

**THESIS PROTOCOL: CAREGIVING BURDEN IN
MINORITY ETHNIC FAMILY CAREGIVERS OF
DEMENTIA.**

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Introduction

The estimated number of people living with dementia (PwD) in the United Kingdom is 885,000, with approximately 225,000 from minority ethnic (ME) populations (Alzheimer's Society, 2014). This is projected to increase to 172, 000 by 2051, an estimated seven-fold increase compared to the two-fold increase in the White British population (Wohland et al, 2011). Higher rates are associated with increased dementia risk factors in South Asian and Black Caribbean populations, for example, Type II diabetes, hypertension, cardiovascular disease, and low socioeconomic status (Adelman et al, 2009). First generation migrants who settled in the UK between the 1950's – 1970's are now at an age where there is an elevated risk of developing dementia (Cheston & Bradbury 2016). The term 'ethnic minority' is used to refer to a group of individuals who share cultural traditions, religion, linguistic traits or other qualities which differ to those of the majority population (Ramaga, 1992). In the present study, the term ethnic minority will refer to people from non-white origins living in the UK.

Dementia is a chronic neurological condition, associated with a progressive decline in cognitive abilities, including communication, executive functioning, memory, processing speed, visuospatial abilities and activities of daily living (Yuill & Hollis, 2011).

Despite governmental emphasis on meeting the needs of PwD and their families, through the publication of the Prime Ministers Challenge on Dementia Care (Department of Health, 2012) and the National Dementia Strategy (Department of Health, 2009), experiences of dementia in ME communities remains misunderstood (Botsford et al, 2011). They continue to remain underrepresented in dementia services, underequipped to meet their needs (Mukadam et al, 2011) and instead, care is predominantly provided by an informal family caregiver. Approximately 10% of family caregivers are from ME communities, with South Asian being the largest group, followed by Black Caribbean (Carers UK, 2011). Family caregivers are defined as individuals who voluntarily support a relative with cognitive, physical or emotional difficulties, usually over a long period of time without financial recompense (Bridges, 1995).

Caring for PwD is associated with elevated levels of caregiver burden, which is defined as challenges felt by carers in relation to physical and emotional health, familial relations, employment and finances (Pearlin et al, 1990). Pearlin and colleagues' (1990) model of caregiver stress outlines four key components that exacerbate burden of care. These include 1) the background context (e.g., level of support and impact of other life events); 2) primary stressors (e.g., psychological and behavioural difficulties in dementia); 3) secondary role strain (e.g., family conflict and impact on social life; 4) intrapsychic strains (e.g., personality and role captivity of caregiver).

Literature suggests that ME caregivers are at an increased risk of burden, anxiety and depression compared to White British caregivers (Parveen et al, 2013). The multiple jeopardy hypothesis stipulates that ME caregivers are more likely to experience poorer outcomes due to the extra challenges they face. This includes stigma associated with dementia in their communities, stigma of belonging to an ME community and negative stereotypes associated with being a migrant and belonging to a lower socioeconomic status (Bamford et al, 2014). Increased caregiver burden in ME communities can also be explained by the Stress and Coping Models where elevated levels of caregiver burden are thought to result from elevated levels of stressors and low levels of resources as well as poor coping processes (e.g., Pearlin et al, 1990). Elevated levels of caregiving stressors (e.g., poverty) and limited access to formal support (e.g., dementia carer support groups) might result in increased levels of burden in ME caregivers compared to White British caregivers.

There are a number of reasons why people from ME populations are more likely to care for family members with dementia, these include: language and cultural barriers (Jolley et al, 2009); differences in health beliefs; fear of discriminatory health care practices and mistrust of services (Mukadam et al, 2011); high familism values, defined as having strong attachment and identification to the family, with strong feelings of reciprocity and loyalty (Losada et al, 2010); cultural and religious norms around caring for elders (Jutlla, 2015).

Traditional family-orientated models of care provision are typically adopted in ME communities, where family caregivers live with the PwD and provide care in their home (Ahmad et al,

2020; Herat- Gunaratne et al, 2020; Hossain, 2021; van Wezel et al, 2016), in some cases, extended family members live together and share caring responsibilities (Sagbaken et al, 2018). In other cases, a ‘rotational 24-hour care model’ is adopted, where PwD is moved between relatives’ homes (Nielsen et al, 2021). It is also common for individuals to enter ‘care marriages’ (Berdai Chaouni et al, 2020), where wives are expected to move in with their husband’s family and provide care for parents-in-laws (Arora et al, 2018).

