

# 2024 Texas Alzheimer's Disease and Related Dementias Caregiver Survey Report



**TEXAS**  
Health and Human  
Services

Texas Department of State  
Health Services

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# Executive Summary

The Texas Department of State Health Services (DSHS) Alzheimer's Disease Program (ADP) and Chronic Disease Epidemiology Branch (CDE) distributed the 2024 Alzheimer's Disease and Related Dementias (ADRD) Caregiver Survey in collaboration with the Texas Alzheimer's Disease Partnership (Partnership). This survey informs program activities after the ADP received the Centers for Disease Control Building Our Largest Dementia (CDC BOLD) funding in September 2023.

Caregivers submitted their responses through an online Qualtrics survey disseminated via emails and on the ADP website. CDE analyzed the submissions, with 393 responses included in the analysis.

Most respondents to the survey identified as non-Hispanic, White females aged 55 years or older. Care recipients were predominantly non-Hispanic White females and were most often the caregiver's spouse or parent. Over 90% of caregivers reported significant financial stress, and almost three-quarters described caregiving responsibilities as a contributing factor to employment disruptions, including early retirement or leaving the workforce. Responses also demonstrated the extensive time commitment associated with caregiving, with many caregivers providing care independently and often on a 24/7 basis.

While most caregivers rated their current health as good, nearly two-thirds reported a decline in their physical health due to caregiving responsibilities. Over two-thirds of caregivers indicated high levels of emotional stress.

Most caregivers reported receiving information on key topics such as diagnosis, stages of the disease, and treatment, but fewer had accessed resources on respite care, financial planning, or long-term care options. Caregivers noted faith-based groups and caregiver support groups as useful programs providing helpful information. On the other hand, caregivers expressed higher levels of dissatisfaction with hospitals and healthcare providers, as well frustration with understanding insurance and the healthcare system. Many caregivers requested clearer guidance on navigating available resources and specialized training tailored to their unique needs.

# Introduction

In 2021, the Alzheimer’s Disease Program (ADP) at the Texas Department of State Health Services (DSHS), in collaboration with the Chronic Disease Epidemiology Branch (CDE) and the Texas Alzheimer’s Disease Partnership (Partnership), conducted a state-wide survey of unpaid caregivers of individuals with Alzheimer’s or other related dementias to better understand the unique challenges faced by and needs of these caregivers. The survey was disseminated again in 2024 by DSHS, after receiving [CDC BOLD funding](#), to track any potential changes between the two surveys and to inform program activities for the new cooperative agreement (CA).

This survey represents efforts to utilize strategies established in the [Texas State Plan for Alzheimer’s Disease 2024-2028](#), including the strategy of collaborating and sharing information on the impact of ADRD on family caregivers, and advancing research focused on family caregivers.

The results from this survey and subsequent analysis will be used to inform and guide future programmatic activities, develop resources for various populations of interest, and contribute to the growing evidence base on the challenges and realities of unpaid caregiving in Texas.

# Methods

## Survey Development

The development of the initial survey began in November 2019 when initial questions and data points of interest were collected from Partnership members. CDE then had informational calls in February 2020 with eight Partnership member organizations (n=10 people) who work with unpaid caregivers to further develop survey questions and the survey dissemination plan. The survey was pilot tested by 28 Partnership members in June 2020. Following the pilot test, the survey was revised with suggested language, response options, and additional questions.

Based on stakeholder feedback, four new questions were developed for 2024 to gather more information on the need for Spanish-language resources for caregivers in Texas. The survey consisted of 32 multiple choice questions and an open-ended question that gathered data on unpaid caregivers' experiences on providing care or assistance to persons with Alzheimer's disease or other dementias. The survey was also translated into Spanish and then disseminated, via Qualtrics, across multiple communication channels, including the ADP website, emails to Partnership members, and through relevant state agency networks. The complete survey tool can be found in [Appendix A](#).

## Sampling Method

Snowball sampling was used to recruit respondents. Partnership members and key stakeholders forwarded the email with the survey link to unpaid caregivers or to people who might know unpaid caregivers. Once an unpaid caregiver completed the survey, they were encouraged to forward the survey link to other unpaid caregivers.

## Responses and Analysis

The survey was open from July 3 through September 30, 2024. During the survey collection period, 633 individuals opened the survey link, with 434 of those individuals completing the survey. Of these, 41 respondents did not currently or in the previous 12 months provide unpaid care or assistance to a relative or friend with Alzheimer's disease or other dementia or had not lived in Texas in the past 12 months and were excluded. A total of 393 respondents were included in the final analysis.

Results from the survey were analyzed by the CDE branch. A CDE epidemiologist analyzed quantitative data using SAS v9.4. The analysis methods include frequency distribution calculations to summarize responses to survey questions, such as demographic information, caregiving status, living arrangements, and geographic distribution. Specific questions address the duration and nature of caregiving activities, whether care was currently being provided or had been provided in the past 12 months, and whether caregivers or recipients resided in Texas during this time. Age categories for caregivers and care recipients were recoded to allow comparisons across age groups, including deceased care recipients.

Advanced coding techniques were used to prepare the data for subsequent analysis. For instance, survey responses about education levels and geographic location were standardized into numeric variables, enabling comparisons, and facilitating the integration of multiple datasets.

Qualitative data were exported from Excel and cleaned in Microsoft Word, then uploaded to ATLAS.ti for further analysis. Two CDE program evaluators used a combination of deductive and inductive coding to organize caregiver responses into different thematic areas, such as financial stress, necessary support, and emotional or mental health challenges. An initial codebook from coding activities was created then further refined via meetings between the two coders to check for coding agreement and to resolve any identified differences in the application of codes. Once coding was completed, results were grouped thematically and used to provide further context and explanation to emerging patterns and results in the quantitative data.

# Results

## Demographics

Figure 1: Sex of caregiver and care recipient (n=385)

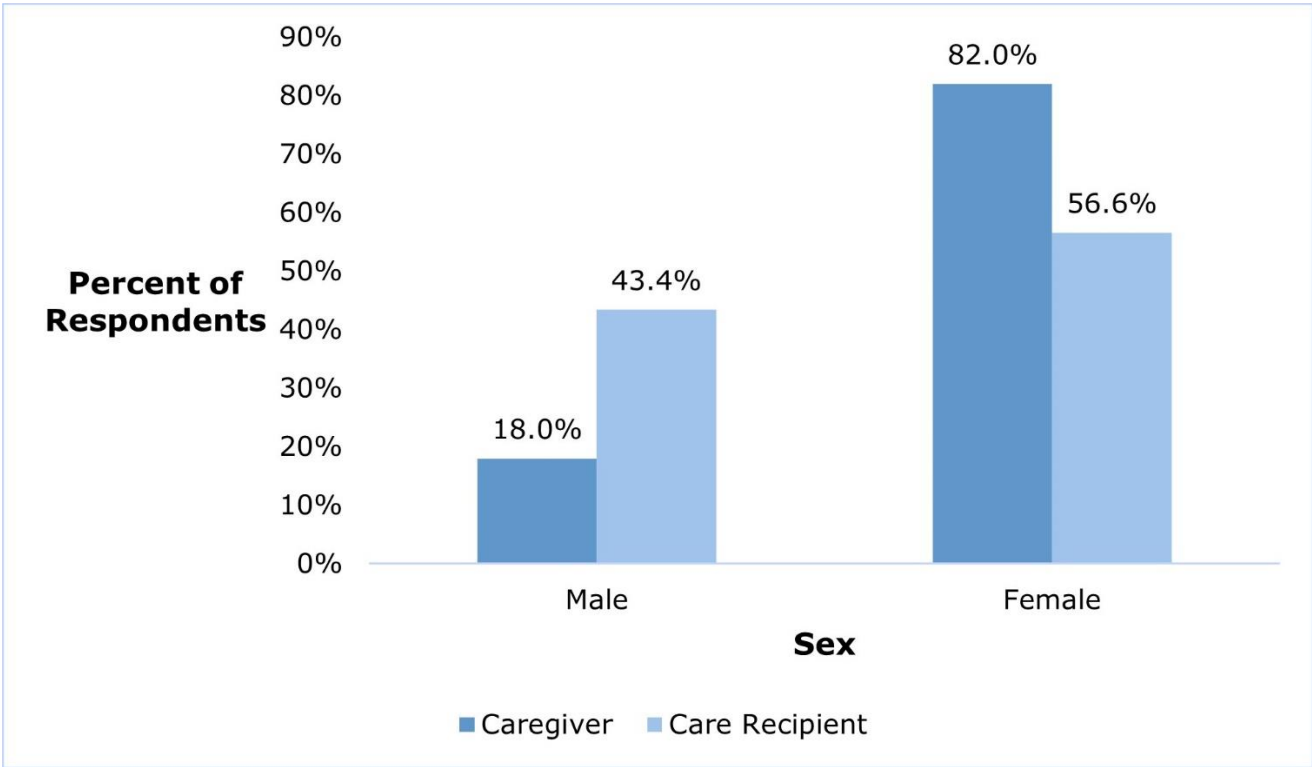


Figure 1 shows that 82% of caregivers identified as female, while only 56.6% of care recipients identified as female.

**Table 1: Frequency and percent of caregiver's and care recipient's age range**

Age	Caregiver frequency (n)	Caregiver percent (%)	Care recipient frequency (n)	Care recipient percent (%)
<b>25-34 years</b>	14	3.6	0	0
<b>35-44 years</b>	29	7.5	0	0
<b>45-54 years</b>	53	13.7	3	0.8
<b>55-64 years</b>	111	28.8	22	5.7
<b>65-74 years</b>	106	27.5	79	20.6
<b>75-84 years</b>	66	17.1	171	44.7
<b>85 years or older</b>	7	1.8	108	28.2
<b>Total<sup>a</sup></b>	386	100.0	383	100.0

Caregivers reported most frequently being between the age of 55-64 years (28.8%), 65-74 years (27.5%), or 75-84 years (17.1%). Only about 1 in 4 participants reported being younger than 55 years of age (24.8%). Care recipients were unsurprisingly older than caregivers, with most care recipients reported as being 75 years of age or older (72.9%).

**Table 2: Frequency and percent of the top five counties where caregivers and care recipients lived.**

Counties	Caregiver frequency (n)	Caregiver percent (%)	Care recipient frequency (n)	Care recipient percent (%)
<b>Tarrant</b>	53	13.7	52	13.5
<b>Harris</b>	40	10.3	42	10.9
<b>Travis</b>	34	8.8	30	7.8
<b>Bexar</b>	31	8.0	31	8.1
<b>Denton</b>	20	5.2	17	4.4
<b>Rest of counties</b>	210	54.1	212	55.2
<b>Total<sup>b</sup></b>	388	100.0	384	100.0

<sup>a</sup> Percents may not equal 100% due to rounding or missing values.

