FAMILY MEMBERS EXPERIENCE OF HELP SEEKING WHEN A LOVED ONE OF AFRICAN CARIBBEAN HERITAGE EXPERIENCES MEMORY LOSS

By

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Thesis overview

This thesis is submitted in partial fulfilment of the requirement for the degree of Doctor of Clinical Psychology (ClinPsyD) at The University of Birmingham. This thesis comprises of three chapters:

Chapter one is a literature review consisting of a meta-synthesis comparing reasons for vaccine hesitancy in Black ethnic communities in the UK and USA to other ethnic minority communities.. The COVID-19 pandemic saw those from ethnic minorities being disproportionately affected by the virus, but despite the eventual availability of the vaccination, low uptake was observed within this group. Vaccine hesitancy is defined as 'the delay in acceptance or refusal of vaccination when vaccination services are available' (MacDonald, 2015), and was found to be particularly high within Black ethnic communities. Despite extensive research considering vaccine hesitancy in ethnic minorities, the literature tends to disseminate this information under the acronym of 'BAME' (Black, Asian and Minority Ethnic), assuming reasons for vaccine hesitancy are the same across all ethnic minority communities. Considering the evidence to suggest vaccine hesitancy is highest within the Black community, there is a paucity of literature looking at this ethnic group specifically to understand what factors influence vaccine hesitancy.

The aim of this research was to investigate if reasons for COVID-19 vaccine hesitancy differed for Black ethnic communities in the UK and USA compared to other ethnic minority communities. The meta-synthesis reviewed available literature pertaining to vaccine hesitancy in ethnic minorities. They sought to extract data in the form of quotes from self-identifying Black ethnic individuals and compared this to other ethnic minority individuals, to see if there were similarities or differences in reasons for vaccine hesitancy. A third group of data was collected comprising of quotes which were not attributable to a specific ethnic minority group, these were compared to see if any further themes for vaccine hesitancy could be identified.

Findings suggest that reasons for vaccine hesitancy did differ between ethnic minority communities. Black ethnic communities in the UK and USA experienced vaccine hesitancy owing to historical and contemporary examples of mistrust towards government and health professionals. Many cited examples of where Black bodies had been used to advance medicine such as the Tuskegee Syphilis study and referenced this as evidence to not trust the government in accepting the vaccine. These reasons were found exclusively in Black

communities and were directly contrasted with other ethnic minorities. Ethnic minorities were more likely to refuse the vaccine based on religious or cultural practice and were more likely to accept the vaccine if advised by a medical professional. Findings from the unknown ethnicity group, which represented views of all ethnic minorities suggested vaccine hesitancy was owing to a lack of ethnic minority representation, in the development and promotion of the COVID-19 vaccination. It was felt that there was not appropriately disseminated information to address concerns around risks or side effects in the ethnic minority community, which contributed to vaccine hesitancy. The use of social media provided a 'safe space' for fellow vaccine hesitant ethnic minorities to share information and discuss their concerns about the vaccine, away from the critical eye of wider (white) society.

Chapter Two is an Empirical Study which considers help seeking when a loved one of African-Caribbean heritage experiences memory loss. African-Caribbean adults are one of the highest risk communities for dementia in the UK yet remain underrepresented in dementia services. The aim of this study was to see what the barriers are to help seeking when a loved one of African-Caribbean heritage experiences memory loss. Using semi-structured interviews, fourteen family members who provide care or support to a loved one of African-Caribbean heritage, participated to share their experiences of help seeking and what the potential barriers are to them accessing services. Using Reflexive Thematic Analysis (Braun and Clarke, 2022), interviews were transcribed and coded by the author and five themes were generated. '*Perceptions of The Windrush Generation'*, '*Cultural acknowledgement of dementia'*, '*Stigma and Shame'*, '*Keeping it in the family'*, and '*Racism and mistrust of professional services'*.

Evidence demonstrated that specific cultural scripts and attitudes towards professional services are held within the African-Caribbean community, influenced by their migration to the UK and experiences of racism and told by their descendants and spouses. This in turn has shaped their attitudes towards help seeking, as experiences of being made to feel like an outsider and unwelcome led to many from the *'Windrush Generation'* to '*keep quiet and carry on"* out of fear of further discrimination, choosing not to be expressive about their needs or concerns pertaining to their health or wellbeing. When experiencing early symptoms of memory loss, awareness and understanding in this community carry strong associations of stigma and shame. Memory loss was typically seen as synonymous with ageing, but more severe cognitive decline was attributed culturally as a sign of madness. These issues contribute to the individual not wishing to draw attention to themselves by informing

professional services, therefore family members provide care for the loved one at home as a form of protection from community stigmatisation and potential racist treatment from professional services.

Chapter Three presents a public domain document in the form of a press release providing an overview of the literature review and the empirical paper. Taken together, this thesis provides insight into how health inequalities and systemic racism impact and influence the Black community's engagement with authorities and professional services. The results of both demonstrate the significant implications of how mistrust towards professional services exacerbate health inequalities and widen disparities for health outcomes for Black populations.

Dedication

For my girls Rihanna Grace and Sienna Rose.

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CHAPTER ONE

WE ARE NOT ALL THE BAME: A META-SYNTHESIS COMPARING REASONS FOR VACCINE HESITANCY FROM BLACK COMMUNITIES WITHIN THE UK AND USA TO OTHER ETHNIC MINORITY COMMUNITIES

Abstract

Aims: This meta-synthesis aimed to systematically synthesise qualitative literature examining reasons for vaccine hesitancy amongst black communities within the UK and USA in comparison to other ethnic minority communities.

Method: A systematic literature search was performed on four databases, which identified 12 papers that met the inclusion criteria. These papers were evaluated using the Critical Skills Appraisal Programme (CASP) tool. From this, quotes identified as from black participants were extracted and coded using reflexive thematic analysis (Braun & Clarke, 2019). Quotes from other ethnic minority and unknown ethnic minority communities were also extracted and coded to compare reasons for vaccine hesitancy to Black ethnic communities.

Results: Themes were organised according to the three ethnic communities; each of these were divided into sub-themes. **Black Ethnic Communities** (Four Themes: *Mistrust and Suspicion, Mistreatment of Black Communities, Black Guinea Pigs, The Information Vacuum*). **Other Ethnic Minority Communities** (Two Themes: *Obedience, Cultural and Religious Explanations to Vaccine Hesitancy*). **Unknown Ethnic Communities** (Three Themes: *The 'Whiteness' of the Take the Vaccine Message, Travel Restrictions, Social Media*).

Conclusion: Trust was the dominant contributor to vaccine hesitancy in Black ethnic communities. This was largely influenced by historical and contemporary examples of medical malpractice and systemic racism, referencing the Tuskegee Syphilis study and the murder of George Floyd. These experiences were distinct to the Black ethnic group and is consistent with literature pertaining to mistrust in the Black community.

Introduction

This review seeks to understand the reasons for vaccine hesitancy in Black ethnic communities within the UK and USA. Terminology relating to race and ethnicity has evolved with societal changes over time to reflect what is deemed as suitable and acceptable for use. Race is now accepted as a socially constructed term without any biological basis, as it was once considered a damaging construct used to divide different groups of people, making one race superior over another (Flanagin et al., 2021). Ethnicity is defined as cultural factors such as language, religion, cuisine, ancestry, and nationality that specific communities share which can evolve as a community changes (Lewis et al., 2023). In the US, individuals of Black ethnicity are defined as Black or African American and this is defined as a person having origins in any of the Black racial groups of Africa (United States Census Bureau, 2022). In European countries, such as the United Kingdom, Black ethnicity is categorised as Black African, Caribbean or Black British (Farkas, 2017) and in the 2021 census a write in box was added to the category Black African ethnic group to allow individuals to expand further on their country of origin.

Defining Black ethnicity is difficult, as it requires navigating a complex history, culture and identity which has been influenced by migration, ancestry, and colonialism, which in turn makes identification differ across regions and individuals. As this research focuses primarily on the reasons for vaccine hesitancy in Black individuals from the UK and USA, the term Black communities has been used to represent the views of those who identify with a Black ethnicity defined as anyone who may have ancestral roots that can be traced back to Africa inclusive of those who may identify as being of mixed Black heritage (e.g., Mixed Black and White ethnicity). Whilst the author recognises the use of this term may overlook the vast regional differences between Black individuals from the UK and USA, they seek to draw attention to similarities within Black communities that influence vaccine hesitancy.

The 2020 Pandemic and Covid-19

The highly contagious coronavirus disease (COVID-19), caused by the SARS-CoV-2 coronavirus has been responsible for an unprecedented six million deaths worldwide to date (Cascella et al., 2023) causing significant social and economic disruption. (Clemente-Suárez et al., 2021). Originally identified in December 2019 by a cluster of pneumonia cases

reported to health authorities in Wuhan, China (Pokhrel et al., 2020), later identified the virus as COVID-19. It was initially believed to only be contracted through animal to human transmission (Guo et al., 2020) but was later identified to be transmitted by droplet inhalation or direct contact with another infected person (Lu et al., 2020). In the United States (US) and the United Kingdom (UK), the first reported case was in January 2020 and was identified after both individuals had travelled from Wuhan (Flynn et al., 2020; Holshue et al., 2020), alerting authorities that the virus can be generated through air travel (Rahman et al., 2021). Within months, cases of COVID-19 were confirmed in almost every country (Fang et al., 2020) and in March 2020, The World Health Organisation (WHO) declared the COVID-19 outbreak a pandemic and the world entered lockdown (Hu et al., 2021).

As rising mortality and infection rates were reported, governments globally introduced safety measures to reduce transmission, such as wearing masks, closing schools and non-essential business, as well as introducing travel bans and lockdowns (Bliśtanovà et al., 2021). By December 2020, the virus was responsible for 1.8 million deaths globally (World Heath Organisation [WHO],2021) with 350,831 and 72,178 deaths recorded in the US (Centers for Disease Control and Prevention [CDC],2022) and the UK respectively (UK Health Security Agency,2023).

As efforts were made to understand and control COVID-19, it became clear that the disease did not affect everyone equally, with emerging evidence suggesting that ethnic minorities experienced disproportionate infection and outcomes both in the UK and internationally (Bentley, 2020; Mathur et al., 2021,). In the UK, compared with white British individuals, Indian, African & Caribbean individuals were at higher risk of receiving a positive test, being admitted to Intensive Care and having a COVID-19 related death (Mathur et al., 2021). Those from Black ethnic communities were four times more likely to die from COVID-19 in both hospital and community settings (Office for National Statistics, 2020), with rates of death for Black males being 4.3 and Black females being 4.2 times higher than White ethnicities (Moorthy & Sankar, 2020).

Similar findings were found in the US, where African American and Latinx communities were disproportionally represented in the total number of COVID-19 cases and total deaths (Tirupathi et al., 2020). African Americans accounted for 71% of total deaths which is concerning when this group only represents 31% of the American population (Gold et al., 2020, Tirupathi et al., 2020).

Health Inequalities and COVID-19

The complex interplay between factors that increased the risk of COVID-19 to ethnic minorities during the pandemic can largely be attributed to health inequalities. Health inequalities are systematic, avoidable and unfair differences in health outcomes that can be observed between populations (McCartney et al., 2019) and are influenced by factors such as socioeconomic status. During the pandemic, ethnic minorities were disproportionately employed in essential frontline work (Grooms et al., 2022; The Health Foundation, 2020) placing them at higher risk of infection due to the nature of the work, i.e. health care workers, requiring close personal contact, increasing risk of transmission of the virus (Nguyen et al, 2020). In the US, Black Americans were more likely to hold essential worker positions (Brown, 2023), which increased their risk of exposure to the virus (Bunch, 2021). Similar data from the UK, showed that most staff employed in frontline healthcare positions during the pandemic belonged to an ethnic minority group (Bailey & West, 2020), with 20.7% of the 1.2 million staff employed by the NHS, belonging to a Black, Asian or Minority ethnic background (NHS Digital, 2020). Of the 119 NHS staff who died during the pandemic, 64% were from an ethnic minority group (Cook et al., 2020) demonstrating an increased risk of death within these communities (Chaudhry et al., 2020).

Whilst safety measures advised the public to work from home where possible, to reduce contact and therefore the spread of the virus, this message was conveyed through the 'white lens' of exploiting ethnic minorities to sustain the economy at the expense of their personal health and wellbeing (Brown, 2023), as many ethnic minorities continued to work in essential, frontline roles that necessitated face-to-face contact (Yearby & Mohapatra, 2020). To protect workers from the virus, appropriate personal protective equipment (PPE), such as masks and gloves, were required in healthcare settings. Due to demand, some countries experienced a severe shortage of PPE for healthcare workers (Cohen & van der Meulen Rodgers, 2020), with ethnic minorities being disproportionately affected by these shortages (Carvalho et al., 2020).

These risks were compounded further by the lack of financial provision provided for ethnic minorities if they contracted COVID-19. Black workers in the US were less likely to have health insurance or afforded sick leave (Hawkins & Hernández, 2022; Roberts & David, 2021), creating a pressure to manage their own health needs in the context of being a frontline worker with less opportunity to shield or self-isolate (Kumar et al., 2021). The risk

was elevated as ethnic minorities were more likely to live in overcrowded or multigenerational households (Mamluk & Jones, 2020; Rasheed et al., 2021) thereby increasing the risk of transmitting the virus to family members at home.

Pre-Existing Health Conditions and Ethnic Minorities

The intersectionality of health and race demonstrated ethnic minorities had a decreased ability to fight infection due to pre-existing underlying health conditions. Evidence suggested that, during the pandemic, individuals with chronic pre-existing health conditions were at higher risk for covid progressing to severe stages (Treskova-Schwarzbach et al., 2021). Ethnic minorities are more likely to have a higher burden of comorbidities such as coronary heart disease, hypertension, stroke and diabetes (Brown et al., 2007; Sucato et al, 2023), making them more susceptible to disease and disproportionately impacting clinical outcomes (El-Khatib et al., 2020; Otu et al., 2020).

Vaccination Development and Propaganda

Vaccinations are one of the most significant and effective methods to prevent deadly and infectious diseases (Chakraborty et al., 2023). In December 2020, after months of various clinical trials, approval and manufacturing, the Medicines and Healthcare products regulatory agency (MHRA) approved the first COVID-19 vaccine developed by Pfizer/BioNTech (Medicines and Healthcare products Regulatory Agency, 2020). The UK was the first country to launch a vaccination programme in response to the pandemic, aiming to reduce mortality by developing a prioritisation strategy to immunise health and social care workers, people over 80, and nine key priority groups which covered adults with underlying health conditions. (Bahl et al, 2021; Mounier-Jack et al., 2023).

Factors Moderating Vaccine Acceptance

Whilst the vaccine was promoted to help prevent serious illness and death, acceptance of a COVID-19 vaccination differed greatly around the world. In the US and UK, vaccine uptake was slower than expected with less than 5.5 million and 2.3 million people respectively accepting the vaccination in the first month (Sah et al., 2021; Vaughan, 2021). Evidence from systematic reviews found that safety, effectiveness, and side effects were identified as the most common predictors of COVID-19 vaccine acceptance around the world (Roy et al., 2022). More specifically, highest levels of acceptance were found in China (91.9%),

Malaysia (94.3%) Indonesia (93.3%) and the UK ranged between 73-80%. Lowest rates were observed in Africa (15.4%) and Iraq (13%) (Sallam, 2021; Salomoni et al., 2021).

Global and US systematic reviews found factors such higher education, being White or Asian, and being aged 45 and over were determinants of high vaccine acceptance. Lin et al. (2020) found that White Americans consistently expressed higher receptivity to the vaccine, with similar findings in Asian American participants. Lowest acceptance was found in Black ethnic communities.

Vaccine Hesitancy

Vaccine hesitancy is defined as a delay in acceptance or refusal of vaccination despite availability of vaccination services (MacDonald, 2015). Whilst this is not novel to ethnic minority communities, most systematic reviews attribute reasons for not accepting the vaccine to: a heightened sense of risk, loss of trust, and inappropriate communication about vaccines from trusted healthcare providers (Hussain et al., 2022). They also found an under-representation of individuals from ethnic minority backgrounds in vaccine trials (Kamal et al., 2021), low-income, and uncertainty about safety and side effects contributed to vaccine hesitancy. Religious reasons and lack of trust in healthcare systems were correlated with having the lowest vaccine acceptance (Shakeel et al., 2022; Yasmin et al., 2021).

'BAME' Communities and Vaccine Hesitancy

In the UK, Black, Asian and Minority Ethnic, or 'BAME', is a term used to refer to individuals who do not classify themselves as white. Research and information pertaining to these communities are often presented using this umbrella term. Williams et al. (2022) found 'BAME' communities had three times lower levels of intention to vaccinate than white people. On the other hand, Sethi et al. (2021) found the 'BAME' community were more likely to take an approved vaccine. Finally, whilst Paul et al. (2021) found greater negative attitudes within these communities, this did not influence intentions to accept COVID-19 vaccination.

Whilst research provides foundations to understanding vaccine hesitancy in ethnic minorities, it generates a perception of 'ethnic homogeneity', suggesting that attitudes towards vaccination are equivalent across all communities. Relying on this evidence overlooks key differences in lifestyle and cultural health beliefs specific to individual ethnic

communities and can, in turn, hide the realities of heath inequalities influencing different communities (Agarwal & Watson, 2021).

Whilst some research reports that Black ethnicities experience higher levels of vaccine hesitancy (Robertson et al., 2021), this position comes from US participants and captured using quantitative data (Gatewood et al., 2021; Kelly et al., 2021; Viswanath et al., 2021). The UK reports similar findings, but results are presented under 'BAME' (Bhatia, 2020) which fails to consider the nuanced differences between different ethnic communities and reasons for vaccine hesitancy. Therefore, to improve vaccine uptake in the future, it is it important that different ethnic communities are looked at separately.

Evidence consistently demonstrates Black communities have a low uptake of vaccinations (Iyengar et al., 2021) despite being one of the highest risk communities susceptible to COVID infection and mortality (Aldridge et al., 2020). It is therefore imperative to gain an understanding of what influences these decisions.

Aims of Review

The primary aim of this review is to provide a synthesis of the qualitative evidence investigating reasons for vaccine hesitancy in Black ethnic communities within the UK and USA. Direct quotes from Black participants will provide insight into social and historical factors that may influence decision making when choosing to accept or refuse the vaccine. The secondary aim is to compare these quotes to those from other ethnic minority communities to identify any similarities or differences in views expressed for vaccine hesitancy.

The research is positioned alongside previous systematic reviews conducted which considered vaccine hesitancy in ethnic minority populations. Whilst a minority of papers focused on Black communities specifically, those considering vaccine hesitancy in ethnic minority communities tended to report themes relating to mistrust of governments, the speed in which the vaccine was completed and side effects.

The author anticipates the comparison to other ethnic minority communities will highlight some reasons that are specific to the Black community and that these reasons may be considered for public health campaigns which in turn will be more effective if they focus on specific issues pertaining to the Black community.

Method

Various approaches can be used to synthesise qualitative literature as the aim is to understand how people view their social worlds (Atkins et al., 2008; Mays et al., 2005). The most commonly used approach is a meta-ethnography (Hannes & Lockwood, 2011), which is an interpretive approach developed by Noblit and Hare (1988). The aim is to synthesise client experiences through the process of translating studies into one another to create novel interpretations of the data being studied (Malpass et al., 2009). The value of this approach is that it preserves the interpretive properties of the primary data (Dixon-Woods et al,. 2004) by synthesising existing qualitative research to arrive at a new meaning (Luong et al., 2023).

Whilst this approach provides a synthesis of in-depth meanings, experiences and perspectives of individuals, it considers the whole data set in order to provide a higher order interpretation (Cahill et al., 2018). Synthesis in meta-ethnography uses translation and attempts to understand how concepts from different studies may be representative of each other (Soundy & Heneghan, 2022). As this review sought to understand the unique experiences of Black populations and attitudes towards the COVID-19 vaccine, the use of a meta-ethnography was deemed less favourable as the reviewer is required to re-interpret meaning across different qualitative studies to arrive at a new meaning (Atkins et al., 2008). One of the difficulties involving ethnic minorities in qualitative research is that it combines *all* experiences together, therefore a meta-ethnography would not be useful to understand vaccine uptake in Black populations.

Meta-synthesis refers to the amalgamation of qualitative research studies to develop a theory or model that can explain the findings of a group of similar qualitative studies (Walsh & Downe, 2005). Synthesis of qualitative studies requires a re-conceptualisation of findings and then re-interpreting them to create new insights beyond those attainted from individual studies (Campbell et al., 2003). The process involved requires the reviewer to synthesise data beyond the primary qualitative studies and use this to identify gaps in the research by providing evidence to contribute to the existing knowledge (Mohammed et al., 2016).

This meta-synthesis focuses on synthesising direct quotes and experiences that have been identified within the literature as being articulated from Black participants. Quotes will be coded and thematically organised using Reflexive Thematic Analysis (Braun & Clarke, 2019) and compared to those of other ethnic minority communities to see if there are

similarities or differences held between attitudes for vaccine hesitancy. A full account of the reflexive thematic process used can be found in Data Analysis.

Literature Searches

A systematic literature search of four databases (PsycInfo, PubMed, Scopus, Web of Science) was conducted between April – May 2023 and considered published literature from December 2020 - May 2023. PsycInfo was selected for its coverage of psychological literature, whilst PubMed and Scopus were used to capture health literature; Web of Science was selected to cover both areas.

Search terms were categorised into three umbrella categories which aimed to attract literature containing these concepts: *Vaccination terms* were any term related to COVID-19 vaccination or the pandemic; *Hesitancy terms* referred to hesitation or intention to take or refuse the vaccination; *Ethnic status* captured different ethnic minority communities to ensure that literature containing views from Black participants were included. All terms were discussed and reviewed as part of research supervision, and with a research librarian, before final terms were decided. Search terms can be found in Table 1.1.

Table 1.1

Search terms.

Vaccination Terms	
Terms relating to the COVID vaccination.	*vaccin** OR *inocul** OR *immunis** *AND COVID** *Coronavirus* OR *SARS-CoV-2* OR *pandemic*
Hesitancy Terms	
Terms relating to hesitancy or intention to obtain or refuse the vaccine, combined using OR function.	*uptake* OR *accept** OR *hesitan** OR *refus** OR *confiden** OR *decision** OR *concern* OR *barrier* OR *facilitator*
Ethnic Status	
Terms relating to the ethnic group of individuals. Broad terms were used to capture papers that did not explicitly specify individuals from a Black African or	

Black Caribbean background but may have included Black participants within their demography.	*ethnic minorit** OR *ethnic** OR *minorit** OR *rac** OR *Black** OR *African** OR *Asian** OR *Caribbean* OR *BME* OR *BAME* OR *migrant*

Inclusion and Exclusion Criteria

Title and abstracts of papers were screened according to inclusion and exclusion criteria outlined below. Studies were included if they (1) used qualitative methodology; (2) reported material about accepting, hesitating, or refusing a COVID vaccine; (3) were published in a peer-reviewed journal; (4) published in English; and (5) contained direct quotations from participants that could be explicitly attributed to a Black participant or other ethnic minority participants.

Only peer reviewed papers were selected for analysis therefore book chapters, grey literature and dissertations were excluded from the data set. This review relied upon systematically synthesising data extracted from qualitative studies pertaining to vaccine hesitancy in ethnic minorities, therefore articles, protocols or suggestion papers were excluded as they did not contain or capture the direct experiences or opinions of those within our target demographic.

Papers were excluded if they did not include ethnic minorities. Mixed methods studies were considered for inclusion if the qualitative data and analysis were distinct and direct quotations were included. Solely quantitative literature was, excluded from the data set. Inclusion and exclusion criteria, including rationale, is outlined in Table 1.2.

Table 1.2

Inclusion and exclusion criteria.

Inclusion Criteria	Exclusion Criteria
Qualitative research papers with direct quotes from participants	Qualitative studies that do not contain any direct quotes from participants
	Quantitative studies
At least some of the participants were required to self-identify as being of Black African or Black	No participants identified as belonging to a Black, Asian or Other Ethnic minority group

Caribbean heritage to be included in data set as this was required to fulfil the aims of the review.	
Literature needed to contain some material capturing attitudes towards accepting or rejecting the COVID-19 vaccination in ethnic communities. The term hesitancy was included as this reflected the views of those who were delaying their decision to obtain the vaccination	Studies that did not report attitudes specifically about intentions to vaccinate
Literature was only considered from peer-reviewed journals to ensure only high-quality research studies were included as part of this review and thus will improve the overall validity of the results.	Books, dissertations, or grey literature were not included.
To consider all relevant research in this area, qualitative literature was considered from the first publication of COVID-19 research in December 2019 when the first reported case of COVID-19 to May 2023 when searches for the review were conducted.	Articles produced after this time have not been considered
Studies were required to report original results.	Information articles, review papers and protocols were excluded as they did not contain original quotes or experiences from ethnic minority participants.

Selection Summary

Inclusion and exclusion criteria were applied to papers identified. Reference lists of these papers were screened for further relevant papers. Unavailable papers, or papers that could not be accessed in their entirety, were excluded from the analysis. To strengthen the transparency, consistency and completeness in the reporting of the data (Sohrabi et al., 2021), the author adopted the use of PRISMA: Preferred Reporting. Items for Systematic reviews and Meta-analysis (Moher et al., 2009), a 27-item checklist and four phase flow diagram designed to demonstrate the process followed to identify and extract literature used for analysis.

Searches identified 629 papers. Following title review, three duplicates and 537 records were removed for not meeting the inclusion criteria. The abstracts of 89 papers were read to determine eligibility in line with inclusion criteria. Seventy papers were excluded as Black ethnic communities did not participate in the study, there was no material about attitudes to vaccination, or did not report original data. Nineteen papers were retained and read in full and, following this, a further seven papers were excluded as quotes from Black participants could not be explicitly identified. Hand searches from these papers using reference lists did not return any further papers. Full search strategy, including reasons for exclusion, can be found in Figure 1.1.

Twelve papers were considered for review and are summarised in Table 1.3. Nine papers were from the UK and three were from the US. Nine papers used empirical qualitative methods and three used mixed-method design. The studies collectively presented data from 566 participants who identified as belonging to an ethnic minority, 281 of which who identified as belonging to a Black ethnic group. Of quotations extracted, final analysis was based on 111 quotes being extracted from self-identified Black participants, 66 from other ethnic minority communities and 113 from unknown ethnic minority.

Figure 1.1

PRISMA diagram of the screening and review process.

