Pediatric Hospice Palliative Care

Guiding Principles and Norms of Practice

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

Canadian Network of Palliative Care for Children
Réseau canadien de soins palliatifs pour les enfants

March 2006

Canadian Hospice Palliative Care Association
Annex B, Saint-Vincent Hospital
60 Cambridge Street North
Ottawa, Ontario, Canada
K1R 7A5

Phone: (613) 241-3663
Toll-free in Canada: (800) 668-2785
Fax: (613) 241-3986
E-mail: info@chpca.net
Web Site: http://www.chpca.net/

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Preface

In Canada, in a geographical area with 250,000 people and a child population of about 50,000, about 50 children are likely to have a life threatening condition and, at any given time, about half of those children will need hospice palliative care. Each year, about 5 will die from a life-threatening illness (Goldman, 1998).

Although the number of childhood deaths each year may seem small, the emotional, social and financial impact is extraordinary. A child's death is a painful, sorrowful loss for parents, siblings, extended family members, teachers, health care caregivers, volunteers and others. During the dying journey, children and their families suffer from reduced quality of life, loss of family income, inconsistency in the availability and quality of hospice palliative care, and the lack of true choices about where the child dies (75% to 80% of deaths among children in Canada occur in hospital intensive care units which may not be the first choice for children and families).

The practice of hospice palliative care, which began in the 1970s, is designed to enhance choice, relieve suffering, and ensure the best quality of care during living, dying and grieving. Until recently, hospice palliative care had focused predominantly on the needs of adults who are dying, and the needs of children have been overlooked. This is changing. Groups such as Children's International Palliative Projects and Services (ChIPPS) and the Canadian Hospice Palliative Care Association Pediatric Interest Group [Canadian Network of Palliative Care for Children (CNPCC)] have brought together leaders in the field to share ideas and advance the field of pediatric hospice palliative care.

Children with life threatening conditions and their families have the right to receive hospice palliative care that is planned, coordinated and delivered by formal caregivers who understand how to enhance a child's quality of life. Over the past year, the CHPCA's Canadian Network of Palliative Care for Children (CNPCC) have worked to adapt the Canadian Hospice Palliative Care Association's (CHPCA) national principles and norms of practice for pediatric care.

How to Use this Document

This document is designed to guide health care professionals in establishing standards of practice, service delivery, program and policies for pediatric hospice palliative care, regardless of whether that care is delivered at home, in a hospital, in a long term care facility, or in a hospice. Its goal is to promote a standard consistent approach to pediatric hospice palliative care in Canada.

A standard approach to pediatric hospice palliative care will help to:

- ensure all families have access to high quality care

- make formal caregivers and organization more effective at identifying family issues, the care required, and the resources required to provide that care

- ensure all caregivers are knowledgeable and skilled, and have the support they need to fulfill their roles

- identify any gaps in care and encourage formal caregivers to expand their services or develop partnerships with other caregivers to fill the gaps.

Everyone providing pediatric hospice palliative care is encouraged to use the principles and norms set out in this document to guide their activities. Norms are simple statements that describe the "usual" or "normal" practice. Pediatric hospice palliative care programs use that statement to develop more detailed, measurable standards.

For example, the norm for assessing a child and family's need for pediatric hospice palliatives care is a fairly general statement:

> "Assessment is comprehensive and timely so clinicians have adequate information to guide the plan of care."

An organization would then establish minimum standards that formal caregivers must meet to achieve that norm. For example:

> "The assessment will be done using (name of assessment form). All questions must be completed."

> "The assessment will be done within 24 hours of the child being referred to the program."

While working from common principles and norms encourages consistency, it doesn't imply uniformity. Organizations will differ in the way they develop and function, and in the policies, procedures and strategies they develop to guide their practice.

Acknowledgements

The CHPCA's Canadian Network of Palliative Care for Children (CNPCC) would like to acknowledge the many people who contributed to developing this document, including:

- the CHPCA Standards Committee, the group that developed *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*, which formed the basis for this document

- the Pediatric Hospice Palliative Care Committee of British Columbia. B.C. Children's Hospital and Canuck Place Children's Hospice in B.C., who provided expertise in pediatric palliative care

- the Pediatric Hospice Palliative Care Standards Committee at the Hospital for Sick Children in Toronto who provided expertise in pediatric palliative care

- members of the CHPCA's Canadian Network of Palliative Care for Children (CNPCC)

Background

What is pediatric hospice palliative care?

Pediatric hospice palliative care is an active, holistic approach to care which focuses on relieving the physical, social, psychological and spiritual suffering experienced by children and families who face a progressive, life-threatening condition, and helping them fulfill their physical, psychological, social and spiritual goals. Its philosophy is to provide optimal comfort and quality of life, and sustain hope and family connection despite the likelihood of death. Pediatric hospice palliative care aims to provide comprehensive care for children and their families through the living, dying and grieving processes. It affirms life and regards dying as a process that is a profoundly personal experience for the child and family.

Pediatric hospice palliative care is planned and delivered collaboratively by an interdisciplinary team. It is a child and family centred approach to care that is based on shared decision-making and sensitivity to the family's cultural and spiritual values, beliefs and practices. *(Adapted from the Canadian Hospice Palliative Care Association, and Precepts of Palliative Care for Children/Adolescents and Their Families, 2003).*

How does hospice palliative care for children differ from hospice palliative care for adults?

Pediatric hospice palliative care is based on the same principles as adult hospice palliative care but also recognizes the unique needs of families faced with a child's illness and death.

- Children and adolescents are in a process of physical, emotional, cognitive and spiritual development. Depending on their developmental stage, they have different skills and different emotional, physical and development issues/needs.

- Children and adolescents communicate differently, and their understanding of illness, death and dying depends on their stage of development. Health care professionals understand that a child's concepts of illness and dying continue to evolve over time, and develop in association with life and illness experience (Bluebond-Langner, 1978; Eiser, 1995). Religious/cultural beliefs, patterns of coping, disease experience, previous experience with loss/death, sadness, and other emotions associated with grief, all influence a child's understanding of death (Eiser, 1995; McConnell & Frager, 2003; Work Group on Palliative Care for Children, 1999; Committee on Bioethics and Committee on Hospital Care, 2000).

- Children are members of many communities, including families, neighbourhoods and schools, and their continuing role in these communities should be incorporated into their

dying journey. School is an integral part of their lives, and it is essential they have ongoing opportunities to pursue education.

- Children respond differently to therapies and drugs. They experience unique symptoms, such as fatigue, nausea, vomiting and shortness of breath, depression and anxiety which are not well understood. They experience and express pain differently than adults, and require individualized treatment.

- Children are not as able to advocate for themselves, and often rely on family members to make decisions for them.

- Many life-threatening conditions that affect children are rare and only affect children. Many of the illnesses are familial and may affect more than one child in the family. The diseases are often unpredictable in terms of prognosis, and children may require years of caregiving.

- Parents bear a heavy responsibility for the care of their child, which may include making decisions in the best interest of the child at a time when they are highly stressed and grieving the loss of their child's health as well as dealing with other losses such as financial stability and the loss of time to spend with other children. Families of children who have life-threatening conditions tend to be younger and have fewer resources. Their quality of life is significantly improved when the ill child's quality of life is enhanced.

- The grief associated with a child's death has devastating, long-term implications for the entire family. Siblings have unique needs during and after a child's death.

What is the role of pediatric hospice palliative care during illness?

Pediatric hospice palliative care may be combined with therapies designed to reduce or cure illness, or it may be the only focus of care. Figure 1shows the relative focus of care over time. The straight dashed line is used to distinguish therapies intended to modify disease from those that are intended to relieve suffering and/or improve the quality of life (i.e., hospice palliative care). The actual mix of concurrent therapies will vary for each child/family care situation based on their expectations and needs, goals of care, and treatment priorities.

Figure 1: The Role of Pediatric Hospice Palliative Care
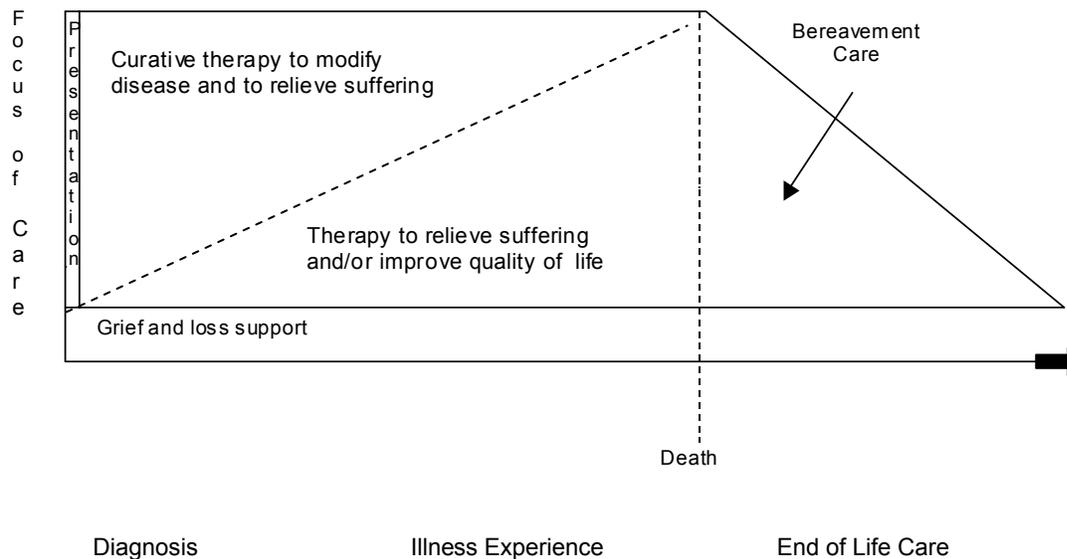
Pediatric hospice palliative care should be available to children and families throughout their illness experience and beyond, whenever they have expectations and needs and are prepared to accept care. Pediatric hospice palliative care is appropriate for any pediatric patient and/or family living with a life-threatening condition due to any diagnosis. Formal caregivers work with other professionals, the child and family to provide pediatric hospice palliative care concurrently with active care. Although the child's care may focus more on palliation as the illness progresses, active treatment is part of hospice palliative care and both play an important role throughout a child's illness.

