Chapter 6

CURRENT NURSING APPROACHES FOR SYMPTOM MANAGEMENT AND ASSESSMENT OF QUALITY OF LIFE IN CHILDHOOD CANCERS[1]

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INTRODUCTION

Childhood cancers are generally of embryological origin and heterogeneous. These are types of cancer that can spread quickly if left untreated and have different types than adults (World Health Organization- WHO, 2021). From the children's and their parents' aspect, it is a life-threatening, long-term, chronic disease that causes facing lots of difficult life experiences and life-threatening situations (Lynn Woodgate et al., 2003). It is reported that world-wide almost 400.000 children between 0-19 years are diagnosed with cancer, annually (Steliarova-Foucher et al., 2017; WHO, 2021). Approximately 176.000 children are diagnosed with cancer and 90.000 lost their lives due to cancer in developing countries, annually (Union for International Cancer Control-UICC, 2015). Due to improving treatments and advances in technology, especially in developed countries cancer survival rates of children raised to 80% (UICC, 2015). However, in underdeveloped and developing countries it is reported that only 30% of children diagnosed with cancer could survive (Lam et al., 2019; WHO, 2021). The most diagnosed cancer types in childhood are leukemias, central nervous system tumors, lymphoma, neuroblastoma, and solid tumors (renal& bone tumors) (Steliarova-Foucher et al., 2017; WHO, 2021). The incidence varies world-wide, and it is reported 179.6 in the United States of America, 135 in China, 187.6 in Switzerland, and 163.8 in Turkey,

[1] This chapter is based on the background section of Dr. Gizem Kerimoglu Yildiz's Ph.D. dissertation entitled: "The Effect Of a Tablet Game and Training Book Developed For Children Who Receive Chemotherapy On Symptom Management And Quality Of Life".

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per million in children aged 0-19, between 1999-2013 years (International Incidence of Childhood Cancer-III, 2022).

Among all cancer types, the most diagnosed cancer type is Acute Lymphoblastic leukemia (ALL) which is a subtype of leukemia. The incidence of diagnosing ALL in children between 0-14 ages in Europe is 35, per million (Bomken & Vormoor 2009). There are specific risk factors in the etiology of childhood cancers. Childhood cancers are affected by congenital and prenatal factors, instead of environmental factors. However, in adolescents and young adults, both congenital and environmental factors could play important roles (Bleyer et al., 2007). In this case, cancer is not only based on genetic or hereditary factors but may occur as a result of more than one cause due to possible genotoxic exposure, as well as decreased ability to repair DNA damage appropriately (Hendershot, 2009).

With the rapid advancement of technology, treatment modalities in childhood cancers have also changed. In the past, surgery and radiation were seen as the only treatment options, but in the 21st century, with the addition of anticancer drugs to the treatment, the chance of success in the treatment has increased considerably. Today, in addition to surgery, radiotherapy, and chemotherapy applications, biological and molecular target-based therapies, stem cell transplantations, and cell/gene therapies are used in children according to the type and course of the disease (Zupanec& Tomlison, 2009). However, despite increased treatment success and survival rates, cancer treatment, unknown prognosis, and medical procedures leave children with stressful and life-threatening experiences (Ruland et al., 2009; Williams et al., 2012).

During the treatment, most of the children receive long and intensive chemotherapy. This condition often requires long term hospitalization and interferes with the child's normal development, activities, and social interactions (Ruland et al., 2009). Children often experience treatment-related physical symptoms such as alopecia, anorexia, constipation/diarrhea, mucositis, nausea/vomiting, and pain. They may experience some psychosocial problems such as anxiety, depression, fatigue, irritability, unhappiness, and a decrease in sleep quality (Gordijn et al., 2013; Wolfe et al., 2015).

EVALUATION OF COMMON SYMPTOMS AND NURSING CARE IN CHILDREN RECEIVING CHEMOTHERAPY

Cytotoxic drugs used in chemotherapy act by preventing the proliferation and destruction of cancer cells. However, they also affect normal cells (Mihelic, 2005).

