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Understanding the Impact of Patient Activation Levels on Alzheimer's Caregiving in China

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Background

- Alzheimer's disease presents a significant and growing burden in China[1]. China has the highest prevalence of dementia globally with an estimated 15 million people aged ≥ 60 years affected
- Caregiving of AD patients usually falls on informal caregivers in China due to limited resources and cultural norms[2]. Caregiving for AD patients presents a huge burden in terms of anxiety, depression, lower functional status as well as poorer physical health
- The Patient Activation Measure (PAM) is a validated tool used to assess an individual's capacity for health self-management, encompassing knowledge, skills, and confidence which are associated with positive health outcomes[3]. However, the influence of caregiver PAM levels on the reduction of AD caregiver burden in China is largely unknown.

Objective

- To describe the humanistic and economic burden, including the impact on health-related quality of life, daily activity, productivity, and mental health, experienced by caregivers of patients with Alzheimer's disease in China
- To compare the humanistic and economic burdens across different PAM levels among caregivers of patients with Alzheimer's disease in China

Methods

Study design and data source:
- We conducted a retrospective analysis using data from the 2017 and 2020 China National Health and Wellness Survey (NHWS).
- The China NHWS is a self-administered, internet-based survey of adults 18 years and older.

Study population and data variables:

Study population
- Caregiver aged 18 years
- Caregiver of an adult relative with AD

Socio-demographic data of caregiver
- Relationship to patient with AD
- Age, sex, education level, employment and marital status

Statistical Analysis

Unadjusted comparisons of caregiver demographics, clinical variables, and patient-reported outcomes were performed between the different PAM level groups. We used chi-square tests for categorical variables and ANOVA tests for continuous variables. A p-value of <0.05 was considered statistically significant.

Patient Reported Outcome measures:

1. Patient Activation Measure (PAM): A 13-item scale measuring a patient's knowledge, beliefs, and confidence in interacting with healthcare professionals. Higher scores indicate higher levels of activation [3].

Level 1: Overwhelmed and disengaged

Level 2: Becoming aware, but still struggling

Level 3: Taking action

Level 4: Maintaining behaviors and pushing further

2. SF-12: A12-item self-reported outcome scale measuring general, mental, and physical health related quality of life (HRQoL).

3. Work Productivity and Activity Impairment (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]

4. Patient Health Questionnaire-9 (PHQ-9): A 9-item clinical screening tool, used to help assess depression symptoms. Scores range from 0-27, with higher scores indicating greater symptom severity.[6]

5. 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]

Results

Table 1: Sample Characteristics:
- Among caregivers of AD patients in China (n=324), mean age was 43 years with 66.0% of caregivers reported having college degrees and employment rate of 78.7%
- 46% were males of which 54.5% were at PAM1, 51.0% PAM2, 44.7% PAM3 and 34.0% PAM4)

	Caregivers of relatives with AD (n=324)	Patient Activation Measure levels of caregivers of Relatives with AD			
		PAM - Level 1 (n=22)	PAM - Level 2 (n=49)	PAM - Level 3 (n=179)	PAM - Level 4 (n=47)
		A	B	C	D
% Men	45.99%	54.55%	51.02%	44.69%	34.04%
% Married	74.07%	72.73%	63.27%	72.63%	85.11%
% College graduate (four year) or more	66.05%	68.18%	63.27%	62.01%	76.60%
Age 18-34	33.95%	45.45%	32.65%	32.40%	34.04%
Age 35-44	22.53%	18.18%	26.53%	21.23%	17.02%
Age 45-54	16.05%	18.18%	10.20%	13.41%	27.66%
Age 55-64	15.74%	18.18%	16.33%	18.44%	10.64%
Age 65+	11.73%	-	14.29%	14.53%	10.64%
Employed %	78.70%	95.45%	75.51%	74.30%	82.98%

Table 2: Relationship with Alzheimer's patient
- Across all PAM levels, caregivers were principally taking care of family members with Alzheimer's; 38.9% taking care of parents; 20.4% parents-in-law, 17.6% spouses/partners and 16.7% grandparents

