Parity of access to memory services in London for the BAME population: a cross-sectional study

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Abstract:

Objective: To investigate whether referrals to memory services in London reflect the ethnic diversity of the population. **Methods:** Memory service data including referral rates of BAME was collected from London Clinical Commissioning Groups (CCGs). **Results:** The expected percentage of BAME referrals using census data was compared against White British population percentages using the chi squared test. We found that within 13,166 referrals to memory services across London, the percentage of people from BAME groups was higher than would be expected (20.3 versus 19.4%; $\chi^2 = 39.203$, d.f.=1, $p<0.0001$) indicating that generally people from BAME groups are accessing memory services. Seventy-nine percent of memory services had more referrals than expected or no significant difference for all BAME groups. When there were fewer referrals then expected, the largest difference in percentage for an individual ethnic group was 3.3%. **Conclusions:** Results are encouraging and may indicate a significant improvement in awareness of dementia and help seeking behaviour among BAME populations. Prevalence of dementia in some ethnic groups may be higher so these numbers could still indicate under-referral. Due to the data available we were unable to compare disease severity or diagnosis type.

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Background

It is estimated there are 850,000 people living with dementia in the UK, and the number of people affected is expected to increase to over one million by 2025 [1]. Dementia remains probably the most important health problem in economic terms, costing the UK economy £26.3 billion per year [2]. Over time there has been a greater focus on diagnosing dementia earlier in the illness and several countries have launched campaigns to improve dementia diagnosis and treatment [3]. The National Dementia Strategy [4] was launched in February 2009 in the UK. Its main aims were to increase awareness about dementia, improve rates of diagnosis and improve the quality of care that people with dementia receive. Additional funding of £150 million was provided to Primary Care Trusts in order to improve diagnosis rates, primarily through increasing access to diagnostic services. The launch of the National Dementia Strategy was found to be associated with an increase in dementia diagnosis rates and prescriptions of anti-dementia medications [5;6].

In the UK, at the last census, Black and Minority Ethnic (BAME) people accounted for 15% of the English population and 39% of the London population [7;8]. The BAME population in the UK is generally younger than the White British population [9]. The ethnic minority population as a whole is predicted to increase to 27% of the population by 2026 and the proportion of older people within those ethnic minority groups, is also predicted to increase [10]. The prevalence of dementia will therefore rise rapidly in this group of people over time.

A systematic review of data gathered regarding ethnic differences in dementia service use (primarily in the United States) found people from minority ethnic groups present later in the illness and then use fewer dementia diagnostic and treatment services, making them prone to worse outcomes [11]. In the USA, median survival time for African-American people diagnosed with dementia is shorter than in the White population [12]. In London, people from BAME groups presenting to memory services were found to have lower cognitive scores than their White British counterparts [13]. These findings could indicate help-seeking or referral at a later stage in the illness among BAME groups or that cognitive testing has not taken into account language or cultural differences. The reasons behind late presentation for diagnosis are likely to be due to concerns about the stigma of a diagnosis, perceived social pressure to look after relatives without external help and difficulties in knowing about or being able to access services [14;15].

In order to ensure equity of treatment and outcomes across all ethnic groups it is essential that all people with dementia have access to early diagnosis and treatment if appropriate. Previous studies of interventions to improve dementia diagnosis rates have mostly targeted healthcare professionals or the majority population [16] and evaluations of the National Dementia Strategy have also not identified whether any impact has been made on diagnoses in BAME populations [5;6]. In the UK, the majority of dementia diagnoses will be made in specialist memory clinics and general practitioners (GPs) tend not to diagnose dementia or initiate medication for it, so the proportion of people from BAME groups in memory services will give an indication as to parity of access to dementia diagnosis among different groups. In this paper we sought to evaluate parity of access for all ethnic groups to memory services in London.

Aim

To investigate whether referrals to memory services in London reflect the ethnic diversity of the underlying population.

Methods

Data Collection

We contacted all memory services in London covering 32 Clinical Commissioning Groups (CCG) by letter in October 2016 requesting ethnic distribution data for referrals to their service from 1st April 2015 to 31st March 2016. A reminder was sent out in May 2017 to services that had not already participated.

