Canadian Pediatric Palliative Care Nursing Competencies

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INTRODUCTION

Hospice palliative care nursing competencies developed in Canada to date have been primarily adult focused. The Canadian Nurses Association (CNA) and the Canadian Hospice Palliative Care Nurses Group developed nursing competencies that form the basis of the national certification exam for Hospice Palliative Care Nursing. While these valuable competencies can apply to many aspects of pediatrics, components specific to the pediatric field are missing.

To facilitate nationally consistent education and ongoing development of nurses entering the growing field of pediatric palliative care (PPC), a core group of thirteen nurses representing seven of the nineteen specialized PPC programs in Canada came together to develop PPC Nursing Competencies.

Using the CNA's eight domains of Hospice Palliative Care Nursing as the framework, pediatric competency documents created at Canuck Place, Roger Neilson House, and Emily's House, and pediatric specific competencies included in frameworks developed in Nova Scotia and Ontario were collected and mapped to each other and to the CNA competencies. Over a year, the core team meet regularly to review and synthesize the existing competencies and address any gaps to create a draft list of competencies. The draft list was circulated across Canada to other nurses in PPC. Ten additional nurses from across Canada provided feedback and endorsed the list of competencies.

While the CNA competencies are aimed at nurses who have two years of experience in the specialty, the core team felt it was important to distinguish competencies for nurses working as **generalists** (e.g., palliative care is not the primary focus of their practice or they are new to PPC) or **specialists** (e.g., primary focus of practice is PPC and generally have specialized education/ experience) in order to cover the breadth of knowledge and roles within PPC. Each competency is designated as being at the generalist or specialist level. Specialist PPC nurses would be expected to be competent in all of the generalist competencies as well as the specialist ones.

The competencies are applicable across all settings where children with life-threatening conditions and their families receive care including home, clinic, hospital, hospice, and long-term care. The competencies may also be applied across all types of nurses (e.g., Registered/ Licensed Practical Nurses, Registered Nurses, Nurse Practitioners) recognizing that all nurses must work within their scope of practice.

In addition to guiding education and orientation activities, the competencies can be used to enhance reflective practice for individual nurses at both the generalist and specialist level, when considering their current strengths and challenges and to plan strategies to increase their competence and advance their learning.

Our hope is that by delineating and using these competencies to guide nursing education and practice across the country, the quality and consistency of PPC delivery will be enhanced.

TERMS and DEFINITIONS

Key terms used throughout the competencies are defined below. For definitions of other terms please refer to the *Lexicon of Terms for Pediatric Palliative Care*.[1]

Child and Pediatric encompass fetuses who may be diagnosed with a life-threatening condition in utero (e.g., perinatal palliative care), infants, children, and youth age 0 – 19 years. However, these competencies may also be applicable to young adults who are cognitively or developmentally delayed.

Family is the social unit most proximate to the child. It may variably consist of parents, siblings, grandparents and/or other household members.[1]

Life-threatening conditions include those for which curative treatments may be feasible but may fail, or those for which a cure is not possible and from which an affected child is expected to die.[1] Related terms include life-shortening, life-limiting, serious illness, or medical complexity. For consistency we have chosen to use life-threatening conditions throughout the document.

Pediatric Palliative Care is an active and total approach to care provided to children with life-threatening conditions and their families from the time of recognition or diagnosis of disease, throughout the illness, at the time of death and beyond. It is typically provided by an interprofessional team with consideration given to biopsychosocial-spiritual elements to meet desired outcomes. Care is focused on comfort rather than cure, although both approaches may exist simultaneously. PPC includes management of symptoms, provision of respite, coordination of services, delivery of end-of-life care, and provision of bereavement support.[1]

[1] Spicer, S., Macdonald, M.E., Davies, D., Vadeboncoeur, C., & Siden, H.B. (2015). Lexicon of Terms in Pediatric Palliative Care. *Pediatrics & Child Health, 20*(3), 155-156.

