Original Article

A Comparative Review of Palliative Care Development in Six Countries Represented by the Middle East Cancer Consortium (MECC)

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Abstract
Palliative care development and services were reviewed in the region represented by the six members of the Middle East Cancer Consortium: Cyprus, Egypt, Israel, Jordan, the Palestinian Authority, and Turkey. The multimethod review synthesized evidence from ethnographic field visits to inpatient units, home care hospice teams and free-standing hospices, including interviews with hospice and palliative care clinicians, administrators, volunteers, policy makers and academic researchers. Public health data and relevant literature were collated together with internet-accessed information on services and health care systems. A total of 69 services were located; two country members have a history of relatively sustained development of hospice and palliative care, but provision across the Middle East Cancer Consortium region is highly variable at a local level. Considerable barriers to service development were identified in a region already struggling with many military and political conflicts. Key problems are a lack of secure funds and government support, inadequate professional training programs, opioid phobia in professionals and the public, and a lack of awareness and understanding of palliative care needs at public, government, and professional levels. Key areas for further attention were increasing national and international professional training and public education programs, improving opioid legislation and health care policies, negotiating for secure government or health insurance funding provision, raising awareness about the need for pediatric services and for patients with other illnesses, as well as for those with cancer, and working to integrate palliative care into mainstream health service provision and education. J Pain Symptom Manage 2009;37:287–296. *© 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

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Introduction

Hospice and palliative care provision is acknowledged to be a priority in the development of comprehensive health care services, particularly where there are high rates of mortality from cancer and consequently a need for skilled supportive care, pain management, and symptom control at the end of life.[1] Six countries in the geographic region of the Middle East, all members of the Middle East Cancer Consortium (MECC), recognize a pressing need for their health care services to develop hospice and palliative care as part of the overall treatment and care of patients with cancer. Although these needs are felt more acutely by some MECC member countries than others, even in those countries that have had relatively well-established services since the early 1980s, palliative care professionals are still lobbying for secure funding, core undergraduate medical and nursing training, and the recognition of palliative medicine as a medical specialty.

MECC was established in 1996 with the support of the U.S. National Cancer Institute (NCI), Bethesda, MD, USA, initially to set up population-based cancer registries for member countries: Cyprus, Egypt, Israel, Jordan, and the Palestinian Authority—and since June 2004—Turkey.[2] MECC monitors cancer incidence, mortality and epidemiology, promotes preventative health policy and training in cancer registry, and encourages cancer research and educational links.[3] In 2004, the NCI responded to a request from MECC representatives for support in developing palliative care in the region by initiating a MECC education and training program that specifically addressed these needs. The first palliative care workshop took place in Larnaca, Cyprus, February 2–3, 2004, for MECC representatives. The success of that first meeting led MECC to organize a regular series of seminars, as well as sessions within MECC-related cancer conferences, with the aim of raising awareness of palliative care needs, supporting service development, providing access to international experts, and promoting educational links nationally and internationally. In addition to these increasingly popular and well-attended meetings, MECC is responding to the different needs of health care professionals in its individual countries by holding locally-based short training seminars tailored for different levels of service development.[4]

This paper provides a comparative analysis of palliative care service provision compiled from a series of country reports produced by the International Observatory on End of Life Care during the period 2005–2006. The study was commissioned by the NCI and built on a pilot survey conducted in 2004 for the first MECC palliative care workshop. We provide a baseline of the range and status of current services that will contribute to future development and encourage local and international networks.[5]

Palliative care development in MECC countries is assessed by examining the history of services and current provision from the perspective and experience of health professionals as recorded in 2005–2006.[6] The study charts the characteristic patterns of service development in the different regions. The range of opioid availability across the MECC region is outlined and we examine the different kinds of legislation and ways in which health care professionals are working toward more effective access to appropriate opioid medications. We identify the kinds of challenges faced by health care professionals and volunteers and the ways they work to overcome these difficulties when providing palliative care in adverse circumstances. We conclude with some examples of successful palliative care services and the strategies taken to promote future development.

