Caring for a relative with dementia: Navigating racism and cultural expectations

An interpretative phenomenological analysis

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Abstract

Background: Due to the increasingly ageing and rapidly growing population, rates of dementia are predicted to continue to rise over the next 30 years. Evidence suggests that people from Black African and Caribbean (BAC) communities are at increased risk of being diagnosed with a label of dementia. In the UK, dementia policy emphasises providing support to enable people with dementia to live in their own homes with the support of family carers. The current research seeks to explore the meaning BAC familial caregivers attribute to the experience of looking after a relative with dementia. In addition, this study explores how historical experiences of racism can present in dementia and the understanding of this experience from the perspective of familial caregivers. **Method:** This qualitative study used semi-structured interviews to explore caregiving experiences with eight participants. The transcripts were analysed using interpretative phenomenological analysis (IPA). **Results:** Three group experiential themes (GETs) and six subthemes were developed, guided by the exploration into how BAC familial carers make sense of their experience looking after a relative with a label of dementia. Overall, the themes illustrate the complexities of caring for a relative with a label of dementia against a milieu of tension at the intersection of care, culture, ethnicity, and community. Participants shared their experience of witnessing their relative re-experience memories of racist incidents, which was understood to be an enactment of a longing desire for safety and happiness in a country with which they had a complicated relationship. **Conclusion:** Clinical and broader implications of the research findings are presented, and considerations are made for future research to advance understanding of this subject.

Keywords: Dementia, Familial Carer, Trauma, Racism, Cultural Expectations, Interpretative Phenomenological Analysis

Abbreviations & Acronyms

BAC – Black African and Caribbean

BAME - Black, Asian, and Minority Ethnic

BLM- Black Lives Matter

BME- Black and Minority Ethnic

BPSD- Behavioural and Psychological Symptoms of Dementia

CASP - Critical Appraisal Skills Programme

DSM- Diagnostic and Statistical Manual of Mental Disorders

GDPR- General Data Protection Regulation

GET – Group Experiential Theme

ID - Identification

IPA - Interpretive Phenomenological Analysis

JBI - Joanna Briggs Institute

LUUUTT – Lived, Untold, Unknown, Unheard, Told, Telling

NA – Narrative Analysis

NHS – National Health Service

PET – Personal Experiential Theme

PTSD – Post-traumatic Stress Disorder

PWLD – Person with a Label of Dementia

SPIDER - Sample, Phenomenon of Interest, Design, Evaluation, Research type

TA – Thematic Analysis

UK – United Kingdom

USA/US – United States of America/United States

UN – United Nations

WHO – World Health Organisation

Glossary of Key Terms

Culture: A fluid and unbounded concept whereby there are simultaneous and reciprocal interactions between individuals, institutions and groups in society to develop networks of thinking (Brown et al., 2012). The dynamic nature of culture means that if one were to immigrate, one could embrace the new majority culture while also embracing the culture from their country of origin (Brown et al., 2012).

Dementia: An umbrella term used to describe a collection of symptoms caused by changes to the brain. Dementia is a progressive condition which can impact memory, thinking, language and behaviour, as defined by Alzheimer's UK. Dementia can also be understood from a psychological lens as the weakening of the ego (psychodynamic) or the loss of the public self (sociocultural). This research is grounded in biological, social and psychological conceptualisations of dementia.

Elder: In this thesis, elders are older adults with a respected position in their family or society, as defined by the Cambridge Dictionary.

Ethnicity: A multi-dimensional social-political construct based on shared historical, social, and cultural identification (Agyemang et al., 2005; Ford & Kelly, 2005).

Race: Defined as a categorical classification based on shared physical attributes, the term 'race' carries significant social, historical and political baggage (Egede, 2006). While race is a social construct with no basis in biology, the term race in this thesis refers to the characterisation of people based on their physical appearance (Fernando, 2012). The term 'Black African and Caribbean' (BAC) people has been used throughout this thesis to acknowledge the heterogeneous Black community in the UK.

Racism: Within a racialised system, racism can be defined as actions that lead to a difference in power between racialised groups, specifically actions against groups viewed as inferior (Adkins-Jackson et al., 2023; Trawalter et al., 2020).

Whiteness: The invisible racialised advantage which posits those with darker skin as inferior (Patel, 2021) while positioning the experience of White people as the norm.

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Chapter 1: Introduction

Chapter Overview

This chapter provides the conceptual framework underpinning the phenomena of interest, the experience of Black African and Caribbean (BAC) people caring for a relative with a label of dementia. I begin by presenting my position and relationship to the research topic and provide an overview of key terminology to establish a shared understanding of terms and concepts presented throughout this research. This is followed by an introduction to the term 'dementia' and an outline of the historical and current conceptualisations of this label, with an explicit focus on presentations of dementia in BAC communities. There is specific consideration of the ways trauma can present in dementia and an introduction to racialised trauma. The chapter continues with an overview of caregiving experiences in dementia and the intersection with healthcare services. Throughout this chapter, I have contextualised the knowledge presented by grounding it in the socio-political climate, considering the ongoing impact of power and Whiteness on BAC communities in the UK.

Reflexivity: Researcher Background and Biases

Drawing from Olmos-Vega et al. (2022), reflexivity can be defined as the continuous, collaborative, multifaceted process whereby researchers demonstrate awareness and critique of their subjectivity and context throughout the research. Following this, I aim to invert the analytic gaze throughout this research by examining the influence of my social and political standing.

I approach this study from a subjective viewpoint as a Black woman, born and raised in Northwest London by two working-class first-generation immigrant parents from West Africa. I acknowledge that my life experiences, specifically experiences of racism, have shaped my understanding of the research. I also acknowledge my relatively privileged outsider position in that I have no experience of caring for a relative with dementia.

From a young age, my paternal grandmother cared for me at home while my parents worked full-time. I developed an appreciation for her wisdom and patience, and these early experiences, combined with West African cultural values, shaped my beliefs about ageing and elders. My parents' West African upbringing inspired the collectivist culture privileged in my family. Growing up in a collectivist culture led to developing beliefs about the importance of family connectedness, respecting elders, and the wealth of knowledge they offer. These perspectives remain today and were imperative in influencing my decision to focus on the experiences of Black elders with dementia.

As a second-generation immigrant, I am positioned as an insider to relatives with the distinct experience of growing up in Black British culture with parents who immigrated to the UK. As an insider to Black British culture, I was aware that as a researcher and trainee clinical psychologist, this may position me as privileged and distant from the experience of relatives who aptly feel mistrust towards those in positions of power and privilege. These reflections influenced my approach to participant recruitment and data collection, which are detailed further in the Method chapter. Having experienced covert and overt forms of racism, I was inspired to provide a space for relatives to share these experiences in the context of dementia caregiving.

Terminology

Throughout this study, conceptualisations of race, racism, culture, ethnicity, and trauma are presented. Appendix 1 depicts a concept map illustrating the frame in which this thesis is rooted. Researchers argue that reflexivity should be critical, and challenge accepted versions of knowledge (Starfield, 2012). In taking a reflexive approach, the dominant narratives behind race, culture, and ethnicity have been considered critically, and this is reflected in the terminology used throughout this research. Ecological systems theory (Bronfenbrenner, 1974) provides a valuable conceptual framework for considering the levels of environmental systems influencing societal discourse around race, racism, culture, ethnicity and trauma. The following section presents a historical overview and critical definitions of key terminology to establish a shared understanding of the use of these terms within the research. There is specific focus on the macrosystem discourses which encompass socio-cultural values and contexts, and how these interact with the chronosystem which considers environmental changes over time. At the heart of these discourses are considerations into the experiences of the person with a label of dementia (PWLD) closely surrounded by their familial caregiver in the microsystem.

Race, Culture and Ethnicity

Our perceptions of race have developed over time, and this process of evolution has continued alongside shifts in social and political thinking (Fernando, 2012). Race, defined as a categorical classification based on shared physical attributes, is a term that carries great social, historical and political baggage (Egede, 2006). People were first categorised according to race in the late 17th Century, and this was related to the emerging slave trade across the British Empire (Trawalter et al., 2020). Race is often considered a biological concept; however, research has found more significant genetic variations within any one race rather than between different races, positioning race as a social construct (Egede, 2006).

Racial classifications were crucial in facilitating the implementation of political agendas, which required the population to be demarcated and divided into specific groups based on group self-identification and social categorisation (Aspinall, 2009). Indeed, racial classification was vital in the formation of the 1965 and 1976 Race Relations Act, which was implemented to address racial discrimination following increasing numbers of people immigrating to the UK (Goodfellow, 2018). However, this vital legislation did not prevent the deeply entrenched systemic racial discrimination that still exists within many aspects of British society today (Goodfellow, 2018). Taken together, the evidence signifies significant limitations to the usefulness of racial categorisations, specifically for people most impacted by discrimination based on race.

Despite shifts in the political landscape, in modern-day multicultural Britain, people continue to be distinguished by their race, a characterisation based on physical appearance (Fernando, 2012). It is now broadly accepted that race is a social construct with no basis in biology; however, the legacy of seeing and thinking about people in terms of their predetermined racial identity persists (Adkins-Jackson et al., 2023). Since 1991, racial classifications have been included in the census and within commonly used health surveys, thus perpetuating a racialised view of diversity and beliefs about the biological constitution of race (Bradby, 2003). However, it could be argued that even if racial categorisations were abandoned, it would be challenging to separate our current conceptual understandings of differences between people from the historical context informing it (Bradby, 2003; Haeny & Polimanti, 2022). As previously mentioned, racial classification and the values attached to this have been critical in informing the ways society operates and thinks about diversity, particularly in the healthcare and criminal justice systems where there is evidence of racial discrimination impacting outcomes (Goodfellow, 2018). These findings suggest that moving away from racial classification may have little impact on systems with ingrained beliefs about the significance of apparent racial differences. My exploration of familial dementia caregiving experiences has, therefore, been grounded in the ongoing and socially salient racial classifications used in Britain today. A key area of concern in the present study is the experiences of familial caregivers navigating systems where there is an undercurrent of racial discrimination (Goodfellow, 2018) and how caregivers make sense of this experience.

In recent years, researchers have suggested transitioning to using the term ethnicity instead of race (Brown et al., 2012). Ethnicity can be defined as a multi-dimensional social-political construct based on shared historical, social, and cultural identification (Agyemang et al., 2005; Ford & Kelly, 2005). In this way, culture can be defined as a series of shared values and beliefs which influence thinking and actions and are transmitted through generations (Haeny & Polimanti, 2022). Like ethnicity, culture is also a fluid and unbounded concept whereby there are simultaneous and reciprocal interactions between individuals, institutions and groups in society to develop networks of thinking (Brown et al., 2012). The dynamic nature of culture means that if one were to immigrate, one could embrace the new majority culture while also embracing the culture from their country of origin (Brown et al., 2012). Thus, consideration of culture and ethnicity is important in the present study for both caregivers and their relative with a label of dementia.

In the UK, the term ethnic is commonly used to refer to people labelled as culturally different from the majority group (Ndoro & Marimirofa, 2004). White British people lean towards seeing themselves as individuals, while descendants of former British colonies are considered to belong to the 'ethnic' group (Mackenzie, 2007). This forms the context in which caregivers featured in this study and their relatives are viewed.

Further, race and ethnicity are often inaccurately used interchangeably (Agyemang et al., 2005). However, while race is viewed as an unchanging characterisation based on physical appearance, ethnicity is dynamic, meaning one's ethnicity can change over time and is not bound by geopolitical boundaries (Egede, 2006). Of note is that self-identification to a racial or ethnic group does not equate to having shared cultural experiences due to individual differences in other aspects such as social class, acculturation, or country of origin (McLoyd, 2004). Combined, these conceptualisations make ethnicity an unreliable concept to measure and use in research (Agyemang et al., 2005). Nonetheless, researchers suggest classifying labels can be beneficial in research when used alongside additional background information describing the participant over and above the predefined category (Roche et al., 2020). For instance, Agyemang et al. (2005) suggest that in research focusing on race-related experiences, the terminology used is significant and should specify the person's country of origin or use other descriptive terms to indicate the distance from African ancestry (i.e., first-generation migrant).

In Britain, terms such as Black and Minority Ethnic (BME) and Black, Asian, and Minority Ethnic (BAME) are used to refer to people racialised as non-White (Darko, 2021). In Government public health agencies, BAME is often used as a noun modifier (i.e., BAME communities) or adjective (Aspinall, 2020). Further, within gerontology studies and beyond, researchers tend to homogenise participant data according to their minority ethnic status, which can pose challenges when interpreting the findings due to the obscuring of multiple cultural nuances, which may have important implications for the findings (Roche et al., 2020). For example, the term BAME can refer to Africans from various parts of the continent, Caribbeans from one or more islands, South Asians including Indian, Pakistani and Bangladeshi, Southeast Asians including Chinese and Japanese, and people from White minority groups such as Roma (Roche et al., 2020). Using the term BAME alone can be simplistic because it removes the person from the additional context necessary to understand their experiences fully. One important aspect of an individual’s experience is their migration history which is explored in the next section.

History of Migration

To understand the context of the relatives with dementia featured in this research, we must first review the history of migration to Britain, including the circumstances surrounding migration from Africa and the Caribbean.

The migration of Black African and Caribbean people is rooted in Britain’s colonial history. Following the end of World War Two, large numbers of Black Caribbean people migrated to Britain to fill post-war labour shortages in skilled and semi-skilled roles (Zembe, 2024). At this time, Black African and Caribbean people were perceived as colonial subjects with the power to disrupt the social cohesion of Britain (Zembe, 2024). As such, the influx of Caribbean migrants was met with mixed responses due to the perceived threat from the increasing non-White population in the UK (James, 1992). Caribbean migrants often faced systemic racial discrimination, resulting in challenges with employment, housing and integration into British society (James, 1992; Hanley, 2022).

Contrastingly, the presence of Black African people in British has been recorded since the transatlantic slave trade, yet increasing numbers of people began to migrate to the UK in the 1960s as most African countries started to gain their independence (Daley, 1998; Domboka, 2018). Due to colonial patterns across the continent, many African migrants spoke English and were motivated to migrate for educational purposes (Domboka, 2018). However, this early African migration was highly selective (Daley, 1998). Accordingly, the gendered nature of the education system combined with the patriarchal African culture facilitated travel for Black African males with their female counterparts, often arriving later to study in fields such as nursing (Domboka, 2018). Despite differences in migration history, Black African migrants faced similar discriminatory practices to Black Caribbean migrants, leading to social and economic difficulties (Daley, 1998).

As a result of the racial discrimination and social exclusion Black African and Caribbean migrants faced, the communities became increasingly segregated from White British communities and formed tight-knit communities with each other for support (Daley, 1998). Despite these challenges, Black African and Caribbean migrants have significantly enriched British culture through education, music, cuisine, and the arts (St-Jean Kufour, 2003).

Our consideration of the factors surrounding migration to the UK and the differences in migration stories for those from Africa and the Caribbean provides important context for the lives of the relatives with a label of dementia included in this study. Understanding the migration history of the BAC relatives featured in this study provides insight into the degree of heterogeneity within this participant group. Thus, while the umbrella term BAC has been utilised throughout this thesis, I am aware of the array of experiences, histories, socioeconomic positions, and cultural and ethnic framings within this group.

Critical Race Theory. Critical Race Theory (CRT) provides a pertinent framework for understanding the intersection between race, racism, and politics. CRT, a legal scholarship that began in the 1980s and was led by pioneering activists such as Kimberlé Crenshaw and Derrick Bell, presents critical views explaining the entrenchment of racism in American law and society (Crenshaw, 2011). Further, intersectionality, defined as a theoretical framework which challenges the limitations of single-issue analysis (Crenshaw, 1989), highlights how the interconnectedness of various aspects of identity, such as race and gender, can intersect to form nuanced experiences. Through an intersectional lens, we can begin to understand experiences of oppression and privilege in societies (Crenshaw, 1989).

Within CRT, there are key tenets, namely that (i) racism is an ordinary, everyday experience, (ii) social justice advances occur when there is alignment with the interest of the dominant groups, (iii) race is a socially constructed concept, (iv) the intersection of different social identities can create unique forms of privilege or discrimination, and (v) storytelling is an important tool to challenge dominant societal narratives and systemic injustices (Ladson-Billings, 2021). While developed based on the culture and history of colonialism in the USA, CRT has since been applied to the UK context. However, critics have argued that CRT has limited application to the UK due to significant differences in England's educational and social conditions combined with the theory's predication on the African American experience (Warmington, 2019). While there are notable differences in migration histories, policies, and racial dynamics in the UK, CRT does offer a valuable framework for understanding the processes underlying oppression and resistance (Warmington, 2019). Nevertheless, it is important to acknowledge that direct application of the tenets of CRT to the UK context requires a critical understanding of the distinct historical and social factors influencing present-day experiences of racial inequality (Bell, 2023).

Racism

While racial classifications in the Western world were historically introduced as a means of categorising human diversity, the racialisation of people has often been weaponised leading to numerous consequences, most notably experiences of racism (Trawalter et al., 2020). Within a racialised system, racism can be defined as actions that lead to a difference in power between racialised groups, specifically actions against groups viewed as inferior (Adkins-Jackson et al., 2023; Trawalter et al., 2020). Over time, racism in the UK has become a deeply embedded system of oppression constructed based on apparent cultural and physical differences between members of society (Hasford, 2016; Khan, 2018).

Racism can be experienced on an individual or institutional level and can be direct or indirect. Personal racism can be thought of as differences in assumptions about intentions and abilities owing to someone's race (Trawalter et al., 2020). Contrastingly, institutional racism can be defined as the differential socioeconomic opportunities and, thus, access to resources for specific racialised groups, which are upheld by various laws, practises and institutions (Trawalter et al., 2020). Historically, racism in the UK presented as overt and violent incidences, however present-day racism is experienced as a covert but continual sense of marginalisation and through subtle displays of 'micro-aggressions' (Parsons, 2021). Micro-aggressions can be defined as frequent, everyday offences and racial insults, which, when compounded, have a significant impact on one's psychological well-being (Shankley & Rhodes, 2020). Several studies have documented the adverse cumulative effects of racial discrimination on physical and mental health outcomes, such as high blood pressure, heart disease, and psychological distress (Stopforth et al., 2022).

Under the Equality Act (Equality and Human Rights Commission, 2010), racism became illegal in the UK, yet the imprint of racism continues to impact multiple facets of society today (Atrey, 2021). Added to this, in the wake of the Black Lives Matter (BLM) protests, following the highly politicised death of George Floyd in the US, the UK published the independently commissioned Race and Ethnic Disparities report (Commission on Race and Ethnic Disparities, 2021) claiming that there is no evidence of institutional racism in the UK. This report was viewed as a critical rejection of the findings from several other reviews that had cited evidence of systemic inequalities, including the Public Health England Review (Scientific Advisory Group for Emergencies, 2020) and the Windrush Lessons Learned Review (Williams, 2020).

While the Race and Ethnic Disparities report (Commission on Race and Ethnic Disparities, 2021) highlighted a reduction in racial disparities in the UK and concluded that the country is not institutionally racist, this view continues to be contested (Pilkington, 2021). An independent review of the Mental Health Act (MHA; 1983) identified that a disproportionate number of BAC people were detained under the Act, citing complex factors associated with this disparity, including racism and systemic issues (Wessely, 2018). Nonetheless, the documented tensions in naming systemic racism have impacted on people experiencing differential treatment due to their race. Evidence suggests that BAC people grapple with labelling experiences as racist in a society where the existence of racism is denied, and this can impact people's ability to heal and move forward from these experiences when there is a lack of systemic accountability (Haines, 2019). This thesis is, therefore, rooted within this tension in labelling experiences as racist and is specifically concerned with understanding this tension in the context of dementia care provision. Next, we will review the history of racism in Britain to provide further insight into the entrenchment of racism in this context.

History of Racism in Black Britain. To further understand the context of the BAC relatives featured in this research, we must review the history of Black Britain. Given that the extensive and complex history of racism in the UK exceeds the scope of this thesis, the following section presents a brief overview of the history and key events that provide the context for the experiences of participants, their relatives with a label of dementia, and myself as the researcher.

British history is intricately shaped by their role in colonisation and slavery. Following the two world wars, Black people from British colonies were brought to Britain to help rebuild the country (Parsons, 2021). In 1948, the Windrush ship docked in Essex with Caribbean workers invited to fill post-war labour shortages and build up the newly established National Health Service (NHS), which also started the same year (Parsons, 2021). Subsequently, Britain restricted entry to Commonwealth citizens with the introduction of the Commonwealth Immigrants Act (1962), a legacy which continues to prevail in present-day Britain (Eddo-Lodge, 2017).

As racial tensions continued to rise, Enoch Powell, a British politician, delivered the infamous 'Rivers of Blood' speech warning about the threat posed by immigrants, generating further racial division in the UK. This culminated in the formation of the British Black Panther Party and later outpourings of anger and resentment through actions such as the Brixton riots in 1981 (Taylor, 1984). The riots were a direct response to discriminatory policing against the BAC communities (Taylor, 1984). Many years later, the tragic murder of Stephen Lawrence in 1993 marked a fundamental moment in the history of race, racism, and the battle for equality and justice (Parsons, 2021). The Macpherson report (1999), which was produced following the murder of Stephen Lawrence, identified the role of institutional racism in the police investigation.

Racism and Whiteness in Psychology. The field of science has been influential in developing theories about racism, which have informed clinical psychology practises. In the 1830s, Francis Galton developed the concept of eugenics, the practice of improving the human species by identifying desirable genetic traits (Jackson & Weidman, 2005). Galton infamously interpreted data through a racialised lens and falsely concluded that Black people were inferior in measures of ability and intelligence (Jackson & Weidman, 2005). These theories informed psychological theories about knowledge and intelligence. Further, eugenics has been found to influence scientific understandings more broadly through false beliefs about biological pain differences in Black people (Hoffman et al., 2016).

The ideology underpinning this dominance of Eurocentrism in science and clinical psychology is Whiteness, defined as the invisible racialised advantage which posits those with darker skin as inferior (Patel, 2021). Against the milieu of Whiteness, clinical psychology has been criticised for overlooking culture and racism in the delivery of psychological services (Wood & Patel, 2017). Understanding this context is important for this thesis, given my background as a trainee clinical psychologist aiming to contribute knowledge to the field. In focusing on culture, ethnicity, and racism, this thesis aims to challenge the dominant ideologies within clinical psychology by providing insight into experiences which will inform culturally responsive approaches in macro-level systems working with BAC communities in a dementia caregiving context.

Current Socio-Political Context. Events such as the Brexit referendum (2016), the Grenfell fire (2017) and the COVID-19 pandemic have been critical in uncovering present-day intolerance towards racialised communities. Contemporary research suggests that attitudes towards immigrants operate on two levels, overt and covert and that social desirability bias can moderate the expression of attitude, leading to masking of intolerance for immigrants (Creighton & Jamal, 2020). The rise in right-wing ideology, perpetuated by anti-immigrant government policies, led the way for Brexit campaigns steeped in antipathy towards immigration (Creighton & Jamal, 2020).

The year 2018 was of particular significance in contemporary Britain and the landscape of racism. In 2018, the UK marked the 70th anniversary of the NHS and the Windrush generation's arrival in Britain. At the same time, news of the Windrush descendants' denial of citizenship became widespread (Parsons, 2021). This denial was a direct consequence of the Home Office's Hostile Environment policy (2012), whose harsh immigration rules aimed to force immigrants out of the UK while fostering a sense of mistrust by recruiting public sector workers to enforce immigration checks (Parsons, 2021). Additionally, in 2018, the United Nations (UN) Special Rapporteur paid a visit to Britain to evaluate racism and related intolerance and found that despite the policies to address racial equality, the pervasiveness of racism prevailed (Shankley & Rhodes, 2020). The report signified remarkable levels of institutional and socioeconomic marginalisation of people from racialised communities in different aspects of society, including employment, health, policing and housing (Shankley & Rhodes, 2020). This leads to questions about the usefulness of racism-related policies, particularly given how deeply embedded racism is and how vastly those from racialised communities feel the effects.

Despite the abolition of the 'sus law' in the 1980s, the introduction of stop and search practices has unduly impacted BAC people, specifically men, combined with the disproportionate use of force by police towards BAC communities (Parsons, 2021). Most recently, the death of George Floyd in the US in 2020 sparked worldwide unrest and demands for justice led by the BLM movement (Parsons, 2021). Under the Conservative government in the UK, anti-immigration sentiments continued with the Rwanda asylum plan, which was recently scrapped in 2024 under the new Labour government.

Racism in the UK Healthcare System. Iatrogenesis, of Greek origin, is a term used to describe instances where healthcare professionals or institutions cause harm to the people they are intended to help (Peer & Shabir, 2018). Often, iatrogenic harm is thought of as maltreatment that can be physically seen, such as harm resulting from surgical complications, drug side effects, or medication (Peer & Shabir, 2018). However, iatrogenic harm can also be less obvious and includes differential treatment and poorer health outcomes for racialised communities due to implicit bias exhibited by healthcare professionals and systems (FitzGerald & Hurst, 2017; Black & Calhoun, 2022).

In a political context, race-based discrimination occurring in the healthcare system could be interpreted as a means of social control (Majors, 2020). Over time, challenging experiences of social control can lead to race-based stress and, thus, racial trauma. Within the UK healthcare system, race-based discrimination is prevalent in commonly reported experiences of misdiagnosis of severe mental illness for clients of Afro-Caribbean descent (Comas-Díaz et al., 2019).

Racial Trauma

Racial trauma is a term used to describe the race-based stress experienced by people from racialised communities in response to racial discrimination (Comas-Díaz et al., 2019). Racial trauma can include threats of harm or witnessing racial discrimination towards others (Comas-Díaz et al., 2019). In addition, racialised people who experience overt or covert micro-aggressions over an extended period can develop psychological and physiological symptoms akin to PTSD (Majors, 2020). However, it is thought that the label of PTSD may be limited in its understanding of racial trauma. Traditional understandings of PTSD are based on the experience of a finite trauma in the past, whereas racial trauma is thought to be experienced as an ongoing threat and danger due to frequent exposure and re-exposure to race-based stress (Comas-Díaz et al., 2019; Majors, 2020). In response to the inadequacy of the PTSD label, researchers have proposed several alternative frameworks that can be used to conceptualise nuanced trauma features with clients from racialised backgrounds. These include the continuing traumatic stress model, post-traumatic slave syndrome, battered race syndrome and racial battle fatigue (Majors, 2020).

Another significant aspect of racialised trauma is the intergenerational transmission of the effects of historical trauma, including slavery, colonisation, and genocide (Comas-Díaz et al., 2019). This conceptualisation of racial trauma stipulates that people from racialised communities can be impacted by historical trauma from birth and throughout their lives without having experienced the original traumatic event (Comas-Díaz et al., 2019). Trauma can be transmitted through generations in various formats, such as through culture, family structure and genes (Menakem, 2017). Importantly, intergenerational racialised trauma, similar to other forms of trauma, can present as an embodied response in addition to a cognitive one (Menakem, 2017). An embodied automatic trauma response can appear to others as a reaction disproportionate to the present situation (Menakem, 2017).

Through reading these texts, I began to develop my conceptual framework about racial trauma and how trauma can present in dementia. This framework formed the basis of the thesis in its exploration of the extent to which people with a label of dementia are impacted by previous experiences of racism and how this intersected with the care they received.

Language in this thesis

It is important to acknowledge that despite the above criticisms about race and ethnicity, this thesis, like other research on this topic, will exploit and thus perpetuate the problematic use of these terms (Roche et al., 2023). To mitigate this, I have been mindful of the language used to describe participants. For instance, I use the term ‘Black African and Caribbean’ (BAC) people rather than just Black to acknowledge that I am not referencing a homogenous group. Despite the use of the umbrella term ‘BAC’, I am aware of the heterogeneity within this group in terms of their migration history, sociopolitical standing, cultural and ethnic contexts (see Migration History section). To account for this, wherever possible, I have included information about specific countries or communities to contextualise participants further.

Similarly, I have opted to use person-centred language, including the term ‘person with a label of dementia’ (PWLD) throughout this thesis. This term is in response to ideas proposed by Kitwood (1997), which centred around promoting the personhood of a person living with dementia as a rejection of the stigmatising medicalised approach focused on deficits. Kitwood argued that placing focus on the diagnostic label of dementia can risk dehumanising and reducing the individual to their diagnosis (Kitwood, 1997). By placing ‘label of dementia’ after the individual, I aim to focus on the individual’s unique experiences, relationships, and social context of the person rather than the diagnostic label of dementia. This view is explained further in the social constructionist conceptualisation of dementia presented later in this chapter. Importantly, I am aware of the benefits of diagnostic labelling. For example, a diagnosis of dementia can be a means to access relevant support. However, research has demonstrated that within BAC communities in the UK, a diagnosis of dementia can lead to stigma and stereotyping (Berwald et al., 2016). As such, I was mindful of utilising terminology that shifted the narrative away from dementia and the common connotations attached to this label and focused more on the individual who was being cared for.

Lastly, throughout this thesis, I frequently refer to the experience of racialised trauma. Racial trauma can be understood as the stress-based response of people from racialised backgrounds following experiences of racial discrimination (Comas-Díaz et al., 2019). I have chosen to use the term ‘racialised trauma’ rather than post-traumatic stress disorder (PTSD) due to the limitations in traditional conceptualisations of PTSD as being based on a past traumatic experience. In contrast, racial trauma is considered to be experienced as a persistent threat with ongoing exposure and re-exposure to racial discrimination (Comas-Díaz et al., 2019; Majors, 2020). Thus, this terminology was deemed most appropriate to describe the experiences of relatives with a label of dementia.

Dementia

The following section explores the label of dementia. It begins with a brief synopsis of the history of dementia and how our understanding has evolved to the dominant biomedical discourse utilised today. Alternative conceptualisations of the label of dementia, namely psychological, social constructionist, and sociocultural models are also presented.

History of dementia

The first observations of dementia can be traced back to the Ancient Egyptians, who associated the condition with ageing (Bosco et al., 2019). The term 'dementia' originates from Latin and means "being out of one's mind" (Vatanabe et al., 2020). Early uses of the term date to the Ancient Greek period, where it was understood to be a disease of the elders and was used to refer to all kinds of mental illness (Jellinger, 2010; Ciurea et al., 2023).

By the 18th Century, dementia was viewed as a reversible condition affecting people of all ages and marked by changes in cognition, delusions and hallucinations (Vatanabe et al., 2020). Over the next Century, many scientific and intellectual developments influenced how dementia was conceptualised. Research from that time identified a biological basis for mental health conditions shifting away from beliefs about religious or moral aetiology (Vatanabe et al., 2020). The predominance of a biological understanding of dementia paved the way for Alois Alzheimer's identification of Alzheimer's disease, which he observed as cognitive characteristics including memory, language, and comprehension difficulties (Vatanabe et al., 2020).

In the 21st Century, dementia has become an umbrella term used to classify a group of symptoms characterised by progressive impairment in various areas of cognitive functioning (Vatanabe et al., 2020). Research has argued that the biological definition of dementia used to obtain a diagnosis is less commonly known to the public, where more stigmatising definitions such as “lunacy”, “madness”, or “brainsickness” are privileged (Jellinger, 2010). Nonetheless, as our understanding of dementia has developed, it is no longer considered an inevitable part of ageing, and it is this stance on dementia which has led to the development of palliative medication to manage the condition (Boller & Forbes, 1998).

Conceptualisations of Dementia

Biological Model. According to the biological model, dementia is a neurological disease characterised by cognitive and functional decline and changes in personality and behaviour (Bouchard, 2007). Neuropsychiatric symptoms, also referred to as behavioural and psychological symptoms of dementia (BPSD), are thought to be significant in specific dementia subtypes, including vascular dementia (Desmarais et al., 2020). A person with BPSD may experience disturbances in perception, behaviour, thinking, or mood (Bruneau et al., 2020).

As part of the diagnostic process, a biological conceptualisation of dementia is necessary. Among the latest updates to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-V; American Psychiatric Association, 2013), neurocognitive disorder was introduced to replace dementia. The DSM-V (American Psychiatric Association, 2013) stipulates that neurocognitive disorders are marked by severe impairments of one or more cognitive functions, such that engagement with independent activities is impacted. It is interesting to note that the DSM-V criteria neglect to specify BPSD, which could be interpreted as undermining the importance of neuropsychiatric symptoms in the experience of dementia (Bouchard, 2007). Overall, the medicalised model of dementia, with its focus on deficits, and in conjunction with law, conceptualises the PWLD as a powerless, non-person due to the loss of their sense of self (Behuniak, 2010). This view gives rise to treatment focused on providing medication to manage the body by professionals who may also ascribe to the assumption of non-personhood for the PWLD (Behuniak, 2010).

A key criticism of the biological conceptualisation of dementia is the focus on the individual and on providing medication for the illness, which can lead to placing the onus for the diagnosis on the PWLD (Bond & Corner, 2001). For instance, studies indicate that BAC elders are at increased risk of vascular dementia due to higher incidences of biological risk factors, such as diabetes and hypertension (Truswell, 2019). However, this perspective fails to account for the historical and sociopolitical factors placing the BAC community at increased risk of these conditions (Haines, 2019). By placing focus on the biological narrative as an explanation for increased rates of dementia in specific communities, we de-politicise the inequitable access BAC communities face in obtaining support and resources to minimise these risks, thus placing the onus on the individual (Zubair, 2023). Further, Zubair (2023) argues that shifting blame for inflated rates of dementia to individuals and communities reinforces negative stereotypes and maintains the marginalised position of BAC communities, which subsequently impacts their health. Nonetheless, given the rapidly increasing rates of dementia within BAC communities, it was deemed pertinent to contribute to the evidence base focused on the experiences of this population.

Psychological Models. Despite the dominance of the biological framework in shaping our understanding of dementia, it is important to note that dementia research has not always been dominated by the medicalised approach (Shefet, 2022). It has been argued that the medicalisation of dementia is due to our difficulty in managing the emotional discomfort of ageing and, ultimately, death (Shefet, 2022). Psychological frameworks can also provide explanations for the symptoms of dementia and facilitate our understanding and responses to dementia in a way that centralises the humanity of the PWLD (Kitwood, 1997). Various psychological theories of dementia are presented in the following sections.

Psychodynamic Conceptualisation of Dementia. From a psychodynamic perspective, dementia can be thought of as the result of a weakened ego leading to a behavioural regression, characterised by reliance on instinctual behaviours (Shefet, 2022). Freud defined the ego as an organisation of mental processes related to consciousness that helps us make sense of the world (Freud, 1923). As dementia progresses, the brain and mind deteriorate (Evans, 2008).

