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Care of the Child Assisted by Technology

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Objectives  After completing this article, readers should be able to:

1. Describe children who are dependent on technology.
2. List common indications for and complications of gastrostomy tubes.
3. Define invasive and noninvasive mechanical ventilation.
4. Recognize the psychosocial effects of having a child dependent on technology.

Introduction

Over the past 30 years, care for children who have life-threatening conditions has become more sophisticated. As a result, a new population of children who have special health-care needs has evolved: those assisted by medical technology. By definition, such children have a chronic condition that requires daily assistance by a medical device to replace or augment a bodily function to sustain life. (1) Such technologies allow children who previously would have required highly specialized care in a hospital to live at home. Understanding the scope of this population, general concepts, trends, and complications associated with some of the technologies themselves, along with the psychosocial aspects of caring for children assisted by technology at home, is critical for the pediatrician providing a medical home for this growing population of children.

Who Are Technology-dependent Children?

Results of a recent national survey indicate that nearly 13% of children in the United States have special health-care needs. (2) These are children who “have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.” (3) Approximately 50% of these children (6.5% of children nationally) have a disability that impairs their functional daily living. Detailed statistics relating to children dependent on technology are more challenging to obtain; estimates indicate that they comprise 0.16% of the population. (4)

The types of technologies on which children who have complex needs rely vary substantially. (5) Among the most common are forms of respiratory support, such as supplemental oxygen or mechanical ventilation with or without tracheostomy. Other technologies include mechanisms to support nutrition, such as gastrostomy and jejunostomy tubes. Semipermanent venous catheters also are relatively common. Additional examples include but are not limited to enterostomies, bladder catheterization, and renal dialysis. Dependence on such technologies requires regular monitoring by trained personnel as well as education of a child’s caregivers. The children who require these technologies are very diverse and have conditions relating to sequelae of prematurity; neuromuscular disorders; genetic syndromes; congenital anomalies; and complications of injury, infection, and illness. At times, the cause is unclear.

Children assisted by technology are becoming increasingly visible in the community as they leave tertiary care medical centers to live at home. Home care offers many benefits to the child and family. In addition, increases in home care may reduce health-care costs by avoiding lengthy and complex hospitalizations. Most primary care clinicians have several patients assisted by technology in their practices for whom health surveillance, care coordination, and effective advocacy are important.

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Specific Technologies
Among children dependent on technology, some of the devices encountered most commonly support nutritional needs, vascular access, and respiratory concerns. Although an in-depth review of these technologies is beyond the scope of this article, a brief review of indications and complications is warranted.

Nutrition Support
Enteral nutrition has had a tremendous impact on the survival of children afflicted by complex and chronic illness. Enteral feeding allows for passive provision of nutrition directly into the gastrointestinal (GI) tract and is the preferred method of providing nutrition support for patients who cannot eat but who have functional GI tracts. Reasons for dependence on enteral nutrition are wide-ranging but have in common an inability to consume adequate calories to maintain reasonable nutritional status. Neuromuscular disease may be associated with poor oromotor coordination, ongoing risk of aspiration, prolonged feeding times, or oral aversion, all of which can lead to poor weight gain. Other impairments may include systemic illnesses, such as cancer. A variety of formulas are used to address unique patient needs, such as decreased bowel length or diminished intestinal absorption.

A nasogastric tube may be all that is required if a child needs enteral feeding short-term (eg, less than a few months). Longer placement of a nasogastric tube may result in complications such as oral aversion, sinusitis, breakdown of local tissue, and esophageal irritation. If a more sustained need for enteral nutrition is identified, gastrostomy tube placement is a likely option. This generally is achieved by percutaneous endoscopic gastrostomy (PEG) placement, although individual patient characteristics may necessitate open surgical placement. The original tube may be replaced by a medical practitioner after the stoma tract heals, usually after several months. If a PEG tube is dislodged prior to the first change, the replacement tube should not be used until correct placement is confirmed by contrast study. A skin-level gastrostomy button is the most common replacement, although a variety of devices are available.

