Amyloid-β PET Scans, Economic Strain and Financial Decision-Making among Persons with Cognitive Impairment and Care Partners: A mixed-methods analysis of the CARE-IDEAS Study

Article Summary

- In this mixed-methods study, we explored the relationship between receipt of amyloid PET scan results and objective and subjective measures of economic strain from claims and survey report; we also used semi-structured interviews to profile participants experiences of financial decision-making. Prior to this study we knew very little about how diagnosis following an amyloid PET scan affected experiences of economic strain of persons with memory problems, including how economic strain changed over time.

Strengths and limitations of this study

- We present multiple perspectives and measures of economic strain: objective, subjective, and contextual information from patients and care partners.
- The sample is affluent compared to the general Medicare population and, at the time of the scan result, very few of the participants experienced any economic strain by our measures; participants in the quantitative data are almost entirely comprised of persons who identify as White, non-Hispanic.
- We do not have economic strain measures before scan results were communicated.
- The qualitative interviews did not specifically ask participants about economic strain. Rather, they asked more generally about how the amyloid PET scan affected their lives and future plans and many of them volunteered information about financial impacts and decision-making after the scan.

Background

Alzheimer's Disease or related dementia (ADRD) is associated with high costs of care from diagnosis through end of life [1,2]. The total lifetime cost of care for a patient with ADRD in the United States is estimated at $392,874 in 2022 dollars, which is more than twice the amount incurred by individuals without ADRD [3,4]. Despite Medicare and other sources of financial assistance, individuals with ADRD and their family members still incur high out-of-pocket expenses, due to Medicare and other insurance deductibles, co-payments, co-insurance, and services not covered, such as nursing home stays and other long-term care use. On average, Medicare beneficiaries with ADRD pay $10,241 out of pocket annually for health care and long-term care services not covered by other sources [3]. Such estimates likely reflect an underestimate of the true costs to those with ADRD and their families as they fail to account for the costs associated with unpaid caregiving.

Despite the significant financial burden of ADRD, there has been minimal research to date on how a diagnosis of dementia affects current economic strain or experiences of financial planning among persons with ADRD and their care partners. An early ADRD diagnosis could reduce economic strain by enabling people with ADRD and their care partners to plan for future health and long-term care needs, including engaging family members who might provide unpaid care and communicating goals of care and preferences for long-term care. It is hoped that early engagement in financial planning could reduce economic strain later in the disease [5]. Significant advances in using biomarkers to improve accurate and earlier diagnosis of ADRD could provide patients and care partners with information to engage in care and financial decision-making processes much earlier in the disease process. One example of a biomarker is amyloid-β positron emission tomography (PET) scans. Elevated levels of amyloid plaques are suggestive of the neuropathology associated with Alzheimer's disease whereas non-elevated levels of amyloid may suggest the patient's cognitive impairment is attributable to causes other than Alzheimer's disease.

In this mixed-methods study, we aimed to 1) explore the relationship between receipt of amyloid PET scan results and objective and subjective measures of economic strain from claims and survey report, and 2) explore persons with mild cognitive impairment (MCI) or dementia and their care partners' experiences of financial decision-making via semi-structured interviews. Combined objective and subjective economic strain data are meaningful

because it is unlikely that a single definition is sufficient to capture economic strain for this population. Importantly, we obtain the perspective of care partners as well as patients in in-depth interviews, adding richness to understanding experiences of economic strain and financial decision making beyond that of the individual with ADRD. We cautiously hypothesize that patients with elevated amyloid scan results and their care partners will have higher subjective economic strain post-scan, perhaps due to anticipating future strain, and higher objective and subjective economic strain four years post-scan due to the progressive nature of ADRD and the accelerated need for more resources to manage the disease over time. Because the study participants were mostly affluent, White and relatively protected from the economic precarity expected following a test to diagnosis Alzheimer's disease -- one-third held private long-term care insurance whereas only 10% of older adults in the US population held long-term care insurance (LTCI) at that time [6] -- our findings cannot generalize to the population level. We especially are missing representation from average and low-resourced individuals and individuals in minoritized groups. Keeping the selectivity of the study participants in mind, the uniqueness of the economic strain data obtained following a test for early diagnosis (amyloid PET scan) holds value for informing future examinations of economic strain.

Methods and Results: Quantitative and Qualitative

Mixed methods study design

This is a longitudinal prospective cohort study of patient-care partner dyads enrolled in the CARE-IDEAS (Caregivers' Reactions and Experience: Imaging Dementia Evidence for Amyloid Scanning) study. CARE-IDEAS is a prospective cohort supplemental study to the original IDEAS study conceived to examine the impact of amyloid-β PET scans on clinical outcomes in Medicare beneficiaries with MCI or dementia between 2016 and 2018. The current study uses a parallel convergent mixed-methods design to explore objective and subjective experiences of economic strain among dyads, where quantitative and qualitative data were collected and analyzed separately. The goal of the quantitative analysis was to enumerate potential associations between an elevated amyloid scan result and subsequent objective and subjective economic strain. The goal of the qualitative analysis was to explore patient and care partner perspectives and experiences of financial decision-making following the

scan, which might ultimately shield them from economic strain following a diagnosis of dementia or MCI. The qualitive and quantitative findings were mixed via narrative integration in the discussion [7].

Data sources included 1) CARE-IDEAS study variables taken during the baseline assessment (approximately 4-5 months post-PET scan results disclosure) and a follow up assessment (18-24 months post-PET scan results disclosure), 2) Medicare claims data on patients up to four years after the scan, and 3) qualitative interview data from patients and care partners collected between 2020 – 2021 (approximately 2-3 years post-scan).

Quantitative Methods

Data sources and study population

The CARE-IDEAS study recruited a subsample of 2,228 IDEAS participants and 1,872 of their care partners who had agreed to be contacted for further research opportunities. Specifically, we used data from the CARE-IDEAS baseline (T1) and follow up (T2) structured telephone surveys (when available) for both the patient and the designated care partner and the 2015-2020 Medicare Master Beneficiary Summary Files (MBSF) for the patient (the beneficiary). We also used patient data on the amyloid-β PET scan results and other baseline information obtained from the parent IDEAS study. As our outcomes were derived from the Medicare claims and survey data, we had two cohorts: 1) the beneficiary-based cohort and 2) the survey-based cohort. Inclusion criteria for the beneficiary-based cohort required that the patient not receive the Medicare Part D low-income subsidy (LIS) or be enrolled in both Medicare and Medicaid ("dually-enrolled") in the 12 months prior to the amyloid-β PET scan date. Inclusion criteria for the survey-based cohort required that both the patient and care partner completed the survey at T1 and responded to the perceived economic strain items at either one or both time points.

Study variables

Economic strain outcomes. Outcome measures were derived from Medicare claims and survey data as outlined above. First, we estimated via claims whether patients with elevated amyloid suggestive of ADRD have higher objective economic strain, signaled by increased spending of their income and/or assets down to levels to qualify and enroll in Medicaid (e.g., they became newly dually enrolled in Medicare and Medicaid) or to newly receive

LIS compared to Medicare patients without an elevated scan. While state eligibility requirements vary for LIS for partial dual eligibles, Medicare beneficiaries who have limited income and resources can receive a low-income subsidy for Part D (LIS). Full-benefit dual-eligible beneficiaries automatically qualify for LIS. For these two beneficiary-based economic strain outcomes, we calculated time to change in status that indicated additional economic strain as the time between the date of scan and the first day of the month of the new status, dually enrolled or receiving LIS, respectively.

