Department of
ELDER AFFAIRS
STATE OF FLORIDA

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Report from the 2014 Survey of Caregivers for Individuals with Alzheimer's Disease and Related Dementias

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Executive Summary

The 2014 Survey of Caregivers of Individuals with Alzheimer's Disease and Related Dementias (ADRD) follows the recommendation made by the Purple Ribbon Task Force to conduct a statewide survey to determine the status and needs of individuals affected by ADRD. The 2014 ADRD Caregiver Survey was administered to 1,063 caregivers to assess the status and needs of both the caregiver and the ADRD care recipient. Data obtained by the survey can support the Department's efforts in assisting individuals affected by ADRD, enabling them to continue living in their homes and communities and avoiding the probability of early nursing home placement.

Key Findings

- Despite challenges, the majority of caregivers (68%) report that they plan to continue to provide care for their loved one for the near future;

- 54% of caregivers have been providing care for four or more years, and nearly 17% have been providing care for nine years or more;

- The average caregiver provides 78 hours of care in a given week; 23% of caregivers provide around-the-clock care and supervision in a given week;

- 22% of caregivers work full-time and 10% work part-time; 94% of caregivers are not paid for the assistance they provide;

- 34% of caregivers have a health problem, physical condition, or disability that affects the type or amount of care that they can provide, while 53% are experiencing stress or mental health problems that affect the type or amount of care they can provide;

- 41% of caregivers do not have any plans for how to secure their loved one with ADRD in the event of a disaster; and

- 59% of the caregivers surveyed report that respite is the most needed service to continue providing care, especially for those who wish to continue working in their careers without interruptions.

Of those surveyed, 17% of caregivers plan to place their loved one with ADRD in a nursing home (NH), assisted living facility (ALF), or special care facility (SCF) within the upcoming year. Over 40% of caregivers describe the ADRD conditions faced by the care recipient as having more problems with memory than not, issues with language, short attention span, and needing assistance when completing tasks. In order for the care recipient to continue living at home, two out of three caregivers need a companion for the individual with ADRD, while six out of 10 caregivers need assistance with household chores.

Caregiving for individuals with ADRD is often a long-term commitment, with three-quarters (75%) of caregivers reporting they have been providing assistance between one and eight years. Caregiving for these respondents is also time-consuming, with nearly a quarter (23%) reporting that they provide continuous care and supervision for their loved one.

Providing care for someone with symptoms of ADRD may precede any actual diagnosis of ADRD. While 41% of diagnoses were made within the first two years of a demonstrated memory loss, caregivers report that formal diagnosis is often delayed by misinformation and denial. For example, one-third of the care recipients did not have a diagnosis for three or more years after symptoms presented. The main reason reported for the delay in diagnosis was that symptoms of ADRD were mistakenly attributed to normal aging processes.

There is often a profound and negative impact reported regarding the quality of life of the caregiver for individuals with ADRD. Caregiving responsibilities affect the employment and finances of many caregivers. Specifically, caregivers reported having to quit work or retire early (43%) to provide the intense supervision appropriate for the recipient. Since the vast majority (94%) of caregivers are not paid for their assistance, forfeiting paid employment creates a significant financial burden on them.

As a result of their caregiving responsibilities, many reported that their physical health was adversely affected. Others identified the stress of caregiving as the reason for eroded social and emotional well-being. Almost half reported the development of new health problems or worsening of existing health conditions (47%), including degenerative issues such as back and joint problems and arthritis (30%), as well as serious issues such as heart health conditions like hypertension and stroke (17%). More than one-third reported increased stress in response to caregiving demands (37%), and mental health concerns such as anxiety, fear, and depression (15%) reportedly developed or worsened while caregiving for a loved one with ADRD. For many, caregiving responsibilities did not always leave enough time for other family (61%) and negatively affected the quality of family relationships (78%).

Specific circumstances and characteristics of caregivers were explored as possible predictors of the likelihood of placing an individual with ADRD into a facility, including the following: working status of the caregiver, level of burden due to providing care, the caregiver's relationship to the recipient of care, and socio-economic characteristics of the caregiver such as, gender, race, ethnicity, and income. Results indicate that respondents who spent the least amount of time providing care in an average week had lower levels of perceived burden from their caregiving role. These caregivers were generally non-Hispanic white males with higher-than-average annual salaries who were providing care for their parents. These individuals were the most likely to report considering placing their care recipient into a facility within the upcoming year.

Caregiver characteristics like gender, ethnicity, and income were more predictive of a respondent's intent to place a loved one in a facility than the amount of time spent or effort required in providing care.

Respondents with higher levels of caregiver burden who spent more time caregiving in an average week were females of Hispanic, Latino, or Spanish origin with lower annual salaries who were taking care of their spouse or partner. Despite reporting a larger share of burden, these individuals were the least likely to consider placing their care recipient in a facility within the upcoming year. The level of caregiver burden was inspected against their intent to place, and showed different results for caregivers who provide part-time care, compared to those who provide full-time care, those with a lower amount of caregiving burden were more likely to consider placement into a facility within the year.

Introduction

ADRD diagnoses are expected to increase in upcoming years. As of 2016, over five million Americans were living with Alzheimer's disease, and projections estimate as many as 16 million will have the disease by 2050 (Alzheimer's Association, 2016). In Florida, 14% of elders (510,000 individuals age 65 or older) have been diagnosed with Alzheimer's disease (Alzheimer's Association, 2016).

Alzheimer's disease is the 6th most common cause of death in the United States, taking the lives of one in three seniors each year (Centers for Disease Control and Prevention, 2015; Alzheimer's Association, 2016). Women account for approximately two-thirds of Americans with Alzheimer's disease (3.2 million women compared to 1.9 million men), and, although there are more non-Hispanic whites living with Alzheimer's and other dementias than people of any other racial or ethnic group in the United States, older African-American and Hispanic individuals are more likely to have the disease than older, non-Hispanic whites (Alzheimer's Association, 2015).

Caregivers are a critical component in the long-term care framework necessary to help frail elders and adults with disabilities safely remain in their homes and communities. However, the presence of ADRD increases the physical, mental, social, and financial strain of providing care to their loved ones. In 2016, nearly 60% of U.S. caregivers reported high or very high levels of emotional stress and approximately 40% reported suffering from depression as a result of providing care to an individual with ADRD (Alzheimer's Association, 2016). In Florida, more than one million caregivers of individuals with ADRD clocked in more than 1.2 billion hours of unpaid care – care valued at over $15 billion – and the impact of physical and emotional strain due to caregiving caused an accumulation of $726 million of additional health care costs for caregivers (Alzheimer's Association, 2016).

Previous studies have also shown that caregiver burden is directly correlated with the quality of care for the individual with ADRD. According to Mohamed et al. (2010), severity of psychiatric symptoms and behavioral disturbances, lower functional capabilities, and diminished patients' quality of life are significantly linked to higher levels of burden and depression among caregivers. However, research shows that interventions targeting these attributes of Alzheimer's disease are likely to not only alleviate patient suffering but improve caregiver well-being.

Findings in this survey are consistent with research in published literature that repeatedly asserts ADRD is a gendered problem – specifically that it disproportionately affects women worldwide[1] (Berry, 2015), that women have worse outcomes than men from performing caregiving tasks[2] (Chappell, Dujela, & Andre, 2014), that women are much more often the caregivers for others with ADRD than men are[3] (Family Caregiver Alliance, 2003), and that having a female caregiver is more protective against institutional care than having a male one[4] (Luppa, et al., 2012) (Luppa, Luck, Weyerer, Konig, & Ridel-Heller, 2009).

Noting that different types of people experience the challenges of dementia differently has been documented[5] (DiGiacomo, Green, Rodrigues, Mulligan, & Davidson, 2015) as an important element to account for in successful intervention[6] (Corry, While, Neenan, & Smith, 2014). Targeting with information that is specific to the needs and risks of different groups may reduce the impact and burnout for caregivers and may also decrease institutionalization risks for care recipients with ADRD. The gender differences observed in respondents were significant and may suggest exploring targeted outreach.

Examples of targeting efforts might include identifying working male caregivers at their place of employment or via their organization. Outreach efforts like these might focus on those who are considering facility placement and provide them with information on home and community-based alternatives. Conversely, identifying high-burden female caregivers who may be at risk of having diminished ability to continue providing care, might focus instead on connecting them with hands-on assistance, training in caregiving techniques, and additional services to reduce the negative impacts on them to help them remain in a caregiving role.

By addressing the status of both the caregiver and the individual with ADRD, the aging network can ensure a better quality of life for the recipient of care and the caregiver. Noting the types of services that the caregiver receives and how that impacts their caregiving responsibilities can also provide useful information as to whether the programs and services are adequately meeting the caregiver's needs.

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[1] Berry asserts that the gender difference in ADRD is so consistent and holds across multiple countries, that it justifies a gender-targeted approach in health programming.

[2] Chappell et al show that wives are the most vulnerable with regard to the amount of burden they endure and damage to self they experience from providing care to their husbands with ADRD.

[3] Family Caregiver Alliance reports that female caregivers spend 50% more time providing care than males. Likewise, Kasper et al report that daughters provide on average 102 hours of care per month whereas sons provide 80 hours per month.

[4] Male gender and married partnership status were found to be important protective factors (as a result of women's caregiving work) in preventing nursing home use in dementia by Luppa et al. in several different studies.

[5] DiGiacomo et al conducted focus groups and found that tailoring services to socio-demographic and cultural groups is critical in promoting access to health care services.

[6] Corry et al note that caregivers for individuals with long term chronic conditions showed quality of life improvements with targeted education and interventions.

Methodology

Following the recommendations of the Purple Ribbon Task Force Report, the Department developed partnerships with experts in the field of Alzheimer's disease and related dementias. Dr. Leilani Doty, Associate Scientist and co-Director of the Memory Disorder Clinic at the University of Florida, and also the Chair of the Alzheimer's Disease Initiative Advisory Committee, provided feedback on the survey and methodology. In addition, a wide variety of public and private community groups and organizations volunteered to be partners and disseminate information about the survey, assist caregivers when needed, and ensure statewide participation. The main partners in survey dissemination included the following:

- Memory Disorder Clinics;
- Alzheimer's Association;
- Aging and Disability Resource Centers;
- A Place for Mom;
- United Way; Easter Seals;
- Sarasota Friendship Center;
- Bradenton Meals on Wheels Plus;
- Various caregiver support groups;
- Adult Day Care centers; and others.

These partners are located across every Planning and Service Area (PSA) in Florida and are instrumental in reaching a diverse array of caregivers. They were asked to help identify, motivate, and assist caregivers in completing the survey. Partners contacted clients and the public through telephone, email, websites, newsletters, radio programs, support groups, posters, and handouts, as well as in person.

In the survey, caregivers were asked to provide a response as to how they found out about the 2014 ADRD Caregiver Survey. Approximately 90% of respondents heard about the survey from an agency, organization, or provider, while the remainder learned about the survey from the internet, the media, or from friends and family.

Several caregiver groups, including those offered through the Memory Disorders Clinics, the National Alliance for Caregiving, and the Caregiver Coalition of Northeast Florida, provided information about the survey and links to access it online in their newsletters or websites. In addition, DOEA advertised the survey on its website, through public announcements, press releases, and flyers posted in strategic locations such as grocery stores, pharmacies, hospitals, churches, and libraries.

The 2014 ADRD Caregiver Survey was available between May 19, 2014, and December 31, 2014, and it was provided in paper and online formats through the host SurveyMonkey. Respondents were encouraged to complete the survey online, either at home or at the partner's facility. Alternatively, the survey in paper form could be completed and returned to the partnering organization or sent to DOEA for data entry. The survey contained 50 questions in multiple choice, drop down, rating scale, ranking, and open comment formats.

The questions included in the survey reviewed the following issues:

- Demographic information;
- Caregiver and recipient conditions;
- Amount of care provided;
- Services and resources needed by care recipients to stay home;
- Services and resources needed by caregivers to continue providing care;
- Barriers to receiving services or resources;
- Sources of information or services;
- Impact of providing care on the caregiver health and employment;
- Challenges and rewards of caregiving; and
- Plans for the future.

A total of 1,063 caregivers initiated and at least partially completed the survey, with 631 caregivers taking the survey online and 432 caregivers utilizing the paper version of the survey. The following analysis will present the information[7] provided on individuals with ADRD and their caregivers, the types of support available, and what additional support and services were needed for caregivers to continue providing care, along with observing the level of demand and impact of caregiving responsibilities. Predictors of caregiver demographics and characteristics were also analyzed to describe those who were most likely to consider placing their loved one in a nursing home, ALF, or special care facility in the upcoming year.

Caregiver and Care Recipient Characteristics

Location

Caregivers in the analysis came from 263 cities, 48 counties, and 474 ZIP codes. Twenty-nine caregivers responding to the survey lived out of state but were responsible for overseeing the care of someone living in Florida. Nearly 96% of the 1,063 caregivers and their care recipients lived in urban counties; the remaining 4% lived in rural counties. In addition, there were neither caregivers nor care recipients from the following 18 rural counties: Bradford, Calhoun, DeSoto, Dixie, Franklin, Gilchrist, Glades, Gulf, Hamilton, Holmes, Lafayette, Liberty, Nassau, Okeechobee, Taylor, Union, Wakulla, and Washington Counties.

Demographic Characteristics of Caregivers

Approximately 88% of caregivers identified themselves as White or Caucasian, and 7% identified themselves as Black or African American. About 13% of caregivers were of Hispanic, Latino, or Spanish origin. Caregivers were asked to report the number of years of school they had completed, as well as their estimated household income. Responses regarding the number of years of school completed were categorized into three groups and are summarized as follows: 1% of caregivers had not completed high school; 24% percent were high school graduates; and 75% had more than a high-school diploma, some college, or advanced degrees.

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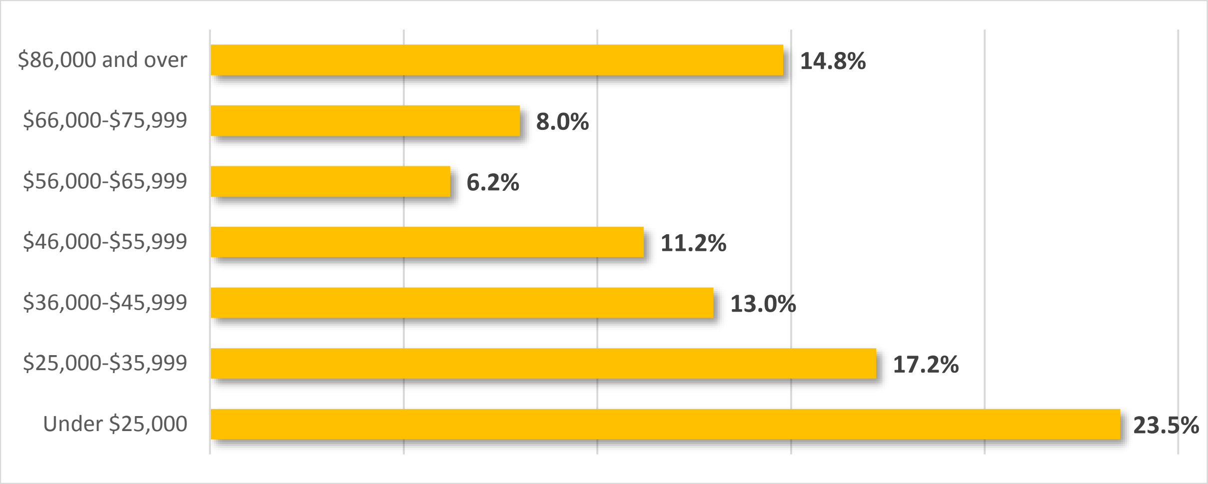
[7] This report presents frequencies and percentages based on the number of respondents to each question. For some multiple choice questions, respondents had to choose between alternatives. In single response questions, frequencies and percentages are reported. In multiple response questions, the percentages may total more than 100%.

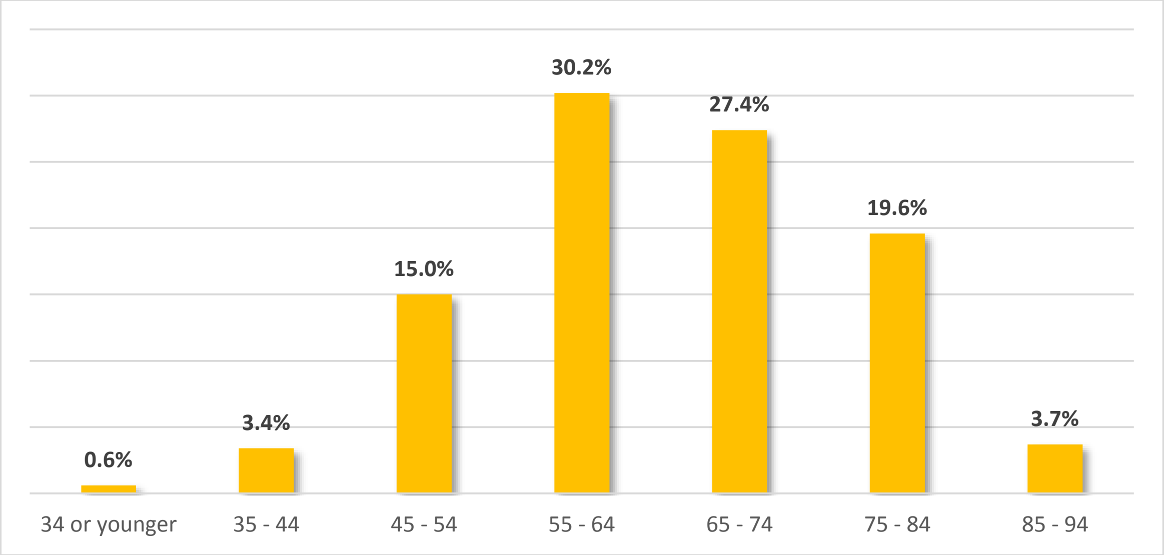
Exhibit 1. Caregiver's Estimated Household Income



DOEA, 2014 ADRD Caregivers Survey, n=714

Exhibit 1 above details the results of the responding caregiver's estimated household income. Note: this question was missing responses[8] from 33% of respondents. However, of the caregivers who answered this question, approximately 24% reported an income under $25,000, while approximately 15% reported an income in excess of $86,000. The mean income of the remaining respondents is $48,818.[9]

Exhibit 2. Age of Caregiver



DOEA, 2014 ADRD Caregivers Survey, n=938

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[8] Income is often declined in survey research across administration methods. However, it is important to note that due to the nature of this as a self-administered survey, respondents were able to skip any questions they did not want to answer. As a result, many measures in this survey had fluctuating denominators below the 1,063 total.

[9] The mean income was calculated by identifying the midpoints of the income ranges between the extremes and weighting by the number of respondents in each category.

Caregivers responding to the survey were more likely to be female than male, with a ratio of eight females to two males. As shown in Exhibit 2 on the previous page, the majority of caregivers (58%) fell between the ages of 55 and 74 years old, while a surprising 23% of caregivers were 75 years or older. For a breakdown of the study sample by key factors compared with rates in the state population, please see Appendix A.

