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Title: Financial Toxicity in Dementia Caregiving: Sociodemographic Predictors in a U.S. Nationally-Representative Survey

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Abstract

BACKGROUND & OBJECTIVES: “Financial toxicity” describes the negative effects of medical expenses on financial security and health-related quality of life. Beyond dementia, financial toxicity is used to address the financial and health consequences of illness. Here, we utilize the Comprehensive Score for financial Toxicity (COST) to examine the experience of financial toxicity in dementia caregiving.

RESEARCH DESIGN & METHODS: We conducted a nationally-representative survey of 317 dementia caregivers. Financial toxicity was defined as COST <26 and categorized as mild (COST ≥14 & <26), moderate (COST >0 & <14), or severe (COST = 0). Nested multivariable regression examined potential predictors of financial toxicity. Mediation analyses were performed to assess whether the influence of basic caregiver demographic predictors were mediated by care recipient clinical characteristics, caregiver socioeconomic demographics, or relational characteristics.

RESULTS: 52.7% of dementia caregivers in the U.S. experience financial toxicity. Of those, 73.1% endure mild, 25.7% moderate, and 1.2% severe toxicity. 69.5% of Black, 54.1% of Hispanic, and 42.3% of White caregivers report financial toxicity, with prevalence significantly higher in Black caregivers compared to White caregivers ($p = 0.017$). Older caregiver age was associated with less financial toxicity ($p = 0.024$). Caregiver employment status mediated this effect, with retirement associated with less financial toxicity ($p < 0.001$) and unemployment associated with greater financial toxicity ($p < 0.001$).

DISCUSSION & IMPLICATIONS: Most dementia caregivers in the US experience financial toxicity, with Black caregivers bearing the highest risk. Older caregiver age protects against financial toxicity, reflecting the relationship between age and employment status.

Keywords: “Caregiver burden”, “healthcare costs”, “neurology”, “cognitive”

Introduction

Dementia often imposes significant financial costs for the families of people with dementia, reflecting the prolonged impact of progressive neurodegeneration on employment and activities of daily living. Assessing these financial effects has posed unique challenges. Standard socioeconomic measures applied to other disorders only highlight the “tip of the iceberg” (El-Hayek et al., 2019) of costs in dementia, as a substantial proportion are indirect (e.g. lost wages subsequent to unpaid care provided by family and friends). Additionally, many direct costs are not covered by health insurance or social programs but are instead paid out-of-pocket by families (Kelley et al., 2015). Different methods used in quantifying these costs yield widely disparate estimates. Other burdens in dementia care include reductions in quality of life and psychological and other health effects of caregiving; efforts to quantify these using standard measures such as quality-adjusted life years have also proven controversial (Getsios et al., 2007; Jönsson et al., 2017).

Another approach to addressing the financial impact of dementia caregiving applies the framework of caregiver burden, strain, or stress. While caregiver burden traditionally includes the financial toll of care provision (Zarit et al., 1986), the most widely-used and well-validated scales used in dementia research either do not specifically assess financial impacts or include only unidimensional item assessments of financial concern within broader composite measures (Bédard et al., 2001; Novak & Guest, 1989; Thornton & Travis, 2003; Zarit et al., 1980). Though two recent papers specifically assessed dementia caregivers' financial burden, their novel two-item scales were not independently validated (Liu et al., 2019; Zhang et al., 2023). Thus, while the financial consequences of dementia for families are widely recognized, there is a lack of measurement tools to serve as targets for clinical and policy interventions.

In other serious medical conditions, the framework of "financial toxicity" has been used to characterize the negative financial effects of illness, medical expenses, and other disease-related costs on patients and caregivers with regards to their financial security and health-related quality of life. This encompasses material hardship, psychological burden, and adverse coping behaviors secondary to the distress associated with both direct and indirect costs of medical care (Benedict et al., 2022). The term "financial toxicity" was first introduced in 2013 to describe patient-level impacts of the cost of cancer care (Zafar & Abernethy, 2013), reflecting structural features of care delivery that have systemic costs that are often quantified in policy but also have individual burdens that have too often gone unaccounted. Since then financial toxicity has been extensively described in cancer, including financial and legal consequences such as bankruptcy or reduced spending on food and clothing, and medical consequences such as such as decreased adherence to treatment, missed outpatient visits, increased acute care utilization, and early mortality (Shi et al., 2023; Smith et al., 2019; Zafar et al., 2013). More recently, the oncology literature has turned from characterizing financial toxicity to proposing interventions such as financial navigation and policy reform (Desai & Gyawali, 2020; Yuan et al., 2023); such developments also call for tools to characterize financial toxicity so that interventions can be targeted to groups in greatest need and the impacts of such interventions can be assessed.