Guiding Principles of Pediatric Hospice Palliative Care

Pediatric hospice palliative care is guided by the same values and principles as adult hospice palliative care (see a Model to Guide Hospice Palliative Care).

In addition, pediatric hospice palliative care reflects the following principles.

1. Child/Family Focused Care

The unit of care is the family, defined as the persons who provide physical, psychological, spiritual and social comfort to the child, and who are close in knowledge, care and affection -- regardless of genetic relationships. Family members may include biological, marital, adoptive/custodial and family of choice ties/connections (including friends and pets).

Children and families facing illness, dying and bereavement have inherent strengths. As part of the process of providing pediatric hospice palliative care, formal caregivers explore the child's/family's needs, hopes, beliefs, fears, expectations and strengths. All aspects of care are provided in a manner that is sensitive to the child's and family's personal, cultural and spiritual values, beliefs and practices, their developmental stage, and their preparedness to deal with the dying process.

The child has the right to age-appropriate information about his/her illness, potential treatments and outcomes. The family and service providers have the right to be informed about the illness, potential treatments and outcomes, while respecting the child's right to confidentiality. Decisions are made by the child and family in collaboration with the formal caregivers and service providers. The care team respects the child's and family's choices.

2. The Value of the Therapeutic Relationship

A therapeutic relationship between health care professionals and the child/family is essential to the provision of pediatric hospice palliative care. Within this relationship, there is potential for healing in the midst of illness, death and bereavement.

3. Continuity of Care

Pediatric hospice palliative care strives to provide continuity of care among formal and informal caregivers, and across the continuum of illness, dying and bereavement.

4. Communication

Effective supportive pediatric hospice palliative care depends on the ability of the child/family and the palliative care team to communicate. Formal caregivers acknowledge and respect the

child's/family's language preference. Interpreter services are used, whenever possible, to meet the care unit's communication needs

5. Accessibility

Pediatric hospice palliative care is accessible to children and their families in a setting of their choice that is appropriate to their needs and resources. Pediatric hospice palliative care is available 24 hours a day, 7 days a week, and families have a contact person to help coordinate their care.

Ethical Considerations in Pediatric Hospice Palliative Care

In their efforts to provide child/family-centred care, pediatric hospice palliative care providers will face a number of ethical issues including:

- **the child's ability to consent to treatment**. Some provinces have established specific ages at which a child is able to consent to treatment. Others require that the child be capable of understanding the treatment being proposed, the benefits and risks, and alternatives, and make the decision without coercion. Emphasizing the competence or capacity of the child rather than age, allows children to participate in decisions regarding their care whenever possible and appropriate. However, not having a legal age of consent can cause parents and professionals to question how much responsibility or information a child should be given in his or her own treatment decisions.

- **the amount/type of information that should be shared with a child (i.e., truth telling)**. Honest and sensitively communicated medical information helps patients and their families understand and deal with health issues and make informed choices about care options (Brinchmann, Fǿrde & Nortvedt; Hébert, 1996; Charlton, 1996; Hébert, Hoffmaster, Glass & Singer, 1999; Kuhl, 2002). When, what and how to disclose information to children must take into account the family's cultural or religious values and the child's capacity to understand. The significance of and approach used for truth-telling, is strongly tied to an individual's or family's religious and cultural practices and values. A child also has the right to waive the option of receiving this information, preferring instead that parents receive information on his or her behalf. If the health care team and the family cannot agree on the information to be shared with the child, the team should consult with an ethicist.

- **family-focused decision making.** Decisions regarding the medical care of children are generally made in a "triadic model" which involves the participation of the child (according to child's ability and capacity), the child's parents and the health care team (Hardart, 2000; Harrison, Kenny, Sidarous & Rowell, 1999). In end of life care, decision making can be perceived by some families as profoundly burdensome if the primary responsibility for choosing among care options is placed on the parents at a time in which they are losing their child (Brinchmann, Fǿrde & Norvedt, 2002). Therefore, the role and participation of the health care team is crucial to imparting information, making recommendations and working collaboratively to reach a consensus on what is in the best interests of the child. With infants and young children, who have no significant decision-making capacity, parents and health care professionals should make decisions that are guided by the best interests of the child. With primary school children, who have some capacity, parents and professionals should provide age-appropriate information, seek the child's consent, take into consideration the

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child's dissent, and ensure the child's best interests are at the core of the decisions. With adolescents, who have greater capacity, care must be taken to determine whether a particular adolescent patient has the ability to understand and communicate relevant medical information, exercise independence, anticipate consequences or risks and demonstrate a stable set of values (Harrison et al., 1999). All decision making should be sensitive to the child's and family's cultural and religious values. It's important that professionals understand how the family's cultural or religious beliefs shape understanding of illness and death. If a conflict arises between the health care caregivers and the child's family about the child's participation in his or her own care, health care caregivers should enlist the assistance of a cultural interpreter, chaplain or ethicist. Pediatric hospice palliative care programs should also have an established process of conflict resolution.

- **pain management**. Health professionals providing pediatric hospice palliative care have an ethical duty to "pursue comfort aggressively" and minimize the child's discomfort, suffering or pain (Wolfe, 2000). They have an ethical responsibility to provide adequate pain control and ensure that children are not under-treated because of ethical confusion, fear of the law or ignorance (Wolfe, 2000). The ethical obligations of beneficence, non-maleficence and the promotion of best interests of the patient should be used in guiding pain management decisions for children at end of life.

- **decisions to forego potentially life-sustaining treatments or to withdraw life support**. During the process of end of life care, health care professionals and parents will discuss foregoing life-sustaining treatment or withdrawing life support, and may participate in making these profoundly difficult decisions. To meet the requirements of non-malficence (i.e., the duty to avoid harm or suffering), professionals must raise these issues sensitively (i.e., identify appropriate timing, and present their recommendations to parents in a sensitive and respectful way). These conversations require comfortable rooms that afford privacy, as well as sufficient time for the family to ask questions, discuss preferences, voice objections and express feelings. These decisions, like all other decisions in pediatric hospice palliative care, should be driven by the best interests of the child. It is important to consider the child's values, beliefs and wishes as well as the options that are least likely to cause more suffering and/or prolong the dying process. It is also important to ensure that the self-interests of the parent(s) or over-riding familial interests do not dominate the decision-making.

The Square of Care: a Conceptual Framework

The conceptual framework for hospice palliative care is known as the Square of Care (see A Model to Guide Hospice Palliative Care), which captures the inter-relationship between clinical and program activities. The Square of Care developed for adult hospice palliative care has been adapted to guide pediatric hospice palliative care.

The Square of Care for pediatric hospice palliative care consists of:

- the child and family, the unit of care, who are at the centre of the square

- the clinical activities involved in pediatric hospice palliative care, which include:
    - Child and Family Care: the types or domains of care the child/family may need, such as disease management, physical care, spiritual care -- shown on the left side of the square

- the Process of Providing Care: the steps health professionals use to provide the domains of care , such as assessment, decision making, care delivery – shown on the top of the square
- the operational activities that support effective pediatric hospice palliative care, which include:
  - program support functions, such as planning, marketing, education and research – shown on the right side of the square
  - governance and administration, including resources, information technology and organizational structure – shown on the bottom of the square.

The Square of Care for pediatric hospice palliative care (next page) illustrates:

1. The relationship of each of the domains of child and family care with the process of providing care

2. The relationship of each of the domains in "Governance and Administration" to each of the domains within "Program Support."

3. The relationship of each activity to the child and family (who bring their own characteristics, such as age, gender, ethnicity, race, education, literacy).

4. The supportive role that program operations (Governance and Administration, and Program Support) play in the clinical activities (Child and Family Care, and the Process of Providing Care).

This document sets out the principles and norms of practice for:

- Child and Family Care
- the Process of Providing Care
- Program Support Functions.