Engaging in traditional models of family caregiving enables adult children to reciprocate parental care received as children (Ahmad et al, 2020; Nielsen et al, 2021). Studies in Norway (Næss & Moen 2015; Sagbakken et al, 2018), reported that ME caregivers described caring for parents as morally upright and as a means of reciprocating kindness received in childhood. Similarly, studies in the Netherlands revealed guilt, shame (Sagbakken et al, 2018) and anxieties around not being ‘good children’ if they did not care for parents (Nielsen et al, 2021). Therefore, seeking support could be interpreted as failure (Ahmad et al, 2020).

Using ‘familism’, as a basis for their research Losada et al, (2010), found that traditional beliefs regarding family obligations in Asian and Latino/Hispanic communities resulted in dysfunctional thoughts, rooted in the need to completely dedicate themselves to caring responsibilities irrespective of their own needs and emotions. In a similar study Stebbins and Pakenham (2001) explored the association between dysfunctional thoughts and emotional distress in carers of people with cognitive difficulties. They concluded that dysfunctional thoughts and higher level of adherence to these thoughts were associated with elevated levels of emotional distress. According to the cognitive model of caregiver distress (Losada et al, 2006) a carer’s beliefs and thoughts (i.e., dysfunctional thoughts), manifest as a result of socio-cultural influences, family histories and personal experiences. These thoughts can then serve as barriers when attempting to cope adaptatively with caregiving responsibilities, increasingly the possibility of poor psychological outcomes.

Alongside the belief that caring is a ‘natural obligation’ (Botsford et al, 2011), ME communities are more likely to believe that relatives will not be appropriately cared for, might be abused, and will

not be understood by health care professionals (Sagbakken et al, 2018). A recent systematic review (Johl et al, 2016) reported that ME family caregivers do not perceive health and social care services as culturally competent and able to meet their needs, this coupled with experiences of discrimination and language barriers results in reluctance to seek support and a greater sense of responsibility to care for family members.

However, some research suggests assuming that ME communities prefer to ‘look after their own’ and that they can do so due to support from wider family systems might not be true (Parveen et al, 2017). For example, extended families are no longer the norm in British South Asian families, due to economic changes resulting in working aged adults moving away from family for employment and taking on the more dominant UK culture around family systems (Katbamna et al, 2004; Parveen et al, 2017). Research also suggests that carers from South Asian communities may sever ties with family and friends and choose to ‘hide’ PwD to avoid stigmatisation (Baghirathan et al, 2020; Berdai Chaouni & De Donder, 2019), particularly in communities where dementia is framed within the context of ‘madness’ or ‘craziness’ (Botsford et al, 2012) and superstition (Baghirathan et al, 2020).

There is considerable research suggesting that ME family caregivers are more likely to experience higher levels of caregiver burden compared to White British caregivers (Carers UK, 2011; Wittenberg et al, 2018), however, there is limited research considering the specific factors associated with this increased burden. This proposed study seeks to add to the current literature by exploring factors associated with increased caregiver burden in ME family caregivers of dementia. This will facilitate the delivery of care practices that reduce caregiver burden which will serve to improve their wellbeing and the people they care for. This is paramount given the increasing recognition that family caregivers need to be better supported (La Fontaine et al, 2016).

Research Aims and Question

The projected increase in dementia amongst people from ME communities, will inevitably result in an increase in the number of family caregivers from ME communities, a figure that currently sits at 540, 000 (Wittenberg et al, 2018). Literature repeatedly highlights the significant pressure that

family systems in ME communities face to provide care. Expectations that stem from cultural norms within the communities, prior negative experiences of services and often unvoiced pressure from health and social care services themselves (Osman & Carare, 2015).

The current cost of dementia care within the UK is £34.7 billion, a number projected to increase to £94.1 billion by 2040. Given the current unprecedented financial constraints faced by health and social care services, unpaid family caregivers act as a huge resource. It is estimated that family caregivers provide care worth £13.9 billion a year. It is therefore paramount that their experiences of caregiving continue to be a research priority (Wittenberg et al, 2018).

Approximately 60,120 ME caregivers in England experience poor health and are more likely to experience moderate to high levels of burden than their White British counterparts (Carers UK, 2011; Wittenberg et al, 2018). Despite this consistent evidence, there continues to remain limited research exploring predictors of caregiver burden in ME family carers of dementia within the UK. Therefore, this research is guided by the following question: What factors are associated with increased burden in minority ethnic family caregivers of dementia?

