

“In the Bengali vocabulary, there is no such word as care home”. Caring experiences of UK Bangladeshi and Indian family carers of people living with dementia at home.

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Conflict of Interest

We have no conflict of interest to declare

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Abstract

Background and objectives: We aimed to explore experiences of South Asian carers of people with dementia receiving health or social care in the UK, purposively recruited to encompass a range of migration, economic and cultural experiences. While previous work in this area has reported carers' understanding of and attitudes to dementia, we explored how carers' cultural identities and values influenced their experiences, negotiation of the caring role and relationship with services.

Research Design and Methods: We conducted semi-structured interviews with 10 Bangladeshi and Indian family carers of people living with dementia at home. We recruited participants from community settings in London and Bradford, UK. Interviews were audio recorded, transcribed and thematically analysed.

Results: We identified four themes: an expectation and duty to care, expectation and duty as a barrier to accessing formal care (family carer reluctance, care recipient reluctance and service organization), culturally (in)sensitive care, and the importance of support from informal care networks.

Discussion and implications: Interviewees described tensions between generations with different understandings of familial care obligations. Expectations to manage led to burden and guilt, and the cost of caring, in terms of lost employment and relationships was striking. Unlike in previous studies, interviewees wanted to engage and be supported by services, but were frequently offered care models they could not accept. There was a tension between a state-provided care system obliged to provide care when there are no alternatives, and family carers who feel a duty to always provide alternatives. Informal social networks often provided valued support.

Keywords

Qualitative, culture, Asian

Introduction

In the UK, approximately 850,000 people are currently living with dementia. By 2050, this number is predicted to rise to two million. This is likely to include a seven-fold increase in the number of people with dementia from minority ethnic groups, compared to a two-fold increase in people with dementia from the majority population (Prince et al., 2014). Dementia incidence in minority ethnic groups might differ from the majority population for a number of reasons. These include social integration, socioeconomic factors such as lower income, less formal education, worse employment conditions, and differing prevalence of genetic variants linked to dementia, with lower prevalence of the APOE-e4 genotype found in Asian Americans compared with the majority United States (US) population (Mayeda, Glymour, Quesenberry & Whitmer, 2017). Black and Asian ethnic groups also experience more cardiovascular risk factors including obesity and diabetes, which are risk factors for dementia (All-Party Parliamentary Group on Dementia, 2013).

South Asian ethnic groups (primarily comprising people with ethnic roots in India, Bangladesh and Pakistan) are the largest non-White minority ethnic UK group, accounting for 5% of the population, or approximately 3.3 million people (Office of National Statistics, 2016). Most migration from India and Pakistan to the UK occurred after India and Pakistan achieved independence from the British Empire in 1947. The migration that occurred in the following decades came from a number of different locations and was in relation to industrial labour shortages. Large-scale migration from Bangladesh occurred during the Civil War that resulted in the creation of Bangladesh in 1971 (Spencer, 1997). Over a third of ethnic minority individuals living in the UK are UK born. Second generation immigrants tend to be better educated than their parents' generation, and better educated than their White native peers (Dustmann, Frattini & Theodoropoulos, 2011).

Compositions of national minority ethnic populations may differ between Western countries, but common, complex dilemmas arise from the effects of globalization on family life and traditional kinships. People from minority ethnic groups with dementia are more likely to be cared for at home by family members, with little or no support from formal health and care services, compared to White majority populations (Cooper, Tandy, Balamurali, & Livingston, 2010). In studies comprising primarily White majority populations in Western countries, family carers of people with dementia report worse mental and physical health, more absences from work, and lower life quality than non-carers (Livingston et al., 2017). South Asian carers may experience more burden, anxiety and depression than their White British counterparts, due to exposure to the multiple jeopardies of the stigma of dementia, racism, and lower socioeconomic status (Parveen, Morrison, & Robinson, 2013). Within the UK, Pakistani and Bangladeshi communities experience particularly high levels of inequalities, both in comparison with other minority populations and the wider population more generally (Harding & Balarajan, 2001).