Figure 2: The Square of Care (Ferris et al, 2002)

Assessment	Information Sharing	Decision Making	Therapeutic Interventions	Care Delivery	Evaluation of Care
History, Physical examination, Laboratory tests, Diagnostic studies	Confidentiality, Communication, Translation	Goals of care, Treatment priorities, Withholding, Withdrawing therapy, Advance care planning, Capacity, Futility, Requests for hastened death	Medications, Therapies, including integrative therapies, Equipment, Supplies, Benefits, risks, burdens, Adverse effects, Interactions, Education	Access, Response times, Care planning, Interdisciplinary team Collaboration, Essential services Coordination, Resources, Discrimination/prejudice, Continuity, Safety, Consultation	Evaluation, Ongoing Clinical Care

PROCESS OF PROVIDING CARE

Child & Family Care Domain		Child / Family — Fixed Characteristics: Age, gender, ethnicity, race, education, literacy	Administration
Illness/Disease Management	Diagnosis, Prognosis, Disease-modifying therapies		
Physical	Pain, other symptoms, Function, Fluids/nutrition, Senses		**Funding**
Psychological	Emotion, Coping responses, Cognition, affect, depression, anxiety, Independence, control, Fears, sense of burden, Dignity		
Social	Family, friends, relationships, Environment/safety, Privacy, intimacy, Financial, legal		**Planning**
Spiritual	Meaning, value, Existential, Transcendental, Faith, religion		**Marketing and Advocacy**
Developmental	School and education, Developmental milestones, Family issues -Parents -Siblings -Child		**Quality Management**
Practical	Activities of daily living, Caregiving, Caregiver training, support		**Caregiver Support/ Worklife**
End of Life/ Preparation for Death	Life closure, gift giving, Legacy creation, Rites, rituals, celebrations, funerals, Last hours of living		**Education**
Loss, Grief, Bereavement	Loss, Anticipatory, acute and chronic grief, Bereavement		Research

GOVERNANCE & ADMINISTRATION

- Vision, mission, values, norms of practice
  - Organizational structure
- Human resources
- Space and environment
- Medical and office equipment
- Health records
- Communication and information technology
  Safety, security, emergency systems
  - Financial accountability
  - Legal, regulatory compliance
  - Diagnostic, therapeutic services

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I. Child and Family Care

Child and family care consists of 9 types or domains of care, including:

- illness/disease management
- physical care (including pain and symptom management)
- psychosocial care
- social care
- spiritual care
- developmental care
- practical care
- end of life, preparation for death care
- loss, grief and bereavement care.

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1. Illness/Disease Management

Principle

PP1.1   Children and families have access to appropriate illness-modifying therapy.

PP1.2   Children and families have access to information on the impact of illness-modifying therapy on quality of life.

PP1.2   Children and families have access to supports to help overcome any barriers to accessing appropriate illness-modifying therapy (e.g., travel costs, child care for siblings, loss of work income).

Norms of Practice

PN1.1   Each member of the family, including the child and siblings (when possible taking into account the children's developmental milestones and the family's cultural beliefs) understands the child's diagnoses.

PN1.2   Formal caregivers estimate the child's prognosis based on best available evidence when possible.

PN1.3   Formal caregivers appropriately communicate the meaning and implications of the estimated prognosis with the child and family, taking into account the child's age and stage of development and the family's cultural values, and without destroying hope.

PN1.4   Formal caregivers use appropriate language with children and families, including clear language related to dying and death, to minimize misconceptions and facilitate discussions to help prepare children and families for end of life.

PN1.5   Formal caregivers know the child's history of therapeutic interventions and their effectiveness, resolved and unresolved issues, and adverse events.

PN1.6   Formal caregivers offer the child/family illness-modifying therapy that is appropriate to the child's/family's goals of care and has the potential to relieve the child's suffering and/or improve quality of life without disproportionate risk or burden.

2. Physical Care
(including pain and symptom management)

Principles

PP2.1   Symptoms include emotional and spiritual distress, such as boredom, depression, loneliness and sadness, as well as physical suffering. Effective symptom management addresses physical, cognitive, emotional, psychosocial and spiritual symptoms in order to ease the "total" pain a child and family experiences.

PP2.2   Pain and other symptoms are managed effectively to achieve the greatest possible relief for the child and family.

PP2.3   Age, cognitive ability, illness trajectory, cultural values and previous experience with pain/symptoms can affect a child's perception and experience of pain/symptoms, as well as the family's perception of the child's pain.

PP2.4   Alternative and complementary therapies for pain and symptom management are accepted methods of healing when chosen by the child and family, unless they are likely to cause significant harm.

PP2.5   Access to pain management expertise/leaders is available 24 hours a day, 7 days a week.

Norms of Practice

PN2.1   Formal caregivers assess specific patient and family needs related to pain and symptom management. Assessment is ongoing and based on age appropriate and valid assessment tools.

PN2.2   The plan of care addresses the physical expectations and needs of the child and family, and includes an effective pain and symptom management plan as well as plans for appropriate management of potential pharmacological side effects and complications.

PN2.3   Commonly addressed symptoms include but are not limited to:
- cardio-respiratory symptoms (e.g., respiratory distress/failure, cough, edema, hiccups)
- gastrointestinal symptoms (e.g., nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, feeding intolerance)
- general symptoms (e.g., anorexia, cachexia, fatigue, bleeding, odour, pruritus, infection, skin breakdown)
- neurological symptoms (e.g., seizures, level of consciousness, mobility, weakness, muscle spasms, swallowing, speech, body alignment and contractures)
- psychological and psychosocial symptoms (e.g., anxiety, depression, spiritual distress).

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PN2.4   The palliative care team uses physical and occupational therapy resources to optimize the child's function and mobility.

PN2.5   Formal caregivers adjust the child's fluid and nutritional intake to accommodate changes in the child's ability to swallow and retain fluids in the intravascular space as well as changes in renal and hepatic function and other quality of life issues.

PN2.6   The child's sensory experiences of sight, hearing, touch, taste and smell are optimized.

PN2.7   The most effective, least invasive, evidence-based pain and symptom care interventions are used, based on the child's needs, to provide comfort, connection and communication between the ill child and his or her family, friends/peers and community.

PN2.8   Complementary non-pharmacological symptom management techniques (e.g., music, art, books, journaling, guided imagery, clown therapy and play, hypnosis) are offered when appropriate, based on the assessment of the child's needs and interests.

PN2.9   Formal caregivers who do not have the knowledge to ensure a child is as pain and symptom free as possible refer the child/family to specialized pediatric hospice palliative pain and comfort management services. These consultations may occur throughout the illness trajectory (i.e., when the focus of care is active, palliative or end of life/terminal). When this expertise is not available locally, formal caregivers use telephone or other means to consult with an appropriate service.

PN2.10 All interventions and their effectiveness are documented and the data used to inform care decisions.

PN2.11 Team members are involved in observing, evaluating and documenting symptom management interventions and their effectiveness.

PN2.12 Formal caregivers receive ongoing education/training in pain and symptom assessment and management, including recognizing cues and feedback, and adjusting/evaluating symptom management strategies.

3. Psychosocial Care

Principles

PP3.1   Pediatric hospice palliative care addresses the psychological well-being of the child and family, and takes into account the emotional, cognitive, and behavioral impact of the illness, and each family member's personality, coping strategies, and past experiences.

PP3.2   Hospice palliative care for children and their families depends on a holistic collaborative approach to spiritual, social, cultural, and psychological care.

Norms of Practice

PN3.1   The child/family's emotional well being is assessed. Formal caregivers ask the child and family about their specific thoughts, feelings, hopes, wishes, fears and memories, and develop an awareness of the child's and family's psychological expectations and needs, and their personalities, emotional status, coping strategies, cultural beliefs, past experiences, and any pre-existing psychological conditions.

PN3.2   The plan of care addresses psychosocial needs and provides emotional support and therapies that promote the child's and family's coping skills and positive adjustment, supports their achievement of personal goals, and optimizes their quality of life.

PN3.3   Feelings of anxiety, depression, anger, anticipatory grief, helplessness, and hopelessness are acknowledged and addressed, taking into account the child's level of development and the family's cultural beliefs.

PN3.4   The child's cognitive function is preserved and developed as much as possible.

PN3.5   The child's sense of independence and control are supported.

PN3.6   Formal caregivers support the child's and family's desire for intimacy, privacy, connection and physical contact.

PN3.7   Formal caregivers address the child's fears, sense of being a burden and desire to protect their family, as well as the child's and family's feelings of grief (e.g., loneliness, unresolved guilt, anger, hopelessness), taking into account the child's stage of development and the family's cultural beliefs.

PN3.8   Formal caregivers strive to ensure that the child and family have opportunities for personal growth, joy and celebration. The care plan includes occasions for education, play, and interaction with family and peers, as well as other developmentally appropriate activities. Legacy building may be important (Hockley, 2000).

PN3.9   The child's and family's dignity is preserved

PN3.10 Formal caregivers provide psychological care for the family during the bereavement process. If families ask for/require more bereavement support, they are offered referrals to community resources.

4. Social Care

Principles

PP4.1　Pediatric hospice palliative care is offered in a social context, and is based on an understanding of the child's and family's place in a network of extended family, friends, and community and the implications for interaction, communication, and decision-making with and within the family.

PP4.2　Pediatric hospice palliative care takes into account relationship and communication issues within the extended family, the health-care setting, and the family's communities, including the need for assistance with conflict resolution.

PP4.3　Pediatric hospice palliative care is culturally sensitive, and takes into account the beliefs, values, actions, customs, and the unique health care needs of the child and family.

Norms of Practice

PN4.1　Formal caregivers develop a non-judgmental awareness of the family's social context through a formal assessment as well as through conversations with the child and family. Formal caregivers ask the child and family about family relationships, available support systems, and resources, and share what they learn with other members of the team.

PN4.2　The plan of care addresses the social expectations and needs of the child and family, and strives to support the importance, meaning and role of each person involved with the child.

PN4.3　The child and family are supported in reconciling relationships as desired. When relationships are irreconcilable, the focus becomes healing and forgiveness.

PN4.4　When desired by the family, formal caregivers educate and support the child's and family's network of extended family, friends and community as appropriate.

PN4.5　Formal caregivers strive to create/maintain an environment that is safe and comforting, provides ample opportunity for communication, intimacy and privacy, supports family relationships, and supports the family/caregiver therapeutic relationship.

