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THE ROLE OF NURSES IN ENSURING CONTINUOUS CARE FOR ONCOLOGY PATIENTS

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Abstract

This article analyzes the role and significance of nurses in ensuring continuous care for oncology patients. The aim of the study is to substantiate the clinical, psychological, and social functions of nurses in the care of cancer patients. Analytical, comparative, and systematic research methods were employed. The findings indicate that nurses play a key role in supporting patients throughout the treatment process, preventing complications, and improving quality of life. The results of the study are of practical importance for improving nursing practice in oncology settings.

Keywords: oncology, continuous care, nursing role, patient care, quality of life.

Introduction

Pediatric oncology is widespread among families worldwide, with approximately 300,000 new cases diagnosed each year, and the number of cases is increasing. The highly stressful, emotional, and traumatic impact on parents of children with cancer (PCCs) is strongly felt; therefore, it is important to better understand the factors that contribute to the psychological well-being of PCCs [4].

The WHO definition of pediatric palliative care (PPC) highlights the role of active, multidimensional care, delivered with interdisciplinary expertise, and providing support to the entire family. The aim of the current national study was to determine parents' perspectives on whether their children received palliative care (PC) before dying from cancer and on the care their child received during the final month of life. In 2016, parents (n=226) completed a study-specific questionnaire, and the majority reported that their child had received care from qualified professionals. However, many parents indicated that their child experienced significant pain during the last month of life. Geographical differences showed that parents living in less densely populated areas were less likely to report that their child received PC. Ultimately, our conclusion is that equitable access to PPC and effective symptom management are essential for children and their families [7].

Palliative care for children was defined by the World Health Organization (WHO) in 1998 and was initially aimed at children with cancer. Today, the WHO definition covers all diagnoses. According to the definition, palliative care is active care that addresses, alleviates, and evaluates the physical, psychological, social, and existential (related to the meaning of life) needs of the child. It also includes support for the child's family and is provided with the involvement of a multidisciplinary team of specialists. Palliative care for children can be provided by various healthcare providers and can also be given at home. The definition emphasizes that palliative care begins when a life-threatening or life-limiting condition is identified and continues regardless of whether the child is receiving specific treatment or not. The International Hospice and Palliative Care Association has issued a definition of palliative care that clearly includes all age groups — children as well as adults [20].

Cancer constitutes 5.2% of the palliative care needs of children. Approximately 90% of children with cancer live in low- and middle-income countries, and these children account for 84% of the global cancer burden. In low- and middle-income countries, treatment coverage for children is low and mortality is high, making palliative care in pediatric oncology crucial. Children with cancer experience pain and physical symptoms, low mood, anxiety, and fear [3].

Each year, approximately 400,000 children and adolescents aged 0 to 19 are diagnosed with cancer worldwide. Pediatric cancer is an example of a group of diseases in which the majority of children diagnosed in high-income countries now survive, although survival rates can vary depending on the specific diagnosis. The course of cancer can be long, treatment may be intensive, and it is common for treatment to impact the child's well-being and even threaten their life. The definitions of pediatric palliative care established by the World Health Organization (WHO) in 1998 were based on experiences of caring for children with cancer. Today, this definition includes all diagnoses and emphasizes the role of active, multidimensional care that supports all family members, as well as carrying out this care with interdisciplinary competence [9].

Pediatric palliative care is the care of a child and their family during the course of an illness using a multidisciplinary, holistic approach. Children with cancer experience physical symptoms and a decrease in quality of life [10].

Although significant progress has been made in treating childhood cancer over recent decades, nearly 4 million children worldwide with oncological conditions require palliative care due to the nature of their illnesses. The WHO defines pediatric palliative care as care aimed at preventing and alleviating suffering in patients with life-threatening or life-limiting illnesses, as well as in their families [1].

