Investigating Mental Health Outcomes for Informal Caregivers Before and During the COVID-19 Pandemic

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I. Abstract

Caregiving, particularly informal caregiving, has been identified as a risk factor for depression and other adverse mental health outcomes, which may have been especially impacted by the COVID-19 pandemic. Here, I investigate informal caregiver mental health outcomes before and during the pandemic, focusing on disparities between those providing care for Alzheimer's and dementia patients and caregivers for other conditions. I use data collected by the Behavioral Risk Factor Surveillance System, a nationally representative survey conducted by the Centers for Disease Control and Prevention. My analytic samples include 66,894 caregivers (2015-2022) and 33,320 caregivers (2019-2022) — in 2019, a question was added to the caregiver module allowing respondents to specify whether their care recipient had ADRD in addition to another illness or disability. I estimated OLS and logistic regression models to predict number of poor mental health days and likelihood of experiencing any or frequent poor mental health days in the past 30 days. Providing informal care for a person with ADRD was associated with an additional 0.53 days of poor mental health on average ($p<0.05$) and 1.16 greater odds of experiencing at least one poor mental health day in fully adjusted models ($p<0.01$). Results also show that the magnitude of the disparities in caregiver mental health outcomes remained largely unchanged before and during the COVID-19. This calls attention to the greater need for public resources and support to address the high toll of caregiving seen among those providing care for individuals with Alzheimer's and dementia.

Keywords: Alzheimer's disease and related dementias, informal caregivers, mental health, COVID-19 pandemic

II. Introduction

Over one in five Americans — about 53 million people — provide informal, unpaid care for a personal relation who has a chronic illness or disability or is of older age ("Caregiving for Family and Friends," 2019). Caregiving, particularly informal caregiving, has been identified as a risk factor for depression and other adverse mental health outcomes, which also contribute to poor physical health, such as impaired immune function, and increased risk of mortality (Chakraborty et al., 2023). The need for informal caregiving in the U.S. is likely to rise, especially as the ratio of family caregivers to those in need of care is projected to drop from 7.2 in 2010 to 4.1 by 2030 and 2.9 by 2050 (Redfoot et al., 2013).

The extent to which caregiving impacts the well-being of the caregiver varies by the type of care provided and the specific condition or illness of the care recipient (Grunfeld et al., 2004). Caring for patients with some conditions requires long, intensive hours, such as in late-stage dementia, where activities of daily living (ADLs; e.g., bathing, dressing, eating) are severely impaired, while for others, the demands on informal caregivers are typically lower because the care recipient remains able to perform most ADLs. Caregivers providing care for individuals with Alzheimer's disease and related dementias (ADRD) spend more hours, on average, providing care each year compared to caregivers for individuals with other conditions, such as gastrointestinal and lung cancers (Demirbas et al., 2023). This number is likely much higher, however, as caregiving hours in this study were reported only for those caring for friends or relatives with an official dementia diagnosis. Prior work demonstrates that individuals may exhibit dementia signs and associated cognitive changes up to nine years prior to receiving an official diagnosis (Swaddiwudhipong et al., 2022).

Due to these challenges, 60% of informal caregivers for individuals with ADRD rated the emotional stress of caregiving as "high" or "very high" in 2017, and nearly half of dementia caregivers described providing care as "highly stressful" compared to 35% of caregivers of people without dementia ("2017 Alzheimer's Facts and Figures," 2017). Many studies on the mental health of caregivers for individuals with dementia, however, rely on small samples or recruit in clinical settings and thus are unable to speak to the mental health toll of caregiving at the population level and gauge the full extent of caregiving effects on mental health (Brodaty & Donkin, 2009).

Most recently, researchers have suggested that the well-being of caregivers may have been especially impacted by the COVID-19 pandemic (Carbone et al., 2021; Gaigher et al., 2022). The World Health Organization reported that the pandemic triggered a 25% increase in worldwide prevalence of depression and anxiety (Kupcova et al., 2023) due to stress of contracting COVID-19 and public health measures like travel restrictions, social distancing, and quarantines that increased feelings of loneliness. While numerous studies have explored the profound impact of the pandemic on the mental and emotional well-being of various subpopulations of individuals, including dementia patients (Gaigher et al., 2022) and those with chronic illnesses (Fekadu et al., 2021), few have investigated the pandemic's effect on caregivers, particularly informal caregivers. Informal caregivers, especially those who care for vulnerable older adults, were likely to be at least temporarily disconnected from the individual and community resources they rely on for assistance, such as respite services and social support circles, leisure time outside the home for personal interests and activities, and medical service providers available to work directly in the home (Bristol et al., 2021). It is therefore essential to examine caregiver health both independently and in conjunction with care recipient well-being (Wennberg et al., 2023) to identify ways to best support informal caregivers, those for whom they provide care, and the population overall.

My study investigates informal caregiver mental health outcomes before and during the COVID-19 pandemic, focusing on disparities between those providing care for ADRD patients and those who provide care for patients with other conditions. I use high-quality, nationally representative data.

I ask, first: Did informal caregivers for individuals with ADRD have a higher risk of poor mental health than caregivers for individuals with other conditions? Second, did the magnitude of the disparity in poor mental health outcomes between caregivers for people with ADRD and caregivers for people with other conditions change during the pandemic?

My results contribute to the sparse body of literature on caregiver well-being and enrich our understanding of caregiver needs, particularly those of caregivers for individuals with ADRD. Currently, over 55 million people worldwide are living with dementia — a number expected to double every 20 years, reaching 78 million in 2030 ("Alzheimer's Disease International," 2021). As the number of care recipients increases, so too will the demands on informal care providers. It is therefore essential to understand the effects of caregiving on caregiver mental well-being to make strides toward improving overall population health.

III. Background

a. The Growing Burden of Dementia

Over six million Americans and 50 million people worldwide are living with Alzheimer's disease, with numbers projected to double by 2050 (Alzheimer's Association, 2023). Alzheimer's disease and related dementias (ADRD) are characterized by the progressive degeneration of cognitive functions, which hinder an individual's ability to engage in normal activities and relationships (DeTure & Dickson, 2019). In the later stages of the disease, individuals often require assistance with activities of daily living, including bathing, eating, and dressing. Research has shown that informal caregivers for people living with dementia (PLWD) — individuals who provide unpaid care for family members or close friends — experience a unique caregiving burden due to the nature of ADRD. The average number of caregiving hours for ADRD surpasses those for other conditions, including gastrointestinal and lung cancers by as many as 1,000 hours annually (Langa et al., 2001; Fisher et al., 2011; Espinola et al., 2023)

In tandem with cognitive decline, PLWD may also exhibit behavioral problems, including agitation and physical or verbal aggression (Maggio et al., 2021). Such characteristics can exacerbate health outcomes for caregivers. Studies have shown that behavioral problems of the care recipient can predict emotional strain and depressive symptoms of the caregiver (Fisher et al., 2011). Adding to the experienced stress and anxiety of informal caregivers for ADRD is that most of these caregivers are female, who often have household responsibilities on top of providing care to a family member, and lack an in-depth understanding of dementia (Aledeh et al., 2020).

b. Effects of COVID-19 on Informal Caregivers

The frequency of informal care provision and toll on caregiver mental health among certain populations were reported to have increased during the COVID-19 pandemic (Ngamasana et al., 2023). The pandemic was declared a public health emergency on January 31, 2020, by the U.S. Department of Health and Human Services. Standard public health measures were implemented to curb the spread of the virus, including travel restrictions, quarantines of confirmed cases and close contacts, and the closure of many public-facing services. These measures, though effective in reducing case numbers (Talic et al., 2021), also had profound impacts on mental and emotional well-being for those of all age groups in the U.S. — including both PLWD and their caregivers (Chyu et al., 2022). Research has found that older adults with dementia were at higher risk of worse psychiatric symptoms and “severe” behavioral problems due to pandemic-induced social isolation and lockdown measures (Numbers & Brodaty, 2021).

c. Unique Challenges for ADRD Caregivers

Recent studies with small samples of caregivers in Italy and India found that ADRD caregivers in these national contexts experienced greater stress and anxiety due to the COVID-19 pandemic (Maggio et al., 2021; Rajagopalan et al., 2022). One cause of this heightened mental burden was a general fear of contracting COVID-19 itself, particularly at earlier stages of the pandemic when little was known about the short- and long-term effects of the virus (Dellafiore et al., 2022). Uncertainty surrounding COVID-19 was found to cause more severe anxiety among caregivers during the first lockdown (23%) than the second (16%), suggesting that greater familiarity made subsequent COVID-19 containment measures easier to cope with and adjust to (Bakker et al., 2022). Further, resilience — defined as attributes and actions that allow the maintenance of health despite adversity — is known to be a protective factor for some of the negative effects of pandemic measures. Researchers found that COVID-19 control measures and pandemic-induced changes to daily life challenged resiliency, increasing caregiver stress (Geshcke et al., 2022).

Adverse mental health outcomes for small samples of Argentinian and Italian caregivers during the pandemic were attributed to the absence of caregiving support resources and the social isolation induced by the pandemic's lockdown periods, social distancing, and other public safety measures (Cohen et al., 2020; Mazzi et al., 2020). Caregivers in Italy reported that quarantine induced a "significant change" in their lifestyle, resulting in a reduction of time devoted to personal interests and an increase in intrafamilial psychological conflicts (Bussè et al., 2022). Worse outcomes were also identified for younger caregivers, who experienced the effects of social isolation more strongly due to greater social and community involvement prior to the pandemic (Losada et al., 2022).

Research found that caregiver stress also increased (Cagnin et al., 2020) in association with deteriorating behavioral and neuropsychiatric symptoms in PLWD (Losada et al., 2022; Rainero et al., 2021). Research has attributed increased social isolation and reduction of available social and physical activity community resources as primarily responsible for this perceived decline in the functional and cognitive capabilities of PLWD (Losada et al., 2022; Gaigher et al., 2022; Barguilla, 2020), with 26% and 37% of a sample of Italian PLWD showing new behavioral symptoms and a decline in motor function, respectively (Rainero et al., 2021). The pandemic also brought along additional challenges for informal caregivers, including learning to navigate telehealth for their care recipients and experiencing reduced family contact, labor issues, and economic losses (Tam, 2021).

d. Demographic, Economic, and Geographic Disparities

Stress and anxiety among caregivers further varied by demographic and economic factors that made some caregivers more susceptive to adverse mental health outcomes. More educated caregivers reported significantly lower overall anxiety and depression scores compared to their less educated counterparts (Mazzi et al., 2020). Similarly, those with self-reported “comfortable” income levels exhibited significantly lower depression and anxiety compared to those under financial burden (Seibert et al., 2022). Meanwhile, non-Hispanic Black and female dementia caregivers were found to be at greater risk for care burden due to racial disparities in dementia caregiving and the COVID-19 pandemic. Black dementia caregivers provided significantly more help with activities of daily living and a significantly higher level of emotional support to their care recipients than other groups and therefore reported the highest perceived care burden and worst psychological well-being during the pandemic compared to Black caregivers for people with other conditions and White caregivers for those with and without dementia (Moon et al., 2022). Sex was found to predict caregiver health outcomes, with worse long-term depression, anxiety, and sleep quality for female caregivers one year after the onset of the COVID-19 pandemic (Bussè et al., 2022).

Notably, despite extensive evidence supporting the presence of a unique, increased burden among caregivers for people with ADRD, some studies found no change in caregiver stress (Seibert et al., 2022) or even an increase in positive experiences among ADRD caregivers (Elugbadebo et al., 2022). Limitations within these findings, however, include that caregivers who were more severely impacted by COVID-19 — and thus experienced greater depression and anxiety — may have opted not to participate in the study, and that these samples may not have been subject to the same extent of pandemic-era restrictions that induced social isolation and adverse mental health outcomes. For instance, citizens in Nigeria, where Elugbadebo and colleagues conducted their research, were still allowed to visit public markets during the pandemic, and another study found low compliance with pandemic restrictions in the city of Ilorin, Nigeria (Shodunke et al., 2022).

e. State of Existing Research

Existing investigations into the experiences of caregivers for people with ADRD before and during the pandemic, however, remain limited in scope and sample size. These studies, for the most part, have been conducted in Europe, Asia, and South America, with few analyzing specifically the informal caregiving population for people with ADRD in the U.S. Though many pandemic experiences were similar across nations, the U.S. also instituted specific policies and practices on a timeline distinct from other governments, warranting additional investigation. Of those studies conducted in the U.S., research has shown that care partners of older adults were mostly female, White, and married and reported moderate stress and psychological impact of the COVID-19 pandemic (Marziliano et al., 2022). Another study conducted in the U.S. identified disparities in mental health outcomes, with anxiety and depressive disorder symptoms exhibiting greater prevalence among caregivers who were younger, Hispanic or Latino, living with disabilities, and engaging in moderate-to-high intensity caregiving (Czeisler et al., 2021). Many of these U.S.-based studies, however, rely on small sample sizes not reflective of the national population.

f. Study Objectives

This investigation adds to existing literature by, first, exploring the mental health outcomes of caregivers for individuals with ADRD as compared to other types of caregivers in the years prior and during the COVID-19 pandemic using nationally representative data. It answers whether informal caregivers for individuals with ADRD experienced more poor mental health days or a greater likelihood of experiencing any or frequent poor mental health days than their counterpart caregivers for other conditions. Our work further fills gaps in existing research on the pandemic's effects by elucidating the mental health outcomes of caregivers for dementia and how the pandemic may have disproportionately affected the mental health of certain caregivers based on the type of caregiving and condition of care recipient.

