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RESEARCH ARTICLE

Referral patterns and diagnostic outcomes in an outpatient Australian tertiary cognitive neurology service: 2009–2019

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Abstract

Introduction: Young-onset dementia (YOD) and atypical dementias often experience diagnostic delays, particularly in outpatient settings where timely referrals are crucial.

Methods: A 10-year retrospective audit (2009–2019) of 626 patients at a specialist cognitive neurology clinic reviewed demographics, referral sources, and time to diagnosis. Data were compared between YOD and late-onset dementia (LOD), and with and without dementia groups.

Results: Fifty-three percent of patients were diagnosed with dementia (mean age: 65 ± 11.9 years). Non-neurodegenerative conditions were more frequent in < 65 years (61%). Among YOD cases, Alzheimer's dementia (AD) and behavioral variant frontotemporal dementia accounted for 40% and 34% of diagnoses, respectively, while AD predominated in LOD (65%). Language-variant dementias were similar between groups (14%). Diagnostic delays in YOD averaged 1 year longer than in LOD.

Discussion: Higher YOD and language-variant dementia referrals to specialist services reveal diagnostic delays, underscoring the need for better referral and diagnostic pathways.

KEYWORDS
cognitive neurology, dementia, frontotemporal dementia, outpatient, younger-onset dementia

Highlights

- Delayed diagnosis common in young-onset dementia (YOD) and atypical dementia.
- Specialist clinics see more YOD and language-variant dementia referrals.
- YOD has longer time from symptom onset to diagnosis compared to late-onset cases.
- Behavioral variant frontotemporal dementia (bvFTD) a more common diagnosis in YOD patients.

1 | INTRODUCTION

There are at least 60 million people globally with a diagnosis of dementia, including an estimated 487,500 Australians.[1] Time to diagnosis for people with dementia in high-income countries is 2–4 years, increasing to 5–7 years for people with atypical dementias or young-onset dementias (YOD).[2] YOD is usually defined as a dementia where symptom onset occurs at under 65 years of age.[3] Despite only accounting for 9% of all dementia diagnoses,[4] a diagnosis of YOD has unique consequences for individuals, their families, and society, particularly where there is delayed diagnosis. These patients may have young families and can be disproportionally impacted by decline or loss of income for both patient and carers, and significant emotional burden, exacerbated by prolonged searching for a diagnosis.[5] Authors of an Australian 10-year retrospective cohort study of YOD patients (2021) proposed that an inpatient model of evaluation could reduce time to diagnosis by about 12 months to an average of 3.4 years[6] in comparison to outpatient models.[7] They hypothesized that this may be linked to the more rapid assessment and multidisciplinary approach available in the inpatient setting.[8] However, most people with dementia are evaluated in outpatient settings.

In the state of Victoria, Australia, the state government funds a regionally-based, geriatrician-run, cognitive dementia and memory service (CDAMS), which are mostly nested within aged care services.[4] These tend to focus on the diagnosis of typical dementias in older adults and represent the most common destination for dementia referrals in the state.[9] The posited benefits of an outpatient approach are reduced overall costs and burden on the hospital system, which has been highlighted by the recent COVID-19 pandemic. These "memory clinics" are staffed by a variety of medical professionals, including geriatricians, aged persons psychiatrists, neurologists, primary care physicians, nurse consultants, and dementia-specific allied health clinicians. Chua *et al.* reported a mean age of 77.2 years for patients presenting to geriatrician-run outpatient memory clinics in Singapore. This remained relatively consistent over a 12-year period from 2005 to 2017.[10] Most had received a dementia diagnosis (85.3%): 43% with probable Alzheimer's dementia (AD), 13% with vascular cognitive impairment (VCI), and 39% having a combination of both.[10]

By comparison, cognitive neurology services for dementia diagnosis have been established for decades internationally but have only been available in Australia this millennium. We know little about whether patient referral patterns differ from non-neurologist-led in- and outpatient specialist services such as CDAMS, and how this impacts factors such as time to diagnosis. Cognitive neurology services aim to provide a more comprehensive assessment of atypical and young-onset dementias.

We present a retrospective analysis of demographics, diagnostic journey, and clinical characteristics, of patients referred between 2009 to 2019 to a specialist cognitive neurology outpatient dementia assessment and diagnosis service in metropolitan Melbourne, Australia. We aim to characterize referral patterns, diagnostic challenges, and differences in patient demographics, while also providing a comparison between patients with and without dementia, and those with YOD and late-onset dementia (LOD) diagnoses.

