When Risk and Crisis Collide: An Intersectional Risk Theory Lens on the Lives of Older Minority Ethnic People in the UK During COVID and its Aftermath

By

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ABSTRACT

This study explores the experiences of older minority ethnic people in the UK during and after the COVID-19 pandemic, drawing on focus groups and interviews. Using intersectional risk theory, I examined how multiple identities - age, ethnicity, gender, class, disability, comorbidities - shaped participants' experiences differently. What emerged was a complex picture of epistemic mistrust. Participants questioned government messaging not from conspiracy thinking, but from lived experience of being overlooked by systems meant to protect them. Death and bereavement took on particular meaning when filtered through intersecting identities. The pandemic hastened decline and produced multiple losses, yet participants found strength in religious worldviews and collective traditions. Living in multigenerational households proved both protective and risky, offering care networks while increasing exposure. Resilience emerged as central, but not in the way policy makers typically understand it. Rather than individual grit, participants demonstrated collective coping rooted in cultural values and community bonds. However, this community-generated resilience had limits. Without institutional support, it became insufficient against structural disadvantages. The findings challenge assumptions about "hard to reach" communities. Participants made rational choices based on their lived contexts and historical experiences with healthcare systems. Their apparent "non-compliance" often reflected deeper systemic failures rather than personal shortcomings. This research argues that sustainable health equity requires more than targeting individual behaviours. Structural interventions must support and amplify existing community resilience while addressing the root causes of health inequalities. As we prepare for future uncertainties, centring the voices and experiences of those most marginalised offers crucial insights for building more equitable responses. The study demonstrates how researcher positionality and "safe spaces" can elicit hidden stories that traditional research approaches miss.

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I would like to dedicate this thesis to my late dad, Michael Makande, who has always believed in me.

for baba, papa, dad!

She believed she could, so she did!

AUTHOR'S DECLARATION

I declare that this thesis and the work presented in it are my own and have been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University.
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated.
3. Where I have consulted the published work of others, this is always clearly attributed.
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work.
5. Where elements of this work have been published or submitted for publication prior to submission, this is identified and references given at the end of the thesis.
6. This thesis has been prepared in accordance with the Staffordshire University and Buckinghamshire New University regulations.
7. I confirm that if the submission is based upon work that has been sponsored or supported by an agency or organisation that I have fulfilled any right of review or other obligations required by such contract or agreement.

Bridget Makande

GLOSSARY OF ACRONYMS

BAME : Black, Asian and Minority Ethnic

CAQDAS: Computer-Assisted Qualitative Data Analysis Software

COVID-19: Coronavirus Disease 2019

FGD: Focus Group Discussions

GP: General Practitioner

HIV/AIDS: Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome

IGF: Intersectional Grief Framework

IRT: Intersectional Risk Theory

NHS: National Health Service

OHRC: Ontario Human Rights Commission

ONS: Office for National Statistics

PhD: Doctor of Philosophy

PHE: Public Health England

QoL: Quality of Life

RTA: Reflexive Thematic Analysis

SAGE: Scientific Advisory Group for Emergencies

SAR: Social Amplification of Risk

SARS: Severe Acute Respiratory Syndrome

SDoH: Social Determinants of Health

TMT: Terror Management Theory

UK: United Kingdom

UN: United Nations

WHO: World Health Organisation

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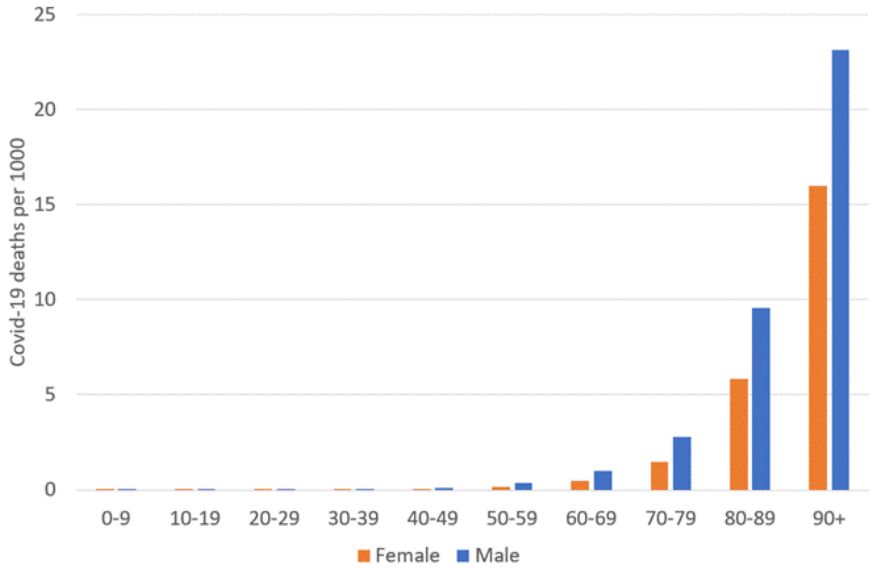
INTRODUCTION

This research seeks to explore the lived experiences of older people of minority ethnic backgrounds in the United Kingdom (UK) during the COVID-19 pandemic and its aftermath. The advent of COVID-19, caused by novel coronavirus 2 (SARS CoV-2) rapidly evolved into a pandemic with global impact (Cucinotta and Vanelli, 2020). It highlighted the cumulative risks of COVID-19 and made its discriminatory impact visible through the higher death toll of people with older age, ethnic minorities, male, comorbidities and poverty (Khunti et al. 2020). COVID-19 was both an emblem and amplifier of social and healthcare inequalities (Lupton, 2022; British Medical Association [BMA], 2024). While racism and discrimination are key factors, other risks also exacerbate inequalities. These include nutrition habits, smoking, harmful alcohol use, obesity, physical inactivity, and cultural lifestyles (McGowan and Bambra, 2022; Khunti et al. 2020). As highlighted by Public Health England (PHE)(2020), these are risk factors for many diseases (cardiovascular, cancers, diabetes, respiratory) which can worsen COVID-19 outcomes. Health inequalities cut across society and are not confined to minority ethnic groups. Health also follows a social gradient and COVID-19 also disproportionately impacted the physical and mental wellbeing of minority ethnic communities (Van Bortel et al. 2022).

The two graphs below from the Office of National Statistics (ONS) (2020) and National Institute For Health Research (2020) confirm higher COVID-19 mortality among those aged 65+ and among minority ethnic groups, reflecting overlapping vulnerabilities.

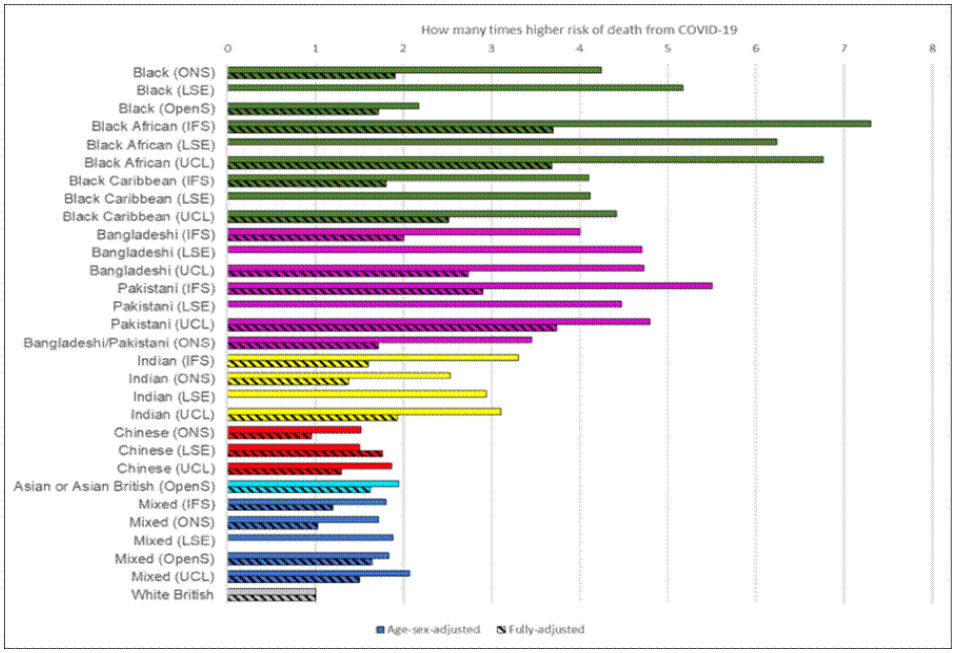
Graph 1: The number of deaths from coronavirus per age group for each 1000 people in the UK in 2020.



Source: ONS (9 June 2020)

As shown in graph 1 above, the UK Office for National Statistics (ONS, 2020) reported that in 2020 the COVID-19 mortality rate in England and Wales at ages 80 to 84 years was 6,5 times higher than at ages 65 to 69 years, and 57 times higher than at ages under 65 years. As for death inequalities per ethnicity, University College London Global Health's (2020) research established that minority ethnic groups had 2 to 3 times higher death risks as compared to the general population (Aldridge et al. 2020). For those who went into critical care, there was approximately 50% COVID-19 mortality rate for minority ethnic patients compared to 44% white patients (Khawaja et al. 2020), which pointed towards the interplay of ethnic minorities' overlapping disadvantages. Graph 2 below demonstrates the heightened risk of death that minority ethnic communities faced in comparison to white British people in general.

Graph 2 :Heightened risk of death that minority ethnic communities faced in comparison to white British people



Graph 2: This graph is based on 5 primary research studies as of 20/05/2020.

Source: National Institute for Health Research (NIHR, 2020).

Aim and objectives of the research

This study seeks to explore the lived experiences of older minority ethnic people in the UK during the COVID-19 pandemic and its aftermath. The aim of the study will be achieved through the following objectives:

- Using an intersectional risk approach, explore the lived experiences of older minority ethnic communities in the UK during COVID-19 and its aftermath, and contextualise the challenges the pandemic presented on them.
- To establish the specific health needs and the modifiable behavioural risk factors of older minority ethnic communities during the pandemic and its aftermath, while demonstrating the importance of taking into account appropriate intersectional approaches and being sensitive to the

social gradient (The Organisation for Economic Co-operation and Development (OECD), 2023).

- To identify and examine the older minority ethnic communities' coping and resilience strategies during the pandemic and its aftermath.
- To boost pandemic preparedness and through adopting a bottom-up approach and forge the formulation of tailored policy recommendations regarding future pandemic mitigation and support for older minority ethnic people.

Significance of the Study

COVID-19 is caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), which first emerged in December 2019, with the earliest known human cases identified in Wuhan, Hubei Province, China (Roberts, Rossman, and Jarić, 2021). The COVID-19 pandemic represented an unprecedented public health crisis that exposed and intensified existing social and health inequalities within the UK. Although previous pandemics, including the influenza pandemics of 1918–1920, 1957–1958, and 1968–1969, resulted in substantial mortality, COVID-19 was unique in the extent to which it transformed everyday life (Lupton, 2022). WHO (2022) estimated that approximately between 2020 and 2021 14, 9 million people died from COVID-19 worldwide. Transformations were experienced through prolonged lockdowns, social distancing measures, shielding, self-isolation requirements, travel restrictions, and the closure of workplaces, places of worship, community centres, and social spaces (Lupton, 2022). For many people in the UK, the pandemic constituted the most significant public health emergency experienced during their lifetime, affecting physical health, social relationships, access to services, and community participation.

Existing evidence demonstrates that older adults and minority ethnic populations experienced disproportionately adverse outcomes during the pandemic, including higher risks of infection, hospitalisation, mortality, social isolation, and disruptions to healthcare access. Individuals positioned at the intersection of older age and minority ethnic status were therefore likely to face unique and compounded challenges. However, despite the rapid growth of COVID-19 research, older minority ethnic people

have remained relatively invisible within the evidence base. Much of the existing research has tended to focus on age or ethnicity as separate categories of analysis, rather than examining how these identities intersect to shape experiences and outcomes (Paudyal et al., 2022; Hewitt and Kapadia, 2021). Consequently, the lived experiences of older minority ethnic people remain underrepresented in both COVID-19 research and wider sociological scholarship.

Although the severity of the pandemic reduced following the development and widespread uptake of vaccinations (WHO, 2024), its consequences continue to be felt. Excess mortality remains a significant concern, particularly among older people (Alicandro et al. 2023). These deaths are attributable not only to the direct effects of COVID-19 infection but also to indirect consequences, including pressures on the National Health Service (NHS), delayed diagnoses, disrupted treatment pathways, and challenges in the management of chronic conditions (Dale et al. 2023). This is especially important given the higher prevalence of conditions such as cardiovascular and respiratory diseases, diabetes, and liver disease among some Asian and Black populations, all of which are associated with increased vulnerability to adverse health outcomes (Teagle et al. 2022). Reflecting the continuing impact of the virus, 705 COVID-19 cases were recorded in UK hospitals as of 10 December 2025, with the highest rates occurring among those aged 85 years and over (GOV.UK, 2025). Furthermore, the UK COVID-19 Inquiry (2025) reported that more than 230,000 deaths in the UK had been attributed to COVID-19 where the virus was recorded on the death certificate.

Long COVID also remains a major public health concern. In March 2024, approximately two million adults and children in the UK (3.3% of the population) reported experiencing Long COVID symptoms, many lasting more than a year and significantly affecting everyday activities (NHS, 2024). Emerging evidence suggests that minority ethnic populations experience disadvantages in relation to Long COVID, including difficulties associated with misdiagnosis, misrecognition, and access to healthcare support (Mullard et al. 2024). These challenges highlight the importance of understanding the longer-term consequences of the pandemic beyond the acute phase of infection.

This study is therefore significant because it seeks to amplify the voices and experiences of older minority ethnic people, a population that has often been overlooked in COVID-19 research. By exploring how participants experienced and interpreted the pandemic, the study contributes to a more nuanced understanding of the social, cultural, and structural factors that shaped their experiences. Given the enduring effects of COVID-19 on physical health, mental wellbeing, healthcare access, and social participation, understanding these lived experiences is crucial for informing more equitable public health, social care, and healthcare responses to future pandemics and other large-scale public health emergencies.

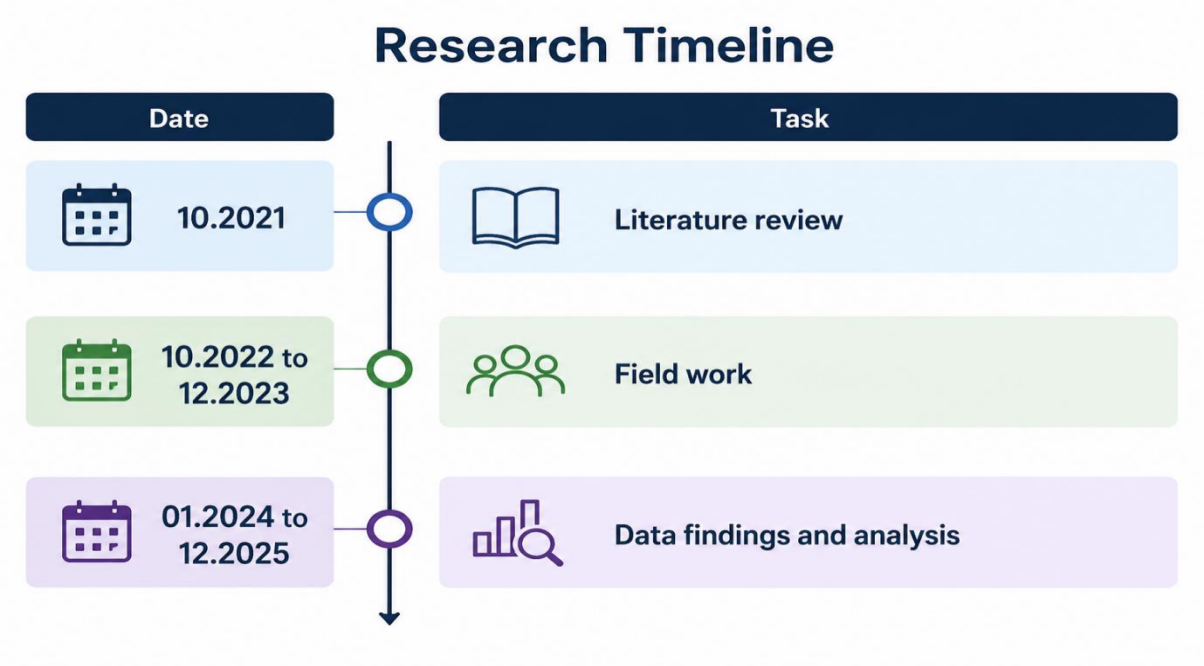
In the UK, the first COVID-19 case was confirmed in January 2020 (LBC, 2020). The UK government subsequently implemented various measures, as shown in Figure 1 below.

.

Figure 1: Timeline of key COVID-19 Events in the UK

DATE	KEY EVENT	REFERENCE
31st January 2020	First confirmed COVID-19 cases recorded in the UK.	LBC (2021)
5th March 2020	First COVID-19 related death recorded in the UK.	UK Parliament (2021)
23rd March 2020	First national lockdown announced. Citizens were instructed to stay at home, Schools and non-essential businesses closed, and social gatherings prohibited.	UK COVID-19 Inquiry (2024) GOV.UK (2022)
May 2020	Dominic Cummings' Barnard Castle controversy. Public concern arose following reports that the Prime Minister's adviser had breached COVID-19 restrictions, raising questions about fairness, accountability and trust in government.	
May-July 2020	Gradual easing of first lockdown restrictions, including reopening of some schools, workplaces and retail sectors.	GOV.UK (2022)
14th October 2020	Introduction of the three-tier system in England to manage regional infection rates.	GOV.UK (2022)
5th November – 2nd December 2020	Second national lockdown in England in response to rising infection rate.	GOV.UK (2022)
8th December 2020	Launch of the COVID-19 vaccination programme using the Pfizer-BioNTech vaccine.	GOV.UK (2022) The Guardian (2020)
4th January 2021	Third national lockdown announced following a surge in cases associated with the Alpha variant.	GOV.UK (2021a)
8th March 2021	Step 1 of the government`s roadmap out of the lockdown, including the reopening of schools.	GOV.UK (2021b)
12th April 2021	Step 2 of the roadmap: non-essential retail, outdoor hospitality and personal care services reopened.	GOV.UK (2021b)
17th May 2021	Step 3 of the roadmap: indoor hospitality, entertainment venues and limited. international travel resumed.	GOV.UK (2021b)
19th July 2021	Most legal COVID-19 restrictions in England lifted (Freedom Day)	GOV.UK (2022)
Autumn 2021	Booster vaccination programme expanded, prioritising older adults and clinically vulnerable groups.	GOV.UK (2022)
December 2021	Omicron variant became dominant: plan B measures introduced including face coverings, and COVID certification for some venues.	GOV.UK (2022)
Jan 2022	Downing Street apologises to Buckingham Palace following reports of gatherings held the night before the funeral of the Duke of Edinburgh during COVID-19 restrictions.	UK COVID-19 (2024, 2025) Inquiry
24th February 2022	Most remaining legal restrictions removed under the new “Living with COVID” strategy	GOV.UK (2022)
April 2022	Prime Minister Boris Johnson and Chancellor Rishi Sunak receive Fixed Penalty Notices for breaching COVID-19 regulations relating to Downing Street gatherings in 2020.	UK COVID-19 Inquiry (2024)
2024-2025	UK COVID-19 (2024, 2025) Inquiry reports published, examining the Government's handling of the pandemic, including decision-making, accountability and public trust.	

Figure 2



This research study began in October 2021, as illustrated in the timeline presented in Figure 2 above. Government breaches of lockdown rules as those shown in figure 1 above had an impact on people's trust and show how COVID-19 has affected trust beyond the actual timeline of restrictions. Although my research began at the tail end of the COVID restrictions, I was collecting my data soon after numerous scandals about breaches of rules so these issues were in the mind of my research participants, and they are referred to in the data findings.

Motivation for the study

My motivation stems from both professional and personal experience. As a domiciliary carer and later a social worker, I witnessed the loneliness and challenges older people face during their last days. My academic interest in older people's health and social care intertwined with personal experience when reflecting on my late father's last days in Zimbabwe, where despite his career in education, he lacked adequate health care. Furthermore, distance prevented me from offering care during that time. Through this, I reflected on how some older people sustain economies during working ages yet face challenges later.

Understanding my lived experience is essential for readers. I am a Black African woman, born and raised in Zimbabwe. My parents worked in education, my mother as a Primary School headmistress and my father as an education officer managing schools in Manicaland Province. This upbringing instilled a passion for reading and research leading to this thesis. I fled Zimbabwe alone and sought refuge in Belgium as an adult, worked as a carer, then moved to the UK to continue this work, mostly caring for older White clients. This ignited my interest in the experiences of older Black people in the UK, motivating this research into older minority ethnic people's lived experiences during and after the pandemic. Behind this thesis is a story of resilience.

A. RESEARCH FRAMEWORK

This chapter outlines the rationale for adopting Intersectional Risk Theory (IRT) as the framework for this study. Informed by intersectionality, the study centres the theoretical framework of IRT, which is a synergy of intersectionality and the sociology of risk theory (Giritli Nygren and Olofsson, 2014).

Intersectional risk theory

The meaning of risk is fluid, dynamic, changes over time and space, and is contextual (Lupton, 1999). Generally, risk is the social construction of the possibility of being harmed, and tends to refer to a threat, hazard, danger or harm (Lupton, 1999), often linked to modernisation and globalisation (Beck, 1992; Giritli Nygren, Öhman and Olofsson, 2017).

Risks are deeply embedded in society and cannot be managed through objective and technical assessment that excludes the social construction of risk (Zinn, 2006; Slovic, 1987). Lupton (1999) disputes those notions of risk that involve apportioning blame to lay people. Lupton also criticises experts who undermine lay people's views on risk by arguing that they are adversely influenced by bias or cultural or emotional responses.

This study adopts a sociological interpretation of risk, in which risk and uncertainty are linked (Giritli Nygren, Olofsson and Öhman, 2019; Zinn 2006, 2016; Roeser et al. 2012). According to sociological risk approaches, social problems that are often associated with marginalised people are identified and managed as risks (Olofsson et al. 2014). Examples of these problems include the COVID-19 pandemic. Giritli Nygren et al. (2017) also highlight discrimination as a social risk, in that it can deter people from seeking medical help. Joshi and Swarnakar (2021) identify the stigma associated with COVID as a social risk. Infectious diseases such as HIV/AIDS, SARS and COVID-19 generate stigma based on socio-cultural factors (Singer et al. 2017; GOV.UK, 2021). Stigma leads to blame and shame of the Other, which becomes a tool for control (Lupton, 1999; Douglas, 1992) when it leads to people not seeking medical help (Singer et al. 2017). Furthermore, stigma can lead to anxiety and other mental health challenges (Rewerska-Juśko and Rejdak, 2022).

IRT is a relatively new area of scholarship (Olofsson et al. 2014). This study contributes to filling this gap by applying IRT to explore the lived experiences of older minority ethnic people. This is achieved through an understanding of the issues below, namely that:

i) Risk and inequality are mutually constitutive.
ii) Risk involves power dynamics.
iii) Risk reflects and reproduces values and beliefs.

These key tenets are used to unpack the sociological notion of risk and its relation to intersectionality which as a Black feminist concept, 'has emerged as the primary theoretical tool to interrogate hierarchy, hegemony, and exclusivity' (Giritli Nygren et al. 2019, p.2). It pertains to the interrogation of oppressive structures and inequalities that are historically and contextually embedded (Crenshaw, 1989; Collins, 2000).

i. Risk and inequality are mutually constitutive

The unequal distribution and effects of contemporary risks (Giritli Nygren et al. 2019) tend to reinforce structural inequalities. As a result marginalised individuals and communities face increasing vulnerability making risk and inequality central themes in human rights discourse (United Nations, 2020). Accordingly feminist and intersectional scholars have increasingly examined risk through this lens (Hannah-Moffat, 2007).

Feminist and intersectional approaches are mutually reinforcing. Intersectionality enriches risk research by revealing how globalisation and the interplay of social categories contribute to new forms of inequality and risk production (Hankivsy and Kapilashrami, 2020). On the other hand, risk research contributes to intersectional analysis by exposing how governance structures reproduce both new and historical inequalities (Giritli Nygren et al. 2019).

Risk is multidimensional as risk factors rarely operate in isolation (Hankivsy and Kapilashrami, 2020). Thus analysing lived experience of crisis such as COVID-19 through a single axis lens whether class, age, or race is both reductionist and inadequate (Olofsson et al. 2014) as Crenshaw's (1989) and Collins (2000) argue. By merging intersectionality with sociological risk, researchers can achieve a richer

understanding of how individuals experience risk (Crenshaw, 1989). This approach is what underpins the analytical framework of this research.

Furthermore, people's experiences of risk depend on their identity. Instead of separately analysing how each personal characteristic (e.g. race, disability and age) affects people's experiences of risk, it is important to analyse how all relevant personal characteristics, taken together, determine experiences of risk (Giritli Nygren and Olofsson, 2014). Giritli Nygren and Olofsson (2014) add that risk must not be construed as fixed and consistent but as fluid and contextual.

Risks occur along lines of difference and therefore affect diverse populations unequally (Olofsson et al. 2014). Groups and individuals who are disadvantaged socio-economically systematically face greater risks (Hankivsy and Kapilashrami, 2020). For example, the COVID-19 pandemic had a discriminatory impact on minority ethnic communities (Oskorochi et al. 2023). IRT facilitates a deeper understanding of the interlocked drivers of systemic institutionalisation. Furthermore, the effects of contemporary crises such as the cost of living, climate and wars, which are all forms of social risks, have a discriminatory impact on society (Gadd et al. 2023; Munro, Allen and Marmot, 2023). Intersectionality, as a critical conceptual and analytical tool of risk, foregrounds the connection between the social construction of risk and the reproduction of social inequalities, and between the social construction of risk and intersections of age, race, social class, gender, ethnicity, disability and other social categories (Olofsson et al. 2014; Zinn, 2016).

By analysing how individuals are exposed to risk, IRT theorises the 'mutual constitution of risk and social inequalities' (Olofsson et al. 2014, p.417). It views inequality as intersectional and constructed and not natural (Olofsson et al. 2014 p.420). Consequently, research into how risk and inequalities interact and co-constitute can improve people's understanding of social inequalities.

ii. Risk and power dynamics

Risk has an intrinsically complex relationship with power and uncertainty (Zinn, 2016; Beck, 1992; Dean, 2022). This relationship is evident in the governmentality perspective, and emphasises how expert knowledge sets norms used to assess,

shape and control society. Experts shape how risks are defined and managed through binary distinctions between normality and abnormality (Alaszewski, 2023).

Lupton (1999) rejects the governmentality perspective. IRT places intersectionality at the centre of how risk is understood, showing how risk perceptions and responses are closely intertwined with power relations (Giritli Nygren and Olofsson, 2014). It interrogates the power dynamics in risk perceptions. Risk perceptions reflect and are shaped by the same social power structures that drive inequality in society (Lupton, 2006). IRT is a conceptual terrain upon which risk and perceptions of risk are understood as socially embedded. Accordingly, risk discourses construct certain populations as being more vulnerable to risk than others, depending on various factors (Lupton, 2006). Social constructions such as race, age, ethnicity, class and disability interoperate in specific historical, social, cultural, political and economic contexts to produce social hierarchies and complex power relations (Collins and Bilge, 2016; Crenshaw, 1991). IRT considers these social hierarchies as non-homogeneous, socially constructed, historically and culturally specific, performative spaces in which power and knowledge are (re)produced and contested (Olofsson et al. 2014). IRT acknowledges the different contexts of risk (Giritli Nygren et al. 2017). Examples include social, industrial and organisational structures and power relations in which individuals and their practices exist and are embedded (Giritli Nygren et al. 2017). Dean (2022) adds that risk and power intersect at the societal level, in organisations and in every situation at national, policy and international level.

The risk discourse interrogates how individuals construct perceptions of risk and act upon them; how these understandings and actions are influenced by social norms and power relations; and how understandings of risk, social norms and power relations interact to produce particular risk management practices (Evans et al. 1997; Coles and Eikhof, 2021).

iii. Risk constitutes values and beliefs

IRT looks at who assigns risk, to whom, and based on what assumptions. Different values and beliefs give rise to perceptions of risk that are constructed in the contexts of organisational, industry and societal norms (Giritli Nygren et al. 2017; Dean, 2022). That people perceive risk differently thus reflects their values and beliefs, world views

and concepts of the social order. Douglas (1992, p.8), shares the same view through her notion of the cultural theory of risk which posits that ‘any community has several cultures, and that each culture defines itself by contrast with others’.

Risk is shaped by society and culture. People understand and respond to risks differently depending on their background and social context (Lupton, 1999; Douglas, 1992). This idea aligns with standpoint theory which argues that marginalised groups have unique insights based on their lived experiences (Collins, 2000; Smith, 1997). Being subordinated in lived experiences gives one a specific kind of knowledge which differs from the experiences of the privileged (Harding, 2016; Collins, 2000). Standpoint theory destabilises the dominant androcentric knowledge production that excludes marginalised groups (Dean, 2022).

Since socio-cultural constructions of risk are important, acknowledging the influence of societal norms and values in addition to structural perspectives on risk perception is key (Zinn, 2006). Scholars such as Douglas (1992), Douglas and Wildavsky (1982) and Zinn (2006) posit that socio-cultural and social-moral factors can shape perceptions of risk. Although risk perception is a critical determinant of health- and safety-related behaviour, there is no consensus on the strength of the relationship between perception and behaviour (Herbec et al. 2022; Thøgersen-Ntoumani et al. 2022; Ferrer and Klein, 2015; Wang, Zhang and Feng, 2023). Therefore, realist approaches without a constructionist approach to understanding the notion of risk and uncertainties are reductionist and limiting (Alaszewski, 2009 p.492; Peter, 2020).

People make risk related decisions based on belief, desires and emotions-not always logic or reason (Douglas and Wildavsky, 1983; Shrader-Frechette, 1991; Roeser and Pesch, 2016a; Costa and Carrus, 2024). Emotions, which are especially prevalent during pandemics and uncertainties can be a determinant in risk perception and one’s decision making about risk issues (Slovic et al. 2004; Slovic, 2010).

Even expert views of risk are shaped by personal and cultural assumptions. For example, experts focus on long-term statistics such as annual projections of risk and mortality, while the public may worry more about immediate threats such as daily current hazards (Slovic and Weber, 2002). Thus, Slovic and Weber (2002) and Lupton (2006) argue that lay people do not have a wrong understanding of risk, they have a

different understanding of risk. This falls in line with Douglas's (1992) cultural theory, which accounts for cultural values in risk perceptions.

Conclusion

Intersectional Risk Theory, with its sociological foundation, offers a fitting framework for this study. The COVID-19 pandemic was not only a medical crisis but also a deeply social event, necessitating an analytical lens that extends beyond scientific paradigms. A purely realist approach neglects the nuanced ways risk and uncertainty are socially constructed and experienced. By incorporating social risk concepts through an intersectional lens, this study captures the complexity of how older minority ethnic people in the UK perceived and responded to the risks of COVID-19. IRT enables the integration of intersecting identities such as race, ethnicity, age, gender, and disability into a comprehensive understanding of risk perception, illuminating the broader social forces that shaped their behaviours and choices during the pandemic.

The following chapter provides a literature review through an intersectional lens, focusing on the structural and contextual forces that shaped COVID-19-related risks for older minority ethnic people in the UK.

CHAPTER 1: LITERATURE REVIEW

1.1 RACE, RACISM AND INTERSECTING IDENTITIES

Introduction

This section explores the link between various intersecting social identities (which include race, gender, class, ethnicity, disability, age, and comorbidities) and health inequalities, focusing on older minority ethnic people in the UK.

1.1.1 Identity

The notion of identity is complex (Tatum, 2018). It is linked to the 'Who am I?' narrative, which reflects that one's identity is shaped by various factors (Erikson, 1968; Tatum, 2018). Identities are socially constructed (Weber, 2001; Andersen and Collins, 2007): 'their significance stems not from some natural state, but from what they have become as the result of social and historical processes' (Andersen and Collins, 2007). Although context influences identity processes (Tajfel and Turner, 1986), the individual is not passive but plays an active role in constructing their identity (Swann, 2005). This process is what Winter and Reed (2016) term identity 'personal construction'.

Giddens (1990), Beck (1992) and Bauman (2000) argue that the concept of identity and selfhood has grown in importance due to social changes, individualism and increased choices in late modernity. Buckingham (2008) links the etymology of 'identity' to the Latin root '*idem*', which means 'the same', however, the term implies both similarity and difference. There is no consensus among scholars on the typology of identity. Vignoles et al. (2011) view identity elaboratively and distinguish four identities (individual or personal, relational, collective and material), which they integrate in their definition of identity. Vignoles et al. (2011, p.4) define identity as: 'the confluence of the person's self-chosen or ascribed commitments, personal characteristics and beliefs about herself; roles and positions in relation to significant others; and their membership in social groups and categories (including both their status within the group and the group's status within the larger context); as well as their identification with treasured material possessions and their sense of where they belong in geographical space.'

The concept of social identity can be traced to Tajfel and Turner (1986), who studied the role of intergroup dynamics and perceptions of group membership in understanding group identity. Tajfel (1982, p.2), cited in Kish Bar-On and Lamm (2023), defines social identity as 'that part of the individual's self-concept which derives from their knowledge of their membership in a social group (or groups) together with the value and emotional significance attached to that membership'. However, Ashmore et al. (2001) critique Tajfel's definition as being too individualistic and not recognising the fluidity of identities and the socio-cultural contexts that influence identity, which are key aspects in the analysis of people's differential lived experiences.

The social identity perspective recognises multiple, intersecting identities and social (collective) levels (Tajfel and Turner, 1986; Vignoles et al. 2011). It also recognises individuals as having multiple aspects of identity that coexist, intersect and interact (Tajfel and Turner, 1986; Crenshaw, 1989; Collins, 2000; Amiot et al. 2007; Anthias, 1992). Consequently, the salience and relevance of one aspect of identity depends on the social context (Crenshaw, 1989; Collins, 2000a; Vignoles et al. 2011). This points to the notion of intersectionality (Crenshaw, 1989). Crenshaw (1989) views paying attention to a single social category as reductionist because it inhibits the recognition of individual experiences of systemic patterns (such as racism, ageism, classism, ableism and sexism). Viewing identities through multiple lenses helps in providing a better understanding of the complexity of identity and how its processes operate to expose marginalised communities to heightened risk of social problems.

Identity is analysed in relation to the social and institutional processes that determine the privileges that produce and reproduce racial, gender, class and other forms of social differences (Cho, Crenshaw and McCall, 2013). Positionality theory best articulates the relationship between one's identity and access to power and resources (Collins, 1993; Kezar, 2002; Misawa, 2010). Positionality according to Kezar (2002) and Collins (2002, 1993) refers to an individual's relational position within overlapping social identities. Kezar (2002) acknowledges the utility of standpoint theory in exploring diverse perspectives but identifies conceptual limitations that are addressed by positionality theory. Unlike standpoint theory which often isolates social identities and their power implications, positionality theory rejects essentialist and static conceptions of identity (Alcoff, 1988; Collins, 1993; Kezar, 2002). Positionality theory

further holds that individuals derive meaning through the interplay of their multiple identities (Longino, 1992). Misawa (2010) argues that positionality is deeply embedded in power structures. It determines one's proximity to power, access to resources and shapes perspectives and engagements with the world (Cruse et al. 2023).

The Ontario Human Rights Commission (2001) employs the wheel of power/privilege (Figure 1) to illustrate how individuals or groups may be advantaged of disadvantaged. The spirograph also highlights how proximity to power is shaped by intersecting factors such as race, class, age and gender.

Figure 3: The wheel of power/privilege

Source: The Ontario Human Rights Commission (2001)

McIntosh (1988) defines privilege as the unearned privilege arising from the marginalisation of others. Positionality determines proximity to power and access to resources. It also shapes how individuals view and engage with the world (Andersen and Collins, 2007). Social identities help determine who has power and privilege and who faces marginalisation. Haslam et al. (2009) argue that the social identity approach enhances understanding of its key role in shaping health-related policies and

practices. This is achieved by identifying risk drivers and patterns shaped by power dynamics underlying health inequalities.

1.1.2 Race, racism and ethnicity

Exploring race and racism is crucial for understanding structural marginalisation and heightened vulnerability to crises such as COVID-19. Documenting experiences of racism is vital as its chronic and cumulative effects significantly compromise health (Geronimus et al. 2006; Chae et al. 2014) and increase vulnerability to illness such as COVID.

Race and ethnicity are distinct yet often conflated concepts. Sheth (2009, p.4) characterises race as a 'mode or vehicle of division, separation, hierarchy, exploitation, rather than a descriptive modifier'. Race functions as a tool of power, characterising people by physical traits to maintain social hierachies and privilege (Smedley and Smedley, 2005; Markus, 2008; Sheth, 2009). On the other hand, ethnicity refers to shared cultural attributes such as heritage, values, traditions, language and nationality) (Smedley and Smedley, 2005; Phinney and Ong, 2007; Markus, 2008).

Additionally, race and ethnicity are socially constructed and historically contingent with their meanings and boundaries changing across historical time and cultural context (Mukhopadhyay, Henze and Moses, 2013), however they should not be used interchangeably (Phinney and Ong, 2007; Suyemoto et al. 2020). Moreover, these authors hold that differentiating between race and ethnicity in research that involves the intersection of race and ethnicity enables the capture of more nuanced and valid data and consequently more robust analysis. Suyemoto et al. (2020) agree with Crenshaw's (1989) concept of intersectionality, which upholds the separate but simultaneous intersectional interaction of social identities. Furthermore, differentiating race from ethnicity is essential for individuals and groups (such as Caribbeans and Asians) who may not fit within the dominant constructions and may struggle to be identified as Black (Brah, 2005; Suyemoto and Donovan, 2015). Failing to distinguish race from ethnicity risks homogenising diverse and reinforcing marginalisation (Suyemoto et al. 2020).

A historical lens is essential for understanding how race and ethnicity have been shaped in the UK. Scholars such as Goldberg (2006) posit that contemporary racial contours are understood by linking them with the past. The following section therefore traces race, racism and ethnicity in the UK.

1.1.3 Slave trade and colonialism

With Britain's involvement in the slave trade from 1562, racial ideologies emerged (Williams, 1944; Hanley, 2016). Racism also infiltrated into mental health diagnosis, when Europeans used their power to control those African slaves who ran away by diagnosing their abscondment as an illness, Drapetomania (Fernando, 2017). After abolishing slave trade and slavery, Britain expanded trade with Asian colonies and imported labourers to Africa and the Americas (Pomeranz, 2000; Bhattacharya, 2021). Between 1881 and 1914, imperial competition triggered the Scramble for Africa (Gjersø, 2015). This consequently led to the British colonisation of, among others, Caribbean territories (Gjersø, 2015). The mortality of World War I and the consequent labour shortages led Britain to import Africans as labourers (Gyimah, 2019).

By the end of the nineteenth century, Britain's dominance reinforced White supremacy (Armitage, 2000; Goldberg, 2006). Goldberg (2006) states that, from the fifteenth century, European expansion, enslavement, exploitation and colonialism, of which Britain was part, evoked the White supremacist power dynamics that formed and fashioned racism. Racism functioned as a justification for enslavement and a tool for maintaining White dominance (Fanon, 1986). Britain forged a racial hierarchy with White Europeans at the top and Africans and Asians at the bottom, supported by an evocation of strong perceptions based on stereotypes (Parmar et al. 2022). Fanon (1963) references colonialists' use of zoological and bestiary terms, derogatory representation and cartoon caricatures to dehumanise African men and women and demonstrate that they were savage, uncivilised and lacked empathy, and thus ideologies of race and racism were perpetuated. Colonial graphic representations often depicted cheerful Black labourers supporting imperial economies. In the colonies, White women symbolised moral purity whereas Black women were stereotyped as hypersexualised and grotesque even though these same Black women were employed as domestic help in White households (Jones, 2016). Many Black and

Asian women were coerced into sexual exploitation under colonial regimes (Carby, 2007).

Thus, colonialism and imperialism (the goal of which was exploitative) stimulated racial antagonism, which was essentially a political-class conflict exposing a power relations dynamic between White Europeans, Africans and Asians (Cox, 2001, in Back and Solomos, 2000). Mahmud (1999) describes the relationship's embodiment of domination and difference, with race being the primary marker of difference over which the colonialists' exerted influence and superiority. Go (2012) exposes the colonialists' exploitation of contradictions. The European rhetoric of civilising the nations was accompanied by colonial coercion, economic exploitation, exclusion and the inferiorisation of the colonial subjects who were deemed not worth of full rights.

Fanon (1986) critiqued European humanism and exposed the colonised's struggles with identity and inferiority. Fanon, (1963), expressed concern about how the colonised others viewed themselves, their position within colonised societies and their struggle against colonialism, revealing their loss of self-esteem, control over their lives, self-respect and humanity. Fanon challenged society to think about the colonised subject's feelings of inferiority and despair and their inaction because of the wish to avoid confrontation.

Fanon (1963, p.250) further argued that colonialism's systemic negation of the colonised subjects' identity over a sustained period caused them to question their identity: 'In reality, who am I?' Colonialism disrupted colonised people's capacity for self-determination (Gibson, 2003). Fanon (1963) saw colonial domination as being total and disruptive to the colonised's cultural life such that reclaiming their identity afterwards became difficult. Fanon's critique extends beyond Algeria, offering insights into global dynamics (Go, 2012).

1.1.4. Racism in post-World War II in Britain

Minority ethnic group identities in Britain have been shaped by the nation's imperial history, colonialism, decolonisation, conflicts and migration (Shankley and Rhodes, 2020). Following World War II, the British Nationality Act (1948) led to a surge in

immigration to Britain (Sigona, Kato and Kuznetsova, 2021). In search of willing workers to rebuild its infrastructure and economy, Britain endorsed labour migration from across the Commonwealth and other colonies and bestowed citizenship on labour migrants from the Caribbean, India, Pakistan and Bangladesh (Dawson, 2007). They worked mainly in manual labour across manufacturing and service sectors (Dawson, 2007). Racial discrimination in access to housing and the colour bar in the workplace in part explains the South Asian settlement in northern English towns; Caribbean migrants mostly settled in London and other major cities (Gulliver and Prentice, 2015). Notably areas with historical migrant settlement corresponded with COVID-19 mortality hot spots in the UK.

Beyond Commonwealth sources, immigrants also arrived from mainland China, Taiwan, Vietnam, Singapore and Malaysia in the second half of the twentieth century. The first Chinese to settle in Britain replaced British seamen, and were recruited on different terms to those of other migrants (Png, 2023). This put them higher in the racial hierarchy than Blacks and Indians, although they were regarded as inferior to the White British (Png, 2023). Unlike other Asians communities, Chinese migrants did not form cohesive groups based on shared religion, caste or class (Davies, 2014; Ashour and Al-Khafaji, 2022).

Post-war period immigration became highly racialised in British politics with immigrants framed as problematic (Solomos, 1993). The British resisted new arrivals through protests and street fights, for example in Liverpool and Notting Hill in 1948 and 1958 respectively (Schwarz, 2018; Staveley-Wadham, 2022). This led to the emergence of legal controls from the 1950s and a fall in the number of migrants to Britain. This did not prevent the anti-migrant rhetoric of Enoch Powell's Rivers of Blood speech (1968) (Runnymede Trust, 1997), and although the government passed the Race Relations Act (1965, 1976) to alleviate the aggression faced by coloured immigrants, such legal instruments were ineffective: in 1991, 26,000 racially motivated acts of vandalism were reported (Human Rights Watch, 1997). The government investigated the major riots, but it was only after the judicial enquiry into Stephen Lawrence's 1993 murder that the police started implementing measures against racial discrimination. The government's commitment to tackling hostility towards migrants remained questionable (Macpherson, 1999). Although race and ethnicity are two of

the nine protected characteristics listed in the Equality Act (2010), discrimination on the grounds of race and ethnicity is still prevalent in the UK, and racial attitudes and practices continue to shape the experiences of minority groups in Britain (Bhopal, 2018; Shankley and Rhodes, 2020).

Racism has evolved, transformed or shifted over time under new terms (Goldberg, 2006). Racial prejudice is being redefined in terms that emphasise cultural difference rather than skin colour. Present racisms in Britain relate to cultural undesirability or the threat that other cultures pose to integration or to the national cultural heritage (Anthias, 1992; Song, 2004). Scholars call this cultural racism (Michaels et al. 2023).

Research in the United States of America (USA) shows that racism experienced through cultural norms can perpetuate negative health outcomes for ethnic minorities (Michaels et al. 2023). Brexit revealed widespread concerns among some White Britons regarding xenophobia, populism and Eurocentrism (Hobolt, 2016) while the Macpherson Report (2021) highlights structural social-economic exclusion of racial and ethnic communities coupled with escalated explicit racial, ethnic and religious intolerance. Additionally, Anti-Muslim rhetoric has been expressed through stereotypes such as uncivilised, criminality and hostile thus presenting the Islamic religion and culture as being of an undesirable character (Anthias, 1992). This is symbolic racism, which entails blaming a group for any disadvantages it faces while downplaying the existence of historic and systemic racism (Milner, Franz and Braddock, 2020).

Racist stereotyping promotes hostility and stigma undermining the wellbeing of marginalised groups (Ball, Steffens and Niedlich, 2022; Macpherson, 1999), which affects the confidence and wellbeing of marginalised communities. Stereotyping leads to stigma which consequently undermines social cohesion, prompts social isolation, worsens severe health problems and negatively impacts the wellbeing of those subjected to it (WHO, 2020). The Independent Scientific Advisory Group for Emergencies (SAGE, 2020) criticised the stereotyping of minority ethnic populations and ethnicity as causative of COVID-19 transmission (Hayre, 2020). Stereotyping of the virus as Chinese caused a threefold increase in hate crimes against Chinese in London during the first three months of 2020 (Gray and Hansen, 2021). Furthermore,

Rethink Mental Illness Organisation (2020) highlighted the stigma and taboo attached to mental health among minority ethnic communities, which results in problems left unattended until crisis point.

Gilroy (1987, 2004), who describes identity as a political construct grounded in collective belonging criticises how notions of cultural incompatibility are used to label some groups as alien and a threat to national unity. Gilroy (1987) sees ethnic diversity as essential to a just, multicultural but stresses that racism must be explicitly acknowledged to be effectively addressed. According to Gilroy (2004), the setting of identity boundaries exposes the power and authority that can underpin identity dynamics. Excluding groups deemed incompatible with British cultural norms undermines the Equality Act (2010). Post 9 September 2001, Britain's political discourse shifted, marked by a decline in support for multiculturalism and an emphasis on British values and national identity particularly under Prime Minister David Cameron (Williams, 2021).

Contemporary racism in Britain often takes subtler and more covert forms (Shankley, Hannemann and Simpson, 2020). Williams (2021) cites the 2017 Grenfell Tower fire as exposing the intersections of poor governance, inadequate housing, environmental racism, gender and class inequality. Most of the Grenfell tenants were from minority ethnic groups. The Grenfell Tower tragedy affirms Mbembe's (2003, p.17) claim that racism can be deadly.

Bourne (2019) critiques the government's shift from addressing institutional racism to focusing on unconscious bias. Highlighting racism as not only a result of individual bias but as also a structural issue is important. Hewitt and Kapadia (2021), for example, note that older minority ethnic people face increased challenges due to institutional racism. Gill and Kalra (2021) highlight the absence of racial inequality data in COVID-19 mortality statistics in the Race and Ethnic Disparities (2021) report, arguing that the government uses racial categorisation to perpertuate marginalisation. Whereas statistics on race would expose the disproportionate deaths within minority ethnic populations as a result of factors such as overcrowded housing and systemic abuse in state institutions, the government focuses only on underlying medical conditions and lifestyle choices (Gill and Kalra, 2021). Razai et al. (2021) echoing Gill

and Kalra's (2021) view, criticise the Ethnic Disparities report's reductive approach which downplays racism and omits ethnicity altogether. Intersecting forms of racism and social disadvantages compound health inequalities for minority ethnic groups (Williams, 2021).

Racism is embedded in different power relations and embodies a group's ability to impose their beliefs as hegemonic and as a basis on which to deny others rights or equality (Anthias, 1992). Anthias argues that the dominant group thus causes others to be inferior, exemplifying the power dynamics that act to create class hierarchies. Collins (2000 p.287) describes domination as pressure exerted on subordinated groups to enforce the dominant group's culture. Furthermore, those who do not experience marginalisation 'fail to see how their thoughts and actions uphold someone else's subordination' (Collins, 2000). Even though Collins was writing regarding African-American women, her views about power dynamics apply to any racial group being marginalised. Gidda (2020) reports that during the pandemic, police forces in England and Wales were up to seven times more likely to issue fines to minority ethnic people for violating lockdown rules than to White people, implying that their race exposed them to the risk of unfair treatment by the police and their institutional power.

Race and racism do not exist in a vacuum. Rather, they intersect with other identities (gender, ethnicity, sexuality, age, class and abilities) to shape lived experience. While the Equality Act (2010) lists protected characteristics, it treats them as isolated, failing to capture their interactive nature. To this end, health inequalities and corresponding disparities exposed by COVID-19 can be analysed through an intersectional lens. An intersectional lens better explains how multiple inequalities co-create disadvantage while disproportionately affecting minority ethnic groups.

1.1.5 Fluidity of racialised identities and minority ethnic groups

Identity is fluid and is shaped by individual, social and cultural processes and its meaning shifts with historical and social context (Brah, 2005; Hall, 1989; Vignoles et al. 2011; Kezar, 2002). Self-perception and how others perceive an individual can change over time, reflecting the absence of a fixed identity (Kezar, 2002). Plantation societies created racialised identities for Africans and Indians after the abolition of

slavery (Mahmud, 1999). Here, Indians were initially seen as a way to control formerly enslaved Africans as they were stereotyped as obedient and industrious. However, this view about Indians shifted when Chinese workers were recruited. The Chinese were labelled as highly intelligent than all the other races (Mahmud, 1999; Fouéré, 2015).

Anthias (1992) argues that British identity categories stem from historically situated political decisions often shaped by legislation. For example, because some minority ethnic communities found the terms Black and White too homogenous, in the 2011 census the category 'Black British' was changed to 'Black/African/Caribbean/Black British' (GOV.UK, 2019; Aspinall, 2012). Shankley et al. (2020) also emphasise that historical migration patterns influence identity classifications. In Britain, some of the main minority ethnic groups are historically linked to the post-war migration (Finney and Simpson, 2009).

People often hold multiple, overlapping identities (Tajfel and Turner, 1986; Crenshaw, 1989; Collins, 2000; Amiot et al. 2007; Anthias, 1992). Consequently the notion of where and how the boundary of an ethnic group is constructed is diverse, contextual and relational (Anthias, 1992). For instance, Jamaicans may identify as Afro-Caribbean, and South Asians sometimes identified as Black in anti-racist contexts (Brah, 2005; Anthias, 1992) respectively. Additionally, the use of the Asian identity brought together various regional, linguistic and religious groups, such as Indians and Pakistanis, or Muslims and Sikhs (Anthias, 1992).

Although African Caribbeans and South Asians shared similar structural positions in low skilled work post-migration, they were racialised through distinct ideologies (Brah, 2005; Song, 2004). Not being White, however, was a common referent in the racism confronting them. Thus, to emphasise the relationship of domination and subordination they were described using the colonial code 'coloured people' (Brah, 2005; Song, 2004). In post-war Britain, the term 'coloured' was later rejected as offensive, reinforcing racial hierarchies (Banton, 2018). After all the term was being used to distinguish between two racial groups (the White as superior and the Other as inferior) (Ifekwunigwe, 2004; Banton, 2018). During the 1960s and 1970s, African-Caribbean

and South Asian activists adopted “Black” as a political identity influenced by the Black Power movements in America (Narayan, 2019). Black assumed a political colour used with pride against colour-based racisms. African-Caribbean and South Asian activists united under the shared experience of anti-colonial struggles (Brah, 2005). Similarly, Anthias (1992) argues that ethnicity can be rooted in shared experience, drawing together diverse cultures, which also tallies with Gilroy's (2004) referencing of identity as ‘an outcome of shared and rooted experience’.

