

Primary care service utilisation pattern in dementia: a 10-year longitudinal population-based study

[Anna Tjin^{1,2}, Msc., Thang Leng Leng², PhD., Prof Robert Stewart^{1,3}, PhD]

¹*King's College London, Psychological Medicine, IOPPN*

²*National University of Singapore, Faculty of Arts and Social Sciences, Singapore*

³*South London and Maudsley NHS Foundation Trust, London SE5 8AZ, England, United Kingdom of Great Britain and Northern Ireland*

Key highlights:

- Primary care use changes markedly before and after dementia diagnosis.
- Vascular dementia shows the steepest rise in pre-diagnostic contacts.
- Moderate to severe cognitive impairment consistently reduced engagement.
- AChEI use and comorbidities increased post-diagnosis, while psychotropic use reduced consultations.
- Agitation, low mood, and poor living conditions reduced pre-diagnosis contacts; daily living issues raised post-diagnosis use

Introduction

Dementia generates rising healthcare demand, yet it comprises heterogeneous subtypes with distinct clinical and care profiles. Evidence on subtype differences in service use is mixed: while some studies report no differences, others show higher utilisation and costs in vascular dementia (VD), dementia with Lewy bodies (DLB), frontotemporal dementia (FTD), and Parkinson's disease dementia (PDD) compared with Alzheimer's disease (AD), largely due to greater comorbidity, frailty, and neuropsychiatric symptoms. Dementia severity and behavioural or psychological symptoms may better account for variation than subtype alone, though differences in service quality, particularly for those with vascular comorbidities, have also been reported. Most dementia care, both pre- and post-diagnosis, is delivered in primary care alongside carers, yet the system is constrained by underdiagnosis, diagnostic delays, and inconsistent referral pathways, as well as by variation driven by comorbidities, sociodemographic, cognitive, and physical factors. These systemic and individual influences shape outcomes and compound demand over time. Longitudinal primary care trajectories are therefore critical to distinguish disease-driven use from patterns reflecting delayed diagnosis, suboptimal

management, or barriers to care, to identify high-risk groups, and to inform equitable resource allocation. In this retrospective cohort study, we investigated primary care utilisation over the five years before and after diagnosis, considering subtype, cognitive and functional status, and sociodemographic characteristics. We hypothesised that non-Alzheimer's dementias would exhibit higher utilisation due to greater comorbidity and neuropsychiatric symptoms, that poorer cognitive and functional status would increase contacts, and that sociodemographic factors would shape distinct utilisation patterns.

Methods:

Data were obtained from the South London and Maudsley NHS Foundation Trust (SLaM) Clinical Record Interactive Search (CRIS) system and linked with Lambeth DataNet (LDN) primary care records. SLaM serves over 1.3 million residents across four South London boroughs. CRIS provides de-identified electronic health records under approved governance (Oxford Research Ethics Committee C, 23/SC/0257). LDN contains structured patient-level data from all 45 general practices in Lambeth, including demographics, diagnoses, consultations, referrals, and prescriptions. The cohort comprised individuals receiving a first dementia diagnosis in SLaM services between 1 January 2008 and 31 December 2023.

Dementia subtypes (FTD, VD,PDD) using ICD-10 codes. Dementia with Lewy bodies (DLB) was additionally identified using natural language processing applied to free-text clinical notes, prioritising precision through rule-based and machine-learning methods. Unclassifiable cases were grouped as "Other." For individuals with multiple subtype codes, the subtype recorded at first diagnosis was retained. Covariates included age at diagnosis, sex, cognitive status, functional status, antidepressant use, and sociodemographic characteristics. The primary outcome was annual primary care utilisation, defined as the number of primary care contacts per person-year. The index date was the first recorded dementia diagnosis. Service use was extracted for five years before and after diagnosis, censored at death, deregistration, or 31 December 2023.