Financial toxicity has also been increasingly studied in non-oncologic conditions (Gompers et al., 2023; Scholes-Robertson et al., 2023). The COmprehensive Score for financial Toxicity (COST) assesses monetary and psychological features of financial burden and has been psychometrically validated to quantify financial distress experienced by patients (de Souza et al., 2017) and, using a modified version, their caregivers (Sadigh et al., 2022).

Previous work applying the COST in other clinical contexts has found racial and ethnic disparities in financial toxicity affecting Hispanic and Black patients (Benedict et al., 2022; Esselen et al., 2021). Disparities have also been documented between rural and urban settings, with rural patients experiencing greater financial toxicity and out of pocket costs compared to those in more urban regions (Scholes-Robertson et al., 2023). Financial toxicity has been shown to have a clear relationship with both income and employment status (de Souza et al., 2017; Mols et al., 2020), but there appear to be mixed results regarding its association with age in determining whether the young or the old are at higher risk (Skinner et al., 2023; Wang et al., 2024).

Financial toxicity has not yet been applied to characterize monetary burdens in dementia caregiving, despite the well-known costs of dementia. The absence of valid measurement tools may hinder the development and targeting of dementia-specific interventions to address financial toxicity. To address this gap, in this preregistered nationally-representative study, we utilize the COST to examine financial toxicity in dementia caregiving and identify potential sociodemographic and clinical correlates.

Methods

Study Design and Participants

As outlined in our preregistration (https://osf.io/ry2fc), this study was conducted as part of a larger nationally-representative cross-sectional survey of US dementia caregivers. Data collection procedures were based on a preregistered sample size calculation, including deliberate oversampling for Hispanic and Black caregivers. These populations are at increased risk for financial toxicity in other conditions, and so were oversampled to facilitate demographic comparisons in our analysis. Power analyses in our preregistration were estimated using two-sample tests of means. For demographic characteristics, at a significance level of 0.05 and power of 0.8 we prospectively estimated we would have power to detect a difference of d = 0.37 ("small-medium") between either Black or Hispanic respondents and White respondents.

Participants were drawn from the NORC AmeriSpeak panel at the University of Chicago, a large, IRB-approved, probability-based panel representative of the U.S. household population. To build their panel, NORC randomly selects U.S. households using area probability and address-based sampling with information from the decennial Census. They then utilize a two-stage recruitment: (1) initial recruitment through mailers and phone contact and (2) for those households that do not respond, a nonresponse follow-up consisting of enhanced incentives and in-person interviews. The panel provides sample coverage of approximately 97% of the U.S. household population. Those excluded from the sample include people with P.O. Box only addresses, some addresses not listed in the USPS Delivery Sequence File, and some newly constructed dwellings. Individuals not randomly selected are not invited to join the panel.

Standard, preexisting data on all participants in the panel include basic demographics such as gender, age, race/ethnicity, and rural/suburban/urban residence. Other variables are also available based on responses to previous surveys. We determined the eligibility of sampled panel members with a dementia-specific screening question based on a stem used in five AARP/NAC Caregiving in the US surveys from 1997-2020 (Caregiving in the U.S. 2020: A Focused Look at Family Caregivers of Adults Age 50+, 2020): “At any time in the last 12 months, have you provided unpaid care to a relative or friend 50 years or older who has Alzheimer’s disease, dementia, or other mental confusion, to help them take care of themselves? This may include helping with personal needs, household chores, money management, arranging services, or regular visits to see how they are doing. This person need not live with you.” Those who answered affirmatively were invited to participate. The survey was fielded from July 22, 2022, to August 8, 2022, offered in both English and Spanish, and conducted either on the internet (including mobile web) or over the phone. All Spanish translation for this study was conducted by a team of accredited specialists, consisting of a sworn translator, a legal translator, and a Spanish linguist. This includes translation for both measures used in this study’s survey, as there is no formally validated

Spanish version for the COST modified for caregivers nor for the Quick Dementia Rating Scale (QDRS). Because the COST requires respondents to have provided care in the past 7 days, only participants who were currently providing care were eligible to be included in the financial toxicity analysis. As a result, this study's sample represents a subset of the parent sample identified by the dementia-specific screening question. Written informed consent was obtained from participants during AmeriSpeak panel enrollment. All study activities were approved by the Institutional Review Board for NORC at the University of Chicago.

Measured Variables

Financial Toxicity. We utilized the COST modified for caregivers (Sadigh et al., 2022) to measure financial toxicity in our study population. The COST includes 11-items that assess both material and psychological features of financial burden, including direct costs related to care (e.g. out of pocket expenses), indirect costs (e.g. employment changes and loss of income), and psychological responses (e.g. financial worry and personal control over finances). Participants are prompted to consider how the statements apply to them in the past 7 days. Responses are fixed on a scale from 0 = "not at all" to 4 = "very much". Total scores are calculated from 0 to 44; lower scores represent greater financial toxicity. A COST grading system was developed and validated in correlation with health-related quality of life (De Souza et al., 2017). The categories include none (COST ≥26), mild (COST ≥14 & <26), moderate (COST >0 & <14), and severe (COST = 0). A recent systematic review of the psychometric properties of different measures of financial toxicity in cancer survivors has recommended the COST as the most suitable worldwide available measure

(Zhu et al., 2022); a validation study of the original COST measure demonstrated a Cronbach α of .92 and a test-retest intraclass correlation coefficient of 0.80 (de Souza et al., 2017), and the COST modified for caregivers demonstrated a Cronbach α of 0.91 (Sadigh et al., 2022).