Findings will help policy makers and commissioners deliver services that are inclusive, non-discriminatory, and sensitive to the diverse needs of ME communities. It is hoped that this will encourage ME caregivers to access services to reduce their burden, improve their wellbeing and those that they provide care for. This is particularly important given the number of national policies (e.g., Department of Health, 2009; Department of Health, 2012) outlining the importance of reducing health inequalities experienced by PwD and their families from ME communities.

Method

Design

There is limited research exploring the specific factors associated with caregiver burden in ME family caregivers of dementia in the UK, therefore a qualitative approach will be an appropriate means of developing meaning and understanding (Creswell & Creswell, 2017) and exploring likely complex caregiving experiences (Barker et al, 2015).

Participants

Inclusion criteria:

- Minority ethnic family carers for people with dementia. The term minority ethnic family carer will refer to people from all non-white origins living and caring for a family member with dementia in the UK.
- Minimum age of 18 years old, there will not be an upper age limit. Carers under 18 years old will be excluded from the study.
- Must have been caring for a family member with dementia for a minimum of six months.
- Minority ethnic family caregiver who previously cared for a person with dementia, not longer than two years ago.
- Ability to take part in a semi-structured interview in English.
- Ability to provide written informed consent.
- Living in the UK, there will be no restriction on geographical location within the UK.
- Must have access to the internet to access the interview via Microsoft Teams.

Exclusion criteria:

- Non-family caregivers.
- Caregivers from White British backgrounds.
- Caregivers of non-dementia related health conditions.
- Caregivers under 18 years of age.
- Caring for a family member living with dementia for less than six months.
- Inability to speak and understand English.
- Does not have access to the internet or Microsoft Teams.

Prospective participants will be sampled from the following sources: Alzheimer's Society, a charity for PwD and their family caregivers; "community leaders" (prominent members of ME communities such as Imams and Granthi's); memory clinics and older adult community mental health teams within NHS Trusts across England.

A poster outlining the nature of the study along with the information sheet will be emailed to NHS Trusts and non-NHS organisations. Clinicians will be asked to put the recruitment poster and information sheets in waiting rooms. Clinicians will also be asked to share the recruitment poster and information sheet with caregivers when they access their services or attend an appointment with their family member with dementia. Before sharing the information sheet and poster with potential participants, clinicians will be asked to complete a brief screening form with caregivers to ensure that they meet the inclusion and exclusion criteria. The poster and information sheet will detail an email address that potential participants can contact if they are interested in participating or would like to know more about the study. Potential participants who express an interest in the study will be asked to sign and return a consent form. Participants will be asked to return the signed consent form within two weeks.

Snowballing and inward purposive sampling will be used to collect data, this method is beneficial when working with hard to reach, underprivileged and geographically isolated ME caregivers in the UK (Hossain, 2021). Volunteer sampling will also be used, with potential participants also recruited through social media where the study poster will be shared. Sampling issues are a well-known challenge in research with ME communities, sample sizes are often limited by relatively low response rates, reasons for this include closed communities (Wilkinson et al, 2003); mistrust of researchers; fearing harm; time and resource constraints (Thakur et al, 2021). Time and resources constraints will be addressed through financial compensation and flexible interview times; mistrust and closed communities will be addressed through engagement with community leaders. It is hoped that the chief investigator's own ME status will also facilitate increased trust. To account for limited diversity within the Southwest of England, there will be no restriction on geographical location within the UK.

Thematic analysis guidelines recommend 6-10 participants for small scale research projects (Clarke & Braun, 2021). With some research suggesting that theoretical saturation occurs after 10 interviews, with few new themes being identified with additional interviewees (Fugard & Potts, 2015). Therefore, 10 participants will be sought, this is also in line with the University of Exeter's Doctoral Programme's recommendations.

Method of Data Collection

Ten sixty-minute semi structured interviews will be used to collect data over the video conferencing platform, Microsoft Teams. All interviews will be audio recorded using the record feature on Microsoft Teams. This will save participants time and money associated with travelling and allow for greater flexibility when arranging interview times (Muir et al, 2020), this will overcome time and resource factors associated with decreased likelihood of research participation in ME communities.

The interview schedule will gain insight into factors associated with increased caregiver burden in ME family caregivers of PwD. A user consultation group will be utilised to develop the content and format of the interview schedule. Open ended questions will be used to provide a flexible frame of reference for further exploration (see appendix A). Once participants have completed the interview, a debrief will be provided and they will have the opportunity to reflect on their interview experience. Participants will be informed that they can access findings from the study upon its completion via email.

