

From detection to preparing for the end-of-life: a qualitative exploration of the South Asian family carers' experiences of the journey with dementia

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ABSTRACT

People of South Asian (SA) origin have a higher prevalence of dementia compared with the United Kingdom (UK) population as a whole. Little is known about how family carers of SA origin perceive dementia, manage access to dementia services, and how plans and preparations are made for end-of-life for loved ones with dementia. This qualitative study aimed to explore the experiences of carers of people with dementia of SA origin, living in the UK. Through semi-structured interviews, the perspective of caregivers of a person with dementia was explored from point of diagnosis to end-of-life preparation. Sixteen caregivers participated in face-to-face interviews. Four key themes are presented *i) lacking awareness at the start; ii) living with the challenges of dementia; iii) preparing for end-of-life; iv) preferences for burial*. Carers described difficulties in making sense of early symptoms and the behaviour changes they observed among their relatives with dementia. They described the tensions in trying to follow their religious and cultural identities of honouring the dignity and choices of the person with dementia. This study reports on the perspectives of SA carers of people with dementia, particularly exploring the end-of-life preparation and wishes of people with dementia in the UK. Family carers may benefit from accessing more culturally sensitive support when dementia is diagnosed, including such support when receiving formal day-to-day care. Importantly the findings suggest that planning and preparing to provide end-of-life for people with dementia should recognise and respect family and cultural contexts and religious beliefs.

Keywords

South Asian; dementia; family carer; advanced care plan; end-of-life care; qualitative research

“What is known about this topic”

- Caring for a person with dementia can pose many challenges for families, especially as the condition progresses and more care is required
- Awareness about dementia is reported to be lower among people from South Asian communities compared to the general population in the UK

- South Asian carers provide a greater level of care than any other ethnic group in England

“What this paper adds”

- South Asian caregivers face nuanced barriers when accessing mainstream services, particularly those related to end-of-life planning and care
- The importance of recognising culture and religion when providing health and social care to people with dementia and their families
- South Asian families face notable challenges in planning and implementing end-of-life care

INTRODUCTION

Approximately 850,000 people in the UK have dementia, with an annual cost of £26 billion (Prince et al., 2018). The total number of people with dementia in the UK is forecast to increase to over 1 million people by the year 2025 and over 2 million people by the year 2051 and this is set to increase individual and family burden, as well as increased pressures on health and social care (Pickett et al., 2018). There is evidence that dementia is proportionally more common in ethnic groups within the UK, particularly in people of South Asian origin, due to higher vascular risk factors in this group (APPG on Dementia, 2013; Parveen & Oyebode, 2018; Uppal & Bonas, 2014). Ethnic groups make up over 14% of the UK population and in the 2011 census, South Asians (Bangladeshi, Pakistani and Indian) made up 5.3% of the total UK population (Blakemore et al., 2018). However, it is difficult to define ethnic identity with any degree of accuracy, yet ethnic identity has a profound impact on the lives of people belonging to a certain ethnic group or culture in receiving countries. In the UK, South Asians or British South Asians are terms that refer to people whose ancestry originates in South Asia, such as those in Bangladesh, India, and Pakistan. Regardless of the fact that they are being grouped under the umbrella term “South Asians” in the current study, they may differ from one another by racial, linguistic, cultural, and religious factors. Similarly, research shows that South Asian ethnic groups are not homogenous, and it is inaccurate to portray culture as a set of common ideas shared by everyone of the same ethnic group. (Blakemore & Boneham, 1994; Blakemore & Boneham, 2004;

Milne & Chryssanthopoulou, 2005). Even within their own communities, the South Asian people are very diverse in terms of acculturation, migration, patterns of settlement and adaptation, educational attainment, income, religious affiliation, and length of residency in the UK (Milne & Chryssanthopoulou, 2005). Therefore, the data for this research included British South Asian adults who self-reported that they were not White, not Black, not Arab, and not from other races or ethnicities. In other words, this population is not intended to be treated as a homogeneous group and we have included participants of different racial and religious backgrounds in this study.