Caregiver Demographics. NORC provided data on caregiver age, gender, race/ethnicity, rurality, education, household income, and employment status.

NORC asks panel members about their gender using the question “How do you describe yourself?” with the categorical responses of male, female, transgender, and do not identify as male, female, or transgender as possible answer choices. In this manuscript, we follow contemporary usage and use the terms “women” and “men” when referring to social gender categories.

Race and ethnicity were self-reported by panel members and provided by NORC as a combined variable. The first category was Hispanic, followed by several non-Hispanic categories including Asian, Black, multiracial, other race, and White. Respondents who self-identified as non-Hispanic and Native Hawaiian or other Pacific Islander were included in the Asian category and those who self-identified as non-Hispanic and American Indian, Alaska Native, or another race were included in the other race category.

NORC assesses rurality using Rural-Urban Commuting Area (RUCA) codes as applied to participants’ census tract or ZIP code, with RUCA codes 4-10 equivalent to “Rural” and RUCA codes 1-3 corresponding to either “Suburban” or “Urban” depending on whether participants reside in the largest city in the area.

Employment status is reported as self-employed, working as a paid employee, temporarily laid-off, looking for work, retired, disabled, or otherwise not working.

Care Recipient Demographics and Clinical Characteristics. To supplement the standard demographics pre-collected for all panel members, we also obtained participant-reported information about their care recipients including age, gender, race/ethnicity and rurality. Given the experience of dementia caregiver burden has been shown to vary with dementia diagnosis and severity (D'Onofrio et al*.,* 2015*;* Kang et al*.,* 2014), we also asked participants for clinical information, namely their care recipient's dementia diagnosis, dementia stage, and whether dementia was the primary condition for which they required care.

Participants could choose from the following list to describe their care recipient's diagnosis: Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia, Parkinson's disease dementia, primary progressive aphasia, Huntington's disease, dementia only (no other label), mild cognitive impairment, other, no diagnosis, or I don't know.

Dementia stage was classified as very mild, mild, moderate, or advanced using the QDRS-derived Clinical Dementia Rating (CDR) score. Caregivers completed the memory and recall, orientation, decision making and problem-solving abilities, activities outside the home, function at home and hobby activities, and toileting and personal hygiene portions of the QDRS, to which the rules for CDR scoring were applied (Galvin, 2015).

Interpersonal Variables. To characterize caregivers' interactions with care recipients and assess how various dyad dynamics may or may not impact the experience of financial toxicity, we asked participants about care recipients' relationship to them, their care recipient's residence setting, how frequently they visited their care recipient, and whether they were their care recipient's primary caregiver.

To avoid collinearity with care recipient gender, care recipient relationship to the caregiver was collected in gender-neutral categories: spouse/partner; parent; sibling; grandparent; another relative; a friend, neighbor, or someone else not in your family.

Participants could describe care recipients' residence setting as in the caregiver's household, a home by themselves, a home with someone else, an independent living or retirement community, an assisted living facility, a nursing care or long-term facility, or somewhere else.

Visit frequency was collected using the following categorization: more than once a week, once a week, a few times a month, once a month, a few times a year, or less often than a few times a year.

Primary caregiver status was assigned to caregivers who reported they either provided all the unpaid care, provided most of the unpaid care with help from others, or split most of the unpaid care with others evenly.

Statistical Analysis

Survey weights were provided by NORC. Our survey was not designed with adequate power to estimate differences in perspectives among Asian, other race, multiracial, transgender, and non-binary participants. To avoid model estimation errors due to small cell counts, responses from participants within these groups were excluded from racial/ethnic and gender comparisons in our analysis. For similar reasons, employment status, caregiver-recipient relationship, and recipient residence setting were collapsed to the following: employment status (working, retired, disabled, other unemployed), care recipient relationship to caregiver (spouse/partner, parent, other relative, non-relative), recipient residence setting (in the caregiver's home, in a separate home, in long-term or residential facility). We modeled three diagnostic subgroups (Alzheimer's disease, unspecified dementia, and mild cognitive impairment) as binary predictors and did not attempt to model the influences of other diagnoses given small cell counts.

