Understanding barriers to the early diagnosis of mild cognitive impairment and dementia due to Alzheimer's disease from the perspective of physicians and patients: results from a real-world survey in Germany

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Aims

- To understand the barriers to early diagnosis of mild cognitive impairment (MCI) and dementia due to Alzheimer's disease (AD) in the effort to improve early intervention and appropriate treatment initiation.

Background

- AD follows a progressive course from preclinical AD, to MCI due to AD, to mild, moderate, and then severe AD dementia. [1]
- Approximately 1.8 million people are living with dementia in Germany, placing significant demand on the healthcare system and resources. [2]
- With the currently evolving treatment landscape, it is increasingly important for patients with AD to be diagnosed as early as possible to benefit from new pharmaceutical interventions.[3,4] Understanding the current barriers to diagnosis from both the physician and patient perspective is key to improving early identification.

Methods

- Data were drawn from the Adelphi Real World Dementia Disease Specific Programme™, a cross-sectional survey with elements of retrospective data collection, of physicians (primary care practitioners, neurologists, psychiatrists, neuro-psychiatrists, psycho-geriatricians) and patients with MCI and dementia due to AD (clinically diagnosed or biomarker confirmed) in Germany from February–May 2023.[5] Neurologists reported barriers to the early identification of MCI due to AD and mild AD dementia. Physicians then completed patient record forms for nine consecutively consulting patients, plus an oversample form for patients with biomarker-confirmed MCI due to AD. These forms captured information on patient demographics, physician first consulted, diagnosing physician, time from first consultation to diagnosis, and Mini-Mental State Examination (MMSE) scores at initial diagnosis and time of data collection.
- Patients self-reported health-related quality of life via the EQ-5D-5L (German tariff)[6] and reasons for delaying visit to a doctor.
- Patient-reported data were segmented by MMSE scores: 29–26, 25–21, 20–11.
- Due to low sample size, patients with an MMSE of ≤10 have been excluded from analysis.

Methods continued

- Oversample forms were included in the data provided by patients to increase the sample size of those at the earlier stage of disease; these patients were not included in the data reported by physicians.
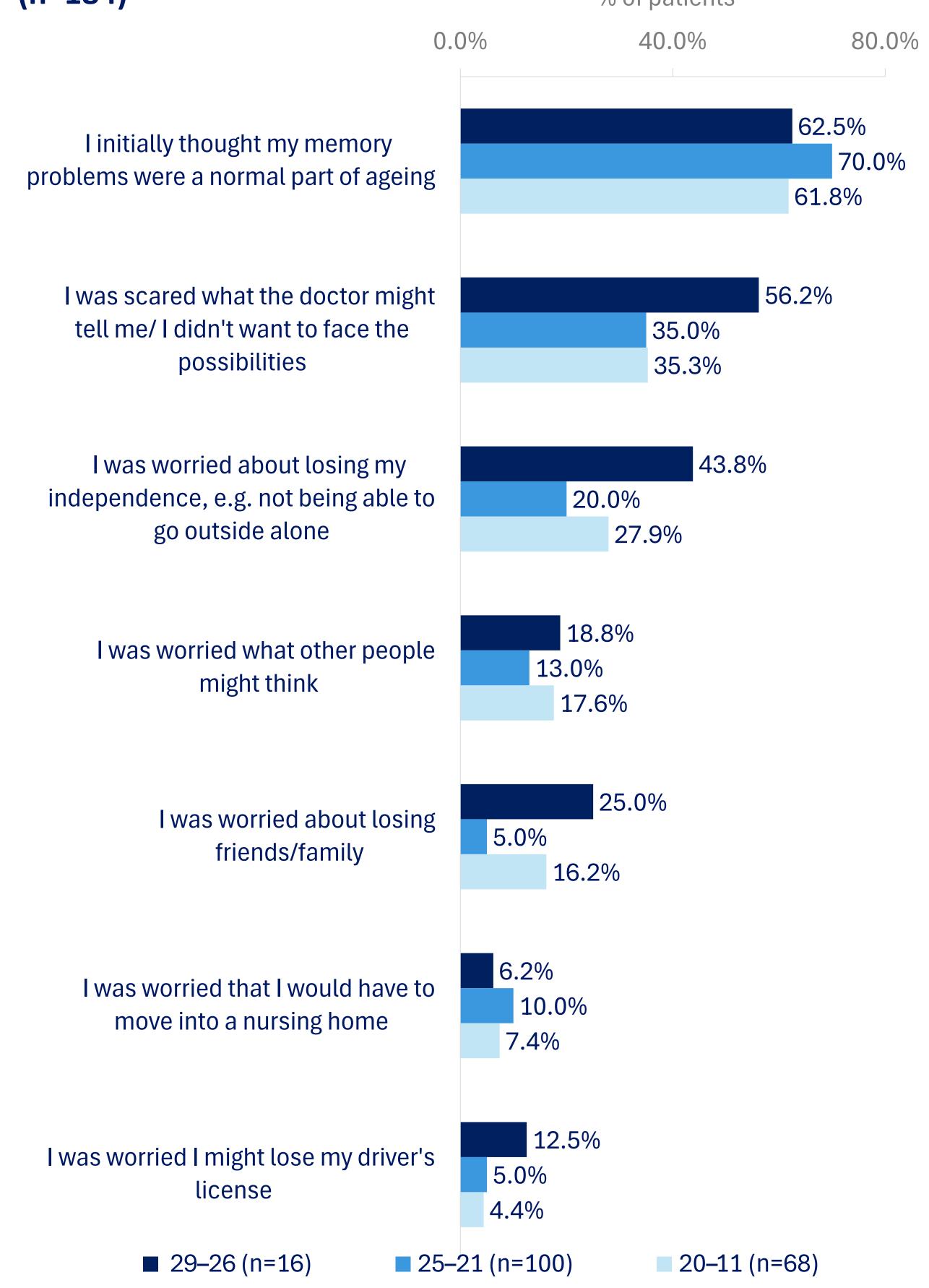- Analyses were descriptive.

