

Original Article

Nursing Care of a Child Patient with Congenital Laryngomalacia Diagnosed with Cerebral Palsy and Acute Lymphocytic Leukemia According to "Orem's Self-Care Insufficiency Theory": A Case Report

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Abstract

Introduction and Aim: Orem's Self-Care Deficit Nursing Theory is one of the most frequently used theories in nursing practice. According to Orem, nurses should reduce the individual's needs to a level that they can meet in case of lack of self-care, increase the individual's self-care abilities, or undertake the care needs themselves in cases where self-care inadequacy cannot be eliminated. Patients diagnosed with cerebral palsy and acute lymphatic leukemia and their relatives need supportive and educational nursing approaches and guidance according to Orem's Self-Care Deficit Nursing Theory.

Methodology: The eleven-year-old male patient was admitted to the hospital with the complaint of high fever. Patient diagnosed with congenital laryngomalacia and cerebral palsy. The patient was diagnosed with Acute Lymphocytic Leukemia 5 years ago as a result of further investigations (bone marrow, biopsy, peripheral smear) with high fever and skin rashes. In this case report, the nursing care of the child patient was examined according to the "Self-Care Deficit Nursing Theory". Therapeutic self-care needs were determined by evaluating the patient's self-care agent and self-care power.

Results: Since the self-care needs of the patient with insufficient self-care power will be met by the nurse and the mother, the 'Completely Deficit Nursing System' and the 'Supportive and Educational Nursing System' were applied to support the mother and other family members who provide self-care. Nursing diagnoses for the patient were impaired in the oral mucous membrane, activity intolerance, disruption in sleep patterns, self-care deficiency syndrome, disruption in the continuity of family processes, and parental role conflict.

Conclusions: It was concluded that Orem's Self-Care Theory can be a useful and effective model in providing professional care, providing a comprehensive holistic assessment of the child and his family during the care of patients with cerebral palsy and acute lymphocytic leukemia.

Keywords: Acute Lymphocytic Leukemia, Cerebral Palsy, Pediatrics, Self-Care, Model

Introduction

Acute Lymphocytic Leukemia (ALL) is characterized by the uncontrolled proliferation of bone marrow blast cells, and it is a disease with a malignant course. Immature cells cause bone marrow deficiency by infiltrating the bone marrow, and this is seen in the blood in the form of anemia, thrombocytopenia, leukopenia, or leukocytosis. These changes are accompanied by clinical symptoms in the patient such as paleness,

fatigue, hemorrhage, fever, and severe infection (Kato and Manabe, 2018; Malard and Mohty, 2020). In the profession of nursing, using theories and models in the fields of education, management, practice, and research is important for the formation of a conceptual framework and provision of guidance for these fields (Şengün Inan et al., 2013). Theories make sense of scientific results, allow the systematization of information, and create benefits in the

professionalization of nursing. Therefore, it is important to use theories and models in the profession of nursing (Afrasiabifar et al., 2020; Yuk Chiu Yip, 2021). Making use of models and theories while providing care for children with diseases that have a difficult and complex care and treatment process such as ALL will increase the quality of the care given to these patients (Sevgili et al., 2019).

In the case reported in this study, congenital laryngomalacia was present in addition to ALL. Laryngomalacia is the most frequently encountered cause of neonatal stridor, and it constitutes 45-75% of congenital laryngeal diseases. This stridor exacerbates especially with feeding, crying, lying in the supine position, and agitation. Symptoms emerge right after birth or within the first weeks. Mild and moderate cases recover within 12-24 months. However, severe laryngomalacia patients may not recover spontaneously, and they may require surgical intervention. The presence of comorbid neurological diseases increases the severity and duration of the disease (Gergin, 2019).

