

Summary report on the

**Expert meeting to develop
a regional roadmap for
palliative care in the
Eastern Mediterranean
Region**

WHO-EM/NCD/145/E

Beirut, Lebanon
26–27 September 2019



REGIONAL OFFICE FOR THE

**World Health
Organization**

Eastern Mediterranean

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1. Introduction

In 2014, WHO Member States adopted World Health Assembly resolution WHA67.19 on the strengthening of palliative care as a component of comprehensive care throughout the life course, calling upon countries to improve access to palliative care services, with an emphasis on community-based care and integration at the primary health care level. Palliative care is recognized by WHO as a crucial part of the global action plan for the prevention and control of noncommunicable diseases 2013–2020, and is embedded in the definition of universal health coverage, the Sustainable Development Agenda and WHO's thirteenth general programme of work (GPW 13). In 2017, the importance of palliative care was underlined as part of World Health Assembly resolution WHA70.12 on cancer prevention and control in the context of an integrated approach, which partly led to the development of the WHO regional framework for action on cancer prevention and control, in which palliative care services are one of the six key areas for strategic intervention.

Palliative care is explicitly recognized under the human right to health and is fundamental to improving the quality of life, well-being, comfort, and human dignity of individuals. It is an effective person-centred health service. In addition to cancer, palliative care is required for a wide range of chronic diseases including cardiovascular diseases, chronic respiratory diseases, AIDS, tuberculosis, diabetes, as well as for some acute conditions such as injuries and haemorrhagic fever. Additionally, it is encompassed in the WHO global strategy on people-centred and integrated health services, which offers a framework for the strengthening of palliative care programmes across diseases. Palliative care is most effective when considered early in the course of an illness, and not only improves the quality of life for patients but also reduces unnecessary hospitalizations and the use of health-care services.

Each year an estimated 40 million people globally are in need of palliative care, 78% of whom live in low- and middle-income countries. Official country data from around the world shows that the Eastern Mediterranean Region is the WHO region with the second lowest availability of palliative care services and is far below the global average when it comes to the availability of oral morphine, inclusion of palliative care in national health policies, funding for palliative care and access to palliative care services at the primary health care and community level. The increasing noncommunicable disease burden, coupled with the fact that the Region is the WHO region with the highest projected increase in cancer incidence by 2030, makes driving forward the palliative care agenda a key part of the Region's public health approach to cancer and other life-threatening illnesses.

However, palliative care in most of the Eastern Mediterranean Region remains at an early stage of development, with insufficient strategic planning by governments for palliative care services and only an estimated 5% of adults in need of palliative care in the Region actually receiving it. The situation is compounded by complicated political contexts and weak health care systems, coupled with conflicts affecting some countries, weakening health services and further increasing the demand for palliative care.

WHO has developed guidance documents on the integration of palliative care and symptom relief into primary health care, paediatric health services and the response to humanitarian emergencies and crises, all of which are highly relevant to the Region's health systems and geopolitical situation. In addition to three guidance documents, a guide on the planning and implementation of palliative care services has been developed for programme managers.

In order to address the above gaps, WHO, the American University of Beirut (AUB), the Global Palliative Care Program at Massachusetts General Hospital and Harvard Medical School, and the Lebanese nongovernmental organization Balsam, brought together regional and international experts active in the field for the first regional expert meeting on palliative care. The meeting was held in Beirut, Lebanon, on 26–27 September 2019. The objectives of the meeting were to:

- take stock of the current situation of palliative care in the Region and exchange country experiences;
- develop a draft roadmap for palliative care covering the four domains of WHO model of palliative care; and
- discuss and agree on the organizational structure of a regional expert network on palliative care, to support the development and implementation of the abovementioned road map.

The meeting was attended by 22 participants from nine countries of the Region (Egypt, Iraq, Kuwait, Lebanon, Morocco, Pakistan, Saudi Arabia, Sudan, Qatar), as well as international experts and WHO Secretariat with representation from country, regional and headquarters levels. Participants were diverse and included clinical doctors, nurses, pharmacologists, public health professionals and academics.

