

Children Who Give Care Are Overlooked

DAVID LEWELLEN

Charlie and A.J. Poole were 10 and 9 years old in 2013 when their grandmother, Helen Pomakoy, moved in with them. Her Alzheimer's had been getting worse, and the boys' mother, Sara, decided that bringing her to their McLean, Virginia, home was the best option.

Helen Pomakoy lived with them for two years before her death in 2015, and the family's life changed drastically. The boys rarely had friends over. When their grandmother got confused in the middle of the night, they would help to calm her, and then go to school the next morning without falling asleep again. Their schoolwork suffered, and teachers didn't know what was going on. The boys would bring dinner to her and give her medication (she would take it from them, but not from their mother), and they would make sure she didn't do anything dangerous, such as turning on the stove. Although she would get confused and lash out at adults, Charlie and A.J. often were able to calm her.

Now in their teens, the boys recently started a website, alittlebitofhappy.org, to reach out to other children in their situation. They now know, Charlie said, that "a lot of people have it a lot worse. No one's helping them. They should get something, like to put on their college applications, or some recognition. Something to know that people care."

The Pooles were part of the out-of-sight, out-of-mind legion of children who take on the very adult responsibilities of looking after a sick family member. The only national study of the issue, in 2005, estimated that 1.4 million children ages 8-18 offer some kind of care to a relative.¹ Few hospital administrators or school principals in the United States have thought about the burden that such children carry, or how to lessen it.

Caregiving may cover tasks that a healthy adult would normally do, such as cleaning, cooking or shopping. It may be helping an adult with bathing, dressing or toileting. It may be lifting a parent out of bed or administering medication. Or it could

be something as simple as sitting with an aging grandparent while the parent is gone.

"It's a category not talked about and not considered by our political institutions," said Elizabeth Olson, PhD, assistant professor of geography and global studies at the University of North Carolina-Chapel Hill. "It's difficult to convince people of the importance of this without documentation."

CAUGHT BETWEEN PRIORITIES

American advocates are caught between two priorities of gathering information about young caregivers and trying to set up support systems for the ones they find. At present, understanding the issue is vastly complicated by the lack of data. Melinda Kavanaugh, PhD, LCSW, assistant professor of social work at the University of Wisconsin-Milwaukee, has been able to find only 22 relevant articles in the social work literature. To learn more about the needs of such children, Kavanaugh said, it would help to insert one question about caregiving into existing longitudinal studies. "We're so keen to analyze adverse child events," she said, "but this is not one of them."

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In the midst of the intense interest in juvenile health, Kavanaugh shakes her head at how caregiving issues are overlooked. Young caregivers are at risk for accidents or sprains from lifting an adult and also are at higher risk for depression or anxiety. And, she pointed out, “If they’re up all night taking care of their parent, they aren’t sleeping. If no one is cooking, they’re eating junk food. If they’re inside watching a parent, they’re not getting exercise.”

Just being aware that the issue exists can make a difference. If medical personnel see a child in a patient’s room, “ask what the kid is doing there, because they may be engaged in care,” Kavanaugh said. “And ask what you can do to support them.”

As a hospital social worker in her previous career, Kavanaugh saw that readmissions were closely related to what kind of environment the patient was going home to. And if the health care team can, first, notice the child in the room; second, ask if the child ever cares for the patient; and third, show the child how to do the procedure correctly — then the patient has a lesser chance of being readmitted. Similarly, hospitals also could offer child-centered caregiver classes to lessen the children’s fear of doing the wrong thing.

Researchers and advocates for the issue tend to focus on different areas. In the absence of large data sets, Kavanaugh is working one disease at a time, because most diseases have their own foundations and networks of families. But, she sighed, “I want a lot more data on everything.”

AN INVISIBLE NUMBER

The number of children giving significant care to a family member is “a largely invisible phenomenon,” said Carol Goodheart, a psychologist in Princeton, New Jersey, and the former president of the American Psychological Association. Along with most other researchers, she believes that the reported number of 1.4 million young caregivers is probably lower than the actual figure. Part of the difficulty is that researchers are not allowed to survey children without parental consent.