<sup>b</sup> Percent was calculated by using the total number of responses for this question (388) as the denominator for each county.



Most caregivers reported living in urban areas (74%), while the rest of the caregivers were considered rural (26%). Tarrant (13.7%), Harris (10.3%), Travis (8.8%), Bexar (8.0%), and Denton (5.2%) were the counties most frequently represented. Tarrant (13.5%), Harris (10.9%), Travis (7.8%), Bexar (8.1%), and Denton (4.4%) counties were also the most frequent counties of residence for care recipients in this survey. The remaining counties included among caregiver responses are included in [Appendix B](#).

**Table 3: Frequency and percent of the caregiver’s and care recipient’s race/ethnicity<sup>c</sup>**

<b>Race/ethnicity</b>	<b>Caregiver frequency (n)</b>	<b>Caregiver percent (%)</b>	<b>Care recipient frequency (n)</b>	<b>Care recipient percent (%)</b>
<b>Non-Hispanic, White</b>	279	73.4	279	73.8
<b>Hispanic/Latino</b>	62	16.3	60	15.9
<b>Black/African American</b>	28	7.4	28	7.4
<b>Asian/Pacific Islander</b>	10	2.4	9	2.4
<b>Other</b>	2	0.5	2	0.5
<b>Total<sup>d</sup></b>	381 <sup>e</sup>	100.0	378 <sup>f</sup>	100.0

Most caregivers were non-Hispanic, White (73.4%), with Hispanic/Latino (16.3%) and Black or African American (7.4%) being the next highest represented. Asian/Pacific Islander represented 2.4% of caregivers. Care recipients were also predominantly non-Hispanic, White (73.8%), with Hispanic/Latino (15.9%) and Black or African American (7.4%) mirroring caregivers in terms of frequency and order.

<sup>c</sup> Respondents could select as many options as applied. If respondents selected Hispanic/Latino, they were included in the Hispanic/Latino category and excluded from the others selected.

<sup>d</sup> Percents may not equal 100% due to rounding or missing values.

<sup>e</sup> Missing 12 responses.

<sup>f</sup> Missing 15 responses.

**Table 4: Frequency and percent of care recipient’s relationship to the caregiver (n=391)**

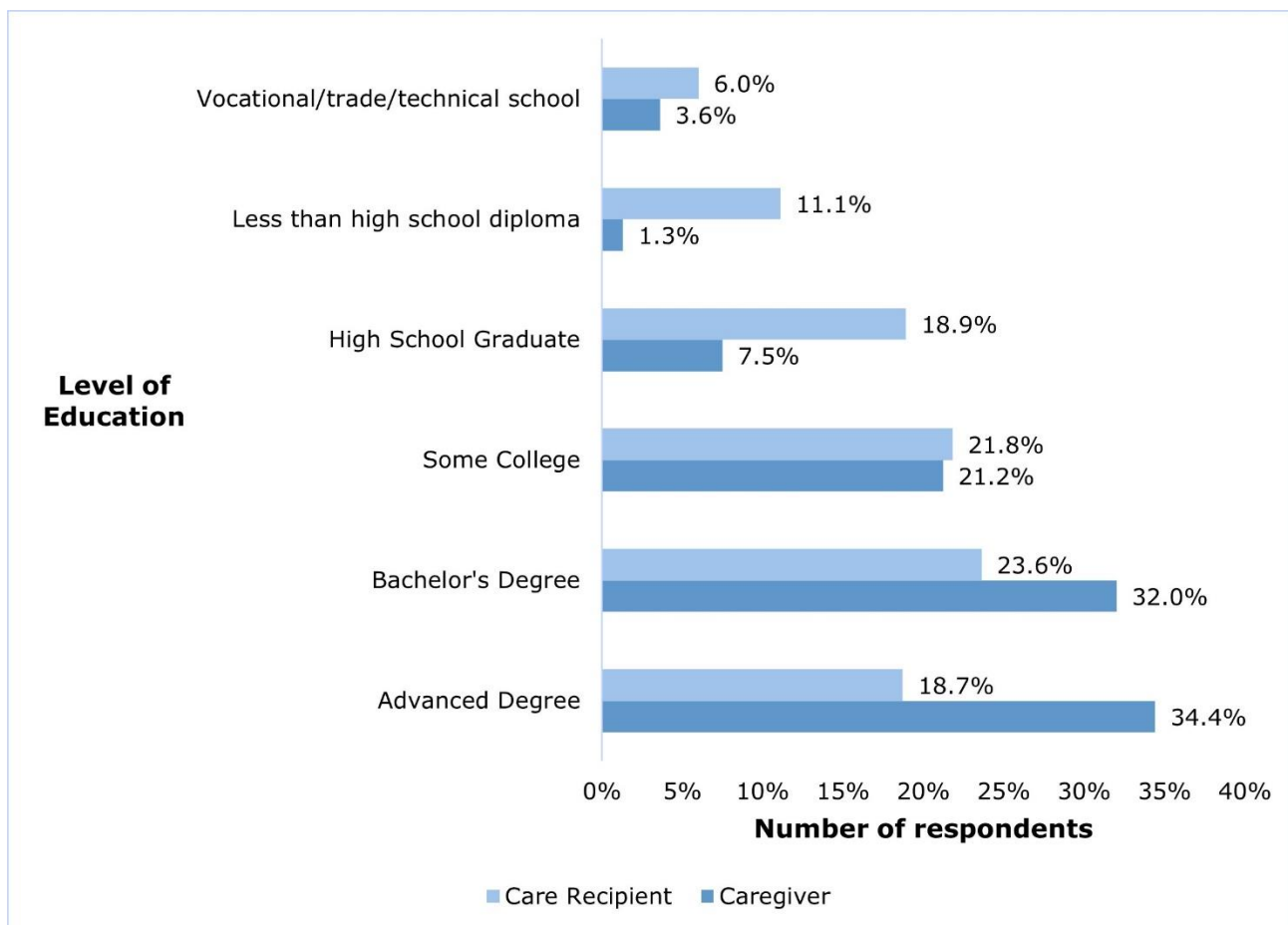
<b>Relationship</b>	<b>Frequency (n)</b>	<b>Percent (%)</b>
<b>Spouse</b>	156	39.9
<b>Mother</b>	142	36.3
<b>Father</b>	40	10.2
<b>Sibling</b>	11	2.8
<b>Mother-in-law</b>	9	2.3
<b>Grandmother</b>	9	2.3
<b>Grandfather</b>	6	1.5
<b>Father-in-law</b>	5	1.3
<b>Non-relative</b>	5	1.3
<b>Daughter</b>	1	0.3
<b>Other</b>	7	1.8
<b>Total<sup>9</sup></b>	391	100.0

Most care recipients were providing unpaid care or assistance to their spouse (39.9%). Parents (either a mother (36.3%) or father (10.2%)) represented the second most frequent relationship between care givers and care recipients. Other types of care recipients varied extensively, including siblings (2.8%), grandparents (3.8%), and in-laws (3.6%). Caregivers selecting other were prompted to specify the relationship, with all citing some type of extended family relationship (i.e., aunts, cousins, or sibling’s in-law).

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<sup>9</sup> Percents may not equal 100% due to rounding or missing values.

**Figure 2: Percent of caregiver's and care recipient's highest education level completed<sup>h</sup> (n=387)**



About two-thirds of caregivers had an advanced or a college degree (34.4% advanced degree; 32% bachelors) or had attended some college (21.2%). Care recipients were most likely to have a bachelor’s degree (23.6%), some college (21.8%), or be a high school graduate (18.9%) rather than having an advanced degree (18.7%).

**Table 5: Frequency and percentage of caregivers who are the person who provides the most care to the care recipient (n=218)**

Category	Frequency (n)	Percent (%)
<b>Yes</b>	165	75.7
<b>No</b>	53	24.3
<b>Total</b>	218	100.0

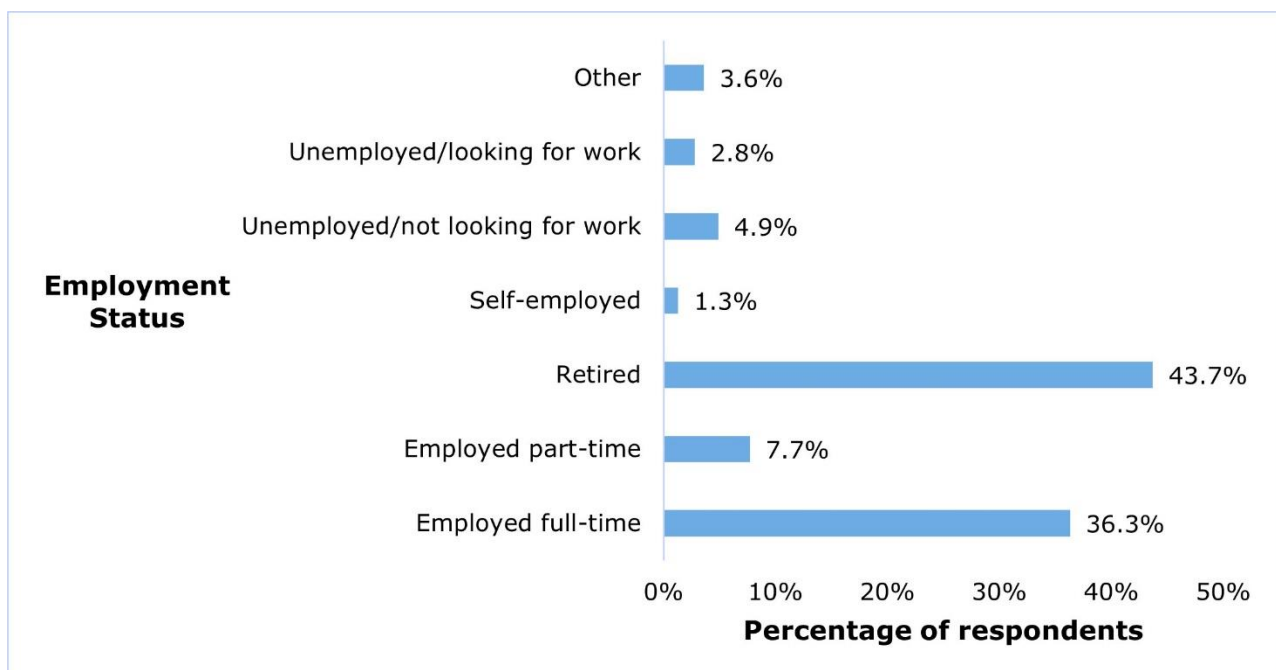
<sup>h</sup> Percents may not equal 100% due to rounding or missing values.

