A grounded theory analysis of the experiences of carers for people living with dementia from three BME communities: balancing the need for support against fears of being diminished.

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Abstract (268 words)

An estimated 25,000 people of Black, Asian and other Minority Ethnic (BAME) origins live with dementia in UK - a number which is expected to increase seven-fold by 2051. People from many BAME communities experience dementia in a markedly different way to their white British counterparts. For instance diagnosis is more likely to occur at an advanced stage of the illness, while there is a lower take-up of mainstream dementia services. This research study focused on the experiences of care-givers for family and friends living with dementia from South Asian, African-Caribbean and Chinese communities in Bristol. Data was collected through interviews with twenty-seven participants and eight focus groups attended by 76 participants. Additionally, interviews were carried out with 16 paid staff and volunteers working for Voluntary and Community Sector Organisations (VCSOs) that provided services for older people from these three communities. As concepts emerged during data analysis, so these were checked with each community. The grounded theory, “fear of diminishment” was present across all communities: participants both needed and wanted support, but they were reluctant to accept this if it came at the cost of being diminished as a person. To resolve this dilemma, informants turned to BAME-led VCSOs, which provided ongoing support and advocated on behalf of their members. However, the services provided by these VCSOs varied and reflected differences in the ways in which communities enacted the theory. Given the increasing importance of cultural diversity within dementia care, this study has important implications for communities across the UK and elsewhere, and
The dementia experiences of carers of people from BAME communities points towards the need for sustainable and equitable resourcing of dementia care within BAME-led VCSOs.
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Introduction.

There are an estimated 25,000 people of Black, Asian and other Minority Ethnic (BAME) origins who are living with dementia in the UK. Moreover, whilst the total number of people who are living with dementia in the UK is expected to double by 2051, the number of people with dementia from BAME communities is expected to increase seven-fold by this date (APPG on dementia, 2013). This higher rate of increase reflects both patterns of immigration to the UK and the increased risk factors for dementia experienced by certain BAME groups (Jutlla, 2013). For example, many BAME communities experience higher overall levels of health inequalities. Moreover, amongst some BAME communities there are increased levels of specific dementia risk factors: thus people of Caribbean and South Asian origins are at greater risk of developing cardio-vascular disease and Type II diabetes than are white British people (Finney et al, 2016).

Not only does research consistently suggest a higher prevalence rate for dementia for older people from many BAME communities compared to the white population (e.g. Adelman, Blanchard and Livingstone, 2009), but it also suggests that there are different patterns of service utilisation (Moriarty, Sharif and Robinson, 2011). Thus, people from BAME communities are likely to have less access to, and different experiences of both mental health (Department of Health, 2005), and dementia specific, health services. Typically, people from BAME communities remain under-represented in specialist dementia services and are more likely to draw on those services with which they are
more familiar such as religious institutions (Parveen, Peltier and Oyebode, 2017). Even where people from BAME communities use dementia specific health care services, then they often do so at a later stage in the illness than do their white British counterparts, and are consequently at greater risk of not being prescribed appropriate medication for dementia (Mukadam, Cooper and Livingston, 2011; Tuerk and Sauer, 2015).

Given the central role that carers play in facilitating access to care, it is important to understand the experiences of carers of people who are living with dementia from BAME communities. A recent review of the literature suggested a number of different factors played a role in later diagnosis, including memory loss being viewed as a normal process of ageing, a poor understanding of what support services provide and the impact of stigma (Johl, Patterson and Pearson, 2016). However, further research in this area is needed, including, for instance, a greater understanding of the needs of those communities, such as the Chinese community, which have hitherto been poorly represented in the literature.

**Methodology**

The reporting of results of this study follows the COREQ guidelines for qualitative research (Tong, Sainsbury and Craig, 2007).

*Study Context and Participants.* Bristol, like many UK cities, has a culturally diverse population. Over 90 different languages are spoken in Bristol, with Bristolians being born in at least 50 different countries and following more than 45 religions (Bristol City Council, 2011, 2015). In 2013, Bristol reorganised its dementia services, so that assessment and diagnosis was now primarily made within primary care (Dodd *et al*, 2014). At the same time, the contract for specialist dementia services was awarded to Bristol Dementia partnership, which brought together an NHS Trust and the Alzheimer's
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Society to collectively provide the Bristol Dementia Well-being service or BDWS. No specific contracting arrangements were made for people who were living with dementia from BAME communities. While roughly equal proportions of people with dementia from BAME communities and the white British population are registered with the BDWS, there are different patterns in service use: importantly, significantly fewer people of BAME origins with dementia and their carers attend BDWS provided services such as Memory Cafés or courses for carers of people with dementia (Baghirathan et al, 2017).

**Aim:** The aim of this study was to generate a grounded theory. The following questions guided the study: firstly, what experiences do people from three different BAME communities who provide care for people who are living with dementia in Bristol have of dementia-specific care? Secondly, why do they think people might be reluctant to access dementia care services?

