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*Research Article*

# Perspectives of Minority Ethnic Caregivers of People with Dementia Interviewed as Part of the IDEAL Programme

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Postwar migrants from the Caribbean and Indian subcontinent (Bangladesh, India, and Pakistan) to the UK are now experiencing the onset of age-related diseases such as dementia. Our evidence base, both quantitative and qualitative, documenting the experiences of family caregivers of people with dementia is largely drawn from studies undertaken with white European, North American, and Australasian populations. Consequently, there is a need for research in the field of dementia caregiving to reflect the increasing diversity in ethnic identities of the older adult population of the UK. Using semistructured interviews, we investigated the experiences of 18 caregivers of people with dementia in Black Caribbean, Black African, and South Asian (Indian, Pakistani, and Bangladeshi) communities in England. Participants were recruited from the Join Dementia Research platform and were predominantly female intergenerational carers. We identified the following three themes: motivation to care (spending time with the care recipient and reciprocity), positive and negative consequences of caregiving (rewards and consequences), and the cultural context of caregiving (cultural norms and values supporting caregiving and negative attitudes towards dementia). Our findings develop existing literature by identifying (a) the importance of spending time with the person they care for, (b) the absence of faith as a caregiving driver, and (c) the challenge of watching the declining health of a parent. We highlight how the different motivations to care are intertwined and dynamic. This is illustrated by the linking of obligation and reciprocity in our dataset and positive and negative experiences of caregiving.

## 1. Introduction

The population of postwar migrants to the UK from the Caribbean and Indian subcontinent (Bangladesh, India, and Pakistan) is now ageing "in place" having not "returned home" as many may have originally intended [1, 2]. Consequently, this population is experiencing the onset of age-related diseases such as dementia [3]. Such conditions often generate long-term care needs which are met by a combination of formal services, family members, and the wider social network. There is a significant quantitative literature focusing on the experiences of family caregivers of people with dementia [4] exploring issues such as relationship quality and wellbeing [5, 6]; positive and negative dimensions of caregiving [6–8]; resilience [9]; and caregiver needs [10, 11] alongside access to diagnostic services and care [12, 13]. However, this literature, and our evidence base about dementia caregiving more broadly, is largely founded on research with White European, North American, and Australasian populations. There remains a clear need for

research in the field of dementia caregiving to reflect the increasing diversity in identities of the older adult population of the UK and other countries [4, 14, 15]. In this paper, we focus upon caregivers of people with dementia who identify as belonging to the South Asian and Black minority ethnic groups in Britain.

There is some evidence reporting variations in the experiences of caregivers from different minority ethnic groups [16]. A review from the United States concluded that non-White caregivers, either Hispanic or Black, were less likely to be spouses, reported lower levels of caregiver stress, burden, or depression, held stronger beliefs regarding filial piety, and were more likely to use prayer or religion as a coping strategy than their white peers [17]. Similarly, the review by Janevik and Connell [18] suggested that minority caregivers were less likely to be spousal and have less social support than their White counterparts. More recently, a systematic review of quantitative studies from the United States reports better psychological outcomes for African American caregivers compared with White and Hispanic populations [19]. Evidence from the UK suggests lower levels of relationship quality and higher levels of stress and role captivity, the perceived constraints resultant from undertaking the caregiving role, among minority ethnic caregivers of people with dementia compared with white peers [20]. Studies of caregiving for people with dementia from minority ethnic groups have reported the experiences of Black African and Caribbean people in the UK and USA [21, 22], Asian groups in the UK [23, 24], and a diverse range of minority groups across Europe [25]. These studies report the following four common themes: perception of dementia as a normal part of ageing; poor and/or culturally inappropriate service access and quality; the centrality of the family in caring for people with dementia; and the importance of religion and community as motivators to care [22, 25, 26]. It is notable that these reviews largely focus upon the burdens and negative aspects of caregiving across the following three key domains: health, material, and social/personal consequences for caregivers (see also [27]). However, there is a developing literature examining the positive aspects of caregiving in dementia [28] and amongst diverse populations in, for example, Australia [29, 30].

As part of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) dementia research programme [31, 32], we undertook a dedicated integrated workstream focused upon the experiences of dementia in minority ethnic groups. This workstream explored three topics. First, we compared living well outcomes, quality of life and life satisfaction, for people with dementia and caregivers from minority groups with their matched peers from the white community [20]. Second, we sought to establish the experiences and views of community leaders, people with dementia, and caregivers from minority groups to establish the context within which people from these groups experience ageing and, specifically, dementia. That phase informed the design and implementation of our third topic which focused upon exploring the experiences of dementia caregivers from Black Caribbean, Black African, and South Asian (Indian, Pakistani, and Bangladeshi) communities which we report in this paper.