Prevalence estimates of dementia within South Asian communities in the UK are highly variable. A recent systematic review (Blakemore et al., 2018) reports overall rates similar to whole UK population, however also recognises high potential for false negative rates due to lack of culturally adapted diagnostic measures, and that dementia within South Asian communities within the UK will increase at a faster rate in line with general UK South Asian projected population growth. Added to that is evidence of increased prevalence of dementia risk factors (e.g. diabetes, stroke, cardiovascular disease) within the South Asian population that increase incidence (Singh, Dhamoon, & Alladi, 2018).

There is much less research evidence on dementia carer numbers within South Asian communities within the UK; Carers UK in 2011 (Carers UK, 2011) estimated the number of ethnic minority informal carers (all care) in England at 500,000 in 2011, though this may be an underestimate as evidence shows differences in the conceptualisation of “carer” within ethnic communities where many see this as a continuation of “family care and duty” and therefore do not identify as a “carer” (Lawrence, Murray, Samsi, & Banerjee, 2008). Furthermore, the Race Equality Foundation found that dementia prevalence in these communities is likely to be significantly underestimated (Truswell, 2014). It is projected that the UK prevalence of dementia within ethnic groups will be at 50,000 in 2026 and this will treble by 2051 representing a much faster growth than the UK population rates as a whole (APPG on Dementia, 2013).

NICE guidance (2018) has acknowledged clear challenges for ethnic minority groups with dementia, and AAPG (2013) highlighted that objectives from the National

Dementia Strategy within the UK are not fully inclusive of ethnic groups issues. Existing research has focused primarily on South Asian community members' knowledge and understanding of dementia and access to health services (Hossain, Stores, Hakak, Crossland, & Dewey, 2019), with little currently known about the experience of family-based care over time. Available evidence shows that caregiving is burdensome for relatives of South Asian people with dementia (Hossain, 2020; Lawrence et al., 2008). Whilst informal caregiving for those with dementia can be challenging and burdensome for all communities (del-Pino-Casado, Priego-Cubero, López-Martínez, & Orgeta, 2021) there may be additional challenges for South Asian communities in the UK with evidence of issues in receiving accurate diagnosis for their family member resulting in delay in accessing appropriate formal support services (Blakemore et al., 2018). This is important as the caregiver journey can last for many years from the point of diagnosis, with an average survival time of 6 years (Alzheimer's Association, 2021), and dementia accounting for approximately 15% of all registered deaths in the UK (ONS, 2020). In addition, there is a particular omission from current literature on the considerations for end-of-life stage care from a South Asian perspective. Advance care planning and preferred place of death are important outcomes for end-of-life care plans (Orlovic, Callender, Riley, Darzi, & Droney, 2020), and research has shown differences in perspectives and preferences dependent on ethnic and cultural influences (Cain, Surbone, Elk, & Kagawa-Singer, 2018). Through this study, we aim to add to the current paucity of literature on ethnic groups experiences of dementia in the UK, with a particular focus on the perspectives of the family member caregivers of persons with dementia by exploring the key issues from early detection of dementia to advance care planning and end-of-life care.

Aim

The purpose of this study was to explore the experiences of carers of people of South Asian origin with dementia in the UK from first signs to end of life care.

METHODS

Study Design and Setting

This an exploratory study, which adopts interpretivist-constructionist theory to acknowledge how meaning is constructed through subjective experiences and is therefore multivalent contextual and shaped by individuals, this approach further

recognises the active role played by the researcher in this process (Finlay, 2011). Current study involved in-depth semi-structured interviews with informal carers of people with dementia of South Asian origin. Ethical approval was obtained from Keele University ethical review panel. To ensure confidentiality, all interview data were anonymised, and each participant was allocated a unique number. The study was supported by a Patient Advisory Group (PAG), composed of South Asian community leaders and third sector organisation workers from the West Midlands, which contributed to the design of topic guides and discussed preliminary findings.

