The Worldwide Hospice Palliative Care Alliance

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Abstract

The Worldwide Hospice Palliative Care Alliance (WHPCA) is an international non-governmental organization registered as a charity in England and Wales that was established in 2008 following a series of international gatherings that highlighted the important need for palliative care to be included in global policy and health planning. The vision of the WHPCA is a world with universal access to hospice and palliative care. Its mission is to foster, promote and influence the delivery of affordable, quality palliative care. This article describes the evolution of the WHPCA and what it has been able to accomplish in the eight years since its formation. These accomplishments include effective advocacy with United Nations bodies, acceptance as a non-governmental organization in official relations with the World Health Organization and the UN Economic and Social Council, publication of many position papers on critical aspects of palliative care, publication of the Global Atlas of Palliative Care at the End of Life, development of toolkits for palliative care development, publication of the international edition of ehospice, and management of World Hospice and Palliative Care Day each year. Some of the many challenges to the growth and development of palliative care globally are described along with future plans.

Key Words

Palliative, hospice, Global Atlas, WHA resolution, ehospice

Background

Lack of access to palliative care is a major problem worldwide. Every year, 40 million people need palliative care, 20 million at the end of life, yet only about three million are able to access the care they need.1 As a consequence, 18 million people die with avoidable pain and suffering. This is due to multiple reasons including a lack of access to pain medications and other essential medicines, lack of health professionals trained in palliative care, few national level policies, weak government commitment, and a lack of funding for training and implementation.

Advocacy for palliative care on the international stage has been very limited in the 50 years since the founding of St. Christopher’s Hospice in the United Kingdom. There are now over 95 countries with national hospice or palliative care provider associations and four regional associations that represent and advocate for palliative care in their respective geographical areas. However, when global health policy is being set at the United Nations (UN) and its numerous bodies very few voices speak up for the inclusion of palliative care in the discussion and resulting policy language.

The Worldwide Hospice Palliative Care Alliance (WHPCA) emerged from a series of global meetings at regional palliative care conferences starting in 2005 in Seoul, Korea. Working groups were formed to address advocacy, children’s palliative care, quality and standards, education, and national association development. Of these meetings, both the International Children’s Palliative Care Network and the WHPCA emerged. The WHPCA (originally the Worldwide Palliative Care Alliance) became a company limited by guarantee and a charity registered in England and Wales in November, 2008. The International Children’s Palliative Care Network initially
operated under the WHPCA’s charitable registration, but became a separate charity in 2011.

The vision of the WHPCA is a world with universal access to hospice and palliative care. Our mission is to foster, promote and influence the delivery of affordable, quality palliative care.

Accomplishments
Advocacy. WHPCA has achieved significant successes in integrating palliative care into international policies and health development agendas. At the UN High Level Summit on the prevention and control of non-communicable disease (NCD) in 2011, WHPCA and other advocates successfully pushed for the inclusion of palliative care into the political declaration on the prevention of NCDs. WHPCA successfully contributed to the inclusion of a palliative care indicator into the monitoring and evaluation framework of the Global NCD Action Plan. WHPCA is helping to lead ongoing advocacy work at the World Health Assembly (WHA) with Human Rights Watch and other palliative care partners. This work led to the adoption of the palliative care resolution by the WHA in 2014; “Strengthening of palliative care as a component of comprehensive care throughout the life course.”

Palliative care has now been recognized as part of the continuum of universal health coverage under the newly adopted UN Sustainable Development Goals (prevention—promotion—treatment—rehabilitation—palliation). The WHA resolution on palliative care calls on all countries to promote hospice and palliative care services. Implementing this resolution requires a worldwide effort to assist governments and non-governmental organizations (NGOs) in overcoming the barriers to deliver palliative care. At the national level, hospice and palliative care organizations are becoming more engaged, organized, and effective.

International, regional, and national palliative care organizations are working collaboratively to improve palliative care strategic advocacy with support from the Open Society Foundations’ International Palliative Care Initiative.

WHPCA supported our international partners, the European Association of Palliative Care, International Association for Hospice and Palliative Care, and Human Rights Watch to develop the Prague Charter calling on governments to integrate palliative care into their health systems and health budgets. We have performed important work leading to the inclusion of palliative care in the new World Health Organization (WHO) Stop TB Strategy launched in 2012, raising awareness of palliative care needs for patients with multidrug-resistant tuberculosis (see Palliative Care for Tuberculosis in this issue).

