International Psychogeriatrics (2023), 35:7, 381–390
doi:10.1017/S1041610220000794

Ethnic disparities in the uptake of anti-dementia medication in young and late-onset dementia

Clarissa Giebel,[1,2] Monica Cations,[3,4] Brian Draper,[5] and Aravind Komuravelli[6]

[1]*Institute of Population Health Sciences, University of Liverpool, Liverpool, UK*
[2]*NIHR ARC NWC, Liverpool, UK*
[3]*South Australian Health and Medical Research Institute, Adelaide, Australia*
[4]*College of Medicine and Public Health, Flinders University, Adelaide, Australia*
[5]*School of Psychiatry, University of NSW, Sydney, Australia*
[6]*North West Boroughs NHS Foundation Trust, Warrington, UK*

ABSTRACT

Objectives: People with dementia can face barriers when trying to access care after a diagnosis, particularly in young-onset dementia (YOD). Little is known about the effects of ethnicity on the use of anti-dementia medication and variations between age groups. The aim of this study was to analyze national data on variations in the uptake of anti-dementia medication between people with YOD and late-onset dementia (LOD).

Design: Cross-sectional longitudinal cohort study.

Setting: Data from the U.S. National Alzheimer's Coordinating Centre were obtained from September 2005 to March 2019.

Participants: First visits of people with a diagnosis of Alzheimer's disease (AD) dementia, Lewy body dementia (LBD), and Parkinson's disease dementia (PDD) were included.

Measurements: Logistic regression was used to analyze the effects of education and ethnicity on use of cholinesterase inhibitors and memantine, accounting for YOD/LOD, gender, living situation, severity stage, and comorbidities.

Results: In total, 15,742 people with AD dementia and LBD/PDD were included, with 11,019 PwD having completed a first follow-up visit. Significantly more people with YOD used memantine than those with LOD, while fewer used cholinesterase inhibitors. PwD from minority ethnic backgrounds used memantine and cholinesterase inhibitors less often than those from a White ethnic background. Logistic regression analysis showed that ethnicity was a significant determinant of both memantine and cholinesterase inhibitors usage, while education was only a significant determinant for memantine usage.

Conclusions: Findings highlight the impact of social factors on current usage of anti-dementia medication and the need for more resources to enable equitable use of anti-dementia medication.

Key words: young-onset dementia, socio-economic status, health inequalities, medication, access, care

Background

Dementia affects an estimated 50 million people worldwide (Alzheimer's Disease International, 2016). However, not every person with dementia (PwD) receives equal access to care after their diagnosis (Cooper *et al.*, 2016), if they even get access to a diagnosis in the first place (Mayeda *et al.*, 2016).

Correspondence should be addressed to: Clarissa Giebel, Waterhouse Building B Block 2nd Floor, University of Liverpool, Brownlow Street, Liverpool L69 3GL, UK. Phone: +44(0)151 794 9966. Email: Clarissa.Giebel@liverpool.ac.uk.
Received 15 Nov 2019; revision requested 03 Feb 2020; revised version received 05 Apr 2020; accepted 27 Apr 2020. First published online 02 June 2020.

Socio-economic status (SES) can affect access to general health care utilization and treatments (Brinda *et al.*, 2016; Giebel *et al.*, 2019a; Saini *et al.*, 2020), including education, gender, ethnicity, poor housing, debts, and income. Research into the effects of SES on dementia treatment is limited. Cooper and colleagues (2016) report that people from more advantaged backgrounds were 25% more likely to receive access to anti-dementia medication compared to people with dementia from more disadvantaged backgrounds. People from Black and minority ethnic (BME) groups are frequently reported to experience difficulties in accessing post-diagnostic dementia care

services and to receive a diagnosis in the first place (Giebel *et al.*, 2019b; Mayeda *et al.*, 2016; Nielsen *et al.*, 2019). In addition to access to care services and tailored support, post-diagnostic care also includes access to cognitive enhancing medication, depending on the dementia subtype. People with Alzheimer's disease (AD), Lewy body dementia (LBD), or Parkinson's disease dementia (PDD) may benefit from cholinesterase inhibitors including donepezil, galantamine, and rivastigmine (Raina *et al.*, 2008), or memantine for cognitive enhancement and in some cases management of behavioral and psychological symptoms of dementia (Emre *et al.*, 2010; Folch *et al.*, 2018). Stevnsborg and colleagues (2016) provide some of the only existing evidence reporting that being from an immigrant background significantly lowered the likelihood of receiving anti-dementia medication in Denmark, while general investigations into ethnicity and psychotropic medication use in dementia suggest no racial or ethnic variations (Grace *et al.*, 2018).

Post-diagnostic support is particularly poor for people with young-onset dementia (YOD) (Cations *et al.*, 2017; Innes *et al.*, 2014; Nielsen *et al.*, 2019). People with YOD and their family carers often experience a lack of information and tailored support, considering the different needs of people with YOD compared to those with late-onset dementia (LOD) due to their age differences and different stages of life (Giebel *et al.*, 2020; Mayrhofer *et al.*, 2018; Millenaar *et al.*, 2016). Being aged under 65, people with YOD are usually in employment and can struggle having to leave work, also potentially leading to financial difficulties (Dourado *et al.*, 2018). In addition, family carers might already have caring duties, all of which can contribute to increased levels of carer burden (Millenaar *et al.*, 2014). However, to date, it appears that no research has investigated how people with YOD (compared to LOD) receive access to anti-dementia medication, depending on their social background.