PN4.6　Formal caregivers appreciate the intense physical, emotional, social and economic demands placed on a family caring for a child at home, or during prolonged and/or repeated hospitalizations. The family's ability to meet these demands with existing resources is assessed. (Hockley, 2000)

PN4.7　Formal caregivers are aware of the potential impact of cultural diversity on interaction, communication, and decision-making and have access to cultural profiles that help them understand child and family preferences (e.g., in some cultures truth-telling is a means

of empowering the patient, while other cultures perceive truth-telling as robbing the individual of hope) (Candibet al, 2002).

PN4.8   Formal caregivers ask the child and family about their own unique beliefs, values, and practices, and attempt to harmonize the beliefs and practices of the health-care system with those of the child and family, without causing stress for the child. Consultation is available to family and formal caregivers when there is a conflict based on cultural values and beliefs.

5. Spiritual Care

Principles

PP5.1   Spiritual care supports the child's and family's sense of: hope and self-worth; meaning and purpose; interconnectedness with others; and connection to powers larger than themselves.

PP5.2   Individual family members may differ in their adherence to religious or spiritual practices.

Norms of Practice

PN5.1   Formal caregivers ask about the child's and family's beliefs and values, and determine what distinguishes spiritual from religious practice for the child and family, and share this information with the rest of the team.

PN5.2   Formal caregivers acknowledge and respect the things that are meaningful and valuable to the child and family.

PN5.3   The plan of care addresses the child's and family's spiritual expectations and needs, including any potential for conflict.

PN5.4   Formal caregivers address the child's and family's existential questions and spiritual issues (e.g., the child dying before the parent) if able or make referrals to spiritual counsellors.

PN5.5   Formal caregivers help the child and family access appropriate spiritual and/or religious resources, preferably those already known to the family. Where possible, personal spiritual advisors become part of the child's care team

6. Developmental Care

Principles

PP6.1   Children and adolescents are in a process of physical, emotional, cognitive and spiritual development. Depending on their developmental stage, they have different skills and different emotional, physical and development issues/needs.

PP6.2   Children and adolescents communicate differently, and their understanding of illness, death and dying depends on their stage of development and their experience with death (e.g., pets, loved ones). Their concepts of illness and dying continue to evolve over time, and develop in association with life and illness experience.

PP6.3   Learning is an essential integral part of children's lives. Education opportunities are incorporated into their dying journey if they desire.

PP6.4   In families experiencing the death of a child, the child and his/her siblings may exhibit behaviours above or below the norms associated with their age, stage and illness/condition. Pediatric hospice palliative care provides care and support that is adapted to the children's developmental needs.

Norms of Practice

PN6.1   The child and his/her siblings' developmental needs are assessed and addressed in the family-centred plan of care (see the growth and development charts in Appendix #).

PN6.2   Formal caregivers adapt care to support the children's development..

PN6.3   Schooling is arranged to meet the needs of the child and/or siblings where possible, and children have opportunities to socialize with their peers.

PN6.4   Parents receive guidance and support in their efforts to parent a child with a life limiting condition.

PN6.5   If the child has difficulty communicating, formal caregivers identify a variety of verbal, nonverbal, and/or symbolic methods appropriate to the child's developmental level and communication style (see Appendix #).

7. Practical Care

Principle

PP7.1   Practical care, including assistance with activities of daily living and caregiver support, is an integral part of pediatric hospice palliative care. The child's and family's practical needs must be met to ensure quality of life.

Norms of Practice

PN7.1   The plan of care identifies the community and other resources required to address the child's and family's practical expectations and needs related to such areas as activities of daily living and caregiver support.

PN7.2   The family's need for assistance with physical care of the child is addressed.

PN7.3   The family's equipment and supply needs are addressed.

PN7.4   The family's need for financial support for the child's care is addressed.

PN7.5   The family's need for support, relief and respite is addressed. Families are referred to home care, respite services, volunteer visiting, hospices, long term care facilities and community support groups as appropriate, and have support coordinating the services and resources they need.

PN7.6   Informal caregivers are trained and supported by the interdisciplinary team.

8. End of Life/Preparation for Death Care

Principles

PP8.1   Preparation for death, taking into account each child and family's unique needs, can be healing and is an integral part of pediatric hospice palliative care.

Norms of Practice

PN8.1   The plan of care helps children and families prepare for and manage the child's end of life and death.

PN8.2   Symptoms and physiological changes associated with the last hours of living and death are anticipated, discussed with the child and family in a way that reflects their ability to cope with the information, and managed effectively.

PN8.3   Decisions about advance care planning, including conversations regarding a possible autopsy, are clearly articulated and reviewed with the family

PN8.4   Formal caregivers provide information about organ and tissue donation, and are available to discuss these issues at the family's request.

PN8.5   The child and family are encouraged to prepare for death by participating in rites and rituals that are important to the family, and/or in life closure, gift giving, legacies and other meaningful activities if desired.

PN8.6   Formal caregivers offer to provide assistance with or suggestions for a funeral, memorial or other meaningful services/celebrations of life if desired by the child and family.

PN8.7   The family is offered grief support as well as grief and bereavement materials to help prepare for a child's death.

PN8.8   The child's death is determined (i.e., pronounced), documented and communicated in accordance with regulation, policies and laws.

PN8.9   The child's body is handled with respect and dignity in accordance with the wishes of the child and family. The family is given time with the deceased child.

9. Loss, Grief, Bereavement Care

Principles

PP9.1   Loss, grief and bereavement care is delivered in the context of wellness not pathology. Death, even the death of a child, is a normal part of life, and grief is a normal response to loss. Pediatric hospice palliative care focuses on: identifying the family's strengths; mobilizing personal, family, social and community resources; and providing emotional, practical, social and spiritual support (not treatment) for people experiencing grief and bereavement. Positive emotions and states of mind promote well-being and adjustment in bereavements (Bonnano et al, 2005).

PP9.2   Loss, grief and bereavement care includes: a compassionate acknowledgement of the child's death, a bereavement care plan based on an assessment of the family's strengths and needs, emotional and practical support, and help accessing other community resources.

PP9.3   The relationships that families develop with the child's formal caregivers and the family's experience of illness have a profound impact on their subsequent experience of death and bereavement.

PP9.4   The family's grieving process will extend over many months or even years. Family members may experience a range of grief responses, and will require appropriate support to meet their needs. Some may benefit from referrals for counselling and appropriate treatment or alternative therapeutic approaches..

PP9.5   Pediatric hospice palliative care supports the family in creating/performing rituals that give unique personal meaning to the experience of illness, death and bereavement and respect the family's culture and preferences.

Norms of Practice

PN9.1   Families of children with progressive life-threatening illnesses have access to the services of hospital and community professionals with specialized expertise in grief and bereavement care. These professionals may become involved with a family at any point in their illness experience, depending on the family's preference and need.

PN9.2   Following the death of a child, family members are offered bereavement care including: information, peer support, support from trained volunteers, support groups and support/counselling from bereavement care professionals. A bereavement care plan is developed based on an assessment of the family's strengths and needs and discussions with the family.

PN9.3   Formal caregivers support the patient and family in their grieving process by, for example, having ongoing contact with the family, and acknowledging the child's birthday or the anniversary of the child's death.

PN9.4   Formal caregivers offer families a variety of supports and resources to address the ongoing physical, emotional and spiritual needs associated with loss and grief including, but not limited to:

- de-briefing sessions
- help planning/preparing for funeral services, burial ceremonies and/or other culturally appropriate rituals
- bereavement counselling
- referrals to community bereavement services
- support accessing grief and bereavement resources in hospital, home and community settings (e.g., support groups, peer support and trained volunteers).

PN9.5   Community cultural leaders may be asked to participate in loss, grief and bereavement care.

PN9.6   The responsibility for providing quality bereavement care is assumed by a member of the care team who has developed a relationship with the family and who is skilled in grief and bereavement care.

PN9.7   Families are offered ongoing bereavement support/contact for a minimum of one year. Formal caregivers acknowledge the death and offer condolences two to three days after the death occurs, and contact families by phone or letter two to four weeks after the child's death and at appropriate times over the year to provide support and information.

PN9.8   Team members have access to guidelines to help them provide appropriately, timely, evidence-based follow up contact with families.

PN9.9   Individuals who indicate a need are offered access to grief counselling.

PN9.10   Formal caregivers receive education and support to help them: develop the knowledge, skills and attitudes that foster quality bereavement care; assess family needs; and identify individuals who need more support/counselling.

PN9.11   Formal caregivers working with children and families who face progressive, life-threatening illness are offered grief and bereavement support as a regular part of staff support and on an as-needed basis (e.g., debriefing difficult deaths).

II. The Process of Providing Care

The process of providing care consists of 6 steps or functions:

- assessment
- information sharing
- decision making
- therapeutic interventions
- care delivery (including interdisciplinary team care and continuity of care)
- evaluation/confirmation of care

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10. Assessment

Principles

PP10.1   Assessment guides the clinician in understanding the child's experience of his or her illness/condition.

PP10.2   Assessment and reassessment are comprehensive, interdisciplinary and timely so clinicians have adequate information to guide the plan of care.

PP10.3   The assessment is supported by appropriate documentation.

Norms of Practice

PN10.1   Assessors gather appropriate information about the child's and family's history, respecting their privacy and using reliable assessment techniques and tools. Assessment information is shared with team members.

PN10.2   History taking and physical examination are completed initially and at regular intervals (depending on child's condition) to ensure formal caregivers have adequate information to guide the plan of care.

