

New Trends and Recent Care Approaches in Pediatric Oncology Nursing

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ABSTRACT

Increased incidence of children diagnosed with cancer and survivors was an impact on changes in pediatric hemato-oncology nursing care. In this review article, it is aimed to investigate the new trends and recent care approaches in pediatric oncology nursing. The recent care topics were common in the literature as family-centered care, technology-based care, program development, primary care of child, health-care provider, survivors and home care, and nonpharmacological care. All of the topics contribute to perform evidence-based care for health

promotion and well-being in pediatric hemato-oncology nursing. Research reviews showed that many current topics for the care of children and their parents have entered in the literature. There is a need for more randomized controlled studies to improve the level of evidence of new nursing approaches.

Key words: Cancer, care, evidence-based practices, nursing, oncology, pediatric

Introduction

The incidence of cancer in childhood is increasing.^[1] It is estimated that the incidence of childhood cancer in the United States is increased by 0.6%/year. The most common cancer type in childhood is leukemia.^[2] Advances in the treatment of childhood cancer have been shown an improvement in prognosis in recent years.^[3] Therefore, survivor rate of children with cancer is going to rise in the past decade.^[4]

Increased incidence of children diagnosed with cancer has led to changes in the treatment and prognosis of the

disease as well as in nursing care. In this review article, it is aimed to review the new trends and recent care approaches in pediatric oncology nursing. We could say that the literature, especially over the past 5 years, mostly focused on the topics as family-centered care, technology-based care, program development, primary care of child, health-care provider, survivors and home care, and nonpharmacological care. Each category could interact with each other. All

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of the topics in the categories contribute to perform evidence-based care [Figure 1]. Health-care services in today’s societies require evidence-based practices across disciplines. Standards, guidelines, and reports could be used in specific care.^[5]

In this manuscript, it is aimed to review the new trends and recent care approaches in pediatric oncology nursing.

The specific study questions are as follows:

1. What are the recent evidence-based practices for children with cancer in their complex nursing care
2. What are the common key topics and concepts influencing the development of new care approaches to understand the underlying mechanisms facilitating an effective care to children with cancer?

Search Strategies

The discussion paper provided a search of PubMed, CINAHL, and Ovid Medline. Search was conducted using the keywords of pediatric, children, parent, cancer, hematology, oncology, nursing, care, health to explore the developments relating to new trends, and recent care approaches in pediatric oncology nursing.

Studies had to meet the following criteria to be included in this manuscript: (a) to be published between 2011 and 2017 and (b) to consist of children and adolescents with cancer or their parents. Exclusion criteria were as follows: (a) not published as a full article, (b) not published in English, and (c) published articles about new development in drugs and medicine.

This search yielded 61 articles which were focused on recent nursing approaches in pediatric oncology. Two

authors reviewed the studies for the eligibility criteria and the scope of the review. The paper was designed to provide brief information about the new trends and recent care approaches in pediatric oncology nursing. For this reason, this paper discusses recent trends under seven subtitles as follows: “Family-Centered Care,” “Technology-Based Care,” “Program Development,” “Primary Care of Children,” “Health Care Providers – Cost Containment,” “Survivors and Home Care,” and “Nonpharmacological Approach.”

Family-Centered Care

In the past decades, it has seen significant changes in the way of care in pediatric oncology wards. Parents have more participated in their children’s medical and surgical care and communicated more effectively with their child and provided much supportive care. There is an increasing emphasis on the benefits to provide family-centered care in pediatric oncology wards.^[6] Family-centered care provides patient-family-professional interactions and collaborations in care delivery.^[7]

Family-centered care and partnership-in-care models and themes such as decision-making and information seeking are more focused in recent studies in the field of pediatric hemato-oncology nursing^[8-10] [Figure 2]. For example, for one recent study, Coyne *et al.* stated that seriousness of the illness affects the roles of children and parent in decision-making. Children involved in minor decisions (choices about care delivery) instead of major ones to provide control and trust sense.^[8] The information-seeking behaviors and decision-making

