Invisible caregivers

More than a million children and adolescents are caring for family members. What are the consequences for their development?

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What Kyllian Warman remembers most about her childhood is caring for her father, an alcoholic who eventually developed liver and colon cancer. She helped her mother feed him, dress him, give him medicine and clean up after him, all while also watching her younger brother.

"If I wasn't taking care of my dad, I would support my mom, helping her do taxes, go through bills and do housework. I just thought, 'This is what I have to do. Everybody's got to make it out of this alive,'" says Warman, who is now 20.

Warman was just one of thousands of American children who perform such caregiving duties every day. According to the latest data available from the National Alliance for Caregiving (NAC) and the United Hospital Fund, in 2005 at least 1.3 million U.S. children ages 8 to 18 helped to care for a sick or disabled relative, with 72 percent of these caring for a parent or grandparent and 11 percent for a sibling.

But the total number may be even higher, experts say. In 2012, there were 6.1 million U.S. children who had a parent with a disability, according to the National Council on Disability, which research, including the NAC study, suggests leads to children providing care.

"People don't stay in the hospital as long as they used to, and are living much longer with chronic health conditions that can become quite severe before they die," says Carol D. Goodheart, EdD, a psychologist in Princeton, New Jersey, and former APA president. Her 2010 Presidential Initiative Task Force developed the association's Family Caregiver Briefcase of information and resources.
Yet as important as these young caregivers may be, the work they do is largely invisible. Many don't identify themselves as caregivers, especially if their work is culturally typical, says Kim Shifren, PhD, a professor of psychology at Towson University in Towson, Maryland. At age 14, she cared for her mother who had a heart attack. "I would feed her and dress her and help her bathe. I didn't think of myself as a burdened caregiver. I just stepped up and did it," she says.

Acknowledging the roles these children play and supporting them can make the difference between an experience that builds empathy and resilience or one that leads to mental health and adjustment issues, experts say.

"There's nothing wrong with having to provide caregiving to a parent, but there's something wrong if you're not getting support yourself or your needs are not getting met in the process," says Grant Charles, PhD, an associate professor in the School of Social Work at the University of British Columbia, who studies child caregiving.

**Children at risk?**

A growing number of studies show how caregiving may affect children and adolescents. One is the 2015 Adolescent Health Survey by the McCreary Centre Society, a Vancouver nonprofit working to address youth health needs. In its survey of almost 30,000 high school students in British Columbia, 20 percent of respondents said they were caregivers. Almost half were under age 15 and 60 percent were female. The survey also found that child caregivers were twice as likely to have attempted suicide in the past year and more likely to be bullied than children and adolescents without caregiving duties.

Such duties range from helping family members bathe and eat to just keeping them company, according to a paper by Julia Belkowitz, MD, an assistant professor of pediatrics at the University of Miami. In her survey of 500 middle-school caregivers in south Florida, she found that children spent about two-and-a-half hours each school day and four hours each weekend day helping family members eat, bathe, get around and dress their wounds, as well as providing them emotional support and accompanying them to doctor's visits.

Research by Kenneth Pakenham, PhD, professor in the School of Psychology at the University of Queensland in Australia, suggests that just having an ill person in the household increases children's risk of poor adjustment outcomes — and that risk escalates with higher levels of caregiving. His research also found that caregiving duties tend to be more intensive when the children are caring for parents (Psychology and Health, 2015). In addition, Pakenham and others have found that child caregivers are more common in low-income families.

Other research suggests that caregiving can lead children to experience social withdrawal, declining school performance, stress, mental health problems and a decline in physical well-being. In one study, Donna Cohen, PhD, a professor in the department of child and family studies at the University of South Florida, found that young caregivers reported a significantly higher incidence of anxiety or stress symptoms (*Journal of Behavioral Health Services and Research*, 2012).

According to the NAC study and others, student caregivers report problems attending and staying awake in school and finishing homework.
Most young caregivers also experience social isolation, says Melinda Kavanaugh, PhD, an assistant professor of social work at the University of Wisconsin–Milwaukee.

