

The Challenges of Cancer Caregiving

As the population ages, more family caregivers are being pressed into service.

November 30, 2023 By Fred Hutch News Service and Bonnie Rochman

The cost of caregiving for patients with cancer can be measured in countless ways: emotionally, professionally, financially and in terms of time, to name a few.

Jean Bryant, a fundraiser for Fred Hutchinson Cancer Center, has experienced them all. As a caregiver for her teen son and then her husband, both diagnosed with different types of lymphoma, she knows as well as anyone about the toll of being a caregiver for someone with cancer.

It's an experience that has forever marked her, one that she said has taught her to acknowledge the "unknown struggles" of others, "all the while recognizing and coexisting with the underlying trauma that remains shallow, just under the surface. I stay guarded hoping the other shoe doesn't drop in the near future."

In the wake of a cancer diagnosis, the focus is rightly on the patient. But November is National Family Caregivers Month, which offers an opportunity to expand the spotlight to encompass the army of caregivers who do everything from take notes during medical visits, keep loved ones company during long hours of chemotherapy and care for them at home as they cope with side effects from grueling treatments.

Family caregivers provided the equivalent of \$600 billion in unpaid care in 2021 as they devoted 36 billion hours to tending to sick friends and relatives, including those with cancer, according to an AARP report, [Valuing the Invaluable](#), released in March. The financial estimate increased from \$470 billion in 2017, part of a trend that has seen the cost attached to family caregiving grow over the past quarter century. About 38 million people identify as family caregivers.

The cost estimate is based on 18 hours of weekly care valued at an average hourly compensation of \$16.59 per hour, less than the minimum wage in the Seattle area. In other words, the estimated cost of family caregiving is undervalued — and not only in dollar terms.

The report also states that the value of caregiving provided at no charge by family members dwarfs the value of paid care provided by professional caregivers.

The need for caregiving is expected to rise as adults ages 65 and older will outnumber children

under 10 by 2034. At the same time, the proportion of the population able to serve as caregivers is expected to be impacted by a myriad of reasons including:

- Working caregivers — 61% of family caregivers hold down full- or part-time jobs — may have fewer career advancement opportunities, which can result in lower salaries and less ability to assume caregiving duties.
- Sandwich generation caregivers who are responsible for caring for both children and aging adults are also more likely to have jobs that take away from their ability to provide care.
- Paid caregiving has an average annual turnover rate of up to 60%, which can leave family members little choice but to step up to care for loved ones.
- As caregivers are becoming more diverse, they are experiencing unique challenges. Asian American caregivers, for example, report feeling they have no choice other than to serve as a caregiver. Black caregivers say they don't often receive paid or unpaid caregiving support. LGBTQIA+ caregivers are more likely to report feeling financially and emotionally stressed by their caregiving roles.

Caregivers Are the 'Lifeline of the Person With Cancer'

As more cancer care is delivered in outpatient treatment centers such as Fred Hutch, the burden on cancer caregivers is evolving. In the past, more people with cancer received more of their care in hospitals, where trained doctors and nurses oversee treatment. Now it's more common for patients to be cared for at home during their treatments and in the months after, requiring caregivers to track dozens of medications, deal with side effects, navigate insurance and communicate with extended family and friends, among other responsibilities.

It's not uncommon for caregivers to be expected to handle medically-intensive tasks such as wound care, catheter care, giving injections and IV medication administration, said Kate Washington, author of "[Already Toast: Caregiving and Burnout in America.](#)"

She shouldered some of those tasks when caring for her husband at the time. "A generation ago, nurses would have done this and now families are expected to do this at home after getting half an hour of training," she said.

Being a caregiver is a critical but potentially overwhelming role, notes the section of the [American](#)

[Cancer Society's website](#) that details a caregiver's tasks, which can include everything from help with bathing and food preparation to offering emotional support while paying bills and providing transportation to medical appointments.

Caregivers are the “lifeline of the person with cancer,” ACS states. “In many cases, the caregiver is the one person who knows everything that’s going on with the patient.”

