Modification and Implementation of NCCN Guidelines™ on Palliative Care in the Middle East and North Africa Region

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Abstract
Palliative care is an important component of cancer treatment. Advancing palliative care in the developing countries is essential to improving patient care. The issues limiting its practice must be addressed, especially in light of the initiative to adapt the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) to the Middle East and North Africa (MENA) region. Palliative care is in its early stage of evolution in the MENA region, and its practice encounters many challenges and barriers. Adaptation of guidelines should take into consideration the situation and conditions in the targeted region to improve the standard of care to an internationally acceptable level. A group of experts in the MENA region reviewed the literature and collaborated to assess the current status of palliative care and recommend modifications to the NCCN Guidelines based on the unique needs of the region. (JNCCN 2010;8[Suppl 3]:S41–S47)

An initiative was launched to adapt several of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) to the Middle East and North Africa (MENA) region. Palliative care was one area of cancer treatment selected because of its high level of importance. To better understand how to adapt the NCCN Guidelines on Palliative Care in this region, the current status of palliative care had to be assessed. This article addresses the practice of palliative care in the MENA region.

Population and Religion
In our review, we evaluated 19 Arab countries of the MENA region, with 12 of these in Asia (Saudi Arabia, Kuwait, Qatar, United Arab Emirates, Bahrain, Oman, Yemen, Iraq, Palestinian Authorities, Jordan, Syria, and Lebanon) and the remainder in Northern Africa (Egypt, Sudan, Libya, Morocco, Tunisia, Algeria, and Djibouti).1,2 The total population of the MENA region exceeds 326 million (Table 1), with Arabic the official and most common language. The predominant religion is Islam, although other religions exist for the native population or expatriates. These countries have a wide heterogeneity of culture, religious practices and adherence, and social issues.

Palliative care principles are aligned and applicable to all religions and faiths.3 Although palliative care concepts and practice are more accepted by health care professionals, patients, and families, than in the past, families may tend to withhold, and persuade health care providers to withhold, information from patients, even at end of life. Furthermore, resistance to opioid use by individuals and providers in this region is usually a result of misconceptions and attitude, in addition to religious misinterpretation.4

Economy and Health Care Finance
The economic classifications of these countries vary widely, ranging from those that are wealthy to those...
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Family Model

An obvious shift is occurring from the traditional extended family model to a more nuclear, mobile, and isolated family structure. Families and individuals tend to rely more and more on the health care system and hospitals for the care of sick loved ones. This shift has resulted in overuse of health care resources, emergency visits, and in-patient beds for chronic and palliative care needs.

Cancer Epidemiology

Despite the advancement in medical technology and innovative therapeutics and pharmaceutical products, a huge increase in cancer incidence has occurred not only in the MENA region but also worldwide. Cancer ranges from the third to the fifth leading cause of death. In 2005, approximately 200,000 cancer deaths occurred in MENA countries, with approximately 60% of deaths in individuals younger with very limited resources. Household incomes, health care expenditure, and human development also vary widely. People tend to migrate from rural to urban areas, increasing the isolation of the rural areas and placing more governmental focus on large cities, resulting in an underserved rural population.

Health care systems in many countries have limited resources and low expenditures. The government may provide most cancer care, either partly or fully, to a portion of the population based on available resources and services; however, many countries may not have access to all treatment modalities. In view of this fact and other constraints, many patients are unable to access the system or afford treatment.

Private cancer care is provided on an out-of-pocket basis rather than through organized insurance, and most countries do not have a national cancer control program.