In modeling the influence of race and ethnicity, White, non-Hispanic caregivers were designated as the reference category, as our research question was focused on differences between Hispanic and White caregivers and between Black and White caregivers, and not on differences between Hispanic and Black caregivers. Locale was dichotomized as rural vs urban/suburban residence, with urban/suburban residence set as the reference category given documented disparities in financial toxicity experienced in rural compared to settings with greater infrastructure and access to care resources.

Predictor selection was performed according to our preregistered analytic plan. Four nested, survey-weighted, linear models were constructed, with COST as the outcome variable. Model 1 included base caregiver demographic characteristics: age (mean-centered and scaled by decade), gender, race/ethnicity, and rurality. Model 2 included all predictors from Model 1 and added care recipient characteristics: age, gender, race/ethnicity, rurality, dementia stage, dementia diagnosis and whether dementia is the primary condition for which the care recipient requires care. Care recipient race/ethnicity and rurality were specifically tested for collinearity with caregivers, with a threshold of <80% concordance. Model 3 included all predictors from Model 2 and added supplemental caregiver characteristics: education, household income (defined as the midpoint of the participant's income bracket, scaled per $10,000 and median-centered), and employment status. Model 4 included all predictors from Model 3 and added relational characteristics: care recipient relationship to caregiver, care recipient residence, primary caregiver status, and visit frequency. In all models, predictors were tested for multicollinearity, with a cut-off of adjusted Generalized Variance Inflation Factor (aGVIF) <5 required for inclusion in our final analysis. The four models were then compared sequentially. Beginning with Model 1, ANOVA was conducted with the nearest model (Model 2) to evaluate whether the added predictors significantly explained more variability in the outcome than the simpler model, with a significance threshold of $p = 0.05$; if yes, this was repeated for Model 2 vs. Model 3; and if yes, then Model 3 vs. Model 4. To determine whether the effects of significant predictors in the base model (model 1) were mediated by statistically significant variables introduced in the selected adjusted model, a model-based causal mediation analysis was performed with statistical significance testing based on a Monte Carlo procedure running 10,000 simulations. Statistical analyses were performed using R 4.1.3 and the *tidyverse*, *survey*, *srvyr*, and *mediation* packages. The de-identified data set and code used in this study have been posted online for public access and can be found at osf.io/r3fsh/.

Results

Sample Characteristics

There were 317 active caregivers who were included in the financial toxicity subsample. Caregiver and care recipient characteristics are summarized in Table 1. Consistent with our planned racial/ethnic oversampling, there were 61 (19%) Hispanic caregivers and 75 (24%) Black caregivers. Six caregivers (2%) completed the survey in Spanish. The remaining 311 (98%) elected to participate in English.

Descriptive Statistics

In this nationally-representative sample of dementia caregivers, the modified COST for caregivers demonstrated good internal consistency with a Cronbach α of 0.88. In a survey-weighted analysis, 52.7% of caregivers reported some degree of financial toxicity (38.5% mild, 13.6% moderate, 0.63% severe). Black caregivers were more likely than White caregivers to experience financial toxicity (OR 2.65, p= 0.017) using the four-category COST grading system (Figure 1).

Model Findings

Care recipient race/ethnicity was excluded as a predictor from modeling because it was 80% concordant with caregiver race/ethnicity. Similarly, while our preregistered analysis plan included visit frequency, this variable could not be separated from residential setting (as many care recipients live in the same home as the caregiver) and so was also excluded from modeling. Our preregistered predictor selection procedure, comparing each nested model to the next most complex model to determine whether the added predictors significantly improved predictions of the variance of the COST score, identified model 4 as the preferred adjusted model.

Coefficient estimates for predictors in the base model (Model 1, adjusted for key caregiver demographics) and in the adjusted model (Model 4, adjusted for key caregiver demographics, care recipient clinical characteristics, supplemental caregiver demographics, and caregiver-recipient relational characteristics) are presented in Table 2. In the base model, older caregivers reported less financial toxicity (beta [scaled per decade] = 0.99, p = 0.024; note that increasing COST score indicates lower financial toxicity), while race, ethnicity, and rurality were not significantly associated with financial toxicity.

After incorporating care recipient clinical characteristics, supplemental caregiver demographics, and caregiver-recipient relational characteristics in model 4, age was no longer significantly associated with financial toxicity. In this model, caregiver employment status and primary caregiver status were significant predictors of financial toxicity; retirement was associated with significantly less financial toxicity (beta = 9.4, $p < 0.001$), and both unemployment and primary caregiver status were associated with significantly greater financial toxicity (beta = -4.7, -5.3; p = 0.006, 0.003, respectively).

