



## NURSING CARE FOR CHILDREN WITH HYDROCEPHALUS: A LITERATURE REVIEW

## HİDROSEFALİSİ OLAN ÇOCUKLARDA HEMŞİRELİK BAKIMI: BİR LİTERATÜR TARAMASI

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## Abstract

*This study was conducted to review how caregivers of children with hydrocephalus and shunt can care for their children. In the literature, it has been stated that counseling the caregivers of children with hydrocephalus about shunt care will reduce the difficulties experienced in the care and follow-up of the shunt, and that it can prepare the caregivers emotionally while struggling with the difficulties they will encounter. In this review, the problems that may arise in shunt care and the issues to be considered in nursing care were summarized. The problems that arise about the care of the shunt must be determined by the caregivers who take care of the child with hydrocephalus. Nurses have an important role in helping caregivers cope with disease management, supporting them and reducing the negative effects of the caregiver role.*

**Keywords:** Hydrocephalus, nursing, children, shunt.

## Özet

*Bu çalışma hidrosefalisi olan şantı olan çocukların bakım vericilerinin, çocuklarına nasıl bakım verebileceğini gözden geçirmek amacıyla yapılmıştır. Literatürde hidrosefalili çocuklara bakım verenlere şant bakımı konusunda danışmanlık verilmesinin şantın bakım ve takibinde yaşanan güçlükleri azaltacağı ve karşılaşılabilecek zorluklarla mücadele ederken bakım verenleri duygusal olarak hazırlayabileceği belirtilmektedir. Bu derlemede şant bakımında ortaya çıkabilecek sorunlar ve hemşirelik bakımında dikkat edilmesi gereken hususlar özetlenmiştir. Şantın bakımı ile ilgili ortaya çıkan sorunların hidrosefalisi olan çocuğa bakım veren bakıcılar tarafından belirlenmesi önemlidir. Hemşireler, bakım vericilerin hastalık yönetimi ile baş etmelerine yardımcı olma, onları destekleme ve bakım veren rolünün olumsuz etkilerini azaltmada önemli bir role sahiptir.*

**Anahtar Kelimeler:** Hidrosefali, hemşirelik, çocuklar, şant.

## OVERVIEW / GENEL BAKIŞ

Chronic disease is defined as "a condition that deviates from the normal, may cause permanent disability, is formed as a result of irreversible pathological changes, requires special training for the rehabilitation of the patient, and is expected to require care, surveillance, and supervision for a long time". Chronic diseases seen in childhood require the adaptation of family and children to emerging processes and continuity of care. Hydrocephalus, which is one of the chronic diseases, is a condition characterized by enlargement of the ventricular system and increase in intracranial pressure as a result of disruption of the balance between absorption and production of cerebrospinal fluid (CSF) due to congenital or acquired causes. Congenital neurological disorders are often associated with hydrocephalus. There are three reasons for the development of hydrocephalus; excessive production of cerebrospinal fluid in the choroid plexuses, obstruction in the brain ventricles and subarachnoid space where cerebrospinal fluid circulates, infection, trauma, or failure in the absorption of cerebrospinal fluid from the subarachnoid space (1-4). It is stated that hydrocephalus is the most common cause of neurosurgery in children, its incidence varies between 0.4-0.8 per 1000 live births, the shunt is mostly used in its treatment, 10000 pediatric patients are admitted to the hospital with shunt dysfunctions every year, the expenditures for hydrocephalus are over 2 billion dollars every year, and shunt infections are the most important complication of shunts (2,5-9). In addition to shunt infection, there are technical problems such as occlusion of the ventricular or peritoneal end of the shunt, rupture, displacement or excessive drainage of the shunt. In these cases, attention should be paid to postoperative wound care, surgical technique, and the type of shunt used. The general health condition of young children affects the shunt procedure and the survival of the children (3,10,11). In a study, it was determined that families of children with hydrocephalus were afraid to care for their children, had difficulties in the follow-up and care of the shunt, ensuring the movement of the child, providing personal hygiene and care, feeding and excretion, pain control, and the need for special education about school life (12). These complications that may occur after shunt surgery cause a prolonged hospital stay and increase the care burden, which is expressed as the physical, psychological, social and economic burden that parents may experience while providing care (13,14). It is important to develop coping strategies by informing caregivers about the problems they may experience to prevent the emergence of these problems, accelerate patient recovery, and provide cost-effective care (14-22). Shunt infections can be prevented when mothers as caregivers are informed. Therefore, while providing shunt care to children with hydrocephalus, healthcare professionals play an important role in informing caregivers in areas where they may experience problems (23,24).

