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Dementia services for people from Black, Asian and Minority Ethnic and White-British communities: Does a primary care based model contribute to equality in service provision?

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Abstract

This study set out to investigate whether there were disparities in service provision for people from Black, Asian and Minority Ethnic (BAME) communities compared to White British (WB) communities within a primary care led dementia service in the UK. Data were extracted from 30 cases from three BAME (African-Caribbean, South Asian and Chinese) communities who had been referred to a dementia service between April 2016 and December 2017. We then extracted data from 30 WB cases matched for gender, age (within 5 years) and General Practitioner surgery. We compared service provision for both samples around assessment, diagnosis and post-diagnostic support. The primary source of information in the BAME sample was less likely to be recorded as being the main carer and more likely to be an adult child. Cases from both samples were equally likely to have a CT scan. People from BAME communities were less likely to receive a cognitive assessment, and when they did they scored at a lower level. There was no difference between samples for the diagnoses that cases received, but BAME cases were more likely to be assessed as being low rather than medium or high risk. While cases from both samples were equally likely to receive medication, BAME cases were more likely to be seen by a psychiatrist. Significantly more people from the WB sample were recorded as using or being offered more than one form of community support. This study of a primary care-based dementia service suggests that while many areas of service provision showed no evidence of inequality, important differences remain including the time at which people present for assessment and the range of post-diagnostic services which are discussed. Further research is required to establish the likely causes of these disparities.

KEYWORDS

accessibility, Alzheimer's disease, dementia, ethnicity, primary care

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1 | INTRODUCTION

In the UK roughly 850,000 people live with dementia, of whom an estimated 25,000 people are of Black, Asian and Minority Ethnic (BAME) origins (Dementia Statistics Hub, 2019). While the overall number of people living with dementia is set to more than double by 2050, the number of people with dementia from BAME communities expected to increase seven-fold (All-Party Parliamentary Group on Dementia, 2013). The disproportionately higher rate of increase for dementia within BAME compared to white communities is partly accounted for by patterns of migration to the UK and by higher levels of specific dementia risk factors within some BAME communities. For example, there is a higher incidence of cardio-vascular disease and Type II diabetes among people of Caribbean and South Asian origins than among White British (WB) people (Finney et al., 2016; Mayeda et al., 2014). Research suggests a higher prevalence rate for dementia for older people from British African-Caribbean communities, compared to the indigenous white population (e.g. Adelman, Blanchard, & Livingston, 2009).

Despite this increased risk, people from BAME communities often present later for assessment and diagnosis for dementia than do white people (Cooper, Tandy, Balamurali, & Livingston, 2010; Mukadam, Cooper, & Livingston, 2011). People from ethnic minorities are also less likely to be diagnosed with dementia (Mukadam, Cooper, Basit, & Livingston, 2011). A study of a memory clinic in Nottingham suggests South Asians have a 0.47-fold reduced likelihood of timely access, compared to WB outpatients with older age, lower index of deprivation and previous access to rapid response mental health services being associated with reduced likelihood of timely access (Ogliari et al., 2020). More generally across the UK as a whole, diagnoses of dementia were 18% lower than expected for Asian women and 12% lower for men (Pham et al., 2018). After a diagnosis people from BAME communities continue to remain under-represented in specialist dementia services and are more likely to draw on community-based services including religious institutions (Baghirathan et al., 2018; Parveen, Peltier, & Oyebode, 2017). These disparities in service provision have been attributed, in part, to a series of barriers that reduce access to dementia services for people from many BAME communities. These include cultural-specific factors such as lower levels of awareness about dementia (Giebel et al., 2014; Moriarty, Sharif, & Robinson, 2011; Werner, Goldstein, Karpas, Chan, & Lai, 2014) and greater levels of stigma (Johl, Patterson, & Pearson, 2016; Mukadam, Cooper, & Livingston, 2011). Access to services may be impeded by a range of health service delivery factors including staff who do not have sufficient training (Bhattacharyya & Benbow, 2013), long-waiting lists (Kenning, Daker-White, Blakemore, Panagioti, & Waheed, 2017) or services failing to take adequate steps to overcome linguistic and cultural barriers to decision-making (Farooq, Kingston, & Regan, 2015; Giebel et al., 2014; Greenwood, Habibi, Smith, & Manthorpe, 2015).

