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Report

Miguel Antonio Sánchez-Cárdenas,[1,2] Eduardo Garralda,[1,2] Danny van Steijn,[1,2] Nasim Pourghazian,[3] Slim Slama,[3] Marie-Charlotte Bouësseau[4] and Carlos Centeno[1,2]

[1]ATLANTES Global Observatory of Palliative Care, Institute for Culture and Society, University of Navarra, Pamplona, Spain (Correspondence to: E. Garralda: egarralda@unav.es). [2]Instituto de Investigación Sanitaria de Navarra, Pamplona, Spain.

[3]Noncommunicable Disease Prevention Unit, Department of Universal Health Coverage/Noncommunicable Diseases, World Health Organization Regional Office for the Eastern Mediterranean, Cairo, Egypt.

[4]Integrated Health Services Department, World Health Organization Headquarters, Geneva, Switzerland.

Abstract

Background: The increasing number of people experiencing serious health-related suffering due to severe illness is an urgent issue in the WHO Eastern Mediterranean Region (EMR). Although palliative care can mitigate much of this suffering, its current development and indicators to measure progress remain unknown.

Aims: To describe the development of the Atlas of palliative care in the Eastern Mediterranean Region 2021.

Methods: Recently, the WHO Regional Office for the Eastern Mediterranean, together with a network of palliative care experts, identified the best indicators and collected data across the Region. These indicators include national palliative care strategies, number of specialized palliative care services per population, inclusion of palliative care in the health benefits package and national health budget, and the use of pain medication. These and other useful information form the Atlas of palliative care in the Eastern Mediterranean Region 2021.

Results: The Atlas shows that provision of specialized palliative care services and pain medication in the Region is low. Several of the indicators suitable to the region are new and include the level of public awareness of palliative care, inclusion of palliative care in health insurance plans, availability of centres of excellence for palliative clinical care, and availability of grants to finance palliative care research.

Conclusion: Adoption of favourable policies, educational initiatives, and the involvement of stakeholders, represent an opportunity for future development of palliative care in the EMR.

Keywords: Palliative care, EMR, indicators, pain management, severe illness, health-related suffering

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Global palliative care needs

Palliative care offers holistic care (medical, psychological, social and spiritual) for people with pain and serious health-related suffering due to severe illness. Palliative care is intended to

improve the quality of life of patients, their families and caregivers (1). In recent times, palliative care has been progressively and unequally implemented, especially in low- and middle-income countries (2). In these countries the prevalence of serious health-related suffering is high and projections estimate increasingly greater need by 2060 (3). Currently, 61 million adults and children experience unnecessary health-related suffering that can be addressed and treated by palliative care (3). The ageing population, the increase in morbidity and mortality in people with chronic noncommunicable diseases, and more than 8 million children each year with complex problems (4), reaffirm the urgency for addressing this emergency especially given the 87% increase in global suffering predicted for 2060 (3).

Global commitments and aspirations

Globally, ongoing debates about health equity in the context of the United Nations (UN) Sustainable Development Goals (SDGs) have highlighted the need to invest in comprehensive health systems (5). UN Member States have committed to achieving the 17 goals of the 2030 development agenda, which includes a 10-year timeline to integrate palliative care into Universal Health Coverage (UHC) as an essential service under the larger umbrella of Goal 3: Ensuring healthy lives and promoting well-being at all ages as an essential part of sustainable development. Besides endorsing the Baseline report of the decade for healthy aging, WHO, together with the UN (6), has for several years requested Members States to improve access to palliative care as a central component of UHC and health systems strengthening (2014). The relevance of palliative care was highlighted during the 73rd World Health Assembly (2020), highlighting how in times of change and threats to humanity (pandemics, climate change and forced displacement) palliative care is vital to health and social protection systems that are ready to respond to suffering. In 2019, the Berlin Declaration (7) indicated that this was a critical juncture to consolidate strategies to better understand how to improve access to palliative care.

