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Dementia in UK South Asians: A scoping review of the literature

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Abstract (298 Words)

Objective

Over 850,000 people live with dementia in the United Kingdom (UK). A proportion of these people will be South Asians, who make up over 5% of the total UK population. Little is known about the prevalence, experience, and treatment of dementia in the UK South Asian population. The aim of this scoping review is to identify and summarise dementia studies conducted in the UK South Asian population to identify the gaps in the literature which should be addressed in future research.

Method

Databases were systematically searched using a comprehensive search strategy to identify studies. The methodological framework for conducting scoping reviews was followed. An extraction form was developed to chart data and collate study characteristics and findings. Studies were then grouped into six categories: prevalence and characteristics; diagnosis validation and screening; knowledge, understanding and attitudes; help-seeking; experience of dementia; service organisation and delivery.

Results

A total of 6481 studies were identified and screened. Twenty six studies were eligible for inclusion in the scoping review. Studies of prevalence, diagnosis, and service organisation and delivery are limited. We did not find any clinical trials of culturally appropriate interventions for South Asians with dementia in the UK. The existing evidence comes from small scale service evaluations and case studies.

Conclusions

This is the first scoping review of the literature to identify priority areas for research to improve care for UK South Asians with dementia. Future research should first focus on developing and validating culturally appropriate diagnostic tools for UK South Asians and then conducting high quality epidemiological studies in order to accurately identify the prevalence of dementia in this group. The cultural adaptation of interventions for dementia

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3 and testing in randomised controlled trials is also vital to ensure that there are appropriate
4 treatments available for UK South Asians to access.
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8 **Strengths and Limitations of the Study**

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- 10 • The first scoping review of the literature to identify priority areas for future research
11 and care of UK South Asians with dementia.
- 12 • Comprehensive and systematic search which was conducted in line with published
13 guidelines for scoping reviews.
- 14 • A comprehensive and broad search strategy was developed however, a lack of
15 standardisation around some key search terms could mean some studies were not
16 identified.
- 17 • This review is not able to provide a definitive answer to any of the key themes
18 discussed but its purpose is to map the literature and provide a much needed
19 framework to guide future research directions for UK south Asians with dementia.
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Introduction

As the global population ages the prevalence of dementia increases; there are an estimated 47 million people living with dementia worldwide and this figure is set to increase to over 75.6 million by 2030.^{1,2} In the United Kingdom (UK) alone there are over 850,000 people living with dementia at a cost of £26 billion per year.¹ The rising prevalence of dementia and its associated cost and burden has generated an increased focus on the timely screening, diagnosis and treatment of dementia.

Ethnic minority groups make up over 14% of the total UK population, many of whom are South Asian (Pakistan, India, and Bangladesh). In the 2001 census South Asians made up 3.9% of the total UK population and by 2011 this figure had risen to 5.3%.³ It is estimated that there are over 25,000 people from ethnic minority groups living with dementia in the UK.⁴ However, the true prevalence of dementia within the UK South Asian community is yet to be established.

There are potential difficulties in identifying, diagnosing, and treating dementia in UK South Asian population. In the South Asian community only 35% of older people can speak English and only 21% can read and write English, with most relying on their first language which for many is Urdu.^{3,5} There is also lack of awareness of dementia within the South Asian community with many people viewing memory loss as a normal part of ageing or understanding it using religious beliefs.⁶ For those who do seek help there is a lack of culturally appropriate services and accurately translated neuropsychological assessments for UK South Asians.⁷

The aim of this scoping review is identify and summarise dementia studies conducted in the UK South Asian population in order to identify gaps in the literature which need to be addressed in future research.

Methods

A scoping review was conducted in accordance with the methodological framework for scoping reviews published by Arkskey and O'Malley (2007) and further developed by Levac et al. (2010).^{8,9} The framework includes guidance on the following areas: identifying the research question, searching for relevant studies, selecting studies, charting the data, and collating and summarising results.

Inclusion criteria and exclusion criteria

Studies that had included UK South Asian dementia patients were eligible for inclusion, as well as those that had focused on family carers, and healthcare professionals working with dementia patients. We did not exclude studies based on methodology or year of publication. Published dissertations were included but any unpublished dissertation was not. Systematic reviews and narrative literature reviews were not included but reference lists were searched to identify additional primary studies for inclusion. Conference proceedings were not included.

We excluded studies that did not report on South Asian participants alone, as a comparator group, or where data could not be separated from data for participants of other ethnicities.

We excluded studies that were not published in the English language.

Search strategy

Search terms were kept broad to identify the maximum number of studies which were eligible for inclusion. The search strategy was developed within the team to identify all studies relevant to ethnicity and dementia, this was then refined through hand checking to those which included UK South Asian participants. Search terms included: Dementia, Alzheimer* Disease; ethnic*, Asian, Black, African, minority, ethnic group, multi-ethnic. See additional material 1 for the full search strategy.

The search was conducted without a study design filter in order to retrieve studies using all methodologies, including: systematic reviews, qualitative studies, quantitative studies, case studies, and service evaluations.

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3 The following databases were searched: Cochrane Register of Controlled Trials (CENTRAL),
4 MEDLINE (OVID), PsycINFO (Ovid), Embase (Ovid), Cochrane database of systematic
5 Reviews. The search was initially conducted in April 2016 and updated in June 2017. In
6 addition to the database searches, we hand searched the reference lists of all relevant
7 systematic reviews and literature reviews that were returned in the search to identify any
8 additional papers for inclusion.
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13 14 15 *Screening and charting the data*

16 Electronic search results were managed using EndNote X7 and Microsoft Excel. Titles and
17 abstracts of all citations were first screened by author (AB), those that were not related to
18 dementia and South Asians, or had been conducted outside of the UK, were discarded. The
19 full text of all potentially eligible papers were then obtained and assessed against the
20 inclusion criteria (AB and WW). Where the full text of papers was not available authors were
21 contacted to request the paper. Any ambiguities about whether or not a study met the
22 inclusion criteria were resolved by discussion at a meeting attended by all authors.
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30 Studies that met the review criteria were charted using a data extraction sheet designed by
31 AB and WW. Data were primarily extracted by AB and reviewed by WW. Data was extracted
32 for the following domains: year of publication, study design, ethnicity, aim of study, study
33 setting (community/primary care/hospital), eligibility criteria, participants
34 (patient/carer/healthcare staff), type of dementia, age of participants, sample size, main
35 findings.
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42 43 *Data synthesis*

44 Studies were grouped into categories according to their primary focus (AB, CK, WW):
45 prevalence and characteristics; service organisation and delivery; views and experiences;
46 validation, screening and diagnosis. All data are reported in a narrative format. As this is a
47 scoping review there is no formal review of the quality of the included literature.^{8,9}
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Results

Description of included studies

The initial search identified 9085 studies, 6481 after duplicates were removed. Screening of the titles and abstracts left 120 studies that met the criteria for full text review, 25 were then selected for inclusion.¹⁰⁻³⁴ To update the review the search was rerun in June 2017; 1 new paper was found to be eligible for inclusion, bringing the total number of included studies to 26.³⁵ Figure 1 shows the flow of study selection and numbers of excluded studies with reasons.³⁶

Table 1 shows a summary of the findings for all 25 included studies. For the purpose of narrative review we grouped the studies into six categories: prevalence and characteristics; diagnosis validation and screening; knowledge, understanding and attitudes; help-seeking; experience of dementia; service organisation and delivery.

Prevalence and Characteristics

We identified four articles that had looked at either the prevalence or characteristics of dementia in UK South Asians.^{12,15,25,33}

Bhatnagar (1997) looked at the prevalence of dementia in a community sample of people from the Indian subcontinent living in Bradford, UK.¹² Diagnostic interviews were conducted with 100 participants and the prevalence of dementia was reported as 4%. However, the reliability of the diagnosis when tested using a Hindi translation of the Geriatric Mental State (GMS-A), which found a prevalence of 7%, was poor. The authors suggest that this is due to a lack of cultural adaptation of the measure. For example some interviewees would have little understanding of western calendar months, a knowledge of which forms part of the screening measure.¹²

Two articles reported characteristics of ethnic elders from the Indian subcontinent living in west London and attending a psychogeriatric service.^{25,33} Both published reports were from the same sample population, the first consisting of cross sectional data from a census conducted in August 1995,³³ and the second a two year study of all new cases entering the

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3 service between August 1995 and July 1997.²⁵ Sample sizes were small with South Asians
4 making up only 12%²⁵ and 17%³³ of the total number of recruited participants. Redelinghuys
5 et al. 1997³³ found that only a small subsample of participants had dementia, with no
6 significant difference found between those from the Indian subcontinent (n=6, 15%) and
7 white British elders (n=43, 22%). However, Odutoye et al. 1999 [24] reported that over that
8 time period there was a significant difference in the incidence of dementia with elders from
9 the Indian subcontinent being less likely to have a dementia.
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16 Haider et al. (2004) conducted a study of the behavioural and psychological signs and
17 symptoms of dementia using the Behavioural Pathology in Alzheimer's disease Rating Scale
18 (BEHAVE-AD) rating scale.^{15,37} They compared a sample of patients from the Indian
19 subcontinent with a White British sample living in West London. They did not find any major
20 differences between the two groups.
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27 In summary studies have attempted to identify the prevalence of dementia in South Asians
28 living in the UK. Most have reported that there is no difference in the prevalence between
29 South Asian and White British participants. However, sample sizes in these studies have
30 been unanimously small and the studies are over 14 years old, therefore it is difficult draw
31 conclusions about the definitive prevalence.
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38 *Diagnosis, Validation & Screening*

39 Three papers were identified that discussed diagnosis of dementia in UK South Asians or
40 validation of screening tools. Firstly, Shah et al. (1998) investigated the stability of dementia
41 diagnosis over time in a Gujarati population in Leicester using a Gujarati version of the Mini-
42 Mental State (MMSE) examination.²⁹ They reported that the diagnosis of dementia was
43 stable at follow-up over a period of more than 2 years (26-32 months) which indicates that
44 the measure has good test-retest reliability in this population.
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51 Secondly, two studies were identified which had looked to validate the MMSE dementia
52 screening instrument for use in the UK South Asian population. Lindsay et al. (1997)
53 investigated whether a Gujarati version of the MMSE could be used as a screening
54 instrument.²² They reported that the MMSE performed well in the identification of
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3 moderate to severe dementia but was less effective in detecting cases of mild dementia in
4 the Gujarati group when compared to a group of White British participants. Similarly, Rait et
5 al. (2000) tested the MMSE in a population of South Asians, including Gujarati and Pakistani
6 participants.²⁷ They found high levels of sensitivity and specificity for the MMSE but with a
7 lower cut-off score for the identification of mild dementia in the South Asian group.
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10 Findings indicate that the Gujarati version of the MMSE may be effective at identifying
11 dementia, especially where the diagnosis is certain and therefore symptoms are moderate
12 to severe. However, it may be less effective in identifying dementia where symptoms are
13 mild or diagnosis is uncertain.
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19 *Knowledge, Understanding, and Attitudes*

20 We identified six studies which had set out to understand knowledge, understanding and
21 attitudes to dementia in the UK South Asian community. Knowledge about dementia in
22 Indian (n=91) and White UK/Irish/European (n=55) people was assessed using the Dementia
23 Knowledge Questionnaire (DKQ) by Purandare et al.²⁶ They found that both groups had poor
24 knowledge of causes and symptoms, and Indian older people had significantly less 'basic
25 knowledge' about dementia. Here the authors define 'basic knowledge as including
26 knowledge of epidemiology, aetiology, and symptomatology as measured by the Dementia
27 Knowledge Questionnaire (DKQ).³⁸ A further series of focus groups investigated general
28 population knowledge of dementia with 28 Sikh participants.³¹ Again they found poor
29 knowledge of dementia and that Sikh participants placed greater emphasis on physical
30 illnesses than disorders such as dementia. La Fontaine held focus groups with a population
31 sample of 49 Punjabi Indian participants.¹⁹ One of their key findings was the failure of
32 participants to directly refer to dementia or even to use lay terms to discuss it which the
33 authors conclude indicates a lack of recognition of dementia as a concept.
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50 Turner et al. (2005) explored knowledge and attitudes to dementia in a qualitative
51 community study of South Asian (n=96) and White older people (n=96) and also found
52 reduced knowledge of dementia in the South Asian group. Furthermore, their findings
53 highlighted differences in attitudes to dementia care, with the South Asian group reporting
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3 that care should be provided by family and friends.³² In interviews with 10 South Asian
4 family carers Lawrence et al. (2008) looked at traditional versus non-traditional care giver
5 ideology.²⁰ The majority of South Asian carers possessed a traditional ideology in that they
6 saw care giving as natural, expected, and virtuous. However, where understanding of
7 dementia is poor problems can occur within the family caring relationship due to beliefs
8 about the causes of dementia in the South Asian community and the attribution of blame on
9 to the person with dementia.¹⁰

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16 Adamson et al. (2005) interviewed 15 South Asian carers living in five cities across the UK.¹⁰
17 The study looked at the relationship between individual experiences, cultural factors and
18 social structures within this minority population. Carers tended to interpret their caring
19 roles as an expected part of their cultural heritage and a continuation of their family
20 relationships. They also likened the experiences of this group to other chronic illness care
21 and suggest that the understanding of the experiences of chronic care may be useful in
22 understanding experiences in informal care for dementia.