## 2. Materials and Methods

As our specific topic area is a developing area within dementia research, we used an exploratory descriptive qualitative approach (EDQ) [33]. This is especially suited to emergent research questions where there is limited literature and/or it is unclear if existing literature fully represents the study context and priority is given to the experiences of participants. Our study population was caregivers of people with dementia from two minority ethnic groups, Black African/Caribbean and South Asian, as these are the "oldest" of the postwar migrant communities in the UK. Participants self-defined both their caregiving role for a person with dementia and their minority ethnic community membership. Our original recruitment strategy was via our established links with community groups rather than recruiting from healthcare settings or service providers. This procedure was selected to maximise the credibility of our study and the coauthor EvdH spent considerable time with these groups. COVID-19 restrictions precluded the continued implementation of this strategy, and we moved on to using the Join Dementia Research (JDR) platform. This is a UK-based online service that enables volunteers, including people with dementia and their caregivers, to register their interest in taking part in research studies. We concluded recruitment to the study when we achieved data saturation. COVID-19 restrictions also meant that interviews were conducted remotely rather than in person. At the preference of the participants, interviews were undertaken by telephone rather than online. All interviews were undertaken by the coauthor EvdH, an experienced qualitative researcher with an established record in community engagement, which supports the credibility of our findings.

Our semistructured interview guide was developed and informed by previous research, the aims of the IDEAL programme, and insights gained from our engagement with community leaders and community members. When asking about dementia, we used the term "memory problems" as our community engagement participants advised us that this term is more familiar than dementia and potentially less stigmatising to members of their respective communities. Our flexible interview guide covered five key areas: details of participant and the person they cared for; experiences of caregiving; support received from family, friends, community, and formal services; reflections of the importance of ethnicity on their experiences; and suggestions for how services/families and communities can respond to needs of people with dementia and their carers from minority ethnic groups. Probes were used as appropriate including inviting participants to develop their response and to invite them to consider positive and negative aspects of their responses. Interviews were undertaken in English between October 2020 and December 2021 and were professionally transcribed verbatim. The data were managed using NVivo Version 12. All participants gave informed consent which was audio recorded and stored

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electronically. The research was approved by the College of Health and Life Sciences Research Ethics Committee at Brunel University London (references: 10598-LR-Mar/2018-12350-2 and 11745-MHR-Jul/2018-13456-2). Our inductive thematic analysis used the model proposed by Braun and Clarke [34]. This is the preferred approach for EDQ studies [33] as it explores the experiences of participants; in this study, caregivers of people with dementia from minority ethnic groups. EvdH and CRV independently reviewed the audio files and transcripts to gain familiarity with the data. Discussion, review, and refinement with the wider team generated the following three overarching caregiving themes: (a) motivations to care; (b) consequences of caregiving; and (c) the cultural context of caregiving.

Rigour or trustworthiness in EDQ is assessed by four parameters, i.e., credibility, authenticity, criticality, and integrity. Credibility relates to the resonance between the representation of participant views by the researchers and that of the participants themselves. This is enhanced by community engagement, input by peers into the interview schedule content, and member checking to test the veracity of our analysis and interpretation. Our initial member-checking strategy was to return to participants and test out our findings and interpretation with them. This was disrupted by our COVID-19 as was our change in the interview mode from in person to telephone interviews with JDR members. However, in spring 2022, EvdH discussed the results of the study with members of the original community groups who endorsed the themes as encapsulating their experiences. Authenticity was evaluated by EvdH and CRV listening repeatedly to the interviews and transcripts which confirmed that participants had fully engaged with the questions and that their voices were fully present. Criticality is demonstrated by discussion of findings with the wider team, feedback from "critical friends," and participant validation.

It is also important to acknowledge our positionality. Our interviewer, the wider authorship team, and participants were not ethnically matched. Authors such as Roche et al. [22] have noted this dissonance in terms of ethnic identity between the researcher and researched and that the consequent positionality of the researcher as an outsider and/or insider can influence the research relationship and subsequent data and outcomes. However, the intersectionality theory suggests that both researchers and participants have multiple identities such as age, class, and gender which operate simultaneously [35]. Consequently, the proposed binary insider/outsider relationship divide in terms of ethnicity, or other characteristics such as class or gender, does not reflect the complexity of the researcher/research participant relationship. Our interviewer was predominantly an "insider" in terms of age, gender, and experience of caring for a parent with dementia and an outsider for ethnic identity, and for education, the relationship varied.