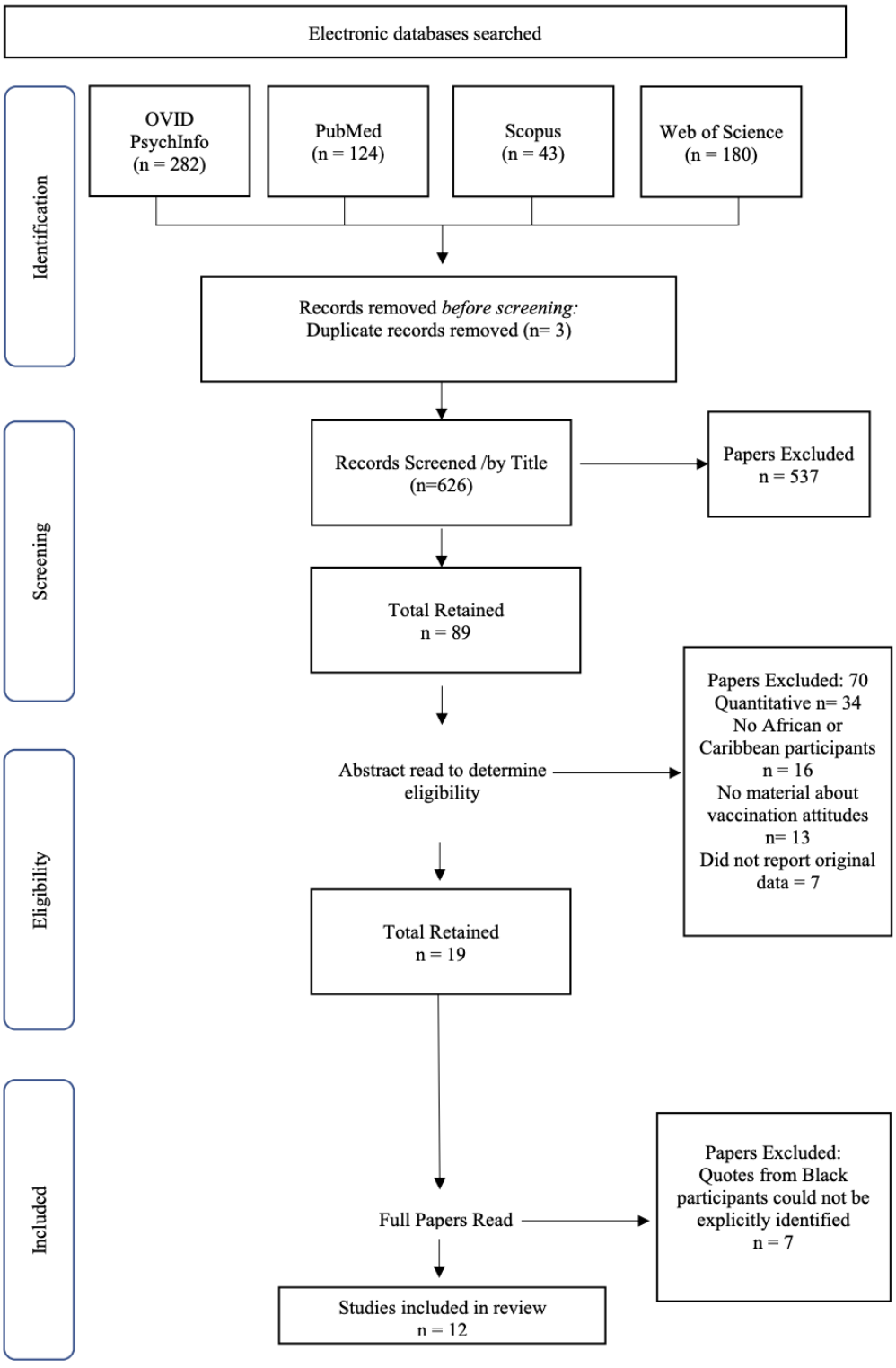

Electronic databases searched
Identification
OVID PsychInfo (n = 282)
PubMed (n = 124)
Scopus (n = 43)
Web of Science (n = 180)
Records removed *before screening:* Duplicate records removed (n= 3)
Screening
Records Screened /by Title (n=626)
Papers Excluded n = 537
Total Retained n = 89
Eligibility
Abstract read to determine eligibility
Papers Excluded: 70
Quantitative n= 34
No African or Caribbean participants n = 16
No material about vaccination attitudes n= 13
Did not report original data = 7
Total Retained n = 19
Included
Full Papers Read
Papers Excluded: Quotes from Black participants could not be explicitly identified n = 7
Studies included in review n = 12

Table 1.3

Summary of final papers selected for review

Title, author, year of publication	Aim(s) of Study	Methodology	Participants	Geographical Location	Data Collection & Analysis	Number of Quotes Extracted
Bateman et al. (2022) Exploring COVID-19 Vaccine Hesitancy among stakeholders in African American and Latinx Communities in the Deep South Through the lens of the health belief model	To explore vaccination intention among African American and Latino (or Latinx) participants	Qualitative	67 Participants (n=49 African American) (n=18 Latina) Researcher ascribed ethnicity	USA	Semi structured interviews, 4 Focus Groups Data was recorded and transcribed using Thematic Analysis.	13 African American 3 Latina
Bell et al. (2022) COVID-19 vaccination beliefs, attitudes, and behaviours among health and social care workers in the UK: A mixed-methods study	To gain insight into beliefs attitudes and behaviours in health and social care workers	Mixed Methods	20 Participants (n=3 Black British) (n=6 Asian or Other Asian) (n=2 Mixed white & black: Other mixed background) Participant Self-Ascribed Ethnicity	UK	Semi Structured Interview Data was transcribed verbatim and analysed using Reflexive Thematic Analysis	3 Black British 1 Mixed White & Black Caribbean 1 British Asian
Charura et al. (2022) Covid-19 Vaccine Hesitancy, Medical Mistrust and mattering in ethnically diverse communities	To explore factors that may underpin hesitancy towards the covid-19 vaccine and intention to vaccinate in ethnically diverse communities	Mixed Methods	161 Participants (n=16 Asian) (n=125 Black) (n=18 Mixed race) (n=2 Any other ethnic group) Participant Self-Ascribed Ethnicity	UK	Online questionnaire with open and closed questions Quantitative data was analysed using descriptive statistics, bivariate correlations and multiple regressions. Analysis was conducted using SPSS 26.0 and MPlus 8.1 For Qualitative data thematic analysis was used.	17 Unknown Ethnicities
Eberhardt et al. (2022a) A qualitative study exploring attitudes and perceptions of the COVID-19 booster vaccine in minority ethnic individuals in North East England	To explore attitudes and perceptions of covid-19 booster vaccination among ethnic minority individuals in northeast England	Qualitative	16 Participants (n=13 Black British / African) (n=2 Indian) (n=1 White eastern European) Researcher ascribed ethnicity	UK	Semi Structured Interviews Interviews were analysed using inductive thematic analysis.	23 Black African 1 Black British 8 Indian

Eberhardt et al. (2022b) Exploring COVID-19 Vaccine Confidence with People from Black and Asian Backgrounds in England	To understand factors affecting hesitancy in black and Asian individuals in England	Qualitative	95 Participants (n=47 Black African or Caribbean) (n=2 Any other black background (n= 3 Mixed White & Black African or Caribbean) (n=24 Pakistani) (n=16 Bangladeshi) (n=2 Mixed white and Asian or other Asian background) Researchers deliberately recruited ethnic minorities who then self-ascribed their ethnicity. (n=1 Other ethnicity)	UK	Online Engagement Platform Written responses including text accompanying multimedia uploads were analysed using thematic analysis.	19 Unknown Ethnicity
Majee (2022) The past is so present: Understanding COVID-19 vaccine hesitancy among African American adults using qualitative data	To explore vaccine attitudes and intentions among faith based wellness programme	Qualitative	21 Researcher ascribed ethnicity	USA	Interviews Interviews were transcribed verbatim and analysed using inductive thematic analysis.	27 African American
Magee et al. (2022) Facilitators and barriers to covid-19 vaccination uptake among ethnic minorities: A qualitative study in primary care	Explore covid-19 vaccination hesitancy in primary care patients from south Asian and black African or Caribbean ethnicities	Qualitative	38 Participants (n=21 Black British) (n= 12 Asian / British Asian) (n=5 Mixed ethnicity) Participant Self-Ascribed ethnicity	UK	Telephone Interviews Interviews were audio recorded and transcribed using NVivo. Data Analysis was inductive and informed by thematic analysis.	7 Black Caribbean 5 Black African 3 Mixed Black Ethnicity 3 Black British 1 Mixed African/Caribbean 1 Black British African 1 Black British Caribbean 1 Mixed White Caribbean 1 Asian British
Naqvi et al. (2022) Understanding covid-19 vaccine hesitancy in ethnic minorities groups in the UK	Explore the drivers for vaccine hesitancy in ethnic minority groups in the UK	Qualitative	12 Participants representing Black, Arab and Asian backgrounds including Indian, Pakistani and Asian Other Researcher ascribed ethnicity	UK	Semi Structured Interviews Content analysis was used to code interview transcripts, a framework method was used to organise and chart the codes. These were	8 Unknown Ethnicity

					reviewed and mapped to interpret the data to develop initial themes. Themes were then used to identify gaps in the existing literature.	
Sagoo et al. (2022) UK ethnic minority healthcare workers perspectives on covid-19 vaccine hesitancy in the UK ethnic minority community: A qualitative study	To understand UK ethnic minority healthcare workers perspectives on covid-19 vaccina hesitancy	Qualitative	15 Participants (n=7 Black British African/Caribbean) (n-7 Asian / British Asian) (n=1 Mixed/ multiple ethnicity) Researcher ascribed ethnicity.	UK	Interviews & One Focus Group Analysis was inductive and conducted using thematic analysis.	13 British Asian 14 Black African / Caribbean
Valero Martinez et al. (2023) Attitudes toward covid-19 vaccine uptake: A qualitative study of mostly immigrant racial/ethnic minority older adults	To understand the attitudes of older adults from immigrant populations towards the covid-19 vaccination and its influence on vaccination decision making.	Mixed-Methods	100 Participants (n=5 Black) (n=48 Chinese) (n=30 Latina) (n=11 White) (n=5 Other) (n=1 American Indian) Researcher ascribed ethnicity	USA	Semi structured telephone interviews Interviews were transcribed verbatim and coded using Dedoose which is software for qualitative analysis. Data was then analysed using thematic analysis.	15 Latinx 2 Black 9 Chinese 1 American Indian 2 Other
Williams et al. (2022) Public decisions about COVID-19 vaccines: A UK-based qualitative study	To explore UK public decisions about whether to get covid-19 vaccines and the facilitators and barriers behind participants decisions	Qualitative	29 Participants (n=9 Black Asian, Minority Ethnic) (n=20 White) Researcher ascribed ethnicity	UK	6 Online Focus Groups Data was analysed using framework analysis.	50 Unknown Ethnicity
Woodhead et al. (2021) Race, ethnicity and covid-19 vaccination: a qualitative study of UK healthcare staff	Understand uptake in ethnic minority staff groups	Qualitative	25 Participants (n=2 Black African) (n=4 Black Caribbean) (n=4 Asian) (n=14 White) (n=1 Other) Researcher ascribed ethnicity	UK	Semi structured interviews, Inductive thematic analysis	11 Asian 3 Black African 1 Black British Caribbean 2 Other Ethnic

Quality Appraisal

Quality appraisal allows researchers to systematically examine research to assess its reliability and ensure credible conclusions can be drawn from the data. The process ensures that research appraised makes a valuable contribution to the field. Quality appraisal for the selected papers was made using the Critical Appraisal Skills Programme (CASP, 2018) checklist. This tool was selected as it addresses the principles and assumptions of qualitative research, it is suitable to use across various qualitative research methodologies and it is recommended by the Cochrane collaboration for synthesis of qualitative research as it allows clinicians to judge the trustworthiness and value of research evidence reliably and efficiently (Noyes et al., 2023). The tool consists of 10 statements which assess quality by considering the use of appropriate methodology to the value of the results. The researcher is required to consider the quality of studies by answering 'Yes', 'No' or 'Cannot Tell'. Hints are provided alongside statements to help researchers feel more confident in their appraisal. The researcher added an additional category 'Ethnic Minority Inclusion', which aimed to assess the inclusion of non-white participants in the research. The rule for assessing these items was twofold. Firstly, to determine if the researchers deliberately recruited ethnic minorities. This would determine whether they aimed to consider the specific experiences of vaccine hesitancy in ethnic minorities or if the research considered vaccine hesitancy more generally assuming homogeneity is reason. It is thought that those with an exclusive focus would produce a higher proportion of quotes from ethnic minorities. Secondly, this item assessed if the researchers' cultural background was known as this may have influenced the reporting of the data.

The lead author completed the screening process and adopted a colour rating system and mapped these onto the quality markers in the CASP tool. Green was assigned to papers who achieved a 'Yes" for demonstrating meeting the criteria and red if the paper did not demonstrate this and achieved a 'No'. Blue was used if the researcher could not tell if that item was present. Studies were only excluded based on quality if they failed to meet the minimum requirements of the two initial screening questions which identified if there was a clear aim of the research and if qualitative methodology was used. No papers were excluded for quality. Quality appraisal is displayed in Table 1.4.

Table 1.4

CASP Checklist for quality of research papers

	Bateman (2022)	Bell (2022)	Charura (2022)	Eberhardt (2022a)	Eberhardt (2022b)	Majee (2022)	Magee (2022)	Naqvi (2022)	Sagoo (2022)	Valero-Martinez(2022)	Williams (2022)	Woodhead (2021)
Are the results of the study valid												
Was there a clear statenent of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is the qualitative methodology appropriate	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the research design appropriate to address the aims of the research	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the recruitment strategy appropriate to the aims of the research	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the data collected in a way that addressed the research issue	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Has the relationship between researcher and participants been adequately considered?	Y	C	Y	Y	C	Y	Y	N	Y	C	Y	Y
What are the results												
Have ethical issues been addressed clearly?	C	Y	Y	Y	Y	Y	Y	Y	N	N	N	N
Was the data analysis sufficiently rigorous?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Will the results help locally												
How valuable is this research to the field of psychology?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ethnic Minority Focus												
Did the paper deliberately recruit ethnic minorities?	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Could participants from a Black ethnic background be specifically identified in this research?	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y
Is the cultural background of the researchers known?	N	N	N	N	N	Y	Y	N	Y	N	N	Y
Y= Yes, N= No, C= Cannot Tell												

Overall quality across for the papers were of a good standard with all scoring a 'Yes' for a clear statement of aims and appropriate qualitative methodology. Some papers scored 'No' for quality relating to ethical issues as there was no clear statement about how this was managed during the research. There was a varied response to the 'ethnic minority focus' as it was not always clear what the cultural background of the researchers were and whether this influenced the data. A particular strength is that all papers except Bell et al., (2022), included a statement in their recruitment strategy to deliberately recruit ethnic minorities.

Data Extraction

To specifically focus on vaccine hesitancy in Black ethnic minorities, the researcher chose to extract and work with direct quotations alone. Data extraction involved reading identified papers in full and highlighting all available quotes that were presented as 'results' or 'findings' and pertained to an ethnic minority. Whilst this approach allowed the researcher to understand the direct experiences of Black participants compared with other ethnic minorities, the ethnicity of all participants was not always specified. Therefore, all quotations were collated and organised into three categories:

- Quotes attributable to Black Participants
- Quotes attributable to 'Other' Ethnic Minority Participants
- Quotes not attributable to a specific Ethnic Minority Participant

Data extraction resulted in 111 quotes identified as from Black participants, 66 from other ethnic minority participants, and 113 that could not be attributed to a specific ethnic minority participant.

Data Analysis: Reflexive Thematic Analysis

Reflexive Thematic Analysis is a method of data analysis used in qualitative research, developed by Braun & Clarke (2019). The purpose is to develop patterns of meaning across a dataset by using codes, and then using these to develop themes that seek to address the research question.

The reflexive process consists of six stages (outlined in Table 1.5) where the researcher is required to become familiar with and systematically code the data before moving onto the development, review, and refinement of the themes. This approach was selected as it recognises the researcher as having an active role in knowledge production (Braun & Clark, 2013) and

recognises the researcher's position as an African-Caribbean woman. Appreciating how this position may influence the interpretation of the data, the reflexive process considers how the results represent the researcher's interpretations of patterns or meaning across the dataset (Byrne, 2022).

Table 1.5

Phases of Reflective Thematic Analysis

Phase Number	Description of Process Involved
Phase 1: Familiarising yourself with the dataset	Becoming deeply and intimately familiar with the content of the dataset, through the process of immersion. Reading papers and highlighting the quotes relevant to Black people, other ethnic minorities and unknown ethnicities.
Phase 2: Coding	Identifying segments of data that appear potentially interesting, relevant or meaningful to the research question. Code-labels are analytically meaningful descriptions and aims to capture single meaning or concepts. Coding will be completed at the semantic level which captures explicit surface level meaning. Once the entire dataset is coded, code labels are collated and compiled.
Phase 3: Generating Initial Themes	This phase involves compiling clusters of codes which share an idea or concept which may answer the research question. Theme development is an active process which are developed around the researcher's knowledge and insights and the research question. Themes describe broader, shared meanings.
Phase 4: Developing and reviewing themes	The researcher revisits the initial data set to assess whether the initial themes make sense in relation to the full dataset and viability of the overall analysis. This process aims to see if the themes represent the most important patterns across the dataset in relation to the research question. Revision of the data becomes a dynamic process of the researcher reviewing the content to ensure it fits well with the patterns across themes and in relation to the overall research question.
Phase 5: Refining, defining and naming themes	This phase requires the researcher to establish whether each theme is clearly demarcated and built around a strong core concept. The themes should fit together to build an overall story about the data. During this phase, an informative name for each theme is created and a short synopsis is written. If themes still require more work then this is the opportunity to develop and refine them further.
Phase 6: Writing Up	Data is pulled together to form the analytical narrative by compiling data extracts to inform the reader of a coherent and persuasive story about the dataset. The aim of this stage is to address and answer the research question.

Using the stages outlined above, the researcher familiarised themselves with all quotes pertaining to Black participants by reading, re-reading and making brief notes. Considering the research question, each quote was coded semantically until the whole dataset

was coded. Codes were then organised into categories, which began to contribute to initial themes. Braun & Clarke (2006) suggest that after initial codes are identified, the researcher should begin to identify relationships between themes that are underpinned by an underlying theoretical framework. The aim is to go beyond the descriptive coding, resulting in a conceptual framework that explains the wider data set informed by existing literature to move from describing patterns to providing a deeper theory driven analysis of a concept.

Through review and comparing to the wider data set, themes were developed in relation to the research question. Data was then refined, defined and themes were named.

This process was repeated for quotes pertaining to other ethnic minority participants and compared to the themes produced from Black participants to see if any other themes were derived. Finally, this was repeated with the quotes that could not be attributed to any specific ethnic minority group to see if any new themes were generated that were not found in the Black or other ethnic minority communities. Examples of code and theme development can be found in appendix 1.

Steps to Ensure Credibility

Credibility is enhanced in qualitative research via research supervision. Institutional checking in research refers to the researcher using the supervisory space to obtain reactions to initial research procedures and findings (Stahl & King, 2020). The researcher met with both supervisors who checked codes and themes for coherence and attended a 'meta-synthesis support group' where student peers discussed the methodological process offering a detached opinion on credibility of findings. The use of a reflexive diary was encouraged to allow the researcher to consider how being Black may impact how they viewed the data and how this may influence the interpretation of the findings.

Results

Synthesis resulted in four themes being identified from the Black participants within the UK and USA. *Mistrust and Suspicion,* considers the relationship between Black individuals and authorities. *Mistreatment of Black communities* discusses contemporary examples of how Black people have been violated throughout society. *Black Guinea Pigs* discusses historical medical malpractice using Black bodies for experimentation. *The Information Vacuum* considers the lack of reliable sources for credible information about the vaccine and the vulnerability of the Black community. Each theme was developed from the coding process

as outlined in reflexive thematic analysis (Braun et al., 2019) which details the steps taken by the author to arrive at the final themes for analysis. A breakdown of each step and table of which papers contributed to each theme can be found in appendix one. Some papers were more explicit in the use of attributable Black participant quotes, therefore were more heavily relied on in the generation of themes. Whilst the author has attempted to balance the use of quotes to increase the validity of the themes, caution should be taken that these themes are representative of Black communities in the UK and US and based on papers who explicitly displayed quotes illustrative of Black or ethnic minority participants to support their findings.

The other ethnic minority group identified two themes. *Obedience* considers how some communities felt more inclined to accept the vaccine based on instructions from authorities. *Cultural and Religious Explanations for Vaccine Hesitancy* looks at how some ethnic communities felt their cultural and religious practice provided some protection from the virus. The unknown ethnic Group identified three themes, *The 'Whiteness' of the Vaccination message* refers to how the vaccine was developed and promoted by white people without ethnic minority collaboration and contribution. *Travel Restrictions* describes the pressure to vaccinate to safeguard personal liberties. *Social Media* considers how social media became a safe space to discuss the vaccine during the pandemic. Theme summaries are in table 1.7

Table 1.7

Summary of Themes

Black Ethnic Communities	Other Ethnic Minority Communities	Unknown Ethnicity Group
Results identified dominant themes amongst the Black community living within the UK and USA that contributed to vaccine hesitancy was mistrust and suspicion. These positions influenced how the community responded to or engaged with the vaccination programme during the pandemic and was largely influenced by examples of historical and contemporary mistreatment of Black people. The results interweave to tell a story of how structural violence has propelled fear within a community resulting in a disengagement and disillusionment of governments, medical professionals, and pharmaceutical companies. Fear surrounded what the true intention of the vaccine was, and a scarcity of reliable trustworthy information led the Black community to question whether there was an alternative agenda in promoting them to accept the vaccine.	Minority ethnic communities included quotes from participants that did not identify as being of Black heritage and included representation from Chinese, Asian and Latinx communities, from both the US and UK. Similar to the Black Community, concerns around vaccine safety and lack of trust in the government were reasons for vaccine hesitancy. A key difference in this group was a greater level of obedience to accept the vaccine influenced by messages conveyed by authority figures, contradicting attitudes found within the Black community. There was also consideration of how cultural and religious practices influenced the readiness to accept the vaccine.	Quotes from these participants could not be attributed to a particular ethnic group and so represent views from all ethnic minorities. Views represented in both the Black and Other ethnic minority themes were also expressed here, however in the unknown ethnicity group, there was reference to accepting the vaccination based on travel requirements if this restricted returning to their home country. The perceived '*whiteness*' of the vaccination message and lack of cultural sensitivity in the promotion of the vaccine contributed to hesitancy. The use of social media during the pandemic provided a 'safe space' for ethnic minorities to discuss their concerns about the vaccine away from the critical eye of wider (white) society.
Theme 1: Mistrust and Suspicion Theme 2: Mistreatment of Black communities Theme 3: Black Guinea Pigs Theme 4: The information Vacuum	Theme 1: Obedience Theme 2: Cultural and Religious Explanations for Vaccine Hesitancy	Theme 1: The '*Whiteness'* of the take the vaccination message Theme 2: Travel Restrictions Theme 3: Social Media

Black Ethnic Communities

Theme 1: Mistrust and Suspicion

Mistrust and suspicion were dominant themes for Black communities, both in the UK and US. Participants discussed how a lack of transparency from the government and from medical professionals contributed to vaccine hesitancy. This attitude stems from a longstanding history of systemic racism in which Black people have negatively faced the consequences of health inequalities (Kalin, 2021). This participant quote taken from Williams et al., (2002) illustrates:

> The government doesn't have a very good track record with the sense that there was the Thalidomide tablets that were given to pregnant women back in the '60s, the blood transfusions that were imported from people volunteers in state penitentiaries in America that were contaminated, brought into the United Kingdom…. there's been several vaccinations given to toddlers . . . that came from America—I think about 1000 children have died. . .. I'm not one to trust governments, they tend to rush into things. – Williams et al., 2022.

Bell et al. (2022), refer to participants' recollections of deeply embedded racism observed within governments which has influenced health inequalities for decades, causing Black communities to question why they should trust the government recommendations on vaccination:

> We feel for decades, we have been on the receiving end of health and social inequalities. Now, were being presented with a new vaccine that has been developed in quick time and we are now priority group number 1 – Bell et al., (2022).

Suspicion arose from the fear of being maliciously targeted, or even killed by those making and promoting the vaccine, which further perpetuated feelings of mistrust. Suspicion led to interpretation that the vaccine was intentionally created to attack or kill Black people as expressed by this participant: "*You don't know whether they are going to vaccinate something for you to live longer or to die tomorrow" (Majee et al., 2022).* Suspicion towards the government made this participant feel that they were being purposely targeted, and accepting the vaccine will result in death:

> If you get these vaccines, you're going to die. They want to kill you. All those things which are coming up saying don't take vaccines, these vaccines will actually make you die. And you see our own people that [are] dying more. (Eberhardt et al., 2022a).

Government attempts at promoting the vaccine to the Black community created suspicion owing to a longstanding history of health and social inequalities (Morgan et al., 2023). This attitude led to many Black individuals to observe the impact of the vaccine in others before accepting it themselves, as suggested by this participant: "*I think the wisest thing to do is just let things play out and take it last. I think everyone in my circle's quite like that, just see what happens"* (Magee et al., 2022). This participant agreed: "*I would not be first in line to get it. I'd have to let thousands of Americans get it before—and I see their reaction before I get it"* (Bateman et al., 2022).

Mistrust was commonplace in US literature towards the American Government, but Black communities in the UK shared similar sentiments of mistrust towards the British Government. This participant comments on mistrust within the Black British community:

> I think just from my experience, there's a lot of conspiracies that I've heard about. Because I mean I identify myself as a Black British person and so within my community I've heard a lot of just not trusting the vaccine . . . somebody sent me a video about [UK Government Health Secretary] Matt Hancock . . .suggesting that the vaccine was tested first amongst the BAME group (Williams et al., 2022).

This theme demonstrates that for Black communities in the UK and US, mistrust and suspicion contributed to vaccine hesitancy. This was influenced by historical mistreatment of Black people, causing them to question whether the vaccine was something designed by the government and medical professionals to intentionally harm this community.

Theme 2: Mistreatment of Black Communities

The historic and continued mistreatment of Black communities by White people in power was referenced in the literature as a reason for vaccine hesitancy. These views did occur less frequently and so the results of this theme should be treated with caution. Views expressed were underpinned by a deep-rooted 'mistrust' as this community have observed the disregard for Black lives by citing historical and contemporary examples of mistreatment. Black people in the US continue to report experiencing on-going discrimination in healthcare, unfair treatment by the police, and racial slurs or microaggressions (Bleich et al., 2019).

For many Black participants primarily in the US, the murder of George Floyd in 2020 at the hands of a white police officer was cited as a stark reminder that, in counties such as the US and UK where there is a White majority, there is a disregard for Black lives. This participant suggests that these experiences influenced attitudes towards the vaccination:

> They continue to show us how much disregard they have for our lives, in so many ways, I mean, George Floyd. They continue to show us that no, it's not in the past. It's not over. 'We still have it out for y'all.' Those kinds of past experiences in our community are the hesitation (Majee et al., 2022).

Hesitancy towards the vaccine was influenced by legacies of mistreatment remembered and passed on generationally within the Black community. Some apprehension was related to past experiences of mistreatment which had caused widespread harm. This participant who declined the vaccine reflects on this : *"I don't know if it would but you know like, I guess […] they only just found out that it has birth defects and can cause disabilities"* – Woodhead et al., (2021).

The notion that 'time is a healer', allowing the community to move on from these historical and contemporary events, was seen as 'naivety' and failing to recognise the deep sense of hurt experienced within the Black community. At the time of the pandemic, this may have led some Black communities to feel as though White communities were inadvertently dismissing the hesitancy felt and erroneously believing Black people did not take the risks of the pandemic seriously. It may have been felt that a critical eye was cast on the Black community for not accepting the vaccination, with little consideration of the historical factors that influenced these decisions. This participant describes the frustrations they felt and how trust has been perverted by governments, and memories of this continue to be strong within the culture.

> Mistrust […] has been building up in [...] especially African countries and people with African descent. [...] When you were growing up, this was information that was going around. [...] (Eberhardt et al., 2022a).

Historical and contemporary examples of mistreatment serve as a stark reminder to the Black community about the value of Black lives in society. These events were compounded by mistrust and suspicion resulting in vaccine hesitancy.

Theme 3: Black Guinea Pigs

The roll out of the covid vaccination programme led many Black communities to reflect on, and reference, the most notable historical example of medical mistreatment as a significant reason for hesitancy towards the vaccine. The Tuskegee Syphilis Study concerned Black males who were experimented on by the US Government for four decades. Those men with syphilis were not only unaware they had the illness, but the US Government failed to provide treatment for the condition, resulting in loss of life (Brandt, 1978). This participant reflects on this: *"The Tuskegee experiments where Black men were injected with syphilis and never treated, they just monitored to see how it's going. We remember that"* (Majee et al., 2022), The introduction of the vaccine exacerbated feelings that Black people were treated as 'Guinea Pigs': *"There's a lot of seniors I know they said they're using them as guinea pigs" – (Valero-Martinez et al,(2021)*and experimented on to advance the wellbeing of wider society:

> I'm not sure because I think that they've been experimenting on Black people with the drugs all over the place. They would want for us to go and take this thing and if it works on us and they pass it on to everybody else (Magee et al., 2022)

When asked their reasons for hesitancy, many Black individuals reflected on experimentation in their response: *"We want to make sure [we are] not being experimented on, like the Tuskegee or the syphilis thing"* (Majee et al., 2022). Others refused the vaccine and quite explicitly stated Tuskegee for their reasoning: "*Well, I have one phrase, the Tuskegee experiment*" (Bateman et al., 2022). These suspicions and views stem from Black bodies being used for medical advancement since the days of slavery (Savitt, 1982). The impact of this has contributed to a generational trauma which has impacted the Black community and influenced their relationship with medicine. The term 'guinea pig' was referenced by many Black participants, reflecting the notion that Black bodies were something to be experimented on, suggesting that attempts to encourage acceptance of the vaccine would be futile as demonstrated by this participant: *"I don't think there would be anything that would encourage people from this area to be, quote/unquote, guinea pigs. We've seen the history, what has happened"* (Bateman et al., 2022). The historical influences and memories of these experiences exacerbated pre-existing suspicion and fed into the hesitancy to accept the vaccine and that the historial use of experimentation on Black bodies reduced confidence to accept the vaccine:

> They said they brought COVID, HIV to Nigeria, there has been a lot of experiments being done to Black people. And that has reduced their confidence in that our people are not involved. [...] I think there has been a history of an incident that they have maybe come to Africa to test one or two drugs. So, in this situation, anything that is made abroad, there is always a [...] question mark, because people will always think, are they coming in again? [...] I don't know, I've never really read the history. [...] These are the things that break our confidence. (Eberhardt et al., 2022a).

Another participant denotes that historical evidence of using Black bodies for experimentation was a key factor in vaccine hesitancy:

> I think it's [hesitancy] always been a traditional theme within the BAME community and this is a historical thing. We know about cases of slaves as basically Guinea pigs for [the Tuskegee] syphilis [study]. And even pregnant ladies being used. For example, the Sims speculum was actually developed from pregnant slaves. And they were really subjected to a lot of horrific examinations that would not be deemed acceptable in this day and age. So I think that there's a history behind this [hesitancy] and there's a reason why the BAME community [is] more hesitant towards any new intervention– Sagoe et al., (2022)

Examples throughout history of using Black bodies for experimentation, led the Black community to believe the COVID-19 vaccination was yet another example of using Black bodies to advance medicine. Many reflected on these examples to support their feelings mistrust and suspicion towards accepting the vaccine.

Theme 4: The Information Vacuum

Lack of information was an experience felt within all communities during the pandemic and was not a position unique to the Black community. The lack of information added an additional layer of uncertainty to the already suspicious Black community. The information vacuum refers to a time where there was an absence of reliable information regarding the vaccine. The lack of ability to rely on official bodies to convey reliable, trustworthy information contributed to Black communities feeling a sense of uncertainty and speculation, leading to misinformation being disseminated to fill the void. This view is articulated by this participant: *"I guess because there was no information coming from the government, there was an empty space, and echo chamber, and people filled the space with conspiracy theories"* (Magee et al, 2022). Vulnerability surrounding the trustworthiness of information

from the Government conflicted with other sources of information that may have been available to the Black community. The vastness of available information caused some members of the Black community to become confused as to the credibility, causing a conflict in their decision making:

> Besides what is online there appears to be a vagueness about the side effects that I'm sure some people have had. I think there should be more transparency especially for Black and brown healthcare workers - Bell et al., (2022).

Uncertainty about the vaccine, based on the lack of information available, coupled with being 'told to take the vaccine', left some participants feeling frightened. They suggested that, with more information, these feelings could have been avoided: *"I wanted to be fully informed rather than just told to take it. . . I was left frightened and with little information which was totally avoidable"* (Bell et al., 2022).

