Consensus Based Definition of Palliative Care

One of the challenges in the implementation of palliative care has been a lack of consensus on what palliative care is, when it should be applied, to whom and by whom. The terms "palliative care" and "hospice care" have been used for many years, with different interpretations and several PC organizations have in turn, adopted their own definitions.

The current WHO definition for palliative care for adults was developed in 2002 and poses many challenges, limits palliative care to problems associated with life-threatening illnesses, rather than the need of patients with severe, chronic and complex conditions. The definition for children is even older (1998) and poses similar challenges.

In 2017, the Lancet Commission on Global Access to Palliative Care and Pain Relief published the report *Alleviating the Access Abyss in Palliative Care and Pain Relief—An Imperative of Universal Health Coverage* and developed a framework to measure the global burden of serious health-related suffering (SHS), generating the evidence base to address this burden. The estimated SHS was based on 20 conditions or illnesses many of which are acute (such as malnutrition, low birth weight, hemorrhagic fevers, injuries, poisoning, etc.) and may be transitory if treated adequately and timely. This new approach by the Commission resulted in an even broader concept of PC and not surprisingly, the Commission recommended the WHO definition to be reviewed and revised to encompass health-system advances and low-income settings where medical professionals often have the difficult task of caring for patients without necessary medicines, equipment, or training.

Following the recommendation of the Lancet Commission and as an organization in formal relations with WHO, the IAHPC designed, developed and implemented a project to revise and adopt, based on consensus, a new definition for palliative care.

Objective

The objective of this project was to develop, based on consensus, a PC definition that is focused on the relief of suffering that is timely and applicable to all patients regardless of the diagnosis, prognosis, geographic location, point of care and income level.

Methods

During 2018, the IAHPC developed a process based in three phases, including a large survey with over 400 IAHPC members from 88 countries. A paper with the description of the methodology has been submitted to a peer reviewed journal for dissemination.

Results

The resulting definition consists of two sections and follows a similar structure to that of the WHO: a concise introductory statement and a list of components in bullet points. A third section was added after participants suggested adding a set of recommendations to governments.

Palliative Care Definition

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.

Palliative care:

- Includes, prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs. Whenever possible, these interventions must be evidence based.
- Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care.
- Is applicable throughout the course of an illness, according to the patient's needs.
- Is provided in conjunction with disease modifying therapies whenever needed.
- May positively influence the course of illness.
- Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process.
- Provides support to the family and the caregivers during the patient's illness, and in their own bereavement.
- Is delivered recognizing and respecting the cultural values and beliefs of the patient and the family.
- Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary).
- Can be provided by professionals with basic palliative care training.
- Requires specialist palliative care with a multiprofessional team for referral of complex cases.

To achieve palliative care integration, governments should:

- 1. Adopt adequate policies and norms that include palliative care in health laws, national health programs and national health budgets;
- 2. Ensure that insurance plans integrate palliative care as a component of programs;
- 3. Ensure access to essential medicines and technologies for pain relief and palliative care, including pediatric formulations;
- 4. Ensure that palliative care is part of all health services (from community health-based programs to hospitals), that everyone is assessed, and that all staff can provide basic palliative care with specialist teams available for referral and consultation;
- 5. Ensure access to adequate palliative care for vulnerable groups, including children and older persons;
- 6. Engage with universities, academia and teaching hospitals to include palliative care research as well as palliative care training as an integral component of ongoing education, including basic, intermediate, specialist, and continuing education.