

AHEAD OF WHAT'S NEXT.

Alzheimer's Caregivers: Behavioral vs. Cognitive Challenges

Prepared for the Alzheimer's Foundation of America
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Background & Objectives

The Alzheimer's Foundation of America is interested in the issues and concerns that affect Alzheimer's caregivers.

- **Key objectives of this study were to:**
 - Examine caregivers' awareness and management of Alzheimer's-related behavioral and cognitive symptoms;
 - Understand the types of support caregivers have in managing Alzheimer's symptoms;
 - Assess the impact that behavioral and cognitive symptoms have on caregivers; and
 - Evaluate options that caregivers may consider for future care.

- **Results from this study are intended for public release.**

Method

This survey was conducted online in the United States by Harris Interactive on behalf of the Alzheimer's Foundation of America from April 11 - May 1, 2012.

The survey was conducted among 750 U.S. adults who are caregivers of individuals with Alzheimer's. Qualified respondents were U.S. adults (18+) who care for, but are not professional caregivers, of someone with Alzheimer's who lives alone or with the caregiver.

All sample surveys and polls, whether or not they use probability sampling, are subject to multiple sources of error which are most often not possible to quantify or estimate, including sampling error, coverage error, error associated with non-response, error associated with question wording and response options, and post-survey weighting and adjustments. Therefore, Harris Interactive avoids the words "margin of error" as they are misleading. All that can be calculated are different possible sampling errors with different probabilities for pure, unweighted, random samples with 100% response rates. These are only theoretical because no published polls come close to this ideal.

In reviewing this report, please note that:

- Percentages may not add up to 100% due to rounding, the acceptance of multiple responses, or the exclusion of any "not sure" or "decline to answer" responses.
- An asterisk (*) signifies a value of less than one-half percent. A dash (-) represents a value of zero.
- Throughout the report,
 - The term "behavioral symptoms" are those such as aggression, withdrawal, wandering, and irritability
 - The term "cognitive symptoms" are those such as memory loss and confusion

Summary of Findings

Caregiver Awareness of Alzheimer's Behavioral and Cognitive Symptoms Prior to Diagnosis

The majority of caregivers say that at the time of Alzheimer's diagnosis, they were aware that the disease has behavioral as well as cognitive symptoms. Despite this knowledge, many caregivers interpreted the person they care for behaviors as a normal part of aging. Caregivers surveyed now believe that those false impressions delayed the Alzheimer's diagnosis.

- Of those who provided care prior to diagnosis, nearly three-quarters (72%) say that at the time of diagnosis, they were aware that Alzheimer's has behavioral symptoms and cognitive symptoms.
- Two-thirds of those (64%) who provided care prior to diagnosis say that (at that time) they thought the behaviors just a normal part of aging.
- Among these caregivers, two-thirds (67%) state that these thoughts delayed the diagnosis of Alzheimer's.

Ultimately, it appears that cognitive symptoms gave the caregivers a stronger indication that a visit to the doctor was necessary.

- For the majority of caregivers, mostly or only cognitive symptoms (41%) or a combination of cognitive and behavioral symptoms (40%) contributed to the doctor's visit that ultimately resulted in the Alzheimer's diagnosis.
- Behavioral symptoms were less likely to have been the main reason that prompted the doctor's visit, with only 12% saying that it was mostly or only behavioral symptoms that contributed to the visit.
 - White caregivers (44%) are more likely than Black/African American (28%) or Hispanic (22%) caregivers to say that it was mostly or only cognitive symptoms that contributed to the doctor's visit.

Summary of Findings (cont.)

Knowledge and Management of Alzheimer's Behavior and Cognitive Symptoms

Caregivers indicate they are slightly more informed about the cognitive symptoms associated with Alzheimer's than the behavioral symptoms. A sizeable portion of caregivers also feel more capable of managing cognitive than behavioral ones.

- A small majority of caregivers state they are very well or well informed about cognitive (65%) and behavioral (57%) symptoms associated with Alzheimer's.
 - Around two in ten say they feel *very* well informed about cognitive (25%) or behavioral symptoms (20%).
- When it comes to managing the cognitive and behavioral symptoms of Alzheimer's, around one-half of caregivers (48%) state they manage cognitive and behavioral symptoms equally well.
- For other caregivers, many say they manage cognitive symptoms better than behavioral symptoms:
 - Nearly four in ten (38%) say they manage the cognitive symptoms better, while around one in ten (14%) believe they manage behavioral symptoms better.
 - Black/African American are more likely than White caregivers to believe they manage behavioral symptoms better (27% vs. 13%).

Although some caregivers state they do not manage behavioral symptoms as well as cognitive ones, caregivers overall do try to learn about ways to manage behavioral symptoms and report they speak with treating physicians about both types of symptoms.

- Nearly six in ten caregivers (59%) say they talk to the person they care for's treating physician equally about behavioral and cognitive symptoms.
 - Around one in ten (13%) say that they talk to the treating physician **more** about behavioral than cognitive symptoms.
 - Around two in ten (18%) say that they talk to the treating physician **less** about behavioral than cognitive symptoms.

Summary of Findings (cont.)

- Nearly all caregivers say they have learned ways to manage the person they care for's behavioral symptoms. While the most common way is speaking with healthcare professionals (67%), such as the treating physician (59%), social worker (17%), or another type of healthcare professional (24%), caregivers have also looked to other resources:
 - Around four in ten have looked at books or brochures (44%) or looked online (40%), which includes online resources, such as a website or webinar (36%) or an online caregiver chat/discussion board (9%).
 - Around one-third have also learned about ways to manage behavioral symptoms through family members (33%) or Alzheimer's agencies (29%).

Specific Behaviors that Caregivers Manage

Caregivers see a variety of behaviors in the person they care for, ranging from mild behaviors, such as sleeplessness, to more severe ones, such as anger or aggression.

- The most frequent behaviors that caregivers experience (daily to once a week) are irritability (58%), sundowning (57%), anxiety (55%), sleeplessness (51%), personality changes (49%), and anger (45%).
 - Black/African American and Hispanic caregivers are more likely than White caregivers to report the person they care for exhibits aggression, delusions and/or hallucinations.

Summary of Findings (cont.)

Caregivers have mixed feelings on how well they are coping with the Alzheimer's-related behaviors in the person they care for. About one-half believe that they are coping very well or well. There are a few behaviors exhibited such as irritability and anger, that caregivers feel they are less able to cope well with.

- While around one-half of caregivers say they are coping very well or well with the person they provide care to's involuntary outbursts of crying or laughing (54%), delusions and/or hallucinations (53%), anxiety (52%), wandering (50%), sleeplessness (49%), or sundowning (47%), fewer feel they are coping well with more severe behaviors and emotions such as paranoia and/or suspiciousness (45%), personality changes (44%), aggression (41%), inappropriate sexual behavior (41%), anger (39%), or irritability (38%).
 - Female are less likely than male caregivers to feel they are well able to cope with aggressive behavior (35% vs. 48%).

Caregivers report the main symptoms the person they care for currently displays that were not exhibited prior to diagnosis are personality changes and sundowning.

- Slightly more than four in ten caregivers say the person they care for currently experience personality changes (45%) and sundowning (44%) versus prior to diagnosis.
 - Black/African American caregivers are more likely than White caregivers to say that the person they care for did not exhibit aggression prior to diagnosis (42% vs. 24%).

As for the factors that can trigger behavioral symptoms, frustration is most frequently cited.

- Two-thirds of caregivers (67%) say that frustration is a trigger for the person they care for, followed by unfamiliar surroundings (43%); a desire to go "home" (37%); unfamiliar people (34%); activities of daily living, like bathing or dressing (31%); excessive environmental stimuli (e.g., noise) (29%); and fear (27%).

Summary of Findings (cont.)

Caregiver Management of *Behavioral* Symptoms

Caregivers talk to and/or confide in a variety of people about the behavioral symptoms of the person they care for. Caregivers typically seek support most from family, friends, and treating physicians.

- Six in ten talk to and/or confide in family members who do not share caregiving responsibilities (64%), friends (62%), and the treating physician (60%).
- Other individuals caregivers speak to are people who share the caregiving responsibilities, such as other family members or professional caregivers (40%).
- About one-quarter (23%) talk to or confide in healthcare professionals who are not the treating physician or a social worker, while fewer talk to actual social workers (11%).

Summary of Findings (cont.)

Treatments and Interventions Used for *Behavioral* Symptoms

Medication

Of caregivers who talk to and/or confide in treating physicians about the person they care for behavioral symptoms, medication is the treatment or intervention most often recommended.

- Eight in ten of these caregivers (80%) report the treating physician has suggested some type of medication. Caregivers often state the treating physician suggested a name brand medication specifically for Alzheimer's, such as Aricept or Exelon (67%), followed by generic medications specifically for Alzheimer's, such as donepezil hydrochloride (30%). One-quarter of these caregivers (26%) also state the treating physician suggested other medications for specific behaviors, aside from those specifically approved for Alzheimer's.
- For the patients taking these medications, the medications seem to be helping the behavioral symptoms to some extent – 68% of caregivers of patients who take Razadyne/galantamine hydrobromide say that it has helped at least a little, 62% say the same for Exelone/rivastigmine, 59% for Aricept/donepezil hydrochloride, and 51% for Namenda/memantine HCl.
 - A few say Exelon (27%), Namenda (21%) Aricept (19%) and Razadyne (13%) has helped “a lot.”
- Among caregivers for who the person they care for's treating physician recommended medications to treat specific behaviors, anti-depressants (e.g., Celexa, Zoloft) were most recommended (45%); followed by anti-anxiety medications (28%), antipsychotics (21%) and mood stabilizers (12%).

Summary of Findings (cont.)

There is reluctance among caregivers to consider clinical trials related to medication specifically used to control the behavioral symptoms of Alzheimer's or a related dementia.

- Only one-quarter of caregivers (24%) say they are likely to consider a clinical trial, with more than half (55%) saying that they are somewhat or not at all likely to consider this.
 - Hispanic caregivers (22%) are more likely than White (9%) or Black/African American (7%) caregivers to be very likely to consider a clinical trial.
 - Male caregivers are more likely than females to consider clinical trials (32% vs. 20%).

Non-drug Interventions

While medications help Alzheimer's patients with behavioral symptoms to some extent, caregivers indicate slightly more success using various non-drug interventions.

