

## Special Article

## Can You Hear Us Now? Equity in Global Advocacy for Palliative Care



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**Abstract**

*Evidence-based advocacy underpins the sustainable delivery of quality, publicly guaranteed, and universally available palliative care. More than 60 million people in low- and middle-income countries (LMICs) have no or extremely limited access to either palliative care services or essential palliative care medicines (e.g., opioids) on the World Health Organization Model List. Indeed, only 12% of the global palliative care need is currently being met. Palliative care advocacy works to bring this global public health inequity to light. Despite their expertise, palliative care practitioners in LMICs are rarely invited to health policymaking tables - even in their own countries - and are underrepresented in the academic literature produced largely in the high-income world. In this paper, palliative care experts from Bangladesh, Colombia, Egypt, Sudan, Uganda, and Zambia affiliated with the International Association for Hospice & Palliative Care Advocacy Focal Point Program articulate the urgent need for evidence-based advocacy, focusing on significant barriers such as urban/rural divides, cancer-centeredness, service delivery gaps, opioid formulary limitations, public policy, and education deficits. Their advocacy is situated in the context of an emerging global health narrative that stipulates palliative care provision as an ethical obligation of all health systems. To support advocacy efforts, palliative care evaluation and indicator data should assess the extent to which LMIC practitioners lead and participate in global and regional advocacy. This goal entails investment in transnational advocacy initiatives, research investments in palliative care access and cost-effective models in LMICs, and capacity building for a global community of practice to capture the attention of policymakers at all levels of health system governance. J Pain Symptom Manage 2022;64:e217–e226. © 2022 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

**Key Words**

*Palliative care, hospice, global health, social justice, advocacy, policy, opioids, essential medicines, partnerships*

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## Introduction

Evidence-based advocacy underpins the sustainable delivery of quality, publicly guaranteed, and universally available palliative care.<sup>1,2</sup> Although palliative care is recognized as a component of a right to the highest attainable standard of physical and mental health, and is now included in universal health coverage,<sup>3,4</sup> only 12% of global palliative care need is currently being met.<sup>5</sup> More than 60 million people living in low- and middle-income countries (LMICs) with no access to either palliative care services or essential palliative care medicines (e.g., opioids for pain and symptom management), experience preventable serious health-related suffering.<sup>6</sup> Equitable palliative care access has become increasingly elusive in the face of COVID-19 and other humanitarian crises.<sup>7–11</sup> Palliative care advocacy works to bring that global public health inequity to light.

Advocacy for integration of palliative care into primary healthcare, with service delivery at the community level, takes a rights-based approach to global health governance that entails participation of all affected populations in advocacy and oversight. Advocates in countries with fragile health systems that lack effective prevention, treatment, rehabilitation, and palliative care services, call for committed, multisectoral engagement that puts patient and caregiver wellbeing and the relief of serious health-related suffering at the center of health system concern. Advocacy requires building institutional capacity that brings together practitioners, academics, policymakers, and service recipients.<sup>12</sup>

Advocacy spearheaded by the International Association for Hospice and Palliative Care (IAHPC) explicitly includes historically excluded voices from LMICs to overcome the global palliative care divide.<sup>6,13</sup> Despite their expertise, palliative care practitioners in LMICs are rarely invited to health policymaking tables even in their own countries, and are under-represented in the academic literature produced largely in the high-income world.<sup>14</sup>

The IAHPC elevates advocacy voices from LMICs through its Advocacy Focal Point (AFP) program (Table 1).<sup>15</sup> The AFPs work on a voluntary basis and are trained through the IAHPC e-advocacy course. They work with their governments to quantify their current health-related suffering burden, using a living dataset from the 2017 Lancet Commission on Global Access to Palliative Care and Pain Relief and then proposing strategies to alleviate that burden.<sup>6,16</sup> Strategies include integrating palliative care into community-based primary health care delivery and improving rational access to and availability of, essential controlled medicines aligned with international standards using the Lancet Commission's Essential Package.<sup>6</sup> AFPs use data shared across inter-governmental and civil society platforms as evidence for policy proposals aimed at producing measurable improvements.

