Title: Caregiving by Choice or Constraint? Mental and Financial Well-Being Among Informal Caregivers

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INTRODUCTION

Family and friends play a critical role in caring for adults with disabilities, e.g., by helping with activities such as bathing, eating, financial management, and supervision.[1] Indeed, most adults with disabilities receive at least some help from an unpaid family member or friend, hereafter an informal caregiver.[2] Informal caregiving is ubiquitous in the United States with most adults having prior experience, current experience, or future expectations of being a caregiver.[3] Correspondingly, the economic valuation of informal caregiving in the United States is substantial, although estimates range widely from $221 billion to $642 billion based on subgroups (e.g., caregivers for people with dementia, older adults) and estimation methodology (e.g., replacement wage versus opportunity costs).[4-6] Even the lower bound of these estimated costs often excludes the out-of-pocket costs caregivers incur and still far exceed Medicaid expenditures for long-term care which is notable as Medicaid is the primary payer for long-term care in the United States.[7,8] Without a national long-term care insurance system, family caregivers are the backbone of the long-term care delivery and financing system in the United States – a dependency likely to intensify as the population ages.

The effects of family caregiving on mental health and financial well-being are largely negative and can subsequently impact caregivers, the quality of care provided, and, ultimately, patient outcomes.[9-11] Family caregiving is consistently associated with increased stress, depressive symptoms, and other negative mental health indicators. [9,12] These effects may be observed in the short-term during the caregiving episode but also in the long-term once caregiving is complete, as evidenced by greater lifetime depression.[13] These negative consequences are a function of caregiving as a chronic stress experience, causing deleterious mental health outcomes and financial strain.[14] The financial consequences of caregiving are overwhelmingly negative. Compared to non-caregivers, causal estimates from the economics literature demonstrate that informal caregivers are more likely to earn less, work fewer hours, and, ultimately, leave the labor force at greater rates than their non-caregiver counterparts.[10,11,15-20] Unsurprisingly, family caregivers consistently identify financial support as desired supports (e.g., direct payments, tax credits).[21-24] Given the financial burden of caregiving and care, the relationship between mental health and financial outcomes of caregivers is intertwined.

While there are many negative outcomes documented of informal caregiving, positive outcomes have been documented.[12,25,26] For people who prefer to be a caregiver, the role can bring a sense of purpose, meaning, and fulfillment. Yet, the existing evidence of the cost and effects of unpaid care often overlooks preferences to be a family caregiver, much less allow for seemingly conflicting preferences (e.g., wanting to but also knowing that one is expected to do so). Understanding preferences for becoming a family caregiver is key because preferences can impact selection into who becomes a caregivers as well as impacting outcomes related to mental health and financial well-being. For example, an individual who provides care because they want to may choose to become a caregiver regardless of the affordability of long-term care and may provide the amount and type of care that aligns with their preferences. In contrast, an individual who provides care because formal long-term care is unaffordable may not have become a caregiver if affordable alternatives were available. As a result, they may have substantially less discretion over whether to provide care, the intensity of care they provide, and the caregiving tasks they perform. These considerations are critical as over half of family caregivers in the United States report little to no choice in undertaking the role.[27,28] Because limited evidence considers the role of preferences to provide care when considering the effect of caregiving on mental health and financial well-being, we examined the national prevalence of preference for informal caregiving, predictors of anticipated informal caregiving, and associations of caregiving with

mental health, mental health care use, and medical debt after taking preferences for informal caregiving into account.

