

RESEARCH ARTICLE

Carer burden and psychological distress in young-onset dementia: An Australian perspective

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Abstract

Objectives: Carer burden in dementia is associated with poor outcomes, including early nursing home placement for people with dementia and psychological distress for their carers. Carers of people with young-onset dementia (YOD) are particularly vulnerable to carer burden. Yet they are often overlooked by clinicians as dementia services are generally designed for older people. We sought to estimate the rate of burden and psychological distress in carers of YOD at a state-wide tertiary service based in Australia.

Methods: We conducted a cross-sectional study examining 71 dyads from a Neuropsychiatry service. We collected patient demographic and clinical data including the Neuropsychiatry Unit Cognitive Assessment tool (NUCOG) and Mini-Mental State Examination (MMSE). Carer data, such as demographics and psychological distress, were obtained using Depression Anxiety Stress Scale 21 (DASS-21). Carer burden was rated using the Zarit Burden Inventory-short version (ZBI).

Results: Higher carer burden, measured using ZBI, was associated with longer duration of dementia and greater severity of overall cognitive impairment. Carers who felt burdened reported higher levels of stress, depression, and anxiety measured using DASS-21. Multiple linear regression analysis found carer burden was independently predicted by duration of dementia, total cognition score and carers experiencing psychological stress.

Discussion: We found that patient variables of dementia duration and cognitive impairment and carer variable of carer stress to be associated with carer burden. Poor executive function was associated with carer stress. Early identification and management of carer burden and psychological distress is important for outcomes. Ideally, this should be provided by a specialist YOD service.

KEYWORDS

carer burden, carer psychological distress, carer wellbeing, early-onset dementia, young-onset dementia

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Key points

- In an Australian tertiary neuropsychiatric service, almost a half of informal carers of young-onset dementia reported feeling significantly burdened.
- Furthermore, over a third of the carers felt depressed, anxious, or stressed.
- Higher carer burden was associated with longer duration of dementia and greater severity of overall cognitive impairment.
- Early identification and management of carer burden and psychological distress is important to achieve better outcomes for both the patient and carer.

1 | BACKGROUND

Carers of people with dementia face high levels of carer burden, defined as the negative impact on the carers' physical, psychological, social and financial state.¹ Despite the negative consequences of carer burden including psychological distress, carers are often overlooked by clinicians, and have been labelled 'the invisible patient'.²

Young-onset dementia (YOD) accounts for 5%–9% of all dementias.^{3,4} As dementia is seen as a disease of the elderly with community-based services biased towards those older than 65 years old, carers of these younger people may feel less supported and are at higher risk of adverse effects. For example, it has been reported that carers of YOD were twice as likely to report feeling burdened and experience worse quality of life compared to carers of dementia of later onset.^{5–7} In response, the Australian YOD Special Interest Group⁸ called for prioritisation of investments in YOD carer support research and funding. There has been a similar commitment in a consortia of 6 European countries.⁹

Of the limited research about the prevalence of burden and psychological strain in carers of YOD, cross-sectional studies conducted at outpatient cognitive clinics in Singapore and England found 52.6% and 58.3% carers experiencing high burden respectively.^{7,10} An Australian study based in New South Wales reported the mean Zarit Burden Interview score was 12.3 (cut-off for high burden being a score of 17 or greater) but did not comment on the prevalence.⁵ With regards to psychological strain, another Australian study reported 58% of carers felt depressed.¹¹

There are several reasons why carers of YOD experience high burden. YOD occurs at a period when individuals and their carers are likely to be at their maximal earning capacity, have financial responsibilities and are caring for dependents. The diagnostic process can be protracted,^{12,13} and by the time the disease is confirmed, families are likely to have gone through an extremely difficult period, involving confusion and uncertainty,¹⁴ likely job loss,¹⁵ and financial costs in engaging health care services and significant disruption to what had been 'normal' family practices.¹⁶ After diagnosis, people with YOD and their families generally find there is very little dedicated support or resources available to help them understand, cope and deal with the disease and its various impacts on their lives.^{8,17}

Predictors of carer burden in YOD can be grouped into carer factors and patient characteristics. For carer factors, females, spouses and those who use an emotion-focused coping strategy or have

neurotic traits tend to report higher levels of burden.^{18–21} Behavioural disturbance including aggression, apathy and disinhibition, often present in behaviour variant frontotemporal dementia, are associated with higher levels of burden on carers.^{7,22} Duration of dementia has mixed results.^{6,19,20} The degree of cognitive impairment in YOD was not shown to predict carer burden.^{7,20–24}

The consequences of carer burden is particularly devastating for people with YOD who may be forced prematurely into an aged care system that is ill-equipped for their specific needs.²⁵ Despite the recent public inquiry in Australia²⁶ calling for increased support for people with YOD and their carers, there is little recent data about the needs of YOD carers. Better understanding of carer burden and psychological strain, including identification of higher risk carers may help services and policymakers.