The aim of this study was to examine ethnic variations in current use of anti-dementia medication in people with YOD and LOD. Research suggests that people with YOD experience difficulties in accessing dementia care (Cations *et al.*, 2017; Nielsen *et al.*, 2019). In addition, based on limited previous evidence in this field (Cooper *et al.*, 2016; Raina *et al.*, 2008), we hypothesized that being from a minority ethnic background and having lower levels of education would be related to lower likelihood of current usage of anti-dementia medication, with epidemiological research showing a link between ethnicity and dementia in general (Mayeda *et al.*, 2016). With very limited literature to date, findings from this study can greatly inform how we can enable everyone living with YOD and LOD to receive improved access to dementia care, specifically to anti-dementia medication. With health inequalities in dementia being present in low-, middle-, and high-income countries (Alzheimer's Disease International, 2016), it is important to understand potential uptake issues of an expensive element of dementia care – medication.

Methods

Participants and dataset

This study used data from the United States National Alzheimer's Coordinating Center (NACC) dataset, which collects longitudinal data from 34 Alzheimer's Disease Centers (ADC) across the U.S.A. on demographic characteristics, dementia progression, and clinical diagnosis by clinicians from people with any cognitive status living in the community and long-term care institutions (Beekly *et al.*, 2007; Morris *et al.*, 2006). At each ADC, written informed consent was obtained from participants and approved by the ADC's Institutional Review Board (IRB). Research using the NACC database was approved by the University of Washington IRB. Clinicians and each study center provide a dementia diagnosis. A diagnosis of AD dementia was based on recommendations from the National Institute on Aging – Alzheimer's Association workgroups (McKhann *et al.*, 2011). Diagnoses of LBD and PDD were based on the Dementia with Lewy Bodies Consortium (McKeith *et al.*, 2017).

Data were requested in May 2019 (ID: 1264), and the dataset contained cases from September 2005 to March 2019. Of the total 139,149 cases of the dataset, including follow-up visits, only first visits were selected, resulting in 40,031 cases. Of these, only people with a diagnosis of AD, LBD, or PDD were selected, as only these subtypes are eligible to receive anti-dementia medication. Of these, 212 were removed due to missing data on education and/or ethnicity, and 375 cases removed due to having a Clinical Dementia Rating (CDR) (Hughes *et al.*, 1982) score of "0," indicating no dementia. A total of 15,742 PwD were included in this analysis (see Figure 1 for case selection). Eleven thousand and ten PwD also attended a second NACC visit. The reason for including data on the first follow-up visit was to gain a better understanding of changes to medication usage after a NACC visit (Visit 1).

People aged 64 or younger at their NACC visit were categorized as YOD, and people aged 65 and above were categorized as LOD. It is possible that people at their first visit were aged 65 or above but

https://doi.org/10.1017/S1041610220000794 Published online by Cambridge University Press

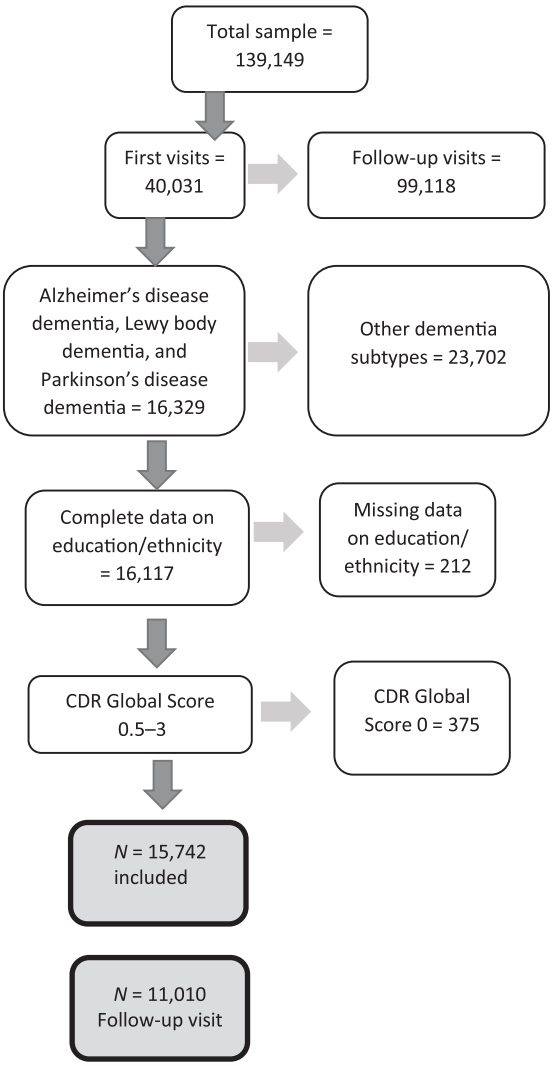

Figure 1. Selection of cases for inclusion in analysis.

had received their diagnosis when they were aged below 65. However, because the NACC dataset does not collect age at diagnosis, unless this is part of the NACC visit, it is not possible to identify these people.

Data variables

This study included a selection of demographic variables from the overall NACC database, including age, gender, ethnicity, years of education, primary language, living situation, dementia diagnosis, and dementia subtype diagnosis. The CDR scale (Hughes *et al.*, 1982) was used to identify the severity of the dementia, with scores ranging from 0.5 (questionable), 1 (mild), 2 (moderate), to 3 (severe). Neuropsychiatric behaviors were measured using Neuropsychiatric Inventory Questionnaire (NPI-Q) (Kaufer *et al.*, 2000), which contains 12 items asking for level of severity from mild to moderate and severe. A maximum severity score of 36 could be generated. In addition, data on medication were included, specifically data on cholinesterase inhibitors (donepezil, rivastigmine, and galantamine) and memantine. Medication usage for the past 2 weeks at the time of the NACC visit was recorded by asking the participant to state their medication or provide a current list of medication. Family members attending the appointment were asked for verification (where available).