Procedure

Ethical approval will be obtained from NHS Research Health Authority and the University of Exeter School of Psychology Ethics Committee, prior to participant recruitment. Information sheets will be given to potential participants and informed consent will be obtained. Participants will be invited to an online interview on Microsoft Teams, which will be encrypted. Participants will be advised around appropriate technology including a stable internet connection (Seitz, 2016). They will be encouraged to use a quiet and private space to talk, to facilitate a safe and open space for potentially sensitive discussions.

Data Analysis

The chief investigator will transcribe forty percent of the data, the rest of the data will be transcribed using Devon transcription service, a service that has been approved by the University of Exeter A confidentiality agreement between the sponsor and external professional transcription service will be in place.

Interview transcripts will be entered into the NVivo data management programme. Following this thematic analysis will be used, comprising six stages outlined by Clarke and Braun (2021) becoming familiar with data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining themes; 6) writing up findings. Thematic analysis has been selected as this is an efficient data analysis process, allowing for a thorough investigation of the phenomenon of interest through interpretation of data obtained from interviews (Alhojailan, 2012). Whilst interpretative phenomenological analysis, is an effective way of understanding how individuals make sense of their experiences (Smith, 2015), thematic analysis was chosen as the preferred data analysis method as it allows for the identification of common themes that arise from the experiences of different caregivers. Caregiving is complex, and thematic analysis will encapsulate this complexity by identifying and exploring several themes and subthemes that might emerge from their experiences.

Research supervisor Dr Taline Artinian will provide expertise and supervision when carrying out thematic analysis of study results. Dr Taline Artinian is a lecturer and research tutor on the Doctorate in Clinical Psychology programme at the University of Exeter, with extensive experience carrying out qualitative research and supervising qualitative research at doctorate level.

A social constructionist framework, which focuses on how meanings and experiences are produced through social contexts and subjective interactions with the world will be used to undertake thematic analysis (Doan, 1997). In terms of minority ethnic caregivers of dementia, they carry out their caregiving role and experience it by generating a meaning for it, which is both culturally and socially bound through place and time. This framework contrasts with the constructivism approach, which suggests that meaning is an individual and internalised process generated from a set of cognitive processes (Raskin, 2008).

A service user consultation group will be consulted on the data analysis processes, this will ensure quality and an approach based on ethical considerations (Smythe & Murray, 2000). They will also be asked to provide their own personal interpretations of anonymised transcripts. It is hoped that this will identify additional themes, challenge the researchers' assumptions, and improve the reporting of living with dementia (Barber et al, 2011). Supervision will be used to reach an agreement on the data analysis.

The chief investigator will reflect on their own position through research supervision, thematic analysis group supervision and logging a reflective diary.

User Consultation

User consultation is recognised as best practice and of significant value to research (Morrow et al, 2010). It offers a range of benefits, including increased credibility and relevance of research to clinical practice and service users (Lindenmeyer et al, 2007; Thompson et al, 2009). All discussions with the service user consultation group will be documented by the researcher on Microsoft word and discussed with the research supervisors for consideration.

The ‘Doctorate in Clinical Psychology and Post Graduate Research Lived Experience Group’ at the University of Exeter will be consulted at various stages of the research project, including recruitment, designing interview questions and data analysis.

Service user involvement in recruitment will improve recruitment rates, and retention (Domecq et al, 2014), if the initial recruitment strategy does not produce enough participants, they will help identify alternative approaches. They will also be consulted on posters used to advertise the project, to provide insights into the cultural appropriateness, clarity, and readability to ensure that its effectively communicates the purpose of the study. Consultation will also be sought on the most effective way to engage minority ethnic caregivers and build trust.

Service users will be involved in designing interview questions, feedback will be sought on appropriateness of language used and clarity of questions. They will also be consulted for their views on interview method, including interview length and techniques for ensuing interviewee comfort and engagement. The service user group will be consulted on the data analysis processes, this will ensure quality, and an approach based on ethical considerations (Smythe & Murray, 2000). They will also be asked to provide their own personal interpretations of data, this will identify additional themes, challenge the researchers’ assumptions and improve the reporting of findings, ensuring that they are relevant to ME family caregivers of PwD (Barber et al, 2011).

Ethical Considerations

Ethical approval will be sought from the NHS Health Research Authority and the University of Exeter's Ethics Committee, prior to participant recruitment.

Informed consent

An information sheet (see appendix B) outlining the purpose of the study will be given to all potential participants. They will be provided with an opportunity to discuss the research process and any questions they have with the researcher. Written consent (see appendix C) will be sought from participants who agree to participate in the study and obtained through an electronic signature, and they will be informed of their right to withdraw their consent at any time during the interviews. Following completion of the interviews, participants will be informed that they have 30 days to withdraw their data should they wish to. This will allow the researcher sufficient time to recruit additional participants if required, without impacting the restricted project timeline. Participants who withdraw will have all their data deleted from the study.

