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"The Most Difficult 'Job' There Is" – Characteristics and Challenges of Unpaid Caregivers of Persons with Alzheimer's and Related Dementias in Texas

RESEARCH

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ABSTRACT

Objective: To understand the conditions and impact on caregivers providing unpaid care to persons with Alzheimer's disease or related dementias in Texas.

Methods: A cross-sectional survey consisting of 29 questions (n = 358) was distributed to unpaid caregivers (UCs) using snowball sampling.

Results: Respondents were predominantly female (81.7%), age 55+ (83.6%), retired (55.2%), white (83.9%), and were the primary care provider to the care recipient (CR). Caregivers averaged 68 hours/week of care. Numerous challenges were reported, including increased emotional stress (62.3%), negative impact on work (61.7%), declining physical health (62.0%), and increased financial stress (34.1%). Respondents were asked to provide open-ended feedback regarding their caregiver experiences. Topics include emotional and physical health, caregiving's impact on their professional and personal lives, and the availability of resources.

Discussion: Caregiving can be extremely burdensome to a caregiver's health, work, and finances. Future studies focusing on the challenges and needs among UCs in Texas are warranted.

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INTRODUCTION

Alzheimer's disease (AD) is a progressive brain disease that slowly destroys memory, thinking ability, and the capacity to carry out daily activities. The later stages of the disease are severe enough to require comprehensive, long-term care (Alzheimer's Association, 2022). More than one in nine Americans, aged 65 or older has Alzheimer's disease, and that number is expected to double by 2050 (Alzheimer's Association, 2022). Currently, there is no cure to remedy the disease.

Unpaid caregivers (UCs), also known as family caregivers, are individuals who provide care or assistance to family or friends, without pay (Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion, 2022). In 2019, the Texas Department of State Health Services (DSHS) estimated that 4.4 million people in Texas are UCs, of which 24% reported that they care for those living with Alzheimer's disease, dementia, or other cognitive impairment disorder as the main or secondary condition (Alvarado-Torres & Cooper, 2021).

UCs fill a vital role in the growing necessity to provide care for people with Alzheimer's disease and other dementias. UCs must balance and manage the needs of the care recipient (CR) and other family members with their own physical, mental, and emotional health. Caregivers face a variety of challenges, including the costs of long-term care or memory-care facilities or in-home paid caregiving, legal and financial considerations, and loss of employment (Alzheimer's Association, 2022). The quality of care that a CR receives depends largely on the health and capacity of UCs, who must manage the responsibility of caregiving with their social, professional, and other familial obligations.

Although there are nationwide studies that provide a comprehensive profile of UCs in the United States (Alzheimer's Association, 2022; AARP; National Alliance for Caregiving, May 2020), data on the needs particular to UCs in Texas is limited. Thus, this study aimed to understand the conditions of and impact on caregivers providing unpaid care to persons with Alzheimer's disease or related dementias in Texas. To achieve this, the DSHS Alzheimer's Disease Program (ADP) collaborated with DSHS Chronic Disease Epidemiology Branch (CDE) and the Texas Alzheimer's Disease Partnership (a volunteer-based group composed of members from diverse backgrounds and expertise from state, local, and community organisations), academic and research institutions, the health care sector, and family members of individuals affected by AD and other dementias, to develop the Texas Alzheimer's Disease and Related Dementias Caregiver Survey. The survey was developed to identify baseline metrics for UCs' demographics, perceived needs, and challenges. Results are intended to inform future programmatic efforts responsive to the specific needs of UCs in Texas, as well as identify areas where future research is needed.

METHODS

SURVEY DEVELOPMENT

ADP, CDE, and (Partnership) members collaborated to develop data collection tools. Initial questions were identified by Partnership members during an in-person meeting in November 2019, with additional calls organised in February 2020 to further refine questions and develop a survey dissemination plan. After consensus was built, the survey was programmed into Qualtrics (Qualtrics, 2020) and distributed to Partnership members who pilot-tested the survey. Subsequent feedback and suggestions, as well as new questions, were then incorporated. The final version of the survey consisted of 29 questions on UCs' experiences providing care to a relative or friend with AD or other forms of dementia. A final voluntary open-ended question asking for any additional feedback on the experience of caregiving was added at the end of the survey to gather additional contextual information.

SAMPLING STRATEGY

Initial participants were identified and recruited to the survey via an email link shared by Partnership members in January 2021. The survey link was also posted to DSHS' organizational LinkedIn and Twitter social media pages in February 2021 to increase dissemination. After an initial round of recruitment, snowball sampling was used to recruit additional respondents. Snowball sampling is a non-probabilistic sampling technique in which initial survey respondents recruit or are asked to recommend other respondents within the same target population (Allen, 2017). To increase survey reach, respondents were encouraged to forward the survey to other UCs using the following message: "We are relying on partner organizations and respondents to help us reach all individuals that provide/provided unpaid care or assistance to individuals with AD and other dementias in Texas. If you know a caregiver who should receive this survey, please forward them the following survey link."

DATA COLLECTION AND ANALYSIS

The survey was open from January 4th, 2021, to March 5th, 2021. During this period, 443 individuals began the survey. Of these, 85 respondents did not meet inclusion criteria–they were not currently, nor in the previous 12 months, providing unpaid care or assistance to a relative or friend with AD or other dementia; and/or, they had not lived in Texas during the past 12 months. A total of 358 respondents were included in the final analysis.