Labels for minority ethnic groups in Britain have therefore evolved, from “coloured” to Black, Asian and Minority Ethnic (BAME), to ethnic minority (Williams, 2021; Song, 2004). Public bodies dropped “BAME” due to its lack of specificity (GOV.UK, 2024). Critics argue BAME obscures diversity and depoliticises identities, while others note it creates static categories (Luxon, 2020; Williams, 2021). Milner and Jumbe (2020) advocate using ‘racial minorities’ highlighting systemic hierarchies. Luxon (2020) and Williams (2021) instead prefer ‘minority ethnic’ which this study adopts. These shifts align the self-categorisation theory (Tajfel and Turner, 2004), which posits that individuals categorise themselves depending on the salience of identity context. The self-categorisation theory recognises collectiveness (based on factors such as ethnicity and gender) as key to group membership (Reimer et al. 2020). Ethnic labels remain contested, reflecting shifting political and social strategies. Modood (1994) warns against assuming homogeneous cultural needs within diverse groups. Brah (2005) likewise highlights sensitivity to plurality. An intersectional framework therefore facilitates nuanced analysis of ethnicity’s impact on health (Williams, 2021).

It is widely acknowledged that no single term can fully capture all the complex histories of racial subjugation and cultural diversity among Britain’s ethnic minorities, nor is consensus likely. While terminology matters especially when it concerns identity, the primary focus should remain on race in Britain (Ballinger, 2021; Mistlin 2021).

1.1.6 Racially informed intersectional inequalities

1.1.6.1 Mental health and inequalities

Racism can affect both mental and physical health. Williams (2021, p.27) and Chae et al. (2021) explain that exposure to everyday racial micro-aggressions, their anticipation and the expended emotional labour in managing them can induce fear, stress and reduced mental health. Chronic negative mood over time disrupts immune related physiological systems (O'Connor, Thayer and Vedhara, 2021). Geronimus et al. (2006) add that the constant stress of racism can lead to premature biological ageing and worsen health outcomes with emotional, physical and behavioural symptoms, a process they term 'weathering'. Psychological harm caused from racism increases susceptibility to infections like COVID-19 and reduces vaccine efficacy (Geronimus et al. 2006).

In the UK, mental illness is closely associated with social inequalities, such as education, poor housing, poverty, unemployment and social isolation, which are prevalent among minority ethnic groups (Public Health England [PHE], 2018). According to Fernando (2017), in the UK, race and culture interact with stratifications such as class, gender and poverty to affect mental health services, and thus systemic and institutional racism permeates diagnosis, assessments and interventions. While Black people are four times more likely to be detained under the Mental Health Act (2007), more White people receive treatment with better outcomes (Rethink Mental Illness, 2021). Fernando (2017) highlights how schizophrenia is racialised with minority ethnic groups more likely to receive restrictive treatments and less likely to be offered talking therapies. Fernando (2010) decries the whiteness of knowledge in mental health with its implications of White supremacy, and calls for adopting anti-racist mental health approaches to appropriately address contemporary understandings of race, ethnicity and culture. Bhui et al. (2021) add that mental health interventions that are insensitive to ethnic and cultural differences lead to escalated risks rather than resilience and recovery.

1.1.6.2 Socio-economic status

An individual's socio-economic status is determined by their positionality and proximity to power and resources. There is a link between social status and health and the lower one's status is in society, the higher the risk of illness and death. The Joseph Rowntree Foundation (2024) references the social, emotional and psychological effects of deprivation, which in turn affects mental and physical health.

Most minority ethnic groups are disproportionately affected by socio-economic deprivation (Lewis et al. 2023; Raleigh, 2023). The disproportionality is linked with structural racism which exacerbates socio-economic inequalities and consequently negatively impacts health (O'Connor et al. 2021). Older minority ethnic groups face double the poverty risk in comparison to their white peers (Lewis et al. 2023).

The interaction of the COVID-19 health crisis and resultant lockdowns with factors such as income, age, gender and ethnicity exacerbated existing inequalities and opened up new fissures (Blundell et al. 2020; Williams, 2021). The UK government's austerity measures which were launched in 2010, which cut social care and housing support, unfortunately placed an additional burden on older minority ethnic people (Williams, 2021; Lewis et al. 2023).

Additionally, housing inequities in the UK, a result of historical racialised discrimination mean that minority ethnic groups are also more likely to live in overcrowded housing (Gulliver and Prentice, 2015). Bangladeshi, Pakistani and Black households experience 30%, 16% and 12% more overcrowding in Britain (respectively) compared to 2% of White households (Office of National Statistics [ONS], 2020). These conditions engender chronic ill health and increase exposure to respiratory and health challenges (Darlington-Pollock and Norman, 2017) such as COVID-19. As a result, ethnicity and poor housing intersect in exposing minority ethnic people to high risk of coronavirus infection.

1.1.7 Childcare in multigenerational households

Multigenerational households are more common in minority ethnic communities populations than among White British people (ONS, 2021). The practice is associated with the traditional collective lifestyles of minority ethnic communities, which emphasise strong family ties (Arian, 2022). For example, Arian's (2022) research on Pakistani communities in the UK established that 35% of their households are multigenerational, comprising three or four generations.

Burgess et al. (2017) identify two main forms of multigenerational living, which are three-generation families, with grandparents living with younger generations (for example, their children and grandchildren), and two adult winds of the same family living together. During the pandemic, living in multigenerational households and undertaking childcare roles exposed older minority ethnic grandparents to a higher risk of infection (Kenway and Holden, 2020; Mirza and Warwick, 2022; McGrath and Peake, 2020). There is no doubt living in multigenerational households positively shaped social capital (Maye-Banbury and McNally, 2020). However, it also complicated efforts to isolate the vulnerable and heightened the risk of COVID-19 transmission (Kenway and Holden, 2020; Mirza and Warwick, 2022; McGrath and Peake, 2020).

Kinship care was also a risk factor that exposed older minority ethnic people to COVID. In Britain, kinship care is more prevalent in deprived areas and among minority ethnic communities (Wijedasa, 2017), with around half of the 200,000 children being raised by grandparents over the age of 70 (Hall et al. 2021). The grandparents' increased childcare duties during the pandemic were also related to the fact that, in the UK, minority ethnic people form the largest percentage of workers in key sectors, such as health and social care and the food supply chains industry (The Health Foundation, 2020). It is these key sectors that sustained the functioning of society, especially during the lockdowns, but made the workers in them more vulnerable to catching coronavirus. Additionally, minority ethnic populations are over-represented in occupations like taxi driving and security, which suffered higher COVID-19 death rates due to a greater risk of infection (Mirza and Warwick, 2022). Therefore, while during the pandemic, the minority ethnic people (including grandparents and the frontline key workers) provided essential and salient reproductive labour (Gordon-Bouvier, 2021;

Murtola and Vallelly, 2023; Camps Calvet et al. 2024), the duties they undertook exposed them to COVID risk.

Kenway and Holden (2020) show that in multigenerational homes, South Asian women aged 65 or older faced higher COVID-19 mortality than their male counterparts. The differential circumstances in which widowed women reside in multigenerational homes could make them more vulnerable than men (Bennett, 2014). Thus, the intersection of ethnicity, gender, household status and occupation heightened the risk of infection with COVID.

1.1.8 Disability

Disability significantly shapes health and wellbeing. In the UK, people with disabilities were disproportionately affected during the pandemic as they accounted for six in ten COVID-19 deaths (ONS, 2021a). Elevated risks reflect a combination of underlying conditions and exclusion from support systems, while pandemic measures (e.g., masking) hindered communication for older adults with sensory impairments. For example, those with sensory loss showed heightened psychological distress (Mheidly et al. 2020; Brotto et al. 2021; Merten et al. 2023). Socio-economic disadvantage and disability are closely linked. Nearly half of people in poverty had a disability or lived with someone who did (Voluntary Organisation Disability Group, 2023). Older minority ethnic groups faced heightened disability risk and worse pandemic outcomes due to the higher poverty rates among them (Age UK, 2021).

Consistent with the Social Model of Disability, structural barriers and not impairment alone constrain participation (Oliver, 2013). This is so because disability is socially constructed, context-dependent and heterogeneous and therefore warrants an intersectional lens to understand COVID-19 vulnerability (Wickenden, 2023). Furthermore, ethnicity and age compound impairment risk. For example, South Asian and African Caribbean groups show elevated cardiometabolic risk and reduced physical functioning (Whincup et al. 2010; Williams, Cox and Cooper, 2020). South Asians reported two to four times higher disability and functional limitations than Whites in Southall and Brent Revisited (SABRE) study (1988-1991) (Tillin et al. 2012). Consequently, disability in later life reduces quality of life and increases mortality and

institutionalisation risk (Ferrucci et al. 2004). On the other hand, stigma and social devaluation intersect with age and ethnicity, further compounding stigmatisation (Goffman, 1963; Williams et al. 2020). Here intersectionality is valuable but should not collapse identities into a hierarchy of disadvantage (Wickenden, 2023; Watermeyer and Swartz, 2023).

1.1.9 Social isolation, loneliness and age

There is a link between social isolation, loneliness, age and ethnicity. Individuals aged 50 years and over, especially those in poor health or low socio-economic status face the highest risk of loneliness (Chatzi and Nazroo, 2021). Older minority ethnic people often reside in deprived neighbourhoods, reflecting structural inequalities that heighten their vulnerability to loneliness, poor ageing outcomes and deteriorating health (Marmot, 2020; Santos et al. 2022). Ageism exacerbates isolation and loneliness among older people, leading to harmful health and social consequences (Brooke and Jackson, 2020). South and East Asian individuals in the UK experience elevated loneliness shaped by lifelong structural disadvantages and discrimination (Cotterell et al. 2025). The Mental Health Foundation (2022) highlights that racism driven socio-economic and health disparities limit social participation, intensifying loneliness in minority ethnic communities.

Retirement, chronic illness, widowhood and economic hardship are key contributors to loneliness among older people (Windle et al. 2011). While social isolation among older people was already a public health issue before COVID-19, the pandemic's restrictive measures worsened older people's experiences (AgeUK, 2020). Although living in multigenerational households is common in minority ethnic communities it does not always guard against loneliness, which is deeply subjective and often concealed among older minority ethnic (Khan, 2014). During the pandemic, loneliness triggered mental health problems such as anxiety and depression among older adults (Armitage and Nellums, 2020). Organisations such as Good Things Foundation (2020) promoted online platforms to foster social support and belonging, but digital access and literacy gaps hindered their effectiveness. A digital divide persists between older minority ethnic people and older White British populations due to a digital skills gaps, disabilities and financial limitations (Kings Fund, 2023).

1.1.10 Comorbidities and *e*xperiences of *i*llness

Comorbid conditions reflect social patterns and are shaped by socio-economic status, ethnicity, age, race and disability (Álvarez-Gálvez et al. 2023). Older individuals from Indian, Pakistani, Bangladeshi and Black Caribbean backgrounds face higher rates of multimorbidities such as hypertension, diabetes and cancer, which increases their mortality risk from COVID-19 (Walker et al. 2021). In Britain, Black men are twice as likely as White men to be diagnosed with and die from prostate cancer (Lloyd et al. 2015). Additionally 73% of the Black adults are obese compared to 63% of White and 58% of Asian adults (Platt and Warwick, 2020). Reduced healthcare access among minority ethnic groups contributes to unmanaged comorbidities, increasing vulnerability and mortality risk. These comorbidities made older minority ethnic people more susceptible to COVID infection, illness and death (PHE, 2020; Walker et al. 2021). Research exploring genetic and biological links to COVID-19 severity in minority ethnic groups remains inconclusive (Patel, Kooner and Zhang, 2023).

Research shows a positive correlation between the social determinants of health (SDoH) and the prevalence of chronic disease and COVID-19 (Embury, 2022). Preventable chronic disease and COVID-19 deaths require action on structural health disparities (The King's Fund, 2022; ONS, 2024; WHO, 2024). Preventive care and early intervention are crucial in reducing health inequalities across population groups (NHS, 2025). This links with the SDoH framework (WHO, 2021; Buzelli et al. 2022). WHO (2021) defines SDoH as the environmental conditions influencing how people are born, grow, live, work and age, and access healthcare systems. These conditions are shaped by structural forces like economic systems, political decisions and social policies (WHO, 2021). Satcher (2010) and Hiam et al. (2024) identify education, housing, food access, green spaces, healthcare, justice and freedom from discrimination (racism, classism, sexism) as key social and structural factors. Addressing these conditions requires collective action involving government and civil society, rather than solely relying on individual responsibility (Satcher, 2010; Hiam et al. 2024; Wilensky and Satcher, 2009). Wilensky and Satcher (2009) call for the inclusion of health in all policies, since not all social determinants are directly controlled by the health sector, however social and economic policies still affect health outcomes. They argue that addressing health disparities requires focusing on the life course

alongside current circumstances and not just one's present health conditions. Wilensky and Satcher (2009) stress the importance of targeting children when applying SDoH strategies as early development influences long-term health outcomes.

Following their UK cross-sectional survey of children which established ethnic differences in type 2 diabetes in the children, Whincup et al. (2010) called for the early prevention of diabetes before adult life. The unequal distribution of social conditions across groups by ethnicity, race, gender, and deprivation sustains health inequalities in the UK (Hiam et al. 2024). Hiam et al. (2024) notes the intersection of multiple factors. In the UK, residents in the most deprived areas face multiple disadvantages including structural racism, and most often lack resources to reduce health risks (Hiam et al. 2024). Minority ethnic groups are more likely to live in poverty, poor housing and deprived areas (Joseph Rowntree Foundation, 2024), highlighting how ethnicity and poverty intersect, and expose the groups to increased risk of ill health. Hiam et al. (2024) observe that older adults are also disproportionately affected by the cost-of-living crisis which negatively affects their life expectancy. Older minority ethnic people embody intersecting identities that increase their risk of illness, comorbidities and death from COVID-19 and other chronic conditions. Limited data on their early life and migration experiences constrains understanding of how past life circumstances in the country of origin shaped current health outcomes. This lack of insight highlights the importance of examining how illness is understood, interpreted and managed within individuals' social and cultural contexts.

Since illness refers to the social meaning of a disease (Conrad and Barker, 2010), understanding individuals' experiences supports holistic care and wellbeing. Illness encompasses how individuals, families and healthcare professionals perceive, manage and respond to disease (Lubkin and Larsen, 2013). Perceptions of illness are shaped by social, cultural and personal factors (Missel et al. 2022) including identity and past experiences (González-González et al. 2021; Missel et al. 2022; Larsen, 2013). Larsen (2013) notes that an individual's coping strategies or responses to illness are influenced by their perceptions of the illness. This in turn affects their decisions on the treatment and adherence.

Lived experiences of COVID-19 and LC remain under researched due to the disease's novelty (Sun et al. 2021; Rofail et al. 2022; Hoste et al. 2023). However studies report emotional and psychological challenges including fear, anxiety, terror, depression and mental fatigue linked to LC. (Rofail et al. 2022; Russell et al. 2022; Hoste et al. 2023). These effects significantly disrupt daily life and wellbeing (Rofail et al. 2022). Existing research lacks intersectional analysis of identities such as age, ethnicity, race, gender and disability. Without this insight, healthcare providers cannot effectively support older minority ethnic individuals.

Conclusion

Understanding the history of Britain's race relations is essential to explaining contemporary health inequalities. Although overt racism has declined, institutional and unconscious biases persist. Acknowledging such implicit bias is critical to addressing institutional racism. This section traced how racism has both shaped and been shaped by enslavement, imperialism, colonialism and migration. White colonial powers embedded racism through exploitation, degradation, oppression and dominance to assert control and superiority. Racism remains entrenched in institutional structures, contributing to poor health outcomes for minority ethnic groups. Britain's current health disparities stem from its colonial and racial legacy. COVID-19 exposed the racialised nature of healthcare risk and revealed entrenched racial and class injustices. The formation and fluidity of identities are shaped by multiple factors, which include ethnic histories, government policy, societal norms and national discourse on race and British identity. Older minority ethnic individuals already physically, socially and emotional vulnerable face overlapping identities that heighten their COVID-19 risk. Intersecting factors, such as comorbidities, disability, race, ethnicity and socio-economic status compound their vulnerability to COVID-19 and chronic disease mortality. Structural racism and discrimination further increase the risk of ill health and death for these groups. An intersectional lens is essential to analyse the layered risks affecting these communities. Accordingly, the next section examines the epistemology of risk, blame and trust.

1.2 EPISTEMOLOGY OF RISK, TRUST AND BLAME

In the previous section, the role of intersecting identities in shaping COVID-19 risk patterns, health and health outcomes was discussed. This section builds on this by critically analysing notions of risk, trust and blame.

Introduction

This section examines the historical development of risk and how its meanings have been shaped across different social and historical contexts. The negative and positive contexts of risk are also discussed here whilst also distinguishing the technical-scientific and lay persons' knowledge perspectives. The chapter further explores the social amplification of risk approach (SAR), trust, risk, communication and conspiracy theories in relation to risk.

1.2.1 Tracing the changes in understanding of risk

The meaning of the concept of risk has shifted across time and space (Luhmann, 1993; Lupton, 1999; Alaszewski, 2009) and is shaped by specific situations and contexts (Lupton, 2006). While the etymology of 'risk' remains debatable, it is commonly linked to danger and harm (Luhmann, 1993; Lupton, 1999; Li, Hills and Hertwig, 2020). In pre-modern times, risk was regarded as divine punishment with events such as storms and floods interpreted as divine retribution (Luhmann, 1993).

The seventeenth century saw a marked shift in risk perception, driven by industrialisation, capitalism, surveillance institutions, urbanisation, rationalism and Enlightenment thought (Beck, 1992; Lupton, 1999). People began to see themselves as capable of understanding and controlling nature (Lupton and Tulloch, 2002). Risks became framed as systematic, measurable and predictable phenomena (Beck, 1992b). Insurance companies applied statistics and probabilities to guard against losses (Lupton, 1999; Lupton and Tulloch, 2002). Beck (1992) refers to this shift as the "scientisation" of risk.

Risk and uncertainty are some of the defining characteristics of contemporary Western society (Beck, 1992; Aven and Renn, 2009; Alaszewski, 2023). The link between them has led scholars to describe contemporary society as risk-averse (Adam, Beck and van Loon, 2000). Contemporary risks include environmental or ecological, lifestyle, medical, interpersonal, economic, criminal, etc (Aleszewski, 2023; Lupton, 1999, 2022; Beck, 1992; Giddens, 1998). Today risk is defined as 'the probability that a

particular adverse event occurs during a stated period, or results from a particular challenge' (Newby, 1997 citing Risk Royal Society). Aven and Renn (2009), emphasise the uncertainty about the severity of events and consequences on humans or on what they value. This study therefore conceptualises risk through the lens of human agency and its consequences.

Fear, insecurity, panic and anxiety often accompany experiences of risk and uncertainty (Bauman, 2000; Giddens, 1990; Lupton, 1999; Crawford, 2004; Beck, 2009; Alaszewski, 2023). Beck (1992) argues that such responses are associated with contemporary social transformations and heightened awareness of risk. Emotions such as fear, anger or disgust are intertwined with perceptions of risk (Lupton, 2013). Pandemics such as COVID-19, HIV/AIDS and SARS generate strong emotional responses such as anger and disgust among both experts and lay persons. These strong emotional responses often fuel blaming and exclusion while disproportionately affecting vulnerable groups (Lupton, 2013). Recognising these emotional dimensions is vital for understanding the pandemic's impact on older minority ethnic populations in the UK.

1.2.2 Negative and positive contexts of risk

Hamilton et al. (2007) challenge the exclusive framing of risk as negative, especially in health contexts, noting that it can also have neutral or positive dimensions. Lupton and Tulloch's (2002) study shows that some individuals pursue risk to achieve personal fulfilment or self-actualisation. Building on this, Lupton (2006) refuted stereotypes of risk takers as reckless or uninformed. While people often seek to avoid risk, Lupton (2006) found voluntarily engagement in calculated risks (e.g. surfing or rock climbing) as part of informed decisions.

Risk is subjective and is largely shaped by social factors and power (Douglas and Wildavsky, 1983; Lupton, 1999; Zinn, 2008). Since it is socially constructed, expert-led technical definitions often face criticism (Roeser et al. 2012). Lupton (1999) positions technical approaches as weak socio-cultural models. Wester (2012) in Roeser et al. (2012) argues that values, ideology and belonging often outweigh knowledge in shaping perceptions. What one considers as risky depends not only on knowledge but also on socio-cultural and individual values (Douglas, 1992). This is crucial for understanding behavioural responses and mitigating impacts.

1.2.3 Risk knowledge and perception of risk

Various scholars differentiate technical-scientific risk knowledge from lay perspectives. Proponents of the former emphasise objectivity and precision, positioning expert knowledge as best for quantifying risk (Kosovac et al. 2019; Lupton, 1999). Zinn (2006) critiques the distinction between objective vs. subjective risks, arguing that no universal rationality exists and responses must be context-specific. Thus, the British public's apparent risk-aversion reflects rationality shaped by past scientific controversies not irrationality.

Sociological scholars challenge the exclusive reliance on technical framings of probabilities and calculation. Beck (1992, p. 55) claims that in risk society, knowledge comprises 'admixtures' and 'amalgams' of perceptions, values and beliefs rather than objective truths. Nickel and Vaesen (2012) and Irwin and Wynne (1996) link dismissal of lay knowledge to the knowledge deficit model which assumes scientific supremacy. Within this model, laypeople are framed as uninformed with scientific knowledge as normative standard (Irwin and Wynne, 1996). They argue that public misunderstanding not from ignorance but from a lack of empowerment to engage with risk discourse. Without expert access, laypeople assess risks differently often reaching divergent conclusions (Nickel and Vaesen, 2012; Powell, 2018). Nickel and Vaesen (2012) argue that with inclusion, laypeople are capable of critical reflection on risk. Wynne (1992, 2001) rejects portrayals of laypeople as passive recipients who must unquestioningly accept expert risk decisions. He further adds that public engagement rooted in lived experiences can enrich both personal and collective understandings of risk, especially in contexts like climate change and pandemics. It is therefore important to engage the public in discussions of risks such as climate change or pandemics.

Nickel/Vaesen (2012) and Irwin/Wynne (1996)'s reasoning connects with standpoint theory, which views marginalised groups as epistemologically privileged and best positioned to validate their perspectives (Smith, 1997; Collins, 2000). Technical knowledge alone excludes nuance (Nickel and Vaesen, 2012). Although Alaszewski (2009) acknowledges rational assessment's value, he warns that realism alone is reductionist if it excludes socio-cultural approaches. The exclusion of the public

reflects power imbalances: experts dominate decision-making, rendering laypeople invisible. Risk approaches must therefore recognise different forms of knowledge (Zinn, 2006) and acknowledge other actors (e.g., older minority ethnic people) as worthy contributors.

1.2.4 Risk perception

Pidgeon (1998, p.5) defines risk perception as ‘people's beliefs, attitudes, judgements and feelings, as well as the wider cultural and social dispositions they adopt towards threats to things that we value’. Therefore, subjectivity underlies risk perception. Basu (1973) argues that risk perception diverges from rational decision theory’s normative assumptions. Alaszewski and Horlick-Jones (2003) challenge models assuming laypeople assess risks illogically. They cite ineffective measles, mumps and rubella (MMR) vaccine campaigns that relied on safety assurances to change parental behaviour. Similarly, Duff (2003) highlights that drug campaigns in Australia show effective risk communication must reflect youth perceptions; otherwise, scientific messages remain disconnected, fueling mistrust of government. Recognising non-expert knowledge is therefore essential.

Risk perception during pandemics is shaped by factors such as adaptive capacity, cognitive bias, communication channels, geography, occupational exposure and inequities in access to risk mitigation resources (Schweizer et al. 2022; Herbec et al. 2022; Hanna et al. 2023). Misconceptions such as misinformation, misunderstanding or cognitive biases significantly affect behaviours (Herbec et al. 2022; Hanna et al. 2023). An example is cognitive bias, over/underestimating chances of favourable or unfavourable events (Herbec et al. 2022). Cognitive biases may reduce perceived risk, undermining motivation for protective behaviours (Herbec et al. 2022). Herbec et al.’s study on vulnerable British adults found that even those at high risk due to age, ethnicity, comorbidities or gender often failed to adopt protective behaviours, worsening inequalities. Recognising the role of cognitive bias helps explain older minority ethnic groups’ responses to interventions such as COVID-19 vaccination.

1.2.5 Decision theory and risk

Understanding risk response is central to analysing behaviour. The belief-desire model helps explain why individuals accept specific risks (Roeser et al. 2012). Roeser et al. (2012) emphasise the distinction between descriptive decision-making and normative rationality, while Basu (1973) frames decision theory around normative assumptions. Bruch and Feinberg (2017) argue that differences in beliefs and desires shape behavioural responses to risk (see also Roeser et al. 2012). Under conditions of uncertainty, decision-making may deviate from rationality (Slovic, 2016; Slovic et al. 2004; Tulloch and Lupton, 2003). However, emotions such as anxiety or fear may enhance rather than undermine rational decision-making (Roeser and Pesch, 2015). Linking risk and decision theory is therefore useful for understanding behaviour during crises such as COVID-19.

Scholars also note that risk perception and responses vary widely. Schweizer et al. (2022) argue that responses depend on perceived levels of risk. Individual differences may arise from intersecting identities, including class, gender, race, ethnicity, social status, health, and disability (Finucane et al. 2000; Herbec et al. 2022). This suggests that certain groups (e.g. older people from minority ethnic backgrounds) may perceive risk differently due to structural inequalities. Herbec et al. (2022) further link risk perception to health behaviour theories, suggesting that perceiving certain factors as risky can motivate protective behaviours, although individual capacity and contextual constraints remain crucial.

1.2.6 The Social Amplification of Risk (SAR) approach

Kasperson et al.'s (1988) Social Amplification of Risk (SAR) approach explains why public attention to risk may diverge from expert assessment. Differences in perceptions of risk's nature, scale or severity can amplify or downplay concern (Schweizer et al. 2022). High risk may be downplayed by the public while low probability risks may be amplified. SAR also clarifies how amplified risk signals shape public reactions (Unlu et al. 2024; Vaesen, 2012).

SAR emphasises that risk events interact with social, institutional and psychological dynamics to shape perception and behaviour (Vaesen, 2012). It also highlights that amplification can trigger secondary impacts beyond the initial risk event (Kasperson

et al. 1988). Beck (1992; p.80) notes catastrophes can erode democratic freedoms while Lupton (2022, p.93) highlights stigma and declining institutional trust. Lupton (2022) observed ageism during the pandemic, especially online. Fjaeran and Aven (2021) describe such ripple effects as weakening trust. Unlu et al. (2024) suggest that SAR contributed to vaccine hesitancy in Finland. SAR helps explain how media amplification influences behaviour, particularly among older minority ethnic groups.

1.2.7 Risk and trust

Trust is dynamic, multifaceted and evolving (Möllering, 2001, 2005; Khodyakov, 2007). Taylor-Gooby (2006) draws from scholars such as (Gilson, 2003; Lewicki and Bunker, 1996; Mayer et al. 1995). He defines trust as both rational judgement and emotional bonds formed through empathy and interaction. Trust also involves accepting vulnerability based on faith in the others' intention (Chauhan and Campbell, 2021; Rousseau et al. 1998).

Trust is often characterised as institutional or interpersonal (Luhmann, 1990; Rousseau et al. 1998). Institutional trust refers to confidence in impersonal systems or institutions (Giddens, 1990) Giddens (1990) describes it as "faceless" because it relies on belief in abstract frameworks. Interpersonal trust termed "facework trust" by Giddens (1990) emerges through direct social relations. It is built via interaction and engagement (Chauhan and Campbell, 2020). Kroeger (2016) sees facework trust as a bridge to institutional trust grounded in how institutional agents embody system values. Giddens (1990) suggests that institutional trust hinges on trust in system representatives, framing trust as linear.

In Giddens' (1990) account of late modernity and in contemporary analyses of risk (Alaszewski, 2023) risk and trust are interconnected. Giddens (1990) notes that risk influences decisions to trust, whereas trust manages risks from ignorance and uncertainty. Gilson (2003) and Alaszewski (2023) argue that trust is vital in healthcare, influencing behaviour under uncertainty. Alaszewski (2023) adds that public trust in government increases willingness to act on risk information. For patients to agree to have medical procedures or use services, trust is key (Powell, 2018). Therefore, understanding risk and trust is key to interpreting older minority ethnic people's

responses to government vaccination campaigns, COVID-19 risks and relationships with health services.

Various conditions shape public trust (Newman et al. 2020; Siegrist, 2021; Giddens, 1991). Factors such as age, socio-economic status and class are central. Giddens (1991) adds that past experience and partial understanding of risks influence trust. Siegrist (2021) argues that past trust is rooted in past experience, shaping future expectations. Giddens (1991, p.3) supports Möllering, (2006) idea of a 'leap of faith' (see also Möllering, 2001). Giddens explains that trust grounded in such a leap, suspends doubts when knowledge is incomplete; it is unnecessary when knowledge is complete. This leap reflects a quasi-religious belief tied to ontological security.

Trust is also inherently relational (Powell, 2018). Although the link between trust and risk perspective remains debatable it often aligns with shared identities or values (Goldenberg, 2023;Tulloch and Lupton, 2003; Vignoles et al. 2021; Siegrist, 2021). Siegrist (2021) terms this "value similarity" which is a foundation of social trust. Vignoles et al. (2021) found that appeals to shared identity (family, community, nation, humanity) during COVID-19 enhanced public compliance.

Davis and Lohm (2020) write that pandemic communication is also trusted communication. Persuading publics to act is therefore asking them to trust experts' knowledge. The different position of experts and laypeople in society also influences trust (Salita, 2015; Bennett, 2020; Calnan, 2020a). These positions reflect widening knowledge gaps and comprehension differences on risk issues. For example, in the UK, most COVID-19 guidelines were issued by virologists and epidemiologists, leading to uneven understanding and diminished trust (Calnan, 2020a). Therefore, power differences both hinder comprehension and fuel mistrust, making trustworthy institutional environments essential.

Lupton (2022) describes the contemporary era as "post-trust" society. Social theorists such as Giddens (1990, 1991) and Beck (1992, 1999), argue that public trust in governments and science has eroded in late modernity. This erosion is linked rising perceptions of risk. Giddens (1991) and Beck (1992) suggest that in earlier phases of modernity, there was more widespread trust of the state and welfare institutions to protect them from harm. However, Beck (1992) and Giddens (1991) argue that late modernity has shifted responsibility toward individuals emphasising reflexivity and

leading to a reduction of trust in professionals. Several factors explain this decline in public trust in institutions like healthcare (Fjaeran and Aven, 2021). These include epistemological doubts about knowledge authenticity, waning confidence in science, industrialisation's effects and neglect of lay concerns. Charura et al. (2023) found COVID-19 vaccine hesitancy among UK ethnic minorities linked to mistrust in medicine and science, with higher hesitancy than White British populations (Razai et al. 2021). Porter and Porter (1988) trace vaccine hesitancy's historical roots to colonial-era resistance to smallpox vaccination where fears about side effects drove opposition. Understanding these contexts helps explain contemporary vaccine hesitancy.

Racism in healthcare settings also lowers trust among minority ethnic groups (Paul et al. 2022). In their study on COVID-19 vaccine uptake, Paul et al. (2022) found that 6.69% of ethnic minority participants cited racism in medical settings as a reason for refusing vaccination. These findings reflect Schultz's (2006) idea that marginalisation fosters cautious and resistant trust. Such disparities provide deeper insights into racial inequities in health outcomes. Trust is shaped by intersecting identities such as age, gender and disability which affect healthcare access and outcomes (Fjaeran and Aven, 2021; Mitchell and Glendinning, 2008). One example is the 1969 UK case where 21 women of Indian origin were unknowingly fed iron-59 in chapatis, exposing them to health risks (Neuberger et al. 2023; Gilbert, 2023). This scandal illustrates how racism and sexism erode trust; the women's anger and anxiety reflect the emotional cost of betrayal (Crawford, 2004; Lewis and Weigert, 1985).

Contradictory risk information, rapidly changing COVID-19 guidance, and political scandals deepened public uncertainty and epistemic mistrust (Hanna et al. 2020, 2023). King's College reported trust in the UK government's pandemic response fell from 69% to 51% (2020). Bostrom (1997) notes that even when experts disagree about harm, clear communication is essential. Lupton (1999) adds conflicting advice leaves laypeople unsure whom to trust. Lupton (2022) further stresses that minority ethnic groups face intensified mistrust due to historical and structural factors.

When laypeople feel excluded and alienated from risk discourse, trust deteriorates (Vaesen, 2012; Wynne, 2001; Powell, 2018). Inclusive public engagement fosters trust building because such risks affect health and life chances (Möllering, 2001; Lupton,

2022; Alaszewski, 2023). Vaesen (2012) argues engagement is a robust, not naive basis for societal confidence. Beck (1992) and Giddens (1991) warn that institutional inaccessibility fuels alienation. For example, lack of transparency in the SAGE eroded trust (Scally et al. 2020) (see Chapter 1.1.4). Rebuilding trust requires robust public engagement (Zinn, 2006).

1.2.8 Risk and blame

Risk is political and is used to attribute blame and responsibility (Douglas, 1992; Beck, 1992; Giddens, 1991). Douglas (1992) argues that risk operates as a cultural strategy that helps communities interpret dangers, especially those posed by outsiders. What one group sees as risk may be a moral violation to another (living in multigenerational homes was treated as a COVID-19 risk factor in some debates) (Ghosh et al. 2021).

Douglas (1992) links moralisation to blame. Camorrino (2023) defines blame as a cycle of accusations, indignation and exclusion that relives anxiety about risk. The "Other" is often perceived as the source of risk and becomes the target of blame (Olofsson et al. 2014; Douglas, 1992). This relies on knowledge gaps and moral judgements, that marginalise labelled threats (Lupton, 2022). Thus risk discourse entangles morality and ethics (Montelius and Giritli Nygren, 2014; Douglas, 1992; Giritli Nygren and Fahlgren, 2013). In Douglas' (1992) cultural theory, being at risk equates to irresponsibility and deviance, opposing the idealised "civilised" norm.

Blame reinforces power structures, cementing dominant social positions (Joshi and Swarnakar, 2021; Singer, 2007; Singer et al. 2017). The 'Other' denotes those seen as deviant by dominant groups (Lupton, 2022); risk discourse thus becomes a tool for 'Othering' and social exclusion (Montelius and Nygren, 2014). Lupton (2022) critiques this treatment of individuals, and groups as outsiders for perceived irresponsibility, arguing that it reinforces stigma and labelling. COVID-19, HIV/AIDS and SARS produced stigma tied to cultural representations of knowledge, attitudes, norms and behaviours (Bhavna and Pradip, 2021; Singer, 2015 p.37; Newman et al. 2020).

During COVID-19, Chinese people were stigmatised as virus spreaders (Brown, 2020). Hanna et al.'s (2020) research found some adults blamed young people for carelessly spreading the virus. The media also amplified stigma by using ageist language to Other older people. People with disabilities were also stigmatised (Antova,

2020; Shakespeare *et al.*, 2022; Voluntary Organisation Disability Group, 2023). This is significant since age increases the likelihood of disability (Gbessemehlan et al. 2024). Brown (2020) condemned the homogenous categorisation that contributed to older adults' neglect during the pandemic. Minority ethnic groups were blamed for spreading COVID-19. Meghji and Niang (2022) critique PHE's cultural pathologisation of these communities and argue that structural inequality and not culture underlies mistrust and testing fears, calling instead for material improvements (e.g. better housing).

Rebuilding trust between experts and laypersons is essential. Vaesen (2012) suggests experts who acknowledge limitations and accept critique improve legitimacy and public trust. Fjaeran and Aven (2021) recommend an uncertainty-based approach to risk governance rather than a narrow, probabilistic one, i.e. explicitly acknowledging uncertainities and knowledge limits when defining and communicating risk to reduce amplification.

Breakwell (2020) views trust and mistrust as coexisting. Mistrust is a critical trust combining reliance with scepticism (Breakwell, 2020). Fjaeran and Aven (2021) argue that healthy sceptism can strengthen risk understanding. Critical trust is regarded as enhancing institutional accountability while maintaining public legitimacy. This challenges the binary framing of trust versus mistrust, allowing a more nuanced view of how society navigate uncertainty. Thus, understanding trust and mistrust is vital to the effective operation of social systems. Nickel and Vaesen (2012) cited in Roeser et al. (2012) emphasise experts' moral duty to avoid needlessly provoking fear. Powell (2018) urges UK health experts to remain critically reflective and sensitive to diversity in healthcare delivery.

1.2.9 Risk, social construction and cultural values

Risk is not purely objective, rather it is socially constructed through cultural meanings, political discourse and institutional power (Douglas, 1992; Lupton, 2006; Alaszewski, 2009). Sociologists therefore interpret risk through social and cultural lenses. Due to socio-cultural differences, individuals and groups vary in how they identify, perceive and respond to risks (Alaszewski, 2009; Lupton, 2006; Douglas, 1992). Douglas (1992, p.40) highlights risk's moral, ethical and political dimensions and describes

perception as a ‘culturally standardised response’. Communities express cultural identity by the risks they prioritise.

Power dynamics are central to Douglas’ (1992) cultural theory. Giritli Nygren and Fahlgren (2013) argue that norms and values arise from hegemonic discourse, creating context-dependent privileges. Tulloch and Lupton (2003) critique Douglas for oversimplifying risk’s moral boundaries since risk is complex and dynamic. Lupton (1999a) notes Douglas underplays intersections of gender, age and class in shaping perceptions which is a shortcoming from an intersectional perspective. Proponents of intersectionality would also find this problematic. Nevertheless Douglas (1992) shows how risk embeds in identity and group dynamics since values shape what is seen as risky and how people respond. Cultural theory therefore illuminates how identities construct distinctions between the self and the Other (Douglas, 1992), yet its limited attention to intersecting identities remains a key weakness. This omission restricts its applicability to intersectional and IRT-informed analyses, particularly in understanding how older individuals from minority backgrounds responded to the pandemic and related government regulations.

1.2.10 Risk, individualism and inequalities

Beck (1992) and Giddens (1991) argue that contemporary societies are characterised by increasing individualisation, whereby responsibility for managing social and health risks has shifted from collective institutions towards individuals. Within their framework of late modernity, individuals are expected to make reflexive decisions about their lives and assume greater responsibility for navigating uncertainty and risk. However, this type of historical periodisation has been challenged by Povinelli (2016), who argues that dividing societies into distinct stages of development risks reproducing linear and Eurocentric accounts of social change. Instead, Povinelli (2016) proposes the concept of late liberalism to emphasise how contemporary societies remain shaped by overlapping colonial histories, historically rooted power relations and forms of governance that continue to influence institutions and everyday practices. From Povinelli’s (2016) perspective, contemporary experiences of social life, including experiences of inequality and vulnerability, should not be understood solely as

products of a new historical phase but also as shaped by enduring relations of power and colonial histories.

This thesis draws on Beck's (1992) and Giddens' (1991) concept of late modernity as an analytical framework for understanding perceptions of risk, while recognising Povinelli's (2016) reasoning that these processes are unevenly experienced and shaped by broader relations of power.

A key dimension of contemporary risk discourse is the individualisation of responsibility. Neoliberal forms of governance promote individual responsibility for managing risk, encouraging individuals to regulate their own behaviour and minimise potential harms (Lupton, 1999; Montelius and Giritli Nygren, 2014). This shifts the blame away from the state and toward individuals (Bauman, 2000). Montelius and Giritli Nygren (2014) critique governments' expectations that individuals self-govern when confronted with risks, arguing that this leads to social divisions. The creation of binaries around who is risky reinforces societal divisions (Lupton, 2006, 1999). The individual is expected to be enterprising and able to self-regulate health to avoid health risks (Montelius and Giritli Nygren, 2014). Lupton (1999) notes that this governmentality approach equates lack of self-control with moral failing. Yet identity-based disparities mean not everyone can self-govern equally (Montelius and Giritli Nygren, 2014). Montelius and Giritli Nygren, (2014) argue that risk is entangled with power and takes place along lines of social difference. Self-governance depends on access to cultural capital, habits and values (Ohta et al. 2019). Povinelli's (2016) critique of late liberalism similarly suggests that expectations of individual responsibility can obscure the enduring effects of colonial, racialised and socio-economic inequalities. Older minority ethnic people, already marginalised, face additional barriers to self-governance during crises such as COVID-19.

Bauman (2000) contends that socio-economic inequalities constrain marginalised communities' choices. Those facing structural inequalities are disproportionately disempowered by individualisation (Brannen and Nilsen, 2005). Thus, marginalised groups such as older minority ethnic people and people with disabilities are especially vulnerable to disempowerment. Beck and Beck-Gernsheim (2002) and Bourdieu and Bourdieu (2002) argue that individualisation cannot address systemic problems such as poverty and social exclusion. Welfarism as a safety net is critical for individualisation

to be viable (Beck and Beck-Gernsheim, 2002). The pandemic deepened inequalities based on socio-economic status, gender, age and race (Brown and Zinn, 2021; Lupton, 2022). Fear of others as risk carriers strained social bonds and intensified loneliness (Lupton, 2022). Sim et al. (2020) add that business closures and physical distancing triggered panic buying, disproportionately affecting marginalised groups unable to stockpile. COVID-19 illuminated the challenges of individualisation, especially for vulnerable groups such as older people, minority ethnic people and those living with disabilities (Ganguli-Mitra et al. 2020).

It is reported that during the pandemic, social structures and institutions maintained and reproduced social inequalities. For example, research by the Institute for Community Studies in the UK (2019-2020) revealed growing concern over increasing societal individualism. Participants felt increasingly vulnerable amid rising socio-economic disparities. While community solidarity initially supported some vulnerable people, later resilience was at risk because of growing inequalities (Morrison, Fransman and Bulutoglu, 2020). Such resilience weakened as inequalities widened (Morrison, Fransman and Bulutoglu, 2020). Ganguli-Mitra et al. (2020) criticise the shielding model for being discriminatory and overlooking the complex lives of those deemed vulnerable. Ganguli-Mitra et al. (2020) argue it was ageist, as it placed unfair responsibility on vulnerable individuals to manage their own health and wellbeing. Olofsson et al. (2014) argue that framing risk as individualised masks structural inequalities and entrenches power hierarchies.

With the transformation of the nuclear family (Beck, 1992), growing old and the welfare of older people have been transformed from a collective social responsibility to an individual experience. Powell and Taylor (2016) assert that the complex interplay of risk, choice, ageing and structure significantly shapes ageing trajectories. Powell and Taylor (2016) note that in the UK, extending working lives is a welfarist tactic to manage ageing in a risky society. This illustrates that growing older in the risk society is fraught with uncertainty, as argued by Beck (1992) and Giddens (1991). Giddens (1991) adds that self-identity is forged through navigating day-to-day choices in a culture of risk. Individuals are expected to balance opportunities and risks in daily decision-making. However, as Povinelli (2016) argues, these choices are never made under equal conditions but remain embedded within historically produced social

inequalities. This is especially challenging for marginalised groups such as older minority ethnic people.

In conclusion, while Beck (1992) and Giddens (1991) provide a valuable framework for understanding how contemporary societies increasingly individualise responsibility for managing risk, Povinelli (2016) cautions against treating these processes as the universal outcome of a distinct stage of late modernity. Instead, Povinelli's (2016) concept of late liberalism highlights how contemporary experiences, including experiences of risk and vulnerability, remain shaped by enduring colonial, political and socio-economic inequalities. Accordingly, researchers and policymakers must critically address diversity, inclusion and inequality within the framework of individualised risk rather than attributing responsibility solely to individuals. Risk should therefore be understood not only as an individual responsibility but also as a phenomenon shaped by intersecting structures of power, inequality and social difference.

1.2.11 Risk and communication

Scholars highlight that communication shapes and amplifies risk perceptions and that public responses to media are complex. Calnan (2020a) and Lupton (2022) agree that risk communication unfolds in social settings marked by competing interests, power relations and conflicting agendas. However, Lupton (2006) cautions that extensive media coverage does not always generate concern among audiences. Audiences may dismiss messages as inaccurate or irrelevant to their context (Lupton, 2006). Health related decisions are shaped by factors such as personal experiences, social networks and professional or commercial advice (Lupton, 2006). Although media is an important source of information on health risks, social networks and interaction with health professionals significantly influence decisions like vaccination (Petts and Niemeyer, 2004; Lupton, 2016). Bodemer and Gaissmaier (2012) in Roeser et al. (2012) argue that patients who misunderstand expert advice may struggle to make informed health decisions. Clear risk communication is therefore vital to address misconceptions, knowledge gaps and anxieties (Bostrom, 1997).

Lupton (2022) also criticises officials who downplay risk as this may amplify anxiety. COVID-19 communication in the UK was blamed for contributing towards fake news and conspiracy issues (Schweizer et al. 2022; Calnan, 2020b). These scholars argue that social media reinforced misinformation, polarising public knowledge and

undermining official risk strategies. For example, vaccine misinformation bred public mistrust (Open Knowledge Foundation, 2020). However, limited research explores how such messaging affected older minority ethnic individuals. Understanding this is crucial particularly considering future pandemics and efforts to achieve health equity.

1.2.12 Risk and conspiracy theories

Conspiracy theories often stem from misconceptions, information gaps (Van Prooijen and Jostmann, 2013; Van Prooijen and Douglas, 2018). Douglas and Sutton (2023) define conspiracy theory as covert efforts by actors to shape outcomes. Douglas et al. (2017) identify three psychological drivers namely: epistemic, existential and social motives. Epistemic motives arise when individuals try to make sense of complex, ambiguous events (Peters, 2021; Garrett and Weeks, 2017; Douglas and Sutton, 2023). Existential motives stem from threats, helplessness and lack of control during crises such as COVID-19 (Van Prooijen, 2020; Peters, 2021; Douglas and Sutton, 2023). Social motives reflect attempts by groups to protect identity and cohesion when facing perceived threats from dominant institutions (Van Prooijen and Douglas, 2018; Douglas and Sutton, 2023).

Conspiracy thinking is more prevalent among marginalised and stigmatised communities (Crocker et al. 1999; Davis et al. 2018; Van Prooijen and Douglas, 2018). It correlates with low education, income, unemployment, limited social ties, poor media literacy, being male and unmarried, and lower ethnic status (Uscinski and Parent, 2014; Douglas et al. 2016; Craft et al. 2017; Freeman and Bentall, 2017). Some research highlights positive effects such as cohesion, empowerment and scrutiny of authority *(*Swami and Coles, 2010; Dentith, 2016; Locke, 2009; Franks et al. 2017). However, others link conspiracy beliefs to risky behaviours, vaccine hesitancy and decreased health-seeking (Bertin et al. 2020; Biddlestone et al. 2020; Chayinska et al. 2022; Hughes et al. 2022; Natoli and Marques, 2021). Conspiracy believers face greater mental health risks (Natoli and Marques, 2021; Hughes et al. 2022; Zwar, König and Hajek, 2022). Additionally, conspiracy beliefs deepen social divisions, foster blame, and erode trust (Douglas and Sutton, 2023). Thus, such theories reflect widespread mistrust between marginalised communities and institutions (Douglas and Sutton, 2023).

While conspiracy theories provide insight into public trust and behaviour, limited research has explored their impact on older ethnic minority ethnic groups. Understanding how narratives are formed, transmitted and interpreted by older minority ethnic groups is crucial to address vaccine hesitancy and preparing well for future pandemics.

1.2.13 Critiques of historical periodisation

While Giddens (1991) and Beck (1992) distinguish between premodern, modern, and late modern forms of society, several scholars have questioned both this historical periodisation and the assumption that societies develop through a linear sequence of stages. Povinelli (2016) argues that dividing societies into distinct historical stages can imply linear and evolutionary models of social development. Instead, Povinelli (2016) argues that contemporary societies are shaped by overlapping colonial histories and historically rooted power relations. These histories continue to influence contemporary societies through institutions, governance and everyday practices. It is from this perspective that modernity should not be understood as a distinct historical phase that replaces earlier forms of social life, but as a complex and contested set of social relations (Povinelli, 2016).

Different scholars have also critiqued the distinction between tradition and modernity. For example, Rudolph and Rudolph (1984) challenge the assumption that tradition and modernity represent opposing stages of social development. Through drawing on political developments in India, Rudolph and Rudolph (1984) demonstrate how institutions often regarded as traditional, such as caste and religious identities did not disappear with modernisation. Instead, these institutions have adapted to the democratic political processes, thus showing how some traditions have remained active and influential within contemporary societies (Rudolph and Rudolph, 1984).

Dube (2016) extends this critique by arguing that modernity is neither singular nor universally experienced but is historically produced through diverse colonial and social processes. He emphasises that different groups experience and negotiate modernity in varied ways rather than moving through a common developmental pathway. Collectively, these perspectives challenge linear understandings of social development and suggest that traditions, religious beliefs and cultural practices should

not be viewed as remnants of an earlier era but as continuing and evolving aspects of contemporary social life.

These critiques caution against interpreting religious beliefs, cultural practices or lay understandings and perceptions of risk as premodern. Rather, Povinelli (2016), Rudolph and Rudolph (1984) and Dube (2016)'s criticism suggest that diverse forms of knowledge and meaning-making continue to coexist within contemporary societies.

The next section explores literature on the older minority ethnic people's ageing, wellbeing and resilience, with a particular focus on the populations in the UK.

1.3 AGEING, WELLBEING AND RESILIENCE

Introduction

This section explores literature on ageing, wellbeing, and resilience, focusing particularly on older minority ethnic populations in the UK. Ageing is a life course process experienced, however this chapter centres on older age, especially the third and fourth ages which are key to understanding older minority ethnic experiences. These stages are most relevant to the lived realities, vulnerabilities, and agency of older minority ethnic individuals, especially during the COVID-19 pandemic.

1.3.1 Ageing

Ageing is a lifelong, multifaceted process. Walker (2018) defines it as a continuum beyond retirement, shaped by both intrinsic (biological) and extrinsic (environmental/social) factors with the latter often exerting greater influence. In the UK, older adults' health is shaped by extrinsic risk factors such as poverty, social exclusion, and limited physical activity, issues more acutely experienced by minority ethnic groups (Foster et al. 2019; Everest et al. 2022). These socially patterned risks reinforce inequalities (Everest et al. 2022). SDoH (education, income, housing, social support) are central to understanding ageing disparities (WHO, 2021).

From a life-course perspective, health outcomes accumulate across the lifespan (Walker, 2018; Elder, 1998; Jones et al. 2019). Chronic conditions often emerge from earlier systemic inequalities (Kuruvilla et al. 2018). Walker (2018) argues that whilst ageing is universal, progressive, intrinsic and generative, it is heterogeneous. Some older adults with illness remain active, while others without illness experience disability (Depp and Jeste, 2006; Verropoulou and Tsimbos, 2017).

The Disablement Model highlights that impairments can lead to functional limitations, but outcomes are shaped by psychosocial factors such as quality of life and access to care (Femia, Zarit and Johansson, 2001; Oliver, 1998). Minority ethnic groups face higher disability risks especially older women due to intersecting disadvantages (Williams, Cox and Cooper, 2020). These dynamics were evident during the pandemic, where frailty and disability intersected with structural inequalities.

