2021 TEXAS ALZHEIMER'S DISEASE AND RELATED DEMENTIAS CAREGIVER SURVEY REPORT

TEXAS
Health and Human
Services

Texas Department of State
Health Services

Contents

Executive Summary

The Texas Department of State Health Services (DSHS) Alzheimer's Disease Program (ADP) and the Chronic Disease Epidemiology Branch (CDE) collaborated with the Texas Alzheimer's Disease Partnership (Partnership) to create the 2021 Texas Alzheimer's Disease and Related Dementias Caregiver Survey. The purpose of the survey was to learn more about the experiences of unpaid caregivers for people with Alzheimer's disease and other dementias (**State Plan**).

Most respondents were female, 55 years of age or more, retired, and White. Most care recipients were female, 75 years of age or more, retired, and White. Most respondents described themselves as caregivers, worked, and had connected with other people.

Respondents indicated providing care for an average of 68 hours per week. The most frequent response was providing care for 24 hours a day, seven days a week. Many care recipients had received unpaid care from two people or more.

Many respondents indicated that caregiving had affected their health, work, and finances. Most respondents prayed, talked, read, and browsed the internet to cope with caregiving. The most common topic respondents received information or resources on was the diagnosis. Respondents were most satisfied with topics about the safety of the care recipient.

The most common source of information and resources was caregiver support groups. Respondents were most satisfied with faith-based sources of information and resources. Respondents were not satisfied with government agencies as sources of information and resources. Respondents found health care providers easy to find and use. Respondents did not find insurance plan navigators easy to find or use.

Many respondents also shared their experiences, recommendations, questions, and comments.

Introduction

The *Texas State Plan for Alzheimer's Disease 2019-2023* (**State Plan**) is a resource for stakeholders across the state that 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.

The Texas Department of State Health Services (DSHS) Alzheimer's Disease Program (ADP), in collaboration with the DSHS Chronic Disease Epidemiology Branch (CDE) and the Texas Alzheimer's Disease Partnership (Partnership), created the *2021 Texas Alzheimer's Disease and Related Dementias Caregiver Survey*. The survey fit into the Priority Area #7: Importance of Data Collection and Evaluation, of the State Plan by collaborating with stakeholders in a coordinated and systematic way and identifying and addressing data needs. The purpose of the survey was to learn more about the experiences of current and former unpaid caregivers for people with Alzheimer's disease.

Methods

Survey Development

CDE worked with ADP and Partnership members to develop, test, and refine the survey before it was disseminated. Initial questions and data points of interest were collected from Partnership members during the November 19, 2019 Partnership meeting. CDE then had informational calls between February 3-26, 2020 with eight Partnership member organizations (n=10 people) who work with unpaid caregivers. The purpose of these calls was to further develop survey questions and the survey dissemination plan.

For the pilot test, a link to the survey was sent to 45 Partnership members who previously indicated that they worked with unpaid caregivers, including those who participated in the informational calls. The pilot test period was June 9-June 15, 2020. The response rate to the pilot test was 62.2% (n=28). Following the pilot test, the survey was revised with suggested language, response options, and additional questions.

CDE programmed the survey in Qualtrics. The survey consisted of 29 questions that gathered quantitative and qualitative data on unpaid caregivers' experiences on providing unpaid care or assistance to a relative or friend with Alzheimer's disease or other dementia. The survey can be found in **Appendix A**.

Sampling Method

The snowball sampling method was used to recruit respondents for the survey. Snowball sampling is a non-probabilistic sampling technique in which respondents recruit other respondents with the same characteristics. This sampling method is used when the target population is hard to reach or have rare traits.[1]

An Alzheimer's Disease Program staff member emailed the survey link to all Partnership members (n= 314) on January 4, 2021. The CDE program evaluator also emailed the survey link to those who participated in the informational calls (n = 10) on January 19, 2021. Partnership members and key stakeholders forwarded the email with the survey link to unpaid caregivers or to people who might know unpaid caregivers. The survey link was posted to the DSHS LinkedIn and Twitter social media pages on February 22, 2021.

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[1] Allen, M. (2017). The sage encyclopedia of communication research methods (Vols. 1-4). Thousand Oaks, CA: SAGE Publications, Inc doi: 10.4135/9781483381411

Once an unpaid caregiver completed the survey, they were encouraged to forward the survey link to other unpaid caregivers that they knew to increase the reach of the survey.

Responses and Analysis

The survey was open from January 4 - March 5, 2021. During the survey collection period, 395 people started the survey. Of these, 33 respondents did not meet the inclusion criteria: they 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, they had not lived in Texas in the past 12 months. Two respondents did not pass the second question and were excluded. Thus, a total of 360 respondents were included in the final analysis. Some respondents did not answer every question; incomplete responses were included in the analysis.

Results from the survey were analyzed by a CDE program evaluator. Quantitative data was analyzed using SPSS v24. Qualitative data was analyzed using Atlas.ti.

A CDE program evaluator analyzed quantitative data using a descriptive approach. For the qualitative responses, the program evaluator used inductive content analysis method. Inductive coding is commonly used in qualitative research and can be applied to open data[2]. It follows a "bottoms up" data analysis that allows the creating of codes, categories and sub-categories, and themes after the data is collected[3].

Results: Quantitative Data

Demographics

The majority of respondents (77.5 percent) were currently providing unpaid care or assistance to a relative or friend with Alzheimer's disease or other dementia. The remaining 22.5 percent of respondents had provided unpaid care or assistance to a relative or friend with Alzheimer's disease or other dementia in the past 12 months.

The majority of respondents identified as female (81.8 percent), while 17.9 percent identified as male. Only 0.3 percent of the respondents identified as non-binary. Similarly, the majority of the respondents identified the care recipient as female (52.6 percent), and 46.9 percent of respondents identified the care recipient as male. Only 0.3 percent of the respondents identified the care recipient as non-binary.

The vast majority of respondents were 55 years or older (83.5 percent) (**Figure 1**). Specifically, 32.7 percent of the respondents were 55 to 64 years of age, 30.1 percent of the respondents were 65 to 74 years of age, 17.5 percent of the respondents were 75 to 84 years of age, and 3.2 percent of the respondents were 85 years or older. Only 16.6 percent of the respondents were 45 years or younger. The vast majority of the respondents indicated the care recipient's age to be 55 years or older (92.8 percent). Specifically, 38.6 percent of the respondents indicated the care recipient's age was 75 to 84 years old, followed by 85 years or older (32.0 percent), and 65 to 74 years old (22.2 percent). Only 7.2 percent of the respondents indicated the care recipient's age to be 55 years old or younger.

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[2] Kyngäs, H. (2020). Inductive content analysis. In The application of content analysis in nursing science research (pp. 13-21). Springer, Cham.

[3] Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs. 2008 Apr;62(1):107-15. doi: 10.1111/j.1365-2648.2007.04569.x. PMID: 18352969.

