

# PEDIATRIC CRITICAL CARE: A NEW MILLENNIUM

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## THE TECHNOLOGY-DEPENDENT CHILD

**John C. Haffner** <sup>1</sup> MD  
**Scott J. Schurman** <sup>2</sup> MD

<sup>1</sup> Divisions of Critical Care Medicine (JCH)

<sup>2</sup> Nephrology (SJS), Department of Pediatrics, University of South Florida College of Medicine and All Children's Hospital, St. Petersburg, Florida

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*Address reprint requests to*  
John C. **Haffner**, MD  
Division of Critical Care Medicine  
Department of Pediatrics  
880 Sixth Street South, Suite 370  
St. Petersburg, FL 33701

**Advances in technology allow survival to hospital discharge of patients who in the past would have died or been institutionalized indefinitely. The end result of technologic adaptations to the care of infants and children is an expanding population of technology-dependent pediatric patients. In turn, the primary care and coordination of subspecialty intervention for these children is largely the responsibility of the general pediatrician--efforts that invariably consume a disproportionate share of physician and staff time. Thus, working knowledge of issues pertaining to the care of technology-dependent children are important for all pediatric practitioners.**

## THE POPULATION

In 1987, the US Office of Technology Assistance defined *technology-dependent child* as "one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability."<sup>[62]</sup> In an effort to clarify the population considered technology dependent, the US Office of Technology Assistance defined four groups and estimated the number of children in each group at that time. Group I, ventilator-dependent children, was estimated to number from 680 to 2000; group II, children requiring prolonged intravenous medications and parenteral nutrition, was estimated at 620 to 8975; group III, children dependent on other device-based respiratory or nutritional support, was estimated at 1000 to 6000; group IV, children dependent on other medical devices and daily or near daily nursing, was thought to number more than 30,000. These estimates suggested that, in the late 1980s, there were likely more than 45,000 technology-dependent children in the United States. Since that time, improved pediatric care technologies have included microprocessors in neonatal ventilators and infusion pumps; enteral feeding tubes; and surgically

placed, semipermanent intravenous catheters. The result has been improved survival of neurologically impaired children and premature neonates, although often with significant morbidity. Thus, the number of children meeting the US Office of Technology Assistance definition of technology dependent continues to expand.

## **OXYGEN**

Supplemental oxygen is used for children with chronic lung disease, such as bronchopulmonary dysplasia, with or without the need for mechanical ventilation. Space, mobility, expense, and needed concentration are the primary considerations when choosing an oxygen source. Home oxygen is supplied in three forms: liquid oxygen, oxygen cylinders, and oxygen concentrators.

Liquid oxygen has several advantages. Liquid oxygen tanks are light and portable. They have a longer duration of use than oxygen cylinders, are able to be filled at home using a home base unit, do not require electricity, and do not generate heat or noise. The primary disadvantage is expense, and many third party payers do not approve, and home health companies do not provide, liquid oxygen.

Oxygen cylinders commonly are carried by home health care companies. Cylinders are less expensive than liquid oxygen, and cylinders of various sizes are available. Smaller C and D cylinders can be used with carrying cases for easier mobility. E cylinders can be made mobile with a two-wheel dolly system. Large H cylinders may be used at home for several weeks if the flow need is less than 1 L/min. Oxygen cylinders, like liquid oxygen, do not require electricity and do not generate heat or noise. Disadvantages include bulkiness and the need for frequent replacement.

Oxygen concentrators generate their own oxygen and are less expensive than liquid oxygen or oxygen cylinders. Oxygen concentrators are not portable, however, and can be used only at home. They require a substantial amount of electricity and generate significant heat and noise. The increase in electricity costs caused by the use of an oxygen concentrator and the indirect need for enhanced home cooling can present a significant uncompensated expense for many families. In addition, oxygen concentrators deliver a decreased concentration of oxygen as the liter flow requirement increases and therefore may not be suitable for some patients. In general, a combination of oxygen sources is necessary to provide appropriate emergency back-up and portability. Thus, oxygen concentrators, large H cylinders, or liquid oxygen base stands can be used at home, with small cylinders or portable liquid oxygen used as back-up and for travel.