Confidence in accepting the vaccine may have been increased by providing the Black community with more information about the vaccine and, more specifically, how it impacts Black bodies. Having members of the Black community to promote the vaccine would have helped to increase trust: *"You can't just tell people to just take a vaccine. You have to educate them around it, and it has to be people who are from your community that you can trust to overcome these hurdles*" (Bateman et al., 2022). Sagoe et al., (2022) suggest information overload, complexity and contradiction generate mistrust which contributes to vaccine hesitancy, therefore providing information about safety, potential side effects and robustness of the vaccine trials may be useful in mitigating vaccine hesitancy.

The contentious relationship between Black people and authorities was compounded by existing mistrust, causing many to question the credibility of information being disseminated by the government. Lack of information and mistrust, contributed to reduced confidence to accept the vaccine in the Black community.

Other Ethnic Minority Communities

Theme One: Obedience

Generally, there was a sense that those from other ethnic communities were less likely to experience vaccine hesitancy because there was a shared collectivist attitude and obedience to authority and authority figures. This view was exclusively expressed by other ethnic minorities and not from Black participants. Views expressed tended to focus on the impact of taking the vaccine and how this would have a positive impact on the individual and wider society. In contrast to Black participants, ethnic minorities appeared to be more willing to accept the vaccine and cited reasons such as the government, medical professionals and professional duty as influencing these decisions.

This participant expressed that they took the vaccine because that is what the government asked, demonstrating obedience to authority: *"The government asked us to vaccinate, so we did it to support their policies"* (Valero-Martinez et al., 2022). Another participant supported this view: *"I still believe in government and believe in science […] It seems that Americans are used to freedom. They are like this. Chinese people are more obedient"* (Valero-Martinez et al., 2022). Trust in the Food and Drug Administration (FDA), a department in the US responsible for promoting and protecting public health by regulating the safety of new medical products, provided reassurance to this participant to confidently accept the vaccine: *"I trust the [FDA] and I know they are not going to approve a vaccine that is going to hurt us"* (Bateman et al., 2021).

Medical professionals were seen as a credible source to instil confidence in the vaccine promotion. Ethnic minorities were more likely to seek further information about the vaccine from their doctor and subsequently accept the vaccine if advised to do so. Anxieties around vaccine hesitancy were assuaged when advised by a medical professional. This participant was against accepting the vaccine until their doctor advised them to do so: *"My wife was against the vaccine, but she's now following the rules that the doctor told he"* (Valero-Martinez et al., 2022).

Underlying health conditions was a concern, but specific advice from medical professionals allowed participants to make informed choices to accept the vaccine:

> So, I was afraid to get the vaccine because of my cancer. But then I sought information with [my doctor] and she guided me. She told me that I was fine to get it.

> I talked to my cancer doctor. He said I was fine. I should get it. So, I said OK. Now I'm going to get it [the COVID-19 vaccine]. (Eberhardt et al., 2022a).

Medical influence was key in supporting ethnic minorities; having a medical professional who can demonstrate cultural competency by understanding hesitancies unique to ethnic minorities was imperative to increasing vaccine acceptance. This participant, who is a doctor, reflects on using his position to advise people to accept the vaccine:

> It's understanding people's cultures and being culturally competent, culturally aware. People who are in positions like myself speaking to your own communities and family members to give out positive messages to the family members and wider community to say, I would take the COVID vaccine and therefore you should be doing it as well. (Woodhead et al., 2021).

Another form of obedience found in ethnic minorities was the impact of accepting the vaccination as part of their professional or moral duty. Several participants made references to an obligation to take the vaccination to reduce the risk of transmission in others. This participant spoke about the pressures of accepting the vaccine to ease pressures on the NHS:

> From the worker perspective I suppose there is this um, obligation in many respects to have the vaccine to make sure that you are reducing the risk of either contracting COVID yourself or spreading COVID in the health service, given the pressures that we're under (Woodhead et al., 2021)

It was assumed that healthcare workers would be more willing to accept the vaccine as they were more likely to see the health effects of the virus first-hand:

> I can imagine the majority of staff will take it, especially in the healthcare setting because you see a lot of it first-hand how it's affecting people so I can't imagine a lot of people would say no to it (Woodhead et al., 2021)

Vaccine hesitancy in ethnic minorities was reduced if advised by medical professionals or government officials.

Theme Two: Cultural and Religious Explanations for Vaccine Hesitancy

Practices unique to a particular ethnic group provided some communities with a perceived protection against the virus therefore rendering the vaccination obsolete. Many looked at their countries of origin to see how coronavirus was transmitted and managed, perceiving the

transmission and death rates to be much lower than compared to the UK or US. Many ethnic minorities sought solace through their religion or religious institutions to guide and advise during this difficult time. Religious faith and cultural practices were cited as providing protection from the virus (Kanozia & Arya, 2021).

Protection was symbolised through culinary practices and religious observance and was seen as providing something unique to the individual to protect them during the pandemic and from the risk of covid. The influence of religion and religious institutions was contentious throughout the literature and appeared to be synonymous with whether individuals accepted or refused the vaccine. This participant discusses the negative impact the church had on influencing vaccine acceptance: *"Churches have a lot to do with it. Yes. Because a lady says, 'my church says no, that [the vaccine] is not necessary"* (Valero-Martinez et al., 2022). Another reflects on the messages conveyed by the church about the vaccine: "*I saw in the news a cult, a church that the minister or I don't know what he was, he told the followers not to get the vaccine"* (Valero-Martinez et al., 2022).

Religion played a significant role in influencing decision making around accepting the vaccine owing to concerns and hesitancies related to the components used during vaccine development. Misinformation influenced attitudes towards the vaccine as described by one participant:

> A lot of people use kind of religious reasons for not taking it. Um 'cause there was something in the news today about some of the components of the vaccine is um, genes from kind of unborn babies or something crazy like that so, a lot of religious people will not take the vaccines for those sorts of reasons. (Woodhead et al., 2021).

This participant discusses how the administration of the vaccine interfered with their religious observance: *"I have also decided to postpone having my first vaccine because my second vaccine would fall in Ramadan and I will not miss my fasting"*. (Bell et al., 2022). Hesitancy experienced by some ethnic minorities surrounding religion was contrasted by this participant's view. She discusses her confidence in accepting the vaccine based on protection from her faith:

> I got the vaccine with faith in the Lord, in God, that nothing is going to happen to me, and I will get all the ones that they give me. [...] I'm not scared. I got it very calmly, with faith. (Valero-Martinez et al., 2022)

This participant spoke specifically about the food eaten in their home country and how engaging in their culinary practice and cultural food preparation provided individuals with protection against the virus:

> A few months back India was number two in the number of cases and deaths from Covid and one fine day it just vanished. So, everyone is trying to ask what is being done differently in India. . . and I guess that mindset is being transferred to racial communities here [in the UK]. So people are discussing our [Indian] food habits, and we do eat a lot of spicy food and spices so I've actually seen people talking about saying that 'ok it's our food which is different. . . There are people even saying 'avoid the vaccines, stick to your spices, your curries and you'll be fine' (Williams et al., 2022).

For some ethnic minorities, the role of religion or cultural practice contributed to vaccine hesitancy. Some perceived these factors as a level or protection from the virus and therefore did not require vaccination, whereas others saw their faith in religion as a protective factor to accept the vaccine.

Unknown Ethnicity

Theme One: The '*Whiteness'* of the 'Take the Vaccine' Message

The promotion and implementation of the vaccine appeared to be conveyed exclusively by white professionals, therefore generating the notion of 'whiteness' in the 'take the vaccine' message. This stance added to the frustrations and uncertainty felt by ethnic minorities leading them to feel that their reservations and concerns were not adequately addressed. This participant reflected on the government's efforts to appeal to ethnic minorities about the vaccine, the lack of genuine dialogue with ethnic minorities demonstrated the normative 'white' position to accept the vaccine:

> It very much reflects the white gaze (throw a bunch of 'BAME [Black, Asian, and Minority Ethnic]' people together as though they are not from separate and heterogenous communities, appeal to racial stereotypes (e.g. Indian doctors), push the desired narrative with a script of 'facts' and 'debunking' rather than encouraging genuine dialogue, etc.). It felt like the way the NHS tries to appeal to us, there is no effort to actually understand and address the reasons for our reluctance/ refusal and

> thus came across as patronizing/inauthentic...speaking at us rather than to us." (Eberhardt et al., 2022b).

Involving ethnic minorities in discussions around the vaccine would reduce vaccine hesitancy, this participant suggests this requires a holistic approach:

> Go to the community and get their opinions about how to roll this out and what they want and feel in the process. This should be a holistic approach to well-being, rather than just a one size fits all approach of 'take the vaccine.' (Eberhardt et al., 2022b).

The lack of ethnic minority representation is something all ethnic minorities felt was necessary to increase trust in accepting the vaccine. In the UK, a campaign using ethnic minority celebrities was implemented to help encourage those from ethnic minorities to accept the vaccine. The tokenism within these gestures was seen as disrespectful, as expressed by this participant:

> It is totally disrespectful to think that any celebrity can change anyone's decision about the vaccine. We have common sense to make decisions, we don't need no celebrities to tell us to be safe, clearly there is no trust because everything is done on a one size fits all (Eberhardt et al., 2022b).

Lack of ethnic minority representation in the development and promotion of the vaccine led to a feeling that the vaccination was for White people. Contributing to vaccine hesitancy within ethnic minorities as it was perceived that there was nowhere to discuss how the vaccine may impact people of colour. The lack of meaningful engagement with ethnic minorities to assuage any concerns about the vaccine, contributed to vaccine hesitancy.

Theme Two: Travel Restrictions

Travel restrictions during the pandemic caused a global shutdown of major airports and a worldwide banning of international flights. With many ethnic minorities having families back in their home countries, the threat of being unable to travel without being vaccinated caused many individuals to reconsider the vaccine. For some, this led to individuals feeling pressured to accept the vaccine and did so out of necessity: *'I'm only doing it because the government seem to be saying that they won't let me travel without it ... feeling pressured to take it'*. (Charura et al., 2022). Others felt the vaccination was not about their health but influenced by their ability to travel: *"I need to travel so it's not really about my health"*. (Charura et al., 2022).

Deliberation between accepting or refusing the vaccination was based on the uncertainty of the restrictions placed on civil liberties. These participants spoke about delaying acceptance of the vaccine until it became essential or mandatory:

> I'm two minds really about whether to get the vaccine or not but I have a feeling people will be pressurised into having it through the vaccine passports or certificates, whether that could be for traveling or getting jobs, so I think people will be indirectly forced into getting it (Williams et al., 2022).

> I don't intend on taking it, unless it's a must, unless, I heard you have [a vaccine] to travel, but right now I am going to refuse it, until the very last moment. But I know at some point I will have to take it (Williams et al., 2022).

Ethnic minorities felt coerced into accepting the vaccine if this threatened their civil liberties. Acceptance was considered as a last resort if mandated by the government.

Theme Three: Social Media

Social Media was a source of communication and a way of keeping in touch for all communities during the pandemic. Within ethnic minorities, and an extension of the *'Information Vacuum'* found in the Black community, the use of social media for ethnic minorities became a trusted source or a way of verifying information. Alternatively, it was regarded as a way of validating one's position and acted as a 'safe space' for ethnic minorities to seek allies in vaccine hesitancy. In mainstream society, the '*whiteness of the 'take the vaccine' message'* meant that those who did not comply, or were curious about the vaccine, were viewed negatively. This participant speaks about the divide felt within society between vaccine acceptors and refusers was apparent in online spaces:

> It really divides those who do have the vaccine and those who don't, and I see quite a lot on social media people who post like very critical things of people who are on the opposite side (Williams et al., 2022).

This participant reflects on using the internet to have discussions with people who have similar concerns about the vaccine:

> I also interact quite a lot on the internet and a lot of people that I speak to on the internet, they say the same thing that you know they just have this concern about the vaccine. (Williams et al., 2022).

Some participants reflected on the use of social media and how this was instrumental within ethnic minorities for information. Information pertaining to risk factors contributed to decisions to not accept the vaccine: "*You see stories on social media about rare blood clotting or rare immune systems. Those stories are very off-putting, because then you see that there is a risk factor to the COVID-19 vaccines"*. (Naqvi et al., 2022). Social media often discussed reports from official websites which were then discussed or debunked online, making it difficult for some ethnic minorities to know what to trust: *"I think it is very confusing. The things they have on official websites, social media talks about it, and you don't know what to trust"* (Naqvi et al., 2022). There was also a sense that those outspoken against the vaccine, or with an alternative view to the mainstream, were banned from online mediums. This aroused suspicion, causing some people from ethnic minority communities to question whether an ulterior motive was at play. One participant shares their thoughts on this: *"I go on YouTube, there are some very clever people, some scientists, who are speaking against the vaccinations, but they get banned. That makes you think why are they doing this? Let us make up our mind"*. (Naqvi et al., 2022).

Social media provided a platform for vaccine hesitant ethnic minorities to share information about risk and concerns around the vaccine away from the critical eye of wider (white) society. Whilst information may have been inaccurate, it felt credible as it was usually communicated by fellow ethnic minorities, bringing a sense of comfort and comradery during an unprecedented time of uncertainty.

Discussion

This meta synthesis aimed to evaluate 12 qualitative studies to understand vaccine hesitancy in Black ethnic communities in the UK and US. It further aimed to ascertain similarities or differences in vaccine uptake between the Black communities and other ethnic minority communities. Reasons for vaccine hesitancy in ethnic minorities are often presented as one homogenous entity, suggesting the reasons for vaccine hesitancy are the same across communities, ignoring the nuanced differences between various ethnic minority communities. Evidence demonstrates that vaccine hesitancy is highest in Black communities (Gaughan et al., 2022), therefore understanding the specific reasons for vaccine hesitancy within this community and how this may differ from other ethnic minority communities, will help inform public health campaigns about how to effectively target and engage Black communities to reduce health inequality.

Summary of Findings

The study compared reasons for vaccine hesitancy from Black ethnic communities in the UK and US to those from other ethnic minority communities and demonstrates that reasons for vaccine hesitancy in Black communities differs to those from other ethnic minority communities.

For this meta-synthesis, some papers included comments about the perceptions of black communities that were in line with the final themes but were excluded from the final presentation of the results because they did not include interview excerpts or quotes to support their claims. Therefore, final themes presented, were based solely on explicit quotes that could be attributed to Black participants.

Mistrust and suspicion were the driving factor for vaccine hesitancy in Black ethnic communities in the UK and US and reflects attitudes of mistrust within Black communities derived from a lack of information, historical injustice and mistrust, which led to deeply felt fear and vaccine hesitancy. These findings are consistent with a systematic review conducted by Hussain et al., (2022), who considered reasons for vaccine hesitancy in ethnic minorities in the UK. Their evidence suggested that those from Black British communities were more likely to state *'they did not trust the vaccine'* compared to white British / Irish individuals.

Our findings from other ethnic minority communities, demonstrated obedience towards authorities to accept the vaccine owing to social responsibility and a duty of care to protect the self and others, were consistent with themes found in Valero-Martinez et al., (2022), Woodhead et al., (2021) and Williams et al., (2022). These findings are also supported by Abba-Aji et al., (2022), who reports that Asian individuals, followed by white and then Hispanic individuals, had the highest rates of vaccine acceptance. Their findings report that in all studies reported, Black ethnic groups in the UK and US had a substantially higher vaccine hesitancy and were less likely to take the vaccine compared to other ethnic minorities This hesitancy observed in Black communities was driven by mistrust and safety concerns towards the vaccine. For other ethnic minority communities, factors such as convenience, language barriers, fear or deportation and reduction of liberty were reasons cited for vaccine hesitancy. Echoing Abba-Aji et al., (2022), our findings demonstrate that ethnic minority communities were also more likely to feel pressured to accept the vaccine if these impacted freedoms, reflecting the findings by Bell et al., (2022) and Charura et al.,

(2022), who found ethnic minorities worried about the impact of vaccine hesitancy on freedoms or employment status and therefore influenced acceptance of the vaccine.

A literature review considering vaccine hesitancy in Black Americans by Roat et al., (2022) found mistrust in medical establishments was identified as a major barrier in each article included in the review. They reference a long history of abuse and exploitation by medical professionals and cite the Tuskegee syphilis as being the hallmark example of mistreatment of Black individuals. This, along with political influence, impacted the confidence in Black Americans to accept the vaccine and is consistent with our findings. Ethnic minorities were more likely to cite religious belief or cultural practice as protection from the virus, resulting in vaccine hesitancy.

The *'whiteness' of the vaccine message'* found in the unknown ethnicity group was something that united all ethnic minorities, who collectively believed that the development and promotion of the vaccine, with the lack of ethnic minority involvement and engagement, resulted in vaccine hesitancy. The lack of representation contributed to vaccine hesitancy in ethnic minorities and similar attitudes were echoed in the Black ethnic community in the theme *'Black guinea pigs'*, where it was felt that the vaccine was being developed to be tested on the Black community first and, if effective, would then be disseminated amongst other ethnic minority communities. This position was reinforced in the theme of '*mistreatment of Black communities'* where members felt that society continued to show a disregard and lack of respect for Black lives. These strong opinions were underpinned by established legacies of violation and mistrust which were not found in other ethnic minorities.

'The information vacuum' theme found in the Black ethnic communities shared similarities with *'Social media'* in the unknown ethnicity group and discussed how a lack of information fed into feelings of hesitation causing ethnic minorities to disseminate or rely on information from social media. Social media was used to discuss vaccine hesitancy and seek out alternative or perhaps more balanced information about the vaccine as supported by Naqvi et al., (2022). For Black people, this was received as a further attempt to purposely keep them 'in the dark' about the vaccine, which further fuelled feelings of mistrust towards the vaccine. Increasing the knowledge of vaccines in ethnic minority communities was seen as a strategy to increase confidence. Hussain et al., (2022) found that intention to vaccinate in ethnic minorities was closely linked to the collective importance of vaccination and that by

offering information on the development and addressing safety concerns helped to reduce vaccine hesitancy.

The findings are consistent with the extensive literature demonstrating institutional mistrust as a factor for vaccine hesitancy (Razai et al., 2021; Willis et al., 2021). For many Black communities in the UK and US, the deep-rooted mistrust towards the Government caused them to become wary and suspicious towards attempts to encourage vaccine uptake. This was interpreted by some as a deliberate attempt by authorities to target the Black community and kill them through administering the vaccine. Attitudes of mistrust towards authorities within the Black community are often influenced by structural racism where institutions create and perpetuate racial inequalities through policy, practice and norms (Braveman et al., 2022). The existence of racism is so deeply embedded and established within structures that they have become normalised, making it difficult for people to explicitly identify (Sharif et al., 2021). The longstanding history of systems disadvantaging Black communities is reflected in the findings, where some participants described a wariness towards trusting anything from the Government.

Systemic racism was further exemplified by the unlawful killing of George Floyd, a Black man, at the hands of law enforcement in the US, during the pandemic. This awakened society to the deeply entrenched racial injustice that has been experienced by Black people for decades. George Floyd was a contemporary example of racial inequality and highlighted the continued mistreatment of Black people in society. His death sparked defiant protests of public mourning and righteous rage from individuals of all races demanding accountability for the countless Black lives taken at the hands of law enforcement (Francis & Wright-Rigueur, 2021). The outrage embodied the deep sense of hurt experienced by the black community and gave rise to yet another example of systemic racism. Historical systemic racism led many participants to reference George Floyd as a contemporary example of the disregard for Black lives and cited this as a reason for vaccine hesitancy. This could be interpreted as things still not changing from the perspective of the Black community resulting in a sense of frustration as the wariness to accept the vaccine was a dismissal of the pain felt within this community.

References to the Tuskegee Syphilis study contributed to a major source of contention within the Black community (Restrepo & Krouse, 2021) and many felt the introduction of the vaccine was another attempt to use Black bodies to test the vaccine before disseminating

amongst wider society. The phrase ‘Guinea Pigs’ were referenced throughout as a stark reminder that this community have been exploited in the name of scientific advancement, leading to generational mistrust and hesitancy towards the medical industry. Finally, the lack of reliable sources of information is consistent with previous literature (Ochieng et al., 2021) and experienced by all communities during the pandemic but, for the Black community, this came with a pre-established foundation of mistrust towards the government, the lack of information exacerbated feelings of vulnerability and created scepticism toward the true intention of authorities, contributing to vaccine hesitancy within the Black community.

Our findings demonstrate the nuanced differences between ethnic minorities that contribute to vaccine hesitancy. For Black communities specifically, historical, and contemporary examples of mistreatment exacerbate mistrust which ultimately result in vaccine hesitancy.

Strengths and Limitations

This meta-synthesis appears to be the first to review and synthesise qualitative literature with a focus on differentiating between Black communities and other ethnic minority communities about vaccine hesitancy.

Conducting a meta-synthesis allowed the author to extract direct quotes from Black communities to help understand their reasons for vaccine hesitancy, allowing the author to focus on issues specific to this community that influence vaccine hesitancy. The importance of this demonstrates there are nuanced differences between ethnic minorities which are often lost or misrepresented amongst the acronym of ‘BAME.’. Being aware of factors unique to the Black community will help improve future health campaigns to rebalance health inequality.

The quality of the twelve papers reviewed were rated as high, with eleven of the studies deliberately recruiting ethnic minorities. This is a strength, as research considering the experiences of Black communities are often underrepresented in the literature so deliberate targeting of this group will help raise the profile and awareness about the issues that affect them.

It should be noted however, that whilst these papers deliberately recruited ethnic minorities for their research, some did not support their findings with illustrative quotes from interviews and so could not be considered in our final analysis. This imposed a limitation as our method only allowed for inclusion of data that could be explicitly attributed to a Black or ethnic

minority participant. This meant that papers who used illustrative quotes from their interviews were more heavily relied on and are therefore overrepresented in the final analysis therefore caution must be taken when considering the overall findings. Appendix one demonstrates the extent to which each paper contributed to each theme.

A further limitation is that this whilst the author extracted the experiences of Black communities, in doing so they inadvertently created the problem they sought to address. The homogenous grouping of 'Black communities' considered Black individuals from both the US and UK who each have different ways of categorising Black ethnicities. Whilst the report aimed to understand reasons for vaccine hesitancy in Black communities, only views from research published in the USA and UK were utilised, therefore the views expressed in this review may not be representative of Black people in other locations around the world. As highlighted in the introduction, the classification of Black ethnicity differs depending on geographical location and can be further complicated by how an individual self-identifies. Whilst the homogenous nature of grouping Black communities is problematic, it does provide insight into factors such as mistrust being a contributor for vaccine hesitancy in the UK and USA. Further research could build on from this to ascertain whether these views are also represented in other Black communities in different locations around the world. Geographical influences and experiences of migration will differ within different Black communities and therefore future research should consider separating these communities further and provide clarity into how ethnicity is defined or categorised.

A similar limitation can be said of the other ethnic minority grouping as their experiences of vaccine hesitancy were grouped together. Future research would benefit from exploring these individual ethnic and cultural communities further to produce findings representative of the population affected.

The review is limited by only the author completing the screening and analysis process who chose to omit grey literature, dissertations, or non-reviewed sources of information. Inclusion of these may have added a further richness to the data. The author identifies as belonging to the Black community and therefore there may be bias in their selection of quotes which may have impacted the interpretation of the data. Whilst data was discussed as part of research supervision, the research supervisors are racially different to the author and therefore may not have interpreted the data in the same way. As the author worked exclusively with the quotes extracted from the literature, they were taken out of context from

the overall theme and wider dataset, therefore the narrative created as part of this research, may differ from how it was intended as part of the original dataset.

Implications and Recommendations

The response of the Black community in the UK and US to COVID-19 and vaccine uptake has highlighted the deep-seated mistrust of government and authorities. Our research provides essential learning not only for how vaccination programmes are developed and promoted, but more generally for wider health and social issues. Governments must consider how they are to approach and engage the Black community regarding institutional initiatives and communications about public health and social issues.

Awareness and compassion of historical mistreatment and its enduring traumatic impact will help address healthcare inequalities and begin to tackle systemic racism. This involves actively working with the Black community, where continued exposure to experiences of adversity and discrimination lead to negative effects on physical and mental health (Kaufman et al., 2023). Our theme the *'Whiteness' of the 'Take the Vaccine' message'*, demonstrated the value of how ethnic minority representation in vaccine development and promotion is fundamental to increasing trust in these communities.

To effectively engage with Black communities, public health officials must have a better understanding of the barriers or factors that hinder engagement with public health campaigns. Creating spaces that allow open and honest dialogue with those who have lived experience to share their views with professional services would help foster a mutual understanding of the difficulties faced within this community. Allowing professional services to hear these views and understand the unique perspectives will allow Black communities and professionals to work collaboratively to improve access to, and increase uptake, of the vaccine.

The inclusion will lead to targeted campaigns and alleviate the frustrations of the 'one size fits all' mentality that is often represented in the literature or promoted by governments. Working with the Black community exclusively and other ethnic minorities as individual entities by dismantling the acronym 'BAME', will help work towards health parity when it is understood how health inequalities impact ethnic minority communities differently.

Having a clear understanding of what impacts vaccine hesitancy in the Black community allows public health campaigns to understand these issues and address them directly by engaging in meaningful dialogue. Ongoing consultations with respected Black individuals at both community and authority level is essential, as well as actively involving these figures in the dissemination of information.

This should be a priority, as it is important that those disseminating the information reflect the Black community to help provide reassurance and build trust. As highlighted in the results, representation matters, and if vaccine messages are coming from those who visibly look like those who are being targeted, vaccine hesitancy may reduce and uptake may improve.

At the developmental stage of new medical initiatives or trials, involving Black people in the workforce and within clinical trials to demonstrate transparency and collaboration in the process will increase trust by observing representation. The use of Black volunteers to trial new vaccines before inviting community uptake will hopefully demonstrate the efficacy of the vaccine and its safety within Black participants. For Black communities and other ethnic minority communities, being included at the developmental stage will reduce feelings of mistrust as it will increase the transparency of new vaccines and medications. In doing so, this will help increase confidence in accepting a vaccine where they have been a part of the developmental process and therefore have a clear understanding of how the drug works and be informed about any potential side effects.

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CHAPTER TWO

FAMILY MEMBERS EXPERIENCE OF HELP SEEKING WHEN A LOVED ONE OF AFRICAN-CARIBBEAN HERITAGE EXPERIENCES MEMORY LOSS. A REFLEXIVE THEMATIC ANALYSIS

Abstract

Introduction: African-Caribbean adults have a higher prevalence and incidence rate of attracting dementia compared to their white counterparts. Barriers to seeking help for dementia are well researched in ethnic minorities, but this is often presented under one homogenous group suggesting parity in reasons for not accessing services. Given the risk to this community, there is a relative paucity with a specific focus on the African-Caribbean community. The aim of this study was to consider family experiences of help seeking when a loved one of African-Caribbean heritage experiences memory loss and what the barriers are to accessing professional services.

Method: Fourteen participants were recruited from community settings and invited to participate in a semi-structured interview either face to face or online. Using Reflexive Thematic Analysis, interviews were transcribed and coded by the author with final analysis resulting in five themes.

Results: Five themes were generated from the data: *'The Perception about the Windrush Generation'* considered the impact of migration and how this shaped attitudes to help-seeking. '*Lack of cultural acknowledgement of dementia'*, '*Stigma and Shame'*, '*Keeping it in the family'* and '*Racism & Mistrust of services'*.

Conclusions: African-Caribbean communities are at a higher risk of attracting a dementia diagnosis but owing to historical experiences of racism and mistreatment, are less likely to approach professional services for help. Fear of cultural and societal stigmatisation surrounding dementia diagnosis, contributed to attitudes of help seeking and as a form of protection, families chose to provide care to their loved one at home.

Introduction

An estimated 944,000 people are living with dementia in the UK, with this number expecting to rise to 1.6 million by the year 2050 (Alzheimer's Research UK). Dementia is an umbrella term used to describe a complex set of disorders that share an irreversible decline in global intellectual, social and physical functioning (Banerjee et al., 2009). Whilst it is noted to be a global health concern affecting 1 in 11 people (NHS, 2023) and was the highest cause of mortality in 2023 (Office for National Statistics, 2023), growing evidence suggests that dementia affects those from ethnic minorities at a disproportionate rate compared to their white counterparts (Mukadam et al., 2023a). Reasons for this have largely been attributed to dementia specific risk factors such as type 2 diabetes and cardiovascular disease (Dodd et al., 2022, Mukadam et al., 2023b).

Whilst the evidence provides insight into who is at risk and what factors contribute to this, research tends to colloquially present this information under the umbrella term of Black and Minority Ethnic or 'BAME' which fails to tell us more about how this illness affects individual cultural communities.

Evidence from primary care records demonstrate that Black men and women were 25% and 28% respectively more likely to receive a dementia diagnosis compared with white people (Pham et al., 2018). For Black adults in the UK, Dementia rates are 22% higher when compared to white people (Alzheimer's Research UK; University College London, 2018) but these figures give little indication as to which members of the Black community this pertains to as data is often presented as 'Black' without making the distinction between Black African and African-Caribbean communities.

As discussed in chapter one, ethnicity is a complicated phenomenon to describe how an individual self-identifies, as this if often influenced by an individual's cultural understanding as well as their unique stories around migration. For this chapter, African-Caribbean refers to anyone who traces their ancestry back to the Caribbean region and roots from within Caribbean countries. The term acknowledges both their African ancestry and their cultural, historical and geographical connection to the Caribbean.

A growing body of evidence suggests that in the UK the prevalence of dementia in African-Caribbean ethnic communities is greater than the white population and on average, they are diagnosed 4.5 years younger than white British counterparts (Adelman et al., 2018). Black African-Caribbean communities are also more likely to be diagnosed with a vascular or mixed type dementia highlighting the threat of this illness to this community (Bhattacharyya, 2012; Tuerk & Sauer, 2015). Age also impacts the onset of dementia in African-Caribbean people, according to the 2021 census, African-Caribbean people aged over 60 make up 22.3% of the population (Office for National Statistics [ONS], 2022), with predictions indicating the prevalence of dementia in Black communities increases by 1.2 times for each year above age 60; double the prevalence of every 5 years found in white people (Adelman et al., 2018).

