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ABSTRACT • Palliative care (PC) for older adults constitutes an important human rights challenge and a major public health care priority due to the aging of the population and the lack of health care services addressing the needs of the older people. In Lebanon, the surge in the number of older people with complex needs is unmatched by any increase in the services offered to them. PC in Lebanon is still underdeveloped and is subject to a number of challenges. These challenges are alarming and must be overcome through introducing health care providers to basic PC principles as recommended by the National Committee for Pain Relief and Palliative Care (NCPRPC).

Keywords: older adults, palliative care, Lebanon

INTRODUCTION

Palliative care (PC) for older adults constitutes an important human rights challenge and a major public health care priority due to the aging of the population and the lack of health care services addressing the needs of the older people. Patterns of disease with advancing age are also changing with the majority of older adults now dying of chronic degenerative disorders such as heart failure and dementia. Furthermore, with earlier diagnosis and new treatment options, some types of malignancies have become chronic conditions. As a result, PC services are urgently needed to address the complex health care problems and disabilities older people face in the course of their illness and at end-of-life (EoL).

PC is defined by the World Health Organization as an approach that improves the quality of life (QoL) of patients suffering from life-threatening illnesses as well as their caregivers [1]. PC providers address a wide range of physical, psychosocial, and spiritual symptoms to prevent and relieve suffering. In Lebanon, while the majority of recipients of PC services are oncology patients, a growing proportion suffer from chronic progressive degenerative non-malignant conditions. As such, a natural alliance be-

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RÉSUMÉ • Globalement, les soins palliatifs (SP) pour les personnes âgées sont soumis à plusieurs barrières dues au vieillissement de la population et au manque de services de soins de santé adaptés à leurs besoins. Au Liban, l'accroissement du nombre de personnes âgées est soumis à des défis alarmants. Les SP au Liban sont sous-développés ce qui nécessite un passage à l'action et notamment l'évolution des formations du personnel de santé visant à introduire les principes de base des SP tels que recommandés par le Comité national pour le soulagement de la douleur et les soins palliatifs (NCPRPC).

tween PC and geriatric medicine exists, where approximately 70% of PC referrals involve patients older than 65 years. PC should be offered to all individuals suffering from any illness that affects their QoL across the lifespan [2].

Improving the care of older adults with chronic illness has been the objective of palliative and hospice care organizations throughout the world. WHO leaders and advocates of PC have been called on to publish monographs with the goal of integrating PC into healthcare services worldwide and providing PC to all patients with life-limiting illnesses. As a result, standards of practices and consensus statements in the care of older people have been published. These practices focus on the needs of older adults and their families and on effective pain and symptom management intended to relieve suffering and improve the QoL.

The purpose of this article is to review the literature on PC in older adults in Lebanon and reemphasize the recommendations of the National Committee on Pain Relief and Palliative Care (NCPRPC) for service development and further research in this hitherto neglected area of patient care.

PALLIATIVE CARE SERVICES

Populations around the globe are aging. In the United States, it is expected that one in five Americans will be 65 years or older by the year 2030 [3]. The majority of deaths among older adults occur due to chronic debilitating illnesses [2]. Towards the end-of-life, older adults may suffer from pain, low mood, dyspnea, insomnia, mental confusion, fatigue, and urinary and bowel incontinence, among other progressive symptoms [4]. All

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these symptoms can be thoroughly managed and mitigated through the introduction of PC early in the course of illness.

Internationally, few services address the complex needs of older adults who require PC support and few regional policies exist to reinforce and implement existing services. Countries like the United States and Sweden have clear national policies that guide the delivery of community support services to older adults [5]. These policies address diverse services such as the provision of adequate nutrition, transportation, and home support, though none clearly addresses the palliative and EoL care needs of older adults. In the United Kingdom, PC services have been developed to address the needs of predominantly young and middle aged individuals living with cancer rather than older people suffering from non-malignant life-threatening and life-limiting illnesses [6].

PC services should cater to the increasing number of older adults around the world. A literature review was conducted to address the need for comprehensive PC services for cancer and non-cancer older patients.

This review highlighted the commonalities between geriatrics and PC in terms of diseases, the focus on patient-centered care, and continuity of care in addition to the interdisciplinary approach to provide holistic patient care [7]. Other commonalities include bereavement support, ethical decision-making, preserving functional independence, and advanced care planning. Moreover, three key components of PC in older adults were identified, namely: active, total, and holistic modalities of care [8-9]. The active approach is characterized by minimizing futile measures and employing an active approach to prevent, identify, and treat distressing symptoms. A total approach addresses the three dimensions of PC namely the physical, psychological, and spiritual. Finally, a holistic approach ensures patient-centered PC services tailored to the needs of older adults.

