

Survey: Alzheimer's Caregivers: Behavioral vs. Cognitive Challenges

A survey, "Alzheimer's Caregivers: Behavioral vs. Cognitive Challenges," conducted for the Alzheimer's Foundation of America (AFA) by Harris Interactive examined how behavioral symptoms—common examples are irritability, anxiety and aggression—compare to cognitive symptoms—common examples are memory loss and confusion—of people with Alzheimer's disease or a related dementia in their impact on diagnosis, disease management, caregivers' well-being and other issues. Findings are based on an online survey of a nationwide cross-section of 750 adults (aged 18+) who are caring for a family member or friend with Alzheimer's disease or other dementia. The survey was conducted from April 11-May 1, 2012, and was funded in part by Avanir Pharmaceuticals. AFA released the findings in September 2012.

Awareness of Symptoms

- Nearly three-quarters of respondents (72 percent) say that at the time of diagnosis, they were aware that Alzheimer's disease has behavioral and cognitive symptoms.
- Yet, two-thirds of respondents who provided care prior to diagnosis believed their loved one's behaviors were "just a normal part of aging."
- Among them, 67 percent said these thoughts delayed obtaining a diagnosis.
- Both behavioral and cognitive symptoms (40 percent) or mostly or only cognitive signs (41 percent) far outweighed behaviors (12 percent) in contributing to the doctor's visit.
- The most frequent behaviors, exhibited daily to about weekly, are irritability (58 percent), sundowning (57 percent), sleeplessness (51 percent), personality changes (49 percent) and anger (45 percent).

Physician Interaction

- Nearly six in 10 caregivers (59 percent) say they talk to the treating physician just as frequently about both groups of symptoms.
- Caregivers have learned to manage behaviors most commonly through speaking with healthcare professionals (67 percent); books or brochures (44 percent); online resources (40 percent), including discussion boards; family members (33 percent) or Alzheimer's agencies (29 percent).

Treatments and Interventions

- 80 percent of caregivers report that the clinician suggested medication: either a prescribed name brand drug (67 percent) or a generic version (30 percent) specifically for Alzheimer's disease or a related dementia; or medications to treat specific behaviors aside from those approved for Alzheimer's disease (26 percent), such as anti-depressants (45 percent), anti-anxiety medications (28 percent), antipsychotics (21 percent) and mood stabilizers (12 percent).
- Among caregivers who confide in physicians or social workers, a majority of physicians (82 percent) and social workers (92 percent) have suggested behavioral modifications, environmental changes, communication techniques, and other non-drug interventions.
- Social workers outweigh physicians in suggesting support groups for caregivers (57 percent vs. 28 percent) and the diagnosed (53 percent vs. 27 percent).
- About one-third of caregivers say non-drug options help "a lot" in reducing symptoms, especially keeping routines (53 percent), watching TV (38 percent) and positive reinforcement (36 percent).

- Non-drug options that have helped “a little” are sticking to routines (91 percent), speaking slowly and simply (81 percent), distracting and redirecting to positive activities (81 percent), positive reinforcement/reassurance (81 percent), and watching TV (75 percent).
- Among individuals taking at least one Alzheimer’s-specific medication, 21 percent of caregivers say it helps a lot and 38 percent say it helps a little.
- Among individuals taking at least one medication to treat specific behavior symptoms other than a specific Alzheimer’s medication (a non-Alzheimer’s disease specific medication), 47 percent of caregivers say it helps a lot and 58 percent say it helps a little.
- 24 percent would likely or very likely consider a clinical trial for medication to control behaviors.

Managing Symptoms

- Caregivers believe behavioral symptoms are triggered most often by a loved one’s frustration (67 percent) followed by unfamiliar surroundings (43 percent) and a desire to go “home” (37 percent).
- Nearly half (48 percent) say they manage both classes of symptoms equally well; 38 percent say they manage cognitive loss better than behaviors, and 14 percent report the reverse.
- Caregivers are coping “not well at all” or “somewhat well” with irritability (62 percent), anger (61 percent), inappropriate sexual behavior (59 percent), aggression (59 percent), personality changes (56 percent), paranoia and/or suspiciousness (55 percent). But they are faring “very well” or “well” are involuntary outbursts of crying or laughter (54 percent), delusions and/or hallucinations (53 percent) and anxiety (52 percent).

Impact on Caregiver’s Life

- Caregivers report that cognitive and behavioral symptoms have impacted their lives the same.
- As a result of the individual’s behavioral symptoms, caregivers have stopped or limited time with friends and family (43 percent); given up recreational activities (39 percent); stopped or cut time at work (26 percent). Fewer have stopped physical exercise (18 percent) or sought professional help (15 percent).
- Caregivers cite fatigue (56 percent) and difficulty sleeping (50 percent) as top ailments stemming from the individual’s behavioral symptoms.
- Nearly three-quarters of caregivers help manage behavioral and cognitive symptoms by talking to family or friends, and around half do physical activities like walking or running, or mental activities, like doing a crossword puzzle.

Impact on Future Care

- Caregivers are more receptive to hiring a paid professional when the person’s behavior starts to impact a caregiver’s physical health (42 percent) or mental health (40 percent).
- Caregivers would consider long-term care placement if aggression becomes too difficult (59 percent), the person self-harms (54 percent) or they fear harm to other family members (48 percent) or themselves (45 percent).
- When the individual begins to wander, 32 percent would hire a professional caregiver, 37 percent would opt for long-term care, and 36 percent would not consider either option.

Racial or Gender Disparities

- White (44 percent) are more likely than Black/African American (28 percent) or Hispanic (22 percent) caregivers to say that mostly or only cognitive symptoms prompted the doctor’s visit.
- Black/African American (27 percent) are more likely than White caregivers (13 percent) to believe they better manage behavioral symptoms than cognitive ones.

- Black/African American and Hispanic are more likely than White caregivers to say that the person is aggressive (44 percent and 43 percent vs. 27 percent) or has delusions/and or hallucinations (41 percent and 44 percent vs. 26 percent).
- Black/African American (42 percent) are more likely than White caregivers (24 percent) to say their loved one did not display aggression prior to diagnosis.
- Black/African American are more likely than White or Hispanic caregivers to go to a house of worship to help them manage both cognitive (47 percent vs. 23 percent and 17 percent) and behavioral (39 percent vs. 23 percent and 14 percent) symptoms.
- Black/African American (70 percent) are more likely than White caregivers (44 percent) to say adult day programs and support groups for diagnosed individuals help reduce behaviors.
- Women (35 percent) are less likely than men to feel they cope well with aggression (48 percent).
- Hispanic (23 percent) are more likely than White (13 percent) and Black/African American caregivers (seven percent) to have sought professional mental help for themselves due to their loved one's behaviors.

Alzheimer's Disease

- Currently, an estimated 5.1 million Americans have been diagnosed with Alzheimer's disease.
- Advanced age is the greatest known risk factor, with the incidence of the disease doubling every five years beyond age 65.
- Studies show that 60 percent to 80 percent of people with the brain disorder may experience behavioral and psychological symptoms at any given time. Someone has a 90 percent risk of developing these symptoms during the progression of the disease, especially in the advanced stages.
- Alzheimer's disease is the sixth leading cause of the death in the United States.

The full report and complete methodology can be found at <http://goo.gl/48VXK>.

AFA provides information about behavioral challenges on its Web sites, www.alzfdn.org and www.carecrossroads.org, and operates a toll-free helpline (866-232-8484) with licensed social workers who can answer questions related to these and other issues.