In this paper, palliative care experts from Bangladesh, Colombia, Egypt, Sudan, Uganda, and Zambia affiliated with the IAHPC AFP Program articulate this urgent need for evidence-based advocacy, focusing on significant barriers such as urban/rural divides, cancer-centeredness, service delivery gaps, formulary limitations, public policy, and

Table 1

**The International Association for Hospice & Palliative Care Advocacy Focal Point Program Context and Process**

Advocacy Context	Advocacy Process
<ul style="list-style-type: none"> <li>• IAHPC is a non-state actor in official relations with the WHO and maintains consultative status as a nongovernmental organization with the UN Economic and Social Council</li> <li>• The IAHPC is invited to register a delegation to member state meetings, post statements on meeting website, and take the floor to make statements regarding the need for palliative care at discretion of meeting Chair</li> <li>• Statements are best made by palliative care practitioners or service recipients, including patients and caregivers with lived experience</li> <li>• IAHPC Advocacy Focal Point (AFP) Program developed to focus palliative care advocacy on specific countries per specific criteria with country to have: an identified palliative care organization with a designated leader; permanent mission representation in Geneva on the WHO Executive Board; relative government stability; and opioid availability, even if limited.</li> <li>• The 2021-2022 AFP cohort represents palliative care associations in Australia, Argentina, Bangladesh, Burkina Faso, Canada, Colombia, Costa Rica, India, Kenya, the Russian Federation, the USA, and Zambia</li> <li>• AFPs are IAHPC members, serve in a volunteer capacity, donate their time whenever possible, and are registered on IAHPC delegations to the World Health Assembly, the Commission on Narcotic Drugs, the Open-Ended Working Group on Ageing, and regional meetings convened by WHO</li> </ul>	<ul style="list-style-type: none"> <li>• Prior to multilateral meetings where palliative care is relevant, IAHPC's Senior Advocacy and Partnerships Director sends a statement based on the meeting agenda, to the Secretariat to post on the meeting website and then to all AFPs</li> <li>• AFPs adapt IAHPC statement to their national context and forward to government representatives at Ministry of Health and Permanent Missions in the country where meeting is planned</li> <li>• AFPs request their own delegations include palliative care in official statements and adopted resolutions (member states tend to listen to one another rather than unelected NGOs); official statements must come from national palliative care organizations rather than from IAHPC</li> <li>• AFPs follow-up with government contacts post-meeting, building an effective relationship between national palliative care association and policymakers</li> <li>• Evidence-based advocacy entails familiarity with multilateral institutional landscape in which IAHPC functions and key international conventions and political declarations that call for integration of palliative care into <i>all</i> UN member states' health systems; AFPs are prepared with necessary resources and required to take the IAHPC Advocacy Course, currently in a multi-module format for members to learn the institutional landscape, international law governing palliative care medicine access, and techniques for effective partnership building with government agencies</li> </ul>

Table 2  
Included Countries by Level of Palliative Care Development per the *Global Atlas of Palliative Care*<sup>5</sup>

Category	Definition	Country
Category 3a	Isolated palliative care provision: palliative care activism is inconsistent or patchy in scope and not well supported; funding is commonly donor dependent; limited morphine availability; minimal palliative care services that are limited in relation to population size.	<ul style="list-style-type: none"> <li>• Bangladesh</li> <li>• Egypt</li> <li>• Sudan</li> </ul>
Category 3b	Generalized palliative care provision: palliative care activism in a number of locations with increased local support in relevant areas; several funding sources; morphine availability; many hospice-palliative care services from diverse providers; training and education initiatives led by hospice and palliative care organizations.	<ul style="list-style-type: none"> <li>• Colombia</li> <li>• Zambia</li> </ul>
Category 4a	Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision: critical mass of palliative care activism in several locations; variety of palliative care providers and service types; health professional and community awareness of palliative care; implementation and consistent evaluation of a palliative care strategy; morphine and other strong analgesic availability; palliative care impact on policy; significant training and education initiatives by several organizations; existence of a national palliative care association.	<ul style="list-style-type: none"> <li>• Uganda</li> </ul>

education deficits. Country-specific narratives should be considered with respect to their level of documented palliative care development (Table 2). Per the *Global Atlas of Palliative Care*,<sup>5</sup> the countries included here fall into Category 3a – isolated palliative care provision (Bangladesh, Egypt, Sudan); Category 3b – generalized palliative care provision (Colombia, Zambia); and Category 4a – palliative care at preliminary stage of integration (Uganda). These experts' advocacy efforts are situated in the context of an emerging global health narrative that stipulates palliative care provision as an ethical obligation of all health systems.<sup>17</sup>