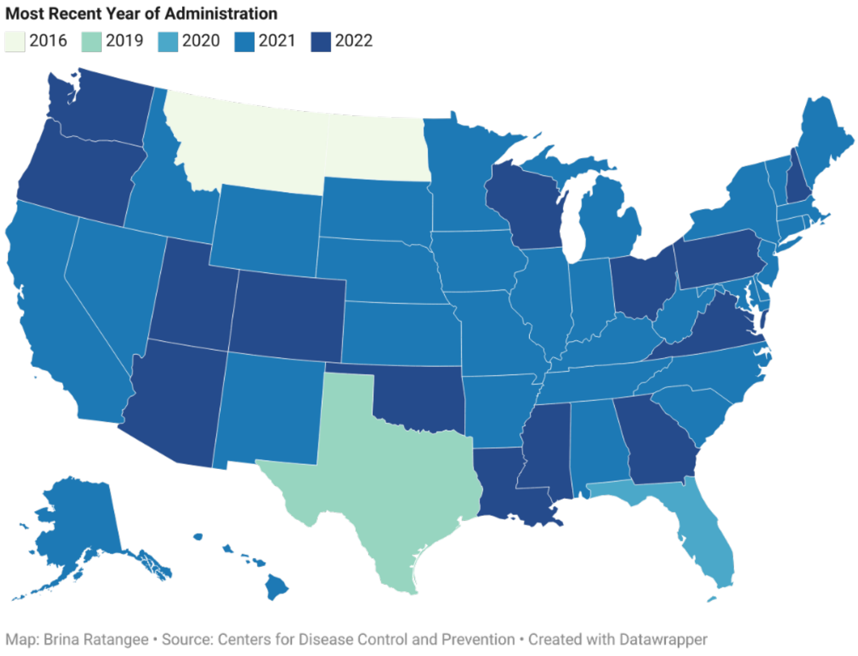
IV. Methods

a. Data

I used data collected between 2015 and 2022 by the Behavioral Risk Factor Surveillance System (BRFSS), a nationally representative survey conducted by the Centers for Disease Control and Prevention together with state administrators. The survey collects data on U.S. adults' health-related behaviors, chronic health conditions, health service use, and sociodemographic characteristics (*Centers for Disease Control*, 2022). The BRFSS collects data in all 50 states, the District of Columbia, and three U.S. territories and interviews over 400,000 community-dwelling adults aged 18 and older each year. Conducted in both English and Spanish, the BRFSS selects respondents through Random Digit Dialing on landlines and, beginning in 2011, cell phones. An optional caregiving module was introduced to the BRFSS dataset in 2015, though these questions have not been asked by every state, district, and territory since (Figure 1; 24 in 2015, 21 in 2016, 12 in 2017, five in 2018, 10 in 2019, eight in 2020, 39 in 2021, and 15 in 2022).

Figure 1

Most Recent Year of BRFSS Caregiver Module Administration by State, 2015-2022. Guam and the U.S. Virgin Islands have never asked the optional caregiver module, and Puerto Rico last asked it in 2022.



This module was further expanded in 2019 by including a question asking caregivers if their care recipient also had cognitive impairment, in addition to another illness or condition. Prior to 2019, the questionnaire only allotted space for one health condition to be selected. This yielded potentially incomplete information, as caregivers may provide care to individuals with more than one major health problem, illness, or disability (*Centers for Disease Control and Prevention*, 2022).

b. Measures

The BRFSS measured mental health status using the following question: "Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?" I measured poor mental health using three indicators: the total poor mental health days in the past 30 days (5.78 days for 2015-22; 6.24 for 2019-22); whether any poor mental health was experienced in the past 30 days (46% for 2015-22; 49% for 2019-22); and whether poor mental health was experienced for more than half of the past 30 days (39% for 2015-22; 40% for 2019-22) for those who experienced at least one day of poor mental health.

Specifying the variables in this way helps one begin to understand how caregiving status can impact mental health. Positive associations for the “any poor mental health” indicator would suggest that caregiving status is a factor in whether an individual is likely to experience a day of poor mental health at all, while associations for the “frequent poor mental health” indicator suggests either that caregiving carries a severe mental health toll or that caregivers are already predisposed to poor mental health, changing the way in which interventions are created and implemented.

c. Main Predictors

Caregivers were identified by whether BRFSS respondents answered “Yes” or “No” to the question: “During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?” I categorized informal caregivers by their responses to the question: “What is the main health problem, long-term illness, or disability that the person you care for has?" For the 2015-2022 data, caregivers who responded with "Dementia and other Cognitive Impairment Disorders" were identified as caring for individuals with ADRD. For the 2019-2022 data, caregivers who responded with "Alzheimer's disease, dementia or other cognitive impairment disorder" were identified as caring for individuals with ADRD. Those who responded with another condition — arthritis/rheumatism, asthma, cancer, chronic respiratory conditions, developmental disabilities, diabetes, heart disease, HIV, mental illnesses, other organ failure or diseases, substance use or addiction disorders, injuries, old age, or other — but who also answered "Yes" to the question "Does the person you care for also have Alzheimer's disease, dementia, or other cognitive impairment disorder?" were categorized as caring for individuals with ADRD and another condition.

I constructed two main predictor variables. First, used in the analysis of data collected from 2015 to 2022, is an indicator of whether a caregiver was providing care to a person with ADRD (9.8%). Second, used in the analysis of data collected from 2019 to 2022, is a categorical variable classifying caregivers as providing care to a person with ADRD and another condition or conditions (12.5%), ADRD only (10.6%), or another condition only (76.9%). The total number of informal caregivers surveyed was 119,396 between 2015-2022 and 72,169 between 2019-2022.

d. Other Measures

I constructed other sociodemographic variables, which I used as controls in regression models.

Demographic variables: Race/ethnicity was categorized as Non-Hispanic White, Non-Hispanic Black, Hispanic, and non-Hispanic other, the latter of which contained all BRFSS respondents who selected Asian, Native Hawaiian or Other Pacific Islander, American Indian or Alaska Native, Mixed Race, or Some other group. I created a categorical variable for age, designating the groups as 18-29, 30-44, 45-59, 60-74, and 75+ years old. Marital status was categorized as married or partnered – including those who responded to the BRFSS questionnaire with member of an unmarried couple, divorced/widowed/separated, and never married.

Economic variables: I created a categorical variable to indicate whether the respondent's household has children under age 18. Education was categorized as some/less than HS, HS graduate, some college, and college graduate; all BRFSS respondents who indicated that they had never attended school or only attended grades 1-8 or 9-11 were designated as some/less than high school. The income variable was classified into the categories less than $25K, $25K to $49,999, $50K to $74,999, and $75K or more. I categorized employment as employed for wages, unemployed, not in labor force, and retired – those who responded as being employed for wages or self-employed were grouped into the first category, while those who responded as being a homemaker, a student, or unable to work were grouped into the third.

I created a binary variable for the self-assessed health rating, assigning respondents who indicated excellent, very good, or good health as 0 and those who indicated fair or poor health as 1. In addition to controlling for year of data collection, I created a time indicator for before versus during the COVID-19 pandemic. All responses provided before March 11, 2020, were classified as before the pandemic, while those provided after were categorized as during the pandemic.

e. Analytic Sample

Inclusion criteria for the analytic sample were: individuals must have self-identified as informal caregivers and not have any missing data on any control or outcome variables.

I excluded caregivers from the four states, territories, and districts — District of Columbia, Delaware, Montana, and New Hampshire — whose residents were only surveyed once by the BRFSS from 2015-2022 because the year of the interview and state indicators were collinear. The remainder of the states, territories, and districts were all surveyed at least twice by the BRFSS. After this exclusion, the total number of informal caregivers decreased to 116,063 between 2015-2022 and 70,513 between 2019-2022.

The 2015-2022 data had a sample of 119,396 caregivers prior to dropping those with missing values for predictor, control, and outcome variables. I dropped 7,065 observations who did not specify type of caregiver; 196 missing level of education; 1,177 who did not provide their age; 2,875 who did specify their sex; 19,545 who did not provide their race/ethnicity; 162 who did not self-assess their health; 1,269 who did not report the number of poor mental health days they had experienced in the past month; 212 who did not provide the number of children in their household; 269 who did not share their marital status; 17,949 who did not provide their annual income; and 204 who did not share their employment status. Additionally, 1,579 observations were dropped for those from New Hampshire, Delaware, the District of Columbia, and Montana.

The 2019-2022 data had 72,169 observations prior to dropping those with missing values for predictor, control, and outcome variables. I dropped 4,558 observations that did not indicate type of caregiver; 135 with missing data on level of education; 823 who did not provide their age; 19,021 who did not provide their race/ethnicity; 83 who did not self-assess their health; 745 who did report the number of poor mental health days they experienced in the past month; 150 who did not report the number of children in their household; 163 who did not share their marital status; 12,739 without income information; and 121 who did not share their employment status. Additionally, 311 observations were dropped for those from Delaware and New Hampshire. The final analytic samples consisted of 66,894 respondents for 2015-2022 and 33,320 for 2019-2022.

f. Analytic Strategy

After examining the descriptive characteristics of the caregiver sample, I estimated regression models predicting each poor mental health outcome using the two predictor variables. I used ordinary least squares (OLS) regression models to predict the number of poor mental health days and logistic regression models to predict any poor mental health day and reporting more than half of poor mental health days in the last thirty days. I present results for each outcome in a separate table (Tables 1a-4b).

Each table contains four regression models, adjusting incrementally in blocks for demographic variables (sex, age, race/ethnicity, marital status), economic variables (children, education, income, employment), state, year, and self-rated health. I performed this stepwise regression to account for potentially confounding variables and enable greater model interpretability, allowing me to understand the contribution of each category of control variable to the overall model. Coefficients from logistic regression models have been exponentiated to odds ratios.

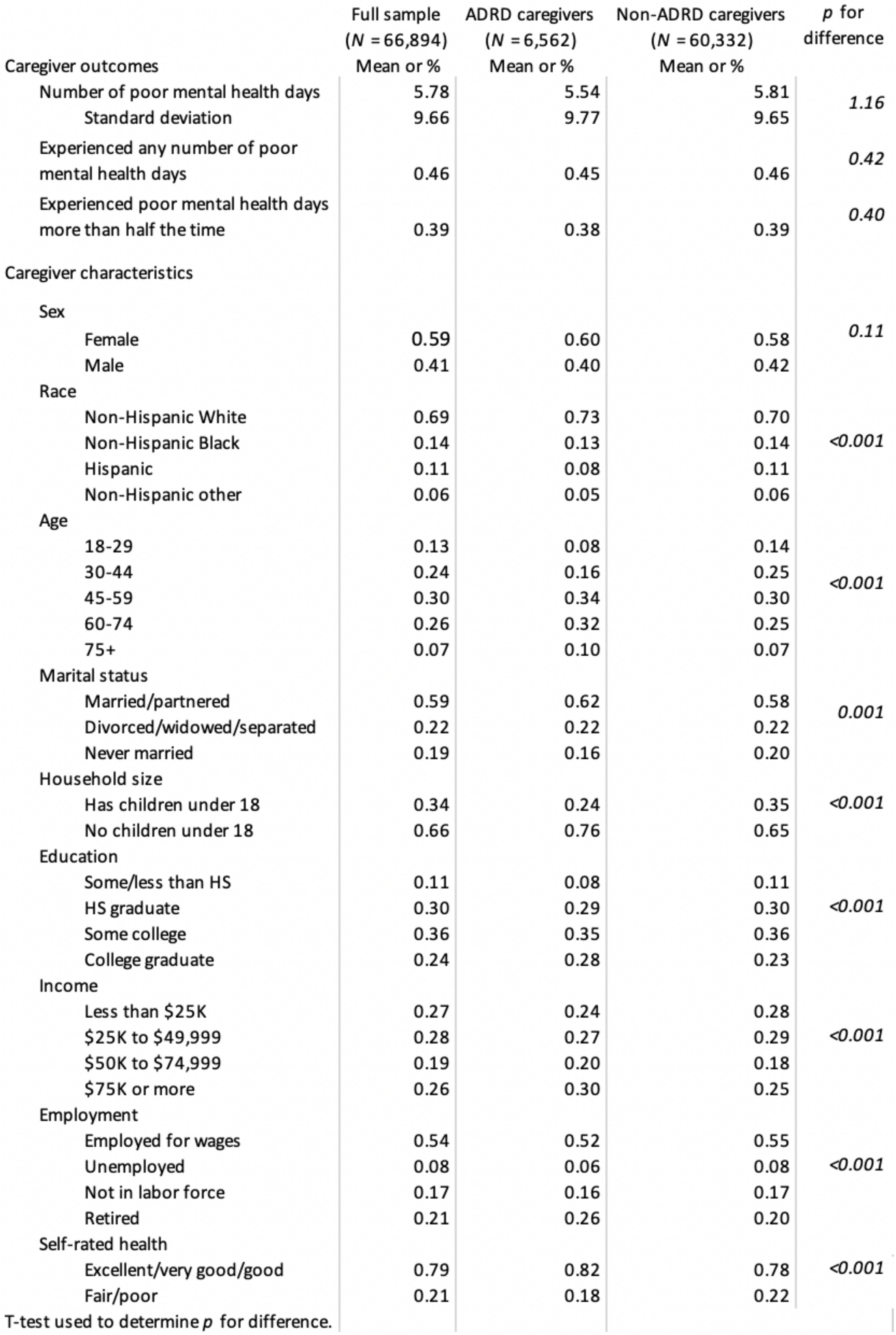
To evaluate whether the observed patterns differed before and during the pandemic, I estimated analogous fully adjusted regression models with interactions between caregiving status and the timing of the interview (before versus during the COVID-19 pandemic). Results from these models are presented as figures 1-6. The full model results have been included as appendices. I used Stata/BE software version 17.0 to conduct all analyses. I applied BRFSS-provided survey weights to ensure that our estimates were reflective of the U.S. population.