## **TRACHEOSTOMY**

Children with tracheostomies are an important subpopulation of technology-dependent children. Upper airway obstruction is the commonest reason for tracheostomy in children.<sup>[5] [7] [17] [59]</sup> Other problems requiring tracheostomy include long-term mechanical ventilation and inability to protect the airway, as in children with neurologic impairment or neuromuscular disease. Tracheostomy generally is performed by an otolaryngologist or general pediatric surgeon. After the procedure, inpatient monitoring is required until the first tube change on approximately the fifth postoperative day. Well-humidified gas and frequent suctioning can help to prevent tracheal secretions from becoming thick and obstructing the tracheostomy tube. This care is particularly important in the initial postoperative period because the tracheostomy has not matured yet. Other early tracheostomy complications often can be prevented or more easily treated in the hospital and include accidental decannulation and pneumomediastinum.<sup>[7] [67]</sup>

Tracheostomy-related deaths frequently are associated with obstruction, decannulation, and tube reinsertion into a false passage.<sup>[8]</sup> Appropriate teaching and home support generally can prevent such catastrophic outcomes,

and although the mortality rate for children with tracheostomies is 11% to 40%, death caused by tracheostomy events is rare.<sup>[7] [67]</sup> Thus, teaching includes tube changing and suctioning techniques; wound care; and recognition of common late complications, such as tracheal granuloma, tracheocutaneous fistula, and stomal infection. Emergency procedures, replacement of decannulated tubes, and recognition of respiratory distress are reviewed routinely.<sup>[18]</sup> In particular, supervised practice of tube replacement is vital and may proceed after the initial tube change and evaluation of stomal patency. Recommendations for changing the tube at home vary from once a week to once a month.<sup>[18] [57]</sup> More frequent tube changes may reduce the risk for tube plugging and infection and generally make the caregiver more comfortable with the replacement procedure.<sup>[50]</sup>

Tracheostomy tubes vary in composition, size, presence or absence of a cuff, and ability to be customized to specific patient needs. The tubes are made of one of three materials. Metal tubes typically have an inner cannula that can be removed for cleaning. The inner cannula increases airway resistance, however, especially in smaller patients, and metal tubes therefore are used rarely in children. Polyvinyl chloride and silicone rubber tubes are flexible or made rigid in circumstances in which external tracheal compression is an issue.<sup>[50]</sup> These tubes are generally comfortable with reduced airway resistance. Tracheostomy tubes to accommodate children of all sizes are available, and many manufacturers customize tubes to meet individual needs. Tubes may have extenders for children with short, fat necks. Swivels can be incorporated into the tube to decrease tension on the tube for children receiving mechanical ventilation. Cuffs may be added to reduce the risk for aspiration or aid ventilation in patients requiring positive end-expiratory pressure (PEEP). Two additional important variations promote translaryngeal airflow. Fenestrated tubes aid the production of speech by allowing airflow and secretions to pass through the tracheostomy tube and across the vocal cords. Fenestrated tubes may promote the development of granulation tissue at the site of fenestration,<sup>[50]</sup> however, and suction catheters may pass through the fenestration, causing injury to the tracheal mucosa. Given these potential complications, speaking valves are used in most children in whom speech is desired. These one-way valves attach to the tracheostomy allowing air to pass into the tube on inspiration and forcing air through the vocal cords on expiration. Speaking valves require a tube that does not occlude the airway, and releasing the pressure on a cuffed tube or downsizing of the tube may be necessary. Speaking valves have covers that flip open to facilitate suctioning without removal of the entire valve.

At some point, decannulation is possible for many children. Tracheostomy tubes can be downsized gradually and then capped. Alternatively, the patient may have bronchoscopy to evaluate readiness of the airway. The tube then can be removed and the patient observed in hospital overnight.

## **MECHANICAL VENTILATION**

Long-term mechanical ventilation at home has evolved tremendously from the negative pressure with iron lungs used in polio victims of the 1940s.<sup>[26]</sup> Multiple home ventilatory options are available to children with chronic respiratory failure. Negative pressure still is used in certain patients using a cuirass, and diaphragmatic pacing can be successful for patients with respiratory failure of neurologic origin.<sup>[65]</sup> Most children receive some type of positive pressure ventilation, however. Options include noninvasive positive pressure ventilation for patients not needing respiratory assistance 24 hours a day. Continuous positive airway pressure and bilevel positive airway pressure can be performed with nasal prongs, a nasal mask, or full-facemask. For patients with full-time ventilatory needs, multiple positive pressure ventilators appropriate for home use are available. Newer models have features such as internal PEEP valves and are as light as 5.6 kg. With supplemental batteries, patients now may take trips of as many as 15 hours' duration.