Data analysis

Data were analyzed using SPSS 25. Demographic characteristics were analyzed using frequency analysis. Independent *t*-tests and chi-squared tests were used to compare demographic characteristics and medication use by education and ethnicity. Binary logistic regression analysis was employed to analyze the proportion of variance in anti-medication usage explained by social factors of education and ethnicity, while accounting for YOD and LOD (age), gender, dementia subtype, living situation, and NPI-Q severity. Two binary logistic regression models were analyzed, focusing on cholinesterase inhibitors and memantine as the binary outcome variable, respectively, for Visit 1, with the same binary logistic regression models run for data from Visit 2. For this purpose, data on use of donepezil, galantamine, and rivastigmine were coded into one binary variable of using either of these medications ("1") or none ("0"). Ethnicity was recoded into a binary variable to compare the effects of "White" ethnic background against minority ethnic groups. Statistical significance was set at $p < .05$.

Results

Participant characteristics

Table 1 reports the demographic characteristics of the sample. Of the 15,742 people with dementia, 2,569 were living with YOD and 13,173 were living with LOD. Of the total sample, 92.8% had a diagnosis of AD dementia and 11.2% a diagnosis of LBD or PDD, with some having had a mixed diagnosis. PwD were mostly female (52%) and from a White ethnic background (82.4%), with people from minority ethnic backgrounds including Black or African-American, American Indian or Alaska native, native Hawaiian or other Pacific islander, Asian, or other. English was the primary language for the large majority of PwD (91.1%), followed by Spanish (6.5%). Chi-squared test showed that significantly more people with YOD lived alone as opposed to people with LOD ($\chi^2(1,15708) = 76.929$, $p < .001$). On average, PwD had 14.5 (±3.8) years of

https://doi.org/10.1017/S1041610220000794 Published online by Cambridge University Press

Table 1. Demographic characteristics of people with young- and late-onset dementia

CHARACTERISTICS	YOD (n = 2,569)	LOD (n = 13,173)	TOTAL SAMPLE (n = 15,742)
Gender			
Female	1264 (47.7%)	6,853 (52.0%)	8,193 (52%)
Male	1385 (52.3%)	6,320 (48.0%)	7,549 (48%)
Ethnicity			
White	2241 (84.6%)	10,791 (81.9%)	12,967 (82.4%)
BAME	408 (15.4%)	2,382 (18.1%)	2,775 (17.6%)
Primary language			
English	2418 (91.3%)	11,987 (91.1%)	14,328 (91.1%)
Spanish	175 (6.6%)	844 (6.4%)	1,018 (6.5%)
Other	54 (2.1%)	332 (2.5%)	384 (2.4%)
Living situation			
Lives alone	270 (10.2%)	2,241 (17.1%)	2501 (15.9%)
Lives with others	2377 (89.8%)	10,900 (82.9%)	13207 (84.1%)
Residency			
Community	2554 (97.5%)	12,042 (93.5%)	14,517 (94.2%)
Assisted living	28 (1.1%)	489 (3.8%)	517 (3.4%)
Nursing home	37 (1.4%)	342 (2.7%)	379 (2.5%)
Relationship status			
Married	2028 (76.6%)	8543 (64.9%)	10,508 (66.8%)
Widowed/divorced/separated	418 (15.7%)	4049 (30.8%)	4,455 (28.3%)
Never married	139 (5.2%)	369 (2.8%)	505 (3.2%)
Domestic partner/other/unknown	64 (2.4%)	212 (1.6%)	274 (1.7%)
Dementia subtype			
AD dementia	2451 (92.5%)	12,222 (92.8%)	14,606 (92.8%)
LBD/PDD	278 (10.5%)	1495 (11.3%)	1,759 (11.2%)
CDR global score			
0.5	1229 (47.8%)	6,346 (48.2%)	7,575 (48.1%)
1	908 (35.3%)	4,400 (33.4%)	5,308 (33.7%)
2	283 (11.0%)	1,605 (12.2%)	1,888 (12.0%)
3	149 (5.8%)	822 (6.2%)	971 (6.2%)
Mean (SD)			
Age	58 (5)	83 (7)	74 (10)
Years of education	15 (3)	14.5 (3.8)	14.5 (3.8)
NPI-Q severity total	6.2 (5.1)	5.6 (4.6)	5.7 (4.7)

All values in N (%) unless stated otherwise.
AD, Alzheimer's disease; LBD, Lewy body dementia; LOD, Late-onset dementia; NPI-Q, Neuropsychiatric Inventory Questionnaire; PDD, Parkinson's disease dementia; YOD, Young-onset dementia.

education (range 0–30 years). The majority of PwD were in the mild stages of the condition (81.8%) by scoring a CDR Global Score of 0.5 or 1. Independent samples t-test showed that people with YOD had more severe neuropsychiatric symptoms than people with LOD [$t(2965.653) = 4.817$, $p < .001$].

Of the 15,742, 11,010 PwD had attended a second NACC visit. Chi-squared tests revealed no significant differences in the proportion of people with AD and LBD/PDD between Visit 1 and Visit 2 [$\chi^2(1,26739) = .865$, $p = .352$]. There were no significant differences in people with YOD and LOD between Visit 1 and 2 [$\chi^2(1,26739) = .171$, $p = .679$] and no significant differences in ethnicity groupings between Visit 1 and 2 [$\chi^2(1,26739) = 10.242$, $p = .069$].