V. Results

Tables 1a and 1b show weighted descriptive characteristics of the analytic sample for the 2015-2022 data and 2019-2022 data, respectively. For the 2015-2022 data, in which caregivers were distinguished as either caring for a person with an ADRD or caring for a person without ADRD, a greater proportion of ADRD caregivers compared to non-ADRD caregivers were older (42% versus 32% over age 60), non-Hispanic White (76% versus 70%), less likely to have a child under age 18 (25% versus 35%), with higher education (28% versus 23% were college graduates), higher-earning (51% versus 45% had an annual income of over $50,000), retired (27% versus 20%), and reported better self-rated health (82% versus 78% reported health as “excellent,” “very good,” or “good”; all *p*-values<0.001).

Table 1a

Descriptives data based on Behavioral Risk Factor Surveillance System (BRFSS) data of Alzheimer's disease and related dementias (ADRD) caregivers and non-ADRD caregivers, 2015-2022.



	Full sample (*N* = 66,894)	ADRD caregivers (*N* = 6,562)	Non-ADRD caregivers (*N* = 60,332)	*p* for difference
Caregiver outcomes	Mean or %	Mean or %	Mean or %	
Number of poor mental health days	5.78	5.54	5.81	*1.16*
Standard deviation	9.66	9.77	9.65	
Experienced any number of poor mental health days	0.46	0.45	0.46	*0.42*
Experienced poor mental health days more than half the time	0.39	0.38	0.39	*0.40*
Caregiver characteristics				
Sex				
Female	0.59	0.60	0.58	*0.11*
Male	0.41	0.40	0.42	
Race				
Non-Hispanic White	0.69	0.73	0.70	*<0.001*
Non-Hispanic Black	0.14	0.13	0.14	
Hispanic	0.11	0.08	0.11	
Non-Hispanic other	0.06	0.05	0.06	
Age				
18-29	0.13	0.08	0.14	*<0.001*
30-44	0.24	0.16	0.25	
45-59	0.30	0.34	0.30	
60-74	0.26	0.32	0.25	
75+	0.07	0.10	0.07	
Marital status				
Married/partnered	0.59	0.62	0.58	*0.001*
Divorced/widowed/separated	0.22	0.22	0.22	
Never married	0.19	0.16	0.20	
Household size				
Has children under 18	0.34	0.24	0.35	*<0.001*
No children under 18	0.66	0.76	0.65	
Education				
Some/less than HS	0.11	0.08	0.11	*<0.001*
HS graduate	0.30	0.29	0.30	
Some college	0.36	0.35	0.36	
College graduate	0.24	0.28	0.23	
Income				
Less than $25K	0.27	0.24	0.28	*<0.001*
$25K to $49,999	0.28	0.27	0.29	
$50K to $74,999	0.19	0.20	0.18	
$75K or more	0.26	0.30	0.25	
Employment				
Employed for wages	0.54	0.52	0.55	*<0.001*
Unemployed	0.08	0.06	0.08	
Not in labor force	0.17	0.16	0.17	
Retired	0.21	0.26	0.20	
Self-rated health				
Excellent/very good/good	0.79	0.82	0.78	*<0.001*
Fair/poor	0.21	0.18	0.22	

T-test used to determine *p* for difference.

Table 1b

Descriptives data based on Behavioral Risk Factor Surveillance System (BRFSS) data of Alzheimer's disease and related dementias (ADRD) caregivers and non-ADRD caregivers, 2019-2022.

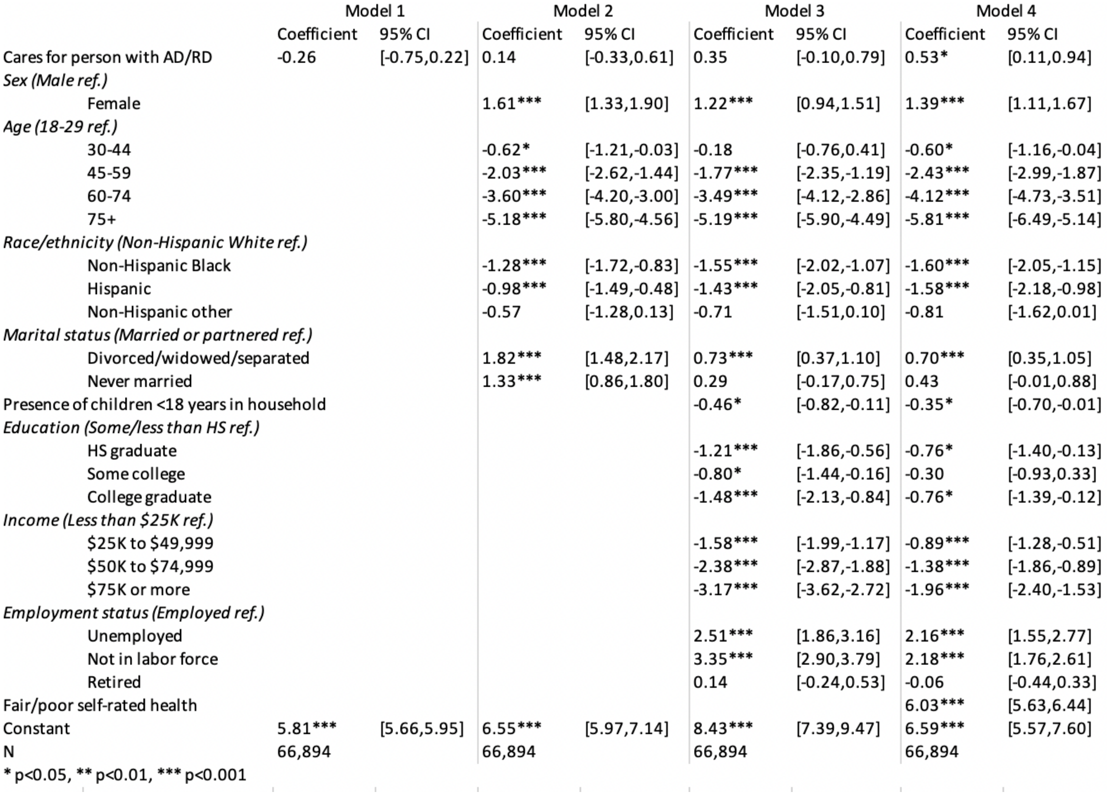
	Full sample (N = 33,320)	Non-ADRD caregivers (N = 25,620)	ADRD caregivers (N = 3,525)	p for difference	ADRD+ caregivers (N = 4,175)	p for difference
Caregiver outcomes	Mean or %	Mean or %	Mean or %		Mean or %	
Number of poor mental health days	6.14	6.06	5.99	*0.77*	6.75	*0.02*
Standard deviation	9.63	9.52	9.60		10.27	
Experienced any number of poor mental health days	0.48	0.48	0.48	*0.51*	0.50	*0.51*
Experienced poor mental health days more than half the time	0.40	0.39	0.39	*0.23*	0.43	*0.23*
Caregiver characteristics						
Sex						
Female	0.59	0.58	0.60	*0.005*	0.64	*0.005*
Male	0.41	0.42	0.40		0.36	
Race						
Non-Hispanic white	0.67	0.66	0.72	*0.03*	0.68	*0.03*
Non-Hispanic black	0.14	0.14	0.13		0.12	
Hispanic	0.14	0.14	0.10		0.14	
Non-Hispanic other	0.06	0.06	0.05		0.06	
Age						
18-29	0.12	0.13	0.08	*<0.001*	0.08	*<0.001*
30-44	0.23	0.24	0.14		0.21	
45-59	0.28	0.27	0.32		0.31	
60-74	0.28	0.27	0.35		0.31	
75+	0.09	0.08	0.11		0.09	
Marital status						
Married/partnered	0.57	0.57	0.61	*0.001*	0.57	*0.001*
Divorced/widowed/separated	0.24	0.23	0.23		0.27	
Never married	0.19	0.20	0.16		0.16	
Household size						
Has children under 18	0.33	0.35	0.22	*<0.001*	0.27	*<0.001*
No children under 18	0.68	0.65	0.78		0.73	
Education						
Some/less than HS	0.11	0.11	0.08	*0.001*	0.10	*0.001*
HS graduate	0.30	0.31	0.30		0.26	
Some college	0.36	0.36	0.35		0.39	
College graduate	0.23	0.22	0.27		0.25	
Income						
Less than $25K	0.25	0.26	0.22	*0.003*	0.25	*0.003*
$25K to $49,999	0.31	0.31	0.28		0.30	
$50K to $74,999	0.21	0.21	0.22		0.20	
$75K or more	0.23	0.22	0.28		0.26	
Employment						
Employed for wages	0.52	0.53	0.49	*<0.001*	0.50	*<0.001*
Unemployed	0.08	0.08	0.06		0.07	
Not in labor force	0.16	0.16	0.16		0.18	
Retired	0.24	0.23	0.29		0.25	
Self-rated health						
Excellent/very good/good	0.78	0.78	0.81	*0.007*	0.75	*0.007*
Fair/poor	0.22	0.22	0.19		0.25	
Fair/poor	0.22	0.22	0.19		0.25	

T-test used to determine p for difference.

For the 2019-2022 descriptives data (Table 1b), in which caregivers classified as caring for a person with ADRD and another condition, caring for a person with only ADRD, or caring for a person without ADRD, a greater proportion of caregivers for people with ADRD or ADRD and another condition, compared to caregivers for those without ADRD, were older (46% and 40% versus 35% over age 60, *p*<0.001), non-Hispanic White (75% and 70% versus 67%, *p*=0.003), less likely to have a child under age 18 (23% and 28% versus 35%, *p*<0.001), with higher education (27% and 25% versus 22% were college graduates, *p*<0.001), higher-earning (51% and 46% versus 43% had an annual income of over $50,000, *p*<0.001), and retired (30% and 25% versus 23%). Caregivers for people with ADRD only reported better self-rated health than those caring for individuals without ADRD (80% versus 78%, *p*<0.001); however, caregivers for ADRD and another condition reported worse self-rated health than caregivers for a condition other than ADRD (25% versus 22% ranked health as "fair" or "poor", *p*=0.01).

Table 2a

OLS regression models predicting the number of poor mental health days experienced last month by caregiving status, controlling for sociodemographic characteristics, 2015-2022. Survey weights applied.



