

Administering Hypertonic Saline to Patients with Severe Traumatic Brain Injury

Diane Schretzman Mortimer, Jon Jancik



Abstract: Hypertonic saline (HTS) is an osmotic agent that can help patients in the acute phase of severe traumatic brain injury. HTS extracts fluid from swollen cerebral tissue to both control intracranial pressure and diminish the deleterious effects of secondary brain injury. Neuroscience nurses in intensive care and acute care units, who may administer HTS as resuscitation fluid, continuous infusion, or bolus dose, need to be familiar with physiologic actions, potential side effects, and appropriate HTS administration techniques. Neuroscience nurses collaborate with other members of the interdisciplinary team to ensure that HTS is administered safely.

Severe traumatic brain injury (TBI) is a major health problem in the United States. There are approximately 50,000 new cases per year, including 17,500 deaths (Narayan et al., 2002). Head injury, which causes significant mortality in all age groups (Bullock et al., 2000), is the leading cause of death in infants and children (Simma, Burger, Falk, Sacher, & Fanconi, 1998). TBI is a contributing factor in more than 60% of all trauma-related deaths (Bullock et al.).

The high mortality rate associated with severe TBI probably is in part due to the deleterious effects of secondary brain injury. The primary injury is often followed by secondary events hours and even days later (Bayir, Clark, & Kochanek, 2003). The occurrence of devastating secondary events accounts for the fact that inpatient mortality rates continue at an alarming 25%–33%, even at the best head injury centers in the country (Narayan et al., 2002). In fact, as many as 90% of patients who die from TBI show some evidence of secondary brain injury (Shackford et al., 1998).

Hypertonic saline (HTS) is an osmotic agent that may diminish the effects of secondary brain injury in patients with TBI. Given during the acute phase of head trauma

Questions or comments about this article may be directed to Diane Schretzman Mortimer, MSN RN CNRN, at Diane_Mortimer@urmc.rochester.edu. At the time this article was written, she was a staff nurse in the Neuro-Trauma Surgical Intensive Care Unit, Hennepin County Medical Center, Minneapolis, MN, and a clinical instructor at the University of Minnesota School of Nursing in Minneapolis. She currently is a student at the University of Rochester School of Medicine and Dentistry, Rochester, MN.

Jon Jancik, PharmD BCPS, is a clinical specialist in the Neuro-Trauma Surgical Intensive Care Unit at the Hennepin County Medical Center, Minneapolis, MN.

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care, this treatment is inexpensive and has manageable side effects. It has been determined to be safe and effective in multiple human trials. HTS can be given during resuscitation, via continuous infusion, or as a bolus dose (Doyle, Davis, & Hoyt, 2001). Nursing care for patients receiving HTS includes careful administration and close monitoring of laboratory values and patient status (Johnson & Criddle, 2004).

This article provides guidelines for HTS administration and a general plan for nursing care. The recommendations are based on protocols and results reported in previously published studies.

Secondary Brain Injury

The pathological cascade of secondary brain injury that may occur in the hours and days after a primary traumatic injury can have devastating consequences. Secondary injury may be attributable to factors associated with cerebral ischemia. Cerebral ischemia can be caused by hypoxia, systemic hypotension, or relative hypoperfusion produced by intracranial hypertension (Bayir et al., 2003).

Secondary injury can cause both cerebral edema and worsened cerebral ischemia. It can also lead to intractable increased intracranial pressure (ICP), which contributes to development of secondary brain damage and subsequent morbidity and mortality. In addition, TBI itself may lead to an inflammatory response that can promote and aggravate secondary brain damage (Bayir et al., 2003).

The prevention and treatment of secondary brain injury involves a multifaceted strategy. Critical care monitoring includes ICP assessment, cerebral perfusion pressure, and, if available, cerebral oxygenation. Patients are positioned with appropriate head elevation and body alignment and sedated with medications such as narcotics, analgesics, anesthetics, and barbiturates. Hemodynamics are stabilized using fluids and pressors. Oxygenation is optimized with careful airway and ventilator management. Cerebral edema can be treated with surgery or medications or both. Osmotic agents (e.g., mannitol, HTS) are also a part of this effort (Fields, Blackshear, Mortimer, & Wallace, 2004).

Clinical Effects of HTS

Hypertonic saline refers to any saline solution with a concentration of sodium chloride (NaCl) higher than

physiologic (0.9%). Commonly used preparations include 2%, 3%, 5%, 7%, and 23% NaCl. HTS may have an important role in preventing and treating the effects of secondary brain injury. It works primarily by an osmotic effect but also has other effects (Doyle et al., 2001). The clinical effects of HTS are outlined in Table 1.

Osmotic Effect

HTS exerts an osmotic effect. It draws fluid out of edematous cerebral tissues because it has a higher concentration of sodium and a lower concentration of water than blood. When HTS is administered intravenously, plasma osmolarity increases. The higher sodium concentration causes blood to be hypertonic compared to cerebral tissue, which has a lower sodium concentration. These concentration differences set up an osmotic gradient that promotes the flow of excess water from cerebral tissue to the blood via osmosis. Osmosis occurs because water moves passively along the concentration gradient. Water moves from areas of lower concentration to areas of higher concentration (Feig & McCurdy, 1977).

This osmotic effect can be used to combat cerebral edema. By reducing the water content of the injured brain, HTS can reduce mass effect. HTS can also control ICP, leading to a decrease in secondary brain injury (Qureshi & Suarez, 2000; Qureshi et al., 1998; Qureshi, Suarez, Castro, & Bhardwaj, 1999).

Hemodynamic Effect

The hemodynamic effect of HTS occurs because it is an effective plasma volume expander. Volume expansion improves blood pressure and cerebral perfusion pressure. Improved perfusion yields better oxygenation to areas of the brain that are at risk for secondary damage (Doyle et al., 2001; Kramer, 2003).