- Caregivers mention that in addition to receiving suggestions for medication to treat behavioral symptoms, a majority of treating physicians have also suggested sticking to routines (62%), as well as other non-drug options such as communication techniques (37%), support services for either the caregiver (28%) or for the diagnosed individual (27%), environmental changes (28%), and distraction/redirection especially during bathing, dressing and other daily activities (25%).
- Caregivers confirm that some of these non-drug options can be effective at managing behavioral symptoms. One that is particularly effective is sticking to routines – 91% say it has helped at least “a little”, including 53% who say it has helped “a lot.” Other options that have helped at least a little include: speaking slowly and simply (81%), distracting/redirection to positive activities (81%), providing positive reinforcement/reassurance (81%), and watching TV (75%).
 - About one-third of caregivers say that these non-drug interventions help “a lot.”

Summary of Findings (cont.)

Impact of Behavioral and Cognitive Symptoms on Caregivers' Lives

As expected, caregivers report their lives have been affected by the person they care for's symptoms. However, the activities that have been impacted do not differ for behavioral and cognitive symptoms.

- Some caregivers have stopped or decreased spending time with friends and family (behavioral: 43%, cognitive: 45%), given-up recreational activities (behavioral: 39%, cognitive: 37%), or stopped or decreased time at work (behavioral: 26%, cognitive: 29%).
- Fewer have stopped physical exercise (behavioral: 18%, cognitive: 17%), sought professional mental health (behavioral: 15%, cognitive: 13%), begun or increased their smoking (behavioral: 5%, cognitive: 6%), or ended a relationship (4% for each).
 - Hispanics are more likely than Black/African-American caregivers to have sought professional mental help for themselves (23% vs. 7%).

Caregivers also report experiencing health changes as a result of providing care . These changes, however, generally do not differ based on the symptoms that they are managing.

- Caregivers most often say fatigue (behavioral: 56%, cognitive: 55%) and difficulty sleeping (behavioral: 50%, cognitive: 47%) are top ailments followed by headaches (behavioral: 27%, cognitive: 23%) and weight gain (behavioral: 22%, cognitive: 25%).
- Some caregivers experience back pain particularly for behavioral versus cognitive symptoms (23% vs. 16%).
- Few caregivers (less than one in six) say that they have experienced a major decline in mental or physical health because of behavioral or cognitive symptoms. Less than one in ten report weight loss or more frequent colds/infections.
 - Hispanic caregivers are more likely than White caregivers to say they have experienced a major decline in mental health due to cognitive behaviors (23% vs. 12%).

Summary of Findings (cont.)

Caregiver Support Managing Behavioral and Cognitive Symptoms

Caregivers turn to various means to help cope when they are managing care for a person with Alzheimer's-related behavioral or cognitive symptoms. While they employ a range of methods, their preferences are generally the same regardless of the behavioral or cognitive symptoms.

- Nearly three-quarters of caregivers talk to family or friends to help them manage the symptoms (behavioral: 68%, cognitive: 70%). Around half also do physical activities, such as walking or running (behavioral: 54%, cognitive: 53%) or mental activities, such as reading a book or doing a crossword puzzle (behavioral: 48%, cognitive: 49%). They also are likely to accept offers of help from family, friends, or volunteers (behavioral: 45%, cognitive: 46%).
 - Black/African American caregivers are more likely than White or Hispanic caregivers to go to a house of worship for both behavioral and cognitive symptoms. For behavioral symptoms, Black caregivers are also more likely than Whites to seek different ways to manage symptoms, such as accepting offers of help from family, friends, or volunteers; using relaxation techniques; or relying on a home health aide/personal care aide.
- Fewer caregivers talk to a healthcare professional, such as a social worker or a doctor, when they are seeking personal help managing behavioral or cognitive symptoms. Only around four in ten caregivers say that they talk to a healthcare professional to help them manage with behavioral (43%) or cognitive (39%) symptoms.

Summary of Findings (cont.)

Getting a Professional Caregiver or Placing Person with Alzheimer's in Long-term Care

Perhaps unsurprisingly, there are circumstances in which Alzheimer's-related behavioral symptoms can push the caregiver to the point where they start to consider other options for additional help such as getting a paid professional to come into the home or placement into long-term care.

- For behaviors that are more manageable or less intrusive, caregivers seem to see less need for a professional caregiver or long-term care.
 - Around one-half of caregivers say that they *would not* consider either option for the person they care for when it comes to factors such as having medication management to control behavioral symptoms (50%), having professional expertise with non-pharmacological interventions (51%), or even when the person's behavior is affecting the caregiver's ability to go to work (48%).
- When the afflicted behavior starts to impact the caregiver's physical or mental health, caregivers are somewhat more receptive to hiring a paid professional (impacting physical health: 42%, impacting mental health: 40%).
- When the person cared for behavior becomes more severe and puts the caregiver or individual with Alzheimer's at greater physical risk, or when the loved one's health deteriorates, caregivers are more likely to consider placing their loved one into long-term care.
 - About half of caregivers say they would consider long-term care if the person they care for aggression becomes too difficult to handle (59%), the afflicted self-harms (54%), if they fear injury or harm to themselves (45%) or other family members (48%), if afflicted is barely aware of his or her surroundings (45%), or if there are other chronic medical conditions in addition to Alzheimer's (44%).

Summary of Findings (cont.)

- White caregivers are more likely than Black/African Americans to consider placing the person they care for in long-term care if the person has a chronic medical condition in addition to Alzheimer's (46% vs. 30%), if the person is barely aware of his/her surroundings (48% vs. 27%), if the person's aggression is too difficult to handle (62% vs. 43%), or if the person self-harms (55% vs. 40%).
- Black/African Americans are more likely than White caregivers to hire a professional if the person is barely aware of his/her surroundings (40% vs. 26%).
- Hispanics are more likely than Black/African American caregivers to place the person they care for in long-term care if the person's behavior impacts their ability to go to work (35% vs. 20%).
- Female caregivers are more likely than their male counterparts to consider placing their loved one in long-term care if they have a fear of injury/harm for themselves (52% vs. 35%) or for other family members (53% vs. 40%)
- When the individual begins to wander, caregivers are split on how they would deal with this – about a third (32%) would hire a professional caregiver, slightly more than a third (37%) would place the loved one into a long-term care facility, and the remainder (36%) would not consider either option.

Summary of Findings (cont.)

Caregiver and Patient Profile

Caregivers in this study:

- Are mostly females (61%); rising to 86% female among Black/African Americans
- On average are 56 years old; though Black/African Americans (47 years old) and Hispanics (47 years old) are younger compared to Whites (58 years old)
- Tend to provide care to and reside with female family member (77% live with the Alzheimer's patient; 62% provide care for a female)
- Are most likely to look after a parent (56%), followed by a spouse (26%); White caregivers (31%) are more likely than Black/African American (1%) or Hispanic (14%) caregivers to care for a spouse who has Alzheimer's
- On average, the Alzheimer's diagnoses was 4.5 years ago; Hispanic caregivers are more likely than White caregivers to be caring for someone who was diagnosed with Alzheimer's for a longer period of time (6 years vs. 4.4 years)
- On average, have spent 4.1 years providing care for their loved one with Alzheimer's
- On average, spend about 57.2 hours per week providing care for their loved one; those who live with the person with Alzheimer's spend more than triple the amount of time than those who do not live with the Alzheimer's patient (67.9 hours vs. 21.9 hours)
- Are more likely to be employed full-time or self-employed (35%) or retired (37%); one in ten (11%) are employed part-time
- Are more likely to care for a person who takes Aricept/donepezil hydrochloride (49%), followed by Namenda/memantine HCl (36%), Exelon/rivastigmine (14%), and Razadyne/galantamine hydrobomide (6%). Sixteen percent are not sure what medication the person takes; ten 10% say the person takes another medication.

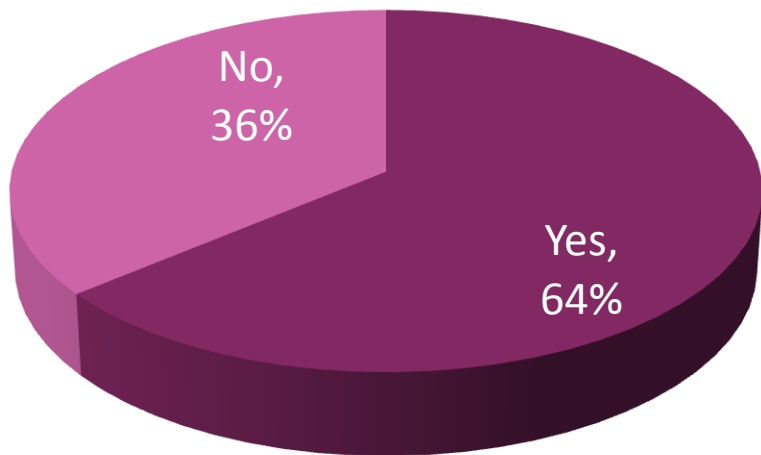


Detailed Findings

Prior to Alzheimer's diagnosis, six in ten caregivers thought their loved one's behaviors were a normal part of aging. Of those, two-thirds believe this thinking delayed the actual diagnosis.

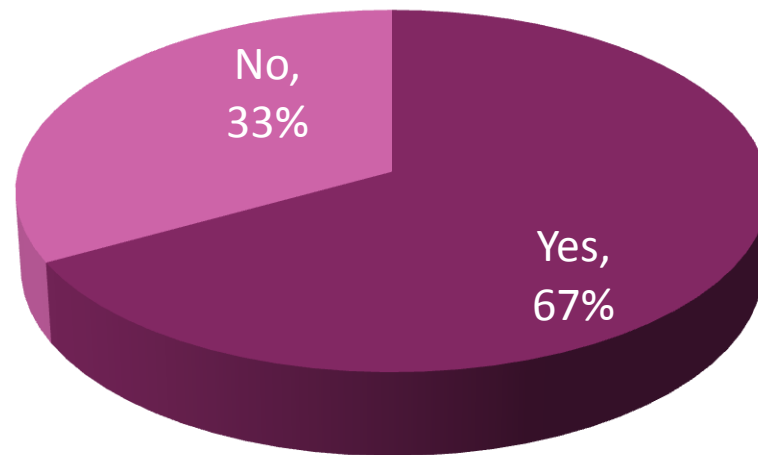
Prior to Diagnosis, % of Caregivers Who Thought Behaviors of Person They Care For Were a Normal Part Aging

(Among those who cared for person with Alzheimer's prior to diagnosis)



% of Caregivers Who Believe Diagnosis Was Delayed Because Thought Behaviors Were a Normal Part of Aging

(Among those who cared for person with Alzheimer's prior to diagnosis)



Base: Caregivers who cared for the person with Alzheimer's prior to diagnosis (n=716)

Q735. Prior to the person you care for's diagnosis of Alzheimer's disease or a related dementia, did you think any of his/her behaviors were a normal part of aging?

