Chapter 24
Palliative Care in the Arab World

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24.1 Role of Palliative Medicine in Cancer Care

Palliative Care is the active holistic care of patients with serious or life-threatening illnesses. It aims to improve the quality of life of patients and families by managing symptoms such as pain and preventing and relieving suffering [1, 2]. Patients diagnosed with advanced cancer tend to experience an enormous symptom burden, aggressive medical care, as well as emotional and spiritual distress, all of which can result in poor quality of life throughout the course of the disease [3, 4]. Palliative care aims to support cancer patients by managing sources of distress throughout the course of treatment. This includes early detection and management of pain and other symptoms, providing psychosocial support to help patients and their families cope with cancer and its treatment, and supporting them as they make decisions about their treatment goals [4].

There is a common misconception that palliative care should only be offered towards the end of life and only after options for disease-directed therapies are exhausted. However, in recent years research has demonstrated that involvement of palliative care providers early in the cancer trajectory has advantages to patients, their families, and the healthcare system [4–7]. Patients receiving early palliative

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care have a better quality of life, less depression, and longer survival while receiving less aggressive care compared to patients receiving standard oncological care [4]. Research evidence has led the American Society of Clinical Oncology (ASCO) to recommend that patients with advanced cancer begin receiving palliative care early in the course of their illness and in parallel to active cancer treatment [8].

Palliative care is in the early stages of development in the Arab world. It was first introduced in Jordan and Saudi Arabia in the early 1990s [9]. Several other countries followed over the next 30 years, but many countries still have no palliative care activity [1, 9, 10].

Cancer is among the leading causes of death in Arab countries, and cancer incidence is projected to continue to increase. Patients diagnosed with cancer in the region tend to present at later stages of illness and therefore have high palliative care needs [11, 12]. Unfortunately, few of the patients who could benefit from palliative care receive it. The number of palliative care providers in the region are not enough to meet the needs of the population, and services tend to be concentrated in urban areas and less accessible to people living in more remote rural communities [12].

24.2 Cost-Effectiveness of Palliative Care

Health expenditure among patients with cancer and patients near the end of life tends to be high. Research has shown that palliative care significantly reduces the cost of cancer care [10, 13]. Patients who receive palliative care have fewer visits to physicians and emergency departments primarily because pain and other symptoms are adequately managed. The role of palliative care in promoting open conversations about prognosis and clarifying goals of care also plays an important role in mitigating health care costs by reducing medical interventions that are unlikely to be of benefit and may in fact increase suffering. Palliative care has been associated with reduced hospital admissions, decreased hospital length of stay, and decreased ICU admissions [10].

In addition to reducing the direct costs to the healthcare system, the early introduction of palliative care during the course of the cancer trajectory decreases unnecessary and burdensome personal and societal costs [4]. Palliative care can have a significant impact on the cost of informal caregivers and productivity loss which can be responsible for almost half of the total cost of illness [14].

24.3 Palliative Care Needs in Arab Countries

There are several approaches to estimating the palliative care needs of a country. Population-based methods estimate palliative care needs using mortality statistics, cause of death, hospital data on symptom prevalence, and data on opioid

consumption [2, 15]. It is estimated that less than 1% of the 23,569 people who needed palliative care in 2017 in the Eastern Mediterranean Regional Office (EMRO) in the Eastern Mediterranean received it [10].

In 2017, the Lancet Commission on Global Access to Palliative Care and Pain Relief (GAPCPR) introduced an approach to estimating Serious Health-related Suffering (SHS) as a proxy for the unmet palliative care needs of populations [16]. The Lancet Commission report was the culmination of a broader project that estimated the palliative care needs of countries across the globe. Table 24.1 is a summary of the data on SHS for Arab countries based on the work for the GAPCPR [17].