### Bangladesh

The Constitution of Bangladesh stipulates that a fundamental principle of state policy is to “ensure to its citizens” . . . (a) the provision of the basic necessities of life, including food, clothing, shelter, education and medical care” (Article 15a).<sup>18</sup> Although the Operational Plan of Bangladesh supports the establishment of palliative care services,<sup>19</sup> the Ministry of Health and Family Welfare does not prioritize their development. Catastrophic out-of-pocket expenditures create financial suffering that deepens the medical poverty trap for poor people experiencing the double burden of communicable and noncommunicable diseases in Bangladesh.<sup>20</sup> Countless health vacancies create major human resources shortages in both urban and rural areas, leaving service delivery deserts for many Bangladeshis with serious health-related suffering.

Despite a palliative care physician training program in-country and increased access to morphine formularies, Bangladesh lacks the infrastructure to ensure effective delivery of controlled essential medicines to patients with palliative care needs (e.g., moderate to severe pain). Increased advocacy is needed for more educational resources at medical, nursing, social work,

spiritual care, and pharmacy schools - including the required integration of palliative care content into curricula across disciplines - to ensure all health professionals graduate with generalist palliative care skills. To date, there is no palliative care content in medical undergraduate curriculum. However, it has recently been included in a nursing undergraduate program as a pilot (personal communication, Directorate General of Nursing and Midwifery, Government of the People's Republic of Bangladesh, June 27, 2022).

As palliative care becomes prioritized throughout the health education landscape, the training of community health workers (CHWs) and other committed citizens as palliative care assistants to meet the holistic needs of patients with health-related suffering and at the end-of-life is a viable option to expand service access. Bangladesh has demonstrated a successful track record with leveraging the skills of CHWs in three prior national programs (e.g., diarrheal disease, expanded immunization, family planning).<sup>21</sup> Multi-organizational pilot initiatives - such as the Compassionate Narayanganj project that continues to establish palliative care services in the informal settlement of Narayanganj City Corporation near Dhaka - have proven feasible.<sup>22</sup> It is essential to collect both cross-sectional and longitudinal patient and family outcomes data related to palliative care assistant programs to strengthen evidence-based advocacy in Bangladesh and influence decision-makers to invest in other aspects of palliative care provision.

Although Bangladesh is more than 60% rural, palliative care services are concentrated in the capital city, Dhaka, with rare exceptions (e.g., Cox's Bazaar refugee camp).<sup>23</sup> Rural patients experiencing serious illness encounter opioid deserts plagued by stockouts, high transportation costs, under-trained health workers, pharmacies unable to fill prescriptions and government clinics running deficits. Ministry officials who fail

to respond to formal nongovernmental organization requests are seen as unaccountable to local people and civic organizations. Although authorities at the Department of Narcotics will engage in conversations about opioids, oral morphine continues to be available at a limited number of pharmacies in the capital city but rarely in rural areas.

### Colombia

All palliative care interventions and medications are covered by the General Social Security Health System in Colombia as part of the national palliative care law. Congress passed Law 1384 in 2010,<sup>24</sup> guaranteeing palliative care as a component of comprehensive cancer care for patients and their families, ensuring availability of opioids. Law 1733 enacted by Congress in 2014 expanded palliative care coverage for patients with other chronic, degenerative, or irreversible conditions left out by Law 1384.<sup>25</sup> The Statutory Health Law passed in 2015 complements Law 100,<sup>26</sup> establishing a link between the fundamental right to health for all citizens and essential public health interventions that aim to address the social determinants of health. The Statutory Health Law presents a model for comprehensive, integrated health care delivery (*Modelo de Atención Integral en Salud*),<sup>27</sup> from promotion of healthy behaviors to prevention, treatment, rehabilitation, and palliation.