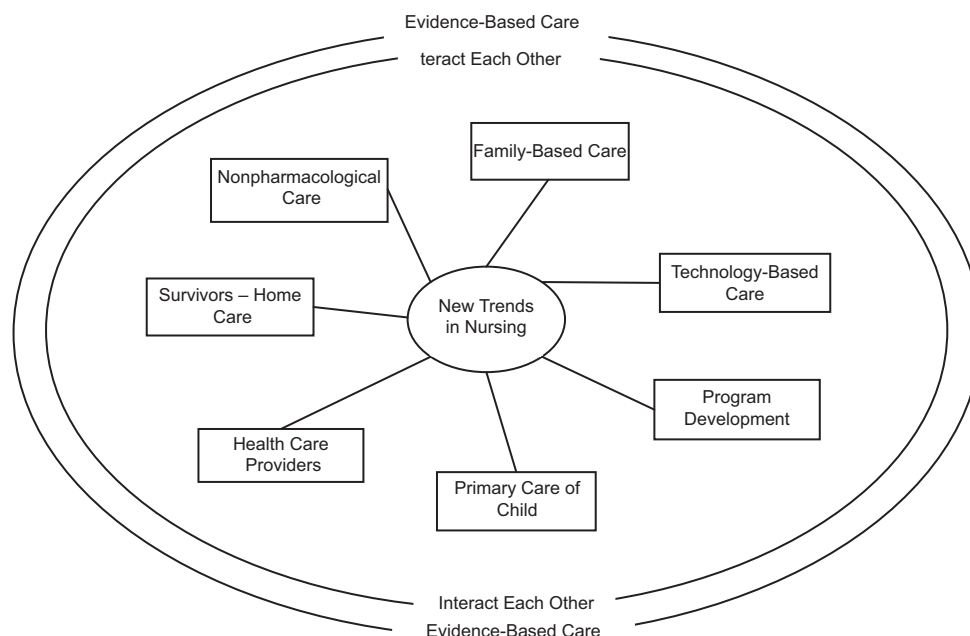


Figure 1: Most Common Topics About New Trends in Pediatric Oncology Nursing Care

experiences of parents of children with cancer were investigated in another study and found that parents mostly sought information about their child's illness, treatment, and caregiving issues. Furthermore, they defined that parents were directed primarily by health-care providers during their decision-making process.^[10] One study focused the immigrant parents' experiences about family-centered care in pediatric oncology wards in Canada. They found that parents were generally satisfied from this care. However, some areas of concern identified like inconsistency in the quality of care and mechanical manner of a few staff.^[11] In a literature search study, cultural and religious factors of parents in pediatric palliative care about decision-making were investigated and it was recommended to provide culturally sensitive end-of-life care because of the dynamic status of culture.^[12]

For long-term illnesses, caregiver of children's has challenges to provide care interventions as well as parenting styles.^[13,14] Williams *et al.* searched the impact of childhood cancer on parenting styles and strategies. It was found that parenting strategies and styles could change throughout the illness period.^[15] Quality of life, family resilience, care burden, parental stress, and social support also investigated in some studies.^[16-21] For example, Rosenberg *et al.* (2014) conducted a study to determine resilience and influencing factors in families.^[18] It was determined that lower social support and family function were affected the resilience of parents of children with cancer. Ceylan *et al.* aimed to examine the caregiver burden experienced at hospital ($n = 58$) and home ($n = 44$) by parents who have a child aged 0–18 years diagnosed with cancer. The caregiver burden of the parents at hospital environment was higher than the parents at home environment.^[17] Altay *et al.* searched the social support needs of mothers ($n = 88$) of children with cancer. This study revealed that all families express a need for social support, but the percentage that receives social support was lower than their needs.^[16] In another review article, evidence suggests that the standard

of care should consist of at least one contact with bereaved parents of children with cancer to identify the risks for negative psychosocial effects.^[22]

Family-centered care provides building trust, listening to parent concerns, and valuing parents' knowledge of their child.^[23] Adequate and regular basis information is necessary about child illness, treatment, and care for parents. Dealing with individuals and providing support and spare time are key components to helping parents about their children with cancer. Nurses should consider not only the physical needs of the child and his/her family but also the family's emotional and social needs.