Palliative care needs in Eastern Mediterranean Region

The WHO Eastern Mediterranean Region (EMR) has a population of almost 679 million people living in 22 States, and has various social and health contexts that influence the development of palliative care. In 2016, 4 138 382 deaths were registered in the Region and 43% of them were related to conditions suitable to receive palliative care. Cardiovascular disease and cancer were the two main causes of serious health-related suffering (8).

Previous regional studies on how to estimate capacities of countries

In 2007, WHO developed a public health model which highlights palliative care strategies to influence policy, education, services and availability of drugs to guarantee access to palliative care services by those who need them (9). However, there are still countries with inadequately developed palliative care. To account for this low implementation that is more evident in low- and middle-income countries, there is a need to characterize and profile access to palliative

care and establish new models that outline the reality of palliative care in these countries.

Over the past decade, various palliative care development assessment strategies have been used in Africa, Latin America, Asia, Europe, and globally (10–13). These strategies have helped establish indicators that reflect relevant public health components. The two most prevalent components to date are the use of pain medication and the provision of palliative care services; both of which have been important tracers to understand the level of development of palliative care (14,15). New components have been developed in recent years, such as financing, professional activity, community and patient empowerment, and research. There is a need to explore and consider other components in the development of palliative care and design new indicators that are sensitive to the context where they are used.

In 2017, a cross-sectional evaluation of palliative care in the EMR was developed through the first Atlas of Palliative Care in the Eastern Mediterranean Region (16). Other studies (17–19) have identified barriers in the Region such as the absence of palliative care in national policies, gaps in access to essential analgesics, insufficient education in palliative care for health professionals and volunteers, little public awareness and lack of collaborative work in scientific societies. Currently, the emergency situation in most of the EMR countries, the presence of refugees and displaced populations, represent a major barrier to the development of palliative care.

EMR stakeholders take the lead in finding region-specific indicators

The WHO/EMRO and in-country experts in the EMR experts have committed to evaluating the development of PC in the EMR using region-specific indicators that are meaningful to their geographical context. Following an expert meeting convened by the WHO/EMRO in Beirut, Lebanon, in September 2019, a dialogue began at the regional level on the development of a regional roadmap and workplan on palliative care, which included a set of quality indicators as one of the deliverables. WHO proposed consultations with experts in the Region to identify the most relevant and feasible indicators for measuring the development of palliative care, using previously published indicators by the ATLANTES Global Observatory of Palliative Care. WHO promoted the creation of a network of palliative care experts in the Region, whose mission is to promote the development of national systems for evaluation and improvement of the quality of palliative care services. With the involvement of this network, WHO/EMRO proposed the creation of a set of indicators specific to the EMR context and circulated it to palliative care experts in the region for comments needed to update the previously published Atlas of palliative care in the Eastern Mediterranean Region (16).

Recent publications of ATLANTES Global Observatory of Palliative Care identified 25 indicators

spanning 5 components with a high content validity and level of agreement among different international experts. This made it necessary to debate the viability of each indicator in countries with different contexts in relation to the World Bank income level, Human Development Index and UHC progress (16). Besides the palliative care indicators, various public health studies have reported the need to assess contextual factors in the process of determining equity in access to health services (17). Therefore, the development of a regional atlas of palliative care considers the use of macroindicators in specific geographic contexts to monitor the activity of the elements that determine the development and integration of palliative care into health systems.

Consensus of regional palliative care experts on indicators

WHO/EMRO proposed the circulation of a set of indicators to update the information published in the Atlas of palliative care 2017 in the Eastern Mediterranean Region (16). An initial list of indicators was sent to members of the regional network, carrying out a 2-round Delphi consensus process to identify a final set of regional indicators with which to develop the monitoring process (reported in another paper in this edition of EMHJ). The consensus process followed 2 steps: identification of a network of in-country experts, and the 2-round Delphi process.