Although most medications are included in the "basic plan of attention" or can be prescribed through the health system, this does not translate into adequate access.<sup>21</sup> The supply chain for medically-indicated opioids in Colombia is broken at several junctures. The Colombian Observatory of Palliative Care (OCCP)<sup>22</sup> tracks opioids manufactured and distributed by the Fondo Nacional de Estupefacientes (National Narcotics Fund)<sup>23</sup> but not those imported by the private sector, rendering official opioid consumption reports incomplete. Although authorities report that national opioid availability is sufficient given population need, inconsistent government communications often leave patients with palliative care needs unable to access prescribed analgesics if they live outside major cities. High transportation costs and geographical barriers, like those in Bangladesh, often create insuperable burdens for rural patients and caregivers forced to fill prescriptions in urban areas.

National authorities who submit opioid estimates to the International Narcotics Control Board need more training regarding population level quantification for controlled essential medicines. Education for officials at all levels of health care governance and service delivery is essential to ensure safe and effective opioid access for patients with palliative care needs. Effective prescription monitoring would better track opioid use for

both palliative and non-palliative purposes and generate accurate reports of both filled and unfilled prescriptions. The national tracking system's failure to account for pharmacy stockouts of prescribed opioids generates erroneous official estimates of population need. The narratives that either patient needs are being met or that pain relief was not required because no opioid was dispensed are invalid. Population level registries that rigorously quantify the need for opioids to treat pain and symptom relief in serious illness and at end-of-life should be developed to provide a rationale for accurate advocacy. The OCCP launched the first National Palliative Care Strategic Plan (2022–2026) on April 7, 2022, which will support further development of palliative care in the country by providing guidance on the implementation of palliative care services, access to medicines, and education.<sup>28</sup>

### Egypt

Egyptian advocates identify lack of government policies recognizing palliative care as an essential service as a significant barrier. Palliative care in Egypt is in the early developmental stages. The few available services operate with minimal resources that are usually allocated for specific populations (e.g., patients with cancer at The Kasr Al-Ainy Center in Cairo). The Ministry of Advanced Education for Physicians only awards the Diploma in Palliative and Supportive Care to oncologists.

Many palliative care advocates identify knowledge gaps among the public, practitioners, and decision-makers as a significant barrier. Lack of opioid availability is another. Currently, only 30 mg slow-release morphine tablets are registered with the public authorities. The lack of cost-effective analgesia (e.g., immediate-release oral morphine) is catastrophic for patients with cancer and other life-limiting illnesses and injuries. The dose-limiting law that arbitrarily limits opioid dosage per prescription contributes to inadequate pain control. Per the Egyptian Narcotics Control Law,<sup>29</sup> the maximum dose limit for morphine tablets or its salts is 420 mg and for ampules of morphine or its salts is 60 mg – neither of which can be exceeded in a single prescription. Slow-release oral morphine is usually available in tertiary hospitals and large cities, but unavailable in small health centers or outpatient pharmacies. Only hospitals providing oncology services and government pharmacies dispense prescribed opioids.

Educational barriers include lack of palliative care training for physicians, pharmacists, and nurses and the lack of recognition of palliative care as a specialty. Although the need for generalist palliative care education remains enormous, cancer care professionals are now better informed than before. This shift is the result of palliative care physicians' individual contributions to

oncology conferences and their lobbying of the Egyptian Cancer Society. Recently, this June 4, 2022, for the first time in Egypt, the palliative medicine unit of Kasr Al-Ainy Faculty of Medicine – in collaboration with the Oncology, Anesthesia, and Pharmacology Departments – completed delivery of the first undergraduate palliative medicine course for fourth year medical students of Kasr Al-Ainy School of Medicine at Cairo University. To our knowledge, there is no national plan for palliative care policy and development. The palliative care budget is limited to oncology services and the only policy change in a decade has been inclusion of palliative care in the National Plan for Cancer Control. The National Plan reimburses palliative care only for oncology patients, leaving patients who face serious non-cancer conditions without regulated or guaranteed financial protections to access palliative care services and to subsequently experience needless health-related suffering.