Results

- Overall, 90 physicians (40 primary care physicians, 35 neurologists, 5 psychiatrists, 5 neuro-psychiatrists, 5 psycho-geriatricians) reported data for 627 patients. Patient demographics are shown in **Table 1**.
- In total, 254 patients self-reported data.

Table 1: Patient demographics

	n=627
Mean (SD) patient age	
Years	73.4 (7.4)
Patient biological sex, n (%)	
Female	313 (49.9)
Patient relationship status, n (%)	
Married	418 (66.7)
Patient ethnicity, n (%)	
White	612 (97.6)
Mean (SD) BMI	**n=625**
BMI (kg/m²)	25.5 (3.2)
Current physician diagnosis, n (%)	
MCI due to AD	230 (36.7)
Dementia due to AD	397 (63.3)
Top 3 Concomitant conditions, n (%)	
Patients with a concomitant condition	491 (78.3)
Arterial hypertension	256 (40.8)
Diabetes (with/without chronic complications)	111 (17.7)
Depression	91 (14.5)

- Overall, 92.5% of patients reported delaying visiting a physician (patients with an MMSE score of 29–26: 94.1%; 25–21: 90.1%; 20–11: 95.8%). Patient-reported reasons for delaying first consultation are presented in **Figure 1**.
- Primary care physicians were most frequently first consulted (78.8%). Neurologists were primarily responsible for diagnosis (55.6%), followed by primary care physicians (26.1%). Of patients not diagnosed at first consultation, median [interquartile range] time to diagnosis was 8.4 [4.3, 18.1] weeks.
- On average patients had a mean (SD) MMSE score of 21.2 (3.9) at diagnosis.
- The most commonly-reported assessments used to diagnose patients were feedback from patient/patient's family (90.8%), the patient's family history (87.9%), and behavioural/cognitive assessments (91.6%). Overall, 12.7% of patients underwent biomarker testing.
- Perceived barriers to early identification of MCI due to AD and mild AD dementia are presented in **Figure 2**.
- At the time of data collection, patient-reported mean (SD) EQ-5D-5L scores were 0.82 (0.19) for patients with an MMSE score of 29–26, 0.76 (0.20) for 25–21 and 0.70 (0.19) for 20–11.

Figure 1: Top seven patient-reported reasons for delaying visit to a doctor, by MMSE at initial diagnosis (n=184)*

