Exploring the Experiences of Ethnic Minority Informal Caregivers Looking After Older Adults with Dementia and Neurological Conditions

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Thesis portfolio Abstract

Background: The increasing global prevalence of neurological conditions, such as dementia, poses significant challenges for healthcare systems. Within this context, informal caregivers play a crucial role in providing long-term care. Research indicates ethnic minority caregivers often provide more intensive and prolonged care compared to their White British counterparts. However, they are less likely to self-identify as "carers" or seek formal support services. This reluctance is often attributed to cultural norms, a strong sense of familial duty, and systemic barriers within healthcare services. Additionally, existing research often homogenizes the experiences of ethnic minority caregivers, failing to account for the diverse influences of migration histories, cultural practices, and socioeconomic contexts. African and Caribbean communities, which represent a significant portion of the UK's Black, Asian, and Minority Ethnic (BAME) population, exemplify this complexity.

Aim: This thesis explores ethnic minority informal caregiving through two studies: A systematic review synthesizing the experiences of ethnic minority informal caregivers for individuals with neurological conditions in Europe. An empirical qualitative study investigating how African and Caribbean caregivers in the UK conceptualize dementia and navigate support systems.

Method: The systematic review employed thematic synthesis to analyse studies on ethnic minority caregivers across Europe. The empirical study used semi-structured interviews, analysed through reflexive thematic analysis, to explore how African and Caribbean caregivers construct meaning around dementia and navigate support services.

Results: The systematic review included 18 studies and identified three key themes (1) Caregiving as an identity reinforcer, (2) Balancing identities, expectations, and traditions, and (3) Fulfilment and reconciliation of historic and current life narratives. The empirical study included 8 semi-structured interviews and revealed three interrelated themes: (1) Cultural and generational interpretation of dementia, (2) Love, duty, sacrifice and coping with caregiving role and, (3) Negotiating and advocating for support.

Conclusion: The findings highlight a generational shift in how African and Caribbean caregivers understand dementia and access support. Ethnic minority younger caregivers across Europe navigate tensions between traditional caregiving values and Western healthcare norms, shaping an insider/outsider identity. Both the systematic and empirical studies suggest that caregiving serves as a space for identity preservation within these communities. This research highlights the need for culturally competent dementia care that considers the wider system and challenges the oversimplification of ethnicity in caregiving studies. It advocates for an intersectional approach in research and policy, recognizing the interplay of ethnicity, migration, and identity in caregiving experiences.

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"A person is a person through other persons" - Desmond Tutu

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Chapter 1- Introduction

Chapter 1- Introduction

This chapter provides a foundation for the thesis Portfolio and is presented in four sections. The first section offers background information, including a discussion on use of language and its implications. The second section explores theories related to dementia, race, ethnicity, cultural identity, and migration, examining their relevance to ethnic minority populations. It also discusses theories of health and help-seeking behaviours. The third section enquires into current research on caregiving within ethnic minority communities. Finally, the fourth section critiques existing research paradigms, encouraging the reader to consider these critiques given this research Portfolio social constructionist and social justice positionality.

Background

The global rise in neurological conditions, including dementia, due to aging populations is placing unprecedented pressure on healthcare systems worldwide (Feigin et al., 2020; Prince et al., 2015; Dorsey et al., 2018). Informal caregivers, who are unpaid individuals providing care within their social networks play a central role in supporting people with neurological conditions particularly where formal services are limited or underused (World Health Organization, 2019; Greenwood et al., 2015; Milne & Chryssanthopoulou, 2005; Roche, 2023).

In Europe, nearly 6.5% of dementia cases involve foreign-born individuals, many from ethnic minority backgrounds (Canevelli et al., 2019; Diaz et al., 2015), they are less likely to engage with specialist dementia-specific care (Denktaş et al., 2009; Stevnsborg et al., 2016; Greenwood et al., 2015). For example, in the Netherlands, only 1% of Moroccan and 7% of Turkish older adults with dementia use home care services, compared to 16% of the non-migrant Dutch population (Alzheimer Nederland, 2014). Barriers to using these services are reported to include stigma surrounding dementia (or/ and neurological conditions), limited availability of culturally sensitive services, and stereotypes, such as the belief that ethnic minority families “look after their own” (Alzheimer Europe, 2018; Parveen et al., 2017).

In the UK, dementia affects an estimated 850,000 people, with prevalence projected to rise significantly in the coming decades (Alzheimer's Society, 2021). This increase is particularly pronounced among Black, Asian, and Minority Ethnic (BAME) communities, where prevalence is expected to grow sevenfold by 2051, compared to a twofold increase in the White British population (Alzheimer's Society, 2021; All-Party Parliamentary Group on Dementia, 2013). Despite this, individuals from BAME communities experience significant disparities in accessing dementia care, with delayed diagnoses often linked to cultural stigmas, limited awareness, language barriers, and the lack of culturally appropriate healthcare services (Adelman et al., 2011; Greenwood et al., 2015).

Informal caregiving is particularly significant within BAME communities in the UK, where carers often balance extensive caregiving responsibilities with paid employment and other family obligations (Yeandle et al., 2007; Carers UK, 2011). Research has consistently shown that BAME caregivers are more likely to provide high-intensity care (≥20 hours per week) and are less likely to access formal care services due to cultural preferences, language barriers, and mistrust of the system (Yeandle et al., 2007; Dilworth-Anderson et al., 2020). Carers UK (2011) further reported that BAME caregivers are twice as likely as White caregivers to provide over 50 hours of care per week, often alongside paid employment.

Providing intensive caregiving often results in significant financial strain for BAME carers, who are disproportionately of working age (25–64 years). Carers UK (2014) found that 45% of BAME carers reported financial hardship due to caregiving, compared to 33% of White carers, with many experiencing reduced household income due to job loss or reduced working hours. Many carers do not self-identify as "carer", partly because there is no direct translation for the term "carer" in languages like Bengali, Gujarati, and Punjabi (Carter et al., 2024; Greenwood et al., 2015). When services are sought, they are often perceived as culturally incompatible or inflexible (Greenwood et al., 2015).

Dementia research often homogenises ethnic minority communities, overlooking the diversity of experiences shaped by migration histories, cultural norms, and socioeconomic contexts (Greenwood et al., 2015; Parveen et al., 2017;Milne & Chryssanthopoulou, 2005; Roche, 2023). African and Caribbean communities, which constitute a substantial proportion of the BAME population in the UK, exemplify this complexity (Roche.,2023). There are only two studies in the UK that have looked at the experiences of African and Caribbean caregivers, one of which is a thesis Portfolio (Roche.,2023). Shrestha et al. (2023), in their meta-ethnographic review of 11 peer-reviewed studies, highlight that caregiving dynamics and motivations are changing. These shifts are driven by socio-economic factors such as smaller family sizes, fewer family members available for caregiving, and increased social mobility. (Milne & Chryssanthopoulou, 2005; Dilworth-Anderson et al., 2020). These shifts challenge the assumption that minority families “look after their own” (Greenwood et al., 2015; Roche, 2023).

To address this gap, this thesis Portfolio will include two studies. The first will be a systematic review of the literature, on the experiences of ethnic minority informal caregiving for individuals with neurological conditions within the European context. Focusing on the European context is crucial, as migration experiences, healthcare systems, and the broader socio-political landscape differ significantly from those in non-European context (Duran-Kiraç et al., 2023). The second reports on a qualitative empirical study, focusing specifically on the sense making and understanding of dementia among African and Caribbean caregivers in the UK.

Use of Language

From a social constructionist and social justice perspective, language actively shapes collective understandings of reality, identity, and experience (Berger & Luckmann, 1979; Burr, 2015). As Burr (2015) emphasises, language operates within power dynamics, reflecting and reinforcing dominant ideologies that structure social hierarchies (Foucault, 1978). For instance, Foucault’s (1978) concept of “regimes of truth” illustrates how institutions wield discursive power to legitimize certain narratives while silencing others. These dynamics are evident in the ways dominant groups use language to categorize marginalized communities, influencing perceptions of legitimacy, resource distribution, and inclusion/exclusion (van Dijk, 1993; Spivak, 1988).

While this thesis Portfolio primarily uses terminology consistent with current literature, readers are encouraged to critically engage with terms like 'language barriers,' 'stigma,' 'culture,' 'hard to reach,' and 'ethnicity,' recognizing their significant implications, particularly for minority communities, and their influence on discourse, research, policy, and service provision.

The author uses the terms "ethnic minority," "BAME", and "BME" interchangeably throughout the thesis Portfolio to describe groups considered minorities within their respective contexts. It is crucial to recognise that the composition of ethnic minority populations varies across Europe. For instance, ethnic minorities comprise 18.3% of the UK population, including Asian, Black, and Mixed groups (UK Government, 2021). In the Netherlands, they represent 10% , primarily Turkish, Moroccan, and Surinamese communities (Sleutjes et al .,2018). Belgium's minorities include Moroccan, Turkish, and Congolese groups (Van Pottelberge et al., 2021) while Norway's 11.4% minority population consists of Pakistani, Somali, and Iraqi groups (IMDi, 2024.).

It is also important to highlight that the term care partners are gaining traction within caregiving literature to recognize the bidirectionality of the caregiving relationship (Prizer & Hudson, 2023). However, within this project, the term caregiver is retained for consistency with existing research on minority communities and to accurately reflect participant-communicated experiences.

Theories of Dementia

Given that this thesis explores how dementia is understood and conceptualized by minority communities within Western contexts, it is essential to consider the historical evolution of dementia within these settings. Historically, dementia was perceived as either a natural consequence of aging or a supernatural phenomenon (Ballenger, 2020). This perception shifted in the 19th and 20th centuries with the emergence of the biomedical model, which framed dementia as a pathological condition rooted in biological and neurological dysfunction (Karenberg & Förstl, 2006). This model was transmitted across Western societies through media and globalization, shaping public understanding and expectations of dementia care (Mukadam et al., 2011). While the biomedical model significantly advanced diagnostic and treatment approaches, it entrenched a Eurocentric perspective that often neglected the sociocultural dimensions of dementia (Fletcher,2023).

A significant challenge to the biomedical model was introduced by Tom Kitwood (1997), who proposed the person-cantered approach to dementia care. Kitwood emphasized that individuals with dementia should not be reduced to their neurological symptoms but should be understood within their social, relational, and cultural environments. His personhood model reconceptualized dementia as a socially embedded experience, arguing that the quality of care and interpersonal interactions significantly influence a person's well-being (Kitwood, 1997; Ballenger, 2017). This approach was a direct critique of medicalized dementia care, which often depersonalizes individuals by focusing solely on symptom management.

Building on Kitwood's work, Clare (2010) further challenged purely biomedical models by advocating for a subjective, experience-based understanding of dementia. Her "Living Well with Dementia" framework prioritizes identity preservation, autonomy, and emotional well-being, emphasizing that cognitive decline does not necessarily equate to a loss of self (Clare, 2010). Her research integrates neuropsychological rehabilitation principles with holistic care approaches, reinforcing the idea that person-cantered support enhances the quality of life for individuals with dementia. Notably, Clare's model has been incorporated into NHS dementia care guidelines, promoting non-pharmacological interventions that prioritize dignity, agency, and meaningful engagement (Clare, 2010).

Race, Ethnicity, Culture, and Identity.

Understanding race, ethnicity, culture, and identity is important when thinking about dementia research, policy and service provision. Research on dementia in ethnic minority communities has long been criticized for its reliance on static, homogenizing definitions of race, ethnicity, and culture, which fail to account for the dynamic, intersectional nature of identity (Milne & Chryssanthopoulou, 2005; Roche et al., 2021).

Race, historically rooted in physical traits, and ethnicity, defined by shared history and cultural practices, are often used interchangeably in health studies. However, these broad constructs risk oversimplifying lived experiences and reinforcing stereotypes (Matsumoto & Juang, 2022; Sirugo et al., 2023). For example, broad categorizations like “BAME” often obscure intra-group diversity, attributing structural barriers such as disparities in healthcare access to vague “cultural differences” rather than systemic inequities (Sirugo, Williams, & Tishkoff, 2023). This reductionist approach persists despite evidence that identity is fluid, shaped by migration, acculturation, and social contexts, and is deeply intertwined with caregiving practices and help-seeking behaviours (Ciechowska & Kusztal, 2020; Berry, 1992).

Dementia studies frequently homogenize ethnic minority groups, overlooking how migration trajectories or generational status mediate caregiving experiences. (Milne & Chryssanthopoulou, 2005; Roche, 2023). Studies acknowledging acculturation stress, such as those by Berry (1997) focusing on immigration identity and adaption rarely explore generational differences. First-generation immigrants, as shown by Maehler and Daikeler (2024), often maintain strong ties to their cultural roots while navigating host-society norms, creating dual identities that evolve in response to systemic barriers. Conversely, second-generation immigrants face cultural straddling, balancing individualistic host-society values with collectivist familial expectations, which can influence perceptions of dementia care (Gill-Chawla & Heckman, 2024).

While valuable, examining dementia care solely through ethnicity and culture can be reductive. It often overlooks intersectionality, identity formulation, impact of migration and generational differences. Recognizing the complexities of identity, culture, and social context is essential for inclusive dementia care policies and practices that reflect diverse experiences within minority communities (Milne & Chryssanthopoulou, 2005; Roche et al., 2021).

Theories of migration and African and Caribbean people in the UK

Theories of migration provide critical frameworks for understanding the shared experiences of African and Caribbean migrants in the UK. Lee's (1966) Push-Pull Model, for instance, has been widely applied to explain how post-war labor shortages in the UK (pull factors) and economic or political instability in migrants' countries of origin (push factors) motivated migration. Caribbean migration during the Windrush era (1948–1971) and later African migration driven by conflict (e.g., Somali civil war refugees) exemplify this dynamic (UNHCR, 2022). Similarly, Wallerstein's (2004) World Systems Theory highlights how colonial histories structured migration flows while perpetuating systemic inequalities, leaving many African and Caribbean migrants economically and socially marginalized upon arrival in the UK.

In the UK context, Miles (1993) argues that migration is often framed through the lens of ethnicity, emphasising challenges such as maintaining cultural ties and adapting to new environments. Miles links this framing to Britain's colonial history and systemic racism, which position ethnic minorities as perpetual outsiders a dynamic starkly exemplified by the Windrush Generation. This group, arriving in the UK between the 1940s and 1970s to address labor shortages, faced systemic exclusion from housing, employment, and healthcare (Roche, 2022; Gentleman, 2019). Comparative work by Alba and Foner (2015) echoes these themes, highlighting how in western Europe, including the UK, struggle with integrating migrant communities while navigating multicultural identities. This contrasts with the U.S., where discussions of ethnicity and identity are more explicitly tied to race and the historical legacy of slavery (Du Bois, 1996; Bonilla-Silva, 2018).

European narratives, as Binaisa (2013) notes, often focus on the tension between maintaining homeland connections and adapting to host-society norms, reflecting a Eurocentric bias that frames migrants as “problems” to be assimilated.

Migration has profoundly reshaped caregiving practices within African and Caribbean communities. First-generation migrants, often from societies with collectivist caregiving traditions, faced systemic exclusion in the UK (e.g., the Windrush Scandal), fostering deep mistrust in formal healthcare systems (Williams,2020). Research highlights how structural racism and exclusionary practices marginalized Caribbean migrants, fostering scepticism towards formal care services (Karlsen & Nazroo, 2002; Reynolds, 2006). Younger generations, while not having directly experienced migration, navigate cultural straddling, balancing familial traditions with the norms of their birth country (Roche,2023). This generational dissonance complicates care decisions for older relatives, particularly when dementia or declining capacity limits elders’ ability to advocate for themselves (Roche, 2023; Reynolds, 2006). These dynamics, shaped by historical migration patterns and structural inequities, underscore the limitations of Eurocentric care models that neglect intersectional identities (Crenshaw, 2015).

Models of Health, Illness, and Help-Seeking

Understanding dementia care requires acknowledging how cultural frameworks shape perceptions of health, illness, and help-seeking. Collectivist cultures, which prioritize familial interdependence and social harmony, often perceive dementia relationally, framing caregiving as a moral duty rather than a medical issue (Hanssen & Thai, 2019) . In such contexts, research suggests that seeking external help may be stigmatized as neglecting familial responsibility, leading to delayed professional care in favour of kinship or traditional support systems (Duran-Kiraç et al., 2021; Roche, 2023). Conversely, individualist cultures, which emphasize autonomy, are argued by Calia et al. (2019) to medicalize dementia, positioning professional intervention as the default solution. While dominant models like the Health Belief Model (HBM) frame help-seeking as an individual’s rational choice to pursue biomedical care (Rosenstock, 1966), critics such as Airhihenbuwa (1995) contend that this perspective pathologizes communities who rely on collective decision-making or non-Western healing practices.

These challenges are compounded by cultural perceptions of dementia as a natural part of aging (Mukadam et al. ,2010). These critics can also be applied to interventions offered to caregivers. Psychological support programs, for instance, are critiqued by Calia et al. (2019) and Martin and Martin (2002) for prioritizing self-care strategies over culturally grounded coping mechanisms. Yet, as Martin and Martin (2002) assert, traditional values like respect for elders and collective responsibility can transform caregiving into a source of empowerment, counterbalancing histories of marginalization. These dynamics, as Roche (2021) argue, highlight the limitations of Eurocentric models that homogenize minority experiences or reductively attribute reluctance to seek help to "lack of awareness."

Caregiving within Ethnic Minority Communities

Caregiving within ethnic minority communities is multifaceted shaped by cultural values, religious beliefs, and socioeconomic factors (Roche .,2023). According to Dilworth-Anderson et al. (2002), these elements influence how care is perceived, provided, and accessed, creating unique challenges and strengths for caregivers and those living with dementia. Familism, the belief that the extended family should care for older relatives, is a central theme in many ethnic minority communities (Lillekroken et al., 2023). This sense of familial obligation often leads caregivers to take on responsibilities without seeking external support (Mukadam et al., 2011; Parveen et al., 2017). Research suggests that cultural attitudes toward caregiving significantly impact how carers adjust to their role, influencing their concerns, hopes, and attitudes toward support systems (Lawrence et al., 2008).

Coping strategies used by BME communities often rely on social and spiritual support networks. Kinship structures help distribute caregiving responsibilities, but their effectiveness varies based on cultural factors such as gender roles and dementia perceptions (Roche,2023). In some communities, women predominantly assume caregiving roles (Hossain & Khan, 2019). Cultural interpretations of dementia, often seen as spiritual afflictions (Roche, 2022), contribute to stigma and delayed help-seeking (Lillekroken et al., 2023). However, religious coping strategies, such as prayer and faith, provide emotional solace and resilience (Dilworth-Anderson et al., 2002). Over time, evolving religious practices and generational shifts may alter caregiving attitudes (Milne & Chryssanthopoulou, 2005; Roche, 2022).

In the European context, caregiving among ethnic minorities reflects both cultural continuity and adaptation to new social environments. Zarzycki et al. (2023) note that early family socialization fosters caregiving responsibilities, often seen as reciprocating parental support. However, acculturation introduces tensions as families navigate traditional values and modern societal pressures (Ahmad., 2019). Caregivers balance cultural expectations with socio-economic challenges, often without adequate culturally sensitive support systems (Roche, 2023).

African and Caribbean Informal Caregiving

Berwald et al., (2016) exploring the perception of dementia within African and Caribbean communities found that it is often seen as a "white person's disease." The authors concluded that this assumption of dementia contributed to relucent help-seeking behaviours, leading to delayed diagnoses and under use of dementia services. Similarly, Roche (2023), explored the impact of migration experiences and socio-economic challenges on dementia caregiving practices within African and Caribbean communities. Through thematic analysis, the study identified three key themes. First, dementia was perceived as a *"killer" and foreign disease,* with participants viewing it as an external and fatal condition not traditionally recognized within their communities. Second, aging was described as a "permanent visitor," an ongoing and intrusive presence shaping individuals' daily lives and identities. Lastly, kinship, care, and cultural distance emerged as a critical theme, emphasizing the role of strong familial bonds in caregiving while highlighting a cultural gap between traditional caregiving practices and expectations within the UK healthcare system.

Roche (2023) study involved interviews with individuals with dementia, family caregivers, and professionals. This research provided a rich understanding of how this group makes sense of dementia. However, there was a lack of differentiation in generational experiences, and given the study's broad focus on a wide range of experiences, it is crucial to capture the lived experiences of caregivers in greater detail. Understanding their sense-making, experiences, and perceptions of dementia is essential for developing culturally appropriate services and policies.

As Truswell (2018) noted in his briefing paper, the higher prevalence of vascular dementia among African Caribbean individuals, coupled with the strain on traditional kinship networks due to generational shifts and economic pressures, further complicates the issue. Younger generations are increasingly relying on external services yet, stigma and mistrust of healthcare institutions persist due to past experiences of discrimination and culturally insensitive care (Truswell.,2018). Therefore, future research must prioritize the voices of informal caregivers to ensure that services and policies reflect their needs and address the unique challenges they face.

Critique of the current research methodology in dementia studies

A critical issue in dementia research within ethnic minority communities lies in the research paradigms employed and the identities of the researchers involved. Roche et al (2021), in their systematic review of studies examining the experiences of dementia among Black and Minority Ethnic (BME) communities, found that research often aggregates individuals from diverse backgrounds without adequately considering the impact of this diversity or the ethnicities of the researchers themselves. Their findings revealed that only 56% of the reviewed studies reported consulting or involving individuals from these communities during the research process. This underrepresentation raises concerns regarding the accuracy, cultural relevance, and inclusivity of dementia-related findings.

Ontologically, dementia research faces a challenge between emic and etic perspectives (Headland et al., 1992). The emic approach prioritizes insider perspectives, focusing on the lived experiences of ethnic minority caregivers and their culturally specific understandings of dementia. In contrast, the etic perspective applies an outsider's view, utilizing universal concepts and theories, such as biomedical frameworks to explain behaviours and phenomena. However, these externally imposed models may not align with the cultural beliefs and practices of the studied communities (Pool & Geissler, 2008). This epistemological bias highlights the need for inclusive methodologies that incorporate both perspectives to achieve a more comprehensive and culturally sensitive understanding of dementia care.

The prevailing Eurocentric bias in dementia research not only marginalizes culturally specific interpretations but also limits the development of appropriate diagnostic tools and the urgency for tailored policies and interventions (Milne & Chryssanthopoulou, 2005; Roche, 2022). This bias may further contribute to the delayed diagnoses commonly observed among ethnic minority communities (Adelman et al., 2009;Tuerk & Sauer, 2015).

Therefore, increasing the representation of ethnic minority researchers in dementia studies is crucial to enhancing the quality of findings and ensuring the advocacy of culturally relevant interventions and policies.

Reflexivity and Positionality

I approach this research with both personal and academic experience. My experience with dementia caregiving stems from first-hand involvement in supporting my mother as she cared for my grandfather following dementia diagnosis. Additionally, during the writing of this thesis, my grandmother was diagnosed with a stroke, deepening my awareness of the complexities of caregiving and the dynamic of systems and generational influences. Academically, my research background includes a master's dissertation exploring the understanding of dementia within the Somali community. These experiences inform my approach to this study and privileged me with an insider/ outsider positionality.

Aim and Structure of the Thesis Portfolio

The overarching aim of this thesis portfolio is to develop a nuanced understanding of the experiences of informal caregivers from ethnic minority communities, specifically those caring for loved ones with neurological conditions. Recognising the growing prevalence of dementia within African and Caribbean communities in the UK and the underutilization of support services by caregivers, this portfolio integrates empirical and critical research components to explore the unique cultural, systemic, and historical contexts shaping caregiving practices. This work aims to contribute to a more inclusive and culturally sensitive understanding of informal caregiving and inform the development of appropriate support systems.

