Review

Exploration of Dementia Help Seeking Behaviours Amongst UK South Asian Communities: A Systematic Review

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Abstract

In the UK, 25,000 people from ethnic minority background live with dementia. Although dementia associated risk factors are common amongst South Asians, they tend to present at services later and when in crisis. This review explores UK South Asian communities perception of dementia to understand factors impacting their decision to seek help. Search terms assisted by the PICO strategy were inputted into five databases and ten qualitative papers identified. Meta-ethnography methodological framework was implemented for analysis. Four overarching understandings were identified: unfamiliarity with dementia (related to carers initial interpretation of dementia symptoms as normal ageing), cultural expectations to provide care (influenced by communities believes), services not being able to meet cultural needs impacted carers from seeking help and protective factors (religion and community belonging appear to help carers manage their needs). Carers decisions to seek help from dementia services were often influenced by cultural norms and negative experiences of services. They, consequently, turned to alternative approaches to best suit

meet their needs. Understanding South Asian's carers dementia help seeking behaviour would help services adapt and cater appropriately for service users' needs.

Keywords
Dementia; help seeking behaviour; South Asian; community

1. Introduction

Dementia is a progressive condition associated with cognitive deterioration [1]. Dementia impacts memory [2] and the ability to complete activities of daily living [3]. Depression [4] and anxiety [5] are frequently reported, similarly to behavioural symptoms such as agitation [6]. These neuropsychiatric co-morbidities all influence social aspects such as income [7] and social connection [8].

As a result of an increasingly ageing population, approximately 57 million people live with dementia worldwide [9] with over 800,000 in the UK, of which 25,000 are from ethnic minority communities [10]. According to the Dementia UK report, commissioned by the Alzheimer's Society, the number of people living with dementia in the UK is set to increase to over one million by 2025 [11]. Moreover, Alzheimer's Research UK predicts the cost of dementia in the UK will increase from £25 billion per year to £30 billion by 2030 [12]. As a result, the World Health Organisation has recognised dementia as a public health matter [13].

From the British Social Attitudes survey (2016) only 1% of adults could identify 7 risk factors of dementia [14]. The most common risk factors such as diabetes [15], cardiovascular disease [16], hypertension [17] and low socioeconomic status [18, 19] are highly prominent in South Asian (SA) communities [20] and associated with increased health inequalities [21]. However, people from ethnic minority groups are less likely to access dementia services [22, 23], present to services [24] and receive dementia diagnoses later [25], and, consequently, present to secondary care in crisis [26]. Additionally, as initial symptoms of dementia develop decades before the official diagnosis [27], those who receive an earlier diagnosis experience better outcomes [28], including having a greater autonomy over care decisions while capacious [29].

Previous reviews exploring ethnic communities perceptions of dementia provided a broad scope of how certain groups understand dementia and their experience of accessing services. Kenning et al. [30] explored ethnic minorities experiences of dementia amongst predominantly North American and Australian populations. They found participants awareness of dementia as an illness and what services were available impacted communities from seeking help. Participants differing cultural views of care giving were highlighted. Similar findings were reported for ethnic minority carers living in Western European countries [31]. The view dementia is a type of "madness" reinforced participants worries that communities would discover and impact help-seeking behaviours.

Giebel et al. [3] and Uppal and Bonas [32] examined SA communities perception of dementia globally. These reviews analysed papers published before 2012 and found themes around the unawareness of dementia, services and treatments impacted service uptake. Stigma associated with dementia and secrecy from the community were present, with communities having their

preferred coping strategies, such as prayer or meditation [3]. Hossain et al. [33] explored qualitative papers published before 2014 and found SA communities beliefs about treating dementia differed. Thus, participants utilised alternative approaches such as Ayurvedic medicine, homeopathic remedies and consulting healers. Similarly, concepts of family obligation to provide care for a relative with dementia were reported.

In the UK, Blakemore et al. [34] conducted a broad scoping review of SA communities to identify gaps in research. They analysed mixed methods papers published before 2016 with any study design, including case studies and questionnaire validations. The poor prevalence of dementia diagnosis was attributed to culturally insensitive diagnostic tools. Services not understanding participants values contributed to negative experiences.