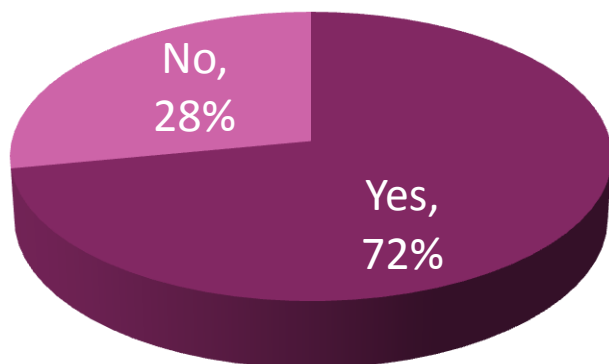
Base: Caregivers who thought that behaviors were a normal part of aging (n=482)

Q740. Did thinking that the person you care for's behaviors were a normal part of aging delay the diagnosis of Alzheimer's disease or related dementia?

Seven in ten caregivers were aware Alzheimer's has behavioral and cognitive symptoms prior to diagnosis. Most caregivers say it was a combination of behavioral and cognitive symptoms, or (only or mostly) cognitive symptoms, that contributed to the doctor's visit that resulted in the diagnosis.

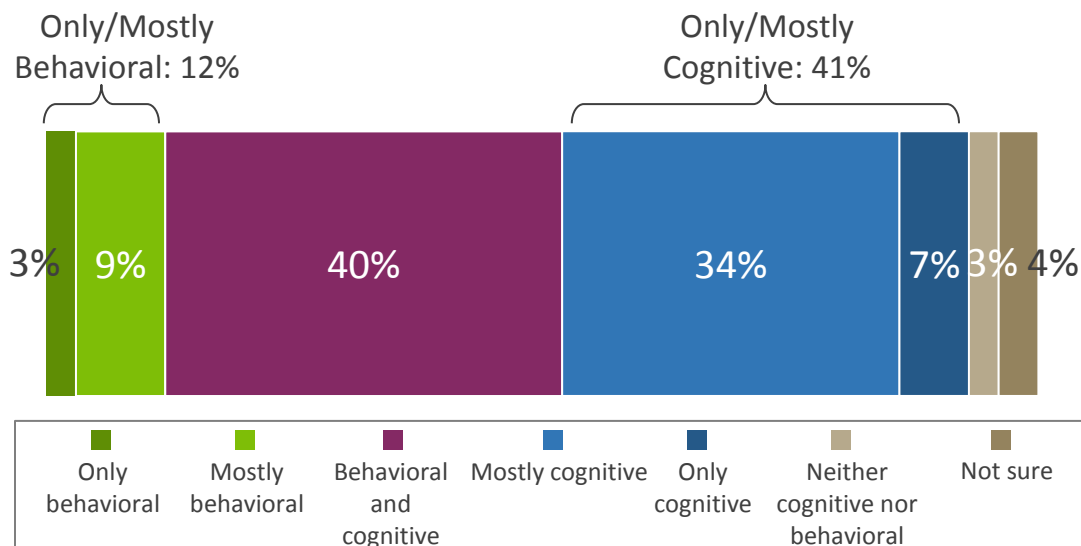
Prior to Diagnosis, % of Caretakers Who Were Aware Alzheimer's Typically Has Behavioral and Cognitive Symptoms

(Among those who cared for person with Alzheimer's prior to diagnosis)



Type of Symptoms That Contributed to Doctor's Visit That Resulted Alzheimer's Diagnosis

(Among those who cared for person with Alzheimer's prior to diagnosis)



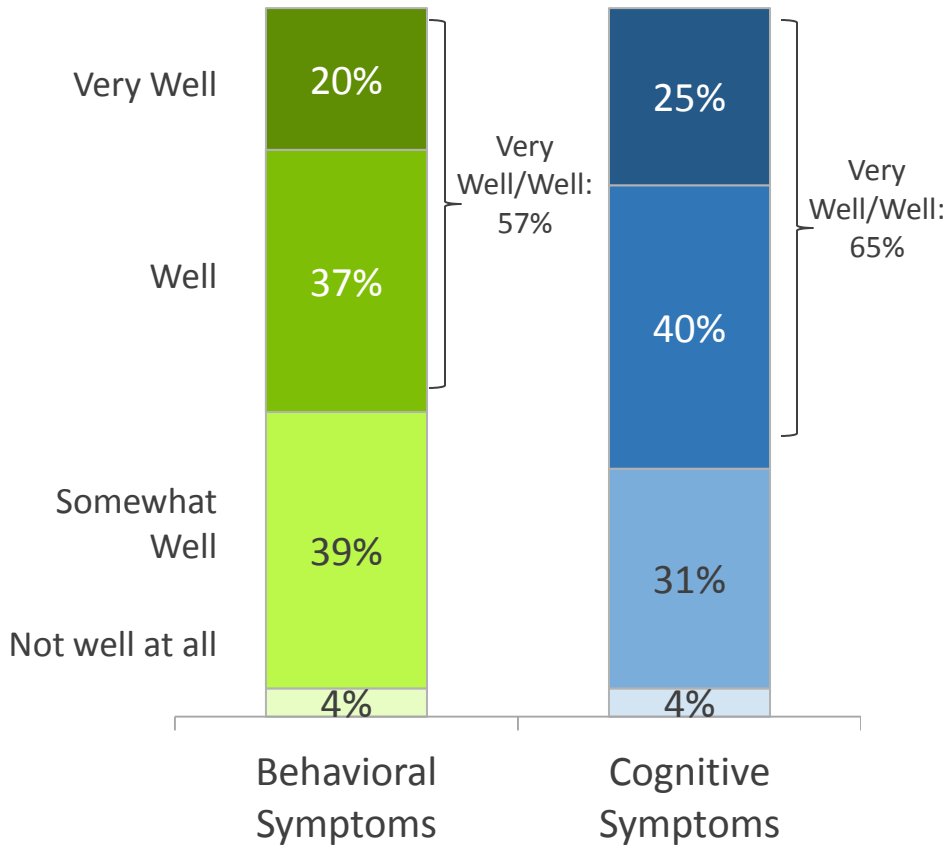
Race/
Ethnicity

White caregivers (44%) are more likely than **Black/African American** (28%) or **Hispanic** (22%) caregivers to say mostly or only cognitive symptoms contributed to the doctor's visit. **Hispanic caregivers** are more likely than **White caregivers** to say mostly or only behavioral symptoms prompted the visit (23% vs. 11%).

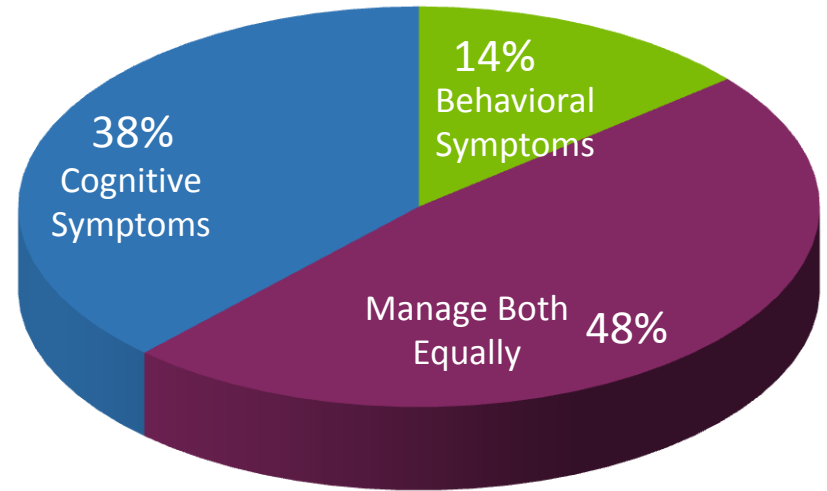
Base: Caregivers who cared for the person with Alzheimer's prior to diagnosis (n=721)
 Q745. When the person you care for was diagnosed with Alzheimer's disease or a related dementia, were you aware that the condition typically has behavioral symptoms in addition to cognitive symptoms?
 Base: Caregivers who cared for the person with Alzheimer's prior to diagnosis (n=730)
 Q750. Was it the behavioral and/or cognitive symptoms that contributed to the doctor's visit that ultimately resulted in the diagnosis of Alzheimer's disease or a related dementia in the person you care for?

Over half of caregivers say they are very well or well informed about the behavioral and cognitive symptoms associated with Alzheimer’s disease. About one-half also believe that they manage both symptoms equally well, although four in ten feel they manage cognitive symptoms better.

How Informed Caregiver Feels About Behavioral and Cognitive Symptoms



Symptoms Caregiver Manages Better

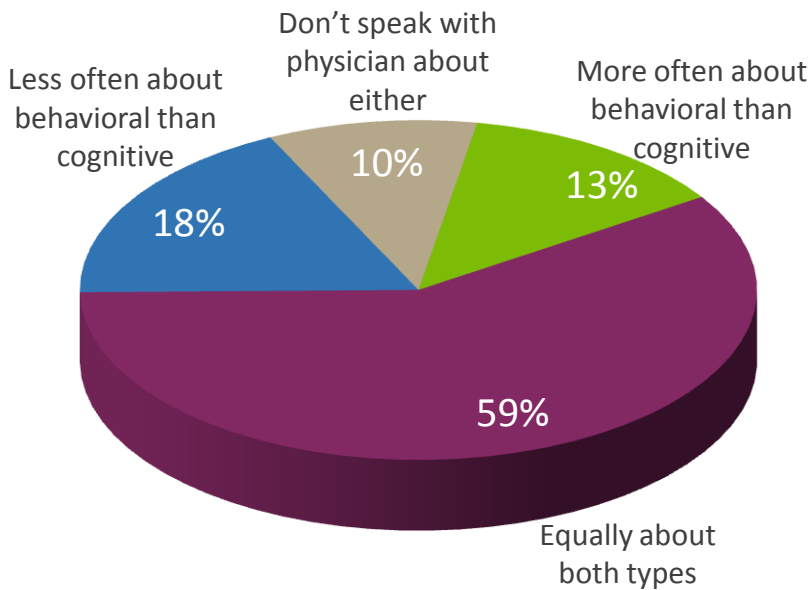


Race/Ethnicity
 Black/African American caregivers are more likely than White caregivers to feel they manage the behavioral symptoms better (27% vs. 13%).