METHODS

Data and Sample. This is a cross-sectional study of a nationally representative survey of adults aged 19 and older in the U.S. We used data from the seventh Annual Wave of the Cumulative Life Stressors Impact on Mental Health and Well-Being (CLIMB) study, a nationally representative survey conducted through AmeriSpeak Panel. Managed through NORC at the University of Chicago, the AmeriSpeak sampling frame covers approximately 97% of U.S. households.[29-34] AmeriSpeak panel participants are regularly invited to complete surveys and received a $3 incentive on web and telephone panelists were offered the cash equivalent of $5 for participating in this wave of CLIMB. The CLIMB Survey has operated since 2020, surveying U.S. adults annually in March-April; the study was designed to measure trends in population health, assets, and policy preferences in U.S. adults. To be eligible for this survey, respondents had to be age 18 or older in 2023 and English-speaking. The online and phone survey was fielded between March 2026, and April 2026. Of the 7,969 adults invited to participate, 4,184 (52.5% survey completion rate) had qualified completed surveys in 2026. All respondents provided informed consent (electronically if taking the survey online and verbally if taking the survey on the phone).

In 2026, the CLIMB survey instrument included a panel of new questions regarding expected future status as a family caregiver to which they could respond: not at all likely, not too likely, somewhat likely or very likely). Survey respondents who answered not too, somewhat or very likely were then asked about their motivation for potentially becoming a caregiver. Thus, we restricted the analytic sample to retain caregivers who had any possible future expectation of being a caregiver and had non-missing values for key demographic characteristics (age, sex, race, marital, education, region, rurality, political ideology, household income and household size) (n=3,184).

This study was found to be exempt by the institutional review board of NORC at the University of Chicago for original data collection and was deemed not human subjects research for deidentified secondary data analysis by Johns Hopkins University. Analyses were conducted from June 2026 through July 2026. We followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines.[35]

Measures.

We examined three main outcomes: probable depression, forgone mental health care due to cost, and medical debt. Probable depression was defined as a binary variable using a score of 10 or higher on the Patient Health-Questionnaire-9 (PHQ-9) which has been validated to have a sensitivity of 88% and specificity of 88% as a screener for depression relative to the gold standard of a clinical diagnosis.[36] Forgone mental health care due to cost was defined as whether the individual ever wanted to see a health professional about their mental health but did not due to the cost of getting care in the past 12 months.[37] Medical debt was defined as reporting any problems paying or an inability to pay any medical bills, such as bills for doctors, dentists, medication, or home care within the last 12 months. Survey respondents were asked to include any medical bills they had problems paying over the past 12 months, even if the initial bill was incurred more than 12 months ago, consistent with other work.[37-39]

Key Explanatory Variables of Interest include current caregiving status. We defined informal caregiving as providing care to a relative or friend 18 years or older to help them take care of themselves (e.g., helping with personal needs, household chores, managing a person's finances) within the last 12 months, as aligned with prior work.[3,21,28,40]

Additional explanatory variables of interest included gender, age, race and ethnicity, education, household income, household size, marital status, metropolitan residence, Census region, and self-reported political ideology (*very liberal; somewhat liberal; moderate; somewhat conservative; very conservative*).

Finally, while we are not able to directly capture motivations to become a caregiver for people who are not informal caregivers, we leverage responses capturing the motivation for potentially becoming a caregiver in the future as a proxy for caregiving preferences. Respondents were asked to select the reasons why they may expect to provide care in the future: wanted to; no one else could; respondent/care recipient are unable to afford paid long-term care services (e.g., personal care aide, assisted living); expected to do so; or "other". Respondents could select multiple motivations. Collectively, these response options capture a variety of motivations for caregiving, including attitudes, norms of solidarity/reciprocity, and perceived barriers of distance/time/money.[41] We coded motivations for becoming a caregiver because no one else could; respondent/care recipient are unable to afford a paid long-term care services; or expected to do so as constraint-driven motivations, whereas wanting to be a caregiver as a voluntary motivation and "other" reasons as unknown motivation.

See Appendix A for survey questions.

Statistical Analysis.