	Model 1		Model 2		Model 3		Model 4	
	Coefficient	95% CI	Coefficient	95% CI	Coefficient	95% CI	Coefficient	95% CI
Cares for person with AD/RD	-0.26	[-0.75,0.22]	0.14	[-0.33,0.61]	0.35	[-0.10,0.79]	0.53*	[0.11,0.94]
Sex (Male ref.)								
Female			1.61***	[1.33,1.90]	1.22***	[0.94,1.51]	1.39***	[1.11,1.67]
Age (18-29 ref.)								
30-44			-0.62*	[-1.21,-0.03]	-0.18	[-0.76,0.41]	-0.60*	[-1.16,-0.04]
45-59			-2.03***	[-2.62,-1.44]	-1.77***	[-2.35,-1.19]	-2.43***	[-2.99,-1.87]
60-74			-3.60***	[-4.20,-3.00]	-3.49***	[-4.12,-2.86]	-4.12***	[-4.73,-3.51]
75+			-5.18***	[-5.80,-4.56]	-5.19***	[-5.90,-4.49]	-5.81***	[-6.49,-5.14]
Race/ethnicity (Non-Hispanic White ref.)								
Non-Hispanic Black			-1.28***	[-1.72,-0.83]	-1.55***	[-2.02,-1.07]	-1.60***	[-2.05,-1.15]
Hispanic			-0.98***	[-1.49,-0.48]	-1.43***	[-2.05,-0.81]	-1.58***	[-2.18,-0.98]
Non-Hispanic other			-0.57	[-1.28,0.13]	-0.71	[-1.51,0.10]	-0.81	[-1.62,0.01]
Marital status (Married or partnered ref.)								
Divorced/widowed/separated			1.82***	[1.48,2.17]	0.73***	[0.37,1.10]	0.70***	[0.35,1.05]
Never married			1.33***	[0.86,1.80]	0.29	[-0.17,0.75]	0.43	[-0.01,0.88]
Presence of children <18 years in household					-0.46*	[-0.82,-0.11]	-0.35*	[-0.70,-0.01]
Education (Some/less than HS ref.)								
HS graduate					-1.21***	[-1.86,-0.56]	-0.76*	[-1.40,-0.13]
Some college					-0.80*	[-1.44,-0.16]	-0.30	[-0.93,0.33]
College graduate					-1.48***	[-2.13,-0.84]	-0.76*	[-1.39,-0.12]
Income (Less than $25K ref.)								
$25K to $49,999					-1.58***	[-1.99,-1.17]	-0.89***	[-1.28,-0.51]
$50K to $74,999					-2.38***	[-2.87,-1.88]	-1.38***	[-1.86,-0.89]
$75K or more					-3.17***	[-3.62,-2.72]	-1.96***	[-2.40,-1.53]
Employment status (Employed ref.)								
Unemployed					2.51***	[1.86,3.16]	2.16***	[1.55,2.77]
Not in labor force					3.35***	[2.90,3.79]	2.18***	[1.76,2.61]
Retired					0.14	[-0.24,0.53]	-0.06	[-0.44,0.33]
Fair/poor self-rated health							6.03***	[5.63,6.44]
Constant	5.81***	[5.66,5.95]	6.55***	[5.97,7.14]	8.43***	[7.39,9.47]	6.59***	[5.57,7.60]
N	66,894		66,894		66,894		66,894	

* p<0.05, ** p<0.01, *** p<0.001

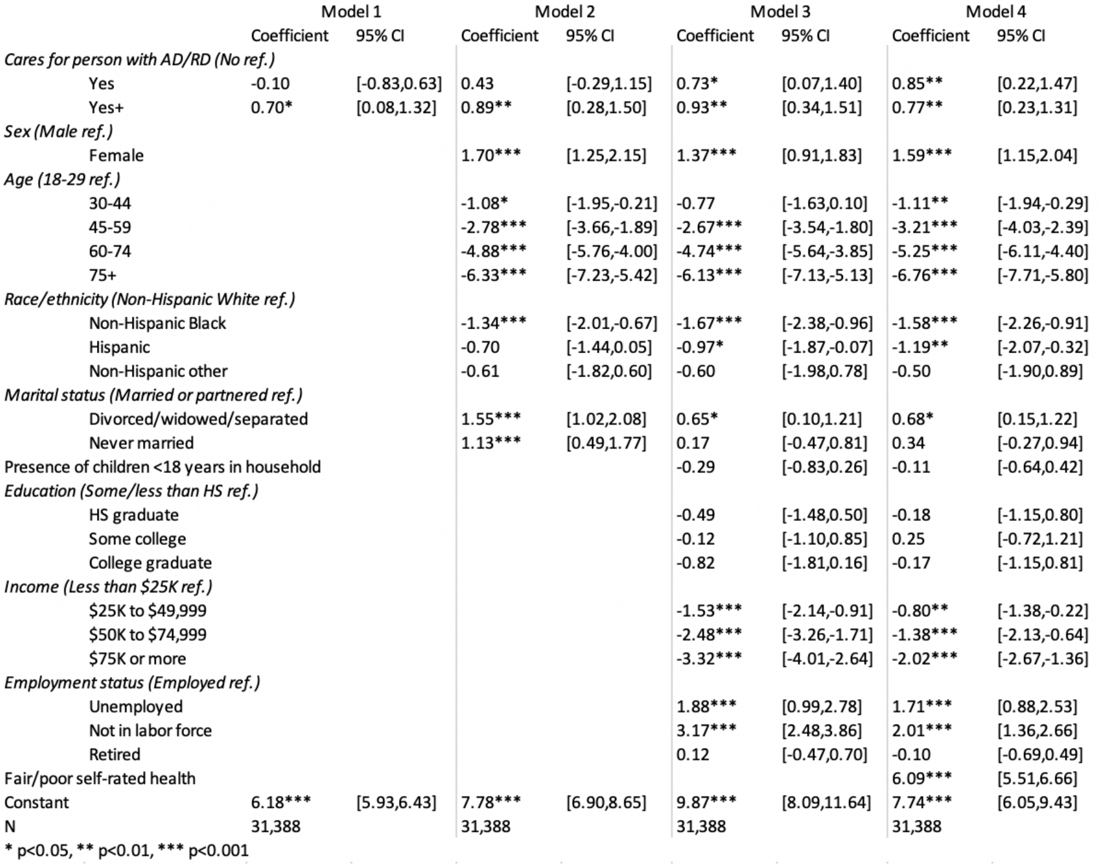
Table 2a shows results from OLS models predicting number of poor mental health days by whether a caregiver provided care for a person with ADRD using data collected between 2015 and 2022. The difference in number of poor mental health days experienced by caregivers for individuals with ADRD was not statistically significant in the unadjusted model (Model 1) or models adjusting only for demographic variables (Model 2). This model also showed that female caregivers experienced an additional 1.61 days of poor mental health per month on average ($p<0.001$) compared to male caregivers; caregivers over age 75 experienced 5.18 fewer poor mental health days on average ($p<0.001$), while 30-44-year-old caregivers experienced only 0.62 fewer poor mental health days on average, all compared to caregivers between the ages of 18 and 29 ($p<0.05$). The results from this model also show that non-Hispanic Black and Hispanic caregivers experienced 1.28 and 0.98 fewer poor mental health days per month on average, respectively, than non-Hispanic White caregivers ($p<0.001$); and unmarried caregivers experienced 1.82 and 1.33 additional poor mental health days per month on average than married caregivers — for divorced/widowed/separated and never married caregivers, respectively ($p<0.001$).

The difference in number of poor mental health days experienced by caregivers for individuals with ADRD was also not significant when controlling for demographic and economic variables (Model 3). I find that the presence of children under age 18 in the caregiver's household was associated with 0.46 fewer days of poor mental health per month on average than for those without children ($p<0.05$); caregivers with college degrees experienced 1.48 fewer days each month of poor mental health on average compared to those with some high school education but no diploma ($p<0.001$); those with higher incomes experienced between 1.58 and 3.17 fewer poor mental health days on average than caregivers who earned less than $25,000 annually ($p<0.001$); and, though retirement status was not associated with increased poor mental health days, being either unemployed or outside the labor force was associated with 2.51 and 3.35 additional poor mental health days on average, respectively (*p*<0.001).

The final OLS regression model (Model 4) for number of poor mental health days in the 2015-2022 data controlled for the same demographic and economic variables used in previous models, as well as caregivers' self-assessed health rating. Like in the previous models, being female, divorced/separated/widowed, and unemployed or not in the labor force were all associated with increased days of poor mental health each month on average (*p*<0.001 for all). When controlling for self-rated health, the difference in poor mental health days for caregivers of individuals with versus without ADRD was statistically significant, indicating that ADRD caregiving status predicts 0.53 additional days of poor mental health on average per month (Table 2a, *p*<0.05).

Table 2b

OLS regression models predicting the number of poor mental health days experienced last month by caregiving status, controlling for sociodemographic characteristics, 2019-2022. Survey weights applied.



	Model 1		Model 2		Model 3		Model 4	
	Coefficient	95% CI	Coefficient	95% CI	Coefficient	95% CI	Coefficient	95% CI
Cares for person with AD/RD (No ref.)								
Yes	-0.10	[-0.83,0.63]	0.43	[-0.29,1.15]	0.73*	[0.07,1.40]	0.85**	[0.22,1.47]
Yes+	0.70*	[0.08,1.32]	0.89**	[0.28,1.50]	0.93**	[0.34,1.51]	0.77**	[0.23,1.31]
Sex (Male ref.)								
Female			1.70***	[1.25,2.15]	1.37***	[0.91,1.83]	1.59***	[1.15,2.04]
Age (18-29 ref.)								
30-44			-1.08*	[-1.95,-0.21]	-0.77	[-1.63,0.10]	-1.11**	[-1.94,-0.29]
45-59			-2.78***	[-3.66,-1.89]	-2.67***	[-3.54,-1.80]	-3.21***	[-4.03,-2.39]
60-74			-4.88***	[-5.76,-4.00]	-4.74***	[-5.64,-3.85]	-5.25***	[-6.11,-4.40]
75+			-6.33***	[-7.23,-5.42]	-6.13***	[-7.13,-5.13]	-6.76***	[-7.71,-5.80]
Race/ethnicity (Non-Hispanic White ref.)								
Non-Hispanic Black			-1.34***	[-2.01,-0.67]	-1.67***	[-2.38,-0.96]	-1.58***	[-2.26,-0.91]
Hispanic			-0.70	[-1.44,0.05]	-0.97*	[-1.87,-0.07]	-1.19**	[-2.07,-0.32]
Non-Hispanic other			-0.61	[-1.82,0.60]	-0.60	[-1.98,0.78]	-0.50	[-1.90,0.89]
Marital status (Married or partnered ref.)								
Divorced/widowed/separated			1.55***	[1.02,2.08]	0.65*	[0.10,1.21]	0.68*	[0.15,1.22]
Never married			1.13***	[0.49,1.77]	0.17	[-0.47,0.81]	0.34	[-0.27,0.94]
Presence of children <18 years in household					-0.29	[-0.83,0.26]	-0.11	[-0.64,0.42]
Education (Some/less than HS ref.)								
HS graduate					-0.49	[-1.48,0.50]	-0.18	[-1.15,0.80]
Some college					-0.12	[-1.10,0.85]	0.25	[-0.72,1.21]
College graduate					-0.82	[-1.81,0.16]	-0.17	[-1.15,0.81]
Income (Less than $25K ref.)								
$25K to $49,999					-1.53***	[-2.14,-0.91]	-0.80**	[-1.38,-0.22]
$50K to $74,999					-2.48***	[-3.26,-1.71]	-1.38***	[-2.13,-0.64]
$75K or more					-3.32***	[-4.01,-2.64]	-2.02***	[-2.67,-1.36]
Employment status (Employed ref.)								
Unemployed					1.88***	[0.99,2.78]	1.71***	[0.88,2.53]
Not in labor force					3.17***	[2.48,3.86]	2.01***	[1.36,2.66]
Retired					0.12	[-0.47,0.70]	-0.10	[-0.69,0.49]
Fair/poor self-rated health							6.09***	[5.51,6.66]
Constant	6.18***	[5.93,6.43]	7.78***	[6.90,8.65]	9.87***	[8.09,11.64]	7.74***	[6.05,9.43]
N	31,388		31,388		31,388		31,388	