Parents who have children with shunts should know about of shunt infection, nausea/vomiting, constipation and pain, providing nutrition, seizures control and drug use, care of incision site and skin

and maintaining body temperature, and hygiene of their children (12,24-26). In this review, it was aimed to present nursing care for the problems that caregivers who have a child with hydrocephalus and have a shunt may encounter.

What to do for nursing care of children with hydrocephalus and having shunt?

## 1. Preventing shunt infection

It is stated that hydrocephalus is a life-long and life-threatening health problem and families have many problems during the treatment process (5,6,25-27). It has been reported that shunts are mostly used in the treatment of hydrocephalus, 10,000 pediatric patients are admitted to the hospital with shunt dysfunctions every year, the expenditures for hydrocephalus are over 2 billion dollars each year, and the most important shunt complication is shunt infections (2,5-9) In the literature ventriculoperitoneal (VP) shunt infection rates were reported as 3-20% and most of the infections occur in the first two months and 90% in the first 6 months (28,29,30). It is important to monitor for signs of shunt infection. Half-drowsiness, seizures, restlessness, nausea, vomiting, abdominal pain, fever, loss of appetite, change in consciousness, redness, discharge, swelling, pain, short-term respiratory arrest, neck stiffness, and weakness in the baby may indicate shunt infection. Care should be taken and medical attention should be sought in these cases. It is possible to reduce the infection rate with precautions to be taken in the perioperative period (31,32). One of the factors that cause the emergence of these situations is the increase in intracranial pressure. To prevent increased intracranial pressure;

- Pressure should not be applied to the surgery site.
- The baby should not be placed on the side of the shunt.
- Before the baby cries, his/her needs should be met promptly.
- Medications should be given on time to avoid seizures.
- In VP shunts, it should not be placed face down to prevent pressure on the peritoneum.
- The baby should not be suddenly shaken.
- The baby's head height should not be lowered suddenly.
- Blows to the head should be avoided.
- Constipation should be avoided (31).

## 2. Nutrition

The main purpose of nutrition is to ensure growth and development, to maintain body functions and to renew cells. When optimal nutrition is not provided in sick children, clinical outcomes may be affected, malnutrition may occur, recovery time may be delayed, hospital stays may be prolonged, and the number of hospitalizations may increase (33,34). Decreased cognitive ability chronic constipation, use of antiepileptic drugs, unbalanced nutrition that may occur as a result of oral motor dysfunction which can be seen more in children with neurological diseases than in healthy children. Nutritional imbalances can lead to problems such as growth retardation, malnutrition, delayed wound healing, agitation and decreased peripheral circulation (35-37). Therefore, nutrition has an important place in the care of the baby with a shunt. At the same time, it is important to maintain the nutritional habits of the baby to reduce morbidity and mortality in the postoperative period and to obtain the maximum benefit from the results of the surgical procedure. ERAS (Enhanced Recovery After Surgery) protocols, which are used to improve surgical results and reduce complications, are being developed in patients undergoing pediatric surgery (35,38-44). The World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) recommend exclusive breastfeeding for the first 6 months after birth, switching to complementary foods after the 6th month, and continuing breastfeeding until the age of two. Breast milk contains all the fluids, energy and nutrients necessary for the development and protection of children's health, providing adequate and balanced nutrition, and growth and development (45,46). Besides, breastfeeding at the age of 0-1 years protects the baby against infections and increases the bonding between mother and baby. It also helps the baby to develop a sense of confidence (47). If the child is going to take food other than breast milk, attention should be paid to the temperature of the food and the time it is given to the baby. Rapid administration of nutrients can cause vomiting and diarrhea. While the baby is feeding (with formula or breastfeeding), the baby's head should always be kept slightly elevated for the shunt to work properly. It should be fed little and often to prevent vomiting. After feeding, the baby should be burped by patting the back and laid on its side to the side where there is no shunt. Attention should be paid to the hygiene of the containers in which the baby is fed. Caregivers should pay attention to hygiene. In addition, it is not appropriate to give foods such as cow's milk, tea and herbal teas, honey, broad beans, salt, and sugar to babies in the 0-1 age period since those ones may result in allergic reactions (48,49).