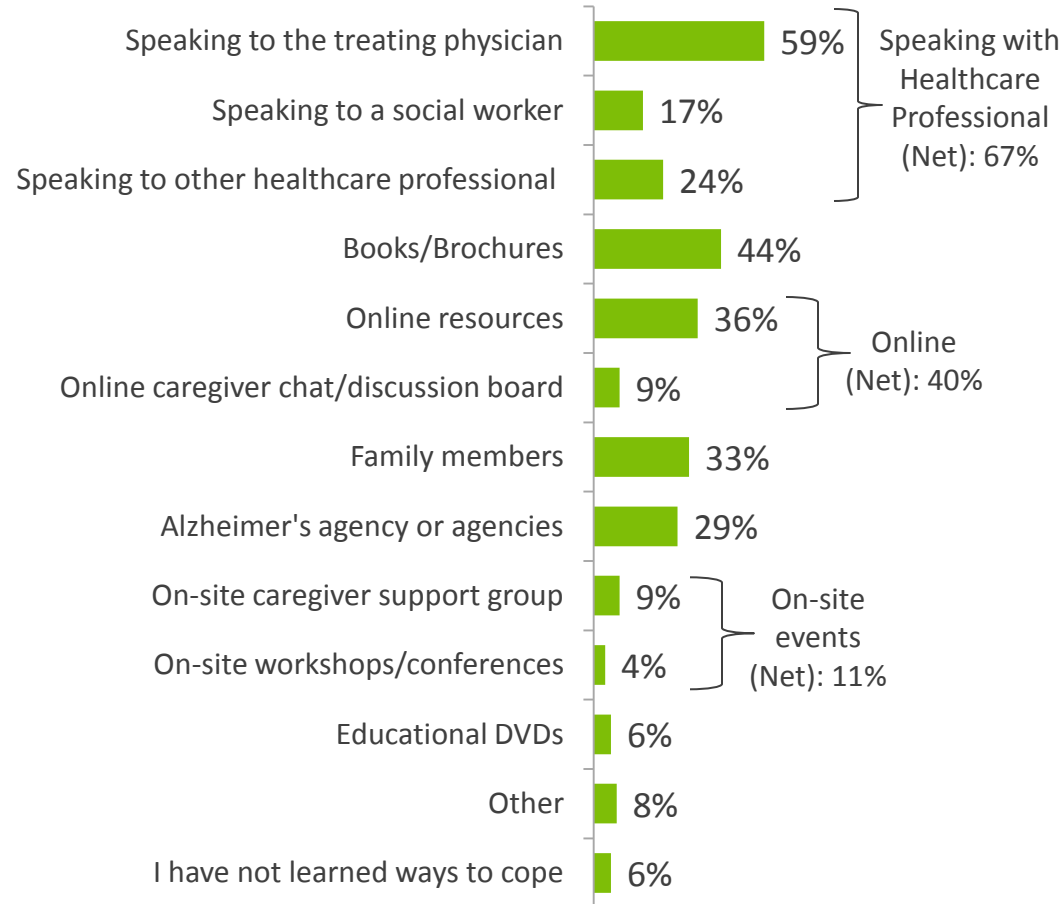
Base: Caregivers (n=750)
 Q915. Currently, how informed do you feel about the following types of symptoms associated with Alzheimer’s disease or a related dementia?
 Q925. How well do you manage with the cognitive symptoms as opposed to the behavioral symptoms of Alzheimer’s disease or related dementia in the person you provide care for?

Over one-half of caregivers report speaking with treating physicians equally about behavioral and cognitive symptoms. Caregivers are most likely to learn about ways to manage behavioral symptoms by speaking with healthcare professionals, reading books/brochures, or looking online.

Frequency of Caregiver Speaking with Treating Physician About Behavioral and Cognitive Symptoms



How Caregivers Learned Ways to Manage Behavioral Symptoms



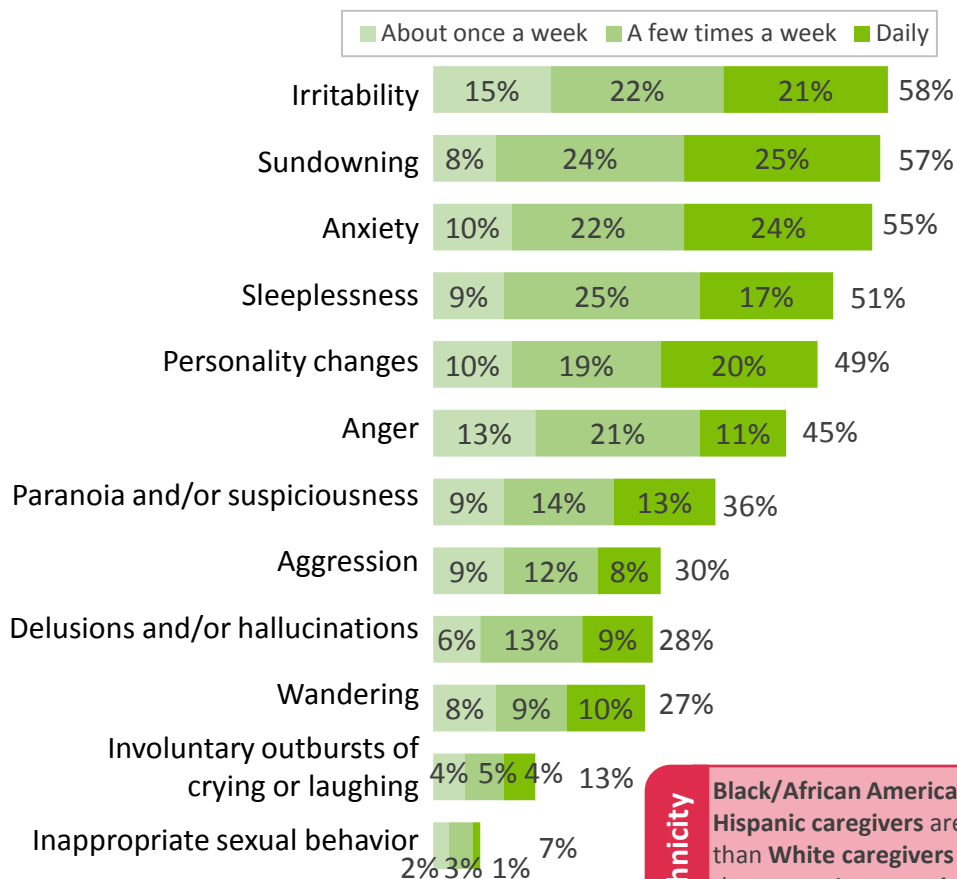
Base: Caregivers (n=750)

Q1005. How often do you speak with the treating physician about behavioral symptoms compared to cognitive symptoms in the person you care for with Alzheimer's disease or a related dementia?

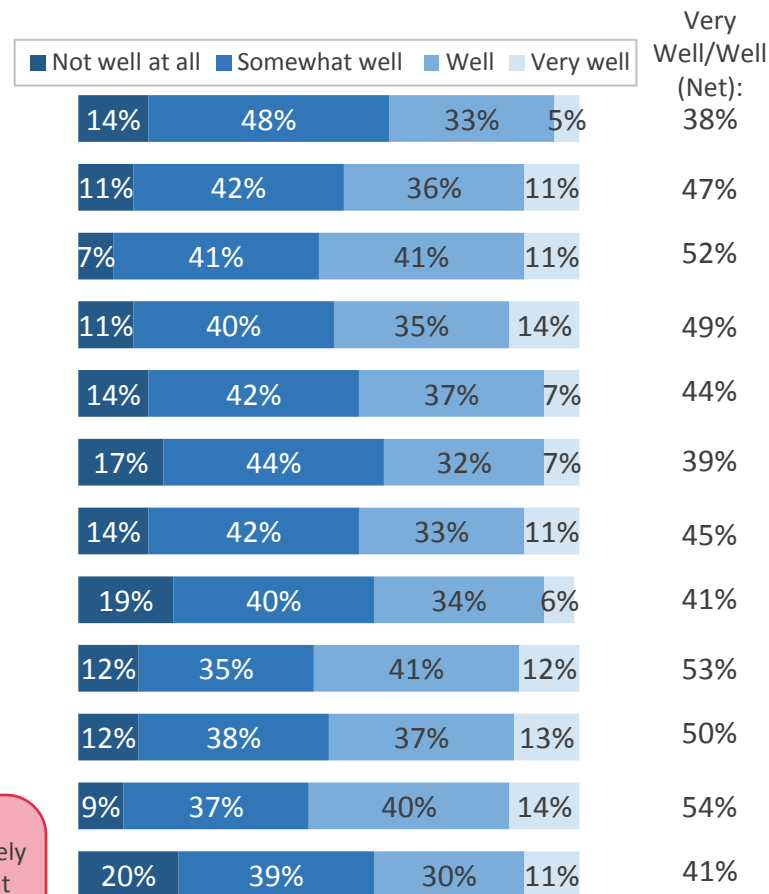
Q1045. How did you learn about ways to manage behavioral symptoms associated with Alzheimer's disease or a related dementia?

Caregivers report that irritability, sundowning, and anxiety are the three most frequent behaviors they see in the person with Alzheimer's. Caregivers vary in how well they feel they are coping with these behaviors.

Frequency of Behaviors Occurring in Alzheimer's Patient



How Well Caregiver is Coping with Behavior



Race/Ethnicity
 Black/African American and Hispanic caregivers are more likely than White caregivers to say that the person is **aggressive** (44% and 43% vs. 27%) or have **delusions and/or hallucinations** (41% and 44% vs. 26%).