This study aimed to evaluate the extent of carer burden and psychological distress in carers of YOD. Furthermore, we sought to understand the specific factors that may predict the levels of burden in the YOD group. We hypothesised that female carers, longer duration of dementia, behaviour variant frontotemporal dementia and carer psychological distress would lead to increased levels of burden on the carers.

2 | METHODS

2.1 | Study setting

Participants were recruited from Neuropsychiatry at Royal Melbourne Hospital, Victoria between 2016 and 2020. Neuropsychiatry is a tertiary assessment service for individuals with neuropsychiatric symptoms. It is also the state-wide YOD service in Victoria with some care provided to neighbouring states. The assessments are conducted in the inpatient and outpatient setting. The service admitted approximately 80 patients per year during the study period, with 31 (38%) people being diagnosed with dementia. Patients with YOD are offered follow-up care in the service's YOD Clinic. Since 2019, patients and carers have had the option of accessing the service via telehealth.²⁷

All patients received comprehensive neuropsychiatric assessment including neuropsychiatry, neurology, neuropsychology, social work, speech pathology, occupational therapy, neuroimaging (structural and functional), and blood and cerebrospinal fluid biomarkers.

Diagnoses were based on contemporaneous diagnostic criteria, such as Alzheimer's disease based on the National Institute of Aging-Alzheimer's Association Criteria,²⁸ vascular dementia (VD) based on NINDS-AIREN criteria,²⁹ and frontotemporal dementia based on the Rascovsky criteria.³⁰

2.2 | Participants, recruitment & ethics

All primary, informal carers who looked after patients with YOD at Neuropsychiatry were identified as potential participants. YOD was defined as symptoms onset before the age of 65 years. Carers were defined as a spouse, relative or friend who identified as being primarily responsible for the care of the person with YOD.

Participants were recruited by the treating clinician or the research assistant during their routine care at the Neuropsychiatry inpatient service or Neuropsychiatry YOD Clinic. Their participation was voluntary and did not affect the care provided at the service. Patients provided written consent unless there was a capacity issue in which case the carer consented on their behalf. Carers provided who provided written consent to participate in the study were asked to complete questionnaires related to their experience of caring for the person who was having an assessment at Neuropsychiatry. This study was approved by the Melbourne Health Research Ethics Committee (approval numbers 2016.038 and 2018.371).

2.3 | Measures

Demographic information about the patients and carers were obtained including their age, sex, and relationship. Other patient characteristics obtained included past psychiatric history, family history of dementia and whether the postcode they lived in was considered an urban or a rural area according to the.³¹ Patient clinical information was also obtained including dementia type and duration of dementia symptoms. We collected information from carers, including whether they lived together.

We used validated questionnaires to obtain patient cognition, carer burden and carer psychological distress listed below.

2.3.1 | Patient cognition

The Neuropsychiatry Unit Cognitive Assessment tool (NUCOG) is a reliable and valid measure of the five cognitive domains (attention, visuospatial, memory, executive function, and language). It has a total score of 100 with a higher score indicating better cognition.³² Scores above 80 are considered normal. Some patients were unable to complete the NUCOG due to their severe cognitive impairment. In these cases, clinicians completed Mini-Mental State Examination (MMSE).³³ A NUCOG 'equivalent' total score was calculated from the MMSE total score for these patients using a formula obtained from the original NUCOG authors (Walterfang and Velakoulis personal

communication). This was based on data that compared 562 subjects with both MMSE and NUCOG, with the correlation r^2 being 0.91. The information about these participants' MMSE scores and calculated NUCOG scores are in Appendix Table A1.

