

## 'Hidden population'

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

by **Mary McGrath** • Editorial Intern

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.

### Caregivers take on myriad tasks

Today, 10 years after the study's release, the number of caregiving youths likely has grown due to changes in the economy



More than 1.3 million U.S. youths provide 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.

and health care system, said Julia L. Belkowitz, M.D., FAAP, co-author of a new study titled "Caregiving Youth Project: A School-Based Intervention to Support a Hidden Population in Need."

Dr. Belkowitz's research investigates data from children enrolled in the Caregiving Youth Project at eight southern Florida middle schools. All sixth-graders at participating schools completed screening questionnaires to determine whether they met initial characteristics of a youth caregiver. Eligibility for services was confirmed with an interview and documented on an intake form. More than 700 children completed intake forms and were eligible for services.

Dr. Belkowitz and her team reviewed forms from 550 active participants in the Caregiving Youth Project. Sixty-three percent were girls, and the median age of caregivers was 12 years old.

Youth caregivers reported spending a median of two hours on school days and four hours each weekend day performing caregiving tasks at home. Estimates of median caregiving task time reported by family members were slightly lower at 1.5 hours on weekdays and 2.75 hours on weekend days. These tasks include assisting family members with getting around, eating, dressing, toileting, bathing and continence care. Youth caregivers also kept the family member company, provided emotional support, cleaned the house, shopped for groceries, administered medications, translated in clinical settings and handled medical equipment at home.

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### 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.



Dr. Siskowski

"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



Dr. Belkowitz

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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," Dr. Belkowitz said. "Ask what roles the child is taking on at home."

If a child's response indicates that he or she is shouldering heavy caregiving responsibilities, Dr. Belkowitz encourages pediatricians to be a support for the family.

While the AACY operates only in southern Florida, its website is a portal to many national resources. The AACY hopes to expand its services through partnerships with other organizations and the launch of the Caregiving Youth Institute.

Deborah served on the AACY board from 2010-'11. She said she still carries some of the weight from her past challenges, but she hopes by sharing her experiences, she can empower other youth caregivers to thrive.

## RESOURCE

For more information about the American Association of Caregiving Youth and the Caregiving Youth Project, visit [www.aacy.org/](http://www.aacy.org/).

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