Therefore, besides the therapeutic effects of chemotherapy, some symptoms such as pain, anorexia, cachexia, change in taste, alopecia, nausea/vomiting, constipation, diarrhea, dehydration, mucositis, fatigue, depression, and anxiety could be seen (Selwood et al., 2010). These symptoms can occur singly or together. Clusters of symptoms increase the severity of symptoms and affect the functionality and quality of life of children (McCulloch et al., 2018). Failure to adequately control symptoms may result in individual discontinuation, reduction of treatment dose, or interruption of treatment (Kornblith et al., 2003). The impact, severity, and incidence of single or multiple symptoms should be evaluated continuously and regularly throughout treatment. Many measurement tools have been developed for a more practical assessment of the effectiveness of children's symptom management and practices. In the evaluation, it should be noted that during the treatment sypmtom frequency and severity may vary, and for this, the continuity of the evaluation should be ensured (McCulloch et al., 2018).

Since the symptoms experienced by children are unique to them, the child should be considered as a whole and a holistic approach should be provided. Nurses can identify symptoms at an early stage, plan, implement and develop nursing activities in a child-specific manner, and set standards of care. Thus, nurses can improve their quality of life (Lee& Frazier, 2011; McCulloch et al., 2018). Informs children and caregivers about symptoms and what they can do for effective symptom control. Some of the common symptoms associated with chemotherapy in children are;

Oral Mucositis (OM): It is a common and serious problem of chemotherapy that causes alterations in quality of life and significant morbidity (Cheng et al., 2008). The "direct" or "indirect" effects of chemotherapy on cells can cause this condition (Sonis, 2010). Its direct effects are on cell proliferation, maturation, and regeneration. Indirect effects are the occurrence of oral mucositis-associated infection, which develops due to the deterioration of the repair process of the immune system due to the suppression of the bone marrow by chemotherapeutic drugs (Cheng et al., 2008; Javed et al., 2012). Mucositis generally occurs 5-7 days after the begining of chemotherapy (Javed et al., 2012). It peaks between 7-14 days and starts to heal after 14 days if an infection does not occur. If infection occurs, first of all, redness, edema, and lesions are can be seen on the oral mucosa. These, then result in ulceration inside the mouth (Kobya Bulut & Tüfekçi, 2016; Raber-Durlacher et al., 2010). OMs limit oral nutrition with the effect of mucosal tissue deterioration, ulceration, decreased saliva production, bleeding, pain, and infections (bacterial, viral, and fungal) (Raber-Durlacher et al., 2010). When mu-

cositis occurs, the child cannot tolerate any kind of liquids. Talking, eating, and swallowing become progressively more difficult. It may be necessary to switch to total parenteral nutrition because oral nutrition cannot continue (Kobya Bulut & Tüfekçi, 2016).

Nurses have important responsibilities in reducing the development of OM, taking the necessary precautions to intervene in the problem, and providing effective care (Ardahan Sevgili& Şenol, 2019; Kobya Bulut &Tüfekçi, 2016). The nurse should provide care in line with the recommendations of The Multinational Association of Supportive Care in Cancer/ International Society for Oral Oncology (MASCC/ISOO) and aim to reduce secondary factors. The MASCC/ISOO oral care protocol recommends the use of soft toothbrushes, the use of valid tools to assess pain and oral health, patient and caregiver education, and dentist involvement in care (Lalla ve ark., 2014). Current studies emphasize the use of sodium bicarbonate, saline solution, povidone-iodine, benzydamine hydrochloride, glutamine, zinc, human growth hormone, palifermin, low-dose laser therapy, cryotherapy, and honey. However, a standard practice has not been established since there is no consensus on which of these practices is more effective (Kobya Bulut & Tüfekçi., 2016; Peterson et al., 2015). Nurses should aim to reduce secondary factors that may cause mucositis in the management of oral complications associated with chemotherapy. Regular oral examination should be performed, the presence of mucositis should be diagnosed promptly, and fungal/bacterial infections should be detected and prevented at an early stage (Ardahan Sevgili& Şenol, 2019; Javed et al., 2012).