Methods

Qualitative and quantitative approaches were used to collect and collate data from a wide range of sources. Ethnographic field visits to service providers in Cyprus, Israel, Jordan, and the Palestinian Authority included

inpatient units, home care hospice teams, free-standing hospices, hospital-based services, and dedicated nongovernmental organizations (NGOs). Forty-eight group and individual interviews, 12 e-mailed written interviews and questionnaires were conducted across the MECC region with hospice and palliative care professionals and staff, including clinicians, administrators, volunteers, and academic researchers, some of whom are pioneers in service development. Evidence was synthesized from published and "grey" literatures (such as hospice newsletters, technical documents, and media reports). Quantitative data were collated from public health statistics, hospice and palliative care service records, internet-accessed information, and published reports on country health care systems.

We used the definitions for supportive care, palliative care, and end-of-life care, generally considered appropriate to different stages of illness, broadly in accordance with the European Society of Medical Oncology definitions.[7]

Results

Historical Development and Current Provision

In 2005–2006, a total of 69 palliative care services were identified in the region represented by MECC: Cyprus, Egypt, Israel, Jordan, the Palestinian Authority and Turkey, covering a population of 162.9 million, with an estimated 2.34 palliative care services per million people. Some 95% of all palliative care in the region is specifically set up for cancer patients. At a local level, although some services only provide care for cancer patients, in others there is limited provision for patients with illnesses such as AIDS, heart failure, and neurological conditions, despite the primary causes of death across the MECC region being cardiovascular and heart disease.[8,9] Cancer is the second commonest cause of disease-related death and this represents a significant palliative care need in the MECC region. This need is particularly acute in countries with less well-resourced or accessible health care services, where a higher proportion of patients present at a late stage of the disease.[10]

Specialist pediatric palliative care is extremely limited in the region, although most pediatric services offer hospital-based supportive care to terminally ill children.[11] The few services dedicated to pediatric palliative care are found only in Israel and Jordan. Bereavement support for families in both pediatric and adult services is being developed in Cyprus, Israel, and Jordan.

Patient capacity is estimated at around 168 inpatient beds in either free-standing hospice units or specialist hospital units, and at any one time, there is capacity for around 653 home care patients. The estimated, known palliative care workforce consists of some 434 health professionals. Trained volunteers are active in many services, particularly in not-for-profit home care services. Exact numbers of volunteers are unknown. All these figures fluctuate depending on the level of funding, differences in national health care systems, state of development, and workforce capacity. Israel, for example, provides additional end-of-life home care capacity via an extensive community medicine system. Locally, however, specialist palliative care provision is found to be highly variable across the region (Table 1).

Palliative care is provided through a diverse range of services (Table 2). Size and capacity varies from small home care services run by charitable organizations from one office desk or the front seat of a mobile desert unit, to large organizations supporting a range of hospice and palliative care activities, including education, clinical work, funded research and the lobbying of government. Many specialist services in the region are not-for-profit organizations, dependent on charitable funds, although in Cyprus, Israel, and Jordan most, but not all, key services have a proportion of

Table 1
MECC Country Population Size in Relation to Number of Services Providing Palliative and Supportive Care

MECC Countries	Population (millions)	Specialist Palliative Care Services	Supportive Care[a]
Egypt	76.1	3	1
Turkey	68.8	0	7
Israel	6.2	28	80
Jordan	5.3	4	7
Palestinian Authority	3.6	0	4
Cyprus	0.8	5	3

[a]Supportive care in this context is broadly defined as pain and symptom management with access to at least one health care professional with some basic palliative care training or, in countries with specialist service, access to informal voluntary advice from local palliative care services.

Table 2
Adult and Pediatric Supportive and Palliative Care Provision in MECC (2005)

	Adult Services									Pediatric Services			
	Free-Standing Unit	Hospital Unit	Hospital-Based Consultation	Home Care	Day Care	Outpatient Clinic	Drop-in Center	Mobile Unit	NGO Support[a]	Pediatric Unit	Pediatric Hospital Support	Pediatric Home Care	Total
Cyprus	1	—	—	2	2	2	—	—	3	—	—	—	10
Egypt	2	1	—	1	—	1	—	—	—	—	—	—	5
Israel	3	4	2	7	2	2	1	1	2	1	5	1	31
Jordan	—	1	2	2	—	1	—	—	—	—	1	1	8
Palestinian Authority	—	—	—	—	—	5	—	—	1	—	2	—	8
Turkey	—	—	7	—	—	—	—	—	—	—	—	—	7
Total	6	6	11	12	4	11	1	1	6	1	8	2	69