Structure of the Thesis Portfolio

- ***Chapter 1: Introduction;*** This chapter provides background information on dementia research, focusing on language use, theoretical frameworks, and caregiving within ethnic minority communities. It explores health and help-seeking behaviours, critiques existing research paradigms on dementia and caregiving in ethnic minority group.
- ***Chapter 2: Systematic Review;*** This chapter synthesizes existing qualitative research on the experiences of ethnic minority caregivers across Europe, providing a broader context for the empirical study.
- ***Chapter 3*****:** ***Empirical Qualitative Study***; This chapter presents a qualitative study exploring how informal caregivers from African and Caribbean communities understand, make sense of, and experience dementia caregiving, including their use of support services.

- ***Chapter 4*****:** ***Extended Methodology****; This* chapter provides a critical reflection on the methodologies and philosophical frameworks that underpinned the empirical research. It justifies the adoption of qualitative methods and explores their alignment with the aim of the study. It also includes the author's reflections on the research process.
- ***Chapter 5: Critical Appraisal and Discussion***; This final chapter synthesizes the findings from the empirical study and systematic review, placing them within the existing literature. It discusses the implications for clinical practice, policy development, and future research directions.

Chapter 2 - Systematic Review and Meta-synthesis

Preserving Identity Through Caregiving: A Systematic Review and Meta-synthesis of Minority Informal Caregivers' Experiences Caring for Older Adults with Neurological Conditions

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See Appendix A for Formatting guidelines for authors

Preserving Identity Through Caregiving: A Systematic Review and Meta-synthesis of Minority Informal Caregivers' Experiences Caring for Older Adults with Neurological Conditions

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Abstract

Neurological conditions, including dementia, Parkinson's disease, and stroke, are rising globally, increasing reliance on informal caregivers, particularly within ethnic minority communities. Little is known about the experiences of ethnic minority caregivers within the European context. This review aimed to explore how ethnic minority informal caregivers construct meaning about, and navigate, their caregiving roles. Four electronic databases were systematically searched in August 2024. Eighteen qualitative studies met the inclusion for thematic synthesis including the experience of 258 caregivers, studies originating from the UK (n = 14), Norway (n = 2), the Netherlands (n = 1), and Germany (n = 1). Three overarching caregiving narratives emerged: (1) Caregiving as an identity reinforcer, highlighting how caregiving functions as a mechanism for upholding cultural identity and preserving the dignity and personhood of the care recipient; (2) Balancing identities, expectations and traditions; reflecting the ways caregivers navigate competing expectations between traditional caregiving norms and the demands of modern life; and (3) Fulfilment and reconciliation of historic and current life narratives, illustrating how caregivers construct emotional and spiritual meaning while drawing on past strategies of resilience and resistance as coping mechanisms. The findings demonstrate that caregiving within ethnic minority function as site of identity maintains and preservation as well as changing norms to caregiving. The findings are discussed and contextualized within existing theories and literature, offering implications for policy, healthcare services, and future research.

Keywords: Informal caregiving, ethnic minority caregivers, neurological conditions, caregiving identity, generational difference.

Introduction

Neurological conditions, including dementia, Parkinson’s disease, and stroke-related impairments, are rising globally due to aging populations (Feigin et al., 2017; Prince et al., 2015; Dorsey et al., 2018). In Europe, this trend presents significant challenges for healthcare systems, leading to an increasing dependence on informal caregivers, particularly within ethnic minority communities (World Health Organization, 2019; Stenberg & Hjelm.,2022). Informal caregiving refers to the unpaid care provided to a family member or friend with a chronic illness, disability, or long-term care needs (Revenson et al., 2016). It remains a fundamental pillar of care provision within society and is particularly prevalent in ethnic minority communities (Wells., 2024). A longitudinal study (2009–2020) of data from UK households shows that ethnic minority groups provide more care within their households and more intensive care compared to White carers (Wells, 2024). Caregiving in these communities is often influenced by cultural expectations and familial obligations, where values such as collectivism and filial responsibility frame caregiving as a moral and natural duty embedded within cultural identity (Dilworth-Anderson et al., 2002). However, reliance on informal care is further complicated by systemic barriers such as language difficulties, lack of culturally sensitive care services, and limited engagement with healthcare providers. These barriers contribute to the use of informal support systems (Mukadam et al., 2011; Parveen & Oyebode, 2018). In addition, cultural interpretations of neurological conditions can delay diagnosis and help-seeking behaviours. Symptoms of dementia, for example, are often misattributed to “normal aging” or explained through spiritual or supernatural causes (Mukadam et al., 2011)

Much of the limited existing literature on informal caregiving within ethnic minority communities has focused specifically on dementia care, highlighting the emotional, physical, and socioeconomic strain experienced by caregivers. These burdens are particularly pronounced among women, who often assume primary caregiving responsibilities with limited external support (Adelman et al., 2014; Lillekroken et al., 2023). Furthermore, acculturation processes add another layer of complexity, as younger generations navigate tensions between traditional caregiving expectations and the individualistic norms of host societies, leading to evolving attitudes and practices (Berry, 1992;).

Shrestha et al. (2023) conducted a meta-ethnographic review synthesizing findings from 11 peer-reviewed studies on informal caregiving in Europe. The review specifically examined the experiences of caregivers supporting older adults, with a primary focus on dementia care, rather than other specific diagnoses or illnesses. The study highlighted a significant shift in caregiving roles across generations, with younger family members increasingly diverging from traditional caregiving norms. Influenced by the individualistic values of host societies, younger generations were less likely to view caregiving as an intrinsic familial duty, contrasting with the older generation's strong adherence to cultural expectations of filial responsibility (Shrestha et al.,2023; Zarzycki et al., 2023). Despite the growing prevalence of informal caregiving within diverse populations, much of the existing research remains concentrated in America and often centres on dementia care. Differences in migration histories, healthcare systems, and social support structures across Europe introduce unique challenges for ethnic minority caregivers that remain underexplored.

Aims of the review

The systematic review aims to explore the research evidence on how informal caregivers from ethnic minority backgrounds providing care for older adults with neurological conditions understand and make sense of their caregiving experiences.

Research questions:

- How do cultural beliefs, traditions, and social norms shape the caregiving experiences of informal caregivers?
- What are the challenges faced by informal caregivers, and how do they cope with these challenges?

Method

This systematic review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO) (registration number: CRD42024573775) on 31st July 2023. The reporting of the review synthesis followed the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines (Tong et al., 2012) (Appendix B) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021) to ensure transparency. The review is underpinned by social constructionist approach, recognizing that caregiving experiences are shaped through culturally and socially situated narratives rather than being objectively fixed.

Search Strategy and study identification:

A comprehensive search strategy was developed in collaboration with a specialist librarian. The search terms (Appendix C) were informed by previous systematic reviews. These terms were structured using the SPIDER framework (Sample, Phenomenon of Interest, Design, Evaluation, and Research Type) to align with the qualitative focus of the review (Cooke et al., 2012). The search was conducted across four major electronic databases: MEDLINE**,** CINAHL**,** Academic Search Complete, and PsycINFO**,** chosen for their relevance to healthcare, social sciences, and psychology research. The primary database searches were completed in August 2024. Supplementary manual searches were conducted by examining the reference lists from included studies and relevant systematic reviews on caregiving and ethnic minorities. Complementary searches were performed using Google Scholar. Search results were imported into Rayyan to facilitate removal of duplicates and streamline the screening process for titles, abstracts, and full-text articles.

Eligibility / Inclusion Criteria

Inclusion criteria were selected to ensure that primary, peer-reviewed, qualitative research was included in the analysis, with direct quotes reported to enable the analysis of raw data. Studies had to explore caregiving experiences within the European context to be eligible. Only studies published between 2002 and 2024 were included. Research primarily focused on formal or paid caregivers, care recipients' experiences, residential care decision-making, service engagement, or intervention outcomes was excluded. Additionally, randomized controlled trials (RCTs), systematic reviews, policy reports, and thesis were excluded. Studies that examined perspectives of formal professionals who did not share ethnic backgrounds with caregiving participants were also excluded, ensuring cultural and experiential relevance (Degrie et al., 2017). Furthermore, studies not published in English or those lacking reliable translations were excluded to maintain accuracy in interpretation and analysis (Robinson et al., 2012) The inclusion and exclusion criteria are summarised in Table 1 below.

Table 1.

Inclusion/ Exclusion criteria

Inclusion criteria	Exclusion criteria
• Peer-reviewed qualitative or mixed-methods studies. • Studies reporting qualitative data • Focus on informal caregivers from ethnic minority backgrounds. • Caregivers residing in European countries. • Exploration of caregiving processes and subjective experiences. • Studies published between 2002 and 2024.	• Perspectives of formal professionals without shared ethnic backgrounds. • Formal or paid caregiving. • Care recipient experiences or residential care decision-making. • Studies purely on service engagement, barriers, or intervention outcomes. • RCTs, systematic reviews, or policy reports. • Studies not published in English or lacking reliable translations.

Study Selection Process

The lead reviewer (AE) conducted an initial screening of all titles and abstracts to identify studies that met the eligibility criteria. Following this, full-text articles were assessed against the predefined inclusion and exclusion criteria. To ensure consistency and methodological rigor, a second reviewer (YP) independently screened 20% of abstract , full text, and quality appraisal. All discrepancies were easily resolved through discussion between the two reviewers. A third reviewer (FG) was available to resolve any disagreements through consultation.

Quality Appraisal

The quality of the included studies was assessed using the Critical Appraisal Skills Program (CASP) tool, guided by Cochrane Collaboration guidelines (Noyes et al., 2019). A scoring system from Duggleby et al. (2010) rated eight of the ten CASP questions on a three-point scale: 1 (weak), 2 (moderate), and 3 (strong). AE conducted the initial appraisal, with YP independently assessing 20% of studies for reliability. No studies were excluded following quality appraisal.

Whiffin et al.'s (2021) framework (see table 2) was used to evaluate the relevance, resonance, and rigor of studies in relation to their potential value in answering the review's question. Relevance assessed alignment with the review's aims, resonance focused on data richness and insights, and rigor was appraised using the CASP tool. Studies were categorized as "Core," "Central," or "Peripheral" to prioritize those most critical to the thematic synthesis.

Table 2.

Classification of papers based on the criteria proposed by Whiffin et al (2021)

Core	**Relevance:** These studies directly address the review questions. **Resonance:** Findings are reflective of the experiences, challenges, and coping mechanisms used by caregivers. **Rigour:** The relevance of use of appropriate methodological approaches.

Central	These studies are broadly aligned with the review's objectives but may not fully explore all aspects.
Peripheral	**Relevance:** Findings may touch on caregiving experiences but lack full alignment, emphasizing unrelated aspects of caregiving. **Resonance:** Findings are shallow, predictable, or fail to contribute meaningfully to understanding the unique challenges of ethnic minority informal caregivers. **Rigor:** Methodological may be weak.

Trustworthiness

Lincoln and Guba's (1985) framework are used to establish trustworthiness in qualitative research, focusing on credibility, dependability, transferability, and confirmability. Within this review to enhance credibility, immersive analysis and critical reflexivity were prioritized, supported by peer debriefing and research team discussions to strengthen the robustness of findings. Dependability was addressed through a systematically documented and transparent methodology, ensuring procedural rigor. Efforts to support transferability included providing detailed descriptions of study contexts and incorporating illustrative participant quotes, allowing readers to assess the applicability of findings to other contexts. Finally, confirmability was pursued by grounding interpretations in the data and explicitly documenting all methodological and analytical decisions, fostering transparency and accountability (Nowell et al., 2017; Lincoln & Guba, 1985).

Reflexivity

Qualitative research is a co-constructed process where meaning is actively produced rather than discovered (Berger, 2013; Charmaz, 2006). Consequently, the process of analysis and interpretation is inherently shaped by the researcher's positionality, which influences the construction of knowledge and the framing of findings.

The research team included two trainee clinical psychologists (AE,YP) and two clinical neuropsychologists (AS, FG). AE, a first-generation African female with personal caregiving experience and prior research on dementia in the Somali community, conducted and analysed the interviews. FG provided qualitative research expertise and has personal lived experience of being the primary caregiver for his dad who had dementia. AS contributed to cross-cultural perspectives. To ensure rigor, AE maintained a reflective diary, and peer discussions facilitated critical refinement of interpretations.

Data extraction

Data extraction included the country where the study was conducted, the aims, the condition of care recipient methods of data collection and analysis, caregivers' ethnicity, socioeconomic information (age, gender, occupation, education), the number of caregivers interviewed, their relationship to the care recipient, and the key findings. Studies details were extracted and summarised by AE and later checked by FG (see table 4).

Thematic Synthesis

Thomas and Harden's (2008) "thematic synthesis" framework was used to guide synthesis of the data through a narrative lens (Riessman et al., 2005). Data used for analysis and thematical synthesis included everything under "finding "or "results" section including quotations and author interpretations and reflections from each paper (Thomas et al., 2008).

Coding Text and Developing Descriptive Themes

AE conducted a thorough read and re-read of the results sections of each study, documenting initial reflections. Semantic and latent codes were systematically applied to quotes extracted from the papers and transferred into Microsoft Word for detailed exploration. A codebook was developed iteratively, beginning with studies categorised as "core," which were coded first to establish a foundational framework. This codebook was subsequently applied to "central" studies and later to "peripheral" studies, which contributed fewer codes. To ensure systematic data management, all codes were organised within Excel (Appendix D). Throughout the analytical process, codes were refined, expanded, and contrasted to generate richer descriptive codes that captured the nuances and complexities of the narratives presented in the studies.

Generating Analytical Themes

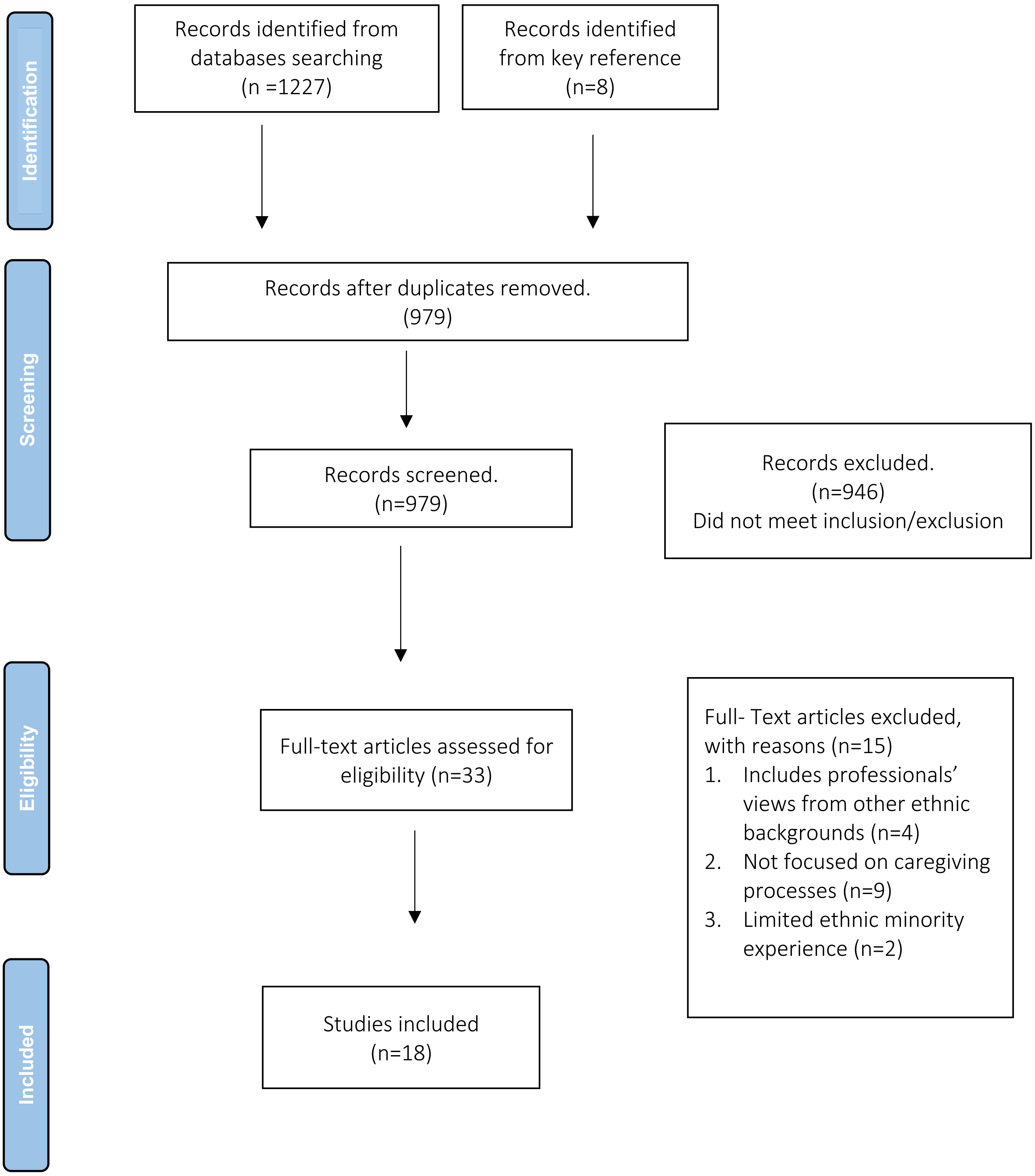
After developing initial codes, the review questions were revisited to ensure alignment with the review's aims, inquiry focused on understanding how cultural beliefs, traditions, and social norms shape caregiving experiences. Overarching descriptive themes were refined to capture the complexity of these narratives. Guided by a narrative functional lens (Daiute, 2014; Riessman et al., 2005), this approach attended to both dominant (thick) narratives that shape broader discourses and less frequently reported (thin) narratives. This approach facilitated an exploration of caregiving experiences beyond dominant discourses, offering a deeper understanding of how caregiving is constructed, contested, and negotiated within different socio-cultural contexts. To ensure transparency and critical interpretation of data, the process involved reflective discussions with the research team, FG and AS, throughout.

Results

Search outcome

Electronic database searches identified a total of 1,227 records. After duplicate removal (N = 248), 979 unique records remained. Titles and abstracts of these 979 articles were screened, resulting in the exclusion of 946 records. Following this, 33 full-text articles were assessed for eligibility. Final exclusions (N = 15) were due to reasons such as including professionals' views from other ethnic backgrounds (N = 4), not focusing on caregiving processes (N = 9) or providing limited ethnic minority experience (N = 2). This systematic review included 18 studies in the final qualitative synthesis (See figure 1).

Figure 1 *PRISMA flow diagram*


Identification
Screening
Eligibility
Included
Records identified from databases searching (n =1227)
Records identified from key reference (n=8)
Records after duplicates removed. (979)
Records screened. (n=979)
Records excluded. (n=946) Did not meet inclusion/exclusion
Full-text articles assessed for eligibility (n=33)
Full- Text articles excluded, with reasons (n=15)
1. Includes professionals' views from other ethnic backgrounds (n=4)
2. Not focused on caregiving processes (n=9)
3. Limited ethnic minority experience (n=2)
Studies included (n=18)

Quality of the studies

Most of the included studies were rated as moderate to high quality (n=11), clearly outlining aims, methodology and its rational. However, some of the studies received lower scores due to limited or absent reflexivity. Of the eighteen studies included, six were identified as core, eight as central, and two as peripheral following appraisal. Studies classified as core were prioritised during data extraction due to their alignment with the aims of the systematic review and methodological rigor. In contrast, peripheral studies were mainly used to provide contextual background rather than directly influencing the thematic synthesis .

Characteristic and findings of included studies

Eighteen studies were included for thematic synthesis after full-text screening. The studies originated from the UK (n = 14), Norway (n = 2), the Netherlands (n = 1), and Germany (n = 1). Data collection methods included one-on-one interviews, focus groups, and narrative interviews, with analysis approaches varying from thematic analysis, content, and narrative analysis. A total of 258 participants were identified as caregivers, predominantly female (229 females vs. 29 males where reported). However, some studies included perspectives from broader community members, staff groups, or volunteers, which were excluded from the synthesis to focus solely on caregivers. As such, the reported number of caregiver participants should be interpreted with caution. Caregivers were primarily spouses (n = 43), daughters (n = 63), and other family members. Many of the studies focused on caregivers supporting individuals with dementia at various stages, although details about the care recipients were rarely provided.

The studies included caregivers from a diverse range of ethnic backgrounds, reflecting varied cultural caregiving experiences. South Asian caregivers, including those from Bangladeshi, Indian, and Pakistani backgrounds, were featured in several studies, emphasizing themes of familial duty, cultural stigma, and reliance on religious coping mechanisms. African-Caribbean caregivers experiences often focused on the reliance on faith, community ties, and independence from institutionalized care. Only one study captured the experiences of Latin American caregivers in the UK (Guerra et al.,2024), highlighting family-first caregiving ideologies and the role of extended networks. Eastern European caregivers, including Polish and Ukrainian caregivers emphasised cultural traditions and independence in their caregiving roles, while caregivers such as Turkish, Moroccan, and Moluccan backgrounds, highlighted intergenerational caregiving as both a religious and cultural duty. Greek Cypriot caregivers explored caregiving ideologies rooted in strong family relationships and cultural heritage. Chinese caregivers emphasized privacy and traditional caregiving responsibilities, and Sikh caregivers were featured in one study exploring how migration influences caregiving roles and service access (Jutlla ,2015).

Recruitment strategies varied widely across the studies, often reflecting the challenges of engaging participants from ethnic minority communities. Approaches included purposive sampling, snowball sampling, and outreach through community organizations such as mosques, cultural groups, and dementia services. Researchers often adopted creative solutions to overcome recruitment barriers, such as partnering with BAME-led voluntary and community sector organizations (VCSOs), engaging with trusted community spaces, and offering psycho-education workshops to build rapport and encourage participation.

