

Palliative care models and innovations in 4 Eastern Mediterranean Region countries: a case-based study

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Abstract

Background: There is a global agreement that palliative care should be universally accessible. However, in low- and middle-income countries and conflict zones, most people lack access to it. In the Eastern Mediterranean Region (EMR), no country has achieved integration of palliative care into its health care system, and only 4 countries have better-than-isolated palliative care provision.

Aims: To promote and guide palliative care improvement in the EMR, with case studies showing the successes and challenges of palliative care implementation from 4 countries in the Region.

Methods: We developed a structured, succinct, case-writing format and invited palliative care leaders in the EMR to use it to describe successes and challenges in palliative care implementation in their countries.

Results: Within the EMR, in addition to many challenges and needs, there are examples of successful palliative care policy development, community-based service creation, and paediatric palliative care implementation.

Conclusion: The experiences of the regional palliative care leaders documented in succinct, structured case studies, can help guide regional palliative care development in the EMR and other regions.

Keywords: Palliative care, EMR, integration, community-based service

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Introduction

World Health Assembly Resolution 67.19 expresses the unanimous conviction of the 194 Member States of the World Health Organization (WHO) that palliative care is “an ethical responsibility of health systems” and that universal access to palliative care is necessary for achievement of Universal Health Coverage (UHC) (1). There is global agreement that palliative care should be integrated with disease prevention and treatment and as an essential part of primary health care (2–5). The types of suffering and palliative care needs vary by geopolitical situation, socioeconomic condition and culture (6). In general, people in low- and middle-income countries (LMICs) and in conflict zones endure less healthy social conditions and have less access to disease prevention, diagnosis and treatment and to social support than people in high-income countries (HICs), and thus have greater palliative care needs. Yet, only a small minority of people in need of palliative care in LMICs have access to it (7, 8). None of the 22 countries of the Eastern Mediterranean Region (EMR) has achieved integration of palliative care into its healthcare system, and only 4 countries have better than isolated palliative care provision (7).

In 2019, an Eastern Mediterranean Region Palliative Care Expert Network (EMRPCN) was convened by the WHO Office for the Eastern Mediterranean (WHO/EMRO) in collaboration with the American University of Beirut Medical Center and Harvard Medical School with the long-term goal of developing strategies and pathways for integrating palliative care into the regional healthcare systems. There was agreement that the strategies should provide guidance on national palliative care policy development, accessibility of essential medicines including morphine, training of healthcare professionals in palliative care, implementation of palliative care services, and quality assurance (9). However, considering the large differences within the EMR in culture, economics and social stability, it was agreed that the strategies should remain general or contain different guidance for different cultural, economic or social conditions (10–12). Ideally, the strategies should be based upon studies of the types, severity, prevalence and duration of suffering in each country (8, 13) and informed by case reports of successes in palliative care integration. We present here such cases produced by EMRPCN.

Methods

Members of EMRPCN were invited to submit concise (750–1500 words) reports of specific palliative care models or innovations that were adapted to the needs of a specific population and to the country's health system and potentially applicable elsewhere. Proposed topics included:

- creation of laws, policies or regulations
- financing
- essential medicine accessibility, especially oral immediate-release morphine
- education and training
- implementation of clinical services
- research / evidence building / measurement / quality improvement
- community outreach and engagement of civil society
- health system strengthening and promotion of UHC

Each writer was provided with a case-writing format and instructions adapted from those developed by the Case Writing Team of the Global Health Delivery Project at Harvard University (14). They were requested to tell the story of a palliative care model or innovation by responding briefly to a set of questions (Table 1). Submitted case reports were edited where necessary to conform to the prescribed structure and length.

Results

Full case reports were submitted by palliative care leaders from Egypt, Islamic Republic of Iran, Lebanon and Saudi Arabia (Table 2). One report addressed policy, 2 focused on community-based services, and 1 reported on paediatric palliative care.

Discussion

Access to palliative care is limited in LMICs worldwide (8,15) and in the EMR (7,16,17). Barriers to integration of palliative care into healthcare systems in the EMR include: absence of national policies on palliative care; lack of training and practice opportunities for physicians and other healthcare professionals; inadequate staffing of existing palliative care services; lack of opioid analgesics; and lack of understanding of palliative care among policy-makers and the general public (10,15,16). Our case reports address several of these barriers and provide examples of methods to overcome these barriers.

