

Higher Patient Activation Levels May Mitigate Alzheimer's Caregiving Burden

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Introduction

- ! **Over 6 million Americans are currently living with Alzheimer's disease, which costs the U.S. economy an estimated \$360 billion in 2024.** More than 11 million Americans provide unpaid care for people with Alzheimer's or other dementias and an estimated value of \$346.6 billion in unpaid care (from 2023).¹
- ! **Each stage of AD imposes different responsibilities on caregivers, increasing their humanistic and economic burden.** The suffering and emotional burden of caregivers from the caring responsibilities lead to a decreased quality of life, poor mental health, weariness, and social isolation among other impacts.²
- ! **The Patient Activation Measure® or PAM® is a widely used and validated measure of patient activation. Patient activation refers to an individual's knowledge, skill, and confidence for managing their own health.** More activated patients are more likely to be adherent to treatment regimens, to engage in healthy behaviours, and to have better clinical outcomes.³
- ! **Use of PAM as a tool to tailor and adapt care has been established for a variety of interventions** however, for caregivers of patients with Alzheimer's disease and specifically their burden as patients themselves, there is sparse evidence advocating for the development and implementation of tailored interventions based on levels of caregiver activation.

Objective

- ! To describe the humanistic and economic burden (i.e., scores for validated scales that measure health-related quality of life, activity, productivity and mental health impact) for caregivers of patients with Alzheimer's disease in the US.
- ! To compare the humanistic and economic burden for the various PAM levels for caregivers of patients with Alzheimer's disease in the US.

Methods

Design & Data Source

- ! We conducted a retrospective analysis of data collected from the 2022 National Health and Wellness Survey (NHWS).
- ! The US NHWS is an annual, self-administered, internet-based cross-sectional survey of adults (≥18 years old).

Study Population and Data Variables

Study population

- ! Caregiver aged ≥18 years
- ! Caregiver of an adult relative with Alzheimer's disease

Socio-demographic data of caregiver

- ! Relationship to patient with Alzheimer's disease
- ! Age, gender, race/ethnicity, education level, employment status

Patient-Reported Outcome Measures

Patient Activation Measure

A 13-item scale measuring a patient's knowledge, beliefs, and confidence in interacting with healthcare professionals. Higher scores indicate higher levels of activation.

Level 1: Overwhelmed and disengaged
Level 2: Becoming aware, but still struggling
Level 3: Taking action
Level 4: Maintaining behaviors and pushing further

Healthcare resource utilization (in the past 6 months)

Traditional provider visits, EHR visits, and hospitalizations

RAND-36

Measuring general, mental, and physical health-related quality of life (HRQoL). Scores range from 0-100, with higher scores indicating better HRQoL.⁴

Work Productivity and Activity Impairment (WPAI)

WPAI measures lost work productivity and impairment in non-work daily activities. Scores are expressed as percentages, with higher values indicating greater impairment and less productivity.⁵

Patient Health Questionnaire-9 (PHQ-9)

A nine-item clinical screening tool, used to help assess depression symptoms. Scores range from 0-27, with higher scores indicating greater symptom severity.⁶

Caregiver Reaction Assessment (CRA)

A 24-item scale used to assess caregiver burden. Five subscales assess: impact on health, caregiver's esteem, impact on schedule, impact on finances, and lack of family support.⁷

Statistical Analyses

Unadjusted comparisons of caregivers' demographic, clinical and patient-reported variables between PAM level groups were conducted using chi-square tests and ANOVA tests for categorical and continuous variables, respectively. Two-sided p-values were considered statistically significant.