Technology-Based Care

Since the technology usage increases in worldwide, pediatric oncology nurses are in a unique position to collect data, monitor, and design specific educational and psychosocial support with technology-based interventions for children and their families. These interventions could include web-based platforms or programs, smartphones, tablets, computers, and text messaging [Figure 3]. Technology-based interventions provide the usage of different senses such as auditory, visual, touch, and attractions for children and parents. Information and support needs of children and parents should be provided on a continuing basis, accessible, and understandable way.

For educational and psychosocial support with technology-based interventions, one study was conducted to assess the effectiveness of an evidence-based website. The parents and children were given separate passwords, and they had accessed the 140 pages about cancer, family, and living with cancer topics for a 4-month period. The findings suggest that the use of the website was enhanced the cancer knowledge of children and families.^[24] In another similar website study, the internet program including animations, images, videos, discussion boards, surveys, and interactive forms consisted of 12 interactive modules. Adolescents found the program satisfactory and helpful when they were first diagnosed with cancer.^[25] Videoconferencing is another method used to connect children with cancer to their home school. This technology-based intervention could provide benefits including stronger relationships with classmates and teachers, peer acceptance, and school reintegration.^[26]

In another technology-based study for data collection and self-evaluation, the computerized symptom capture tool based on iPad app was used to explore the symptoms which adolescents experienced during the chemotherapy treatment. The symptoms were investigated with graphical images and brief, free text responses. Participants described the program helpful to understand their symptoms better, and symptoms were gathered effectively.^[27] Similar to