Caregivers were asked if they considered themselves to be the person who provided most of the unpaid care or assistance to the care recipient. More than three out of four (75.7%) of the caregivers considered themselves to be the person who provided most of the unpaid care or assistance to the care recipient.

The final question of the survey asked if caregivers had additional information or comments about being a caregiver. This open-ended question had 147 responses (37% of total survey respondents).

## Effect of Caregiving on Work

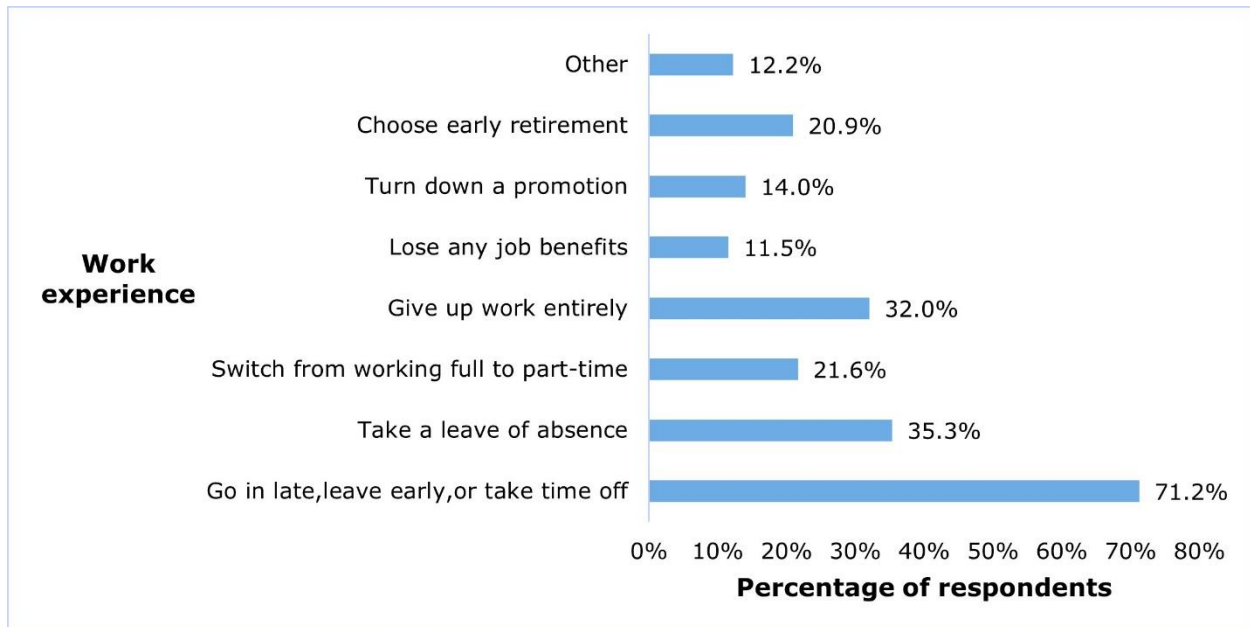
**Figure 3: Percentage of caregiver's current employment status<sup>i</sup> (n=389)**



Almost half of the caregivers (43.7%) were retired from their professional careers. More than a third (36.3%) were still employed full-time, while 7.7% of caregivers worked part-time jobs. Fewer caregivers (7.7%) were unemployed, with 2.8% looking for work and 4.9% not looking for work.

<sup>i</sup> Percents may not equal 100% due to rounding or missing values.

**Figure 4: Caregiver’s experience working and providing care or assistance to the care recipient<sup>j</sup> (n=278)**



When asked how their work had been affected by caregiving, 71.2% of caregivers have had to go in late, leave early, or take time off to fulfill their duty. Almost one-third (35.3%) had taken a leave of absence due to caregiving and 32% gave up work entirely.

The final question of the survey asked if caregivers had additional information or comments about being a caregiver. In response to this question, 18 individuals (12%) cited the impact caregiving has had on their careers. Caregivers mentioned how difficult it is to maintain a full-time job while giving care (n=9), with some mentioning having to do so to keep employment benefits. One caregiver commented that

“It is very difficult to maintain a full-time job, caring for a toddler (or any children), being a wife, and also caregiving for my mother. There is very little relief, and it is stressful all the time.” (White female caregiver to mother, aged 35 – 44).

Two caregivers discussed how caregiving has affected their retirement, causing them to retire early and take a cut in pay or has led to their retirement funds

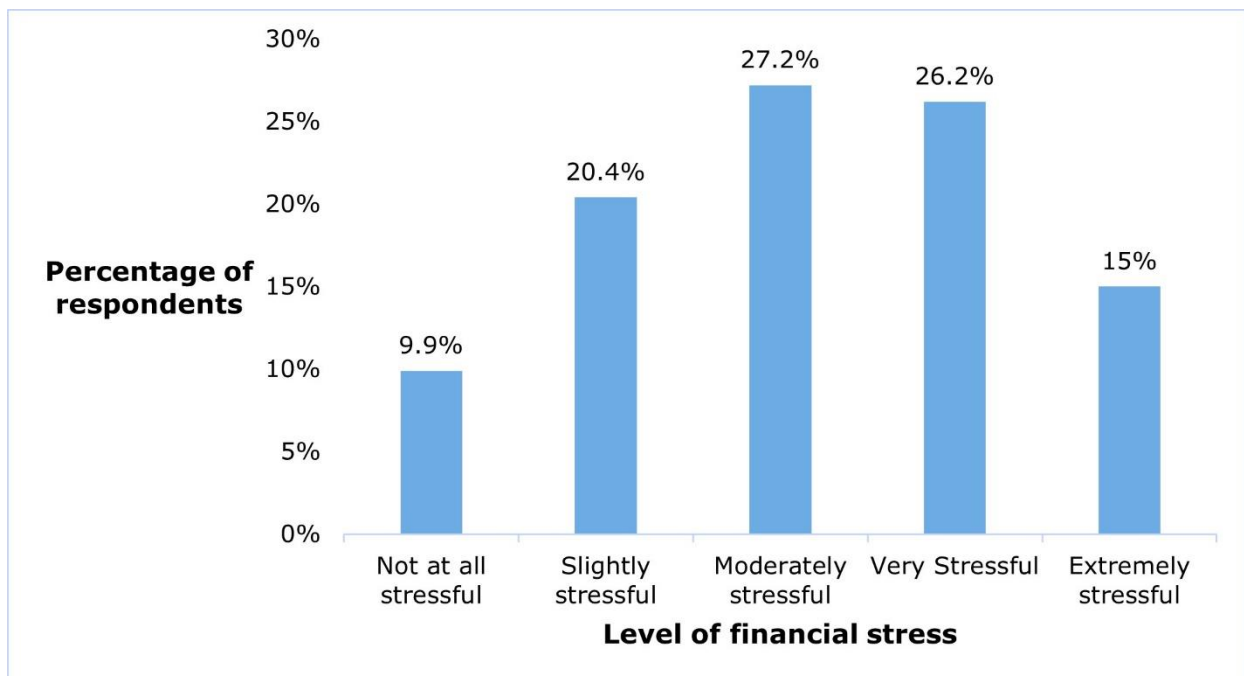
<sup>j</sup> Percent was calculated by using the total number of responses for this question (278) as the denominator for each experience. Respondents could select all experiences that apply. Therefore, the total percent will not equal to 100%.

running low. Seven caregivers commented about how caregivers should receive compensation for performing their caregiving responsibilities, especially when forced to miss work. A caregiver put the challenge this way:

“I had to retire earlier than I expected so that I could be home to take care of my husband. I lost about 13 thousand dollars a year at least, if not more.”  
(White female caregiver to spouse, aged 55 – 64)

## Financial Stress of Caregiving

**Figure 5: Distribution of caregivers' financial stress due to caregiving<sup>k</sup> (n=388)**



Caregivers were asked to indicate levels of financial stress from providing care or assistance to the care recipient. Over half (53.4%) indicated the experience was moderately or very stressful. Fifteen percent experienced extreme financial stress, while 20.4% only experienced slight stress. Less than a tenth (9.9%) of caregivers shared that they felt no financial stress from being a caregiver.

There were 36 (24%) caregivers in the open-ended question who mentioned the financial burden caregiving has placed in their lives. They commented on how expensive care was, with one caregiver sharing,

<sup>k</sup> Percents may not equal 100% due to rounding or missing values.

“I’ve sacrificed my career advancement, my savings, my retirement. Why aren’t there resources available to the average family to get in-home help with hygiene care, meals, companionship, etc. for our Alzheimer’s family member without making the average person go bankrupt in the painful process of caring for a loved one? We either have to quit work or spend our salaries on hiring paid caregivers to come in to help.” (White female caregiver to a spouse, aged 65 – 74)

Difficulties with utilizing insurance to pay for care were also cited as reason for an increased financial burden by 14 caregivers. Some caregivers (n=7) discussed how they were trapped in a financial middle ground, where their income was too high to qualify for aid but too low to afford necessary care. One caregiver explained:

“For middle income families, there is no help or support. We qualify for nothing. I had to help my father pay for my mother’s care in the memory care unit at over \$5k/month.” (White female caregiver to mother, aged 55 – 64)

Finally, other caregivers expressed concern about their ability to afford care in the future as the disease progressed and their loved one needed more extensive and specialized care.

## Tasks of Caregiving

**Table 6: Frequency and percentage of how many people provide care to the care recipient (n=385)**

Number of people	Frequency (n)	Percent (%)
<b>1 person</b>	170	44.2
<b>2 people</b>	107	27.8
<b>3 people</b>	57	14.8
<b>4 people</b>	32	8.3
<b>5 or more people</b>	19	4.9
<b>Total<sup>l</sup></b>	385	100.0

Caregivers were asked how many people provide care to the care recipient, including the respondent. Almost half of caregivers (44.2%) indicated they watched the care recipient on their own. The rest of the respondents (55.8%) provided care in conjunction with other caregivers. While approximately half of caregivers

<sup>l</sup> Percents may not equal 100% due to rounding or missing values.

provided care to the recipient on their own, the number of reported caregivers from other respondents indicates the time-intensive commitment of providing care, sometimes requiring up to five or more individuals to provide care.

**Table 7: Frequency and percent of tasks the caregivers help the care recipient with<sup>m</sup> (n=388)**

<b>Task</b>	<b>Frequency (n)</b>	<b>Percent (%)</b>
<b>Managing visits with health care providers</b>	363	93.6
<b>Transportation</b>	359	92.5
<b>Grocery shopping</b>	358	92.3
<b>Helping with medication</b>	347	89.4
<b>Managing finances/paying the bills</b>	324	83.5
<b>Preparing meals</b>	306	78.9
<b>Housework</b>	293	75.5
<b>Managing behavioral issues</b>	286	73.7
<b>Seeking services from a legal provider</b>	243	62.6
<b>Getting dressed</b>	227	58.5
<b>Bathing or showering</b>	218	56.2
<b>Eating and/or drinking</b>	212	54.6
<b>Getting in and out of beds and chairs</b>	182	46.9
<b>Toileting and/or changing diapers/pads</b>	174	44.9
<b>Other</b>	47	12.1

Caregivers were asked to choose from a list with which tasks they helped the care recipients. The most frequently chosen tasks were managing visits with healthcare providers (93.6%), transportation (92.5%), and grocery shopping (92.3%). Helping with medication (89.4%), managing finances/paying the bills (83.5%), and preparing meals (78.9%) were also frequently selected tasks.