**Inclusion criteria:** For pragmatic reasons we chose to define BAME communities relatively narrowly in terms of two communities with a significant presence in Bristol (people of Caribbean and South Asian origins) and a third, smaller, community (people of Chinese heritage) as this community is under-represented in the research literature (Jolley et al, 2009; Seabrooke and Milne, 2004). Conversely, in order to capture as wide a sample of experience as possible, we defined “carers” relatively broadly as including both informal carers (members of the family or friends of the person with dementia) and volunteers and members of staff from BAME-led Voluntary and Community Service Organisations (VCSOs) that provide services to older people. This latter group of VCSO carers were included as our initial scoping suggested that these organisations play a pivotal role in providing care for people living with dementia.
Design and theoretical framework. A grounded theory approach to data analysis was used (Strauss and Corbin, 1990). The goal of the Grounded Theory approach is to generate theories that explain how some aspect of the social world 'works' and which is therefore grounded in the world of the participants (Glaser, 1978; Walsh et al., 2015). Grounded theory makes use of a “constant comparative approach” (Glaser and Strauss, 1967) and thus the analysis of the data began while collection was still in progress. This allowed specific themes to be identified and explored in subsequent interviews. For instance, during background discussions with members of Caribbean communities, the potential relevance of the construct of being “locked up” to dementia emerged. The researcher was then able to use this topic as a prompt during interviews and focus groups to check whether it was meaningful for participants.

Study organisation. The study was overseen by a steering group made up of representatives from local BAME-led VCSOs, providers of services for people with dementia and their carers and academics from the University of the West of England (UWE). A female researcher (SB) who has Sri Lankan origins and had experience in working with both local BAME communities and in dementia care was employed to carry out interviews and to conduct focus groups. The researcher was based jointly at the university and with a VCSO in Bristol and was supervised and trained by an experienced dementia researcher and clinician (RC). The study received permission from the ethics committee of the Faculty of Health and Applied Sciences at UWE1.

Relationship with participants. Active recruitment was preceded by a range of activities designed to increase awareness of the project and thus to maximise participation (Lewis and Ritchie, 2003). For instance, SB spoke at groups attended by older people from

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different BAME communities, with simultaneous translation being provided through bi-
lingual members of staff. On the advice of members of the Chinese community, flyers and 
Participant Information Sheets were translated into traditional and simplified Chinese.

Recruitment. The heterogeneity of voices within and across all three communities 
involved in this research necessitated the use of a wide sampling strategy. Two sets of 
informants (all of whom had experience of providing care for people living with 
dementia in the community) were recruited: people from three BAME communities 
(African-Caribbean, South Asian and Chinese) who were either currently or had recently 
provided care to a friend, neighbour or relative who was living with dementia in their 
own home; and people who worked in the community as a volunteer or member of staff for a BAME-led VCSOs that provided services to older people who were living with 
dementia in the community. Family carers were recruited from either the BAME-led 
VCSOs or were referred to the project by the BDWS. Volunteers and VCSO staff in each of 
the three communities were recruited initially through personal contacts from the 
steering group, and then by using a snowballing approach (Heckathorn, 1997). All 
informants were provided with an information sheet about the project, before 
completing a written consent form.

Data collection. Participants were offered the choice of either being part of a focus group, 
or being interviewed individually. A semi-structured interview (SSI) schedule was 
created, based on tools used by similar research studies (Scott and Sharma, 2016; La 
Fontaine et al, 2007; Giebel et al, 2015) following permission being given by the authors. 
The SSI was piloted and revised after the first two interviews. Topic guides for the focus 
groups followed the same structure (see appendix one) with data collection taking place 
between March and September 2016. All interviews and focus groups were audio
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recorded, with the digital recordings being securely stored. Where required, trained interpreters were present during interviews and focus groups. All focus groups were carried out at the premises of BAME-led VCSOs, while interviews were either carried out at participants’ homes or in the premises of the VCSOs, depending on the wishes of the participants. As a mid-point review of recruitment showed that it was proving difficult to hear from Caribbean men, the researcher, SB, visited settings (such as barbershops and social clubs) where she could initiate these discussions. These conversations were not recorded, although verbal consent was given to allow the researcher to take contemporaneous field notes. Material from these conversations are not directly reported here, but instead helped to shape the interpretative context for the project.

Method of Approach. The word ‘dementia’ is neither always easily translatable nor commonly used in some South Asian and Chinese communities. Consequently, the researcher became familiar with the different terms or phrases that might refer to dementia. She also initially avoided using the English word ‘dementia’, instead describing various behaviours that could reflect a cognitive impairment, such as asking if they had noticed that friends or relatives were more likely to become disoriented in familiar places, such as their gurdwara, or becoming more forgetful.

Data collection. In all, 27 interviews with family carers (see table 1 for details) and eight focus groups with 76 participants (table 2) were carried out. A total of forty-seven people from different South Asian communities (Muslim, Hindu and Sikh), thirty-one people from the Chinese community and twenty-five people from African-Caribbean community contributed to the study. The average interview time was forty minutes. The average focus group duration was one hour, with ten participants on average taking part in each group. More women (78) than men (25) took part, particularly in the focus
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groups. In addition, 16 interviews with staff or volunteers at BAME-led VCSOs also took place (table 3). This relatively high number of participants reflects our wish to engage as fully as possible with three highly diverse communities.