Medication use by YOD/LOD

Among the 2,569 cases with YOD, 29.7% ($n = 764$) were currently using memantine and 24.4% ($n = 628$) were using one form of cholinesterase inhibitor. In LOD, 26.2% ($n = 3,455$) were using memantine and 28.2% ($n = 3,771$) were on a form of cholinesterase inhibitor. Chi-squared tests revealed significant variations in medication usage by age group. Significantly, more people with YOD were accessing memantine than those with LOD [$\chi^2(1,15742) = 13.510$, $p < .001$], while significantly more people with LOD were accessing cholinesterase inhibitors [$\chi^2(1,15742) = 14.948$, $p < .001$].

At Visit 2, of the 1,776 people with YOD, 38.2% ($n = 679$) were currently using memantine and

https://doi.org/10.1017/S1041610220000794 Published online by Cambridge University Press

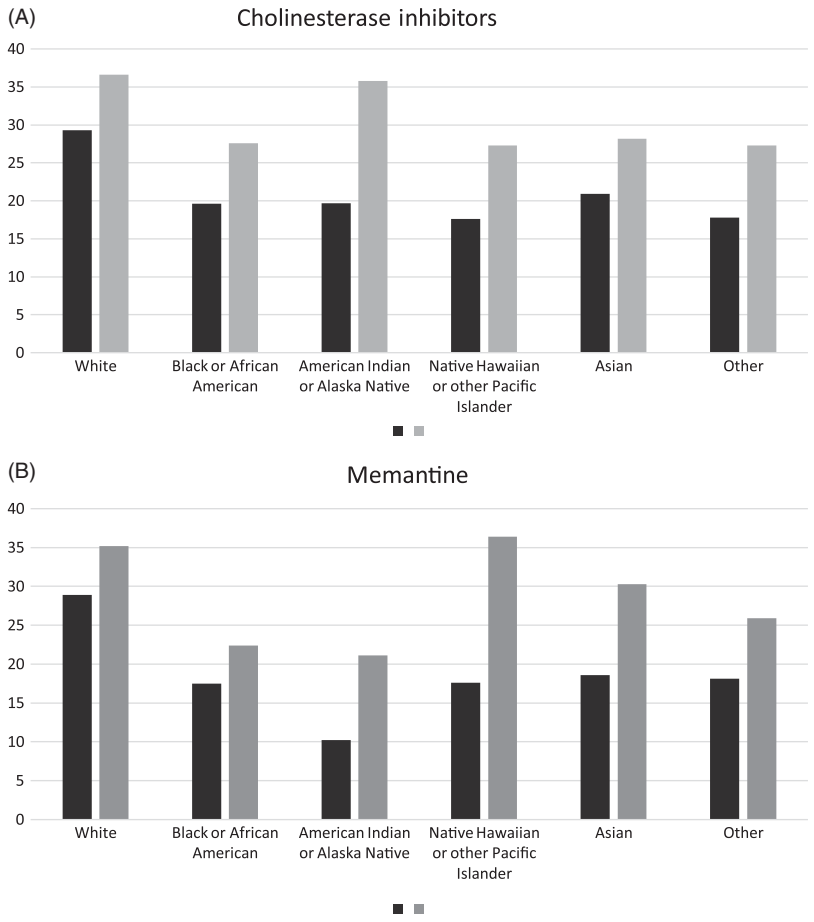

Figure 2. Usage of cholinesterase inhibitors (A) and memantine (B) by ethnicity. Figure shows percentage of each ethnic group who have used (A) cholinesterase inhibitors and (B) memantine at Visit 1 (black bar) and Visit 2 (grey bar).

33.2% (n = 590) were using cholinesterase inhibitors. Of the 9,234 people with LOD, 32.4% (n = 2,992) were using memantine, with 35.6% (3,286) using cholinesterase inhibitors. Chi-squaredtests revealed that significantly more people with YOD were using memantine than those with LOD [$\chi^2(1,11010) = 22.779$, $p < .001$]. More people with YOD and LOD were currently using memantine ($\chi^2(1,26739) = 132.336$, $p < .001$) and cholinesterase inhibitors ($\chi^2(1,26739) = 176.610$, $p < .001$) at Visit 2 compared to Visit 1.

Variations of anti-dementia medication usage by social determinants

Figure 2 shows cholinesterase inhibitor and memantine usage for PwD by ethnicity at Visit 1 and 2. Chi-squaredtests showed that anti-dementia medication usage was highest in PwD from a White ethnic background, with PwD from minority ethnic backgrounds being less likely to access either cholinesterase inhibitors [$\chi^2(5,15742) = 109.720$, $p < .001$] or memantine [$\chi^2(5,15742) = 159.316$, $p < .001$]. PwD from native Hawaiian or other Pacific Island backgrounds were least likely to use cholinesterase inhibitors (17.6%), while PwD from American Indian or Alaska Native backgrounds were least likely to use memantine (10.2%). At the follow-up visit, chi-squared tests also showed significantly higher memantine [$\chi^2(5,11019) = 92.073$, $p < .001$] and cholinesterase inhibitor usage [$\chi^2(5,11019) = 50.441$, $p < .001$] in PwD from a White ethnic background. Across all ethnic groups except Native Hawaiian or other Pacific Islanders, current usage of cholinesterase inhibitors and memantine was significantly higher at Visit 2, as shown in Table 2.