1.3.2 The life course

Laslett (1980, 1991) conceptualises the human life course as comprising four distinct stages. The first is characterised by dependence, socialisation, immaturity and learning. The second is notable for independence, maturity, work responsibilities and child-raising (Laslett, 1991; Günder, 2014); the third is identified as an era for personal achievement and fulfilment following retirement; the fourth is late old age, a time of final dependence, decline and death (Laslett, 1987, 1991, 1994; Günder, 2014).

Laslett (1987) characterises the third age as a post-retirement stage of health, autonomy and fulfilment shaped more by culture than chronology. Higgs and Gilleard (2015) frame it as a cultural field of lifestyle and identity. Third-agers often pursue travel, volunteering, and community participation, hallmarks of “successful ageing” (Higgs et al. 2009; Centre for Ageing Better, 2024). However, access is stratified by age, class, gender, and race (Phillipson, 2015; Skerrett, Spira and Chandy, 2022). For minority ethnic elders, comorbidities, cultural exclusion, and inequities often limit such opportunities (Centre for Ageing Better, 2023; Teagle et al. 2022). The pandemic disrupted these avenues underscoring the need to foreground intersectionality in ageing discourse.

The fourth age is a stage of frailty, decline, dependence, and social detachment (Laslett, 1987; Higgs and Jones, 2009; Melzer et al. 2015). It is often seen as a symbolic space of lost agency (Gilleard and Higgs, 2010), and linked with institutionalisation, medicalisation and autonomy loss (Schröder-Butterfill and Marianti, 2006; Gilleard and Higgs, 2013). In cultures valuing independence (Galčanová and Kafková, 2018), this threatens identity and dignity. The fourth age entails losses such as mobility, health, privacy, relationships and identity (Gilleard and Higgs, 2010; Koss and Ekerdt, 2017; Kafková, 2016).

Third and fourth agers can experience negative framing by younger cohorts. As explained by Terror Management Theory (Greenberg et al. 1997; Van Lange et al. 2012), such negative framings generate fear. COVID-19 heightened this fear (Pyszczynski et al. 2021). Yet, experiences vary by social identity, inequality, and access to care. This underscores the need for an intersectional lens on ageing and health.

Frailty is central to fourth-age discourse, though definitions remain contested (Higgs and Gilleard, 2015). It is described as loss of physiological reserves, vulnerability, and cumulative decline (Bunt et al. 2017). Etman et al. (2012) found frailty risk linked to age, gender, and education, with women and less-educated individuals most affected. Gale et al. (2015) showed frailty prevalence is higher among women (16% vs 12%), who also live longer with it due to socioeconomic disadvantage (Zhang et al. 2018). For minority ethnic elders, frailty is compounded by intersecting inequalities which were exacerbated during COVID-19.

Higgs and Gilleard (2015) argue that Laslett's (1987) dichotomisation of the third and fourth ages destroys the common bond that exists among older people, thus creating divisive categories in the community. Older people commonly experience ageism and social marginalisation (Landolfi, 2023). Jones et al. (2008) reject Laslett's (1987) third age because it excludes those with fewer resources, such as marginalised older people, the socio-economically disadvantaged or older minority ethnic people. Cribb (2023) adds that the dichotomisation of the third and fourth ages can exacerbate the distinction between rich and poor older people in retirement, worsening inequalities between older minority ethnic people and older White people in the UK.

1.3.3 Population ageing in the UK

Population ageing is the rising share of older people, driven by low fertility and higher longevity (Harper et al. 2016). By 2050, one in six globally will be 65+ (United Nations, 2020). Concerns about resource imbalance and older adults as burdens reflect a conflict perspective. Such narratives fuel intergenerational tensions (Lemercier, 2022). Critics such as Longino (2005) and Boudiny (2013) reject deficit models, highlighting elders' economic and social contributions.

Walker (2018) critiques the UK government's limited preparedness for ageing-related challenges including the long-term care crisis and escalating costs linked to increased life expectancy. The COVID-19 pandemic coupled with persistent NHS strain has further intensified concerns about the system's ability to meet older adults' health and social care needs (Reeves, Islam and Gentry, 2023). The UK Health Foundation reported that by July 2023, the waiting list for routine hospital treatment in England had reached 7.68 million, the highest ever (Dunn, Ewbank, and Alderwick, 2023), The

Nuffield Trust (2024) further noted that nearly 390,000 individuals had been waiting over a year for treatment.

Projections suggest the existence of a dual trend while more older adults aged 65 years and over remain independent over the next 20 years, demand for intensive health and social care will rise among those aged 85 years and over due to higher rates of dependency, dementia and comorbidities (Kingston, Comas-Herrera and Jagger, 2018). The Centre for Ageing Better (2023) highlights the growing number of ageing minority ethnic individuals in the UK, noting that this population faces distinct health and care needs shaped by intersecting social identities, differing from those of their White British counterparts. This trend poses significant challenges for future health and care service provision.

Discussing ageing from a gender perspective, men face higher risks of cancer and heart disease, women of arthritis, depression, osteoporosis (Zhang et al. 2018). Women live longer, 62% of those 80+ are female (UN, 2020) but spend more years with impairments (UN, 2015). In the UK, 58% of carers are women (ONS, 2011), leading to greater psychological strain. Widowed women often enter old age with fewer resources due to earlier disadvantages (Lundberg, 2020). Carmel (2019) attributes this to systemic paternalism. Yet policy rarely accounts for gendered ageing (HelpAge, 2002).

Giddens (1990) and Bauman (2000) argue that, in late modernity, individualism and the predominance of nuclear families can heighten the exclusion of older people. Butler defines ‘ageism’ as prejudice based on age, reinforced by stereotypes (Iversen, Larsen and Solem, 2009). Media amplify ageism, portraying older adults as frail “pensioners” or “oldies” (AGE UK, 2014; Lupton, 2022; Carney, Maguire and Byrne, 2024). During COVID-19, this equated ageing with vulnerability and mortality, while ignoring intersecting factors such as ethnicity and comorbidities. Survivors were largely overlooked (Rahman and Jahan, 2020).

Ageism is disproportionately experienced by minority ethnic and disabled older people (Centre for Ageing Better, 2023). In healthcare, it leads to infantilisation and neglect (Chrisler et al. 2016). Terror Management Theory suggests professionals may unconsciously distance themselves from older patients to avoid confronting mortality (Thomas, 2019). Negative stereotypes also exacerbate dementia risks (Levy et al.

2016), especially among minority ethnic older people, who already face higher rates (Alzheimer UK, 2021). Older women encounter double discrimination, ageism and sexism (Carmel, 2019). Government shielding advice for “all over-70s” was criticised as blanket discrimination (Derrer-Merk et al. 2022). As Lord Hope argued in The Times (2020), not all 70-year-olds are vulnerable. The policy ignored diversity in health and independence.

1.3.4 Wellbeing

Health and wellbeing are mutually reinforcing (GOV.UK, 2014), though definitions remain contested across scholars, communities, and cultures (Manthorpe et al. 2010; Rusk, 2022). Michaelson and Mahony (2012, in Jarden and Roache, 2023) define wellbeing as how people feel, function personally and socially, and evaluate their lives. Despite variation, most definitions converge on the idea of feeling good and functioning well.

Wellbeing encompasses emotional, behavioural, cognitive, and relational domains (Jarden and Roache, 2023). Positive psychology emphasises prevention and health promotion (Ruggeri et al. 2020) but is criticised for its individualistic focus and limited attention to social and structural contexts (Ciarrochi et al. 2016). Joshanloo, Van de Vliert, and Jose (2021) similarly argue that wellbeing is inseparable from socio-political environments, a critique particularly relevant to older minority ethnic populations during the COVID-19 pandemic.

Understandings of wellbeing differ. Lay perspectives emphasise mental health, feeling valued, balance, and harmony (Jarden and Roache, 2023). Fave et al. (2016) identify family, relationships, and health as central to meaning. Although wellbeing is widely recognised as multidimensional, disagreement persists over its components, models, and measurement (Jarden and Roache, 2023; Carter and Andersen, 2019).

A common distinction is made between objective and subjective wellbeing, both of which are measurable (Voukelatou et al. 2021). Objective wellbeing uses indicators such as life expectancy, poverty, and mortality (Western and Tomaszewski, 2016), while subjective wellbeing refers to life satisfaction, emotions, and purpose (Stevenson and Rao, 2014), including health, morale, meaning, and freedom from loneliness or depression (Carmel, 2019).

In the UK, wellbeing is monitored by the Office for National Statistics (ONS) (Hutchings, 2021). ONS (2021) data show that during COVID-19, life satisfaction, happiness, and sense of worth declined, while anxiety increased, particularly among those with poorer baseline health. These trends coincided with reduced cohesion and widespread disruption, reflecting broader social, economic, and environmental determinants of wellbeing (Hutchings, 2021). Higher subjective wellbeing is associated with better health, faster recovery, healthier ageing, and longer life expectancy (DoH, 2014), while lower wellbeing predicts poorer outcomes and shorter lifespans.

Wellbeing is also shaped by cultural norms, values, and practices (Joshanloo et al. 2021; Idemudia and Adekunle, 2023). Joshanloo et al. (2021) contrast individualistic cultures, which prioritise hedonic values such as happiness and pleasure, with collectivist cultures that emphasise eudaimonic values including belonging, relationships, and harmony (Uichol, 1995; Ford et al. 2015). Faith traditions such as Buddhism and Islam view suffering as inevitable yet spiritually meaningful, fostering moral and personal growth (Kristiansen and Sheikh, 2012; Dorji and Sherpa, 2021). During COVID-19, collectivist groups often interpreted adversity as temporary and culturally meaningful (Dorji and Sherpa, 2021).

In contrast, individualistic societies often frame wellbeing as personal and private, with autonomy central (McNulty and Fincham, 2012). This emphasis can contribute to detachment and loneliness (Mauss et al. 2012), echoing Walter's (2007) account of British private grief and the turn to bereavement support groups (Kellehear, 2005; Fang and Comery, 2021). Joshanloo et al. (2021) caution that wellbeing measures grounded in individualistic assumptions privilege Western perspectives and risk marginalising collectivist understandings, underscoring the need for cross-cultural sensitivity.

1.3.5 Intersection of older age and other factors on wellbeing

Priorities shift with age: older adults emphasise relationships, health, support, respect, and dignity (Ward, Barnes and Gahagan, 2012). These reflect a strong link to social connectedness. Age and wellbeing are closely tied: subjective wellbeing (SWB) and health are bidirectionally related (Steptoe, Deaton and Stone, 2015). Beyond health,

resources, family, roles, and activities shape wellbeing, which change with age e.g. retirement reduces social networks, undermining wellbeing (Gilleard and Higgs, 2010). COVID-19 worsened mental health among older adults (Kola et al. 2021; ONS, 2020). Zaninotto et al. (2022) found depressive symptoms rose from 2.5% pre-pandemic to 28.5% by late 2020, with increased loneliness and poorer quality of life. Anxiety also rose. Interestingly, those 75+ showed lower depression than 50-59-year-olds, suggesting greater resilience.

Research shows gendered disparities: UK minority ethnic women experience greater health inequalities (Watkinson et al. 2021). Informal caregiving roles, often undertaken by women reduce socioeconomic status, health, and wellbeing (Carmel, 2019). Caring for relatives with dementia intensifies stress (Liu, Heffernan and Tan, 2020). The pandemic exacerbated strain: dementia is more prevalent among older minority ethnic people, who also face greater barriers to care (Saul, 2020). This compounded carers' burden and patients' risks. Cosco et al. (2017) emphasise the importance of promoting wellbeing in adversity for both ageing individuals and societies.

1.3.6 Vulnerability and resilience

Resilience is best understood in relation to vulnerability. Mercadal (2021) defines social vulnerability as 'the levels of risk faced by an individual, group, community, or society, of suffering harm due to a catastrophe or loss, as well as to their capacity of recovering from it, reducing it, preventing it, and/or coping with it'.

Siller and Aydin (2022) stress that inequalities of age, ethnicity, gender, comorbidities, and disability create and reinforce vulnerability through structural disadvantage. Resilience has been framed across social, psychological, community, and ecological perspectives (Quinlan et al. 2016). Juen and Siller (in Siller and Aydin, 2022) define resilience as the ability to adapt through social processes).

Siller and Aydin (2022) emphasise that during the pandemic, vulnerability and resilience among minority groups were deeply interconnected. In the UK, inequalities such as overcrowded living conditions, poor housing, and higher rates of comorbidities exacerbated minority ethnic communities' vulnerability (Kenway and Holden, 2020; ONS, 2020b; PHE, 2020). Older people within these communities were particularly at risk, facing heightened risks of infection, severe illness and mortality (Ayalon and

Tesch-Romer, 2018; PHE, 2020; Maestripieri, 2021). Government infection control measures (e.g., social distancing) further disadvantaged these populations by disrupting essential cultural practices, such as bereavement rituals and communal grief support, thereby affecting their emotional wellbeing (Brown and Kirk-Wade, 2021; Mayland et al. 2021). Vulnerability among older minority ethnic people was compounded by structural, systemic, and individual-level factors (Keys et al. 2021; Siller and Aydin, 2022).

Siller and Aydin (2022) argue that racism intersects with socio-economic identity to heighten minority ethnic groups' vulnerability. Rooted in historic structural disadvantage, racial and ethnic inequalities magnified pandemic impacts (Keys et al. 2021; Siller and Aydin, 2022). For example, systemic issues such as housing inequalities and lower incomes among older minority ethnic people stem from historical racism (Williams, 2021; Gulliver and Prentice, 2017). Scholars critique the British government's failure to acknowledge institutional racism arguing this denies the structural roots of inequality. Siller and Aydin (2022) further contend government's duty lies in addressing socio-economic risks, yet pandemic measures overlooked realities such as multigenerational housing, limiting compliance.

These observed patterns of vulnerability highlight the shortcomings identified by the UK Covid-19 Inquiry (2024) which found that pandemic planning lacked a clear and comprehensive definition of vulnerability. Early strategies often focused narrowly on clinical conditions, overlooking the wider social and economic factors that shaped actual risk, leaving many vulnerable groups (including older minority individuals) insufficiently protected. In response, the Inquiry recommends developing a single, adaptable UK-wide definition of vulnerability that incorporates the protected characteristics outlined in the Equality Act (2010) and accounts for the broader impacts of emergencies. Evidence presented to the Inquiry underscores that multiple intersecting factors (such as age, underlying health conditions, disability, race, ethnicity, and socioeconomic status) can combine to increase vulnerability to COVID-19 and its consequences. Furthermore, submissions from the Federation of Ethnic Minority Healthcare Organisations (FEMHO) and the Race Equality Foundation highlighted how structural inequalities, including racism and discrimination, further

compounded risks for certain groups (UK Covid-19 Inquiry, 2025). Taken together, these findings underscore the importance of an intersectional approach to understanding and addressing layered vulnerabilities, linking lived experiences with systemic policy gaps.

1.3.7 Inequalities, community cohesion and resilience

Hutchings (2021) noted that life satisfaction rose before the pandemic due to strong community cohesion. Community cohesion refers to people's sense of belonging, mutual trust and cross-group relationships (Lai, Zhou and Yuan, 2021). Research indicates that during crises, strong cohesion buffers adversity through unity, and support (Abrams et al. 2021). Abrams et al. (2021) further emphasise that shifts in cohesion hindered some groups' ability to provide support. Cohesion was also undermined by misinformation targeting minority groups, and by higher risks in deprived areas.

Community resilience refers to a community's capacity to endure, adapt to and recover from stressors (Olcese et al. 2024). At the start of the pandemic, some UK groups united to support vulnerable people with food and prescriptions (Abrams et al. 2021). Despite challenges, many ethnic faith communities demonstrated resilience by adapting practices (Simpson et al. 2021). For instance, leaders and mourners shifted funeral to new livestreaming or private prayer to maintain cultural continuity (Simpson et al. 2021). Structural inequalities hindered cohesion among minority ethnic groups (Abrams et al. 2021). One example is digital exclusion: limited access to devices and internet prevented participation in essential online services (Mistry and Jabbal, 2023). The Topol Review (2019) flagged minority ethnic groups' higher risk due to digital illiteracy and resource gaps. Worryingly, research is limited on its role as a health determinant (WHO, 2021; Chidambaram et al. 2024).

Longitudinal research by Wright, Steptoe and Fancourt (2020) found that concerns over medication, food and safety worsened UK adults' mental health. Zaninotto et al. (2021) reported that older adults in the UK struggled with pandemic related declines in mental wellbeing. Findings revealed disproportionate deterioration among women and those living alone (Zaninotto et al. 2022). Unexpectedly, higher-income older adults also faced sharp Quality of Life (QoL) declines, linked to financial anxieties

(Wright and Fancourt, 2021) and halted social activities (Zaninotto et al. 2022). Even so, declines among White older adults, were less severe than for minority ethnic peers facing enduring disadvantage (Zaninotto et al. 2022). Nonetheless, UK research remains generalised, rarely disaggregating by ethnicity, age and disability.

Although COVID-19 cases have declined, its effects now intersect with the cost-of-living crisis, wars, climate change, and rapid digitalisation. These overlapping challenges disproportionately affect vulnerable populations, particularly older minority ethnic people. Resilience, as vulnerability's counterpart, protects against adversity. Understanding older minority ethnic people's resilience is crucial for easing pandemic impacts.

Conclusion

This section demonstrates that older minority ethnic individuals in the UK experience ageing differently from White British peers due to intersecting social identities. Structural inequalities and socio-political dynamics highlighted in theories of late modernity can exacerbate vulnerabilities. During COVID-19, these individuals faced greater risks of infection and adverse ageing. Their wellbeing was significantly compromised, negatively influencing physical and mental health showing wellbeing-health interdependence. Recognising and responding to these dynamics is essential for developing effective equity driven interventions for older minority ethnic people.

The next chapter explores how the older minority ethnic people coped with ageing and grief during the pandemic.

1.4. DYING, DEATH, BEREAVEMENT AND GRIEF

Introduction

This chapter critically analyses human responses to dying, death, bereavement and grief with a focus on older minority ethnic people in the UK. It considers intersecting factors exposing them to disproportionate experiences of death, bereavement and grief.

COVID-19's direct and indirect effects varied across groups (Maestripieri, 2021). Mortality was disproportionately higher among older adults, minority ethnic groups, people with disabilities, men, and those of lower socio-economic status (GOV.UK, 2020; McGowan and Bambra, 2022). Risk increases significantly for those over 70, particularly with frailty (Williams, 2021). The UK Commission on Bereavement (UKCB, 2022) reports that the pandemic intensified challenges around death, bereavement and grief. Between 2020 and 2021, 6.8 million people were bereaved up from 6.1 million between 2018-2019 (UKCB, 2022). While death, bereavement and grief are universal (Adiukwu et al. 2022), COVID-19 exposed new and existing geographies of illness, death, grief and bereavement shaped by intersecting identities (Ho and Maddrell, 2021).

1.4.2 Perceptions on death and death inequalities

Death is a universal yet understandings of it are culturally and philosophically contested (Oyebode and Owens, 2013). Identity characteristics often intersect to shape how individuals perceive, experience and respond to death, especially in relation to funerary and bereavement customs (Oyebode and Owens, 2013; Gire 2014).

There is no unified consensus, either between laypeople and professionals or among professionals themselves on what constitutes death (Sallnow et al. 2022; Gire, 2014). Gire (2014) highlights cultural variation in the recognition of death. For example, in rural Malawi death is confirmed by the village head (Sallnow et al. 2022), in South Africa's Zulu communities the eldest family member listens for the final heartbeat (Le Roux-Kemp, 2008). Van Rooyen (1992, cited in Le Roux-Kemp, 2008) argues that death is not simply a biological endpoint, but rather it is a culturally interpreted, value

laden moment. Biological definitions frame death as the irreversible cessation of cellular, tissue and metabolic function (Tomasini, 2017). However, life-prolonging technologies and artificial support systems have complicated this clinical framing (Le Roux-Kemp, 2008). Despite definitional ambiguities, a medical declaration of death remains essential to initiate funerary rituals and other social practices (Le Roux-Kemp, 2008).

Older minority ethnic people faced higher infection and mortality risk than White counterparts (ONS, 2020a). As a result, older minority ethnic individuals were more likely to face bereavement, grief, and related mental health challenges particularly depression (O'Connor, 2019). The disproportionate impact reflected underlying social, structural and economic inequalities (Selman et al. 2023). UK mortality rates remain higher than pre-pandemic levels (O'Dowd, 2023). Excess deaths persist due to COVID-19, healthcare strain, and comorbidities, disproportionately affecting Asian and Black communities (ONS, 2023). The pandemic exposed entrenched and emerging death inequalities (Williams, 2021). Inequalities stem from intersections of age, ethnicity, gender, disability and comorbidities. For example, older Pakistani men's cardiovascular risk was compounded by disadvantage, elevating COVID-19 mortality (Pineda-Moncusí et al. 2025).

1.4.3 Effect of death on social order

Death disrupts the social order embedded in everyday interpersonal relations (Willmott, 2000). For older persons, bereavement often disrupts long standing relationships which shape identity (e.g. partners, friends and siblings) (Fang, 2022). The loss may prompt struggles with widowed, guilt, loneliness, depression, or anxiety while also reactivating previous grief and eroding coping (Koffman et al. 2005; AGE UK, 2020; Fang and Comery, 2021). Sudden, traumatic bereavement such as during the pandemic exposes older adults to heightened mental and physical health risks (AGE UK, 2020; Fang and Comery, 2021). Bereavement also compounds challenges associated with ageing. Fang and Carr (2021) note that cumulative loss, compounded by frailty, illness or cognitive decline can diminish older people's sense of purpose. Gerber et al. (2020) studying older Australians found that repeated bereavements and accumulated loss significantly harmed physical and mental wellbeing. They term these

outcomes the “ripple effects of grief” thereby demonstrating the need for timely bereavement support.

Disengagement theorists argue that older people’s deaths minimally disrupt society due to their social withdrawal and retirement (Blauner (1966, cited by Walter, 2008) and Palgi and Abramovitch (1984). However others contest this, noting older people continue to actively contribute to society (Longino (2005). Rather, death compels individuals, families and communities to symbolically and practically reconstitute social order through death rituals and cultural beliefs (Kastenbaum and Costa, 1977, Durkheim, 1915).

1.4.4 Intersectional grief framework

Bereavement defined as the state of losing someone to death (Koffman et al. 2005; Everett, 2023) is regarded as one of life’s most stressful events (O’Connor, 2022). Grief refers to the multifaceted emotional, cognitive, behavioural and physical responses that follow bereavement (Stroebe, 2018; Zisook and Shear, 2009). Adiukwu et al. (2022) note that grief may include symptoms such as distress, sadness, sorrow, anxiety, confusion, guilt, intense longing for the deceased, rumination, and even a continued sense of the deceased’s presence through memories or symbols. Beyond loss of life, the COVID-19 pandemic, brought secondary losses of social or physical support, financial security, agency, autonomy and safety, and pets (Lupton, 2022; Pinto et al. 2023). Zisook and Shear (2009) argue that grief can also extend to lost opportunities or diminished abilities. Understanding how these diverse forms of loss affect older minority ethnic individuals during and after the pandemic is necessary for shaping support interventions.

Human experiences of bereavement, grief, trauma and healing do not occur in a vacuum (Everett, 2023). Although bereavement and grief are universal, responses vary by context and are shaped by race, ethnicity, age, culture, class, gender and socio-economic status (Worden, 2018; Everett, 2023). Key factors influencing grief include prior trauma, relationship with the deceased, type of loss (e.g. anticipated or traumatic, personality, social context and existing stressors) (Worden, 2018; Everett,

2023, citing the Centre for Advancement of Health, 2004). Everett (2023) calls for 'Intersectional Grief Literacies' to analyse grief experiences.

It is crucial to understand how intersecting social categories shape perceptions of death, dying, bereavement and grief (Everett, 2023). Drawing from her experiences as a Black woman, Everett (2023) stresses the need for frameworks that reflect the complex realities of grief, bereavement, trauma and healing in marginalised communities. This aligns with Collins' (2000) view that marginalised groups navigate interlocking systems of race, class and gender. Neglecting intersectionality risks a reductionist analysis that limits opportunities for individuals to heal and live healthy lives (Everett, 2023). Applying intersectionality clarifies how older minority ethnic individuals access and engage with bereavement and grief support during pandemics. Everett's (2023) Intersectional Grief Framework (IGF) grounded in Crenshaw's (1989) theory of intersecting identities offers a nuanced understanding of how older minority ethnic people navigated grief during and after COVID-19.

Everett (2023) notes the dearth of research on how intersecting identities shape grief in marginalised populations. While grief is universal, responses vary and no single, bereavement process fits all (Worden, 2018; Everett, 2023). Everett (2023) warns against generalising hospice-based grief research to all deaths. Similarly, Mayland et al. (2021) criticise the lack of evidence on bereavement and grief care for minority ethnic groups in the UK during the pandemic. Such data are essential for tailoring bereavement support as the UK's ageing population grows more diverse amidst widening inequalities (Everett, 2023; ONS, 2023b; Allen and Boyce 2023).

Relying on grief research centred on older White widowed women to interpret the experiences of older minority ethnic people is epistemologically flawed. Older minority ethnic people face racism, ageism and heightened health risks shaping grief distinct from older White counterparts. COVID-19 further increased their vulnerability (Greenberg and Rafferty, 2021; Fang and Comery, 2021). Standpoint theory (Smith, 1997; Collins, 2000), affirms older minority ethnic individuals hold epistemic privilege in articulating lived experiences. Yet limited qualitative research has silenced their voices.

1.4.5 Religions and ethnicities on death, bereavement and grief

Most contemporary Western societies including the UK are religiously and ethnically diverse, with Muslims forming the largest religious minority (Kristiansen and Sheikh, 2012). The 2021 UK Census reports that 6.5% of the population identified as Muslim, 46% as Christian, 37% had no religion, and the remainder included Hindu, Buddhist, Sikh and Jewish, and others (ONS, 2021).

Cultural and religious backgrounds shape understandings of life, illness, dying and grief (Bear et al. 2020; Walter, 2010; Kristiansen and Sheikh, 2012; Gire, 2014; Pentaris, 2011). For instance, the Buddhist principle of impermanence fosters acceptance of death as natural. Muslims similarly regard life and death as divinely predestined (Kristiansen and Sheikh, 2012). Christians believe in the resurrection of the dead and everlasting communion with God (Choudry, Latif and Warburton, 2018). Therefore, older minority ethnic individuals hold diverse perspectives shaped by religious and cultural backgrounds. For example, individuals define good and bad death differently based on different religions.

The concepts of “good death” and “bad death” remain contested, including whether COVID-19 deaths are bad death. Meier et al. (2017) identify factors shaping good or bad death by including personal preferences regarding the dying process, pain management, religiosity, spiritualty, emotional wellbeing, sense of life completion, treatment choices, dignity, family presence, and quality of life. During the pandemic, Bear et al. (2020) explored these across various faith communities and vulnerable groups in the UK. For Christians, a good death brings the community together through ritual (Bear et al. 2020). Seymour et al. (2018) further note that a good death can facilitate healthier bereavement outcomes. Muslims emphasise family presence and Quranic recitation and prayers (Dua) (Bear et al. 2020). Pain, trials and suffering are often interpreted as signs of Allah’s love (Kristiansen and Sheikh, 2012).

Biomedical perspectives emphasise the medicalisation of dying, prioritising pain relief and patient comfort to preserve dignity and holistic wellbeing (Meier et al. 2016). In Chinese culture, good death includes effective pain management, sustaining hope and connection (Pentaris, 2011). In African contexts, a good death involves the presence of loved ones, rituals (even modified) and honouring burial/cremation preferences (Bear et al. 2020). Across communities, a good death involves loved ones’ presence,

rituals (even modified) and honouring the deceased's burial or cremation preferences (Bear et al. 2020).

A 'bad death' is marked by discomfort, pain, breathing difficulties, social isolation, psychological distress and inadequate care (Dorji and Sherpa, 2021). Seale (2004) emphasises that a bad death lacks dignity. Religions such as Islam and Buddhism associate bad death with suicide, unjust killing, euthanasia, or dying away from home in a medical institution (Grove, Lovell and Best, 2022; Shah and Chandia, 2010; Dorji and Sherpa, 2021).

Pandemic lockdowns intensified fears of bad deaths, particularly among older minority ethnic groups with trauma histories and limited healthcare (PHE, 2020; Bear et al. 2020; Fang and Comery, 2021). Infection control often separated dying individuals from loved ones, which compounded suffering and increased the bereavement on families (Heath et al. 2020). Turner and Caswell (2022) note that separation from family during dying fosters emotional isolation increasing the likelihood of a lonely death. Family presence alleviates anxiety and creates meaningful final moments (Keeley, 2017). During the UK COVID (2025) Inquiry hearings, Covid-19 Bereaved Families for Justice (a group formed by people who lost loved ones to COVID-19 and believe many deaths were preventable) also reported experiences of bad deaths. Evidence given by the families confirm that separation from family during dying and denial of opportunities to perform funeral rites, such as washing the deceased according to their cultural traditions during lockdowns intensified bereavement and aggravated trauma, impacting their mental and physical health (UK Covid-19 Inquiry, 2024; COVID-19 Bereaved Families for Justice, 2025). Documenting minority ethnic end of life experiences is essential for developing culturally responsive support.

1.4.6 Government lockdowns and other infection control restrictions

Across most cultures, rituals and traditions hold deep significance during times of illness and death (Selman et al. 2023; Koffman et al. 2005). Government-enforced lockdowns and infection control measures significantly disrupted funeral and burial rituals. Walter (2007) notes that while White British communities often prefer private expressions of grief, many minority ethnic groups value communal and celebratory

funeral practices. Lockdown restrictions disproportionately impacted minority communities.

Fang and Comery (2021) observe that lockdown measures led to alterations in funerals and ceremonies, including cancellations, postponements, or significant modifications. Selman et al. (2023) highlight that UK infection control measures disproportionately affected communities whose death rituals include body washing, viewing the deceased, or large gatherings. Such practices are central to Black Caribbean and other African communities, who could not gather in large numbers (UKCB, 2022). Both Christian denominations and Muslim communities similarly place importance on social or community-based funerals (Bear et al. 2020; Kristiansen and Sheikh, 2012).

Funeral rites including viewing the body and standing by the grave serve as critical starting points for emotional healing and reinforcing social bonds (Kastenbaum, 2004; Kastenbaum and Costa, 1977; Gire, 2014). Their absence causes significant distress (O'Rourke, Spitzberg and Hannawa, 2011). Lockdown measures therefore heightened emotional vulnerability while digital exclusion further limited older minority ethnic people's ability to participate in online funeral services. Bear et al. (2020) report that both Muslims and some Christians feared enforced cremation. Some Christians, Muslims, and Judaists generally oppose cremation, viewing it as the violent destruction of the human body (Walter, 2012). By contrast, Hindus prefer it (Oyebode and Owens, 2013). Sikh, Hindu, Muslim, and Jewish groups also feared delays in releasing bodies from hospitals during the pandemic (Bear et al. 2020). Douglas' (1992) concept of cultural boundaries helps explain how divergent rituals led to stigmatisation and scapegoating of minority groups as viral spreaders. The cultural practices of older minority ethnic individuals thus increased vulnerabilty to blame during COVID-19.

Walter (2007) and Giddens (1990) argue that late modernity is marked by fragmented social relations, especially around death and bereavement, often leaving mourners isolated. White British grief is often more private in contrast to the communal expressions of grief among the Zulu of South Africa (Le Roux-Kemp, 2008), Muslims and Black Caribbeans (UKCB, 2022). Walter (2007) argues that grief in late modernity is increasingly professionalised, with medical interventions promoting a healthy

grieving process. Walter further suggests that this medicalisation reflects a rationalist framework that can marginalise religious and traditional understandings of grief (Giddens, 1990; Walter, 2007). Yet paradoxically, the fragmentation associated with late modernity has also prompted individuals to actively create new spaces for mutual support through sub-groups, local communities and online platforms, reflecting broader arguments that people proactively form new social networks to enact their caring obligations (Walter, 2007; Trnka and Trundle, 2014; Breen et al. 2022). In contrast, among ethnic minority communities, voluntary and community organisations often play a key role in facilitating collective discussions about grief and bereavement, reinforcing communal rather than individualised approaches to mourning.

1.4.7 Intersectionality-informed experiences of grief

Grief may become complicated when intensified by risk factors (Dayes et al. 2023). Shear, Ghesquiere and Glickman (2013) define complicated grief (prolonged acute grief) as a mental disorder. Some scholars argue that classifying grief as "normal/abnormal" is reductive (Everett, 2023; WHO, 2022; Dayes et al. 2023).

UK research identified pandemic related risk for complicated grief, including the inability to say goodbye, restricted funeral arrangements, lack of professional and social support and unexpected deaths due to delayed diagnoses (Harrop et al. 2023). The Ubele Initiative Report (Murray and Rolston, 2020) notes that not saying farewell in culturally appropriate ways extends beyond burial itself to rituals before and after death. Their absence created additional stress for minority ethnic groups.

Mayland et al. (2021) highlight barriers hindering bereavement care. These are institutional racism, lack of awareness, culturally inappropriate models and stigma surrounding mental health. Dayes et al. (2023) also note that humans avoid confronting existential threat, a phenomenon Becker (1973) famously termed "the denial of death." Many communities treat grief as taboo, further limiting conversations (Pitman et al. 2018). Dayes et al. (2023) also point to the lack of appropriate language for discussing death as a barrier to meaningful conversations. Language barriers further complicate access to bereavement support (Mayland et al. 2021; Selman et al. 2023).

In the UK, COVID-19 disproportionately intensified bereavement challenges among disadvantaged groups (Bear et al. 2020). Fang and Comery (2021) describe COVID-19 as a “pandemic that comprised many epidemics”, reflecting the heightened marginalisation of bereavement experiences among vulnerable populations. Mayland et al. (2021) criticise the inadequacy of culturally responsive bereavement services for meeting the needs of minority ethnic communities. Digital exclusion further blocked access to virtual services like those from Cruse Bereavement Care (Mistry and Jabbal, 2023). The failure of UK institutions to address the needs of marginalised groups, especially older minority ethnic individuals disproportionately affected by COVID-19 echoes Butler's (2009) concern that some lives are regarded as less valuable or even non-grievable. Ensuring equitable access to bereavement and grief support is critical as such care is a fundamental component of health and social services (WHO, 2022b).

The pandemic exacerbated risk for disenfranchised grief. Disenfranchised grief arises when loss is not socially acknowledged, for example when individuals grieve in silence without support (Dayes et al. 2023). Vulnerability increases with intersecting identities such as gender, age, and ethnicity (Bindley et al. 2019). Black Caribbeans face more mental health problems than White British due to financial concerns and ethnocentrism (Koffman et al. 2005). Older minority ethnic people faced higher risk, particularly with the loss of frontline workers (Phiri et al. 2021). Bereavement increases risks of physical and mental health problems, especially for older people already living with comorbidities (Pearce et al. 2021). Minority ethnic women faced heightened risk of widowhood due to higher male mortality (ONS, 2021).

1.4.8 Gender, ethnicity, socio-cultural factors and grief

Bereavement experiences are shaped by gender (Wang et al. 2023). During COVID-19, women were more likely than men to lose spouses (Perkin *et al.* 2020). Women also face higher risks of poverty, housing insecurity, and bureaucratic hurdles (Koffman et al. 2005). Older widows, especially minority women, are particularly vulnerable.

Women often face compounded emotional burdens, worsened by stereotypes of Black women as “strong” (Bignall et al. 2019). Men, by contrast, are less likely to express grief due to norms of stoicism, which harm health outcomes (Stroebe et al. 2001; Seidler et al. 2020). Older bereaved men often report loneliness despite fewer financial burdens (Independent Age, 2017). These dynamics suggest widowed minority women face severe mental health risks, while men may avoid seeking support. Bereavement services must therefore tailor interventions to gendered realities.

Ethnicity and socio-cultural factors also profoundly shape bereavement. Bereavement is a risk factor for isolation (Seymour et al. 2018), but for older minorities it may trigger reflections on ageing abroad, anxiety about funerals, or repatriation. Large families or networks do not guarantee adequate support (Mayland et al. 2021). In some groups, such as Roma/Traveller communities, grief is rarely discussed, increasing risks of mental health issues. Stigma around mental illness further discourages help-seeking (Ryder, 2019). These findings stress the need for nuanced, culturally sensitive grief support that reflects diverse practices and beliefs.

Media shaped grief by marginalising older people. Deaths of older individuals were portrayed as less important than those of the young (Haffower, 2020). Harmful stereotypes such as #boomerremover presented older people as frail and disease spreaders (Sparks, 2020; Meisner, 2021). Online ageism even framed their deaths as population control (Brooke and Jackson, 2020). Media also privileges certain deaths, e.g. celebrities, while marginalising ordinary people (Walter, 2007; Harrop and Pearce, 2022). Families of COVID victims criticised government silence over the memorial wall, interpreting it as disregard for marginalised lives (Harrop and Pearce, 2022). Media focus on celebrity deaths thus exposes inequalities in whose lives are valued.

In the UK, ageistic sentiments also came from politicians. Evidence presented to the UK Covid-19 inquiry included private messages from the former PM Boris Johnson where he allegedly referred to COVID as ‘nature’s way of dealing with old people’, highlighted an ageistic attitude within government decision-making (Kettell and Kerr, 2025).

Conclusion

COVID-19 deepened inequalities in bereavement and grief, particularly for older minority ethnic communities. These groups are diverse, differing by ethnicity, gender, socio-economic status, health, and nationality, each shaping grief experiences and access to support. Viewing bereavement through an intersectional lens reveals grief as socially situated, shaped by overlapping identities. Without this recognition, policy risks one-size-fits-all approaches that neglect marginalised needs. Unaddressed grief harms mental, physical, and social wellbeing. Robust, culturally sensitive bereavement systems are therefore vital. Interventions must reflect cultural, religious, gendered, and social realities, while centring the voices of older minority ethnic people in research and policy. The next chapter explores the methodological framework that shaped this study.

CHAPTER 2: METHODOLOGICAL FRAMEWORK

Introduction

The foregoing chapter reviewed literature and identified knowledge gaps. This chapter explains the methodological choices made to address the research aim and objectives.

This qualitative study is grounded in an interpretive-constructivist paradigm and employs reflexive data driven thematic analysis to explore the lived experiences of older minority ethnic individuals during and after COVID-19. A qualitative approach captures participants' behaviours, meaning making processes and intersecting inequalities (Leach et al. 2020; Kazdin, 2003; Fuentes and Cookson, 2020). Reflexivity was used throughout to address bias and enhance rigour.

2.1 Research paradigm

This research follows five steps namely: philosophy; approach; choice; strategy, and data collection/analysis. The study draws on feminist methodology, recognising its aims of challenging marginalisation, especially where women face multiple disadvantages (Collins, 2000; Stanley and Wise, 2002).

2.2 Research philosophy

Beliefs about reality (ontology), knowledge (epistemology) and values (axiology) shape research approaches. The study engaged with epistemology, ontology and axiology. Epistemologically, this research study draws on an interpretivist-constructivist paradigm emphasising lived experience and enabling in-depth understanding (Haydam and Steenkamp, 2020; Cohen, Manion and Morrison, 2018; Creswell, 2007). Ontologically it assumes participants construct their own truths through their accounts of COVID-19 and its aftermath. The researcher's active presence shapes knowledge which is always partial (Stanley and Wise, 2002). Axiologically, the study is value laden and shaped by both researcher and participants. Objectivist detachment rooted in realism and quantification does not align with the aims of this study. Given this study's inherent subjectivity, reflexivity therefore

enhanced transparency and rigour (Bryman et al. 2014; Hayden and Steenkamp, 2020).

Interpretivism focuses on understanding participants' 'world of human experience' (Cohen, Manion, and Morrison, 2018 p.19), enabling construction of social reality (Locke et.al 2020) in their articulation of their experiences of COVID-19 and its aftermath. Both researcher and participants interpret experience through social context, history and worldview (Schwandt, 1994). This study explored both individual and collective accounts of older minority ethnic people during COVID-19 and its aftermath.

2.3 Research approach

This study employed inductive reasoning, meaning insights were derived from participants (Grams, 2022). By contrast, deductive reasoning begins with theory-derived premises and seeks to test them (Cohen, Manion and Morrison, 2018).

Multiple perspectives were gathered through the literature review and primary data. While the study was informed by theoretical constructs, patterns of meaning were inductively drawn from participants' perspectives (Creswell, 2013 p.25). Constructs were identified a priori through a review of both published and grey literature. Literature guided the identification of the phenomenon, participant selection, and question framing (Eisenhardt, 1989).

2.4 Methodological choice

A qualitative research methodology was chosen to give voice to marginalised older minority ethnic groups and explore participant-driven meanings. Secondary statistical data complemented primary findings, grounding inferences contextually (Yang, 2022). Mixed methods were rejected as lacking the depth and nuance required to explore participants' lived experiences (Creswell, 2003; Thomas, 2003).

2.5 Research strategy

An interpretive-constructivist paradigm with Reflexive Thematic Analysis (RTA) was adopted to examine participants' lived experiences. As noted in 2.2, in an interpretive-constructivist paradigm, through interaction with the participants, knowledge will be co-created. As experts in their own lived experiences, participants actively co-construct knowledge, reality, and meaning through their interactions with the researcher (Schwandt, 1994; Williamson, 2006). Participants in this study will interpret and make sense of their experiences during the pandemic and its aftermath. In my role as the researcher, I aim to understand and interpret the meanings participants assign to their lived experiences by engaging with their social world from their own perspectives. Therefore, meaning making will be a collaborative process between participants and the researcher. Interviews will be positioned as a tool of social construction by enabling conversations that actively elucidate meaning in the production of knowledge (Silverman, 2017; Charmaz, 2017).

Interpretative Phenomenological Analysis (IPA) is well regarded for its ability to handle emotionally complex themes (Smith and Osborn, 2015) and could be considered an appropriate form of analysis for this study given the pandemic's complexity, its novel unprecedented nature, and its impact on society. However, IPA favours a small homogenous sample who share a similar experience whereby individuals' accounts are collated whilst accommodating commonalities across the group (Smith et al. 2009). IPA was unsuitable due to the study's large and heterogenous sample. While case studies provide depth through a holistic lens, they limit generalisability (Locke et.al 2020). Furthermore, a case study's lack of a codified design like the other research strategies social scientists employ erodes its merits as a notable research method (Ebneyamini et al. 2018). Grounded Theory which develops theory from emerging data (Locke et.al 2020) was also not appropriate as this study was grounded in existing theoretical paradigms. This study focused on giving a voice to the lived experiences of the older minority ethnic people during COVID-19 and its aftermath. UK COVID-19 regulations in 2020 limited in-person engagement, rendering ethnography impractical, given its reliance on immersion (Creswell, 2007).

2.6 Sampling

Purposive sampling was pivotal in reaching the information-rich participants, thus ensuring the study rigour and credibility (Campbell et al. 2021). Unlike random sampling, purposive sampling targets individuals likely to hold relevant insights on the phenomenon under investigation (Mason, 2017). Defining the study population is key. I therefore stipulated inclusion criteria:

- The study took place in Thames Valley area.
- Aged 60+ as of 2020
- Member of an ethnic minority in the UK
- Resident in the UK before and during COVID-1
- Possession of mental capacity

The age 60 years follows United Nations' (2022) definition which includes individuals aged 60 years and above, a group often considered 'hard to reach' was achieved, with eight participants over 80 and the oldest aged 86 years. Data from the demographics questionnaire **(Appendix A)** completed by FGD participants was used to select participants for the individual interviews. A heterogeneous sample was sought to broaden the applicability of findings across diverse contexts (Mason, 2002). Participants were thus diverse in gender, ethnicity, living conditions and marital status. This diversity was essential for capturing breadth and nuance of individual lived experiences. A heterogeneous sample is particularly important for this research which centres intersectionality. Key informants in the form of community service providers who work with older people in the community were also interviewed individually. Community leaders included leaders of religious groups, voluntary and other social networking groups such as day centre managers. While provisional sample estimates are useful for planning, data saturation remains the primary determinant of adequacy (Robinson, 2014).

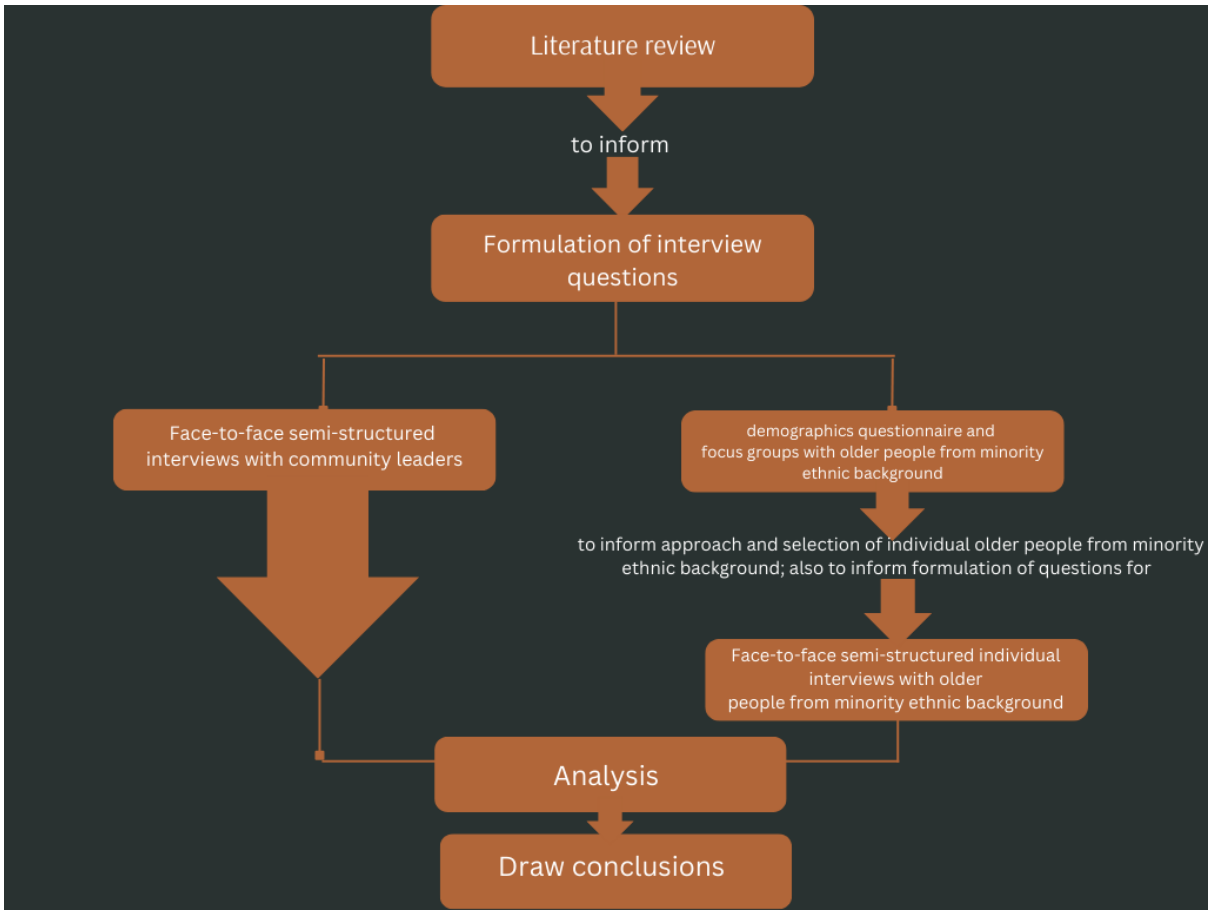
2.7 Data collection

While online interviewing tools are increasingly used in research (Lo Iacono, Symonds and Brown, 2016), face-to-face interviews semi-structured were preferred for their ability to capture both verbal and non-verbal cues. I also avoided online interviewing to prevent marginalising digitally excluded participants and ensure inclusive

knowledge production. Digitally excluding some participants would have been an act in contradiction of the key goal of Black feminist research (Collins, 2000, Hooks, 1989).

Data collection was sequential (see Figure. 4 below). Initial interviews with key informants (community leaders) informed the development of themes for subsequent focus group discussions (FGD) with the older minority ethnic participants. The recurring themes in the FGDs informed themes in individual face-to-face interviews with some older minority ethnic individuals.

Figure 4: Sequence of Data Collection



Data collection encompassed 3 phases:

- **Phase 1: Key informant Interviews**

Between eight and ten community leaders were anticipated. Ultimately, eleven key informants were interviewed. Open-ended dialogues with key informants provided insights on challenges they faced, and the coping mechanisms during COVID-19. Each key informant interview lasted approximately 45 minutes. First contact was made

with a community leader. Sampling developed into snowballing, which helped obtain contacts of more community groups. This approach ensured purposiveness of the sample (Mason, 2002).

- **Phase 2: Seven FGD's with older minority ethnic people**

With assistance from community leaders, participants were identified. FGD participants were recruited from various community groups for older minority ethnic people to allow for collation of varied data from heterogenous minority ethnic groups (see table 1 below). Despite planning for eight to ten FGD's, some older minority ethnic people refused participation for various reasons. Seven FGD's with 29 participants were conducted. Each FGD lasted up to one hour. To enable rich dialogue, adequate interaction, and engagement amongst group members (Collins, 2000), I ensured that each focus group had a maximum of five participants. Fewer participants would limit discussion while more than five participants would restrict participants' contribution (Cameron, 2005).

Ellard-Gray et al. (2025) asserts that holding informal sessions with older people's groups to introduce the research aids in building rapport with the research participants. Considering this, I also showed them a video on COVID-19 as another way to build rapport. All FGD's, which I moderated, were conducted where community groups meet. This approach follows Creswell's (2009) emphasis on engaging research participants in natural, familiar settings. The interview arrangements were facilitated by the community service providers. Before FGD's, participants completed demographics forms covering ethnicity, age, economic status, living arrangement and gender identity **(Appendix A).** This data helped gain the characteristics of potential participants. Given this research's intersectional approach, data from demographics forms purposive sampling of individual interviewees. I used the demographic data gathered to gain a sense of the characteristics of the participants, and in guiding me in purposeful sampling of the participants with potential relevant lived experiences for the individual interviews with the older people. FGD's enabled an in-depth exploration of broad issues and perspectives through group dynamics, interaction, interplay, and spontaneity (Stokes and Bergin, 2006).

Phase 3: Sixteen semi-structured individual face-to-face interviews

FGD's usually lack narrative depth and understanding, and personal experiences may not be discussed (Liamputtong, 2011). Follow-up individual interviews with sixteen older minority ethnic people were conducted to overcome this limitation. Immediate feedback strengthened rapport and improved subsequent interviews. Individual interviews lasted up to one hour. These enabled an in-depth and open-ended dialogue with individual older minority ethnic people who lived through the COVID-19 pandemic. Open-ended questions with a curious and facilitative stance encouraged stories whilst being mindful of their needs (Dickson-Swift et al. 2007).

Semi-structured interviews offered flexibility in phrasing and sequencing, facilitating the collection of rich, relevant data (DeJonckheere and Vaughn, 2019). Technical terms were clearly explained to ensure all research participants understood the topics. Most questions were open-ended, accompanied by prompting and probing to encourage insightful responses and rich dialogue (Edwards and Holland, 2013; Collins, 2000; Oakley, 1981). The interviews were underpinned by a sensitive interviewing framework (Dempsey et al. 2016), given topic sensitivity. Great care was taken in designing the interview agenda, the nature and manner of posing the questions, monitoring voice and tone (Edwards and Holland, 2013; Thompson, 2010). I monitored my voice and tone by rehearsing. Questions covered experiences of older minority ethnic people and mirrored participants' feelings, attitudes and coping strategies (**see Appendix C,** p.349).