Separate longitudinal models were estimated for pre- and post-diagnosis periods to capture changes in utilisation trajectories. Mixed-effects regression models with random intercepts were used to account for repeated measures within individuals. Time (years from diagnosis) was modelled continuously with interaction terms to assess differential trends by dementia

subtype and cognitive status. Models were adjusted for age at diagnosis, sex, and antidepressant use as fixed effects. Subgroup analyses examined variation by subtype and cognitive status. Results are reported as adjusted incidence rate ratios with 95% confidence intervals.

Results. The cohort comprised 4,384 participants, of whom AD (62%) and VD (18%) were the most frequently recorded subtypes. Mean primary care contacts in the year preceding diagnosis were 4.27 consultations per quarter. Primary care contacts over time by dementia subtype are shown in **Figure 1**. The “Other” dementia category exhibited the largest absolute change in contact frequency during the year before diagnosis. For AD and VD, contact counts increased in the year immediately preceding diagnosis and were lower in subsequent years. For DLB and PDD, contact counts fluctuated across the pre-diagnostic period, with lower levels approximately three years before diagnosis and higher levels one year before diagnosis. Post-diagnosis, contact frequencies in AD, VD, and other dementias were numerically lower than peak pre-diagnostic values. In PDD, additional increases in contact counts were observed at years 2 and 5 after diagnosis. In DLB, contact counts were similar in years 1 and 2, increased at year 4, and declined at year 5.

In the linear mixed-effects model ($n = 4,379$), time was associated with increasing contact frequency in the pre-diagnosis period, with a significant interaction observed for VD compared with AD. Lower contact counts were observed among participants with worse cognitive impairment and among those prescribed antipsychotics. Across Health of the Nation Outcome Scales (HoNOS) domains, agitation, depressed mood, relationship problems, and living condition problems were associated with negative coefficients, whereas hallucinations were associated with a positive coefficient. Positive coefficients were also observed for age and for Black or British Black ethnicity compared with White ethnicity. In the post-diagnosis model, dementia subtype was associated with contact frequency, with higher contact counts observed in PDD compared with AD. As in the pre-diagnosis period, worse cognitive impairment at diagnosis and antipsychotic use were associated with reduced contact frequency. Hypnotic and anxiolytic use had a negative coefficient, whereas acetylcholinesterase inhibitor prescriptions had a positive coefficient. Comorbidities were positively associated with contact frequency. Among HoNOS domains, only problems with daily living showed a significant positive association. For sociodemographic factors, older age and Black or British Black ethnicity (relative to White ethnicity)

were associated with increased contacts, while individuals of mixed ethnicity had higher contact frequency and those of “other” ethnicity had lower contact frequency post-diagnosis.

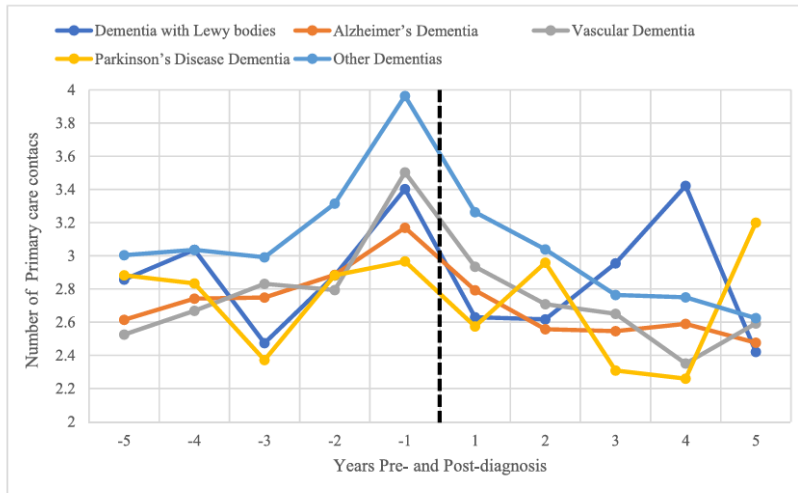
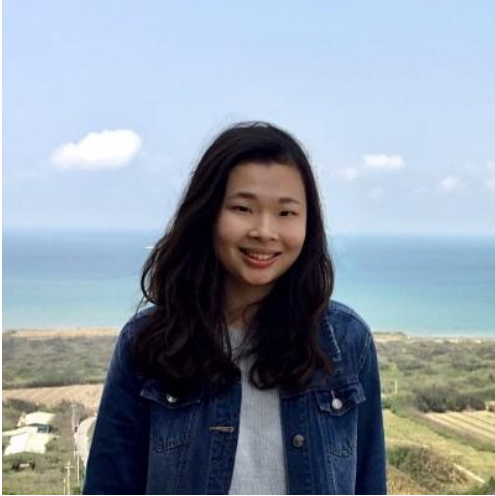