Domain 1: Child and Family Centered Care

1.1 Assists the child and family in exploring their responses to the diagnosis and experience of living with a life-threatening condition. **(Generalist)**

1.2 Explores the cumulative losses inherent in the experience of a life-threatening condition and its impact on the child and family (e.g., anticipatory grief). **(Specialist)**

1.3 Assesses and understands the connection between the life-threatening condition and:
1.3a cultural practices (e.g., values, beliefs, traditions)
1.3b spiritual practices (e.g., values, beliefs, traditions)
1.3c family dynamics, structure, roles, responsibilities (e.g., role change, stressors)
1.3d family composition
1.3e life experiences of the child and family
1.3f the impact on siblings (taking into account their developmental needs)
1.3g developmental stages of individuals and family members as a whole. **(Generalist)**

1.4 Assists the child and family to identify and develop coping strategies in adapting to the life-threatening condition and the dying experience. **(Specialist)**

1.5 Uses effective verbal and non-verbal communication skills (e.g., presence, empathy, reflective listening) to facilitate discussion and explore understanding with the child and family regarding:
1.5a diagnosis
1.5b prognosis
1.5c change in health status (e.g., delivering bad news)
1.5d goals of care
1.5e decision-making
1.5f conflict resolution
1.5g literacy
1.5h advance care planning
1.5i treatments, procedures and investigations
1.5j location of care/death
1.5k organ/tissue/body donation and autopsy
1.5l dying and death
1.5m loss, grief, and bereavement
1.5n adverse events. **(Specialist)**

1.6 Demonstrates the ability to use sensitive, effective communication strategies with distressed children, parents, and the extended family. **(Generalist)**

1.7 Assists the child and family to determine components that contribute to their quality of life through exploration of beliefs and values about living and dying. **(Generalist)**

1.8 Supports the child and family in making informed choices that are consistent with their values and beliefs as the illness progresses. **(Specialist)**

1.9 Responds to the uncertainty and vulnerability experienced by the child and family. **(Generalist)**

1.10 Assists the child and/ or family to explore and address sensitive, personal, and privacy issues related to:
1.10a intimacy
1.10b sexuality
1.10c sexual function
1.10d body image
1.10e gender identity
1.10f self-concept and self-esteem
1.10g abuse/ neglect (e.g., physical, verbal, emotional, financial). **(Specialist)**

1.11 Assists the child to develop, maintain and promote functional capacity and independence, to the extent possible, as the illness advances. **(Generalist)**

1.12 Recognizes and addresses stressors (e.g., exhaustion of family members) of caring for a child with a life-threatening condition. **(Generalist)**

1.13 Uses strategies that promote the possibility of child and family spiritual growth throughout the experience of living with a life-threatening condition (e.g., life review/ legacy, reconciliation strategies, being present) or caring for someone with a life-threatening condition. **(Generalist)**

1.14 Assists the child and family to identify and receive care in the setting of choice, or the care settings that best meet their needs, including at the end of life. **(Specialist)**

Domain 2: Pain Assessment and Management

2.1 Demonstrates knowledge of the concept of "total pain" and its multidimensional factors. **(Generalist)**

2.2 Identifies the multidimensional factors that influence the child's "total pain" experience and identifies potential interventions. **(Specialist)**

2.3 Demonstrates knowledge of the physiology of pain regarding:
2.3a transduction
2.3b transmission
2.3c modulation
2.3d perception. **(Generalist)**

2.4 Demonstrates an understanding of the classifications of pain and their importance in effective management including:
2.4a acute
2.4b chronic
2.4c neuropathic
2.4d nociceptive (somatic & visceral). **(Generalist)**

2.5 Demonstrates knowledge of the unique considerations of pain assessment and management for children. **(Generalist)**

2.6 Demonstrates knowledge and use of developmentally appropriate pain assessment tools for children who are non-verbal, pre-verbal, or cognitively impaired. **(Generalist)**

2.7 Conducts, documents, and evaluates a comprehensive, developmentally appropriate pain assessment which may include use of validated tools, child/ parent/ guardian report as well as physiological signs. **(Generalist)**

2.8 Integrates principles of pain assessment and management into the delivery of care. **(Generalist)**

2.9 Identifies, addresses, and educates to overcome barriers to pain management, including myths and misconceptions related to opioids. **(Generalist)**