## 3. Nausea and vomiting

Conditions that cause increased intracranial pressure in infants with hydrocephalus may cause nausea and vomiting. In studies conducted with children with shunts, it has been reported that one of the presenting complaints in shunt infections is nausea-vomiting (32,50,51). Situations that can cause nausea-vomiting are as following;

- Presence of pressure on the surgery site

- The development of any infections in the baby
- Laying the baby on the shunted side
- Baby's crying
- Increased fever
- Seizure
- Laying the baby face down
- Sudden shaking of the baby
- Sudden lowering of head height
- Baby hitting his/her head or falling
- Touching the area without the recommendation of a doctor
- Constipation

Any infection development in the baby (3,52,53). Therefore, to prevent nausea and vomiting, it is necessary to strengthen the immune system of the child, not to press on the shunt, not to shake suddenly, to meet the needs of the child promptly, to prevent constipation and to protect the children from traumas (3,54,55).

#### 4. Pain

Pain is a feeling that helps to keep the person away from damaging stimuli and aims to protect the damaged tissue during the healing process. According to the Association for the Study of Pain (IASP) terminology, pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage (56,57). Children experience pain due to invasive procedures and some underlying diseases. Everyone's experience of pain should be respected (58). In general, the pain is at its highest level in the first 2 days after the surgery and decreases up to 7 days (59). Control of pain after surgery provides relief for patient, accelerates early recovery, improves the patient's quality of life, reduces the likelihood of complications and the disease, and shortens the length of stay in the hospital (60-64). One of the five special groups that the American Association of Pain Management Nursing (ASPMN) represents as having difficulties in defining their pain in clinical practice guidelines is newborns, infants, and children. While diagnosing pain in this special group, the causes of pain are investigated, pain behaviors are observed, parents' feedback is received on this issue, and pharmacological and non-pharmacological methods are applied in pain management (65). Pain in children also affects the child, their caregivers, and the healthcare professionals. Informing caregivers

about the control of pain also reduces the anxiety of the family and facilitates treatment adherence (66). If pain control is not achieved, insomnia and physical dysfunction may occur (60,67). In addition, in cases where pain control cannot be achieved, the stress mechanism is activated, wound healing may be delayed and inflammation may result. In the literature, it is stated that pain management is a major problem in the field of pediatrics and it is insufficient to manage pain (60,67,68). In the study of Smeland et al., (69) it was stated that 55% of the nurses have pediatric pain assessment guidelines, 84% use pediatric pain assessment scale guidelines for children and adolescents, and 47% use non-pharmacological methods. Nurses should use age-appropriate pain scales when assessing pain in groups that cannot express themselves, such as children. In addition, nurses should determine the location, severity, depth, duration, aggravating and decreasing factors of pain, question previous pain experiences, measure vital signs in painful situations, and record pain assessment (70,71). The use of non-pharmacological interventions in pain management in children has also been recommended in international guidelines. Mothers should be told that the baby should have a good sleep, breast milk and its scent can calm the baby, massage to the places outside the shunt areas will relax the child, music can relax the baby, and contact with the child can relieve the pain (72,73).