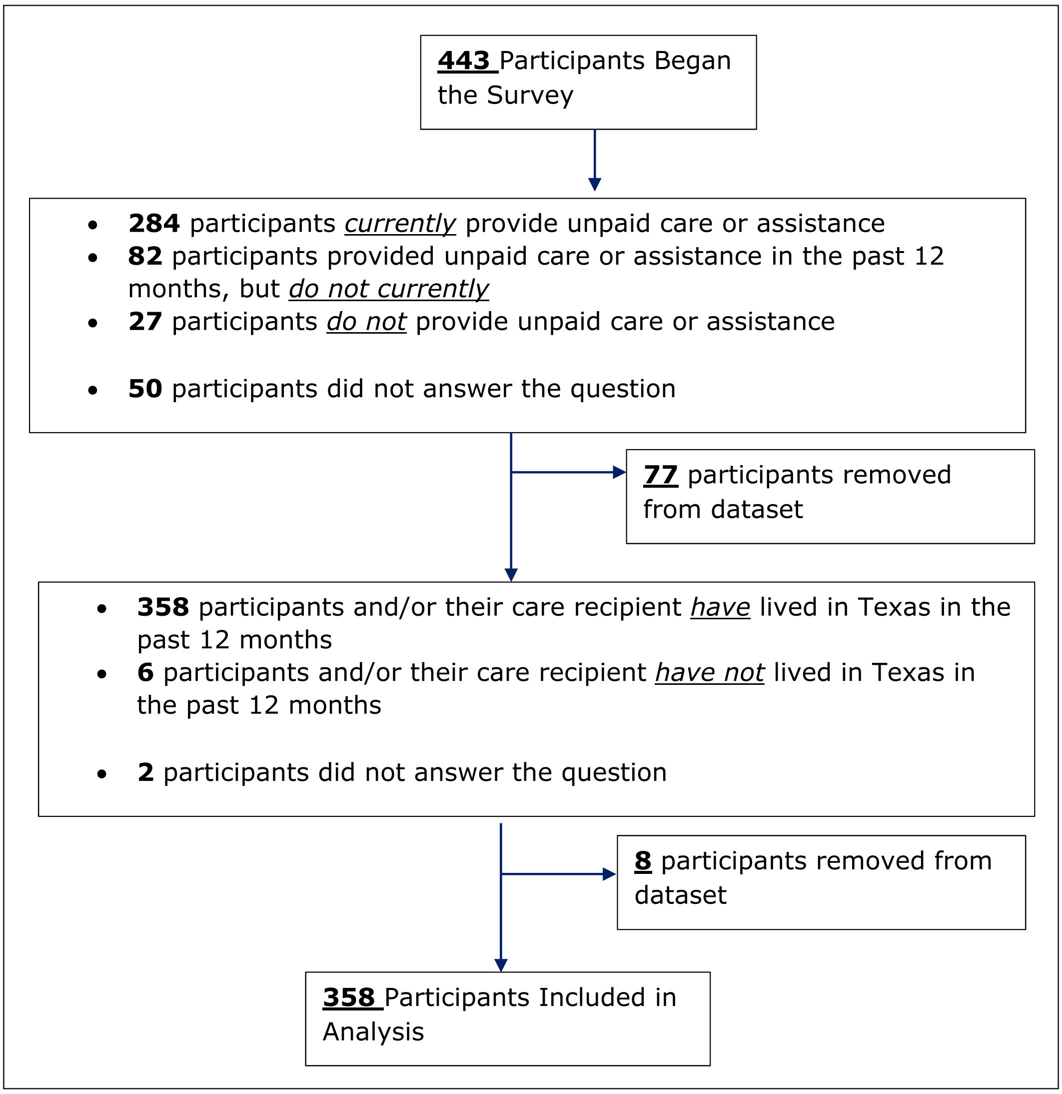

Figure 1 Presents the participant flow through the study, including where participants exited or continued with the survey.

Figure 1 showcases a full description of the participant flow. Some respondents did not answer every question; these incomplete responses were included in the analysis. Descriptive statistics for this analysis were generated using SAS 9.4 software (SAS Institute Inc, 2013). SAS was also used to conduct Chi-Square testing in order to measure the association between select demographic characteristics and categorical survey responses. Fisher's Exact test was utilized when dealing with small cell counts with complementary non-directional tests ($p < 0.05$ as the threshold for statistical significance).

Open ended responses were exported from Qualtrics (Qualtrics, 2020), cleaned and formatted in Microsoft Excel, and analysed using Atlas.ti (GmbH, 2022). Two members of the research team conducted independent inductive coding and met on multiple occasions to discuss coding agreement and resolve differences in code interpretation and application. Qualitative results were then grouped thematically, summarised, and paired with quantitative results of similar topics to provide further contextual background.

RESULTS

DEMOGRAPHIC INFORMATION

There was a significant association between UCs and their identified gender, such that there was a higher proportion of females (81.7%) versus males (18.1%) ($p < 0.001$). The majority of UCs were White (83.9%) and 55 years or older (83.6%). Most commonly, respondents had completed more than high school education (91.4%) and were retired (55.2%). See Table 1 for full demographic information of survey respondents.

Caregivers were asked about their relationship with the CR. We found significant associations between relationship and gender ($p < 0.05$). Among female and male UCs, the most frequent relationship to the CR was their spouse, 46.6% and 71.4%, respectively (both $p < 0.001$). When comparing female and male UCs, the odds of female UCs taking care of their mothers is 2.24 times greater than male UCs (95% CI: 1.12–4.50), and the odds of male UCs taking care of their spouses is 2.86 times greater than female UCs (95% CI: 1.58–5.18). Statistically significant differences in the relationship

	MALE (n = 63)		**FEMALE (n = 285)**		**TOTAL (n = 348)**	
	n	**%[a]**	**n**	**%[b]**	**n**	**%[c]**
Age (years) (n = 347)						
25–34[≠]	0	0.0	3	1.1	3	0.9
35–44[≠]	3	4.8	12	4.2	15	4.3
45–54	3	4.8	36	12.7	39	11.2
55–64[*]	13	20.6	99	35.0	113	32.6
65–74	21	33.3	84	29.7	105	30.3
75–84[*]	19	30.2	42	14.8	61	17.5
≥85[≠]	4	6.3	7	2.5	11	3.2
Race/Ethnicity[d] (n = 348)						
White	56	88.9	236	83.1	292	83.9
Hispanic/Latino	3	4.8	38	13.4	42	12.1
Black/African American[≠]	1	1.6	12	4.2	13	3.7
Asian/Pacific Islander[≠]	2	3.2	4	1.4	6	1.7
Native American/American Indian[≠]	0	0.0	2	0.7	2	0.6
Other[≠]	3	4.8	4	1.4	7	2.0
Education Level (n = 349)						
Less than Highschool[≠]	1	1.6	5	1.7	6	1.7
Highschool graduate	4	6.3	19	6.7	23	6.6
Vocational/trade/technical school[≠]	2	3.2	11	3.9	13	3.7
Some college	11	17.4	75	26.3	87	24.9
Bachelor's degree	20	31.8	93	32.6	113	32.4
Advanced degree	25	39.7	82	28.8	107	30.7
Current Employment Status (n = 344)						
Retired[*]	47	74.6	143	51.1	190	55.2
Employed full-time[*]	7	11.1	66	23.6	74	21.5
Employed part-time	6	9.5	22	7.9	28	8.1
Unemployed – Not looking for work	2	3.2	28	10.0	30	8.7
Unemployed – Looking for work[≠]	0	0.0	8	2.9	8	2.3
Other[≠]	1	1.6	13	4.6	14	4.1
Relationship to the CR (n = 347)						
Spouse[*]	45	71.4	132	46.6	177	51.0
Mother[*]	11	17.4	91	32.2	103	29.7
Father	2	3.2	27	9.5	29	8.4
Mother-in-law[≠]	2	3.2	8	2.8	10	2.9
Grandmother[≠]	0	0.0	7	2.5	7	2.0
Sibling[≠]	2	3.2	5	1.8	7	2.0
Non-relative[≠]	1	1.6	6	2.1	7	2.0
Other[≠]	0	0.0	6	2.1	6	1.7
Father-in-law[≠]	0	0.0	1	0.4	1	0.3

(Contd.)