Recipient of Care Profile

Characteristics of the individuals receiving care, including their race and marital status are described in Exhibit 3 to the right. Like their caregivers, the majority of ADRD care recipients were white (90%). Approximately half of care recipients were married or partnered (48%), while most others were widowed (41%). As presented in Exhibit 4 below, the majority of care recipients were between the ages of 75 and 94 years old (74%). Like their caregiver counterpart, ADRD care recipients were more likely to be female than male, with a ratio of six female care recipients to four males.

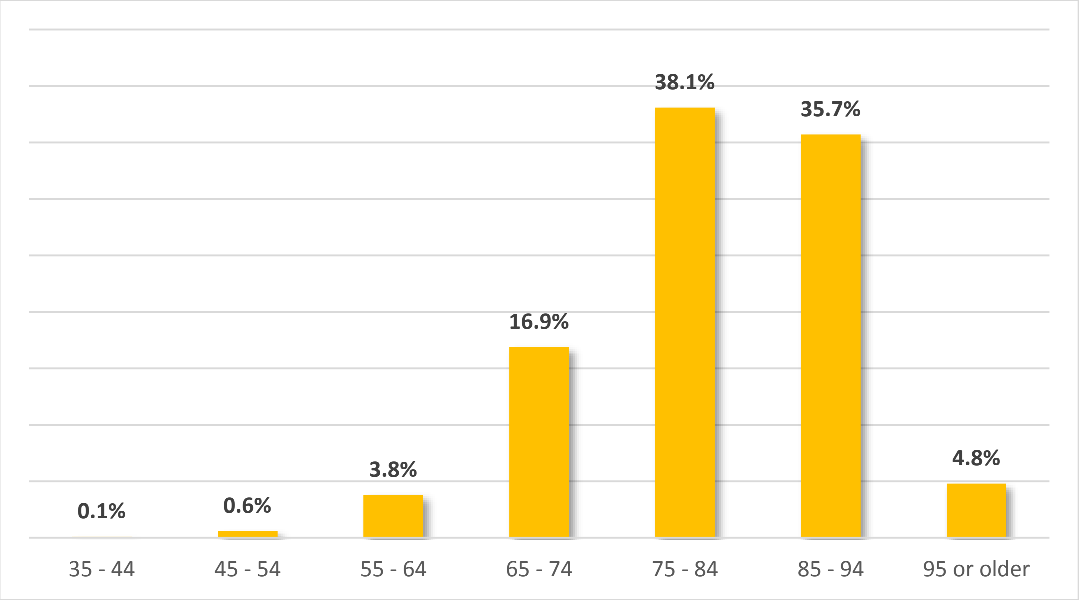
Exhibit 3. Race, Ethnicity, and Marital Status of ADRD Care Recipients

Race	Count	Percent
White or Caucasian	810	86.7%
Black or African American	61	6.5%
American Indian or Alaska Native	2	0.2%
Asian	4	0.4%
Other	55	5.9%
Don't Know	2	0.2%
Total	934	100%
Ethnicity	**Count**	**Percent**
Hispanic	109	11.7%
Non-Hispanic	824	88.1%
Don't Know	2	0.2%
Total	935	100%
Marital Status	**Count**	**Percent**
Married or partnered	456	48.3%
Widowed	385	40.7%
Divorced or separated	76	8.0%
Never married	26	2.7%
Don’t know	3	0.3%
Total	946	100%

DOEA, 2014 ADRD Caregivers Survey, n=934-946

*Note: these are individual questions with separate response rates.

Exhibit 4. Age of the Recipient of Care



DOEA, 2014 ADRD Caregivers Survey, n=945

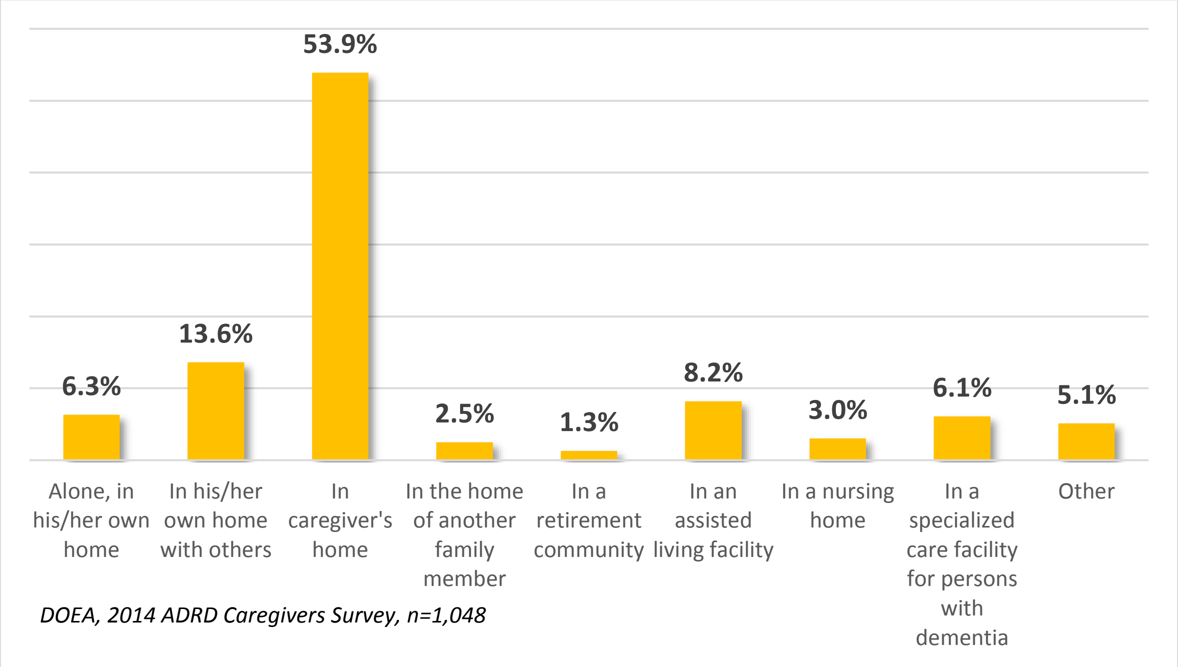
Length, Pay, and Hours of Care

According to the Alzheimer's Association, more than one million caregivers of individuals with ADRD in Florida clocked in over one billion hours of unpaid care – care valued at over 15 billion dollars in 2015. Providing care and supervision for an individual with ADRD can cause caregivers stress, financial burdens, and erosion of their social networks of support (Brodaty & Donkin, 2009). The majority of caregivers in the survey were not receiving assistance with providing care to the individual with ADRD. If the caregiver was receiving assistance with caregiving, it was most likely due to the caregiver paying for such services. Results indicate that 19% of caregivers in the study reported receiving unpaid assistance from friends and family, 23% reported receiving assistance from social service programs like Medicaid, and 36% were paying for assistance. These problems can interact and become compounded when the duration of care spans many years, as is often the case with ADRD. Caregivers make it possible for many individuals to remain at home, so identifying and reducing caregiver burnout presents an opportunity to reduce and delay the use of nursing homes and skilled nursing facilities. This section will present the reported durations of care, residence types of care recipients, and frequencies of caregiver pay.

Duration of Care and Residence Type

Survey results reveal that the majority of caregivers have had considerable experience providing care to the individual with ADRD. More than half (54%) of the respondents had been providing care for four or more years, and almost 17% had done so for nine or more years. Less than ten percent of caregivers were new to the role, with only 8% reporting providing care for less than one year. For over half (54%) of respondents providing care to their loved one, the care recipient was residing in the caregiver's home, as shown in Exhibit 5 below. Many caregivers (17%) reported assisting an individual with ADRD who resided in an assisted living facility, nursing home, or specialized memory care facility, while very few caregivers reported providing care to an individual with ADRD who lived alone in the community (6%).

Exhibit 5. Current Residence of Person Receiving Care



DOEA, 2014 ADRD Caregivers Survey, n=1,048

Caregiver Pay and Time Spent Caregiving

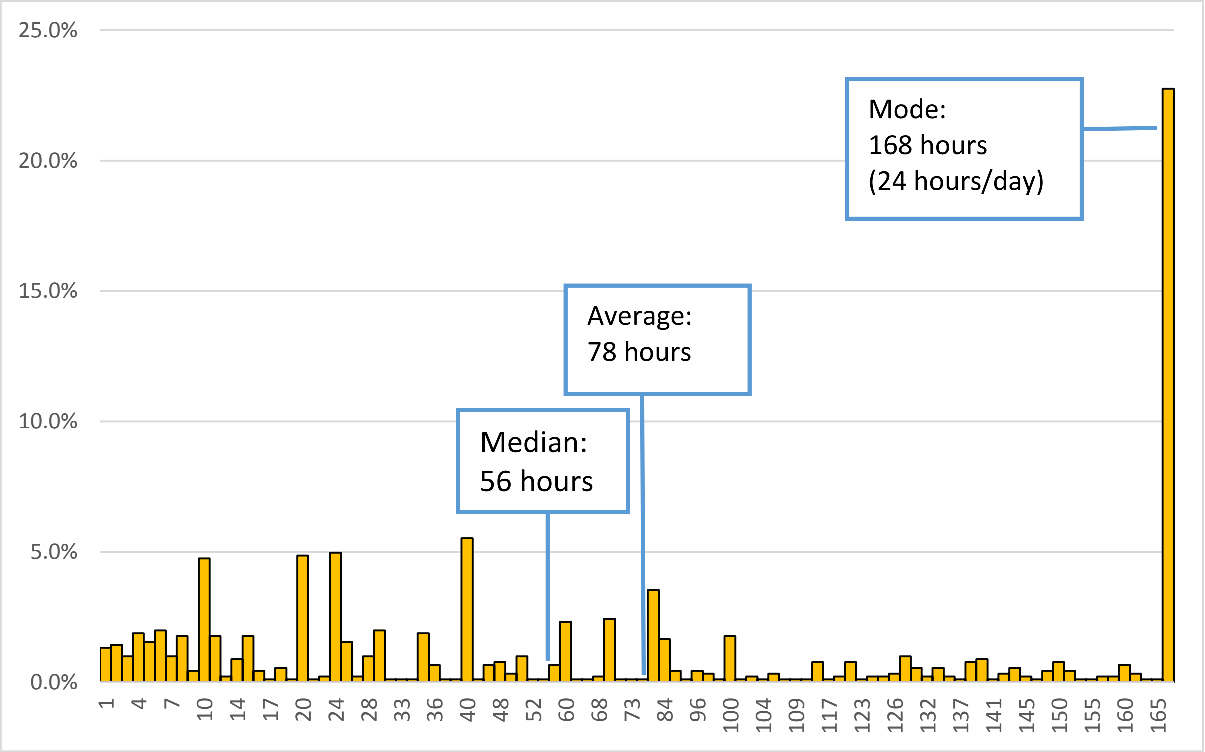
Caregiver respondents generally did not receive pay for their time spent providing care. Less than 10% of respondents were paid caregivers, with 94% of caregivers reporting they were not receiving pay for the assistance they provided. Moreover, a significant portion of caregivers (18%) reported that they were also providing care to younger loved ones, such as children or grandchildren, in addition to the care they provided for an individual with ADRD.

6% of caregivers are paid for the assistance they provide to individuals with ADRD.

DOEA, 2014 ADRD Caregivers Survey, n=986

The time spent caregiving can be intensive and can limit the personal time available for the caregiver to work, maintain other relationships, and connect with sources of information and support outside of the home. Shown in Exhibit 6 below, the median number of hours spent providing care in a typical week was 56 hours. However, 23% of caregivers reported providing around-the-clock care and supervision for the ADRD recipient, averaging 168 hours of care in a typical week.

Exhibit 6. Number of Hours Providing Care in and Average Week



DOEA, 2014 ADRD Caregivers Survey, n=905

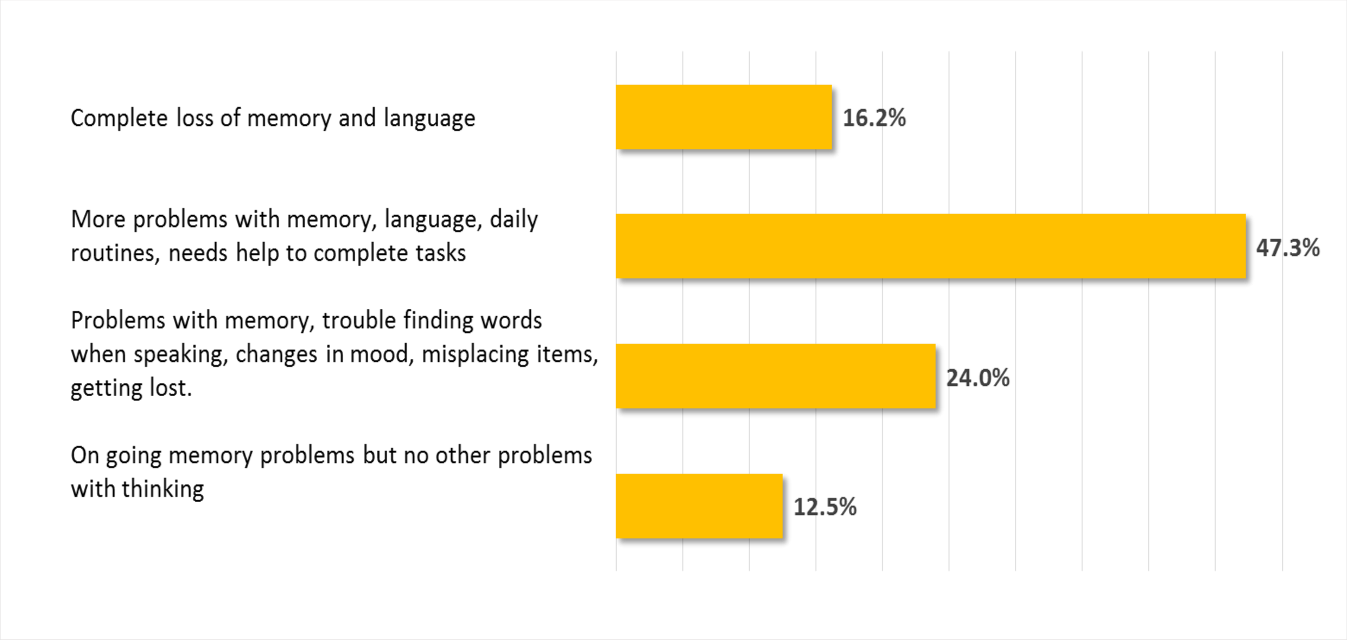
Cognitive Impairment Characteristics, Behaviors, and Symptoms

The memory and cognitive impairments that characterize ADRD vary in their severity and rate of progression. Likewise, many individuals with ADRD also have changes in mood and behaviors that can be challenging for caregivers to cope with.

Level of Cognitive Impairment in the ADRD Care Recipient

Caregivers were asked to describe the level of cognitive impairment of the recipient of care shown in Exhibit 7 below. The most common cognitive impairment characteristic reported by caregivers (47%) was "more problems with memory, language, short attention span, trouble with the daily routine of fixing meals, dressing, bathing, etc., needs help to complete tasks," while "ongoing memory problems but no other problems with thinking" was the least common cognitive impairment characteristic reported (13%). This signifies that the majority of care recipients had ADRD symptoms that had progressed to a level that required assistance or supervision from a caregiver.

Exhibit 7. Caregiver Description of Recipient Impairments



DOEA, 2014 ADRD Caregivers Survey, n=985

Common Behaviors and Symptoms

Caregivers were also asked how often the recipient of their care suffered from a list of problems and behaviors, with durations ranging from "Never" to "Always." The types of behaviors and symptoms experienced by individuals with ADRD that are generally considered less severe are detailed in Exhibit 8 below. Results show that the majority of caregivers reported that these symptoms intermittently occurred, with "sometimes" selected most frequently for all behavior types except "Restless, wanders."

The most common behavior is late-day confusion, or "sundowning,"[10] with approximately three out of four recipients of care at least "sometimes" experiencing this symptom of ADRD and 22% experiencing it "always." Communication disorders were the next most commonly reported issue, with over two-thirds of care recipients (69%) experiencing difficulty speaking to others and 65% experiencing difficulty understanding language.

Exhibit 8. Frequency of Symptoms of ADRD, Reported by Caregiver*

Behaviors & Symptoms	Never	Seldom	Sometimes	Usually	Always	Total
Sundowning	14.5%	14.2%	25.4%	23.7%	22.2%	902
Difficulty speaking to others	14.2%	17.1%	33.4%	18.6%	16.7%	956
Sleep problems	18.4%	19.6%	31.4%	17.4%	13.2%	946
Difficulty understanding language	16.6%	18.7%	38.8%	14.9%	11.1%	936
Depression	14.8%	19.7%	38.1%	17.2%	10.1%	923
Restless, wanders	32.8%	22.6%	25.1%	11.6%	8.0%	930
Acts distrustful, suspicious	25.2%	21.8%	32.5%	12.6%	7.9%	939
Anxious, irritable	13.1%	19.0%	42.4%	18.6%	6.8%	951
Not getting along with others, being disagreeable	23.9%	27.6%	36.4%	8.9%	3.2%	940

DOEA, 2014 ADRD Caregivers Survey, n=902-956

*Note that these are individual questions with separate response rates.

Major Behaviors and Symptoms

Exhibit 9 below illustrates the types of major challenging behaviors experienced by caregivers. Some 34% of caregivers reported that the individual with ADRD shows no boundaries and talks to or touches strangers at least "sometimes," if not more often. Additionally, 35% caregivers reported that the care recipient behaves with verbal aggression, such as shouting or name calling at least "sometimes," if not more often. Approximately half of reporting caregivers indicated that the person receiving their care has been lost outside or has been missing, and over one-quarter (28%) of caregivers reported their care recipient has been physically aggressive or violent towards others, although less than 3% of care recipients "usually" or "always" exhibit these behaviors.

Exhibit 9. Major Challenging Behaviors of Individuals with ADRD Reported by Caregiver*

Behaviors	Never	Seldom	Sometimes	Usually	Always	Total
Verbal aggression, such as shouting or name calling	41.2%	24.2%	23.6%	7.5%	3.5%	939
No boundaries, talks to/touches strangers	45.7%	20.6%	15.6%	9.3%	8.7%	921
Been lost outside, gone missing	52.5%	19.9%	14.5%	6.2%	7.0%	876
Physically aggressive/violent toward self, injures self	84.5%	10.1%	3.9%	0.5%	0.9%	937
Physically aggressive/violent toward others, such as hitting, pushing others	72.3%	15.0%	9.9%	1.7%	1.1%	938

DOEA, 2014 ADRD Caregivers Survey, n=876-939

*Note: these are individual questions with separate response rates.