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30 In summary, several studies have explored the knowledge of dementia and beliefs and
31 attitudes to care in UK South Asians. All report that knowledge is poor and this group are
32 often more focussed on physical illness rather than conditions such as dementia. Care is
33 preferred to be provided by family and within the community and therefore, UK South
34 Asians may not access formal healthcare for dementia. Giebel et al. (2016) have adapted the
35 Barts Explanatory Model Inventory Checklist (BEMI-C) for use with South Asian ethnic
36 minority groups (BEMI-Dementia).³⁵ They conducted 25 qualitative interviews with South
37 Asians and identified 123 new perceptions around their understanding of dementia. These
38 were added to the BEMI-C to create a new checklist (BEMI-D) to better assess the barriers to
39 dementia service uptake in this group.

40 41 42 43 44 45 46 47 48 49 *Help-seeking*

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51 Five papers were identified that focused on different aspects of help-seeking for dementia
52 in the UK South Asian population.
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3 Two studies had looked at barriers to help-seeking for dementia. Firstly, in a community
4 sample of English or Bengali speaking UK South Asians who did not have a diagnosis of
5 dementia Mukadam et al (2015) identified the barriers and facilitators to help-seeking for
6 memory problems.²⁴ They identified four main categories of barriers which interacted to
7 prevent timely diagnosis of dementia: barriers to help-seeking for memory problems; the
8 threshold for seeking help for memory problems; ways to overcome barriers to help-
9 seeking; what features an educational resource should have. Secondly, Hailstone et al.
10 (2016) devised and validated a theory of planned behaviour (Attitudes of People from Ethnic
11 Minorities for Help-seeking for Dementia: APEND) questionnaire to predict medical help-
12 seeking for dementia in UK South Asians.¹⁶ They found that attitudes to dementia predicted
13 77% of variance in help-seeking with the strongest predictor being perceived social
14 pressure.

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16 Furthermore, there were two studies which had specifically identified religious explanations
17 as barriers to help-seeking for dementia in South Asians. Mackenzie et al. (2006)
18 interviewed 11 Pakistani and 5 Indian carers and found that stigma resulted from religious
19 and magical beliefs around the causes of dementia and resulted in concealment from their
20 own community and delays in help-seeking.²³ Giebel et al. (2016) looked at the differences
21 in the perceptions of South Asians who do and do not consult a General Practitioner (GP)
22 about dementia.¹⁴ They found those who did not consult a GP were significantly more likely
23 to consider memory problems as given by god, with the view that medical intervention was
24 therefore inappropriate. In a case study of a Muslim, Pakistani patient accessing healthcare
25 for dementia in the UK, Regan et al. (2016) further highlight the importance of
26 understanding a person's religious community and its role in providing both support and
27 reducing stigma and isolation.³⁴

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29 The included studies highlight that attitudes and beliefs about dementia can serve as
30 barriers to accessing healthcare, in particular understanding dementia within a religious
31 context can delay help seeking. However, religious communities can also play a vital role in
32 supporting patients with dementia and in reducing stigma. This may be the case across
33 other ethnic minority communities in the UK, not just South Asians. It is therefore important
34 to learn more about the religious context in which people understand dementia and for

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3 healthcare providers to engage with local communities and religious leaders in order to
4 work in partnership with them to increase support and reduce stigma.
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8 *Experiences of Dementia* 9

10 We identified three articles that looked at understanding the experience of dementia for UK
11 South Asians. Bowes et al 2003 explored the experiences of South Asian patients with
12 dementia in Scotland.¹³ Interviews were conducted with 11 health professionals, and four
13 case studies were built up through multiple interviews with 4 people with dementia, as well
14 as interviews with their family and carers. The authors reported overwhelmingly negative
15 experiences of dementia and of health services from the case studies. From the interviews
16 with health professionals the authors concluded that there was a need to develop and
17 promote culturally sensitive services. Furthermore, the article by Jutlla (2015) looked at the
18 experiences of 12 Sikh carers, caring for a family member with dementia, in
19 Wolverhampton.¹⁷ In particular they looked at the influences of migration experiences and
20 migration identities. They found that knowledge a person's background and experiences is
21 important for understanding how they then experience health services and caring roles. This
22 is presented as an advocate, not just for culturally appropriate services, but also for person-
23 centred dementia care.
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36 Lawrence et al. (2011) looked at experiences of dementia in three ethnic groups, 11 Black
37 Caribbean, 9 South Asian and 10 White British older people with dementia.²¹ The paper
38 reported a comparison in the personal experiences of the condition in the three groups.
39 They reported similar themes across groups with a key finding being that patients assessed
40 their condition by the degree to which it interfered with 'valued elements of life'. The
41 authors concluded that development of culturally sensitive approaches to care should
42 promote roles, relationships and activities that the patient values.
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50 *Service Organisation and Delivery* 51

52 We found three articles that discussed service organisation and delivery for South Asian
53 patients with dementia in the UK. Firstly, in 1999 Shah, a Gujarati Psychogeriatrician,
54 published a descriptive account of his own experiences working with 12 Gujarati patients in
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3 their language.³⁰ Four of the patients had a diagnosis of dementia. He identified particular
4 problems in eliciting cognitive symptoms due to problems with the translation and the lack
5 of culturally appropriate assessments.³⁰ Secondly, Kaur et al. (2010) writes about the role an
6 Asian link nurse for Punjabi speaking people of Asian origin in a dementia service in
7 Wolverhampton.¹⁸ The authors reported success in providing appropriate and culturally
8 sensitive help and information for healthcare professionals, voluntary services, and South
9 Asian patients with dementia. Thirdly, Seabrooke and Milne (2009) discuss the Dementia
10 Collaborative Project in North West Kent which aimed to raise awareness of memory
11 problems in South Asians and facilitate access to screening and diagnosis.²⁸ The authors
12 reported an increase in referrals to a specialist clinic for memory assessments, some of
13 which were for South Asian patients, and an increase in health professional's knowledge of
14 memory problems in South Asians.
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Discussion

This review has scoped and synthesised the available literature on dementia in the UK South Asian population. We identified 26 studies which we found focussed on prevalence, diagnosis and screening, knowledge and attitudes, help seeking, experience, and service organisation and delivery. Overall, this review highlight that research on dementia in UK South Asians is limited.

There have been few studies of the prevalence of dementia within UK South Asians and where studies have set out to identify prevalence, sample sizes have been small. Furthermore, studies of dementia prevalence in South Asians are old, with the most recent being published in 2004.¹⁵ There is a need for large epidemiological studies of dementia in UK South Asians in order to confirm the prevalence nationally. There is also a need for studies embedded within epidemiological work that can explore the current experience of South Asians with dementia in the context of dementia healthcare.

We found only two studies that aimed to validate the MMSE screening tool within the UK South Asian population.^{22,27} These two studies limited South Asians to a screening process with no access to receiving a confirmed diagnosis. We did not identify any studies that had addressed the introduction and validation of a purely diagnostic assessment for UK South Asians, such as the Addenbrooke's Cognitive Examination Version III or the Motreal Cognitive Assessment.^{39,40} This compromises current knowledge of dementia prevalence within in UK South Asians, as without a culturally appropriate, validated diagnostic assessment individuals cannot be diagnosed. The lack of a culturally adapted and validated diagnostic tool risks that UK South Asians who enter into the diagnostic process will receive higher rates of false positive or false negative scores. This invalidates the current diagnoses given to UK South Asians.

Most of the existing research has been conducted in the community which reflects the fact that UK South Asians do not often access formal healthcare services for memory problems. We need to develop culturally sensitive screening tools, diagnostic tests, and interventions whilst also engaging communities. It is important to develop interventions in parallel with

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3 community engagement to ensure that there are culturally appropriate services ready to be
4 accessed if engagement is successfully increased.⁶
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8 We were unable to identify a single clinical trial of an intervention for dementia in the UK
9 South Asian population, either amongst patients or carers. This highlights a critical gap in
10 ongoing dementia research and indicates a neglect of 5.3% of the UK population that
11 identify as South Asian and calls into question whether it is appropriate to implement
12 existing interventions for this ethnic group without any assessment of their feasibility,
13 acceptability, and effectiveness.³ This review has identified a number of different views and
14 perceptions held about dementia by UK South Asians. Therefore, existing interventions need
15 to be adapted or new interventions which can accommodate for these differences need to
16 be developed for this particular population.
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25 This review has highlighted factors which impact on our ability to conduct intervention trials
26 in this population; these may include issues surrounding diagnosis and the lack of
27 appropriately validated diagnostic instruments, as well as attitudes and beliefs about
28 dementia which may affect recruitment. Much of the qualitative work identified in this
29 review has highlighted the religious explanations by which the South Asian community often
30 understand symptoms of dementia. Studies report that this causes a barrier to help seeking
31 and will result in delayed treatment. Furthermore, due to religious explanatory models for
32 dementia patients and family carers often perceive treatment as inappropriate. Culturally
33 sensitive community engagement work is needed to engage the South Asian community and
34 encourage understanding of dementia. New interventions should also acknowledge and
35 include the family approach to care which is seen as of paramount importance in the South
36 Asian community.
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47 We suggest that undertaking the cultural adaptation and validation of diagnostic
48 assessments within UK South Asians would improve the diagnostic process. From our
49 findings relating to service organisation and delivery we can see strategies emerging that
50 may increase engagement from this population, such as the ethnic matching of staff and
51 increasing engagement work with South Asian community. These strategies should now be
52 considered when designing clinical trials to test culturally adapted interventions.
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3 This review is the first review to scope all of the literature on dementia in the UK South
4 Asian population. We scoped the literature in line with the guidelines for scoping reviews
5 and conducted a systematic search of the literature.⁹ It is possible that there are other
6 studies that were not identified as part of this search; in part this could be due to a lack of
7 standardisation of the terminologies used in the literature.
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13 The purpose of this review was to map the literature and to provide a useful framework to
14 guide future research directions. It is not designed to provide a definitive answer in any of
15 the key themes discussed because there are important differences across the included
16 studies (e.g. quality, design, and population) which were not extensively evaluated.
17 However, given that this area is under-investigation this scoping review is particularly suited
18 because it can provide a comprehensive account of current progress and challenges which
19 can be used to develop future research and priorities to improve care for UK South Asians.
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26 27 28 *Conclusion*

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30 A number of studies have been published on dementia in the UK South Asian population.
31 However, studies of prevalence, diagnosis, and service organisation and delivery are limited.
32 We found no clinical trials of culturally appropriate interventions for South Asians with
33 dementia in the UK. The existing evidence comes from small scale service evaluations and
34 case studies.
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41 Future research efforts should concentrate on developing and validating culturally
42 appropriate diagnostic tools for UK South Asians. Epidemiological studies are needed to
43 accurately identify the prevalence of dementia in this group. Cultural adaptation and clinical
44 trials of appropriate interventions are needed to run in parallel to diagnosis and community
45 engagement work to ensure there are effectiveness and acceptable treatments for South
46 Asians to access once identified with dementia.
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References