	MALE (n = 63)		FEMALE (n = 285)		TOTAL (n = 348)	
	n	%[a]	n	%[b]	n	%[c]
Describes themselves as a caregiver (n = 344)						
Yes	56	88.9	240	85.7	297	86.3
No	7	11.1	40	14.3	47	13.7
Provides/ed most of the unpaid care to the CR (n = 159)						
Yes	23	88.5	108	81.8	132	83.0
No	3	11.5	24	18.2	27	17.0
Including themselves, how many people provide/have provided unpaid care to the CR (n = 335)						
1 person	35	57.4	142	52.0	177	52.8
2 people	15	24.6	59	21.6	74	22.1
3 people	6	9.8	41	15.0	47	14.0
4 people≠	1	1.6	16	5.9	17	5.1
5 or more people≠	4	6.6	15	5.5	20	6.0

Table 1 Unpaid Caregiver Demographic Information.

Note: Missing values were excluded when calculating percentages. Not all respondents provided answers to every question. Totals may not add up to 100% due to rounding and/or missing values within demographic categories.

* Refers to statistically significant difference between females and males according to the p-value cutoff of <0.05.

≠ Statistical significance between genders was not able to be determined as there was an insufficient sample size (<20 total respondents).

[a] Percentages refer to the percent of male respondents within that response category among all total male participants which responded to the survey question.

[b] Percentages refer to the percent of female respondents within that response category among all total female participants which responded to the survey question.

[c] Percentages refer to the percent of total respondents within that response category among all total participants which responded to the survey question.

[d] Respondents could select as many responses as applied.

between UC and CR were also observed across racial and ethnic identities. White UCs, of all genders, most frequently provided care to a spouse (56%, $p < 0.001$) and had 3.73 times (95% CI: 1.95-7.13) the odds of their non-white counterparts (25.5%, $p < 0.001$) caring for their spouses. When all non-white UCs were combined (any respondent who did not identify as white), the most common relationship between the UC and the CR was mother (50.9%, $p < 0.001$); additionally, the odds of the CR being a mother among non-white UCs are 3.04 times (95% CI: 1.68–5.49) as much compared to their white counterparts ($p < 0.001$). Table 2 presents full information regarding the relationship between UCs and CRs.

IMPACT ON WORK

Respondents were asked about their employment status, as well as the impact of caregiving on their professional lives. In a typical week, UCs spent an average of 67.8 hours on caregiving, while 30% of UCs indicated that they provided care 168.0 hours per week, or 24 hours of care per day. Male UCs were more likely to be retired (74.6%) than employed either full- or part-time (20.6%). While female UCs were also more likely to be retired (51.1%), a larger proportion of female UCs were still working full- or part-time while caregiving (31.5%). The odds of being retired were 2.90 times higher (95% CI: 1.57–5.35) for male UCs (74.6%) than their female (51.1%) counterparts ($p < 0.001$), whereas female UCs have 2.47 times the odds of being employed full-time (95% CI: 1.07–5.67) than their male counterparts (23.6% vs. 11.1%; $p = 0.029$). Additionally, the odds of white UCs, of all genders, to be retired were 2.56 times (95% CI: 1.40–4.69) greater than their non-white counterparts (58.1% vs 35.2%, $p < 0.002$). Significant associations were also found between gender and changes to UC employment status. The odds of female UCs giving up work entirely (33.9%) to focus on caregiving are 3.46 times (95% CI: 1.16–10.3) higher than their male (12.9%) counterparts, ($p = 0.019$) while a higher proportion of male UCs (25.8%) switched from full- to part-time work than females (11.6%) ($p = 0.046$). No significant changes were observed across race/ethnic identity regarding changes to work status. Table 3 provides full results for the impact of caregiving on UC's work.

	CARE RECIPIENT'S RELATIONSHIP TO THE UNPAID CAREGIVER								
	GRAND-MOTHER	**MOM**	**MOTHER-IN-LAW**	**DAD**	**FATHER-IN-LAW**	**SPOUSE**	**SIBLING**	**NON-RELATIVE**	***p*-VALUE[a]**
Gender									
Female n = 283(%)	7 (2.5%)	91 (32.2%)	8 (2.8%)	27 (9.5%)	1 (0.4%)	132 (46.6%)	5 (1.8%)	6 (2.1%)	<0.001
Male n = 63(%)	0	11 (17.5%)	2 (3.2%)	2 (3.2%)	0	45 (71.4%)	2 (3.2%)	1 (1.6%)	<0.001
p-value[b]	--	0.021	--	0.099	--	<0.001	--	--	N/A
Race/Ethnicity									
White n = 291(%)	4 (1.4%)	74 (25.4%)	10 (3.4%)	22 (7.6%)	1 (0.3%)	163 (56.0%)	6 (2.1%)	6 (2.1%)	<.0001
Black n = 13(%)	1 (7.7%)	6 (46.2%)	1 (7.7%)	1 (7.7%)	0	3 (23.1%)	0	1 (7.7%)	--
p-value[c]	--	0.112	--	1.000	--	0.0196	--	--	N/A
Hispanic n = 42(%)	3 (7.1%)	20 (47.6%)	1 (2.4%)	7 (16.7%)	0	9 (21.4%)	1 (2.4%)	0	<.0001
p-value[d]	--	0.003	--	0.073	--	<.0001	--	--	N/A
Other[e] n = 14(%)	0	9 (64.3%)	0	0	0	5 (35.7%)	0	0	--
p-value[f]	--	0.003	--	0.610	--	0.136	--	--	N/A
Multi-Race Excluding White[g] n = 55(%)	3 (5.5%)	28 (50.9%)	0	7 (12.7%)	0	14 (25.5%)	1 (1.8%)	1 (1.8%)	<.0001
p-value[h]	--	0.0001	--	0.194	--	<.0001	--	--	N/A

Table 2 Unpaid Caregiver Relationship to Care Recipient.

-- Results are statistically unreliable to report, as total sample number tested is less than 20.

N/A: Non-applicable.

a: Refers to results from the Chi-Square Test for Equal Proportions; using an alpha value of 0.05, p-values can be interpreted as significant if $p < 0.05$. This indicates that at least one proportion is not equal to the others and the sample distribution is significantly different among relationships within each demographic category.

b-d, f, h: Refers to results from Chi-Square Test of Association between demographic groups and relationship; using an alpha value of 0.05, p-values can be interpreted as significant if $p < 0.05$. This indicates that there is a statistically significant association between the selected demographic and having a particular relationship with the care recipient. All race/ethnicity groups were compared to White participants.

e: The "other" race/ethnicity group is comprised of Asian/Pacific Islanders, Native American/American Indians, and those who selected "Other" in response to the question, "Please indicate your race/ethnicity."

g: "Multi-Race Excluding White" is also referred to as "Nonwhite" throughout the article. This includes all individuals who did not select "White" when providing their race/ethnicity identity.