Sampling and Recruitment

Purposive and snowball sampling techniques were used to recruit participants to support data saturation (Saunders et al., 2018). Snowball techniques are useful for under-served groups and when there are limited resources, although there is a higher risk of selection bias (Quay, Frimer, Janssen, & Lamers, 2017). Potential participants were identified through community support groups, 'gatekeepers' to religious institutions (large Mosques, Temples and Gurdwaras) and via care homes and day centres within the West Midlands area. Contact was made via these channels by the interviewing researcher (ST) via email, telephone and leaflets to facilitate recruitment with potential participants actively responding to indicate their wish to take part. Study advertisements were distributed via charity organisations Alzheimer's Research UK (ARUK), the Alzheimer's Society and the Dementia Information and Support for Carers (DISC), and Join Dementia Research (JDR). People with dementia and caregivers who expressed an interest in taking part were able to contact the research team via post, email or telephone. At the time of the interviews, out of 16, two family carers were already in bereavement (one at 6 months, one at 19 months). Upon completion of the interview, each participant was offered a gift voucher as an acknowledgement of their contribution; the gift voucher was mentioned in the Participant information leaflet (which had been approved by ethics), but we agree may have acted as an incentive to participation.

Data Collection

Face-to-face semi-structured interviews were used to generate data. Participants were offered the choice as to where the interviews could take place, including their own home, workplace or a mutual place of their choosing. Before commencing the

interview, written informed consent was obtained. The topic guide was developed based on a review of relevant literature, the research team's expertise on dementia and our involvement and engagement with ethnic minority communities, as well as feedback from the Patient Advisory Group (PAG). Each interview lasted approximately one hour and was audio-recorded with consent, and transcribed, the transcripts forming the data for analysis (Green and Thorogood, 2013). Reflexive field notes were kept following the interviews which facilitated the interviewer (ST) to record observations from the interviews.

Data Analysis

All interviews were transcribed verbatim and checked for accuracy. Thematic analysis was performed by using the principles of constant comparison (Guest, MacQueen, & Namey, 2012). Thematic analysis allowed researchers to find meaning in various data sets, revealing collective and shared experiences (Braun & Clarke, 2006). Both manual and computer-assisted analysis, using NVivo 12, were undertaken. The process of coding was done systematically for each transcribed interview and sometimes multiple codes were applied to a single part of the text. Transcripts were read multiple times to familiarise authors with the content and to create a thematic framework. Preliminary themes were discussed with the team. Thematic analysis enabled authors to understand the phenomena under investigation, at an interpretive level. To ensure rigour and credibility of the research findings, we adhered to the COREQ checklist (Tong, Sainsbury, & Craig, 2007). Nonetheless, the research team met regularly to review the iterative approach to analysis. After 8 interviews, the team were confident that the main codes had been identified. Subsequent interviews did not yield any further substantive insights but supported further data comparison, refinement of key themes and provided reassurance that saturation had been achieved.

RESULTS

Data collection with sixteen family carers of people with dementia took place between January to October 2018. Family carers' demographics are shown in table 1 (Appendix 1). Four main themes are detailed below, with data extracts, and participant identifiers, to illustrate the themes.

Key themes

Lacking awareness at the start

Family carers described an awareness that something was happening to their relatives with dementia, however, they did not recognise that the changes might indicate dementia. Almost all participants commented that there was a lack of awareness of dementia within their community, with most commenting that they only became aware of it following the diagnosis of dementia in their relative:

When my dad didn't actually understand dementia, he'd leave mum locked up in the house and go off and I had no idea that that was happening. I was like oh gosh, this is...this is really shocking. P1

A few participants commented that lack of awareness of dementia was a particular issue for some first-generation South Asian people:

I think if you're more from the first generation, it's probably not understood, it's much more... a physical kind of, a real... P10

Carers reported a range of features that raised suspicions that something was wrong, including memory loss, behavioural changes, personality changes and reduced activities. Memory loss and forgetfulness was the most common feature reported by the carers. However, half of the respondents felt that memory loss was a normal part of ageing.

