

Practice Standards and Competencies for Nurses Providing Pediatric Non Malignant Hematology Care in Atlantic Canada

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Atlantic Provinces Pediatric Hematology Oncology Network (APPHON)/

Réseau d'Oncologie et Hématologie Pédiatrique des Provinces Atlantiques (ROHPPA)

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**Practice Standards and Competencies for Nurses Providing
Pediatric Non Malignant Hematology Care in Atlantic Canada based on
APPHON's Levels of Care Approach to Care Delivery**

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Practice Standards and Competencies for Nurses Providing Pediatric Non-Malignant Hematology Care in Atlantic Canada

Introduction

The Atlantic Provinces Pediatric Hematology and Oncology Network (APPHON/ROHPPA) is the Atlantic professional voice for health professionals providing hematology and cancer care to children/youth and their families. In 2004, APPHON/ROHPPA developed a framework and guidelines for the delivery of hematology and cancer care to children in the Atlantic Provinces described in their Levels of Care document (revised 2006). Within this framework, nurses and other health professionals at health centres that care for this patient population will be required to have the competencies required to provide the level of care that their centre has been assessed able to provide. This document describes Nursing practice standards and competencies for those nurses providing hematology care to children/youth and their families based on each Level of Care. The nurse at each level of care should be able to demonstrate knowledge and skill consistent with that level of care.

In pediatric practice, in contrast to adult practice, hematology nursing care usually refers to non-malignant hematology disorders. The scope of pediatric hematology nursing is vast including subspecialties within this broad title. Diagnoses range from inherited [gene and chromosomal disorders] versus acquired [caused by virus, radiation, chemical, medications exposure]; rare to common; mild to severe; acute versus chronic; and transient versus permanent. They include red blood cell disorders, marrow failure syndromes, disorders of thrombosis & hemostasis, and defects of the phagocyte system, as well as a few malignant/premalignant diagnoses.

Nurses can be termed generalists or specialists. Registered Nurses are prepared as generalists through basic nursing education [Canadian Nurses Association, Framework for the Practice of Nurses in Canada, 2007, p. 16]. As nurses acquire and develop nursing skills and competencies, they move along a continuum of practice from novice to expert [as described by Benner, 1984], building on entry-level competencies. They gain expertise through clinical practice and increased knowledge through continuing education [formal and informal]. A specialist nurse develops expertise in a chosen area of practice by enhancing her education in that specific field or nursing specialty. She may develop this specialized knowledge and skills through self learning, specialty certification, mentorship, academic programs or other pursuits.

The nurses who care for this pediatric population with mainly non-malignant hematology disorders in Atlantic Canada, include generalists and specialists in Emergency Departments and Ambulatory Care Units, pediatric or cross trained nurses on pediatric specific or shared inpatient units, pediatric and oncology nurses who care for the pediatric oncology population, and specialized nurses who care for the hematology and/or bleeding disorder pediatric population or a combined adult/child population.

The nursing care required for this population is dependant on the diagnosis and treatment plan, e.g., children with bleeding disorders on home infusion programs may require very little nursing care at a home hospital. At centres providing basic level care, care would mainly be laboratory visits [with no nurse involvement] or in Emergency Departments for disease or treatment complications or emergencies. There the child would be assessed and treated, or stabilized, and transferred to another centre that could provide more complex care if required. Care would be directed by the physician. Nurses at this level would be generalists [or emergency nurse specialists] expected to have the competencies required by a generalist nurses or an emergency nurse specialist. This includes general assessment skills, transfusion of urgent or emergency blood products, intravenous antibiotic administration, etc. Therefore, this document starts at the intermediate level where additional competencies would be expected.

Standards and competencies specific for pediatric hematology nursing could not be found. They do not exist in Canada. However, there are national and international related associations that have produced care standards and practice guidelines. The Canadian Association of Nurses in Hemophilia Care [CANHC] [2006] described the role of the Hemophilia Nurse Coordinator in five key areas of practice: clinical practice, communication, outreach services, administration and research. They delineated the competencies required in these five areas including knowledge base, skills and application. The Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders [2007, page 27] identified the scope of nursing practice/service in reference to core accountabilities. The Atlantic Provinces Pediatric Hematology Oncology Network [APPHON/ROHPPA] developed Practice Standards and Competencies for Nurses Providing Pediatric Cancer Care in Atlantic Canada [2007] based on APPHON's Levels of Care approach to care delivery, by adapting the Canadian Association of Nurses in Oncology's [CANO] 2006 Practice Standards and Competencies for the Specialized Oncology Nurse].

The Association of Pediatric Hematology Oncology Nurses [APHON] recognizes that APHON members care for children with hematological and oncological disorders. They developed a CD-ROM educational course, APHON's Foundations of Pediatric Hematology Nursing: A Comprehensive Orientation and Review Course [2007], with overviews of nursing issues involved in caring for children and adolescents with non-malignant blood diseases. In the future they are planning to develop [collaboratively with specialized hematology associations] a Statement on the Scope and Standards of Practice of Pediatric Hematology Nursing.

This document describes nursing practice standards and competencies for those nurses providing care to children with non-malignant hematology disorders and their families in the Atlantic Provinces. These were developed adapting, building upon, and expanding standards and competencies recognized by APPHON and CANHC, and the educational foundations developed by APHON as noted above]. Competencies recognized by the CANHC for a hemophilia nurse coordinator are consistent with competencies for the subspecialty level nurse. And standards and many of the competencies determined by

APPHON for the nurse caring for the oncology population are consistent with those required by the nurses who care for the pediatric hematology population. Many nurses in Atlantic Canada, in fact, care for both populations.

This document has been developed with the understanding that the nurse is currently meeting nursing standards of practice as identified by her/ his provincial professional nursing association, and complying at minimum with basic ethical principles.

The practice standards and associated competencies identified in this document are minimum standards from which to practice. The scope and depth of knowledge and skill of the nurse should pertain to the particular patient population that he/she is caring for, not to all hematology populations.

Each nurse is professionally responsible to remain current in practice through experience, ongoing education, and appropriate, up-to-date training.

Included in this document is a self-assessment tool. The tool can be used by the nurse, the nurse's manager, or other appropriate person to evaluate practice. The tool should help evaluate knowledge, skill and practice needs to further advance practice. Managers or other appropriate persons can also use the tool to obtain and maintain the structures, processes and educational programs that need to be in place to help the nurse continue to meet these minimum standards.

The basis of pediatric hematology care delivery in the Atlantic Provinces is a family-centered, shared care philosophy. Within this context, the individual with a hematologic diagnosis refers not only to the person with this diagnosis but also includes the family. Care may be shared between and among different professionals, different settings, and across provinces.

Each nurse is expected to be able to search for further information as needed, and seek appropriate guidance or direction as care needs require. This is irrespective of the level of care one is practicing within or whether one is practicing as a generalist or specialist nurse.

Competencies are pertinent throughout the entire health care experience and apply to all settings where nurses provide care.

Development of Practice Standards and Competencies for the Nurse Providing Pediatric Non-Malignant Hematology Care in Atlantic Canada

Individual's Experience with Non-Malignant Hematology Disorders

Practice Standards and Competencies for the Nurse Providing Pediatric Cancer Care in Atlantic Canada

- Health Assessment
- Supportive and Therapeutic Relationships
- Management of Treatment Side Effects and Cancer Symptoms
- Teaching and Coaching
- Facilitating Continuity of Care/ Navigating the System
- Decision Making and Advocacy
- Professional Practice and Leadership. [2007]

The Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders

Scope of nursing practice/service core accountabilities:

- services that enhance health by assessing, monitoring, detecting and preventing complications associated with certain health situations or treatment plans.
- services that enhance health by assessing, monitoring, detecting and treating the human responses.
- services directed towards prevention of disease and injury and/or the promotion, maintenance or restoration of health.
- skills necessary for the administration and teaching of infusion therapies. [2007, p.27]

Hemophilia Nurse Coordinator Job Description

Key areas of practice:

- clinical practice
- communication
- outreach services
- administration
- research

Canadian Association of Nurses in Hemophilia Care [CANHC] [2006]

APHON's Foundations of Pediatric Hematology Nursing: A Comprehensive Orientation and Review Course

Association of Pediatric Hematology Oncology Nurses [APHON/ROHPPA] [2007]

Practice Standards and Competencies for the Nurse Providing Pediatric Non-Malignant Hematology Care in Atlantic Canada

Health Assessment
 Supportive and Therapeutic Relationships
 Management of Disease Symptoms and Treatment Side Effects
 Teaching and Coaching
 Facilitating Continuity of Care/ Navigating the System
 Decision Making and Advocacy
 Professional Practice and Leadership

Self Assessment Tool

Practice Standards for the Nurse Providing Pediatric Hematology Care in Atlantic Canada

Practice Standard: Health Assessment

The nurse providing hematology care conducts timely assessments sensitive to language and culture of the child/youth with a hematology disorder and his/her family across the continuum of care. The nurse considers the needs and responses of the individual, family, and the context of the situation in determining the scope and depth of assessment required at a particular time.

Practice Standard: Supportive and Therapeutic Relationships

The nurse providing hematology care engages in a caring, supportive, therapeutic relationship with the child/youth with a hematology disorder and his/her family. The relationship is sensitive to the child/youth's changing physical, psychosocial, and spiritual reactions and responses.

Practice Standard: Management of Disease Symptoms and Treatment Side Effects

The nurse providing hematology care integrates and applies knowledge of hematology disorder pathophysiology, disease progression, treatment modalities, treatment side-effects and complications, and symptom problems to assess, plan, implement and evaluate the outcomes of best practice/evidence-based care and other clinical interventions.

Practice Standard: Teaching and Coaching

The nurse providing hematology care prepares the child/youth with a hematology disorder and his/her family for the many different aspects of the disorder experience and provides guidance to assist them to understand and manage the many different aspects of the experience through education, psychosocial and spiritual support, and counselling.

Practice Standard: Facilitating Continuity of Care/Navigating the System

The nurse providing hematology care promotes continuity of care, and facilitates care delivery across care settings and among health care providers by sharing information and communicating the child/youth's and family's current situation, plan of care and goals and the individual/family needs. The nurse assists the child/youth and family to navigate the health care system through understanding its structure, system and process and providing them with strategies to work within the health care system.

Practice Standard: Decision Making and Advocacy

The nurse providing hematology care enables the child/youth's and family's self-determination and informed decision making by exploring and respecting their values and information needs, enabling this process with other inter-professional health care team members, advocating on their behalf, assisting them in developing skills so they can advocate for themselves, and communicating and documenting the child/youth's and family's preferred approach to care and wishes

Practice Standard: Professional Practice and Leadership

The nurse providing hematology care engages in critical thinking, integrates evidence-based knowledge (or best practice), exercises ethical judgment, and advocates for changes when institutional policies fail to meet the needs of patients dealing with a hematology disorder.