### **Sudan**

The situation in Sudan is similarly grim. Only three hospitals dispense oral morphine and unpredictable stockouts affect hundreds of patients with serious health-related suffering. Palliative care has no representation at the Ministry of Health, the specialty is not recognized, and the government appears unwilling to integrate palliative care into the health system. Oral opioids are available only for patients with cancer, who similarly have no access if they live far from the three prescribing hospitals in the urbanized center.

In recent months prior to this writing, Sudan emerged from a three-week national morphine and chemotherapy stockout with no official guidance on when availability would return. It was a difficult time for patients, their caregivers, and for the frontline clinicians who reported patients screaming with unrelieved pain. The few health professionals with palliative care degrees in Sudan often serve as volunteers and were credentialed through international organizations. Political changes and bureaucratic red tape have hindered development of a national palliative care association. It can take months for advocates to secure appointments with ministry officials, only to have them replaced within one year, leading to extended gaps in advocacy initiatives. Since October 2021, the country has been in political upheaval. The security situation often left both patients and health workers unable to access hospitals and has prevented patients from traveling to the capital city from rural areas for medicines and services. Lack of palliative care services drive affluent patients to search for potentially futile treatment overseas; the poor go into debt to do the same. The majority of the patients with serious illness (whatever

their socioeconomic status) who are left behind will die with preventable, yet unalleviated, pain and suffering.

### **Uganda**

Uganda has made tremendous progress in increasing access to opioids for palliative care and pain management in recent decades. Local reconstitution and economical options for packing morphine have increased affordability and the government subsidizes morphine as an essential medicine.<sup>30</sup> To increase access and mitigate the rural-urban imbalance and high patient/physician ratio, government regulations authorize certified nurses to prescribe and dispense morphine to patients at home. The nurse prescription programme has demonstrated efficacy, informing duplication in other African contexts.<sup>31</sup> Training courses for nurses and clinical officers in prescription and palliative care are available at the Institute for Hospice and Palliative Care in Africa.<sup>32</sup>

The broader health system remains unprepared for this new cadre of human resources, creating employment barriers for trained palliative care workers and highlighting the urgency of continued advocacy. Access is facilitated as palliative care is integrated into the public health system country-wide.<sup>33</sup> The Palliative Care Association of Uganda is advocating for the government to approve a palliative care policy to give structured guidance on priorities, including implementation, monitoring, and evaluation. Despite the progress, only about 11% of the patients with palliative care needs have access and structural bottlenecks to accessing morphine for pain relief persist. Such barriers include opioid phobia and poor supply chain management practices leading to intermittent stockouts. The need for alternative formulations for patients unable to use oral formulations remains a priority.

### **Zambia**

Zambia's Ministry of Health launched the country's first National Palliative Care Strategic Plan (2021–2026) on May 26, 2021, which will support further development and integration of palliative care in the country.<sup>34</sup> Despite this important advancement, there is a dearth of palliative care specialty education, teachers, curricula, and centers of excellence, as well as inconsistent access to short-term training programs in Zambia.<sup>35</sup> There are only three individuals with masters-level palliative care education at the time of this writing – one physician, one nurse, and one social worker. Training is often outsourced to Kenya, South Africa, Uganda, and the United Kingdom, placing financial constraints on an already overwhelmed workforce and stressing families with other more pressing

socioeconomic needs.<sup>36</sup> The University of Zambia has developed a Master of Science in Palliative Care curriculum under the School of Nursing Sciences, which is open to all health professionals. A cascade of human resources – including fellowship and/or internship opportunities – will be needed to implement what is planned.

There has been no national palliative care association in Zambia for almost a decade now due to insufficient donor funding and failure to raise local resources to support the operations of a formal association. Lack of health worker education and poor financial investment in palliative care capacity building has negatively affected service provision and development. Essential medicines for palliative care have also not been available to effectively alleviate suffering. To overcome these challenges, the palliative care strategic plan proposes to establish the Zambia Hospice and Palliative Care Alliance, which will convene practitioners and organizations across sectors. As this precarious alliance builds institutional capacity, advocates anticipate further resource generation and a rise in international visibility to advance policy and improve the overall advocacy voice within Zambia. The Alliance will also act as the advocacy vehicle for palliative care and quality services provision.