My dad was never forgetful, so then he'd start forgetting, so I'll give you an example, he'd forget my name, call me somebody else's name. P5

Like, we know people get old and they become senile and they lose their memories and, and can't do what they used to do. P9

Four carers mentioned that initially the family had concerns that the person developing dementia was fabricating problems:

Because dad used to think that mum was making it up and mum was doing it deliberately... mum was deliberately being lazy. P1

Carers reported that they noticed changes in their loved one's behaviour such as aggression or being withdrawn:

He'd start shouting and screaming in the middle of the night, he wouldn't understand as much. P6

Living with the challenges of dementia

After recognising something was happening to their relatives with dementia, family carers started to make sense of dementia, and looked for the cause.

Some respondents commented that dementia came from God:

Understanding meaning, yeah because what we believe, being that, in Islam, that all diseases come from the heavens, they come from Allah's will, it's come and it's a testing time for everybody" P12

A minority of participants (two carers) mentioned black magic as a possible cause of dementia.

I mean in South Asian people, uhh a lot of them put it down to black magic. P11

Many participants mentioned the stigma associated with dementia itself, seeing it as something shameful and embarrassing. Several participants made comparisons between dementia and physical health issues, such as heart attack, where the latter was easier to talk about in South Asian culture, compared to the former, which is a mental illness:

We'd never tell anybody about the diagnosis. So if my dad had a stroke we could quite easily phone a relative and just say, oh we've had an awful week, dad's been in hospital, he's had a you know, this, you know, this kind of medical problem or that kind of problem. But you mustn't talk about those kind of things like umm, being mentally ill or having something wrong with like your cognition

because umm... I suppose people would find it quite strange... they might think that they've gone mad. Literally we told nobody. P 9

Participants also reported stigma associated with seeking help from others outside of the family:

Because culturally we have to look after our parents. We'll just deal with. We don't want extra support, whatever it is, you see... I think that's sort of negative. By asking somebody else, it could sort of like a negative on them. P4

The majority of the participants described how experiences of formal support services had been largely negative, with the perception of long delays, lack of support provided, high cost, barriers in terms of language when liaising with formal services:

... and it was just really a case of we saw a consultant who said that there's no cure for dementia, Alzheimer's and dementia and this is your lot basically you've just gotta cope. There wasn't any sort of support mechanism. P1

Carers described how the care packages provided were perceived as inadequate particularly about how their personal, religious and socio-cultural values were not respected:

I think a care package should actually take, take into account people's belief and people's umm cultures and religion. This person is obviously still got dementia, but they are still following their beliefs and it still has to be adequate to that, that basically. P10

Participants described their specific cultural and religious beliefs concerning personal care such as washing and cleaning. When the cultural and religious sensitivities to nakedness were not taken into account by paid carers, which was reported to be a common experience, it caused distress for the person with dementia. Sometimes the nakedness referred to areas of the body that were religiously and culturally based and not just intimate areas (e.g. knees, head-covering).

Carers described that there was a perceived lack of cultural and religious understanding amongst some paid carers in addressing the religiously appropriate personal hygiene needs. Several participants commented that when paid carers were from a similar cultural background, there was increased understanding and an improvement in the relationship between the carers and person with dementia/ family members. This was for cultural and religious reasons and resulted in distress in people with dementia when they were not addressed:

The washing was, you know, wipe downs, not proper washing, it was done by females which you know, everyone's got a job to do. But obviously I'm sure they probably had male carers that might have been more appropriate. P10

In addition, some participants reported that for their relatives with dementia, it was important that same-sex paid carers were allocated when providing personal care.