There are no published estimates of the projected increase in SHS in Arab countries specifically. However, an analysis by the World Health Organization (WHO) region projects the highest proportional increase of the burden of SHS (170%) to be in the EMRO in between 2016 and 2060. Cancer is predicted to be among the five health conditions that will contribute to the largest increase in SHS and contribute to the largest number of deaths [18].

Table 24.1 People experiencing serious health suffering (SHS) for cancer, leukemia, and other diseases who could have benefited from palliative care in 2015 in Arab countries [17]

Country	Cancer (#)	Cancer (Per 1000 pop)	Leukemia (#)	Leukemia (Rate per 1000)	People with SHS (#)	Rate of people with SHS (Per 1000 pop)
Algeria	40,000	1.016	1140	0.0288	157,000	3.96
Bahrain	1000	0.444	20	0.0131	2000	1.64
Comoros	1000	0.863	10	0.0068	4000	5.02
Djibouti	1000	0.880	30	0.0352	13,000	14.73
Egypt	127,000	1.385	3620	0.0408	428,000	4.67
Iraq	31,000	0.855	1560	0.0429	143,000	3.93
Jordan	7000	0.921	240	0.0320	24,000	3.16
Kuwait	1000	0.381	70	0.0174	7000	1.82
Lebanon	9000	1.617	230	0.0401	31,000	5.29
Libya	6000	1.034	190	0.0301	26,000	4.17
Mauritania	3000	0.637	20	0.0059	32,000	7.80
Morocco	42,000	1.234	760	0.0221	163,000	4.75
Oman	2000	0.399	100	0.0219	9000	2.02
Palestine	No data	No data	No data	No data	No data	No data
Qatar	1000	0.411	40	0.0189	3000	1.27
Saudi Arabia	18,000	0.559	650	0.0207	83,000	2.65
Somalia	10,000	0.901	280	0.0258	98,000	9.11
Sudan	28,000	0.688	970	0.0242	229,000	5.68
Syria	23,000	1.243	800	0.0434	123,000	6.64
Tunisia	13,000	1.198	310	0.0277	62,000	5.51
UAE	3000	0.291	100	0.0105	11,000	1.15
Yemen	15,000	0.547	1030	0.0386	105,000	3.91

24.4 Palliative Care Policies

National health policies are an important indicator of healthcare priorities. They outline strategies and define resource allocation, which are both essential for the development of programs and services. The inclusion of palliative care in national health plans and legislation are essential steps towards the integration of palliative care into healthcare systems [19]. National policies, funding for palliative care services, and the presence of a dedicated palliative care unit within the ministry of health are all considered important indicators of palliative care development [20].

The data on these indicators is limited in most Arab countries. Palliative care is only recognized as a specialty in Lebanon and Saudi Arabia [21]. More recently, other countries such as the UAE have moved towards the recognition of palliative care as a specialty. Tunisia is the only country with a stand-alone national palliative care strategy. Several Arab countries have a palliative care strategy included in their national cancer control plan or their non-communicable disease (NCD) action plan. In general, palliative care services are covered in countries with publicly funded healthcare, but patients must pay for palliative care in countries with private healthcare systems such as Lebanon and Jordan.

24.5 Palliative Care Services

There are several models for palliative care service delivery. Services can be delivered at home, in the ambulatory setting, in the hospital, in nursing homes or in dedicated hospices. Most palliative care programs in the region are hospital-based, either in the form of hospital-based consultation services or dedicated inpatient units. Saudi Arabia, Jordan, and Egypt have the highest number of palliative care programs. No palliative care service providers have been identified in Syria, Libya, Yemen, Djibouti, or Somalia [11, 20, 21]. Figure 24.1 shows the number of palliative care programs in the Eastern Mediterranean Region (EMR) [21].

Even in countries with the most developed palliative care services, the services remain at the early stages of development and are not yet integrated into the national health system [10, 11]. Palliative care remains restricted to patients who have a limited prognosis and are no longer candidates for disease-directed therapies [22]. Most palliative care service providers in the region are located in large urban cities and primarily in tertiary care centers resulting in limited access to people living in rural areas [12].