<sup>m</sup> Note: Percent was calculated by using the total number responses for this question (388) as the denominator for each task. Respondents could select all tasks that apply. Therefore, the total percent will not equal to 100%.



**Table 8: Distribution of average number of hours per week providing care as compared to part-time and full-time job hours (n=365)**

<b>Employment Equivalent</b>	<b>Frequency (n)</b>	<b>Percent (%)</b>
<b>Part Time Job (1 – 20)</b>	92	25.2
<b>Full Time Job (21 – 40)</b>	90	24.7
<b>Full and Part Time Jobs (41 - 60)</b>	44	12.1
<b>Two Full Time Jobs (61 – 80)</b>	34	9.3
<b>More Than Two Full Time Job (&gt;80)</b>	105	28.8
<b>Total<sup>n</sup></b>	365	100.0

Caregivers were asked to estimate the number of hours per week that they provided care to their recipient. Half (49.9%) of caregivers spent less than 42 hours each week, while the other half (50.1%) spent more than 43 hours each week, more than a typical full-time job. The most common response was 168 hours per week (10.1%), which translates to 24-hour, 7 day a week care.

While open-ended responses covered a range of caregiving tasks, nineteen (13%) specifically mentioned the time commitment required to be an unpaid caregiver. One caregiver described their struggle:

“[I don’t know] how to effectively manage daily activities such as getting the care recipient out of bed, keeping up with appointments, house cleaning, home repairs, yard work, etc. when the care recipient can't remember for more than a minute what is supposed to happen, when it is going to happen, and what has to be accomplished to get ready for the event or appointment.”  
(White female caregiver to spouse, aged 75-84)

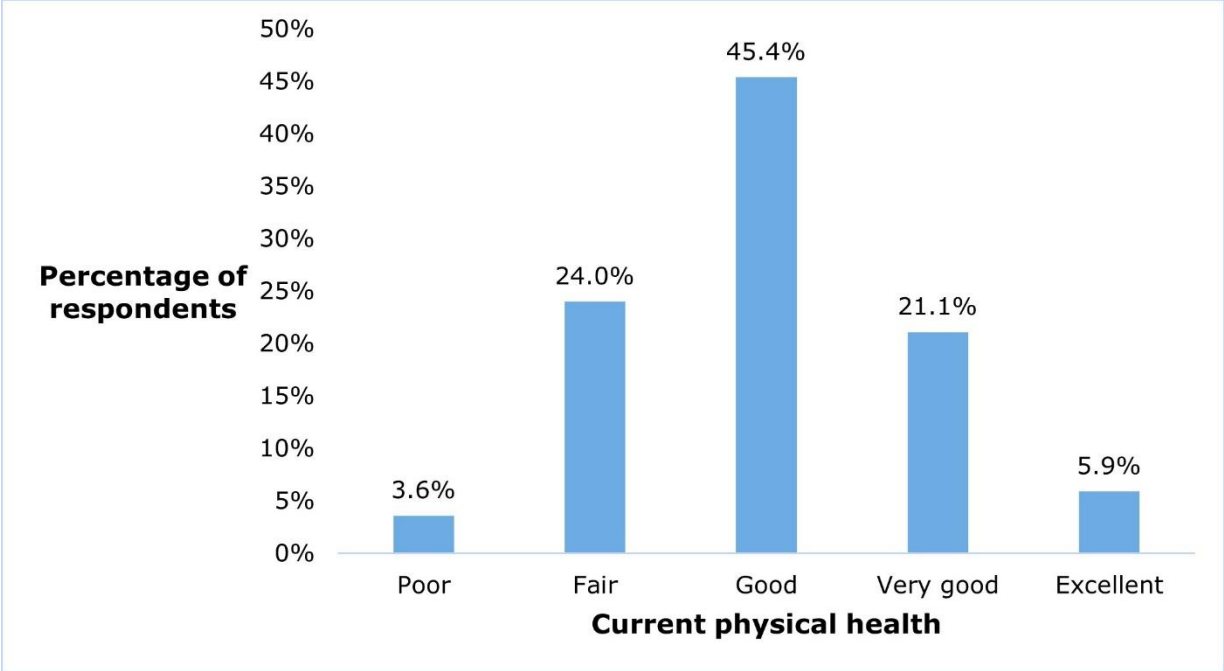
Some caregivers (n=7) shared about how their personal life has been completely overtaken by their responsibilities as a caregiver, causing them to be unable to take care of themselves. Other caregivers (n=3) cited researching for care and resources as a large time commitment as well. One caregiver commented, “It has completely taken over my life and I often think I will die first.” This conveys the extreme effort and time required for caregivers to give to their efforts, along with four responses that mention caregiving for 24 hours each day.

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<sup>n</sup>Percents may not equal 100% due to rounding or missing values.

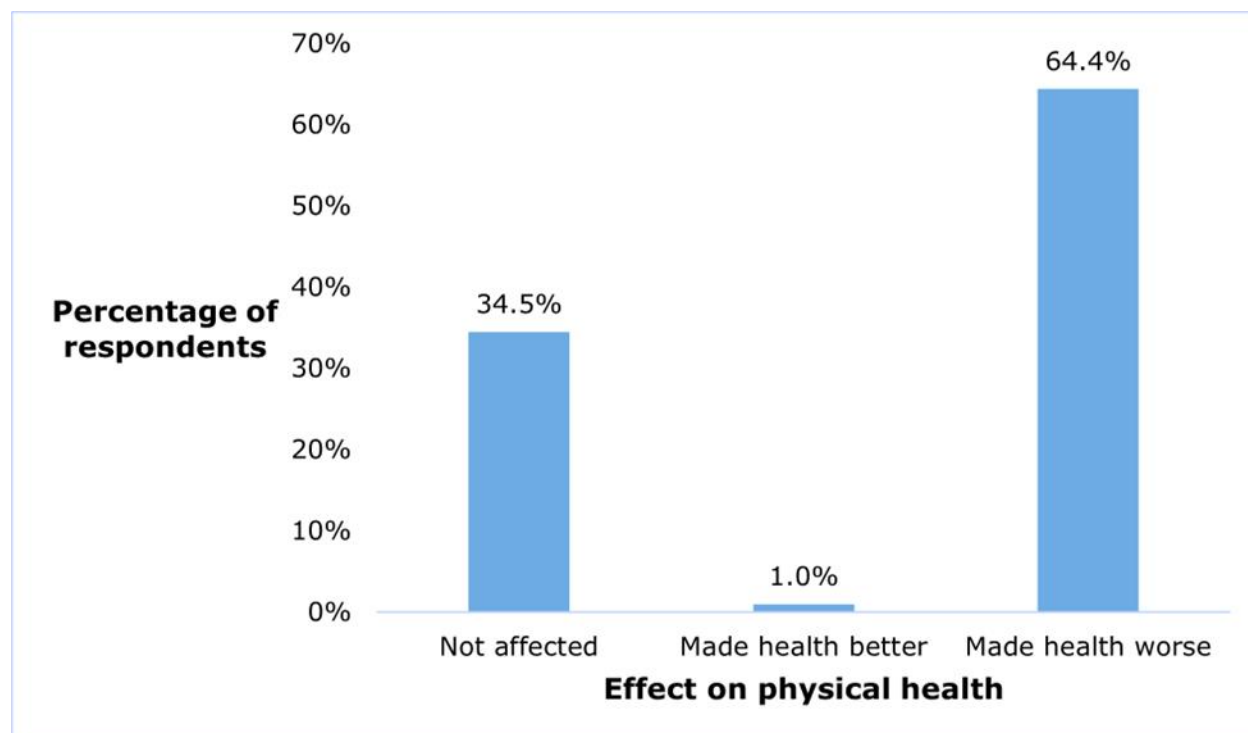
# Effect of Caregiving on Physical Health

**Figure 6: Distribution of caregiver’s self-description of their physical health (n=388)**



Caregivers were asked to provide a self-description of their physical health. Most caregivers selected good (45.4%) or fair (24%). A small percentage viewed their health as poor (3.6%), while the rest indicated their health as very good (21.1%) or excellent (5.9%).

**Figure 7: Caregiving effect on caregiver's physical health (n=388)<sup>o</sup>**



Caregivers were asked to share how caregiving had affected their physical health, with approximately two thirds (64.4%) indicating that their health had been made worse by being a caregiver. About a third (34.5%) selected that they were not affected.

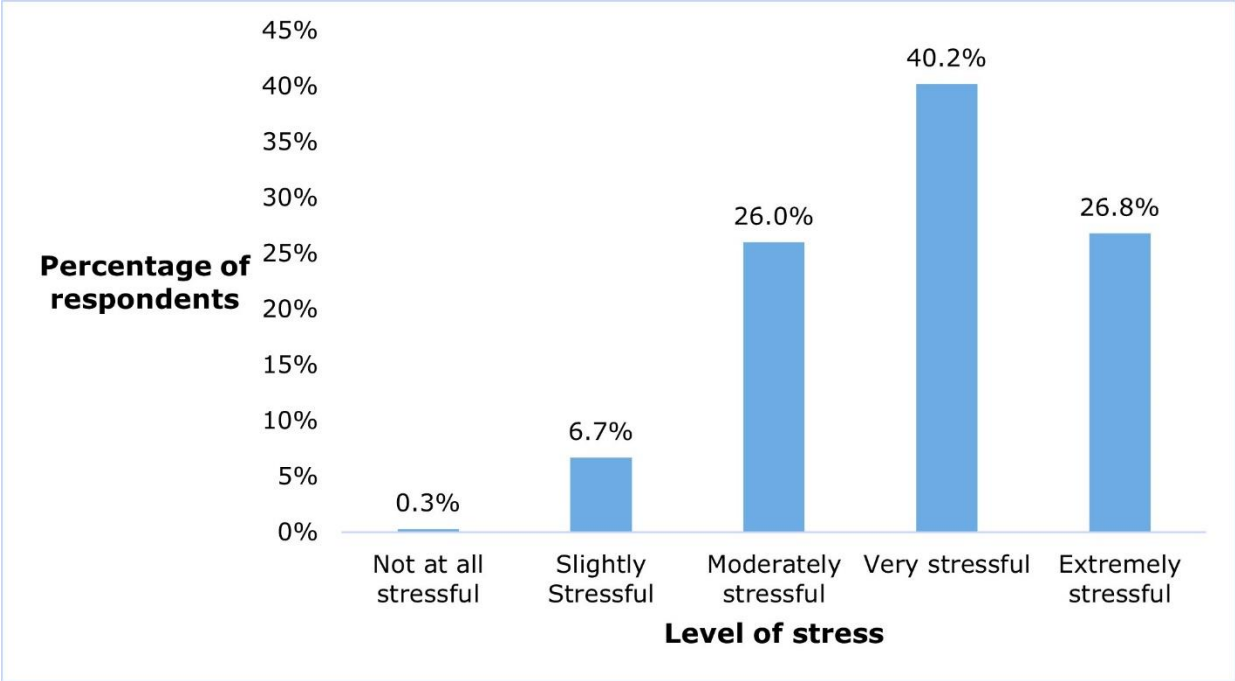
There were 23 open-ended responses (16%) that included commentary about how physical health was affected by being a caregiver. Caregivers emphasized how caregiving does not only affect one aspect of their wellness, but it “drains you [both] emotionally and physically”. The main physical health effect mentioned by caregivers was physical exhaustion or fatigue (n=10). Four mentioned how they found themselves with their own medical condition because of the stress of caregiving, including one caregiver who shared her experience:

“It is very difficult especially when she does not sleep at night and [does] not allow you to sleep. I was a zombie the next day. After a couple of days, she would sleep. The other thing is walking out of the house. I was always too tired to go on these walks. I ended up with a stroke. That is why it was difficult.” (Black female caregiver to mother, aged 65 – 74)

<sup>o</sup> Values may not equal 100% due to rounding.

# Mental and Emotional Stress of Caregiving

**Figure 8: Distribution of caregivers' emotional stress due to caregiving (n=388)**



Caregivers were asked to select how emotionally stressful providing care to the care recipient was for them. More than two thirds (67%) of caregivers indicated that the experience was very or extremely stressful. Almost one third (32.7%) identified the experience as slight or moderately stressful. Only 0.3% of caregivers felt no stress while providing care.

**Table 9: Frequency and percent of activities to cope with the demands of providing care or assistance to the care recipient<sup>P</sup> (n=388)**

<b>Activity</b>	<b>Frequency (n)</b>	<b>Percent (%)</b>
<b>Talking with or seeking advice from friends or relatives</b>	280	72.2
<b>Praying</b>	254	65.5
<b>Browsing the internet to find information</b>	249	64.2
<b>Reading about caregiving</b>	230	59.3
<b>Exercising or working out</b>	179	46.1
<b>Talking to the care recipient’s health care provider</b>	173	44.6
<b>Attending a caregiving support group</b>	153	39.4
<b>Talking to my health care provider</b>	137	35.3
<b>Talking to a professional or spiritual counselor</b>	133	34.3
<b>Using stress reduction techniques</b>	120	30.9
<b>Taking medication</b>	117	30.2
<b>Using an in-home health service for the care recipient</b>	94	24.2
<b>Using respite care</b>	43	11.1
<b>Other</b>	41	10.6
<b>I do not engage in any activities to cope</b>	13	3.4

Caregivers were asked to select from a list of activities they did to cope with providing care or assistance to the care recipient. Talking with or seeking advice from friends or relatives was the most frequently selected response (72.2%), followed by praying (65.5%) and browsing the internet to find information (64.2%). Over half of caregivers (59.3%) also chose reading about caregiving as a method of

<sup>P</sup> Percent was calculated by using the total number of responses for this question (388) as the denominator for each activity. Respondents could select all activities that apply. Therefore, the total percent will not be equal to 100%.

coping, while 13 caregivers (3.4%) indicated that they do not engage in any activities to cope with the stress of caregiving.

One of the most frequently mentioned challenges shared in the open-ended question was the emotional difficulty of being a caregiver (n=43, 29%). Responses allude to the difficulty of watching people they love change because of the disease. As one caregiver put it:

“The emotional strain of watching your parent die an inch at a time cannot be overstated.” (Female caregiver to a mother, aged 65 – 74)”

Responses often conveyed a sense of grief and sense of being overwhelmed by their circumstances. Many (n=18) mentioned frustration or needing patience to deal with the care recipient’s failing memory or health system.

Along with emotional challenges, sixteen caregivers (11%) mentioned dealing with mental health issues or stress due to caregiving. Many (n=12) mentioned stress, with one caregiver saying that “it is stressful all the time”. Mental illness was claimed by three caregivers who said they believe they “suffer from depression”.

Another factor that leads to emotional and mental stress is the changing nature of relationships between caregivers and their social circles. Many caregivers (n=18) shared feelings of isolation caused by their role as a caregiver. One caregiver confessed:

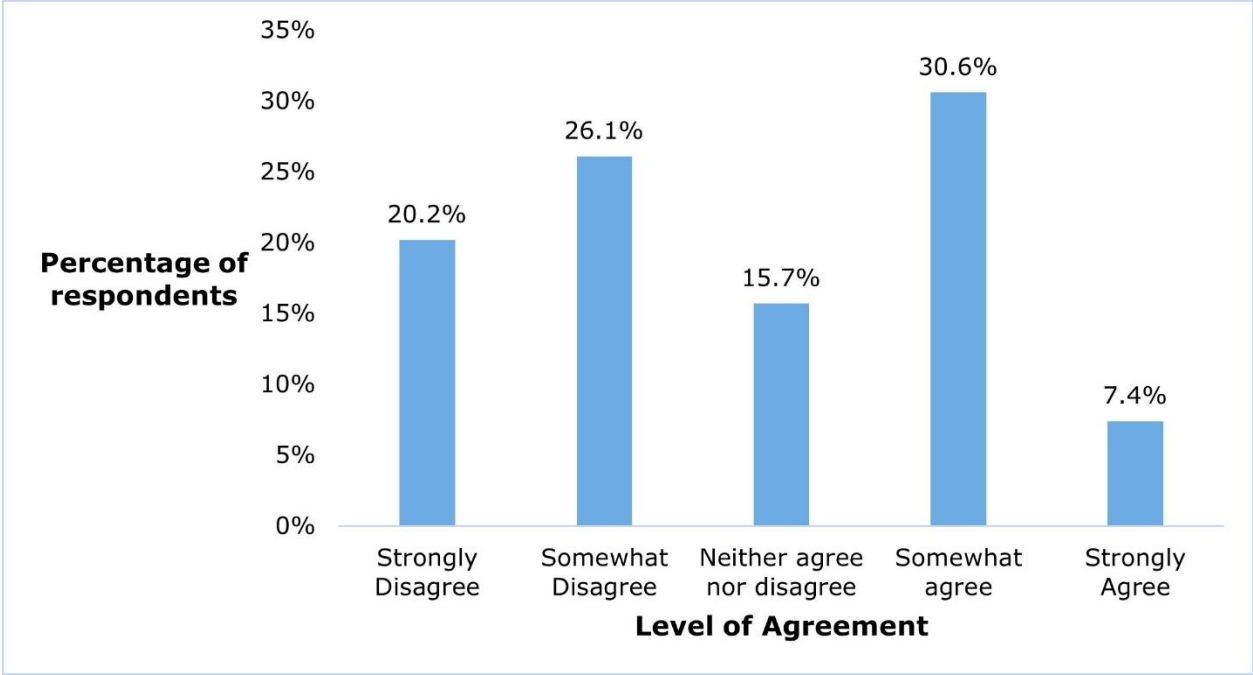
“This is one of the loneliest and most stressful things I have ever done, and you can’t really understand it unless you’ve gone through it.” (White female caregiver to spouse, aged 65 - 74)

Isolated caregivers feel as if they do not have people in their life who will relate to what they are going through.

The primary relationship caregivers mentioned was their spousal relationship (n=7), with one person being “very concerned about the impact on my marriage”, while another calling caregiving “...a long journey, but so is marriage and we managed to get through it”. Some also discussed how family dynamics (n=8) have affected their mental and emotional health. For three caregivers, family members had differing ideas about how the situation with the care recipient should be handled, causing them stress. Three others shared how they had to help family members who were overwhelmed with giving care on their own.

# Information and Resources for Caregivers

**Figure 9: Caregiver’s perceived knowledge of information and resources for providing care for ADRD<sup>a</sup> (n=376)**



Caregivers were asked if they agreed or disagreed about having the information and resources needed to provide unpaid care or assistance to the care recipient. More caregivers disagreed or were neutral (62.0%) than agreed (38.0%).

<sup>a</sup> Percent may not equal 100% due to rounding or missing values.

**Table 10: Frequency and percent of ADRD topics about which caregivers have received information and resources<sup>r</sup> (n=368)**