PN10.3   The initial assessment may take one or more visits and involve one or more formal caregivers (depending on their expertise. It includes:
- the physical examination and history taking, including symptoms
- identifying and prioritizing issues (expectations and needs) important to the child, family, and caregivers
- assessing the child's and family's developmental level, personal, cultural and spiritual values, beliefs and practices

- assessing family structure, life/environmental context, family strengths, and family support

PN10.4 The child's and family's perspectives are incorporated into the assessments of new and ongoing issues.

PN10.5 Based on the assessment, the appropriate formal caregivers suggest laboratory tests, diagnostic studies and participation in clinical research when they have the potential to benefit the child without undue risk or burden.

11. Information-sharing

Principles

PP11.1   The child has the right to be informed about: his or her condition/illness, available treatment options and clinical trials, and their potential benefits, risks and burdens. The child also has the right to be invited to participate in decision making, depending on the child's stage of development and the family's cultural beliefs.

PP11.2   Parents/substitute decision makers, with the guidance of professionals, determine how, when, and what information is shared with the child, taking into account the specific child, family and situation characteristics, such as temperament, cognitive abilities, developmental level, cultural beliefs and values.

PP11.3   Parents/substitute decision makers are entitled to information about: the child's disease or condition; available treatment options and their potential benefits, risks and burdens; and palliative care.

PP11.4   Effective communication and information sharing with the child and family gives formal caregivers the information they need to provide effective care.

Norms of Practice

PN11.1   Before sharing information, formal caregivers establish limits of privacy as defined by the child and family, and establish what the child and family already know and what they would like to know, in accordance with the ethical principle of truth telling.

PN11.2   Accurate information is shared in a timely way and when the recipients are ready to receive it.

PN11.3   Formal caregivers explore the expressive functioning/communication styles within the family, how family members normally share information, and any beliefs that may keep them from speaking with one another about difficult emotions / fears / worries.

PN11.4   Information is shared in a language, manner and setting understandable and acceptable to the child and family.

PN11.5   Interpretation services are provided by skilled medical interpreters who understand medical concepts and terminology, rather than by family members or someone who "speaks the language".

PN11.6   Formal caregivers regularly assess the child's and family's understanding and reactions to information, and their desire for additional information.

PN11.7   When the family and formal caregivers disagree about information to be shared with the child, they use the principles of negotiation and conflict resolution to reach agreement. If they cannot reach agreement, they have access to the services of a people with expertise in conflict resolutions (e.g., child advocate, ethicist).

12. Decision-making

Principles

PP12.1 The child and family have the right to make informed decisions based on information about all treatment and support options (including no treatment), determine goals for care, and establish priorities for present and future care.

PP12.2 The child who has the capacity (i.e., information, age, stage of development) to make decisions gives consent to any treatment. At any time, the child may refuse any treatment or ask to have any treatment withdrawn. The care team respects the child's choices.

PP12.3 When a child lacks the capacity to make decisions, approaches to decision-making are guided by ethical and legal principles of substitute decision-making.

PP12.4 Even when a child is found to be incapable of decision making, he or she is still encouraged to contribute to the plan of care as much as possible.

Norms of Practice

PN12.1 The decision-making process respects the confidentiality of the family and complies with privacy legislation, Decisions made by families are shared with team members on a need-to-know basis and, with the permission of the family, shared with, outside agencies to help them understand the plan of care. Caregivers are responsible for keeping the information confidential.

PN12.2 Formal caregivers regularly assess the child's and family's goals for care, the appropriateness of therapeutic interventions in light of those goals, the potential therapeutic burden of each intervention, and the child's decision-making capacity. This information is reviewed by the child, family and caregivers, and the plan of care adjusted accordingly.

PN12.3 Children and families are informed about appropriate therapeutic options available to address their expectations and needs.

PN12.4 Children and families have access to assistance, without coercion or prejudice, in selecting treatment priorities and settings of care from appropriate options.

PN12.5 Requests to withhold or withdraw therapies are discussed openly. Based on their capacity to make decisions, children are given the opportunity to discuss advance directives or care planning.

PN12.6 Requests for care that appears to have no benefit to the child and family, and the factors underlying those requests, are discussed openly.

PN12.7 Requests for hastened death (i.e., euthanasia or assisted suicide), and the factors underlying those requests, are addressed in a timely way.

PN12.8 When there is conflict between the formal caregiver, the family, and/or the child, all options are discussed openly and consensus is reached which reflects the best interests of the child. Reaching consensus may require mediation.

13. Therapeutic Interventions

Principles

PP13.1   Medications, therapies, equipment and supplies consistent with the goals of care and treatment priorities of the child and family are used appropriately, safely, and in a manner that optimizes their potential benefit and minimizes their risks and burden.

Norms of Practice

PN13.1   All therapeutic interventions are provided in a manner that:
- is safe and secure
- consistent with best practice guidelines
- minimizes the risks of adverse effects and the burden for the child and family.

PN13.2   Formal caregivers establish an effective process for:
- handling hazardous materials, including biological substances
- disposing of controlled medications and biological wastes.

PN13.3   Equipment and supplies may be adapted for use by children, but are always used in a manner consistent with manufacturers'/suppliers' safety instructions.

PN13.4   Members of the interdisciplinary team encourage or participate in legal therapeutic interventions..

PN13.5   Formal caregivers educate the child, family and caregivers about the appropriate use of medications, therapies, equipment and supplies, and regularly check and reinforce their proper use.

PN13.6   Incidents and adverse events are reported and recorded in a timely way.

14. Care Delivery

Principles

PP14.1 Children and families have equal and timely access to pediatric hospice palliative care services when they need them and are prepared to accept them, wherever they live, in whatever setting – regardless of diagnosis, prognosis, geographic location, age, gender, spiritual/cultural values, or financial circumstances.

PP14.2 Pediatric hospice palliative services are provided without discrimination or prejudice, in a manner acceptable to the child and family.

PP14.3 Pediatric hospice palliative care is provided by an interdisciplinary team of competent and compassionate formal caregivers who work collaboratively with the child and family. The team may include, but is not limited to, physicians, nurses, social workers, psychologists, pharmacists, case managers, rehabilitation professionals, chaplains, child life specialists, and trained volunteers. One team member is responsible for coordinating care and communication with the family, and for acting as a system navigator.

PP14.4 Communication with the child, family and other members of the child's community is ethical, open and honest.

PP14.5 Pediatric hospice palliative care provides continuity of care from diagnosis to bereavement, and across care settings.

Norms of Practice

PN14.1 Care is provided by an interdisciplinary team of formal caregivers with the appropriate assessment, planning, caregiving and communication skills.

PN14.2 The team responds to requests for initial referral and ongoing follow-up in a timely manner.

PN14.3 Team members support therapeutic relationships that family members have established. The child's primary care and specialist caregivers remain informed and involved in the child's care, if the child and family wish them to do so.

PN14.4 Essential services are available 24 hours per day, 7 days a week. The child, family and all team members know the contact information for after hours and/or urgent care.

PN14.5 Pediatric hospice palliative care consultation and/or services are available within a reasonable distance from the child's home or by other means (e.g., telephone Internet).

PN14.6 The interdisciplinary team creates a network of hospital and community supports (e.g., ethicists, physiotherapists, occupational and speech therapists, dieticians, therapeutic clowns, art and music therapists, complementary health professionals) to address the child's and family's needs. Expert consultation is sought in a timely manner.

PN14.7   The team develops and negotiates an individualized, flexible plan of care with the child and family.

PN14.8   The team works with the child and family to develop a collaborative, culturally sensitive decision-making process. All decisions are implemented and documented in a timely manner.

PN14.9   Core members of the interdisciplinary team meet and consult regularly with the child and family in the child's home if possible. The interdisciplinary team reviews the plan of care regularly and revises it as necessary.

PN14.10   The team establishes effective ways to communicate and share appropriate information with the child, family and team members, which respect the family's confidentiality and privacy.

PN14.11   Care is provided in collaboration with the child and family.

PN14.12   Care is provided in a language and manner that are understandable and acceptable to the child and family.

PN14.13   There is no evidence of discrimination or prejudice by formal caregivers.

PN14.14   Formal caregivers respect the personal boundaries necessary to achieve effective therapeutic relationships.

PN14.15   Formal caregivers have the resources they need to deliver the plan of care.

PN14.16   Care is coordinated by designated formal caregiver(s) in collaboration with the child and family. There is continuity of the plan of care across all settings of care, and among all caregivers and programs/services involved with the child and family.

PN14.17   There is consistency and continuity of caregivers.

PN14.18   Clinical practices reflect agency policies and procedures.

PN14.19   Available programs and services collaborate to address the pediatric hospice palliative care needs of a community

15. Evaluation of Care

Principles

PP15.1   Pediatric hospice palliative care is an ongoing process of assessing, evaluating and adjusting the services provided to meet the child's and family's needs and reduce their suffering. Formal caregivers continually strive to improve the quality and effectiveness of hospice palliative care.

Norms of Practice

PN15.1   The child's and family's overall understanding, satisfaction, sense of complexity, level of stress, concerns, questions and desire for additional information is assessed during therapeutic encounters.

PN15.2   During each therapeutic encounter, the formal caregiver assesses and reinforces the child, family's and informal caregiver's understanding of:
- the situation
- the plan of care
- the appropriate use of medications, therapies, equipment and supplies.

PN15.3   During each therapeutic encounter, the formal caregiver assesses the child's, family's, and informal and formal caregivers':
- satisfaction with the process of providing care and their overall situation
- perception of the complexity of the situation
- perception of the level of stress
- ability to provide and participate in the plan of care.