Data analysis. Recordings of interviews and focus groups were transcribed, with data from other incidents, discussions and conversations recorded in field notes. Following Grounded Theory methodology (Bryant and Charmaz, 2007; Glaser & Strauss, 1967; Strauss and Corbin, 1990), analysis and data collection were carried out concurrently. Data coding was initially carried out by the researcher (SB), with the emerging open codes being modified and refined through weekly meetings with the academic lead (RC), which anchored the discussion of the codes to the primary evidence. Codes were then sorted into categories, examples of which are shown in table 4.

As part of the constant comparative method (Glaser and Strauss, 1967), an ongoing process of memo-writing in the form of a treasury of quotations for each community was compiled as an intermediate step that linked the codes with the integrated analysis. These memos were hand sorted as part of the process of searching for participants’ main concern. In order to validate the emerging analysis, for each of the three communities, a separate summary of the codes and the emergent categories and linking themes was circulated to the managers of two Caribbean-led VCSOs, the directors of two South Asian-led VCSOs, and to senior staff within two Chinese-led VCSOs. These discussions helped to isolate a central ‘story line’ or theory (Strauss and Corbin, 1990) for the project, which concerned a dilemma in which people balanced the need to find support and help against their need not to be diminished by this help. As data emerged, so it was related to this story line, modifying our understanding of both the data, and the way in which this theory was enacted across different communities. Categories related to
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the theory were identified (selective sampling) and sorted into two main strategies (subcategories).

Finally, continuing our process of ensuring that our emergent theory made sense to the wider community, a formal presentation of the main findings of the study was made to an invited audience of 73 people made up of participants from all three BAME communities as well as commissioners, staff from BDWS and other interested parties. Separate workshops were then held with participants from each of the different communities to check the validity of the findings. Workshop participants were asked: “does what you have heard today reflect your experiences?”; “did you receive any new information that would influence your response to dementia?” and “what else do you think needs to be recognised?”

Findings: the theory of diminishment - “balancing the need for support against the need not to be diminished by that support”.

Informants in this study consistently articulated a dilemma - they both needed and wanted support, but they were reluctant to accept this support if it came at the cost of being diminished as a person. This story line was articulated by almost all participants, but was enacted differently depending, for instance, on the social norms and values within that person’s community. Yet, while the way in which the risk of diminishment was experienced varied across participants and communities, these concerns arose from a shared experience of living with dementia within a wider culture that was often experienced as lacking in empathy or understanding.

The risk of being diminished.

Participants were clear that not only did their relative or friend experience their growing cognitive impairment as a diminishment, but also that they also risked further
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diminishment from the provision of services that did not meet their cultural needs. In addition, we consistently heard that care-givers also experienced their own needs for support as risking an indirect diminishment themselves. For many participants from all three communities, the benefits that might accrue from contact with statutory services were balanced against a concern that such contact would diminish them. For some participants this fear of diminishment concerned a risk of both they and their relative being isolated and vulnerable within what was perceived to be a largely all-white service. For others, especially within Chinese communities, the risk of diminishment involved the familial shame that would arise if the stigmatised condition of their relative’s illness was exposed.

_Diminishment within Caribbean communities._ Throughout data collection, the reluctance of some people from Caribbean communities, and in particular Caribbean men, to engage with statutory services was associated with concerns that visiting the doctor to discuss memory loss or other concerns was to risk being “locked up”. Indeed, there is a clear external reality to these fears within the Caribbean community as disproportionately high numbers of black people are detained under the Mental Health Act 2007 - spending longer periods of time in hospital as a consequence than did any other ethnic group (Care Quality Commission, 2011). Thus, the lead worker at one Caribbean older people’s social group said:

> When people do have dementia, the family member really has to put their foot down, to let someone in [to provide care]. The person in dementia gets paranoid about letting someone in ... it’s an invasion.

For some Caribbean participants the isolation of being the only visible person from a BAME community within a service thereby risked their cultural needs being
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ignored or disregarded. One man (C9) described how the apparent ‘closeness’ of Caribbean people to white British people can cloud the accurate understanding of different norms and cultural identities. For instance, the preference of Caribbean people for eating well-cooked meat or ‘hard food’ such as yam was not always appreciated, whilst there was also widespread ignorance of the reliance of many older people who grew up in the Caribbean on Creole or patois - distinct languages that may require an interpreter. Similarly, a Caribbean woman, talked of seeking a Day Centre for a family member with dementia:

I spent ages looking for a day centre that was culturally appropriate. [...] You know: Caribbean meals. I went to a lot of different places and one place I almost...a place [...] that offered day care. They had quite a lot of people who came from BME backgrounds but they did not have any spaces and it was more expensive than a lot of places.