Previous qualitative studies have interviewed UK family carers for people with dementia from South Asian ethnic groups. Attitudes towards caring as natural, a continuation of family relationships, virtuous, and expected predominate in their accounts and of those of people living with dementia (Blakemore et al., 2018; Lawrence, Murray, Samsi, & Banerjee, 2008; Lawrence, Samsi, Banerjee, Morgan, & Murray, 2011; Mukadam, Cooper, Basit, & Livingston, 2011).

However, previous assumptions that minority ethnic communities require less health care services due to their cultural values are now being challenged. A recent report concluded that although many minority ethnic carers feel culturally obliged to provide care, this does not mean that they feel willing or prepared to do so (Parveen & Oyeboode, 2018).

Stigma, fear and mistrust of formal services have been cited as possible explanations for the low rate of help-seeking from formal services reported in South Asian, and other minority ethnic communities (Blakemore et al., 2018). Fear of a move to long-term care may also prevent minority ethnic families or individuals with dementia from seeking help from formal services (Blakemore et al., 2018). South Asian family carers may be more likely to conceptualise dementia as a natural aging process, possibly as an attitudinal response to the stigma associated with dementia (Lawrence et al., 2008). Several studies have found low levels of knowledge about dementia in UK South Asian communities, as well as beliefs about causation that attribute blame to the care recipient (Hossain & Khan, 2019).

Like other diaspora groups, people of South Asian ethnicity living in the UK find meaning and identity from their cultural and ethnic heritage (customs, tradition, religion and language) and from their nationality and British norms, values and heritage (Dey, Balmer, Pandit, Saren, & Binsardi, 2017). Kitwood's model of personhood described dementia as a socially embedded phenomenon, with functioning and wellbeing determined by interactions of a person's neurological impairment and their social environment (Kitwood, 1997). Migration is also a socially embedded process that depends on and creates local and transnational social networks. Previous research on transnational kinship ties has predominantly focused upon those of 'economically productive' age or the care of dependent children. Their influence on the care and support of older relatives both 'at home' and in the country of migration are less well studied (Victor, Martin, & Zubair, 2012). Intergenerational differences bring further complexity, with the potential for different values and cultural identities determining care recipients' and carers' expectations (Lawrence et al., 2011).

In this paper, we aim to explore the experiences of South Asian family carers for people with dementia in the UK, purposively recruited to encompass a range of migration, economic and cultural experiences. While previous work in this area has reported carers' understanding of and attitudes to dementia and dementia caring, we sought to understand how carers' cultural identities, values and experiences influenced their experiences, negotiation of the caring role and relationship with services. Previous work in South Asian communities described a tendency to access formal health and social care services as a "last resort" (Victor, 2014). By recruiting family carers who were in contact with health and/or social care services, we sought to understand how South Asian family carers engaged with formal services experienced and used them.

Design and Methods

The study was located within a critical realist position (Houston, 2001) seeking to understand the lived experience of how family carers from South Asian backgrounds perceive their role as carers of relatives living with dementia. London (Camden and Kings Cross) Research Ethics

Service (reference: 17/LO/1713) and the UK Health Research Authority (HRA) approved the study in November 2017.

Participants

South Asian ethnicity was defined using the British Sociological Society definition and included people who self-identified as Indian, Pakistani or Bangladeshi. We purposively recruited family carers who had at least monthly contact with a care recipient with dementia who was living at home. We recruited from National Health Service (NHS) memory clinics in North London and Bradford, UK and through the researchers' professional contacts. We sought to recruit participants from either gender, a range of marital statuses, ages, educational backgrounds and occupations; people born in the UK and overseas. Recruitment continued until theoretical saturation was achieved.