Second, in terms of subjective measures, survey items ascertained whether care partners of patients with an elevated scan reported higher perceived economic strain compared to care partners and patients without an elevated scan. We used the three-item subscale of the Caregiver Reaction Assessment (CRA) [8] to assess subjective economic strain associated with caregiving, along with items asking both patients and care partners about perceived difficulty paying monthly bills. The three CRA subscale items asked care partners to agree or disagree, using a 5-point Likert scale (1=disagree a lot, 5=agree a lot), with statements asserting that 1) I have adequate financial resources for caregiving, 2) It is difficult to pay for the patient's needs, and 3) Caring for the patient is a financial strain. We dichotomized these items into "not adequate" vs. "totally adequate" and "no difficulty vs. "any difficulty". Both patients and care partners were then asked to report the level of difficulty they experience paying their monthly bills, which we dichotomized into "no difficulty vs. "any difficulty".

Exposure. The Amyloid PET scan results were the exposure, received by all participants. Amyloid PET scan results indicated elevated versus non-elevated levels of amyloid plaque in the brain. Elevated levels of amyloid plaques indicate neuropathology associated with Alzheimer's disease, whereas non-elevated levels suggest that cognitive impairment is attributable to causes other than Alzheimer's disease. The scans were interpreted at the PET facility where they were conducted as part of the IDEAS study. Results were shared with providers who in turn informed recipients and their partners. The median time between recipients' amyloid PET scans and the subsequent CARE-IDEAS baseline survey was 4.5 months, suggesting that most if not all participants had been informed of their scan results prior to the baseline interview.

Covariates. We controlled for demographic, health, and other variables assessed at T1, including sex, age, relationship of the patient to the care partner (spouse or not), education, having private long-term care insurance (LTCI), consulting a financial planner, and self-reported health status. Relevant medical history variables (1=yes, 0=no) were pulled from clinical assessment in the IDEAS parent study data, and included atrial fibrillation, ischemic heart disease, hypertension, dyslipidemia, diabetes, active depression, history of stroke, and traumatic brain injury. These were then summed to create a count of comorbidities variable.

Quantitative Statistical Analysis

We described the characteristics of the study cohorts using proportions for categorical variables and means with standard deviations or medians with quartiles for continuous variables grouped by amyloid-β PET scan result. We examined these characteristics separately among those without prior year LIS, without prior year dual-eligible status, and dyads with at least one timepoint of economic survey data. We presented standardized mean differences, and evaluated group differences using chi-square tests for categorical variables and Kruskal-Wallis tests for continuous variables. Quantitative analyses were conducted on the Centers for Medicare and Medicaid Services Virtual Research Data Center using SAS 9.4. Missing covariate values were imputed using the mode for categorical variables, and the mean for continuous variables, with values taken from the study sample.

Beneficiary-based analyses. We described the rate of acquiring Medicaid (dual-enrollment) and low-income supplement (LIS) at both time points. For both the LIS and dual-eligible status economic strain outcomes, we calculated the cumulative incidence, accounting for the competing risk of death and ran separate adjusted Cox proportional hazards regression models to test associations between an elevated scan result and dual-eligible status and LIS within 4 years post-scan, respectively. Due to the small number of events for both economic strain outcomes, we were powered to include a small number of relevant covariates (age, sex, education, and race) and selected diagnoses (hypertension). Patient participant censoring occurred at the earliest of the following censor points: death, end of Medicare patient data, or the end of the study period (December 31, 2020).

Survey-based analyses. To examine the association between patient and care partner characteristics and survey-based economic strain measures at T1 and T2, we ran separate multivariable logistic regression models with random intercepts to account for within-subject repeated measures. In separate models, we regressed CRA composite scale scores and patient and care partners self-reported difficulty paying monthly bills ratings at both time points (T1, T2) on scan result, time point indicators and their interactions with scan result, and adjusted for T1 covariates. Non-collinear patient covariates included medical diagnoses, age, sex, education, race, self-reported health, no long-term care insurance, no financial planner, and comorbidity count.

Quantitative Results

Cohort characteristics. As evidenced in Table 1, the beneficiary-based cohort for the Medicaid outcome analysis (n=2,076) had a mean age of 75 and was mostly White, highly educated, in good health, and well-resourced as evidenced by the high rates of having consulted a financial planner and having long-term care insurance (cohort for LIS analysis is in Table A1). Nearly all care partners were spouses. The number of respondents in the survey-based cohort (Table 2) was slightly smaller than the beneficiary-based cohort, reflecting the inclusion criteria of the survey sample (n=1,723). Characteristics were similar across the two cohorts, with the minor exception that more care partners were in fair or poor health in T1 in the surveys (12.5% versus 10%). For the survey-based cohort models, we imputed values for patient age (N=<11, <1%), patient education (N=21, 1%), no financial planner (N=24, 1.1%), and no long-term insurance (N=123, 5.8%).

There were some key differences in patients in the beneficiary-based cohort who received an elevated (1,371) versus non-elevated scan result (n=705). Individuals with an elevated scan were older (by 1 year on average) and healthier. Rates of some diagnosed conditions were lower in the elevated scan patient group, including hypertension, diabetes, active depression, and a lower mean count of comorbidities. Care partners characteristics did not differ by patient scan results (Table 1).

Table 1. Medicare-beneficiary-based cohort characteristics of patients with cognitive impairment, conditional on not having Medicaid in year prior to survey date, by scan results at T1

Variable	Overall	Non-Elevated Scan	Elevated Scan	Std Diff	p-value
N	2,076	705	1,371		
Patient Characteristics					
Age, Mean (SD)	74.56 (5.55)	73.77 (5.50)	74.96 (5.54)	21.6%	< .001
Male	1,211 (58.3%)	419 (59.4%)	792 (57.8%)	3.4%	.47
Care partner is spouse or significant other	1,743 (84.0%)	583 (82.7%)	1,160 (84.6%)	5.2%	.26
Non-Hispanic White*	1,927 (92.8%)	646 (91.6%)	1,281 (93.4%)	6.9%	.13
No college*	851 (41.0%)	296 (42.0%)	555 (40.5%)	3.1%	.51
Has not consulted financial planner	1,203 (57.9%)	415 (58.9%)	788 (57.5%)	2.8%	.54
Does not have long-term care insurance	1,419 (68.4%)	476 (67.5%)	943 (68.8%)	2.7%	.56
Self-reported poor to fair general health*	350 (16.9%)	143 (20.3%)	207 (15.1%)	13.6%	.003
Patient Medical History					
Atrial fibrillation	188 (9.1%)	70 (9.9%)	118 (8.6%)	4.6%	.32
Ischemic heart disease	199 (9.6%)	67 (9.5%)	132 (9.6%)	0.4%	.93
Hypertension	1,015 (48.9%)	374 (53.0%)	641 (46.8%)	12.6%	.007
Dyslipidemia	965 (46.5%)	339 (48.1%)	626 (45.7%)	4.9%	.29
Diabetes	298 (14.4%)	128 (18.2%)	170 (12.4%)	16.1%	< .001
Active Depression	379 (18.3%)	152 (21.6%)	227 (16.6%)	12.8%	.005
History of stroke or TIA	205 (9.9%)	80 (11.3%)	125 (9.1%)	7.4%	.11
Traumatic brain injury	112 (5.4%)	41 (5.8%)	71 (5.2%)	2.8%	.54
Count of comorbidities, Mean (SD)	1.87 (1.52)	2.09 (1.59)	1.75 (1.47)	22.4%	< .001
Care Partner					

Variable	Overall	Non-Elevated Scan	Elevated Scan	Std Diff	p-value
Self-reported poor to fair general health	214 (10.3%)	68 (9.6%)	146 (10.6%)	3.3%	.48
General health status (self assessed), Mean (SD)	2.38 (0.89)	2.43 (0.84)	2.35 (0.91)	9.1%	.005

Note: This cohort was used to examine newly acquiring Medicaid (e.g., becoming a dually eligible beneficiary), conditional on not having Medicaid at the time of the T1 survey. The characteristics of the LIS sample (newly acquiring LIS), shown in Table A1, were very similar.