Independent samples t-test showed that education differed significantly between those who received cholinesterase inhibitors (M = 14.7 ± 3.6 SD) and those who did not (M = 14.5 ± 3.8 SD) [$t(8266.431) = 2.899$, $p = .004$] at Visit 1, but not at Visit 2 [$t(11017) = 1.713$, $p = .087$]. Years of education was not found to differ between those who received memantine and those who did not [Visit 1: $t(7890.304) = .955$, $p = .340$; Visit 2: $t(7594.308) = 1.316$, $p = .188$].

https://doi.org/10.1017/S1041610220000794 Published online by Cambridge University Press

Table 2. Current medication usage by ethnic group for Visits 1 and 2

ETHNIC GROUP	VISIT 1	VISIT 2	χ^2 TEST
Cholinesterase inhibitors			
White	3,797 (29.3%)	3,374 (36.6%)	$\chi^2(1,22175) = 130.437$, ***p = .000***
Black or African-American	375 (19.6%)	338 (27.6%)	$\chi^2(1,3140) = 27.094$, ***p = .000***
American Indian or Alaska Native	29 (19.7%)	34 (35.8%)	$\chi^2(1,242) = 7.731$, ***p = .005***
Native Hawaiian or other Pacific Islander	3 (17.6%)	3 (27.3%)	$\chi^2(1,28) = .368$, $p = .544$
Asian	72 (20.9%)	68 (28.2%)	$\chi^2(1,585) = 4.132$, ***p = .042***
Other	63 (17.8%)	59 (27.3%)	$\chi^2(1,569) = 7.131$, ***p = .008***
Memantine			
White	3,739 (28.9%)	3,243 (35.2%)	$\chi^2(1,22175) = 99.297$, ***p = .000***
Black or African-American	334 (17.5%)	275 (22.4%)	$\chi^2(1,3140) = 11.857$, ***p = .001***
American Indian or Alaska Native	15 (10.2%)	20 (21.1%)	$\chi^2(1,242) = 5.490$, ***p = .019***
Native Hawaiian or other Pacific Islander	3 (17.6%)	4 (36.4%)	$\chi^2(1,28) = 1.248$, $p = .264$
Asian	64 (18.6%)	73 (30.3%)	$\chi^2(1,585) = 10.791$, ***p = .001***
Other	64 (18.1%)	56 (25.9%)	$\chi^2(1,569) = 4.893$, ***p = .027***

p values in italics and bold indicate significance.

Social predictors of anti-dementia medication usage

Logistic regression analysis showed that age group, ethnicity, living situation, dementia severity, and gender were significant determinants of usage of cholinesterase inhibitors. People with LOD as opposed to YOD had a greater use of medication ($p < .001$), as well as people from a White ethnic background ($p < .001$). Men were more likely to use cholinesterase inhibitors ($p < .001$) as well as those PwD living with others ($p < .001$). PwD in the moderate and severe stages had reduced rates of cholinesterase inhibitor and memantine usage ($p < .001$; $p < .001$, respectively). Years of education ($p = .599$), NPI-Q ($p = .998$), and severe CDR Global rating ($p = .468$) were not found to be predictive of usage of cholinesterase inhibitors.

At the follow-up visit, the same factors were found to be statistically significant, including ethnicity ($p < .001$), YOD/LOD ($p < .001$), living situation ($p < .001$), gender ($p = .016$), and CDR mild and moderate as opposed to minimal severity ($p < .001$; $p < .001$).

The second logistic regression model showed that YOD vs LOD, ethnicity, education, dementia severity, and living situation were significant determinants of use of memantine. People with YOD as opposed to LOD were more likely to use memantine ($p = .009$) and those living together with others ($p < .001$). PwD from White ethnic backgrounds ($p < .001$) and those with higher levels of education ($p < .001$) were more likely to use memantine. PwD in the mild ($p < .001$) and moderate stages ($p = .008$) were significantly more likely to use memantine than those with minimal dementia, while PwD with severe dementia were less likely to use memantine ($p < .001$). Gender was not found to be significant.

At the follow-up visit, ethnicity ($p < .001$), education ($p < .001$), living situation ($p < .001$), gender ($p = .020$), as well as CDR Global ($p_{mild} < .001$; $p_{moderate} < .001$; $p_{severe} < .001$) compared to minimal severity were found to be significant determinants of memantine usage. Age group ($p = .172$) was not found to be significant.

Table 3 reports the findings of both Visit 1 regression models.

Discussion

This is one of the first studies to show that people from minority ethnic backgrounds and with lower levels of education have reduced uptake of anti-dementia medication. Living with others and being male, as well as having YOD/LOD also contributed to higher levels of medication usage. These findings have significant implications for how to shape policy to enable improved access to necessary dementia health care for all.