Neutropenia and Infections: Neutropenia, a common side effect of chemotherapy, is an abnormally low neutrophil count. It is defined by calculating the absolute neutrophil count, and a neutrophil count below 500 is a risky situation (Williams et al., 2012). Generally, it is stated that neutropenia can last 7-10 days, but it differs according to the age of the patients, the chemotherapy agents they receive, their concomitant diseases, and their bone marrow stores (Caggiano et al., 2005). Neutropenic precautions (aprons, masks, and gloves) are taken to prevent infection transmission to patients (Williams et al., 2012). Routine care requires washing hands and using aseptic techniques (Wheeler et al., 2011). In addition, it is necessary to provide food with a low risk of bacterial contamination, to prepare food in suitable conditions, to choose appropriate food, and to clean the ventilation system frequently (Schlesinger et al., 2009).

Nurses should perform a complete oral mucous membrane assessment at least twice a day. General neutropenia assessment includes evaluation of areas where

tissue integrity is impaired (catheter entry sites, OM, etc.), breathing sounds, abdomen (bowel sounds, abdominal tenderness, etc.), and perineal area (Kaplow& Spinks, 2015). Nurses should inform the child and parent about taking the necessary precautions for the low absolute neutrophil count, the results, the precautions to be taken during the hospital treatment and at home in case of discharge (Bradford, 2017; Kaplow& Spinks, 2015).

Nausea/vomiting: Nausea and vomiting are the most serious symptoms seen in cancer patients as a result of chemotherapy (Montazeri et al., 2013). American National Cancer Institute defines nausea as an unpleasant feeling that causes the urge to vomit and vomiting as the removal of stomach contents from the mouth with a reflexive movement (United States Department of Health& Human Services, 2009).

Nausea and vomiting remain a problem despite advances in treatment protocols (Kottschade et al., 2016). Many individuals experience unpleasant experiences in this process (Montazeri et al., 2013). If nausea and vomiting are not properly controlled during treatment, nutritional deficiencies, anorexia, weight loss, dehydration, electrolyte imbalance, deterioration in social interactions, difficulty in sleeping, and anxiety may occur (Montazeri et al., 2013; Taspinar& Şirin, 2010). Studies show that non-pharmacological practices such as acupressure, acupuncture, music, visually guided imagination, and progressive muscle relaxation reduce chemotherapy-induced nausea and vomiting (Dibble et al., 2000; Garcia et al., 2013). However, the use of these methods in children is still controversial (Gordon et al., 2014). Nurses have an important role in preventing, diagnosing, and managing the symptoms of nausea and vomiting. Nurses should determine the knowledge level and needs of children and families, and provide patient education and support accordingly (Ardahan Sevgili& Şenol, 2019; Bergvist& Wengström, 2006; So et al., 2013).

Pain: Pain is a complicated, multidimensional, unpleasant, and subjective experience. It causes a decrease in the quality of life of individuals. It has sensory, cognitive, social, and behavioral factors (da Cunha Batalha& Mota, 2013), and may be related to disease or invasive procedures (lumbar puncture, venous access, intramuscular injection, port opening, finger piercing, bone marrow aspiration, etc.) (Griffiths et al., 2003). Studies show that persistent and unrelieved pain in children has detrimental effects on physical, psychological and social well-being of the children (Koller& Goldman, 2012). Pain diagnosis and management are very important in increasing the functionality of patients and maintaining their quality of life (Wool& Mor, 2005). In the diagnosis of pain, the child's age, cog-

nitive-developmental level, communication skills, previous pain experience, and associated beliefs should be considered (Ismail, 2016).

Pain can be managed with pharmacological or non-pharmacological applications (Taddio et al., 2010). Pharmacological applications include the use of opioids, non-steroidal anti-inflammatory drugs, sedatives, and local or general anesthesia (Koller et al., 2012). It is stated that non-pharmacological methods such as patient education, supportive psychotherapy, and cognitive behavioral applications (massage, listening to music, distraction, visually guided daydreaming) are effective, but the results are not consistent and their clinical significance is insufficient (Koller et al., 2012). The multidisciplinary team (doctor, nurse, patient, family, etc.) should come together and cooperate in the management of pain. (Hochstenbach et al., 2016). Nurses can provide pain management at an ideal standard by using appropriate parent-child communication techniques, regularly assessing pain, and using appropriate pain diagnosis forms (Ardahan Sevgili& Şenol, 2019; Simons, 2015).