Preparing for end-of-life

Respondents reflected on end-of-life preparations and burial practices for their family members with dementia. Family carers described how they had witnessed poor delivery of care towards their relatives. They wanted timely planning discussions, discussion about whether hospital admission was necessary or not, and most importantly, planning for the death certificate to be signed promptly to enable early funeral, or transporting the deceased person to their countries of origin.

Participants described that an advanced directive had not been prepared but several mentioned that wills had been arranged or the final wishes of the person with dementia made known to family members. Most participants had not completed advanced directives or made power of attorneys, when asked about it during the interviews. One participant felt frustrated that her family members had their 'head in the sand':

I brought the power of attorney, lasting power of attorney. I brought those forms moons ago. Although I'm mum's carer, I don't make financial decisions for mum, dad does. I'm like saying we need to deal with this, we need to attend to this, but it's just like heads in the sand and no one can see them. P1

When asking about advanced planning some respondents attributed the dynamics of the family in the South Asian community. Five participants described how they would typically avoid discussing death and/or completion of a will due to issues related to stigma. People with dementia might misunderstand their intentions such as the carers were after their properties only rather than providing quality care.

They don't like to talk about the will, if the children say have you made, we need to make a will, they think that they want to take everything away from them (laughs), they're just after the property, money, children are. So they're very reluctant to talk to their parents about the will and power of attorney. That's a, another big stigma about will. P13

Some participants reflected on withdrawing treatment at the end-of-life, such as, caregivers reported that doctors sometimes had to stop treatment for their relatives with dementia, a decision that was very difficult to accept. The carers later approved the doctors' decision; however, they did not disclose that choice to their relatives without dementia. For example, the following carer hid the decision to withdraw treatment for her father with dementia from her mother. As a medically knowledgeable family carer, she could bear the pain and understand the situation, but she described her mother would rather put the blame on her for doing so.

But that's what they decided (hospital) and the GP decided the same, so. I didn't really tell my mum. Luckily my dad was quite bad at taking medicine, so like umm, we had like old medicine and stuff, but he became too ill. He became too ill to take it. The carers couldn't get him to eat. I didn't tell my mum because she would feel like, oh I failed, for the daughter. Umm, and, she, she would umm she would be upset with me forever more and I didn't really want that. She'd blame me. P9

Some participants stated that practical difficulties prevented them from engaging in any conversations or sharing decisions with healthcare services about end-of-life care planning when their family members were living with dementia. They emphasised that interpreters could help them to convey their messages or discuss with the service

providers on their behalf about any decisions that needed to be made during the last stages of dementia for their parents:

Language was obviously an issue. The communication isn't right, so, you know, there needs to be people in place who can interpret the needs of people on the ground basically, to make sure umm, everything's understood, what is needed.

P10

Preferences for burial

Several participants described how in Muslim culture, the burial should take place as soon as possible, while another also added that they preferred not to have a post-mortem:

Religious thing as well because when it's time to go, it's time to go. When somebody's buried, it kind of eases the pain when they've gone. But if they're hanging around in the mortuary or you know, in a freezer somewhere, you've always got that kind of like pain that they're still, they haven't gone yet. P11

One family carer described how they expected a rapid delivery of their relative's dead body so that they could bury him next to his mother's grave as he wished. However, family carers expressed frustration as they did not receive the body until two weeks had passed:

There was a whole week, two weeks, my dad was in a coroner's place in City Centre in a fridge in City Centre. Because he died in hospital, they had to do the autopsy. So we couldn't get him released for like two weeks. P9

About half of participants commented that within their culture, it was common for the body or ashes to be taken abroad to the countries of their origin. Some also mentioned that they wanted the burial or cremation to be according to their religious and/or cultural beliefs and practices.