*All Covariates were taken from the T1 survey data. We dichotomized education into no college (<12 years, high school graduate) vs. some college and higher (some college, Bachelor's degree, Master's, Professional, or Doctoral degree). Due to the highly homogenous nature of the study sample, race and ethnicity were recoded and dichotomized into non-Hispanic white vs. other (Hispanic white, non-Hispanic Black or African American, and other). Self-reported health status was dichotomized from a 5-point Likert scale into "Fair/Poor" (4=fair, 5=poor) vs. "Good+" (1=excellent, 2=very good, 3=good).

Table 2. Survey-based economic strain cohort characteristics, perceived financial strain survey measures, by scan results at T1

Variable	Overall	Non-Elevated Scan	Elevated Scan	Std Diff	p-value
N	1,723	538	1,185		
Patient Characteristics					
Age, Mean (SD)	74.47 (5.49)	73.65 (5.47)	74.85 (5.46)	21.9%	< .001
Male	1,050 (60.9%)	346 (64.3%)	704 (59.4%)	10.1%	.05
Care partner is spouse or significant other	1,524 (88.5%)	474 (88.1%)	1,050 (88.6%)	1.6%	.76
Non Hispanic White*	1,603 (93.0%)	496 (92.2%)	1,107 (93.4%)	4.7%	.35
No college*	699 (40.6%)	225 (41.8%)	474 (40.0%)	3.7%	.48
Has not consulted financial planner	991 (57.5%)	312 (58.0%)	679 (57.3%)	1.4%	.79
Does not have long-term care insurance	1,168 (67.8%)	368 (68.4%)	800 (67.5%)	1.9%	.71
Self-reported poor to fair general health*	285 (16.5%)	108 (20.1%)	177 (14.9%)	13.6%	.008
Patient Medical History					
Atrial fibrillation	155 (9.0%)	56 (10.4%)	99 (8.4%)	7.1%	.17
Ischemic heart disease	168 (9.8%)	51 (9.5%)	117 (9.9%)	1.3%	.80
Hypertension	860 (49.9%)	299 (55.6%)	561 (47.3%)	16.5%	.002
Dyslipidemia	803 (46.6%)	264 (49.1%)	539 (45.5%)	7.2%	.17
Diabetes	246 (14.3%)	94 (17.5%)	152 (12.8%)	13.0%	.01
Active Depression	308 (17.9%)	114 (21.2%)	194 (16.4%)	12.4%	.02
History of stroke or TIA	175 (10.2%)	63 (11.7%)	112 (9.5%)	7.3%	.15
Traumatic brain injury	94 (5.5%)	30 (5.6%)	64 (5.4%)	0.8%	.88
Count of comorbidities, Mean (SD)	1.88 (1.53)	2.14 (1.61)	1.76 (1.48)	24.2%	< .001

Variable	Overall	Non-Elevated Scan	Elevated Scan	Std Diff	p-value
Care Partner					
Self-reported poor to fair general health	212 (12.3%)	68 (12.6%)	144 (12.2%)	1.5%	.78
General health status (self assessed), Mean (SD)	2.37 (0.96)	2.44 (0.96)	2.34 (0.97)	9.6%	.05

*All Covariates were taken from the T1 survey data. We dichotomized education into no college (<12 years, high school graduate) vs. some college and higher (some college, Bachelor's degree, Master's, Professional, or Doctoral degree). Due to the highly homogenous nature of the study sample, race and ethnicity were recoded and dichotomized into non-Hispanic white vs. other (Hispanic white, non-Hispanic Black or African American, and other). Self-reported health status was dichotomized from a 5-point Likert scale into "Fair/Poor" (4=fair, 5=poor) vs. "Good+" (1=excellent, 2=very good, 3=good). For the survey-based cohort models, we imputed values for patient age (N=<11, <1%), patient education (N=21, 1%), no financial planner (N=24, 1.1%), and no long-term insurance (N=123, 5.8%).

Beneficiary-based economic strain analyses outcomes. The cumulative incidence rates show that the number of patients who became newly eligible for Medicaid was extremely low 4 years after the baseline survey date (1.3%) and was similar across scan results (elevated: 1.1%, non-elevated: 1.8%) (Figure A1). Similarly, newly receiving LIS was slightly more common than newly receiving Medicaid (e.g., dually covered), reflecting looser eligibility requirements for LIS, but incidence was still extremely low. Just 44/2,076 patients at 4 years were newly eligible for LIS, representing 2.4% of the patient sample. Again, incidence rates were similar between scan groups (elevated: 2.8%, non-elevated: 1.8%).

The adjusted hazard ratios from the Cox proportional models also show no significant association between scan result and eligibility for Medicaid status or LIS (Table 3).

Survey-based economic strain analyses outcomes. None of the subjective economic strain outcomes differed by scan result. However, we observe that, on average, the full sample of patients and care partners expressed greater difficulty paying bills in T2 than T1 (Figure 1, Panels A and B). The increase in having at least some difficulty paying bills was relatively large in magnitude, going from 17-19% of patients who expressed difficulty paying bills in T1 to 28-34% at T2 (Figure 1, Panel A and Table A1). The difficulty of paying bills was also significantly higher for care partners at T2, (from 18-20% to 24-33% in T2) (Figure 1, Panel B and Table A1).

Qualitative Methods

Recruitment

A subsample of patients and care partners who completed both survey timepoints and agreed to be contacted for future research opportunities were invited to participate in semi-structured interviews approximately 18-months after the amyloid scan. We oversampled patients and care partners who did not identify as non-Hispanic White to increase the diversity of perspectives. Participants were mailed an invitation to participate with a consent form before they were approached by the research team. Interviews were only conducted with participants who gave their informed consent.

Data collection

Table 3. Cox model results for incident Medicaid and Low-Income Subsidy status up to four years after the initial scan date (could not have Medicaid or LIS in 12 months prior to scan date)

	Unadjusted		Adjusted	
	HR (95% CI)	**p**	**HR (95% CI)**	**p**
Outcome = dual-eligible status				
Elevated scan v. not elevated	1.39 (0.71, 2.70)	.33	1.20 (0.60, 2.43)	.60
Outcome = LIS				
Elevated scan v. not elevated	0.56 (0.26, 1.24)	.15	0.49 (0.21, 1.11)	.09

Covariates included were diagnosis (MCI or dementia), patient age, sex, education (no college, vs. college or more), and race.

A total of 100 semi-structured, telephone-based interviews were completed following a topic guide. The topic guide included questions regarding participants experiences of getting the scan, how they felt about the result, and whether the scan result affected their future plans. The interviews were conducted by three research assistants and a research coordinator under the supervision of senior researchers. The interviewer first reviewed the consent form and then asked the participant to state the purpose of the interview, in their own words, as an additional check of capacity. Interviews lasted approximately 30 to 60 minutes and were recorded, with permission from the participant.