Adapted from Bingley and Clark.[5]
[a]Nongovernmental organization (NGO) support indicates the presence of organizations that fund or voluntarily provide supportive or palliative care services (this may be the stated sole purpose of the NGO [e.g., Cyprus Anti-Cancer Society] or additional to other more general services in health or social care support offered by the organization [e.g., Patient's Friends Society in the Palestinian Authority]).

support from government or health insurance funds. Israel has the most comprehensive funding via a combination of charitable, government and private health care insurance systems. Jordan has a similar combination of funding sources but has less charitable funding. Cyprus relies almost entirely on charitable funding, with the government providing small annual subsidies. Egypt has one small charity-funded service; otherwise, like Turkey and the Palestinian Authority, no funding sources exist specifically for palliative care. Patients at the end of life in these countries can only access general pain and symptom management from health care systems provided by the government, limited private medical insurance, and one or two NGOs.

Throughout Cyprus, Jordan, and Israel, there is a strong tradition of involvement by trained volunteers. For example, some home hospice organizations were originally set up entirely by volunteer health care professionals and members of the public.

The history and current state of hospice and palliative care service development varies greatly across the region. We assessed development using a typology that defines different stages of development. Four categories are used: "no services identified," "capacity building," "localized provision," and "approaching integration." These are fully defined in Table 3.

Since the early 1980s, both Cyprus and Israel, countries with relatively small populations, have developed a range of specialist services for adults with cancer that are "approaching integration" with the wider health and social care system, although Cyprus can only achieve relatively limited integration within the health care education system as there is no higher education on the island. Aside from these constraints, both Israel and Cyprus actively work toward a wider integration of palliative care with general health care services. Palliative care in Cyprus was initiated in the early 1980s by a small group of nurses working with cancer patients in one nursing home. Neophyta Kouppi, now the Matron at the Arodaphnousa Hospice, Nicosia, recalls these early days:

> Few people in Cyprus knew about hospice and palliative care. We started because we

Table 3
Typology of Stages of Palliative Care Development

No Services Identified	Capacity Building	Localized Provision	Approaching Integration
	• Initial awareness of palliative care needs • Expressions of interest registered with key organizations (e.g., MECC, WHO, EAPC) • International links established with other hospice-palliative care service providers • Conference participation • Visits to hospice-palliative care organizations • Education and training (visiting teams/overseas training) • Preparation of development strategy, i.e., lobbying of policy makers/ health ministries for palliative care to be part of a National Cancer Control Plan (NCCP)[a]	• Initial capacity building activities • Local campaigning and publicity • Services set up (i.e., home care or free-standing hospices) and funding source established • Government legislation in progress (NCCP to include palliative care) • Opioids available • Training within hospice organization plus external courses • Developing academic links • Developing research activity	• Capacity building and localized activities • Regular campaigning and publicity countrywide • Range of providers and service types • Broad awareness of palliative care needs • Some integration with mainstream health providers • Opioid, NCCP, and palliative care health policy/legislation agreed or in statute book • Established education centers • Academic links and development of core curricula for undergraduate and postgraduate health professional training • Research activity—national/ international publications

Adapted with permission from Wright and Clark.[12]
MECC = Middle East Cancer Consortium; WHO = World Health Organization; EAPC = European Association for Palliative Care.
[a]NCCPs are part of a package of legislation to ensure government health care provides for cancer prevention and treatment programs; palliative care health professionals lobby their governments to include at most basic provision (at least acknowledgment of need) for palliative care as part of the NCCP. This is part of palliative care development strategy that is encouraged by WHO, EAPC, and other supportive international organizations.