To address engagement with services, it is important to understand what is preventing SA communities from seeking help. Although a specific model exploring ethnic minorities experiences of seeking is missing, Adam et al. [35] review utilised the Theory of Planned Behaviour (TPB) model [36] to explore help-seeking behaviours for mental health services. This theory proposes that an individual's intention depends on their attitude towards the behaviour, subjective norms, and perceived behavioural control, which subsequently influences their action ([36]; Figure 1).
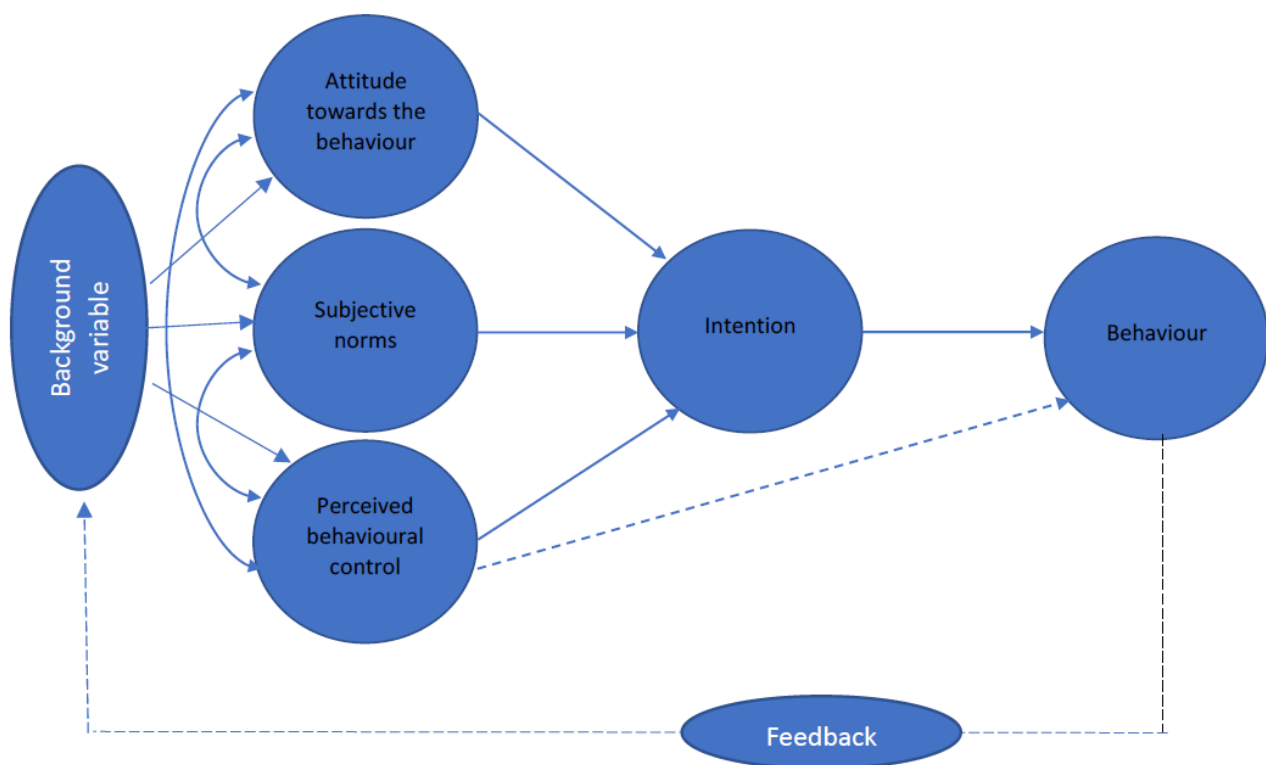

Figure 1 Theory of Planned Behaviour Model. One's background (personality, age, gender, nationality and cultural background, acculturation, stigma and socioeconomic status) influences person's beliefs about a behavior, whereas personal attitude is the sum of knowledge, attitudes, and prejudices. According to the model, perceived behavioural control, together with behavioural intention, can be used directly to predict behavioural achievement(s). Modified after Ajzen (1991) [36].

TPB has been previously used to explore the help-seeking behaviours in ethnic minority groups. Thus, Black women who internalised the strong woman archetype were less likely to seek help for

depression [37]. Similarly, subjective norms such as shame were found to impact South Asian Muslims decision to access mental health services [38]. With the development of interventional work to address issues relating to help-seeking [39, 40], the TPB has gathered support to address help-seeking behaviour [41]. Since TPB incorporates individuals cultural beliefs, this theory is most relevant to provide a holistic view in addressing this issue.

TPB can, thus, help not only contextualise SA communities experiences but also understand dementia help-seeking behaviour: an individual's intention to seek help depends on their attitude towards dementia and seeking help from services, the subjective norms they hold regarding dementia, services and help-seeking behaviour, and how accessible it is to seek help. We have adopted an interpretive–constructivist approach to understand SA communities perception of dementia and the available care their relative(s) receive(d). This review understands reality is shaped by individuals' subjective experiences; therefore, it is important to interpret these subjective experiences of caregivers to fully understand what prevents communities from seeking help from available mental health and social care networks. We, therefore, provide a focused systematic exploration of SA communities perception of dementia in the UK to understand factors preventing them from seeking help from services. The findings should inform for shaping the inclusiveness of dementia provisions among the UK population and explore their generalisability to other ethnic communities.

2. Methods

2.1 Methodological Framework

We used Sattar et al. [42] guide based on the Noblit and Hare [43] meta-ethnography framework to inform this review. This guide provides the most updated framework by incorporating developments from recent publications and formally operationalising its use. This methodological framework was deemed suitable as it aims to synthesise the primary papers findings as well as provide additional analytical re-interpretation compared to descriptive findings found in narrative papers [44]. This in turn can enable better understand [45] the barriers SA communities in the UK experience in seeking help for dementia. This approach is commonly used in healthcare research [46] and has helped highlight patients experiences [47]. The method of differentiating data by participants quotes, primary authors interpretation, and the reviews interpretation in the form of first, second and third-order constructs respectively were used in this review.