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[10] The term 'sundowning' refers to a state of confusion at the end of the day and into the night. Sundowning isn't a disease but a group of symptoms that occur at a specific time of day that may affect people with dementia, such as Alzheimer's disease. Sundowning can cause a variety of behaviors such as confusion, anxiety, aggression, or ignoring directions. Sundowning can also lead to pacing or wandering. The exact cause of this behavior is unknown, but some research suggests that low-lighting, changes in routine, sleep apnea, and lack of exercise exacerbate late-day confusion. (Definition provided by Dr. Glenn Smith, http://www.mayoclinic.org/)

ADRD Types & Diagnosis

Diagnosing Alzheimer's and related dementias is a lengthy process. According to the Alzheimer's Association, the diagnostic work-up contains multiple steps including: an initial evaluation that also observes medical history, followed by a mental status evaluation, a clinical examination, and laboratory tests. Such lengthy processes can delay ADRD diagnosis and can suppress the disclosure rates reported by physicians. In addition, misunderstanding and lack of knowledge of ADRD symptoms by caregivers can also delay proper treatment and diagnosis. The following section of the analysis will present the types of ADRD experienced by the individuals receiving care, the duration of symptoms, and the length and reasons for any delays in receiving an ADRD diagnosis.

Diversity of ADRD

The types of diagnoses of individuals with ADRD reported by their caregivers is detailed in Exhibit 10 to the right. Alzheimer's disease is the most common diagnosed disease reported, representing 47% of all diagnoses reported in the survey. Following Alzheimer's disease, the most common diagnoses of recipients of care were mild cognitive impairments (13%), vascular dementia (11%), mixed dementia (11%), and stroke (9%).

Exhibit 10. ADRD Diagnoses of Care Recipient**

Type	Count	Percent
Alzheimer's Disease	499	46.9%
Mild Cognitive Impairment	145	13.6%
Vascular Dementia	115	10.8%
Mixed dementia	113	10.6%
Stroke	98	9.2%
Lewy Body Disease	47	4.4%
Frontotemporal Dementia	44	4.1%
Frontal Dementia	39	3.7%
Parkinson's with Dementia	34	3.2%
No Diagnosis	32	3.0%
Parkinson's Disease	22	2.1%
Parkinsonism*	11	46.9%

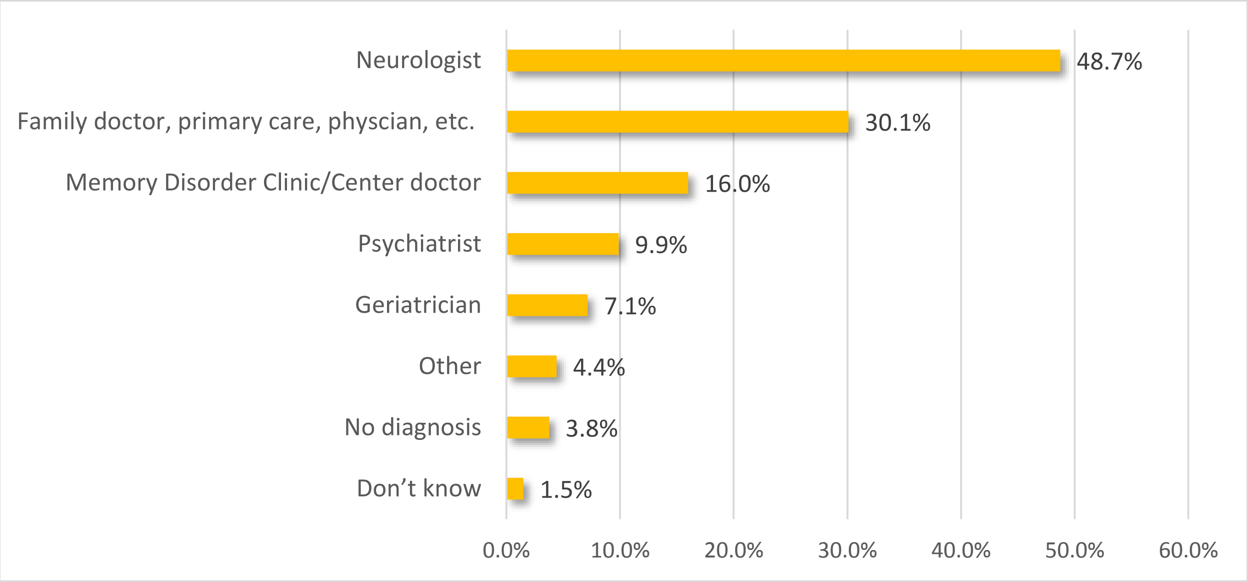
DOEA, 2014 ADRD Caregivers Survey, n=1,199

* Progressive Supranuclear Palsy or Cortical Basal Dementia

**Note: Respondents were able to select multiple responses

Due to the difficulty of identification and the frequency of disease comorbidity, it is not uncommon for individuals to have multiple diagnoses of ADRD. As such, it is not surprising that 30% of caregivers reported multiple types of diagnoses for the individual receiving their care. When asked who provided the diagnosis, caregivers reported that the care recipient received their diagnosis from either a neurologist (44%), primary care physician (27%), memory disorder clinic physician (14%), or other specialists (15%). The distribution of responses is shown in Exhibit 11 on the following page.

Exhibit 11. Source of Formal ADRD Diagnosis



DOEA, 2014 ADRD Caregivers Survey, (For a list of totals, refer to Appendix A, Exhibit 1)
Note: these are individual questions with separate response rates.

Delay of Diagnosis

Many care recipients of the caregivers surveyed have lived with their ADRD symptoms for years without receiving a diagnosis thus delaying proper treatment. Approximately one- fifth (19%) had one year of symptoms or less before seeking diagnosis, 43% of care recipients received their ADRD diagnosis one to two years after their symptoms began, approximately 38% of care recipients received a diagnosis after three to four years of symptoms, and 18% of care recipients had five or more years of symptoms before receiving an ADRD diagnosis. It was less likely for a care recipient to have more than ten years of symptoms before receiving an ADRD diagnosis (4%) compared to less.

Survey results reveal that 45% of caregivers thought that the ADRD symptoms the care recipient was experiencing was a normal part of aging (see Exhibit 12). This signals a possible deficiency in the education caregivers may be receiving regarding the types of behaviors and symptoms that occur in dementia and, more broadly, may indicate that many inaccurately believe that memory loss is a normal facet of aging.

Exhibit 12.Reasons for Delay in Seeking Diagnosis for ADRD Symptoms*

	Count	Percent
I thought the symptoms were a part of normal aging.	509	47.9%
I didn’t want to know.	50	4.7%
I didn’t think anything could be done.	64	6.0%
I didn’t know where to find help.	87	8.2%
Cost of health care.	39	3.7%
Insurance would not cover the medical test(s).	17	1.6%
Other	366	34.4%

DOEA, 2014 ADRD Caregivers Survey, n=1,132
*Note: Respondents were able to select more than one response

Respondents in this survey are not alone in the belief that memory loss is normal in elders. Current research reported by the Alzheimer's Association shows that 60% of individuals incorrectly identified symptoms of Alzheimer's disease as a typical part of the aging process. Other reasons for the delay in medical diagnosis of ADRD cited by caregivers who were surveyed include the caregiver not wanting to know (4%), the cost of health care (3%), and medical insurance not covering the needed procedures (2%). An additional 32% of caregivers responded that they delayed seeking an ADRD diagnosis for the individual receiving their care with "other" and provided an open-ended response such as: denial by the person with ADRD, their caregivers, and/or family members; the refusal of care recipients to see a physician; caregivers not living close-by; and family disagreement regarding how to respond to their loved ones' cognitive decline. Several respondents also commented with doctor-related issues, such as their doctor diagnosed another cause for the symptoms, they had difficulty in getting a referral from a primary physician, or had problems finding the right physician to make an ADRD diagnosis.

Long Term Services and Supports

Responses indicate that 20% of caregivers were receiving unpaid caregiving assistance from friends or family, 19% were receiving unpaid assistance from others, 36% were paying for caregiving assistance, and 23% were receiving caregiving help from social services. However, the majority of caregivers reported that they needed further support to continue providing care to the care recipient with ADRD. Additionally, 11% of caregivers reported that they are on a waitlist to receive the services and support they needed. (See Appendix A, Exhibit 1 for a full distribution of responses by question.)

The top 10 services table (listed in Exhibit 13 on the following page) shows that over half of responding caregivers needed services for themselves or their loved one. The most often cited service was companionship (someone different to spend time with the care recipient), with two out of every three caregivers expressing the need for this service (66%). More than half of respondents identified a need for services to support an activity of daily living task such as chores, managing money or medicine, using transportation, shopping and personal care. Likewise, more than one-half reported a need for legal advice and adult day care.

> *More than half of respondents identified a need for essential services to support an activity of daily living such as personal care or preparing meals.*

Exhibit 13. Services Needed by Care Recipients to Continue to Live at Home*

Services	Count	Percent
Companionship	606	**66.2%**
Household chores	546	**60.1%**
Managing medicines	557	**59.9%**
Using transportation	521	**59.4%**
Managing money, bills	515	**59.0%**
Shopping	514	**58.6%**
Legal advice	484	**57.2%**
Preparing meals/Meals on Wheels	498	**56.5%**
Personal care (including bathing, dressing, eating, drinking, using the bathroom, moving around or walking)	508	**54.7%**
Adult day care services	486	**54.5%**
Using the phone	434	48.1%
Support group	400	46.6%
Home safety (managing fall risk, storing unsafe items)	380	43.2%
Personal emergency response system	360	41.8%
Case management	348	41.6%
Home health/medical care, including injections, skin and wound care	333	40.1%
Individual or family counseling	336	39.5%
Plan and alert system for wandering off and getting lost	316	37.0%
Telephone reassurance	225	27.8%
Emergency placement for unsafe behaviors (e.g., violence, aggression), caregiver illness, or weather emergencies	227	26.9%

DOEA, 2014 ADRD Caregivers Survey, n=227-606

*Note: these are individual questions with separate response rates.

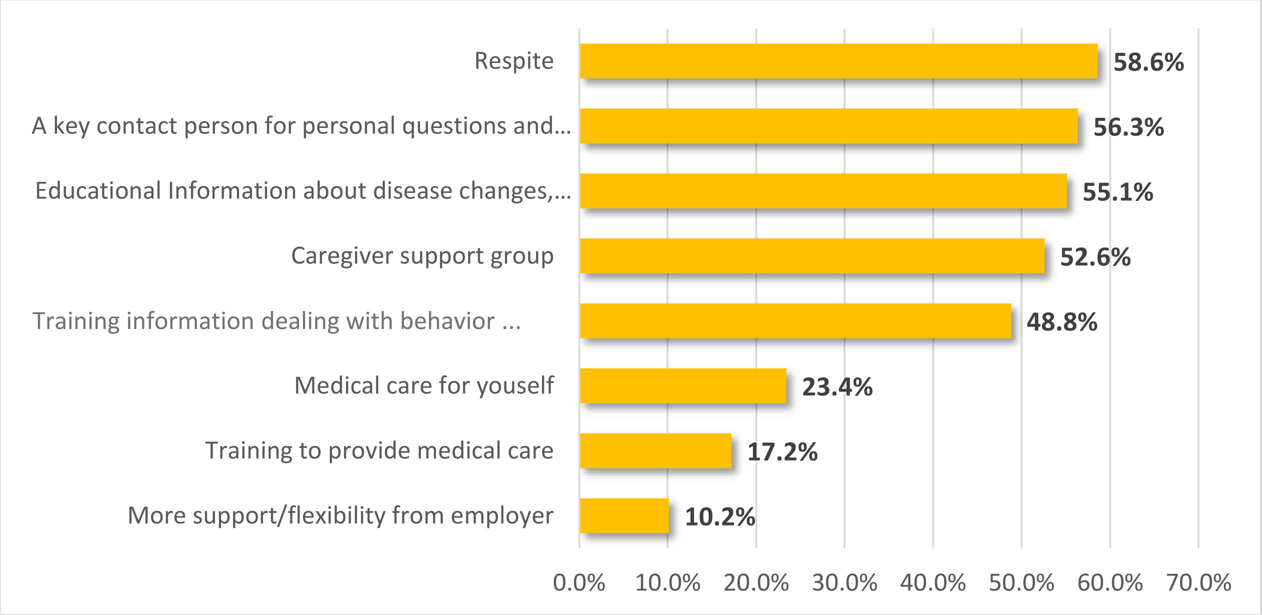
Additional Services and Resources Needed for the Caregiver to Continue Providing Care

Caregivers reported the types of services and resources they needed in order to continue providing care in general. Results in Exhibit 14 on the following page indicate that 59% of caregivers reported needing respite. This specific service has been addressed throughout the survey in open-ended responses as highly necessary for the ability to continue care for the individual with ADRD, as well as for the quality of life of both the caregiver and the individual with ADRD. Open-ended responses regarding the need for respite included the following:

- “I need more than a short break.”
- “What I need the most now is respite to be able to work more hours.”
- “Respite care is not provided for me to leave him to go to the store, doctor, etc. Have to try to get family. I need help.”

Following respite, the services most frequently reported as needed by caregivers to continue providing care included a key contact person for personal help and questions (56%); educational information about disease changes, coping strategies, and resources (55%); and a caregiver support group (53%).

Exhibit 14. Services & Resources Needed for Caregiver to Continue Providing Care*



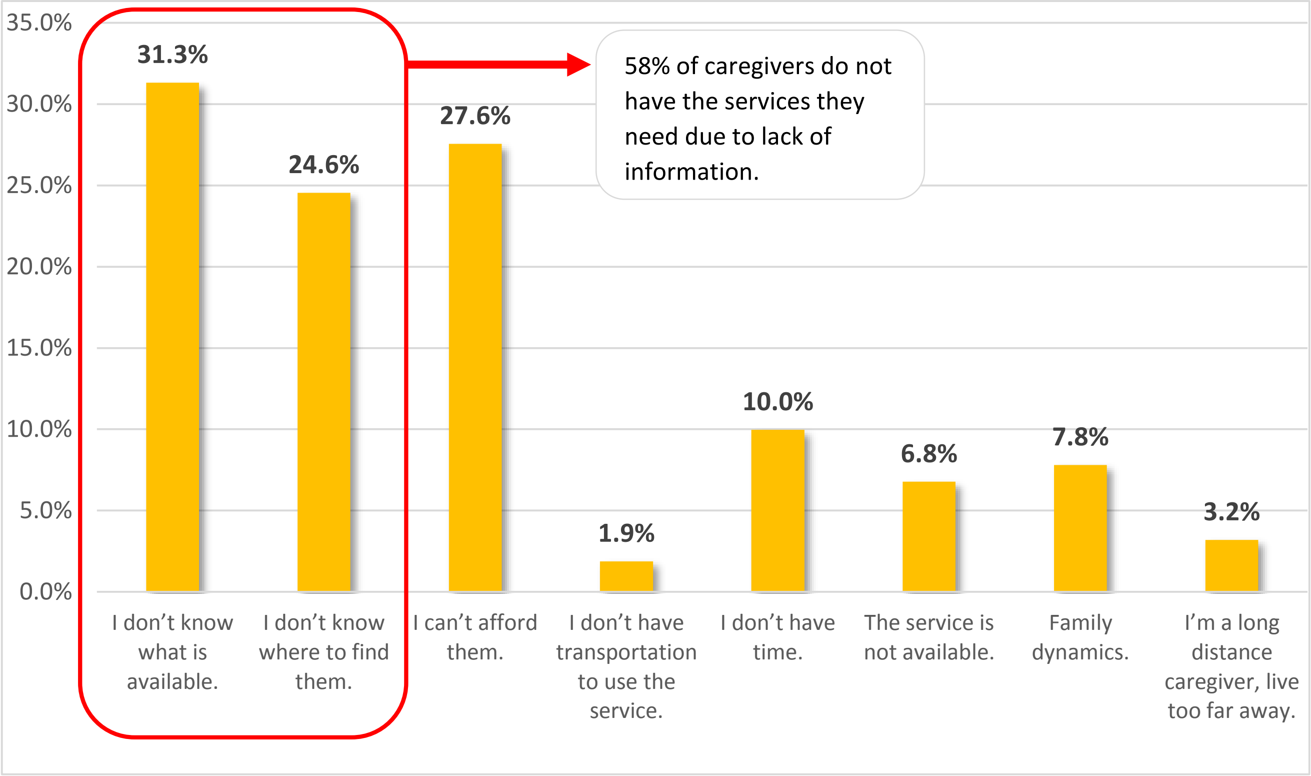
DOEA, 2014 ADRD Caregivers Survey, (For a list of totals, refer to Appendix A, Exhibit 1)
*Note: these are individual questions with separate response rates.

Barriers to Receiving the Services and Resources that Caregivers Need

There were numerous caregivers in the study that were in need of resources to help provide care to the individual with ADRD in the home and community, as well as resources for themselves to have the ability to continue providing care. Detailed in Exhibit 15 below are reported reasons for why caregivers were unable to receive the services they needed for themselves and the individual with ADRD.

Most caregivers (56%) reported that they did not have the services they needed due to lack of information. That is, 31% of caregivers did not know what services and resources were available, while 25% did not know where to obtain them. Improvements in outreach of information regarding important resources and services available can help caregivers receive what they need in order to continue providing care to the individual with ADRD. In addition to the lack of information on how to receive the services needed, more than one-quarter of caregivers (28%) reported that they could not afford the services needed, indicating outreach is needed to those who are lower income and may be eligible for financial assistance.

Exhibit 15. Reasons the Caregiver Does Not Have the Services They Need*



58% of caregivers do not have the services they need due to lack of information.

DOEA, 2014 ADRD Caregivers Survey (For a list of totals, refer to Appendix A, Exhibit 1)
*Note: respondents were able to select more than one response.

Sources for Information on Services to Help with Caregiving

Caregivers reported the resources they used to receive information on services to help them with their caregiving role. Understanding what resources are most successful in communicating to the caregiver can alleviate the issues of caregivers having a lack of information. This is important because the majority of caregivers identified a lack of information about ADRD disease changes, coping strategies, and resources as a barrier to continue providing care. It is also important to note the areas that need improvements in the availability and access to information and services. As detailed in Exhibit 16 on the following page, over one-half of caregivers obtained information and services through medical professionals (62%) and the internet (51%). It was less common for caregivers to obtain information on services through Veteran Administration Medical Centers (8%), veteran support groups (6%), or a group family home (5%).

Results showed that it was more likely for caregivers with higher education to use the internet to receive information on services to help with caregiver, while it was more likely for caregivers with lower levels of income to receive this information through family members or friends. Results indicated that over 90% of caregivers who reported receiving information through the internet had at least a high school diploma (96%), compared to 3% of caregivers who have less than 12 years of schooling. Furthermore, approximately one out of five caregivers who had a household income of less than $25,000 reported that they received their information on services through friends or family (21%).

Top 3 sources of information for Caregivers:

Medical professionals

Internet

Family & Friends

Exhibit 16. Resources Used for Information or Services to Assist with Caregiving*

Resources	Count	Percent
Medical professional	656	61.7%
Internet	539	50.7%
Family members or friends	529	49.8%
Alzheimer’s Association	438	41.2%
Adult day care center	380	35.7%
Support group	371	34.9%
Home care service provider, home health agency	367	34.5%
Florida Department of Elder Affairs	334	31.4%
Area Agency on Aging/ Aging and Disability Resource Center	299	28.1%
Memory Disorder Clinic	287	27.0%
Other social service agency	259	24.4%
Neighbors	257	24.2%
Assisted living facility (ALF)	199	18.7%
Faith community, such as church, synagogue, etc.	182	17.1%
Hospital	155	14.6%
Public library	95	8.9%
Nursing home	87	8.2%
Veterans Administration Medical Center (VAMC)	81	7.6%
Other veterans services and support groups	67	6.3%
A group/family style home (adult family care home)	48	4.5%

DOEA, 2014 ADRD Caregivers Survey, n=48-656

*Note: these are individual questions with separate response rates.