Causal mediation analyses (Figure 2) revealed that employment status was a significant mediator in the effect of age on financial toxicity. This was demonstrated by two models. In one analysis examining the mediating effect of retirement, older caregiver age was associated with increased retirement, and retirement was associated with less financial toxicity (average causal mediation effect p = 0.002). In a second analysis examining the mediating effect of unemployment, older caregiver age was associated with less unemployment, and unemployment was associated with more financial toxicity (average causal mediation effect p = 0.047). In an exploratory model including the demographic predictors from the base model plus only employment status, age was no longer significant and the parameter estimate for age reversed sign (Model 1 beta per decade 0.99 to exploratory beta per decade -0.37, p = 0.5). Thus, older caregiver age was negatively associated with financial toxicity only through the relationship between age and employment status, with no significant effect of age of financial toxicity in the adjusted model.

Discussion

In this preregistered, nationally-representative study, we found that most dementia caregivers in the United States experience financial toxicity. The prevalence of financial toxicity is greater among Black caregivers than White caregivers, though this difference was not reflected in models of COST as a continuous measure. Older caregivers experienced less financial toxicity, though notably this effect of age on the experience of financial toxicity was found to be mediated by employment status. Older caregivers were more likely to be retired and less likely to be otherwise unemployed; retired caregivers experienced less financial toxicity and unemployed caregivers experienced more financial toxicity.

Our findings suggest the prevalence of financial toxicity in dementia caregiving is similar to that described in cancer caregiving (Nguyen et al., 2023; Sadigh et al., 2022). Dementia care is associated with costs nearly 57% greater than that of cancer in the last five years of life (Kelley et al., 2015). New trends in dementia treatment, potentially heralded by the FDA's approval of monoclonal antibody treatments for Alzheimer's disease, could further increase financial burdens associated with dementia care. The yearly cost of lecanemab has been projected at $26,500 per year (Jönsson et al., 2023); which does not include the costs of infusion services, increased physician follow-up, and substantial baseline and surveillance imaging (Knopman & Hershey, 2023). Medicare part B generally covers about 80% of covered medications and services, so many patients and families will incur thousands of dollars in out-of-pocket expenses. While a new era of targeted molecular treatments for dementia holds great potential promise, our findings on financial toxicity indicate that such potential benefits may be practically inaccessible for many families.

Our finding of increased prevalence of financial toxicity among Black caregivers comports with findings in other serious and chronic health conditions. These findings may reflect the combined influences of historical inequities limiting generational wealth transfer (Himmelstein et al., 2022), ongoing socioeconomic racial disparities, and disparities in resource access and efficacy for caregiver support. Current literature suggests Black caregivers utilize support services less frequently, perhaps due to decreased awareness of their existence and barriers that limit access (Chin et al., 2011; Parker & Fabius, 2020). When Black caregivers do utilize resources for support, interventions have been less effective (Graham-Phillips et al., 2016; Herrera et al., 2013). In their analysis of the implementation of dementia caregiver support services, Graham-Phillips et al reported that Black caregivers received less intervention contact compared to caregivers of other backgrounds (Graham-Phillips et al., 2016). More research is needed to better understand why caregiver support services are under-utilized and less effective in this community.

Older caregiver age is associated with less financial toxicity. This finding could be considered surprising given that studies in the greater field of informal caregiving have suggested older caregivers are at higher risk of caregiver burden (Choi et al., 2024), possibly due to increased risk of age-related physical and cognitive decline that can be exacerbated by caregiving responsibilities and contribute to caregiver burden (Schulz et al., 2020). Even so, there is a growing body of literature highlighting the unique burdens experienced by the “sandwich generation,” caregivers who provide care for both their children and parents, grandparents, or in-laws (Fenstermacher et al., 2022). Sandwich generation caregivers tend to be younger and experience more substantial financial and emotional distress compared to caregivers not caring for minor children (Lei et al., 2023).

We found diminished financial toxicity among older dementia caregivers is mediated by caregiver employment status, as retired caregivers experience less financial toxicity and unemployed caregivers experience more. Interestingly, while employment status was a significant predictor for financial toxicity, income was not. Financial toxicity has been shown to be negatively associated with income in the field of cancer (de Souza et al., 2017), but it appears that employment status may be a better metric to assess for financial vulnerability in dementia. Income does not capture non-monetary assets, nor does it account for debts, and so may diverge from wealth. Lifetime accumulation of wealth is increasingly a prerequisite for retirement in the US, as trends like the replacement of defined-benefit pension plans with defined-contribution accounts have shifted responsibility from employers and institutions to households. Older Americans control a significant portion of the wealth in the United States; in 2024, Americans aged 55 years and older owned over 70% of wealth in the US, with Americans 70 years and older owning over 30% (Distribution of Household Wealth in the U.S. since 1989, 2024). These findings have implications for the targeting of interventions to address financial toxicity among dementia caregivers, as targeting resources to younger and unemployed caregivers may have a larger impact than distributing support based on income.

Our study did not find a significant association between rurality and financial toxicity among dementia caregivers. This may reflect the relatively lower cost of living in rural areas, which can lessen financial strain. For instance, although rural Americans have lower median incomes than urban households, people living in rural areas have lower poverty rates than their urban counterparts (Bishaw & Posey, 2016).

