Rare Caregiving in America: Study Findings

Study Background

This is a first-of-its-kind study of 1,406 caregivers ages 18+ living in the United States who provide care to a child or adult with a rare disease or condition. Sponsored by the National Alliance for Caregiving, in partnership with Global Genes, data was collected in fall 2017 by Greenwald & Associates. Rare diseases or conditions are those that affect fewer than 200,000 people.¹

The purpose of the study is to: 1) describe the experiences and challenges of this targeted group of caregivers; and 2) to understand the impact of rare conditions upon not the person with the rare condition, but rather, the unpaid caregiver and the broader well-being of this caregiver.

The study design, questionnaire, data, and final report were guided and reviewed by an independent Advisory Committee. This Committee included twelve national caregiving and rare disease researchers, clinicians, genetic counselors, and patient advocates (including caregivers and a patient with a rare disease).

The study was funded by the following organizations: The Allergan Foundation, Alexion Pharmaceuticals, Inc., Amgen, Amicus Therapeutics, Biogen, the Family Support Research and Training Center (FSRTC) at the University of Illinois-Chicago, Mallinckrodt Pharmaceuticals, Retrophin, Shire, Ultracegenyx Pharmaceutical, Inc., and Vertex Pharmaceuticals.

A Snapshot: The Rare Caregiver: The rare caregiver is most likely an immediate relative caring for a someone in the same home.

- It is estimated that at least 25 million Americans currently have a rare disease or condition.
- Most rare caregivers (62%) are providing care to a child under the age of 18.
- The average age of the care recipient (the person with a rare disease or condition) is 20.9 years old.
- Most rare caregivers (59%) are immediate relatives caring for their own child under 18.
- Nearly all rare caregivers (89%) live in the same household as their care recipient.
- 71% of the care recipients have a rare condition or disease that is genetic in nature.
- 43% report there is a treatment available for the underlying disease or disorder.
Rare Caregiving in America: Study Findings

- 82% report that treatments or therapies are used for symptom management rather than disease treatment.
- Roughly one out of every three rare caregivers report having difficulty in accessing treatments or therapies for symptom management (34%) or treatment(s) for the underlying disease (31%).

A Life-Altering Experience: A rare caregiver can become a role that fundamentally alters the way the caregiver lives their daily life for many years.

- Most rare caregivers have been providing care for a significant length of time: 8.9 years, on average – more than double the caregiving commitment found among caregivers generally.
- Rare caregiving is also time-intensive. Rare caregivers of adults spend about 37 hours a week providing care on average – about 12 more hours a week than general caregivers.
- Even more striking is the amount of care provided by rare caregivers of a child: 53 hours a week, on average, compared to 30 hours for general child caregivers.
- Four in ten rare caregivers report having fair or poor emotional or mental health.
- Rare caregiving takes a clear toll on the physical health of caregivers, with 30% rating their physical health as fair or poor and 58% finding it difficult to take care of their own health.
- Nearly all rare caregivers have experienced financial impacts because of their caregiving role. Common impacts include cutting back on household spending (81%); not saving for long-term goals (62%); and using up personal savings (59%). Nearly one in ten has filed for bankruptcy (9%).
- Two out of three rare caregivers have worked while providing care (65%), and nearly all report a bleed over into their work life, more so than general caregivers who work. Nearly all have gone in late or left work early to provide care (91%).

Voice of Care: Rare disease expert is an added role for rare caregivers.

- Nearly all rare caregivers become the “voice of care,” doing Caregiving Support Activities of care communication (94%) and advocacy (94%).
- The majority act as teachers, educating health care professionals about their care recipient’s rare disease or condition (89%).
- Rare caregivers can also find themselves becoming researchers, finding and accessing clinical trials. One in four report their care recipient has participated in
Rare Caregiving in America: Study Findings

a clinical trial (26%), and when that occurs, the rare caregiver often helps with tasks such as paperwork (77%), transportation (65%), trial response documentation (62%), and communication coordination (59%).

- They function as nurses, performing medical/nursing tasks: 84% help their care recipient with medical/nursing tasks. These tasks are a defining feature of rare caregiving, with rare caregivers being called upon to do these tasks for the duration of their role as caregiver.

- Rare caregivers report feelings of pride in improving the understanding of the underlying rare disease or condition (94%).

**Strain & Stress:** Rare caregivers spend their time taking on a variety of tasks for their care recipient, which translates into a high burden caregiving situation.

- Two out of every three rare caregivers have a high caregiver burden on the Burden of Care Index (67%) – far higher than general caregivers.

- Rare caregivers say providing care to their care recipient is emotionally stressful (67%), twice as high as that of general caregivers.

- To a lesser degree, rare caregiving can be a physical strain to caregivers, with 37% reporting high strain. The key feature of physical strain seems to be doing more hands-on care, such as conducting medical or nursing tasks and Activities of Daily Living.

- Rare caregivers may need more support from the doctors and care professionals they interact with. Fewer than half (48%) have had a doctor, nurse, or social worker ask what was needed to provide care to the recipient, and just one in four have had these discussions about their own care needs (26%).

- Despite their higher-burden care situation, rare caregivers are no more likely to rely on paid help, with just one in three reporting use of paid help or aides (33%).

- Support service use is also not common, with just 22% having used respite and 14% relying on an outside transportation service.

- About half of rare caregivers have difficulty maintaining friendships (51%) and report feeling alone (53%).

**The Ripple Effect on Families:** Rare caregivers note the ripple effect of rare disease caregiving on their family.

- Other immediate and extended family members are called upon to help provide care, with 59% reporting help from at least one other unpaid caregiver.

- This domino effect of care can extend to youth in the family, with 24% reporting their care recipient receives unpaid care from at least one youth under age 18.
Rare Caregiving in America: Study Findings

- One in ten rare caregivers are also students (10%) and often struggle to fulfill their school responsibilities.
- 74% mention struggling with a sense of loss for what their care recipient’s life could have been, and fewer than half feel their role has had a positive impact on their family (44%).
- Most report feeling close to their care recipient (85%), and more than half feel a sense a purpose due to their role (56%).
- Rare caregiving can impact the finances of the rare caregiver and their family unit, with half of rare caregivers facing high levels of financial strain (51%) and three out of every four worrying about the ability of their own family or their care recipient’s family to pay for care (74%).
- Future planning is not the norm among rare caregivers: 35% have a contingency plan in place in case they are unable to provide care, and only 29% have plans in place for their care recipient’s future care (financial, health, and living arrangements).

---

i National Institutes for Health: https://rarediseases.info.nih.gov/diseases/pages/31/faqs-about-rare-diseases
iv Medical/nursing tasks are a body of caregiving tasks that are highly skilled in nature and are things typically handled by someone like a health care aide, nurse, or other care professional. See: Reinhard, S.C., Levine, C., & Samis, S. “Home Alone: Family Caregivers Providing Complex Chronic Care,” AARP Public Policy Institute & United Hospital Fund, 2012.
v Refers to Burden of Care Index, which aims to measure the intensity or demands of the caregiving situation.
vi 40% high burden among general adult caregivers in “Caregiving in the U.S. 2015” and 38% among general child caregivers in “Caregiving in the U.S. 2009”.
vii 34% high stress among general caregivers of a child from “Caregiving in the U.S. 2009” and 38% among general caregivers of an adult from “Caregiving in the U.S. 2015”.