Adapted from Atlantic Provinces Pediatric Hematology Oncology Network/ Réseau d' Oncologie et Hématologie Pédiatrique des Provinces Atlantiques (APPHON/ROHPPA) (2007), Practice Standards and Competencies for the Nurse Providing Pediatric Cancer Care in Atlantic Canada, and the Canadian Association of Nurses in Oncology/Association Canadienne des Infirmières en Oncologie (CANO/ACIO) (2006). Practice Standards and Competencies for the Specialized Oncology Nurse. Toronto, Canada: CANO/ACIO.

Atlantic Provinces Pediatric Hematology/Oncology Network's (APPHON) Levels of Care

[adapted from excerpts of the APPHON Levels of Care document, July 2006 revision]

The Levels of Care document contains the framework developed to guide decision-making to ensure that pediatric hematology and cancer care is provided in a safe, effective, multi-disciplinary, family-centred manner, and that children and adolescents will have equitable access to effective services as close to home as safely feasible. These criteria support the treatment of children with cancer or serious blood disorder in their home community within defined and accepted standards of care.

The criteria for the levels of pediatric hematology/oncology health care refer to resources (personnel, knowledge/competencies, facilities and equipment) needed to provide each level of intervention safely and effectively. Interventions will be designated as requiring basic/foundation care to sub-specialty pediatric hematology/oncology care. Each level of care requires all of the components of the previous level of care plus the additional components added for that level of care.

Home Care:

It is acknowledged that a significant portion of each child's care will be undertaken in her/his home. At varying stages of the child's course of treatment and health, the intensity of care received at home will vary. Care may include home infusions of factor product.

Physician's Office:

Physician office care will encompass basic/foundation ambulatory care including routine physical examination, regular child health monitoring, monitoring for therapy complications and side effects, emotional and psychological support, school re-integration, and provision of basic/ foundation supportive care. The child and family's home community physician is essential to maintaining continuity of care.

Basic/Foundation Care:

Centres delivering basic/foundation level care will provide low intensity, low risk ambulatory care. This includes the ability to have an emergency triage system 24 hours/day, 7 days per week able to provide immediate stabilization of a critically ill child when necessary, and provide or initiate emergency treatment for things such as bleeds or febrile neutropenia before transferring to a site able to provide more complex care. Non emergency care includes minimal supportive care such as count monitoring, immunizations, or subcutaneous (SC) injections of G-CSF.

Intermediate Care:

Intermediate level centres will provide ambulatory and low risk inpatient care [such as care and insertion of insulflon catheters, administration of intravenous Rho (D) immune globulin (WinRho SDF™) and intravenous immune globulin for Idiopathic Thrombocytopenic Purpura (ITP), and rehydration for nausea and vomiting.

Advanced Care:

Advanced level centres will provide increasingly more complex care [may include admission for such things as prevention and treatment of low risk febrile neutropenia and other hematology complications and emergencies. Where local expertise is available and timing is appropriate, surgical interventions such as placement of a port-a-cath may occur.

Sub-Specialty Care:

Sub-specialty hematology level care includes comprehensive care teams, interdisciplinary pediatric specialists, and investigation/diagnosis expertise and equipment capability. Treatment and supportive care include complex care for high-risk patients. These centres are care, academic and research resources.

Practice Standard: Health Assessment

The nurse providing hematology care conducts timely assessments sensitive to language and culture of the child/youth with a hematology disorder and his/her family across the continuum of care. The nurse considers the needs and responses of the individual, family, and the context of the situation in determining the scope and depth of assessment required at a particular time.

Competencies for Practice Standard: Health Assessment within an Intermediate Level of Care

The nurse practicing within this Level of Care demonstrates the standard by:

Physical Assessment and Health History

- performing and documenting a physical assessment and health history, focusing on known symptoms, complications, and emergencies for that particular child/youth's diagnosis and treatment.
- systematically collecting relevant data from the child/youth, family, and others using varied strategies that are sensitive to the needs of the individual and family, and the context of the situation.
- recognizing co-morbid conditions and variances from normal growth and development.
- collecting relevant clinical data using a variety of sources (vital signs, laboratory profiles, medication profiles, diagnostic imaging tests) to obtain a picture of the child/youth's physical response to the disorder and/or treatment at the time of assessment.
- identifying the various components of the CBC and other blood test results pertinent to the child/youth's disorder, and the implications of abnormalities [includes calculating the ANC].
- assessing and monitoring for potential acute and chronic physical changes to the child/youth's response to illness

- with ongoing reassessments of the clinical situation as required. Recommended to use a tool [e.g. pain flow sheet] to facilitate assessment.
- assessing, in a non judgmental way, the use of present complementary and/or alternative health practices.
- identifying if the child/youth is on a clinical trial.

Symptom Assessment

- assessing the child/youth for the presence of disease or treatment specific symptom problems (recommended that a validated assessment tool is used).
- analyzing data obtained from symptom assessments to plan, implement, and evaluate nursing interventions during urgent and emergent illness episodes.

Psychosocial, Spiritual and Cultural Assessment

- assessing the child/youth's and family's religious and spiritual practices and resources that they find helpful in times of crises.
- assessing and respecting cultural influences as they relate to the illness experience, treatment, family coping mechanisms and communication.
- assessing the child/youth and family's supportive and informational needs in relation to their desired needs.

- assessing the child/youth and family's preferred role in decision making.
- assessing the financial, social and practical concerns that may impact the care experience.
- screening for psychosocial, spiritual, and cultural distress (using validated tools as appropriate).
- promoting the child/youth and family's dignity and privacy when making any assessments.

- identifying coping strategies used by the child/youth and family, and recognizing those strategies relevant to appropriate adjustment.

Sexual Health

- assessing sexual health changes as a result of symptoms, disease, and treatment

**Competencies for Practice Standard: Health Assessment within an
Advanced Level of Care**

All the Competencies in the Intermediate Level Plus:

The nurse practicing within this Level of Care demonstrates the standard by:

Physical Assessment and Health History

- describing the impact of the disease and treatment on the child/youth's developmental level.
- recognizing co-morbid conditions and variances from normal growth and development **AND** assessing how they may impact on the illness process and the child/youth/family's response to illness.

- regularly assessing and monitoring for potential acute and chronic physical changes to the child/youth's response to illness with ongoing reassessments of the clinical situation using focused assessment tools (e.g. pain flow sheet) as appropriate.

Psychosocial, Spiritual and Cultural

- exploring and documenting the impact and meaning of illness on the child/youth and family, taking into account their present life circumstances and their view of quality of life.

Competencies for Practice Standard: Health Assessment within a Subspecialty Level of Care

All the Competencies in the Advanced Level Plus:

The nurse practicing within this Level of Care demonstrates the standard by:

Physical Assessment and Health History

- performing and documenting an initial and regular ongoing **comprehensive** physical assessments and health histories, focusing on known symptoms and complications for that particular patient population.
- using a variety of sources to collect relevant clinical data (vital signs, laboratory profiles, medication profiles, diagnostic imaging tests) to obtain a **comprehensive** in-depth picture of the child/youth's physical response to the illness/disorder.
- identifying the various components of blood test results pertinent to the hematology disorders relevant to her specialty and the implications of abnormalities.
- assessing, in a non judgmental way, the use of **past, present, or anticipated** complementary and/or alternative health practices.
- recognizing abnormalities or unexpected outcomes and synthesizing information to promote effective understanding of the situation.

Symptom Assessment

- conducting **in-depth** assessments that explore the specific symptom experience for the child/youth's treatment and Integrating it with specific symptoms for the haematology disorder.

- **critically** analyzing data obtained from ongoing symptom assessments to plan, implement, and evaluate nursing interventions during urgent and emergent illness episodes.

Psychosocial, Spiritual and Cultural Assessment

- conducting a systematic, comprehensive psychosocial, spiritual and cultural assessment that includes exploring the child/youth and family's responses to the diagnosis, their main concerns, feelings, fears, goals and understanding of prognosis.
- assessing if the child/youth has any pre-existing mental health needs including therapies and outcomes (if relevant).

Sexual Health

- assessing the child/youth (as appropriate) and family's understanding of possible changes in sexual health and fertility, and the need for sexual practice protection and birth control [if relevant].
- assessing and describing changes in body image, personal relationships, intimacy, and self-esteem.
- assessing the impact of puberty and the hematology disorder in relation to bleeding [as applicable, e.g. menstruation and excessive bleeding, sexual activity with groin and joint bleeds]
- assessing emotional responses to changes in sexual health.

Practice Standard: Supportive and Therapeutic Relationships

The nurse providing hematology care engages in a caring, supportive, therapeutic relationship with the child/youth with a hematology disorder and his/her family. The relationship is sensitive to the child/youth's changing physical, psychosocial, and spiritual reactions and responses.

Competencies for Practice Standard: Supportive and Therapeutic Relationships within an Intermediate Level of Care

The nurse practicing within this level of care demonstrates the standard by:

- demonstrating the ability to communicate with the child/youth taking into account his/her age and stage of development.
- using communication skills that include clarification, reflection, exploration, summarization and open-ended questions to facilitate the child/youth's and family's disclosure of their concerns and feelings.
- being able to actively listen to the child/youth and family recognizing that at times supportive presence may be the most appropriate intervention.
- being able to succinctly communicate [document and discuss] the child/youth's and family's reactions and responses, maintaining confidentiality, but sharing what the health care team needs to know to understand the child/youth's and

- family's situation and provide individualized care.
- being aware of the boundaries that should be maintained to have the relationship continue as a helping therapeutic relationship.
- recognizing the child/youth's and family's changing responses to the illness experience and responding appropriately to these different reactions.
- seeing the child/youth and family independent of the disease and supporting them as their lives are impacted by the disorder.
- applying knowledge to identify if a child/youth and/or family may need additional psychosocial and supportive care and referring to appropriate resources.
- assisting the child/youth and family to identify realistic goals.
- recognizing the importance of school reintegration activities.

Competencies for Practice Standard: Supportive and Therapeutic Relationships within an Advanced Level of Care

All the competencies of the Intermediate level of care plus:

The nurse practicing within this level of care demonstrates the standard by:

- describing the illness experience and the different needs, feelings, fears, concerns and losses that the child/youth/family may experience, and
- being able to comfortably participate in discussions of difficult issues and content with the child/youth/family (e.g. life altering complications, disease progression, prognosis, mortality, dying, sexual health practices or changes).
- being able to succinctly communicate [document and discuss] with the health care team, not only reactions and responses, but also the child/youth's and family's perspective, current experience, their cultural and spiritual beliefs, and the impacts on the response to treatment.

- applying knowledge of family dynamics and disease adaptation to support the child/youth's/family's adjustment to managing and living with the uncertainties of a chronic illness.
- applying supportive care strategies and best practice/evidence-based psychosocial care interventions that are within the scope of practice to facilitate effective coping.
- assisting the child/youth and family to establish/maintain relationships with individuals or groups who have significant meaning to them.
- being present to offer support to the child/youth and family during invasive procedures such as venous access and N/G tube insertion.
- facilitating participation in reintegration activities, e.g. determines child/youth has been referred (or refers) to Child Life Specialist.