Results

Table 1. Sample characteristics

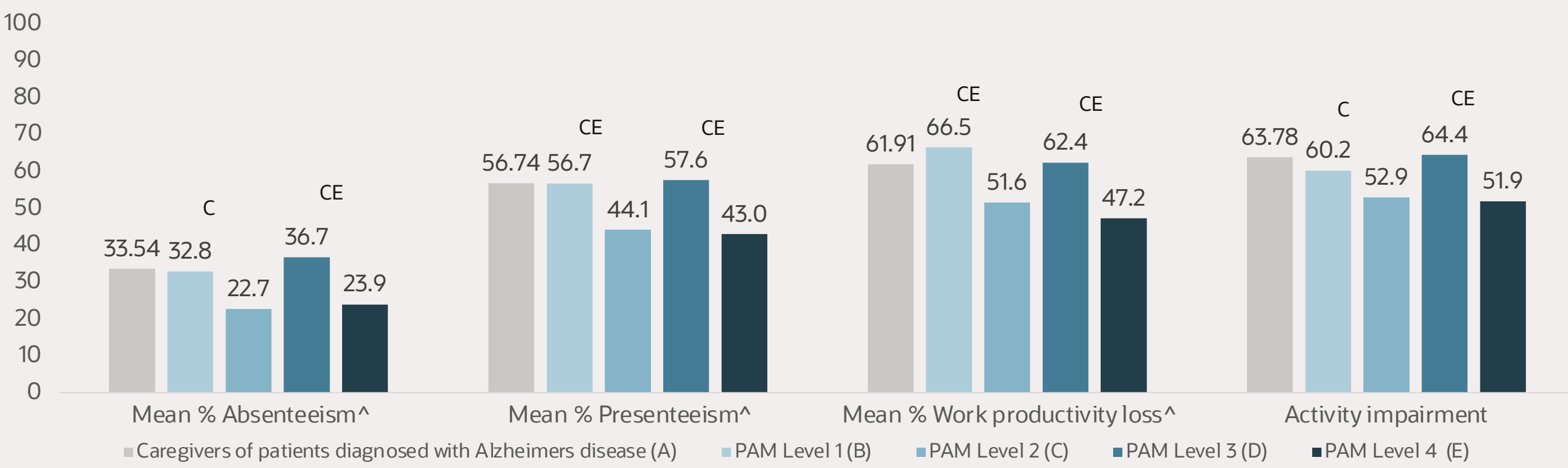
- ! Among caregivers (N=1,608), males accounted for 63.0% of PAM level 1 (PAM1), 47.3% of PAM level 2 (PAM2), 58.3% of PAM level 3 (PAM3), and 55.1% of PAM level 4 (PAM4).
- ! 33.3% of PAM1 level of education was "high school or less" vs 9.5% of PAM4.
- ! Across all PAM levels, caregivers were employed, 77.5% of PAM1, 67.0% of PAM2, 84.0% of PAM3, and 81.8% of PAM4 (n=127).

	Caregivers of patients diagnosed with Alzheimer's disease (n=1,608)	Caregivers of patients diagnosed with Alzheimer's disease: Patient Activation Level			
		Level 1 (n=138)	Level 2 (n=167)	Level 3 (n=799)	Level 4 (n=127)
	A	B	C	D	E
Male	56.2%	63.0% ^C	47.3%	58.3% ^C	55.1%
Age 18-34	34.8%	50.7% ^{DE}	40.7%	35.3%	29.9%
Age 35-44	32.7%	29.0%	21.0%	31.8% ^C	23.6%
Age 45-54	15.1%	10.1%	15.6%	14.1%	18.9% ^B
Age 55-64	10.9%	5.8%	15.0% ^B	11.3%	17.3% ^B
Age 65+	6.7%	4.4%	7.8%	7.5%	10.2%
White	58.4%	53.6%	50.9%	66.2% ^{BC}	70.1% ^{BC}
Non-White	41.6%	46.4% ^{DE}	49.1% ^{DE}	33.8%	29.9%
High school or less	23.0%	33.3% ^{DE}	27.5% ^{DE}	18.8% ^C	9.5%
Some college or Associate's Degree	19.2%	19.6%	20.4%	19.4%	22.8%
College degree or higher	57.7%	46.4%	52.1%	61.8% ^{BC}	67.7% ^{BC}
Employed (full-time, part-time, self-employed)	82.5%	77.5% ^C	67.1%	84.0% ^C	81.9% ^C

Letters indicate statistically significant difference @ p<0.05 between subgroups

Figure 1. Work and activity impairment scores

- ! Absenteeism (32.8% vs 23.9%), presenteeism (56.7% vs. 43.0%), overall work productivity loss (66.5% vs 47.2%), and activity impairment (60.2% vs 51.9%) were greater for PAM1 than PAM4 (all ps<0.05).