> wanted to help the cancer patients to have somebody to care about them. Because after the Turkish invasion and all the problems we'd had in the general hospital with refugees with cancer and nobody to look after them and all those problems, we thought we needed to build a home for them and take care for them. But we didn't know about hospice philosophy. Later on, we heard about hospice care and that was after, I think, the second meeting in London with Cicely Saunders.[13]

Since 2005, there have been two not-for-profit NGOs providing seven dedicated palliative care services, including inpatient, home, and day care, along with a range of additional services that ensure access for urban and rural populations throughout the Greek Cypriot south of the island and are open to those able to travel from the north. Both organizations work, wherever possible, alongside government hospital oncology services, to provide comprehensive palliative care provision within the health care system.

In Israel, palliative care was initiated during the late 1970s with a nursing organization offering home care. By the early 1980s, the first inpatient hospice was established. By 2005, nearly 30 dedicated services provide a wide range of inpatient, home, and day care. In addition, Israel has around 80 community health centers providing supportive care at the end of life. There are over 500 oncology nurses nationwide, most of whom have completed a formal postgraduate oncology nursing qualification, which includes symptom management and palliative care. An estimated 30 oncology nurses have completed further palliative care training.

Jordan is at the stage of "localized provision." Starting in the early 1990s, the first small home care hospice was established in the capital Amman, but this is only able to offer care to a very limited number of patients in the urban area. A World Health Organization program, the Jordan Palliative Care Initiative, was established in 2001 to develop a palliative care training program in Jordan.[14] By 2005, this had resulted in a new home care hospice and hospital-based palliative care teams in the main cancer hospital, the King Hussein Cancer Centre, and training seminars in palliative care in other major oncology units in Amman and Irbid. The majority of cancer patients

in Jordan present with advanced disease for which palliative care is the only appropriate therapy. Currently, only a small number of these patients are cared for in King Hussein Cancer Centre, and most have no access to specialist palliative care services. The long-term aim is to extend palliative care services into all the major hospitals and into more remote rural areas via the newly created community health care system.

Turkey and Egypt, countries with the largest populations, are in the very early stages of "capacity building." In 2005, both countries reported very limited palliative care provision, almost all of which occurs within existing oncology and specialist pain control units. There are only a few programs for service development despite the needs of their vast populations. In Turkey, there are plans for an inpatient hospice in Istanbul and a hospice unit is under development in the capital city, Ankara. Only seven of the country's oncology or pain units were found to have one or more consultants with some palliative care training, but they are often actively promoting palliative care awareness and education. For example, Turkish medical oncologist Deniz Yamaç explains why she feels it has been crucial to run communication skills workshops for other health care professionals involved in palliative care development:

> Turkey is a little different from Europe, people know about end of life but they don't say it, about half can talk about it, about cancer, but some don't want [to hear] the name of cancer. You can act according to the patient which is in front of you. You must feel it; you must have the information before you and be open. I ask my patients, "What do you know about your disease, your illness, what do you need?" So I can see my way how to act, how to talk, but I don't think that all Turkish doctors [who] are concerned with cancer know that, so I do the workshops in communication. Not to know—how to tell. They [the patients] should know. It's their life. I try to tell it but not to break their heart.[15]

In Egypt, while there are many oncology units that provide some level of pain and symptom control for patients at the end of life, there are, as yet, no active government hospital or home care specialist palliative care services, although there is a small group of health care professionals dedicated to palliative care development. There is one charitable organization providing some inpatient and day care services in two small free-standing hospices.

The Palestinian Authority is on the border between "no services" and some limited "capacity building." There are no specialist palliative care services; pain and symptom control is provided in hospital-based oncology units and clinics. There are, however, a few health care professionals with some specialist training and awareness, although they have to work within a health care system with extremely limited access to basic services. There is one NGO offering psychosocial support via a self-help group network for women with breast cancer during treatment and also, if needed, at the end of life.