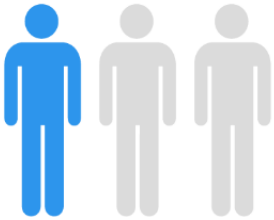
Impact of Caregiving While Employed

An important section of the survey is the documentation of the impact of caregiving responsibilities on the caregiver’s employment, health, financial situation, and several social-emotional aspects of their lives. In each of these areas, caregivers generally reported a pervasive and profound impact.

Impact of Caregiving While Employed

Caregiving while employed can cause stress and financial strain on the caregiver, especially for those providing care for individuals with ADRD who require specialized attention and, at times, around-the-clock supervision or care. As reported earlier, the caregivers surveyed dedicated an average of 77.5 hours of caregiving in a week, and for some, this was on top of their part-time or full-time jobs, leaving minimal personal and social time for the caregiver. Some 32% of caregivers surveyed worked either part-time or full-time; approximately two out of nine caregivers worked full-time (22%) and 1 out of 10 worked part-time (10%).

Approximately **1 out of 3** caregivers said that caregiving had affected their employment

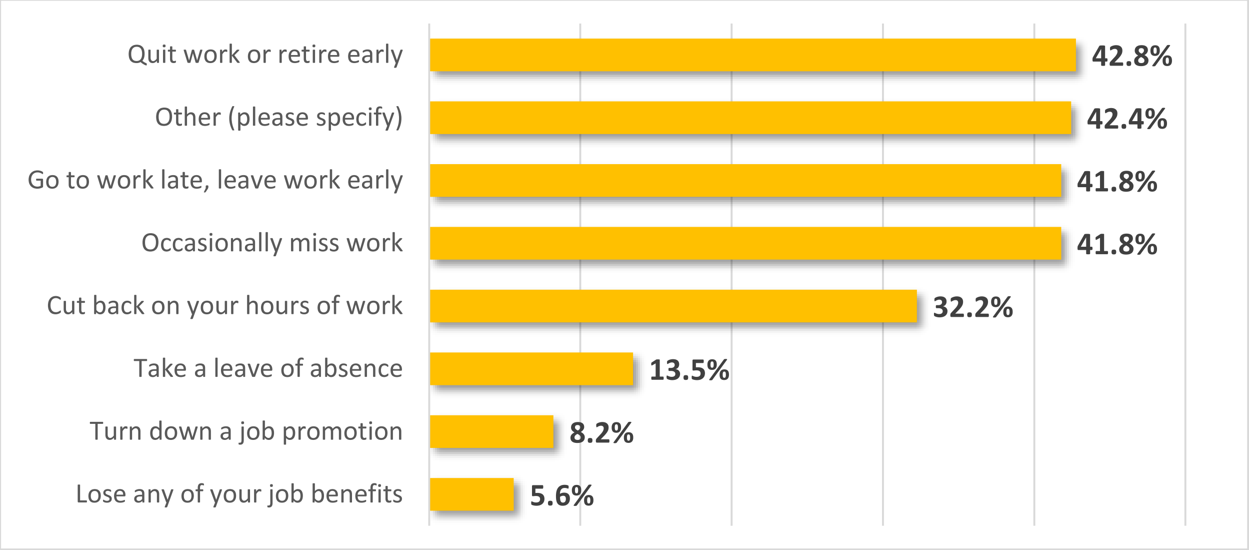


The effects of caregiving while employed were evident in the open-ended survey responses and comments. The most common effects included caregivers having to quit work or retire early (43%), occasionally having to miss work (42%), and having to go to work late and/or leave work early (42%). In addition, 42% of caregivers selected “other” and provided an open-ended response. Examples include the following:

- “I had to give up numerous opportunities for out-of-town work.
- Caregiving cut my income by more than one half. My Social Security will be much less than I anticipated.”
- “My mother often called me at the workplace as many as 20 to 25 times a day. I’ve lost several jobs due to interruptions and care needs for her.”
- “I was fired from my last job due to absences because of caring for two elderly parents with memory and additional health issues.”

The areas of employment that had been negatively affected as a result of competing caregiving responsibilities are described in Exhibit 17 on the following page. Approximately one out of three caregivers said that caregiving had affected their employment (34%).

Exhibit 17. How Caregiving Adversely Impacts Employment*

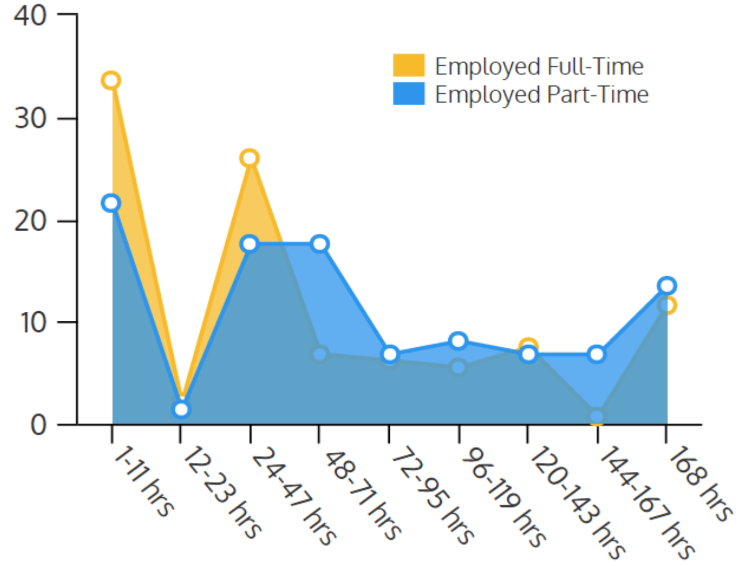


DOEA, 2014 ADRD Caregivers Survey (For a list of totals, refer to Appendix A, Exhibit 1)
*Note: Respondents were able to select multiple responses, and these are individual questions with separate response rates.

Full-Time vs. Part-Time Working Caregivers

Differences between full-time working and part-time working caregivers are detailed in Exhibit 18 below. As shown, differences exist in the number of hours dedicated to providing care in an average week. Full-time working caregivers tended to spend fewer hours providing care. One out of three caregivers (34%) who worked full-time provided less than 12 hours' worth of caregiving within an average week. Comparatively, part-time working caregivers often provided between one and three days of care in an average week (35%). Full-time working caregivers may have had to obtain assistance to take care of individuals with ADRD while they are away from home at work. More than a quarter of full-time working caregivers had unpaid help from friends or family (27%), and four out of ten full-time working caregivers paid to have additional help with their caregiving responsibilities.

Exhibit 18. Number of Hours Spent Caregiving in and Average Week While Employed Full-Time vs. Part-Time



DOEA, 2014 ADRD Caregivers Survey, n=220

Impact of Caregiving on Emotional and Physical Health

According to the Alzheimer's Association, caregivers of individuals with ADRD have reported experiencing high levels of stress that not only can be harmful to the caregiver's emotional state but also to their overall health (Alzheimer's Association, 2015). When observing the responses of caregivers in the survey, approximately one out of three caregivers (34%) had a health problem, physical condition, or disability that affected the kind or amount of care they could provide. Of these caregivers, about half reported that their caregiving responsibilities created or worsened their health conditions, problems, or disabilities (47%).

Exhibit 19 below details the types of health problems, disabilities, or conditions that affected the care the caregiver provides. As shown, over half of caregivers reported that stress or mental health problems affected the care they provide. That is, 37% of caregivers reported experiencing stress, and 15% reported mental health problems such as anxiety, fear, depression, or emotional problems. Other health conditions mentioned by caregivers included chronic fatigue, loss of mobility or hearing, and cancer.

Approximately **1 out of 3** caregivers had a health problem, physical condition, or disability that affected the kind or amount of care that they can provide

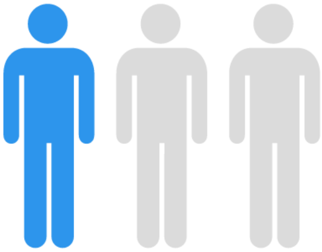
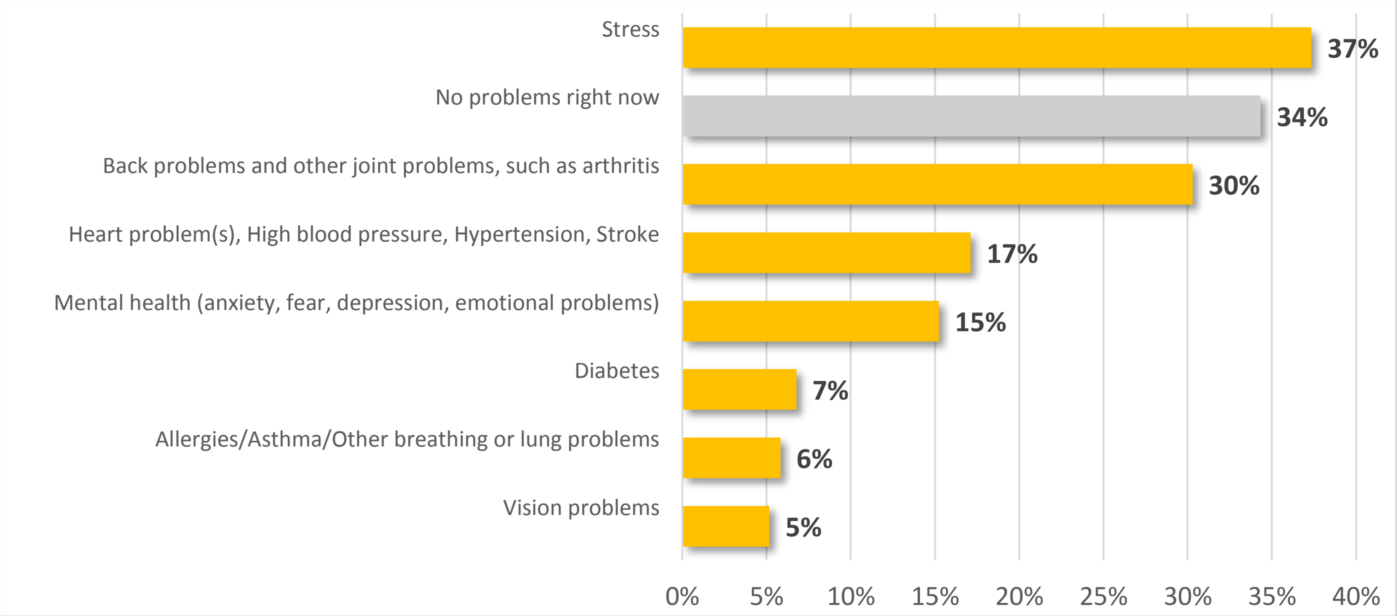


Exhibit 19. Caregiver Health Problem, Condition, or Disability that Affects the Care They Can Provide*



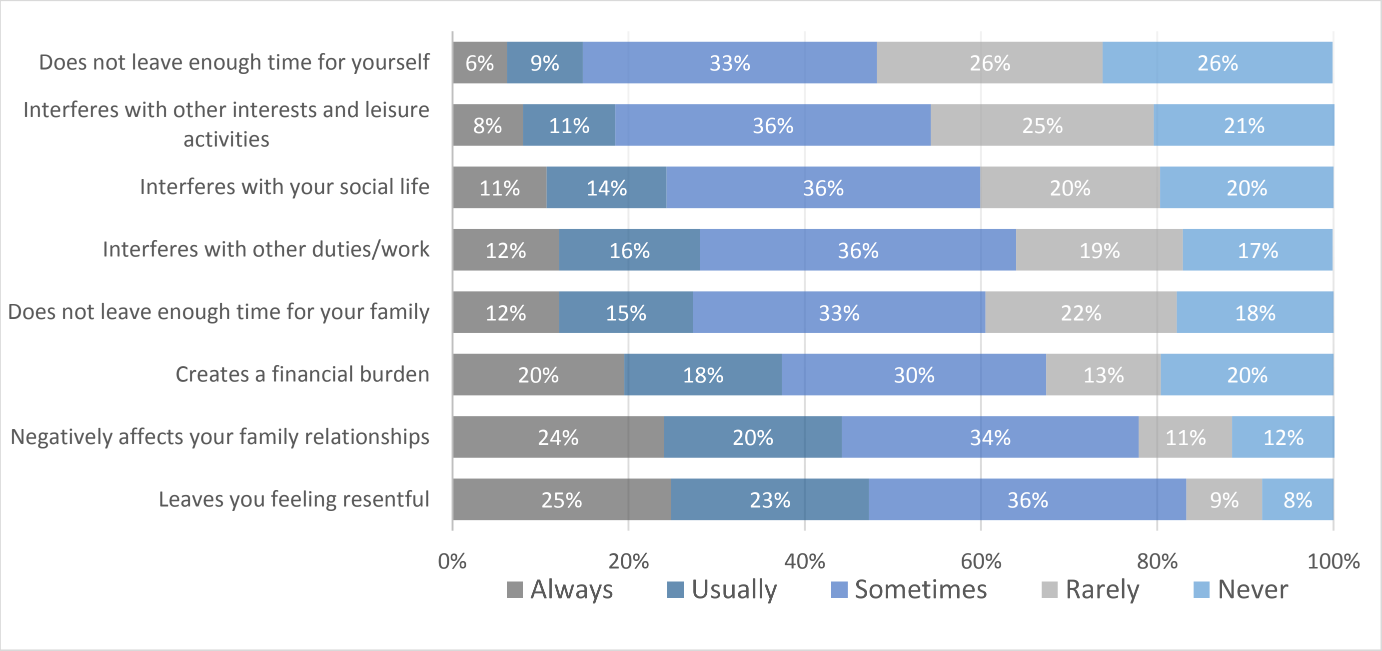
DOEA, 2014 ADRD Caregivers Survey (For a list of totals, refer to Appendix A, Exhibit 1)

*Note: Respondents were able to select multiple responses, and these are individual questions with separate response rates.

Impact of Caregiving: Burdens and Rewards

The burden of caregiving responsibilities has a major impact on the caregiver. In particular, feeling resentment can cause strain between the caregiver and the individual with ADRD and can negatively affect the quality of care provided. The following subsection illustrates the burden of caregiving that a caregiver may be experiencing, as well as the perceived rewards and benefits of caregiving. Exhibit 20 below describes how often caregivers experience various types of caregiving burdens.

Exhibit 20. How Often Caregivers Experience Burdens from Caregiving*

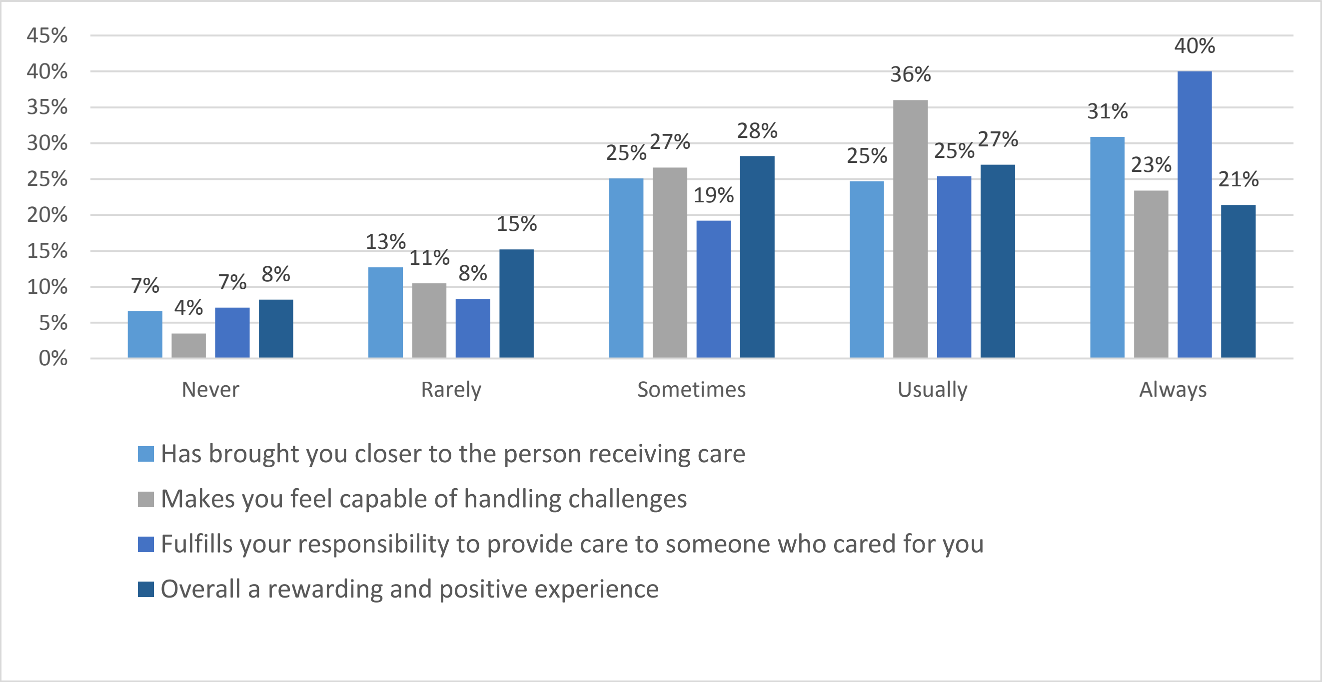


DOEA, 2014 ADRD Caregivers Survey (For a list of totals, refer to Appendix A, Exhibit 1)

Note: these are individual questions with separate response rates.

Over half of responding caregivers felt the impact of major burdens from caregiving at least "sometimes." A quarter of the respondents felt that caregiving left them feeling resentful (25%) "always" and that caregiving also "always" negatively affected their family relationships (24%). However, the majority of caregivers also reported strong positive feelings for providing their loved one with the support they need. Exhibit 21 on the following page shows the frequency of positive feelings felt because of caregiving. Approximately three out of ten caregivers (31%) "always" felt that caregiving brought them closer to the person receiving care, and four out of ten caregivers (40%) "always" felt that caregiving fulfilled their responsibility to provide care to someone who cared for them. This finding is consistent with research on caregiving reported elsewhere by Chappell et al. (2015) that asserts that women have complex and role-specific experiences of caregiving as both a burden and an opportunity to connect in new ways and show their loved ones' respect in their final years. In this particular research, positive rewards experienced in caregiving was highest for daughters providing assistance to their parent, and negative feelings of burden were highest for wives caring for their spouses.

Exhibit 21. How Often Caregivers Feel Rewards from Caregiving*



DOEA, 2014 ADRD Caregivers Survey (For a list of totals by question, refer to Appendix A, Exhibit 1)

*Note: these are individual questions with separate response rates.