% of patients

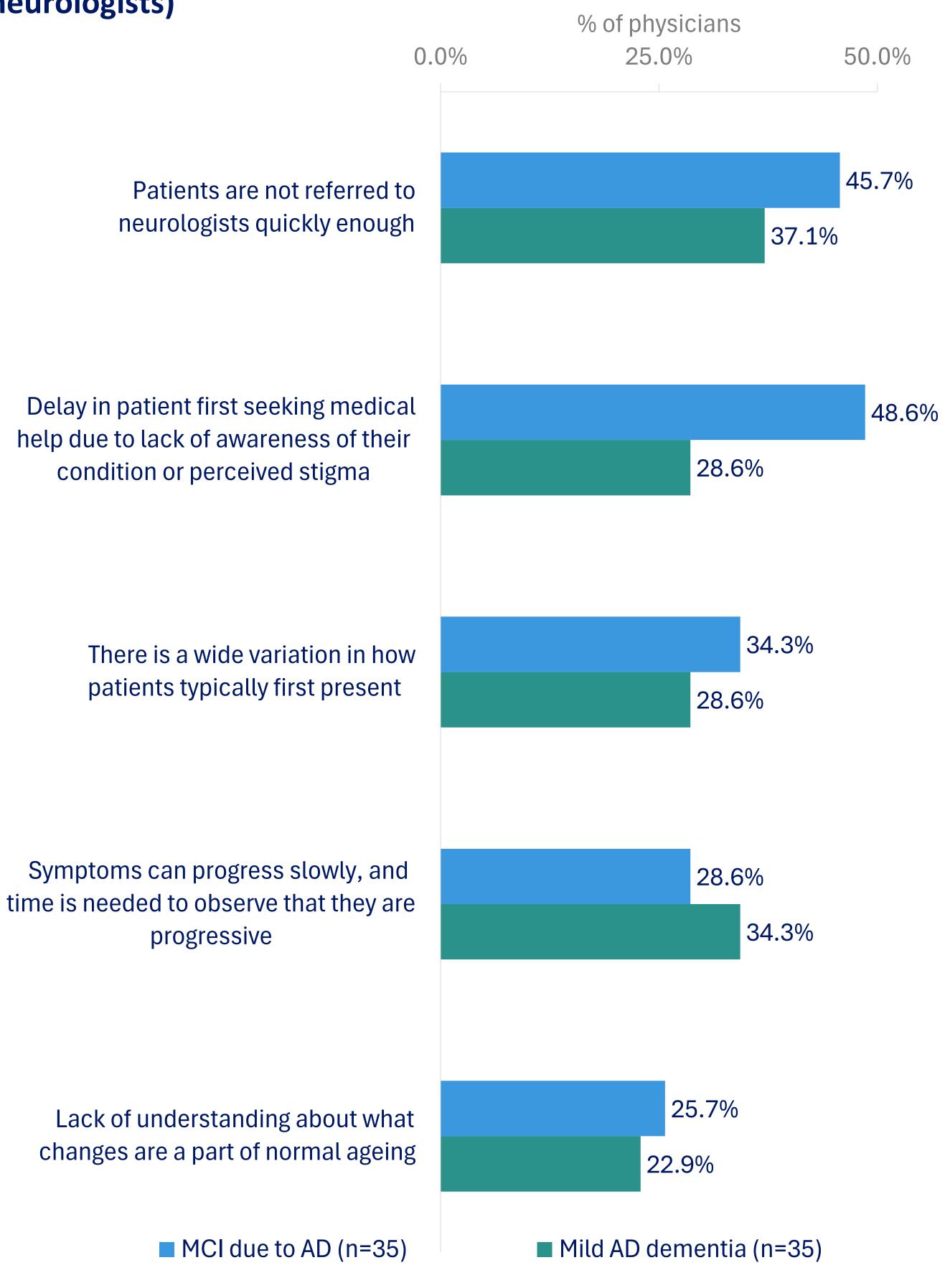| Reason	29–26 (n=16)	25–21 (n=100)	20–11 (n=68)
I initially thought my memory problems were a normal part of ageing	62.5%	70.0%	61.8%
I was scared what the doctor might tell me/ I didn't want to face the possibilities	56.2%	35.0%	35.3%
I was worried about losing my independence, e.g. not being able to go outside alone	43.8%	20.0%	27.9%
I was worried what other people might think	18.8%	13.0%	17.6%
I was worried about losing friends/family	25.0%	5.0%	16.2%
I was worried that I would have to move into a nursing home	6.2%	10.0%	7.4%
I was worried I might lose my driver's license	12.5%	5.0%	4.4%

*patients with an available MMSE score at initial diagnosis who reported delaying first visiting a doctor

Figure 2: Top five neurologist-reported barriers to early identification of MCI due to AD and mild AD dementia (n=35 neurologists)

% of physicians

Barrier	MCI due to AD (n=35)	Mild AD dementia (n=35)
Patients are not referred to neurologists quickly enough	45.7%	37.1%
Delay in patient first seeking medical help due to lack of awareness of their condition or perceived stigma	48.6%	28.6%
There is a wide variation in how patients typically first present	34.3%	28.6%
Symptoms can progress slowly, and time is needed to observe that they are progressive	28.6%	34.3%
Lack of understanding about what changes are a part of normal ageing	25.7%	22.9%

Limitations

- The DSP is based on a pseudo-random sample of physicians or patients.
- Cause and effect cannot be determined due to the cross-sectional methodology.
- The sample size varied and at times was low (e.g. patient-reported reasons for delaying first consulting a physician for those with an MMSE of 29–26).

Conclusions

- At diagnosis, patients had, on average, an MMSE score of 21.
- Key barriers to early identification were a lack of patient awareness of initial symptoms and delays in referrals to neurologists.
- Efforts to improve the diagnostic pathway are necessary to diagnose AD in its earliest stages, initiate treatment, and improve patient outcomes

References: 1 . Gustavsson, A., et al., Alzheimers Dement, 19(2), 658-670. **2.** Blotenberg, I., et al., DA International, 120(27-28), 470. Ausó, E., et al., JPM, 10(3), 114. **3.** Perneczky, R., et al., Brain, 146(3), 842-849. **4.** Anderson, P., et al., CMRO, 39(12), 1707-1715. **5.** Herdman, M., et al., Qual. Life Res, 20, 1727-1736.