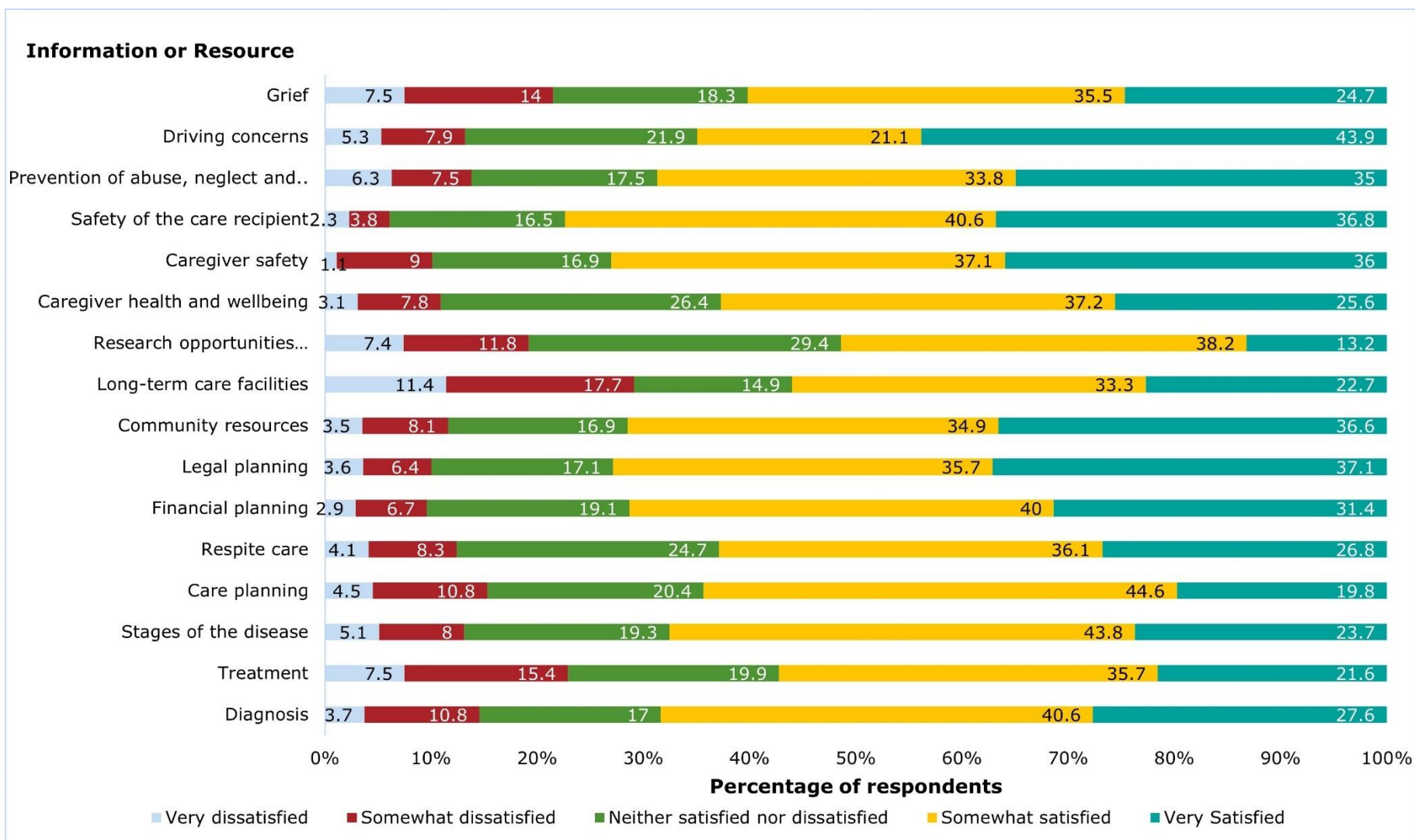
<b>Topic</b>	<b>Frequency (n)</b>	<b>Percent (%)</b>
<b>Diagnosis</b>	293	79.6
<b>Stages of the disease</b>	276	75.0
<b>Treatment</b>	245	66.6
<b>Community resources</b>	174	47.3
<b>Care planning</b>	161	43.8
<b>Driving concerns</b>	144	39.1
<b>Legal planning</b>	141	38.3
<b>Caregiver health and wellbeing</b>	135	36.7
<b>Long-term care facilities</b>	129	35.1
<b>Safety of the care recipient</b>	114	31.0
<b>End-of-life/hospice</b>	111	30.2
<b>Financial planning</b>	110	29.9
<b>Respite care</b>	98	26.6
<b>Grief</b>	95	25.8
<b>Caregiver safety</b>	90	24.5
<b>Prevention of abuse, neglect, and exploitation</b>	78	21.2
<b>Research opportunities for treatments in development</b>	68	18.5
<b>Other</b>	14	3.8

Caregivers were asked to indicate which Alzheimer’s and other dementia-related topics about which they had received information or resources. The three main topics selected were diagnosis (79.6%), stages of the disease (75%), and treatment (66.6%). The rest of the topics were selected by less than half of caregivers, with the least having received information about research opportunities for treatments in development (18.5%) or prevention of abuse, neglect, and exploitation of the care recipient (21.2%).

<sup>r</sup> Percent was calculated by using the total number of responses for this question (388) as the denominator for each topic. Respondents could select all topics that apply. Therefore, the total percent will not be equal to 100%.



**Figure 10: Distribution of caregiver’s level of satisfaction with information and resources received**



Caregivers rated their level of satisfaction with the resources they received<sup>s</sup>. The top three topics the most caregivers were satisfied or extremely satisfied were safety of the care recipient (78.4%), legal planning (72.8%), and caregiver safety (73.1%). On the other hand, the three topics most caregivers were dissatisfied or very dissatisfied with were long-term care facilities (29.1%), treatment (22.9%), and grief (21.5%).

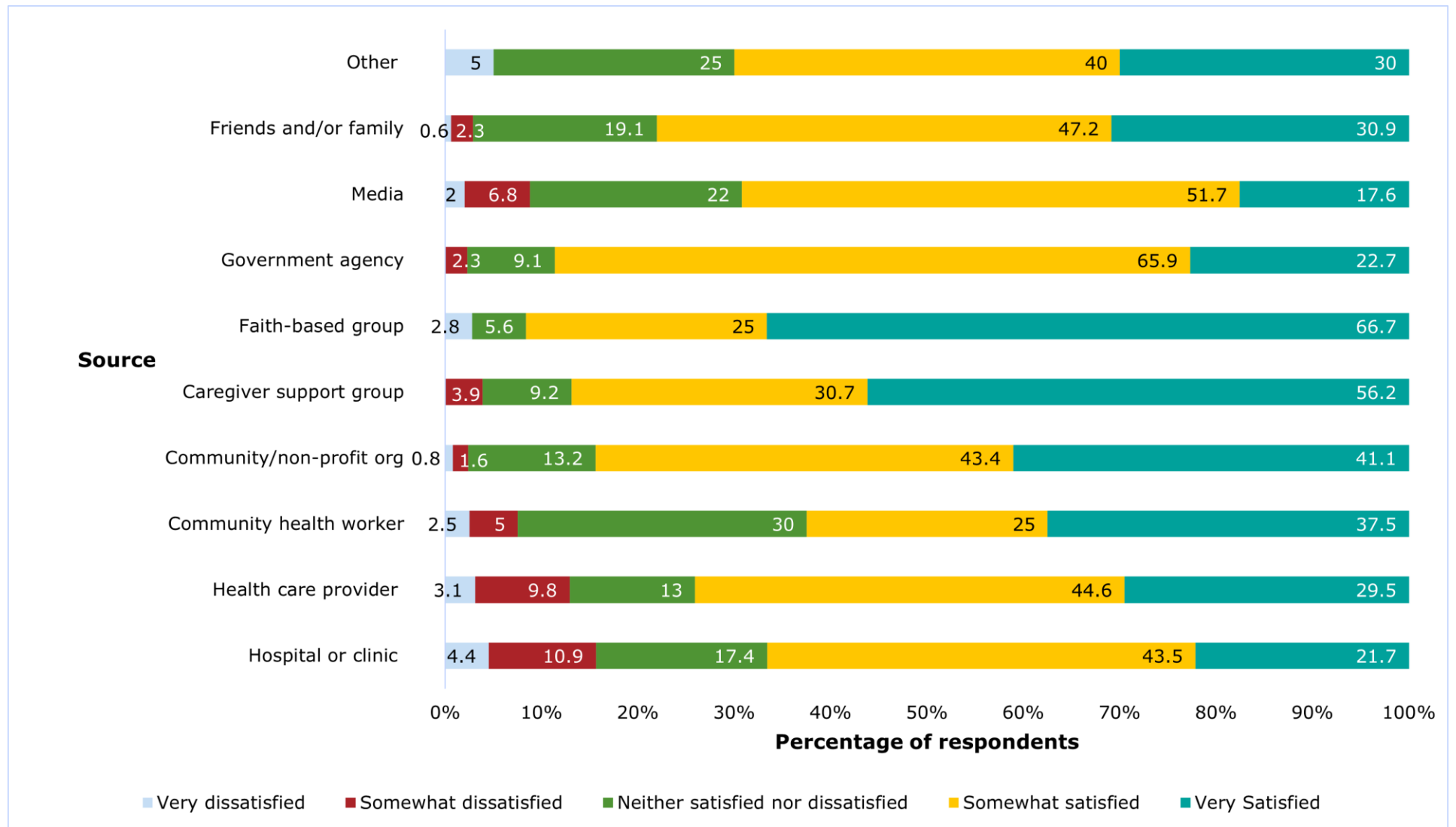
**Table 11: Frequency and percentage of caregiver’s sources of information or resources (n=384)**

Source	Frequency (n)	Percent (%)
<b>Media (e.g., internet, online, print, etc.)</b>	206	53.6
<b>Health care provider</b>	195	50.8
<b>Friends and/or family</b>	176	45.8
<b>Caregiver support group</b>	153	39.8
<b>Community/non-profit organization</b>	138	35.9
<b>Hospital or clinic</b>	45	11.7
<b>Government agency</b>	44	11.5
<b>Community health worker</b>	38	9.9
<b>Faith-based group</b>	37	9.6
<b>Other</b>	36	9.4

Caregivers were asked to select from a list of sources of information and resources on ADRD topics. The most common sources caregivers selected were media (53.6%) and health care providers (50.8%). Less commonly selected but also frequent were friends and/or family (45.8%), caregiver support groups (39.8%), and community/non-profit organizations (35.9%). The least accessed sources of information were faith-based groups (9.6%), community health workers (9.9%), and government agencies (11.5%).

<sup>s</sup> Percents may not equal 100% due to rounding or missing values.

**Figure 11: Distribution of caregivers' satisfaction with sources of information and resources**



Caregivers rated their level of satisfaction with the sources of information and resources on ADRD topics<sup>t</sup>. Most were satisfied with the sources of information, and the top three were faith-based groups (91.7%), government agencies (88.6%), and caregiver support groups (86.9%). The three sources caregivers were dissatisfied or very dissatisfied with were hospitals or clinics (15.3%), health care providers (12.9%), and community health workers (7.5%).

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<sup>t</sup> Percents may not equal 100% due to rounding or missing values.

**Table 12: Frequency and percent of caregiver’s perceived ease of finding and using information or services<sup>u</sup>**

Topics (n)	Strongly agree frequency (n)	Strongly agree percent (%)	Somewhat agree frequency (n)	Somewhat agree percent (%)	Neither agree nor disagree frequency (n)	Neither agree nor disagree percent (%)	Somewhat disagree frequency (n)	Somewhat disagree percent (%)	Strongly disagree frequency (n)	Strongly disagree percent (%)
<b>Involvement in care recipient’s planning (380)</b>	233	61.3	87	22.9	28	7.4	14	3.7	18	4.7
<b>Community support orgs/service providers (378)</b>	33	8.7	102	27	76	20.1	71	18.8	96	25.4
<b>Health care providers (384)</b>	48	12.5	114	29.7	64	16.7	77	20.1	81	21.1
<b>Insurance plan navigator (263)</b>	9	3.4	25	9.5	42	16	45	17.1	142	54
<b>Respite care (286)</b>	15	5.2	38	13.3	52	18.2	50	17.5	131	45.8
<b>I had what I needed. (376)</b>	28	7.5	115	30.6	59	15.7	98	26.1	76	20.2

Caregivers were asked to specify the extent to which they agreed or disagreed with a series of statements about navigating people and services. Most caregivers (84.2%) were involved in the care recipient’s care planning with health care providers. Less than half of caregivers (42.2%) agreed that it was easy to find and use health care providers to address the care recipient’s needs, and even less (35.7%) agreed community support organizations were easy to use. Insurance plan navigators (12.9%) and respite care (18.5%) were seen as the least easy resources.