Diarrhea/ Constipation: Diarrhea and constipation are common as a result of the chemotherapeutic agent targeting rapidly proliferating cells (Andreyev et al., 2014). Diarrhea usually occurs within 24-96 hours after a chemotherapy infusion (Gibson& Stringer, 2009). Therefore, diarrhea and constipation should be evaluated with the onset of chemotherapy. Health professionals should evaluate the normal bowel functions of patients before starting chemotherapy, and decide how to continue the treatment by monitoring the change processes after the diagnosis of cancer and the start of chemotherapy (Andreyev et al., 2014). The clinical outcome of the effects of chemotherapy on the gastrointestinal tract affects the patient's quality of life and creates psychological symptoms such as anxiety and stress, which may ultimately lead to delay in the treatment of patients, dose reduction, and treatment pause (Andreyev et al., 2014; Escalante et al., 2017).

Pharmacological and non-pharmacological methods can be used in the management of diarrhea and constipation (Escalante et al., 2017). Antibiotics may be given if the cause of diarrhea is bacteria (Stern& Ippoliti, 2003). Nutritional management is crucial for diarrhea. It is necessary to store foods well, wash hands, avoid raw meat, cook foods at appropriate temperatures, store foods below 4^0C, and follow the expiry date of foods (Stern& Ippoliti, 2003). Pharmacological types of laxatives are given for constipation (Twycross et al., 2012). Non-pharmacological methods include physical exercise, fibrous food intake, and increased fluid intake, often requiring lifestyle changes for constipation (Escalante et al., 2017). Abdominal massage reduces the severity of gastrointestinal symptoms (consti-

pation, etc.). However, massage does not reduce the need for laxatives (Lämas et al., 2009). Nutrition should include frequent and high-protein meals in small portions, and daily fluid intake should be met (Spapen et al., 2001). Individuals should avoid spicy foods and drinks (Stern& Ippoliti, 2003). Nurses have an important position in evaluating children's bowel excretion problems. Stool frequency and amount are constantly monitored. The abdomen sholud be evaluated for bowel sounds and it should be noted if there are abdominal tenderness or stiffness. The perianal area should be examined for tissue integrity. Hydration status, skin turgor, and mucous membranes are frequently evaluated (Viele, 2003).

Alopecia: It occurs as a result of the exposure of rapidly proliferating keratinocytes in hair follicles to cytotoxic drugs. Although temporary, it is a common side effect of systemic chemotherapy treatment in children. It usually occurs within 3 weeks of the first course of chemotherapy (Van den Hurk et al., 2013). Alopecia constantly reminds patients and their relatives of cancer and its treatment. While young children accept alopecia more easily and do not need hair replacement, adolescents may have serious difficulties adapting to alopecia. Alopecia negatively affects body image and self-esteem, and children may experience feelings of depression, and loss of self-confidence (Choi et al., 2014). Since children are also sensitive to the perceptions of others, they may be affected from their social relations and their social interactions may decrease (Harrison& Sinclair, 2003).

In the management of alopecia, nurses cooperate with children and their parents, informing them that they may experience alopecia in the future. By talking about hair loss expectations, their reactions to their positive or negative perceptions are evaluated. Wigs, scarves, hats, etc., options may be offered. Children can be directed to age groups with similar experiences. During and after chemotherapy, coping strategies of the children about hair loss are evaluated. The nurse can inform the children that their hair will grow back after the treatment is over, but that its density, color, and structure may be different (Choi et al., 2014).

Nutritional problems: Cachexia due to malnutrition or cancer is one of the common consequences of pediatric cancers and their treatment (Selwood et al., 2010). Drugs which is taken with chemotherapy damage the gastrointestinal mucosa and cause abdominal pain, reduced absorption of nutrients, and often severe enterocolitis (Klanjsek& Pajnkihar, 2016). Malnutrition reduces tolerance to chemotherapy and resistance to infections, alters drug metabolism, prolongs treatment, and increases mortality (Totadri et al., 2017). In studies, it is stated that nutritional problems in children with cancer are caused by psychological problems such as refusal of children to eat hospital meals, protesting the situation,

physical problems such as cancer and chemotherapy treatment changing the perception of taste and smell, pain due to mucositis, nausea and vomiting (Klanjsek& Pajnkihar, 2016; Robinson et al., 2012).