RESEARCH IN CONTEXT

1. **Systematic review**: We reviewed existing literature on diagnostic timelines, referral characteristics, and outcomes for individuals with young-onset dementia (YOD) and atypical dementias. Research has shown that delayed diagnoses are more common in YOD compared to late-onset dementia (LOD), potentially due to atypical presentations and limited diagnostic resources. Our review focused on comparative studies of diagnostic patterns in YOD populations across neurology clinics, enabling us to contextualize our findings within the broader landscape of dementia care pathways.
2. **Interpretation**: Our analysis of 10 years of outpatient referrals to a specialist cognitive neurology clinic reveals a higher proportion of language variant dementia and YOD referrals than is reported in general clinic populations. Patients under 65 were frequently diagnosed with non-neurodegenerative conditions. Notably, the time to diagnosis was longer for those with YOD, underscoring the challenges in identifying dementia in younger populations.
3. **Future directions**: Future research should explore mechanisms to expedite diagnostic pathways for YOD, including refining referral protocols and enhancing clinician awareness of YOD presentations. Studies could also investigate factors contributing to the diagnostic delay in YOD, such as symptom overlap with non-neurodegenerative conditions, to optimize diagnostic accuracy and reduce delays.

2 | METHODS

2.1 | Ethics

This study was approved by Eastern Health Hospital Ethics Committee on July, 16 2018 (LR27-1213).

2.2 | Setting

The Eastern Cognitive Disorders Clinic (ECDC) was established in 2006 and is based at Box Hill Hospital, in Melbourne, Victoria. The service was run by a single clinician until 2010, two neurologists from 2010 to 2018, and since 2018 has included three cognitive neurologists

and one to two cognitive neurology fellows. ECDC is a diagnostic clinic with a particular expertise in the diagnosis and management of young-onset dementia, frontotemporal dementia (FTD), speech and language onset dementias, and for those with cognitive syndromes that pose diagnostic difficulties, such as people with pre-existing neurological conditions.[11] ECDC provides a comprehensive multi-disciplinary diagnostic service, offering assessment with cognitive nurse consultants, speech pathologists, occupational therapists, neuropsychologists, and cognitive neurologists as part of our evaluation model. Cross-referrals with geriatricians, psychiatrists, and psychogeriatricians are common.

All patients receive comprehensive clinical assessment including screening questionnaires for carers and patients with detailed neurological review, and may include: neuropsychological assessment, structural neuroimaging with MRI including a high-resolution isotropic T1-weighted sequence for volumetric analyses, functional fluorodeoxyglucose-positron emission tomography (FDG-PET) and selected other PET imaging, and speech pathology assessment. Multidisciplinary team (MDT) meetings are held weekly, and diagnoses are charted after case discussion and clinical review. Patient demographics are stored in databases with referral source and diagnosis. Since 2019, patient data has been stored in an Human Research Ethics Committee (HREC) -approved clinical database (REDCap).

Where possible, patients were evaluated with an Addenbrooke Cognitive Examination-Revised or III (ACE-R/III) neurocognitive assessment and Mini-Mental State Examination (MMSE).[12,13] From 2011, patients and their informants were mailed paper copies of behavioral scores to complete, including the Cambridge Behavioral Inventory–Revised (CBI-R), which explores five dimensions of behavior with a focus on FTD syndrome[14] and the Melbourne Life Questionnaire, modeled on the Hodges Sydney Life Questionnaire.

2.3 | Data sources

Available case records were reviewed for all patients presenting to the clinic between 2009 and 2019. Electronic medical records were available at Box Hill Hospital from 2009 for most patients, and archived paper records available prior. Individual case review allowed for review of initial referral forms, ongoing management issues, and final diagnoses. Neurologist letters to general practitioners (GPs, primary care physicians) and other specialists were also reviewed. Any patients with ongoing investigations or in whom the final diagnosis was not clear at the time of manuscript preparation were re-discussed at the MDT and formal diagnosis made via consensus according to published diagnostic criteria.

We collated age, sex, occupation, age at presentation, age at symptom onset, initial referral source, number of clinicians seen to confirm diagnosis, final diagnosis, ACE-R/III results, imaging obtained, neuropsychological and speech assessment data, and patient outcome if known. All patients seen over the evaluation period were included despite missing data, and only available data was used for statistical analysis. The extent of missing data varied across variables, with specifics summarized in Table 1. Missing data were primarily due to variations in medical record completeness, particularly in the early years of the study before electronic records were implemented. We note that we migrated from traditional paper medical records to electronic medical records over this period, so only patients with available/extant records were able to be included in this review.