He did leave certain instructions, for example, he said that when I pass away, I want my body to be taken back home, back to India, I don't want to be buried here and stuff like that and this when I pass away. P5

The decisions to take their relatives to their countries of origin came at a high emotional and financial cost. Family carers described unpleasant experiences of transporting their deceased relatives to their countries of origin. They were anxious about the repatriation of the deceased persons from the UK to their home countries could cause additional damage to their dead bodies. Despite their distress and worries, they did ship their relatives' dead bodies to their birth countries to be buried:

They're gonna put him in the coffin... they're going to break all his bones and shove him in, all crumpled up. I was like, ooh, oh my God, that is horrible, I can't imagine people would do that to my beautiful dad's body, you know, so we were kind of like, ooh, what we going to do. But my dad was absolutely adamant he wants to go back to Bangladesh, so we did that. P9

Like above, two participants also reported that while the previous practice had been to repatriate the body or ashes abroad, it was now a common practice to bury or scatter ashes in the UK, where the family were located.

Before they used to take in India, the ashes...journey to India to take ashes back and it's, it's a religious place where they take the ashes to, Sikh people are different place and Hindu people do different place. But now, most of the children start putting the ashes in the river here. P13

DISCUSSION

The findings of this study highlight several key aspects associated with the understanding and experiences of some carers of people of South Asian origin living with dementia in the UK. Regarding the emergence of initial symptoms of dementia, findings suggest limited recognition of these symptoms like dementia, suggesting a potentially low level of knowledge about dementia within South Asian communities. Although early signs of dementia such as memory loss or other behavioural and personality changes were noticed by carers, they were not linked to dementia initially and were generally perceived as part of normal ageing. Consideration of the caring journey and the perspectives and challenges of family caring, a clear issue was dealing with the stigma associated with having a family member with dementia as well

as issues on the current and future provision of end-of-life care services. Findings on end-of-life preparation are particularly novel as no previous qualitative research has been established to report on this phenomenon and emphasizes to the cultural and religious influences in the planning of end-of-life for those with dementia within a South Asian context.

The body of published research on dementia and caregiving within South Asian communities is sparse, especially from those who live in non-South Asian countries. Our findings regarding knowledge and awareness of dementia among South Asian participants appear consistent with prior studies, such as the person with dementia as being possessed by evil spirits or as a result of black magic, or as God's punishment for previous life's sins, and stigma associated with dementia (Adamson, 2001; Mackenzie, 2006). To date, no studies have examined carer perspectives on planning and preparing for the end-of-life of their relatives with dementia in the UK. Recent evidence suggests that most South Asian people with dementia are managed at home by their family carers (Hossain & Khan, 2020). Contrary to what is previously reported, our study shows that owing to inadequate information about dementia, advanced care planning, and end-of-life caregiving, family caregivers experienced contextual uncertainty when caring for their relatives with dementia at home. Carers reported the lack of a unified approach to defining dementia; this is well described in the literature (Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007; Hossain and Khan, 2019; Mukadam et al., 2011; Uppal et al., 2013).

Similar to other studies, the current study has found that the caregiver's wellbeing was compromised when they gave priority to the person with dementia, causing the caregiver to feel unappreciated and isolated (Blakemore et al., 2018; Giebel et al., 2019). During this study, family caregivers were also required to advocate for their relatives' needs, which added a layer of responsibility to existing multifaceted responsibilities, especially where cultural sensitivity was lacking (Greenwood, Habibi, Smith, & Manthorpe, 2015). Despite this paradox, caregiving for elderly relatives with dementia was an opportunity to gain blessings and virtue, rather than serving as a burden.