Barriers into accessing services by ethnic minorities have been attributed to a lack of knowledge about healthcare services, language barriers and cultural stigma (Robinson et al., 2022) and supported by a large evidence base. Mukadam et al (2011a), produced a qualitative study and found that ethnic minorities presented to services when they were no longer able to cope, this builds on from their previous systematic review where they found ethnic minorities were less likely to present to services owing to barriers such as perceiving memory loss as a normal part of ageing, denial and community stigma (Mukadam et al., 2011b). A further systematic review concluded that ethnic minorities were more cognitively impaired at referral to diagnostic dementia services in the US and Australia (Cooper et al., 2010).

Evidence currently considering service utilisation in the UK is limited and tends to be combined with other ethnic minorities, whilst this evidence may include the views from African-Caribbean people, it is unclear which reasons are specific to them. Dodd et al., (2022), compared service utilisation for dementia for 'BAME' communities to White British communities and found that ethnic minorities were less likely to receive a cognitive assessment and were more likely to be scored as low risk for harm to self and others. White British people were more likely to be offered more community resources such as dementia support groups, memory cafés, sports clubs and social events at retirement homes. Ethnic minority support was smaller and consisted of day centres, church luncheon clubs and attending the gym. Whilst evidence presents reasons for barriers to accessing services, due to the homogenous reporting of the data there is no evidence to suggest the barriers are representative of the African-Caribbean community. Making it difficult for research and

policy makers to understand the needs of this community, as it assumes all ethnic minorities respond to memory loss or engage with professional services in the same way.

A similar picture can be found in mental health help seeking, where evidence suggests that stigma, discrimination, or beliefs around mental illness within social or familial networks may influence engagement with services in Black communities (Degnan et al. 2022). More specifically in the UK, African Caribbean people report avoiding services due to perceived discrimination or fears of racist maltreatment (Mclean et al., 2003). This suggests that Black communities may be less likely to access support from professional services and are more likely to seek support informally from friends, family, spiritual or community-based groups (Obasi & Leong, 2009).

Berwald et al., 2016 completed a qualitative study focusing on perceptions of memory loss in Black African and Caribbean populations and found differences unique to these communities not found in wider ethnic minorities. They found that dementia was viewed as a 'white persons' illness, forgetfulness did not indicate illness or a problem worthy of medical attention. Memory loss was viewed as a normal part of ageing, reducing the urgency to seek help from professional services. Resulting in Black communities informally providing care privately at home or drawing upon support from community-based services including religious institutions and culturally specific day centres (Gove et al., 2021; Parveen et al., 2017). This evidence demonstrates that Black ethnic minorities may experience memory loss differently and this informs their attitudes towards help seeking. Further research is warranted to understand their reasons for this.

The African-Caribbean community is of particular interest owing to their unique history of migration to the UK and remain demographically the oldest of the 'Black' communities in the UK (Truswell, 2018). Adelman et al (2009) suggests this community are first born immigrants who came to the UK between the late 1940s and 1970s and would reflect those who came to England as part of the *'Windrush Generation'*. The Windrush Generation is used to describe a collective of individuals from mainly Caribbean countries who migrated to the UK after the end of the second world war (Reddie, 2020). Given the age profile of these individuals, it would suggest that this ageing generation of African-Caribbean individuals and their descendants would be those at risk of dementia.

For this community, the experiences of migration and discrimination reinforces a cultural expectation of endurance and resilience when experiencing adversity, which in turn

contributes to this community being hesitant to seek help (Truswell, 2018). Engaging with professional services has always been a contentious issue for the Black community, exacerbated further by historical experiences of neglect, racism and discrimination by healthcare providers who are either unwilling or unable to cater their needs (Ozduzen et al,. 2022). Mistrust in healthcare professionals prevents the development of a strong patient-professional relationship and thus negatively influences patient behaviour and health outcomes (Bazargan et al., 2021).

Keating and Robertson (2004) propose a '*circle of fear'* that exists between Black communities and professional services. They describe a relationship that exists when Black people approach professional services and how professionals respond. Fear that exists between Black patients and White professionals compound issues of mistrust further resulting in a misunderstanding of prognosis for the individual and an unawareness of how the illness presents in Black individuals by professionals. Unhelpful responses from professionals and the stigma surrounding diagnosis, creates an inadvertent pressure for families to then provide care to their relatives (Mukadam et al., 2011a; Mukadam et al., 2011b).

To date, one study has focused on perceptions of dementia and help-seeking in African-Caribbean's. Berwald et al., (2016) advances the knowledgebase by providing evidence to demonstrate there are nuanced differences for help seeking in Black communities. However, findings also incorporated views of Black African's who may have different experiences owing to their unique cultural scripts and history of migration to the UK. Given the risk of dementia to the African-Caribbean community and the age profile of this demographic, it is imperative that services are equipped to recognise this risk and incorporate this into health care planning and service provision.

The aim of this research is to understand family members experiences of help seeking when a loved one of African-Caribbean heritage experiences memory loss and what the barriers are to accessing services. Understanding the unique perspectives of the 'Windrush Generation' will illuminate their experiences to help inform services and policy makers to create culturally sensitive services that can meet the needs of this 'high risk' community.

Method

Ethics

The research study received ethical approval from the University of Birmingham's Research and Governance committee (Appendix 1) and the NHS Health and Research Authority (Appendix 2).

Local NHS Research & Development approvals were obtained from Birmingham & Solihull Mental Health Foundation Trust (Appendix 3), Birmingham Community Healthcare Trust (Appendix 4) and Black Country Partnership Trust (Appendix 5).

A level 3 research risk assessment and mitigation plan (RAMP) was submitted to The University of Birmingham, no legal risk or liabilities were identified as part of this study. The study obtained risk assessments approval to authorise the researcher to work alone in participants homes or community settings as part of data collection (Reference: SOPHS_23_90_SH) (Appendix 6).

Recruitment

The researcher contacted organisations in the West Midlands that provided support to the African-Caribbean community. This included community centres, churches and charity organisations. Of these, a centre which provides day care provision for the older adult African-Caribbean community, signposted interested families to the study information which was presented in the form of a poster. Interested participants details were passed to the researcher who contacted them directly.

Opportunity sampling was utilised by targeting specific areas within Birmingham with a large African-Caribbean population focusing on Black owned businesses such as hairdressers, barbers, and Caribbean takeaway shops. The researcher provided these establishments with posters pertaining to the study and discussed the research aim, inclusion criteria and what would be required for participation. Interested participants could contact the researcher directly using the contact telephone number or scanning the QR code which took them to a webpage which contained information about the study.

Recruitment and study information was posted via social media websites Instagram, X and LinkedIn. Recruitment material was displayed and promoted by local NHS trusts who displayed study posters in patient areas of memory assessment services and outpatient clinics. Recruitment documents can be found in appendix 7.

Interested participants were contacted by the researcher who made an initial screening telephone call. The purpose of this was to assess eligibility and provide a brief overview of the aims of the study and answer any questions from participants. If suitable and still interested, participants were sent the information sheet and consent form. Participants were informed that they would have 48 hours to read the information to make an informed decision to participate. After this time the researcher contacted participants and if still interested, verbal consent was obtained, and an interview was booked.

Eligibility Criteria

Table 1.1 displays the inclusion and exclusion criteria.

Table 1.1

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Participants providing care or supporting an individual aged who is experiencing memory loss.	Participants who may have been experiencing behavioural symptoms associated with dementia
Adults can be male or female but must be a minimum of 16 years old to participate.	Participants themselves had any current or previous difficulties with memory loss
Family member is of African-Caribbean or Mixed race African-Caribbean heritage	Loved one is not of African-Caribbean heritage
Can verbally communicate in a language coherent to the interviewer.	Participants with a co-morbid major mental health difficulty such as psychosis or schizophrenia.
Has capacity to understand the research project to provide informed consent for participation.	Genetic disorders such as down syndrome and severe learning or intellectual disabilities. Non-English speakers

Participants

Minimum sample sizes of six is a suggestion for Reflexive Thematic Analysis to produce enough meaningful data to identify patterns across the dataset (Braun and Clarke., 2022) and 6-15 participants are recommended for interviews in small research projects (Braun and Clarke, 2013). Eleven participants interviewed as individuals, and three interviewed as a family consisting of two siblings and a spouse. This included male (*n=5*) and female participants (*n=9*) where the majority were a child of the loved one, they provided care for. Average age of participants was 53.9, with twelve identifying as being of African-Caribbean

heritage and two identifying as being of mixed White & African-Caribbean heritage. Demographic information for participants can be found in table 1.2

Table 1.2

Demographic Information for Participants

Participant "Name"	Age	Sex	Relationship to Individual	Format & Length of Interview
Ami	52	Female	Daughter	Face to Face 45:29
Cherry	57	Female	Daughter	Face to Face 55:19
Colette	55	Female	Daughter	Online 49:52
Dennis	56	Male	Son	Online 44:17
Linus	58	Male	Son	Online 55:01
Lloyd	72	Male	Son	Face to Face 51:11
Marcus	43	Male	Son	Face to Face 1:05
Mila	39	Female	Daughter	Online 56:50
Sherona	36	Female	Daughter	Face to Face 1:35
Shervon	52	Female	Daughter	Face to Face 1:23
Winston	56	Male	Son	Online 1:03
Grace, Shirley & Olive	52.56 & 71	Female	Daughter, Daughter & Spouse	Face to Face 1:42

Procedure

Once confirmed, Interviews that were conducted face to face (n=7) took place in a variety of locations including participants homes, public libraries, community centres and at the University of Birmingham. Online interviews (n=5) were conducted using Microsoft Teams.

At the beginning of the interview, an introduction was made by the researcher who outlined the aims of the study. Participants were informed that participation was voluntary, and that all data would be stored securely. Pseudonyms would be given to protect the identity and provide confidentiality to the data. Participants had the right to withdraw from the study at any time and, should they choose to do so, their data would be destroyed. Participants were informed of the risk of becoming distressed as they may be discussing sensitive topics.

Participants were invited to ask any questions and their right to withdraw was reconfirmed, if they were still agreeing to proceed, informed consent was given by signing the consent form and the interview was conducted. For online interviews the consent form was emailed and returned to the researcher with an electronic signature.

The researcher began by building rapport before moving onto the interview schedule. Throughout the interview, the researcher would reconfirm consent and check participants were still comfortable to proceed. Once the interview was finished, a debrief statement was read and participants were provided with information for support services. Participants were thanked for their time and informed how their information and data would be used and stored. Interview time ranged from 44:17 to 1:42 with an average time of 63.73 minutes. Participant study documents are in appendix 8.

Data was collected using an encrypted Dictaphone and transcribed by the researcher. For online interviews using Microsoft Teams, the record and transcribe feature was used which could be downloaded once the interview was completed. Once transcribing was completed by the researcher all recordings were deleted. Each participant was given a pseudonym to maintain their confidentiality and their transcript was saved under this name before being uploaded electronically to the research data store. Signed consent forms were uploaded securely to the server and all recordings deleted from the Dictaphone.

Data management and storage was in line with the University of Birmingham's data protection policy and code of practice for research. A full data management plan was submitted alongside ethical approvals which allowed the researcher to access the secure server where documents pertaining to the study could be stored (Appendix 9). Access to the server was only permitted by the researcher and chief investigators who each held separate log in and password details.

Data Collection

The interview schedule was developed by the researcher and chief investigators and consisted of five topic areas including: *Initial reactions to memory loss* which considered both the *loved one* and *family's* perspective of noticing initial changes in memory. *Help seeking,* which asked questions around decision making to approach professional services and *cultural understandings of memory loss* which looked at if the family held any specific cultural beliefs around memory loss. Questions were informed by previous research about memory loss and help seeking in Black or minority ethnic communities - who identified issues such as stigma, lack of trust in healthcare systems (Mukadam et al., 2011a) and how the impact of migration on coping with adversity (Botsford et al., 2011) may influence attitudes to accessing services. Table 1.3 shows topic areas and example questions:

Table 1.3

Interview Schedule Topics and Example Questions

Topic Area	Example Questions	Rationale
Memory Loss	*What kind of things does your loved one forget?*	To gain an understanding of what changes have been observed since the onset of the difficulties
Loves Ones Reaction to memory loss	*How has your loved one reacted to the memory loss?*	Understanding the loved ones and family reaction to the memory loss will give insight into
Family members reaction to memory loss	*Have you had to make any adaptations to your daily routine? Prompt: Changing living arrangements, attending appointments, shopping.*	what key factors may have influenced the decision to seek or not seek help
Help Seeking	*What were the barriers (if any) you experienced when seeking help?*	To understand the process of help seeking and factors that may influence the decision making to seek help.
Cultural Understanding	*Does your family hold any specific cultural beliefs around memory loss? Prompt: Religious explanations, spiritual possession, witchcraft, karma.*	Some members of the African-Caribbean community may hold alternative explanations / beliefs for memory loss.

Semi-structured interviews were selected to gather data from participants as this method utilises open questioning to allow the researcher to be flexible and participants to discuss issues important to them that the researcher has not anticipated (Braun et al, 2013). The series of questions are developed beforehand and are constantly reviewed in light of content being produced by the participant (Schmidt as cited in Flick et al., 2004). Question wording and order was centred around the main aim and issues related to the core research question and aligned with contextualism epistemology, allowing the researcher to be responsive to the participants developing account (Braun et al., 2013). This method of data collection lent itself to reflexive thematic analysis as detailed accounts of help seeking provided by participants could be analysed to identify patterns of meaning but recognises the active role of the researcher in the generation of knowledge and analysis (Braun et al., 2022).

Face-to-face contact between researcher and participant is viewed as the ideal or ‘gold standard’ to collect interview data (Novick, 2008) owing to the live interaction to build rapport and guide the interview schedule. Using Microsoft teams allowed interviews to be conducted online emulating a real-life conversation (Keen et al., 2022) and was used to reach participants unable to meet in person. Interviews took place between June 2023 and February 2024.

Questions were discussed and continually reviewed during research supervision to ensure correct data was being collected. This was to ensure a consistent richness to the data and that the schedule evolved in relation to new issues arising. All interviews were listened to and transcribed by the researcher. Interview schedule can be found in appendix 10.

Data Analysis

Ontological and Epistemological Positioning

Ontology relates to what we think we know based on what exists or is real and considers whether there is shared or multiple realities. Realism ontology suggests there is an objective reality that exists independently of human perception or interpretation. Epistemology relates to what it is possible to know and meaningful ways of generating knowledge (Braun et al., 2022). It is concerned with what knowledge is possible and how one goes about obtaining it and characterises this into positivism and interpretivism. Positivism is concerned with people providing an accurate knowledge of the world (Lyons & Coyle, 2021) and its goal is to generate explanatory associations or relationships to try and predict the phenomena in question (Park et al., 2020) suggesting knowledge can be objectively investigated. Interpretivism is concerned with exploring the meaning people attach to their experiences and how these meanings are created, negotiated and sustained (Schwandt, 2003), these realities are based on individual experience. As memory loss is something that exists and can be studied objectively (Positivism), each individuals experience of this will influence how they make sense of this (Interpretivism) a way of addressing both of these paradigm is to consider critical realism and contextualism as this research aims to capture participants own explicit accounts of their experience of help seeking. The ontological position it seeks to adopt is critical realism (Lyons et al., 2021) which acknowledges that whilst a reality exists independent of the researcher it cannot be accessed in a definitive way and recognises there will be an element of bias brought to the investigation by the researcher. Contextualism recognises knowledge cannot be separated from the participant and the researchers' values and practices shape the knowledge they produce (Braun et al., 2022; Campbell et al, 2021).

As researchers make assumptions about the nature of reality it is important to reflect on their position to the research and how this may influence the research process and data produced. Reflexivity is the acknowledgement of the researcher about the role played by their interpretative framework in creating the analytical account (Lyons et al., 2021) and recognising their relationship to the research.

Researcher

The lead researcher is of African-Caribbean heritage. They have some experience of help seeking as their grandparents both were diagnosed with dementia. They have no previous clinical or research experience of working with memory loss or dementia. The researcher approached the study with a scholarly and personal interest in wanting to understand the nuanced experience of help seeking when a loved one experiences memory loss and how this may be compounded by belonging to the African-Caribbean community. Conducing the research from this position allowed the researcher to gain trust, build rapport and create a shared understanding of African-Caribbean communities and their decision making for seeking professional help.

Reflective Thematic Analysis

Based on prior research some assumptions could be made about what issues were likely to be relevant when considering memory loss in African-Caribbean communities. Analytical approaches such as Interpretative phenomenological analysis (IPA) was deemed less suitable owing to it aiming to produce accounts of lived experience from an idiographic perspective rather than one prescribed by pre-existing theoretical preconceptions (Smith & Osborn, 2015). Given this, it was important to allow some scope for new ideas to emerge. The highly systematic approach of a framework analysis (Gale et al., 2013) was considered less appropriate. The lack of resources and access to specific information about the African-Caribbean community on memory loss made Grounded Theory inappropriate for use. Reflexive Thematic Analysis (RTA)was considered as it appeared to provide a compromise between a very open approach and a very structured or theory-focused one. From an epistemological point of view, it is relatively open and can accommodate the position adopted in this study of trying to capture the explicit experiences of the participants, while acknowledging the influence of the researchers on the outcome.

RTA is a qualitative research method which recognises the subjective position of the researcher in relation to the data. It can provide analysis of people's experiences on a specific issue or the factors and processes that influence a particular phenomenon (Braun et al., 2022). The aim of the research was to understand help seeking in African-Caribbean populations so analysis was conducted through a contextualist paradigm which considers the nature of meaning to the individual and accepts researcher subjectivity was also part of the analytical process and how they play an active role in the production of knowledge.

RTA involves a six-phase process, beginning with dataset familiarisation and systematic coding; before developing, reviewing and refining themes. Finally producing the written report (Braun & Clarke, 2022). The phases of RTA are displayed in table 1.4, examples of the process can be found in Appendix 11.

Table 1.4

Six Phases of Reflective Thematic Analysis

Phase Number	Description of Process Involved
Phase 1: Familiarising yourself with the dataset	Becoming deeply and intimately familiar with the content of the dataset, through the process of immersion. Reading and re-reading transcripts and relistening to audio and making brief analytical ideas related to the dataset.
Phase 2: Coding	Identifying segments of data that appear potentially interesting, relevant or meaningful to the research question. Code-labels are analytically meaningful descriptions and aims to capture single meaning or concepts. Coding may be done at a range of levels, Semantic which captures explicit surface level meaning
Phase 3: Generating Initial Themes	This phase involves compiling clusters of codes which share an idea or concept which may answer the research question. Theme development is an active process which are developed around the researchers knowledge and insights and the research question. Themes describe broader, shared meanings.
Phase 4: Developing and reviewing themes	The researcher revisits the initial data set to assess whether the initial themes make sense in relation to the full dataset and viability of the overall analysis. This process aims to see if the themes represent the most important patterns across the dataset in relation to the research question. Revision of the data becomes a dynamic process of the researcher reviewing the content to ensure it fits well with the patterns across themes and in relation to the overall research question.
Phase 5: Refining, defining and naming themes	This phase requires the researcher to establish whether each theme is clearly demarcated and built around a strong core concept. The themes should fit together to build an overall story about the data. During this phase, an informative name for each theme is created and a short synopsis is written. If themes still require more work, then this is the opportunity to develop and refine them further.
Phase 6: Writing Up	This where the data is pulled together the analytical narrative by compiling data extracts to inform the

reader of a coherent and persuasive story about the dataset that seeks to answer the research question.

Quality Appraisal and Reflexivity

Steps to Enhance Credibility

The researcher attended monthly research supervision where the progress of the project was reviewed. During supervision, the researcher would discuss recruitment and what data was being produced from the interviews. Allowing the researcher to adapt questions and discuss findings to ensure the research aims were being met.

Once data was collected, an initial review of the data was discussed and emerging themes were identified, this was then corroborated as part of an RTA support group the researcher attended. Themes were discussed during research supervision but as the chief investigators were racially dissimilar to the participants, it felt pertinent to assess the credibility of the findings amongst members of the African-Caribbean community to capture whether the data resonated with their experience.

Member-checking is a tool that enables researchers to involve participants to provide input to the findings (McKim, 2023). Once the final draft of research themes was completed and discussed during supervision, a final review set of the themes were written up and disseminated amongst participants via email to read and provide feedback on the findings. A liberal use of direct quotations from the interviews were used so that readers had access to some of the material which the themes were based, allowing them to judge whether the themes were appropriately based on the data.

McKim (2023) proposes that, to conduct meaningful member checking, the researcher should send beforehand the questions to be considered when reviewing the data. Questions are designed to seek clarity for any areas and to correct information that may be missing or misrepresented. Making revisions based on participant feedback adds credibility to the study findings and ensures participants experiences are accurately represented. Member checking questions can be seen in Table 1.5.

Table 1.5.

Member Checking Questions

Member Checking Question

After reading through the findings, what are your general thoughts?
How accurately do you feel the findings captured your thoughts / experiences?
What could be added to the findings to capture your experiences better?
If there is anything you would like removed, what would that be and why?

Eight participants provided feedback on the results via email. Examples of feedback can be found in Table 1.6, full exerts can be found in Appendix 12.

Table 1.6

Examples of Feedback from Member Checking

Member Checking Questions	Responses from participants
After reading through the findings, what are your general thoughts?	*"My general thoughts are that these themes capture the experience very well, I am glad to see research being carried out in such an important area, that is currently under researched for the Black community"*
How accurately do you feel the findings captured your thoughts / experiences?	*"It was fully captured, especially Themes 1, 2, and 5. This notion of keeping calm and carrying on acts as a major barrier to seeking help/seeking help at an early stage"*
What could be added to the findings to capture your experiences better?	*"Reading through the sample of results presented I think it captures the experience very well and have nothing further to add"*
If there is anything you would like removed, what would that be and why?	*"Nothing to be removed"*

Once feedback was received, no final amendments were required, the final phase of RTA was complete.

Reflexivity

A reflexive diary is considered by Braun et al (2013) as a tool to develop a richer, thoughtful, complex analysis informed by a reflexive position. They regard reflexivity as part of '*quality control'* in qualitative research. The researcher kept a reflexive diary which detailed any thoughts or feelings that were generated during the interview and analysis process, this was discussed as part of supervision to ensure that upon final analysis this did not influence the

interpretation of the results. A short example from the Reflexive diary can be seen in table 1.7 and full excerpt in Appendix 13.

Table 1.7

Example of Reflexive Diary Entry

Interviews Week One
This week I conducted my first interviews, and I was struck by the similarities that were found across each participant, I noticed a shared experience of loyalty to their loved one and that despite the hardship and inconvenience caregiving sometimes comes with, placing their loved one into care was not an option

Results

Following analysis, five themes emerged based on family members experiences of help seeking when a loved one of African-Caribbean heritage experiences memory loss. The Perception about the Windrush Generation, Cultural acknowledgement of dementia, Stigma and Shame, Keeping it in the family and Racism and mistrust of services. An overview and brief description of themes can be found in table 1.7.

Table 1.7

Overview of themes and brief description

Theme Name	Overview
The Perception about the Windrush Generation *Keep Quiet and carry on & Outsiders*	Children and spouses discussed how their loved ones experiences of migration against the backdrop of racism in the UK, had potentially influenced those of African-Caribbean heritage 'The Windrush Generation' to develop an attitude where experiences of adversity were not discussed as they feared further discrimination. Racism was a daily occurrence, and this community were made to feel unwelcome like outsiders, resulting in them not talking about their difficulties or approaching services for help. This contributed to developing an attitude where difficulties or hardship were not expressed, resulting in an attitude of 'Keep Quiet and Carry on'
Lack of cultural acknowledgement of Dementia	Within Caribbean culture, the word Dementia was not widely understood. Difficulties with memory were attributed to a normal part ageing and therefore were not seen as indicative of cognitive decline requiring medical attention. The lack of cultural acknowledgement of dementia led to this community not seeking help for difficulties associated with memory loss. This also gave rise to a community who were unwilling to acknowledge the potential onset of dementia owing to its cultural association with madness.
Stigma and Shame Dementia seen as madness or punishment Denial and Hiding	Whilst memory loss was seen as a problem associated with ageing, dementia was seen as a sign of madness or a punishment for wrongdoing in earlier life. To attract a diagnosis of dementia would confirm the onset of madness or be an admittance of wrongdoing and therefore seen as a punishment. The shame and stigma associated with this led to individuals minimising their symptoms and in turn

	family members not seeking help and choosing to keep their loved one at home as a form of protection and to hide away the difficulties.
Keeping it in the family	Cultural scripts around caring and caregiving contributed to attitudes of not help seeking, Traditional family values influenced decisions to provide care, and this was particularly evident for female family members. Families spoke about a sense of duty they felt to provide care for their loved one, therefore reducing the necessity to seek help from professional services
Racism and mistrust of services	Racist interactions with professionals led to a mistrust to approach services for help when a loved one experiences memory loss. Examples of discrimination or second-rate treatment led members of this community to keep their loved one at home as a form of protection. This also influenced their decisions to consider care homes, where many feared their loved one may be racially abused, or staff may lack cultural awareness.

Theme 1: The Perception about the Windrush Generation

Keep Quiet and Carry On

When discussing their loved one's memory loss, many participants reflected on the personal challenges of their parents or loved one migrating to the UK and how those belonging to the Windrush generation would have been deeply impacted by the emotional strain associated with this experience. Participants shared how aspects of slavery, against a backdrop of racism in the UK, shaped a generation of people to not express details of hardship. Participants reflected on how the experience of migration taught their loved ones to deal with adversity quietly and determinedly, by keeping a low profile and not asserting their needs. This, in turn, influenced family members' decision making about care and help seeking if they perceived it to be incongruent with their loved ones wishes and preferences.

Experiencing migration influenced an attitude within the generation to develop a *'strong will'* which is interpreted as a determinism to carry on so difficulties are often minimised. Colette reflects on her mother: "*She's Jamaican born you know they've had their challenges; they've come to this country and had more challenges so that fighting strong willed thing is there you know"*. The strong will described by Colette was mirrored by other participants sharing how their elders adopted a '*keep quiet and carry on'* mentality resulting in a generation of individuals who were not expressive about how they felt. Sherona shared a similar sentiment:

> There's been a lot of trauma and I would say there's a community based belief that we get on with it, or we cope as much as we can and that falls to my mom's generation, we go by the old school we don't need to talk about these things so we shut up shop and cope with things the best we can - Sherona

This stoic attitude has influenced this generation's attitudes towards dealing with difficulties, it can be seen how their response to experiencing memory loss would incorporate attitudes of *"keeping quiet and carrying on*" and that their difficulties were not worthy of the attention from services or other people.

Outsiders

Migrating and being shunned by White people and treated as *'outsiders'* appeared to influence the attitudes of the Windrush generation into not accepting or seeking help from professionals, contributing to a reluctance to engage with services. Experiences of racism

became a daily occurrence as noted by Winston: "*Daily experiences of racism are normalised".* These "*everyday occurrences of racism, prejudice and abuse"* also described by Winston may have contributed to this generation of individuals finding it difficult to approach or engage with professional services as the implicit message being communicated was that they were not welcome. This attitude is captured by Sherona:

> My mom's community, they have lived a life on the periphery and I think that has shaped and forged their decisions in that they think 'it's not for me' or 'I am not included' and I think it's from a culture of when mainstream things were not for them, or [they were] actively being curtailed in their aspirations in needing or wanting to be in places but those places not being receptive - Sherona

These experiences appear to have laid the foundation for a generation to develop attitudes towards services where it is perceived they are not welcome, feeling an 'outsider' and feeling as though services were designed for the utilisation of White people. Ultimately, this has created a reluctance for Black people from the Windrush generation to engage with professional services.

Theme 2: Lack of Cultural Acknowledgement of Dementia

A perceived lack of knowledge and appreciation of dementia being an issue within Caribbean culture, and cultural scripts established within the community contributed to a difficultly in seeking help from professional services. Following the rhetoric that this generation did not discuss hardship of life or deterioration of health, many participants reflected on the cultural incongruence surrounding perceptions of memory loss and how this was often attributed to normal forgetfulness associated with ageing. Ami references this: *"he has said a few times you know, when your old you forget stuff so yeh I think he puts it down to age"*. Whilst Dennis describes forgetfulness as part of his mother's character and is interpreted as the family not acknowledging this as the potential onset of dementia:

> I first noticed repetitiveness in conversations, she might ask me a question but then within 5 minutes she would ask me the same question that I've already answered, it was simple things like that I first noticed that was mom's trait anyway so you'd almost think, oh it's just mom being mom – Dennis

Many referenced the influence of Caribbean culture, and the lack of cultural identification that memory loss may be indicative of a serious issue. This, in turn, may lead to

an ambiguous understanding of memory problems making it less clear about what should be done in response and resulting in professional help not being sought. Ami shares her views of acknowledgement within Caribbean culture:

> It's just the culture in general, they don't handle mental health or anything like that very well you know it never has…from a Jamaican perspective they don't deal with any type of mental health or accept it as well as a culture in general – Ami

Mila supports this in her understanding of dementia with her father: *"Where he's from in the Caribbean, it's not something you would see or label so culturally it doesn't fit".* The indication that dementia is not something that is 'seen' or 'labelled' culturally impacts the community's understanding, contributing to a lack of knowledge or awareness. Winston suggests: "*It's not readily knowledgeable in our people".* Dementia is not acknowledged or discussed within Caribbean communities which can inadvertently reinforce the silencing around these experiences. Winston likens these unspoken realities to that of racism and prejudice: "*It's an unspoken thing, so like racism and prejudice is the elephant in the room where there would be the denial of dementia would have been the denial of racism".*

The lack of acknowledgement of dementia within Caribbean culture contributes to a potential delay in seeking help from professional services. Symptoms of memory loss are not taken seriously or are normalised as part of the ageing process. Culturally, dementia is not spoken about as this is often associated with madness, this label carries with it the negative connotations of shame which therefore leads to a reluctance to seek help or draw attention to these difficulties.