Limited previous research into ethnic inequalities in dementia has primarily focused on variations in diagnosis rates and on access to general formal dementia services (Cooper *et al.*, 2010; Mayeda *et al.*, 2016; Raina *et al.*, 2008). Also investigating the NACC database, Mayeda *et al.* (2016) reported dementia incidence was highest in African-Americans and American Indian/Alaskan natives. In a systematic review, Cooper *et al.* (2010) reported that African-Americans were 30% less likely to be prescribed anti-dementia medication. However, to

https://doi.org/10.1017/S1041610220000794 Published online by Cambridge University Press

Table 3. Logistic regression analysis of factors associated with cholinesterase inhibitors and memantine usage

	B	STANDARD ERROR	*p*-VALUE	ODDS RATIO	95% CONFIDENCE INTERVAL
Cholinesterase inhibitors					
Constant	− 1.712	.129	**.000**	.181	
Gender	− .146	.042	**.001**	.865	.796–.939
Ethnicity	− .494	.059	**.000**	.610	.543–.685
Education	.008	.006	.169	1.008	.997–1.019
YOD/LOD	.301	.055	**.000**	1.351	1.213–1.504
Living situation	.401	.063	**.000**	1.494	1.319–1.692
NPIQ total	.005	.005	.292	1.005	.996–1.014
CDR mild	.463	.046	**.000**	1.589	1.452–1.739
CDR moderate	.546	.063	**.000**	1.727	1.525–1.955
CDR severe	− .026	.092	.778	.974	.814–1.166
Memantine					
Constant	− 2.160	.136	**.000**	.115	
Gender	− .039	.044	.379	.962	.883–1.048
Ethnicity	− .694	.063	**.000**	.500	.441–.565
Education	.019	.006	**.003**	1.018	1.006–1.030
YOD/LOD	− .124	.054	**.022**	.883	.794–.982
Living situation	.563	.070	**.000**	1.756	1.530–2.016
NPIQ total	− .021	.005	**.000**	.979	.970–.988
CDR mild	1.163	.050	**.000**	3.201	2.900–3.533
CDR moderate	1.782	.066	**.000**	5.939	5.218–6.759
CDR severe	1.570	.086	**.000**	4.807	4.065–5.685

$N = 15{,}742$.
CDR, Clinical Dementia Rating; LOD, Late-onset dementia; NPI-Q, Neuropsychiatric Inventory Questionnaire; PDD, Parkinson's disease dementia; YOD, Young-onset dementia.
Nagelkerke R^2 (cholinesterase inhibitors) = .042; Nagelkerke R^2 (memantine) = .146.
Significance of bold values are set at $p < .05$.

date it appears that only one other study reported the effects of immigrant status on anti-dementia medication usage (Stevnsborg *et al.*, 2016), with findings supporting the results of the current study. Moreover, the current findings expand on Stevnsborg *et al.*'s (2016) study by purposefully investigating different ethnic minority groups including PwD being born in the U.S.A. and having immigrated to the U.S.A., with no distinction made between the two.

Research suggests limited levels of awareness of dementia in ethnic minorities (Nielsen *et al.*, 2016). In a UK-based investigation of perceptions of memory problems and dementia, Giebel and colleagues (2019b) showed that many South Asian minorities believed that dementia was God-given and rather trusted in alternative remedies as opposed to medication. Thus, while people from BME groups may be aware of dementia, some may actively choose not to use prescribed medication. However, it may also be possible that people from BME backgrounds have lower levels of health literacy and therefore may struggle accessing and using medication in the first place and are less likely to adhere to medication uptake (Mantwill *et al.*, 2015). The large effect sizes of ethnicity on anti-dementia medication usage in this study further underpin the strength of these findings. However, one needs to take into consideration that while large routine databases can provide high power, statistically significant findings may also be found where differences are minute. Further research is needed to better understand the reasons behind the low uptake of anti-dementia medication across the different BME groups.

Low levels of education were also found to be linked to reduced usage of memantine, yet not cholinesterase inhibitors. Memantine is used to treat cognitive impairment in dementia and most often prescribed in moderate to severe dementia. While some evidence suggests health literacy to be positively associated with medication adherence (Zhang *et al.*, 2014), this may not explain why those with lower educational achievements are less likely to use memantine. One possible reason may be the link between lower education and reduced levels of income, so that people are less financially able to pay for the high medication costs in the U.S.A. (Kesselheim *et al.*, 2016). This would corroborate recent reports of a widening gap in income inequalities in the U.S.A., which leads to increased socioeconomic health inequalities (Bor *et al.*, 2016) and can thus make it difficult for PwD with lower levels of education to use the right dementia care they need.

https://doi.org/10.1017/S1041610220000794 Published online by Cambridge University Press

Differences in medication usage were also found between YOD and LOD. In particular, people with YOD were more likely to use memantine and less likely to use cholinesterase inhibitors than people with LOD. With no variations in severity levels between YOD and LOD, the stage of dementia and level of impairment do not explain the variations in uptake of anti-dementia medication. Research has shown that a proportion of people with YOD initially diagnosed with AD are subsequently diagnosed with fronto-temporal dementia (Draper *et al.*, 2016), which has higher levels of neuropsychiatric symptoms than AD in certain domains (Shrikanth *et al.*, 2005). In our study, people with YOD experienced significantly higher levels of neuropsychiatric behaviors, therefore suggesting that people with YOD are receiving more memantine due to the behavioral problems. Follow-up data from Visit 2 showed that there were no variations in the diagnosis rates of people with AD and LBD/PDD. However, a greater proportion of PwD at Visit 2, across all ethnic groups but one (Native Hawaiian or other Pacific Islander) were currently using memantine and cholinesterase inhibitors compared to at Visit 1. This might be explained by varied pre-visit journeys by individuals, whereas taking part in the routine NACC visits may have contributed to improved use of anti-dementia medication.

Findings of this study add novel contributions to the limited evidence base and advance on previous literature. In particular, previous studies have shown that limited people with dementia from a BME background generally took part in clinical drug trials to be able to assess the effect of medication on their symptoms (Faison *et al.*, 2007). Furthermore, ethnic minority older adults are often found to delay help seeking for dementia symptoms (i.e. Mukadam *et al.*, 2011), which may also be an underpinning reason as to why BME people with dementia in this study did not use anti-dementia medication.