## Discussion

Many of the challenges to palliative care provision described in the IAHPAC AFP country exemplars are shared experiences across LMICs: lack of palliative care training and education for all health professionals, zero to little access to opioids and other controlled essential medicines for pain and symptom management, and multiple barriers to engaging decision-makers or gaining traction to prioritize palliative care policies. A major takeaway of the AFP program is that advocacy can foster mutually beneficial transnational partnerships between governmental, non-governmental, academic, faith-based, and grassroots organizations that emphasize engagement of practitioners and patients/families with palliative care needs throughout all stages of planning, implementation, and evaluation.<sup>37</sup> The inclusion of the patient voice is essential to effective advocacy efforts, although their involvement is sometimes curtailed by the unpredictability of progressive disease trajectories. Using video or written transcription of patient testimony with permission to present to policymakers may be one solution. In addition, caregivers, family members, and other social supports bear witness to suffering and provide key statements about the benefits of palliative care in service profiles and in interviews with the media and policy stakeholders.

The Lancet Commission on Global Access to Palliative Care and Pain Relief called for “international collective action... to ensure that all people, including poor people, have access to palliative care and pain relief for life-threatening and life-limiting health conditions and end-of-life care.”<sup>6</sup> Public officials and practitioners in high-income countries with developed palliative care services have an ethical obligation to share knowledge and resources with an attitude of cultural humility and a commitment to global equity and restorative justice. Such actions must be taken by fostering mutually beneficial, respectful, and long-term Global South-South, South-North, and North-South partnerships driven by local needs and goals.<sup>9,38,39</sup> However, there is no one-size-fits-all approach to transnational advocacy and strong, sustainable partnerships remain vital to realizing the equitable representation and leadership of palliative care advocates from LMICs. Transnational advocacy teams may build on lessons learned at the country level to support partners and colleagues “on the ground” who are beginning advocacy work and assist in developing constructive relationships with government decision-makers. Local advocates may benefit from the prior successes and pitfalls of their global colleagues or can leverage the high credibility and reputation of “international experts” in the field. However, such collaborations must be carefully designed, planned, and implemented to prevent imbalanced partnerships, colonializing attitudes and consequences, and any assumptions of homogeneity across cultures and borders.<sup>40,41</sup>

Whether partnerships are characterized as North-South or South-South, transnational advocacy teams can upend traditional interprofessional hierarchies that disempower some health workers and prevent them from using their experience to effectively advocate for their patients. Promoting equality of voice within and among palliative care teams will allow each professional to work to the full extent of their training, licensure, and scope of practice toward improved access.<sup>42,43</sup> In many LMICs, where physicians are scarce, the nurse may be the sole member of the “team”, often required to meet myriad biopsychosocial and spiritual patient/family needs while fulfilling logistical and administrative responsibilities.<sup>44</sup> Regardless of the human resources available, an all hands-on-deck effort is required to address health-related suffering in countries where palliative care development remains precarious.

Several of the AFPs in the IAHPAC program highlight pervasive and dire gaps in palliative care education for all health professionals throughout LMICs. Education is the thread that binds community interests with professional expertise. International education initiatives can build on partnerships among all countries to adopt contextually appropriate palliative

care models, reduce duplication, and develop culturally and socially responsive service delivery. Experts from regions where community-level palliative care infrastructure has demonstrated sustainability can work with their counterparts to develop effective service and advocacy plans in more fragile settings and build coalitions around local interests. Research that informs advocacy must focus on balancing improved access to palliative care and generic essential medicine with strengthened and informed regulatory authorities to prevent harmful, non-medical opioid use.<sup>45</sup>

The IAHPAC AFPs concur that advocacy is essential since so few policymakers grasp how palliative care can benefit their populations and strengthen their health systems. Advocacy illuminates how palliative care is essential to pandemic preparedness and response, supports healthy ageing, and builds political trust.<sup>2,8,46</sup> It is key to the realization of equitable and socially just care for people with serious illness and those at the end of life. Appeals to finance ministers can highlight how integration of palliative care into health systems can mitigate against the medical health poverty trap that produces destitution and homelessness due to catastrophic household expenditures and loss of employment for both patients and caregivers.<sup>6</sup> To support advocacy efforts, palliative care evaluation and indicator data should assess the extent to which LMIC practitioners lead and participate in global and regional advocacy. This goal entails investment in capacity building for an international community of practice and an inclusive, globally representative advocacy collective that will capture the attention of policymakers at all levels of health system governance. See [Table 3](#) for additional specific recommendations.