Competencies for Practice Standard: Supportive and Therapeutic Relationships within a Subspecialty Level of Care

All the competencies of the Intermediate and Advanced levels of care plus:

The nurse practicing within this level of care demonstrates the standard by:

- being able to not only participate in discussions of difficult issues/content (e.g. life altering complications, disease progression, prognosis, mortality, dying, sexual health practices or changes), but initiate difficult discussions.
- using critical thinking skills and integrating best practice/evidence-based knowledge with the information collected from the health assessment to anticipate, plan, implement and
- evaluate nursing interventions aimed at restoring optimum health in all its dimensions.
- applying knowledge to identify if the child/youth and family require additional psychosocial and spiritual supportive care (e.g. depression) and referring in a timely manner.
- initiating school reintegration activities
- describing appropriate emotional, psychosocial, and behavioural responses for children/youth dealing with serious illness, as well as their siblings.
- being present for the child/youth and family during invasive procedures such as deep sedation and bone marrow aspiration and biopsy.

Practice Standard: Management of Disease Symptoms and Treatment Side Effects

The nurse providing hematology care integrates and applies knowledge of hematology disorder pathophysiology, disease progression, treatment modalities, treatment side-effects and complications, and symptom problems to assess, plan, implement and evaluate the outcomes of best practice/evidence-based care and other clinical interventions.

Competencies for Practice Standard: Management of Disease Symptoms and Treatment Side Effects within an Intermediate Level of Care

The nurse practicing within this Level of Care demonstrates the standard by:

- understanding the disease process, disease progression, prognosis, clinical presentation (signs and symptoms), risk factors, treatment plan, and possible complications of disease and treatment for the child/youth's situation.

Treatment Modalities

Pharmacological Therapy

- demonstrating an understanding of the mechanism of action, indications for, and side effects of the pharmacological agent[s] within the child/youth's treatment plan. [This includes but is not limited to corticosteroids, hormonal therapy, immunosuppressive therapy, iron therapy, vitamin and other supplements, growth factors, immunization, analgesics, antibiotics, oral contraceptives, anticoagulants, and anti-fibrinolytics.]
- demonstrating an understanding of and following standards/guidelines related to the principles of appropriate handling and administration of the pharmacological agent[s] within the child/youth's treatment plan.

- interpreting and following the portion of the child/youth's treatment plan pertinent to the setting. Seeks further direction as needed.
- notifying child/youth/family of blood results with ability to discuss impact of those results related to treatment.
- implementing and evaluating best practice/evidence-based nursing interventions on an ongoing basis to decrease the severity of side-effects and short and long term complications of pharmacological agent[s] relevant to the child/youth's treatment.

Surgery for diagnosis/treatment

- demonstrating an understanding of the role surgery plays in the aspects of the child/youth's diagnosis and treatment [if pertinent]

Other therapies

- demonstrating an understanding of the role of non pharmacological modalities pertinent to the child/youth's care such as safety measures, activity restrictions, physiotherapy, R.I.C.E.
- demonstrating an understanding of the mechanism of action, indications for, side effects, preparation, appropriate handling, administration, and dosage calculation of the blood products and related agents included in following the portion of the child/youth's treatment

plan pertinent to the setting. This includes but is not exclusive to PRBCs, platelets, cryoprecipitate, factor products, Win Rho SDF™ and IVIG for ITP.

- demonstrating an understanding of the reason for hematopoietic stem cell transplants for the treatment of the specific child/youth's disorder, and having the ability to implement and evaluate best practice/evidence-based nursing interventions for expected side effects and complications for the specific child/youth.
- demonstrating an understanding of the role of non pharmacological complementary/alternative health practice modalities such as acupuncture, massage, and therapeutic touch in a child/youth's care, and the possibility that they may interact with the child/youth's existing treatment or cause unfavourable/ harmful side effects/symptoms.

Palliative Therapies

- providing palliative care symptom management based on a broad understanding of palliative care.

Symptom and Side Effects Management

- applying knowledge of the hematology diagnosis of the child/youth [including etiology of disease symptoms and treatment complications] to anticipate disease and treatment side effects and symptoms, and to prevent or minimize problems/symptoms as they occur [using established best practice/evidence-based guidelines and interventions], and evaluating the effect of these interventions on an ongoing basis.
- demonstrating who to contact for further direction if symptom management not effective or in the

event of an unusual, unexpected symptom/side effect

Hematology Complications and Emergencies

- describing and identifying clinical presentation (signs and symptoms), risk factors, and standard treatment management of common complications related to the specific child/youth's hematology disorder and treatment. This could include but not be limited to chronic arthropathies, inhibitor or antibody development, blood born infections, aplasia, iron overload, endocrine dysfunction, or chronic organ damage.
- describing and identifying clinical presentation (signs and symptoms), risk factors, and standard treatment management related to hematology emergencies specific to the child/youth's hematology disorder and treatment. This could include but not be limited to life threatening or serious bleeds [e.g. intracranial, spontaneous, excessive blood loss, compartment syndrome], infection [e.g. acute bacteria, febrile neutropenia], crises [e.g. aplastic, vaso-occlusive, hemolytic, splenic sequestration, megoblastic], etc.
- using established guidelines to facilitate assessment and management of febrile neutropenia.

Sexual Health Issues

- consulting professionals with expertise to help the child/youth and family address sexual functioning changes, other symptoms related to sexual health changes, body image issues, self-esteem issues and relationship issues they have identified as a concern.

Safe Use of Treatment Delivery Devices (Technology)

- demonstrating an understanding of the importance of appropriate gauge and type of needle required for peripheral venous access for factor product infusion.
- demonstrating an understanding of the safety issues associated with technical devices used in the child/youth's treatment such as central venous access devices, transfer devices in factor kits, insuflon catheters, ambulatory pain pumps, etc.

- assessing and anticipating problems/issues associated with these devices.
- being able to safely manage the care of the child/youth with these devices as per existing organizational standards.

Procedural Skills

- demonstrating skill and knowledge in the provision of enteral feeding care [including insertion or assistance with insertion of a nasogastric tube [N/G], provision of feedings, and care of a feeding tube.

Competencies for Practice Standard: Management of Disease Symptoms and Treatment Side Effects within an Advanced Level of Care

All the competencies of the Intermediate level of care plus:

The nurse practicing within this level of care demonstrates the standard by:

Procedural Skills

- demonstrating skill and knowledge in provision of parenteral nutrition.

Competencies for Practice Standard: Management of Disease Symptoms and Treatment Side Effects within a Subspecialty Level of Care

All the competencies of the Intermediate and Advanced levels of care plus:

The nurse practicing within this level of care demonstrates the standard by:

- understanding the incidence, etiology, pathophysiology, laboratory findings, disease process, disease progression, prognosis, clinical presentation (signs and symptoms), risk factors, genetic implications, standard treatments/ control and nursing considerations in relation to

the management of the major hematology disorders in children/youth that are pertinent to the nurse's practice/specialty. This includes distinguishing between congenital and acquired disorders, and acute and chronic disorders. These disorders include but are not limited to:

- Disorders of Red Blood Cell
 - Hereditary Spherocytosis
 - Sideroblastic Anemia
 - Hemolytic Anemias
 - Anemias of Poor Production {Iron, B12, and Folic Acid Deficiency}

- Thalassemia
- Sickle Cell Disease
- Bone Marrow Failure
 - Acquired Aplastic Anemia
 - Marrow Failure Syndromes
 - Panctopenias, e.g., Fanconi's Anemia, Shwachman-Diamond Anemia
 - Red Blood Cell, e.g., Blackfan-Diamond Anemia
- Disorders of Thrombosis & Hemostasis
 - Disseminated Intravascular Coagulation [DIC]
 - Idiopathic Thrombocytopenia [ITP]
 - Platelet Dysfunction/Disorders
 - Venous Thrombosis
 - Inherited Bleeding Disorders/ Factor Deficiencies
 - Hemophilia A and B [factor VIII and IX]
 - Von Willibrands Disease
 - Factor XII Deficiency
 - rare factor deficiencies [factor I, II, VII, X, XI, XIII]
- Defects of the Phagocyte System
 - Neutropenia, e.g., cyclic, auto-immune, chronic benign, drug induced
- Other:
 - Polycythemia
 - Transient Myeloproliferative Disorder [TMD]
 - Myelodysplastic Syndrome [MDS]

Treatment Modalities

Pharmacological Therapy

- demonstrating an understanding of the classifications, mechanism of action, indications for, and side effects of the pharmacological agent[s] pertinent to the nurse's practice/specialty including required

monitoring and supportive care. [This includes but is not limited to corticosteroids, hormonal therapy, immunosuppressive therapy, iron therapy, vitamin and other supplements, growth factors, immunization, analgesics, antibiotics, oral contraceptives, anticoagulants, and anti-fibrinolytics.]

- demonstrating an understanding of and following standards/guidelines related to the principles of appropriate handling and administration of all pharmacological agents pertinent to the nurse's practice/specialty. This includes monoclonal antibodies.
- anticipating, planning, implementing and evaluating best practice/evidence-based nursing interventions on an ongoing basis to decrease the severity of the side effects and short and long term complications of all pharmacological agents pertinent to the nurse's practice/specialty including monoclonal antibodies.

Surgery for diagnosis/treatment

- anticipating, planning, implementing and evaluating best practice/evidence-based care interventions on an ongoing basis to decrease the severity of side-effects and short and long term complications of surgery.

Other Therapies

- demonstrating an understanding of the principles and indications for hematopoietic stem cell transplants as pertinent to the nurse's practice/specialty.
- anticipating, planning, implementing and evaluating best practice/evidence-based care interventions on an ongoing basis to decrease the severity of side-effects and short and

long term complications of hematopoietic stem cell transplants as pertinent to the nurse's practice/specialty.

Palliative Therapies

- providing increasingly complex palliative care symptom management based on a comprehensive understanding of palliative care.

Hematology Complications and Emergencies

- understanding the disease process, disease progression, prognosis, clinical presentation (signs and symptoms), risk factors, and standard treatment management related to the hematology [disease and treatment] complications as relates to the nurse's practice or specialty. This includes but is not limited to:
 - chronic arthropathies
 - inhibitor and antibody development
 - blood born infections including HIV and Hepatitis C
 - alloimmunization
 - aplasia
 - iron overload
 - endocrine dysfunction
 - chronic organ damage
- understanding the disease process, disease progression, prognosis, clinical presentation (signs and symptoms), risk factors, and standard treatments management related to the hematology [disease and treatment] emergencies as relates to the nurse's practice or

specialty. This includes but is not limited to:

- life threatening & serious bleeds
 - intracranial hemorrhage/CVA
 - spontaneous bleed
 - excessive blood loss from menorrhagia, epistaxis/other mucosal bleeding
 - compartment syndrome, nerve compression, vision loss, airway compromise
- crises
 - aplastic
 - haemolytic
 - megoblastic
 - vaso-occlusive
 - splenic sequestration
- cardiopulmonary failure
- acute chest syndrome
- sepsis
 - febrile neutropenia
 - acute bacterial infections
 - septic shock

Sexual Health Issues

- discussing the changes, stresses and challenges that a maturing adolescent may experience in relation to sexual practices, body image issues, self-esteem issues and relationship issues as a result of diagnosis or blood borne infections

Procedural Skills

- demonstrating skill and knowledge in provision of the preparation and monitoring of the child/youth and family, and assisting the physician with bone marrow aspirations and biopsies.