We chose the 10 years preceding the coronavirus disease 2019 (COVID-19) pandemic as representative of our referral patterns.

2.4 | Diagnostic categories

We used the following published criteria for primary diagnoses:

1. McKhann criteria for Alzheimer's dementia.[15,16]
2. Rascovsky criteria for behavioral variant frontotemporal dementia (bvFTD).[17]
3. Gorno-Tempini classification for language onset dementias.[18]
4. McKeith criteria for dementia with Lewy bodies (DLB)[19] (with consultation to consensus report updates from the DLB Consortium)
5. National Institute of Neurological Disorders-Canadian Stroke Network for VCI and vascular dementia.[20]
6. Peterson criteria for mild cognitive impairment (MCI).[21]
7. Tang-Wai criteria for posterior cortical atrophy (PCA).[22]

Where diagnostic consensus criteria did not exist (e.g., for rare dementias) we arrived at diagnosis after MDT discussion. Neuropathological confirmation was used for final diagnosis if available. Diagnostic criteria changed for several of the dementias over the study period (e.g., Neary criteria[23] updated to Rascovsky for bvFTD[17]), so the most current criteria were used and diagnoses reviewed retrospectively. Mixed diagnoses were used where appropriate (e.g., motor neuron disease (MND)/FTD, VCI/AD). Patients in whom a confirmed diagnosis could not be made on initial consultation were followed up until a conclusive diagnosis could be made. In patients eligible for clinical trials, additional imaging and biomarker studies were also incorporated where available (e.g., tau and amyloid PET). Some patients elected to participate in brain banking services following death (Victorian Brain Bank Network).

Dementia diagnostic groupings were compared between YOD and LOD. YOD was defined as dementia with symptom onset before the age of 65.[3] When symptom onset age was unclear, the closest available estimate from the patient history was used.

2.5 | Statistical analysis

Statistical package for the social sciences (SPSS) version 28 was used for analyses. Normality was tested using Kolmogorov–Smirnov test and non-parametric tests were used for measures which were not normally distributed. Chi-squared analysis was used to compare different categorical variables, with Inverse Probability weighted *t*-tests used for differences in means and to account for missing variables in calculations where appropriate. Descriptive analysis was used for demographics.

TABLE 1 Number of individuals with missing data for each listed variable in the study.

Assessed variables	All referrals ($n = 626$)	Dementia ($n = 334$)	Non-dementia ($n = 292$)	*p*-value	YOD ($n = 146$)	LOD ($n = 188$)	*p*-value
No. of clinicians seen to reach diagnosis	166	75	91	**0.019**	29	46	0.385
Time to diagnosis	267	84	183	**<0.001**	34	49	0.649
ECDC visits to confirm diagnosis	305	98	207	**<0.001**	48	50	0.259
Initial ACE-R/III score	271	123	148	**<0.001**	46	77	0.096
Neuropsychological assessment	137	58	79	**0.004**	17	41	**0.022**
MRI	55	21	34	0.031	6	17	0.121
FDG PET	174	66	108	**<0.001**	25	43	0.247
Referral	42	32	10	**0.004**	6	23	0.093
Relevant medical history	339	142	197	**<0.001**	60	82	0.726

Note: Only variables with missing data are shown; variables not listed had complete data. Chi-squared analysis was conducted to assess whether missingness was random.

Bold text to highlight statistically significant values.

Abbreviations: ACE-III/R, Addenbrooke Cognitive Examination-Revised or III; ECDC, Eastern Cognitive Disorders Clinic; FDG-PET, fluorodeoxyglucose positron emission tomography; LOD, late-onset dementia; MRI, magnetic resonance imaging; YOD, younger onset dementia

3 | RESULTS

3.1 | Demographics

There was a total of 626 referred patients over the 10-year period between 2009 and 2019 with available records, with the mean age at referral of 65 (± 11.9) years (range 17–99 years old), majority male (59%). Over the 10-year period, 589 referrals were received from within Victoria (94%) with the remainder from interstate. Of the 589 patients living in Victoria, 43 were referred from outside the metropolitan area (7.3%).