Vasoregulatory Effect

The use of HTS may also have beneficial effects on cerebrovascular regulation in the brain's microcirculation. Decreasing edema in the vascular endothelium of injured tissues lowers vascular resistance, allowing more blood to flow through the vessels. Thus, HTS modulates the hypoperfusion often seen in secondary brain injury. The effective increase in microvessel diameter can also help the injured brain combat hyperemia by allowing blood to flow out of the region (Doyle et al., 2001; Kramer, 2003; Pascual, Khwaja, Chaudhury, & Christou, 2003).

Immunomodulatory Effects

HTS can play a role in enhancing the immune modulation of brain cells. Head trauma can activate the inflammatory cascade, causing leukocytes to migrate and adhere to injured neurons. This inflammatory process can ultimately cause the injured cells to die. HTS, by a mechanism that is not yet fully established, can prevent leukocytes from becoming activated and adhering to brain cells, minimizing secondary pathologic events (Hartl et al., 1997).

Neurochemical Effects

HTS has neurochemical properties. After TBI, neuronal

Table 1. Clinical Effects of Hypertonic Saline

Type of Effect	Action
Osmotic	Reduces cerebral water content
	Reduces mass effect
	Prevents or treats elevations in intracranial pressure (ICP)
Hemodynamic	Increases mean arterial pressure and cerebral perfusion pressure
	Improves perfusion of organs
Vasoregulatory	Optimizes perfusion of brain
	Prevents or treats increases in ICP
Immunomodulatory	Modulates inflammatory response to traumatic brain injury
	Reduces secondary pathologic events
Neurochemical	Normalizes neuronal cell membrane potential and electrolytes
	Limits secondary injury from neurochemical changes
Hypertonic	Prevents hyponatremia

Note. From "The Use of Hypertonic Saline in the Treatment of Traumatic Brain Injury," by J. Doyle, D. P. Davis, and D. B. Hoyt, 2001, *Journal of Trauma*, 50, pp. 367–383.

membranes may become destabilized, and the neurochemical environment can be disrupted. As a result, detrimental excitatory amino acids accumulate, leading to eventual cell death. HTS may modulate this process by normalizing neuronal cell membranes, by restoring normal electrolyte and neurotransmitter levels in brain cells, and by restoring normal cell volumes. Thus, HTS can limit secondary injury from neurochemical changes (Suarez, 2004).

Hypertonic Effect

HTS has an important role in countering hyponatremia in the brain. Low serum sodium levels following TBI can lead to extracellular volume depletion, cerebral ischemia, and cerebral edema. These can all result in dangerous increases in ICP. HTS can help avoid the negative effects of hyponatremia by increasing serum sodium levels in the acute phase of head trauma care (Johnson & Criddle, 2004; Suarez, 2004).

Administering HTS by Continuous Infusion

HTS can be administered via continuous infusion for acute head trauma care. The HTS infusion rate can vary from 30 ml per hr to upwards of 150 ml per hr (Qureshi et al., 1998). The rate is adjusted according to serum sodium levels (Khanna et al., 2000). The HTS solution can either supplement or replace the maintenance intravenous solution, depending on the patient's electrolyte levels and fluid requirements (Qureshi et al., 1998). A summary of nursing care for patients receiving continuous HTS infusions follows.

Administer via Central Line

If the NaCl concentration is greater than 2%, HTS must be administered through a central line. It cannot be given peripherally, because HTS in concentrations of 3% or higher can cause local vascular irritation. HTS would also be harmful to local tissues if the intravenous site became infiltrated. The presence of HTS in the tissues of the arm and hand can cause cells of these tissues to become extremely edematous as fluid is pulled in. This dangerous edema can cause tissue damage and even lead to necrosis (Suarez, 2004).

Monitor Laboratory Values Carefully

Patients receiving continuous HTS infusions should have their serum sodium levels checked at least every 6 hr. The main objective of continuous HTS therapy is to provide an optimal osmolar gradient while avoiding the dangerous effects of hypernatremia. Maintaining serum sodium levels of 145–155 mmol/L is likely to achieve this goal (Qureshi & Suarez, 2000; Qureshi et al., 1998; Qureshi et al., 1999). Serum sodium levels should be maintained no higher than 155 mmol/L. Higher levels are dangerous. Patients with serum sodium levels higher than 160 mmol/L are at increased risk for treatment-related renal failure, pulmonary edema, and heart failure (Qureshi & Suarez, 2000). If serum sodium levels remain above 160 mmol/L for more than 48 hr, the risk of these problems increases even more. Furthermore, if serum sodium levels climb beyond 160 mmol/L, patients are at risk for seizures (Qureshi et al., 1998).

Serum osmolarity levels should also be monitored. HTS is an osmolar agent, and it directly affects serum osmolarity levels. These levels, which do not change as rapidly as serum sodium levels, should be checked every 12 hr while patients are receiving continuous HTS infusions. The target serum osmolarity is less than 320 mOsmol/L. At higher levels, patients are at increased risk for treatment-related renal failure (Qureshi & Suarez, 2000; Suarez, 2004).

Manage the Drip

HTS needs to be administered at a carefully controlled rate. Like other critical infusions, HTS should be run on a pump. HTS is not compatible with all medications. In particular, drugs that are only compatible with normal saline are not compatible with HTS. It is important to check with institutional pharmacists before administering other medications through the HTS line. Transfusions of blood or blood products cannot be given through the HTS line. These products must be given with normal saline, because the highly concentrated HTS solution could cause lysis of red blood cells (Qureshi & Suarez, 2000).

Collaborate with Other Providers

Nurses must inform other healthcare team members about HTS administration. For example, if the patient receiving HTS goes to surgery, the nurse has to ensure that the anesthetist carefully monitors the HTS drip and serum sodium levels. In addition, the nurse should

communicate goals of the patient's HTS treatment to the various medical teams involved (Johnson & Criddle, 2004; Wright, 1999).

Monitor Fluid Status

Fluid status must be closely monitored. HTS therapy is associated with fewer renal complications when patients are euvoletic than when patients are hypovolemic. If it occurs, hypovolemia can be treated with intravenous fluids or blood products, depending on the patient's needs (Suarez, 2004). On the other hand, giving HTS may cause some patients to become hypervolemic.