Population data was extracted for each CGG from census predicted data for 2015 (https://data.london.gov.uk/dataset/gla-population-projections-custom-age-tables). Census data on ethnicity is broken down into 10 categories; White, Black Caribbean, Black African, Black Other, Indian, Pakistani, Bangladeshi, Chinese, Other Asian and Other.

Data Analysis

We included all referrals in order to maximise power. Memory service ethnicity categories were matched with the census categories by two researchers separately and then compared and discussed for accuracy. Data from memory services within the same CCG were combined in order to compare referrals to the underlying population structure. The percentage of referrals for each ethnicity out of the total sample of referrals was calculated. From the census data, the percentage of each ethnicity in each London borough was calculated for patients 65 years and over. This age group was chosen as this is the population at significant risk for dementia [17].

We compared the observed number of referrals against the expected number based on population percentages across all of London for each major ethnic group using the chi-squared test with a pre-specified cut-off of 0.05 to test statistical significance of any deviation. The chi squared test could not be used to compare referrals within each memory service or in individual ethnic categories due to low frequencies so we compared referral and population percentages for total BAME referrals in individual memory services and each ethnic group graphically. For this comparison we grouped all Black ethnic groups and South Asian (Bangladeshi, Pakistani, Indian) groups as these are the largest non-White ethnic groups in the UK.

Results

Data was received from 19 CCGs which is 59% of London CCGs. The CCGs were broadly representative of London in terms of location (North vs South, Inner vs Outer London) and including areas with and without a high percentage of minority ethnic groups.

A total of 13,166 referrals to memory services across London were included in the data analysis. The number of referrals ranged from 156-1717 per CCG. The mean percentage of referrals that had missing data was 8.9 (Standard deviation 7.4, range 0-22%).

Table 1 shows the number and percentages for each ethnic group across London and the total number and percentage referred to memory services. Referrals of people from BAME groups was higher than would be expected from the population percentages (20.3 versus 19.4%; $\chi^2 = 39.203$, d.f.=1, $p<0.0001$) compared with the White British population and most minority ethnic categories either formed a higher percentage of memory service referrals compared to that expected from population data or were not significantly lower than the expected percentage. The exceptions to this were the Chinese and Pakistani groups which

had significantly lower percentages of referrals (0.5 and 0.2 respectively). The percentage of people referred from White ethnic groups was much lower than expected (69.5 vs 80.6%).

Figure 1 presents the percentages of total BAME groups in the population (65 years and over) and percentage of observed and expected referrals to memory services. Of the 19 participating memory services, nine had more referrals to the memory service from the BAME community than expected with the percentage difference ranging from 0.9 to 10.9. Six services had no difference and four had fewer than expected. Of the services who had fewer referrals than expected, percentage differences were 1.1%, 2.3%, 5.4% and 8.4% respectively. Memory services in boroughs with the highest percentage of BAME groups in the population received less than the expected percentage of referrals from minority groups.

Figures 2 and 3 show differences between observed and expected percentage of referrals across the Black and South Asian groups respectively. Twelve out of 19 of the memory services received the same or more referrals of Black people compared to what was expected based on population percentages. For those services receiving less referrals than expected, the differences were often very small with a maximum differences of 2%. In the South Asian population, 11 out of 19 memory services received the same percentage or more of South Asian referrals compared to the percentage in the population. The largest deficit in referrals was 5%.

Discussion

This is the first study to compare the rate of referral of people of differing ethnicity to memory services to those of the underlying population and it found that overall they access services at a higher rate than the White majority population aged over 65 years. Our study indicates that there is fairly equal access between White and the total BAME population in relation to referrals to memory services across London. Of the 19 participating services, nine had significantly more referrals to the memory service from the BAME community than expected, six had no difference and four had fewer than expected. The largest ethnic groups in London, the Black and South Asian community generally access diagnostic services the same or a greater percentage compared with population percentages.

These findings could be reflective of greater awareness about dementia in primary care and among the general population over the last few years and an increase in referral numbers across the board. Some ethnic groups such as Pakistani and Chinese were under-represented. It may be that some ethnic groups are under-referred but that awareness or pro-active referrals in other ethnic groups compensates for this so that total BAME referrals are similar to the underlying population.