"These kids are as young as 12 when developmentally all they want to do is belong, but they feel like, 'I'm the weird kid,'" says Kavanaugh. "They're the ones staying up all night because a grandparent wanders or a dad is running down the street naked. That can lead to bullying and other harmful impacts."

Caregiving children may also experience intense anxiety about performing their responsibilities — and about the future. "One of the biggest fears is, 'Is the person going to die? What's going to happen to me?'" says Connie Siskowski, PhD, founder of the American Association of Caregiving Youth (AACY), a nonprofit based in Palm Beach County, Florida, that provides resources and support for caregiving children.

Her own experience illustrates what many children face. Siskowski was living with her grandparents after her parents' divorce and cared for her grandfather, who had congestive heart failure, while her mother worked two jobs to support the family. At age 13, while trying to give him medicine in the middle of the night, she discovered he had died.

**Positive vs. negative experiences**

Research also highlights the positive effects caregiving experiences can have on children. A big factor in making it a worthwhile experience may be the strength of their family relationships. "Caregiving does give the opportunity to teach the child that they have an important role in this world and that can be very healthy for them," says Joan Asarnow, PhD, professor of psychiatry and behavioral sciences at the University of California, Los Angeles.

In a survey of 100 young caregivers ages 10 to 25, Pakenham found that most agreed that they had gotten many benefits from caregiving, including becoming more kind to others, learning patience, and changing their life goals for the better (*Journal of Health Psychology*, 2007). However, he also found that having a choice in caring for a family member played a role in gaining these benefits, and was strongly associated with positive affect and life satisfaction. Those who felt forced into caregiving roles were less likely to report these positive effects.

Personality traits may also be important. In a study in press in the International Journal of Psychology Research, Shifren and colleagues found that former child, adolescent and emerging adult caregivers' levels of optimism may buffer them from early negative caregiver experiences and are associated with less reported depressive symptoms and more well-being in these individuals in adulthood.

Social connectedness, particularly with peers, can also be a factor in determining whether caregiving is a positive experience for children. "Talking about caregiving normalizes the situation," says Charles of the University of British Columbia.

Among the programs that help foster such connections is AACY's *Caregiving Youth Project* in Palm Beach County, Florida. It offers social events, an overnight camp and respite, as well as classes in health care and cooking to boost kids' caregiving confidence and competence. "The kids love learning they're not alone, and families are encouraged when they feel cared about," Siskowski says. The organization also provides tutoring and computers and helps
caregivers in high school focus on graduation and planning for the future, including scholarships and career opportunities.

For school-age siblings of children with disabilities, Sibshops, an international network, provides peer support and education programs. "When you start looking at the services siblings get versus parent [caregivers], it's pretty easy to see who's getting the short end of the stick," says founder and director Don Meyer. "But these siblings have the same issues, and are going to be in the lives of that person longer than the parents will."

While it can be difficult to identify kids who need services, advocates say screening questions on caregiving from a school psychologist, guidance counselor, school nurse or pediatrician could help them spot this potential underlying issue.

"We're not going to eliminate kids as caregivers, so why don't we arm them with more skills, training and practice?" says Kavanaugh, who has studied families in which children help care for a parent with Huntington's disease.

"It's really powerful to see a kid responsible for these levels of care. Overwhelming, scary, frightening, but at the same time, awe-inspiring."

Updated caregiver resources now available

APA released an expanded and updated version of its Family Caregiver Briefcase in May, including additional material on youth caregivers.

"Whether they conduct research or practice in schools or health settings, psychologists are a tremendous resource to help identify these children and teens," says Carol Goodheart, EdD, who spearheaded the briefcase as APA's 2010 president. "We hope to provide the information psychologists need to play essential roles in identifying at-risk youth and enhancing the coping, growth and healthy development of these young caregivers."

Further reading

- American Association of Caregiving Youth website
- APA Family Caregiver Briefcase


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