

Non-English speaking background patients in a predominantly English-speaking region may be more likely to present with a dementia other than Alzheimer's disease

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ABSTRACT

Information on 54 patients was retrospectively collected to compare the presentation trends of cognitive disorders in those of non-English speaking background (NESB) to English speaking background (ESB) attending an Australian memory clinic that extensively uses fluorodeoxyglucose positron emission tomography (FDG PET) in the diagnosis of cognitive concerns. NESB patients were less likely to be diagnosed with Alzheimer's disease (AD) as the sole neurodegenerative diagnosis (Fisher exact test, $p = 0.08$), and NESB patients with dementia were more likely to have non-AD dementia (Fisher exact test, $p = 0.06$). They experienced symptoms 18 months longer before receiving a formal diagnosis ($t(46) = 2.2$, $p = 0.03$). Older elderly NESB females were under represented in those presenting to the clinic (Fisher exact test, $p = 0.04$). The clinical work-up of NESB patients as opposed to those of ESB relied more heavily on FDG PET (Fisher exact test, $p = 0.04$). ESB and NESB patients may have different attitudes towards dementia, affecting how they present, and biomarkers may be more heavily relied on when language affects history taking and neuropsychological testing.

Keywords: Dementia; Memory Clinic; Non-English Speaking Background; Positron Emission Tomography

1. INTRODUCTION

Memory clinics are increasingly being established as centres of diagnostic excellence [1]. One study that focused on equity of access to a memory clinic service serving the north-western suburbs of Melbourne Australia noted that non-English speaking background (NESB) patients were under represented [2]. Furthermore, NESB patients were more likely to be diagnosed with a psychiatric disorder, and present in the later stages of dementia, though they present with similar rates of dementia subtypes, compared to English speaking background (ESB) patients.

Rapid progress in the last few years in the dementia field includes translational studies promoting the integration into routine clinical practice of biomarkers like fluorodeoxyglucose positron emission tomography (FDG PET), which has been consistently demonstrated to have far greater sensitivity and specificity in discriminating between neurodegenerative subtypes, compared to clinical diagnostic criteria [3]. FDG PET also has the greatest contribution to routine tests for predicting mild cognitive impairment (MCI) conversion to Alzheimer's disease (AD) compared to cerebral spinal fluid protein levels or MR imaging [4]. Hence memory clinics that incorporate FDG PET as part of the diagnostic work-up may further improve diagnostic accuracy.

The aim of this study was to explore presentation and diagnostic trends of NESB and English speaking background (ESB) patients attending an Australian memory clinic service in Melbourne that extensively uses FDG PET in the diagnostic work-up process, and to see if these trends match those previously reported [2].

2. METHODS

2.1. Participants and the Memory Service

We conducted retrospective analyses of all attending patients' records whose initial consultation and/or feedback session at the Austin cognitive dementia and memory service (AMS) fell in the months of January 2010 and February 2010. Other patients who attended follow-up for other reasons during this period were not studied. The AMS is located in the north-eastern suburbs of Melbourne Australia and is widely regarded as a centre of excellence, providing assessments of predominantly local residents but also those from further away who pose diagnostic difficulties. Unlike other memory clinics [2], there is onsite access to FDG PET. In addition, one of the clinical staff is both a neurologist with a special interest in dementia as well as a nuclear medicine specialist with a special interest in PET neuroimaging. There is also a psychogeriatrician on staff.

2.2. The Client Pathway

The client pathway through the AMS is similar to that described previously [2]. However, instead of using the Cambridge Examination for Mental Disorders in the Elderly [5], initial cognitive examination of those sufficiently proficient in English is mainly performed using the Addenbrooke's Cognitive Examination Revised (ACER) [6] as well as the Geriatric Depression Scale [7]. The mini mental state examination (MMSE) [8] and clock drawing test scores are available from the ACER. MMSEs in some foreign languages including Greek and Italian are used via an interpreter if patients cannot communicate in English. An interpreter is also used for the overall assessment if the patient is unable to communicate sufficiently proficiently in English.

Structural neuroimaging with a CT and/or an MRI scan is also often performed to assess focal atrophy including hippocampal atrophy, assess any ischaemic changes, and exclude other causes of cognitive impairment. Where a firm diagnosis is not apparent during the initial consultation, because of the complexity of the presenting signs and symptoms and/or a language barrier, the patient is usually referred for a brain FDG PET scan, and/or a thorough neuropsychology assessment.