<sup>u</sup> Percents may not equal 100% due to rounding or missing values.

**Table 13: Frequency and percent of ever connecting with other people with ADRD and their families (n=384)**

Category	Frequency (n)	Percent (%)
Yes	273	71.1
No	111	28.9
<b>Total</b>	<b>384</b>	<b>100.0</b>

Caregivers were asked if they ever connected with other people living with Alzheimer’s disease and other dementias and/or their families to ask questions, share experiences and/or assist with navigating services. Most caregivers (71.1%) indicated they had connected with other people.

Caregivers shared about information and resource needs they have in the open-ended question, as well as about resources they have experienced before. Caregivers identified tangible needs that, if addressed, would help them in their caregiving responsibilities, including more training options available that fit their unique circumstances (such as support resources for younger caregivers, or resources designed specifically for male caregivers). Information needs were also cited, with many caregivers describing needing assistance in navigating available resources (n=9), with one caregiver commenting that “knowing what to search for or ask for is hard.” Other information needs were about medicine and pharmaceuticals, alternative treatments, and tracking cognitive decline.

Sixteen caregivers discussed their dissatisfaction with the care they received or specific health care providers (11%). Half (n=8) believed their care providers did not have the knowledge to properly care for their care recipient, while almost half (n=7) mentioned poor bedside manner. From one caregiver:

“I found it very difficult working with health care providers. They seemed to lack appropriate knowledge and strategies related to dementia and Alzheimer’s disease. I felt I was on my own most of the time as a daughter/caregiver. It was extremely stressful and frustrating.” (White female caregiver to mother, aged 65 – 74)

Caregivers also mentioned respite care (n=12) but were dissatisfied with its cost and the reliability of respite workers. One recipient stated, “[S]afe affordable respite care is an impossible dream.”

For some caregivers, their rural location was mentioned as the reason for their difficulty in accessing resources or specialized care (n=7). One caregiver said there is “no assistance in rural areas [or] high cost to any kind of assistance”.

Useful programs caregivers had experienced before were mentioned by thirteen respondents. Caregiver support groups were the most often shared positive (n=6), though some caregivers also had positive perceptions of hospice (n=5). Otherwise, various internet resources (n=3) were listed as well as a few local programs.

## Language Needs of Caregivers

**Table 14: Frequency and percent of caregivers who need a Spanish interpreter at in-person appointments (n=384)**

Category	Frequency (n)	Percent (%)
Yes	15	3.9
No	369	96.1

Caregivers were asked if they need a Spanish interpreter for in-person visits to health care providers, care facilities, or other services. Though most selected no (96.1%), a small portion (3.9%) do need interpreter services.

**Table 15: Frequency and percent of caregivers who bring a family member to interpret at in-person appointments (n=15)**

Category	Frequency (n)	Percent (%)
Yes	8	53.3
No	7	46.7

Caregivers who indicated needing a Spanish interpreter at appointments were asked if they bring a family member to interpret at in-person visits. More than half (53.3%) chose that they do so.

**Table 16: Frequency and percent of language caregivers need printed materials to be written in (n=388)**

Language	Frequency (n)	Percent (%)
English	366	94.3
English and Spanish	13	3.4
Spanish	6	1.5
English and Chinese	2	0.5
Blind, need verbal information	1	0.3

Caregivers were asked what language they need printed materials written in, and most chose English (94.3%). Some chose Spanish (1.5%), and a few selected both English and Spanish (3.4%). Other options mentioned were English and Chinese (0.5%) and verbal information instead of written (0.3%).

## Summary of Findings

There were 393 eligible submissions of the 2024 Texas ADRD Unpaid Caregiver Survey.

- Most caregivers were college-educated (87.5%), non-Hispanic, White (73.4%) female (82.0%) caregivers between 55 to 84 years old (73.4%) providing care to their spouse or parent.
- Almost all caregivers (90.1%) were feeling some level of financial stress due to caregiving, with most being retired (43.7%) or employed full-time (36.3%).
- Over half of respondents (55.8%) were providing care in conjunction with another caregiver, with many (10.1%) reporting doing so for 24 hours a day, 7 days a week.
- Over two-thirds (72.4%) of caregivers had good or better physical health, but almost the same amount (64.5%) reported a decline in their physical health because of caregiving.
- Almost every caregiver felt some level of emotional stress (99.7%) due to caregiving and only a few (3.4%) had no coping activities.
- Most caregivers (84.2%) were involved in their care recipient's health planning and had connected with other patients/families who were also dealing with ADRD (71.1%).
- Caregivers most frequently used the media (53.5%) and/or a health care provider (50.8%) as their sources of information about ADRD and caregiving, though the most helpful resources reported were faith-based groups (91.7%) and caregiver support groups (86.9%).
- Caregivers were most often informed about the topics of diagnosis (79.6%) and stages of the disease (75.0%).



## Conclusion

DSHS ADP, in collaboration with CDE developed and disseminated the *2024 Texas Alzheimer's Disease and Related Dementias Caregiver Survey*. The purpose was to learn more about the experiences of current and former unpaid caregivers for people with Alzheimer's Disease.

According to the responses, caregiving has an extensive impact on the life of those who undertake it. Beyond the effect on physical, emotional, and financial health, caregivers' time spent working and social lives must now accommodate the needs of their care recipients. The importance of the availability of easily accessible information in the places caregivers' frequently attend, such as at their care recipient's healthcare provider's office, is evident, as well as the need for resources and programs to support caregivers within their geographic area.

The survey fits into Priority Area #7: Importance of Data Collection and Evaluation of the State Plan. The results of this survey help better understand the needs of unpaid caregivers in Texas to inform the priorities of future work for ADP and the Partnership.

# General Information

## Author Information

Prepared by Dane Bossert, MPH  
Program Evaluator  
Chronic Disease Epidemiology  
Health Promotion and Chronic Disease Prevention Section

Reviewed by Justin Buendia, Ph.D.  
Manager  
Chronic Disease Epidemiology  
Health Promotion and Chronic Disease Prevention Section

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## Contact Information

### **Alzheimer's Disease Program**

Chronic Disease Branch  
PO Box 149347, MC 1945  
Austin, TX 78714-9347

1100 West 49th Street  
Austin, Texas 78756

Phone: (800)-242-3399

Fax: (512)-458-7254

[alzheimers@dshs.texas.gov](mailto:alzheimers@dshs.texas.gov)

[dshs.texas.gov/alzheimers](https://dshs.texas.gov/alzheimers)

# Appendix A. 2024 Texas Alzheimer's Disease and Related Dementias Caregiver Survey

**2024 Alzheimer's Disease and Related Dementias Caregiver Survey** The Alzheimer's Disease Program (ADP) of the Texas Department of State Health Services (DSHS) is conducting this survey to learn more about the experiences of current and former unpaid caregivers.

**Who should participate?** You are invited to participate in this survey if you provided unpaid care or assistance to a relative or friend with Alzheimer's disease or other dementia in the past 12 months. To be eligible to participate in this survey, you and/or care recipient must have lived in Texas in the past 12 months.

**How long will the survey take?** The survey should take no longer than 15 minutes to complete.

**How will my responses be used?** Your responses will remain anonymous. A summary of the results will be used by the ADP and the Texas Alzheimer's Disease Partnership (Partnership). The Partnership is coordinated by the ADP and includes stakeholders from across Texas who are part of community support organizations, medical and service organizations, and others. A summary of the results will be used to better understand the needs of unpaid caregivers and progress made toward the strategies and activities listed in the Texas State Plan for Alzheimer's Disease 2024-2028 (state plan). The state plan is a resource for stakeholders across the state. The plan encourages a coordinated effort among Texas stakeholders to address the needs of Alzheimer's disease and other dementias and ensure the health and well-being of Texas. Some of the strategies and activities are related to providing caregiver support. Read the 2019-2023 state plan here: <https://www.dshs.texas.gov/alzheimers/>.

**What is the deadline for completing the survey?** Please complete the survey by September 30, 2024. If you have any questions, please contact Megan Rowe, Alzheimer's Disease Program Manager, at [megan.grafrowe@dshs.texas.gov](mailto:megan.grafrowe@dshs.texas.gov).

**Definitions** Please use the following definitions when responding to the survey:

*Care recipient* refers to the person with Alzheimer’s disease or other dementia who receives/received care or assistance.

*Caregiver* refers to the person who provides/provided care or assistance to a relative or friend with Alzheimer's disease or other dementia.

*Health care provider* refers to any professional who provides health care services, such as doctors, nurses, mental health professionals, and dentists.

*Respite care* refers to a short-term break from caregiving responsibilities. The intent of respite care is for others to take over caregiving responsibilities so that caregivers may receive temporary support to rest and recharge in order to continue to provide care.

1. In the past 12 months, have you provided unpaid care or assistance to a relative or friend with Alzheimer's disease or other dementia?
  - a. Yes, I currently provide unpaid care or assistance
  - b. Yes, I provided unpaid care or assistance in the past 12 months, but do not currently
  - c. No
2. In the past 12 months, have you and/or the care recipient lived in Texas?
  - a. Yes
  - b. No
3. Please indicate your age and the care recipient's age. If the care recipient is deceased, please indicate their age at the time of passing.

What is your age?	Under 18 years old ... 85 years or older
What is/was the <u>care recipient's</u> age? If the care recipient is deceased, please select their age at the time of passing.	Under 18 years old ... 85 years or older

4. Please indicate your race/ethnicity. Select all that apply.
  - a. White
  - b. Hispanic or Latino
  - c. Black or African American
  - d. Native American or American Indian
  - e. Asian/Pacific Islander
  - f. Other (Please specify)

5. Please indicate the care recipient's race/ethnicity. Select all that apply.

- a. White
- b. Hispanic or Latino
- c. Black or African American
- d. Native American or American Indian
- e. Asian/Pacific Islander
- f. Other (Please specify)

6. Please indicate the Texas county you and the care recipient live in.

What Texas county do you live in?	Anderson ... Not applicable
What Texas county does/did the <u>care recipient</u> live in?	Anderson ... Not applicable

7. Please indicate your education level and the care recipient's education level.

What is the highest level of education that you have completed?	Less than high school diploma ... Advanced degree
What is the highest level of education the <u>care recipient</u> has completed?	Less than high school diploma ... Advanced degree

8. Please indicate your sex and the care recipient's sex.

What is your sex?	Male ...
What is/was the <u>care recipient's</u> sex?	Male ...