Base: Caregivers (n=750)

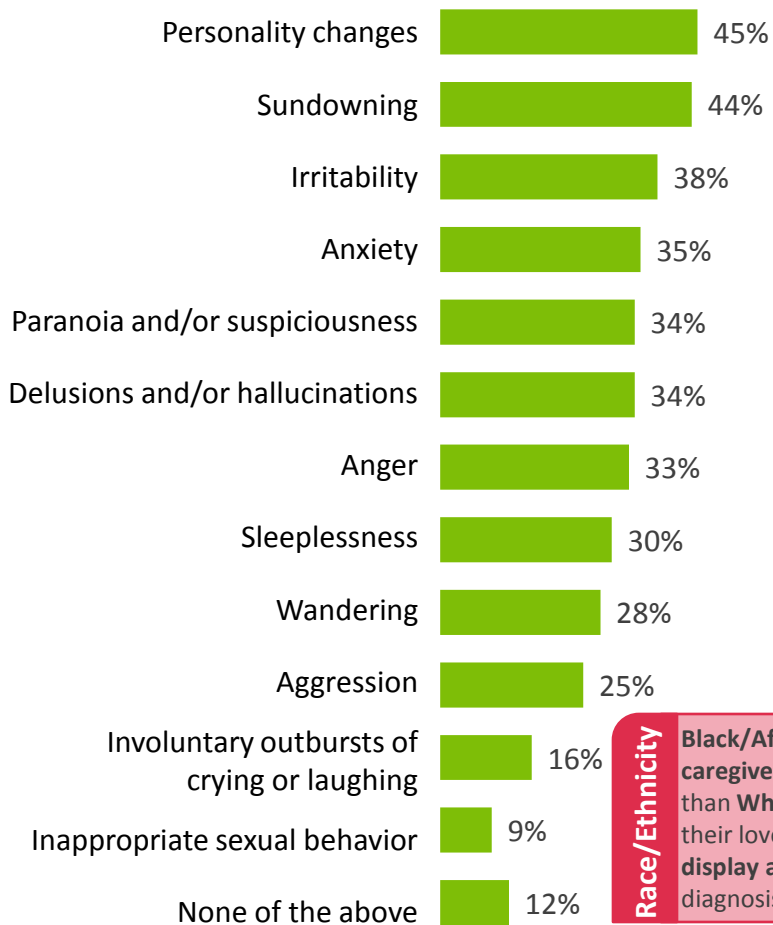
Q810. How often do the following behaviors occur in the person you care for with Alzheimer's disease or a related dementia?

Q815. As a caregiver, how well are you coping with the following behaviors in the person you care for with Alzheimer's disease or a related dementia?

Caregivers state the two main behaviors not present in the person prior to diagnosis are personality changes and sundowning. Two-thirds state frustration is a big trigger for behavioral symptoms.

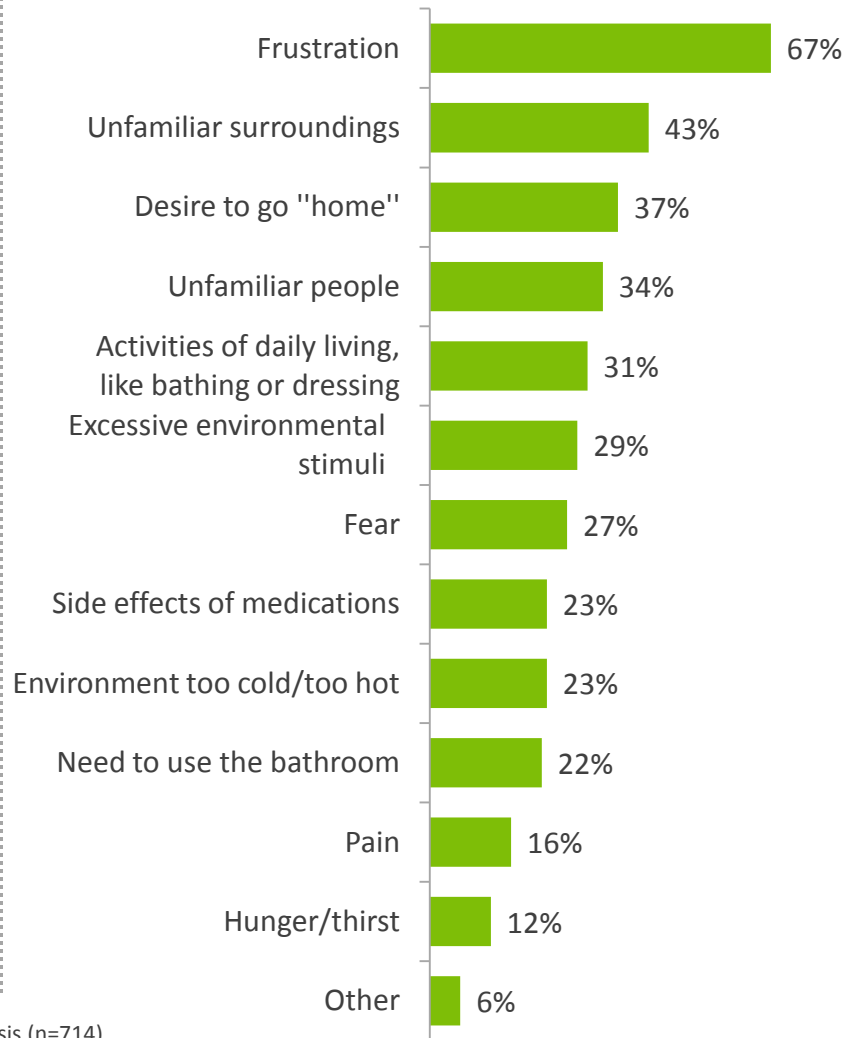
Current Behaviors Not Present Prior to Diagnosis

(Among those who cared for person with Alzheimer's prior to diagnosis)



Race/Ethnicity
 Black/African American caregivers are more likely than White caregivers to say their loved one **did not display aggression** prior to diagnosis (42% vs. 24%)

Triggers of Behavioral Symptoms



Base: Caregivers who cared for the person with Alzheimer's prior to diagnosis (n=714)

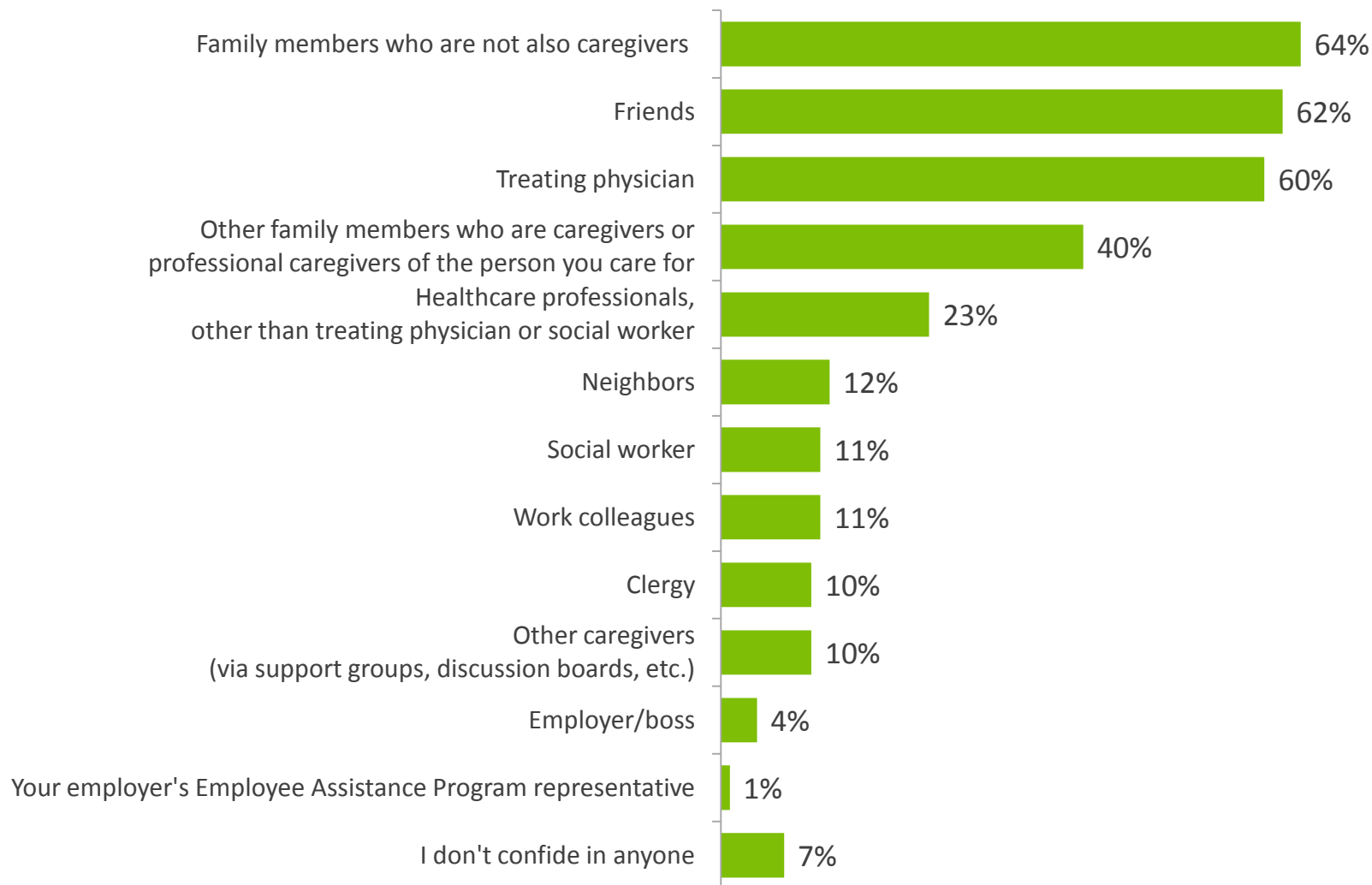
Q805. Which of the following behaviors does the person with Alzheimer's disease or a related dementia currently display that he or she did not display prior to diagnosis?

Base: Caregivers (n=750)

Q825. Which of the following have you been able to link as triggers of the behavioral symptoms of the person you care for?

Caregivers are most likely to talk to and/or confide in their family, friends, or treating physician about behavioral symptoms.