### **5. Seizures and antiepileptic drug use**

Seizures may accompany the diagnosis of hydrocephalus. Seizures may result in increasing of hospitalizations and costs, and as a result, treatment success may decrease (74,75). It is stated that children diagnosed with hydrocephalus frequently have seizures, which causes anxiety in parents. In this case, it is necessary to control the seizures with treatment and to inform the families about the antiepileptic drugs use (76,77). Factors triggering the seizure are known as not meeting the baby's needs on time, insomnia, restlessness, febrile illness, constipation, extreme fatigue, excessive bright light, noise, having head trauma and not taking antiepileptic drugs on time. All these situations are stressful for the baby and stress triggers a seizure attack (78,79). It is necessary to prevent the occurrence of these situations. If seizures cannot be prevented, the environmental safety of the baby should be ensured during the seizure, bed borders should be removed, a calm and quiet environment should be provided, the seizure should be recorded if possible, and contractions should not be interfered with. In addition, families should be informed about first aid training for seizures and the side effects of seizure medications. Nurses have an important role to play in this regard. Parents should be told that uncontrolled seizures require medical attention (75,80,81).

### **6. Caring for incision site and skin care**

Incision care is of importance in preventing infection and related complications in the postoperative period (82). Center for Disease Control and Prevention defines surgical site infection as infection occurring within 30 or 90 days following the surgical intervention and states that 90 days of surveillance should be performed for surgical site infection in ventricular shunts. Patients under the

age of one year, whose skin integrity is impaired, and who is not paid attention to providing asepsis in dressings are at risk for surgical site infections. Additionally, shunt infection is mostly caused by coagulase-negative staphylococci found in the normal skin flora. In this respect, incision site care/dressing and skin integrity should be provided in children who have undergone shunt surgery (83-85). It has been reported that surgical site infections cause complications such as pain, loss of limb, death, repetitive surgical procedures, prolonged hospital stay, having to seek medical support again, disability, and addiction (86). The incision site should be kept dry and clean, the baby's head should not be touched with water until the stitches are removed, the dressing should be changed if it is dirty and wet, the incision site should be evaluated for swelling, bleeding, redness, the head should be kept elevated at 30-45 degrees, and aspirin should not be given to prevent bleeding. Baby's diaper should be kept clean, the genital area should be observed for irritation and rashes, and the places where redness may occur depending on the sleeping position of the baby (on the auricle, back of the head, hip bones, shoulder area, back area, knee area, soles of the feet, ankles, elbows, upper auricle). on the sides) should be supported with small rollers. Parents should be educated on these issues (82,83).

## **7. Constipation**

Constipation is a condition that can persist for 2 or more weeks in children. In constipation, a decrease in the frequency of bowel movements or increased stool hardness causes pain during defecation (87,88). Chronic constipation may occur in more than half of children with neurological problems as a result of long-term use of laxatives, central nervous system damage, medications used, immobility, hypotonicity, and low intake of fibrous foods and fluids. The European Society for Paediatric Gastroenterology Hepatology and Nutrition recommends taking a medical history, changing dietary habits and increasing fiber intake to prevent constipation in these children (35,37). According to The Constipation Guideline Committee of the North American Society for Pediatric Gastroenterology, nurses are equipped to identify the needs of patients with pediatric constipation problems and initiate treatment. Patient and family education is required in constipation. In the treatment of children with hydrocephalus, constipation should be prevented because constipation may increase intracranial pressure and negatively affect the treatment process (87,88). In the study of Erbaş and Bulut (12), it was reported that families had difficulty in providing nutrition and emptying their children with shunts, and 70.7% of the problems in this regard were constipation. To prevent constipation; babies should be fed little by little and frequently, stool softeners and probiotics should be used on the advice of a doctor, the foods given to the baby should be at the appropriate temperature, and dietician support should be sought if constipation occurs frequently. In addition, the baby should not push or strain as this may increase intracranial pressure (89-91).