Several sociodemographic and clinical characteristics of our sample draw attention to the differences between caregiver-recipient dyads seen in the clinical setting and in the broader population. For example, in our survey only 9.2% of caregivers were caring for a spouse. While spouse caregivers are often seen in specialty clinics and in dementia clinical trials, this lower proportion is consistent with estimates from other national surveys such as those from the AARP/NAC (Caregiving in the U.S. 2020: A Focused Look at

Family Caregivers of Adults Age 50+, 2020). Additionally, 52% of caregivers reported they were caring for a loved one with “very mild” dementia as defined by the QDRS-derived CDR score, which roughly corresponds to a clinical diagnosis of mild cognitive impairment. While there are roughly 6.2 million Americans living with dementia, it is estimated that 10.5-13.6 million Americans over the age of 65 live with mild cognitive impairment (“2023 Alzheimer’s Disease Facts and Figures,” 2023).

We acknowledge several limitations in this study. The first is non-response bias, an inherent limitation of survey-based research. This source of bias is especially pertinent for our study, which aimed to characterize financial distress. While the NORC AmeriSpeak panel includes several features to limit the influence of non-response bias, including its two-stage recruitment process, it is likely that the most burdened caregivers did not or could not participate due to time constraints or limited mental bandwidth, which could systematically bias our survey towards underestimating financial toxicity. While our study design included purposeful oversampling of Hispanic and Black caregivers to facilitate estimates and demographic comparisons in these groups, we did not oversample transgender, non-binary, Asian American and Pacific Islander, Native American, and multiracial caregivers, limiting our ability to estimate and compare financial toxicity across these groups. The lack of a formally validated Spanish translation for both the modified COST for caregivers and the QDRS, as well as the small proportion of caregivers who elected to participate in Spanish, limits the interpretation of these results for primarily-Spanish-speaking caregivers. More work is needed to validate these measures in Spanish so the experience of this population can be studied with higher confidence. Additionally, the COST is designed for active caregivers. Thus, the sample included in this study represents only a subset of the parent survey, with a smaller sample size than anticipated in our preregistration. Even so, our study represents one of the largest nationally-representative surveys of dementia caregivers to date (Behavioral Risk Factor Surveillance System Overview: BRFSS 2015, 2016; Caregiving in the U.S. 2020: A Focused Look at Family Caregivers of Adults Age 50+, 2020; Freedman et al., 2023). Finally, by defining ‘primary caregiver’ to include people who split caregiving evenly with others, we expand the generalizability of the significant association between primary caregiver status and more severe financial toxicity to a wider population, but at the cost of our ability to make specific statements about participants who strictly provide a majority of care to patients. Further studies are required to examine the financial toxicity of dementia caregivers and its association with the portion of care provided.

Conclusion

Most dementia caregivers in the US experience financial toxicity, with Black caregivers bearing the highest risk. Older caregivers experience less financial toxicity, mediated by the relationship between caregiver age and employment status. Our findings are concordant with prior efforts to estimate the financial costs and measure related burdens of dementia caregiving. These findings provide guidance for future interventions to address pervasive social and financial impacts of dementia caregiving, particularly among Black caregivers and younger caregivers of working age.

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Tables/Figures

Table 1. Sample Demographics

Characteristic	N = 317[1]
Caregiver gender	
Men	125 (39%)
Women	192 (61%)
Caregiver age	49 +/- 17
Caregiver race/ethnicity	
Hispanic	61 (19%)
Asian	6 (1.9%)
Black	75 (24%)
Multiracial	11 (3.5%)
Other	4 (1.3%)
White	160 (50%)
Caregiver rurality	
Rural	50 (16%)
Suburban	142 (45%)
Urban	125 (39%)
Caregiver education	
Less than high school	18 (5.7%)
High school graduate or equivalent	76 (24%)
Vocational/tech school/some college/associates	134 (42%)
Bachelor's degree	45 (14%)
Post grad study/professional degree	44 (14%)
Caregiver income	
Under $20,000	56 (17.3%)
$20,000 to under $50,000	97 (31.1%)
$50,000 to under $100,000	102 (32%)
$100,000 or more	62 (19.5%)
Caregiver employment status	
Disabled	31 (9.8%)
Retired	56 (18%)
Unemployed	60 (18.9%)
Working	170 (53%)
Care recipient age	76 +/- 11
Care recipient gender	
Men	105 (33%)
Women	211 (67%)
Transgender	0 (0%)
Do not identify as man, woman or transgender	1 (0.3%)
Care recipient rurality	
Rural	121 (38%)

