European Association for Palliative Care: Forging a Vision of Excellence in Palliative Care in Central and Eastern European and Former Soviet Union Countries

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Abstract

The European Association for Palliative Care (EAPC) represents many thousands of health care workers and volunteers working in or with an interest in palliative care. In 2016, the EAPC has individual members from 48 nations across the world, and collective members from 57 national palliative care associations in 32 European countries. Throughout its history, the EAPC has produced guidance on a range of palliative care issues. The biennial congresses and research congresses and the comprehensive Web site (www.eapcnet.eu) are renowned and well utilized platforms for dissemination and exchange of palliative care information. The EAPC has also published a newsletter specifically for Eastern European and Central Asian countries that has been available in both English and Russian from 2005 to 2012. In addition, for a period of time, a Russian Web site (www.eapcspeaksrussian.eu) was also available. A survey of palliative care in Central and Eastern European nations sponsored by Open Society Foundation’s International Palliative Care Initiative found that in most countries, the national language is preferred rather than using English or Russian for the provision of information. Accordingly, the EAPC Web site provides translations of white papers, position papers, and blog posts in a number of languages.

Key Words

EAPC, palliative, Eastern Europe, Budapest, Hungary, Czech Republic

Mission

The European Association for Palliative Care (EAPC) was established in 1988, with the aim of promoting palliative care in Europe and to act as a focus for all those who work, or have an interest, in the field of palliative care at scientific, clinical, and social levels. In 2016, the EAPC has individual members from 48 nations across the world, and collective members from 57 national palliative care associations in 32 European countries, representing several thousand health care workers and volunteers working in, or with an interest in palliative care. The EAPC is a not-for-profit, non-governmental organization recognized by the Council of Europe.

The EAPC is committed to the support and development of palliative care throughout Europe, as shown in the mission statement of EAPC: “The EAPC brings together many voices to forge a vision of excellence in palliative care that meets the needs of patients and their families. It strives to develop and promote palliative care in Europe through information, education and research using multi-professional collaboration, while engaging with stakeholders at all levels.”

Publication of this article was supported by Public Health Program of Open Society Foundations. The authors declare no conflicts of interest.

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Accepted for publication: March 2, 2017.
This broad mission statement takes into account the range of, and differences in, the health care systems throughout Europe, and also recognizes each country’s unique cultural and differing economic situations. Although this diversity can be challenging to the development of palliative care, it also offers rich opportunities to learn from different models and to develop creative and flexible solutions that really fit the needs of the patients and their families.

**EAPC Activities**

The main areas of work of the EAPC are communication and information among palliative care professionals, research at a European level, and advocacy work with stakeholders. The EAPC hosts a biennial world congress aimed at providing a forum for presentation of research findings, information exchange, networking, and communication. The congresses attract participants from all over the world, and over 2800 delegates attended the EAPC congress in Copenhagen in 2015. The EAPC Web site (www.eapcnet.eu) is a well-used resource and provides access to the findings of EAPC task forces, for example, the curricula for undergraduate or postgraduate medical students and for nurses or the series of white papers, including, for example, white papers on standards and norms in palliative care, on core competencies in palliative care, on dementia, or on euthanasia and physician-assisted suicide. Currently, task forces are active on a number of different areas of interest in palliative care, including spiritual care, pediatric palliative care, primary care, and public health, providing platforms for collaboration in international working groups. Recently, the EAPC signed a memorandum of understanding with the European Association of Neurology, and a work plan is currently being formed.

The EAPC Research Network has produced guidance on symptom assessment and control with a number of expert papers, and has contributed to consensus building in different palliative care areas with pan-European surveys. The research network is linked to the European Palliative Care Research Centre in Trondheim (http://www.ntnu.edu/prc). The research network also organizes biennial research congresses that interlink with the main congresses of EAPC.

Research findings, results from task forces and other topical papers are published in the two official journals of EAPC, the *European Journal for Palliative Care* and *Palliative Medicine*.

**EAPC Activities for Developing Countries**

Nearly half of the countries in the European region are classified as developing countries using the World Bank’s classification. Although the economies of many countries are improving rapidly and health care systems are developing, major gaps between Western and Eastern European countries remain. These gaps are evident, for example, with lower participation from Eastern European countries in the EAPC congresses and task forces, where health care professionals from these countries experience difficulty in accessing funding, educational leave to attend, or language issues.

The EAPC endeavors to support professionals, and to foster the development of palliative care in resource-poor European countries. One such initiative is offering EAPC members from developing countries reduced delegate rates for congresses, and also by offering a number of traveling bursaries (funded by Open Society Foundation’s International Palliative Care Initiative [IPCI]) to attend congresses. The 9th EAPC Congress in Budapest, Hungary, in 2007 was the first EAPC congress to take place in a Central or Eastern European country. This was followed in 2013 when the 12th EAPC World Congress took place in Prague, Czech Republic. Hosting an EAPC congress has the added benefit of enabling local palliative care professionals and those from neighboring countries to attend with ease. In Budapest, in 2007, the EAPC award was given to George Soros, Director of the Open Society Institute, in recognition of his influence on the development of palliative care in Hungary and Eastern Europe.