TABLE 1 : Overview of research participants

ETHNICITIES	PARTICIPANTS
Caribbeans Indians Pakistani Bangladeshi Jamaicans Chinese Kenyans Cameroonians	11 Key Informants 7 Focus Groups (with a total of 29 participants) 16 Individual older minority ethnic people
Total participants	**56 participants**

Data saturation point was employed: recruiting participants stopped when saturation was reached. This was attained when themes reoccurred and it was certain that themes' meanings, and the depths, breadth and nuance were understood (Hennink et al. 2019). As shown in Table 1 above, saturation point was reached at 56 participants.

Interview questions appear in:

- **Appendix A**: Demographics questionnaire (p345-6)
- **Appendix B**: Interview grid for the community leaders (p.347-8)
- **Appendix C**: Interview grid for FGDs with the older minority ethnic people (p.349-350)
- **Appendix D**: Interview grid for individual older minority ethnic people (p351-2)

2.8 Data analysis

Data collection/generation and analysis occur concurrently to avoid too much data and being overwhelmed (Ravindran, 2019). Ravindran adds that initiating data collection concurrently enables researchers to address and saturate gaps in subsequent interviews. Fielding and Lee (1998 p.40) reference the 'inflationary character' of data analysis, which involves eagerness to learn more about a phenomenon.

Understandings emerging from analysis modify further data collection (Fielding and Lee,1998). Qualitative analysis is therefore inherently cyclical.

2.8.1 Thematic analysis

Thematic analysis which is a systematic, yet flexible method that helps researcher to identify, organise, describe, analyse and interpret patterns within data (Braun and Clarke, 2006). Braun and Clarke (2019, 2020) distinguish three thematic analysis methods: reflexive approaches, coding reliability approaches and codebook approaches. Reflexive analysis operates within a qualitative values framework, employing analytical tools shaped by researcher subjectivity (Ponterotto, 2005). In this approach, themes are developed from codes and are conceptualised as patterns of shared meaning underpinned by a central organising concept (Braun and Clarke, 2014). Reflexive Thematic Analysis (RTA) suited this qualitative research methodology which is inductive (data driven) (Braun and Clarke, 2006; Patton, 2002). Data is not coded in an 'epistemological vacuum' because researchers cannot free themselves of their theoretical and epistemological commitments (Braun and Clarke, 2006 p.84). Data cannot be separated from the researcher's perspective because their beliefs, background and assumptions influence how they make sense of it. Therefore, the way a researcher sees, interprets, and codes data is shaped by their own beliefs and assumptions based on how they perceive the world. Coding reliability approaches are suitable for quantitative research and both coding reliability approaches and codebook approaches involve early theme development.

RTA is an interpretive paradigm firmly situated within a qualitative research design (Braun and Clarke, 2020). RTA enables determination of outcome and focus by researchers, aligning with interpretivism. This study employs a data-driven RTA grounded in a constructivist paradigm, aligning with the study's interpretivist orientation (as highlighted in 2.5). RTA facilitates the identification of patterns in data, and the description and interpretation of these patterns (Braun and Clarke, 2020, 2013). Unlike other discourse analytic approaches such as Discourse Analysis, RTA emphasises interpretation rather than micro details of language (Braun and Clarke, 2013). This study is not committed to a discourse orientation, and it is also not aimed at developing a Grounded Theory from the data set and analysis. Content Analysis

though applicable to both quantitative and qualitative data analysis emphasises descriptive coding and frequency counts making it less suitable for this study's interpretive aims (Braun and Clarke, 2006). Thematic analysis provides a detailed and nuanced approach, which aligns with research seeking to gain an in-depth understanding of the pandemic on older minority ethnic people. Content Analysis is more positivist not aligning with this study ontologically (Humble and Mozelius, 2022).

The thematic analysis was guided by Braun and Clarke's (2006) recursive steps: familiarisation with data, coding, generation of initial themes, review of themes, defining and naming themes, and writing up. Reflexivity throughout the research was key (Braun and Clarke, 2006). Thematic analysis involves decision making on what counts as a theme and what level themes should be identified (Braun and Clarke, 2006; Boyatzis, 1998). Engaging in ongoing reflexive dialogue throughout this study's analytic process was important (Braun and Clarke, 2006).

2.8.2 Epistemological implications of using computer software and manual methods in qualitative data analysis

The choice of qualitative data analysis methods depends on the study's nature, design and size, the researcher's experience, and available resources (Froggatt, 2001). Researchers may use computer software, manual methods, or a combination of both. Computer-assisted qualitative data analysis software (CAQDAS) is time-efficient, enabling rapid searching of large datasets (Seale, 2000 in Silverman, 2017), and enhances accuracy, transparency, rigour, validity, and reliability (Morrison and Moir, 1998; Woods et al. 2016). Common CAQDAS packages include Nvivo, MAXQDA and Quirkos, each with specific strengths and limitations (Zamawe, 2015).

Manual analysis of large datasets may increase disruption and human error (Fielding and Lee, 1998; Welsh, 2002), but it is effective for small or less homogeneous datasets (Froggatt, 2001; Richards, 1999). Combining manual and computer-assisted approaches optimises researcher–data interaction while maintaining a digital audit trail, producing optimal analytical outcomes (Maher et al. 2018).

2.8.3 Data processing, analysis and writing

This study combined Nvivo with manual methods to optimise engagement with a substantial dataset. Nvivo was used alongside Braun and Clarke's (2006) reflexive thematic analysis (RTA) six recursive phases, applied flexibly to suit the study (Patton, 1990). Nvivo is compatible with thematic analysis (Zamawe, 2015) and is widely used for organising and analysing qualitative data (Dhakal, 2022). As a methodologically flexible tool, it supports a wide range of research designs and analytic approaches (Jackson and Bazeley, 2019).

Nvivo's node system enabled efficient coding and theme development while reducing the burden of manual copy–cut–paste techniques (Zamawe, 2015). Its ability to link codes, memos and data sources supported interpretation and relationship-building within the data. Nvivo also functioned as an effective data management system, saving time when working with large datasets which included the interview transcripts and journal notes.

All interviews were audio-recorded, securely stored, and verbatim transcribed, including verbal and non-verbal utterances. The transcription process initiated early interpretative engagement with the data, supported by memoing in Nvivo (Lapadat and Lindsay, 1999). Repeated, active reading facilitated familiarity with the data's depth and breadth, while mitigating researcher distancing which is associated with software use (Zamawe, 2015).

Initial coding was conducted in Nvivo by creating nodes from in-situ keywords and tagging relevant excerpts. Codes were treated as iterative analytic tools (Locke et.al, 2020), repeatedly revisited alongside memo writing and reflection. This process prevented "coding fetishism" (Richards, 2002) and maintained a balance between coding, analysis and interpretation. No a priori codes were imposed. Categories emerged inductively from the data. Codes were reorganised through deleting, merging and restructuring nodes into potential themes. Hierarchical coding supported inductive theme development, with attention paid to areas of dense coding as indicators of key themes. Nvivo's visual tools aided analysis of focus group data, while memos and annotations were used reflexively to capture analytic insights, recognised as full-status data (Richards, 1999; Miles and Huberman, 1994).

Combining electronic and manual methods enhanced analytical rigour, transparency and trustworthiness. Nvivo supported creativity, reflexivity and skilled data handling, reinforcing that rich data emerged through analysis as much as collection (Richards, 1999). While Nvivo facilitated searching, browsing and linking, interpretive connections between memos were developed manually, reflecting the view that software organises data while meaning-making remains researcher-led (Lewins, 2016). Nvivo search queries and word frequency tools were used to identify commonly used terms and early thematic patterns. Electronic searches were combined with manual techniques to capture meanings not detectable through keyword searches, particularly where participants used varied language or synonyms. This was crucial for accurate interpretation.

Data analysis was iterative, involving constant comparison, interpretation and refinement of themes (Miles and Huberman, 1994). Themes reflected patterned meanings relevant to the research question rather than frequency alone (Braun and Clarke, 2006). Analysis moved beyond description to latent interpretation, examining underlying assumptions and conceptualisations within a constructionist paradigm (Braun and Clarke, 2006; Byrne, 2022). Within RTA, themes were generated through sustained engagement with the data, mediated by the researcher's positionality, skills and experience (Braun and Clarke, 2021), enabling the construction of an interpretive account from which conclusions were drawn (Van der Walt, 2020).

Writing is an integral part of data analysis (Braun and Clarke, 2006). I started writing notes in notebooks at study commencement. Notes included key aspects emerging during initial informal discussions with community leaders. I later uploaded these notes to the Nvivo memo feature.

The next section explores my experiences in the field as a researcher.

CHAPTER 3: CENTRING AND ENGAGING MARGINALISED COMMUNITIES IN QUALITATIVE RESEARCH DURING CRISIS

Introduction

There is a multitude of literature on qualitative research methodology for health-related research about older people in general. With COVID-19, some UK studies also examined older minority ethnic often by framing age with one other identity such as race (Paudyal et al. 2022; Hewitt and Kapadia, 2021). Yet focusing only on one intersection (e.g., age+ethnicity) risks obscuring how multiple identities (disability, class, religion) interact to produce unique vulnerabilities (Bowleg, 2012). “Heterogeneity is a hallmark of ageing, and older people constitute a broad group, from the robust and healthy through to those with frailty and dependency.” (Goodwin et al. 2023). Because identities shape inequality differently, research must recognise heterogeneity within ageing groups (Christokkersen, 2017).

This chapter contributes to the literature on intersectionality-informed qualitative methodologies centring older minority ethnic people in the UK. Intersectionality is a framework that explains how multiple identities intersect at the micro level while reflecting interlocking oppressions (Bowleg, 2012). This discussion is grounded in my empirical study of older minority ethnic people in the UK during and after COVID-19. Engaging marginalised groups meaningfully is key to reducing inequalities (Baah, Teitelman and Rigel, 2019). Yet such engagement carries methodological and ethical challenges. This section reflects on these challenges, on centring participant agency, and on my positionality as a Black migrant woman researcher. I use the term “marginalised,” highlighting systemic exclusion rather than individual disengagement (Sevelius et al. 2020).

This chapter explains my empirical research and justifies my choice of specific qualitative research methods which consider the particularity and vulnerability of the respondents as older minority ethnic people. Additionally, the chapter connects the theoretical to the practical. The study also addresses the reasons why some older minority ethnic people in the UK hesitate to engage in crisis related research, based

on interviews with my research participants and offers a critical reflection on how I ensured that their agency and perspective was centred. The discussion concludes with reflections on my positionality as a Black migrant woman conducting research and key insights derived from the study.

3.1 The topic: Studying the experiences of older minority ethnic people in the UK through and after the COVID-19 pandemic

This study uses an intersectionality-informed qualitative research methodology, to contextualise the challenges the pandemic presented on the older minority ethnic people.

Intersectionality which is rooted in Black feminist scholarship and activism was first coined by Kimberlé Crenshaw in 1989 to describe how the interconnectedness of various socially identities collectively oppress and marginalise Black women. Crenshaw (1991) critiques the separation of systems of oppression in research approaches through isolating and focussing on one system of oppression, whilst occluding the others. A 'hallmark' of intersectionality is 'the necessity of addressing all oppressions' (King, 1988). Ackerly and True (2010, p.30) add that in feminist research, 'any situation, person, or research phenomena can be understood only in terms of intersecting and overlapping contexts and social forces such as race, age, gender, sexuality, income, nationality, historical experiences, among others. These different social categories manifest themselves in people's lived experiences.

Guided by intersectionality as an analytical framework, this research examines how multiple social identities (beyond age and ethnicity alone) influenced the experiences of older minority ethnic people in the UK during and after the COVID-19 pandemic.

3.2 Intersectionality-Informed qualitative research methodology

Knowledge production in academia has historically been Eurocentric and gendered. Feminist scholars critiqued the privileging of quantitative methods as 'objective' and qualitative as 'subjective' (Oakley, 1998; Westmarland, 2001). Quantitative research has been associated with terms such as positivist, objectivist, scientific, statistics and

masculinity. On the contrary qualitative research has been linked with interpretivism, non-scientific, subjectivity, and femininity (Westmarland, 2001; Denzin and Lincoln, 2005; Maynard, 1994; Hussain and Asad, 2012). Feminist scholars pushed back against these caricatures of qualitative research, advocating for the recognition of qualitative research as a legitimate and rigorous knowledge paradigm. All researchers enter the research field with pre-established opinions, feelings, values, life experiences and theories (Harding 1987; Stanley and Wise 1993). Both researchers and the research participants exist in communities which are not neutral or value free.

While critiques of Eurocentric and gendered knowledge are valid, these critiques often treat gender and race in isolation as they pertain to epistemology. This obscures the impact of the synergy of Eurocentricity and gendered knowledge production on those at the intersection thereof, such as Black women. Essentialising either identity such as gender or race risks speaking for all women while suppressing individuality (Collins, 2000; Hammersey, 1992). Just as race-based epistemologies should not view race as the primary axis of marginalisation, feminist epistemologies should not view gender as the primary axis of marginalisation because gender is not separable from other axis of marginalisation such as race, ethnicity, sexuality, class, and disability (Crenshaw, 1989; Collins, 2000; Hammersey, 1992). Scholars such as Collins (2000) add that Black women are not a homogeneous category and no homogeneous Black women's standpoint exists. The awareness of the multiplicity and complexity of experience (difference) is one of the fundamental characteristics of Black feminist ontology (Stanley and Wise, 1983 p.223). It is in this context that Black feminist thought including intersectionality emerged. Black feminists such as hooks (1989) and Christian (1987) critique the colonisation of the feminist theory. Christian (1987) defines the epistemological marginalisation within white feminism as 'the race for theory', a theory of the white feminists' experience which replicates the exclusion dynamics on grounds of race. This constitutes racism (Ramazanoglu, 1989a, 1989b).

The following sub-section delves into the core tenets of intersectionality as a product of Black feminist epistemology.

3.3 Core tenets of intersectionality-informed qualitative research

Collins (2006, p.3) identifies four tenets of Black feminist epistemology. I use these tenets for my intersectionality-informed methodology. These are: (1) knowledge is built from lived experience (2) dialogue is central to knowledge production (3) knowledge is built centring ethics of caring, (4) researchers must exercise personal accountability.

3.3.1 Knowledge is built from lived experience

Some scholarship posits that researchers must maintain a certain distance from the research subjects (Patton, 2002 p.51), but Black feminist epistemology views this as objectifying (Collins, 2006). This highlights the value of first-hand knowledge from those directly experiencing the phenomenon. These individuals referred to as 'connected knowers' are central to Black feminist research methodology. Researcher gains knowledge by building relationships, empathising and learning from the participants' lived experiences and therefore they are both experts who co-construct knowledge. Collins (2000) postulates that researcher is connected to, rather than detached from the people and lived experiences she/he is studying, as opposed to being isolated and disembodied. This connection fosters collaborative knowledge co-creation and ultimately a holistic epistemology.

This tenet resembles points that have been made by feminist scholars. Feminist research constitutes a knowledge paradigm which is grounded in feminist subjectivity, ontology, epistemology, theory and ethics (Wickramasinghe, 2009; Landman, 2006). It engages with issues of difference, power dynamics, oppression, whilst committing to political activism and social justice (Hesse-Biber and Yaiser, 2004 p.3). Feminist research views lived experience as situated knowledge shaped by the unique perspectives of the marginalised individuals. It is therefore argued that marginalised groups such as women, disabled individuals, and ethnic minorities are the connected knowers (Collins, 2000 p.258) who offer critical insight into their lived realities and are therefore better positioned to identify and critique systemic marginalisation (see Doucet and Mauthner, 2005).

Harding (1986) uses the term ‘strong objectivity’ to explain that marginalised groups’ perspectives can facilitate more objective accounts of the social world. Through incorporating diverse perspectives, strong objectivity seeks to address and mitigate biases and power imbalances (Doucet and Mauthner, 2005). Collins (2000) also highlights ‘safe spaces’ that enable open discourse, where Black women can freely share their experiences. In such spaces, empowerment and awareness of social justice are cultivated (Collins, 2000).

3.3.2 Dialogue as a mode of assessing and acquiring knowledge

Collins (2000) emphasises the production of knowledge through dialogue between the researcher and the researched. This focus on dialogue makes qualitative research methodology particularly suited to intersectionality (Bowleg, 2012). Dialogue refers to an exchange between equal subjects, contrasting with the hierarchical subject-object dynamic of positivist methods (Collins, 2000). Also important is the participation and engagement of all individuals in the dialogue which creates connectedness and leads to validation of knowledge (Collins, 2000).

Dialogue humanises research, fostering trust and validating participant knowledge (bell hooks, 1989; Hesse-Biber and Leavy, 2007). When interviews as a form of dialogue are conversational in nature, and the interviewer invests her personal identity in the relationship, a natural environment is enhanced which eases tension (Oakley,1981). Oakley supports her notion by drawing into her 1981 interviews with mothers during which her own identity as a mother levelled against a power hierarchy in the researcher-researched relationship. This equal exchange creates safe, natural spaces where Black women can comfortably share their experiences during the knowledge production (Collins, 2000). It is also important to highlight that first-person researcher narratives and use of participant quotations centre the relational dynamics of knowledge production (Reinharz, 1992).

3.3.3 Theoretical Perspectives on Ethics of Care and Emotional Labour

The ethics of care has been extensively explored by scholars such as Joan Tronto and Pettersen (see Hankivsky, 2014). The ethical principle of care examines the dynamics and tensions within caring relationships between researchers and research participants, while also recognising the importance of caring for the researcher's own wellbeing (Pettersen, 2011). The ethics of care therefore foregrounds the prevention of harm and suffering for both participants and researchers (Sevenhuijsen, 1998, cited in Hankivsky, 2014, p. 253). Rather than being rigid, impersonal, or abstract, Hankivsky (2014) views the ethics of care as a flexible framework that can be adapted to specific contexts and needs.

Hankivsky (2014) further notes that much of the care ethics literature focuses on gender and gendered manifestations of power. However, Collins (2006) characterises Black feminist epistemology as holistic, rejecting the separation of researchers from their research and of thoughts from feelings. Within this framework, emotions such as empathy are regarded as legitimate components of knowledge production rather than as obstacles to objectivity. Collins argues that an ethics of care should extend beyond gender and race to encompass the broader, intersecting systems of power that shape people's experiences. Collins (2006) further argues that centring lived experiences and dialogue requires knowledge to be constructed within an ethics of caring. Such an approach is particularly important when researching marginalised populations, where researchers must engage reflexively to minimise harm and recognise unequal power relations.

Closely related to the ethics of care is the concept of emotional labour. Kirk (2024) defines emotional labour as the way healthcare staff manage their emotions to ensure that patients feel safe. Although Kirk (2024) discusses emotional labour within healthcare settings, the concept is equally applicable to research. In the context of research, researchers are often required to regulate and manage their emotions to create a safe, supportive, and trusting environment for participants (Kirk, 2024). Researching sensitive topics has the potential to be emotionally challenging for both the researcher and the researched (Legard et al. 2023). Conducting research, particularly on sensitive issues therefore constitutes emotional work and renders emotional labour an integral aspect of the researcher's role (Bergman Blix and Wettergren, 2025).

Emotion is central to social life, including the conduct of social research (Hanna et al., 2028). Reflecting on emotions within research is particularly important because participants' emotional responses may also generate emotional impacts for researchers (Hanna et al., 2028). Rather than viewing emotions as a threat to research quality, Bergman Blix and Wettergren (2015) argue that emotions can be valuable sources of insight, interaction, and knowledge production within qualitative research.

3.3.4 Personal accountability

Collins notes that since knowledge is built upon lived experience in Black feminist epistemology, the assessment of this knowledge is also an assessment of an individual's character, values, and ethics (2006). This calls for researcher accountability as Black feminist research methodologies position both researcher and researched as equal subjects (Oduro, 2022). Personal accountability is important as the researcher is elevated to a more active role in such research, making it possible for potential biases to emerge in their work (Oduro, 2022). This elevates the demand for higher standards of personal accountability.

Such personal accountability requires simultaneous awareness of biases about different, yet possibly intersecting identities such as disability, race, gender, and age. Bias can be managed through acknowledgment and acceptance of one's subjectivity, emotions and socially grounded positions in the research (Ramazanoglu, 1992). Westmarland (2001) references use of her experience as a night shift taxi driver in interviewing female taxi drivers, which did not hinder the research process. Instead, it created a more relaxed environment for both the researcher and the researched.

Accountability also demands awareness of power dynamics which shape knowledge production (Collins, 2000; Bhopal and Deuchar, 2015). Power is multi-layered and not fixed to particular social categories, but is instead shaped by intersecting experiences (Anyan, 2013; Bhopal and Deuchar, 2015). Power differences are an integral aspect of any research, but they are more apparent, difficult, and challenging when researching marginalised communities (Reicherzer et al. 2013; Sevelius et al. 2020; Bhopal and Deuchar, 2015). Power can be experienced in several ways in research ranging from between the researcher and research participants or between the

researcher and the sponsoring institution (Bhopal and Deuchar, 2015). Furthermore, institutional constraints can challenge research independence. Power also manifests in methodological processes (Bhopal and Deuchar, 2015). In anthropology, methods often emerge through interaction with the field, whereas other disciplines may predefine methods based on epistemological positions.

Power dynamics also stem from the identities and histories of both researcher and participants. Participants may have faced systemic discrimination while the researcher may also belong to a marginalised group (e.g., by race, age, and or class). An equal relationship between the researcher and the participant can yield richer data (Finch, 1984; Oakley, 1981). While some scholars such as Cotterill (1992) caution against over-familiarity, the key concern is avoiding any reproduction of exploitation and marginalisation in research (Muhammad et al. 2015 p.1046; Parson, 2019). Having a researcher who shares the same lived experiences as the researched can therefore be helpful for the researcher to be aware of certain sensitivities when conducting the research, for example. Insider status does not guarantee epistemic access (Dwyer and Buckle, 2009). Shared identity does not automatically enhance knowledge. In some cases, it may hinder mutuality and reciprocity (Doucet and Mauthner, 2008: Ribbens and Edwards, 1997). Therefore, positionality and reflexivity are critical tools in intersectionality-informed research.

Positionality refers to a researcher's worldview and their stance toward the research context (Holmes, 2020).episte Bhopal and Deuchar (2015 p.140) note the importance of understanding researcher positionality in 'intersectional terms as a result of multiple social belongings such as (gender, age, race, ethnicity, sexual identity, biography and so on), that may impede or allow for certain relationships and insights.' The consideration of positionality is a key feature in all research and especially research with human subjects (Parson, 2019; Bhopal and Deuchar, 2015). Recognising one's positionality helps anticipate the possible methodological challenges of undertaking the research and implement strategies to prevent harm to both participants and researcher (Parson 2019). Thus, this tenet connects to the previous tenet, ethics of care.

According to Collins (1998) and Shinozaki (2012), intersectional reflexivity involves researchers interrogating their positionality and attending to the dynamic, contextual nature of power. As opposed to identifying one factor, intersectional reflexivity highlights the complex interaction between social categories which appear at different moments in the research process (Guillemin and Gillam, 2004). Reflexivity is an important tool to navigating power dynamics (Hamilton, 2020). Reflexivity helps researchers examine their own identities such as ethnicity, class and gender, and the power and the associated power and priviledge (Letherby 2002). Reflexivity helps address potential biases (Letherby, 2002). It allows researchers to identify and manage how their own social background, values, dispositions, attitudes, assumptions and perceptions shape the research process (Hesse-Biber, 2007 p.129). In feminist research, reflexivity also fosters accountability to research participants in the research process (Doucet and Mauthner, 2005). Bhopal and Deucher (2015) emphasise the importance of the researcher reflexively and continuously interrogating their positionality, power, and privilege to avoid the reinforcement of participant marginalisation or inequality. Being an insider does not ensure privileged insight.

Parson (2019) posits that intersectionality provides an additional perspective on how a researcher's identity can influence the research process irrespective of one belonging to a marginalised group. A researcher still holds power and privilege in the research. Power is fluid and shaped by the identities of both researcher and participant as well as context (Bhopal and Deuchar, 2015). For example, whilst the researcher may have power in the research through determining strategy, tactics, and procedures, participants have a right to decline participation (Goering et al. 2008 p.45). Brindley and Bowker (2013) as cited in Bhopal and Deuchar (2015) highlight that power imbalances may inhibit participants' autonomy, creating a 'myth of voluntariness.' Thus, power dynamics in research is complex. Participatory research is gaining ground in Black feminist studies as it promotes inclusion and recognises the complexity of intersecting identities (Frisby et al. 2009, p.24). Intersectionality blends well with approaches that aim for balanced power between researcher and participants.

Having outlined the core tenets of Black feminist epistemology that underpin intersectionality, the next section explores methodological challenges I encountered and how these were addressed through the same principles.

3.4 Connecting the theoretical to the practical

This section demonstrates how the central tenets of Black feminist epistemology and intersectionality informed the design, ethical considerations, and methodological decisions in my research on the experiences of older minority ethnic people in the UK during and after the COVID-19 pandemic. I also discuss the practical challenges encountered and strategies employed to navigate them.

3.4.1 Qualitative research and intersectionality

As Collins identified, Black feminist epistemology values knowledge derived from dialogue over adversarial debate. Subsequently, I adopted a qualitative research methodology to capture participants' behaviours, social interactions, and the ways they make sense of the happenings in their environment. This methodological choice is particularly suited to capture the complexity and multiplicity tied to the experiences of people located at the intersection of interlocked systems of oppression.

3.4.2 Ethics of Care and Emotional Labour in Practice

Ethics guide practical research decisions (Fisher and Anushko, 2008), with a 'no damage' approach being central to ethical practice (Guillemin and Gillam, 2004). Throughout this study, I sought to adopt an ethics of care approach by remaining attentive to participants' wellbeing, relational dynamics, and issues of power and positionality (Ackerly and True, 2010). Ethical approval was obtained from the Buckinghamshire New University Ethics Panel, ensuring compliance with UK legal and ethical requirements, including the Data Protection Act (2018).

Given the sensitivity of discussing the impacts of COVID-19 among older minority ethnic people, several safeguards were implemented before data collection commenced. Community service leaders acted as gatekeepers and advised on potential emotional risks. They also helped identify individuals who may not have been suitable to participate, including those who lacked mental capacity. Participants were

provided with a signposting guide containing telephone and online contact details for local and national organisations offering mental health and wellbeing support should they require additional assistance following participation. Informed consent procedures included explanations of voluntary participation, confidentiality, anonymisation, data management, and participants' right to withdraw from the study.

The interviews were conducted using a sensitive interviewing framework (Dempsey et al., 2016) in recognition of the potentially distressing nature of discussions surrounding illness, bereavement, isolation, and other consequences of the COVID-19 pandemic. Participants were reminded that they could pause, take breaks, decline to answer questions, or terminate the interview at any stage without consequence.

An ethics of care also shaped decisions made during fieldwork. For example, following advice from a gatekeeper, I chose not to interview a survivor of domestic violence because participation was considered likely to cause further emotional harm. Instead, the matter was referred to appropriate safeguarding services. Although this resulted in the loss of a potential participant, prioritising wellbeing over data collection was consistent with the ethical commitments underpinning the study.

I also sought to accommodate participants' individual needs wherever possible. Some older participants required breaks during interviews because of age-related fatigue. To minimise disruption to the flow of conversation, I provided a summary of what had been discussed before resuming the interview, enabling participants to continue their narratives comfortably. While most interviews were conducted face-to-face, one participant who was blind and a wheelchair user was unable to travel to the community centre due to mobility difficulties and limited carer support. To ensure her inclusion in the study, I conducted the interview online via Zoom. These adaptations reflected a commitment to participant-centred research and demonstrated the practical application of an ethics of care.

3.4.3 Emotional Labour During Fieldwork

Emotional labour was a significant aspect of this research. Kirk (2024) defines emotional labour as the management of emotions to ensure that others feel safe. Although developed in the context of healthcare, the concept is equally applicable to qualitative research, particularly when participants are discussing sensitive and emotionally charged experiences. Throughout the study, emotional labour involved

managing my own emotions while creating a supportive environment in which participants felt safe, respected, and able to share their experiences openly.

Participants often expressed strong emotions during interviews, including sadness, grief, frustration, and anger. Several became tearful while recounting experiences of bereavement, illness, loneliness, discrimination, and the broader effects of the COVID-19 pandemic. In these situations, I sought to balance my role as a researcher with the need to respond compassionately and ethically. This involved offering participants opportunities to pause or stop interviews, providing breaks, tissues, water and offering reassurance when needed. Where appropriate and with consent, I also offered comforting touch.

While some participants became visibly distressed, many chose to continue the interview and expressed relief at having had the opportunity to discuss experiences that they had rarely shared with others. These encounters reinforced the importance of approaching qualitative interviewing not simply as a method of data collection but as a relational and emotional process requiring care, attentiveness, and sensitivity.

The emotional nature of these interviews required ongoing emotional labour. I had to remain empathetic and emotionally present while simultaneously listening carefully, probing sensitively, and maintaining the focus of the interview. This balancing act was particularly important given the vulnerability of some participants and the sensitive nature of the topics under discussion.

3.4.4 Researcher Reflexivity and Emotional Impact

The emotional dimensions of the research did not affect participants alone. Instead, they also affected me as the researcher. Prior to commencing fieldwork my supervisors prepared me for the possibility that the research might evoke emotional responses among both participants and myself. This preparation encouraged me to think critically about the emotional dimensions of the study and to develop strategies for responding appropriately to emotionally challenging situations. It also provided opportunities to reflect on how my own background and experiences might shape my engagement with participants and their narratives.

As a Black woman researching inequalities arising from structural barriers, emotions were present from the outset of the research process, beginning with the selection of the research topic itself. While my experiences were not identical to those of

participants, my positionality provided insight into some of the issues discussed during interviews, including experiences of discrimination, exclusion, and marginalisation. This insider understanding facilitated rapport, trust, and empathy, enabling participants to speak openly about their experiences. However, it also meant that some participants' narratives resonated deeply with my own life experiences and personal struggles.

Participants' emotional testimonies affected me in profound ways. There were occasions when I became emotional, particularly when participants described experiences that echoed my own lived experiences or insider knowledge. Discussions of discrimination were especially impactful because I have also experienced discrimination, albeit in different contexts and circumstances. Some participants' accounts reopened emotional scars associated with my own experiences and ongoing struggles with discrimination and ageism, wounds that I am still nursing and healing. Listening to these narratives required me to navigate my dual position as both researcher and someone who could personally relate to aspects of participants' experiences, while continuing to provide support and maintain professional responsibilities.

At the same time, I found participants' courage deeply moving. Many spoke openly about painful experiences of loss, illness, isolation, exclusion, and discrimination despite the emotional difficulty involved in revisiting such memories. Their willingness to share these experiences prompted me to reflect on how challenging it can be for individuals to articulate painful aspects of their lives. Their openness represented not only participation in research but also an act of trust. This trust carried significant responsibility and reinforced the importance of representing participants' experiences respectfully and ethically.

To support my own wellbeing, I engaged in ongoing reflexive practice and drew upon supervisory support throughout the research process. Supervision provided a valuable space in which to discuss emotionally demanding interviews, reflect on my responses, and develop strategies for managing the emotional labour associated with the study. Given that the research frequently involved discussions of death, illness, grief, isolation, discrimination, and other forms of loss, these opportunities for reflection and support were particularly important.

Looking back, I view emotions not simply as challenges to be managed but as important and enriching dimensions of the research process. Emotions provided valuable insights into participants' experiences, facilitated rapport and trust, and deepened my understanding of the meanings participants attached to their lives and circumstances. They functioned not only as emotional responses but also as sources of knowledge, data, and connection. In this sense, emotions served as a means of interaction and relationship-building, supporting Bergman Blix and Wettergren's (2015) argument that emotions are integral to qualitative research practice rather than separate from it.

3.5 Understanding hesitancy among marginalised participants

Marginalised groups often hesitate to participate in research due to language barriers, mistrust, time constraints, cultural differences, health concerns, and prior negative experiences (Sevelius et al. 2020; Wilson et al. 2018; Ellard-Gray et al. 2015). Historical exploitation of minority communities can reinforce this hesitancy (Stanley and Wise, 1983). In my study, multiple intersecting vulnerabilities compounded mistrust and reluctance.

Participants cited several barriers, including:

- mistrust of government and public institutions, and thus fear of victimisation
- research fatigue
- poor health and caregiving responsibilities
- doubts about the research yielding positive outcomes for their communities
- fears of psychological distress from recounting personal losses

Some participants refused participation because they did not self-identify with the research framework. For instance, one female participant argued that older minority ethnic people were not disproportionately affected by COVID-19 and actively disrupted a focus group session, culminating in an intervention by the community leader. She held the opinion that the pandemic affected everyone in the same way, and that consequently my research was premised on an untrue foundation.

> *There is always this tendency by some minority ethnic people like you to unnecessarily claim racism and discrimination to get sympathy. In this country, there is no racism and discrimination. I do not want to take part in your research! No!*

To further show her discontent, during the FGD session, she walked in and attempted to disrupt and stop the proceedings. The community leader intervened to stop the disruption.

Other older minority ethnic people refused to take part in the research because they did not trust me. Although we shared some visible identities and experiences, they were suspicious that I could hand over the research findings to the British government, and they would be victimised. Their fears were fed by their experiences of discrimination in the UK. Intersectionality compounds mistrust of perceived outsiders (Ellard-Gray, 2015). Whilst I was an insider by virtue of sharing some identities with them such as same skin colour, same facial features etc, I was also an outsider because I was coming in as a PhD research student from a university setting. I visited the community centres several times and engaged in networking activities such as sewing and sharing lunch meals with the older minority ethnic people to build trust and rapport. In their empirical research, Sutherland and Fantasia (2012) engaged in knitting with the potential participants at the recruitment site which helped create a non-intimidating atmosphere and trust. This increased the participants' willingness to participate in the research. The community leaders also helped boost the trust through explaining how as a researcher I uphold ethics standards.

Therefore, the issues relating to the hesitancy of the older people to take part in my research were multi-faceted and complex. As a researcher, it was important for me to capture the reasons for hesitation and to tailor my research methodology in a manner that mitigates their hesitation, while still ensuring that my chosen methodology still enabled me to derive fruitful data. I went about this challenge by recruiting research participants and building trust with them, considering the specific reasons for the hesitation they expressed. I respected the potential participants' choices and ensured that participation was voluntary.

3.5.1 Recruiting research participants and trust building

Recruiting marginalised groups is complex given histories of slavery, colonialism and racism (Crenshaw, 1989; Collins, 2006), that foster mistrust (Devlin, 2020). Unlike

majority groups, extra steps are needed. In my research, hesitancy to participate was shaped by participants' multiple intersecting vulnerabilities.

I adopted a gatekeeper approach, working with community service leaders trusted by the communities. The gatekeeper had a two-fold function: validating the researcher's ethical stance and guiding recruitment of suitable participants. Initial meetings clarified research aims, funding, methods, and expectations, and led to adjustments in terminology, such as replacing 'BAME' with 'minority ethnic people' to better reflect the community preferences (Smith et al. 2020). Gatekeepers also advised on safeguarding and participants' mental capacity, thus ensuring ethical inclusion. Making numerous informal visits to service settings helped build rapport and facilitated access (Dempsey et al. 2016). Therefore, older minority ethnic participants were recruited via gatekeepers affiliated with support organisations. Gaining access was challenging, but the gatekeeper approach to recruitment was undoubtedly useful and beneficial.

Sustained relationship-building was essential. I attended cultural activities such as singing at a Hindu women's club, sharing lunch with Muslim men, and sewing at a Caribbean women's club to establish rapport and demonstrate respect for participants' practices and identities. Informal interactions before data collection allowed participants to ask questions, reducing tension and enhancing trust (Dempsey et al. 2016).

Participants must not feel coerced (Barrow et al. 2022). To ensure voluntary participation, I carefully explained consent procedures, read forms aloud for participants with low literacy, and accommodated scheduling requests. Some consulted their children first. In some cases, participants signed consent with an X to protect anonymity. Sensitive interview settings at familiar community venues helped participants feel safe (Collins, 2000; Creswell, 2009). Decisions around recording were negotiated, prioritising participants' comfort over research needs when concerns arose. This minimised research tension and helped build rapport (Dempsey *et al.* 2016).

Before interviews, I explained consent carefully and gave as much as needed. Some consulted their children first. I supported participants with low literacy skills by reading out to them and explaining the information on the forms. One man however became angry after my explanation and challenged me to prove the worthiness of my research and to prove that the British government has the needs of minority ethnic people at heart. He swore at me, declined to participate in the research, and walked out. The community service leader apologised. As a result of this mistrust, some research participants refused to write down their names and signatures on the consent forms, opting to identify themselves with the symbol 'X' instead. Interviews were sometimes rescheduled due to poor health or fatigue.

During interviews when one participant wanted to strongly critique the government, he requested that I switch off the recording equipment because he was afraid that the data would be used by the government to victimise him. This posed a dilemma namely that of balancing the needs of my research with the participant's concerns. I prioritised the latter and reassured him and he agreed to recording.

In other cases, some older people asked to have the interviews in the presence of their children. Their children's presence helped establish a "safe space" as defined by Collins (2000). This boosted their trust in me as a researcher.

3.6 Positionality, power differences, and managing relationships

Collins (2000) argues valuing lived experiences requires accountability. I reflected on my positionality as a Black woman, shifting between insider and outsider (Strunk and Locke, 2019; Bhopal and Deuchar, 2015). As a Black woman I had insights others might not have and my identity influenced research framing. Yet I had privilege as a PhD researcher and social worker. Power was fluid, negotiated with participants and gatekeepers. I am therefore aware that my identity as a Black woman may have influenced the research process in different ways. For example, my selection and phrasing of the research theme, as someone who is aware of some community concerns as a Black woman myself, was undoubtedly influenced by my identity.

Power differences are an integral aspect of any research, but it is even more crucial when researching marginalised communities (Bhopal and Deuchar, 2015; Vanner, 2015). As the researcher, although I am a Black woman, I still hold a privileged status within the research process. Furthermore, I had a significant role in producing knowledge. Despite occupying a position of power as the researcher, I still had to continuously negotiate my relationship with gatekeepers and participants, illustrating the fluidity of power in research contexts see (Bhopal and Deuchar, 2015). We negotiated about various issues such as the interview dates and times. This dynamic of dominance and marginalisation is central to process itself. There is also power in determining the parameters of the research itself as the researcher. I therefore took great care in designing the interview agenda and monitored the content and tone of my questioning. The interview agenda included questions covering the experiences of older people and which mirrored the participants feelings, attitudes, and coping strategies. Furthermore, the questions which were not separating out aspects of identity reflected the intersectionality aspect, (Christoffersen, 2017). How questions are posed to participants can shape their responses (Bowleg, 2008). Therefore, questions that frame identity categories as separate should be avoided. Examples of questions I asked are:

- What were your experiences with the pandemic?
- Do you think that your identity influenced your experience of the pandemic?
- What were your experiences with the lockdowns?
- Do you think that your identity influenced your experience of the lockdowns?
- How did you manage day to day risk of catching the virus since you were living with your daughter who worked in the frontline as a carer and with school-going grandchildren?
- How did you minimise risk of catching the virus, given that whilst you are diabetic, and have a heart condition, you lived with your expended family?

Christensen and Jensen (2012) define this as taking “everyday life as a point of departure” (p.117). Such questions invited the participants to reflect on the salient intersections in their lives. This allowed data reflecting the complexity of their lived experiences.

Given the complexities and sensitivity of the research, I took cognisance of Tew's (2002) discourse on power. Tew emphasises the importance of those holding positions of 'power over' relinquishing power to those in weaker positions to create equity and empowerment. For individual interviews, I relinquished power to each participant (Robson, 2007) by letting them choose appropriate interview timing. I ensured empathy, an attribute which Collins (2000) highlights as essential in feminist research.

Shared experiences can affect research process and research outcomes. However, through an intersectional lens, shared identities do not necessarily make a researcher more sensitive or free from enacting harm. As a Black migrant woman I shared marginalised identities with participants, facilitating access but also posing challenges. Being part of a stigmatised group offered me a privileged entry point. I have experienced racism and as a mature student, ageism. These shared experiences built trust and informed my design of interview grids and interpretation.

Intersectional reflexivity helped manage potential bias. Shared experiences aided rapport but remained mindful of maintaining analytical distance. Shared identity reduced social barriers so participants felt at ease. Stigma fosters solidarity among those who experience it (Pham et al. 2023; Cortland et al. 2017; Chaney et al. 2022). However, trust and open communication sometimes threatened data. For example, one participant asked me to omit some details about the government and white British whom he labelled racists.

In all research, subjectivity is inevitable as researchers' identity cannot be removed (Stanley and Wise, 1993; Westmarland 2001). I acknowledged potential bias and sought to avoid approaching through a lens of unexamined privilege. In view of the subjectivity of this research, objectivity was enhanced through reflexivity (Guillemin and Gillam, 2004; Holmes, 2020; Hayden and Steenkamp, 2020). I also educated myself about issues I did not share with participants such as disability and diverse cultures. Intersectionality highlights how researcher identity shapes research even within marginalised groups (Parson, 2019). Accordingly, I continuously interrogated my positionality to avoid reinforcing inequality.

3.7 Intersectional reflexivity

Embedding an intersectional lens within reflexivity is essential for recognising how researchers simultaneously experience priviledge and marginalisation (Rodriguez and Ridgway, 2023). I engaged in intersectional reflexivity, acknowledging and critiquing intersecting identities, privileges and disadvantages (Rodriguez and Ridgway, 2023). I engaged in reflection before, during, and after action.

Through its rejection of generalisation of Black women's experiences and knowledge (Harding, 1991), the development of intersectionality as a concept can be considered "a reflexive move" (Carstensen-Egwuom, 2014 p.267). Embedding an intersectional lens within reflexivity is essential for recognising how researchers simultaneously experience privilege and marginalisation (Rodriguez and Ridgway, 2023). I engaged in intersectional reflexivity and reflection throughout the research process before, during, and after data collection (Gibbs cited in Jasper, 2013; Schön, 2013) to critically examine my intersecting identities, privileges, and disadvantages (Rodriguez and Ridgway, 2023). Reflexivity, central to feminist methodology, enables researchers to navigate shifting power dynamics and the "differential effects" of intersecting axes of oppression, including race, gender, class, and age (Collins, 1998, p. 211; Woods et al. 2015).

Reflecting on my positionality, I recognised how my identities as a Black migrant woman, a PhD student, and a social worker simultaneously facilitated access and conferred privilege. Shared characteristics such as skin colour and migrant background fostered trust and rapport with participants, while my academic and professional status positioned me as an authority within the research context. Intersectional reflexivity enabled me to draw on the fluidity of these identities, attending to both my insider status and the power I held as the researcher.

This reflexive approach shaped methodological decisions and interactions. For example, participants' concerns regarding discrimination informed my sensitive interviewing framework (Dempsey et al. 2016), while their reluctance to engage with British medical professionals highlighted the importance of acknowledging lived experiences as valid knowledge (Conti and O'Neil, 2007). One participant's refusal of prescribed diabetes medication, informed by prior experiences of discrimination, demonstrated the need to avoid further marginalisation by dismissing her reasoning.

Similarly, some participants preferred healthcare providers sharing their ethnic background, reflecting historical and structural inequities in medical treatment during COVID-19.

Intersectional reflexivity also addressed relational dynamics. While shared ethnicity facilitated dialogue, differences sometimes generated discomfort. During meetings with older Muslim men in a mosque, my attire and appearance prompted anxiety about unintentionally disrespecting their cultural norms. Reflexively attending to this tension highlighted the complex interplay of social categories in researcher–participant relationships (Vanderbeck, 2005; Rodriguez and Ridgway, 2023).

Ethical dilemmas further reinforced the need for reflexivity. When a participant became emotional recounting her husband's death, I initially considered halting the interview to prevent distress. However, she indicated that sharing her experience was therapeutic, demonstrating that difficult conversations can also be empowering (Russell, 1999). Similarly, participants used metaphors to express complex emotions, such as describing the end of lockdowns as "a bird being released from a cage," which enriched the interpretive process and highlighted their agency.

Intersectional reflexivity was also critical in recognising participants' strengths and contributions. Older minority ethnic participants were active community members and decision-makers in their own lives, challenging assumptions of passivity and disempowerment. By prioritising participants' perspectives, I navigated power differentials and reinforced the principle that knowledge is co-constructed (Collins, 2000; Yuval-Davis, 2012).

3.8 Conversations post-interviews

Ending interviews with care and providing post-interview support is essential in qualitative research (Naughton-Doe et al. 2022). After the sensitive interviews with the older people at each community centre, I had debriefs with the community service leaders. These debriefs formed a key part of my role as the researcher because I was able to give feedback to the community service leaders and make suggestions where necessary. For example, following a highly emotive FGD with one of the groups, I suggested that the community service leader engages mental health experts to

conduct mental health sessions with the older people as a form of therapeutic care and support. I assured participants that I would return to share the research findings upon completing the thesis.

Conclusion

In conclusion, this chapter has demonstrated that an intersectionality-informed methodology, grounded in Black feminist epistemology, prioritises lived experience, dialogue, ethics of care, and researcher accountability. Employing this approach enabled me to address the vulnerabilities of older minority ethnic participants during COVID-19 while navigating complex ethical and methodological challenges.

Participants' hesitation, rooted in mistrust, discrimination, and health concerns, required tailored strategies such as engagement through trusted community leaders, flexible scheduling, and sensitive interviewing. Reflexivity and intersectional analysis facilitated recognition of power dynamics, ethical dilemmas, and participants' agency, ensuring that their perspectives guided the research process.

Conducting research during a public health crisis posed unique challenges but provided crucial insights into structural inequalities and resilience among older minority ethnic populations. Engaging marginalised communities is essential to addressing health disparities and informing responses to future crises.

The following chapter presents a detailed analysis of the data.

FINDINGS AND ANALYSIS

The previous two chapters discussed my methodological stance and the practicalities of data analysis to justify the research's methodological rationale. Chapters 4 to 7 analyse findings by major themes derived from the data and linked to literature in order to address the research aim and objectives. These findings will inform the conclusion and recommendations in Chapter 8. For information about the participants quoted in this research, please refer to **Appendices C and D**. All names used in this study are pseudonyms.

The findings and analysis are presented visually in the mind map below.

Figure 5: Mind map

Self-designed using Canva

Chapter 4 discusses and analyses older minority ethnic people's narratives on their lived experiences during the COVID-19 pandemic and its aftermath. Here, I draw on data from my qualitative research offering insight on how the older minority ethnic people perceived the COVID-19 pandemic, the COVID-19 vaccine and vaccination, and the choices they made about their lives during the pandemic. It is evident that the research participants' perceptions were different given their varied identities: ethnicity, age, gender, nationality, and lived experiences with comorbidities and disability.

CHAPTER 4: TRUST AND RISK

Introduction

Trust emerged as a recurrent theme among participants. This chapter first explores the complexities of trust and its implications for older minority ethnic participants. As this chapter demonstrates, trust shaped older minority ethnic people's relationship with scientific experts and the UK government, as well as their perception of the COVID-19 pandemic, and the COVID-19 vaccine.

The chapter's second section dissects vaccine hesitancy which was present among older minority ethnic people. Alongside identifying intersecting vaccine hesitancy determinants specific to older minority ethnic people, this section also brings nuance by approaching the issue of vaccine hesitancy among this group by using Vandrevala et al.'s (2023) sensemaking paradigm.

4.1 Older minority ethnic people and mistrust

According to Giddens (1990) and Alaszewski (2023), risk and trust are interconnected concepts which have become increasingly important in society's functioning because of the complexities and uncertainties associated with late modernity. Giddens (1990) notes that risk influences the decision to trust, whereas trust is a way of managing the risk generated by ignorance, knowledge gap and uncertainty. Given the uncertainties and consequences of unmanaged risk, trust is particularly important in systems such as healthcare as it can influence behavioural responses (Gilson, 2003; Alaszewski, 2023). Taylor-Gooby (2006) defines trust as a 'cognitive element (grounded in rational and instrumental judgements) and an affective dimension (grounded in relationships and affective bonds) generated through interaction, empathy and identification with others.'

Trust can be theorised as consisting of two limbs (Giddens, 1990; Luhmann, 1990; Rousseau et al. 1998; Goldenberg, 2023). On the one hand there is interpersonal trust, which entails trust between persons. An example of interpersonal trust is the trust

between British laypeople and NHS medical doctors. Giddens (1990) defines this as facework trust. On the other hand, institutional trust entails trust placed in a system or institution such as a government body. Giddens (1990) defines this as faceless trust because of its dependency on faceless or abstract systems. For trust to exist and thrive, for example in the health sector, interpersonal and institutional trust must coexist. Within the COVID-19 context, health outcomes are also influenced by trust. For example, adequate levels of vaccine intake are dependent on people trusting healthcare institutions and healthcare experts.

It is evident that the participants in this research project lacked both institutional and interpersonal trust. The absence of institutional trust led to a lack of interpersonal trust, a linear aspect of trust (Giddens, 1990). While older minority ethnic people's vulnerabilities to COVID-19 (such as older age, living with comorbidities, and disability) are well documented (PHE, 2020; Walker et al. 2021; Teagle et al. 2022), trust influenced the decisions they made regarding their health, and it also influenced their health seeking behaviour including regarding COVID-19 vaccine intake and vaccination.

4.1.1 Lack of institutional trust

Most research participants voiced a lack of institutional trust in the government and the experts. Some research participants held the view that the government and experts sometimes spoke of higher COVID-19 cases among minority ethnic populations in a stigmatising and blameful manner. P2 in FGD3 states:

> *The government inflated the statistics so that it suited their usual narrative that us migrants are negligent of our health. It was exaggerated stigmatisation. They just want us to lose our confidence and live in fear thinking we are dying. COVID is killing everyone in the same way.*

Some participants in FGD1 also comment:

> *The reason more Asians and Blacks were dying than whites was to do with racism and selective treatment in hospitals. I think when our people were admitted in hospitals, they were not receiving good healthcare because of*

racism, and it is this which explains the higher deaths amongst our communities. (P2)

Well, I noticed that the graveyards in the neighbourhood filled up very quickly which was a clear indication of how bad the COVID was, but again it's not only Asians and Blacks who died but everyone. (P1)

The older minority ethnic people's mistrust of NHS morbidity and mortality data stems from divergent risk perceptions between laypeople and experts. Whereas laypeople tend to emphasise subjective aspects of risk; experts emphasise statistics, calculative, and objective aspects of risk (Beck, 1992). The research participants' denial of the government statistics on the mortality rates of COVID-19 underscores their mistrust. Their concerns come against the background that institutions such as PHE (2020) viewed UK minority ethnic people's higher COVID death rate through the lens of cultural pathologisation. PHE (2020) blamed these groups for a lack of trust in the NHS, fear of being tested, and delaying seeking medical treatment. Meghji and Niang (2022) critique PHE (2020) for blaming minority ethnic people. As racial inequality is the root cause of inequalities, the British government should tackle the higher COVID death rate through material solutions such as improving housing conditions instead of blaming minority ethnic people.

Hiam et al. (2024) who share the same sentiments as Meghji and Niang (2022), critique the individualist approach to health and wellbeing which assigns blame to those with ill health instead of interrogating systems of marginalisation that create the conditions for creating or exacerbating ill health. In the context of COVID-19, Hiam *et al.* (2024) critique the blaming of those who were infected with coronavirus or died from COVID-19 as people who were negligent and did not take adequate precaution. Hiam *et al.* (2024) hold the view that it is the government's responsibility to acknowledge the wider social context and address the factors (such as low income, racial discrimination, poor housing or lack of housing, and lack of high-quality education) which diminish people's abilities to live healthy lives. These structural and systemic barriers disproportionately affect marginalised groups, particularly older minority ethnic people (Christoffersen, 2017; Marmot, 2020).