2.3.2 | Carer burden

We measured carer burden using the Zarit Burden Inventory-short version (ZBI). The ZBI-short version is a 12-item questionnaire measuring subjective burden. It has a total score of 48 points, with higher scores reflecting higher levels of stress. A score of 17 or more is indicative of high burden.³⁴

2.3.3 | Carer psychological distress

The Depression Anxiety Stress Scale 21 (DASS-21) is a 21-item self-report measure of depression, anxiety and stress.^{35,36} Overall distress was evaluated by summing each of the three sub-scale scores. Total scores range from 0 to 63, with higher scores indicating a greater level of distress. Each of the sub-scale scores ranged from 0 to 21, with higher scores corresponding to increased levels of depression, anxiety and stress. The cut-off scores for the three subscales are nine, seven, 14, respectively. The total DASS-21 score is a measure of general distress.

2.4 | Data analysis

Statistical analysis was performed using Jamovi v1.6³⁷ and SPSS v24.³⁸ For all variables, variance homogeneity and Gaussianity were tested with the Shapiro-Wilk test. Continuous variables are given in Table 1 as mean values \pm SD. The primary statistical tests were two-tailed, and an α level of 0.05 was used. ZBI scores were correlated with patient and carer variables using Student *t* test, Spearman's correlation and Welch's test. Variables that were identified in the univariate analysis as being possibly associated with ZBI total score (where $p < 0.10$) were selected for the multiple linear regression model to find the set of variables that predicted ZBI total score. The model was checked for outliers, normality of residuals and collinearity. Backward elimination, based on Akaike information criterion was used to determine the final model.³⁹

3 | RESULTS

3.1 | Patient and carer characteristics

71 patient-carer dyads were included. For the patients, there were 23 females (32.4%) with a mean age of 58.1 (SD = 7.59) years at the time of this study. 38 (53.5%) patients lived in an urban setting, with the majority (91.5%) living in Victoria.

TABLE 1 Summary of patient demographics, clinical factors, and their correlation with carer Zarit Burden Inventory-short version (ZBI) scores

	N	Descriptive	Univariate correlation with carer burden (ZBI)
Age	71	Patient: 58.1 (SD 7.59) Carer: 52.8 (SD 12.4)	0.02 ($p = 0.86$) ^a -0.08 ($p = 0.60$) ^a
Sex	71	Patient: 23 (32.4%) females Carer: 45 (63.4%) females	0.27 ($p = 0.80$) ^b 0.15 ($p = 0.88$) ^b
Patient previous history of psychiatric illness	71	35 (49.3%)	0.79 ($p = 0.43$) ^b
Patient family history of dementia	71	26 (36.6%)	0.905 ($p = 0.37$) ^c
Patient location: Victoria	71	65 (91.5%)	0.905 ($p = 0.37$) ^c
New South Wales		4 (5.7%)	
Queensland		1 (1.4%)	
Tasmania		1 (1.4%)	
Patient living in urban versus rural	71	Urban = 38 (53.5%) Rural = 33 (46.5%)	-1.28 ($p = 0.20$) ^b
Carer living with patient	71	Yes 66 (93%)	0.25 ($p = 0.038$)^a
Duration of dementia ^a	71	3.73 years (SD 2.36)	0.263 ($p = 0.019$)^a
YOD type	71	AD = 24 (33.8%) bvFTD = 21 (29.6%) PCA = 10 (14.1%) VD = 4 (5.6%) CBS = 4 (5.6%) SD = 3 (4.2%) DLB = 2 (2.8%) PD-D = 2 (2.8%) CA = 1 (1.4%)	1.02 ($p = 0.31$) ^b 0.52 ($p = 0.61$) ^b -1.21 ($p = 0.23$) ^b 0.34 ($p = 0.74$) ^b 0.04 ($p = 0.96$) ^b -1.33 ($p = 0.19$) ^b -0.71 ($p = 0.48$) ^b 0.54 ($p = 0.59$) ^b -1.01 ($p = 0.32$) ^b
NUCOG total (without MMSE)	60	Mean 64.7 (SD 17.5)	-0.220 ($p = 0.089$) ^a
NUCOG total (with MMSE)	71	Mean 60.5 (SD 20.1)	-0.305 ($p = 0.011$)^a
NUCOG language	60	Mean 16.4 (SD 2.81)	-0.159 ($p = 0.23$) ^a
NUCOG executive	60	Mean 11.1 (SD 4.17)	-0.240 ($p = 0.067$) ^a
NUCOG memory	60	Mean 11.2 (SD 3.83)	-0.096 ($p = 0.47$) ^a
NUCOG visual	60	Mean 14.2 (SD 3.9)	-0.172 ($p = 0.19$) ^a
NUCOG attention	60	Mean 13.4 (SD 4.14)	-0.140 ($p = 0.29$) ^a
DASS depression	46	Mean 8.43 (SD 8.23)	0.381 ($p = 0.011$)^a
DASS anxiety	46	Mean 7.30 (SD 7.70)	0.884 ($p = 0.027$)^a
DASS stress	46	Mean 13.5 (SD 8.62)	0.496 ($p < 0.001$)^a
DASS distress (total)	46	Mean 29.2 (SD 22.6)	0.576 ($p < 0.001$)^a

Note: Bolded values signified correlations where $p < 0.05$.

