



The International Association for Hospice and Palliative Care: Advancing Hospice and Palliative Care Worldwide

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Abstract

The International Association for Hospice and Palliative Care (IAHPC) is a membership-based organization dedicated to the development and improvement of hospice and palliative care worldwide. The mission of IAHPC is to improve the quality of life of adults and children with life-threatening conditions and their families. The vision of IAHPC is universal access to high-quality palliative care, integrated into all levels of health care systems in a continuum of care with disease prevention, early diagnosis, and treatment, to assure that any patient's or family caregiver's suffering is relieved to the greatest extent possible. IAHPC focuses on the advancement of four areas of palliative care: education, access to medicines, health policies, and service implementation. IAHPC works on three levels: at the grass roots, developing resources, and educational strategies that enable health workers to provide cost-effective palliative care; at the national level, working with government representatives to improve national policies to ensure adequate care and access to medicines; and at the international level, advocating with the UN organizations to ensure that access to palliative care and to essential medicines for palliative care and pain treatment is stipulated and incorporated as an obligation of member states. J Pain Symptom Manage 2018;55:S96–S103. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Access to medicines, advocacy, education, global, palliative care, policy

Introduction

The International Association for Hospice and Palliative Care (IAHPC) is a membership-based organization dedicated to the development and improvement of hospice and palliative care worldwide.

The mission of IAHPC is to improve the quality of life of adults and children with life-threatening conditions and their families by

- facilitating and supporting palliative care training at all levels of the health care system;
- providing guidance and technical assistance on palliative care policy, advocacy, clinical guidelines, and service implementation, including assistance to governments and nongovernmental organizations;
- fostering palliative care research and evidence-based practice; and

- facilitating collaboration between hospice and palliative care providers, organizations, institutions, and individuals.

The vision of IAHPC is universal access to high-quality palliative care integrated throughout health care systems providing a continuum of care with disease prevention, early diagnosis, and treatment, to ensure that any patient's or family caregiver's suffering is relieved.

IAHPC focuses on supporting and advancing the World Health Organization's (WHO) public health palliative care strategy: education, access to opioids (especially oral morphine), health policies, and service implementation. IAHPC is an NGO in formal relations with the WHO.

IAHPC works on three levels: at the grass roots, developing resources, and educational strategies that

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enable palliative care workers to provide cost-effective palliative care; at the national level, working with government representatives to improve national health policies to ensure adequate care and access to medicines; and at the international level, advocating with UN organizations to ensure that access to palliative care and to essential medicines for palliative care and pain treatment is stipulated and incorporated in relevant United Nations (UN) organizations documents, hopefully also resulting in recommendations if not obligations to UN's Member States. The work of IAHPIC is grounded in evidence-based public health policies and practices and in human rights-based approaches to treatment and care.

History

IAHPIC began as the International Hospice Institute, founded by Josefina Magno, MD, in 1980. International Hospice Institute members developed the IAHPIC, with a perspective designed not to promote a unique palliative care model but to encourage and enable each country according to its resources and conditions to develop its own model of palliative care. The IAHPIC was first incorporated in New Jersey in 1997 and closed in 1999 when the board elected Professor Eduardo Bruera as the Chair of the Board of Directors and Liliana De Lima as the Executive Director, who were both living in Texas. The new IAHPIC office was incorporated in Texas in 2000 and recognized as a 501c3 organization by the US Government that same year.

Since IAHPIC's inception, the legal, regulatory, political, cultural, and economic barriers on access to palliative care, lack of education, and having access to controlled medicines for palliative care have been addressed by the organization through different strategies. This document describes the main programs and some of the projects implemented by IAHPIC to advance its mission.

Programs

IAHPIC has several ongoing programs that support governments, institutions, NGOs, and individuals to advance hospice and palliative care around the world. The following section describes IAHPIC Programs and provides brief examples of some of its grantees.