	CURRENT EMPLOYMENT STATUS OF UNPAID CAREGIVERS						
	FULL-TIME	**PART-TIME**	**UNEMPLOYED, BUT LOOKING**	**UNEMPLOYED, NOT LOOKING**	**RETIRED**	**OTHER**	***p*-VALUE**[a]
Gender							
Female n = 280(%)	66 (23.6%)	22 (7.9%)	8 (2.9%)	28 (10.0%)	143 (51.1%)	13 (4.6%)	<.0001
Male n = 63(%)	7 (11.1%)	6 (9.5%)	0	2 (3.2%)	47 (74.6%)	1 (1.6%)	<.0001
p-value[b]	0.029	0.663	--	0.083	<.001	--	N/A
Race/Ethnicity							
White n = 289(%)	58 (20.1%)	21 (7.3%)	4 (1.4%)	20 (6.9%)	168 (58.1%)	18 (6.2%)	<.0001
Black n = 13(%)	4 (30.8%)	1 (7.7%)	3 (23.1%)	1 (7.7%)	4 (30.8%)	0	--
p-value[c]	0.313	1.000	--	1.000	0.051	--	N/A
Hispanic n = 41(%)	12 (29.3%)	4 (9.8%)	2 (4.9%)	5 (12.2%)	15 (36.6%)	3 (7.3%)	<.001
p-value[d]	0.178	0.532	--	0.216	0.009	--	N/A
Other[e] n = 14(%)	2 (14.3%)	4(28.6%)	1 (7.1%)	1 (7.1%)	5 (35.7%)	1 (7.1%)	--
p-value[f]	1.000	0.021	--	1.000	0.098	--	N/A
Multi-Race Excluding White [g] n = 54(%)	16 (29.6%)	6 (11.1%)	4 (7.4%)	6 (11.1%)	19 (35.2%)	3 (5.6%)	<.001
p-value[h]	0.117	0.405	--	0.270	0.002	--	N/A

-- Results are statistically unreliable to report, as total sample number tested is less than 20.

N/A: Non-applicable.

a: Refers to results from the Chi-Square Test for Equal Proportions; using an alpha value of 0.05, p-values can be interpreted as significant if $p < 0.05$. This indicates that at least one proportion is not equal to the others and the sample distribution is significantly different among employment responses within each demographic category.

b-d, f, h: Refers to results from Chi-Square Test of Association between demographic groups and employment; using an alpha value of 0.05, p-values can be interpreted as significant if $p < 0.05$. This indicates that there is a statistically significant association between the selected demographic and having a particular employment status. All race/ethnicity groups were compared to White participants.

e: The "other" race/ethnicity group is comprised of Asian/Pacific Islanders, Native American/American Indians, and those who selected "Other" in response to the question, "Please indicate your race/ethnicity."

g: "Multi-Race Excluding White" is also referred to as "Nonwhite" throughout the article. This includes all individuals who did not select "White" when providing their race/ethnicity identity.

IN YOUR EXPERIENCE WORKING AND PROVIDING CARE TO THE CARE RECIPIENT, DID YOU EVER HAVE TO DO ANY OF THE FOLLOWING?			
GENDER			
CHANGES RELATED TO WORK	**FEMALE N = 189(%)**	**MALE N = 31(%)**	***p*-VALUE**[a]
Accommodate Schedule	114 (60.3%)	20 (64.5)	0.657
Leave of Absence	45 (23.8%)	8 (25.8%)	0.810
Switch to Part-time	22 (11.6%)	8 (25.8%)	0.046
Give up Work Entirely	64 (33.9%)	4 (12.9%)	0.019
Lose Job Benefits	15 (7.9%)	2 (6.5%)	--
Turn Down Promotion	12 (6.4%)	3 (9.7%)	--
Early Retirement	49 (25.9%)	11 (35.5%)	0.268
Other	24 (12.7%)	2 (6.5%)	0.546

Note: Percentages within genders will not sum to 100%, as participants were able to select more than one response option.

-- Results are statistically unreliable to report as total sample number tested is less than 20.

a: Refers to results from Chi-Square Test of Association between gender and change to work responses; using an alpha value of 0.05, p-values can be interpreted as significant if $p < 0.05$. This indicates that there is a statistically significant association between the two gender identities and the change to work the participant needed to do while providing care.

(Contd.)

IN YOUR EXPERIENCE WORKING AND PROVIDING CARE TO THE CARE RECIPIENT, DID YOU EVER HAVE TO DO ANY OF THE FOLLOWING?									
RACE/ETHNICITY									
CHANGES RELATED TO WORK	**WHITE n = 176(%)**	**BLACK n = 11(%)**	***p*-VALUE[a]**	**HISPANIC n = 32(%)**	***p*-VALUE[b]**	**OTHER[c] n = 9(%)**	***p*-VALUE[d]**	**MULTI-RACE EXCLUDING WHITE[e] n = 44(%)**	***p*-VALUE[f]**
Accommodate Schedule[g]	111 (63.1%)	5 (45.5%)	0.338	20 (62.5%)	0.951	6 (66.7%)	1.000	23 (52.3%)	0.189
Leave of Absence	43 (24.4%)	2 (18.2%)	1.000	9 (28.1%)	0.657	4 (44.4%)	0.235	11 (25.0%)	0.938
Switch to Part-Time	25 (14.2%)	0	0.365	3 (9.4%)	0.583	4 (44.4%)	0.035	5 (11.4%)	0.623
Give Up Work Entirely	55 (31.3%)	4 (36.4%)	0.744	9 (28.1%)	0.725	1 (11.1%)	0.281	12 (27.3%)	0.608
Lose Job Benefits	15 (8.5%)	2 (18.2%)	--	1 (3.1%)	--	1 (11.1%)	--	2 (4.6%)	--
Turn Down Promotion	13 (7.4%)	0	--	1 (3.1%)	--	2 (22.2%)	--	2 (4.6%)	--
Early Retirement	48 (27.3%)	1 (9.1%)	0.293	9 (28.1%)	0.921	2 (22.2%)	1.000	11 (25.0%)	0.761
Other	21 (11.9%)	0	0.616	5 (15.6%)	0.564	1 (11.1%)	1.000	5 (11.4%)	0.917

Note: Percentages within race/ethnicity and between race/ethnicities will not sum to 100%, as participants were able to select more than one response option and more than one race/ethnicity.

-- Results are statistically unreliable to report as total sample number tested is less than 20.

a-b, d, f: Refers to results from Chi-Square Test of Association between the selected race/ethnicities and change to work responses; using an alpha value of 0.05, p-values can be interpreted as significant if $p < 0.05$. This indicates that there is a statistically significant association between the race/ethnicity identity and White participants responses to the relevant change to work.

c: The “other” race/ethnicity group is comprised of Asian/Pacific Islanders, Native American/American Indians, and those who selected “Other” in response to the question, “Please indicate your race/ethnicity.”

e: “Multi-Race Excluding White” is also referred to as “Nonwhite” throughout the article. This includes all individuals who did not select “White” when providing their race/ethnicity identity.

g: Participant reported they needed to go in late, early, or take time off from work while providing care to the care recipient.

Table 3 Employment Status of Unpaid Caregivers.

In open-ended responses, participants further discussed the impact of caregiving on their professional careers. Most frequently, UCs discussed a no-win choice of either leaving the workforce to provide care or needing to find expensive in-home or other long-term care options for the CR. For those respondents who did end up placing the CR in a long-term or memory-care facility, most expressed dissatisfaction with both the quality and cost of the care provided. However, participants cited no other options available to them.