Common barriers mentioned in the reports include lack: of national palliative care policy or strategy; of an official specialty in palliative care; of hospital and community-based palliative care programmes and community-based hospice programmes; of understanding of palliative care among healthcare providers and the public; of palliative care training for medical and nursing under- and post-graduates; and of opioid accessibility for patients in need.

While all 4 cases mentioned the necessity of government policies and regulations to enable implementation and scale-up of palliative care, the case from Lebanon focuses on 1 crucial policy: approval of an official medical specialty in palliative care. While most palliative care is provided by generalist clinicians and specialists in other disciplines, palliative care specialists are needed to serve as teachers, implementers, and leaders of palliative care departments and services (18). Recognition of palliative care as an official medical specialty and training accredited palliative care specialists, as has begun in Jordan and Saudi Arabia (18, 19), are critical and necessary steps in creating and scaling-up high-quality, sustainable palliative care training and services and obtaining health insurance coverage for these services. The case report from Lebanon provides

Table 1 Structured survey to guide case-writing on palliative care MIs

Question	Follow-up questions
What problem did the model or innovation address?	What was the understanding of the barriers to prevention/relief of suffering in the population served by the model or innovation?
What was/is the goal of the model or innovation?	
What was/is the scope of the model or innovation? National? Local?	
What were/are the specific barriers to the model or innovation, and how did/do they overcome them?	
What were/are the costs and savings from the model or innovation, if known?	
How did/do the model or innovation grow or develop, or what enabled/enables them to grow or develop?	Partnerships? Laws or regulations? Other catalysts?
How do or could the model or innovation fit into, relate to, influence, or strengthen the public health care system, if at all?	How might the model or innovation promote universal health coverage?
In what ways were sustainability and scalability considered?	What are the threats to its sustainability?
How do/did the model or innovation measure their outcomes?	What are the outcomes?
How did/do the MIs improve their outcomes or adapt to the evolving clinical or political situation?	

Required questions are in bold font. MIs = models and innovations.

Table 2 Palliative care models and innovations in the Eastern Mediterranean Region**POLICY: Recognition of palliative care as an official medical specialty in Lebanon****Problem:**

Approval of palliative care as an official medical specialty, a critical step in palliative care development, has not occurred in Lebanon.

Goal:

Official recognition of palliative care as a medical specialty.

Scope:

National

Barriers / overcoming the barriers:

Obtaining official approval for a new medical specialty often is complicated. The body responsible for approval of any new medical specialty in Lebanon is the Medical Specialties Committee at the Ministry of Public Health (MoPH). The Director-General of the MoPH chairs the Medical Specialties Committee, which meets monthly. The process of establishing a new specialty is initiated when multiple individual requests are submitted to the MoPH by practicing physicians with documented clinical expertise in the requested specialty. Once several requests have been received by the MoPH, the Medical Specialties Committee must review and discuss them. If the addition of the new specialty is deemed justified, the Director-General submits a recommendation on behalf of the Committee to the Minister of Health to modify the official List of Medical Specialties, specifying the associated training requirements. Once approved, a Ministerial Decree is issued officially approving the specialty. A nongovernmental National Committee for Pain Control and Palliative Care (NCPCC) was established in 2010 in Lebanon with a mandate to draft a strategy for the development of palliative care. Recognition of palliative care as a medical specialty was among the goals. The Subcommittee on Practice drafted proposed licensing requirements for palliative care physicians that were published in the Lebanese Medical Journal. The nongovernmental Lebanese Center for Palliative Care, Balsam, began actively advocating for the recognition of palliative medicine as a medical specialty after its founder and medical director obtained certification in Hospice and Palliative Medicine by the American Board of Family Medicine, a member of the American Board of Medical Specialties in 2012. No other physicians who were board-certificated in hospice and palliative medicine in Lebanon at the time, but the Balsam team was able to identify a few board-certified Lebanese physicians who were living and working abroad and licensed to practice in Lebanon. The submission of requests for inclusion of palliative medicine into the list of medical specialties at the MoPH was coordinated through Balsam in collaboration with members of the NCPCC.

Effect on the public healthcare system:

Not yet discernible.

Outcomes:

Palliative medicine was officially recognized as a medical specialty in Lebanon on 28 June 2013, 6 months after submission of the initial request and within 2 years of the establishment of the NCPCC. The process would not have been successful without strong political support from within the MoPH and the coordinated efforts of palliative care advocates represented by the NCPCC.