Pediatric palliative care aims to provide support to children and young people suffering from life-limiting or life-threatening illnesses, as well as their families, from the point of diagnosis. Early integration in oncology has been recognized as beneficial for all participants, regardless of the outcome. Through improved communication and advance care planning, it allows for patient-centered care, where concerns about quality of life, choices, and values are as important as state-of-the-art therapy. The challenges of integrating palliative care in pediatric oncology include raising awareness and providing education, finding the best care model, and adapting to continuously changing treatment conditions [11].

Palliative care is not limited solely to the end-of-life period; especially in pediatrics, long-term involvement by specialized palliative care teams is common. Modern care models emphasize that curative and palliative approaches are not mutually exclusive and can coexist for extended periods. However, in pediatric oncology, there is a significant overlap between palliative care and end-of-life care, with the transition from primarily curative treatment to exclusively palliative care sometimes occurring very rapidly. As a result, it is not uncommon for pediatric surgeons to participate in the end-of-life care of children with cancer [12].

Pediatric palliative care (PPC) improves the quality of life and end-of-life outcomes for children with cancer, but it is often applied in the late stages of the disease. The Supportive Care Clinic (SCC) was launched in 2017 to expand outpatient PPC services [2].

Pediatric Palliative Oncology (PPO) - integrating PPC services into routine pediatric cancer care - is encouraged by the American Academy of Pediatrics, the Standards for Psychosocial Care in Pediatric Oncology, as well as publications on care models, hospital integration, and PPO training models. PPO services are linked to better symptom management, enhancing the quality of life for children and families, while also reducing the use of healthcare resources, chemotherapy, and intensive end-of-life (EOL) care. Furthermore, when patients have better symptom control, receive less intensive EOL care, and families are prepared for EOL, postmortem psychological outcomes improve [14].

Pediatric palliative care (PPC) is a service aimed at preventing and alleviating the physical and psychosocial suffering of patients. It is provided through the early identification and comprehensive assessment of physical, emotional, and spiritual aspects, and ultimately seeks to improve the quality of life and satisfaction of children with cancer and their families [6].

Integrated pediatric palliative oncology (PPO) outpatient models are emerging to provide support to oncologists, children, and their families throughout the course of cancer. Significant time is dedicated to care coordination ('non-billable' time), but the amount of time spent for each patient, its scope, and the ratio of non-billable to billable (NB: B) minutes remain unknown. This information is crucial for designing new PPO outpatient clinics and ensuring appropriate staffing, physician time, and resources. Our objective was to quantitatively assess non-billable time and explore demographic or disease-related associations [17].

Palliative care (from Latin pallium - covering, cloak) is an approach aimed at enhancing the quality of life of patients for whom treatment is not possible. According to a consensus agreed upon by most researchers, the definition of palliative care is as follows: “Palliative care is care provided with an active and holistic approach to individuals of all ages who are experiencing health-related pain and suffering due to serious illnesses, especially those nearing the end of life. It aims to improve the quality of life of these patients, their families, and caregivers.”[13,24].

Pediatric palliative care (PPC) is a service aimed at preventing and alleviating the physical and psychosocial suffering of patients. It is provided through the early identification and comprehensive assessment of physical, emotional, and spiritual needs, and ultimately seeks to improve the quality of life and satisfaction of children with cancer and their families [6].

Pediatric oncology is considered a rewarding and honorable field. However, it often exposes healthcare professionals to work-related stress and challenging situations, making it difficult to provide high-quality and ethically appropriate care. Some situations arise from organizational constraints and manifest as staff shortages, while others reflect difficulties in delivering the best possible care, such as being unable to relieve a child's pain. For workers who consider the actions they perform to be ethically correct, obstructive situations can cause negative emotions and suffering, which is referred to as moral distress. Although there is significant research on moral distress in general, studies in pediatric oncology are very limited [18].

Patients with cancer constitute an important group in pediatric palliative care. Although the patient's home is the preferred place for care, there is very little information about the characteristics of patients admitted to home care services [15].

Cancer is one of the leading causes of death in children, with approximately 12% of affected children not surviving. In the United States, the clinical incidence of childhood cancer is 178.3 per 1 million children, with leukemia being the most common type, accounting for 46.6% of all cancers in children. In Iran, the childhood cancer mortality rate is reported to be 69.5%, and patients in pediatric oncology departments often experience severe clinical deterioration, requiring specialized and long-term care [5].