Nutrition forms the basis of supportive care in children with cancer (Selwood et al., 2010; Totadri et al., 2017). Nurses should closely monitor the metabolic changes in children throughout the treatment, determine the presence of conditions that may cause cachexia, and provide adequate and balanced nutrition for the child (Ardahan Sevgili& Şenol, 2019; Murphy et al., 2016; Klanjsek& Pajnkihar, 2016; Selwood et al., 2010).

QUALITY OF LIFE IN CHILDREN RECEIVING CHEMOTHERAPY

Quality of life (QoL) is a concept developed to express the well-being, happiness, and satisfaction with life of the individuals following the definition of health made by WHO in 1948 (Eilertsen et al., 2012). In children, this concept has been used for a very short time (Klassen et al., 2017). Definitions of QoL in pediatric oncology fields are shaped according to adult oncology studies following WHO guidelines. Accordingly, the QoL in children with cancer is multidimensional and includes the social, physical, and emotional functionality of the child/adolescent and family (Yeh et al., 2004). In addition, individual experiences, beliefs, expectations, and perceptions are important factors (Dzolganovski, 2009).

In studies on the QoL of children with cancer and their families; it has been determined that treatment protocols, loss of control, hospital environment, and fear of relapse and death are the main stressors for children and their families. When these children were compared with their healthy peers, it was stated that their social and emotional health status was significantly weaker and all signs of posttraumatic stress disorder were observed in individuals who survived after treatment (Dzolganovski, 2009; McCaffrey, 2006). Until a short time, the measurement of QoL in children was made according to parental notification, but today scales that can be filled by both children and parents have been developed (Klassen et al., 2011; Vogels et al., 1998; Varni et al., 1998). Since the QoL is a subjective situation, it is accepted that the patient is the person who will give the best information in reporting his/her own QoL. (Varni et al., 1999). However, parents of very young children or children with insufficient cognitive capacity can take their place (Russell et al., 2006). Some examples of QoL scales used in children with cancer are given in Table 1.

Table 1: Examples of Pediatric QoL Scales		
Scale	**Developer (Year)**	**Target group**
Adolescent QoL Instrument-AQoL	Ward-Smith et al., (2007)	Adolescents
QoL for Children with Cancer Scale-QOLCC	Yeh et al., (2004)	13-18 years
Pediatric QoL Cancer Module–PedsQL 3.0-Cancer Module	Varni et al., (2002)	2-7, 8-12, 13-18 years
KINDL Oncology Module	Ravens-Sieberer& Bullinger (2000)	7-17 years
The Pediatric Cancer QoL Inventory-PCQOL	Varni et al., (1998)	8-12 years 13-18 years

COMPUTER-DESIGNED GAMES/APPLICATIONS FOR CHILDREN RECEIVING CHEMOTHERAPY

Hospitalization and chronic diseases can often cause anxiety and stress in children and their families (Koukourikos et al., 2015; Potasz et al., 2013). Play is a way of communication and self-expression for the child. Healthcare professionals, especially nurses, should not forget that play is an important tool for both the child's needs and coping (Koukourikos et al., 2015). Nurses should apply therapeutic play techniques that they can use in appropriate situations. Therapeutic play is practiced for the psychological well-being of the child in the hospital setting. It is planned regarding the age, cognitive development, and health status of the children. It reduces the trauma of illness and hospitalization on the child and allows for evaluation of the child's feelings about the treatment/procedures and the level of knowledge about the disease (Çavuşoğlu, 2013; Li et al., 2013).