C2

Diminishment within South Asian communities. For some South Asian participants, dementia was framed within a context of superstition. For example: the word pagal might be used to describe behaviours were similar to dementia. This word is used in a number of Indian languages and can denote a madness caused by evil spirits or previous bad actions. However, the overall impression from South Asian contributors was of a lack of knowledge about dementia as a distinct health condition coupled with an emerging awareness of the need for more information. Making dementia visible was more acceptable if this was done in settings they were familiar in, run by their own community members. For instance, the coordinator of local VCSO specifically for Muslim people said:

I don’t think it is talked about. People are just getting their head around mental health. I don’t think it has even occurred to people to think this is an issue that we have got to deal with. They are still coming to terms with the taboo around mental health. Dementia will be the next thing to tackle ... From my experience, people think it is just mental health or forgetfulness or they put it down to old age. They don’t realise it's dementia
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However, some South Asian participants appeared to be more open about going to the doctor with symptoms that might be due to dementia. For example, during a Focus Group with older South Asian women (principally Hindu or Sikh women of Indian origins) one participant candidly talked about seeing her GP for a cognitive assessment. She was not diagnosed with dementia but said she would return if she noticed any further symptoms. Similarly, a Sikh man who was asked if the wider community at the Gurdwara would be open to hearing about dementia replied:

Yes, yes. Any message you want to give, we announce from the stage. Nearly 70, 80, 100 people get to hear.

Diminishment within Chinese communities. For informants from Chinese communities, the risk of being diminished by dementia stemmed from the meaning associated with dementia within their own community. While a number of different linguistic terms are used to describe dementia-like symptoms in Cantonese and Mandarin, all had negative overtones. For example with the Mandarin word ‘Chī-dāi’ (癡呆), the character “chi” translates into English as “idiotic” or “silly”, while the character “dai” means dull-witted. The equivalent Cantonese word is ‘Chi-ngo’. Participants described how the social act of talking about caring for a relative with dementia was, itself, an act of diminishment as it exposed a part of oneself, and one’s family to outside judgement. Thus, speaking through an interpreter, C11, a Chinese woman, described how her sons preferred that she should not talk about her husband’s diagnosis of dementia outside the family “because it was not appropriate and [...] people might look down on them”.
In addition, just as for the other communities that were involved in our study, so Chinese participants too described experiences in which their ethnicity had become salient. One Chinese man (C13) described feeling patronised by the surgeon treating his mother: “he didn’t have to turn around and look at me the way he did. And [then he] looked at the nurse. And you know the way some people can look at each other and then walk away? It was very down-putting ...I felt really totally messed up by it ... he just looked at me and thought, ‘What a stupid Chink’.” The process of diagnosis and assessment was typically described as a struggle by Chinese participants, and a number described how this had taken several years in the UK within repeated attempts by family members to have a formal assessment carried out through their GP. For C11, her family’s difficulties in openly acknowledging that her husband was struggling was compounded by difficulties in having her GPs take the problem seriously. Consequently, it was only when they visited her wider family in Hong Kong that a diagnosis was finally made.

Protecting not diminishing.

While participants from all three communities described contact with statutory services in terms of a risk of being diminished, their need for support was at least partially being met through a reliance on BAME-led VCSOs. Bristol has a number of long-standing VCSOs providing services and/or social groups, led by people of BAME origins, as well as established, faith-based networks including mosques, gurdwaras and black-led churches. These organisations were consistently described as a ‘lifeline’ by contributors. Whereas in mainstream organisations, people of BAME origins risked being either entirely isolated or in a small minority, this was not the case in these VCSOs. However, while all of the BAME-led VCSOs saw their role as providing support across their communities, none of them had been specifically tasked or financed to provide support
for people who were living with dementia. Consequently staff within these VCSOs consistently asked for more support from statutory services so that they could better meet the dementia needs of their members.

Protection within Caribbean communities. Many informants described a wish to hide the vulnerabilities that arose from dementia for as long as possible. A Caribbean man, whose aunt has dementia said:

There have been a couple of very well-known community figures who have died but they have been living in nursing homes for a couple of years before their death and they have dementia. People of African-Caribbean background. People of community standing. People have not known apart from close family that these people are still resident in the city. I think there is a degree of, I think it is about protection. [...] And I think, looking at the families, it is not so much shame about the condition itself, it is more about managing the person’s dignity or an idea of managing the person’s dignity.

Two factors contributed to a reliance on BAME-led VCSOs and churches within the Caribbean community. Following the descriptions given by informants, we have termed these two protection strategies as walk on by, and we look after our own:

Walk on by: Throughout the study informants described the reluctance of some people from Caribbean communities, and in particular men, to engage with statutory services. A woman focus group participant explained this in terms of a reluctance to use dementia-specific services such as Memory Cafés: “They don’t want to talk about it, African Caribbean people .... they don’t want to stand out.” Another participant added: “You would talk more amongst people who know you more”.

We look after our own; as one carer (C9) stated: “the older generation of black men are still likely to look out for each, after each other, if one of them had dementia or other illnesses”. Similarly a volunteer a VCSO commented: “it is in our culture. We care for each
other until the very end. *When people do go into care homes, into hospital, it is at the very last* (S2). Indeed, even where people were living in a care home, the community could still take practical action to reduce the threat of diminishment. Thus, when one Caribbean man was placed in a residential home where all the pictures surrounding him were of English landscapes and culture, members of the social group he had been part of took in pictures showing Caribbean culture and landscapes.