A model proposed by Evans (2008) suggests three stages of dementia as guided by psychoanalytic ideas and neurodegenerative processes. In the first stage, the person experiences a loss of external objects, which results in expressions of anxiety and depression. Over time, the ego weakens, and the pleasure principle, responsible for the gratification of instinctual needs, becomes more dominant. The second stage, characterised by loss and depression, occurs as the person begins to lose their capacity for effective verbal communication. Evans (2008) argues that defences, such as repression, are diminished during this stage, and disinhibited behaviours increase. According to this model, the final stage of dementia features further deterioration in verbal communication capabilities, resulting in reliance on early communication strategies such as projective identification, which involves splitting off and attributing aspects of self to an external object.

Behavioural Conceptualisation of Dementia. Behavioural theories enhance our understanding of BPSD, specifically behaviours that challenge. By formulating and demonstrating curiosity about the underlying causes of the behaviours exhibited in dementia, caregivers and healthcare professionals can assist by using targeted interventions to benefit the PWLD (Javed & Kakul, 2023). For instance, the Unmet Needs Model (Cohen-Mansfield & Werner, 1995) posits that as dementia progresses and the PWLD becomes less able to communicate their needs and provide for themselves, they begin to communicate their unmet needs through behaviour. These needs may relate to physical pain or discomfort, mental distress, inadequate social contact or environmental conditions. Moreover, the model states that when experiencing an imbalance between personality and established habits, physical and mental states, and below optimal environmental conditions, the PWLD is more likely to exhibit behaviours that challenge.

While the Unmet Needs Model provides a helpful basis for caregivers to support the PWLD in meeting their needs, one criticism of this theory relates to the challenges in identifying unmet needs. Given that unmet needs are internal, one could argue that it may be challenging to establish and meet the need for a PWLD who is unable to self-report on which need has yet to be met. As such, this model and its ideas would need to be used alongside other sources of information, such as observation or reports from other clinicians, to establish which need is unmet.

Sociocultural Model. Sociocultural influence refers to cultural, social, and psychological influences shaped by group-based values, norms, and ethnic traditions (Byrd et al., 2023). Within racialised communities, research has highlighted individual beliefs and cultural nuances in conceptualisations of dementia. A commonly reported finding in gerontology research is that people in BAC communities view dementia as a normal part of ageing, and it is thought that this view of dementia prevents timely engagement with services (Johl et al., 2014; Tuerk & Sauer, 2015).

However, a recent study exploring barriers to help-seeking in BAC communities offered an alternative explanation. Here, researchers found that several BAC participants viewed dementia as an illness affecting White people as it was not something that they had experienced in their country of origin, or if they had witnessed dementia-related symptoms in another, there were community systems in place to provide support (Berwald et al., 2016). In addition, many participants in the Berwald et al. (2016) study felt forgetfulness was not indicative of an illness, deeming it unnecessary to seek support for these symptoms.

Under the sociocultural approach to dementia, Fletcher (2021) suggests that researchers should demonstrate openness to differences in conceptualisations of dementia, combined with humility about the researcher's beliefs, as this would be beneficial in developing anti-racist (i.e., promoting racial equality) dementia, research which upholds BAC voices and experiences. Fletcher (2021) argues that the different types of knowledge contained within racialised communities are not valued, and thus, people from racialised communities are viewed as deficient in their culturally acceptable awareness of dementia and in need of saving from themselves. This view of deficiency in cultural conceptualisation is demonstrated in Truswell (2016b), where there is an account of an intervention to change views about dementia within Chinese communities, which involved creating a new term for dementia in their native language. It could be argued that developing new terminology involves imposing a Western understanding of dementia while simultaneously showing a lack of appreciation for the language already used to express an understanding of dementia.

Additionally, while researchers have indicated that due to differences in the conception of dementia, there is a reticence to help-seeking behaviour in BAC communities, the consideration of who benefits from knowing dementia is less frequently considered. Fletcher (2021) argues that holding onto systemic beliefs that a dementia diagnosis is universally desirable within racialised communities is overly simplistic. Further, this author claims that outcomes traditionally considered ‘poor’ under the White gaze, including low diagnostic rates, are often not labelled as poor outcomes by the people most affected by these outcomes (Fletcher, 2021). Additionally, it has been argued that when interpreting statistics about help-seeking in BAC communities, it is essential to consider how the historically hostile political and social environments BAC elders would have encountered during their early days in the UK may have shaped their beliefs about healthcare systems (Mackenzie, 2007). For example, the researchers argue that racialised people's memories of xenophobia and racism may impact their desire to engage with healthcare services (Mackenzie, 2007). Altogether, sociocultural views of dementia are valuable in their contribution to dementia conceptualisations within specific communities.

Social Constructionist Model. The social constructionist approach views reality as a construction shaped by social interactions in the world (Bosco et al., 2019). In their conceptualisation of dementia, social constructionists recognise the biological basis of dementia while also acknowledging that cognitive impairment may also be influenced by social factors such as care settings, relationships, or societal responses from others about dementia (Behunlak, 2010). Our opinions and stereotypes about dementia are viewed as being informed by societal views, such as those perpetuated in media reports and the discourse of politicians and policymakers (Bond & Corner, 2001).

Under the social constructionist model, dementia is viewed as the loss of the 'self', specifically the 'public self', which is thought to deteriorate following negative interactions with others (Spector & Orrell, 2010). This loss of self or personhood is thought to occur as a culmination of processes that distance the PWLD to avoid others having to engage with them in their entirety as people (Spector & Orrell, 2010).

In considering the interaction between neurological and psychosocial factors, Kitwood (1997) developed a model of care which aimed to maintain the PWLD’s personhood. He highlighted the importance of maintaining the PWLD’s self-esteem as damage to their self-esteem through acts such as deception or outpacing (i.e., speaking about or doing something at a pace too fast for the PWLD) would lead to a cycle of failure and discouragement (Spector & Orrell, 2010). While the social constructionist conceptualisation of dementia and subsequent focus on person-centred care has led to positive changes in care provision, critics argue that this individualised approach to the dementia experience fails to account for sociopolitical factors (Bartlett & O’Connor, 2007). As a result, research and care have increasingly focused on quality of care and communication and less commonly contributed to our understanding of macro-level issues such as the interaction between class, gender, disability and social structures (Bartlett & O’Connor, 2007).

Through exploring the various conceptualisations of dementia, I have developed an understanding of the complexity surrounding this diagnostic label. This thesis, therefore, has taken a social constructionist approach in framing dementia to encompass biological, social, and psychological theories. Additionally, this research is grounded in sociocultural conceptualisations of dementia from the caregivers’ perspectives in BAC communities.

Dementia in the UK

The World Health Organisation (WHO) estimate that there are 55 million people with a label of dementia worldwide and that dementia is a leading cause of disability and dependency in the older adult cohort (WHO, 2023). Within the older adult population, researchers have identified differences in the prevalence of dementia for people from BAC communities compared to their UK-born White counterparts (Adelman et al., 2011). Critics argue that comparisons between UK BAC elders and their White British counterparts are problematic because they assume the position that being White is the norm and impose the White gaze to perpetuate the narrative of cultural difference, causing a barrier to timely diagnosis and access to care, (Zubair, 2023). Researchers claim it is essential to separate the meanings of race and ethnicity and understand their relation to dementia (Roche et al., 2023).

Nonetheless, due to the progressively ageing and rapidly growing population, it is expected that the prevalence of dementia and the associated costs for caring for a person with a label of dementia will continue to increase gradually over the next 30 years (Schwarzinger & Dufouil, 2022). These statistics posit dementia as a national and global political issue

(Hampson & Morris, 2017), deeming this research into dementia caregiving experiences an important contribution to our understanding of a worldwide issue.

A growing body of evidence suggests African and Caribbean elders are at increased risk of vascular dementia due to higher incidences of risk factors, such as hypertension and diabetes, within this population (Truswell, 2020). It is unclear when and where the relationship between dementia, race and ethnicity originated (Roche et al., 2023); however, it is important to acknowledge who benefits from this association.

Caregiving in dementia

In the UK, few people from BAC communities with a label of dementia live in care facilities, suggesting care is mostly provided by familial caregivers at home (Lillekroken et al., 2021). Indeed, the Living Well with Dementia strategy (Department of Health and Social Care, 2009) encourages support for the PWLD to take place in the community. A recent systematic review highlights the duality of familial caregiving. Caregivers felt the care relationship was valuable and was an opportunity to reciprocate support for a loved one, while also acknowledging the emotional, physical and socioeconomic toll (Lillekroken et al., 2021). In addition, the notion of biographical continuity (Adamson & Donovan, 2005) provides a helpful framework for understanding the circumstances surrounding the uptake of care provision within families. The caregiving experience in BAC communities is explored further in the literature review in the next chapter.

In the UK, little is known about familial dementia caregiving experiences of Black African or Black Caribbean people and how they navigate through care systems. Therefore, the present study is concerned with understanding the meaning attributed to providing care for a relative with dementia and understanding expectations and interactions with services.

Conclusions of Empirical Literature and Aims of the Thesis

This section summarises the macro-level discourses and theories about race, racism, racial trauma and dementia impacting BAC caregivers and their relatives with a label of dementia. This thesis is rooted in a vast conceptual framework highlighting the nuanced experiences of the relatives with a label of dementia against a legacy of migration, marginalisation and racism. To date, research has demonstrated the impact of systemic racism on physical and mental health outcomes (Stopforth et al., 2022). However, there is less investigation into the subtle and nuanced impact of less overt forms of racial discrimination that can also have a lasting psychological impact on people. Further, research has indicated that trauma can present within dementia as the re-experiencing of a primary traumatic event (Bruneau et al., 2020). The present study, therefore, seeks to explore the extent to which a BAC relative with a label of dementia has been affected by primary experiences of racism. I aim to develop an analysis of dementia caregiving experiences, and the sense-making of re-enactments rooted in historical experiences of racism. I hope that this will contribute to advancements in dementia caregiving. This thesis seeks to address critical gaps in our understanding of the intersection between historical experiences of racism and dementia care provision. This study contributes to a growing body of knowledge about the BAC caregiving experience, and the findings from this research will have significant implications for professional practice, specifically in the development of culturally responsive care models. In terms of education, the findings from this study could inform educational frameworks to prepare practitioners to care effectively for the diverse population of people with a label of dementia.

This thesis aims to understand the psychological impact of historical experiences of racial discrimination for people with a label of dementia who migrated to the UK during a time when expressions of racism were commonplace. The exploration of the psychological impact of racism is from the viewpoint of familial carers, where the focus will be to (i)understand the meaning attributed to the experience of witnessing a relative with a label of dementia re-experience an incidence of racism. It is important to note that an additional aim was added partway through the study to broaden the research scope due to participant recruitment issues. Consequently, this thesis also aims to (ii) explore the meaning familial caregivers attributed to the overall caregiving experience.

To summarise, this thesis is rooted in historical psychologically traumatic experiences of racial discrimination and understanding the long-term psychological impact for Black African and Black Caribbean people who (i) migrated to the UK where they were subsequently racialised as Black and experienced racism and (ii) later received a diagnosis of dementia. The aims of this thesis are:

1. To explore how familial caregivers make sense of their relative re-enacting experiences of racism.
2. To explore the meaning familial caregivers attribute to the caregiving experience.

Chapter 2: Review of Literature

Chapter Overview

The following chapter presents a thematic synthesis of existing qualitative research related to BAC familial caregiving experiences for a relative with a label of dementia. Specifically, this literature review seeks to present a summarised understanding of what is known about the experience of caring for a relative with a label of dementia. A second literature review about existing knowledge related to reliving trauma in dementia is also presented. Lastly, the chapter highlights the gaps in the literature, which form the rationale and aims of the current study.

The current research aims to explore (i) the meaning attributed to the caregiving experience for BAC people caring for a relative with a label of dementia and (ii) how familial caregivers make sense of their relative re-enacting experiences of racism. As such, it was deemed essential to separate the research question into its two elements and conduct separate literature reviews for each. This decision was also made due to the dearth of research on caregiving experiences in BAC communities and the limited research focused on the behavioural manifestations of trauma in dementia from the perspective of the caregiver. By conducting the literature reviews separately, there is scope to identify what is known generally about trauma reenactments in dementia, which will allow for the findings in this study about racialised trauma to be compared to a range of trauma presentations.

Literature Review One: Caregiving in BAC Community for a Relative with Dementia

This literature review aimed to explore what is known about BAC caregiving experiences for a relative with a label of dementia. The experiences of informal BAC caregivers have previously been explored through qualitative and quantitative methodologies (Carson & McFarlane, 2024; Whitney et al., 2023). Studies focused on caregivers are deemed a crucial area to explore as research suggests that care for a BAC person with a label of dementia is more likely to take place in their home or that of the extended family (Cloutterbuck & Mahoney, 2003).

A recent systematic review by Lillekroken et al. (2021) identified essential aspects typifying the care experience of ethnic minority groups in Europe. Similar to existing reviews, this was focused on the experience of multiple ethnic groups and aggregated findings in a way that did not consider important ethnic and cultural nuances between people labelled as minority ethnics. In order to tackle the challenge posed by the erasure of cultural differences, the current literature review will focus solely on the experience of BAC familial carers to understand whether there are cultural nuances that feature in their caregiving experience for a relative with dementia. As previously mentioned, culture is a difficult concept to define. Post-modernist paradigms consider culture to be socially constructed, fluid entities entwined with political ideology (Holliday, 2015). Within this postmodern paradigm, this review will consider the impact of culture on caregiving experiences.

Method

This literature review focused on summarising and synthesising literature relating to the question: "What are the experiences of Black African and Caribbean informal carers looking after a relative with dementia?". The review adopted a thematic approach to synthesise qualitative research and present common themes. This approach was considered most appropriate to the research question. In addition, given the view that race and culture are socially constructed, qualitative research provides a broader scope to consider these constructs through the subjective experience.

Search Strategy. The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) framework for qualitative research synthesis (Cooke et al., 2012) was adopted to determine critical aspects of the research question (Table 1). This tool was selected because it suits qualitative research questions well (Cooke et al., 2012).

Table 1

The SPIDER tool

Criterion	Definition
Sample	Black African and Caribbean men and women
Phenomenon of **I**nterest	Dementia caregiving/informal care provision
Design	Interviews, focus groups››
Evaluation	Experiences, views, perceptions, feelings
Research	Qualitative, mixed methods, peer-reviewed

In January 2024, an electronic search of the databases APA PsycInfo, CINAHL, MEDLINE, and Web of Science was conducted. The crucial research question elements identified using the SPIDER tool were used to inform the terms employed during database searches (Table 2). As part of the search strategy, the option 'linked full text' was selected, and the following limiters were applied: articles published in 'English' and in a 'Peer Reviewed Journal'.

Table 2

Database Search Terms

	Search Terms
1.	Black OR Afro Caribbean OR ethnic OR ethnic minorit* OR BAME or BME
2.	Carer OR caregiver OR family member OR relative OR “informal carer” OR Relative
3.	Dementia OR Alzheimer's OR cognitive impairment OR memory loss OR cognitive decline
4.	Experience* OR “lived experience” OR perception OR attitude OR view OR feelings OR “point of view”
5.	1 AND 2 AND 3 AND 4

Inclusion Criteria. Given the review question, qualitative studies presenting BAC participants' experiences separate from those of participants of other ethnicities were included. There were no restrictions on the age of participants. Similarly, there were no limitations to the date of publication or the location of the research. This inclusive approach was employed to include a variety of perspectives. Studies were limited to those published in English due to the time restrictions of the research project.

I acknowledge that the information presented needs to be more extensive as it is focused on peer-reviewed articles and does not draw on BAC knowledge currently held within these communities. As Truswell (2016a) identifies, storytelling is a valued historical and current medium for exchanging information. However, due to limitations in the scope of this research, it was not possible to access this valuable source of knowledge to construct an overview of what is known about BAC caregiving experiences.

Data Extraction. Data was extracted and managed using Mendeley bibliographic software. In total, 891 articles were exported. Article titles were screened, and 55 articles were identified as suitable for abstract review. The screening and selection process is reported in the PRISMA (2009) flow diagram (Appendix 2). Overall, nine articles were identified as meeting the eligibility criteria and thus were included in the review.

Quality Assessment. There has been much debate about how and why one might assess the quality of qualitative research; however, one argument suggests that assessing qualitative research quality can be beneficial in reducing the likelihood of drawing unreliable inferences (Thomas & Harden, 2008). The quality of the studies included in this review was assessed using the Critical Appraisal Skills Programme Checklist (CASP, 2018). The CASP tool does not have an official scoring system but employs a series of questions based on ten principles to appraise qualitative research critically. The quality appraisal of the articles included is detailed in Appendix 3. It is essential to note that studies were not excluded from the review based on poor quality as there is no standardised approach for excluding qualitative research from reviews (Thomas & Harden, 2008). In addition, there may have been reasons for the omission of information, making it challenging to confirm that quality criteria have yet to be achieved.

Each study clearly stated the aim and appropriately utilised qualitative methodology. Qualitative methodology was judged through the use of terms including “experiences”, “attitudes”, “beliefs”, and “perceptions”. All studies justified the research design employed. The majority of studies used purposive sampling to recruit BAC familial caregivers. Three studies reported supplementing their recruitment strategy with snowball sampling (Adamson & Donovan, 2005; Baghirathan et al., 2018; Ramos et al., 2023). Only some studies provided additional justification for their recruitment strategy. For instance, Ramos et al. (2023) stated that their use of network sampling aligned with their aim to achieve a representative and diverse sample.

Interviews and focus groups were most commonly used to explore caregiving experiences. All studies provided information about using a topic guide, and a minority provided additional information about how the guide was developed. For example, Botsford et al. (2012) interviewed a sample of Greek Cypriots and African Caribbean people in the first instance to identify attitudes about the research focus. They used this data to influence the interview schedule questions. Only two studies (Baghirathan et al., 2018; Botsford et al., 2012) presented adequate critical examination of the researcher’s relationship to participants, considered how this may impact results and described their solution to overcome this difficulty. A further three studies provided brief acknowledgement of aspects of identity that may impact the study, but this needed to be developed into more advanced discussion later in the paper. An example of this was found in McLennon et al. (2020), who described the data collection process by the primary investigator, who was Caucasian, and the research assistant, who was African American. The authors state they considered the ethnicity of the researchers during data collection to reduce barriers to participation. However, there was no further detail on these aspects of the researchers' identity, nor was there consideration of how this may have impacted the research process or findings. Additionally, no studies mentioned the use of inclusive practices such as participatory research which may have broadened the perspectives and interpretation of the data.

Seven studies demonstrated satisfactory consideration of ethical issues, for example, by mentioning ethical approval from a university or ensuring participants provided informed consent. The majority of studies used either grounded theory methodology (Adamson & Donovan, 2005; Baghirathan et al., 2018; Botsford et al., 2012; Lawrence et al., 2008) or an interpretive phenomenological approach (Fox et al., 1999; Mars et al., 2017; Ramos et al., 2023; Sterritt & Pokorny, 1998). Most studies provided a sufficiently detailed description of the analysis process and used verbatim quotations to evidence their findings.

All nine studies included statements of findings related to the initial research question about BAC familial caregiving experiences. Each study included a discussion section where the broader implications of the study were considered.

Main Findings

The following section summarises the key findings of the thematic synthesis guided by the steps outlined by Thomas and Harden (2008). By focusing on the papers' results sections, I identified 'key concepts' in the form of verbatim quotations of BAC familial caregivers. I reviewed the data and coded line-by-line in relation to the review question to develop descriptive themes. I went through the iterative process of grouping codes by looking for similarities and differences. Lastly, I developed a new understanding of the data through generating analytical themes, thus moving beyond the original authors' interpretations.

Study Characteristics. This review includes nine papers about studies conducted in the United Kingdom (*n* = 4) and the United States (*n* = 5). Further details about study features are found in Appendix 3. Five papers from the United States pertain to the experiences of

BAC familial caregivers only. One study (Baghirathan et al., 2018) expanded the definition of carers to include informal carers alongside volunteers and staff from a community service organisation.

Ethnicity of Participants and Researchers. Various terms were used across the papers to describe the ethnicity of participants. Altogether, the included studies offer insight into the experiences of 137 participants described as African American ($n = 70$), Black American ($n = 5$), African Caribbean ($n = 52$), or Black Caribbean ($n = 10$). Only one study (Adamson & Donovan, 2005) provided partial insight into participants' background (i.e., country of origin or birth).

Theme One: Bound by Duty. In seven studies, caregivers reported feeling a sense of duty or obligation to care for their relative.

For several participants, the obligation to provide care was due to their filial duty (Mars et al., 2017; Ramos et al., 2023) or part of their ongoing commitment to their spouse (Adamson & Donovan, 2005; Lawrence et al., 2008): "*If a man marry a woman, or woman marry a man, they are committed until death. I knew I was committed and I did not look after her because she had Alzheimer's, no matter what caused it I would*" (African/Caribbean, husband).

Many participants named culture and tradition as key determining factors in their decision to care for their relatives (Adamson & Donovan, 2005; McLennon et al., 2020; Sterritt & Pokorny, 1998). One participant described caregiving as an act which aligned with their values (Sterritt & Pokorny, 1998): "*When you do your part, you'll have nothing to grieve over. You feel sorry,...but your conscience is clear*" (African American).

For others, caregiving fell to them as it was a continuation of their role within the family (Adamson & Donovan, 2005; Fox et al., 1999) or because it was affiliated with their professional identity (Fox et al., 1999; Lawrence et al., 2008). This role continuation was illustrated by one participant in Adamson and Donovan (2005):

> *Well that decision was sort of made, you know, it just happened because I'm the eldest of four and my sister—we lost two sisters, two middle ones, so it's just the first one and the last one who are alive. But I've always been the one, you know, to see to mother's affairs, and so it's been like that. I think as the eldest it was expected of me and because I have been willing* (African/Caribbean daughter)

Theme Two: An Act of Love and Protection. In addition to viewing caregiving as a familial responsibility, several caregivers reported feeling motivated to care as it was an opportunity to show love to their relatives.

For some participants, providing care for their relative was understood as a token of appreciation for the sacrifices their parents had made while they were growing up (Adamson & Donovan, 2005; Mars et al., 2017): "*I guess the main thing that keeps me going is, I know what kind of mother she was, and I know that she did everything possible for us growing up*" (African American).

Similarly, several participants viewed caregiving as a privilege (Lawrence et al., 2008) and reported feeling rewarded by their relative's presence (McLennon et al., 2020; Sterritt & Pokorny, 1998). One participant felt motivated by acting based on how they would prefer to be cared for (Ramos et al., 2023): "*Well, I think about how I would want someone to take care of me and treat me kindly, so this is why I do not mind doing things for my family and helping them*" (Black American, woman).

Caregiving was also expressed as an act of protection for relatives. Some participants felt it necessary to be available for their relative to protect them from harm (Lawrence et al., 2008). For others, their instinct was to protect their relative's dignity (Baghirathan et al., 2018):

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

Theme Three: An Overwhelming and Lonely Experience. While the caregiving experience was often expressed as being bound in a sense of duty or love, for some participants, it was also an overwhelming and isolating experience for various reasons.

Several participants commented on feeling overwhelmed due to being the sole decision-maker (Fox et al., 1999; Ramos et al., 2023). For others, their overwhelm was felt as they were overcome with devastation (Mars et al., 2017) or depression (Adamson & Donovan, 2005). One participant in Mars et al. (2017) shared about the distressing experience of caring alone for someone with a label of dementia: "*Most devastating thing in my life. I had the experience of having to care for someone who in many instances did not remember who you were, who I was. It was extremely difficult*" (African American, husband).

In contrast, some participants expressed feeling they were best placed to be the sole carer as they could guarantee an adequate level of care (Adamson & Donovan, 2005; Ramos et al., 2023): "*I feel fine. Because I know that I am going to take care of him the right way. I am not worried about how he is being taken care of because I am going to be doing the job*" (Black American, woman).

A few participants commented on feeling stuck in their decision to provide care (Botsford et al., 2012) and unable to seek support from other family members (Lawrence et al., 2008). For one caregiver in Lawrence et al. (2008), the feelings of overwhelm were such that they expressed wanting to escape from their caring responsibilities:

> *You know, sometimes I feel like driving away and not coming back, you know. You know, just drive, could be anywhere. You do understand how people could just drive away, because often you hear of people who just disappear and you realise they are not killing themselves, they are just disappearing to start a new life* (Black Caribbean, daughter)

A minority of caregivers expressed having supplementary practical support from siblings to manage caring for their parent (Adamson & Donovan, 2005). Conversely, participants frequently reported feeling unsupported by their extended family (Adamson & Donovan, 2005; Fox et al., 1999; Mars et al., 2017; McLennon et al., 2020). Feeling a lack of support was most commonly due to the caregiver expecting practical support, which was not actioned (Adamson & Donovan, 2005; Fox et al., 1999; Mars et al., 2017), thus shattering the stereotypical image of the close BAC family: "*The family is not this close knitted thing*" (African American, son). For others, there was a prevailing sense that their caregiving efforts were not being acknowledged by relatives (McLennon et al., 2020):

> *Two of my mother's sisters, they are determined that she should be in a nursing home rather than with me. Even now, they have sent letters to the nursing home, they have sent letters to the hospital. They have called Adult Protective Services. I don't know what their problem is, and I don't really care. I'm doing the best I can to take care of my momma* (African American daughter)

Theme Four: Feeling a Sense of Loss. Though some viewed caregiving as rewarding, other participants felt a sense of loss due to their care responsibilities. This loss was expressed in various ways across the studies.

For some participants, there was a sense of loss for the life that they had hoped for (Adamson & Donovan, 2005; Fox et al., 1999; McLennon et al., 2020), as depicted in this quote:

> *You know, because retirement was going to be the time when I was going to be able to do all the things that I wanted to do when I was working. You know, get my house up together, get my garden up together, maybe not tour the world, but, you know, you could get up and go when you feel like it. Or if somebody invites you out at the spur of the moment, you could just go. But now I can't do that and people say to me 'how are you enjoying retirement?' and I say 'what retirement?' You know I've only retired from paid employment, and that is a fact* (African/Caribbean, daughter)

Several participants described feeling the clash caused by having to choose between looking after themselves and their relative (Adamson & Donovan, 2005; Lawrence et al., 2008; Mars et al., 2017; Ramos et al., 2023): "*Now I am getting old. I got back problems. I got so much pain in my arm. All those things because he is heavy. I am 121 pounds. I have to watch over him and watch myself*" (Black American, woman).

For some caregivers, there was a fear of losing their identity: "*I'm an independent person, I'm a very independent Black woman and I...I want to…to stay that way and I'm a bit confused at the moment. I don't know what is best for both of us*" (Black Caribbean, wife).

Additionally, one participant in the Mars et al. (2017) study described the physical and emotional toll of having to run two households:

> *It started off as being quite stressful. She became bedridden and that required lifting, moving, and turning. It was a physical strain on the body and then it was stressful because also I have my immediate family, having to leave my household and having to run two households* (African American)

Theme Five: Religion and Coping. Given the challenges faced by caregivers, several articles reported religion and spirituality as an essential source of strength and support (Adamson & Donovan, 2005; Fox et al., 1999; Mars et al., 2017; McLennon et al., 2020; Sterritt & Pokorny, 1998).

Across studies, participants identified religion as a motivator to persist with caregiving: "*What keeps me going is my faith, I pray a lot*" (African American wife). Other caregivers would pray to God for the strength to cope with the daily challenges of caring for their relative with dementia: "*When I'm tired and frustrated, I pray to God to give me the strength to deal with her*" (African American).

Many caregivers believed that needing to care for their relative was a test from God that could be overcome through faith. This belief was depicted by one participant in the McLennon et al. (2020) study:

> *And God is with me because my mother taught me that God will take care of it, and I feel it in my heart, and I just feel like, as far as I'm concerned, He sent us trials and tribulations, and He will give me strength, through the grace of God. It can be painful, but if you have God. God has helped me through the trials and tribulations. I have to accept it. I have my family, and my church family, and I just try to make her comfortable as much as I can. I just take it a day at a time.* (African American daughter)

Additionally, caregivers found that support from the church was beneficial. One participant in Adamson and Donovan (2005) described the transformative experience of receiving permission from a woman religious (nun) to hold negative views about caregiving:

> *[The catholic church] have helped me tremendously one time when I was really bitter I went down and the nuns were marvellous. Sister Mary was great, she said, 'you're allowed to feel that way', you know, and that really helped me—we had lots of little*

> *sessions just her and me, and she's a great woman and has helped tremendously* (African/Caribbean, daughter)

Theme Six: Navigating Services. Caregivers across the different articles expressed mixed views about the effectiveness of health and social care services.

Several participants shared positive opinions about formal services meeting their needs (Lawrence et al., 2008; Sterritt & Pokorny, 1998). In Ramos et al. (2023), one participant shared the importance of using services to provide respite for familial caregivers:

> *The most important issue in family caregiving is making sure that you know that family, especially the caregiver, has a break. It is best to have given out that support because outside support is important, and when you do not get that, it is like wear and tear on you* (Black American woman)

However, in most articles, caregivers shared negative views of statutory services (Adamson & Donovan, 2005; Baghirathan et al., 2018; Fox et al., 1999; Ramos et al., 2023). These experiences are related to a lack of appropriate cultural care provision, unaffordable care, or differences in care provision dependent on area. One participant in Baghirathan et al. (2018) expressed the challenge of finding affordable, culturally appropriate care facilities in the UK:

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

In the Fox et al. (1999) article, participants shared experiences marked by interactions with unprofessional and rude staff and described the arduous process of arranging support for their relative. One participant shared an experience of feeling judged while trying to arrange support for their parent:

> *Welfare workers are the rudest people in the world…People who work for the State are just rude…They had me characterised when I went in there. They didn't know that I went to try to ask why my mom wasn't getting benefits. But they make you feel like you're beneath yourself. I had never had to deal with them before. I've always worked, I always took care of my kids…I would never want to be involved with [welfare department] again. I refuse to go back there for help ever again* (African American, husband)

Discussion

This literature review aimed to understand the current status of knowledge on the familial dementia caregiving experience for people from BAC communities. Several studies have explored the caregiving experience from the perspective of a BAC family member looking after a relative with a label of dementia. Key features of the BAC familial caregiving experience that emerge from the literature include the cultural duty to provide care, care as an act of love and protection, the isolating experience of looking after a loved one, feeling a sense of loss, the role of religion and coping strategies, and the challenges with navigating services.

This literature review highlights the limitations in our understanding of BAC familial caregiving experiences. There has been much research and discussion about caregiving experiences in the context of culture, specific dementia diagnoses (e.g., Alzheimer's), or a specified relation to the PWLD (e.g., partner, daughter), yet few studies have considered aspects of race or racism within these experiences. Focus on race and racism is an important consideration due to the broader sociopolitical context within which dementia caregiving occurs, as detailed in the conceptual map (Appendix 1). This thesis seeks to expand on the current knowledge base by considering the intersection between care, culture, dementia, and racism, offering a nuanced understanding of how these factors interact from the perspective of a familial caregiver.

Moreover, while four of the nine studies included in this review were based on the experiences of caregivers in the UK, none were focused solely on the experiences within BAC communities. Instead, these studies grouped and compared caregiving experiences with other racialised groups. Additionally, information about participants' country of origin was often omitted, further limiting our understanding of the BAC caregiving experience in the UK. The grouping and subsequent homogenisation of experiences in the UK-based studies featured in this literature review, aligns with research highlighting the challenge of usefully interpreting these findings (Roche et al., 2020).

The homogenising of experiences in UK-based studies contrasted the approach of the US-based studies, which often focused exclusively on the experiences of African American caregivers. However, the culture, experiences and migration histories of people in the USA are disparate to that of the UK, limiting the applicability of these understandings to UK BAC communities.

This thesis aims to fill the gap in the literature by exploring UK-based experiences of BAC familial caregivers for a relative with dementia. The UK-based studies in this review utilised a grounded theory approach to generate theories about the caregiving experience. Given the lack of research into caregiving experiences within the BAC community, the current research aims to delve deep by exploring the sense-making of the idiographic BAC caregiving experience. By focusing solely on BAC familial caregiving experiences, this study aims to identify areas of convergence and divergence within the caregiving experiences of people within these communities. This field of inquiry is important given the inflated rates of dementia experienced by BAC people and the knowledge that a considerable proportion of care is provided by family members (Baghirathan et al., 2018). Providing insight into BAC familial caregiving experiences may lead to changes in statutory services and facilitate the use of practical approaches to support BAC relatives with caregiving responsibilities appropriately. In addition, increased awareness of the BAC caregiving experience in a UK context will provide valuable teaching opportunities for frontline workers.

Literature Review Two: Reliving Trauma in Dementia

This literature review aimed to examine current knowledge about a PWLD reexperiencing trauma. There is a growing body of research highlighting the bidirectional relationship between trauma and dementia (Desmarais et al., 2020). However, less is known about the experience of caring for a PWLD who has a history of trauma. In 2021, I conducted a meta-ethnography to understand what is already known about reliving trauma in elders with dementia (Appendix 4). This thematic synthesis is an updated version of the previous literature review.

Method

The following review focused on synthesising literature guided by the questions: "What is known about the reliving of trauma in dementia?" and "What are the experiences of caregivers supporting someone reliving trauma in dementia?". It is important to note that the review question does not specify a type of trauma, nor is it focused solely on the experience of familial caregivers. This approach was adopted to widen the scope of understanding about this niche phenomenon.

This literature review adopted a thematic analysis approach (Braun & Clarke, 2015) to review existing qualitative research and present common themes. I decided to focus on qualitative research, which is most appropriate to the research question.

Search Strategy. The SPIDER framework (Cooke et al., 2012) was used to define the central aspects of the research question (Table 3) before an electronic search of the APA PsycInfo, CINAHL, MEDLINE, and Web of Science databases was performed.

Table 3

The SPIDER tool

Sample	A person with dementia, a carer for a person with dementia
Phenomenon of **I**nterest	Reliving a trauma in dementia
Design	Interviews, focus groups, case reports
Evaluation	Experiences, views, perceptions, feelings
Research	Qualitative, mixed methods

The search terms are presented in Table 4. As part of the search strategy, the option ‘linked full text’ and articles published in 'English' were selected.