Self-Care Deficit Theory in Nursing

“Self-care deficit theory” started to be developed by Dorothea Elizabeth Orem in 1956 as the first theory of self-care and was shaped between 1971 and 2001 (Orem, 2001). It consists of three main components: a wholly compensatory system, a partly compensatory system, and a supportive-educative system. The main concepts in the theory are humans, health, nursing, and environment. Other concepts are self-care, therapeutic self-care, self-care agency, self-care deficit, self-care demand, nursing agency, and nursing system. Self-care involves continuous physical, cognitive, emotional, interpersonal, and social developments and functions that need to be performed by individuals against situations they encounter in their normal life. Orem’s Self-Care Deficit Theory is one of the most frequently used theories in nursing practice. Researchers in the field of nursing have conducted experimental studies and case analyses using this theory (Yildirim Keskin and Cevik, 2016; Khademian et al., 2020; Tok Yildiz and Kasikci, 2020; Afrasiabifar et al., 2020; Zhang and Pan, 2021).

The purpose of this case report is to examine a pediatric patient with congenital laryngomalacia and cerebral palsy diagnosed with acute lymphocytic leukemia based on “Orem’s Self-Care Deficit Theory”. The patient was selected

randomly from among ALL patients who were staying at the pediatric oncology inpatient clinic. Written consent was obtained from the patient’s family, and the family was ensured that identifying information would be kept confidential. The child and his family were also informed that participation in this study was voluntary, **and** it would not affect his treatment at the clinic.

Case Report

Patient Information: Name: I.B.E. Age: 11 years Sex: Male Complaint: High fever. Medical history: The patient, who had congenital laryngomalacia, also had cerebral palsy related to it. Five years before, the patient had been diagnosed with Acute Lymphocytic Leukemia as a result of further examinations (bone marrow biopsy, peripheral smear) due to high fever and skin rashes. The patient presented to the hospital with the complaint of high fever, and the routine peripheral smear test of the patient who had been in remission for the last 5 years showed blasts, and further examinations led to the diagnosis of relapsed ALL. A femoral vein catheter was fitted to the patient.

Basic Conditioning Factors

Age: 11 years, 2 months, 1-day Sex: Male. Health status: Acute lymphocytic leukemia, cerebral palsy, and congenital laryngomalacia present. Developmental status: Height: 150 cm (75th-90th percentile), Weight: 26 kg (3rd-10th percentile) Head circumference: 43.5 cm (< 3rd percentile)

Socio-cultural characteristics: The patient lives in an apartment with his family. He attends a special education center five days a week. He participates in physiotherapy and rehabilitation two days a week. He has 1 sister who is the second child of the family. He does not like noise and warm environments at all. He prefers his mother cuddling, hugging, and talking to him, and these make it easier for him to fall asleep.

Healthcare system: The Social Security Institution (SGK).

Family type: Extended family (living with paternal grandparents, sister, mother, and father).

Living situation: The patient’s basic needs are met by his mother and his grandmother. The social lives of the family and child are limited. He constantly watches videos on the phone when he is not in special education or physiotherapy.

Environmental settings: They are constantly in communication with their relatives.

Resource presence-sufficiency: Low economic status (income lower than expenses). The patient receives financial and psychological family support.

Diagnosis and Analysis of the Case According to Orem's Self-Care Deficit Theory:

Self-Care: Self-care involves behaviors learned through curiosity, education, and experiences that are started and maintained by individuals themselves to preserve life, health, and comfort (Karadag et al., 2017; Pektekin, 2013). According to Orem, a person who is able to manage their self-care has self-care agency. The term agency refers to the capacity of *the person who performs the act*. A person who meets the care needs of individuals who do not have self-care agency is called a dependent care agent (Yuk Chiu Yip, 2021). Agent of care: As the child whose case is presented in this report was not able to perform his self-care activities independently or sustain his life healthily, his agent of care was his mother. Dependent care agent: Mostly the mother, sometimes the grandmother.