Oncology patients can receive palliative care through their primary care providers, by their oncologist, or by a palliative care specialist. Regardless of who is providing the care, they should be able to address different sources of distress associated with illness which include the physical, the psychosocial and the existential. This usually requires the involvement of a multidisciplinary team that includes physicians, nurses, social workers, psychologists, and a spiritual care provider. With few exceptions, palliative care programs in Arab countries are physician-led with limited involvement of other disciplines and treatment is largely focused on physical symptoms with limited attention to psychosocial or spiritual needs [22].

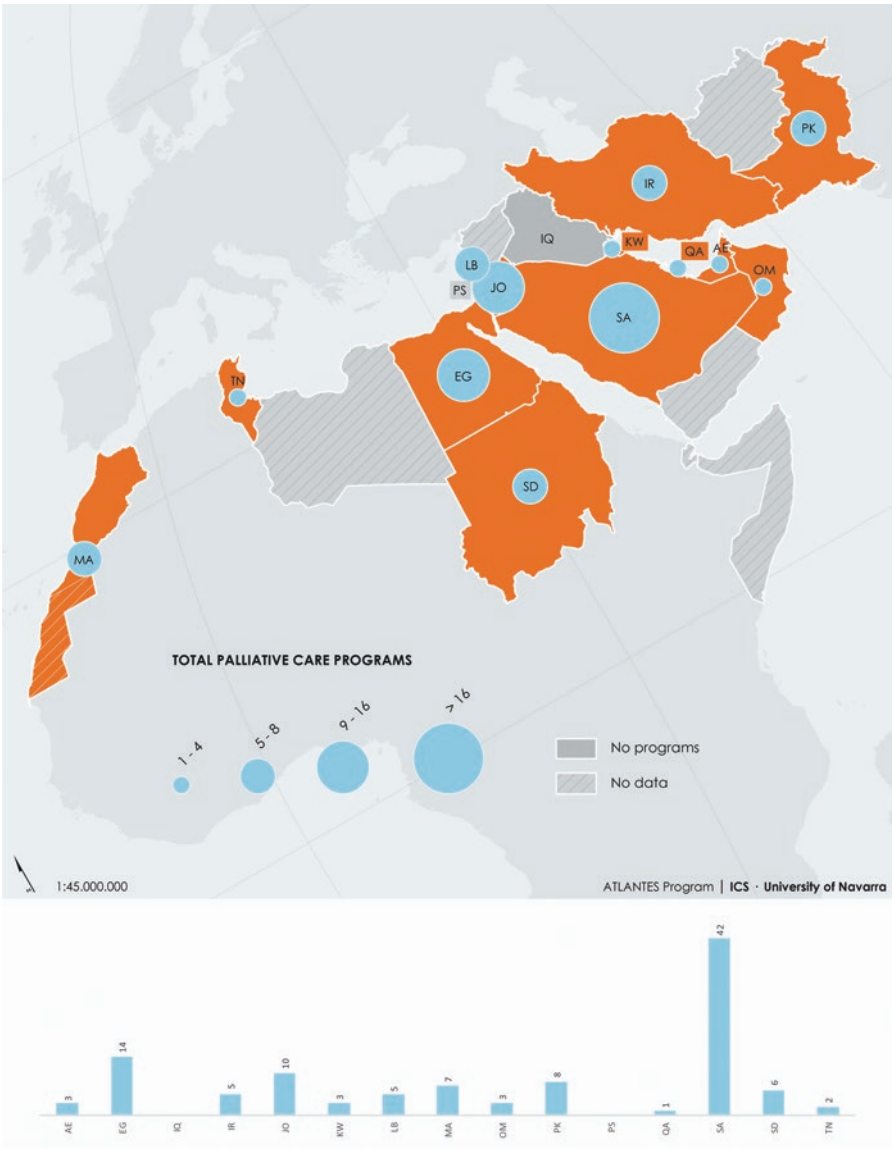

Fig. 24.1 Number of palliative care programs in countries of the Eastern Mediterranean. Reproduced with authorization from the IAHPC [21]