2.2 Search Strategy

The PICO strategy and initial scoping searches were used to formulate a meaningful review question and search terms:
- Population was defined as communities within South Asian countries;
- Phenomenon of interest was to explore the perceptions SA communities have regarding dementia;
- Context was defined as SA communities currently settled within the UK;
- The outcome was to understand views SA communities may have regarding dementia which may prevent them seeking help.

The included studies were not limited by study design, with inclusion of case reports, randomized controlled trials, non-controlled trials, case control, and cross-sectional studies. Systematic and narrative reviews were excluded, however, analyzed as sources for potential references. The exclusion criteria were non-experimental papers, papers using quantitative methodology and those investigating healthcare and social care populations. Papers specifically looking at healthcare workers were excluded, as the main purpose of the review is to explore attitudes held by SA communities as opposed to those who gain greater awareness through exposure at work. Finally, qualitative papers were decided to be the focus of this review as this methodology provides a more nuanced and in-depth perspective of what prevents SA communities from seeking help. Studies were screened on title and abstract and then by full text independently by the two authors (SW, EBM-L). Disagreements were resolved internally and did not require arbitration by a third reviewer.

The search for the review was conducted using the following databases: APA PsychINFO, CINAHL, Medline and Scopus (specifically selected as they provide extensive peer-reviewed research on topics regarding healthcare) during February 2023. Additionally, Grey literature was searched on the British Library EThOS service. A combination of search terms relating to "South Asian" countries AND "dementia" AND "attitudes" of these communities were used in each database (Appendix A). To broaden the selection of literature search terms were truncated to produce more results.

2.3 Data Screening

A total of 3,478 papers were identified. Due to the feasibility of this review, papers written in non-English languages were excluded. A decision was made to restrict papers published within the last 10 years. The rationale for this was to provide an updated and focused exploration, as the last review of a similar but broader topic searched for papers before 2016 [34]. Furthermore, technology has advanced vastly within the 10 years which may make information more accessible and influence attitudes SA communities have regarding dementia [48].

After removing 367 papers due to duplication, the remaining 1,899 papers were entered into Endnote, a reference management software to aid in screening. Papers were screened in two stages; initially by titles and abstracts based on the reviews inclusion criteria, which left 32 papers and then screening in full text, which left 10. Once deemed suitable, the relevant papers were included for quality appraisal and data extraction. Although a more inclusive screening approach could have been taken to avoid omitting potentially relevant papers (i.e. by including all papers relating to Asian communities regardless of setting), a decision was made to exclude non-relevant papers during the initial phase to help narrow the focus of the review to a more manageable amount (Figure 2; Appendix B).
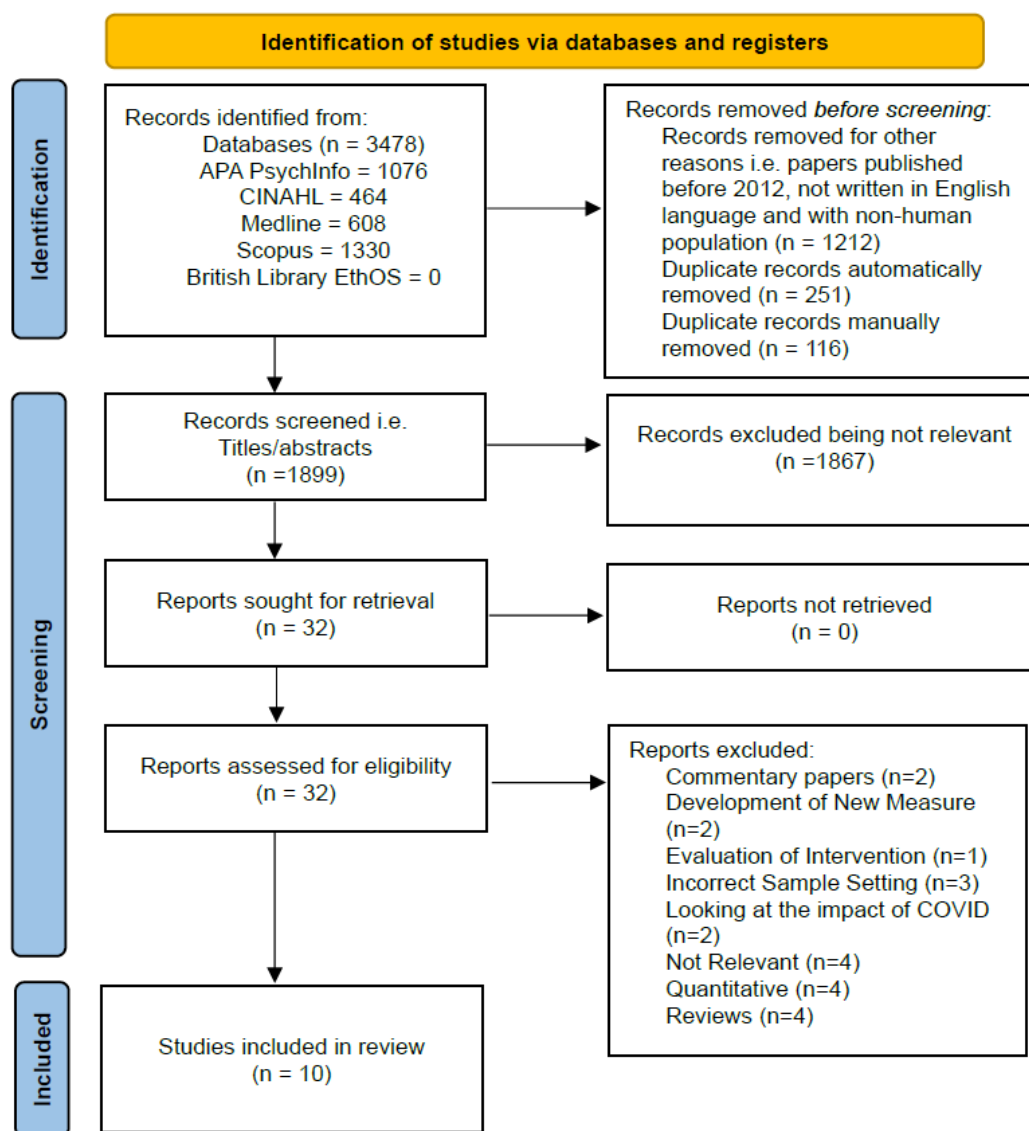
Figure 2 Identification of included studies. PRISMA Diagram (after [49]).