*Protection within South Asian communities.* Just as for Caribbean informants, so a number of South Asian participants described a strong reluctance to use services that they felt were culturally inappropriate. Indeed, it was striking that all of the South Asian informants in the study had ensured that their relatives with dementia did not enter nursing homes or supported accommodation. Even where participants had drawn on services, then they often did so at a personal cost. Thus one woman who changed her holiday plans rather than accept the respite care place offered to her mother:

> They said, ‘Put her in a home’. I said, ‘How can I put her in a home where she doesn’t speak the language, there’s her food, the TV channels she is familiar with? It would just push her back. […] She would just lie there and cry

C25

At the same time, many participants felt that the services they were being offered could provide the necessary flexibility. This was true both for the approach of some NHS staff, and also how the provision of direct payments gave them greater autonomy. Thus, a South Asian man (C21) used Direct Payments to arrange for a member of their community to care for his mother at home, while a grandson (C27) who was caring for both grandparents applied for benefits from an Age UK Benefits Advisor which he felt allowed him to meet all their care needs.
Protection within Chinese communities. Protection against being diminished by dementia also clearly motivated many Chinese informants who were concerned to avoid a loss of face in their own community. Staff from a Chinese-led VCSO explained this through the Mandarin word, *diu lian* (丢脸) which relates to the English concept of humiliation arising from a loss of face. In traditional Confucian societies, including China and Hong Kong, where a person’s behaviour is constantly evaluated by others, *lian* or face refers to one’s dignity, self-respect, feeling of social concern, and ability to fill social obligations in front of other people (Bedford and Hwang, 2003; Bedford, 2004). This is a social emotion in the sense that it arises only when the shameful aspect of oneself is exposed (Gilbert, 1997). Consequently, protective strategies typically seek to avoid exposure. Thus, a Chinese woman whose husband has a dementia diagnosis described how she was losing contact with friends:

*Chinese people protect themselves, you know [...] some people, they very protect themselves. They don’t want to, you know, let other people know where they live. It’s not easy to make friends. That put me off [...] Even when I know them so many years, they still don’t want to tell me where they live.*

Carer 11

For C11, whose husband had dementia, her previous experiences of poor care in the UK meant that the family relied on consulting a doctor in Hong Kong on their annual trip. It was here that his diagnosis had been made, and although she had been given a letter to take to their doctor when they returned to the UK, she continued to feel that the services they were offered was inadequate. Instead she had provided all his care, with some daytime support from their two sons but no external support except that provided, latterly, by a local VCSO. For the Chinese informants that we worked with, the social care provided by Caribbean or South Asian VCSOs, could not be replicated within their own
community due to their wish to avoid exposure of dementia. Indeed we heard anecdotal reports that many older people would not even tell their own children when they are struggling. Instead, informants relied on home visits by staff from a Chinese VCSO where they could be confident that their privacy and confidentiality would be maintained.

**Discussion**

**Culture and dementia.** The findings from this study are consistent with the wider mental health literature on race and equality, which draws a picture of people from BAME communities in the UK being more likely both to be diagnosed with mental health problems and to disengage from mainstream mental health services (McGuire and Miranda, 2008). Within the more specific context of dementia, this study also supports a series of recent studies which suggest that people from BAME communities remain under-represented in specialist dementia services and more likely to fall back draw on those services with which they are more familiar such as religious institutions (Parveen, Peltier and Oyebode, 2017; Mukadam, Cooper and Livingstone, 2011; Tuerk and Sauer, 2015). While this may be associated with a lack of knowledge about dementia (Jutlla 2013; Milne and Seabrooke, 2011; Venneri and Malik 2014) or a lack of knowledge about available services (Moriarty et al 2011) it is important to frame this pattern of service use, and non-use, within a wider context of culture, race and ethnicity.

The theory that emerged from this study was that carers made an active choice about the services they used, balancing the need for support against a fear of identity diminishment. More generally, providing support during periods of illness or trauma including dementia can also be viewed as part of a wider process of cultural socialization in which the norms, attitudes and practices that act as the unique identifiers of a community are passed across generations (Dilworth-Anderson, Williams and Gibson,
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2002). This may be evident within those cultural perceptions about illness and disease that shape the meanings groups assign both to dementia and to the meaning of providing care. For example, in this study, the descriptions of Chinese informants who described dementia in terms of "sticky blood" parallel those in the United States of Hispanic participants who viewed people who were living with dementia in their community as being "crazy" or having "bad blood" (Henderson and Gutierrez-Mayka, 1992). In both communities, this stigma could come to be shared by the entire family, so these cultural meanings created barriers to seeking assistance outside the family system. Such meaning systems are also contextually situated, that is they arise within wider sociopolitical and historical frames that shape the meanings that different groups assign to dementia, which in turn influences caregiving experiences and outcomes (Fox Hinton and Levkoff, 1999). This is compounded by anticipatory fears of discrimination and previous negative experiences of service providers (Nazroo, 1997, 2003).

**Study strengths.** The use of grounded theory is particularly well-suited for understanding social processes that have attracted relatively little previous attention (Milliken, 2010). While the needs of people from BAME communities who are living with dementia in the UK is beginning to receive attention, many areas, particularly, the experiences of people of Chinese origins have been largely neglected. Grounded theory focuses on producing a central explanatory theory of how participants’ actions are motivated by their main concern (Moe and Brinchmann, 2017) and the recurrent strategies that they use to resolve this concern (Christiansen, 2011). Thus, the theory of diminishment states that carers of people with dementia from BAME communities balance their need for practical support against a concern not to be diminished by that support. Significantly, the reliance on BAME-led VCSOs that provide generic or pastoral care, rather than dementia-specific services stems from a desire to protect the self from
diminishment (Simmons, 2006). The sources of diminishment, and the protective strategies that this leads to are summarised in table 5.