Qualitative analysis

The audio-recorded interview recordings were transcribed, anonymized, and imported into NVivo 12 for analysis. The qualitative data were initially organized using exploratory content analysis and double coded by five qualitative researchers (EC, EB, MSB, WZ, TW) for accuracy. All data related to patient and care partner experiences of economic strain were collated and further analyzed following Braun and Clark's procedures for thematic analysis [10]. First, all authors reviewed the qualitative data, then the five qualitative researchers each made an initial list of codes and notes on their initial impressions. These codes and notes were discussed in a team meeting and used to create consensus list of codes, which were subsequently applied to the data by two authors (EC and WZ). Examples of codes include: "Financial status at time of diagnosis", "Aware of increasing care needs", and "Decision to enroll in long-term care insurance". Codes with overlapping meanings were grouped into categories. During our analysis, we noticed that participants expectations of the patient's future care needs and associated financial concerns differed depending on the level of cognitive impairment and scan result. To explore this further, we used the query function in NVivo 12 to explore the data collected within the categories by the patient's diagnosis. We then identified cross-cutting patterns in the data, related to participants' experiences of economic strain in relation to the amyloid scan result summarizing patterns into themes.

Qualitative Results

We interviewed 38 patients and 62 care partners. Table A2 provides an overview of the characteristics of the qualitative sample of participants. We identified three themes relating to patient and care partner experiences of financial decision-making following an amyloid scan in light of the scan results: 1) the need to make or update financial plans, 2) perceived care needs and financial resources for meeting care needs, and 3) involvement of family members in financial decision making. See Table A5 for illustrative quotes within these identified themes.

Making or updating financial plans in light of the scan result

Many participants reported making plans for their care in older age (e.g., drafting wills, enrolling in long-term care insurance, and consulting financial planners) before receiving the amyloid scan. Participants with MCI without elevated amyloid acknowledged the existence of such plans, should they be needed in the future, but did not report updating them or making new ones. Participants with MCI and elevated amyloid reported the scan result gave them a better understanding of what to expect for their future care needs. They described updating their plans or making new ones in light of the scan result:

> "We made sure we already had wills and things, but we made sure to update them. We got our affairs in order. We went through everything together, all of our finances, everything together. I remember shortly after the diagnosis, we spent a couple of weeks together in the basement going through everything so that we both be aware of where everything was." (Care partner, MCI with elevated amyloid)

And:

> "[The scan] helped me strategize and make plans, and get all the financial and legal ... new wills and all of those things organized. So yeah, it's been a very, very useful thing." (Patient, MCI with elevated amyloid)

On the other hand, one participant described how the results from the amyloid scan prompted them to engage in financial decision-making, specifically related to estate planning, but was prohibited by the cost of a lawyer:

> "Well, the process is, we had it done, and now I'm waiting to get some money from my 401k so I can pay for the attorneys to [write up a will]. It's so expensive. That's where I'm at right Now" (Patient, MCI with elevated amyloid)

Perceived care needs and financial resources for meeting care needs

Participants described their anticipated care needs after receiving the scan results and how they would meet these expected costs. For example, participants with dementia mainly described needing nursing home care in the future and discussed how they would pay for this. Some expressed concerns that they would live in a nursing home longer than their economic resources would allow for: "I don't need much. We're fairly comfortable, so I don't have any financial fears. My only fear is living too long and spending all that money in a nursing home." (Patient, Dementia without elevated amyloid).

Participants discussed how they would leverage their economic resources (including Medicare, long-term care insurance, retirement savings, support from children, and their personal wealth) to meet their future care needs. Participants who described having the resources to meet their anticipated care needs reported feeling they had control over their future care. They described having flexibility, contingencies, and the ability to take things as they come: "But, we do have a financial advisor who has worked with us, and we've got several financial buckets. And we've got care. And if it comes down to it, we sell our house." (Care partner, MCI with elevated amyloid). Participants who reported not having enough resources to meet their future care needs were worried about how they would pay for future care:

> "I know, if it gets bad enough, I'll end up in a nursing home. That's one area that I don't have financial stability on. I do not have one of those home care policies or anything or not home care but nursing home policy… I'll probably have to go on [Medicaid] and whatever facility they put me in." (Patient, MCI with elevated amyloid)

Whether the person with cognitive impairment had long-term care insurance was an important factor in whether participants reported having the resources for meeting their future care needs. Often, this decision was made long before the onset of symptoms.

> "The problem is long ago when we purchased her long-term care insurance ... This is a real serious thing for us ... We had the chance to get a kind of a 10% family discount if we both got the insurance. And I foolishly said, "Well, I don't need to yet." This is before the mild cognitive impairment was clear. So as soon as I took my first pill of Aricept, I became poison to the insurance companies, and I am uninsurable." (Patient, MCI without elevated amyloid)

Involvement of family members in financial decision making

Participants talked about how financial decisions regarding future care could affect their families. Some participants decided to keep discussions about their care needs within the caregiving dyad, whereas some sought to involve others. If participants involved others in financial decisions, they sought to involve people who they perceived as trustworthy and knowledgeable. Participants sometimes sought relatives or close friends to act as trustees or executors to the scan recipients' finances: "Well, I don't really discuss the planning with my children. I keep them up to date. They're adults, but occasionally I talk with my wife about it and it sort of is a factor in our financial planning." (Patient, MCI without elevated amyloid).

While some participants noted the importance of involved, trusted individuals (e.g., children) in financial plans, they were also concerned their future care needs and associated costs could negatively impact their family. These concerns included becoming a financial "burden" in the later stages of dementia and diminishing their family's shared wealth. Participants specifically cited concerns about accumulating debt or diminishing the inheritance intended for their children or spouse:

> "Well, like most people, I just don't want to be a burden on my family, especially with kids. We're working very hard to make sure that we're debt-free and we actually have been giving the kids

things, so that when the time comes, they already have things we want them to have and they don't have to go through a lot of probate and all that sort of stuff." (Patient, MCI with elevated amyloid)

Integrated findings

In this mixed methods study, we explored patient and care partner experiences of economic strain and financial decision making following an amyloid PET scan. In our analysis of quantitative data, we found low levels of objective economic strain in this cohort, as indicated by very low rates of Medicaid status (1-2%) and low-income supplement (LIS) (2-3%) in both post-scan time periods. We also found no association between scan result and subsequent subjective economic strain. However, subjective outcomes from survey data indicated that substantially more participants reported at least some difficulty with paying bills around 18 months after the scan compared to around 4 months after the scan, irrespective of the scan result. Our qualitative analysis suggests that experiences of economic strain may be nuanced. For example, receiving an elevated amyloid scan result influenced participants' expectations for their future care needs and prompted them to engage in financial decision-making. Participants with elevated amyloid described expecting to need potentially costly nursing home care. Participants who did not report having the resources to pay for their perceived future care described being worried about their financial stability in the future. They also described concerns that paying for their future care would have a negative economic impact on their family. Taken together, these findings indicate that amyloid scans can shape patient and care partner expectations of their future care needs and costs, which can inform financial decision-making, but may not translate into changes in objective or subjective measures of economic strain.

