

Introducing a lexicon of terms for paediatric palliative care

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The nascent field of paediatric palliative care (PPC) has evolved significantly over a short period of time, as has its terminology. With an emerging literature of program descriptions and clinical research in PPC, the time has come to establish within Canada a shared vocabulary using a stock of terms that carry a particular meaning for those working within the field. A list of such terms is called a 'lexicon'. Lexicons for PPC have been developed in other countries (1) and for adult populations in Canada (2). PedPalASCNET (A Network for Accessible, Sustainable and Collaborative Research in Pediatric Palliative Care) (3), a Canadian Institutes of Health Research-funded PPC research collaborative, developed a Lexicon of Terms in Pediatric Palliative Care through a collaborative, iterative process. Members of a working group surveyed the literature and met in person and via a Web conference throughout a 13-month process. The result is a set of definitions that includes 18 terms of importance in the PPC literature. The Lexicon reflects the terms used in Canada in the care for children with chronic, complex and life-threatening conditions. For example, an 'advance directive' is defined as "a document that records preferences for using or limiting certain medical treatments in order to meet short- and long-term goals of care" (4). The Lexicon will serve clinicians and researchers as a standard for the use of terms in PPC in descriptions of their work. It is not intended to replace sensitive family-centred communication with patients and families using terms that are helpful to them. The Lexicon, first published in 2014, can be accessed at <<http://pediatricpalliative.com/publications>> and will be periodically updated by PedPalASCNET. The current version of the Lexicon is presented in Appendix 1.

APPENDIX 1: A LEXICON OF TERMS FOR PAEDIATRIC PALLIATIVE CARE

Advance Care Planning (ACP): Advance care planning is a process of discussions between **families** and health care providers about preferences for care, treatments and goals in the context of the patient's current and anticipated future health. It may include preparation of an **advance directive** or other documents that reflect health care decisions.

Advance Directive: An advance directive is a document that records preferences for using or limiting certain medical treatments in order to meet short- and long-term goals for care.

Bereavement support: Services offered to persons affected by imminent or actual death in ways that support the **biopsychosocial-spiritual** realms of functioning.

Biopsychosocial-spiritual care (or whole person care): A model of holistic care that addresses the body, mind, relationships and spirit. This model includes developmentally appropriate support for physical well-being, individual life philosophy, sense of peace, purpose, and connection to others. A Thematic Areas of Focus diagram represents our biopsychosocial-spiritual model: <http://pediatricpalliative.com/research>

Whole person care is a more recently developed term that explicitly addresses the physical, emotional, spiritual and existential experience of illness. The concept of whole person care is more fully described at <http://www.mcgill.ca/wholepersoncare>

Caregivers: Family members and others who provide care to a **child** over a period of time. This term is more broad than "**family**" and recognizes the relationships that are created by volunteers or professionals who support the child and family.

Child or Children: Infants, children and youth ages 0–19 years.

Chronic complex conditions (CCC): Conditions (or diseases) that are multisystem, often progressive over time, and may affect cognitive and physical development. Symptoms may span many years. The conditions may be rare and variable in presentation, severity and trajectory. Often there is lack of disease-specific research. Prognosis may change over time as treatment options become available or fail.

Desired outcomes: Aims of **paediatric palliative care** include: **child** and **families'** sense of support and satisfaction with care; enhancement of informed decision making over time; relief of **biopsychosocial-spiritual** suffering of the **child** and **families**; improved quality of life for the **child** and **family**; attainment of goals; personal growth; and **caregiver** support and sustainability.

End-of-life (EOL) care: Care that is provided when a person's death seems imminent based on the judgment of the healthcare team and/or **family**. Services provided may include symptom management, **biopsychosocial-spiritual** care, and other support to address the needs and wishes of the **child** and **family**.

Family: The family is the social unit most proximate to the **child**. It may variably consist of parents, siblings, grandparents and/or other household members.

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Hospice: This term has variable meanings. In Canada, it is most often used to describe a facility (free-standing in the community or associated with a hospital) that provides a variety of **paediatric palliative care** services.

Interprofessional: Also described as multidisciplinary or interdisciplinary, this term refers to the provision of care and research that may draw from fields of medicine, nursing, psychology, social work, spiritual care, child life, education, anthropology and others. Clinicians and researchers have a sense of shared responsibility demonstrated by collegial sharing of ideas, patient and social advocacy, and multicentre research. Connections among professionals may exist formally or informally.

Life-threatening conditions (LTC): Also called life-limiting or life-shortening conditions (or diseases) in various countries, the preferred encompassing term supported by PedPalASCNET in Canada is life-threatening conditions. These are conditions for which there is a likelihood of death before adulthood. It can be helpful to conceptualize these conditions, based on typical disease trajectories, using a framework developed by the Association for Children with Life-Threatening or Terminal Conditions and Their Families (ACT) (now called Together for Short Lives): http://www.togetherforshortlives.org.uk/professionals/childrens_palliative_care_essentials/approach.

Life-threatening conditions include those for which curative treatments may be feasible but may fail, or those for which a cure is not possible and from which an affected child is expected to die. Life-threatening conditions are frequently **chronic complex conditions** with significant impact upon the lives of the **child** and **family**.

Paediatric Palliative Care (PPC): An active and total approach to care provided to **children** with **life-threatening conditions** and their **families** from the time of recognition or diagnosis of disease, throughout the illness, at the time of death and beyond. It is typically provided by an **interprofessional** team with consideration given to **biopsychosocial-spiritual** elements to meet **desired outcomes**. Care is focused on comfort rather than cure, although both approaches may exist simultaneously. PPC includes management of symptoms, provision of **respite**, co-ordination of services, delivery of **end-of-life care**, and provision of **bereavement support**.

Paediatric Palliative Care (PPC) Research: The study of the populations receiving and providing **paediatric palliative care** services. This research aims to provide knowledge, evidence and advocacy through the study of disease trajectories, treatments and interventions, **family** and **caregiver** experiences, and health systems in order that **children** and families receive the **desired outcomes**.

Perinatal Palliative Care: Paediatric palliative care that is provided during pregnancy, delivery, discharge and/or death when an unborn or newborn baby is identified as having a potentially **life-threatening condition**. In Canada, this care is usually integrated with other **paediatric palliative care** services, while in the United States, independent teams may provide this care and refer to it as perinatal hospice.

Respite: Care provided by **caregivers** to allow **children** and **family** rest, recreation and support while the ill **child's** needs are tended to in the home, **hospice**, alternate community or hospital setting.

Supportive Care: A term that describes care that aims to relieve a person's symptoms or suffering during illness or bereavement. When describing the care of a person with a **life-threatening condition**, it may at times be used interchangeably with the term **palliative care**, although it may also be used in other contexts to describe minimally invasive treatments (for example, fluid support) when death is not anticipated. As such, it is important to be specific about its intended meaning within a given context; use of the term "**palliative care**" is encouraged.

REFERENCES

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