Table 4

Database Search Terms

1. Survivor* OR trauma OR adversity OR stress OR life event* OR PTSD
2. Dementia OR Alzheimer's OR cognitive impairment OR memory loss OR cognitive decline
3. Carer OR caregiver OR family member OR relative OR “informal carer” Or "formal carer"
4. Experience* OR “lived experience” OR perception OR attitude OR view OR feelings OR “point of view”
5. 1 AND 2 AND 3 AND 4

Inclusion/Exclusion Criteria. There was no limit to the publication date, and articles were not limited to those that had been peer-reviewed. I decided to include non-peer-reviewed articles, allowing for consideration of ideas outside of the dominant narrative about dementia and trauma presentations (Wood, 2021). However, I am also aware of the limitations of non-peer-reviewed research, specifically that articles could be deemed less rigorous (Wood, 2021). This challenge was partly managed through conducting a quality assessment for each paper. Articles were excluded if the care recipient did not have a diagnosis of dementia or if there was no mention of participants reliving trauma.

Given the nature of dementia and the ethical issues that have been cited as barriers to including the PWLD in research, it was deemed essential to include papers from the viewpoint of the PWLD in addition to caregivers. Qualitative papers were defined as those characterised by an interpretative paradigm, which included interviews, observational studies, and focus groups. Due to the limited literature on trauma reenactments in dementia, the inclusion criteria also encompassed case series and case reports.

Data Extraction. All data was extracted and managed using Mendeley bibliographic software. The screening and selection process is reported using the PRISMA (2009) flow diagram (Appendix 5). Overall, nine articles were identified as meeting the eligibility criteria and thus were included in the review.

Quality Assessment. The Joanna Briggs Institute (JBI) critical appraisal tools (Joanna Briggs Institute, 2017) were used to assess the quality of the articles included in this review. This tool provides a framework to evaluate methodological quality and bias in case reports and case series, which form the basis of this review. One study used a descriptive and inductive qualitative approach and was assessed for quality using the appropriate JBI checklist. The appropriate JBI critical appraisal tool was used with each article to ensure consistency.

The JBI appraisal tools have no official scoring system but use a range of questions to appraise the quality of research. Questions are answered ‘yes, no, or unclear’ with the guidance stipulating that a ‘no’ response negatively impacts the quality of the research. However, no papers were excluded from this review based on a negative quality appraisal due to the limited guidance supporting the process of excluding qualitative research (Thomas & Harden, 2008). Instead, this review adopts an inclusive approach while being mindful of the unknown impact that this decision may have on the synthesis of results (Atkins et al., 2008). In addition, it is important to note that a poorly rated quality assessment may be due to various factors, including limitations to the quality assessment tool, making it challenging to eliminate studies based on the rating alone.

Each case series provided clear inclusion criteria for the case studies presented. The papers reliably reported the condition (i.e., dementia and trauma) and used appropriate methods to establish these conditions. For instance, Bruneau et al. (2020) presented details about the dementia diagnostic process alongside a formulation with symptoms indicative of trauma. Demographic information for the cases and the clinic sites were clearly reported for each of the papers.

Commonly across all the case series, there was poor reporting of whether all cases of trauma and dementia were being reported or if the case series involved a small, select sample. As a result, it was difficult to ascertain the extent to which dementia and trauma presented within these clinical settings.

Main Findings

The following section summarises the key findings of the thematic synthesis. After reviewing the articles, three themes related to the review questions were identified.

Study Characteristics. This review includes nine papers (Bruneau et al., 2020; Couzner et al., 2022; Craftman et al., 2020; Hamilton & Workman, 1998; Johnston, 2000; Martinez-Clavera et al., 2017; McCartney & Severson, 1997; Ritchie et al., 2021; van Achterberg et al., 2001) detailing observations of PWLD reliving a trauma. Papers were based on observations in the United Kingdom (*n* = 1), United States (*n* = 4), Australia (*n* = 1), Canada (*n* = 2), and Sweden (*n* = 1). Articles consisted of case reports (*n* = 2), case series (*n*

= 6), or descriptive qualitative research ($n = 1$) reporting on the experiences of 24 PWLD ($n = 18$ males) and 24 carers. Further details about study features are found in Appendix 6.

Theme One: Behavioural Expression of Trauma. Across eight of the papers, authors described behavioural manifestations of trauma in response to different triggering situations. The most common observation was of the PWLD being triggered during personal care (Bruneau et al., 2020; Couzner et al., 2022; Martinez-Clavera et al., 2017; Ritchie et al., 2021). Other triggering situations that were noted included being physically restrained (Bruneau et al., 2020), feeling abandoned by carers (Couzner et al., 2022), being in noisy environments (Martinez-Clavera et al., 2017) or the removal of food (Couzner et al., 2022). In the majority of cases featured in the eight papers, the PWLD was referred to services for support following difficulties with verbally or physically "aggressive behaviour". These included screaming, hitting, biting, refusing help, head banging, throwing objects and slamming doors.

Many case studies depicted reenactments by war veterans with a label of dementia relating to situations from their time on active duty (Bruneau et al., 2020; Johnston, 2000; Martinez-Clavera et al., 2017; van Achterberg et al., 2001). For example, Martinez-Clavera et al. (2017) described observations from carers about one veteran who would reenact war scenarios in the care home: "*At times, he appeared to be trying to clear people from the lounge as he believed there were bombs being dropped.*" Other papers described behavioural reenactments related to protection from thieves (Bruneau et al., 2020), escaping a sexual assault (McCartney & Severson, 1997), or situations occurring during the Holocaust (Martinez-Clavera et al., 2017; van Achterberg et al., 2001). Two papers shared a unique observation whereby some reenactments also involved the PWLD speaking in their native language, German (Martinez-Clavera et al., 2017; van Achterberg et al., 2001): "*Shortly after* *admission, she began to have near-constant reexperiencing of her life in the camps and started speaking in German"* (van Achterberg et al., 2001).

Traumatic experiences were also reported to manifest as visual hallucinations (Bruneau et al., 2020; Hamilton & Workman, 1998; Martinez-Clavera et al., 2017). For instance, one case study described how one veteran "*started to have distressful visual hallucinations such as seeing deep holes on his bedroom's floor, Chinese people in the corridor, and a dog urinating on his bed*" (Bruneau et al., 2020).

Theme Two: Distinguishing Between Symptoms: Dementia vs PTSD. Several papers commented on observations about the similarities between behavioural expressions of trauma and behaviours exhibited by people with a label of dementia (Bruneau et al., 2020; Couzner et al., 2022; Craftman et al., 2020; Hamilton & Workman, 1998; Martinez-Clavera et al., 2017; McCartney & Severson, 1997; Ritchie et al., 2021). Authors commonly reported the challenge in distinguishing between PTSD symptoms such as flashbacks, vivid nightmares, severe anxiety, visual hallucinations and BPSD which have similar symptomatology to dementia (Bruneau et al., 2020; Johnston, 2000; Martinez-Clavera et al., 2017; McCartney & Severson, 1997). The impact of the misinterpretation of symptoms was discussed in several papers. For instance, Johnston (2000) discussed the danger posed to caregivers supporting a PWLD who experiences a violent outburst due to cognitive impairment and the reliving of traumatic experiences.

From the perspective of caregivers, Ritchie et al. (2021) described the symptoms of trauma and dementia as being the "*same but different*" due to the heightened emotional expression of PWLD and trauma. This experience was also helpfully summarised by Craftman et al. (2020):

> *There are similarities (between survivors with and without dementia), but it worsens when they (survivors) become demented, clearly . . . Everyone has their memories, but*

when you have dementia, you cannot sort out what is what (a memory recall or an episode in the present time)

For those with co-occurring dementia and PTSD, papers indicate the importance of the formulation in making sense of which symptoms could be explained by each diagnostic label (Bruneau et al., 2020; Couzner et al., 2022; Craftman et al., 2020). Additionally, the family were identified as key in establishing the trauma history, although it was acknowledged that difficult and traumatic experiences were not always shared within families (Craftman et al., 2020).

Theme Three: A Trauma-Informed Approach. In numerous papers, authors argue for the use of a trauma-informed approach to effectively support a PWLD who is reexperiencing trauma (Bruneau et al., 2020; Couzner et al., 2022; Craftman et al., 2020; Martinez-Clavera et al., 2017; McCartney & Severson, 1997; Ritchie et al., 2021).

Several trauma-informed strategies were noted such as staff making adaptations to their approach to provide a safe and trusting environment for the PWLD; reducing triggers by providing gentle touch, being transparent about actions, and being mindful of use of language (Couzner et al., 2022; Craftman et al., 2020; Martinez-Clavera et al., 2017). In the Craftman et al. (2020) study, nursing assistants highlighted the importance of engaging in person-centred care and crucially following the PWLD in their expression of their situation.

Discussion

This thematic synthesis focused on extant literature on the observations of PWLD who have experienced trauma. The papers included in this review provided insight into how trauma can present in dementia, specifically the reexperiencing of traumatic events. Most studies in this area have focused on the experiences of White male veterans (*n* = 7) and have illustrated observations based on PWLD in the USA. Only one paper (Martinez-Clavera et al., 2017) focused on the experiences of PWLD and trauma in UK, demonstrating the extent of the limitations to our understanding of this phenomenon. Further, research on the reexperiencing of trauma in dementia has been mostly restricted to small-scale case studies, which provide a helpful starting point for further research.

In considering the experience of caring for a PWLD reliving trauma, this thematic synthesis has highlighted how little we know. Only two papers provided insight into the experiences of formal caregivers. In contrast, other papers alluded to the experience of family members in their explanation of how the PWLD came to be under their observation. The information provided is beneficial to somewhat advancing our understanding about the necessary support and treatment for a PWLD who is reenacting a trauma, but our understanding is limited. In light of the rapidly increasing rates of dementia and the association between dementia and trauma, further exploration is needed.

The papers included in this review were mostly case studies or series. These allowed for in-depth detailed descriptions of the phenomena (i.e., reexperiencing trauma in dementia), and generated new insights into the interaction between dementia and trauma. However, due to the use of case study methodology, it is difficult to establish whether there was a reporting bias towards verification of the reenactment experience. Few papers reported on rigour processes which may have mitigated against this bias, suggesting further research using different methodologies may be beneficial. Overall, this review has highlighted a crucial gap in our knowledge about the reliving of trauma in dementia.

This thesis aims to fill the identified gap in the literature by exploring the experience of UK-based caregivers in BAC communities who have witnessed their relative with a label of dementia reliving trauma. Most of the existing research employed small-scale case studies, which provided crucial insight into clinical observations of trauma presentations in dementia. This study aims to expand on current understandings of trauma presentations in dementia using qualitative methodology to explore the perspectives of familial caregivers. This aspect of investigation is important due to the role of family carers and the insight afforded by their proximity to the PWLD. Within existing research, there has been much focus on the experience of White male veterans reexperiencing trauma in dementia. Given the rapidly increasing rates of dementia for elders within BAC communities in the UK, the current research aims to expand our understanding by focusing on the experience of trauma reenactments in this group. Further, in the UK, the exploration into racial trauma is limited, yet this area of inquiry is important for BAC elders who have a diagnosis of dementia and have experienced racial discrimination since migrating to the UK. The lack of research into racial trauma for UK-based BAC elders highlights the need for nuanced investigation into the intersection between culture, trauma, and dementia.

To conclude, the literature reviews presented provide an overview of current knowledge about the BAC dementia caregiving experience and the reexperiencing of trauma in dementia. The current study seeks to address gaps in our understanding, develop a comprehensive framework for supporting PWLD from BAC communities and their relatives, and advance systemic change. These objectives are discussed further in the Discussion chapter.

Chapter 3: Method

Chapter Overview

This chapter provides an overview of the research process detailing the ontological and epistemological positions behind the research and chosen methodology. It continues with an introduction to interpretive phenomenological analysis (IPA), the methodology employed in this research, and discussions about the philosophical underpinnings and the rationale for selecting this approach. Considerations of the effect of my positioning as the researcher are presented, followed by broader assessments of the quality of the research. The research design, procedure and analysis are described, and a summary of ethical considerations is provided. The chapter concludes with details of preliminary plans for disseminating the research findings.

Ontology & Epistemology: Interpretive Phenomenology

In research, consideration and understanding of the philosophical paradigm underpinning the enquiry are vital aspects of the investigative process. Ontology, the study of being, focuses on the nature of reality (Kant, 2014). Ontological beliefs relate to epistemological orientation, that is, the nature of knowledge (Greco, 2017). Identifying ontological and epistemological positioning at the start of the research process is essential in grounding the decision-making processes and engagement with the nature of the data being generated throughout the different stages of the research (Moon & Blackman, 2017).

Phenomenology, the philosophical study of 'being', argues that the world, body, and mind should be explored concurrently, thus nullifying statements that separate theories of knowledge from the nature of being (Zahavi, 2018). In addition, interpretive phenomenology is concerned with using interpretation to understand the ‘being’ of an observable occurrence (Wright-St Clair, 2014). As such, I will explain my epistemological and ontological positioning by describing the epistemological focus of interpretive phenomenology towards phenomenology, hermeneutics, and ideography.

Phenomenology can be viewed as a means of enquiry informing how to be a researcher and think (Wright-St Clair, 2014). Husserl, the originator of phenomenology, argued that our experience should be examined in how it occurs and in its terms through our return to the 'things themselves' (Smith et al., 2009). This principle makes phenomenology apt for this study exploring BAC familial caregiving experiences and the re-living of racial trauma from the subjective perspective of the caregiver. The phenomenological enquiry focuses on the content of consciousness and the directedness or intentionality of consciousness towards objects (Zahavi, 2018). Intentionality implies that subject and object cannot be separated and that we are an inclusive and embodied part of our reality. In the case of this study, exploration is focused on understanding participants' orientation towards caregiving and the meaning it has for them. A development in ideas about intentionality is found in the ontological position coined by Heidegger as 'Dasein', which acknowledges the mutual constitution between a person and the world (Smith et al., 2009). Hence, a phenomenological view appreciates the reality of caregiving as each participant perceives it.

Phenomenological investigation requires the researcher to put aside their understanding of the experience or their ‘natural attitude’ to engage with the phenomena and make sense of it in its own right, thus adopting a phenomenological attitude (Eatough & Smith, 2017; Smith et al., 2009). This process, known as ‘bracketing’, involves reflexively inverting the gaze to focus on our perception as researchers and to transcend our fore understanding to access the essence of the phenomena (Smith et al., 2009). In my study, I considered caring for a relative with dementia to be a taken-for-granted experience, meaning it is an everyday, unconscious experience which we do not fully engage with and one which is perceived in the context of pre-existing expectations. Therefore, an interpretive phenomenological approach was critical in bringing this phenomenon to the fore. Later theorists, namely Heidegger and Gadamer, expressed that bracketing is only partially conceivable and should be viewed as part of a dynamic and cyclical process of interpretation (Smith et al., 2009). In this study, my preconceptions about BAC caregiving experiences, dementia, and racism preceded the discussions with participants. However, my understanding of these experiences was enhanced through the interviewing process. The interviews also highlighted relevant aspects of my understanding that had yet to be identified.

Interpretive phenomenology aligns with the philosophical view of hermeneutics, defined as a theory about the use of interpretation as a vehicle to understand phenomena (Smith et al., 2009; Wright-St Clair, 2014). Heidegger posits that the meaning of phenomena can be visible or concealed, and that examining both the manifested and latent meanings is essential due to their connection with each other (Smith et al., 2009). As the researcher, my role was to make sense of the phenomena (caregiving) as it appeared, which was facilitated through interpreting the interview text.

The hermeneutic circle is a significant notion associated with the interpretive phenomenological view. It describes the dynamic practice of interpretation and the relational shift between the part and the whole (Smith et al., 2009). In the current study, this involved shifting focus between a singular participant interview and considering the context of the research project or selecting single extracts while being mindful of the complete transcript.

Idiography's focus on the particular is an additional commitment to interpretive phenomenological philosophy. It pledges to the particular by aiming to understand phenomena from the individual's perspective and attending to the depth and detail of analysis (Smith et al., 2009). Through this lens, our being is understood through relationships and interactions with the world (Smith et al., 2009). This was adhered to in this study through focus on the detailed analysis of each participant’s account of their caregiving experience.

Methodology

Rationale for Qualitative

The purpose of this research is to explore the meaning of the lived experience of BAC familial carers of elders with dementia. A qualitative methodological approach was deemed most appropriate, explicitly following a phenomenological orientation. Using a qualitative approach is consistent with existing research exploring the experiences of carers (Greenwood et al., 2019; Johl et al., 2014; Nair et al., 2022). A phenomenological qualitative approach would privilege a more profound understanding for the researcher and highlight idiographic accounts of the caregiver's lived experiences. Further, qualitative approaches privilege sharing knowledge through stories, a powerful and essential practise entwined with the history of BAC people (Truswell, 2016a). Therefore, a qualitative approach is most appropriate for engaging with the BAC experience and rejects White-centred positivist approaches, which can be a poor fit for the BAC experience.

Alternative Methodologies

Throughout this research process, I considered alternative qualitative methodologies, which also privilege the subjective participant experience. Thematic analysis (TA) is a qualitative methodology focused on exploring and identifying patterns of meaning in data (Clarke & Braun, 2014). This method was considered as it would have resulted in descriptions of commonalities and differences in BAC caregiver's experiences. However, although TA appears appropriate to the present study, this approach does not fully align with the research aim. Due to the dearth of investigation on this topic, this research sought to explore the meaning underlying idiographic caregiving experiences in more depth and detail than possible using a TA approach.

I also considered narrative analysis (NA), a qualitative approach that focuses on understanding experiences through interpreting narrative accounts (Reissman, 1993). NA was considered for this research due to its focus on the individual's story with consideration of the sociopolitical context (Weatherhead, 2011). The additional consideration of context was considered especially important in exploring the experiences of BAC caregivers with a deep-rooted sociopolitical history (see Chapter 1). However, NA's focus on how a story is constructed, the cultural and linguistic resources used in storytelling, and questioning why a story is portrayed in a particular manner (Reissman, 1993) was not entirely appropriate for the present research. Instead, interpretative phenomenological analysis was selected due to its focus on making sense of narratives as part of the broader exploration of meaning underlying the caregiving experience, which felt more aligned with the research aims.

Interpretative Phenomenological Analysis

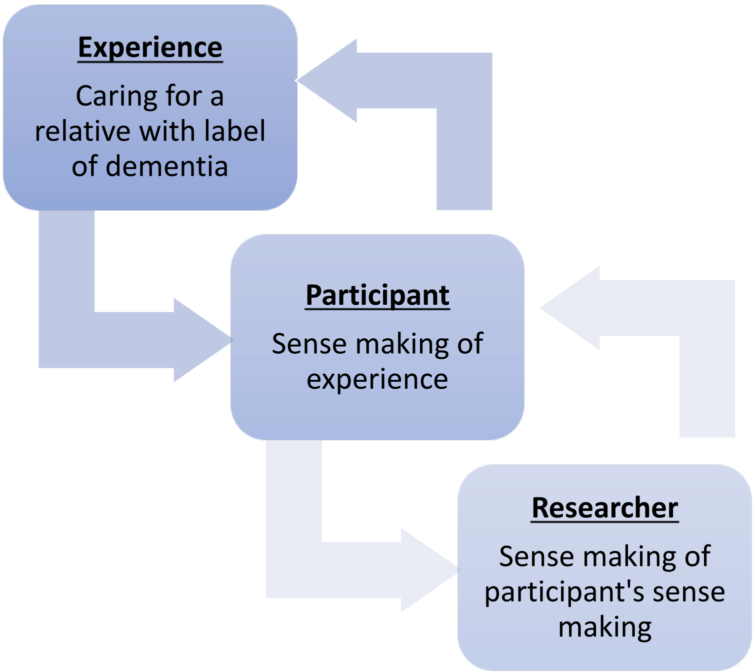
In considering the interpretive phenomenological onto-epistemological stance, an interpretative phenomenological analysis (IPA) framework was selected as the research methodology. IPA allows the researcher to enter the subjective experience of carers while also focusing on sense-making for both participant and researcher. This sense-making was necessary for the BAC familial carers' participant group, as their voices are often absent from research, as established in the literature review.

IPA also lends itself to investigating rare topics where the sample is well-defined and relatively homogenous (Smith & Osborn, 2008). Indeed, Pietkiewicz and Smith (2014) indicate that IPA is well suited to research focused on the emic perspectives of participants. The emic perspective in research refers to using an insider's perspective as the starting point of analysis (Markee, 2012). Given the niche nature of the research question and the lack of research in this area, IPA is befitting as it allows a flexible and detailed emic exploration of familial caregiving experiences in BAC communities and explores how dementia care provision intersects with the re-experiencing of traumatic memories.

IPA acknowledges that there is no direct route to another's experience. However, the methodology supports the researcher to get close to the experience by considering the meaning attributed and viewing this meaning as a representation of the experience itself (Smith et al., 2009; Smith et al., 2022). The role of the researcher is to make sense of the participant's sense-making of the experience, known as the double hermeneutic (Figure 1). This process involves a cyclical engagement between the 'part', the interactions with a participant and the 'whole', the researcher's knowledge of the experience (Smith et al., 2009).

Figure 1

The Double Hermeneutic Process



The interpretations provided in an IPA study are grounded in the text and move to a deeper level of interpretation through the detailed consideration of participant accounts.

Reflexivity: Researcher Positionality

Qualitative research requires the researcher to reflexively engage with the participants and the research process (Pietkiewicz & Smith, 2014). Reflexivity is critical in IPA, where researchers are encouraged to reflect on their preconceptions in order to privilege the phenomena (Smith et al., 2022), which for this study is BAC caregiving experiences and the reliving of racial trauma in dementia. Throughout this research process, I have become acutely aware of my inability to separate aspects of my identity. Indeed, Dwyer and Buckle (2009) note that the researcher's personhood and membership status to the participant group are ubiquitous in the enquiry. Still, I acknowledge that my various positions had vast and differing implications for the study; thus, I engaged in reflexivity throughout this research process in supervision and through reflexive research journal entries, to identify my biases, privileges, and challenges concerning the participants, which enabled greater research sensitivity.

As a Black British, African, female, trainee clinical psychologist and researcher, I approached this research from multiple intersecting lenses. In addition, I have no experience of dementia caregiving but have experienced racism. Qualitative researchers have long considered the effect of holding insider or outsider status. Dwyer and Buckle (2009) affirm that rather than this simplistic and restrictive dualism, a third position exists in the hyphen of insider-outsider, the space between. I consider myself to be occupying the space in between. Although I am an outsider to the familial caregiver status, I can relate to the experience of wanting to love and protect an older relative. In addition, as a researcher, my extensive reading of the literature relating to dementia care provision in BAC communities adds to the ambiguity of labelling myself as a true outsider. Holding this in-between position gave me a more profound knowledge of the caregiving experience.

As a Black British woman, I noticed that there was a degree of gender and ethnic identity matching with participants, which may have impacted the ways participants spoke about their experiences. For example, participants may have assumed I had implicit knowledge about aspects of their experience relating to their ethnicity (e.g., racial discrimination) or gender (e.g., the gendered role of care) due to the perceived similarities in our gender and ethnic background. I reflected on these challenges in my reflexive research journal entries and through discussions with research supervisors. I valued the triadic supervisory relationship and connected with both supervisors during insightful discussions about various aspects of my positionality. Through these different reflective outlets, I was able to acknowledge that while my insider status may have provided validity to claims about implicit knowledge between participants and I, I am not privy to fully understanding this experience in caring for a relative. In being aware of occupying the insider-outsider position, I was mindful of asking clarifying questions to minimise the impact of assumptions about participants' caregiving experience. Similarly, I acknowledge my bias in coming at the research with an understanding of West African cultural customs, which may have precluded participants' need to speak on these explicitly. Research indicates that despite a match in ethnicity between researcher and participant, it is essential to exercise cultural competence and sensitivity (Karan & Raghavan, 2017). Here, cultural competence can be defined as acknowledging the need for an individualised approach to meet the needs of diverse populations (Carpenter-Song et al., 2007). Cultural competence was demonstrated in this study through my openness to exploring each participant's construction of their experience from their perspective, and this stance is in keeping with IPA. In addition, after each interview, I reflected on my embodied experience (i.e., bodily response accompanying my emotions) in reflexive research journal entries. These reflections provided insight into the participants and experiences I felt more or less drawn to, and I viewed this as indicative of an aspect of my fore-understanding. Increased awareness of my positionality and fore-understanding about the caregiving experience was fundamental during the interpretive process as it allowed me to ensure the interpretations were driven by the data rather than my identified fore-understanding.

As a trainee practitioner psychologist, I am positioned as an outsider in a position of power within the system that participants may engage with for support while caring for their relatives. I also held a powerful position as the primary researcher. I held and interpreted the participants' shared stories and decided which narratives would be presented in the final analysis. The differences between participants and I may have discouraged potential participants from volunteering to participate in the research. I was mindful of my position of power and explicitly acknowledged this with participants. I viewed this difference in power as an opportunity to learn from the caregivers. I positioned them as experts in their experience and explained that their idiographic narratives interested me the most.

Assessment of Research Quality

Various assessment tools can be used to measure research value to ensure a high standard in an IPA study. Yardley's (2000) principles were used to assess the quality of this study.

Sensitivity to Context. Sensitivity was demonstrated from the outset of the research through consideration of the existing literature on familial caregiving in BAC communities and the experience of reliving trauma in dementia. In addition, the current and historical societal discourses about dementia and the effect this may have on carers participating in this research were considered. The literature review highlighted gaps in knowledge, which became the focus of this study.

During data collection, I demonstrated sensitivity to context by focusing on the interactional nature of the interview situation (Smith et al., 2009). In my interview opening, I set the parameters of the interview (i.e., that it would be participant-led) and acknowledged the inherent power differential between the participant and me. I aimed to develop a rapport and put participants at ease by asking open and broad questions about their experience at the start of the interview, funnelling down to the more emotional and challenging questions. I allowed the interview to be led mainly by the participant, thus limiting the constriction to the discussion parameters. However, I was also mindful of the research questions and would take the lead to direct towards the topic when necessary.

Sensitivity to context was also demonstrated through my close engagement with the idiographic aspects of the caregiving experience and commitment to the double hermeneutic process during the data analysis. Using verbatim quotations in the Results chapter demonstrates my sensitivity to the raw data.

Commitment and Rigour. As the primary researcher, I demonstrated commitment by attending a series of IPA workshops led by Dr Elena Gil-Rodriguez to support the development of my skills to conduct experiential research. This skills development supported my demonstration of commitment during data collection and analysis, during which time I paid close attention to the language used to talk about caregiving experiences. Additionally, I demonstrated rigour during the interviews by using probing questions, picking up on emotional cues and choosing when to focus on depth during exploration. I immersed myself in the data by independently transcribing and analysing each interview, demonstrating my commitment to the idiographic experience.

Rigour was demonstrated by identifying a research question before selecting a reasonably homogenous sample of BAC familial caregivers who matched the research enquiry. Furthermore, I demonstrated rigour by providing a narrative account of the findings, mindful of the balance between the convergence and divergence of experiences. To demonstrate this, I drew on accounts from multiple participants.

I effectively used supervision to obtain feedback on each stage of the research process, thus demonstrating rigour. In addition, I considered this study's limitations and introduced new literature to account for unexpected findings in the Discussion chapter.

Transparency and Coherence. I endeavoured to enhance transparency by thoroughly describing the methodology and analytical processes. In addition, I included details of these processes, such as the interview schedule and a transcript demonstrating the analytic process, in the appendices. Throughout the research, I have embedded reflexive entries to offer transparency on my sense-making of participants' accounts and how this interacted with my biases and experiences.

While writing the research, I positioned myself as the reader to enhance the readability and coherence. With support from supervisors, I drafted and re-drafted the analysis to ensure the themes fit together and that the interpretations were clear and coherent. Lastly, I ensured the research was written to be consistent with the principles of IPA, with a commitment to demonstrating the double hermeneutic process of the phenomenological experience of providing care to a relative with dementia.

Impact and Importance. This study focused on caregiving experiences in BAC communities. It provided insight into the intersection between dementia care, culture, and racism, which yielded new insights into how BAC people caring for a relative with dementia can be supported. In addition, there is a notable absence of research focusing on racialisation and racism in gerontology research (Torres, 2020). This racism-sensitive study provides insight into this area of enquiry, and through privileging the idiographic experience, I hope the stories shared resonate with other BAC caregivers. The original contributions of this study to clinical psychology and the broader implications are presented in the Discussion chapter.

Procedure

Participants & Sampling

Following interpretive phenomenological methodology, this study sought to select a purposive, homogenous sample that could offer insight into the familial dementia caregiving experience of BAC people. While Smith et al. (2022) indicate that in IPA, there is "no right answer to the question of sample size", they suggest professional doctorate IPA studies should typically involve six to ten interviews. It is important to note that larger sample sizes do not indicate increased work quality (Smith et al., 2022). As such, I recruited a sample of eight, which correlates with other IPA investigations. A sample of this size would facilitate exploration using IPA and allow for simultaneous focus on individual accounts while emphasising commonalities among the homogenous sample (Love et al., 2020). A small sample size also enables space to develop a comprehensive understanding of the sense-making underlying cultural expectations and experiences of racism in dementia caregiving without losing sight of the research essence (Ellis, 2016). Given the limitations of extant research, I aimed to contribute to the knowledge base with rich, high-quality findings yielded through the in-depth analysis process.

Inclusion & Exclusion Criteria

Given the aims of the study, the following inclusion criteria were adhered to in the recruitment of participants:

i. Aged over 18 years
ii. English-speaking
iii. Self-identifies as Black and of African or Caribbean descent
iv. Experience caring for a family member with a label of dementia
v. Experience in engaging with statutory services while providing care
vi. Consent to audio record the interview.

Recruitment

Recruitment took place between April 2023 and January 2024. Contemporary research indicates that carers from racialised communities describe being in a precarious position when it comes to getting support (Baghirathan et al., 2018). Carers report balancing their need for assistance from services alongside their concerns of being diminished by the exact source of support. Given these challenges, I was mindful of not utilising recruitment strategies that could perpetuate this cycle of harm. Guided by community psychology principles, I valued indigenous resources and collaborated with existing expertise in BAC communities (Sanborne, 2002). For example, I emailed the manager of a day centre specifically catered to BAC elders with dementia. After building a rapport through an initial meeting, I shared the research poster (Appendix 7) and arranged to visit the centre to speak to carers.

The research poster was also disseminated to my personal and professional networks through social media platforms such as Facebook, Twitter, Instagram, and LinkedIn, as well as via WhatsApp. Through these methods, I was able to recruit five participants. Participants were also encouraged to share the research with potential participants in their network. This method led to the identification of three further participants.

Although I recruited my target number of participants, this was challenging, and recruitment could have been faster. However, I experienced a low response rate from caregivers and made necessary adaptations to the research focus. Initially, recruitment concentrated on identifying participants whose relatives had experienced flashbacks to racist or discriminatory experiences, as depicted in the research poster (Appendix 7). This criterion garnered responses and participation from two caregivers who identified with this criterion. Following the initial interviews and through reflection and discussion with research supervisors, I realised the limitations to my understanding of the reexperiencing of trauma in dementia. Based on the existing research, I had conceptualised the reexperiencing of trauma as a physical reenactment, and I reflected on the impact of this restrictive view on the challenges with recruitment. I decided to amend the focus of the research to broadly consider the BAC familial caregiving experience and explore the reexperiencing of trauma as one aspect within the broader experience of caring for a relative with a label of dementia.

For caregivers who decided to participate in the research, they occasionally faced additional challenges impacting on their ability to engage with research. For instance, one participant needed to postpone their scheduled interview due to their relative being hospitalised for complications related to dementia. This experience provided insight into the challenges of recruiting participants in active caregiving roles, where the nature of dementia meant that the situation could change rapidly. The dynamic caregiving situation affected this participant's availability for activities outside of providing care. This issue may have also applied more broadly to other participants who wanted to take part in the research but felt unable to due to their circumstances. I also struggled to get email responses from organisations but found that in-person visits to centres effectively overcame this challenge. I had considered offering participants remuneration but decided against this due to concerns around motivations to participate. However, recent research has demonstrated that modest remuneration levels can improve recruitment without impacting motivation (Gabel et al., 2023), so my decision may have warranted further consideration.

Following an expression of interest, participants were contacted through an initial phone call and screened to ensure suitability using the inclusion criteria as a guide. This initial contact was also an opportunity to provide information on the study's aims and to gain informal verbal consent to participate. Participants were also allowed to ask questions. Subsequently, and in agreement with the participant, the interview was scheduled up to two weeks in advance and at a date and time convenient for both the researcher and the participant. This timeframe allowed participants enough time to read and understand the requirements of the study and to ask questions. Once a date and time were agreed upon, the researcher sent an email containing the participant information sheet, consent form, interview Zoom link, and password.

Participant Characteristics

Demographic information was collected through an online form and during the initial telephone discussion as part of the screening process before the interview. This data provided the context of each participant's background. Participants provided details about their age, ethnicity, family member they cared for, and length of time as a carer. This information was supplemented through discussion in the interview. Table 5 summarises participant demographics, and more detailed accounts are provided in the participant summaries presented in the following sub-section.

Table 5

Summary of participants' demographics

Characteristic	Number of participants	
	n	%
Age		
35-44	2	25
45-54	1	12.5
55-64	5	62.5
65+	0	0
Gender		
Female	6	75
Male	2	25
Ethnicity		
Barbados	1	12.5
Carriacou	4	50
Ghana	1	12.5
Sierra Leone	1	12.5
St Kitts	1	12.5

It is important to note that half of the participant sample were known and related to each other and that the majority of care was provided for and by females. The Discussion chapter provides further consideration of the gendered role of care and those being cared for.

Participant Summaries

This section contains brief biographical summaries to contextualise the sense made of each of the participants' interview accounts. The information provided is from participants' accounts and presented here as it was deemed essential to acknowledge the broader context outside the specific research question. Four participants, Yvonne, Fiona, Faye, and Pauline knew and were related to each other. These were the only known relationships between participants.

Florence. Florence (35), a Black Caribbean female, was the first relative interviewed. During the semi-structured interview, Florence shared experiences caring for her maternal great-aunt for five years. Florence spoke about how her desire to connect with family in the UK led to reconnecting with her long-lost great-aunt. At the time of meeting, Florence's aunt had already received a label of Alzheimer's. Florence soon uncovered financial abuse towards her great-aunt by a relative entrusted to provide care. At this point, Florence supported her aunt to report the abuse to the relevant authorities and decided to relocate to take over the care provision. Florence remained in a caring role until her great-aunt died in 2021.

Jamal. Jamal (59), the second relative interviewed, described himself as a Black Caribbean male with caring responsibilities for his dad. During the online interview, Jamal shared experiences of his journey towards accepting the label of vascular dementia given to his dad and the challenges in providing care. Jamal states that following an escalation in his dad's behaviour, including an attempt to harm his mum, he made the difficult decision to have his dad sectioned. Following this, Jamal's dad moved to a care home facility, where Jamal continued in his role by supplementing the care provided. Jamal continued to care for his dad until his death during the COVID-19 pandemic.

