

ALZHEIMER'S DISEASE FAMILY CAREGIVER SURVEY FACT SHEET

A 2011 GfK Roper survey of 674 Alzheimer's disease family caregivers reveals similar experiences for caregivers despite gender, ethnic and age differences. Following are highlights of the survey results:

Caregivers Have Mixed Emotions, Cite Communication as Major Stressor

How Do Caregivers Feel? – “Accepting” was the most commonly associated word with the caregiving experience – 26% ranked it first and 50% ranked it among their top three words.

- Female caregivers were more likely than their male counterparts to associate “drained” or “exhausted” (19% to 11%).
- Men were more likely than women to use the words “frustrated” or “impatient” (15% to 9%).

Communication Breakdowns – Across all demographics, the loss of their loved ones' ability to communicate was ranked second among what frightens caregivers the most, only behind general health and physical capabilities. Nearly half (49%) said communication breakdowns between them and the patient greatly impact their overall stress level. The majority (54%) of caregivers are decreasing attempts to engage in conversations with their loved one.

Using New Ways to Communicate – Despite the stress associated with communication, most caregivers have adopted new ways to communicate with their loved one (71%). The most common alternative methods include observing facial expressions (84%) and body language (79%) and using pictures/photos (66%).

Better Communicators – Three-fourths of family caregivers reported that being a caregiver has made them a better, more effective communicator.

Impact of Caregiving on Daily Life Is Extensive and Powerful

Neglecting Own Life – Almost half of caregivers (46%) reported that five or more other aspects of their lives have been affected as a result of their caregiver responsibility, causing them to:

- Skip a social obligation (74%)
- Neglect other personal/family responsibilities (65%)
- Skip the gym or exercising (52%)
- Get to work/school late or leave early (51%)
- Cancel a vacation or trip (49%)
- Stay home from work or school (46%)

Caregiving is Second Job – On average, family caregivers of Alzheimer's patients who are most involved spend 43% of their time per week providing care, and for most that's in addition to already working a full- or part-time job (62%).

Concerns About the Future – Approximately, 9 in 10 caregivers said they'd see a doctor immediately if they noticed Alzheimer's symptoms in themselves.

Caregivers Are Not Going it Alone, but Need Stronger Support Systems

Caregiving is Not a Solo Act – Only a minority (12%) of caregivers said they are the only ones involved in caring for a loved one with Alzheimer's.

Supporting the Caregiver – While the majority of caregivers said their friends and family members seem to understand their responsibilities as a caregiver (54%), fewer than half say that their network knows how to help them relieve stress associated with caregiving (38%).

Seek Physician Advice – Caregivers said they would seek out additional treatment options for their loved one if there were a noticeable decline in daily function (55%), desire to keep them out of a nursing home (39%), or a change in their behavior (38%).

Snapshot: Alzheimer's Family Caregivers

- **Gender:** 60% Female, 40% Male
- **Age:** 52.5 (mean)
 - 7% “Millennial Caregivers”, under age 30, caring for grandparents
- **Ethnicity:** 78% Caucasian; 15% African American; 12% Hispanic
- **Years Spent Caregiving:** 4.1 years (mean)
- **Care recipients:** 63% parents/in-law; 16% grandparents
- **Work Status:** 49% full-time; 14% part-time; 24% retired
- **Family Status:** 69% married; 21% parents with children under age 18

Caregivers Seek Tips

- Caregivers said it would be very/somewhat helpful to get tips on:
- Being an effective caregiver (74%)
 - Finding/evaluating long-term care (73%)
 - Home safety issues (62%)
 - New/different treatment options (80%)
 - Communicating with friends/family about the patient (65%)

Some Notable Differences Exist Among African-American, Hispanic Caregivers

African-American/Hispanic Caregivers – African-American caregivers reported spending more time caring for their loved one with Alzheimer’s disease, compared to Caucasian caregivers. When compared with both Caucasians and Hispanics, African-American caregivers reported having strong support networks that have a better understanding of not only the caregiver’s commitment, but also how to relieve stress associated with caregiving.

On several topics, both African-American and Hispanic caregivers rate the effectiveness of their communication efforts with the patient higher than their Caucasian counterparts. The use of alternative communication methods is widely adopted by all groups, but a greater percentage of Hispanic and African-American caregivers reported using such methods compared to Caucasian caregivers (81% of African-Americans and 80% of Hispanics compared to 69% of Caucasians).

About the Caregiver Survey

GfK Roper Public Affairs & Corporate Communications conducted the online survey on behalf of the National Family Caregivers Association and Forest Laboratories, Inc. The survey was conducted among 674 Alzheimer’s disease (AD) caregivers between March 28 and April 25, 2011, including oversamples to reach 100 African-American and 100 Hispanic AD caregivers in the total sample. The results are weighted by age, race and education to reflect the population of Alzheimer’s disease caregivers.

Demographics

The majority of caregivers are full-time employees (49 percent); some are part-time employees (14 percent) or retired (24 percent). Sixty-nine percent of caregivers are married and 21 percent are with children under the age of 18. The average number of caregiving years is 4.1. Among the caregivers surveyed, 72 percent of patients cared for are female, and 28 percent male. The average age of the patient is 82 years old, with 86 percent of patients 75 or older.

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