- 1 Alzheimer's Disease International. *Policy Brief for G8 Heads of Government. The Global Impact of Dementia 2013-2050*, <http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf> (2013).
- 2 World Health Organisation. *the Epidemiology and Impact of Dementia: Current state and future trends*, <http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf> (2015).
- 3 Office for National Statistics. *Ethnicity and National Identity in England and Wales*, <<https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/article/s/ethnicityandnationalidentityinenglandandwales/2012-12-11>> (2012).
- 4 All-Party Parliamentary Group on Dementia. *Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities*, <https://www.alzheimers.org.uk/download/downloads/id/1857/appg_2013_bame_report.pdf> (2013).
- 5 Khan, F. & Tadros, G. Complexity in cognitive assessment of elderly British minority ethnic groups: Cultural perspective. *Dementia* **13**, 467-482, doi:doi:10.1177/1471301213475539 (2014).
- 6 Kenning, C., Daker-White, G., Blakemore, A., Panagioti, M. & Waheed, W. Barriers and facilitators in accessing dementia care by ethnic minority groups: a meta-synthesis of qualitative studies. *BMC Psychiatry* **17**, 316, doi:10.1186/s12888-017-1474-0. (2017).
- 7 Regan, J. L. Redefining dementia care barriers for ethnic minorities: The religion-culture distinction. *Mental Health, Religion & Culture* **17**, 345-353, doi:<http://dx.doi.org/10.1080/13674676.2013.805404> (2014).
- 8 Arksey, H. & O'Malley, L. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* **8**, 19-32 (2007).
- 9 Levac, D., Colquhoun, H. & O'Brien, K. Scoping studies: advancing the methodology. *Implementation Science* **5**, 69 (2010).
- 10 Adamson, J. Awareness and understanding of dementia in African/Caribbean and South Asian families. *Health Soc Care Community* **9**, 391-396 (2001).
- 11 Adamson, J. & Donovan, J. 'Normal disruption': South Asian and African/Caribbean relatives caring for an older family member in the UK. *Social Science and Medicine* **60**, 37-48 (2005).
- 12 Bhatnagar, K. & Frank, J. Psychiatric disorders in elderly from the Indian sub-continent living in Bradford. *International Journal of Geriatric Psychiatry* **12**, 907-912 (1997).
- 13 Bowes, A. & Wilkinson, H. 'We didn't know it would get that bad': South Asian experiences of dementia and the service response. *Health Soc Care Community* **11**, 387-396 (2003).
- 14 Giebel, C. *et al.* Perceptions of self-defined memory problems vary in south Asian minority older people who consult a GP and those who do not: A mixed-method pilot study. *International Journal of Geriatric Psychiatry* **31**, 379-387 (2016).
- 15 Haider, I. & Shah, A. A pilot study of behavioural and psychological signs and symptoms of dementia in patients of Indian sub-continent origin admitted to a dementia day hospital in the United Kingdom. *International Journal of Geriatric Psychiatry* **19**, 1195-1204 (2004).
- 16 Hailstone, J., Mukadam, N., Owen, T., Cooper, C. & Livingston, G. The development of attitudes of people from ethnic minorities to help-seeking for dementia (append): A questionnaire to measure attitudes to help-seeking for dementia in people from south asian backgrounds in the uk. *International Journal of Geriatric Psychiatry* Mar, No Pagination Specified, doi:<http://dx.doi.org/10.1002/gps.4462> (2016).
- 17 Jutla, K. The impact of migration experiences and migration identities on the experiences of services and caring for a family member with dementia for Sikhs living in Wolverhampton,

- 1
2
3 UK. *Ageing & Society* **35**, 1032-1054, doi:<http://dx.doi.org/10.1017/S0144686X14000658>
4 (2015).
- 5 18 Kaur, H., Jutla, K., Moreland, N. & Read, K. How a link nurse ensured equal treatment for
6 people of Asian origin with dementia. *Nurs Times* **106**, 12-15 (2010).
- 7 19 La Fontaine, J., Ahuja, J., Bradbury, N. M., Phillips, S. & Oyebode, J. R. Understanding
8 dementia amongst people in minority ethnic and cultural groups. *J Adv Nurs* **60**, 605-614
9 (2007).
- 10 20 Lawrence, V., Murray, J., Samsi, K. & Banerjee, S. Attitudes and support needs of Black
11 Caribbean, south Asian and White British carers of people with dementia in the UK. *Br J*
12 *Psychiatry* **193**, 240-246, doi:<http://dx.doi.org/10.1192/bjp.bp.107.045187> (2008).
- 13 21 Lawrence, V., Samsi, K., Banerjee, S., Morgan, C. & Murray, J. Threat to valued elements of
14 life: the experience of dementia across three ethnic groups. *Gerontologist* **51**, 39-50,
15 doi:<http://dx.doi.org/10.1093/geront/gnq073> (2011).
- 16 22 Lindsay, J. *et al.* The Mini-Mental State Examination (MMSE) in an elderly immigrant
17 Gujarati population in the United Kingdom. *International Journal of Geriatric Psychiatry* **12**,
18 1155-1167 (1997).
- 19 23 Mackenzie, J. Stigma and dementia: East European and South Asian family carers negotiating
20 stigma in the UK. *Dementia: The International Journal of Social Research and Practice* **5**, 233-
21 247, doi:<http://dx.doi.org/10.1177/1471301206062252> (2006).
- 22 24 Mukadam, N., Waugh, A., Cooper, C. & Livingston, G. What would encourage help-seeking
23 for memory problems amongst South Asians? A qualitative study. *International*
24 *Psychogeriatrics* **27**, S57-S58 (2015).
- 25 25 Odutoye, K. & Shah, A. The characteristics of Indian subcontinent origin elders newly
26 referred to a psychogeriatric service. *International Journal of Geriatric Psychiatry* **14**, 446-
27 453 (1999).
- 28 26 Purandare, N., Luthra, V., Swarbrick, C. & Bums, A. Knowledge of dementia among South
29 Asian (Indian) older people in Manchester, UK. *International Journal of Geriatric Psychiatry*
30 **22**, 777-781, doi:<http://dx.doi.org/10.1002/gps.1740> (2007).
- 31 27 Rait, G. *et al.* Validating screening instruments for cognitive impairment in older South
32 Asians in the United Kingdom. *International Journal of Geriatric Psychiatry* **15**, 54-62 (2000).
- 33 28 Seabrooke, V. & Milne, A. Early intervention in dementia care in an Asian community:
34 Lessons from a dementia collaborative project. *Quality in Aging* **10**, 29-36 (2009).
- 35 29 Shah, A., Lindsay, J. & Jagger, C. Is the diagnosis of dementia stable over time among
36 elderly immigrant Gujaratis in the United Kingdom (Leicester)? *International Journal of*
37 *Geriatric Psychiatry* **13**, 440-444 (1998).
- 38 30 Shah, A. Difficulties experienced by a Gujarati geriatric psychiatrist in interviewing Gujarati
39 elders in Gujarati. *International Journal of Geriatric Psychiatry* **14**, 1072-1074 (1999).
- 40 31 Uppal, G. K., Bonas, S. & Philpott, H. Understanding and awareness of dementia in the Sikh
41 community. *Mental Health, Religion & Culture* **17**, 400-414,
42 doi:<http://dx.doi.org/10.1080/13674676.2013.816941> (2014).
- 43 32 Turner, S., Christie, A. & Haworth, E. South Asian and white older people and dementia: a
44 qualitative study of knowledge and attitudes. *Diversity in Health and Social Care* **2**, 197-209
45 (2005).
- 46 33 Redelinguys, J. & Shah, A. The characteristics of ethnic elders from the Indian subcontinent
47 using a geriatric psychiatry service in West London. *Aging and Mental Health* **1**, 243-247
48 (1997).
- 49 34 Regan, J. L. Ethnic minority, young onset, rare dementia type, depression: A case study of a
50 Muslim male accessing UK dementia health and social care services. *Dementia* **15**, 702-720,
51 doi:doi:10.1177/1471301214534423 (2016).
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2
3 35 Giebel, C. *et al.* Adaptation of the Barts explanatory model inventory to dementia
4 understanding in South Asian ethnic minorities. *Aging and Mental Health* **20**, 594-602
5 (2016).
- 6 36 Moher, D., Liberati, A., Tetzlaff, J., Altman, D. & Group, T. P. Preferred reporting items for
7 systematic reviews and meta-analysis: The PRISMA statement *PLoS Medicine* **6**, e1000097,
8 doi:10.1371/journal.pmed1000097 (2009).
- 9 37 Reisberg, B. *et al.* Behavioral symptoms in Alzheimer's disease: phenomenology and
10 treatment. *Journal of Clinical Psychiatry* **48** (1987).
- 11 38 Graham, C., Ballard, C. & Sham, P. Carers' knowledge of dementia and their expressed
12 concerns. *International Journal of Geriatric Psychiatry* **12**, 470 (1997).
- 13 39 Mathuranath, P., Nestor, P., Berrios, G., Rakowicz, W. & Hodges, J. A brief cognitive test
14 battery to differentiate between Alzheimer's disease and frontotemporal dementia.
15 *Neurology* **55**, 1613-1620 (2000).
- 16 40 Nasreddine, Z. *et al.* The Montreal Cognitive Assessment, MoCA: A brief screening tool for
17 mild cognitive impairment *Journal of the American Geriatric Society* **53**, 695-699 (2005).
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Figure 1: Flow of included studies ³⁶

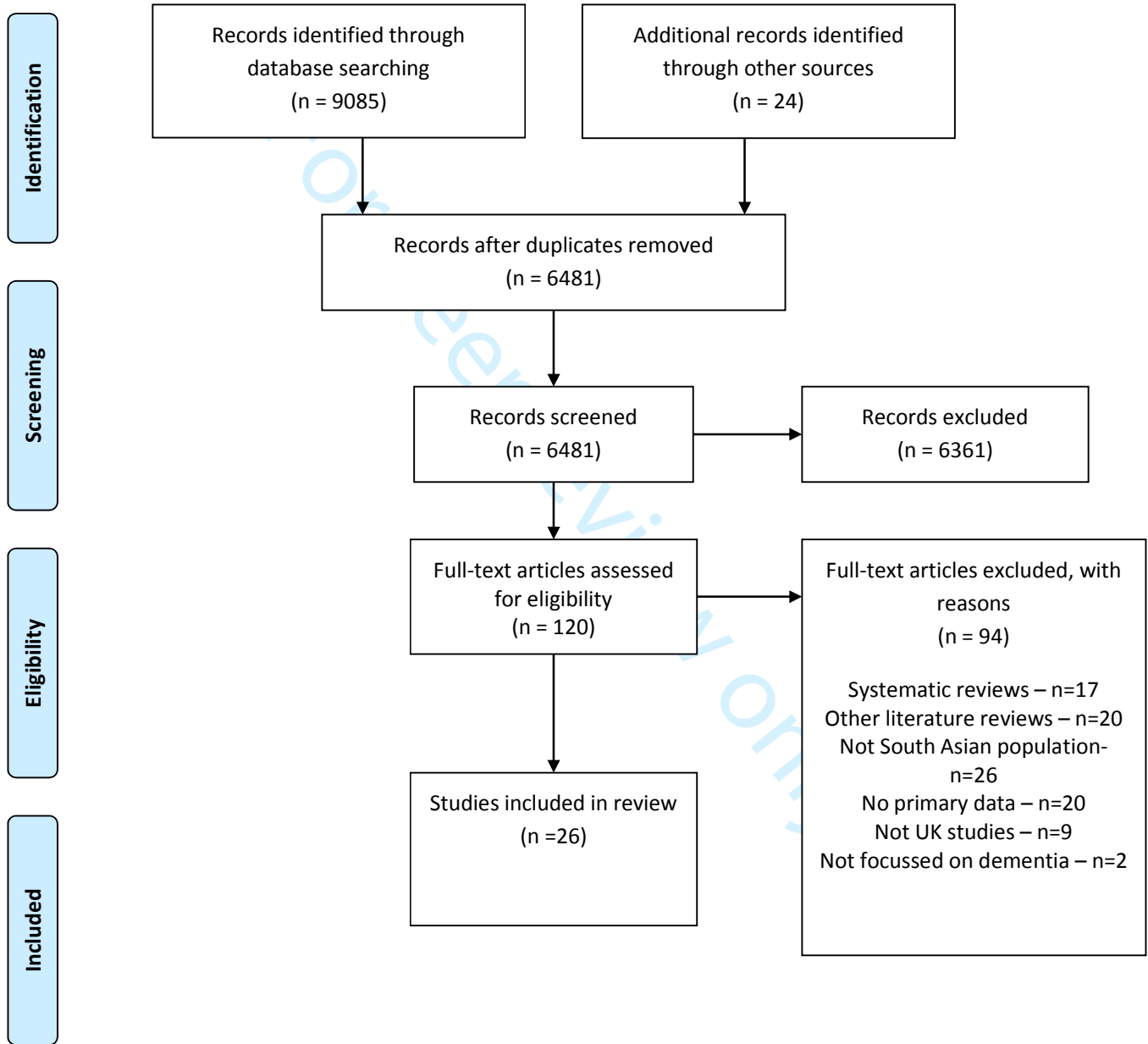


Table 1: Summary of characteristics and findings of included studies

Author	Year	Study Design	Total Sample Size	Sample	Setting	Summary of Main Findings
Adamson et al. ¹⁰	2001	Qualitative	30	n=12 (40%) South Asian carers of people with dementia.	Healthcare services (carer support, day centres, psychiatric services)	Lack of knowledge of dementia found in South Asian group. South Asian participants talked about symptoms being a result of past actions in life and apportioning blame. They also believed that other physical conditions and their associated medications could cause dementia, such as antidepressants for depression.
Adamson et al. ¹¹	2005	Qualitative	36	n=15 (42%) South Asian carers of people with dementia	Community	South Asian participants talked about caring for family as a cultural norm and wider families were more likely to live together to facilitate this.
Bhatnagar et al. ¹²	1997	Cross-sectional study	100	Aged 65-89y, from Indian subcontinent and living in Bradford	Community	Prevalence of dementia 4% as diagnosed by psychiatrist and 7% using Hindi translation of diagnostic measure (GMS-A).
Bowes et al. ¹³	2003	Qualitative	11	11 interviews with carers 4 case studies of South Asian patients	Community	Carer interviews: demand for services, a need to develop awareness and knowledge in the community, and to promote a culturally sensitive response from services. Case studies: negative experiences of dementia, poor quality of life, need for support, lack of access to appropriate services, little knowledge about dementia, isolation from both community and family life.
Giebel et al. ¹⁴	2016	Mixed method pilot	33	3 groups - South Asian, over 60y: without memory problems; memory problems not consulted GP; memory problems had consulted GP	Community	Those who had not consulted a GP often considered memory problems to be given by God and did not identify medical support as appropriate for them. Those who had attended a consultation with GP identified forgetfulness and loss of social meaning as symptoms of dementia

