National Associations Survey: Advancing Hospice and Palliative Care Worldwide

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Background

As part of a cooperative effort among several international associations to advance hospice and palliative care worldwide, and in connection with the Second Global Summit of National Hospice and Palliative Care Organizations in Seoul, South Korea, the U.S.-based National Hospice and Palliative Care Organization (NHPCO) conducted a survey of all known national hospice/palliative care organizations between November 2004 and March 2005. The goals of this data-gathering effort were two-fold: first, to obtain descriptive data about national-level associations to feed into an internationally available database; and second, to assess the status of the provision of palliative services across countries, including strengths and needs, particularly in the areas of standards development and access to care.

Methods

An English-language online and hard copy questionnaire was created, comprising 10 questions in four subject areas: Organizational Structure, Standards for Hospice and Palliative Care, Service Provision, and Palliative Medicine. The survey was sent electronically or via postal mail to 93 national hospice/palliative care associations in 69 countries. The targeted respondents were identified with the help of international organizations, including The International Association for Hospice and Palliative Care and Help the Hospices in the United Kingdom.1 In addition, an announcement of the study was made in the December, 2004 issue of World Hospice and Palliative Care Online.2 Up to three follow-up reminders were sent.

Results

A total of 58 national associations from 51 countries responded to the online and hard copy survey, yielding a response rate of 62.4% overall and 73.9% by country. A breakdown by geographical region is presented in Table 1.

Organizational Structure

Most national associations (n = 46) responding to the survey are incorporated nonprofit organizations or charities, four are part of another organization, and two are quasi-governmental organizations. Six associations, mainly from Europe, are nonincorporated entities. A total of 25 national associations report having regional affiliates, and an additional 20 have state or local affiliates. Paid employees (full- or part-time) are working in 43 national associations, while 15 associations rely solely on volunteers.

Standards of Hospice and Palliative Care

A total of 20 countries have established standards for hospice and/or palliative care, up from only 11 countries reporting such national/regional standards in 2002.3 See Table 1 for details on standards by region. An additional 28 countries have indicated their desire to develop such national/regional standards.
All responding organizations reported hospice and/or palliative care service provision within their boundaries. While the majority (n = 32) considers any patient with a terminal prognosis eligible for hospice and palliative care, 12 countries provide access for cancer patients only, and 7 limit eligibility to specific diagnoses with a terminal prognosis.

Reliance on multiple sources of funding for hospice/palliative care programs is common among respondents. Government funding is a revenue source for most hospice and palliative care programs worldwide (n = 42), followed by private contributions (n = 36), and private health insurance (n = 18). Many programs in Africa, South America, and Eastern Europe also rely on overseas donations and grants.

Insufficient training of nurses and physicians in hospice and palliative care, and insufficient funding for hospice and palliative care services were identified as the principal areas of unmet need. Rural/remote areas and high drug prices were also designated as posing substantial barriers for access to adequate end-of-life care. Table 2 gives an overview of the areas of unmet need and barriers to care cited by survey respondents.

### Palliative Medicine

Palliative medicine or the provision of palliative care was identified as a recognized medical specialty in 18 of the 51 countries that responded to the survey. Opioids are readily available in 33 mainly industrialized countries, while 15 countries, mostly from the developing world, report limited opioid availability. Opioids were reported as rarely available in Honduras, Ukraine, and Nigeria.

### Discussion

Despite enormous diversity in culture and setting, shared principles and practice make the provision of hospice and palliative care recognizable wherever it exists in countries around the world. The availability of hospice and palliative care on an international scale is expanding but still limited. Great progress has been made in the last 20 years, and there are now not only isolated palliative care providers throughout the world but also emerging national organizations in at least 69 countries. However, the scope of available services is highly variable and access to effective palliative care still does not exist in many areas worldwide.

Growth in hospice and palliative care internationally is dependent, in part, on communication through an expanding global network that facilitates sharing of knowledge, promotes collaboration, and provides inspiration. Also key to the success of these national efforts is the ability to achieve important milestones, including the formation of a formal association structure, the development and acceptance of national standards of care and program operation, the inclusion of and funding for...
palliative care as part of the native national health care system, the removal of unnecessary restrictions on the availability of opioid analgesics, and the acceptance of palliative care as a medical specialty or subspecialty.

**Conclusions**

Continued tracking of program development and identification of unmet need is one means to achieve improved access to effective hospice and palliative care worldwide. The results of this survey begin to paint a picture of progress being made and barriers that remain in the development of hospice and palliative care on an international level. These data can also serve as the baseline for the measurement of changes as they occur and have the potential to be used to identify countries that can function as exemplars in hospice and palliative care development.

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**References**