Our study makes several assumptions which may not be valid. Firstly, we have compared referral percentages with percentages of the population aged over 65 as this is the age at which dementia risk becomes significant. Also, expecting referral percentages to equal population percentages assumes that prevalence of dementia is the same in all ethnic groups. Previous research has shown that people of Afro-Caribbean descent in the UK have both a higher prevalence of dementia and an earlier age of onset than the White British population [18], so although the numbers referred in this group is higher than would be expected from the population percentages, we would expect even more based on the higher prevalence. There is no robust data on the prevalence of dementia in the South Asian community in the UK either but as they have a higher prevalence of cardiovascular risk factors [19], which increase the risk of dementia [3], the prevalence of dementia might be

assumed to be higher than the White British population so referral percentages might still be less than they should be.

Overall, however, the parity of referral numbers is encouraging and may be an early indication of positive impact from years of fruitful campaign and raising of awareness, by voluntary and statutory organisations and researchers, or from the development of a more racially and culturally diverse population within memory service and GP staff.

Strengths and limitations

We have been able to compare memory service referral percentages with underlying population structures in London for the first time. We only received data from 19 out of 32 CCGs in London, so the data may not be representative of the practice across the capital. It also may not be representative of the UK population in general, as London is more ethnically diverse and therefore is likely to have more awareness around equality of access for healthcare. We only analysed referrals for which ethnicity is recorded and as there was a significant amount of missing data, it is possible referrals from minority ethnic groups were made but not recorded or that the majority ethnic group was least likely to be recorded in referrals which could account for the apparent deficit in referrals for people of White ethnicity. Previous research indicates that ethnicity tends to be most often not recorded for people from the majority population [20]. We have only analysed data from memory services and compared this with the underlying population over the age of 65. Referrals for young onset dementia is therefore not addressed. Our data only focused on the referrals but not people who receive a diagnosis of dementia, nor did we know how many people were diagnosed with other conditions such as Mild Cognitive Impairment. We also have no information on type of dementia diagnosis made, the severity of dementia at the point of diagnosis or length of symptoms before the diagnosis is being made. We only had data on referrals for one year so could not check for trends in referrals over time or link this to changes in policy such as the National Dementia Strategy. There may be differences in referral patterns by age group or within certain ethnic groups but our study was not large enough to examine these.

Conclusion

Our finding is that memory services in London in general receive more than the expected number of referrals from the BAME population and for the main ethnic minority groups, the number of referrals to memory services is higher than expected. This is very encouraging and may indicate a significant improvement in awareness of dementia and help seeking behaviour among BAME population and a more responsive and equitable primary care service. Many questions about equity of access in specific ethnic groups remain, as do questions about timeliness of diagnoses received. We believe there should be further analysis to explore inequality and targeted resource and service development for timely diagnosis and appropriate aftercare among the expanding number of people with dementia and their carers in the BAME communities.

Table 1: Observed and expected numbers of referrals to memory services across London (% difference = % referred - % in population)

	Number in over 65 population	% in over 65 population	Number of referrals expected	Number referred to memory services	% referred to memory services	% difference, χ^2 p-value
White	506920	80.6	10615	9153	69.5	Ref
Bangladeshi	3200	0.5	67	105	0.8	0.3, 0.0002
Black African	14440	2.3	303	263	2.0	-0.3, 0.94
Black Caribbean	25210	4.1	526	652	5.0	0.9, <0.0001
Black Other	6650	1.1	139	119	0.9	-0.2, 0.95
Chinese	6150	1.0	129	60	0.5	-0.5, <0.0001
Indian	28420	4.6	595	517	3.9	-0.7, 0.93
Other Asian	18060	2.9	378	303	2.3	-0.6, 0.37
Pakistani	6080	1.0	127	150	1.2	0.2, 0.01
Other	13600	2.2	285	505	4.0	1.8, <0.0001
Total BAME	121810	19.4	2551	2674	20.3	0.9, <0.0001

Figure 1: BAME population percentage and referrals to memory services in over 65s

(Letter denotes individual CCG)