In the UK, diagnosis of dementia is usually through a specialist, multidisciplinary memory assessment service or memory clinic. People presenting with a suspected dementia are initially referred to the memory clinic by their General Practitioner (GP; a primary care physician), with the person subsequently being discharged back to primary care for follow-up. However, this model of service provision has a series of potential problems. First, while memory clinics are effective diagnostic services, they may not necessarily provide effective post-diagnostic support (Mellis, Meeuwsen, Parker, & Rikkert, 2009; Passmore & Craig, 2004). Second, as health service policy has prioritised timely, often early, diagnosis so the number of people being referred for assessment has risen resulting in increased waiting times. Finally, by being located within specialist secondary, and sometimes tertiary, level services so people and their families need to negotiate a series of gatekeepers before they can access services. This may especially disadvantage people from some BAME communities who are more likely to use primary, rather than secondary care services (Morris, Sutton, & Gravelle, 2005).

In response to these pressures on memory services, other ways of assessing and supporting the diagnosis of dementia have been instigated in the UK (Greaves & Greaves, 2011), and also in Canada (Lee et al., 2010), Thailand (Boongird, Thamakaison, & Krairit, 2011) and Norway (Engedal, Gausdal, Gjøra, Gausdal, Gjøra, & Haugen, 2013). These emergent services utilise resources available within primary care to provide early and timely diagnosis. Within the UK, this trend towards locating dementia services within primary care is in line with wider health service policy for many other long-term conditions and is hoped to bring a series of advantages. First a streamlined model of assessment may free up additional funding for post-diagnostic support. Second, basing dementia assessment in primary rather than secondary or tertiary care, reduces the number of gatekeepers and should, in principle, enable greater access to such services by people from BAME communities who may otherwise be deterred from attending specialised, dementia services (Banerjee et al., 2007).

What is known about this topic?

- People from some Black, Asian and Minority Ethnic (BAME) communities utilise primary care more that secondary care appointments.
- Specialist dementia services may disadvantage people from communities where there are lower levels of awareness about dementia and greater levels of stigma.

What this paper adds?

- BAME cases were less likely to receive a cognitive assessment than WB cases. When an assessment was recorded, BAME cases scored a lower level than the WB cases; consistent with existing literature suggesting that BAME communities may present later for assessment.
- In other domains in this study, there was no evidence of a disparity of service provision between BAME and WB cases suggesting a primary care-based dementia service may contribute to equal service provision.

Since 2015, assessment and diagnosis of dementia has been conducted in Bristol, UK, by a primary care led dementia service. GPs assess and diagnose dementia with the support of dementia practitioners if and when required. Where patients have a more complex presentation (e.g. where younger onset dementia is suspected), then the care pathway recommends that GPs refer to the multidisciplinary team comprising of psychiatrists and psychologists. Regardless of where they are diagnosed, all service users who have a diagnosis of dementia are referred to the service for support, continuing until they either die, or leave the area. This study set out to explore whether there were disparities in service provision in the areas of assessment, diagnosis and post-diagnostic support in this primary care led dementia service for people from BAME compared to people from WB communities.

2 | METHODS

We compared a sample of 30 pseudonymised consecutively referred case records held within this service from three BAME communities (South Asian, Chinese and Caribbean) to a matched sample of 30 case records from people from the WB community. We compared the service received by the two samples on three domains: assessment (brain scans, cognitive and risk assessment); diagnosis received (who made the diagnosis and what diagnosis was given); and post-diagnostic support (well-being plan, behavioural and psychological symptoms (BPSD), contact with services and staff, medication and access to community resources).

2.1 | Case identification

Cases were initially included if they had been referred into the service and diagnosed with dementia between April 2016 and the end of March 2017. A total of 674 people were referred during this period, of whom 619 were recorded as being WB. In addition, 24 people were of Caribbean origin, four of Pakistani or Indian origin, one of Chinese origin and 14 other people came from different BAME communities. In twelve cases, ethnicity was not recorded.