Nurses must carefully observe indicators of fluid status, such as intake and output, patient weight, and available hemodynamic values. Chest X rays should be obtained daily to assess for signs of pulmonary edema (Qureshi & Suarez, 2000).

Provide Age-Appropriate Care

Nurses need to exercise special caution when administering HTS to older adults via continuous infusion. Normal age-related changes as well as concomitant renal, cardiac, and pulmonary illnesses can put older adults at increased risk for complications of HTS therapy. Older adults may develop treatment-related complications more rapidly than younger adults. Older adults' serum sodium levels and fluid status should be carefully monitored to prevent or minimize these problems (Whitney, Pugh, & Mortimer, 2004).

Nurses administering HTS to children should follow the facility's protocol. HTS has safely and effectively been utilized in children with TBI. It is particularly beneficial in treating refractory increases in ICP in these injured young people (Khanna et al., 2000; Knapp, 2005; Peterson, Khanna, Fisher, & Marshall, 2000; Simma et al., 1998).

Administering HTS in Special Situations

Acute ICP Elevations

HTS can also be administered in bolus form to treat acute ICP elevations. A dose of highly concentrated HTS, such as 30 ml of 23.4% NaCl, is given through a central line over approximately 15 min (Suarez et al., 1998). The bolus dose of HTS can help decrease ICP and improve cerebral perfusion (Horn et al., 1999; Qureshi & Suarez, 2000).

Studies indicate that bolus HTS therapy can be administered as frequently as every 6 hrs. Interestingly, a bolus of 23.4% NaCl does not cause considerable increases in serum osmolarity or serum sodium levels. This therapy can be administered even if serum sodium levels are at high end of the goal range. It is nonetheless prudent to closely monitor laboratory values. If a patient's serum sodium or osmolarity levels begin to rise, the frequency of boluses may need to be decreased (Suarez et al., 1998).

The Resuscitation Phase

HTS is attractive as a resuscitation fluid because it can help achieve hemodynamic stabilization, which can

optimize brain perfusion. HTS can achieve these effects with smaller volumes than hypotonic or isotonic intravenous fluids. It can be beneficial for patients to receive smaller amounts of fluid to prevent exacerbations of cerebral edema and increases in ICP (Cooper et al., 2004; Kramer, 2003; Shackford et al., 1998; Wright, 1999).

A drawback to using HTS in the resuscitation phase is that clinicians need to know the patient's serum sodium levels before initiating HTS therapy. If the initial serum sodium level is 130 mmol/L or lower, a rapid increase could cause central pontine myelinolysis, a devastating complication. Emergency providers, therefore, should not administer HTS to hyponatremic patients. It may be difficult for paramedics and emergency room staff members to assess this important laboratory value soon enough to resuscitate with HTS. In the future, if emergency care providers can assess the serum sodium levels more quickly, resuscitation with HTS may become more common (Kramer, 2003).

Adverse Effects of HTS

Nurses who are administering HTS to patients need to exercise vigilance as they assess for adverse effects. This is especially true because HTS is mainly used during the acute phase of head injury care, when patients are at particular risk for physiologic complications. Some adverse effects have been documented in clinical situations; others are mainly theoretical issues (Suarez, 2004).

Central Pontine Myelinolysis

The most serious potential complication is central pontine myelinolysis (CPM). CPM has occurred in situations in which serum sodium levels rise quickly (in a matter of minutes). This syndrome, which is characterized by a rapid and irreversible demyelination of the pons, is manifested by a decreased level of consciousness and severe quadriplegia. These symptoms are difficult to immediately identify in patients with severe TBI, although the consequences of CPM would be devastating (Doyle et al., 2001). CPM has not been reported in human trials using HTS for TBI.

Avoiding CPM is of utmost concern. Careful monitoring is necessary to avoid rapid rises in serum sodium. Gradual changes in serum sodium, no greater than 10–20 mEq/L per day, are recommended. As another precaution, HTS should not be started if serum sodium levels are lower than normal. Patients with hyponatremia should be treated with normal saline until their serum sodium levels normalize; then HTS can be started (Qureshi & Suarez, 2000).

Renal Failure

Acute renal insufficiency is a primary concern with the use of hyperosmolar therapies for TBI. Renal problems can be minimized by maintaining euvolemia. Central venous pressures, pulmonary artery monitoring, or both, are used if needed. Other interventions include carefully monitoring laboratory values and contacting a renal specialist if any signs of renal insufficiency appear (Doyle et al., 2001; Qureshi & Suarez, 2000).

Volume Overload

Because HTS therapy involves drawing fluid from tissues into the blood, its use could cause pulmonary or peripheral edema or heart failure. If for some reason the blood became hypotonic to the peripheral or central tissues, fluid would move from the blood to the tissues. This fluid movement could lead to edema of the brain, vital organs, and peripheral tissues. Careful monitoring of laboratory values and fluid status is needed to avoid or minimize these problems (Suarez, 2004).

The Role of HTS in the Subacute Phase of Head-Injury Care

Questions about how long to continue HTS therapy have not been definitively resolved. Most studies of HTS have only examined its effects during the acute phase of head trauma care. During the subacute phase, however, patients may still require HTS. The treatment goal is to combat downward-trending serum sodium levels and to prevent associated episodes of cerebral edema (Horn, et al., 1999).

The subacute phase of treatment lasts for approximately 7–10 days after the last ICP spike during the acute phase. Serum sodium levels should be maintained in the high-normal range, around 145–150 mmol/L, during this time. Actions aimed at maintaining serum sodium levels need to be individualized based on the patient's electrolyte levels, fluid status, and recovery stage (Qureshi et al., 1998).

Interventions geared toward preventing decreases in serum sodium levels can include administering salt tablets and implementing an appropriate fluid restriction. If necessary, the HTS infusion can be continued. Patients without central lines who require continuous HTS therapy can receive 2% NaCl via a peripheral line (Qureshi et al., 1998).