A case conference attended by all the clinical staff occurs shortly after all the investigations are completed, to decide on a formal diagnosis and the management plan to be given to the patient and carer, which are relayed at a subsequent feedback session. The clinical staff are familiar with the cultural and language barriers which the NESB patients face, and this is given careful consideration when deciding on a formal diagnosis. Hence diagnoses are not rigidly based on psychometry test performance, which is carefully interpreted in the context of a

patient's circumstances. Diagnoses are based on standard criteria, for example Petersen's criteria [9] for MCI, NIA-Reagan criteria for AD, NINDS-AIREN criteria for vascular dementia (VD), Lund-Manchester criteria for Frontotemporal dementia (FTD), and the International Consensus Consortium criteria for dementia with Lewy bodies (DLB).

This study was approved by the Austin Health Human Research Ethics Committee.

2.3. Statistical Analysis

Categorically-scaled data were analysed using Fisher's exact test. Continuously-scaled data were analysed using Student's t-test. Statistical significance was deemed to have been attained when the two-tailed p-value was less than 0.05. Data was reported as mean (SD) unless otherwise indicated.

3. RESULTS

3.1. Patient Baseline Characteristics

Of the 110 appointments booked in January and February 2010, 31 were initial consultations, and 23 were feedback sessions. The mean age of patients was 73.5 years, 50% were female, and 35% were of NESB (**Table 1**) (The country of origin for NESB patients is given in **Supplementary Table 1**). A trend towards greater proportion of ESB patients >75 years of age compared to NESB patients was noted, and this was driven by the significantly lower proportion of female NESB patients >75 year of age compared to female ESB patients (Fisher exact test, $p = 0.04$). While the reported rates of ESB and NESB patients living with their spouses/partners were similar, NESB patients were less likely to live alone (Fisher exact test, $p = 0.08$). NESB patients were also less likely to have received at least secondary education (Fisher exact test, $p < 0.001$), and performed worse on cognitive testing. For example, they scored 3.3 points on average lower in the MMSE ($t(51) = 2.57$, $p = 0.01$) compared to ESB patients. While ESB and NESB patients had similar rates in reporting any negative changes in behaviour and/or functional decline in activities of daily living, they had longer duration of symptoms (48 months on average) before receiving a formal diagnosis compared to ESB patients (30 months on average; $t(46) = 2.2$, $p = 0.03$).

3.2. Clinical Diagnostic Work-Up

Both ESB and NESB patients had similar rates of referral for a thorough neuropsychology assessment (**Table 1**). While both groups had similar rates of structural neuroimaging with a CT and/or an MRI, the clinical diagnostic work-up on NESB patients (15 out of 19) relied

more heavily on FDG PET compared to ESB patients (17 out of 35; Fisher exact test, $p = 0.04$). Waiting times for FDG PET were the main cause of NESB patients delaying their feedback by 1.8 months on average compared to ESB patients ($t(52) = 2.1$, $p = 0.04$).

3.3. Dementia Subtype Diagnoses

Thirty-two (59.3%) were diagnosed with dementia, and of these 11 (34%) were diagnosed with non-AD dementias (Table 2). Presentation rates of dementia as well as depression and/or anxiety without cognitive impairment in ESB and NESB patients were similar. However, a higher proportion of ESB patients (17 out of 35) compared to NESB patients (4 out of 19) were diagnosed with the AD dementia subtype alone (Fisher exact test, $p = 0.08$). NESB patients who presented with dementia (6 out of 10) were also more likely to be diagnosed with non-AD dementia compared to ESB patients (5 out of 22; Fisher exact test, $p = 0.06$).

4. DISCUSSION

4.1. Presentation Patterns and Diagnostic Trends

Baseline demographic findings are similar to previous

reports [1,2]. NESB patients experienced symptoms 18 months longer on average before receiving a formal diagnosis, supporting a previous report of increased symptom severity at presentation [2]. It was reported in the same study that NESB patients were younger than ESB patients, which may be explained by a significantly smaller proportion of older elderly female NESB patients presenting.

The findings of a higher proportion of NESB patients with dementia presenting with non-AD dementia subtypes compared to ESB patients differs from LoGiudice *et al.* (2001). It is known that the unique cognitive and behavioural manifestations of non-AD dementias can often be discounted for psychiatric disorders clinically [10]. However the integration of FDG PET in the diagnostic work-up may have increased confidence in diagnosing non-AD dementia subtypes in our NESB cohort, which could account for the discrepancy in our results.