Yvonne. Yvonne (58) was the third relative to be interviewed online via Zoom. Yvonne identifies as a Black British female who took care of her mum. Yvonne described her journey into the caring role as motivated by her desire to honour her mum's wish to be cared for at home. Yvonne shared the challenges of juggling multiple responsibilities in her intersecting roles as mother, wife, daughter, and now, carer. With the support of her family and professional carers, Yvonne looked after her mum for several years and ensured she memorialised the experience through pictures and videos. Yvonne remained in her role as primary carer for her mum until she died.

Brian. Brian (43) was the fourth relative interviewed. Brian identifies as a Black British male with care responsibilities for his mum. As the eldest of his siblings, Brian felt a sense of duty to provide care for his mum after she received a label of Alzheimer's. While living with his mum, Brian and his sister noticed changes in his mum's behaviour, which led to a timely diagnosis of dementia. Brian shared that as a result of his appropriate questioning of his mum's behaviour and subsequent fast actions, his mum was able to take medication to slow the effects of the dementia. For five years, Brian cared for and protected his mum while grappling with his understanding of dementia. Brian cared for his mum until she died in 2023.

Fiona. Fiona (62) was the fifth relative interviewed via Zoom. Fiona describes herself as a Black British female. During the interview, Fiona shared her ongoing experiences caring for her mum. Fiona discussed the mental and physical toll that she has experienced while witnessing the gradual changes to her mum's personality and memory. Over the last eight years, Fiona has been the primary carer for her mum and describes coming into the role based on living close to her mother. With the assistance of professional carers, Fiona has supported her mum as she battles with the loss of her independence. Fiona also shared about her mum’s experience being driven out of a day centre and managing her ongoing challenges with an imperfect care system.

Evelyn. Evelyn (62) was the sixth relative interviewed. Evelyn identifies as a Black British female who takes care of her mum. Evelyn shared about her initial response to noticing changes in her mum's behaviour and how challenges in maintaining her mum's safety led to a transition to an assisted living facility. Here, Evelyn shares how she battled with cultural stigma and shame from the community while trying to maintain a sense of cultural familiarity through food and clothing. Due to various difficulties, Evelyn could not regularly provide cultural foods, ultimately altering her mum's tastebuds. As the dementia has progressed, Evelyn describes experiencing the loss of the mum she once knew. Now living in a care home, Evelyn continues supporting her mum.

Faye. Faye (54) was the seventh relative interviewed and described herself as a Black Caribbean female. During the online interview, Faye shared experiences caring for her mum over the last ten years, supported by professional carers. She shared how she attempts to maintain her mum's sense of identity with reminders of her 43 years as a midwife. Faye disclosed challenges in navigating healthcare and justice systems following an incident while her mum was being cared for in a home. After sustaining severe injuries in a fall, Faye shared that she continues to fight for answers. Faye continues to look after her mum and strives to incorporate natural remedies and foods into her care provision.

Pauline. Pauline (57) was the final relative interviewed. Pauline identifies as an Afro-Caribbean female with caring responsibilities for her mum, who has a label of vascular dementia. Pauline shared her experience of seeing a rapid deterioration in her mum's memory and changes to her behaviours. Pauline shared her struggle in comprehending the diagnosis as her mum was both physically and cognitively active. Today, Pauline provides care for her mum with the assistance of professional carers. Pauline's mum previously attended a day centre but was forced to leave, leaving her limited opportunities to connect with others and her culture outside the home. Pauline continues to care for her mum and establish connections with her culture through music and dancing.

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After each interview, I reflected on my sense of the participant, as I felt these reflections may be beneficial during the analysis and sense-making process. For example, after meeting with Faye, I reflected on my embodied discomfort due to the defensiveness I felt throughout the interview. In trying to analyse and make sense of her experiences, I wondered if her use of tone and language could be explained by the anger she felt towards services, and I questioned whether she had projected some of the anger onto me. I may have become an object representing the systems of power that had caused her and her relative harm. These reflections facilitated my interpretation of the depth of her mistrust towards services in the Results chapter.

Data Collection

A semi-structured interview was employed to guide the researcher's exploration of the essence of the lived experiences of BAC familial caregivers. Research has demonstrated that a detailed, semi-structured interview benefits the researcher and the participant. A semi-structured interview assists in the researcher's navigation through the topic, and participants are provided with an element of control over the direction of conversations (Noon, 2018). In addition, this interview method is among the most commonly used to explore individual experiences and is a prominent feature in published IPA research (Love et al., 2020).

An interview schedule (Appendix 8) was developed collaboratively with a familial caregiver and clinicians knowledgeable in research methodology. To co-create the interview schedule, I approached a Black African woman known within my network who had care responsibilities for an elderly relative (with no label of dementia). I used this approach as it felt essential to gain insight from a familial carer despite them meeting only some of the inclusion criteria. I was also conscious of how my ‘outsider’ status meant I was far removed from the reality of providing care for a relative, and insight from a caregiver would be invaluable. Additionally, in considering the conceptual framework of this thesis, I was mindful that co-creating the interview schedule may mitigate feelings of powerlessness that people from BAC communities can experience while navigating systems (Adkins-Jackson et al., 2023). Lastly, in considering the findings from the thematic synthesis about the BAC caregiving experience, I was aware of the limited insight provided by study authors into the development of interview schedules and the impact of power in research on BAC participants. As such, I aimed to approach this process differently.

I met with the caregiver on one occasion for one hour to consider the wording of the questions and the accessibility of terminology for caregivers who may not have clinical knowledge or background. Additionally, the questions in the interview schedule were guided by IPA principles. In the IPA workshop facilitated by Dr Elena Gil-Rodriguez, I was encouraged to consider the wording of my questions from the perspective of the methodology and to be mindful of falling into ‘therapist mode’. For example, in line with IPA, I was advised to take a stance of deliberate naivety, remain open, and avoid paraphrasing or over-empathising, as this may impact how information is shared.

Although I consulted with a carer, it is essential to acknowledge that the voice of the relative with dementia was missing in the design and development of this research. As such, the interview schedule contained prompts based on systemic interviewing techniques. Circular questioning, a Milan family therapy approach, was used to highlight connections and distinctions between the participant and their relative with a label of dementia (Brown, 1997).

For example, I asked, "What do you think your relative would say about their current experience?”. Participants were encouraged to broaden their lens and consider viewing the behaviours associated with dementia from the perspective of their relative.

In addition, within BAC communities, the embodied experience is often privileged (Haines, 2019). The interview schedule included questions encouraging participants to share their embodied responses within their caregiving experience. For example, participants were asked, “How did you feel about your relative reliving these experiences?” It is important to note that while considered beneficial and good practice in research, a pilot interview was not conducted prior to data collection with participants. This decision was made due to the challenges with recruitment and the researcher’s judgement that the cost of losing a study participant’s data in a pilot interview outweighed the benefit of piloting the interview schedule.

Data was collected through one online interview, guided flexibly by the interview schedule and prompts. Interviews lasted approximately one hour and were audio-recorded through Zoom video conferencing software. Of note is that most interviews were conducted in English alone except for one, which involved using English interspersed with Krio. This difference was due to the participant and I having a shared nationality, allowing the participant to express their experience and its meaning on a deeper level. The interview schedule was structured with open-ended questions, beginning with a broad focus on meaning-making about caring for a relative and narrowing down to the consideration of their relative re-experiencing race-related discrimination within dementia. The participants were positioned as experiential experts in line with a hermeneutic phenomenological perspective. As such, the interview guide was adhered to flexibly, as the participant had an essential role in determining the direction of discussions (Smith et al., 2022).

Interviews

Participants were interviewed remotely via Zoom and were advised to consider their surroundings before the interview commenced. Each participant was given the choice to have their camera switched on or off throughout the interview. Participants were reminded that their participation was voluntary and that they had a right to withdraw at any stage. Before starting the recording, participants were briefed on the context behind the research. Participants were informed of the themes that would be discussed as part of the research and encouraged to share any topics they did not feel comfortable discussing. The researcher and carer developed a protocol detailing how the carer would communicate their distress during the recorded interview. The participant was also reminded to refer to the information sheet for organisations that may be able to help outside of the interview.

Each interview was audio recorded using the built-in feature of Zoom. Prior to starting the recording, participants were asked to provide verbal consent to record. This procedure was also explained in the consent form. The researcher started the recording in the Zoom call after initial greetings and stopped after the final question was fully answered. Throughout the interview, the researcher noted specific topics or expressed emotions that warranted further exploration. These topics of interest were written to avoid disrupting the flow of conversation and minimise disruption to participants' thinking. In addition, aspects of the discussions that could not be identified in an audio recording (i.e., facial expressions, body language) were noted.

At the end of the interview, participants were thanked for their time and debriefed. They were asked to reflect on their experience completing the interview, specifically with a researcher of a similar ethnicity. In cases where the participant was distressed by our discussions, they were signposted to organisations that could provide additional support.

Additionally, following each interview, the researcher noted their reflections in an electronic reflexive research journal. These reflections were guided by prompts obtained from Dr Elena Gil-Rodriguez's IPA workshop and focused on capturing feelings and embodied responses (i.e., physiological response accompanying an emotion) to the interview and participant and considerations about aspects to improve or adapt for the following interview. For instance, the researcher reflected on answers to the following questions: "How do you feel after the interview? Where do you feel this emotion in your body? What might this emotion be communicating?". Each journal entry was dated and stored in a single electronic password-protected file. These journal reflections formed part of the interview and analytic process. Following the initial interview, the researcher reflected on how the participants had used the space and acknowledged that they had valued having the space to offload and talk about experiences that had not been discussed in detail with anyone outside their close family or friends. This experience informed the approach for subsequent interviews. The researcher allowed participants to talk openly about their experiences before trying to steer the conversation towards questions relating to the research aims. In this way, participants could influence the direction of the research.

Ethical Considerations

Ethical Approval

Ethical approval was obtained from the University of Essex Research Ethics Sub-Committee 2 (ETH2122-1269) in April 2023 (Appendix 9). The information sheet provided participants with the ethics reference number and details for contacts regarding concerns or complaints about the research.

Informed consent

Participant Information Sheet. Each participant was provided with a written information sheet (Appendix 10) containing details about the study's goals, what participation involves and contact details for researchers. The participant information sheet was developed in collaboration with a carer who advised on the accessibility of the language used. Crucially, due to challenges with recruitment, the participant information sheet was adapted part way through the study to account for broadening the research focus. Participants were invited to participate to discuss their caregiving experiences, and questions about reexperiencing memories of racist incidents were explored as part of the broader experience of providing care for a relative with a label of dementia. It was decided that the explicit mention of the expression of racialised trauma (i.e., experiencing flashbacks of racist or discriminatory experiences) be removed from the participant information sheet to reflect the expanded focus of the study. The research focus was discussed in the pre-interview conversation and reiterated at the beginning of the interview to ensure participants provided informed consent.

Consent Form. Before the interview, each participant had to complete a written consent form. Participants were informed that their participation was voluntary and that they had a right to withdraw from the interview at any point without explanation or prejudice. At this stage, participants were reminded that their participation in the research had no bearing on the care they or their relatives receive or will receive.

Confidentiality & Anonymity

Participants were interviewed via Zoom in their homes at a pre-arranged time and date. In considering confidentiality, they were advised to consider their surroundings' suitability, given the interview's content. At the start of the interview, the researcher ensured the participant was in a safe and confidential space.

The interviews were recorded using Zoom, and due to limitations with the recording feature, the audio and video were recorded by default. Following the interview, the researcher only accessed the audio recording to transcribe and analyse data. In addition, Zoom recordings are automatically uploaded to their cloud storage. After receiving the email notification that the recording was ready to download, the audio recording was transferred and stored in a secure password-protected file using only the participant ID (i.e., Interview 6).

Each participant was assigned a pseudonym to maintain confidentiality. This pseudonym was used during the interview transcription process and the reporting of results (i.e., verbatim quotes). In addition, place names, the names of any relatives, clinicians, or others mentioned, and any specific identifying details were removed from the transcript and thus analysis. Prior to the interview, the limits of confidentiality in qualitative research were explained to participants.

Given the use of snowball sampling to obtain several participants, the confidentiality limitations were reiterated at the start of the interview. Participants were informed that efforts would be made to anonymise information in the ways stated above; however, some stories from other participants may be recognisable.

Data Management & Security

Participants' personal information, contact details and demographic information were stored digitally in a single password-protected spreadsheet on a secure computer, and the document was only accessible to the research team. This is in line with the General Data Protection Regulation (GDPR).

The audio-recorded interviews and subsequent transcripts discussing sensitive experiences of caring for a relative with dementia were stored in a password-protected file on a secure computer. The transcription was pseudonymised and stored securely. Participants' identifiable data (e.g., consent forms and demographic information) were stored separately from documents containing the name-pseudonym associations. In line with the University of Essex Research Data Management Policy, the data will be retained for ten years after the completion of the study.

Risk

Due to the nature of the topics being discussed, creating a safe and comfortable environment to facilitate participant disclosures was imperative. Participants completing the interviews through Zoom were advised to find an appropriate setting for the interview and were given the option to turn their cameras on or off.

As the interviews were conducted remotely, the researcher's capacity to monitor and respond to adverse reactions was limited. This was all the more challenging for the researcher to manage for participants who opted to have their camera switched off, as the researcher was unable to use visual cues to identify signs of distress and was reliant on audio and verbal cues only. At the start of the research, the researcher acknowledged the limitations of an online interview and then developed an individualised protocol for managing the participant's distress. If participants became distressed, the researcher would respond according to what was agreed in the preliminary interview. Where appropriate, participants were reminded of their right to withdraw without reason at any interview stage.

The researcher was aware of their privileged position as they could metaphorically enter carers' lives to explore this sensitive topic. As such, the researcher needed to take responsibility for prioritising building rapport with participants to aid the research process. As part of this, the researcher considered the power dynamics within the relationship between the participant and the researcher. This power dynamic was also mentioned in the participant information sheet and discussed at the start of the interview. Additionally, the researcher considered how they would manage their emotional responses to participant distress or distressing narratives shared during the interview. The researcher made extensive use of a reflexive research journal, reflective spaces for researchers and discussions with supervisors to manage emotional responses while conducting this research.

Analytic Procedure

Transcribing Interviews

The audio-recorded interviews were transcribed verbatim. Smith et al. (2009) stipulate that recording as much detail as possible during transcription is vital in IPA as this information will likely support the analytic process. As such, I included all the non-verbal communication, significant pauses, hesitations or false starts, and laughter. Each interview recording was listened to repeatedly before fact-checking by reading the transcript while listening to the recording. At this stage, identifiable information was removed, and participants were given pseudonyms. The transcribed interview was transferred to a line-numbered transcript (Appendix 11).

Analysis

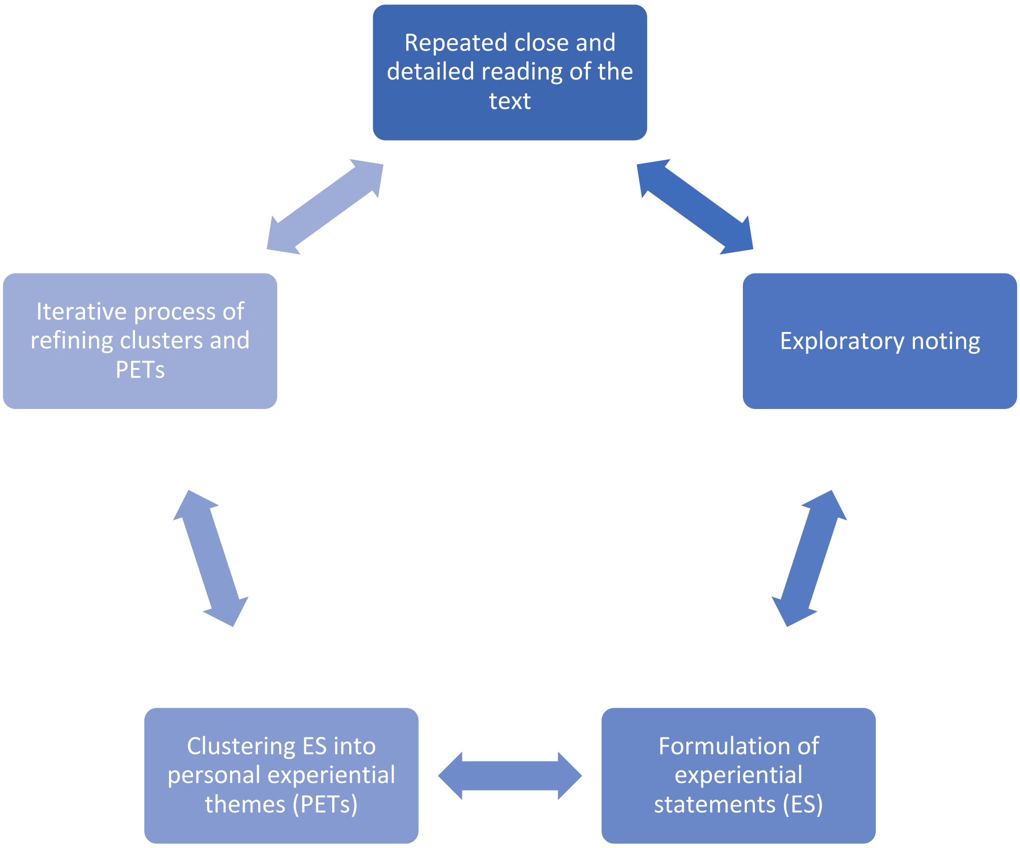
Following the transcription of all interviews, data was analysed using IPA and adhered to the process outlined by Smith et al. (2022). This process was both cyclical and iterative and required moving through and revisiting various stages (Figure 2) while remaining committed to the ideographic experience by returning to individual case transcripts.

Reading and Re-reading. I began immersing myself in the data by closely reading and re-reading a printed transcript. I initially listened to the recording while reading the transcript to facilitate this immersion process. This strategy helped develop a lasting association between the participant's voice and their words, which was beneficial in the subsequent analysis (Smith et al., 2022). I reflected on my initial response to the transcript in my reflexive log and highlighted sections of the transcript with deep meanings. This process required slowing down and being open to the participant’s narrative.

Exploratory Noting. During this stage, I engaged in the double hermeneutic process by making sense of participant's interpretations of their caregiving experiences. The focus was on identifying the objects of concern, how participants talked about them, and the meaning of these experiences. Using different coloured ink, I approached this stage of the analysis by making notes on the descriptive (black ink), linguistic (green ink), and conceptual (red ink) elements of the data in the extensive margin of the transcript (Appendix 12).

Figure 2

Stages of IPA Analysis (Smith et al., 2022)



Descriptive noting pertained to the content of words and phrases, while linguistic comments focused on specific use of language and linguistic devices (e.g., metaphors, idioms, alliteration), non-verbal communication, and attention to what was omitted from the narratives. Conceptual coding raised the level of analysis by considering the meaning underlying idiographic accounts of experiences.

Reflexive Memo 2: 17th February 2024

I found the exploratory noting stage most challenging as the inherent flexibility of IPA meant that the process was not prescriptive. As a novice researcher, this was difficult and felt overwhelming as I frequently questioned whether I was engaging in the interpretive process in the 'right' way. I also found that by immersing myself in the data, I occasionally had dreams related to the interview content. I was reminded of the work of Dwyer and Buckle (2009), who stated that there is a reciprocal relationship between our personhood as researchers and the analysis process. I used supervision and peer support to manage the discomfort about the analysis and noted my dreams in the reflexive log. Over time, I understood there is no 'right' way to conduct the analysis, but the important thing is that the interpretations are grounded in the data. I spent a long time reviewing the transcripts and adding to notes as I noticed new meanings or use of language. This step was a crucial part of the analysis and formed the basis of the following steps, so I allowed myself the time to revisit the transcript and exploratory noting as much as was needed.

Formulating Experiential Statements. Using mainly the exploratory notes, I returned to the start of the transcript to develop experiential statements based on what was understood about the meaning of the experience for the participant. Experiential statements were noted in pencil in the smaller left-hand margin of the transcript. The process involved fragmenting the text and using sections of exploratory notes to devise phrases capturing what had been discovered about the meaning underlying the experience. Throughout this stage, experiential statements were iteratively formulated, which required switching focus between subsections of exploratory notes and the whole transcript.

Searching for Connections Across Experiential Statements. After constructing the experiential statements, I typed them into a Microsoft Excel spreadsheet alongside identifiers, including the page number and corresponding transcript text. I reviewed the statements to identify which were similar and could be merged and which could be discarded at this stage. I aimed to reduce the total number of experiential statements to 50 or less, as this was a reasonable amount considering the scope of the research. My research question guided the clustering process (Smith et al., 2022). I kept a record of the choices made and saved multiple iterations of spreadsheets as part of my audit trail.

Once satisfied with the clustering of experiential statements, I printed them out and cut them up, so each statement was on a separate piece of paper. I randomly distributed the statements, laid them out on the floor and explored possible connections between them. I took photos of each cluster before repeating the process to identify a different configuration of experiential statements. Again, this process involved darting between the parts (experiential statements) and the whole (transcript/quotes). I continued this process until I felt satisfied that I had identified the best way to demonstrate the interconnections.

Naming and Consolidating PETs. The final clusters of experiential statements were each given a title reflecting its characteristics (i.e., similarity, polarisation, narrative, or functional analysis) and labelled as a personal experiential theme (PET). Where appropriate, PETs were also divided into sub-themes. Each PET and subsequent sub-themes were tabulated alongside a location identifier (page and line number) and a quote. This table formed the case-level summary.

The five processes outlined above were repeated for each interview transcript. In keeping with IPA's idiographic commitment, I was mindful of avoiding using the analysed interview as a basis to interpret and analyse subsequent transcripts. I would regularly reflect on emerging themes and adhere rigorously to the analytic processes to manage this.

Lastly, all eight case-level summaries were reviewed to identify themes common across cases. These cross-case PETs were clustered and tabulated into group experiential themes (GETs).

Dissemination

This research has been submitted to the University of Essex in partial fulfilment of the Doctorate in Clinical Psychology. Following completion of the research, the key findings will be presented to participants in an accessible format. I will explore opportunities to disseminate the research to relevant NHS services to facilitate the implementation of changes to their approach in working with familial carers from BAC communities and their relatives with a label of dementia. I hope that my research will highlight the ways in which historical experiences of racism and discrimination can present in BAC elders with a label of dementia and that knowledge of this will support the use of a trauma-informed approach to care. Furthermore, through disseminating the research, I hope that services will understand the importance of providing culturally responsive care and that they will become mindful of the complexities of thinking but not talking about experiences of racism encountered through caregiving. Prospective dissemination plans include publishing the results in several open-access journals, including Alzheimer's and Dementia: The Journal of the Alzheimer's Association and Frontiers in Aging Neuroscience.

Chapter 4: Results

Overview and Presentation of Findings

This chapter provides a narrative account of the interpretative phenomenological analysis (IPA) of the experiences of eight participants. Through engaging in the stages of analysis and hermeneutic interpretation, three group experiential themes (GETs) and six subthemes were developed, guided by the exploration into how BAC familial carers make sense of their experience looking after a relative with a label of dementia and witnessing the re-enactment of experiences of racism. Each theme appears in at least half of the participants' accounts, and a table illustrating this breakdown is included in Appendix 13.

Throughout the narrative, I refer to participants using pseudonyms, and potentially identifiable information is redacted to preserve anonymity. I have included verbatim quotations from transcripts in italics referencing the participant and page number (e.g., Brian, p. 3). I have used square brackets to indicate words added to aid the readability of quotes or to exemplify non-verbal communication, e.g., laughter. Lastly, ellipses signify a short pause in the participant's narrative. Table 6 summarises the GETs and sub-themes, and the narrative exemplifies the convergence and divergence of experiences across the participant accounts.

I acknowledge that the interpretations presented are based on my perspective, and this is just one interpretation of the experiences shared by relatives. I have also incorporated reflexive excerpts throughout this analysis as a disruption to the text to represent my internal processes while analysing the interviews and constructing themes.

Table 6

Summary of Themes

Group experiential theme	Sub-theme
	1a. In a chokehold with unspoken cultural expectations

Group experiential theme	Sub-theme
1. Tension at the intersection of care, culture, and community	1b. Sharing the caregiving load: “It was a team around the adult”
2. Battling with broken systems	2a. Inconsistent recognition of vulnerability
	2b. A lack of equity in care: “Mum's tastebuds were so institutionalised”
3. Longing for a place of safety and happiness	3a. Reliving past experiences
	3b. Feeling silenced: The lasting imprint of racism

Group Experiential Theme One: Tension at the Intersection of Care, Culture, and Community

This theme illustrates all eight participants’ sense-making throughout the journey from transitioning to becoming a caregiver for their relative and navigating cultural expectations about how care should be provided. As dementia progressed, participants reported witnessing their relative experience a cultural disconnection, which led participants to use alternative means to provide the PWLD with a sense of familiarity with their culture. Participants shared the favourable and unfavourable aspects of caregiving grounded in cultural ideals.

In a Chokehold with Unspoken Cultural Expectations

Each participant shared their transition experience to their new caregiving role and how this intersected with cultural beliefs. For a minority of participants, the additional responsibility of caring for their relative was an extension of their existing role with no formal discussion or decision-making process (“*I've been looking after her ever since um being diagnosed*” Faye, p. 8). This lack of discussion around additional caregiving could be interpreted as the adherence to an unspoken expectation to provide care for elders.

Yvonne expressed a different experience and talked about the cultural and faith-based customs underlying the decision to care for her mum: "*it does say in the word [Bible] that we need to look after our hoary head, as in grey as in older older folks and and also its tradition as well in that in that um my mother's parents was looked after by a family member"* (Yvonne, p. 32). Yvonne's grounding of her experience in family and cultural "*tradition*" suggests that her transition to caregiving was of particular significance and an accepted practise. The mention of the family caregiving practise for her "*mother's parents*" indicates the presence of a family tradition with an implicit expectation to adhere to this same practise. This suggests minimal room for deviation from this cultural norm due to its temporal and religious grounding.

Similarly, for Brian, taking on the care responsibilities for his mum was determined by culture and his birth order, suggesting a sense of powerlessness in the decision-making process: "*Well one, I'm the oldest of the my my siblings*" (Brian, p. 14). In contrast, Fiona expressed a decision to care governed by convenience and proximity to her relative: "*It it came on because I'm the closest one living next to her, you know*" (Fiona, p. 13). Fiona and Brian mention factors outside their control that govern their transition into a caregiving role, which suggests a solid adherence to cultural expectations over personal motivations to provide care.

Florence's experience differs from the other participants in that she conveys caring responsibilities as an imposition that mistakenly 'found' her rather than the reverse: "*I left [Caribbean] on scholarship to come to the UK to study, and in the midst of it all I ended up falling into a caring role, you know…that really and truthfully went by mistake to be fair"* (Florence, p. 54). One interpretation could be that Florence experienced caregiving as an accidental disruption to her life path that she was unable to avoid due to deep-rooted beliefs about family looking after each other.

In their new role as caregivers, participants commented on the wounding experience of witnessing their relative become less connected to their culture of origin as dementia progressed. This challenge was depicted prominently in Brian's account:

> *People back home, there's only two people back home who knew about mum's condition um so the rest we didn't tell them. We just um I either I blocked the number deleted number or we just when they call we hope that mum is is having a good day* (Brian, p. 18)

Brian places much emphasis on protecting his mum, and this includes enforcing cultural disconnection in attempts to hide the dementia from the extended family ("*we didn't tell them*"). This protective instinct appears to be linked to a sense of shame as he had already expressed: "*Certain people in the family we had to tell just in case they do speak to her, they don't think she's gone cuckoo*" (Brian, p. 17). Here, Brian provides insight into perceptions of dementia with the use of the term "*cuckoo*", meaning mad or crazy. This term relates to public perceptions of dementia and is an inherited legacy from the early days of psychiatry and institutionalisation practises.

Evelyn describes her complex entanglement with cultural expectations while caring for her mum in a supported living facility. Evelyn states that despite her mum being open to eating various foods, "*it was our duty and our obligation to make sure she got some of her own cultural food*" (p. 15). Here, Evelyn's reference to *"duty"* and *"obligation"* suggests a strong moral sense to adhere to an unspoken expectation to maintain her mum's cultural connection through familiar foods, insinuating that there was a threat to her cultural identity. Evelyn continues to depict her challenge with managing cultural expectations about care provision:

> *But in terms of being a carer of, you know, somebody that is of African heritage, particularly us, as you know we're a very, very proud set of people, it it it's been really really challenging to-to push back some of the guilt, the taboo* (Evelyn, p. 21-22)

Evelyn's reference to pride in the context of her heritage insinuates a culture filled with respect and the desire to maintain the respect of others, including elders, through providing care in the family. Evelyn describes a battle to resist the ensuing guilt due to her actions, which go against cultural ideals. As mentioned earlier, Evelyn's adherence to the expectation of food provision may have also had the dual benefit of showing her value as a daughter and reducing the "*guilt, the taboo*" from the community due to being unable to care for her mum at home.

For Jamal, being unable to fulfil a cultural ritual due to the COVID-19 pandemic left him with uncomfortable feelings of guilt:

> *I go to funerals and it's a big occasion, but I we couldn't give the big occasion to my dad because so fast— we was in the church, the service was at 2:30 I was back home by 4:30. And I said to myself my dad don't deserve that he deserved a little bit better. He wasn't the greatest dad, but he was there you know, he-he was there in spirit* (Jamal, p.78)

Jamal appears to be struggling to accept the inadequacy of his dad's funeral. His sudden switch in pronouns from "*I"* to "*we*" could be understood as a realisation of the shared responsibility of the funeral not being as big an event as he is accustomed to. Jamal appears to equate the inadequacy of the funeral to the status of his relationship with his dad. This tussle highlights how disruption to a cultural ritual can lead to complex feelings impacting the grieving process.

Several participants shared how, despite the challenges in adhering to cultural expectations, the care relationship provided unique opportunities to connect. Brian shared that his world became smaller due to his caring responsibilities (“*I wasn't outgoing as much, I was if I wasn't at work I was at home”*), yet this afforded him extra time to connect with his mum: “*So my my lifestyle changed, and um but to be honest, I think it was better for me. I was I was able to spend more time with mum than I would have done if she wasn't ill”* (Brian, p. 8). Brian appears to hold a ‘both and’ position while being honest about how slowing down his lifestyle provided him with additional quality time to spend with his mum.

Florence shared a comparable experience of reciprocity in her caregiving role:

> *So it was more so being that social support. We shared a lot of stories, um, you know, I got to learn a lot about my my heritage and my family, and you know. It was like this missing piece that I felt that I I found* (Florence, p. 42-43).

Florence’s gratitude for the opportunity to obtain unique knowledge and wisdom from her great-aunt is evident. The simile “*like this missing piece*” highlights Florence’s previous struggles with aspects of her cultural identity, but she filled a void and felt complete through sharing narratives with her great-aunt. This suggests that caring for an elder with dementia can be a powerful and affirming experience.

Equally, Yvonne described cultural practices centred around food and cooking rituals (“*you will be woken up by the smell of bread or the smell of food you know, cause that's the way she-she cared for her family*”, p. 16). As such, Yvonne kept her mum connected to this cultural tradition by encouraging her to partake in cooking: “*I'd always get her to participate in the kitchen, so she feels, you know, important she's still valued”* (Yvonne, p. 54). Yvonne’s actions to help her mum feel still “*valued”* may also be interpreted as showing she is loved, given the link between cooking and a display of love.

Likewise, Jamal shared a rare moment of emotional connection which occurred as he was processing having “*just done the personal care of my dad”* (p. 31):

> *Dad turned around and said to me, "You know son you've made me feel like a king". And that negated everything that he'd ever done, in my eyes, because he said that to me. And then it's almost like it was almost like a license I can move on and carry on* (Jamal, p. 31)

The simile "*like a king*" suggests that his dad felt respected and that he had restored his authoritative standing. Perhaps Jamal's actions in caring for his dad had enabled him to reconnect with aspects of his identity, such as being the head of the family, which he had become detached from due to dementia. This reconnection with self was also restorative to their complex father-son relationship and provided positive reinforcement for Jamal to continue providing care.

This sub-theme explored participants' experience managing the tensions of adhering to cultural expectations while providing care and acknowledged the positive aspects of caregiving. In addition to adhering to cultural expectations, participants reported leaning on support from the community to provide care. This is detailed further in the subsequent subsection.

Sharing the Caregiving Load: "It was a team around the adult"

This sub-theme examines all eight participants' experience of care provision as a collective endeavour involving support from other family members and the wider community. As the primary caregiver, several participants commented on reaching out to siblings for support when feeling overwhelmed. This was illustrated in Brian's account: *"I had to complain to my siblings most of the time that you people gotta come to the house and deal with mum and talk to mum because she's getting a lot*" (Brian, p. 25-26). Brian's use of "*complain*" indicates his sharing of feelings of dissatisfaction about difficult experiences with his mum and using this as a vehicle to receive support.

For Yvonne, her cries for help were responded to by her family of procreation, who stepped in to support because "*there are times when it was it was it was a lot on me*" (p. 64):

> *Sometimes my husband would say, you go and have a bath or you go and do this, or my my young people now they would they they they were tolerant. They were we were like a team around, you know it's not a team around child, it was a team around the adult, you know* (Yvonne, p. 64-65)

Here, Yvonne describes a coordinated effort implemented by her family to provide care for her mum indicating that care provision is a shared endeavour.

Fiona expands on the previous accounts with her description of emotional and psychological support received from her relatives:

> *You just have to to manage it, you know, and having other people with the same experiences it's when I say speak to my my my my cousin, or you know. Say "Oh yeah, my my my mum done that, or my mum's doing that now", you know, you know, so...it doesn't feel like you're alone if you understand me, you know* (Fiona, p. 63-64)

Fiona describes feeling compelled to accept the situation with her mum ("*You just have to to manage it*") but comforted by the solidarity of shared experiences with cousins, indicating the power of the shared experience in normalising aspects of dementia caregiving.

In Evelyn's account, she shares how care provision for her mum extended beyond her immediate family:

> *So, there's that um giving and taking that exists within our community but I think what has really, really, really impressed me is the fact that people wanna spend time. Because it's easy to send two thermal vests or nice new slippers but to actually spend time* (Evelyn, p. 78).

Evelyn expresses the extent of her gratitude for people spending time with her mum in the supported living facility and grounds these actions as being part of a cultural practise of "*giving and taking*". Evelyn appears to be struck by the selflessness of people giving up their time. This may have been important to Evelyn as she felt held and supported by her community while navigating a complex healthcare system.

