

2ND Global Summit of National Hospice and Palliative care Associations Declaration on Hospice and Palliative care March 2005

The problems

Worldwide more than 52 million people die each year including adults, children and young people. Approximately one out of ten deaths is due to cancer. Over 40 million people, including over 29 million Africans, are infected with HIV/AIDS and are living with the disease. Also, there are growing numbers of individuals with other chronic diseases and life-threatening conditions. These people will all need hospice palliative care at some time. It is imperative that all governments fund and develop plans that support the continuum of prevention, treatment and palliative care.

Of patients with advanced cancer 70% have pain and 70% - 90% of those with advanced AIDS have uncontrolled pain. In developing countries, the majority of people are diagnosed after their disease has become incurable. Due to the stigma of an HIV/AIDS diagnosis, many do not take advantage of care and support programs (if available at all) until the final stages. Limited access and availability also results in advanced diagnosis and no treatment. Unrelieved suffering on this scale is unacceptable and unnecessary.

Access to trained hospice and palliative care health care professionals, community volunteers and careworkers (family caregivers, carers) via existing health care infrastructures is a worldwide problem. Access to pain and symptom management is also a global problem.

What we know

Major advances have been made in pain and symptom management in people with progressive incurable diseases. Great strides have taken place in understanding the psychological, social and spiritual aspects of dying and death. Health professionals, family members, volunteers and others are working together to create dynamic partnerships for the relief of suffering. Hospice and palliative care supports families at the time of death and in the bereavement period.

Hospice and Palliative care is based on meeting the physical, social, spiritual and psychological needs in all stages. Hospice and palliative care is also based on interdisciplinary care that incorporates medicine, nursing, social work, psychology, pastoral care, physiotherapy, occupational therapy and related disciplines.

We agree that:

Hospice and Palliative care must be included as part of all governmental health policy, as recommended by the World Health Organization (WHO). Governments must:

- Make access to hospice and palliative care a human right
- Make resources available for hospice and palliative care programs and services
- Establish clear, informed and self-standing policies with action plans for implementation.
- Include hospice and palliative care in their national cancer control programs.
- Include hospice and palliative care in the management of progressive life-threatening diseases.
- Include palliative care in their national AIDS strategies.
- Integrate hospice and palliative care education and training into the undergraduate and post-graduate curricula of medicine, nursing, research and other disciplines
- Provide training, support and supervision of non-professional careworkers
- Make necessary drugs available.
- Make oral opioid analgesics available and accessible for patients with life limiting illnesses.
- Identify and eliminate barriers in the laws and regulations in different countries to the adequate use of opioid analgesics such as morphine.
- Ensure systematic assessment of needs of hospice and palliative care to precede, when appropriate, the establishment of service at the local regional and/or national level.
- Make hospice and palliative care services comprehensive in nature and better integrated into the health care system
- Strive to make hospice and palliative care available to all citizens in the setting of their choice including acute care hospitals, long-term care facilities (nursing homes), and residential hospices and in the patient's home

Every individual has the right to pain relief. Since affordable and effective methods exist to relieve pain and most other symptoms, cost should not be an impediment.

Hospice and palliative care must be provided according to the principles of equity, irrespective of age, race, gender, sexual preference, ethnicity, faith, social status, national origin and the ability to pay for services. Palliative care must be available to all populations including vulnerable groups such as prisoners, sex workers and drug users.

The experience gained from the hospice and palliative care of cancer should be extended to the care of people with other chronic incurable diseases worldwide.

Families and other informal care givers are essential contributors to the delivery of effective hospice and palliative care. They should be recognized and empowered by government policy.

National hospice and palliative care organizations have a key role to play in advocating for good health policy development in their countries. Governments and these organizations (NGO) must work together to further develop hospice palliative care programs and services.

The progress on this declaration will be assessed and made public in two years time.

Seoul, Korea - March 16, 2005

Based on The Barcelona Declaration on Palliative Care - December 9, 1995