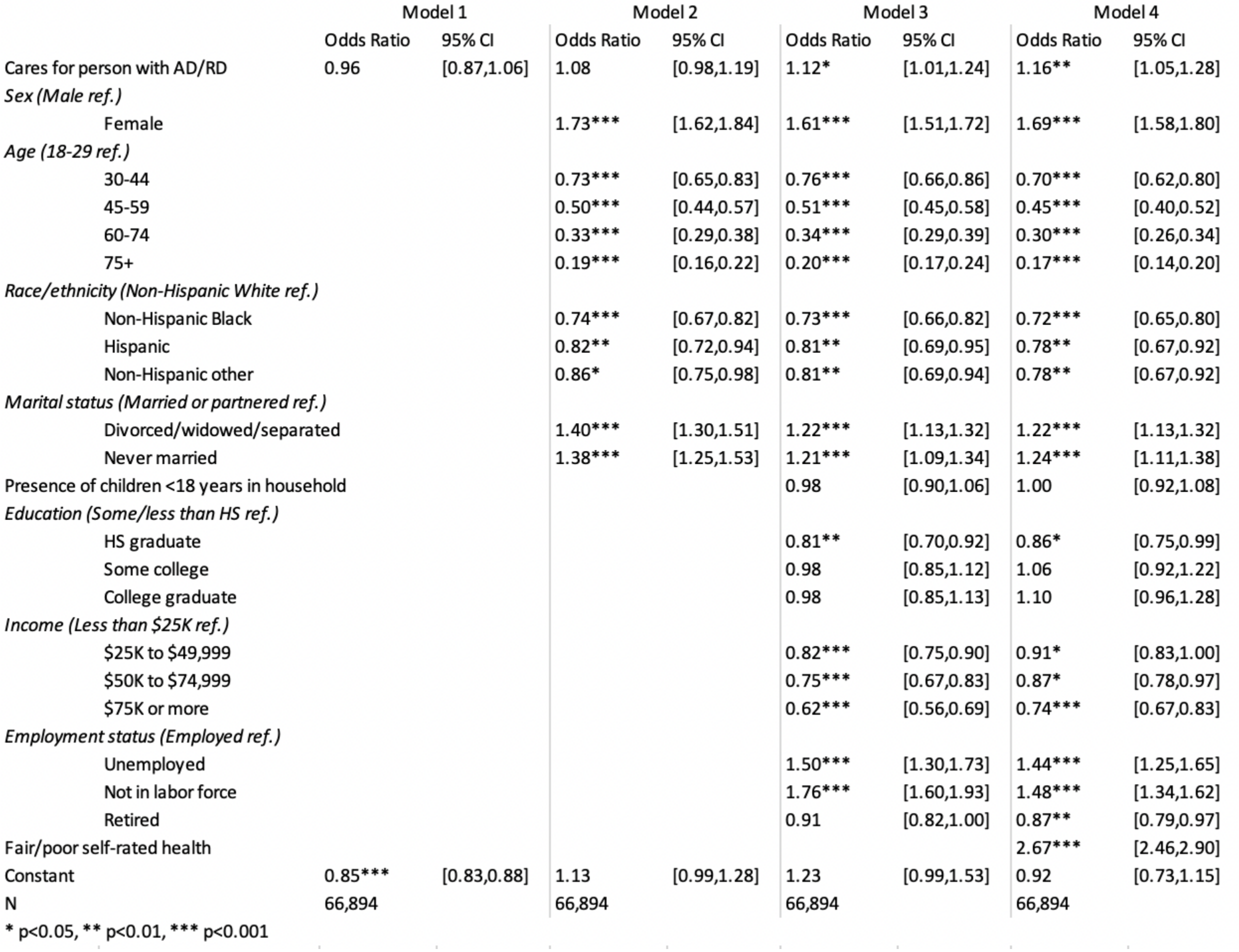
* p<0.05, ** p<0.01, *** p<0.001

In Table 2b, using data collected between 2019 and 2022, I distinguish between people who cared for individuals with ADRD alone and ADRD together with other conditions. In the unadjusted model (Model 1), status as a caregiver for ADRD and another condition was found to be associated with 0.70 additional poor mental health days per month on average compared to caregivers for conditions other than ADRD ($p<0.05$), though no statistically significant differences were found for caregivers only providing care for an ADRD patient. When adjusting for demographic factors in the subsequent model (Model 2), caregivers for ADRD and another condition similarly exhibited 0.89 more poor mental health days on average ($p<0.01$), while caregivers for ADRD alone did not. Here, sex, age, race/ethnicity, and marital status were all associated with a statistically significantly higher number of poor mental health days experienced per month on average, with ages older than 18-29 years old and races/ethnicities other than non-Hispanic White associated with a lower poor mental health day count on average. On the other hand, being female and having a marital status other than married/partnered were associated with, on average, 1.70 and 1.55 more days of poor mental health per month, respectively ($p<0.001$).

Model 3 controls for both demographic and economic variables, including children, education, income, employment status, state, and year of data collection. Both caring for ADRD and caring for ADRD and another condition were significantly associated with an increased number of poor mental health days per month, at 0.73 and 0.93 days on average, respectively ($p<0.05$; $p<0.01$). All demographic variables statistically significant in the second model maintained their significance; statistically significant economic variables included income and employment status, with income over $25,000 predicting fewer 1.53 poor mental health days on average per month and unemployed status predicting 1.88 more poor mental health days on average (both $p<0.005$). In fully adjusted models (Model 4), caring for a person with ADRD and ADRD and another condition are shown to be associated with 0.85 and 0.77 additional poor mental health days on average per month, respectively, compared to caring for a condition other than ADRD (Table 2b, *p*<0.01). A self-assessed health rating of fair or poor was associated with 6.09 additional poor mental health days on average per month (*p*<0.001).

Table 3a

Logistic regression models predicting any poor mental health days last month by caregiving status, controlling for sociodemographic characteristics, 2015-2022. Survey weights applied.



	Model 1		Model 2		Model 3		Model 4	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI
Cares for person with AD/RD	0.96	[0.87,1.06]	1.08	[0.98,1.19]	1.12*	[1.01,1.24]	1.16**	[1.05,1.28]
Sex (Male ref.)								
Female			1.73***	[1.62,1.84]	1.61***	[1.51,1.72]	1.69***	[1.58,1.80]
Age (18-29 ref.)								
30-44			0.73***	[0.65,0.83]	0.76***	[0.66,0.86]	0.70***	[0.62,0.80]
45-59			0.50***	[0.44,0.57]	0.51***	[0.45,0.58]	0.45***	[0.40,0.52]
60-74			0.33***	[0.29,0.38]	0.34***	[0.29,0.39]	0.30***	[0.26,0.34]
75+			0.19***	[0.16,0.22]	0.20***	[0.17,0.24]	0.17***	[0.14,0.20]
Race/ethnicity (Non-Hispanic White ref.)								
Non-Hispanic Black			0.74***	[0.67,0.82]	0.73***	[0.66,0.82]	0.72***	[0.65,0.80]
Hispanic			0.82**	[0.72,0.94]	0.81**	[0.69,0.95]	0.78**	[0.67,0.92]
Non-Hispanic other			0.86*	[0.75,0.98]	0.81**	[0.69,0.94]	0.78**	[0.67,0.92]
Marital status (Married or partnered ref.)								
Divorced/widowed/separated			1.40***	[1.30,1.51]	1.22***	[1.13,1.32]	1.22***	[1.13,1.32]
Never married			1.38***	[1.25,1.53]	1.21***	[1.09,1.34]	1.24***	[1.11,1.38]
Presence of children <18 years in household					0.98	[0.90,1.06]	1.00	[0.92,1.08]
Education (Some/less than HS ref.)								
HS graduate					0.81**	[0.70,0.92]	0.86*	[0.75,0.99]
Some college					0.98	[0.85,1.12]	1.06	[0.92,1.22]
College graduate					0.98	[0.85,1.13]	1.10	[0.96,1.28]
Income (Less than $25K ref.)								
$25K to $49,999					0.82***	[0.75,0.90]	0.91*	[0.83,1.00]
$50K to $74,999					0.75***	[0.67,0.83]	0.87*	[0.78,0.97]
$75K or more					0.62***	[0.56,0.69]	0.74***	[0.67,0.83]
Employment status (Employed ref.)								
Unemployed					1.50***	[1.30,1.73]	1.44***	[1.25,1.65]
Not in labor force					1.76***	[1.60,1.93]	1.48***	[1.34,1.62]
Retired					0.91	[0.82,1.00]	0.87**	[0.79,0.97]
Fair/poor self-rated health							2.67***	[2.46,2.90]
Constant	0.85***	[0.83,0.88]	1.13	[0.99,1.28]	1.23	[0.99,1.53]	0.92	[0.73,1.15]
N	66,894		66,894		66,894		66,894	

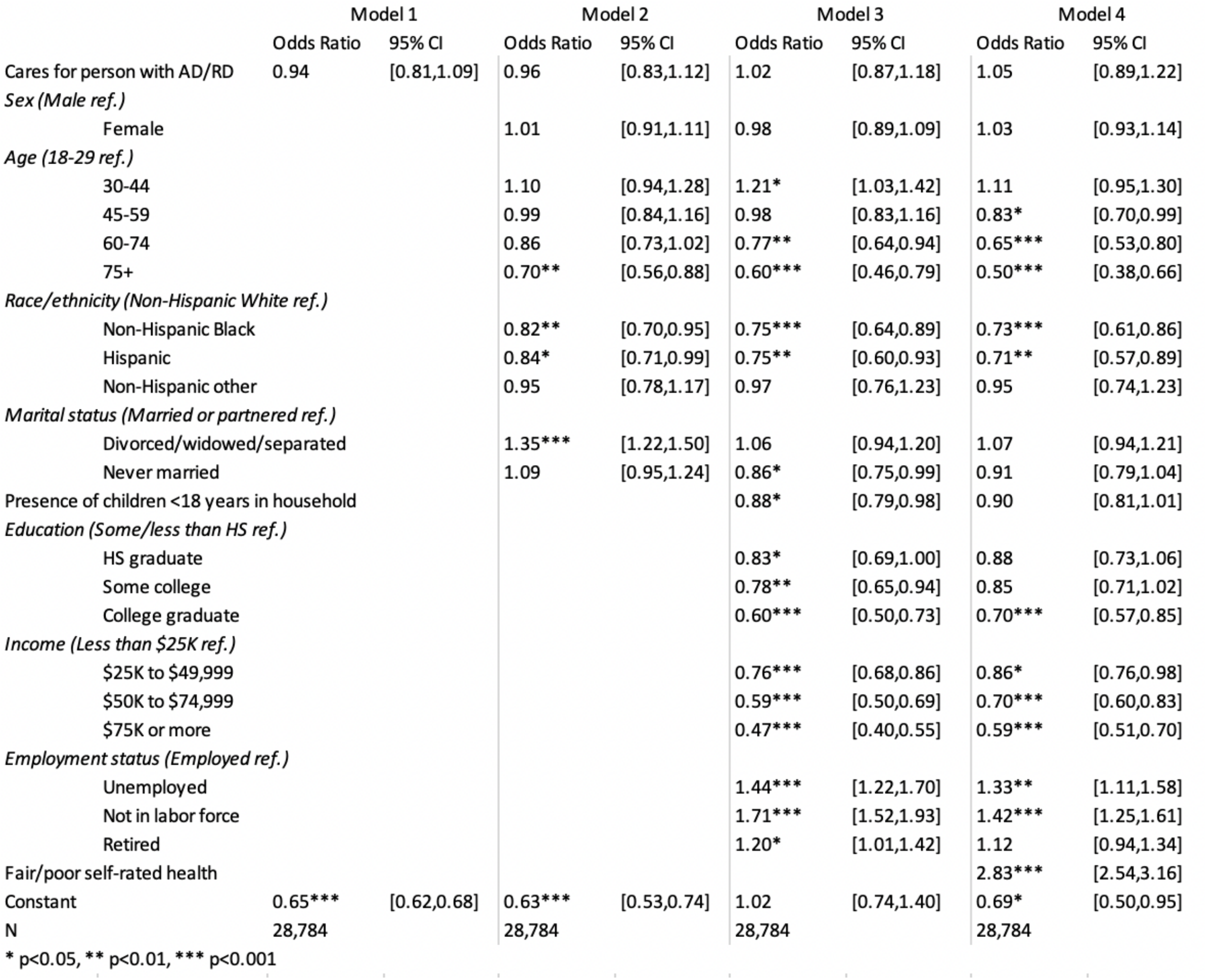
* p<0.05, ** p<0.01, *** p<0.001

In Table 3a, I further examine whether ADRD caregiving status was associated one's likelihood of experiencing any number of poor mental health days per month compared to other caregiving statuses. The difference between caring for ADRD and conditions other than ADRD on likelihood for experiencing at least one day of poor mental health was significant for this outcome variable when controlling for demographics, economic variables, state, and year of data collection (Model 3; OR=1.12, *p*<0.05). Like with the outcome variable of number of poor mental health days per month, the models showed that caregivers who were female (OR=1.61, *p*<0.005), not married/partnered (OR=1.22, *p*<0.005), and unemployed (OR=1.50, *p*<0.005) or not in the labor force (OR=0.76, *p*<0.005) all had increased odds of experiencing at least one day of poor mental health per month compared to their male, married/partnered, and employed counterparts. Caregivers who were 30 and older (OR=1.61, *p*<0.005), a race/ethnicity other than non-Hispanic White, high school graduates (OR=0.81, *p*<0.01), or earning incomes over $25,000 (OR=0.82, *p*<0.005) had decreased odds of experiencing at least one poor mental health day.

I also control for self-rated health which has been shown to be a well-suited measure for an individual's actual health — upon controlling for demographics, economic variables, state, year, and self-rated health (Model 4), I found that caring for an individual with ADRD yielded 1.16 greater odds of experiencing at least one poor mental health day compared to caregivers for individuals without ADRD (Table 3a, *p*<0.01). ADRD caregiving status was not associated with increased odds of experiencing frequent poor mental health days (>14) each month in fully adjusted models (Table 4a).

Table 4a

Logistic regression models predicting more than half poor mental health days last month by caregiving status, controlling for sociodemographic characteristics, 2015-2022. Survey weights applied.