Table 3

Details of studies included in thematic synthesis

Author (Year, Country)	Research Aim	Condition	Qualitative Data Collection (analysis)	Caregivers' ethnicity	Socio-Economic Information (Age, Occupation, Education, Gender)	Total Number of Caregivers	Relationship to Care Receipt	Method of Recruitment	Key Results	Relevance to synthesis (CASP)
Baghirathan et al., (2020, UK)	Explore caregiving experiences and reluctance to access dementia services.	Dementia	Interviews, focus groups. (Grounded theory)	South Asian, Chinese, African-Caribbean	Not provided; Male (12), Female (15)	27 family caregivers	Parent (14), Spouse (7), Sibling (1), Grandparent (1), Other family (4), Neighbour (3)	Referrals from Bristol Dementia Well-Being Service and community organizations	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.	Core (19)
Strudwick and Morris (2010, UK)	Understand experiences of African-Caribbean informal stroke carers.	Stroke	Interviews (thematic analysis)	African-Caribbean	Median age 62 (30-72); Education and occupation not provided; Male (1), Female (8)	9 caregivers	Spouse (5), Cohabiting partner (1), Daughter (2), Other family member	Stroke Association family support coordinators; African-Caribbean social groups	Themes identified included: 'independence from services', 'faith in God', 'family ties' and 'avoiding institutionalised care.' These were reported to be unique to African and Caribbean stroke caregivers' experiences.	Central (17)
Guerra et al. (2024, UK)	Explore caregiving experiences in Latin American families in the UK	Dementia	Interviews (thematic analysis)	Latin American	Mean age 49.8 (28-72); Occupation varied (full-time, part-time, retired); Male (1), Female (9)	11 caregivers	Parent (5), Grandparent (3), Spouse (1), Sibling (1), Other family (1)	Latin American Facebook groups, community outreach, and through author running psychoeducation sessions in community organisations.	Themes include Family comes first, dementia as an illness that is accepted within wider network, person with dementia conceptualised as child taking away responsibility of difficult behaviours and caring expectations lead to incompatibility with formal services.	Core (20)

Lawrence et al. (2008, UK)	Explored attitudes, experiences, and needs of carers across ethnic groups.	Dementia	Interviews (grounded theory)	Black Caribbean, South Asian, White British	Age range 33-87; Education and occupation not provided; Male (7), Female (25)	32 caregivers	Reported as Varied relationships.	Community mental health teams, carer services, and community organisations	Theory outlined was categorised into Traditional versus non-traditional caregiving ideology. Traditional caregivers saw role as expected, natural and virtuous. Non-traditional ideology saw role as conflict with expectation, unnatural and lacking in virtue.	Core (17)
Botsford et al. (2011, UK	Explored experiences of partners from minority ethnic communities.	Dementia	Interviews (grounded theory)	Greek Cypriot, African-Caribbean	Mid-60s to late 80s; Education and occupation not provided; Male (7), Female (6)	13 caregivers	Spouses and significant others	Community Mental Health Services for Older People	Theory identified outline that partners of people with dementia engaged in an ongoing process of ‘redefining relationships. Greek Cypriot partners tended to emphasize family relationships whilst African Caribbean partners tended to view themselves as independent from family.	Central (19)
Næss and Moen (2015, Norway)	Navigate dementia within cultural beliefs and Norwegian healthcare.	Dementia	Interviews, focus groups (narrative analysis)	Norwegian-Pakistani	Did not repot on occupation, education and age of family caregivers. Reported gender as balanced representation of men and women	Total 22 participants (8 family caregivers and the rest Norwegian Pakistani healthcare employees and community members)	Family caregivers (specific relationships not provided)	Diagnostic clinics: recruitment sources for focus groups reported as mosques and community organizations.	Norwegian-Pakistani families view caregiving for older adults as a familial duty rooted in intergenerational reciprocity. They reconcile this traditional approach with the biomedical perspectives of their host culture. Cognitive changes like dementia are normalized as part of "normal ageing," reducing the likelihood of timely help-seeking behaviours.	Central (15)

Van Wezel et al. (2016, Netherlands)	Describe perspectives of female family carers in ethnic communities.	Dementia	Interviews, focus groups (generic qualitative approach)	Turkish, Moroccan, Surinamese Creole	Age range: Turkish (31-74), Moroccan (20-48), Surinamese (50-84); All female; Occupation and education not specified	41 caregivers	Daughters (55), Daughters-in-law (9), Spouse (3), Other (2)	Recruitment through care providers, ethnic community leaders, and dementia educators	Caregiving viewed as a religious and cultural duty. Respect and appreciation are valued.	Core (18)
Mackenzie (2006, UK)	Explore cultural understandings of dementia and engagement with services.	Dementia	Interviews(thematic analysis)	Pakistani, Indian, Polish, Ukrainian	Education , occupation and age not provided: Male (4), Female (17)	21 caregivers	Spouses and daughters	Community radio advertisements; religious and community organizations	South Asians link dementia to spiritual beliefs, while Eastern Europeans emphasize independence.	Peripheral (15)
Parveen et al. (2011, UK)	Convergence/divergence in caregiving experiences across ethnic groups.	Mixed	Focus groups (content analysis)	Bangladeshi, Indian, Pakistani, White-British	Age range: 24-80; occupation and education not reported ; Male (2), Female (28)	30 caregivers	Spouses (18) , 2 daughters (2) , 5 daughters-in-law, 4 parents, 1 aunt	Caregiver support groups	British South Asian caregivers are primarily extrinsically motivated to provide care due to a sense of duty and obligation, which influences their positive adaptation to the caregiving role over time, despite limited support from family and formal services.	Core (18)

Armstrong (2022, UK)	To explore the impact of Covid-19 on Black and South Asian people living with dementia and their carers in the UK, specifically focusing on their views on trust and mistrust using an ecological model.	Dementia	Interviews (Thematic analysis)	Black, South Asian	Age range 29-85; reported all caregivers had some further education with 4 having degrees or equivalent, occupation status of caregivers is not reported; Male (1), Female (10)	11 caregivers (4 of the participants were person with dementia)	Spouses (5), Parents (6)	GP practices, online dementia recruitment websites, social media, local organizations	COVID-19 exacerbated mistrust and exclusion at each level of the socioecological model.	Peripheral (18)
Hossain (2020, UK)	Impact of caregiving on Bangladeshi caregivers' well-being.	Dementia	Interviews, focus groups(thematic analysis)	Bangladeshi caregivers	Age, education and occupation information of caregiver's nit provided: Male (3), Female (12)	15 caregivers	Family caregivers (specific relationships not provided)	Alzheimer's Society, community leaders, and mosque Imams	Caregiving has significant physical, psychological, social, and economic impacts. Despite these burned caregivers draw strength from strong sense of family obligation, religious beliefs, and interpersonal motive to provide care at home.	Peripheral (18)
Jutlla (2015, UK)	Explore migration's impact on caregiving in Sikh communities.	Dementia	Narrative interviews (grounded theory)	Sikh carers	Age range 44-70; education and occupation information not provided Male (3), Female (9)	12 caregivers	Spouses (5), Intergenerational caregivers (7)	Not specified	Migration identities shape caregiving perceptions and service experiences.	Central (18)

Hossain (2019, UK)	Gender perspectives on caregiving roles in Bangladeshi families.	Dementia	Interviews, focus groups (thematic analysis)	Bangladeshi family carers	Not reported	21 participants in focus group and 6 in one-to-one semi-structured interview. *not specifically stated how many were caregivers.	Daughters, daughters-in-law, and spouses. *Not specified	Purposive sampling, Snowball sampling.	The key themes identified include: (1) caregiving as a culturally assigned duty, predominantly for women in South Asian families; (2) denial of caregiving roles, with some participants resisting traditional expectations; (3) stigma associated with caregiving, both within families and as paid carers, driven by fear of community judgment; and (4) overcoming barriers to change, emphasizing the need for education and challenging traditional gender norms to foster more equitable caregiving roles.	Central (18)
Arora (2020, Norway)	Explore female Pakistani carers' views on future care accessibility.	Dementia	Interviews (content analysis)	Pakistani carers	Age range 23-40 years. 7 carer daughters had full-time jobs, and one was a student. Of the two carers who were daughters-in-law, one worked part-time and the other was a student. All of the participants either had higher education or were pursuing	10 caregivers	Daughters (8), Daughters-in-law (2)	Snowball sampling, starting with meeting women at a local mosque, at an activity centre, and through key informants.	Themes identified included: (1) caring for family in Norway as in Pakistan, (2) fears of placement in a care home, (3) concerns about care by outsiders, (4) worries about societal judgment, and (5) adherence to expectations of being a 'good' carer.	Central (19)

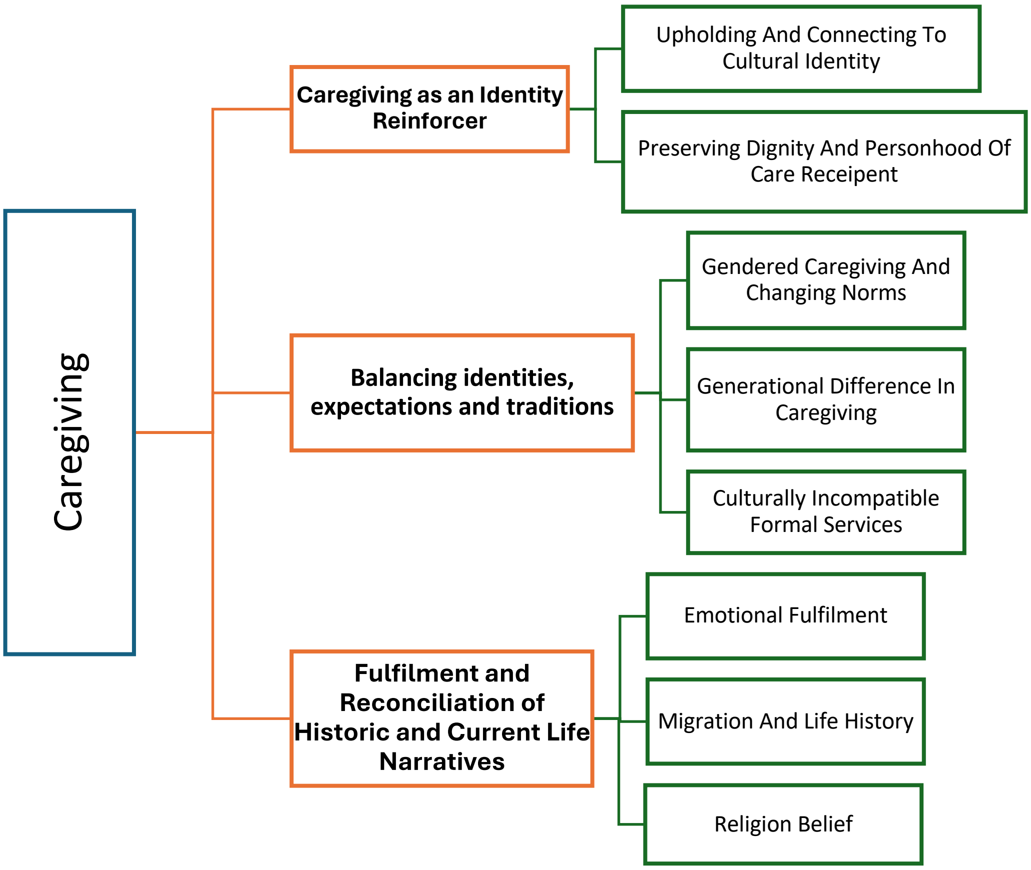
					higher education.					
Ahmad (2020, Netherlands)	Understand caregiving task division in migrant communities.	Dementia	Interviews (content analysis)	Chinese, Moluccan, Moroccan-Berber and Turkish.	Age range is from 39 to 70. All participants were female. Two participants had no formal education, two had secondary education, one had higher education, and one had only primary education. Employment roles were not explicitly reported.	6 caregivers	Parent (5) Spouse (1)	Care providers and community networks	Three overarching themes emerged: (1) sharing with family, (2) sharing with formal services, and (3) sharing with both family and formal services, shaped by factors such as migration history, social class, gendered care norms, relationship to the care-recipient, social networks, religion, and family roles.	Core (18)
Monsees et al. (2020, Germany)	Explore caregiving and healthcare barriers for Turkish families.	Dementia	Semi-structured life-story interviews followed by “shadowing” participants in their daily lives. Data was analysed using intersectionality as an analytical lens.	Turkish family caregivers	Ange range from 31-57. Female (7) and male (1). Education and occupational information is not provided.	8 caregivers	Parents (7), Grandparents (1)	Snowball sampling via care providers and community organisations	The results categorised into five main themes: care situation, prior knowledge, challenges, utilization of healthcare ser- vices, and recommendations.	Central (18)

Hossain (2019, UK)	Explore the perspectives of Bangladeshi family carers' knowledge and day-to-day experiences living in England.	Dementia	Semi-structured Interviews (thematic analysis)	Bangladeshi family carers	Age range from 23- 64 (mean age 44.16 years) ; Two worked full-time, two reduced their hours, and one never worked. One received carer's benefits as their only income after leaving their job; Male (2), Female (2)	6 caregivers	Parent (5) and Spouse (1).	Snowball sampling, starting with community-based organizations and recruiting through word of mouth.	Themes included early symptoms and the diagnosis of dementia, as well as myths and stigma associated with the condition.	Central (15)

Themes and Subthemes drawn from the analysis.

In this synthesis, the experiences of informal caregivers from ethnic minority communities, focusing on the functions of their roles, have been categorised into three dimensions: (1), Caregiving as an identity reinforcer, highlighting how caregiving functions as a mechanism for upholding cultural identity and preserving the dignity and personhood of the care recipient; (2) Balancing identities, expectations and traditions; reflecting the ways caregivers navigate competing expectations between traditional caregiving norms and the demands of modern life; and (3) Fulfilment and reconciliation of historic and current life narratives, illustrating how caregivers construct emotional and spiritual meaning while drawing on past strategies of resilience and resistance as coping mechanisms.

Figure 2. *Themes and Subthemes drawn from the analysis.*



Theme 1: Caregiving as an Identity Reinforcer

This theme captures how informal caregivers understand and define their caregiving role. Caregiving was seen to fulfil two distinct functions: upholding and connecting to cultural identity and preserving the personhood and dignity of the care recipient. Caregivers drew upon cultural scripts transmitted through reciprocal care practices, familial obligations, and religious beliefs.

Across the synthesized data, the dominant framing of caregiving was through the lens of cultural or familial obligation. This was also embedded within a recurring, underlying thinner narrative of identity, which was captured and conceptualized in various ways. The caregiving identity was often framed through constructs such as “fear of diminishment” (Baghirathan et al., 2020), “traditional ideology” (Lawrence et al., 2008), “family comes first” (Guerra et al., 2022), “redefining relationships” (Botsford et al., 2011), and the reconciliation of intergenerational reciprocity with the biomedical model of illness prevalent in host cultures (Arora, 2020).

Subtheme 1.1 Upholding and Connecting to Cultural Identity

In many of the studies reviewed, caregivers often viewed their role as a natural extension of their familial and cultural traditions. They adhere to a cultural script that outlined their responsibilities and provide a sense of meaning to their caregiving experience. This script connects caregiving to wider cultural and social value, fostering a sense of belonging and identity within their community. For example, a Turkish caregiver talked about the value of caregiving within her wider community:

> This is our tradition, our culture, 99% of Turkish people think like that *(*Monsees et al., 2020, Germany).

This was also echoed by caregivers from the Caribbean community, emphasizing caregiving as a deeply embedded cultural norm:

> It is in our culture. We care for each other until the very end (*Baghirathan* et al., 2020, UK).

These narratives reveal how cultural scripts position caregiving as a moral and social duty, fostering pride and purpose in fulfilling the role and reinforcing the caregiver's identity. Caregiving is also often seen as an act of reciprocity, repaying the care and sacrifices of previous generations. This concept is grounded in gratitude and family loyalty. As one caregiver expressed:

> I don’t see how after everything my grandma has done for me and the way she has cared and loved me […] I can’t put into words how much I intend to be able to pay her back. It needs to come from you (Guerra et al., 2022, UK)

Caring for a loved one was also framed as an extension of these familial bond and away of strengthening or rebuilding broken relationship.

> [Author’s interpretation] This strong family duty meant family members with previous poor relationships with relatives with dementia also provided care. Sometimes, this provided new perspectives on memories and resulted in positive changes in relationships (Guerra et al.,2022, UK)

Religious beliefs also emerge as a crucial factor in shaping caregivers’ understanding of their role. For many, caregiving is viewed as a religious or spiritual obligation, aligning their actions with a sense of divine duty and moral righteousness.

> From an Islamic point of view, the respect you have for your parents would mean you look after them – that’s just what a good Muslim should do (Van Wezel et al., 2016, Netherlands)

Religious frameworks reinforce constructs of being a ‘good’ Christian or Muslim, providing spiritual motivation and validating the importance of caregiving as a component of faith. By upholding identity through these lenses, caregivers maintain a sense of purpose, pride, and alignment with their cultural and religious values.

Subtheme 1.2: Preserving the personhood and dignity of the care recipient

Caregivers often reasoned that their motivation to provide care extended beyond the act of duty to include a moral responsibility to maintain the care recipient's identity and dignity. This continuity is seen to be important for the emotional and cognitive well-being of the care recipient. For ethnic minority caregivers, culturally specific practices such as language, food, and entertainment preferences were constructed as protective mechanisms against the erosion of identity that might otherwise occur in care home settings. A South Asian caregiver highlighted this:

> 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. (Lawrence et al., 2008,UK)

Similarly, another caregiver highlights that placing a loved one in the care home in isolation of their language and cultural connections, would push their cognitive decline even further.

> If my mother were to end up in a home with only Dutch women, then there would be no communication. She wouldn't be able to have her say; she'd just sit there not talking. Then they get even more isolated and even more closed off from the world, and there's no interaction. And I think that the dementia would then progress rapidly. (Van Wezel et al., 2016, Netherlands)

The preserving cultural and personal identity is not just about pride but a tangible strategy for safeguarding the humanity of their loved one.

> And he was an object... to them, the people there they was just another person, who have another stroke. (Strudwick et al., 2012)

For many caregivers, this preservation of dignity involves protecting their loved ones from dehumanization and ensuring their unique cultural and personal identities are respected. As one Caribbean caregiver explained:

> A degree of, I think it is about protection [...] And I think, looking at the families, it's not so much about the condition itself. It is more about managing the person's dignity or an idea of managing the person's dignity (Baghirathan et al., 2020)

Across the studies caregivers constructed their role as one that extended beyond the basics of providing physical care. It also functioned as way of preserving individuality, humanity, and personhood as the condition progressed. By providing care for their loved ones, they helped them maintain connections to familiar cultural practices, language, and routines.

Theme 2: Balancing identities, expectations and traditions

Across the data synthesized, the challenges younger generations face in navigating a clash between their parents' traditional expectations and their own acculturated values were either explicitly highlighted or implicitly assumed. While a dominant narrative frames traditional caregiving practices as fostering resilience and adaptability, a thinner narrative emerges where younger and second-generation caregivers struggle to integrate these traditional expectations with their modern realities. Rather than fully rejecting or embracing tradition, they attempt to reinterpret cultural and religious scripts of what "good care "constitutes.

Together with these generational differences in caregiving perceptions, evolving gender norms, and culturally incompatible healthcare services further create tensions. This ongoing negotiation of identity reflects the complex realities caregivers face, particularly within the context of their host culture and its healthcare norms.

Subtheme 2.1: Generational difference in caregiving

While caregiving is seen as part of a cultural script reinforced by familial bonds and religious beliefs, the perception of caregiving and how it is carried out creates tension between older and younger generations of ethnic minorities, particularly within a European context.

> I said I grow up in Jamaica and it’s probably a cultural thing. Whereas my younger siblings don’t quite have the same dedication, they’ll do it because it’s Dad but it’s not their duty *(*Lawrence et al., 2008, UK).

Younger generations, particularly second generation often face internal conflicts as they navigate caregiving within the expectations of traditional cultural norms and their acculturated values. While many younger caregivers still view caregiving as an obligation, their interpretation of what constitutes "good care" tends to differ (Van Wezel et al., 2016, Netherlands). Older caregivers generally believe in providing direct, hands-on care, whereas younger caregivers may see their role as arranging or facilitating professional care rather than performing all caregiving duties themselves.

> Care for your elderly is what the Islam says. And sometimes I think that they interpret that wrongly: providing care doesn’t mean actually doing it all yourself, but making sure that you arrange for proper care. That’s the way I look at it (Van Wezel et al., 2016, Netherlands)

This generational difference in the perception of caregiving reflects a shift in caregiving dynamics, with younger caregivers balancing traditional cultural expectations against the realities of modern life and their own interpretations of caregiving responsibilities.

> My culture doesn’t accept changes. They expect you to do what is traditional. I can’t decide how I want to care for my mother because they consider it a bad choice. If I share the care for my mother with a professional, they’ll tell me I’m a bad daughter for not caring for my mother after all she has done for me. (Van Wezel et al., 2016, Netherlands)

The above quote highlights the cultural pressure faced by caregivers, particularly those seeking to balance caregiving responsibilities with their personal lives and acculturated values. For younger caregivers, balancing caregiving responsibilities with other roles, such as those of a spouse, parent, or employee, adds another layer of complexity. The competing demands often leave caregivers feeling emotionally and physically exhausted:

> Do you put your parents first, your children first, your husband first or what you know? You try to give them all little bits of time. My husband was actually lying in bed last night and I was sort of asleep, and I heard him moan and he said to me, ‘you know, you are never around, you are never there for me anymore,’ and I thought bloody hell, you know, I’m sleeping, I ignored him I was so exhausted. *(Lawrence et al., 2008,Uk)*

Lawrence et al. (2008) highlights that caregivers holding traditional caregiving ideologies often find the experience rewarding. These caregivers adapt better to the demands of caregiving due to co-shared responsibilities within the extended family network and their willingness to use available support services. In contrast, caregivers with non-traditional (i.e. not holding the cultural script prescript by their respective communities) ideologies frequently perceive caregiving as burdensome, viewing it as a disruption to their lives, with many describing their lives as being "on hold."

Subtheme 2.2: Gendered caregiving and changing norms.

Across the different ethnic minority community’s caregiving was framed as a responsibility traditionally assigned to women. This perception reinforces gendered expectations and significantly influences caregiving experiences.

> It will be the wife or the daughter, because that is how it is. The caregivers are women. (Guerra et al., 2022, UK).

However, the growing participation of women in the workforce has created challenges in fulfilling traditional caregiving roles. In some cases, caregiving responsibilities have shifted to male family members to accommodate these changes.

> My wife, she was working as well. That is the main reason I quit my job to care for my mom. (Hossain.,2020, UK)

A shift in caregiving roles is also evident, with male partners and younger generations taking on responsibilities traditionally viewed as feminine. In some communities, men have started adopting caregiving tasks to support their loved ones.

> I told him, it is very hard because your uncles are going to say things about your grandma. And he says, ‘Mom, I am not hurt by doing these doings for my grandma, did not she clean my butt when I was young?’ (Guerra et al., 2022, UK).

While this shift is talked about by caregivers, it is often met with hesitation. As the caregiver’s statement suggests, many families still perceive caregiving as primarily a female responsibility, with men contributing more to the practical aspects rather than taking on the full emotional and nurturing roles.

Subtheme 2.3: Culturally incompatible formal services

For many caregivers, past experiences with formal care services heavily influenced their willingness to engage with these systems or seek support. Caregivers often cited instances of discrimination, stereotyping, and cultural insensitivity, which not only undermined trust but also reinforced their reluctance to rely on formal systems. Particularly among Caribbean communities, the fear of being misunderstood or mistreated shaped attitudes toward engaging with formal services.

> [Author's interpretation] …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 (Baghirathan et al., 2020).

Experiences of discrimination and stereotyping were significant barriers for ethnic minority caregivers in accessing adequate health and social care. A Bangladeshi caregiver shared the experience of inadequate care provided to her father.

> Three times he fell out of bed, one day he left on the floor for 9 hours. It's discrimination against minority people. (Hossain.,2021*).*

Another caregiver highlighted assumptions made about her aunt due to her age and ethnicity, leading to neglect in care.

> And there was a nurse assigned to give her speech therapy. And the nurse did not give her the speech therapy. And when I approached her, see, my aunt being Afro-Caribbean, and she was about 78 years old, they thought it would be a difficult job (Strudwick et al., 2012, UK).

Caregivers often felt that formal services failed to recognize or respect their cultural preferences. For some caregivers, the lack of support led to reflections and awareness of being othered and their migration to the county and worry of not getting support if they complain.

> You've got to struggle so hard because we are... in this country and then you come here... and they didn't give you much support (Strudwick et al., 2012, UK).

> If we complained about anything, they would withdraw the carers (Strudwick et al., 2012, UK).

Beyond these systemic barriers, caregivers also face social condemnation within their communities for use of formal services. The use of home care is often viewed as a failure to fulfil cultural and familial responsibilities, leading to condemnation from the wider community. This creates a dual burden for caregivers, who must balance cultural expectations with their personal circumstances, often at great emotional and social cost. As noted earlier, the dominate (thick) narrative of caregiving being a familiar duty creates a unique challenge for younger caregivers, who may feel pressured to uphold traditional practices while also navigating the practical and emotional demands of caregiving in a contemporary context.

Theme 3: Fulfilment and Reconciliation of Historic and Current Life Narratives.