Theme 3: Stigma and Shame

Dementia Seen as Madness or Punishment

Whilst forgetfulness was seen as a normal part of ageing, the label of dementia was attributed as a sign of 'madness', therefore the association of dementia with madness contributes to a reluctance to seek help because of the shame this could bring to the individual and the family. Mila reflects on the culture and how this influences understanding and acceptance: *"Memory problems either means related to age but if you start presenting with other types of symptoms like Alzheimer's then it's more like your mad".* Ami describes in patios (Jamaican dialect) the narrative of the culture when discussing dementia: "*You know, dem mad inna di head".* The implications of this, combined with their experiences of 'keeping quiet and carrying on' and

the lack of cultural awareness around dementia, deter the Black community from help seeking.

The stigma associated with dementia, and the shame surrounding admitting the difficulties, may lead people to deny they have problems and to be reluctant to seek help. This influenced how the person experiencing memory loss accepted help, as reported by Ami in reference to her father: *"[He is a] Typical hard Jamaican man [he says] nothin' wrong with mi head you think I'm going mad"*. Mila supports this and discusses how dementia is perceived as a sign that you are going mad and no longer functioning:

> Culturally, for my dad and my Dad's generation, I think it's [dementia] something that is seen as life is over for you. It's not just a memory problem it's seen as […] sorry I have no other way but to say like you're mad, like you're mad you are not functioning anymore - Mila

Another cultural aspect that contributes to stigma is the belief that dementia, or other mental illnesses, were ailments that exist as a punishment for bad things the person may have done in earlier life. This influenced the help seeking process, as it was suggested that people are reluctant to talk about illness for fear of this being perceived as an admittance to wrongdoing:

> With a lot of Black people you did such and such a thing and now you're being punished and that's it, I think that's one of the reasons why our people are very reluctant to talk about the illness to admit they've got illness because it admits that you have done something wrong it's like a taboo you've done something wrong – Lloyd.

Denial and Hiding

Stigma and shame may contribute to the individual denying or minimising their difficulties and family members 'hiding them away' to protect them. Shervon suggests that when a difficulty arises, hiding the loved one is a form or protection:

> A lot of people in my culture if there's a problem or a difficulty they would hide their parents to protect them, they would look after them inside they wouldn't tell them [authorities] they would protect them, they wouldn't say I'm gonna phone this one this one or this one you involve too many authorities then this might happen. So they

> try to shield them or protect them whether that's right or wrong they shield them - Shervon

Ami provides further examples of how difficulties are 'hidden away' and discusses how they are managed in Jamaica:

> In Jamaica probably a couple of doors up from my aunt's, there's a family who has a child with severe difficulties and they've made a brick house outside the house and the child is locked up in that […] I'm just giving you an example of how its managed over there – Ami

Stigma and shame may lead to the loved one denying that they are experiencing difficulties and, if they do present to services, make a concerted effort to minimise their difficulties. This contributes to a false sense of coping similarly to '*Keeping quiet and carrying on'*. Dennis shares how their mother would respond in professional appointments:

> We made an appointment to speak to the memory clinic, first time they said Mom's ok and we were like, no, she's not but because mom would get asked certain questions and she'd be like she'd play up to it and she'd answer the questions like Bam, bam, bam, bam and then they think, oh, yeah, there's nothing wrong with her - Dennis

An experience shared by Mila, who describes how her father would dress well and try hard to be presentable in professional settings, to mask difficulties, therefore making it difficult to obtain appropriate support:

> My dad would arrive at appointments suited and booted, he had his best clothes on, he's got his best voice to articulate whatever it is he feels there is to articulate and presenting himself well. You know you can't really hide memory problems but he's concentrating and using all of his efforts to come across as a well put together Black man in this professional setting, so it's hard because my mom is trying to explain the difficulties but if the person presents in a certain way which is masking all the difficulties, then you're not getting the help you need- Mila

The shame and stigma associated with dementia founded on claims that it is a sign of madness or admittance of wrongdoing that you are consequently being punished for, contributes to the individual masking or minimising their difficulties and reduces the aspiration to seek help. Incorporating cultural scripts generated from the Windrush generation to carry on and work through adversity coupled with the lack of cultural awareness of

dementia, gives rise to feelings of shame that the attraction of a dementia diagnosis would lead to stigmatisation within the community.

Theme 4: Keeping It Within the Family

A sense of duty was felt towards providing care to a loved one and this was largely attributed to cultural and family scripts around caring, instilled from childhood. Many female participants referenced that part of their upbringing as a girl '*conditioned*' them to become caretakers, equipping them with the skills to take care of a loved one if they became ill. Giving rise to the notion of a cultural expectation to provide care and keep their loved one at home:

Sherona highlights the differences she felt between the expectations placed on her as the first-born daughter and the sense of duty to provide care:

> I honestly believe that there's so much conditioning that goes into the first girl child and it's almost like this pivotal moment, everything that's got you to this point has led you to caregiver number one. I feel like within our community there's this idea that you learn how to cook, you learn how to care for your siblings and adults and it's almost like there's this incredible sense of […] duty. I have this conversation with my siblings and they don't feel they have the same need of duty, I feel duty bound and that's a feeling for some reason they don't have – Sherona

Cherry reflects on how being a daughter has also led to a cultural expectation to provide care to their loved one:

> I think because of his age as well he can be quite sexist and I think from my point of view if me and my sister were boys it would be different but I think because were girls it's an expectation that you're a girl so you should provide care – Cherry

Participants reflect on their upbringing and how this influenced their role in caregiving and how, as Colette suggests, this was a cultural norm: "*This is the way my mom grew me to actually be there and so it's a normal part of me, my extended family is the same everyone chips in [with care] and so that's what I've known".* Family members also reflected on the difficulties that come with the role, as voiced by Cherry: *"I do want the best for my dad, but you know there's only so much I can actually do really as I say everyone's got there*

limit and I'm not a natural carer". Some saw it as a sense of entitlement and felt they were taken for granted by their loved one and wider family members:

> There's many layers to this entitlement, in the first stage people are grateful then it becomes like no you will do this, and it's that transition that's occurred. I don't know how we got there but also I've been conditioned to believe that it's my duty because if I don't then who will? and actually it is my role - Sherona

> My brother said 'well you're the carer', but actually it's a bit more complicated than that he seems to think that I should stay at home with my mom 24/7, he thinks I'm a machine, I'm not a machine I've got feelings. I'm not just chief cook and bottle washer you know that's not what I am, I'm not the dresser. There was a film called the dresser and this man would dress the main character and that literally was his role, he wasn't seen as anything else, he did everything and then when the guy died he didn't leave the dresser anything in his will because he left everything to everyone else because he saw his role as just the dresser even though he spent 40,50,60 years looking after him, in that vain that's how my brother sees me, I'm the carer that's your job that's your duty – Shervon

Individuals from African-Caribbean communities identify with caring for their loved one as a sense of family duty, especially for daughters. Cultural scripts depict that when a loved one experiences memory loss, as a form of protection they should remain at home and be managed by the family. The 'Keep quiet and carry on' attitude outlined in the Windrush Generation theme appears to be passed on generationally, where family members are taught to provide care and not involve others outside of the family or community, therefore minimising feelings of stigma and shame associated with seeking help from professional services.

Theme 5: Racism and Mistrust of Services

Experiences of racism within professional services, and the general historical mistreatment of Black communities, contributed to a lack of trust in services, causing Black people to question whether being Black would influence their loved one's quality of care, and generated concerns around whether their loved one would receive a 'second-rate' service or be subjected to racial abuse within care homes. These experiences contributed to the

community becoming reluctant to engage with services, reinforcing their perceptions that services are set up for White people and that as a form of protection, provide care at home.

'Don't Bother Because I'm Black'

Participants shared examples about encounters where they felt their race may have negatively influenced professional interactions. Providing real examples of experiences where poorer outcomes could be specifically attributed to their race. Shervon felt being Black influenced professionals to 'not bother': *"I think cos we're black they are just not bothering as much and that's an attitude that's just there whether that's an attitude that's conscious or unconscious I don't know but it's there because we are Black".* Colette felt that completing demographic information may disadvantage the level of treatment received:

> You know when they do that thing? When your asked to complete forms and they ask you what ethnicity you are? I have a feeling that behind the scenes that possibly [they see you are Black] that is what happens which is why you know, you're left to it, they're not gonna help - Colette.

Sherona shares an example of how having a racially ambiguous name leads to assumptions being made, which are then changed when professionals are presented with a Black person. She believes that this leads to professionals relaxing the level of care or service provided:

> I think sometimes they see the name and assumptions are made before she's got there and when she's turned up that's when the differences [in care] occur cos you're not expecting someone of colour, you're not expecting someone with a headwrap. I feel as though some professionals when they are presented with her in front of them unfortunately there's a prejudice or a bias that comes forth [they think] ok so we can kind of slack we can push back there's no urgency that's needed there's no need for us to be on top form – Sherona

Second-Rate Services

A sense of second-rate treatment was sensed from participants when discussing their interactions with professionals, echoing the feeling that there was no urgency when it came to their loved one. A potentially serious incident was not reported to Colette by the company who provided carers for her mother, leaving Colette to question whether she would receive this response if she were white:

> I went to my mom's house and there was a burn mark on the floor, no one had called me to say there was a mark or if my mom had had an accident. I called the office to ask if both carers had gone in they said yes and reported no concerns. That was a red flag and really upset me because mom could have been hurt. Within an hour they were at the door saying my mom gave them a different story. It makes me wonder if they would have treated me differently if I were white - Colette

Incidents like this contributed to feelings of mistrust towards professional services leading many participants to question the quality of care their loved one would receive. Doubt and suspicion were influenced by pre-existing attitudes towards authorities and questioning the positioning of Black people within society. Linus reflected on how they felt society and the medical industry *"does not do things in [Black people's] best interests"*. Interactions with professional services influenced levels of trust based on a deeper sense of mistrust generated at an institutional level. Sherona suggests that there is a scepticism felt towards professionals based on previous experiences of mistreatment:

> I would say it's a difficult one with the community 100% there's definitely mistrust and especially in the age of information we know all the Tuskegee experiment we know that various sort of clinical projects are taking place globally that have had detrimental impacts on people of colour - Sherona

Winston refers to mistrust being based on society not being fairly set up for Black people: *"It's not been normal how we've been treated in the past".* This is supported by Linus: *"When you really start to look into the way how society's been constructed, you start to go so who is this set up for? It's not really set up for us".* This influenced attitudes towards approaching professionals, as participants were wary or apprehensive of the potential repercussions when involving authorities to help their loved one. This fear influenced decision making to engage with professionals as demonstrated by Cherry:

> I think I don't wanna get people involved because I don't know what the financial implications are, my dad's got some finances and I don't want the government or the housing to take it so I think I'm just a bit more resistant to give out more information and I don't know what the repercussions are because further down the line I don't know are they gonna come back and say well we need to have that off you? - Cherry

This also contributed to loved ones becoming wary when presenting to professionals, as demonstrated in this excerpt from Colette who discusses how her mother changed her

mind about engaging with services after initially agreeing to their support, owing to fear of the consequences of their involvement:

> Now I requested one of the doctors to do a memory test with mum and she was happy to, she and I had the conversation because we were now at the point where I was having to write things down like the dates and things to remind her. She was happy to have the memory test but he [Clinician] wanted to repeat it to confirm his findings, which is normal and she said 'on no account do I want him to assess me again, because they're gonna write it down and have it on record and I don't know what they're gonna do with my house and my money – Colette

Unhelpful Responses

Mistrust permeated decisions to engage with professionals. Shervon reflected on how involving authorities can lead to decision making and outcomes that are incongruent with Caribbean culture, where sometimes an individualised approach would be better:

> Sometimes when you get involved with some of these authorities they go by the book and sometimes you can't go by the book for every single person you know you got to deviate with for the person and sometimes going by the book isn't right, Sometimes the book is written for certain cultures and not for other cultures and sometimes the book doesn't understand other cultures and other things that happen and they just deal with it in that way but instead of dealing with it that way they go round it that way and its ok but they just go straight – Shervon

Professional responses to family members when approaching services for help exacerbated mistrust further, with many participants reflecting a negative experience when visiting their GP for their loved one's memory loss, and a sense that their concerns were not taken seriously. Participants also felt that they were not provided with adequate information or informed of the next steps/stages of care, leaving families feeling lost and unsure where to turn to support their loved one, Grace describes this as feeling at a loose end: "*when the doctor says this is it and you don't know where to turn for help they don't offer no other help they don't say where to go, were just at a loose end really".* This led to families feeling frustrated with the lack of support they received from doctors. Cherry questions: *"the doctors I think are easy to diagnose but are they supportive in supporting the carers or the family?".*

This frustration was also felt by Ami: "*I think in terms of the GPs, I mean other than referring us to the mental health team for the assessment the GPs don't really do anything"*

There was also a sense of frustration felt that the response from professionals was inadequate often resulting in families being told to adopt a 'watch and wait' attitude. This often resulted in a perceived delayed response to the urgency of the difficulties being experienced or referrals made to services with no follow up. Olive shares: "*the doctor referred us to [service] they said they would get back in touch with us but they haven't"* or, as reported by Mila, the delay in response is owing to test results being lost *"you're having to chase up what's going on because not hearing anything, then you get back in touch with them and it's a case of, oh, sorry, we've lost the test results"*. Sherona shares a similar experience:

> They said the receptionist should have called her in and given her an immediate emergency appointment so she could get antibiotics but they were talking about oh well for whatever reason that got lost […] but how does it get lost? – Sherona

Culturally (Un)Informed Care

With the deterioration of memory loss causing some families to consider long term solutions to care, several participants raised anxieties around the consideration of a care home. This was discussed as part of a multi layered process around decision making intersected with race. Many spoke about the complex interplay between cultural scripts around providing care and how their perception of care homes influenced this, with many worried about whether their loved one would be racially abused or if the care home would be able to adequately cater to their cultural needs. Others viewed care homes as not something Black people do:

> I don't know but I'm just speaking from my own experiences I can't speak about anyone else's but Black people don't tend to go into homes as much as other cultures and culturally I don't know many people in my culture that have got their own family in a home within my culture they look after them at home and try to protect them that way and I don't really know anyone that's in a home - Shervon

> Do I want to put them in a care home further down the line? […] I don't really want to, I suppose there is that perception that maybe as Black people we don't put our people in care homes whereas white people might find it a bit easier more acceptable maybe - Cherry

Ami felt that a cultural misunderstanding or language barrier may result in poor treatment outcomes for her father. She reflects on the lack of perceived culturally informed care:

> They just generally are not understanding for example my dad saying 'my foots hotting me', to another [white] professional they wouldn't understand what he's on about or where the pain was, you have to understand how they [elders] are explaining things do you know what I mean? Unless there's someone from an African-Caribbean background working there then they wouldn't have a clue, even things like the food he's old school again he might eat the odd English dish but it's very rare he likes his Caribbean food - Ami

Placing their loved one in a care home was a difficult decision for families to consider as the lack of Caribbean-specific care homes made it difficult for families to be assured their loved one's cultural needs would be understood or met. Cherry reflects on the scarcity of Caribbean care homes:

> I will look after him cos we know that care homes aren't always the best places to be but you know what I suppose if you get the right care home and they are happy and comfortable there but its finding that and cos there aren't that many, well I'm assuming that there aren't many that are just Caribbean well I don't suppose there are any Caribbean at all - Cherry

Olive and her family were aware that they would find it difficult to find an African-Caribbean specific care home, they suggest that if he was in a predominantly White care home, he could eat English meals if he has his Caribbean condiments:

> We carried on with our plans [to look for a care home] we knew it wasn't going to be African-Caribbean he can socialise and integrate with anyone as long as we've got a bottle of hot pepper sauce we can put that on anything and were good to go – Olive

Whilst Dennis and his family did consider an African-Caribbean care home, experiences shared by his partner made them reconsider. This led to a new concern of whether his mother would be racially abused in a predominantly white care home:

> We did look into African-Caribbean care homes but my partners friend said her mom was in one and they were really rude to each other…and then on the flip side we were

> thinking but if mom goes to a predominantly white one will she be racially abused? We just didn't know – Dennis

The care home Linus' mother resided in did not cater to Caribbean cuisine leading the family to bring in daily Caribbean meals. After consultation, the care home agreed to provide Caribbean food:

> Mom was in a home so my sister wanted us to have a rota so each of us could bring my mom Caribbean food even though were paying the home to feed her…She wanted us to be buying more food to feed her with… anyway, the home have said they're going to do some Caribbean food for her, which is great that they're accommodating of that - Linus

This theme highlights the historical events that have led to a mistrust in services. Racism experienced and discussed in the theme 'The Windrush Generation' provide insight into a fear that services may offer their loved one a second-rate service or may be racially abused or discriminated against. This filtered into decision making around care homes and raised concerns about their ability to meet the cultural needs of their loved one and again may experience racial abuse or discrimination leading many families to provide care to their loved one at home.

African-Caribbean communities are reluctant to seek help due to a fear of being treated as second-class citizens, and this fear is based on real, lived experience.

Discussion

This research aimed to understand family member's experiences of help seeking when a loved one of African-Caribbean heritage experiences memory loss. Fourteen participants, family members of people experiencing memory problems were recruited and completed semi-structured interviews where they were asked about their experiences of engaging with professional services. Using Reflexive Thematic Analysis, interviews were transcribed and coded.

Summary of Findings

Five themes were generated from the data. *The Perception about the Windrush Generation* discussed the perceived impact of migrating to the UK, a sense of not feeling welcome by services as an African-Caribbean person and working through adversity at a time where racism was a daily occurrence, told through the lens of their children or spouses. They

discussed how these experiences contributed to a generation who did not express their hardship or share their difficulties, impacting their ability to seek help. '*Lack of cultural acknowledgement of dementia'* considered the lack of vocabulary around dementia as a disease amongst some of the African-Caribbean community, and how this may shape attitudes to perceive memory loss as a normal part of ageing, resulting in a delayed response to seek help. The theme *Stigma and Shame* built on the notion that dementia is often culturally attributed to a sign of 'madness' or a form of punishment for wrongdoing in earlier life, which could elicit stigma or shame from other community members. Those affected may mask or minimise their difficulties, causing delays or barriers to services that could support them. *Keeping it in the Family* considered how family and cultural expectations around caregiving influenced the decision to provide care for their loved one at home. The impact of this was twofold as it impacted the family's ability to seek help owing to a sense of duty to provide care, and also affected some families' decisions around care homes. It was felt that the loved one was more likely to be protected and taken care of if kept at home. Finally, *Racism and Mistrust of Services* detailed examples of how racist interactions or responses from professionals caused participants to question the level of care and provision their loved one would receive if they were to make use of those services.

This position supports the broader mental health literature which demonstrates that experiences of discrimination impact engagement because of mistrust and poorer therapeutic relationships (Clement et al., 2015). Degnan et al., (2022) also found that for Black communities in the UK, engagement with mental health services was impacted by perceptions about illness and perceived racial or ethnic discrimination. Their findings are consistent with wider literature which suggest that more ethnically homogenous social networks were associated with improvement in engagement with services from both a staff and service user perspective. Whilst it is useful to consider wider reasons why Black communities may not access services, it is important to note that when discussing access to services for memory loss, this is a different area and one which may differ due to generational differences which impact attitudes and understanding of services and how to access them.

Considering generational differences, our study supports the findings found by Berwald et al (2016) who investigated barriers to help seeking in Black African and Caribbean British communities. In their original paper, they found that the Black community attributed dementia to be a 'White person's illness' that does not affect Black people. This

supports our findings from the *'Lack of cultural acknowledgement of dementia'* theme where a similar sentiment was voiced from the participants. Both studies found that culturally, memory loss was seen as an accompaniment of old age and that Dementia did not translate culturally, demonstrating a lack of awareness within the community. A similar sentiment was implied from our findings, but to the African-Caribbean community specifically, the connotations of dementia were attributed to a sign of madness or punishment.

Stigma and Shame were noted as reasons for delaying help seeking and built on from the association of viewing dementia as a form of madness or punishment. Whilst there is limited evidence exploring associations of dementia and punishment (Adebisi & Salawu, 2023, Jett, 2005), our findings could suggest that African-Caribbean communities minimise their difficulties to both professionals and loved ones owing to the shame and stigma this may hold as being perceived as mad within the community. Berwald et al (2016), found similar findings and notes stigma, pride and embarrassment as factors that hinder help seeking.

Another similarity was found around information sharing and family duty to provide care. Berwald et al., (2016), noted that participants expressed a lack of trust in the healthcare systems ability to appropriately manage confidential information and how disclosure of personal information could be used against them by official agencies. This was reflected in our theme '*Racism and Mistrust of Services'* which went on to consider not involving professionals out of fear of the potential ramifications. They also found a similar sense of duty to provide care within Black communities and note that family was considered 'instead of' not 'in addition' to professional help, supporting our theme *'Keeping it in the family'*. Whilst the reasoning to delay help seeking for memory loss was similar in our research (it was not seen as a serious problem), the rationale for delaying help seeking differed. Berwald et al (2016) discussed practical barriers of help seeking such as limited appointment time or obtaining an appointment, whereas our research demonstrated incidents of racist interactions impacted some African-Caribbean's confidence in help seeking.

Whilst the findings show some overlap to Berwald et al (2016) research which focused on Black communities generally, new insights are offered regarding what barriers prevent those specifically of African-Caribbean heritage to seek help from professional services. New findings highlighted how attitudes towards care homes, the impact of migration and, more specifically, how perceptions about being part of the Windrush Generation may have contributed towards attitudes about accessing professional services when a loved one experiences memory loss.

The Perception about the Windrush Generation provided insight into an attitude that was shaped by their experiences of migration and racism in the UK as perceived by their descendents and spouses. The existence of racism in Britain is something many Black people experience, but the 'othering' of African-Caribbean elders at the time of the Windrush migration created a vulnerability in this community to not seek help out of fear of further discrimination or racist abuse. Experiences of racist interactions with professionals captured in '*Racism and Mistrust within Service's'* may have shaped the African-Caribbean community's experience of the healthcare system, leaving them to feel marginalised and their difficulties not taken seriously. This manifests as an attitude to not seek help owing to perceived racial biases from professionals which will then impact their level of care. This is supported by Swords & Sheni (2022) who found 65% of Black people in Britain reported being discriminated against by healthcare professionals because of their ethnicity. More widely, Sim et al (2021) conducted a systematic review considering perspectives of ethnic minority patients and found they were more likely to feel alienated due to white supremacy which resulted in inadequate treatment. A further systematic review of healthcare consumption in ethnic minorities by Chauhan et al (2020) found that ethnic minorities were more likely to experience unsafe health care. Our findings support the literature by suggesting that experiences of discrimination and unfair treatment owing to institutional racism directly impacts this community's confidence to seek help when experiencing difficulties.

The reality of feeling 'othered' were reignited for the Windrush Generation in 2010, when the UK Government introduced a 'hostile environment' to reduce UK immigration and destroyed disembarkation records belonging to the Windrush Generation; without these, individuals were unable to demonstrate their residency (Boyd et al., 2018). Those affected were unable to prove they were in the UK legally and therefore were prevented from accessing healthcare, work, housing and threatened with deportation. The government later issued an apology, but these contemporary acts of 'othering' continue to diminish trust within this community, providing validation for their reasons to not seek help or involve professional services.

'Keeping it in the family' demonstrated cultural and familial expectations to provide care as well as captured attitudes towards help seeking when the symptoms of memory loss progress. Findings illuminated attitudes towards care homes, with many feeling that this was not an option for them and not something that is culturally adhered to. Our findings support Baghirathan et al., (2020) who found that, Caribbean communities wished to protect their loved one by hiding the vulnerabilities that arose from dementia by caring for them at home.

Building on from this, the consideration of care homes from our research was hindered by concerns around a lack of cultural sensitivity or their loved one being racially abused. Baghitarathan et al (2020), supports this and listed diminishment of identity within Caribbean communities as a reason for not considering care homes. They cited reasons of isolation and being the only visible Black person within a service as a risk to their cultural identity owing to different cultural norms such as food or language. This was highlighted in our results as participants spoke about not using care homes owing to fear of racial abuse or staff being unable to meet their cultural needs.

These cultural scripts place an inadvertent pressure to provide care, instilling a sense of duty as articulated by the participants. Truswell (2019) suggests that family pressures to provide care may be generated from cultural expectations as many of the Windrush Generation would have migrated from rural communities, with multiple generations and close relatives living in close proximity which would help manage and share the demands of care. Our findings demonstrate that traditionally held Caribbean values around collectivism and caring as well as cultural awareness of dementia are barriers to seeking help in this community.

Our findings support existing research that discuss barriers for accessing dementia services for ethnic minorities (Kenning et al., 2017; Mukadam et al., 2011, Mukadam et al., 2011b; Werner et al., 2014) and provide evidence to suggest that help seeking for dementia is culturally specific (Mukadam et al., 2013) and differs between ethnic minority communities. This study is unique in its focus as it reports findings specifically from the African-Caribbean community and their experiences of help seeking when a loved one experiences memory loss. Whilst the wider literature pertaining to ethnic minorities is useful, it fails to capture the nuanced experiences of the African-Caribbean community and those belonging to the Windrush Generation and how this, specifically shaped attitudes and experiences of help seeking from professional services in the UK.

Strengths and Limitations

The study targeted African-Caribbean communities and received a good response for participation resulting in fourteen participants recruited into the study. Evidence suggests that Black communities are less likely to participate in research (Smart & Harrison, 2017) owing to mistrust and discrimination (Hainsworth et al., 2022). The importance of engaging members of the African-Caribbean community in research can begin to address the power

imbalances to help reach this community who are deemed high risk. Our research contributes to the evidence base to help policy makers and stake holders understand the unique position of these individuals to work towards health equity. Further involvement of these participants through the use of member checking increased the credibility of the research findings as those who participated in the study were actively involved in the final results and were used to ensure the findings were representative of their experiences.

Building on from this, deliberately focusing on the experiences of the African-Caribbean community and Windrush Generation, provided a unique focus considering the historical factors that have contributed to their decisions around help seeking and identified barriers specific to this cultural group within the UK. Whilst our findings shared some overlap with Berwald et al (2016) who considered barriers in Black communities more generally, this study is the first of its kind to focus solely on the experiences of the African-Caribbean community.

The author identified as being of African-Caribbean heritage who had experience of help seeking for dementia services. Belonging to this ethnic community provided a cultural understanding of the norms and values generated within Caribbean culture. This was a particular strength as it was felt participants were more likely to be trusting to share their experiences and participate in the study.

Limitations to be considered include participants were all recruited from the West Midlands. Birmingham is home to the largest African-Caribbean community in the UK representing 8% of the population (Gov.uk, 2019), Results may not be representative of those who may live in rural parts of the UK or those in parts of the UK where the African-Caribbean community is less well represented. The data also only represented individuals who acknowledged that a family member did have dementia so findings may not be representative of those who are less willing to accept or acknowledge this.

The study was promoted and advertised in NHS locations but received no participants through these channels. All participants were recruited from community settings; therefore, the findings may not be representative of anyone currently engaged with a professional health service. Incorporating the experiences of those currently engaged with health services would provide insight into how the journey of help seeking may differ to those who chose to not seek help and provide care at home.

Whilst the author enhanced the credibility of the findings through member checking and the use of research supervision, ultimately, they are responsible for the final interpretation of the data. Owing to the reflexive process, the researcher acknowledges that their own personal experiences of barriers to help seeking and opinions will have influenced the interpretation of the results, leading to a bias in the overall data.

Implications & Future Research

Clinical and Service Implications

Evidence generated from the '*lack of cultural acknowledgement'* and '*stigma and shame'* themes suggest the need to raise awareness of dementia in the African-Caribbean community. Our findings demonstrate that for some members of the African Caribbean community, there are several barriers that prevent them from presenting to services when symptoms of memory loss arise. As a consequence of this, individuals may only present to services when the symptoms reach crisis point and the individual or family member are no longer able to cope. This delay contributes to worse treatment outcomes and limited intervention options available from professional services. To overcome this, professional healthcare services should work with community organisations who support individuals from the African Caribbean community to help raise awareness of memory loss and dementia. In doing so, they can promote early detection and encourage access to services for preventative care. This ultimately would help increase awareness and reduce the incidence and severity of dementia within the African Caribbean community.

Targeted messaging to dispel the misconception that dementia is not a White disease and is more prevalent in the Black community. As mistrust is associated with services, these messages need to be disseminated within the African-Caribbean community, ideally by an individual of African-Caribbean heritage. As highlighted in chapter one, which discussed issues associated with vaccine hesitancy, representation was seen as something that increased trust. It could be argued that those from an African Caribbean background may be more likely to share cultural experiences, values, and understand the specific health challenges that may be prevalent in Black communities. This shared cultural background helps deliver the messages in a way that resonates with the individual and feels more relevant to their cultural and life experiences.

Given the mistrust and alienation some members of the African-Caribbean community feel towards services, further thought could be given to culturally specific services that are perceived as belonging to, and being for, the African-Caribbean community. This could be co-ordinated by appointing a dedicated lead who works with professional services to actively monitor access to dementia services and balances this with the needs of the community. Creating services for African-Caribbean communities which are run by Black led organisations will provide culturally informed advocacy, information, and guidance by supporting members of the African-Caribbean community to access the support they need. Having a professional workforce who shares the cultural background and possesses the knowledge and authority can help empower and inspire trust. It can break down barriers and remove feelings of alienation by seeing information being disseminated by individuals and services who understand their context.

Future research should build on our findings, specifically investigating what barriers prevent some members of the African Caribbean community to seek help, and use this knowledge to help develop targeted strategies and campaigns to increase engagement with professional services. Having an awareness of these barriers could help to develop culturally tailored care models that address the specific needs of the African Caribbean community. Incorporating culturally specific beliefs, practices and values into healthcare delivery could improve effectiveness of earlier intervention and, therefore, treatment outcomes.