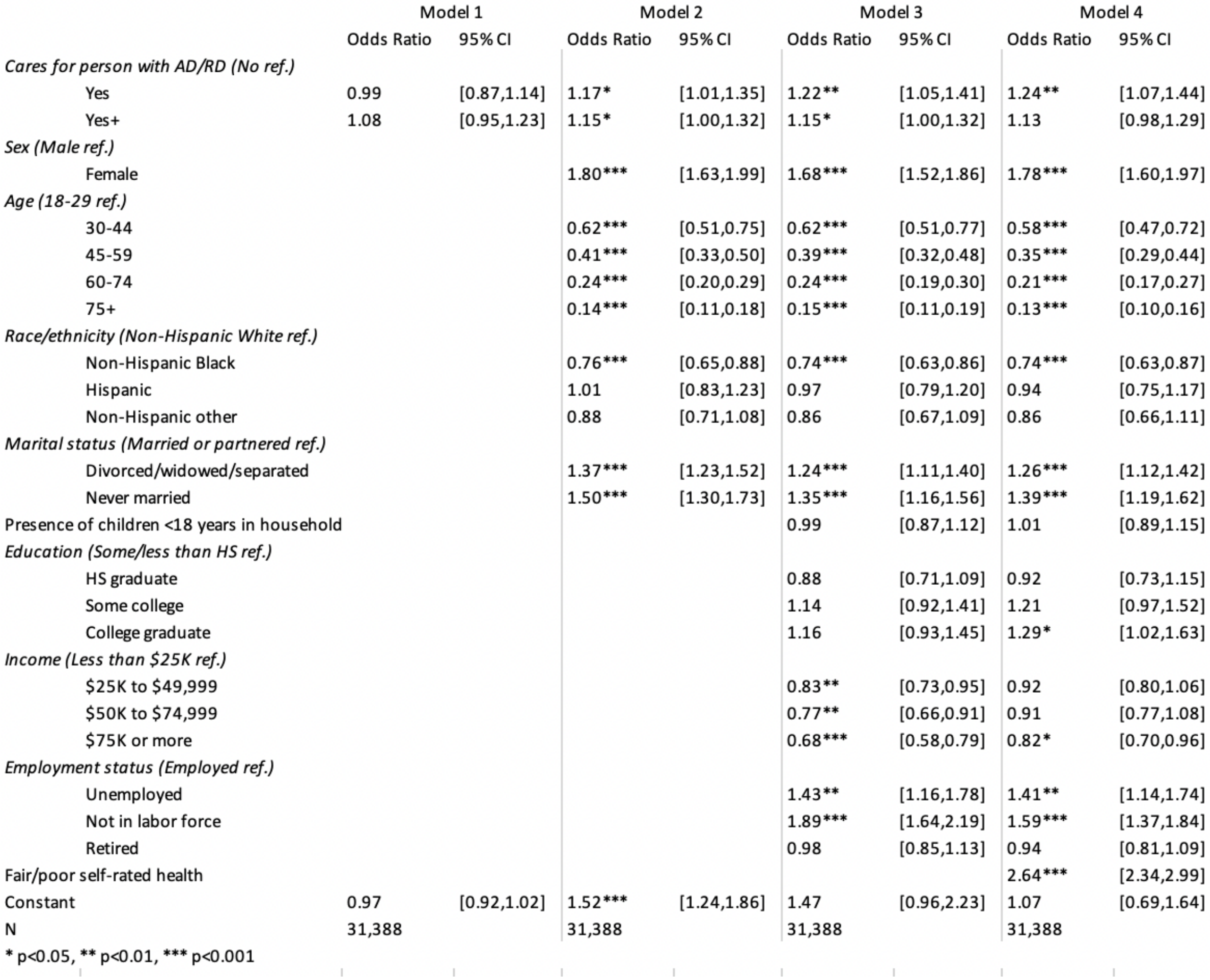


	Model 1		Model 2		Model 3		Model 4	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI
Cares for person with AD/RD	0.94	[0.81,1.09]	0.96	[0.83,1.12]	1.02	[0.87,1.18]	1.05	[0.89,1.22]
Sex (Male ref.)								
Female			1.01	[0.91,1.11]	0.98	[0.89,1.09]	1.03	[0.93,1.14]
Age (18-29 ref.)								
30-44			1.10	[0.94,1.28]	1.21*	[1.03,1.42]	1.11	[0.95,1.30]
45-59			0.99	[0.84,1.16]	0.98	[0.83,1.16]	0.83*	[0.70,0.99]
60-74			0.86	[0.73,1.02]	0.77**	[0.64,0.94]	0.65***	[0.53,0.80]
75+			0.70**	[0.56,0.88]	0.60***	[0.46,0.79]	0.50***	[0.38,0.66]
Race/ethnicity (Non-Hispanic White ref.)								
Non-Hispanic Black			0.82**	[0.70,0.95]	0.75***	[0.64,0.89]	0.73***	[0.61,0.86]
Hispanic			0.84*	[0.71,0.99]	0.75**	[0.60,0.93]	0.71**	[0.57,0.89]
Non-Hispanic other			0.95	[0.78,1.17]	0.97	[0.76,1.23]	0.95	[0.74,1.23]
Marital status (Married or partnered ref.)								
Divorced/widowed/separated			1.35***	[1.22,1.50]	1.06	[0.94,1.20]	1.07	[0.94,1.21]
Never married			1.09	[0.95,1.24]	0.86*	[0.75,0.99]	0.91	[0.79,1.04]
Presence of children <18 years in household					0.88*	[0.79,0.98]	0.90	[0.81,1.01]
Education (Some/less than HS ref.)								
HS graduate					0.83*	[0.69,1.00]	0.88	[0.73,1.06]
Some college					0.78**	[0.65,0.94]	0.85	[0.71,1.02]
College graduate					0.60***	[0.50,0.73]	0.70***	[0.57,0.85]
Income (Less than $25K ref.)								
$25K to $49,999					0.76***	[0.68,0.86]	0.86*	[0.76,0.98]
$50K to $74,999					0.59***	[0.50,0.69]	0.70***	[0.60,0.83]
$75K or more					0.47***	[0.40,0.55]	0.59***	[0.51,0.70]
Employment status (Employed ref.)								
Unemployed					1.44***	[1.22,1.70]	1.33**	[1.11,1.58]
Not in labor force					1.71***	[1.52,1.93]	1.42***	[1.25,1.61]
Retired					1.20*	[1.01,1.42]	1.12	[0.94,1.34]
Fair/poor self-rated health							2.83***	[2.54,3.16]
Constant	0.65***	[0.62,0.68]	0.63***	[0.53,0.74]	1.02	[0.74,1.40]	0.69*	[0.50,0.95]
N	28,784		28,784		28,784		28,784	

* p<0.05, ** p<0.01, *** p<0.001

Table 3b

Logistic regression models predicting any poor mental health days last month by caregiving status, controlling for sociodemographic characteristics, 2019-2022. Survey weights applied.



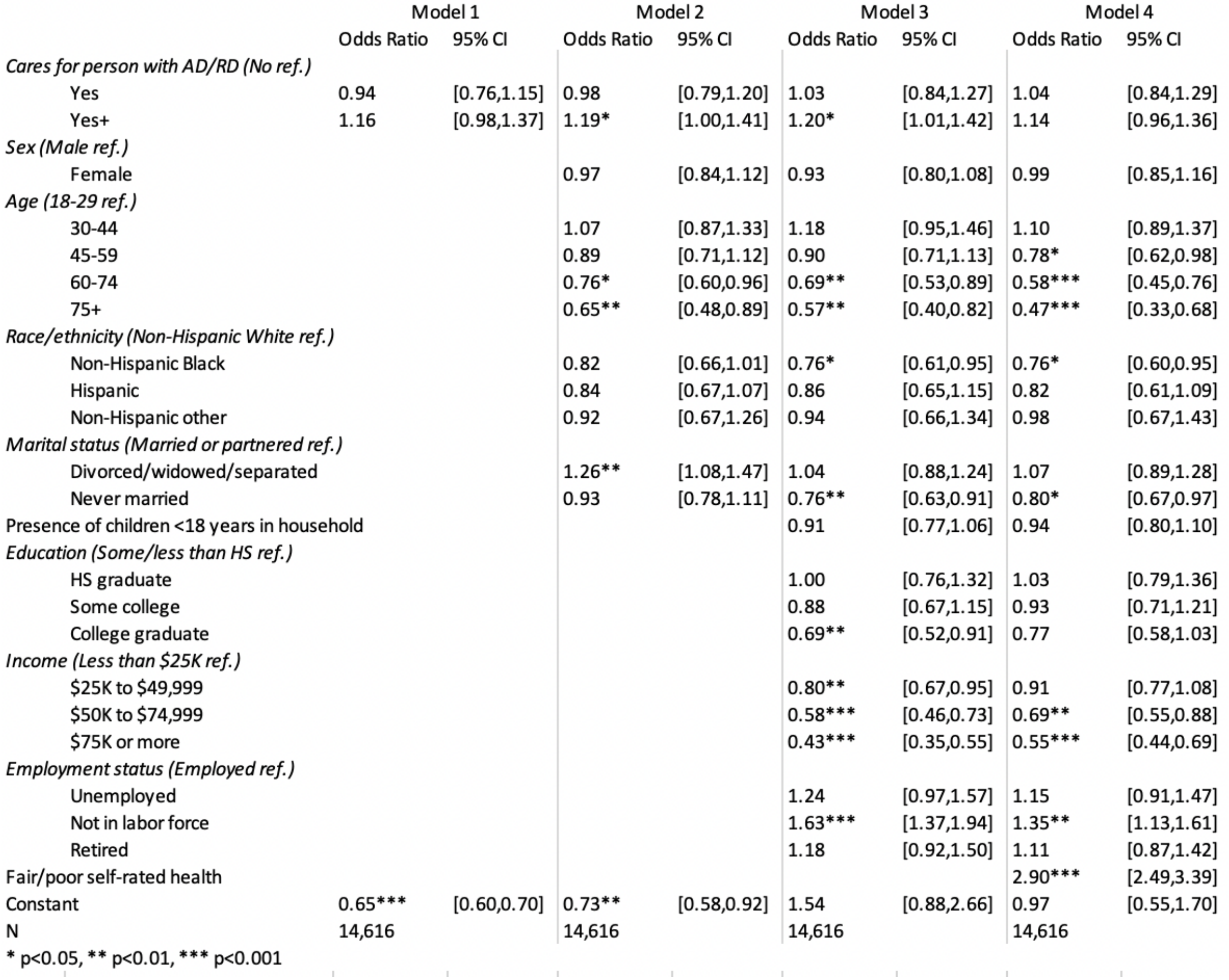
	Model 1		Model 2		Model 3		Model 4	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI
Cares for person with AD/RD (No ref.)								
Yes	0.99	[0.87,1.14]	1.17*	[1.01,1.35]	1.22**	[1.05,1.41]	1.24**	[1.07,1.44]
Yes+	1.08	[0.95,1.23]	1.15*	[1.00,1.32]	1.15*	[1.00,1.32]	1.13	[0.98,1.29]
Sex (Male ref.)								
Female			1.80***	[1.63,1.99]	1.68***	[1.52,1.86]	1.78***	[1.60,1.97]
Age (18-29 ref.)								
30-44			0.62***	[0.51,0.75]	0.62***	[0.51,0.77]	0.58***	[0.47,0.72]
45-59			0.41***	[0.33,0.50]	0.39***	[0.32,0.48]	0.35***	[0.29,0.44]
60-74			0.24***	[0.20,0.29]	0.24***	[0.19,0.30]	0.21***	[0.17,0.27]
75+			0.14***	[0.11,0.18]	0.15***	[0.11,0.19]	0.13***	[0.10,0.16]
Race/ethnicity (Non-Hispanic White ref.)								
Non-Hispanic Black			0.76***	[0.65,0.88]	0.74***	[0.63,0.86]	0.74***	[0.63,0.87]
Hispanic			1.01	[0.83,1.23]	0.97	[0.79,1.20]	0.94	[0.75,1.17]
Non-Hispanic other			0.88	[0.71,1.08]	0.86	[0.67,1.09]	0.86	[0.66,1.11]
Marital status (Married or partnered ref.)								
Divorced/widowed/separated			1.37***	[1.23,1.52]	1.24***	[1.11,1.40]	1.26***	[1.12,1.42]
Never married			1.50***	[1.30,1.73]	1.35***	[1.16,1.56]	1.39***	[1.19,1.62]
Presence of children <18 years in household					0.99	[0.87,1.12]	1.01	[0.89,1.15]
Education (Some/less than HS ref.)								
HS graduate					0.88	[0.71,1.09]	0.92	[0.73,1.15]
Some college					1.14	[0.92,1.41]	1.21	[0.97,1.52]
College graduate					1.16	[0.93,1.45]	1.29*	[1.02,1.63]
Income (Less than $25K ref.)								
$25K to $49,999					0.83**	[0.73,0.95]	0.92	[0.80,1.06]
$50K to $74,999					0.77**	[0.66,0.91]	0.91	[0.77,1.08]
$75K or more					0.68***	[0.58,0.79]	0.82*	[0.70,0.96]
Employment status (Employed ref.)								
Unemployed					1.43**	[1.16,1.78]	1.41**	[1.14,1.74]
Not in labor force					1.89***	[1.64,2.19]	1.59***	[1.37,1.84]
Retired					0.98	[0.85,1.13]	0.94	[0.81,1.09]
Fair/poor self-rated health							2.64***	[2.34,2.99]
Constant	0.97	[0.92,1.02]	1.52***	[1.24,1.86]	1.47	[0.96,2.23]	1.07	[0.69,1.64]
N	31,388		31,388		31,388		31,388	

* p<0.05, ** p<0.01, *** p<0.001

In Table 3b, I further saw significant increases in odds of experiencing any poor mental health days by ADRD caregiving status in models adjusting for demographics (Model 2) and demographic and economic variables (Model 3), as well as in fully adjusted models (Model 4). Caring for an individual with ADRD predicted 1.17 times increased odds of experiencing a poor mental health day, while caring for an individual with ADRD and another condition predicted 1.15 times increased odds of experiencing a poor mental health day compared to caring for a non-ADRD condition ($p<0.05$). These odds increased to 1.22 and 1.15, respectively in models adjusting for demographics, economic variables, state, and year of data collection (Model 3; *p*<0.01; *p*<0.05). A self-rated health of fair or poor predicted 2.64 times increased odds of experiencing at least one poor mental health day (*p*<0.001). In fully adjusted models, caring for a person with ADRD alone — but notably not for ADRD and another condition — was associated with 1.24 times greater odds of experiencing at least one poor mental health day per month compared to caregivers for individuals without ADRD (Model 4; *p*<0.01).

