiver quality of life, morbidity, and survival.

#### 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) to discuss the mandate and make recommendations. After a thorough assessment of the current situation in Lebanon and benchmarking with other countries, the subcommittee 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. Being in its infancy, palliative care in Lebanon has the chance to be built in a robust evidence-based manner if scientific research is conducted before the creation and implementation of services.

The proposed priorities are grouped under three main areas; public policy, education, and practice (see box 2).

Regarding public policy and organization of services, several research topics have been recommended. The committee recommended conducting a situation analysis and needs assessment of palliative care services in Lebanon first in order to delineate the type and extent of services available. Findings from such studies will inform the field of palliative care in Lebanon and will provide a unique chance to build and expand on services that are sci-

### 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, and policy.
2. To recommend research methods to address the gaps in information related to pain relief and palliative care in Lebanon.

##### Membership

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entifically proven to be needed. Lebanon should not just replicate what has been created in other countries as each society has its specificities and unique needs. What has been proven to be needed in one society does not necessarily translate into being needed in Lebanon.

In parallel, the attitude of the public with regard to early referral and end-of-life care should be studied. This will help create services that are socially acceptable. In addition, research about public awareness is essential for the success of any palliative care intervention. The majority of Lebanese with a mental disorder for example, do not consult their physician. Contrary to popular belief, this is not due to taboo but rather to lack of awareness about mental health disorders and the fact that help can be provided. The same applies to palliative care where physicians and patients alike may be unaware of the existence of such services to make referrals and initiate palliative care treatment. Additionally, there may be a lack of awareness accompanied with a lack of knowledge about the availability of palliative care interventions which do not hasten death but on the contrary can improve the quality of life. Lack of awareness can be remedied by developing campaigns and educational programs geared for health professionals and the public about palliative care which will help increase early referrals and improve end-of-life care.

Other important research topics in Lebanon related to

public policy in palliative care are the study of advanced directives and advanced care planning as well as a situation analysis on legislation of withdrawal of life support measures.

The needs assessment studies can lead to the development of different models for service delivery in palliative care. Specific models may have to be created for specific patient populations namely for children, the elderly, the cognitively impaired among others. These models then become research topics by themselves. The effectiveness of the adopted palliative care models needs to be studied on a regular basis with different patient populations and at the different institutional levels.

Another research priority is education in palliative care. The committee recommended conducting a needs assessment and a situation analysis on palliative care educational programs in Lebanon.

The level of knowledge about palliative and end-of-life care and the attitudes and practices among health care professionals should be studied. All health care providers encounter terminal illness in their professional lives and hence they should be aware and knowledgeable about the services provided and the treatment options available. Pain and symptom management should be an integral part of the curricula of medical and nursing schools. Consequently, interprofessional palliative care educational programs are deemed important and are highly recom-

## BOX 2

### PALLIATIVE CARE RESEARCH PRIORITIES

#### **A. Public Policy and 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 and 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

mended to better prepare the health professionals to work as a team in palliative care. These interprofessional programs, although important, their effectiveness in preparing the palliative care health professionals needs to be studied and compared to the traditional monodisciplinary programs currently in use.

The third research priority area as recommended by the subcommittee on research is practice. Extensive and rigorous research should be conducted about the practice of palliative care in Lebanon. This type of research is essential and provides the evidence for developing clinical practice guidelines and pathways which contribute to evidence-based practice and to the improvement of palliative care services in Lebanon. Some examples of research topics in palliative care practice include: pain and symptom management in cancer and non-cancer patients, in children, in the elderly, and among the cognitively impaired. The practice setting can also benefit from research addressing issues regarding disclosures and truth-telling taking into consideration family values and beliefs, as well as research on attitudes towards opioid use and availability. Finally, research with a specific focus on end-of-life care for cancer and non-cancer patients will shed more light on this important area in the field of palliative care.

Research priorities in palliative care are not set in stone. They should be revisited and modified on a regular basis based on national needs and international developments.

#### RECOMMENDED RESEARCH METHODS TO ADDRESS PRIORITIES

##### **1. Situation analysis**

Mapping of all the palliative care services offered in Lebanon be it in hospitals, hospices and home care, will entail undertaking a national survey, to document what is being done currently and where the services are located. A review of the curriculum of all medical, nursing, and pharmacy schools is in order to assess whether palliative and end-of-life care is addressed and how it is integrated in the teaching curricula. While contacting academic programs in the different universities, one could plan for in-depth interviews, to gauge their opinions about introducing pain management and palliative care in their curricula. The in-depth interviews will be based on a semi-structured questionnaire with both closed- and open-ended questions. Situation analysis data collection regarding interprofessional education could also be planned at the same time as the curriculum review.

##### **2. Knowledge, attitude and practice (KAP) surveys**

Investigating awareness of the public as well as health professionals through cross-sectional KAP surveys is instrumental, to plan and execute well-targeted awareness campaigns. The population-based KAP surveys should be a representative sample of the surveyed population.

A plan for an awareness campaign should constitute

an integral part of KAP survey implementation, where the initial KAP data collected at baseline (pre-intervention information) will be compared to a post intervention survey. The evaluation of the success of the awareness campaigns will be measured by the change observed in a set of measurable outcomes such as early referrals among others.

These population-based surveys could be complemented by focus group discussions, with families related to the patient, physicians, and nurses.

##### **3. Institutional and government policy**

Policies governing what is currently being implemented regarding palliative and end-of-life-care and opioids prescription for pain relief should be documented at the institutional and governmental level.

Distinguishing between what the legislation postulates and what is the current practice regarding opioid prescription, withholding and withdrawal of life-sustaining treatment could be investigated through a series of case-studies.

A nominal group of experts should get together to debate and rank the different modalities of opioid availability and prescription, in order to build consensus on what are the most effective policies to improve patient care.

##### **4. Initiating research that will feed into evidence-based interventions**

Most of the research to date has focused on terminally ill cancer patients. A systematic review of the available literature will provide evidence on improving palliative care among cancer patients.

Other vulnerable groups should be targeted such as children and the elderly. Intervention studies should be devised to assess and compare those who received palliative care to those who did not in terms of specific outcome measures.

Implementing translational research in five years will allow the evidence generated from the research to be linked to policy and improvement of patient end of life experience.

#### CONCLUDING REMARKS

The major change allowing for an improved structural strategy in the delivery of palliative care in Lebanon is the fact that efforts are being centralized under a clear governmental initiative and mandate. The individual group efforts, mostly research, conducted by local experts have set a solid foundation. In order to assess national needs and provide a multi-faceted comprehensive plan, accounting for public need and resources, the National Task Force on Pain Relief and Palliative Care was a crucial necessity.

The Research Committee proposed three arms research priorities including public policy and organization of services, education and practice in order to serve as evidence based platforms to guide national authorities into organiz-

ing and optimizing palliative care.

Future recommended policies and practices need to be comprehensive addressing cancer and non-cancer patients, in children, in the elderly and among the cognitively impaired.

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