Author	Year	Study Design	Total Sample Size	Sample	Setting	Summary of Main Findings
Giebel et al. ³⁵	2016	Questionnaire validation	25	n=25 South Asian	Community	123 new perceptions around South Asian their understanding of dementia were identified. These were added to the BEMI-C to create a new checklist (BEMI-D).
Haider et al. ¹⁵	2004	Pilot study	62	n=31 South Asian, aged 65-96y n=31 White British, aged 65-90y	Day Hospital	South Asian participants score lower on the BEHAVE-AD phobia and anxiety subscale. Alzheimer's disease associated with vascular dementia with affective disturbance.
Hailstone et al. ¹⁶	2016	Questionnaire Validation	58	Mean age 60y 59% female (n=34) 1 st and 2 nd generation South Asians	Community	Strongest predictor of willingness to seek help for dementia was perceived social pressures from significant others. Attitudes in the questionnaire predicted 77% of variance in willingness to seek help, but no relationship was found with dementia knowledge.
Jutlla et al. ¹⁷	2015	Qualitative	12	South Asian Sikhs caring for someone with dementia and living in Wolverhampton, UK	Community	Understandings participant's migration experiences and identities is important for understanding family carers experience of services when caring for someone with dementia.
Kaur et al. ¹⁸	2010	Service Evaluation	N/A	An Asian Link Nurse working in Wolverhampton, UK	Community Mental Health Team	Having an Asian Link Nurse was vital in providing education about dementia for South Asian people.
La Fontaine et al. ¹⁹	2007	Qualitative	49	South Asians aged 17-60y who were English, Hindi or Punjabi speaking	Community	Interviews highlighted that cognitive impairment was rarely mentioned when talking about ageing. Ageing was seen as a time of withdrawal and isolation. There was a sense of stigma and a lack of knowledge about mental health services which leads to exclusion from these services.
Lawrence et al. ²⁰	2008	Qualitative	32	n=10 (31%) South Asian carers of people with	Community	South Asian carers possessed a traditional caregiver ideology, conceptualising caregiving as natural,

Author	Year	Study Design	Total Sample Size	Sample	Setting	Summary of Main Findings
				dementia		expected and virtuous. This informed their attitudes towards formal healthcare services.
Lawrence et al. ²¹	2011	Qualitative	30	n=9 (30%) South Asian Aged 67-87y	Mental Health Services	Interviews highlighted that participants engaged in a process of appraisal where they assessed how much their condition affected valued elements of their life.
Lindesay et al. ²²	1997	Questionnaire Validation	1297	n=149 (11%) South Asian, Gujarati	General Practice	Mean MMSE scores were lower in the Gujarati group due to the effects of age, education and visual impairment. The MMSE performed comparably in both groups as a screen for moderate to severe dementia but was less effective for Gujarati's with mild dementia.
Mackenzie et al. ²³	2006	Qualitative	21	n=16 (76%) South Asian carers of people with dementia	Community	In the South Asian group stigma was linked to religious and magical explanations for the onset of dementia which affected carers ability to access support.
Mukadam et al. ²⁴	2015	Qualitative	53	South Asians aged 18-83y	Community	Stigma around dementia was linked to ideas of 'madness' a lack of physical explanations and a lack of treatment. Barriers to help seeking were that memory problems were an inevitable part of ageing. Denial of symptoms was evident in order to maintain position in the family and community, and due to fear of institutionalisation.
Odutoye et al. ²⁵	1999	Cross Sectional Study	242	n=29 (12%) South Asians newly referred to psychogeriatric unit between 1995-1997 aged 58-96y	Psycho-Geriatric Unit	South Asians were less likely to have dementia than White British elders ($\chi^2 = 5.05$, 1df, $P < 0.03$).
Purandare et al. ²⁶	2007	Cross Sectional	246	n=191 (78%) South Asian, mean age 72.4y	Community – day centre	Knowledge of dementia was poor in both South Asian and White British people. South Asians had less

Author	Year	Study Design	Total Sample Size	Sample	Setting	Summary of Main Findings
		Study		(sd 10.6).		knowledge about basic aspects of dementia ($p<0.001$) and the epidemiology of dementia ($p<0.001$) as compared to White British people.
Rait et al. ²⁷	2000	Validation of Screening Instrument	120	Community resident South Asians aged over 60y. n=65 Gujarati speaking, mean age 70y (sd 6.8) n=39 Pakistani group, mean age 68y (sd 6.0)	Community	Both modified screening tests (MMSE and AMT) had high sensitivity scores but ethnic background was found to influence the cut-off scores for these measures. The MMSE cut-off score was found to be significantly higher in the Pakistani group (≥ 27 , sensitivity 100%, specificity 95%) compared with the Gujarati group (≥ 24 , sensitivity 100%, specificity 77%).
Regan et al. ³⁴	2016	Case Study	N/A	Case study of a male Muslim patient with young onset fronto-temporal dementia	Dementia Services	Mostly negative experiences of accessing services and an inability to access support from either family or the religious community. Services not equipped to support people with young onset dementia from an ethnic minority.
Seabrooke et al. ²⁸	2009	Service Pilot	4	South Asian patients aged 65-93y with memory problems	Primary Care	Inviting older Asian patients with memory problems to see a specially trained Asian nurse using a culturally appropriate information leaflet encouraged a small number of people to access the service.
Shah et al. ²⁹	1998	Longitudinal	11	Gujarati people over 65y living in Leicester, UK	Community	Seven of the 11 followed-up (64%). Diagnosis of dementia was reconfirmed in 6 out of 7 cases (86%) and there was evidence of further cognitive decline.
Shah et al. ³⁰	1999	Case Study – descriptive methodology	12	Gujarati patients (aged 65-90y) seen by Gujarati Psychogeriatrician.	Psycho-Geriatric Unit	n=4 (33%) with diagnosis of dementia. Difficulties interviewing Gujarati patients reported. Identifying cognitive signs and symptoms reported as most difficult. Few patients speak English and majority could not read or write.
Uppal et al. ³¹	2014	Qualitative	28	Sikh participants over 18y	Community	Three key themes: awareness and interpretation of the characteristics of dementia; multiple perspectives of

Author	Year	Study Design	Total Sample Size	Sample	Setting	Summary of Main Findings
				Able to speak either Punjabi and/or English		the same symptoms; and causes of dementia.
Turner et al. ³²	2005	Qualitative	192	n=96 (50%) South Asian, aged 58-85y.	Community	South Asian people had less specific knowledge of dementia and believed that dementia was a normal part of ageing. Also less likely to think that medical treatment was available. Care was seen as provided by the family in the first instance.
Redelinghuys et al. ³³	1997	Cross Sectional Study	235	n=39 (17%) South Asians, aged 65-95y using a geriatric psychiatry service in South London.	Geriatric Psychiatry	n=6 (15%) of the South Asian group had dementia compared with n=43 (22%) of the White British elders. There were no differences found between the two groups in terms of use of health and social services.

GMS-A – Geriatric Mental State; BEHAVE-AS – Behavioural Pathology in Alzheimer’s Disease Rating Scale; MMSE – Mini Mental State Examination; AMT – Abbreviated Mental Test; BEMI-D – Barts Explanatory Model Inventory Checklist; BEMI-D – Barts Explanatory Model Inventory Dementia.

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Competing Interest Statement

The authors declare they have no competing interests.

Author Contribution

AB and CK ran the search and screened papers. AB, CK, GDW, MP, WW identified and agreed eligible papers. AB wrote the paper and CK, GDW, MP, NM, WW edited and revised the paper for critical content.

Data Sharing Statement

No additional data are available.

Ovid Medline(R) 1946 to April Week 2 2016

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Search History (9)

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Dementia in UK South Asians: A scoping review of the literature

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1 **Dementia in UK South Asians: A scoping review of the literature**

2 **Running head:** Dementia in UK South Asians

3 **Key Words:** Dementia, United Kingdom, South Asian, Scoping Review

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42 **Word Count:** 4892

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3 44 **Abstract (299 Words)**
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5 45 *Objective*

6 46 Over 850,000 people live with dementia in the United Kingdom (UK). A proportion of these
7 47 people are South Asians, who make up over 5% of the total UK population. Little is known
8 48 about the prevalence, experience, and treatment of dementia in the UK South Asian
9 49 population. The aim of this scoping review is to identify dementia studies conducted in the
10 50 UK South Asian population to highlight gaps in the literature which to be addressed in future
11 51 research.
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18 53 *Method*

19 54 Databases were systematically searched using a comprehensive search strategy to identify
20 55 studies. A methodological framework for conducting scoping reviews was followed. An
21 56 extraction form was developed to chart data and collate study characteristics and findings.
22 57 Studies were then grouped into six categories: prevalence and characteristics; diagnosis
23 58 validation and screening; knowledge, understanding and attitudes; help-seeking; experience
24 59 of dementia; service organisation and delivery.
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32 61 *Results*

33 62 A total of 6483 studies were identified, 27 studies were eligible for inclusion in the scoping
34 63 review. We found that studies of prevalence, diagnosis, and service organisation and
35 64 delivery, in UK South Asians are limited. We did not find any clinical trials of culturally
36 65 appropriate interventions for South Asians with dementia in the UK. The existing evidence
37 66 comes from small scale service evaluations and case studies.
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44 68 *Conclusions*

45 69 This is the first scoping review of the literature to identify priority areas for research to
46 70 improve care for UK South Asians with dementia. Future research should first focus on
47 71 developing and validating culturally appropriate diagnostic tools for UK South Asians and
48 72 then conducting high quality epidemiological studies in order to accurately identify the
49 73 prevalence of dementia in this group. The cultural adaptation of interventions for dementia
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3 74 and testing in randomised controlled trials is also vital to ensure that there are appropriate
4 75 treatments available for UK South Asians to access.
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77 **Strengths and Limitations of the Study**

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11 78 • The first scoping review of the literature to identify priority areas for future research
12 79 and care of UK South Asians with dementia.
13 80 • Comprehensive and systematic search which was conducted in line with published
14 81 guidelines for scoping reviews.
15 82 • A comprehensive and broad search strategy was developed however, a lack of
16 83 standardisation around some key search terms could mean some studies were not
17 84 identified.
18 85 • This review is not able to provide a definitive answer to any of the key themes
19 86 discussed but its purpose is to map the literature and provide a much needed
20 87 framework to guide future research directions for UK south Asians with dementia.
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104 Introduction

105 As the global population ages the prevalence of dementia increases; there are an estimated
106 47 million people living with dementia worldwide and this figure is set to increase to over
107 75.6 million by 2030.^{1,2} In the United Kingdom (UK) alone there are over 850,000 people
108 living with dementia at a cost of £26 billion per year.¹ The rising prevalence of dementia and
109 its associated cost and burden has generated an increased focus on the timely screening,
110 diagnosis, and treatment of dementia.

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112 Ethnic minority groups make up over 14% of the total UK population, many of whom are
113 South Asian (Pakistan, India, and Bangladesh). In the 2001 census South Asians were 3.9% of
114 the total UK population and by 2011 this figure had risen to 5.3%.³ It is estimated that there
115 are over 25,000 people from ethnic minority groups living with dementia in the UK.⁴
116 However, the true prevalence of dementia within the UK South Asian community is yet to
117 be established. As the overall prevalence of dementia in the UK increases so too will the
118 prevalence amongst the growing population of UK South Asians. Increased prevalence
119 places increased burden on health care services to understand the presentation of dementia
120 in UK South Asians in order to identify, diagnose, and treat this population.