Program Support

This program is designed to provide financial and technical support to organizations or institutions in developing countries that are implementing strategies to improve and advance hospice and palliative care

and access to medicines. Some examples of Program Support grants include the following:

- The Hospice and Palliative Care Inpatient Unit in Spata, Greece to build and provide palliative care for patients in Spata.
- Moonshine Agency from Australia, to support a biographical documentary of Dr. M. R. Rajogopal in India. Moonshine Agency is a multi-award winning independent production company specializing in creating film, television, and interactive projects that move audiences to action. The film tells the story of how Dr. Rajogopal was drawn unexpectedly into palliative care, how it shaped his professional life, and how he has advanced palliative care in India through broad social action.
- The Palliative Care Network to support both the free annual online international palliative care congress and its best poster prize. Palliative Care Network's mission is to provide a free platform aimed at empowering palliative care professionals to teach, interact, and exchange ideas with fellow colleagues globally to promote collaboration and an exchange of knowledge.
- The Mehac Foundation in India to deliver community-based services to improve the quality of life of individuals and families suffering from mental illness. Since 2008, the foundation has been able to provide care to nearly 2000 patients and their families. To improve access for up to 100 more persons with their families, the IAHPIC is funding the salary of a physician and a social worker for one year.

Meetings, Seminars, and Workshops

The program provides financial and technical support to international and regional palliative care organizations, institutions and programs to help develop and implement palliative care educational seminars, congresses and workshops on access to essential medicines, clinical issues, and curricula development. One of the projects in this program includes the workshops on availability and rational use of opioids.

- Availability and rational use of Opioids Workshops. IAHPIC adapted the University of Wisconsin's Pain and Policy Studies Group's strategy to bring together palliative care experts and government officials to review national legislation governing opioid availability. The objective of the workshops is to improve safe and effective access to pain medicines for legitimate medical use. The strategy is based on the concept of balance that governments should take the necessary steps to ensure the availability and accessibility of

controlled medications for legitimate medical use while also preventing diversion and nonmedical use. An initial pilot workshop was implemented in Colombia in 2007, and later, seven workshops were implemented between February 2010 and March 2015 in 12 additional countries. Participation in the workshops is by invitation only, and there is no application process. The workshops have been done in collaboration with the corresponding Ministry of Health in each country as well as the representative of the Pan American Health Organization, the regional WHO office for the Americas. The workshops result in an action plan to eliminate overly restrictive barriers in the laws and regulations governing controlled medicines. Reports from the participants indicate that the workshops and the resulting action plan have been effective in the elimination of barriers and improving availability in most of the countries.^{1,2} Some of these improvements include

- increased availability of medicines and different formulations (Chile, Colombia, Costa Rica, and Peru),
- improvements in the registration process for pharmaceutical products in Costa Rica,
- opioid medications were included in the national health plan (Colombia) and programs to subsidize opioid medications for poor patients were implemented (Peru),
- extension of prescription privileges to GPs and other medical specialties in Panama,
- extension of the prescription validity (10–30 days in Colombia and Bolivia),
- elimination of maximum dosage per prescription (Bolivia, Colombia) and extended number of days for the provision of the special prescription pad (from 1 day to 5 days in Chile),
- improvements in education for medical doctors (Costa Rica and Peru) and pain courses added in undergraduate and postgraduate curricula (Chile),
- improvements in relationships between prescribers and NCAs in Colombia, Panama, El Salvador, and Peru.

Traveling Scholarship Program

The program provides financial support to palliative care workers from developing countries to attend a meeting, conference, seminar, internship, or to enroll in a university program or other educational activity on palliative care.

Through the Traveling Scholarship Program, regional and local leaders from low- and middle-income countries are provided with funds for their

travel to an international palliative care meeting or congress. Candidates apply online through the IAHPIC web site <http://hospicecare.com> and an IAHPIC appointed committee selects the candidate and the amount to be granted based on the determined criteria. Preference is given to applicants whose posters, oral presentations, or sessions are accepted for the congress, to individuals living and working in developing countries, and to applicants who have not received Traveling Scholarships in the previous three years. In 2015, IAHPIC awarded 44 grants through the Traveling Scholarship Program. The following are examples and comments from awardees of these programs:

- Bagasha Peace who attended the 14th World Congress of the European Association in Palliative Care in Copenhagen stated “I am very grateful to IAHPIC for having given me this grand opportunity. I feel very empowered and motivated to create and implement changes and provide the best palliative care service possible.”
- Omella Sainterant from Haiti, who attended the 14th Palliative Care Initiators’ Course at Hospice Africa Uganda indicated “It taught me how to improve the care and support I offer to my patients and their families at the teaching hospitals where I work.”
- Liz Gwyther from South Africa, who attended the Global Colloquium in Palliative Care in Dublin, commented that “The IAHPIC Traveling Scholarship is of great assistance, especially to people in resource-constrained countries.”
- Christian Ntizimira from Rwanda, who attended the 22nd Canadian Conference on Global Health said “I was able to learn different strategies to engage and involve the community in Palliative Care and Hospice.”

Traveling Fellowship Program

This program provides financial assistance to individuals who are invited to teach or work in a low- or middle-income country. Applicants must have received an invitation from a host institution and be willing to spend several days teaching palliative care to local faculty. Traveling Fellows should have a significant amount of experience in palliative care and sufficient expertise to be able to teach students and others. In 2015, the IAHPIC awarded four Traveling Fellowships.

Participants often feel that they have gained much more than they have given. This is the case of Mark Schubauer who received a scholarship to teach at the Cancer Hospital, Chinese Academy of Medical Sciences who stated, “There are times when the promise of medical technology and innovation in medicine has

been realized and many people benefit. There are also times when the unexamined conceit of technology obscures the certain reality of death.”

Projects

In addition to the ongoing grant programs, the IAHPHC has developed and implemented several projects designed to serve as a resource for the global palliative care community. Examples include the following sections:

IAHPHC List of Essential Medicines for Palliative Care

In 2007, IAHPHC prepared a list of essential medicines for palliative care based on the recommendations of palliative care experts and taking into consideration the efficacy and safety of the medications. To develop the list, IAHPHC formed a committee including IAHPHC board members and external experts. The list was developed using a modified Delphi process, a general survey among palliative care experts from around the globe, and a face-to-face meeting with representatives from 26 international palliative care and pain relief organizations in Salzburg, Austria. The resulting list includes 33 medications essential in the treatment of the most common symptoms in palliative care and provides guidance to institutions and organizations who are implementing new palliative care services. Several published reports on access to pain relieving medications reference the IAHPHC list of essential medicines for palliative care.^{3–5}

WHO List of Essential Medicines for Palliative Care

Following the development of the IAHPHC Essential List of Medicines for Palliative Care, WHO asked IAHPHC to submit an application to develop a similar list of medicines for palliative care based on “published evidence.” IAHPHC formed a working committee which included IAHPHC board members and external experts, and the application was reviewed and approved by the WHO Expert Committee on the Selection and Use of Essential Medicines in April 2013. IAHPHC also submitted a request to the WHO Secretariat to move the palliative care list out of the Oncology Section (8.4) of the 18th edition of WHO Model List into a new, separate section (Section 2) called Medicines for Pain and Palliative Care. The 18th edition of the WHO Model List included several changes, two of which continue to be extremely important for the field of palliative care.⁶

1. The new section includes three subsections: non-opioids and nonsteroidal anti-inflammatory drugs; opioid analgesics; and
2. A list of medications used to treat the most common symptoms occurring in palliative care.

These changes are also included in the 19th edition of the WHO Essential Medicines List.⁷ The WHO Essential Medicines concept states that there is a minimum list of medications needed for a basic health care system, including the most efficacious, safe, and cost-effective ones for priority conditions. The provision of adequate palliative care is dependent on access to treatment and medications, and the inclusion of a list of medicines for palliative care in the WHO Model List is a great step in improving care for patients with palliative care needs.

The list of essential medicines for palliative care within the WHO Model List serves as a reference for governments and hospital administrators to ensure that medications needed for palliative care are available in institutions around the world. IAHPHC published a book based on this application.⁸

List of Essential Practices in Palliative Care

The development of the List of Essential Practices followed the same procedure used to create the IAHPHC List of Essential Medicines in Palliative Care developed in 2007 and the Opioid Essential Prescription Package developed in 2011.