Opening remarks were made by Dr Ali Taher, Director, Naef K. Basile Cancer Institute, Dr Ziyad Ghazzal, Hospital Director, AUB Medical Center on behalf of Dr Fadlo Khoury, President of AUB, Dr Iman Shankiti, WHO Country Representative in Lebanon, and Dr Mohammad Haidar, Adviser to the Minister of Health, on behalf of His Excellency, Minister of Health, Dr Jamil Jabak. Speakers reiterated their commitment to palliative care as an integrated part of the health care system, beyond cancer and at all levels, using a holistic, patient-centred approach and ideally delivered by multidisciplinary teams.

2. Summary of discussions

Drawing on recently-released WHO guidance on integrating palliative care into health care, one of the major aims of the meeting was to initiate the development of a draft roadmap focusing on four domains: appropriate policies that integrate palliative care services into the structure and financing of national health care systems; adequate drug availability; education of health professionals and the public; and implementation of palliative care services. Accordingly, three working groups discussed the four domains and the regional draft roadmap, focusing on the following areas.

- Policy – covering policies, laws, regulations and national strategies that affect the integration of palliative care services into national health care systems, both in terms of structure and financing, as well as policy to support adequate opioid availability and accessibility.
- Human resources – covering issues pertaining to education of health professionals as part of undergraduate and postgraduate programmes, capacity-building for primary and secondary palliative care, and licensing criteria and prescribing regulations.
- Clinical services – covering models of care, integration of palliative care with illness prevention, diagnosis and treatment, and the organization, implementation and quality assurance of palliative care services as part of existing health care services at all levels of national health care systems.

Policy

Collecting evidence. In order to formulate effective policies it is important to understand the differences between countries with respect to palliative care awareness, practices and health care systems, including the regulation of opioid use and accessibility. Collecting evidence about palliative care practices, cost, effectiveness and

conceptions, as well as case studies of the successful experiences, is the first step before preparing a policy brief.

Policy briefs. According to a recent study, the increase in the burden of serious health-related suffering between 2016 and 2060, will have the highest proportional increase in the Eastern Mediterranean Region (170% increase). Palliative care advocacy groups should aim to construct effective policy briefs in order to convince policy-makers to make a change. The policy brief should include the following items: situational analysis, burdens, trends, current capacities, cost of the model of care, possible return on investment and a survey on opioid availability, affordability and accessibility. The latter may be used as a tool to change legislation/policies that hinder access to opioids.

From policy brief to a change in policies. Influencing policy-makers necessitates involving non-state actors, regional collaborators, WHO and others. An intergovernmental collaboration between the ministry of health and the ministry of social affairs may be necessary to ensure an effective response to social suffering, such as the suffering associated with extreme poverty, which is a fundamental part of palliative care. Furthermore, making an economic case for palliative care interventions and their cost-saving potential might encourage governments to include palliative care packages under the national insurance package.

Addressing misconceptions on palliative care. It is important to address misconceptions about palliative care, such as that it is only for the dying or that it is only an alternative to disease-modifying treatment. The group suggested producing a short film to describe what palliative care is and why it is needed. The film can show evidence about the benefits of community-based and home-based palliative care, as well as the benefits of integrating palliative care with disease treatment, while including testimonies from patient representatives.

Human resources

Capacity-building – secondary level training. Participants discussed the different levels of training in palliative care. The discussion focused on giving the appropriate training to the right people to create an effective workforce for the delivery of palliative care services. The “human resources” working group clarified the difference between level 1 and level 2 training as:

- Level 1 training (primary): a brief training provided to physicians, nurses, or medical/nursing students over 3–4 sessions and covering basic information on communication and symptom management. It aims to introduce learners to the basic concepts in palliative care
- Level 2 training (secondary): is more in-depth training provided to physicians and nurses and is usually delivered over 100–120 hours. The training can be provided to both primary and secondary level health care providers. It aims to provide learners with skills in symptom management and communication that would allow them to provide primary palliative care to patients.