SERVICE IMPLEMENTATION/EDUCATION: Establishing home-based palliative care services in the Islamic Republic of Iran**Problem:**

Patients with end-stage chronic illnesses in the Islamic Republic of Iran commonly continue to receive specialized disease treatment in hospitals and die in intensive care units (ICUs) despite a national shortage of hospital and ICU beds and the high expense of this treatment. There are no hospices in the Islamic Republic of Iran; community-based palliative care has rarely been both available and affordable; and opioid prescription for outpatients is problematic.

Goal:

To make safe and cost-effective palliative home care accessible throughout the country and thereby to increase patients' and families' satisfaction care, to reduce length of stay in hospitals, and to improve the quality of nursing care.

Scope:

National

Barriers / overcoming the barriers:

Reasons for the lack of palliative home care in the Islamic Republic of Iran include cultural values and laws that make it difficult for nurses to enter homes, a lack of clinicians trained in palliative care, and antipathy toward opioids (opiophobia).

Recognizing this problem, the Ministry of Health and Medical Education (MOHME) in July 2016 approved a new regulation (Code D/101/691, Article 22) enabling establishment of home care units within hospitals and home care and counselling centres in the community. The hospital-based home care unit is responsible for identifying and referring patients to community home care centres. A doctor at this centre examines the patient and creates a care plan that is executed at home by a nurse. A physician visits the patient at home as needed. Universities of medical sciences are empowered to license 1 home care centre for every 50 000 people. In addition, private home care centres for cancer patients were established by a charitable organization in Isfahan and Tehran.

To assist with this initiative, the MOHME Nursing Deputy developed continuing nursing education courses in palliative and home care, and palliative care programmes that are now required for home care nurses. Efforts are now underway to include required training in palliative and home care in undergraduate and graduate nursing curricula.

Remaining social and legal barriers include a persistent belief among healthcare policymakers that nurses should work in hospitals and not provide primary care or home care; a lack of clinical guidelines for palliative home care; a lack of health insurance coverage for home care; and a lack of indicators to monitor the quality of home care.

Effect on the public healthcare system:

Following World Health Organization guidance, a promising way forward would be to include palliative home care as an essential element of primary health care provided by existing public urban and rural health centres. This likely would reduce costs for the public healthcare system, help to unburden hospitals, and promote universal health coverage by assuring follow-up and end-of-life care in the community for seriously ill people.

Sustainability / scalability:

Currently, home care is not covered by major health insurance companies (Iranian health insurance, and social security insurance) and families must pay out of pocket. The Nursing Deputy of the MOHME has submitted to the Iranian High Council of Insurance a proposal for a basic package of palliative home care to be covered by insurance coverage that could be funded by increasing the cost of some other services.

Outcomes:

Today, there are approximately 700 active home care centres throughout the country. Better indicators of home care outcomes are needed such as pain control, quality of life, patient and family satisfaction, rehospitalization rates, emergency department visits, and costs.

Table 2 Palliative care models and innovations in the Eastern Mediterranean Region (concluded)