First, we described the sociodemographic characteristics and preferences for caregiving among the overall sample and by informal caregiving status. Because caregiving is a non-random event, underlying differences based on observed and unobserved characteristics likely exist between informal caregivers and their non-caregiving peers. We used entropy balancing to address the non-random selection bias into who becomes an informal caregiver after adjusting for socioeconomic characteristics and expected motivations for becoming a caregiver in the future to proxy preferences of caregiving (voluntary-only driven, constraint-only driven, both voluntary- and constraint-driven reasons). Finally, we estimated the association of informal caregiving on each outcome of interest: probable depression, forgone mental health care due to cost, and presence of medical debt) using logistic regression after entropy balancing.

Our primary specification included proxy preferences of caregiving in the entropy balancing as the 4-level mutually exclusive categorization of: voluntary-driven only, voluntary- and constraint-driven, constraint-driven only, and not specified motivations. However, to place our work in the context of existing literature which has not controlled for caregiving preferences, we also re-run all analyses excluding covariates indicating preferences for caregiving.

In all analyses, we used survey weights to adjust for sampling design and nonresponse to yield a nationally representative sample. We calculated the average differential association of each covariate using the method of recycled predictions.

RESULTS

Table 1 presents the descriptive statistics of the study sample. In our sample, the average age was 44, 52% were women, 56.3% were white, 48.7% were married, 34.7% had a high school level of education or less, 33.5% resided in urban areas, 50.8% in suburban areas and 15.7% in rural areas, 24.8% identified as liberal, 50.2% as moderate and 25.0% as conservative. Compared to non-caregivers, informal caregivers were slightly older (46 vs. 44), and more likely to be women (61.0% vs. 49.1%), have a high school level of education or less (39.5% vs. 33.1%) and less likely to be married (44.4% vs. 50.1%), $p<0.05$. Compared to non-caregivers, informal caregivers were also more likely to be in the bottom tertiles for household income (45.0% vs. 34.8%) and household savings (45.9% vs. 39.1%).

In the overall sample, 22.6% of respondents screened positive for probable depression, 12.2% reported forgone mental health care due to cost, and 17.7% reported any medical debt. Compared to non-caregivers, informal caregivers were more likely to screen positive for probable depression (30.3% vs. 20.2%), have a mental health crisis in the last 12 months (14.4% vs. 6.2%), report forgone mental health care due to cost (19.2% versus 10.0%) and report any medical debt (28.9% vs. 14.1%).

When considering non-mutually exclusive motivations for becoming a future caregiver, 56.4% of respondents reported wanting to be a caregiver, 39.4% stated there was no one else to do so, 37.0% reported because long-term care was unaffordable, and 23.7% reported because they were expected to do so (Table 2). Compared to non-caregivers, current informal caregivers were more likely to report wanting to be a caregiver (62.2% vs. 54.6%) and because there was no one else to do so (44.5% vs. 37.8%), $p<0.05$. Notably, 38.5% of respondents reported constraint-driven motivations for becoming a caregiver only, 29.1% reported constraint-driven and voluntary-driven motivations for becoming a caregiver, 27.4% reported voluntary-driven motivations only and 5.1% declined to select any motivation. Informal caregivers were less likely to select constraint-driven only motivations for becoming a caregiver compared to non-caregivers (e.g., 34.8% vs. 39.6%, $p<0.05$).

After applying weights from entropy balancing, we examined standardized differences of all covariates in the model. Thresholds for acceptable standardized mean differences range from 10% to 25% with absolute standardized mean differences ≤10% as optimal.[42-44] We achieve balance defined as absolute standardized mean differences of 0% across all covariates, as expected, see Figure 1.

In our primary weighted outcome models, we find that being a caregiver is associated with an 8.6 percentage point increase in the predicted probability of screening positive for probable depression ($p<0.05$), 6.4 percentage point increase in the predicted probability of forgone mental health care due to cost ($p<0.05$); and 8.9 percentage point increase in the predicted probability of having any medical debt, see Table 3, Panel A.

In our secondary analyses excluding preferences for caregiving from our model, we find similar results: informal caregivers are 9.92 percentage points more likely to screen positive for depression ($p<0.05$), 8.84 percentage points more likely to have forgone mental health care due to cost ($p<0.05$) and 12.28 percentage points more likely to have any medical debt. These results are slightly attenuated to the null, as expected if preferences were an omitted variable bias.