Technologic advances have made home ventilation easier, but the patient and family still may be overwhelmed by these new responsibilities. An organized approach to the transition home should be the top priority for the health care team and family. Patients require long-term ventilatory support for various reasons, including bronchopulmonary dysplasia, central hypoventilation syndrome, neuromuscular disease, spinal cord injury, severe scoliosis, and terminal disease states. Not all of these patients are candidates for home ventilation.

Physiologic and psychosocial criteria must be met before committing a patient and family to home ventilation, with exceptions made on a case-by-case basis.

One review of home ventilation for children outlines core guidelines for discharge to home.<sup>[30]</sup> Oxygen requirement must be less than 40%. Pco<sub>2</sub> levels should be maintained within safe limits on the home equipment and frequent ventilator adjustments should not be necessary before discharge.<sup>[14]</sup> The patient should demonstrate appropriate growth, and all other medical conditions should be stable. Numerous issues not directly related to the child's state of health also must be assessed. The family home must be evaluated for appropriate utilities and space for needed equipment. Home nursing and a contract with a durable medical equipment company providing all supplies must be arranged before discharge. Rehabilitation services and transportation arrangements must be secured, and caregivers must use and demonstrate proficiency in the use of home equipment and complete patient care before discharge. Not all patients are ideal candidates for discharge to home ventilation, but exceptions may be considered. For example, a terminally ill patient with a high oxygen requirement and other medical instability may be considered for home ventilation if all options have been discussed with the patient, family, and primary care physician.

Once home, patient goals vary. Children with chronic, stable disease, such as spinal cord injury, may not require significant change in their home ventilation. Others with progressive disease, such as neuromuscular disorders or scoliosis, may require regular reassessment of support.<sup>[34]</sup> Alternatively, many children with bronchopulmonary dysplasia require less support over time. Adjustments in the ventilatory needs of these patients should be assessed frequently by the child's pulmonologist or intensive care pediatrician.

## **ACCESS PROBLEMS WITH ENTERAL NUTRITION**

Perhaps no technology has supported the survival of more chronically ill children than advances in the provision of enteral nutrition. Enteral nutrition is the nonvolitional delivery of nutrients by a tube to the gastrointestinal (GI) tract. Chronically ill children, such as those with neurologic impairment, cancer, HIV infection, cystic fibrosis, or receiving long-term mechanical ventilation, often cannot achieve appropriate nutrition for maintenance and growth by oral intake.<sup>[35]</sup> Most of these patients, however, have an intact GI tract that properly regulates the absorption of macro- and micronutrients. Important factors in the selection of a patient for initiation of tube feeding include the impact of the underlying medical condition on the ability to take oral nutrition and evaluation of nutritional status, oral intake, and future needs.<sup>[35]</sup> Consultation with a pediatric gastroenterologist or pediatric nutritionist often aids in these assessments.

Once the decision to begin enteral feeding has been made, the issue of tube placement must be resolved. For children requiring tube feeds for more than 6 weeks, nasogastric tubes are generally undesirable. These tubes can cause sinusitis and nasal and esophageal irritation and can be dislodged easily by small or combative children.<sup>[3]</sup> Caretakers must be well trained in tube replacement, and improper insertion can lead to aspiration, particularly in neurologically impaired patients.<sup>[3]</sup> Thus, given the function of the stomach in digestion and as a reservoir gradually releasing nutrients into the small bowel, gastric feeding by gastrostomy tube is the preferred mode of enteral support for most children.