As the global population ages, palliative care must be included in policies on healthy aging. WHPCA and partners have participated in high-level policy meetings and worked to include palliative care in WHO policies including the recent WHO World Report on Aging and Health. Palliative care is also a critical need for those with Alzheimer disease and other dementias. WHPCA is working with Alzheimer Disease International and the Global Alzheimer’s Disease and Dementia Action Alliance to increase awareness of palliative care for patients with dementia.

Global Atlas of Palliative Care at the End of Life
The WHPCA is an NGO in official relations with the WHO and is in consultative status with the UN’s Economic and Social Council. NGOs in official relations must develop a joint working plan with WHO that benefits both organizations. For the WHPCA, the most recent product of these relations was the development of the Global Atlas of Palliative Care at the End-of-Life in 2014. The Atlas was envisioned as an advocacy tool to help paint a picture of the status of palliative care worldwide that could be monitored periodically.

The Atlas addresses a number of key questions:

1. What is palliative care?
2. Why is palliative care a human rights issue?
3. What are the main diseases requiring palliative care?
4. What is the need for palliative care?
5. What are the barriers to palliative care?
6. Where is palliative care currently available?
7. What are the models of palliative care worldwide?
8. What resources are devoted to palliative care?
9. What is the way forward?

The WHO’s definition of palliative care for adults and children is included, and the Atlas adds further explanation to clarify that 1) palliative care is needed for long-term as well as life-threatening and/or life-limiting conditions, 2) there is no time or prognostic limit on the delivery of palliative care, 3) palliative care is needed at all levels and settings of care, and 4) palliative care should be integrated alongside curative care.

The case has been made that palliative care is a human right and is part of the obligation of governments to provide access to health facilities, goods and services, and essential medicines, through a public health strategy. Denying access to pain relief can amount to inhuman and degrading treatment according to the UN Special Rapporteur on Torture. “Governments must guarantee essential medicines—which include, among others, opioid analgesics—as part of their minimum core obligations under the right to health, and take measures to protect people under their jurisdiction from inhuman and degrading treatment (pg 13).”

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For the first time, WHO, in the *Atlas*, has acknowledged the full range of diagnostic groups that need palliative care including the largest need being for cardiovascular disease followed by cancer, lung disease, HIV/AIDS, diabetes, kidney failure, cirrhosis of the liver, dementias, drug-resistant TB, Parkinson disease, rheumatoid arthritis, and multiple sclerosis.1

The minimum need for palliative care in 2011 at the end of life globally was 20 million persons of 54.6 million total deaths. Excluded were all non-HIV and TB infectious disease deaths, injuries, and sudden deaths. When accounting for the fact that palliative care is needed before the end of life, the number doubles to 40 million each year.1

The *Atlas* estimates that there were approximately 13,000 specialist palliative care provider organizations in 2011 serving approximately three million patients globally or <10% of the 40 million need. Provision of palliative care is very uneven globally with almost 80% of the need in low- and middle-income countries, yet 80% of the services currently available in high-income countries. Most palliative care is delivered in North America, Western Europe, and Australia.1

When using the WHO’s public health model for palliative care, barriers to palliative care include the lack of policy, medicines, education, and service delivery. Lack of inclusion of palliative care in policies does not allow for palliative care to be included in national health planning, funding, or recognition of the specialty. Policies such as needs assessment, national standards, national strategy for implementation, and laws defining palliative care and access to essential medicines are needed to establish the field.

Lack of access to essential palliative medicines is a global crisis. The International Narcotics Control Board estimates that 75% of countries have no or very inadequate access to strong analgesics.8 WHPCA estimates that over 18 million people die in pain each year. Without access to oral opioids, the standard of care for moderate to severe pain in palliative care, palliative care cannot be effectively delivered.

Every health professional who works with severely ill patients should at least have a basic education in palliative care. Most patients needing palliative care should be receiving it as part of primary health care. Yet, palliative care curricula are still not taught in medical schools, nursing schools, social work and psychology graduate training, or in religious education.

Implementation of palliative care has been mainly driven by charities and private sector providers. To reach the enormous unmet need for palliative care, we need governments to realize that palliative care is an essential, not optional, part of every health care system. Palliative care should be interwoven into primary health care, and countries should designate specific funding streams, especially to drive the provision of home-based care, which is cost-effective in providing better quality more appropriate care at less cost because of prevention of unnecessary hospitalizations.