2.10 Develops, evaluates, reassesses, and revises the pain management plan in collaboration with the child, family, and interprofessional team. **(Specialist)**

2.11 Demonstrates knowledge of the stepped approach to pain management based on severity and type of the pain. **(Generalist)**

2.12 Demonstrates knowledge of medications commonly used for pain management and their potential side effects, interactions, or complications. **(Generalist)**

2.13 Uses techniques of medication administration appropriate to the types and severity of pain (e.g., breakthrough doses, route, scheduling, and titration). **(Generalist)**

2.14 Demonstrates in-depth knowledge of medications commonly used for pain management and anticipates and manages side effects, interactions, or complications including:
2.14a constipation
2.14b opioid-induced neurotoxicity (e.g., myoclonus, delirium, hyperalgesia)
2.14c pruritus/ urticaria
2.14d nausea/ vomiting
2.14e respiratory depression (e.g., opioid-naive)
2.14f sedation. **(Specialist)**

2.15 Demonstrates knowledge of indications for opioid rotation. **(Specialist)**

2.16 Demonstrates knowledge of opioid dosing, breakthrough dose calculations, and equianalgesic conversions. **(Specialist)**

2.17 Demonstrates understanding of the use of adjuvant medications in managing pain (e.g., non-steroidal anti-inflammatory drugs, corticosteroids, anticonvulsants, antidepressants, antipsychotics, chemotherapy). **(Specialist)**

2.18 Demonstrates understanding and use of non-pharmacological interventions in managing pain (e.g., radiation therapy, surgery, physiotherapy, rehabilitation therapy). **(Generalist)**

2.19 Demonstrates understanding and incorporates developmentally appropriate non-pharmacological strategies to manage pain into practice (e.g., heat, massage, cold, skin-to-skin contact). **(Generalist)**

2.20 Demonstrates understanding and incorporates complementary and alternative therapies for pain management into practice (e.g., traditional, homeopathic). **(Specialist)**

2.21 Acknowledges and supports the child’s and family's decision to seek complementary and alternative therapies for pain management and encourages them to inform the health-care team about their use. **(Generalist)**

2.22 Supports children and families to learn strategies to manage pain. **(Generalist)**

2.23 Evaluates the effectiveness of pain interventions. **(Generalist)**

Domain 3: Symptom Assessment and Management

3.1 Demonstrates knowledge of the unique considerations of symptom assessment and management for children. (**Generalist**)

3.2 Conducts, documents, and evaluates a comprehensive, developmentally appropriate assessment of symptoms, which may include use of validated tools, child/ parent/ guardian report as well as physiological signs. **(Generalist)**

3.3 Recognizes the following common and expected symptoms:

3.3a Neurological:

i) extrapyramidal symptoms
ii) fatigue/ sleep disturbances
iii) sedation
iv) fatigue
v) paresthesia/ neuropathy
vi) seizures
vii) spinal cord compression
viii) increased ICP
ix) dystonia
x) dysautonomia
xi) spasticity
xii) neuro-irritability **(Generalist)**

3.3b Cognitive:

i) agitation/ restlessness/ irritability
ii) confusion
iii) regression
iv) delirium **(Generalist)**

3.3c Cardiovascular:

i) edema
ii) mottling
iii) cyanosis
iv) superior vena cava syndrome **(Generalist)**

3.3d Respiratory:

i) obstructive apnea
ii) central apnea
iii) secretions
iv) cough
v) dyspnea
vi) pleural effusion
vii) hiccups **(Generalist)**

3.3e Gastrointestinal:

i) reflux
ii) bowel incontinence
iii) bowel obstruction
iv) constipation
v) diarrhea
vi) jaundice
vii) nausea
viii) vomiting

ix) dysphagia
x) feeding intolerance
xi) anorexia
xii) drooling
xiii) ascites **(Generalist)**

3.3f Nutritional and Metabolic:
i) feeding intolerance
ii) anorexia
iii) cachexia
iv) dehydration
v) ascites **(Generalist)**

3.3g Genitourinary:
i) bladder spasms
ii) urinary incontinence
iii) urinary retention **(Generalist)**