At the same time, there is an important caveat to this theory: people of BAME origins are not a homogenous group. There are many distinct differences within and between communities, including diet, custom as well as their discursive construction of age-associated cognitive impairment. Thus referring to a “South Asian” community, risks disregarding the profound differences in culture, religion and language that exists between, say, a Muslim woman whose grew up in Pakistan, and a third-generation Sikh man. While our study suggest that people from all three BAME communities that we have worked with had a common experience of balancing their need for support against concerns that they will be diminished by that support, the nature of that diminishment, and the protective strategies they used varied widely.

**Study limitations.** Grounded theory has been criticised for failing to recognise the way in which the researcher is embedded within a particular social frame (Bryant and Charmaz, 2007). Throughout this project we therefore shared drafts of the research both within our Steering group (which is made up of representatives from the statutory sector and Caribbean and Chinese communities) and with outside sources. However, the constrained timescale for the study impeded our ability to hear either from local people from other BAME communities (such as those of Somali or Polish origins) or from people from BAME communities outside Bristol. Similarly, we relied heavily on recruiting participants through our partnerships with local BAME-led VCSOs, which may have meant that we did not hear from more isolated people of BAME origins who do not attend such organisations.
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The policy context. People from BAME communities are more likely to experience health inequalities (Finney et al, 2016) including poorer access to and experience of health services. For people from BAME communities who are living with dementia, research indicates that these inequalities include being less likely to receive a diagnosis of dementia or doing so at a later stage in the illness (Mukadam, Cooper and Livingstone, 2011) and not being prescribed appropriate medication for dementia (the Race Equality Foundation, 2016). Consequently, a key challenge for dementia services in the UK and elsewhere is to find ways of meeting the needs of people from “seldom heard” communities (SCIE, 2008).

From the evidence of this study, establishing dementia services that people from BAME communities will use involves more than providing culturally-appropriate training for health and social care staff or translating information leaflets into a variety of different languages. Instead, innovative, and pro-active services are required that enhance the “dementia competency” of BAME-led VCSOs and religious institutions (Regan et al, 2013). For many participants in this study, being located within familiar faces and settings truly seemed to reduce their feelings of vulnerability. Attending or taking up services of BAME-led VCSOs enabled people to be seen for the entirety of their identity, including cultural and ethnic heritage, not just as a recipient of services due to their diagnosis of dementia. Accordingly, dementia policy needs to take this into account and adequately fund both the invisible dementia care work that BAME-led VCSOs currently provide, and also augment this through appropriate training, support and liaison.

All the senior workers who contributed to this study in the BAME-led VCSOs and religious institutions from each of the three communities were open about the limitations of the services that they could provide. There was an almost universal
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request for more support and increased resources: more information about dementia, better training for staff and volunteers and the development of equitable partnerships with mainstream dementia services. Given the increasing numbers of people with dementia who come from BAME communities, it will become ever more important to continue to make these arguments, even if the current fiscal climate of austerity means that these messages are difficult for service commissioners and the creators of National policies to hear.
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Conflict of Interest.

None.

5,843 words
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References


Bristol City Council (2011), *Census data*, Bristol City Council: Bristol.


Bryant A and Charmaz K (2007) Feminist Qualitative Research and Grounded Theory: Complexities, Criticisms, and Opportunities, in A. Bryant, & K. Charmaz (Eds.), *The
The dementia experiences of carers of people from BAME communities

*SAGE Handbook of Grounded Theory.* London: SAGE Publications. doi: http://dx.doi.org/10.4135/9781848607941.n19

Care Quality Commission (2011) *Count Me In,* Care Quality Commission, London, UK.


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Jutlla, K. Ethnicity and Cultural Care in Dementia: a review of the research. *Journal of Dementia Care, 12* (2), April/May 2013


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Table 2: details of participants in Focus Groups.

Table 3: details of participants working within BAME-led Voluntary and Community Sector Organisations’ (VCSOs).

Table 4: examples of codes and categories.

Table 5: an overview of strategies and categories.
Table 1: details of participants in one-to-one interviews with care-givers for family and friends with dementia.

