UNDERSTANDING SYMPTOM PRESENTATION, RECOGNITION AND DIAGNOSIS FOR PEOPLE WITH ALZHEIMER’S DISEASE IN JAPAN

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Acknowledgements

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Introduction

Alzheimer’s disease (AD) is associated with significant human and economic burden globally.

Informal caregivers (e.g. family members) are frequently responsible for care of AD patients, particularly as symptomatology worsens over time.

Japan possesses some of the highest rates of AD, with a point prevalence of 3.8%.

The number of sufferers is expected to almost triple by 2025. Thus, caring for these individuals and their caregivers is a critical public health issue.

Objectives

- The current study examines the characteristics and experiences of AD patients as reported by informal caregivers in Japan, with attention given to the disease trajectory and treatment patterns.

- The relationship between severity level and patient diagnosis, symptom identification, and treatment will also be explored.
Methods: Design and Sample

- This study collected new data from caregivers identified in the 2012 and 2013 Japan National Health and Wellness Surveys (NHWS; total n=60,000), plus caregivers invited from Lightspeed Research opt-in ailment panels

- Caregivers included those who were:
  - Adults (18 years and above)
  - Caring for an individual diagnosed with AD (according to caregiver self-report)
  - Not receiving payment for caregiving duties
  - Having provided informed consent
Methods

- **Sociodemographic, health characteristics & behaviors:**
  - Sex and age (for both patients and caregivers)
  - Marital status, employment, income, education, children in household
  - Smoking, drinking alcohol, exercise, body mass index
  - Health insurance
  - Change in employment status due to caregiving

- **Level of long-term nursing care** (LTGI: Long Term Care Insurance):
  - Categorized according to the actual distribution of patients
    - Don’t know,
    - No long-term nursing care insurance,
    - Support level 1 or 2
    - Nursing care level 1, 2, 3, 4, or 5
Methods

♦ **Disease severity:**
  • Patient disease severity assigned based on LTCI nursing care level
  • LTCI levels were trichotomized for analysis into categories reflecting increasing severity mapping roughly onto Government-Certified Disability Index (GCDI) levels:
    - (1) Mild/moderate = no LTCI, support levels 1 or 2, or level not known
    - (2) Severe = nursing care levels 1, 2, or 3
    - (3) Very severe = nursing care levels 4 or 5

♦ **Patient disease trajectory:**
  • Years since AD diagnosis, years since AD symptoms first noticed
  • Symptoms exhibited and who noticed them
  • Diagnosing physician and evaluations
  • Prescriptions currently taken for AD
Methods

- **Statistical analyses:**

- Descriptive results examined for study variables

- Bivariate comparisons used Chi square and binomial proportion tests for categorical variables and independent sample t tests for continuous variables compared across LTCl-based severity groups.
Results

♦ **Caregiver demographics**
  - N=300 caregivers
  - Mean age 53.9 years (SD=11.0)
  - 55.0% male, 62.3% married or living with a partner
  - 51.0% at least one dependent adult, 17.7% at least one dependent child
  - 69.0% currently employed, 77.2% previously employed
  - 26.7% changed employment status due to caregiving

♦ **Patient demographics:**
  - Mean age: 83.7 years (SD=7.6)
  - 78.7% female
  - Significantly more patients >90 years old in the severe (22.0%) and very severe (31.9%) LTCI groups compared with mild/moderate severity (5.4%)
Results

- **Caregiving involvement/intensity**
  - 39.7% secondary caregivers, 30.0% primary (shared responsibilities), 30.3% primary only
  - Caregivers personally responsible for 35.4 hours (SD=44.1) per week of care
  - 36.0% responsible for over 24 hours of care per week

- Caregivers devoted more time with each increase in severity ($ps<0.05$)

![Graph showing total average hours of care required per day (Mean, SD)]
Results

♦ **Disease trajectory**
  - Caregivers couldn’t recall when AD symptoms first appeared in 35.3% of cases
  - Caregivers couldn’t recall when patients were diagnosed in 25.0% of cases
  - Among remaining 194 patients, AD symptoms were first noticed at least 2 years prior to the survey for the vast majority (92.8%)
  - Among 225 patients, 88.9% were diagnosed at least 2 years prior

♦ Significantly more AD diagnoses occurred 6 to <10 years prior (29.2%) or 2 to <4 years prior (13.9%) among very severe vs. mild/moderate & severe
  - Higher proportion of patients in very severe group had AD symptoms noticed 6+ years prior (48.6%), vs. severe (23.0%) or mild/moderate (10.8%)
Results

- AD symptoms most frequently first detected by the caregiver (58.7%) or patient’s family (45.7%); 13.7% first detected by a healthcare provider

- Memory problems were the most frequent first symptom exhibited (77.3%), followed by repetition (55.7%)
  - In the severe vs. mild/moderate groups, significantly more caregivers (60.7% vs. 43.2%) and fewer patients (1.6% vs. 8.1%) first noticed patients’ symptoms

- Memory problems were significantly more likely to have been the first AD symptoms exhibited in the severe LTCI group (84.7%) vs. mild/moderate severity (67.6%)
Results

- **Disease evaluation**
  - Patients most commonly diagnosed by a neurologist, primary care physician or internist, or psychiatrist

![Healthcare provider who diagnosed the patient](data:image/png;base64,iVBORw0KGgoAAAANSUhEUgAAAN8AAADHCAYAAABauDPpAAAACXBIWXMAAAsAAABd0FVPhIgAAAAvndLCsAAAA5JREFUeNQZSjyABgMAAQcGyQcUAAAABJRU5ErkJggg==)

- Evaluation to confirm diagnosis involved brain imaging (65.3%) or mental status test (62.3%)
Results

- **AD treatment.**
  - Majority of patients currently taking a symptomatic treatment of AD: donepezil (48.0%) or memantine (26.7%)
  - Some patients currently on more than one of the symptomatic treatments

- Memantine significantly more frequently used as current medication for patients in the very severe (27.8%) and severe (29.3%) vs. mild/moderate severity groups (10.8%)

- Yokukan-san (a traditional herbal preparation) significantly more frequently used in the very severe (13.9%) vs. severe (5.8%) group; mild/moderate severity (5.4%) was not significantly different from either
Strengths & Limitations

♦ Strengths
  - Large-scale representative sampling methodology
  - Study format enabled recruitment of a cohort of relatively young, employed informal caregivers

♦ Limitations
  - Online format limits responses from those without access to internet, comfort with technology, or time
  - Cross-sectional design limits conclusions based on causal relationships
  - Self-report surveys rely on participants’ memory of events and thus are vulnerable to recall and other reporting biases
Conclusions

♦ Memory problems were the most frequent first symptoms noticed by caregivers that subsequently led to a diagnosis of AD

♦ Findings suggest that caregivers and family play an important role in promoting early identification of symptoms, diagnosis, and treatment

♦ This research provides baseline data on symptom presentation, diagnosis, disease severity and caregiver burden in patients with AD

♦ Future work should continue to explore the trajectory of disease and caregiving experience, and raise awareness among patients, family members, and the medical community
Further reading

Impact of caring for persons with Alzheimer’s disease or dementia on caregivers’ health outcomes: findings from a community based survey in Japan

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Abstract

Background: This study assessed how family caregivers for patients with Alzheimer’s disease (AD) or dementia in Japan differed from non-caregivers in characteristics and health outcomes (i.e., comorbidities, health-related quality of life [HRQoL], productivity, and resource use). Caregivers were hypothesized to experience significantly poorer outcomes than non-caregivers.