Planning for the Future

This section of the analysis will focus on the intentions of the caregiver as they made plans for the future. Results indicated that 41% of caregivers did not have a plan for when a disaster occurred in order to ensure the safety of the individual with ADRD, and 17% of caregivers intended to place the recipient of care into a nursing home or special memory care facility within the upcoming year.

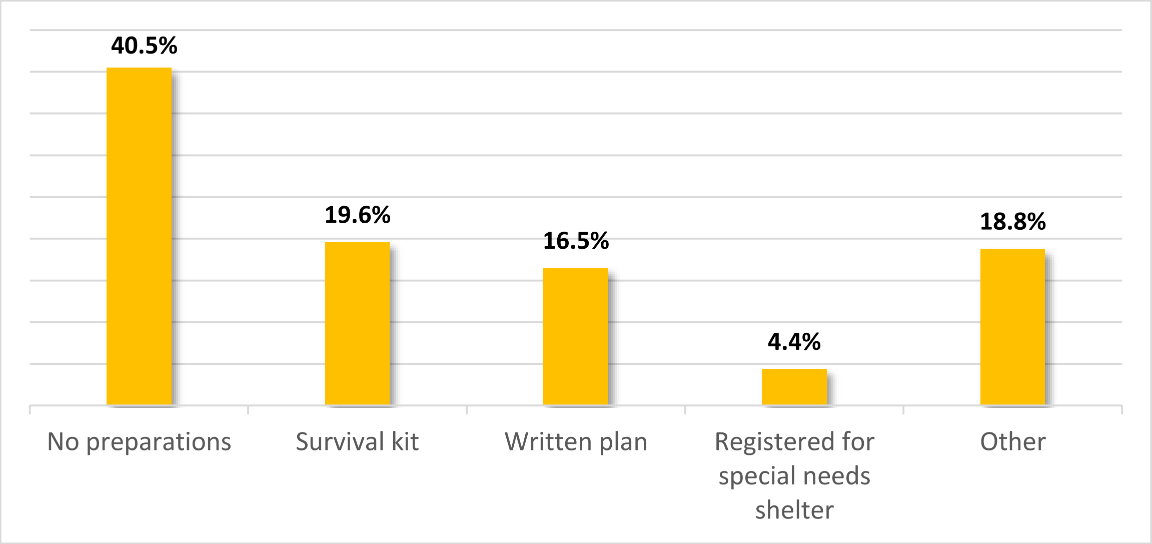
Disaster Preparedness

It is essential for caregivers to have a plan for when a disaster occurs, especially because individuals with ADRD are highly vulnerable at these times. Disasters, such as hurricanes, can cause disruptions in routines and traveling, and they may place the care recipient in unfamiliar environments. All such changes can cause increased agitation, increased likelihood of wandering, and other behavioral symptoms, as well as mismanagement of medications and disruptions in vital support and services.

For those caregivers who are working outside of the home or those who do not live in the same state or city as the individual receiving care, disaster planning is especially important as they may not be able to get to the care recipient during or following a disaster. Unfortunately, the majority of caregivers surveyed were unprepared or only minimally prepared for an emergency or disaster.

Exhibit 22 below illustrates the responses of the caregivers in regards to disaster preparedness, showing that approximately 4 out of 10 caregivers had not made preparations for a disaster (41%). In comparison, 59% of caregivers made some effort to prepare for a disaster, reporting having taken such precautions as a survival kit (20%), a written plan (17%), and registration with a special needs shelter for the care recipient (4%). The caregivers who provided "other" open-ended responses (19%) described plans to go to other family homes outside of the disaster area or temporarily move the care recipient into the caregiver's home.

Exhibit 22. Caregiver Plans for Disasters*



DOEA, 2014 ADRD Caregivers Survey (For a list of totals, refer to Appendix A, Exhibit 1)

*Note: Respondents were able to select more than one response.

Continuing Care in the Near Future

A critical aspect of planning for the needs of persons with ADRD and their caregivers is capturing whether caregivers will be able to continue their care activities in the future. Despite reporting many challenges, the majority of caregivers surveyed planned to continue to provide care for their loved one. Over two-thirds of caregivers (68%) said that they felt they would be able to continue providing care in the near future; 7% said that they would not be able to do so; and 25% indicated that they did not know.

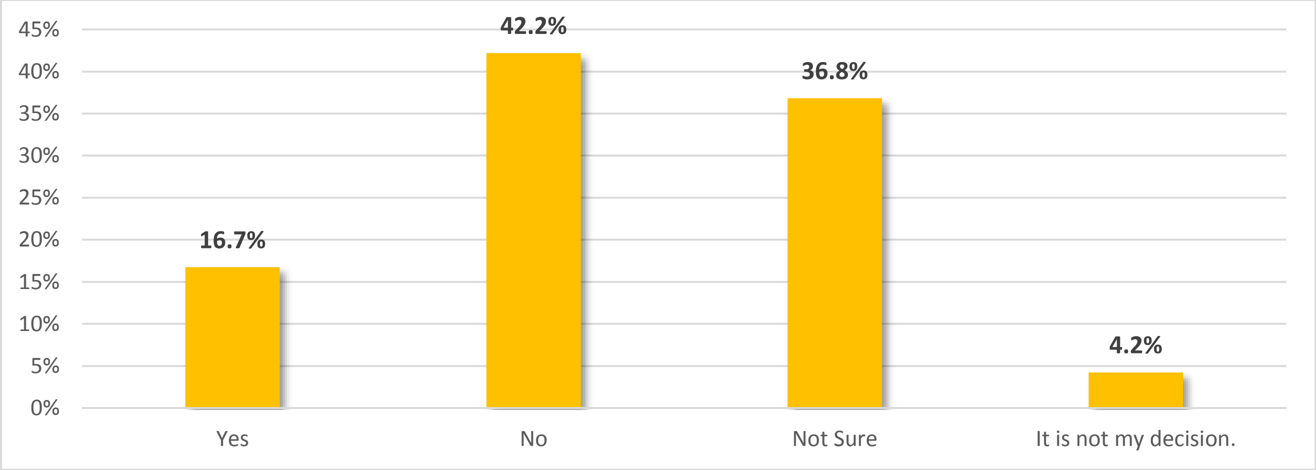
Intent to Place in a Facility within the Upcoming Year

Over 90% of care recipients of the caregivers surveyed lived in the community with the support of their caregiver. However, some caregivers were considering placing their loved one into a nursing home or skilled care facility in the upcoming year. This measure[11] helps to recognize associated factors in considering placement and assists with identifying what organizations and services can do to support caregivers so they can keep their ADRD care recipient in their home, community, or in an assisted living facility (ALF).

Results in Exhibit 23 below show that out of the 801 eligible respondents, most caregivers (42%) planned to continue providing care to their loved one in the home and community, while nearly 37% said they "did not know" if they had intentions to place within the upcoming year. Meanwhile, approximately 17% of caregivers who reported that they did intend to place their loved one into a nursing home, assisted living facility, or special care facility within the upcoming year. Less than 5% of caregivers said "it is not my decision" whether to place their loved one into a facility (4%). Over 15% of caregivers (17%) reported that they intended to place their loved one in a nursing home, ALF, or special care facility in the upcoming year.

Predictors for Intent to Place: Caregiver Situation and Characteristics

Exhibit 23. Intent to Place in a Facility within the Upcoming Year*



DOEA, 2014 ADRD Caregivers Survey, n=801
**Note: caregivers of individuals who are currently residing in a nursing home or special care facility were not included in the reporting of the results of intent to place. For results restricted only to those in private residences, please see Appendix A, Exhibit2.*

The following situations and characteristics were explored:

- Working status of the caregiver;
- Burden level or negative impacts of providing care on the caregiver; and
- Caregiver characteristics (age, gender, race and ethnicity, and income)

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[11] The intent to place variable is constrained to only include caregivers of individuals who live in the home, community, or assisted living facility and to exclude those who already reside in a nursing home or special care facility for persons with dementia. To view the results constrained to exclude caregivers of individuals living in nursing homes, special needs facilities, and assisted living facilities, refer to Appendix A, Exhibit 2.

Hours Spent Caregiving in a Week and Receipt of Help with Caregiving

The overall results from this analysis suggested that it is the lowest intensity care providers, that is, those who spent the fewest hours providing care in an average week, who were most likely to report the intent to place their loved one in a nursing facility within the year.

As detailed in Exhibit 24, over half of responding caregivers who provided care for 11 or fewer hours in an average week (61%) stated they were considering placement in the upcoming year. In comparison, just over a quarter of caregivers (29%) who provided care for 12 to 23 hours a week, and less than half (46%) of caregivers who provided care for 120 to 143 hours in an average week, stated they intended to place their loved one in a care facility in the coming year.

Exhibit 24. Intent to Place in a Facility by Hours of Caregiving per Week

Hours Per Week	Yes, Intent		No, Intent	
	#	%	#	%
1-11 hours	37	60.7%	24	39.3%
12-23 hours	2	28.6%	5	71.4%
24-47 hours	15	18.1%	68	81.9%
48-71 hours	8	25.8%	23	74.2%
72-95 hours	5	19.2%	21	80.8%
96-119 hours	3	15.8%	16	84.2%
120-143 hours	13	46.4%	15	53.6%
144-167 hours	3	16.7%	15	83.3%
168 hours	24	22.6%	82	77.4%

DOEA, 2014 ADRD Caregivers Survey, n=379

When observing whether having (paid or unpaid) assistance with providing care affected the caregiver's intention to place, results indicated that for those who are not receiving assistance, they were almost twice as likely to report an intention to place (63%) than having those who have paid or unpaid help (37%). As such, it is unlikely that paid help can be an explanatory mediator in the observed relationship between hours of caregiving in a week and intent to place (for although receiving help decreases odds of intent, the caregivers with the lowest intensity of care provision had the highest odds of intent).[12]

Low, Medium, and High Hours of Caregiving Responsibilities in an Average Week

The number of hours spent caregiving in an average week can affect the level of stress and burden experienced by the caregiver, as well as influence their need to place a loved one into a nursing home, assisted living, or special care facility due to inability to provide care. To observe differences in intent to place, responses were split based on the number of hours a caregiver provided care in an average week. Reported hours were separated into three groups: low (1 to 36 hours), medium (37 to 60 hours), and high (61 hours or more).

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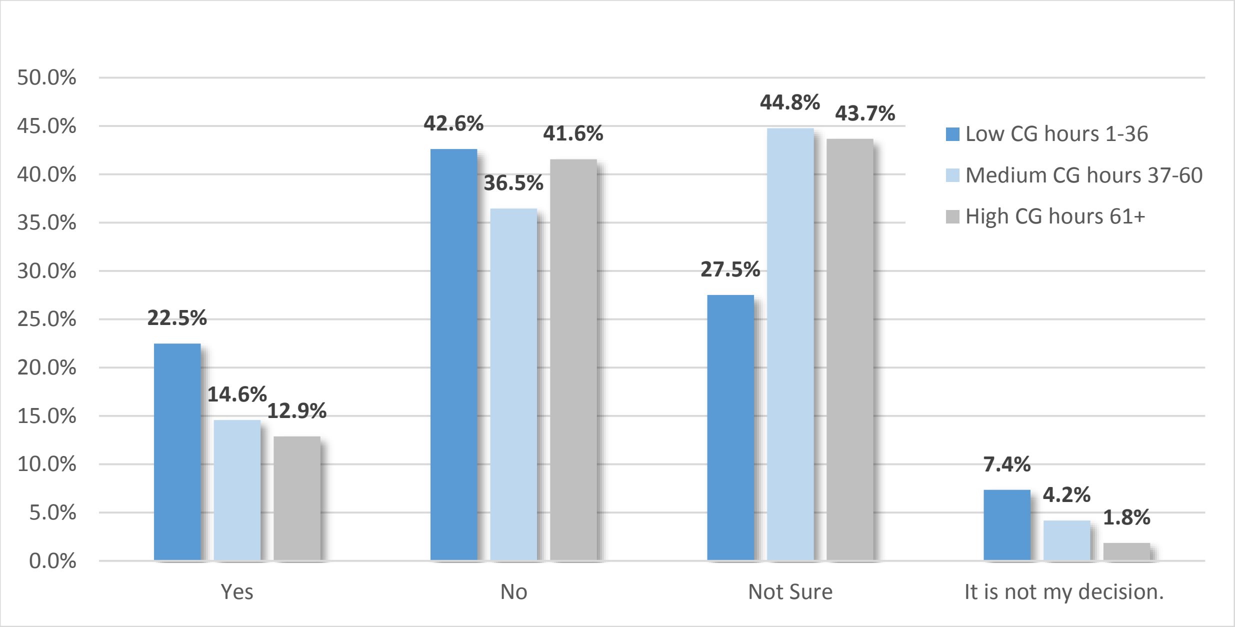
[12] Paid vs. unpaid assistance with providing care do not meaningfully impact rates of intention to place. For caregivers with paid/unpaid assistance, 18% reported having the intention of placing within the upcoming year compared to 17% of caregivers without any assistance. For more information, refer to Appendix A, Exhibit 6.

Results in Exhibit 25 below contrast the number of caregiving hours in an average week against the caregivers who stated intent to place in a nursing home during the next year. Respondents with low caregiving hours in an average week reported the highest likelihood (23%) of intention to place within the year compared to caregivers who provide medium and high hours of care. Although there were many respondents who selected "Not Sure" in every category of hours spent, those doing the least amount of caregiving were 9.6 percentage points more likely to be consider nursing home placement than caregivers who were spending the most amount of time providing care.

Exhibit 25. Caregiver Time Spent Providing Care by Intent to Place



DOEA, 2014 ADRD Caregivers Survey, n=734

To better understand the array of demands on caregivers, the relationship between the number of hours of caregiving and other issues were also analyzed. The number of hours spent caregiving in an average week differ by the level of burden felt by caregivers, as well as whether their caregiving has impacted their physical and mental health, their employment, and their relationship with the care recipient. Similar to the categories used for intent to place, noted above, three categories of the amount of time spent providing care to individuals with ADRD were created for this analysis. A "low" amount of hours providing care was defined as between 1 to 36 hours, "medium" amount was 37 to 60 reported hours providing care, and "high" amount of hours dedicated to providing care was considered 61 hours or more. Exhibits 26, 27, and 28 on the next page reveal that respondents at every level of caregiving hours reported that their health conditions or disabilities had worsened, their employment had been negatively impacted, and that they suffered from feelings of worry, stress, and burden due to caregiving responsibilities. (Note: the response rates in these analyses reflect only the respondents that provided information on both measures, compared with any partial responses omitted.)

As shown in Exhibit 26 below, over half (56%) of the caregivers who provided 61 hours of care or more in an average week reported that their health status has worsened as a result of their caregiving responsibilities.

Exhibit 26. Number of Hours Spent Caregiving in an Average Week by Worsening of Health Conditions, Disabilities, or Problems*

	Yes		No		DK/Does not apply	
	Count	Percent	Count	Percent	Count	Percent
Low CG hours 1-36	138	40.2%	104	30.3%	101	29.4%
Medium CG hours 37-60	40	38.8%	33	32.0%	30	29.1%
High CG hours 61+	224	55.7%	103	25.6%	75	18.7%

DOEA, 2014 ADRD Caregivers Survey, n=848

The number of hours spent caregiving in an average week has an effect on employment. Examples given included showing up late to work, retiring early, or having to quit a job entirely. Those caregivers who provided 37 to 60 of hours of care in an average week had the highest percentage of those with impacts to employment. Results shown in Exhibit 27 below indicate that 42% of those caregivers who provided care between 37 to 60 hours in an average week reported that their caregiving responsibilities had negatively impacted their employment.

Exhibit 27. Number of Hours Spent Caregiving in and Average Week and the Impact on Employment*

	Yes		No		DK /does not apply	
	Count	Percent	Count	Percent	Count	Percent
Low CG hours 1-36	115	34.0%	139	41.1%	84	24.9%
Medium CG hours 37-60	41	42.3%	33	34.0%	23	23.7%
High CG hours 61+	129	34.1%	165	43.7%	84	22.2%

DOEA, 2014 ADRD Caregivers Survey, n=813

The number of hours spent caregiving in an average week also impacted the subjective feelings of burden experienced by the caregiver, such as financial worries and strains on friendships and other relationships. Those caregivers who provide 37 to 60 hours of care in an average week reported the highest amounts of burden, with 22% of those in the 37-to-60-hour group reported the highest perceived burden – approximately 10% higher than caregivers who spent over 61 hours proving care in an average week and 5% higher than those who provided up to 36 hours of care.

Exhibit 28. Number of Hours Spent Caregiving in and Average Week by Level of Caregiver Burden*

	High		Medium		Low	
	Count	Percent	Count	Percent	Count	Percent
Low CG hours 1-36	66	17.9%	137	37.1%	49	13.3%
Medium CG hours 37-60	24	22.4%	33	30.8%	20	18.7%
High CG hours 61+	55	12.8%	133	31.0%	101	23.5%

DOEA, 2014 ADRD Caregivers Survey, n=618

Measuring and Contrasting Aggregate Burden on Caregivers

To observe differences in level of caregiver burden and to see if strain on the caregiver was a significant factor in their intent to place a loved one in a nursing facility, questions regarding negative feelings and effects from caregiving from the previous section of the survey were placed into a scale of "burden" from caregiving[13]. (Note: the denominator in each combination varies based on the responses available for the measures used.)

The "low burden" category in this analysis includes caregivers who "rarely" or "never" experienced negative feelings about caregiving; "medium burden" includes caregivers who "sometimes" felt burden from caregiving; and "high burden" includes caregivers who "usually" or "always" felt burden from caregiving. Results detailed in Exhibit 29 to the left show that one in four caregivers who experienced low levels of burden (25%) were likely to consider placing their loved one into a facility within the upcoming year – a likelihood much higher than those with higher levels of burden. Caregivers with the lowest burden were twice as likely to consider placing their care recipient into a nursing facility compared to caregivers with the highest burden.

Exhibit 29. Caregiver Burden by Intent to Place

Level of Burden by Intent		Count	Percent
High	Yes	10	7.4%
	No	89	65.9%
	Not sure	30	22.2%
	It is not my decision.	6	4.4%
Medium	Yes	53	18.5%
	No	118	41.1%
	Not sure	104	36.2%
	It is not my decision.	12	4.2%
Low	Yes	38	24.7%
	No	41	26.6%
	Not sure	69	44.8%
	It is not my decision.	6	3.9%

DOEA, 2014 ADRD Caregivers Survey, n=576

Gender of Caregiver

When observing the differences between male and female caregivers and their intention to place their loved one in a care facility in the upcoming year, results show that females were less inclined to consider placement compared to males. Detailed in Exhibit 30 to the right, approximately one out of seven female caregivers (15%) reported an intent to place, compared to approximately two out of nine male caregivers (23%) – a percentage point difference of 8%. There is a 5-percentage-point difference by gender, with 44% of female caregivers reporting they would not place their loved one, compared to 38% of male caregivers said they who would not.

Exhibit 30. Gender by Intent to Place

		Count	Percent
Females	Yes	92	14.8%
	No	270	43.5%
	Not sure	231	37.2%
	It is not my decision.	28	4.5%
	Total	621	100.0%
Males	Yes	39	23.2%
	No	64	38.1%
	Not sure	60	35.7%
	It is not my decision.	5	3.0%
	Total	168	100.0%

DOEA, 2014 ADRD Caregivers Survey, n=789

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[13] This scale was developed based on prior research conducted by Chappell, et al. (2015) that similarly combines different domains of stress and concern for caregivers into a scale of "burden" of the aggregate toll of a variety of strains.