This theme explores the coping stories of caregivers, highlighting how they navigate the challenges of their roles by actively reconciling their identities through various strategies. It highlights how emotional fulfilment, religious beliefs, and migration experiences provide a framework for managing the complexities of caregiving.

Subtheme 3.1: Emotional fulfilment

Despite the burden and strain of caregiving, many caregivers reported deriving emotional fulfilment from the role. This was especially true for caregivers who saw caregiving as a natural expression of their love and duty to their family.

> To see my mother disappear makes me sad. But the moment she laughs or tells me something about her past, it makes it all worthwhile. More than when she was not sick, I feel that I have a second chance of connecting with my mother. I'm so thankful for this chance (Van Wezel et al., 2016)

For caregivers, the sense of fulfilment derived from their role served as a counterbalance to the challenging aspects of caregiving, making the experience more manageable. This fulfilment, as illustrated by the caregiver's account, facilitated the rebuilding of relationships. This dynamic affirmed both their role as caregivers and their identity within the relationship.

Subtheme 3.2: Religion beliefs

Religion emerged as a significant source of strength and support for many caregivers, offering both emotional resilience and a sense of purpose. For some, caregiving was intertwined with religious beliefs, seen as a spiritual obligation and a way to gain blessings and merit.

> [Authors interpretation] Faith and the sense of caregiving as a virtuous act provided emotional strength, enabling carers to find meaning in their sacrifices despite challenges. (Strudwick et al., 2010)

> However long we are here for, we will give help, we need to do our duty. As long as God gives us strength and enough help to carry out the duties for as long as they live (Parveen et al., 2011)

These narratives reflect how religion provided caregivers with the emotional strength and motivation to continue providing care. It transformed the role into an act of virtue and service, aligning with their spiritual identity and giving them a sense of purpose and strength to navigate the challenges they faced.

Subtheme 3.3: Migration and life history

Many caregivers included in the studies synthesised were first-generation immigrants to their host cultures/countries. By virtue of their migration and life history, caregivers had developed various ways of coping and adapting to challenges. For example, Eastern Europeans used "keeping it within the family" as a symbol of survival for people whose identities and existence have been historically challenged in inhuman ways.

> I think, because of Eastern European culture, everything's kept within the family, to tell people outside that family circle or close friends is not a thing. they do. Your private life is your private life . . . There's pride in it as well (Mackenzie.,2006)

For the Chinese community, the notion of 'Keeping face' and maintaining privacy and social harmony was important and served as a source of protection for the caregivers and their loved ones. While for African Caribbeans often described the use of community-based caregiving as a way of protection from being diminished or discriminated against.

> [Authors interpretation] Caregivers engage in protection strategies used in the Caribbean community are "walk on by" and "we look after our own (Baghirathan et al., 2020).

For Latin Americans and Greek Cypriots, as well as South Asians, family ties and support were a marker of coping with the challenges of caregiving.

The studies synthesised conceptualised these strategies as barriers to timely help seeking for care. However, an alternative interpretation could be that these are adaptive coping skills developed in response to the challenges of migration and relocation, which becomes crucial for preserving one's sense of self in a new environment. Similarly, as a loved one's identity is progressively reshaped by a neurological condition, caregivers may draw upon these established coping mechanisms to navigate the unfamiliar narrative of illness. Therefore, preserving and reconstructing both their own and their loved one's sense of self and shared identity.

Discussion

Main Findings and Their Relevance to the Literature and Theories.

Caregiving narratives were categorized into three overarching themes: (1), Caregiving as an identity reinforcer, highlighting how caregiving functions as a mechanism for upholding cultural identity and preserving the dignity and personhood of the care recipient; (2) Balancing identities, expectations and traditions; reflecting the ways caregivers navigate competing expectations between traditional caregiving norms and the demands of modern life; and (3) Fulfilment and reconciliation of historic and current life narratives, illustrating how caregivers construct emotional and spiritual meaning while drawing on past strategies of resilience and resistance as coping mechanisms.

Through reflexive thematic analysis, guided by narrative functional analysis (Daiute, 2014), the review identified "thick" and "thin" caregiving narratives. The dominant thick caregiving narrative across the studies framed caregiving as an extension of cultural, familial, and religious identity, reinforcing it as both a moral duty and a natural obligation. This perspective aligns with collectivist caregiving norms, where caregiving is embedded in intergenerational scripts that emphasize familial responsibility (Zarzycki et al., 2023; Dilworth-Anderson et al., 2005).
Caregivers in this review described their role as a means of preserving both the dignity care receipt and upholding their cultural identity. This aligns with the Caregiving Identity Theory (CIT)

(Montgomery & Kosloski, 2009), which posits that caregivers actively develop and negotiate their identities over time through caregiving experiences, shaped by social expectations, role enactment, and meaning making.

Ethnic identity, as defined by Phinney (1990), is an individual's sense of self as a member of an ethnic group, encompassing both a feeling of belonging and the meanings attached to that membership. Ethnic identity is not static but develops through exploration, where individuals engage with their cultural background, acquire cultural knowledge, and navigate social expectations (Phinney & Ong, 2007; Umaña-Taylor et al., 2014). Building on this, Duncan and Smith (2023) found that Black American caregivers view caregiving as a means of preserving family identity, cultural traditions, and moral responsibility. Similarly, Willis (2012) argues that ethnic identity becomes more pronounced after migration, as individuals transition into minority status within a host country. Contextualizing the review's findings within these perspectives, one could argue that caregiving transcends functional support within ethnic minority families, instead serving as a mechanism for reinforcing cultural continuity and maintaining collective identity within the European context.

Existing literature predominantly frames ethnic minority caregiving within the dominant narrative of cultural and familial obligations (Dilworth-Anderson et al., 2005; Parveen & Oyebode, 2018). However, there has been limited exploration of how caregiving is actively reshaped by migration and identity processes (Roche, 2022). The studies included in this review introduce theories such as "fear of diminishment" (Baghirathan et al., 2020) and adherence to "traditional ideology" (Lawrence et al., 2008), both of which suggest that informal caregiving practices within ethnic minority communities are driven by fears over cultural erosion and identity loss. While these theories do not explicitly frame caregiving as an ethnic identity marker, they strongly imply that caregiving is influenced by perceived threats to cultural decline. This reinforces caregiving not only as a familial duty but also as a means of cultural identity and by extension self-identity preservation.

Within migration contexts, caregiving takes on an increasingly symbolic function, allowing caregivers to assert cultural resilience and belonging in societies where they are a minority or face systemic discrimination (Willis, 2012; Duncan & Smith, 2023; Roche, 2022; Shrestha et al., 2023). Rather than being static or inherited obligations, caregiving is a negotiated and adaptive practice, shaped by continuity with cultural heritage and the realities of caregiving within new environments. While dominant thick narratives construct caregiving as an unquestioned duty, the synthesis also identified thinner narrative tensions, particularly in how caregiving is negotiated across generations. Acculturation theory (Berry, 1997) provides a useful framework for understanding intergenerational caregiving conflicts, which emerge as younger caregivers navigate competing cultural schemas. In collectivist caregiving models, caregiving is positioned as an expected and non-negotiable life role, embedded within kinship support systems that reinforce shared familial obligations (Roche, 2022). However, in individualistic societies, caregiving is often viewed as a personal choice, one that can be outsourced to professional services (Dilworth-Anderson et al., 2005).

Shrestha et al. (2023) similarly observed that second-generation caregivers face a moral dilemma, as acculturation exposes them to Western individualistic values that emphasize autonomy and professional care options. Their findings confirm that while some caregivers wished to adjust traditional caregiving norms to align with host country expectations, others felt compelled to adhere to cultural expectations despite increasing caregiving burden and conflict with other life roles.
The dominant thick caregiving narrative constructs caregiving as a feminized task, reinforcing expectations that women serve as primary caregivers within the family structure. In some ethnic minority communities, caregiving is often designated as the responsibility of the eldest daughter or the daughter-in-law (Shekhani, 2024; Shrestha et al., 2023). However, thinner, more contested narratives emerged, particularly among second-generation caregivers, as acculturation pressures led to the reinterpretation of traditional caregiving roles.

Despite this shift, male caregivers reported encountering social stigma when engaging in caregiving responsibilities, reflecting the tension between caregiving and dominant constructions of masculinity (Shrestha et al., 2023). These findings underscore the fluidity of caregiving identity, highlighting how caregivers resist, reinterpret, and challenge traditional caregiving expectations to align with their evolving personal realities.

Caregivers frequently cited religion and emotional fulfilment as essential mechanisms for managing caregiving stress. Religious narratives served as both a source of resilience and a site of reinterpretation. Consistent with broader literature, religious frameworks provided caregivers with a sense of meaning, purpose, and validation, transforming caregiving into an act of spiritual fulfilment (Dilworth-Anderson et al., 2005). Within the review, many caregivers framed their roles through Islamic teachings on filial piety or Christian concepts of sacrificial love, which legitimized their caregiving sacrifices. However, more flexible religious narratives emerged, where caregivers engaged in selective reinterpretation of religious duties, allowing them to justify alternative caregiving arrangements. These findings suggest that religious caregiving norms are not rigid but are actively reshaped and redefined in response to changing social contexts and demands.

A less frequently explored finding was the resilience cultivated by ethnic minority caregivers through migration and historical adversity. The survival strategies developed through "keeping face," "keeping it within the family," adaptability, and reliance on family and community networks, while often constructed in the synthesized studies as barriers to help-seeking, can also be understood through a narrative functional and identity lens as pre-existing coping strategies applied to caregiving in a new context. For instance, kinship networks, originally formed to counteract social exclusion, provide emotional and practical support, thereby reducing caregiving burden (Roche, 2022). This aligns with the notion of caregiving as a site for identity preservation and negotiation.

Overall, the findings of the review illustrate that caregiving within ethnic minority communities is a dynamic and complex process, shaped by migration histories, cultural narratives, and evolving intergenerational expectations. Caregiving is not only influenced by social and cultural constructs but is also actively negotiated through narratives that reflect shifting identities and modern-day realities.

Strengths and Limitation

Research into ethnic minority communities is often criticized for assuming racial and ethnic identities as fixed categories, which in turn shapes the interpretation and findings, reducing the methodological rigor of these studies (Milne & Chryssanthopoulou, 2005; Roche, 2022). Within this review, reflexive thematic analysis and narrative functional analysis (Daiute, 2014; Riessman et al., 2005) were adopted to capture the nuanced ways caregivers made sense of their experiences and constructed their roles. This approach allowed to move away from viewing caregiving practices within ethnic minority communities as static rather attuned to the ways in which caregivers talked about their experiences.

However, this review has several limitations. First, the review included studies published after 2002. This inclusion decision was based on the rationale that earlier caregiving experiences may reflect perspectives of older caregiver cohorts, whose experiences might differ significantly. However, a broader inclusion of studies across time periods could have provided a deeper understanding of intergenerational caregiving transitions.

Another limitation is the lack of reported reflexivity across many of the synthesized studies, which impacted their overall quality ratings in the CASP assessment. Many studies failed to report on researcher positionality, limiting the transparency of how researcher perspectives, assumptions, and biases may have influenced data collection, analysis, and interpretation. This gap is particularly significant in cross-cultural research, where reflexivity is essential for understanding how knowledge is co-constructed between researchers and participants.

Clinical Implications

The findings offer new insights into caregiving within ethnic minority communities, framing caregiving not merely as a cultural expectation but as a process deeply tied to identity preservation. With the growing reliance on informal caregivers to support the aging ethnic minority population, service providers must recognize caregiving as a culturally embedded practice rather than a universal, one-size-fits-all role. This calls for adapted care models that integrate both informal family caregiving and formal support services, allowing caregivers to balance cultural obligations with external support. Culturally competent interventions, such as linguistically tailored resources, faith-based caregiving support, and flexible care programs, could help bridge the gap between traditional caregiving expectations and professional care services.

Furthermore, services supporting informal caregivers need to be attuned to the stressors and tensions faced by younger and second-generation caregivers, who often experience caregiving as a process of reconciliation between cultural tradition and personal autonomy. These tensions can impact the caregiver-care recipient relationship, leading to emotional strain and intergenerational conflict. Given that narrative analysis in this review revealed how identity preservation shapes caregivers' experiences and highlights untold caregiving stories, engaging with caregivers’ personal narratives could serve as a valuable approach in caregiver support programs. Encouraging narrative-based interventions, such as storytelling workshops, peer support groups, or narrative therapy, may help caregivers reflect on and reconcile their roles while validating their caregiving experiences.

Future Directions

The findings of this synthesis highlight caregiving as a process of identity preservation, where challenges to the caregiving role are often experienced as threats to identity. These challenges are exacerbated by acculturation pressures, particularly for younger generations navigating the dual expectations of collectivist cultural values and individualistic societal norms. Future research should further explore caregiving through an identity-based theoretical framework, focusing on how younger caregivers conceptualize, negotiate, and adapt to these conflicting pressures. Examining how cultural identity, migration history, and acculturation strategies influence caregiving identity formation could provide deeper insight into intergenerational caregiving adaptations.

Second, the underrepresentation of male caregivers in the synthesized studies highlights a critical gap in caregiving research. Only 29 of the 258 caregivers included in this review were male, despite growing evidence of shifting gender norms, where men are increasingly assuming caregiving responsibilities traditionally assigned to women (Shrestha et al., 2023). This gap underscores the need for dedicated research on male caregivers within ethnic minority communities, particularly examining how cultural expectations intersect with evolving gender identities.

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Chapter 3 - Empirical Study

"The Younger Generation Is Totally Different"- A Qualitative Exploration of How African and Caribbean Informal Caregivers Make Sense of Dementia and Navigate Support Services in the Uk

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"The Younger Generation Is Totally Different"- A Qualitative Exploration of How African and Caribbean Informal Caregivers Make Sense of Dementia and Navigate Support Services in the UK

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Abstract

Dementia prevalence is increasing in the UK, disproportionately affecting African and Caribbean populations who remain underrepresented in services. Existing small-scale research often homogenizes ethnic groups, framing their understanding of dementia as limited and culturally influenced. This study explores how informal African and Caribbean caregivers make sense of dementia, navigate caregiving roles and engage with support systems. A semi-structured interviews were conducted with 8 African and Caribbean caregivers and analysed using Reflexive Thematic Analysis (RTA), informal by narrative framework. Three themes emerged: (1) Cultural and generational interpretation of dementia ,(2) Love, duty, sacrifice and coping with caregiving role, and (3) Negotiating and advocating for support. The study highlights the interwoven nature of cultural, generational, and community narratives, generating tensions that both present a challenge pathway to support-seeking and act as sources of support. The findings highlight the need for culturally informed dementia care that addresses systemic barriers, recognizes diverse caregiving experiences, and acknowledges the evolving needs of different generations within these communities.

Introduction

Dementia is an increasing concern in healthcare planning, with an aging population contributing to its prevalence. In the United Kingdom, approximately 850,000 people currently live with dementia, including 25,000 from ethnic minority backgrounds. Projections indicate that dementia prevalence within ethnic minority communities will increase sevenfold by 2051, compared to a twofold rise among the White British population (All-Party Parliamentary Group on Dementia, 2013). This demographic shift highlights the critical role of informal caregivers—unpaid individuals who provide support to family members, friends, or neighbours.

Informal caregivers allow individuals with conditions such as dementia, stroke, and Parkinson's disease to remain in their homes, reflecting a preference shared by most people in the UK (Prince et al., 2014). However, caregiving experiences vary significantly across ethnic groups, shaped by cultural norms, systemic barriers, and migration histories. Among Black and Minority Ethnic (BME) populations, caregiving is reported to be embedded in values of familial responsibility, intergenerational reciprocity, and moral obligations to support elders (Parveen & Oyebode, 2018; Zarzycki et al., 2023).

Despite their significant contributions, many do not self-identify as caregivers, viewing caregiving as a natural extension of familial roles rather than a distinct responsibility. This perception is further reinforced by linguistic barriers; for instance, languages such as Bengali, Gujarati, and Punjabi lack direct translations for the word "carer" (Greenwood et al.,2015). Consequently, caregiving is often framed as a cultural obligation rather than a role that requires external support (Greenwood et al.,2015).

UK-based research on dementia caregiving among ethnic minorities remains limited, often relying on small-scale studies and non-representative samples. Existing studies frequently aggregate diverse ethnic groups under the broad "BAME" label, overlooking the distinct cultural, historical, and systemic factors that shape caregiving experiences within African and Caribbean communities (Milne & Chryssanthopoulou, 2005; Roche, 2023). This homogenisation risks erasing critical nuances, such as the unique caregiving values rooted in migration histories or the impact of systemic inequities on access to care (Roche,2023).

In contrast, research from the United States offers valuable frameworks for understanding dementia caregiving, particularly within African American communities. Studies emphasize the role of spirituality, religiosity, and extended family networks as critical coping mechanisms for caregivers (Milne & Chryssanthopoulou, 2005). These findings also highlight how systemic racial inequalities and historical mistrust of healthcare systems shape caregiving practices (Roche, 2022). However, applying these insights to the UK context is challenging due to significant differences in migration patterns and socio-political histories. For example, older Caribbean migrants in the UK often maintain strong ties to their homelands, influencing caregiving roles and obligations (Roche, 2022). These dynamics differ from the experiences of African American caregivers, who navigate entrenched intergenerational inequalities within the US healthcare system.

Comparative studies have provided valuable insights into dementia care; however, they often fail to address the unique challenges faced by African and Caribbean caregivers in the UK. These challenges include cultural stigma surrounding dementia, linguistic barriers, and the complex interplay of migration histories (Roche,2023; Milne and Chryssanthopoulou,2005). Notably, limited research has focused specifically on the dementia experiences of this population. However, two key studies offer crucial insights. Berwald et al. (2016) study explored barriers to help-seeking for memory problems within UK Black African and Caribbean communities. This qualitative study found that within the Black African and Caribbean community dementia was perceived as a "white person's disease," leading to reluctance in acknowledging symptoms and seeking assistance. In his doctoral thesis, Roche (2023) conducted a large-scale, multi-setting qualitative study with ethnographic observations to investigate the lived experiences of 32 Black African and Caribbean individuals in the

UK, including people with dementia, family carers, and health and social care professionals. The study identified key themes, Dementia perceived as a "killer" and foreign disease, Aging viewed as a permanent visitor and Kinship, care, and cultural distance. These themes reflect shared experiences of migration, limited social and economic capital, and the ways in which threats to identity and belonging shaped how this community made sense of dementia.

While existing studies provide valuable insights into the experiences of African and Caribbean communities regarding dementia care, the limited number of such studies underscores the need for further exploration to gain a comprehensive understanding. Demographic changes, including smaller family sizes and increased social mobility, may further complicate caregiving dynamics. These shifts can reduce the availability of family members to provide care, potentially leading to a decline in both the willingness and expectation to assume caregiving roles (Milne & Chryssanthopoulou, 2005). Additionally, acculturation plays a significant role, influencing responses, attitudes, and meaning making related to dementia. Generational differences in acculturation strategies—such as integration, assimilation, separation, and marginalization (Berry, 1992) can lead to diverse caregiving practices and attitudes towards formal support services. For instance, Zarzycki et al. (2023) highlight how cultural motivations shape informal caregiving, indicating that acculturation processes significantly impact caregivers' motivations and experiences. Therefore, there is a pressing need to explore how informal caregivers from these communities made sense of dementia and navigate support services.

Research Aim:

This study aims to explore how African and Caribbean informal caregivers made sense of dementia and navigate support services.

Method

Design

Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2019), framed by narrative and systemic lenses, was employed to explore how African and Caribbean caregivers construct their understanding of dementia and navigate support services. Guided by a social constructionist approach (Burr & Dick, 2017), this study acknowledges that caregivers' realities are shaped by the language and cultural contexts in which they are embedded. The narrative lens emphasizes the stories caregivers construct to make sense of their roles and experiences (Riessman et al., 2005), while the systemic perspective situates these narratives within broader socio-cultural contexts and structural systems, including familial, cultural, community, and healthcare frameworks (Bronfenbrenner, 1979).

Quality Assurance

To uphold rigor and credibility, this study followed Braun and Clarke's (2006) 15-point checklist for thematic analysis, alongside Yardley's (2000) framework for ensuring quality in qualitative research. Additionally, the COREQ (Consolidated Criteria for Reporting Qualitative Research) (Tong et al., 2007) was utilized to structure the reporting process and enhance transparency and methodological clarity (Appendix E).

Research Team

The research team consisted of a trainee clinical psychologist (AE) and two clinical neuropsychologists (AS and FG). AE, a first-generation African female with personal experience of a grandparent diagnosed with dementia, conducted, and analysed the interviews, drawing on prior research experience on dementia within the Somali community as part of her master's dissertation. FG provided qualitative research expertise and has personal lived experience of being the primary caregiver for his dad who had dementia. AS contributed insights into cross-cultural research. The team's diverse backgrounds and multidisciplinary perspectives fostered deep reflections on the research process contributing to the study’s design, data collection, analysis, and discussions. Importantly, the research team had no prior clinical, service-based, or research affiliations with the participants or the recruitment centres.

Publica and Patient involvement (PPI)

Recruiting participants from BAME communities is well-documented as challenging due to cultural mistrust, limited researcher-community connections, and systemic barriers (Farooqi et al., 2022). To address these challenges, AE engaged community gatekeepers through patient and public involvement (PPI), fostering trust and dialogue about best practices for culturally sensitive engagement. Recognising that formal dementia diagnoses are less common in these communities, the inclusion criteria were broadened to include memory difficulties suggestive of dementia (e.g., forgetfulness). To further build trust and rapport, AE’s picture and profile were included in the participant information sheet, enhancing transparency and participant engagement (see Appendix F).

Participants

Eligible participants self-identified as African or Caribbean, were over the age of 18, and were either informal caregivers or had a family member living with dementia or memory difficulties indicative of dementia. Non-English-speaking participants were excluded due to the lack of funding for interpreters and the methodological challenges of accommodating translators within the study’s limited timeframe.

Recruitment

Participant were recruited through dissemination of the study poster and study information (Appendix H) via BAME community organizations and social media platforms. A third-sector charity organization that provides services for individuals with dementia and their families in an urban area of London with a high Black and Caribbean population served as the primary recruitment site. Recruitment took place between March and August 2024.

Sample Size

Data saturation was not used to determine sample size (Guest et al., 2006) given the social constructionist positioning of the study. Instead, the focus was placed on capturing diverse narratives that reflect caregiving experiences. Although purposive sampling was initially planned (Patton, 2015), recruitment challenges, such as caregivers' competing responsibilities and reliance on a single primary recruitment site, meant that convenience sampling was adopted.

Ethical Approval

Ethical approval for this study was granted by the University of East Anglia Faculty of Medicine and Health Sciences Ethics Committee (Appendix I). The study adhered to the British Psychological Society Code of Human Research Ethics (2021). Participants provided informed consent, and confidentiality was maintained through anonymization and secure data storage. Participants were informed of their right to withdraw from the time before data analysis.

Data collection

Semi-structured interviews, lasting between 45 and 120 minutes, were conducted via Microsoft Teams. At the beginning of each interview, AE introduced herself, shared her professional background and motivations for conducting the study, and reviewed the study's objectives, procedures, and ethical considerations to ensure informed participation. At the time of the interview participants were asked to be at in a safe and confidential space.

An interview topic guide (Appendix J) structured the discussions, focusing on caregiving experiences, interactions with support services, and family and community attitudes toward dementia. The guide was adapted from AE’s master’s dissertation and informed by relevant literature.

All interviews were both visually and audibly recorded with participants' consent and transcribed using Avidnote AI, a GDPR-compliant transcription tool. AE manually reviewed and corrected the transcripts, addressing any errors caused by accent variations to ensure accuracy and preserve the richness of participants' accounts. AE kept a reflective diary and note to help with the analysis process.