Opioid Availability and Legislation

Opioids are available throughout the region. There is government legislation in place for the prescription of generic or proprietary opioid medication for all pain and symptom management, including palliative care, in Cyprus, Egypt, Israel, the Palestinian Authority, and Turkey. Jordan has temporary regulations that allow opioid prescription, and since 2004, a local pharmaceutical company has been licensed to produce generic morphine sulfate for use within the country and for export around the region. However, guidelines and adequate education about opioid prescribing vary between countries, and so-called "opioid phobia," leading to inadequate pain and symptom management, remains a continuing issue throughout the region. At the local level, Cyprus and Israel have successfully introduced training programs to educate health professionals, including pharmacists, in the effective use of opioids in palliative care.[16,17] Dr. Amitai Oberman illustrates the continuing importance of opioid awareness:

> I give a couple of lectures to pharmacists. It's fascinating to talk to them because they have their own perspective, and stories. I can give them a call and say, "Look … please help us with this," and it's usually fine. They've got their own laws and rules; they're not allowed to be flexible—you can't give this, and this has to be written down—and still when

a patient gets a script of MCR, they put on the back sometimes a notice saying "poison" on it. We're working on them to try and convince them it's not really clever to put "poison." But there's still this thing about narcotics in Israel. But it is changing. Some of the old pharmacists keep putting, just out of habit, I think, "poison" and during my talks about, I have these slides showing them what are the obstacles to the perception of opioids and then I show them, and I say to them, "Who wants to take a drug which is poisonous?"[18]

In Jordan, the World Health Organization Palliative Care Initiative has likewise sought to improve opioid prescription through education and training of physicians and pharmacists. Turkey has an ongoing publicity program to educate government officials, health professionals, and the public.

Opioid consumption is highest in Israel and Cyprus, countries with the most developed specialist palliative care services and more integrated opioid education programs. Opioid consumption remains relatively low in Egypt, Jordan, and Turkey. The Palestinian Authority has limited and erratic access to a small range of opioid medications.

The commonest opioid medications used in palliative care are reported to include codeine, pethidine (meperidine), and generic morphine preparations. Since 2000, the International Narcotics Control Board (INCB) has recorded a trend of an increasing use of more expensive proprietary opioids in pain management for all conditions, including palliative care. Physicians are tending to prescribe more fentanyl, particularly in the form of transdermal patches. Figure 1 shows comparative increases in fentanyl use over the years 2000−2005. These rates are shown in terms of "defined daily doses for statistical purposes" (S-DDD). S-DDD replaces the term "defined daily doses" previously used by the INCB. The S-DDDs are technical units of measurement for the purposes of statistical analysis and are not recommended prescription doses. Certain narcotic drugs may be used in certain countries for different treatments or in accordance with different medical practices, and, therefore, a different daily dose could be more appropriate.[19,20]

However, in Israel and Turkey, alongside this higher use of fentanyl, the INCB records

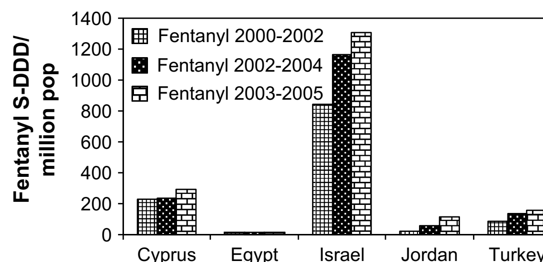

Fig. 1. INCB recorded average defined daily doses for statistical purposes (S-DDD) of fentanyl per million inhabitants from 2000 to 2005 in Cyprus, Egypt, Israel, Jordan, and Turkey.

a decrease in use of cheaper generic morphine, as illustrated in Fig. 2.[20] In Jordan, Cyprus, and very marginally in Egypt, the increase in proprietary opioids is relative to a general, though moderate, increase in opioid prescribing, including generic morphine preparations. The exact reason for this prescribing pattern is not clear, but there may be a combination of factors, including steps in medical education to attempt to address opioid phobia and promote opioid use in pain management, together with the constraints of health care budgets, or in Jordan's case, the presence of local pharmaceuticals that influence the use of cheaper generic opioids.