4.1.2 Epistemic mistrust and the lack of interpersonal trust

In FGDs 1 and 3, the participants' mistrust of the NHS's morbidity and mortality data (section 4.1.1) reveals epistemic mistrust. This is echoed by scholarship which articulates epistemic mistrust, a lack of trust in the knowledge and relevance of the knowledge communicated by the government and the experts (Brauner et al. 2023; Kelsall, 2023; Tanzer et al. 2024). Brauner et al. (2023) argue that epistemic mistrust is particularly prevalent in late modernity, where laypeople are exposed to vast amounts of information about risks, much of it conflicting or contradictory. This information-rich environment encourages individuals to question the validity of expert knowledge and the institutions on which it is based, making some more susceptible to conspiracy theories. However, rather than acting as passive recipients of information, laypeople actively evaluate competing claims and construct their own understandings of risk. Brauner et al. (2023) argue that these understandings are shaped not only by governments and experts but also by family members, friends, community networks, and other laypeople, resulting in more nuanced and complex perceptions of risk.

My research also established epistemic mistrust linked with uncertainties which emerged from conflicting and contradictory information about COVID-19 and the vaccine. Older minority ethnic people stressed that the government and scientific experts' frequent changing positions regarding the efficacy of masks resulted in them losing confidence in the government and the experts in managing the COVID pandemic. In FGD3, participant 1 questions:

> *…. masks?.... no masks?…. cloth masks?….. That was very confusing for us. They said they are the experts, but they also seemed not to know anything.*

In the same FGD, participant 2 who concurs with participant 1 argues:

> *from the way they communicated about the pandemic, it was clear that they also didn't know what was happening. They were also in the dark.*

The research participants also condemn the quick changes on the government strategy to quell the spread of coronavirus, such as the move from legal lockdowns to the living with COVID-19 strategy when COVID-19 deaths were still very high. Furthermore, participants criticised the government for restricting the movements of older people, particularly given that some government leaders continued to socialize despite the restrictions. These leaders breached the rules, were investigated by the

police, and were fined, actions that were also criticised by the COVID-19 Inquiry (2024, 2025).

Hannah (72), who lives alone, bemoans how she had to spend Christmas in solitude because of the government lockdowns, '*yet the government officials were having parties and not restricted!'*

> *For the first time in my whole life, I had to be alone during Christmas. I could not travel to be with my children, and I missed celebrating Christmas with them.*

Therefore, the participants' extracts above point out the government's lack of honesty about uncertainties and the knowledge gaps about the pandemic. This contributed to their lack of trust in the government and scientific experts. Additionally, the older people express feeling excluded, alienated, and not valued as ethnic minorities in developing the national pandemic guidelines. They question their exclusion from the formulation of national pandemic guidelines. Some Chinese people had strong sentiments about this because they felt that their expert knowledge on qigong, yoga, and meditation offers effective solutions to breathing challenges, which was one of the symptoms associated with COVID-19 illness. Sipho (66), a Chinese alludes to the fact that *'qigong, yoga and meditation heals individuals suffering from COVID by opening up blocked veins in human bodies.'* He expresses his frustration:

> *despite me emailing the government officials via our member of parliament to request for a meeting to give my justification of how the answer to healing from COVID and long COVID lay in qigong, yoga, and meditation, I did not get any response. In my emails I explained how qigong, yoga, and meditation as holistic practices that combine breathing, movement, and meditation can successfully heal COVID suffers by unblocking blocked veins. I also told them about Chinese people being healed from their hospital beds by watching and following qigong, yoga, and meditation online. They ignored my several emails. They never responded.*

The research participants' concern about their knowledge and views regarding COVID-19 being excluded are congruent with Sozudogru's (2020b, 2020a) critique of the lack of disciplinary diversity in the UK government's coronavirus advisory body, SAGE. Sozudogru's (2020a, 2020b) argument is based on the premise that pandemics are complex problems with biological, environmental, social, and political

causes and consequences. Consequently, combatting them would require a wide array of specialist knowledge and experience, and not only medical expertise. Additionally, this argument also points to the importance of upholding standpoint epistemology in devising measures to address pandemics (Harding, 2016; Schaubroeck and Hens, 2022). In line with Schaubroeck and Hens' (2022) reasoning, knowledge by marginalised groups such as older minority ethnic people is valid. Therefore, their exclusion from SAGE was unfair and unjustified. However, whereas standpoint theory considers social identities in isolation and associated power dynamics, positionality theory best defends the criticality of the inclusion of the older minority ethnic people in SAGE given their varied identities. Positionality theory which underpins the perspective that individuals deduce meanings based on their various identities (Longino, 1992), resists the fixed, static, and essentialist view of standpoints (Alcoff, 1988; Collins, 1993; Kezar, 2002).

The UK Covid-19 Inquiry report 2 also criticises the exclusion of the older people from the advisory board. The report highlighted that although the COVID-19 pandemic affected people of all ages and backgrounds, older people especially those living with frailty and multimorbidities were among the most severely impacted and were not specifically considered during the early stages of pandemic planning (UK Covid-19 Inquiry, 2025). The 2025 Covid-19 Inquiry recommends that it is important that in future pandemics, specialists in ageing and frailty be also included in the advisory board.

Participant Abdul (85), who has a chronic heart condition and high blood pressure, blames older minority ethnic people's worsened health on pollution and the British food:

> *We were healthy when we arrived from our native countries, and we worked manual jobs. I can't even understand why we are now unhealthy. Why are we now suffering more health wise than the white community of our same age? Why did we die more during the pandemic? We used to walk long distances to go to work in the industrial sites. I blame our ill-health on the British foods. We used to eat healthy foods in our native countries. It is hard to lead healthy lifestyles in the UK, for example there is too much pollution.*

As another example of a lack of institutional trust, some FGD5 participants' lived experiences of racism and discrimination in the UK led to their mistrust of the government:

> *You remember how they treated us during the Windrush scandal when they deported us migrants after we had worked hard for this country? I have been in this country since 1965. We contributed towards the growth of this country. One never knows what they will do next*. (P1)

> *And you know the Grenfell Towers incident - the pain and hurt which resulted from the government neglecting the poor community? Our women have been with the victims through the pain and hurt. We have knit blankets and donated them to the fire victims. So as a women's group we are touching base to support them in the pain and hurt because we understand their situation.* (P3)

These findings align with Siegrist (2021) and Sevelius et al. (2020) who argue that past negative experiences can reinforce mistrust when individuals perceive current experiences as repetitions of past harms. Negative encounters with systems particularly involving perceived discrimination have the tendency of eroding trust. Participants' sentiments about racism in the UK echo scholarship on how racial and ethnic discrimination shapes the lived experiences of minority groups (Gulliver and Prentice, 2015, 2017; Bhopal et al. 2018; Shankley and Rhodes, 2020; Williams, 2021). Their lived experiences of discrimination contributed to the belief that the government framed COVID-19 through a racialised lens, further eroding their trust. In reflecting on their lived experiences during COVID-19, participants referenced significant past events that exemplify structural racism and discrimination in the UK. For example, the 2017 Grenfell Tower Inferno exposed the intersection of environmental racism, gender, and class dynamics because most of the victims had a minority ethnic background, were of lower socio-economic class, and were mostly women (Williams, 2021).

Many participants identified with the Grenfell Tower Inferno victims who shared similar positions marked by ethnicity, class and gender. As shown in the demographics table **(Appendix D1)** (page 353)**,** the research participants identified that they are living with a wide range of comorbidities including high blood pressure, various forms of cancer, diabetes, and heart conditions and disability. Additionally, they mentioned that they

are struggling financially because of the cost-of-living crisis and the fact that they are living on pension from the minimum wage jobs they occupied during their working lives, whose value has been drastically reduced due to inflation. By drawing such parallels, participants suggested that their COVID-19 experiences resonate with other crises rooted in systematic racism and discrimination in the UK.

Participants also cited the UK government's deportation of Black Caribbeans, many of whom were British nationals as a source of continued vulnerability and fear. Slaven (2024) claims that the racial injustice of the UK government's 2018 hostile immigration policy resulted in some Black Caribbeans who were legally present and had long settled in the UK being denied jobs, healthcare, pensions, or being deported. Black Caribbean people's experience exposes the research participants to exacerbated vulnerability as minority ethnic people. Beyond instilling fear in the research participants, these historical experiences of racism and discrimination in the UK contributed to daily feelings of uncertainty and anxiety. Older minority ethnic people's feelings of fear and uncertainty are in line with the notation by scholars such as Geronimus et al. (2006) and Chae et al. (2014) that the chronicity of racism and discrimination can trigger anxiety and adverse effects on one's health. Additionally, scholars such as Ball, Steffens and Niedlich (2022) and Filibeli et al. (2023) cite racist stereotyping and its embodiment and infusion with hostility and hatred as negatively affecting the wellbeing and confidence of marginalised populations in the UK.

Rudo (68), who lives with diabetes, arthritis, asthma, and high blood pressure explained how mistrust of her doctor led her to discontinue her diabetes medication:

> *I take insulin injection once a week for my diabetes. I am, however, getting myself off the injection. You know I don't have confidence in what these doctors say. They say don't eat too much fruit because it will raise your sugar levels. I choose to eat a lot of fruit because fruit has natural sugars, which will reverse my diabetes. If I need glucose, I eat fruits. I am controlling my diabetes with natural herbs from my country. I have also reduced my prescribed tablets. Instead of taking the prescribed 2 tablets daily, I now take them every other day. When I take the prescribed dosage, I feel drowsy, and I can't function. And I become forgetful. So, this has an impact on my brain as well. This medication is not good for my health!*

Farai (80), an older male participant concedes that because of his mistrust of the NHS, he does not consult the GP when he is unwell:

> *No, I don't want. It's my own life. I use herbs from my birth country, Bangladesh. I also raised my children using herbs and not medicines and vaccines. And my children are very strong. One even plays soccer very well. You know, these doctors just talk too much; they say us Asians and Africans will suffer from this and that, that we have high blood pressure, diabetes, and so on. They don't see any good in us. Nothing is good in this country.*

Whilst PHE (2020) culturally pathologises minority ethnic groups, portraying them as being in poorer health than the white majoritarian population (see Chapter 1.2.8), they perceive themselves differently. Farai's statement illustrates how perceptions of racialised medical discourse contribute to his disengagement from formal healthcare systems. The research participants' unwillingness to consult the NHS medical doctors and reluctance to rely on their prescriptions reflects a lack of interpersonal trust rooted in broader institutional mistrust, particularly towards government structures. As representatives of the state , doctors function as the "facework" or frontline of government systems (Giddens, 1990).

During FGDs, participants identify that:

> *The other pain is when people were not allowed to visit our family members in hospitals; no one knows what was being done to these patients who were not even talking. We will never find out, unless someone whistle blows.* (FGD2, P2)

> *There are a lot of injustices in our communities, and brave people must speak out against them. I once whistle blew a racial abuse of an elderly Black woman by white carers. Pads were not being changed properly and so on. If only the diversity message is put out there, it would be marvellous.* (FGD5, P1)

> *When I felt very unwell, my wife rang 999 for the ambulance against my will and that of my children because we were worried that I would face discrimination and not get medical attention in the hospital. The news reports about the shortage of hospital beds, ventilators, nurses and doctors was scary. The television news on the deaths of old people also scared us. And the thought*

> *that my family would not be allowed to visit me scared us even more. Who was getting medical care? I stayed at home, despite collapsing several times. I did not think I would survive to this day. But thank God, I am still alive!* (FGD1, P4)

Most of the research participants expressed fear that reports of shortages of ventilators and hospital beds in the mainstream media would result in their neglect as minority ethnic people. This sentiment is also noted in scholarship, such as in Fang and Comery's (2021) reference to NHS's prioritisation approach which arose due to shortages in medical care resources. The ongoing UK Covid-19 (2024) Public Inquiry referenced the unpublished document, titled Covid-19 Decision Tool, which distinguished three elements which would have been considered in prioritising care during the pandemic: age, clinical frailty, and comorbidities. People with high scores would reportedly be excluded from intensive care (Pickover, 2024; Peart, 2024). During the Covid-19 Public Inquiry, the UK national medical director Professor Sir Stephen Powis raised concern that the prioritisation tool was not used appropriately (Peart, 2024).

Although the exact influence of age and frailty on care decisions during the pandemic remains uncertain, anecdotal evidence suggests that some patients died after being denied intensive care admission, possibly on the grounds of their age and perceived frailty (Wilkinson, 2020). Viewed in this context, the older minority ethnic people's fears are legitimate. Their fears are also further legitimised given their lived experiences of historic racism and discrimination whereby hierarchisation was employed in the UK during imperialism (Parmar, Earle and Phillips, 2022). Parmar, Earle and Phillips (2022) assert that racial hierarchisation placed White Europeans at the top and Asians and Africans at the bottom, supported by an evocation of strong perceptions based on stereotypes. In the same way that colonialism and imperialism exposed power relations through racial antagonism (Cox, 2001 in Back and Solomos, 2000; Mahmud, 1999), the older minority ethnic people's thoughts and fears reflect the embodiment of domination, superiority, and difference with race being the primary marker of differential treatment.

Alongside older minority ethnic people's underlying mistrust and lack of interpersonal trust is the presence of strong emotions evoked by the context of the pandemic. The

next sub-section briefly discusses how emotions impacted older minority ethnic people's behaviour and perceptions of the pandemic.

4.2 Pandemic and emotions

Pandemics such as COVID-19 are intensely emotionally charged events. Gould (2009, p. 31) defines emotion as 'a body's processing of social conditions, and of its context.' According to Roeser and Pesch (2016), emotions during events characterised by risk do not always result in irrational decisions. Lupton (2013) who shares the same views as Roeser and Pesch (2016) articulates her views through the theoretical concept of emotion-risk assemblage. The concept presents emotions and perceptions of risk as intertwined and as mutually influencing each other (Lupton, 2013). This means that socially situated construction of risk occurs simultaneously with feelings (such as fear and anxiety) (Cottingham and Fisher, 2016). Because risk is embedded with emotional experiences, one's lived experience influences the way they manage their emotions in view of anticipated or potential risks (Lupton, 2013). Therefore, the concept of emotion-risk assemblage views the construction of risk as inherently linked to one's lived experience and the social context rather than through a rational lens which is based on calculations of costs and benefits as championed by scientific experts (Cottingham and Fisher, 2016). It is also against this background that PHE (2020) blaming the older minority ethnic people for the choices they make is unjustified (see 4.1.1, p.102).

All participants conveyed intense emotional responses to their COVID-19 pandemic experiences. As reflected in my study, emotions shaped participants' perception of risk. Fatima (73), who lost her husband at home to COVID gives an emotional account:

> *----- the doctor put a breathing machine, and my husband said he couldn't breathe on the machine which the doctor had put him on. So, I ordered another oxygen cylinder, plucked out the NHS doctor's machine and put my husband on the machine that I bought. The doctor came and removed my machine. He pulled the machine out without telling me you know. (silence).*
>
> *Up to today, I don't trust the NHS doctors. I don't like going to them even when I am unwell.* (She starts crying).

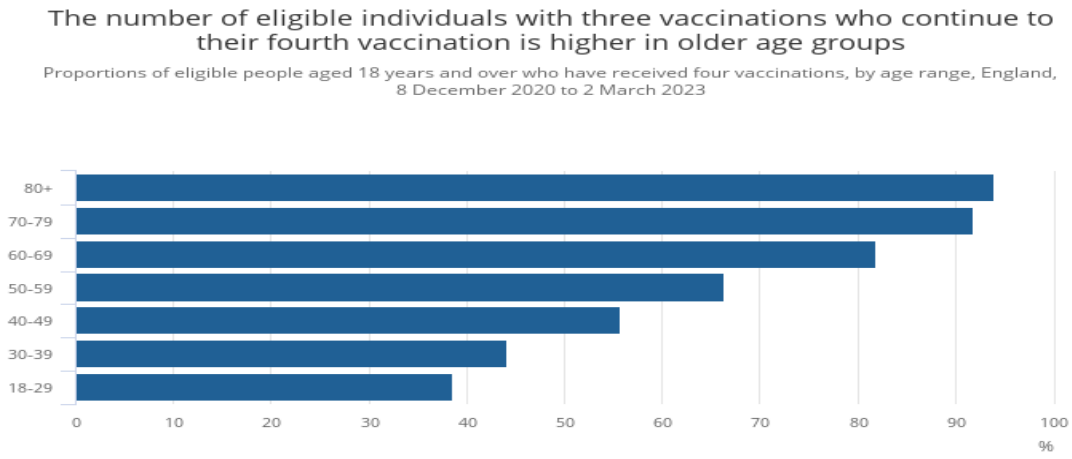
Fatima's heightened fear and mistrust of the medical doctor and the belief that the doctor left her husband to die drove her to replace the oxygen cylinder with her privately sourced machine. Evidence from my research therefore supports Roeser and Pesch's (2016) submission about the role of emotions in situations characterised by risk. Fatima's account illustrates how emotion informed her risk perception. Fatima's desperation to save her husband and her mistrust of the NHS doctor and the oxygen cylinder led her to remove it and replace it with hers. Even in the context of being overwhelmed with emotions, given her fear of racism and discrimination, Fatima's reaction was a rational decision which made sense to her. The reluctance by participant 4 in FGD1 to go to hospital *'despite collapsing several times'* (section 4.1.2, p108) and Fatima's reaction echo Lupton's (2013, p.641) concept of emotion-risk assemblage which describes the interactional character of emotion and risk – 'emotions create risks and risks create emotions'. Emotions thus both infuenced and were shaped by participants' perceptions of risk. Furthermore, the older people's reactions confirm Lupton's (2013) articulation of emotions as rational and contextual, and that the emotional character of risk processes does not imply lack of rationality or lack of conscious calculations by laypersons. However, as alluded by Lupton (2013), there is a dearth of research on the emotions that underpin individuals' responses to involuntary risk. These findings demonstrate the importance of further research into how intersecting identities such as race, ethnicity, age, disability and class- shape emotional responses to health risks during pandemics.

This first section demonstrated how a lack of both institutional and interpersonal trust, as well as heightened emotions during such a time distinctly determined older minority ethnic people's perception of risk. Risk also influenced how older minority ethnic people viewed vaccines and how they approached vaccine intake. The second section pivots to discuss vaccine hesitancy specifically as it pertains to older minority ethnic people.

4.3 Vaccine hesitancy

Vaccination is regarded as the cornerstone of public health and as one of the tools pivotal to controlling and managing infectious diseases such as COVID-19 (Rémy, Zöllner and Heckmann, 2015; University Of Cambridge, 2024). While COVID-19 vaccination was central to the UK government's pandemic response, vaccination hesitancy remains a public health concern (Razai et al. 2021; University Of Cambridge, 2024). During the COVID-19 pandemic in the UK, there were disparities in the uptake of COVID-19 vaccination. Among people from minority ethnic backgrounds, there were high levels of vaccine hesitancy (Razai et al. 2021). There are also disparities in the uptake of the COVID-19 boosters in the UK with more older age groups taking the boosters than the younger age groups. As shown in graph 3 below, as of March 2023, COVID-19 fourth dose vaccine uptake by demographic shows highest uptake amongst those aged between 80 and over (94%), in comparison with 91,9% for the 70 and 79 age group, 44.1% for those aged between 30 and 39, and 38,6% for those aged between 18 and 29 (NHS, 2023).

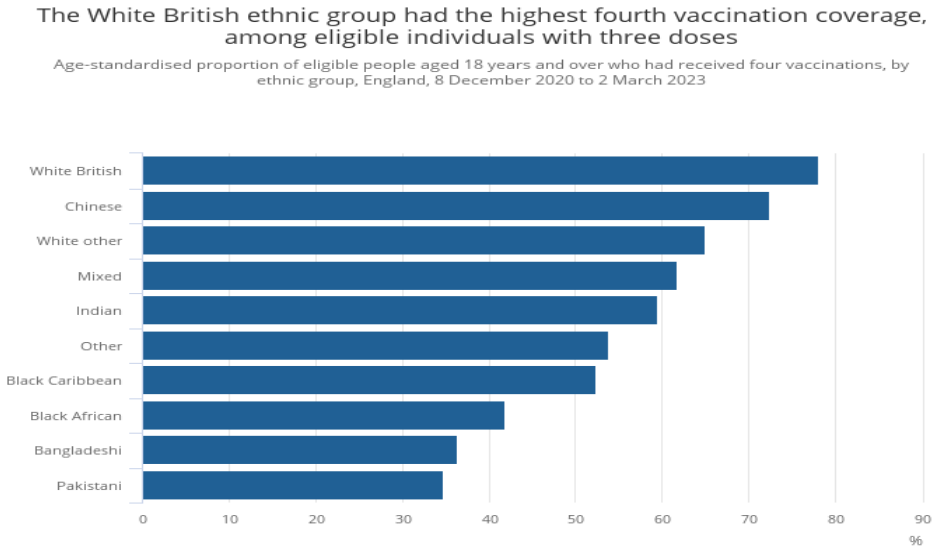
Graph 3: Proportions of eligible people aged 18 years and over who have received four vaccinations, by age range in England during the period 8 December 2020 to 2 March 2023



Source: Death registrations and Census 2021 from the Office for National Statistics, National Immunisation Management Service, Hospital Episode Statistics and General Practice Extraction Service data for Pandemic Planning and Research

As shown in graph 4 below, there is also disparities in booster uptake according to ethnicities, with the minority ethnic groups having lower uptake than the White British people. NHS (2023) records that as of March (2023), 78, 1% White British and 72,4% Chinese had received their fourth dose in comparison with 34,8% Pakistani, 36,3% Bangladeshi and 41,8% Black African. However, this data is not disaggregated according to age and other identities.

Graph 4: Proportion of eligible people aged 18 years and over who had received four vaccinations, by ethnic group in England during period 8 December 2020 to 2 March 2023.



Source: Death registrations and Census 2021 from the Office for National Statistics, National Immunisation Management Service, Hospital Episode Statistics and General Practice Extraction Service data for Pandemic Planning and Research

There has been wide ranging controversy and no consensus among scholars regarding the conceptual breadth of 'vaccine hesitancy'. WHO (2022, p. vii) defines vaccine hesitancy as 'a motivational state of being conflicted about or opposed to, getting vaccinated, including intentions and willingness.' The phenomenon leads to individuals delaying or refusing immunisations despite the availability of vaccination services (MacDonald, 2015). It is difficult to have a clear picture of vaccine hesitancy because hesitancy may not be directly related to vaccine uptake and individuals may

accept or reject vaccination with or without hesitation (Bussink-Voorend et al. 2022). Furthermore, high vaccine hesitancy may not necessarily lead to low vaccine uptake while low vaccine hesitancy may not necessarily lead to high uptake of the vaccine (Dubé et al. 2013). An individual might accept a vaccine but delay in taking it (vaccine hesitancy) due to varying factors such as the fear of needles, lack of concern about diseases which are vaccine preventable such as measles, and access barriers (Goje and Kapoor, 2024). Additionally, MacDonald (2015) critiques classifying individuals who do not take up vaccines due to system failures as vaccine hesitant because their failure to take up the vaccines is not out of personal reasons. Therefore, understanding the contextual factors surrounding vaccine hesitancy is important for devising vaccine specific strategies to address it.

Vaccine hesitancy is complex and varies across context, time, place and depending on the vaccines (Betsch, Böhm and Chapman, 2015; MacDonald, 2015). It is attributed to multiple factors such as attitudes, beliefs, behaviours, and emotions (Goje and Kapoor, 2024; Freeman et al. 2022). Vaccine hesitancy lies on a continuum between individuals who accept vaccines without doubting and those who refuse vaccines without doubts. Therefore, this implies that vaccine hesitant individuals constitute a heterogenous group that lies between the two positions of the vaccine acceptors and the vaccine refusals. Ethnic minorities are heterogeneous and possess differing social, cultural, and economic profiles. Accordingly, they hold varying degrees of indecisiveness about vaccination (for example as shown in graph 4 above). Furthermore, the rationale behind their vaccine hesitancy can be very specific considering the intersection of their age, ethnicity, disability, socio-economic status, and other identity characteristics. Understanding the dynamics of vaccine hesitancy is pivotal to tackling vaccine-preventable diseases, mitigating their impact, and promoting health. It is therefore important to gain insight into why older ethnic minority people in the UK are vaccine hesitant.

The various complex factors that influence vaccination hesitancy are termed vaccine hesitancy determinants (Dubé et al. 2013; Larson et al. 2014; Morales et al. 2022; MacDonald, 2015). Scholarship has identified several models on the grouping of vaccine hesitancy determinants. Examples include WHO's three C model (MacDonald, 2015), the five C model (Betsch et al. 2018), and the five A model (Thomson, Robinson, and Vallée-Tourangeau, 2016). Table 2 below gives a summary

of the 3 models. WHO's three C model which includes complacency, convenience, and confidence (Dubé et al. 2013; MacDonald, 2015) consolidates the main aspects that constitute the various models. For example, the five C model adds calculation of risks and collective responsibility to the factors identified in the three C model (Rancher et al. 2023). However, the three C model seems to embrace the aspect of calculation of risk under complacency and confidence (MacDonald, 2015; Tostrud, Thelen and Palatnik, 2022).

Table 2 : Comparison of the 3C model, 5C Model and 5A model

3C Model (MacDonald, 2015)	**5C Model** (Betsch et al. 2018)	**5A Model** Thomson, Robinson, and Vallée-Tourangeau (2016)
confidence	confidence	acceptance
complacency	complacency	awareness
convenience	constraints	access
implicitly included under confidence and complacency	calculation	awareness
implicitly included	collective responsibility	not included
not included	not included	activation

To begin with, under WHO's three C model, confidence encompasses trust in the vaccines' effectiveness and safety, trust in the system responsible for delivering the vaccines including the health professionals, and trust in the policy makers who make decisions regarding vaccines (MacDonald, 2015; Shearn and Krockow, 2023). Further, vaccination complacency refers to the perceived risk of contracting the disease (MacDonald, 2015). Complacency is associated with low perceptions of risks of vaccine-preventable diseases, consequently leading to vaccination not being deemed a necessary preventive action (MacDonald, 2015; Shearn and Krockow,

2023). MacDonald (2015) also claims that self-efficacy (which is one's ability to take action to be vaccinated) is influenced by complacency (the perceived risk of getting unwell from the disease) and therefore determines vaccine hesitancy. Lastly, vaccine convenience refers to the perceived level of access to vaccinations. This includes factors such as proximity to the vaccination sites or geographical accessibility, physical availability, affordability, language, and health literacy (MacDonald, 2015; Shearn and Krockow, 2023; Betsch, Böhm and Chapman, 2015). Low convenience means even if an individual considers vaccination as important, specific barriers will prevent the individual from getting vaccinated (Betsch, Böhm and Chapman, 2015).

My research distinguishes a broad spectrum of factors that influenced COVID-19 vaccine hesitancy amongst older minority ethnic people in the UK during the pandemic. Across the interviews, several major themes emerged regarding the research participants' decisions on COVID-19 vaccines and vaccination. In this study, WHO's three C model, which postulates three person-level centred determinants for vaccine hesitancy (MacDonald, 2015) is used to provide a theoretical way of analysing and understanding the older minority ethnic people's response to the COVID-19 vaccine and vaccination. I therefore group and analyse the themes using the three C's: confidence, convenience and complacency (MacDonald, 2015).

Before embarking on this analysis, it is important to offer important background information from my research surrounding vaccine hesitancy among my research participants. Older minority ethnic people in the UK, a subsect of minority ethnic people, were vaccine hesitant. Data from my findings shows varying degrees of indecisiveness about the vaccine and vaccination. This reflects the older minority ethnic people's heterogeneous profiles, characterised by distinct social, cultural, and economic variations. The reasons behind their vaccine hesitancy varied, considering the intersection of their age, ethnicity, disability, socio-economic status, and other identity characteristics. Table 3 below illustrates the vaccine hesitancy data from my study.

Table 3: Vaccine Hesitancy amongst participants in my study

Took the vaccine	Refused to take the vaccine	Taking the boosters	Not taking the boosters or unsure
54 of which 13 were not hesitant, while 41 were initially hesitant but later took the vaccine	3	18	39

In line with WHO's (2015) definition of vaccine hesitancy as the delay in acceptance or refusal of vaccination despite the availability of vaccination services, forty-four of the participants were vaccine hesitant. While most of the research participants eventually accepted the COVID-19 vaccine, initially they were apprehensive and undecisive about getting the vaccine. The three participants who refused vaccination did not hesitate. Therefore, the research participants' responses to the calls for vaccination align with Bussink-Voorend et al.'s scholarship, who critique WHO's definition of vaccine hesitancy. Bussink-Voorend et al. (2022) critique the characterisation of vaccine hesitancy as a behavioural phenomenon because people may accept or reject vaccination with or without hesitation. My study further reveals that the reasons for vaccine hesitancy among the older minority ethnic people are directly intertwined with their experiences of intersectional healthcare inequalities.

4.4 Confidence

This section explores confidence as a key determinant of vaccine hesitancy focusing on trust in the vaccine, healthcare professionals and institutional systems. The discussion begins with a focus on the lack of trust, then moves on to exploring the role of value alignment in fostering confidence and considers how experiences of racism undermine trust in vaccination. The sub-section on confidence ends with a nuanced view on vaccine hesitancy among older minority ethnic people, making use of Vandrevala et al.'s (2023) sensemaking paradigm.

4.4.1 Lack of trust

Most of the research participants identified mistrust as central to their vaccine hesitancy particularly towards the COVID-19 vaccine, government authorities and the NHS. Their lack of institutional and interpersonal trust further eroded confidence in the vaccine and its development. Participants linked their fears about adverse effects to historical unethical medical experiments on minority ethnic communities in the UK, thereby fearing a recurrence of such under COVID-19 vaccination. Abdul (85), a male participant who suffers from a chronic heart condition and high blood pressure, explains:

> *I have fears that these COVID vaccines may cause future complications in human bodies. This has happened in the past with other vaccines. But after many years the medical experts admitted that they should not have prescribed the vaccine for the diseases. So, I am afraid of such an experience. From what I know it takes about ten years for big experiments to be done before bringing a vaccine on the market. So how come the COVID vaccine was developed in a few months?*

Other participants also expressed sceptism about the vaccine's rapid development, raising concerns about its efficacy and safety. In FGD7, some participants question:

> *How is it that they quickly manufactured the COVID vaccine, yet they have failed to get a vaccine to prevent HIV/AIDS, despite many people still dying from it? I don't think they tested the vaccine adequately on different people before distributing it. They just rushed*. (P4)

> *It took them many years to research on the flu vaccine, so isn't it strange how they quickly discover the COVID vaccine?* (P3)

Tendai (77) feared '*being used by the government as guinea pigs or as second-class citizens for trials with untested vaccines.'* Similarly, Sipho (66), one of the three participants who refused the vaccine questioned the prioritisation of vaccination for COVID-19 over other illnesses:

> *I was not happy and not confident with the vaccine. I feel that they were experimenting on us ordinary people. There are many other diseases in the*

world, such as diabetes, cancer and so on, for which we don't get vaccinated but only get medication to manage them. So why are they emphasising on vaccination for COVID, and not for the other diseases?

The participants' concerns reflect deep mistrust rooted in historical instances of unethical medical research in the UK involving ethnic minority communities. The research participants in my study express fear, which is affirmed and exacerbated by historical experiences such as the 1969 chapati research experiment in which 21 South Asian women in the UK were fed chapati laced with radioactive isotopes to study iron deficiency without their consent (Gilbert, 2023; Neuberger et al. 2023). The 1969 chapati experiment exposed 21 women to health risks, and some of the women have developed health complications (Gilbert, 2023). This indicates the importance of honesty in science if it is to be trusted (Goldenberg, 2023). The medical research scandal, which illustrates the intersection of racism and sexism and how it can impact trust, raises ethical issues because prior to the research being conducted, the 21 women were not informed that the medical research would expose them to risk of adverse health effects. Against the backdrop of this scandal, the research participants' fear which emanates from their awareness of the historic exploitation of marginalised minority ethnic communities in medical research, is legitimate. Tendai's use of the term *'used'* reflects the power asymmetries in medical research where marginalised groups bear disproportionate risks.

Thirty nine of the fifty-six participants were not receiving COVID-19 boosters. This finding aligns with University Of Cambridge (2024) which found that since 2022 after the initial dose, booster uptake has declined in the UK despite a rise in COVID-19. The research also found the highest rates of under-vaccination in people of minority ethnic background, younger people, men, and people in areas of higher deprivation.

The thirty-nine participants who were not receiving the COVID-19 boosters cited various reasons for avoiding the boosters. The reasons included rejuvenated mistrust of the vaccine and its unknown adverse effects, especially because people could receive boosters from different manufacturing pharmaceutical companies than the initial COVID vaccine. Wada (74) subsequently questions how one body could be injected with vaccines from different manufacturers.

> *It's like being brewed using different ingredients. I first received Astra Zeneca, and because there were so many negative things said about Astra Zeneca, for a booster I asked to have Pfizer. Since receiving the booster, I struggle with migraines, tiredness and lack of appetite. I won't go for another booster.*

Another participant Delilah (76), describes feeling:

> *dizzy, nausea, muscle pain, and fatigue. I also get breathless from doing small tasks or from walking short distances. These problems started when I got the COVID vaccine. I am not going to get the boosters because before getting the vaccine I never used to be so unwell. My two friends are also having health problems since getting the vaccine, and that's worrying.*

Senzia (68), who is blind and lives with comorbidities refused to have the vaccine and the boosters. She expresses strong sentiments in arguing against getting the vaccine because she perceives the inevitable aftereffects as a risk:

> *I didn't want to have a vaccination. We were hearing things about side effects and people just dying without being unwell. I couldn't risk it. I've had a brain aneurysm. If I end up with a blood clot, I won't survive. I don't want to die yet. I will die when my time is right, COVID or no COVID. But I'm not going to have anything pumped into my body.*

In all the FGDs, participants remarked that they felt unsafe receiving boosters whose adverse effects were unknown. This further eroded their trust and deepened booster hesitancy. Furthermore, participants such as Wada (74) and Delilah (76) who were experiencing symptoms or said they knew people who were experiencing symptoms (which included breathing problems, tiredness, and reduced appetite), associate these symptoms as the vaccine's adverse effects. Although the clinical understanding of long-term COVID-19 remains inconclusive, the symptoms described by participants align with those identified as in the literature (Dietz and Brondstater, 2024). While Senzia refused to take the vaccine, she says she was also medically exempted from wearing masks, lives with comorbidities (brain aneurysm, asthma and is a cancer survivor) **(Appendix D1)** (p.353), and is blind, conditions which heighten her vulnerability to coronavirus infection:

I am exempted from wearing a mask because I'm asthmatic or I would struggle to breathe if I got something on my face.

Beyond the mistrust of the government and scientific experts, some research participants express their mistrust and anger toward pharmaceutical companies that manufacture COVID-19 vaccines. For example, in Jeremiah (79)'s view, the manufacturing of vaccines was a money-spinning venture, and it was not aimed at enhancing the health and wellbeing of the people:

The money makers have profited by making everyone take the vaccine. They made billions of pounds from this. I am not going to believe anything they say anymore. It's been proven that it was all lies. The COVID vaccine was a strategy to enrich the already rich. All the talk about protecting people was complete fallacy. Any normal thinking person will say you lied to me once, you will lie again and again. I compare this with the parable of a shepherd boy who used to look after sheep up in the mountains. When he got bored, he would go out into the village and shout 'wolf, wolf!' All the men would come out in panic, and he would laugh at them because there would be no wolf. He did the same for several days and laughed at the men. When a wolf eventually turned up and attacked his sheep, he rushed to the village and shouted 'wolf, wolf' but nobody came to help him because no one believed him anymore. The wolf killed half of his folk. He went to the village crying and asking why they didn't come to help him. 'My sheep are dead,' he cried. But they told him that they no longer believed him because of his previous lies.

Jonas (74) expresses anger at the COVID vaccine manufacturing companies for enriching themselves:

The rich people who have shares in the big manufacturing companies got richer, whilst us ordinary people became poorer. This is an unfair world!

These views echo concerns that have been raised by The People's Vaccine Alliance which criticised vaccine monopolies for inflating costs of the COVID-19 vaccine fivefold (Marriott and Maitland, 2021). Such dynamics deepened mistrust, especially in communities already disproportionately affected by COVID-19 and pre-existing inequalities (Williams, 2021; Lewis et al. 2023).

4.4.1.1 Relational aspect of trust and the role of value similarity in COVID-19 vaccine uptake

i) Relational aspect of trust in relation to healthcare providers and community leaders

Ethnic minority populations often trust individuals who share their identity more than they trust mainstream society or institutions (Uslaner and Conley, 2003). I draw on the self-categorisation theory, which recognises the salience of shared identity and collectiveness as key to group membership (Tajfel and Turner, 2004; Reimer et al. 2020), to explain the older minority ethnic people's trust behaviour. Findings from my research established that the older minority ethnic people trusted those with whom they shared identity markers, supporting scholarship linking identity with group membership.

The research participants tended to trust the information about COVID-19 and the COVID-19 vaccine when the information was given directly by people who shared their identity. Participants expressed greater comfort receiving the COVID-19 vaccine from health professionals who shared their ethnic or religious background. This contrasts how the older minority ethnic people doubted the authenticity of a pandemic when the message came from the UK government. It was until their community leaders relayed the message that some of the older minority ethnic people began to take the message about the existence of COVID seriously. Moses, a community leader for a Muslim group, recognises the role that community leaders played in building trust around the pandemics:

> *Through pastoral care, the Imams and the Islamic scholars imparted and interpreted academic knowledge about the virus. The older people in our community seemed to appreciate and receive the message about the pandemic and calls for vaccination when it was coming from the Muslim leaders and Muslim healthcare professionals like GPs and nurses that they know or recognise.*

Several Muslim participants also relate how the Imams (Muslim faith leaders) in the community influenced their perception of the COVID-19 pandemic and the vaccine. This shows how highly faith leaders are held in the Muslim community. Jonas (74), a male participant, is cognisant of how impactful a Muslim medical doctor was in positively influencing them to believe in the existentialism of COVID:

> *I was shocked by what I saw. This same doctor had now changed in appearance. At the start of the pandemic, he had been wearing a big beard, a Muslim religious man, but now he was clean-shaven. I engaged him and you know what he said to me. "Look here my brother. I am a Muslim man, and I have been practising Islam, reading and praying every day and wearing my long beard, a good sign of my Muslim religion. Some of you have seen me before with my long beard," and that made me relook at him and rethink, and I was then convinced: this is real, something real is coming up, COVID. Because once a Muslim always a Muslim. Once a Muslim has a beard, a beard has grown, you never shave your beard, no matter what happens.*

For Jonas, the Muslim doctor's removal of his beard which he had kept for many years symbolised the gravity of the COVID pandemic because keeping a beard is an obligatory Islamic religious identity. However, the views on removing beards which are a religious obligatory requirement during COVID-19 are nuanced. While Amer, Latif and Haris (2022) concur that the beard is a religious identity, their online cross sectional survey that sought to explore the impact of keeping a religious beard during the pandemic on male medical healthcare professionals established that the requirement that Muslim healthcare professionals shave their beards as a preventative measure to prevent spreading of coronavirus by ensuring a perfect seal of the masks, posed a risk on their mental and emotional wellbeing. For example, half of their research participants felt that their religious identity was violated.

My study thus reveals the relational aspect of trust and the role of value similarity in COVID-19 vaccine uptake. Alongside the influential role of health professionals who shared the same religious identities as some research participants as well as the importance of community leaders encouraging vaccine intake, the setting up of COVID-19 vaccine clinics inside Mosques and the manning of the clinic by volunteers from Muslim backgrounds also enhanced trust and vaccine uptake among older

minority ethnic people. Specifically, running COVID-19 vaccine clinics inside mosques alleviated fears that any undocumented older people may have had of exposing themselves to deportation. Mustaf, a community leader, outlines the salience of conducting vaccine clinics in the mosques:

> *You know inevitably, there are people in our community that are illegal and who don't have paperwork, and who would not have been able to access the vaccination through the NHS vaccination centres due to fear of the government. So, having the vaccines inside a mosque was kind of a neutral zone, you know, for the massive amount of people with no regular documentation in the UK. These are people who don't have NHS numbers. They felt freer to walk in and get their vaccination done at the Mosques. Yeah, they felt it was more convenient for them to have their vaccination in the mosque. So yeah, that was successful. We found many people that we vaccinated that otherwise may not have gone for a vaccination. And amongst these there were some, that were very vulnerable in terms of poor health and so on.*

While the government announced that everyone was eligible for vaccination, minority ethnic people without legal stay in the UK felt fragile and vulnerable and this contributed toward their vaccine hesitancy. Mustaf, the community leader, conceded that their fragility and vulnerability also deterred some people from going to the hospital for treatment of COVID-19 because they were afraid of *'being interrogated about legal stay.*' The tension between legal status and vaccine eligibility created uncertainty thereby deterring undocumented individuals from seeking care. On one hand being legal is perceived as mandatory for one to stay in the UK and benefit from healthcare. On the other hand, the government announced that everyone could receive the COVID-19 vaccine. This tension deterred some older minority ethnic people from receiving the vaccine and accessing health care. The success of mosque-based vaccination clinics highlights the value of culturally congruent health interventions. Also prevalent is the importance of improving vaccine accessibility pathways, such as vaccination booths inside religious sites. Adopting a no questions asked approach would encourage uptake among undocumented individuals. These are important measures that can be employed in future pandemics.

This study affirms that shared identity fosters trust through in-group dynamics (Claridge, 2020). Furthermore, my research is also congruent with scholarship that posits that betrayal leads to erosion of trust (Claridge, 2020). The older minority ethnic people feel betrayed by the UK government and science experts based on previous and historical experiences with racism and discrimination in the context of healthcare. Ethnicity and race therefore shaped individual and collective trust patterns. Further research is needed to explore additional factors influencing minority ethnic trust in health systems. Understanding these dynamics is key in developing effective health care policies, community interventions and strategies for building trust among minority ethnic people in multi-ethnic societies.

ii) Relational aspect in multigenerational households

The vaccine hesitant participants in the individual interviews said that while they had initially been reluctant to take the COVID vaccine, their decision to eventually take the vaccine was shaped and influenced by the conversations that their children and grandchildren had with them through the intergenerational dynamics. They reference how their children and grandchildren - most of whom work in the health care sectors as carers, nurses, and doctors - positively influenced them to get vaccinated. Kenzo, a community leader, relates how some older people's decisions were influenced by their younger family members with whom they live:

> *There was a group that were willing to listen to whatever information they received regarding the vaccine, whether it was for or against the vaccine. They were quite indifferent. And if the younger generation, say for example, because I'm a pharmacist and I have a background in clinical trials, if I went and spoke to my mom and suggested to her to take the vaccine, she would take the vaccine. That's how some older people were influenced in their decisions on the vaccine. Because again, I'm a trusted point of contact for my mother and I have some sort of authority in that matter. Whereas if it is someone who is conspiratorial in nature and doesn't believe in vaccines, they may turn to their parents and say no, don't get the vaccine because the government is out to get you. So, parents could be easily swayed by their family members.*

Vimbai (77) shared that while she is aware that she is vulnerable given her ill health (neurological disorder, high blood pressure, sleeping disorder and chronic fatigue), her and her husband were both not keen to stop their weekly cleaner from coming to clean their house despite her refusal to take the vaccine. Vimbai reiterates about how her children kept emphasising how risky it was for them if the cleaner continued coming to their house:

> *We were aware that our cleaner did not take the vaccine because she told us that she was against it. My children were upset with me and my husband because we were not keen to stop her cleaning services. Well, she is a migrant with children, and she must work many hours for her family's upkeep. We felt pity for her, and we did not want her to struggle financially.*
>
> *Well, after her cleaning, we would then make sure that we kept all windows open for a couple of hours.*

The family influence on the older people's decisions regarding vaccination is notable, given that existing data in the UK reveals that minority ethnic people constitute the largest percentage of workers in key sectors such as health and social care (The Health Foundation, 2020). The older minority ethnic people's children who work in the healthcare sector imparted the knowledge they had about the importance of the COVID vaccine and subsequently influenced their parents to receive the vaccine. Thus intergenerational influence especially from children employed in health and social care acted as a protective factor.

Simultaneously, while the research participants only engaged in interpersonal interaction with pro-vaccination family members and were therefore positively influenced to receive the COVID vaccine, the reliance of the older people on their children for matters relating to vaccines could expose them to vulnerability. For example, the presence of a family member in the household who is against vaccines could negatively influence the older people. Notably, no participants reported being dissuaded from taking the vaccine by family members.

Hence, this highlights the salience of young family and community leaders in enhancing health empowerment through fostering interpersonal interactions. This confirms findings that vaccine hesitant people are often influenced by diverse interpersonal source rather than solely media channels (Scharkow et al. 2020; Murphy

et al. 2021). However, while to Scharkow et al. (2020) and Murphy et al. (2021), vaccine hesitant people's direct exposure to information was via media sources, my research established their exposure to information via families and community leaders.

4.4.1.2 Adverse effects of intersectional racial, ethnic, and age discrimination on trust

The adverse effects of racial and ethnic discrimination on the trust of people of minority ethnic backgrounds are documented in scholarship. For example, Schultz (2006) links marginalisation in healthcare as contributing to cautious and resistant trust. On the other hand, Paul, Fancourt and Razai's (2022) longitudinal research in the UK established a link between experiences of racism in healthcare and lower trust in healthcare among minority ethnic groups. Consistent with Paul, Fancourt and Razai's longitudinal research, my study establishes that racial discrimination contributes to low trust in the health system and COVID-19 vaccine refusal. Thus, racial discrimination erodes both institutional and interpersonal trust, discouraging engagement with the NHS services. While the research by Paul, Steptoe and Fancourt (2021) amongst mostly white research participants established links between low trust in healthcare systems and low negative attitudes towards vaccines including COVID-19 vaccines, the research participants' mistrust in my study is distinguished by the influence of their multiple identities (including race, ethnicity, and older age) on their lived experiences. My study builds on evidence linking discrimination with adverse health outcomes, especially vaccine hesitancy. Using Intersectional Risk Theory, the study clarifies how multiple identities (including race, ethnicity and older age), compound vulnerability and mistrust. Consistent with Crenshaw's (1989) intersectionality, social identities interact to shape lived experiences and exacerbate risk. When public experiences with systems are negative, for example through perceived discriminatory and racist practises, trust gets eroded.

This is illustrated by fears that vaccines contained microchips for racist and discriminatory means. Rudo (68) believed that the vaccine was part of a government effort to track and deport migrants. She stated:

The government was using COVID vaccines with microchips to identify, track and deport us migrants out of the UK. There is so much negative talk about us migrants in news and meetings by big officials especially since the Brexit.

The microchipping narratives made some of the participants doubt the genuineness of the UK government in protecting them from COVID through the COVID vaccines because they associated the vaccine as *'a control and surveillance system by the government to monitor migrants'* Vimbai (77). The microchipping fears were also exacerbated by the older minority ethnic people's lived experiences of racism, which confirms Sevelius et al. 's (2020) and Siegrist's (2021) views that past negative experiences can compound mistrust of others. Although participants had no direct experience of microchipping, other encounters with racism and discrimination in the UK shaped these fears.

Furthermore, during FGD2, one of the five research participants mentions the fear of being *'eliminated or their children and grandchildren being made infertile'* via vaccinations as one of the reasons for hesitating to take the vaccine:

There is a lot of talk by rich countries about the world being overpopulated. Because they want fewer people in the world, they will eliminate some. We don't worry about big families. The more we are the happier and merrier we are, but they don't value that. They associate the problems that this country is facing with us, for example with climate issues and NHS. We are seen as the problem. (P5)

I am worried that my children and grandchildren, the future generation, will be made infertile by the governments, who are using the depopulation agenda via the COVID vaccines. The COVID vaccine is one of the governments' monitoring and control tactics and this is worrying. (P3)

The research participant's concern reflects on the population ageing discourse which existing literature notes (Walker, 2018; Lemercier, 2022). Older people are sometimes viewed as a burden especially in view of increased life expectancy. In the context of the COVID-19 pandemic and the challenges that NHS is facing in managing the waiting lists for major medical interventions, older people can be viewed as a burden. Participants felt that their racialised identity intensified experiences of ageism, compounding their vulnerability than older White British people. While it is

acknowledged that ageism is experienced by all older people, the older minority ethnic people link their ageism with racism and discrimination. Thus, the older minority ethnic people spoke of the fear of being deprioritised as a means of reducing the demographic burden on services like the NHS.

4.5 The sensemaking paradigm

Older minority ethnic people's mistrust of government and healthcare professionals shaped their construction and social interpretation of the meaning of the COVID-19 pandemic and the COVID-19 vaccine. Their construction and social interpretation of what was happening during the pandemic and regarding the vaccine were fuelled by and were coherent with their lived experiences of racism and discrimination. Vandrevala et al. (2023) define this seeking to make sense of happenings (which are characterised by knowledge gaps and misconceptions) as a sensemaking paradigm. My study is consistent with Vandrevala et al.'s (2023) research, which used the sensemaking theory to unpack the theoretical process underlying the development of conspiratorial beliefs around COVID-19 within Black African and Caribbean communities in the UK. Vandrevala et al.'s (2023) research established that historical and contemporary mistrust and the uncertainties associated with the pandemic gave rise to conspiratorial thoughts by the Black African and Caribbean communities in the UK.

Whereas Vandrevala et al.'s (2023) research focused on only Black African and Caribbean communities and used participants of various ages (adults and older people), my study focuses on participants holding intersecting social identities (including race, older age, living with comorbidities, disability etc). The older minority ethnic people in my research felt threatened by the COVID pandemic itself and by racism, ageism, and other forms of discrimination. They perceived threat as multifaceted, encompassing both the virus itself and systems of racism, ageism and discrimination. Racism and discrimination posed a group identity threat for older minority ethnic people.

As the research participants are knowledgeable about the reasons which underlie the emergence of the thoughts they have regarding the happenings during the pandemic and relating to the vaccine, the term 'conspiratorial thoughts' does not adequately

define the thoughts which the research participants in my study had. It is therefore not an accurate term for them. For my study, I use the term sensemaking narratives, as borrowed from Vandrevala et al. (2023). The sensemaking narratives of the older minority ethnic people are based on contexts which are linked to their identities. Thus, framing their concerns as “conspiracy theories” is reductive, rather they represent rational “sensemaking narratives” grounded in lived experience and historical injustice. The reasons that drove the older minority ethnic people to being hesitant about the COVID-19 vaccine gained some form of legitimacy due to how they were informed by experiences of discrimination in the context of healthcare. This differs from conspiratorial thoughts which scholars such as van Prooijen and Jostmann (2013) and van Prooijen and Douglas (2018) view as characterised by misconceptions and knowledge gaps.

Having discussed some factors related to confidence that led to vaccine hesitancy, the next sub-section elaborates on factors related to vaccination complacency.

4.6 Vaccination complacency and risk

Vaccination complacency refers to the perceived risk of the disease (MacDonald, 2015). Risk is a subjective phenomenon, which is largely influenced or determined by social factors and power relations (Douglas and Wildavsky, 1983; Lupton, 1999a; Zinn, 2008). Risk perception, which MacDonald (2015) defines as complacency is influenced by socio-cultural and individual values (Lupton, 1999; Peter, 2020; Douglas, 1992). Therefore, societal contextualisation of risk perception is key to understanding people’s behaviours in response to risk. My study confirms that in the context of the pandemic, the older minority ethnic people’s perception of risk was contextual. The way they perceived risk was dependent on their socio-cultural and individual values and lived experiences. Several of the research participants’ low risk perception influenced them to be vaccine hesitant.

First, this section discusses the role of optimism bias in the older minority ethnic people’s vaccination complacency. The second sub-section elaborates on how some older minority ethnic people weighed the adverse effects of the COVID-19 vaccine against the benefits of being vaccinated.