PN15.4   Formal caregivers systematically use the results of their evaluations to revise the plan of care and improve care for the child and family.

III. Program Support Functions

Program support functions include:
- governance and administration
- planning
- marketing and advocacy
- evaluation
- research
- education
- caregiver support/worklife

16. Governance and Administration

Principles

PP16.1   Governance and administration are essential to the development, maintenance and accountability of pediatric hospice palliative care programs.

PP16.2   Broad-based governance includes community representatives, formal and informal caregivers, the child and family.

Norms of Practice

PN16.1   The program's organizational structure supports all of its activities.

PN16.2   All aspects of the program's governance, administration, strategic and business planning, and operations are reviewed regularly.

17. Planning

Principles

PP17.1   The organization's mission, vision, values, purpose/activities and developmental directions are defined and regularly reviewed through a strategic planning process.

PP17.2   The resources and functions to implement the strategic plan are defined through a business planning process.

Norms of Practice

PN17.1   The program's vision, mission, values, principles, and standards of practice and professional conduct guide its strategic and business planning as well as clinical and operational activities.

PN17.2   The organization has a strategic plan to guide the developments of its infrastructure and principle activities. The strategic plan includes:
- a needs assessment
- mission and vision statements
- values, principles, principal activities and service delivery models
- developmental goals, objectives, strategies and tactics for developing the organization

PN17.3   The organization has a business plan which defines the resources and functions to support its infrastructure and principal activities. The business plan includes:
- a governance and administrative structure
- a plan(s) to acquire/manage resources
- a plan to implement principal activities and the infrastructure
- a quality management plan
- a communications/marketing plan.

PN17.4   The business plan is congruent with the strategic plan.

PN17.5   The organization has a process to regularly review and update its strategic and business plans.

18. Marketing and Advocacy

Principle

PP18.1   Marketing (i.e., education) and communications increase awareness of pediatric hospice palliative care services and increase families' access to them.

PP18.2   Planning and advocacy, based on information and research, are essential to develop and maintain public policy, resources and practice guidelines for quality pediatric hospice palliative care.

PP18.3   Public education and advocacy are effective strategies to promote pediatric hospice palliative care and ensure it is available for children and their families.

Norms of Practice

PN18.1   Children, families, caregivers and the public have easy access to information about the community's pediatric hospice palliative care services.

PN18.2   Education materials are written in a manner that is accessible for the intended audience, and reflects the community's language preferences and the way they like to receive information.

PN18.3   The organization has a communication/marketing strategy to support fundraising if required.

PN18.4   The organization has a plan for media liaison, including communication in the event of an adverse situation.

PN18.5   The pediatric hospice palliative care program collaborates with internal and external legislators, regulators, health care funders and caregivers, other hospice palliative care caregivers, professional societies and associations, as well as planning bodies, including children and families and the public to influence policy, and develop and enhance pediatric hospice palliative care.

PN18.6   Children and families have access to advocates or system navigators who act on their behalf.

19. Quality Management

> The team meets the unique needs of dying clients by:
>
> - Helping clients manage their pain and symptoms
>
> - Helping clients and families plan for death
>
> - Addressing clients' and families' psychosocial and spiritual needs
>
> - Helping clients and families link with support groups and hospice caregivers
>
> - Respecting the clients' and families' cultural beliefs about dying

Principles

PP19.1   Ongoing evaluation improves the quality of pediatric hospice palliative care services.

PP19.2   The goal of evaluation and quality management is to:
- assess the effectiveness of the service in achieving its goal (i.e., changing the experience of illness and bereavement) and providing quality care
- ensure the needs of the children and families are understood and met
- ensure the care and services provided are safe, effective and efficient
- continually improve the care and services provided.

Norms of Practice

PN19.1   The pediatric hospice palliative care program has policies and procedures based on accepted best practices and on evidence-based norms of practice (when available) for hospice palliative care and for grief and bereavement support as well as standards of professional conduct.

PN19.2   Accreditation standards related to the unique needs of palliative patients are addressed (Achieving Improved Measurement, 2004).

PN19.3   The program has a systematic approach to evaluation (e.g., quality review cycles) that includes documentation, data collection, and a regular review process.

PN19.4   The program annually reviews quality management, policies and procedures, and practice guidelines.

PN19.5   Performance improvement evaluation includes: routine measures of clinical outcomes, adverse events, medication and other therapeutic errors, resource utilization, child and family satisfaction, and complaint resolution.

PN19.6   Clinical outcomes are identified and measured using sound instruments (when available).

PN19.7   Families are aware of how to voice complaints or grievances, and are assured they will continue to receive quality service.

PN19.8   Formal caregivers obtain ongoing feedback from the families and children they serve, and work to integrate this information into their practices.

20. Research

Principles

PP20.1   The development, dissemination and integration of new knowledge is essential to advance quality pediatric hospice palliative care.

PP20.2   Children, families and others who consent to participate in research are treated sensitively and ethically. Participation in research can be positive and therapeutic.

PP20.3   Research priorities are informed by the Canadian Agenda for Research in Palliative Care, (CHPCA, 1999), the Canadian Institute of Health Research (CIHR), the Institute of Medicine (Field M, Berhman R, 2003) and other related research bodies and pediatric/adult health and hospice palliative care leaders (see appendix G for a list of potential research priorities and potential research questions).

Norms of Practice

PN20.1   Capacity building opportunities, such as interdisciplinary research fellowships, are available to help to develop new investigators.

PN20.2   Knowledge informs clinical practice and models of service delivery.

PN20.3   Knowledge is disseminated and integrated into clinical practice.

PN20.4   Knowledge is disseminated using appropriate methods of knowledge transfer and knowledge translation.

PN20.5   Knowledge is disseminated in provincial, national and international forums (e.g., peer reviewed journals, conferences, relevant websites).

PN20.6   The program encourages opportunities for cross-disciplinary and multi-site research partnerships.

PN20.7   Qualitative research methods are recognized as meaningful in understanding the experience of living with a life threatening condition, dying, death, and grief.

PN20.8   Research is conducted within the guidelines of the relevant scientific and ethics research boards and guided by national policies for ethical conduct.

21. Education

Principles

PP21.1 Pediatric hospice palliative care providers have specialized knowledge/expertise in the delivery of hospice palliative care to their respective populations. This knowledge is continually evolving.

PP21.2 Health care professionals in both academic centres and the community continually share information and experience about: the relief of physical, cognitive, emotional and spiritual suffering;, and the societal value of grief and bereavement support, particularly for siblings, classmates, and friends. This enhances the quality of hospice palliative care available to children, families and communities.

Norms of Practice

PN21.1 Pediatric hospice palliative care programs offer professionals, volunteers and informal caregivers opportunities for life long learning and the development of additional academic and practice expertise.

PN21.2 Formal caregivers have access to various educational initiatives, including adult hospice education, palliative care conference presentations, palliative care rounds with national pediatric hospice palliative care experts (teleconference), informal discussions with hospital and community health care professionals, and academic coursework.

22. Caregiver Support/Worklife

Principles

PP22.1   Formal and informal caregivers' physical, psychological, and spiritual well-being is integral to the provision of pediatric hospice palliative care.

Norms of Practice

PN22.1   Employees and volunteers are satisfied with the psychological and spiritual support they receive from the program.

PN22.2   Ongoing programs are in place to address employee issues and improve work life satisfaction.

PN22.3   The program works to identify and minimize occupational risks and stresses.

PN22.4   Formal and informal caregivers have access to ongoing support, including grief and bereavement support.

PN22.5   Formal caregivers have the opportunity to reflect on their own comfort and ability to enter into difficult conversations with children and families. They support one another and are willing to ask for help when feeling unsure/uncomfortable.

IV. Resources

Resources include:
- human, physical, technology, clinical resources
- financial resources

23. Human, Physical, Technology, Clinical Resources

Principles

PP23.1   Pediatric hospice palliative care programs need appropriate, adequate resources to fulfill their mission.

Norms of Practice

PN23.1   There are adequate human resources to support the program's activities.

PN23.2   The space and environment are sufficient and appropriate to support the program's activities.

PN23.3   The medical and office equipment and supplies support the program's activities.

PN23.4   The health records and other documentation help the team provide quality child and family care.

PN23.5   The communication and information technology systems support child and family care and all aspects of program operations.

PN23.6   The safety, security and emergency systems support the program.

PN23.7   The program is in compliance with legislation and regulations governing its clinical practice and operations.

PN23.8   The program has access to relevant diagnostic and investigative options to support its clinical activities.

24. Financial Resources

Principles

PP24.1   Adequate financial resources are essential to support pediatric hospice palliative care activities and ensure the program's long-term viability.

PP24.1   Resources are managed effectively to ensure the best care for the child and family.

PP24.3   Bereavement support can be preventative and limit the potential for long-term health implications for the bereaved.

Norms of Practice

PN24.1   The program has established, consistent effective budgeting, accounting, and billing practices that meet legal and accounting standards.

PN24.2   The program has sufficient funding to achieve its goals.

PN24.3   Fundraising activities and grant stewardship (if appropriate for the program) are consistent with the mission, vision and values of the program.

PN24.4   The program is financially accountable.

Appendix A
Glossary of Commonly Used Terms

(borrowed and/or adapted from "A Model to Guide Hospice Palliative Care" CHPCA,2002 with permission, "When Children Die", IOM Report, 2003 and "Proposed Norms of Practice for Pediatric Hospice Palliative Care, Pediatric Palliative Care Committee, British Columbia, 1999)

Accountability is the financial and professional responsibility to those receiving care and the community.