Race & Ethnicity of the Caregiver

Race and ethnicity of the caregiver was also contrasted to see if there was any variance in intent to place by group. Although statistically, small cell sizes often discourage multi-split inferences into comparisons by both race and ethnicity, the observed differences presented were significant. Detailed in Exhibit 31 to the right, compared to non-Hispanic White respondents, caregivers who were of Hispanic, Latino, or Spanish origin were less likely to consider nursing facility placement, as well as caregivers who were non-Hispanic Black or African American.

Exhibit 31. Race & Ethnicity by Intent to Place

Race		Count	Percent
Hispanic Latino or Spanish Origin (of any race)	Yes	12	11.0%
	No	56	51.4%
	Not sure	39	35.8%
	It is not my decision	2	1.8%
	Total	109	100.0%
White & Non-Hispanic	Yes	120	17.7%
	No	275	40.6%
	Not sure	255	37.6%
	It is not my decision	28	4.1%
	Total	678	100.0%
Black/African American & Non-Hispanic	Yes	6	10.5%
	No	32	56.1%
	Not sure	15	26.3%
	It is not my decision	4	7.0%
	Total	57	100.0%

DOEA, 2014 ADRD Caregivers Survey, n=844

Results show a 7-percentage-point difference between non-Hispanic White and Hispanic caregivers who reported they would place their loved one into a facility within the year. As well, there was an 11-percentage-point difference between Hispanic and non-Hispanic White caregivers who would not place their loved one into a facility within the year. In general, non-Hispanic Black caregivers were the most confident in their intent to keep their loved on in the community, with over half reporting they would not place their loved one into a facility within the year (56%).

Caregiver Relationship

The relationship between the caregiver and the individual with ADRD may affect the decisions about care arrangements and may be a predictor of the stability of the caregiving commitment. The relationship between caregiver and care recipient may also be an important distinction because other research has found that spouses have the highest level of negative physical, emotional, and financial impacts from their caregiving compared with other relationships (DiGiacomo et al, 2015; Chapell et al 2015). In this survey; however, these strains did not increase intent to place, as individuals caring for their spouse were more willing to continue providing care than those who were caring for their parent with ADRD. Exhibit 32 on the following page details that out of all the relationship types between the caregiver and the individual with ADRD receiving care, caregivers of parents had the highest frequency of considering placement into a nursing home, ALF, or special care facility within the upcoming year. That is, half (50%) of caregiver respondents who intended to place in the coming year were those who are providing care to their parents. Comparatively, over one-third (38%) of caregivers providing care for spouses or partners were considering nursing facility placement within the year.

Exhibit 32. Intent to Place, by Relationship Between Caregiver and ADRD Recipient

Recipient of Care Relationship to Caregiver	Intent to Place							
	Yes		No		Not sure		It is not my decision	
	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Spouse or Partner	50	37.6%	164	49.0%	152	51.7%	1	2.9%
Parent	66	49.6%	124	37.0%	116	39.5%	17	50.0%
Grandparent	3	2.3%	12	3.6%	3	1.0%	2	5.9%
Adult child	-	0.0%	4	1.2%	1	.3%	-	0.0%
Friend	3	2.3%	8	2.4%	4	1.4%	6	17.6%
Mother or Father-in-law	2	1.5%	7	2.1%	5	1.7%	1	2.9%
Sibling	5	3.8%	11	3.3%	4	1.4%	3	8.8%
Other In-law	-	0.0%	-	0.0%	2	.7%	-	0.0%
Other relative	4	3.0%	5	1.5%	7	2.4%	4	11.8%

DOEA, 2014 ADRD Caregivers Survey, n=796

Caregiver Health and Effect on Caregiving

Approximately one out of three caregivers (34%) reported that they had a health problem, physical condition, or disability that affected the care that they could provide for their loved one with ADRD. In the contrast, by presence of caregiver health issues below, only slight differences (3%) can be observed in the caregivers' stated intention to place the care recipient with ADRD into a nursing home, assisted living, or special care facility within the upcoming year. As detailed in Exhibit 33 below, approximately one-quarter (24%) of caregivers who reported having a health problem, physical condition, or disability intended to place, compared to 21% of those who did not suffer from any of these issues.

Exhibit 33. Intent to Place, by Presence of a Health Problem, Physical Condition, or Disability

		Intent to place	Count	Percent
Do you have any kind of health problem, physical condition, or disability that affects the kind or amount of care that you can provide?	Yes	Yes	70	23.0%
		No	101	33.2%
		Not sure	118	38.8%
		It is not my decision.	15	4.9%
			304	100%
	No	Yes	116	21.3%
		No	240	44.0%
		Not sure	170	31.2%
		It is not my decision.	19	3.5%
			545	100%
	Don't know	Yes	15	27.8%
		No	15	27.8%
		Not sure	20	37.0%
		It is not my decision.	4	7.4%
			54	100%

DOEA, 2014 ADRD Caregivers Survey, n=903

Severity of Symptoms in Individuals with ADRD

Exhibit 34 below presents the severity of symptoms experienced by the individual with ADRD, as described by their caregiver against the reported intent to place the recipient of care into a nursing home or special care facility. Results indicate that the severity of symptoms was a factor in placement considerations. Notably, the percentage of intent to place increased as the symptoms presented by the individual with ADRD worsened.

> *Notably, the number of caregivers with intent to place increased as the symptoms presented by the individual with ADRD worsened.*

For those caregivers who described the recipient of care's ADRD conditions as the least severe, such as "having on-going memory problems but no other problems with thinking," 10% reported an intent to seek placement. Conversely, of those caregivers who described the recipient of care's ADRD conditions as most severe, such as "complete memory loss and in need of constant help to complete personal care tasks," 35% reported intent to place their loved one in a nursing home or specialty care facility in the coming year.

Exhibit 34. Symptom Types in Individual with ADRD by Caregiver's Intent to Place*

		Intent to place:	Count	Percent
Which of the following best describes the condition of the person receiving your care?	Ongoing memory problems but no other problems with thinking.	Yes	11	9.5%
		No	64	55.2%
		Not sure	36	31.0%
		It is not my decision.	5	4.3%
	Problems with memory, trouble finding words when speaking, changes in mood or personality. Misplacing items, getting lost.	Yes	34	15.4%
		No	108	48.9%
		Not sure	68	30.8%
		It is not my decision.	11	5.0%
	More problems with memory, language, short attention span, trouble with fixing meals, dressing, bathing etc., needs help completing tasks	Yes	107	25.4%
		No	140	33.2%
		Not sure	160	37.9%
		It is not my decision.	15	3.6%
	Complete loss of memory and language, sleep problems, clumsy using hands or walking, needs constant help to complete personal care tasks.	Yes	48	34.5%
		No	39	28.1%
		Not sure	45	32.4%
		It is not my decision.	7	5.0%

DOEA, 2014 ADRD Caregivers Survey, n=989

*Note: respondents were able to select more than one response.

Multivariate Logistic Regression Models for Intent to Place

With all other factors held constant, low burden, non-Hispanic males who were caring for a parent had higher odds of considering placing their loved one in a nursing home compared to high burden, Hispanic women who were caring for their spouse or partner.

Caregiver characteristics were placed into a binary logistic regression model to test their significance[14] as predictors and to observe the odds of the caregiver having the intention to place a loved one into a nursing home or special care facility within the upcoming year. Significant predictors of intent to place based on these analyses include the caregiver's sex, ethnicity, race, relationship to recipient of care, and level of caregiver perceived burden.

Results of introducing each predictor into stepwise models indicate that there is an interaction between many characteristics but resulted in an increased likelihood of having the intent to place a loved one into a nursing home or special care facility if the caregiver is a non-Hispanic White male experiencing low burden and providing care to a child or parent. The results of these predictive models can also be interpreted such that intent to place decreases if the caregiver of the individual with ADRD is a female, non-white Hispanic, experiencing high burden and providing care to a spouse or intimate partner.

It is important to note that the caregiver's race was rendered non-significant in determining intent to place after introducing the level of burden that is experienced by the caregiver. This suggests that original observed differences by racial and ethnic groups are explained by differentials in the amount of negative impacts from caregiving these groups experienced and also confirms findings in the research literature that posit burden scales are an important factor in predictive models in caregiving. Other characteristics of the caregiver were considered in the step-wise models but did not hold their significance in predicting intent to place. To view more details on the results of the logistic regressions models, refer to Appendix A, Exhibits 2-5.

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[14] It is customary to require significance threshold at .05; however, due to low separated cell values available in the survey responses, the significance of the caregiver characteristics in the models are determined by observing their p-value with a threshold of 0.1. It is recommended that future research attempt to include a higher number of caregivers to afford greater statistical power in comparisons between demographic characteristics.

Focusing Outreach by Caregiver Types

The multivariate findings reveal two different types of caregivers present in the survey: working men who were considering placing their parent in a facility and un/under-employed women who were not considering placing a spouse. Their differences in characteristics, relationships, and responses regarding the impact of caregiving suggest the opportunity to refine current outreach efforts and develop more targeted strategies to address the unique needs of these groups. Given the importance of retaining caregivers and reducing the risk of institutionalization for ADRD individuals, further research is recommended to identify a variety of outreach strategies.

Information

Caregivers *most* likely to consider placing recipient of care into a facility

The majority of caregivers considering placing their ADRD loved one in a facility were adult children caring for their parent, males who had a higher income, were non-Hispanic White, and reported relatively low levels of caregiver burden. The type of outreach that may be beneficial to these caregivers could include providing information on recognizing early ADRD symptoms and the benefits of early treatment, as well as information regarding the array of long-term care services available in the home and community. These working caregivers may also need specific hours of respite and assistance with providing care or transportation services to get their loved ones to adult day care.

Assistance

Caregivers *least* likely to intend to place recipient of care into a facility

These caregivers assert the strongest intention to continue providing care at home but are at a very high risk of being unable to continue doing so. They tend to be spouses caring for their partner, females with low income, under- or unemployed, experiencing high levels of caregiving burden and dedicating more than a hundred hours of supervision and caregiving in an average week. These individuals may be in need of further training and information on ADRD needs and care techniques, as well as additional services like respite or assistance providing care to help decrease experienced level of burden and stress.

The results of this analysis show important distinctions by demographic characteristics of caregivers. These findings are consistent with broader caregiver literature, findings from other states, and research on caregivers for care recipients with conditions other than ADRD. However, as a note of caution, the distribution of survey respondents lacked the equivalent diversity typically required for generalizability to the state population with regards to education level and gender (with 99% of reporting caregivers having attained a high school diploma or above and with 80% being female). It is unknown whether these characteristics are equivalent to the sub-population of individuals with ADRD or to the demographics of caregivers more broadly, but the findings may not represent the range of needs and experiences of less-educated or male caregivers due to the possibility of more extreme responses when represented from smaller sample sizes.

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Appendix A

Key Factors of Florida's ADRD Caregiver Population

It is estimated that there are 2.67 million caregivers in Florida to adults with limited capacity to handle ADL's (Shea, 2015). It has been estimated that a caregiver's economic value is $11.93 per hour, which totals to $29.7 billion in free care (Shea, 2015). According to Florida Department of Health, in 2014 Alzheimer's disease ranked sixth as a major cause of death with a death rate of 29.7% out of 100,000 deaths (Florida Department of Health, Bureau of Vital Statistics, 2014). In 2015, it was estimated that half a million individuals age 65 and older had Alzheimer's disease. This rate it expected to increase by 44% in 2025 to 720,000 individuals with Alzheimer's disease age 65 and older (Alzheimer's Association, 2016). The "State of the States in Family Caregiver Support" report released in 2014[15] estimated that there are 1,766,000 informal caregivers in Florida, about half of whom are estimated to be caring for a loved one with Alzheimer's disease or related form of dementia.

Exhibit 1. Frequency and Percentage for All Categorical Questions*

PSA	Frequency	Valid Percent
PSA 1	29	2.8
PSA 2	27	2.6
PSA 3	115	10.9
PSA 4	71	6.7
PSA 5	86	8.2
PSA 6	149	14.1
PSA 7	155	14.7
PSA 8	140	13.3
PSA 9	178	16.9
PSA 10	71	6.7
PSA 11	33	3.1
Total	1054	100.0
Rurality	Frequency	Valid Percent
RURAL	45	4.3
URBAN	1009	95.7
Total	1054	100.0
01. Is the person you are caring for your…	Frequency	Valid Percent
Adult child	5	.5
Mother or Father-in-law	16	1.5
Partner	18	1.7
Grandparent	24	2.3
Friend	26	2.5
Sibling	29	2.8
Other relative (please specify)	44	4.2
Spouse	418	40.1
Parent	462	44.3
Total	1042	100.0

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[15] https://www.caregiver.org/sites/caregiver.org/files/pdfs/state2014/state_profile_fl_2014_final.pdf
https://www.caregiver.org/caregiver-statistics-demographics

02. Are you the primary caregiver for this person? (A primary caregiver is the person who consistently takes primary responsibility for someone who needs help taking care of themselves.)	Frequency	Valid Percent
Yes	925	88.7
No	118	11.3
Total	1043	100.0
03. How long have you been caring for this person?	Frequency	Valid Percent
Less than 1 year	88	8.4
1 - 3 years	389	37.3
4 - 8 years	393	37.7
9 - 12 years	90	8.6
More than 12 years	82	7.9
Total	1042	100.0
04. Do you also care for younger loved ones, such as children or grandchildren?	Frequency	Valid Percent
Yes	189	18.2
No	847	81.8
Total	1036	100.0
05. Do you live more than an hour away from the person receiving care?	Frequency	Valid Percent
Yes	71	6.8
No	955	91.4
It depends on traffic/transportation	14	1.3
Don't know	5	0.5
Total	1045	100.0
06. Where does the person receiving your care currently live?	Frequency	Valid Percent
Other (please specify)	53	5.1
Alone, in his/her own home	66	6.3
In his/her own home with others	143	13.6
In your home	565	53.9
In the home of another family member	26	2.5
In a retirement community	14	1.3
In an assisted living facility	86	8.2
In a nursing home	31	3.0
In a specialized care facility for persons with dementia	64	6.1
Total	1048	100.0
07. Do you also care for younger loved ones, such as children or grandchildren?	Frequency	Valid Percent
Yes	189	18.2
No	847	81.8
Total	1036	100.0
08. Do you live more than an hour away from the person receiving care?	Frequency	Valid Percent
Yes	71	6.8
No	955	91.4
It depends on traffic/transportation	14	1.3
Don't know	5	.5
Total	1045	100.0

DOEA, 2014 ADRD Caregivers Survey

09. Where does the person receiving your care currently live?	Frequency	Valid Percent
Other (please specify)*	53	5.1
Alone, in his/her own home	66	6.3
In his/her own home with others	143	13.6
In your home	565	53.9
In the home of another family member	26	2.5
In a retirement community	14	1.3
In an assisted living facility	86	8.2
In a nursing home	31	3.0
In a specialized care facility for persons with dementia	64	6.1
Total	1048	100.0
10. In an average week, how many hours do you provide care for this person?	Frequency	Valid Percent
0-20	262	29.0
21-40	167	18.5
41-60	53	5.9
61-80	61	6.7
81-100	42	4.6
101-120	25	2.8
121-140	47	5.2
141-160	38	4.2
>160	209	23.1
Total	904	100.0
11. Are you currently being paid for your caregiving assistance?	Frequency	Valid Percent
No	926	93.9
Yes	60	6.1
Total	986	100.0
12. In an average week, how many hours do you provide care for this person?	Frequency	Valid Percent
0-20	262	29.0
21-40	167	18.5
41-60	53	5.9
61-80	61	6.7
81-100	42	4.6
101-120	25	2.8
121-140	47	5.2
141-160	38	4.2
>160	209	23.1
Total	904	100.0
11. Are you currently being paid for your caregiving assistance?	Frequency	Valid Percent
No	926	93.9
Yes	60	6.1
Total	986	100.0
12. Do you currently receive unpaid caregiving help from family or friends?	Frequency	Valid Percent
Yes	187	18.9
No	800	81.1
Total	987	100.0

**Comments and elaborations not included.*
DOEA, 2014 ADRD Caregivers Survey

12b. If Yes, how many hours of help?	Frequency	Valid Percent
0-20	131	71.6
21-40	25	13.7
41-60	8	4.4
61-80	5	2.7
81-100	3	1.6
101-120	1	.5
121-140	4	2.2
141-160	3	1.6
>160	3	1.6
Total	183	100.0
13. Do you currently pay for additional help to assist with your caregiving?	Frequency	Valid Percent
Yes	351	36.1
No	620	63.9
Total	971	100.0
13b. If Yes, how many hours of help?	Frequency	Valid Percent
0-20	168	48.7
21-40	99	28.7
41-60	16	4.6
61-80	10	2.9
81-100	4	1.2
101-120	1	.3
121-140	6	1.7
141-160	7	2.0
>160	34	9.9
Total	345	100.0
14. Do you currently receive caregiving help from social services	Frequency	Valid Percent
Yes	226	23.4
No	738	76.6
Total	964	100.0
14b. If Yes, how many hours of help?	Frequency	Valid Percent
0-20	133	58.8
21-40	71	31.4
41-60	5	2.2
61-80	4	1.8
81-100	1	.4
101-120	0	.0
121-140	0	.0
141-160	0	.0
>160	12	5.3
Total	226	100.0
15. Are you on a wait list to receive help?	Frequency	Valid Percent
Yes	108	10.9
No	881	89.1
Total	989	100.0

DOEA, 2014 ADRD Caregivers Survey

15b. Please tell us about how long you have been waiting.	Frequency	Valid Percent
Submitting now	2	2.1
Up to 1 year	55	57.9
More than 1 year, but less than 2	11	11.6
More than 2 years, but less than 3	14	14.7
More than 3 years, but less than 4	6	6.3
More than 4 years, but less than 5	2	2.1
5 years or more	5	5.3
Total	95	100.0
16. Which of the following best describes the condition of the person receiving your care? The person has...	**Frequency**	**Valid Percent**
Complete loss of memory and language, sleep problems (too little or too much), is clumsy using hands or walking, need constant help to do personal care..	160	16.2
More problems with memory, language, short attention span, trouble with the routine of fixing meals, dressing, bathing, etc., needs help to complete tasks.	466	47.3
Problems with memory, trouble finding words when speaking, changes in mood or personality, misplacing items, getting lost	236	24.0
Ongoing memory problems but no other problems with thinking.	123	12.5
Total	985	100.0
17. How long has the person receiving your care shown signs of a memory or thinking disorder, such as forgetting things, losing items, or being unable to speak well?	**Frequency**	**Valid Percent**
Less than 1 year	48	4.9
1 - 2 years	217	22.0
3 - 4 years	309	31.3
5 - 10 years	336	34.0
More than 10 years	78	7.9
Total	988	100.0
18. Has the person receiving your care had a medical diagnosis of Alzheimer's disease or a related disorder?	**Frequency**	**Valid Percent**
Yes	841	85.4
No	122	12.4
Don't know	22	2.2
Total	985	100.0
19. What was that diagnosis? (Check all that apply)	**Frequency**	**Percent**
Alzheimer's disease	499	46.9
Mild cognitive impairment	145	13.6
Other	148	13.9
Vascular dementia	115	10.8
Mixed dementia	113	10.6
Stroke	98	9.2
Don't know	50	4.7
Lewy body	47	4.4
Frontotemporal dementia	44	4.1
Frontal dementia	39	3.7
Parkinson's disease with dementia	34	3.2
No Diagnosis	32	3.0
Parkinson's disease	22	2.1
Parkinsonism - Progressive Supranuclear Palsy or Cortical Basal Dementia	11	1.0