121
122 There are difficulties in identifying, diagnosing, and treating dementia in UK ethnic minority
123 groups, including the South Asian population.^{5,6} This is due to low levels of literacy, language
124 barriers, and a lack of appropriately translated and culturally adapted screening and
125 diagnostic tools for this ethnic group.⁷ For example, in the South Asian community only 35%
126 of older people (aged over 65 years) can speak English and only 21% can read and write
127 English, with most relying instead on their first language which for many is Urdu.^{3,8,9} This
128 makes the completion of screening tools and diagnostic tests challenging. In addition to
129 barriers of language and literacy there is a lack of awareness about dementia within the
130 South Asian community. Many South Asian people view memory loss as a normal part of
131 ageing or understand symptoms of dementia by religious belief.⁷ This difference in the
132 understanding and explanation of the presentation of dementia may result in reduced help-
133 seeking.⁷ Lack of help-seeking prohibits early intervention and treatment which is important
134 to reduce the burden of dementia for patients, family carers, and the wider healthcare

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3 135 system.^{5,6,10} If we are to encourage UK South Asians to seek help early and improve our
4 136 ability to engage this group with formal healthcare for dementia we need to provide
5 137 culturally appropriate services for them to access. Currently there are a lack of both
6 138 culturally appropriate services and accurately translated neuropsychological assessments
7
8 139 for UK South Asians.¹¹
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13 141 In order to identify the scope of the literature on dementia in the UK South Asian population
14 142 we have conducted a scoping review. Scoping reviews are designed to assess the nature and
15 143 extent of the literature which is available on a topic.¹² The scoping process aims identify
16 144 where there are gaps in the evidence around the prevalence, identification, diagnosis, and
17 145 treatment of dementia among UK South Asians.¹³ This will then allow recommendations to
18 146 be made for future research; the results of which we hope will inform the identification,
19 147 diagnosis, and treatment of dementia in UK South Asians.
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166 **Methods**

167 To examine the literature on dementia in UK South Asians we conducted a scoping review in
168 accordance with the methodological framework for scoping reviews published by Arskey
169 and O'Malley (2007) and further developed by Levac et al. (2010).^{14,15} The Arksey and
170 O'Malley framework was found to be the most commonly used methodology for scoping
171 reviews in a systematic review of scoping reviews.¹³ The framework includes guidance on
172 the following areas which are outlined in the sections below: identifying the research
173 question, searching for relevant studies, selecting studies, charting the data, and collating
174 and summarising results.

175

176 *Inclusion criteria and exclusion criteria*

177 Studies that had included UK South Asian dementia patients were eligible for inclusion, as
178 well as those that had focused on family carers, and healthcare professionals working with
179 dementia patients. We did not exclude studies based year of publication. Published
180 dissertations were included but any unpublished dissertation was not. Systematic reviews
181 and narrative literature reviews were not included but we hand searched the reference lists
182 of all the relevant reviews which were returned in the search in order to identify additional
183 primary studies for inclusion. Conference proceedings were not included.

184

185 We excluded studies that did not report on South Asian participants alone, as a comparator
186 group, or where data could not be separated from data for participants of other ethnicities.

187 We excluded studies that were not published in the English language.

188

189 *Search strategy*

190 Search terms were kept broad to identify the maximum number of studies which were
191 eligible for inclusion. The search strategy was developed within the team to identify all
192 studies relevant to ethnicity and dementia, this was then refined through hand checking to
193 those which included UK South Asian participants. Search terms included: Dementia,
194 Alzheimer* Disease; ethnic*, Asian, Black, African, minority, ethnic group, multi-ethnic. See
195 additional material 1 for the full search strategy.

196

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2
3 197 The search was conducted without a study design filter in order to retrieve studies using all
4 198 methodologies, including: systematic reviews, qualitative studies, quantitative studies, case
5 199 studies, and service evaluations.
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10 201 The following databases were searched: Cochrane Register of Controlled Trials (CENTRAL),
11 202 MEDLINE (OVID), PsycINFO (Ovid), Embase (Ovid), Cochrane database of systematic
12 203 Reviews. The search was initially conducted in April 2016 and updated in June 2017. In
13 204 addition to the database searches, we hand searched the reference lists of all relevant
14 205 systematic reviews and literature reviews that were returned in the search to identify any
15 206 additional papers for inclusion.
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21 208 *Screening and charting the data*

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23 209 Electronic search results were managed using EndNote X7 and Microsoft Excel. Titles and
24 210 abstracts of all citations were first screened by author (AB), those that were not related to
25 211 dementia and South Asians, or had been conducted outside of the UK, were discarded. The
26 212 full text of all potentially eligible papers were then obtained and assessed against the
27 213 inclusion criteria (AB and WW). Where the full text of papers was not available authors were
28 214 contacted to request the paper. Any ambiguities about whether or not a study met the
29 215 inclusion criteria were resolved by discussion at a meeting attended by all authors.
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37 217 Studies that met the review criteria were charted using a data extraction sheet designed by
38 218 AB and WW. Data were primarily extracted by AB and reviewed by WW. Data was extracted
39 219 for the following domains: year of publication, study design, ethnicity, aim of study, study
40 220 setting (community/primary care/hospital), eligibility criteria, participants
41 221 (patient/carer/healthcare staff), type of dementia, age of participants, sample size, main
42 222 findings.
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48 223

49 224 *Data synthesis*

50
51 225 Once the pool of eligible studies was agreed we grouped them in to categories according to
52 226 their primary focus (AB, CK, WW). These categories were defined as: prevalence and
53 227 characteristics; service organisation and delivery; views and experiences; validation,
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228 screening and diagnosis. All data are reported in a narrative format. As this is a scoping
229 review there is no formal review of the quality of the included literature.^{14,15}

230

231

232 **Results**

233 *Description of included studies*

234 The initial search identified 6483 studies after duplicates were removed. Screening of the
235 titles and abstracts left 122 studies that met the criteria for full text review, 26 were then
236 selected for inclusion.¹⁶⁻⁴¹ To update the review the search was rerun in June 2017; 1 new
237 paper was found to be eligible for inclusion, bringing the total number of included studies to
238 27.⁴² Figure 1 shows the flow of study selection and numbers of excluded studies with
239 reasons.⁴³

240

241 Table 1 shows a summary of the findings for all 27 included studies. For the purpose of
242 narrative review we grouped the studies into six categories: prevalence and characteristics;
243 diagnosis validation and screening; knowledge, understanding and attitudes; help-seeking;
244 experience of dementia; service organisation and delivery.

245

246 *Prevalence and Characteristics*

247 We identified five articles that had looked at either the prevalence or characteristics of
248 dementia in UK South Asians.^{18,21,31,39,41}

249

250 Bhatnagar (1997) looked at the prevalence of dementia in a community sample of people
251 from the Indian subcontinent living in Bradford, UK.¹⁸ Diagnostic interviews were conducted
252 with 100 participants and the prevalence of dementia was reported as 4%. However, when
253 tested using a Hindi translation of the Geriatric Mental State (GMS-A) which found an initial
254 prevalence of 7%, the reliability of the diagnosis was poor. The authors suggest that this is
255 due to a lack of cultural adaptation of the measure. For example some interviewees would
256 have little understanding of western calendar months, a knowledge of which forms part of
257 the screening measure.¹⁸

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3 259 A cross-sectional study conducted in inner-city Liverpool also used the Geriatric Mental
4 260 State interview to assess the prevalence of dementia in English speaking versus non English
5 261 speaking Asian participants.⁴¹ The authors do not use the term South Asian but rather Asian.
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7
8 262 However, we have included this paper as it is clear from the categorisation of other ethnic
9
10 263 groups included in the study that Asian refers to participants from South Asia who make up
11 264 2% of the total study sample. The authors interviewed 12 Asian participants using the
12
13 265 Geriatric Mental State Examination and found a prevalence of dementia of 9% amongst the
14
15 266 English speaking sample.

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17 267
18 268 Two articles reported characteristics of ethnic elders from the Indian subcontinent living in
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20 269 west London and attending a psychogeriatric service.^{31,39} Both published reports were from
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22 270 the same sample population, the first consisting of cross sectional data from a census
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24 271 conducted in August 1995,³⁹ and the second a two year study of all new cases entering the
25
26 272 service between August 1995 and July 1997.³¹ Sample sizes were small with South Asians
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28 273 making up only 12%³¹ and 17%³⁹ of the total number of recruited participants. Dementia
29
30 274 was diagnosed by physicians and eligible patients were identified by case note review.
31
32 275 Redelinghuys et al. 1997³⁹ found that only a small subsample of participants had dementia,
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34 276 with no significant difference found between those from the Indian subcontinent (n=6, 15%)
35
36 277 and white British elders (n=43, 22%). However, Odutoye et al. 1999³¹ reported that over
37
38 278 that time period there was a significant difference in the incidence of dementia with elders
39
40 279 from the Indian subcontinent being less likely to have a dementia.

41 280
42 281 Haider et al. (2004) conducted a study of the behavioural and psychological signs and
43
44 282 symptoms of dementia using the Behavioural Pathology in Alzheimer's disease Rating Scale
45
46 283 (BEHAVE-AD) rating scale.^{21,44} They compared a sample of physician diagnosed patients
47
48 284 from the Indian subcontinent with a White British sample living in West London who had
49
50 285 been referred to a day hospital for treatment. They did not find any major differences
51
52 286 between the two groups.

53 287
54 288 In summary studies have attempted to identify the prevalence of dementia in South Asians
55
56 289 living in the UK. Most have reported that there is no difference in the prevalence between
57
58 290 South Asian and White British participants. However, sample sizes in these studies have

291 been unanimously small and the studies are over 14 years old, therefore it is difficult draw
292 conclusions about the definitive prevalence. Several studies do not report sufficient detail
293 on the methods and instruments by which dementia was diagnosed and if there was any
294 translation or cultural adaptation.^{21,31,39} Bhatnagar et al. (1997) noted that there is a lack of
295 cultural adaptation of dementia measures for South Asians which may result in high false
296 positive and false negative diagnoses which may result in unreliable prevalence rates.¹⁸
297

298 *Diagnosis, Validation & Screening*

299 Three papers were identified that discussed either the diagnosis of dementia in UK South
300 Asians or validation of screening tools. Two studies were identified which had looked to
301 validate the MMSE dementia screening instrument for use in the UK South Asian
302 population. Lindsay et al. (1997) investigated whether a Gujarati version of the MMSE
303 could be used as a screening instrument in a Gujarati population in Leicester.²⁸ The authors
304 report that they followed the precedent of Ganguli et al. (1995) in developing this Gujarati
305 version of the MMSE.⁴⁵ They initially selected the items using consensus, translation and
306 back translation, pretesting and validation against psychiatric diagnosis.²⁸ Lindsay et al.
307 (1997) report that the MMSE performed well in the identification of moderate to severe
308 dementia but was less effective in detecting cases of mild dementia in the Gujarati group
309 when compared to a group of White British participants. In a second study, using the same
310 sample as Lindsay et al. (1997)²⁸, Shah et al. (1998) investigated the stability of dementia
311 diagnosis over time.³⁵ They reported that the diagnosis of dementia was stable at follow-up
312 over a period of more than 2 years (26-32 months) which indicates that the measure
313 Gujarati MMSE has test-retest reliability in this population.

314 Rait et al. (2000) tested the MMSE in a population of South Asians, including Gujarati and
315 Pakistani participants.³³ The authors state that, as there were no definitive guidelines
316 available for translating questionnaires such as the MMSE, they engaged both academics
317 and members of the South Asian community to assess the cultural sensitivity of the items in
318 three groups. The items were translated by a professional translation group and then back-
319 translated with the South Asian community group. They report that modifications were
320 made to the MMSE which centred around education and literacy and the modified MMSE
321 was tested in a pilot study.⁴⁶ They found high levels of sensitivity and specificity for the

322 MMSE but with a lower cut-off score for the identification of mild dementia in the South
323 Asian group.

324 Findings indicate that the Gujarati version of the MMSE may be effective at identifying
325 dementia, especially where the diagnosis is certain and therefore symptoms are moderate
326 to severe. However, it may be less effective in identifying dementia where symptoms are
327 mild or diagnosis is uncertain.

328

329 *Knowledge, Understanding, and Attitudes*

330 We identified six studies which had set out to identify knowledge, understanding and
331 attitudes to dementia in the UK South Asian community. Knowledge about dementia in
332 Indian (n=91) and White UK/Irish/European (n=55) people was assessed using the Dementia
333 Knowledge Questionnaire (DKQ) by Purandare et al.³² They found that both groups had poor
334 knowledge of causes and symptoms, and Indian older people had significantly less 'basic
335 knowledge' about dementia. Here the authors define 'basic knowledge as including
336 knowledge of epidemiology, aetiology, and symptomatology as measured by the Dementia
337 Knowledge Questionnaire (DKQ).⁴⁷ A further series of focus groups investigated general
338 population knowledge of dementia with 28 Sikh participants.³⁷ Again they found poor
339 knowledge of dementia and that Sikh participants placed greater emphasis on physical
340 illnesses than disorders such as dementia. La Fontaine held focus groups with a population
341 sample of 49 Punjabi Indian participants.²⁵ One of their key findings was the failure of
342 participants to directly refer to dementia or even to use lay terms to discuss it which the
343 authors conclude indicates a lack of recognition of dementia as a concept.