The profile of BAME communities living with dementia in Bristol is largely made up of people from people from African-Caribbean communities (60%), South Asian (30%) and Chinese (10%) communities (Baghirathan et al., 2018). Accordingly, we extracted data in the following proportions: 18 people of African-Caribbean descent, nine people from South Asian communities (5 from Pakistani and 4 from Indian origins) and three people from Chinese communities. In order to make up for the shortfall of referrals from Chinese and South Asian communities during our data extraction period, we included an additional five people from South Asian communities and two people from Chinese communities referred to the service up until December 2017. Once we had identified 30 cases from BAME communities, these were then matched against potential cases from the records listed as WB ethnicity using three criteria: registered GP surgery; gender; and age (within a 5-year range). If there was no match within that surgery then another case from a similar, nearby surgery was used.

2.2 | Data collection, management and storage

Ethical approval was granted by the University of the West of England's Faculty Ethics Committee on 25th July 2017 [REC number: HAS.17.07.189] with a data sharing agreement agreed between the University and the NHS Trust providing the service. Both the University ethics department and the Research and Development department of the NHS Trust approved this project as a service evaluation therefore consent was not obtained. Data were extracted by two employees of the service using an adapted data extraction form from the EVIDEM trial (Iliffe et al., 2015). The extracted data were pseudonymised so that personal data were not identifiable. The researchers who were not part of the clinical service at no time had access to service user records. Data were entered onto an SPSS spreadsheet, with parametric data analysed using independent samples *t*-tests and non-parametric data using chi-squared with Fisher's correction where relevant.

3 | RESULTS

3.1 | Background information

3.1.1 | Language

As cases were matched for age and gender, the average age of both samples was similar and comprised of roughly similar proportions of men and women. English was the main language of all 30 cases from the WB sample. The languages reported in the BAME sample was English (21), Cantonese (1), Hakka (1), Urdu (3) and Punjabi (4). Four people from the BAME sample required an interpreter/translator to facilitate interactions with service staff.

3.1.2 | Pre-morbid medical history

Significantly more cases from the BAME sample ($n = 15$) were recorded as having a history of diabetes compared to the WB sample ($n = 3$) ($\chi^2(1) = 11.43$, $p < 0.001$). None of the other differences between the two samples for different clinical conditions was significant. Further demographic data can be found in Tables 1 and 2.

3.1.3 | Care arrangements

The service records the relationship of the main informant during an assessment, and whether this person was also identified as a carer (see Table 3). In only one case, was the main informant from the BAME sample identified as the service user's spouse or partner, whereas adult children were identified as the main informant for 24 cases. In the WB sample, spouses or partners were identified as the main informant in eight cases and adult children in 12. The difference between the two cohorts in terms of the proportion of informants who were either a spouse/partner or an adult child was significant ($\chi^2(1) = 9.00$, $p = 0.003$). Importantly, the roles of informant and carer were significantly more likely to be separate in the two samples ($\chi^2(1) = 4.67$, $p = 0.031$): for the WB sample, 20 of the 28 informants were identified as also being carers, whereas only 12 of 26 carers in the BAME sample acted as both informant and carers. This is despite the fact there were similar number of married/cohabiting participants in the BAME (10) and the WB (9) cohorts.

TABLE 1 Demographic information

	Black, Asian and Minority Ethnic ($N = 30$)	White-British ($N = 30$)
Gender		
Female	22	23
Male	8	7
M_{age} (years) on 15-02-18	81.00	80.57
SD	9.18	9.84
Ethnicity		
White British	0	30
Indian	4	0
Pakistani	5	0
Chinese	3	0
Caribbean	18	0
Marital status		
Married	9	9
Cohabiting	1	0
Single	3	7
Widowed	10	7
Divorced	4	5
Separated	1	0
Not known	2	2
Living circumstances		
Lives alone	9	9
Lives with spouse/partner	9	8
With other family	5	4
Residential care	5	4
Sheltered accommodation/supported living	2	3
With lodgers	0	2

3.2 | Assessment procedures

3.2.1 | Brain scan assessments

CT head scans were recorded equally across the two samples (BAME = 25, WB = 27) with one case from the BAME sample recorded as receiving an MRI scan.