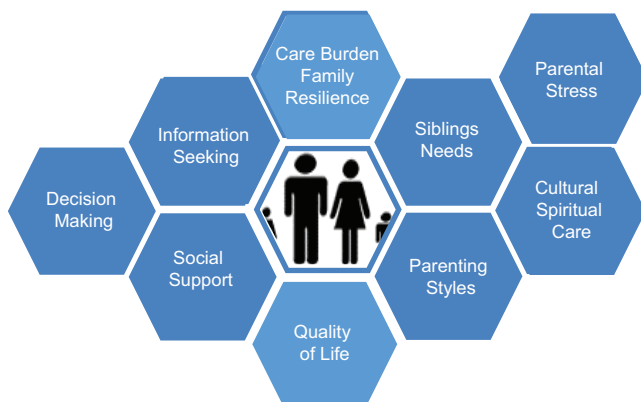


Figure 2: Common Concepts in Family Centered Care

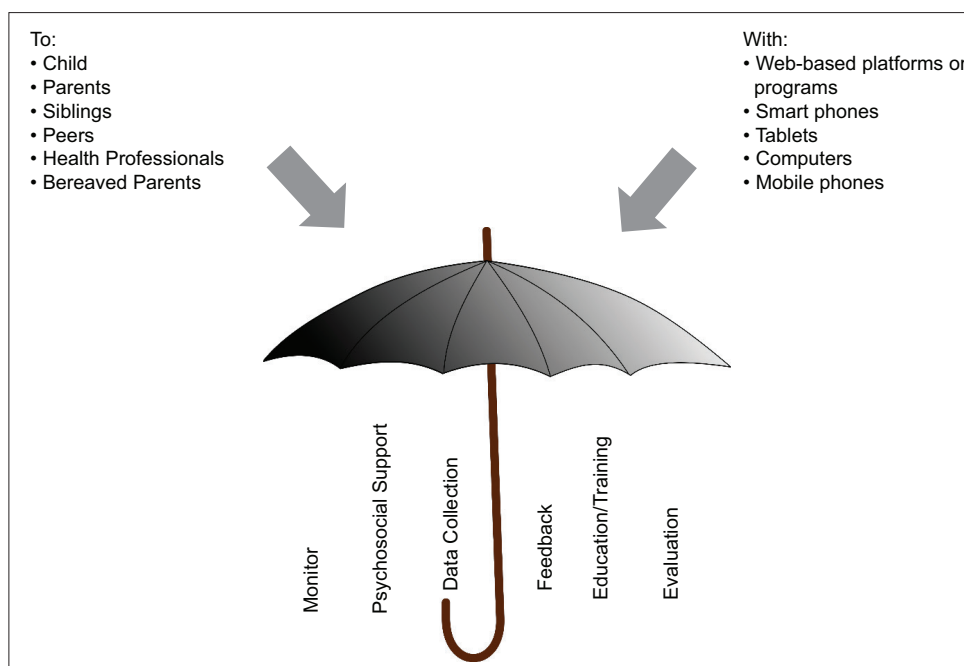


Figure 3: Potential Applications of Technology Based Approaches to Pediatric Oncology Nursing Care

this study, Baggott *et al.* created the Sisom, an animated computer tool for children and young people with chronic illnesses to evaluate the reports of symptom. They stated that Sisom provides a systematic and engaging method to evaluate symptoms reported from children.^[28] In another study, children and parents completed the computer-based symptoms and quality of life questions and feedback was given about the scores to intervention group. Emotional subcategory of quality of life in the intervention group was found higher than control group.^[29] Furthermore, web-based video recording and data collection could be useful and cost-effective on Facebook.^[30] The technology-based interventions could be used for health-care professionals to improve evidence-based follow-up cares, a web-based support system for clinical decision-making.^[31] For example, an e-learning training program about reproductive health in the adolescents with cancer for oncology nurses consisted of a 10-week web-based program. The curriculum of the program included distance learning-based follow-up, expert e-learning discussions, brief quizzes, ask-the-expert modules, and interactive group discussions.^[32]

Expanding the scope of technology-based interventions is a desirable goal. How rapid ongoing technology-based interventions will adapt to the oncology care settings is currently unknown. Therefore, more technology-based interventions are needed to improve the evidence-based approaches. Developing an effective and practicable technology-based intervention for children in their growth and development period has a very broad scope and has big potential to positively impact pediatric cancer care outcomes.

Program Development

Recently, working with a vision and mission for development and quality improvement of pediatric oncology settings is required to extend the implementations of programs. Outcome of childhood cancer treatment can be improved substantially by implementations of programs. There are different kinds of programs in pediatric oncology settings such as helping children and parents to reduce their anxiety, educate about illness and treatment, adhere the treatment, provide symptom control, improve the care and follow-up system, and school reentry programs [Figure 4].

In India, a social support program by voluntary organization was implemented, and new quality improvement services were applied to pediatric oncology patients. The results of the program were as a reduction in waiting time in the hospital, decreased in anxiety levels, better drug compliance, and improved follow-up.^[33] On the other hand, an end-of-life program was constituted to evaluate the outcomes for children with brain tumors. Program was included four components: regularly discussions, medications for symptom control, family consultation, and home visits. Patients who received the program were less hospitalized and better symptom management than the control group.^[34] Another study was conducted to determine the effect of a 5-day program including drawing, writing, and mutual storytelling techniques on the anxiety level of children aged 9–16 years undergoing cancer treatment in hospital. They found that anxiety level of children was lower after the intervention than beginning.^[35]