344

345 Turner et al. (2005) explored knowledge and attitudes to dementia in a qualitative
346 community study of South Asian (n=96) and White older people (n=96) and also found
347 reduced knowledge of dementia in the South Asian group. Furthermore, their findings
348 highlighted differences in attitudes to dementia care, with the South Asian group reporting
349 that care should be provided by family and friends.³⁸ In interviews with 10 South Asian
350 family carers Lawrence et al. (2008) looked at traditional versus non-traditional care giver
351 ideology.²⁶ The majority of South Asian carers possessed a traditional ideology in that they

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3 352 saw care giving as natural, expected, and virtuous. However, where understanding of
4 353 dementia is poor problems can occur within the family caring relationship due to beliefs
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6 354 about the causes of dementia in the South Asian community and the attribution of blame on
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8 355 to the person with dementia.¹⁶
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11 357 Adamson et al. (2005) interviewed 15 South Asian carers living in five cities across the UK.¹⁶
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13 358 The study looked at the relationship between individual experiences, cultural factors and
14
15 359 social structures within this minority population. Carers tended to interpret their caring
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17 360 roles as an expected part of their cultural heritage and a continuation of their family
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19 361 relationships. They also likened the experiences of this group to other chronic illness care
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21 362 and suggest that the understanding of the experiences of chronic care may be useful in
22
23 363 understanding experiences in informal care for dementia.
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25 364
26 365 In summary, several studies have explored the knowledge of dementia, and beliefs and
27
28 366 attitudes to care in UK South Asians. All report that knowledge is poor and this group are
29
30 367 often more focussed on physical illness rather than conditions such as dementia. This
31
32 368 finding that this group do not identify with dementia as a concept further highlights the
33
34 369 need for valid and reliable measures to be developed to identify and then diagnose
35
36 370 dementia in this group.
37

38 371
39 372 Our findings show that care is preferred to be provided by family and within the community
40
41 373 and therefore, UK South Asians may not access formal healthcare for dementia.

42 374 Giebel et al. (2016) have adapted the Barts Explanatory Model Inventory Checklist (BEMI-C)
43
44 375 for use with South Asian ethnic minority groups (BEMI-Dementia).⁴² They conducted 25
45
46 376 qualitative interviews with South Asians and identified 123 new perceptions around their
47
48 377 understanding of dementia. These were added to the BEMI-C to create a new checklist
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50 378 (BEMI-D) to better assess the barriers to dementia service uptake for this group in the
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52 379 future.
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3 383 *Help-seeking*

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5 384 Five papers were identified that focused on different aspects of help-seeking for dementia
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7 385 in the UK South Asian population.

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9 386

10 387 Two studies had looked at barriers to help-seeking for dementia. Firstly, in a community
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12 388 sample of English or Bengali speaking UK South Asians who did not have a diagnosis of
13
14 389 dementia Mukadam et al (2015) identified the barriers and facilitators to help-seeking for
15
16 390 memory problems.³⁰ They identified four main categories of barriers which interacted to
17
18 391 prevent timely diagnosis of dementia: barriers to help-seeking for memory problems; the
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20 392 threshold for seeking help for memory problems; ways to overcome barriers to help-
21
22 393 seeking; what features an educational resource should have. Secondly, Hailstone et al.
23
24 394 (2016) devised and validated a theory of planned behaviour (Attitudes of People from Ethnic
25
26 395 Minorities for Help-seeking for Dementia: APEND) questionnaire to predict medical help-
27
28 396 seeking for dementia in UK South Asians.²² They found that attitudes to dementia predicted
29
30 397 77% of variance in help-seeking with the strongest predictor being perceived social
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32 398 pressure.

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34 399

35 400 Furthermore, there were two studies which had specifically identified religious explanations
36
37 401 as barriers to help-seeking for dementia in South Asians. Mackenzie et al. (2006)
38
39 402 interviewed 11 Pakistani and 5 Indian carers and found that stigma resulted from religious
40
41 403 and magical beliefs around the causes of dementia and resulted in concealment from their
42
43 404 own community and delays in help-seeking.²⁹ Giebel et al. (2016) looked at the differences
44
45 405 in the perceptions of South Asians who do and do not consult a General Practitioner (GP)
46
47 406 about dementia.²⁰ They found those who did not consult a GP were significantly more likely
48
49 407 to consider memory problems as given by god, with the view that medical intervention was
50
51 408 therefore inappropriate. In a case study of a Muslim, Pakistani patient accessing healthcare
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53 409 for dementia in the UK, Regan et al. (2016) further highlight the importance of
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55 410 understanding a person's religious community and its role in providing both support and
56
57 411 reducing stigma and isolation.⁴⁰

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3 413 The included studies highlight that attitudes and beliefs about dementia can serve as
4 414 barriers to accessing healthcare, in particular understanding dementia within a religious
5 415 context can delay help seeking. However, religious communities can also play a vital role in
6 416 supporting patients with dementia and in reducing stigma. This may be the case across
7 417 other ethnic minority communities in the UK, not just South Asians. It is therefore important
8 418 to learn more about the religious context in which people understand dementia and for
9 419 healthcare providers to engage with local communities and religious leaders in order to
10 420 work in partnership with them to increase support and reduce stigma.
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422 *Experiences of Dementia*

423 We identified three articles that looked at understanding the experience of dementia for UK
424 South Asians. Bowes et al 2003 explored the experiences of South Asian patients with
425 dementia in Scotland.¹⁹ Interviews were conducted with 11 health professionals, and four
426 case studies were built up through multiple interviews with 4 people with dementia, as well
427 as interviews with their family and carers. The authors reported overwhelmingly negative
428 experiences of dementia and of health services from the case studies. From the interviews
429 with health professionals the authors concluded that there was a need to develop and
430 promote culturally sensitive services. Furthermore, the article by Jutlla (2015) looked at the
431 experiences of 12 Sikh carers, caring for a family member with dementia, in
432 Wolverhampton.²³ In particular they looked at the influences of migration experiences and
433 migration identities. They found that knowledge a person's background and experiences is
434 important for understanding how they then experience health services and caring roles. This
435 is presented as an advocate, not just for culturally appropriate services, but also for person-
436 centred dementia care.

437

438 Lawrence et al. (2011) looked at experiences of dementia in three ethnic groups, 11 Black
439 Caribbean, 9 South Asian and 10 White British older people with dementia.²⁷ The paper
440 reported a comparison in the personal experiences of the condition in the three groups.
441 They reported similar themes across groups with a key finding being that patients assessed
442 their condition by the degree to which it interfered with 'valued elements of life'. The

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3 443 authors concluded that development of culturally sensitive approaches to care should
4 444 promote roles, relationships and activities that the patient values.
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8 446 *Service Organisation and Delivery*
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10 447 We found three articles that discussed service organisation and delivery for South Asian
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12 448 patients with dementia in the UK. Firstly, in 1999 Shah, a Gujarati Psychogeriatrician,
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14 449 published a descriptive account of his own experiences working with 12 Gujarati patients in
15
16 450 their language.³⁶ Four of the patients had a diagnosis of dementia. He identified particular
17
18 451 problems in eliciting cognitive symptoms due to problems with the translation and the lack
19
20 452 of culturally appropriate assessments.³⁶ Secondly, Kaur et al. (2010) writes about the role an
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22 453 Asian link nurse for Punjabi speaking people of Asian origin in a dementia service in
23
24 454 Wolverhampton.²⁴ The authors reported success in providing appropriate and culturally
25
26 455 sensitive help and information for healthcare professionals, voluntary services, and South
27
28 456 Asian patients with dementia. Thirdly, Seabrooke and Milne (2009) discuss the Dementia
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30 457 Collaborative Project in North West Kent which aimed to raise awareness of memory
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32 458 problems in South Asians and facilitate access to screening and diagnosis.³⁴ The authors
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34 459 reported an increase in referrals to a specialist clinic for memory assessments, some of
35
36 460 which were for South Asian patients, and an increase in health professional's knowledge of
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38 461 memory problems in South Asians.
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3 462 **Discussion**

4
5 463 We have conducted the first scoping review of dementia in the UK South Asian population.
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7 464 We identified 27 studies which were focussed on the prevalence, diagnosis and screening,
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9 465 knowledge and attitudes, help seeking, experience, and service organisation and delivery for
10
11 466 dementia in this group. Overall, this review highlights that research on dementia in UK
12
13 467 South Asians is limited. Studies on prevalence are out-dated, we lack culturally adapted
14
15 468 instruments to diagnose dementia, and community engagement work is in its infancy.

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17 469
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19 470 There have been few studies of the prevalence of dementia within UK South Asians and
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21 471 where studies have set out to identify prevalence, sample sizes have been small.
22
23 472 Furthermore, prevalence studies are old, with the most recent being published in 2004 and
24
25 473 therefore, the current prevalence of dementia in UK South Asians is unknown.²¹ There is a
26
27 474 need for large epidemiological studies of dementia in UK South Asians in order to confirm
28
29 475 the prevalence nationally. There is also a need for studies embedded within epidemiological
30
31 476 work that can explore the current experience, both quantitatively and qualitatively, of South
32
33 477 Asians with dementia in the context of dementia healthcare. Future cohort studies of this
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35 478 nature should provide data grouped by ethnicity and that ethnic groups are well defined to
36
37 479 allow results to be included in future reviews.

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39 480
40
41 481 We found only two studies that aimed to validate the MMSE screening tool within the UK
42
43 482 South Asian population.^{28,33} These two studies limited South Asians to a screening process
44
45 483 with no access to receiving a confirmed diagnosis. We did not identify any studies that had
46
47 484 addressed the introduction and validation of a purely diagnostic assessment for UK South
48
49 485 Asians, such as the Addenbrooke's Cognitive Examination Version III or the Motreal
50
51 486 Cognitive Assessment.^{48,49} This compromises current knowledge of dementia prevalence
52
53 487 within in UK South Asians, as without a culturally appropriate, validated diagnostic
54
55 488 assessment individuals cannot be diagnosed. The lack of a culturally adapted and validated
56
57 489 diagnostic tool risks that UK South Asians who enter into the diagnostic process will receive
58
59 490 higher rates of false positive or false negative scores. This invalidates the current diagnoses
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491 given to UK South Asians. We suggest that undertaking the cultural adaptation and

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3 492 validation of diagnostic assessments according to published guidelines would improve the
4 493 diagnostic process.⁵⁰
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6 494
7
8 495 Most of the existing research has been conducted in the community which reflects the fact
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10 496 that UK South Asians do not access formal healthcare services for memory problems. We
11
12 497 need to develop culturally sensitive screening tools, diagnostic tests, and interventions
13
14 498 whilst also engaging communities. It is important to develop interventions in parallel with
15
16 499 community engagement to ensure that there are culturally appropriate services ready to be
17 500 accessed if engagement is successfully increased.⁷

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20 502 We were unable to identify a single clinical trial of an intervention for dementia in the UK
21
22 503 South Asian population, either amongst patients or carers. This highlights a critical gap in
23
24 504 ongoing dementia research and indicates a neglect of 5.3% of the UK population that
25
26 505 identify as South Asian and calls into question whether it is appropriate to implement
27
28 506 existing interventions for this ethnic group without any assessment of their feasibility,
29
30 507 acceptability, and effectiveness.³ This review has identified a number of different views and
31
32 508 perceptions held about dementia by UK South Asians. Therefore, existing interventions need
33
34 509 to be adapted, or new culturally sensitive interventions should be developed and trialled
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36 510 which can accommodate for these differences.. From our findings relating to service
37
38 511 organisation and delivery we can see strategies emerging that may increase engagement
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40 512 from this population, such as the ethnic matching of staff and increasing engagement work
41
42 513 with South Asian community. These strategies should now be considered when designing
43
44 514 clinical trials to test culturally adapted interventions.

45 515
46 516 This review has highlighted factors which impact on our ability to conduct intervention trials
47
48 517 in this population; these may include issues surrounding diagnosis and the lack of
49
50 518 appropriately validated diagnostic instruments, as well as attitudes and beliefs about
51
52 519 dementia which may affect recruitment. Much of the qualitative work identified in this
53
54 520 review has highlighted the religious explanations by which the South Asian community often
55
56 521 understand symptoms of dementia. Studies report that this causes a barrier to help seeking
57
58 522 and will result in delayed treatment. Furthermore, due to religious explanatory models for
59
60 523 dementia patients and family carers often perceive treatment as inappropriate. Culturally

524 sensitive community engagement work is needed to engage the South Asian community and
525 encourage understanding of dementia. New interventions should also acknowledge and
526 include the family approach to care which is seen as of paramount importance in the South
527 Asian community.