3.2.2 | Cognitive assessments

Significantly more of the WB cases (25) received a cognitive assessment compared to BAME cases (16) ($\chi^2(1) = 6.24$, $p = 0.012$). Where cognitive assessments were carried out, the main instrument used was the Addenbrooke's Cognitive Examination III or ACE III (Noone, 2015), with assessment being carried out within 6 months of referral to the service. Roughly equal numbers of people from the BAME sample (13) and the WB sample (16) were assessed using the ACE III. The average score on the ACE III was lower for cases from the BAME sample ($M = 45.15$, $SD = 13.35$) than for cases from the WB cohort ($M = 60.94$, $SD = 18.69$) ($t(27) = 2.40$, $p = 0.024$). For three cases (all from the BAME sample), the ACE was only partially completed (with scores out of 87, 97 and 42 rather than 100). In these cases, total scores were pro-rated.

TABLE 2 Significant past medical history

	Black, Asian and Minority Ethnic ($N = 30$)	White-British ($N = 30$)
Diabetes	15	3
Cardio-vascular conditions (stroke, heart disease, hypertension)	22	20
Sight or hearing loss	7	8
Cancer	3	2
Musculoskeletal conditions	10	10
Depression or anxiety	10	11
Serious mental health problems	3	0
Other condition or illness	28	27

TABLE 3 Recorded main informant for the service user

		Black, Asian and Minority Ethnic ($N = 30$)	White-British ($N = 30$)
Spouse	Husband	0	5
	Wife	1	3
Children	Son	8	6
	Daughter	16	6
Extended family	Brother	0	2
	Mother	1	0
	Grandchild	1	0
	Nephew/niece	1	1
	Sister-in-law	0	1
	Daughter-in-law	0	1
Non family	Friend/chaperone	1	2
	Support worker	0	1
	Not identified	1	2

TABLE 4 Diagnosis

Type of diagnosis	Black, Asian and Minority Ethnic ($N = 30$)	White-British ($N = 30$)
Alzheimer's disease	8	11
Vascular dementia	9	9
Lewy-body dementia	1	0
Mixed dementia	4	5
Unspecified	7	4
Mild cognitive impairment	1	1

3.2.3 | Risk assessment

Every case had their level of risk assessed across five domains: harm to self, harm from others, harm to others, accident and other risks. For each domain, risk is assessed on a series of measures. There was no difference between participants from the BAME and WB samples for each of the five separate risk domains. Every case received an overall categorisation of risk in terms of three levels: low, medium and high. The majority (73%) of cases within the BAME sample were assessed as low risk. People from BAME communities were significantly more likely to be classified as low, rather than medium or high risk than were people from the WB sample ($\chi^2(1) = 4.44$, $p = 0.035$).

3.3 | Diagnosis

3.3.1 | Who makes the diagnosis?

Slightly more people from the BAME sample (8) than the WB sample (6) had been diagnosed by their GP. More commonly both BAME ($n = 22$) and WB cases ($n = 17$) received their diagnosis from staff working for the service (i.e. dementia practitioners and psychiatrists). For seven cases (all from the WB sample), the diagnosis was made outside the service; by nurses based in general hospitals, hospital liaison staff, neurologists and in one case when the person was overseas.

3.3.2 | Types of diagnosis

Roughly equal numbers of people from both the BAME ($n = 22$) and the WB sample ($n = 25$) were diagnosed as having Alzheimer's Disease, Lewy-Body, Vascular or mixed dementia (see Table 4). While slightly more people from the BAME sample were diagnosed with an unidentified from of dementia ($n = 7$) than were people from the WB sample ($n = 4$), this difference was not significant. One person from the BAME sample and one from the WB sample was given a diagnosis of Mild Cognitive Impairment after a lengthy assessment due to the complexity of the initial presentation.

3.4 | Post-diagnostic support

3.4.1 | Well-being plans

Well-being plans are a core element of post-diagnostic support. The service user and family carers agree a well-being plan as part of the initial assessment with either a dementia practitioner or navigator. The plan assists in identifying areas of importance, medicine regimes, support groups and activities and other support that users might require. An interim plan should be in place within 20 days following assessment. This target had been missed in eight cases, six times with BAME cases and twice within the WB cases. This difference was not significant ($\chi^2(1) = 2.31$, $p = 0.129$). The consequences of missing the target appears minimal; the longest wait for a plan to be recorded was an additional week.