Many model programs are profiled in the *Atlas*, particularly in low- and middle-income settings where the need is greatest. Financial, philanthropic, bilateral, research, and educational resources for palliative care are given along with a set of policy recommendations that include:

- The need to improve the evidence base for palliative care, particularly for populations such as children, older people, and marginalized groups.
- Review and development of guidance on how to develop palliative care across levels of care, community systems, and disease groups for policy makers.
- Major scale up of country level palliative care services integrated into healthcare systems to ensure access.
- Specific recommendations for technical agencies, national governments, and bi-lateral donors, funders, and foundations are given.

The *Atlas* has been a particularly useful tool for the global palliative care community. Spending the time working with the WHO to achieve clearance for the *Atlas* helped immensely as having the WHO logo on the *Atlas* gives important credibility to the publication and content. The *Atlas* has been downloaded over 32,000 times and is available free at: http://thewhpc.org/resources/global-atlas-on-end-of-life-care.

**Palliative Care Toolkits**

The WHPCA has developed a number of very useful toolkits and policy statements to help guide global palliative care development. The *Palliative Care Toolkit*, developed with Palliative Care Works, is a comprehensive guide to developing palliative care services in resource poor settings. The *Toolkit* includes guidance on what is palliative care, how you can do palliative care in your own setting, how to build a team, dealing with communication and difficult issues, pain and symptom control for a wide range of distressing symptoms, helping children and families, advocating in the community, and a whole host of additional resources including tools for assessment, documentation of services, a simple medical records system, volunteer kits, and much more. This *Toolkit* is available for free download in Bengali, English, French, Portuguese, Russian, Spanish, Swahili, and Vietnamese translations at: http://thewhpc.org/resources/category/palliative-care-toolkits-and-training-manual.

**ehospice International**

The WHPCA manages the international edition of ehospice (www.ehospice.com/international), a part...
of the ehospice charity that has 13 editions worldwide. The purpose of ehospice international is to share information in a news format on hospice and palliative care developments worldwide. This includes important milestones, advocacy, research that matters, news summaries, and best practices in palliative care from around the world. All ehospice has over 5000 articles archived. The Web site has had over three million page views by over a million visitors since inception in 2013.

World Hospice and Palliative Care Day

The WHPCA is home to World Hospice and Palliative Care Day (www.worldday.org). World Hospice and Palliative Care Day is celebrated worldwide every second Saturday in October. Each year a different theme is chosen. The 2017 year’s theme is “Universal Health Coverage: Don’t leave the suffering behind.” In 2016, the theme was “Living and dying in pain: It doesn’t have to happen.” Other past themes have focused on dispelling myths about palliative care, identifying who provides palliative care, and hidden lives hidden patients that highlighted neglected populations including children, young adults, the mentally ill, homeless, HIV and TB patients, Lesbian, Gay, Bisexual, Transgender, Intersex (LGBTI) people, sexual minorities and sex workers, those affected by war and disaster, and those with dementias.

Myths about palliative care that were addressed included “having hospice and palliative care means you will die soon, hospice and palliative care are just for people with cancer, palliative care manages pain only with addictive narcotics, and you can only get palliative care in the hospital.” The “Who Cares” campaign highlighted that there are an estimated 10.6 million working in hospice and palliative care including 400,000 professional staff, 1.2 million volunteers, and over nine million family caregivers. This year’s campaign highlights the reality that 75% of the world’s population (5.5 billion) lacks adequate access to pain relieving medications and about 18 million people die each year in untreated pain, while we have the knowledge and medicines to relieve almost all moderate-to-severe pain.

Current Challenges

Advocacy for palliative care worldwide is a very challenging proposition. In addition to realizing the potential of the mandate from the WHA resolution on palliative care is the need to continue to keep a focus on palliative care in the new sustainable development goals, including universal health coverage and the new focus on NCD. To realize the promise of the WHA resolution on palliative care will require training millions of health care workers globally, changing ingrained attitudes about use of controlled medicines, valuing the importance of conversations about the end-of-life, convincing government leaders that political will and resources are needed to change policies, and establishing tens of thousands of teams organized to deliver palliative care in some of the world’s most challenging environments. WHPCA and the global palliative care community are gearing up to face this challenge.

Future Plans

WHPCA has chosen six countries to focus efforts on building palliative care, one in each WHO region (Bangladesh, Ethiopia, Jordan, Panama, Philippines, and Ukraine). We are working with our members on the ground in these countries to overcome the above barriers and to establish indigenous culturally appropriate palliative care services that are integrated into the existing health care services and systems. We need models that can be replicated in each region to begin to address the enormous unmet need for palliative care and relief of suffering globally. Failure is not an option. Dame Cicely Saunders, founder of the modern hospice movement has said “Go around and see what is being done and then see how your own circumstances can produce another version; there is need for diversity in this field.”

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References