When comparing PC services provided to cancer and non-cancer older patients it was found that symptoms associated with non-cancer conditions are more complex and harder to treat, in addition to increased difficulties encountered in estimating prognosis [10]. In a systematic review of eleven studies intended to identify tools and variables to help PC providers predict survival and assess PC in non-cancer older patients, it was found that key predictors of survival included increased dependency, comorbidities, poor nutrition, and weight loss, in addition to abnormal vital signs and laboratory values [10]. These predictors were identified for dementia, chronic obstructive pulmonary diseases, and heart failure. Since the reviewed literature lacked data about the relationship between PC and survival, one of the recommendations was for further research on the psychosocial outcomes of PC in older adults and their caregivers.

Comprehensive assessment of older adults is considered the best measure to address the complex needs of this patient population. The use of valid and reliable assessment tools and the establishment of protocols tai-

lored for older adults with dementia are recommended, and fall squarely within the domain of geriatric medicine. Assessment tools must take into consideration symptoms commonly experienced by terminally ill older adults such as fatigue, pain, and dyspnea [11-12]. The literature also highlights the importance of addressing psychospiritual needs of dying older adults and preserving their dignity through relief of symptoms such as pain, foul smelling wounds, and disfiguring skin conditions [7]. Dignity could also be preserved by minimizing invasive procedures such as indwelling catheters, feeding tubes, and injections. Finally, the QoL of dying older adults can be enhanced by the availability of family support, financial security, and trained professional staff all of which are known to influence bereavement and the grieving process.

Family dissatisfaction and bereavement difficulties were found to be associated with lack of optimal EoL care provided to older adults in nursing homes in the USA [13]. In context of the Lebanese social structure, family commitment to care of their infirm at home can simultaneously be a source of satisfaction and stress. Societal expectations and obligations can trigger a sense of fulfillment and bonding with a loved one, but this "closure" is balanced by an inevitable feeling of helplessness and hopelessness, particularly in the absence of a qualified social support structure [14]. Caregiver burnout and depression are more prevalent in chronic degenerative disorders, such as dementia, rather than in malignancies.

Palliative Care and Dementia

Dementia is a disease that causes severe impairment in memory, cognition, and behavior, which subsequently leads to disability and increased dependency. Globally, over 35.6 million people live with dementia with the majority being older adults. This disease not only affects the patients, but also has negative repercussions on health-care providers and patient families [15]. Twenty-nine articles were reviewed in order to explore the barriers to EoL care delivery in older adults with dementia and the means to overcome them. Four themes were identified: "difficulties associated with diagnosing the terminal phase of the illness (prognostication); issues relating to communication; medical interventions; and the appropriateness of palliative care intervention." [16]. The authors stressed the importance of improving PC delivery for older adults with end-stage dementia through exploring their needs and assisting in the allocation of appropriate PC services.

Frail older adults are known to have complex needs and tend to suffer from various chronic diseases that impede their QoL. This population requires extensive counseling in order to make sound decisions regarding complex medical and surgical treatments and procedures. Many older adults receive aggressive treatments or undergo complex procedures that may lead to unnecessary suffering and death [17].

A model called "The Palliative and Therapeutic

Harmonization (PATH)" was introduced to guide medical and surgical decision-making in frail older adults in Canada [18]. One hundred and fifty older adults accompanied by their primary caregiver completed the PATH program. Participants were frail, had multiple comorbidities, and were taking several medications. Participants and their primary caregiver had three encounters with the researchers. The first encounter was meant to assess the participants; the second was to communicate with both the participants and their primary caregiver about dementia, frailty, and decision-making; and the third was to empower the participants to make sound decisions. Following the completion of the program, participants and their primary caregivers declined 75% of their scheduled procedures which included cardiac surgeries and hemodialysis. Additionally, 76.7% of the participants were not able to fully participate in planning for their care due to dementia or delirium, therefore the decision was made by their primary caregiver [18]. It was concluded that PC programs tailored for frail older adults allow them and their caregivers to make sound decisions regarding their care. Implementing such a program in the Lebanese healthcare system will require investment in qualified providers and a national commitment to improving care of the frail older adult.

Life-Threatening Disorders and Palliative Care

Cardiovascular diseases are still the leading causes of mortality and morbidity worldwide [19]. Over 50% of patients diagnosed with heart failure are older than 75 years [20], and older adults living with heart failure tend to score low on QoL questionnaires. Moreover, older people tend to complain of several symptoms like fatigue and dyspnea which increase their dependence and subsequently impair their QoL. The means by which older adults cope with their symptoms are correlated with their understanding of their illness which, most of the time, is poor. This leads to exacerbation of symptoms of heart failure which subsequently leads to high admission and readmission rates [21].