A network of highly qualified informants was identified and consolidated to identify and report the explored dimensions using reliable data sources. The criteria for selecting experts were knowledge of the national situation of palliative care in their country and the endorsement of WHO/EMRO for their participation in the consensus and data collection. At least 1 expert was identified in 12 of the 22 countries in the Region. Experts could not be identified in Bahrain, Djibouti, Libya, Somalia, Tunisia, United Arab Emirates and Yemen (Table 1).

The ATLANTES Global Observatory of Palliative Care facilitated a dialogue with regional experts to collate their input and agree on a set of regional indicators that would provide a baseline for monitoring progress in the Region. An initial selected list of indicators from previous studies such as the WHO public health framework (9), the mapping of PC development levels in 198 countries (2) and the Brief manual on health indicators monitoring palliative care development (15) was sent to members of the regional network, carrying out a 2-round consensus process to identify context-relevant indicators. In the first round, indicators were rated by experts on a 1–9 scale for the criteria of relevance and feasibility, allowing for new indicators that could be crucial in their context, or the possibility to adapt existing ones. In the second round, the same indicators plus the new ones that were suggested by experts in the first round were sent to the experts, providing the group's average score and their previous score so they could rerate the indicators considering the perspectives of other group members (Table 2) .

During the consensus process, indicators related to cultural responsiveness and acceptance of the concept of palliative care, volunteering in palliative care, availability of palliative care for displaced persons or refugees, palliative care services offered for older people, and palliative care services offered for nonmalignant diseases were proposed, but did not reach the consensus score for inclusion in the regional monitoring of palliative care.

Regional survey with agreed indicators

An electronic survey using agreed indicators was disseminated to the same network of experts and some newly identified experts. To respond to the survey, the in-country experts contacted the national authorities to obtain the most accurate data related to the development of palliative care in their respective countries. In each of the phases of the monitoring process, the preliminary results were discussed continuously with the network of experts and relevant WHO units to provide feedback on the process and align with the objectives of the working group.

Atlas of palliative care in the EMR

The first Atlas of palliative care in the Eastern Mediterranean Region (16) provides a systematic and comprehensive evaluation of palliative care in the Region. It contains data on the most relevant and feasible indicators to monitor the development of palliative care. Some indicators have been scored unanimously for their importance and feasibility, although slightly lower in terms of feasibility. Examples of these top indicators are: (1) the existence of a current national palliative care strategy; (2) the number of specialized palliative care services (for adults and children) in the country per population; and (3) inclusion of a line item for palliative care in the national health budget by the Ministry of Health or equivalent government agency. Other indicators included are the availability of morphine and other strong opioids, and the reported annual opioid consumption, excluding methadone, in morphine equivalence per capita. Most of these indicators have previously been considered critical for assessing palliative care development in the Region and were therefore strongly recommended to be part of the final set of regional indicators (16,19). However, compared to a previous international consensus on indicators, the importance of some regional indicators differs (20). Four indicators in this study scored above the mean obtained in the international consensus: (1) availability of morphine and other strong opioids; (2) specialized palliative care services per population (for children and adults); (3) prequalification education for doctors and nurses; and (4) inclusion of palliative care services in the basic package of health services (20). Several indicators were new and specifically suitable to the region: (1) the level of public awareness of palliative care; (2) inclusion of palliative care in health insurance plans; (3) availability of centres of excellence for palliative care; and (4) grants to finance palliative care research.

The findings are presented in clear and simple graphics, tables, figures and maps and provide comparative data about the state of palliative care across several dimensions and countries. The information is structured in an introduction (explaining the methodology), thematic maps (main indicators shown separately on a regional map allowing comparisons), and country infographics (detailed country-by-country information of all gathered indicators) (Figure 1).

A summary of the main information about the development of palliative care in each of the 12 participating countries is presented in Table 3 .