Who Caregivers Talk to and/or Confide In About Behavioral Symptoms



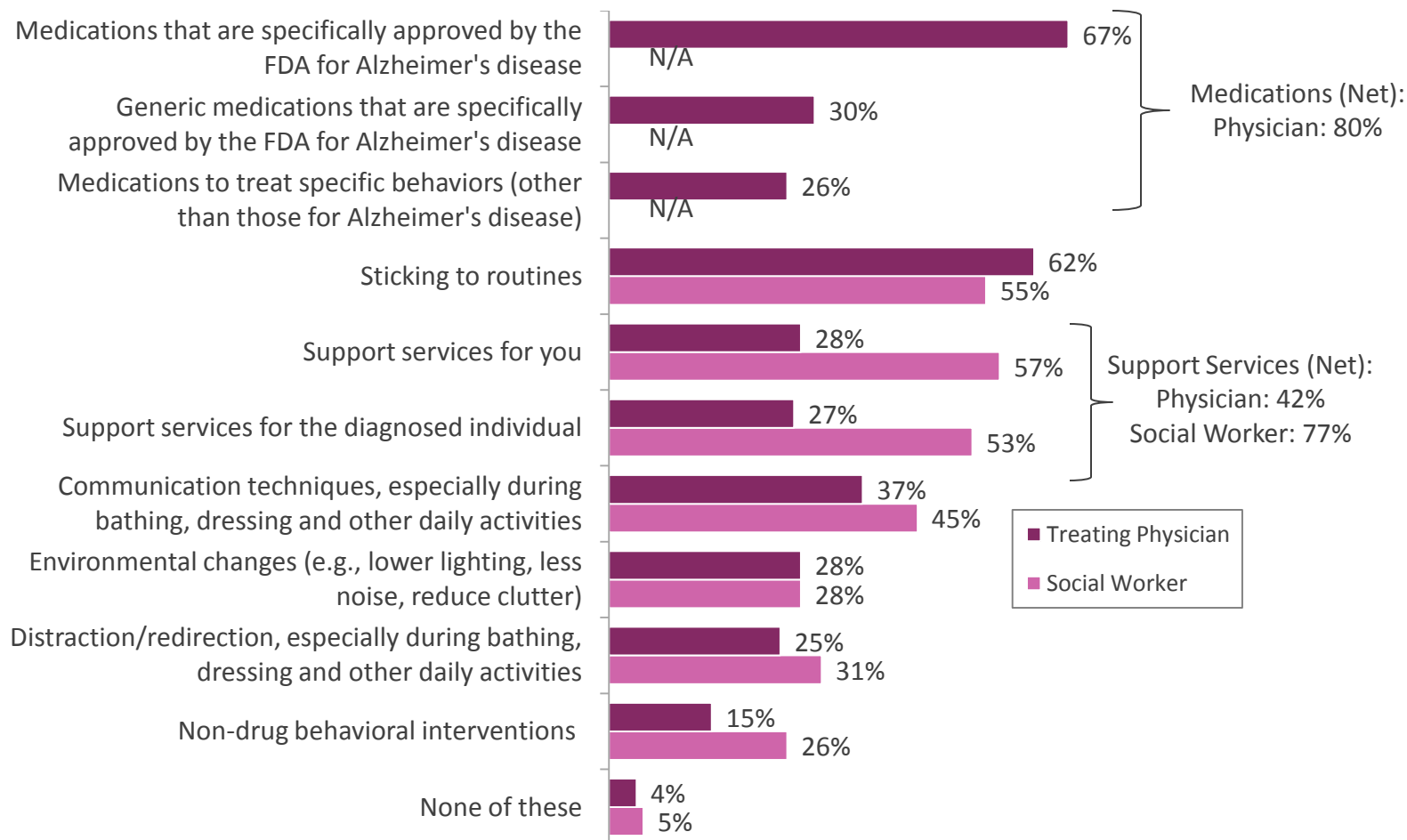
Base: Caregivers (n=750)

Q1010. Which of the following people do you talk to and/or confide in about the behavioral symptoms of the person you care for?

Among caregivers who have talked to treating physicians about behavioral symptoms, eight in ten say the physicians recommended medication. Other suggestions include sticking to routines, support services, and communication techniques.

Treatments and/or Interventions Healthcare Provider Suggested for Behavioral Symptoms

(Among those who talk to and/or confide in a treating physician or social worker)

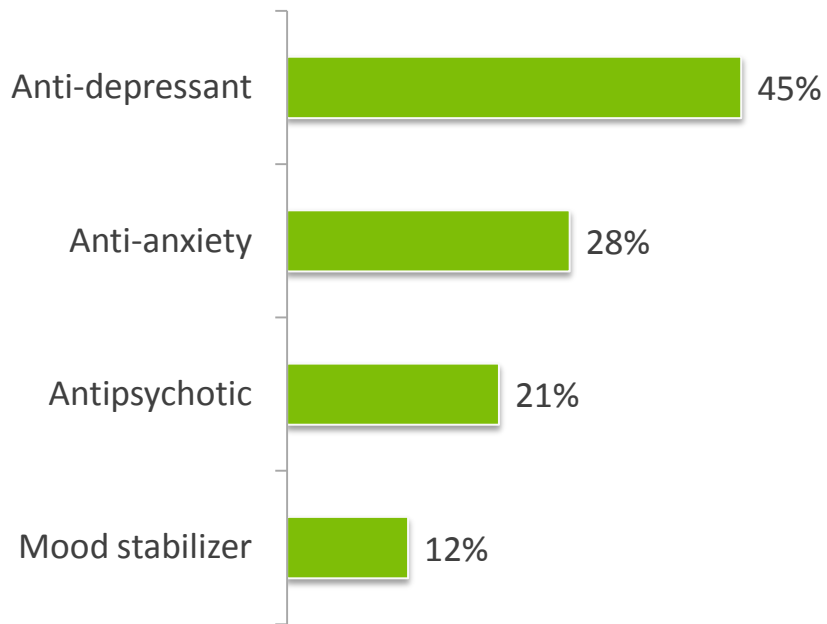


Base: Caregivers who talk to/confide in treating physician (n=445); Caregivers who talk to/confide in social worker (n=95)
 Q1020. Which of the following treatment(s) and/or intervention(s) for behavioral symptoms did the [insert healthcare provider selected at Q1010] you spoke with suggest?

Among caregivers who have received patient medication recommendations from treating physicians for specific behaviors, anti-depressants were most commonly recommended, followed by anti-anxiety and antipsychotic drugs. At least one-half of caregivers of patients who take Alzheimer’s-specific medication report those medications also help with behavioral symptoms to some extent.

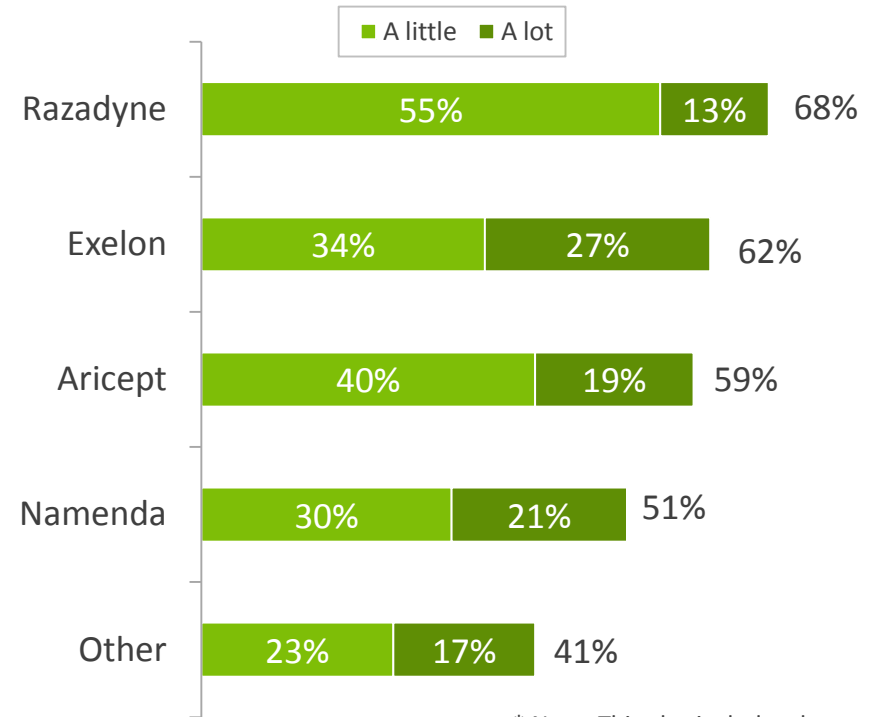
Types of Medications Suggested by Physician to Treat Specific Behaviors (other than those approved for Alzheimer’s)

(Among those who talk to treating physicians that have suggested medications for specific behaviors)



How Much Medications Help with Behavioral Symptoms

(Among caregivers of those who take medication*)



* Note: This also includes those who take the generic form of each medication

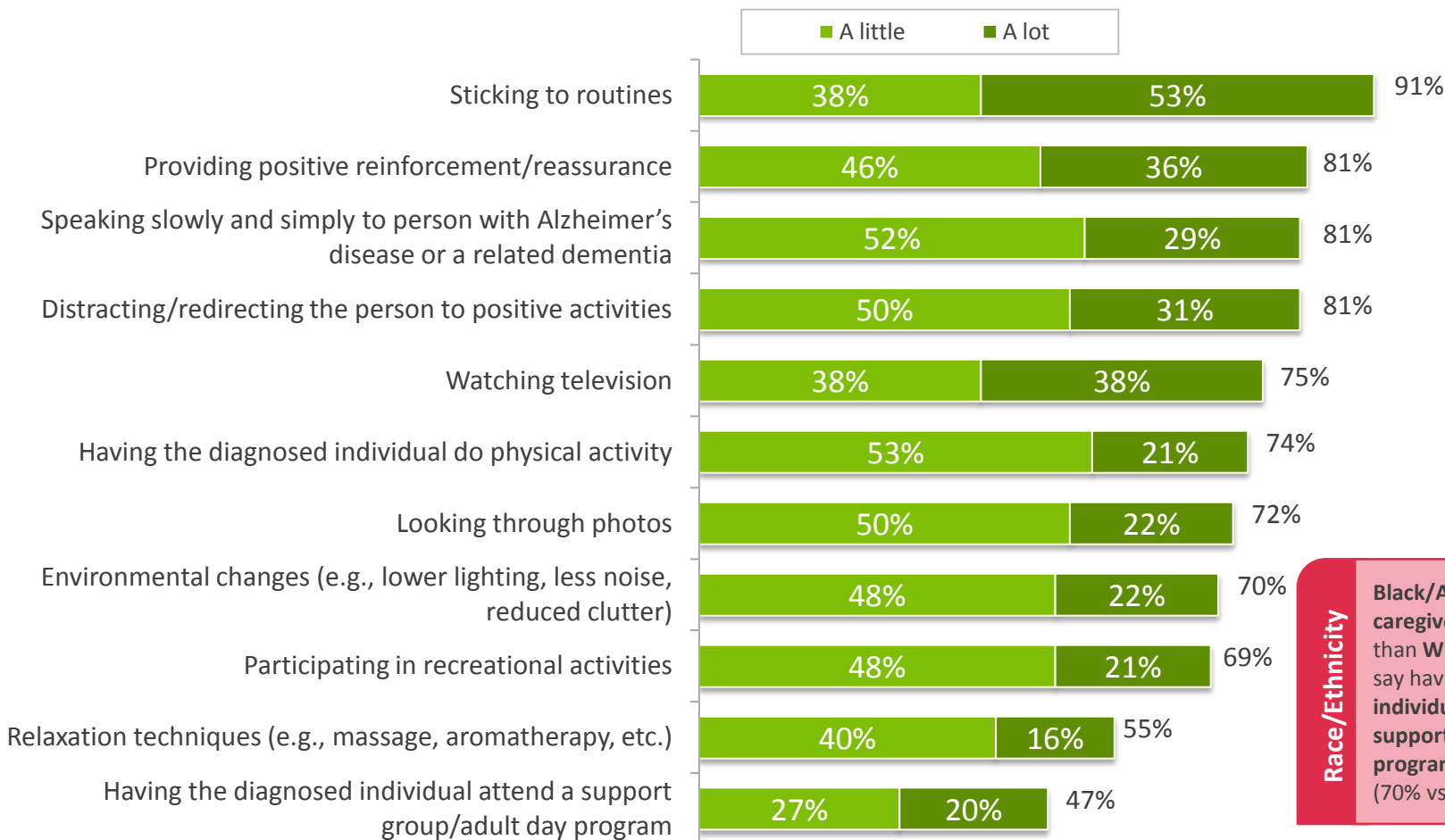
Base: Caregivers who talk to treating physicians that have suggested medications to treat specific behaviors (n=113)
 Q1025. You mentioned that the treating physician suggested medication(s) (**other than** Aricept, Exelon, Namenda, Razadyne, specifically approved for Alzheimer’s disease) to treat specific behaviors. Please let us which type of medications were suggested and if the person you care for is currently taking this type of medication.