Discussion

As noted, we did not find any differences in quantitative measures of objective and subjective economic strain by scan result. There are several possible explanations for this finding. First, patients and care partners in this study were highly educated and over half had consulted a financial planner and/or purchased long-term care insurance, and therefore were unlikely to experience incident economic strain following the scan. Additionally, our claims-

based measures in particular represented a catastrophic change in financial security, newly qualifying for Medicaid or newly qualifying for a Medicare Part D prescription drug subsidy (LIS) by becoming low-income, and therefore may be a rare outcome. Subjective strain, by contrast, increased over time regardless of scan result, with much higher rates of individuals reporting difficulty paying bills. Second, participants with non-elevated levels of amyloid were in poorer health than participants with elevated amyloid both in terms of self-reported general health and the number of comorbid conditions [11]. Therefore, it is possible that increases in objective and subjective economic burden among dyads with elevated amyloid is driven by care needs and costs associated with ADRD, whereas objective and subjective burden among dyads with non-elevated amyloid is driven by poor general health and multimorbidity.

Findings from our qualitative analysis highlight that the scan result prompted many patients with elevated amyloid and their care partners to make or update financial or future care plans. This is in contrast to previous qualitative research from the UK, which found that people with dementia and their care partners were reluctant to make financial plans due to feelings of uncertainty regarding the future and put off engaging in financial decision making [12]. It is possible that a diagnosis in light of an amyloid scan result gave patient and care partners greater certainty about future care needs than a diagnosis without a scan. Participants in this study described how they would leverage existing financial resources to pay future long-term care costs. However, participants who reported having inadequate resources expressed concerns about how they would meet the costs of their future care. Participants discussed how their future care needs and associated costs may affect their wider family unit. Patients specifically cited concerns that they might financially "burden" their families and that paying for their care would deplete their savings and family wealth. Similar concerns have been reported by people with dementia and their caregivers in the United Kingdom [13]. Giebel et al [13] also noted that both participants with dementia and their care partners who had the resources to make advanced financial plans for their care were satisfied with arrangements for their future care. Similarly, participants in this study who reported having the financial resources necessary to meet the patient's care needs described having the flexibility to "take things as they come." Despite many participants reporting engaging in financial decision-making or describing having the resources to meet the

patient's anticipated care needs, participants still experienced increased difficulties with paying their bills. It is possible that engaging in financial decision-making or feeling able to meet future care needs is not sufficient for preventing economic strain.

As the prevalence of ADRD continues to grow rapidly, it is imperative to understand and minimize the economic impacts on those living with the disease and their care partners. To date, there has been limited research on both objective and subjective economic strain experienced by patients and their care partners, particularly once diagnosed. While our study strived to fill that gap by identifying and using multiple measures of objective and subjective economic strain, more research is needed to elucidate how best to define and measure the economic impacts of ADRD on patients and care partners. For example, our study showed that "difficulty paying bills" resonated with patient and care partner perceptions of economic strain, potentially because bills are a recurring cost to them, and it appeared more sensitive than other measures. Although promising, a wider range of measures are needed to reflect the multifaceted and evolving nature of economic strain highlighted in our study and to capture the heterogeneous disease journey experienced by ADRD patients and their care partners. These efforts are particularly important given the evidence that deterioration in financial capacity is an early indicator for ADRD [14]. Measures of both objective and subjective strain could be integrated into the intake or diagnostic work-up questionnaires used by primary and geriatric care providers or within the electronic health record (EHR). Documenting both health and financial concerns at the time of diagnosis of MCI or dementia and throughout the ADRD continuum could help connect patients and care partners with available resources. Best practices could be gleaned from work integrating screening for the social determinants of health and financial toxicity associated with cancer treatment into routine care [15 16].

Relatedly, it has been proposed that early diagnosis of ADRD informed by an amyloid PET scan can motivate advanced care and financial decision-making, which can reduce economic burden for patients and care partners. Many of our interviewees noted that an elevated scan spurred consideration of and action on their financial matters, or they derived comfort that those matters had been set in motion or established earlier. Patients and care partners with limited financial means or non-financial support to access these resources before or following

diagnosis may be placed at even greater risk for economic strain. Therefore, more research and practice, and policy innovation are needed to identify, test, and implement advanced care and financial decision-making strategies to address the diverse economic support needs of patients and care partners and ensure equitable access to these critical resources. Potential actions to be explored could include leveraging health systems as a point of contact for these patients, including the use of financial navigators; coverage of advanced care and financial planning in Medicare and Medicaid; provider and other health professional education on available resources; and, leveraging community-based resources, such as the Area Agencies on Aging or other state-funded, dementia support for patients and care partners.

Our study has several limitations. First, this sample is affluent compared to the general Medicare population and participants began the study with extremely low objective economic strain, which means they are not representative of the general Medicare population. Consequently, we have a sample that is expected to be among the most resilient to economic strain following a dementia diagnosis and therefore less likely at risk for the objective measures of economic strain, such as LOI or Medicaid eligibility. Second, to join the sample, individuals had to find their way to a specialized center with scan technology, have an atypical case (e.g., progressive, unexplained MCI or dementia of uncertain cause), and provide informed consent for research (that is, these participants were not receiving routine medical care). Third, our analysis does not capture financial strain among participants who died during the follow-up windows; they may have had different financial strain experiences given that we know health care expenditures are high in the year immediately preceding death [17-19]. Additionally, for the subjective strain survey data measures, we do not have reports of strain prior to receiving the scan result, as the first survey was delivered after the scan results were likely communicated to the patients and care partners. As such, we have short-term economic strain (4-6 months) following scan result, and longer-term economic strain (18-24 months). We do have prior measures of economic stain the full year before the scan date for objective measures assessed by claims (e.g., Medicaid status at 4 years), however, overall, economic strain may arise later in the disease trajectory. Fourth, our quantitative data almost entirely comprises persons who identify as White, non-Hispanic, which is a major limitation given racial inequality in economic strain in the

United States. The subset of participants who completed the qualitative interviews was more racially diverse, but this does not overcome the problem. Fifth, and finally, unlike the survey, in-depth interviews occurred during the pandemic, which may have shaped perceptions of financial strain. Also, given qualitative data collection occurred last, more individuals likely progressed from MCI to dementia than in the survey data; these individuals may then have been unable to participate in the qualitative interviews or were represented by their care partner's experience.

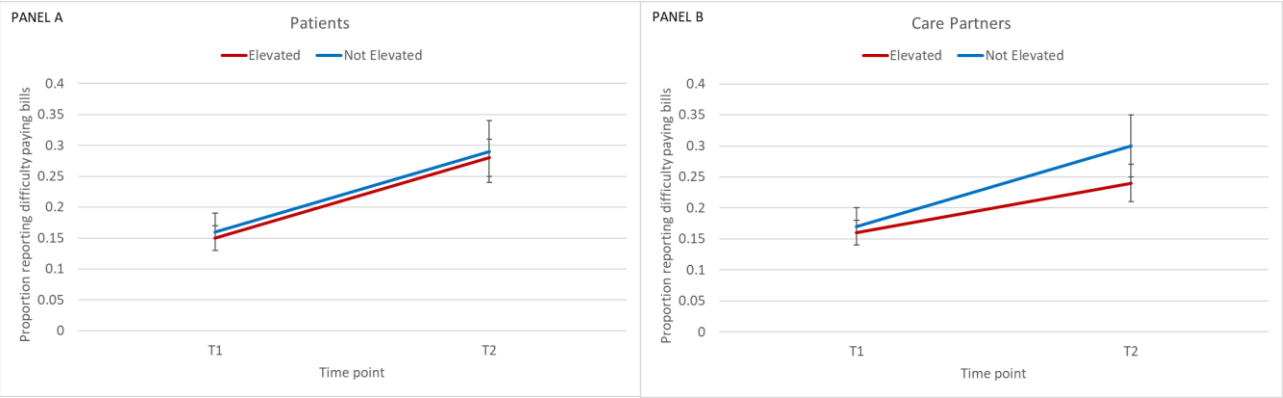
Limitations aside, a strength of this paper is the variety of economic strain measures collected and the presentation of multiple perspectives. Prior to this study, we knew very little about how diagnosis following an amyloid PET scan affected economic strain of persons with memory problems, including how economic strain changed over time. Given the selectivity of the sample, we anticipate these were the most protected individuals from bad economic outcomes. Given that early diagnosis efforts, today will likely come from anti-amyloid therapy era techniques (e.g., Amyvid scan) beyond amyloid PET scans and be applied to large populations [20], similar inquiries on economic strain could be useful for evaluating such efforts to obtain earlier diagnosis of dementia. Also, future positive studies are likely to entail significantly more diagnostic, therapeutic, and safety monitoring expenses than could have been considered in the 2016-2018 timeframe of this study thus continuing to assess economic strain from diagnostic and therapeutic approaches to dementia will be vital.