<table>
<thead>
<tr>
<th>Country</th>
<th>Population</th>
<th>Mortality From Cancer (Estimated Cause of Death 2005)</th>
<th>Opioid Consumption 2007 (kg)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Algeria</td>
<td>33.4 M</td>
<td>19,000</td>
<td>2</td>
</tr>
<tr>
<td>Bahrain</td>
<td>0.7 M</td>
<td>370</td>
<td>1</td>
</tr>
<tr>
<td>Djibouti</td>
<td>0.5 M</td>
<td>460</td>
<td>NA</td>
</tr>
<tr>
<td>Egypt</td>
<td>83 M</td>
<td>42,000</td>
<td>9</td>
</tr>
<tr>
<td>Iraq</td>
<td>27.5 M</td>
<td>15,000</td>
<td>NA</td>
</tr>
<tr>
<td>Jordan</td>
<td>6 M</td>
<td>3700</td>
<td>11</td>
</tr>
<tr>
<td>Kuwait</td>
<td>2.5 M</td>
<td>700</td>
<td>11</td>
</tr>
<tr>
<td>Lebanon</td>
<td>4 M</td>
<td>2600</td>
<td>4</td>
</tr>
<tr>
<td>Libya</td>
<td>6 M</td>
<td>2700</td>
<td>NA</td>
</tr>
<tr>
<td>Morocco</td>
<td>33 M</td>
<td>13,000</td>
<td>9</td>
</tr>
<tr>
<td>Oman</td>
<td>3.2 M</td>
<td>1200</td>
<td>2</td>
</tr>
<tr>
<td>Palestinian Authority</td>
<td>4 M</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Qatar</td>
<td>0.9 M</td>
<td>160</td>
<td>1</td>
</tr>
<tr>
<td>Saudi Arabia</td>
<td>27.6 M</td>
<td>12,000</td>
<td>13</td>
</tr>
<tr>
<td>Sudan</td>
<td>39 M</td>
<td>22,000</td>
<td>NA</td>
</tr>
<tr>
<td>Syria</td>
<td>19 M</td>
<td>5000</td>
<td>NA</td>
</tr>
<tr>
<td>Tunisia</td>
<td>10.1 M</td>
<td>6000</td>
<td>20</td>
</tr>
<tr>
<td>United Arab Emirates</td>
<td>4.4 M</td>
<td>1200</td>
<td>2</td>
</tr>
<tr>
<td>Yemen</td>
<td>22 M</td>
<td>10,000</td>
<td>NA</td>
</tr>
<tr>
<td>TOTAL</td>
<td>326.8 M</td>
<td>157,090*</td>
<td>85</td>
</tr>
</tbody>
</table>

Abbreviation: NA, not available.
*Cancer mortality exceeds 200,000 accounting for all MENA countries.
than 70 years (Table 1). Cancer incidence is underreported in most of these countries, either because of the lack of cancer registries or the absence of effective data collection.

**Traditional Cancer Care Model**

The traditional cancer care model in MENA countries almost follows an older cancer care model, which is marked by delayed patient presentation as a result of late detection, poor access, and late referrals, followed by an active anticancer treatment approach at diagnosis, ending with death or cessation of anticancer therapy. Less attention is paid to pain and symptom management, and poor end-of-life care is available, if at all. Except for a few centers mentioned later, no hospice palliative care model exists in most of these countries. Even in countries in which palliative care service is available, patients tend to be referred to palliative care late in the trajectory of their illness.

**Need for Palliative Care**

The needs of patients with cancer in the MENA region does not differ greatly from those of patients in the rest of the world. Patients diagnosed with cancer have multiple domains of suffering, including physical, social, spiritual, practical, and psychological, as a result of multiple levels of interactions with the disease itself, or with relatives, care providers, health care systems, and the community.

Palliative care should start from cancer diagnosis for all patients, regardless of the type or stage, and continue through the cancer journey for both survivors and advanced cases to end-of-life care. Palliative care should be delivered simultaneously with disease-modifying treatment. The need for palliative care increases as the disease progresses, until it is the only focus of care.

More than 80% of cancer cases are advanced at presentation, making palliative care the only option for patients and highlighting the importance of making palliative care services available for those patients and their families.

Using the WHO formula and multiplying cancer mortality (Table 1) by the percentage of advanced cases provides an approximate number of patients in the MENA region needing palliative care before they die in the given year, which was 160,000 for 2005 (200,000 x 0.8 = 160,000). Similarly, assuming one caregiver is needed per patient with advanced cancer, the number of caregivers can be estimated (> 160,000 in 2005).

**WHO Definition of Palliative Care**

The WHO defines palliative care by noting that palliative care improves quality of life of patients and families facing a life-threatening illness by preventing and relieving suffering through early identification, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and considers dying a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the patient’s family cope during the illness and through bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life and may also positively influence the course of illness; and
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes investigations needed to better understand and manage distressing clinical complications.