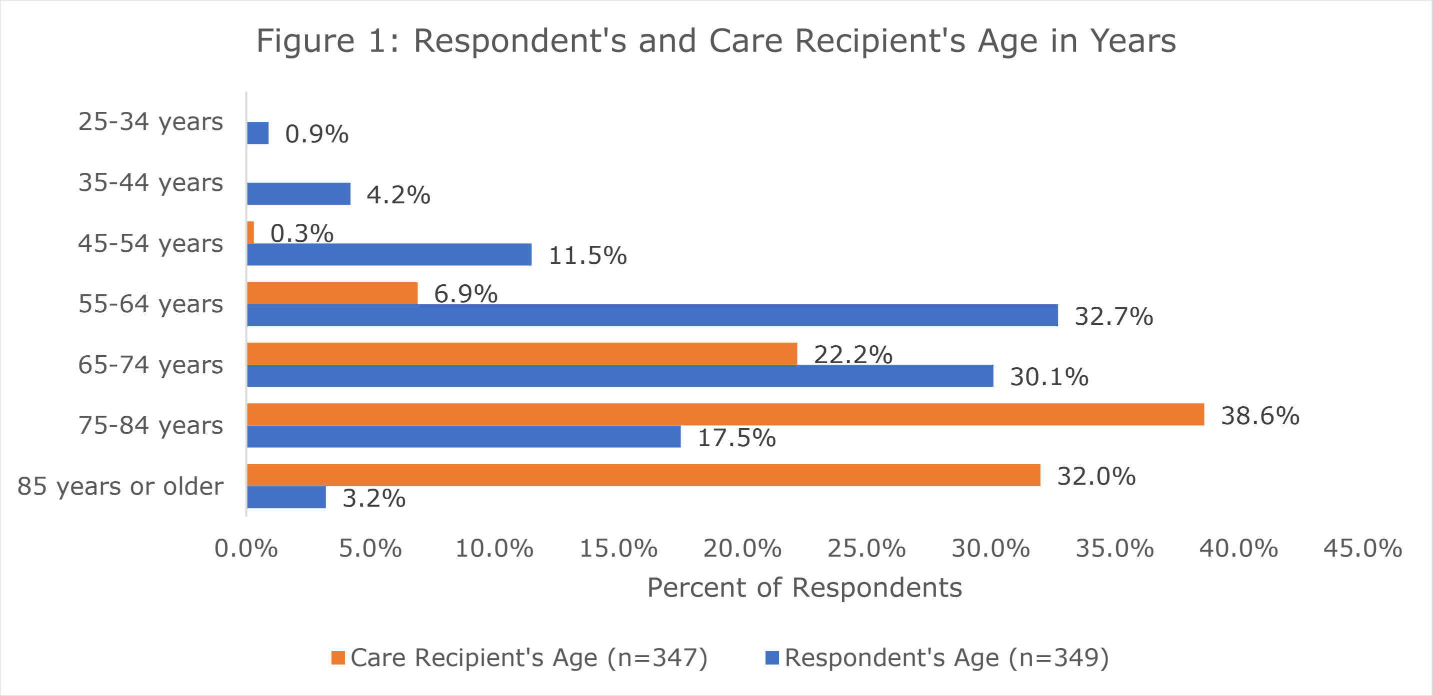


Figure 1: Respondent's and Care Recipient's Age in Years

As shown in Table 1, most of the respondents indicated that they were White (81.2 percent). Fewer respondents said they were Hispanic or Latinos (11.6 percent), Black or African American (3.6 percent), Native American or American Indian (1.1 percent), Asian or Pacific Islander (0.6 percent), and other (1.9 percent). Similarly, most of the respondents indicated that the care recipients were White (81.2 percent). Fewer respondents said the care recipient was Hispanic or Latinos (11.6 percent), Black or African American (3.6 percent), Asian or Pacific Islander (1.1 percent), and Native American or American Indian (0.6 percent), and other (1.4 percent).

Table 1: Frequency and percent of respondent's and care recipient's race/ethnicity[*].

Race/Ethnicity	Respondents (n=361)		Care Recipients (n=359)	
	Frequency (n)	Percent (%)	Frequency (n)	Percent (%)
White	293	81.2	294	81.9
Hispanic/Latino	42	11.6	38	10.9
Black/ African American	13	3.6	12	3.3
Asian/Pacific Islander	4	1.1	3	0.8
Native American/American Indian	2	0.6	7	1.9
Other	7	1.9	5	1.4
Total	**361[**]**	**100.0**	**359[***]**	**100.0**

[*] Respondents could select as many responses as applied. Missing values were excluded for calculating percentages.
[**] Missing = 9.
[***] Missing = 10.

Table 2 presents the top four Texas counties in which the respondents indicated lived in the past 12 months. Most of the respondents lived in Tarrant County (23.1 percent), Harris County (10.5 percent), Dallas County (7.7 percent), and Nueces County (4.6 percent). The remaining 54.1 percent of respondents lived in other counties in the past 12 months. The complete list of respondents and care recipients county of residence can be found in **Appendix B** and **Appendix C**, respectively.

Twenty-three percent of care recipients were from Tarrant County, 10.6 percent were from Harris County, 7.8 percent were from Dallas County, 4.3 percent were from Nueces County. The remaining 54.3 percent of respondents lived in other counties in the past 12 months.

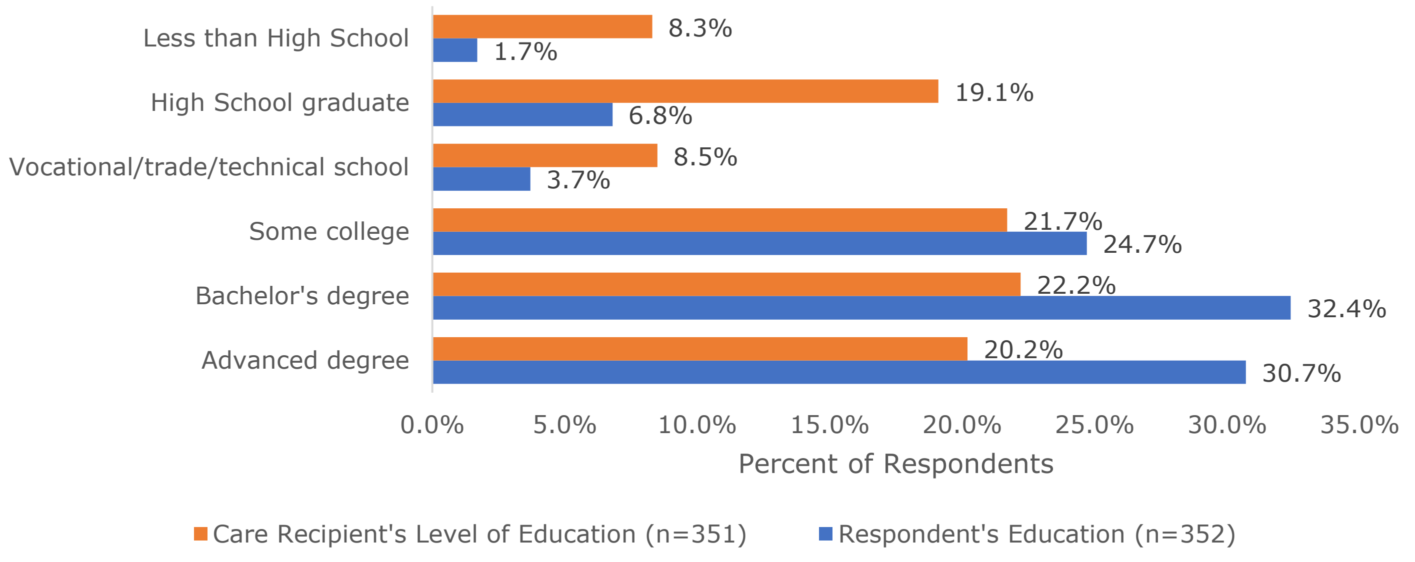
Table 2: Frequency and percent of the top four respondent's and care recipient's county of residence in the past 12 months[*].

Texas Counties	Respondents (n=351)		Care Recipients (n=348)	
	Frequency (n)	Percent (%)	Frequency (n)	Percent (%)
Tarrant	81	23.1	80	23.0
Harris	37	10.5	37	10.6
Dallas	27	7.7	27	7.8
Nueces	16	4.6	15	4.3
Other Counties	190	54.1	189	54.3
Total	**351**[**]	**100.0**	**348**[***]	**100.0**

[*] Missing values were excluded for calculating percentages.
[**] Missing = 9.
[***] Missing = 12.

As shown in Figure 2, the vast majority of the respondents (91.5 percent) reported having higher than a high school education. Specifically, 32.4 percent reported having a bachelor's degree, 30.7 percent reported having an advanced degree, 24.7 percent reported having some college education, and 3.7 percent reported having a vocational, trade, or technical school. Only 8.5 percent reported having a high school education or lower.
The majority of respondents (72.6 percent) reported that the care recipient had higher than a high school education. Specifically, 22.2 percent had a bachelor's degree, 21.7 percent had some college, 20.2 percent had an advanced degree, and 8.5 percent had a vocational, trade, or technical education. Almost three out of 10 (27.4 percent) reported that care recipients had a high school education or lower.

Figure 2: Respondents and Care Recipient's Level of Education



As seen in Table 3, the vast majority (96.3 percent) of the respondents provided unpaid care or assistance to a relative or sibling. Over half (50.7 percent) of the respondents provided unpaid care or assistance to their spouse. Fewer respondents reported their mother (30.1 percent), father (8.3 percent), mother-in-law (2.9 percent), grandmother (2.9 percent), sibling (2.0 percent), non-relative (2.0 percent), and father-in-law (0.3 percent). Respondents who selected "other" (1.7 percent) specified these relationships, including sister-in-law, aunt, partner, significant other, best friend, and domestic partner.

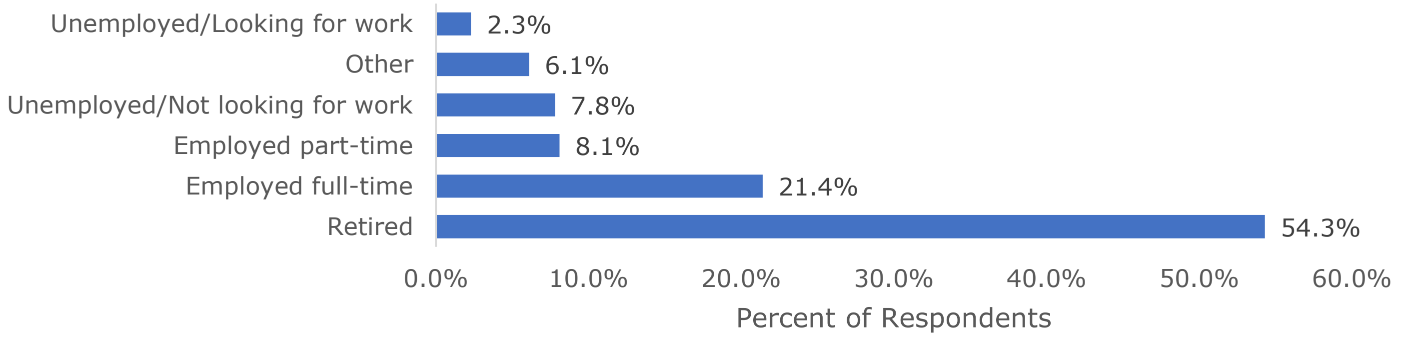
Table 3: Frequency and percent of care recipient's relationship to the caregiver. (n=349)

Relationship	Frequency (n)	Percent (%)
Spouse	177	50.7
Mother	105	30.1
Father	29	8.3
Mother-in-law	10	2.9
Grandmother	7	2.0
Sibling	7	2.0
Non-relative	7	2.0
Other	6	1.7
Father-in-law	1	0.3
Total*	**349**	**100.0**

*Missing = 11. Missing values were excluded for calculating percentages.