3.2 | Referral source

Two hundred and eighty-seven people (46%) had received a provisional diagnosis prior to review with the aim of referral for a second opinion. Referrals came from primary care physicians/GPs (38%), medical specialists (45%), and from another cognitive specialist (8%). Remaining referrals came from allied health/nursing professionals, doctors in training from inpatient admissions, or were not able to be accurately determined from existing records (e.g., referral letter lost) (Table 2). A recruitment flowchart demonstrating all referrals to diagnosis is included in Figure 1.

3.3 | Referral question

Of the 626 patients, 458 (73%) had a clear referral question. The most common was for "memory concerns" comprising 38% ($n = 240$) of all referrals. "Diagnostic clarification/second opinion" was the next most common referral question at 11% ($n = 70$) followed by "Query behavioral/personality problems" at 10.4% ($n = 65$), then "language concerns" at 5.5% ($n = 35$). The remaining 48 referrals comprised a mix of referrals for genetic counselling, eligibility for clinical trials, and evaluation of other specific cortical findings concerning for neurodegeneration.

Two hundred and eighty-seven (45%) patients had a past medical history relevant to their clinical presentation and subsequent diagnosis. These included previous psychiatric history, developmental problems, language impairment, cerebrovascular disease, head trauma, and probable pre-existing neurodegenerative disease diagnosis. The presence of previously diagnosed language impairment (*p*-value 0.004) or probable neurodegenerative conditions (such as MCI) (*p*-value < 0.001) were both significantly more likely to occur in patients ultimately diagnosed with dementia compared to those not diagnosed with dementia (Table 2).

3.4 | Dementia diagnosis

The mean age for all patients given a dementia diagnosis was 68 (± 9.4 years, 59% men), and those with a non-dementia diagnosis 61 (± 13.3 years, 58% men). When those with dementia were divided into YOD and LOD, the mean age of the YOD group was 60 (± 6.6) years and the LOD group 75 (± 5.6) years (Table 2).

Three hundred and thirty-four people (53% of patients) were given a primary diagnosis of dementia. The remaining 292 (47%) received a diagnosis of MCI-not dementia, psychiatric illness (depression, anxiety, post-traumatic stress disorder [PTSD]), developmental/learning disabilities exacerbated by aging, FTD phenocopy, or functional/subjective cognitive impairment (Table 3).

Two hundred and seventy-three people were aged under 65 (44%) at initial ECDC review. Of these, 107 were diagnosed with dementia. Patients under 65 were significantly more likely to receive a non-dementia diagnosis (61%) compared to those 65 years and older,

TABLE 2 Variables/demographics of all patients presenting to Eastern Cognitive Disorders Clinic 2009–2019.

Demographic Variables	All Referrals ($n = 626$)	Dementia ($n = 334$)	Non-dementia ($n = 292$)	p-value (dem vs. non-dem)	YOD ($n = 146$)	LOD ($n = 188$)	p-value (YOD vs. LOD)
Gender (male) (%)	366 (59)	197 (59)	169 (58)	NS	83 (57)	114 (60)	NS
Referral age (years) mean (SD)	65 (11.9)	68 (9.4)	61 (13.3)	**<0.001**	60 (6.6)	75 (5.6)	**<0.001**
Referral							
Referral source (primary care)	240	108	132	NS	42	66	NS
Referral source (specialists)	284	158	126	NS	83	75	NS
Referral source (Cognitive specialists)	47	30	17	NS	10	20	NS
Relevant medical history							
Psychiatric history	42	20	22	NS	11	9	NS
Developmental	7	2	5	NS	0	2	NS
Language impairment	37	28	9	**0.004**	14	14	NS
Vascular/trauma	9	3	6	NS	1	2	NS
Probable pre-existing neuro-degenerative disorder	176	132	44	**<0.001**	61	71	NS

Note: Specialist referral source indicates any referral from a medical clinician, excluding primary care. This includes geriatricians, psychiatrists, surgeons, and others.
Bold text to highlight statistically significant values.
Abbreviations: dem, dementia; LOD, late-onset dementia; YOD, younger onset dementia.