## 3. Results

We recruited 18 participants, 14 from JDR, and most interviews lasted for about 90 minutes (range 45–120). Ten participants self-defined as Black Caribbean/Black/Black African/Black British and 8 as South Asian (from India, Pakistan, or Bangladesh) (see Table 1). Participants were predominantly aged 50+ (14/18), female (17/18), and intergenerational caregivers (15/18) (see Table 1). The majority was daughters caring for a parent (in law) (13/18). Three spousal caregivers participated. Four caregivers were non-resident, one of whom was providing transnational care to their dependent at home in the country from which they had originally migrated.

Our analysis was undertaken for the whole group and identified the following three overarching and integrating themes: motivation to care, the consequences of caregiving, and the cultural context of caregiving. Within each theme, we present the full range of views expressed both positive and negative. However, we acknowledge that the themes are interlinked, and our "static" presentation of the data does not always clearly demonstrate the complex, temporal, and dynamic context within which caregiving was enacted. Participants are identified by ID number and which community they identified with; B = Black Caribbean/Black/Black African/Black British or SA (South Asian) = Indian or Pakistani.

*3.1. Motivations to Care.* Two subthemes characterised the narratives around the motivation for participants to undertake their caregiving role: spending time with the care recipient and reciprocity, both of which were predominantly positively orientated.

*3.1.1. Spending Time.* There was an unambiguously positive narrative presented by our participants that caring offered them an opportunity to spend time with the person they were caring for. This was expressed as, "*Oh, I get to spend an awful lot of time with her, which is really nice*" (2061B); "*we do silly things together and I think that's very nice and I think it's nice because we've spent so much time together*" (2463SA) and "*It's kind of like now this has given me that chance, because look, time has slowed . . . it has slowed down but now it's the opportunity to spend that time with her*". Some explicitly mentioned that they might not have had this opportunity were it not for undertaking their caregiving role: "*Getting to see to my dad on a good day, when you get to see him. Otherwise, I would be at work so I get to see that flash where he is himself, his normal, lovely self*" (2341SA) and "*It's really nice to hear about the old days, and I think because my mum and dad spent so much of their life working, we never really had those moments to, sort of, sit . . .*" (2451B). There were, of course, nuances within this theme. The spending time narrative was linked with allaying concerns about "someone else" from the sector coming in and providing implicitly poor quality as this comment illustrates: "*I'm glad I'm doing it for my mum, we have a nice time together, we get on well. At least I know that she's being looked after well*" (2492B).

*3.1.2. Reciprocity.* A key narrative in the caregiving literature is that of reciprocity or mutual support across and between generations. This is evident across a range of different family/kin-based domains of which caregiving is only one.

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Table 1: Characteristics of the participants.

| Study ID | Sex | Caring for | Carer age | Self-defined ethnicity | Coresidence |
|---|---|---|---|---|---|
| 2401 | F | Parent: mother | 55–59 | British Caribbean | No |
| 2492 | F | Parent: mother | 40–44 | Black African | Yes |
| 2380 | F | Parent-in-law: mother | 50–54 | Indian | Yes |
| 2360 | M | Spouse | 75–79 | Bangladeshi | Yes |
| 2341 | F | Parent: father | 55–59 | Indian | Yes |
| 2371 | F | Grandmother | 30–34 | Indian | No |
| 2392 | F | Parent: mother | 55–59 | Indian | Yes |
| 2010 | F | Parent: mother | 55–59 | Black Caribbean | No |
| 2053 | F | Parent: mother | 50–54 | Black | No |
| 2061 | F | Aunt | 60–64 | Black | No |
| 2071 | F | Sister | 70–74 | Black | Yes |
| 2331 | F | Parent: mother | 55–59 | Indian | Yes |
| 2421 | F | Parent: mother | 45–49 | Black | Yes |
| 2431 | F | Parent: mother | 45–49 | Black | Yes |
| 2440 | F | Spouse | 75–79 | Indian | Yes |
| 2451 | F | Parent: mother | 50–54 | Black | Yes |
| 2463 | F | Parent: mother | 55–59 | Pakistani | Yes |
| 2472 | F | Parent: mother | 55–59 | Black | Yes |