In our study, family caregivers were resistant to formal caregivers of the opposite sex providing care to their relatives; formal care agencies did not appear to be aware of cultural and religious attitudes and beliefs about this. Family carers wished for greater consideration about these beliefs to facilitate greater levels of trust. Other research has reported similar findings, Hossain and Khan (2020) for example, found that receiving personal care from someone of the opposite sex was forbidden within their family groups. The authors further describe how service providers, through their community engagement objectives, can overcome the barriers of accepting services, helping them to become learning entities by providing them with same-sex carers and information for developmental strategies. Echoing the previous evidence, the current study clarifies through partnerships and shared strategies between South Asian communities and the service providers, each with diverse knowledge and resources, working together to create answers for complex end-of-life care needs.

It is a taboo to talk about death in advance in some South Asian communities because people fear that this may bring death closer (Biondo et al., 2017). This may have partly explained the lack of plans for end-of-life care among our participants. While it seemed that family caregivers and relatives followed their religious values strictly before the death of the person with dementia, there was no planning and preparation. Their religious practices heavily influenced their burial practices. Moreover, withdrawing treatment was one of the hardest decisions family carers had to make regarding their relatives with dementia's end-of-life care which was something rarely reported in previous studies. There is evidence that within the South Asian community, there is a stigma attached to seeking help from outside services, such as care homes, which is another driver to caring for the person towards the end-of-life in their own home (Adamson & Donovan, 2005; Hossain et al., 2018).

South Asian religious and cultural factors may influence how clinicians and carers reflect dignity in end-of-life preparation for people with dementia (Hossain & Mughal, 2020). However, regardless of ethnic differences, human dignity has been recognized as a key concept in medical ethics and underlined as a principal obligation of healthcare professionals worldwide (Kadivar, Mardani-Hamoooleh, & Kouhnavard, 2018). The Department of Health (2008) recommends a good death would involve being person-centred: being treated as an individual, with dignity and respect, without

pain and other symptoms, in familiar surroundings and the company of close family and friends. Echoing the Department of Health (2008) suggestions, Alzheimer's Society (2021a) described that substantial, organized and holistic care is required to guarantee that all people with dementia end their lives with dignity, free from pain and in the place of their choosing.

Implication for practice and future research

The provision of advanced care planning as early as possible is key means to make informed decisions as well as to improve end-of-life care outcomes for people with dementia and their family carers (Alzheimer's Society, 2021b; The National Institute on Aging (NIA), 2021). Within this remit, the current research has important implications for health and social care service providers working with South Asian families of people with dementia and their family carers. Future research may benefit from investigating how fulfilling the religious and cultural needs of their relatives with dementia financially impacted the family carers lives. From the family carers perspective, there is a great need for dialogue with the policymakers about releasing the dead bodies of South Asian people with dementia which may facilitate religious burials. It is also important for South Asian community to have an open dialogue about the cultural and religious aspects. That may assist and avoid shipping their relatives' dead bodies abroad to reduce the psychological and economic worry for the family carers. Nonetheless, there is a prerequisite of good quality training and education for clinicians, care workers need to be identified, especially in how to take care of people with dementia from minority ethnic older people groups with dignity and respect.

Strengths and limitations

The research provides an empirical contribution to existing work in this area. However, there is limited qualitative research examining the knowledge and understanding of dementia, planning and preparing for end-of-life and accessing dementia end-of-life care planning services among the South Asian carers in England or elsewhere. This current study gives insights into how family caregivers for relatives with dementia understand the pragmatic and sensitive challenges regarding dementia, for example, advanced care planning in end-of-life. Findings also raise awareness about information and support needs of South Asian caregivers, such as end of care planning and burials. In addition, our study adds new evidence on how South Asian

caregivers face nuanced barriers, for example, when they try to access mainstream services, particularly those related to end-of-life planning and care. Recruitment was facilitated by the use of an interviewer who is South Asian, the process of recruitment was also enhanced by contacting community leaders through trusted gatekeepers to some third sector and charity organisations, and religious institutions in the West Midlands. Sharing the same cultural identity increased the research validity through an understanding and closeness with participants in the research (Kanuha, 2000). Having a researcher and gatekeepers who were from the same community and shared the same culture and religion as the participants created good relationships among the South Asian community and encouraged participation in the research. The Patient Advisory Group (PAG) was involved in the development of the study, drafting a topic guide and public-facing documents for the ethics application, and discussing data analysis.