4.6.1 Optimism bias

Optimism bias is a key factor in determining some participants' perception and response to vaccination calls. Optimism bias refers to one underestimating or overestimating the chances of them being vulnerable to risk (Pascual-Leone et al. 2021; Herbec et al. 2022b). During pandemics, optimism bias can expose individuals to heightened risk of disease infection when individuals deter from adhering to protective measures. Simultaneously, optimism bias can also be a coping strategy when it buffers individuals' anxiety and stress, especially in view of the uncertainties associated with pandemics (Pascual-Leone et al. 2021).

Some of the research participants in my study underestimated their chances of catching coronavirus. Furthermore, they did not identify themselves as a risk group. Consequently, their attitudes made them vaccine hesitant. In FGD5, one participant referenced his physical strength, which he claimed is characteristic of African and Asian bodies and which therefore reduces their vulnerability to infection with coronavirus:

> *You know Africans are strong; our bodies are used to living under hardships- look at how we do manual work back home, ploughing the fields and walking very long distances. That is why we worked long hours in the industries when we came to England. We survived hunger and illnesses in Africa, such as HIV/AIDS and Ebola. So COVID can't beat us!* (P3)

Kumbi, 66, who did not take the vaccine minimised the risk posed by COVID, and equated being infected by the coronavirus to:

> *just a flu with flu symptoms, which will be in my body for a while but quickly disappears. The virus comes to visit my body, looks for somewhere to stay and while its job is to survive, our bodies are stronger than the white men's bodies. Even our skin is hard and strong. So, Coronavirus cannot survive in us.*

Additionally, Sipho (66) showed optimism bias by arguing that spirituality can help prevent coronavirus from infecting individuals:

> *The virus does not like it in our bodies- thank you. My body has got too much oxygen flowing! I'm strong and this strength in my body is a natural vaccine. It is stronger than the artificial man-made vaccine. It is about telling the virus that*

this is not a comfortable place for it to stay and be able to make itself into a stronger virus, so it will leave. Yeah! You know what? Sometimes it takes making positive declarations about what you want to see happening in your life – talking to the virus and instructing it not to come to you. Is positive declaration not a vaccine?

These participants have a low perception of the individual risk of catching and becoming ill from the coronavirus. They believe that COVID does not pose a significant threat to their bodies. This constitutes optimism bias. Additionally, optimism bias whereby the older minority ethnic people underestimate their exposure to the risk of COVID while overestimating their resilience leads to vaccine hesitancy and their opposition of an artificial measure in the form of a COVID-19 vaccine.

Similar findings were reported in Herbec et al.'s (2022) research, which sought to establish risk perception for severe COVID-19 among vulnerable adults in the UK. Herbec et al. (2022) concluded that optimism bias played a role in exposing vulnerable adults to the risk of COVID. In Herbec et al.'s (2022) research, some research participants were less motivated to make positive lifestyle changes despite falling in the high-level risk bracket such as being of older age, being an ethnic minority, being a key worker, being overweight and practising unhealthy behaviour. This exacerbated health inequalities.

In my research, 44 participants had low-risk perceptions (as seen in the table under section 4.3 (p.116), because they were hesitant but later took the vaccine) despite their identities which exposed them to heightened vulnerability (such as being of older age, being ethnic minority, living with comorbidities, disabilities or being male) of catching and spreading coronavirus. Optimism bias contributed towards their vaccine hesitancy. However, some participants highlighted several factors which influenced them to eventually accept taking the vaccine, thus showing that eventually these factors weighed above the optimism bias. In FGD4, participants highlighted other factors such as the desire to be able to visit family abroad and peer pressure:

Most of my family lives abroad. I eventually got the vaccine because I worried about not being able to travel to visit my family back home because I didn't have the vaccination card. (P2)

I was afraid so I waited for others to take it, and because most people were getting vaccinated, I then also took it. But I am not taking the boosters. (P3)

It is therefore important that policymakers should take optimism bias into account in dissemination of culturally sensitive vaccination and health information and in empowering individuals during pandemics. Such diversity was essential to capturing the breadth and nuance of individual lived experiences.

4.6.2 Weighing the adverse effects of the COVID vaccine against the benefits of vaccination

Some research participants (Wada and Delilah) weighed the option of the possible adverse risks associated with receiving the COVID vaccines against the possible benefits. Wada (74) and Delilah (76) referenced the adverse effects they are experiencing from the COVID vaccine (refer to 4.4.1, p.119). Wada and Delilah reported experiencing migraines, tiredness, and lack of appetite; and muscle pain and breathlessness respectively. When deciding not to take the vaccine, Senzia (68) also weighed the option. They had fears that receiving the COVID-19 vaccine would cause negative outcomes which would outweigh the benefits of being vaccinated, which contributed to vaccine hesitancy.

With some older minority ethnic people's reasoning, their vulnerability as older minority ethnic people was accentuated by the fact that they felt that the risk of accepting the COVID vaccine meant they were accepting the clinical intervention (in their bodies which they believe are strong and healthy) by a vaccine whose adverse effects they were uncertain of. For these older minority ethnic people, the fear of the risk associated with the uncertainty linked with taking the COVID vaccine was fed by mistrust. Fear, insecurity, panic and anxiety which Beck (1992) and Lupton (2013) define as modernisation's blind spots and emotion-risk assemblages respectively accompany risk and uncertainty. The older minority ethnic people therefore weighed the risks to the benefits, which is evidence that they are not ignorant and reckless. Instead, they made informed decisions which made sense to them based on their beliefs and risk perception. The older minority ethnic people's beliefs and values structured what they saw as risky and how they responded to it.

This confirms Douglas' (1992) articulation of risk as interwoven in identities and group dynamics' perception of risk as social process and how this results in some risks being recognised while others are suppressed depending on one's underlying values, beliefs, biases, and preferences that are associated with their way of life. However, by only focusing on risk perception as driven by an individual's cultural beliefs, Douglas' (1992) articulation of risk falls short of considering the influence of other social identities on perception of risk as Intersectional Risk Theory does.

4.6.3 Threat on religion

Pammy, a research participant who is Muslim perceived the COVID vaccine as a danger and threat to the Muslim religion. She questioned and queried the vaccine's ingredients because she did not want to disobey the Islamic dietary restrictions and norms. Pammy (71) expresses her worry:

> *I was worried because I did not want to disobey Allah by taking a vaccine that had pork. I was convinced that the vaccine had certain ingredients which are not good for the body. So, I was worried and scared, but I did get the vaccine in the end because through the live television broadcasts which we watched from home, our Imam took time to explain to us that the COVID vaccines had no pork. He gave us the light and the go ahead.*

Pammy was sceptical of COVID vaccines because she thought that the vaccines contained forbidden elements such as pork or other non-halal ingredients. However, while pork gelatine is used as a stabilising agent in some vaccines such as influenza vaccines, COVID vaccines do not contain gelatine (NHS, 2023). The reassurance by Imam, whom they have respect for, led them to accept the COVID vaccine. Some Muslim participants therefore weighed two options. For Pammy, on the one hand, getting the vaccine would mean contaminating their bodies and disobeying the Islamic expectations. On the other hand, not getting the vaccine would mean upholding their respect and obedience to Allah by adhering to the Islamic religion's expectations. However, going by the latter option would expose them to risk getting coronavirus infection. This evidences that some Muslim participants' perception and interpretation of the risk of COVID was culturally informed. Pammy and her fellow Muslim research participants here function as connected knowers (Collins, 2000). This is so since it is

their own embodied religious knowledge, rather than generic public health messaging, that allowed them to weigh halal compliance against infection risk, with the Imam acting as a trusted intermediary who translated biomedical guidance into religiously legitimate terms.

In the context of the COVID-19 pandemic, older minority ethnic individuals in the UK drew simultaneously on religious, cultural, and biomedical understandings when interpreting risk, illness, and vaccination. These perspectives underscore the need to situate participants' experiences within their social, cultural, and historical contexts, rather than interpreting them through a linear dichotomy between traditional and modern forms of knowledge, as reflected in the arguments of Povinelli (2016), Rudolph and Rudolph (1984), and Dube (2016) (discussed in the literature review, 1.1.12 p50-1).

Clearly, evidence from my study therefore illustrates the need for robust data disaggregated by ethnicities and age to facilitate a nuanced understanding of vaccine hesitancy amongst minority ethnic groups in the UK.

Now that vaccination complacency and risk has been discussed, the third sub-section now turns to factors tied to convenience.

4.6.4 Convenience

Issues relating to accessibility influenced the older people's decisions regarding the COVID vaccine. Hence, in making their decisions, the accessibility of the vaccine was a determinant factor. Whilst accessing the first COVID vaccine was easy for the older minority ethnic people, for example because several vaccination clinics were located in community centres and Mosques (see 4.5.1). Some participants in FGDs noted that after Mosques and community-based clinics closed, they no longer received boosters due to increased logistical challenges. In FGD6, participant 1 explains:

> *It's not easy to make online bookings for boosters, and to travel long distances to receive the boosters. These days contacting NHS is not easy because you must stay on hold on the phone for a long time. If you must get the bus, buses*

are sometimes not reliable too. It is such an effort to go to the places they are giving vaccinations.

Therefore, the removal of the COVID-19 vaccine infrastructure (such as the closure of the vaccine clinics in the mosques) led to fewer older minority ethnic people receiving boosters because making online bookings and travelling to pharmacies to receive boosters requires increased effort. Most of the participants regarded this as cumbersome and often time consuming. When receiving vaccination is cumbersome and time consuming it can therefore be exclusionary, especially for marginalised populations such as the unwell, those with mobility challenges or do not have the physical capacity to travel to the vaccination sites, and those who are digitally excluded. Additionally, some of the participants' reference to lack of digital knowhow which posed challenges for them to navigate through digital technology gadgets and access vaccination sites, are congruent with the digital exclusion challenges that some marginalised groups in the UK face as presented by scholarship such as The Topol Review (2019).

The community leaders also confirmed that the removal of the vaccine clinics from the community centres led to fewer people taking up the boosters. Additionally, most of the community leaders commented that due to cuts in funding of community projects by local authorities, they have reduced their community activities. Whereas during the start and peak of the pandemic most community leaders spearheaded vaccination empowerment projects, due to cut in funding some community groups had stopped meeting while others continued networking but could no longer afford to continue running the vaccination empowerment projects that they ran during the pandemic. Xaba, a community leader bemoans the cutting of funding by the local community in their neighbourhood:

Since the cut down in funding by the local authority, we have stopped running some of the activities which we used to run. For example, we used to hire a weekly gym instructor to support us with physical activities, but due to cut in funding, we can no longer afford paying him. When the government announced the availability of the COVID vaccine, we empowered the communities by making and distributing simple fliers explaining the importance of getting the

COVID vaccine and protecting oneself against infection with coronavirus. Our fliers were in our various vernacular languages, and this helped our communities understand the messages.

Another community leader, Laiza also spoke about the role that the board members for the community group which she runs played in empowering the older people:

Our board members remained actively engaged with our members throughout the pandemic via monthly online newsletters and via WhatsApp group chats. We used these platforms to spread messages about the importance of the COVID vaccine, without necessarily imposing our views. Of cause not all members have access to internet and WhatsApp, but we still managed to reach out to most of them.

Mustaf, who leads a Muslim networking group describes the empowerment role that the Imam played in promoting the importance of getting the COVID vaccine:

Via live televised sessions in various vernacular languages which our congregations could watch from their homes, Imam encouraged Muslims to get the COVID vaccine. He also explained to our congregates that it was safe for the Muslims to take the vaccine because it had no pork ingredients. For our older people, seeing the Imam speaking to them on television in languages that they could relate to and understand, and the message coming from someone they know motivated them to get the vaccine.

Therefore, the various health literacy empowerment projects whereby the community leaders explained the importance of the COVID vaccine were reassuring to people and helped boost older people's confidence in the vaccine. The older minority ethnic people trusted the messages which were coming directly from the community leaders most of whom they share identities with, such as ethnicity and age group. This illustrates the need for policy makers to ensure that community networking groups for older people of minority ethnic background get adequate funding to sustain their community projects because they contribute towards boosting the older people's positive health outcomes.

Adam (77) mentions that he was hesitant to be vaccinated because his choice of where to receive the injection was not respected. He says:

> I *was denied the option to receive the injection on the buttocks instead of on the arms, yet this is how I prefer getting my injections from when I was young when I lived in my country. I rang my GP several times asking him to inform the NHS nurses that they should inject me on my buttocks, but they refused. I really don't like it on my arms, and I can't understand why I am forced to have it on my arms.*

He related how he had repeatedly consulted his GP requesting him to forward his request to the NHS nurses who were administering the COVID-19 vaccines, but his request was not accepted. Adam believes that injections on the buttocks are more effective as medical interventions than injections on arms. His preference for receiving injections on the buttocks reflects the influence of the socio-cultural context in medical choices and decisions. Adam's belief regarding the place of injection demonstrates how perceptions regarding medical interventions can differ according to one's social identity.

Now that I have discussed the factors tied to convenience, in the next section I proceed to give a summary of this chapter in order to highlight the salient issues that emerged in relation to trust and risk amongst the older minority ethnic people.

Conclusion

This chapter has demonstrated the role of trust in healthcare systems and how it determined the older minority ethnic people's health seeking behaviour. The chapter commenced by illustrating how the lack of both institutional and interpersonal trust was central in influencing older minority ethnic people's perception of the COVID-19 pandemic and their health-seeking behaviour regarding the COVID-19 vaccine intake and vaccination. The chapter identified how the participants' mistrust of the government and experts' knowledge on COVID-19 pandemic and the COVID vaccine caused epistemic mistrust.

Second, the chapter dissected vaccine hesitancy which was present among older minority ethnic people and identified the various vaccine hesitancy determinants specific to older minority ethnic people. The chapter grouped the vaccine hesitancy determinants into four overarching themes: fear of the risks tied to the vaccine due to mistrust of the vaccine, the government, and the NHS; how optimism bias shaped their

perception of risk; family and community leaders' influence; infrastructure and convenience in relation to the accessibility of the vaccine. The analysis of these four overarching themes led to the general conclusion that it is not appropriate to attribute the reasons driving vaccine hesitancy among older minority ethnic people to belief in conspiracy theories, as this connotes irrationality. An analysis through the lens of sensemaking paradigm revealed that the term 'conspiracy theories' does not consider how experiences of intersectional disadvantage due to racism, sexism, and other systems of marginalisation contribute to vaccine hesitancy among older minority ethnic people.

Thus, this research has also established that building trust between the government and older minority ethnic people is critical and imperative in combatting vaccine hesitancy. Additionally, the older minority ethnic people's renewed vaccine hesitancy when it comes to boosters shows that there is lack of consistency by the group regarding vaccine take up. This is concerning as it may exacerbate existing inequalities through heightened exposure to and sickness due to the virus.

This study builds on previous research on trust in minority ethnic people in the UK. Trust among older minority ethnic people can be facilitated and enhanced through communication, relationships based on trust, transparency, honesty, and acknowledgement of their input in critical healthcare decisions relating to issues that affect their lives.

Furthermore, older minority ethnic people understand risk differently from scientists based on their lived experiences of racism, ageism, and ableism. Therefore, what to a scientist may have appeared to be an irrational decision may have been rational to older minority ethnic people. Older minority ethnic people feared racism and discrimination more than potential vaccine side effects. My research reaffirms the existing literature's position that asserts that laypeople's lived experiences of racism and discrimination determine their perception and response to risk. During the COVID-19 pandemic, older minority ethnic people's fear for racism and other forms of discrimination in the UK influenced and shaped their decisions regarding the vaccine. Consequently, their beliefs and desires shaped their decision-making response to health matters during the pandemic.

Additionally, the research participants' reasoning (such as the belief that the African bodies are strong and resistant) which drove them into being vaccine hesitant made sense to them, in the light of their experiences, thus confirming the sensemaking paradigm. It therefore also follows that older minority ethnic people's seemingly risk-averse attitude to risk must not be interpreted as irrational but rather as a rational response to past experiences (such as scientific and research scandals) causing their fear for racism and discrimination and influencing vaccine hesitancy. Subsequently, in line with positionality theory, it is critical that the agency of older minority ethnic people be recognised. Therefore, they should be included in matters and issues pertaining their health and social care, especially in future pandemics.

Lastly, this study highlights the need for disaggregated data to understand vaccine hesitancy among diverse older minority ethnic groups in the UK, and to get a nuanced understanding of the agentic positions that older minority ethnic people hold regarding vaccines as highlighted by the sense-making argument.

CHAPTER 5: DYING, DEATH AND BEREAVEMENT DURING THE COVID-19 PANDEMIC AND ITS AFTERMATH: REFLECTIONS FROM MINORITY ETHNIC PEOPLE IN THE UK

Introduction

In the last chapter, I analysed how the lack of institutional and interpersonal trust influenced older minority ethnic people's perception of the COVID-19 pandemic and their health-seeking behaviour, determining their COVID-19 vaccine intake and vaccination. Drawing on data from my research, this chapter first explores how the older minority ethnic people's interlocking identity characteristics shaped their perceptions and experiences of dying, death, bereavement, and grief during COVID-19.

The first section discusses how older minority ethnic people's perception and experiences of death influenced their ageing during the pandemic. Moreover, this section explores older minority ethnic people's risk of disenfranchised and complicated grief. In the second section of this chapter, I dissect older minority ethnic people's coping strategies. Throughout the chapter, I also embrace the impact of older minority ethnic people's experiences on their ageing trajectory.

5.1 Intersecting axes of inequity: dying, death, bereavement and grief

Death, bereavement, and grief are universal human experiences. Simultaneously, the COVID-19 pandemic highlighted existing and revealed new geographies of illness, death, bereavement and grief due to the pandemic's amplification of inequalities, depending on intersecting identity characteristics (Bear et al. 2020). In the UK, older minority ethnic people had a greater susceptibility to infection with coronavirus and a higher risk of experiencing death, bereavement and grief as compared to white British people because of their social identities such as ethnicity, lower class, living with comorbidities and disability (O'Connor, 2019; ONS, 2020a; Ayalon and Tesch-Romer, 2018; PHE, 2020; Maestripieri, 2021).

Understanding bereavement dynamics among older minority ethnic people is important, especially since mortality in the UK remains higher than it was before the

pandemic (O'Dowd, 2023). The UK continues to experience deaths from COVID-19, although the rates have reduced. In the week ending 17 January 2025, 20.2% of registered deaths involved influenza or pneumonia (2,962 deaths), while 0.9% involved coronavirus (COVID-19) (130 deaths) (ONS, 2025). A total of 705 COVID-19 cases were recorded in UK hospitals as of 10 December 2025, with higher cases amongst those 85 years and older (GOV.UK, 2025). Additionally, the UK continues to experience excess deaths long after the peaks associated with the COVID-19 pandemic in 2020 and 2021. The excess deaths are also higher among older people than younger populations (Alicandro et al. 2023; ONS, 2023). The causes of the excess deaths are highlighted as multiple (Dale et al. 2023). These causes are assumed to include the direct effects of COVID-19 infection, as well as acute pressures on NHS services that negatively impact outcomes from acute illnesses and disrupt the detection and management of chronic diseases. Cardiovascular diseases, including heart failure, diabetes, acute respiratory infections and liver diseases, contributed to the excess deaths (GOV.UK, 2024). Importantly, these are some of the ethnic-specific comorbidities that affect more Asian and Black people than White British people (Teagle et al. 2022). This implies that older minority ethnic people continue to experience a heightened risk of bereavement.

The intersection of several identity characteristics creates variations in people's perceptions and experiences of death and death practices (Oyebode and Owens, 2013; Gire, 2014; Everett, 2023). Additionally, Everett (2023) submits that human beings do not experience bereavement, grief, trauma or healing in a vacuum. Kissane *et al.* (1997, cited in Koffman et al. 2005), who share the same view as Everett (2023), point out that bereavement and grief are complex, multidimensional processes influenced by physical, psychological, social and cultural factors. Therefore, although experiences of bereavement and grief are universal, people's responses to them depend on the context, which is shaped by their race, ethnicity, age, culture, class, gender and socio-economic status (Worden, 2018; Everett, 2023). Against this background, Everett (2023) advocates the use of 'Intersectional Grief Literacies' to analyse experiences of bereavement and grief.

Understanding the role of the multiplicity of categories in determining perceptions of death, dying, bereavement and grief is therefore key (Everett, 2023). From her experiences as a Black woman who experienced grief, Everett (2023) highlights the

importance of using frameworks that embrace complexity and align with the realities of how marginalised communities experience grief, bereavement, trauma and healing.

5.1.1 Perceived ageism in dying and death

To begin with, data from my research reveals that older minority ethnic people's intersecting identities determined their perceptions of dying, death, bereavement and grief. In FGD1, participant 4 expresses fears of death-related ageism.

> *There was a lot of negativity everywhere, in news about deaths of us old people. I could sense that our deaths were regarded as less important than those of younger people, and that scared me because I didn't want to be the next one to go.* (P4)

Furthermore, as revealed in the foregoing chapter (section 4.1.1 p.101), P2 in FGD3 references the many reports on deaths during the COVID-19 pandemic, which showed more deaths amongst the older minority ethnic groups than the White British states:

> *The government inflated the statistics so that it suited their usual narrative that us migrants are negligent of our health. It was exaggerated stigmatisation. They just want us to lose our confidence and live in fear thinking we are dying. COVID is killing everyone in the same way.*

These ignited more fear in older people because the reports made them believe they were targeted deaths and that only older people would die. This is intertwined with mistrust of the NHS medical professionals. Overall, this contributed towards the emergence of their fears of being hospitalised and facing discrimination in hospitals. For example, as evidenced in section 4.1.2 (p.101), FGD1, P2 expresses strong sentiments about this.

> *The reason more Asians and Blacks were dying than whites was to do with racism and selective treatment in hospitals. I think when our people were admitted in hospitals, they were not receiving good healthcare because of racism, and it is this which explains the higher deaths amongst our communities.*

The research participants' fear of death-based ageism and its leading to their reluctance to seek medical help in hospitals resonate with Chrisler, Barney and Palatino's (2016) reasoning, which highlights that ageist behaviour in healthcare settings can contribute towards the infantilisation and dismissal of older patients' concerns, consequently leading to them receiving inadequate support.

Additionally, considering the background of the media's contribution to the marginalisation of some groups in relation to death during the COVID-19 pandemic, the research participants' fear of death-related ageism is legitimate. For example, their fears echo media's presentation of the death of older people as less important than that of young people (Fraser et al. 2020). Furthermore, in relation to the online COVID-19 discourse, there was a rise in harmful stereotypes, derogatory memes and hashtags such as #boomerremover (Fraser et al. 2020; Sparks, 2020; Meisner, 2021) which presented older people as a homogeneously frail group and causative of COVID-19 transmission (Brooke and Jackson, 2020; Fraser et al. 2020; Sparks, 2020; Meisner, 2021). The online ageist attacks also emphasised sentiments about overpopulation by targeting the elimination of older people (Meisner, 2021). Drawing on Vandrevala et al.'s (2023) sensemaking paradigm, such differential treatment gives weight to the concerns of the older minority ethnic people and makes their reasoning sensible.

To further dissect the older minority ethnic people's thoughts and narratives, I also draw on the overpopulation narrative whereby older people are viewed as a burden in society especially given increased life expectancy, the COVID-19 pandemic and the challenges that NHS is facing, for example, in managing the waiting lists for major medical interventions (Walker, 2018; Lemercier, 2022). While all older people can encounter ageism, ageism experienced by older minority ethnic people is unique because it can intertwine with racism. The overpopulation narrative could, therefore, be wielded in a racialised manner to exacerbate the harm experienced by older minority ethnic people during the COVID-19 pandemic. Ultimately, this implies that older minority ethnic people's experiences of death-related ageism put them at heightened risk of negative ageing.

5.1.2 Older minority ethnic people's lived experience of loss

Fourth age is the period in life generally marked by growing cognitive, physical, and social losses: loss of self-expression, choice, pleasure, work, spouse, mobility, functional health, and social capital (Gilleard and Higgs, 2010; Kafková, 2016; Koss and Ekerdt, 2017; Pothen, Dore and Idler, 2019). The COVID-19 pandemic significantly intensified the characteristic losses associated with the fourth-age, namely cognitive, physical, social and emotional decline particularly for older minority ethnic individuals (Gilleard and Higgs, 2010; Kafková, 2016; Koss and Ekerdt, 2017; Pothen, Dore and Idler, 2019).

For all the research participants in my study, loss took various forms, including the loss of loved ones. Participants shared emotional and heart-wrenching accounts of illness, dying and death, bereavement, and grief revealing how COVID-19 deepened personal and familial losses. Farai (80), who lost his daughter (a schoolteacher) to COVID-19 continues to experience emotional distress from her death. He also recounts the emotional toll on his ten-year-old son's wellbeing:

> *Since his mama's death, he has been struggling socially and at school. We do our best to support him. We pray that he gets to accept this unexpected change in his life, but he is young, you know. My son-in-law has married another woman. She is a lovely woman, and we are happy that she fits well into the family.*

Hamza (70) reflects on the profound change following the loss of his sister and brother-in-law key social companions in his retirement.

> My younger sister and her husband, who was a taxi driver in London died of COVID during the same month.

Therefore, research participants such as Hamza and Farai spoke of losing their loved ones, most of whom were working in the frontline or key sectors in the UK. Hamza's brother-in-law and Farai's daughter worked in key sectors as a taxi driver and teacher respectively. This reflects the increased exposure of minority ethnic populations in the UK who often occupy frontline roles that provide essential and salient reproductive labour and duties (Gordon-Bouvier, 2021). These duties exposed them to the coronavirus. This also comes against the background that by March 2020, between

62% and 75% of the health and social care staff who had died from COVID-19-related deaths in the UK were from minority ethnic backgrounds (Phiri et al. 2021).

Three older female participants who lost their husbands to COVID-19 describe profound distress following these sudden and unexpected deaths. Momo (82), an older female participant whose husband died in the hospital after she had not seen him for two weeks, conceded that she was in denial upon receiving the news from the hospital about his death, especially because of the lonely death.

> *A month earlier, the hospital had rung me, telling me that my husband had fallen from the hospital bed. He could no longer talk, so I never heard from him about what had happened. How could my husband fall from a hospital bed?* (silence) *I didn't believe that. I think they dropped him from the trolley, but I couldn't question that. I had no energy to start these arguments. Just imagining the way my husband was struggling alone was eating me away.* (changes voice tone and lowers down her voice)*. Then, after two weeks, the hospital rang me again and told me that he had died. I was shocked. How could it be? It was hard to believe. I could not be with him during his last days. Now, I am alone.* (silence)

In the same way, Elisheba (67), a participant widowed due to COVID-19, relates the sudden unexpected changes in her life that have followed since the sudden death of her husband:

> *It felt like just waking up from sleep, and he was gone, just like that.* (she clicks her fingers). *It feels unreal that he is gone. I am happy I have supportive friends here whom I can often meet.*

Additionally, one of the spiritual community groups also lost their community leader to COVID-19. His death affected the running of the networking group. Kerina, the new community leader for the group, gives an account of the impact of the loss of the late community leader:

> *The loss of our community leader, who was my dad to COVID resulted in our networking group delaying regrouping after the government lockdowns had ended. He was good, and he managed the group well for many years. It was hard to come to terms with the loss and the sudden change for our group. He was responsible for applying for yearly funding*

for our group activities, and when he passed away, we got stranded because we didn't have the knowledge. He had been doing it for years.

Adam (77) speaks about how the ripple effects of the pandemic (loss of his job and networking opportunity) led to him feeling lonely.

You see because of the lockdowns, I lost my job as an interpreter in the courts because no court sessions were being held. After the lockdowns, our group did not meet for sometime. You see, I am someone who likes to chat to with others. Staying at home was very hard for me

For Fatima, Momo and Elisheba the loss of their husbands during the pandemic led to disbelief and denial because the deaths were sudden and unexpected. This aligns with literature which reveals that older people who lose partners in sudden, unexpected and traumatic ways (such as in the pandemic) face the risk of increased mental and physical challenges (AGE UK, 2020; Fang and Comery, 2021). Additionally, the various research participants' revelations indicate how the death of their loved ones was disruptive in the families and the community. For example, the ten-year-old boy has been struggling to cope with his mother's death, whilst the older man has also been struggling to cope with the death of his daughter. Furthermore, he is worried about his grandson's wellbeing because he is also struggling with grief. Thus, his grief is compounded by the dual burden of personal loss and concern for his grandson.

The death of a community leader also disrupted the functioning of the voluntary networking group he led. Scholarship reveals that older people's networking groups foster companionship, thus preventing loneliness amongst older people (Silva, 2024; McDaid and Park, 2023). Vlachantoni *et al.'s* (2022) research to establish the impact of changing social support on older persons' onset of loneliness during the COVID-19 pandemic in the UK established an association between the reduction in older people's social networks and increased loneliness levels. Consequently, disrupting networking activities in the community exposed the older people such as Adam (77) to loneliness. An additional risk was their quality of life being negatively affected. They report having looked forward to the networking activities resuming following the end of the lockdowns because the weekly networking sessions form a big part of their engagements since, as evidenced in the demographics data **(Appendix D1,** p. 353),

they retired from work. This challenges disengagement theory which posits that older adults' death minimally disrupt society due to their withdrawal from formal roles (Blauner, 1966), as cited by (Walter, 2008; Kastenbaum, 1979; Palgi and Abramovitchi, 1984). The death of the older leader had a big impact in the social lives of those people he associated with.

By leading the networking group, the older community leader fostered both his own and others' social engagement and well-being thereby enhancing successful ageing and that of the networking group members. This also confirms scholarship, which posits that third agers' engagement in activities such as shopping, travel, voluntary work, community service, and time with family and friends enhances their self-realisation and life satisfaction, which are key to their identity (Higgs and Jones, 2009; Centre for Ageing Better, 2024). Subsequently, they age successfully. Thus, older people's informal contribution to society should not be undervalued (Longino, 2005). As my study shows, the death of older minority ethnic individuals disrupted established social interactions and community dynamics, echoing Willmott's (2000) assertion that death unsettles social order. Mukhulis (83) bemoans that due to COVID, they could not repatriate the deceased relatives to their countries of origin, sentiments which were also shared by participants in two FGD.

> *Not being able to take the bodies of our loved ones back to our country was very hard. We were forced to have them buried here. At my age, I have many plans in place for my end, and then your end suddenly changes. I have been saving money through our club so that they can take my body back home. My burial place is important and means a lot to me as a Black man. I want to be buried where my (he touches his stomach to show me what he meant, which was his umbilical cord) is. I worried a lot about this.*

Gabriel (68) describes the importance of 'mkando', a monthly contribution among African diaspora members to cover repatriation and burial costs, emphasising culturally meaningful end of life planning.

> *For years, I have been paying 'mkando' because when I die, I don't want my children to struggle financially with my repatriation, funeral and burial. I would like to lie where my ancestors are. (makes a sarcastic laugh) However, with*

COVID, our club members could not benefit from the contributions. How sad this was.

For all the participants, bereavement was compounded by the loss of significant relationships and the inability to perform culturally meaningful funeral rites which are central to identity and well-being. This jeopardised their pyschosocial well-being and shaped their ageing trajectories. Lalive d'Epinay, Cavalli, and Guillet (2009) allude to the negative impact of loss of close connections when one has forged long affective ties on older people's mental and physical health.

5.1.3 The gendered aspect of bereavement

My research reveals that experiences of bereavement during the pandemic were shaped by gender, both in emotional expression and in access to support systems. As revealed in Fatima (73)'s quotation in Chapter 4, section 4.2 (p.110), Momo (82), and Elisheba (67), their husbands' deaths to COVID was distressing. Their experiences align with scholarship that illustrates gender based differences in bereavement, particularly in how emotional and psychological impacts manifest (Koffman et al. 2005; Perkin et al. 2020; Wang, Zhang and Feng, 2023). Koffman et al. (2005) add that women's bereavement and grief are associated with emotional and psychological challenges, such as distress, uncertainty and demoralisation, which exposes women to a higher risk of grief-associated mental health challenges than men. Fatima, Momo and Elisheba are at heightened risk of grief-associated mental health challenges. Koffman et al.'s (2005) research, which was conducted before the pandemic, also established social inequity in bereavement in the UK according to gender. For example, women (especially pensioners) experience more financial disadvantages than men post-death and are at higher risk of poverty and housing challenges, because of factors such as women's unpaid informal care roles (Halleröd, 2013; Dabergott, 2022; Centre For Progressive Policy, 2023). Structural inequities in bereavement are also reinforced by institutional, governmental and societal systems. When pursuing burial-associated administrative issues, some bereaved women struggle to interact with the respective organisations' bureaucracies and administrative logistics (Towers, Reed and Balazs (2023). While my research did not explore financial implications in detail, it shows the need for further research to examine bereavement

related inequalities by gender, ethnicity and age. There is a need for further research to establish the impact of social inequity in bereavement in the UK according to older age, gender and ethnicity. It is important to understand the role of structural vulnerability to bereavement during pandemics with older age and ethnicity as intertwining social identities and its impact on the older minority ethnic people's ageing experiences.

In my research, whilst it was only female participants who openly spoke about their challenges with bereavement and grief following the loss of their husbands during the pandemic, there were also two men who said they lost their wives during the COVID-19 pandemic. However, citing the emotional struggles they are undergoing due to the sudden and unexpected loss, they refused to take part in the research. They said they did not want to reignite the emotional pain of the loss of their wives. I brought this to the attention of the respective community leaders because this could be a pointer to the need for mental health support following the COVID-19 pandemic. The men's reluctance to talk about their experiences reflects on scholarship which reveals the association between dominant masculine traits and norms, such as societal expectations of men being strong, with poorer mental and physical outcomes (Stroebe, Stroebe and Schut, 2001; Seidler et al. 2020; Sileo and Kershaw, 2020). Yet traditional masculine characteristics of being practical and problem-solving do not address nor exempt men from experiencing the emotional challenges associated with bereavement (Stroebe et al. 2001). Thus, in comparison with women, men tend to be reluctant to express emotions or seek help for mental health difficulties (Oliffe et al. 2019; Seidler et al. 2018). Additionally, Ryder (2019) comments that mental health stigma can cause ethnic minorities to distance themselves from trauma discourses. Furthermore, according to Independent Age's (2017) research on older people and bereavement in the UK, men tend to feel lonelier and more isolated in bereavement than women, even though women experience more negative financial impacts and practical issues. The men's responses to bereavement diverged markedly from those of the women in the study. For example, Momo reveals that she finds comfort in coming to interact with her friends at the networking group.

Notably, whilst on the networking days, the men came to the community centre, they sat quietly in isolation without interacting with anyone. They are, therefore, at risk of social isolation and loneliness, which Seymour, Bushnell and Dobson (2018) allude

to. Bereavement is a key factor for isolation and loneliness in later life, particularly for older minority ethnic individuals (Seymour et al. 2018).

Therefore, evidence from my research shows that older minority ethnic widows and widowers have a high risk of experiencing mental health challenges relating to bereavement. Given men reluctance to seek help, bereavement support must proactively engage older minority ethnic men through culturally and gender-sensitive interventions. As established in my research, which also echoes submission by Holm, Severinsson and Berland (2019), monitoring and interventions shortly after spousal loss are essential to ensure the bereaved spouse's well-being.

On a different angle, Holm, Severinsson and Berland (2019), citing Doka and Martin (2011), argue that whilst grieving patterns are influenced by gender, they are not determined by it. Holm, Severinsson and Berland (2019) argue against essentialising grief as a feminine experience, suggesting that both men and women may grieve emotionally or instrumentally. Holm, Severinsson and Berland (2019) add that grieving follows no gendered pattern because men and women can both be emotive or instrumental (which entails physically expressing grief, such as through being restless). It is plausible that bereavement and grieving patterns can differ when death is a result of a pandemic such as COVID-19. Thus, understanding bereavement and grieving patterns following a pandemic for the older minority ethnic people is important, to ensure appropriately tailored bereavement support interventions in the event of future pandemics. These findings highlight the importance of tailoring bereavement support to reflect the diverse and gendered realities of older minority ethnic populations, especially during and after crises such as pandemics.

5.1.4 Loss, emotions and risk

Emotions are central to how individuals perceive and respond to risk during periods of uncertainty such as pandemics (Slovic et al. 2004; Slovic, 2010; Roeser and Pesch, 2016a). Lupton's (2013) "emotion-risk assemblage" concept illustrates how emotions such as anger, disgust, fear, panic and anxiety both shape and emerge from risk experiences. Risks can generate emotional responses and in turn emotional states can influence perceptions of risk (Lupton, 2013). Pandemics such as the COVID-19 pandemic, HIV/AIDS, and SARS can generate emotions (such as anger and disgust)

in experts and lay persons (Lupton, 2013). Lupton (2024) also observes that public health interventions can evoke emotional reactions from the public. These in turn may provoke emotional responses from experts, highlighting the reciprocal nature of emotion in crisis management. Roeser's theory challenges the assumption that emotions such as fear and anxiety necessarily lead to irrational behaviour arguing instead that they can support reflective and morally informed risk judgements (Roeser and Steinert, 2023). Instead, emotions can foster reflections and evaluative knowledge about risk (Roeser and Pesch, 2016a; Roeser, 2020; Roeser and Steinert, 2023). Understanding the emotional dynamics of pandemics is crucial as unchecked emotions can lead to stigmatisation, marginalisation, blaming, exclusion and the marginalisation of already vulnerable groups (Lupton, 2013). It therefore follows that understanding the emotional dimension of risk is vital in seeking to determine the emotional impact of the COVID-19 pandemic on older minority ethnic people in the UK.

My research provides valuable insight into the emotional landscape of bereavement during the COVID-19 pandemic. Participants expressed a range of complex emotions in response to the pandemic and the loss of their loved ones. For example, Thula (65), a male research participant, expresses the changing emotions he felt upon hearing about the death of his parents in the hospital.

> *My parents were in hospital for close to a month after they caught COVID. We were not allowed to see them. I went to the hospital several times, asking that I see my parents, but the hospital refused to let me in. I couldn't help them in their time of need!*
>
> *When the hospital told me that they had died, I was very angry at the nurses and the doctors! I asked them, how? If you said the vaccines work, so why are they dead?*
>
> *And then we couldn't give them the send-off we would have wanted. It has been over a year since they died, and their belongings are still as they were in their house. Their house remains unoccupied. Disposing their belongings hurts and is too hard for me and my siblings. Where do we start? I visit their graves every day. It's like I am dreaming.*

Thula's account exemplifies Lupton's (2013) emotion-risk assemblage where grief, anger and mistrust toward institutional actors emerged from the circumstance surrounding his parents' death during the pandemic. The sudden and unexpected death resulted in him questioning the efficacy of the vaccine and his lack of trust in the vaccine, aligning with WHO's definition of vaccine hesitancy as delayed acceptance or refusal of vaccines despite availability (MacDonald, 2015). The bereaved family members who lost their loved ones due to COVID-19 revealed a plethora of emotions ranging from denial, anger, guilt, incomprehension, and hopelessness. These emotional responses ranging from denial to hopelessness are consistent with established patterns of grief among older people (Koffman et al. 2005; Fang and Comery, 2021; Adiukwu et al. 2022). While Thula is grieving the sudden and unexpected loss of his parents, his grief is compounded by the fact that he has to cope with the distanced funeral and burial. The lockdown guidelines, which enforced distanced funerals and burials as a measure to control the spread of coronavirus, were devised by science experts (SAGE, 2020). Thula's emotional response mirrors Lupton's (2013) argument that the strategies experts use to mitigate pandemics can lead to emotional responses from the public. The inability to see his parents whilst they were unwell in the hospital and their distance due to the lockdown rules put in place by experts affected him emotionally.

Sakhile (64), a female schoolteacher participant, clarifies how she caught COVID-19 at school and its impact on her life.

> *I caught COVID in school and didn't know I had caught the coronavirus. I always went to see my mom, and so when I visited her, I didn't know that I had the virus. My mom caught the COVID and died within a couple of days. Then started the family feuds. My sisters are blaming me for not having been cautious. I feel guilty for my mother's death. I could not cope, and so I have since retired from teaching. Whenever I stood in class, I felt overwhelmed by emotions.*

Sakhile remarks how hard life has been for her since the death of her mother because while she is grieving her mother's death, she is also grieving the loss of her siblings' affection because they are blaming her for her mother's death. Echoing Fang and Comery (2021), who submit that bereavement can negatively impact ageing, prompt struggles with guilt, and erode coping, Sakhile had to retire earlier than she wanted

to because she was feeling guilt and struggling to cope with bereavement and grief (see 1.4). Furthermore, as noted earlier in Chapter 1.4.4 (p.59ff), although bereavement and grief are universal, responses vary by context (Everett, 2023).

Becker (1973) conceptualises this tendency as the “denial of death”, a common cultural defence against existential threat (Dayes et al. 2023). Dying, death and bereavement are notions that people culturally tend to shy away from, and this tends to be prevalent in cultures where grief is considered taboo, stigmatised and is therefore hidden (Dayes et al. 2023; Pitman et al. 2018). Dayes et al. (2023) also indicate difficulty in finding the language to use to talk about death, contributing to making conversations about death difficult. Whilst discourse about death, bereavement, and inheritance are regarded as taboo topics, the sudden inevitability of death during the pandemic drove some of the older minority ethnic people to engage in these conversations. Kettina (74) gives an emotional account of how she drowned in fear when her illness with COVID deteriorated, and she had to be hospitalised.

> *My condition got so bad that my family called the ambulance. As I sat in my bedroom, I looked at the ceiling and thought deeply. I doubted that I would come back alive. I asked my daughter-in-law for my favourite jewellery, a necklace, and gave it to her. I said you take this, it's yours. She looked at me and wept.*

Mustaf, the community leader also revealed that ‘*some older Muslims started buying shrouding materials’* given the inevitability of death during the pandemic. Therefore, the pandemic raised the participants’ anxiety but emboldened their views about topics which they normally regarded as taboo. By planning for their eventual death, the older minority ethnic people diverted from cultural norms which recognise discourse about death as taboo. Therefore, whilst the fourth age is associated with decline and death (Higgs and Gilleard, 2015), COVID changed the narrative.

5.1.5 Distanced funerals and burials and disenfranchised grief

Disenfranchised grief has been associated with the COVID-19 pandemic. Dayes *et al.* (2023) define disenfranchised grief as complicated grief that arises from a loss that is not openly acknowledged or mourning processes that are not recognised socially, thereby contributing towards grief complexities. Bindley et al. (2019), who examined

inequity following unexpected death, established how specific groups of bereaved people can be disadvantaged and disenfranchised in multiple ways by varied dimensions of structural vulnerability, with identities such as gender, age, ethnicity and education intersecting as axes of inequity. For example, Koffman et al. (2005) established higher levels of depression, anxiety and other health-related problems in bereaved Black Caribbeans than among White British because of financial concerns, thus highlighting the intersectional impact of ethnicity and socio-economic status. They also highlighted the role of ethnocentrism in bereavement. Older minority ethnic people were at greater risk of encountering disenfranchised grief associated with the loss of their children because UK frontline workers are mostly migrant workers.

For all the research participants in my study, the loss of their loved ones during the pandemic was complex and distressful because they could not practice the rituals that were in line with their cultural norms. For example, Thula and his siblings have struggled to clear their parents' house over a year after their death. Thula points out that in their African culture:

> *distribution of their deceased's belongings immediately following their death would have formed part of the grieving and coping process- distribution of the deceased's clothes and other belongings. Wearing their clothes brings back to memory the good times we shared.*

Thula (65), who speaks of struggling to dispose of his late parents' belongings in their house because he is still in denial, also says, *'Not being able to view my parents' bodies makes me sad. I struggle to accept that I will never see them again.'* Because that process did not happen, it remains challenging for the family to confront the distribution process. The forging of cherished memories and reaffirmation of family bonds that happens through family support when a loved one dies, which (Keeley, 2017) alludes to, did not happen. Consequently, this exposes the bereaved to heightened distress and disenfranchised grief. My study also identifies the role of ethnocentrism intertwined with other identities in bereavement. Older minority ethnic people, for example, Thula and his siblings, were at greater risk of encountering disenfranchised grief because of the lack of opportunity to conduct funerals and burials in line with their cultural norms.

Noma (77), who is Hindu, bemoaned the distanced burials. She comments that whereas the Hindu religion accepts cremation, they were worried about the loss of opportunity to practice the Hindu funeral rites.

> *The distanced funerals were not ideal, and I struggled to adjust to them when I lost my sister to COVID. This is a ritual that you have practised your whole life, and then you just must stop it. That's hard. I mean, we couldn't do the ritual prayers that we have to do at the grave on the burial day, and again, it must be eleven days after the death. We couldn't participate in these rituals and prayers. And it's not rituals that you can postpone. It's distressing and sad.*

Thula and Noma's situations confirm Dayes et al.'s (2023) assertion that grief complexities that arise from a loss that is not openly acknowledged or mourning processes that are not recognised socially lead to disenfranchised grief. Thula and Noma, who could not practice funeral and burial rituals, are both at risk of experiencing disenfranchised grief. In my study, the research participants' experiences of bereavement and grief are different from that of older white British people because the former are disenfranchised in different multiple ways owing to varied dimensions of structural vulnerability, with identities such as ethnicity and living with comorbidities intersecting as axes of inequity. My study thus reaffirms submissions by Bindley et al.'s (2019) and Everett (2023) that people's different identities result in differential experiences with bereavement and grief. As discussed earlier (see 5.1.2, p. 147), Gabriel and Mukhulis expressed fears about not being buried near ancestral homes. This reflects Seymour et al.'s (2018) point that bereavement can trigger anxiety over disconnection from ancestral roots particularly when funeral repatriation becomes impossible.

5.1.6 Complicated grief

Several participants in my study demonstrated signs of complicated grief a form of mourning that is prolonged and deeply disruptive to daily life. As Mouton (2024) citing McCall (2004, p.70) defines complicated grief as "a holistic grief response that is more intense than would be otherwise indicated; longer lasting than typical; and at the same time, pervasively affects the grieving person's daily life (and behaviours) in significant and negative ways" various risk factors can complicate grief (Dayes et al. 2023).

Harrop et al.'s (2020 to 2021) research on risk factors for complicated grief, which was conducted during the pandemic in the UK, identified several. These included the denial of an opportunity to say goodbye to the dying person, lack of professional and social support, restricted funeral arrangements, and unexpected deaths owing to delayed diagnoses (Harrop et al. 2023). It, therefore, follows that disenfranchised grief can lead to complicated grief.

Some of the research participants in my study are at risk of complicated grief. Momo (82), who lost her husband, speaks about how she continues to imagine *'what he was thinking in his mind when he did not see me anywhere when he was dying alone in the hospital.'* While the impact of minority ethnic people undergoing lonely death during the pandemic remains unknown, the bereaved families' spoken distress reveals the mental health challenges they faced due to their relatives' sudden, unexpected, traumatic and lonely deaths during the pandemic. Further to living with the pain of the lonely deaths of their loved ones in the hospitals, most of the research participants also spoke of the struggles they encountered in trying to adjust to the distanced funerals. Hannah (72), says:

> *Bidding my neighbour by simply standing by the roadside and waving as her coffin passed by at a distance was hard. We had been close friends for decades.*

Two community leaders highlighted that during the pandemic lockdowns, communication on the death of fellow community members whom they networked with was not always practical. Therefore, they only learnt of some of their fellow community members' deaths after the lockdowns, following re-engagement in community activities. This led to delayed grieving, a form of complicated grieving. Mustaf, a community leader, recognises that:

> *Most of our congregation is a lot older. Most of them passed away during the COVID-19 pandemic. We just saw the old cemetery full, such that a new one was opened, and within a short time, we already had about 15 graves. Life never used to be like that. You know, in Mosques, most people like to be consistent about their places of prayer. After the lockdowns, when we started congregating again at the Mosque, that's when I saw several places empty, only to hear that so and so passed away during the lockdowns. It was sad.*

> *Some of the deaths were not directly from COVID. However, the older people's immunity had already been weakened by COVID and had still suffered from the Long COVID. They died from other diseases because their weakened systems increased their vulnerability.*

Laiza, a community leader for women's coffee meetings, also describes the emotional impact on older women when they learnt about the death of fellow women during the pandemic.

> *During the lockdowns, most communication was via WhatsApp. And so, we couldn't always easily reach out to some members because some do not use the internet. After the lockdowns, we learnt the death of some of the members of our women's club. One could see how the loss of friends affected women. It was sad, especially because we had to make delayed contact with the bereaved families to pay our condolences.*

It is, therefore, evident that some of the research participants in my study are at risk of experiencing complicated grief or prolonged grief disorder, which is intense and persistent grief (Szuhany et al. 2021; Harrop et al. 2023). The research participants' feelings are congruent with the risk factors that Harrop et al.'s (2023) research identified as associated with prolonged grief disorder during the pandemic in the UK. Harrop et al.'s (2023) research identified several factors, including the denial of an opportunity to say goodbye to the dying person, lack of professional and social support, restricted funeral arrangements, and unexpected deaths owing to delayed diagnoses (Harrop et al. 2023). Additionally, Murray and Rolston's (2020) Ubele Initiative Report on bereavement support for minority ethnic people in the UK postulates that: 'the inability to be able to say farewell to a loved one within culturally sensitive and recognised circumstances goes beyond the burial; the before and after celebrations and reminiscence, paves the way to being able to manage the stress and anxiety that the actual loss situation generates'. Therefore, not being able to bid farewell in line with their cultural norms exposed the participants in my research to additional stress and anxiety.

For example, Gabriel (68), a Cameroonian woman who runs an event-hosting business that includes food catering for ceremonies (such as weddings, funerals,

traditional marriage, and birthdays), points out that due to government restrictions, her community missed celebrating the lives of the dead, which is their cultural norm.

> *It was all quiet and sober funerals. We missed the singing and dancing around in honour of the departed and handing back their souls, we missed the eating and drinking whilst we comforted each other for the loss of our loved ones. I run a catering business as a side hustle; see the website. (She draws next to me and shows me her website with colourful photographs.)*
>
> *I get hired to provide African food at funerals, traditional marriage functions, weddings, and birthdays. I also rent out chairs and tables, but all this stopped during the pandemic.*

Gabriel‘s sentiments above resonate with Pinto and et al.'s (2023) scholarship which points out that, in the UK, infection control measures had a disproportionate impact on communities whose death rituals involve cleansing or viewing the deceased’s body or coming together in large groups to mourn with the bereaved. These include Black Caribbeans and other African communities who could not meet in large numbers to celebrate the lives of the deceased members of their community as per their cultural norms (UKCB, 2022).

The research participants’ emotional reactions to bereavement show the importance of understanding emotions during pandemics because emotions can consequently negatively affect individuals’ mental health. It follows that understanding the emotional dimension of risk is vital in seeking to determine the emotional impact of the pandemic on older minority ethnic people in the UK.

Thus far, this section has established that the pandemic changed the ageing and life course trajectory and dynamics of older minority ethnic people. While frailty, decline and death are not age-specific as they vary according to various identity factors, my study established that the COVID-19 pandemic hastened the decline and death of older minority ethnic people because it was not only the old who died but also the young old, some of whom were living with comorbidities and whose immunity was already weakened (as highlighted by Mustaf: 5.1.4 above). Whereas fourth age is associated with decline and death (Higgs and Gilleard, 2015), the COVID-19 pandemic created fear about death among all the research participants who were of varied ages (from 63 years to 86 years). This comes against the background that older

minority ethnic people's high risk of comorbidities exposed them to a high risk of coronavirus infection, illness and dying from COVID (Walker et al. 2021). My study is, therefore, consistent with Gerber et al.'s (2020) research, which sought to establish the impact of grief on the physical and mental health of older Australians and revealed that multiple bereavements during the older people's life course negatively impact their physical and mental health and wellbeing. Whilst my study only focused on deaths that happened during the pandemic, the older minority ethnic people endured multiple losses, including the loss of loved ones, jobs, income, networking opportunities, and funeral and burial opportunities that were in line with their cultural norms. Gerber et al. (2020) define these resultant consequences as the ripple effects of grief, for which older people must receive timely bereavement support to mitigate them. There is a paucity of research on the impact of bereavement on older minority ethnic people in the UK. Most of the existing research on the impact of bereavement on older people in the UK has not included the older minority ethnic people. This, therefore, calls for the need for research on the impact of bereavement, which centres on multiple social identities, including older age, ethnicity, disability, and gender, to meet the specific needs and preferences of different minority ethnic groups.