Abbreviations: AD, Alzheimer's dementia; bvFTD, behaviour variant frontotemporal dementia; CA, cerebellar ataxia; CBS, corticobasal syndrome; DASS-21, Depression Anxiety Stress Scale 21; DLB, dementia with Lewy Bodies; MMSE, Mini-Mental State Examination; NUCOG, Neuropsychiatry Unit Cognitive Assessment Tool; PCA, posterior cortical atrophy; PD-D, Parkinson's disease with dementia; SD, semantic dementia; VD, vascular dementia; ZBI, Zarit Burden Inventory-short version.

^aSpearman test.

^bStudent's t test.

^cWelch's test (used when data had unequal variance).

Of the carers, there were 45 females (63.4%) with a mean age of 52.8 (SD = 12.4). Majority of the carers identified as being a partner ($N = 57$, 80.3%), with 9 children (12.7%), 4 siblings (5.6%) and 1 parent (1.4%). 66 (93%) carers lived with the patient.

The most frequent YOD type was Alzheimer's disease ($N = 24$, 33.8%). This was followed by behaviour variant frontotemporal dementia ($N = 21$, 29.6%), posterior cortical atrophy ($N = 10$, 14.1%), VD ($N = 4$, 5.6%), corticobasal syndrome ($N = 4$, 5.6%), semantic dementia ($N = 3$, 4.2%), dementia with Lewy bodies ($N = 2$, 2.8%), Parkinson's disease-dementia ($N = 2$, 2.8%) and cerebellar ataxia ($N = 1$, 1.4%).

Mean duration of dementia was 3.73 years (SD = 2.36) with a mean diagnostic delay of 2.81 years (SD = 1.75). Of the patients who could complete a NUCOG ($n = 60$), the mean of the total score (NUCOG without MMSE) was 64.7 (SD = 17.5). With inclusion of the MMSE conversion score for those that could not complete a NUCOG (NUCOG total with MMSE, $n = 71$), the mean total score was 60.5 (SD = 20.1). For the NUCOG subdomain scores ($N = 60$), the mean scores were: language 16.4 (SD = 2.81), executive 11.1 (SD = 4.17), memory 11.2 (SD = 3.83), visuospatial 14.2 (SD = 3.9), and attention 13.4 (SD = 4.14).

3.2 | Factors correlating with carer burden and psychological distress (Table 1)

33 (48%) carers reported having high burden as measured by ZBI ($n =$ number 69, mean = 17.5, SD = 10.5). For carer psychological distress, 16 (35%) of carers felt depressed ($n = 46$, mean = 8.4, SD 8.2), 19 (41%) felt anxious ($n = 46$, mean = 7.3, SD = 7.7) and 16 (35%) felt stressed ($n = 46$, mean = 13.5, SD = 8.62).

Demographic factors including patient sex and age, carer sex and age, patient family history of dementia, regionality, and patient psychiatric history did not correlate with carer burden.

Carers who lived with patients ($r = 0.250$, $p = 0.038$), longer duration of disease ($r = 0.263$, $p = 0.019$), and lower NUCOG total score (with MMSE; -0.305 , $p = 0.011$) correlated with increased carer burden. NUCOG total (without MMSE) and subdomain scores did not correlate with carer burden. Carer stress ($r = 0.381$, $p = 0.011$), depression ($r = 0.884$, $p = 0.027$), anxiety ($r = 0.496$, $p < 0.001$) and overall distress ($r = 0.576$, $p < 0.001$) all correlated with carer burden.

Carer stress was associated with NUCOG executive domain ($r = -0.381$, $p = 0.014$). We did not find any association between the other NUCOG and DASS domains.

Multiple linear regression analysis (Table 2) found three variables to be independently associated with carer burden, which were duration of disease, total cognitive score (NUCOG and MMSE) and carer stress ($R^2 = 0.505$, adjusted $R^2 = 0.467$, $p < 0.001$).