Analysis

Braun and Clarke's six-phase process (Braun & Clarke, 2022b) was employed to reflexively analyze the interviews, iteratively moving through the following non-linear phases: (1) familiarization with the data, (2) generation of initial codes, (3) identification of themes, (4) reviewing potential themes, (5) defining and naming themes, and (6) producing the report. Coding was manually completed and Excel was used to manage the dcoding data. The analysis was primarily inductive, with codes derived directly from the data, followed by organize findings in alignment with the research question.

Both semantic and latent coding were utilized to capture the nuances in caregivers' perspectives, their narratives of caregiving, and their communities' views and use of support services. The narrative lens was applied to guide the analytical process, shaping how data were interpreted and structured within Reflexive Thematic Analysis (Braun & Clarke, 2022b). This involved moving beyond identifying recurring themes to examining how caregivers made sense of their experiences, constructed meaning around their caregiving roles, and positioned these narratives within broader cultural and social contexts. To enhance analytical rigor, the research team collaboratively reviewed codes and interpretations (Yardley, 2000). Consistent with Farooqi et al.'s (2022) recommendations, caregivers were invited to review the themes to ensure the findings accurately reflected their experiences, to enhance the credibility and trustworthiness of the study (Appendix K).

Results

Participants

To characterize the sample and provide sensitivity to context (Yardley, 2000), demographic details of participants are presented in table 1. In total eight participants were interviewed for the study. Seven participants were female, one male. Most (n=6) were aged 55 or older. Half (n=4) were first-generation immigrants, residing in the UK for over 15 years (originating from Jamaica, Somalia, and Nigeria); the other half were second-generation, born in the UK. Care recipient relationships varied: four cared for mothers, two for husbands, one for a father, and one for both a mother (living abroad) and a husband (who had experienced a stroke). While care recipients accessed various services (carers at home, community teams, day centres), only two participants reported accessing counselling for caregiving related stressors. Educational attainment ranged from secondary education (n=2) to undergraduate (n=2) and postgraduate degrees (n=4).

Key Themes

Three key themes were identified, reflecting how caregivers make sense of dementia and navigate support systems:

1. Cultural and Generational Interpretation of Dementia
2. Love, Duty, Sacrifice, and Coping with the Caregiving Role
3. Negotiating and Advocating for Support

The themes, along with subthemes and example quotes, are detailed in Table 2.

Table 1.

Demographic Characteristics of Participant

Participant ID	Ethnicity	Age Range	Gender	Generational Status	Birth Country	Time in UK	Relationship to Care Recipient	Care Services for Recipient	Use of Professional Services (Self)	Education Level
P1	African South American	55+	Female	Second Generation	England	Since Birth	Husband	Carers come in to assist with care + Day care centre	No	Undergraduate
P2	Caribbean	55+	Female	Second Generation	UK	Since Birth	Mother	Older adult community mental team + Day care centre	No	Post-graduate
P3	Caribbean	55+	Female	First Generation	Jamaica	15+	Mother	Older adult community teams +Carers come in to assist with care + Day centre	Yes	Undergraduate
P4	African	30–34	Male	Second Generation	UK	Since Birth	Father	No	No	Post-graduate
P5	African	40-44	Female	First Generation	Somalia	15+	Mother	Carers come in to assist with care	No	Secondary education
P6	African	55+	Female	Second Generation	UK	Since Birth	Mother	Carers assist with care and day care centre	No	Post-graduate
P7	African	55+	Female	First Generation	Nigeria	15+	Husband	Carers assist with care and day care centre	Yes	Secondary education. (Completing undergraduate)
P8	African	55+	Female	First Generation	Nigeria	15+	Mother (in Nigeria) and husband with stroke	Living at home carer	No	Post-graduate

Table 2

Themes, subthemes, and key quotes

Theme	**Subtheme**	**Quote**
Theme 1: Cultural and Generational Interpretation of Dementia	**Generational Shifts in Understanding Dementia**	The younger generation is totally different... We Google what we need and tell the doctor what we believe is happening. (P1)
	Pathways to Diagnosis	I tried to learn as much as I could to understand what was happening and how I could support my mum. (P6)
Theme 2: Love, Duty, Sacrifice and Coping with Caregiving Role	**Act of Love that Reinforces Relationships**	*We have been very close friends. We love each other…* (P7)
	Threat to Social Identities	*I had a period of real grief for all the things I lost as an individual and all the things he lost as an individual. And what does this mean for our marriage? What does this mean for our life? (P1)*
	Ways of Adapting to the Caregiving role	*Because of our faith, my Christian faith kind of got me through that. That was the hardest bit, and I think then the family kind of came together*
Theme 3: Negotiating and advocating for support	**Mistrust of Support Services**	*People tend to trust those they know, especially when it's a really hard thing that is happening (P1)*
	Fighting for Support	*The fact is that social service, they always want to cut, cut.... you are always fighting for your rights (P7)*
	Hybrid Use of Formal Services	*My mum got into the day center…..There was a Caribbean group …. They played the music, and most people there were from the Caribbean (P3)*

Theme 1: Cultural and Generational Interpretation of Dementia

This theme explores how caregivers, and their wider communities understand and respond to dementia. It highlights how cultural and generational interpretations influence the recognition of dementia related symptoms and pathways to diagnosis.

Subtheme 1.1: Generational Shifts in Understanding Dementia

The understanding of dementia within communities varies widely, shaped by generational differences, cultural norms, and access to information. Caregivers reflected on the different ways in which dementia is conceptualised between older and younger generations. Older generations often perceive dementia through the lens of traditional or superstitious beliefs, leading to stigmatization or spiritual explanations. As caregiver P8 highlighted this generational difference, describing how, in her community, people with dementia are stigmatised or dementia related changes being understood with in religious context.

> Stigmatized as being a witch or their symptoms attributed to spiritual or moral failings (P8)

Similarly, other caregivers described how dementia is often seen as a natural consequence of aging, reinforcing the idea that it is an expected part of life rather than a condition requiring intervention. P5 illustrated this perception by talking about within her Somali community dementia related changes is attributed to age.

> Oh, yeah, she's getting old. She's mixing her words... old age (P5)

In contrast, caregivers highlighted a generational shift in how dementia is constructed, where younger individuals, through lived experiences and increased access to resources, deviate from dominant narratives within their communities. Participant P3 described this shifting perspective, reflecting on how her mother's diagnosis served as a pivotal moment in her meaning-making process and how she actively redefined dementia within her wider family system.

> I think maybe in my generation, I don't know, people in their 60s are now understanding [dementia]. Well, actually, no, it's more than that. It's not just old age or stuff like that. It's more than that. Yeah. Because I think my uncle had it too. Because my mum is going through it, I now understand what my cousin experienced as well. (P3)

P3's experience highlights how second-generation caregivers reinterpret dementia beyond aging narratives. By drawing on her shifting understanding, she facilitated a shift in her family's recognition and collective narrative of dementia.

Caregivers from younger generations also spoke about how drawing on to research and exposure to knowledge has enabled them to take a more proactive approach in understanding and responding to dementia. Caregiver P1 emphasized this shift, explaining how use of researching first used to be informed and advocate for support.

> The younger generation is totally different... We Google what we need and tell the doctor what we believe is happening. (P1)

Caregivers from younger generations also spoke about how drawing on research and increased exposure to knowledge has enabled them to take a more proactive approach in understanding and responding to dementia. P1 emphasized this shift, explaining how research played a key role in becoming informed and advocating for support. This increased access to information stands in contrast to older generations, who often lacked the same resources and exposure, limiting their understanding of dementia within the Western medical framework. P6 reflected on this gap, noting:

> I think it's just a lack of access to the information that would clarify what dementia is and what to look for (P6)

Subtheme 1.2: Pathways to Diagnosis

The process of seeking a dementia diagnosis often begins with recognizing behavioural changes in loved ones. Caregivers described discussing these changes within their families before consulting and using formal pathways to make sense of what was happening. While some caregivers encountered a relatively straightforward route to diagnosis, others experienced significant delays, influenced by family resistance and the misattribution of dementia-related changes to other factors.

Caregivers such as P4, P6, and P7 noted that recognizing dementia-related changes early led to relatively prompt diagnoses. P6, for instance, described recognising that '*things were not quite right'* in her mother and spoke to her mother's GP, leading to a confirmed diagnosis within three weeks following a GP referral. Similarly, P7, a nursing student, noticed repetitive behaviours and misplaced items in her husband, prompting a visit to the doctor and subsequent referral to a memory clinic, where a formal diagnosis was given. However, for some caregivers, the pathway to diagnosis was less straightforward. P5 described a complex and fragmented process, navigating multiple healthcare systems.

> They did not want to acknowledge it… There was Canada, where they said, 'Oh, we think something is going on…' but in the UK, they considered, 'Could this be an early sign of dementia?' But in Turkey, her relatives, which is my sister, paid quite a lot of money. And from there, they said… there's nothing wrong (P5)

P5's search for meaning in her mother's condition was shaped by her family's resistance, as dementia did not fit their expected narrative. She made sense of her mother's struggles through her experience of caring for her grandmother, an experience her family had accepted more easily because of her grandmother's advanced age. In contrast, her mother's younger age disrupted the family's understanding of illness and aging, creating tension. This resistance made it difficult for them to accept dementia as an explanation, driving a complex and ongoing search for alternative answers.

While some caregivers identified changes early, others initially attributed them to alternative explanations, such as grief, stress, or exhaustion. P2, for example, made sense of her mother's symptoms in relation to losing her husband.

> At first, I just thought it was grief and she just the loss because they'd been so close (P2)

For some, diagnosis only became possible at a point of crisis. P3 described how her mother's dementia was only formally recognized after she wandered outside late at night, prompting police involvement and eventually leading to a mental health team referral. This experience highlights how, in some cases, it was not until a significant incident disrupted everyday life that dementia was acknowledged and acted upon. Researching and engaging in a process of self-education was also central to the diagnostic journey for many caregivers. P1, P5, P7, and P8 described actively researching and connecting with organizations like Alzheimer's charities to better understand what was happening to their loved ones.

> Started reading and researching and finding out, you know, what makes people carry on in this way (P8)

> I tried to learn as much as I could to understand what was happening and how I could support my mum (P6)

For some, prior education and professional backgrounds informed their understanding of dementia. P5 referenced her past caregiving role with her grandmother as a way of interpreting her mother's symptoms, while others, like P6 and P8, drew on their academic and professional experiences to construct meaning and understanding of dementia.

> I worked in the hospital over many years where I was serving food and used to go to geriatric wards. That was what kind of enabled me to realize that my mom's condition is dementia because of her behaviours (P8)

Theme 2: Love, Duty, Sacrifice and Coping with Caregiving Role

This theme explores the motivations and values that caregivers described in relation to their roles, the challenges they encountered, and the strategies they used to manage their role caregivers emphasized how caregiving was shaped by love, duty, and cultural beliefs, while also acknowledging the personal sacrifices and emotional toll it carried.

Subtheme 2.1: Act of Love that Reinforces Relationships

Caregivers often viewed their roles as extensions of family traditions and cultural values. For some, caregiving was seen as a continuation of the support they had experienced within their families, making it a natural and expected responsibility. These cultural and familial frameworks shaped how caregiving was understood and approached. For P8, caregiving was a natural and unquestioned duty, shaped by the sense of reciprocity within family life:

> She was our responsibility. She is the one that raised us, and therefore, we must do our best for her (P8)

Similarly, P3 reflected on how her Jamaican cultural values of respect for elders shaped her caregiving role:

> We were brought up that way, and I suppose it is a cultural thing because we are Jamaicans, that you respect your elders (P3)

For others, caregiving was deeply tied to a sense of love and companionship, particularly for those caring for a spouse. P7 spoke about how her emotional connection to her husband sustained her through the difficulties of caregiving:

> We have been very close friends. We love each other. And when this thing happened, I felt this is a challenge. It could be me. Nobody can tell. And it didn't reduce my love and care for him (P7)

Caregiving was also framed as an act of gratitude and reciprocity. P1 expressed the importance of acknowledging the sacrifices that loved ones had made:

> You have got to remind yourself, well you know, it’s your mother, she gave up an awful lot for you, you know, it’s small enough to do for her (P1)

For some, faith reinforced their commitment to caregiving, positioning it as a moral or spiritual responsibility. P5 described caregiving as religious duty:

> In our culture, the person that looks after their parents is someone who's really blessed (P5)

While some caregivers embraced their role out of love, duty, or faith, others had a more complex journey moving through uncertainty and struggle before finding meaning in their responsibilities. For caregivers navigating multiple identities, responsibilities were often shaped by a balance between cultural tradition and practical necessity. Although gender norms often dictated caregiving expectations, some families divided tasks in ways that reflected practicality rather than tradition. P2 described how caregiving responsibilities were naturally distributed among her siblings:

> We all have our roles… My brother is good at DIY, my sister manages the finances, and I focus on the day-to-day caregiving. It just naturally fell into place. (P2)

While some caregiver noted expectations for daughters or female relatives to assume caregiving responsibilities, others described how roles were determined by proximity or willingness, reflecting the evolving nature of caregiving dynamics. P1 shared how caregiving in her family was not strictly gendered but instead shaped by logistical considerations:

> He will take care of everything, from washing dishes to cleaning the kitchen. You'd expect our daughter to do that, but she lives farther away with her family. (P1)

For many caregivers, the role was not solely about obligation it was also an expression and continuity of their relational identity. Spousal caregivers described their commitment as an extension of their relationship. P7 spoke about her unwavering love for her husband, despite the despite the challenges it presents:

> We have been very close friends. We love each other. And when this thing happened, I felt this is a challenge. It could be me. Nobody can tell. And it didn't reduce my love and care for him (P7)

Similarly, P8, tied her caregiving role to the depth of her marriage commitment:

> We have been married for 51 years. And, you know, for me, it was marriage. until death do us part. So, for better or for worse. (P8)

These narratives highlight how caregiving, despite its difficulties, was often framed as an act of loved one that reinforced rather than diminished personal relationships.

Subtheme 2.2: Threat to Social Identities

Despite the deep sense of commitment that many caregivers felt, the role also carried significant emotional, social, and threat to pre-existing relational identities, particularly the loss of identity as a wife and daughter. Caregivers spoke about the overwhelming demands of caregiving and the difficulties of balancing their responsibilities with other aspects of their lives. These demands left some feeling emotionally depleted and for some the COVID-19 pandemic intensified these struggles by removing social support systems, making caregivers feel even more alone in their role. P2 described the extent to which caregiving impacted her mental health:

> I felt suicidal at that time. That was the lowest I've ever felt, and then, because no one could go anywhere and visit anybody, it was quite hard (P2)

The stress of caregiving often exacerbated existing health conditions, with some caregivers noting how it affected their physical resilience and well-being. P2 explained how the pressure of caregiving exacerbated her pre-existing health conditions:

> I suffer with allergies, but it can make my allergy feel a lot worse because I'm so stressed. And my blood pressure because I have suffered blood pressure as well. (P2)

The sacrifices required of caregivers, particularly the loss of personal time and social connections, further contributed to the emotional strain. P4 described how caregiving impacted his social life and overall well-being:

> It has really stopped me from going for some social gatherings... I sacrificed my time being with him, taking care of him. The emotional part is seeing my dad passing through a lot of pains... It has been giving me sleepless nights. (P4)

Caregivers also spoke about the loss of personal identity, as their roles as wives, daughters, or professionals were overshadowed by caregiving responsibilities. P1 and P2 described the grieving process they have gone through not just for their loved ones, but for the parts of themselves that had been lost in the process.

> I had a period of real grief for all the things I lost as an individual and all the things he lost as an individual. And what does this mean for our marriage? What does this mean for our life? (P1)

The expectation to keep caregiving within the family unit, meant that caregivers often felt the pressure to endure their struggles privately.

> Maybe it's the African way of doing things. You know, it's like you don’t want to be shamed. You want to keep your problem to yourself. (P7)

> Because they're afraid of being judged or what people think of them. (P6)

Through the process of caregiving, many caregivers found that caregiving itself became a site of redefining relationships and identity. They navigated what it meant to be both a wife and a caregiver, questioning which role they would negotiate and accept as part of their shifting identity. The lines between self and responsibility blurred, leaving caregivers struggling to reclaim aspects of their identity beyond caregiving.

Subtheme 2.3: Ways of Adapting to the Caregiving role

Caregivers described a range of strategies they use to navigate the challenges of caregiving, varying from practical approaches like “*getting on with it*” (P6) to personal reliance on faith and family support. For many caregivers, practicality and resilience were central to their coping mechanisms. This attitude of perseverance was often rooted in necessity rather than choice, driven by the demands of caregiving.

> …And I can't just allow it to weigh me down because it's a challenge. The only thing I believe in is finding a solution to the problems, not looking at the challenges (P4)

> ... I’m just the sort of person that would just get on... Doing what needs to be done. I’ve just fitted it into my schedule. (P6)

This approach of adaptation and perseverance reflected the inner resilience many caregivers cultivated as they balanced caregiving with other aspects of their lives.

> Not only do I look after my mom, I also have my grandkids. My eldest daughter has four kids, and one of them is a set of twins who are only 18 months old. (P3)

For others, faith provided a crucial anchor, offering emotional solace and a sense of purpose amidst the challenges. Some caregiving reflected belief that caregiving was a form of spiritual duty helped them reconcile their sacrifices.

> Because of our faith, my Christian faith kind of got me through that. That was the hardest bit, and I think then the family kind of came together (P2)

Faith also helped caregivers manage their grief of what was and make sense and find meaning in their new roles. P1, who had given up her career as a therapist, described how her faith provided a sense of solace and helped her process the grief she experienced in response to her husband's diagnosis. Through faith, she found the strength to adapt to her new reality and redefine her sense of purpose in caregiving.

> Apart from my relationship with Christ and speaking to Him, I had to become a client for myself. This helped me to process my emotions and reconcile with what I felt I had lost (P1)

Family support emerged as another pillar of coping, with caregivers relying on children, siblings, and extended relatives to share responsibilities.

> They help their dad, getting him ready for bed, doing whatever needs to be done if I'm having a hard day. They just take over. (P1)

For the older generations, the community served as a vital source of acceptance, connection, and belonging. This sense of solidarity was especially significant for those who had faced systemic challenges, such as racism or social exclusion, in the past.

> In the 70s, growing up because of all the racism and all the difficulties... we kept having our own little community….because it was everything was just this unit, and so we went to our Black churches and just kept within the community because it was difficult to be accepted (P3)

The community not only provided emotional support but also acted as a practical network of care and advice. Participants described how faith, cultural identity, and the expertise of community members, such as healthcare professionals, were often sought for guidance and assistance:

> I think it's always been a long-standing thing of people seeking help within the community, seeking help with their faith, seeking help...if they got, within the community, people who are doctors and nurses, they will seek their support. You know because it's...I would like to say it's generational (P1)

The shared cultural and generational identity fostered by these communities created a protective space for many caregivers, offering a sense of practical solidarity. However, reliance on community support also brought about a complex tension. Caregivers often expressed concerns about judgment within these close-knit networks, such as churches, leading to fears of isolation or stigma. While community connections provided critical support, they also reinforced the expectation for caregivers to manage their responsibilities independently, sometimes in silence, in order to maintain dignity and avoid perceived criticism.

Theme 3: Negotiating and advocating for support.

While many caregivers used formal services to support themselves or their loved ones, their experiences revealed a complex process of navigating systemic challenges. This included negotiating mistrust of services tied to previous experiences, integrating familial care with external support (hybrid care), engaging in persistent fight to secure appropriate resources, and navigating generational differences to help seeking.

Subtheme 3.1: Mistrust of Support Services

Caregivers consistently expressed scepticism toward formal institutions and healthcare professionals. This mistrust was deeply rooted in past negative experiences with formal services.

One caregiver shared her experience of feeling that professionals were more focused on prescribing medication than providing emotional support:

> I remember when I was just, you know, recovering from cancer… I was feeling low… but the kind of question that they were asking me kind of made me feel I don't like the direction of this question is going to end up about them giving me medication that I don't need. And maybe I don't need medication. I just need a listening ear (P8)

This reflects a broader fear of healthcare professionals' intentions, with participants questioning whether their needs were truly being understood or met.

> My mom had gone to the doctors and, you know, she had a problem and before she got in the room, the doctor started writing like he knew what was wrong and gave her these pills. And she couldn't tell him no because he's the doctor after all (P1)

For caregiver P5 and her family, mistrust in local healthcare systems led them to seek answers across three different countries to understand her mother's condition. Highlighting the lengths caregivers are willing to go when trust in local services is eroded. This pervasive mistrust often pushed caregivers to rely on community networks where they felt their experiences and struggles were better understood.

> People tend to trust those they know, especially when it's a really hard thing that is happening (P1)

These narratives underscore the systemic barriers faced by caregivers, where scepticism and negative past experiences often intersect to shape how they navigate care systems.

Subtheme 3.2: Fighting for support

Caregivers frequently talked about the persistent advocacy required to secure adequate services for their loved ones. This advocacy often involved battling systemic inefficiencies and proving the necessity of care in a system that many found unresponsive or dismissive.

> The fact is that social service, they always want to cut, cut.... you are always fighting for your rights (P7)

> It is has been a battle, absolutely total battle because in social care, adult social care than just is not enough workers (P3)

Others described the lengths they went to in order to validate their loved ones' needs, often feeling that evidence alone was required to be taken seriously:

> I had to record her... I had to do it... for people to believe me (P5)

One participant reflected on the additional burden faced by individuals from Black communities, emphasising the need for excellence and persistence in advocating within formal systems:

> As a Black person, you've got to be good, but you've got to be extremely, extremely good at what you do and what you know, to be able to probe and get through that system, to get through the different systems (P3)

Even for those with professional experience in social work, adjustments to care plans often required prolonged and exhaustive negotiations, underscoring the inadequacy of available resources and the complexity of navigating these systems.

Subtheme 3.3: Hybrid Use of Formal Services

Caregivers often described adopting a hybrid approach to caregiving, balancing formal support services with personal, family, and community-led care. This approach was shaped by mistrust of care homes, cultural caregiving expectations, and a desire to maintain autonomy in decision-making while meeting their loved ones' cultural and personal needs. Many caregivers preferred to keep primary caregiving within the family, where they retained control over maintaining their loved one's personhood while relying on formal services to support specific daily tasks, such as assisting with mobility or facilitating attendance at culturally appropriate day centres.

> We keep everything in-house. We don't like the outside to know what's going on, and oftentimes, the people I've encountered relied on family and friends to make sense of the situation, and there was always someone that they could talk to (P1)

Caregivers expressed hesitancy about placing their loved ones in care homes, often viewing them as a last resort rather than an immediate solution. While some caregivers discussed care homes as a respite option, most preferred a mixed approach, supplementing familial care with external services rather than relying exclusively on institutional settings.

> We have a care agency that comes in and helps her during the day (P6)

Concerns about institutional settings often stemmed from negative perceptions of care homes, particularly regarding lack of cultural sensitivity, depersonalized treatment, and loss of autonomy. P1 articulated a common concern among caregivers, emphasizing the importance of culturally familiar spaces.

> Our father was there for respite and lost weight. We would go in, help him eat, and attend to him. We've had friends in care homes, and we would visit. Simple things like deodorant aren’t provided. People's dignity isn't always maintained, and the way they're spoken to and handled lacks love (P1)

For many caregivers, cultural familiarity in formal services was critical. While care homes were viewed with scepticism, day centres with culturally specific groups (i.e Caribbean day centres) were embraced.

