

Tough Courage: *Oncology Nursing Forum* Addresses Childhood Cancer Then and Now

Cancer is a devastating diagnosis for anyone, but none more so than for children and their parents—so many questions to be asked, so much information to sift through and absorb, and so many difficult decisions to be made. It is no wonder that a diagnosis of childhood cancer is often met with fear, anger, guilt, and feelings of being overwhelmed, yet also a determined resilience on the part of families to do whatever it takes to help their child get well again (Rishel, 2010).

Childhood cancer is not very common in the United States, making up fewer than 1% of all annual cancer diagnoses. In 2012, approximately 12,060 children younger than 14 years were diagnosed with cancer (Siegel, Naishadham, & Jemal, 2012). For the children and their families, however, the incidence of disease is not their primary concern. Far more important is the fear of what the future holds as well as how they will navigate the journey that has been unwillingly forced on them.

Sadly, the rates of cancer occurrence in children have been rising ever so slightly since the 1970s. However, because of major treatment advances during the same time period, 83% of children with cancer will experience a survival rate of five years or more. This is significant as the five-year survival rate for childhood cancer in the 1970s was 58% (Siegel et al., 2012).

In the 1970s

One of the earliest articles published by *Oncology Nursing Forum* (ONF) on childhood cancer was Bakke's (1978) informational article focused on nursing considerations in caring for adolescents with osteosarcoma, specifically teenagers whose treatment plan included amputation of the affected limb. Several key considerations for pediatric oncology nurses were discussed, most importantly that when caring for children (regardless of age), nurses must thoroughly assess each child's history of growth and development, any current or previous behavior issues, how the child manages or copes with stress, and any other external influences (e.g., family disruption) that could impact the child's ability to manage the course of treatment and recovery. Because osteosarcoma is primarily a disease of adolescents, Bakke (1978) emphasized understanding the "current

social and cultural demands on teenagers, the importance they place on peer acceptance and the changes and stresses faced by the family" (p. 14). Nurses caring for these patients were cautioned about the need to continually reassess the family's comprehension and understanding of what was happening to their child and, concomitantly to the family itself; the amount and type of information that each family member not only wanted but was able to handle at any given point in time; and family patterns of communication (Bakke, 1978). Family members also needed to be heard and assessed by the nurse. Having an opportunity to safely vent potentially conflicting emotions was reported as being particularly important in establishing the ability of the parents to provide meaningful support to their adolescent child. Because of the very aggressive treatment regimen for most patients with osteosarcoma at that time (including limb amputation and extensive chemotherapy), nurses were implored to be sensitive to the adolescents' developmental needs and make "appropriate and perceptive interventions" (Bakke, 1978, p. 14) when working with patients and families.

Today, osteosarcoma remains a disease primarily of adolescence that is believed to be related to rapid bone growth typically found during this developmental period. Treatment for osteosarcoma generally begins with chemotherapy in an effort to shrink the cancerous tumor. The duration of treatment is dependent on tumor size, whether any malignant cells have spread, and how well the tumor responds to treatment. Once the course of chemotherapy is finished, surgeons will operate to remove any remaining tumor and surrounding bone, oftentimes sparing the child's limb from amputation. Any bone that is missing can be replaced with artificial bone at the time of surgery. If any microscopic cancer cells remain following surgery, they can be treated with additional chemotherapy (Ta, Dass, Choong, & Dunstan, 2009).

Although the current treatment of osteosarcoma is somewhat less invasive than it was in the 1970s, the nursing assessment and management of the patient and family remain almost the same. The early emphasis by Bakke (1978) on the need to complete a holistic assessment of the child and family was right on point. A thorough assessment of the child's growth and development pattern; behavioral responses to things such as stress and pain; the pattern of family life, including their communication styles; and other key concerns is vitally important to the foundation of providing high-quality nursing care. Pediatric oncology nurses have many

more tools at their fingertips today than they did in 1978, usually including an interdisciplinary team with professionals such as child-life specialists, who are able to assist with providing the supportive care these children and their families deserve.

From the 1980s to the Present

In the late 1970s and early 1980s, articles on bone marrow transplantation (BMT) or associated conditions such as aplastic anemia began appearing in the scientific literature. The *Oncology Nursing Forum* published an article by Wiley and DeCuir-Whalley (1983) that reviewed allogeneic BMT as a treatment for children with acute leukemia. The article discussed the basic principles of BMT (including histocompatibility), donor considerations, preparatory treatment, transplantation procedure, clinical course post-transplantation, common complications, cost, and overall survival and relapse rates. For future research, Wiley and DeCuir-Whalley (1983) suggested an exploration of a lack of suitable bone marrow donors. Interestingly, the lack of suitable bone marrow donors remains a challenge today. One improvement is that large cancer centers that specialize in BMT for children have access to bone marrow registries that have been developed to find a suitable, matched donor when no immediate family member is available.

Many of the initial articles in *ONF* were reviews of the state of the science; for example, Truog and Wozniak (1990) published an article on the use of cyclosporine-A (CSA-A) as treatment for the prevention of graft-versus-host disease in children who received BMT. The study focused on the immunologic basis for use of CSA-A, the need for accurate measurement of drug trough levels, and the many severe toxicities of this drug, particularly in a pediatric population.

In 1997, Mehta, Reed, Kuhlman, Weinstein, and Parsons published their study on controlling conditioning-related emesis in children who were undergoing BMT. This is an example of the evolution of *ONF* from a clinical review journal to a journal focused on presenting relevant new research. The study demonstrated that using ondansetron for the control of nausea and vomiting in children receiving high-dose chemotherapy prior to BMT was more effective than using

the then-standard treatment of perphenazine in combination with diphenhydramine. Indeed, 67% of the children in the study who received ondansetron experienced no more than two episodes of emesis during the conditioning phase of the transplantation treatment program (Mehta et al., 1997).