4.2. Factors That May Impact on Patients' and Carers' Willingness to Attend a Memory Clinic

Amnesia is the main cognitive deficit experienced initially in a typical AD sufferer. Our NESB patients were less likely to present with AD dementia subtype as the

Table 1. Patient characteristics.

Patients	English speaking background (ESB)			Non-English speaking background (NESB)			All combined
	Male	Female	Combined	Male	Female	Combined	
Number	16	19	35	11	8	19	54
Age	74.7(15.1)	74.9(11.2)	74.8(12.9)	74.1(10.9)	67.0(11.6)	71.2(11.5)	73.5(12.5)
≤75 years of age	6	8	14	5	7	12	26
>75 years of age ^a	10	11	21	6	1	7	28
Living with spouse/partner	13	8	21	8	5	13	34
Living alone ^b	3	6	9	1	0	1	10
Secondary education and above ^c	10	11	21	4	2	6	17
Mini Mental State Examination (MMSE) score ^d	24.1(3.4)	22.2(4.3)	23.1(4.0)	18.6(5.5)	21.4(5.0)	19.8(5.4)	21.9(4.8)
Addenbrooke's Cognitive Examination Revised (ACER) score	73.5(15.6)	65.3(17.7)	69.2(17.0)	60.6(11.6)	58.3(24.8)	59.5(18.0)	66.2(17.7)
Reported negative change in behavior or function	10	14	24	9	6	15	39
Structural neuroimaging (MRI ± CT/CT only)	10/4	14/3	24/7	7/3	7/	14/3	38/10
Neuropsychology assessment	9	14	23	10	6	16	39
FDG PET ^e	9	8	17	9	6	15	32
Months from initial consultation to feedback ^f	2.4(2.3)	5.0(2.8)	3.8(2.8)	5.7(2.8)	5.5(4.0)	5.6(3.2)	4.5(3.1)
Months from start of symptoms to feedback ^g	27(18)	33(22)	30(20)	41(36)	59(35)	48(36)	36(27)

^aComparing proportion of females of >75 years of age between ESB and NESB patients (Fisher exact test, $p = 0.04$). ^bComparing ESB to NESB patients who reported living alone (Fisher exact test, $p = 0.08$). ^cComparing ESB patients to NESB patients who had at least secondary school education (Fisher exact test, $p < 0.001$). ^dComparing MMSE scores between ESB and NESB patients ($t(51) = 2.57$, $p = 0.01$). ^eComparing the use of FDG PET in the diagnostic work-up between ESB and NESB patients (Fisher exact test, $p = 0.04$). ^fComparing the duration between the initial consultation to receiving a formal diagnosis between ESB and NESB patients ($t(52) = 2.1$, $p = 0.04$). ^gComparing the duration between the onset of symptoms to receiving a formal diagnosis between ESB and NESB patients ($t(46) = 2.2$, $p = 0.03$).

Table 2. Diagnoses.

Patients	English speaking background (ESB)			Non-English speaking background (NESB)			Combined total
	Male	Female	Total	Male	Female	Total	
Normal	0	1	1	1	1	2	3
Depression &/or anxiety without cognitive impairment	4	3	7	1	2	3	10
Mild cognitive impairment	1	0	1	3	0	3	4
Alzheimer's disease (AD) ^a	8	9	17	2	2	4	21
Mixed AD and non-AD dementias ^b	1 ^A	4 ^B	5	3 ^C	1 ^D	4	9
Frontotemporal dementia (FTD) ^b	0	0	0	0	1	1	1
Vascular dementia (VD) ^b	0	0	0	1	0	1	1
Other	2	2	4	0	1	1	5

^AThis patient had mixed AD and VD. ^B1 patient had mixed AD and DLB, 2 patients had mixed AD and VD, and 1 patient had mixed AD and Parkinson's disease dementia. ^C2 patients had mixed AD and FTD, and 1 patient had mixed AD and DLB. ^DThis patient had mixed AD and DLB. ^aComparing rates of AD (without non-AD dementia) between all presenting ESB and NESB patients (Fisher exact test, $p = 0.08$). ^bComparing total rates of non-AD dementias between ESB and NESB patients who present with dementia (Fisher exact test, $p = 0.06$).

sole cognitive diagnosis, perhaps because they and their carers had more tolerance towards higher degrees of amnesia before help was sought. This may be because of differences in available family supports and in the cultural expectations of caregiving placed on family members (as suggested by NESB patients being more likely to live with someone), relative isolation due to cultural and language barriers (as they perform worse on cognitive testing which are culturally and language biased), lack of education about dementia and available services (as suggested by them being significantly less educated), and social stigma in seeking help (as suggested by an under representation of older elderly females). It has also been shown that there is preservation or enhancement of social-emotional function in early AD [11], which may be a barrier to presentation paradoxically.