Establishment of a gastrostomy tube generally allows provision of a child’s full caloric and hydration needs through this conduit. Feeding regimens are highly individualized and may include various combinations of boluses and continuous feedings. Some children receive gastrostomy feedings only at night. Promotion of oromotor skills often is encouraged for the child dependent on a gastrostomy tube. If a child can eat safely by mouth without risk of aspiration, there may be no contraindication to oral feedings. Maximal oromotor development can be fostered by encouraging oral feeding prior to the initiation of a bolus, using hunger as a drive to practice oromotor skills. Nutritional follow-up for adjustments in energy goals and formula choice varies, depending on a child’s growth trajectory and dietary needs.

Gastroesophageal reflux disease may be exacerbated by gastrostomy tube placement, necessitating additional intervention if medical management fails. One of the serious risks of ineffectively treated reflux disease is aspiration of gastric contents and recurrent pulmonary infection. Treatments include placement of a gastrojejunostomy tube to provide postpyloric feedings, fundoplication with or without pyloromyotomy to expedite gastric emptying, and rarely, surgical placement of a jejunostomy tube.

A number of common mechanical complications are associated with gastrostomy tubes and include dislodgment of the tube, deterioration of the tube itself (including balloon rupture), skin infection, leakage, development of granulation tissue, and tube migration, which can cause gastric outlet obstruction. If a gastrostomy tube becomes dislodged, it must be replaced within a few hours to prevent significant stricture of the stoma. If a replacement gastrostomy tube is unavailable, a bladder catheter can be substituted on a temporary basis.

Education of caregivers by specialists in gastrostomy care can decrease the risk of the most common complications dramatically. Routine examination of the site, daily cleansing of the skin with soap and water, flushing and rotation of the tube, and regular tube changing (at least every 3 months) are imperative to maintain optimal condition of the stoma and function of the tube. In addition to learning gastrostomy care and administration of feedings, parents must watch for common problems such as leakage, tube blockage, and balloon deflation. Parents must know how to replace a gastrostomy tube.

Some children who are unable to consume adequate nutrients by oral or enteral routes may require parenteral nutrition (PN). This is achieved with a carefully balanced solution of dextrose, amino acids, lipids, electrolytes, vitamins, minerals, and trace elements administered intravenously. Children who may require partial or full parenteral support include those who have short bowel syndrome, malabsorptive states, inflammatory bowel disease, severe dysmotility states, and other less common GI disorders. Among the direct complications of PN are cholestasis, osteopenia, and metabolic derangements. Outpatient management of the child receiving chronic PN requires the support of a specialty team as well as
regular nursing in the home to oversee care and monitor for signs of complication. The appropriate PN formula generally is determined under the guidance of a nutritionist or gastroenterologist. Routine laboratory monitoring is required.

**Venous Access**

Indwelling venous catheters are used for many purposes in addition to the provision of PN, including administration of chemotherapy, medications required for a prolonged period of time (e.g., pain medications), and transfusions. Venous catheters also allow venous access in children who have poor peripheral access yet may need frequent laboratory testing. Indwelling catheters may become infected or have mechanical complications. Infection may be localized or associated with systemic bacteremia. If bacteremia is documented, the catheter often must be removed until the infection has cleared. Occlusion may result from the growth of a fibrin sheath around the intravascular portion of the catheter. A one-way valve effect may be observed, allowing catheter infusion but preventing blood withdrawal. A radiopaque dye study can help to delineate the situation. Thrombotic obstruction sometimes can be remedied with a fibrinolytic agent.

**Respiratory Support**

The most common form of home respiratory support is supplemental oxygen, which may be required for a transient period (in the patient recovering from pneumonia) or for long-term usage (in the child who has chronic lung disease). Mechanical ventilation becomes a consideration when a child exhibits chronic respiratory failure. The primary reasons that children may need mechanical ventilation include neuromuscular disease, central hypoventilation, upper airway obstruction, and chronic lung disease.