Self-Care Agency: It is the status of initiating or implementing health behaviors to maintain life, health, and well-being (Orem, 2001). According to Orem, self-care agency is acquired from the person's environment, and the person's environment affects their self-care (Kumar, 2007). Because the self-care agency and perceptual, cognitive, and sensory capacity of the patient who had cerebral palsy were very weak, he could not be assessed using the "Self-Care Agency Scale". For the same reasons, the following parameters that could reveal his self-care agency could not be objectively assessed, and the assessment was made solely based on the observations made of the patient.

Self-confidence and self-respect: Inadequate, does not make eye contact while speaking, verbal communication not possible.

Energy control and initiation skills: Unwilling.

Intellectual capacity: Does not make eye contact while speaking, verbal communication not possible, indifferent to his environment (low).

Motivation: Only the mother motivates him.

Self-care decision-making: The mother makes all decisions.

Technical information access and implementation skills: Cannot play computer games or write, can only look at videos on the screen, and sometimes give loud reactions (low).

Perceptual and cognitive status and communication skills: Does not make eye contact while speaking, verbal communication not possible, indifferent to his environment (low).

Skills of managing self-care behaviors to reach goals and integrating self-care behaviors into individual and social life: The mother performs most behaviors (dressing, toileting, feeding) in his place (low).

Therapeutic Self-Care Requisites

I-Universal self-care requisites:

Eating: Has a neutropenic diet during his hospital stay.

Oral health: Deformation in the teeth. His oral care is provided with soft oral care swabs due to his thrombocytopenia.

Activity: He is moved in the room in a wheelchair with the help of his mother due to his neutropenia and fall risk.

Sleeping: Sleeps 5 hours at night in total. Constantly wakes up crying.

Cognitive perception: His cognitive perception is weak. Does not verbally respond to questions. Receives special education.

II-Developmental self-care requisites: The eleven-year-old pediatric patient is in early adolescence. This is a period where the person is sensitive to physical changes and has a higher desire for independence. He has been hospitalized in the neonatal intensive care unit for a long duration due to congenital laryngomalacia, and due to the cerebral palsy developing in relation to this condition, he has muscle weakness and deformities in the hands and feet. He has no communication with peers.

III-Self-care requisites regarding deviation from health: Orem defined health deviation self-care as a "requirement in conditions of illness, injury, or disease" (Karadağ, 2017). The patient, who has congenital laryngomalacia, also has cerebral palsy related to it. Five years before, the patient had been diagnosed with Acute Lymphocytic Leukemia as a result of further examinations (bone marrow biopsy, peripheral smear) due to high fever and skin rashes. The peripheral smear test of the patient who had been

in remission for the last 5 years showed blasts, and further examinations led to the diagnosis of relapsed ALL. The patient has a femoral vein catheter.

Cerebral palsy (does not attend physiotherapy during his hospital stay).

Malnutrition (mucositis present).

Dental problems (cavities and fractures present).

Mental retardation (has a history of congenital laryngomalacia).

Sleep disorder (developing secondary to his disease).

Social isolation (no peer communication due to lack of appropriate communication capacity).

Self-Care Deficit: Self-care deficit in the self-care agent: The patient with cerebral palsy cannot meet his self-care needs due to problems secondary to his disease. His agent of care is his mother. Dependent care agency: The communication between the mother, who is both the self-care agent and dependent care agent, and the child is much better than that between the child and other family members. The mother notices the child's needs and problems and implements approaches accordingly. Self-care deficit in the dependent care agent: Although the mother notices the needs and problems of her child and has better communication with him than other family members do, as she also has to take care of her other child, she cannot allocate enough time for the patient. In this case, it was seen that the pediatric patient with congenital laryngomalacia and cerebral palsy who was diagnosed with acute lymphocytic leukemia was highly insufficient to meet his self-care needs according to Orem's Self-Care Deficit Theory. For this reason, nursing interventions to achieve the patient's self-care in the scope of the "**Wholly Compensatory**" role of the nurse were planned. Additionally, the mother of the patient, who was meeting the self-care needs of the patient, was assessed in the scope of the "**Supportive-Educative**" role of the nurse, and counseling was planned.