Participants agreed to focus on secondary level training at this stage, rather than primary level training, which has already been integrated into the undergraduate curricula in a number of countries in the Region, and because variability in the structure and curricula of medical and nursing schools increases the complexity of implementation.

There was a suggestion to make a recommendation that all medical and nursing schools include training on palliative care in their curricula with content from regional organizations. However, the consensus was to focus efforts on the training of physicians, nurses and other specialists in practice at both the primary and secondary health care levels. This

should be coupled with the establishment of communication and referral systems between these levels in parallel with the training.

It was suggested that level 2 training should ideally be: provided by local trainers; multidisciplinary. in line with practice standards; available in Arabic, English and French; involve ministries of health; and lead to certification and licensing for prescribing.

Operational mechanism – curriculum development. There are three existing curricula currently being implemented in Jordan, Morocco and Sudan for providing secondary level training in palliative care to physicians and nurses. Participants from Morocco and Sudan presented their experiences in implementing those curricula.

Sudan has a curriculum adopted from Uganda for providing a six-week training course to physicians and nurses. Their secondary level training is provided in English to non-palliative care specialists and primary health care providers, but the language is usually adjusted based on the background of trainees attending the sessions. The training is provided on Saturdays to allow working physicians and nurses to attend. Physicians have the option to do an internship after completion of the training. They receive a certificate upon completion. However, certification is not linked to prescribing and does not lead to increased compensation since the governmental authorities are not involved in the training.

Morocco has a similar curriculum to that in Sudan, but their secondary level training is provided in French over eight weeks. Sessions are also conducted on Saturdays and participants receive a certificate after completion of the training. Only one private centre provides this training, once per year. The government is not involved in conducting the training, but participants can still prescribe opioids because in

Morocco, unlike other countries in the Region, physicians do not need an authorized permission to prescribe opioids.

The WHO model curricula offer an alternative to these level 1 and level 2 training schemes for the development of regional curricula. They include the following elements.

- Introductory course: 3–4 lectures on the definition and practice of palliative care.
- Basic courses in palliative care: one mainly for primary care doctors and medical students in their final year, and one for nurses and for nursing students in their final year. Both consist of 30 hours of classroom training and five hours of bedside teaching.
- Intermediate-level course in palliative care: mainly for doctors specializing in fields that entail caring frequently for patients with palliative care needs and those who teach. It consists of the 35-hour basic course supplemented by another 36 hours of bedside teaching and case discussions.
- Specialist training in palliative medicine: to train palliative care teachers, leaders, and implementers. Training may last 1–2 years; for most countries, this would be a long-term goal, and palliative care specialist training will not be part of the current roadmap.

Participants agreed that the two country examples, in addition to a palliative care diploma curriculum (developed and applied in Jordan by Dr Mohammed Bushnaq), and the model curricula recommended by WHO, can be reviewed and adapted to develop a unified curriculum for the Region.

Operational mechanism – partnering with ministries. Participants agreed that the involvement of ministries of health and higher education in the capacity-building process is essential for licensing and certification procedures. Participants from Lebanon and Pakistan

noted that their countries have other regulatory bodies (such as professional syndicates and associations) that are involved in regulation. These bodies should also be involved in this process at an early stage to enable the necessary changes to be made to licensing, the setting of standards and monitoring of practitioners.

Operational mechanism – linking capacity-building to policy and practice. Participants emphasized the importance of linking the capacity-building process to policy and practice. One potential obstacle identified was the inability to implement the proposed capacity-building package in the absence of the corresponding policies and regulations. Trainees will not be able to practice palliative care if opioids are not available and if they are not licensed to prescribe them. Participants agreed on the need for policy consensus and government buy-in to make implementation feasible.

Participants from Lebanon and Sudan noted that they have access to their governments, and the Lebanese Ministry of Public Health expressed strong commitment to support the integration of palliative care into the health care system. Experiences from these two countries can be used as pilot projects for other countries in the Region. Participants agreed to initiate policy dialogue in their countries with the support of WHO that can share data from other regions and facilitate discussion with governments. Linking palliative care capacity-building to other health priorities in countries would help progress the dialogue with governments.