Advance directives are the formal or informal instructions patients give about the type of care and treatment they want in response to potential illnesses or conditions.

Alternative, complementary, integrative therapies describe independent healing systems outside the realm of conventional medical theory and practice.

Anticipatory grief is the feelings/behaviours that occur before or in advance of an expected loss and may include the death or loss of expectations/hopes for a child or for a "normal life".

Assessment is the identification, description, evaluation and validation of information.

Autonomy is the state of being self-governed.

Bereavement describes the situation of having experienced loss through death rather than the emotional content of the experience.

Beneficence is the provision of benefits and the balancing of harms and benefits for the purpose of doing the most good.

Care is the interventions, treatments and assistance given to the child and his or her family.

Child is a person up to the age of 18 years but, for purposes of pediatric hospice palliative, "child" includes anyone whose diagnosis is made in childhood even if the person is older than 18.

Complicated grief or bereavement is a response to loss that is more intense and longer in duration than usual.

Comfort care is another term for palliative or hospice care, which is considered more understandable and acceptable to patients and their families, especially children.

Confidentiality is the protection and control of information.

End-of-life care is care that focuses on preparing for an anticipated death and managing the end stage of a fatal medical condition.

Family refers to two or more people, whether living together or apart, related by blood, marriage, adoption or commitment to care for one another.

Formal caregiver is a member of an organization and accountable to defined norms of conduct and practice. A formal caregiver may be a professional, support worker or volunteer.

Grief describes people's feelings and emotions in response to death, including but not limited to sadness, anger, frustration, guilt, longing, helplessness, hopelessness, and powerlessness.

Grieving is the physical, social, spiritual, emotional and behavioural reactions to loss

Health care or interdisciplinary team is a team of caregivers who work together to develop and implement a plan of care and may include many different disciplines. Children and families are also part of the health care team.

Hospice is often used interchangeably to describe a philosophy, a program of care or a site of care. The term is commonly used to refer to an organization or program that provides, arranges, coordinates and advises on a wide range of medical and supportive services for dying patients and those close to them, and often provides these services in or near the patient's home. Some hospice programs also provide grief and bereavement support.

Informal caregiver is someone close to the family who provides care, usually a member or friend of the family.

Life threatening conditions are those for which there is no reasonable hope of cure and from which children will die.

Norm is a statement of usual or average practice and is considered less rigid than a standard.

Nonmaleficence is the avoidance of doing harm.

Pediatric hospice palliative care is a model of care that seeks to prevent, relieve, reduce or soothe the symptoms suffered by the experience of living with a life threatening condition and/or its treatment while also maintaining the child and family's quality of life.

Pain is an individual, subjective unpleasant sensory and emotional experience that is primarily associated with tissue damage or described in terms of tissue damage or both.

Plan of care is the overall approach to the assessment, management, and evaluation of a patient's care, and is designed to address the expectations and needs the child and family consider priorities.

Policy is a course of action to guide and determine present and future directions

Preferred practice guideline is the recommended approach to care, and may be consensus or evidence-based. The guideline must be flexible enough to allow caregivers to meet the wide range of child/family expectations and needs.

Principle is a fundamental truth.

Quality care is the continuous striving by an interdisciplinary team or program to meet the expectations and needs of the children and families it serves.

Quality of life is well being as defined by each individual and often includes various domains such as: physical health, mental health, social and role functioning, sense of well-being, freedom from bodily pain and other physical distress, satisfaction with health care, and overall sense of general health.

Respite care may be a setting of care, a program or a service that provides additional services. Respite care may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility or hospice.

Setting of care refers to the location that hospice palliative care is provided and may include the child's home, tertiary or rehabilitative hospitals or long term care facilities, and respite or hospice settings.

Spirituality is an existential construct of the ways in which a person makes meaning and organizes his or her sense of self around a personal set of beliefs, values and relationships.

Standard is an established measurable condition or state used as a basis for comparison for quality and quantity.

Substitute decision maker is a person or agency of substitute recognized by law to act for, and in the best interest, of the child.

Supportive care is another term for palliative or hospice care that is considered to be more understandable and acceptable to patients and their families, especially children.

Suffering is a state of distress associated with events that threaten the intactness of a person. Perceptions of suffering may be influenced by culture, developmental levels, and social mores related to the death of a child.

Therapeutic relationship is a relationship between skilled caregivers and the patient/family that aims to change the patient's and family's experience of illness and bereavement.

Truth-telling is the communication of what is known or believed to be true without deceit or falseness.

Unit of care is the people who are the focus of a plan of care.

Value is a fundamental belief on which practice is based.

Volunteer is a person who freely gives of his or her time, talent and energy.

Appendix B
Informed Consent

Formal caregivers must follow a **valid informed consent process** to ensure that the child (or substitute decision maker, parent or legal guardian) has a clear understanding of a proposed procedure or treatment and the options available. This is done in the context of the clinical needs of the child.

Valid informed consent:

- must be specific to the proposed health care (a specific procedure, or course of treatment
- is given voluntarily without coercion or incentive
- is not obtained through misrepresentation or fraud.

To obtain valid informed consent:

- The health care caregiver provides the information a reasonable person requires to make the health care decision, including:
    - the condition for which health care is proposed
    - the nature of proposed health care (i.e., methods)
    - the risks and benefits of proposed health care that a reasonable person would expect to be told and that are material to the child
    - alternative courses of health care
- The child is given the opportunity to ask questions and receive answers about the proposed health care.

Appendix C
Cultural Care

This set of 8 questions was developed several years ago by Arthur Kleinman who is a psychiatrist and medical anthropologist and have been revised and updated for use in various health settings. The questions are designed to help health care caregivers understand the patient's "explanatory model" or beliefs about illness and treatment.

1. What do you call the problem?

2. What do you think has caused the problem?

3. Why do you think it started when it did?

4. What do you think the sickness does? How does it work?

5. How severe is this sickness? Will it have a short or long term course?

6. What kind of treatment do you think the patient should receive? What are the most important results you hope he/she receives from the treatment?

7. What are the chief problems the sickness has caused?

8. What do you fear most about the sickness?

Kleinman, A., et al. Culture, Illness and Care: Clinical Lessons from Anthropological and Cross-Cultural Care Research. Annals of Internal Medicine, 1978:88

Appendix D
Techniques for Negotiating Issues Influenced by Culture that are Important in End of Life Care

This table can be used as a template for techniques and strategies to address the significant spiritual, social, cultural, and psychological issues in hospice palliative care.

Issues	Possible Consequences of Ignoring the Issue	Techniques and Strategies to Address the Issue
Responses to inequity in care	Lack of trust	Address directly: "I wonder whether its hard for you to trust a physician who is not _____(of your same background)?"
	Increased desired for futile aggressive care at the end of life	Make explicit that you and the patient and their family will work together in achieving the best possible care.
		Work to improve access and reduce inequities.
	Lack of collaboration with patient and with the family.	Understand and accommodate desires for more aggressive care, and use respectful negotiation when this is contradicted or medically futile.
	Dissatisfaction of care by all parties involved	
Communication/language barriers	Bi-directional misunderstanding.	Take time to:
		Avoid medical or complex jargon.
	Unnecessary physical, emotional,	Check for understanding: "So I can make sure I am

	and spiritual suffering.	explaining this well for you, please tell me what your understanding is about your illness and the treatment we're considering."
		Hire bilingual, bicultural staff and train in medical translation to be bridges across cultures. Translators are preferable in person, but use ATT language line or similar services, if trained staff unavailable.
		Avoid use of family as translators, especially minors.
Religion and spirituality	Lack of faith in the physician Lack of adherence to the treatment regime	"Spiritual or religious strength sustains many people in times of distress. What is important for us to know about your faith or spiritual needs?" "How can we support your needs and practices?" "Where do you find your strength to make sense of this experience?"
Truth telling	Anger, mistrust, or even removal of patient from health care system if team insists on informing the patient against the wishes of the family. Hopelessness in the patient if he or she misunderstands your reason for telling him or her directly.	Informed refusal: "Some patients want to know everything about their condition, others prefer that the doctors mainly talk to their families. How would you prefer to get this information?" Use of hypothetical case, e.g., "Others who have conditions similar to yours have found it helpful to consider several options for care, such as nutrition, to keep them feeling as well as possible." Be cognizant of nonverbal and indirect communication when discussing serious information.
Family involvement in decision-making	Disagreement and conflict between family and medical staff when the	Ascertain the key members of the family and ensure that all are included in discussions as desired by the patient:

	family, rather than the patient, insists on making decisions.	"Is there anyone else I should talk to about your condition?" Talk with whoever accompanies the patient and ask the patient about this individual's involvement in receiving information and decision-making.
Hospice care	Reduced use of hospice services, leading to decreased quality of end of life care.	Emphasize hospice as an adjunct or assistance to the family but not as a replacement: " When the family is taking care of the patient at home, hospice can help them do that."

Kagawa-Singer, M. & Blackhall, L. (2001). Negotiating cross-cultural issues at end of life. Journal of American Medical Association, 286, pg. 2995.

Appendix E
Bereavement Risk Assessment

The assessment of bereavement risk presupposes that some individuals will experience grief in a way that does not fit a "normal" or expected pattern or level of intensity. Factors that influence complicated grief are:

- stage of the life cycle particularly when:
    - the bereaved parent is an adolescent and family support is perceived as inadequate.
    - the surviving parent of a deceased child is a single mother/father as a result of divorce or being widowed
    - an only child has died.