<table>
<thead>
<tr>
<th>ID</th>
<th>Contact with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1. Caribbean woman</td>
<td>Both parents have dementia</td>
</tr>
<tr>
<td>C2. Caribbean woman</td>
<td>Stepmother has dementia</td>
</tr>
<tr>
<td>C3. Caribbean woman</td>
<td>Mother has dementia</td>
</tr>
<tr>
<td>C4. Caribbean woman</td>
<td>Mother &amp; sister had dementia. Niece recently diagnosed</td>
</tr>
<tr>
<td>C5. Caribbean woman</td>
<td>Father has dementia</td>
</tr>
<tr>
<td>C6. Caribbean woman</td>
<td>Mother has dementia</td>
</tr>
<tr>
<td>C7. Caribbean woman</td>
<td>Former nurse, supporting neighbours</td>
</tr>
<tr>
<td>C8. Caribbean man</td>
<td>Aunt has dementia</td>
</tr>
<tr>
<td>C9. Caribbean man</td>
<td>Nephew of man with dementia</td>
</tr>
<tr>
<td>C10. Chinese woman</td>
<td>Believes her husband has dementia</td>
</tr>
<tr>
<td>C11. Chinese woman</td>
<td>Husband has dementia</td>
</tr>
<tr>
<td>C12. Chinese woman</td>
<td>Mother has dementia</td>
</tr>
<tr>
<td>C13. Chinese man</td>
<td>Mother has dementia</td>
</tr>
<tr>
<td>C14. Chinese man</td>
<td>Mother has dementia</td>
</tr>
<tr>
<td>C15. Chinese man</td>
<td>Mother had dementia</td>
</tr>
<tr>
<td>C16. Chinese man</td>
<td>Wife has dementia</td>
</tr>
<tr>
<td>C17. Chinese woman</td>
<td>Husband had dementia</td>
</tr>
<tr>
<td>C18. Chinese woman</td>
<td>Husband had dementia</td>
</tr>
<tr>
<td>C19. Chinese woman</td>
<td>Daughter trying to get dementia diagnosis for Mother</td>
</tr>
<tr>
<td>C20. Chinese woman</td>
<td>Trying to get dementia diagnosis for Mother</td>
</tr>
<tr>
<td>C21. South Asian (Muslim) man</td>
<td>Trying to get dementia diagnosis for Mother</td>
</tr>
</tbody>
</table>
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<table>
<thead>
<tr>
<th>Case</th>
<th>Ethnicity and Relationship</th>
<th>Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>C22.</td>
<td>South Asian (Sikh) woman</td>
<td>Mother had dementia</td>
</tr>
<tr>
<td>C23.</td>
<td>South Asian (Sikh) man</td>
<td>Older man, attends Older People’s Group at Gurdwara where some members have/may have dementia</td>
</tr>
<tr>
<td>C24.</td>
<td>South Asian (Sikh) man</td>
<td>Older man, attends Older People’s Group at Gurdwara where some members have/may have dementia</td>
</tr>
<tr>
<td>C25.</td>
<td>South Asian (Muslim) woman</td>
<td>Mother has dementia</td>
</tr>
<tr>
<td>C26.</td>
<td>South Asian (Sikh) man</td>
<td>Wife has dementia</td>
</tr>
<tr>
<td>C27.</td>
<td>South Asian (Sikh) man</td>
<td>Full-time carer for grandmother with dementia</td>
</tr>
</tbody>
</table>
Table 2: details of participants in Focus Groups.

<table>
<thead>
<tr>
<th>Setting</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1. A Chinese-led older people’s VCSO</td>
<td>12 (10 women, 2 men)</td>
</tr>
<tr>
<td>F2. A Chinese-led older people’s VCSO</td>
<td>8 (8 women)</td>
</tr>
<tr>
<td>F3. A Caribbean-led older people’s VCSO</td>
<td>4 (4 women)</td>
</tr>
<tr>
<td>F4. A Caribbean-led older people’s VCSO</td>
<td>12 (10 women, 2 men)</td>
</tr>
<tr>
<td>F5. A South Asian-led older people’s VCSO</td>
<td>18 (15 women, 3 men)</td>
</tr>
<tr>
<td>F6. A South Asian-led older people’s VCSO</td>
<td>8 (8 women)</td>
</tr>
<tr>
<td>F7. A South Asian-led older people’s VCSO</td>
<td>6 (6 men)</td>
</tr>
<tr>
<td>F8. A South Asian-led older people’s VCSO</td>
<td>8 (7 women, 1 man)</td>
</tr>
</tbody>
</table>
Table 3: details of participants working within BAME-led Voluntary and Community Sector Organisations’ (VCSOs).

<table>
<thead>
<tr>
<th>Gender</th>
<th>Role</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>S1. Female</td>
<td>Chair</td>
<td>A Caribbean-led older people’s VCSO</td>
</tr>
<tr>
<td>S2. Female</td>
<td>Treasurer</td>
<td>A Caribbean-led older people’s VCSO</td>
</tr>
<tr>
<td>S3. Female</td>
<td>Treasurer</td>
<td>A Caribbean-led older people’s VCSO</td>
</tr>
<tr>
<td>S4. Female</td>
<td>Coordinator</td>
<td>A Caribbean-led older people’s VCSO</td>
</tr>
<tr>
<td>S5. Female</td>
<td>Director</td>
<td>A South Asian-led older people’s VCSO</td>
</tr>
<tr>
<td>S6. Male</td>
<td>Director</td>
<td>A South Asian-led older people’s VCSO</td>
</tr>
<tr>
<td>S7. Female</td>
<td>Director</td>
<td>A South Asian-led older people’s VCSO</td>
</tr>
<tr>
<td>S8. Female</td>
<td>Coordinator</td>
<td>A Chinese-led older people's VCSO</td>
</tr>
<tr>
<td>S9. Female</td>
<td>Director</td>
<td>A VCSO supporting BME carers</td>
</tr>
<tr>
<td>S10. Male</td>
<td>Coordinator</td>
<td>A social group for people of BME origins supporting people living with HIV+</td>
</tr>
<tr>
<td>S11. Male</td>
<td>Coordinator</td>
<td>Consortium of BME-led older people's VCSOs.</td>
</tr>
<tr>
<td>S12. Female</td>
<td>Manager</td>
<td>A Carers’ Support Service, managed at a Chinese-led VCSO</td>
</tr>
<tr>
<td>S13. Female</td>
<td>Coordinator</td>
<td>Older People’s Group at a BME-led VCSO supporting people recovering from mental health or addiction.</td>
</tr>
<tr>
<td>S14. Female</td>
<td>Key worker</td>
<td>Residential home with set number of flats reserved for people of Chinese origins</td>
</tr>
<tr>
<td>S15. Female</td>
<td>Manager</td>
<td>Residential home with set number of flats reserved for people of Chinese origins</td>
</tr>
<tr>
<td>S16. Male</td>
<td>Coordinator</td>
<td>A South Asian-led older people's VCSO</td>
</tr>
</tbody>
</table>
Table 4: examples of codes and categories.