Absenteeism, presenteeism, and overall work productivity loss are among those employed (full-time, part-time, or self-employed). Letters indicate statistically significant difference @ p<0.05 between subgroups

Table 2. Health Outcomes

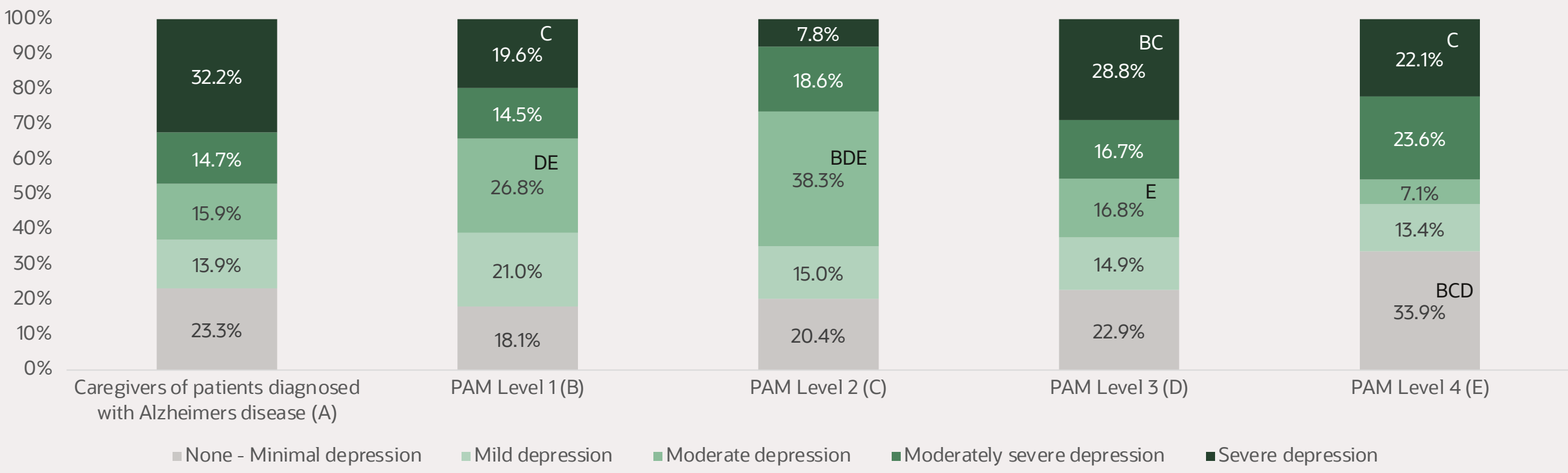
- ! PAM4 compared with PAM1 utilized less emergency room visits (mean=1.8 vs. 2.34, p<0.05).
- ! Compared with PAM1, PAM4 caregivers had better RAND36 physical (38.83 vs. 35.07, p<0.05) and mental health (38.65 vs. 32.87, p<0.05) composite scores.

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	A	B	C	D	E
Healthcare resource utilization (past 6 months, for the caregiver themselves), Mean					
Number of visits to any traditional healthcare provider	5.37	5.96	5.5	5.38	5.9
Number of visits to ER	1.61	2.34 ^{CD}	0.72	1.43 ^C	1.8 ^C
Number of times hospitalized	1.5	2.04 ^C	0.86	1.43 ^C	2.09 ^C
RAND-36 scores (for the caregiver themselves), Mean					
Physical health composite T score	35.45	35.07	37.34 ^B	36.30	38.83 ^{BD}
Mental health composite T score	35.40	32.87	35.19 ^B	35.58 ^B	38.65 ^{BCD}
Global health composite T score	33.63	31.88	34.38 ^B	34.16 ^B	37.31 ^{BCD}

Letters indicate statistically significant difference @ p<0.05 between subgroups

Figure 2. PHQ-9 scores

- ! 62.8% of caregivers had moderate to severe depression.
- ! PAM1 had greater moderate to severe depression than PAM4 (60.8% vs. 52.7%, p<0.05) while PAM4 had a higher proportion of none to minimal depression (33.9% vs. 18.1%, p<0.05).