Results were similar when including non-mutually exclusive indicators for motivations instead of the mutually-exclusive indicators.

DISCUSSION

Usually nationally representative data from Spring 2026, we found that around one third of U.S. adults are currently serving as informal caregivers in the U.S. Among current informal caregivers, around 28% were caregivers for voluntary reasons; that is, they wanted to be caregivers and did not cite reasons of financial or other constraints motivating caregiving. We find evidence that current informal caregivers are more likely than non-caregivers to want to be caregivers under future expectations of caregiving. After taking caregiving preferences into account, we find that current informal caregivers are more likely to have worse mental health, higher unmet need for mental health care due to cost, and worse financial health outcomes compared to their non-caregiving peers. Thus, informal caregivers may have higher mental health treatment needs (due to higher levels of probable depression) but are more likely to report unmet need for mental health care due to cost and higher levels of medical debt than non-caregivers. These findings have implications for targeted training and support for informal caregivers.

These findings build on a growing literature that assesses mental health and financial standing of informal caregivers. The literature to date has largely captured mental health and financial burden of caregivers for specific patient populations, for example, among caregivers of persons with cancer,[45-48] Parkinson's disease,[49] and Alzheimer's disease.[6] However, this study uses nationally representative data on all U.S. adults, allowing comprehensive insights into burden of poor mental health and use of health services for a national sample of caregivers across a range of adult care recipient diagnoses. Additionally, we are able to adjust for preference for caregiving. That we are able to detect associations with poor mental health, unmet need for mental health care, and medical debt even after adjusting for preference for caregiving and other demographics through entropy balancing suggests significant differences in these outcomes between informal caregivers and non-informal caregiver peers.

Informal caregivers face unique mental health and financial challenges. Our findings show that informal caregivers are more likely to have lower income, be female, have lower education and were less likely to be married or be employed than non-informal caregivers. Our team has identified an asset framework which protects against poor health and provides access to health promoting resources including health services.[50] That informal caregivers report fewer assets than non-caregivers may put them at a greater risk for poor health, lack of health services utilization, and financial precarity, which could further worsen health challenges. This study is novel in its use of entropy balancing to adjust for differences in current informal caregivers and non-informal caregiver characteristics, including a proxy measure for preferences for caregiving. While around one third of caregivers reported a preference for future caregiving, others report anticipated future caregiving due to constraint. That caregivers have worse health outcomes even when accounting for preferences to be caregivers suggests that burdens of caregiving are pervasive even when an adult wants to be an informal caregiver.

This study is subject to several limitations. First, we leverage a single wave of CLIMB data. Next steps include exploiting the longitudinal nature of CLIMB to use prior caregiving status, adjusted for caregiving preferences, with subsequent mental health and financial well-being measures. Second, our measurement of preferences for caregiving is based on a hypothetical situation which does not specify a specific care-recipient. Therefore, our measurement of preferences is likely to include some measurement error and unobserved heterogeneity. Despite these limitations, our findings contribute to the literature examining the effects of informal caregiving and offer key insights about why individuals expect to become caregivers in the future.

Notwithstanding these limitations, this study finds that informal caregivers, even among those who have a preference for caregiver, report worse mental health, unmet need for mental health care, and medical debt than non-caregivers. Documenting the extent of challenges that caregivers face—with aligned solutions to address challenges, can help future caregivers to be prepared and bolster health to maximize caregiver outcomes.

