Eleven-year-old Deborah Brown lined up 12 pills. It was a potent mix of medications, including secobarbital, phenobarbital and methaqualone. Even a small mistake in dosing could be fatal. The pills were for Deborah’s mother to be taken every six hours to ease the pain of aggressively metastasizing cancer.

Deborah frequently cut school to make sure her mother was all right. One day, she found her passed out and bleeding.

“The day I found my mother in the bathtub, I thought I had killed her,” Deborah said.

But her mother had a pulse, and Deborah helped her into bed. Despite the trauma, Deborah continued to help care for her mother, in addition to cooking, cleaning and minding two younger brothers.

Deborah was 12 when her mother died. Her father took on extra hours at work to pay the medical bills, so she continued to run her family’s household.

“My parents always used to joke that I would be the first female astronaut,” Deborah said. “But then my grades started going down.”

Although Deborah felt alienated from her friends and community, she was not alone in her role as a caregiving youth. A 2005 study by the National Alliance for Caregiving found that 1.3 million to 1.4 million youths in the United States provided ailing family members with substantial physical and/or mental assistance, helping with everything from mobility assistance to administering medication, according to a 2005 study by the National Alliance for Caregiving.

Support for caregivers

Instrumental in serving these children is the Caregiving Youth Project, which provides skills-building groups in schools, family strengthening, community resource referrals, computer access, tutoring and extracurricular activities.

The project is under the auspices of the American Association of
Caregiving Youth (AACY), which was founded in 1998 by Connie Siskowski, R.N., Ph.D. As a teenager, Dr. Siskowski cared for her grandfather. Upon learning that many other nations have support systems for caregiving youths, Dr. Siskowski pioneered the United States’ first program dedicated to serving youths under the age of 18 who care for ill, elderly, injured or disabled family members.

AACY works to raise awareness in the spheres of education, community and health care. By encouraging teachers and advocates to look for external factors that may cause students’ academic troubles, the need for at-home assistance can be identified early. Students who are caregivers often attend school fatigued, unkempt and without homework completed.

“Because they are ‘parentified’ in their home lives, caregiving students may have trouble adjusting to authority figures at school,” said Dr. Siskowski, adding that this can cause behavioral issues.

Dr. Siskowski pointed to communities’ ignorance of caregiving youths’ social, emotional and academic challenges because their lives may look typical. Additionally, parents who rely on their children might fear being labeled as “bad” parents. This stigma can prevent them from seeking help.

Improvements in health care also mean more advanced medical technology is available to those cared for at home, Dr. Siskowski said. While the equipment can be life-saving, the burden of care can fall to family members because they can’t afford private health care personnel.

Both Dr. Siskowski and Dr. Belkowitz urge medical professionals to help identify and raise awareness of caregiving youths.

“One of the most important things pediatricians can do is to ask children about the health status of other family members. Ask what roles the child is taking on at home.”

— Julia L. Belkowitz, M.D., FAAP

Dr. Siskowski

For more information about the American Association of Caregiving Youth and the Caregiving Youth Project, visit www.aacy.org/.

Dr. Belkowitz

RESOURCE
More than a million youths taking on caregiving role need support to shoulder heavy responsibilities

Mary McGrath

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'Hidden population'

More than a million youths taking on caregiving role need support to shoulder heavy responsibilities

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