SERVICE IMPLEMENTATION / EDUCATION: Integration of palliative care into primary health care in Saudi Arabia
<p>Problem: Although palliative care was available in some tertiary and secondary level hospitals in Saudi Arabia, it was not available at the primary care level.</p> <p>Goal: To create a sustainable and reproducible model of palliative care integration into primary health care (PHC).</p> <p>Scope: The model created at a single PHC centre (PHCC) is designed to be reproducible at all 46 PHCCs in the King Fahad Medical City (KFMC) system in Riyadh and throughout the country.</p> <p>Barriers / overcoming of barriers: There were no models of palliative care at the primary care level in Saudi Arabia. However, palliative care for patients with serious illnesses was included by the government in its “Vision 2030, Model of Care” initiative to improve health care. On the basis of this policy, the existing inpatient palliative care team at KFMC began integration of palliative care into primary care at one PHCC in 2018. Family physicians working at the PHCC were trained for 3 months in basic palliative care and then began providing services with support from specialists at KFMC. After 1 year, they felt confident to run the weekly palliative care clinic independently.</p> <p>Costs / savings: There is no cost to the patient for palliative care at the PHCC, and it is easily accessible for those living in that community. By contrast, a visit to the private clinic at a tertiary hospital costs about US\$ 100 without medications and investigations, and more travel is required. Thus, providing palliative care at PHCCs appears to provide financial risk protection and convenience for patients and families. It also may reduce admissions and length of stay in hospitals and thereby reduce cost for the healthcare system, but no comparative study of costs has been performed as yet.</p> <p>Effect on the public health care system: This model will likely strengthen the healthcare system by unburdening the inpatient and outpatient services at hospitals and thereby reducing costs and facilitating access to hospitals by patients whose needs cannot be met in the community.</p> <p>Sustainability / scalability: Planning is underway to replicate this model in all PHCCs in Saudi Arabia.</p> <p>Outcomes: As of January 2020, 110 patients and 200 caregivers were seen in the PHCC palliative care clinic; 20% were receiving active oncology treatment; no-show rate was 45%; and overall satisfaction score was 90%.</p> <p>Next steps: Creation of multidisciplinary palliative care teams at primary care level.</p>
SERVICE IMPLEMENTATION / EDUCATION: paediatric palliative care in Egypt
<p>Problem: Paediatric palliative care did not exist in Egypt, and seriously ill children suffered due to lack of appropriate care.</p> <p>Goal: To establish paediatric palliative care services at the Children’s Cancer Hospital – Egypt (CCHE), the national referral centre for paediatrics.</p> <p>Scope: National</p> <p>Barriers / overcoming of barriers: Major barriers in Egypt to palliative care in general and paediatric palliative care in particular include lack of government policies on palliative care, inaccessibility of opioid analgesics, inadequate education, and negative attitudes among physicians toward opioids, delivering bad news, and comfort-oriented care.</p> <p>In 2010, CCHE launched the first paediatric palliative care (PPC) programme in the Eastern Mediterranean Region. The multidisciplinary PPC team provides care in the emergency room, an outpatient clinic, and inpatient units, and home care is provided 5 days per week within metropolitan Cairo by nurses and social workers. Consultation is provided by telephone for patients outside of Cairo. Oral morphine is available for the PPC team’s patients, and a 15-day supply can be dispensed. The PPC team offers training in palliative care to residents and oncology fellows, nurses, nurse aids, psychologists, and social workers from Egypt and other countries.</p> <p>Costs / savings: Data on costs and possible savings from palliative care or hospice services are not available.</p> <p>Effect on the public health care system: No data</p> <p>Outcomes: Approximately 50 children per month receive PPC from the CCHE palliative care team. They represent 20% of the children treated in the hospital.</p>

an example of how determined and skilful advocacy can achieve this goal.

Two cases describe the inaccessibility of opioid analgesics due to overly restrictive regulations, lack of training in opioid therapy, or unjustified fear of opioids. While no cases specifically addressed strategies to overcome these barriers to palliative care, multiple case reports have been published by participants in the International Pain Policy Fellowship (20–25). Unfortunately, no countries from the EMR participated in this Fellowship. We propose creation of a similar 2-year fellowship to assist EMR countries to develop balanced

national opioid policies using the International Pain Policy Fellowship as a model.

Three of the cases address the inseparability of palliative care service implementation and training in palliative care (26–28). Integration of sustainable, high-quality palliative care services into healthcare systems requires an enabling foundation in government policy as well as coordination of opioid accessibility and training, and establishment of clinical services (9). If opioids are made accessible before appropriate prescribing regulations and training, they may either expire on the shelf or be prescribed injudiciously. If training is

provided before opioids are available and before there are places to practice, the training is wasted and the trainees may become frustrated. If palliative care services are established before staff are trained and opioids are accessible, the quality of care may be poor.

In the EMR, as in other regions, most patients in need of palliative care are at home (3). For this reason, primary care physicians in the EMR have the potential to expand access to palliative care (29). Two cases have addressed integration of palliative care with primary health care as recommended by WHO (1, 2) and the importance of cultivating political support for palliative care integration.

The case from the Islamic Republic of Iran demonstrates the benefits of having a strong palliative care advocate within ministries of health to coordinate the key aspects of palliative care implementation. Based on government policy to enable palliative home care, the Nursing Deputy of the Iranian Ministry of Health and Medical Education led development of continuing nursing education courses in palliative and home care, and then advocated successfully for this training to be required for homecare nurses. The case from Saudi Arabia also indicates the importance of strong palliative care leadership within major medical centres. Based on government policy and the recognition that most palliative care needs are in the community, a palliative

care leader at a major medical centre arranged to pilot integration of palliative care into primary care at an affiliated primary care centre, intensively trained family physicians in palliative care at the centre, and provided ongoing mentorship and supervision. This model of following training courses with long-term mentoring is more likely to improve trainees' behaviour than training without follow-up (30). The cases also demonstrate the crucial relationship between primary care providers who provide basic palliative care in the community and palliative care specialists in referral hospitals who can provide clinical mentoring and case consultation and receive transfers of patients with complex problems.