> 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. *(Female UC to grandmother, 45–54 years old)*

> … my mother requires 24/7 supervision. If we did not have the financial resources for her to live in a memory care environment, I would have to retire early and spend every waking moment supervising her when I am at the peak of my earning and professional career. The memory care environment is very imperfect, expensive, and unsatisfactory, but there are no other options that I know of. I don’t feel like we have any choices. *(Female UC to mother, 65–74 years old)*

FINANCIAL STRESS

Participants were asked to rate the financial stress associated with caregiving on a scale from “Not at all” to “Extremely” stressful. The majority (85.6%) attributed some level of financial stress associated with providing care to the CR. More than half the participants (51.6%) indicated slight to moderate financial stress, and one-third (34%) of respondents indicated feeling very or extremely financially stressed. We found significant associations between gender and financial stress. The odds of female UCs being very or extremely financially stressed were 3.27 times (95% CI: 2.41–4.39) greater than their male counterparts (38.1% vs 15.9%, $p < 0.001$). Reported financial stress also differed among select racial and ethnic identities, with a higher proportion of black UCs reporting their financial stress linked to caregiving as very or extremely stressful (69.2%) than their white (32.3%) and Hispanic (38.1%) counterparts ($p < 0.05$ for both). Table 4 presents full financial stress results.

Finances represented a significant source of stress for UCs in open-ended responses. UCs cited financial difficulties related both to the cost of in-home or facility-based care and the financial losses associated with completely or partially leaving the workforce. UCs frequently spoke of having to use their own funds to support care for the CR, with few available financial support options. Additionally, respondents noted that any respite or relief available to them had financial costs attached, limiting their usefulness and availability.

UCs also expressed frustration with current requirements around qualification for additional assistance, particularly Medicaid. Many respondents expressed frustration that they were deemed to have "too much money" to qualify for assistance, despite the fact that they could not afford regular care. As one participant described their situation,

> The cost of respite care and in-home services makes these options very limited to the CR who is neither wealthy nor qualifies for Medicaid assistance. *(Female UC to mother, 55–64 years old)*

PHYSICAL AND EMOTIONAL HEALTH

Over two in five respondents (42.1%) described their physical health as good, and one-third (33.5%) of respondents described their physical health as very good or excellent (Table 4). Two in ten respondents (24.3%) described their health as fair or poor. However, 62% of respondents indicated that providing care or assistance to the CR worsened their physical health. No statistically significant differences were observed across gender or race/ethnicity when respondents were asked if their health had worsened since providing care to the CR.

Caregiving demands an intense time commitment and can necessitate a complete restructuring of the UC's life, often leading to negative physical and emotional consequences. Previously simple activities that required no future planning, such as shopping, resting, or sleeping were often cited as activities that now required scheduling and pre-planning, and carried financial costs in order to have another person supervise or watch the UC. The 24/7 nature of CR supervision often took a toll on UCs in their responses.

> Just because they are asleep one minute it doesn't mean that in the next minute they aren't [sic] up and wandering. *(Female UC to spouse, 55–64 years old)*

> As an unpaid UC for an individual with dementia is a 24-hour a day, 7-day a week job. If you get any relief/respite, you have to pay for it out-of-pocket to have help come into the home… to provide care while you go do shopping, errands, etc. *(Female UC to mother, 65–74 years old)*

HOW FINANCIALLY STRESSFUL IS/WAS PROVIDING CARE TO THE CARE RECIPIENT FOR YOU?				
	NOT AT ALL OR SLIGHTLY	MODERATELY	VERY OR EXTREMELY	*p*-VALUE[a]
	n (%)	n (%)	n (%)	
Gender				
Female n = 283	96 (33.9%)	79 (27.9%)	108 (38.2%)	0.0002
Male n = 63	31 (49.2%)	22 (34.9%)	10 (15.9%)	0.0005
p-value[b]	0.023	0.269	0.0007	N/A
Race/Ethnicity				
White n = 291	114 (39.2%)	83 (28.5%)	94 (32.3%)	<.0001
Black n = 13	1 (7.7%)	3 (23.1%)	9 (69.2%)	--
p-value[c]	0.021	1.000	0.013	N/A
Hispanic n = 42	14 (33.3%)	12 (28.6%)	16 (38.1%)	0.381
p-value[d]	0.467	0.995	0.456	N/A
Other[e] n = 14	4 (28.6%)	8 (57.1%)	2 (14.3%)	--
p-value[f]	0.426	0.034	0.239	N/A
Multi-Race Excluding White[g] n = 55	13 (23.6%)	19 (34.6%)	23 (41.8%)	0.016
p-value[h]	0.028	0.369	0.171	N/A

Table 4 Financial Stress associated with caregiving.

-- Results are statistically unreliable to report, as total sample number tested is less than 20.

N/A: Non-applicable.

a: Refers to results from the Chi-Square Test for Equal Proportions; using an alpha value of 0.05, p-values can be interpreted as significant if $p < 0.05$. This indicates that at least one proportion is not equal to the others and the sample distribution is significantly different among financial stress responses within each demographic category.

b-d, f, h: Refers to results from Chi-Square Test of Association between demographic groups and financial stress; using an alpha value of 0.05, p-values can be interpreted as significant if $p < 0.05$. This indicates that there is a statistically significant association between the selected demographic and having a particular financial stress response. All race/ethnicity groups were compared to White participants.

e: The "other" race/ethnicity group is comprised of Asian/Pacific Islanders, Native American/American Indians, and those who selected "Other" in response to the question, "Please indicate your race/ethnicity."

g: "Multi-Race Excluding White" is also referred to as "Nonwhite" throughout the article. This includes all individuals who did not select "White" when providing their race/ethnicity identity.

Almost all respondents (99.4%) indicated some level of emotional stress linked to caregiving. Table 5 presents full results regarding respondents' physical and emotional health. Notably, over half of the respondents (62.3%) indicated that providing care was either very or extremely emotionally stressful. The odds of female UCs being very or extremely emotionally stressed while providing care were 2.0 times (95% CI: 1.15–3.50) greater than their male counterparts (65.3% vs. 48.4%, p = 0.013). No statistically significant associations were observed between race/ethnicity and emotional stress.

UCs reported significant qualitative impact on their mental and physical health due to their caregiving responsibilities. UCs discussed continual feelings of anxiety, emotional and physical fatigue, social isolation, and a prevailing sadness about the situation. UCs discussed how the difficulty in providing care encompassed all aspects of their lives, and that this often led to feelings of “just hanging on” or “barely getting by”–a sense of exhaustion that permeates many of the offered responses.

A consideration for UC’s emotional health was a feeling of social isolation linked to their caregiving responsibilities. UCs repeatedly mentioned the disappearances of social lives, an inability to see friends and family, the shifting or inevitable changing of relationships with a family member as the disease progressed, and an isolating feeling of having no one in their social circle who understands the challenges associated with caregiving.