Methods of providing mechanical ventilation can be noninvasive or invasive. Noninvasive ventilation allows for ventilatory assistance without establishing an endotracheal airway and has included external devices that generate intermittent negative pressure (e.g., “iron lung”). The current modes of delivery, however, generally involve the application of positive pressure via nasal device or face mask. Often, noninvasive ventilation is used for patients who require support only nocturnally or intermittently.

The most common types of ventilator support include continuous positive airway pressure (CPAP) and bilevel positive airway pressure (BiPAP). BiPAP provides a higher inspiratory pressure and a lower expiratory pressure and may include a rate. Invasive long-term mechanical ventilation requires the creation of a tracheostomy to allow for support with positive pressure. A range of positive-pressure portable ventilators now exists for home use. Despite the logistic feasibility of setting up home mechanical ventilation, the realities for the family are complex, and the importance of extensive education and preparation cannot be underestimated.

Tracheostomies may be placed to accommodate long-term positive pressure ventilation, but they also may be needed to alleviate upper airway obstruction caused by congenital malformation or neuromuscular causes or to allow for more effective pulmonary toileting. In these circumstances, mechanical ventilation may not be necessary. Common long-term complications of a tracheostomy include cannula obstruction, accidental decannulation, recurrent tracheitis, suprastomal obstruction, tracheal ulceration or granuloma, persistent tracheocutaneous fistula, and hemorrhage.

The parents of a child who has a tracheostomy must be able to assess respiratory status and perform tracheostomy hygiene, suctioning, and tube changes. They also must be prepared for emergencies, such as decannulation. All caregivers should undergo cardiopulmonary resuscitation education. It is important to notify local emergency medical services if a child in the community has a tracheostomy or is ventilator-dependent so these services are aware of the child’s specialized medical needs. Local power companies and any snowplowing agencies should be aware of where a child dependent on a ventilator resides. Backup power should be available.

Children receiving mechanical ventilation can be integrated successfully into the school setting, but the child must have a trained caregiver accessible who can assess respiratory status and suction and change the tube. Some children can use a speaking valve with their tracheostomy tube to facilitate communication. Some may be able to vocalize around an uncuffed tracheostomy tube or even one that is cuffed but partially deflated. The ability to speak has tremendous developmental value and promotes independence.

From the standpoint of the primary care practitioner, children who have tracheotomies require continuous monitoring of their respiratory status. A high level of home nursing care may be necessary to maintain good pulmonary toilet. A child who has a tracheostomy may be more prone to respiratory infections caused by organisms that bypass the defense mechanisms of the upper airway. The tracheostomy may become plugged if secretions are
not humidified adequately. Children assisted by technology often are vulnerable to respiratory decompensation in the setting of infection. For children younger than 2 years of age who meet criteria, palivizumab administered monthly during the winter viral season can provide passive protection against respiratory syncytial virus.

**Psychosocial Issues**

Children dependent on technology may not appear “different” from peers. Some technology is relatively easy to conceal, such as enterostomies, gastrostomy tubes, and central venous lines, but ventilators are not. Playmates and peers may not understand the equipment or the child’s need for privacy to perform some procedures, such as catheterization.

Being different from one’s peers is especially stressful for adolescents. Issues of body image, independence, and identity may be exacerbated in those assisted by medical technology. At any age, the underlying condition or the technology may make participation in regular childhood activities difficult. Care must be taken to foster independence in all children assisted by technology, including those who have continual one-to-one assistance.

Families caring for children assisted by technology at home require support. Many studies have looked at the effects on caregivers, and results indicate a range of mixed benefit and concern. Much of the quantitative research applies more to children who have a chronic disability or illness, but there is a growing body of qualitative work that evaluates the psychosocial impact of caring for a child assisted by technology.

