

# Palliative care in the Eastern Mediterranean Region: An overview

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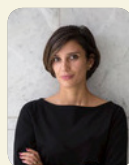
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Cancer and other chronic diseases are already a significant and growing public health problem in the Eastern Mediterranean Region (EMR). Cancer is the fourth-ranked cause of death in the region, and the burden is predicted to increase in the future. Given the impact of the late presentation of cancer and the growing incidence of other chronic illnesses, as well as the increasing number of people having other severe life-threatening diseases, including the COVID-19 pandemic, the call for action to improve and strengthen palliative care is of paramount importance in the EMR.

There is considerable variability in the development and organization of palliative care services across the countries of the EMR. Yet, data revealed that the development of palliative care in the majority of EMR countries continues to remain uneven, uncoordinated and poorly integrated across broader healthcare systems. Weak commitments and limited investment in palliative care services are significant challenges to advancing palliative care in the region.

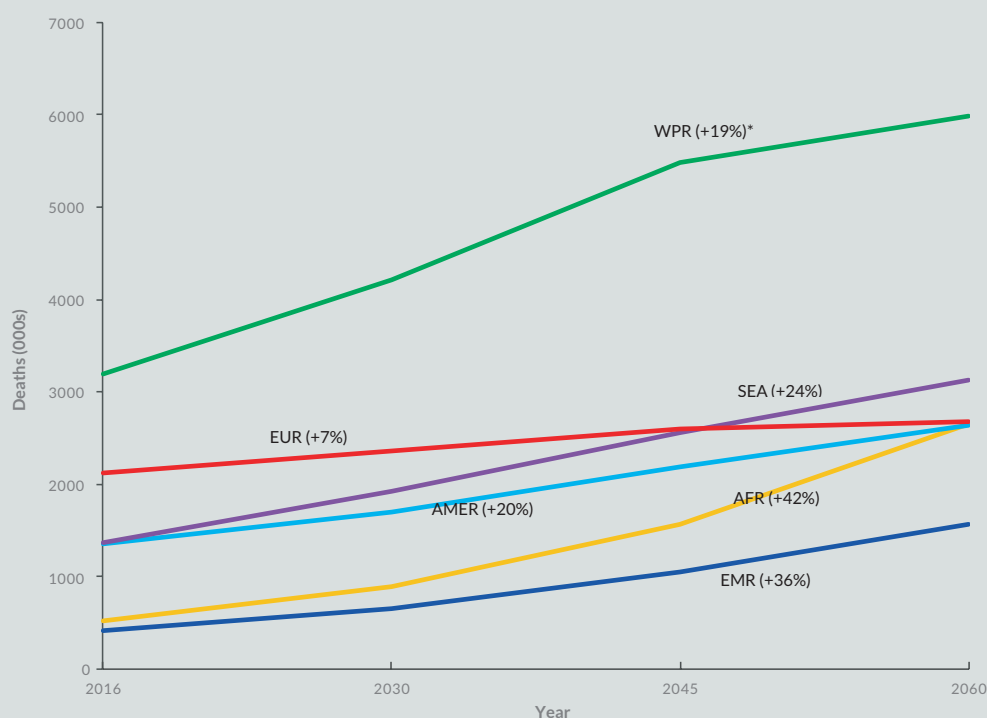
To improve access to palliative care services, countries need to invest in integrating palliative care into primary care. Given the particular cultural-religious context in most EMR countries, home-based palliative care services are vital and require special attention. Most importantly, all countries need to review and amend the regulatory limitations on the prescription of palliative care medicines.

Palliative care is an interdisciplinary medical approach that aims to improve the quality of life and alleviate the suffering of patients and their families, facing problems associated with life-threatening diseases, through the prevention and relief of pain and other forms of physical, psychosocial and spiritual distress. Palliative care, not only improves the quality of life of patients and their families

but also reduces unnecessary hospitalizations and use of healthcare services, and is thus a cost-saving public health intervention (1, 2).