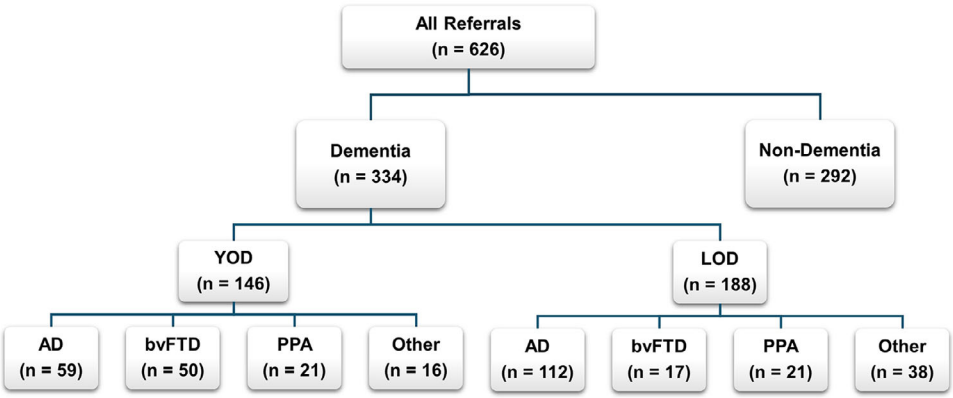

FIGURE 1 Flowchart illustrating diagnostic outcomes for all 626 referrals to the Eastern Cognitive Disorders Clinic. Of these, 334 (53%) were diagnosed with dementia, while 292 (47%) were classified as non-dementia cases. Dementia diagnoses were further categorized into young-onset dementia (YOD; $n = 146$, 44%) and late-onset dementia (LOD; $n = 188$, 56%). Among YOD cases, the most common diagnoses were Alzheimer's disease (AD; $n = 59$, 40%) and behavioral variant frontotemporal dementia (bvFTD; $n = 50$, 34%). In the LOD group, AD was the most common diagnosis ($n = 112$, 60%). The prevalence of primary progressive aphasia (PPA, including semantic dementia and progressive non-fluent aphasia) was similar between YOD and LOD groups ($n = 21$ each).

who were more likely to receive a dementia diagnosis (64%) (p-value < 0.001) (Table 3).

3.5 | Follow-up and time to diagnosis

We were able to determine the total number of clinicians seen by each patient referred to the clinic, inclusive of initial GP referral to the final ECDC specialist review, for 460 of our 626 referrals. The mean number of clinicians seen by patients given a dementia diagnosis was 3.3 (± 0.8) compared to those given non-dementia diagnosis of 2.8 (± 0.7) (p-value < 0.001) (Table 4).

The mean age of reported symptom onset for all patients was 61.7 (± 12.2) years. Those given a dementia diagnosis were statistically more likely to be older at symptom onset at 64.8 (± 9.7) years compared to the non-dementia group at 58.2 years (± 13.7, p-value < 0.005). In

TABLE 3 Initial referral outcomes from all patients presenting to Eastern Cognitive Disorders Clinic 2009–2019 by age group.

Dementia and non-dementia diagnosis by age group				
Parameter	**Dementia**	**Non-dementia**	**Total**	***p*-value**
All referrals	334 (53%)	292 (47%)	626	NS
Under 65 years	107 (39%)	166 (61%)	273	<0.001
65 years and over	227 (64%)	126 (36%)	353	<0.001

Note: Percentages represent the proportion within each age group, not total dementia cases. Patients under 65 years of age were significantly more likely to be diagnosed with a non-dementing illness, while those 65 years and over where more likely to receive in a dementia diagnosis. Percentages reflect the proportion of patients within each age group diagnosed with dementia or non-dementia, rather than the distribution of total dementia cases across age groups.

the YOD group, mean symptom onset was 56.1 years (± 6.1), while onset in the LOD group was 71.6 years (± 5.6, *p*-value < 0.005) (Table 4).

The time to diagnosis between the dementia and non-dementia groups was comparable at around 4 years. However, time to final diagnosis for YOD patients (4.6 years ± 2.48) was longer than LOD (3.6 years ± 2.03) patients by 1 year (*p*-value < 0.001) (Table 4).

Once reviewed by an ECDC specialist, 58.2% of patients were given a final diagnosis on the first visit; 21.6% of patients required a second visit, and 10.6% a third. No statistically significant difference was found between YOD and LOD groups (Table 4).

3.6 | Diagnostic conversions

Of the 287 (45%) patients with a pre-existing diagnosis, 163 (57%) had a change in this referral diagnosis following their ECDC review. Of the 340 patients given an initial provisional diagnosis by an ECDC clinician, 79 (23%) had a change in diagnosis after further investigation and ongoing review. Seventeen patients were changed from a provisional diagnosis of possible dementia to a non-dementing diagnosis. Sixty-two patients had an initial dementia diagnosis changed to another dementia syndrome diagnosis. The reasons for a change in diagnosis for 33 patients included imaging findings on magnetic resonance imaging (MRI), FDG-PET, and amyloid-PET. Twenty-five patients did not progress as expected over time, leading to an alternative diagnosis, such as FTD phenocopy. Three were confirmed with genetic testing, and one was confirmed on autopsy.