Over half (54.3 percent) of the respondents reported being retired (Figure 3). Almost three out of 10 (29.5 percent) respondents reported being employed, of which 21.4 percent were employed on a full-time basis and 8.1 percent on a part-time basis. One tenth (10.1 percent) of the respondents indicated they were unemployed, of which 7.8 percent were not looking for work and 2.3 percent were looking for work. Among those that indicated other employment status (6.1 percent), responses included: self-employed, housewives or homemakers, full-time caregivers, and working from home on a part-time basis.

Figure 3: Caregiver's Current Employment Status (n=346)

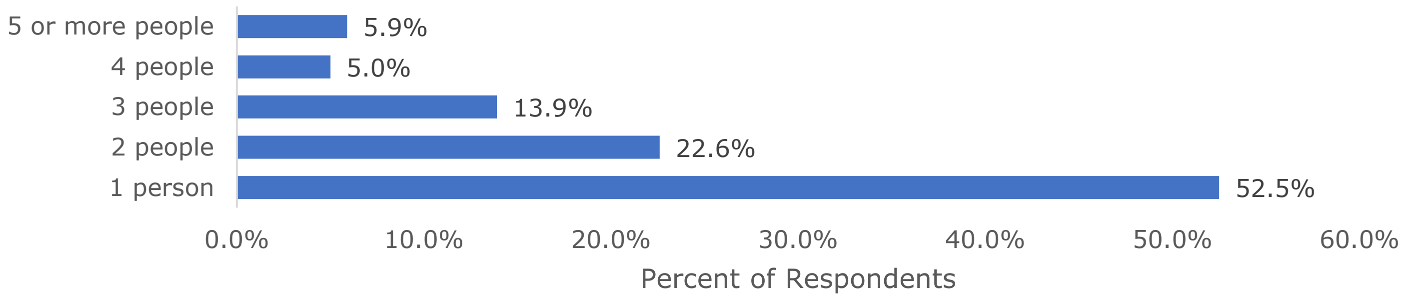


Caregiving

Respondents were asked if they described themselves as caregivers. The vast majority of the respondents personally described themselves as caregivers (86.1 percent).

Respondents were asked to provide the number of people that provided unpaid care or assistance to the care recipient, including themselves (Figure 4). Including themselves, over half (52.5 percent) of the care recipients received unpaid care or assistance from only one person. Notably, 47.4 percent of the care recipients received unpaid care or assistance from two or more people, including the respondent. Of these, 22.6 percent of care recipients received unpaid care or assistance from two people, 13.9 percent from three people, 5.0 percent from four people, and 5.9 percent from five or more people.

Figure 4: Number of People Provided Unpaid Care or Assistance to the Care Recipient (n=337)

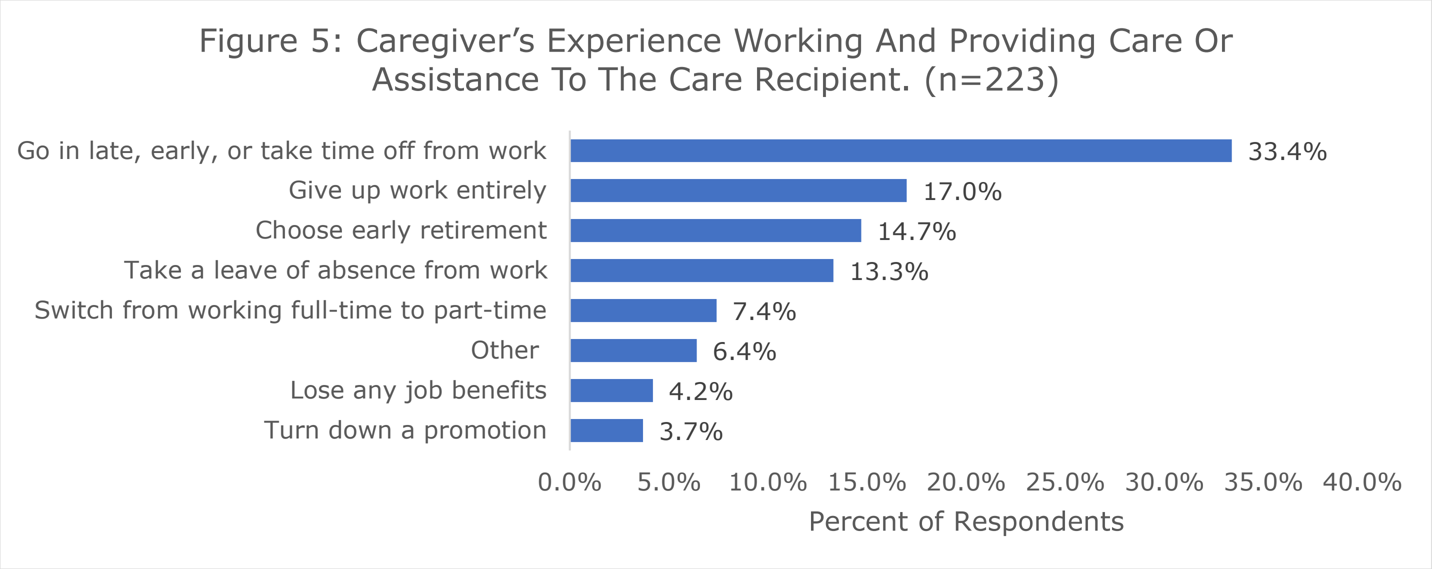


Respondents were also asked if they considered themselves to be the person who provided most of the unpaid care or assistance to the care recipient. The majority (82.6 percent) of the respondents considered themselves to be the person who provided most of the unpaid care or assistance to the care recipient.

Caregiving and Work

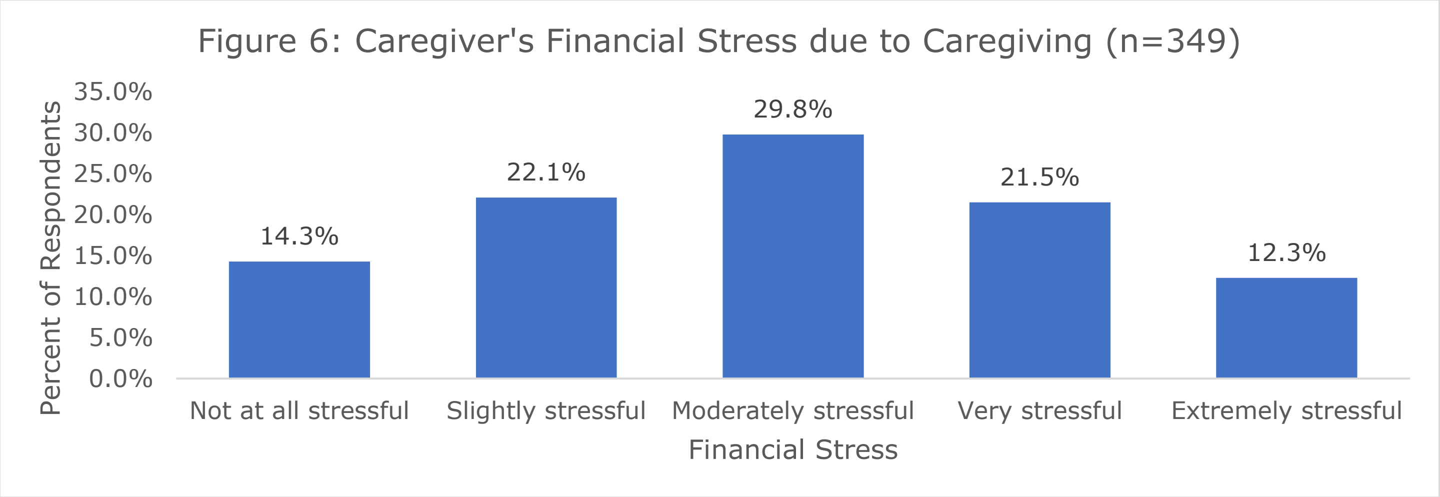
Respondents were asked how caregiving or providing assistance to the care recipient impacted their work. The majority of the respondents (61.9 percent) indicated that it has impacted their work in some way (Figure 5). Respondents most commonly indicated they had to go in late, early, or take time off from work (33.4 percent). Respondents also chose early retirement (14.7 percent), took a leave of absence from work (13.3 percent), switched from working full-time to part-time (7.4 percent), lost any job benefits (4.2 percent), and turned down a promotion (3.7 percent). Seventeen percent of caregivers reported they had to give up working entirely to provide care or assistance to the care recipient.

