

Special Article

Funding for Palliative Care Programs in Developing Countries

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Abstract

There are many palliative care developments in resource-poor regions of the world. Most of them are supported by third-party donors and grant makers. The funding necessary to cover essential palliative care services usually exceeds the financial means of many developing countries. Health care services may have to be complemented by nongovernmental organizations that are dependent on fund raising and voluntary donations from a variety of external sources. Coordinated action by international funding agencies is needed to ensure that the world's poorest people have access to essential medications and appropriate palliative care. To this end, international networking in the palliative care field is vital. There are now a number of collaborative networks that make a significant contribution to the development and sustainability of hospice and palliative care across many resource-poor regions of the world. J Pain Symptom Manage 2007;33:509–513. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Funding, hospice, palliative care, developing countries, collaborative networks

Introduction

The World Health Organization (WHO) has highlighted the importance of palliative care in the developing world,^{1,2} yet many countries provide limited or no palliative care services.³

With only a few exceptions, palliative care is not incorporated within health care systems. As a result, there is no allocation of public funds or institutional resources,⁴ and no reimbursement for services rendered through health insurance programs.

The levels of funding necessary to cover essential palliative care services are usually far beyond the financial means of developing countries. Governments may not have the economic ability or political will to implement palliative care policies, and services may have to be complemented by those provided by

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nongovernmental organizations (NGOs) that are often dependent on fund raising and voluntary donations from a variety of external sources.

Coordinated action by international funding agencies is needed to ensure that the world's poorest people have access to essential medications and appropriate palliative care.⁵ The Council of Europe recommendation (2003)⁶ suggested that international networking should be promoted in the palliative care field, with collaboration between funders, NGOs, providers, and in-country governmental agencies.⁷ There are several international collaborative networks that make a significant contribution to the development and sustainability of hospice and palliative care across many resource-poor regions worldwide.

Open Society Institute

The Open Society Institute's (OSI's) International Palliative Care Initiative (IPCI) began in 1999 as a joint initiative of the Project on Death in America and the Network Public Health Program. The initiative supports work in Central Eurasia, Southeast Asia, the Middle East, Central and Eastern Europe, Southeastern Europe, Ukraine, Russia, South Africa, and Southern and West Africa. IPCI's objective is to serve as a catalyst to enhance the integration of palliative care into health care policy. Its primary goals include public and professional education, health care policy and standards development, access to essential palliative care medications, and advocacy. IPCI supports individual grants for palliative care faculty development in cancer, AIDS, geriatrics, and pediatrics in universities, medical academies, and public and private hospitals. International pain policy fellowships focus on the legal frameworks governing the availability and affordability of opioid analgesics for pain management.

To date, IPCI has supported palliative care centers of excellence in Hungary, Mongolia, Poland, Romania, Russia, Serbia, South Africa, and Uganda and palliative care needs assessments in Azerbaijan, Macedonia, Moldova, Tajikistan, and Ukraine. Needs assessments are planned for Albania, Kazakhstan, and Tanzania. In order to monitor palliative care development and opioid availability worldwide,

IPCI has supported the International Observatory on End of Life Care (IOELC) and the WHO Collaborating Center for Pain and Policy Studies. IPCI consultants have worked on education and policy in Georgia, Jordan, and Mongolia, and IPCI staff have provided technical assistance and support to several countries receiving Global Fund and the President's Emergency Plan for AIDS relief (PEPFAR) support.

IPCI convenes palliative care leaders, policy makers, and donors to collaborate on and coordinate palliative care advocacy initiatives. IPCI hosts an annual Salzburg Seminar for Palliative Care for health care physicians and nurses, as well as an annual OSI seminar. IPCI supports individuals, national and regional associations, and international organizations with grants ranging in size from \$1,000 to \$150,000 annually. IPCI has collaborated with the WHO and is collaborating with the International Atomic Energy Agency on the Programme of Action for Cancer Therapy (PACT) program to advance cancer prevention, treatment, and palliative care through the "Atoms for Peace" program. Additional collaborations with the U.S. National Cancer Institute support the integration of palliative care in cancer care for patients in the Middle East, Georgia, and Africa. IPCI collaborates with multiple national, regional, and international donors such as the Diana, Princess of Wales Fund, Eleanor Foundation, Elton John AIDS Foundation, Help the Hospices, International Association of Hospice and Palliative Care, National Hospice and Palliative Care Organization, and the Worldwide Palliative Care Alliance.

International Association for Hospice and Palliative Care

The International Association for Hospice and Palliative Care (IAHPC) is a global organization dedicated to the promotion and dissemination of palliative and hospice care around the world. The mission of IAHPC is to increase the availability and access to high-quality hospice and palliative care for patients and families; it does this by promoting communication, facilitating and providing education, and by becoming an information resource for patients, professionals, health care providers, and policy makers.

The organization has developed several programs with the aim to support individuals and organizations. These are

- *Traveling Fellowship Program:* This program covers the cost of travel of an individual who has been invited to teach in a developing country for at least two weeks. From 1999 to date, 42 individuals have traveled to programs in 25 different countries.
- *Traveling Scholarship Program:* This program provides financial support to individuals from developing countries to cover the cost of travel to an international meeting. They are selected for their outstanding leadership capabilities and past accomplishments in palliative and hospice care. Since the start of the program, IAHPC has supported 53 palliative care leaders from developing countries.
- *Faculty Development Program:* The main objective of this program is to institutionalize palliative care in teaching hospitals and universities. The program promotes formal education in health care institutions by funding faculty palliative care positions for nurses or physicians in developing countries. An agreement is signed between IAHPC and a teaching institution so that when the grant period ends, the program is fully entrenched in the system.
- *Clearing House Program:* IAHPC has sent more than 4,000 kg of donated journals and books to more than 500 individuals, hospices, institutions, and libraries in developing countries.