The list of essential practices in palliative care for health workers working in primary care includes those practices aimed at meeting the most prevalent physical, social, psychological, and spiritual needs of palliative care patients and their families. IAHPHC formed a working group which included board members of IAHPHC and external advisors from the field. The working group developed a plan of action and methodology which included a Delphi process among 425 health practitioners, primary care providers, and palliative care experts from 63 different countries, and a ranking survey with representatives from 45 international palliative care and pain relief organizations.

The IAHPHC List of Essential Practices includes 23 practices with different levels of intervention under the following domains of care: Physical Care; Psychological/Emotional/Spiritual Care; Care Planning and Coordination; and Communication Issues. Different reports from the literature indicate that the list of Essential Practices have served as guidance for the development of services and training programs.⁹

Palliative Care Competencies for Undergraduate Medical Universities and Nursing Schools

This project began in 2014 in Colombia with a series of meetings with students and faculty members in Bogota, Cali, Manizales, and Ibague to evaluate the interest and willingness of universities to adopt changes in their curricula. The meetings were followed by workshops in Bogota and Cali to identify the necessary competencies, and the resulting recommendations were approved by consensus of all the participants.

Follow-up workshops were implemented in 2015 to discuss and communicate effective teaching methodologies to the teachers who participated. The initiative was developed and implemented in collaboration with the Foundation FEMEBA from Argentina and the University of Aachen in Germany. Funding was provided by Atlantic Philanthropies in the U.S., the DAAD Foundation from Germany, and the De Lima Böhmer Foundation from Colombia. Several reports have been published on the process and outcomes of the initiative.^{10,11} Additional countries (Chile, Panama, and Argentina) have requested support from IAHP to implement this process and discussions are ongoing.

Opioid Price Watch

In 2014, the IAHP launched the Opioid Price Watch (OPW) (<http://hospicecare.com/opioids/reports/map/>) project to monitor and report the dispensing prices of opioids around the world. This project is a component of the agreement of work as an NGO in formal relations with the WHO. The project was funded with a seed grant from the US Cancer Pain Relief Committee. IAHP formed a working group which included IAHP board members and external advisors from the field. IAHP developed and implemented an OPW pilot test and reported the information collected on the availability, price, and affordability of five opioids (fentanyl, hydromorphone, methadone, morphine, and oxycodone) in 13 formulations.

The pilot project was completed, and a report was published in the *Journal of Pain and Symptom Management*. The report is free to all via Open Access.¹² The report presents data on availability, dispensing prices, and affordability submitted by 30 participants from 26 countries. Using the data on availability and dispensing prices, IAHP calculated the affordability of one 30-day treatment of morphine and developed a flash map housed on the [IAHP website](#).

In 2015, a second phase of OPW was implemented, and new data were collected from 67 pharmacies in 43 countries around the world. The new data are currently being analyzed and will be presented for publication and dissemination.

Atlas of Palliative Care for Latin America

In 2014, the IAHP partnered with the Latin American Association for Palliative Care (ALCP) to develop the Atlas of Palliative Care in Latin America (<http://cuidadospaliativos.org/uploads/2013/12/Atlas%20of%20Palliative%20Care%20in%20Latin%20America.pdf>). The main objective of the Atlas was to evaluate the development of palliative care in Latin America. Examples of secondary objectives include facilitating access to information and communication among

institutions and associations dedicated to palliative care in the region, identifying key people in palliative care in each country, and promoting the development of palliative care in the region. Other organizations and institutions collaborated on the project including the European Association for Palliative Care, the Spanish Society for Palliative Care, and the University of Navarra (Spain). The project was supported with a grant from the Open Society Foundation's International Palliative Care Initiative.

The ALCP Atlas presents a vision of the palliative care situation in 19 countries in Latin America whose official language is either Spanish or Portuguese, based on surveys responded to by 58 palliative care and pain professionals. This is the first systematic study to present information on palliative care in Latin American countries.^{13,14}

Since the first edition, new developments have been reported and changes in policies have occurred in countries throughout Latin America and the Spanish Caribbean. The ALCP is currently implementing a survey to publish a second edition of the ALCP Atlas. The publication is expected to be released in 2017.