Nursing System

Problems Identified by the Nurse:

- Eating disorder
- Oral motor problems
- Dental problems (cavities, fractures)
- Drooling problem

- Urinary problems
- Sleep disorder
- Social isolation
- Risk of tissue integrity

The nursing diagnoses of the case based on his needs according to Orem's Self-Care Deficit Theory are presented in Figure 1.

Nursing Agency: According to the Nanda Nursing Diagnosis Guide, present and potential nursing diagnoses for the case and his mother were determined.

- Deterioration of the oral mucosa due to inadequate oral nutrition and oral hygiene
- Activity intolerance caused by physical movement and posture disorders originating from neuromuscular influence as a result of brain damage
- Changes in family dynamics related to having a child with a chronic disease
- Sleep pattern disorder caused by problems secondary to the disease
- Inadequacy in the performance of basic self-care skills caused by neuromuscular disorder
- Bleeding risk related to thrombocytopenia
- Risk of injury due to spasticity and uncontrollable muscle movements
- Inefficacy of parental role performance due to changes in the daily routine of the mother.

Nursing Diagnosis 1: Deterioration of the oral mucosa due to inadequate oral nutrition and oral hygiene

- **Expected Outcomes:** The wounds in the mouth of the patient will heal.
- **Recommended NIC Interventions:** Improvement of oral health, education.
- **Nursing Interventions:** Oral mucosa was assessed based on the mucositis classification of WHO every shift change. Oral care was provided 3 times a day with sodium bicarbonate, Tanflex mouthwash, and Mikostatin. The mother was explained that his neutropenia could increase his susceptibility to infections and that oral care

is important, and she was given applied education on oral care.

• **Evaluation regarding Expected Outcomes:** Lesions in the mouth showed recovery, but oral mucositis continued.

Nursing Diagnosis 2: Activity intolerance caused by physical movement and posture disorders originating from neuromuscular influence as a result of brain damage

• **Expected Outcomes:** The child’s movement will be facilitated to an extent that he can tolerate.

• **Recommended NIC Interventions:**

• **Nursing Interventions:** In-bed exercises were applied with an expert physiotherapist. Daily self-care needs including eating, oral care, body hygiene, dressing, and undressing were met with the support of the mother.