A program was constituted for children with acute lymphoblastic leukemia (ALL), also. Yeh *et al.* investigated the effects of the home-based aerobic program on reducing fatigue in these children. It was determined in the first analysis that fatigue level has decreased in the intervention group compared to the control group.^[36] In another study for parents and siblings of pediatric oncology patients, a respite care program was developed, and the respite care providers were hospital volunteers attended a 3 h respite care training session. Reasons for the caregiver respite care request included a need to leave the hospital for short periods such as eating a meal or talking with the medical team. Caregivers and staff satisfaction level were found higher about the program.^[37] On the other hand, Helms *et al.* reviewed the school reentry programs for children with cancer. They stated that these programs have significant effect to enhance academic achievement and decrease the levels of depression in children.^[38]

Programs for children with cancer, which contain issues such as nutrition, physical activities, and symptom management, could be effective and useful. Nurses have an important role on constituting and applying the programs. Using multiple interventions during the program and approaching systematically about the issue could improve the well-being of children with cancer.

Primary Care of Children

Primary nursing is a care model that supports the professional nursing practice. Within primary nursing, a therapeutic relationship is established between a nurse and an individual child and the family. In recent studies, physical patterns such as nutrition, sleep, and rest of care in

children with cancer were evaluated with current treatment protocols and cancer types. For example, the prevalence of undernutrition was found higher in children with solid tumors than children with hematological malignancies.^[39] In another study to define the nutritional problems of children with cancer, it was found that the most common problems were a loss of appetite, refusal to eat depends on fatigue, and body pain and stomatitis. Parents' most information requirements about their children's nutrition were as food–drug interactions, eating frequency, and time.^[40] Linder and Christian investigated the night time sleep characteristics of 15 children for three nights. They found that nighttime sleep was less than that required for healthy school-age children and awakenings during night time were frequent.^[41]

On the other hand, symptoms and symptom clusters in children who have been receiving cancer treatment are closely monitored in care in recent years. Children could be experienced multiple symptoms during the treatment.^[42-45] Children's emotional status, comfort level, and psychosocial aspects are also important during and after the treatment. Therefore, these aspects, especially, were investigated and given importance in care. A study was conducted to explore the children's experiences of comfort in their drawings. The findings showed that children found comfort, especially from their family and hospital staff. The children also described that they comforted family members and comforting others also comforted children.^[46] Another study was also aimed to investigate the emotions of children with cancer by children's drawings. The results showed that impulsivity, mistrust, and anger were observed higher than healthy children's drawings.^[47] Social support and psychological symptoms of adolescents with leukemia were investigated in a study, and they found a negative relationship between them.^[48] Furthermore, transition from children's to adult services is an essential issue to provide empowerment the adolescents and young adults in recent care approaches.^[49] Common concepts in primary care, health-care providers, survivors and home care, and nonpharmacological care topics are given in Figure 5.

Patient outcomes improve when care is based on empirical evidence. There is, however, a recognized need for more evidence and specific recommendations related to caring for special populations of patients such as children undergoing treatment for cancer.

Health-Care Providers-Cost Containment

Studies about pediatric oncology nurses and cost containment contribute the literature for outcomes of care. One study showed the cost-effectiveness of an education