Table 4b

Logistic regression models predicting more than half poor mental health days last month by caregiving status, controlling for sociodemographic characteristics, 2019-2022. Survey weights applied.



	Model 1		Model 2		Model 3		Model 4	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds Ratio	95% CI
Cares for person with AD/RD (No ref.)								
Yes	0.94	[0.76,1.15]	0.98	[0.79,1.20]	1.03	[0.84,1.27]	1.04	[0.84,1.29]
Yes+	1.16	[0.98,1.37]	1.19*	[1.00,1.41]	1.20*	[1.01,1.42]	1.14	[0.96,1.36]
Sex (Male ref.)								
Female			0.97	[0.84,1.12]	0.93	[0.80,1.08]	0.99	[0.85,1.16]
Age (18-29 ref.)								
30-44			1.07	[0.87,1.33]	1.18	[0.95,1.46]	1.10	[0.89,1.37]
45-59			0.89	[0.71,1.12]	0.90	[0.71,1.13]	0.78*	[0.62,0.98]
60-74			0.76*	[0.60,0.96]	0.69**	[0.53,0.89]	0.58***	[0.45,0.76]
75+			0.65**	[0.48,0.89]	0.57**	[0.40,0.82]	0.47***	[0.33,0.68]
Race/ethnicity (Non-Hispanic White ref.)								
Non-Hispanic Black			0.82	[0.66,1.01]	0.76*	[0.61,0.95]	0.76*	[0.60,0.95]
Hispanic			0.84	[0.67,1.07]	0.86	[0.65,1.15]	0.82	[0.61,1.09]
Non-Hispanic other			0.92	[0.67,1.26]	0.94	[0.66,1.34]	0.98	[0.67,1.43]
Marital status (Married or partnered ref.)								
Divorced/widowed/separated			1.26**	[1.08,1.47]	1.04	[0.88,1.24]	1.07	[0.89,1.28]
Never married			0.93	[0.78,1.11]	0.76**	[0.63,0.91]	0.80*	[0.67,0.97]
Presence of children <18 years in household					0.91	[0.77,1.06]	0.94	[0.80,1.10]
Education (Some/less than HS ref.)								
HS graduate					1.00	[0.76,1.32]	1.03	[0.79,1.36]
Some college					0.88	[0.67,1.15]	0.93	[0.71,1.21]
College graduate					0.69**	[0.52,0.91]	0.77	[0.58,1.03]
Income (Less than $25K ref.)								
$25K to $49,999					0.80**	[0.67,0.95]	0.91	[0.77,1.08]
$50K to $74,999					0.58***	[0.46,0.73]	0.69**	[0.55,0.88]
$75K or more					0.43***	[0.35,0.55]	0.55***	[0.44,0.69]
Employment status (Employed ref.)								
Unemployed					1.24	[0.97,1.57]	1.15	[0.91,1.47]
Not in labor force					1.63***	[1.37,1.94]	1.35**	[1.13,1.61]
Retired					1.18	[0.92,1.50]	1.11	[0.87,1.42]
Fair/poor self-rated health							2.90***	[2.49,3.39]
Constant	0.65***	[0.60,0.70]	0.73**	[0.58,0.92]	1.54	[0.88,2.66]	0.97	[0.55,1.70]
N	14,616		14,616		14,616		14,616	

* p<0.05, ** p<0.01, *** p<0.001

Like in the data spanning 2015-2022, caregiving status was not associated with experiencing frequent poor mental health days each month in fully adjusted models (Table 4b; Model 4). Providing care for an individual with ADRD and another condition showed 1.19 and 1.20 increased odds of experiencing frequent poor mental health in models adjusting for demographics and demographic and economic variables, respectively, but these results did not survive in fully adjusted models when accounting for fair or poor self-rated health, which was associated with 2.90 increased odds of experiencing frequent days of poor mental health each month ($p<0.001$).

In my second research question, I investigated whether the magnitude of the disparity in poor mental health outcomes for caregivers for individuals with ADRD differed during the COVID-19 pandemic as compared to caregivers for individuals without ADRD.

Figure 2a shows that that providing informal care for a person with ADRD was associated with a higher number of poor mental health days. Figure 3a shows also greater likelihood of experiencing at least one poor mental health day. The magnitude of differences stays largely unchanged before and during the pandemic. Figure 4a shows that the likelihood of experiencing increased likelihood of frequent days of poor mental health was not statistically significantly different for those caring for a person with ADRD in comparison to other caregivers, both before and during the pandemic. Taken together, these findings indicate that the magnitude of mental health disadvantage for ADRD caregivers did not increase during the pandemic.

Figure 2a

Interaction plot displaying number of poor mental health days in the last month by caregiving status and timing (before or during) of the COVID-19 pandemic, 2015-2022.

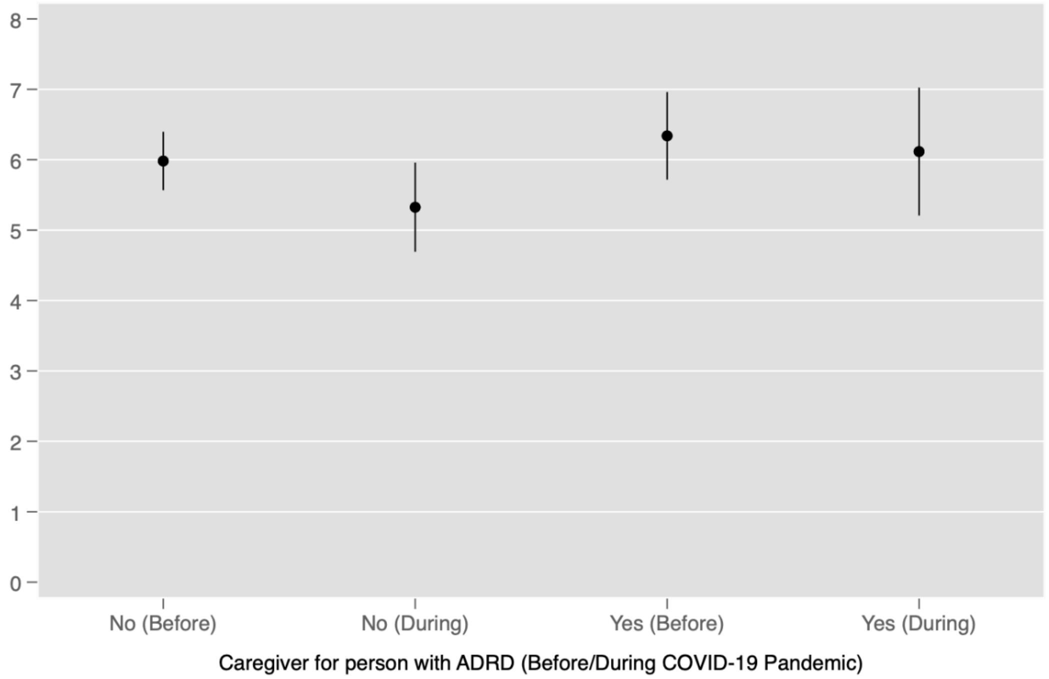


Figure 3a

Interaction plot displaying predicted probability of experiencing any poor mental health days in the last month by caregiving status and timing (before or during) of the COVID-19 pandemic, 2015-2022.

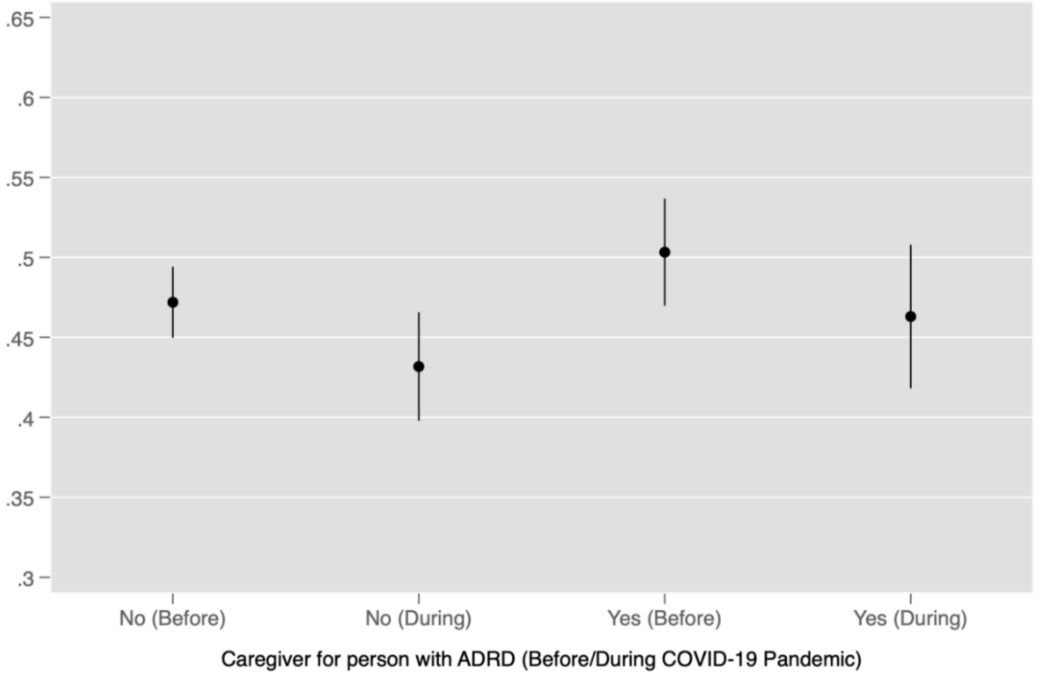
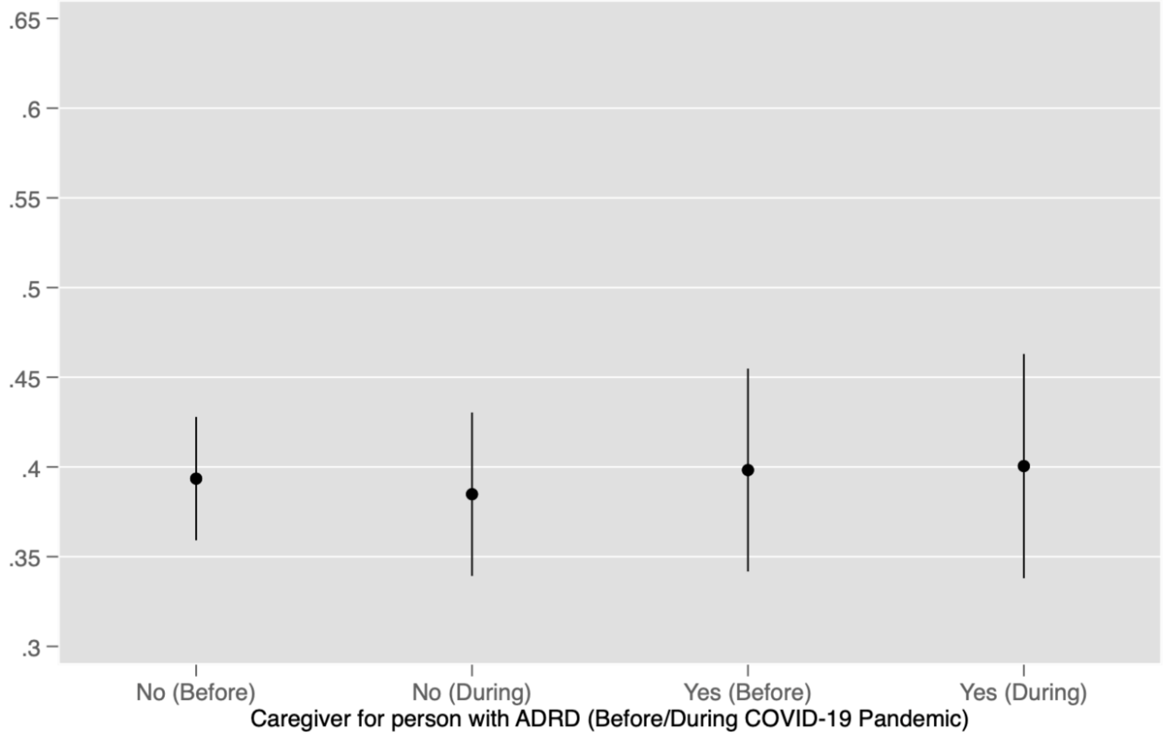


Figure 4a

Interaction plot displaying predicted probability of experiencing frequent poor mental health days (<14) in past month by caregiving status and timing (before or during) of the COVID-19 pandemic, 2015-2022.



Similarly, Figure 2b shows that providing informal care for a person with ADRD and another condition was associated with a higher number of poor mental health days than caregivers for people with solely ADRD or another condition prior to the pandemic. During the pandemic, however, caregiving for individuals with ADRD only was associated with a higher number of poor mental health days than caring for those with ADRD and another condition or only another condition.