Practice Standard: Teaching and Coaching

The nurse providing hematology care prepares the child/youth with a hematology disorder and his/her family for the many different aspects of the disorder experience and provides guidance to assist them to understand and manage the many different aspects of the experience through education, psychosocial and spiritual support, and counselling.

Competencies for Practice Standard: Teaching and Coaching within an Intermediate Level of Care

The nurse practicing within this level of care demonstrates the standard by:

- assessing the child/youth and family's readiness to learn, their learning styles, and their preferred scope and depth of information to develop a relevant teaching plan.
- applying the principles of adult, child, and family learning when planning, implementing and evaluating best practice/evidence based nursing interventions to educate and coach the child/youth and family about the disease/disorder experience.
- adjusting one's teaching and coaching style to address factors such as life stage, culture, education and family decision-making and communication styles that impact on learning.
- providing relevant information to the child/youth and family at the appropriate times re local resources and services (agency and community).
- reinforcing relevant information/education to the child/youth and family at the appropriate times through the experience including:
 - disease process, signs and symptoms of the disease
 - diagnostic tests
 - genetic factors
 - treatment plan and goal of care
 - treatment side effects [immediate, early, late and delayed], scheduling and administration, pain, bleeding and other symptom recognition/assessment and control [including prevention, correct practices, and importance of early intervention and follow-up care to reduce long term complications]
 - physical care through treatment and recovery
 - possible emergencies and complications of the child/youth's disease and or treatment, and how to access emergency care
 - central venous line and other venipuncture access
 - self supportive care or home therapy, e.g. administration of colony stimulating factors, home infusion of factor product.
 - palliative care, end of life care & bereavement
 - psychosocial, spiritual care
- identifying limitations in one's skill and knowledge base and referring to others when appropriate.

- assisting the child/youth and family to identify and build on their strengths when seeking and managing new information and situations.

- facilitating access to information per child/youth or family's request.
- describing one's role within the team to the child/youth and family.

Competencies for Practice Standard: Teaching and Coaching within an Advanced Level of Care

All the competencies of the Intermediate level of care:

Competencies for Practice Standard: Teaching and Coaching within a Subspecialty Level of Care

All the competencies of the Intermediate and Advanced levels of care plus:

The nurse practicing within this level of care demonstrates the standard by:

- facilitating the child/youth and family's understanding of the chronic nature of the diagnosis [if appropriate] and enhancing their ability to cope with a chronic health condition.
- assisting the child/youth and family to understand the importance of adopting healthy lifestyle behaviours to optimize treatment outcomes. This includes safety and protective measures, adapting activities, choices, hygiene, adherence to treatment, etc.
- demonstrating an understanding of genetic implications, risk factors/patterns of inheritance and testing of the inherited/congenital hematology disorders.

- assisting the child/youth and family to access and understand relevant genetic information and supporting the child and family through their experience.
- assisting the child/youth and family in understanding the processes of genetic counselling and referring them to appropriate genetic information resources and genetic professionals.
- assisting the child/youth and family to understand the risks and benefits of treatment choices, including clinical research trials and complimentary/ alternative health practices, taking into consideration their own values and beliefs.
- providing relevant education to the child/youth and family about the treatment plan, purpose, side effects [immediate, early, late and delayed] and management, and scheduling and administration.

Treatment includes:

Pharmacological therapy
Surgery [e.g. Splenectomy]
Haematopoietic stem cell transplantation
Transfusion therapy
Research [e.g. gene therapy]
Supportive care & symptom management

- providing relevant information/education to facilitate the child/youth and family's development of self-care to anticipate and manage:
 - o the signs and symptoms of the disease and treatment effects, i.e. pain, bleeding and other symptom recognition. This includes prevention, correct practices, importance of early intervention and follow-up care to reduce long term complications
 - o possible emergencies and complications [including vascular, neurological, hepatitis, HIV, inhibitors, thrombo-embolism, allergic reactions], and how to access emergency care
 - o self supportive care or home therapy such as administration of colony stimulating factors or

home infusion of factor product.

- providing relevant education to the child/youth and family at the appropriate times using principles of effective teaching to ensure the child/family understanding related to:
 - o disease process progression and prognosis
 - o diagnostic tests
 - o central venous line and other venous access
 - o plan and goal of care
 - o physical care through treatment and recovery
 - o psychosocial, spiritual care
 - o recovery, rehabilitation, and survivorship
 - o palliative care, end of life care & bereavement
- sensitively preparing the child/youth and family for the impact of sexually relevant complications, and/or potential puberty or fertility changes, and the need to maintain safe sexual behaviours and practices and/or birth control measures.
- preparing the child/youth and family for possible changes to body image and self-esteem.

Practice Standard: Facilitating Continuity of Care/ Navigating the System

The nurse providing hematology care promotes continuity of care, and facilitates care delivery across care settings and among health care providers by sharing information and communicating the child/youth's and family's current situation, plan of care and goals and the individual/family needs. The nurse assists the child/youth and family to navigate the health care system through understanding its structure, system and process and providing them with strategies to work within the health care system.

Competencies for Practice Standard: Facilitating Continuity of Care/Navigating the System within an Intermediate Level of Care

The nurse practicing within this level of care demonstrates the standard by:

- applying knowledge to assist the child/youth and family navigate the health care system, anticipate gaps and problems they may encounter, and guide them in approaches to facilitate access to care.
 - facilitating the coordination of care by collaborating and working within an interdisciplinary team, and exchanging information with health care providers within different settings, about the care provided the child/youth and family and issues that have arisen during these experiences.
 - applying knowledge of the child/youth and family's changing needs as they move across the continuum of care, supporting them through any transitions.
 - initiating, advocating and mobilizing resources required by the child/youth and family, to facilitate needs being met at different points of time and care settings.
- collaborating with the child/youth and family to assess and anticipate their needs for resources and support their goals of care.
 - applying knowledge of the impact of the diagnosis on the child/youth and family's roles and relationships and facilitating role redefinition and adaptation (of child/youth, family, others).
 - clarifying and validating the child/youth and family's expectations of the health care system.
 - instructing the child/youth and family about the appropriate person to contact for concerns and problems.
 - being aware of the agency and community resources and systems that could be useful to the child/youth and family.
 - participating in developing a care plan that promotes continuity across settings.

Competencies for Practice Standard: Facilitating Continuity of Care/Navigating the System within an Advanced Level of Care

All the competencies of the Intermediate level of care

Competencies for Practice Standard: Facilitating Continuity of Care/Navigating the System within a Subspecialty Level of Care

All the competencies of the Intermediate and Advanced levels of care plus:

The nurse practicing within this level of care demonstrates the standard by:

- preparing the child/youth and family to understand the process of care delivery and anticipating concerns about treatment delays and acceptable standards for wait times for care delivery.
- initiating discharge and transfer of care to local health facilities and maintaining follow up of patients within her practice responsibilities, including maintaining ongoing contact with patients and families to ensure homecare program compliance.
- acting as a resource for multidisciplinary providers from other community health centres and agencies [including family physicians, emergency departments, ambulatory care areas, inpatient units] in providing advice and consistency/continuity in the quality of care.
- acting as a liaison between child/youth, family, and health care professionals at different health centres and community agencies.
- using strategies to help children/youth [and their families] to prepare for transition to adult health care by developing social supports, healthy lifestyle behaviours, educational/vocational/financial planning, self advocacy and self esteem, sexual health, and independent health care behaviours.
- coordinating and facilitating continuity of care during transition from pediatric to adult care.
- helping to prepare the child/youth and family to understand the concept of palliative care and end of life care as the need arises and facilitating access to palliative care experts.
- coordinating and facilitating comprehensive care team meetings
- assisting camp planners by helping in the planning of camp activities and programs, and providing educational knowledge and skills learning for campers and staff.

Practice Standard: Decision Making and Advocacy

The nurse providing hematology care enables the child/youth's and family's self-determination and informed decision making by exploring and respecting their values and information needs, enabling this process with other inter-professional health care team members, advocating on their behalf, assisting them in developing skills so they can advocate for themselves, and communicating and documenting the child/youth's and family's preferred approach to care and wishes

Competencies for Practice Standard: Decision Making and Advocacy within an Intermediate Level of Care

The nurse practicing within this level of care demonstrates the standard by:

- clarifying with the family (and child/youth) that they understand the implications and outcomes of care and treatment before providing/administering it to them.
- applying a non-judgmental approach to facilitate the child/youth and family's decision making to make informed choices or refers to an appropriate expert who can guide them.
- advocating for the child/youth and family's wishes and decisions when developing the plan of care.
- integrating and applying knowledge of the influence of culture, developmental stage, age and gender influences on decision making
- using negotiation and collaborative skills to advocate for the individual.
- assessing the child/youth and family's preferred role in decision making at the time of decision making and on an ongoing basis if appropriate.
- collaborating with others who need to be part of the decision-making process.
- documenting the child/youth and family's goals and preferences for decision making and the processes used to arrive at these decisions.

Competencies for Practice Standard: Decision Making and Advocacy within an Advanced Level of Care

All the competencies of the Intermediate level of care:

Competencies for Practice Standard: Decision Making and Advocacy within a Subspecialty Level of Care

All the competencies of the Intermediate and Advanced levels of care plus:

The nurse practicing within this level of care demonstrates the standard by:

- helping the child/youth and family understand the treatment plan and available options, and the implications of the treatment decisions/choices that are made, including those related to long term outcomes and informed consent in clinical trial participation
- acting as the child/youth and family's advocate especially in areas such as treatment plan, conflict management and resolution, and child/family dissatisfaction situations.

- intervening and/or facilitating between the child/ youth and family when differences regarding self-determination arise.
- supporting proactive strategies to enable child/youth and/or family self-advocacy such as regular review of disease knowledge to ensure youth and parents can describe conditions/ abilities/ adaptive devices, etc, and having youth interact directly with the health care team.

Practice Standard: Professional Practice and Leadership

The nurse providing hematology care engages in critical thinking, integrates evidence-based knowledge (or best practice), exercises ethical judgment, and advocates for changes when institutional policies fail to meet the needs of patients dealing with a hematology disorder.

Competencies for Practice Standard: Professional Practice and Leadership within an Intermediate Level of Care

The nurse practicing within this level of care demonstrates the standard by:

- using research and best practice/evidence based knowledge in assessing, planning, providing and evaluating care, whenever possible in the provision of care.
- reflecting on one's practice to examine thoughts, feelings, actions, beliefs, assumptions and knowledge in providing care and use this to improve practice.
- Integrating and applying knowledge about continuous quality improvement and program evaluation, to improve the quality of patient care and patient satisfaction, taking into consideration care cost and resource allocation issues.
- Identifying potential or actual gaps in care, informing the appropriate member(s) of the health care team, and working to creatively problem solve them.
- recognizing the importance of maintaining therapeutic relationships, a balanced life and seeking professional help when needed.
- practicing according to current professional standards, laws, and regulations.
- understanding and applying basic ethical principles.
- reflecting on one's personal ethical beliefs.
- successfully completing PALS would be an asset.
- participating in various continuing education activities expanding his/her nursing knowledge and skill pertinent to the hematology nursing care she provides, [e.g. attending relevant workshops/in-services and reading relevant articles].