Senner, Johnston, and McLachlan (2005) added to the scientific literature with their research on peripheral versus central venous collection of CSA-A blood levels in pediatric stem cell transplantation recipients. By that time, the familiar phrase “bone marrow transplantation” had changed to “hematopoietic stem cell transplantation” (HSCT), a more accurate description of the physiology of the transplantation process. The researchers found that blood sampling from the CSA-A-naïve lumen of a double-lumen central line was appropriate for measuring and monitoring drug blood levels, particularly if dosing was intermittent versus continuous (Senner et al., 2005). The researchers further determined that if the infusion of CSA-A was continuous, a peripheral venous blood sample was the most accurate method of testing for drug trough levels; however, they cautioned that painful procedures in children should be avoided whenever possible (Senner et al., 2005). As a result, many pediatric BMT nurses identify one lumen of the child’s central line that will carry the CSA-A drug, label that line so everyone will know it is “contaminated” with drug, and use one of the other lumens for drawing CSA-A trough levels.

In 2008, *ONF* published an article about issues surrounding stem cell transplantation. A prospective, longitudinal study measuring growth patterns and gastrointestinal symptoms in children following HSCT demonstrated that children exhibited poor growth patterns in the first four months following transplantation and experienced numerous gastrointestinal symptoms before and after transplantation (Rodgers et al., 2008). HSCT is a highly complex, aggressive medical treatment with numerous potential post-transplantation complications. The authors recommended that the evaluation of the patient’s symptom experience related to gastrointestinal distress be accompanied by a thorough assessment of the patient’s well-being. A comprehensive assessment can assist with defining an appropriate treatment

plan while supporting improved nutritional health following HSCT (Rodgers et al., 2008). The authors suggested that further research was needed to explore the meaning of symptoms that children experience during the HSCT process and their perceived significance. Additional studies designed to analyze nursing interventions and the use of patient and parent educational interventions were proposed to improve standards of care for children who received HSCT.

Moving Forward

Nursing research with a focus on childhood cancer has continued to evolve since the 1970s, and *ONF* has been at the forefront of this movement. Common themes exist in the articles from the journal’s early days to the present. For example, continued fine tuning of nursing assessments is needed to meet the needs of patients and their families and those of the changing health-care environment. Research in parental decision making and supportive care is critical as well as learning more about survivorship needs of children and families. Hand in hand with survivorship is the ongoing need for work on long-term effects of newer treatment modalities on children’s growth and development as well as the challenge of secondary malignancy development.

According to Bakke (1978), teenagers with osteosarcoma and their families “have demonstrated a tough courage in facing the double difficulties of an amputation and the diagnosis of a malignancy” (p. 16). What was true in 1978 is true today: Children with cancer and their families demonstrate “tough courage” every day and nurses have an obligation to pursue, through research and dissemination of knowledge, new and innovative ways to address the myriad issues they face. *ONF* has been, and continues to be, the leader in the publication of the cutting-edge research that pediatric oncology nurses use as the foundation for their practice.

Cindy J. Rishel, PhD, RN, OCN[®], is a clinical associate professor and administrator of nursing research and practice in the College of Nursing at the University of Arizona Medical Center in Tucson. No financial relationships to disclose. Rishel can be reached at cindy.rishel@uahealth.com, with copy to the editor at ONFEditor@ons.org.

Digital Object Identifier: 10.1188/13.ONF.308-310

References

- Bakke, K. (1978). Nursing considerations for the adolescent osteosarcoma patient with amputation. *Oncology Nursing Forum*, 5(4), 14–16.
- Mehta, N.H., Reed, C.M., Kuhlman, C., Weinstein, H.J., & Parsons, S.K. (1997). Controlling conditioning-related emesis in children undergoing bone marrow transplantation. *Oncology Nursing Forum*, 24, 1539–1544.
- Rishel, C.J. (2010). Conceptual framework for the study of parental end-of-life decision making in pediatric blood and marrow transplantation. *Oncology Nursing Forum*, 37, 184–190. doi:10.1188/10.ONF.184-190
- Rodgers, C., Wills-Alcoser, P., Monroe, R., McDonald, L., Trevino, M., & Hockenberry, M.J. (2008). Growth patterns and gastrointestinal symptoms in pediatric patients after hematopoietic stem cell transplantation. *Oncology Nursing Forum*, 35, 443–448. doi:10.1188/08.ONF.443-448
- Senner, A.M., Johnston, K., & McLachlan, A.J. (2005). A comparison of peripheral and centrally collected cyclosporine A blood levels in pediatric patients undergoing stem cell transplant. *Oncology Nursing Forum*, 32, 73–77. doi:10.1188/05.ONF.73-77
- Siegel, R., Naishadham, D., & Jemal, A. (2012). Cancer statistics, 2012. *CA: A Cancer Journal for Clinicians*, 62, 10–29. doi:10.3322/caac.20138
- Ta, H.T., Dass, C.R., Choong, P.F., & Dunstan, D.E. (2009). Osteosarcoma treatment: State of the art. *Cancer Metastasis Reviews*, 28(1–2), 247–263. doi:10.1007/s10555-009-9186-7
- Truog, A.W., & Wozniak, S.P. (1990). Cyclosporine-A as prevention for graft-versus-host disease in pediatric patients undergoing bone marrow transplants. *Oncology Nursing Forum*, 17, 39–44.
- Wiley, F., & DeCuir-Whalley, S. (1983). Allogeneic bone marrow transplantation for children with acute leukemia. *Oncology Nursing Forum*, 10(3), 49–53.