Although the frontline narratives provided in this manuscript vary by culture and context, it is important to note that space limitations prevented us from consulting with advocates in countries from Category 1 (no known palliative care activity); Category 2 (capacity-building palliative care activity); or Category 4b (palliative care at advanced stage of integration) per the *Global Atlas of Palliative Care*.<sup>5</sup> The absence of voices from these categories limits the generalizability of our recommendations, particularly for countries that have no or extremely limited palliative care infrastructure. Initiatives that integrate and prioritize the expertise of advocates from these countries will be key to achieving global equity in advocacy for palliative care.

## Conclusion

Evidence-based palliative care advocacy is an art<sup>1,2</sup> – and sometimes a difficult one to practice unless advocates' interests and values align seamlessly with those of decision-makers. However, in the face of indifference, ignorance, or outright disagreement, effective

Table 3

### Recommendations for Local Palliative Care Advocacy

- **Tell Compelling Stories:** Collect testimonies of health professionals, patients, and caregivers that describe the benefits of timely palliative care provision in all settings, such as palliative care service access that may help prevent or mitigate catastrophic health spending by supporting patients and caregivers to return to work.
- **Share the Data:** Educate interprofessional colleagues and collaborating teams about the value of publicly provided palliative care in addressing problems for patients, families, health professionals, and health systems throughout the serious illness trajectory based on high-quality evidence.
- **Grow Networks:** Cultivate local press contacts and invite them to accompany teams on home visits with appropriate permissions to disseminate stories about the positive impacts of palliative care through newspaper, radio, social media platforms, and other outlets, thus raising the public's awareness of and knowledge about palliative care.
- **Know the Players:** Compile dossiers – including social media profiles – on decision-makers at all levels of policymaking, from local and district levels to national and sub-national, so that information and testimonies collected can be made available directly to them through social media platforms (e.g., Twitter, Instagram, Facebook, LinkedIn).
- **Create Coalitions:** Develop partnerships with other grassroots and nongovernmental organizations and faith communities, including those serving older persons, persons with disabilities, refugees and migrants, persons experiencing homelessness, and other marginalized or minoritized communities.
- **Broaden the Approach:** Build alliances with other professional organizations, including those that represent other medical specialties (e.g., surgery) and health professionals (e.g., nurses, physicians, social workers, spiritual care providers, pharmacists) to raise awareness of the value of palliative care for their work, thereby creating transversal advocacy strength to approach policymakers who might be more inclined to listen to one group over another (e.g., surgeons rather than palliative care nurses).
- **Inform the Next Generation:** Raise awareness of palliative care among all students in the health professions by inviting them to spend time with palliative care teams in all settings with aims of creating demand for palliative care courses in undergraduate and graduate level curricula and increasing the pipeline of palliative specialists in the future.
- **Strengthen Communication Skills:** Seek leadership coaching to strengthen professional presentations, speaking, and messaging to prepare for both one-to-one and group meetings with the media, policymakers, professional and partner organizations, and in preparation to address the public.

advocacy requires restraint, grace, and a strong commitment to envisioned goals. The vision of the IAHPAC and the AFP program is a world free from health-related suffering.<sup>47</sup> This vision transcends preferences and attitudes of an individual or political nature and calls on palliative care advocates to set aside personal opinions in order to develop trusting relationships with decision-makers. A critical aim is for advocates to establish an identity as expert partners who can provide guidance for policy and program development.

Policymakers at all levels of governance can no longer afford to ignore, disregard, or silence the voices of palliative care advocates, particularly those from the Global South whose countries experience the highest burden of serious health-related suffering coupled with the most arid deserts of palliative care access.<sup>5,6</sup>

Evidence-based advocacy can drive measurable and sustained change while enhancing both the quantity and quality of palliative care services for patients, families, and communities in need. Palliative care advocacy is no longer an option but an imperative.

Can you hear us now?

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