Although spouse caregivers were in the minority in our sample, there were clear examples of reciprocity based around a shared life together: "*Caring, this kind of 24 hours being with* (her) *and it has a reward because me and my wife we are 54 years* (married) *you see*" (2360SA). Intergenerational caregivers characterised spending time with their parent/relative as a form of reciprocity or "giving back": "*You know so you get to spend time with somebody and you try and make it quality time and for me trying to really appreciate my mum, everything that she's done for me and my sisters*" (2010B). Another spoke of "*the opportunity to spend that time with* (my grandmother) *and give her back to her because she looked after me and my brothers when we were from a young age*" (2371SA). However, some participants hinted at a more "obligation"-framed reciprocity with an implicit "intergenerational contract": "*you know, your parents brought you up, so then you have to look after your parents, when they are ill*" (2421B) or more explicitly concern about handing over the care of their parent to others was also articulated: "*I mean, I know the words are loaded, I don't mean abandon the parent to someone else's care, you know, you look after one's own*" (2341SA).

*3.2. The Consequences of Caring.* This theme exemplifies the interplay between the negative and positive consequences of caring. Negative consequences focused upon the impact on the caregivers in terms of the loss of personal freedom or their potential future selves, compromised health status, and loss of wider opportunities. Positive outcomes, while less numerous, centred around the rewards of our caregivers arising from feeling they were positively supporting their relative. For clarity, we report these elements separately. However, caregivers clearly recognised there was a dynamic balance between these elements, where they coexist and their interrelationship changes over time: "*I think I've not got the balance quite right. I think it's too isolated and lonely but emotionally very rich and rewarding*" (2331SA).

*3.2.1. Negative Outcomes of Caregiving.* The all-encompassing nature of the role had consequences for caregivers. This included loss of freedom, *"for me I feel my freedom has utterly just gone in an instant"* (2392SA), and spontaneity in their lives, "*You can't just go off and do something because obviously you know you've got somebody to look after*" (2492SA). Social contact with friends was compromised: "*I have not seen my friends for three years and so I do feel quite trapped sometimes*" (2431B). Loss of wider opportunities "*I've always wanted to educate go into career progression or go and travel and explore, because I'm quite active more than other family members, but that has had to just come to a halt*" (2371SA) and the challenge of the role reversal of caregiving. "*Being responsible for someone else's life–role reversal*" (2010B) were also evident. Expectations of help from family were not always forthcoming and generated disappointment and wider discontent: *"It's really hard when you expect your family to help, and they don't help"* (2421B). The impact upon caregivers of watching the decline in their relative's health and agency was palpable: "*Watching a parent unravel is a very difficult thing to witness*" (2463SA) and "*Her not being able to be in charge of what was happening and having to depend on other people. I think I found that the most difficult*" (2010B).

*3.2.2. Positive Outcomes of Caregiving.* These included feeling that their caregiving was making a difference to their relative: *"seeing her happy, you see. That is the biggest favour"* (2360SA). The emotional fulfilment gained from caregiving was also evident: *"I think it's one of the most rewarding things I've ever done, and I have had a career in the corporate world and thought I wanted to be a highflyer, but this has sort of a depth of meaning that is just really beyond anything one could get, I think, in that world"* (2331SA). Another carer reported the benefit of the quality of their relationship with their parent: "*It's sort of these are obviously the last whatever months or last ever years and it*

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*just feels nicer. This is the best of our relationship, you know, so it's sort of going off on a high really, I suppose. Let me put it like that"* (2463SA).

*3.3. The Cultural Context of Dementia Care.* Caregiving is, for all groups, enacted with a temporal and cultural context. Participant responses encapsulated a tension between cultural values which supported caregiving and negative attitudes towards dementia. The cultural norms and values of our two communities supported the caregiving ethos: "*You know for black people, West Indian Communities more likely to be around mums and dads and helping*" (2010B); *"I often wonder whether I've taken on, this responsibility on because of my background and my values"* (2331SA). However, some felt hostility from their community because of the perceived stigma of dementia: *"It's difficult, because my community can be very sort of cards to the chest and not want to share that type of information"* (2061B) and *"Friends* (are) *not getting in touch because of stigma* (of dementia)" (2380SA). To address this, participants thought their respective communities needed greater knowledge about dementia: *"Alzheimer's not really known in her* (mother's) *community"*; "*Good information (is) needed about the condition. For some translation of information would be important"* (2371SA); and "*More open communication in the community* (about dementia)" (2071B).

