Caregiving can last for decades, new research shows

15 September 2020, by Bev Betkowski

To most people, "caregiving" means looking after ailing relatives in their final years. But the reality is much different, with the actual workload lasting up to 30 years for some, according to University of Alberta research.

The study, the first of its kind to gauge caregiving across a person's lifetime, debunks the myth that looking after an ailing loved one is a short, one-off experience, said study lead Janet Fast, a family economist in the Faculty of Agricultural, Life & Environmental Sciences.

"Caregivers often give up a lot. Providing care to a family member or friend with a chronic health condition, disability or aging-related need can go on for just a few years for some caregivers, while it can span several decades for others. Caregiving is not typically viewed as what can be a very emotional and challenging period of time," she said.

Lengthy caregiving can take a high personal toll, including chronic stress, loneliness, poor health, disrupted careers or pensions and crumbled relationships, added study co-author Jacquie Eales, who worked with Caregivers Alberta to create a video series about the different patterns and challenges of long-term caregiving that may build up and disadvantage caregivers in later life.

"Some of these people are in crisis mode all the time."

The study, drawing on a Statistics Canada survey of family care, identified five different lifetime patterns of caregiving. Some start early, others in mid-life or later, and they vary in intensity.

A "compressed generational" care trajectory was the most common pattern, with over half of caregivers starting their responsibilities at age 63 on average, with the shortest duration of four years, typically looking after a spouse or parent. Just 13 percent of them had a second episode of caregiving with almost no overlap between care episodes.

The next most frequent pattern, known as the broad generational care trajectory, started when caregivers were in their early 50s, involved more than one care episode—typically caring for parents, partners or sometimes friends—and lasted for a total of 14 years.

One of the most challenging trajectories is intensive parent care, with caregivers starting in their early 50s for an average duration of 11 years, but with a heavier load of caring for more than one parent or parent-in-law at the same time.

"Typically they'd spend the last 15 years of their career working full-time, maybe at their peak earning years leading up to retirement," said Fast. "The challenge is they're often also caring for multiple parents at the same time, making it impossible to balance paid work and caregiving."

Career care describes people in their early 30s who
find themselves looking after close family members for 30 or more years—often children with disabilities, but also parents or partners with chronic or mental health conditions.

The fifth pattern, serial care, also can go on for 30 years, has the highest number of care episodes and the most overlap of caring for more than one person at a time. Most of these caregivers—71 percent—were female, "the kind-hearted woman who helps everybody," Eales noted. Many in this category had a lifelong pattern of caring, first for parents and then other family members and friends.

Recognizing different patterns of caregiving across the life course is important in building effective, supportive policies that can help people cope, Fast said.

"Knowing more about the diversity among caregivers lets us develop policies and programs for them that are more apt to be successful. If we understand how early caregiving experiences can accumulate, disadvantaging people in later life, we can intervene at a time and in a way that reduces the long-term impact."

Young caregivers or parents looking after children with disabilities, for instance, may need extra support to get into and stay in the workforce. Leaves of absence for compassionate care and critical illness exist in Canada, but don't necessarily reflect the many years some Canadians devote to caring for family members and friends.

"As a result, some may be forced to retire early or are let go from their jobs because they can't perform well under the circumstances," Fast said.

"There are ways we can do better, such as creating more family-friendly workplaces that give caregivers the flexibility they need. Or with income supports or pension credits that compensate for income losses that many caregivers experience, or by restructuring the way formal care services are provided so that they address the needs of caregivers as well as the needs of the person being cared for."

**More information:** Trajectories of family care over the lifecourse: Evidence from Canada: [Provided by University of Alberta](https://www.cambridge.org/core/journal)