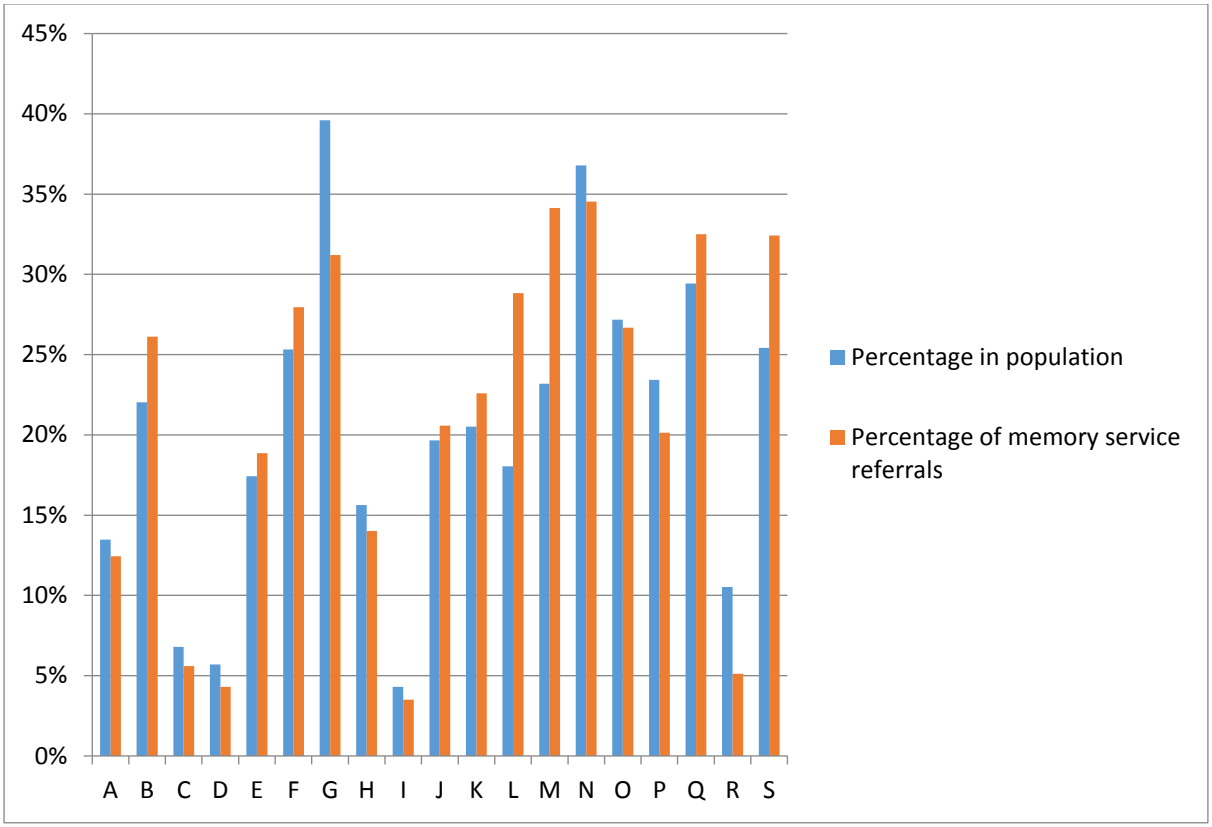


Figure 2: Population percentage and referrals to memory services in Black population over 65

(Letter denotes individual CCG)