Suggestions for improvements in dementia care included providing services that are designed and delivered in culturally inclusive ways and covered a variety of topics such as "*information in Gujarati or whatever language they* (the person diagnosed with dementia) *speak"* (2440SA); *"food culture that the person with dementia recognises"* (2331SA); *"language and culturally adapted services"* (2341SA); *"linking them up with people of their own culture"* (2401B); and "*everybody in the* (dementia) *team must be culturally aware"* (2472B). To increase service uptake, better representation in information about dementia and the services available was a key suggestion: "*It sounds really simple, but I do think that having more images of people of colour will make people think, Oh, alright then, I can use that service. Oh, they will talk to me"* (2451B) and *"Literally think it's somebody who looks like us, sounds likes us, has experience of what we've gone through, who could talk to us about all the different things"* (2472B). There was a recognition that that families may need support in caring for people with dementia and that this needs to be recognised by the wider communities and service providers and commissioners: "*Is a sort of belief that people from… maybe from South Asian communities have just kind of, take it in-house and the belief that people maybe from minorities don't need support because they already have probably a support and I think oftentimes that's probably not true"* (2463SA). Finally, one participant observed that research also needs to take into account the increasingly diverse nature of the population affected by dementia as patients, carers, health-, and socialcare professionals: *"There are going to be complexities around sort of people coming from different backgrounds, but I think it's important that* (research) *studies take that onboard and people make a concerted effort to involve people from minorities no matter what the research is. Alzheimer's involves everybody–it doesn't understand race"* (2463SA).

## 4. Discussion

We undertook 18 qualitative interviews with caregivers of people with dementia from two key minority ethnic populations in the U.K.: Black/Black Caribbean and those from the Indian subcontinent. Our sample size is comparable with other previous studies addressing this issue [36–38]. Both the ethnic group membership and caregiver status were self-defined. Our participants were predominantly female, intergenerational coresident caregivers. This participant profile offers a specific lens through which dementia caregiving is experienced in terms of minority ethnic group identity, gender, age, and caring relationship. Our analysis identified three key themes. Two of these, motivations to care and the consequences of caring, are widely reported in the dementia caregiving literature. These themes are not specific to minority ethnic caregivers or, indeed, to caregivers of people with dementia. Our third theme, the cultural context of caregiving, features in most caregiving research with minority ethnic groups across a range of jurisdictions. Our research extends existing research focused on caregiving in minority ethnic groups by both identifying positive aspects of caregiving and demonstrating how positive and negative experiences are interlinked and dynamic. We identify the following three substantive areas where our findings provide developments to our existing literature: (a) the importance of the opportunity to spend time with the person they care for; (b) the absence of faith as a driver for caregiving; and (c) the challenge of watching the declining health of a parent.

Before discussing our substantive findings, it is important to consider the limitations of our research in order to contextualise our discussion and facilitate comparison with previous research. As noted earlier, we fully acknowledge the dissonance in identified ethnicities between our research team and our research participants. However, we argue that other dimensions of identity such as age, gender and, in part, education show a greater alignment between the researcher and participants. As such, we consider that the insider/outsider relationship is more complex than a simple binary divide. As with many other studies, our project plans were disrupted by COVID-19 and restrictions on social contact. This required us to change our participant recruitment protocol and interview method. Our original plan was to recruit participants via range of community organisations in the London/Southeast region where EvdH had engaged in an extensive programme of awareness raising about dementia and the IDEAL study more broadly. The COVID-19 pandemic significantly compromised this strategy and most of our participants, 14 out of 18, were recruited from the Join Dementia Research platform. This may have introduced some differences of experiences of dementia caregiving than if had recruited via community groups as originally planned. Potentially, we recruited more dementia aware and engaged caregivers fluent in English, predominantly daughters (in law) that care than a community sample would

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have generated. Potentially, this population might be more "secular" in their world view, which might have contributed to the lack of a strong faith based caring narrative. However, we have given voice to a specific and important group of caregivers. Also, our recruitment method had to change to remote interviewing because of the pandemic. All of our participants opted for telephone rather than online interviews. We did not ask why participants opted for this mode of interview but might speculate that as the majority were coresident carers, a phone interview could provide privacy which perhaps an online one might not. It may also be plausible that the interviewee preferred the anonymity of the telephone when discussing their caregiving experiences [39] or the reduced "stress" on watching the screen. There is some evidence comparing online interviews compared with phone but there is some suggestion that online interviews are longer than online interviews with and without the screen on [40]. Finally, in our study materials, we used the term "memory problems" rather than dementia. We acknowledge that while memory problems are a defining feature of dementia for many, not everyone with dementia has memory problems, at least in the earlier stages. Consequently, by using this terminology, we may have excluded some potential caregivers from the study.