Debrief

The study will not involve deception, participants will be informed of the study's rationale prior to participation. Once they have completed the study, participants will be given a debrief form (see appendix d) containing the chief investigator and research supervisors contact details. If participants believe that support is required in relation to sensitive topics raised, their immediate support needs will be identified and they will be signposted to appropriate services, for example, Alzheimer's society.

Data Protection and Participant Confidentiality

All data collected from participants will be stored securely and confidentially. Data collected from participants will include consent forms, audio recordings of the interview and anonymised transcripts of interviews. All data will be immediately stored onto a password protected laptop and on the University of Exeter's SharePoint, in a protected folder that is only accessible to the chief investigator and research supervisors. Screening forms completed by participating organisations will remain at the participating site and will not be shared with the sponsor.

Data will be pseudo-anonymised during the study. All participants will be allocated a unique identification number, and their data will be labelled with their unique number instead of their name. A

spreadsheet which links participants' unique ID number, and their name will be kept separate from their study data. This will be stored on a password-protected University of Exeter secure SharePoint which is only accessible by the research team.

All interviews will be audio recorded and transcribed verbatim. All personally identifiable information will be removed during transcription (e.g., names), anonymising the data. Once an interview has been recorded it will be immediately uploaded on to the University of Exeter's SharePoint, in a protected folder that is only accessible to the chief investigator and research supervisors. The recordings will then be immediately deleted from Microsoft Teams. All audio recordings will be deleted 12 months after the interview, this time frame takes into consideration the length of time it will take to transcribe and analyse data whilst completing the doctorate in clinical psychology programme. This time frame also coincides with when the chief investigator will have submitted the research to University of Exeter's doctorate in clinical psychology programme and completion of programme studies.

The chief investigator will carry out the interview in an isolated room in their place of residence, where there will be no unauthorised persons able to watch or listen to the interview. This will ensure the privacy and confidentiality of participants.

Identifiable data will not be shared outside of the research team, and the data custodian will be the research supervisor, Dr Katrina Chesterman.

Participants' contact details (i.e. email address) and consent forms will be stored separately from their interview data and contact details will be destroyed securely once participants have been emailed a voucher thanking them for participating in the study. At the end of the interview, participants will be given the option of receiving the results of the study via email once they become available. If they agree to this, they will be made aware that this will involve the research team retaining their preferred contact details until the results have been disseminated. They will also be informed that, as per the study period, their contact details will be kept securely and will only be accessible to the research team. Personal contact details will be deleted after findings have been shared with participants. It is expected that this will be 12 months following the completion of the interview. Consent forms will be retained for three years in accordance with the length of time study data (i.e. transcripts) will be retained.

With participants' consent, anonymised transcriptions will be archived in the University of Exeter's Research Data Archive and a data access statement will be made available in the publication of the study. For any participants who do not consent to their transcripts being archived for the purpose of data access, their data will not be included, and the remaining archived data will clearly state that the full dataset was not archived for this reason. Archived data will be retained for 3 years, in accordance with the University of Exeter's Research Data Policy.

Significance

As previously outlined, the number of PwD from ME communities in the UK and subsequently the number of family caregivers from ME communities is expected to rise substantially (Wittenberg et al, 2018). Dementia places a significant demand on family caregivers, including increased supervision of PwD due to neuropsychiatric changes; managing cognitive, behavioural and mood disturbances; loss of functional abilities; adapting to changes in relationship dynamics (Racine et al, 2022).

Family caregivers of dementia are frequently referred to as the "invisible second patients" (Brodaty & Donkin, 2022), due to the significant psychological, physical, social and financial implications caring responsibilities can have on their lives (Bökberg et al, 2017; Chaves Pedreira et al., 2018; Hermanns & Mastel-Smith, 2012; Hokanson et al., 2018). The detrimental effects on psychological wellbeing are consistently reported in the literature (Campbell et al, 2008; Cooper et al, 2006; Gaugler et al, 2008) and are higher in dementia caregivers compared to other caregivers, differences which are even greater when compared to non-caregivers (Pinquart & Sörensen, 2003). It is widely acknowledged that family carers are often more emotionally affected by the illness compared to the patient. Caregivers also report a higher level of physical health difficulties and a higher risk of mortality (Brodaty & Hadzi-Pavlovic, 1990) compared to non-caregivers (Cherry et al., 2017). Financially, they incur losses through reduced earnings, reduced employment and hidden unpaid costs associated with caregiving. They often lack social support, contact and experience social isolation through reduced time with friends and sacrificing hobbies (Brodaty & Donkin, 2022)