Palliative care is required for the management of a wide range of life-threatening diseases of both noncommunicable (e.g. cancer, cardiovascular and chronic respiratory diseases), communicable (HIV/AIDS), as well as serious traumas

Figure 1: Cancer mortality projections by WHO region (developed using GLOBOCAN data, 2020)



WPR (Western Pacific Region), EUR (European Region), SEA (South-East Asia Region), AMER (Region of the Americas), AFR (African region), EMR (Eastern Mediterranean Region). \*Average percentage increase per 15-year interval. Data source: WHO Health statistics and information systems: [https://www.who.int/healthinfo/global\\_burden\\_disease/projections/en/](https://www.who.int/healthinfo/global_burden_disease/projections/en/)

and neurological diseases (3). In the context of the global commitment to palliative care, the World Health Assembly Resolution (WHA67.19) calls for governments to commit to evidence-based, accessible palliative care (4).

The Universal Health Coverage goals also call for the “full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation, and palliative care.” The Global human rights architecture includes pain relief and palliative care (5, 6).

In the EMR, cancer and other chronic diseases are already recognized as an important and growing public health problem. Cancer is the fourth-ranked cause of death in the region and the burden is predicted to increase in the future (Figure 1) (7). Moreover, cancer is generally diagnosed at a relatively advanced stage in most EMR countries, which in turn makes the need for palliative care more crucial in the region (8). This review article provides an overview of the development of palliative care in EMR countries and highlights the main challenges.

### Organization and provision of palliative care in the EMR

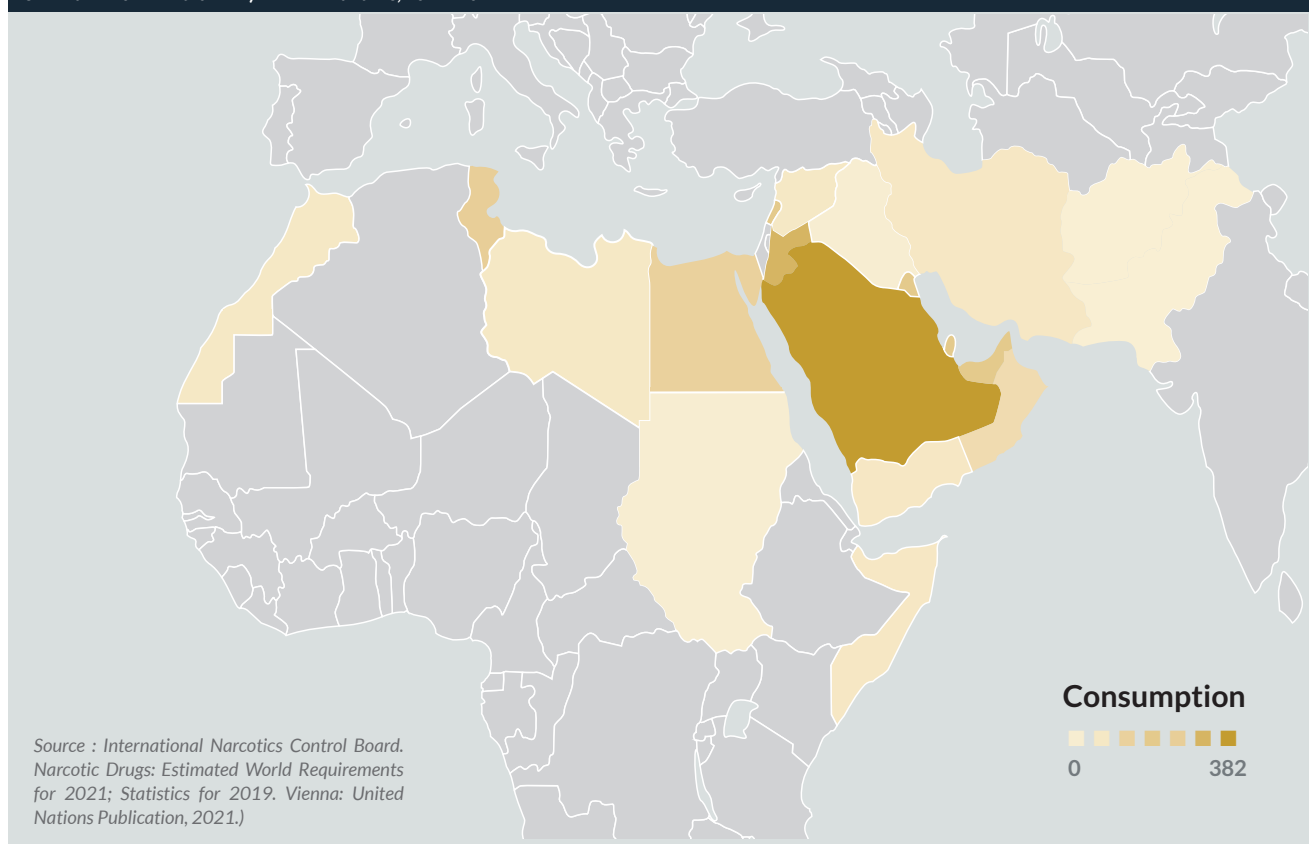
According to the WHO Guidelines for the Provision of Palliative Care, ideally, palliative care services should be provided from the time of diagnosis of a life-limiting illness,