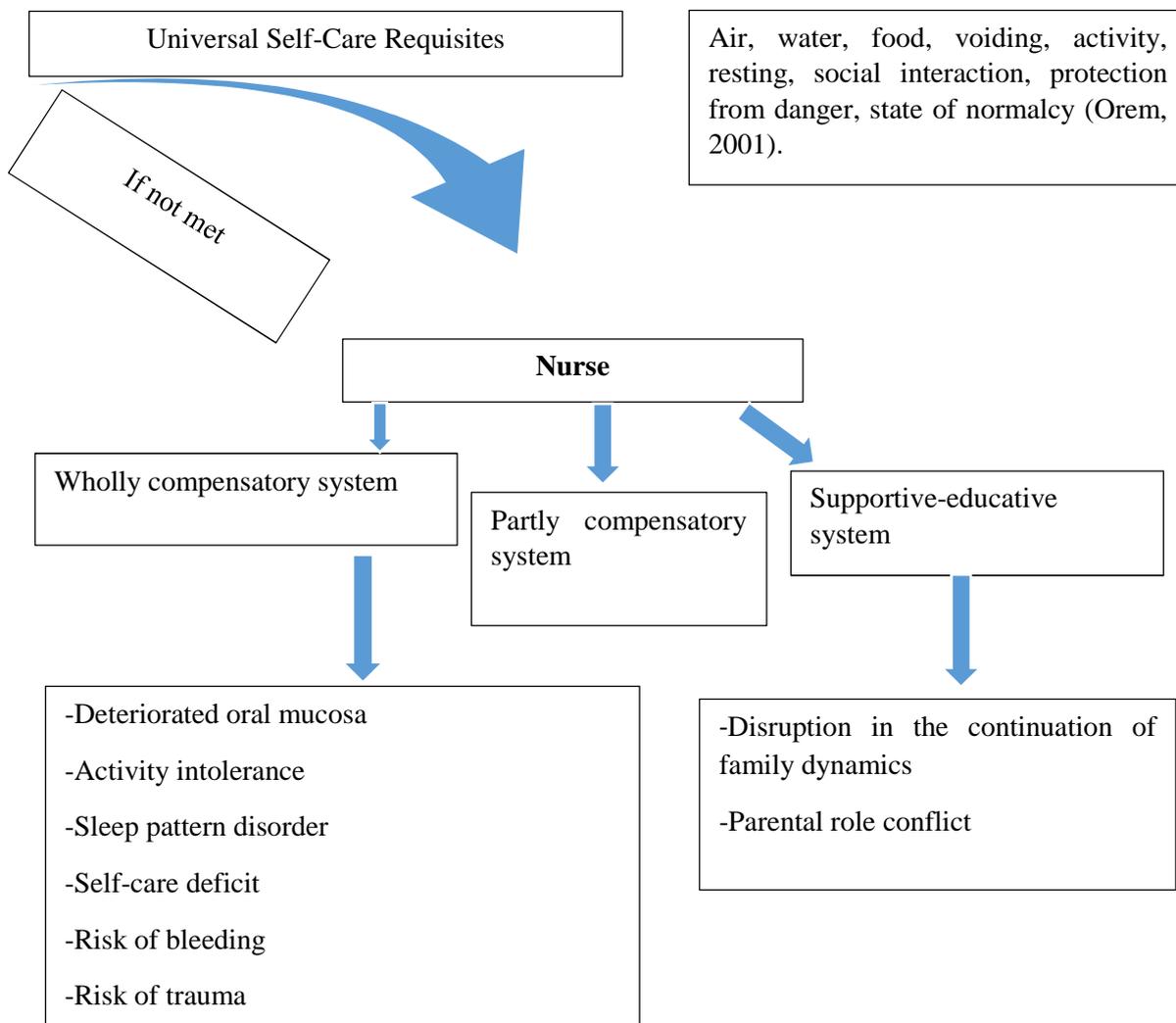


Figure 1. Concept Map According to Orem’s Self-Care Deficit Theory

- **Evaluation regarding Expected Outcomes:** The child's performance of in-bed exercises was facilitated.

- **Recorded:** Education, exercise.

Nursing Diagnosis 3: Changes in family dynamics related to having a child with a chronic disease

- **Expected Outcomes:** Task sharing in the family will be facilitated, support systems will be determined, the family members will be ensured to share opinions and make mutual decisions, they will be encouraged to express their feelings about the current situation, and they will become able to cope with the child's disease effectively.

- **Recommended NIC Interventions:** Improvement of the coping mechanism.

- **Nursing Interventions:** The family was guided towards support groups. They expressed their feelings about the disease.

- **Evaluation regarding Expected Outcomes:** It was ensured that the mother joined support groups. The duties and responsibilities of the family were determined.

- **Recorded:** Observations, interventions.

Nursing Diagnosis 4: Sleep pattern disorder caused by problems secondary to the disease

- **Expected Outcomes:** Sleep quality and duration will be increased.

- **Recommended NIC Interventions:** Increased sleep quality and duration.

- **Nursing Interventions:** Factors reducing the sleep quality of the patient (hourly medication at night, treatment interventions, frequent aspiration procedures due to intensive secretion, blood drawing) were identified.

- **Evaluation of Expected Outcomes:** Factors reducing the sleep quality of the patient were identified. Practices to facilitate his sleep (calming music, ensuring the darkness of the setting, and minimum noise) were applied.

- **Recorded:** Observations, interventions.