4 | DISCUSSION

This study aimed to better understand the prevalence of carer burden in people with YOD and the carer and patient factors that predict it. We found almost half of the carers experienced high burden as measured by ZBI, comparable to previous findings internationally.^{7,10} In contrast to an earlier study between 2011 and 2014 in a neighbouring state, the mean burden (ZBI) score was significantly higher⁵ ($N = 85$, mean = 12.3, SD = 8.0, unpaired t-test $p < 0.001$). In addition, over a third of the carers felt depressed, anxious, or stressed. This highlights the pressing need for carers of YOD in receiving more support, which might include counselling.

Despite the significant burden on carers, we found that almost all our patients (93%) still lived with their carers. This supports previous literature which has shown that people with YOD stay at home longer despite higher carer burden.^{40,41} This is in contrast to the quarter of Australians with older-onset dementia living in a nursing home in 2021.⁴² This may be evidence of the lack of YOD-specific supported accommodation in Australia, which has been highlighted as a gap in our health system.^{8,26} Carers may be willing to endure greater burden to avoid their loved ones being transferred into residential aged care, thus investigating more thoroughly what support carers might need would be important for appropriate interventions. The Royal Commission also recommended that there would be no one under 65 entering residential aged care by 2025.

4.1 | Factors correlated with carer burden & mental health

Longer duration of dementia symptoms was correlated with increased burden. This supports the 'wear and tear' hypothesis, where the longer a carer continues their role, the more likelihood of a

TABLE 2 Multiple linear regression model predicting carer burden (Zarit Burden Inventory-short version (ZBI))

Model	R	R ²	Adjusted R ²	Overall model test			
				F	df1	df2	p
1 NUCOG total (with MMSE)	0.579	0.335	0.319	21.2	1	42	< 0.001
2 Duration of dementia symptoms (years)	0.679	0.462	0.435	17.6	2	41	< 0.001
3 DASS stress (carer)	0.710	0.505	0.467	13.6	3	40	< 0.001

Abbreviations: DASS-21, Depression Anxiety Stress Scale 21; MMSE, Mini-Mental State Examination; NUCOG, Neuropsychiatry Unit Cognitive Assessment Tool; ZBI, Zarit Burden Inventory-short version (ZBI).

negative outcome.¹⁹ People with YOD are physically healthier and have fewer medical comorbidities than those with older-onset dementia.⁴⁰ Thus, carers of YOD are likely under greater burden and distress trying to manage behavioural and psychological symptoms of dementia of a person that is still physically healthy,⁴³ which has been reported to be similar to that of carers of older-onset dementia who manage these symptoms.⁴⁴

Our study found that cognitive impairment correlated with carer burden, which is contrary to existing research.^{7,20,22,23,24} Cognitive impairment is likely a measure of clinical progression of dementia, thus it seems logical that greater impairment would represent further progression, leading to more carer burden.

In contrast to previous studies, demographic factors such as carer sex,²⁰ living regionally⁴⁵ and family history of dementia⁷ were not associated with increased burden. Despite concerns that regional location may limit access to community based services,⁴⁵ our study did not find a significant correlation with carer burden. This may be due to the study participants having access to a dedicated YOD telehealth-based service. Previous research¹² has demonstrated that a specialised YOD service can reduce delay of diagnosis and link patients and carers with community services, despite rural location. This has also been shown in other neurodegenerative illness including amyotrophic lateral sclerosis.⁴⁶

Moreover, young-onset behaviour variant frontotemporal dementia was not shown to be associated with increased carer burden. This was unexpected given previous research of people with older-onset dementia showing behaviour variant frontotemporal dementia were associated with greater burden on carers.^{47,48} This may be due to the factors specific to YOD such as being physically healthier and age onset having greater financial consequence.

The cognitive profile of YOD is diverse even allowing for the heterogeneity with the diagnostic categories. Examination of the nature of the cognitive domains found that the executive domain of the NUCOG was significantly associated with DASS stress. Patients with poorer executive function, leading to disorganisation, poor planning and rigidity, are more likely to show disinhibited behaviours and act impulsively. Unsurprisingly, these behaviours lead to increased carer stress,^{7,22} thus explaining this association. As people with YOD are more likely to be physically able than those with older-onset dementia,⁴⁹ these difficult behaviours may subsequently be more problematic. Individuals who score poorly on executive function should be identified as higher risk for carer stress. Clinicians should consider providing more relevant behavioural management strategies for associated behaviours such as impulsivity.