However, a collectivist approach to caregiving was only sometimes a positive experience. For some participants, the involvement of extended family in providing care opened the door to exploitation of the PWLD, as depicted in Brian's account:

> *We also didn't want especially people from back home to take advantage of mum's mindset. Like for example, like ask her for money and she will just send money. Eventually we even had to take change her code on her bank account, so she herself doesn't have access to it.* (Brian, p. 37-38)

For Brian, the culture of giving and taking mentioned above appears to have been abused by relatives abroad who recognised his mum's vulnerability. To manage this situation, Brian puts safeguards in place yet avoids sharing the diagnosis with said relatives*: "We didn't want the news to be spread around the whole, the whole world*" (p. 36-37). Perhaps Brian is battling with his desire to protect his mum from financial abuse while also being mindful of the shame that may ensue with shared knowledge of her diagnosis.

Similarly for Florence, learning about the financial abuse her great-aunt had endured at the hands of extended family members left her feeling shocked and disappointed: "*But equally it shows that even people within your own community it doesn't have to be people from the other race to oppress like, people take advantage of vulnerable people regardless*" (Florence, p. 33-34). Here, Florence acknowledges the uncomfortable reality of abuse in the BAC community. The use of "*oppress*" and "*people from the other race*" appears to liken the experience to that of oppressive practises perpetrated by dominant groups, thus illustrating the opposing side to community care provision.

Further, through sharing care responsibilities within families and communities, several participants described becoming aware of the magnitude and impact of dementia in BAC communities:

> *But until mummy was diagnosed with it, I never, never heard of it. Yeah, and it's just seeing that I know so many people with it or knew, you know what I mean, that's passed, you know. Uncles passed of it, mum's sister's living with it, mum's sister-in-law's living with it, so you know, mum's best friend had it - she's passed, you know what I mean. My godmother had it; she's passed. So it's how suddenly you're just thinking, oh my God, what's this? Everyone's got it [laughs]* (Fiona, p. 20)

Fiona illustrates her journey from facing this unknown condition to learning how it has impacted her family. As she lists all the people who have received a label of dementia, she conveys a growing sense of concern, culminating in her questioning at the end. Fiona's incongruent laughter appears to be indicative of her discomfort and fear at how common dementia has become in her network. Perhaps this existential fear is one she battles while caring for her mum.

Pauline echoes Fiona’s concerns as she tries to ascertain the cause of the increased cases of people being diagnosed with a label of dementia:

> *Well you’re thinking well if it is it genetic, you know. And who's next? You know [laughs]. You know, cause um and and I'm thinking I said, is it trauma? Is this linked to like childhood trauma? Did they have? I dunno. I dunno.* (Pauline, p. 58)

In the absence of clear answers, Pauline attempts to make sense of the inflated numbers of people with dementia in the BAC community but concludes with uncertainty and unanswered questions. Pauline's processing appears to mirror the general sense of uncertainty in the literature about the cause of dementia, particularly in racialised communities. Pauline's questioning, “*And who’s next?*” reveals her vulnerability against this condition, and her incongruent emotional expression could be interpreted as protection from her fear that she may also receive a diagnosis of dementia in future.

Nevertheless, despite the growing impact of dementia in BAC families, there is a prevailing sense of positivity and comfort felt through supporting each other. Fiona goes on to describe how she copes during difficult times:

> *But when people are sharing the same experiences, and some of them are sort of like, you you may laugh at it, you know what I mean, but sometimes it's good to laugh and joke a lot, so you're not taking it too serious* (Fiona, p. 63)

Fiona's attempts to find humour in the face of challenges could be a coping mechanism to distract from and reduce the burden of caregiving. Humour could also be a defence mechanism, and perhaps for Fiona, this was a way of defending against the emotional pain of losing her mum to dementia and her existential angst about the changes that are yet to come.

Overall, this sub-theme portrays participants' journey in navigating cultural expectations and the favourable and unfavourable aspects of collective caregiving. Alongside managing the complexities of cultural expectations, participants shared their struggles in navigating the healthcare and criminal justice systems. This is explored further in the following subsection.

Group Experiential Theme Two: Battling with Broken Systems

All participants, except Brian, expressed that in addition to managing the expectations of others in the community, they also faced a battle against broken systems of power and oppression.

Inconsistent Recognition of Vulnerability

This sub-theme explores seven participants' experiences navigating statutory services. Each participant's systemic encounters were marked by selective recognition of their relative’s vulnerability. Florence reflected on her experience of her great-aunt's vulnerability becoming visible after she was admitted to the hospital despite reports of her “*spiralling, wandering*” (p. 48) beforehand: “*She caught COVID ended up in hospital; from there they recognise that she was extremely vulnerable*” (Florence, p. 50). Under extreme circumstances and faced with the prospect of death, the system appeared to enact the rescuer role to protect Florence's great-aunt from harm. Yet, this protection was notably absent prior to her being hospitalised when her vulnerability was just as present, suggesting other factors influenced how vulnerable she was deemed to be.

Evelyn outlined how her mum's vulnerability was invisible in situations where the label of dementia needed to be acknowledged: *You know, simple things like mum will go into hospital, we know that they have a category system whereby they'll put a purple butterfly on the board on her bed. And they will forget to do it* (Evelyn, p. 72). Evelyn expressed how failings in the hospital occurred at the most basic level (“*simple things*”) of recognition, which may have led to inaccurate assumptions about her mum's ability to comprehend and engage with others, thus increasing the burden on the family to be present.

Fiona's account corroborates this experience when she describes how the invisibility of her mum's vulnerability led to the implementation of a punitive response at a day centre: “*She was going there but she got to a point where she went on the transport, she um was taking off her seat belt so they said they can't have her anymore*” (Fiona, p. 35). Fiona conveys a sense of finality and punishment that appears incongruent with her mum's actions (“*taking off her seat belt*”), yet this display of her vulnerability resulted in being ostracised from a key source of support.

Pauline shared a similar account of her mum's vulnerability being overlooked, leading to exclusion from a day centre:

> *She went there and um, the first day um, I think obviously they had activities and they probably asked her to join in and um she took very long to actually got up from where she was sitting cause, you know, obviously they become very stubborn, and on that one occasion they say she couldn't come back.* (Pauline, p. 17)

Pauline's use of "*first day*" and "*one occasion*" suggests that finite decisions were made promptly with no consideration of the 'obvious' context (dementia) underlying her mum's behaviours ("*they become very stubborn*"). The impact of this exclusion was felt through her mum's cultural disconnection and isolation due to no longer having access to a place to engage with peers.

For Pauline's mum, her dismissal from the day centre led to limited interactions with people with a label of dementia from a similar ethnic and cultural background. This isolation led to concerns that she was becoming increasingly disconnected from the Caribbean culture. Pauline's comment below illustrates a phantasy of how the situation could be different:

> *Just say for instance my mum went to a a place where on a Monday they play Soca, on a Tuesday they probably did line dancing or you know but they were actually catering to her needs. See what I mean? Um, at least that would have rekindled something in her* (Pauline, p. 34-35)

Given that Pauline expressed distress at the loss of her mum's essence, the use of "*rekindled something in her*" suggests that she feels hopeful that regular collective engagement with aspects of culture would support rousing mum's familiar essence, suggesting her identity is intricately interwoven with her Caribbean heritage. Perhaps the wish to rekindle her mum's identity demonstrates Pauline's ongoing battle to accept the dementia and its deleterious impact on her mum's sense of self.

Similarly, Faye's account depicts how the invisibility of her mum's vulnerability led to her incurring severe injuries ("*eight broken ribs, one broken in two places"*) during a respite stay in a care home:

> *Their [care home] exact words were, she was dancing in the lounge and had fallen and was rushed to hospital. Well they didn't actually bring her to a hospital she actually went in the ambulance by herself, and they called me on WhatsApp in [country]. I was in shock* (Faye, p. 15-16)

Faye talks about how, despite sustaining severe injuries, her mum travelled "*in the ambulance by herself",* suggesting limited recognition of how vulnerable she was following the fall. This action could be interpreted as the system exerting its power to deny adequate support to a vulnerable elder with injuries, which leads to questions about who the system feels deserves that support.

This experience was substantiated in Florence's questioning of the police response after reporting her great-aunt's experience of financial abuse: "*And I was like but, where in Heaven's name like, if you are saying you're here to protect the vulnerable he has clearly been abusing the position he's had in her life, you know*" (Florence, p. 30). Florence portrays a sense of anger and frustration through the informal expression "*where in Heaven's name*" as she questions how her great-aunt was excluded from the police protection of the "*vulnerable*" despite clear instances of a need for protection. Perhaps Florence is mirroring her great-aunt's helplessness when those in privileged positions took advantage of her vulnerability.

For Yvonne, her mum's vulnerability was only made visible through fighting against the system and taking action to advocate for her mum's wishes:

> *And she* [nurse] *said, "Oh, why not?" I said, "Because she's her skin is very sensitive at the moment, and she had blood taken yesterday, so you can use that blood that you took yesterday to do your whatever you wanna find out". And she goes, "Who are*

> *you?" I said, "I'm her daughter" "Have you got power of attorney?" I just went to my phone, and I said, "Yeah. Look". And then she just walked away.* (Yvonne, p. 36)

During this interaction, there appears to be a shift in the power dynamics, leading to an escalation, culminating in Yvonne being asked to evidence her authority to make decisions ("'*Have you got power of attorney?*'"), despite the decision being led by her mum ("*And she goes I don't wanna take blood*", p. 34). The battle depicted could be interpreted as a consequence of the rigidity of the medical system and their desire to maintain their position of power.

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While developing this theme, I struggled to label the meaning underlying the injustice participants had experienced. I was struck by hearing these narratives, but sadly not surprised, and experienced a visceral sense of anger at how the majority of participants were mistreated. Perhaps this was off the back of the 2020 events surrounding George Floyd or the numerous incidents of violence against the Black community that I had been exposed to in the years since. I felt exhausted hearing about systemic injustices that felt all too familiar. However, I was hesitant to label these as race-related incidents, particularly where the participants had not interpreted them as such. I held a 'both and' position while engaging in the hermeneutic process and aimed to stay true to the participant's accounts. I also questioned whether the absence of mention of race meant that racial discrimination was not a consideration in their minds.

For a minority of participants, the inconsistent recognition of their relative's vulnerability caused iatrogenic harm, demonstrated through feelings of mistrust towards services. Mistrust was a prominent feature in Faye's account of how she supported her mum following the injury: "*I monitored mum's every movement in the hospital cause these days in* *hospitals, [scoffs] well, you know, it's just I don't know whether whether they're looking after or they want to take away*" (Faye, p. 29-30). Faye's hypervigilance is illustrated through her description of monitoring her "*mum's every movement in the hospital*". Her feelings of uncertainty about the motives of hospital staff ("*I don't know whether whether they're looking after or they want to take away*") could be interpreted as uncertainty about whether her mum's life is valued within a system that has the power to both protect and take life. In her powerlessness, perhaps Faye's focus on being present is her attempt to manage the situation and have a semblance of control.

Likewise, Yvonne reports that being present and championing her mum's needs has been an effective strategy to mitigate harm:

> *And I think sometimes having a voice for them because they, you know, they have them as like research, pin bags and and that's how I felt and I I wasn't having it. So, we would do a 24 hour shift some one during the day, and then one person in the night* (Yvonne, p. 37).

Her use of "*and I I wasn't having it*" conveys a sense of frustration and a lack of tolerance for the abuse she believes is perpetrated within healthcare systems. Yvonne's mention of "*they have them as like research, pin bags*" conjures up images of experimentation and is perhaps linked to the historical medical abuse through the use of Black bodies for human experimentation. The pin bag analogy illustrates the extent of Yvonne's mistrust in the healthcare system and grounds her motivation to protect her mum from experiencing abuse through "*having a voice*" for her and providing "*24 hour*" supervision.

This sub-theme delved into participants' experiences of having their relative's vulnerabilities muted during encounters with systems of power and the subsequent impact on how participants provided care. In addition to this challenge, participants reported experiencing a lack of equity in care, which is detailed in the following subsection.

A Lack of Equity in Care: "Mum's tastebuds were so institutionalised"

For a minority of participants, challenges in navigating the complex intersection between race, culture and care provision resulted in a lack of equity in the care their relative received. Evelyn describes having to supplement care provision at a supported living facility: "*But the the the problem that we had in terms of um our ethnicity is that we were paying for this full package, but we still had to provide some of her own food*" (Evelyn, p. 15). Despite paying for a "*full package*" of care, Evelyn implies that the food provision was inadequate in meeting her mum's cultural needs as she needed to "*provide some of her own food*". Evelyn describes paying for a service that did not cater to the needs of all, leading to feeling a sense of burden and "*unnecessary I think strain to cook meals that I don't even cook for myself and my family on a regular basis*" (p. 36).

When circumstances could no longer permit the provision of cultural foods, Evelyn described seeing her mum slide down the slope of cultural disconnection:

> *A few months down the line, my mum's tastebuds were so institutionalised because of the challenges of and then when you you did provide, you know, Saturday soup and whatever, her tastebuds had forgotten them, which was quite sad.* (Evelyn, p. 17)

Evelyn's description of "*institutionalised*" tastebuds conjures up images of coldness and disconnection, contrasting the intimate feelings of connectedness that are accessible through food and the shared dining experience. The familiar connection to culture provided through eating 'back home' foods was tethered due to her mum's taste assimilating ("*her tastebuds had forgotten*") to the dominant White culture of the supported living facility, leading to an apathetic taste for once familiar foods. Indeed, the aforementioned threat to cultural identity was realised despite Evelyn's efforts to mitigate this.

While receiving what Faye deemed to be inappropriate care ("*they were giving her um some drug to make her drowsy*", p. 31), she described having to be present and vocal at all times to protect her mum:

> *Yeah, she's done 43 years as a midwife and when they heard that they were like, "Oh oh, she's one of us!" I said, "Yes, that's right! So just leave her" so as soon as I said that, they left her* (Faye, p. 31)

Given that Faye had already expressed uncertainty about whether her mum's life was valued by people in positions of power, the mention of her mum's profession ("*she's done 43 years as a midwife*") could be understood as a final attempt to prove her mum's worth in order to receive equitable care.

Faye also depicts an ongoing battle with the police to receive a report which would ordinarily be issued following an incident:

> *Well, to be honest, it was very, very, you know, it was traumatic for me to to basically, you know, be I've been asking for the police report ever since the incident happened this year and to now I've been sort of fobbed off, passed from Peter to Paul* (Faye, p. 27)

Faye describes the distressing experience of being dismissed by police ("*I've been sort of fobbed off*") and feeling trapped in a cycle rife with a lack of culpability for her mum's fall. This experience and the resulting trauma could be linked to well-known historical and recent experiences of police misconduct that have contributed to a loss of public trust in the police.

Florence portrays a similar experience characterised by dismissal from police after reporting the financial abuse her great-aunt endured:

> *When it came to the financial abuse, it feels as if no one really took it that seriously I don't know if it's they figured, you know, in our community, that's the way we are; people send money home, people give, I don't know* (Florence, p. 52)

Florence's description of "*it feels as if no one really took it that* seriously" could be understood as her feeling that her aunt's vulnerability was disregarded. She attempts to make sense of this by considering whether the cultural practice of providing economically for the family could explain the dismissal, yet a sense of uncertainty prevails ("*I don't know*"). Imaginably, this prevailing doubt about the dismissal of her experience could relate to the poor treatment BAC people have become accustomed to during encounters with the criminal justice system. Several cases of harm perpetrated by the police, such as George Floyd and Sandra Bland, have been documented in the UK and abroad.

Without answers, participants applied their reasoning to explain the disparities in care. Faye describes a phantasy about how things would be different if her mum were not Black: "*And I was just thinking, you know, if my mum was a frail White woman, you know, this thing would have been sorted out ages ago*" (Faye, p. 28). Faye's reference to a "*frail White woman*" could be interpreted as her identification of the power of vulnerability in the other. Yet, she demonstrates an awareness that this power has not been afforded to her mum owing to her race, indicating a clear perception that race is a determining factor in the quality of care received.

Similarly, Florence talks about the role of race in her experience: "*I feel the only reason why people were allowed to do what they did and get away with what they did was because my aunt was Black*" (Florence, p. 93). Florence labels racialisation as the sole ("*only*") reason for perpetrators not receiving any sanction for the financial abuse.

For both participants who believed race played a role in their mistreatment, they immediately excused this reasoning as depicted by Florence: "*I do feel that way. And I know I shouldn't say that*" (Florence, p. 93). Florence communicates psychological stress in feeling as though she did not have permission to openly name racism despite believing this was a contributory factor perpetuating the financial abuse. Perhaps this tension is representative of a broader reluctance and tentativeness to speak about racial discrimination on behalf of a relative, particularly in cases where the bias is more covert than overt.

Faye provides an equally dismissive account retracting her statement about race: “*I'm sorry to bring it back to colour but this is how I feel um as a Black woman, you know, just to know that still there's no answers, you know*” (Faye, p. 28). Faye's apology could be interpreted as her feeling that it is unacceptable to label racism, yet she immediately justifies her feeling by stating*, “But this is how I feel, um, as a Black woman*”. Faye's account conveys an internal tussle as she desperately searches for answers in a system that has not afforded her the closure to move forward (“*still there's no answers*”). There appears to be a mirroring here between Faye’s experience and recent cases of miscarriages of justice in racialised communities with a lack of accountability (e.g., the Windrush scandal and Grenfell fire).

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I resonated with the two participants who questioned their experiences in the context of race/racism but were quick to apologise for labelling the discrimination. It reminded me of microaggressions that I have faced where I felt a tentativeness to label the experience and often tried to dismiss the uncomfortable feelings by attributing other explanations to the mistreatment. Perhaps it is because this feels more comfortable and less confronting than considering the alternative. This experience of tentativeness and inhibition was mirrored in my interpretive work as I felt anxious about labelling the subtleties described as racial discrimination. I toyed with the idea and was even tentative in my discussion about this aspect of the analysis in supervision. However, it felt important to represent these experiences, and I feel honoured that participants felt safe enough to share and label racism with me. I wonder if my 'insider' status as a Black female played a role in participants' ability to share these thoughts.

Despite the challenges, there were some exceptional examples of positive care provision from professionals of BAC descent who demonstrated flex in the face of rigid systemic rules. Evelyn presents an account of her experience with carers flexing in the sheltered assisted living facility: “*Some of the carers there of African and Caribbean origin, you know they were so kind they will fry plantain and bring it in for mum*” (Evelyn, p. 15). The “*kind*” actions described by Evelyn could be interpreted as carers signifying their understanding of the importance of her mum maintaining a cultural connection through food. This kindness was exemplified further through carers in the nursing home, whom Evelyn described as “*people that look like us*” (p. 44) and their ways of communicating with her mum: “*It's so important to hear those voices call her mamma or auntie*” (Evelyn, p. 44). Evelyn conveys how carers expressed an implicit understanding of her mum's culture by providing culturally responsive care by addressing her mum as “*mamma or auntie*”. These actions may have contributed to her mum feeling respected and reconnected her to her culture and sense of self. The carers' actions connect to the South African philosophy of Ubuntu, which emphasises people's interconnectedness and shared humanity.

Florence illustrated a similar account of flex shown by a social worker in the investigation into financial abuse:

> *She came to the house, she sat in the front you know. Um she listened. It wasn't are you sure this? Are you sure that? You know, you, you definitely get the difference of... there's a major difference I can, I can't describe it. But it's not so much so of are you sure? Are you sure? You know. It's more like I hear you* (Florence, p. 90)

Florence speaks to the indescribable experience of feeling supported, which she summarises as “*it's not so much so of are you sure? Are you sure? You know. It's more like I hear you*”. One interpretation is that feeling supported involves being heard and validated, which is also an embodied experience that is difficult to put into words.

This sub-theme probed into participants' experience of a lack of equity in care provision and the role of racism and racialisation in sustaining the inequity. The impact of racial trauma on dementia is discussed in the following subsection.

Group Experiential Theme Three: Longing for a Place of Safety and Happiness

This theme represents a minority of participants' sense-making after witnessing their relatives relive past experiences. These re-enactments pertained to their relative's experiences of racism or the desire to return to their home country. However, for the majority of participants, there was an absence of narratives relating to their relative's experiences of racism.

Reliving Past Experiences

A subgroup of participants reported that while caring for their relative, they had witnessed behaviour that was not befitting of the current context, and they had interpreted this behaviour in the context of a previous event. Florence provided a notable account of this experience when she went out with her great-aunt:

> *I remember we were walking going to Portobello and I was like, "Oh, excuse me, can you take a picture for us?" And I asked this White gentleman, and she said, "No, wait 'til you find one of our people" [laughs]. She was like, "No, wait 'til you find one of our people. No, no, no"* (Florence, p. 56-57)

Florence's reference to "*one of our people*" combined with her great-aunt's adamant refusal to engage with the man indicates that she may have felt a lack of identification towards the man owing to his race, resulting in heightened fear and mistrust. Further, Florence interpreted her great-aunt's response during this incident as an enactment of trauma: "*So it was definitely a bit of fear like it gripped her, you know. She was quite frail, and I felt the strength of her grip*" (Florence, p. 74). Florence's description conjures up images of her aunt contending with an extreme embodied fear ("*like it gripped her, you know*") of the consequences of asking a White man to take a photo of them. Florence contrasts the "*strength of her grip*" with her great-aunt's frail appearance to emphasise how much she was enthralled by fear. This visceral reaction could be interpreted as a representation of the extent of her great-aunt's fear of the White other.

Florence could not identify with her aunt's fear and described her feeling*s: "It was kind of embarrassing, a little uncomfortable for me because I didn't want the gentleman to feel, but hmm hmm, she didn't let me take the picture at all*" (Florence, p. 74). Florence's embarrassment and discomfort could be understood as a result of her inability to identify with her great-aunt's experience. Instead, Florence aligns with the stranger, who she does not view as a threat, perhaps due to having not experienced racial segregation. This may have caused further confusion for her aunt to see a Black person aligning with the feared White other.

Florence was able to situate her great-aunt's fear in the context of a time when her aunt experienced racial segregation in the UK: "*Typically she would always mention them going places where there would be people like them, socialising with people who were like them, you know, Black people, and I probably always got from her she just knew where to be*" (Florence, p. 77). Florence's depiction of her aunt "*socialising with people who were like them*", mirrors her aunt's instructions to "*wait 'til you find one of our people*", suggesting that her aunt had re-enacted a longstanding fear and mistrust towards people she could not identify with, specifically White people.

For other participants, the experience of witnessing re-enactments was demonstrated through their relative's attempts to go 'back home'. Fiona talks about an incident where her mum left home trying to get back to the Caribbean:

> *I remember once she er she left the house and er as I say, the place um she's um the village is called Dover, yeah? And she actually got on a got on a bus, and she was going to Dover* (Fiona, p. 51)

Here, Fiona describes her mum's physical attempt to return 'back home' and perhaps she was seeking to return to a place where she felt she belonged. Indeed, Fiona understood her mum's behaviour in the context of the circumstances surrounding her arrival in the UK. Fiona states that her mum "*always said the story to us that she only intended to stay here a year so she only she only bought one coat*" (Fiona, p. 44). Fiona's reference to "*one coat*" indicates her mum's transitory view of life in England, which suggests home, and thus safety and belonging, was conceived to be found back in the Caribbean. This transitory view may have limited her mum's socialisation to the new culture, making the desire to return home even greater when her surroundings no longer felt familiar due to dementia, as she had never intended to stay in England to an advanced age.

Pauline illustrates a similar sentiment in describing an encounter where her mum asked to go home: *And I'm like, "Leaving to go where? You're at your house" "No, no, no, no, this is not my house. I want to go home", you know* (Pauline, p. 51). Here, Pauline appears to refer to a "*house*" or building, which her mum adamantly states she does not recognise. Pauline's language switch to "*home*" as the place where her mum would like to go could be interpreted as a longing for a place where she belongs and experiences an embodied sense of familiarity.

Fiona continues and attempts to make sense of her mum's changing definition of 'home':

> *She wants to be home, and that's probably that's home where she was really happy as well at a certain age you understand me, you know. It's that it's like a safety net, isn't it? Yeah, somebody wants to go home, you feel safe in your your mother's arms.* (Fiona, p. 57)

In this excerpt, Fiona identifies that for her mum, 'home' was not defined as where she lived for over 60 years but rather where she felt most safe and happy. Fiona equates happiness to safety through the "*safety net*" analogy, which could be interpreted to mean a home is not just a building but instead relates to a feeling of security and being held. Fiona's account suggests that her mum sought the safety and happiness she experienced in the Caribbean but not the UK. Given her reference to the loss and role reversal she experienced with her mum ("*because we are looking after her now whereas she was looking after us [laughs,] you know*" p. 12), Fiona may also have been subconsciously referencing her own experience of a loss of safety, given the loss of her mum as a caregiver. Experiencing a lack of safety was a recurring theme and was alluded to in her mum's account of her early days in England: "*I always remember her saying that she was the like the first Black, they were the first Black people to live on that road where she is now, you know*" (Fiona, p. 47). Despite Fiona stating her mum "*didn't really talk about it [racism] to me anyway*" (p. 46), her reference to her family being "*the first Black people*" on the road suggests a significance in that isolating experience with implications of discriminatory instances that her mum did not feel able to share. There is a sense of protectiveness in the absence of shared stories of racism. This is explored further in the following subsection.

Feeling Silenced: The Lasting Imprint of Racism

For the majority of participants, stories about their relative's past experiences of racism were not disclosed, which meant that identifying behaviours as re-enactments of race-related incidents was challenging. There was a noticeable absence of shared narratives about racism; however, there was an acknowledgement of the existence of racism in the lives of their relative. This acknowledgement was illustrated in Brian's account:

> *I think it's um [scoffs] racism, I think is um everybody I won't say accepts it, but knows it exists so it's it's it's it's it's part of life. But no, she's never really said anything specific about her having a racial situation* (Brian, p. 55-56)

For Brian, the normalisation of the existence of racism could be interpreted as his understanding of why his mum did not speak about her experiences of racism. Brian's difficulty expressing his sentiment, illustrated through stuttering ("*it's it's it's it's it's part of life*"), could be understood as being part of a broader tussle with the discomfort of knowing that racial discrimination is perpetrated but feeling helplessly compelled to accept it. Perhaps this mirrored Brian's mum's experience and contributed to her keeping narratives about racism to herself.

The normalisation of racism was also supported in Florence's consideration of the type of stories her great-aunt shared: "*In my mind it [racism] seemed pretty commonplace for her, if it makes sense so you don't speak about something that's ordinary, you speak about something that's out of the ordinary*" (Florence, p. 76). Florence's distinction between the ordinary and extraordinary suggests that all experiences are not equally weighted and that the stories about racism that were told were more likely to be unusual instances. This suggests the extent of the racism her great-aunt endured may never be fully understood as so many untold stories have gone forever.

Evelyn corroborates the idea about experiences being weighted differently in her narrative about how the routineness of racism meant her mum ignored racist remarks:

> *But I think my mum and her generation they were so focused on the prize why they came, you know, when they came they had a whole army to send money back home for, so they weren't as "I'm not even paying you any mind" you know, [laughs] "You don't have to like me" that that was mum's line "You don't have to like me, as long as I get paid every month". Yeah, yeah, they had it bad* (Evelyn, p. 63)

Evelyn conveys a sense of resistance as she demonstrates how her mum's focus on economic emancipation ("*focused on the prize*") for her family appeared to mitigate the traumatic impact of racism. Evelyn describes her mum attending to specific aspects of her experience ("*as long as I get paid every month*") while ignoring racist comments ("*'I'm not even paying you any mind'*"). Her mum's selective attention could be interpreted as a strategy to manage the complex relationship with a country that at times was not accepting of her (" *'You don't have to like me'*") but that she was dependent on as a means to achieving a larger goal.

In trying to understand the absence of narratives about racism, Faye provided an enlightening explanation for the reason she believed her mum did not speak about experiences of racism: "*Caribbean people they tend to not say much*" (Faye, p. 20). Faye's depiction of a cultural belief involving restricting information shared with others could be interpreted as a traumatic retention that has passed through generations but no longer serves its original purpose.

Jamal shared how he was aware that his dad experienced racism, but accounts of these instances did not come from his dad:

> *My uncle used to tell me more about stories and what they had to put up with, you know, when when he first come to this country. My dad never spoke to us about about it. Never spoke to us about it* (Jamal, p. 65)

Jamal's repetition of "*never spoke to us about it"* emphasises the absence of intergenerational stories of racism from his dad, which may have served as parental protection from the challenging situations they endured. Interestingly, Pauline also talks about hearing stories of racism from her uncles instead of her parents:

> *My mum was very is an introvert my mum never really talk about a lot of things. Um a a a all of all of those really came from like my uncles and them but my mum didn't really talk about a lot of stuff like that. Well, not to me, anyway* (Pauline, p. 54)

Pauline refers to her mum as being "*an introvert*", which she believes precluded her mum from sharing stories about painful experiences. Her reference to "*Well, not to me,* *anyway*" suggests a sense of uncertainty about whether her mum did have an outlet to share these narratives or whether they have remained in her memory as untold stories.

Evelyn shared a different experience characterised by openness and a sharing of narratives. She talked about how her mum prepared her for racism: "*She [mum] actively discouraged us from speaking [language]. She said, "You are English children. You have to have your nice accent because this country is tough". So my mum prepared us for racism*" (Evelyn, p. 56-57). Evelyn states she was "*discouraged"* from speaking her mum's mother tongue to facilitate the development of a "*nice*" English accent. One interpretation of her mum's caution against speaking her native language is that her mum had internalised narratives of oppression perpetuated by systems of power related to the perceived inferiority of those with non-English accents. Perhaps this strategy was necessary to survive and raise children in a "*tough*" country rife with racism and discrimination.

Similarly, Faye shared a story from her mum about a discriminatory incident from her early days in the UK. The incident involving police and a false allegation ("*a young White female has just been mugged and it was three Black ladies that had did it*") resulted in her mum assertively challenging the police: "*Well mum was the one that made a complaint to the MP, and she said that she had got compensation*". This incident bears parallels to the assertive way that Faye has managed the situation with the police following her mum's fall. Conceivably, there may have been an intergenerational transmission of mistrust towards the police, which influenced the way Faye has supported and provided care for her mum. Indeed, Faye states: "*She [mum] told me about um, you know how back then you know how how racist you know, things were and sadly hasn't changed much*" (p. 26). This excerpt provides insight into the depth of Faye's beliefs about systemic racism, which have been compounded by recent experiences that have strengthened these beliefs.

The next chapter discusses the substantive findings in the context of existing literature. In addition, the research's strengths and limitations are presented alongside consideration of the clinical and wider implications.

Chapter 5: Discussion

Chapter Overview

This chapter summarises the research findings, drawing on established literature and theories to make explicit links with prior knowledge of familial caregiving in Black African and Caribbean (BAC) communities. The novel contributions to knowledge emerging from the study will also be discussed alongside contributions to clinical psychology and broader implications. This research's methodological strengths and limitations and future directions for the research are presented before offering concluding personal reflections.

Discussion of Findings

This study explored the experiences and sense-making of BAC people caring for a relative with a label of dementia and explored how they make sense of their relative reliving experiences of racism. The literature review highlighted limited empirical research focused solely on the experiences of familial care provision in UK BAC communities. Much UK-based research focuses on the experiences of 'minoritised' communities with little consideration of aspects of race or racism within these experiences. Thus, this study was designed to share stories and contributions to knowledge from BAC voices. In addition, little is known about the experience of observing a PWLD reliving trauma from the perspective of the caregiver. This study aimed to address the gaps in research by exploring experiences of witnessing the reliving of racialised trauma by a PWLD. Using IPA, rich personal accounts from eight BAC relatives were analysed and developed into three group experiential themes presented in the next section.

Group Experiential Theme One: Tension at the Intersection of Care, Culture, and Community

Familial caregivers in this study made sense of their caregiving experience by viewing it as a duty to care for their relatives, with some expressing this duty as a privilege. This sense of duty was centred around cultural beliefs about respect for elders and filial obligations to provide care. In order to make sense of these beliefs, we can look at the structure of BAC families. Research suggests that elders, especially grandmothers, are held in high esteem within BAC families, which contributes to maintaining matriarchal structures in the family (Ramos et al., 2023). The matriarchal family context may contribute to the sense-making about the feeling of duty experienced by participants to care for their female relatives with a label of dementia. However, this theory only partially explains the experience of some participants.

Furthermore, researchers have found that BAC older adults who had migrated to the UK expressed the view that familial care for elders is an obligation and that the failure to provide care within the family could be perceived as shameful (Ma & Joshi, 2021). Given that this review focused on older adults' beliefs, one could argue that the participants in the current study exhibit an intergenerational transmission of beliefs about who within the BAC family unit should provide care for elders and the impact of not fulfilling this commitment. Further research could usefully explore the transmission of beliefs about dementia caregiving within BAC families.

As guided by the aim to understand the meaning attributed to caregiving, participants expressed experiencing caregiving as an extension of their existing role with an implicit expectation to care for their relative. This experience mirrors existing research findings, as highlighted in the literature review, indicating that some Black Caribbean and South Asian carers in the UK drifted into the caregiving role after their spouse or relative received a label of dementia (Adamson & Donovan, 2005). Biographical continuity could somewhat explain the extension of participants' existing role. This concept describes how caregiving can be considered part of a person's ongoing identity (Lawrence et al., 2008). Biographical continuity also relates to research indicating that BAC caregivers do not identify with the title of carer (Milne & Chryssanthopoulou, 2005), perhaps due to the continuity of their role. However, in contrast to earlier findings, the participants in this study did not explicitly express a rejection of the carer label, although it is important to note that this was not an area of focus in the study. Taken together, one could argue that there are limitations to the concept of biographical continuity in explaining the complete participant experience for the BAC caregivers in this study. Further research on the notion of biographical continuity concerning the caregiver label and its meaning to familial caregivers in the BAC community may be beneficial.

Notably, the concept of biographical continuity in dementia care provision does not apply to just BAC communities, thus limiting the need to racialise this element in the sense-making of the caregiving experience. Given that researchers have demonstrated the role of biographical continuity in dementia caregiving outside of BAC communities, one could argue that there is a universality to this aspect of dementia care and sense-making about the caregiver role, which supersedes apparent racialised boundaries. Notwithstanding the commonality of biographical continuity in making sense of familial caregiving, one must also be mindful of the inherent differences in experiences of BAC caregivers and how this may contribute to the sense-making of biographical continuity. Indeed, Adamson and Donovan (2005) identified that racialised caregivers reflected on their pre-caring life, including aspects of their ethnicity, to understand their new status as caregivers. Due to the racialised lens through which BAC people are viewed and thus experience the world, participants in the present study drew on these narratives to make sense of biographical continuity. Continued efforts are needed to ensure formulations about BAC familial caregivers consider the cultural nuances that can make universal, human aspects of the caregiving experience different for specific caregivers.