Table 2: Alzheimer's patient relationship to caregiver	Caregivers of relatives with AD (n=324)	Patient Activation Measure levels of caregivers of relatives with AD			
		PAM - Level 1 (n=22)	PAM - Level 2 (n=49)	PAM - Level 3 (n=179)	PAM - Level 4 (n=47)
	A	B	C	D	E
My spouse/partner	17.6%	22.7%	16.3%	16.8%	10.6%
My mother/father	38.9%	31.8%	40.8%	38.0%	42.6%
My mother-in-law/father-in-law	20.4%	13.6%	14.3%	20.7%	21.3%
My brother/sister	5.6%	13.6%	10.2%	5.0%	2.1%
My grandparent	16.7%	4.6%	16.3%	16.8%	29.8%[BD]
My son/daughter	4.3%	9.1%	4.1%	3.9%	4.3%
Other family member	7.1%	9.1%	4.1%	8.4%	4.3%
Other	11.4%	13.6%	16.3%	8.9%	19.2%

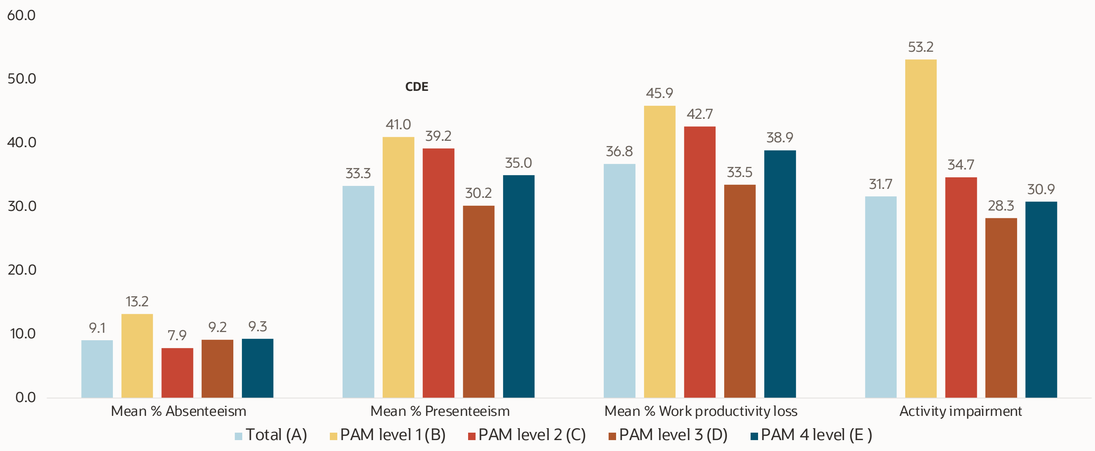
Table 3: Health outcomes
- Caregivers at PAM level 3 reported more visits to general practitioners (GPs) least in the past 6 months (35.2%) compared to caregivers at other PAM levels (PAM level 1:59.1%, PAM level 2: 53.1%, PAM level 4: 55.3%)
- Caregivers at PAM level 4 had more ER visits in the last 6 months (55.3%) compared to caregivers at PAM level1 (31.8%), PAM level 2 (24.5%) and PAM level3 (24.0%)
- Caregivers at PAM level 3 had better SF-12 mental health scores (46.9) compared to caregivers at all other levels

Table 3: Health Outcomes	Caregivers of relatives with AD (n=324)	Patient Activation Measure levels of caregivers of relatives with AD			
		PAM - Level 1 (n=22)	PAM - Level 2 (n=49)	PAM - Level 3 (n=179)	PAM - Level 4 (n=47)
	A	B	C	D	E
% Visited GP in the past 6 months	42.3%	59.1%[D]	53.1%[D]	35.2%	55.3%[D]
% Any HCP in the past 6 months	81.5%	100%[CD]	83.7%	77.1%	87.2%
% Visited ER in the past 6 months	39.5%	40.9%	30.6%	35.8%	55.3%[CD]
% Hospitalized in the past 6 months	27.2%	31.8%	24.5%	24.0%	36.2%
Mean Mental SF-12 Score	45.42	39.86	43.34	46.9[BCE]	44.19
Mean Physical SF-12 Score	47.92	46.01	47.84	47.78	48.84

Table 4: Caregiver reaction assessment (CRA)
- On the CRA scale, caregivers at PAM level 3 and 4 had significantly higher self-esteem score (3.46 and 3.57) compared to caregivers at caregivers at PAM 1 and 2 (2.9 and 3.1)
- However, caregivers at PAM level 4 also reported having higher disrupted schedule scores (3.55) compared to all other caregivers
- Caregivers at PAM level 2 in China reported the highest level of financial problems (2.99).