20. Was the diagnosis provided by a…	Frequency	Percent
Neurologist	518	48.7
Family doctor/primary care physician/general practitioner/ARNP (nurse)	320	30.1
Memory Disorder Clinic/Center doctor	170	16
Psychiatrist	105	9.9
Geriatrician	76	7.1
Other	47	4.4
No diagnosis	40	3.8
Don't know	16	1.5

21. How long did the person who receives your care show signs of a memory or thinking disorder before a diagnosis by a doctor or other medical professional was made?	Frequency	Valid Percent
(No diagnosis)	49	5.0
Less than 1 year	180	18.3
1 - 2 years	398	40.6
3 - 4 years	190	19.4
5 -10 years	126	12.8
More than 10 years	38	3.9
Total	981	100.0

22. Which of the following may have delayed a diagnosis (Check all that apply.)	Frequency	Percent
I thought the symptoms were a part of normal aging	509	47.9
Other	366	34.4
I didn't know where to find help	87	8.2
I didn't think anything could be done	64	6
I didn't want to know	50	4.7
Cost of health care	39	3.7
Insurance would not cover the medical test(s)	17	1.6

23. Please check the frequency of the behaviors below that apply to the person receiving your care	Percent of Responses to Challenge					Frequency
	Never	Seldom	Sometimes	Usually	Always	
Difficulty speaking to others	14.2	17.1	33.4	18.6	16.7	956
Difficulty understanding language	16.6	18.7	38.8	14.9	11.1	936
Sundowning - decreased abilities in late afternoon or evening	14.5	14.2	25.4	23.7	22.2	902
Not getting along with others, being disagreeable	23.9	27.6	36.4	8.9	3.2	940
Acts distrustful, suspicious	25.2	21.8	32.5	12.6	7.9	939
Verbal aggression, such as shouting or name calling	41.2	24.2	23.6	7.5	3.5	939
Sleep problems	18.4	19.6	31.4	17.4	13.2	946
Anxious, irritable	13.1	19.0	42.4	18.6	6.8	951
Depression	14.8	19.7	38.1	17.2	10.1	923
Restless, wanders	32.8	22.6	25.1	11.6	8.0	930
No boundaries, talks to/touches strangers	45.7	20.6	15.6	9.3	8.7	921
Gets lost outside, missing	52.5	19.9	14.5	6.2	7.0	876
Physically aggressive/violent toward self, injures self	84.5	10.1	3.9	0.5	0.9	937
Physically aggressive/violent toward others, such as hitting, pushing others	72.3	15.0	9.9	1.7	1.1	938

DOEA, 2014 ADRD Caregivers Survey

24. What ADDITIONAL SERVICES AND SUPPORT are needed for the PERSON RECEIVING CARE to continue to live at home? (Yes/No)	Frequency, Yes	Valid Percent
Companion	606	79.0
Household chores	546	72.3
Using transportation	521	71.8
Managing medicines	557	71.5
Managing money, bills	515	71.1
Shopping	514	70.5
Legal advice	484	69.6
Preparing meals/Meals on Wheels	498	67.8
Adult day care	486	66.7
Personal care	508	64.9
Using the phone	434	58.1
Support group	400	57.4
Home safety	380	52.9
Case management	348	52.8
Personal emergency response system	360	51.9
Individual or family counseling	336	49.0
Home health/medical care	333	48.9
Wandering alert	316	45.6
Telephone reassurance	225	35.4
Emergency Placement	227	33.4
25. What ADDITIONAL SERVICES AND SUPPORT are needed by you, the CAREGIVER, in order to continue providing care?	**Frequency, Yes**	**Valid Percent**
More support/flexibility from employer	108	19.0
Training to provide care such as injections, wound and skin care	183	25.7
Medical care for yourself	249	32.8
Training information on dealing with behaviors related to ADRD	519	65.0
Caregiver support group	559	69.0
Educational information about disease changes, coping strategies, and resources	586	71.3
A key contact person for questions and help	599	73.8
Respite	623	75.7
26. What (if anything) prevents you from receiving services or resources you need but don't have? (Check all that apply.)	**Frequency**	**Percent**
I don't have transportation to use the service	20	1.9
I'm a long distance caregiver, live too far away	34	3.2
The service is not available	72	6.8
Family dynamics	83	7.8
I don't have time	106	10.0
I don't know where to find them	261	24.6
Nothing	270	25.4
I can't afford them	293	27.6
I don't know what is available	333	31.3

DOEA, 2014 ADRD Caregivers Survey

27. Have you received information or services from any of the following to help with your caregiving?	Frequency	Percent
A group/family style home (adult family care home)	48	4.5
Other veterans' services and support groups	67	6.3
Veterans Administration Medical Center (VAMC)	81	7.6
Nursing home	87	8.2
Public library	95	8.9
Hospital	155	14.6
Faith community, such as church, synagogue, etc.	182	17.1
Assisted living facility (ALF)	199	18.7
Neighbors	257	24.2
Other social service agency, such as the departments of Children and Families, Veterans' Affairs, Health, or the Agency for Health Care Administration	259	24.4
Memory Disorder Clinic	287	27.0
Area Agency on Aging/Aging and Disability Resource Center	299	28.1
Florida Department of Elder Affairs	334	31.4
Home care service provider, home health agency	367	34.5
Support group	371	34.9
Adult day care center	380	35.7
Alzheimer's Association	438	41.2
Family members or friends	529	49.8
Internet	539	50.7
Medical professional, such as a family doctor, nurse, social worker	656	61.7
28. Have you made a plan or other preparations for what to do in case there is a disaster, such as a hurricane? (Check all that apply.)	**Frequency**	**Percent**
No, I do not have a plan or other preparations.	431	40.5
Yes, I have a survival kit.	208	19.6
Yes, I have a written plan.	175	16.5
Yes, I have registered with my county for a Special Needs Shelter.	47	4.4
29. Do you have any kind of health problem, physical condition, or disability that affects the kind or amount of care that you can provide?	**Frequency**	**Valid Percent**
Yes	316	33.6
No	568	60.4
Don't know	57	6.1
Total	941	100.0
30. What health problem, condition or disability affects the care you can provide: (Check all that apply.)	**Frequency**	**Percent**
Vision problems	55	5.2
Allergies/Asthma/Other breathing or lung problems	62	5.8
Diabetes	72	6.8
Mental health (anxiety, fear, depression, emotional problems)	162	15.2
Heart problem(s), High blood pressure, Hypertension, Stroke	182	17.1
Back problems and other joint problems, such as arthritis	322	30.3
No problems right now	365	34.3
Stress	397	37.3

DOEA, 2014 ADRD Caregivers Survey

31. Have your caregiving responsibilities created or worsened any of these conditions, problems or disabilities?	Frequency	Valid Percent
Yes	437	46.6
No	273	29.1
Don't know/Does not apply	228	24.3
Total	938	100.0
32. Are you currently employed?	**Frequency**	**Valid Percent**
Other (please specify)	50	5.3
Yes, full-time	207	22.0
Yes, part-time	97	10.3
Retired	376	39.9
No	213	22.6
Total	943	100.0
33. Have your caregiving responsibilities affected your employment?	**Frequency**	**Valid Percent**
Yes	302	33.6
No	393	43.7
Don't know	205	22.8
Total	900	100.0
34. If you checked above that your caregiving responsibilities affected your employment, did you have to do any of the following? (Check all that apply.)	**Frequency**	**Percent**
Lose any of your job benefits	17	5.6
Turn down a job promotion	25	8.3
Take a leave of absence	41	13.6
Cut back on your hours of work	98	32.5
Occasionally miss work	127	42.1
Go to work late, leave work early	127	42.1
Quit work or retire early	130	43.0

DOEA, 2014 ADRD Caregivers Survey

35. As a caregiver, how often do you feel that caregiving…?	Always	Usually	Some-times	Rarely	Never
Financial burden	19.6	13.0	30.0	17.9	19.5
Not enough time for yourself	26.1	25.6	33.4	8.6	6.2
Not enough time for your family	17.8	21.7	33.2	15.2	12.1
Interferes with other duties/work	17.0	18.9	35.9	16.0	12.1
Negatively affects your family	11.6	10.6	33.7	20.2	24.0
Interferes: friendships/social life	19.7	20.4	35.6	13.6	10.7
Interferes: interests and leisure	20.5	25.3	35.8	10.5	8.0
Feel resentful	8.1	8.6	36.0	22.5	24.8
Brought you closer to the person	30.9	24.7	25.1	12.7	6.6
Feel capable of handling challenges	23.4	36.0	26.6	10.5	3.5
Fulfills your responsibility	40.0	25.4	19.2	8.3	7.1
Is a rewarding, positive experience for you, overall	21.4	27.0	28.2	15.2	8.2

DOEA, 2014 ADRD Caregivers Survey

36. Will you be able to continue to care for this person for the foreseeable future?	Frequency	Valid Percent
Yes	640	68
Don't know	232	24.8
No	63	6.7
Total	935	100.0
37. Do you think you will need to place the person receiving your care in a nursing home, assisted living facility, or specialize care facility within the coming year?	Frequency	Valid Percent
It is not my decision.	39	4.3
No	359	39.3
Not sure	314	34.4
Yes	201	22.0
Total	913	100.0

DOEA, 2014 ADRD Caregivers Survey

DEMOGRAPHICS OF PERSONS WITH ADRD IN SURVEY		
38. What is the gender of the person receiving care?	Frequency	Valid Percent
Female	582	62.0
Male	356	38.0
Total	938	100.0
39. What is the age of the person receiving care?	Frequency	Valid Percent
35 - 44	1	.1
45 - 54	6	.6
55 - 64	36	3.8
65 - 74	160	0.9
75 - 84	360	38.1
85 - 94	337	35.7
95 or older	45	4.8
Total	945	100.0
40. What is the marital status of the person receiving care?	Frequency	Valid Percent
Now married	447	47.3
Partnered	9	1.0
Widowed	385	40.7
Divorced or separated	76	8.0
Never married	26	2.7
Don’t know	3	.3
Total	946	100.0
41. What is the race of the person receiving care?	Frequency	Valid Percent
Other (please specify)	55	5.9
White or Caucasian	810	86.7
Black or African American	61	6.5
American Indian or Alaska Native	2	.2
Asian	4	.4
Don't know	2	.2
Total	934	100.0
42. Is the person receiving your care of Hispanic, Latino, or Spanish origin?	Frequency	Valid Percent
Yes	109	11.7
No	824	88.1
Don't know	2	.2
Total	935	100.0

DEMOGRAPHICS OF CAREGIVER RESPONDENTS

43. What is your gender?	Frequency	Valid Percent
Female	726	78.1
Male	204	21.9
Total	930	100.0
44. What is your age?	Frequency	Valid Percent
34 or younger	6	.6
35 - 44	32	3.4
45 - 54	141	15.0
55 - 64	283	30.2
65 - 74	257	27.4
75 - 84	184	0.2
85 - 94	35	3.7
Total	938	100.0
45. What is your marital status?	Frequency	Valid Percent
Now married	685	73.1
Partnered	23	2.5
Widowed	50	5.3
Divorced or separated	121	12.9
Never married	58	6.2
Total	937	100.0
46. What is your race?	Frequency	Valid Percent
Other (please specify)*	44	4.8
White or Caucasian	813	88.0
Black or African American	60	6.5
American Indian or Alaska Native	2	.2
Asian	4	.4
Native Hawaiian or Other Pacific Islander	1	.1
Total	924	100.0
47. Are you of Hispanic, Latino, or Spanish origin?	Frequency	Valid Percent
No	806	87.2
Yes	118	12.8
Total	924	100.0
48. Do you speak a language other than English at work or home? (Check all that apply)	Frequency	Valid Percent
Yes, I speak Spanish	103	10.9
Yes, I speak Creole	2	0.2
Yes, I speak Russian	3	0.3
Other (Please Specify)*	35	3.7
No	798	84.8
Total	941	100.0
49. Education Level	Frequency	Valid Percent
Less than HS (<12 yr)	42	4.7
High School Grad (12 yr)	204	23.1
Some College (13-15 yr)	233	26.3
College Grad (16 yr)	202	22.8
Post Grad (>16 yr)	204	23.1
Total	885	100.0

**Comments and elaborations not included.*

DOEA, 2014 ADRD Caregivers Survey

50. Please estimate your own household income.	Frequency	Valid Percent
Under $25,000	168	23.5
$25,000 - $35,999	123	17.2
$36,000 - $45,999	93	13.0
$46,000 - $55,999	80	11.2
$56,000 - $65,999	44	6.2
$66,000 - $75,999	57	8.0
$76,000 - $85,999	43	6.0
$86,000 and over	106	14.8
Total	714	100.0

Multivariate Analyses

Constraining Intent to Place by Living Situation of Individual with ADRD

Within the analysis, caregivers of individuals with ADRD who live in an assisted living facility were considered when observing the rates of caregiver with an intention of placing the recipient of care into a nursing home, ALF, or special care facility within the upcoming year. The following exhibit constrains the reporting rate of caregiver's intention to place to not include caregivers who are providing care to individuals residing in an assisted living facility. Exhibit 2 results indicate that only 98 (12.5%) of care recipients lived in private residences with caregivers who reported an intent to place the recipient of care with ADRD into a nursing home, ALF, or special care facility within the upcoming year. This low frequency did not provide sufficient statistical power to afford further comparisons by demographic group.

Exhibit 2. Intent to Place by Caregivers of Individuals Living in Private Residences

Intent to Place	Count	Percent
Yes	98	12.5%
No	349	44.5%
Not sure	306	39.0%
It is not my decision.	31	4.0%

DOEA, 2014 ADRD Caregivers Survey, n=784

Intention to Place by Caregivers Considering Assistance

Having assistance with providing care, either paid or unpaid, only slightly affects whether the caregiver has a higher intention of placing the recipient of care with ADRD into a nursing home or special needs facility within the upcoming year. Exhibit 3 to the right details that 18% of caregiver with paid or unpaid assistance have the intent to place compared to 17% of caregivers who do not have additional assistance with providing care.

Exhibit 3. Intent to Place by Caregivers with Paid or Unpaid Assistance with Caregiving

	Paid or Unpaid Assistance		No Assistance	
Intent to Place	Count	Percent	Count	Percent
Yes, Intent	77	17.7%	187	16.7%
No, Intent	180	41.4%	473	42.2%
Not sure	160	36.8%	411	36.7%
It's not my decision	18	4.1%	50	4.5%
Total	435		1121	

DOEA, 2014 ADRD Caregivers Survey, n=1,556

*Note that caregivers can report receiving or not receiving both paid or unpaid assistance with care inflating the total respondent of the question.

Binary Logistic Regression Model: Further Details

Caregiver characteristics were placed into a binary logistic regression model to test their significance[16] as predictors, and to observe any variance by status in the odds of the caregiver having the intention to place a loved one into a nursing home, ALF, or special care facility within the upcoming year. Several factors were tested as predictors for the caregiver's intent to place that are not presented in the final models due to collinearity and failure to achieve significance threshold. These factors include: caregiver working status, hours of care provided in an average week, income, living situation, physical health condition, disability, years of care provision, and burden level.

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[16] The significance of the caregiver characteristics in the models are determined by observing their p-value with a threshold of 0.1.

Despite their initial relationship with intent to place, and their presence in previous research literature conducted by others, in these analyses these factors were highly correlated with each other or had high standard error, and as such were rendered non-significant when included in the model with demographic controls. In future research, a larger sample would allow for interaction terms to distinguish these groups, to correct for the co-linearity between them, and make their retention in the final model useful.

The binary logistic regression models are described in Exhibit 4 on the following page, and are interpreted in terms of odds ratios. The stepwise method of introduction of each factor against the odds of intent to place allow for the observation of the independent weight of each factor. In each of the models, the caregiver's sex remains a significant predictor in their intent to place and is most notable when the caregiver's relationship to the recipient of care is included in Model 5.

The significance of caregiver characteristics in the model are determined by observing the p-value in the "Sig." column, with a threshold of 0.1, where greater than or equal to 0.01 is considered a strong significance, less than 0.05 is considered significant, and less than 0.1 is showing weak significance. If any of the independent variables (caregiver characteristics) have a p-value that is less than 0.1, they are considered a significant predictor of a caregiver's intention to place. The coefficients of the in the "B" column determine if there is a negative or positive slope to the odds ratio.

Model 1 was positive and significant for the sex of the caregiver, suggesting that male caregivers have 1.8 times higher odds than female caregivers of intending to place their loved one into a nursing home. Ethnicity is introduced in a step-wise fashion in Model 2 and suggests that caregivers who are not of Hispanic, Latino, or Spanish origins have two times higher odds of intending to place their loved one into a nursing home compared to caregivers who are of Hispanic, Latino, or Spanish origin. When the caregiver's race is introduced in Model 3, the coefficients suggest that caregivers who are non-Hispanic white have a 2.1 higher odds of stating the need to place their loved one into a nursing home compared to any other race/ethnicity. With all other factors held constant in Model 3, males and non-Hispanic white caregivers have higher odds of stating that they will place their loved one into a nursing home within the upcoming year.

In Model 4, the caregiver's relationship to the recipient of care is introduced in a step-wise fashion. Results show that caregivers of parents have higher odds of having an intent to place compared to caregivers of spouses or partners. In the final model, the level of caregiver burden is introduced. The scale of caregiver burden shows a strong significant correlation to the caregiver's decision on whether to place their loved one into a nursing home in the upcoming year. With each unit reduction in level of experienced caregiver burden, the odds of placing a loved one into a nursing home in the upcoming year increase by a factor of 1.12. As seen in the previous section, when observing the level of caregiver burden by intention to place, caregivers who experience high burden have a lower rate of intention to place compared to caregivers who experience low burden.

This correlation is now confirmed against demographic controls in Model 5. Furthermore, when considering caregiver burden in Model 5, all other factors remain significant except the caregiver's race, which changes and is no longer a significant predictor of having an intent to place. Including caregiver burden in the model also increases the odds of the caregiver reporting the need to place their loved one into a nursing home, ALF, or special care facility in the upcoming year when considering if the caregiver is a non-Hispanic white male, who is providing care to their parent or in-law.