> My mum got into the day center…..There was a Caribbean group …. They played the music, and most people there were from the Caribbean (P3)

caregivers highlighted the importance of culturally appropriate care providers, ensuring that loved ones felt understood and respected in their interactions with formal caregivers. P6 described how caregivers of a similar cultural background provided the best support, as they understood dietary needs, language, and social expectations:

> I think the best care has come from those of a similar background to my mum. Some of the care staff are Yoruba, like my mum, so they understand her and sometimes speak to her in her language. They know things like diet, which someone from a different background might not. (P6)

Caregivers strategically engaged with formal services while maintaining primary control over caregiving within their families. Their reluctance to fully entrust care to institutions was rooted in concerns about quality of care, cultural alignment, and loss of autonomy. Instead, caregivers sought hybrid solutions, integrating formal support selectively through day centres, in-home care services, or culturally aligned care staff while preserving their role as primary decision-makers and emotional anchors in their loved ones’ care.

Discussion

To our knowledge, this study is among the first to explore how informal African and Caribbean caregivers understand dementia and engage with support services. Our reflexive thematic analysis of semi-structured interviews revealed three key themes: cultural and generational interpretations of dementia; meaning making of the caregiving role; and navigating support. These interconnected themes highlight how African and Caribbean caregivers make sense of dementia, and how their engagement with support systems is shaped by community narratives, generational shifts in undertesting dementia, and systemic inequalities.

The findings of this study show interplay between culturally situated meanings of dementia and dominant biomedical discourses among African and Caribbean caregivers. Caregivers reflected that within their communities and families, dementia is often attributed to aging, spiritual causes, or misattributed symptoms to stress or grief. These interpretations, often rooted in traditional beliefs about aging and spirituality (Johnston et al., 2019), frequently delayed their loved ones' pathways to diagnosis.

Despite these culturally embedded interpretations, caregivers in the study highlighted the younger generation's active role in reshaping the meaning of dementia. Through their experiences of obtaining a diagnosis for a family member, increased access to education and professional experiences, and engagement with online resources, younger caregivers facilitated a growing recognition of dementia as a condition requiring intervention. This increased access to information, reflecting broader trends in health information seeking (Allen et al., 2016), empowers younger generations to reshape traditional narratives.

This generational shift mirrors Carter et al.'s (2023) study exploring pathways influencing dementia diagnoses in ethnically diverse urban areas. Their findings on "insider-outsider identities" resonate with this study, suggesting a move away from traditional community constructions of dementia toward a growing recognition of dementia as a medical condition rather than an inevitable aspect of aging. This shift highlights the dynamic interplay between cultural perspectives and biomedical understandings.

Interestingly, despite the shift towards biomedical understandings of dementia, cultural values remain deeply intertwined with caregivers' motivations and values. The continuity of family identity, shaped by collective memory and relational obligations, served as a primary driver for assuming the caregiving role. This aligns with broader research emphasizing cultural norms and caregiving practices as vital for maintaining family cohesion (Roche,2023; Dilworth-Anderson et al., 2002;).Carricaburu and Pierret's (1995) concept of biographical continuity provides a helpful framework, positioning caregiving not as a disruption but as a natural extension of existing familial roles and narratives. Within this framework, caregiving becomes a means of reinforcing caregivers' identities within their families, gives their relationships with meaning and purpose. Furthermore, caregivers framed their role as a way of preserving the personhood and dignity of their loved ones. This resonates with Kitwood's (1997) person-centered approach to dementia care, who prioritizes the preservation of identity as central to compassionate care.

In line with the aim of exploring how African Caribbean caregivers make sense of support services, the findings revealed a prevailing narrative of mistrust in formal care systems, rooted in past negative experiences that shaped caregivers' help-seeking behaviours. This mistrust, compounded by the lack of culturally sensitive services, reinforced a reliance on existing community-based support networks. These networks, while often effective for older generations, could also perpetuate a social construction of caregiving as solely a family responsibility. This dominant narrative created tension, particularly for younger generations, and sometimes delayed or discouraged engagement with formal support services.

Baghirathan et al. (2020) highlighted how such culturally embedded norms provided a crucial buffer against caregiving burdens for ethnic minority groups, particularly within systems marked by inequities. Similarly, Guerra et al. (2024) study emphasized caregivers' preference for community-based information and support, reflecting a shared cultural understanding and trust reported absent in interactions with external systems.

To navigate these complex dynamics, caregivers in our study described strategically engaged with formal services while maintaining primary control over caregiving within their families. Their reluctance to fully entrust care to institutions was rooted in concerns about quality of care, cultural alignment, and loss of autonomy. Instead, caregivers sought hybrid solutions, integrating formal support selectively through day centers and requesting cultural aligned social care support, while preserving their role as primary decision-makers and emotional anchors in their loved ones’ care.

Strengths and Limitation

This study's quality assurance was guided by Yardley’s (2000) four principles: sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance. Consultations with gatekeepers from BAME communities via Patient and Public Involvement ensured culturally sensitive engagement with caregivers. Recognizing that formal dementia diagnoses are less common in these communities the study adapted its language regarding dementia to include memory difficulties. Consistent with Farooqi et al.'s (2022) recommendations, caregivers were invited to review the themes to ensure the findings accurately reflected their experiences, to enhance the credibility and trustworthiness of the study.

The lead researcher (AE), a first-generation African woman, embodied both an insider (emic) and outsider (etic) positionality, which likely influenced the research process. The emic perspective as someone who shared cultural similarities with participants was hoped to enhanced trust and rapport, allowing for more open and meaningful discussions (Farooqi et al.'s 2022). Throughout the study AE has kept to reflective diary to ensure transparency.

The study initially aimed to recruit participants from multiple sites; however, only one site yielded consenting participants, which limited the diversity of experiences captured. Most participants were already engaged with support services, making it harder to explore the perspectives of those who do not access formal support. Additionally, only one of the eight participants identified as male, meaning the study provides limited insight into the experiences of male African Caribbean caregivers.

Clinical Implication

This study's findings indicate that younger generations, influenced by Western conceptualizations of dementia, demonstrate a shifting understanding and an increased openness to using formal services. This group navigates the complexities of balancing familial caregiving values with the realities of daily life and the potential burden of caregiving.

It is crucial for services supporting caregivers to recognize these evolving narratives and their implications, particularly as second-generation individuals become the next generation of caregivers. Clinicians supporting caregivers must equipped with the competencies in helping them make sense of how their cultural values, beliefs, and expectations shape their caregiving experiences.

This sense-making can be facilitated through the use of the Cultural Formulation Model (Lewis-Fernández & Díaz, 2002) and the Cultural Formulation Interview (Lewis-Fernández et al., 2014), which provide structured frameworks for understanding the cultural dimensions of caregiving experiences. Additionally, Ecological Systemic Formulation, rooted in Bronfenbrenner's Ecological Systems Theory (1979), can help way of validating, and contextualize their experiences within the broader societal and structural systems they navigate, including family dynamics, systemic inequalities, and cultural expectations.

Future research

Future research should explore the sense-making of African and Caribbean caregivers on a broader scale, incorporating diverse cohorts, including both those who engage with formal services and those who do not. Particular attention should be given to generational differences.

While the study's main focused was on sense making of dementia and use of support services, caregivers in this study talked about emotional and psychological impact of caregiving. More research is needed to investigate the impact of caregiving on caregivers' well-being, their use of psychological support services, and the unique intervention needs within these communities.

Additionally, given the limited representation of male caregivers in this study, future research should specifically examine the experiences of African and Caribbean male caregivers to better understand their challenges, coping strategies, and support needs.

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Chapter 4-Extended Methodology

Providing additional information on the philosophical and theoretical underpinnings, recruitment strategies, reflexivity practices, and reflective processes.

Extended Methodology

This section provides a detailed discussion of the philosophical and theoretical frameworks guiding the research, recruitment strategies, reflexivity and reflections on the motivations guiding the study and the interview process.

Philosophical and theoretical methodology

Decolonising Research Methodologies

This research is underpinned by social justice values, prioritizing fairness, equality, and inclusivity. These principles guide the study's aim to amplify the voices of African and Caribbean caregivers, address systemic inequities, and advocate for culturally sensitive dementia care.

In dementia research, the lived realities of minoritized communities are often oversimplified into cultural stereotypes or overshadowed by Eurocentric frameworks (Roche, 2023). Traditional research paradigms frequently reduce caregiving within these communities to purely cultural phenomena, neglecting the nuanced practices rooted in historical traditions and survival strategies shaped by systemic oppression (Duncan & Smith, 2023; Thambinathan & Kinsella, 2021).

Held (2019) underscore the importance of incorporating diverse epistemologies and ensuring equitable participation of non-Western voices in knowledge production. Decolonising methodologies align with this ethos, promoting the co-creation of knowledge with participants, such as inviting feedback on emerging themes and codes. This collaborative approach fosters epistemological equity (Dei, 2008), ensuring that findings authentically reflect participants' lived experiences.

Guided by the principles of decolonising research methodologies, this study seeks to generate knowledge that is both equitable and justice driven. By adopting a social justice lens, the research sought to avoid perpetuating power imbalances or oversimplifying the experiences of minoritized communities. The author prioritises the use of language that resists othering or reductive narratives, fostering an inclusive and authentic representation of African and Caribbean caregivers' experiences in both data collection and analysis (Smith, 2023; Roche, 2023).

Ontology and Epistemology

Ontology examines the nature of being and what is considered real within a research context (Campbell et al., 2021). This study adopted relativist stance, acknowledging the existence of multiple subjective realities shaped by cultural, social, and personal contexts (Berger & Luckmann.,2011).

Epistemologically, the study is grounded in social constructionism, which emphasizes the co-construction of realities through language, interactions, and discourse (Burr & Dick, 2017). This approach is particularly suited to exploring psychological and social phenomena, such as caregiving practices, as products of cultural, economic, and systemic influences.

Theoretical Framework

Social constructionism frames how caregivers construct their perceptions of dementia and caregiving, recognizing that dementia is understood through socio-cultural contexts (Burr, 2003). For example, in BAME communities, the absence of specific terminology for dementia often leads to alternative constructs, such as attributing symptoms to age-related changes or spiritual beliefs.

Narrative theory emphasizes storytelling as central to meaning making (Riessman, 2008). Caregivers' narratives provide insights into how they interpret their roles and navigate challenges, reflecting cultural values like familial responsibility and loyalty while revealing tensions around seeking external support services.

Systemic ideas examine caregiving within relational and structural contexts (Vetere & Dowling, 2008). For African and Caribbean caregivers, systemic analysis explores how cultural norms, such as prioritizing family-based care, intersect with structural barriers like limited access to culturally appropriate services. Together, these frameworks provide a comprehensive understanding of caregiving experiences.

Recruitment

Recruiting participants from BAME are reported to be challenging due to several factors outlined by Farooqi et al. (2022) in their toolkit for increasing the participation of BAME groups in health and social care research. According to Farooqi et al these challenges stem from inadequate engagement with communities and individuals, which arose from issues such as researchers' lack of cultural competency, historical negative research experiences, and limited connections with community networks. To address these challenges, the toolkit suggested employing effective patient and public involvement (PPI), leveraging the cultural competency of researchers, and providing meaningful feedback.

In this research project, the toolkit was used to facilitate recruitment and engagement, particularly within African and Caribbean communities. To address potential challenges, the study incorporated the following strategies:

1. Use of Patient and Public Involvement (PPI): The study employed PPI through consultation with third-sector organizations to determine the most effective ways to engage with community members.
2. Cultural Competency of the Researcher: The lead researcher (AE) belongs to the African community, which helped establish rapport and trust, ultimately enhancing participant engagement.
3. Feedback to Participants: The analysis and themes of the findings were shared with participants, who were asked whether the results accurately reflected their experiences. They were also given the opportunity to provide feedback (see Appendix K for participant feedback).

Issues with online recruitment

Initially, online recruitment was included to increase diversity and capture a broad range of caregiver experiences. However, concerns arose regarding email patterns raising questions about potential fraudulent participants. In response, AE conducted a review of literature on imposter participants in online qualitative research, aligning with strategies outlined by Lawlor et al. (2023). The research team reflected on the risk that fraudulent participants posed to data integrity and, following consultation with the chair of the UEA Faculty of Medicine and Health research ethics committee', the following plan was put in place to mitigate risks:

1. To continue with the interview of the person who was already offered an interview.
2. Emails were sent to individuals who had expressed interest (via email or forms), thanking them for their engagement and informing them that online recruitment had closed.
3. All recruitment materials were removed from LinkedIn, and the study's Instagram page was deactivated.

Reflexivity

Reflexivity involves researchers critically examining how their positionality (e.g., social, cultural, and professional backgrounds) shapes the research process, from design to interpretation of findings (Braun & Clarke, 2022). This practice serves as both a quality assurance and a method of knowledge generation, requiring researchers to transparently address how their assumptions and experiences influence interactions with participants and data analysis (Finlay, 2002; Berger, 2013).

The researcher's positionality impacts studies in three key ways (Berger, 2013): Access to participants: Shared cultural or experiential backgrounds can foster trust and openness. Depth of disclosure: Participants may share more freely with researchers perceived as empathetic insiders. Interpretation of data: Researchers' biases and frameworks shape how narratives are analysed and contextualized.

As a Black African woman, interviewing mainly female caregivers, I was aware of my emic (insider) position during the interviews and research process. This shared background privileged my access to the participants' meaning-making processes, as they were more likely to engage openly (Roche.,2022; Farooqi et al.,2022) However, this also meant that participants often assumed I already "knew" certain cultural understandings, which shaped the way they articulated their experiences. For instance, participants would say:

> "You know how our cultures are."
>
> "We are from a similar community."

These comments positioned me as someone within the narrative, yet at times, I found myself lacking full knowledge of the specific stories being referenced. At the same time, I was acutely aware of my etic (outsider) positionality as a researcher facilitating the knowledge construction process. In some instances, I experienced being 'othered', as my role as a researcher placed me in a position of authority over the research process, despite my shared background with participants. This dual insider-outsider dynamic required continuous critical reflexivity to navigate the boundaries between shared experience and analytical distance in the interpretation of the data.

Reflections

Personal Reflection and Motivation for Research

My interest in dementia research was born following my grandfather's diagnosis and the realisation that there was no direct translation for the term "dementia" in the Somali community I grew up in. This language gap mirrored the broader challenges my family faced in understanding and navigating my grandfather's condition as his dementia progressed. Witnessing these struggles sparked my curiosity about how others in my community perceived dementia, leading to my unpublished master's dissertation, which explored Somali communities' perceptions of the condition and the influence of cultural beliefs on caregiving experiences.

Through this research, I interviewed six Somali participants aged 18 to 40, some of whom shared their experiences of caring for family members with dementia-like symptoms (operationalised as memory loss or forgetfulness). A prominent theme that emerged was the mosaic-like understanding of dementia, where participants blended biomedical explanations with cultural and spiritual beliefs. This reconciliation of different explanatory models reflected a shared struggle to navigate the stigma often associated with mental illness. Participants' framing of dementia was significantly influenced by their acculturation, balancing traditional Somali perspectives (shaped by family and community) with Western viewpoints encountered through education, work, and other interactions within the host cultural.

Another key finding was participants' openness to engaging with formal support services, provided these services were culturally adapted to align with their values. However, this openness often conflicted with cultural expectations of filial caregiving, creating tensions as participants managed caregiving responsibilities alongside competing demands. This insight resonated with me personally, as it contrasted with my own family's experience, where caregiving was entirely familial, and external support was met with hesitation and scepticism.

While conducting the literature review, I observed a lack of nuanced research on dementia within BAME communities at the time (though this area has since expanded). Much of the existing work oversimplified dementia care within minority communities as a purely cultural phenomenon, rather than approaching it with curiosity and the depth it warrants. This gap motivated me to amplify underrepresented perspectives and contribute to a more inclusive and nuanced understanding of dementia and caregiving within minoritized communities.

Reflection from the interview

Throughout the research process I have kept a reflective journal to document my experiences, observations, and of the emotional impact of the research project. Keeping a reflective diary aligns with the methodological approach, emphasizing critical reflexivity in qualitative research. Below are extracts from my reflective journal, written after two interviews with a participant whose story had a significant impact on me.

- Example of extract from my journal that was significantly impactful on a personal level and made me aware of how situated I was in the narratives the caregivers were sharing during the interview.

> *"I wonder why hearing [P3] story impacted me this much. I wonder if it was the fact that she was an older daughter who had previously cared for her siblings and then transitioned to caring for her children, clients as a social worker, and now her mother. You can really see how much emotion she is carrying in the way she talks about her experiences, despite now being in a position where she navigates her responsibilities better, having received support and developed assertiveness skills to negotiate with her siblings. I am in awe of her advocacy for herself and her mother and her recognition of the importance of using the resources around her. It made me reflect on whether this was influenced by her experience of migration. Did migration make her resilient and adaptable? Or did it make her more susceptible to caregiving expectations? Why did she seem to have more cultural motivation, while her sister appeared detached? Have I related to her because she reminds me of my identities of being an older daughter and being in the helping profession? And my fears of potentially adopt the responsibility of being carer for my parents?"*

This interview resonated with me on a personal level, particularly as an older daughter in a helping profession. It surfaced fears about potentially adopting the solo responsibility of caregiving for my parents in the future. This connection made me more attuned to the intersection of personal identity, migration history, and resilience in shaping caregiving experiences. It made me think critically about care-sharing dynamics within families and question why I have not asked about the proximity of siblings to cultural expectations and how closely or distantly they align with these norms. As well as, how that might impact their caregiving roles and responsibilities. This interview really influenced in how I engaged in the systematic review.

- Example of extract where I had difficulties connecting and highlighting the importance of keeping these reflection diaries.

> *"It was so difficult to relate to him. This may have been due to my concerns about online participants impersonating caregivers. He seemed so practical and clinical about the way he talked about the care he provided for his dad almost like a 'just get on with it' attitude. This was so different from the other interviews. There was also a noticeable disconnection from the community and culture. Why why was this ? is it his age? . Did I ask the questions or relate to him differently? He also felt awkward talking about how he identifies, even though he was able to put something down in the demographic questions. Maybe I need to rewatch the interview a few times from different perspectives."*

This extract reflects my reflections following an interview with a participant who had expressed interest online during a period when the research team was considering discontinuing online recruitment due to concerns about potential impostor participants. In hindsight, I wondered whether the participant's practical and clinical way of discussing his caregiving experiences and his attitude toward dementia and service use might have been influenced by his gender and generational factors. He was the only male participant in the study and the youngest. These factors could potentially explain the detachment and difficulties I noted in my journal. Recognizing these dynamics has been helpful in analysing this interview, providing insights into how gender and generational influences might shape perspectives on caregiving and dementia.

Chapter 5 - Critical Appraisal and Discussion

Critical Appraisal and Discussion.

This final chapter synthesizes the findings from the empirical study and systematic review, placing them within the existing literature. It discusses the implications and recommendation for clinical practice, policy, and future research directions. The starts with reflections of the thesis process.

Reflections on the Research Process

Over the course of this thesis project, my understanding of ethnic minority caregiving has evolved in ways I had not initially anticipated. At the outset, my focus was to understand how African and Caribbean caregivers navigate dementia and access support services. However, as I engaged more with the literature and explored broader caregiving experiences, it became clear that research methodologies, researcher positionality, and interpretive frameworks significantly shape how caregiving is understood and represented (Smith, 2012).

I entered this research already aware of the limited empirical studies on ethnic minority caregiving, having previously explored this topic in my master's dissertation (see Chapter 2). While there has been some expansion in this field, a striking observation emerged after reading Roche et al. (2021), who found that out of 25 studies on ethnicity and dementia, only 14 included authors or advisors from ethnic minority backgrounds in the analysis process. Interestingly, I only came across Roche et al. (2021) after completing my analysis of both systematic and empirical studies, yet their critique strongly resonates with my findings.

Roche et al., (2021) highlight the dominance of an "outsider" perspective in research, where predominantly White researchers study Black communities without fully engaging with their social and historical contexts. This results in the exoticization of Black experiences, reinforcing stereotypes that portray Black communities as either unaware of dementia or culturally resistant to formal care, rather than acknowledging the role of systemic exclusion in shaping their experiences (Roche,2023).

This critique of the research led me to reflect on knowledge production: who constructs narratives about ethnic minority caregiving, and how this shapes policy and practice (Fernando, 2012).

As a Black British researcher of African descent training in Clinical psychology in a western institution, I am acutely aware of how my positionality shapes this work. My academic training in dominant epistemological frameworks inevitably influences my perspectives, even as I critique them. Adopting a reflexive stance central to qualitative inquiry rooted in social constructionism (Berger & Luckmann, 2011) has been important part of my role in knowledge production and dissemination.

This is not to dismiss existing research but to emphasize that knowledge is dynamic. There is no singular “truth”; research must remain open to critique and expansion. This reflection underscores the necessity of reflexivity in challenging Western-centric models that obscure the complexity of ethnic minority caregiving (Spivak, 1988)

Summary of the portfolio findings:

The systemic review finding

The systematic review explored how ethnic minority informal caregivers of older adults with neurological conditions in Europe make sense of their experiences. Three overarching themes were identified: 1), Caregiving as an identity reinforcer (2) Balancing identities, expectations, and traditions; and (3) Fulfilment and reconciliation of historic and current life narratives.

The findings highlighted that within ethnic minority communities, caregiving served a function in upholding and preserving cultural identity in European context. Moreover, findings highlight the complex and often conflicting expectations caregivers face. Younger generations, expressed feeling of being torn between traditional family obligations and their own personal aspirations, reflecting the challenges of navigating caregiving within evolving cultural contexts.

The findings highlight that caregiver grappled with these conflicting expectations, demonstrating how younger generations engage in acculturation processes that reshape caregiving practices. For many, the definition of “good care” is shifting. Rather than providing direct hands-on care, younger caregivers increasingly view securing professional support as an act of fulfilling their duty (Van Wezel et al., 2016). This reinterpretation of caregiving does not necessarily signal a rejection of cultural values but rather an adaptation that reflects changing healthcare systems, economic realities, and evolving personal and professional commitments.

Faith emerged as a common source of strength, with many caregivers turning to prayer or framing caregiving as a spiritual responsibility. The review also captures culturally embedded coping mechanisms that continue to shape caregiving practices across different communities. Strategies such as “keeping it within the family” among Eastern European caregivers , “walk on by” and “we look after our own” in Caribbean communities (Baghirathan et al.,2020), and “keeping face” in Chinese communities reflect long-standing traditions that govern how support is mobilized(Baghirathan et al.,2020). Similarly, extended kinship ties remain central within Latin American (Guerra et al.,2024), Greek Cypriot communities (Armstrong,2022), reinforcing the role of collective responsibility in caregiving. These survival strategies, originally developed as mechanisms of resilience during migration, now serve as practical responses to caregiving in environments where formal support remains inadequate or culturally inaccessible.

The empirical study’s finding.

The empirical study explored how African and Caribbean informal caregivers make sense of dementia and navigate support services. Using reflexive thematic analysis, the study identified three key themes: Cultural and generational interpretation of dementia, Love, duty, sacrifice and coping with caregiving role and negotiating and advocating for support. These interconnected themes highlight how African and Caribbean caregivers make sense of dementia, and how their engagement with support systems is shaped by community narratives, generational shifts in undertesting dementia, and systemic inequalities.

The findings indicate a shift from the dominant dementia discourse. Among the older generation, dementia is often framed as a natural part of aging or attributed to spiritual causes. Within this perspective, caregiving is seen as a familial or religious duty, expected to be upheld by family members or trusted individuals within the community network. This reinforces collective responsibility, cultural values, and traditional caregiving practices, ensuring that care remains embedded within familiar and culturally meaningful frameworks.