Our first two themes, motivations to care and the consequences of caregiving, are evident in both the dementia specific and broader caregiving literature. Reciprocity as a driver to care and the constraints on social, health, and economic opportunities of caregiving are well established [41–43]. Whilst not understating the challenges caregiving posed for participants, it is important to note that there were also positive benefits from caregiving articulated by our participants in terms of the opportunity that it afforded to spend time with their family member. Our data showed the importance of caregiving as an opportunity to spend time with their family member that they might not otherwise have had. Linked to this was the pleasure or satisfaction caregivers gained from seeing their loved one happy. Benefits of caregiving have been previously reported but rarely in studies of minority ethnic caregivers [5, 6, 44] but rarely in studies of minority ethnic caregivers. We also observed the linking of obligation and reciprocity, in the same caregiving narratives. The concept of obligation-based reciprocity demonstrates how motivations to care can be intertwinned and are not always discrete concepts. Further work to explore this concept would be a useful addition to the caregiving literature in general and demonstrates how understanding why we care is complex and dynamic and not easily reduced to "simple" explanations. One key stressor that accompanied the caregiver role was coping with the physical and mental decline of a spouse or parent (in law). This finding may not be specific to our study context as it has been reported in a study of spousal dementia caregivers during COVID-19 [45]. There is clear potential for further research in this area.

Our data demonstrated one notable dissonance with existing literature around the role of religion and religious obligations as a primary motivator to care in minority ethnic groups. This has been consistently reported in studies from the UK [37, 46, 47] and elsewhere [48–50] but was notably absent in our study. The absence of religiosity as a driver to care may reflect the derivation of our sample from JDR, a secular organisation, emerging generational differences, the cultural difference between the interviewer and the participant. It may also reflect our inductive approach and EQD study design approach to asking about motivations to care by letting participants say what was important to them.

As with other studies of dementia caregiving among minority ethnic groups, the suggestions for improving dementia care emphasised ensuring cultural/ethnic appropriateness across the dementia journey from diagnosis to long-term care. However, the fact that research is still identifying challenges around providing culturally appropriate services indicates the limited progress made in this area. A key goal for any new dementia strategy is to make services inclusive of the increasingly diverse nature of the population with dementia and their caregivers (see, for example, the ADAPT South Asian Dementia Pathway; [51, 52]). References were also made to the potential stigma attached to dementia by some members of both minority ethnic groups. Although reported in other studies this may be a "generational" issue that will be less prevalent with the increasing diversity of the population of people with dementia.

## 5. Conclusion

The increasingly heterogeneous nature of the UK population, including older adults, is reflected in the nature and characteristics of the populations now experiencing age-related diseases such as dementia, and the consequent need for care and support from their families and communities, as well as from formal health- and socialcare services. We are very mindful of the critique of Roche et al. [22] that dementia caregiving research needs to be inclusive in terms of the questions asked, the communities engaged, and the development of a diverse research community. We need to address the limitation that our study, alongside many others, focuses upon ethnicity rather than other dimensions of identity such as class and gender. The intersection between these axes of social identity may also influence the nature, characteristics, and experiences of caregiving [53]. This was beyond the scope of this exploratory study but highlights an important area for future research with important policy and practice implications. We also need to incorporate the temporal generational perspective by considering how caregiving experiences may change for second and third generations who have lived their whole lives in the UK. For researchers, policymakers, and practitioners, incorporating generational and intersectional perspectives is a challenging but necessary research agenda if we are truly to understand the complexity of caring for people with dementia from diverse backgrounds.

## Data Availability

The data used to support the findings of this study are available from the corresponding author upon reasonable request.

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## Additional Points

*Study Registration*. Improving the experience of Dementia and Enhancing Active Life: a longitudinal perspective on living well with dementia. The IDEAL-2 study was registered with UKCRN, registration number 37955.

## Ethical Approval

A favourable opinion of the study was given by Brunel University London; reference number: 11745-MHR-jul/2018 13456-2.

## Disclosure

The funder was not involved in the manuscript writing, editing approval, or decision to publish.

## Conflicts of Interest

The authors declare that they have no conflicts of interest.

## Authors' Contributions

LC, CQ, and CV conceptualized the study and acquired the funding. EvdH and CV developed the interview guide and undertook the analysis. EvdH conducted all interviews. CP and CQ provided methodological expertise. CV drafted the article, and all the authors have contributed to the revision of the article and approved the version to be published.

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