3.7 | Investigations

The ACE-R/III were done routinely in clinic from 2011 for those who were evaluable. Three hundred and fifty-five patients had ACE-R/III assessments. The mean ACE-R/III score across all referrals was 74.5 (± 17.68). In the dementia group the mean score was 67.3 (± 17.5), significantly lower than the non-dementia group 84.7 (± 11.2, *p*-value < 0.001). YOD and LOD patient scores were similar at 66.9 (± 19.3) and 67.9 (± 15.8), respectively (Table 4).

More neuropsychological assessments were performed in people with a dementia diagnosis than those without (221 vs. 116), regardless of whether they had a YOD and LOD diagnosis (Table 4).

When comparing neuroimaging modalities, there was a significant difference between the use of MRI in dementia (305) and non-dementia (240) (*p*-value 0.006). No difference was seen between the LOD and YOD groups. Significantly more FDG-PET scans were requested in those with a dementia diagnosis (198) compared to those without dementia (91) (*p*-value < 0.001) (Table 4).

TABLE 4 Evaluation to diagnosis for all patients presenting to Eastern Cognitive Disorders Clinic 2009–2019.

Parameter	All referrals	Dementia	Non-dementia	*p*-value	YOD	LOD	*p*-value
Average number of clinicians seen to reach diagnosis (SD)	3 (0.83)	3.3 (0.85)	2.8 (0.71)	**<0.001**	3.29 (0.81)	3.27 (0.88)	NS
Age of reported symptoms onset (years)	61.75 (12.18)	64.84 (9.68)	58.21 (13.7)	**<0.005**	56.1 (6.14)	71.63 (5.6)	**<0.005**
Time to diagnosis (years) (SD)	4.06 (2.7)	4.08 (2.28)	4.0 (3.6)	NS	4.58 (2.48)	3.6 (2.03)	**<0.001**
ECDC visits to confirm diagnosis	1.77 (1.34)	1.77 (1.29)	1.77 (1.48)	NS	1.88 (1.5)	1.69 (1.1)	NS
Change in ECDC diagnosis (yes) (%)	79	62	17	**<0.001**	28	34	NS
Initial ACE-R/III score	74.53(17.68)	67.25 (17.5)	84.73 (11.2)	**<0.001**	66.93 (19.3)	67.94 (15.8)	NS
Neuropsychological assessment (Yes)	387	221	116	NS	108	113	**0.005**
MRI (Yes)	545	305	240	**0.006**	138	167	NS
FDG PET (Yes) (%)	289	198	91	**<0.001**	98	102	NS

Bold text to highlight statistically significant values.

Abbreviations: ACE-R/III, Addenbrooke Cognitive Examination-Revised or III; ECDC, Eastern Cognitive Disorders Clinic; FDG-PET, fluorodeoxyglucose positron emission tomography; LOD, late-onset dementia; MRI, magnetic resonance imaging; YOD, young-onset dementia.

TABLE 5 Comparison of dementia diagnosis for all patients presenting to Eastern Cognitive Disorders Clinic 2009–2019.

Dementia diagnosis	All dementia ($n = 334$)	YOD ($n = 146$)	LOD ($n = 188$)	p-value
Alzheimer's dementia	**171**	**59**	**112**	**<0.001**
Amnestic predominant	81	26	55	NS
Logopenic aphasia	35	10	25	NS
Posterior cortical atrophy	23	18	5	**0.001**
Frontal variant	10	3	7	NS
Mixed	22	2	20	**<0.001**
Frontotemporal dementia	**67**	**50**	**17**	**<0.001**
bvFTD—definite	6	5	1	NS
bvFTD—probable	45	34	11	**<0.001**
bvFTD—possible	16	11	5	NS
Primary progressive aphasia	**42**	**21**	**21**	NS
SD	21	11	10	NS
PNFA/PAOS	16	9	7	NS
NOS	5	1	4	NS
Other				
Vascular	17	6	11	NS
PSP	13	4	9	NS
DLB	7	1	6	NS
CBS	8	1	7	NS
PDD	1	0	1	NS
Agyrophylic grain disease	1	0	1	NS
Spinocerebellar ataxia	1	1	0	NS
Neurosyphilis	1	1	0	NS
Diffuse leukodystrophy	1	1	0	NS
NOS	4	1	3	NS

Note: Amnestic predominant and mixed Alzheimer's dementia was statistically more common in the LOD group while posterior cortical atrophy and frontotemporal dementia was more common in the YOD group.
Bold text to highlight statistically significant values.
Abbreviations: bvFTD, behavioral variant frontotemporal dementia; CBS, corticobasal syndrome; DLB, dementia with Lewy bodies; NOS, not otherwise specified; PDD, Parkinson's disease dementia; PNFA/PAOS, progressive non-fluent aphasia/primary apraxia of speech; PSP, progressive supranuclear palsy; SD, semantic dementia.