Procedure

Interviews took place in the homes of the care recipients or family carers. All participants gave written, informed consent. The qualitative interview followed a topic guide (see supplementary material), developed by the co-authors and refined as the study progressed, in response to emerging themes. The guide explored the relationships between people living with dementia, family carers, NHS professionals, wider family or informal networks and the local community. We asked what the family carer felt independence meant for their relative, and what they considered to be the priorities in supporting them to be able to continue living at home for as long as possible. We specifically explored whether and how the culture, ethnicity, language or religion of the family carer influenced their experiences. Interviews lasted on average 60 minutes and participants' were offered a £20 voucher for their participation.

Data Analysis

All interviews were digitally recorded, anonymised and professionally transcribed by an external company. We used QSR International's NVivo 11 software (QSR International, 2015) for qualitative data analysis and took an inductive thematic analysis approach following the analysis steps identified by Braun & Clarke (Braun & Clarke, 2006, 2012): familiarisation with the data; generation of initial codes; search for themes; reviewing themes; defining themes; and write up of results. A. Burton and R. Herat-Gunaratne independently read each transcript and coded the transcripts into meaningful fragments to include all instances where culture, religion, language or ethnicity were discussed in relation to the participant's role as carer, or their relationship with services. These initial codes were labelled e.g. "reluctance to use care homes" and "importance of culturally specific food". The codes were then reviewed by and discrepancies discussed with N. Mukadam and C. Cooper. We used the constant comparison method to identify similarities and differences in the data and to organise the codes into a coding frame. Analytical activity ran in sequence with data collection with emerging codes and themes informing further interviews and modification of the topic guide.

Results

Participants and Demographics

17 family carers were approached for the interview. Ten completed interviews (58.8% response rate), six declined and one was not eligible as they were not from a South Asian background. Of the ten interviewed family carers, eight were recruited from London (seven from NHS memory clinics and one from a professional contact at University College London), and two from an NHS memory clinic in Bradford.

Mean age was 49.4 (range 32 to 69); there were three daughters, four sons, two wives and one husband of the care recipient. Half (n=5) were female. Six were of Indian ethnicity, and four were Bangladeshi. Half (n=5) were born outside the UK and they had spent a mean of 34.2 years living in the UK. One was educated to primary school level, three to secondary school, three to degree and three to postgraduate level. Six had been caring for the care recipient for 1-3 years and four for more than 10 years. Seven were employed, one unemployed and two were retired. Seven lived with the care recipient. Seven owned their home and three rented their accommodation. Eight were married or cohabiting, one was divorced and one was widowed. Half of their relatives with dementia were in receipt of home care, three accessed day centres or dementia cafes and one family carer described nurses visiting their relative's home twice daily to administer medication, while two family carers relied solely on informal family support networks. Nine family carers described receiving support from informal networks including family, friends and neighbors. All participants spoke English with sufficient proficiency to conduct the interviews in English. Table 1 lists the ethnicity and relationship to the person living with dementia for each recruited family carer.

Themes

Four main themes emerged from the interviews, which we describe with subthemes below. These were: 1) expectation and duty to care, 2) expectation and duty to care as a barrier to accessing formal care, 3) culturally (in)sensitive home care, and 4) support from informal care networks.

Theme 1. Expectation and duty to care

The family carers spoke of a natural expectation and duty to care for their parents and of caring in terms of reciprocity for care that they had received or observed in earlier years. This duty of care was perceived to be at odds with the individualistic Western culture in which they had been brought up.

“So, talking about the background they are from, there is an expectation now that we could have been quite selfish, or sort of absorbed the Western way of life, as we have chosen to raise you in this Country, but we made a conscious decision to not do that, and we basically invested all of our life savings in you. Now it's over to you” Carer three, Bangladeshi, son

“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 and I was little. I was about four, five and I used to do stuff for them. Giving some water probably, so growing up I have seen that not much but I have seen that this is how it is” Carer four, Indian, daughter

Most of the family carers said that they did not want their relative with dementia to move to a care home, even towards the later stages of illness progression.