Incorporating community collaboration into existing healthcare services is one way to establish trust within the African Caribbean community. Future research could investigate whether culturally specific services who liaise between Black community organisations and healthcare providers are effective at influencing trust and increasing healthcare utilisation and healthcare outcomes.

The Windrush generation are a finite resource whose experiences are still largely misunderstood. Compassionate understanding about the experiences of this community will help shed light into how healthcare providers can meet their needs and raise awareness and understanding of dementia within this community.

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CHAPTER THREE: PRESS RELEASES

We are not all the 'BAME' Black people do not want to take the COVID-19 vaccination

Research demonstrates that Black people globally showed higher rates of not accepting the COVID-19 vaccine compared to all other ethnic minority communities. What is the reason for this? Well historically, Black people have been used to advance medicines in the form of unethical testing which has led to this community to be mistrusting of both government and medical professionals. We know that the evidence states that those from ethnic minority communities generally were less likely to accept the vaccine, but this is usually presented as one large group and doesn't factor in that different ethnic minority communities may have different reasons for not accepting the vaccine…

… and they did!

We looked at research that considered responses for not accepting the vaccine in ethnic minorities and separated them into individuals who identified as being from a Black ethnic group in the UK and USA and compared these to those who belonged to other ethnic minority communities. We also created a group for quotes that could not be linked to a specific ethnic minority group to see if any new information was found. What we found, is that Black people were less likely to accept the vaccine based on fear and suspicion that the government or medical professional were unethically testing on them. They also felt that there was a lack of information around the vaccine which led many to be unsure what information could be trusted as demonstrated in this participant quote:

> *"A lot [of information is available]. Sometimes it's only bad, but we don't know what can we trust? It's good, or it's not good. Especially me, I end up in the middle, I don't know"*

Generally, other ethnic minority communities were more likely to accept the vaccine based on government recommendation and advice from medical professionals. In the unknown ethnicity group, it was found that ethnic minorities as a collective felt that the vaccination message was promoted by white people and that the lack of ethnic minorities included in the development and promotion of the vaccine, contributed to vaccine hesitancy, it was felt that governments and medical professionals should engage with the community to help minimise 'fake news' and address any concerns:

> *"Go to the community and get their opinions about how to roll this out and what they want and feel in the process. This should be a holistic approach to well-being, rather than just a one size fits all approach of 'take the vaccine'."*

The results demonstrate that reasons for vaccine hesitancy do differ for different ethnic minority communities. If governments and medical professionals are keen to increase vaccine uptake within Black ethnic minority populations, it is important that they listen to their concerns and attempt to instil trust by actively engaging with the community and providing reliable information through trusted sources.

Memory Loss or Madness? The Windrush Generation and understanding of dementia

Memory loss is a sign of madness! Within African-Caribbean communities, there is a belief that if someone is having trouble with their memory, that this may be a sign of madness. Owing to this association, African-Caribbean people do not to seek help from professional services when experiencing memory loss, and instead choose to be cared for by their families at home. Currently there are over 944,000 people living with dementia in the UK and this number is expected to rise above 1.6 million by 2050, with evidence demonstrating that those from African-Caribbean populations remain one of the highest risk communities because of risk factors such as diabetes and cardiovascular disease. Black women are 28% and Black men 25% more likely to receive a dementia diagnosis compared to their white British counterparts.

So, what does this mean? Well currently there is evidence to demonstrate that African-Caribbean populations are underrepresented in dementia services and are more likely to receive this diagnosis much later in the illness, which therefore impacts treatment outcomes. With such high numbers of people getting dementia, the numbers do not match the representation in services and there does not seem to be much research into factors that contribute to this.

Using semi-structured interviews, we interviewed fourteen family members, who's loved one is affected by memory loss to understand their experiences and how this impacts their ability to get help from a professional.

What we found is that many of the individuals experiencing memory loss came to the UK as part of the 'Windrush Generation', and the experience of migration played a role in shaping their attitudes towards professionals. Experiences of racism contributed to an attitude of feeling unwelcome and that services were not for them. This instilled an attitude of stoicism within this community to not make a fuss if experiencing difficulties. This led to a generation of individuals who are not expressive and therefore do not share their difficulties, making it hard for the family to get help. They also carry distinct cultural scripts around dementia and associated this as a form of madness or punishment:

"With a lot of Black people you did such and such a thing and now your being punished and that's it, I think that's one of the reasons why our people are very reluctant to talk about the illness to admit they've got illness because it admits that you have done something wrong it's like a taboo you've done something wrong"

The shame and stigma associated with madness contributed to many choosing to hide their difficulties and family members becoming responsible for providing care. Experiences of racism through interactions with professionals made them fear that their problems would not be taken seriously and that their loved one may receive second rate or even racist treatment.

The findings demonstrate that a lack of awareness into the factors that contribute to the barriers to seek help within the African Caribbean community, lead to a delay in help seeking. Services need to be accommodating in showing an appreciation of the trauma associated with migration and how this influences attitudes of mistrust towards professionals. Active engagement with the community by disseminating culturally specific information about dementia will help increase awareness to this community and in turn, result in an increase in service utilisation.

Appendices for Chapter One: Literature Review

Appendix 1: Examples of the coding process

Familiarisation of the data

	Aim	Method	Participants	Concept / Category	Concept / Category	Concept / Category	Concept / Category	Concept / Category	Concept / Category	Comments
Bateman (2022) Exploring COVID-19 Vaccine Hesitancy among stakeholders in African American and Latinx Communities in the Deep South Through the lens of the health belief model	To explore vaccination intention among african america and latinax participants	Semi structured intervirews, 4 Focus Groups	67							
Bell (2021) COVID-19 vaccination beliefs, attitudes, and behaviours among health and social care workers in the UK: A mixed-methods study	To gain insight into beliefs attitudes and behaviours in health and social care workers	Mixed Methods - Semi structured interviews	**20**	Black african or mixed black african were more likely to state concerns about a lack of research and indian participants were more likely to state concerns about side effects	Black caribbean or mixed black caribbean were more likely to state distrust in government, the pharmaceutical industry, vaccine manufactueres and or the media	Trust is undermined by beliefs in systemic racism, Participsnts spoke about past medical racism (Tuskegee syphilis study) as being commonly reported amongst colleagues from black ethnic groups. Black women being adverseley by healthcare providers	Social Care Workers also reported lower levels of trusy, which appeared more linked to relationships with their employer and feeling pressurised to vaccinate	Speed of vaccine and side effects, wait and see approach, changing guidance , interval change	Trials have not been sufficiently trialled in ethnic minority groups	Grrat paper which spoke about the differences between ethnic minorities and what the differences are. Highlighted that there are differences even between black caribbean and black african views in vaccine hesitancy
Charura (2022) Covid-19 Vaccine Hesitancy, Medical Mistrust and mattering in ethnically diverse communities	To explore factors that may underpin hesitancy towards the covid-19 vaccine and intention to vaccinate in ethnically diverse communities	Online questionnaire which had open and closed questions	161 Participants Asian N=16 Black N=125 Mixed race N=18 Any other ethnic group n=2	Mattering refers to feeling like you are depended on, important and valued. When people feel undeserved undervalued marginalised they are more likely to be treated as less important	Pressure and coercio featured as part of increasing likelihood of vsccine uptaje . A sense of pressure contributed to perceptions of there being another agenda by medical professionals	Vaccine hesitancy is not evidence of an anti vax position	To lower hesitancy and increase vaccine uptake meaningful engagement with these communities is needed that includes health professionals collaborating with community allies champions faith leaders and other trusted members of diverse communities	Larger samples would permit comparisons across different ethnic groups in regard to hesitancy and would therefore tailor support and information		
Eberhardt (2022a) A qualitative study exploring attitudes and perceptions of the COVID-19 booster vaccine in minority ethnic individuals in North East England	To explore attitudes and perceptions of covid-19 booster vaccination among ethnic minority individuals in north east england	Semi structured interviews	16 ethnic minoritiies (11 females, 5 males)							Some people viewed their ethnicity as a protective factor but others saw it as a ris
Eberhardt (2022b) Exploring COVID-19 Vaccine Confidence with People from Black and Asian Backgrounds in England	To understand factors affecting hesitancy in black and asian individuals in	**Online platform of activiites**	**95 (51 female, 42 men, 2 other)**							

	Themes				
Bateman (2022) Exploring COVID-19 Vaccine Hesitancy among stakeholders in African American and Latinx Communities in the Deep South Through the lens of the health belief model	Theme 1: Mistrust Subtheme 1: Historical Mistrust, subtheme 2: Vaccine development mistrust,Subtheme 3: Mistrust of politicians	Theme 2: Fear Subtheme 1: Fear of Exposure, Subtheme 2: fear of the unkown Subtheme 3:Fear of deportation	Theme 3: Information, Subtheme 1 Lack of information, Subtheme 2: Correct and complete information,		
Bell (2021) COVID-19 vaccination beliefs, attitudes, and behaviours among health and social care workers in the UK: A mixed-methods study	Themes: Access, Perceptions of covid-10 risk and severity, trust, beliefs arounf vaccine effectiveness, perceptions of covid-19 importance, pressure to get vaccinated, concerns about allergies, vaccination concern in women of childbearing age, vaccine communication and information soruces and religion	Trust in policy makers			
Charura (2022) Covid-19 Vaccine Hesitancy, Medical Mistrust and mattering in ethnically diverse communities	Theme 1: Participants beliefs that it is important to take the vaccine and seeing it as a social responsibility	Theme 2: Experiencing pressure and feelings of being forced to take the vaccine with limited/no choice	Theme 3: General mistrust linked to personal and historic experiences of the health system rather than an anti-vax position	Theme 4: Being hesitant , reluctant and concerned about being socially or medically restricted.	
Eberhardt (2022a) A qualitative study exploring attitudes and perceptions of the COVID-19 booster vaccine in minority ethnic individuals in North East England	Theme 1:Perceived vulnerability to covid-19 and side-effects of the vaccine	Theme 2: Negative experiences with covid-19 vaccine	Theme 3: Negative viewws related to covid019 vaccination a) The covid--29 booster vaccine as inconvenient or unnecessary b)lack of confidence in covid-19 vaccine due to its hasty development c)lack of trust due tto historic events involving medical experimentation of ethnic minorities	Theme 4: The influence of social media on covid-19 vaccination intention	Theme 5: Strategies to increase confidence in the covid-19 vaccine a)enlisting community leaders b)education
Eberhardt (2022b) Exploring COVID-19 Vaccine Confidence with People from Black and Asian Backgrounds in England	Theme 1:A variety of views in the covid-19 vaccine	Theme 2: Targeted messaging of black and asican people was counter productive	Theme 3: Confusion over the purpose of the vaccine roll out	Theme 4: hesitancy to take the vaccine	Theme 5: local netowrks as a trusted source of information
Majee (2022) The past is so present: Understanding COVID-19 vaccine hesitancy among african american adults using qualitative data	Theme 1: Contextual influences, subtheme: historical influences, perception of the pharmaceutical industry, communication and media environment	Theme 2: Individual group influenes, subtheme: knowledge/awareness of vaccine, perception of healthcare providers, personal, family and community members experience with vaccine	Theme 3: Vaccine andvaccination specific issues Subtheme: introudction of a new vaccine	theme 4: Role of Living well by faith, subtheme: Trusted source of vaccine	

Extracting Quotes from data set



Coding of all quotes

| | | |

Organising Quotes into Black, Other ethnic minorities and Unknown

BLACK	AME	Unknown Ethnicity
"Well, I have one phrase, the Tuskegee experiment."	"And with the government rules, they're breaking the rules, you know the stories that go around . . .how can you trust a government that keep on breaking the rules?" P36, British Asian, 36yrs, Male	I think it's important to follow the rules.
"I don't think there would be anything that would encourage people from this area to be, quote/unquote, guinea pigs. We've seen the history, what has happened…"	"For so many people, you're like a sitting duck. If you go to a particular place… they could think, 'If I go to that place, I will get the vaccine, but probably I will get something more, like arrested or deported or something – County Latinx Participant"	Everyone should take the vaccine to protect all of the population.
"A lot of people look at vaccines as just experiments… we don't know if this is really gonna work."	"I trust the FDA and I know they are not going to approve a vaccine that is going to hurt us." Latinax participant	Ethnic minorities have a role to play in the management and spread of Covid-19 and should take this responsibility seriously
"I would not be first in line to get it. I'd have to let thousands of Americans get it before—and I see their reaction before I get it." (Mobile County, African American)."	"Just havin' authority figures telling us that this is good for us and showing us… bein' vaccinated… That's the best way to actually carry the message" – Latinax participant	Too many unanswered questions.
""I think it should've started from the top, as far as the president should've set the tone for everyone. I think we should have been given the correct information."	'I have also decided to postpone having my first vaccine because my second vaccine would fall in Ramadan and I will not miss my fasting'. (Survey ID234—HCW, female, Asian or Asian British:—Pakistani)	…the data does not add up as no long-term research has been done.
"We have had maybe 3 or 4 classmates to pass away from it, from this deadly disease, and we just don't know how to handle it."	"Some of my friends from Africa, I've seen this fear that if you get [a] vaccination, how safe we are, there's a question. Because, you know, there will be some nega- tive [effects], like 5 to 10%. But they don't see the posi- tive 90%. They just look for the 10% and then mostly they're staying away from vaccination. (Participant 4)"	…. I would get it, but it is still in the trial stage. I'll wait awhile.
"We've never had anything like this, and it's just the unknown" (Dallas County, African American)."	"Due to the poor knowledge of vaccines, [people] will hesitate to take it because when we are vaccinated, we may feel sick for two days. (Participant 6)"	I'm only doing it because the government seem to be saying that they won't let me travel without it …feeling pressured to take it.
"I wouldn't recommend anyone to take it, especially the people I care about, until I actually know does it really help people."	"The people who have taken the vaccination, if they talk, if they can share their experience there, there might be some[thing] useful to the others to get vac- cinated. (Participant 4)"	…I have I've been forced into taking because of my profession.
"Knowledge is power. When we become more knowledgeable about what we're taking and why, then we'll be more apt to want to do it. Provide us with more information on what is being done and what has been done in other areas, and not make us feel like we're the guinea pigs."	"As I'm staying alone, I have a fear that if I get some- thing a fever or something, which [is] beyond my con- trol, if I get hospitalised. (Participant 4)"	Do not trust these medical professionals.
"You can't just tell people to just take a vaccine. You have to educate them around it, and it has to be people who are from your community that you can trust to over- come these hurdles."	But not every statement posted in the social media is true. Unless we visit a website or we visit the accurate apps or the clear website, we don't get the proper information. Fake news spreads so fast. (Par- ticipant 6)"	Will not be forced by legislation or coercion.
""I don't see how they're gonna get those people to believe in the vaccine for the virus that they don't believe in."	"In the social media, sometimes we may get some information, which is maybe [inaccurate] sometimes, but if you follow the official channels of NHS, […] we can get the right information. (Participant 4)"	do not trust this government as they do not have our best interest at heart.
"A lotta people are actually seeing it as, 'Well, I'm not gonna get sick from it because I don't have an underlying health condition.' Just misinformation, miscommunication."	"People are actively engaged in social media. So, if we get something, […] the advertising […] on Face- book or maybe like LinkedIn, like YouTube, if you [tell] people to get the vaccination, […] advertise [it] in the media. (Participant 4)"	…… I can understand the distrust about medical care from an ethnicity distrust perspective but NOT from an overall anti-vax perspective.
"We feel that for decades, we have been on the receiving end of health and social inequalities. Now, we are being presented with a new vaccine that has been developed in quick time and we are now priority group number 1' (Survey ID52 –HCW, male, Black or Black British:— African)"	"If we educate the person, he may understand and he may […] volunteer himself to take the vaccine. Unless we teach or we […] explain or we make them under- stand they will not take [the vaccine] so […] we need to educate them. (Participant 6)"	I would like more information about the COVID vac- cine trials on my ethnic group.
"I'm tired of people talking about those BAME people without understanding that they're different groups, and without trying to understand why.' (Interviewee#14 –HCW, female, Black or Black British: —Caribbean)."	"I don't want to put stuff in my body that's going to make it worse. . . Why would I put Pfizer that in some studies, they've ended up with an enlarged heart and arrhythmia?. . . I already have those issues. I'm not going to exacerbate them." P29, Asian British, 56 years, Female	….Unethical medical experimentation that has occurred for over a century may be the cause of the fear and mistrust of doctors and medicines. For example…the drug [name of drug given] was illegally tested in a clinical trial in Nigeria, which resulted in people's death, others suffered blindness, deafness, and brain damage… it is difficult to trust medical professionals and their practices peradven- ture history repeats itself on Ethnic Groups.
'I wanted to be fully informed rather than just told to take it. . . I was left frightened and with little information which was totally avoidable.' (Survey ID350 –HCW, female, Mixed:— White and Black Caribbean)"	". . .At the time they were like, yes, it's safe, [Thalidomide], it took them five years to realise the connection. . .So if here we are taking this vaccine during pregnancy . . . but at the same time, we don't know the long-term effects. So why are you risking it?" P38, British Asian, 31 years, Female	Especially because of the impact on my civil liberties if I don't have the vaccine.
'I would like to know more about side effects. Besides what is online there appears to be a vagueness about the side effects that I'm sure some people have had. I think there should be more transparency especially for Black and brown healthcare workers.' (Survey ID872 – HCW, female, Black or Black British:—Other)"	"I think it was fear that was driving it (spreading misinformation) to be honest. It was such a difficult time and there were people who were really scared, there was almost like a paranoia." P20, Asian British, 40 years, Female	I need to travel so it's not really about my health.
"Africa was, I think, the last part [of the world] where COVID came out. [...] It didn't hit so much. So that thing also made [people] think that Africans can't get it. (Participant 5)	"And with the government rules, they're breaking the rules, you know the stories that go around . . .how can you trust a government that keep on breaking the rules?" P36, British Asian, 36yrs, Male	I am doing it for convenience's sake with fear that if I refuse it might affect my future care and treatment
Back home in Africa, the majority of people didn't get vaccinated. They go through the pandemic, and every- body is fine. Some of them got it [COVID-19]. Some of them didn't get the vaccination, but they're surviving, and people's lives continue. [...] The government [...] shouldn't be worried about people passing COVID to others, because now we're normalising, our life [has] become normal, everybody's doing whatever he's doing in his life' (Participant 15)"	So short-term probably engagement in terms of leaflets and maybe little snippets of a video, say on the BBC, about the vaccine, and about its safety and something about clinical trials. Maybe some of this stuff is already out there, but if stuff like that goes viral it counteracts some of the negative and misinformed things that are in videos that are doing the rounds." P20, Asian, 40 years, Female	"I am not against the COVID-19 vaccine, however I do not feel confident about having the vaccine at the moment, as I feel that it is new and still in its trial phase. I worry about side effects that could develop in the long-term as well as the short-term side effects that have been reported recently. I do not feel that there has been enough time to understand all risks and make an informed decision. (Participant 80)"

Papers contributing to Black Communities

Theme	Majee	Bateman	Valero-Martinez	Eberhardt	Magee	Williams	Bell	Sagoe	Woodhead	Total
1. Mistrust	1	1	0	1	1	2	1	0	0	7
2. Mistreatment	1	0	0	1	0	0	0	0	1	3
3. Black Guinea Pigs	1	2	1	1	2	0	0	1	0	8
4. Information vacuum	0	1	0	0	1	0	2	1	0	5
Total	3	4	1	3	4	2	3	2	1	25

Appendices for Chapter Two: Empirical Project

Appendix 1: University Sponsorship letter

UNIVERSITY OF BIRMINGHAM
FINANCE OFFICE

Dr Stephanie Howarth
School of Psychology
University of Birmingham

Tuesday, 7 February 2023

Dear Dr Howarth

Project Title: **Family experiences of help seeking when a loved one of Afro-Caribbean heritage, experiences memory loss.**
IRAS ID: **319096**
Sponsor Reference: **RG_22-143**
UoB Ethics Reference: **ERN_2022-0384**

Under the requirements of UK Policy Framework for Health and Social Care Research, the University of Birmingham agrees to act as Sponsor for this project. Sponsorship is subject to you obtaining a favourable ethical opinion, HRA approval and NHS R&D management approval where appropriate.

As Chief Investigator, you must ensure that local study recruitment does not commence until all applicable approvals have been obtained. Where a study is or becomes multi-site you are responsible for ensuring that recruitment at external sites does not commence until local approvals have been obtained.

Following receipt of all relevant approvals, you should ensure that any subsequent amendments are notified to the Sponsor, REC, HRA and relevant NHS R&D Office(s), and that an annual progress report is submitted to the Sponsor, REC and NHS R&D departments where requested.

Please ensure you are familiar with the University of Birmingham Code of Practice for Research (http://www.birmingham.ac.uk/Documents/university/legal/research.pdf) and any appropriate College or School guidelines.

Finally please contact researchgovernance@contacts.bham.ac.uk should you have any queries.

You may show this letter to external organisations.

Yours sincerely

Appendix 2: NHS Health Research Authority Ethical Approval

NHS
Health Research Authority

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Telephone: 02071048083

02 May 2023

Dr Stephanie Howarth
University of Birmingham
52 Pritchatts Road
Edgbaston, Birmingham
B15 2TT

Dear Dr Howarth

Study title:	**Family experiences of help seeking when a loved one of Afro-Caribbean heritage, experiences memory loss.**
REC reference:	**23/YH/0056**
Protocol number:	**1**
IRAS project ID:	**319096**

Thank you for your recent correspondence, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of

research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:
https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at:
https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at
https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the	1	01 November 2022

research [Recruitment Posters]		
Copies of materials calling attention of potential participants to the research [Recruitment Posters]	1	23 March 2023
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Confirmation of Insurance]		
Interview schedules or topic guides for participants [November 2023]	1	
IRAS Application Form [IRAS_Form_10022023]		10 February 2023
IRAS Checklist XML [Checklist_18042023]		18 April 2023
Letter from sponsor [Confirmation of Sponsorship]	1	
Letters of invitation to participant [Participant Demographic Information]	1	01 November 2022
Other [REC Actions]	1	23 March 2023
Participant consent form [Participant Consent form]	1	01 November 2022
Participant information sheet (PIS) [Participant Information Sheet]	1	01 November 2022
Participant information sheet (PIS) [Participant Information (PIS)]	2	22 March 2023
Research protocol or project proposal [Research Proposal]	1	01 November 2022
Response to Request for Further Information		
Summary CV for Chief Investigator (CI) [CI CV]		
Summary CV for student [Melissa Brown CV]		01 November 2022
Summary CV for supervisor (student research) [Dr Stephanie Howarth CV]		01 November 2022
Summary CV for supervisor (student research) [G Riley]		13 February 2023
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flow chart of participants]	1	01 November 2022

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 319096 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Appendix 3: NHS Research and Development Confirmation – Birmingham Community NHS Trust

Dear Melissa,

Notification of Research Registration

Birmingham Community Healthcare (BCHC) NHS Foundation Trust is pleased to confirm that your research has been registered. Please note that the following information is needed before we can promote your project:

- Protocol v1 01.11.2022 [the protocol you have provided has a different date to the one listed in REC Favourable opinion letter dated 02.05.2023]
- Recruitment Posters v1 23.03.2023 [the posters you have provided does not include a version number or date. We have taken the date and version number from the REC Favourable opinion letter].

It is noted that HRA approval is not required and they have issued a letter dated 12.05.2023 confirming this.

To help the R&I department keep an accurate record of your research please can you send them the following:

- A monthly report summarising the status of the project.
- Any amendment made to the research, including any changes to study documents.
- Any incident or complaint relevant to the conduct of the research within this Trust. This includes any event that could have, or did, lead to loss of data, a confidentiality breach, damage to property, and/ or harm to participants.
- When recruitment at BCHC has ended. Currently this is September 2023.
- A summary of the research findings when data analysis has been completed.

Please contact the R&I team if you need any support or if you have any queries regarding the above.

May we take this opportunity to wish you success with your research.

Kind regards
Research and Innovation
Birmingham Community Healthcare NHS Foundation Trust



Appendix 4: NHS Research and Development Confirmation – Birmingham and Solihull Mental Health NHS Foundation Trust

Dear Melissa

IRAS ID: 319096 - Family experience of help seeking for a loved one with memory loss(V1) - Confirmation of Local Capacity and Capability at Birmingham and Solihull Mental Health NHS Foundation Trust

This email confirms that Birmingham and Solihull Mental Health NHS Foundation Trust has the capacity and capability to deliver the above referenced study. Please find attached the agreed Organisation Information Document as confirmation.

Start and end dates:

We agree to start this study on **with immediate effect.**

We understand that recruitment will end on **12 March 2025**. We are aware that at this point, archiving is the responsibility of researchgovernance@contacts.bham.ac.uk.

Recruitment figures:

Please note that you will be contacted by the R&D department periodically to obtain your current recruitment figures.

The target date for first patient recruited is **23 June 2023** – 30 days post confirmation of local capacity and capability.

During your study:

During the study, researchers are required to fulfil the following duties:

- Inform R&D of any amendments to the study, both substantial or non-substantial
- Inform R&D when the study has completed at the Trust - Inform R&D of the total recruitment number at the Trust - Submit a final report to the R&D department.

All of the above can be submitted to researchanddepartment@bmhft.nhs.uk

If you wish to discuss further, please do not hesitate to contact us.

Finally, we would like to wish you all the best with your research.

Kind regards
Research and Development

Appendix 5: NHS Research and Development Confirmation – Black Country Healthcare NHS Trust

Dear Melissa,

I hope that you are keeping well.

Following the completion of our internal approvals process, I am pleased to advise that Black Country Healthcare NHS Foundation Trust will start promotion activities for your research project with immediate effect.

Best wishes

Research and Innovation
Lime Room
The Beeches
Penn Hospital
WV4 5HN

Click to follow us on Facebook, Twitter and Instagram!



Appendix 6: Risk Assessment Form

SOPHS_23_80_SH - approved for Research Family experiences of help seeking when a loved one from Afro-Caribbean heritage experiences memory loss

To:
Melissa Brown (ClinPsyD Clinical Psychol FT)

Thu 29/02/2024 14:54

SOPHS_22_230_CAP_Home visits_R2.docx
51 KB

You RA SOPHS_23_80_SH – has been approved for Research Family experiences of help seeking when a loved one from Afro-Caribbean heritage experiences memory loss
Using already approved SOPHS_22_230_CAP_HomeVisits

UNIVERSITY OF BIRMINGHAM

GENERAL HEALTH AND SAFETY RISK ASSESSMENT FORM

Site	**Fieldwork**	**Department**	**LES/School of Psychology**
Activity Location	In participants' own homes participants recruited from 'Join Dementia research'	**Activity Description**	An initial visit to the participants' own home to ex participant information leaflet will be left with the A second visit to the participants' own home durin some paper copies of questionnaires/measures du
Assessor		**Assessment Date**	**29_02_2024**
Academic / Manager Name		**Academic / Manager Signature**	

Hazard Assessment				**Control Assessment**					
Hazard Category	Hazards Identified	Who might be harmed? Staff Students Contractors Others	How might people be harmed?	Existing Control Measures	Initial Risk Rating S	L	R	Are these adequate ? Yes/No	Changes to/ Additional Controls

Organisational/ social	Safety of the researcher when conducting the home visits	Researcher	Researcher is put at risk due to lone working	1) All participants will be recruited from the Join Dementia Research website which matches participants to studies, so all participants will have been previously in contact with other researchers through the website. 2) On the day of a visit, the researcher leading the visit will send a text message to their supervisor indicating the time of the visit and an expected finish time. 3) On termination of the visit, the researcher will send a second text message to indicate that they have safely returned to the University/ home. 4) If the supervisor has not received the exit text message by the specified time, they will attempt to call the researcher. If they cannot make contact, they will attempt to call the participants the researcher was scheduled to visit. If they still cannot make contact, they will call the police. 5) All visits will be carried out during working hours to ensure the supervisor is available and to ensure that the visits occur during daylight. 6) The researcher will ensure upon arrival that there are no other people present at the house other than the participants and will terminate the visit if others enter the house during the visit. 7) The researcher must adhere to University of Birmingham policy around public transport use during fieldwork – page 11 of: https://intranet.birmingham.ac.uk/hr/documents/public/hsu/hsuguidance/18FW.pdf 8) The researcher must familiarise themselves with relevant public transport timetables and does not rely on the last available option to travel home. 9) The researcher will ensure that they are carrying a debit card or sufficient money for a taxi and ensure they have the number of a reputable taxi firm stored in their phone. 10) The researcher will terminate the visit if they do not feel safe and have a charged mobile phone on them at all times.	4	1	4		

Social	Participants are upset by the content of the researcher activities which have an emotional emphasis	Participants	Participants may be upset by the content of the researcher which has an emotional emphasis	1) Ethically approved informed consent and debriefing procedures will be followed. 2) The researcher will look out for signs of discomfort from the participants, which may be subtle (e.g., disengaging from the ongoing activity). If signs of discomfort are shown, the researcher will remove them from the emotional content. 3) The participants will be offered breaks during the visit and will be informed that they are allowed to reschedule any visit or terminate the visit at any point if they find it too distressing to carry on with the study at that time. 4) If they experience any significant distress, they will be directed to sources of support. If it is deemed serious by the researcher, they will be asked for their consent to contact an appropriate form of support such as their GP. The researcher will make sure to check that the participants are not distressed or that they have access to support if they do seem distressed before they leave.	2	1	2		

Risk Scoring System

The most commonly used ***consequence / severity*** domain for health and safety risk assessments is the "Impact on the safety of staff, students and public" consequence domain of the Model Matrix as shown below. To calculate the risk both the ***consequence /***

severity and the ***likelihood of occurrence*** (as shown below) needs to be calculated for the health and safety hazard. In each case, the most likely outcome should be considered. If the most likely outcome of the consequence does not relate to the impact on the safety of staff, students and public, then a more appropriate domain included in the full Matrix should be used.