Among those who reported other (6.4 percent), some responses included: loss of pension benefits due to early retirement, changes in work hours, started working from home, changed jobs to work different hours, missed work-related travels or conventions, worked weekends, chose demotion, among others.



Caregiving and Financial Stress

Respondents were asked to indicate levels of financial stress from providing care or assistance to the care recipient (Figure 6). The vast majority (85.7 percent) of respondents indicated some level of financial stress (from slightly stressful to extremely stressful) due to providing care or assistance to the care recipient. Over half (51.9 percent) of respondents experienced slight to moderate financial stress due to providing care or assistance to the care recipient. While 33.8 percent of respondents indicated that providing care or assistance to the care recipient was very or extremely financially stressful. Only 14.3 percent of the caregivers indicated no financial stress due to providing care or assistance to the care recipient.



Caregiving Tasks

First, respondents were asked to indicate from a list which tasks they provided help to the care recipient. As presented in Table 4, the most commonly selected tasks were: managing visits with health care providers (e.g., scheduling appointments, talking to the doctor, advocating for care recipient, etc.) (94.4 percent), providing companionship (93.2 percent), transportation (91.5 percent), managing finances or paying the bills (90.0 percent), and helping with medication (88.8 percent).

Among those who helped the care recipient with other tasks (12.1 percent), some of these tasks included: emotional, social, or religious support; socialization; communication with family, siblings, or others; security; housework; caring for pets; and "every aspect" of the care recipient's life.

Table 4: Frequency and percent of tasks the caregivers help the care recipient with*. (n=340)

Tasks	Frequency (n)	Percent (%)
Managing visits with health care providers	321	94.4
Providing companionship	317	93.2
Transportation	311	91.5
Managing finances/paying the bills	306	90.0
Helping with medication	302	88.8
Grocery shopping	290	85.3
Preparing meals	283	83.2
Providing supervision to protect the care recipient from health and safety threats	279	82.1
Housework	265	77.9
Managing behavioral issues	245	72.1
Seeking services from a legal provider	235	69.1
Getting dressed	181	53.2
Bathing or showering	168	49.4
Eating and/or drinking	165	48.5
Getting in and out of beds and chairs	139	40.9
Toileting (getting to and from the bathroom) and/or changing diapers/pads	136	40.0
Other	41	12.1

*Missing = 20. Missing values were excluded for calculating percentages.

**Respondents could select as many responses as applied.

Second, respondents were asked how many hours they spent in an average week doing the tasks presented above (Table 5). Respondents indicated they averaged 67.5 hours per week providing these tasks, with a median of 50.0 hours per week, and a mode of 168 hours per week (or 24 hours of care every day) (n=31).

Table 5: Frequency and percent of caregiver's average hours per week providing care to the care recipient*. (n=318)

Metrics	Hours per Week
Mean	67.5
Median	50.0
Mode	168.0**
Range: Minimum	0.0
Range: Maximum	168.0**

*Missing = 42.

**Three respondents indicated more than the maximum hours per week. Results were coded as 168 hours per week.

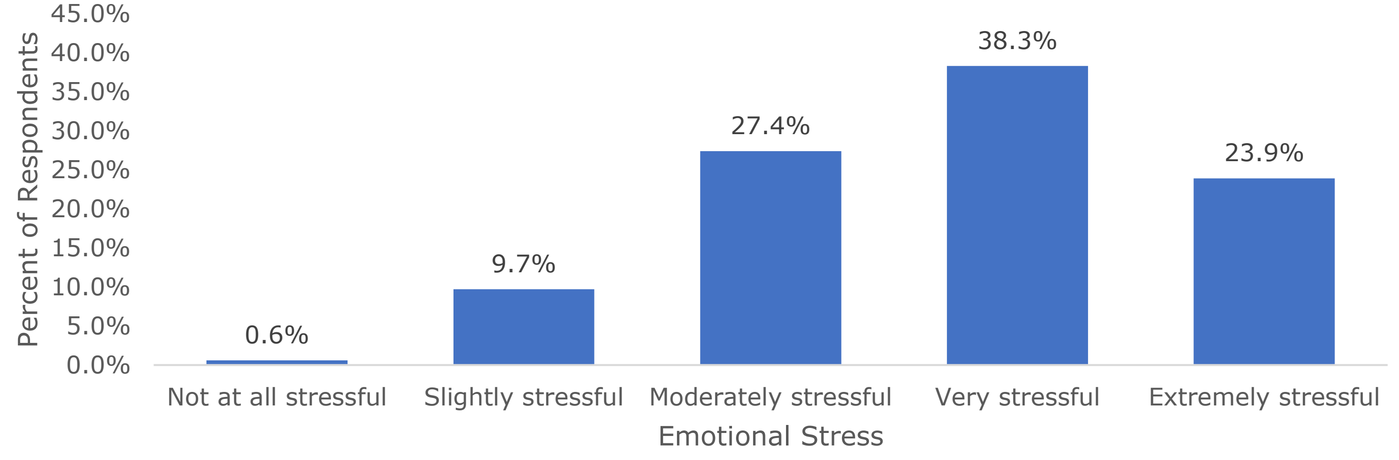
Caregiving and Physical and Emotional Impact

First, respondents were asked to describe their own physical health. Over two in five respondents (42.5 percent) described their own physical health as good. One-third (33.3 percent) of respondents described their physical health as very good or excellent, while 23.3 percent described it as fair or poor.

Second, respondents were asked how providing care or assistance to the care recipient affected their physical health. The majority of respondents (61.7 percent) indicated that providing care or assistance to the care recipient had made their physical health worse. Many respondents (36.6 percent) indicated that it had not affected their physical health.

Third, caregivers were asked to indicate how emotionally stressful it was to provide care or assistance to the care recipient. As presented in Figure 7, almost all respondents (99.3 percent) indicated some emotional stress (from slightly stressful to extremely stressful) in providing caregiving or assistance to the care recipient. Notably, over half of respondents (62.2 percent) indicated that providing care was either very or extremely emotionally stressful. Almost one in four respondents (37.1 percent) indicated it was slightly to moderately emotionally stressful.

Figure 7: Emotional Stress of Providing Caregiving (n=339)



Caregiving and Coping Activities

Respondents were asked to select from a list of activities they did to cope with providing care or assistance to the care recipient. As shown in Table 6, most of the respondents indicated they prayed (75.8 percent) to cope with the demands of providing care or assistance to the care recipient. Fewer respondents indicated they talked with or sought advice from friends or relatives (67.6 percent), read about caregiving (61.4 percent), and browsed the internet to find information (61.1 percent).

Among the respondents that reported other coping activities (13.0 percent), some included having used facilities or daycares, exercise or housework, help from others, therapy, counseling or support groups, consuming alcohol, education, among others.