Lab reports can be checked less frequently than during the acute phase because they are not as dynamic in the subacute phase. If patients are not receiving HTS, serum sodium levels should be checked daily. If patients are receiving HTS, levels should be checked at least every 12 hr (Qureshi et al., 1998).

During the subacute phase, when patients may no longer be in critical care units, communication and collaboration are especially important. Nurses need to educate patients, family members, and other staff members about the plan of care. Nurses need to collaborate with other team members, including rehabilitation staff, to ensure that appropriate monitoring of sodium therapy continues until hyponatremia and its associated complications are no longer likely to occur (Wright, 1999).

Discontinuing HTS Therapy

HTS is continued until patients are no longer considered to be at risk for hyponatremia. The timing varies among patients, but, in general, the risk for hyponatremia persists throughout the subacute period. When the decision is made to discontinue HTS therapy, the drip can be weaned

off. The drip rate, regardless of NaCl concentration in the HTS fluid, can be halved every 6 hr. When the rate is 20 ml per hr or less, the drip can be discontinued. During the weaning, serum sodium levels should be checked every 12 hr. If levels increase or decrease unexpectedly, they can be checked more often and addressed appropriately. Management depends on the patient's fluid and electrolyte status and overall clinical condition. After HTS therapy has been discontinued, serum sodium levels do not need to be monitored frequently (Qureshi et al., 1998).

Summary

Hypertonic saline is an important part of the treatment of patients with severe TBI. HTS can prevent and treat cerebral edema and its disastrous sequelae. Its complex physiologic actions mandate that HTS administration include careful monitoring of laboratory values and vigilant assessment for potential side effects. Neuroscience nurses who administer HTS to these vulnerable patients must provide safe, high-quality collaborative care.

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Stressors of Parents of Children with Epilepsy and Intellectual Disability

Janice M. Buelow, Angela McNelis, Cheryl P. Shore, Joan K. Austin

Abstract: Past research suggested that parents of children who have both epilepsy and intellectual disability are at risk for increased stress, but the specific causes of stress have not been studied. Descriptions of the specific stressors are needed before effective interventions can be designed. The purpose of this study was to identify and explore these sources of stress. We invited parents of children with a diagnosis of both epilepsy and mild intellectual disability (i.e., estimated IQ of 55–75) to participate in one open-ended interview that was tape recorded and transcribed verbatim. Data analyses revealed five categories of sources of stress: concern about the child, communication with healthcare providers, changes in family relationships, interactions with the school, and support within the community. This study is a first step in developing a more thorough understanding of sources of stress for parents of children with epilepsy and intellectual disability. The identification of stressors provided a foundation for an assessment checklist and suggested avenues for future intervention.

Parents of children with epilepsy are known to experience stress related to their child's condition, which is compounded when the child also has mild intellectual disability (Hoare & Kerley, 1991). Our recent research shows that children with both epilepsy and intellectual disability have a poorer quality of life and more mental health problems than children with epilepsy alone (Buelow et al., 2003). However, little is known about the particular sources of stress that might be experienced by parents of these children, including their unmet psychosocial care needs (i.e., need for information or support).

In the United States, epilepsy affects approximately 326,000 school-aged children; 45,000 new cases are diagnosed every year. Of these children 10%–20% may also have a diagnosis of intellectual disability or mental retardation (Epilepsy Foundation, 2003; Forsgren, Edvinsson, Blomquist, Heijbel, & Sidenvall, 1990; Sillanpaa, 1992). These numbers are even higher when children with serious learning problems but without a diagnosis of intellectual disability are included (Dodson, 2001). Family

problems such as parental stress remain understudied despite the large number of children affected by both disorders. Most past research has focused on parents of children with either intellectual disability or epilepsy and normal IQ but not on parents of children with both conditions. The purpose of this study was to identify sources of stress for parents of children with both epilepsy and serious learning problems.

Review of Relevant Literature

Multiple studies have shown that families of children with chronic conditions (including intellectual disability) experience more stress than families of children without chronic conditions (Abbeduto et al., 2004; Dyson, 1991, 1996; Saloviita, Italinna, & Leinonen, 2003; Wallander & Varni, 1989; Weiss, 1991). Moreover, increased family stress is associated with child behavioral problems, less parental confidence in parents' ability to manage their child's behavior, and problematic mother-child interactions (Emerson, 2003; Feldman, Hancock, Reilly, Minnes, & Cairns, 2000; Hauser-Cram et al., 2001; McIntyre, Blacher, & Baker, 2002; Raina et al., 2004; Shore, Austin, Huster, & Dunn, 2002; Snowdon, Cameron, & Dunham, 1994; Weiss, 1991). There are similar findings for children with epilepsy. Increased family stress, lower socioeconomic status, and fewer family adaptive resources (e.g., extended family support, family mastery) have been associated with a higher incidence of behavioral problems in children with epilepsy (Austin, Dunn, Johnson, & Perkins, 2004; Carlton-Ford, Miller, Nealeigh, & Sanchez, 1997).

Ineffective parental responses or negative parental attitudes toward the child's condition can increase family stress. In a longitudinal study of 224 children with new-onset epilepsy (Austin et al., 2004), low family mastery (i.e., sense of control, family organization, level of cooperation, family emotion) and low parental confidence in the ability to manage the child's behaviors were associated with increased child behavioral problems. In another study, parents of children with severe epilepsy reported more stigma and more negative attitudes toward their child's epilepsy than did parents of children with less severe seizure conditions. In the latter study, negative perceptions were associated with more behavioral problems (Carlton-Ford et al., 1997).

As the number of stressors increases, family functioning (e.g., family organization, communication) worsens (Dyson, 1991; Failla & Jones, 1991; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Trute & Hiebert-Murphy, 2002; Wallander & Varni, 1989). Families of children with both epilepsy and intellectual disability probably

Questions or comments about this article may be directed to Janice M. Buelow, PhD RN, at jbuelow@iupui.edu or 317/274-9639. She is an assistant professor at Indiana School of Nursing, Indianapolis, IN.

Angela McNelis, PhD RN, is an assistant professor at Indiana University School of Nursing, Indianapolis, IN.