“You know, the fact that... We know, at least from seeing other people, that if she were put into a care home or whatever she’d probably go downhill much quicker”. Carer two, Indian, husband

One participant noted that the word “care home” did not exist within their community. The theme of giving back to your parents was seen in the same context.

“...no such word existed. This is testament to the culture and the community from which they derived.” It is an expectation and a belief that we bore you at young age, raise you to manhood, and then you return onto us the favor till death do us part” Carer three, Bangladeshi, son

This duty and expectation could come at a high personal cost with some carers relating how this commitment to caring for their relative had led to the end of employment or relationships or would lead them to give up employment if their relative’s health deteriorated:

“In the end, if they say I can’t work, I have no choice, I will say, okay, yes, because family comes first. So I will look after him, and I will stay with him, and I will go around with him. Yes” Carer nine, Indian, wife

“Before I used to manage, just me and him. My son was working in [location], as an investment banker, but then one day he came and then he noticed I’m struggling with him, so he left the job and came here to look after both of us”. Carer ten, Indian, wife

“I have lost the partner. What can I do about that? I’m not, not going to go with my parents. My priorities were straight, because essentially it was find a solution for them, if you want to be with me, she essentially made me pick, and I said there’s the door, you know. These are my parents. So that’s how it ended.” Carer three, Bangladeshi, son

Theme 2: Expectation and duty as a barrier to accessing formal care

Subtheme A. Family carer reluctance to accept formal care

Carers spoke of the difficulties caused by these cultural expectations to manage care without formal support, including a reluctance to seek help at an early stage when difficulties may be less severe.

“Because I think the problem is that you also see relatives say I’m doing this all on my own. But there’s a sense of a badge of honour that no, I don’t need carers or I can cope and they don’t realise the bigger picture. So I think it’s important that not only do you have professionals bring that to their attention, but also that they can speak to other carers. To try and sort of see the potential benefit of doing so at an early stage, I think any intervention you can start at the earliest possible stage is best” Carer one, Indian, daughter

The expectation to manage led to burden and guilt. One participant considered how accessing a psychosocial support programme might have helped them cope.

“I really needed something like that because I have suffered so much with guilt you know, and if I’d had something like that to help me to cope, I just, it obviously would have been... Hopefully I would have coped better and I would have had a better relationship with my mum” Carer one, Indian, daughter

Subtheme B. Care recipient reluctance to accept formal care

While half of the participant’s discussed accessing home care services, some family carers who had asked for help from formal services faced dilemmas in receiving it. This included a reluctance of care recipients to receive some elements of formal care, preferring their families to provide their care:

“I don't know how she's going to react to someone from outside coming and taking care of her. Because she knows, like, her own children are there, her daughter-in-law is there” Carer five, Bangladeshi, son

“So, it’s very difficult. She basically refused their assistance in that spectrum. Furthermore, when that interview took place, she basically quite proudly boasted, that my son, they make my food even better, I don’t need your help. So whilst we appreciate the compliment, it also creates another job, doesn’t it?” Carer three, Bangladeshi, son

“So, this was my first experience of having so many carers and they weren’t Indian, you know, as I was saying, they were all from

***different... And you know, they were all kind people, but my mum would always favour me. She'd say [name] will do it, you know, she'd say you go home, you go home"* Carer one, Indian, daughter**

For some carers however, the negative impact of being the only acceptable carer to their relative was balanced by a sense of purpose and enjoyment of the time that they spent with them. This often involved discussions and activities tied up with cultural heritage and traditions from their relative's younger self.