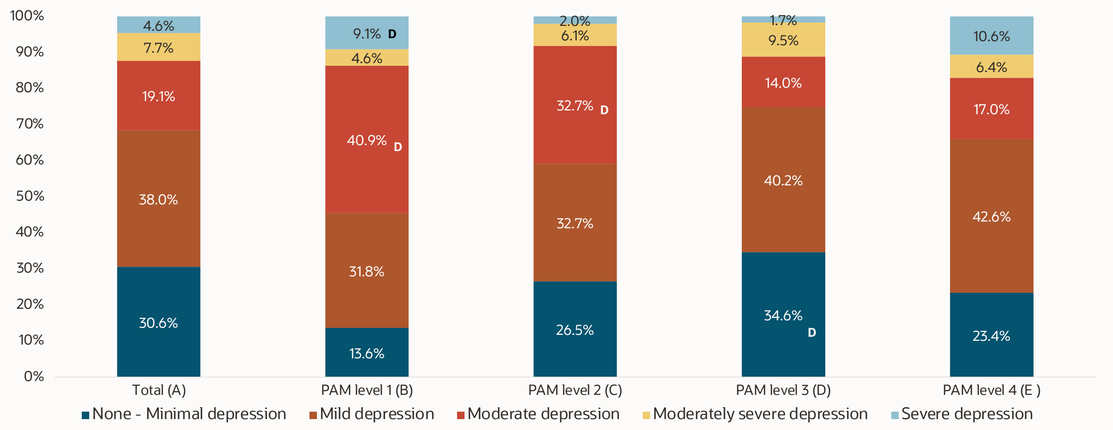
Table 4: Caregiver Reaction Assessment	Caregivers of relatives with AD (n=324)	Patient Activation Module levels of caregivers of relatives with AD			
		PAM - Level 1 (n=22)	PAM - Level 2 (n=49)	PAM - Level 3 (n=179)	PAM - Level 4 (n=47)
	Total (A)	PAM 1 (B)	PAM 2 (C)	PAM 3 (D)	PAM 4 (E)
Self-esteem Summary Score	3.4	2.9	3.2	3.46 [BC]	3.57 [BC]
Disrupted schedule Summary Score	3.1	2.9	3.1	3.0	3.35 [BD]
Lack of family support Summary Score	2.7	2.6	2.8	2.6	2.8
Financial problems Summary Score	2.8	3.0	2.99 [D]	2.7	2.8
Health problems Summary Score	2.9	3.1	3.0	2.9	2.8

Figure 1: Work Productivity and Activity Impairment score
- Activity impairment of PAM level 1 caregivers was significantly higher (53.2) than those of caregivers at other levels (PAM level 2: 34.7; PAM level 3: 28.3; PAM level 4 30.9)



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

Figure 2: PHQ9
- Caregivers at PAM Level 1 had significantly higher level of "moderate depression" (40.9%) compared to caregivers at PAM level 3 and PAM level 4 (14% and 17% respectively).
- Caregivers at PAM level 1 level also reported significantly higher level of "severe depression" (9.1%) compared to caregivers at level 3 (1.7%)



Letters indicate statistically significant difference @ p<0.05 between subgroups

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Conclusion

- Informal caregiving for Azheimer's patients in China represents a huge burden.
- However, caregivers with higher level of patient activation as measure by the PAM scale had slightly better outcomes
- Caregivers who were more engaged (i.e. PAM level 3 and 4) reported better mental health, lower levels of depression, lower work impairment compared to caregivers who were not very engaged in taking care of themselves (i.e. those with PAM level 1 or level 2)
- Caregivers with high PAM levels also showed higher self-esteem derived from their caregiving responsibilities
- Improving caregivers' knowledge and practices of patient activation measures can help alleviate some of the burdens of long-term caregiving for Alzheimer's patients in China

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