Conclusions

In a sample of affluent Medicare beneficiaries, we did not find support for our hypothesis that patients and care partners with elevated amyloid based on scan results would have higher subjective economic strain immediately post-scan nor higher subjective and objective economic strain 18-24 months and 4 years post-scan, respectively, compared to those with a negative scan. However, difficulty paying bills increased substantially for all participants on average over 18-24 months and the interviews indicated the scan prompted participants to make financial plans for future care. Furthermore, the qualitative data revealed that economic strain was very nuanced for this study sample, including revealing worries about today and tomorrow. Participants who did not report

having the financial resources to meet their anticipated care needs were worried about the future. An early diagnosis for cognitive impairment could provide an opportunity to engage in financial decision-making and address existing and future financial burdens for patients and care partners. More efforts are needed to ascertain how economic strain is experienced by diverse patients and care partners and how best to measure and address it across the ADRD continuum.

Figure 1. Model-estimated proportions by scan and time point on difficulty paying monthly bills for patients (Panel A on LHS) and for care partners (Panel B on RHS)



Covariates included were diagnosis (MCI or dementia), patient age, patient sex and patient education (no college, vs. college or more), patient race, patient self-reported health (binary variable), care partner work status, no long-term insurance, no financial planner, and patient comorbidity count.

Note: The increase over time was significant for each group ($p<0.05$).

Figure legends

Figure 1. Model-estimated proportions by scan and time point on difficulty paying monthly bills for patients (Panel A on LHS) and for care partners (Panel B on RHS)

Covariates included were diagnosis (MCI or dementia), patient age, patient sex and patient education (no college, vs. college or more), patient race, patient self-reported health (binary variable), care partner work status, no long-term insurance, no financial planner, and patient comorbidity count.

Note: The increase over time was significant for each group ($p<0.05$).

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Appendix.

APPENDIX TABLE A1

Table A1. Medicare-beneficiary-based cohort characteristics of patients with cognitive impairment, among those with no Part D Low Income Subsidy (LIS) in the prior year of the survey date, by scan result

Variable	Overall	Non-elevated Scan	Elevated Scan	Std Diff	p-value
N	2,059	696	1,363		
Patient Characteristics					
Age, Mean (SD)	74.57 (5.55)	73.79 (5.51)	74.97 (5.54)	21.4%	< .001
Male	1,205 (58.5%)	415 (59.6%)	790 (58.0%)	3.4%	.47
Care partner is spouse or significant other	1,735 (84.3%)	580 (83.3%)	1,155 (84.7%)	3.8%	.41
Non Hispanic white	1,911 (92.8%)	638 (91.7%)	1,273 (93.4%)	6.6%	.15
No college	840 (40.8%)	291 (41.8%)	549 (40.3%)	3.1%	.50
Has not consulted financial planner	1,187 (57.6%)	407 (58.5%)	780 (57.2%)	2.5%	.59
Does not have long-term care insurance	1,408 (68.4%)	469 (67.4%)	939 (68.9%)	3.2%	.49
Self-reported poor to fair general health	341 (16.6%)	138 (19.8%)	203 (14.9%)	13.1%	.004
Patient Medical History					
Atrial fibrillation	187 (9.1%)	69 (9.9%)	118 (8.7%)	4.3%	.35
Ischemic heart disease	193 (9.4%)	63 (9.1%)	130 (9.5%)	1.7%	.72
Hypertension	1,002 (48.7%)	368 (52.9%)	634 (46.5%)	12.7%	.006
Dyslipidemia	957 (46.5%)	335 (48.1%)	622 (45.6%)	5.0%	.28
Diabetes	295 (14.3%)	126 (18.1%)	169 (12.4%)	15.9%	< .001
Active Depression	375 (18.2%)	150 (21.6%)	225 (16.5%)	12.9%	.005
History of stroke or TIA	202 (9.8%)	79 (11.4%)	123 (9.0%)	7.7%	.09
Traumatic brain injury	112 (5.4%)	41 (5.9%)	71 (5.2%)	3.0%	.52

Variable	Overall	Non-elevated Scan	Elevated Scan	Std Diff	p-value
Count of comorbidities, Mean (SD)	1.86 (1.51)	2.09 (1.59)	1.74 (1.46)	22.7%	< .001
Care Partner					
Self-reported poor to fair general health	213 (10.3%)	68 (9.8%)	145 (10.6%)	2.9%	.54
General health status (self assessed), Mean (SD)	2.38 (0.89)	2.43 (0.85)	2.35 (0.91)	9.7%	.004

Note: This cohort was used to examine the association of scan results with LIS, among those patient participants who did not have LIS at T1

Figure A1. Cumulative incidence curves, with rates accounting for the competing risk of death for (A) Part D low-income subsidy (LIS), and (B) Dual Medicare/Medicaid status, for up to 4 years after the date of the Amyloid- β PET Scan.