Conclusion

Structured case studies such as those described in this paper can provide important guidance for healthcare planners and managers. Given that palliative care needs vary by location, culture, and socioeconomic and clinical environments, we propose that easily accessible libraries of case studies be made available in the EMR and other regions around the world.

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Modèles de soins palliatifs et innovations en la matière dans quatre pays de la Région de la Méditerranée orientale : étude de cas

Résumé

Contexte : Il existe un accord mondial sur le fait que les soins palliatifs devraient être universellement accessibles. Cependant, dans les pays à revenu faible et intermédiaire et les zones de conflit, la plupart des personnes n'y ont pas accès. Dans la Région de la Méditerranée orientale, aucun pays n'est parvenu à intégrer les soins palliatifs dans son système de soins de santé, et seuls quatre pays disposent d'une offre de soins palliatifs qui sont en voie d'intégration.

Objectifs : Promouvoir et guider l'amélioration des soins palliatifs dans la Région de la Méditerranée orientale, par le biais d'études de cas montrant les succès et les défis de la mise en œuvre des soins palliatifs dans quatre pays de la Région.

Méthodes : Nous avons mis au point un modèle de rédaction de cas structuré et succinct, et nous avons invité les responsables des soins palliatifs dans la Région de la Méditerranée orientale à s'en servir pour décrire les succès et les défis de la mise en œuvre de ces soins dans leurs pays.

Résultats : Dans la Région de la Méditerranée orientale, outre les nombreux défis et besoins, il existe des exemples de réussite concernant l'élaboration de politiques en matière de soins palliatifs, la mise en place de services communautaires et la mise en œuvre des soins palliatifs pédiatriques.

Conclusion : Les expériences réalisées par les responsables régionaux des soins palliatifs, qui sont documentées dans des études de cas structurées succinctes, permettent de guider la mise en place des soins palliatifs au niveau régional.

نماذج الرعاية الملطفة وأوجه الارتقاء بها في أربعة بلدان بإقليم شرق المتوسط: دراسة حالة

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الخلاصة

الخلفية: ثمة اتفاق عالمي على أنه ينبغي إتاحة الرعاية الملطفة إتاحةً شاملةً عامة. ومع ذلك، يفتقر معظم الناس في البلدان ذات الدخل المنخفض والمتوسط ومناطق الصراع إلى الرعاية الملطفة. وما من بلد في إقليم شرق المتوسط قد حقق دمج الرعاية الملطفة في نظام الرعاية الصحية فيه، بل إن أربعة بلدان فقط هي التي تقدم رعاية ملطفة أفضل من مجرد رعاية العزل.

الأهداف: هدفت هذه الدراسة إلى الترويج لتحسين الرعاية الملطفة في إقليم شرق المتوسط، ووضع توجه وقواعد إرشادية لها، في ضوء دراسات حالة تعرض النجاحات والتحديات التي تجابه تنفيذ الرعاية الملطفة في أربعة بلدان في الإقليم.

طرق البحث: وضعنا صيغة منظمة وموجزة لصوغ دراسات الحالة، ودعونا قادة الرعاية الملطفة في إقليم شرق المتوسط لاستخدام تلك الصيغة لوصف حالات النجاح في تنفيذ الرعاية الملطفة في بلدانهم والتحديات التي تجابهها.

النتائج: بالإضافة للعديد من التحديات والاحتياجات، يضم إقليم شرق المتوسط أمثلة على النجاح في وضع سياسات الرعاية الملطفة، وتوفير الخدمات المجتمعية، وتنفيذ الرعاية الملطفة للأطفال.

الاستنتاجات: إن خبرات رواد الرعاية الملطفة بالإقليم، الموثقة في هذه الورقة البحثية، يمكن أن تساعد في توجيه تطوير الرعاية التلطيفية الإقليمية في منطقة الشرق الأوسط ومناطق أخرى.

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