National guidelines and policies, including the National Dementia Strategy for England (2009), The White Paper, *Healthy lives, healthy people* (2010) and the All Party Parliamentary Group on Dementia (2013) acknowledge the need for greater attention to be paid to the experiences of PwD and their carers from ME communities, to reduce the health inequalities they experience across health and social care and ensure that services are appropriate and high quality. The importance of this is illustrated in literature reporting that PwD and their carers from ME populations often complain of a lack of choice (Kenning et al, 2017) and believe that support and services available do not consider their cultural, religious or linguistic needs (Bhattacharyya & Benbow 2013).

Therefore, exploring factors associated with caregiver burden in ME communities will help policy makers and commissioners adopt appropriate models of care to support ME caregivers, deliver care interventions that are sensitive to the cultural needs of these communities, adopt non-discriminatory and inclusive health policies and increase service uptake. It is hoped that this will reduce caregiver burden and improve their wellbeing as well as the people they care for. With the growing number of people living with dementia, and the impact of caregiving, it is increasingly recognised at national and international levels, that family members need to be better supported in their roles as caregivers (La Fontaine et al, 2016).

Dissemination Statement

It is hoped that the final report and publication will be submitted to a relevant dementia journals (e.g., *Dementia Journal*). The publication of the study will acknowledge that the study was conducted as part of the Doctorate in Clinical Psychology, which was funded by the University of Exeter. All participants who take part in the study will be asked if they would like to receive the publication of the study, when it becomes available. Those participants who express a desire to see the publication will be sent a copy via email.

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Appendix A – Interview Schedule

Demographic questions

1. What is your age?
2. What is your ethnicity?
3. Where do you live?
4. Who are your caring for?
 - Parent
 - Grandparent
 - Sibling
 - Aunt or uncle
 - Mother or father-in-law
 - Grandparent-in-law
 - Cousin
 - Daughter or son
5. How long have you been caregiving for?
 - 6 – 12 months
 - 1 – 2 years
 - 2 – 4 years
 - 4 – 6 years
 - 6 + years
6. What type of dementia does the person you care for have?
 - Alzheimer's diseases
 - Vascular dementia
 - Dementia with Lewy bodies (DLB)
 - Mixed Type Dementia
 - Frontotemporal dementia (FTD)
 - Posterior cortical atrophy
 - Other. Please specify.
7. When were they diagnosed with dementia?
 - 6 – 12 months ago
 - 1 – 2 years ago
 - 2 – 4 years ago
 - 4 – 6 years ago
 - 6 + years ago

Main questions

1. Can you tell me about your experience of caring for your family member?

Prompt: for example, how do you feel about it? Or some of the challenges and rewards etc.

2. Can you tell me if and how caregiving has impacted you?

Prompt: If participants respond with “I don’t know what you mean” or similar statements.

The following prompt will be used: “Some recent research suggests that caregiving can change things physically, socially (e.g. spending less time with friends), emotionally, and financially for caregivers. This might or might not be true for you, caregiving feels different for different people.”

3. You have told me about the impact caregiving has had on you. Can you tell me what might have contributed to this?

Prompt: Past research has suggested that there are a number of things that can increase, decrease or change the impact of caregiving on caregivers. Some people have said the following things. Before I list these, it’s important to say that caregiving feels different for different people, so this might not be relevant to your experiences.

- Limited support from service
- Limited help from family/friends
- Other caring responsibilities
- Expectations to care from other people e.g. family, community, religion, culture
- Types of dementia and symptoms
- Other life stressors
- Quality of relationship with person with dementia.

4. Does your ethnic background influence the way you approach and cope with caring for a family member with dementia?

Prompt: If so, how? Can you give some examples?

Prompt: Are there specific challenges related to your ethnic background that may have contributed to the impact caregiving has had on you?

5. What support systems (e.g. either within your cultural community or beyond) have you found helpful in addressing the impact of dementia caregiving on you?

6. In what ways do you feel the broader healthcare system could better support minority ethnic family caregivers of dementia?

Additional enquiry questions

1. Do you have any support with caregiving?
2. Is the support helpful/unhelpful?

Appendix B - Participant Information Sheet

Title of Project: Caregiving Burden in Minority Ethnic Family Caregivers of Dementia.