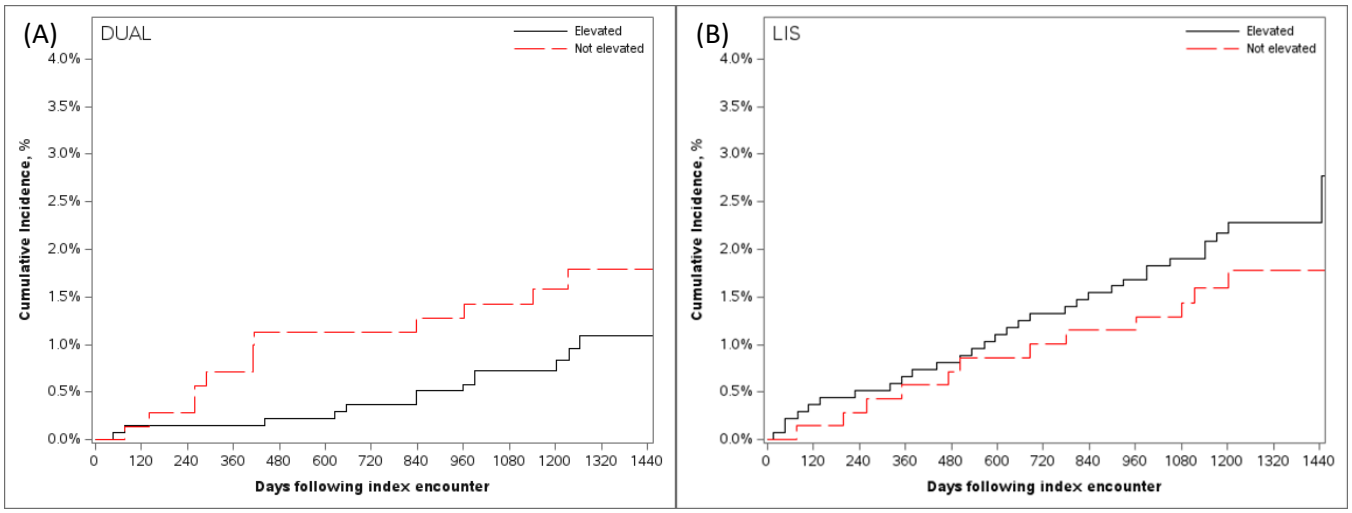
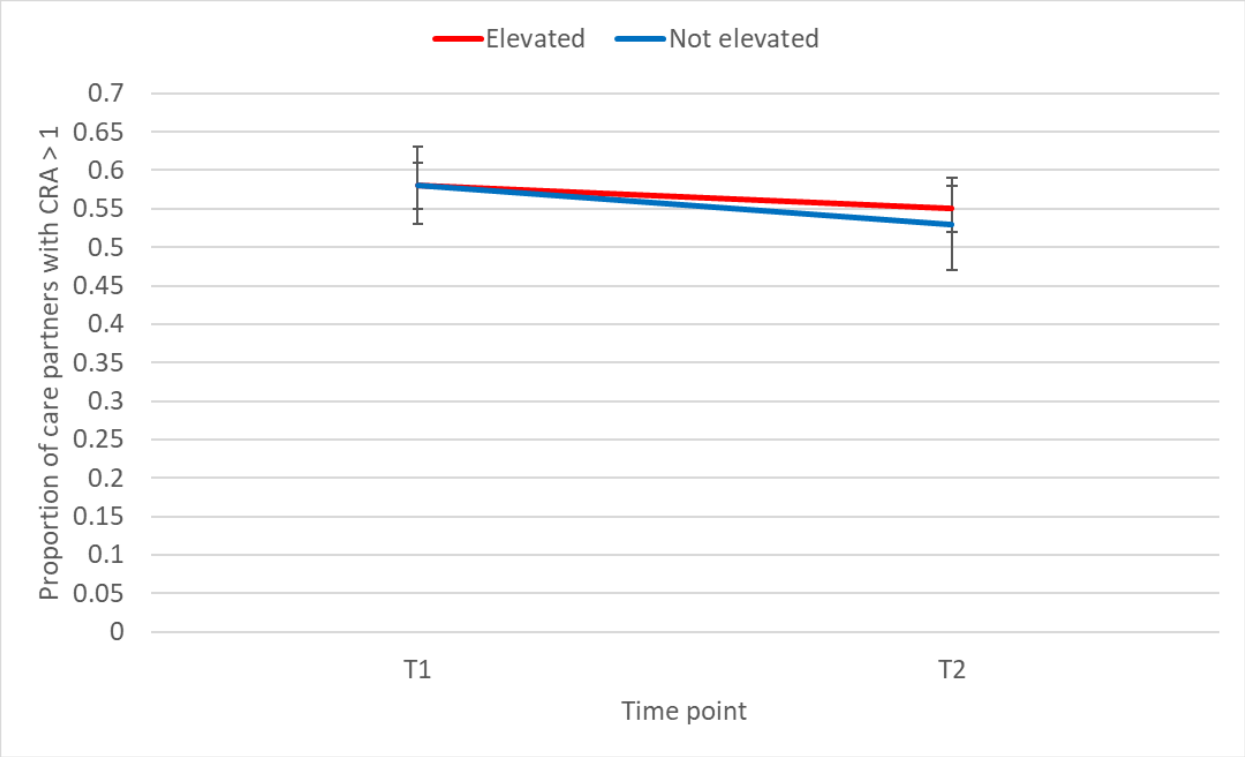


Figure A2. Model-estimated proportion of Care Partners reporting a Caregiver Reaction Assessment Financial Strain sub-score greater than 1 from the survey-data, by scan and time point.



Covariates included were diagnosis (MCI or dementia), patient age, patient sex and patient education (no college, vs. college or more), patient race, patient self-reported health (binary variable), care partner work status, no long-term insurance, no financial planner, and patient comorbidity count.

Note: A CRA score greater than 1 indicates endorsement of some level of financial strain on at least one component question.

Table A2. Survey-based financial strain outcomes, by scan and time.

	TIME 1				TIME 2			
Patient Variables	**Overall**	**Non-Elevated**	**Elevated**	**Std Diff**	**Overall**	**Non-Elevated**	**Elevated**	**Std Diff**
N	1,684	528	1,156		935	316	619	
Difficulty meeting monthly bill payments	294 (17.5%)	102 (19.3%)	192 (16.6%)	7.1%	278 (29.7%)	106 (33.5%)	172 (27.8%)	12.5%
Care Partner Variables								
N	1,718	537	1,181		1,246	382	864	
Difficulty meeting monthly bill payments	315 (18.3%)	106 (19.7%)	209 (17.7%)	5.2%	330 (26.5%)	124 (32.5%)	206 (23.8%)	19.3%
N	1,699	534	1,165		1,200	534	1,165	
Financial resources not adequate*	795 (46.8%)	253 (47.4%)	542 (46.5%)	1.7%	499 (41.6%)	161 (44.8%)	324 (39.7%)	10.5%
N	1,709	535	1,174		1,325	535	1,174	
Difficult to pay for patient needs*	654 (38.3%)	205 (38.3%)	449 (38.2%)	0.1%	427 (32.2%)	140 (33.4%)	280 (31.1%)	4.9%
N	1,708	533	1,175		1,211	533	1,175	
Caring for the patient is financial strain*	468 (27.4%)	138 (25.9%)	330 (28.1%)	4.9%	326 (26.9%)	98 (27.1%)	224 (26.9%)	0.5%
N	1,685	530	1,155		1,174	356	818	
Financial Strain score > 1	966 (57.3%)	312 (58.9%)	654 (56.6%)	4.5%	627 (53.4%)	190 (53.4%)	437 (53.4%)	0.1%

* Financial strain score is constructed from sum of these three item

Table A3. Associations of financial strain, scan, and time from adjusted models.

Label	CRA score > 1	Difficulty paying monthly Bills Patient	Difficulty paying monthly Bills Care Giver
Odds Ratios :			
T1 v T2, elevated	0.83 (0.49, 1.16)	2.08 (1.10, 3.07)	1.97 (1.11, 2.83)
T1 v T2, non-elevated	0.84 (0.63, 1.05)	2.18 (1.56, 2.81)	2.12 (1.60, 2.64)
elevated v non-elevated at T1	0.98 (0.75, 1.21)	0.95 (0.69, 1.21)	0.93 (0.68, 1.18)
elevated v non-elevated at T2	1.06 (0.77, 1.35)	0.94 (0.65, 1.24)	0.72 (0.52, 0.92)
Marginal Effects:			
T1 v T2, elevated	-0.02 (-0.06, 0.02)	0.13 (0.09, 0.21)	0.08 (0.05, 0.11)
T1 v T2, non-elevated	-0.04 (-0.10, 0.02)	0.15 (0.09, 0.21)	0.14 (0.09, 0.19)
elevated v non-elevated at T1	0.00 (-0.06, 0.05)	-0.00 (-0.05, 0.03)	-0.01 (-0.05, 0.03)
elevated v non-elevated at T2	0.01 (-0.05, 0.08)	-0.00 (-0.08, 0.06)	-0.07 (-0.13, -0.01)

Covariates included were diagnosis (MCI or dementia), patient age, patient sex and patient education (no college, vs. college or more), patient race, patient self-reported health (fair/poor vs. good or better), care partner work status, no long-term insurance, no financial planner, and patient comorbidity count.