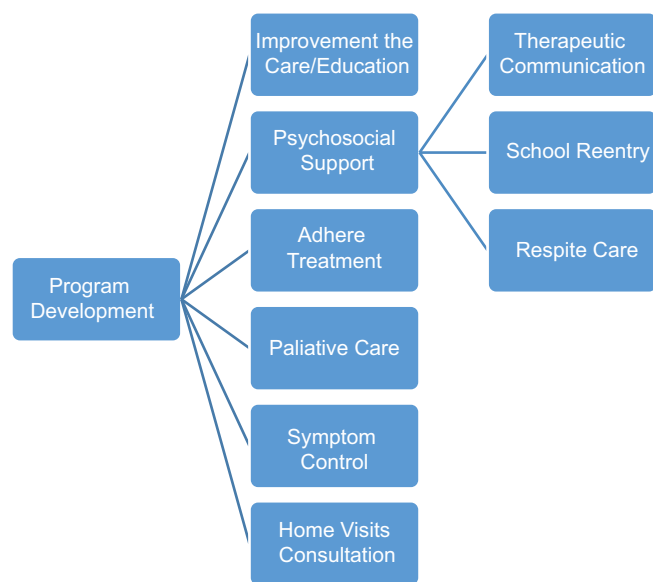


Figure 4: Most Common Program Developments in Recent Nursing Care

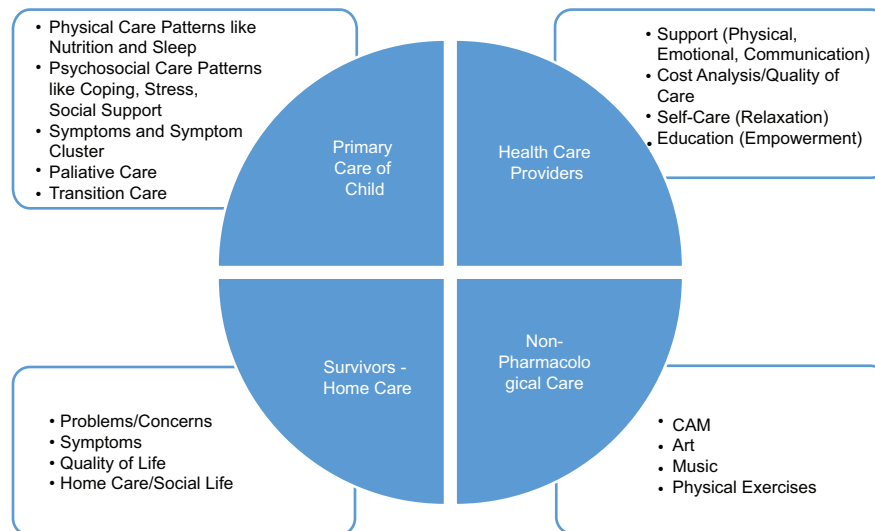


Figure 5: Common Concepts in Primary Care, Health Care Providers, Survivors-Home Care, and Non-Pharmacological Care Topics

course for new hired pediatric oncology nurses and stated that the implemented course cost was markedly less (244\$/nurse) than other models.^[50]

In one recent study, the communication difficulties of pediatric hematology/oncology nurses with children and their families were explored, and nurses defined difficulties in responding to questions, ineffective communication, and conflicts with the patient's families.^[51] Price *et al.* also investigated the perspectives of health-care professionals on end-of-life issues for children with cancer. Challenging issues were found as truth-telling, symptom management, communication with families, the emotional effect of the withdrawal of treatment, and sibling support.^[52] Altounji *et al.*, 2013 stated that implemented three off-site self-care retreats to create a therapeutic and supportive environment allowing time for relaxation, reflection, and serenity. Program was included presentations, group discussions, and relaxation activities for pediatric oncology nurse.^[53]

Empowerment the nurses will improve the quality of care by reducing the feelings of exhaustion and incompetence in care. The roles of the pediatric hemato-oncology nurses are expanding within holistic care settings, and well-trained specialized nurses provide safe, effective, and quality care to children with health problems.

Survivors and Home Care

The number of cancer survivors has been increasing, and the health-care issues of survivors also became more obvious because of the increasing risk for long-term morbidity and mortality. Physical and emotional symptoms and problems/concerns, home care, social life, and quality of life were the most investigated topics in recent studies with survivors. For example, Arpacı and Kilicarslan Toruner (2016) assessed the problems and symptoms in

childhood ALL survivors ($n = 91$). They found the most common physical problems and symptoms as respiratory system infections (40.7%), reduction in bone mineral density (26.4%), exercise intolerance (45.1%), and pain (41.8%).^[54] In another study, problems/concerns of survivors of cancer were examined and they found that most of the survivors had at least one physical and one emotional concern. Concerns were increasing in female survivors, younger survivors, and survivors who received more intensive treatment.^[55]