Palliative Care Indicators

In 2012, the IAHP in collaboration with the ALCP formed a working committee to develop palliative care indicators applicable at the national (macro level). The working group included experts in epidemiology, palliative care, management and development of health projects, members of the ALCP board, and the IAHP Executive Director.

The discussions centered on indicators to evaluate palliative care within the context of public health system, and not at the local or organizational level. The framework for the discussion was the WHO Public Health Strategy for palliative care with its four dimensions:

- Suitable public health policies,
- Education,
- Medicine availability,
- Implementation of palliative care services.

The committee developed 10 indicators: one in health care policy, three in education, three in infrastructure, and three in medicines. The document is available in English and Spanish on the ALCP web site (<http://cuidadospaliativos.org/home/>) under the Resources section, and a report using the indicators to analyze national progress in Latin America has been published.^{15,16}

Pallipedia

Pallipedia is the IAHP free online palliative care dictionary (<http://pallipedia.org/>). The goal of Pallipedia is to facilitate access to high-quality information

on palliative care to the global palliative care community. The dictionary includes over 1200 definitions. Dr. Roberto Wenk, the past IAHPIC Chair, is the editor of Pallipedia. A full review and update of the dictionary was completed in 2015.

Advocacy

IAHPC has a long history of advocating in collaboration with other organizations for the availability of appropriate care for patients with palliative care needs. This advocacy includes the recognition of access to palliative care as a component of the right to health care and access to essential medicines.^{17–19}

In May 2014, the World Health Assembly, the governing body of WHO, unanimously adopted a groundbreaking resolution urging countries to ensure access to palliative care for people with life-threatening illnesses²⁰ (<http://apps.who.int/medicinedocs/en/d/Js21454zh/>). The resolution outlines clear recommendations such as including palliative care in all national health policies and budgets, in the curricula of all health professionals, and highlights the critical need for countries to ensure that there is an adequate supply of essential palliative care medicines including those needed to alleviate pain and other symptoms.

Also in May 2014, Katherine Pettus, PhD, was hired as IAHPIC's Advocacy Officer (AO), first part time and then full time in 2015. Over the course of two years, IAHPIC has established strategic relationships and built partnerships with organizations and individuals, at the international, regional, and local levels. During 2015, IAHPIC focused on generating awareness and disseminating information at international fora on how national and international drug policies affect public health outcomes by limiting patients' access to controlled medicines for the treatment of moderate-to-severe pain. These international fora include the WHO, the Commission on Narcotic Drugs (CND), the Human Rights Council, and the UN General Assembly (UNGA). Some specific outcomes are outlined in the following:

CND and UNGASS2016

As a representative of IAHPIC, the AO was elected Vice-Chair of the Vienna Non-Governmental Organization's Committee on Drugs and was selected to serve on the Civil Society Task Force, which was created at the request of the President of the UN General Assembly, to prepare for the UN General Assembly Special Session on Drug Policy (UNGASS2016). On the Civil Society Task Force, the IAHPIC AO represents affected populations around the world with low or no access to controlled medicines, presenting their case to UN member states and suggesting remedial strategies, after formal consultation with sector leadership. As a

result of these interventions and ongoing bilateral meetings with key representatives and delegations in Vienna, the language concerning controlled medicines in the "Outcome Document" presented by the CND to the UN General Assembly in April 2016 included constructive suggestions regarding the need to improve opioid availability.

WHO and Geneva-Based Organizations

Through the AO, IAHPIC has established fruitful relationships with several individuals at the Human Rights Council, in particular the Special Rapporteur for Health, Dr. Dainius Puras, and the Independent Expert on the Rights of Older Persons, Dr. Rosa Kornfield Matte. Both have issued several statements recognizing palliative care and access to controlled medicines as a human right.

Geneva NGO Committee on Aging

The IAHPIC, through its AO, is a member of the Geneva NGO Committee on Aging and is advocating for the rights of older persons, including access to essential medicines and will participate in drafting a convention with the Geneva NGO Committee on Aging.