adapting to the needs of patients and their families as the disease progresses into its terminal phase. Thus effective palliative care services should be integrated into the existing health system at all levels of care, especially community and home-based care (4, 9). Hence, there is a need to involve the public and the private sectors, adapted to a specific cultural, social and economic setting. Furthermore, to respond to the requirements in a community and make the best use of scarce resources, palliative care services should be strategically linked to prevention, early detection, and treatment services for both adults and children (4, 9).

While many countries in the EMR have not yet considered palliative care as a public health need, it is therefore not included in their health agendas. Yet, several initiatives and best practices have been developed in the region, such as in Jordan, Saudi Arabia, Oman, Qatar, Morocco, Lebanon and Egypt; however, services have been in large part restricted in reach and not fully integrated into the national health strategy (10-14, 15).

Most palliative care services are provided in tertiary hospitals and cancer centres in urban areas and major cities, with few benefits reaching rural areas. In most countries, palliative care services continue to be limited to cancer patients, and predominantly those at a more advanced stages of illness, and few centres provide paediatric palliative care services.

Figure 2: Average consumption of narcotic drugs, in defined daily doses for statistical purposes per million inhabitants per day (excluding preparations in Schedule III and methadone) in EMR countries, 2017–2019



Palliative care practice is also limited to specialists, and there has been no concerted effort to integrate it into primary care. The limited number of palliative care specialists in the region has severely restricted access to palliative care (14).

Nearly half of the EMR countries have no outpatient or inpatient practice for palliative care, no home care, or hospice care. No spiritual care providers, occupational therapists, or psychotherapists are made available for patients in paediatric oncology centres. Children usually die in the hospital, unlike adult patients who prefer to die at home due to the difficulty of parents dealing with their child's death process (14).

Palliative care services are provided in standalone centres in Kuwait, though no sufficient evidence on the outcomes of such experience (15).

Almost in all countries in the EMR, service provision has been challenged due to a lack of commitments and prioritization in the national programming and budgeting. Funding has not been consistent, and many of the service providers are nongovernmental organizations that depend on donations (14). This has made organizations vulnerable to fluctuations in funding and has resulted in a significant variability in the quality of care provided.

In Jordan, all Jordanian patients with cancer (adults and children) are fully financially insured for the treatment modalities (e.g. chemotherapy, radiotherapy, bone marrow

transplantation and palliative care services) by the government. However, palliative care is mainly given to cancer patients treated at King Hussein Cancer Centre and the Albasheer Hospital (16).

In Qatar, all expenses related to cancer therapies including palliative care and other modalities are being met by the Government of Qatar at the National Center for Cancer Care and Research (NCCCR).

Nevertheless, countries such as Lebanon and Jordan started their first palliative care programmes as inpatient services, then home-care services were initiated, for example the Almalath Foundation in Jordan was established in the 1990s (14, 16). In the Gulf States (Kuwait, Qatar and Saudi Arabia) palliative care was initiated as inpatient and outpatients services in large academic training centres. Hospital-based services include dedicated units as well as outpatient consultation services (14).

Hospice services are very limited in the region, apart from a few examples such as the paediatric hospice in Kuwait (Abdulla House) (17).

The availability of opioids and opioid consumption in the region tends to reflect the patterns of service availability (Figure 2). Countries with more developed palliative care service providers have a higher opioid consumption and generally have a wider variety of opioids. Most countries in the region have access to morphine and fentanyl, while methadone and

hydromorphone tend to be available in fewer countries. Laws and regulations regarding opioid prescription vary depending on the specialty of the physician prescribing (14). For example, opioid prescribing is limited to oncologists in Tunisia, physicians practising in governmental hospitals in Iraq or physicians in the larger regional hospitals in Oman. Some countries like Lebanon, Jordan and Qatar have expanded prescribing to pain specialists and palliative care physicians. Most of the countries in the EMR allow outpatient opioid prescription to be valid only up to 14 days. Whereas few countries allow dispensing the same prescription up to 30 days (14).