A study was assessed the quality of life of adolescents' survivors of childhood cancer and found that survivors had a higher quality of life scores than the adolescent who were undertreatment.^[56] Furthermore, another study was investigated the physical activity levels and quality of life in adolescent survivors. It was found that physical activity decreased after diagnosis and quality of life was higher when the physical activity was high.^[57] Cantrell *et al.* (2017) examined the relationships among self-esteem, hopefulness, and quality of life to help the development of evidence-based practice guidelines for pediatric oncology nursing practice. They found that self-esteem and hopefulness are positively related and contribute to the quality of life among young adult female survivors.^[58] The difficulties regarding the home care of children following hematopoietic stem cell transplantation were investigated in a study with 73 children and their parents. Primary physical problems that were found after discharge from the hospital were fever (43.8%) and decreased appetite (37%). Socially, 43.8% of families reported that their children had difficulties with school.^[59]

Survivors and transplant patients have many problems and symptoms related to disease and treatment. Therefore, planning and implementation of nursing interventions to develop health status in children are important. Nursing

interventions should include the providing information about potential problems and care to patients and families to increase the quality of life.

Nonpharmacological Approach

The success of cancer therapy is improving due to invasive treatments. Furthermore, significant side effects including pain, nausea, fatigue, and distress could be seen in children with cancer. Therefore, primarily holistic approaches and focus on wellness and healing powers are going to increase using complementary and alternative medicine (CAM). In one study, CAM usage among parents of children with cancer was found 73.3% and the most common type was defined as biologically based therapies such as dietary supplements and herbal products. They stated that CAM usage did not affect the 5-year survival rate.^[60] We could see the CAM usage also in palliative care. Schütze *et al.* showed the CAM usage as 49% and the most common types of CAM as homeopathy and mistletoe preparations in pediatric patients during palliative care.^[61]

Hypnotherapy could be advisable, especially during painful procedures in pediatric oncology settings. It is also recommended to use art therapy and music therapy as distraction and imagery. These CAM methods showed potential to improve the well-being of patients.^[62] Thrane also reviewed the literature and stated that integrative medicine including virtual reality, various mind–body techniques, creative arts therapy, listening to music, and hypnosis was effective for pain and anxiety in children with cancer.^[63] Another review study was determined that exercise interventions could reduce the levels of general fatigue in children and adolescents with cancer.^[64] In Australia, pediatric hospitals providing oncology care having a registered music therapist as part of the allied health team.^[65] We need more and better supported by randomized quality studies to make clear recommendations about the usage of CAM in pediatric oncology settings. It is believed that evaluating the efficacy and safety and then counseling the family about the usage of CAM in children will make a significant contribution for nursing care.

Conclusion

A key component of a successful and effective pediatric cancer treatment is the delivery of care by skilled professional nurses. Key initiatives of the pediatric oncological care include evaluation of models of nursing care and methods to optimize the transition process between research results and primary care providers; expansion of educational programs related to care for both nurses and children/families; development of evidence-based practices for health promotion and well-being; development of

guidance recommendations to enhance and standardize the nursing care of children with cancer. Collectively, nursing care including screening, prevention, promotion, research, advocacy, education, and care coordination is keys to moving quality of care forward.

In this review manuscript, it was aimed to search the new nursing care trends, especially the past 5 years in the pediatric hemato-oncology field. However, some new developments could not be mentioned or not reached because of the variety in the literature. In the field of pediatric oncology, it appears that many current topics for care of children and their parents have entered in the literature. There is a need for more randomized controlled studies to improve the level of evidence of new nursing approaches. Following current approaches in care and implementing innovations will increase the quality of life of the children and their families who are followed or watched with the diagnosis of cancer.

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Conflicts of interest

There are no conflicts of interest.

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