9. What is/was the care recipient's relationship to you?
- a. Grandmother
  - b. Grandfather
  - c. Mother
  - d. Mother-in-law
  - e. Father
  - f. Father-in-law
  - g. Spouse
  - h. Sibling
  - i. Daughter
  - j. Son
  - k. Non-relative
  - l. Other (please specify)
10. What is your current employment status?
- a. Employed full-time
  - b. Employed part-time
  - c. Unemployed/Looking for work
  - d. Unemployed/Not looking for work
  - e. Student
  - f. Retired
  - g. Other (please specify)
11. In your experience working and providing care or assistance to the care recipient, did you ever have to do any of the following? Select all that apply.
- a. Go in late, early or take time off
  - b. Take a leave of absence from work
  - c. Switch from working full-time to part-time
  - d. Give up work entirely
  - e. Lose any job benefits
  - f. Turn down a promotion
  - g. Choose early retirement
  - h. Other (please specify)
  - i. Not applicable

12. How financially stressful is/was providing care or assistance to the care recipient for you?
- a. Not at all stressful
  - b. Slightly stressful
  - c. Moderately stressful
  - d. Very stressful
  - e. Extremely stressful
13. For this survey, a "caregiver" refers to the person who provides unpaid care or assistance to a relative or friend with Alzheimer's disease or other dementia. Some people identify with the term "caregiver," while others do not. Do/did you describe yourself as a "caregiver" to the care recipient?
- a. Yes
  - b. No
14. Including yourself, how many people provide/provided unpaid care or assistance to the care recipient?
- a. 1 person
  - b. 2 people
  - c. 3 people
  - d. 4 people
  - e. 5 or more people
  - f. Don't know
15. Do/did you consider yourself to be the person who provides/provided most of the unpaid care or assistance to the care recipient?
- a. Yes
  - b. No

16. Which of the following tasks do/did you help the care recipient with? Select all that apply.
- a. Getting in and out of beds and chairs
  - b. Getting dressed
  - c. Bathing or showering
  - d. Toileting (getting to and from the bathroom) and/or changing diapers/pads
  - e. Eating and/or drinking
  - f. Transportation
  - g. Grocery shopping
  - h. Housework
  - i. Managing finances/paying the bills
  - j. Preparing meals
  - k. Helping with medication
  - l. Managing visits with health care providers (e.g. scheduling appointments, talking to the doctor, advocating for care recipient, etc.)
  - m. Seeking services from a legal provider (e.g. drafting a will, drafting a power of attorney, etc.)
  - n. Providing companionship
  - o. Providing supervision to protect the care recipient from health and safety threats
  - p. Managing behavioral issues
  - q. Other (please specify)
17. Thinking about all the kinds of help you provide/provided for the care recipient, about how many hours do/did you spend in an average week doing these things?
- 

18. How would you describe your own physical health?
- a. Excellent
  - b. Very good
  - c. Good
  - d. Fair
  - e. Poor



19. How has providing care or assistance to the care recipient affected your physical health?
- Made health better
  - Not affected
  - Made health worse
20. How emotionally stressful is/was providing care or assistance to the care recipient for you?
- Not at all stressful
  - Slightly stressful
  - Moderately stressful
  - Very stressful
  - Extremely stressful
21. Which of the following activities do/did you do to cope with the demands of providing care or assistance to the care recipient? Select all that apply.
- Praying
  - Talking to a professional or spiritual counselor
  - Talking to my health care provider
  - Talking to the care recipient's health care provider
  - Talking with or seeking advice from friends or relatives
  - Attending a caregiving support group
  - Browsing the internet to find information
  - Reading about caregiving
  - Exercising or working out
  - Using stress reduction techniques (e.g. meditation, yoga, breathing exercises, etc.)
  - Taking medication
  - Using an in-home health service for the care recipient
  - Using respite care
  - Other (please specify)
  - I do/did not engage in any activities to cope with the demands of caregiving

22. To what extent do you agree or disagree with the following statement? I have/had the information and resources I need/needed to provide unpaid care or assistance to the care recipient.
- Strongly agree
  - Somewhat agree
  - Neither agree nor disagree
  - Somewhat disagree
  - Strongly disagree
23. Which of the following Alzheimer's and other dementia-related topics have you received information and resources on? Select all that apply.
- Diagnosis
  - Treatment
  - Stages of the disease
  - Care planning
  - Respite care
  - Financial planning
  - Legal planning
  - Community resources (e.g. classes, support groups, local Alzheimer's related nonprofits)
  - Long-term care facilities (i.e. nursing homes, assisted living facilities, etc.)
  - Research opportunities for treatments in development (i.e. clinical trials)
  - Caregiver health and wellbeing
  - Caregiver safety (e.g. methods for preventing and managing aggressive conflicts, etc.)
  - Safety of the care recipient (e.g. safe storage of medication, wander prevention methods, etc.)
  - Prevention of abuse, neglect and exploitation of care recipient
  - Driving concerns
  - Grief (e.g. loss of care recipient, changing role as a daughter, son, spouse, etc.)
  - End-of-life/hospice
  - Other (please specify)
  - None of the above

24. How satisfied or dissatisfied are/were you with information and resources you received on each topic?

	Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied
Diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stages of the disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care planning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<u>Respite care</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financial planning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Legal planning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community resources (e.g. classes, support groups, local Alzheimer's related nonprofits)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Long-term care facilities (i.e. nursing homes, assisted living facilities, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research opportunities for treatments in development (i.e. clinical trials)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied
Caregiver health and wellbeing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiver safety (e.g. methods for preventing and managing aggressive conflicts, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<u>Safety of the care recipient</u> (e.g. safe storage of medication, wander prevention methods, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prevention of abuse, neglect and exploitation of care recipient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Driving concerns	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Grief (e.g. loss of care recipient, changing role as a daughter, son, spouse, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
End-of-life/hospice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
None of the above	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. Where have you received information and resources on Alzheimer's and other dementia-related topics? Select all that apply.
- a. Hospital or clinic (without contact with a health care provider)
  - b. Health care provider
  - c. Community health worker
  - d. Community/not-for-profit organization
  - e. Caregiver support group
  - f. Faith-based group
  - g. Government agency
  - h. Media (e.g. internet/online, print, etc.)
  - i. Friends and/or family
  - j. Other (please specify)

26. How satisfied or dissatisfied are/were you with the information and resources you have received from the following sources?

	Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied
Hospital or clinic (without contact with a <u>health care provider</u> )	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<u>Health care provider</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community health worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community/not-for-profit organization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiver support group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Faith-based group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Government agency	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Media (e.g. internet/online, print, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends and/or family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. Have you ever connected with other people living with Alzheimer’s disease and other dementias and/or their families to ask questions, share experiences and/or assist with navigating services?

- a. Yes
- b. No

28. To what extent do you agree or disagree with the following statements?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applicable
I am/was involved in the <u>care recipient's</u> care planning with <u>health care providers</u> .	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is/was easy to find and use community support organizations/service providers to address the <u>care recipient's</u> needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is/was easy to find and use <u>health care providers</u> to address the <u>care recipient's</u> needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An insurance plan navigator helped me and/or the <u>care recipient</u> to find and connect with services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is/was easy to find and use <u>respite care</u> services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

29. As a caregiver, do you need a Spanish interpreter for in-person visits to health care providers, care facilities, or other services?

- a. Yes
- b. No

30. Do you bring a family member with you to interpret for you at in-person visits to health care providers, care facilities, or other services?

- a. Yes
- b. No

31. What language do you need printed materials to be written in?

- a. English
- b. Spanish
- c. English and Spanish
- d. Other (please specify)

32. Is there Spanish-language support available for you as a caregiver?

- a. Yes
- b. No

33. Please provide any additional comments or information you'd like to share about being an unpaid caregiver.

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**Do You Know Other Caregivers That Should Participate?** We are relying on partner organizations and respondents to help us reach all individuals that provide/provided unpaid care or assistance to individuals with Alzheimer’s disease and other dementias in Texas. If you know a caregiver who should receive this survey, please forward them the following survey link:  
[https://txdshs2.gov1.qualtrics.com/jfe/form/SV\\_bNN5go2hz28sG0e](https://txdshs2.gov1.qualtrics.com/jfe/form/SV_bNN5go2hz28sG0e)



# Appendix B: Caregiver's County of Residence

Table 17: Frequency and percent of caregiver county of residence (n=388)

Counties	Frequency (n)	Percent (%) <sup>v</sup>
Angelina	4	1.0
Aransas	2	0.5
Atascosa	1	0.3
Austin	2	0.5
Bastrop	1	0.3
Bell	1	0.3
Bexar	31	8.0
Bosque	1	0.3
Brazoria	6	1.5
Brazos	9	2.3
Burnet	1	0.3
Caldwell	1	0.3
Cameron	8	2.0
Cherokee	1	0.3
Collin	10	2.6
Comal	4	1.0
Dallas	12	3.1
Denton	20	5.2
DeWitt	1	0.3
Duval	1	0.3
Ector	1	0.3
Ellis	1	1.5
El Paso	6	1.5
Erath	1	0.3
Fort Bend	10	2.6
Galveston	12	3.1
Gillespie	4	1.0
Grayson	3	0.8
Gregg	1	0.3
Guadalupe	1	0.3
Harris	40	10.3
Hays	2	0.5
Henderson	2	0.5
Hidalgo	1	0.3
Hood	10	2.6
Houston	1	0.3
Hunt	1	0.3

<sup>v</sup> Total may not be equal to 100% due to rounding or missing values.

<b>Counties</b>	<b>Frequency (n)</b>	<b>Percent (%)<sup>v</sup></b>
<b>Jackson</b>	1	0.3
<b>Jim Wells</b>	1	0.3
<b>Johnson</b>	1	0.3
<b>Karnes</b>	1	0.3
<b>Kaufman</b>	2	0.5
<b>Kendall</b>	1	0.3
<b>Liberty</b>	3	0.8
<b>Live Oak</b>	2	0.5
<b>Lubbock</b>	4	1.0
<b>McLennan</b>	2	0.5
<b>Montgomery</b>	11	2.8
<b>Nueces</b>	6	1.5
<b>Parker</b>	1	0.3
<b>Randall</b>	2	0.5
<b>Rockwall</b>	3	0.8
<b>San Patricio</b>	2	0.5
<b>Smith</b>	9	2.3
<b>Tarrant</b>	53	13.7
<b>Taylor</b>	1	0.3
<b>Tom Green</b>	1	0.3
<b>Travis</b>	34	8.8
<b>Van Zandt</b>	1	0.3
<b>Victoria</b>	3	0.8
<b>Walker</b>	3	0.8
<b>Washington</b>	1	0.3
<b>Webb</b>	4	1.0
<b>Wichita</b>	2	0.5
<b>Williamson</b>	18	4.6
<b>Wise</b>	1	0.3
<b>No response</b>	5	1.3
<b>Total</b>	<b>388</b>	<b>100.00</b>

Alzheimer's Disease Program  
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