Limitations

Information on medication is limited to usage within the past 2 weeks and reported by PwD, leaving the data vulnerable to a reporting bias. However, many PwD are accompanied by their carer who can verify medication use and/or bring a list of medication. It is important to highlight that the NACC database does not collect the age at diagnosis but only the age at each visit. Therefore, it is possible that some people above the age 64 were classed as LOD, while they received their diagnosis below the age of 65 and should have been classed as YOD. Furthermore, one limiting factor in using anti-dementia medication may have been community clinicians' failure to recognize AD dementia or DLB, so that people with dementia have thus not received and been unable to use the necessary medication.

One further limitation was that these data do not provide information on the reasons behind usage/non-usage. For example, it is unclear whether some people might not use anti-dementia medication due to an access issue (by not being prescribed the medication or not being financially able to pay for the medication) or due to an adherence issue in who actually takes the medication.

Conclusions

Findings from this study help clarify social variations in the uptake of anti-dementia medication across different ethnic groups and between people with YOD and LOD. This is one of the first studies showing these great inequalities in the uptake of anti-dementia medication and directly addresses the recently published WHO report (2019) on the essential conditions required to achieve good health for all. Policy guidelines need to take account of these inequalities by ethnicity and education and potentially support the financial uptake of anti-dementia medication better to address and reduce social inequalities.

Conflict of interest

MC has been employed in the past 5 years to assist with Alzheimer's disease drugs trials funded by Janssen and Merck.

Source of funding

The NACC database is funded by NIA/NIH Grant U01 AG016976. NACC data are contributed by the NIA-funded ADCs: P30 AG019610 (PI Eric Reiman, MD), P30 AG013846 (PI Neil Kowall, MD), P50 AG008702 (PI Scott Small, MD), P50 AG025688 (PI Allan Levey, MD, PhD), P30 AG010133 (PI Andrew Saykin, PsyD), P50 AG005146 (PI Marilyn Albert, PhD), P50 AG005134 (PI Bradley Hyman, MD, PhD), P50 AG016574 (PI Ronald Petersen, MD, PhD), P50 AG005138 (PI Mary Sano, PhD), P30 AG008051 (PI Steven Ferris, PhD), P30 AG013854 (PI M. Marsel Mesulam, MD), P30 AG008017 (PI Jeffrey Kaye, MD), P30 AG010161 (PI David Bennett, MD), P30 AG010129 (PI Charles DeCarli, MD), P50 AG016573 (PI Frank LaFerla, PhD), P50 AG016570 (PI David Teplow, PhD), P50 AG005131

https://doi.org/10.1017/S1041610220000794 Published online by Cambridge University Press

(PI Douglas Galasko, MD), P50 AG023501 (PI Bruce Miller, MD), P30 AG035982 (PI Russell Swerdlow, MD), P30 AG028383 (PI Linda Van Eldik, PhD), P30 AG010124 (PI John Trojanowski, MD, PhD), P50 AG005133 (PI Oscar Lopez, MD), P50 AG005142 (PI Helena Chui, MD), P30 AG012300 (PI Roger Rosenberg, MD), P50 AG005136 (PI Thomas Montine, MD, PhD), P50 AG033514 (PI Sanjay Asthana, MD, FRCP), and P50 AG005681 (PI John Morris, MD).

This report is independent research funded by the National Institute for Health Research Applied Research Collaboration North West Coast (ARC NWC). The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research or the Department of Health and Social Care.

Description of authors' roles

CG conceptualized the idea for this study, analysed the data, and drafted the manuscript. MC and BD provided feedback on and shaped the analysis. All co-authors read through drafts of the manuscript and approved the final draft.

References

Alzheimer's Disease International (ADI) (2016). *Improving Healthcare for People Living with Dementia: Coverage, Quality and Costs Now and in the Future*. London: ADI.

Beekly, D. L. *et al.* (2007). The National Alzheimer's Center (NACC) database: the uniform data set. *Alzheimer Disease & Associated Disorders*, 21, 249–258.

Bor, J., Cohen, G. H. and Galea, S. (2016). Population health in an era of rising income inequality: USA, 1980–2015. *The Lancet*, 389, 1475–1490.

Brinda, E. M., Attermann, J., Gerdtham, U. G. and Enemark, U. (2016). Socio-economic inequalities in health and health service use among older adults in India: results from the WHO Study on Global AGEing and adult health survey. *Public Health*, 141, 32–41.

Cations, M. *et al.* (2017). Why aren't people with young onset dementia and their supporters using formal services? Results from the INSPIRED study. *PLOS One*. doi: 10.1371/journal.pone.0180935.

Cooper, C., Tandy, A. R., Balamurali, T. B. S. and Livingston, G. (2010). A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. *American Journal of Geriatric Psychiatry*, 18(3), 193–203.

Cooper, C. *et al.* (2016). Observational cohort study: deprivation and access to anti-dementia drugs in the UK. *Age & Ageing*, 45(1), 148–154.

Dourado, M. C. N. *et al.* (2018). Young-onset Alzheimer dementia: a comparison of Brazilian and Norwegian carers' experiences and needs for assistance. *International Journal of Geriatric Psychiatry*, 33(6), 824–831.

Draper, B. *et al.* (2016). Time to diagnosis in young-onset dementia and its determinants: the INSPIRED study. *International Journal of Geriatric Psychiatry*, 31(11), 1217–1224.

Emre, M. *et al.* (2010). Memantine for patients with Parkinson's disease dementia or dementia with Lewy Bodies: a randomised, double-blind, placebo-controlled trial. *The Lancet Neurology*, 9(10), 969–977.