Most countries have improper pain assessments and suboptimal pain management, with a significant shortage of opioids (14).

Cultural misconceptions and population demographics have also been barriers to the growth of palliative care services (14, 18, 19). Choosing to avoid aggressive interventions such as resuscitation when care is deemed futile is impossible in some countries (20). For example, in the United Arab Emirates, it is not legal to place a “Do Not Resuscitate – DNR” order on a patient’s chart (21). However, many palliative care services in countries like Saudi Arabia, Jordan, Kuwait, Qatar, Lebanon and Egypt hospice and palliative care practices are based on international standards with proper cultural adaptation to meet their local public needs. Therefore, stopping aggressive interventions at end of life and futile management replaced by comfort care are the norm. On the other hand, DNR is ethically, religiously and legally acceptable in Jordan, Saudi Arabia and Qatar for terminally ill patients especially for those with advanced cancer with no potential curable options (22).

### Training, education and research

Education is the main prerequisite for providing palliative care. In most studies on palliative care needs in the region, educational needs are mentioned as one of the most important common needs (23). However, due to the vastness of the area, various socioeconomic situations and different incidence rates of cancer, a concentrated (focused) curriculum for palliative care provision may not be very desirable (1). Since educational programmes should be developed based on the role and duties of the care providers, the level of development of palliative care and the authority of the health professionals, such as physicians and nurses, in each country will determine the palliative care educational needs. However, the World Health Organization (WHO) has proposed guidelines to be implemented in low- and middle-income countries as a practical model (2).

Palliative care education programmes are categorized based on the level and needs of healthcare providers, for example, general knowledge about palliative care and end-of-life care are provided in many countries, for general practitioners and

undergraduates students, while palliative care medical training currently exists in only a few countries in the region (14, 23).

This training is provided in two ways: formal academic education and non-formal education via short-term programmes and workshops (3). Since university-level medical and nursing education exists in most countries in the region, these items are included in the curriculum of the related disciplines (4–6). For instance, in Lebanon, a 21-hour course is included in the curriculum of medical students (13).

There is some specialist training, which is certified, to train leaders and researchers in palliative care (3), but this exists only in some countries in the region. In Jordan, for example, there are different levels of specialized academic education in palliative care, including a master’s degree in palliative care nursing, and a pain diploma granted by The School Nursing in Jordan (5). In Saudi Arabia and Jordan, palliative care is recognized as a subspecialty by the local medical council (24). In Saudi Arabia, Qatar, Jordan and Iran, a subspecialty fellowship programme in palliative medicine is being implemented (4, 6, 8, 9, 24). In Lebanon, a palliative care fellowship programme is developed, though not implemented as yet (8, 24).

Short-term and informal programmes are the second type of educational training courses where individuals receive certificates and will be able to provide specialty services. These are available for nurses and physicians in some countries of the region.

Cross-border collaborations promoting palliative care training and education for physicians and nurses are being practised in the region, where well-resourced centres such as King Hussein Cancer Centre in Jordan and the Oman Cancer Association in Oman, KFSHRC in Riyadh, Saudi Arabia and Kuwait Palliative Care Centre in Kuwait are running regular short and long training courses to build regional capacity and support low-resource countries (14, 23).

Challenges do exist, including the lack of expert instructors in this field, limited resources for online training and the lack of commitment to and recognition of palliative care programmes as an independent discipline (11–13).

### Palliative care research

Research is often considered as an inseparable part of palliative care. Since there is a wide range of cultures, religions and historical and social backgrounds in the countries of the region, the priorities and research needs vary according to the conditions of each country. The requirements of the palliative care system in each country should be addressed with regard to the situation of that country (14).

Despite the importance of research and increasing attention to this issue, carrying out research and publishing papers in these countries are in their early stages. Most countries

face challenges related to insufficient research support, problems in accessing resources, a shortage of researchers and instructors in the field of palliative care and language barriers. Overcoming these challenges requires measures such as developing mentorship, conducting educational courses on research methodology and training researchers through train-the-trainer courses. Successful examples of these strategies include training courses on palliative care research in cooperation with the Oman Cancer Association and the Oncology Nurses' Society for nurses and physicians in the region (10). Furthermore, collaboration between some Middle East and North Africa countries and international research support programmes such as the R4HC-MENA's (Research for Health in Conflict in the Middle East and North Africa) programme, that is supported by United Kingdom, opened active channels of training and conducting research. Many countries in the Middle East including Jordan, Turkey, Lebanon and Palestine were involved in this project whose aim was to support research development and capacity building via conducting many collaborative research studies and staff training (25, 26).