**Current Palliative Care Services**

Palliative care provision and development varies widely among countries. Based on a pilot study report from the International Observatory on End of Life Care, countries were divided into 4 categories based on the level of hospice and palliative care development. Countries in the first level, or category 1, have no available services for palliative care. Those in the second level, or category 2, are in the capacity-building stage, in which the need for palliative care is recognized and some awareness courses are
available. Countries in the third category, or level 3, have a local provision, with one or more palliative care programs established. Those in the fourth category, or level 4, have palliative care fully integrated into the health care system.

None of the MENA countries approached integration. Although some cancer centers in a few countries have succeeded in integrating palliative care into their existing institutions, the program is not developed in the entire country.

An increasing number of countries are establishing a localized provision of palliative care, including Egypt, Iraq, Jordan, Morocco, Saudi Arabia, and United Arab Emirates. At the time of this report, Qatar, Tunisia, Sudan, and Kuwait started or are starting to implement palliative care services.

Countries that have begun implementing various palliative capacity-building activities but have no formal services available are Algeria, Bahrain, Lebanon, Oman, and Palestinian Authority. Djibouti, Libya, and Syria have no known palliative care activities. Few countries are privileged to have well-established centers of excellence for comprehensive cancer care, such as the Kingdom of Saudi Arabia.

Most palliative care services in these countries deliver excellent care to a certain portion of population, but do not offer wider coverage. In addition, palliative care is still not included in the cancer control plan or any national health care policy.

**Barriers to Palliative Care Provision**

Many barriers exist to the availability, access, and provision of palliative care, such as those summarized in Table 2.

**Opioid Availability**

Pain is underreported and undertreated in most of the world. Morphine consumption has been used by the WHO to measure pain control and, ultimately, provision of palliative care. According to the International Narcotics Controlling Board report in 2007, the total estimated reported morphine consumption is 84 kg for all MENA countries.

Opioid availability varies across the region. Highest consumption has been reported in Tunisia based on the absolute quantity, total population, and total reported cancer mortality.

Barriers to pain control are almost universal, and include fear of opioids, unavailability of medications, poor access to medication, lack of education, and fear of addiction.

The amount of morphine needed can be predicted through calculating the estimated need of oral morphine for each patient who died of cancer. Assuming that each patient will require 100 mg/d of oral morphine in the last 3 months of life, an estimated 10 g of oral morphine will be needed per patient. Then, in multiplying this number by the esti-

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**Table 2** Barriers to Palliative Care Provisions in Middle East and North Africa Region

| Health care professionals | • Negative attitude to caring for the dying patients  
| • Fear of opioids use because of absence of or inadequate training,  
| • Fear of side effects  
| • Fear of prosecution  
| • Resources focused on cure and acute care  
| • Perceived sense of failure |
| Patients and families | • Fear of addiction  
| • Fear of abandoning  
| • Unrealistic hope  
| • Diversity in religious interpretation |
| Health care system | • Acute care focus dictates the allocation of resources to acute care rather than palliative care  
| • Lack of space and resources for palliative care  
| • Less priority of palliative and end-of-life care in the health care strategy  
| • Scarce long-term and community services |
| Manpower | • Lack of palliative care expert physicians, nurses, medical social workers, and medical religious advisors  
| • Lack of interdisciplinary teams |
| Drugs | • Lack of opioids  
| • Very strict opioid prescriptions and dispensing policies  
| • Unavailability of opioids in peripheral centers  
| • Lack of essential medications |
| Education | • Lack of palliative care education programs and curriculum at all levels of education |
| Funding | • No funds for education, building programs, or hiring experts |
| Policy | • Lack of national policies, including those regarding palliative care |
The estimated number of patients who died of cancer (Table 1; 200,000), the predicted need of oral morphine required to control pain in those patients is determined to be approximately 2000 kg. This number is less than 5% of the reported consumption of less than 100 kg.

Notably, this estimation does not take into account the other needs for opioids to control pain in cancer survivors, such as non-cancer-related or postoperative pain, further illustrating the huge gap existing between the actual need and the current consumption.

One major factor contributing to opioid underuse in the MENA countries is that they are not available. However, simply making opioids available will not solve the problem; a simultaneous and effective educational program is needed for health care workers, patients, families, communities, religious workers, government, and leaders, along with sufficient manpower to develop palliative care initiatives.