Base: Caregivers of Alzheimer’s patients who take medication (variable bases)
 Q1035. You mentioned that the person you care for is currently taking the medication(s) below. How much do they help the behavioral symptoms of the person with Alzheimer’s or a related dementia that you care for?

Sticking to routines, providing positive reinforcement, speaking slowly and simply, and distracting/redirecting the person with Alzheimer's to positive activities are a few non-drug interventions caregivers feel are most effective in reducing behavioral symptoms.

Effectiveness of Non-drug Interventions in Helping Reduce Behavioral Symptoms

(Among those who have tried the intervention)

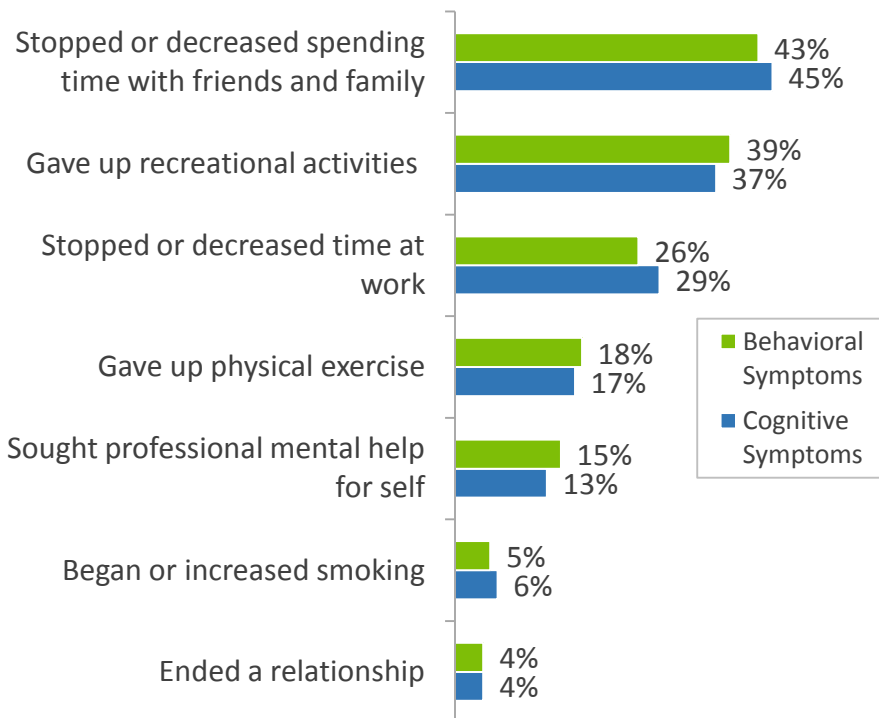


Race/Ethnicity
 Black/African American caregivers are more likely than White caregivers to say having the diagnosed individual attend a support group/adult day program helps a lot/a little (70% vs. 44%).

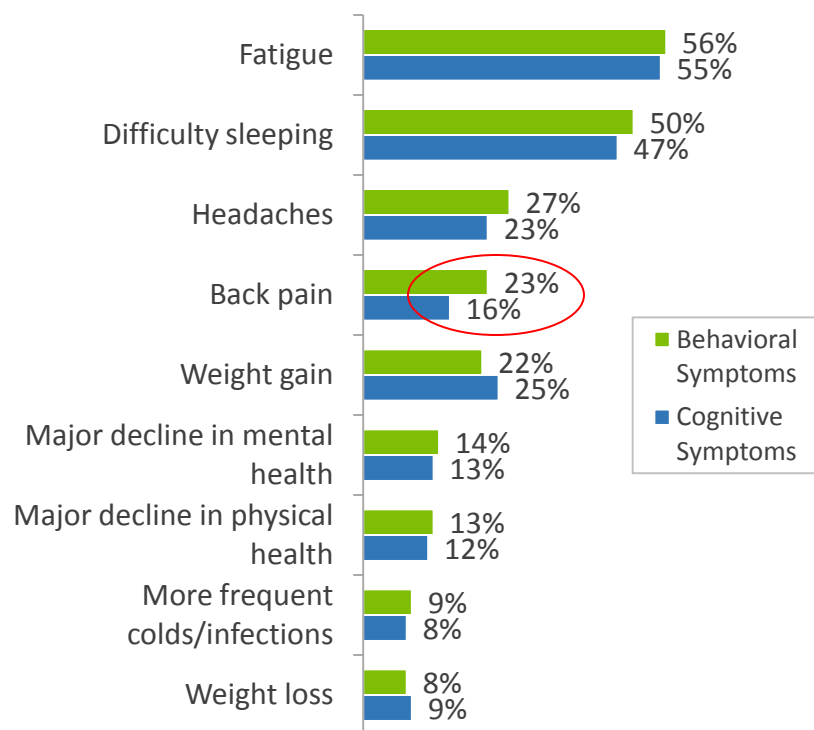
Base: Caregivers who have tried the interventions (variable bases)
 Q1040. How much has each of the following non-drug interventions (i.e., behavioral modifications and environmental change) that you may have tried, helped reduce the person you care for's behavioral symptoms associated with Alzheimer's disease or a related dementia?

Alzheimer's patients' behavioral and cognitive symptoms generally seem to impact caregivers' personal lives and health in the same way. Back pain is an exception as caregivers are more likely to blame behavioral versus cognitive symptoms for that particular ailment.

Activities Caregiver Has Done as a Result of Behavioral or Cognitive Symptoms



Health Changes Caregiver Has Experienced As a Result of Behavioral or Cognitive Symptoms



Race/
Ethnicity

Hispanic caregivers are more likely than Black/African American caregivers to say they have sought professional mental help for themselves as a result of behavioral symptoms of the person they care for (23% vs. 7%).

Race/
Ethnicity

Hispanic caregivers are more likely than White caregivers to say they have experienced a major decline in mental health due to cognitive symptoms of the person they care for (23% vs. 12%).

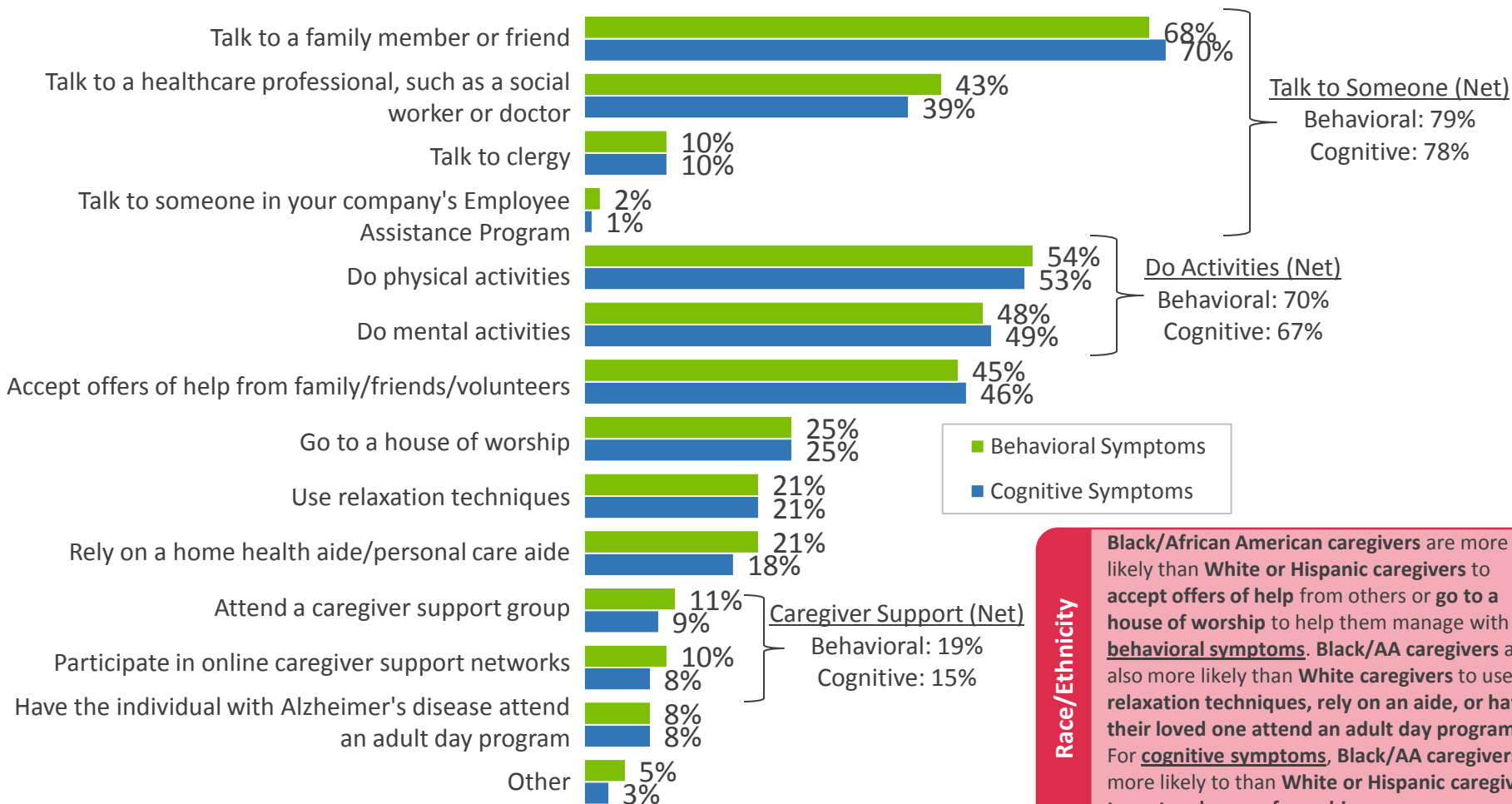
Base: Caregivers (n=750)

Q942. For each of the life experiences listed below, please tell us which ones you have done as a result of behavioral symptoms of the person you care for, and which ones you have done as a result of cognitive symptoms?