That rings true for Bryant, who has distilled the responsibilities of caregiving into three main areas: organization (navigating a house of medical supplies and calendar full of cancer-related appointments, scans and transfusions), adaptability (adjusting and recalibrating when medical complications arise) and advocacy (serving as the patient’s representative with providers and insurers).

The around-the-clock nature of caregiving means that a seasoned caregiver must juggle all three. “I managed everything,” said Bryant. “We did not have paid help.”

Apart from traditional caregiving duties, Bryant also tried to keep life as normal as possible and maintain emotional equilibrium at home for the entire family. “From a mental health perspective, you have to try to avoid going down the rabbit hole with thoughts of what-if or worst-case scenarios,” she said. “You have to build positive memories and not let cancer dictate every minute of your and their day. There’s so much out of control that you try to control what you can.”

Bryant’s son, Jack, was first diagnosed at age 13 with a rare Hodgkin lymphoma and was treated at Seattle Children’s. Bryant noticed that like herself, most other primary caregivers of children with cancer were women. “It’s like the mama bear instinct. It’s an innate thing to protect and care for your child.”

Women Shoulder the Bulk of Caregiving

A study conducted by Fred Hutch radiation oncologist [Ralph Ermoian, MD](#), and Emily Stiles, a third-year medical student at the University of Washington School of Medicine, backed up Bryant’s observations. They looked at the experiences of 45 children treated at Fred Hutch’s proton therapy facility and found that while 83% of patients had both a mother and father in their household, only the mother attended appointments 58% of the time.

“For the initial consult, both parents are often involved,” said Stiles. “Beyond that, moms often show up alone.”

The results — which have been presented at conferences but are not yet published — are not particularly surprising, said Ermoian: “A greater burden of care falls on women.”

In his 12 years in practice, he’s seen mothers assume more responsibility for day-to-day care, bringing a child to treatment and providing support over time.

Data from AARP's 2020 report, [Caregiving in the United States](#), indicates that women as caregivers are the norm, especially in more complex care scenarios. The organization says the typical "[high-intensity caregiver](#)" is a woman in her late 40s who is caring for a parent in their late 60s with multiple conditions, including at least one hospitalization within the past year. High-intensity caregivers are more likely to be Latinx or Black than caregivers for patients with less complex conditions.

In her experience, Bryant has observed that a woman's female friends rally after a cancer diagnosis and help provide support to a husband serving as a caregiver. "When a woman is diagnosed, her friends step up and go with her on chemo days," she said. "You don't really see the opposite happening with men."

Washington noticed the same thing when she served as caregiver for her then-husband. Most friends who showed up to help ease the strain of caregiving were women; the in-home caregivers she hired to help manage the aftermath of his treatment for non-Hodgkin lymphoma — he was left blind and partially incontinent, couldn't walk unattended and needed assistance in all acts of daily living — were female, too.

Now amicably separated from her husband, who has recovered his vision and the ability to live independently, Washington said this is largely due to the toll that caregiving exacted on their marriage. "The relationship we had as a married couple shifted to a caregiver/patient relationship," she said. "We both suffered trauma — his primary and mine secondary — and our responses to that trauma were very different. It proved impossible to bridge all those gaps even after his health stabilized."

In her book, Washington makes the case that caregiving should not fall solely to families. "As much as our society frames caregiving as an individual or family problem to solve, I argue that it's something that the health care system and our larger society have to deal with."

"Caregivers are being pulled into a level of care and time commitment they can't even consent to meaningfully," she said. "There is no real way to say 'no' because there's no other option."

SIDEBAR

Cancer & Caregiving Series

November is National Family Caregivers Month, which expands the spotlight to encompass the army of caregivers who do everything from taking notes during medical visits and keeping loved ones company during long hours of chemotherapy to caring for them at home as they cope with side effects from grueling treatments. The series of articles from Fred Hutch News Service also includes:

- [Self-care guidance for caregivers](#) from seasoned caregivers.

- Advice for cancer patients on [being your own best support](#) and where to find community from other patients.
- Tips on [staying organized](#) from two women who are caring for spouses going through blood cancer treatment.

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<http://beta.docker.tusaludmag.com/article/challenges-cancer-caregiving>