> You become a different person, no one understands what you are going through but other caregivers. *(Female UC to spouse, 55–64 years old)*

Another uniquely difficult experience associated with caregiving for a person with Alzheimer’s or other dementia is the knowledge that the person receiving care will inevitably forget who family and loved ones are, and that the person they used to be will disappear. As one UC put it,

> It’s harder than anyone could ever imagine to watch the disappearance of your spouse as you already knew them. *(Female UC to spouse, 65–74 years old)*

HOW EMOTIONALLY STRESSFUL IS/WAS PROVIDING CARE TO THE CARE RECIPIENT FOR YOU?

	NOT AT ALL OR SLIGHTLY	MODERATELY	VERY OR EXTREMELY	*p*-VALUE[a]
	n (%)	n (%)	n (%)	
Gender				
Female n = 274	23 (8.4%)	72 (26.3%)	179 (65.3%)	<.0001
Male n = 62	12 (19.4%)	20 (32.3%)	30 (48.4%)	0.0004
p-value[b]	0.011	0.340	0.013	N/A
Race/Ethnicity				
White n = 291	26 (8.9%)	76 (26.1%)	181 (62.2%)	<.0001
Black n = 12	1 (8.3%)	3 (25.0%)	8 (66.7%)	--
p-value[c]	1.000	1.000	1.000	N/A
Hispanic n = 41	6 (14.6%)	9 (22.0%)	26 (63.4%)	0.004
p-value[d]	0.258	0.567	0.946	N/A
Other[e] n = 14	3 (21.4%)	6 (42.9%)	5 (35.7%)	--
p-value[f]	0.138	0.215	0.033	N/A
Multi-Race Excluding White[g] n = 53	9 (17.0%)	16 (30.2%)	28 (52.8%)	0.0031
p-value[h]	0.075	0.538	0.125	N/A

-- Results are statistically unreliable to report, as total sample number tested is less than 20.

N/A: Non-applicable.

a: Refers to results from the Chi-Square Test for Equal Proportions; using an alpha value of 0.05, p-values can be interpreted as significant if p<0.05. This indicates that at least one proportion is not equal to the others and the sample distribution is significantly different among emotional stress responses within each demographic category.

b-d, f, h: Refers to results from Chi-Square Test of Association between demographic groups and emotional stress; using an alpha value of 0.05, p-values can be interpreted as significant if p<0.05. This indicates that there is a statistically significant association between the selected demographic and having a particular emotional stress response. All race/ethnicity groups were compared to White participants.

e: The “other” race/ethnicity group is comprised of Asian/Pacific Islanders, Native American/American Indians, and those who selected “Other” in response to the question, “Please indicate your race/ethnicity.”

g: “Multi-Race Excluding White” is also referred to as “Nonwhite” throughout the article. This includes all individuals who did not select “White” when providing their race/ethnicity identity.

(Contd.)

HOW HAS/DID PROVIDING CARE TO THE CARE RECIPIENT AFFECTED YOUR PHYSICAL HEALTH?				
	MADE BETTER n (%)	NOT AFFECTED n (%)	MADE WORSE n (%)	*p*-VALUE[a]
Gender				
Female n = 274	3 (1.1%)	96 (35.0%)	175 (63.9%)	<.0001
Male n = 62	3 (4.8%)	26 (41.9%)	33 (53.2%)	<.0001
p-value[b]	0.079	0.308	0.119	N/A
Race/Ethnicity				
White n = 283	3 (1.1%)	103 (36.4%)	177 (62.5%)	<.0001
Black n = 12	0	2 (16.7%)	10 (83.3%)	--
p-value[c]	--	0.224	0.222	N/A
Hispanic n = 41	3 (7.3%)	15 (36.6%)	23 (56.1%)	0.0006
p-value[d]	--	0.981	0.427	N/A
Other[e] n = 8	0	5 (62.5%)	3 (37.5%)	--
p-value[f]	--	0.152	0.267	N/A
Multi-Race Excluding White[g] n = 53	3 (5.7%)	19 (35.9%)	31 (58.5%)	<.0001
p-value[h]	--	0.940	0.577	N/A

-- Results are statistically unreliable to report, as total sample number tested is less than 20.

N/A: Non-applicable.

a: Refers to results from the Chi-Square Test for Equal Proportions; using an alpha value of 0.05, p-values can be interpreted as significant if $p < 0.05$. This indicates that at least one proportion is not equal to the others and the sample distribution is significantly different among physical health change responses within each demographic category.

b-d, f, h: Refers to results from Chi-Square Test of Association between demographic groups and physical health change; using an alpha value of 0.05, p-values can be interpreted as significant if $p < 0.05$. This indicates that there is a statistically significant association between the selected demographic and having a particular physical health change response. All race/ethnicity groups were compared to White participants.

e: The “other” race/ethnicity group is comprised of Asian/Pacific Islanders, Native American/American Indians, and those who selected “Other” in response to the question, “Please indicate your race/ethnicity.”

g: “Multi-Race Excluding White” is also referred to as “Nonwhite” throughout the article. This includes all individuals who did not select “White” when providing their race/ethnicity identity.

Table 5 Emotional and Physical Health.

DISCUSSION

The purpose of this study was to learn more about the current experiences of UCs for people with AD and other dementias in the state of Texas. The findings in this study indicate important differences between different populations of UCs, as well as a strong need for additional financial, institutional, and social support to allow UCs to continue providing quality care for CRs.

Our study population generally reflected the age, gender, and relationship to the CR that is seen throughout the literature – older (55 years +), female, and caring for either a spouse or a parent (Greenwood, Pound, Brearley, & Smith, 2019; Di Lorito, et al., 2021; Hernández-Padilla, et al., 2021; Edwards, Bouldin, Taylor, Olivari, & McGuire, 2020). While female caregivers represent the majority of the UC population, and the number of male UCs is likely to continue to grow as the population ages, significant differences in care responsibilities and how individuals respond to the responsibilities of caregiving continue to exist (Friedemann & Buckwalter, 2014). Perceptions of stress, expected responsibilities, and approaches to managing stress all differ across genders. A prior study of husbands providing spousal care found that male caregivers experienced caregiving through a “work” lens, focusing on essential tasks, and blocking emotional reactions (Calasanti & Kind, 2007). This difference is also observed in our study, with female caregivers more likely to experience significant emotional stress than their male counterparts, while several male caregivers noted that they struggled to find information or resources they felt were designed for their experiences as a male caregiver. Differences across racial or ethnic identities have also been observed in prior studies. A meta-analysis of 116 studies of family caregiving found that black caregivers experienced lower levels of caregiver burden and depression than their white counterparts; and that Hispanic caregivers experienced higher rates of depression than white UCs (Pinquart & Sorensen, 2005). However, this analysis did not specifically isolate studies of caregiving for AD or other dementias, potentially not accounting for the unique characteristics of caregiving for AD and other dementias. Our results observed no significant differences between racial or ethnic groups and emotional stress. However, potential differences should not be discounted. Previous studies have suggested that factors such as co-residence with family members, cultural beliefs on providing care to family members or requesting assistance, and the ability to access and afford formal care, play important roles in UCs experiences, and are likely to differ across different racial or ethnic groups (Friedman, Shih, Langa, & Hurd, 2015).