***"She was a head cook at an Indian restaurant back in the 60s and was an exceptional cook in her time. And she doesn't cook any more but that's partly down to mobility and partly down to losing track part way through. But if we cook together and she, kind of, directs and supervises and I cook she remembers most of it actually. So that's her long term memory kicking in rather than her short term. If I, say, talk about the recipe and what do you add, she can actually say most things just like that, you know, for cooking a variety of curries"* Carer seven, Bangladeshi, son**

***"He was born in 1938, so we're talking seven years before World War II ended. He has some amazing stories my friend, from the '50s and '60s, and randomly, very randomly, they will just erupt from him. I don't know where they come from in his brain, I don't know how they arrive, but he will tell me stories, of once in 1964 his favourite Bollywood actor, he went to a cinema in Lahore or something like that, and he had to pay a touter just to get a ticket to get in to watch it"* Carer three, Bangladeshi, son**

Subtheme C. Service organization as a barrier to accepting formal care

One carer felt penalized for his decision to move in with his parent, as service provision was subsequently reduced. The request to reduce the care after he moved in seemed to tap into a sense of duty and lack of entitlement to services alongside anger due to the imperative to move in with and care for his parent. This might be considered more consistent with endemic UK values.

***After some time. They got in touch with me and they said we've observed that you are in the house with them in the evening, we are under the cosh, budgets, unfortunately we cannot send someone in the evening, can you manage that yourself?..... If they are going to reduce it from three to two (visits a day), I'm still grateful. Beggars can't be choosers. If you can't, then fine. They're my parents. I'll manage it.* Carer three, Bangladeshi, son**

Theme 3: Culturally (in)sensitive care

For carers and care recipients who had formal support at home, culturally competent care delivery was understandably very important. For many it worked best if the home care worker was from the same ethnicity or country, and critically if they spoke the same language.

“Her mother tongue is Bengali, and she doesn't understand Spanish or English. That's a big difference. So that person has to know that language” Carer five, Bangladeshi, son

For some family carers however, finding a home care worker who spoke the same language as their relative was a challenge.

“The care agency didn't have that many Asian carers anyway, let alone Gujarati speaking ones. So, it was very difficult, and if I tried to get carers from other countries, like English speaking ones, or you know, I had a French carer. And it didn't, you know, mum wasn't happy with that.” Carer one, Indian, daughter

However for one carer, culturally specific care was accessible when needed.

“I think at the moment we are getting a sitting in service and that's quite helpful because when they come, and we get a sitting in service from someone like a company that you know, Bengalese speaking person, not all the carers have it so, especially we, you know, sitting in service twice a week so she can go out.” Carer seven, Bangladeshi, son

A perceived lack of understanding by home care workers of the cultural importance of food was also identified as a barrier to seeking support from home care services for some family carers.

“It's that people are set in their ways and it's a different sort of food. So, you know, if somebody came to cook for him, it wouldn't be the same home cooking that he's used to. You know, spicy food and all that. It won't be, like, sausage and mash or something like that. So, it's not going to be convenient for him, also, to have that diet for him. So, home cooking is the best” Carer six, Indian, daughter

For some family carers it was more important that home carers respected and understood the cultural background of the care recipient rather than being from the same ethnic background.

“But, actually, some of that food culture and calling her mum and that whole Eastern respect, South Asian respect, is an important aspect, I think, of how she operates as a person” Carer eight, Indian, son

A lack of culturally relevant support offered to carers was also a barrier to accessing formal care, particularly for sons who were involved in caring for their mothers.

“And the [Name] programme just assumes that the carer will do this for their mother, for example. But actually, maybe, doesn’t understand the cultural sensitivities of things like that” Carer eight, Indian, son

An awareness that in most care homes, Western cultures would be dominant was also a barrier for some to considering residential care:

“...care homes they don't overly cater for the South Asian context and there's less people, I'm all for a multi-cultural but it would be great to have some more people from a similar culture so you have that connection” Carer eight, Indian, son

Theme 4. Support from informal care networks

The importance of the informal care network was described by the majority of participants as preferable to solely relying on formal care. This network included the immediate and wider family, friends and neighbors. One carer described the importance of their partner being involved in current care arrangements.