Competencies for Practice Standard: Professional Practice and Leadership within an Advanced Level of Care

All the competencies of the Intermediate level of care plus:

The nurse practicing within this level of care demonstrates the standard by:

- applying leadership skills in promoting practice change.

- applying knowledge of best practice/evidence-based interventions to one's practice.
- applying knowledge of team dynamics ensuring that nursing expertise is visible in influencing inter-professional care processes for patient outcome.

Competencies for Practice Standard: Professional Practice and Leadership within a Subspecialty Level of Care

All the competencies of the Intermediate and Advanced levels of care plus:

The nurse practicing within this level of care demonstrates the standard by:

- regularly participating in various continuing education activities continuously expanding his/her nursing specialty knowledge and skill [e.g. completion of credited courses, consulting with colleagues and other experts in the field, attending relevant workshops/seminars/in-services and reading relevant articles].
- actively participating in relevant professional associations and organizations that promote hematology care and advance hematology nursing [e.g. CANHC].

- actively participating in the education of fellow nursing and other allied health colleagues and students, acting as a mentor and a resource in the specialty of hematology or bleeding disorder nursing/care.
- maintaining contact with the public, health professionals, and members of related support organizations on a local, provincial, intraprovincial [Maritime and Atlantic Provinces], and national level.
- meeting with representatives from community agencies, school administrators, school leaders, child care providers, and other interest groups.
- representing nursing in organizational/community forums focused on the educational needs of the patient population.

- participating and collaborating in research and research activities [nursing and interdisciplinary] based on one's expertise and stage of clinical/professional practice. This may include being part of a research team, using research in one's practice, identifying researchable problems, initiating a research study, obtaining informed consent, assessing patients for appropriateness of study participation, educating patients/family/caregivers on issues related
- to clinical research including ensuring their awareness of the risks and benefits of study participation, advocating for and ensuring fair and ethical treatment of all patients who have consented to participate in research projects, acting as a liaison between patient groups and study coordinators/principal investigators, participating in or facilitating the accurate and timely collection of specimens or data, etc.
- critically analysing interdisciplinary research literature and recommending changes in clinical practice based on valid and generalizable findings.
- promoting and implementing the use of valid, relevant and current research findings into policies, procedures and standards of nursing care specific to his/her specialty.
- critically analysing care situations to identify potential ethical issues
- applying an ethical framework to support child/youth and family decision-making processes and accessing the resources to assist as required.
- disseminating specialty knowledge or research findings through presentation and/or publication at local, regional, national, and international levels.
- contributing to the existing body of nursing knowledge through presentations, conferences and journal publications.

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Practice Standards and Competencies for Nurses Providing Pediatric Non-Malignant Hematology Care within the APPHON Levels of Care Approach to Care Delivery: Self-Assessment Tool

Introduction

The purpose of this tool is to enable the nurse to reflect on his/her own practice to identify personal learning needs and evaluate his/her ability to practice to the scope of the specialty of hematology. It can also be used by Nurse Managers, Administrators and others as a guide for evaluating the nurse's performance based on current recommended standards of care and competencies.

This tool describes the competencies expected of the nurse within 3 of APPHON's Levels of Care - intermediate, advanced, and sub-specialty. The competencies are founded on APPHON's (2007) Practice Standards and Competencies for Nurses Providing Pediatric Cancer Care in Atlantic Canada, CANO's (2006) Practice Standards and Competencies for the Specialized Oncology Nurse, APPHON's (2007) Foundations of Pediatric Hematology Nursing: A Comprehensive Orientation and Review Course, and CANHC's (2006) Hemophilia Nurse Coordinator Job Description.

The tool is organized based on the seven (7) domains of the nurse providing pediatric hematology care within the APPHON Levels of Care approach to care delivery: Health Assessment, Supportive and Therapeutic Relationships, Management of Disease Symptoms and Treatment Side Effects, Teaching and Coaching, Facilitating Continuity of Care/Navigating the System, Decision Making and Advocacy, Professional Practice and Leadership

The tool is completed based on the level of care the nurse works in on a regular basis. Only those competencies that apply to the level of care that the nurse is working in plus all competencies from previous levels are completed. Each competency is identified by either "I" for intermediate level, "A" for advanced level, or "S" for subspecialty level to correspond with the level of care. Remember, the scope and depth of knowledge and skill of the nurse providing hematology care should pertain to the particular patient or patient population that the nurse is caring for, not to all populations of hematology patients.

I) Practice Standard						
The practice standard (core competency) encompasses the knowledge, skill, judgment and application necessary to effectively practice within the practice domain.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not Applicable
Competency A competency describes the behaviours expected of the nurse providing pediatric hematology care in meeting the practice standard.						
1) I demonstrate.....						
2) I integrate and apply.....						

The framework for evaluating the nurse's performance is adapted from Haag-Heitman & Kramer (1998), which is based on Benner's (1984) "novice to expert theory" and Dreyfus' (1986) model of skill acquisition. It is the same framework used to assist in evaluating the specialized oncology nurse described by CANO (Specialized Oncology Nurse Competencies, 2006).

Level	Skills and Knowledge
Novice	Marginal conceptual understanding, minimal clinical experience, very little knowledge of the topic area, textbook/classroom knowledge <ul style="list-style-type: none"> • You seek assistance in making clinical decisions • You have minimal skills or practice in this area
Advanced Beginner	Conceptual understanding, minimal clinical experience, some knowledge of the topic area <ul style="list-style-type: none"> • You have had limited exposure to clinical situations • You are able to identify normal findings • You are guided by what you need to do rather than by patient responses
Competent	Conceptual understanding and skill performance (competent), clinically experienced <ul style="list-style-type: none"> • You have had varied exposure to many situations • You are able to identify normal and abnormal findings • You have an awareness of patient and family view points • You are able to manage complex situations • You are able to prioritize
Proficient	Conceptual understanding, proficient performance, clinically experienced, able to make quick and accurate clinical judgments <ul style="list-style-type: none"> • You have had extensive exposure in most situations • You are able to anticipate potential assessment changes • You are able to prioritize in response to changing situations • You are able to interpret the patient and family experience from a wider perspective
Expert	Analysis, synthesis, application, highly skilled clinically, extensive and well-developed knowledge <ul style="list-style-type: none"> • You have had extensive exposure with deep understanding of the situation • You are able to rapidly and consistently identify actual and potential assessment changes • You are able to rapidly change priorities under all conditions • You are able to keep personal values in perspective and therefore able to encourage and support patient and family choices.
Not Applicable	The topic area is not relevant to the person's practice. In the nurse's current nursing role, this knowledge/skill would not be required.

Self-Assessment Tool

Directions

1. Read each statement carefully and reflect on it based on the evaluation criteria.
2. Check the appropriate level for each statement.
3. Total the number of each level at the end of each category.
4. Proceed to the end of the tool.

1) HEALTH ASSESSMENT: INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard: The nurse providing hematology care conducts timely assessments sensitive to language and culture of the child/youth with a hematology disorder and his/her family across the continuum of care. The nurse considers the needs and responses of the individual, family, and the context of the situation in determining the scope and depth of assessment required at a particular time.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
Physical Assessment and Health History						
I. I perform and document a physical assessment and health history, focusing on known symptoms, complications, and emergencies for that particular child/youth's diagnosis and treatment.						
I. I systematically collect relevant data from the child/youth, family and others using varied strategies that are sensitive to the needs of the individual and family, and the context of the situation.						
I. I recognize co-morbid conditions and variances from normal growth and development.						
I. I collect relevant clinical data (vital signs, laboratory profiles, medication profiles, diagnostic imaging tests) to obtain a picture of the child/youth's physical response to the disorder and/or treatment at the time of assessment.						
I. I identify the various components of the CBC and other blood test results pertinent to the child/youth's disorder, and the implications of abnormalities [includes calculating the ANC].						
I. I assess and monitor for potential acute and chronic physical changes to the child/youth's response to illness with ongoing reassessments of the clinical situation as required. Recommended to use a tool [e.g. pain flow sheet] to facilitate assessment.						
I. I assess, in a non judgmental way, the use of present complementary and/or alternative health practices.						
I. I identify if the child/youth is on a clinical trial.						
A. I describe the impact of the disease and treatment on the child/youth's developmental level.						
A. I recognize co-morbid conditions and variances from normal growth and development AND assess how they may impact on the illness process and the child's/youth /family's response to illness.						
A. I regularly assess and monitor for potential acute and chronic physical changes to the child/youth's response to illness with ongoing reassessments of the clinical situation using focused assessment tools (e.g. pain flow sheet) as appropriate.						

1) HEALTH ASSESSMENT: INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard: The nurse providing hematology care conducts timely assessments sensitive to language and culture of the child/youth with a hematology disorder and his/her family across the continuum of care. The nurse considers the needs and responses of the individual, family, and the context of the situation in determining the scope and depth of assessment required at a particular time.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
S. I perform and document an initial and regular ongoing comprehensive physical assessment and health history, focusing on known symptoms and complications for that particular patient population.						
S. I use a variety of sources to collect relevant clinical data (vital signs, laboratory profiles, medication profiles, diagnostic imaging tests) to obtain a comprehensive , in-depth picture of the child/youth's physical response to the illness/disorder.						
S. I identify the various components of blood test results pertinent to the hematology disorders relevant to my specialty and the implications of abnormalities.						
S. I assess, in a non judgmental way, the use of past, present, or anticipated complementary and/or alternative health practices.						
S. I recognize abnormalities or unexpected outcomes and synthesize information to promote effective understanding of the situation.						
<i>Symptom Assessment</i>						
I. I assess the child/youth for the presence of disease or treatment specific symptom problems (recommended that a validated assessment tool is used).						
I. I analyze data obtained from symptom assessments to plan, implement, and evaluate nursing interventions during urgent and emergent illness episodes.						
S. I conduct in-depth assessments that explore the specific symptom experience for the child/youth's treatment and Integrate it with specific symptoms for the hematology disorder.						
S. I critically analyze data obtained from ongoing symptom assessments to plan, implement, and evaluate nursing interventions during urgent and emergent illness episodes.						
<i>Psychosocial, Spiritual and Cultural Assessment</i>						
I. I assess the child/youth's and family's religious and spiritual practices and resources they find helpful in times of crises.						
I. I assess and respect cultural influences as they relate to the illness experience, treatment, family coping mechanisms and communication.						
I. I assess the child/youth's and family's supportive and informational needs in relation to their desired needs.						
I. I assess the child/youth's and family's preferred role in decision making.						
I. I assess the financial, social and practical concerns that may impact the care experience.						