The participants in this study considered caregiving in a positive light, suggesting that traditional caregiver ideology (Lawrence et al., 2008) contributes to the sense-making of the caregiving experience. Traditional caregiver ideology can be defined as a belief system whereby caregiving is viewed as a privilege and an opportunity to reciprocate the lifelong love and support received from a relative (Lawrence et al., 2008). As the notion of caregiver ideology holds explanatory power for the participants within this study, this affirms that ethnicity is one of many factors mediating the BAC caregiving experience.

Despite the usefulness of ideas about traditional caregiver ideology, one major limitation of this explanatory view is that it does not account for the sociopolitical context, which may have restricted work opportunities for BAC individuals (Fox et al., 1999). Research has indicated that due to racial discrimination, many first-generation immigrants were systematically deprived of specific job roles and more likely to work in low-income jobs, developing skills akin to those used when caring for a relative (Malfitano et al., 2016). Through social learning (Bandura, 1977), second-generation immigrant children learn caregiving skills, predisposing them to positive portrayals of caregiving. This predisposition may have influenced the caregivers in this study to view caring for their relative as a duty and a privilege, as they had been primed to view care provision in this manner. Indeed, several participants reported having job roles in the public sector providing care in health settings prior to becoming a caregiver for their relative with a label of dementia. Taken together, the evidence suggests that the views, sense-making, and approaches to caregiving for familial caregivers in the present study may be influenced by external social and political factors that prime individuals towards developing particular care-related skill sets, in addition to intrinsic motivators.

Overall, participants in this study shared positive stories about sharing care tasks with other family members, namely their siblings or members of their family of procreation. This finding suggests participants make sense of caregiving as a collectivist experience. This collectivist approach to care provision was illustrated through participants and their families taking turns to visit, having a rota for care provision within the home, or contacting siblings for support when feeling overwhelmed. The view of families sharing care responsibilities has been demonstrated in existing research where it was suggested that traditional Caribbean culture, with its emphasis on close family ties, meant that partners of a PWLD utilised the support of family members (Botsford et al., 2012). Interestingly, the Botsford et al. (2012) study opposes the findings of the present research in their suggestion that Caribbean partners of a PWLD expressed an individual or couple orientation to their care provision and preferred to manage independently. This opposing view could be explained by differences in generational beliefs and relation to the PWLD, as those featured in the current research were second-generation immigrants often caring for their parents or close relatives rather than a romantic partner. Additionally, recent research has reflected on the complex insider and outsider cultural identity of second-generation immigrant caregivers in their help-seeking behaviours and navigation of services on behalf of their relative with a label of dementia (Carter et al., 2024). This view could explain some participants' openness to using services alongside maintaining aspects of their cultural identity through collectivist care provision.

A notable finding in this study, which opposes the dominant view in existing literature, was the disclosure of the negative side of providing care for a relative with a label of dementia alongside support from extended family members. For some participants, the collectivist approach to caregiving gave rise to incidents of abuse, shattering the idealist view of the collectivist caregiving experience. Furthermore, traditional cultural beliefs around familial care provision meant participants were made to feel guilty within their communities for care provided outside of the family. Similar findings were also reported in the Samson et al. (2016) study, which found that African American caregivers experienced feelings of guilt and shame for using institutional care for their relative with a label of dementia. Despite this study being conducted in a different cultural context in the US, there is some overlap in the experiences reported, suggesting a resonance in the role of guilt in making sense of dementia caregiving.

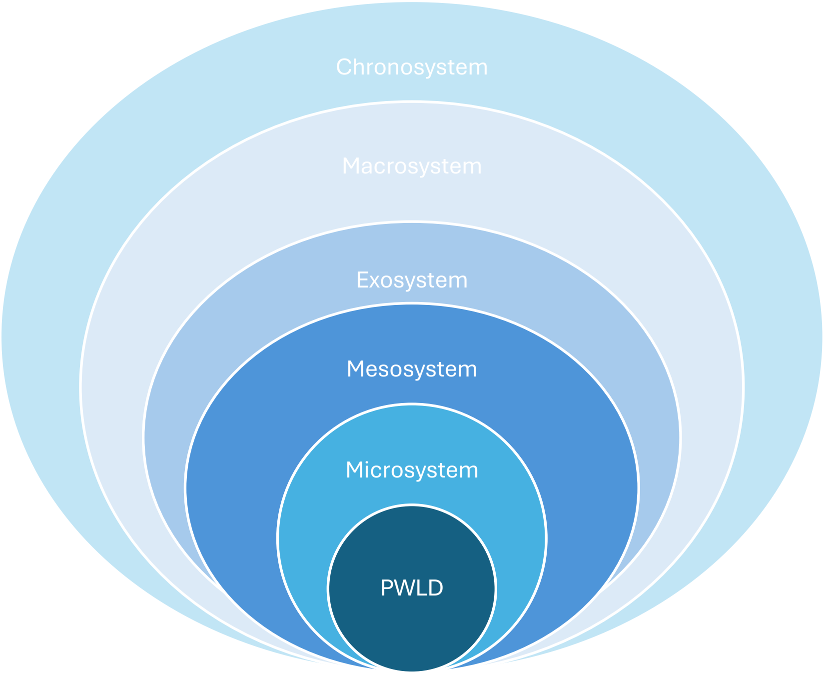
Nevertheless, the feelings of guilt, combined with the broader stigma and dominant narratives about ageing and dementia, added to the challenge of providing care for a relative with a label of dementia. Research indicates that PWLD from BAC communities experience multiple jeopardy due to the societal stigma associated with dementia, being viewed as a racialised minority and migrant within society and the systemic inequalities which lead to holding a lower socioeconomic status (Bamford et al., 2014). At the intersection of these factors, caregivers and their relatives can experience poorer health-related outcomes and increased stress (Parveen & Oyebode, 2018). This finding applied to several participants in the present study, particularly those battling their health issues while caring for their relative.

Bronfenbrenner's ecological systems theory (1974) provides a helpful framework for understanding the impact of cultural beliefs and expectations in the BAC caregiving experience (Figure 3). Through placing the PWLD in the centre, ecological systems theory demonstrates the complex interactions between the caregiver (microsystem), extended family (exosystem), and the attitudes and cultural beliefs of people in BAC communities and beyond (macrosystem). For the participants in this study, the interactions between the familial caregiver and their environment may have played a key role in shaping the caregiving experience. For instance, one participant shared their complex relationship with the criminal justice system as they fought for justice on behalf of their relative. The tensions in managing these interactions heightened the participant’s mistrust of services in the exosystem, which led to questions about the interaction between systemic racism (macrosystem) and the justice system (exosystem). These tensions impacted the PWLD as the participant became hypervigilant in their care provision in an attempt to protect their relative from experiencing further harm.

Similarly, for a second participant, tensions in navigating cultural expectations about care provision and the inadequate cultural service provision, both in the exosystem and attempts to maintain the PWLD's ethnic identity (microsystem), placed undue stress on the caregiver as they attempted to manage competing demands. These tensions between maintaining cultural identity and engaging with the system impacted the relative with a label of dementia as they acculturated to the dominant culture and lost their taste for foods from 'back home'. Importantly, dementia-related public policy at the macrosystem level often focuses on interactions in the systems close to the PWLD, with less emphasis on the broader influential systems which broadly impact BAC and other racialised communities. For instance, the Living Well with Dementia National Strategy (Department of Health and Social Care, 2009) promotes the biological conceptualisation of dementia, focusing on the individual and their caregiver to develop awareness of this view and seek a timely diagnosis before being cared for in the community, usually by informal familial caregivers. In depoliticising dementia, the onus falls on the PWLD and their relatives or support system in the microsystem to manage, rather than the government making changes to systemic inequalities at the macrosystem and exosystem levels. Bronfenbrenner's ecological systems theory (1974) helpfully describes the tensions experienced by most caregivers in this study and the importance of understanding how the different systems work together to impact the PWLD.

Figure 3

Ecological Systems Theory (Bronfenbrenner, 1974)



Another nuanced finding in the present study relates to BAC caregivers' sense-making of care provision as a transformative and affirmative experience. There is much literature about the burden of caregiving; however, the positives of informal care provision in BAC communities should be more frequently discussed. Previous research has identified complexities in deriving rewards through caregiving. In the Lawrence et al. (2008) study, participants expressed opposing views; either they felt they no longer experienced rewards from the relationship with their relative or viewed caregiving as a virtuous endeavour that would be rewarded under religious or spiritual beliefs. In this study, participants expressed different views as they felt they had benefitted from the caregiver dyad through sharing stories with the PWLD. This finding relates to literature about oral storytelling in BAC communities as a vital means to share knowledge (Truswell, 2016b). One participant shared how, through her relative, she had learnt about her heritage and felt a sense of completeness armed with this new knowledge. This links to the literature that teaches us about storytelling's power in its ability to evoke healing and resistance, particularly in African communities

(Chioneso et al., 2020). In considering the less prominent narrative about dementia caregiving, participants revealed the importance of an ancient cultural practice in providing meaning to their caregiver role, which may benefit further investigation.

Through sharing experiences with other familial caregivers, participants became more conscious of the magnitude of dementia within BAC communities. This finding resonated with three of the four participants from the same family, who expressed heightened levels of fear and surprise at how much dementia had impacted their relatives. Research has commonly found higher rates of dementia in people of BAC descent (Truswell, 2016a). However, higher incidences of dementia are often reported as owing to race, positing the responsibility on the individuals while overlooking the sociopolitical context that places people from these communities at risk of dementia. Research suggests that socioeconomic disadvantage, alongside experiences of racism and oppression, can be predictors of poor health in racialised elders, placing them at risk for dementia (Milne & Chryssanthopoulou, 2005). These explanations may have applied to the elders with a label of dementia featured in this study.

Interestingly, considerations of socioeconomic disadvantage and racism did not feature in most participants' sense-making of inflated dementia rates in BAC communities. The lack of consideration of societal factors may have been a result of living and functioning within a system that does not acknowledge racism (Haines, 2019), making it challenging to link these factors to dementia rates. Instead, participants expressed curiosity and questioned whether the diagnostic label of dementia was related to their relative’s diet, social isolation or poor cognitive health. These deliberations about the biological and individualised aetiology of dementia align with the dominant narratives in gerontology research, as mentioned throughout this thesis, and with government strategy and policies. For instance, the Major Conditions Strategy (Department of Health & Social Care, 2023), emphasises the importance of challenging health inequalities in dementia, including tackling socioeconomic deprivation.

Yet, the action plan moves in a different direction, with significant funding targeted at increasing the number of people receiving diagnoses of dementia rather than understanding and making changes to preventable factors, placing people at risk of dementia. Importantly, government strategy should focus on the intersection of sociopolitical, biological, and psychological factors to make sense of dementia rates within BAC communities.

Contrastingly, some participants questioned whether the label of dementia was related to their relative's historical experiences of trauma. To make sense of this, we can look to modern literature, which commonly cites the impact of trauma on the body and the contribution of trauma to physical health conditions. Racialised trauma is carried in the body, and for Black bodies (defined as bodies of people of African or Caribbean descent), racialised trauma can live deep and, over time, can contribute to stress-related conditions such as diabetes and high blood pressure, which are risk factors for vascular dementia (Menakem, 2017). Remarkably, the history of diabetes can be traced back to colonisation, where the removal of highly nutrient foods resulted in food scarcities and changes to diet, which have been passed down genetically through generations (Williams & Buttfield, 2016). Presently, epigenetics, meaning the result of external influences, such as sociopolitical factors, offers an alternative framework to explain racial differences in rates of diabetes (Encinosa, 2021). These findings indicate that an intersectional approach considering the nuances of being a BAC person in the UK should be considered to make sense of inflated rates of dementia diagnoses within these communities (Zubair, 2023). Familial carers, such as those featured in the current study, would also benefit from hearing a more nuanced conceptualisation of their relative's dementia diagnosis, as this may assist with their sense-making process as caregivers and allow them the opportunity to broaden their conceptual framework of dementia.

Group Experiential Theme Two: Battling with Broken Systems

The caregivers in the present study were in a precarious position navigating healthcare systems on behalf of their relatives. They shared how the inconsistent recognition of their relative’s vulnerability by people in positions of systemic privilege had led to various negative consequences and contributed to their sense-making of the caregiving experience. While the study set out to explore the meaning caregivers attributed to the caregiving experience, the results highlighted unexpected insights into their experience managing the intersection between care, culture, and the community.

The participants' experience witnessing a PWLD decline into cultural disconnection due to inadequate service provision is consistent with existing research. As stated in the literature review, Baghirathan et al. (2018) found that Black Caribbean carers were reticent to engage with services that were unable to meet their cultural needs for fear of identity diminishment. In the case of the present study, those fears were realised in the form of one PWLD who developed “institutionalised tastebuds” due to services not meeting their need for cultural foods. Acculturation theories appear relevant in explaining the cultural disconnection experienced by the PWLD in care settings.

The fourfold acculturation theory (Berry, 1980) posits four approaches to the acculturation process: integration, assimilation, separation, and marginalisation. The participant whose parent lost their taste for once familiar cultural dishes appears to have undergone a process of assimilation to adopt the taste of the cultural norm of the care home over their original culture. Contrastingly, another participant described their relative experiencing a separation from the dominant culture with food. This participant made sense of their caregiving role as one that involved a responsibility to preserve their relative’s belief in the healing properties of foods native to Carriacou by serving these foods in place of medication provided by the biomedical system in the dominant culture. Notably, the participants in this study demonstrate how individual differences in acculturation may not be by choice and that contextual factors can restrict the acculturation process. Overall, the present study findings posit that consideration of acculturation theory and how one has approached aspects of acculturation would be beneficial in determining ways to best support the PWLD in maintaining a connection to their culture of origin, as this forms an integral part of their identity.

Participants reported concerns that statutory services did not value their relative's life. This view could be understood in reference to literature, such as the work of Frantz Fanon (1952). This work considered how societal constructions of Blackness have led to beliefs about Black people not being accepted in society owing to their race. Fanon (1952) argued that Black people from once-colonised lands desired recognition and acceptance into the dominant White society. In doing so, Black people internalised a sense of inferiority, while White people simultaneously internalised a sense of superiority. A lack of societal acceptance could, in part, explain the differences in treatment for the PWLD in this study, particularly those who were rejected from daycare centres that were designed to support all. In addition, the impact of Whiteness, which positions the experience of White people as the norm, should not be understated in its influence on the treatment of BAC communities engaging with healthcare and criminal justice systems (Menakem, 2017). Participants made sense of their mistreatment through the lens of Whiteness and imagined how their experience could have been different if they were from the dominant culture. Theories about constructions of Blackness and the impact of Whiteness suggest that the factors influencing mistreatment in healthcare services may be vast, including systemic and personal considerations. These findings extend our understanding of how racial classification and discrimination can impact on the caregiving experience.

Participants' mistrust towards services could be viewed as the manifestation of iatrogenic harm, defined as the resulting harm from differential treatment and poor health outcomes for people from minoritised backgrounds (FitzGerald & Hurst, 2017; Menakem, 2017; Black & Calhoun, 2022). Iatrogenic harm is thought to be due to implicit bias exhibited by healthcare professionals and systems (Black & Calhoun, 2022). Indeed, it is crucial to consider that healthcare professionals are also subject to the same social conditions as participants and the PWLD (Haines, 2019). However, the impact of the current social conditions can be felt in various ways. The implicit bias of professionals can be perpetuated by their actions, which aim to generate a sense of safety by retaining their privilege (Haines, 2019). This power struggle was depicted in the accounts of participants whose attempts to advocate for their relatives were met with hostility from healthcare staff, thus positing the caregiving experience as one that involves a lack of safety.

In response to differential treatment, participants made repeated attempts to seek justice and accountability for the harm their relative had endured. These actions relate to literature describing the tension for those from BAC communities who wish to heal from harmful systemic practices but struggle to achieve healing against a milieu offering limited accountability (Haines, 2019). This lack of accountability led to participants tentatively identifying racialisation as the explanation for their mistreatment. At a macrosystem level, the effects of racialisation have been ignored, most recently demonstrated in the Race and Ethnic Disparities report (Commission on Race and Ethnic Disparities, 2021), which denied systemic racism as a factor impacting healthcare. For the participants in this study, experiencing the silencing of racism makes labelling racial discrimination increasingly challenging in a context where racism is denied (Harries, 2014).

The anecdotal examples of exceptional care provided by BAC professionals towards participants and their relatives demonstrate the power of healing and acts of resistance (Wade, 1997). Here, acts of resistance can be defined as small actions demonstrating determined resistance against systems of power (Wade, 1997). This finding aligns with research which found that Black clinicians working with Black clients leaned into shared racial and cultural identities to co-create a joint understanding and validation of experiences (Lipscomb & Ashley, 2020). For the participants in the present study, validating experiences were transformative and memorable, restoring some faith in the services they sought support.

Group Experiential Theme Three: Longing for a Place of Safety and Happiness

The present study provided novel insights into the psychological impact of historical experiences of racial discrimination for BAC elders growing old in a country with which they have a complex relationship. Participants recounted how their relatives had reexperienced memories that appeared to be rooted in a time when they felt the impact of racism after having immigrated to the UK. For some participants, their reenactment was through trying to physically return to the Caribbean Island they called home. This finding is akin to that of a recent study where researchers found that first-generation immigrant elders with a label of dementia expressed a desire to return to their homeland in response to worsening memory difficulties (Carter et al., 2024). Attempting to return home aligns with the literature highlighting the importance of having a sense of safety, belonging, and dignity (Haines, 2019). Here, traumatic experiences and oppressive practices can negatively impact these fundamental needs, resulting in an internal struggle which splits safety, belonging, and dignity from each other (Haines, 2019). In trying to return to the Caribbean, the PWLD appeared to be enacting a desire to meet and reunite their need for safety, belonging, and dignity in a place where these needs were once met.

The reenactment of memories was also depicted through the embodied fear response of one PWLD towards a White man. This study was novel in its depiction of the reliving of memories of discriminatory experiences for a PWLD. Notably, the findings in this research do not claim to make causal inferences between past experiences of racism or racial discrimination and a diagnostic label of racial trauma for the PWLD. In the absence of perceptions about incidents of racial discrimination from the PWLD, it would not be appropriate to label the reenactment of memories as a reenactment of racial trauma. Here, racial trauma is defined as race-based stress experienced in response to racial discrimination (Comas-Díaz et al., 2019). The gap in understanding perceptions of racist experiences from the perspective of the PWLD highlights the importance of knowing the life story of BAC elders with a label of dementia. For the caregivers who were aware of their relative's experiences of racism, they were able to make connections between current behaviours and past traumatic experiences. Yet, it is important to acknowledge that these perceptions were obtained from the caregivers and not the PWLD, which may limit the extent to which we can claim the behaviours witnessed by familial caregivers were reenactments of a primary incident. The tentativeness in labelling racial trauma and the reenactment of discriminatory memories speaks to the challenge of naming an experience that is not yet nameable. However, the majority of familial caregivers were not aware of their relative's historical experiences of racism, and this finding aligns with existing research presented in this thesis literature review. The Craftman et al. (2020) study explored views of care staff supporting elders with a label of dementia who were reliving experiences related to the Holocaust. These researchers found that establishing the history of the PWLD was challenging as traumatising experiences had not been communicated to relatives.

The LUUUTT model (Pearce & Pearce, 1998) provides a helpful framework to explain the manner of storytelling about experiences of racism in BAC families. The model suggests tensions exist between the story lived or told and the unknown, untold, unheard, and untellable stories. For the PWLD, stories about the racism they experienced were untold and unheard by relatives. The retention of untellable stories by the PWLD appeared to be a protective action; however, it also inhibited the depth of understanding of the extent of the challenges faced when immigrating to the UK. Additionally, the silence around racism through the retention of stories limited the caregiver's understanding of the PWLD's perception of the racist memories and whether they would classify their experience as traumatic as perceptual insight is important in being able to accurately label an experience as traumatic. This may be an important area for future investigation, as discussed later in this chapter. One participant who described a Caribbean cultural practice of not sharing difficulties with others provided an alternative view on the retention of stories. This view is well-established in research (Berwald et al., 2016). Although posed as a cultural practice, this could also be understood as traumatic retention, defined as once adaptive responses to a traumatic experience that become internalised and passed down through generations (Menakem, 2017).

Strengths and Limitations

To my knowledge, this is the first IPA study focusing exclusively on the sense-making of caregiving experiences for BAC familial carers in the UK. Existing research has extensively explored attitudes, needs, and understanding of dementia from the perspective of carers within BAC communities. Yet, less attention is placed on the meaning of the caregiving experience. In addition, the present study has contributed to knowledge about the interconnectedness between memories of racial discrimination and dementia, explicitly unearthing insight into how behaviours of BAC elders with a label of dementia may be interpreted as a reenactment of memories related to incidences of racism. By focusing on racialisation and racism in gerontology research, this study is unique in its contribution to scholarship on ageing, ethnicity, and race (Torres, 2020).

One key strength of this study was recruiting participants from a 'hard-to-reach' population. By focusing exclusively on the experiences of BAC participants, this research championed their voices to develop a nuanced understanding of their experiences. While the study sample was small, limiting its generalisability, this research privileged subjectivity to enhance knowledge about the BAC caregiving experience. The use of IPA has raised the level of understanding by focusing on the depth and meanings underlying the experience.

In considering the challenges and opportunities of the participant group featured in this study, one advantage is the inclusion of four participants who knew and were related to each other. This was beneficial as it allowed for a deeper understanding of the impact of dementia within this family and highlighted the shared experiences among the caregivers. However, I was also mindful of the limited generalisability of these experiences outside of this family and the challenge of maintaining confidentiality among these participants who may recognise the stories shared and presented in this thesis. In addition, the majority of the participants were females who shared their experience caring for a female relative with a label of dementia, which aligns with existing research emphasising the gendered role of care within BAC communities.

Although IPA guidelines stipulate using a relatively homogenous sample (Smith & Osborn, 2008), the degree of homogeneity in this study sample could be contested. Participants were invited to participate based on their shared caregiver status and ethnicity. It is worth noting that despite not being specified in the recruitment advert or inclusion criteria, all participants were second-generation immigrants from the south of England, primarily female offspring supporting their female relative, thus signifying an additional level of homogeneity. Further, most caregivers were of Caribbean descent, with half the sample originating from the same family. However, due to recruitment challenges, some participants who did not align with the previously mentioned characteristics were included in the study. Two participants of African descent and two males were included in the sample. It is difficult to determine whether this sample adheres to the notion of being ‘relatively homogenous’;

however, it was appropriate to the aims and context of the research question and adhered to interpretive phenomenological epistemology by focusing on recruitment based on experiencing the phenomena.

While I consider my identity as a Black British African woman to have been an overall strength in this research, I have also reflected critically on the role this ethnic and gender concordance may have played in the research process. In the interviews, participants were each asked for their views about partaking in an interview with a researcher from a similar ethnic background. Most participants spoke to the usefulness of having shared cultural understandings, with one participant (Florence) even expressing that she felt more motivated to participate in research for the BAC community conducted by someone from said community. Nonetheless, the perceived similarities between the participants and I impacted the interview process and may have led to assumptions of understanding on both sides. In addition, my gender may have impacted the sample demographics and invertedly encouraged women to volunteer to participate due to their identification with our shared identity. Furthermore, as the person in a position of power, directly asking participants for their views about the interview experience ignores the inherent power differential that may contribute to participants providing a socially desirable response.

Still, researchers suggest that for investigations into dementia and ethnicity, having shared values and a similar background between researcher and participant can contribute to increased comfortability, willingness and openness, producing rich interview data (Roche et al., 2020). Indeed, having the same nationality as one participant allowed them to intersperse Krio phrases into the interview and to express cultural nuances that would not have the same meaning if spoken in English alone.

Notably, the absent voice of the PWLD is a limitation of this research. There has been considerable debate about the ethical considerations needed when including a PWLD in research, namely procedures for gaining informed consent from individuals with limited capacity to consent to participation. One study by Ritchie et al. (2021) included the views of veterans with a label of dementia and described the adaptations made to the consent procedures. This included gaining consent at regular intervals during interviews and seeking written consent from a third party with the authority to make decisions on behalf of the PWLD. These considerations would be beneficial for future studies of this nature, and this is discussed further in the future directions section of this thesis.

Although BAC elders with a label of dementia were not included in the design of this study, their views were considered through the use of systemic questioning strategies in the interviews. Participants were asked circular questions to facilitate a broader exploration of experiences and to bring the voice of the PWLD into the research.

While this thesis' conceptual framing has primarily taken a trauma-focused lens, this could be viewed as a limitation of the study. Focusing on trauma implies that the pathology of trauma is located within the PWLD rather than focusing on the psychological and societal contexts perpetuating the harm (Gómez et al., 2015). Future research could usefully frame these findings using a feminist lens or through consideration of critical race theory.

Implications of the Study

Despite the limitations, this study significantly contributes to our knowledge of dementia care provision for BAC communities in the UK. One key finding to emerge from the present study concerns the reexperiencing of memories for a PWLD. For the participants who had access to the relevant historical information, they were able to identify and formulate their relative's behaviour in the context of previous experiences. However, more commonly, participants were unaware of specific race-related experiences their relative had encountered and, as such, were less able to hypothesise the correlation between their relative's behaviour and earlier discriminatory incidents. Importantly, due to the impact of the silence around racism and the tentativeness in caregivers labelling reenactments of memories as racial trauma, there are significant implications for the clinical practice of healthcare workers caring for a PWLD. It would be beneficial for healthcare workers to be taught about the subtleties of how historical experiences of racism can present in a BAC PWLD, particularly when they find themselves in a vulnerable position and require care. The expanded knowledge about trauma reenactments should usefully be taught to healthcare workers to support their consideration of the variety of ways that memories of racial discrimination can present. This will help guide a trauma-informed approach to care provision for BAC PWLD who have experienced racism.

Given the role BAC familial caregivers play in supporting a PWLD, the evidence from this study suggests that an alternative approach to dementia care provision is needed. To establish an understanding of the PWLD's perceptions and experiences, which would facilitate the labelling of experiences as reenactments of trauma, individuals and systems involved in their care provision should prioritise identifying the PWLD's life story. Clinicians should adopt an approach that supports people with caring responsibilities, both formal and informal, to develop an in-depth understanding of the life story of the PWLD (Craftman et al., 2019; Mackenzie, 2007). This approach would need to be embedded into service culture with input from clinical commissioning groups to ensure these considerations are included in the service development plan. Additionally, clinicians should prioritise identifying an individual’s life story and incorporate approaches such as narrative therapy techniques (e.g., tree of life) into memory assessments or psychoeducation provided following the diagnosis of dementia.

While findings from the present study align with existing literature about inadequate culturally responsive care provision, they also highlight the challenges caregivers face to maintain a cultural connection on behalf of their relatives, which adds to and complicates their care responsibilities. Participants recognised that their relative's identity was culturally entwined with their African or Caribbean roots. As such, they felt it essential for their relative to remain connected to this aspect of their identity. Services need to adopt an inclusive approach to account for these findings. Participants reported experiencing rigidity, except from carers or clinicians of BAC descent who seemingly understood the importance of maintaining a cultural connection. This understanding of cultural nuance must be prevalent across all levels of organisations. The use of frameworks such as Ecological Systems Theory (Bronfenbrenner, 1974) may be beneficial to support clinicians to extend their thinking beyond the individual level and to consider the importance of the PWLD's culture and ways this can be incorporated into care provision. For instance, participants spoke about the familiarity experienced when dressing their relatives in cultural clothing or providing them with cultural foods. In addition, music was an essential feature in rousing familiarity of the PWLD's culture. These findings can be incorporated into reminiscence work or groups to facilitate a sense of connection alongside safety, belonging, and dignity (Haines, 2019). Facilitating explicit culturally tailored groups may be beneficial. Caregivers and, where possible, the PWLD should be involved in planning culture-based interventions to ensure they are appropriate and relevant to the PWLD's context.

Participants in this study repeatedly referenced incidences where their relative's vulnerability was muted during interactions with services. The consequences of this inconsistent recognition of the PWLD's vulnerabilities were vast. Consequences were experienced through unsuitable care provision, serious physical injury, and exclusion from daycare facilities, to name a few. When acknowledging the pressures public care services face, such as budget cuts and chronic understaffing, we can recognise how these incidences may have come to pass. However, from the perspective of the BAC caregiver, they presented as additional challenges and with a lack of accountability and recognition of the iatrogenic harm, this contributed towards mistrust of services. Clinicians will need to consider these dynamics and reflexively consider their role in perpetuating harm to BAC PWLD and their familial caregivers. Given the drive for clinical psychologists to take on leadership positions, drawing attention to these dynamics and facilitating reflections may form an essential part of their role. Notably, while these considerations have been presented in the context of dementia caregiving, they can also be applied to familial care provision for other health conditions.

Finally, participants expressed concerns about the prevalence of dementia within BAC communities. Through connecting with others in their communities, caregivers developed their awareness of the extent to which dementia is impacting BAC families. They also reported a sense of solidarity felt through sharing similar experiences with other familial caregivers. This finding indicates that although there is increasing awareness of dementia, the extent and impact of the diagnosis in BAC communities are less understood by caregivers. Clinicians and commissioners need to focus on raising awareness of the realities of living with someone with a label of dementia. Services should endeavour to connect with caregivers in the community, providing safe reflective spaces to allow familial caregivers to come together and share the realities of caring for a relative who is becoming unrecognisable. These spaces will also help to reduce the societal stigma attached to dementia. Additionally, caregivers would benefit from understanding the impact of sociopolitical factors in addition to a biomedical conceptualisation of their relative's dementia label. Clinicians should endeavour to formulate alongside the PWLD and, where appropriate, their caregiver to develop a broader conceptualisation of the label of dementia that accounts for a variety of contributing factors.

Future Directions

Considering this study’s original contributions to knowledge alongside the limitations, the following section presents directions for future research.

Given the dearth of gerontology research about the intersecting dimensions of dementia, ethnicity, and race, continued investigation in this area is encouraged. The current study explored caregiving experiences from the perspective of participants who were second-generation immigrants in the UK. Future investigations could usefully expand on the knowledge base generated in the present study about dementia care provision from the perspective of second-generation BAC caregivers. Additionally, while the participants were grouped in this study, future work could explore the experiences of Black African and Black Caribbean participants separately.

The novel findings of the current study could be extended through practical action research, whereby African and Caribbean chefs could be invited into care homes to participate in a cooking project. The aim would be to bridge the gap between the knowledge generated in the present study and practice and to improve the provision of culturally responsive care for BAC relatives with a label of dementia. Fundamentally, the action research project would need to be co-produced alongside the PWLD, their familial carers and the care home staff. Given the importance of family values and the togetherness facilitated through food-centred practices, the meals could be shared with residents from all ethnic and cultural backgrounds. Per action research principles, researchers will need to engage in a continuous cycle of transformation between theory, practice and reflection (O'Brien, 1998).

As the voice of BAC relatives with a label of dementia was absent from the current study, future research would benefit from carefully considering methodologies that could involve the PWLD in various stages of the research process. For instance, the PWLD could engage in creative life story work using photography or music to cue the PWLD to share their life story. This narrative could guide the direction of the research interviews, thus generating rich discussion. Additionally, awareness of their relative's life story would also be beneficial in supporting carers with their sense-making of their relative's experiences.

Self-reflexivity

Firstly, I will start by expressing my heartfelt gratitude to the participants in this study, who were open and vulnerable in sharing their stories. In doing this research, I knew that whichever topic I chose for my thesis, I wanted to look at it from the lens of a BAC person in the UK, as I wanted to walk alongside and share the voices less heard in psychological research. I knew that choosing a topic that explored racism would be emotionally taxing, but I felt honoured to have the opportunity to listen and share these narratives. I was struck by the similarities between participants' experiences and interactions with services and was simultaneously disappointed. It felt like a stark reminder of how far we, as a society, have to go to provide equitable services for all. I vividly recall my physiological response while hearing about these caregivers' challenges, which will stay with me. I felt angry for the participants and could feel the heat rising within my body, which may have been my body connecting to and mirroring the emotions of the participants. This feeling was a motivational force that kept me going when writing this thesis became particularly challenging.

I also have vivid memories of the ways caregivers looked at me when I showed understanding and empathy towards their experiences. For some caregivers, the research interview was their first opportunity to speak about their care experience with someone outside their family. At times, this meant that parts of the interview were filled with an overwhelming offload of information and feelings. I allowed participants to speak as it felt almost therapeutic for them to speak freely. In hindsight, I was not prepared for the extent to which this research would be emotionally demanding. I appreciated thesis supervision and journal entries as a space to discuss my reflections. I also attended a reflective group for Black researchers and found value in connecting with peers who had similar experiences of conducting research from an insider perspective.

Reflexivity has been an integral aspect of this research process. I included reflexive memos in most chapters of this thesis to provide additional insight into my thought processes. I am conscious of my impact on this research, mainly because the interpretations presented are based on my understanding of shared experiences. I, like the participants, have also been impacted by the sociopolitical context in the UK and the repeated race-related incidents that have been reported over the time I have conducted this research.

As a novel researcher, I found various aspects of the research process taxing. Being reasonably new to qualitative research, I had not anticipated the amount of data I would be presented with nor the time it would take to complete the analysis. I also placed much pressure on myself to ensure I was doing the analysis "right” and given my goal to share participants' stories at an academic level, I wanted to ensure their experiences were at the fore. My hesitation and anxiety meant that the process was slow at times. However, I am hopeful that the work produced has achieved my goal of portraying the nuances in the experiences of these participants and contributing to our understanding of familial caregiving in BAC communities and how caregiving, memories of racism, and dementia can interact. The findings have taught me about the reality of caring for a relative with dementia and the intersectionality of this experience with BAC second-generation immigrants in the UK.

Throughout this process, I have found supervision to be an invaluable space to receive support. My two supervisors had very different skill sets, experiences, and worldviews, facilitating rich and helpful discussions during supervision. I also valued speaking to peers who were also using IPA, as this validated the process and my thinking during different stages of the analysis.