Caregiving is a time-intensive responsibility that can vary in intensity based on the severity of the CR's disease and its progression. This study found that UCs employment was impacted due to providing care to the CRs, consistent with other findings in the larger body of literature. This finding is consistent with the report by NAC and the AARP (AARP; National Alliance for Caregiving, May 2020), where 61.0% of UCs indicated that providing care had impacted their work in some way. In our study, women were more likely to give up work than men, mirroring results from other studies examining gender differences in caregiving (Hernández-Padilla, et al., 2021). In general, female caregivers bear the brunt of caregiving responsibility (Friedman, Shih, Langa, & Hurd, 2015). Notably, the present study found that the average hours of care per week the UCs provided to be 67.5 hours. This finding is somewhat higher than reported in nationwide and statewide reports (AARP; National Alliance for Caregiving, May 2020; Alzheimer's Association, 2022). Possible explanations for this difference could be the number of spousal caregivers in our sample, or the variability in how the number of hours of care is provided across different sources. For instance, the authors of the report by NAC and AARP (AARP; National Alliance for Caregiving, May 2020) maxed the number of hours of care provided in a week to 77 hours, equivalent to 14 hours per day, and then predicted the average hours of care in a week by using an imputation model. This study capped the reported hours of care per week provided to 168, equivalent to 24 hours per day, and calculated the average.

Limitations or restrictions on a UC's ability to work inevitably lead to financial stress, a finding seen in previous work and repeated here. A five-year follow-up study of informal caregivers showed that UCs of someone with Alzheimer's or other dementia experience higher financial strain when compared to caring for someone who does not have the condition (Skufca & Rainville, 2021). The study observed that 78.0% of UCs report having out-of-pocket expenses and that, on average, 26.0% of their income goes to caregiving activities. According to their study, UCs of someone with Alzheimer's or other dementia have an out-of-pocket expense of $8,978 per year, compared with UCs of someone without those conditions who have out-of-pocket expense of $6,663 per year (Gaugler, 2022). Costs associated with the care of someone with Alzheimer's or other dementias are estimated to range from 159 to 215 billion dollars a year (Friedman, Shih, Langa, & Hurd, 2015), and there is extensive evidence that dementia is a significant cause of increased healthcare costs for older adults; Medicare beneficiaries with a chronic illness and dementia account for three times greater Medicare costs than those individuals without dementia (Gaugler, 2022). As lower marriage and birth rates continue to shrink the pool of potential caregivers for an aging population (Choi, et al., 2021), the question of the financial implications of unpaid caregiving will continue to grow in importance.

UCs in this study expressed significant emotional and mental stressors associated with the task of caregiving. The emotional and mental stressors associated with caregiving noted in this survey – such as exhaustion or fatigue, social isolation, feelings of burnout, and severe stress – have been reported extensively throughout the literature (Di Lorito, et al., 2021; Stirling, et al., 2010; Greenwood, Pound, Brearley, & Smith, 2019). Frequently, this is referred to as 'caregiver burden' (Chiao, Wu, & Hsiao, 2015; Richters, Melis, van Exel, Olde Rikkert, & van der Marck, 2017), or 'caregiver overload' (Hernández-Padilla, et al., 2021), which typically presents as a state of emotional exhaustion or stress fatigue. This was a frequent theme in the open-ended responses of our survey, and largely reflected the emotional and mental burden UCs reported experiencing in numerous studies across diverse contexts, genders, and ethnic or racial identities (Isik, Soysal, Solmi, & Veronese, 2019; Chiao, Wu, & Hsiao, 2015; Friedman, Shih, Langa, & Hurd, 2015; Richters, Melis, van Exel, Olde Rikkert, & van der Marck, 2017; Friedemann & Buckwalter, 2014; Di Lorito, et al., 2021). Much of this burden associated with caregiving is linked to the fact that symptoms associated with AD or other dementias – anxiety, agitation, aggressive behaviours, sleep disturbances – are closely related to caregiver burden and are associated with negative UC outcomes in terms of health, quality of life, and social isolation (Isik, Soysal, Solmi, & Veronese, 2019). Previous studies have also shown that caregiver burden increases as AD or other dementias progress, with caregivers of people with dementia exhibiting higher levels of unmet needs and lower levels of use of supportive services (Stirling, et al., 2010).

The feeling of loss associated with caring for a spouse or parent with Alzheimer's or dementia has also been reported in other studies, particularly among those UCs who provide care to their spouses (Di Lorito, et al., 2021; Greenwood, Pound, Brearley, & Smith, 2019). One element of caregiving that was not explicitly discussed in this survey, but is worth examining when considering our results, is the differences in emotional stress and burden between spousal caregivers and adult child caregivers of parents. Previous studies have observed high levels of depression and caregiver burden in spousal caregivers when compared to other family member caregivers (Friedemann & Buckwalter, 2014), and reported more emergency room visits and were more likely to seek treatment for anxiety than comparison spouses (Elliot, Burgio, & Decoster, 2010). These comparatively negative outcomes for spousal caregivers are unsurprising, given the unique considerations of the relationship between spouses, and align with open-ended responses seen in our study that discussed the emotional pain around the changing relationship between spouses linked to the disease.

LIMITATIONS AND STRENGTHS

The findings of this study should be viewed through the lens of several limitations, notably the representativeness of the study population. While the survey was distributed through a statewide network of partners, there is significant underrepresentation along ethnic, racial, and geographic lines. This is most notable concerning the Hispanic/Latino population in Texas, which has the second largest Hispanic/Latino population in the United States (U.S. Department of Health and Human Services Office of Minority Health, 2022). Additionally, 40% of Texans reporting being of Hispanic/Latino origin (United States Census Bureau, 2021). Any description of the UC population is incomplete without greater representation from this group. Future studies on this topic should make greater efforts to reach these populations. This could be achieved through strategic outreach to relevant stakeholders, as well as making the survey available in multiple languages and via multiple distribution channels. The survey was also disseminated during the COVID-19 pandemic, potentially impacting responses on use of services discontinued or suspended due to infection prevention and control measures, changes in work status, or impact on physical and emotional health. Another limitation is that the severity of the disease and its impact on the burden of the UC was not an explicit consideration of the survey, despite the fact that disease severity is a significant predictor of UC burden (Kaizik, et al., 2017).

Despite these limitations, this study has notable strengths. First, the Partnership's input and engagement in the development of the survey was pivotal in ensuring that the questions were appropriate for the targeted survey population. For example, the use of a "warm hand-off" in survey distribution (Partnership members distributing the survey to their network of UCs) conveyed an increased survey response and completion as opposed to other survey distribution strategies. Second, the sample size was relatively large (n = 360), considering this is the first survey conducted in Texas that aimed to capture the experiences of UCs providing care for people with AD or related dementia.

