Caring for chronically ill kids
Many parents are struggling to manage their children's care. Here's why.

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It’s the news no parent wants to hear: Your child has been diagnosed with a chronic, potentially life-threatening illness.

Lucky, treatments for diseases like asthma, diabetes and cystic fibrosis have made these diseases manageable. But the latest research on parents' involvement in children's chronic illnesses indicates that parents may be struggling to find a balance between letting their children take responsibility and letting go too soon, which puts their children at risk for medical complications that can lead to hospitalization.

When this under-supervision occurs, it can be for a number of reasons, psychologists say: a lack of understanding about a disease, the potential for the primary caretaker to become depressed and ill-equipped and, in later years, a parent who is simply worn out by teenage rebellion. Parents, it seems, may be giving over the child's care to the child too early, says Suzanne Bennett Johnson, PhD, a Florida State University School of Medicine professor and APA's 2012 president.

"We do have some parents who stymie the child by exerting too much control, but there's a clinician's fallacy about the over-involved parent," she says.

What parents and health-care providers need, she and others say, are more realistic expectations of children's abilities to manage such illnesses.

Lack of understanding
Psychologists and physicians can begin to address this problem by making sure the parent and child understand the severity of the illness and the potentially fatal impact of not treating it thoroughly, says Johnson.

That can be difficult when the child’s symptoms are not consistently present, says Kristin A. Riekert, PhD, who co-directs the Johns Hopkins Adherence Research Center. In a 2003 study in Pediatrics (Vol. 111, No. 3), Riekert and other researchers at Johns Hopkins University looked at asthmatic children in Baltimore elementary schools to see which parents were giving the physician-prescribed asthma medication. They found that poor communication between a physician and the primary caregiver led to the child’s underuse of asthma medicines. In addition, they found that caregiver beliefs about asthma management were the most significant factor in whether the child's medication protocol was followed. In addition, a lack of time during a meeting with a physician was often cited as the main reason for poor communication — indicating physicians need to spend more time explaining the disease and the treatment.

Health-care providers also need to remember that with diseases like asthma, the parent wants to see a difference when a child uses a medication, Riekert says. A child may skip using his inhaler for a few days and appear fine, for example, and the parent may believe that he or she doesn’t really need it. "It’s not uncommon to see a reaction of 'no symptoms, no asthma,' among inner-city families," Riekert says.

This dynamic also can be true of epilepsy. Avani Modi, PhD, assistant professor of pediatrics at Cincinnati Children’s Hospital Medical Center, is conducting a five-year study funded by the National Institutes of Health that examines adherence to anti-epileptic medications for children with new-onset epilepsy. She says some parents may fail to give the child his or her medications on a day-to-day basis, but then administer the medication each day right before seeing the child’s physician — the phenomenon known as white-coat compliance.

"This can be dangerous with epilepsy as the physician measures the drug levels every time the child goes in [for a clinic visit]," says Modi. "If the parent has just started giving the medication, it may not be indicative of what is going on most of the time and clinical decisions may be made on this false level."

So far, her data indicate that roughly 40 percent of children newly diagnosed with epilepsy adhere almost religiously to the medication protocol, with 13 percent completely dropping off and the other 47 percent taking medications only some of the time. The only medical/sociodemographic factor that correlates with adherence is higher socioeconomic status — nothing else, including the epilepsy type or medication, matters.

Adolescent turmoil
No matter which chronic illness a child has, adherence falls off around adolescence, researchers say. Teenagers yearn for privacy, and resent their parents asking them to keep their bedroom or bathroom doors open in case of a medical emergency. "There is growing evidence that the patient, family and health-care team need to anticipate, in a collaborative manner, how care will be handled during adolescence," says Anne E. Kazak, PhD, a professor of pediatrics in the University of Pennsylvania School of Medicine. "At the end of adolescence, after all, most teens will be more autonomous in general as they enter early adulthood."

Plus, after what can be as long as a decade of dealing with a child’s chronic illness, parents may be tempted to turn over the medical management once the child hits 13.

"That may not be developmentally appropriate," Modi says. While adolescents are old enough to understand a disease, she says, often they do not see the consequences of ignoring the treatments.

"With a disease like CF, an hour a day of medication and therapy takes them away from their social activities, from their friends, from their clubs. It’s not malicious, but they forget to keep up and the consequences can be serious," she says.

Parents may think they need to lay off nagging their teens to take along their insulin to a friend’s house or packing their inhaler before a day out. Riekert remembers a teenage CF patient who went on at length about how much he hated his parents nagging him. When she asked what would help him manage his CF, he grumbled, and said, “for them to bug me.”

"It can be accepted as a necessary evil," Riekert says.

Parents and medical teams don’t understand that the parent doesn’t have to set up the treatment," she says. "We need to remind the parent how important their presence is. It’s like a child sitting at the kitchen table doing his homework — he is more likely to do it if the parent is there.”

What else improves adherence among teens? More time with mom and dad, according to a 2006 study by Modi and Quittner published in the Journal of Pediatric Psychology (Vol. 31, No. 8). In the study, they asked adolescents about barriers to adherence and what would motivate them to be more compliant.

"We have been very surprised — often when a child is asked what he or she would like to receive as a reward, it’s a special outing with his or her mother or father," Quittner says. "It’s important to spend that time together.”

Modi encourages parents to think of their child managing his illness as a process akin to learning how to drive.

"There needs to be a learner's permit," she says. "At some point, you let go, but there needs to be a bridge to the child managing his or her medication. We work with parents on that so by the time the child is 17 or 18, they can relinquish control.”

Depression and anxiety
One of the more common challenges parents face when managing the care of their chronically ill children is that they simply may not have the ability to cope. "Generally, the research shows that when moms are depressed, adherence will go down," Johnson says.

New insight on that problem is coming from the first large-scale international study to evaluate levels of depression and anxiety.
among children with cystic fibrosis and their parents.

The study evaluated nearly 1,000 mothers and 182 fathers.

"What we are seeing is that 30 percent of [mothers] meet the clinical criteria for depression ... double the rate of a regular sample," says Quittner, principal investigator for the study, known as the TIDES International Depression/Anxiety Epidemiological Study.

The study also found that more than 55 percent of the children's primary caregivers were anxious. These parents feel isolated and stressed by such challenges as obtaining insurance when a child has a pre-existing condition and the financial strain of co-payments for doctors' visits and medications.

In particular, says Quittner, "mothers often don't get enough support from their spouse and they end up handling the load."

The preliminary results of her study indicate that health-care providers need to spend more time evaluating depression and anxiety. "We are going to recommend annual screenings of both children with CF and their parental caregivers for anxiety and depression, and recommend paths for intervention," Quittner says.

Guiding these parents toward treatment will likely improve their child's health.

The other good news for struggling parents is that the difficult years of a child's illness can make the family stronger, Johnson says. A 2006 study in the Journal of Pediatric Psychology (Vol. 31, No. 4) by researchers Lamia P. Barakat, PhD, Melissa A. Alderfer, PhD, and Kazak, indicated that adolescent cancer survivors and their mothers reported at least one positive outcome stemming from the illness, with 86 percent of mothers saying that cancer "had a positive impact on how they think about their lives."

"There's a tendency to assume that a chronic illness will be a negative experience for the family," Johnson says. "While it is stressful, families are quite resilient, and psychologists should emphasize that."

It's also important for health-care providers to be sympathetic to parents. Even when efforts fall short, parents are dedicating a major chunk of their lives to managing their child's illness, says Kazak. "Most families are doing the best they can," she says.