The Worldwide Hospice Palliative Care Alliance (WHPCA) assessed and categorized countries according to the level of development of their palliative care system into four categories. Group 1 includes countries with no known hospice or palliative care activity; group 2 includes countries with capacity building activity; group 3 consists of countries with isolated or generalized palliative care services; and finally, group 4 comprises countries with hospice or palliative care services integrated into mainstream service provision (Table 24.2) [10].

Table 24.2 Arab countries by level of palliative care development according to World Palliative Care Alliance (WPCA) [10]

Level of palliative care development	Countries
Level 1—No known palliative care activity	Comoros, South Sudan, Djibouti, Iraq, Somalia, Somaliland, Syria, Yemen
Level 2—Capacity building palliative care activity	UAE
Level 3 a—Isolate palliative care provision	Algeria, Mauritania, Bahrain, Egypt, Kuwait, Lebanon, Libya, Morocco, Palestine, Sudan, Tunisia
Level 3 b—Generalized palliative care provision	Jordan, Oman, Qatar, Saudi Arabia
Level 4 a—Palliative care services at preliminary stage of integration	None
Level 4 b—Palliative care at advanced stage of integration	None

24.6 Medication Availability

Access to opioids is regulated by governments to minimize diversion. Governments have employed different approaches to balance having safe access to opioid analgesia for the treatment of pain while minimizing diversion. Both prescribing and dispensing are closely regulated and require special forms and documentation. There is major variability in prescribing regulations among Arab countries. They include restricting prescribing by medical speciality, by diagnosis, by location or level of care, by dose or by number of days supplied.

Pain control is an essential component of palliative care, and opioid consumption is widely utilized as an indicator of pain control and palliative care development. The ability to switch patients from one opioid to another (opioid rotation), when they develop side effects or there are contraindications to using one of the opioid analgesics, is essential to proper pain management. Therefore, access to different formulations is important for proper pain management. Opioid consumption is usually reported in oral morphine equivalents (OME).

Overall, morphine consumption in Arab countries is relatively low compared to the global average and very low compared to opioid consumption in Europe and North America. The mean opioid consumption in the Eastern Mediterranean Region (EMR) in 2014 was 0.384 mg/person, which is 16 times less than the average global consumption [11]. Table 24.3 includes a list of the opioids available in Arab countries and the opioid consumption in 2017 according to data from the International Narcotics Control Board (INCB). The average consumption in Arab countries was 3.23 OME per person in 2017 compared to the average global consumption of 75.98 OME per person in the same year [23]. Misconceptions about the use of opioid analgesics, limited training of physicians and nurses in pain management, and prescribing restrictions all contribute to low consumption of opioid analgesics and inadequate pain control in the region.

Table 24.3 Opioid consumption in Arab countries in oral morphine equivalence (OME) (mg/person) [10]