In almost all cases, the person living with dementia was involved in drawing up their full well-being plan for both samples. There were no differences between the two samples in the involvement of carers, GPs or psychiatrists in the full well-being care plans. Dementia practitioners (typically nurses and occupational therapists who are employed by the NHS Trust) were marginally more likely to be involved in drawing up the full well-being plan with people from the WB sample ($n = 26$), compared to the BAME sample ($n = 20$), ($\chi^2(1) = 3.78$, $p = 0.052$). In contrast, dementia navigators (who are employed by a voluntary sector organisation) were more likely to be involved in drawing up the plan with people within the BAME sample ($n = 24$), than with WB cases ($n = 13$), ($\chi^2(1) = 9.03$, $p = 0.003$).

3.4.2 | Behavioural and psychological symptoms

The presence or absence of 11 different psychological (e.g. delusions and hallucinations) and behavioural symptoms (e.g. pacing and wandering) were recorded. There was no difference between the overall number of BPSD recorded for cases from the BAME sample ($M = 1.74$, $SD = 1.79$) and for WB sample ($M = 1.90$, $SD = 1.08$) cases ($t(54) = 0.40$, $p = 0.692$). Significantly more cases from the WB sample ($n = 12$) than from the BAME sample ($n = 5$) were recorded as having anxiety ($\chi^2(1) = 4.02$, $p = 0.045$).

3.4.3 | Contact with services

While contact with practitioners, navigators and psychologists was equally likely for both samples, significantly more people from the BAME sample (14) than from the WB sample (5), had contact with a psychiatrist ($\chi^2(1) = 6.24$, $p = 0.012$). As cognitive functioning scores from cases from the BAME sample were lower, potentially indicative of a more complex presentation, then this might account for why more BAME cases had psychiatric input. However, there was no difference overall between ACE III scores for cases who were referred to a psychiatrist ($n = 9$, $M = 56.89$, $SD = 23.86$) and those who were not ($n = 23$, $M = 53.57$, $SD = 16.98$), ($t(30) = 0.44$, $p = 0.661$). Another reason for this difference in referral rates might have been the need for psychiatric expertise in the assessment, either for those patients who do not speak English as a first language (which consequently makes the assessment process more complex), or because of the apparent presence of psychotic symptoms. All four BAME cases who required interpreters during their assessment were referred to a psychiatrist. Two cases were prescribed anti-psychotic medication which included one service user who had been assessed with the aid of an interpreter.

3.4.4 | Medication

Equal numbers of people ($n = 16$ in both samples) were prescribed acetyl-cholinesterase inhibitors. There was no difference between the two samples in prescriptions of anxiolytics, anti-depressants and anti-psychotic medication.

3.4.5 | Access to community resources

Significantly more people from the WB sample ($n = 15$) compared to the BAME sample ($n = 7$) were recorded as using or being offered at least one form of community support, ($\chi^2(1) = 5.08$, $p = 0.024$). Post-diagnostic and community resources recorded as attended by the WB sample included: memory café; young people with dementia support group; Alzheimer Society tea dance; Royal Legion; day centre; community tea dance; 50+ club; walking football; music and memories group; exercise class; Tai Chi; social events at retirement home, and community centres. The range of such support recorded as attended for the BAME sample was smaller and consisted of: day centre; sporting memories; having a night sitter; Church luncheon club; 'Paws' for well-being, and attending the gym. Roughly similar numbers for both samples (BAME = 4; WB = 5) had been given general information about support, but it was not evident from the record whether this support had been taken up.

4 | DISCUSSION

This study set out to identify whether there were disparities in service provision for people from BAME communities compared to WB communities within a primary care led dementia service in the UK. While the size of the two samples in this study was comparatively small, the findings point towards both similarities and differences in the provision of care. We compared the records of 30 cases from three BAME communities with a matched sample of WB cases. Data were extracted from cases referred to the service between the start of April 2016 and the end of December 2017. While in many areas there was parity of service provision, areas of residual inequality are indicated within both assessment and post-diagnostic support for the person living with dementia.

4.1 | Background factors: the context of care

Both samples had, as would be expected within an elderly population, relatively high levels of physical health conditions such as heart problems and arthritis. In addition, BAME cases were also significantly more likely to have a history of diabetes, which is itself a risk factor for developing dementia, and has been shown elsewhere to be more common in people from some minority ethnic communities (Mayeda et al., 2014).