## 8. Maintaining Body Temperature

Fever in children is one of the most common causes of hospital admissions. Prolonged fevers, which can affect the cardiopulmonary, digestive and nervous systems, increase basal metabolic rate and oxygen consumption (92,93). In a study of children with disabilities, including children with hydrocephalus, fever was reported to be the leading symptom leading to doctor visits (94). In the study of Yılmaz, (32) it was reported that fever (91.7%) was the most frequent complication in children with shunt. Febrile conditions may be a sign of an infectious disease. Body temperature measurement sites in children are the rectal area, inside the oral area, axillary region, and tympanic membrane (95,96). Yiğit and Sanlioğlu (97), reported that 90.9% of the parents of febrile children were worried about their child's fever, 61.2% were afraid of their child's convulsions, 79.4% knew the normal limits of fever. When the baby has a body temperature above 37.7 0C, this may be accompanied by crying, moaning, restlessness, tendency to sleep and weakness. In such a case, the body temperature should not be lowered suddenly. Cold application should be applied to the baby for 15-20 minutes (in the groin area of the baby, on the back of the foot, in the armpit area). If the fever does not decrease, antipyretics recommended by the doctor should be given. Hypothermia, defined as a body temperature below 35 0C, usually indicates the severity of the injury and the complexity of surgical procedures. Therefore, it is an indicator of adverse events on its own. Furthermore, pediatric hypothermia is an uncertain topic with harmful or beneficial effects (98,99). Nurses, as the health professionals who interact most with children and parents during their hospitalization, should inform families about hyperthermia (92,93).

## 9. Hygiene

Inadequate hand hygiene practices after surgical procedures may cause surgical site infections (83). Hand hygiene, distance rules, contact precautions, and environmental sanitization are important in preventing surgical site infections (100,101). In the study of Erbaş and Bulut (12), it was reported that families had difficulty (76.1%) in providing personal hygiene and care for their children with shunts. Hands should be washed before and after the procedures according to hygiene rules. To protect the baby from the upper respiratory tract infections, caregivers should use masks and gloves when approaching the baby if there is someone around with flu symptoms. Glasses, plates, forks, spoons, etc. should be washed well. The baby should be cleaned daily and it should be ensured that the clothes and bedding are clean. It should be paid attention to the hygiene of drinking water and food. Bedding should not be shaken in the presence of the baby; dust should be avoided. Dirty water should be prevented from splashing around, on hair, face, and clothes. Cleaning should be done from the least dirty area to the dirtiest area. Attention should be paid to individual cleanliness and order to prevent the spread of microorganisms. Nails should be cut short. It should be ensured that the nail beds are strong and the nail tips are smooth (102-104).

## The importance of nursing care in hydrocephalus

Family caregivers play an important role in planning the care of patients with chronic diseases. In this regard, nurses have to deal with many points that improve the quality of care. Nurses can improve the quality of care by increasing the competence of caregivers and teaching them new skills that increase patient safety. Studies have shown that when nurses support caregivers and engage them in care, outcomes improve; however, more studies are needed in this area (105). Children with hydrocephalus have special health needs and need special care from their families at home (106). In hydrocephalus, all caregivers, especially mothers, who provide the most care for the child, do not have much technical and emotional experience (2,3). Therefore, family members may feel fear in the first postoperative days because of the uncertainties (106). Nursing care is important to prevent the problems that occur in hydrocephalus; therefore, nurses should have knowledge about neurologic functions, symptoms, and treatment of the disease by considering the best quality of life of the child (107). Caring for children with serious illnesses that require complex treatment can impair the health of families and children. Therefore, families should be empowered through education and support (108-110). In a qualitative study by Gürol et al. (111) investigating the problems in mothers of children with hydrocephalus, it was reported that families who were given information had information about the treatment and prognosis of the child, while families who were not given information thought that their children could recover. While all mothers stated that they had to make changes in their daily lives during the treatment process, the majority of the mothers stated that they experienced physical and psychological changes such as sadness, stress, sleep problems, irritability, headaches and fear, and economic problems. Providing caregivers with written cards and developing guidelines on the care of patients with shunts in the hospital setting is an effective and important method to ensure patient safety (112).

## SUMMARY / SONUÇ

Chronic diseases affect not only patients but also their caregivers. When caregivers are informed about shunt care, shunt complications can be reduced and caregivers can actively participate in care. Besides, cost-effective care maintenance is ensured. Therefore, nurses play an important role in supporting and strengthening the coping styles of caregivers of children with hydrocephalus and having shunts. Nurses should educate caregivers about the care of the children after shunt placement because caregivers do not know what to do and when to do it since shunt complications are frequently seen and have unpredictable nature.

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