SUGGESTIONS FOR FUTURE RESEARCH

More data are needed to better understand the challenges and needs among UCs in Texas based on race and ethnicity, gender, and relationship to the CR. Future research should build on the current survey results and focus on increasing responses from populations and geographic areas of the state that were underrepresented in this study. Future research should also endeavour to explore differences in outcomes across UC and CR relationships, as well as across gender and age of caregivers.

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COMPETING INTERESTS

The authors have no competing interests to declare.

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REFERENCES

AARP; National Alliance for Caregiving. 2020. *Caregiving in the United States 2020*. Online Report. DOI: https://doi.org/10.26419/ppi.00103.001

Allen, M. 2017. *The SAGE Encyclopedia of communication research methods*. Thousand Oaks, California, United States. DOI: https://doi.org/10.4135/9781483381411

Alvarado-Torres, R and **Cooper, M.** 2021. *Texas Alzheimer's disease and related dementias caregiver survey report.* Texas Department of State Health Services. Available from: https://www.dshs.texas.gov/sites/default/files/uploadedFiles/Content/Prevention_and_Preparedness/alzheimers/pdf/2021%20Texas%20Alzheimer's%20Disease%20and%20Related%20Dementias%20Caregiver%20Survey%20Report.pdf.

Alzheimer's Association. 2022. *Special report – more than normal aging: understanding mild cognitive impairment.* Available from: https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf.

Calasanti, T and **Kind, N.** 2007. Taking 'women's work' 'like a man': Husband's experiences of care work. *The Gerontologist*, 47(4). DOI: https://doi.org/10.1093/geront/47.4.516

Chiao, C, Wu, H and **Hsiao, C.** 2015. Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Review*, 62(3): 340–350. DOI: https://doi.org/10.1111/inr.12194

Choi, JJ, Heisler, M, Norton, EC, Langa, KM, Cho, T-C and **Connell, CM.** 2021. Family care availability and implications for informal and formal care used by adults with dementia in the US. *Health Affairs*, 40(9): 1359–1367. DOI: https://doi.org/10.1377/hlthaff.2021.00280

Di Lorito, C, Bosco, A, Godfrey, M, et al. 2021. Mixed-methods study on caregiver strain, quality of life, and perceived health. *Journal of Alzheimer's*, 80: 799–811. DOI: https://doi.org/10.3233/JAD-201257

Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion. 2022. *For caregivers, family and friends*. (C. f. Control, Editor). Available from: https://www.cdc.gov/aging/caregiving/index.htm.

Edwards, VJ, Bouldin, ED, Taylor, CA, Olivari, BS and **McGuire, LC.** 2020. Characteristics and health status of informal unpaid caregivers – 44 states, District of Columbia, and Puerto Rico, 2015–2017. *Morbidity and Mortality Weekly Report*, 69(7): 183–190. DOI: https://doi.org/10.15585/mmwr.mm6907a2

Elliot, A, Burgio, L and **Decoster, J.** 2010. Enhancing caregiver health: findings from the resources for enhancing Alzheimer's caregiver health II intervention. *Journal of the American Geriatrics Society*, 58(1): 30–37. DOI: https://doi.org/10.1111/j.1532-5415.2009.02631.x

Friedemann, M-L and **Buckwalter, KC.** 2014. Family caregiver role and burden related to gender and family relationships. *Journal of Family Nursing*, 20(3). DOI: https://doi.org/10.1177/1074840714532715

Friedman, EM, Shih, RA, Langa, KM and **Hurd, MD.** 2015. US prevalence and predictors of informal caregiving for Dementia. *Health Affairs,* 34(10). DOI: https://doi.org/10.1377/hlthaff.2015.0510

Gaugler, JE. 2022. Unpaid dementia caregiving: a policy and public health imperative. *Public Policy and Aging Report*, 32(2): 51–57. DOI: https://doi.org/10.1093/ppar/prac002

GmbH, At. 2022. Atlas ti. Berlin, Germany. Available from: https://atlasti.com/.

Greenwood, N, Pound, C, Brearley, S and **Smith, R.** 2019. A qualitative study of older informal carers' experiences and perceptions of their caring role. *Maturitas*, 124: 1–7. DOI: https://doi.org/10.1016/j.maturitas.2019.03.006

Hernández-Padilla, JM, Ruiz-Fernández, MD, Granero-Molina, J, Ortiz-Amo, R, López Rodríguez, MM and **Fernández-Sola, C.** 2021. Perceived health, caregiver overload and perceived social support in family caregivers of patients with Alzheimer's: Gender differences. *Health and Social Care in the Community,* 29(4): 1001–1011. DOI: https://doi.org/10.1111/hsc.13134

Isik, AT, Soysal, P, Solmi, M and **Veronese, N.** 2019. Bidirectional relationship between caregiver burden and neuropsychiatric symptoms in patients with Alzheimer's disease: A narrative review. *International Journal of Geriatric Psychiatry*, 34(9): 1326–1334. DOI: https://doi.org/10.1002/gps.4965

Kaizik, C, Caga, J, Camino, J, O'Conner, CM, McKinnon, C, Oyebode, JR … Mioshi, E. 2017. Factors underpinning caregiver burden in Frontotemporal dementia differ in spouses and their children. *Journal of Alzheimer's Disease*, 56(3): 1109–1117. DOI: https://doi.org/10.3233/JAD-160852

Pinquart, M and **Sorensen, S.** 2005. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *Gerontologist*, 45(1): 90–106. DOI: https://doi.org/10.1093/geront/45.1.90

Qualtrics. 2020. Qualtrics XM. Provo, Utah, United States. Available from: https://www.qualtrics.com.

Richters, A, Melis, RJ, van Exel, NJ, Olde Rikkert, MG and **van der Marck, MA.** 2017. Perseverance time of informal caregivers for people with dementia: construct validity, responsiveness and predictive validity. *Alzheimer's Research and Therapy*, 9(1). DOI: https://doi.org/10.1186/s13195-017-0251-0

SAS Institute Inc. 2013. SAS Software. Cary, North Carolina, United States. Available from: https://www.sas.com/en_us/home.html.

Skufca, L and **Rainville, C.** 2021. Caregiving out-of-pocket costs study. *AARP Research*. DOI: https://doi.org/10.26419/res.00473.001

Stirling, C, Andrews, S, Croft, T, Vickers, J, Turner, P and **Robinson, A.** 2010. Measuring dementia carers' unmet need for services – an exploratory mixed method study. *BMC Health Services Research*, 10(1). DOI: https://doi.org/10.1186/1472-6963-10-122

U.S. Department of Health and Human Services Office of Minority Health. 2022. *Profile: Hispanic/Latino Americans*. Retrieved from Minority Population Profiles: https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlID=64.

United States Census Bureau. 2021. *Texas: 2020 Census Bureau*. Retrieved from Texas Added Almost 4 Million People in Last Decade: https://www.census.gov/library/stories/state-by-state/texas-population-change-between-census-decade.html.

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