Cheryl P. Shore, PhD RN, is an assistant professor at Indiana University School of Nursing, Indianapolis, IN.

Joan K. Austin, DNS RN FAAN, is a distinguished professor at Indiana University School of Nursing, Indianapolis, IN.

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experience more stressors than families of children who have only one of these conditions. Understanding how the family environment is associated with the child's behavior is important, because the family environment may be amenable to nursing interventions.

In summary, both parents of children with epilepsy and parents of children with intellectual disability experience stress, and parental stress is associated with negative child outcomes. Some parental stressors (e.g., behavioral disruptions) are associated with all chronic childhood conditions (Dyson, 1993; Feldman et al., 2000; Hauser-Cram et al., 2001; Hoare & Kerley, 1991; Weiss, 1991), but behavioral problems occur more frequently among children with neurological conditions than among children with other types of disorders (Howe, Feinstein, Reiss, Molock, & Berger, 1993). Furthermore, parents of children with epilepsy might experience additional sources of stress because of the episodic nature of epilepsy and the stigma associated with it (Carlton-Ford et al., 1997; Hoare & Kerley). Prior research has focused mainly on children with epilepsy and normal IQ or on children with chronic conditions, including intellectual disability. Families of children with both epilepsy and serious learning problems, including those with intellectual disability, are understudied. Examining this unique population is important in order to provide direction for the development of family interventions.

Methods

Design

We used semistructured interviews with open-ended questions to identify and explore the sources of stress and psychosocial care needs of parents of children with both epilepsy and intellectual disability. This study was part of a larger study to identify mental health and quality-of-life problems in children with both epilepsy and serious learning problems or mild intellectual disability as well as to determine the effect of these conditions on their parents.

Sample

Primary caregivers of children with epilepsy and intellectual disability were recruited from outpatient pediatric neurology and epilepsy clinics, a pediatric neurologist in private practice, and school nurses. Twenty parents including 18 mothers, one father, and one mother-stepfather dyad, were studied. Their children ranged in age from 9 years to 16 years, with a mean age of 12.2 years ($SD = 2.5$ years). Seven children were male, and 13 were female. All children were at least one grade level behind their peers at school, and all parents reported that their children had significant learning problems and had been diagnosed as being mildly mentally handicapped. Eighteen children were in classrooms for students with special needs. Two were in regular classes but received additional classroom assistance.

All had a definite diagnosis of epilepsy and had been treated with medication. Two children had been diagnosed with epilepsy at birth due to birth trauma and subsequent seizures. Two children had been diagnosed with epilepsy at older ages (8 and 14 years). The remaining 16 children had been diagnosed with epilepsy in early childhood (i.e., ages 2–6 years). Learning problems had been diagnosed before seizures occurred in only two children.

Three parents were divorced, one mother was separated from the father, and one mother had never been married. In three other families, the biological parents were divorced and the mother had remarried. Family income ranged from less than \$10,000 per year to more than \$80,000 per year. Six families reported incomes of less than \$20,000 per year. Sixteen families had children in addition to the affected child.

Procedure

The study was approved by the university institutional review board. After obtaining informed consent, the first author interviewed participating parents using an open-ended interview guide. Face-to-face interviews, lasting approximately 1 hr, were tape recorded. A review of the literature, along with the clinical experience of the first author, provided a foundation for the development of the starter questions. Parents were asked to talk about their problems and concerns regarding the child's classroom behavior, other school behavior, and interactions with teachers. The interview guide included questions about the family's leisure activities and the support parents would like to have from friends, extended family, and the healthcare system. As new topics emerged, they were explored in depth. The questions asked were not limited to those in the interview guide.

Data Analysis

Each interview was transcribed verbatim. The first author and a coauthor analyzed the transcriptions based on a list of a priori codes (i.e., school, community, home, medical care) corresponding to the interview questions (Miles & Huberman, 1994). Descriptive codes were then grouped into broader conceptual categories and subcategories. To ensure auditability, the first author kept a decision trail of notes regarding coding and identification of categories and subcategories. The investigators independently placed data into the categories. They then met to compare findings and to identify new categories and subcategories. This process continued until total agreement between researchers was reached. A summary grid for each category and subject was prepared to assist in the identification of patterns and themes (Knafl & Howard, 1984).

Results

Five categories of sources of stress were identified: concern about the child, communication with healthcare providers, changes in family relationships, interactions with the

school, and support within the community (Table 1). Each category is described in detail below. Unmet psychosocial care needs are integrated into these categories because conceptually they can be viewed as sources of stress.

Concern About the Child

The concerns fell into three specific areas: the child's future and transition issues, behavioral problems, and consequences of seizures (e.g., injury, death, decreased cognitive status).

Child's future and transition issues. All of the parents interviewed were concerned about what would happen to their child in the future. Parents were afraid that the child would always have to live with them because the child would not have the skills to live independently. They worried that the child's quality of life would suffer because of the disorders. One mother said, "I tell him he can do whatever he wants to do in life. I just support him." But when asked how she would help with that, she said, "I don't see him going to college. I'm having a hard time just getting him through grade school."

Despite these pressing worries, only three parents talked about actual plans to help their child make the transition to adulthood. One stated, "I would love to have her live with me forever, but that wouldn't be fair to her. I want her prepared. We really see her being able to live on her own, ideally with a roommate. We felt that we had to make sure her bases were covered." Throughout the interview, this mother described a process of goal setting and intervening to meet the goals.

Behavioral problems. Nineteen of the twenty parents discussed their child's behavior and their own difficulties in managing problem behaviors, which ranged from inattention to combativeness. Four parents described aggressive physical behavior that interfered with all activities outside the home. One child had been removed from school for assaulting a teacher. Other parents described behaviors that were socially problematic (e.g., inappropriate vocalizations or conversations) and made the child stand out. One mother said, "Everybody knows when he comes into a room."