3.3h Immune System:
i) fever
ii) temperature dysregulation
iii) anaphylaxis
iv) infections
v) sepsis
vi) pyrexia **(Generalist)**

3.3i Musculoskeletal:
i) pathologic fractures
ii) weakness **(Generalist)**

3.3j Skin and Mucous Membranes:
i) mucositis
ii) pruritus
iii) xerostomia
iv) wounds: pressure ulcers, fistulas, tumour necrosis **(Generalist)**

3.3k Hematologic:
i) anemia
ii) thrombocytopenia
iii) neutropenia
iv) hemorrhage **(Generalist)**

3.3l Psychosocial and Spiritual:
i) acceptance/ adjustment
ii) anger
iii) anxiety/ worry/ burden
iv) connection
v) denial
vi) depression
vii) fear
viii) forgiveness
ix) grief
x) guilt
xi) hope

xii) hopelessness
xiii) meaning
xiv) purpose
xv) suicidal/ homicidal ideations
xvi) withdrawal **(Generalist)**

3.3m Emotional and Behavioural:
i) anxious
ii) sad/ withdrawn
iii) fatigue
iv) irritable
v) confused **(Generalist)**

3.4 Recognizes and responds to manifestations of the following common emergencies:
3.4a acute bowel obstruction
3.4b delirium
3.4c electrolyte imbalance (e.g., hypercalcemia, hyperkalemia)
3.4d hemorrhage
3.4e pain crisis
3.4f pulmonary embolism
3.4g seizures
3.4h sepsis
3.4i spinal cord compression
3.4j superior vena cava syndrome. **(Generalist)**

3.5 Anticipates potential symptoms and prepares and educates families about what may be expected. (**Specialist**)

3.6 Analyses the assessment to identify the possible causes of symptoms. **(Specialist)**

3.7 Identifies and implements interventions to correct reversible causes of symptoms while taking into consideration the child and family's goals of care. (**Specialist**)

3.8 Develops, evaluates, reassesses, and revises the symptom management plan in collaboration with the child, family, and interprofessional team. **(Specialist)**

3.9 Advocates for illness-modifying therapies (e.g., oral chemotherapy) consistent with the child's and family's goals of care, and that have the potential to relieve the child's suffering and/ or improve quality of life without disproportionate risk or burden. (**Specialist**)

3.10 Demonstrates knowledge of medications commonly used for symptom management and their potential side effects, interactions, or complications. (**Generalist**)

3.11 Uses medication administration techniques appropriate to the types and severity of symptoms, and condition of the child (e.g., routes, scheduling, titration, pumps). (**Generalist**)

3.12 Demonstrates understanding and incorporates developmentally appropriate non-pharmacological strategies to manage symptoms into practice (e.g., heat, massage, cold, skin-to-skin contact). (**Generalist**)

3.13 Demonstrates understanding and incorporates complementary and alternative therapies for symptom management into practice (e.g., traditional, homeopathic). **(Specialist)**

3.14 Acknowledges and supports the child's and family's decision to seek complementary and alternative therapies for symptom management and encourages them to inform the health-care team about their use. **(Generalist)**

3.15 Explores family's goals for use of complementary and alternative therapies and educates as necessary. (**Specialist**)

3.16 Supports children and families to learn strategies to manage symptoms. **(Generalist)**

3.17 Evaluates the effectiveness of interventions to manage symptoms. **(Generalist)**

Domain 4: Care at the End of Life

4.1 Recognizes, anticipates, and manages the symptoms of imminent death. **(Generalist)**

4.2 Demonstrates knowledge of pain and symptom assessment and management strategies unique to the final days/ hours of life. **(Generalist)**

4.3 Educates the child and family on the signs of imminent death including:
4.3a cognitive changes (e.g., decreased level of consciousness, restlessness)
4.3b physical changes (e.g., respiratory changes, skin discolouration, decreased urinary output)
4.3c psychosocial changes (e.g., social withdrawal, decreased communication).
(Specialist)

4.4 Provides education to the family about pharmacological and non-pharmacological comfort measures associated with imminent death (e.g., oral care, eye care, skin care, positioning) and supports them to provide these measures as appropriate. **(Generalist)**