Urban/Suburban	195 (62%)
Dementia stage	
Very mild	164 (52%)
Mild	94 (30%)
Moderate	37 (12%)
Advanced	22 (6.9%)
Dementia diagnosis[2]	
Alzheimer's Disease	62 (20%)
Frontotemporal Dementia	8 (2.5%)
Huntington's Disease	3 (0.9%)
Lewy Body Dementia	13 (4.1%)
Parkinson's Disease Dementia	16 (5.0%)
Primary Progressive Aphasia	6 (1.9%)
Vascular Dementia	16 (5.0%)
Mild Cognitive Impairment	43 (14%)
Unspecified dementia	57 (18%)
No formal diagnosis	63 (20%)
Unknown diagnosis	33 (10%)
Dementia = primary condition requiring care	188 (59%)
Recipient relationship to caregiver	
Spouse/partner	29 (9.2%)
Parent	119 (38%)
Other relative	112 (36%)
Non-relative	55 (17%)
Recipient residence setting	
In home with caregiver	81 (26%)
In a separate home	185 (59%)
Long term/residential	49 (16%)
Primary caregiver	
You yourself provide all the unpaid care	112 (35%)
You provide most of the unpaid care and others help	72 (23%)
You and others split most of the care evenly	68 (21%)
Others provide most of the care and you help	62 (20%)

[1] n (%); Mean +/- Standard Deviation, [2]Respondents selected all that applied

Table 2. Nested Multivariable Linear Regression Outputs

Characteristic	**Base model**			**Adjusted model**		
	Beta	**95% CI**[1]	**p-value**	**Beta**	**95% CI**[1]	**p-value**
Caregiver age (per decade)	0.99	0.13, 1.9	**0.024**	-0.45	-1.6, 0.66	0.43
Caregiver gender (men)	-0.89	-3.8, 2.0	0.55	-0.88	-3.5, 1.8	0.51
Caregiver race/ethnicity						
Hispanic	-2.4	-6.5, 1.8	0.26	-1.4	-5.0, 2.2	0.45
Black	-1.7	-4.7, 1.2	0.25	1.4	-1.5, 4.4	0.34
White	—	—		—	—	
Caregiver rurality	-0.62	-4.0, 2.7	0.71	0.94	-3.3, 5.2	0.67
Care recipient age				0.55	-0.70, 1.8	0.39
Care recipient gender (men)				0.93	-1.8, 3.6	0.5
Care recipient rurality				1.8	-1.4, 5.0	0.27
Dementia stage				-1.2	-2.9, 0.49	0.16
Alzheimer's diagnosis				0.68	-3.1, 4.5	0.72
Unspecified dementia diagnosis				0.44	-3.4, 4.3	0.82
MCI diagnosis				-0.03	-3.8, 3.7	0.99
Dementia = primary condition				-0.25	-3.0, 2.5	0.86
Caregiver education				0.81	-0.69, 2.3	0.29
Caregiver income (per $10K)				0.14	-0.16, 0.45	0.36
Caregiver employment status						
Working				—	—	
Retired				9.4	5.7, 13	**<0.001**
Disabled				0.24	-5.0, 5.5	0.93
Other unemployed				-4.7	-8.1, -1.3	**0.006**
Relationship to caregiver						
Other relative				—	—	
Parent				-1	-4.0, 2.0	0.51
Spouse/partner				1.5	-4.1, 7.2	0.59
Non-relative				-0.39	-4.4, 3.6	0.85
Care recipient residence						
In home with caregiver				—	—	
In a separate home				2.4	-0.68, 5.6	0.12
Long term/residential				-0.6	-4.9, 3.7	0.78
Primary caregiver				-5.3	-8.8, -1.9	**0.003**