Evidence points to improvement in children’s physical, emotional, psychological, and social development when they are managed at home. Caregivers also benefit from the transition in focus from acute care to convalescence and return to routine family life. However, having medical technology at home can alter the sense of what “home” is, with the addition of new machines and sounds blurring the distinction between hospital and the familiar safety and comfort generally associated with home. The conflicting themes of “distress and enrichment” complicate all aspects of life and can be overwhelming. (6)

Caregivers report anxiety associated with the sense of responsibility for managing many aspects of the child’s medical care in the home and express concern about the possibility of a medical emergency. Changing medical and technical needs of the child may exacerbate such tension. Mothers of children assisted by technology have impaired health related to pain, social functioning, and mental health and demonstrate substantially more depressive symptoms than do mothers of children who are not assisted by technology. Physical exhaustion is compounded by emotional exhaustion, and social isolation frequently is identified. (7)(8)

Caregivers report that health-care professionals do not always recognize the emotional complexity of the caregivers’ lives or the level of sophisticated skill mastery achieved in caring for their technology-dependent children. Caregivers need respite and advocacy. Unfortunately, achieving respite in this population is not always easy. Many barriers to child care exist. Simply finding a babysitter can be remarkably challenging because a child assisted by technology often requires skilled management. Common strategies used by families to address these unique stressors include relying on a supportive network of family and friends, seeking spiritual support, and seeking contact with other families in similar circumstances.

**General Management Principles**

In addition to providing routine pediatric well-child care aimed at sustaining overall health as well as addressing issues specific to the child’s medical technology, the pediatrician must work with the child’s parents to provide family-centered care in a medical home to foster growth and development, consistent with national health goals described by the United States Department of Health and Human Services in the Healthy People 2010 objectives. (9) Continual communication among team members along with care coordination are critical and allow for the most complete, efficient, and sensitive care of the child. Such a team approach is likely to be cost-effective, reducing duplication and fragmentation of services because the model encourages communication between the physician and all other team members. For children dependent on technology, this model has particular relevance because the number of subspecialists and therapists involved in the care of these children can be substantial.

Some families may live in the vicinity of a clinic or tertiary care center that provides comprehensive care for children who have complex needs, often in association with an academic institution. Such centers may offer multidisciplinary care that includes social work and case management in addition to broad-spectrum specialty expertise. Primary care is offered in some of these venues; others offer the opportunity for community practitioners to work collaboratively with specialists.

Many children dependent on technology receive centralized care through their community pediatricians. For many practitioners, the realities of providing this ideal
comprehensive care can be challenging. A busy office schedule may not accommodate the prolonged visit time that complex patients require, reimbursement continues to fall short of the effort and time put forth by practitioners, and knowledge among staff members about the best community resources to address the medical and psychosocial concerns may be incomplete. Home visits may be appropriate for some children dependent on technology, but few practices have the resources to conduct them.

The pediatrician often is called on to advocate for school placement of children assisted by technology who may require continuous and extensive levels of skilled care. The federally mandated Individuals with Disabilities Education Act (IDEA, 1990) and Supreme Court rulings, including Tatro versus Irving School District (1984) and Garrett versus Cedar Rapids (1999), create opportunities for children assisted by technology to participate in school settings. Children who have special health-care needs may require special instruction, classroom arrangements, equipment, therapies, and in-school care. In all cases, children should have access to an appropriate, safe educational placement that allows for the least restrictive environment possible. Children spend a large percentage of time at school, which provides the opportunity for socialization and skill development.

Resources are growing to assist the primary care practitioner and specialists in providing a medical home. Operational definitions of the medical home have been refined by the American Academy of Pediatrics Council on Children with Disabilities. (10) Concrete approaches to creating a medical home can include identifying children who have special health-care needs within a practice; seeing patients for longer, more frequent visits; reviewing input from specialists; using assessment tools to identify the need for community resources; and creating a roster of useful resources for the office. (11)

Review of how well pediatricians are doing nationally at meeting the Maternal and Child Health Bureau’s core outcomes for children who have special health-care needs has revealed success rates generally exceeding 50%. (12) However, much work lies ahead, particularly around transition to adulthood, accessibility of services, and coordination of care. In 2007, employers, insurers, and practitioners formed the Patient-centered Primary Care Collaborative to promote greater access to medical homes for both children and adults because of the recognition that the medical home approach is effective at meeting the complex concerns of patients who have complex medical conditions. (13)