Faison, W. E. *et al.* (2007). Potential ethnic modifiers in the assessment and treatment of Alzheimer's disease: challenges for the future. *International Psychogeriatrics*, 19(3), 539–558.

Folch, J. *et al.* (2018). Memantine for the treatment of dementia: a review on its current and future applications. *Journal of Alzheimer's Disease*, 62(3), 1223–1240.

Giebel, C. *et al.* (2019a). What are the predictors of A&E attendance in deprived neighbourhoods? Results from a cross-sectional household health survey in the North West of England. *BMJ Open*, 9, e022820. doi: 10.1136/bmjopen-2018-022820.

Giebel, C. *et al.* (2019b). Age, memory loss and perceptions of dementia in South Asian ethnic minorities. *Aging & Mental Health*, 23(2), 173–182.

Giebel, C., Eastham, C., Cannon, J., Wilson, J., Wilson, J. and Pearson, A. (2020). Evaluating a young-onset dementia service from two sides of the coin: staff and service user perspectives. *BMC Health Services Research*, 20(187). doi: 10.1186/s12913-020-5027-8.

Grace, E. L., Allen, R. S., Ivey, K., Knapp, S. M., Burgio, L. D. (2018). Racial and ethnic differences in psychotropic medication use amongst community dwelling persons with dementia in the United States. *Aging & Mental Health*, 22(4), 458–467.

Hughes, C. P. *et al.* (1982). A new clinical scale for the staging of dementia. *The British Journal of Psychiatry*, 140(6), 566–572.

Innes, A., Szymczynska, P. and Stark, C. (2014). Dementia diagnosis and post-diagnostic support in Scottish rural communities: experiences of people with dementia and their families. *Dementia*, 13(2), 233–247.

Kaufer, D. I. *et al.* (2000). Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 12(2), 233–239.

Kesselheim, A. S., Avorn, J. and Sarpatwari, A. (2016). The high cost of prescription drugs in the United States: origins and prospects for reform. *JAMA*, 316(8), 858–871.

Mantwill, S., Monestel-Umana, S. and Schulz, P. J. (2015). The relationship between health literacy and health disparities: a systematic review. *PLOS One*. doi: 10.1371/journal.pone.0145455.

Mayeda, E. R., Glymour, M. M., Quesenberry, C. P. and Whitmer, R. A. (2016). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & Dementia*, 12(3), 216–224.

Mayrhofer, A., Mathie, E., McKeown, J., Brunn, F. and Goodman, C. (2018). Age-appropriate services for people

diagnosed with young onset dementia (YOD): a systematic review. *Aging & Mental Health*, 22(8), 933–941.

McKeith, I. F. *et al.* (2017). Diagnosis and management of dementia with Lewy bodies: fourth consensus report of the DLB Consortium. *Neurology*, 89, 88–100.

McKhann, G. M. *et al.* (2011). The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, 7(3), 263–269.

Millenaar, J. K. *et al.* (2014). The experiences and needs of children living with a parent with young onset dementia: results from the NeedYD study. *International Psychogeriatrics*, 26(12), 2001–2010.

Millenaar, J. K. *et al.* (2016). The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: a systematic review. *International Journal of Geriatric Psychiatry*, 31(2), 1261–1276.

Morris, J. C. *et al.* (2006). The Uniform Data Set (UDS): clinical and cognitive variables and descriptive data from Alzheimer Disease Centers. *Alzheimer Disease & Associated Disorders*, 20, 210–216.

Mukadam, N., Cooper, C., Basit, B. and Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics*, 23(7), 1070–1077.

Nielsen, T. R., Nielsen, D. S. and Waldemar, G. (2019). Barriers to post-diagnostic care and support in minority ethnic communities: a survey of Danish primary care dementia coordinators. *Dementia*. doi: 10.1177/1471301219853945.

Nielsen, T. R. and Waldemar, G. (2016). Knowledge and perceptions of dementia and Alzheimer's disease in four ethnic groups in Copenhagen, Denmark. *International Journal of Geriatric Psychiatry*, 31(3), 222–230.

Raina, P. *et al.* (2008). Effectiveness of cholinesterase inhibitors and memantine for treating dementia: evidence review for a clinical practice guideline. *Annals of Internal Medicine*, 148, 379–397.

Saini, P. *et al.* (2020). Predictors of emergency department and GP use among patients with mental health conditions: a public health survey. *British Journal of General Practice*, 70(690), e1–e8. doi: 10.3399/bjgp19X707093.

Srikanth, S., Nagaraja, A. V. and Ratnavalli, E. (2005). Neuropsychiatric symptoms in dementia – frequency, relationship to dementia severity and comparison in Alzheimer's disease, vascular dementia and frontotemporal dementia. *Journal of the Neurological Society*, 236(1–2), 43–48.

Stevnsborg, L., Jensen-Dahm, C., Nielsen, T., Gasse, C. and Waldemar, G. (2016). Inequalities in access to treatment and care for patients with dementia and immigrant background: a Danish nationwide study. *Journal of Alzheimer's Disease*, 54(2), 505–514.

World Health Organisation (WHO) (2019). *Health, Prosperous Lives for All: The European Health Equity Status Report (2019)*. Copenhagen: WHO.

Zhang, N. J., Terrz, A. and McHorney, C. (2014). Impact of health literacy on medication adherence: a systematic review and meta-analysis. *Annals of Pharmacotherapy*, 48(6), 741–751.

https://doi.org/10.1017/S1041610220000794 Published online by Cambridge University Press