In Turkey and Egypt, opioid-based pain control is mostly prescribed in specialist pain units. However, Turkish physicians and pharmacists continue to face considerable legislative and practical difficulties in prescribing and dispensing opioids, as the rates of use shown above illustrate.[21]

Education and Training

Cyprus, Israel, and Jordan have active specialist postgraduate education and training programs for health professionals. Israel and Jordan have palliative care as an integral part of undergraduate clinical training of nurses. In Cyprus, the Arodaphnousa Hospice, Nicosia, offers a two-week introductory placement for second- or third-year student nurses from the School of Nursing. Israel provides a short unit for fifth-year medical students and is currently negotiating to have palliative care recognized as a subspecialty.[22] However, many health professionals in MECC member countries seek training overseas, taking up funding opportunities where possible to access specialist

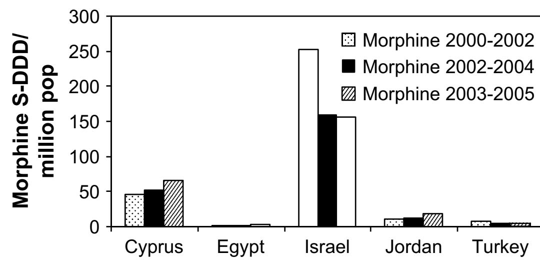

Fig. 2. INCB recorded average defined daily doses for statistical purposes (S-DDD) of morphine per million inhabitants from 2000 to 2005 in Cyprus, Egypt, Israel, Jordan, and Turkey.

postgraduate programs or short seminars in other countries, particularly the United States and the UK. International conferences and seminars are found to be supportive. The short seminar program of palliative care training organized by MECC since 2004 has proved particularly helpful for health care professionals from MECC countries with less access to opportunities for palliative care education in their own health care systems.

Israel, and to a lesser extent Cyprus, have significant research activity, with international dissemination through peer-reviewed journals and well-established links with international organizations, for example, the European Association for Palliative Care and the European Society of Medical Oncology. Where there are NGOs with an emphasis on palliative care (in Cyprus, Israel, Jordan, and the Palestinian Authority), they offer public as well as professional information, including telephone helplines, educational leaflets, and in some cases, self-help group networks for patients and volunteer training. In larger organizations, professional education programs are offered in the form of short training seminars, conferences, and support for overseas training.

Challenges and Future Plans Within Palliative Care Development

There are a number of barriers to palliative care service development that are reported throughout all the MECC member countries. These include:

- inadequate government legislation to include palliative care in general health care systems,
- problems of restricted access to opioids,
- issues of "opioid phobia," with limited training in the use of opioids,
- the continuing lack of core education and training,
- limited resources with very little secure funding.

Cyprus and Israel have developed a relatively robust network of provision; they still have funding problems within individual services and continue to negotiate with government to include palliative care as part of national health care systems and core health education. For other member countries, with less robust and developed palliative care services, the challenges tend to be greater, and this is especially difficult, for example, where the health care service is under severe pressure, as in the Palestinian Authority. In this instance, palliative care is less likely to be prioritized over provision of basic public health and acute health care services.

Future plans throughout the region include strategies that have proven useful in other regions and countries around the world, the key to which is palliative care service providers negotiating directly with governments to

- implement policies that support the integration of palliative care into the health care system and incorporate palliative care into the National Cancer Control Plan,
- improve or establish secure funding,
- ensure adequate access to, and education about, opioids and other essential palliative care medications,
- ensure all health professionals have access to postgraduate training in palliative care,
- support the introduction of palliative care as a medical specialty, part of core medical and nursing curricula education,
- support the expansion of inpatient and home care hospice services throughout health care systems.

Health professionals across the region also would like to see palliative care extend to a greater range of illnesses at the end of life.

Conclusion

There are considerable barriers to palliative care service provision in a region already

struggling with high cancer mortality rates as well as many military and political conflicts. Health care professionals identify the major problems as lack of secure funds and government support and inadequate professional training programs, including the failure to recognize palliative care as a specialty or to integrate basic training at the undergraduate level. Other barriers to service development include "opioid phobia" in professionals and the public, and a continuing lack of awareness and understanding of palliative care needs at public, government, and professional levels.

Health care professionals in all six MECC member countries report working toward future development by increasing professional training and public education programs, improving opioid legislation and health care policies, negotiating for secure government or health insurance funding provision, and raising awareness about the need for pediatric services and for patients with other illnesses as well as for those with cancer. An important aspect of service development in all MECC member countries is the move to integrate palliative care into mainstream health service provision and education.

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