2.4 Quality Appraisal

The Critical Appraisal Skills Programme [50] qualitative appraisal tool was specifically chosen to assess the quality of papers. The tool systematically assesses the reliability and clinical significance by exploring the author's transparency and reflexivity [51], which is vital when interpreting participants perspectives and has shown great effectiveness [52]. The tool itself is endorsed by the Cochrane Handbook [53] and is commonly used to appraise healthcare research [54]. Using this tool, we completed a full quality appraisal of included papers.

Papers were scored against the 10-item CASP criteria. Papers were deemed as good quality if scored "yes" on 7-10 of the CASP criteria; fair quality if scored "yes" on 4-6 of the criteria; and poor quality if scored "yes" on 1-3 of the criteria. For this review only papers of good quality were included in the result section to ensure a good quality review. Finally, the tool categories fall into domains which can be used to assess specific aspects more broadly. For example, questions 1 to 5 assess the paper study validity; questions 6 to 7 assess the paper results; finally questions 8 to 10 assess the paper clinical applicability.

2.5 Data Extraction

As the inclusion criteria for this review was specifically looking at SA communities currently settled in the UK, only papers located in the UK were selected. This review adapted its table of characteristics based on Noyes et al. [55] example of "contextual and methodological information" to consider (Appendix C). An example of the meta-ethnography first, second and third-order overarching constructs is presented in Appendix D. Both reviewers completed screening, data extraction, quality appraisal and developed overarching constructs.

3. Results

3.1 Study Characteristics

Nearly all selected papers used purposive and snowball sampling techniques to engage with participants with research by either approaching ethnic minority-led charities or voluntary services, places of worship, or directly from National Health Service (NHS) memory services (Table 1). Papers conducted either one-to-one semi-structured interviews or utilised focus groups by using vignettes to stimulate conversations. Of the 10 papers, two [56, 57] focused on novice SA communities who had no prior experience with dementia whereas all other papers explored South Asian carers experiences. Three papers explored Bangladeshi participants [56, 58, 59]; one each explored Indian [60] and Pakistani [61] participants, whereas the remaining explored either a combination or did not specify which South Asian countries [10, 57, 62, 63].

3.2 General Themes

Four overreaching general themes were synthesised from the selected papers: unfamiliarity with dementia, cultural expectations, issues with services and protective factors (Figure 3). These were developed after comparing and contrasting first and second-order constructs.