The scoring system is provided as a tool to help structure thinking about assessments and to provide a framework for identifying which are the most serious risks and why.

	Consequence / Severity score (severity levels) and examples of descriptors				
	1	**2**	**3**	**4**	**5**
Domains	**Negligible**	**Minor**	**Moderate**	**Major**	**Catastrophic**
Impact on the safety of staff, students or public (physical / psychological harm)	Minimal injury not requiring first aid or requiring no/minimal intervention or treatment. No time off work	Minor injury or illness, first aid treatment needed or requiring minor intervention. Requiring time off work for <3 days	Moderate injury requiring professional intervention Requiring time off work for 4-14 days RIDDOR / MHRA / agency reportable incident	Major injury leading to long-term incapacity/ disability (loss of limb) Requiring time off work for >14 days	Incident leading to death Multiple permanent injuries or irreversible health effects

Likelihood score	**1**	**2**	**3**	**4**	**5**
Frequency	**Rare**	**Unlikely**	**Possible**	**Likely**	**Almost certain**

Broad descriptor	This will probably never happen/occur	Do not expect it to happen/occur but it is possible it may do so	Might happen or occur occasionally	Will probably happen/occur but it is not a persisting issue	Will undoubtedly happen/occur, possibly frequently
Time-framed descriptor	Not expected to occur for years	Expected to occur at least annually	Expected to occur at least monthly	Expected to occur at least weekly	Expected to occur at least daily
Probability Will it happen or not?	<0.1 per cent	0.1–1 per cent	1.1–10 per cent	11–50 per cent	>50 per cent

The overall ***level of risk*** is then calculated by multiplying the two scores together.

Risk Level = Consequence_Severity x Likelihood (C x L)

	Likelihood				
Likelihood score	**1**	**2**	**3**	**4**	**5**
	Rare	**Unlikely**	**Possible**	**Likely**	**Almost certain**
5 Catastrophic	5	10	15	20	25
4 Major	4	8	12	16	20
3 Moderate	3	6	9	12	15

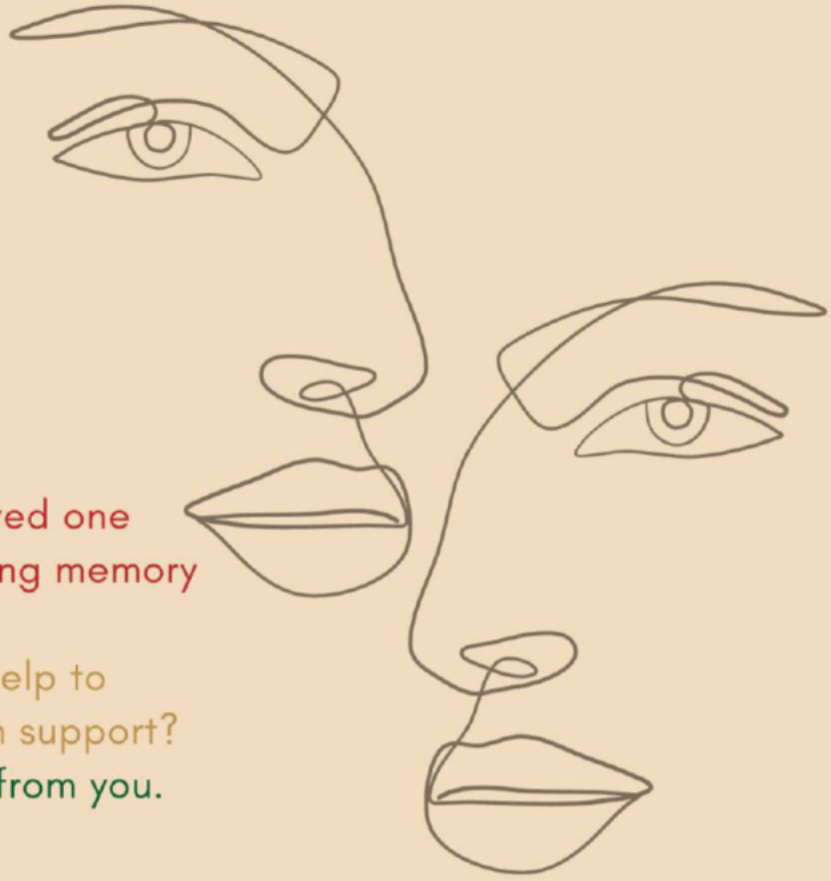
2 Minor	2	4	6	8	10
1 Negligible	1	2	3	4	5

The Initial Risk Rating is the level of risk before control measures have been applied or with current control measures in place. The Residual Risk is the level of risk after further control measures are put in place.

Appendix 7: Recruitment Documents - Posters

UNIVERSITY OF BIRMINGHAM

FAMILY MEMBERS EXPERIENCE OF HELP SEEKING WHEN A LOVED ONE OF AFRO-CARIBBEAN HERITAGE EXPERIENCES MEMORY LOSS



Do you have a loved one who is experiencing memory loss?

Are you seeking help to provide them with support?

We want to hear from you.

We are looking for adult family members who are supporting a loved one aged over 65 who is experiencing changes associated with memory loss, to help understand their experience of help seeking from a family members perspective.

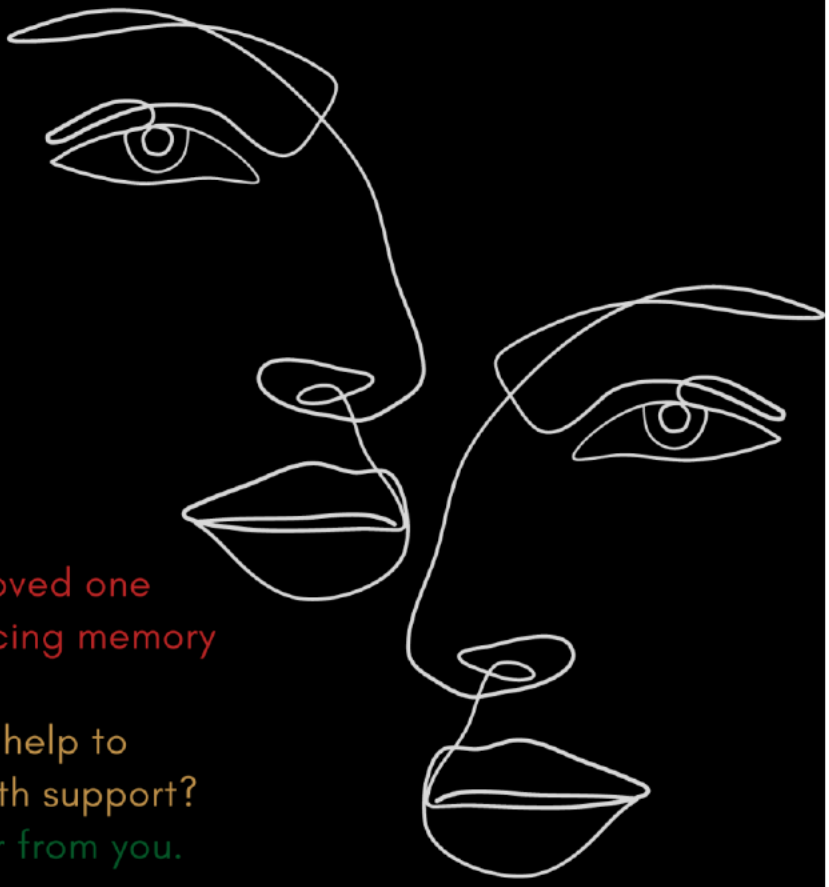
Many individuals from Afro-Caribbean populations choose not to approach services when experiencing memory loss, which can delay treatment and result in poorer outcomes.

Participants will be asked to engage in an interview about their experiences of help seeking lasting approximately 60-90 minutes.

For more information or to register your interest in this study, scan the QR code.

For more information, use contact details to get in touch or, Scan the QR code

FAMILY MEMBERS EXPERIENCES OF HELP SEEKING WHEN A LOVED ONE OF AFRO-CARIBBEAN HERITAGE EXPERIENCES MEMORY LOSS



Do you have a loved one who is experiencing memory loss?
Are you seeking help to provide them with support?
We want to hear from you.

We are looking for adult family members who are supporting a loved one aged over 65 who is experiencing changes associated with memory loss, to help understand their experience of help seeking from a family members perspective.
Many individuals from Afro-Caribbean populations choose not to approach services when experiencing memory loss, which can delay treatment and result in poorer outcomes.
Participants will be asked to engage in an interview about their experiences of help seeking lasting approximately 60-90 minutes.
For more information or to register your interest in this study, scan the QR code.

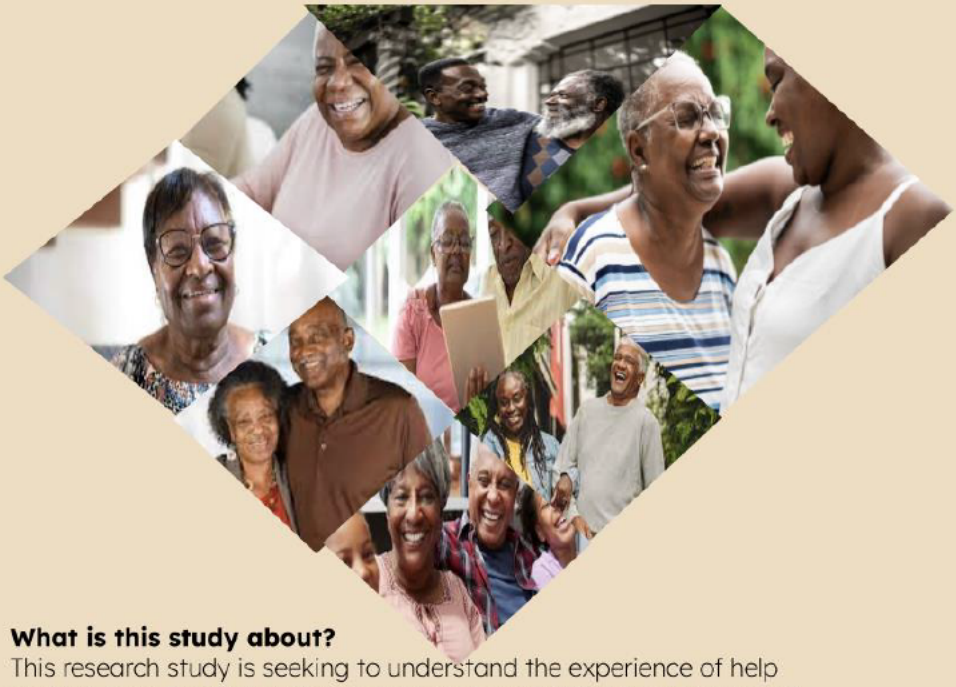
UNIVERSITY OF BIRMINGHAM

Melissa Brown
Trainee Clinical Psychologist

For more information and to apply to participate, Scan the QR code

Recruitment Documents – Information webpage when QR code is scanned

FAMILY MEMBERS EXPERIENCE OF HELP SEEKING WHEN A LOVED ONE OF AFRO CARIBBEAN HERITAGE EXPERIENCES MEMORY LOSS



What is this study about?

This research study is seeking to understand the experience of help seeking from family members who may be providing care or support to a loved one with Afro-Caribbean heritage who may be experiencing memory loss.

We are looking for:

Adults aged 16+ providing care and support for a loved one experiencing some of but not limited to difficulties with memory such as forgetting, misplacing items, becoming confused or getting lost.The loved one is not currently receiving professional help from a respite home or healthcare provider.

Why participate?

This research will help provide a unique insight into the journey families go on before seeking help or support from professional services. The study will help contribute to future research that will help provide those from afro-caribbean populations experiencing memory loss receive support or intervention sooner resulting in better treatment outcomes.

What will we be doing?

You will be interviewed to discuss your experiences of help seeking for your loved one who is experiencing difficulty associated with memory loss. This can include cognitive, functional, behavioural or personality changes. Interviews will last approximately 60-90 minutes and you will be compensated with a £20 shopping voucher as a token of gratitude.

Interested?

For more information or to schedule a study appointment, contact Melissa Holland Brown on [redacted] or email: [redacted].:

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Melissa Holland Brown
Trainee Clinical Psychologist
[redacted]

Appendix 8: Participant Study Documents

Participant Information Sheet



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Participant Information Sheet

Family experiences of help seeking when a loved one of African-Caribbean heritage experiences memory loss.

Thank you for your interest in the above research, before you decide to take part in this study it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully and discuss it with others if you wish. The contact details of the researchers can be found at the end of this document and you can discuss with them anything that is not clear or things you would like more information on. Finally, please take your time to read and ensure you fully understand this information before deciding whether you wish to take part.

What is the purpose of this study?

Current research shows that individuals from African-Caribbean populations have the highest incidence rate for dementia diagnosis and are also more likely to approach professional services for help and support in the advanced stages of the illness. Whilst we know that many individuals with memory loss symptoms tend to seek help and support from local community groups such as churches and day centres, little is known about the decision making process of where and when to seek help from made by the family members and what factors influence these decisions. The results of this study will help inform professional services of the unique challenges experienced within this group which will in turn offer recommendation for earlier intervention and support. It is anticipated this research will be completed by March 2025.

Why have I been asked to participate in this study?

You have identified yourself as having a family member from an Afro-Caribbean population and have observed changes to your loved one associated with memory loss. You may have been involved in the decision making around whether to seek support from professional or community services. This study is interested in understanding the decision making process that families consider when choosing to seek help.

Do I have to take part?

Your participation in the study is entirely voluntary and you have the right to withdraw from the study before analysis of the data is commenced.

Safeguarding Concerns

Whilst all the information you provide during your participation in this study, If any risk to the individual or family member is suspected, then safeguarding procedures will be observed by reporting this to the chief investigator and following safeguarding procedures.

What will happen to me and my data during the research?

Information with be gathered via interview which will take place either face to face or virtually, these will be recorded by Dictaphone so they can be transcribed by the researcher. Interviews will last approximately between 60-90 minutes, and you will be asked various questions about the changes you have observed and how these may have changed over time. You can choose whether you wish to complete the interview alone or with other family members who share the care with you.

Audio recordings will be listened to and transcribed by the researcher and each recording will be identified by a code known only to the researcher. All participants will be given pseudonyms to protect the identity of the individuals and data will not be used or made available for any purposes other than the research project. These recordings will be destroyed at the end of the study.

What are the possible risks or disadvantages to me taking part?

As you will being asked questions around a sensitive topic, you may find reflecting on these events distressing. If at any point this becomes distressing to you or your family, you can seek support from the researcher who is a trainee clinical psychologist who can pause the interview, provide support and signpost you to further support.

What are the possible benefits of taking part?

As individuals with dementia from an Afro-Caribbean population is a largely unresearched area, your participation in this study will help future research and clinical practice understand the unique experiences of these groups before seeking professional help. This will help provide more evidence to offer support and earlier intervention for treatment.

How will my information and data be kept confidential?

Data management and storage will be conducted in line with the University of Birmingham and NHS data protection policy and code of practice for research. Any information collected using participants recruited through the NHS may be required to be stored on NHS premises. As the lead researcher is an employee of the local trust they seek to recruit from, they will have access to collect, store and manage data securely which can only be accessed through the use of a personal smartcard which provides encrypted IT access and storage.

Participants information will be stored securely and not shared with anyone who is not directly involved in the study. Participants will each be given pseudonyms to anonymise their identities and the true identities will only be known by the lead researcher. All data obtained will be stored on an encrypted USB stick.

Data will be recorded using an encrypted Dictaphone and uploaded to an encrypted device, stored on a password protected computer. Once these have been listened to and transcribed,

they will be destroyed. Signed documents including consent forms will be uploaded electronically and stored on a securely encrypted device, and the hard copies will be destroyed using secure confidential waste disposal.

What will happen to the results of the research project?

As this study will be part of a University thesis all data obtained will be included as part of the results section which is expected to be published in March 2025. It is not anticipated that any data collected as part of this research will be used beyond this date and therefore will be destroyed. As per university policy, the thesis remains the property of the university and will be archived for 10 years after publication.

Who is organising the research?

This research project is being completed as part of my qualification for the Doctorate in Clinical Psychology at The University of Birmingham.

Who has granted ethical review for this study?

This project has been reviewed by The University of Birmingham's Psychology Research Ethics Committee and NHS Ethics Committee.

Who can I contact for further information?

Melissa Brown (Trainee Clinical Psychologist & Lead Researcher)

Dr Stephanie Howarth (Clinical Psychologist & Research Supervisor)

Dr Gerard Riley (Clinical Psychologist & Research Supervisor)

I have read and understood the information and I wish to still take part?

Great news, please contact the lead researcher who can provide you with the necessary consent forms and provide you with a timeline of how and when the research will be conducted.

Where can I go for further support?

Age UK

Age UK is a charity dedicated to providing advice and support for older people.
The charity helps older people achieve and maintain their independence and wellbeing.
Age UK can help with support services such as home help, foot care, dementia support, help with shopping and social activities.

Age UK Advice Line: 0800 678 1602

https://www.ageuk.org.uk

Alzheimer's Society

Alzheimer's society provides practical advice, information and emotional support for individuals and families affected by memory loss. They provide social and recreational programmes tailored to the needs of people living with dementia. Their aim is to help individuals socialise with others who understand what it is like to experience dementia.

Dementia Connect Support Line: 0333 150 3456
https://www.alzheimers.org.uk

Butterflies Memory Loss Support Group

Butterflies memory loss support group provide support to families and individuals affected by memory loss who may not have a formal diagnosis of dementia. They provide workshops for carers to help them to develop ways of coping and with the challenges they face.

Butterflies Memory Loss Support: 07821519212
https://www.butterflies.org.uk

Dementia UK

Dementia UK is a specialist dementia nurse charity, who provide support and care for families affected by all forms of dementia – including Alzheimer's disease. Admiral nurses help families manage complex needs, consider the person living with dementia and the people around them. They can also provide advice to other healthcare professionals.

Dementia Helpline: 0800 888 6678
https://www.dementiauk.org

Mind

Mind provide advice and support to empower anyone experiencing a mental health problem. Their website features information on different mental health presentations and they also have an information line which can provide signposting services on where to get local support, treatment options and advocacy services.

Mind Infoline: 0300 123 3393
https://www.mind.org.uk

Our Roots CIC

Our roots is a community interest company who engage in community development and promotion of mental health & wellbeing. They specialise in improving social integration and cohesion. Our roots provide services for counselling, emotional health and mental health.

Our Roots: 0121 439 9045
https://www.ourrootscic.com/about-our-roots-cic/



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Participant Consent Form

Family experiences of help seeking when a loved one of African-Caribbean heritage experiences memory loss.

I agree with the following statements	Yes	No
I confirm that I have read and understood the participant information sheet		
I have had the opportunity to ask questions and had them answered		
I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified		
I agree that data gathered in this study will be stored anonymously and securely and will be archived for 10 years following publication at The University of Birmingham		
I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason		
I agree to take part in this study		

Participants Signature:

…….

Participant Name (Print) and Date:

…….

Lead Researcher Signature:

…….

Lead Researcher Name (Print) and Date:

…….



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Participant Eligibility and Demographic Information

Family experiences of help seeking when a loved one of African-Caribbean heritage experiences memory loss.

Please complete the following information	
Age	
Sex	
Gender Identity	
Ethnic Background	
Religion	
Relationship to Individual	
Previous History of Mental Health Difficulties (Please give details)	

Participants Signature:

…….

Participant Name (Print) and Date:

…….

Lead Researcher Signature:

…….

Lead Researcher Name (Print) and Date:

…….



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Participant Debrief Sheet

Family experiences of help seeking when a loved one of African-Caribbean heritage experiences memory loss.

Thank you for your participation in this research.

This research aimed to explore family experiences of help seeking when a loved one of African Caribbean heritage experiences memory loss. These changes often experienced by the individual can include personality changes and challenging behaviours which can affect the relationships between family members.

Research has shown that those form African-Caribbean populations are less likely to seek help for memory difficulties from professional services and instead receive support from their family, local religious groups or day centres. This often leads to a delay in assessment and diagnosis, which then contributes to poorer treatment outcomes.

Without seeking professional help, care is usually provided in an unofficial capacity from family members who will face specific challenges by nature of the changes a person will experience as the difficulties progress.

This has been shown to have implications for the family who usually provide care to their loved one who may be unsure how or when to seek help from professional services. By interviewing yourself and others in this position, we hope to have gained a more in-depth understanding of how the symptoms and changes associated with memory loss are experienced over time and gain an understanding of what factors have influenced your decision to seek help. Research with a specific focus on African-Caribbean populations and their experience of help seeking is underrepresented, so we hope the results of this study will help to inform effective support for individuals and their families affected by memory loss.

Thank you for your participation in this research.

If you have any further questions or concerns, please contact a member of the research team:

Mrs Melissa Brown (Researcher)
[redacted]
Dr Stephanie Howarth (Chief Investigator & Research Supervisor)
[redacted]
Dr Gerard Riley (Research Supervisor)
[redacted]

UNIVERSITY OF BIRMINGHAM

Family experiences of help seeking when a loved one of African-Caribbean heritage experiences memory loss.

Support Services

Where can I go for further support?

Age UK

Age UK is a charity dedicated to providing advice and support for older people.
The charity helps older people achieve and maintain their independence and wellbeing.
Age UK can help with support services such as home help, foot care, dementia support, help with shopping and social activities.

Age UK Advice Line: 0800 678 1602
https://www.ageuk.org.uk

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Dementia Helpline: 0800 888 6678
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Mind

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Our Roots: 0121 439 9045
https://www.ourrootscic.com/about-our-roots-cic/

Who can I contact for further information?

Melissa Brown (Trainee Clinical Psychologist & Lead Researcher)
[redacted]

Dr Stephanie Howarth (Clinical Psychologist & Research Supervisor)
[redacted]

Dr Gerard Riley (Clinical Psychologist & Research Supervisor)
[redacted]

Appendix 9: University Data Management Plan

University's Data Management Plan

1. Overview
a. Researcher's Name: Ms Melissa Brown
Title of Research Project: **Family members experiences of help seeking when a loved one of African Caribbean heritage experiences memory loss**
b. Length of Project (incl. Start Date & End Date): September 2022 – March 2025
c. A brief statement of the aim(s) of the project: To explore family members experience of help seeking when a loved one experiences memory loss. What are the barriers to those from an African Caribbean community seeking help when a loved one experiences memory loss, what influences their decision to seek help or provide care at home.

2. About the Project Data
a. Briefly describe the data that you will collect for the project: Using semi structured interviews, participants will be interviewed either individually or jointly with their family carer if preferred. Asking open questions generated form the broader categories of: • Initial changes and reactions observed over time • What sense has been made of these experiences • Help seeking and professional input for support • Cultural understanding of memory loss This will provide a broad understanding of the symptoms they have observed and how this has influenced their decision to or not seek help
b. Frequency of new data (how often will you get new data and over what time period?): Data will be collected over a 6–12-month period and will be provided from up to 15 family members. Once this data has been collected, we do not anticipate to generate any new data once interviews have been completed.
c. What format is the data in? The data will be provided in the form of an audio recording which will then be transcribed using specialist transcribing software.
d. Could the data be considered high value and/or vulnerable (e.g., is your data likely to attract "hactivists"?)? How could this be mitigated? The data collected as part of this study, while personal to the participants, has no real world financial value. As such I anticipate low interest from external parties wishing to obtain this data. This being said, the data will be stored in encrypted fashion on a secure internal database held at the university.

3. Data Collection and Storage

a. What different versions of the data do you create (e.g., versions of data files)?

Data will be collected in audio format and then digitally transcribed. Both of the data files will be collected using an encrypted Dictaphone and securely stored on an encrypted USB stick and accessed using a password protected computer.

b. What additional information is necessary to understand the data (e.g., abbreviations, supplementary notes)?

Information providing a brief literary overview of dementia and prevalence rates in Black populations. It will also demonstrate the risk factors that make members of the African Caribbean community more vulnerable to the onset.

c. Where will the data be stored?

Any data collected on NHS sites will be securely stored in line with local trust policy in an NHS service. Data collected from charity or third-party organisations will be stored using an encrypted university database as per the data management and storage policy.

d. Describe the system to name and structure any electronic files.

Electronic files will be stored under pseudonym with no personally identifying data in the file name or filing system. All files will follow the same format to ensure consistency, including date of recording and pseudonym of person. Files will be named in date first followed by pseudonym followed by revision / data type.

Structurally, audio raw files and transcriptions will be stored in separate sub-folders in the project folder, with referential filenames to link relevant files.

Project -> Audio -> 20200324_AH mp3
Project -> Transcription -> 20200324_AH.docx

e. Describe the regime for backing up the data.

All original data will be collected and securely stored using encrypted USB stick, this will then be backed up onto secure university servers.

f. Describe the procedure to be used to ensure files can be restored from the backups.

Any data files that have been backed up on the university database will be encrypted and stored securely. If data needs to be restored, then they can be accessed via the university and transferred to the encrypted USB stick.

4. Data Availability to Others

a. Who owns the data?

As this is a university thesis, the data remains the property of the university.

b. Are there restrictions on who can use the data, and if so, what are they?

As the University stores thesis projects for 10 years, the project could be requested via application through the university library. The application would have to prove relevance and use in order to be approved. Raw data would not be included, as it will be deleted when the project is completed. Only final analysis would be included as part of final thesis publication.

c. If the data can be made openly available, at what point can this happen?

Raw data will not be made available as it will be erased once analysis has been completed.

5. Archiving (preserving the data for future use)

a. What data should be kept beyond the end of the project?

No data is required to be kept beyond the end of the project. All raw data files will be destroyed after the project is completed.

b. How long should it be kept?

Not applicable.

c. Where will the data be archived?

Not applicable.

d. Who will create and maintain the archive of data?

Not applicable.

e. Are there restrictions on who can access the archived data?

Not applicable.

f. What are the likely (estimated) costs of preserving the data?

Not applicable.

6. Implementing this Plan

a. Name of person responsible for implementing this plan:
Melissa Brown (Trainee Clinical Psychologist) supervised by Dr Stephanie Howarth (Clinical Psychologist) and Dr Gerald Riley (Clinical Psychologist)

b. Frequency of review and/or updates of this plan:
This plan will be reviewed and updated where necessary during research supervision which takes place approximately every 4 weeks.

c. Actions required in order to implement this plan:

No actions are needed at the present time.

d. List any further information needed to carry out the actions above:

Not applicable.

Notes:

Appendix 10: Interview Schedule

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Family experiences of help seeking when a loved one of Afro-Caribbean heritage experiences memory loss.

Interview schedule

General questions will be asked of all participants. Prompts will be used only if needed to help the person think about, and elaborate on, their answer.

We know that memory loss can have a significant impact on all areas of life for both the individual and those around them. Today I will be asking questions relating to your loved one's experience of memory loss, what sense you as a family have made of these experiences and what you have done to seek help.

The first topic we will discuss is memory loss and your understanding of when you first noticed any changes in [name of person with memory loss]:

Topic: Memory loss

- General question - when did you become aware that [name of person with memory loss] was experiencing problems with their memory?
- General question - what kind of things do they forget? Prompts - forgetting names, faces, getting lost, items (keys, phone, glasses, walking aids, handbag), conversations.
- General question - Does [name of person with memory loss] acknowledge that they do have memory problems?
- General question – Do you, or [name of person with memory loss], have an idea what was causing the memory problems? Prompt – did the memory problems coincide with something else going on at the time? Do you think it is a 'normal' part of ageing?

Compassionate statement: *"Thank you for sharing, that must have been a difficult time for you and your family, are you ok for us to continue? (If yes) I will be asking you about*

[name of person with memory loss] reaction to the memory loss (If no – offer to take a break).

Topic: Family member's reaction to the memory loss

If they do acknowledge that there is a problem:

"So it appears that [name of person with memory loss] has shown some insight into their current difficulties"

- General question - How has [name of person with memory loss] reacted to having these problems? Prompts - what has been their emotional response? how have they coped? Do they do anything to get round the problem?
- General question - What sense do they make of the problem - what do they think is causing the problem?

If they don't acknowledge:

So it appears that [name of person with memory loss] *has shown some difficulty with accepting these recent changes"*

- General question: Have you discussed it with them or suggested there is a problem? If so, how has your loved one reacted to this?
- General question: What is your understanding of why they don't accept there is a problem? Prompt – Denial, Cultural undertraining of memory loss

Compassionate statement: *"I understand how hard this must have been for you and your family, I just want to check in and make sure that you are ok"*

Topic: Participant's own reactions to the memory loss:

- General question – What is your understanding of why [name of person with memory loss]is having this problem?
  Prompts – ageing process, genetics, injury. cultural – spiritual possession, curse, religious reasoning, change in geographical location, diet, educational level, acculturation.
- General question – how do you feel about [name of person with memory loss] having this problem?
- General question – how have you tried to manage the problem, what practical steps have you taken for dealing with it? Prompts – Talking to religious authority figures, seeking help from services.

- General question – Have you had to make any adaptations to your daily routine? Prompts – Preparing things in advance, changing living arrangements, accompanying loved one to attend appointments / shopping.

Compassionate statement: *"Thank you for sharing these personal accounts with me, it must be difficult for you to reflect on these experiences, but you are doing really well"*

In the next section we will be discussing help seeking. Sometimes individuals from a minoritized background can experience stigma and shame which makes them reluctant to seek help from professional services. I would like to gain an understanding of how or where you may have sought help for [name of person with memory loss] in relation to their memory loss.

Topic: Help-seeking

- General question – Has [name of person with memory loss] been to the GP (or health or social services) to discuss the problem?
- General question – What has been your experience with the help seeking process? Prompts – easy to access, clear approach to treatment, sufficient information.
- General question – What were the barriers (if any) you experienced when seeking help? Prompts – not knowing where to go / who to speak to, lack of compassion, personal barriers (shame, stigma, guilt), cultural barriers (language, access, location, interpretation)
- General question – Have you or [name of person with memory loss] tried to get other kinds of outside help in dealing with this? If yes, what other sorts of help? Prompts – other people, looking things up online, seeking help from religious groups, attending community day centres.