528
529 This review is the first review to scope all of the literature on dementia in the UK South
530 Asian population. We scoped the literature in line with the published guidelines for scoping
531 reviews and conducted a systematic search of the literature.^{13,15} However, it is possible that
532 there are other studies that were not identified as part of this search; in part this could be
533 due to a lack of standardisation of the terminologies used in the literature. One potential
534 limitation of our scoping review is that we restricted our eligible studies to those conducted
535 in the UK. Although narrow, our focus on UK South Asians allowed us to identify gaps in the
536 literature for a group which may face specific challenges and barriers to accessing
537 healthcare in the NHS. It would however, be beneficial to review studies of dementia in
538 South Asians globally in order to identify key learning for development of any intervention.

539
540 The scoping review is not designed to provide a definitive answer to questions in any of the
541 key themes discussed in this review because there are important differences across the
542 included studies which were not extensively evaluated (e.g. quality, design, and population).
543 Whilst this is consistent with published guidelines for scoping reviews it means that we are
544 unable to identify any gaps in the literature which arise due to poor quality research.^{13,14}
545 The purpose of this review was to map the literature and to provide a useful framework to
546 guide future research directions. The scoping review methodology is particularly suited to
547 this aim as it provides a comprehensive account of current progress and challenges which
548 can be used to develop future research and priorities to improve care for UK South Asians.¹³

549

550 *Conclusion*

551 A number of studies have been published on dementia in the UK South Asian population.
552 However, studies of prevalence, diagnosis, and service organisation and delivery are limited.
553 We found no clinical trials of culturally appropriate interventions for South Asians with

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3 554 dementia in the UK. The existing evidence comes from small scale service evaluations and
4 555 case studies.
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8 557 Future research efforts should concentrate on developing and validating culturally
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10 558 appropriate diagnostic tools for UK South Asians. Epidemiological studies are needed to
11 559 accurately identify the prevalence of dementia in this group. Cultural adaptation and clinical
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13 560 trials of appropriate culturally sensitive interventions are needed to run in parallel to
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15 561 diagnosis and community engagement work to ensure there are effectiveness and
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17 562 acceptable treatments for South Asians to access once identified with dementia.
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13 592 **Competing Interest Statement**
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15 593 The authors declare they have no competing interests.
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19 595 **Author Contribution**
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21 596 AB and CK ran the search and screened papers. AB, CK, GDW, MP, WW identified and
22 597 agreed eligible papers. AB wrote the paper and CK, GDW, MP, NM, WW edited and revised
23 598 the paper for critical content.
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28 600 **Data Sharing Statement**
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30 601 No additional data are available.
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Figure 1: Flow of Included Studies

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648 **References**

- 649 1 Alzheimer's Disease International. *Policy Brief for G8 Heads of Government. The Global*
650 *Impact of Dementia 2013-2050*,
651 <http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf> (2013).
652
653 2 World Health Organisation. *the Epidemiology and Impact of Dementia: Current state and*
654 *future trends*,
655 <http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf> (2015).
656
657 3 Office for National Statistics. *Ethnicity and National Identity in England and Wales*,
658 <<https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/article/ethnicityandnationalidentityinenglandandwales/2012-12-11>> (2012).
659
660 4 All-Party Parliamentary Group on Dementia. *Dementia does not discriminate: The*
661 *experiences of black, Asian and minority ethnic communities*,
662 <https://www.alzheimers.org.uk/download/downloads/id/1857/appg_2013_bame_report.pdf> (2013).
663
664 5 Mukadam, N., Cooper, C. & Livingstone, G. A systematic review of ethnicity and pathways to
665 care in dementia. *International Journal of Geriatric Psychiatry* **26**, 12-20 (2011).
666 6 Mukadam, N., Cooper, C. & Livingston, G. Improving access to dementia services for people
667 from minority ethnic groups. *Current Opinion in Psychiatry* **26**, 409-414 (2013).
668 7 Kenning, C., Daker-White, G., Blakemore, A., Panagioti, M. & Waheed, W. Barriers and
669 facilitators in accessing dementia care by ethnic minority groups: a meta-synthesis of
670 qualitative studies. *BMC Psychiatry* **17**, 316, doi:10.1186/s12888-017-1474-0. (2017).
671 8 Khan, F. & Tadros, G. Complexity in cognitive assessment of elderly British minority ethnic
672 groups: Cultural perspective. *Dementia* **13**, 467-482, doi:doi:10.1177/1471301213475539
673 (2014).
674 9 Lindesay, J., Jagger, C., Hibbett, M., Peet, S. & Moledina, F. Knowledge, update and
675 availability of health and social services among asian gujurati and white elderly persons.
676 *Ethnicity and Health* **2**, 59-69 (1997).
677 10 Cooper, C., Tandy, A., Balamurali, T. & Livingston, G. A systematic review and meta-analysis
678 of ethnic differences in use of dementia treatment, care, and research. *American Journal of*
679 *Geriatric Psychiatry* **18**, 193-203 (2010).
680 11 Regan, J. L. Redefining dementia care barriers for ethnic minorities: The religion-culture
681 distinction. *Mental Health, Religion & Culture* **17**, 345-353,
682 doi:<http://dx.doi.org/10.1080/13674676.2013.805404> (2014).
683 12 Grant, M. & Booth, A. A typology of reviews: an analysis of 14 review types and associated
684 methodologies. *Health Information and Libraries Journal* **26** (2009).
685 13 Pham, M. *et al.* A scoping review of scoping reviews: advancing the approach and enhancing
686 the consistency. *Research Synthesis Methods* **5**, 371-385, doi:DOI: 10.1002/jrsm.1123 (2014).
687 14 Arksey, H. & O'Malley, L. Scoping studies: towards a methodological framework.
688 *International Journal of Social Research Methodology* **8**, 19-32 (2007).
689 15 Levac, D., Colquhoun, H. & O'Brien, K. Scoping studies: advancing the methodology.
690 *Implementation Science* **5**, 69 (2010).
691 16 Adamson, J. Awareness and understanding of dementia in African/Caribbean and South
692 Asian families. *Health Soc Care Community* **9**, 391-396 (2001).
693 17 Adamson, J. & Donovan, J. 'Normal disruption': South Asian and African/Caribbean relatives
694 caring for an older family member in the UK. *Social Science and Medicine* **60**, 37-48 (2005).
695 18 Bhatnagar, K. & Frank, J. Psychiatric disorders in elderly from the Indian sub-continent living
696 in Bradford. *International Journal of Geriatric Psychiatry* **12**, 907-912 (1997).
697 19 Bowes, A. & Wilkinson, H. 'We didn't know it would get that bad': South Asian experiences of
698 dementia and the service response. *Health Soc Care Community* **11**, 387-396 (2003).

- 1
2
3 699 20 Giebel, C. *et al.* Perceptions of self-defined memory problems vary in south Asian minority
4 700 older people who consult a GP and those who do not: A mixed-method pilot study.
5 701 *International Journal of Geriatric Psychiatry* **31**, 379-387 (2016).
6 702 21 Haider, I. & Shah, A. A pilot study of behavioural and psychological signs and symptoms of
7 703 dementia in patients of Indian sub-continent origin admitted to a dementia day hospital in
8 704 the United Kingdom. *International Journal of Geriatric Psychiatry* **19**, 1195-1204 (2004).
9 705 22 Hailstone, J., Mukadam, N., Owen, T., Cooper, C. & Livingston, G. The development of
10 706 attitudes of people from ethnic minorities to help-seeking for dementia (apend): A
11 707 questionnaire to measure attitudes to help-seeking for dementia in people from south asian
12 708 backgrounds in the uk. *International Journal of Geriatric Psychiatry Mar*, No Pagination
13 709 Specified, doi:<http://dx.doi.org/10.1002/gps.4462> (2016).
14 710 23 Jutlla, K. The impact of migration experiences and migration identities on the experiences of
15 711 services and caring for a family member with dementia for Sikhs living in Wolverhampton,
16 712 UK. *Ageing & Society* **35**, 1032-1054, doi:<http://dx.doi.org/10.1017/S0144686X14000658>
17 713 (2015).
18 714 24 Kaur, H., Jutlla, K., Moreland, N. & Read, K. How a link nurse ensured equal treatment for
19 715 people of Asian origin with dementia. *Nurs Times* **106**, 12-15 (2010).
20 716 25 La Fontaine, J., Ahuja, J., Bradbury, N. M., Phillips, S. & Oyebode, J. R. Understanding
21 717 dementia amongst people in minority ethnic and cultural groups. *J Adv Nurs* **60**, 605-614
22 718 (2007).
23 719 26 Lawrence, V., Murray, J., Samsi, K. & Banerjee, S. Attitudes and support needs of Black
24 720 Caribbean, south Asian and White British carers of people with dementia in the UK. *Br J*
25 721 *Psychiatry* **193**, 240-246, doi:<http://dx.doi.org/10.1192/bjp.bp.107.045187> (2008).
26 722 27 Lawrence, V., Samsi, K., Banerjee, S., Morgan, C. & Murray, J. Threat to valued elements of
27 723 life: the experience of dementia across three ethnic groups. *Gerontologist* **51**, 39-50,
28 724 doi:<http://dx.doi.org/10.1093/geront/gnq073> (2011).
29 725 28 Lindesay, J. *et al.* The Mini-Mental State Examination (MMSE) in an elderly immigrant
30 726 Gujarati population in the United Kingdom. *International Journal of Geriatric Psychiatry* **12**,
31 727 1155-1167 (1997).
32 728 29 Mackenzie, J. Stigma and dementia: East European and South Asian family carers negotiating
33 729 stigma in the UK. *Dementia: The International Journal of Social Research and Practice* **5**, 233-
34 730 247, doi:<http://dx.doi.org/10.1177/1471301206062252> (2006).
35 731 30 Mukadam, N., Waugh, A., Cooper, C. & Livingston, G. What would encourage help-seeking
36 732 for memory problems amongst South Asians? A qualitative study. *International*
37 733 *Psychogeriatrics* **27**, S57-S58 (2015).
38 734 31 Odutoye, K. & Shah, A. The characteristics of Indian subcontinent origin elders newly
39 735 referred to a psychogeriatric service. *International Journal of Geriatric Psychiatry* **14**, 446-
40 736 453 (1999).
41 737 32 Purandare, N., Luthra, V., Swarbrick, C. & Bums, A. Knowledge of dementia among South
42 738 Asian (Indian) older people in Manchester, UK. *International Journal of Geriatric Psychiatry*
43 739 **22**, 777-781, doi:<http://dx.doi.org/10.1002/gps.1740> (2007).
44 740 33 Rait, G. *et al.* Validating screening instruments for cognitive impairment in older South
45 741 Asians in the United Kingdom. *International Journal of Geriatric Psychiatry* **15**, 54-62 (2000).
46 742 34 Seabrooke, V. & Milne, A. Early intervention in dementia care in an Asian community:
47 743 Lessons from a dementia collaborative project. *Quality in Aging* **10**, 29-36 (2009).
48 744 35 Shah, A., Lindesay, J. & Jagger, C. Is the diagnosis of dementia stable over time among
49 745 elderly immigrant Gujaratis in the United Kingdom (Leicester)? *International Journal of*
50 746 *Geriatric Psychiatry* **13**, 440-444 (1998).
51 747 36 Shah, A. Difficulties experienced by a Gujarati geriatric psychiatrist in interviewing Gujarati
52 748 elders in Gujarati. *International Journal of Geriatric Psychiatry* **14**, 1072-1074 (1999).