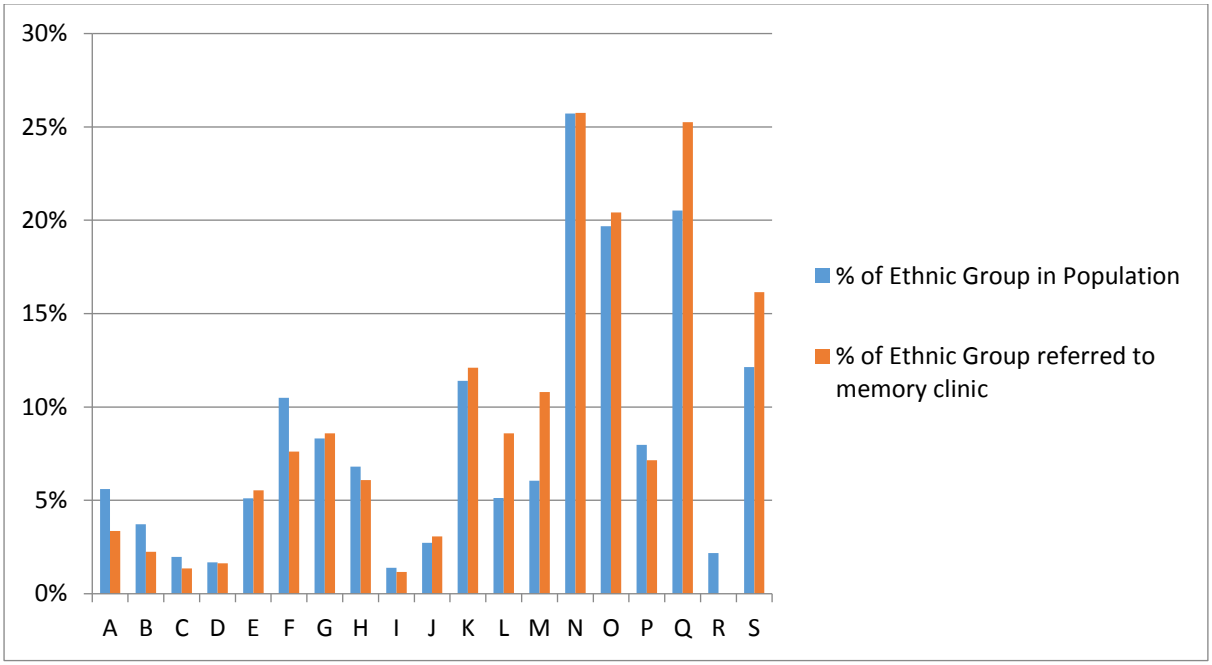
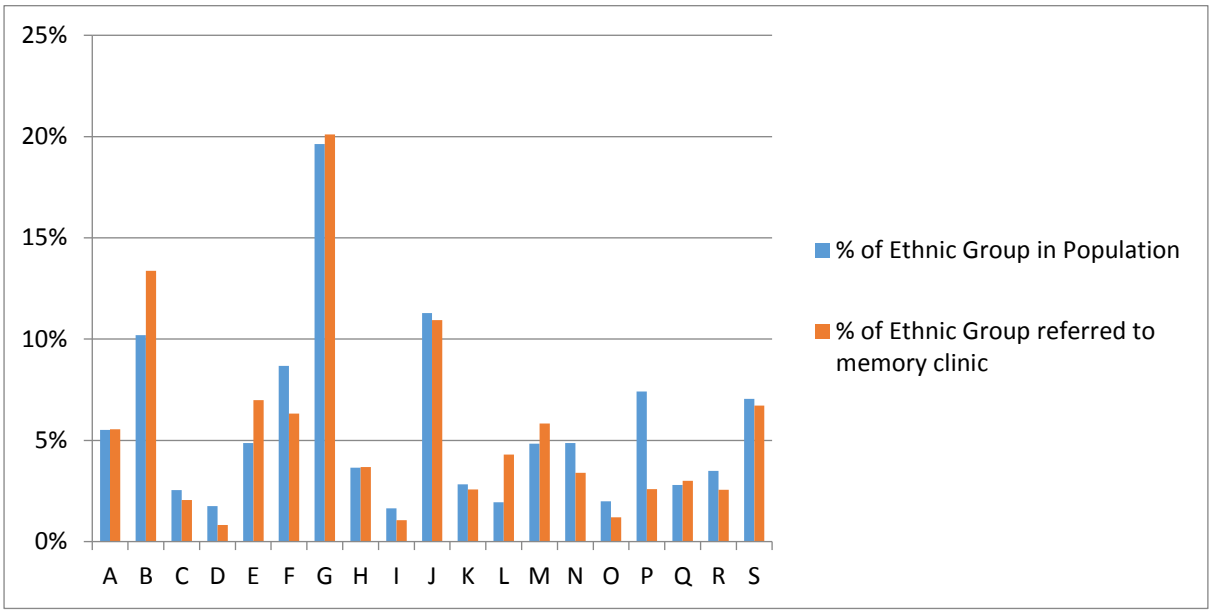


Figure 3: Population percentage and referrals to memory services in the South Asian population over 65

(Letter denotes individual CCG)



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