Cancer patients receiving PC services in the UK tend to be younger than those who do not receive it [22]. This was thought to be a result of differences in attitudes when it comes to EoL and PC. A cross-sectional survey to assess the relation between age and attitude towards death as well as knowledge and attitude towards cancer and PC was conducted.

Comparison was made between 129 participants aged 55-74 and 127 participants who were 75 years and older. It was found that participants were familiar with PC services. Moreover, older people with terminal illness were less likely to ask their physician to end their life despite believing that it is easier to face death as compared to younger participants. It was concluded that under-utilization of PC services by older adults with cancer in the UK is not explained by their overall attitudes towards EoL and PC [22].

One cannot implement PC without addressing goals

of care which include an open discussion of the diagnosis, prognosis, and natural course of a disease. In later stages, goals of care discussions guide patients and their families to make sound decisions regarding EoL care [3]. A study was conducted in the United Kingdom to explore the extent to which older people's views and concerns about dying are consistent with the prevalent model of the 'good death' underpinning PC delivery [6]. Forty in-depth interviews were conducted with older adults living with advanced heart failure. It was found that there was some degree of contradiction between what the participants viewed as 'good death' and the values that serve as the backbone of PC. For instance, many participants chose not to have an open discussion about death and many were unfamiliar with concepts used in PC like autonomy and individuality. It was concluded that the means by which PC knowledge is translated is not tailored to fit the needs of older adults.

In Lebanon, very few studies address the needs of patients receiving PC, and none address the PC needs of older adults per se. Only one study was conducted to uncover the lived experience of Lebanese oncology patients receiving PC [23]. Ten participants were recruited to the study. They expressed the level of distress they experienced as they became more dependent. Many expressed their dislike for pity and others raised concerns about their families, the role of God, their dislike of their stay at the hospital, lack of productivity, fear of pain, and the impact of communication and truth telling on their well-being. Most of the study participants were middle-aged hence the study findings cannot be transferred to older adults receiving PC.

A cross-sectional descriptive survey was used to determine the QoL and prevalence of a wide range of symptoms experienced by Lebanese cancer patients [24]. The effectiveness of treatments offered to manage these symptoms was also addressed. A total of 200 cancer patients completed the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) and the Memorial Symptom Assessment Scale (MSAS).

It was found that lack of energy was the predominant symptom in the sample. Additionally, nausea and pain were the symptoms most treated. Those with a low health status, QoL, and functioning were found to experience more physical and psychological symptoms. It was concluded that several symptoms experienced by oncology patients are inadequately treated. Furthermore, symptoms experienced by oncology patients have a negative effect on their QoL and overall functionality.

PALLIATIVE CARE IN LEBANON A CLINICAL PERSPECTIVE

In Lebanon, as elsewhere, older adults are the fastest growing segment of the population. Today, just under 10% of the population is above the age of 65 years; by 2030, this number is expected to increase to 12%, and will

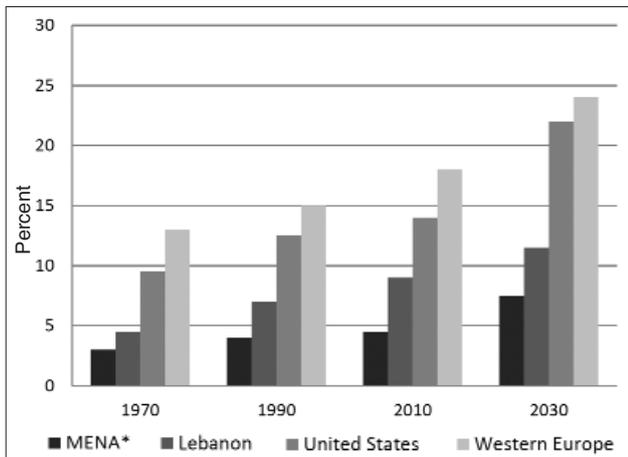


FIGURE 1. Growth of population over age 65 years by region.

Source: Daher M, Hajjar RR. Palliative care for cancer patients in Lebanon. In: Silbermann editor. Palliative Care to the Cancer Patient: The Middle East as a Model for Emerging Countries, 1st ed. New York :Nova Publishers, 2014: 125-40 [25] & Hajjar RR. The Annual Meeting of the American Geriatric Society – Special interest Group on Ethnogeriatrics, Grapevine, Texas, USA, May 2013 [26].