1) HEALTH ASSESSMENT: INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard: The nurse providing hematology care conducts timely assessments sensitive to language and culture of the child/youth with a hematology disorder and his/her family across the continuum of care. The nurse considers the needs and responses of the individual, family, and the context of the situation in determining the scope and depth of assessment required at a particular time.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
I. I screen for psychosocial, spiritual and cultural distress (using validated tools) as appropriate.						
I. I promote the child/youth's and family's dignity and privacy when making any assessments.						
I. I identify coping strategies used by the child/youth and family, and recognize those strategies relevant to appropriate adjustment.						
A. I explore and document the impact and meaning of illness on the child/youth and family, taking into account their present life circumstances and their view of quality of life.						
S. I conduct a systematic, comprehensive psychosocial, spiritual and cultural assessment that includes exploring the child/youth's and family's responses to the diagnosis, their main concerns, feelings, fears, goals and understanding of prognosis.						
S. I assess if the child/youth has any pre-existing mental health needs including therapies and outcomes (if relevant).						
Sexual Health						
I. I assess sexual health changes as a result of symptoms, disease, and treatment.						
S. I assess the child/youth's [as appropriate] and family's understanding of possible changes in sexual health and fertility, and the need for sexual practice protection and birth control [if relevant].						
S. I assess and describe changes in body image, personal relationships, intimacy, and self-esteem.						
S. I assess the impact of puberty and the hematology disorder in relation to bleeding [as applicable, e.g. menstruation and excessive bleeding, sexual activity with groin and joint bleeds].						
S. I assess emotional responses to changes in sexual health.						
Subtotal						

2) SUPPORTIVE AND THERAPEUTIC RELATIONSHIPS: INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care engages in a caring, supportive, therapeutic relationship with the child/youth with a hematology disorder and his/her family. The relationship is sensitive to the child/youth's changing physical, psychosocial-spiritual reactions and responses.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
I. I demonstrate the ability to communicate with the child/youth taking into account his/her age and stage of development.						
I. I use communication skills that include clarification, reflection, exploration, summarization and open-ended questions to facilitate the child/youth's and family's disclosure of their concerns and feelings.						
I. I actively listen to the child/youth and family recognizing that at times supportive presence may be the most appropriate intervention.						
I. I succinctly communicate [document and discuss] the child/youth's and family's reactions and responses, maintaining confidentiality, but sharing what the health care team needs to know to understand the child's and family's situation and provide individualized care.						
I. I am aware of the boundaries that should be maintained to have the relationship continue as a helping therapeutic relationship.						
I. I recognize the child/youth's and family's changing responses to the illness experience and respond appropriately to these different reactions.						
I. I see the child/youth and family independent of the disease and support them as their lives are impacted by the disorder.						
I. I apply knowledge to identify if a child/youth and/or family may need additional psychosocial and supportive care and refer to appropriate resources.						
I. I assist the child/youth and family to identify realistic goals.						
I. I recognize the importance of school reintegration activities.						
A. I describe the illness experience and the different needs, feelings, fears, concerns and losses that the child/youth/family may experience, and comfortably participate in discussions of difficult issues and content with the child/youth/family (e.g. life altering complications, disease progression, prognosis, mortality, dying, sexual health practices or changes).						
A. I succinctly communicate [document and discuss] with the health care team, not only reactions and responses, but also the child/youth's and family's perspective, current experience, their cultural and spiritual beliefs, and the impacts on the response to treatment.						
A. I apply knowledge of family dynamics and disease adaptation to support the child/youth /family's adjustment to managing and living with the uncertainties of a chronic illness.						
A. I apply supportive care strategies and best practice/evidence-based psychosocial care interventions that are within the scope of practice						

2) SUPPORTIVE AND THERAPEUTIC RELATIONSHIPS: INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care engages in a caring, supportive, therapeutic relationship with the child/youth with a hematology disorder and his/her family. The relationship is sensitive to the child/youth's changing physical, psychosocial-spiritual reactions and responses.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
to facilitate effective coping.						
A. I assist the child/youth and family to establish/maintain relationships with individuals or groups who have significant meaning to them.						
A. I am present to offer support to the child/youth and family during invasive procedures such as venous access and N/G tube insertion.						
A. I facilitate participation in reintegration activities, e.g. I determine child/youth has been referred (or refer) to Child Life Specialist.						
S. I not only participate in discussions of difficult issues/content (e.g. life altering complications, disease progression, prognosis, mortality, dying, sexual health practices or changes), but initiate difficult discussions.						
S. I use critical thinking skills and integrate best practice/evidence-based knowledge with the information collected from the health assessment to anticipate, plan, implement and evaluate nursing interventions aimed at restoring optimum health in all its dimensions.						
S. I apply knowledge to identify if the child/youth and family require additional psychosocial and spiritual supportive care (e.g. depression) and refer in a timely manner.						
S. I initiate school reintegration activities						
S. I describe appropriate emotional, psychosocial, and behavioural responses for children/youth dealing with serious illness, as well as their siblings.						
S. I am present for the child/youth and family during invasive procedures such as deep sedation and bone marrow aspiration and biopsy.						
Subtotal						

**3) Management of Disease Symptoms and Treatment Side Effects
INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)**

Practice Standard The nurse providing hematology care integrates and applies knowledge of hematology disorder /disease pathophysiology, disease progression, treatment modalities, treatment side-effects and complications, and symptom problems to assess, plan, implement and evaluate the outcomes of best practice/evidence-based care and other clinical interventions	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
I. I understand the disease process, disease progression, prognosis, clinical presentation (signs and symptoms), risk factors, treatment plan, and possible complications of disease and treatment for the child/youth's situation.						
S. I understand the incidence, etiology, pathophysiology, laboratory findings, disease process, disease progression, prognosis, clinical presentation (signs and symptoms), risk factors, genetic implications, standard treatments/ control and nursing considerations in relation to the management of the following major hematology disorders in children/youth that are pertinent to my practice/specialty. This includes distinguishing between congenital and acquired disorders, and acute and chronic disorders. These disorders include but are not limited to: <ul style="list-style-type: none"> ▪ Disorders of Red Blood Cell <ul style="list-style-type: none"> - Hereditary Spherocytosis - Sideroblastic Anemia - Hemolytic Anemias - Anemias of Poor Production [Iron, B12, and Folic Acid Deficiency] - Thalassemia - Sickle Cell Disease ▪ Bone Marrow Failure <ul style="list-style-type: none"> - Acquired Aplastic Anemia - Marrow Failure Syndromes <ul style="list-style-type: none"> □ Pancytopenias, e.g., Fanconi's Anemia, Shwachman-Diamond Anemia □ Red Blood Cell, e.g., Blackfan-Diamond Anemia ▪ Disorders of Thrombosis & Hemostasis <ul style="list-style-type: none"> - Disseminated Intravascular Coagulation [DIC] - Idiopathic Thrombocytopenia [ITP] - Platelet Dysfunction/Disorders - Venous Thrombosis - Inherited Bleeding Disorders/ Factor Deficiencies - Hemophilia A and B [factor VIII and IX] - Von Willibrands Disease - Factor XII Deficiency - rare factor deficiencies [factor I, II, VII, X, XI, XIII] ▪ Defects of the Phagocyte System <ul style="list-style-type: none"> - Neutropenia, e.g., cyclic, auto-immune, chronic benign, drug induced 						

3) Management of Disease Symptoms and Treatment Side Effects INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care integrates and applies knowledge of hematology disorder /disease pathophysiology, disease progression, treatment modalities, treatment side-effects and complications, and symptom problems to assess, plan, implement and evaluate the outcomes of best practice/evidence-based care and other clinical interventions	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
<ul style="list-style-type: none"> ▪ Other: <ul style="list-style-type: none"> - Polycythemia - Transient Myeloproliferative Disorder [TMD] - Myelodysplastic Syndrome [MDS] 						
Treatment Modalities						
Pharmacological Therapy						
I. I demonstrate an understanding of the mechanism of action, indications for, and side effects of the pharmacological agent[s] within the child/youth's treatment plan. [This includes but is not limited to immunosuppressive therapy, corticosteroids, hormonal therapy, iron therapy, vitamin and other supplements, growth factors, immunization, analgesics, antibiotics, oral contraceptives, anticoagulants, and anti-fibrinolytics.]						
I. I demonstrate an understanding of and follow standards/guidelines related to the principles of appropriate handling and administration of the pharmacological agent[s] within the child/youth's treatment plan.						
I. I interpret and follow the portion of the child/youth's treatment plan pertinent to the setting. I seek further direction as needed.						
I. I notify the child/youth/family of blood results and am able to discuss the impact of those results related to treatment.						
I. I implement and evaluate best practice/evidence-based nursing interventions on an ongoing basis to decrease the severity of side-effects and short and long term complications of the pharmacological agent[s] relevant to the child/youth's treatment.						
S. I demonstrate an understanding of the classifications, mechanism of action, indications for, and side effects of the pharmacological agent[s] pertinent to my practice/specialty including required monitoring and supportive care. [This includes but is not limited to immunosuppressive therapy, corticosteroids, hormonal therapy, iron therapy, vitamin and other supplements, growth factors, immunization, analgesics, antibiotics, oral contraceptives, anticoagulants, and anti-fibrinolytics.]						
S. I demonstrate an understanding of and follow standards/guidelines related to the principles of appropriate handling and administration of all pharmacological agents pertinent to my practice/specialty. This includes monoclonal antibodies.						
S. I anticipate, plan, implement and evaluate best practice/ evidence-based nursing interventions on an ongoing basis to decrease the severity of the side-effects and short and long term complications of the pharmacological agents pertinent to my practice/ specialty including monoclonal antibodies.						

3) Management of Disease Symptoms and Treatment Side Effects INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care integrates and applies knowledge of hematology disorder /disease pathophysiology, disease progression, treatment modalities, treatment side-effects and complications, and symptom problems to assess, plan, implement and evaluate the outcomes of best practice/evidence-based care and other clinical interventions	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
Surgery for diagnosis/treatment						
I. I demonstrate an understanding of the role surgery plays in the aspects of the child/youth's diagnosis and treatment						
S. I anticipate, plan, implement and evaluate best practice/evidence-based care interventions on an ongoing basis to decrease the severity of side-effects and short and long term complications of surgery.						
Other therapies						
I. I demonstrate an understanding of the role of non pharmacological modalities pertinent to the child/youth's care such as safety measures, activity restrictions, physiotherapy, R.I.C.E.						
I. I demonstrate an understanding of the mechanism of action, indications for, side effects, preparation, appropriate handling, administration, and dosage calculation of the blood products and related agents included in following the portion of the child/youth's treatment plan pertinent to the setting. This includes but is not exclusive to PRBCs, platelets, cryoprecipitate, factor products, Win Rho SDF™ and IVIG for ITP.						
I. I demonstrate an understanding of the role of non pharmacological complementary/alternative health practices modalities such as acupuncture, massage, and therapeutic touch, and the possibility that they may interact with the child/youth's existing treatment or cause unfavourable/harmful side effects/symptoms.						
A. I demonstrate an understanding of the reason for hematopoietic stem cell transplants for the treatment of the specific child/youth's disorder.						
A. I anticipate, plan, implement and evaluate best practice/evidence-based nursing interventions for expected side effects and complications for the specific child/youth who has had a hematopoietic stem cell transplant.						
S. I demonstrate an understanding of the principles and indications for hematopoietic stem cell transplants as pertinent to my practice/specialty.						
S. I anticipate, plan, implement and evaluate best practice/evidence-based care interventions on an ongoing basis to decrease the severity of side-effects and short and long term complications of hematopoietic stem cell transplants as pertinent to my practice/specialty.						
Palliative Therapies						
I. I provide palliative care symptom management based on a broad understanding of palliative care						

