

Family Caregiver Research: Executive Summary

Overview

The Coalition to Transform Advanced Care (C-TAC), in partnership with the Cigna Foundation, undertook a digital ethnography of over 6,700 conversations from websites where family caregivers discuss caring for a loved one. This analysis provided a vivid depiction of the state of family caregivers in the United States and the need to do more to support these individuals and their families.

Overall, the **draining nature of the work** is a top issue for family caregivers. They also feel they **lack meaning in caring for loved ones**. Their negative emotions are often interrelated – they feel stressed because they can't leave their loved one or feel underequipped to provide certain types of care, then feel guilty for these reactions. Caregivers also struggled with a **lack of knowledge** about the disease they're caring for, what to expect in the process, and how to cope with the demands of caregiving.

The **financial burden** is also very striking. We are creating a whole generation of caregivers who sacrifice their jobs and personal relationships, have little financial security, and are left with little after their loved one passes away. While these challenges are not necessarily new, this research adds vividness and personal dimensions to the problem.

Key Findings

- Caregiving has a very **high negative impact** on caregivers' lives (69% net negative)
- The biggest impact of caregiving is seen on caregivers' **state of mind** (84%)
 - Majority of the negative emotions (mental fatigue, loneliness, anger, etc.) arise from **caregivers' workload and resentment at lack of support**
 - Caregivers **also feel sad, guilty, helpless and anxious** when they see their **loved ones suffer**
 - Grief (29%), mental fatigue (29%) and fear/anxiety (20%) are the primary emotions that impact caregivers' state of mind
- The **social lives and personal relationships** of caregivers are hampered
 - Over 70% of caregivers believe caregiving has a negative impact on their state of mind, and 26% of believe caregiving has a negative impact on their social lives
 - 41% express **resentment towards other family** because of lack of support in caregiving, with 32% reporting feelings of isolation and 10% reporting feelings of neglect
 - Very **difficult to balance other relationships**
 - Caregivers' inability to leave the patient isolates them from rest of the world
 - They find respite by **sharing their feelings on online forums** with fellow caregivers
- High emotional spending leads to depression (24%) and insomnia (19%)
- Excessive exertion and lack of rest leads to fatigue and aggravated medical conditions
- Compromised career (over 50%) and high medical expenses **deteriorate financial health**
 - **48% are unable to work and report a negative impact on their disposable income, 33% deprioritize work, 94% report a deterioration of financial health**
- Patients expect both **emotional and functional** support from caregivers
 - **Reassurance of caregivers' presence** is most common emotional expectation from patients
- The two most important support systems that caregivers look for include:
 - Family (**24% of caregivers fail to get adequate support from their families**)

- Online Support Groups (**26% of caregivers seek support via online channels**). Online resources serve as a primary source of motivation, empathy and advice for caregivers. Examples include:
 - Nonprofit websites
 - Caregiver forums
 - Diseases-specific Facebook communities

Looking Ahead

Based on these findings, C-TAC's Campaign will focus on:

1. Devising strategies to **honor caregivers** and help them **understand their work is important**.
 - Collaborate with thought leaders to construct a positive image for family caregivers and how to best deliver it.
2. Developing initiatives that **support caregivers in their communities, their jobs, and their homes**.
 - Design ways to connect families with resources in local communities and online.
3. **Strengthening caregiver voices**.
 - Empower family caregivers to make shared and informed treatment decisions with their loved ones and clinicians.
 - Mobilize caregivers to advocate for a more person-centered healthcare system.