In a professional sense, I have learnt a lot from this research that I will take into my qualified clinical psychologist role and beyond. The importance of understanding the individual circumstances of the PWLD and their caregiver cannot be ignored. While I know the importance of formulation within the clinical psychologist role, I will now endeavour to incorporate an understanding of the complexities of BAC familial care provision in my formulations, practice and interactions with caregivers. Furthermore, through developing my understanding of the embodied manifestation of memories and how discriminatory memories can present, I am keen to continue evolving as a practitioner by incorporating embodied practices into my approach alongside talking therapies. Lastly, having a greater understanding of our fundamental needs for safety, belonging, and dignity (Haines, 2019) and the importance of interdependence, I will prioritise fostering togetherness to support the healing process for people experiencing psychological distress.

The participants' descriptions of the exceptional care they received from other BAC professionals resonated with me. Throughout clinical training, I have found myself in situations where BAC clients have entrusted me with information about race-related experiences that they did not feel comfortable sharing with White colleagues. For example, I can recall displaying empathy and understanding for one person who shared their experiences of racism for the first time in the therapy room. On another occasion, I demonstrated my understanding of the plight of the Black Caribbean man who expressed his reticence to attend therapy only after a White colleague left the room. These anecdotal instances, combined with the powerful narratives from participants, have demonstrated the importance of professionals willing to listen and understand an individual's experiences. Incorporating an approach that prioritises fostering a relationship based on trust and understanding may mean taking the time to understand the history and impact of racialised experiences to support the telling of an untold story. This strategy is essential for BAC elders who moved to the UK at a time when racism towards the BAC communities was rife. Reflecting on this reminds me of the following quote, which reflects the experiences of many within BAC communities: *"I was not born with an opinion of the world, but it clearly seemed that the world had an opinion of* *people like me."* from the book Natives: Race and Class in the Ruins of Empire (Akala, 2019).

Conclusion

Understanding the intersecting cultural nuances of familial caregiving in BAC communities is integral to providing culturally responsive care for the PWLD. Current configurations of services have contributed to the diminishment of the cultural identity of the PWLD through rigid care provision predominantly catered to the dominant culture. For care to be equitable, services need to consider the specific needs of each individual. It is also crucial for clinicians to consider the sociopolitical context surrounding care provision for a BAC elder with a label of dementia. Caregivers appreciate feeling heard and understood, particularly when facing challenges in caregiving and seeking systemic accountability for the harm their relatives have experienced.

Given the rapidly ageing and culturally diverse population of the UK, it has become increasingly important to consider the historical context of elders who are most at risk of receiving a label of dementia. By considering traumatic experiences, including racialised trauma, in our formulations, care provision can be tailored. Clinicians need to distinguish between symptoms of trauma and behaviours associated with dementia. Clinical psychologists are central to supporting caregivers and their relatives by encouraging system-wide consideration of various factors in their interactions, formulation, and approach to supporting BAC familial caregivers.

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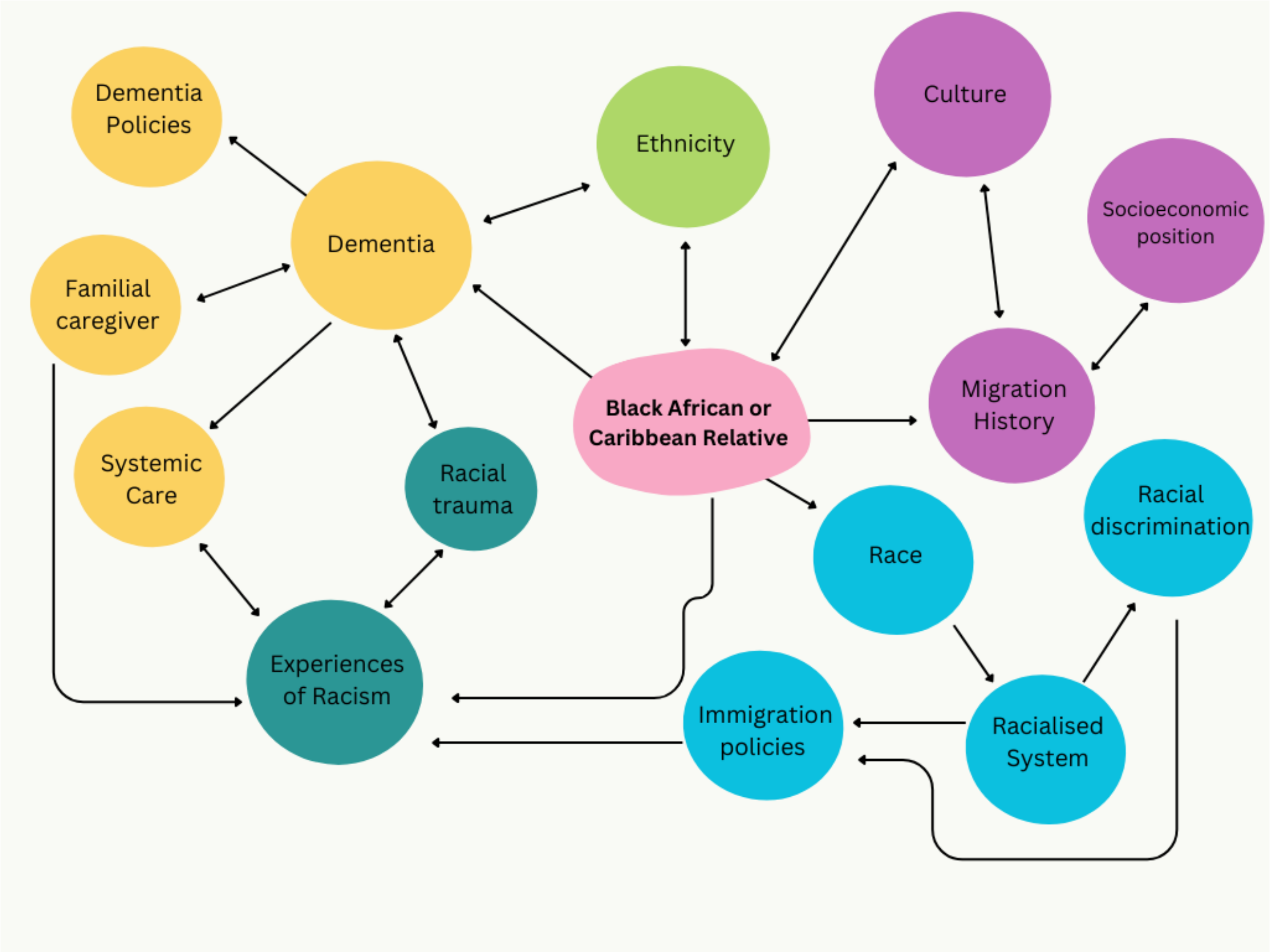
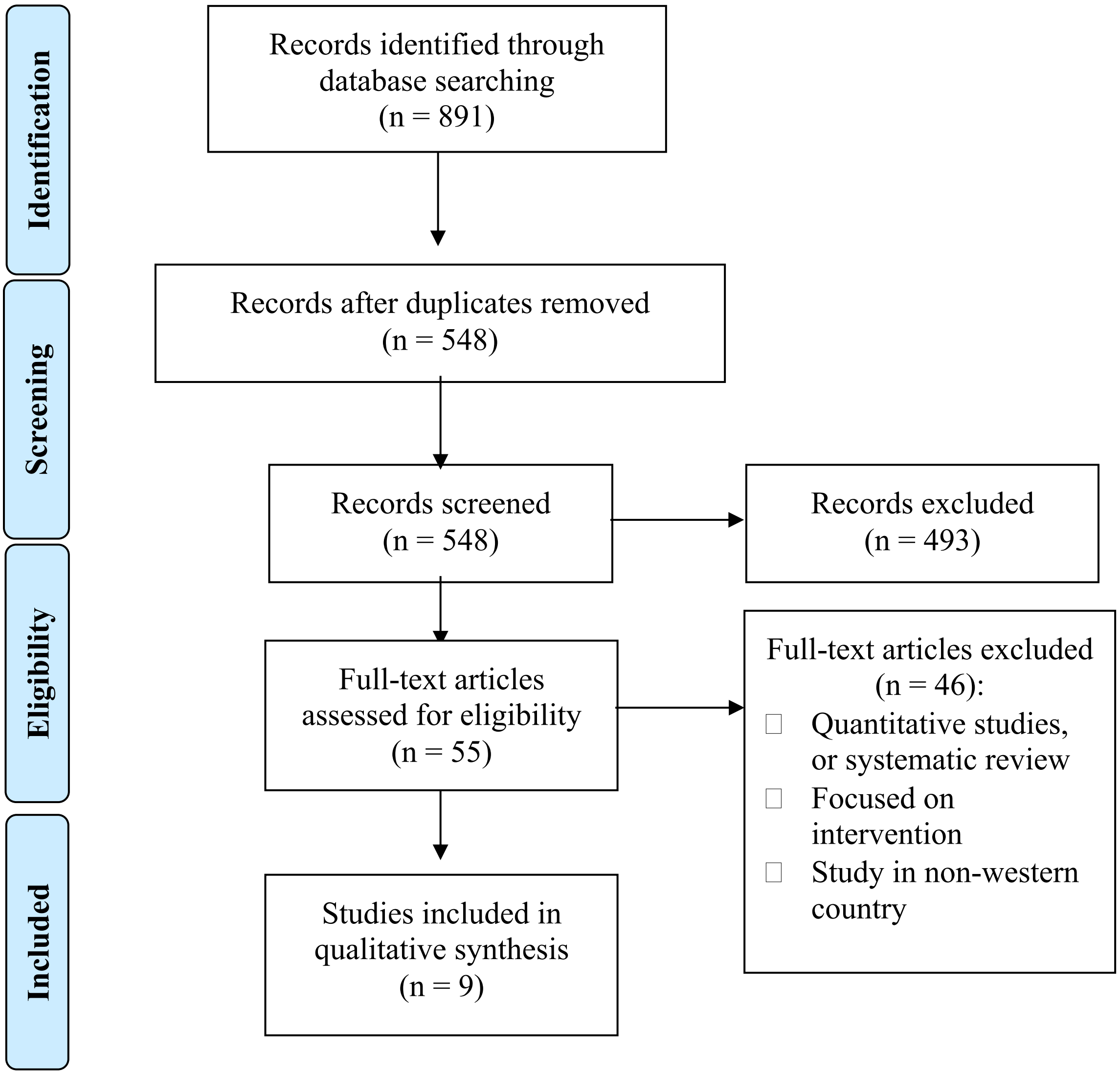
Appendices

Appendix 1: Conceptual Framework Map



Appendix 2: PRISMA flow diagram for Literature Review 1



Appendix 3: Quality Appraisal for Literature Review 1

Study	Aim	Methodology	N	Sample	Country	Data collection method	Main findings
Adamson & Donovan (2005)	To explore experiences caring for an older family member with dementia.	Qualitative – grounded theory	36	*Age:* Not stated *Gender:* Not stated *Ethnicity:* African/Caribbean (*n* = 21); South Asian (*n* = 15)	UK	In-depth semi-structured interviews	Caregivers make sense of their experience by drawing on notions of biographical continuity.
Baghirathan et al. (2020)	To understand the experiences of caregivers for family and friends with dementia from three ethnic groups.	Qualitative – grounded theory	103	*Age:* Not stated *Gender:* Male (*n* = 25) Female (*n* = 78) *Ethnicity:* African Caribbean (*n* = 25); Chinese (*n* = 31); South Asian (*n* = 47)	UK	27 interviews; 8 focus groups	Participants acknowledged a need for support from statutory services but were reluctant to accept support at the expense of identity diminishment.
Botsford et al. (2012)	To examine the experiences of partners of people with dementia in two ethnic groups.	Qualitative – constructivist grounded theory	13	*Age:* mid 60s-late 80s *Gender:* Male (*n* = 7); Female (*n* = 6) Ethnicity: African Caribbean (*n* = 6); Greek Cypriot (*n* = 7)	UK	43 in-depth interviews over 18-month period	Caribbean partners of a PWLD engage in continuous process of redefining relationship. Partners tend to view themselves as individuals and manage care provision alone or with support of service.
Fox et al. (1999)	To explore how race and ethnicity interacts with recognition, meaning making, and responses to dementia in African American familial caregivers.	Qualitative – interpretive phenomenological	10	*Age:* Not stated *Gender:* Male (*n* = 3) Female (*n* = 7) *Ethnicity:* African American (*n* = 10)	USA	Extended individual interviews	Caregiver burden in African American carers can be understood through an anthropological gaze. Consideration of sociopolitical and historical forces is key in making sense of the caregiver's experience.
Lawrence et al. (2008)	To explore attitudes, experiences, and needs of	Qualitative – grounded theory	32	*Age:* 33-87 *Gender:*	UK	In-depth individual interviews	Caregiving can be understood through the lens

Study	Aim	Methodology	N	Sample	Country	Data collection method	Main findings
	family carers of people with dementia from largest ethnic groups in the UK.			Male (*n* = 7); Female (*n* = 25) *Ethnicity:* Black Caribbean (*n* = 10); South Asian (*n* = 10); White British (*n* = 12)			of caregiver ideology. This view of care provision can determine whether the experience leads to feelings of fulfilment, or strain and predicts attitudes towards formal services.
Mars et al. (2017)	To describe the lived experience of informal African American caregivers for family member with Alzheimer's disease and related dementias (ADRD).	Qualitative – phenomenological approach	16	*Age:* 50-85 *Gender:* Male (*n* = 2) Female (*n* = 14) *Ethnicity:* African American (*n* = 16)	USA	Semi-structured interviews	Caregivers felt that did not have enough information, support or guidance about the reality of caring for a relative with dementia.
McLennon et al. (2020)	To understand the experiences of African American daughters caring for parents with ADRD.	Qualitative – content analysis	12	*Age:* 54 (mean) *Gender:* Female (*n* = 12) *Ethnicity:* African American (*n* = 12)	USA	Secondary data analysis	Care experience can be understood through examination of caregiver concerns and coping strategies.
Ramos et al. (2023)	To explore the experiences of Black American women caring for a relative with ADRD.	Qualitative – interpretive phenomenological approach	5	*Age:* 63-81 *Gender:* Female (*n* = 5) *Ethnicity:* Black American (*n* = 5)	USA	Individual interviews	Caregiving is viewed as an obligation. Caregiving can have an impact on the health of the carer. There is a need to consider the support caregivers require to look after their relative with dementia.
Sterritt & Pokorny (1998)	To explore the meaning of caregiving for African American caregivers of family members with Alzheimer's disease.	Qualitative - interpretive phenomenological approach	9	*Age:* 31-80 *Gender:* Not stated *Ethnicity:* African American (*n* = 9)	USA	Individual interviews	Caregiving can be understood as a traditional family value and act of love. Social support is key in mediating the burden experienced by caregivers.

Appendix 4: Meta-Ethnography on the Reenactment of Trauma in Dementia

Abstract

Background: Research has suggested a bidirectional relationship between post-traumatic stress disorder (PTSD) and dementia. In addition, there have been observations of people, mostly army veterans, with dementia re-enacting past traumatic experiences. **Objectives:** To systematically review and present literature on the phenomenon of trauma re-enactments within dementia using a meta-ethnographic synthesis approach. **Methods:** A systematic review of databases, APA PsycInfo, CINAHL, MEDLINE and Web of Science, led to the identification of six studies describing the phenomenon of traumatic experiences being re-enacted in dementia. A meta-ethnographic approach was employed to synthesise the research. **Results:** There were five concepts identified across studies: symptomatic expression of trauma, aetiology, PTSD onset, treatment, and implications. From these, second and third order interpretations were developed. The findings provide a limited understanding of how trauma can manifest behaviourally in dementia. **Conclusion:** Current evidence suggests behavioural and psychological symptoms of dementia may be misinterpreted as consequences of dementia, rather than re-enactments of psychological trauma. Biological and psychosocial explanations have been proposed to understand the relationship between trauma re-enactments and dementia.

Introduction

With an increasingly ageing and rapidly growing population, it is expected that the prevalence of dementia will continue to steadily increase over the next 30 years (Schwarzinger & Dufouil, 2022). According to the World Health Organisation (WHO), there are approximately 50 million people living with dementia globally with older adults presenting as high risk (WHO, 2012). Currently, it is estimated that due to the COVID-19 global pandemic disproportionately affecting older adult death rates, the current number of people living with dementia is slightly lower than in previous years (Schwarzinger & Dufouil, 2022).

The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-V; American Psychiatric Association, 2013) defines dementia as a major neurocognitive disorder characterised by cognitive decline. These cognitive changes are the result of physical changes occurring in the brain. Dementia, an umbrella term, refers to a series of acquired neurocognitive disorders characterised by progressive impairment to several areas of functioning, dependent on the area of the brain affected. Functional impairments may occur in executive functioning, learning, memory, visual perception, and spatial skills (American Psychiatric Association, 2013).

Neuropsychiatric symptoms or behavioural and psychological symptoms of dementia (BPSD) are a major component of certain dementia subtypes, including Alzheimer's disease (Desmarais et al., 2020). BPSD can manifest as disturbances in perception, behaviour, thoughts, and mood (Bruneau et al., 2020). These behavioural, perceptual, and emotional disturbances bear similarity to those experienced as part of other psychiatric disorders, including post-traumatic stress disorder (PTSD; Cloak & Khalili, 2022). Indeed, previous research has described PTSD as a risk factor for dementia (Desmarais et al., 2020).

Within the literature, there appear to be two main schools of thought when considering the relationship between trauma and dementia. A recent systematic review found several studies suggesting an association between PTSD and subsequent dementia (Desmarais et al., 2020). Cases have been reported of existing but well managed PTSD symptoms becoming exacerbated by the onset of dementia or cognitive decline (Johnson, 2000; Mittal et al., 2000).

Contrastingly, researchers have also described cases of delayed onset PTSD, where trauma related symptoms and experiences (e.g., nightmares, intrusive memories) have emerged following the onset of dementia, despite there being no reported symptoms experienced before this time (Bruneau et al., 2020; van Achterberg et al., 2001). Consequently, researchers have proposed a bidirectional relationship between dementia and post-traumatic stress disorder (Dallam et al., 2011; Ritchie et al., 2019).

Several explanations have been proposed to explain the relationship between psychological trauma and dementia. Researchers suggest elders with dementia may misinterpret environmental cues as triggers to the trauma (van Achterberg, 2001). Alternative psychological explanations propose that cognitive impairment disinhibits defence mechanisms that have previously been successful in managing symptoms of trauma (Marinez-Clavera et al., 2017).

Despite the proposed bidirectional association between dementia and trauma, the evidence base examining these disorders is limited (Lapp et al., 2011). Most of the research thus far has been conducted on war veterans, prisoners of war or people who have survived genocides, particularly The Holocaust (Lapp et al., 2011).

One commonality in cases where PTSD was either well established and managed or emerged with the onset of cognitive decline, was a phenomenon of traumatic experiences being re-enacted within dementia. There is an emerging body of research reporting on older adults who have experienced trauma in their lives and relive their traumatic experiences in dementia (Dallam et al., 2011; Johnston, 2000; van Achterberg et al., 2001). A retrospective review conducted by Dallam and colleagues (2011), found that trauma re-enactments are common among older war veterans. Eight per cent of patients over a two-year period were reported to have episodes of war-related vocalisations (Dallam et al., 2011). In addition, most of these patients had incidences of physical combativeness such as protecting others from perceived dangers (Dallam et al., 2011).

The aim of this review is to systematically identify and synthesise the literature on older adults re-enacting trauma in dementia. Using a meta-ethnographic approach, the specific research question was 'What is known about the phenomena of older adults with dementia who re-enact their traumatic experiences?'.

Method

Design

The current meta-ethnography was guided by the framework proposed by Noblit and Hare (1988). This synthesis approach was selected as it is a well-established method for the synthesis of qualitative data (Campbell et al., 2003). In addition, the epistemological positioning of meta-ethnography lies in objective idealism which places emphasis on the commonalities between experiences (Barnett-Page & Thomas, 2009) and as such, this method was deemed suitable.

Noblit and Hare (1988) defined seven iterative phases of meta-ethnography; getting started, deciding what is relevant to the initial interest, reading the studies, determining how the studies are related, translating the studies onto one another, synthesising translations and expressing the synthesis.

Deciding What is Relevant to the Initial Interest

An electronic search of the databases APA PsycInfo, CINAHL, MEDLINE and Web of Science was conducted in December 2021. The search terms employed are displayed in Table 1. As part of the search strategy, the option 'linked full text' was selected. In addition, the following limiters were applied: articles published in 'English', in a 'Peer Reviewed Journal' and involving participants 'Aged 65+'.

Table 1.

Database Search Terms

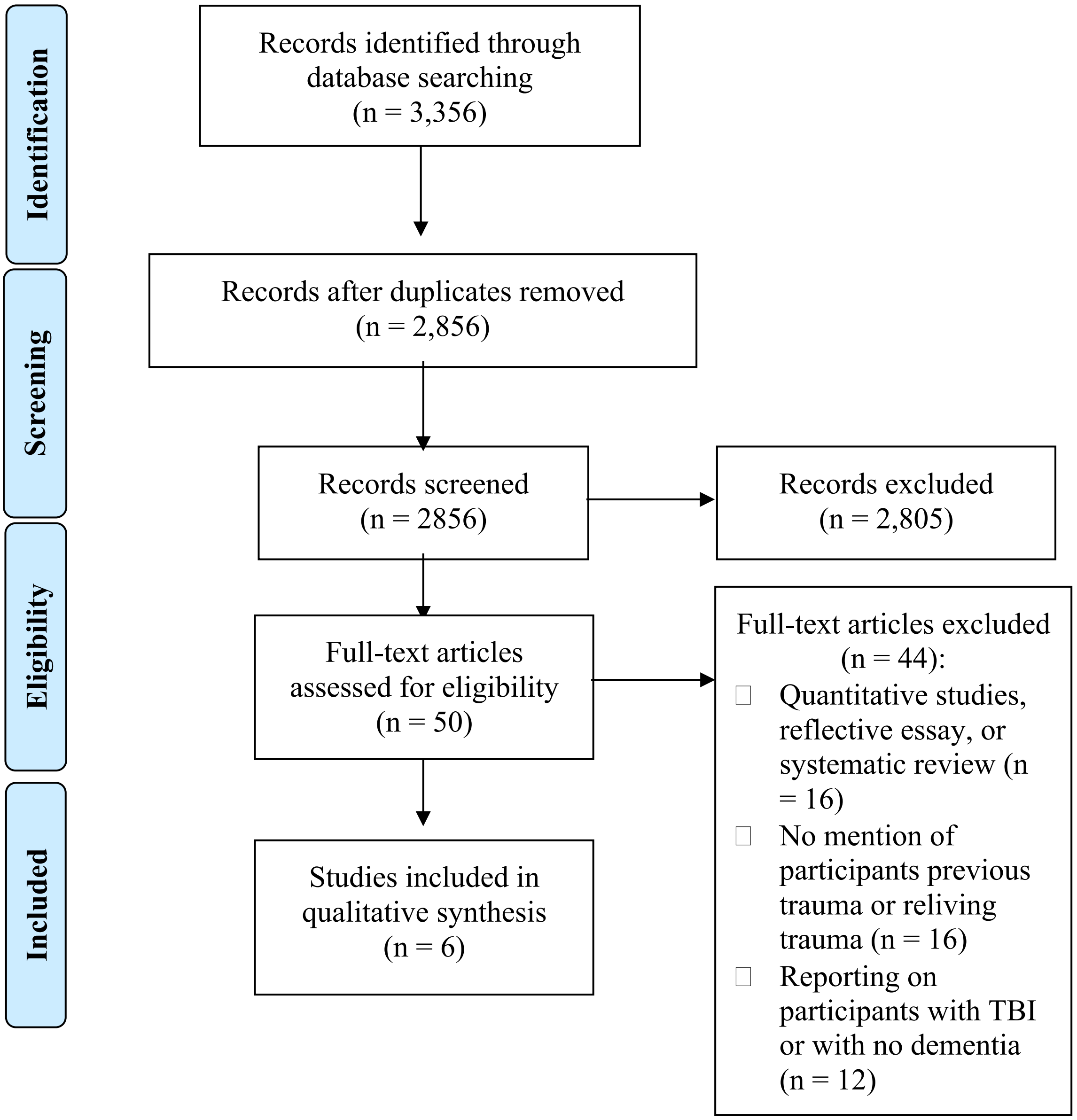
1. Older adult OR elder* OR senior* OR geriatric*

2. Survivor* OR trauma OR adversity OR stress OR life event*
3. Dementia OR cognitive decline
4. 1 AND 2 AND 3

Data was extracted and managed using EndNote bibliographic software. Article titles and abstracts were screened leading to the identification of 61 articles for full text review (Figure 1). The full text review adhered to the inclusion and exclusion criteria (Table 2) to identify relevant studies for the systematic review.

Figure 1.

PRISMA (2009) flow diagram of the search and selection of included studies



Articles were included if they were published, peer reviewed qualitative research exploring the experience of older adults or carers of older adults who were reliving traumatic experiences in their dementia. Given the nature of dementia, it was deemed important to include papers from the viewpoint of carers as well as the person with dementia. Qualitative papers were defined as those characterised by an interpretative paradigm (Starman, 2013) and included observational studies, interviews and focus groups. Due to the limited literature on this topic, the inclusion criteria was extended to include case series and case reports.

Articles were excluded if the older adults included in the research did not have a diagnosis of dementia. However, for research which included older adults with a diagnosis of dementia, there were no exclusions applied according to the type of dementia. Research articles were also excluded if there was no mention of participants reliving trauma.

Table 2.

Inclusion and Exclusion Criteria for Study Selection

Criteria	Inclusion	Exclusion
Sample	Older adults (aged 65+) with a diagnosis or label of dementia and experience of psychological trauma.	Participants under 65 years of age. Older adults who have experienced non psychological trauma or traumatic brain injury only. Older adults who do not have a diagnosis or label of dementia.
Phenomenon of interest	Older adults with dementia reliving early life traumas or reliving traumas experienced prior to onset of dementia or post dementia onset. Research that includes older adults with any type of dementia and specifically mentions participants re-experiencing trauma within their dementia.	Older adults with dementia who experienced trauma with no specific mention of reliving their experiences.
Design	Qualitative and/or mixed methods research.	Quantitative studies, protocols, books, conference papers,

	Studies using qualitative methodology including observational studies, interviews, focus groups, case series and case reports.	dissertations, or non-peer reviewed articles.

In total, five articles were identified as meeting the eligibility criteria and thus were included in the review. A manual search of the reference lists of these papers yielded one further article. All data was exported to NVivo Qualitative Data Analysis Software to support with the organisation and analysis of the studies.

Results

A total of 3,356 records were identified and extracted from the databases. Of these, 500 duplicate studies were removed. Through the initial screen, 50 articles were identified for full text review. Six studies met the eligibility criteria and were included in the final review (Bruneau et al., 2020; Hamilton & Workman, 1998; Johnston, 2000; Martinez-Clavera et al., 2017; McCartney & Severson, 1997; van Achterberg et al., 2001).

The characteristics of the included studies are detailed in Table 3. A total of 12 case reports of older adults reliving traumas in dementia were reported in six articles. The sample sizes were small, ranging from one to three cases. The phenomenon of re-enacting traumas in dementia was observed in Canada, UK, and USA. Most of the reported traumas were war or combat related and had occurred in early life (before the age of 30).

Table 3.

Characteristics of Studies Included in the Review

Author and year	Location	Aim of study	Study design	Participants	Key findings
Bruneau et al. (2020)	Canada	To present cases where PTSD was mistaken for behavioural and psychological symptoms of dementia.	Review	n = 2 Female = 1, Male = 1	Identification of PTSD symptoms is important for patients with dementia. Trauma re-enactments can occur following cognitive decline.
Hamilton and Workman (1998)	USA	To present a case study illustrating posttraumatic stress symptoms may exacerbate during ageing.	Case Report	n = 1 Male= 1	PTSD symptoms, including intrusive distressing episodes when awake, can re-emerge 75 years after experiencing trauma and during cognitive decline.
Johnston (2000)	USA	To present case descriptions of WWII and Korean combat veterans where the onset of dementia was foreshadowed by PTSD symptoms.	Case Series	n = 3 Male = 3	PTSD can remain asymptomatic or controlled in war veterans until the development of dementia. Symptoms of PTSD in this population include the re-enactment of violent traumatic experiences.
Martinez-Clavera et al. (2017)	UK	To present cases of delayed onset PTSD associated with the	Review	n = 2 Female = 1, Male = 1	Delayed-onset PTSD symptomology, including re-enacting of past traumas, can occur following a diagnosis of dementia.

		development of dementia.			
McCartney and Severson (1997)	USA	To present a case of an older patient exposed to sexual assault.	Case Report	n = 1 Female = 1	PTSD following dementia can include the re-experiencing of trauma, which may be interpreted as challenging behaviour secondary to dementia.
van Achterberg et al. (2001)	USA	To present cases of marked increase in PTSD symptoms after onset of dementia.	Case Report	n = 3 Female = 2, Male = 1	Re-enacting trauma in dementia is a phenomenon that extends beyond combat trauma. PTSD symptoms can worsen after the onset of dementia.

Quality Assessment

In recent years, there has been debate about how, or indeed if, quality should be assessed in qualitative research and currently, there is limited evidence to support the exclusion of qualitative research due to quality (Thomas & Harden, 2008; Priestley & McPherson, 2016).

Consequently, the current meta-ethnography used The Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Case Reports (Joanna Briggs Institute, 2017) to assess the quality of the studies included in the review. This tool provides a framework to evaluate methodological quality and bias in case reports. Using a series of eight questions, the JBI Checklist examines the demographic and historical information presented, in addition to the descriptions of current and post-intervention conditions.

The results of the quality assessment indicated that several of the studies provided limited information on the participant's medical, family, and psychosocial history (Martinez-Clavera et al., 2017; McCartney & Severson, 1997. Furthermore, certain studies were found to contain insufficient details on the diagnostic tests or methods used to determine diagnosis (Hamilton & Workman, 1998; Johnston, 2000; vanAchterberg et al., 2001). However, all the studies contained detailed information about the participant's current clinical condition, the interventions employed and the post-intervention outcome for participant's who experienced various types of traumas. As a result, all articles that met the inclusion criteria were included irrespective of their quality appraisal.

Critical Appraisal of Studies

A common problem across studies were the small sample sizes within the case studies. For example, the Hamilton and Workman (1998) case study included one war veteran and the study by van Achterberg et al. (2001) provided observational data on three cases. In the Hierarchy of Evidence Based Resources (DiCenso et al., 2009), case reports are ranked low due to their potential for bias and their isolation from other sources of evidence. However, they were included in this review due to the limited literature on the topic.

In addition, most studies involved observations of participants who were war veterans or had experienced war related traumas. For instance, Martinez-Clavera et al. (2017) included a case of a Falklands war veteran, while Bruneau et al. (2020) describe the case of a woman who grew up in Paris at the time of World War II. While these experiences are important, there appear to be a wider demographic of people who have experienced trauma who are not captured within this research (Lapp et al., 2011). The limited sample observed in the included case reports may limit our understanding of trauma and dementia in the general population.

Each of the case studies included a retrospective account of the symptoms and history of the client, making the information susceptible to inaccuracies. For example, in the Hamilton and Workman (1998) case study, a 94-year-old war veteran's experiences were described with corroborating information about his history which was provided by his family. Similarly, a case described by Martinez-Clavera et al. (2017) described a 90-year-old woman with Alzheimer's disease who appeared to be reliving her early experiences. However, her family disclosed that prior to her dementia, she was reluctant to disclose information about her past, suggesting there may have been inaccuracies or uncertainties in the supporting information they were able to provide. The limitations of retrospective research should be considered when interpretating the data presented in the case reports.

Determining How the Studies are Related

The six studies were repeatedly examined to identify key concepts and themes across the papers. Several common concepts were identified and labelled using NVivo Qualitative Data Analysis Software. The key concepts were symptomatic expression of trauma, aetiology, PTSD onset, treatment, and implications. The symptomatic expression of trauma refers to the ways in which the trauma re-enactment manifests itself. The aetiology is concerned with the attributed causes to the reliving of trauma in dementia, while PTSD onset refers to the timing of the traumatic symptoms. There was frequent reference to the treatments used to manage the re-enacting of trauma and the clinical implications for this phenomenon considered.

Translating the Studies Into One Another

Noblit and Hare (1988) describe different synthesis methods used in meta-ethnography, including reciprocal translational analysis. Through examining the concepts in each of the six studies and conducting a cross comparison (Table 4) it was determined that there was a reciprocal relationship between the papers with overlapping key concepts. From this, a line of argument synthesis was developed. A line of argument synthesis is defined as developing an understanding of the whole using data from the study of its parts (Barnett-Page & Thomas, 2009).

Table 4.

A cross-study comparison of key concepts

Concepts	Studies					
	Bruneau et al. (2020)	Hamilton and Workman (1998)	Johnston (2000)	Martinez-Clavera et al. (2017)	McCartney and Severson (1997)	van Achterberg et al. (2001)
Symptomatic expression of trauma	*	*	*	*	*	*
Aetiology	*	*	*	*	*	*
PTSD onset	*	*	*	*		*
Treatment	*	*	*	*	*	
Implications	*		*	*	*	

Symptomatic expression of trauma

Each case study described the expression of trauma within dementia. Several studies observed this in the form of violent behaviours directed towards others (Bruneau et al., 2020; Martinez-Clavera et al., 2017; McCartney & Severson, 1997). A common feature across all case reports, was the reporting from family members, of re-enactments of past traumatic experiences at home. For example, Johnston (2000) described a veteran wife's experience of being "ambushed" by her husband before he "shot her five times with a .22 caliber rifle". A less common observation across studies was the manifestation of traumatic experiences through visual hallucinations. Bruneau et al. (2020) and Johnston (2000) report instances in the bedroom where older adults with dementia believed there were assailants in the home.

Post-traumatic Stress Disorder Onset

A common belief among studies is that the relationship between PTSD and dementia is bidirectional. Most studies reported late-onset PTSD or the emergence of PTSD symptoms following the onset of dementia (Johnston (2000); Martinez-Clavera et al., 2017; van Achterberg et al., 2001) while two studies reported cases where existing PTSD symptoms became exacerbated by dementia (Bruneau et al., 2020; Hamilton & Workman, 1998). One further study reported a case of an 82-year-old with severe dementia who experienced assault and consequently re-enacted her trauma (McCartney and Severson, 1997).

Aetiology

Commonly, studies attributed the re-enactment of trauma in dementia to damage to neural pathways weakening the inhibitory mechanisms for traumatic memories (Bruneau et al., 2020; Hamilton & Workman, 1998; Martinez-Clavera et al., 2017; van Achterberg et al., 2001). One study also insinuated that traumatic memories may be “more resistant to the deleterious effects of dementia” (van Achterberg et al., 2001).