Country	Opioid use in Morphine equivalence (mg/person)							Total opioid consumption in Morphine equivalence (mg/person)
	Morphine	Codeine	Fentanyl	Oxycodone	Hydro-morphone	Pethidine	Methadone	
Algeria	0.2	0	0.8	0	0	0	0	1
Bahrain	3.1	0	2.2	0.8	0	0.4	0	6.5
Comoros	0.19	0	0.03	0	0	0	0	0.22
Djibouti	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Egypt	0.2	0	2.1	0.016	0.014	0	0	2.33
Iraq	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Jordan	1.3	0	2.2	0.25	0	0.3	0.23	4.28
Kuwait	0.4	0.1	4.4	0.8	0	0.4	0.2	6.3
Lebanon	1.1	0	3.05	0.2	0	0.2	0	4.55
Libya	0.012	0.01	0.5	0	0	0.05	0	0.572
Mauritania	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Morocco	0.8	0	0.6	0	0	0	5.6	7
Oman	0	0	1.1	0	0	0	0	1.1
Palestine	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Qatar	1.08	0	3.3	0.05	0	0.04	0.3	4.77
Saudi Arabia	0.8	1.2	4.6	0.3	0	0.2	0.3	7.4
Somalia	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Sudan	0.116	0	0.064	0	0	0.031	0	0.211
Syria	0.05	0	0.7	0	0	0.1	0	0.85
Tunisia	2.9	0	1.2	0	0	0	0	4.1
UAE	0.4	0	3	0	0.	0	0.3	3.7
Yemen	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Global	4.93	0.18	15.03	10.84	2.21	0.062	42.73	75.982

24.7 Education and Research

Palliative care has not yet been universally integrated into medical and nursing school curricula across the region. Some medical schools in Jordan, Lebanon, Oman are teaching palliative care as a separate module. Other countries like Egypt and Kuwait have integrated palliative care teaching in their undergraduate curriculum as part of modules in oncology or pulmonary medicine [21]. However, most medical schools have yet to include palliative care as part of their standard undergraduate curriculum. Few nursing schools in Jordan, Lebanon, and Tunisia have integrated palliative care principles into their nursing curricula or offer dedicated courses in palliative care [9, 21].

When palliative care first came to the Arab world, there were no specialist training programs in palliative care in the region and most experts practicing in Arab countries were trained internationally. The first palliative care fellowship program was established at the King Faisal Specialist Hospital and Research Center (KFSHRC) in Saudi Arabia in 2000. The program was later accredited in 2013. Many of its graduates have gone on to practice, build programs, teach, and mentor young clinicians in other Arab countries. However, the specialty has yet to be listed under the Arab Board of Medical Specialties, and Arab Board certification in Palliative Medicine is not yet an option for medical graduates.

Over the past 20–30 years, workshops, short courses, and certificate programs have been offered through cancer centers, universities, and organizations across the region. Many of these have been developed and delivered in collaboration with international partners such as the American Society of Clinical Oncology (ASCO), Hospice Africa Uganda, San Diego Hospice, OhioHealth, and Yale University.

Research funding and output in palliative care in the region remain limited. A scoping review of publications on palliative care from the EMR region between 2005–2016 identified 73 unique articles [21].

24.8 Professional Associations

Medical societies are commonly seen as sources of information sharing and educational opportunities. However, they can also play a critical role in setting professional standards, encouraging and supporting research initiatives, advocating for change in the health system, and advancing a medical specialty.

Since palliative care was introduced to the region relatively recently, the activity of palliative care societies in the region remains limited. National palliative care societies have been established in Jordan, Kuwait, Morocco, Saudi Arabia, and Tunisia with varying degrees of activity. However, attempts at establishing a regional palliative care organization have not been successful to date.

24.9 Pediatric Palliative Care

There is a paucity of healthcare experts in pediatric oncology in most Arab countries [24]. The few clinicians trained in pediatric palliative care in the region mostly practice without the support of a multidisciplinary team, program, or department. A manual search of organizations dedicated to pediatric palliative care listed on the website of the International Children's Palliative Care Network (ICPCN) revealed only two organizations in Kuwait: the Kuwait Association for the Care of Children in Hospital (KACCH) and Bayt Abdullah Children's Hospice (BACCH) Sheikh Khalifa Medical City.

Approximately 14,000 children younger than 15 years are diagnosed with cancer each year in Arab countries [25]. Cancer is a primary cause of illness-related mortality among children. However, even in countries with more advanced palliative care systems like Egypt, Lebanon, and Jordan, there are no policies or guidelines dedicated to pediatric palliative care. In some countries, like Morocco, opioid regulations are more restrictive for pediatric patients [26]. The absence of national guidelines, limited knowledge, inadequate training, restricted access to opioids, and limited resources are all barriers to the advancement of pediatric palliative care in the region [27].