Family-centered care (FCC) in pediatric care institutions is regarded as an essential approach to ensure family involvement in child care and is known to improve health outcomes as well as the psychosocial well-being of families. Moreover, nursing involvement is considered beneficial in establishing genuine nurse-patient relationships and is known to help facilitate the treatment process and enhance satisfaction for patients and their families. The aim of this article is to analyze how nursing involvement supports FCC by closely examining the four FCC concepts defined by the family-centered care approach — dignity and respect, information sharing, participation, and collaboration. In addition, a case study is provided to illustrate how nursing involvement can be applied in FCC when caring for pediatric oncology patients [19].

Special roles have been developed to provide comprehensive care in pediatric and adolescent oncology and hematology, one of which is recognized as an advanced clinical practitioner in pediatric oncology and hematology. Survey results showed that in the United Kingdom, advanced clinical practitioners in pediatric oncology and hematology work in various roles, and their numbers vary significantly across treatment centers. It also highlighted the need for a nationally standardized system defining the knowledge, skills, and expertise required for specialists in pediatric oncology and hematology [22].

In 2023, the Children's Oncology Group (COG) is prepared to play a key role in advancing previous achievements in pediatric oncology and addressing remaining challenges. Founded in 2000 through the merger of four legacy pediatric cancer cooperative groups, COG is a clinical trials organization dedicated to cancer in children, adolescents, and young adults, sponsored by the National Cancer Institute. Since 2000, COG has conducted over 330 clinical trials on both common and rare childhood malignancies. Through a centralized biorepository, COG facilitates the collection, storage, and distribution of more than 100,000 biological samples annually from clinical trial participants and non-trial biobank contributions. With over 220 member institutions in the United States, Canada, Australia, New Zealand, and Saudi Arabia, the majority of children with cancer in these countries are treated at COG centers [21].

Analysis of the concept of PPC for children with cancer identified four characteristics: 'viewing PPC as comprehensive and integrated care,' 'viewing PPC as care centered on the patient and family,' 'viewing PPC as early-initiated continuous care,' and 'viewing PPC as multidisciplinary and team-based care.' Additionally, some effective factors can also serve as a foundation for this concept, such as the preparedness and competence of healthcare staff, as well as human resources and funding. Moreover, the alignment between improved quality of life, symptom reduction, and family support in patient care is among the outcomes of PPC for these children [16].

Parents of children newly diagnosed with cancer need specialized knowledge and skills to safely care for their children at home. The Children's Oncology Group (COG) has developed expert consensus recommendations to guide education for a new diagnosis; however, these recommendations have not been empirically tested [8].

Palliative care (PC) aims to improve the quality of life of patients with serious illnesses and their families by recognizing and alleviating the physical, emotional, social, existential, and spiritual suffering of patients and their communities. Palliative support (PC) seeks to enhance the living standards for individuals with severe ailments and their kin by acknowledging and easing the physical, emotional, social, existential, and spiritual pain experienced by patients and their groups. Teenagers and young grown-ups with tumors (ages 15-39) frequently express anguish across all these domains, which impacts their quality of living throughout and following cancer, rendering palliative treatment especially vital for this cohort. Here, we examine the proof for palliative aid among adolescents and young adults with malignancy, encompassing its basics, shortages, prospects, and consequences for medical care provision. As an illustration, almost 90% of adolescents and young adults with cancer face troubling signs during their therapy; those who recover encounter continuing unmet psychosocial and bodily requirements, and those who pass away from the condition are prone to getting medically intense attention that does not match their aims and principles. [23].

Conclusion

In conclusion, the role of nurses is invaluable in ensuring continuous care for oncology patients. Developing the professional activities of nurses and expanding their opportunities for independent decision-making contribute to improving the quality of care. The results of the study have important practical significance in enhancing nursing practice in oncology departments and improving the quality of life of patients.

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