“So a few times a week she will come here and she will make food that my mum and dad are familiar with, from the Asian continent, you know, dhal, rice, lentils, chapattis, sort of vegetable sort of mixes, and then she will leave these curries, if you like. We have essentially got a second fridge on the balcony, and then we will stock it up with food” Carer three, Bangladeshi, son

Participant’s spoke about how neighbors and family friends from the same cultural background helped support the care recipient to live at home.

“In our culture and where we are from, we are all family people and extended family and outsider as well, but we still think they are part of our family. For example, the neighbor, we have a few of them actually and they are not our relatives or anything.... She is now there looking after her and taking care of her” Carer four, Indian, daughter

“So we've got an arrangement where we've now got a family friend that lives in the house with her. And it's a family friend rather than a member of the family” Carer eight, Indian, son

These informal carers were perceived as more acceptable to the care recipient and family, and more able to provide culturally appropriate care than formal providers:

“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 or home carer, anybody else would do” Carer three, Bangladeshi, son

“I think, both myself and my mother, we wouldn't want, like, a full time carer or something, because we don't want somebody around stranger to us as well all the time. She wants to manage as much as she can, but obviously so do I” Carer six, Indian, daughter

When successful, the informal care network was described as collaborative and provided seamless care between multiple family members.

“We make sure when I'm working my brother takes the day off. Like, today they're going to work, so I'm at home. And when we both are at work, my wife takes care of her, so someone's always with her” Carer five, Bangladeshi, son

For many, the wider minority ethnic community also provided an important social resource.

“She loves the social interaction. There's lots of what we call in the church, aunties, and the elderly ladies and a couple of guys. Mum's very lovely with them and they're exceptionally lovely with her, she loves being around people” Carer eight, Indian, son

Some participants however felt isolated from their wider community in the UK, but described being part of a supportive informal network when visiting their Country of origin.

He thinks people in India, they will come around, say hi. Nobody here to come because we are stuck in four walls. But in India, it's open. People next door, when they go past, they will say, hello, Mr [name], are you okay? You know, they will talk to you in Tamil. [Speaks in Tamil], like that. Carer nine, Indian, wife.

Discussion and Implications

We identified four main themes describing the caring experiences of Indian and Bangladeshi family carers of people living with dementia at home in the UK. These were: 1) an expectation and duty to care, 2) expectation and duty as a barrier to accessing formal care (with subthemes describing how family carer reluctance, care recipient reluctance and service organization might contribute to this), 3) culturally (in)sensitive care, and 4) the importance of support from informal care networks.

Interviewees' descriptions of familial obligations to care reflect findings from previous studies of strong expectations of intergenerational piety in minority ethnic communities (Lawrence et al.,

2008), Victor et al., 2012). In previous work that recruited from non-NHS sources, acceptance of care in Pakistani and Bangladeshi UK communities was perceived as being “a last resort” (Victor, 2014), and expectations of familial care was linked to a lack of engagement with services (Victor et al., 2012). By contrast, most of our interviewees were supported by some formal care services such as home care or day centres and all had engaged with NHS services for support in diagnosing or managing their relative’s dementia diagnosis. Interviewees described a willingness to accept care, provided this could be negotiated with the care recipient and provided care was culturally acceptable. However, carer guilt and sense of duty, reluctance of care recipients to accept non-familial care, and experiences that services were not always culturally appropriate – for example, where home care workers did not speak the same language as the care recipient or could not prepare culturally appropriate meals – precluded higher levels of engagement with services.

Our findings illustrate a tension between a state-funded care system obliged to provide care where there is no alternative and family carers who felt culturally obliged to provide care. This was seen in the example of services being withdrawn once a family carer had moved in with his mother, and his acceptance of this situation as his duty. These findings align with conclusions of previous work that services need to support minority ethnic carers to care, rather than presenting services as a substitute to family care (Victor, 2014). A previous study has described how a home care programme for minority ethnic communities in Australia matched home carers and clients for language; this was one strategy in a programme associated with increased client-home care worker engagement (Low et al., 2015).