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Table 1. Sample Descriptive Statistics

	Overall Sample	Informal Caregivers	Non-Caregivers	p-value
	N = 3,184	N = 766	N = 2,418	
Demographics				
Respondent age	44, (17)	46, (17)	44, (17)	0.013
Gender				<0.001
Female	1,646 (51.9%)	467 (61.0%)	1,179 (49.1%)	
Male	1,515 (48.1%)	301 (39.0%)	1,214 (50.9%)	
Race				0.001
White	1,927 (56.3%)	423 (51.6%)	1,504 (57.7%)	
Black	352 (11.2%)	113 (15.9%)	239 (9.7%)	
Hispanic	589 (19.9%)	155 (21.0%)	434 (19.5%)	
Other	293 (12.7%)	77 (11.5%)	216 (13.0%)	
Marital Status				0.012
Married	1,672 (48.7%)	369 (44.4%)	1,303 (50.1%)	
Former married	511 (14.4%)	156 (17.9%)	355 (13.3%)	
Never married	978 (36.8%)	243 (37.7%)	735 (36.6%)	
Education				0.006
Highschool or less	688 (34.7%)	191 (39.5%)	497 (33.1%)	
Some college	1,178 (25.5%)	296 (26.7%)	882 (25.1%)	
Bachelor’s degree	742 (25.0%)	155 (19.9%)	587 (26.6%)	
Post-graduate degree	553 (14.9%)	126 (13.9%)	427 (15.2%)	
Household size				0.671
1	350 (9.8%)	73 (8.3%)	277 (10.3%)	
2	1,001 (29.4%)	262 (30.8%)	739 (29.0%)	
3	657 (21.0%)	154 (20.9%)	503 (21.1%)	
4	566 (18.0%)	131 (17.2%)	435 (18.2%)	
5 or more	587 (21.8%)	148 (22.8%)	439 (21.5%)	
Employment Status				0.036
Employed	2,205 (69.2%)	508 (64.8%)	1,697 (70.6%)	
Unemployed	485 (17.5%)	125 (18.9%)	360 (17.0%)	
Retired	471 (13.3%)	135 (16.2%)	336 (12.4%)	
Region				0.555
Northeast	413 (17.4%)	95 (16.3%)	318 (17.7%)	
Midwest	828 (20.4%)	193 (19.1%)	635 (20.9%)	
South	1,107 (38.4%)	281 (39.3%)	826 (38.1%)	
West	813 (23.8%)	199 (25.4%)	614 (23.3%)	
Urban				0.791

Urban	1,097 (33.5%)	266 (33.8%)	831 (33.4%)	
Suburban	1,551 (50.8%)	375 (51.5%)	1,176 (50.6%)	
Rural	513 (15.7%)	127 (14.7%)	386 (16.0%)	
Ideology				0.764
Liberal	771 (24.8%)	173 (26.0%)	598 (24.4%)	
Moderate	1,588 (50.2%)	394 (49.7%)	1,194 (50.4%)	
Conservative	802 (25.0%)	201 (24.4%)	601 (25.2%)	
Mental Health and Financial Outcomes				
Patient Health Questionnaire (PHQ) Score, mean (SD)	6.0, (6.1)	7.5, (6.5)	5.5, (5.9)	<0.001
Frequency Missing	7	1	7	
Probably Depression (PHQ score >10)				<0.001
0 Not depressed	2,491 (77.4%)	547 (69.7%)	1,944 (79.8%)	
Depressed	664 (22.6%)	220 (30.3%)	444 (20.2%)	
Missing	7	1	7	
Forgone Mental Health Care due to Cost				<0.001
No	2,610 (87.8%)	591 (80.8%)	2,019 (90.0%)	
Yes	332 (12.2%)	120 (19.2%)	212 (10.0%)	
Missing	259	67	192	
Any Medical Debt				<0.001
No	2,424 (82.3%)	529 (71.1%)	1,895 (85.9%)	
Yes	521 (17.7%)	184 (28.9%)	337 (14.1%)	
Missing	264	57	207	
Household Income				<0.001
Low (bottom tertile)	1,046 (37.2%)	313 (45.0%)	733 (34.8%)	
Medium (second tertile)	980 (28.9%)	247 (29.9%)	733 (28.6%)	
High (third tertile)	1,135 (33.8%)	208 (25.1%)	927 (36.6%)	
Household Savings				0.013
Low (bottom tertile)	1,185 (40.8%)	315 (45.9%)	870 (39.1%)	
Medium (second tertile)	1,038 (33.4%)	242 (31.8%)	796 (33.9%)	
High (third tertile)	880 (25.9%)	198 (22.3%)	682 (27.0%)	