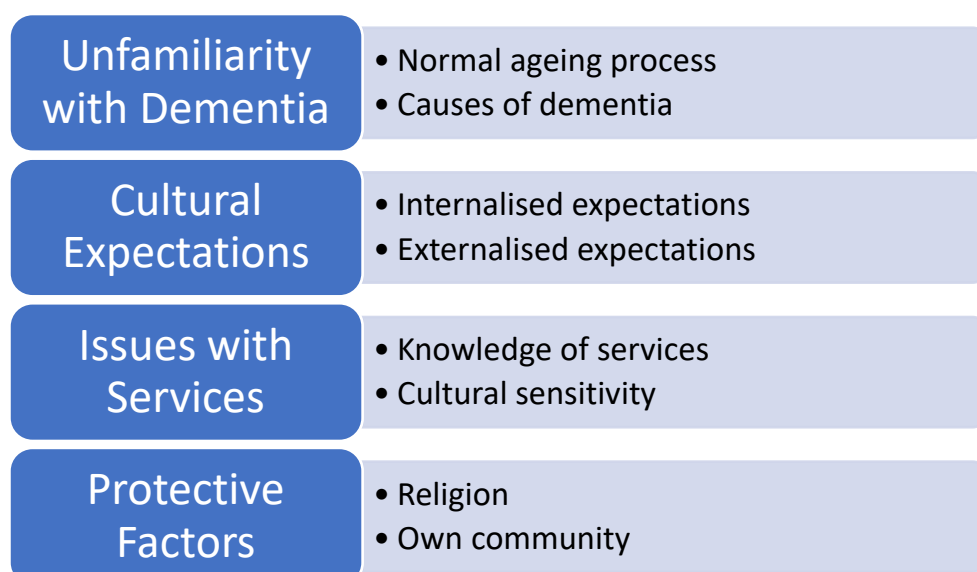| Unfamiliarity with Dementia	• Normal ageing process • Causes of dementia
Cultural Expectations	• Internalised expectations • Externalised expectations
Issues with Services	• Knowledge of services • Cultural sensitivity
Protective Factors	• Religion • Own community

Figure 3 The four identified overreaching general themes to explain the dementia help seeking behaviour in South Asians living in the UK.

3.3 Unfamiliarity with Dementia

Nearly all papers found participants were not aware of dementia [56, 60, 61], especially during the early stages of the illness:

"With my dad, I didn't realise. Because he had never been diagnosed with dementia." [58]

Due to the unfamiliarity of dementia, some participants would wait nearly 10 years before seeking help from services [58]. Participants also stated they only heard of dementia once their relative was officially diagnosed [63] and spent time researching online, reading books, and Alzheimer's Society advisors [58] to learn more.

3.3.1 Normal Ageing Process:

As a result of this, several participants thought early symptoms of dementia, such as unusual behaviour [58], aggression [63] and memory loss [56] were due to the normal ageing process as the body naturally deteriorates [57, 60]:

"We know people get old and they become senile and they lose their memories." [63]

3.3.2 Causes of Dementia:

Some studies also explored participants beliefs about the causes of dementia. Baghirathan et al. [10] found words used to describe dementia in communities language were also used to describe madness caused by evil spirits. Furthermore, black magic [63], karma [60] and accumulation of bad deeds done in a previous life [57] were thought to cause dementia. Finally, several participants expressed their understanding of how dementia develops from religion:

"Allah gives disease, everything happens if Allah wishes. Every disease, every suffering comes from Allah. Allah gives disease, Allah cures, we cannot say anything." [58]

As many participants shared the belief dementia was given by religious figures, they may have felt it redundant to seek help from services as they would be unable to support.

3.4 Cultural Expectations

A common thread across papers was the significant expectations (internalised and externalised expectations) about participants caring role and how it plays an active part in seeking help.

3.4.1 Internalised Expectations:

Participants held high expectations about themselves and their carers role. Thus, participants felt they should care for their relatives themselves and these expectations were often modelled to participants from a young age:

"When I was little I had seen back home my mum and my uncle, my everyone, how they used to look after my grandma and granddad." [62]

This observed behaviour demonstrates to participants, families care for their own without needing the support of "others" or "outsiders" as well as to emulate the care they received:

"If my wife gets dementia as a husband I am there, my children are there" [59]

However, this moral duty to care for their loved ones can act as a barrier to seeking help. Hossain and Khan [59] found that due to carer's ability to self-manage their relatives symptoms for long periods, they only sought help when they no longer could cope and reached a crisis point. This resulted in delayed help-seeking for nearly 10 years after symptoms started to develop.

3.4.2 Externalised Expectations:

Internalised expectations were often influenced by the expectations held wit*hin the wider* religious and cultural communities. Cultural*y it was vie*wed unacceptable to seek help as it was the c*arers duty t*o look after relatives [63]. This was usually found in parent-child rela*tionships. It* was suggested as parents cared for their children; it was the child's duty now to reciprocate that care:

"It is an expectation and a belief that we bore you (at) a young age, raise you to manhood, and then you return onto us the favour till death do us part." [62]

Some studies found participants raised with values of caring for "elders" were taught from religion [61]:

"They expect you to care and provide that care, because that's your duty. They're not interested in how you are coping." [61]

For some, religion was an important aspect of their culture and identity. As they actively work to uphold these values, this in turn may explain why some communities do not seek help. Whereas for some, the reason they maintain these cultural expectations was due to fear of judgement from the community:

"What will the community say so, what would your neighbour say? That man there is abandoning his parents because people conflate." [61]

This was further enhanced by participants reports on how the community would view them as honourable in their caring role without the need to seek external help [62]. Some even described caring alone "*as a badge of pride*" [57]. Additionally, many communities do not disclose their relative's diagnosis [61] and the fear of judgement may explain this. Some described discussing memory problems within the extended family as "disrespectful" [57], while others said dementia was regarded as a "flaw" and "problem," and therefore not openly discussed [60]. The reluctance to highlight one's vulnerability may be due to fear of social exclusion. This was further supported by participants who stated discussing physical health within their community was more socially acceptable than discussing mental health [63]:

"Sometimes you can get a stigma attached to being not quite right mentally because physically, people will accept if something is wrong." [60]

By not discussing dementia and sharing knowledge amongst the community, it continues to restrict the information individuals may have to recognise dementia and seek help.