3.8 | YOD vs. LOD diagnosis breakdown

Fifty-nine YOD patients were given a diagnosis of AD variants or mixed AD with co-pathologies; 50 received a bvFTD diagnosis and 21 (14%) had primary progressive aphasia (PPA) diagnosis (progressive non-fluent aphasia [PNFA] or semantic dementia); see Table 5 for diagnostic breakdowns for all YOD patients (Table 5).

Diagnoses for LOD patients included 112 people (59%) with amnestic predominant or mixed AD; 17 with bvFTD (13.8%) confirmed on imaging/*post mortem*; 21 (12%) with PPA (many who had long duration of symptoms prior to diagnosis making further identification not possible) (Table 5).

When comparing YOD to LOD diagnosis, PCA and bvFTD were both commoner in the YOD group. Mixed variant AD/VCI was more common in the LOD group in keeping with a higher proportion of cerebrovascular disease in this group (Table 5).

4 | DISCUSSION

This study details the characteristics of referrals made to a specialist outpatient cognitive neurology clinic over a 10-year period. The relatively young age of patients referred (65 ± 11.9 years) provided a unique opportunity to review the characteristics of patients likely to fit into YOD and LOD groups. When compared to similar studies, Jaeger *et al.* (2021) reviewed 245 referrals to a tertiary dementia specialist center in Brazil between 2014 and 2018 and found a mean age of 72 years (SD ± 11).[24] Yokota *et al.* (2005) also reviewed the types of referrals to a tertiary dementia center which included 512 patients over 5 years: 464 went on to receive a diagnosis of dementia, with a mean age of 76.1 years (SD ± 8.4).[25] The lower age of referral to our service is likely a reflection of preferential referral bias for older patients with cognitive complaints to "memory clinics" such as CDAMS within Victoria, Australia.

With regard to referral source, the highest individual referral base for patients was directly from GPs or primary care practitioners. Nearly half of the patients referred to our center already had a pre-existing diagnosis and were seeking further diagnostic clarification or a second opinion. Yokota *et al.* (2005) reported the proportion of GP referrals as nearly double that of ours, in keeping with their center acting as an initial referral point for dementia referrals.[25] Draper *et al.* (2016) noted that 75% of patients in their study had GPs involved in some capacity as part of the diagnostic journey towards a dementia diagnosis.[2] Hayhoe *et al.* (2016) identified training for GPs in dementia diagnosis as a key issue in improving time to diagnosis for dementia and as well as reducing the burden placed on specialist centers highlighting the importance of education and training in this group.[26]

Most patients (467, 74%) had been sent with a clear clinical problem with the most common as 'memory concerns' comprising 38% of all referrals. Referrals asking for diagnostic clarifications, or second opinions made up only 11% of our referrals, in contrast to the total proportion referred who already had a provisional primary diagnosis (44% of cases). This is common in Australia, with generalist medical practitioners seeking diagnostic clarification for more complex patients.[26]

Fifty three percent of referrals were given a diagnosis of dementia. This is comparable with UK centers: Ball *et al.* (2020) conducted a review into the proportion of patients being referred to dementia clinics in the UK and estimated between 15-56% of all referrals to specialist dementia centers were given a diagnosis of dementia.[27–30] Yokota *et al.* (2005) reviewed 512 patients referred to a primarily psychiatric run Japanese memory clinic and found only 48 of the patients were given a non-dementia diagnosis.[25] This contrasts with the proportion of dementia diagnosis by the neuropsychiatric memory service from Loi *et al.* (2021) who found approximately 44% of their total 849 referrals were ultimately diagnosed with dementia.[6] We note that, while both studies arise from psychiatry and neuropsychiatry services, the heterogeneity in proportion of dementia diagnosis likely reflects increased referrals by fellow psychiatrists to Yokota *et al.* (2005) who have already excluded a diagnosis of a primary psychiatric disorder.[25]

People with LOD were statistically diagnosed 1 year faster than those with YOD. Those under 65 years were statistically more likely to be diagnosed with a non-dementia diagnosis, including primary psychiatric disorder, neurodevelopmental delay, and functional neurological disorder. This appears at odds with the patient cohort of Pennington *et al.* (2015) who found only a small proportion of non-dementia YOD patients in their audit of the Bristol ReMemBr group database (28 of the total 196 patients, with 23 functional diagnoses).