Parents were concerned about their children's poor self-esteem and frustration. One mother said, "She is very quiet and compliant because her self-esteem is so low. She wants to please others but then has rages." Another believed that her son's anger stemmed from frustration but said, "I think it's wrong of him to sit there and get so darned frustrated, because I feel like he is making choices and I can't understand why he keeps making those choices."

Although most parents discussed issues related to their child's behavior, few directly expressed a need for help with behavior management. One mother did complain that when she discussed behavior with her physician, he did not want to deal with the issue. Only one mother discussed a behavior-management plan that involved working with the school.

Table 1. Sources of Stress for Parents of Children with Epilepsy

Category	Subcategory
Concerns about the child	Future and transition issues
	Behavioral problems
	Consequences of seizures
Communication with healthcare providers	Medication problems
	Need for information
	Time to diagnosis
	Support from extended family
Changes in family relationships	Marital relationship
	Sibling relationships
	Leisure-time activities
Interactions with school	Communication
	Transition issues
	Child safety
	Socialization
Support within the community	Work issues and financial concerns
	Family counseling and respite care

Consequences of seizures. Eight parents discussed the potential consequences of seizures, including injury, death, and cognitive decline. One mother said, "I am constantly afraid that she will be injured when I am not there." Another mother was afraid that her child would die during a seizure. Many parents expressed a fear that their child would continue to experience cognitive decline related to ongoing seizures. One mother said, "I would like to be able to differentiate behavior from seizures, and I want to know what it will do to her brain. Is there deterioration?" The fear of seizures affected parents continually. As one mother put it, "I've never *not* been on high alert since she started having seizures."

Communication with Healthcare Providers

This category encompassed all matters concerning health care and healthcare providers. Although most of the parents seemed fairly happy with their children's healthcare providers, they did discuss concerns about medications and a lack of information regarding their child's illness. Several parents told stories about the problems they had experienced in obtaining a diagnosis.

Medication problems. The most commonly mentioned problem related to medication for seizures. Parents generally thought that the doctor's primary concern was medication management and that doctors often ignored what parents believed were significant side effects of medication. One mother stated, "When I call and tell them my son had another seizure, all they ever want to do is increase medications. They don't try to get to the bottom of the problem." Although they complained

about medications and side effects, parents did not have suggestions as to actions their healthcare provider might be able to take regarding seizure treatment. When asked what she would like to see her healthcare provider do for her and her daughter, one mother stated, "Find a cure."

Need for information. Parents commonly expressed the need for more information about their child's condition, including its future course and situations about which they should be concerned. Some parents commented that seizure count was the only important fact for their physician. They wanted help with some of the issues related to their child's condition, such as school problems and troublesome behavior. They also expressed a need for information related to medications, particularly side effects.

Time to diagnosis. Nine parents complained about the length of time it had taken for the epilepsy to be diagnosed. The children who were diagnosed early had experienced a major event such as birth trauma or meningitis or they had had a generalized tonic-clonic seizure. More subtle seizures often had gone unrecognized for years. One mother explained, "I would talk to her, and she couldn't respond...and she was gone again. I didn't say anything to [the doctor] at that point, you know, because I'll just be a hysterical mother or it's just a behavior problem. Everything was a behavior problem. I got so sick and tired of it." In this particular situation, a teacher noted that the child was having staring spells; only then was a diagnosis finally made. Another mother said, "He just shakes. My sister even asked me why he did that, but I talked to the doctors and they never even suspected."

Changes in Family Relationships

Most parents discussed concerns related to relationships among family members (e.g., between father and mother, parent and child, child and siblings) and the overall effect of the child's problems on the family.

Marital relationship. In some families, the marital relationship served as a source of support in managing the child. Other families reported that communication within the family was poor because all of their energy was directed toward managing the child. For example, one mother stated that, although they remained married, she and her husband rarely communicated. She attributed the poor marital situation to their child's continuing problems.

Only one of the divorced parents believed that the divorce had been directly related to the child's problems. In most of the divorced families, communication was not good. In the three families in which the mother had remarried, the stepfather had an active role in raising the child. One stepfather did not work outside the home so that he could stay home to care for his stepson and to be available if the child was sent home from school.

Sibling relationships. Of the 16 families with multiple children, six parents reported that, because of their child's condition, the affected child and the siblings did not get

along. One mother stated that because her son had been ill for so long, her other children lived with their grandparents and had not bonded with their ill sibling. Other mothers complained that they were unable to give equal time to all siblings. One mother reported that her older daughter had said, "I don't want her down here with us—keep her away," when she had friends over.

In families in which the siblings did get along, one of the siblings often took on a mothering role. Eight parents reported that a sibling often took on a parenting role. One mother said, "His sister is 14, and she takes care of him as I would." One parent had identified one of her other children as the long-term caretaker of the affected child in case the parents died or became disabled.

Parents commonly expressed the need for more information about their child's condition.

Leisure-time activities. Parents reported that they had little leisure time because they had to plan everything ahead of time. One mother stated, "It's really limited our activities outside of the home. If we all want to go for a bike ride, we have to take all these precautions. You can't get on a bike and go for a 5-mile bike ride anymore." Life often centered on the affected child, and the activities chosen were based on the child's abilities. Some parents did not complain of the limitations. When asked what they did for leisure activities, they stated that they normally stayed home and played games or watched movies. One mother said, "My husband and I figure that this is the time of our lives that we devote to our children, and so we just plan our activities to accommodate them."

Support from extended family. Parents talked about their support system or lack of support in handling their child's problem behaviors. Some parents had the support of a spouse, and those families appeared to work together with the child. Other parents talked about extended families, but grandparents, aunts, and uncles often were not comfortable with giving care to the child. One mother said, "His grandparents won't help because they can't manage his behavior, and I won't let them see their other grandchild if they won't take both." Two mothers talked about the inability to use help from friends. One mother said, "I'm afraid to leave her with anyone, because I am afraid she will get hurt."

Interactions with School

There were accounts of both positive and negative interactions with school teachers and administrators. Themes in this category were communication with teachers, administrators, and the school nurse; transition plans; safety issues within the school; and the child's socialization.