3.5 Issues with Services

3.5.1 Knowledge of Services

A common concept expressed in a number of reviewed studies was the unfamiliarity SA communities had regarding services:

"People don't know about the services…. There's lack of knowledge about the services" [57]

Although this view was expressed by an individual with no dementia caring experience, this unawareness of services was not limited to this group. Both Kevern et al. [61] and Hossain and Khan [59] interviewed Pakistani and Bangladeshi carers, who said:

"I wasn't aware of any organizations that could help. GP is always the first people that we go to, or we go to an imam or a faith leader as Muslims." [61]

Furthermore, as organisations did not approach SA communities it was felt these services were therefore not suitable for them:

"No, I did not contact [the] Alzheimer's Society neither [did] they contact me." [59]

Finally, it appeared some carers were fearful of services and the power they may hold:

"I think some people don't want to tell other people that they're forgetting, they're scared that they would think that they're crazy or if they're living alone, try and get them admitted or something." [57]

The lack of knowledge of services and their function could reinforce this associated fear, therefore further impacting communities intention to seek help.

3.5.2 Cultural Sensitivity

Negative preconceptions of dementia services were further compounded by the lack of cultural sensitivity shown by services. Hossain and Khan [59] reported participants frustration with the limited availability of same-sex staff for Muslim communities. This is further supported by Baghirathan et al. [10] who reported participants felt isolated from predominately all-white services that did not meet their cultural needs.

Communication with families is a key area to consider when working with communities, especially where English may not be the first language. However, Hossain and Khan [59] reported participants experiences of limited access to interpreter facilities:

"We couldn't find anywhere in the locality that would meet our cultural, linguistic, religious." [61]

"Care package should actually take, take into account people's belief and people's umm cultures and religion." [63]

3.6 Protective Factors

When trying to understand why SA communities are not seeking help from NHS services, it is important to examine the alternative options being accessed. Understanding what is working well in different communities could potentially help influence how the dementia health service could

adapt. Although religion and culture are significantly influential in many SA communities, only a few papers explored this aspect.

3.6.1 Religion

When interviewing Muslim communities, many participants found strength in their religion and utilised it as a form of coping strategy:

"You find solace in your faith and your religion" [61].

Due to cultural expectations many carers felt unable to seek help and therefore sought guidance elsewhere. In some religious communities, faith leaders were able to valid carers difficult experiences and actively encourage help-seeking behaviour:

"The Imams I've spoken with, said that if it gets to the point where you are struggling as carers and family carers . . . then that's permissible [seeking outside help]" [61].

However, this support does not seem universal across all religious leaders and communities:

"Caring from mum didn't weaken my Islam, but my faith in Muslims, certain people who are meant to be important gatekeepers disappoint me, to be honest with you, because I feel they could do more." [61].

3.6.2 Own Community

Some participants stated the importance of the cultural needs of their relatives and how this can be achieved by people from similar communities:

"I recognize that because my parents are from the Asian subcontinent, they have certain needs which actually my partner fulfils better than any paid service…" [62]

This was further supported by Baghirathan et al. [10] who found participants felt it was important to have autonomy over their relative's care. Some participants went on to suggest accessing ethnic minority-led voluntary community services as a way of choosing a service that met their cultural needs [10].

4. Discussion

Using TPB underpinned with meta-ethnography analysis, we explored South Asian communities' perceptions of dementia to understand factors preventing them from seeking help from services. Although TPB has been used to examine a number of different health behaviours, its use to explore determinants of utilisation of different types of healthcare, i.e. dementia, specifically among people from ethnic background, remains unchartered. The TPB is based on individual's intention to perform any given behaviour and is determined by three global constructs: attitudes (perceptions of the advantages and disadvantages of performing a behaviour), subjective norms (perceptions of the approval of significant others of performing the behaviour), and perceived behavioural control (perceptions about how much control a person feels they have to perform the behaviour) (Figure 1). We identified lack of knowledge about dementia as an illness, coupled with cultural and internalised expectations and subjective norms (Figure 3) to be the main barriers in help seeking behaviour.

The communities were not aware of what dementia is and understood early symptoms as normal ageing [60, 63] (Appendix D). Dementia seems to be initially recognised as not a problem services could help with and therefore services were not accessed. Participants also expressed fear of services and the power they have to remove relatives [57], stressing their negative experiences of culturally insensitive services that drove them to seek alternative approaches to best meet their needs. This may explain why individuals from these communities present at services later, usually when dementia symptoms become unmanageable. Interestingly, some communities explained the causes of dementia were due to evil spirits or given by religious figures. Since dementia was "given" by higher powers, communities may believe there is nothing services could or perhaps should do to help, thus further impacting their decision to access services.