(Missing)	70	10	60

Table 2. Preferences to be an Informal Caregiver

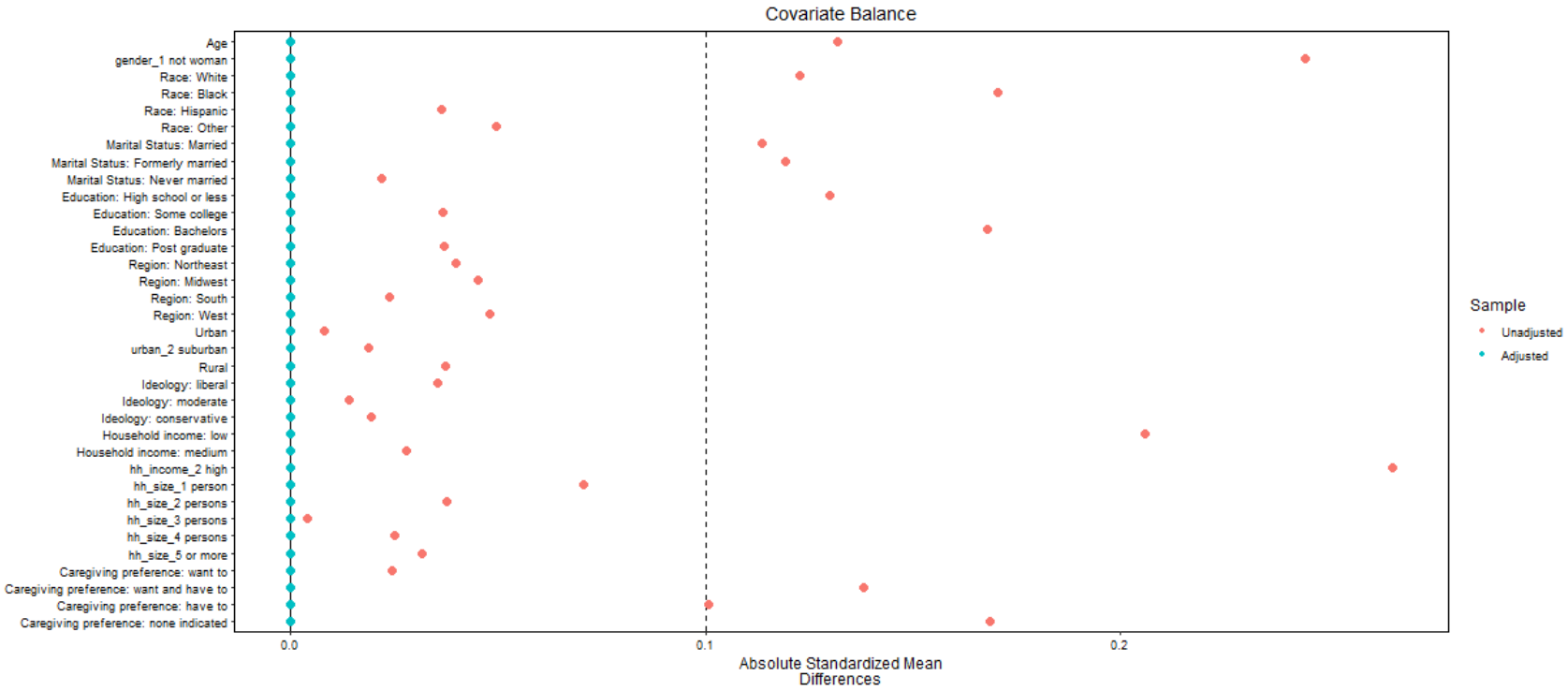
	Overall Sample	Informal Caregivers	Non-Caregivers	p-value
	N = 3,184	N = 766	N = 2,418	
Non-Mutually Exclusive Preferences to be a Caregiver				
Want to be a caregiver				0.003
No	1,388 (43.6%)	292 (37.8%)	1,096 (45.4%)	
Yes	1,773 (56.4%)	476 (62.2%)	1,297 (54.6%)	
There is no one else				0.015
No	1,882 (60.6%)	424 (55.5%)	1,458 (62.2%)	
Yes	1,279 (39.4%)	344 (44.5%)	935 (37.8%)	
Long-term care is unaffordable				0.33
No	1,922 (63.0%)	458 (60.9%)	1,464 (63.6%)	
Yes	1,239 (37.0%)	310 (39.1%)	929 (36.4%)	
Expected to do so				0.136
No	2,399 (76.3%)	559 (73.6%)	1,840 (77.2%)	
Yes	762 (23.7%)	209 (26.4%)	553 (22.8%)	
Mutually Exclusive Preferences to be a Caregiver				0.008
Voluntary-driven only (i.e., only wanted to be a caregiver)	826 (27.4%)	205 (28.2%)	621 (27.1%)	
Voluntary-driven and Constraint-driven	947 (29.1%)	271 (34.0%)	676 (27.5%)	
Constraint-driven only (i.e., expected to do so and did not want to be a caregiver)	1,252 (38.5%)	273 (34.8%)	979 (39.6%)	
Not Specified	136 (5.1%)	19 (2.9%)	117 (5.8%)	