Researchers' names:

- Aleena Yasin, Trainee Clinical Psychologist, University of Exeter.
- Dr Katrina Chesterman, Clinical Psychologist, University of Exeter.
- Dr Taline Artinian, Lecturer and Research Tutor, University of Exeter.

Summary of the study:

You are being invited to take part in a research study. This study is being completed as part of the doctorate in clinical psychology programme at the University of Exeter.

In this research study we will use information from you. We will only use information that we need for the research study. Only the people involved in the research will know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules. At the end of the study, we will save some of the data in case we need to check it. We will make sure no-one can work out who you are from the reports we write. The information pack tells you more about this.

Purpose of the research:

We would like to know about your experiences caring for a family member with dementia. The aim of this research is to understand factors associated with burden in minority ethnic caregivers of dementia.

Why have I been approached?

We are currently hoping to recruit 10 participants who meet the criteria listed below:

- Identify as a person from a minority ethnic background. Here, ethnic minority refers to people from non-white origins living in the UK.
- Caring for a family member with a formal diagnosis of dementia.
- Caring for a family member with dementia for at least six months.
- Previously cared for a family member with a dementia, not longer than two years ago.
- 18+ years old.
- Speak and understand English.
- Live in the UK.

What would taking part involve?

- If you agreed to take part, you will be asked to attend an online interview on the videoconferencing platform, Microsoft Teams. Interviews will last approximately 60 minutes. You do not need Microsoft Teams to take part, you just need to have access to the internet.
- You will be asked questions relating to your experiences of providing care for a family member with dementia. The interview will be conducted by the primary researcher.
- Once you have completed the interview, you will be given the opportunity to discuss and reflect on your interview experience with the primary researcher.
- The interview will be audio recorded, following this it will be transcribed and analysed. You will not be identifiable; all data will be anonymised, and you will be given a pseudonym.
- Your audio recording will be permanently deleted 12 months after the interview has taken place. This timeframe reflects how long it will take to transcribe and analyse the data.
- A transcription service may be used to transcribe your interview recording. A confidentiality agreement will be in place to protect your identity and personal information.

- Your anonymised transcripts may be analysed by the ‘Doctorate in Clinical Psychology and Post Graduate Research Lived Experience Group.’ This group comprises people who have previously or currently access mental health services.

What are the possible benefits and disadvantages of taking part?

You will be given a £15 Amazon voucher to thank you for taking part in the study. There are not any guaranteed benefits from participating in the study. However, the study may provide you with an opportunity to reflect on an important aspect of life caring for a family member with dementia.

There are not any expected risks in participating in the study. However, the topic being discussed might be upsetting or potentially sensitive. If you find the interview upsetting or distressing, you can pause or stop the interview at any time.

How will we use information about you?

We will need to use information from you for this research project. This information will include your:

- Full name
- Email address
- Age
- Gender
- Ethnicity
- Town/City you live in
- Who you are caring for (e.g. parent, grandparent, sibling), the type of dementia they have and when they were diagnosed
- How long you have been caregiving for

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure. Only the research team will see this. We will also follow all privacy rules.

We will write our reports in a way that no-one can work out that you took part in the study. The results of this study will be reported in the doctoral thesis of the main researcher. It might also be published in a journal and presented at conferences. Anonymised quotes may be used in these publications; however, your personal details will not be included in this.

Information may need to be shared by the researcher to social services or emergencies services, if the safety of you or any other person is at risk. This information would be first, shared with within the research team and then reported to social services if necessary. Any imminent risks will be addressed by contacting emergency services.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. You can do this by contacting the main researcher (Aleena Yasin, ay335@exeter.ac.uk).

If you would like to receive a summary of the results of the study, then we will retain your contact details until the summary is sent to you. We anticipate this being approximately 12 months following the completion of the study.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- At www.hra.nhs.uk/information-about-patients/
- Our leaflet available from: www.hra.nhs.uk/patientdataandresearch
- By asking one of the research team (Aleena Yasin, Dr Katrina Chesterman, Dr Taline Artinian)
- By sending an email to ay335@exeter.ac.uk, or
- By sending an email to Brenda Waterman, Data Protection Officer, informationgovernance@exeter.ac.uk

Who is organising and funding this study?

The Clinical Psychology Doctorate Programme at the University of Exeter are funding this research study. The project is being conducted by a Trainee Clinical Psychologist at the University of Exeter, under the supervision of Dr Katrina Chesterman, Clinical Psychologist, University of Exeter and Taline Artinian, Lecturer and Research Tutor, University of Exeter.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given a favourable opinion by the Research Ethics Committee (Ref.24/SC/0243).