Figure 1. Primary care contact levels over time by dementia subtype. * Time is measured in years relative to the index dementia diagnosis (Year 0, marked by dashed vertical line), with negative values representing years before diagnosis and positive values representing years after diagnosis. The number of primary care contacts shown for each year is the average per quarter for that year (i.e. The averaged over the four observation periods for each year), averaged across all individuals in each dementia subtype.

These findings show that primary care use in dementia follows subtype-specific and clinically patterned trajectories, indicating that a uniform care pathway is unlikely to meet the needs of all patients. The sharp pre-diagnostic peak and post-diagnostic decline observed in AD and VD suggest opportunities for earlier recognition and more proactive follow-up after diagnosis, whereas the fluctuating and elevated post-diagnostic contacts seen in dementia with DLB and PDD point to a need for more flexible, anticipatory management strategies. Lower contact among individuals with more severe cognitive impairment and psychosocial problems raises concerns about unmet need and barriers to access in less visible or more vulnerable groups, highlighting the importance of targeted outreach and integrated support with carers and community services. Associations with hypnotic/anxiolytic use further suggest that transitions between specialist and primary care may affect continuity of monitoring. Ethnic differences in contact patterns indicate that service use does not consistently align with clinical need and may reflect delayed help-seeking or inequitable access rather than lower disease burden. Overall, these findings underscore the importance of tailoring primary care pathways to patient need, strengthening

proactive follow-up for high-risk groups, and ensuring equitable access to dementia care.

1. Tjin, A., Thang, L. L., Sondh, H. K., & Stewart, R. (2025). Healthcare service utilisation of people living with non-Alzheimer's dementia: a systematic review. *Journal of Geriatric Psychiatry and Neurology*, 08919887251371725.
2. Mueller, C., Perera, G., Rajkumar, A. P., Bhattarai, M., Price, A., O'Brien, J. T., ... & Aarsland, D. (2018). Hospitalization in people with dementia with Lewy bodies: frequency, duration, and cost implications. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 10, 143-152.
3. Stewart, R., Soremekun, M., Perera, G., Broadbent, M., Callard, F., Denis, M., ... & Lovestone, S. (2009). The South London and Maudsley NHS foundation trust biomedical research centre (SLAM BRC) case register: development and descriptive data. *BMC psychiatry*, 9(1), 51.
4. Perera, G., Broadbent, M., Callard, F., Chang, C. K., Downs, J., Dutta, R., ... & Stewart, R. (2016). Cohort profile of the South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLaM BRC) case register: current status and recent enhancement of an electronic mental health record-derived data resource. *BMJ open*, 6(3), e008721.



Anna Tjin is a co-chair of the Early Carer Network in the International Psychogeriatric Association, as well as a final-year PhD candidate in a joint program between King's College London and the National University of Singapore. My work focuses on using mixed-methods research to gain a holistic understanding of dementia trajectories, healthcare use, and patient outcomes, with the aim of improving care for people living with dementia and caregivers. Please feel free to contact me at anna.tjin@kcl.ac.uk.