Nursing Diagnosis 5: Inadequacy in the performance of basic self-care skills caused by neuromuscular disorder

- **Expected Outcomes:** The child will cooperate with the care process and display calm behaviors.

- **Recommended NIC Interventions:** Intervention to increase self-care.

- **Nursing Interventions:** Activities of daily living (eating, body hygiene, bedsheet change) were held with the mother. The patient's privacy was ensured.

- **Evaluation regarding Expected Outcomes:** The child displayed calmer behaviors in the care process.

- **Recorded:** Interventions.

Nursing Diagnosis 6: Bleeding risk related to thrombocytopenia

- **Expected Outcomes:** Precautions will be taken against the potential of bleeding.

- **Recommended NIC Interventions:** Prevention of bleeding.

- **Nursing Interventions:** The vital signs of the patient (body temperature, heart rate, respiratory rate, blood pressure) were monitored. Laboratory findings indicative of bleeding risk (hemoglobin, platelets, prothrombin time, INR, aPTT values) were followed. Safety precautions were taken to avoid trauma that could lead to injury (removal of bed rails, sharp, penetrating objects that could induce trauma). Oral care was provided with soft oral care swabs instead of a toothbrush.

- **Evaluation regarding Expected Outcomes:** The patient did not have vomiting or active bleeding in his urine, stool, phlegm, gums, or femoral vein catheter. Vital signs, Blood pressure: 100/65 mm Hg, respiratory rate: 28/min, Heart rate: 108/min, Temperature: 36.8 °C. Laboratory findings, aPTT: 31.4 sec, INR: 1.1. PT: 13.4 sec, Hb: 10.2 g/dl, PLT: 10,000/mm³.

- **Recorded:** Interventions.

Nursing Diagnosis 7: Risk of injury due to spasticity and uncontrollable muscle movements

- **Expected Outcomes:** Risk factors of trauma will be determined, and precautions to mitigate the risks will be taken.
- **Recommended NIC Interventions:** Education, risk identification.
- **Nursing Interventions:** Soft toys that would not harm the child were preferred. Bed rails were removed to prevent falling. The bed was lowered to make it easier for getting in and off the bed. The family was informed that they should alert the nurse in the case of their child having a seizure and not leave the child unattended.
- **Evaluation regarding Expected Outcomes:** Bed rails were removed.
- **Recorded:** Interventions.

Nursing Diagnosis 8: Inefficacy of parental role performance due to changes in the daily routine of the mother

- **Expected Outcomes:** Support will be provided for the mother's adjustment, and support groups will be determined.
- **Recommended NIC Interventions:** Supporting role and performance, developing a support system.
- **Nursing Interventions:** The mother was encouraged to express her feelings about the child's condition. She was guided towards talking to other mothers at the clinic who were experiencing the same problems.
- **Evaluation regarding Expected Outcomes:** The mother stated that she experienced stress regarding tools and treatment with which she was not familiar (infusion machine, drugs, emergency equipment) and was afraid of harming her child. Care routines were determined to ensure the ability of the mother to provide care within the hospital's arrangements.
- **Recorded:** Interventions.

Discussion

This case report presents a nursing care example involving multiple nursing diagnoses and problem areas that was based on "Orem's Self-Care Deficit Theory" and provided a holistic and systematic approach regarding a pediatric patient with congenital laryngomalacia and cerebral palsy who was diagnosed with acute lymphocytic leukemia. The agent of care for the patient and

the patient's self-care agency were determined, and his therapeutic self-care needs were identified. As the self-care needs of the patient, who had inadequate self-care agency, would be covered entirely by the nurse and the mother, the 'wholly compensatory system' was implemented. Moreover, to support the mother and other family members who were meeting the self-care needs of the patient, the 'supportive-educative system' was implemented. The nursing diagnoses that were examined for the patient included deterioration of the oral mucosa, activity intolerance, sleep pattern disorder, inadequacy in the performance of self-care, changes in family dynamics, and parental role conflicts.