How can I take part?

You can contact the research team for further information about the study or to confirm that you would like to take part. The main researcher is Aleena Yasin, Trainee Clinical Psychologist (ay335@exeter.ac.uk).

Who can I contact if I have a complaint?

If you are want to complain about any aspect of the research project please contact Dr Katrina Chesterman (k.a.chesterman@exeter.ac.uk) or Dr Taline Artinian (t.artinian2@exeter.ac.uk). If you are not happy after that, you can contact the study Sponsor: Suzy Wignall, University of Exeter, Corporate Services, Research Ethics, Governance and Compliance, G14, Lafrowda House, St Germans Road, Exeter, EX4 6TL. E: res-sponsor@exeter.ac.uk T: 01392 726621

Appendix C – Consent Form

IRAS ID: 335501

Participant Number:

CONSENT FORM

Title of Project: Caregiving Burden in Minority Ethnic Family Caregivers of Dementia.

Name of Researchers: Aleena Yasin, Trainee Clinical Psychologist, University of Exeter.

Dr Katrina Chesterman, Clinical Psychologist, University of Exeter.

Dr Taline Artinian, Lecturer and Research Tutor, University of Exeter.

Please initial box

1. I confirm that I have read the participant information sheet (version 1.1) dated 14.07.24 for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to stop being part of the study at any time, without giving a reason and without my legal rights being affected. I understand that the researcher will keep information about me that they already have.
3. I understand that taking part involves an audio recorded interview which may be stored for up to 12 months following the completion of the interview.
4. I understand that third party services, such as transcription services, may be used to process interview recordings. I understand that confidentiality agreements will be in place to protect my identity and personal information.
5. I agree to the use of anonymised quotes in an academic publication and reports for this study. I understand that my personal details will not be included in this.
6. I understand that any information I share will be held securely by the primary researcher and that my personal information is protected under the GDPR and the Data Protection Act (2018). It will not be held for any longer than necessary.
7. I understand that information may need to be shared without my permission if the safety of me or any other person is at risk.

8. I agree to take part in the above project.

9. OPTIONAL. I would like to know the results of the study. I agree that my contact details can be kept securely and used by researchers from the research team to contact me about the outcome of the study.

Name of Participant

Date

Signature

Name of researcher

Date

Signature

taking consent

If you would like to receive a summary of the results of the study, please supply a contact email address here.....

When completed: 1 copy for participant; 1 copy for researcher/project file.

Appendix D - Debrief Form

The aim of this research is to understand factors associated with burden in minority ethnic (ME) caregivers of dementia. There is considerable research suggesting that ME family caregivers are more likely to experience higher levels of caregiver burden compared to White British caregivers (Carers UK, 2011; Wittenberg et al, 2018), however, there is limited research considering the specific factors associated with this burden. This proposed study seeks to add to the current literature by exploring factors associated with caregiver burden in ME family caregivers of dementia.

It is hoped that research findings will help policy makers and commissioners deliver services that are inclusive, non-discriminatory, and sensitive to the diverse needs of ME communities. It is hoped that this will encourage ME caregivers to access services to reduce their burden, improve their wellbeing and those that they provide care for. This is particularly important given the number of national policies outlining the importance of reducing health inequalities experienced by people with dementia and their families from ME communities.

Your interview will be recorded and transcribed for analysis purposes. All information will be kept in accordance with GDPR and the Data Protection Act (2018) on a password protected device. Your information will remain confidential, and your details will be kept anonymous. Only members of the research team will have access to the data. You have the right to withdraw your data up to 30 days after the completion of the interview by contacting Aleena Yasin, Trainee Clinical Psychologist.

If you would like more information regarding sources of support, please see the following contact details:

Alzheimer's society

Website: <https://www.alzheimers.org.uk/get-support/dementia-support-line>

Tel: 0333 150 3456

Carer's First

Website: <https://www.carersfirst.org.uk/>

Age UK

Website: <https://www.ageuk.org.uk/>

Tel: 0800 678 1602

Samaritans

Tel: 116 123

If you have any questions about this research, please contact Aleena Yasin, Trainee Clinical Psychologist (ay335@exeter.ac.uk) or the research supervisors Dr Katrina Chesterman (k.a.chesterman@exeter.ac.uk) and Dr Taline Artinian (t.artinian2@exeter.ac.uk) or the Chair of Psychology Ethics at the University of Exeter, Professor Ian McLaren, (i.p.l.mclaren@ex.ac.uk), Chair of Psychology Ethics, University of Exeter.