The amount of funding that IAHPC provides to support the programs ranges between \$150,000 and \$200,000 per year. IAHPC raises funds for its programs from different sources. It does not have an endowment or one significant source of funding. By keeping administrative costs to a minimum, IAHPC is able to allocate the largest possible amounts to the initiatives it supports.

The National Hospice and Palliative Care Organization

The National Hospice and Palliative Care Organization (NHPCO) (U.S.) is the primary association for hospice and palliative care

programs and professionals in the United States. A relative newcomer to the effort to develop palliative care internationally, the NHPCO has made contributions to advancing palliative care in sub-Saharan Africa, Eastern Europe, Asia, and Latin America. Although not a funding organization per se, NHPCO has been able to direct some financial and technical resources for palliative care in developing areas of the world.

In 2001, the NHPCO agreed to serve as a U.S. partner to the emerging hospice community in Romania. Since then, national standards have been written and published, contracts have been established for partial service reimbursement, palliative care has become a recognized subspecialty, restrictions on the use of opioids have begun to be lifted, and recently a coalition was formed to promote a national plan for palliative care. Other similar efforts are under way to assist in advancing palliative care in most Eastern European countries, notably Moldova and the Ukraine.

In sub-Saharan Africa, NHPCO formed a partnership with the African Palliative Care Association (APCA). Subsequently, the NHPCO and the (U.S.-based) Foundation for Hospice in sub-Saharan Africa (FHSSA) merged. Through a grant from the Diana Fund to NHPCO, FHSSA has been providing resources to expand APCA's ability to implement palliative care for people living with HIV/AIDS in Africa. Work continues on advocacy for increased accessibility to opioids and essential palliative care medications, training for professionals in palliative care, standards development, development of monitoring and evaluation tools, provision of technical assistance, infrastructure support, and efforts to graft home-based palliative care into existing, primarily faith-based health care organizations.

In addition to focusing on developing national associations, the NHPCO has concentrated its efforts on the development of standards and systems for measuring the quality and quantity of palliative care. The growing Latin American Palliative Care Association is receiving "in-kind" support from the NHPCO to develop its systems for measuring the quantity and quality of palliative care in Latin America. An APCA African Palliative Outcome Scale has been developed and tested. Support for

the development of outcome measures in India is also being supported in cooperation with the IAHPIC.

The NHPCO is contributing to the development of the Worldwide Palliative Care Alliance through the provision of support and technical assistance. An international Standards and Quality work group supported by the NHPCO has been formed to help coordinate measurement activities, including joint support with Help the Hospices for the IOELC project "Mapping Levels of Palliative Care Development: A Global View."⁸

The Diana, Princess of Wales Memorial Fund, Palliative Care Initiative

The Palliative Care Initiative (PCI) of the Diana, Princess of Wales Memorial Fund was launched in 2000. To date, over £2 million has been spent and a further £10 million committed over the next five years, by which time the Fund intends to have spent out its resources. However, the Fund aims to ensure that its activities are sustained beyond the life of the Fund itself.

The PCI works nationally, regionally, and internationally, using the unique name and associations of the Diana, Princess of Wales Memorial Fund, as well as its resources, to promote palliative care at all levels. The Diana, Princess of Wales Memorial Fund has supported palliative care initiatives in the following nine countries: Ethiopia, Kenya, Malawi, Rwanda, South Africa, Tanzania, Uganda, Zambia, and Zimbabwe.

The PCI is proactive, strategic, and objective driven, with a desired outcome that palliative care be accepted as part of, and integrated into, the care and treatment of people with HIV/AIDS, cancer, and other life-limiting illnesses. Building on its work to date, the PCI has identified six objectives:

- Local and national governments, the HIV/AIDS community, and the development community incorporate palliative care into the continuum of care for everyone with a life-limiting illness
- A strong palliative care sector capable of scaling up delivery and influencing health policy

- A workforce, from medical professionals to informal carers, that is trained to ensure the delivery of high-quality palliative care
- An increase in long-term donor funding for palliative care that makes it a sustainable intervention
- A strong, effective, and sustainable regional organization that effectively promotes and supports palliative care in Africa
- An increased evidence base to demonstrate the effectiveness and impact of palliative care in Africa

The objectives are intentionally ambitious. Obviously, the PCI, as a program of a relatively small independent donor, cannot achieve them alone. The PCI will continue to work in partnership with African organizations working on the ground and other national and international partners, including donors. Central to the work of the PCI is a strong evaluation and learning strategy and a fully integrated communications strategy to disseminate information and lessons learned and raise the profile of palliative care.

Conclusion

There are many palliative care developments taking place in resource-poor regions of the world, most of them supported by third-party donors and grant makers. International partners and funding bodies may increase strategic development by emphasizing the need for cooperation. Partnerships between donors, governments, NGOs, and local organizations are essential in developing effective and sustainable prevention and care programs,⁹ particularly in the resource-poor countries of the world.

Financial problems are common to most of the palliative care programs within developing countries. National and international foundations and agencies that provide funding for hospice and palliative care activities in the developing world need to identify those countries with the potential capacity and political will to initiate palliative care services. Palliative care programs and initiatives in developing countries need to identify sources and activities capable of generating funding streams to support the operational costs of the program.

Many other alternatives exist and programs in each country need to evaluate the resources in the community in order to develop and implement resource-generating strategies that have the greatest potential to be successful and cost effective.

Long-term financial survival is the key to solving critical economic and human resource issues that interfere with the smooth development of palliative care activity. Financial autonomy requires dedication and labor, but guarantees sustainability. Several collaborative networks continue to strive to develop a truly international approach to the promotion of palliative care, which is currently denied to the majority of the world's most needy people.¹⁰

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