Letters indicate statistically significant difference @ p<0.05 between subgroups

Table 3. Alzheimer's patient relationship to caregiver

- ! Across all PAM levels, the caregiver's relationship with the person they were caring for was principally "spouse/partner" (39.9% PAM1, 24.6% PAM2, 43.8% PAM3, 40.2% PAM4) or parent (28.3% PAM1, 27.0% PAM2, 34.7% PAM3, 26.8% PAM4).

	Caregivers of patients diagnosed with Alzheimer's disease (n=1,608)	Caregivers of patients diagnosed with Alzheimer's disease: Patient Activation Level			
		Level 1 (n=138)	Level 2 (n=167)	Level 3 (n=799)	Level 4 (n=127)
	A	B	C	D	E
What is your relationship with the person you care for with the following condition(s) [Alzheimer's Disease]?					
Spouse / partner	44.1%	39.9% ^C	24.6%	43.8% ^C	40.2% ^C
Mother / father	28.8%	28.3%	27.0%	34.7%	26.8%
Mother-in-law / father-in-law	9.5%	9.4%	11.4%	8.5%	15.8% ^D
Brother / sister	6.8%	12.3% ^D	9.6%	6.1%	5.5%
Grandparent	13.7%	13.0%	19.8% ^D	13.4%	13.4%
Son / daughter	3.2%	2.9%	2.4%	3.5%	3.2%
Other family member	6.3%	7.3%	11.4% ^{DE}	5.4%	4.7%
Other	3.6%	6.5% ^D	3.6%	3.0%	2.4%

Letters indicate statistically significant difference @ p<0.05 between subgroups

Table 4. Caregiver Reaction Assessment

- ! On the CRA, PAM4 scored higher on self-esteem and lower on health problems even though they scored higher on disrupted schedule and lack of family support subscales (all p values <0.05) relative to PAM1.

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		Level 1 (n=138)	Level 2 (n=167)	Level 3 (n=799)	Level 4 (n=127)
	A	B	C	D	E
Mean Summary Scores					
Self-esteem	3.68	3	3.27 ^B	3.76 ^{BC}	3.76 ^{BC}
Disrupted schedule	3.65	2.96	3.1	3.68 ^{BC}	3.65 ^{BC}
Lack of family support	3.25	2.92	2.83	3.25 ^{BC}	3.2 ^{BC}
Financial problems	3.12	3.01	2.96	3.13 ^C	3.05
Health problems	2.86	3.03 ^{DE}	2.9	2.83	2.76

Letters indicate statistically significant difference @ p<0.05 between subgroups

Conclusion

- ! Study findings demonstrate the substantial burden among caregivers of patients with Alzheimer's, however, higher patient activation mitigates some of the burden.
- ! Caregivers with higher levels of engagement (i.e., higher PAM levels) had better quality of life, work productivity, had less emergency room visits, and scored higher on self-esteem and lower on health problems.
- ! There is an opportunity to meet the essential needs of the Alzheimer's caregivers' population with clinical assessments and complex interventions tailored to their activation level to help reduce their burden.

References

1. Alzheimer's Association. 2024 Alzheimer's Disease Facts and Figures. Alzheimer's Dement 2024;20(5). (Accessed 10 April 2024)
2. Koca E, Taşkapılıoğlu Ö, Bakar M. Caregiver Burden in Different Stages of Alzheimer's Disease. Noro Psikiyatr Ars. 2017; 54(1):82-86.
3. Hibbard JH, Stockard J, Mahoney, ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health services research. 2004; 39(4p1): 1005-1026.
4. Hays RD, Prince-Embury S, Chen H. RAND-36 Health Status Inventory. San Antonio, TX: The Psychological Corporation: San Antonio, TX; 1998.
5. Reilly MC, Zbrozek AS, Dukes EM. The validity and reproducibility of a work productivity and activity impairment instrument. Pharmacoeconomics. 1993; 4(5):353-365.
6. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med. 2001;16(9):606-615.
7. Given CW, Given B, Stommel M, Collins C, King S, Franklin S. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. Research in Nursing and Health. 1992;15(4), 271-283.