According to SCOPUS data on the countries of the region, the number of papers on palliative care produced between 2016 and 2019 has increased from 62 in 2016 to 90 in 2019, which is evidence of increasing attention to this subject (27, 28).

### Regional challenges

Access to palliative care services is a major challenge in the region. It is estimated that only 5% of adults who are in need of palliative care receive it (23).

The variability of health systems in the EMR translates into a vast difference in resources, priorities and health system structures, making planning at regional level challenging (14, 23). This is limited not only to the level of national laws and policies but extends to medical education and training. Diversity in languages also influences the training where medical and nursing school curricula use different languages for instruction and have a widely differing curricular structure.

Conflict, political instability and forced displacement have marred the region for decades and have also impacted on the development of palliative care. Half of the countries in the region have suffered emergencies, political instabilities making it difficult for the establishment of new programmes like palliative care (23, 27). In countries like Tunisia, advocates worked hard to lobby, establish relationships, and develop plans and strategies for the development of palliative care with leaders in the ministry of health only to find themselves having to start from scratch when a new regime with a new leadership took over and priorities shifted (14). This scenario repeats itself in most countries, which poses a major barrier to

improving palliative care.

Although some of the higher income countries have adequate numbers of providers who have received training in palliative care, many of them are expatriates with temporary contracts. This results in a loss of valuable human resources who are essential to the advancement of the field. The lack of recognition of palliative care as a specialty in many countries remains a major barrier to growth as healthcare professionals are discouraged from joining this specialty (14). Many challenges exist (Table 1) within the areas of governance, public awareness, human resources, training and medication for palliative care.

### Palliative care and the COVID-19 pandemic

Worldwide restrictions on social interaction and travel imposed by the COVID-19 pandemic has altered the practice of palliative care (14, 29). The necessary use of personal protective equipment (PPE) and limited contact with patients and families has made this medical practice, which is heavily dependent on communication and physical presence, extremely challenging. Telehealth technologies including telephone and videoconferencing have been used to replace in-person care. Medical management, family conferencing and bereavement support have all been conducted remotely during the pandemic. This may have contributed to facilitating access to patients in remote settings, however, the nature of the physician-patient-family interaction has undoubtedly suffered (30, 31). The level of preparedness of Mediterranean countries to respond to the pandemic varied significantly due to the lack of support and resources (26).

### Paediatric palliative care

According to the evidence, 21.6 million children in the world need palliative care services, about 8.2 million of whom need specialty services, with 98% of the latter group living in low- and middle-income countries. The Middle East has the highest number of children in need of these services, after Africa and Southeastern Asia (33, 34). In various studies, countries are classified in different ways in terms of their potential. In 2011, most countries in the region were placed at level one, i.e. providing no paediatric palliative care (PPC) services. Iran, Qatar and Egypt have been classified as level two, with the capacity to provide palliative care services, and only Jordan and Saudi Arabia are placed on the third level by providing local services (35). Data reported by the Middle East atlas also showed that PPC is still limited and is being implemented in few countries (36). However, in recent years, PPC seems to be developing alongside adult services.

The background of PPC in the region dates back to 2004-2005, and to the establishment of this type of care in Jordan

Table 1: Lists of key challenges for palliative care in the region (14, 23, 28)