Operational mechanism – training centres. Participants agreed that training development should be country-based for effective health system integration and strengthening. They suggested stratification of countries based on the following availability of trainers: countries that already have trainers in palliative care; and countries that have no

specialists in palliative care (for this category, training of trainers opportunities should be created). Trainers can then be linked to regional experts for ongoing mentorship and technical support.

At least one centre should be identified in each country to provide the proposed secondary-level training (or the WHO model basic and intermediate courses). These centres are expected to accept candidates openly and based on a set of pre-determined criteria, without restricting selection to their own students. Participants suggested having a memorandum of understanding between the centre and the ministry. It was suggested that WHO facilitate contact with the ministry of health to enable a national health system-driven process, and to provide technical support in the development of material to assure alignment with WHO recommendations. Furthermore, it was suggested that:

- trainers should be those that have been practicing palliative care for several years;
- trainees should include new registrants each time to guarantee that a larger number of health care professionals receive the training;
- training centres should continue to monitor and follow up on trainees;
- WHO, particularly at country level, should be involved in the contact with training centres and be able to provide technical and financial support as appropriate to the context; and
- trainees should submit a report of activities six months after completion of training to ensure follow-up and clinical appliance.

Clinical services

Interventions that should be included in core and expanded packages for palliative care. Participants agreed that these include those that prevent and treat physical, psychological, social and spiritual suffering. In addition, they highlighted that interventions must go beyond patient care and also provide psychosocial support for

caregivers and palliative care providers. Participants also agreed that interventions should be available for patients across the lifespan, from infants to the elderly, and should be considered for a range of diagnoses, not only cancer. Participants discussed the acceptability of community-based palliative care interventions. Community education and sensitization around palliative care might be necessary in order for patients and families to accept palliative care services and support the necessary policy change through civil society activity.

Regarding spiritual care, participants discussed the role of community religious leaders in providing spiritual support for illness-related suffering and the role of Islamic scholars in enabling informed decisions about use of life-sustaining treatment and end-of-life care. A fatwa (number 12086) issued in 1989 by the Council of Senior Scholars has played a significant role in streamlining palliative care practices in Qatar and Saudi Arabia. It states that withdrawal of life-supporting therapy can be acceptable and decisions on resuscitative measures are exclusive to the medical team, without taking into consideration the opinions of the patient's family. Sometimes religious leaders may have different goals to palliative care providers. For example, some Islamic scholars advise against use of sedating medication at the end of life, while others have written that it is acceptable to use them to alleviate suffering, even if the medications may be sedating. It might be useful to train religious leaders in palliative care principles, while drawing on the available consensus and evidence on palliative care and Islam.

Models of palliative care service delivery for the Region.

Participants agreed that palliative care services should be delivered at multiple levels of care. In all countries, a situation analysis, such as that provided by the Atlas of Palliative Care in the Eastern Mediterranean Region and the Report of the Lancet Commission on

Palliative Care, is needed to understand the needs and the services already provided by governmental, nongovernmental and private organizations. Participants discussed whether palliative care services should first be developed in primary settings and then in secondary and tertiary settings, or should be developed first in tertiary centres. There was no clear consensus on this and it was decided that the prioritization might vary by country, depending on existing resources. There was consensus on the importance of inclusion and access to palliative care services at primary care level as a means to achieve universal health coverage, which should guide its development at the national level in agreement with global and regional commitments.

Primary level of care. Participants agreed that, at the primary level, palliative care should be provided in the community, because most patients in need of palliative care are in the community and either prefer to avoid or are not able to travel to secondary or tertiary care sites. The best format for community-based palliative care would be mobile teams that can make home visits to patients unable to travel. At a minimum there should be a registered nurse with basic palliative care training in each community. The nurse should be directly supported by a physician with at least basic palliative care training and preferably with intermediate or specialist level palliative care training.

If community health workers (CHWs) or health care visitors are present in the community, the palliative care nurse can supervise CHWs in identifying patients in need of palliative care, supervising medication use and providing social support to patients and families. However, most communities in the Region do not have CHW programmes. If possible, the primary level of palliative care services should be provided by a multidisciplinary team including a social worker, although this may not be feasible in all countries of the Region.