Both congresses have been used as the starting point of political initiatives. In 2007, the EAPC in collaboration with the International Association for Hospice and Palliative Care and the Worldwide Hospice Palliative Care Alliance initiated the Budapest Commitment. This collaborative project invited national palliative care associations to participate by setting a goal for themselves and sharing the progress toward these goals with the other associations. An example of this is the German contribution to the Budapest Commitments with the successful finalization of the Charter for the Severely Ill and Dying by the German Association for Palliative Care; Romania, Croatia, and Czech Republic were also among the participating countries.

In 2013, in Prague, the EAPC in collaboration with International Association for Hospice and Palliative Care, Worldwide Hospice Palliative Care Alliance, the Union for International Cancer Control, and Human Rights Watch launched a new initiative to advocate access to palliative care as a human right. The Prague Charter urged governments to relieve suffering and ensure the human right to palliative care. The Prague Charter was translated in 23 languages, including Arabic, Chinese, and Russian. The charter was endorsed by a number of national and
international associations, and the online petition was signed by more than 7500 individuals. The Prague Charter was widely viewed as a powerful tool in establishing palliative care as a human right.

There are significant differences in the provision of palliative care between Eastern and Western European countries. To identify and begin to address these inequities and triggered by the IPCI, a task force on Eastern European palliative care was established and chaired by Carl Johan Fürst. This task force provided advice and evaluated the needs for Eastern European countries. As a result of the work of this group, in 2005, the EAPC established an electronic newsletter for Central and Eastern European and Former Soviet Union countries, produced by a workgroup led by Katalin Hegedus. It was also available in a Russian version. The newsletter included information on new developments in palliative care as well as on training and funding opportunities and provides best practice examples from all over Europe (http://www.eapcnet.eu/Corporate/NewsMedia/EasternEuropeNewsletter.aspx). It was discontinued in 2012 when the EAPC blog was established.

For some time, a Russian version of the EAPC Web site was established by Elena Vvedenskaya. This Russian Web site offered a comprehensive compilation of information for those countries oriented toward the Russian language.

To identify the level of need for information in Russian language and to assess which countries would use Russian information and training, the palliative care information needs in Eastern European and Central Asian countries were surveyed. Funding for this project was also provided by the Open Society Foundation’s IPCI. Survey results clearly demonstrated the need for a trade-off between ease of access to palliative care knowledge and quality of information. The challenge of finding relevant information quickly, particularly when combined with a lack of time, often due to a high (clinical) workload, was identified as a major barrier to accessing information. The Internet was identified as the only accessible information source by some participants, and a large percentage of participants reported not having access to palliative care textbooks or medical journals. The development of a comprehensive and structured Web site, an electronic newsletter, as well as regular meetings and conferences were preferred as information channels.

The survey did not confirm the assumption that offering information in Russian could be a remedy for the lack of understanding of available information in the English language. The overwhelming preference was access to palliative care information ideally in one’s own language, followed by English, and with a much lower priority for information in the Russian language.

After the results of this survey and similar feedback from other countries, the EAPC has increased efforts to translate EAPC publications into languages other than English. In accord with the EAPC translation policy and in agreement with the publishers of the two official journals, the EAPC ensures the copyright for translations of its papers. Offers to translate EAPC papers, documents, and guidelines into national languages are encouraged and welcomed as this allows for wider dissemination. Translation guidelines are provided by EAPC (http://www.eapcnet.eu/Corporate/AbouttheEAPC/EAPCPublications/EAPCTranslationPolicy.aspx). A comprehensive list of documents that have been translated in languages other than English can be found on the Web site (http://www.eapcnet.eu/Corporate/EAPCDocsinOtherLanguages.aspx). There is a wide range of documents in languages from Albanian to Turkish.

For those working in developing countries, the European Journal of Palliative Care regularly publishes perspective papers on national developments from a range of countries. The EAPC is very proud of its social media activity. In particular, the EAPC blog regularly features insights on local or national palliative care developments from a range of countries not only from Europe, but from all over the world (https://eapcnet.wordpress.com). The EAPC blog posts are also frequently translated into other languages related to their setting, including French, Portuguese, Russian, and Spanish translations (www.eapcnet.eu/Corporate/EAPCdocsinotherlanguages/Blogsotherlanguages.aspx).

The social media team is constantly looking for new and innovative ways to reach members and the palliative care community at large. Providing information through as many channels as possible, the social media team regularly uses Facebook, LinkedIn, and Twitter, and recently posted the first Twitter only poster at the 9th World Research Congress for Palliative Care in Dublin (June 2016). This poster compared the twitter feeds from the EAPC congresses with those of the congresses of the European Society of Medical Oncology (http://digitallegacyassociation.org/european-association-for-palliative-care-eapc-poster).

Conclusion

The EAPC aims to bring together those working, or with an interest in palliative care from across Europe and beyond. Through the activities of its members, the EAPC produces high-quality information and guidance. The EAPC Web site provides an invaluable resource for those seeking information on many aspects of palliative care. The EAPC congresses provide an opportunity for the global palliative care
community to meet, network, and learn. Palliative care professionals from Eastern European and Central Asian countries benefit from these activities. In addition, the EAPC has initiated activities that have specifically benefited developing countries, for example, with translations of EAPC publications into a multitude of languages, which can be downloaded freely from the EAPC Web site.

As with all organizations, the EAPC’s strength is its members. The success of EAPC has only been possible thanks to the continuing support of its members and the palliative care professionals from all European regions, who have, and continue to enthusiastically contribute their time, energy, and resources to support the continuing development of palliative care.

References