The patient was diagnosed with **deterioration of the oral mucosa** due to inadequate oral nutrition and oral hygiene. Oral mucositis develops frequently in ALL patients due to chemotherapy, inability to have oral nutrition, and inadequate hygiene. Because of oral mucositis, patients have problems in eating, and their immune systems may deteriorate even further. As it can significantly delay the course of chemotherapy and increase the hospital's supportive care costs, oral mucositis should be prevented or appropriately managed (Garrocho-Rangel et al., 2018). In the case in this study, the oral mucosa of the patient was evaluated based on the mucositis classification of WHO. Oral care was provided 3 times a day with sodium bicarbonate, Tanflex mouthwash, and Mikostatin, and the mother was given education about the importance and implementation of oral care. As a result of the nursing interventions, the lesions of the patient showed recovery, but oral mucositis continued.

The patient had **inadequacy in the performance of basic self-care skills** caused by neuromuscular disorder. The self-care skill levels of pediatric ALL and cerebral palsy patients may be low because of inadequate motor functions and harsh treatment conditions. The families of these children may also experience difficulties in meeting the self-care needs of their children while coping with the treatment process. In children in this population, the child and the family should be considered together in the assessment and management of self-care skills and needs (Andrews et al., 2020). In this case, the self-care agency of the patient and his perceptual, cognitive, and sensory capacity were very weak. As the patient was completely unable to perform his self-care behaviors, all his care needs were

being met by nurses and his mother. The activities of the patient requiring self-care such as eating, body hygiene, and bedsheet change were carried out with the mother, and the necessary education was provided.

Another nursing diagnosis in the case in this study was **activity intolerance**. Because leukemic cells infiltrate the bone marrow, and the disease has extramedullary manifestations, activity intolerance is among the most prevalent symptoms in ALL patients. Activity intolerance makes it more difficult for the patient to perform their self-care behaviors (Erbey, Kömür, Bayram, & Tanyeli, 2018; Ghanbari & Pouy, 2018). Due to neuromuscular involvement, the patient in this study had physical movement and posture disorders. For this reason, in-bed exercises were carried out with a physiotherapy expert. It was observed that the patient could tolerate these movements for a longer duration.

In this study, within the scope of the supportive-educative nursing system, the family of the patient was also considered, and the nursing diagnoses of **changes in family dynamics** and **inefficacy of parental role performance** were evaluated. The quality of life of mothers of children with ALL and cerebral palsy is influenced negatively by various factors such as care burden, fatigue, and psychological symptoms. Thus, to improve quality of life in this population, a holistic approach and psychological interventions, including education (transport, positioning, feeding, and managing the self-care of the child), are needed (Andrews et al., 2020; Chen, Huang, Chen, Wang, & Huang, 2020; Farajzadeh, Maroufizadeh, & Amini, 2020). Therefore, in this study, the care routines of the patient were determined to ensure the ability of the mother to provide care within the hospital's arrangements. In this process, it was aimed to strengthen the autonomy of the mother with her involvement in the care of her child. The family was directed to support groups. The family members expressed their feelings about the child's disease.

Conclusion: This case report presents a nursing care example involving multiple nursing diagnoses and problem areas that was based on "Orem's Self-Care Deficit Theory" and provided a holistic and systematic approach regarding a pediatric patient with congenital laryngomalacia and cerebral palsy who was diagnosed with acute lymphocytic leukemia. Accordingly, it was

concluded that Orem's Self-Care Deficit Theory can be beneficial and effective in providing professional healthcare for the child diagnosed with acute lymphocytic leukemia in the patient care process as it allows the evaluation of both the child and the family. The degree of the preparedness of children in this population and their families for meeting self-care needs after discharge from the hospital should be investigated. It is needed to determine the self-care needs and self-care capacities of children diagnosed with cerebral palsy and acute lymphocytic leukemia and support parents regarding the self-care of their child.

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