Interviewees described appreciating formal services received, yet some roles, such as cooking or feeding were considered important duties for the family carer or informal social networks. In Victor et al’s (2012) interviews with UK Bangladeshi and Pakistani communities, the community was described as providing help in coping with living in a foreign land, social engagement and support in times of stress, but as an inadequate substitute for support by close family members, particularly the children and the spouse (Victor et al., 2012). In our study, where interviewees were caring for older people with, in the main, high levels of care needs, support from informal networks was often substantial, for example different family members taking it in turns to provide care, or a family friend providing live-in care to an interviewee’s relative in their own home. There was a sense that informal networks were substituting for formal services in providing support and respite to family carers, in areas of care, such as meal preparation, where formal services were not able to offer culturally competent care.

Interviewees’ narratives described a high carer burden that was only partly alleviated by support from formal and informal networks. Employment roles and relationships were sacrificed due to the primacy of the duty to care. Caregiver strain is the main reason for nursing home placement (Afram et al., 2014) in studies in primarily Western, White majority ethnic populations. The implications of caregiver strain in minority ethnic populations that “have no word for care home” are less clear. In previous work, we have described how the personhood of care home workers may be neglected by a system focused on delivering person-centred, dementia care (Kadri et al., 2018). While the personhood of the family carers interviewed was not in doubt, there were echoes of this previous work in interviewees’ narratives. Family carers who provided almost all of their relative’s care often saw this as the only available option that met the care recipient’s

needs for culturally appropriate care, yet achieving this often left family carers who wanted a different care arrangement with no recourse to meet their own needs, for example for employment or relationships. These tensions in the transnational caring relationship have also been identified in other cultures and countries, for example in relation to Iranian migrants to Sweden (Torres, 2018).

Our findings suggest that culturally relevant psychosocial interventions and support services could help alleviate family carer burden and stress; by challenging beliefs that seeking help is shameful or contravenes cultural expectations, or providing support to access services that are culturally acceptable to them and the person they care for. Targeted awareness-raising campaigns could help in this too. Our findings also have implications for policies governing minimum standards for paid carer training and training for professionals assessing needs for care support. These should include the cultural perspective of carers who may need more support to express challenges or distress that they are experiencing as a result of caring, and an understanding of how to ensure that care is culturally competent, and how to respond when there are concerns.

Interventions to address the lesser likelihood of people from minority ethnic groups receiving a dementia diagnosis have sought to tackle stigma and perceptions that dementia represents normal ageing rather than illness (Berwald, Roche, Adelman, Mukadam, & Livingston, 2016; Mukadam, Cooper, & Livingston, 2018). The current study is one of the few to explore minority ethnic carers' experiences of post-diagnostic dementia care services. The family carers we recruited from NHS sources may have identified more with Western social norms and values than those in previous studies who were recruited through community sources (Victor, 2014). In addition, there may have been a higher level of acculturation within the current study sample than in previous studies (Meyer et al., 2015; Xiao, Habel, & De Bellis, 2015), as most of the participants were either born in the UK, or had lived in the UK for 30 years or longer. All interviews were conducted in English, so we could not capture the perspective of carers who did not speak English fluently. Previous authors have described a need for ethnic and language matching in research in minority ethnic communities to elicit trust and shared understanding (Victor, 2014), however the interviewers in this study had different nationalities (Sri Lankan and White British) to the interviewees. We were also unable to recruit any participants of Pakistani origin, therefore the information gathered was based only on the views of those from Bangladeshi and Indian ethnic origins.

Conclusion

This study illustrates the tensions faced by a sample of UK Bangladeshi and Indian family carers for people living with dementia at home. Interviewees described tensions between generations with different understandings of familial obligations to care, between carers' readiness to accept non-familial care and formal care systems offering care models they cannot accept; and between a state-provided care system obliged to provide care when there are no alternatives, and family carers who feel a duty to always provide alternatives. Informal social networks often provided valued support, but the cost of caring for those interviewed, in terms of employment and relationship losses was striking.