Table 3. Differential Effects of Informal Caregiving

	Differential Effect (Standard Error)	p-value	95% Confidence Interval
Panel A. Including Adjustment for Preference for Caregiving			
Screen Positive for Probable Depression	10.31 (0.03)	0.0001	(5.00, 15.63)
Any Forgone Mental Health Care due to Cost	8.73 (0.02)	0.0004	(3.90, 13.57)
Any Medical Debt	12.48 (0.03)	0.0001	(7.33, 17.63)
Panel B. Omitting Adjustment for Preference for Caregiving			
Screen Positive for Probable Depression	9.92 (0.03)	0.0003	(4.60, 15.25)
Any Forgone Mental Health Care due to Cost	8.84 (0.02)	0.0003	(4.01, 13.67)
Any Medical Debt	12.28 (0.03)	0.0001	(7.12, 17.43)

NOTES: The differential effect should be interpreted as percentage point change. For example, the differential effect of informal caregiving on the predicted probability of screening positive for probable depression is a 10.31 percentage point increase ($p<0.05$).

Figure 1. Absolute Value of Standardized Mean Differences Before and After Entropy Balancing



Appendix A. Survey Questions

1. At any time in the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves?
This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult does not need not live with you.

1. Yes, I have provided care to an adult in the last year
2. Yes, Someone else in my household has provided care in the last year
3. No

Source: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S. https://www.aarp.org/content/dam/aarp/ppi/2020/05/appendix-a.doi.10.26419-2Fppi.00103.004.pdf

2.How likely is it that, at some point in your life, you will be responsible for caring for an aging parent or another elderly family member? Do you think it is

1. Very likely,
2. Somewhat likely,
3. Not too likely, or
4. Not at all likely?

Source: Modified from Pew Caregiving for Older Family Members Poll: https://www.pewresearch.org/social-trends/2013/01/30/caregiving-for-older-family-members/#:~:text=The%20Pew%20Research%20survey%20finds,do%20this%20in%20the%20future.

3. Thinking about the future, what reasons might lead you to provide care for an aging parent or another older family member? Please select all that apply.

1. Because I want to provide care
2. Because no one else is available to provide care
3. Because hiring paid help would be too expensive
4. Because my family or culture expects me to provide care