early 20 million of our nation’s children suffer from at least one chronic illness, such as asthma, diabetes, seizures, cerebral palsy, cancer, spina bifida or HIV/AIDS, accounting for 90 percent of all pediatric health expenditures, yet representing just 5 percent of the pediatric population. Given the current level of ever escalating health care costs, managing those costs is a high priority for state and federal governments, employers, and families. Technology is increasingly considered as one of the ways to address quality of care and cost issues associated with children with chronic conditions like asthma or life threatening illnesses, such as cancer or HIV/AIDS.

Asthma, for example, is one of the most common chronic childhood diseases, affecting around five million children in the U.S. In 1995, children were hospitalized for asthma 170,000 times, at a cost of $387 million. Asthma also leads to 10 million missed school days each year.

Electronic pediatric personal health records are especially useful for families with chronically ill children as a way to keep track of test results, images, and information about health status, often from a myriad of health care practitioners and hospital stays.

A study done by Dr. Rob Rose, in conjunction with the American Association of Pediatrics, Section on Home Care, compared prices of several different patient case studies. In the care of a five year-old child receiving infusion therapy and requiring daily IV antibiotics for two weeks, the cost of taking care of the child at home was $3,725, while having the child stay in the hospital for two full weeks, receiving the same treatment, cost around $12,750. Not only is a nurse at the home more cost-effective than ten days at a hospital, there is also the added benefit of less disruption to the child and family’s daily life, and better health outcomes for the child.

Advances in information technology are improving the lives of families with chronically or terminally ill children, or children with disabilities by virtue of electronic asynchronous communications, or email, which offers families an opportunity to pose non-urgent questions to clinicians and, in return, offers families peace of mind knowing that their questions will be addressed.

For asthma, the Agency for Healthcare Research and Quality (AHRQ) at the U.S. Department of Health and Human Services (HHS) funded a study that used Telephone-Linked Communications for Asthma (TLC-Asthma) for children suffering from symptomatic asthma. TLC-Asthma is a computer-based telecommunication system that monitors, educates, and counsels asthmatic children and their parents through regular, automated interactions. This type of “TLC” technology has been useful for adults suffering from chronic disease, and many see it as a chance to help children and their families cope with the daily affect of asthma.

Telehealth services, such as remote patient monitoring, provide real-time data or alerts a provider and/or family member when a health indicator, such as changes in glucose levels or heart rate, shows a change outside the established parameters. Two-way interactive video allows providers to “see” a patient in real-time. Studies have shown telemedicine is actually better health outcomes by capturing, storing, and giving providers the opportunity to later reexamine images, such as a child’s eardrum, allowing critical comparisons over time. The benefits of telemedicine for families and providers are considerable, creating fewer disrup-
tions to the child’s routine and requiring less travel time, which is particularly important for families living in rural, geographically remote or isolated locations.

Electronic pediatric personal health records are especially useful for families with chronically ill children as a way to keep track of test results, images, and information about health status, often from a myriad of health care practitioners and hospital stays. Having all of the child’s health information in one place, dramatically reduces the need for duplicative tests because the results were lost or unavailable at the time of the visit. We can reduce health care costs by merely having the right information at the right time. Personal health records are evolving and soon we will have access to our health information electronically via “smart card” technology similar to a bank ATM card. This technological advance will allow the families of chronically ill children to have this important health information with them at all times.

Congress is also taking notice of the need for home-based pediatric care for chronically ill and disabled children. Earlier this year, Senator DeWine and Congresswoman Pryce introduced the Children’s Compassionate Care Act of 2005 (S174 and HR963) that authorizes funds for palliative care for children, specifically allowing the grants to be used to “support communication linkages and care coordination, telemedicine and teleconferencing, and measures to improve patient safety.” The proposed legislation provides grant funds for additional research, and authorizes the National Institutes of Health (NIH) to hire and train more physicians and nurses in pediatric palliative care.

Clearly, caring for a child at home is stressful, and affects every member of the family. Yet, advances in technology can make home care more effective, help the child have better outcomes, and lowering overall health costs -- a good step in reducing stress that families may feel while caring for a chronically ill or disabled child. Home care is becoming increasingly more popular for families and their chronically or terminally ill children and simply put, a better choice overall.

---

About the Author: Robert J. Waters, JD, is a partner with the firm of Gardner Carton & Douglas. He is also Counsel, Center for Telemedicine Law, and Executive Director, Home Care Technology Association of America. Mr. Waters can be reached at rwaters@gcd.com.