

Alzheimer's Disease and Related Dementias Caregiver Survey Results

2021



The Texas Department of State Health Services (DSHS) Alzheimer's Disease Program, 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* to learn more about the experiences of current and former unpaid caregivers and the progress made towards the strategies and activities listed in the State Plan. This one-pager presents the results of the survey.

Survey Sampling Method

The snowball sampling method was used to recruit respondents. The Alzheimer's Disease program emailed the survey to all Partnership members (n=314) and to key stakeholders (n=10). 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 also posted to the DSHS LinkedIn and Twitter social media pages. The survey was open from January 4 to March 5, 2021. A total of 360 respondents were included in the analysis.

Demographics

Respondents

By Gender

82% of respondents identified as female, while 18% identified as male.

By Age

84% of respondents were 55 years old or older.

By Race

81% of respondents were White; 12% were Hispanic/Latino; 4% were Black/African American.

Care Recipient

By Gender

53% of respondents identified the care recipient as female, while 47% were identified as male.

By Age

71% of respondents indicated the care recipient was 75 years old or older.

By Race

82% of respondents indicated the care recipients were White; 11% were Hispanic/Latino; 3% were Black/African American.

Respondent's Profile

Current Work Status

54% of respondents were retired. 21% were employed on a full-time basis and 8% on a part-time basis.

Relationship with Care Recipient

51% of respondents provided unpaid care to their spouse. 38% provided unpaid care to their parents.

Caregiving

Number of People that Provided Care

47% of respondents indicated care recipients had received care from two or more people, including themselves.

Hours per Week

Respondents indicated an average of 67.5 hours per week providing care. 51% reported up to 50 hours on average per week providing care.

Information Needed for Caregiving

50% of respondents indicated they were neutral or disagreed about having had the information and resources needed to provide unpaid care.

Tasks

The vast majority of respondents indicated they helped the care recipient with managing health visits (94%), providing companionship (93%), transportation (92%), managing finances (90%), and helping with medication (89%).

Impact of Caregiving

Work

62% of respondents indicated caregiving has impacted their work in some way. 33% had to go in late, early, or take time off from work.

Financial Stress

86% of respondents indicated some level of financial stress due to caregiving. 64% indicated moderate to extreme financial stress.

Physical and Emotional

99% of respondents indicated some emotional stress from providing care. Of these, 62% reported that providing care was very or extremely emotionally stressful.

Coping Activities

To cope with providing care, respondents reported praying (76%), seeking advice from friends or relatives (68%), reading about caregiving (61%), and browsing the internet for information about caregiving (61%).

Caregiving Information, Resources, and Services

Satisfaction with Places of Information and Resources

Respondents were most satisfied with faith-based groups (95%), caregiver support groups (92%), community or not-for-profit organizations (91%), and community health workers (83%).

Perceived Ease of Finding and Using Services

53% of respondents reported easy-to-find and use health care providers. Respondents reported insurance plan navigators (84%) and respite care services (80%) as the least easy to find and use.

Satisfaction with Alzheimer's Disease and Other Dementia-Related Topics

Respondents were most satisfied with topics on the safety of the care recipient (82%), community resources (82%), prevention of abuse, neglect and exploitation of care recipient (80%), driving concerns (78%), and end-of-life or hospice (78%).

Data Source: 2021 Texas Alzheimer's Disease and Related Dementias Caregiver Survey Report Prepared by Chronic Disease Epidemiology, Health Promotion and Chronic Disease Prevention Section, Texas Department of State Health Services.