Alternative psychosocial explanations for the observed phenomenon have been proposed across studies. For example, researchers have suggested that the unconscious mind uses immature defence mechanisms such as avoidance, splitting and/or projection, to block awareness of the trauma (Martinez-Clavera, 2017). As the dementia progresses, the ability to use these processes becomes more difficult leading to increases in intrusive symptoms (Martinez-Clavera, 2017; van Achterberg et al., 2001).

Treatment

Across studies a common approach to managing the re-enactment of trauma in dementia was with pharmacological methods including antipsychotic medication (Bruneau et al., 2020; Johnston, 2000) or antidepressants (Bruneau et al., 2020; Martinez-Clavera et al., 2017; McCartney & Severson, 1997). There were also some reports of using psychological therapy or psychological approaches (Martinez-Clavera et al., 2017). For example, Martinez-Clavera et al. (2017) report a case of a 90-year-old with Alzheimer’s disease who began to communicate more in her native language, German, as her dementia progressed. It was found that through reminiscence intervention work focusing on the positive aspects of her life, there was an improvement in her behaviour and wellbeing.

Implications

Generally, studies agreed that it is challenging to identify delayed onset PTSD (Bruneau et al., 2020; Johnston, 2000; Martinez-Clavera et al., 2017; McCartney & Severson, 1997). In some cases, this was due to the similarities between PTSD symptoms and BPSD leading to increased opportunities for the misinterpretation of symptoms (Bruneau et al., 2020; Martinez-Clavera et al., 2017). Johnston (2000) also noted that challenges in the identification of delayed onset PTSD can mean that cases are not diagnosed, or that help is not sought until there is a violent incident.

Consequently, the authors recommend that a detailed trauma history should form part of a memory assessment (Martinez-Clavera et al., 2017) to support the identification of an appropriate tailored intervention (Bruneau et al., 2020).

Following Britten et al. (2002), a line of argument synthesis was developed by reflecting on the key concepts and second-order interpretations. Second-order constructs are derived from the data and are defined as the researcher interpretations of the studied experiences (Britten et al., 2002). Third-order constructs differ in that they are the meta-ethnographer's re-interpretation of the researcher's concepts (Britten et al., 2002). The steps of the synthesis are shown in Table 5.

Table 5.

Overview of synthesis with concepts, second and third order interpretations

Concepts found in the studies	Second-order interpretations	Third-order interpretations
Symptomatic expression of trauma	Trauma memories in PTSD can manifest as behaviours directed to others, re-enactments and/or visual hallucinations.	Behavioural and psychological symptoms of dementia (BPSD) can be understood in the context of trauma.
PTSD onset		
Aetiology	Neurodegeneration causes the onset of PTSD symptoms.	Biopsychosocial explanations for reliving trauma.
Treatment	Medication is effective for trauma related behavioural disturbances.	

Concepts found in the studies	Second-order interpretations	Third-order interpretations
Implications	There are challenges associated with interpreting behaviours in dementia.	BPSD should be differentiated from trauma symptomology to access appropriate treatment.

Discussion

This meta-ethnography provides a synthesis of six case reports, illustrating what is known about the phenomenon of re-enacting trauma in dementia. A pattern of key concepts were identified: symptomatic expression of trauma, aetiology, PTSD onset, treatment, and implications. The case studies were found to be reciprocal, and as such, a line of argument synthesis indicated that behavioural re-enactments of traumatic experiences may be misinterpreted as behavioural and psychological symptoms of dementia. As such, behavioural disturbances in dementia may, in some cases, be understood in the context of past trauma. Furthermore, biological, and psychosocial models can be used to understand the link between dementia and the re-enactment of psychological trauma.

Trauma re-enactments were found to take several forms, from the physical re-experiencing of a past event to visual hallucinations relating to the trauma. In some cases, these re-enactments were violent and involved the use of lethal weapons. These incidences were found to commonly occur at home.

The exact aetiology of trauma re-enactments in dementia remains unclear. However, there was a consensus that the neurodegenerative nature of dementia was in some way interacting with the processes that maintain or manage traumatic memories, and which would ordinarily limit the intrusive effects of these memories. There were two kinds of case studies; those where people had a diagnosis of PTSD prior to dementia and others where there was delayed onset PTSD. In both cases, re-enactments of past traumas were observed. Generally, the treatment for these behavioural disturbances was pharmacological rather than psychological. However, this was dependent on the case. Indeed, in the UK, the National Institute of Clinical Excellence (NICE) guidance do stipulate the use of antipsychotics for people with dementia who are distressed due to agitation, hallucinations, or delusions (NICE, 2018).

While several case studies have explored and demonstrated the relationship between dementia and trauma, through the reporting of trauma re-enactments, there has been limited focus on the experiences of non-veterans or civilians who have not experienced any war related trauma. It would be helpful to observe this phenomenon in a non-veteran population to further our understanding of the re-enactment of trauma in dementia for older adults who have experienced a range of traumas. For example, in recent years, immigration and refugee settlement has contributed to increasing the population of ethnic minorities in the UK (Dinesen et al., 2020). The adverse experiences associated with migration, combined with experiences of racism may lead to the development of racialised trauma (Dinesen et al., 2020). It would be beneficial to conduct research on older adults from minoritised backgrounds to observe the phenomenon and understand the experiences of caregivers.

Furthermore, given that the data included in this review was from case studies, it would be helpful to expand on these observations by conducting qualitative research with familial or informal carers. Several of the reported case studies noted that prior to the onset of dementia, the client would not discuss their early traumatic experiences (van Achterberg et al., 2001). It may be helpful for future research to consider the impact of this non-disclosure of traumatic experiences on carers who are witnessing the traumatic events being re-enacted in dementia.

Limitations

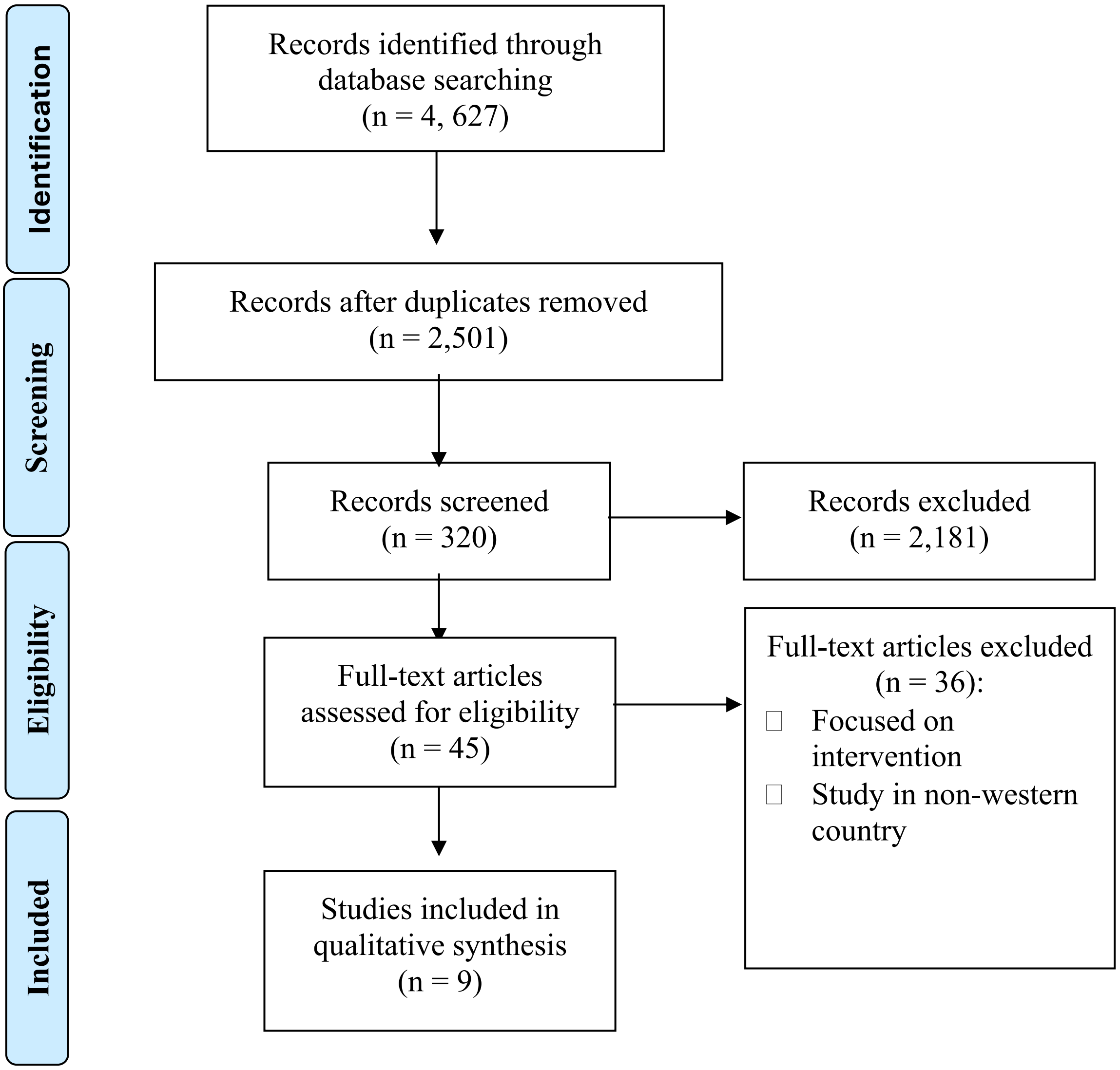
There are several limitations to this review that need to be acknowledged. The search strategy employed focused on studies of dementia and excluded pseudo dementia and traumatic brain injury. These studies may have provided additional insight into the phenomenon. In addition, the data identified and included in this meta-ethnography were from small samples of case studies. More research is needed in this area to understand the relationship between trauma re-enactments and dementia. Furthermore, unlike other systematic reviews, this review did not have multiple reviewers to independently extract and analyse the data. The results and interpretations presented may be biased to the views and limited understanding of the reviewer.

Conclusion

To conclude, trauma re-enactments have been observed in a limited number of published case reports. These re-enactments can take several forms, some of which may put other people at risk of harm. Due to the limited literature, our understanding of psychological trauma re-enactments in dementia is limited. Researchers have proposed several possible causes underlying the relationship between trauma and dementia and it is generally accepted that there is a bidirectional relationship between these two disorders. However, to deepen our understanding of the bidirectional relationship, more research among non-veteran populations is needed.

Appendix 5: PRISMA flow diagram for Literature Review 2

PRISMA (2009) flow diagram of the search and selection of included studies



Appendix 6: Quality Appraisal for Literature Review 2

JBI Tool for Case Series

	Bruneau et al. (2020)	Couzner et al. (2022)	Johnston (2000)	Martinez-Clavera et al. (2017)	Ritchie et al. (2021)	Van Achterberg et al. (2001)
Clear inclusion criteria	✓	✓	✓	✓	✓	✓
Condition measured in a standard, reliable way	✓	✓	✓	✓	✓	✓
Valid methods used for identification of the condition	✓	✓	✓	✓	✓	✓
Consecutive inclusion of participants	X	✓	X	X	✓	X
Complete inclusion of participants	X	X	X	X	X	X
Clear reporting of demographics	✓	✓	✓	✓	✓	✓
Clear reporting of clinical information	✓	✓	✓	✓	✓	✓
Outcomes or follow up results reported	✓	✓	✓	✓	X	X

Reporting of the presenting site(s)/clinic(s) demographic information	X	✓	✓	X	✓	X

JBI Tool for Case Reports

	Demographics described	History described and presented as timeline	Current clinical condition described	Diagnostic methods and results described	Intervention or treatment procedure described	Post-intervention condition described	Adverse harm identified and described	Key takeaway lessons provided
Hamilton & Workman (1998)	✓	✓	✓	✓	✓	✓	NA	✓
McCartney & Severson (1997)	✓	✓	✓	✓	✓	✓	NA	✓

JBI Tool for Qualitative Research

	Congruence between philosophy and methodology	Congruence between methodology and objectives	Congruence between methodology and data collection methods	Congruence between methodology and analysis	Congruence between methodology and interpretation	Researcher culture and theoretical orientation disclosed	Influence of researcher on research addressed	Participant voice represented	Ethical research	Conclusions flow from analysis of data
Craftman et al. (2020)	?	✓	✓	✓	✓	X	✓	✓	✓	✓

Key: ✓ = yes; X = no; ? = unclear

Appendix 7: Recruitment Poster

PARTICIPANTS NEEDED

ARE YOU FROM A BLACK AFRICAN AND/OR CARIBBEAN BACKGROUND?

DO YOU HAVE CARING RESPONSIBILITIES FOR A FAMILY MEMBER WITH DEMENTIA?

HAS YOUR RELATIVE EVER EXPERIENCED FLASHBACKS OF RACIST OR DISCRIMINATORY EXPERIENCES?

WHY IS THIS RESEARCH BEING DONE?

I'm a Trainee Clinical Psychologist interested in understanding the experiences of Black people who care for a relative with dementia. In particular, I am keen to understand your experience of witnessing your loved one reliving a racial trauma in their dementia.

WHAT DO I HAVE TO DO?

If you decide to take part in this study, you will be invited to compete an interview (for up to 1 hour) over Zoom.

TO FIND OUT MORE CONTACT:

Alria Williams
aw21786@essex.ac.uk

University of Essex

This study has received ethical approval from the University of Essex Ethics Sub-Committee 2 (ETH2122-1269)

Appendix 8: Interview Schedule

Aim: To gain insight into the ways Black familial carers make sense of the person with dementia's behaviour and the impact of witnessing these re-enactments of earlier life racialised traumas.

Intro: Thank you for agreeing to participate in this interview. The interview will be audio recorded and should last approximately 1 hour. As I mentioned in the information sheet, your participation is voluntary, and you may stop the interview at any point. Everything you say is confidential and all your answers will stay anonymous.

Overview: I am conducting this research as part of my doctoral thesis. I'm keen to understand the experiences of Black carers who have previously or are currently caring for a relative with dementia. My hope is that having insight into your experiences will help to influence dementia care for people from Afro-Caribbean backgrounds. We will be talking about your personal experience which may be difficult at times, and I am aware of the privilege I hold in asking you to open up about this. If you do need to stop at any time, please do let me know.

I also want to reiterate that there are no right or wrong answers to any of the questions I'm about to ask. I am interested in your experience of being a carer to your X (relative). I have a guide, but I am here to listen to you about your experiences and I do not want to constrain that. I'm interested in what you want to say rather than what I think you want to talk about.

My opinions don't count as data so my input will be minimal as I will be mainly asking questions. This may feel strange at first as it may not feel like a conversation but remember everything you say counts as data and is interesting and important to me. I'll be making notes to remind myself of things you say that I might want to follow up on. If this is disruptive or makes you uncomfortable, please let me know.

Do you have any questions before we start?

Can you tell me about your experience caring for your relative?
Can you tell me how you came to take on a caring role?

What does being a carer mean to you?
Can you tell me how this is different and or the same as the role you had in your relative's life before they were diagnosed with dementia?
What was it about x that made it challenging/easy?

What is your understanding of the label 'dementia'?
Prior to your relative being diagnosed, what was your understanding of dementia?
Has your understanding of dementia changed over time?

What does the term 'racial trauma' mean to you?
Can you tell me, do you think this impacts on your daily life? If so, how?
Can you tell me about specific examples of how racial trauma impacts you?
How did he communicate about his experiences of discrimination or racism? Did this change when public started talking more about race for example during the pandemic after George Floyd was killed?

Can you tell me about your experience of witnessing your relative re-live racial trauma?
Can you think of specific examples of times when this has happened?

Can you tell me about the first time you saw your relative re-enact a racial trauma?
How did you respond at that time? How did you feel?
How do you respond to witnessing these re-enactments now? Has your response changed over time? Have your feelings about witnessing this re-enactment changed over time?

How do you make sense of your relative reliving these traumatic experiences?
How do you account for these experiences? If I asked you to explain it someone, how would you do that? How did you feel about your relative reliving these experiences?

Can you tell me in what way, if any, that witnessing these re-enactments of racialised trauma has impacted on your relationship with your relative?
Can you tell me if witnessing these re-enactments has impacted the way you relate to your relative? If so, how? Can you tell me about any positive impact? Can you tell me about any negative impact?

What do you think your relative would say about your understanding of their experience reliving trauma?
How do you think your relative feels when they are re-enacting a race related trauma?

Is there anything else you would like to add? Is there anything important you would like to share that we haven't already discussed? Is there anything that you thought I would ask you, but I haven't?
How has this experience been talking to someone of a similar background, a Black woman

DEBRIEF:
Thank you again for taking part in this interview. As I mentioned before, this is all part of my thesis in trying to understand the experiences of Black familial carers with the hope that this will influence the quality-of-care elders from the Afro-Caribbean community receive. The results will form part of my thesis and may be published in research journals. I will share the results with you after it has all been analysed. Please do get in touch if you have any questions or concerns following the interview.

Appendix 9: Ethical Approval

From: ERAMS <erams@essex.ac.uk>

Date: Wednesday, 5 April 2023 at 13:22

To: Williams, Alria <aw21786@essex.ac.uk>

Subject: Decision - Ethics ETH2122-1269: Miss Alria Williams

University of Essex ERAMS

05/04/2023

Miss Alria Williams

Health and Social Care

University of Essex

Dear Alria,

Ethics Committee Decision

Application: ETH2122-1269

We are pleased to inform you that the research proposal entitled "The Experiences of Black Familial Carers of Elders Who Re-experience Racial Trauma in Dementia" has been reviewed by the Ethics Sub Committee 2, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

Extensions and Amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

Covid-19:

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

REO Research Governance Team

reo-governance@essex.ac.uk

Ethics ETH2122-1269: Miss Alria Williams

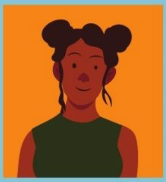
Appendix 10: Participant Information Sheet

University of Essex

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: THE EXPERIENCES OF BLACK FAMILIAL CARERS OF ELDERS WITH DEMENTIA

My name is Alria Williams, and I am a Trainee Clinical Psychologist on the Doctorate in Clinical Psychology at the University of Essex. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

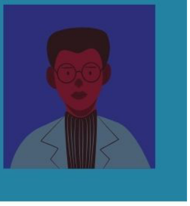


WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to find out about your experiences as someone who has previously or is currently looking after a relative who has dementia. I am conducting this research as part of my doctoral degree. My goal is to understand the unique experience of caring for a relative with dementia.

WHY HAVE I BEEN INVITED TO PARTICIPATE?

I am looking to interview 6-8 adults of Black African and/or Caribbean descent, who care for a family member with dementia. You have been identified through social media or the charity organisation/local support group involved in the care of your relative, and as someone who may have supported a relative with dementia.



DO I HAVE TO TAKE PART?

It is up to you to decide whether you wish to take part in this study. If you do decide to take part, you will be asked to provide written consent. You are free to withdraw from the interview at any time, without giving a reason. Participation or withdrawal from this research will have no impact on the care or support you or your relative currently receives or care they/you will receive in the future.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

If you agree to take part in the research, you will be asked to read and sign a consent form and to provide your contact details and demographic information. I will arrange for your interview to take place via Zoom on a day and time that is convenient for you. The interview will take approximately one hour to complete.

Once your interview is arranged, you will receive a Zoom invitation via email, with the day and time of your interview. Your invitation will also include a password to access the Zoom meeting. If you have any questions or need support to access Zoom, please email me: aw21786@essex.ac.uk.

Before taking part in the interview, you are asked to consider your surroundings. You may wish to take part in your interview in a comfortable environment, where you will not be interrupted, disturbed, or overheard. You will be given an opportunity to ask any questions before the interview starts, and the option to do the interview with your camera on or off. Your interview will be audio and video-recorded using Zoom or an audio recording device. We will only download the audio recording for our analysis.

During your interview you will be asked questions about your experiences of caring for a relative with dementia. The interview questions will depend on what you say as we are interested in finding out what you think and make of your experiences. We do have a series of standardised prompts to support us to stay on topic during the discussions.

Once you have finished the interview, a written account will be created. If you wish to withdraw your interview data, please notify me within three weeks of the interview. You can contact me via email if you would like to withdraw: aw21786@essex.ac.uk.

If you do not wish for your interview to be included, the recording and written account will be deleted and all identifying information including your name and any other names you mention, will be removed. If you agree for your transcript to be included in the study, it will be fully anonymised, and your name and any other identifiable information will be removed.

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?

The current study will ask you questions about your experiences of caring for someone with dementia and you may find this upsetting. If you do become upset, the researcher will check in with you and offer you a break. If you are willing and able, you can continue the interview or express to the researcher that you would like to withdraw. If you need any additional support, you may wish to contact specialised organisations using the details on page 3.

I am aware of my privileged position in gaining insight into your experiences. Any information shared during the interview stage will be treated confidentially and shared only with the research team. If you do not feel comfortable with the information shared, we can have a discussion or you have the option to withdraw from the study.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

By sharing your experiences, you will be contributing towards expanding our understanding of what it is like as a Black person looking after a relative with dementia. This information can be used to inform policy, training for care staff and to contribute towards the provision of support for people from Black African and/or Caribbean backgrounds with caring responsibilities for a relative.

WHAT INFORMATION WILL BE COLLECTED?

Personal information including your name, contact details and demographic information will be collected in the consent form. During the interviews, you will be asked about your experiences of looking after a relative with dementia.

WILL MY INFORMATION BE KEPT CONFIDENTIAL?

Yes, all research data will be kept secure at all times and processed in line with General Data Protection Regulation (GDPR). Digital data will be secured in a password protected file on a password protected computer. Data will be kept for up 10 years in line with the University of Essex data protection policy.

WHAT IS THE LEGAL BASIS FOR USING THE DATA AND WHO IS THE DATA CONTROLLER?

The legal basis for the processing of your personal data is through informed participant consent. The Data Controller is the University of Essex, and the contact is: University Information Assurance Manager (dpo@essex.ac.uk).

WHAT SHOULD I DO IF I WANT TO TAKE PART?

If you would like to take part or have any questions you want to ask before deciding, you can get in contact by email. The first step is to complete a consent form and to provide contact details, which will be used to arrange your interview.

During the interview, it is possible that we may talk about something that you find difficult or upsetting. If this happens, I will ask if you would like to take a break or end your interview. If you would like to stop taking part at this point, you are able to withdraw without giving a reason.

After the interview, you may wish talk with a professional about what upset you. Below are contact details of organisations that you could get in touch with for support if you wish.

MIND provides advice and support to anyone experiencing a mental health problem.

Telephone: 0300 123 3393
Text 86463
Website: www.mind.org.uk

Alzheimer's Society

Telephone: 0333 150 3456
Website:
www.alzheimers.org.uk/get-support/help-dementia-care/getting-support

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?

The results will be used in my thesis and deposited as a digital file stored in the University of Essex library. A copy of the results can be made available to you by email after the study is complete. The study results may also be published in a journal article and available in the public domain. At this stage, any results will be anonymised, and you and your relative will not be identifiable.

WHO HAS REVIEWED THE STUDY?

This research was granted ethical approval by the University of Essex Ethics Sub-Committee 2.

CONCERNS AND COMPLAINTS

If you have any concerns about any aspect of the study or have a complaint, in the first instance please let me know using the contact details below.

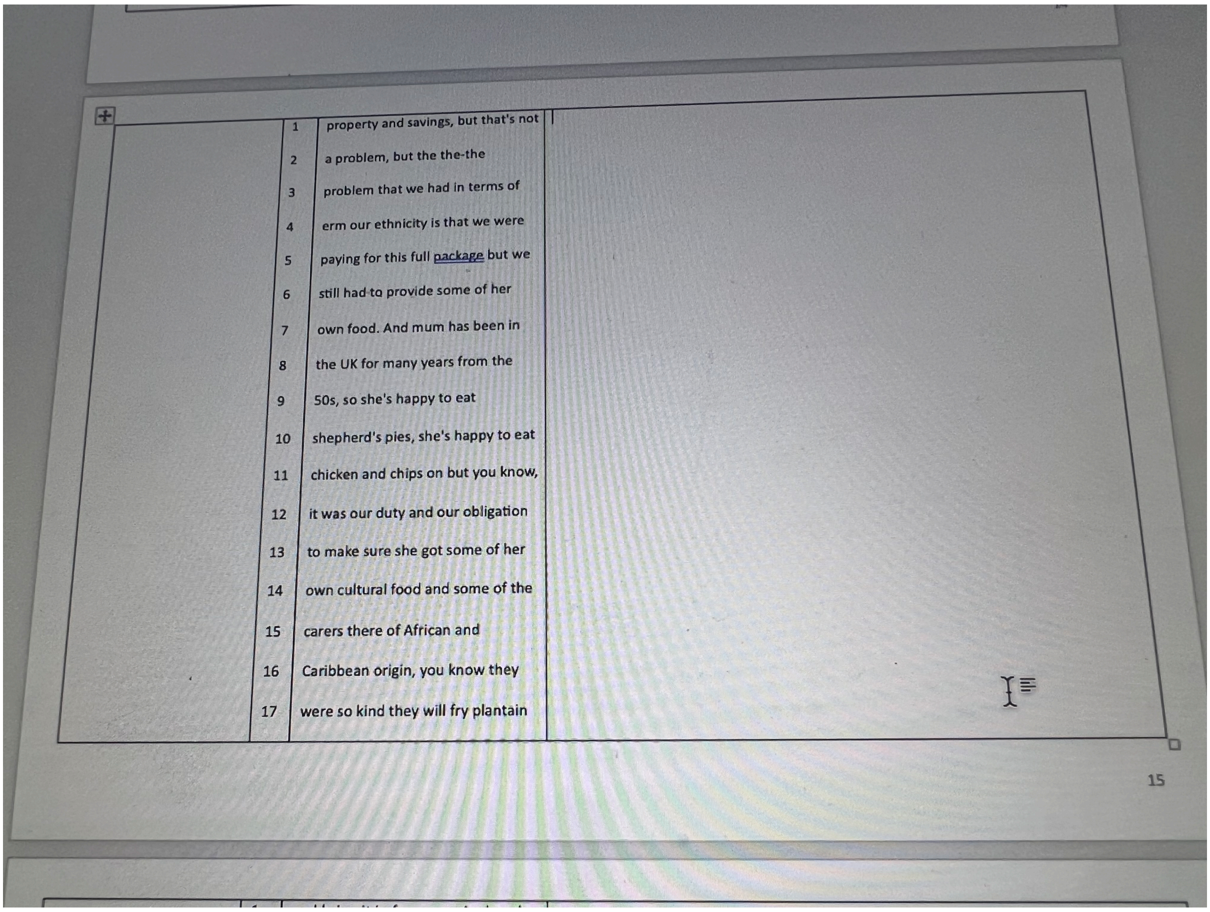
If are still concerned, you think your complaint has not been addressed to your satisfaction or you feel that you cannot approach me, please contact the Director of Research and Impact, School of Health and Social Care, Prof. Camille Cronin (camille.cronin@essex.ac.uk). If you are still not satisfied, please contact the University's Research Governance and Planning Manager, Sarah Manning-Press (e-mail sarahm@essex.ac.uk). Please include the ERAMS reference which can be found at the foot of this page.

NAME OF THE RESEARCHER/RESEARCH TEAM MEMBERS

Principal Investigator: Alria Williams - aw21786@essex.ac.uk
Lead Academic Supervisor: Jasmeet Kaur - jb20603@essex.ac.uk
Second Academic Supervisor: Danny Taggart - dtaggart@essex.ac.uk

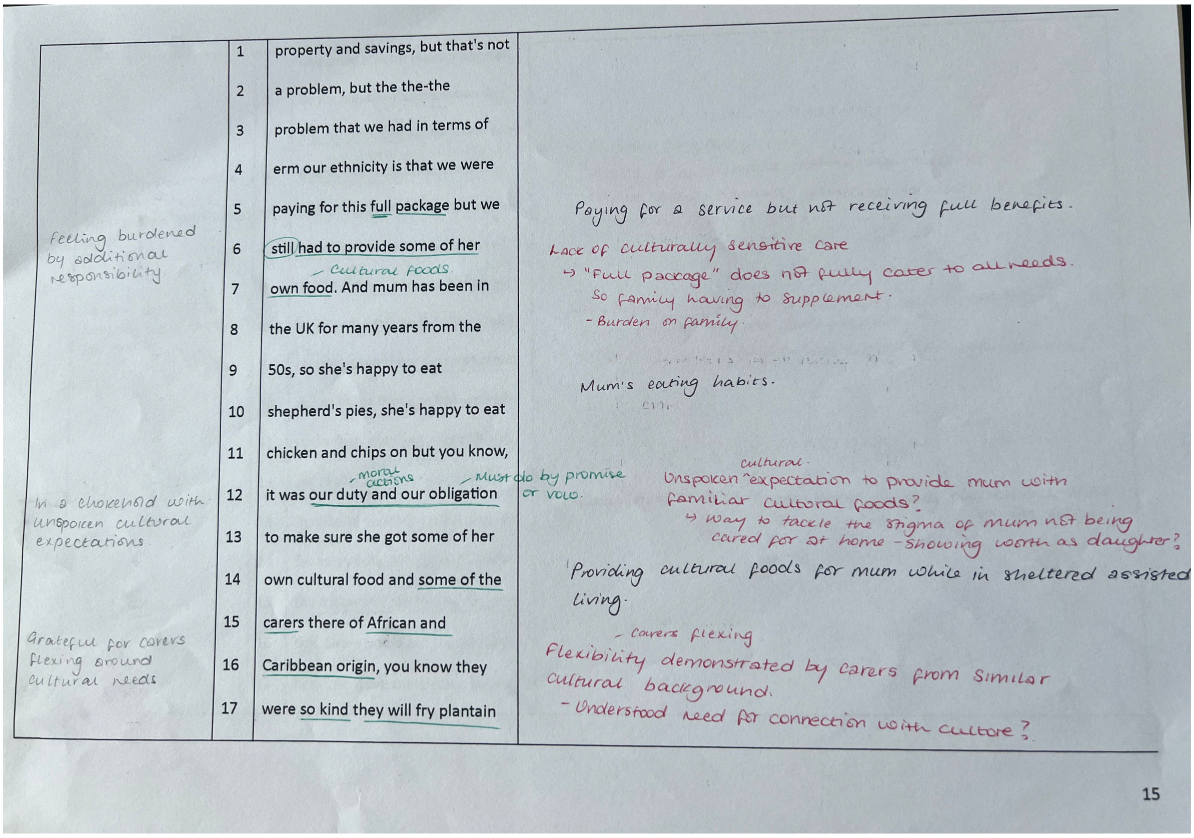
THANK YOU FOR TAKING PART IN THIS RESEARCH PROJECT

Appendix 11: IPA Transcript



property and savings, but that's not a problem, but the the-the problem that we had in terms of erm our ethnicity is that we were paying for this full package but we still had to provide some of her own food. And mum has been in the UK for many years from the 50s, so she's happy to eat shepherd's pies, she's happy to eat chicken and chips on but you know, it was our duty and our obligation to make sure she got some of her own cultural food and some of the carers there of African and Caribbean origin, you know they were so kind they will fry plantain

Appendix 12: Example IPA Coding: Evelyn



	1	property and savings, but that's not	
	2	a problem, but the the-the	
	3	problem that we had in terms of	
	4	erm our ethnicity is that we were	
	5	paying for this full package but we	Paying for a service but not receiving full benefits.
Feeling burdened by additional responsibility	6	still had to provide some of her	Lack of culturally sensitive care ↳ "Full package" does not fully cater to all needs. So family having to supplement. - Burden on family.
	7	- Cultural foods own food. And mum has been in	
	8	the UK for many years from the	
	9	50s, so she's happy to eat	Mum's eating habits.
	10	shepherd's pies, she's happy to eat	
	11	chicken and chips on but you know,	
In a chokehold with unspoken cultural expectations.	12	- moral actions - Must do by promise or vow. it was our duty and our obligation	Unspoken cultural. expectation to provide mum with familiar cultural foods? ↳ Way to tackle the stigma of mum not being cared for at home - showing worth as daughter?
	13	to make sure she got some of her	
	14	own cultural food and some of the	Providing cultural foods for mum while in sheltered assisted living.
	15	carers there of African and	- Carers flexing
Grateful for carers flexing around cultural needs	16	Caribbean origin, you know they	Flexibility demonstrated by carers from similar cultural background.
	17	were so kind they will fry plantain	- Understood need for connection with culture?

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Example PETS:

Cluster D: acts of resistance transcending barriers to cultural connection

Experiential statement	Location identifier	Quote
Feeling pride when correcting negative judgements	P20, 7-11	but it was for-for us it was a great badge of honour to correct people to say, "No, my mum is not in a nursing home, she's in erm her own flat, but she's supported".
Using knowledge to challenge traditional views	P19, 6-13	we actually went to a workshop to help us to understand, because you know everything is on Google but we pointedly went to a workshop to kind of because you know in our culture there's a lot of guilt, shaming
Retaining cultural connection through food and clothing	P40, 7-16	we-we would always make sure that you know her house clothes were of you know her African house clothes, you know, her gown. Mum was famous for always tying her head because when she's cooking she tied her head so when the carers got mum ready they-they-they dressed her up.
	P15, 7-14	And mum has been in the UK for many years from the 50s, so she's happy to eat shepherd's pies, she's happy to eat chicken and chips on but you know, it was our duty and our obligation to make sure she got some of her own cultural food
	P37, 11-16	Even having carnation milk in her tea for me was important because you know, I-I'd said to them that she loves tea and giving her tea in a teacup wasn't cutting it. I said "My mum has a mug of tea" [gestures size of large mug]

Appendix 13: Theme Representation Table

Group experiential theme	Subtheme	Number of participants contributing to subtheme (total *n* = 8)	Number of extracts provided in support of subtheme
1. Tension at the intersection of care, culture, and community	1a. In a chokehold with unspoken cultural expectations	8	7 (Evelyn, Jamal, Fiona, Brian, Faye, Yvonne, Florence)
	1b. Sharing the caregiving load: "It was a team around the adult."	8	6 (Yvonne, Brian, Fiona, Florence, Evelyn, Pauline)
2. Battling with broken systems	2a. Inconsistent recognition of vulnerability	7	6 (Florence, Evelyn, Fiona, Pauline, Faye, Yvonne)
	2b. A Lack of Equity in Care: “Mum’s tastebuds were so institutionalised.”	4	4 (Evelyn, Faye, Florence)
3. Longing for a place of safety and happiness	3a. Reliving past experiences	4	3 (Florence, Fiona, Pauline)
	3b. Feeling silenced: The lasting imprint of racism	5	5 (Brian, Florence, Evelyn, Faye, Jamal)