If yes to first question:

- General question – How was this decision about getting outside help made? Prompts – Who was involved? Was it a whole family decision or a decision made by the family member themselves? Was there disagreement in the family about getting this help?
- General question – Why was this decision taken? Prompts – relate this back to answers about the understanding of why the memory loss is happening.
- General question – How culturally informed was the advice given? Prompt – GP sharing advice in a culturally informed way? Information was understood by the family member, Cultural explanations were considered.

If no to first question:

- General question - Was there a definite decision not to ask for help?

  If yes:

  - How was this decision about getting outside help made? Prompts – Who was

involved? Was it a whole family decision or a decision made by the family member themselves? Was there disagreement in the family about getting this help?

- Why was this decision taken? Prompts – relate this back to answers about the understanding of why the memory loss is happening.

If no:

- Might [name of person with memory loss]at some point go to the GP for help? If yes, what is the reason for holding back? If no, what is the reason for this? Prompts – relate this back to answers about the understanding of why the memory loss is happening.

"Being from an Afro-Caribbean background may mean that you have an alternative way of how you make sense of these memory difficulties"

Topic: Cultural Understanding

General Question – Does your family hold any specific cultural beliefs around memory loss? Prompt – religious explanations, spiritual possession, karma, witchcraft.

If yes:

- What is your understanding of how this may relate to [name of person with memory loss]?
- How would this be traditionally treated? Prompts – Religious intervention (prayer, spiritual intercession, exorcism), Isolation.

If no:

- What is your understanding of what is happening to [name of person with memory loss]?

Does having Afro-Caribbean heritage influence your understanding of what is happening?

If yes:

- Where did these beliefs develop from? Prompts – Tradition, family, societal influence.
- How has this shaped your motivation to seek help? Prompts – More informed on who to contact, better understanding of how to treat.

Sometimes people don't trust doctors and medical services, sometimes people don't trust the government what are your thoughts around that

Research has shown that within ethnic minority populations, there was a hesitancy to accept the covid-19 vaccination during the pandemic. Most research focuses on previous history of medical mistrust and a lack of trust in the government and cites this as a reason for not approaching professional services.

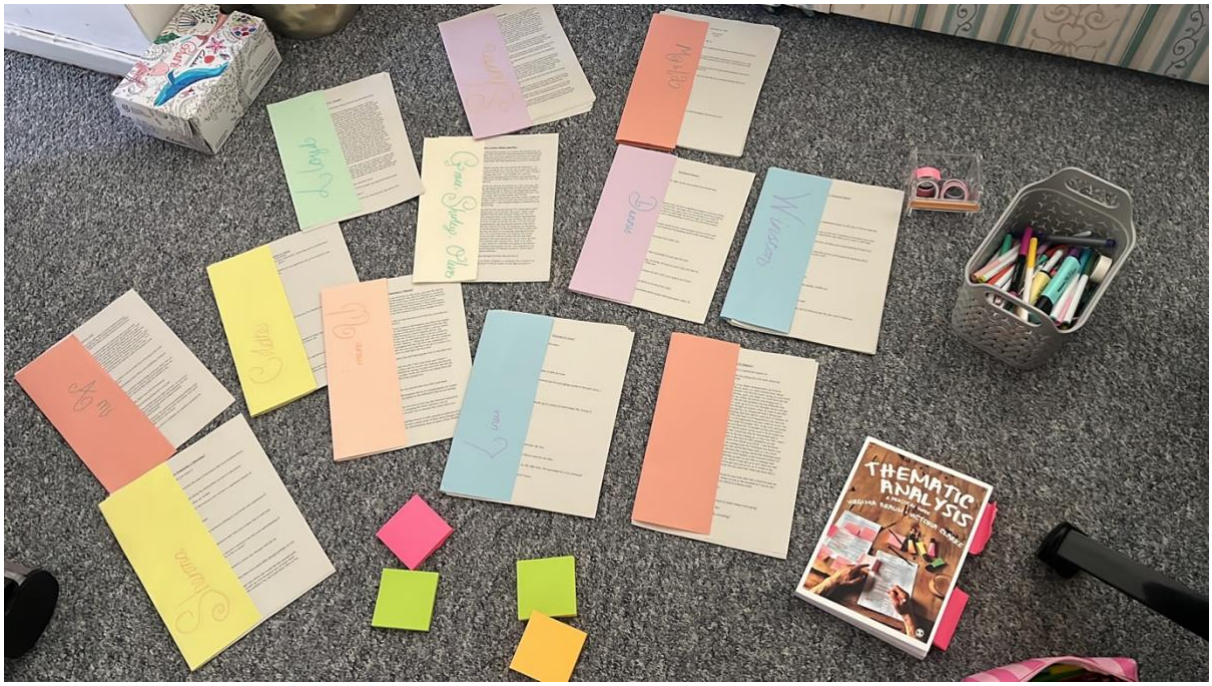
General Question: How far would you agree with this statement? And how far if any did it influence your experience of help seeking?

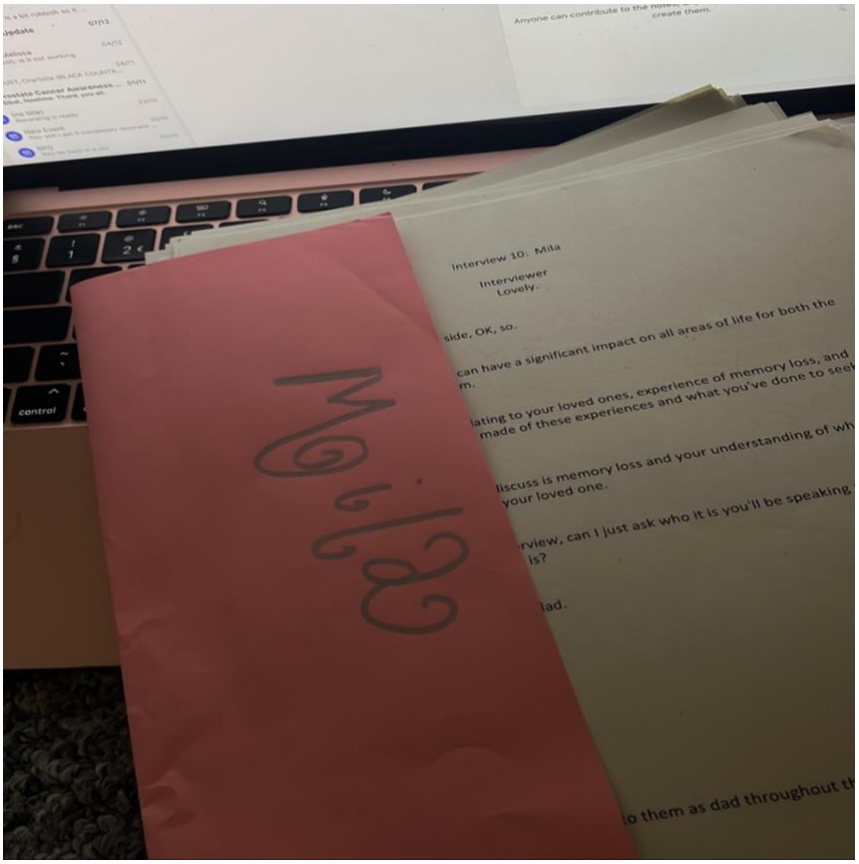
If no:

Compassionate ending: "Thank you for taking the time to meet with me today and answer my questions. This will be really helpful for us to get a better understanding as to why people from an Afro-Caribbean background choose to seek help from services in England, so we can think about how we can support better access for people from this ethnic group. Do you have any questions? Do you feel you need any support?"

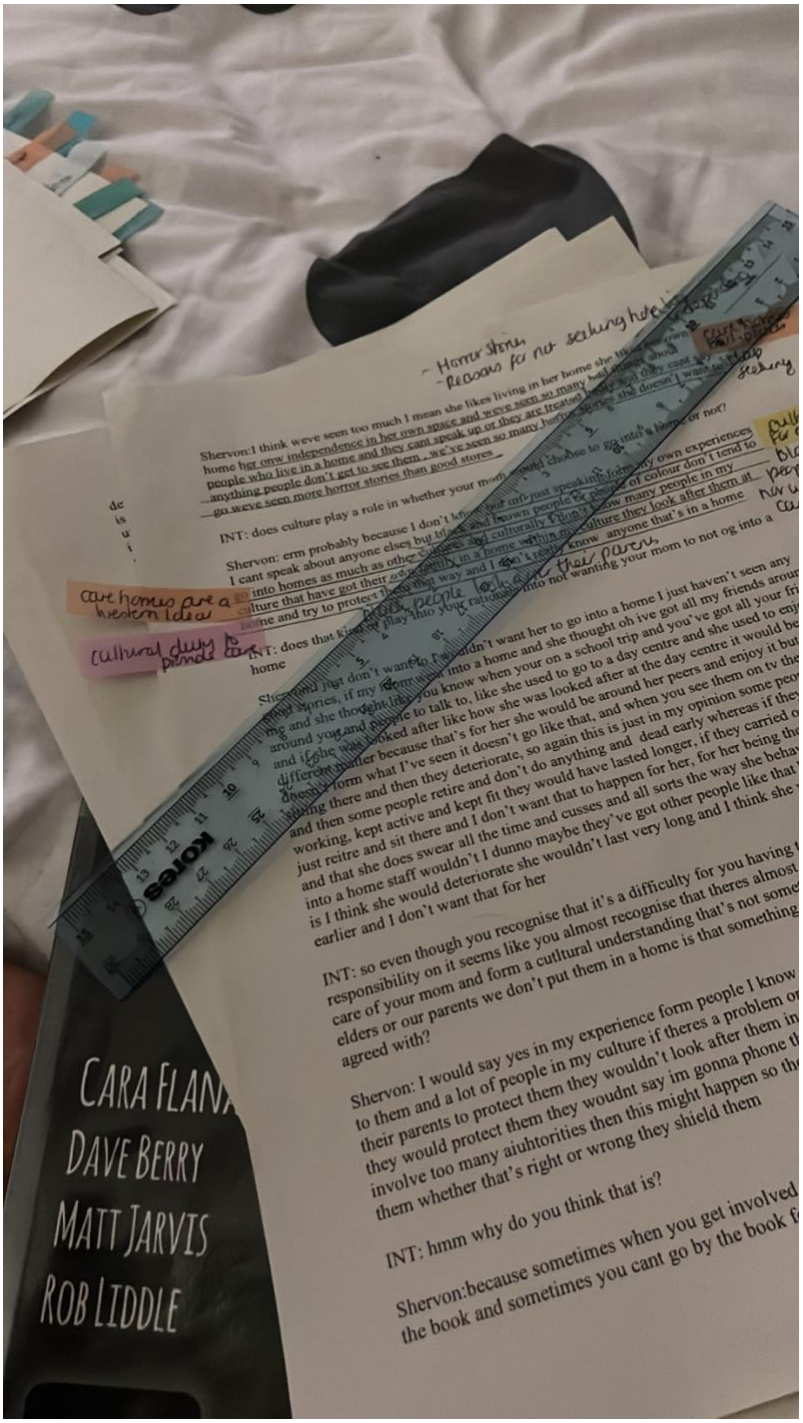
Appendix 11: Examples of Reflexive Thematic Process

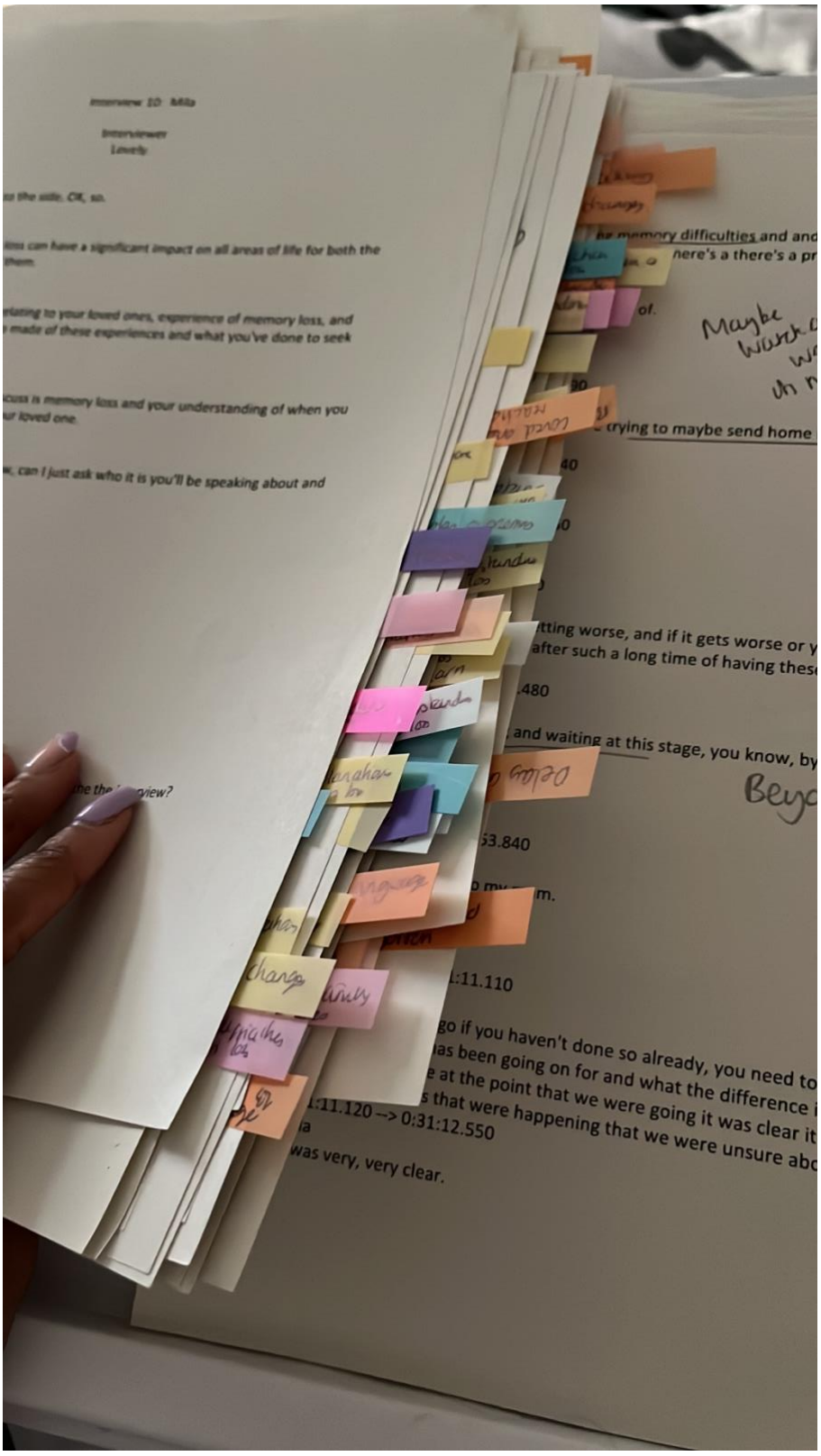
Phase One: Familiarising yourself with the dataset



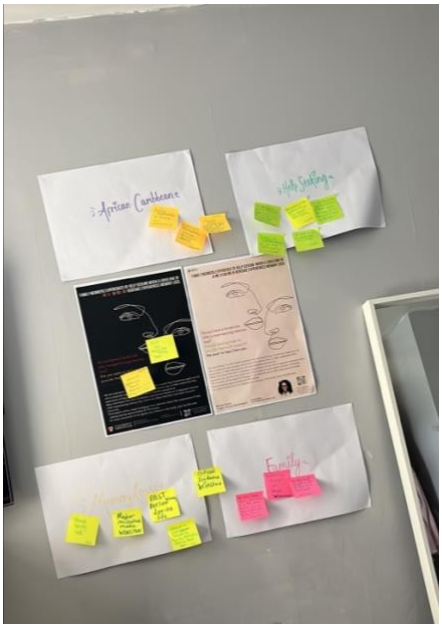


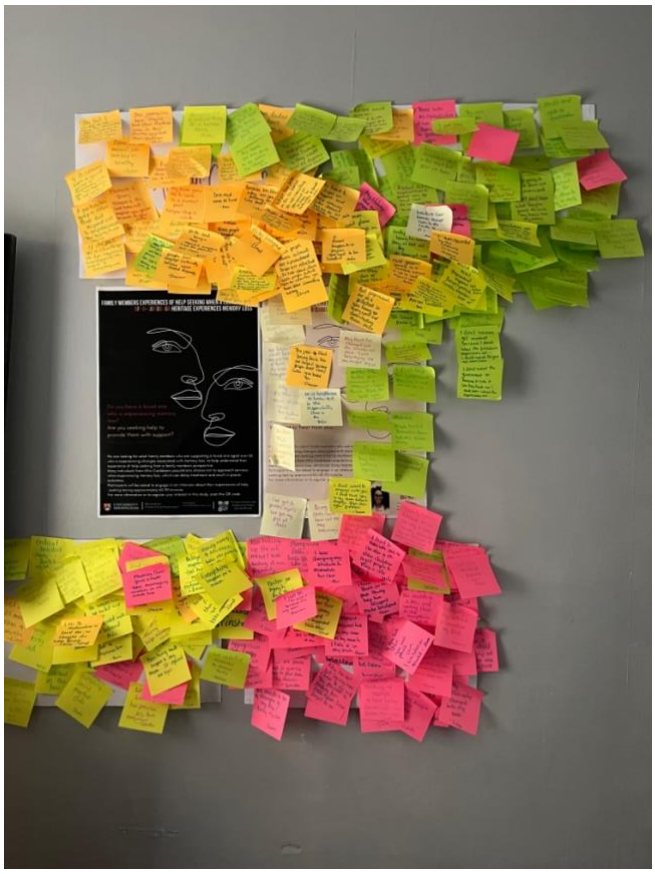
Phase Two: Coding




Interviewer 10 Mila
Interviewer
Lovely
to the side. OK, so.
loss can have a significant impact on all areas of life for both the
them.
relating to your loved ones, experience of memory loss, and
made of these experiences and what you've done to seek
cuss is memory loss and your understanding of when you
ur loved one.
, can I just ask who it is you'll be speaking about and
the interview?
memory difficulties and and
here's a there's a pr
of.
Maybe
crying to maybe send home
40
tting worse, and if it gets worse or y
after such a long time of having thes
480
and waiting at this stage, you know, by
Beyo
53.840
m.
:11.110
go if you haven't done so already, you need to
as been going on for and what the difference i
e at the point that we were going it was clear it
s that were happening that we were unsure abo
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was very, very clear.

Phase Three: Generating initial themes





Phase Four: Developing and Reviewing Themes

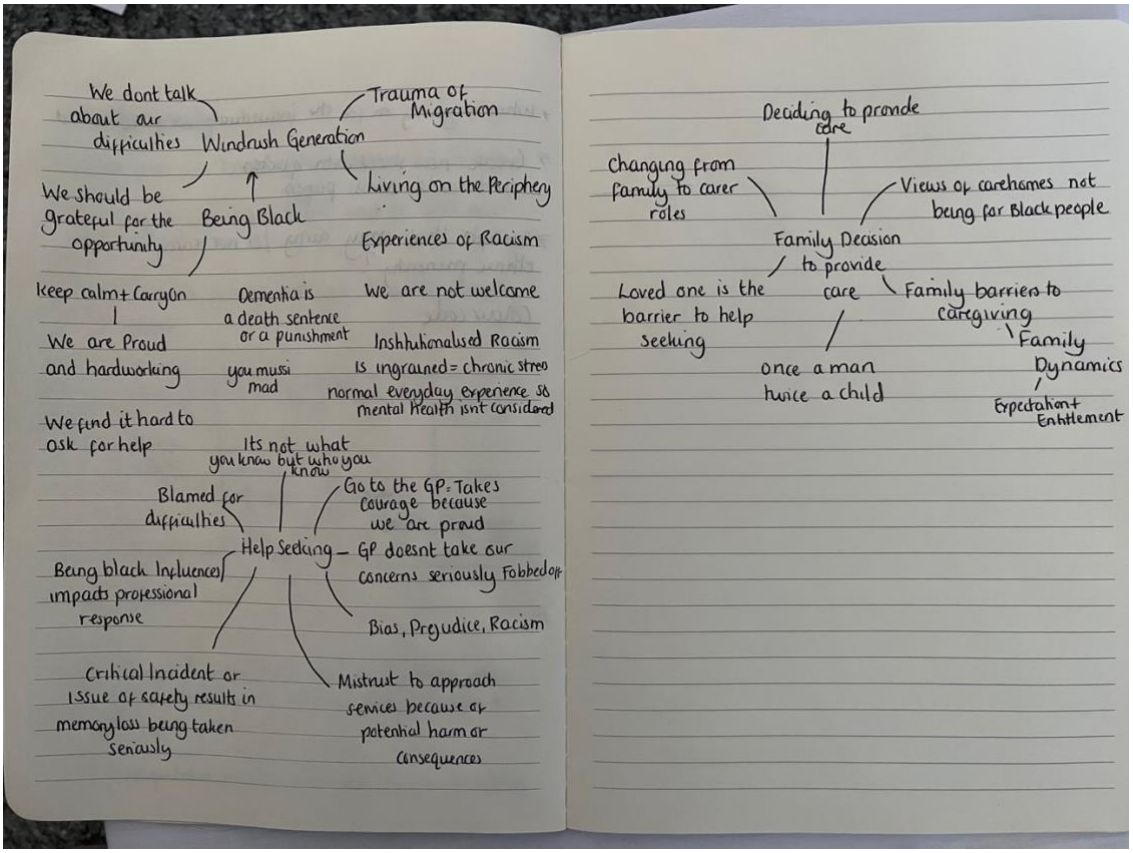




Phase Five: Refining, defining and naming themes



Phase Six: Writing Up



Appendix 12: Member Checking Results and Questions

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Family experiences of help seeking when a loved one of African-Caribbean heritage experiences memory loss.

A total of fourteen Participants were selected for interview. Eleven participants interviewed as individuals, and three interviewed as a family consisting of two siblings and a spouse. This included male (*n=5*) and female participants (*n=9*) where the majority were a child of the loved one, they provided care for. Twelve participants identified as being of African Caribbean heritage and two identified as being of mixed white & African-Caribbean heritage. Seven interviews were conducted face to face and five were completed online. Analysis Resulted in Five Major Themes: (1) The Windrush generation, (2) Lack of Cultural acknowledgement of Dementia, (3) Stigma and Shame, (4) Keeping it within the family and (5) Racism and Mistrust of Services.

Theme 1: The Windrush Generation

Keep quiet and carry on

The experiences of this generation (who are the ones now developing dementia) taught them to deal quietly and determinedly with adversity, to keep a low profile, and not to be assertive about their own needs. This is evident in the report of some of the participants that their parents didn't share with them how difficult it was for them coming to the UK and dealing with what they had to deal with.

> *"She's Jamaican born you know they've had their challenges, they've come to this country and had more challenges so that fighting strong willed thing is there you know"*

If they are experiencing memory and other difficulties, their response would tend towards carrying on, not making a fuss, and not bringing it to the attention of other people or to services.

Outsiders:

Being shunned by White society in the UK also created a feeling that services were for White people and not for them – again contributing to a reluctance to engage with services.

> *" they have lived a life on the periphery and I think that has shaped and forged their decisions in that they think 'its not for me' or 'I am not included' and I think its from a culture of when mainstream things were not for them, or [they were] actively being curtailed in their aspirations in needing or wanting to be in places but those places not being receptive"*

Theme 2: Lack of cultural acknowledgement of dementia

Lack of knowledge and appreciation of dementia as an issue within Caribbean culture. Normal forgetfulness seen as an accompaniment of old age, but severe memory problems or other symptoms are attributed to 'madness'. This lack of cultural identification of the issue, and the lack of a culturally specified response when the issue is identified, may mean that it is less clear what is happening, and less clear what should be done about it – meaning they may be less likely to go down the route of seeking help from others or services.

"Its just the culture in general, they don't handle mental health or anything like that very well you know it never has…from a Jamaican perspective they don't deal with any type of mental health or accept it as well as a culture in general"

Theme 3 Stigma and shame:

Identification of dementia with madness also brings with it the stigma associated with madness, and a reluctance to admit to difficulties because of the shame of being perceived by others as mad. Another cultural aspect that can contribute to stigma is the belief that going mad is punishment for some bad that the person has done earlier in their life. Stigma and shame may lead people to deny that they have any problems, to be reluctant to seek help, and, if they do end up with an appointment in services, making every effort to minimise their difficulties.

"Memory problems either means related to age but if you start presenting with other types of symptoms like Alzheimer's then its more like your mad"

Theme 4 Keeping it within the family:

Cultural and family pressure (in particular oldest girl) in the family to provide any care that's needed, and to keep the person at home – rather than going into care. Family pressures or expectations around keeping the loved one at home led to providing care becoming an expectation or entitlement from the loved one or within the culture.

"I think because of his age as well he can be quite sexist and I think from my point of view if me and my sister were boys it would be different but I think because were girls its an expectation that you're a girl so you should provide care"

Theme 5 Racism and Mistrust of services:

Experience of racism within services, and the general historical mistreatment of Black communities, leads to a lack of trust in services. This leads to concerns that they will get a second-rate service, that information they provide will be misused, that they may get racially abused within care homes – all of which makes them reluctant to engage with services. Another aspect of this is their experience or perception that services are set up for White people and lack cultural sensitivity.

"They just generally are not understanding for example my dad saying my foots hotting me, to another [white] professional they wouldn't understand what hes on about or where the pain was, you have to understand how they [elders] are explaining things do you know what I mean? Unless theres someone from an African Caribbean background working there then they wouldn't have a clue"

Thank you for taking the time to read through the initial results. The results capture the views represented in the entire dataset so there may be material or concepts that do not align with your personal experience, that is okay, this is what emerged from the data as a pattern that was represented amongst different participants. If you have any further comments or feedback or would like further elaboration on any of the themes please do let me know.

If you could consider the following questions and return via email at

Results Checking Questions
After reading through the findings, what are your general thoughts?
How accurately do you feel the findings captured your thoughts / experiences?
What could be added to the findings to capture your experiences better?
If there is anything you would like removed, what would that be and why?

Member Checking Feedback

Member Checking Question	Participant Feedback
After reading through the findings, what are your general thoughts?	*"After reading through the findings, I completely agree with the findings, although our father did explain the difficulties he faced with racism when he came to this country, he gave a few examples but not in great detail. I remember him talking about a racist politician called Enoch Powell whom wanted all black people to return to their home country. Also they were given jobs that most white people were not prepared to do. Racist social clubs that did not allow black people in. He & my mother experienced racism being in a mixed marriage. When they went to purchase their first house my dad said my mom went alone as if he had gone to view the house together, they would not have sold it to them. These are a few of my memories"* *"I have read the document that you have sent through and found it to be very interesting. There were parts and references that at the moment don't reflect my situation, however possibly sometime in the future it will have an impact."* *"We agree / do agree with views and experiences presented."* *"My general thoughts are that these themes capture the experience very well, I am glad to see research being carried out in such an important area, that is currently under researched for the Black community".*
How accurately do you feel the findings captured your thoughts / experiences?	*"I feel the findings are accurate in my thoughts and feelings. Especially in regard to dementia/ mental health as there is a huge stigma in Afro Caribbean culture towards this and seen as very shameful"* *"I don't feel confident in nursing homes etc that they can provide holistic care properly for Afro Caribbean patients in terms of food, understanding the language and general care with hair, skin etc, music, culture & history. I do agree we do not seek or access services due to the above & feel obliged to care for our parents due to this. Unfortunately, whilst caring for our parents we get very little*

	support either and certainly not financially which has a big impact on your own family and mental health" *"The only real comment that I feel relevant, and you may have captured within the wider assessment is that feel the younger generation don't have the same thought process as the elders. The cultural and family pressure (keeping it within the family) comes mainly from the elders, (aunts, uncles etc) in my experience. This could be as the youngsters haven't been bought up in the Caribbean and they are/have been aware of care homes as a norm for the elderly. Its practical once caring for adult becomes detrimental to your/their health that this facility is available, and they would find it quite easy to place the family member one of them."* *"We agree the findings were true to the experiences remembered by our parents generation."* *"It was fully captured, especially Themes 1, 2, and 5. This notion of keeping calm and carrying on acts as a major barrier to seeking help/seeking help at an early stage"*
What could be added to the findings to capture your experiences better?	*"Nothing more to add"* *"Reading through the sample of results presented I think it captures the experience very well and have nothing further to add"*
If there is anything you would like removed, what would that be and why?	*"There is nothing I would like removed from the findings and think you have done an amazing job highlighting the issues"* *Nothing to be removed"*

Appendix 13: Excerpt from Reflexive Diary

Interviews week 1

This week I conducted my first interviews, I have so far interviewed 4 people ranging in age from 36-72.
I was struck by the similarities that were found across each participant and began to notice that in each of them there was a shared experience of loyalty to their loved one and that despite the hardship and inconvenience caregiving sometimes came with, placing their loved one into care was not an option.

It was also apparent that for the family members a sense of making sense was also missing and almost a desperation to get information regarding their loved one from professionals.

There was also a shared sense that the memory loss was 'self inflicted' based on earlier life choices and decisions. This also seemed to potentially play a part in the amount of support or signposting that was recieved.

This chimed with my own reflections and experience of helpseeking and care giving when my mom cared for her parents. My mom would often be frustrated at the expectation and entitlement of her parents to provide care but her sense of "duty" seemed to outweigh this.

Another thing that resonated with me which led to the question of "why did this role fall to you?" - was how in the unofficial acceptance of the role this led to familial conflict within the family unit and tension between siblings on what they thought should be the best way to care for their loved one.

This was something that resonated with my experience as I recall this responsibility falling to my mom and the conflict it caused in the wider family