Cultural expectations were another overarching construct which explored carers beliefs about providing care. Participants' decision to provide care was influenced by religion or expectation to reciprocate the care they received as children from their parents. These internalised expectations were often influenced by modelled behaviour of previous generations, hence the assumption they emulate this duty of care now. Participants caring role may mask the severity of symptoms and conceal the need for services, and contributing to people with dementia present at services later when in crisis. Although participants held these core expectations, some may have been upheld to fear of judgement from their community. The communities' view of accessing outside help as unacceptable prevented carers from seeking help from services as well as restricted the ability to share knowledge amongst their community. This further reinforces the overarching construct of unfamiliarity with dementia preventing carers from seeking help.

Participants' attitudes are also influenced by their subjective norms. Carers cultural understanding of dementia as given by religious figures [58] may suggest the belief services cannot or should not help, thus impacting their decision to seek help and engage with services. Similarly, carers' core belief in reciprocating the assistance they received was influenced by their communities expectations [62]. Therefore, seeking outside help was seen as unacceptable and prevented them from accessing services. Finally, participants negative experiences of culturally insensitive services may have also influenced their attitude and decision to seek help [61].

The carer's perceived behaviour control could be impacted by not only how accessible services are but how suitable they are. Undoubtedly, the initial unawareness of services influences the carers decision to seek help [57]. Furthermore, negative experiences from culturally insensitive services may discourage their use. Carers also expressed a lack of autonomy around their relatives care which may explain their limited engagement with services as they were unwilling to comprise their identity [10]. Therefore, carers utilised protective factors of religion and depending on one's community to fulfil their needs. This suggests that when carers needs were not fulfilled by services, alternative support systems were utilised instead.

The primary strength of this review is that it builds on the existing knowledge obtained from Blakemore et al. [34] review. However, it provides a more focused view of UK SA communities perspectives of dementia. By synthesising existing literature we identified unique overarching understandings not explored previously, i.e. cultural expectations and protective factors can have a significant impact on communities decisions to engage with services. However, the review process of developing overarching constructs is subjective to authors interpretations and values [64] and drawn conclusions may not align with others understandings of the topic. Although we adopted a systematic approach to selecting papers, the ones identified could have been restricted as there

are common inconsistencies when indexing papers, and relevant papers could have been missed [65]. Finally, it is important not to make assumptions and group all SA communities together, since they differ from one another, but rather take into consideration the role different intersectional aspects can have in communities identity and provide services which incorporate these. This review runs the risk of being viewed as holding all SA communities the same and supporting unhelpful assumptions, whereas in reality communities differ greatly.

It is also important to view the strengths and weaknesses the selected papers may have. When examining the domains, all selected papers scored highly on both the validity of studies and the clinical relevance of the results, as assessed by the CASP tool. However, papers differed when considering the relationship between the researcher and the participant. For this methodology and area of interest, it is important to examine how the researchers perspective could influence results. Therefore, these qualitative papers would need to be considered with some caution. Although this review attempts to produce high-quality analysis by excluding papers scoring *fair* or *poor* through the CASP appraisal tool, criteria can be difficult to judge and be subjective [66] and papers which provide valuable insight may be excluded [42]. Furthermore, the depth of knowledge from qualitative research is often restricted due to publication requirements [67], and, therefore, the quality assessed may not accurately reflect the research produced.

Several papers were conducted by the same author and the same specific population i.e. Bangladeshi communities based in Portsmouth [56, 58, 59]. Although purposive and snowball recruitment strategies were indicated, the risk of potentially inviting the same participants might have existed, and this may provide a biased view of dementia. Additionally, the participants attitudes may have changed over continued exposure to the topic through research, further impacting results. Furthermore, although the SA continent comprises 8 countries, not all of these were represented in the included studies (Table 1). Some papers looked at populations more broadly, and either did not specify or categorised them as "Other" [10, 57]. By doing this, papers risk communities being homogenised, and leading to conclusions being inappropriately applied to all communities. Finally, although papers conducting in-depth 1:1 interviews provided a more nuanced understanding of the topic [68], these studies had smaller sample sizes, and therefore conclusions should be used cautiously.

Table 1 Characteristics of selected papers.