Nevertheless, this study had several limitations, and future South Asian research may explore these areas in greater depth. As an example, identifying South Asian people with dementia and their family carers for research presented several recruitment challenges. Previous literature has highlighted challenges in relation to South Asian communities perceived as closed to outsiders (Bowe & Wilkinson, 2002), gender (Hossain & Khan, 2019; Hossain, Stores, Hakak, & Dewey, 2019), language barriers (Quay et al., 2017), and stigma in the context of mental health and illness (Quay et al., 2017). By utilizing purposive and snowball sampling methods, we were able to collect and analyze data from a wide range of viewpoints (Bogdan & Biklen, 1998; Glaser & Strauss, 1967). However, the sampling strategy may still have been impacted by the aforementioned challenges. The views of participants may not reflect the views of the wider population, but are nonetheless important.

Moreover, as a South Asian himself, the interviewing researcher's (ST) insider perspective and shared experiences could introduce personal and cultural bias into the fieldwork and process of analysis. A reflective diary was used by the interviewing researcher to support diligent self-examination and critique; reflective notes were recorded during and after each interview to demonstrate reflexivity, acknowledge the interpretivist-constructionist approach and help ensure the story of the participants did not become over-shadowed by the story of the researcher. The team-approach to

analysis was essential in order to check transcripts, discuss interpretations and challenge potential biases in the analysis.

Also, the focus of this study was on the experiences of informal carers we did not therefore include the views and perspectives of persons with dementia. The inclusion of individuals with dementia might have strengthened and enhanced the findings (Stevenson & Taylor, 2019) and future studies may wish to include these perspectives, perhaps using dyadic interviews, to give greater insights into the experiences. Last but not least, interview participants were recruited from one area of England (West Midlands) which is largely urban area, therefore our findings may not be fully representative to other South Asian communities and settings within the broader UK.

Conclusion

According to the findings of the current study, South Asian participants are unaware of the symptoms of dementia and how they may present. The lack of research on palliative care and end-of-life preparation among South Asians with dementia has reportedly raised more questions than answers concerning access to dementia services, and how end-of-life care plans and preparations are made for those with dementia. There is a need to better implement advance care planning in end-of-care settings for South Asian people with dementia. The results of this study highlight that the participants maintained their cultural and religious values throughout their time in the UK. However, these values and beliefs were not considered, with sufficient sensitivity, during interactions with healthcare providers and systems in the context of palliative and end-of-life preparation for people with dementia from South Asian communities. To overcome these challenges, the current study emphasises the importance of culturally and religiously sensitive education for healthcare professionals and the implementation. Family carers may benefit from accessing more culturally sensitive support when dementia is diagnosed, including preparation for end-of-life care. Planning and preparing to provide end-of-life care for people with dementia should recognise and respect family and cultural contexts and religious beliefs.

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Competing Interests

The authors declared no conflict of interest.

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Appendix: 1

Table 1: Demographic profile of the family carers

Demographics of family carers	
Number of family carers interviewed	16
Gender	Male: 9
	Female: 7
Age range (years)	20-30: 2
	31-40: 4
	41-50: 5
	51-60: 1
	61-70: 1
	71-80: 3
Self-identified Ethnicity	Indian: 9
	Bangladeshi: 6
	Pakistani: 1
Religion	Muslim: 10
	Sikh: 4
	Hindu: 1
	Christian: 1
Relationship to person with dementia	Partner: 3
	Child: 10
	Grandchild: 2
	Daughter-in-law: 1
Numbers of years as a carer	3-4 years: 4
	5-6 years: 4
	7-8 years: 3
	9-10 years: 1
	11+ years: 4

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