*MENA: Middle East and Northern Africa.

approach 18% by 2050 (Fig. 1) [25-26]. With longevity come chronic disease and increased resource utilization, and Lebanon is currently ill-prepared to handle either.

This surge in the number of older adults is expected to be met with various challenges. First, the increase in the older population is not matched by an increase in geriatric support programs provided by the Lebanese government such as pension plans, health and social se-

curity measures, healthcare insurance, and home health care. Second, few studies address the healthcare needs of older adults in Lebanon. To provide optimal supportive services to older patients (from a limited resource pool) a better needs assessment is necessary. Third, training in the care of older adults is absent from the majority of medical and nursing school curricula. Fourth, the number of institutions offering care to older adults is insufficient. Finally, and most importantly, PC services in Lebanon are still limited and suffer from a serious shortage of qualified providers. Very few healthcare providers who offer PC are formally trained and access to medications used at EoL such as morphine remains limited [27].

Longevity also increases the lifetime cumulative risk for many types of cancer.

Epidemiological studies show that all-cause cancer incidence peaks around the age of 70 years (Fig. 2). Over the next few decades, the incidence of cancer in Lebanon is expected to surge in parallel with the aging population. In fact, registry data already indicate an increasing regional burden of cancer. The number of new cases of cancer has increased steadily over the past decade. In 2004, almost 7,200 new cases of cancer were reported in Lebanon, compared to over 8,400 in the most recent report [28]. This worrisome trend is not entirely due to aging; expanded screening efforts and improved registration methods have likely contributed significantly. It is estimated that by 2030, the number of new cancer cases will approach 12,000. Naturally, it is not age alone that shapes cancer prevalence and outcome of a population. An indolent preventive care culture and lackluster approach to cancer screening, coupled with high prevalence of cancer-promoting behavior such as smoking and

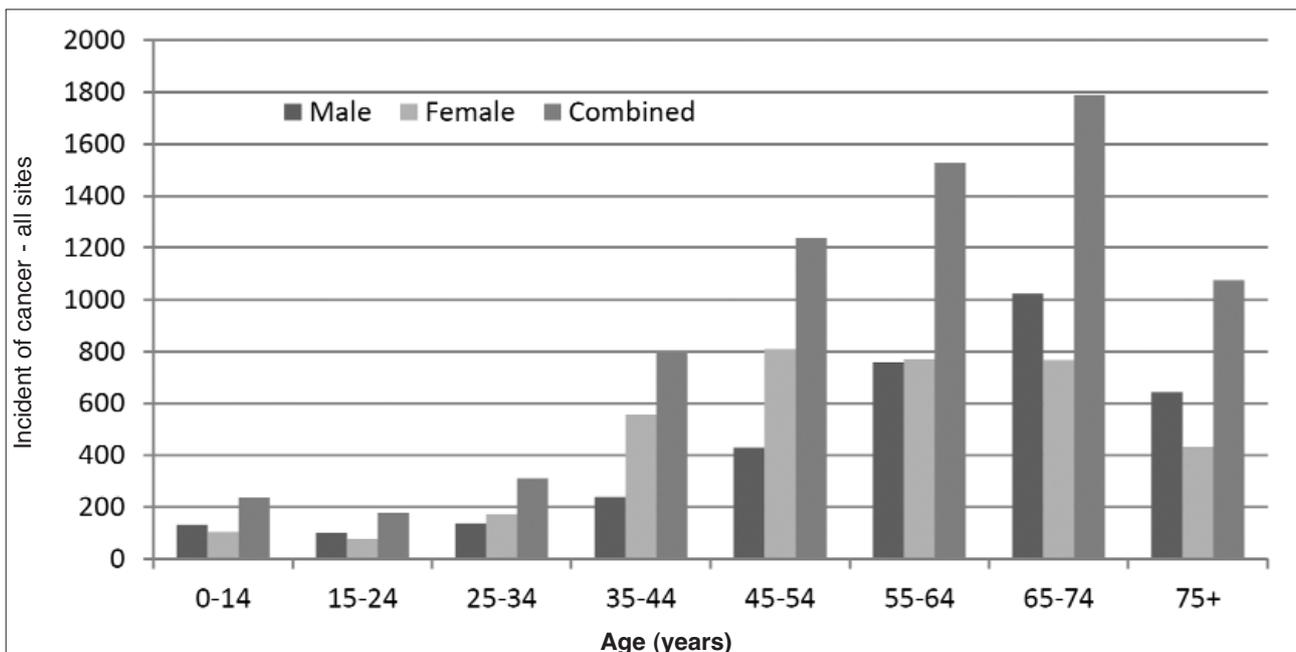


FIGURE 2. Incident cancer cases in Lebanon by age – 2003. All-case cancer excludes non-melanoma skin cancer. Source: National Cancer Registry (NCR). Cancer in Lebanon 2004 with an update of 2000, Beirut, Lebanon [28].

sedentary lifestyle, mean that many cancers present at an advanced stage when the only reasonable treatment option is PC.