Communication. Poor communication with school personnel was a source of stress for many parents. They complained that their concerns often went unheard. One mother stated, "It was horrible. They would not listen

to me, and they wouldn't listen to [my child]." Parents often believed that, despite their best efforts, their children's needs were not being met. Some reported that the school's goals for their children were not congruent with their own. One mother stated, "It's really not his placement, it is just what they have. I think the school wants him to meet their needs." Another mother, describing what she believed was an incorrect placement in a class of children with severe behavioral problems, stated, "I don't want him to practice being a problem; I want him to practice being the best in his group."

For other families, communication with the school was limited. Five parents stated that they never really talked to the teacher. One mother said, "No, I don't talk to them. They just send notes." When asked about the individualized educational plan (IEP), which is developed for every child with special needs, one mother said, "Well, I don't go for them. They just send me a copy." Another mother referred all communication from the school to the child's father, who lived elsewhere. These parents did not complain about the school, but they also did not communicate or have a collaborative relationship with the school, even though their child had serious learning problems and was at least one grade level behind his peers.

Three parents reported that they had good communication with the school and were happy with the way their child was being educated and cared for. These parents saw themselves as their child's advocate. As one parent stated, "I might have been a little annoying in their eyes, but I felt that I was her advocate and how else are they going to know unless I let them know?" These parents believed that they had to be present for their child and that, when they expressed concerns, the schools tried to address those concerns. A father said succinctly, "Parents who are visible get more services for their children."

Transition issues. Almost all parents discussed school-based training for transition from adolescence to adulthood and independent living. Most expressed hope that their child would be able to live independently, but they were discouraged that the relevant transition skills were not being addressed in the schools. One mother stated, "Well, she is just sitting in class when they do algebra, and she listens, but she'll do other work; so she'll just sit in class. But I went to the teacher and said these are the issues: She needs to know how money works, and how time works, and how to balance a checkbook."

Child safety. Parents often expressed concern about their children's safety in school. One mother believed that teachers and other school personnel were not knowledgeable about seizures. Some parents had initiated a training program for the school but felt resentful that they had to take on that role. One mother stated, "I actually had to put in her IEP that every year I do an in-service, and they said, 'Why do all the teachers have to be there?' Well, what happens if somebody has a seizure on the playground?" Two mothers were concerned because there was no nurse at the school. Both parents

spent a considerable amount of time advocating for a school nurse to be assigned to the school.

Socialization. Almost all of the parents discussed their child's problem in making friends. This problem, while most obvious in school, seemed to pervade all areas of life. A few parents said, "My child has no friends." Others reported that their child's behavior interfered with the ability to make friends. Many parents suggested that poor self-esteem and a lack of friends were related. One mother said, "He never gets invited to parties or anything, and I can understand that." She went on to say, "Every once in a while, he will say that he hates himself." Some parents blamed the child's seizures for the socialization problems. One mother said, "He doesn't really have friends outside of school. When he has a seizure at school, it disrupts everything and embarrasses him."

Three parents worked with the other children in their child's classroom to increase understanding about their child's problem. In addition, they worked hard to build their child's self-esteem. One mother stated, "I try to give her as many normal experiences as possible."

Support Within the Community

Eight parents said that they would like to have community support, but only a few could articulate what type of support they could use. During the interviews, however, several concerns surfaced that might be addressed by community programs. They included work issues and financial concerns, family counseling, and respite care.

Work issues and financial concerns. Several mothers discussed problems related to work and family management, including the need to leave work to pick up the child at school, frequent absences from work because of the child, and the need to quit school because of the child's condition. One mother said, "The principal said 'Well, when I can't get a hold of you, I am going to have to call the police.' I'm like, 'I'm in a meeting.'" These parents worried about finances. Some complained that they did not have the money to obtain special services that would help their child, such as a summer camp for disabled children. Two divorced mothers complained that the child's father's failure to help financially increased their financial worries.

Family counseling and respite care. Only three parents stated that family counseling would have been useful to save their marriage and to help the siblings. As explained by the mother of a teenage daughter who had had epilepsy since she was age 5, "I've had to work very, very hard in making it the well-rounded family. It just didn't come. I think that we could have really benefited from family therapy."

Although only two parents discussed respite care, many parents talked about needing a break from their child. One mother stated, "I feel like we are joined at the hip. I am always with him." Another mother stated that she would love to get away but that there was not a safe place to leave her child. One parent said that when she

had left her child in respite care, he had been inappropriately medicated.

Discussion

This study identified the sources of stress for parents of children with both epilepsy and serious learning problems. The areas related to the child, health care, family, school, and community emerged as those most experienced by parents. Although we were primarily interested in sources of the parents' problems, the most striking finding was the intensity of the problems. How painful it must be for a parent to report that their child has no friends. How frustrating it must be for parents' concerns to fail to be addressed by health or school professionals. How difficult it must be for parents to need to continually defend their child and act as an advocate to secure the care they believe the child needs and is entitled to. The impact had been devastating for some families, placing an extreme burden of worry and stress on the parents. It is imperative that healthcare providers, particularly nurses, help these parents and children cope with the burden of the dual diagnosis.

Many of our findings were similar to findings about children with intellectual disability alone. For example, parental worry about the future has been described in research on children with mental retardation (Floyd & Gallagher, 1997). Other problems appear to be specific to this population, such as worry about a child being injured or dying during a seizure (Hoare, 1993). An important finding of this study was the impact of the constellation of problems the families experienced. The double-ABCX model provides a framework for understanding the pileup of stress (McCubbin & Patterson, 1983). We found that all of the parents had a series of problems that might be considered a pileup of stressors related to their child's illness. For example, some parents seemed overwhelmed by the seriousness of the seizures and the child's behavioral problems. These two issues affected almost all areas of their lives and contributed to their overall stress. Because they were dealing with these serious and immediate needs, they may have been unable to address other concerns such as the child's future. For example, when a parent is called to the school because of the child's problematic behavior, behavior becomes the pressing issue to be dealt with, and issues such as long-term transition needs are less likely to be addressed. Moreover, being called to school regularly may affect the parent's ability to work. Our findings support literature suggesting that parents of children with intellectual disability may have more economic constraints (Emerson, 2003; Hauser-Cram et al., 2001).