3) Management of Disease Symptoms and Treatment Side Effects INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care integrates and applies knowledge of hematology disorder /disease pathophysiology, disease progression, treatment modalities, treatment side-effects and complications, and symptom problems to assess, plan, implement and evaluate the outcomes of best practice/evidence-based care and other clinical interventions	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
S. I provide increasingly complex palliative care symptom management based on a comprehensive understanding of palliative care.						
Symptom and Side Effects Management						
I. I apply knowledge of the hematology diagnosis of the child/youth [including etiology of disease symptoms and treatment complications] to anticipate disease and treatment side effects and symptoms, and to prevent or minimize problems/symptoms as they occur [using established best practice/evidence-based guidelines and interventions], and evaluating the effect of these interventions on an ongoing basis.						
I. I demonstrate who to contact for further direction if symptom management not effective or in the event of an unusual, unexpected symptom/side effect						
Hematology Complications and Emergencies						
I. I describe and identify clinical presentation (signs and symptoms), risk factors, and standard treatment management of common complications related to the child/youth's hematology disorder and treatment. This could include but not be limited to chronic arthropathies, inhibitor or antibody development, blood born infections, aplasia, iron overload, endocrine dysfunction, or chronic organ damage.						
I. I describe and identify clinical presentation (signs and symptoms), risk factors, and standard treatment management related to hematology emergencies specific to the child/youth's hematology disorder and treatment. This could include but not be limited to life threatening or serious bleeds [e.g. intracranial, spontaneous, excessive blood loss, compartment syndrome], infection [e.g. acute bacteria, febrile neutropenia], and crises [e.g. aplastic, vaso-occlusive, hemolytic, megoblastic, splenic sequestration], etc.						
I. I use established guidelines to facilitate assessment and management of febrile neutropenia.						
S. I understand the disease process, disease progression, prognosis, clinical presentation (signs and symptoms), risk factors, and standard treatment management related to hematology [disease and treatment] complications as relates to my practice or specialty. This includes but is not limited to: <input type="checkbox"/> chronic arthropathies <input type="checkbox"/> inhibitor and antibody development <input type="checkbox"/> blood born infections including HIV and Hepatitis C <input type="checkbox"/> alloimmunization						

3) Management of Disease Symptoms and Treatment Side Effects INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care integrates and applies knowledge of hematology disorder /disease pathophysiology, disease progression, treatment modalities, treatment side-effects and complications, and symptom problems to assess, plan, implement and evaluate the outcomes of best practice/evidence-based care and other clinical interventions	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
<input type="checkbox"/> aplasia <input type="checkbox"/> iron overload <input type="checkbox"/> endocrine dysfunction <input type="checkbox"/> chronic organ damage						
<p>S. I understand the disease process, disease progression, prognosis, clinical presentation (signs and symptoms), risk factors, and standard treatments management related to hematology emergencies as relates to my practice or specialty. This includes but is not limited to:</p> <input type="checkbox"/> life threatening or serious bleeds <ul style="list-style-type: none"> - intracranial hemorrhage/CVA - spontaneous bleed - excessive blood loss from menorrhagia, epistaxis/other mucosal bleeding - compartment syndrome, nerve compression, vision loss, airway compromise <input type="checkbox"/> crises <ul style="list-style-type: none"> - aplastic - haemolytic - megoblastic - vaso-occlusive - splenic sequestration <input type="checkbox"/> cardiopulmonary failure <input type="checkbox"/> acute chest syndrome <input type="checkbox"/> sepsis <ul style="list-style-type: none"> - febrile neutropenia - acute bacterial infections - septic shock 						
Sexual Health Issues						
I. I consult professionals with expertise to help the child/youth and family address sexual functioning changes, other symptoms related to sexual health changes, body image issues, self- esteem issues and relationship issues they have identified as a concern.						
S. I discuss the changes, stresses and challenges that a maturing adolescent may experience in relation to sexual practices, body image issues, self-esteem issues and relationship issues as a result of diagnosis or blood borne infections.						
Safe Use of Treatment Delivery Devices (Technology)						
I. I demonstrate an understanding of the importance of appropriate gauge and type of needle required for peripheral venous access for						

3) Management of Disease Symptoms and Treatment Side Effects INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care integrates and applies knowledge of hematology disorder /disease pathophysiology, disease progression, treatment modalities, treatment side-effects and complications, and symptom problems to assess, plan, implement and evaluate the outcomes of best practice/evidence-based care and other clinical interventions	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
factor product infusion.						
I. I demonstrate an understanding of the safety issues associated with technical devices used in the child/youth's treatment such as central venous access devices, transfer devices in factor kits, insuflon catheters, ambulatory pain pumps, etc.						
I. I assess and anticipate problems/issues associated with these devices.						
I. I safely manage the care of the child/youth with these devices as per existing organizational standards.						
Procedural Skills						
I. I demonstrate skill and knowledge in the provision of enteral feeding care [including insertion or assistance with insertion of a nasogastric tube [N/G], provision of feedings, and care of a feeding tube.						
A. I demonstrate skill and knowledge in provision of parenteral nutrition.						
S. I demonstrate skill and knowledge in provision of the preparation and monitoring of the child/youth and family and assisting the physician with bone marrow aspirations and biopsies.						
Subtotal						

4. TEACHING AND COACHING: INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care prepares the child/youth with a hematology disorder and his/her family for the many different aspects of the disease experience along the trajectory and provides guidance to assist them to understand and manage the many different aspects of the experience through education, psychosocial and spiritual support, and counselling.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
I. I assess the child/youth's and family's readiness to learn, their learning styles, and their preferred scope and depth of information to develop a relevant teaching plan.						
I. I apply the principles of adult, child, and family learning when planning, implementing and evaluating best practice/evidence based nursing interventions to educate and coach the child/youth and family about the disease/disorder experience.						
I. I adjust my teaching and coaching style to address factors such as life stage, culture, education and family decision-making and communication styles that impact on learning.						
I. I provide relevant information to the child/youth and family at the appropriate times re local resources and services (agency and community).						
I. I reinforce relevant information/ education to the child/youth and family at the appropriate times through the experience including: <ul style="list-style-type: none"> <input type="checkbox"/> disease process, signs and symptoms of the disease <input type="checkbox"/> diagnostic tests <input type="checkbox"/> genetic factors <input type="checkbox"/> treatment plan and goal of care <input type="checkbox"/> treatment side effects [immediate, early, late and delayed], scheduling and administration, pain bleeding and other symptom recognition/assessment and control [including prevention, correct practices, and importance of early intervention and follow-up care to reduce long-term complications <input type="checkbox"/> physical care through treatment and recovery <input type="checkbox"/> possible emergencies and complications [including vascular, neurological, hepatitis, HIV, inhibitors, thromboembolism, allergic reactions], and how to access emergency care <input type="checkbox"/> central venous line and other venipuncture access <input type="checkbox"/> self supportive care or home therapy, e.g., administration of colony stimulating factors, home infusion of factor product. <input type="checkbox"/> palliative care, end of life care & bereavement <input type="checkbox"/> psychosocial, spiritual care 						
I. I identify limitations in my skill and knowledge base and refer to others when appropriate.						
I. I assist the child/youth and family to identify and build on their strengths when seeking and managing new information and situations.						
I. I facilitate access to information per child/youth's or family's request.						

4. TEACHING AND COACHING: INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care prepares the child/youth with a hematology disorder and his/her family for the many different aspects of the disease experience along the trajectory and provides guidance to assist them to understand and manage the many different aspects of the experience through education, psychosocial and spiritual support, and counselling.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
I. I describe my role within the team to the child/youth and family.						
S. I facilitate the child/youth's and family's understanding of the chronic nature of the diagnosis [if appropriate] and enhance their ability to cope with a chronic health condition.						
S. I assist the child/youth and family to understand the importance of adopting healthy lifestyle behaviours to optimize treatment outcomes. This includes safety and protective measures, adapting activities, choices, hygiene, adherence to treatment, etc.						
S. I demonstrate an understanding of genetic implications, risk factors/ patterns of inheritance and testing of the inherited/congenital hematology disorders.						
S. I assist the child/youth and family to access and understand relevant genetic information and support the child and family through their experience.						
S. I assist the child/youth and family in understanding the processes of genetic counselling and refer them to appropriate genetic information resources and genetic professionals.						
S. I assist the child/youth and family to understand the risks and benefits of treatment choices, including clinical research trials and complimentary/ alternative health practices, taking into consideration their own values and beliefs.						
S. I provide relevant education to the child/youth and family about the treatment plan, purpose, side effects [immediate, early, late and delayed] and management, and scheduling and administration. Treatment includes: <input type="checkbox"/> Pharmacological therapy <input type="checkbox"/> Surgery [e.g. Splenectomy] <input type="checkbox"/> Haematopoietic stem cell transplant <input type="checkbox"/> Transfusion therapy <input type="checkbox"/> Research [e.g. gene therapy] <input type="checkbox"/> Supportive care & symptom management						
S. I provide relevant information/ education to facilitate the child/youth's and family's development of self-care to anticipate and manage: <input type="checkbox"/> the signs and symptoms of the disease and treatment effects, i.e. pain, bleeding and other symptom recognition. This includes prevention, correct practices, importance of early intervention and follow-up care to reduce long term complications <input type="checkbox"/> possible emergencies and complications [including vascular, neurological, hepatitis, HIV, inhibitors, thromboembolism, allergic						

4. TEACHING AND COACHING: INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
The nurse providing hematology care prepares the child/youth with a hematology disorder and his/her family for the many different aspects of the disease experience along the trajectory and provides guidance to assist them to understand and manage the many different aspects of the experience through education, psychosocial and spiritual support, and counselling.						
<ul style="list-style-type: none"> reactions], and how to access emergency care <input type="checkbox"/> self supportive care or home therapy such as administration of colony stimulating factors or home infusion of factor product. 						
<p>S. I provide relevant education to the child/youth and family at the appropriate times using principles of effective teaching to ensure child/youth/family understanding related to:</p> <ul style="list-style-type: none"> <input type="checkbox"/> disease process progression and prognosis <input type="checkbox"/> diagnostic tests <input type="checkbox"/> central venous line and other venous access <input type="checkbox"/> plan and goal of care <input type="checkbox"/> physical care through treatment and recovery <input type="checkbox"/> psychosocial, spiritual care <input type="checkbox"/> recovery, rehabilitation, and survivorship <input type="checkbox"/> palliative care, end of life care & bereavement 						
S. I sensitively prepare the child/youth and family for the impact of sexually relevant complications and/or potential puberty or fertility changes, and the need to maintain safe sexual behaviours and practices and/or birth control measures.						
S. I prepare the child/youth and family for possible changes to body image and self-esteem.						
Subtotal						