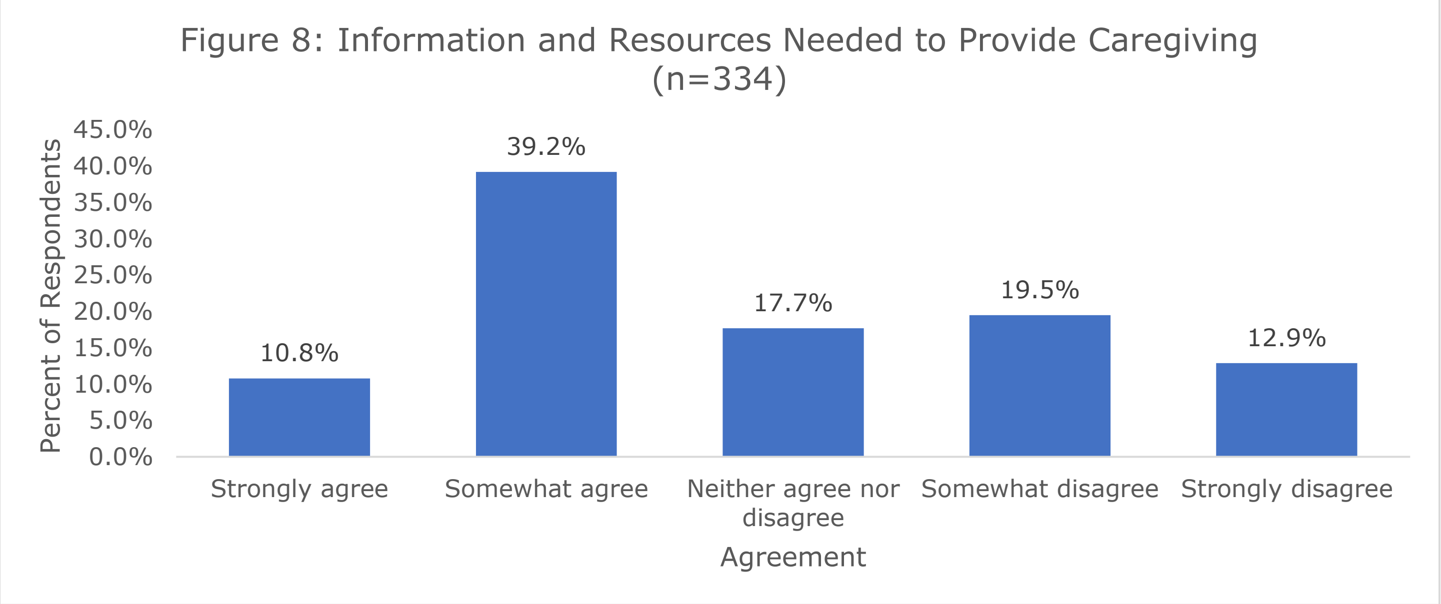
Table 6: Frequency and percent of activities to cope with the demands of providing care or assistance to the care recipient*. (n=339)		
Coping Activities	**Frequency (n)****	**Percent (%)**
Praying	257	75.8
Talking with or seeking advice from friends or relatives	229	67.6
Reading about caregiving	208	61.4
Browsing the internet to find information	207	61.1
Attending a caregiving support group	183	54.0
Exercising or working out	160	47.2
Talking to the care recipient's health care provider	158	46.6
Talking to my health care provider	122	36.0
Talking to a professional or spiritual counselor	115	33.9
Using stress reduction techniques	111	32.7
Taking medication	109	32.2
Using an in-home health service for the care recipient	89	26.3
Using respite care	55	16.2
Other	44	13.0
I do/did not engage in any activities to cope	13	3.8

* Respondents could select as many responses as applied.

** Missing = 20. Missing values were excluded for calculating percentages.

Information and Resources About Caregiving

Respondents were asked if they agreed or disagreed about having the information and resources needed to provide unpaid care or assistance to the care recipient (Figure 8). Half of respondents (50.0 percent) agreed and the other half of respondents (50.0 percent) were either neutral or disagreed with the statement.

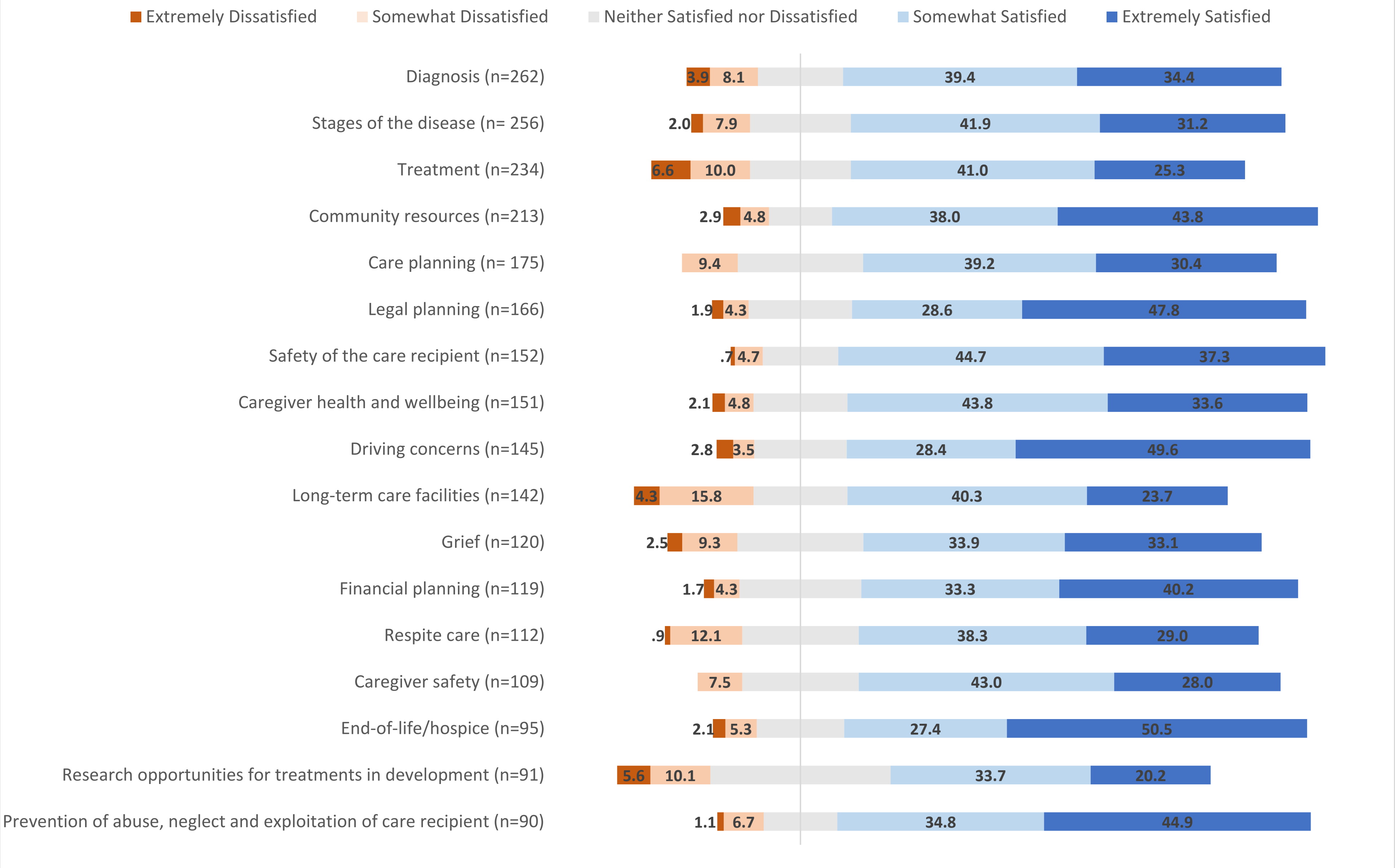


Respondents were asked to indicate which Alzheimer's and other dementia-related topics they had received information or resources about (Figure 9). The majority of the respondents indicated they received information on diagnosis (82.1 percent), stages of the disease (80.3 percent), treatment (73.4 percent), community resources (66.8 percent), care planning (54.9 percent), and legal planning (52.0 percent). Among those who selected “other” (3.1 percent), six respondents indicated they already possessed knowledge from previous experience or education, one respondent indicated having received information or resources on mental health inpatient and outpatient facility. Only one respondent indicated not receiving any information or resources.

Next, respondents rated their satisfaction with the resources they received (Figure 9). The top five topics the most respondents were satisfied or extremely satisfied with were safety of the care recipient (82 percent), community resources (81.8 percent), prevention of abuse, neglect and exploitation of care recipient (79.7 percent), driving concerns (78.0 percent), and end-of-life or hospice (77.9 percent).

On the other hand, the five topics with which the most respondents were dissatisfied or extremely dissatisfied were long-term care facilities (20.1 percent), treatment (16.6 percent), research opportunities for treatments in development (15.7 percent), respite care (13.0 percent), and diagnosis (12.0 percent).

Figure 9: Degree of Satisfaction with Resources and Information Received on Each Topic



Sources of Information and Resources

Respondents were asked to select from a list of sources of information and resources on Alzheimer's disease and other dementia-related topics. The most common sources respondents selected were caregiver support groups (59.9 percent) (Figure10). Fewer respondents selected health care providers (53.1 percent), community or not-for-profit organizations (47.8 percent), the media (47.2 percent), and friends or family (46.9 percent). Community health workers (14.5 percent), faith-based groups (13.3 percent), government agency (8.3 percent), and hospital or clinic without contact with a health care provider (7.7 percent), were the least common sources of information and resources on Alzheimer's disease and other dementia-related topics reported by the caregivers. Among those who indicated other sources of information and resources (7.7 percent), some of the sources included: the Alzheimer's Association, Alzheimer's.org, AARP or other organizations, hospice centers, books, internet, seminars or courses, previous education or occupation, previous experience with a person with Alzheimer's disease or other dementia, and universities.

Next, respondents rated their satisfaction with the sources of information and resources selected. Most respondents were somewhat or extremely satisfied with the sources of information or resources (Figure 10). Notably, respondents were most satisfied with faith-based sources of information (95.2 percent), caregiver support groups (92.2 percent), community or not-for-profit organizations (90.9 percent), and community health workers (83.0 percent). Conversely, respondents indicated they were somewhat or extremely dissatisfied with information and resources they received from government agencies (22.2 percent), hospitals or clinics (16.0 percent), other sources of information or resources (14.3 percent), and health care providers (10.4 percent).