Parents discussed how their child's presence in the family affected the family dynamics. Most frequently, parents discussed changes in family roles. For example, siblings often assumed a caretaker role in relation to their ill sibling. This was not always a negative, however; some siblings displayed genuine concern for their ill brother or sister. In contrast, others felt anger toward

their ill sibling. These behaviors might be attributed to family functioning. One study showed that mothers rated the healthy siblings' adjustment higher if the mothers had confidence in their own ability to manage the child's illness and if the marriage was strong (Gallo, Breitmayer, Knafl, & Zoeller, 1993). These findings point out the necessity of the evaluation and probable inclusion of siblings when working with families. Further exploration of the burden experienced by siblings is warranted.

The lack of social support from the community was unfortunate, because this is one resource that might help parents meet the demands of caring for their child. In previous studies, parents who reported satisfaction with support networks also reported fewer emotional problems (Dunst, Trivette, & Cross, 1986; Sheeran, Marvin, & Pianta, 1997). Support might come from spouses, extended family members (e.g., grandparents), friends, or people in the community. In previous research, satisfaction with outside support has been correlated with satisfaction with family functioning (Snowdon et al., 1994). This is important, because family functioning is a predictor of parental stress (Dyson, 1993). Therefore, one way to improve family functioning and decrease parental stress might be to help parents improve their support system.

It is not surprising that communication with schools was a source of parental stress. Children spend much of their day in school, and these children were experiencing serious learning problems. Parents had to work hard to achieve good communication with the school. Many parents talked about the disparity between their goals and the teachers' or school's goals for their child. All parents discussed their worry about their child's future. Because these children were only mildly delayed, parents might have assumed that their child would one day live independently. Thus, they were looking for assistance toward this goal from the school. Parents, teachers, and school administrators need to collaborate to develop plans that address both present and future expectations for the child and create strategies to help the child meet goals. Teaching independent-living skills would be one such strategy.

Other sources of stress within the school included concern about the child's safety (e.g., injury during a seizure). Research has shown that parents of children with new-onset seizures worry about how to handle seizures in school (Shore et al., 1998). This might be an even greater problem for children who have chronic seizures and limited cognitive abilities and thus, possibly, limited judgment about safety issues. Some school nurses are well-educated about seizure management. However, in many schools there are no school nurses or the nurses lack adequate knowledge about seizures. Although little research exists, two early studies indicated that workshops can be effective in educating teachers about epilepsy (Dreisbach, Ballard, Russo, & Schain, 1982; Rassel, Tonelson, & Appolone, 1981).

Although most parents reported that they liked their healthcare providers, they had many complaints about the health care they had received. For example, many parents complained about the delay in obtaining an accurate diagnosis for their child. It is possible that the frustration associated with this delay negatively influenced their later interactions with healthcare personnel. Despite complaints, parents were not able to articulate either what they expected from their healthcare providers or how they felt their healthcare providers might better help their child. Ideally, parents should not have to figure out the next step for their child's health care and should be able to depend on their healthcare providers to supply this direction. However, our interviews indicate that this was not always the case. These children were in need of comprehensive care, but their care was often narrowly focused on seizure control. The poor communication between parents and physicians is not totally surprising, considering reports that emergency room patients rarely are able to completely explain their presenting problem and that the average time before interruption by a physician during a visit is 12 seconds (Rhodes et al., 2004).

Implications for Nursing Practice and Research

It is clear that the parents of children with both epilepsy and intellectual disability in this sample were experiencing many stressors, some of which are unique to the dual nature of their child's disorder. Some of these sources of stress involved psychosocial care needs related to information and support (Farmer, Marien, Clark, Sherman, & Selva, 2004; Rhodes et al., 2004; Shore et al., 1998). Past research has shown that parental stress is related to child outcomes (Austin et al., 2004; Carlton-Ford, Miller, Brown, Nealeigh, & Jennings, 1995). Austin (1996), in presenting a model for family adaptation to childhood epilepsy, proposed that not only child characteristics but also family demands and resources affect parent and child coping responses and that providing psychosocial nursing care can facilitate good parental and family adaptation. Therefore, assessing family stressors and care needs and helping parents to identify resources and develop coping skills have the potential to improve child outcomes. An important step in helping parents in this process is to assess their stressors and psychosocial care needs. Families rarely bring all of their problems to their physician. Because many stressors arise from a child's medical condition, nurses are uniquely positioned to help parents address these sources of stress. Fig. 1 is a list of potential parental stressors that nurses can use for assessment. Strategies for assisting parents should include assessing for the problem, educating when appropriate, and referring when necessary. Nurses must also understand that, despite their best intentions, they cannot help all parents solve all their problems. Therefore, another important strategy is to

Assessment Item	Date Discussed
Worries about child	
My child's behavior	_____
My child's future	_____
My child's being injured during a seizure	_____
My child's cognitive status because of seizures	_____
Medical care	
Problems with medications	_____
Need for information	_____
Child's diagnosis	_____
Family	
My relationship with my spouse or significant other	_____
My child's relationships with siblings	_____
The other children's role in the family	_____
My time to parent all my children	_____
Time for leisure activities	_____
School	
My interaction with teachers	_____
My interaction with administrators	_____
My interaction with the school nurse	_____
My child's learning the things needed to be independent	_____
My child's safety in school	_____
My child's ability to make friends in school	_____
Community	
Problems with work	_____
Problems with finances	_____
Family support	_____
Respite care	_____

Fig 1. Family assessment guide

simply be a good listener so that parents can have a way to share their frustrations.

Summary

This study suggests that parents of children with both epilepsy and intellectual disability experience a pileup of stressors, which family resources are frequently inadequate to meet. Nurses are ideally situated to identify the needs of these parents and to intervene. Unfortunately, there are very few documented nursing interventions (e.g., patient education) to assist these families. It will be of great importance to develop and test interventions that would ease their difficult burden.

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