There was no difference between the samples in their living circumstances, or the proportion of people who were single or married. For cases from the BAME sample, the main informant was significantly more likely to be identified as adult children rather than the service user's spouse or partner. Cases from BAME sample were significantly more likely to have a carer who did not act as the main informant or point of contact for the service. This suggests the main contact was acting as an informal liaison between the person living with dementia, their main carer and the service and, possibly, in some cases where English was not the person's first language, acting as an interpreter. In the 11 cases where the main point of contact for services and the main carer were different people, then in eight cases the person's ethnicity was recorded as being African-Caribbean, and in three cases as being Chinese. Taken together, this evidence suggests the operational context within which care is being provided is more likely to have been diffuse and complex for BAME service users and their families.

4.2 | Assessment and diagnosis

Many aspects of the assessment process between the two samples were similar. There was no difference in the frequency with which people received scans or the type of diagnosis they were given, with equal numbers of people in each sample (9) receiving a diagnosis of vascular dementia. This latter finding is somewhat surprising as significantly more people in the BAME sample had a pre-morbid history of diabetes, which is an established risk factor for vascular disease. Our data show all the BAME cases received their diagnosis from either their GP or from the primary-care led service. In contrast, seven WB cases received their diagnosis elsewhere, for instance from a neurologist. This suggests people from these three BAME communities are able to access primary care led services more easily than other, secondary and tertiary care systems.

While we were unable to collect data relating to time of onset of cognitive concerns, or the start of the assessment process, cases in the BAME sample were significantly less likely to receive a cognitive assessment and, where cognitive assessments were carried out, then average scores were lower for cases from the BAME sample than for those from the WB sample. This suggests these BAME cases were being diagnosed at a later stage in the illness—which is consistent with findings elsewhere in the UK (e.g. Mukadam, Cooper, Basit, et al., 2011; Mukadam, Cooper, & Livingston, 2011). One likely reason for this is that carers and families from many BAME communities tend to delay help-seeking until they can no longer cope or until others comment on the problems (Baghirathan et al., 2018; Mukadam, Cooper, Basit, et al., 2011). Additionally, staff may be reluctant to carry out cognitive assessments when service users are not fluent in English. In such instances, both a trained interpreter and a culturally validated and translated cognitive assessment tool are required (Mirza, Panagioti, Waheed, & Waheed, 2017; Nielsen et al., 2011).

With the exception of anxiety (which was more common in the WB sample), there was no difference between the two samples for any other area of behavioural and psychological functioning. Similarly, there was no difference in the type of risks identified for the two samples, although people from the BAME sample were more likely to be rated as at low, rather than medium or high risk than were people from the WB sample. While the reasons for this finding are not obvious, two possible factors might play a role: first it has been reported that higher levels of stigma within some BAME communities translates into a tendency to minimise risk and a reluctance to report changes in behavioural and psychological functioning (Mukadam, Cooper, Basit, et al., 2011). In this study BAME cases were less likely to be recorded as being anxious than were WB cases. Second, as BAME cases were more likely to be recorded as having both the involvement of a spouse as a carer and another person (typically an adult child) as an informant, then staff may assume a greater level of support and thus a lower level of risk. Whatever the reasons why a lower risk level was recorded for BAME compared to WB cases, there was a clear, practical consequence. Well-being plans for BAME families were more likely to be drawn up by a dementia navigator who are typically assigned to lead on low risk cases and who are employed by a voluntary sector organisation. In contrast dementia practitioners (typically clinicians employed by the NHS Trust) were involved in developing the well-being plan for all nine cases recorded as high risk regardless of ethnicity and were thus more likely to be allocated to WB rather than BAME families.

4.3 | Post-diagnostic support

Encouragingly, many aspects of post-diagnostic support, including the prescribing of acetylcholinesterase inhibitors was comparable across the two samples. This is despite the fact that people from the BAME sample had lower average scores on cognitive assessments (when these were carried out). In the UK the National Institute for Clinical Excellence or NICE (the clinical body responsible for making evidence-based recommendations about prescribing in the UK) recommends donepezil hydrochloride, galantamine, or rivastigmine should only be considered for mild to moderate Alzheimer's disease. As a consequence, people from BAME communities who tend, as in this study, to score lower on cognitive assessments due to the systemic factors we have touched on above, are up to 30% less likely to be prescribed such mediation (Cooper et al., 2015).