There are several gastrostomy options, and the choice depends on patient factors and caregiver training and practice. Since description of the technique in 1980,<sup>[16]</sup> however, most children have had tube insertion by percutaneous endoscopic gastrostomy (PEG). Minor modifications of the original technique have been described,<sup>[48]</sup> and some health care facilities still prefer to perform the procedure on pediatric patients who are under general anesthesia. PEG tube placement in most children is performed with conscious sedation and appropriate monitoring, however.<sup>[37]</sup> The procedure is performed with endoscopic guidance, and precautions are taken to avoid puncture of any overlying bowel. Inability to access the stomach percutaneously occurs in approximately 3% of PEG procedures, however, necessitating open gastrostomy.<sup>[56]</sup> The end result of PEG is

direct apposition of the stomach to the anterior abdominal wall, with the tube creating a stoma tract. After healing of the tract within 6 to 8 weeks, the tube often is replaced with a skin-level gastric button.<sup>[37]</sup> These devices are usually cosmetically desirable and have a one-way valve to prevent leaking.

Percutaneous endoscopic gastrostomy eliminates the laparotomy necessary with surgical gastrostomy, and retrospective and prospective analyses comparing the two techniques have demonstrated no differences in procedure-related morbidity and significant reduction in cost and recovery time.<sup>[29]</sup> <sup>[55]</sup> Peristomal wound infections within 1 month of PEG occur in 7% to 30% of patients.<sup>[48]</sup> Perioperative prophylactic antibiotic administration has reduced the prevalence of wound infection in some series<sup>[24]</sup> but not others.<sup>[28]</sup> Wound infection and many of the major complications of PEG, such as peritonitis, gastric perforation, hemorrhage, and gastrocolic fistula, often are related to mucosal ischemia as the result of excessive traction on the tube.<sup>[12]</sup> Recognition of this factor means that these complications should occur after less than 2% of PEG procedures.<sup>[12]</sup> <sup>[49]</sup> Nonetheless, caregivers should be instructed to contact the child's physician immediately for unexplained fever, unusual vomiting, gross blood or fecal matter at the tube insertion site, or formula diarrhea.

The commonest problem after PEG is gastroesophageal reflux (GER). The problem predominantly occurs in neurologically impaired children.<sup>[32]</sup> Unfortunately, preoperative, 24-hour pH probes or other studies are unable to predict which patients will develop GER after PEG,<sup>[48]</sup> and GER may improve in some children.<sup>[38]</sup> The approach to this problem in neurologically impaired children varies, and severe GER is a contraindication to PEG in some health care facilities.<sup>[27]</sup> In others, PEG is performed in all patients requiring enteral feeds, and experience to date indicates that 10% to 20% of neurologically impaired children later require fundoplication.<sup>[6]</sup> <sup>[32]</sup> Alternatively, feeding directly into the small intestine can be considered. Percutaneous gastrojejunostomy or surgical jejunostomy generally is reserved for patients with aspiration.<sup>[51]</sup> Diarrhea and tube migration requiring replacement are the predominant complications, although small bowel perforation or intussusception can occur.

Percutaneous endoscopic gastrostomy is contraindicated in children with epidermolysis bullosa given the risk for esophageal trauma and perforation.<sup>[21]</sup> Otherwise, increased complications have not been evident in children with previous abdominal surgery,<sup>[32]</sup> ventriculoperitoneal shunts,<sup>[19]</sup> or peritoneal dialysis.<sup>[45]</sup> With the appropriately sized equipment, the procedure can be performed safely in infants weighing less than 4 kg.<sup>[15]</sup> Significant scoliosis may make access to the stomach difficult,<sup>[33]</sup> forcing open gastrostomy in more of these patients.

Improvement in oral intake may allow for PEG removal for certain patients. In adults, the tube commonly is cut at skin level and the internal components allowed to pass through the GI tract. Retained internal components have been reported using this approach in children,<sup>[44]</sup> and tubes therefore are removed by traction percutaneously or, if an internal crossbar is present, endoscopically. Stomal disruption with peritonitis and visceral perforation with PEG removal have been found.<sup>[13]</sup> One report confirms that such major complications are rare, but 23% of children with a PEG tube in place for 11 or more months had a persistent gastrocutaneous fistula, necessitating surgical closure.<sup>[37]</sup>

## **FORMULA PROBLEMS WITH ENTERAL FEEDS**

The PEG tube is generally ready for use 4 to 24 hours after placement. The formula and mode of feeding prescribed must be individualized to the child's underlying condition, and consultation with an expert in pediatric nutrition is often desirable. Given many available options, choice of the most appropriate formula can be confusing. This decision depends largely on the initial nutritional assessment and factors such as age, GI function, and history of feeding tolerance. Fluid, energy, protein, electrolyte, mineral, and vitamin requirements must be considered, including provision for "catch-up" growth in malnourished children. The Recommended Daily Allowances (RDA) of these nutrients can be helpful guides, although these values were established based on the needs of healthy children. For example, compared with healthy children, neurologically impaired or

ventilator-dependent patients may require less energy but as much or more of other nutrients.