There has been an increasing interest in technology not only in daily life but also in health care in recent years (Blumenthal& Glaser, 2007). This interest has led to the creation of a new field called "mobile health (m-Health)". This field is expressed as "the use of mobile computers, medical sensors, and communication technologies in health care" (Istepanian, 2014). With the addition of machine learning and artificial intelligence applications to these technologies, there have been significant developments in the field of health. Disease processes, influencing factors, and, for example, treatment complications and survival rates in oncology patients became more predictable and controllable. (Ardahan Sevgili& Şenol, 2022).

With the increase in the accessibility of technological tools, the use of mobile technologies by children, adolescents, and health professionals is increasing day by day (Franklin et al., 2008). New mobile devices have begun to change the way healthcare professionals deliver healthcare, contributing to changing communication patterns between children and healthcare professionals, and enabling children to increase their involvement in their care (McNaughton& Light, 2013). It is emphasized that the use of these technologies in health services is more acceptable, especially by children and young people, and that these technologies are important new channels in providing health-related behavior change in children (Franklin et al., 2008). Studies on applications based on computer and mobile devices in patient education have started and it has been seen that patient-centered interactive approaches are preferred more by children and young people (Dragone et al., 2002; Jones et al., 2010). It is stated that video games are an advantageous tool because of their high accessibility, easy updating of content, being interactive, and interesting graphics such as animation-virtual reality (Beale et al., 2003). It is aimed to increase the development, education, and healthy living behaviors of children with video games and mobile applications specially designed to provide therapeutic benefits (Govender et al., 2015). It has been suggested that video game formats can be an effective health education tool for children and young adults with chronic diseases, and psychoeducation practices can be more effective by using this method (Beale et al., 2003). It has been stated that patient education games can enable patients to follow the interventions for their treatment, continue their treatment processes consciously, and learn new skills to support their health status in the long term (Handel, 2011). Some examples of these applications are given in Table 2.

Table 2: Examples of Applications Developed for Children Receiving Chemotherapy

Applications- Developer	Language	Purpose
KeTO-Kerimoğlu Yıldız et al., (2018)	Turkish	Informs children about chemotherapy-related symptoms in children with cancer and shows how these symptoms can be managed entertainingly and interactively.
Sisom-Ruland et al. (2008)	Norwegian English, French, Greek	A computer-based interactive communication tool was developed to identify cancer-related symptoms and problems in children.

Table 2: *continues*		
Applications- Developer	**Language**	**Purpose**
Re-Mission-HopeLab (2006)	English	Provides cancer information and reflects the changes in the body, what needs to be done to reduce the effects of treatment, decisions about the disease, and results in the virtual environment.
Kidz with Leukemia-A space adventure-Dragone et al. (2002)	English	Developed to help children better understand leukemia.

Studies have shown that interactive educational programs such as CDs, and video/computer games used in children with cancer provide more control over children's diseases, increase their level of knowledge about their diseases, and facilitate their participation in self-care activities. In addition, it is stated that children are more adaptable to taking prescribed drugs and show fewer depressive symptoms (Dragone et al., 2002; Jones et al., 2010; Li et al., 2011). Children and parents also stated that these applications are more satisfactory and acceptable, and they use these applications more frequently and for a long time (Dragone et al., 2002; Jones et al., 2010). It is stated that games are effective not only on behavioral and psychological symptoms but also on physical symptoms (Griffiths, 2003). It is stated that these applications are distracting in pain for cancer treatment and thus reduce the need for painkillers, while distracted children experience less nausea due to chemotherapy and lower blood pressure levels after treatment (Gershon et al., 2003; Schneider& Workman, 2000).

CONCLUSION

As a result, it is seen that the role of the nurse in the care of the child receiving chemotherapy is multifaceted. The nurse should take an active part in every stage of care, as well as in the identification and control of symptoms, assessment of possible risks and therefore improving the QoL. A high-quality trust relationship with the child facilitates the child's adaptation to chemotherapy and the management of chemotherapy-related symptoms, thus facilitating symptom management. The quality of life of the child who manages the symptoms effectively will also increase. Therefore, the treatment process and nursing care should be arranged accordingly. Established effective and quality communication is important in terms of ensuring that children know their diagnosis and treatment as much as necessary

and that they see themselves as a part of care activities. With digital information providers (interactive-educational) or therapeutic games, children's information needs should be constantly met and their coping skills should be improved.

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