All these advocacy activities have been in close collaboration with other NGOs who share similar interests with IAHPIC. Some of these include Human Rights Watch, the University of Wisconsin's Pain and Policy Studies Group, the Union for International Cancer Control, the Worldwide Hospice and Palliative Care Alliance, the International Children's Palliative Care Network, and the International Association for the Study of Pain. In addition, IAHPIC has also coordinated these strategies with the relevant regional palliative care associations such as the African Palliative Care Association, the European Association for Palliative Care, and the ALCP.

The goal of many of these initiatives, including the advocacy position itself, is to improve access to controlled medicines for pain treatment and palliative care as components of the right to health. The ultimate goal is to promote the international and national policy environment to expand palliative care services and the rights of persons suffering from life-limiting illnesses, to have access to adequate care.

IAHPIC Web site

IAHPIC has a comprehensive web site <http://hospicecare.com> with more than 500 pages of palliative care information and resources including publications, a directory of services and providers, a directory of educational programs in palliative care, and specific sections on Human Rights, Ethics and Essential Components in Palliative Care. The web site is visited by over 30,000 readers every month from around the globe. During 2015, the IAHPIC web site registered a total of 161,205

visitors with 81% being new visitors. Over 85% of the web site visitors use English-based search engines. The web site can be translated using the Google translator (located in each page except the homepage).

The IAHPIC web site has three main sections:

1. About IAHPIC: Includes information about Who We Are (mission, vision, board, staff members, history, etc.); Programs (traveling scholarships, traveling fellowships); and Publications (news-letter, guidelines).
2. Resources section: Includes sections on Human Rights, Ethical issues, Directories (education and services), and Projects (Opioid price watch, palliative care essentials)
 - International Directories—In November 2014, IAHPIC created a series of international directories, including the following:
 - Global Directory of Palliative Care Programs and Services. This free directory includes almost 1400 listings of programs, services, hospices, and institutions around the globe. The listing includes the name, location, contact information, and description of the services (<http://www.hospicecare.com/global-directory-of-providers-organizations/>).
 - Global Directory of Educational Programs in Palliative Care: This free directory includes almost 190 listings of educational programs throughout the world. Each listing includes the name, institution, location, type of degree (diploma, certificate, master's, doctorate, seminar, etc.), language, and costs (<http://hospicecare.com/global-palliative-care/global-directory-of-education-programs>).
3. Members' section: Provides a gateway to the members, including access to resources, publications, and palliative care journals.

Social Media

Social media usage has given IAHPIC massive worldwide exposure with sharing capabilities and a large number of daily users. IAHPIC's social campaigns are targeted at educating the general public about the issues related to palliative care, generating awareness about access to essential medicines and international policy, and sharing knowledge and information of events and developments in the world. IAHPIC focuses its social media on three platforms:

1. Twitter account: IAHPIC opened its Twitter account in 2014 and currently has over 2400 followers and has earned over 15,200 impressions over the past 28 days. Postings are focused on issues related to access to care, access to medicines,

policy issues, drug conventions, human rights, and palliative care, and news about developments of the field. This platform allows IAHPIC to advocate for the advancement of palliative care, the recognition of pain and palliative care as human rights, and the importance of revising the current laws and regulations on controlled medicines (<https://twitter.com/IAHPIC>).

2. Facebook page: The IAHPIC Facebook (FB) page includes posts about new developments, resources, tools, awards, announcements about palliative care leaders, drug regulatory topics, and UN-related articles and resources. Updates are published daily with some postings reaching over 12,000 readers per week. The FB activity log shows that for any given week, over 3300 people reach the page and over 7000 people "liked" the page (<https://www.facebook.com/iahpc/>).
3. IAHPIC E-Newsletter is distributed via e-mail to all members of the palliative care community. It is a useful source of information about IAHPIC's programs and grant opportunities as well as program development, events, and other palliative care news around the world. The E-Newsletter has 7473 readers and April 2015 marked the 19th anniversary of the IAHPIC Newsletter (<http://hospicecare.com/home>).

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The IAHPIC is extremely grateful for their support and commitment to the alleviation of suffering throughout the world.

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Recommended Readings

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