Another important factor contributing to inadequate pain control is the existence of rigid and strict opioid or narcotic policies (Table 2), which are implemented as a result of fear regarding abuse and misuse. These policies must be revised and made flexible to allow sufficient supply and effective pain control, while at the same time maintaining accountability.

Years ago, WHO advocated establishing recommendations and guidelines to improve cancer pain control. The recommended strategy is summarized in the following steps:15

- The country should make cancer pain relief a high priority in the form of health care policy.
- An educational program should target officials, policy makers, and regulators to increase awareness of the possibility and importance of managing cancer pain.
- An educational program should be established to train health care providers to treat cancer pain.
- Analgesics, including opioids, should be made available.

**Education**

Palliative care educational opportunities are scarce in MENA countries. Formal palliative care education is minimal. Most palliative care expertise is gained through education in countries with more advanced palliative care programs, such as North America and Europe. An increasing number of sensitization courses are occurring in the MENA countries, such as in Jordan, Egypt, and Saudi Arabia.9

More formal palliative care training in the form of advanced fellowships and well-developed palliative care curricula in medical schools do exist in countries like Saudi Arabia; however, other countries have no educational provision at all.

Palliative care education is an integral part of establishing an effective palliative care program. The level of educational needs varies among specialty institutions and communities. Basic palliative care knowledge is essential to all health care providers, regardless of specialty, service, or settings.14 More advanced skills and expert training will be needed for services, with the highest demand in disciplines such as oncology, intensive care, and infectious diseases to ensure implementation of best palliative care practices.14

A palliative care curriculum should be incorporated into undergraduate nursing and medical school education, residency training programs, and high-demanding fellowships such as oncology.

**Funding**

The field of palliative care seems to be a great opportunity for countries with limited resources to provide care for patients while developing the other components of a comprehensive cancer control program, ranging from prevention and early detection to optimal treatment.16 Palliative care should be delivered in a cost-effective manner and can be provided in less-served cities and communities in all countries, not just those with limited resources.

However, funding for palliative care is challenging for many reasons, including underrecognition of the importance of this field, resulting in inadequate resource allocation and government support. Existing and evolving programs in countries with limited resources must identify sources of financial support. Establishing a national policy for palliative care might allow governments to take some responsibility for funding.

Countries with a disadvantaged financial and economic situation may seek support and funding from community resources, nongovernmental entities, local philanthropist associations, or international organizations, such as the International Association for Hospice and Palliative Care.16
Recommendations to Improve Palliative Care in MENA Countries

Every country should aim to integrate pain relief and palliative care into the mainstream of health care. Pain relief and palliative care should be available to all populations, although this article only focuses on those with cancer. However, palliative care can benefit all patients with advanced illness, including those with HIV, dementia, and organ failure.17

Furthermore, palliative care should be available to patients everywhere, not only those in major cities or tertiary cancer centers. Access to these services should be available to peripheral cities and disadvantaged communities. Initiatives to improve palliative care should include policy development, program implementation, opioid availability, and education.14 Palliative care education should be available to all health care providers, medical and nursing schools, and training programs.

The most effective strategy for implementing a palliative care program is a public health initiative that incorporates all levels of the health care system, government leadership, and the community. This approach should benefit not only patients and families but also society as a whole.14

NCCN Guidelines for Palliative Care and Cancer Pain Management

The successful implementation of NCCN palliative care and cancer pain management guidelines depends on acceptance of the following principles:

- Palliative care is an integral part of effective and comprehensive cancer care.
- Palliative care should be introduced as early as the time of diagnosis.
- All health care providers, health care leaders, pharmaceutical leaders, government leaders, and religious scholars dealing with patients with cancer must be aware of the importance of palliative care.
- Basic palliative care education is needed for all oncologists and cancer care providers at all levels of care, including inpatient, outpatient, and extended care facilities in both private and public sectors.18
- Opioids and essential drugs must be available to manage pain and distressing symptoms.
- Cancer and palliative care should be delivered using an interdisciplinary approach; treatment programs should involve effective multidisciplinary teams to deliver the most comprehensive care.18

Adapting the NCCN guidelines to the MENA region may trigger a systemic evaluation of the status and needs regarding palliative care so that the highest possible standards of care can be implemented.

References