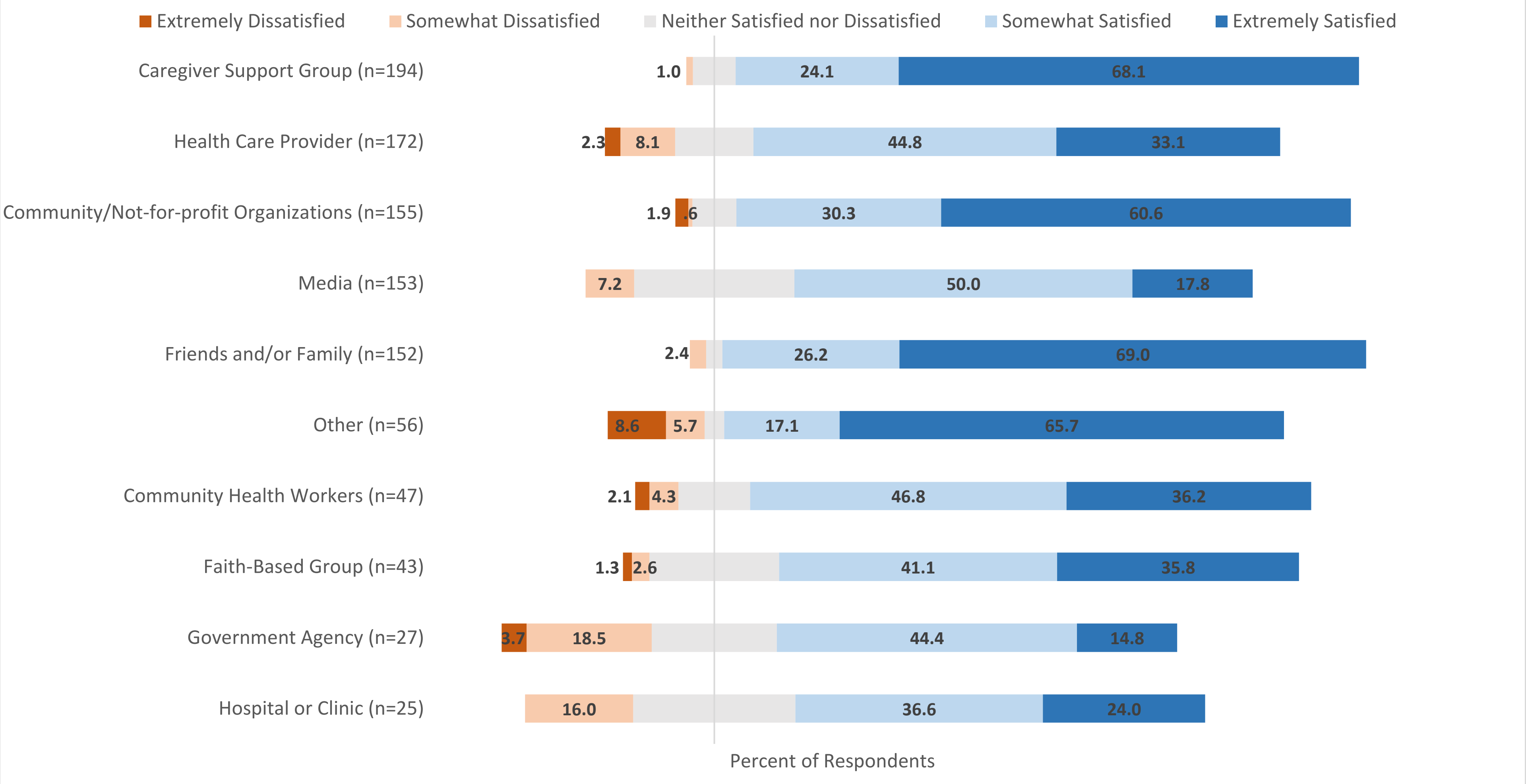


Figure 10: Degree of Satisfaction with the Sources of Information

Perceived Ease of Finding and Using Information or Services

Respondents were asked to specify the extent to which they agreed or disagreed with a series of statements about navigating people and services (Table 7).

The majority of the respondents (77.2 percent) were involved in the care recipient's care planning with health care providers.

Over half of the respondents (53.4 percent) agreed that it was easy to find and use health care providers to address the care recipient's needs. Fewer respondents agreed that community support organizations or service providers (44.7 percent) were easy to find and use.

On the other hand, the majority of respondents (83.9 percent) did not find the insurance plan navigator, respite care services (76.9 percent), and community support organization or service providers (55.6 percent) were easy to find and use to address the care recipient's needs.

Table 7: Frequency and percent of respondent's perceived ease of findings and using information or services[*].

Topics	Strongly Agree n (%)	Agree n (%)	Neither Agree nor Disagree n (%)	Disagree n (%)	Strongly Disagree n (%)	Total (n)
Community Support Organization/Service Providers	41 (12.7)	103 (32.0)	65 (20.2)	58 (18.0)	55 (17.4)	322
Health Care Providers	56 (17.4)	116 (36.0)	50 (15.5)	52 (16.1)	48 (14.9)	322
Involvement in Care Recipient's Planning	208 (57.8)	62 (19.4)	24 (7.5)	9 (2.8)	16 (5.0)	319
Respite Care Services	18 (8.0)	28 (12.4)	57 (25.3)	42 (18.7)	80 (35.6)	225
Insurance Plan Navigator	11 (5.1)	24 (11.1)	36 (16.7)	28 (13.0)	117 (54.2)	216

[*] Respondents could select as many responses as applied. Missing values were excluded for calculating percentages.

Caregiving and Connections

Respondents 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. The majority of respondents (77.6 percent) indicated they had connected with other people.

Results: Qualitative Data

Respondents were asked to share any additional information or comment about being unpaid caregivers. A total of 155 people (43.1 percent) responded to this question. Seven themes emerged from the analysis: Barriers to Services, Impact on Health, Perceived Help of Services, Health Care Facilities, Job, Impact on Work, and Questions, Recommendations, and Comments.

Barriers to Services

The first theme to arise from responses was the barriers that caregivers faced to receiving services for the care recipient or themselves (n=72). The theme was sub-categorized as follows: lack of support or assistance (n=24), lack of resources (n=22), coronavirus disease 2019 (COVID-19) (n=10), difficulty in finding information (n=10), and difficulty in finding help or care (n=6).

Lack of Support or Assistance

Twenty-four respondents mentioned that they lacked the support or assistance needed to provide care. Eight respondents mentioned that they lacked support or assistance from health care services (n=3), from other people (n=2), and other (n=3).

Thirteen respondents mentioned they lacked government support, whether it was on the federal, state or local level, to provide care. One respondent expressed the need for the state to provide more assistance for those who provide care and those with dementia. Another respondent mentioned:

> The support needed for Alzheimer’s patients is not there for anyone under 60. It is awful and needs to change. Everyone thinks it’s an aging disease and it is not. My husband was 47 at diagnosis- no help or support out there for young people from government or associations.

Three respondents mentioned that they lacked the financial support to be able to access services. One respondent commented, “There are not enough resources available for the various stages of Alzheimer's. There are lots of fundraisers for Alzheimer's but not enough financial assistance for the caregiver.”

Lack of Resources or Services

Twenty-two respondents mentioned that they lacked resources, either for themselves or for the care recipient, to access services. One respondent mentioned, “There are not enough resources available for the various stages of Alzheimer's. There are lots of fundraisers for Alzheimer's but not enough financial assistance for the caregiver.”

Fifteen respondents mentioned financial resources as a barrier to accessing health care services. These comments included the unaffordability of care (n=8), and not being able to qualify for programs that covered for the services due to income qualifications (n=3).

Two respondents mentioned that caregivers should be paid. One of the respondents explained that, "If care givers were paid, it could provide some relief from financial burden and enable more care recipients to be maintained at home".

Six respondents also mentioned needing other resources including respite care services, palliative care providers, funding for programs, high personnel turnover, and male care providers. One respondent also noted that services were limited in rural areas.

COVID-19

Ten respondents mentioned COVID-19 restrictions as a factor that limited the accessibility of services for themselves or the care recipient. Respondents mentioned that day programs (n=3), counseling (n=2), support groups (n=1), and others (n=4) were either not available or very limited due to COVID-19. One respondent commented, "The pandemic has caused setbacks in acquiring the outside help that would benefit both of us."

Another respondent noted:

> Our family has no experience with this and because of Covid we feel cut off from my grandmother's medical care team. Trying to reach a doctor or nurse is very difficult. And when we make contact it is always [with] a new nurse or doctor so there doesn't seem to be good continuity of communication and I worry that means her care is also disjointed. We can't be there all the time, we are barely allowed to be with her because of Covid, and she can no longer communicate what her needs are or what is happening when we are gone. It's very very sad.

Difficulty in Finding Information

Ten respondents mentioned that they had difficulty finding information regarding the diagnosis or care for the care recipient. Of these, three respondents noted that the healthcare providers did not provide them with information. One of the respondents commented:

> I received very little assistance with services in the area - I had to research and find those programs on my own. [Doctor] met with us only every 6mos and even then made no suggestions/offered no answers for many questions. I did TONS of online research, joined FB groups and other [in person] support groups to learn as much as I could. For someone dealing with a non-Alzheimer's dementia, there is very little information locally. Very frustrating.