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Table 1: Family carer ethnicity and relationship to the person living with dementia

Participant	Characteristics
Carer one	Indian, daughter, born in the UK, lived with mother who is now deceased
Carer two	Indian, husband, born outside of the UK, living with wife
Carer three	Bangladeshi, son, born in the UK, living separately from mother and father, visits six times a week
Carer four	Bangladeshi, daughter, born in the UK, living separately from mother, visits four times a week
Carer five	Bangladeshi, son, born outside of the UK, living with wife and mother
Carer six	Indian, daughter, born outside of UK, living with mother and father, caring for father
Carer seven	Bangladeshi, son, born in the UK, living with wife and mother
Carer eight	Indian, son, born in UK, living separately from mother, visits four times a week
Carer nine	Indian, wife, born outside of the UK, living with husband
Carer ten	Indian, wife, born outside of the UK, living with adult son and husband

Supplementary material

Family carer interview topic guide

INTRODUCTION

Thank you for agreeing to talk with me. This part of our study aims to help us understand better how to support people with dementia living in their own homes.

In order to make sure that I don't miss anything, I will record our conversation on a digital recorder and then it will be professionally transcribed. Once the interview has been transcribed, I will ensure that everything will be anonymous so you can't be identified. Once again, everything you tell me will be treated with complete confidence.

INTERVIEW

- To start, we'll ask some background information. Could you tell me a little about your relationship with [patient name]?
 - Do you live together?
 - How often do you see them?
 - What sort of support do they need?

- Do you give them any support while they are at home? What does this support look like?

- Does anyone else support them e.g. other family members / paid carers?

- Have you had any education/ support with understanding dementia?
 - where from?
 - Has that been useful?

Independence at home

- To what extent is [the person you care for] is currently able to live independently at home?
- What do you find independence means for the person you care for? What do you feel being independent looks like for them?
- Can you think of a time since [the person you care for] has had memory problems, when they have been able to achieve or do something independently that has been important for them? What happened?
- Can you think of a time since [the person you care for] has had memory problems, when they have not been able to achieve or do something independently that has been particularly difficult? What happened?
- What makes it harder / easier for the person you care for to live independently at home?

Goals and priorities of people with dementia

We are interested in what is most important to try to achieve when planning care for people living with dementia. Here are some of the areas that matter most to people:

- Moving around
- Cognition (memory and other areas of thinking)
- Being safe from falling
- Getting the right medical treatment for memory or other conditions
- Help at home
- Social activities
- Relationships

- Are there things you would add to this list? (prompt for behaviour, safety)
- What do you think is most important for [name of person with dementia]?
 - Why did you choose this?
- What else do you think is important for them? Why?
- Thinking more about the area selected, what do you think it would be a realistic goal for [name] in the next 6 months?
 - What difference would this make to them (probe for independence/ safety/ social connection / health / being able to stay living at home)
 - What support might help [name] and you meet this goal?
 - Are there things that you think might make it easier or harder?
 - Prompt for:*
 - *Client factors: agitation (e.g. resisting care, verbal, physical aggression), personality/ culture/ethnicity/language, health, risks*

- *Family carer factors: (practical, emotional, relationship, health)*
- *Home care agency/ management/legal/ NHS/ social services/ other*
- [if home care recipient] How does the home care help [name] to work towards this? Are there ways of delivering it that would do this better?
- Are there any differences between what goals and priorities matter most to [the person you care for] and what matters to you as a carer?

Interventions to help with meeting goals

We want to develop a support programme to support people with dementia and their family carers to live independently at home and to meet the goals that they select.

- What do you think this should include?
- What do you think would work best?
- What do you think you and the person you care for would find most useful?

We also want to develop some training for home carers working with clients living with dementia.

- What do you think this should include?
- Is there anything you wouldn't want this to include or be like?

Thank you

Is there anything else you would like to add?