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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.

Introduction

Evidence-based advocacy underpins the sustainable delivery of quality, publicly guaranteed, and universally available palliative care. 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 (UHC), only 12% of global palliative care need is currently being met. 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. Equitable palliative care access has become increasingly elusive in the face of COVID-19 and other humanitarian crises. 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.

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. 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.

The IAHPC elevates advocacy voices from LMICs through its Advocacy Focal Point (AFP) program (Table 1). 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. 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. 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 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, 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.

Section snippets

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). Although the Operational Plan of Bangladesh supports the establishment of palliative care services, the Ministry of Health and Family Welfare does not prioritize their development. Catastrophic out-of-pocket expenditures create financial...

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, guaranteeing palliative care as a component of comprehensive cancer care for patients and their family, 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...

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.

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 recognised, and the government appears unwilling to integrate palliative care into the health system. Oral opioids are available only for cancer patients, who have no access if they live far from the three prescribing hospitals in...

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 subsidises morphine as an essential medicine. To increase access and mitigate the rural-urban imbalance and high patient/physician ratio, government regulations authorise certified nurses to prescribe and dispense morphine to patients at home. The nurse...

Zambia

Zambia's Ministry of Health launched the country's first National Palliative Care Strategic Plan (2021 to 2026) on 26 May 2021, which will support further development and integration of palliative care in the country. There is a dearth of palliative care specialty education, teachers, curricula, centers of excellence, and inconsistent access to short-term training programs in Zambia. There are only three individuals with masters-level palliative care education at the time of writing - one ...

Discussion

Many of the challenges to palliative care provision described in the IAHPC 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...

Conclusion

Evidence-based palliative care advocacy is an art - 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 advocacy requires restraint, grace, and a strong commitment to envisioned goals. The vision of the IAHPC and the AFP program is a world free from health-related suffering. This vision transcends preferences and attitudes of an...

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Disclosure/Conflict of Interest Statement

Authors EN, EA, NG, and FMK serve on the International Association for Hospice & Palliative Care (IAHPC) Board of Directors. WER, MJC, AC, MAC, RD, FK, & LR all currently or have previously served as Advocacy Focal Points as part of the IAHPC Advocacy Program. KIP serves as the IAHPC Senior Advocacy & Partnerships Director. These authors have no other conflicts of interest to disclose...

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