- a history of previous losses, particularly if unresolved. Losses may include:
    - loss of a pregnancy
    - loss of a job
    - divorce
    - trauma of any kind (e.g., suicide, homicide, accident) which has resulted in the person being hypervigilant, suspicious or anxious
    - more than one child sick or at end of life, or another child who has died

- the presence of concurrent or additional stressors such as:
    - family tension
    - compromised financial status
    - dissatisfaction with caregiving
    - reliance on alcohol and psychotropic medications, pre-bereavement

- physical and mental illness particularly:
    - current/past history of mental health problems that have required
    - psychiatric/psychological support
    - family history of psychiatric disorders

- high pre-death distress

- inability or restriction in use of coping strategies such as:
    - maintenance of physical self-care
    - identification of prominent themes of grief
    - attributing meaning to the loss
    - differentiation between letting go of grief and forgetting the bereaved
    - accessing available support

- isolated, alienated individuals

- low levels of internal control beliefs, such as:
    - feeling as if he/she has no control over life

- the availability of social support particularly if:
    - people in the immediate environment are, or are perceived to be, unsupportive

- family members are estranged
- care for the child becomes overwhelming
- support from family and friends immediately prior to death was good and following death it subsided
- the bereaved lack a confidant with whom to share feelings, concerns, doubts, dreams and nightmares
- the bereaved is dissatisfied with the help available during their child's illness.

Risk Factors for Complicated Grief in Bereaved Children

Risk factors for complicated grief in bereaved children may be divided into three groups:

1. Features of the loss

- Traumatic

- Unexpected

- The child's own life was in jeopardy

2. Features of the child

- History of psychiatric disorder

- Multiple losses

- Child less than 5 years old

- Adolescent

-

3. Features of the relationship

- Ambivalent/conflicted

- Unsupportive family

- Death of a father (adolescent boys)

- Death of a mother (very young children)

- Mental illness in surviving parent

- Parent acts as gatekeeper and does not allow child to make his or her own decision about getting support or even acknowledging the loss
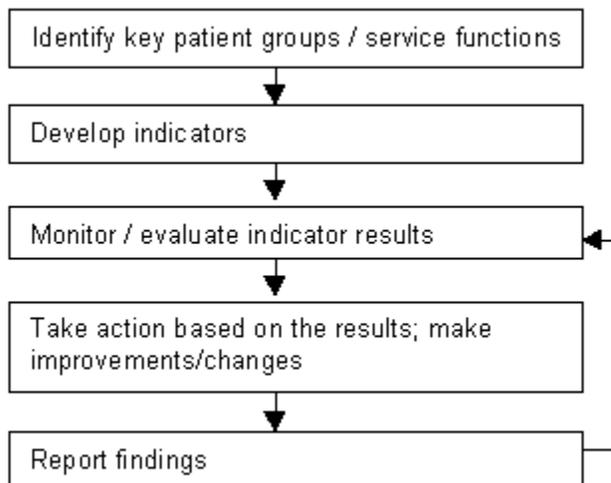
Aranda, S., Milne, D. Guidelines for the assessment of complicated bereavement risk in family members of people receiving hospice palliative care. Centre for Palliative Care, Victoria 2000

Appendix F
Quality Management

The following is a flow chart for developing steps to evaluate, monitor and improve quality of care (The Hospital for Sick Children, QM)

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┌─────────────────────────────────────────────┐
│ Identify key patient groups / service functions │
└─────────────────────────────────────────────┘
                      │
                      ▼
┌─────────────────────────────────────────────┐
│ Develop indicators                           │
└─────────────────────────────────────────────┘
                      │
                      ▼
┌─────────────────────────────────────────────┐
│ Monitor / evaluate indicator results         │◄──┐
└─────────────────────────────────────────────┘   │
                      │                            │
                      ▼                            │
┌─────────────────────────────────────────────┐   │
│ Take action based on the results; make       │   │
│ improvements/changes                         │   │
└─────────────────────────────────────────────┘   │
                      │                            │
                      ▼                            │
┌─────────────────────────────────────────────┐   │
│ Report findings                              │───┘
└─────────────────────────────────────────────┘
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Appendix G
Research Priorities and Questions

There is a paucity of research support the improvement of hospice palliative care for children and their families, although new initiatives to develop research agendas, partnerships and funding are underway. Below are specific areas of research recommended by various sources [1],[2] including clinicians' experience in this field:

- Experiences, perceptions and needs/wishes of the dying child

- Experiences, perceptions and needs/wishes of siblings, parents and significant others

- Ethical and clinical decision making processes at end of life

- The effects of uncertainty in diagnosis, prognosis, and treatment on: communication, care planning, decision making, preparing for death and grief

- Quality of life and psychosocial, spiritual processes and outcomes

- Grief and bereavement outcomes

- Approaches to support evidence-based grief and bereavement practice and standardized volunteer training

- Communication issues

- The quality, effectiveness and cost of health care services and systems

- Prognostic information and the trajectory of illness among children with life threatening condition and unexpected death

- The pain and physical/emotional symptom experiences of dying children and the effectiveness of pharmacological and psychosocial interventions

- The effectiveness/role of complementary therapies

- The effectiveness of clinical interventions

- Family and family caregiver issues

- Interdisciplinary team issues

- Existential and spiritual concerns

- Roles and relationships of different health care caregivers and others with children and families

- Contributions/predictors of delayed recognition of impending death

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[1] Field M, Berhman R. When Children Die: Improving Palliative and End-of-Life Care for Children and their Families, 2003: The National Academies Press, Washington, DC

[2] National Research Advisory Committee, CHPCA, "Canadian Agenda for Research in Palliative Care, 1999 (see http://www.chpca.net)

- Satisfaction with care
- Experience of children in other settings such as school
- Psychological impact of caregiving by health care caregivers
- Development of outcomes measures (such as quality of life measures)
- The role and experience of culture
- The role and effectiveness of hospice volunteers in the care of dying children

Potential Research Questions

What are the experiences of dying children?

What are the experiences of parents who care for a dying child?

What are the fears, wishes, hopes of dying children?

What is the spiritual/existential experience of the dying children?

What is the impact of the dying child's experience on his or her sibling(s)?

What is the quality of life of the dying child and his or her family?

What is the psychosocial sequelae for parents and siblings following the death of a child?

How do care caregivers and families communicate together about end of life care decisions?

What emotional symptoms do dying children experience (depression, loneliness, boredom, sadness)?

What interventions are effective in dealing with physical symptoms such as fatigue, pain, nausea and breathlessness?

What is the role of culture on the dying child and family's end of life and death experience?

How much do children want to be involved in decision making and what strategies are available to help make this happen?

What is the role and effectiveness of the hospital based interdisciplinary team in palliative/end of life care?

What bereavement interventions are helpful?

What are the short-term and long-term costs to society when children and teens are not provided with grief and bereavement support after the death of a sibling or friend?

What gender differences and changes over time in coping mechanisms and parental perceptions of the benefits and harms of life-sustaining and palliative interventions for fetuses or infants with specific, prenatally or postnatally determined lethal diagnosis?*

What is the effect of perinatal death on surviving or future siblings?*

What are the long term as well as short term effects on parent outcomes of interventions 0for parents who have sustained perinatal loss?*

What is the association between acute, sudden, or unexpected death of a child and the development by parents or siblings of more severe grief responses?*

What are the financial costs of families caring for a dying child at home?

What domains of quality of life are relevant for children with advanced illness and their family members?*

What standardized instruments are available to measure end of life outcomes?

What adaptation is required for measures to reflect differences in the ill child's stage of development, the nature of the illness, and other child and family characteristics?*

What is the degree and nature of agreement and disagreement between child self-reports and proxy reports by parents or others?*

What are the costs of caring for dying children in hospital or at home?

What is the role of community hospices in pediatric hospice palliative care?

What ways can we improve coordination and continuity of care for children with advanced illness?*

What are innovative methods to support children, families and caregivers in smaller communities and rural areas that promote continuity of local and regional special care including palliative, and end-of-life care?*

What are the ethical implications for parents of no CPR orders?

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CCHSA (Canadian Council on Health Services Accreditation) http://www.cchsa.ca

Children's Oncology Group (COG) (see http://www.nccf.org/cog/)

Continuous Quality Improvement Network www.thecqinetwork.com

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Food and Drug Administration (FDA) (see http://www.fda.gov/cder/pediatric/faqa)

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NACHRI (National Association of Children's Hospitals)

NAHQ (National Association for Healthcare Quality) http://www.nahq.org

National Institutes of Health, the National Institute of Child Health and Development (NICHD),
the National Institute of Mental Health (see http://www.nih.gov/)

National Institutes of Health, the National Institute of Child Health and Development (NICHD),
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Palliative Care Research Society, United Kingdom, (see http://www.pers.sghms.ac.uk)

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Pediatric Oncology Group of Ontario (POGO) (see http://www.pogo.on.ca/)

Project on Death in America (see http://www.soros.org/death/index.htm)

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The Hospital for Sick Children, Research Institute (see http://riweb.sickkids.on.ca/)

The Hospital for Sick Children, Research Institute (see http://riweb.sickkids.on.ca/)

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http://www.nserc.ca/programs/ethics/)

Hospital for Sick Children Policies or Guidelines

2.19   Guidelines for Bioethics Consultation

2.22   Consent to Treatment Policy

2.60   Levels of Treatment Guidelines for Children with Incurable Disease