<table>
<thead>
<tr>
<th>Transcribed text</th>
<th>Selected open codes</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>It was me who get the kicking end of it. My mother was being looked after. And I can understand the doctor being frustrated but he didn't have to turn around and look at me the way he did. And looked at the nurse. And you know the way some people can look at each other and then walk away? It was very down-putting. And I'm there looking after my mother, the same way the doctor was trying to. I am the carer, I am doing the best I can and...I felt really totally messed up by it ... he just looked at me and thought, 'What a stupid Chink'. That type of look.</em> (C13)</td>
<td>That kind of look</td>
<td>Past experience of services</td>
</tr>
<tr>
<td><em>They don’t want to talk about it, African Caribbean people .... they don’t want to stand out.</em> (F4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>You would talk more amongst people who know you more.</em> (F4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>It is always a family member who would detect something and take them to a doctor. They themselves would not go to the doctor. Not the older set of generation that we have ... I think we could be doing lots more work (to inform next generation down). Many times, they take their elders to the doctor and ... the family member does not get listened to ... I’m hearing that kind of incident quite often.</em> (S4)</td>
<td>We go to the doctor, but the doctor doesn't come to us</td>
<td>Culturally informed assessment</td>
</tr>
</tbody>
</table>
I have heard of dementia but I had never fully understood what it means. So, dementia is just someone who is going a little bit doolally. I didn’t realise what it meant, what the symptoms were, the range of things. (C13)

<table>
<thead>
<tr>
<th>Not knowing about dementia</th>
<th>Dementia awareness</th>
</tr>
</thead>
</table>

There isn’t the word [for dementia] in Gujarati, Urdu or Hindu … Pagal … you will get conversations like that, to do with mental health. Like black magic at play. Or this person is possessed. That’s the two things I’ve come across. (S7)

<table>
<thead>
<tr>
<th>Lost in translation</th>
<th>Dementia awareness</th>
</tr>
</thead>
</table>

I think (with dementia) as we lose some of our ‘performance language’, we become more…have elements of our young selves. So, with my auntie, with her bad language, we talked about this was how she was when she was younger. It was market-place Creole: ‘Wha’ you wan’? Wha’ you look ‘pon? F*** off’. I don’t know how dementia works but part of me thinks: ‘This was you before you started going church. Or you not at church, you at home’ (C8)

<table>
<thead>
<tr>
<th>Language barriers</th>
<th>Culturally appropriate support</th>
</tr>
</thead>
</table>

And Social Services turned around and said, ‘It’s too expensive to combine the care you are asking for at home’ … They said, ‘Put her in a home’. I said, ‘How can I put her in a home where she doesn’t speak the language, there’s her food, the TV channels she is familiar with [i.e. Islamic ones]?’ It would just push her back … She would just lay there and cry. (C25)

<table>
<thead>
<tr>
<th>Lack of appropriate care</th>
<th>Culturally appropriate support</th>
</tr>
</thead>
</table>

It is in our culture. We care for each other until the very end. When people do go into care homes, into hospital, it is at the very last (S2)

<table>
<thead>
<tr>
<th>The community looks after its own</th>
<th>Culturally appropriate support</th>
</tr>
</thead>
</table>
Table 5: an overview of strategies and categories.

<table>
<thead>
<tr>
<th>Communities within study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Experiences of diminishment</strong></td>
</tr>
<tr>
<td>Past experiences of discrimination</td>
</tr>
<tr>
<td>Concerns over being locked up</td>
</tr>
<tr>
<td>Concerns around shame and exposure</td>
</tr>
<tr>
<td>Concerns around visibility</td>
</tr>
<tr>
<td>Competing constructions of ageing and dementia</td>
</tr>
<tr>
<td><strong>Protection strategies</strong></td>
</tr>
<tr>
<td>Reliance on BME-led VCSOs</td>
</tr>
<tr>
<td>Walk on by</td>
</tr>
<tr>
<td>We look out for each other</td>
</tr>
<tr>
<td>Payments for care within community</td>
</tr>
<tr>
<td>Use of services where ethnicity is shared (e.g. diagnosis in Hong Kong, Chinese-focussed residential care)</td>
</tr>
</tbody>
</table>