It must be stressed again at this point that PC is not synonymous with terminal care, nor is it necessarily limited to the older people. In Western societies, where the hospice and PC movement is integrated into the healthcare system and widely accepted, over 40% of enrollees into such programs suffer from non-cancer diagnoses, and 18-20% suffer from chronic degenerative disorders such as dementia and Parkinson's disease. A small but significant number are young adults or children. Consequently, PC skills and services align more seamlessly with those of geriatric medicine, and no comprehensive geriatric medicine program is complete without a PC service.

Among the many obstacles to appropriate PC and pain management for older persons in Lebanon are:

- Lack of trained personnel
- Lack of interdisciplinary approach
- Lack of government guidance and policy
- Lack of opiate availability
- Fear of opiate use by professionals and patients
- Very few community hospice programs and qualified long-term-care facilities
- Late referrals.

Despite these challenges, major strides have been made in the last few years to develop the field of PC. The four major teaching hospitals in Lebanon now all have pain management programs and clinicians committed to PC, but no formal inpatient hospice programs existed until very recently. In a review of PC cases managed over a two-year period at the American University of Beirut Medical Center (AUBMC) (n = 81), approximately 88% of cases were above the age of 65 years and 70% were for management of terminal malignancies [26]. This pattern of utilization is in significant departure from the United States where approximately two-thirds of hospice enrollees have non-malignant diagnoses, according to the Medicare Hospice Benefits report. PC utilization in Lebanon is likely to change (if not the problem of late referrals) as public awareness and acceptance becomes more prevalent. The follow-up survey at AUBMC indicated that more patients and caregivers have become familiar with the concept of PC at EoL, and the service, when utilized, is highly valued. Acceptance, however, continues to be problematic, and many family members equated enrolment in PC with "giving up".

CONCLUSION

Every day frail older adults are exposed to futile interventions that cause or exacerbate various symptoms, prolong suffering, and at times hasten death. It is the PC providers' role to offer counseling to patients and their families in order to reconsider such measures. The PC provider must also be proactive in educating other caregivers on the limitations (medical, social, and ethical) of aggressive futile interventions, and help assimilate PC

into mainstream medicine. This would shift the focus from prolonging life to improving the QoL.

Psychosocial care tends to be overlooked in PC. Symptoms like anxiety and depression are often underdiagnosed in older adults due to coexisting comorbidities. These symptoms are known to affect the QoL of patients and their caregivers by causing suffering and increase in dependence. Additionally, the means that older adults utilize to cope with their illness and its sequel are dramatically influenced by their culture and set of beliefs. This highlights the importance of addressing spirituality in the care of this population.

In Lebanon, the increase in the number of older adults is unmatched by any increase in the services provided to them; this raises serious public health concerns. Additionally, only few studies explore the experience of PC patients, address symptoms that may influence their QoL, and evaluate the quality of PC offered to them. The majority of these studies are focused on oncology middle-aged patients with cancer rather than older adults.

Major strides have been made in the last few years to develop the field of PC and make it an integral part of the healthcare delivery system in Lebanon. The NCPRPC has made a number of recommendations in the domains of education, practice, research, and public policy which can be summarized as follows:

- Training of all health care professionals in basic principles of PC through the inclusion of PC content in undergraduate and graduate curricula.
- Creation of continuing education programs in PC.
- Provision of specialist training in PC for physicians and nurses.
- Development of professional standards and multidisciplinary clinical practice guidelines to guide PC practice.
- Coordination of care and rapid-access to PC services.
- Integration of PC services throughout the health care delivery systems.
- Development of PC research priorities and funding mechanisms for research.
- Revision of legislation governing the delivery of opioid analgesics.
- Development of a model to fund PC services.
- Launching of public awareness campaigns to raise the profile of palliative and EoL care in the country.

The recommendations of the NCPRPC will have significant implications for the provision of PC services for older adults. Additionally, high quality research is still needed in PC of older adults; PC research is limited to cancer, is descriptive in nature, and in most cases lacks the quality to contribute to evidence-based care. As a result, more research in this field is warranted.

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