Policies and regulations	Culture and public awareness
<ul style="list-style-type: none"> <li>• Absence of laws that acknowledge and define that palliative care is part of the healthcare system.</li> <li>• Lack of regional/national robust healthcare strategies related to the establishment and development of palliative care</li> <li>• Lack of national standards of care for describing palliative care.</li> <li>• Absence of clinical guidelines and protocols.</li> <li>• Poor/inconsistent implementation of a national strategy on palliative care implementation.</li> <li>• Weak infrastructure for primary healthcare, home healthcare and community services.</li> <li>• Financial challenges such as lack of insurance coverage for palliative care services</li> </ul>	<ul style="list-style-type: none"> <li>• Misconceptions regarding the use of opioids for pain relief.</li> <li>• Lack of public awareness campaigns.</li> <li>• Value of family decision-making over patient autonomy and choice.</li> </ul>
Medication availability	Education
<ul style="list-style-type: none"> <li>• Limited availability of opioids and specific palliative care medication in the primary healthcare sector (28).</li> <li>• Policy restriction (prescribing, dispensing and administration)</li> <li>• Lack of training and experience of non-specialized palliative care professionals in safely using such medication.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of palliative education in medical schools.</li> <li>• Lack of knowledge about opioids practice and pain management</li> <li>• Lack of palliative education in nursing schools and postgraduate education.</li> <li>• Lack of palliative care education in other healthcare disciplines (social work, physiotherapy, etc)</li> <li>• Expanding Lack of postgraduate palliative care education courses at national level for postgraduates.</li> <li>• Lack of undergraduate and postgraduate level palliative care education training/courses at a national or regional level.</li> </ul>

and Kuwait (6, 37). A 2011 study considered that PPC was a priority due to the young population of most Middle-Eastern countries, as well as delayed cancer diagnosis, and in this regard, some paediatric oncologists began to receive training in seven countries (38, 39). Currently, there is a specialized paediatric palliative team in Kuwait and Jordan providing services in various settings such as home, hospital and hospice (37, 40). The King Hussein Cancer Centre (KHCC) provides home care, inpatient and outpatient services for children (40). In other countries of the region, including Lebanon, Egypt, Iran and Saudi Arabia, PPC services are mostly provided in paediatric specialty hospitals, and the team members consist of paediatric oncologists, nurses and social workers, and other disciplines who have only passed courses on palliative care (6, 38). Therefore, it can be said that in this region, PPC is offered as a general service and the absence of specialty services is still noteworthy.

### The way forward

As projected, the region is expected to have a dramatic increase in cancer incidence in the coming years, with more people needing palliative care. While attention to PC has increased significantly in recent years, huge variations exist in the development and organization of palliative care across the region. Data revealed that the development of palliative care in the majority of EMR continues to remain uneven, uncoordinated and poorly integrated across broader healthcare systems. The main barriers to palliative care

development and integration include misunderstandings about palliative care, the non-inclusion of palliative care in national health policies, lack of education and training for healthcare professionals, limited access to controlled medicines necessary for palliative care, and limited research (2). The 2014 World Health Assembly resolution, which stresses the importance of integrating palliative care as a core component of health systems, and current Universal Health Coverage efforts in the region, provides the region with essential entry points and policy opportunities to strengthen the regional palliative care agenda. EMRO countries are urged to implement the WHA resolution on palliative care that necessitates integrating palliative care into countries' healthcare systems (1). Countries need to take bold actions to overcome barriers and address the increasing needs for palliative care, and emphasis should be directed towards:

- ➔ Scaling up home-based care and expanding access to palliative care services at the primary healthcare level.
- ➔ Addressing regulatory limitations to prescription of and accessibility to essential palliative care medicines.
- ➔ Document and showcase benefits of palliative care for adults and paediatrics, both in terms of health outcomes and health system cost savings; to raise awareness and promote the integration of palliative care into the health systems of the region.
- ➔ Make use of the WHO EMRO regional network of palliative care experts as a platform to exchange experiences and support initiatives in new countries, including mentorship

and educational exchange to promote palliative care research efforts in the region.

- Promoting research as an essential component to develop effective palliative care models, to help provide a strong evidence base to inform palliative care policy especially in limited-resources countries (1).
- Raising awareness about the importance of the early introduction of palliative care is a priority in the region.
- Make use of the existing regional networks and civil society organizations including patient advocates, to provide a platform to exchange experiences and support initiatives in new countries, including mentorship and educational exchange to promote palliative care research efforts in the region.
- Promoting research as an essential component in developing effective local palliative care models and to explore barriers to early referral to palliative care among healthcare professionals as well as patients and their families.

The COVID-19 crisis has brought attention to and enhanced the understanding of palliative care and the central role it plays for both effective health systems and the affected individual's right to healthcare. The ongoing crisis has also highlighted the need to invest in the development of telemedicine and online consultations for palliative care, providing the agenda with an improved means to expand and reach the unmet needs (3). ■

#### *Disclaimer*

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