Difficulty in Finding Help or Care

Six respondents mentioned that they had difficulty finding help or care for the care recipient. One respondent mentioned that, "Even with funds to pay, it is difficult to find dependable, well-trained, reliable part-time helpers." Another respondent added:

> They live in outskirts of city and it is hard to find help willing to drive out there; it is also hard to find reliable good help overall. It seems people who have good caregivers find them by accident and then keep them. Because of difficulty of finding care, I am forced to consider all non-at-home options for their [long-term] care. I prefer they stay at their home which may/may not be possible.

Impact on Caregiver's Health

The second theme to arise from comments was the impact of caregiving on the caregiver's health (n=62). The theme was sub-categorized as follows: Mental Health (n=48) and Physical Health (n=14).

Mental Health

Forty-eight respondents commented experiencing emotional effects due to providing care, the importance of having a support system, moral obligation to provide care, and empathy towards others. Many respondents (n=10) expressed that caregiving had a toll on their overall mental health. One of the respondents commented:

> Watching someone you have lived with for fifty years go away, lose their mind/memories, forget who I am, who their sons are, lose basic communication skills, be in pain 24/7, is hell - I will not consider remarrying because I do not want to take a chance on living through this again - I am as much a prisoner as he is.

Nine respondents commented they felt isolated, lonely, or thought nobody cared for them due to providing care. One of the respondents commented:

> At my age of 80, this is a depressing task as my partner lacks the ability to be a partner so I have to carry the weight of all the daily tasks. I have no one to talk to about plans or projects I would like to do, no help as a partner provides day to day. A big brick wall stands between us and an enjoyable life. Her dementia is much like getting up every day to push a fully loaded wheelbarrow up a hill when you know life could be fun if she was really normal. So much for crying for myself. It is difficult to be a caregiver without a bunch of [self-pity] ...things could be so much worse. Thank God she seems happy and loves me. My only reward.

Eight respondents expressed feeling sad, stressed, or anxious as a result of providing care to the care recipient. Eight respondents expressed providing care to the care recipient was emotionally difficult or hard. Of these, two respondents added that the care recipient was difficult to deal with. One of the respondents commented:

> Very difficult to know mom's condition was terminal, and watch her go through the process of dying. Hardest when she forgot who I was. Gave me an opportunity to be a part of her last days, to hear her tell me about her dreams of heaven and family there.

Seven respondents mentioned the importance of having a support system. One of the respondents commented, "Support is everything. I'm not talking about financially, but a mental break from being a caregiver is needed." Of these, four respondents commented they lacked support from family members or relatives. One of the respondents commented, "They all seem to go on with their lives."

Four respondents expressed a moral obligation or duty to provide care for the care recipient. Two respondents expressed empathy for other caregivers.

Physical Health

A total of fourteen respondents commented on the physical effects of providing care. Seven respondents mentioned the impact caregiving had on their overall physical health. One respondent commented that, "This is very hard physically, mentally and emotionally as well as hard on all family and friends. I would not wish this on anyone." Of these, two respondents indicated that their physical health had been affected due to stress. One respondent commented:

> As a diabetic for more than 30 years, I found that my blood sugar glucose became very variable even with medication. I attribute the variation to stress. Levels have been better controlled now that she lives in a memory care unit.

One respondent explained that they had to put the care recipient's needs before their own. Another respondent commented that they would not be surprised if they had a "heart attack or stroke before this journey is over."

Seven respondents expressed feeling exhausted or tired. Of these, four respondents provided a one-sentence response that said, "Exhausted!", "I'm tired," "I am exhausted!" and "I'm exhausted." Another two respondents explained that constantly waking up at night to check on the care recipient made them feel tired.

Perceived Help of Resources or Services

The third theme was the perceived help of resources or services, which was defined as respondents mentioning the helpfulness or unhelpfulness of various resources or services (n=26). Nineteen respondents commented on various resources they deemed helpful for them. Some of the respondents commented that the Alzheimer's Association (n=6), day programs (n=4), support groups (n=3), prayers (n=2), and others (n=4) were helpful for them.

Seven respondents also mentioned various resources or services they deemed were not helpful for them. Responses included the Alzheimer's Association (n=2), health care providers (n=2), and others (n=3).

Job

The next theme to arise was caregiving as a hard or difficult, 24-hour or full-time job (n=19). Eleven respondents described caregiving as a hard or difficult job. One of the respondents described it as "the most difficult 'job' there is. No hope for long term improvement. Simply observing a slow death in a loved one." Eight participants described providing care as a 24-hour or full-time job. One of the respondents explained that "it's a 24/7 job, even though he is [in] a memory care facility at an assisted living facility."

Health Care Facilities

The theme of "health care facilities" was defined as respondents commenting on experiences with services they received while providing care or expressing the need for more resources (n=8). Eight respondents mentioned negative experiences with health care facilities. Some of the respondents mentioned, "I expected so much more for her and I am sad at the state of our Long Term Care facilities."; "It is hard to find care facilities for respite or long term, that will do a good job on both physical care and personal engagement."; and, "I would still do it over again as the care that people with Alzheimer's/Dementia get in nursing homes is horrific at best. ALL nursing homes/memory care centers need DRASTIC overhauling." One of the respondents mentioned having a negative experience with a hospital and expressed dissatisfaction with the services' quality.

Impact on Work

The theme "Impact on work" was defined as respondents mentioning how caregiving had impacted their work in the short or long-term (n=8). Of these, four respondents mentioned losing their job or job benefits due to providing care to the care recipient. One of the respondents commented that the state or federal government should provide more support to those who leave the workforce to provide care. The respondent added that leaving the workforce temporarily to provide care should not be grounds for losing job benefits.

Two respondents added that due to losing their jobs or job benefits, they endured financial difficulties. One of the respondents commented, "I have had to give up my job therefore my future social security, insurance and well-being to ensure my grandmother gets the best care for what we can afford."

Two respondents also expressed the challenges of working and providing care. One of the respondents commented:

> I have to drive 20 minutes the wrong direction to get her care so I can work. Without day care I would have to quit my job. In addition, she really needs the structured activities and socialization of a day program.

Questions, Recommendations, and Comments

Questions, recommendations, and comments theme was defined as respondents asking any questions, providing recommendations, or comments (n=26). Many respondents provided recommendations on more information or services (n=11). These recommendations included: more community facilities, more availability of adult day programs for caregiver and care recipient, more community outreach activities, more information on topics regarding Alzheimer's disease and other dementia, more information on ways to cope, and more opportunities for interaction with other caregivers, and more information and encourage the use of Hospice Medicare Benefit. One of the respondents indicated that resources should not be gender specific: "Most written resources are for women and by women. Men caregivers need to know 'duty' type things and not 'What are your feelings' questions."

Eleven respondents expressed the need for more help or resources available to provide care. Some of the respondents mentioned, "I need any help I can find."; "It's really hard. We need help!"; and, "We always need help, but the type of help changes as the disease progresses." Of these, three respondents expressed gratitude for providing the survey. One of the respondents added, "I hope this survey is not just an attempt to gather information but will spark some true reform and more resources for we caregivers and the recipients we serve/help."

Four respondents asked questions. The questions included: how to get help and apply for programs, how to respond or deal when a care recipient has an episode of depression, the Medicare or other government options for helping caregivers, and information regarding respite care.

Conclusion

DSHS ADP, in collaboration with the CDE and the Partnership, created the *2021 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.

The survey fits into Priority Area #7: Importance of Data Collection and Evaluation of the State Plan. ADP, CDE, and the Partnership collaborated with key stakeholders in a coordinated and systematic way to identify and address data needs. The results of this survey help better understand the needs of unpaid caregivers in Texas.

Appendix A. 2021 Texas 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 2019-2023 (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 state plan here: **https://www.dshs.texas.gov/alzheimers/**.

What is the deadline for completing the survey?

Please complete the survey by (insert date). If you have any questions, please contact Lynda Taylor, Alzheimer's Disease Program Coordinator, at **Lynda.Taylor@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 care or assistance.

Caregiver refers to the person who provides 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.

Hover over the underlined terms within the survey for the definitions.

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 (*End survey)*

2. In the past 12 months, have you and/or care recipient lived in Texas?
    a. Yes
    b. No *(End Survey)*

End Survey Message: *Thank you! This survey is intended for individuals who have 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 the care recipient must have lived in Texas in the past 12 months. If you have any questions, please contact Lynda Taylor, Alzheimer's Disease Program Coordinator, at* ***Lynda.Taylor@dshs.texas.gov****.*

Demographics

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?	*(Dropdown)* • Under 18 years old • 18 – 24 years • 25 – 34 years • 35 – 44 years • 45 – 54 years • 55 – 64 years • 65 – 74 years • 75 – 84 years • 85 years or older
What is the care recipient's age? If the care recipient is deceased, please select their age at time of passing.	*(Dropdown)* • Under 18 years old • 18 – 24 years • 25 – 34 years • 35 – 44 years • 45 – 54 years • 55 – 64 years • 65 – 74 years

	- 75 – 84 years - 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 county you and the care recipient live in.