4.2 | Service delivery

Given the high prevalence of carer burden, all clinicians looking after patients with YOD should routinely screen for burden and psychological distress in carers. Moreover, counselling and psychology for carers is an essential service that provides care to people with YOD

to address the psychological distress identified in our study. This highlights the need for funding and provision of YOD-specific services to be multidisciplinary. Furthermore, it is well established that YOD presents unique challenges and carers feel either excluded or misunderstood by clinicians.^{41,50} Thus support for YOD carers should ideally be offered by a specialised YOD service rather than generic dementia support service. This supports the recommendations from a recent international Delphi consensus study.⁵¹

For YOD-specific services, carers of those with longer duration of dementia and worse cognition should be monitored closely as given their high-risk of feeling burdened and stressed. Clinicians may consider spending more time supporting informal carers given their essential role in assisting people with patient overall. The heterogenous trajectory of YOD requires persistent psycho-education for carers to be able to troubleshoot behavioural disturbances and maximise their quality of life. Furthermore, clinicians may be able to help carers detect and address their subjective burden and psychological distress to prevent negative consequences. For specialised YOD services that provide care to a wide catchment of patients and carers, remote services such as telephone and internet-based supports have shown promise as useful alternatives.^{9,52} Effective management of carer burden may circumvent earlier placement of people with dementia to residential services.^{1,25}

Limitations of this study are the relatively small sample size, retrospective nature and incomplete NUCOG data due to the limitation of the tool in capturing participants with more severe neurocognitive illness. The design of the study also created restrictions, as it required patients and carers to be fluent in written English. The research was cross-sectional thus limiting temporal relationships. Furthermore, the lack of a comparison group means that we could not examine whether carer burden is higher in people with YOD compared to those with older onset age as suggested in previous studies.^{7,53} Additional objective measures such as identifying neuropsychiatric symptoms and staging of the dementia may also be useful to clarify further relationships. Finally, given this is a single-site study with most participants from one state, that affects the external validity of our findings.

5 | CONCLUSION

This study confirmed that YOD carers experience significant burden and psychological distress in Australia. We demonstrated that longer duration of dementia symptoms, poorer cognition and carer distress predict carer burden. Carers appear to be more distressed by poor executive function, including disinhibition and impulsivity, thus this domain should be prioritised in treatment. Given carer burden is associated with poorer patient and carer outcomes, it is critical for burden to be identified and managed early. This is ideally done in a specialised YOD service. These findings should inform clinicians and policy makers about the clear need for increased funding for community YOD services.

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CONFLICT OF INTEREST

All the authors report no conflicts of interest related to this work.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ETHICS STATEMENT

This study was approved by the Melbourne Health Research Ethics Committee (approval numbers 2016.038 and 2018.371).

PATIENT CONSENT STATEMENT

Participants provided written consent unless there was a capacity issue in which case their substitute decision maker (next of kin) consented on their behalf.

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APPENDIX

TABLE A1 Participants Mini-Mental State Examination (MMSE) and calculated Neuropsychiatry Unit Cognitive Assessment tool (NUCOG) scores

Participant ID	MMSE total score	Calculated NUCOG total score	Clinician comment lack of NUCOG.
3	13/30	29.4	Patient was non-verbal.
5	11/30	39.0	Patient was too impaired;
7	9/30	20.0*	Patient was too impaired.
31	15/30	37.4	Patient with severe Alzheimer's disease with language and parietal difficulties;
39	0/30	20.0*	Patient was disoriented and unable to do three words with very poor short-term memory.
41	8/30	20.0*	NUCOG abandoned due to poor single-word retrieval
45	0/30	20.0*	Patient was disoriented and unable to recall their date of birth.
47	15/30	37.4	Patient unable to complete NUCOG due to poor STM, with neuropsychology moderate dementia severity.
52	7/30	20.0*	Patient unable to complete NUCOG as too agitated, significant receptive and expressive language difficulties.
55	0/30	20.0*	Patient had severe receptive and expressive language problems.
58	9/30	20.0*	Patient had significant short-term memory loss, visuoconstructional deficits and parietal symptoms, being unable to copy a simple triangle.

Note: For cases where the calculated NUCOG total score was very low (ie < 20 including 0), we assigned their score as 20.0 after discussion with experts including the original NUCOG authors. This was to avoid over-estimating their cognitive impairment which may have affected the statistical analysis.