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Association of Pediatric Hematology/Oncology Nurses

A CORE CURRICULUM
Fifth Edition

Essentials of Pediatric Hematology/ Oncology Nursing

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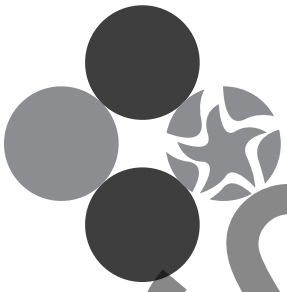

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CHAPTER OUTLINE

Introduction

Kaye Schmidt

Caring for a child with cancer or a blood disorder can be challenging and rewarding at the same time. The rewards come from the strong patient and family relationships developed over time, the growing treatment options leading to cures for patients with cancer, and improved length and quality of life for those with common hematologic disorders. Siegel et al. (2022) report the 5-year relative survival rate for all childhood cancers combined to have increased from 58% in the mid-1970s to 85% during 2011 through 2017 in children (0–14 years) and from 68% to 86% in adolescents (15–19 years). Advancements in supportive care, consistent enrollment in clinical trials, and expansion of treatment options such as immunotherapy and targeted therapy have all led to higher cure rates for childhood cancer. Hemophilia treatment has advanced from challenging times in the 1980s when transmission of HIV occurred through factor replacement products used to treat active bleeding to the administration of prophylactic treatment to prevent bleeds in the 21st century (National Hemophilia Foundation, n.d.). Advances in the treatment of sickle cell disease include prophylactic penicillin, early identification through newborn screening, and hydroxyurea to reduce the incidence of pain crises and acute chest syndrome. Current practices outlined in the American Society of Hematology (ASH) 2020 guidelines include prevention, diagnosis, and treatment of cardiovascular disease in children and adults with sickle cell disease (Brandow et al., 2020). Modern strategies now include transcranial Doppler ultrasound screening and use of chronic transfusion for those at high risk of stroke. Gene therapy is on the horizon as a potential cure for both hemophilia and sickle cell disease.

The challenges for nurses in caring for these patient populations include the complexity of treatment, the need to keep up with constant changes in treatment strategies, and the need to manage active treatment, side effects, and supportive care while providing the psychosocial support required by the patient and family. Nursing is a dynamic profession requiring commitment to lifelong learning to ensure excellence in practice.

As treatment strategies advance, fewer children are diagnosed and treated exclusively in the inpatient setting. More therapies are being moved to the outpatient setting and to home care. Nurses play a key role in preparing patients and families for what to expect in the home and teaching about symptoms that will require the families to return to the clinic or hospital setting. Families are often unprepared for this role and may become overwhelmed with new responsibilities. This has created increased focus on patient and family education and increased demand for home care options and increased need for strong telephone triage programs in the outpatient setting. As a result, the acuity of outpatient care continues to become more complex.

Awareness is growing surrounding disparities by race and ethnicity. Cancer occurrence and outcomes vary by racial and ethnic groups, explained by long-standing differences in socioeconomic status and access to care for prevention, early detection, and treatment (Siegel et al., 2022). Health care increasingly is emphasizing social determinants of health (SDOH). These determinants are conditions in the environment of our patients and families that affect a wide variety of health, functioning, and quality-of-life outcomes and risks (U.S. Department of Health and Human Services, n.d.). The World Health Organization (WHO, n.d.) defines SDOH as the nonmedical factors that influence health outcomes. Patients and families with sickle cell disease face the burdens of chronic disease and often racial disparities, both of which may increase their vulnerability to adverse SDOH (Power-Hays et al., 2020). APHON (n.d.) has incorporated diversity, equity, and inclusion into its strategic plan, with intentional focus on understanding what training and resources are needed to better understand and serve more diverse populations—specifically, those living in vulnerable and marginalized family situations.

As a specialty that involves the care of children of all ages as well as young adults up to age 39 years in some settings, pediatric hematology/oncology nursing requires a strong knowledge base in the normal growth and development of children, adolescents, and young adults. Care is focused on diagnosis, treatment, management of acute and chronic side effects and complications, recognition of psychosocial needs, long-term support for living with a chronic condition, and planning for long-term follow-up.

Philosophy of Pediatric Hematology/Oncology Nursing

Pediatric hematology/oncology nurses are essential contributors to the successful treatment of children, adolescents, and young adults with cancer and blood disorders. As such, they recognize the importance of patient- and family-centered care

that begins at diagnosis and continues throughout the trajectory of care. This may include living with a chronic condition, long-term survival, transition to adult care, and sometimes death resulting in the provision of bereavement care for the family. The philosophy of family-centered care is central to pediatric hematology/oncology nursing practice. The Institute for Patient- and Family-Centered Care (IPFCC, n.d.) defines patient- and family-centered care as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families." The core concepts of patient- and family-centered care include respect and dignity, information sharing, participation, and collaboration. These concepts define the relationship between the patient, the family, and the health care team as a mutually beneficial partnership. This philosophy is exemplified by nursing care that is planned with the patient (at an age-appropriate level) and the family.

Pediatric hematology/oncology nursing thrives on team collaboration. It is believed that the best care is provided to patients and their families when all members of the patient care team are actively involved. A commitment to patient- and family-centered care requires the family and patient to be involved in all decisions surrounding care based on their desired level of participation. It is helpful for the family to maintain as normal a lifestyle as possible throughout treatment, but this requires collaboration among all involved in the patient's care.