Both BAME and WB cases were equally likely to have had well-being plans written within the target time frame and to have involved services users and carers in writing them. Information provided within the well-being plans on the range of the wider post-diagnostic and community support either being recommended or recorded as being attended, however, did differ. The records of the WB sample were significantly more likely to have information about a greater range of support that could be utilised. Once again, the reasons for this difference are not clear. While we are not able to talk with any degree of certainty about what community support was actually used by cases from either sample, research elsewhere (Baghirathan et al., 2018) has suggested the local uptake of post-diagnostic support is influenced by ethnicity. Many people from BAME communities in the Baghirathan study preferred to draw on support networks with which they are familiar (including faith-based institutions such as mosques, churches and gurdwaras) rather than dementia-specific services such as those run by the Alzheimer's Society possibly because they did not perceive these as meeting their cultural needs. It may well be then, where staff signpost clients from BAME communities to alternative forms of support, they did not subsequently go on to record these because their offer was declined. Alternatively, the lower recorded level of post-diagnostic support might reflect either fewer culturally appropriate services are available or such services do exist, but dementia navigators and practitioners are not aware of them. Finally, it is possible staff do not recommend the same range of post-diagnostic support for BAME families because of assumptions they have made about what sort of support people are likely to use. Further research is therefore needed to explore the uptake of post-diagnostic services by people with dementia from BAME communities and the reasons underlying their choice.

A second difference was significantly more (almost half) of the cases from BAME sample had been seen by a psychiatrist. Once again, the reason for this difference between the two samples is not entirely clear; it wasn't attributable to variations in how service users had been referred into the service, or by the lower cognitive levels at assessment of cases within the BAME sample. One possibility is the clinical team perceived BAME cases as more complex, and thus in need of the added experience of psychiatric skills. This level of complexity might be occasioned by the need for an interpreter or concerns about a need for anti-psychotic medication. Even when those cases who either needed an interpreter or who were subsequently prescribed anti-psychotic medication are discounted, then it is still the case that proportionately twice as many cases from the BAME sample (9 out of 25 or 36%) saw a psychiatrist, compared to 5 out of 30 or 17% from the WB sample.

4.4 | Study limitations and strengths

The main limitation was that we were restricted to gathering data from just 60 case records. Additionally, while these case records contained information about contact with practitioners, they do not constitute an account of the actual day-to-day contact people living with dementia and their families have with all services. The study also has a number of methodological strengths including controls to minimise bias included matching cases on gender, age and referring surgery (which we used as a proxy control for socioeconomic status). We further attempted to minimise any selection bias by specifying a data collection time period, identifying cases consecutively as they were referred to the service and using census data to ensure that as far as possible, our sample of 30 people from three BAME communities reflected the overall numbers of people living with dementia in the city.

5 | CONCLUSIONS

In the UK there is a clear trend towards treating many long-term conditions at the primary care level. Given that people from some BAME communities tend to utilise primary care consultations more than secondary care appointments (Morris et al., 2005) and may otherwise be deterred from attending specialised, dementia services (Banerjee et al., 2007), it is important to establish whether locating these services in primary care would enhance access. Moreover, by facilitating diagnosis by GPs and nurses working for the primary care service, rather than within specialised memory clinics by multidisciplinary teams, this shift in service provision also allows for resources to be targeted at post-diagnostic support.

This study reported here has explored whether a primary care-based dementia service can contribute to equal service provision for different ethnic communities. While there was no difference in uptake of many aspects of the service (e.g. writing a well-being plan, access to medication), nevertheless some disparities in service provision are still apparent. Importantly, cases from the BAME sample were less likely to be assessed cognitively, and where they were then their average scores were lower.

However, since the data were collected the service has made changes to address these disparities, including introducing improved assessment processes for people whose first language is not English (e.g. using the RUDAS, Storey, Rowland, Conforti, & Dickson, 2004). The team also employs four community development coordinators to work with BAME communities to improve awareness of dementia and promote equality of access. These changes should further help to improve access to appropriate assessment, diagnosis and support for this section of the population.

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CONFLICT OF INTEREST

ED and RC do not have a conflict of interest to report. RP was employed by the Trust providing the service. SC, SP and TE continue to be employed for this Trust.

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