Note: Marginal effects represent differences in proportions.

Table A4. Characteristics of qualitative sample for financial strain analysis

	Patients	Care partners
Characteristic	N = 38	N = 62
Age, Mean (SD)	73.5 (5.1)	69.5 (9.1)
Male (%)	25 (65.8)	15 (24.2)
Caring for/by a spouse (%)	33 (86.8)	54 (87.1)
Non-Hispanic, White (%)	25 (67.6)	34 (54.8)
No college (%)	10 (27.0)	17 (28.8)
Has or caring for patient with MCI (%)	35 (92.1)	49 (79.0)
Has or caring for patient with elevated amyloid (%)	23 (60.5)	36 (58.1)
Has not consulted financial planner (%)	19 (54.3)	-
Does not have long-term care insurance (%)	24 (63.2)	-

Table A5. Themes relating to patient and care partner experiences of economic strain with supporting quotes

Theme	Supporting quotes
The need to make or update financial plans in light of the scan result	"We made sure we already had wills and things, but we made sure to update them. We got our affairs in order. We went through everything together, all of our finances, everything together. I remember shortly after the diagnosis, we spent a couple of weeks together in the basement going through everything so that we both be aware of where everything was. We just got everything in order." (Care partner, MCI with elevated amyloid) "We got an elder lawyer and we did our living wills, our medical power of attorney. We did our regular will with everything, so that everything is above board and solved" (Care partner, MCI without elevated amyloid) "At the onset, when we got the results, we did go up to a central point where everybody met and we gave everybody the news and we went to his lawyer and revised his will and power of attorney and surrogate, everything." (Care partner, MCI with elevated amyloid) "[The scan] helped me strategize and make plans, and get all the financial and legal ... new wills and all of those things organized. So yeah, it's been a very, very useful thing." (Patient, MCI with elevated amyloid) "Well, the process is, we had it done, and now I'm waiting to get some money from my 401k so I can pay for the attorneys to [write up a will]. It's so expensive. That's where I'm at right Now" (Patient, MCI with elevated amyloid)
Perceived care needs and financial resources for meeting care needs	"[The scan results] just mean I know what to look forward to. I know what's going to happen. I'm 77 years old, so I know that some plans need to be made for me about what my care will be. My husband who's my caregiver right now for the things that I need, and it depends on how long he lives. I would hate to be on a Medicare nursing home." (Patient, MCI with elevated amyloid) "I don't need much. We're fairly comfortable, so I don't have any financial fears. My only fear is living too long and spending all that money in a nursing home, when I'd just as well be in the grave." (Patient, dementia without elevated amyloid) "We are fortunate in that have a very good health insurance in addition to Medicare, and we're able to choose our own doctors. And we have a team. Each of us have a team of people who are at the top of the field and in whom I have the greatest confidence and were I to develop you name it, I would either get a recommendation from an appropriate member of our medical team." (Patient, MCI without elevated amyloid) "Well, we have our plan for our care needs pretty much set up, in the sense that my husband was not able to get long-term care insurance, although I do have it. And so we have saved money to pay for that. Our savings are sitting there, and we are waiting to use them if we need to." (Care partner, MCI without elevated amyloid"

	"I like that he doesn't need much care yet, his pain has increasing, but he's not on any narcotics yet. So I like that he's comfortable in his own home. And I have a friend who has experienced taking care of people in end of life situations, and I've lined her up to help as needed. So I have the resources I need and I have the funds to pay for it. So, that's what I like a lot of people don't." (Care partner, MCI with elevated amyloid) "I know, if it gets bad enough, I'll end up in a nursing home. That's one area that I don't have financial stability on. I do not have one of those home care policies or anything or not home care but nursing home policy." (Patient, MCI with elevated amyloid) "Well, obviously it would depend on what that is and what the needs are. We'll do the right thing. We have proper insurance. We have the ability to be flexible." (Patient, MCI with elevated amyloid) "While my husband was still alive and I had an opportunity to do so, I took out long-term care insurance several years before all of this blew up. But at the time I thought, 'You know, I think I will go with five years instead of three, even though it's more expensive.' Because if I would get into a situation where it was mental more than physical... Most people that go in the nursing home only are there under two years, but not if it's this type of an issue. So I got the five years, so it would hopefully take the brunt of it. I'm glad I made that decision. I hope I never have to use it. I'd love to have the insurance company make money on me" (Patient, MCI, without elevated amyloid) "I do not have one of those home care policies or anything or not home care but nursing home policy. By the time it came out I was too old to get it at a decent price, and so I never got it. I'm not financially wealthy enough to just pay for it for years." (Patient, MCI with elevated amyloid) "The problem is long ago when we purchased her long-term care insurance ... This is a real serious thing for us ... We had the chance to get a kind of a 10% family discount if we both got the insurance. And I foolishly said, "Well, I don't need to yet." This is before the mild cognitive impairment was clear. So as soon as I took my first pill of Aricept, I became poison to the insurance companies, and I am uninsurable." (Patient, MCI without elevated amyloid)
Involvement of family members in financial planning	"Well, like most people, I just don't want to be a burden on my family, especially with kids. We're working very hard to make sure that we're debt-free and we actually have been giving the kids things, so that when the time comes, they already have things we want them to have and they don't have to go through a lot of probate and all that sort of stuff." (Patient, MCI with elevated amyloid) "[We] notified my sister, who is the executor of the trust. And so they are aware of our health conditions and where we are. Other than that, they know there's sufficient funds. You just have to monitor to make sure that we're both mentally able to make those financial decisions" (Care partner, MCI with elevated amyloid)

	"Oh, I do, my wife is, she's my rock. She really is. She's been through so much with me, physically as well as with this… She and I, she knows how I feel. She knows that there may come a time where she can't care for me, and then it's time to make a decision. My insurance is paid up, so anything ever happened to me, she's okay. She'll be okay for the rest of her life, but I just don't want to be a burden on my wife. And I do plan with her because I take her counsel more than anybody else's because as I said, we've been through a lot of things together. And even though I have children, they're separated from it and they live in other areas and they have children, I don't want them to be bothered. Really." (Patient, MCI with elevated amyloid) "We talk to (Wife)' sister regularly. She's involved, and she gives advice. She helped take care of (Wife)' mother and (Wife)' aunt. She made a lot of the decisions for them. We talked to our oldest son, and he's much more involved. Although both sons have given me input as to help on my [inaudible], but my oldest son who is a very successful businessman is very much involved in our financial planning, and he's a trustee. If anything were to happen to me, he's trustee in our wills, in our plans, and on our investment portfolio account. He knows, and is very involved in what our personal situation is." (Patient, MCI with elevated amyloid) "Well, I think if it turns out there were some inexpensive custodial care that would preserve the wealth accumulated for my wife and my children and grandchildren, I might just suck it up and get into some sort of institutional setting. But those are usually pretty expensive. So I don't know. That's the real persistent looming threat. We seem to have the cognitive stuff more or less under control. There's a little slippage, but I'm still working, and it's sort of a persistent worry… So now the big threat in terms of bankruptcy is one of us having a really expensive custodial situation." (Patient, MCI without elevated amyloid)