In contrast to AD, other cognitive domains to memory may be affected first in non-AD subtypes. For example, the salient clinical characteristic of behavioural variant FTD is a profound alteration in character and social conduct, occurring in the context of relative preservation of instrumental functions of perception, spatial skills, praxis and memory [12]. Unlike early AD, behavioural variant FTD has an inverse pattern to the enhancement of social-emotional function [11]. Also in DLB, sufferers often experience movement disorders, fluctuations in cognitive performance and level of consciousness, psychosis, and major depressive episodes, yet there is often a relative preservation of short term memory [13]. Hence deficits in non-memory cognitive domains which are associated with non-AD dementia tend to have greater impact on patients' functional activities of daily living and levels of carer burden. Our data supports the notion that push factors (e.g. carers' stress) rather than pull factors (e.g. patient desiring a thorough checkup to see if their perceived cognitive decline is abnormal) contributed more to NESB

patients attending [2].

4.3. Clinical and Social Implications

There is consensus that an earlier diagnosis of dementia could improve outcome. A modest improvement is cost effective, and may delay admission into long term care, which is the main driver of the direct costs of dementia [14,15]. Unfortunately, memory clinic services assess only a very small proportion of people with dementia in any country or region [1,16]. Increasing the availability of FDG PET to other appropriate specialists may provide a more resource-efficient approach.

It is important to diagnose dementia accurately as treatment approaches are different. For example, neuroleptic sensitivity is more common with DLB which treating clinicians must be mindful of when managing psychosis [13]. Furthermore while acetylcholinesterase inhibitors are effective in AD and DLB [17], they may exacerbate symptoms in FTD [18]. Hence the previously reported increase in psychiatric disorders in presenting NESB patients [2] which could lead to under-diagnosis of non-AD dementias warrants further study.

4.4. Use of FDG PET in the Diagnostic Work-Up of Dementia

The diagnoses of dementia subtypes made in our cohort were consistent with standard clinical criteria. However applying the standard clinical criteria for diagnosis is open to a degree of subjectivity [19]. Hence centres of excellence are increasingly moving towards the use of biomarkers like FDG PET to improve accuracy in the diagnostic work-up [20]. FDG PET is an adjunct tool where an abnormal scan raising the possibility of neurodegenerative pathology *in vivo* is not itself a diagnosis of dementia [3]. The rate of diagnosing dementia as a whole

in the AMS (59.3%) has not increased compared to other memory clinics (>60%), despite our extensive use of FDG PET. However we may be diagnosing more mixed AD and non-AD dementias (17%).

4.5. Limitations

The limitations of this study are the single centre setting, the small numbers, the heterogeneous NESB patient group, and it was not powered to detect for increased rate of psychiatric disorders amongst NESB patients. The AMS covers a different catchment area to that in previous reports, and conclusions drawn from this study may not apply to clinics serving other populations. Nonetheless there is considerable similarity between patients from our catchment area and that in at least one other study [2], which is reflected in our similar baseline demographic findings. Finally a high quality diagnostic work-up that involves the use of FDG PET may improve sensitivity and specificity of diagnoses, but a definitive diagnosis of any neurodegenerative subtype is generally made at post mortem.

5. CONCLUSION

ESB and NESB patients may have different responses towards AD and non-AD dementias, resulting in the propensity for NESBs to present with non-AD dementia. Memory service provision to older elderly NESB females may be under utilised. Our findings support an integrative approach with the use of biomarkers to the diagnostic work-up, particularly for NESB patients who may have language barriers. Larger studies are required to validate these preliminary findings.

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Supplementary Table 1

NESB country of origin	N (%)
Italy	4 (21)
Malta	4 (21)
Greece	2 (11)
Turkey	2 (11)
Chile	1 (5)
Argentina	1 (5)
Macedonia	1 (5)
China	1 (5)
Switzerland	1 (5)
Lebanon	1 (5)
Unknown	1 (5)