Enteral formulas can be categorized as polymeric or elemental. Polymeric formulas contain intact proteins, carbohydrates, and fats. Elemental formulas are designed for patients with malabsorption and are composed of macronutrients of low molecular weight. A formula can be categorized further based on the age of the patient for which it is designed, as infant (aged >1 y), pediatric (aged 1-10 y), or adult.

Standard formulations and volumes of available products often do not fit the requirements and limitations of individual patients. The problem is particularly common in infants. Standard dilution for infant formulas is 84 kJ/fl oz (20 kcal/fl oz). Infants with chronic lung disease, congenital cardiac disease, or renal failure often cannot tolerate the volume necessary to provide adequate nutrients, however. Options include formula concentration or the addition of modular components to prepared formula. *Concentration* means that protein, carbohydrate, and fat are provided in the same proportions as standard formula but at reduced volume. Problems include reduced urine volume to excrete the same amount of electrolytes and products of protein metabolism, also known as the *renal solute load*. If the solute load exceeds renal concentrating capacity, the child must tap endogenous sources of fluid to make urine, suffer an increase in extracellular fluid solute concentration, or both. Renal concentration mechanisms may be immature in infants<sup>[4]</sup> and further compromised in malnourished children<sup>[2]</sup> and those with chronic renal disease. The clinical consequences can be dehydration, hypernatremia, and azotemia. Thus, concentration of formula of more than 100.8 kJ/fl oz (24 kcal/fl oz) generally is not recommended.<sup>[35]</sup>

Instead, increased caloric density can be achieved by the addition of modular components. Modular addition changes the proportion of calories provided by protein, carbohydrate, and fat and must be done with caution. High fat intakes predispose to ketosis. High carbohydrate intakes may increase formula osmolality significantly. Osmolality is a function of the number of particles in a volume of fluid, and adding low molecular weight carbohydrate, particularly to elemental formulas, can produce an osmotic diarrhea. Formula osmolality of less than 400 mOsm/L in infants and 600 mOsm/L in older children generally is recommended.<sup>[35]</sup>

Special formulas have been designed for various clinical circumstances. For example, formulas for patients with renal failure provide 252 kJ/fl oz (60 kcal/fl oz) with reduced electrolyte and phosphate burdens. These formulas are designed for, and have been tested exclusively in, adults, however. No formulas specifically designed for pediatrics are available. For these children and others, modification of adult formulas may be desirable. Limited literature regarding the use of these products in children stresses the necessity of recognition of the macro- and micronutrients delivered and anticipation of the clinical consequences for a particular child.

Enteral feeds can be delivered continuously by infusion pump or as intermittent boluses. In children, continuous feeds commonly are provided predominantly at night and are therefore less time consuming than four to eight bolus feeds, each delivered over 15 to 20 minutes. Other advantages include the ability to increase the volume of delivery more rapidly and therefore reach nutrition goals more quickly.<sup>[42]</sup> Hypermetabolic children and those with GI disease also have less diarrhea, and infants with GER have less vomiting with continuous feeds. Given problems with diarrhea, children with small bowel tubes must be fed continuously. Disadvantages of continuous feeds include the expense and training required with an enteral pump. In addition, bolus feeds are more physiologic and have demonstrated improved nitrogen retention and reduced fluid and fat accumulation.<sup>[42]</sup>

## PARENTERAL NUTRITION

Parenteral nutrition is the delivery of amino acids, high concentration dextrose, lipids, minerals, electrolytes, and vitamins by intravenous (IV) access. Children with severe short gut syndrome, inflammatory bowel disease, intractable diarrhea, or other GI disease may be unable to tolerate adequate enteral nutrition.<sup>[22]</sup> These children

require partial or total parenteral nutritional support.