What county do you live in?	*(Dropdown with Texas counties)*
What county does/did the care recipient's live in?	*(Dropdown with Texas counties)*

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

What is the highest level of education that you have completed?	*(Dropdown)* - Less than high school diploma - High school graduate - Vocational/trade/technical school - Some college - Bachelor's degree - Advanced degree
What is the highest level of education the care recipient has completed?	*(Dropdown)* - Less than high school diploma - High school graduate - Vocational/trade/technical school - Some college - Bachelor's degree - Advanced degree

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

What is your gender?	*(Dropdown)* • Male • Female • Non-binary • Other
What is/was the care recipient's gender?	*(Dropdown)* • Male • Female • Non-binary • Other

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

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
    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): (Textbox)
   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

Providing Care to the Care Recipient

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 (*skip to Question 13*)
    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 <u>most</u> 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 Eating and/or drinking
    e. Transportation
    f. Grocery shopping
    g. Housework
    h. Managing finances/paying the bills
    i. Preparing meals
    j. Helping with medication

    k. Managing visits with health care providers (e.g. scheduling appointments, advocating for care recipient, talking to the doctor, etc.)
    l. Seeking services from a legal provider (e.g. drafting a will, drafting a power of attorney, etc.)
    m. Providing companionship
    n. Providing supervision to protect the care recipient from health and safety threats
    o. Managing behavioral issues
    p. Other (please specify) (textbox)

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? (Textbox)

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?
    a. Made health better
    b. Not affected
    c. Made health worse

20. How emotionally 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

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.
    a. Praying
    b. Talking to a professional or spiritual counselor
    c. Talking to my health care provider
    d. Talking to the care_recipient's health care provider
    e. Talking with or seeking advice from friends or relatives
    f. Attending a caregiving support group
    g. Browsing the internet to find information
    h. Reading about caregiving
    i. Exercising or working out
    j. Using stress reduction techniques (e.g. meditation, yoga, breathing exercises, etc.)
    k. Taking medication

l. Using an in-home health service for the care recipient
m. Using respite care
n. Other (please specify): (Textbox)
o. I do/did not engage in any activities to cope with the demands of caregiving

Information and Resources

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.
    a. Strongly agree
    b. Somewhat agree
    c. Neither agree nor disagree
    d. Somewhat disagree
    e. 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.
    a. Diagnosis
    b. Treatment
    c. Stages of the disease
    d. Care planning
    e. Respite care
    f. Financial planning
    g. Legal planning
    h. Community resources (e.g. classes, support groups, local Alzheimer's-related nonprofits)
    i. Long-term care facilities (i.e. nursing homes, assisted living facilities, etc.)
    j. Research opportunities for treatments in development (clinical trials) Caregiver health and wellbeing
    k. Caregiver safety (e.g. methods for preventing and managing aggressive conflicts, etc.)
    l. Safety of care recipient (e.g. safe storage of medication, wander prevention methods, etc.)
    m. Prevention of abuse, neglect and exploitation of care recipient
    n. Driving concerns
    o. Grief (e.g. loss of care recipient, changing role as a daughter, son, spouse, etc.)
    p. End-of-life/hospice
    q. Other (please specify)
    r. None of the above (*Skip to Question 24*)

24. How satisfied or dissatisfied are/were you with information and resources you received on each topic? *(Qualtrics programming will be used to pipe in selections from the previous question)*

	Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied
Diagnosis					
Treatment					

Stages of the disease					
Care planning					
Caregiver health and wellbeing					
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 (clinical trials)					
Caregiver safety					
Safety of care recipient					
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					

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 healthcare provider)

    b. Healthcare 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): (textbox)

26. How satisfied or dissatisfied are/were you with the information and resources you have received from the following sources? *(Qualtrics programming will be used to pipe in selections from the previous question)*

	Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied
Hospital or clinic (without contact with a healthcare provider)					
Healthcare provider					
Community health worker					
Community organization/not-for-profit organization					
Caregiver support group					
Faith-based group					
Government agency					
Media (e.g. internet/online, print, etc.)					
Friends and/or family					

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 care recipient’s care planning with health care providers.						
It is/was easy to find and use community support organizations/service providers to address the care recipient’s needs.						
It is/was easy to find and use health care providers to address the care recipient’s needs.						
An insurance plan navigator helped me and/or the care recipient find and connect with services.						
It is/was easy to find and use respite care services.						

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

Do You Know Other Caregivers That Should Participate?

30. 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: (insert survey link).

End Survey Message: *Thank you for sharing your experiences with us. The summary of survey results will be used to better understand the needs of unpaid caregivers and the effectiveness of activities listed in the Texas*

State Plan for Alzheimer's Disease 2019-2023 (state plan). If you have any questions, please contact Lynda Taylor at ***Lynda.Taylor@dshs.texas.gov****.*

Appendix B: Respondent's County of Residence

Table 8: Frequency and Percent of the Respondent's County of Residence (n=351) *		
Counties	**Frequency (n)**	**Percent (%)**
Tarrant	81	23.1
Harris	37	10.5
Dallas	27	7.7
Nueces	16	4.6
Denton	12	3.4
Parker	12	3.4
Taylor	12	3.4
Galveston	11	3.1
Hood	10	2.8
Wichita	10	2.8
Smith	9	2.6
Bexar	8	2.3
Collin	8	2.3
Montgomery	8	2.3
Travis	8	2.3
Lubbock	7	2.0
Johnson	5	1.4
Angelina	4	1.1
McLennan	4	1.1
Bell	3	0.9
Brazoria	3	0.9
El Paso	3	0.9
Fort Bend	3	0.9
Hidalgo	3	0.9
Jefferson	3	0.9
San Patricio	3	0.9
Aransas	2	0.6
Brazos	2	0.6
Gregg	2	0.6
Kaufman	2	0.6
Navarro	2	0.6
Rusk	2	0.6
Williamson	2	0.6
Wise	2	0.6
Wood	2	0.6
Anderson	1	0.3
Austin	1	0.3
Brown	1	0.3
Cooke	1	0.3
Coryell	1	0.3
Duval	1	0.3

Erath	1	0.3
Gillespie	1	0.3
Haskell	1	0.3
Hays	1	0.3
Hopkins	1	0.3
Houston	1	0.3
Jim Wells	1	0.3
Jones	1	0.3
Kerr	1	0.3
Palo Pinto	1	0.3
San Augustine	1	0.3
San Jacinto	1	0.3
Scurry	1	0.3
Victoria	1	0.3
Walker	1	0.3
Webb	1	0.3
Willacy	1	0.3
Total	**351**	**100.0**

[*] Missing = 9. Missing values were excluded for calculating percentages.

Appendix C: Care Recipients County of Residence

Table 9: Frequency and Percent of the Care Recipient's County of Residence (n=348)

Counties	Frequency (n)	Percent (%)
Tarrant	80	23.0
Harris	37	10.6
Dallas	27	7.8
Nueces	15	4.3
Parker	13	3.7
Galveston	11	3.2
Wichita	11	3.2
Bexar	10	2.9
Denton	10	2.9
Taylor	10	2.9
Hood	9	2.6
Smith	9	2.6
Travis	7	2.0
Collin	6	1.7
Lubbock	6	1.7
Montgomery	6	1.7
Angelina	4	1.1
El Paso	4	1.1
Johnson	4	1.1
McLennan	4	1.1
Not applicable	4	1.1
Bell	3	0.9
Fort Bend	3	0.9
Hidalgo	3	0.9
San Patricio	3	0.9
Brazoria	2	0.6
Brazos	2	0.6
Gregg	2	0.6
Jefferson	2	0.6
Kaufman	2	0.6
Navarro	2	0.6
Palo Pinto	2	0.6
Rusk	2	0.6
Walker	2	0.6
Williamson	2	0.6
Wood	2	0.6
Anderson	1	0.3
Aransas	1	0.3
Austin	1	0.3

Brown	1	0.3
Cooke	1	0.3
Duval	1	0.3
Erath	1	0.3
Gillespie	1	0.3
Grayson	1	0.3
Hays	1	0.3
Hopkins	1	0.3
Jim Wells	1	0.3
Jones	1	0.3
Kerr	1	0.3
Knox	1	0.3
Liberty	1	0.3
Live Oak	1	0.3
San Augustine	1	0.3
San Jacinto	1	0.3
Scurry	1	0.3
Terrell	1	0.3
Terry	1	0.3
Uvalde	1	0.3
Victoria	1	0.3
Webb	1	0.3
Willacy	1	0.3
Wise	1	0.3
Total*	**348**	**100.0**

*Missing = 12. Missing values were excluded for calculating percentages.

General Informational Page

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