[1] CI = Confidence Interval

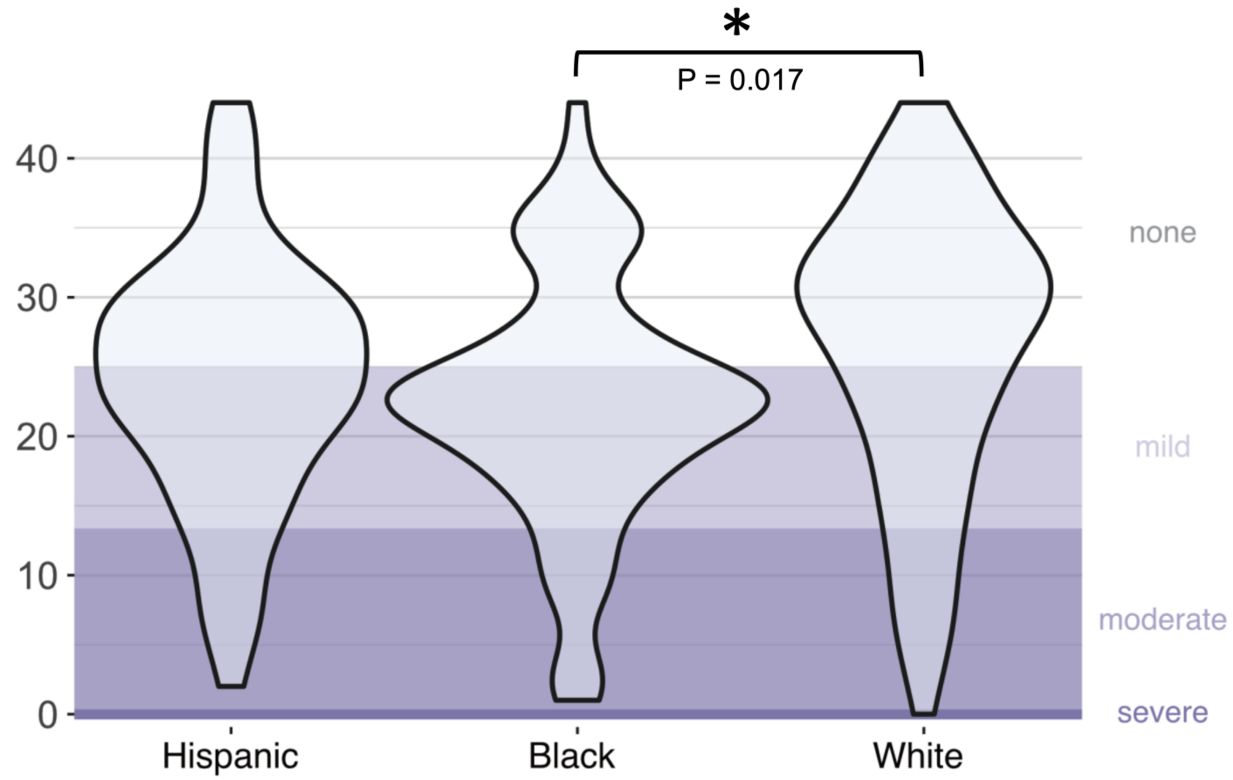

Figure 1. Distribution of COST Scores by Race and Ethnicity. Here, COST was treated as a categorical variable. Black caregivers were more likely to experience financial toxicity (COST ≤25), compared to White caregivers.

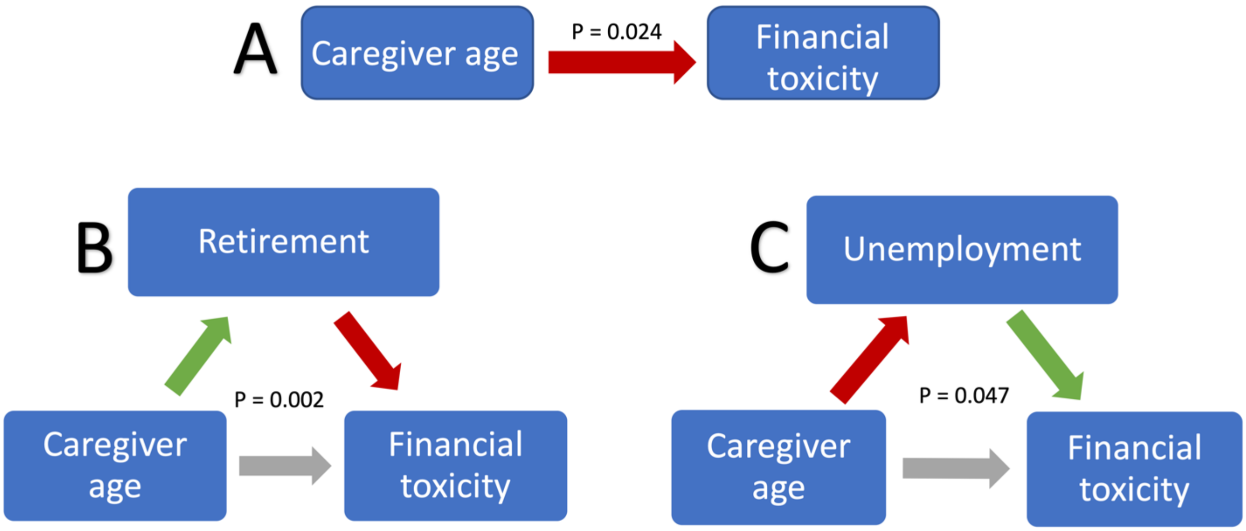

Figure 2. Mediation Analyses. Our base model (model 1) demonstrated that older caregiver age is associated with less financial toxicity (A). Two independent mediation analyses were subsequently performed to evaluate whether retirement status (yes/no) and unemployment status (yes/no) mediated the relationship between caregiver age and financial toxicity, as both variables had a statistically significant association with financial toxicity in the adjusted model (model 4). The first mediation analysis, which examined retirement as a potential mediator (B), revealed older caregivers are more likely to be retired, and retirement is associated with significantly less financial toxicity (B). The second mediation analysis, which examined unemployment as a potential mediator (C), highlighted that older caregivers were less likely to be unemployed, and unemployment is associated with significantly greater financial toxicity.