Chronic parenteral nutrition must be delivered by semipermanent intravenous access. These catheters are placed with tips in high-flow central circulation, usually by the internal jugular or subclavian vein. High-concentration dextrose, amino acid, and electrolyte delivery requires high blood flow for rapid dilution and maintenance of vein integrity.<sup>[31]</sup> Catheters externalized or with subcutaneous access ports generally are placed with the patient under general anesthesia. Unfortunately, catheter obstruction or infection often complicate the provision of long-term parenteral nutrition. Animal studies demonstrate that a thrombotic sheath begins formation after approximately 7 days in the central circulation.<sup>[43]</sup> In humans, one report showed ECG or echogenic evidence of pulmonary thromboembolism in 12 of 21 (57%) of infants with long-term central catheter use. If a thrombus leads to obstruction, thrombolysis with tissue plasminogen activator often restores function.<sup>[54]</sup> Heparin sometimes is added routinely to the parenteral nutrition solution, although the efficacy of this intervention has not improved catheter longevity uniformly.<sup>[1]</sup> Catheter-related infections may lead to bacteremia or involve the catheter exit site or tunnel. The risk for bacteremia likely is increased with handling of the catheter hub,<sup>[20]</sup> and many health care facilities now change intravenous sets less often than the common practice of every 24 hours.<sup>[46]</sup> Treatment of bacteremia with parenteral antibiotics sometimes can salvage the catheter. Infection recurrence often necessitates catheter removal and later replacement, however.

Precise formulation of parenteral solutions is determined by individual patient needs and disease process. Consultation with a pediatric gastroenterologist is often helpful in the initial and ongoing assessment of the parenteral solution. All solutions require basic amounts of protein, carbohydrates, and fats in proper ratios to the total energy provided to allow for positive nitrogen balance.<sup>[11]</sup> The solution also contains calcium and phosphate, but the delivery of these minerals is limited by the risk for precipitation. Carnitine may improve lipid metabolism and often is provided routinely, as are trace elements and vitamins.

Cholestasis is a common non-catheter-related complication of long-term parenteral nutrition and may lead to irreversible liver disease.<sup>[10]</sup> Patients without enteral stimulation and enterohepatic circulation of bile acids have defective biliary secretion. Treatment with ursodeoxycholic acid<sup>[23]</sup> or cholecystokinin octapeptide<sup>[61]</sup> may stimulate biliary secretion. Metabolic bone disease also may complicate long-term therapy. Studies in rats show osteopenia after just 14 days of parenteral nutrition.<sup>[39]</sup> The inability to deliver adequate elemental calcium and phosphate has a major role. Aluminum toxicity also may be important,<sup>[36]</sup> however, and vitamin D excess also has been implicated<sup>[64]</sup> because, during parenteral nutrition, vitamin D may cause bone resorption in the absence of intestinal calcium absorption. In one study,<sup>[64]</sup> the withdrawal of vitamin D from parenteral nutrition for more than 4 years did not affect bone mineral content adversely. Metabolic abnormalities related to lipid infusion also can occur. Delivery at a rate exceeding the capacity of lipoprotein lipase clearance can result in increased serum triglycerides and cholesterol.<sup>[22]</sup> In turn, accumulation of triglyceride-rich particles may disrupt pulmonary diffusion and leukocyte function.<sup>[22]</sup>

Laboratory monitoring of children receiving long-term parenteral nutrition is routine. The frequency depends on the individual patient and disease state and the duration of therapy. Monitoring includes testing of electrolytes, renal and hepatic function, glucose, triglycerides, and cholesterol. Depending on the clinical context, periodic monitoring of plasma aluminum and other trace mineral levels also should be considered.

## **DIALYSIS**

Normally functioning kidneys tightly regulate extracellular fluid volume and solute. In persons with severe renal impairment, dialysis removes excess solute and fluid and prevents uremic symptoms, such as pericarditis and bleeding. In combination with appropriate nutrition and medication, 24-month survival rate for children receiving chronic dialysis is more than 90%.<sup>[63]</sup> Approximately 1000 new patients with end-stage renal disease less than age 20 years are reported to the United States Renal Data System each year.<sup>[63]</sup>