Also, Olson said, adults tend to underestimate the amount of help that a child provides, and society sees the matter as, if not exactly a taboo, at least something very uncomfortable to think about. Some adults are fearful that the situation

might look like neglect. But, she said, “if you talk to a school social worker or a respite care worker, they’ll give you a look and say, ‘I know that child’ — and then you get the story.”

Youth caregiving can be seen as a subset of the overall problem of caregiving, which is a murky field in itself — under-researched, underpaid, and underappreciated. No United States program offers money for caregivers under the age of 18, but relatively little is available for those over 18, either.

“How do you go about paying a 13-year-old?” Kavanaugh asked. “There’s not an easy answer, but the fact that this is not part of the conversation is a problem.”

The “sandwich generation” caregiver, usually a middle-aged woman who is looking after both children and aging parents, is well-known in research and popular culture, but some research-

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ers use the term “bookend caregiver” to describe a child who used to be looked after by grandparents but who eventually cares for them as they age and their health declines. In some cases, the child is particularly worried about being placed in foster care if the grandparent dies, Goodheart said.

Such children can be identified through screening. Goodheart suggested adding a line to standard emergency room or clinic protocols: If the designated caregiver is an adult, ask, “Who else in the home gives care for this person? Who steps in when they can’t do it?”

Some family-centered cultures traditionally have expected that children will care for older people in the family. Kavanaugh has found high levels of such caregiving in a mostly Hispanic school in Milwaukee and in South Africa. “They’re just as stressed, but it’s just what you do,” she said. “That probably makes it worse, because they might feel they have less of an out.”

But children caring for adults is not necessarily a problem or a tragedy.

“Kids give both answers,” Kavanaugh said.

“They love it, and they hate it. It’s hard work, and it makes them feel good. The parents are the same way” — they may be proud of the child for stepping in, but at the same time they wish they weren’t a burden.

Olson added that the situation in such homes is not one-directional; the aging grandparents or sick parents also provide guidance, stability and support for the children. “I often think about it as mutuality of care,” she said.

Goodheart said that as long as they have support and are not overburdened, young caregivers may develop life skills and an early sense of responsibility — and a special relationship with the person they care for. “There can be a great deal of love and sense of purpose there,” she said.

But more difficult situations, in which the adult is extremely ill, addicted or in poverty, may eclipse other areas of the child’s life and make it hard for anyone to thrive, much less a teenager or grade-schooler.

Olson said, “At the university level, caregivers struggle” as they add the difficulties of making the transition to college plus new academic responsibilities to their existing home workloads. Some families decide that one child will go to college and one will stay home to be the caregiver. When young caregivers think about careers, the experiences of some will lead them toward medicine, nursing, social work or other helping professions; others may wind up doing the same kind of work as poorly paid nurse assistants.

BUT IS IT OK?

Socially, Olson said, the United States “can’t decide if it’s OK for children to do this kind of work. We have a really hard time with that.” A century ago, she said, there was a glimmer of interest in training “little mothers” to look after their younger siblings, but the effort died out as a social consensus grew that mothers were the best caregivers for children.

The situation is different in some other countries. Kavanaugh suspects part of it comes from attitudes toward health and society in the United States.

“We don’t say that equal health care is a right for our populace,” she said. “If you’re rich enough to buy it, that’s fine, but if help is offered, it’s on

society’s terms. And so a child takes on a large role in the absence of federal and state support programs.”

Great Britain often is cited as a model, and Fey-lyn Lewis, who is pursuing a PhD in social work at the University of Birmingham in that country, came to the topic through personal experience. When she was in elementary school in Hendersonville, Tennessee, her older brother had to drop out of college to take care of their mother after a failed back surgery left her in chronic pain. As well as seeing to bills, laundry, shopping, helping their mother shower and other necessities, her brother took care of his sister.