- 1
2
3 749 37 Uppal, G. K., Bonas, S. & Philpott, H. Understanding and awareness of dementia in the Sikh
4 750 community. *Mental Health, Religion & Culture* **17**, 400-414,
5 751 doi:<http://dx.doi.org/10.1080/13674676.2013.816941> (2014).
6 752 38 Turner, S., Christie, A. & Haworth, E. South Asian and white older people and dementia: a
7 753 qualitative study of knowledge and attitudes. *Diversity in Health and Social Care* **2**, 197-209
8 754 (2005).
9 755 39 Redelinghuys, J. & Shah, A. The characteristics of ethnic elders from the Indian subcontinent
10 756 using a geriatric psychiatry service in West London. *Aging and Mental Health* **1**, 243-247
11 757 (1997).
12 758 40 Regan, J. L. Ethnic minority, young onset, rare dementia type, depression: A case study of a
13 759 Muslim male accessing UK dementia health and social care services. *Dementia* **15**, 702-720,
14 760 doi:doi:10.1177/1471301214534423 (2016).
15 761 41 McCracken, C. *et al.* Prevalence of dementia and depression among elderly people in Black
16 762 and ethnic minorities. *The British Journal of Psychiatry* **171**, 269-273 (1997).
17 763 42 Giebel, C. *et al.* Adaptation of the Barts explanatory model inventory to dementia
18 764 understanding in South Asian ethnic minorities. *Aging and Mental Health* **20**, 594-602
19 765 (2016).
20 766 43 Moher, D., Liberati, A., Tetzlaff, J., Altman, D. & Group, T. P. Preferred reporting items for
21 767 systematic reviews and meta-analysis: The PRISMA statement *PLoS Medicine* **6**, e1000097,
22 768 doi:10.1371/journal.pmed1000097 (2009).
23 769 44 Reisberg, B. *et al.* Behavioral symptoms in Alzheimer's disease: phenomenology and
24 770 treatment. *Journal of Clinical Psychiatry* **48** (1987).
25 771 45 Ganguli, M. *et al.* A hindi version of the MMSE: The development of a cognitive screening
26 772 instrument for a largely illiterate rural elderly population in india. *International Journal of*
27 773 *Geriatric Psychiatry* **10**, 367-377 (1995).
28 774 46 Rait, G., Morley, M., Lambat, I. & Burns, A. Modification of brief cognitive assessments for
29 775 use with elderly people from the South Asian subcontinent. *Ageing and Mental Health* **1**,
30 776 356-363 (1997).
31 777 47 Graham, C., Ballard, C. & Sham, P. Carers' knowledge of dementia and their expressed
32 778 concerns. *International Journal of Geriatric Psychiatry* **12**, 470 (1997).
33 779 48 Mathuranath, P., Nestor, P., Berrios, G., Rakowicz, W. & Hodges, J. A brief cognitive test
34 780 battery to differentiate between Alzheimer's disease and frontotemporal dementia.
35 781 *Neurology* **55**, 1613-1620 (2000).
36 782 49 Nasreddine, Z. *et al.* The Montreal Cognitive Assessment, MoCA: A brief screening tool for
37 783 mild cognitive impairment *Journal of the American Geriatric Society* **53**, 695-699 (2005).
38 784 50 Mirza, N., Panagioti, M., Waheed, M. & Waheed, W. Reporting of the translation and cultural
39 785 adaptation procedures of the Addenbrooke's Cognitive Examination version III (ACE-III) and
40 786 its predecessors: a systematic review. *BMC Medical Research Methodology* **17**, 141,
41 787 doi:<https://doi.org/10.1186/s12874-017-0413-6> (2017).
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Table 1: Summary of characteristics and findings of included studies

Author	Year	Study Design	Total Sample Size	Sample	Setting	Summary of Main Findings
Adamson et al. ¹⁶	2001	Qualitative	30	n=12 (40%) South Asian carers of people with dementia.	Healthcare services (carer support, day centres, psychiatric services)	Lack of knowledge of dementia found in South Asian group. South Asian participants talked about symptoms being a result of past actions in life and apportioning blame. They also believed that other physical conditions and their associated medications could cause dementia, such as antidepressants for depression.
Adamson et al. ¹⁷	2005	Qualitative	36	n=15 (42%) South Asian carers of people with dementia	Community	South Asian participants talked about caring for family as a cultural norm and wider families were more likely to live together to facilitate this.
Bhatnagar et al. ¹⁸	1997	Cross-sectional study	100	Aged 65-89y, from Indian subcontinent and living in Bradford	Community	Prevalence of dementia 4% as diagnosed by psychiatrist and 7% using Hindi translation of diagnostic measure (GMS-A).
Bowes et al. ¹⁹	2003	Qualitative	11	11 interviews with carers 4 case studies of South Asian patients	Community	Carer interviews: demand for services, a need to develop awareness and knowledge in the community, and to promote a culturally sensitive response from services. Case studies: negative experiences of dementia, poor quality of life, need for support, lack of access to appropriate services, little knowledge about dementia, isolation from both community and family life.
Giebel et al. ²⁰	2016	Mixed method pilot	33	3 groups – South Asian, over 60y: without memory problems; memory problems not consulted GP; memory problems had consulted GP	Community	Those who had not consulted a GP often considered memory problems to be given by God and did not identify medical support as appropriate for them. Those who had attended a consultation with GP identified forgetfulness and loss of social meaning as symptoms of dementia

Author	Year	Study Design	Total Sample Size	Sample	Setting	Summary of Main Findings
Giebel et al. ⁴²	2016	Questionnaire validation	25	n=25 South Asian	Community	123 new perceptions around South Asian their understanding of dementia were identified. These were added to the BEMI-C to create a new checklist (BEMI-D).
Haider et al. ²¹	2004	Pilot study	62	n=31 South Asian, aged 65-96y n=31 White British, aged 65-90y	Day Hospital	South Asian participants score lower on the BEHAVE-AD phobia and anxiety subscale. Alzheimer's disease associated with vascular dementia with affective disturbance.
Hailstone et al. ²²	2016	Questionnaire Validation	58	Mean age 60y 59% female (n=34) 1 st and 2 nd generation South Asians	Community	Strongest predictor of willingness to seek help for dementia was perceived social pressures from significant others. Attitudes in the questionnaire predicted 77% of variance in willingness to seek help, but no relationship was found with dementia knowledge.
Jutlla et al. ²³	2015	Qualitative	12	South Asian Sikhs caring for someone with dementia and living in Wolverhampton, UK	Community	Understandings participant's migration experiences and identities is important for understanding family carers experience of services when caring for someone with dementia.
Kaur et al. ²⁴	2010	Service Evaluation	N/A	An Asian Link Nurse working in Wolverhampton, UK	Community Mental Health Team	Having an Asian Link Nurse was vital in providing education about dementia for South Asian people.
La Fontaine et al. ²⁵	2007	Qualitative	49	South Asians aged 17-60y who were English, Hindi or Punjabi speaking	Community	Interviews highlighted that cognitive impairment was rarely mentioned when talking about ageing. Ageing was seen as a time of withdrawal and isolation. There was a sense of stigma and a lack of knowledge about mental health services which leads to exclusion from these services.

Author	Year	Study Design	Total Sample Size	Sample	Setting	Summary of Main Findings
Lawrence et al. ²⁶	2008	Qualitative	32	n=10 (31%) South Asian carers of people with dementia	Community	South Asian carers possessed a traditional caregiver ideology, conceptualising caregiving as natural, expected and virtuous. This informed their attitudes towards formal healthcare services.
Lawrence et al. ²⁷	2011	Qualitative	30	n=9 (30%) South Asian Aged 67-87y	Mental Health Services	Interviews highlighted that participants engaged in a process of appraisal where they assessed how much their condition affected valued elements of their life.
Lindesay et al. ²⁸	1997	Questionnaire Validation	1297	n=149 (11%) South Asian, Gujarati	General Practice	Mean MMSE scores were lower in the Gujarati group due to the effects of age, education and visual impairment. The MMSE performed comparably in both groups as a screen for moderate to severe dementia but was less effective for Gujarati's with mild dementia.
Mackenzie et al. ²⁹	2006	Qualitative	21	n=16 (76%) South Asian carers of people with dementia	Community	In the South Asian group stigma was linked to religious and magical explanations for the onset of dementia which affected the ability of carers to access support.
McCracken et al. ⁴¹	1997	Cross Sectional Study	579	n=12 (2%) Asian Aged over 65 years	Community	Prevalence of dementia 9% among English speaking Asian participants.
Mukadam et al. ³⁰	2015	Qualitative	53	South Asians aged 18-83y	Community	Stigma around dementia was linked to ideas of 'madness' a lack of physical explanations and a lack of treatment. Barriers to help seeking were that memory problems were an inevitable part of ageing. Denial of symptoms was evident in order to maintain position in the family and community, and due to fear of institutionalisation.
Oduoye et al.	1999	Cross	242	n=29 (12%) South	Psycho-	South Asians were less likely to have dementia than

Author	Year	Study Design	Total Sample Size	Sample	Setting	Summary of Main Findings
³¹		Sectional Study		Asians newly referred to psychogeriatric unit between 1995-1997 aged 58-96y	Geriatric Unit	White British elders ($\chi^2 = 5.05$, 1df, $P < 0.03$).
Purandare et al. ³²	2007	Cross Sectional Study	246	n=191 (78%) South Asian, mean age 72.4y (sd 10.6).	Community – day centre	Knowledge of dementia was poor in both South Asian and White British people. South Asians had less knowledge about basic aspects of dementia ($p < 0.001$) and the epidemiology of dementia ($p < 0.001$) as compared to White British people.
Rait et al. ³³	2000	Validation of Screening Instrument	120	Community resident South Asians aged over 60y. n=65 Gujarati speaking, mean age 70y (sd 6.8) n=39 Pakistani group, mean age 68y (sd 6.0)	Community	Both modified screening tests (MMSE and AMT) had high sensitivity scores but ethnic background was found to influence the cut-off scores for these measures. The MMSE cut-off score was found to be significantly higher in the Pakistani group (≥ 27 , sensitivity 100%, specificity 95%) compared with the Gujarati group (≥ 24 , sensitivity 100%, specificity 77%).
Regan et al. ⁴⁰	2016	Case Study	N/A	Case study of a male Muslim patient with young onset fronto-temporal dementia	Dementia Services	Mostly negative experiences of accessing services and an inability to access support from either family or the religious community. Services not equipped to support people with young onset dementia from an ethnic minority.
Seabrooke et al. ³⁴	2009	Service Pilot	4	South Asian patients aged 65-93y with memory problems	Primary Care	Inviting older Asian patients with memory problems to see a specially trained Asian nurse using a culturally appropriate information leaflet encouraged a small number of people to access the service.
Shah et al. ³⁵	1998	Longitudinal	11	Gujarati people over 65y living in Leicester, UK	Community	Seven of the 11 followed-up (64%). Diagnosis of dementia was reconfirmed in 6 out of 7 cases (86%) and there was evidence of further cognitive decline.
Shah et al. ³⁶	1999	Case Study –	12	Gujarati patients (aged	Psycho-	n=4 (33%) with diagnosis of dementia. Difficulties

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Author	Year	Study Design	Total Sample Size	Sample	Setting	Summary of Main Findings
		descriptive methodology		65-90y) seen by Gujarati Psychogeriatrician.	Geriatric Unit	interviewing Gujarati patients reported. Identifying cognitive signs and symptoms reported as most difficult. Few patients speak English and majority could not read or write.
Uppal et al. ³⁷	2014	Qualitative	28	Sikh participants over 18y Able to speak either Punjabi and/or English	Community	Three key themes: awareness and interpretation of the characteristics of dementia; multiple perspectives of the same symptoms; and causes of dementia.
Turner et al. ³⁸	2005	Qualitative	192	n=96 (50%) South Asian, aged 58-85y.	Community	South Asian people had less specific knowledge of dementia and believed that dementia was a normal part of ageing. Also less likely to think that medical treatment was available. Care was seen as provided by the family in the first instance.
Redelinghuys et al. ³⁹	1997	Cross Sectional Study	235	n=39 (17%) South Asians, aged 65-95y using a geriatric psychiatry service in South London.	Geriatric Psychiatry	n=6 (15%) of the South Asian group had dementia compared with n=43 (22%) of the White British elders. There were no differences found between the two groups in terms of use of health and social services.

GMS-A – Geriatric Mental State; BEHAVE-AS - Behavioural Pathology in Alzheimer’s Disease Rating Scale; MMSE – Mini Mental State Examination; AMT – Abbreviated Mental Test; BEMI-D – Barts Explanatory Model Inventory Checklist; BEMI-D – Barts Explanatory Model Inventory Dementia.

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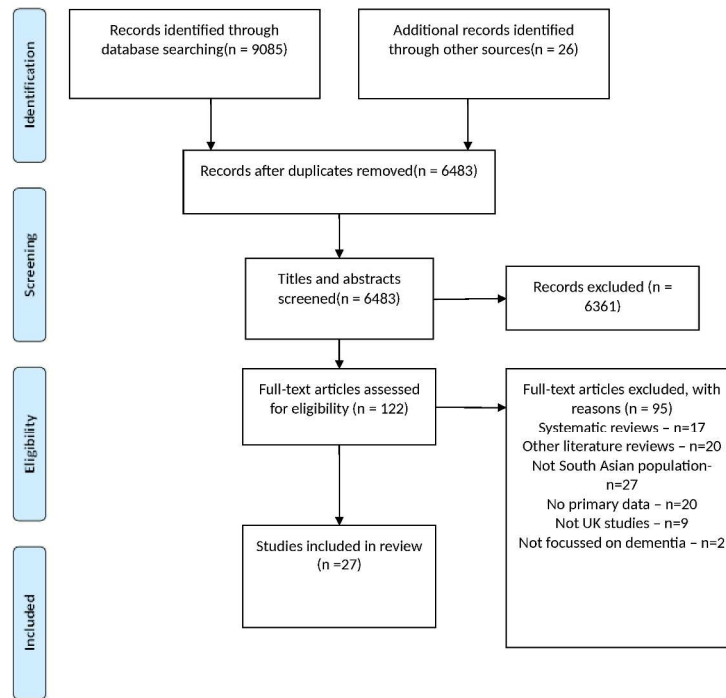
Figure 1: Flow of included studies ⁴³

Figure 1: Flow of included studies

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