In contrast, younger caregivers, particularly those exposed to Western education, professional settings, and digital resources ("Mr. Google is our friend"), and had greater acceptance of biomedical understandings of dementia. However, they do not fully reject traditional beliefs but instead negotiate between insider (traditional) and outsider (biomedical) knowledge. They navigate the tension between viewing dementia as a spiritual or aging-related phenomenon and contemporary biomedical discourses that emphasize formal diagnosis. While they are more likely to seek external support, they do so selectively, often balancing community expectations with the realities of their own professional and personal obligations.

Despite these shifts, cultural values remain deeply embedded in caregivers’ motivations and sense of identity. However, historical mistrust in formal healthcare systems, shaped by past negative experiences and a lack of culturally competent services, reinforces reliance on community-based support networks (Baghirathan et al., 2020). For older generations, these networks provide a trusted space for guidance and caregiving support. However, younger caregivers, who are more engaged with formal services, often experience tensions between cultural expectations and their own caregiving realities.

In response, many caregivers construct hybrid care models, blending family-based caregiving with selective engagement with external services. They advocate for culturally aligned support workers to ensure that external support complements rather than disrupts their caregiving approach (Guerra et al., 2024). These findings highlight the ongoing negotiation between tradition and adaptation, demonstrating how African and Caribbean caregivers reshape caregiving practices within the realities of migration, generational change, and systemic barriers in healthcare.

Combined Discussion with wider literature

This section discusses the evolving narrative of dementia sense-making within the African and Caribbean community, situating the findings within the wider literature. To contextualize the role of caregiving in identity preservation, the discussion engages with broader theoretical and research frameworks, drawing on key theories of identity to highlight how caregiving fosters cultural continuity and self-preservation.

Additionally, this section presents the generational tensions emerging from the systematic review and the empirical study, exploring how these tensions reflect shifting cultural attitudes toward dementia care within the ethnic minority communities (Shrestha et al., 2023).

Changing narrative of dementia with the African and Caribbean community.

The empirical study highlights a generational shift in how dementia is understood and negotiated within African and Caribbean communities. This advances the findings of Roche (2023) and Berwald (2015), where dementia within these communities was predominantly described as a "White people's disease." Caregivers in our study indicated that younger generations tend to frame their understanding of dementia within a biomedical discourse, whereas older generations often interpret dementia as either a natural part of aging or as having spiritual causes. Roche (2023) further supports this notion, finding that Black individuals often described dementia as a "distant disease" affecting White populations, a perception reinforced by media representation.

However, our study extends this discourse by demonstrating that younger caregivers are not only reshaping the narrative around dementia but are also actively engaging in research and advocacy to ensure culturally appropriate care for their loved ones. These findings align with Carter et al.’s (2023) study on dementia diagnosis pathways among ethnic minorities in urban areas, which found that second-generation caregivers adopt an "insider-outsider" perspective, navigating healthcare systems with biomedical knowledge while maintaining cultural values. Both our study and Carter et al. (2023) emphasize how these shifting interpretations of dementia influence the timing of diagnosis and access to care.

This finding is significant given evidence suggesting heightened risks of early-onset dementia among African and Caribbean communities (Adelman et al., 2011) and underrepresentation in memory clinics (Tuerk & Sauer, 2015). Together, these findings show that younger caregivers have a position as “knowledge brokers” highlighting the need for targeted interventions that amplify their advocacy while addressing structural inequities such as culturally tailored diagnostic pathways and community-led health initiatives.

However, this recommendation for targeted intervention is not to suggest that disparities and lack of engagement are solely the result of dementia awareness or that having a biomedical interpretation of dementia automatically equates to an "advanced understanding" of the condition. Rather, the goal is to facilitate a pathway to access support that meets the needs of the person with dementia in a way that is culturally relevant and structurally inclusive. Recognizing the role of caregivers as mediators between cultural beliefs and formal healthcare services highlights the necessity of interventions that focus not just on increasing awareness but also on dismantling the systemic barriers that limit access to appropriate care and resources.

Caregiving as Identity Preservation

The findings of this thesis Portfolio systematic review and empirical study suggest that caregiving serves as a means of preserving cultural identity for ethnic minority communities in European contexts. Caregiving, as identified in the systematic review, functions as a site for upholding and connecting with cultural identity, while also preserving the personhood of the care recipient. The latter, the preservation of dignity and personhood was also observed within the empirical findings, where caregivers emphasized prioritizing the dignity and autonomy of their loved ones as a driving motivation. Similarly, Duncan and Smith (2023) found that Black American caregivers view their roles as preserving family identity, cultural traditions, and moral responsibility.

As suggested by Abramsohn et al. (2019), caregiving identity does not emerge in isolation but is shaped by sociohistorical and cultural contexts. Within Black communities, identity may be constructed through inherited narratives of resilience and contemporary caregiving experiences (Duncan & Smith ,2023) . According to Martin and Martin (2002), traditional helping values**,** such as familial cohesion, spiritual orientation, and respect for elders, provide caregivers with a sense of purpose and control in navigating the emotional and practical challenges of their role. These values, they argue, may serve as a counterbalance to historical trauma and social marginalization**,** positioning caregiving as both a duty and a source of empowerment**.**

Drawing on Biographical Theory (Carricaburu & Pierret, 1995), which suggests that when individuals experience significant life disruption such as caregiving responsibilities or adapting to a new cultural environment, they engage in biographical work to maintain a sense of continuity in their identity. Caregiving, in this context, acts as a bridge between past and present**,** helping ethnic minority caregivers integrate their responsibilities into their life narratives while preserving cultural heritage. In unfamiliar societal structures, caregiving can provide a sense of stability, reinforcing traditional values and familial bonds despite external pressures to assimilate (willis,2012).

The preservation of dignity for care recipients, identified in both the systematic review and empirical study, may reflect caregivers' efforts to embed their loved ones in culturally affirming environments. Kitwood's Personhood Model (1997) helps explain why ethnic minority caregivers often turn to familial and community-based caregiving as a way of preserving dignity and identity in the face of healthcare mistrust. Kitwood emphasizes that personhood is maintained through meaningful relationships, social recognition, and an affirming environment that upholds an individual's history, values, and cultural identity. When ethnic minority caregivers choose to care for their loved ones within familiar, culturally embedded spaces rather than institutional settings, they are not only responding to systemic mistrust but also ensuring that the care recipient remains surrounded by people who recognize and affirm their identity.

By maintaining caregiving within the family and trusted networks, ethnic minority caregivers create an environment where cultural traditions, language, and familiar social roles are reinforced, aligning with Kitwood's framework of person-centred care. This caregiving approach ensures that individuals with dementia or other neurological conditions do not lose their sense of self within impersonal institutional settings but instead remain deeply connected to their identity, relationships, and cultural heritage.

Generational tension within caregiving

A key finding from the systematic review is the generational differences in caregiving approaches. Older generations often perceive caregiving as a non-negotiable cultural obligation, deeply rooted in familial traditions and expectations. In contrast, younger caregivers particularly those raised in the host country, are more likely to conceptualize caregiving as a negotiated responsibility or a morally driven filial duty (Shrestha et al., 2023). This shift reflects broader acculturation processes (Berry, 1992) , where younger caregivers redefine caregiving norms, such as associating quality care with securing professional support rather than providing direct hands-on caregiving (Van Wezel et al., 2016).

While caregiving has historically been gendered, with women disproportionately bearing responsibilities (Pinquart & Sörensen, 2006), shifts in gender roles are evident. Men are increasingly assuming caregiving roles, though they often face stigma and have less access to support networks, reflecting persistent social constructions of caregiving as feminine labor (Shrestha et al., 2023). A meta-analysis of 11 peer-reviewed studies by Shrestha et al. (2023) supports this finding, highlighting that younger generations are modifying traditional caregiving expectations, striving for greater autonomy while maintaining their cultural values. However, despite this evolving perspective, caregiving remains a deeply embedded social expectation in many ethnic minority communities. Failure to provide care within the family is often met with community condemnation (Shrestha et al., 2023).

Carter et al. (2023) further explores these tensions, noting that many caregivers from ethnic minority backgrounds are reluctant to identify as "carers", as they view the label as implying a failure to uphold family obligations. This reluctance underscores the complex interplay between acculturation pressures, community expectations, and structural barriers to formal support. Despite these challenges, Black caregivers continue to provide significantly more hours of unpaid care compared to their White counterparts (Wells, 2024).

Research suggests that while Black caregivers report lower levels of emotional burden, they tend to derive more meaning and a greater sense of reward from their caregiving role (Dilworth-Anderson et al., 2020; Roche, 2023). However, findings from the empirical study highlight that caregivers frequently experience emotional toll and physical health impacts, despite finding meaning in caregiving as an expression of familial and religious duty. The empirical study findings further suggest that while caregiving offers a source of fulfilment, it also presents significant stressors, particularly for younger caregivers who must balance work, family obligations, and cultural expectations.

These generational tensions and dual pressures faced by younger caregivers must be understood within the context of the increasing prevalence of dementia in ethnic minority communities, which is projected to rise sevenfold in the coming decades. Given that ethnic minority caregivers often provide more intensive care while simultaneously managing employment, the emotional, physical, and financial toll of caregiving is expected to increase significantly.

Findings from the empirical study reinforce these concerns, as caregivers frequently reported experiencing emotional distress and physical health impacts despite deriving meaning from their caregiving role. The systematic review and empirical findings together suggest that while caregiving can be a fulfilling experience, it also presents considerable challenges, particularly for younger caregivers navigating multiple responsibilities. Some caregivers from the study reported using counselling and support services to manage caregiver stress, raising the question of how effective such interventions are in alleviating caregiver burden among ethnic minority communities.

Critical Evaluation of the Empirical Study

The empirical study quality assurance was guided by Yardley's (2000) four principles of quality in qualitative research: sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance.

Sensitivity to context. Sensitivity to context is a fundamental principle in qualitative research, requiring attentiveness to the social, cultural, and theoretical frameworks in which the study is situated (Yardley, 2000). In this study, socio-cultural contexts were central to the qualitative approach, ensuring that participants' narratives accurately reflected their lived realities Reflexivity played a key role in this process; the lead researcher engaged in continuous self-reflection throughout the research process, incorporating supervisory discussions and maintaining a reflective diary. Reflexivity is particularly important when conducting research with ethnic minority communities, as researchers must acknowledge their positionality and how it may influence data collection and interpretation (Dwyer & Buckle, 2009; Roche et al.,2021).

Sensitivity to context also involves addressing the power dynamic between the researcher and participants. The study activity sought to mitigate power imbalances that can arise during interviews by fostering an environment of trust and reciprocity. To this end, AE shared her motivations for conducting dementia research and the aims of the current study.

Furthermore, AE critically reflected on her emic (insider) and etic (outsider) positionality, recognizing that this dual perspective presents both advantages and challenges in qualitative research. On one hand, AE’s shared cultural background helped foster trust within the community, encouraging participants to engage openly and disclose personal experiences more readily. On the other hand, this similarity sometimes led to assumed shared knowledge, wherein caregivers provided less elaboration on their caregiving experiences, assuming mutual understanding (Dwyer & Buckle, 2009).

Commitment and rigor. Commitment and rigor were demonstrated through in-depth engagement with the topic, robust data collection, and systematic analysis. Semi-structured interviews were employed, allowing for a nuanced exploration of caregiving experiences while ensuring flexibility in data collection. This aligns with qualitative best practices, which emphasize the importance of maintaining methodological rigor to capture the depth and complexity of participants' lived experiences (Braun & Clarke, 2022).

Transparency and Coherence. Transparency was ensured through detailed documentation of the research process including interview protocols, reflective diary and keeping audit trail of the analysis process (Appendix F). This aligns with Yardley’s (2000) emphasis on clear procedural transparency to enhance the credibility of qualitative research. Coherence was achieved by aligning the research aims, methodology, and analysis framework. The study sought to explore how African and Caribbean caregivers make sense of dementia and navigate support systems, and the use of Reflexive Thematic Analysis allowed for an in-depth exploration of these lived experiences (Braun & Clarke, 2022). The analysis process was documents and themes were shared with research supervisors and caregivers to confirm the accuracy of interpretations. Caregivers were also invited to review findings and provide feedback, ensuring interpretive credibility and reducing the risk of researcher bias in thematic development (Yardley,2000).

Impact and importance. This study provides novel insights into dementia caregiving within African and Caribbean communities, particularly regarding generational shifts in dementia perceptions and the hybrid use of formal and informal support systems. Given that dementia prevalence in these communities is projected to rise, these findings hold significant implications for culturally responsive interventions. A practical impact of this study is its potential to inform the development of culturally competent dementia care services.

This study provides novel insights into dementia caregiving within African and Caribbean communities, particularly regarding generational shifts in dementia perceptions and the hybrid use of formal and informal support systems. The findings highlight prevailing mistrust of services, rooted in historical injustices, past negative experiences, and culturally incompatible care. This mistrust, coupled with the emotional and psychological impact of caregiving highlight important implications policymakers and services. This is particularly significant given that dementia prevalence in these communities is projected to rise, making it imperative for policymakers and healthcare providers to address these longstanding gaps in care. A key practical impact of this study is its potential to contribute to the development of culturally competent dementia care services and pathways that involve post-diagnostic support for caregivers.

Critical Evaluation of Systematic Review

A key strength of the systematic review is the methodological framework that has been used. To the author's knowledge, this is the first review to use Thomas and Harden's (2008) "thematic synthesis" framework to guide synthesis through a narrative lens (Riessman et al., 2005), to preserve the integrity of the findings from the original studies. There is only one other study, Shrestha et al. (2023), that has examined ethnic minority caregiving experiences within a European context. However, this study employed meta-ethnography, comparing existing studies and reporting on pre-conceptualized ideas rather than generating new synthesis.

As noted by Roche et al. (2021), in their study on the experiences of dementia among Black and African Caribbean adults, an important methodological consideration is who conducts the research and how. Their review found that only 56% (14/25) of studies recruited interviewers who matched participants' ethnicity, and only a limited number involved authors or advisors from Black and African Caribbean backgrounds during analysis.

Taking this into account, a key strength of the systematic review methodology in this study is that narrative and thematic analysis allowed for reinterpretation of the data rather than simply accepting pre-existing frameworks. This approach ensures that the experiences of ethnic minority caregivers are explored through a reflexive and culturally sensitive lens.

One key limitation of this synthesis is the limited availability of studies examining the experiences of informal caregivers of older adults with neurological conditions other than dementia. This review identified only two studies focusing on post-stroke caregiving and one study with a mixed sample, including individuals with misdiagnosed conditions such as dementia. As a result, our understanding of the experiences of these groups remains limited. It is unclear whether their caregiving experiences differ significantly or whether distinct practical challenges and support needs arise in comparison to dementia caregiving.

Clinical Implications

For Caregivers

Findings from the systematic review and empirical study highlight that caregiving is deeply influenced by migration history, community expectations, and identity preservation, particularly for ethnic minority caregivers. While caregiving is traditionally viewed as a cultural duty, shifting social norms create challenges for younger and second-generation caregivers, who must navigate conflicting expectations between cultural obligations and modern caregiving realities.

For younger caregivers struggling with role conflict and identity negotiation, narrative therapy (White & Epston, 1990) may be a valuable intervention. This approach can help caregivers reframe their caregiving experiences, externalizing challenges and developing alternative perspectives that integrate both cultural traditions and personal autonomy. Research suggests that narrative-based interventions can reduce emotional distress, strengthen resilience, and improve caregivers' ability to manage role conflicts (Freedman & Combs, 1996). By redefining their caregiving story, individuals can reduce guilt, stress, and pressure associated with cultural caregiving expectations, allowing them to engage in caregiving on their own terms without feeling forced to choose between tradition and personal goals.

Further evidence supporting the importance of culturally tailored interventions comes from the Culturally Adapted START (STrAtegies for RelaTives) trial, developed by Webster et al. (2023). The original START intervention was first developed and tested in the UK as a psychological support program for dementia caregivers (Livingston et al., 2013). It is a manual-based, therapist-delivered intervention that provides coping strategies to improve caregiver well-being and reduce stress. The culturally adapted version was designed to address the needs of family caregivers from Black and South Asian British backgrounds, making it the first study to tailor and test START for these communities in the UK. Participant feedback indicated that adaptations such as culturally neutral names, ethnically diverse images, emphasis on confidentiality, and acknowledgment of caregiving challenges were beneficial across all groups.

For these interventions to be effective, support services must adopt a framework of cultural humility (Kirmayer, 2021). Cultural humility encourages continuous reflection, self-awareness, and openness to caregivers' lived experiences, recognizing that cultural expectations evolve over time. Services and interventions targeted at caregivers from these communities engage in open dialogue with caregivers, acknowledging that caregiving experiences differ across generations, migration histories, and cultural backgrounds. Research shows that when caregivers feel culturally respected and understood, they are more likely to engage with services, leading to better outcomes for both caregivers and care recipients (Livingston et al., 2013; Webstre et al., 2023).

For care receipt

Dementia services and care pathways should incorporate person-centred integrated care, which has been shown to be more effective in meeting the needs of Black families living with dementia when combined with policies promoting greater inclusivity and diversity in the workforce and service delivery (Chua, 2013; Roche,2023; Kitwood, 1997). Findings from the empirical study and systematic review highlight that care recipients benefit most when services prioritise identity preservation, cultural familiarity, and social connection, aligning with Kitwood's (1997) Personhood Model**.** Findings from the systematic review and empirical study indicate that many ethnic minority caregivers' express reservations about mainstream dementia services adequately meeting their needs in these areas. Person centre dementia care should extend beyond individual focused intervention but to encompass the family , cultural practices, spiritual beliefs, and linguistic needs, ensuring that individuals with dementia remain connected to their identity and life history despite cognitive decline (Kitwood, 1997).

Future research directions

Future research directions can be readily identified from the findings of this thesis, alongside methodological issues that warrant further attention. One key area for future research is the underrepresentation of male caregivers, particularly within ethnic minority communities. Additionally, critical reflection on researcher positionality in qualitative studies on race and ethnicity is essential to ensure more nuanced and culturally sensitive findings. Addressing these gaps can contribute to a more comprehensive understanding of caregiving experiences across diverse populations.

Caregiving has traditionally been associated with women, but men are increasingly taking on caregiving roles due to shifting family dynamics, rising life expectancy, and evolving social expectations (Greenwood & Smith, 2019). However, despite this growing presence, male caregivers remain significantly underrepresented in research, particularly within ethnic minority communities (Shrestha et al., 202) Findings from the systematic review and empirical study highlight this imbalance, with only 29 out of 258 caregivers being male, and only one of the eight included caregivers identifying as male in the empirical study. This underrepresentation suggests a gap in the literature, limiting the understanding of male caregiving experiences, particularly in-migrant communities where gender norms and caregiving responsibilities are deeply embedded in cultural traditions (Shrestha et al., 2023). Future research should aim to explore the unique challenges and experiences of male caregivers within these contexts, ensuring that their perspectives are adequately represented in dementia and caregiving scholarship.

Another critical area for future research is the role of researcher positionality in studies on race, ethnicity, and caregiving (Roche et al.,2021). Rai et al. (2022) emphasize the importance of researchers reflecting on their positionality, particularly when investigating communities with whom they have limited direct experience. The ways in which researchers' backgrounds, assumptions, and biases shape data collection and interpretation are critical factors in ensuring meaningful and relevant findings (Roche et al., 2021). In the context of caregiving research, acknowledging and addressing these challenges can enhance the quality and cultural sensitivity of studies, ensuring that they accurately reflect the complexities of caregiving within diverse communities.

Conclusion

This thesis portfolio explored the experiences of ethnic minority informal caregivers. The systematic review explored the experiences of caregivers of individuals with neurological conditions within a European context, while the empirical study focused on how African and Caribbean caregivers make sense of dementia and navigate support services. Together, the findings highlight a generational shift in caregiving. Among African and Caribbean caregivers, this shift is evident in how dementia is understood and how support services are accessed, while in the European context, the systematic review reveals that ethnic minority caregivers face tensions between traditional caregiving values and host country healthcare norms. This creates a dual identity for younger caregivers an insider (connected to tradition) and an outsider (familiar with biomedical and Western healthcare perspectives). A key overarching theme across both studies is that caregiving serves as a site of identity preservation for ethnic minority communities.

These findings offer valuable insights for policy and clinical practice, particularly in developing culturally competent care that is responsive to the growing prevalence of dementia within these communities. More significantly, this thesis challenges the oversimplification of ethnicity and cultural categorizations in dementia research, advocating instead for a more nuanced, dynamic understanding of caregiving. Achieving this requires greater reflexivity in research design and a commitment to inclusivity, including the involvement of advisors and consultants from the communities being studied.

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Appendices

Appendix A - Instructions for Authors and Formatting Instructions for Neuropsychological Rehabilitation

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Appendix B- ENTREQ

Item	Guide and description	Reported on page #
Aim	State the research question the synthesis addresses	28
Synthesis methodology	Identify the synthesis methodology or theoretical. framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	29 & 33
Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until theoretical saturation is achieved).	29
Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	30 & 31
Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psychINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar), hand searching, reference lists) and when the searches were conducted; provide the rationale for using the data sources.	29
Electronic Search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research and search limits).	29
Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies)	29 & 30
Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	Table 3 & 34
Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications the research question and/or contribution to theory development).	Figure 1

Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	31 & 32
Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	31
Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	31
Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	35
Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings “results /conclusions” were extracted electronically and entered into a computer software).	33
Software	State the computer software used, if any.	29 & 33
Number of reviewers	Identify who was involved in coding and analysis.	30
Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts)	33
Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	33
Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	33
Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations or the author’s interpretation	45-56

Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	45-56

Appendix C -Search Terms

(immigrants OR Ethnic groups OR Minority groups OR minority backgrounds OR refugees OR non-western OR cultural minorities OR multi-ethnic OR BME OR BAME) AND (Informal caregivers OR family care OR Unpaid care provider OR Next of kin OR Significant other OR Spouses OR Daughters OR Sons OR relatives) AND (neurological disorders or neurological conditions OR Dementia OR Parkinson* OR epilepsy OR stroke*) AND (qualitative OR mixed methods)

Appendix D- Example of Initial coding of SR data

Quote Extract	Semantic	Latent	Code
It's your mother. And in Jamaica, no matter where we are, I'm hearing that if they're in trouble, if there's a problem, we jump on the bus and we come home. And we all… look after mum." (Winston, husband) (Strudwick et al., 2010, UK)	Reinforces the idea of shared responsibility and mutual support within the family.	Sense of unconditional love and support for the mother; willingness to make sacrifices.	Cultural framing / familial identity
Perhaps one day myself and my wife will also be forgetful, and if our children do not tolerate us, then who will?" (Caregiver) (Næss et al., 2015, Norway)	Anxiety about future vulnerability and dependence, highlighting fear of abandonment and unacceptability of non-familial care.	Highlights intergenerational caregiving expectations and concerns about abandonment.	Cultural framing / intergenerational caregiving
It is natural to me that I take care of my mom." (Caregiver) (Monsees et al., 2020, Germany)	Caregiving is perceived as an intrinsic part of one's identity, deeply connected to family roles.	Caregiving is seen as a natural stage of life, where reciprocal care is expected.	Cultural framing / family identity
It's always an obligation. I don't see how after everything my grandma has done for me and the way she has cared and loved me […] if I have the opportunity, literally, I can't even put into words how insane I find it not to be able to help her. But it needs to come from you." (Participant 2) (Guerra et al., 2022, UK)	Reciprocation of care received in childhood; caregiving is both an obligation and an opportunity.	Caregiving is a moral duty, embedded in personal values.	Reciprocal care
It is our duty towards our family, we wouldn't get anybody else to come and do it. We will have to do it. We won't hand our family over to anyone else, it's our blood. We'll do it ourselves. We will try as long as we are here. We don't want anybody else to look after our family." (British-Bangladeshi female, age 37, caring for her husband) (Baghirathan et al., 2020, UK)	Emphasizes familial duty and responsibility for care, rejecting external help.	Strong sense of familial obligation and protectiveness, distrust toward external care providers.	Familial, Upholding Identity

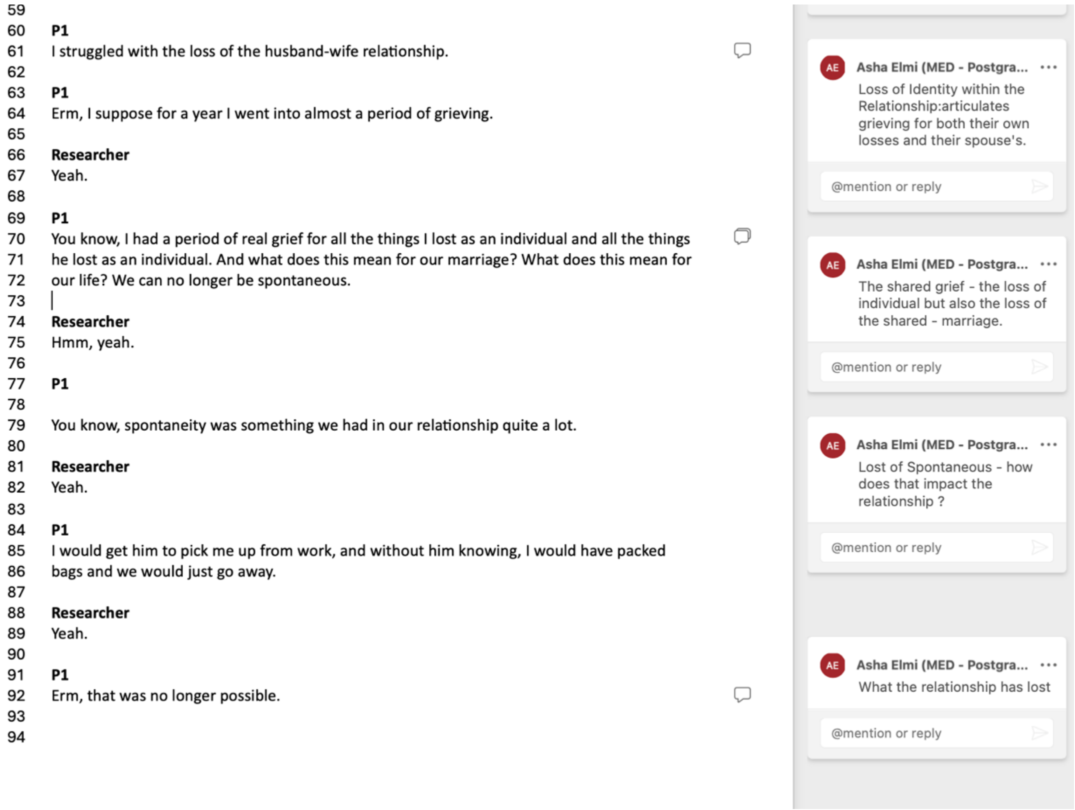
Appendix E- COREQ (COnsolidated criteria for REporting Qualitative research) Checklist.