Author	Aims of study	Recruitment strategy	Ethnicity	Ages	Sample size	Methodological approach	Quality appraisal
Baghirathan et al., 2020 [10]	Ethnic minority carers experiences of dementia.	Approached or referred by ethnic minority-led voluntary, and community services.	African Caribbean, South Asian (Muslim, Sikh and Hindu) and Chinese	Not Reported	27 individual participants and 76 from 8 focus groups	Semi-structured 1:1 interviews and focus groups	Good quality
Herat-Gunaratne et al., 2020 [62]	South Asian carers experiences of dementia.	Purposive recruitment at NHS memory services	Bangladeshi and Indian	Mean age 49.4 (Range: 32 to 69)	10	Semi-structured 1:1 interview	Good quality
Hossain and Khan, 2019 [58]	Knowledge of Bangladeshi carers about dementia	Purposive and snowball sampling	Bangladeshi	Mean age 44.16 (Range: 23 to 64)	6	Semi-structured 1:1interview	Good quality
Hossain et al., 2019 [33]	Dementia attitude in Bangladeshi communities	Purposive and snowball sampling	Bangladeshi	Not Reported	21	2 focus groups using vignetted to prompt conversation	Good quality
Hossain and Khan, 2020 [59]	Barriers experienced by Bangladeshi communities for dementia	Purposive and snowball sampling	Bangladeshi	18+	27	Semi-structured 1:1 interviews and focus groups	Good quality
Hossain et al., 2022 [63]	Experiences of carers from dementia diagnosis to end-of-life care.	Purposive and snowball sampling. Engaging with religious communities and	South Asian (country not specified)	Not Reported	16	Semi-structured 1:1 interviews	Good quality

		day cares					
Jutlla, 2015 [69]	Sikh carers experiences of dementia	N/A	Indian	Range: 44 to 83	12	1:1 narrative interview	Fair quality
Kevern et al., 2022 [61]	Religious influences on carers experiences.	Snowball technique and social media	Pakistani Muslim community	Mean age 43 (Range: 25 to 60)	7	1:1 semi-structured interviews	Good quality
Mukadam et al., 2015 [57]	South Asian's understanding of dementia and help-seeking behaviour	Purposive and snowball sampling	Bangladeshi, Indian, Pakistani and Other	Mean age 57 (Range: 18 to 83)	53	focus groups using vignetted to prompt conversation	Good quality
Uppal et al., 2014 [60]	Sikh communities understanding of dementia	Purposive sampling	Indian	Range: 18 to 55	28	6 focus groups	Good quality

Our findings extend previous reports for dementia help seeking behaviour from people from culturally and linguistically diverse backgrounds. Thus, the UK SA communities rely on filial obligations and close family support, like that of American Latino [70]. In addition, we confirm the importance of religion as opposed to medical healthcare and other dementia support services, previously reported in an UK scoping review that, besides British Indian, included African and Caribbean, and East and Central European participants [71]. In contrast, dementia inadequate knowledge and stigma impact help seeking behaviour irrespectively of ethnic background [72].

Our study highlight the need to normalise dementia and help-seeking behaviour amongst SA communities. For example, faith leaders providing validation of carers difficult experiences and encouraging them to seek help could be a method more widely adopted [61]. Addressing the issues with services would require engagement with communities and listen directly on how to improve, for example understanding the needs of same-sex staff and more diverse interpreter facilities. This may include visiting places of worship or ethnic minority-led voluntary services. Furthermore, training to recognise the importance of cultural identity and beliefs in seeking help behaviour from services would be required. Addressing these issues will hopefully reduce the cost of delayed treatment and ensure people living with dementia experience better life outcomes. As social norms were found to be influenced by cultural expectations, it would be important to explore if these norms are widely shared across ages and generations. This would ensure services continue to adapt and cater for service users' needs appropriately.

In conclusion, our review highlighted the cultural beliefs some SA communities in the UK hold around dementia and illness. SA communities' decision to seek help was often influenced by cultural norms reinforced by communities views on what is acceptable care and judgement if not followed. The reviewed studies highlighted the existing disconnection between UK dementia services and SA communities, which may also explain why these ethnic communities access services later and when in crisis. However, it is still unknown what precisely can help bridge this gap. To address this and provide a meaningful impact, an empirical project is currently in progress to interview South Asian families accessing NHS services to examine their individual understanding of dementia and experiences of accessing services, whilst approaching it from an intersectionality lens. This will help explore whether these cultural social norms have continued across generations and provide a more nuanced perspective. With the information gathered from this empirical project, we hope to identify culturally sensitive strategies that can enable us to co-produce culturally accessible care and support of people with dementia, their families and carers. By using this information services may develop strategies to engage with SA communities about dementia and the help available. It could also identify areas for services to become more culturally sensitive. This in turn would reduce the cost of late of delayed treatment and ensure SA people living with dementia experience better life outcomes.

Author Contributions

Both authors contributed to the conceptualization of the paper, identifying relevant literature, data extraction, assessing the quality of the studies, summarizing and interpreting of the findings. SW wrote the original draft, with both authors contributing to further reviews and editing of the text. Both authors have read and agreed to the published version of the manuscript.

Competing Interests

The authors have declared that no competing interests exist.

Additional Materials

The following additional materials are uploaded at the page of this paper.

1. Appendix A: PICO Strategy - Search terms used for literature review.
2. Appendix B: Results of papers produced per database.
3. Appendix C: Data Extraction Tool.
4. Appendix D: Examples of overarching constructs development.

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