Modalities include hemodialysis and peritoneal dialysis. Approximately 85% of adults in the United States requiring maintenance dialysis receive hemodialysis,<sup>[63]</sup> usually three treatments weekly of 3 to 5 hours' duration are required. Although most adults receive hemodialysis in freestanding units, children generally are dialyzed in hospital-based facilities. Hemodialysis in children requires appropriate equipment and pediatric-trained nephrologists, nursing, nutrition, and social work support. Relatively new advances in machine technology allow for more accurate control of fluid removal during a treatment. This and other treatment precautions reduce the risk for intradialytic hypotension and cramping. Because these problems are related directly to the proportion of a patient's total body fluid volume to be removed, however, they still are common in children and can limit fluid removal significantly. The result can be interdialytic hypertension, and 1 year after initiating long-term hemodialysis, 53% of children require antihypertensive medication.<sup>[40]</sup> Because the nutrition of infants and small children is largely fluid based, obligatory interdialytic fluid restrictions also can make achieving nutrition goals difficult.

Hemodialysis requires vascular access to achieve high-rate blood flow through the hemodialyzer. Most adult patients receive hemodialysis by a surgically created fistula, anastomosis of an extremity artery directly to vein, or graft, anastomosis of artery to vein usually using synthetic material, such as polytetrafluoroethylene.<sup>[53]</sup> A pump draws blood from one needle to the hemodialyzer, and the blood then is returned by a second needle. Unfortunately, many small children have extremity blood flow that cannot maintain fistula or graft patency and therefore must receive hemodialysis using an indwelling central venous catheter, usually by an internal jugular or subclavian vein.<sup>[47]</sup> Data from the North American Pediatric Renal Transplant Cooperative Study indicate that 76% of all children receive hemodialysis by an external catheter.<sup>[40]</sup> These catheters limit patient activities, are cosmetically cumbersome, and require rigorous care. Catheter infection is common, and as many as 50% of catheters require replacement within 1 year as the result of line related bacteremia.<sup>[58]</sup> In an effort to prevent clotting, each lumen is instilled between treatments with high-concentration heparin. Flushing the catheter before heparin removal can produce systemic anticoagulation and bleeding. Thus, hemodialysis catheters must be accessed only by dialysis personnel.

The time required for travel and treatments means that only 45% of children receiving hemodialysis attend school full-time.<sup>[40]</sup> As a result of these social and medical difficulties, only 37% of children initiating dialysis receive hemodialysis, including just 12% of children less than age 6 years.<sup>[40]</sup> The rest begin peritoneal dialysis. The peritoneal membrane is semipermeable and richly vascularized. Compared with hemodialysis, solute removal with peritoneal dialysis is relatively inefficient, but because peritoneal dialysis is performed continuously or daily, the mortality rate among nondiabetic adult patients receiving peritoneal dialysis is nearly identical to that of patients receiving hemodialysis.<sup>[63]</sup> As in hemodialysis, however, access is a major issue. Peritoneal dialysis requires placement of a catheter into the peritoneal cavity, a procedure generally performed in the surgical suite with the patient under general anesthesia. Various catheter designs are available, but most use relatively biocompatible silicone rubber with one or two fibrous cuffs. Sizes to accommodate infants, children, and adolescents are available. The catheter generally is placed through the rectus muscle lateral to the umbilicus, and placement through the rectus and pursestring suture of the fibrous cuff to the peritoneum and the anterior rectus sheath minimizes fluid leak.<sup>[60]</sup> A straight or curved subcutaneous tunnel then is created, with the catheter generally exiting laterally or downward. With healing, collagen growth into the cuff anchors the catheter and, in combination with the tunnel, provides a mechanical barrier to infection.

Prescription of peritoneal dialysis can be as continuous ambulatory peritoneal dialysis (CAPD) or automated peritoneal dialysis (APD). CAPD generally uses four or five "exchanges" of peritoneal fluid per 24 hours, with initial draining of the dwelling dialysate and immediate instillation of new fluid. Y-sets with drain and instillation fluid bags already attached minimize portals for infection and require only one attachment to the patient catheter per exchange. Given its simplicity and reduced cost, most adults maintained on peritoneal dialysis receive CAPD with 2.0- to 2.5-L exchanges.<sup>[63]</sup> The volume of dialysate bags commercially available does not accommodate children easily, however. In addition, infants and small children require that dialysate be warmed before instillation, and daytime exchanges do not accommodate school schedules easily. Thus, approximately 70% of children receive peritoneal dialysis as APD.<sup>[40]</sup> APD uses a "cycler" machine with scales



to measure and gravity to deliver a volume of dialysate. Machines are available with a minimum dwell volume of 50 mL and can be adjusted in intervals of 10 mL. The treatments generally are given at night for 8 to 12 hours. Peritoneal dialysis in children requires structured patient and family training from personnel with pediatric dialysis experience. The family and home environment must be evaluated carefully to ensure that appropriate space in the home is available and that persons performing the dialysis are able to follow competently the procedures that minimize infection and other complications. Under these circumstances, peritoneal dialysis minimizes certain disruptions of everyday life, and 77% of children receiving peritoneal dialysis attend school full-time.<sup>[40]</sup>