Q945. What changes, if any, have you experienced as a result of your loved one's behavioral symptoms and cognitive symptoms related to Alzheimer's disease or a related dementia?

Activities caregivers do to help them manage the person they care for's behavioral and cognitive symptoms are most commonly, talking to others, doing physical activities, and accepting offers of help.

What Caregiver Does to Help Manage Behavioral and Cognitive Symptoms



Race/Ethnicity

Black/African American caregivers are more likely than **White or Hispanic caregivers** to **accept offers of help** from others or **go to a house of worship** to help them manage with **behavioral symptoms**. **Black/AA caregivers** are also more likely than **White caregivers** to use **relaxation techniques**, **rely on an aide**, or **have their loved one attend an adult day program**. For **cognitive symptoms**, **Black/AA caregivers** are more likely to than **White or Hispanic caregivers** to **go to a house of worship**.

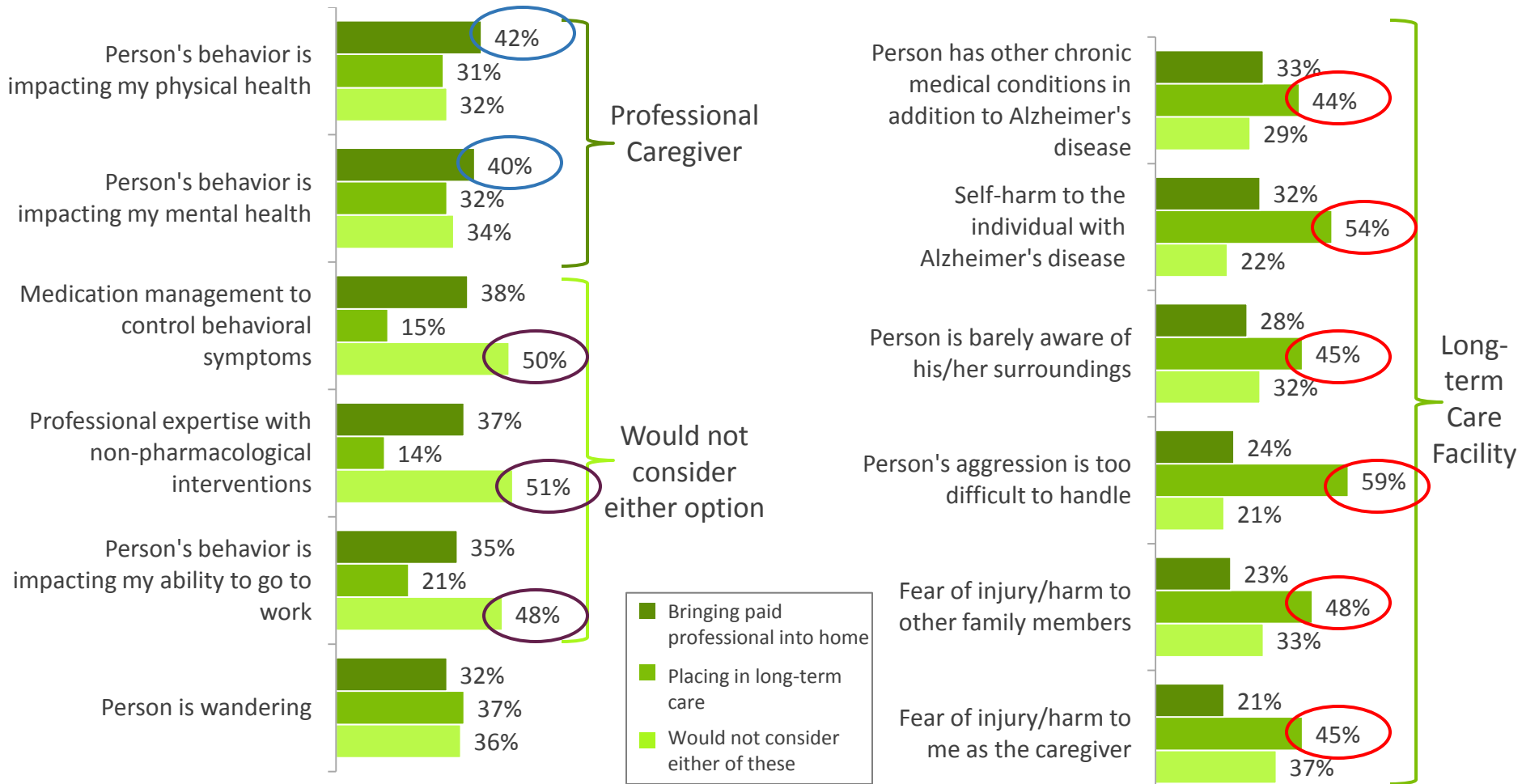
Base: Caregivers (n=750)

Q930. Which of the following do you do to help you manage with behavioral symptoms of the person you care for with Alzheimer's disease or a related dementia?

Q937. Which of the following do you do to help you manage with cognitive symptoms of the person you care for with Alzheimer's disease or a related dementia?

Caregivers are more willing to pay for professional help if the person they care for's behavior is impacting the caregiver's physical or mental health. Also, they are more receptive to placing them in long-term care if they feel there is possibility of physical harm or their health worsens.

Contributing Factors For Hiring Professional Caregiver or Placing in Long-Term Care

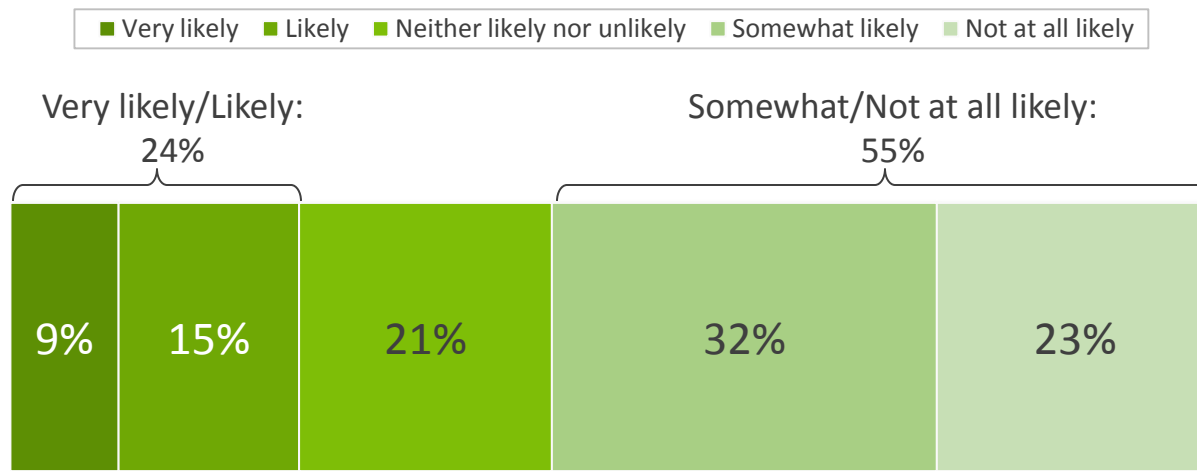


Base: Caregivers (n=750)

Q1105. Taking behavioral symptoms into account, which factors would contribute to bringing a paid professional caregiver into the home or placing the person you care for in a long-term care facility (i.e., assisted living facility, nursing home)?

Overall, caregivers do not seem to be receptive towards considering a clinical trial related to medication that would specifically control behavioral symptoms of Alzheimer's disease. Only about one-quarter say that they would be likely to consider this.

Likelihood to Consider a Clinical Trial for Medication that Specifically Controls Behavioral Symptoms



**Race/
Ethnicity**

Hispanic caregivers are more likely than **White or Black/African American caregivers** to say that they would be **very likely** to consider a clinical trial for medication that specifically controls behavioral symptoms (22% vs. 9% and 7%)

Base: Caregivers (n=750)
Q1115. How likely would you be to consider a clinical trial related to medication specifically to control behavioral symptoms of Alzheimer's disease or a related dementia?



Demographic Profile

Demographic Profile

	Total
Gender	%
Male	39
Female	61
Race/Ethnicity	%
White	81
Black/African American (NET)	8
Black	5
African American	3
Hispanic	7
Asian or Pacific Islander	2
Native American or Alaskan native	-
Mixed racial background	1
Other race	1
Decline to answer	-

	Total
Age	%
18-34	8
35-44	12
45-54	20
55-64	28
65+	32
Mean	56.5 years
Region	%
East	26
Midwest	22
South	35
West	17
Household Income	%
\$34,999 or less	22
\$35,000 - \$74,999	34
\$75,000 - \$124,999	20
\$125,000 or more	13
Median	\$52,000

Demographic Profile (cont.)

	Total
Length of Time Caring for Alzheimer's Patient	%
Less than 6 months	4
6 months to up to 1 year	10
1 year to up to 3 years	33
3 years to up to 5 years	26
5 years to up to 10 years	18
10 years or more	9
Mean	4.1 years
Hours per Week Spent Caring for Alzheimer's Patient	%
Less than 20 hours	32
21-40 hours	26
41-60 hours	9
61-80 hours	10
More than 80 hours	23
Mean	57.1 hours

	Total
Employment	%
Full time	29
Part time	11
Self-employed	6
Not employed, but looking for work	3
Not employed and not looking for work	2
Not employed, unable to work due to disability or illness	4
Retired	37
Student	2
Stay-at-home spouse or partner	7
Highest Level of Education	%
High school or less	23
Some college or associate degree	33
Completed college	19
Completed at least some graduate school	25

Demographic Profile (cont.)

	Total
Gender of Patient with Alzheimer's	%
Male	38
Female	62
Relationship to Caregiver	%
Parent	56
Spouse	26
Grandparent	10
Friend/neighbor	1
Sibling	1
Other	7
Living Situation	%
Lives alone	23
Lives with caregiver	77

	Total
Length of Time Since Diagnosis	%
2 years or less	34
3-5 years	38
6-9 years	17
10 years or more	11
Mean	4.5 years
Medication Currently Taking	%
Aricept or generic	49
Namenda or generic	36
Exelon or generic	14
Razadyne or generic	6
Other	10
Not Sure	16