The following section dissects the role of religion as a coping strategy for older minority ethnic people during the COVID-19 pandemic.

5.2. The role of religion as a coping strategy

5.2.1 Exploring religion's role in shaping views on life, illness, and death

Different cultures, religions and nationalities have different conceptualisations and perceptions about life, illness, dying, death, bereavement and grief (Walter, 2010; Pentaris, 2011; Kristiansen and Sheikh, 2012; Gire, 2014; Bear et al. 2020). For example, Buddhists' principle of impermanence in life helps them understand and accept life and death as inevitable. Thus, they viewed COVID-19 as a transitory and passing pandemic (Dorji and Sherpa, 2021; Pentaris, 2011). Although Muslims also view life and death as inevitable, they place their trust in Allah, whom they believe predetermines everything (Kristiansen and Sheikh, 2012). On the other hand, Christians believe that death marks the beginning of a new eternal life in heaven for

those faithful to God and that the unfaithful are destined for hell, where there is suffering and pain (Gire, 2014; Pentaris, 2011). Whilst Muslims lay their trust in Allah, and Christians lay their trust in God, both religions view life and death as inevitable (Kristiansen and Sheikh, 2012; Gire, 2014; Pentaris, 2011).

By virtue of belonging to diverse religions and ethnicities, older minority ethnic people hold diverse perceptions of death, bereavement and grief. My study established that the pandemic strengthened religiosity. Many participants relied on their faith as a resilience, coping strategy and emotional support amid heightened mortality during the pandemic.

Ali, a Muslim funeral undertaker, details how Muslims' trust in Allah made them not fear death during the pandemic:

> *As Muslims, we are not afraid to face death for as long as we are doing something good for the neighbour and community. Even if we suddenly die, that's not a problem because we all die one day at some point anyway, isn't it? Allah decides, and we follow his decisions in our lives. There is no room for fear when one has Allah as their guide.*

Jonas (74) gives a vivid account of the shift in his feelings as a funeral undertaker during the pandemic:

> *At first, I was afraid. I was afraid to do the pickup of the first, second, and third coronavirus-infected bodies. I read the Quran and thought deeply.* (silence)
>
> *Thereafter, I was just no longer afraid. I just told myself, well, if I am going to die, I will die. Allah, who oversees life and death, will have allowed it. Death can come at any time, at a day old, a few days, weeks, or even a hundred years old and no one can challenge it or avoid it. I told myself that these people need help, and I was there to help them. So, I recited the Quran whilst washing the bodies, and I knew Allah was with me.*

Jonas (74), the funeral undertaker, mentions that while he was initially afraid of the coronavirus, after reflecting on Allah's message as stated in the Quran, he was able to discharge the job he was faced with fearlessly. This involved washing corpses which were infected with coronavirus. He speaks about how his respect for the Islamic teaching, which entails serving the community to please Allah, made him doubtlessly

discharge his duties during the pandemic. Therefore, his religious belief as a Muslim and his adherence to Islamic teachings made him brave the risk of catching the coronavirus. Jonas (74)'s willingness to serve his community despite risks reflects the values of collectivist cultures, which emphasise social harmony and responsibility to others (Uichol, 1995; Ford et al. 2015). Ford et al. (2015) and Uichol (1995) expound that collective cultures uphold the pursuit of happiness in socially engaged ways because harmony with other people is key for these cultures. Thus Jonas (74) placed value on helping the community by burying the dead.

Jonas (74) believed that he did not catch the virus because Allah still wanted him alive:

> *Throughout the pandemic, I never caught the virus. I was taking the infected bodies, washing and shrouding them. Of course, I was fully protecting myself, I did wear gloves, masks, the full PPE, and I washed myself well; I did all that. But the protection and help was from Allah! Because others who wore full PPE still caught coronavirus and died because Allah wanted it to be for a reason. After all, it is Allah who rewards human beings with the knowledge and intelligence to make PPE.*

Other Muslim research participants also reported that, as per their Islamic religion, they remained grateful to Allah in both happy and challenging moments. They acknowledged that even though the COVID-19 pandemic was a difficult time, characterised by challenges, they remained resolute and grateful to Allah for making them go through life's experiences, believing that Allah was protecting them because it was not yet their time to die. Farai (80) articulates his trust in Allah:

> *You don't develop cold feet as a Muslim. The COVID pandemic was a very difficult time, but we came from far. We have faced other challenges in our countries, of course, not as big as COVID. Allah never lets us down. This, too, shall pass. If it's not yet my time to go, then I remain here. When Allah's time is up, I will go, COVID or no COVID.*

Following similar reasoning as Jonas (74) and Farai emphasising trust in Allah, Muslim research participants in FGD4 spoke of reading the Quran to family members who were ill with COVID or dying at home. They argued that distanced prayers were not as powerful as face-to-face prayers. Furthermore, they acknowledged that the Muslim

leaders empowered them to understand Islam in a deeper way than the way they had understood it in the past. One of the FGD participants outlines:

> *When my son was ill with COVID at home, he recited the Quran several times each day and called upon Allah to see him through. The Quran is our guide, so during the lockdowns, it was hard for us because we could not go and recite the Quran to the sick in the hospital. Reciting the Quran from home for sick patients in hospitals is not the same as doing it with them.* (P2)

In the FGD, all the Muslim research participants spoke of missing practising their usual daily routine of going to pray at the Mosque several times a day. They argued that while the Imams used televised prayer sessions they could access from their homes, they missed praying face-to-face together as a community.

> *We missed kneeling together in the Mosque. But we had no choice, so we did what had to be done and not catch the coronavirus. Imams helped us understand and accept the adjustments in our Islamic lives, and understand that it's not about 'going' to the mosque that matters, but the will in our hearts. Instead, what is key is just doing the prayers five times a day, from wherever one is. This can even be done at work during lunchtime. Well, it wasn't easy to make that big change. You were born going to the Mosque several times a day to pray, and then suddenly, at seventy years old, you are told to stop, ummmh.* (shakes his head) (FGD4, P1)

> *You see, the five times is a pillar of Islam's spiritual obligation and praying five times is historically and religiously stated. There are five prayer times, each with a different name. Muslim religion emphasises praying collectively because collectiveness, togetherness, sharing, and connectivity are key in Islam. So, moving away from what you know as a religious obligation was hard. Well, we will all die anyway at some point in our lives. COVID made us more spiritual as Muslims.* (FGD4, P3)

Further to the loss of their loved ones, older minority ethnic people also spoke of their other forms of loss, including loss of the ability to conduct funerals and burials in line with their religious or cultural norms. The Muslim community leaders also testified that most of the older Muslims were worried and anxious about the pandemic, especially during the government lockdown restrictions, because they did not want to be buried

outside the Islamic cultural norms that pertain to the washing of the deceased and the shrouding of the deceased. Mustaf, a Muslim community leader, remarked:

> *We had some people who were really concerned that should they die of COVID, they may not be able to have the Imam leading them in reciting the Quran during their last moments, that they may not be adequately washed, may not be shrouded properly so there was a lot of mental health issues with people getting stressed and distressed and anxious. even though, as leaders, we tried our best to give them reassurance by explaining that there were ways that the deceased would still be washed, that there would be special equipment to enable proper washing of the deceased, and the shrouding so they should not worry, but many were paranoid and worried.*

The Imam quoted above is himself a connected knower (Collins, 2000), whose authority to reassure grieving families derived not from clinical or administrative expertise but from his own embeddedness within the community's religious and emotional world. It was this situated knowledge, rather than formal bereavement protocols, that proved capable of holding the community's anxieties about washing, shrouding and burial during a period when normal religious practice was disrupted.

Similarly, the Christian research participants also viewed catching coronavirus, being ill and dying from it as God-ordained. They believe that one's destiny in life is predetermined by God, and is inescapable. While they said they were afraid of catching coronavirus, they said prayer to God and reflections on Biblical scriptures helped them cope and manage the fears. Delilah (76), a Christian widowed woman who fell ill during the pandemic, notes how her feelings moved from fear of COVID to courage through praying for the renewal of her belief and faith in God:

> *I lost my husband to COVID illness, and by the time he died, I had also caught the virus. I was very unwell. At first, I was afraid. But I reminded myself that as a Christian, there is nothing to fear. I knelt and prayed to God for courage, and the fear departed from my soul. I felt the courage. I have faith in my God!* (she raises her arms and puts her hands together). *Amen!*
>
> *I know that my God loves me, and I take heart. It is faith which kept me going. God lives! I do not feel at risk because God is my protector. Throughout the pandemic, I spent most of my time reading my Bible and praying.*

Delilah also relied on prayer when her son, who works as a taxi driver, was unwell with COVID.

> *My son got very unwell with COVID. He was down for nearly a month and couldn't go to work. We prayed for him as family, and when his situation was worsening, we united with our church members, and they prayed for him on WhatsApp. There is strength in unity, unity in prayer. He eventually got better, but he still struggles with long COVID symptoms. So, he has not returned to his taxi driver job. I know that he will get better. God is faithful.*

Therefore, the Muslim and Christian research participants argued that they believe that Allah and God are more powerful than the virus. Additionally, they also argued that humanity's lived experiences are predetermined events: that Allah and God can decide to allow one to be ill because of a predetermined reason, which makes people reflect and redirect their lives and be obedient. Sakhile (64), another older Christian woman, explicitly spoke of her Christian understanding of the link between God and illness:

> *God can use an illness like COVID to make humans repent and move away from our wrongdoings. Look at what is happening in the world. Huum. So many scary things, so much cruelty. Look at all these wars. People have become inhumane. So, God is using suffering to make us change. Human suffering is a sign that our GOD loves us. He is recalling us from sin. Just like Jesus suffered on the cross to wash away our sins. Who are we to question what God brings on earth?*

My study also shows that the pandemic increased the older minority ethnic people's awareness and anxiety about the inevitability of death, particularly for those who got very unwell with COVID illness. Illness meant a confrontation with one's inevitable mortality and an increased awareness of the impermanence of life, which differed from one's previous experiences where they viewed death in more abstract terms and as an event that they had not yet reached. The Christian and Muslim research participants used Christian and Islam preachings to minimise the psychological impact of impending death, thus the change in their emotions from fear to lack of fear after they reflected on the words in the Bible and Quran, respectively. This echoes Terror Management Theory, which posits that when confronted with death, people undergo

a conflict between the inherent desire to survive and the awareness of life's impermanence whilst navigating strategies to minimise the psychological impact of impending death (Solomon, Greenberg and Pyszczynski, 1991). Therefore, I draw on Terror Management Theory to explain the older minority ethnic people's utilisation of world views in the form of their religions to buffer their fears and anxiety about the salience and inevitability of death (Greenberg, Pyszczynski and Solomon, 1986; Greenberg, Solomon and Pyszczynski, 1997). Their search for ways to minimise their anxiety and worry best explains their change in feelings from fear to non-fear.

5.2.2 Good and bad death

The definitions of "good death" and "bad death" remain contested with ongoing debate on whether death from COVID-19 constitutes a bad death. Meier *et al.* (2017) argue that several factors (such as one's preferences for a specific dying process, pain-free status, religiosity, spirituality, emotional well-being, life completion, treatment preferences, dignity, family, quality of life) influence the perceptions of the two notions: good and bad death. Whereas mainstream medicine promotes medicalisation for optimal pain control and patient comfort to ensure the holistic wellbeing and dignity that define a good death (Meier et al. 2016), older Christian and Muslim participants regarded pain and suffering during COVID-19 as divinely ordained experiences that could lead to spiritual growth. According to the research participants in my study, the human suffering throughout the COVID-19 pandemic would make people reflect on their lives, repent and become better humanity. Therefore, to the research participants, pain and suffering during illness and death do not define a bad death. Instead, pain and suffering lead to a good death and a good end. What is key and leads to a good death for the Christian and Muslim participants is dying in faith and belief, whilst enduring pain and suffering. In FGD3, the Christian participants interpreted pain and suffering as leading to:

> *Everlasting peaceful bliss in God's Kingdom where we will inherit eternal life and we will forever rejoice with no pain and suffering* (P2);
>
> *Us sharing in the pain and suffering that Jesus endured on the cross, which was a way for our sins to be forgiven* (P1);

A reward with bigger blessings as long as God promises that rewards await those who are patient (P3).

Participant 1 in FGD3 elaborated on her belief that God uses suffering including illness as a means of calling humanity to repentance.

> *God can use illnesses like COVID and wars to make humans repent and move away from bad doings. Human suffering is a sign that our GOD loves us. He is recalling us from sin. Just like Jesus suffered on the cross to wash away our sins. Who are we to question what God brings on earth?*

Therefore, the participants' perceptions of good and bad death are different from the medical approach, as highlighted in the scholarship. For example, Dorji and Sherpa (2021) and Arora and Bhatia (2023) associate bad death as characterised by physical discomfort, pain, breathing difficulties, social isolation, psychological distress and ineffective care. Seale (2004) adds that a bad death is undignified. This is consistent with the medical approach, whereas, on the contrary, religions such as Islam and Buddhism associate bad death with death by suicide, unjust murder or euthanasia, and with dying away from home in a medical institution (Shah and Chandia, 2010; Dorji and Sherpa, 2021; Grove, Lovell and Best, 2022). Among my participants, only the element of social isolation aligned with the medical model's characterisation of a "bad death".

On the other hand, in FGD5, the Muslims linked enduring pain and suffering with the COVID-19 pandemic as the pathway to pleasing Allah.

> *This pain and suffering that mankind is experiencing is the gateway to pleasing Allah because it is part of obedience. These are teachings in Quran that we get from a very young age.* (P1)

> *Joanna died because he was so close to God, and God took him as per his plan. In the same way, we are Joannas, and we will all die for different reasons. It may be cancer, heart attack, car accident or another reason. Everybody has to eventually go, Muslim or no Muslim, Christian or non-Christian.* (P2)

> *COVID-19 is a form of punishment. If we repent, we will be forgiven and live in peace and happiness. In 'Jenna'* (heaven)*, there is no coronavirus there. Instead, we stay young forever in 'Jenna'.* (P1)

As articulated by the older Muslims, such as Jonas (74) (see 5.2.1 above, p.160-161), these elements (including reciting the Quran when dying and having the corpse washed and buried within the Islamic norms) also constitute good death, and therefore, Allah would be pleased. The older research participants' beliefs confirm Kristiansen and Sheikh's (2012) position that the Quran and prayers (Dua) offer Muslims emotional comfort and support during illness, human pain, suffering and trials, while human pain, suffering and trials are Allah's sign of love. This contrasts with the medical model which emphasises pain relief, patient dignity and physical comfort as hallmarks of a good death (Meier et al. 2016).

Therefore, the research participants' linking of the pandemic with God's or Allah's will reflects religious interpretations of risk that have been documented across different historical periods. Luhmann (1993) notes that risk and misfortune have often been understood as acts of divine agency and as responses to human wrongdoing. The respondents' reasoning stems from their religious doctrines, which uphold that suffering and negative effects are inevitable, enabling and enriching the development of spiritual virtues (Kristiansen and Sheikh, 2012; Joshanloo et al. 2016; Dorji and Sherpa, 2021; Liu and Wong, 2023). This confirms Dorji and Sherpa's (2021) finding that collectivist cultures often accept suffering as a temporary and necessary part of life.

My study's results are also congruent with Bear et al.'s (2020) research results. The research across various faith communities and vulnerable groups in the UK sought to establish what good death looked like for them. Christians defined a good death as one that 'brings the community together to accompany the dead on their spiritual journey', which is primarily achieved through physical togetherness (Bear et al. 2020). Seymour et al. (2018) add that a good death leads to better bereavement. While Muslims also characterise a good death in terms of loved ones surrounding the deceased, for them, reciting the Quran and encouraging the dying to also recite it as their last words during dying are key (Bear et al. 2020).

For most of the community leaders, even though they did their best to reassure the older people, they highlighted that they were unable to do as much as they would have wanted to do '*in terms of supporting the community emotionally, especially given*

misinformation which was being spread to the older people by word of mouth by their children and grandchildren' (Mustaf). Mustaf adds that:

> *We could not directly reach out to the older people because most of them do not use the Internet or go online, yet this was the main means of communication during the pandemic.*
>
> *When they lost family members to COVID and they were bereaved, they mostly relied on the family members whom they lived with for emotional support. We would contact the younger family members who were more active online.*

Therefore, while the UK government's lockdown measures to quell the coronavirus (Brown and Kirk-Wade, 2021) caused fears of a 'bad death' for many people (including White British and minority ethnic people), in my study, fears of a bad death were amplified for the research participants who were already vulnerable and disadvantaged given their intersecting identities. Furthermore, the definition of bad and good death for the research participants was different from white British people's interpretation because of their different identities. For white British people, good death tends to be modelled along Western ideals of individualistic societies and the medical model, which emphasises factors including pain relief, acceptance and personal autonomy of the dying (Walter, 2003; Zaman et al. 2021; Meier et al. 2016).

This justifies embracing intersectionality in grief analysis because it deepens understanding of how people access and cope with bereavement and grief support resources, for example, during pandemics. Everett's (2023) Intersectional Grief Framework (IGF), which embraces Crenshaw's (1989, 1991) intersections of social identities such as race, gender, class and age, enables a nuanced understanding of how older minority ethnic people navigated through bereavement and grief during the COVID-19 pandemic and its aftermath.

Clearly, evidence from my study, therefore, illustrates the need for robust data disaggregated by ethnicity and age to facilitate a nuanced understanding of challenges with bereavement and grief amongst minority ethnic groups in the UK. Overgeneralising and applying a neutralised grief framework to all humans is limiting and epistemologically flawed.

Conclusion

This chapter explored how intersecting identities shaped older minority ethnic people's experiences of dying, death, bereavement and grief during COVID-19. Although death, bereavement, and grief are universal human experiences, older minority ethnic people's greater susceptibility to infection with the coronavirus and a higher risk of experiencing death, bereavement and grief caused these to become intersecting axes of inequality. The chapter examines the older minority ethnic people's coping strategies. Their experiences have negatively affected their ageing trajectory.

Decline and death of the older people, took specific forms for older minority ethnic people during COVID. The pandemic changed ageing dynamics as COVID-19 hastened the decline and death in these communities. Multiple bereavements during older people's life course, impacted their physical and mental health and well-being causing and requiring older minority ethnic people receive timely and specific bereavement support that considers intersecting systems of marginalisation.

Understanding multiple factors in determining dying, death, bereavement and grief is important. Using intersectional grief literacies in analysing experiences of bereavement and grief is essential. Understanding the impact of loss on older minority ethnic people during pandemics is also important for developing appropriate interventions. While minority religious beliefs on enduring pain and suffering offered significant guidance to older minority ethnic people, some respondents confessed they struggle with grief following the loss of their loved ones during the pandemic and loss of opportunities to practice their cultural death, mourning and burial rituals. This triggered prolonged grief. Older minority ethnic people need timely bereavement support to mitigate ripple effects of grief.

Additionally, the older minority ethnic people's feelings and emotions about the loss of their loved ones reveal the complexities that are associated with sudden and unexpected deaths. Understanding bereavement dynamics amongst older minority ethnic people is important, especially since mortality in the UK remains higher than it was before the pandemic, with statistics being higher amongst the older people than the younger people because of the older minority ethnic people's vulnerability based on their identities. This implies that older minority ethnic people continue to experience a heightened risk of bereavement. Acknowledging and understanding these variations

is important for professionals to design effective interventions to support the bereaved. This study thus suggests the need for culturally sensitive bereavement support tailored to bereaved older minority ethnic people.

This chapter has shown that there is no single and clearly defined process of bereavement or grieving. Therefore, whilst the experience of bereavement and grief is universal, the experiences are unique depending on one's identities. Relying solely on research centred on largely white British participants limits our understanding of bereavement among ethnically diverse older populations. This comes against the paucity of data about older minority ethnic people's experiences of bereavement and grief, especially given the increasing diversity of the UK's ageing population and growing inequalities within the UK. This reflects the starting point for a new research avenue. In line with the positionality theory, older minority ethnic people are epistemologically privileged and best positioned to express their experiences with bereavement and grief. Therefore, research on the older minority ethnic people's experiences with bereavement and grief could improve understanding of the magnitude of the adverse effects of bereavement and grief on the older minority ethnic people's ageing experiences. It is important that policymakers and professionals learn from the shortcomings during the COVID-19 pandemic to avoid the same mistakes reoccurring in future pandemics.

Lastly, the chapter discussed how while older minority ethnic people's intersecting identities exposed them to intersectional disadvantages, which caused differential experiences with bereavement and grief, their intersecting identities were also a source of resilience. Religions such as Christianity, Hinduism, Buddhism and Islam offered frameworks that supported resilience and coping strategies during the pandemic. Aligned with Terror Management Theory, participants' religious worldviews helped buffer their fears of death and anxiety during the pandemic.

The next chapter examines informal caregiving and the experience of loneliness among older ethnic populations.

CHAPTER 6: MULTIGENERATIONAL HOUSEHOLDS, INFORMAL CARE AND LONELINESS DURING THE PANDEMIC

Introduction

In the previous chapter I examined how older minority ethnic people's perceptions of death, bereavement and grief during the COVID-19 pandemic were shaped by their intersecting identity characteristics. This chapter extends that analysis by focusing on informal caregiving as a central factor influencing ageing experience among older minority ethnic people during the pandemic.

This chapter explores older minority ethnic adults' experiences of informal care and loneliness in multigenerational households during the pandemic. The chapter argues that although living in multigenerational households provided social protection benefits, it also intensified caregiving burdens for older women, especially where care responsibilities were unequally distributed and unrecognised.

The first section examines informal caregiving in multigenerational households, focusing on how age, ethnicity and gender intersect, as women predominantly assume caregiving roles. It explores how cultural expectations and limited formal availability of support during COVID-19 lockdown intensified caregiving roles. The section discusses how informal caregiving positively influenced older people's wellbeing and facilitated continuity of care while simultaneously placing physical and emotional strain on older informal caregivers, especially women.

The second section discusses isolation and loneliness amongst the older minority ethnic people. On the one hand, living in multigenerational households was a protective factor that strengthened companionship, while reducing the risk of loneliness and enhanced practical support within the households. However, simultaneously, older people living in multigenerational households value networking and companionship beyond their extended families. This section therefore examines how caregiving and cultural obligations intersected with restrictions on mobility and community contact, creating an emotional burden even in socially 'crowded' households. The second section also explores the challenges that individuals who do not live in multigenerational households, but live alone faced, such as loneliness and

the absence of care during government lockdowns. As shown in **Appendix D1,** (p.353), of the participants interviewed, 18 live in multigenerational households whilst 10 live alone.

The definitions of multigenerational households and intergenerational relationships and interactions, introduced in the literature review, are referenced here to highlight their relevance to informal care practices. Overall, the chapter shows that caregiving in multigenerational households offered both resilience and risk during the pandemic, highlighting the need to recognise informal caregiving as an integral, but often invisible, part of older minority ethnic people's experiences of ageing. In this study, multigenerational households (those in which multiple generations, often grandparents, parents, and children, live together) are distinguished from intergenerational relationships, which refer to interactions between different generations within and beyond the household (Burgess et al. 2017; Hanum and and Scott, 2024).

6.1. Informal care

Informal care in the UK has deep historical roots. Prior to the 1948 NHS Act, the care of older people and those living with disabilities was primarily the responsibility of families, communities, and religious institutions (Greengross, Grant and Collini, 1999). While institutional care has long been a foundation of health and social care in the UK and Europe, governments are increasingly relying on informal care in response to ageing populations and healthcare funding constraints (Broese van Groenou and De Boer, 2016; Dunn, Ewbank, and Alderwick, 2023; Bancalari and Zaranko, 2024). Informal care is therefore widely recognised as the backbone of the UK's health and social care system. In multigenerational households, informal care is shaped by intersecting factors such as age, gender, ethnicity, disability, and comorbidities (Barnes et al. 2024). Older women from minority ethnic backgrounds, in particular, bear the brunt of caregiving responsibilities, often at the expense of their own health and financial security (ONS, 2023).

The demands of informal caregiving frequently lead to both physical and emotional strain which ultimately affects caregivers' health and wellbeing. This is especially relevant as women are typically the primary caregivers for both children and older

adults (Bauer and Sousa-Poza, 2015; Capistrant, 2016; Dukhovnov, Ryan and Zagheni, 2022). Cosco et al. (2017) highlight the importance of promoting wellbeing amid adversity while Carmel (2019) argues that informal caregiving limits older women's participation in paid work, impacting their socio-economic status. Additionally, women balancing informal care with other domestic duties face cumulative stressors (Liu, Heffernan and Tan, 2020). The impact of COVID-19 on informal carers and recipients must be understood in the broader context of systemic inequality, as older minority ethnic people face additional barriers to accessing formal care. As discussed in Chapter 1.1.7, p.25-27, these barriers include language difficulties, digital exclusion, and fear of discrimination.

Older people, a heterogeneous group, experience ageing in diverse ways. Minority ethnic groups in particular are stratified by intersecting factors such as age, class, gender, race, ethnicity, disability, and comorbidities that shape ageing in ways that diverge from standard models (Phillipson, 2015). Laslett (1987) distinguishes between the 'third age' marked by health and independence and the 'fourth age', defined by declining autonomy due to illness or disability. However, this binary overlooks the experiences of many older minority ethnic individuals, whose later-life wellbeing is shaped by lifelong socioeconomic disadvantages. This framework will be explored further in the next section through the lived experiences of participants such as Assita.

For instance, someone with a skilled, well-paid job may enjoy a leisure-filled retirement, while a person in low-paid work may retire into poverty. In the UK, Black pensioners are more likely than their White British counterparts to experience poverty in later life, reflecting structural inequalities that accumulate over a lifetime (West, 2021). Older minority ethnic people's lived experiences are also shaped by living arrangements like multigenerational households which are more prevalent among minority ethnic populations than among White British people (Ronald and Lennartz, 2018; ONS, 2023; Berrington and Perelli-Harris, 2024).

6.1.1 Multigenerational households and intergenerational relationships in minority ethnic communities

This section examines multigenerational households and intergenerational relationships in minority ethnic communities in the UK. Multigenerational households

refers to households where multiple generations (typically grandparents, parents, and children) co-reside, often shaped by cultural norms, practical needs, and economic pressures (Burgess et al. 2017. Multigenerational households can have multiple or different generations co-residing in one house. Hanum, Newcombe and Scott (2024) define this as intergenerational co-residence and they assert that it focuses on interactions, exchanges, and caregiving between generations, both within households and across wider social networks. Understanding these distinctions is essential for situating how household structure and relational dynamics intersect, influencing wellbeing, care responsibilities, and family functioning. The discussion that follows draws on literature and participant narratives to show how these dynamics were experienced, particularly during the COVID-19 pandemic.

Multigenerational households are increasing in the UK due to demographic shifts, population ageing, rising living costs, expensive health and social care, and growing care responsibilities. According to the ONS (2021) census, 2.1% of UK households were multigenerational. Arian (2022) notes that the concept of multigenerational households is rooted in the traditional, collective lifestyles of minority ethnic communities, which emphasise strong familial ties. For example, Arian's (2022) research on UK-based Pakistani communities found that 35% of households are multigenerational, comprising three or four generations. An individual's ability to live in accordance with cultural norms and values partly shapes their wellbeing and optimal functioning (Sasaki, 2014; Joshanloo, Van De Vliert, and Jose, 2021). Against this backdrop, some minority ethnic individuals prefer living arrangements that reflect their collective cultural expectations.

While some scholars use "multigenerational" and "intergenerational" interchangeably, it is important to distinguish between the two. A multigenerational household includes members from more than two generations of the same extended family living together (ONS, 2023), emphasising co-residence across multiple generations (Burgess et al. 2017). Intergenerational relationships highlight interactions between multiple age-based generations (Wing et al., 2022), who may not necessarily be biologically related, as seen in Belgium and France, where university students live with older adults in exchange for companionship (AGE Platform Europe, 2013). Such relationships extend beyond co-residence to encompass contact, interaction, interdependence, solidarity,

and reciprocity between generations, and are shaped by demographic, social, economic, and cultural factors (Hanum and Scott, 2024).

While living in multigenerational households does not always yield positive outcomes (Chen, Shen, and Ruan, 2021; Hanum and Scott, 2024), multigenerational households may also experience emotional, financial, and practical strains within family dynamics (Antonucci et al. 2011; Keohane, 2016; Thomas, Liu, and Umberson, 2017). This study uses the term multigenerational household to describe the household arrangements of related minority ethnic people in which multiple generations commonly co-reside, and intergenerational to refer specifically to the relationships between generations within these households and in their wider social networks. The next section draws on participant narratives to illustrate how these structural and intersectional dynamics were experienced during the pandemic.

6.1.2 Informal caregiving role during the pandemic

Some participants described both giving and receiving care, though caregiving roles were predominantly shouldered by women. Informal care was central to some participants' experiences with older women often serving as primary caregivers for their adult children, spouses and grandchildren. Some older people also received informal care from younger female relatives, including younger-old family members, such as Assita (72) and her sister.

Assita (72) explained:

> *"When the government announced the lockdown, we immediately asked our mother to move in with me and my husband. She was refusing, insisting she can still manage, but we could see that she couldn't cope. Since then, she has not gone back. She is getting older and requires more support. She can still do some small tasks on her own, but for bathing and cooking we now support her. We share the responsibility of supporting her with my sister. You can't leave your mother without support, can you? Blessings come from respecting and honouring your parents. These things are instilled in us when we grow up as children."*

Kettina (74) described receiving care from her daughter-in-law after COVID-19 hospitalisation:

> *"When I caught COVID, I was already struggling with high blood pressure, and a tumour, for which I have been on NHS waiting list for an operation. When I caught COVID I got very unwell. Without my daughter in law, I wouldn't have managed because when I was discharged, I was very weak and struggled with breathing and spent most of the time in bed. She helped me in all sorts of ways – washing, cooking, cleaning my bedroom…"*

Kettina's account highlights the interplay between her pre-existing health vulnerabilities and the critical support provided by her daughter-in-law, illustrating how informal caregiving enabled her to manage daily life despite serious illness.

The pandemic intensified caregiving responsibilities, with women reducing paid work to provide care. Assita and her sister provided personal care and social support (which Hashiguchi and Llena-Nozal (2020) highlight as often characteristic of multigenerational family dynamics) to their older parent, which enabled them to fulfil their daily needs. While Assita's mother initially resisted support in favour of independence, her daughters convinced her otherwise out of concern for her safety. They did this as they understood fully well the risks she faced in continuing to live alone. Assita's mother falls within the 'fourth-age' category as defined by Laslett (1994), which is the period characterised by declining physical ability, loss of agency, and reduced autonomy (Schröder-Butterfill and Marianti, 2006; Gilleard and Higgs, 2013). Assita, who is 72, belongs to the 'young-old' category and she is offering informal care to her mother. This reflects the changing dynamics of ageing in the UK. Improved medical care has increased life expectancy among older minority ethnic populations (Centre for Policy on Ageing, 2010; Wienclaw, 2021). However, the implications of longer life expectancy for older caregivers remain largely underexplored.

Further interview with Assita, and interviews with other participants revealed that according to their cultural norms, taking an older parent to the care home is not an option, as it is interpreted and condemned as neglect of a parent by the children: *'You can't take your mother to the care home, can you? (laughs). No! That's not how we are.' (Assita).* In FGD2, P1 commented:

“I would rather go back home than move into the care home. We go back home. For them, it’s ok to just leave the parent in the care home. I told my children never to take me in there, in case I get dementia and they would chose that for me.”

Younger family members in this study provided support to older relatives without expecting anything in return, which is altruism, a genuine concern for the well-being of the care recipients (Zarzycki and Morrison, 2021; Keene and Batson, 2010). Empathy and concern for others’ wellbeing were primary motivators rather than personal benefit (Keene and Batson, 2010). In this study, cultural, societal norms and obligations, where younger family members are expected to care for elders were key drivers, echoing Burgess et al. (2017)’s findings. Kettina expressed appreciation for the care she received from her younger daughter in law highlighting how intergenerational support can positively impact older people’s wellbeing (Danielsbacka, Křenková and Tanskanen, 2022). This also reflects the importance of family solidarity among older minority ethnic groups as described in (WHO, 2002, 2007).

However, informal caregiving is not without costs. Research has established that informal caregivers are more likely to stop working and to retire earlier than non - caregivers (Jacobs et al. 2019). Since informal caregiving is a hidden labour force and constitutes an unpaid activity, informal caregivers often forego income-earning opportunities which can reduce their pension entitlements in later life (Cascella Carbó and García-Orellán, 2020). As more women than men provide informal care, this accentuates existing gender inequalities in income and retirement security.

My study confirms what other researchers have found: caregiving roles are predominantly taken on by women especially when this entails care that requires touching the body as opposed to practical support, like shopping or mowing the lawn (Kim, 2023). This reflects sexist and patriarchal stereotypes that assign caregiving responsibilities to women. For minority ethnic older women, these expectations intersect with age-related vulnerabilities and ethnic minority status, creating a compounded disadvantage that can be understood as a form of double marginalisation. Gender stereotypes that frame caregiving as a woman’s role still exist (Cunha and Atalaia, 2019). Cunha and Atalaia (2019) found that in 18 European countries, men spend more time in paid work than women (on average, 13.9 hours

more per week) while women spend more time in unpaid care work and household work than men (on average, 14.5 hours more in unpaid care work and 9.3 hours more in household work). As women age, caregiving responsibilities tend to accumulate, and this is particularly pronounced for minority ethnic older women. Many of these women live in multigenerational households, where intergenerational relationships shape daily life and caregiving serves as a central organising principle of the household.

These findings from my study reinforce the point that informal caregiving in intergenerational contexts is both a cultural strength and a potential vulnerability. Care is motivated by love and duty, however the burden unevenly distributed and frequently falling on older women as highlighted in broader caregiving literature (see Bauer and Sousa-Poza, 2015). Further research is warranted to analyse the specific effects of informal caregiving among older minority ethnic caregivers. What are the long-term impacts (social, emotional, and financial) of ageing while simultaneously caring for older parents or relatives living with disabilities? How does informal caregiving affect older women's class position and health trajectory? Since minority ethnic men are less engaged in caregiving, what unique challenges do older women face in such households? These are important questions for ageing research and social policy alike.

This section demonstrates that informal care in intergenerational contexts is a double-edged sword: it offers vital support but can also reinforce gender inequalities and place older women at risk of poverty and burnout.

6.1.3 Grandparenting

In this study, most older participants lived in multigenerational households, often assuming grandparenting roles in various ways. The grandparenting role, while central to family life, varied across households in terms of intensity, responsibilities, and gender dynamics. Some of the participants had the sole responsibility of looking after grandchildren on a full-time basis. Other participants live with their grandchildren and support them on a part-time basis, while others support their grandchildren who live in a different household. The grandparenting roles which were mostly taken by women intensified during the pandemic and reinforced the gendered nature of caregiving.

Grandparenting is a central form of informal care in multigenerational households and intergenerational contexts, particularly among minority ethnic communities, where family interdependence is culturally embedded (Arian, 2022; WHO, 2002). While grandparenting can provide a sense of purpose and strengthen family bonds, its impact on health and wellbeing depends on factors such as family relationships, the grandparent's health, and the age of grandchildren (Wing et al. 2022). During the COVID-19 pandemic, caregiving responsibilities continued to fall predominantly on women, with restrictions, illness, and reduced formal support intensifying these demands for minority ethnic older women.

6.1.3.1 Positive effects of informal grandchild care support on grandparents

This subsection highlights the emotional, social, and functional benefits that grandparents gained from providing informal care. In many cases, caregiving created purpose and helped older people manage loneliness and grief during the pandemic. Most of the participants said they offer informal care to their grandchildren, and that the informal care tasks increased in quantity and intensity during the government lockdowns. Further showing the grandparents' informal childcare role, during my visits to the networking groups, some of the older people came to the community networking sessions with their grandchildren, who were kept engaged in art and painting activities.

Ayman (67), who attended a networking session with her three grandchildren, noted that while they kept her company, supporting them with schoolwork was challenging, especially during the government lockdowns because she assumed considerably increased informal care responsibilities in the form of homeschooling during COVID.

> *I live with my children and grandchildren, and so I didn't feel lonely because there was always someone with me. My son is a taxi driver, and his wife is a carer, and they worked a lot during the pandemic, whilst I was with the grandchildren. But it was hard for me to keep my grandchildren engaged in our apartment, whilst their parents were at work. You know children will always be children – they are very playful, and they were running about in the house, and I couldn't keep up with it. Before COVID, I would go out with them to the park, and on Wednesdays I would come to our club with them, which helps to keep them occupied.*

> *Homeschooling was hard, and I couldn't support them with that because what they learn is not what we learnt back home. I could not understand the schoolwork, and I am also not good with internet.*

This also confirms the revelations by the UK Covid-19 Inquiry (2025) that children suffered from school closures, social isolation, and limited opportunities for play. Evidence given during the hearings highlighted that children were not consistently prioritised, and the government was inadequately prepared for the sudden, large-scale transition to home education, resulting in an insufficient response (UK Covid-19 Inquiry, 2025).

Momo (82) who suffered double bereavement during the pandemic, has been living alone since losing her husband to COVID illness. She explains how the loss of her daughter in law to COVID compounded her informal caring role amid her grief.

> *A few weeks after losing my husband, I again lost my daughter in law to COVID. Losing family members within a few weeks has been difficult. My son has a full-time job, and I help with school runs, and household tasks for them. I miss my husband – It's hard. But supporting my son and grandson keeps me busy, and I don't always have to face the walls thinking.*

The above extracts underscore the significant role that older women played in grandchild care. For participants such as Momo, grandparenting role plays a positive impact in the older people's lives. Grandparenting keeps Momo occupied and distracts her from thinking about her late husband, thus helping her manage her grief. Additionally, the interviews in this study reveal that grandparent childcare support was beneficial especially for working-age parents who by nature of their jobs (such as carers, taxi drivers, and doctors), could not work from home (see above extract by Ayman). This reflects how older people played a vital role supporting frontline workers who could not work from home, particularly in health and social care sectors where ethnic minorities are overrepresented (The Health Foundation, 2020). The older minority ethnic grandparents therefore helped them with childcare and other household chores. Momo also offers practical help (in the form of tasks including cleaning, cooking and looking after her grandson) to her son and grandson, and she

expresses contentment at the role (*tasks keep her busy*), which implies a benefit in terms of keeping grief at bay (her own and that of other family members).

The rise in grandchild care among elderly people during the pandemic was partly due to the overrepresentation of minority ethnic people in key sectors such as health and social care where remote work was not feasible (The Health Foundation, 2020), which meant that younger minority ethnic parents had to go to work while the grandparents looked after the grandchildren within the inter-generational households. Data from this research shows that older people play a productive and valuable role in society even though it is not financially rewarded. They were a hidden labour force who allowed family members who were frontline workers to fulfil their wider social responsibilities. Borrowing from Gu (2022, p.525), this role by grandparents is 'the reserve workforce in the domestic sphere.' Grandparents such as Momo and Ayman are themselves connected knowers (Collins, 2000). Precisely this is so because their caregiving knowledge is embedded in, rather than abstracted from, the daily rhythms of their grandchildren's lives that it remains invisible to formal policy debates. Unfortunately, these formal policy debates continue to treat informal grandparental care as a private family matter rather than as the structurally significant labour this study's data reveals it to be.

Additionally, despite facing health challenges, some older people continue to provide grandchild care which contributes to their sense of life satisfaction. However, while Laslett (1994) and Higgs et al. (2009) allude to life satisfaction of third agers who have retired from work, many of the grandmothers providing long-term childcare support had not previously been employed in formal jobs, as shown in participant profiles (see Appendix D1, p.353). Many of these women have been performing grandparenting roles in multigenerational households since the birth of their grandchildren. This reflects the different dynamics surrounding ageing between older people from minority ethnic background and some older people from the majority white populations. As argued by UNDP (2016) and Jiang, Wu and Li (2024), despite older people's contribution to grandchild care, their efforts often go unrecognised, which ultimately means, policymakers may overlook their specific needs as caregivers. There is limited research on the experiences of older minority ethnic people providing informal

childcare during COVID-19. Further studies are needed to explore how they navigate grandchild care responsibilities, manage intergenerational relationships, and how these responsibilities affect their ageing trajectory, especially during pandemics. Furthermore, there is also need for research to explore how the dynamics of intergenerational relationships are shaped by older age, gender, ethnicity, disability, social class and comorbidities. While interviews indicate that grandmothers/women predominantly serve as caregivers, the role of grandfathers/men in these arrangements remains unclear.

This section highlights how grandparenting, as a form of informal care, is deeply embedded in multigenerational households, shaped by cultural expectations and gender roles. These caregiving roles are often unpaid and undervalued, yet they are central to household and wider societal functioning, especially during COVID.

The evidence presented here challenges ageist narratives by showing that older women continue to play vital roles in sustaining family life under crisis conditions.

6.1.3.2 Negative effects of grandchild care on informal caregivers

While often overlooked in formal care debates, grandparental care is central in many minority ethnic families. These roles intensified during the COVID-19 pandemic, revealing the social and emotional dimensions of informal care by older women. While grandchild care was beneficial to the grandparents, grandchildren and the working younger parents during the pandemic, this study's data shows that grandchild care also had unintended negative effects on some grandparents. Therefore, whilst for Momo, grandparenting had an explicit positive impact in terms of helping her manage her grief, the long hours of grandchild care placed a strain on some older caregivers as revealed by Ayman (67) who struggled to keep her grandchildren engaged indoors. This confirms Danielsbacka, Křenková and Tanskanen's (2022) explanation that grandparental childcare can also negatively impact older people's health and ageing trajectory. Research has revealed that grandparenting can lead to tension in intergenerational relationships, for example when grandparents feel their role is unrecognised or undervalued (Barman and Sahoo, 2024). While these studies focused on informal care in general, my research found that such unrecognition and undervaluing intensified during the COVID-19 pandemic.

Additionally, data from my study established that due to limited digital expertise, some participants could not support their grandchildren with homeschooling during government lockdowns. Homeschooling required digital knowhow, which some older minority ethnic people such as Ayman (quoted above) lacked. This comes in the light that in the UK, digital exclusion intersects with other inequalities and social identities including older age, disability, comorbidities, ethnicity, and lower socio-economic status (Choudrie, Zamani and Obuekwe, 2022; Good Things Foundation, 2024; Romanowski, 2024), thus exacerbating intersectional disadvantage on populations which are already marginalised. For example, research by Link Network (2024) established that digital exclusion was higher among British Asians (36%) and Black British (31%) compared to White British (23%). Digital exclusion disproportionately affects older minority ethnic people, who often occupy disadvantaged positions due to intersecting identities. During the COVID-19 pandemic, this exclusion intensified, as most services, including health and social care moved online. The key role grandparents played in these households aligns with Bronfenbrenner's (1979) ecological model of human development which acknowledges the grandparental role as part of the microsystem that influences grandchild's development within the first context. My study thus shows that grandparents form a vital part of the family environment, shaping the developmental outcomes of young children's lives, especially since the children spend time with the grandparents when they are working. This further points towards the importance of empowering older minority people with language and digital knowledge because this has an influence on the grandchildren's academic and social outcomes and well-being.

Language and digital knowledge constitute human capital (Vercruyssen et al. 2023), which influences children's cognitive environment and subsequently aids learning (Coleman, 1988). Flewitt et al.'s (2024) research which sought to establish how children under three interact with technology in the home revealed that most parents who took part in the research agree that technology offers children opportunities to develop skills with numbers (83%), reading (75%) and creative skills (75%), and most disagree that technology harms learning. However, Flewitt et al.'s (2024) research did not take into consideration digital exclusion aspect which explains that children from disadvantaged populations including minority ethnic populations are digitally excluded.

Treating the children as a homogenous population masks inequalities that affect disadvantaged groups.

My findings reinforce how systems of classism, racism, and sexism intersect to limit older minority ethnic women's access to digital tools and education. These structural barriers prevent them from fully supporting their grandchildren, particularly in educational settings. Future research should explore how intergenerational caregiving practices differ across minority ethnic communities, particularly in light of intersectional challenges such as gender, disability, class and age.

6.1.4 Remodelling living arrangements to facilitate informal care of adult children and grandchildren

This section examines how multigenerational households and intergenerational relationships adapted their physical and relational arrangements to meet increased informal care demands during the COVID-19 pandemic. In addition to caring for grandchildren, several older participants assumed new informal care responsibilities during the pandemic, prompting significant changes in household composition and routines. Wada (74) described remodelling living arrangement during her daughter-in-law's pregnancy:

> *During the pandemic, one of my daughters-in-law was heavily pregnant, and my son, who is a medical doctor was working in the frontline. We were all worried about the risk of coronavirus, especially on my daughter in law and the unborn babies. So, my two sons who are doctors moved to stay in one of our family houses, whilst I stayed with my husband and our two daughters in law. It was a very emotional experience for us, and especially for my pregnant daughter in law and my son because they could not see each other face to face, even after the twins arrived. Everything had to be online. I took care of my daughter in law and my grandchildren. I still help with grandchild care. They are lovely babies, but they cry a lot more than the way my other grandchildren cried at the same age, because they are afraid of people, since they didn't see many people during the lockdowns.*

Nadia (79), who uses a walking stick noted that the informal caring role particularly the physical demands of supporting her 45-year-old daughter with a disabillity had both

physical and emotional impacts. Nadia came to the networking session with her daughter, who was using a wheelchair.

> *During the lockdowns, the carers couldn't come to support my daughter. Caring for my daughter on my own was hard because my daughter uses a wheelchair. She weighs 69kg and it was heavy work for me. Normally she has double carers, and they use a hoist because of her condition. Hard, but what do you do as a mother? You do all you can for your child.*
>
> *I now have backpain and struggle to walk, and I think it's because of the heavy lifting I was doing.*

Nadia's experience and that of Fatima (73) (p.184 and p.110 respectively) vividly illustrates the complexity of caregiving. Fatima, whose husband relied on oxygen and died at home, faced emotional trauma that compounded her fear of racism: *'Up to today, I don't trust the NHS doctors. I don't like going to them even when I am unwell'*. Providing informal care placed both physical and emotional burdens on Nadia and Fatima which adversely affected their health and overall wellbeing in later life. For Nadia, single-handedly providing informal care on her daughter who is living with disability and is normally supported by two carers caused a physical strain on her (backpain and effect on her mobility). On the other hand, for Fatima (73), the informal care she gave to her late husband affected her mentally, especially given her heightened fears of racism. Therefore, this study confirms scholarship which highlights the detrimental effects of provision of informal care on women's health (Bauer and Sousa-Poza, 2015; Capistrant, 2016; Dukhovnov, Ryan and Zagheni, 2022). This comes against the background that women are usually the primary caregivers for family members. Nadia and Fatima's full time informal caregiving highlights their vulnerability which was intensified by their caregiving roles. My study reveals that the intersection of older age, ethnicity and gender in informal care negatively impacts the health and ageing experiences of minority ethnic people. The findings also revealed that caregiving was highly gendered: women undertook personal care tasks, while men typically offered practical assistance such as collecting prescriptions or delivering groceries.

These findings contrast with studies on white middle-class families where intergenerational support flows from parents to children due to parents' stronger socio-

economic positions and financial resources (see Kalmijn, 2024). Whilst economic wealth varies amongst different ethnic groups, older people from minority ethnic background are twice as likely to live in poverty and be in need of support themselves than white pensioners (AGE UK, 2021; Cross, Evans and Collard, 2024).

For my study, during the pandemic the younger family members tended to give informational support to their older parents for example, by empowering the older parents on the importance of receiving the COVID-19 vaccine and interpreting the pandemic guidelines (chapter 4, p.125). For example, as Kenzo, a community leader relates: *'……..If I went to my mom and suggested to her to take the vaccine, she would take the vaccine.'*

On the other hand, in Kalmijn's (2024) research, support was socially stratified, because parents from stronger socio-economic backgrounds tended to provide more financial support while their children explored life including relationships, careers and travel. Culture is central to this study, as co-residence in multigenerational households is maintained regardless of educational or professional background. Wada (74), for instance, lives in a multigenerational household with her children, both medical doctors, alongside other family members from different generations. Wada's case is particularly notable as despite her children's high educational attainments they maintained an intergenerational household. This demonstrated the value they placed on cultural cohesion and familial interdependence. It is noted that, by remodelling their living arrangements during the pandemic, Wada's family demonstrates strong awareness of the risks that COVID-19 poses in multigenerational households, likely influenced by the children's roles as healthcare professionals.

In my study, the research participants' cultures are more family oriented and believe in the value of extended families. The younger family members have strong normative support obligations as children towards their ageing parents which are underpinned by their cultural values. Additionally, my research has reaffirmed Bauer and Sousa-Poza's (2015) position that informal caregiving arrangements are heterogeneous and can vary across contexts (for example based on caregiver's age, culture, health condition, and available support structures). My study has further shown the role of additional factors (care receiver's age, health condition and disability) in influencing informal care. It is important that health and social care policies be adopted which

ensure support that is flexible and adaptable to the various cultures and needs of the caregiver and the people receiving the care. My study therefore calls for the need for a future research avenue that examines the impact of informal care in the context of a pandemic on older minority ethnic people, as it will serve to deepen the understanding of informal caregiving, including its impact on family dynamics.

Among the participants in my study, altruism was clearly evident. In this study, caregiving was not reciprocal. The participants' actions were grounded in cultural and religious values rooted in collectivism and altruism, driven by duty, not expectation.

6.1.5 Grandparents' role in caregiving and risk management for grandchildren in multigenerational households

While living in multigenerational households reduced loneliness, it also placed older adults from minority ethnic groups at greater risk of COVID-19 infection. Informal caregiving amplified this exposure, as grandparents came into close contact with unwell younger family members. P1 in FGD4 recalled caring for her teenage granddaughter during her illness, taking precautions to protect herself.

> *I worried about catching the virus, but I had no choice. These are my grandchildren. We live together and this is my family. One of my teenage granddaughters was down with the virus and stayed in bed for a week. My daughter and I looked after her and after a week, she tested negative. You know, with my diabetes, I am vulnerable, so I made sure that I also protected myself by wearing masks and gloves every time I went into her room to help her.*

Kiri (69) explains how she emotionally supported her teenage granddaughter who faced challenges with her school and social services because she dropped from school because she wanted to protect her grandmother from catching coronavirus. Awareness of her vulnerability to COVID-19 illness drove her to be cautious, each time visitors came to their house. She was, however at heightened risk of infection because she lived with her school going granddaughter.

> *I lived with my daughter, son in law and my granddaughter. We knew that if I caught COVID, my chances of surviving were very little, and so my granddaughter eventually stopped attending school. She never went back to school and the school referred my granddaughter to social services and to a*

psychologist because they said she was having mental health problems. It was a nightmare for us, with social services demanding that we explain why she was not going to school. The situation stressed our family a lot, and my granddaughter would cry. They wouldn't understand that it was for my safety, since I suffer from all these diseases, and that we can't suddenly start living separately because COVID has come. I was feeling stressed and guilty that my granddaughter had to go through all this because she wanted to protect me. I stood by her. She did it for me because she didn't want me to die. I felt that my granddaughter's school was treating my granddaughter unfairly. They didn't understand. What mattered to them was following the government's guidelines. I felt they were condemning us.