Exhibit 4. Stepwise Binary Logistic Regression Models on Caregiver Characteristics Impact on Intent to Place an ADRD Loved one in a Nursing Facility, presented as Odds Ratios

	Model 1	Model 2	Model 3	Model 4	Model 5
Male *(Female referent)*	1.788 **	1.900**	1.952**	2.393**	2.774**
Non- Hispanic *(Hispanic referent)*		1.929*	2.702*	2.765*	3.465*
White *(non-white referent)*			2.118†	2.415†	2.668
Parent/Child *(Spouse/Partner referent)*				2.336**	3.119**
Caregiver Burden *(high burden referent)*					0.896**

*† significant at <.1, * significant at <.05, ** significant at <.01*

The following exhibit describes all information provided by the binary logistic regression model used in the analysis including the odds ratio seen in the column labeled “Exp(B)”.

Exhibit 5. Multivariate Logistic Regression Output: Caregiver Characteristics by Intent to Place

		B	S.E.	Wald	df	Sig.	Exp(B)
Model 1	SEX	.581	.236	6.052	1	.014	1.788
	Constant	-1.077	.121	79.539	1	.000	.341
Model 2	SEX	.642	.240	7.172	1	.007	1.900
	HISPANIC	.657	.340	3.740	1	.053	1.929
	Constant	-1.679	.327	26.283	1	.000	.187
Model 3	SEX	.669	.247	7.320	1	.007	1.952
	HISPANIC	.994	.459	4.693	1	.030	2.702
	RACE	.750	.436	2.967	1	.085	2.118
	Constant	-2.689	.621	18.757	1	.000	.068
Model 4	SEX	.873	.278	9.832	1	.002	2.393
	HISPANIC	1.017	.518	3.850	1	.050	2.765
	RACE	.882	.478	3.407	1	.065	2.415
	RELATIONSHIP	.848	.252	11.351	1	.001	2.336
	Constant	-3.299	.735	20.124	1	.000	.037
Model 5	SEX	1.020	.361	7.989	1	.005	2.774
	HISPANIC	1.243	.603	4.251	1	.039	3.465
	RACE	.981	.623	2.483	1	.115	2.668
	RELATIONSHIP	-1.138	.322	12.460	1	.000	.321
	BURDEN	-.110	.022	25.831	1	.000	.896
	Constant	-1.031	.840	1.506	1	.220	.357

DOEA, 2014 ADRD Caregivers Survey, n=1,063

Exhibit 6 below provides the details for other variables that were considered for the binary logistic regression but were excluded due to lack of significance, correlation, and direction of slope. The variables were not included in the model for the purpose of showing only distinct correlations between the independent and dependent variables.

Exhibit 6. Binary Logistic Regression Output with other Variables in the Model

	B	S.E.	Wald	df	Sig.	Exp(B)
Gender *(female referent)*	-.295	.717	.170	1	.681	.744
Non-Hispanic *(Hispanic referent)*	2.173	1.380	2.479	1	.115	8.788
White *(non-white referent)*	1.637	1.141	2.059	1	.151	5.139
Parent/Child *(Spouse/Partner referent)*	.985	.735	1.797	1	.180	2.679
Caregiver Burden	-.110	.047	5.451	1	.020	.896
Number of hours providing care	-.001	.004	.070	1	.792	.999
Age *(under 65 referent)*	.663	.720	.847	1	.357	1.940
Income *(above $25k referent)*	.450	.689	.428	1	.513	1.569
Caregiving on Employment *(yes affect referent)*	.224	.710	.100	1	.752	1.252
Health *(health has not worsened as a result of providing care referent)*	.077	.695	.012	1	.912	1.080
Providing care for individual with ADRD *(no ADRD referent)*	.268	1.331	.040	1	.841	1.307
Caregiving social services *(yes, receiving help from social services referent)*	.139	.579	.058	1	.810	1.149
Proving care to others *(not providing care to others referent)*	.055	.674	.007	1	.935	1.057
Constant	-4.404	2.084	4.468	1	.035	.012

DOEA, 2014 ADRD Caregivers Survey, n=1,063

Appendix B

2014 ADRD Caregiver Survey

The Florida Department of Elder Affairs (DOEA) is conducting a statewide survey of caregivers of persons with Alzheimer's disease and related disorders (ADRD), including Mild Cognitive Impairment.
As a caregiver of someone with ADRD, your answers will help DOEA better plan for the growing needs of Florida families like yours that are dealing with the challenges of caring for a loved one with a memory disorder.

THE SURVEY IS ANONYMOUS. Please be assured that your responses will be kept strictly confidential. The survey may be completed online or in print.

ONLINE VERSION OF THIS SURVEY
This survey may be completed online at:
https://www.surveymonkey.com/s/2014_ADRD_Caregiver_Survey

INSTRUCTIONS FOR COMPLETING THE PRINT VERSION OF THIS SURVEY

1. Please answer each question as best you can.
2. There are 3 ways to answer questions.
    a. Circle your answer.
    b. Check one box in each row of questions in a table.
    c. Write your answer to questions where there is a line or an empty box.
    d. Write your answer to questions that ask you to "please specify."
3. You can continue longer answers to questions on another page.

RETURNING THE PRINT VERSION OF THE SURVEY
Please return this survey to the survey partner who gave it to you, or mail it to:
Florida Department of Elder Affairs, Planning and Evaluation Unit, 4040 Esplanade Way, Tallahassee, FL

Thank you for taking the time to fill out this survey. Your responses will help efforts to address the impact of Alzheimer's disease and related disorders on Florida's citizens. **(This survey is *anonymous.)***

1. Where do YOU live?
    a. City: ____
    b. County: ____
    c. State :____
    d. Zip code: ____
2. Where does the PERSON receiving your care live?
    a. City: ____
    b. County: ____
    c. State: ____
    d. Zip code: ____
3. How did you learn about this survey?_______________________

I. Your caregiving situation

If you care for more than one person with ADRD, please focus your answers on the person for whom you provided care the longest time.

1. Is the person you are caring for your…
   a. Spouse
   b. Partner
   c. Adult child
   d. Parent
   e. Grandparent
   f. Friend
   g. Other relative (please specify) ____________________________

2. Are you the primary caregiver for this person? (A primary caregiver is the person who consistently takes primary responsibility for someone who needs help taking care of themselves.)
   a. Yes
   b. No

3. How long have you been caring for this person?
   a. Less than one year
   b. 1 - 3 years
   c. 4 - 8 years
   d. 9 - 12 years
   e. More than 12 years

4. Do you also care for younger loved ones, such as children or grandchildren?
   a. Yes
   b. No

5. Do you live more than an hour away from the person receiving your care?
   a. Yes
   b. No
   c. It depends on traffic/transportation
   d. Don't know

6. Where does the person receiving your care currently live?
   a. Alone, in his/her own home
   b. In his/her own home with others
   c. In your home
   d. In the home of a family member
   e. In a retirement community
   f. In an assisted living facility
   g. In a nursing home
   h. In a specialized care facility for persons with dementia
   i. Other (please specify)_______________________________________

7. Do you also care for younger loved ones, such as children or grandchildren?
   c. Yes
   d. No

8. Do you live more than an hour away from the person receiving your care?
    e. Yes
    f. No
    g. It depends on traffic/transportation
    h. Don't know

9. Where does the person receiving your care currently live?
    j. Alone, in his/her own home
    k. In his/her own home with others
    l. In your home
    m. In the home of a family member
    n. In a retirement community
    o. In an assisted living facility
    p. In a nursing home
    q. In a specialized care facility for persons with dementia
    r. Other (please specify)______________________________________

II. Amount of care provided

10. In an average week, how many hours do you provide care for this person?____

11. Are you currently being paid for your caregiving assistance?
    a. No
    b. Yes

12. Do you currently receive unpaid caregiving help from family or friends?
    a. No
    b. Yes. Enter number of hours per week below. _____________

13. Do you currently pay for additional help to assist with your caregiving?
    a. No
    b. Yes. Enter number of hours per week below. _____________

14. Do you currently receive caregiving help from social services (for example, a Medicaid program or other government or state-funded program)?
    a. No
    b. Yes. Enter number of hours per week below. ________________

15. Are you on a wait list to receive help?
    a. No
    b. Yes. Please tell us about how long you have been waiting. ___________

III. Condition of the person receiving your care

16. Which of the following best describes the condition of the person receiving your care? The person has …
    a. Ongoing memory problems but no other problems with thinking.
    b. Problems with memory, trouble finding words when speaking, changes in mood or personality, misplacing items, getting lost.
    c. More problems with memory, language, short attention span, trouble with the daily routine of fixing meals, dressing, bathing, etc., needs help to complete tasks.
    d. Complete loss of memory and language, sleep problems (too little or too much), is clumsy using hands or walking, needs constant help to do personal care.
    e. Other (please describe) ____

17. How long has the person receiving your care shown signs of a memory or thinking disorder, such as forgetting things, losing items, or being unable to speak well?
    a. Less than 1 year
    b. 1 - 2 years
    c. 3 - 4 years
    d. 5 - 10 years
    e. More than 10 years

18. Has the person receiving your care had a medical diagnosis of Alzheimer's disease or a related disorder?
    a. Yes
    b. No
    c. Don't know

19. What is that diagnosis? (Check all that apply)
    a. (No diagnosis)
    b. Mild cognitive impairment
    c. Alzheimer's disease
    d. Vascular dementia
    e. Lewy body disease/dementia
    f. Frontal dementia
    g. Frontotemporal dementia
    h. Parkinson's disease
    i. Parkinson's disease with dementia
    j. Parkinsonism (Progressive Supranuclear Palsy or Cortical Basal Dementia)
    k. Stroke
    l. Mixed dementia
    m. Don't know
    n. Other (please specify) _________________________________

20. Was the diagnosis provided by a . . .
    a. (No diagnosis)
    b. Family doctor/primary care physician/general practitioner/ARNP (nurse)
    c. Neurologist (a medical doctor who specializes in treatment of nervous system diseases)
    d. Psychiatrist (a medical doctor who specializes in treatment of behavior diseases of the brain)
    e. Geriatrician (a medical doctor who specializes in caring for older persons)
    f. Memory Disorder Clinic/Center doctor
    g. Don’t know
    h. Other (please specify)____________________________

21. How long did the person who receives your care show signs of a memory or thinking disorder (e.g., forgetfulness, disorientation) before a diagnosis by a doctor or other medical professional was made?
    a. (No diagnosis)
    b. Less than 1 year
    c. 1 - 2 years
    d. 3 - 4 years
    e. 5 - 10 years
    f. More than 10 years

22. Which of the following may have delayed the diagnosis? (Check all that apply.)
    a. I thought the symptoms were a part of normal aging
    b. I didn’t want to know
    c. I didn’t think anything could be done
    d. I didn’t know where to find help
    e. Cost of health care
    f. Insurance would not cover the medical test(s)
    g. Other (please specify)_____________

Special situations related to ADRD

23. Please check the frequency of the behaviors below that apply to the person receiving your care.	Never	Seldom	Sometimes	Usually	Always	Don't Know/ Does not apply
a. Difficulty speaking to others						
b. Difficulty understanding language						
c. Sundowning – issues in late afternoon or evening						
d. Not getting along with others, being disagreeable						
e. Acts distrustful, suspicious						
f. Verbal aggression, such as shouting or name calling						
g. Sleep problems						
h. Anxious, irritable						
i. Depression						
j. Restless, wanders						
k. No boundaries, talks to/touches strangers						
l. Gets lost outside, missing						
m. Physically aggressive/violent toward self, injures self						
n. Physically aggressive/violent toward others, such as hitting, pushing others						

V. Services and resources needed for THE PERSON receiving care

24. What ADDITIONAL SERVICES AND SUPPORT are needed in order for the PERSON RECEIVING CARE to continue to live at home?	Yes	No	Don't know/ Does not Apply
a. Personal care (including bathing, dressing, eating, drinking, using the bathroom, moving around or walking)			
b. Household chores			
c. Using the phone			
d. Managing money, bills			
e. Legal advice			
f. Preparing meals/Meals on Wheels			
g. Shopping			
h. Using transportation			
i. Home health/medical care for the person with ADRD, including injections, skin and wound care			
j. Managing medicines			
k. Companion – Someone different to spend time with the person			
l. Adult day care services			
m. Individual or family counseling			
n. Support group			
o. Case management			
p. Telephone reassurance			
q. Home safety (managing fall risk, storing unsafe items)			
r. Plan and alert system for wandering off and getting lost			
s. Personal emergency response system			
t. Emergency placement for unsafe behaviors (e.g., violence, aggression), caregiver illness, or weather emergencies			
u. Other (Please specify)			

VI. Services and resources needed for the CAREGIVER

25. What ADDITIONAL SERVICES AND SUPPORT are needed by you, the CAREGIVER, in order to continue providing care?	**Yes**	**No**	**Don't Know/ Does not apply**
a. Educational information about disease changes, coping strategies, and resources			
b. Respite – Allows you a brief break while temporary care is provided			
c. Caregiver support group			
d. A key contact person for questions and help			
e. Training information on dealing with behaviors related to ADRD such as repeated questions, irritability, restlessness, sexually inappropriate behavior, vulgarity; refusal to bathe, eat, drink, or accept care; wandering off and getting lost			
f. Training to provide medical care such as injections, wound and skin care			
g. Medical care for yourself			
h. More support/flexibility from employer			
i. Other (please specify)			

VII. Getting Help

26. What (if anything) prevents you from receiving the services or resources you need but don't have? (Check all that apply.)
    a. Nothing.
    b. I don't know what is available.
    c. I don't know where to find them.
    d. I can't afford them.
    e. I don't have transportation to use the service.
    f. I don't have time.
    g. The service is not available.
    h. Family dynamics.
    i. I'm a long distance caregiver, live too far away.
    j. Other (please specify)______________________________

27. Have you received information or services from any of the following to help with your caregiving?	Yes	No
a. Florida Department of Elder Affairs		
b. Alzheimer's Association		
c. Area Agency on Aging/Aging and Disability Resource Center		
d. Other social service agency, such as the departments of Children and Families, Veterans' Affairs, Health, or the Agency for Health Care Administration		
e. Medical professional, such as a family doctor, nurse, social worker		
f. Memory Disorder Clinic		
g. Hospital		
h. Faith community, such as church, synagogue, etc.		
i. Public library		
j. Family members or friends		
k. Neighbors		
l. Home care service provider, home health agency		
m. Adult day care center		
n. Assisted living facility (ALF)		
o. A group/family style home (adult family care home)		
p. Nursing home		
q. Support group		
r. Veterans Administration Medical Center (VAMC)		
s. Other veterans services and support groups		
t. Internet		
u. Other (please specify)________________		

VIII. In case of an emergency

28. Have you made a plan or other preparations for what to do in case there is a disaster, such as a hurricane? (Check all that apply.)
    a. No, I do not have a plan or other preparations.
    a. Yes, I have a written plan.
    b. Yes, I have a survival kit.
    c. Yes, I have registered with my county for a Special Needs Shelter.
    d. Other (please specify)____________________________________

IX. Impact on your health

29. Do you have a health problem, physical condition, or disability that affects the kind or amount of care that you can provide?
    a. Yes
    b. No
    c. Don't know

30. What health problem, condition, or disability affects the care you can provide? (Check all that apply.)
    a. No problems right now
    b. Back problems and other joint problems, such as arthritis
    c. Heart problem(s)
    d. High blood pressure/Hypertension/Stroke
    e. Diabetes
    f. Allergies/Asthma/Other breathing or lung problems
    g. Stress
    h. Mental health (anxiety, fear, depression, emotional problems)
    i. Vision problems
    j. Other (please specify)____________________

31. Have your caregiving responsibilities created or worsened any of these conditions, problems, or disabilities?
    a. Yes
    b. No
    c. Don't know/Does not apply

X. Impact on your employment

32. Are you currently employed?
    a. Yes, full-time
    b. Yes, part-time
    c. Retired
    d. No
    e. Other (please specify)

33. Have your caregiving responsibilities affected your employment?
    a. Yes
    b. No
    c. Don't know

34. If you checked above that your caregiving responsibilities affected your employment, did you have to do any of the following? (Check all that apply.)
    a. Cut back on your hours of work
    b. Occasionally miss work
    c. Go to work late, leave work early
    d. Take a leave of absence
    e. Lose any of your job benefits
    f. Turn down a job promotion
    g. Quit work or retire early
    h. Other (please specify)___________________________

XIII. Challenges and rewards of being a caregiver

35. As a caregiver, how often do you feel that caregiving…?	Always	Usually	Sometimes	Rarely	Never	Don't Know/ Does not apply
a. Creates a financial burden for you						
b. Does not leave you enough time for yourself						
c. Does not leave enough time for your family						
d. Interferes with other duties/work						
e. Negatively affects your family relationships						
f. Interferes with friendships/social life						
g. Interferes with other interests and leisure activities						
h. Leaves you feeling resentful						
i. Has brought you closer to the person receiving care						
j. Makes you feel capable of handling challenges						
k. Fulfills your responsibility to provide care to someone who cared for you						
l. Is a rewarding, positive experience for you, overall						

XIV. Thinking Ahead

36. Will you be able to continue to care for this person for the near future?
    a. Yes
    b. No
    c. Don’t know

37. Do you think you will need to place the person receiving care in an assisted living facility, nursing home, or special care facility within the coming year?
    a. Yes
    b. No
    c. Not sure
    d. It is not my decision.

XV. Background Information about the PERSON receiving your care

38. What is the gender of **the person** receiving care?
    a. Female
    b. Male

39. What is the age of **the person** receiving care? ___
    a. Don’t know

40. What is the marital status of **the person** receiving care?
    a. Now married
    b. Partnered
    c. Widowed
    d. Divorced or separated
    e. Never married
    f. Don’t know

41. What is the race of **the person** receiving care?
    a. White or Caucasian
    b. Black or African American
    c. American Indian or Alaska Native
    d. Asian
    e. Native Hawaiian or Other Pacific Islander
    f. Don’t know
    g. Other (please specify)___________________

42. Is **the person** receiving your care of Hispanic, Latino, or of Spanish origin?
    a. No
    b. Yes
    c. Don’t know

XVI. Background Information about YOU, the caregiver

43. What is **your** gender?
    a. Female
    b. Male

44. What is **your** age? ___

45. What is **your** marital status?
    a. Now married
    b. Partnered
    c. Widowed
    d. Divorced or separated
    e. Never married

46. What is **your** race?
    a. White/Caucasian
    b. Black or African American
    c. American Indian or Alaska Native
    d. Asian
    e. Native Hawaiian or Other Pacific Islander
    f. Other (please specify)___________________

47. Are **you** of Hispanic, Latino, or Spanish origin?
    a. No
    b. Yes

48. Do **you** speak a language other than English at work or home? (Check all that apply.)
    a. No
    b. Yes, I speak Spanish
    c. Yes, I speak Russian
    d. Yes, I speak Creole
    e. Other (please specify)___________________

49. How many years of school have **you** completed?

    ____

50. Please estimate **your** own household income.
    a. Under $25,000
    b. $25,000 - $35,999
    c. $36,000 - $45,999
    d. $46,000 - $55,999
    e. $56,000 - $65,999
    f. $66,000 - $75,999
    g. $76,000 - $85,999
    h. $86,000 and over
    i. Prefer not to answer

XVII. Your thoughts and comments

This completes the questions in our survey. Is there anything else you would like us to know?