Prognosis
Children dependent on technology comprise a diverse group. As a result, their patterns of dependence also are diverse. Some technologies are used temporarily to enhance or replace a physiologic function until the child is old enough to undergo corrective surgery or “outgrows” the need. For example, children born with severe congenital malformations of the head and neck, such as those who have Pierre Robin syndrome, lymphatic malformations, or syndromes involving craniofacial or airway differences, frequently need to overcome their upper airway obstruction with tracheostomies for several months to years, but many ultimately can be decannulated. The long-term survival of children treated with mechanical ventilation is influenced primarily by the underlying disease. Children afflicted with chronic lung disease caused by prematurity tend to do very well, with eventual weaning from the ventilator and progression to decannulation in most cases. This process is performed gradually through downsizing of the tube, eventually capping it under strict medical guidance. Infants who have necrotizing enterocolitis may require enterostomies that are closed within a few months or a year. Children unable to eat by mouth because of anatomic problems such as esophageal atresia may require gastrostomy tubes for several months until their atresia has been repaired. Children undergoing intensive chemotherapy regimens frequently have central venous lines that are removed once the course of chemotherapy is completed.

Other technologies are necessary for long-term use by children who never will gain the function that the technology provides. Children who have progressive neuromuscular disease or high cervical spine injuries may need permanent mechanical ventilation and the oversight of a pulmonologist. Children who have neurogenic bladders from myelodysplasia or spinal cord injury require bladder catheterization several times a day. A gastrostomy tube may be required when there is dysphagia caused by neuromuscular involvement in cerebral palsy. Children who have short bowel syndromes may be treated with hyperalimentation.

Websites for Families
Aaron’s Tracheostomy page, featuring nuts and bolts information for families who have children who have tracheostomies. Available at: www.tracheostomy.com
Kids With Tubes, featuring nuts and bolts information for families who have children who have gastrostomy tubes. Available at: www.kidswithtubes.org
Summary

- Children assisted by medical technology represent a growing and diverse subgroup who have special health-care needs and chronic illnesses.
- As advances in medical interventions, surgical techniques, and technology applications continue, devices such as gastrostomy tubes, tracheostomies, central venous catheters, and ventilators will continue to be used for this small group of children, both temporarily and chronically.
- Through the development of innovative practices, primary care pediatricians have the opportunity to coordinate and manage the care of such children, who require frequent contact with specialists and tertiary care medical centers, but who must thrive at home and in the community.
- Based on strong research, families of children assisted by technology experience significant psychosocial effects when caring for their children at home.
- Based on some research and consensus, children who have special health-care needs benefit from obtaining care through a medical home.

References

13. Patient-centered Primary Care Collaborative website. Available at: http://www.pcpcc.net/
PIR Quiz
Quiz also available online at pedsinreview.aappublications.org.

25. Which of the following is a relatively common complication of nasogastric tube feeding?
   A. Duodenal ulcer.
   B. Facial cellulitis.
   C. Otitis media.
   D. Sinusitis.
   E. Tonsillitis.

26. Which of the following is a true statement about gastrostomy feedings?
   A. Children who have gastrostomies should not be fed by mouth.
   B. Gastrostomies can cause gastric outlet obstruction.
   C. Gastrostomy tubes should be changed annually.
   D. Oral feedings should be attempted within 30 minutes after a gastrostomy feeding.
   E. Patients who experience reflux after placement of a gastrostomy require fundoplication.

27. Mothers of children assisted by technology have:
   A. Decreased rates of anxiety.
   B. Higher incidences of depressive symptoms.
   C. Improved social functioning.
   D. Increased access to babysitters.
   E. Increased physical energy.

28. The Individuals with Disabilities Education Act (IDEA) stipulates that:
   A. Children who have disabilities have access to an appropriate educational placement in public schools.
   B. Children who have disabilities have access to legal advocacy services.
   C. Communications between the physician and school are confidential.
   D. Nursing care be provided in the school for children who have gastrostomies.
   E. Physicians are legally required to communicate medical information to the school system.