4.5 Assists the family during the dying process to:
4.5a cope with their emotional responses (e.g., uncertainty, fear, anger, guilt, remorse, relief)
4.5b contact the appropriate resources and support (e.g., significant others, spiritual advisor, health professionals, funeral services)
4.5c discuss and make decisions related to funeral arrangements, autopsy, and organ/ tissue donation. **(Specialist)**

4.6 Identifies and honours the child's and family's wishes for privacy and important rites or rituals for life closure, gift giving, legacies, and other meaningful activities, offering presence as appropriate. **(Generalist)**

4.7 Facilitates arrangements for pronouncement and certification of death, in accordance with local regulations. **(Generalist)**

4.8 Facilitates care and transportation of the body in a respectful manner. **(Generalist)**

4.9 Prepares the family for the eventual closure of the nurse-family relationship. **(Generalist).**

Domain 5: Grief, Loss, Bereavement

5.1 Demonstrates knowledge of loss, grief, bereavement, and expressions of grief in children at different developmental stages. **(Generalist)**

5.2 Demonstrates comprehensive understanding of models of grief and bereavement. **(Specialist)**

5.3 Assists the family in understanding the concept of loss and the typical process of grief and bereavement, considering developmental stages, cultural values, and making referrals as needed. **(Generalist)**

5.4 Identifies at-risk families and types of grief including:
5.4a anticipatory
5.4b complicated
5.4c uncomplicated
5.4d disenfranchised
5.4e unresolved. **(Specialist)**

5.5 Recognizes the manifestations of grief including:
5.5a behavioural/ social
5.5b cognitive
5.5c emotional
5.5d physical
5.5e spiritual. **(Generalist)**

5.6 Recognizes the differences between depression and grief. **(Specialist)**

5.7 Supports families through grief and adjustment through trauma informed lens. **(Specialist)**

5.8 Demonstrates knowledge of and facilitates access to community resources for grief and bereavement supports. (**Specialist**)

5.9 Assists the family to anticipate and cope with their grief reactions to loss and death, considering the unique needs of children at various developmental stages. **(Specialist)**

5.10 Assists the family to recognize and value the ill child's legacy. **(Generalist)**

5.11 Understands the factors that shape a child's experience of illness and death and the impact these experiences may have. **(Specialist)**

5.12 Recognizes the roles of the various members of the care team in providing grief and bereavement support. **(Generalist)**

Domain 6: Collaborative Practice

6.1 Identifies the strengths and needs of the child and family in collaboration with the interprofessional team to define goals of care and to develop, implement, and evaluate a plan of care. **(Generalist)**

6.2 Collaborates with the child, family, and other care providers (e.g., primary health-care provider, community team, etc.) to facilitate and coordinate smooth transitions between institutions, settings and services. **(Specialist)**

6.3 Advocates for and facilitates referrals to appropriate interprofessional team members and other support services (e.g., volunteers, personal support workers, non-profit organizations). **(Generalist)**

6.4 Assumes a leadership role in coordinating care and referrals to appropriate team members to ensure appropriate supports are in place for the child and family. **(Specialist)**

6.5 Participates in family conferences/ meetings. **(Generalist)**

6.6 Assumes leadership in family conferences/ meetings. **(Specialist)**

6.7 Assists the child and family to access appropriate information and resources to address:
6.7a physical needs
6.7b practical needs
6.7c psychological needs
6.7d social needs
6.7e spiritual needs. **(Generalist)**

6.8 Contributes to the overall functioning and well-being of the interprofessional team. **(Generalist)**

Domain 7: Education, Research, Professional Identity and Advocacy

7.1 Demonstrates awareness of and integrates the philosophy, values, principles, and practices of pediatric palliative care including knowledge of the variety of life-threatening conditions in children and their anticipated trajectories. **(Generalist)**

7.2 Provides formal or informal education about the philosophy, values, principles, and practices of pediatric palliative care to:
7.2a children and families
7.2b health professionals
7.2c public
7.2d students
7.2e volunteers. (**Specialist)**

7.3 Recognizes the impact of diversity in nurses' personal values and beliefs related to life, death, spirituality, religion, culture, and ethnicity on provision of care. **(Generalist)**