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Lewis, however, was able to enroll in college and graduate school, and she has seen first-hand how the British support system operates. Two hundred nonprofits across the country are specifically dedicated to “young carers,” and schools and local governments have a legal duty to identify them and learn what they need, such as school support, free bus passes and summer camps with other children in similar situations. The young carers also get an allowance of 62 pounds a week, or about \$80 at current exchange rates.

The United States, by contrast, has one nonprofit known to be working on the issue — the American Association of Caregiving Youth, in Boca Raton, Florida. Executive Director Connie Siskowski focuses on working with schools in Palm Beach County to start support groups for young caregivers and meet individual needs, such as wheelchair ramps to houses, home medical alarm systems or hooking a house with a contaminated well into the municipal water system.

“You think you’ve seen it all, and then you see something else,” Siskowski said — such as the

family that had rats in its mobile home. Her group was able to work with an exterminator to provide a permanent solution.

The program has a few affiliates scattered around the country, but that work has sometimes been two steps forward, one step back. In South Florida, it places workers in schools and offers a curriculum for grades six-12 to talk about caregiving. It also sends children to summer camp, because, Siskowski said, “Kids sacrifice not only their education, health and well-being, but also their childhood.”

The wide lack of awareness among political and health care leaders is not intentional, she said, but if people say that children shouldn’t be in that role, “what’s the option? Should they be in foster care instead? There’s no public federal or state recognition of this population. That has to happen. We really need a champion.”

MORE AWARENESS AND SUPPORT

Advocates say that more awareness should lead to more research funding, which could then lead to policies that recognize children’s work and help them to do it. In addition to improving the health of young caregivers, Kavanaugh said, a robust support system also would improve the health of adults receiving care.

Also, Olson said, “In the United States, it’s very effective to frame the argument in terms of economic loss.” Young caregivers are less likely to pursue higher education and more likely to miss time at work if they are employed outside of the home.

Children also care for sick siblings, which may involve all of the same issues but not the role reversal. Julianna Doran, 15, who lives in Boca Raton, has helped care for her 10-year-old brother, Josh, since he was born. Cerebral palsy means that Josh uses a wheelchair and needs help with bathing, feeding, dressing and using the toilet. Both parents work, and their prior back injuries mean that Julianna is the designated lifter.

Participating in activities with Siskowski’s organization, Julianna said, has let her know that “other people are in the same situation, and worse.” She participates in marching band, and her parents fit Josh’s therapy sessions around her schedule. Julianna loves caring for her brother and said his condition is “just a thing that’s there. ... It’s no different than another sibling.”

In studying young caregivers in both Great Britain and the United States, Lewis has found

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they are at higher risk for bullying, school attendance problems and poor school performance. They may be more likely to delay having children of their own, and they may wonder about ever finding a romantic partner.

Great Britain has universal health care, but in the American market-based system, “the family is the safety net,” Lewis said, “and for many families, that is children and young adults.” But, she added, the situation in Britain also is not perfect.

The goal in the United States, Olson said, should be to “remove the barriers that we can remove, so that caregiving becomes a beneficial thing that helps you develop empathy. But if we don’t even recognize it as a thing, that’s hard.”

What does recognition look like? It could be as direct as paying young caregivers. It could be finding funding to buy a laptop computer to help teens with schoolwork, or a slow cooker to make dinner preparation easier and more practical. It could be training on how to give medical care, or simply for a caring adult to remember to check in on how the child is doing.

In schools and hospitals, change begins with increased awareness. If teachers, counselors and health care workers all have their eyes out for young caregivers, “there’s no wrong door, in terms of access,” Lewis said. If a doctor or nurse asks an adult about the home care situation and follows up on the answers, that can be another open door.

“What I hear most is that [child caregivers] want someone to talk to,” Lewis said. “It could be a doctor or a teacher or a caring organization, but that’s something they really want.”

DAVID LEWELLEN is a freelance writer in Glendale, Wisconsin, and editor of *Vision*, the newsletter of the National Association of Catholic Chaplains.

NOTE

1. Gail Hunt, Carol Levine and Linda Naiditch, *Young Caregivers in the U.S.: Findings from a National Survey*, September 2005, www.caregiving.org/data/youngcaregivers.pdf.

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