Pediatric hematology/oncology nurses provide care for a patient population that has an increasing expectation of surviving cancer and living longer with a chronic illness, while striving for continued improvements in quality of life. Care for survivors of childhood cancer continues to be a major focus of nursing practice within the oncology specialty. At the same time, the pediatric hematology/oncology nurse must be competent in providing care for the child and the family when the child is not expected to survive their disease or treatment.

Despite the dramatic improvements in outcomes for children with cancer and blood disorders, the family's needs remain tremendous as they cope with the child's serious, life-threatening disease. For pediatric hematology/oncology nurses, support of children and their families must focus on open communication, verification of understanding, and ongoing promotion of hope. Patients and families look to the health care team for honest information but appreciate the addition of hope to assist them in moving forward on their journey, knowing that every patient's journey is different and unique (Conway et al., 2017).

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History of Pediatric Oncology Nursing

Deborah Echtenkamp

Nursing originally was generic in practice; nurses cared for all patients, regardless of age or diagnosis. It was not until the early 20th century that nurses began to specialize in particular types of care. With the development of the first academic

course devoted exclusively to cancer nursing at Teachers College at Columbia University in 1947, oncology nursing was recognized as a specialty (Craytor, 1982). The first hospital unit dedicated to pediatric cancer opened in 1939 at Memorial Sloan Kettering Cancer Center. At that time, the nurses who cared for children with cancer were pediatric nurses who had no formal training in oncology. Care of a child with cancer was brief due to limited and unsuccessful treatments. Nursing care was focused on helping the child and family face the child's certain death. Supportive care treatments were limited. Children were diagnosed most commonly with leukemia and often bled to death because of the unavailability of blood component therapies such as platelets and packed red blood cells. Intravenous therapies were temporary and difficult to administer; there were no central venous catheters or parenteral nutrition in that period. The nurse's role focused on supporting nutritional needs (nurses themselves often cooked special foods for the child), assessing for the constant threat of infection, managing infections with limited antibiotics, and providing supportive care to the child and family. Struggling to prevent or treat infection with first-generation antibiotics involved working in a reverse isolation environment with patients who had fever and neutropenia. Children with cancer frequently died of overwhelming infection.

As treatments for pediatric cancer evolved, so did the role of the nurse. In the 1950s, nurses were "tumor therapy nurses." They administered chemotherapy, educated parents, coordinated care, and continued to provide comfort care as few patients survived longer than a few weeks (Blacken et al., 2019; Foley & Fergusson, 2011). Jean Fergusson was one of the first tumor therapy nurses working directly with Dr. Sidney Farber to improve the care of pediatric oncology patients. Jean pioneered many of the clinical skills we still employ at the bedside today. The importance of a multidisciplinary team approach to care was introduced during this time by Dr. Farber. Several advances in medicine and nursing occurred during the 1960s. Nurses played a greater role in clinical trials, performing physical assessments and collecting data (Blacken et al., 2019). The need for and the development of an advanced practice nursing role was identified and realized. In addition, family-centered care became a core precept in pediatric care delivery (Foley & Fergusson, 2011).

It was not until the mid-1970s that pediatric oncology nursing became recognized as a distinct subspecialty. With the advent of combination cancer therapies in the late 1960s and 1970s, patients developed specific care needs. In addition, the increased survival rates of children treated for cancer required extensive nursing knowledge of cancer diagnosis and treatment, side effect management, and supportive-care strategies.

In 1974, the Association of Pediatric Oncology Nurses (APON) was formed by a group of nurses who met at the Association for the Care of Children's Health conference in 1973 (Greene, 1983). APON was based on the philosophy that pediatric oncology nursing is a specialty that requires specific knowledge and expertise in the care of children who have cancer. Children with cancer are not small adults but rather individuals who have special and unique needs. Childhood cancers differ significantly from adult cancers. Pediatric cancers are generally systemic rather than organ based and require distinctly different treatment regimens. Genevieve Foley who served as APON's third president (1977–1978) described the three key decisions made during her tenure: signing a contract for a textbook on pediatric oncology nursing, approaching the American Nurses Association (ANA) to develop national standards of practice for pediatric oncology nurses, and the decision not to merge APON with the Oncology Nursing Society (ONS) but to remain a separate organization dedicated to pediatric oncology (Foley, 2017). Today, pediatric oncology nursing is recognized as a distinct subspecialty within both oncology and pediatrics. This distinction was formalized with the development of specialty certification in pediatric oncology nursing in 1993 (Foley & Fergusson, 2011).

In the late 1970s and 1980s nursing committees were formed within the established cooperative group structure of the Children's Cancer Group (CCG) and the Pediatric Oncology Group (POG) (Foley & Fergusson, 2011). Networks were created among pediatric oncology nurses to facilitate their contributions to the disease committees throughout both CCG and POG. Nurses participated as members of protocol, disease, and scientific committees and contributed to concept design, trial analysis, and publications. Nurses were instrumental in developing teaching tools for patients and families and were involved in writing treatment guidelines, assisting with the completion of protocol roadmaps, and serving as resources for other professionals in the cooperative groups (Ruccione et al., 2005).

In 2000, CCG, POG, the National Wilms Tumor Study Group, and the Intergroup Rhabdomyosarcoma Study Group formed a unified group for cancer research named the Children's Oncology Group (COG) (Withycombe et al., 2019). Pediatric oncology nurses are maintaining their important roles within COG. Nursing leaders in COG took an active role in structuring nursing research within the cooperative group (Zupanec et al., 2023). This initiative is paving the way