7.4 Recognizes professional issues unique to pediatric palliative care and identifies and uses appropriate coping strategies that maintain well-being. **(Generalist)**

7.5 Participates in ongoing educational activities and applies new knowledge to clinical practice in pediatric palliative care. **(Generalist)**

7.6 Accesses and integrates knowledge gained from research in pediatric palliative care and related areas into clinical practice. **(Generalist)**

7.7 Accesses and integrates knowledge gained from research in pediatric palliative care and related areas into educational activities and system change. **(Specialist)**

7.8 Identifies need for new knowledge related to pediatric palliative care and leads or participates in research to address knowledge gaps. **(Specialist)**

7.9 Identifies potential barriers to conducting research in pediatric palliative care (e.g., vulnerable population, participant attrition, sample size, lack of validated instruments, ethics approval). **(Specialist)**

7.10 Participates or leads in the development, monitoring, and evaluation of the quality of pediatric palliative care programs and services. **(Specialist)**

7.11 Advocates for the rights of the child and family by:
7.11a recognizing challenges (e.g., burden of care, caregiver job protection, potential misuse of medications/ diversion, abuse)
7.11b identifying the needs of underserved populations (e.g., homeless, indigenous, rural/ remote communities)
7.11c promoting equitable and timely access to appropriate resources including opportunities for education and play. **(Generalist)**

7.12 Advocates for health-care professionals to have continuing education and adequate resources to provide pediatric palliative care. **(Specialist)**

7.13 Advocates for the improvement of health care and social policy supporting pediatric palliative care at the appropriate level (e.g., healthcare/ educational institutions, government). **(Specialist)**

Domain 8: Ethical and Legal Issues

8.1 Collaborates with the child, family and inter-professional team to address ethical issues related to end-of-life care, such as:
8.1a withdrawing/ withholding life-sustaining treatment (e.g., dialysis, nutrition/hydration, ventilation, transfusion, internal defibrillators)
8.1b advance care planning
8.1c medical directives
8.1d medical assistance in dying (MAID)
8.1e futility
8.1f palliative sedation
8.1g principle of double effect
8.1h resource allocation
8.1i truth telling/disclosure. **(Specialist)**

8.2 Uses an ethical framework (e.g., grid, decision-making process) and consultation with ethics services to address challenging situation. **(Specialist)**

8.3 Supports the child and family regarding relevant legal issues (e.g., advance care planning, medical directives, guardianship and substitute decision-maker). **(Specialist)**

8.4 Supports informed choices that the child and family have made regarding ethical concerns **(Generalist)**

8.5 Demonstrates an understanding of the role children may play in care decisions. **(Generalist)**

8.6 Collaborates with the child, family, and interprofessional team to navigate the role that children play in their care decisions. **(Specialist)**

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BC Centre for Palliative Care. *Inter-professional Palliative Competency Framework*, 2018.

Canadian Nurses Association, *Hospice Palliative Care Nursing Certification: Exam Blueprint and Specialty Competencies,* 2019.

Canuck Place Children's Hospice, *Pediatric Palliative Care Nursing Competency Assessment*, 2017

Carver J, Dupere D, Ganong S, Henderson D, Jewers H, McKim A, et al. The Palliative Care Capacity Building Working Group. *The Nova Scotia Palliative Care Competency Framework: A Reference Guide for Health Professionals and Volunteers*. Halifax, Nova Scotia: Nova Scotia Health Authority, 2017.

Emily's House Children's Hospice. *Skills Development Checklist*, 2016

Ontario Palliative Care Network. *The Ontario Palliative Care Competency Framework: A Reference Guide for Health Professionals and Volunteers*, 2019.

Roger Neilson House. *Nursing Competencies Check List*, 2017

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We wish to thank all healthcare providers across Canada who are committed to PPC delivery and particularly the nurses who offered feedback and review of this document during the development process. We also want to that the children and their families who we have encountered through our work. They have allowed us into their rooms and homes at their most vulnerable of times. Their experiences, challenges, and strength continue to teach and inspire us to deliver the best care possible to all children and families.