Potential early complications of peritoneal dialysis include fluid leak around the catheter and failure to properly drain. The latter problem may be reduced by partial omentectomy with catheter placement.<sup>[60]</sup> Patients may complain of pain, particularly with draining. Given diaphragmatic irritation, pain sometimes refers to the chest or shoulder. Fortunately, pain rarely is protracted and severe, and complaints generally subside over time. In contrast, sudden-onset, persistent pain with cloudy peritoneal fluid is the usual sign of peritonitis. Peritoneal dialysis catheter-related infection can occur early or late and is the commonest complication of the procedure. Approximately 40% of children suffer an episode of peritonitis within 1 year of catheter placement, and 60%, within 2 years.<sup>[40]</sup> The rate of infection is slightly higher in children less than age 2 years, and, in approximately 50% of peritonitis episodes, dialysate cultures grow *Staphylococcus aureus* or coagulase-negative staphylococci.<sup>[40]</sup> Patients generally respond to intravenous or intraperitoneal antibiotic therapy, but catheter colonization and damage to the peritoneal membrane lead many patients to require catheter revision or conversion to hemodialysis as a result of infection.

## FAMILY CONSIDERATIONS

Advancing technology has allowed and encouraged the care of children in the home who in the past would have been cared for in hospital ICUs. The goals of home care are increased independence of the patient and family and reduced health care costs. These advancements have brought new stress, however. Changes in the physical structure of the home, changes in the family budget, and new roles and interactions add stress to families, many of whom believe that this aspect of care is not appreciated by the health care system.<sup>[41] [52] [66]</sup>

Financial burdens and stress are common among families with technology-dependent children.<sup>[9] [41] [66]</sup> Although third-party payers may decrease costs with the patient at home, some of these costs are transferred to the family. Lost work time because of reductions in nursing care, travel to medical appointments, and lobbying for continued benefits all can have financial impact. One investigator has described increased depressive symptoms in lower socioeconomic families of technology-dependent children.<sup>[25]</sup>

Physical changes in the home are a source of stress. Many homes need modification with wheelchair ramps; rewiring; or other modifications for ventilators, oxygen cylinders, wheelchairs, and monitors. New roles within the family also must be assumed. Parents must work and care for siblings and also be nurses, respiratory therapists, and equipment technicians.

Frustration, anxiety, and fear are also sources of stress for parents. Fear is a repeated emotion reported by parents of technology-dependent children.<sup>[41] [52] [66]</sup> Parents report frustration over funding, anxiety in performing painful procedures on their children, and fear of not hearing an alarm and finding their child dead.<sup>[52]</sup> Changing personal interactions of family members also adds stress. Nursing personnel in the home and a lack of privacy can inhibit expression of emotion between family members. Differences of opinion among family and nonfamily caregivers can alter the power structure within the home. Siblings may feel isolated or less important in the family compared with the technology-dependent child.<sup>[66]</sup>

Despite the many negative stresses associated with the home care of technology-dependent children, there are

many positives. Some technology-dependent children attain a degree of independence and normalcy, returning to school and other activities. Learning tolerance of other people and feeling more knowledgeable about medical information are positive aspects reported by family members.<sup>[66]</sup> Ultimately and most important, these children are reunited with their families at home.

## SUMMARY

Improvements in the provision of oxygen, mechanical ventilation, tracheostomy care, enteral and parenteral nutrition, and dialysis have expanded the population of technology-dependent children. This article attempts to review pertinent points regarding these services, including common complications. Primary care and subspecialty physicians must smooth the transition of these children to the home environment, but a comprehensive team approach is necessary for the recognition of medical complications and provision of appropriate family teaching and psychosocial supports.

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