Implications for the future

The contents of the Atlas of palliative care in the Eastern Mediterranean Region (16) highlight clear and urgent areas for improvement. It is an excellent tool created by stakeholders to support the planning and development of palliative care in the EMR. The priority actions relate to the lack of specialized palliative care services and low availability and consumption of drugs for alleviating pain. This calls for an increase in the number and types of palliative care services, especially home care, outpatient programmes and paediatric care, as well as optimization of the geographic distribution of palliative care services. The use of opioids could be enhanced by the establishment of a regional and national strategy to improve their use for palliative care and pain relief, as well as assurance of affordable access to palliative care medication being included in the WHO model list of essential medicines, particularly for immediate-release oral morphine (21).

Other areas with room for improvement include health policy related to palliative care and professional education in palliative medicine. According to regional experts, there is an urgent need to: promote the inclusion of palliative care in the national health benefit package for all patients; manage the coverage of palliative care by national health systems or private health insurance; and support the establishment of a national palliative care plan, programme, policy or strategy with a realistic implementation framework in the countries without palliative care regulation. Promoting the teaching of palliative care in medical and nursing schools in the EMR, support for capacity building and research efforts via palliative care associations, and the development and documentation of best practices and peer learning in palliative care within the respective countries are key to palliative care development.

Implementation of continuous monitoring (e.g. every 3 years) based on the indicators developed in the regional consensus and expanding the number of countries are the main challenges in the near future to establishing a consolidated monitoring strategy in the EMR. Luckily, this process highlights a great effort by the stakeholders to coordinate and optimize isolated efforts for improving access to palliative care. Using the resources and capacities within the Region

and involving different stakeholders, results can inform the current and ongoing work of the regional network of experts and the implementation of a regional roadmap to increase palliative care in the Region. Improving access to palliative care in the Region will help achieve the goals proposed in the WHO Thirteenth general program of work (22), WHO's strategy for the Eastern Mediterranean Region, 2020–2023 (23), and Decade of healthy ageing 2021–2030 baseline report (6), improving the quality of life of people with palliative care needs, the healthy ageing approach, and responses to health emergencies and humanitarian crises in the Region.

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Préparation d'un atlas des soins palliatifs dans la Région de la Méditerranée orientale par le biais d'un processus participatif des parties prenantes

Résumé

Contexte : Le nombre croissant de personnes connaissant des souffrances graves liées à la santé en raison d'une maladie sévère constitue un problème urgent dans la Région OMS de la Méditerranée orientale. Bien que les soins palliatifs puissent atténuer une grande partie de cette souffrance, leur évolution actuelle et les indicateurs permettant de mesurer les progrès demeurent inconnus.

Objectifs : Décrire la préparation de l'Atlas des soins palliatifs dans la Région de la Méditerranée orientale 2021.

Méthodes : Récemment, le Bureau régional de l'OMS pour la Méditerranée orientale, en collaboration avec un réseau d'experts des soins palliatifs, a identifié les meilleurs indicateurs et collecté des données dans toute la Région. Ces indicateurs comprennent les stratégies de soins palliatifs nationales, le nombre de services de soins palliatifs spécialisés par habitant, l'inclusion des soins palliatifs dans l'ensemble des prestations de santé et le budget national de la santé, ainsi que le recours aux traitements analgésiques. Ces informations et d'autres éléments utiles constituent l'Atlas des soins palliatifs dans la Région de la Méditerranée orientale 2021.

Résultats : L'Atlas montre que la prestation de services spécialisés en soins palliatifs et la fourniture d'analgésiques sont faibles dans la Région. Plusieurs des indicateurs adaptés à la Région sont nouveaux et comprennent le niveau de sensibilisation du public aux soins palliatifs, l'inclusion des soins palliatifs dans les régimes d'assurance-maladie, la disponibilité de centres d'excellence pour les soins cliniques palliatifs et la disponibilité de subventions pour financer la recherche sur les soins palliatifs.

Conclusion : L'adoption de politiques favorables, les initiatives éducatives et l'implication des parties prenantes représentent une opportunité pour l'évolution future des soins palliatifs dans la Région de la Méditerranée orientale.

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