Item No	Guide Questions/Description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/ facilitator	Which author/s conducted the interview or focus group?	Pg 81
2. Credentials	What were the researcher's credentials? E.g., PhD, MD	Pg 80
3. Occupation	What was their occupation at the time of the study?	Pg 80
4. Gender	Was the researcher male or female?	Pg 80
5. Experience and training	What experience or training did the researcher have?	Pg 80
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Pg 80
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research?	Pg 80
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Pg 83
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Pg 79
Participant selection		
10. Sampling	How were participants selected? e.g., purposive, convenience, consecutive, snowball	Pg 81
11. Method of approach	How were participants approached? e.g., face-to-face, telephone, mail, email	Pg 81
12. Sample size	How many participants were in the study?	Pg 80
13. Non-participation Setting	How many people refused to participate or dropped out? Reasons?	No reported

Item No	Guide Questions/Description	Reported on Page #
14. Setting of data collection	Where was the data collected? e.g., home, clinic, workplace	Pg 82
15. Presence of nonparticipants	Was anyone else present besides the participants and researchers?	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Pg 85
Data collection		
17. Interview guide	Were questions, prompts, and guides provided by the authors? Was it pilot tested?	Pg 82
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Pg 82
20. Field notes	Were field notes made during and/or after the interview or focus group?	Pg 82
21. Duration	What was the duration of the interviews or focus group?	Pg 81
22. Data saturation	Was data saturation discussed?	Pg 3, Pg 14
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Pg 81
25. Description of the coding tree	Did the authors provide a description of the coding tree?	Pg 82
26. Derivation of themes	Were themes identified in advance or derived from the data?	Pg 82
27. Software	What software, if applicable, was used to manage the data?	Pg 81 & 82
28. Participant checking	Did participants provide feedback on the findings?	Pg 83
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g., participant number	Pg 86-102
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Pg 86-102
31. Clarity of major themes	Were major themes clearly presented in the findings?	Pg 86-102

Item No	Guide Questions/Description	Reported on Page #
32. Clarity of minor themes	Is there a description of diverse cases or a discussion of minor themes?	Pg 86-102

Appendix F – Empirical Study analysis process audit trail example



P1
I struggled with the loss of the husband-wife relationship.

P1
Erm, I suppose for a year I went into almost a period of grieving.

Researcher
Yeah.

P1
You know, I had a period of real grief for all the things I lost as an individual and all the things he lost as an individual. And what does this mean for our marriage? What does this mean for our life? We can no longer be spontaneous.

Researcher
Hmm, yeah.

P1

You know, spontaneity was something we had in our relationship quite a lot.

Researcher
Yeah.

P1
I would get him to pick me up from work, and without him knowing, I would have packed bags and we would just go away.

Researcher
Yeah.

P1
Erm, that was no longer possible.

Asha Elmi (MED - Postgra...
Loss of Identity within the Relationship:articulates grieving for both their own losses and their spouse's.

Asha Elmi (MED - Postgra...
The shared grief - the loss of individual but also the loss of the shared - marriage.

Asha Elmi (MED - Postgra...
Lost of Spontaneous - how does that impact the relationship ?

Asha Elmi (MED - Postgra...
What the relationship has lost

Appendix G – Empirical Study Participants Information sheet

African and Caribbean Caregivers Experience Research Project

INFORMATION SHEET

Researcher: Asha Elmi (email: asha.elmi@uea.ac.uk)

Supervisors: Dr AnastasyaShepherd(email:anastasya.shepherd@nchc.nhs.uk)
Dr Fergus Gracey (email:f.gracey@uea.ac.uk)

Why are we doing this research project?

Hello,

My name is Asha, and I am a trainee clinical psychologist of British Somali descent. I am passionate about understanding the healthcare needs of ethnic minority communities and ensuring that professionals and researchers listen to the voices and needs of these communities. As part of my Doctorate in clinical psychology at the University of East Anglia, I am currently working on a research study focusing on the experiences of African and Caribbean family and friends who take care of individuals with dementia.

What will the study involve?

The study involves interviewing individuals regarding their experiences in informally caring for a family member or friend with dementia or memory difficulties, potentially related to dementia. Informal caring involves helping a loved one with dementia with day-to-day tasks such as basic care and shopping. The interview is anticipated to last for up to 80 minutes and will ask about your experiences with caregiving routines, cultural influences, and your perspectives on dementia within your community. With your permission, the interview will be recorded. The interview can be conducted either in person or online depending on your preference. For this study, we do not have an interpreter available. However, if you feel the need for English language support and have family members who can assist, please feel free to bring them to the interview with your consent to interpret. It's important to note that the interpretation process may slightly extend the interview duration.

For online interviews, you will need an email address and access to a computer or smartphone. You will be asked to be in a private and comfortable space to do the interview. If you choose the online option, you can access this information sheet, the consent form, and a form to register your interest to take part via the QR code on the study flyer or by requesting a link from the researcher. Once you've expressed interest in participating, the researcher will contact you to arrange the interview time and date and provide a link for the demographic questions which you will need to complete before the interview.

If you prefer an in-person interview, you can either contact the lead researcher via email or the organisation that you have heard about this research from. The interview will be conducted in a quiet and private space at the organisation from where you heard about the study. This may mean that staff from the organisations you heard the study about may be aware that you are taking part in the study, but they will not know any of the information that you have shared in the interview. Before the interview, you will receive a verbal reminder of the information on this information sheet and the study's purpose. Following this reminder, you will be asked to complete a questionnaire for your demographic information and read and, if comfortable, sign consent to take part in the study.

Why am I invited to join this study?

It is completely up to you whether you decide to take part in this study. This document is here to provide you with more information about the research and give you the opportunity to decide whether you want to participate. If you happen to be caring for someone who has memory problems or dementia, this study could be relevant to you.

What if I change my mind?

Your agreement to join the study is voluntary, and you are under no obligation to participate or complete the interview. You have the right to withdraw from the study up to two weeks after your interview. Please keep this in mind while making your decision to participate in the study.

Are there any risks?

We do not expect any risks to you by participating in this study. However, we will discuss things that some people might find sensitive or hard to discuss. Our researcher is experienced and will be sensitive to your feelings. If you get upset, you can take a break, continue the interview later, or withdraw from the study.

If you prefer attending an in-person interview and have any health difficulties, please note that you can attend the interview with a face mask to reduce the risk of infection.

What are the benefits of taking part?

As a thank you for your time, you will receive a £20 high street shopping voucher. We hope that the findings will help professionals better support people caring for those with dementia in the African and Caribbean communities. Once the data is analysed, we will provide feedback to the community organisations that worked with us. If you want the study's results, please express your interest to the researcher, and we will arrange to send you feedback.

Will my information be kept private?

We prioritise keeping all your information completely private and secure. The interviews will be held in a confidential space, and any information you share with us will be carefully stored in encrypted computer storage at the university. Your privacy is important to us, and we will only disclose your information if we have concerns about your safety or the safety of others around you.

Appendix H – Study Poster

University of East Anglia

VOLUNTEERS NEEDED

AFRICAN AND CARIBBEAN CAREGIVERS EXPERIENCE OF DEMENTIA RESEARCH PROJECT

Your Voice Matters

Hello

I am Asha, the lead researcher on this project. I am passionate about understanding the healthcare needs of people from ethnic minority communities and ensuring that professionals and researchers actively listen to and address the voices and needs of these communities.

Who we are looking for?

- **Are you over the age of 18?**
- **Do you self-identify as African or Black Caribbean?**
- **Do you care for or have a family member or a friend with dementia or age-related memory difficulties?**

What does the study involve?

- **You will have 1-to-1 interview with the lead researcher about your experience of caregiving**
- **You can choose to do this interview online or face to face**
- **As a token of our appreciation for your time, you'll receive a £15 voucher**

What is the research about?

We want to learn from African and Caribbean caregivers about their experiences and understanding of dementia or memory issues that might be related to dementia.

How can I get involved in the research?

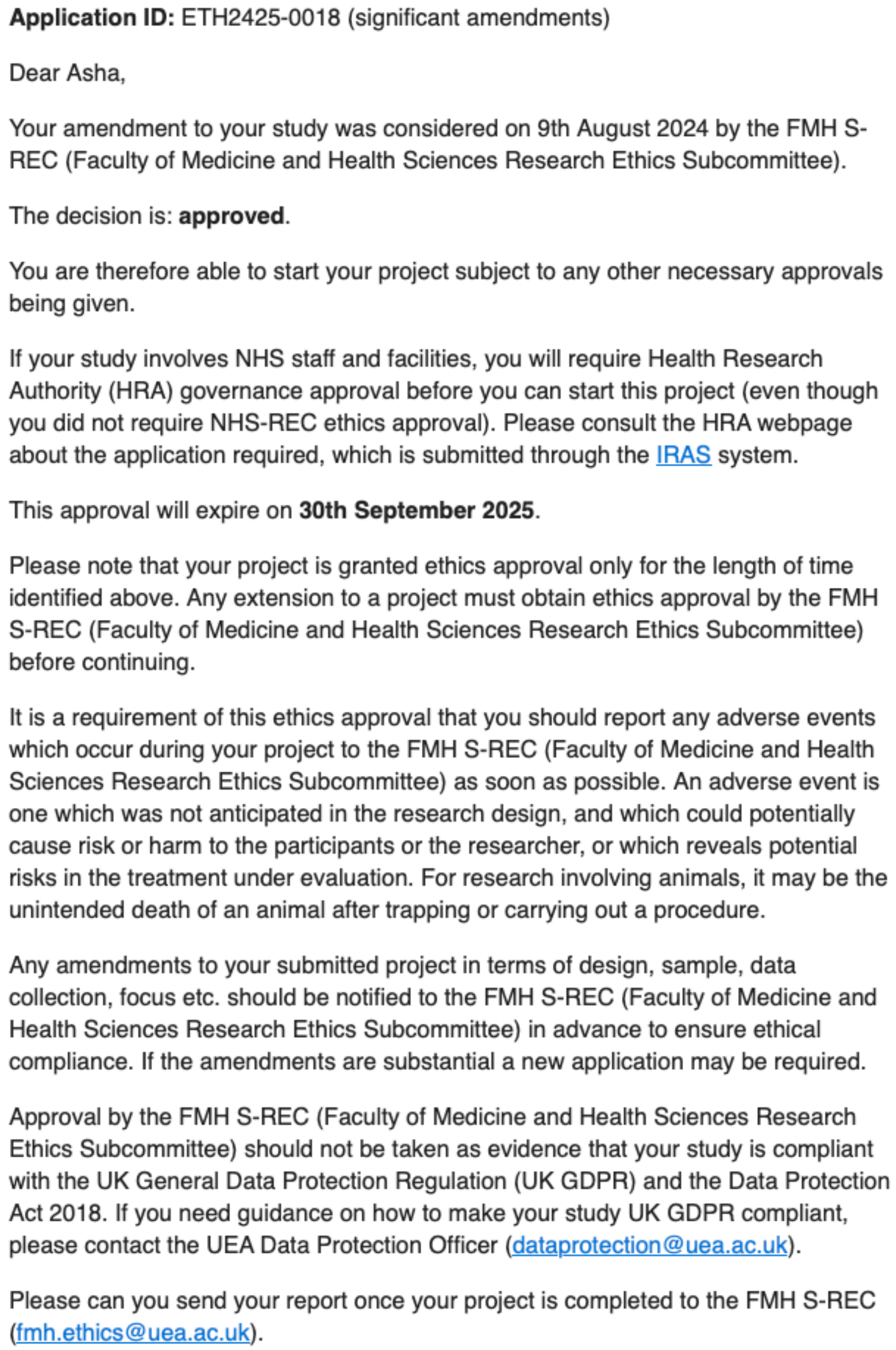
If you want to take part in the research or if you have any questions, email Asha Elmi at asha.elmi@uea.ac.uk

You can also register your interest by scanning the QR code or copy and paste the link below into a browser.

Scan to resigner for the study
and more information

HTTPS://FORMS.OFFICE.COM/E/TUNSERAE7KB?ORIGIN=LPRLINK

Appendix I - Ethical Approval for Empirical Study



Application ID: ETH2425-0018 (significant amendments)

Dear Asha,

Your amendment to your study was considered on 9th August 2024 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

The decision is: **approved**.

You are therefore able to start your project subject to any other necessary approvals being given.

If your study involves NHS staff and facilities, you will require Health Research Authority (HRA) governance approval before you can start this project (even though you did not require NHS-REC ethics approval). Please consult the HRA webpage about the application required, which is submitted through the IRAS system.

This approval will expire on **30th September 2025**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.

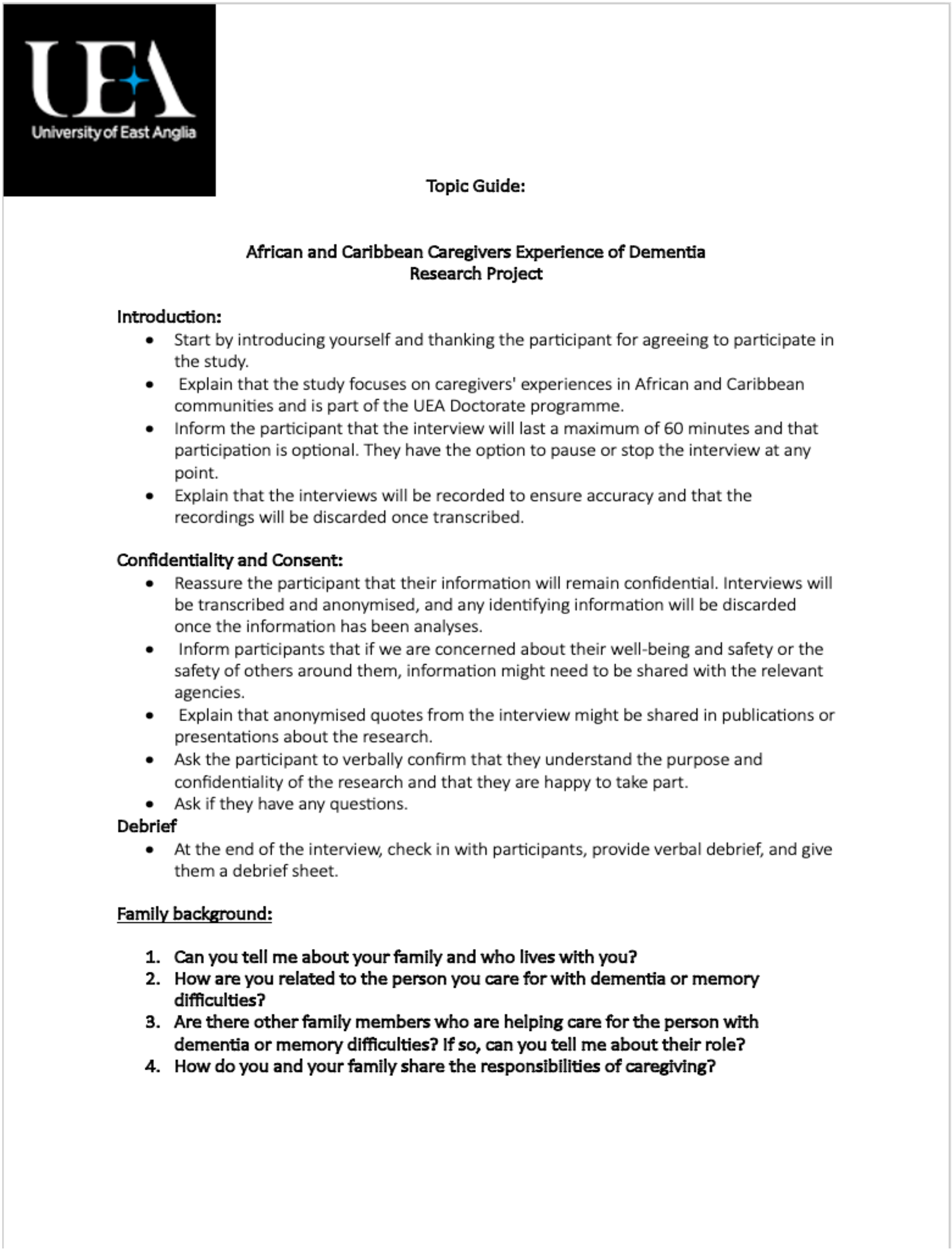
It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).

Please can you send your report once your project is completed to the FMH S-REC (fmh.ethics@uea.ac.uk).

Appendix J - Topic guide



Topic Guide:

African and Caribbean Caregivers Experience of Dementia Research Project

Introduction:

- Start by introducing yourself and thanking the participant for agreeing to participate in the study.
- Explain that the study focuses on caregivers' experiences in African and Caribbean communities and is part of the UEA Doctorate programme.
- Inform the participant that the interview will last a maximum of 60 minutes and that participation is optional. They have the option to pause or stop the interview at any point.
- Explain that the interviews will be recorded to ensure accuracy and that the recordings will be discarded once transcribed.

Confidentiality and Consent:

- Reassure the participant that their information will remain confidential. Interviews will be transcribed and anonymised, and any identifying information will be discarded once the information has been analyses.
- Inform participants that if we are concerned about their well-being and safety or the safety of others around them, information might need to be shared with the relevant agencies.
- Explain that anonymised quotes from the interview might be shared in publications or presentations about the research.
- Ask the participant to verbally confirm that they understand the purpose and confidentiality of the research and that they are happy to take part.
- Ask if they have any questions.

Debrief

- At the end of the interview, check in with participants, provide verbal debrief, and give them a debrief sheet.

Family background:

1. **Can you tell me about your family and who lives with you?**
2. **How are you related to the person you care for with dementia or memory difficulties?**
3. **Are there other family members who are helping care for the person with dementia or memory difficulties? If so, can you tell me about their role?**
4. **How do you and your family share the responsibilities of caregiving?**

Experience of caregiving:

5. Can you describe a typical day for you as a caregiver?
6. Are there any traditions or beliefs in your culture that affect how you care for your family member with dementia or memory difficulties?
7. What would you say was the positive aspect of caring for a loved one and what aspect you would say was challenging?
8. How do you cope with the challenging aspect of caregiving?

Views and understanding of dementia:

9. How does your family feel about caregiving and the issues related to dementia and ageing?
10. How do people in your community talk about and understand dementia and memory difficulties that come with old age?

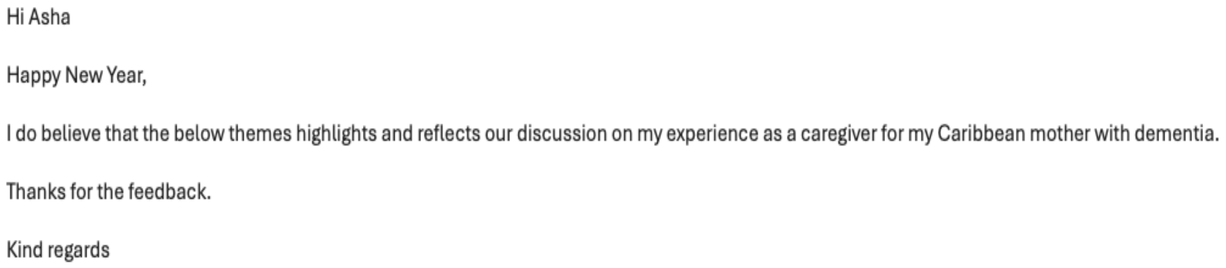
Formal caregiving and use of professional services:

11. Do you think that caring for a family member with dementia has impacted you or your family members emotionally, financially, or socially?
12. What kind of support do you think someone impacted by caregiving responsibilities would need?
13. (If no services are mentioned, ask where this support would come from- professional or community?)
14. How do people in your community view getting support for caregiving responsibilities?
15. Has your family member received any professional support for their difficulties?
16. If so, what kind of support services have they used?
17. Is seeking professional support common within your culture?
18. What could encourage someone in your community to seek professional support for their caregiving responsibilities?

Closing thought:

19. Is there anything else you would like to share or any additional insights you believe are important for the study?

Appendix K – Participants Feedback



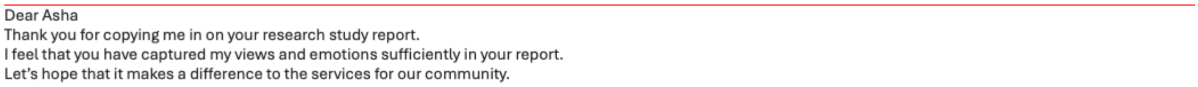
Hi Asha

Happy New Year,

I do believe that the below themes highlights and reflects our discussion on my experience as a caregiver for my Caribbean mother with dementia.

Thanks for the feedback.

Kind regards



Dear Asha
Thank you for copying me in on your research study report.
I feel that you have captured my views and emotions sufficiently in your report.
Let's hope that it makes a difference to the services for our community.