PPA accounted for a higher proportion of the overall diagnosis made at the clinic compared to other studies.[6,31] Loi *et al.* (2021) found PPA made up 3.6% of the total YOD diagnosis (11/306 patients).[31] Onyike *et al.* (2013) performed a review into the epidemiology of FTD and estimated the prevalence of PPA as being closer to 15% but also noted other studies which had recorded total incidences of between 4.1% and 1.3%,[32,33] reflecting heterogeneity around diagnosis and previous classifications. As a cognitive neurology service that specializes in atypical dementias, ECDC likely receives more targeted referrals for language-onset presentations creating a possible positive referral bias.

Forty percent of YOD patients had early onset AD, and 34% had bvFTD (possible/probable/definite). More LOD patients (59.6%) were given an AD diagnosis and only 9% diagnosed with bvFTD (possible/probable/definite). A study by Draper *et al.* (2016) looking at time to diagnosis in YOD found a greater proportion of AD (50%) compared with bvFTD (15%).[2] However, this study was a dementia incidence study, not a single center, and captured referrals from a range of sources including self-referrals and contacting clinicians in the pre-specified catchment.[2] Loi *et al.* (2021), examined referrals from a single service and had a similar number of patients with AD.[6] Interestingly, however, both Loi *et al.* and Draper *et al.* found only 15% of their YOD patients had bvFTD, nearly half that of our study.[2,8] This may be due to our characterization of bvFTD as either possible, probable, or definite,[2,8] leading to over-representation, or again reflect referral bias to a specialist cognitive neurology center. Within the YOD AD cohort, the proportion of cases presenting with PCA is consistent with previous studies,[34,35] however, our finding that mixed AD phenotypes were more prevalent in LOD patients contrasts with prior literature.[35] This discrepancy is likely explained by a combination of referral bias, with more complex atypical presentations being referred to ECDC compared to a typical memory clinic. A greater proportion of mixed AD diagnosis in the LOD group is also explained by a higher number of AD/VCI due to increased vascular risk factors in the over 65s.

4.1 | Limitations of study

This is a retrospective audit of referrals to a single cognitive neurology service. There were missing data as we used a clinical database, and with some demographic data having been recorded inconsistently or lost (e.g., education level). Deeper analysis may require these datapoints in the future.

Testing paradigms have changed over the years including accessibility to FDG-PET, cerebrospinal fluid (CSF), and blood biomarkers, and specific neuropsychological testing. This may have served to improve the time to diagnosis in some patients, particularly in the later years, and may need to be accounted for when performing further analysis. The advent of new technologies[32] and biomarkers[33] have allowed improved diagnostic pathways for dementia diagnosis that are both efficient and cost-effective. Unfortunately, diagnostic pathways vary greatly from region to region, even within nations. A national survey published by the Australian Dementia Network (ADNeT) showed considerable heterogeneity between Australian dementia assessment services,[9] highlighting that a unified, best practice approach to diagnosis is not yet widely implemented.

5 | SUMMARY AND CONCLUSION (FUTURE ANALYSIS)

This study has identified some areas which warrant further investigation. Our patient cohort appeared to have a much greater proportion of patients with PPA in comparison with other studies,[6,31,36] particularly in the YOD group. This is most likely attributable to referral

bias to a neurological service with specialist clinicians for speech and language onset dementias. However, previous epidemiological studies would suggest that PPA may account for a higher proportion of YOD than previously reported.[36]

We identified a greater likelihood of non-dementia diagnosis, high numbers of people referred with language onset dementias, and a greater proportion of bvFTD in referrals under 65 years. Further real-world studies of the experiences of such clinics will help to refine the systems required for earlier and more accurate diagnosis. We hope that blood biomarkers and other diagnostic advances help to shorten time to diagnosis and improve dementia care.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest. Author disclosures are available in the Supporting Information.

CONSENT STATEMENT

Inclusion of all participants who were reviewed at ECDC was approved as part of internal quality assurance. Anonymized data can be shared for future research studies however identifiable data cannot.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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