One potential problem identified was that patients and families might feel uncomfortable seeking palliative care services at the primary level, and would attempt to go straight to the tertiary centre, bypassing the community-based service. Two suggestions were made to address this issue. First, all palliative care providers should be trained and certified in a central facility in order to guarantee the quality of the training. Second, if possible, the community-based mobile teams should be multidisciplinary in order to offer comprehensive services.

Secondary level of care. Secondary palliative care services should be available at district or general hospitals, and provided by multidisciplinary teams consisting at least of a physician, nurse, social worker and spiritual care provider. If possible, other team members should include pharmacists, nutritionists, psychologists or counsellors, and child life specialists. The team should be advised via telephone or other electronic communication by the palliative care specialists at a tertiary referral centre, with a system in place for transfer to the tertiary centre for refractory symptoms.

Tertiary level of care. Tertiary care will be provided in national referral centres. The multidisciplinary team should consist of physicians, nurses, social workers and spiritual care providers. If possible, the teams should also include pharmacists, nutritionists, psychologists or counsellors, and child life specialists. In each country, there should be at least one board-certified specialist palliative care physician. National palliative care training centres should be established with support from regional leaders and the global palliative care community. Regional training centres may also be established to train palliative care physicians in countries that have not yet established national training programmes.

Quality standards for palliative care in the Region. As palliative care services expand, it will be necessary that the palliative care services delivered are high quality, effective and acceptable to patients and families. Regional clinical guidelines for palliative care delivery for adults and children should be developed by palliative care experts and reviewed by representatives from all countries of the Region. The regional expert network on palliative care will develop, in alignment with international quality standards, regional standards for palliative care services regarding: regional clinical guidelines; availability of essential palliative care medication; presence of specialist palliative care physicians; availability of primary, secondary and tertiary palliative care services; training programmes for basic, intermediate and specialist palliative care providers; indicators of patient and caregiver satisfaction with services; and indicators of palliative care efficacy, such as the palliative care outcome scale, translated and validated in the Region.

The setting of indicators to measure outcomes and evaluate the implementation process is essential. They facilitate policy dialogue and encourage policy-makers to commit. WHO headquarters will share their outcome measures and evaluation forms to help establish an evaluation mechanism and a recent publication from the University of Navarra on health indicators for the monitoring of global palliative care development might also be useful for this purpose. One suggestion was to create a “lessons learned” forum within the regional network to share experiences and enable the documentation of case studies of best practices, where applicable.

Draft regional roadmap for the development of palliative care in the Region

Participants discussed and agreed on several high-impact actions in each of the three focus areas that could be achieved in the next two years.

The priority in the policy arena is to create a policy brief on the unmet need for palliative care in the Region and policy solutions for fostering palliative care. The policy brief is to be drafted by February 2020 and disseminated widely. Additionally, participants will analyse prescribing practices for opioids in the Region based on existing data and discussions with experts in each country. The working group will also calculate opioid availability, affordability and accessibility in countries, in alignment with the Opioid Price Watch project, and produce a separate policy brief on opioid availability.

The human resources group will create a regional curriculum for secondary-level training programmes in the Region, based on existing curricula and adaptable to each country setting. The curriculum will be drafted by the end of 2019 and submitted to the regional network for review.

The clinical services working group will create a general outline of palliative care services integrated into each level of health care systems, based on WHO recommendations, to be provided to the policy working group. Case studies will be drafted for several countries in the Region to demonstrate how this basic model of integrated palliative care services could be adapted. These will analyse current palliative care services, the process by which those services were established, and challenges and strengths in each country, and provide recommended next steps for strengthening palliative care programmes in alignment with WHO recommendations. The case studies will be finalized by summer 2020. It was agreed that the first set of case studies should be from Egypt, Lebanon, Qatar and Saudi Arabia. Additionally, a set of quality indicators, building on an available set developed by WHO and other resources, will be drafted for review by representatives from each country in the Region.