24.10 Arab Culture and Palliative Care

Culture and social norms are central to the way people cope with pain, cancer, treatment choices as well as death and dying. The role of the family, social values, religion, and health beliefs all have an important impact on how treatment options are communicated, how decisions are made, and what treatments are received when a patient is sick.

As in many other countries, misconceptions and stigma associated with the use of opioid analgesics create barriers to pain management. Fear of addiction and the belief that opioids should be reserved for the final days of life are prevalent in Arab countries.

The family unit plays a very central role in Arab culture. When someone has a serious illness, the extended family generally contributes to caregiving and providing support to a patient. Decision-making usually rests with the family or a family spokesperson rather than the individual [22]. Family members often withhold information as disclosure of a terminal illness or a cancer diagnosis can be perceived as harmful to the patient [12, 22].

Choosing costly medical interventions and hospital-based care can be one way for the family to express how much their loved one is valued. Families are less likely to choose to keep a patient at home and minimize aggressive interventions towards the end of life. There can be significant social pressure to demand more aggressive

care [22]. Misconceptions about palliative care, pain management, and opioids can be important barriers to patients receiving the care that they need.

Religion also plays a central role in the lives of most patients and frequently influences the choices they make about their care. Families may reach out to a religious resource for guidance in medical decision-making. Religious interpretations vary, and there can be a lack of clarity around legal issues related to medical care at the end of life [22]. These include inconsistent interpretation of the position of Islam on medical interventions that may be considered futile and even pain management. Policies allowing choice around aggressive medical interventions towards the end of life are variable across countries and institutions based on the interpretation of Islamic law.

24.11 Future of Palliative Care

Given the overwhelming evidence regarding the benefit of palliative care to oncology patients, Arab countries should strive to make palliative care a standard component of cancer care and accessible to patients who need it. Current efforts to build palliative care in the region include many innovative programs and successful initiatives led by forward-thinking pioneers with great skills and commitment. However, more often than not, leaders work in isolation from the broader palliative care community. Collaborations and coordination of efforts across borders have been limited. This is indicated by the absence of a functional Arab palliative care association after 30 years of regional activity.

Coordination of regional efforts can encourage the development of policies, guidelines, standards, and regulations. Collaborative efforts can expand training programs and advocate successfully for registration of palliative care as a specialty with the Arab Board of Medical Specializations and eventual board certification. Regional efforts can be helpful in coordinating access to opioid analgesics at the regional level, increasing awareness, engaging communities, and mobilizing resources for education, research, and service delivery.

An example of such an effort is the Palliative Care Regional Expert Network which was launched by the WHO Eastern Mediterranean Regional Office (EMRO) in September 2019. The network was the outcome of a regional meeting held in Beirut with the aim of setting priorities, drafting a roadmap for the development of palliative care in the region, and providing input and technical guidance to support governments as they implement national palliative care priorities, structures, and activities in line with regional and global commitments. The group has brought together leaders in palliative care from 9 countries to think together, share information, and collaborate on projects.

24.12 Conclusion

Serious health-related suffering due to cancer is high in Arab countries and projected to increase through the first half of the twenty-first century. There is great variability in the level of palliative care development across the region, but even in the most advanced countries, services do not meet the needs of the population in the setting of high incidence of cancer at advanced stages. The lack of national policies and funding; limited training opportunities, human resources, and service providers; restricted access to medications; poor public awareness; and the lack of coordination and collaboration among palliative care professionals have hindered the integration of palliative care into health systems in the region. Political instability and regional conflicts have forced many governments to focus on crisis management leaving limited resources to invest in health infrastructure. Regional planning must address all these dimensions to allow healthcare systems to meet the palliative care needs of cancer patients across the Arab world.

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