**5. FACILITATING CONTINUITY OF CARE/NAVIGATING THE SYSTEM
INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)**

Practice Standard The nurse providing hematology care promotes continuity of care, facilitates care delivery across care settings and among health care providers by sharing information and communicating the child/youth's and family's current situation, plan of care and goals and the individual/family needs. The nurse assists the child/youth and family to navigate the health care system through understanding its structure, system and process and providing them with strategies to work within the health care system.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
I. I apply knowledge to assist the child/youth and family navigate the health care system, anticipate gaps and problems they may encounter, and guide them in approaches to facilitate access to care.						
I. I facilitate the coordination of care by collaborating and working within an interdisciplinary team, and exchanging information with health care providers within different settings, about the care provided the child and family and issues that have risen during these experiences.						
I. I apply knowledge of the child/youth's and family's changing needs as they move across the continuum of care, supporting them through any transitions.						
I. I initiate, advocate and mobilize resources required by the child/youth and family, to facilitate needs being met at different points of time and care settings.						
I. I collaborate with the child/youth and family to assess and anticipate their needs for resources and support their goals of care.						
I. I apply knowledge of the impact of the diagnosis on the child/youth's and family's roles and relationships and facilitate role redefinition and adaptation (of child, family, others).						
I. I clarify and validate the child/youth's and family's expectations of the health care system.						
I. I instruct the child/youth and family about the appropriate person to contact for concerns and problems.						
I. I am aware of the agency and community resources and systems that could be useful to the child/youth and family.						
I. I participate in developing a care plan that promotes continuity across settings.						
S. I prepare the child/youth and family to understand the process of care delivery and anticipate concerns about treatment delays and acceptable standards for wait times for care delivery.						
S. I initiate discharge and transfer of care to local health facilities and maintain follow up of children/youth within my practice responsibilities, including maintaining ongoing contact with children/youth and families to ensure homecare program compliance.						
S. I act as a resource for multidisciplinary providers from other community health centres and agencies [including family physicians, emergency departments, ambulatory care areas, inpatient units] in providing advice and consistency/continuity in the quality of care.						

5. FACILITATING CONTINUITY OF CARE/NAVIGATING THE SYSTEM INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care promotes continuity of care, facilitates care delivery across care settings and among health care providers by sharing information and communicating the child/youth's and family's current situation, plan of care and goals and the individual/family needs. The nurse assists the child/youth and family to navigate the health care system through understanding its structure, system and process and providing them with strategies to work within the health care system.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
S. I act as a liaison between child/youth, family, and health care professionals at different health centres and community agencies.						
S. I use strategies to help children/ youth [and their families] to prepare for transition to adult health care by developing social supports, healthy lifestyle behaviours, educational/ vocational/financial planning, self advocacy and self esteem, sexual health, and independent health care behaviours.						
S. I coordinate and facilitate continuity of care during transition from pediatric to adult care.						
S. I help to prepare the child/youth and family to understand the concept of palliative care and end of life care as the need arises and facilitate access to palliative care experts.						
S. I coordinate and facilitate comprehensive care team meetings						
S. I assist camp planners by helping in the planning of camp activities and programs, and providing educational knowledge and skills learning for campers and staff.						
Subtotal						

6. DECISION MAKING AND ADVOCACY: INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care enables the child/youth's and family's self-determination and informed decision making by exploring and respecting their values and information needs, enabling this process with other inter-professional health care team members, advocating on their behalf, assisting them in developing skills so they can advocate for themselves, and communicating and documenting the child/youth's and family's preferred approach to care and wishes.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
I. I clarify with the family (and child/youth) that they understand the implications and outcomes of care and treatment before providing/administering it to them.						
I. I apply a non-judgmental approach to facilitate the child/youth and family's decision making to make informed choices or refer to an appropriate expert who can guide them.						
I. I advocate for the child/youth and family's wishes and decisions when developing the plan of care.						
I. I integrate and apply knowledge of the influence of culture, developmental stage, age and gender influences on decision making.						
I. I use negotiation and collaborative skills to advocate for the individual.						
I. I assess the child/youth and family's preferred role in decision making at the time of decision making and on an ongoing basis if appropriate.						
I. I collaborate with others who need to be part of the decision-making process.						
I. I document the child/youth and family's goals and preferences for decision making and the processes used to arrive at these decisions.						
S. I help the child/youth and family understand the treatment plan and available options, and the implications of the treatment decisions/choices that are made, including those related to long term outcomes and informed consent in clinical trial participation						
S. I act as the child/youth and family's advocate especially in areas such as treatment plan, conflict management and resolution, and child/family dissatisfaction situations.						
S. I intervene and/or facilitate between the child/youth and family when differences regarding self-determination arise.						
S. I support proactive strategies to enable child/youth and/or family self-advocacy such as regular review of disease knowledge to ensure youth and parents can describe conditions/abilities/ adaptive devices, etc, and having youth interact directly with the health care team.						
Subtotal						

7. PROFESSIONAL PRACTICE AND LEADERSHIP: INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care engages in critical thinking, integrates evidence-based knowledge (or best practice), exercises ethical judgment, and advocates for changes when institutional policies fail to meet the needs of patients dealing with a hematology disorder.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
I. I use research and best practice/evidence based knowledge in assessing, planning, providing and evaluating care, whenever possible in the provision of care.						
I. I reflect on my practice to examine thoughts, feelings, actions, beliefs, assumptions and knowledge in providing care and use this to improve my practice.						
I. I integrate and apply knowledge about continuous quality improvement and program evaluation, to improve the quality of patient care and patient satisfaction, taking into consideration care cost and resource allocation issues.						
I. I identify potential or actual gaps in care, inform the appropriate member(s) of the health care team, and work to creatively problem solve them.						
I. I recognize the importance of maintaining therapeutic relationships, a balanced life and seeking professional help when needed.						
I. I practice according to current professional standards, laws, and regulations.						
I. I understand and apply basic ethical principles.						
I. I reflect on my personal ethical beliefs.						
I. I have successfully completed PALS [would be an asset].						
I. I participate in various continuing education activities expanding my nursing knowledge and skill pertinent to the hematology nursing care I provides, [e.g. attend relevant workshops/in-services and read relevant articles].						
A. I apply leadership skills in promoting practice change.						
A. I apply knowledge of best practice/evidence-based interventions to my practice.						
A. I apply knowledge of team dynamics ensuring that nursing expertise is visible in influencing inter-professional care processes for patient outcomes.						
S. I regularly participate in various continuing education activities continuously expanding my nursing specialty knowledge and skill [e.g. complete credited courses, consult with colleagues and other experts in the field, attend relevant workshops/ seminars/in-services and read relevant articles].						
S. I actively participate in relevant professional associations and organizations that promote hematology care and advance hematology nursing [e.g. CANHC].						
S. I actively participate in the education of fellow nursing and other allied health colleagues and students, acting as a mentor and a						

7. PROFESSIONAL PRACTICE AND LEADERSHIP: INTERMEDIATE (I); ADVANCED (A); SUB-SPECIALTY (S)						
Practice Standard The nurse providing hematology care engages in critical thinking, integrates evidence-based knowledge (or best practice), exercises ethical judgment, and advocates for changes when institutional policies fail to meet the needs of patients dealing with a hematology disorder.	Novice	Advanced Beginner	Competent	Proficient	Expert	Not applicable
resource in the specialty of hematology or bleeding disorder nursing/care.						
S. I maintain contact with the public, health professionals, and members of related support organizations on a local, provincial, intraprovincial [Maritime and Atlantic Provinces], and national level.						
S. I meet with representatives from community agencies, school administrators, school leaders, child care providers, and other interest groups.						
S. I represent nursing in organizational/community forums focused on the educational needs of the patient population.						
S. I participate and collaborate in research and research activities [nursing and interdisciplinary] based on my expertise and stage of clinical/professional practice. [This may include being part of a research team, using research in one's practice, identifying researchable problems, initiating a research study, obtaining informed consent, assessing patients for appropriateness of study participation, educating patients/family/ caregivers on issues related to clinical research including ensuring their awareness of the risks and benefits of study participation, advocating for and ensuring fair and ethical treatment of all patients who have consented to participate in research projects, acting as a liaison between patient groups and study coordinators/ principal investigators, participating in or facilitating the accurate and timely collection of specimens or data, etc.]						
S. I critically analyse interdisciplinary research literature and recommend changes in clinical practice based on valid and generalizable findings.						
S. I promote and implement the use of valid, relevant and current research findings into policies, procedures and standards of nursing care specific to my specialty.						
S. I critically analyse care situations to identify potential ethical issues.						
S. I apply an ethical framework to support child/youth and family decision-making processes and access the resources to assist as required.						
S. I disseminate specialty knowledge or research findings through presentation and/or publication at local, regional, national, and international levels.						
S. I contribute to the existing body of nursing knowledge through presentations, conferences and journal publications.						
Subtotal						

Directions

1. Now that you have completed the assessment tool, total the score from all the domains completed.
2. Obtain a ratio of strengths vs. learning opportunities by comparing the **Individual Strengths** total to the **Learning Opportunities** total. This ratio helps direct one in selecting areas for growth. There is no such thing as a good or bad ratio.

HEALTH ASSESSMENT									
Individual Strengths			Learning Opportunities				Ratio		
Expert	Proficient	Total	Competent	Advanced Beginner	Novice	Total			
+		=	+		+	=		:	
_____	_____	_____	_____	_____	_____	_____		_____	_____
SUPPORTIVE AND THERAPEUTIC RELATIONSHIPS									
Individual Strengths			Learning Opportunities				Ratio		
Expert	Proficient	Total	Competent	Advanced Beginner	Novice	Total			
+		=	+		+	=		:	
_____	_____	_____	_____	_____	_____	_____		_____	_____
MANAGEMENT OF DISEASE SYMPTOMS AND TREATMENT SIDE EFFECTS									
Individual Strengths			Learning Opportunities				Ratio		
Expert	Proficient	Total	Competent	Advanced Beginner	Novice	Total			
+		=	+		+	=		:	
_____	_____	_____	_____	_____	_____	_____		_____	_____
TEACHING AND COACHING									
Individual Strengths			Learning Opportunities				Ratio		
Expert	Proficient	Total	Competent	Advanced Beginner	Novice	Total			
+		=	+		+	=		:	
_____	_____	_____	_____	_____	_____	_____		_____	_____
FACILITATING CONTINUITY OF CARE/NAVIGATING THE SYSTEM									
Individual Strengths			Learning Opportunities				Ratio		
Expert	Proficient	Total	Competent	Advanced Beginner	Novice	Total			
+		=	+		+	=		:	
_____	_____	_____	_____	_____	_____	_____		_____	_____
DECISION MAKING AND ADVOCACY									
Individual Strengths			Learning Opportunities				Ratio		
Expert	Proficient	Total	Competent	Advanced Beginner	Novice	Total			
+		=	+		+	=		:	
_____	_____	_____	_____	_____	_____	_____		_____	_____
PROFESSIONAL PRACTICE AND LEADERSHIP									
Individual Strengths			Learning Opportunities				Ratio		
Expert	Proficient	Total	Competent	Advanced Beginner	Novice	Total			
+		=	+		+	=		:	
_____	_____	_____	_____	_____	_____	_____		_____	_____