Regional expert network on palliative care

A regional palliative care expert network will be established to provide technical support to WHO and governments in the implementation of national palliative care policies, structures and activities. Participants reviewed the proposed terms of reference and discussed the structure, organization and their expectations of the network.

Participants agreed not to limit membership of the network to a specific number. It was suggested to try to include representatives from all countries of the Region, while not being limited by the need for full representation. It was agreed that additional efforts should be made to identify and invite health care professionals from countries of the Region that were not represented at the meeting. It was also suggested to establish mentoring opportunities for country representatives requiring them and to support these with scholarships for training courses in palliative care where applicable and if funding is available. In addition, participants agreed to activate their networks to involve patient groups, such as society representatives and nongovernmental organizations, which can help the regional network in advocacy and evaluation. One potential problem with patient groups is that they might be funded by sources that are not neutral. For this reason, it was emphasized that the funding sources of societies be investigated before inviting them.

In relation to the network's organization, participants agreed to subdivide the network into three working groups (policy, human resources and clinical services), with each subgroup expected to hold virtual meetings on a regular basis. The WHO Secretariat will invite members to an online platform called EZcollab that can be used for communication, coordination and exchange of documents and working materials. As for the main network meeting, there was

support for conducting meetings on a regular basis, but no consensus on the frequency of face-to-face meetings. One suggestion was to conduct face-to-face meetings in countries where palliative care conferences are held. The next network meeting will be held around June, but this depends on the planning and progress of work and resource availability.

Regarding the network's responsibilities, terms of service and expectations, participants agreed on the following.

The responsibilities of the regional expert network are to:

- draft a road map on palliative care in the Region, guiding policy and clinical service implementation in all countries of the Region;
- develop a biannual work plan for activities to support the development and implementation of palliative care interventions and activities in countries of the Region;
- assist and advise the WHO Regional Office in providing strategic direction as well as operational and technical support, based on priority actions identified in the regional road map, to Member States in their implementation of palliative care policies and services; and
- establish a mechanism to regularly report on progress in implementing the regional road map, including attending relevant fora and meetings.

Terms of service

- Expert network members are provisionally appointed for a period of two years and are eligible for re-appointment.
- Members of the expert network do not speak on WHO's behalf.

Modalities of work and commitment

- Members will be invited as individuals, not as representatives of their organizations.
- The network will be composed of experts working in the field of palliative care with experience from the Region.
- Members of the network will be appointed by invitation only, striving to ensure representation from countries of the Region.
- Individuals in the expert network will be selected by the WHO Regional Office with input from WHO country offices.
- The expert network will liaise directly with the regional WHO noncommunicable disease management unit and other relevant WHO divisions and collaborate with palliative care partners from the Region.
- The expert network will be subdivided into working groups that are expected to maintain regular communication, web-based meetings, activities and outputs.
- WHO will not remunerate members of the expert network; however, expenses related to travel on behalf of the network will be covered by WHO or other partners, as appropriate.

3. Next steps

- Establish a regional expert network on palliative care, subdivided into three working groups, focusing on policy, human resources, and clinical services.
- Identify and invite to join the regional expert network experts from countries of the Region that were not represented during the first regional expert meeting on palliative care.
- Create an online community on the digital platform EZcollab to facilitate communication, coordination and ongoing work within the regional expert network.

- Develop the following deliverables as outlined in the current version of the regional roadmap on palliative care:
 - policy briefs on (1) the regional burden and need for palliative care and (2) opioid availability and affordability;
 - regional curricula for second-level palliative care training (basic and intermediate);
 - case studies on models of palliative care; and
 - a set of quality indicators for palliative care.
- Use the policy briefs, case studies and other advocacy material, such as videos describing palliative care and addressing misconceptions, for a side event during the 67th session of WHO Regional Committee for the Eastern Mediterranean in Cairo in October 2020 (submission to the Programme Subcommittee of the Regional Committee by February 2020).
- Arrange face-to-face meetings of the regional expert network during the upcoming biennium, depending on the availability of funding, to enable continued collaboration and the strengthening of palliative care in the Region.
- Agree on new deliverables and modes of collaboration for the regional expert network, as needed.



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