Figure 3b shows the greatest likelihood of experience at least one poor mental health day for those caring for individuals with ADRD alone, both before and during the pandemic, compared to caring for those with ADRD and another condition or solely another condition. Figure 4b shows that the likelihood of experiencing greater frequent days of poor mental health was not statistically significantly different for those caring for individuals with ADRD versus other conditions; however, before the pandemic, caregivers for people with ADRD and another condition exhibited a greater likelihood of experiencing frequent poor mental health in the past 30 days compared to caregivers for people with ADRD or another condition alone. Taken together, like in the 2015-2022 data, these findings indicate that the magnitude of mental health disadvantage for caregivers of people with ADRD did not increase during the pandemic.

Figure 2b

Interaction plot displaying number of poor mental health days in the last month by caregiving status and timing (before or during) of the COVID-19 pandemic, 2019-2022.

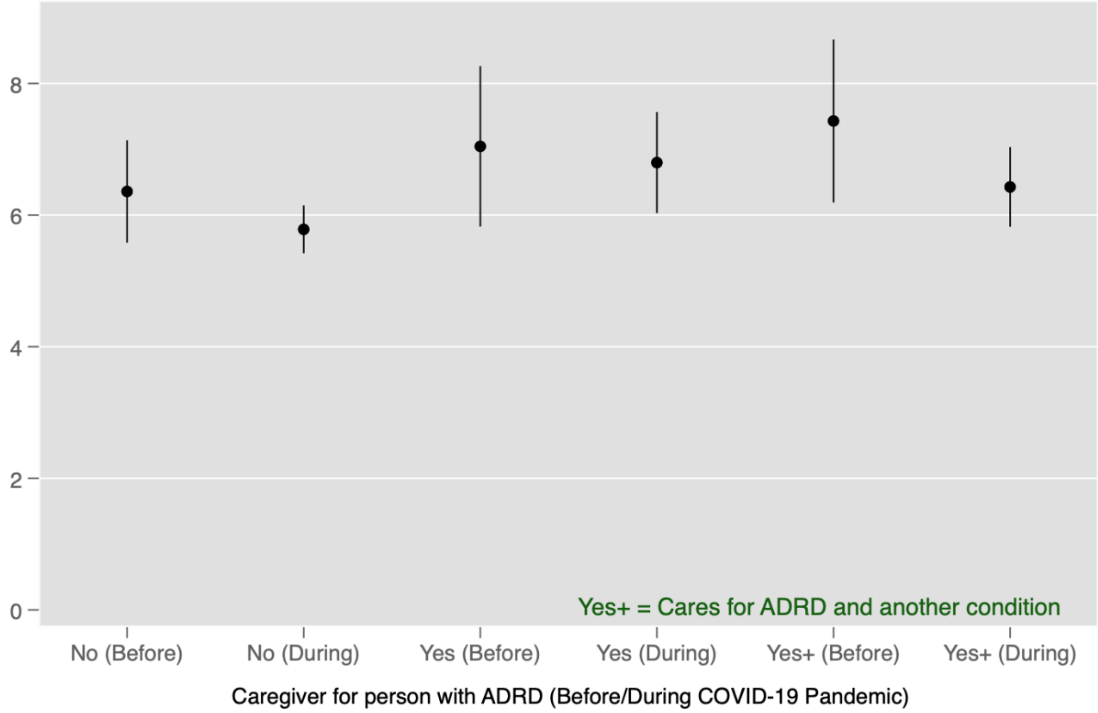


Figure 3b

Interaction plot displaying predicted probability of experiencing any poor mental health days in the last month by caregiving status and timing (before or during) of the COVID-19 pandemic, 2019-2022.

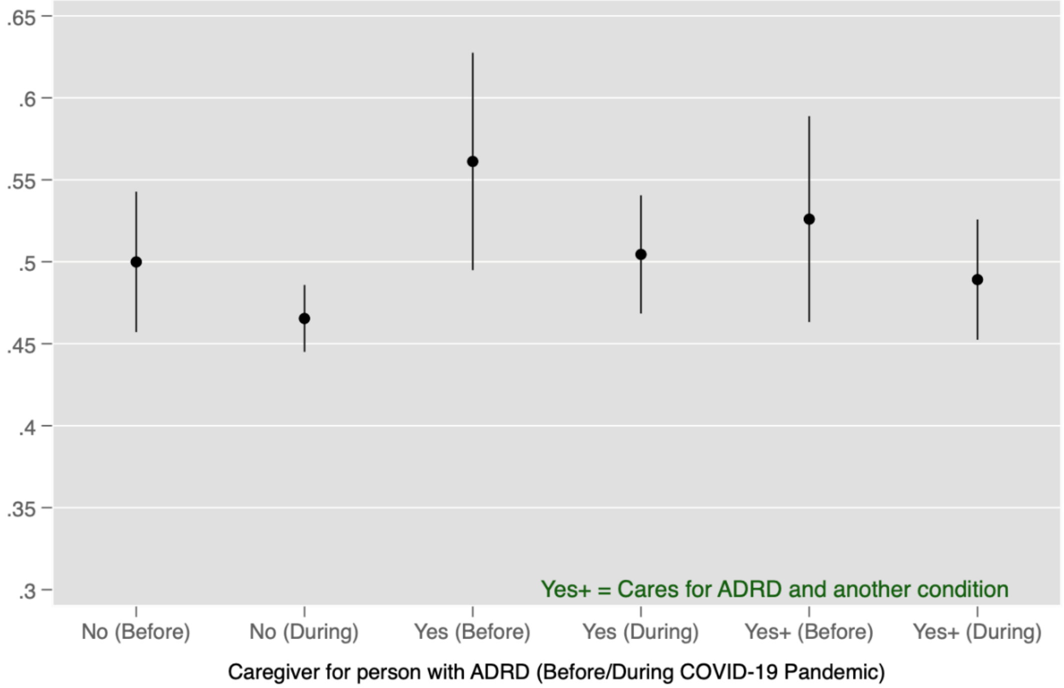
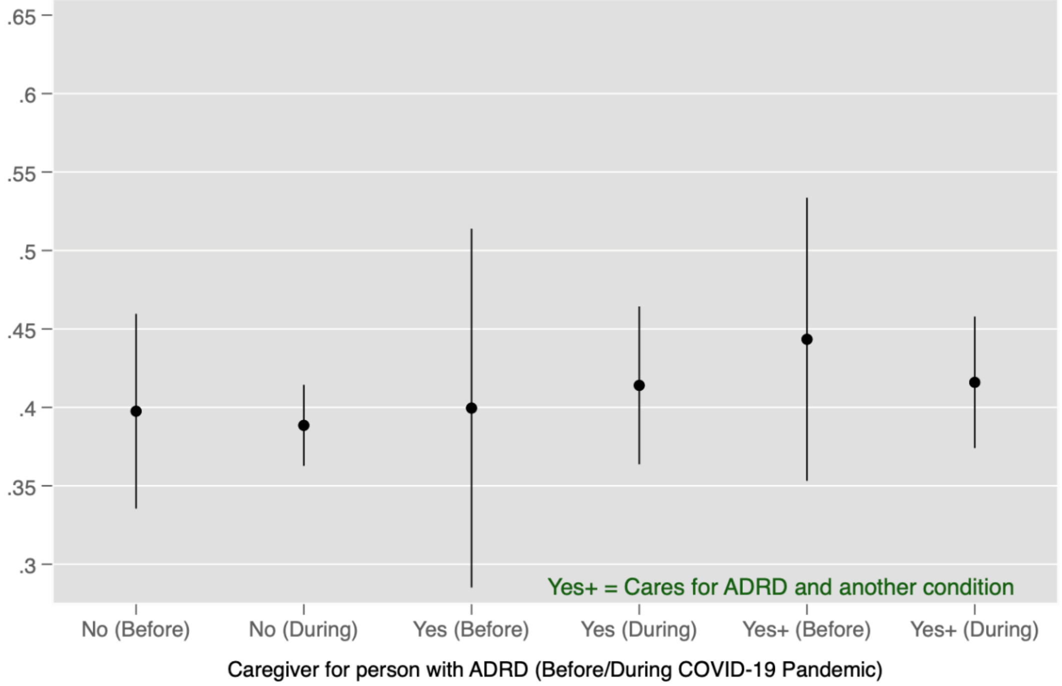


Figure 4b

Interaction plot displaying predicted probability of experiencing frequent poor mental health days (<14) in past month by caregiving status and timing (before or during) of the COVID-19 pandemic, 2019-2022.



VI. Limitations

Despite the study's important contributions, it has several limitations which need to be considered. First, though the BRFSS is a large nationally representative dataset, it is cross-sectional, which limits the conclusions I can draw about the impact of global events like the COVID-19 pandemic on caregiver mental health over time. Further, though the survey made great strides in 2015 to incorporate a caregiver question module, this module remains optional and contains few questions gauging the care recipient's health status. This limitation is magnified by the fact that the CDC only added questions allowing caregivers to indicate providing care for people with both Alzheimer's disease and another condition in 2019, rendering data from 2015-2019 partially incompatible with that from 2019-2022. Prior to 2019, respondents were instructed to select the "main" health condition or illness their care recipients had, which may have obscured some cases of Alzheimer's disease and related dementias.

In constructing my analytic sample, I performed listwise deletion, removing any observations that had missing values for outcome or control variables. Though this method preserved statistical power, it also assumes that those with missing information are a random subset of the sample. However, the most observations were dropped for caregivers who did not specify their race/ethnicity or income, which could be attributed to sensitivity surrounding the disclosure of this information (e.g., those with extremely high or extremely low incomes). As a result, the final analytic sample may have inadvertently narrowed the full range of mental health outcomes experienced by informal caregivers before and during the pandemic. The analysis could be rerun to include observations with missing race/ethnicity or income, though careful consideration is needed to determine which missing outcomes to permit or exclude.

Further, the survey's existing mental health measures are limited and nonspecific: caregivers are asked only for the number of poor mental health days they experienced in the last thirty days. Consequently, my analysis was limited to three outcomes based on this measure. Although the measure has been validated by prior research (Hennessy et al., 1994), one's mental health can fluctuate within a day and across weeks or months at a time. These metrics may not perfectly capture the state of a caregiver's mental health or their daily experiences, especially depending on when they were given the BRFSS questionnaire.

Additional limitations of the analysis pertain to the selection mechanisms that operate both at the state and individual levels. Because the questionnaire is an optional component of the BRFSS and not all states chose to administer it, it may be the case that the experiences of caregivers in states that do not administer the caregiver module is different from those that do. For example, one may speculate that there may be fewer resources and support services for caregivers available in states that opt-out of collecting data about the caregiving experiences. On the individual level, caregivers with more time-consuming caregiving responsibilities may have been less likely to complete the survey due to preoccupation with other duties; in turn, information on these more severe cases may be missing from the BRFSS dataset. Both of these selection mechanisms would translate to the underestimation of the mental health toll of caregiving by my study.

My study would have also been strengthened by measuring the total number of caregivers and the relationship between the care recipient and caregivers, as both may impact the relationship between caregiving and mental health outcomes. However, this information was not collected by the survey. Moreover, while the BRFSS began to collect more detailed information on gender in recent years (Baker, 2019), these data were not available for every state included in my study, and I used sex at birth. Because caregiving is a highly gendered experience, gender would have been a preferable measure. In addition, due to sample size demands, I classified all respondents who were not self-identified as White, Black, or Hispanic, as "other." This classification does not appropriately capture the significant heterogeneity that exists within this group and may not adequately capture the experiences of the racially and ethnically diverse group of caregivers who were assigned to this category.

VII. Conclusion

Using high-quality, nationally representative data, my study investigates the mental health effects of caregiving on ADRD caregivers before and during the pandemic. I found that providing informal care for a person with Alzheimer's disease or related dementias was associated with experiencing a higher number of poor mental health days and a greater likelihood of experiencing at least one poor mental health day per month compared to those caring for individuals with other illnesses or conditions. Though the COVID-19 pandemic has been shown to have severely impacted the caregiving landscape and caregiver resource availability, particularly in the pandemic's early stages, I found that the disparities in mental health outcomes between those caring for PLWD and those caring for other types of care recipients did not disproportionately increase during the pandemic. Potential reasons for the absence of larger disparities following the pandemic's onset could be that informal caregivers, regardless of the illness or condition for which they provide care, were universally impacted due to quarantines, lockdowns, and other pandemic-era public health measures. Therefore, while the mental health toll of caring for a person with ADRD is greater than caring for other conditions, the pandemic itself did not exacerbate this existing disparity due to widespread closure of support services and insularity of home care environments.

Future research on this topic should more precisely define date ranges that distinguish "before" and "during" the COVID-19 pandemic to gauge whether certain periods, such as lockdown or quarantine, were associated with disparities in informal caregiver outcomes. Caregiving is also a highly gendered role, warranting additional investigation into the potential differences in caregiver mental health outcomes by gender. As the number of people living with dementia continues grow, the ratio of informal caregivers to those in need of care continues to diminish. This holds the potential to exacerbate such caregivers' mental health outcomes. My work here offers new insight into the experiences of informal caregivers on a population level, calling attention to the greater need for public resources and support to address the high toll of caregiving seen among those providing care for individuals with Alzheimer's and dementia.

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