As illustrated in the extracts above, both FGD4, (P1) and Kiri were acutely aware of the risk posed by COVID-19 through interactions with younger family members in their multigenerational households. However, the government guidelines and structures in place were not designed to match the minority ethnic people's unique cultural living arrangements. This meant, that individuals and communities' had to adjust and adapt their lives to minimise the detrimental effects of risk, and to cope, which is what resilience entails (Hall and Lamont, 2013; Patel et al. 2017; Juen and Siller cited in Siller and Aydin, 2022).

Data from my study reveals the dynamics of family members from different generations living together in multigenerational households with older people playing a key role in informal care, and the measures they took to protect themselves from catching coronavirus. P1 in FGD4 ensured that she protected herself with a mask and gloves every time she gave informal care to her granddaughter when she was unwell with COVID, and Wada (74)'s family remodelled their living arrangement. Herbec et al. (2022) highlight self-protective skills and capabilities as key strengths in risk mitigation traits that were evident in Kiri, FGD4 P1 and Wada's family. This confirms their capacity for rational and reflexive decision making grounded in both cultural context and an understanding of public health risks. Their understanding of COVID-19 as a serious risk motivated them to take appropriate protective measures, while still maintaining their cultural norms and multigenerational living arrangements.

My study also shows that grandchildren's education was disrupted in the multigenerational households during the pandemic. Due to digital exclusion some grandparents could not support their grandchildren with schoolwork, whilst Kiri's granddaughter dropped out of school. Kiri's granddaughter chose to leave school out of concern for exposing her vulnerable grandmother to COVID-19. This comes in the light that in the UK, children from minority ethnic populations fare worst in education, which negatively impacts their future as adults (GOV.UK, 2022).

Further research is needed to examine the challenges of multigenerational households and intergenerational relations, particularly as these are shaped by intersecting identities such as ethnicity, age, disability, and comorbidities. This is because much of UK-based research on multigenerational households and intergenerational relationships, often grounded in individualised cultural norms does not fully capture the experiences of minority ethnic communities, whose lifestyles tend to be more collective (Burgess and Muir, 2018). The fact that older minority ethnic people uphold their multigenerational household arrangements which are central to their cultural expectations and cannot easily practise social distancing, contrasts sharply with public health guidance that prioritised distancing as a key safety measure. This highlights the different ways in which experts and minority ethnic communities understood and assessed COVID-19 risk. Thus my study highlights the essential connection between public health expertise and lived cultural knowledge within minority ethnic communities in effectively managing pandemics.

6.2. Risk of social isolation and loneliness

This section explores how living in multigenerational households affected the risk of social isolation and loneliness among older minority ethnic people during the COVID-19 pandemic. It also considers how informal care played a part in shaping these experiences.

Living with others in multigenerational households often acted as a protective buffer against loneliness, providing older adults with everyday companionship, emotional support, and practical help. However, these benefits were uneven, and not all households experienced them in the same way. The presence of informal care within the household often reduced feelings of isolation for older adults, as regular

interactions with family members created a sense of belonging and purpose. Loneliness has been defined as a pandemic and a major public health concern linked with heightened negative health outcomes including mental and physical illness, cognitive decline and suicidal behaviour (Jeste, Lee and Cacioppo, 2020; Marmot, 2020; Santos, Paciência and Ribeiro, 2022; Armitage and Nellums, 2020). Social isolation and loneliness are two interrelated but distinct phenomena. Social isolation, which is a risk factor for loneliness is the absence or paucity of social interactions (Gardner et al. 2021). On the other hand, loneliness is a subjective feeling of being alone, separated from others, which implies an imbalance between one's desired social contacts and the actual social contacts, thus the individual lacks a sense of belonging (Hawkley and Cacioppo, 2010; Nicholson, 2012).

For example, several participants described how living with adult children and grandchildren enabled them to maintain routines, share meals, and receive help with daily activities, which mitigated the psychological impact of lockdowns. In these settings informal care involved not only physical assistance but also emotional connectedness. There is a link between social isolation and loneliness and identities such as age, ethnicity, disability, comorbidities, and socio-economic status.

The risk of social isolation and loneliness is highest for individuals aged 50 years and above and for those with poor health and low socio-economic status (Chatzi and Nazroo, 2021). Ageism can also amplify older people's risk of isolation and loneliness (Brooke and Jackson, 2020), while the risk of loneliness can also be linked to structural disadvantages and experiences of discrimination which accumulate throughout the life course (Cotterell et al. 2024). As a result older minority ethnic individuals face heightened risks of social isolation and loneliness due to intersecting factors such as low socio-economic status, comorbidities, and disability.

Dannefer's (2003) cumulative disadvantage theory and minority stress theory help explain the emotional vulnerability of older ethnic minority adults. According to Dennefer (2003), an individual's experiences in their life can shape trajectories in the short-term outcomes and in the long-term outcomes as well. On the other hand, social groups which are disadvantaged in society due to various identities (such as living with disability, being older, or being an ethnic minority) face heightened risk of having mental health challenges. The accumulation of stressors such as those linked to

stigmatisation, prejudice, discrimination and racism across the life course negatively impact the minority ethnic ‘s long term health outcomes (Chatzi and Nazroo, 2021).

These structural inequalities shape how informal care operates, who provides it, how it is received and the challenges faced by both caregivers and care recipients. In the next section, I will start by discussing how loneliness was a risk for the participants who are living with disability and for those who live alone. I also examine how older people valued social connections beyond those within their multigenerational households. Many reported missing their regular networking groups during the government-imposed lockdowns, highlighting the importance of wider social engagement in their wellbeing.

Overall, the findings demonstrate that while informal care within multigenerational households may significantly reduce the risk of loneliness and social isolation, it is not a panacea. The quality of family relationships, the distribution of caregiving responsibilities, and opportunities for social engagement outside the household all play critical roles in shaping older adults’ experiences of isolation and connectedness. These structural inequalities shape not only who becomes lonely, but also how informal care is provided, received, and experienced.

6.2.1. Risk of social isolation and loneliness during the government lockdowns

The UK government’s social restrictive measures during the pandemic exacerbated the risk of social isolation, loneliness, and mental health problems among older people (AGE UK, 2020).

Data from my research showed how some of the participants in my research were socially isolated and lonely during the government lockdowns. Some participants attributed their social isolation and loneliness to partner loss, job loss due to company closures or changes in working arrangements. My findings reveal that older people especially those living alone or with disabilities were at elevated risk during lockdowns. For example, Senzia (68), who is a support worker for women facing domestic violence, is blind and lives with comorbidities, narrates how the government lockdowns negatively impacted her because she could not physically interact with her clients and friends, nor could her personal assistant go to support her.

It was obviously upsetting because I couldn't go to work, and I couldn't be with my clients. I also couldn't spend time with my friends. I just stayed at home alone and answered my clients' phone calls. There were many women experiencing domestic abuse, and my job is to empower them. So, I started supporting them online. But you know with this kind of job, which involves trauma, quite often you want to be physically present with the client.

And then, my personal assistant couldn't come and support me. When I caught COVID, I lost my taste and sense of smell, and yet I rely on my taste and smell, and my hearing. You know when you are blind, you rely on these – they must be working, otherwise, pheew! I was really like 'Oh my God, how am I going to manage if anything happens?' Then indeed I had an accident. I was cooking and the food burnt, and I didn't realise because normally I can tell by the sense of smell. It was really like ghostophobic! But luckily, because of a sixth sense, I noticed it before it got bad, and I survived!

Senzia's case exemplifies how structural exclusion and individual impairment, heightened vulnerability. Senzia reveals her passion for her job, which centres on empowering vulnerable women. Living with a disability, she felt lonely due to the inability to engage directly with her clients or receive personal assistance from her personal support worker. These findings complement scholarship linking loneliness with widowhood and disability (Windle, Francis and Coomber, 2011; ONS, 2021; Voluntary Organisation Disability Group, 2023).

For Senzia, the challenges she experienced during the government lockdowns were also exacerbated by her disability and comorbid conditions namely asthma, a history of cancer in remission, and brain aneurysm. In addition to isolation, she faced risks of COVID-19 infection and physical injury while at home. It is important to mention here, research which highlights that during the pandemic in the UK disabled individuals faced higher risks of illness and death, loneliness and poorer wellbeing compared to those without disabilities (Voluntary Organisation Disability Group, 2023). The UK Covid-19 Inquiry (2025) Report highlighted that the needs of older people and individuals with disabilities were largely overlooked in pandemic planning and decision-making.

However, despite Senzia living with comorbidities and disability, she is an empowered older woman, who empowers other vulnerable women, which shows that disability does not equate to inability. The absence of formal support namely her personal assistant during the pandemic hindered Senzia's ability to fulfil her role in the community. Her experience aligns with Oliver's (1983) Social Model of Disability, which argues that people are disabled by the barriers (including cultural and economic) they face in society and not by their disability or impairment. According to Oliver (2013), it is society which isolates and excludes people living with disability from full participation in society. With appropriate support, individuals with disability can realise their full potential in life. Building on Wright's (2022) reasoning which is in line with Oliver (2013), Senzia's vulnerability during the pandemic can be considered as socially created. She was disproportionately impacted because of the absence of routine health and social care structures to mitigate the changes and risks posed by the lockdowns.

Some research participants lived alone (see Appendix D1, p. 353), a condition that significantly increased their risk of isolation and loneliness during the pandemic lockdowns. Some participants who were living alone were socially isolated and lonely. Makeen (77) recounts how his older friend who lived by himself tragically died alone in his home and remained undiscovered for several weeks. For some, the risk of dying alone became tragically real.

> *My friend who lived alone suffered terribly from COVID illness and died alone at home. He had no family in the UK, and he received meals on wheels. The meals were just being dropped for several days, but no one knew that he had died. People phone and when one doesn't pick the call, they just assume you are sleeping. Because of the government restrictions, he couldn't receive face to face support from friends. It was sad because he was a friendly guy who always used to check on others, yet he died alone.*

Makeen's account of a friend who died alone unnoticed despite continued meal deliveries illustrate the acute risks associated with living alone, especially during a pandemic. Additionally, the study supports Brandhorst and Wilding's (2020) argument that while digital technologies offer new forms of connection especially for migrant communities they cannot replace the intimacy of face to face human interaction. My

study reveals that virtual care was insufficient as hands on support remained essential for individuals living alone such as Makeen, Senzia, and Nadia's daughter who required double carers for daily needs. By contrast, participants living in multigenerational households did not experience this challenge due to the presence of family members who live with them and provided the much-needed support.

Widowed participants frequently described experiencing profound loneliness following the death of their husbands. For example, as Momo (82) reveals (section 6.1.3.1, p.180), she engages in supporting her son and grandson, to keep herself busy. As previously discussed in chapter 5, Fatima (73) who also lost her husband to COVID, acknowledges the significance of community networking activities in mitigating loneliness. Scholarship distinguishes bereavement as a risk factor for social isolation and loneliness (Seymour, Bushnell and Dobson, 2018; AGE UK, 2020). Bereavement often leads to significant changes in social connections and support networks. It is important to emphasise that bereavement is also associated with other factors which are also risk factors for social isolation and loneliness namely depression, loss of self-confidence, poverty, and financial worries (AGE UK, 2020). The evidence suggests that while informal care in intergenerational families often helps in reducing isolation, those who live alone face heightened vulnerabilities including risk of loneliness and lack of support with fulfilling their daily tasks especially during pandemics. Bereavement, disability, and limited access to online resources are factors that intensify social isolation, thus creating major challenges to the well-being and health of elderly members of minority ethnic groups.

Wing et al. (2022) document heightened mortality risks among older White individuals living alone due to limited support for daily tasks such as shopping and prescription collection. By comparison, the findings from this study show that older minority ethnic individuals living alone face similar risks with these risks compounded by intersecting disadvantages. The results are in line with a wide range of previous research showing that the pandemic and the lockdown policies themselves aggravated a sense of loneliness in the older people in the UK. These effects were more pronounced for older adults living alone with this contributing to negative health outcomes (Jeste, Lee and Cacioppo, 2020; Savage et al. 2021).

Although cultural values and household responsibilities provide some degree of protection, effectiveness often remains short of the mark. The effectiveness of such protection varies greatly according to the availability, comprehensiveness, and flexibility of support systems during crises. In addition, the pandemic also exposed the gaps in digital inclusion and the urgency of outreach and provision that is culturally sensitive, especially for older individuals in minority ethnic groups.

6.2.2. The weakening of community networks and its impact on older adults

Community engagement through volunteering and social networking plays a crucial role in the wellbeing of older adults, particularly following retirement (Higgs et al. 2009; Centre For Ageing Better, 2024). However, the government lockdown measures meant people had to redesign their lives. Despite living in multigenerational households and being surrounded by family members, most participants in my study reported that, during the government lockdowns, they missed the weekly social networking activities they usually attended at community centres. Older people value relationships beyond their relationships within the multigenerational households. Yoyo, a community leader substantiates:

> *Members in our group were sad that we couldn't meet. They insisted that the group is their lifeline. You see, some of our members they don't see anyone else except on Thursdays when we meet.*

For many, these groups were their primary sometimes only source of social contact and emotional connection. Mukhulis (83), metaphorically describes his feelings when the government announced the end of the lockdowns. He equates the end of lockdown to being granted freedom.

> *Well, when they announced the end of the lockdowns, I felt like a bird being let out of a cage. I am someone who values being with my friends at the community centre, going out for walks and because of my condition, my daughter explained to me how important it was that I stayed indoors. I kept in touch with my friends via ZOOM but I missed being with them in human form. I stayed indoors everyday with my wife. Well, looking at the positives, I must admit I got to know my wife more. Even though we have been married for a couple of years, but before the pandemic, we wouldn't always be together. But with the pandemic,*

it was now day in, day out together (laughs). I am not complaining, don't get me wrong. So, you learn each other more, which is good really. She is my second wife you see, married her following the death of my first wife.

These narratives demonstrate that, even in situations involving multiple generations, older adults value and rely on social ties outside of the family home. My study confirms scholarship which highlights the risk of loneliness for retired people (Windle, Francis and Coomber, 2011; Wang, Hall and Waters, 2014). Transitioning from working life can lead to challenges such as identity loss, and reduced social interaction, and community networking groups therefore positively fill in this gap, through aiding the transitioning phase. Yoyo and Mukhulis reveal the vital role that community networking groups play in the lives of the older people through providing social relationships and activities. The closure of the networking groups during the government lockdowns led to loneliness and negatively impacted the older people's wellbeing. Despite using social media to stay in touch, Mukhulis' experience highlights that virtual communication could not fully substitute in-person interaction. He also felt lonely despite being in contact with his friends via social media meaning face to face human contact is important for him.

Also important to highlight is that community networking groups are not only important for retired older people. Even older adults who were not employed valued the networking groups as they offer socialising platforms for them beyond their extended families. More so, since most of the research participants have been unemployed while being of working age (see demographics chart, **Appendix D1,** p.353). In the UK, more people from minority ethnic groups are unemployed than the white British people. This is caused by various factors including discrimination and language barriers, or their skills not being recognised in the UK (Zwysen, Di Stasio and Heath, 2021; AGE, UK 2023, 2024). According to ONS (2024), 3.3% people from a White ethnic background as compared to 8.0% for people from minority ethnic backgrounds were unemployed (Powell, Murray and Francis-Devine, 2025). Additionally, as highlighted earlier, people from minority ethnic background, especially women tend to be unemployed and engage in informal care or have lower paying jobs (West, 2021). For minority ethnic people, community groups act as a safeguard against systemic disadvantage, as well as spaces for social interaction. In contexts where resources and recognition are limited, these groups provide essential avenues for connection,

meaning, and support. However, during pandemics such as COVID-19, the ability of community groups to fulfil these roles was severely constrained, as social distancing measures were necessary to prevent the spread of the virus.

Conclusion

Informal care is central to the experiences of older minority ethnic adults in multigenerational households during the COVID-19 pandemic, offering both support against loneliness and significant burdens, particularly for women. Minority ethnic older people were integral in sustaining care, spanning practical and emotional support, especially during the pandemic lockdowns, often taking on responsibilities that went beyond what formal services could provide. While family care provides a sense of belonging and connection, it is not a complete solution, as it can place substantial strain on caregivers and highlight inequalities within households. Recognising informal care as integral, especially among minority ethnic groups, is essential, alongside addressing the mental and physical health needs of caregivers to ensure their well-being. A culturally sensitive approach is critical, one that honours minority ethnic values, strengthens family and community support, and actively addresses systemic inequalities in care, health access, and social inclusion, as older adults continue to navigate an uncertain and evolving post-COVID landscape.

CHAPTER 7: NAVIGATING THE POST-COVID WORLD

Introduction

This chapter addresses the key research question namely: In what ways do older minority ethnic individuals negotiate the intersecting difficulties of the post-COVID world? Building on from evidence from the preceding chapters, it situates participants' lived experiences within broader theoretical and policy frameworks to deepen understanding of vulnerability and resilience in later life. The Intersectional Risk Framework (IRF) is employed here to examine how minority ethnic older adults in the UK experience and navigate the post COVID era. Particular attention is given to how these frameworks illuminate the compounding vulnerabilities participants face in daily life. This approach is timely in the context of post-pandemic world's convergence of crises, including wars, long-term socio-economic insecurity, deteriorating mental health, climate change, the rise of Artificial Intelligence (AI) and its challenges, and additional digitalisation of numerous services. The chapter also explores the impact of the cost-of-living crisis and digital exclusion on older minority ethnic people during the COVID pandemic. It further examines issues related to NHS access and healthcare needs among older minority ethnic individuals. Their heightened vulnerability is analysed alongside coping mechanisms including the use of religion as a protective buffer. This chapter draws on the IRF which brings together intersectional theory (Crenshaw, Hankivsky) and social risk theory (Beck, Giddens) to examine how intersecting identities like age, race, class, and disability intersect with institutional and structural risks in the post-COVID world.

7.1 The polycrisis and cumulative risks

Concerns over multiple crises that are prevalent in the post COVID world emerged as an overarching theme among the older minority ethnic participants. In response to layered adversities such as a racialised history of economic marginalisation, health disparities and chronic underemployment, all participants employed several coping strategies to navigate uncertainty.

The analysis in this section is grounded on the recognition that the cumulative impacts of crises exceed the sum of their parts (see Lawrence et al. 2024). Furthermore, the

risk society is fraught with uncertainty and a growing number of crises across the contemporary world (see Giddens, 1991; Beck, 1992; O'Regan, 2023; Alaszewski, 2023). Similarly Bauman (2000), defines contemporary societies as fluid. Examples of contemporary multiple crises include the COVID-19 pandemic, prolonged socio-economic crises and insecurities, the exacerbated decline in mental health issues, climate issues, the rise of AI and its challenges and contemporary wars (O'Regan, 2023; Siirilä and Salonen, 2024). These different crises are conceptualised as polycrisis, a term originally coined by complexity theorists Edgar Morris and Anne Brigitte Kern in 1999. It describes a scenario in which disparate crises intersect and interact simultaneously, mutually amplifying one another and producing an overall impact greater than the sum of each individual events (O'Regan, 2023; Lawrence et al. 2024; Rasella et al. 2024; Siirilä and Salonen, 2024). The confluence and interaction of the different crises cause complexities and uncertainties in society, and a disruption in life spaces (O'Regan, 2023; Butler, 2023).

It is noted that the cost-of-living crisis, AI and climate change are leading to job losses and negatively affecting people's health (Groome and Palipane, 2020; Qian, Siau and Nah, 2024; Scholes, 2025). People experience crises differently and individuals' perceptions regarding crises vary depending on various factors such as one's socio-economic status, age, disability, health, gender, ethnicity and lived experience (ONS, 2022; Siller and Aydin, 2022; McLoughlin, 2024). For example, 85% of the adults who took part in the ONS (2022) survey on the impact of climate change said they are especially worried about the high temperatures. Research has also established that other crises including high cost-of-living, digital ageism and chronic racism are also negatively affecting older people in the UK (Rosales and Fernández-Ardèvol, 2020; AGE UK, 2021, 2025 Lewis, Yarker and Phillipson, 2023, AGE UK, 2025). Polycrisis is therefore disproportionately affecting disadvantaged communities, thus exacerbating social vulnerability and inequalities, and eroding social trust (Žižek, 2020; UNDP, 2023). Since polycrises affect people on many fronts, the harm experienced by marginalised groups is intensified across those same fronts. It is however noted that there is still limited research on the impact of polycrises on older people in the UK because most research to date has adopted a siloed approach.

In the UK, the various contemporary adversities are posing simultaneous disadvantages to specific vulnerable groups such as older minority ethnic people (UCL

Institute of Health Equity, 2024). While older minority ethnic people are disproportionately affected by current crises, and the unfolding of a proliferation of increasingly complex threats, it is noted that they also have collective disadvantaged lived experiences (including during colonisation and when they migrated to the UK). For example, African Caribbeans and South Asians who migrated to the UK in the post-war period occupied broadly similar structural positions in predominantly unskilled or semi-skilled jobs, and the ideologies that racialised them differed in content (Brah, 2005; Song, 2004). These experiences shape their vulnerability and resilience.

Vulnerability and resilience are closely linked. As highlighted earlier in Chapter 1.3.6, vulnerability which is the risk levels faced by individuals, communities, or societies in experiencing harm from various hazards, as well as their capacity to recover, cope, and prevent such harm is reinforced by inequalities such as age, ethnicity, gender, comorbidities, and disability (Siller and Aydin, 2022). Resilience refers to the capacity to withstand and recover, including adaptation through social processes (Juen and Siller in Siller and Aydin, 2022; Juen, 2016).

Structural factors such as overcrowded housing, poor living conditions, and higher comorbidities increased vulnerability for older minority ethnic people during the pandemic, resulting in higher infection, severe illness, and mortality (Kenway and Holden, 2020; ONS, 2020b; PHE, 2020; Ayalon and Tesch-Romer, 2018; Maestripieri, 2021). Government measures, including social distancing, disrupted cultural practices and communal support affected the minority ethnic people's emotional wellbeing (Brown and Kirk-Wade, 2021; Mayland et al. 2021). Additionally, racism intersects with socio-economic identity which is rooted in historical structural disadvantages and further heightens the vulnerability (Keys et al. 2021; Siller and Aydin, 2022; Williams, 2021; Gulliver and Prentice, 2017). Critics argue that the British government's failure to address institutional racism and socio-economic risks limited the effectiveness of pandemic measures (Siller and Aydin, 2022).

Other scholars such as Donoghue (2020) and Lupton (2022) critique the UK policy of responsibilisation, whereby UK citizens are increasingly positioned as responsible for their own resilience and required to find individual solutions to a wide range of adversities, including socio-economic hardship. This reflects a broader neoliberal logic

in which risk and responsibility are displaced from the state onto individuals and households. Trnka and Trundle (2014), argue that such neoliberal responsibilisation is only one dimension of how responsibility operates in contemporary social life. They add that neoliberal responsibilisation coexists and often conflicts with other moral frameworks, particularly relations of care and social contract ideologies. Therefore, based on Trnka and Trundle's (2014) reasoning, responsibility is not a singular demand for self-management, but a field of tension between individualised accountability, interdependent care relations, and expectations of collective or state protection.

The participants who took part in this research expressed concern about several contemporary crises: the emergence of new diseases, the cost-of-living crisis, wars, the climate emergency, AI and the increased digitalisation of most services including health and social care, younger people's increasing mental health challenges, and growing societal polarisation. It is beyond doubt that these anxieties resonate with Beck's (1992) 'risk society,' in which uncertainty becomes a defining feature of modern life. In the UK context, this is further intensified by processes of responsibilisation, whereby individuals and communities are increasingly expected to manage risks generated by systemic and structural failures (Donoghue, 2020; Lupton, 2022).

However, drawing on Trnka and Trundle (2014), it is important to recognise that such responsibilisation does not operate in isolation. Rather, individuals, particularly older minority ethnic people navigate competing and sometimes contradictory responsibilities. Alongside neoliberal expectations of self-management, they remain embedded in enduring relations of care, such as intergenerational support and family obligation, which may increase exposure to risk or limit their ability to comply with idealised forms of 'safe' behaviour. At the same time, expectations rooted in social contract ideologies shape assumptions about what the state should provide in terms of protection, healthcare access, and equitable treatment. As highlighted in the foregoing chapters, these layered and competing responsibilities are especially challenging for marginalised groups such as older minority ethnic individuals, who often face structural constraints that limit their capacity to act upon the ideal of individualised responsibility.

Through the IRF model, it is possible to view older minority ethnic people as not merely experiencing a set of crises, but an intersection of interlinked risks embedded in their social structure. Their age, migration experience, race-related work patterns, and health status do not exist independently but build up to increase their vulnerability to damage and restrict their potential for institutional care. For instance, the move to online services during the pandemic period, although billed as a one-size-fits-all measure, affected older minority ethnic groups disproportionately because they were already subjected to pre-existing digital exclusion on various compounding axes of age, race, and socioeconomic status. This was a layered vulnerability where access to even basic services such as healthcare was further curtailed. It is also noted that whilst Beck's (1992) individualism thesis emphasises autonomy and independence as human beings' desirable goals, the older minority ethnic people have different experiences due to their unique circumstances and limited resources based on social identities such as ethnicity, race, health status, socio-economic status and disability.

7.2 Austerity and the cost-of-living crisis

An individual's socio-economic status is shaped by their positionality and proximity to power and resources. To this end, ethnic inequalities in health reflect an interplay of various factors (including socio-economic status, age, gender, disability etc) which consequently influence an individual's health outcomes (Raleigh, 2023; Joseph Rowntree Foundation, 2025). There is no doubt that most minority ethnic groups are disproportionately affected by socio-economic deprivation (Raleigh, 2023). The disproportionality is linked with structural racism which exacerbates socio-economic inequalities and consequently negatively impact health (O'Connor et al. 2021).

The interaction of the COVID-19 health crisis and resultant lockdowns with factors such as income, age, gender and ethnicity exacerbated existing inequalities and opened up new fissures (Blundell et al. 2020; Williams, 2021). Further to the effects of the pandemic, the socio-economic impact of the conservative government's fiscal austerity measures which date back to 2010 resulted in cuts in public expenditure on, among other sectors, social care and housing support, and placed an additional burden on the precarious position of older minority ethnic people (Williams, 2021; Lewis et al. 2023). In response to the financial hardships, food banks have significantly

increased in recent years (Francis-Devine, 2025). Food banks are run by local communities to provide emergency food and support to people struggling financially (Francis-Devine, 2025). While food banks certainly offer vital short-term relief, their sheer prevalence is indicative of deeper structural problems of poverty and social exclusion (Francis-Devine, 2025). Researchers contend that food aid dependency can institutionalise destitution and divert responsibility from the state to voluntary organisations (Lewis et al. 2023). That fact highlights the necessity for policy interventions that target root causes rather than symptoms. The reliance on food banks illustrates responsibilisation, where the burden of addressing poverty is shifted from state welfare to voluntary organisations and individuals.

7.2.1 The COVID pandemic and the financial fall out from COVID

Concern over the cost-of-living crisis emerged as a dominant theme in participants' narrative. All participants in this study described how the current cost-of-living crisis intensified pre-existing financial hardships which were already exacerbated during the COVID-19 pandemic. The long term impact of austerity measures in the UK worsened the effects of COVID with its resultant disadvantaging of already hard-hit communities, who are being further impacted by rising cost of living (Arrieta, 2022; Siller and Aydin, 2022). For participants such as Adam (77), their financial hardships were linked with redundancy during the pandemic. Adam (77) linked the COVID pandemic with the loss of his job as an interpreter, which ultimately forced him to take retirement earlier than he had planned.

> *I used to work as an interpreter, interpreting Punjabi to English and vice versa. Because of COVID I lost my job, and suddenly found myself unable to afford internet and telephone bills. Although lockdowns are over, I am no longer getting the piece jobs. Also frustrating is that the Council now charges extra money for the green bins. This makes my life harder.*
>
> *And as if that is not enough, my health has taken its toll on me. Before the lockdowns I used to do about 15 thousand steps each day and go to gym, during lockdowns I spent most of the time sitting and developed arthritis on my legs, gained weight and high blood pressure, and I am struggling to control my diabetes. I would like to resume gym and the long walks, but the arthritis is*

currently too painful. Anyway, I can no longer afford the high costs of gym too. You know because of inflation, gym is now very expensive, such that it's now a luxury for the rich.

Adam's redundancy illustrates how intersecting vulnerabilities of age, race, and immigration status converge. His skills as an interpreter, likely valued in his country of origin, were devalued in the UK job market, placing him in a precarious position even before the pandemic. This pre-existing economic vulnerability was then exacerbated by COVID-19, demonstrating how structural inequalities amplify risk during crises. As discussed below, Adam's deteriorating health condition (diabetes, arthritis, weight gain and higher blood pressure) is closely linked to both the pandemic and the cost-of-living crisis. While the council has increased the price for green bins, which are especially important in line with increased awareness of climate issues, older minority ethnic people such as Adam cannot afford the bins. Though Adam living with comorbidities is keen to resume physical activities, he highlights that he can no longer afford the gym because of the rising cost-of-living. Adam's financial situation has also been exacerbated by his unexpected job loss as an interpreter because of the pandemic, thus showing how the intersection of ethnicity, socio-economic status and comorbidities impacts the health of older minority ethnic people.

Although Jomo (84) holds a BSc degree in Project Management, he worked as a labourer in the construction industry because Pakistani qualifications were not recognised in the UK.

I tried several times to get my degree accepted in the UK, but
I gave up. I was told to study again to make my qualifications suit the UK level. I had to work for my family, and so I worked as a labourer than to start studying again.

Jomo's experience illustrates how intersecting vulnerabilities of age, race, and immigration status collide. The devaluation of his Pakistani qualifications in the UK job market, likely rooted in colonial legacies and ongoing biases against non-Western education, forced him into lower-paying labour jobs despite having a degree. This pre-existing economic vulnerability, amplified by his age and potentially limited social networks in a new country, placed him at greater risk during the cost-of-living crisis.

This illustrates how structural inequalities embedded in credentialing systems, create and perpetuate disadvantage for immigrants. As highlighted in chapter 6, AGE UK's (2023) research links poverty among older minority ethnic people to earlier unemployment, often due to unrecognised skills (AGE UK, 2024).

Financial hardships have also led to increased reliance on food banks. The reliance on food banks, while reflecting vulnerability due to differences in accessing affordable food, also highlights systemic failures in supporting older ethnic minorities facing multiple disadvantages. Most participants reported relying on food banks since the start of the pandemic. Furthermore, community leaders noted that their networking groups in addition to their networking activities have started running food banks to meet their members' growing food needs. During an interview, Lindani, the community leader of a women's networking group brought a large bag full of fruits and vegetables to distribute freely among group members. She explained:

> *I receive and collect food from shops such as Tesco, which I distribute amongst our members. I started this during COVID lockdowns and because of inflation, I get bombarded with requests for food hampers on our WhatsApp group, but I can't get enough food to meet the increased demand. Moreover, I don't have a car, and so I get what I can carry in my bag.*

This distribution of vegetables and fruits to the groups' members reflects the spirit within the community members. As noted in Chapter 4, solidarity aligns with minority ethnic people's collective cultures (Joshanloo, Van De Vliert and Jose, 2021) and the COVID pandemic strengthened this solidarity spirit. Food bank usage has increased in the UK amid the cost-of-living crisis; GOV.UK (2024) reports that 3.3% of all households used food banks in 2023.

Furthermore, as discussed earlier in chapter 4, the cost-of-living crisis prevented some participants from buying groceries in bulk, during the peak of COVID-19 and government lockdowns. According to the demographics data (**Appendix D1,** p.353), most participants live on under £12 000 per annum and have been unemployed or retired from predominantly low wage jobs. Examples include Jerry (77) a retired industry labourer, Bobi (84), a retired construction labourer, Gabriel (68) a retired prison support worker, and Momo (82), a retired shop assistant.

These situations reveal how intersecting factors namely, age, ethnicity, education, occupation, comorbidities and socio-economic status disproportionately affect older people during crises. This research echoes evidence in existing literature showing minority ethnic populations are over-represented in occupations such as taxi driving, security, social care, food preparation and hospitality (Mirza and Warwick, 2022). For example, Black African men are seven times more likely to work in social care roles compared to white British men. Black African women are four times more likely to work in social care than their white British counterparts (Mirza and Warwick, 2022). Mirza and Warwick (2022) and Murtola and Vallelly (2023) concur that although these jobs are mostly marginal, insecure and low paid, those who worked in these jobs during COVID-19 faced higher mortality rates due to elevated infection risks.

Lewis et al.'s (2023) study found the UK cost-of-living crisis pushed 50% of older minority ethnic below the poverty line, increasing risks of deprivation and poor mental health. Age UK (2023) further reports that over 18% of pensioners live in poverty with older minority ethnic people facing double this risk. This study also found that COVID-19 and the economic crisis compounded older adults' vulnerabilities, supporting research which shows that intersecting adversities produce compounded disadvantages for already vulnerable groups. It illustrates how the COVID pandemic and economic crisis intensified multidimensional vulnerabilities, namely economic, social and health related among already disadvantaged groups.

7.2.2 Impact of lack of funding of community groups

Community groups play a key role in the older minority ethnic people's lives and therefore their sustainability is key. In this study, several community leaders bemoaned the reduced and lack of funding for their networking groups. Kenzo, who leads a Muslim group for older men lamented how lack of funding has negatively impacted the running of some key projects that the older minority ethnic people were benefiting from, thereby negatively impacting their participation in physical activities and empowerment on health matters.

> *We do health sessions such as on weight loss for the over 60s in our community or on men's mental health in which we will specifically target men. In the past we produced videos on health matters in different languages such as Urdu,*

which we distributed to our diverse members. But because of the government lockdowns, we stopped the physical exercises and other outdoor activities. Now, due to reduced funding by the local authorities, we have cut down in scope and totally stopped some of our activities. For example, we used to have an expert gym instructor, because we place value on people's physical health. However, we have had to stop his services because we can no longer afford to pay him. We try and do some light exercises on our own, but we feel it does not have the same effect that it had when we were led by an expert. We hope that local authorities reconsider funding our activities and engagements. We are now totally self-funding our own community group, but we think that collaboration between statutory bodies and community groups like ours would be helpful because as community groups we are closer to our members and understand them better. When COVID-19 arrived, as communities we just went along without any proper support structures in place, which is wrong.

The revelation by Kenzo emphasises that better collaboration between statutory bodies and faith groups is important. Furthermore, it is also vital that the government supports the community groups to function more effectively, and that the relationship between the government bodies and community organisations such as spiritual groups should be ongoing and not only be rejuvenated during pandemics. This study points towards the need for the government to support community groups by training some community members as coaches on mental health. This will empower and equip the community with important skills which foster improved people's wellbeing, while enhancing sustainable resilience. This is important during the contemporary crises, and in the event of future pandemics.

This study has revealed that while the minority ethnic people's networking groups are organising themselves and supporting the vulnerable people in their communities, they are stretching themselves. The role of the government and local authorities in supporting the groups is key to ensuring enhanced sustainable resilience. As alluded to by Wright (2022), resilience should not be viewed as a 'self-flowering' quality because communities organising themselves and engaging in 'reflexive self-governance' leads to a tendency of overlooking the differential proximity to resources and power by different individuals and groups. Yet differential proximity to resources and power shapes resilience strategies. Wright (2022) argues that this is a form of

‘bounded resilience’, that is strength that is exercised in unequal social structure confines. It is against this background, that scholars such as Donoghue (2020) and Lupton (2022) critique the UK’s policy of responsibilisation which frames citizens as solely responsible for their own resilience, requiring them to independently navigate and address the adversities they encounter.

A discussion with Rudo (68) substantiates the issues raised by Kenzo above.

> *Whilst I did several activities with my hands during the pandemic, I was not active with my legs. I was less mobile because I stayed at home for a very long time so in the end I struggled to walk. I now suffer from arthritis, and I have a lot of pain in my knee. After the government lockdowns I ended up using a mobility scooter, yeah (silence). I have also had 2 operations on my hands because of the arthritis problem. They said they will put metal plates inside my hands to support me. My hands hurt a lot. I am also diabetic and asthmatic.*

Kenzo and the other community leaders make a plea for the local authorities to reconsider funding the community groups’ activities and engagements because they are important in enhancing the older minority ethnic people’s health and wellbeing. Some members (such as Rudo) whose physical health and mental health deteriorated during the lockdowns could benefit from the resumption of their networking groups’ activities. Rudo‘s physical health rapidly deteriorated due to inactivity during the pandemic such that she started using a mobility scooter. A lack of funding by local authorities could lead to hastening of ageing trajectories for the older minority ethnic people. This comes against the background that older people from minority ethnic background have increased risk of hastened negative ageing because of their identities such as heightened risk of living with comorbidities and disability, and lower socio-economic status (Hayanga, Stafford and Bécares, 2023).

This study therefore demonstrates the importance of the government having ready sustainable measures in place, so that in the event of future pandemics, older people’s health does not hastily deteriorate due to stopping of community activities. Continuity is important for sustainable health. It is important that the UK government does not act in a reactionary way to crises, but that they have existing ready measures in place to tackle any potential adversities or pandemics. The cuts to funding for community organisations intensify social isolation and weaken the mechanisms of resilience,

which have historically supported older people from minority ethnic groups across adversity. Recent evidence is consistent with this identification of the vital role of community capital in mitigating health inequities. Furthermore, while community organisations resist adversity with notable resilience, the IRF indicates that this is unevenly distributed. Pre-existing poorly resourced groups suffer compound pressures and in the absence of particular interventions, there is a threat that pre-existing inequalities are reinforced.

7.3 Health needs and health literacy

The UK has experienced several decades of Neo-liberalism, marked by reduced state funding and the push towards privatisation of public services including the NHS. For older adults, these changes have contributed to diminished support structures and job losses through retrenchments, (Wiggan, 2012; Bayliss, 2022). Williams (2021) adds that the UK's austerity policies increased poverty and inequality.

While the NHS faced structural challenges such as labour shortages and an ageing population in poor health (Alderwick and Dunn, 2025), it remains critical for vulnerable communities, especially older minority ethnic adults who are at heightened risk of living with comorbidities (Hayanga, Stafford and Bécares, 2023). The Health and Care Act (2022) is a potentially positive step toward addressing NHS's challenges. However its impact is yet to be seen in meeting the health and social care needs of the UK's growing and ageing population (King's Fund, 2022, 2023; Carney et al. 2024). The Health Care Act (2022) emphasises the decentralisation and joining up of health and social care services with a view to optimise services (King's Fund, 2022). For example, the role of social prescribing, which entails linking patients to community services for non-clinical interventions is being increasingly promoted (Buck and Ewbank, 2020). Additionally, the newly launched 10 year NHS plan geared to enhancing NHS productivity and efficiency is also a potential positive step toward addressing NHS' challenges (NHS, 2025). The success of the plan is yet to be established.

This study's research participants pointed out the older minority ethnic people's several health needs. These relate to the challenges they face with NHS, health literacy challenges such as language barriers, and other physical barriers, digital

inclusion, lack of health empowerment programmes, and reduced funding for their networking groups' programmes. These barriers intersect, that is digital exclusion, language barriers and limited health literacy compound to create layered disadvantages especially for older minority ethnic adults. This supports the intersectional framework and highlights the need for culturally and linguistically tailored interventions.

Coughlin et al. (2020) argue that the concept of health literacy is becoming increasingly important in contemporary societies due to challenges associated with late modernity. Through its association with social determinants of health, health literacy is relational and modifiable (Sørensen et al. 2024; Coughlin et al. 2020). According to Sorensen et al. (2024) health literacy's multidimensional aspects include knowledge and competencies that people require to access, understand, and appraise to enable them to make informed decisions regarding their health and healthcare, disease prevention etc.

Data from this research shows that health literacy plays a key role in shaping how older minority ethnic adults make decisions about their health, and disease prevention in their daily lives. Health literacy has an adverse effect on the older minority ethnic people's health outcomes. The participants in this study noted some barriers which hinder their understanding of information regarding their health and health care. They identified language and other physical barriers (glass divides and masks) and digital exclusion as negatively affecting their health needs.

7.3.1 Barriers to accessing health care

Language barriers, often overlooked as mere communication issues, become significant health risks when they intersect with other vulnerabilities. For older minority ethnic individuals, limited English proficiency, combined with age-related hearing loss and the increasing shift to telephone consultations, creates a layered barrier to accessing healthcare. This highlights how seemingly neutral administrative changes can exacerbate existing inequalities and create differential access to essential services. For example, in FGD2, the research participants explain that language barriers pose challenges for them especially when explaining their health conditions

to the doctors on the telephone. P1 notes how he struggles to explain his health condition to the GP on the telephone which results in him not positively responding to the prescribed medication. P2 however gets the privilege to talk to the GP's secretary in Punjabi and therefore has a more positive engagement.

> *During the government lockdowns, on the telephone, I could not explain to the doctor which part of my body was aching and how it was aching. I said below my chest, and it feels like burning... I was given different medication twice, but my health got worse. I was deeply worried, but I was told to keep ringing the GP, which was annoying. Struggling with long waits on the telephones is one thing, and then you also struggle with the language. Then you also feel tired because of the long waits on the phone, which makes my health situation worse.* (P1)

> *I live alone and I struggle to express myself in good English, but I am happy that the secretary to the GP speaks Punjabi, so I am free to talk to her in Punjabi*. (P2)

Before the pandemic, in person consultations allowed older minority ethnic patients to indicate symptoms non-verbally when limited by language, facilitating cleaner communication. This made it easier for their communication with the doctors. However, since some consultations are now online, the inability of some older people to explain the medical conditions they experience leaves them at risk of being wrongly diagnosed and being prescribed the wrong medication. This contributes to worsened health outcomes. Ali and Watson's (2018) study is particularly relevant here, having shown that language barriers hinder the provision of timely, appropriate and effective care to patients with limited English proficiency. Ali and Watson's (2018) research established that language limitations are big obstacles in providing adequate, appropriate, effective and timely care to patients with limited English proficiency, aspects which this study also identified. According to ONS (2022), the 2021 Census established that 1 million people in the UK are unable to speak English well, or at all. This comes against the background that most of the people who face language barriers are the older people (ONS, 2013). Additionally Riaz (2017) notes the age related ramifications of those who have language barriers and are aged 75 and over.

They are twice as likely as those who are proficient in English to report to not have good health.

NHS (2021) notes that where language is a barrier, patients are entitled to interpreters. Therefore, the patients may not be aware of the service. The findings indicate that recent NHS reforms have not sufficiently addressed the unique needs of older minority ethnic populations, particularly in relation to face-to-face access and continuity of care. Policymakers should prioritise targeted outreach and culturally competent service provision, whilst paying heed to how health needs are conceptualised in different cultures and by different age groups.

Glass divides in healthcare settings and masks were also highlighted as impeding communication between healthcare professionals and the minority ethnic people. Momo (82) believes that her visits to the surgeries are no longer easy because of a newly created barrier (glass divide), while the masks acted as an additional communication barrier.

> *When the lady at the reception speaks to me through the glass and the mask, I can hardly hear her. I keep asking and asking because it is hard to understand what she will be saying. The communication is always difficult, and it is annoying.*

Therefore, while glass divides were installed in surgeries as protective measures to minimise risk of infection with coronavirus when a patient speaks to the medical experts, they act as a communication barrier. Masks and glass divides hinder further communication between older minority ethnic patients and medical staff, especially when combined with the language barriers. Furthermore, during the pandemic, masks and glass divides reduced the communication power for the older people who have sensorial limitations such as hearing and visual disabilities. Scholarship highlights that hearing loss increases with age and that it is most prevalent amongst older people of ethnic minority background (Taylor et al. 2020). Additional challenges in communication exacerbate communication challenges for them thus affecting the physician-patient relationship, whilst distressing them because they feel more disabled. Consequently, older minority ethnic people are not empowered to discuss and negotiate treatment options with the healthcare professionals, which several

scholars (including Al Shamsi et al. 2020; Gerchow et al. 2021; Wu, Jin and Wang, 2022) emphasise as key for the enhancement of individuals' health outcomes. For example, communication barriers expose the older minority ethnic people to the risk of making uninformed choices regarding their health or failure to adhere to treatment plans as guided by the healthcare professionals. In this study, the older minority ethnic people's challenges with communication heighten their health literacy challenges and consequently negatively affect their health outcomes. Whilst risk society emphasises individual responsibility in enhancing health outcomes, the older minority ethnic people face limitations owing to language barriers.

Most of the older minority ethnic participants voiced concern over the challenges they are encountering with NHS, and that the problems continue despite the lower cases of COVID infections. Some participants bemoaned the inefficiency of NHS, which they argue is leading to the worsening of their health and wellbeing. One of the challenges they highlighted is accessing face to face appointments with GPs.

In a heated FGD4, participants air their perspectives.

> *I am only lucky that I now have a doctor who is my son's friend. So, I no longer face problems with accessing a doctor, but before then it was very hard. The surgery would say only phone at 8 o'clock. And if you get through later after 8, they will say sorry we are now closed and not for taking any more calls for GP's appointments. Then you are told to phone again the next day. And on and on it goes.* (P5)
>
> *People who are ill are not even getting the opportunity to get their illnesses sorted out. You can't even be helped. You can't even get an appointment at the GP. Getting the vaccine or the boosters was also at one's own risk because if you got after effects, it would be hard to get in touch with the GP.* (P3)

This study also highlights how financial barriers limit older minority ethnic people's skills and ability to attend to their health care needs. Financial barriers prevent some from accessing essential healthcare services. For example, Elisheba (67), who is unemployed, and lives alone cannot afford a blood pressure (BP) reading meter and she also cannot read it, with this effectively depriving her of the necessary care when

she needs it. This demonstrates the importance of early intervention when conditions are still manageable. NHS' new 10-year plan has highlighted early intervention to keep people well, which is key to reducing future demand on acute and emergency services (NHS, 2025). By contrast, Kettina (74), a retired nurse, owns a BP reading monitor and uses her health knowledge to seek help from a pharmacist (see section 7.3.5.2). Yet neither access care from a medical doctor, leaving both exposed to potential health risks. This study shows that older minority ethnic individuals risk making uninformed decisions about their health. This calls for urgent government action to ensure well-functioning health and social care services for timely access. Prioritising such services is vital, especially with one in seven projected to be over 75 by 2040 (GOV.UK, 2016).

In navigating the COVID-19 pandemic and any other future pandemics it is important to identify the communication barriers older minority ethnic people face alongside the coping strategies they deploy in response. Greater awareness among healthcare professionals of the specific vulnerabilities experienced by older ethnic minorities, including their risk of psychological distress in important. Such awareness can inform more inclusive interventions during the pandemics and ensure that appropriate support resources are made available.

COVID has transformed nature of doctor-patient interaction, and accelerated changes that may have been already emerging. The rushed nature of medical consultations, in turn, caused by the pressures confronting the NHS, poses certain risks for older adults from minority ethnic groups. The convergence of time-limited consultations with language barriers, differences in communication styles based on differing cultures, and potential lack of trust towards healthcare provision based on past experiences of discrimination, (such as the UK government's 2018 hostile immigration policy that resulted in some Black Caribbeans who were legally present and had long settled in the UK being denied jobs, healthcare, pensions, or being deported) can produce inaccurate diagnoses, inappropriate treatment, and increased lack of trust in healthcare professionals. It demonstrates how pressures at the structural level in terms of service delivery can have a disproportionate impact on marginalised groups. The speeding or hastening of medical examinations by medical doctors resulting in inadequate medical care emerged as a key theme in this study.

FDG3 participants 3 and 4 respectively comment:

> *We no longer have government lockdowns, but we are still being made to stand outside the surgeries before being attended to by the doctors which is not good at all. We get wet, cold and more unwell. No consideration is being made of our situation as older people. The doctors are speeding up the examination time, yet we paid a lot of tax when we worked. It makes me panic.* (P3)

> *I have a friend who passed away during COVID. The GPs gave up on him. He didn't get adequate medical attention. I therefore question: with all this happening, when will NHS normalise health services because we are tired of this suffering? I don't see things getting any better. I am not happy with the present government because it is selfish and heavily taxes the poor people. The rich people are profiting from privatisation of big bodies like NHS. I think they have shares in the running of these big bodies.* (P4)

Kettina (74) also expresses her frustration with the medical care, which she argues is overwhelmed. Kettina explains her previous experience whereby she got medication and the vaccinations which worsened her medical condition has made her lose confidence in the medical care.

> *I have always felt that my GP does not give adequate attention to my health needs. She is fast when examining me. During COVID I was given medication which worsened my medical conditions, and I challenged them. They tried me on various medications, and they gave me vaccine injections, which worsened my condition. I complained until they stopped the new medication. I took advantage of my previous medical knowledge. Now going to the GP for medical help frightens me. In this area, GP services are very bad. There are only 16 surgeries, and they say they have too many patients. I think one of the main problems is GPs are now tasked with other social tasks such as recommending people for social housing, food banks and so on which leaves them overwhelmed with work. People queue to get recommendations and stamps from GPs to access food banks. I also notice that some of the GP's work is being pushed to the pharmacist, for example testing for UTI infection.*

Kettina's quote reveals that the link between the social prescribing link workers and GPs is not working effectively. The role of Social prescribing link workers is to work in

collaboration with GP's to holistically and proactively identify socio-economic and environmental factors which directly and indirectly impact health, especially those resulting from injustice and inequality (Polley et al. 2017; NHS, 2022). Their effectiveness in improving health outcomes has however not yet been established (Kiely et al. 2022).

Research participants were also critical of the lack of continuity in medical care because when they contact surgeries for medical help, they do not always get timely support, and they get attended to by different doctors. Wada (74) relates

> *The lack of continuity in accessing one's GP makes it hard for us because you talk to different GPs about the same problem, whilst not getting the required help. But even if we know that we have such and such problems, the question is whom we even speak to. We have no one to air our problems to. In the past we used to have community nurses and health visitors who used to easily come to our homes when we were unwell, but this is now a thing of the past.*

Senzia (68) explains that because of the pandemic and the fact that NHS is overwhelmed, she has a pending operation.

> *I've got this operation pending because NHS cannot cope. They're going to go into my brain. They should have done it, but COVID came, and now I am on a waiting list.*

The delay in Senzeni's operation is a reflection on NHS's challenges in meeting the health and social care needs of the UK's population, a situation which was aggravated by the pandemic (King's Fund, 2022, 2023; Carney et al. 2024). The NHS is currently undergoing restructuring (Alderwick and Dunn, 2025), but its success cannot yet be ascertained. Having delays in major medical interventions could pose health risks which could consequently lead to lack of trust in medical professionals and increased disruption to traditional doctor-patient relationship.

Collectively the findings reveal how intersecting structural barriers ranging from physical, digital and linguistic contribute to the marginalisation of older adults with sensory impairments. The IRF shifts focus from individual deficits to systemic failures in the design of inclusive healthcare systems.

7.3.2 Digital exclusion

This section explores how intersecting factors of age, disability, living alone, gender, and digital exclusion do compound vulnerability among older minority ethnic people. These experiences reveal how structural inequalities have been intensified by the shift to digital healthcare, especially during COVID-19.

This study also highlights how digital exclusion limits older minority ethnic people's skills and ability to attend to their health care needs. In Chapter 4, participants described how limited digital knowledge hindered access to health services they required during the pandemic. This challenge was especially applicable for the older minority ethnic people who do not live with their children. Those living with their children received support in navigating digital systems. This study support findings from the Topol Review (2019), highlighting that minority ethnic people are at heightened risk of racialised digital exclusion due to digital illiteracy and lack of access to digital resources. Despite these disparities, there remains a significant gap in research on digital exclusion, particularly among older adults from minority ethnic backgrounds (WHO, 2021; Chidambaram et al. 2024). This study points towards the need for the policy makers investing in basic digital training skills targeted at older people. Furthermore, this study also points towards the urgent need for research on digital exclusion among older minority ethnic groups in the UK. Understanding its impact is crucial to addressing health inequalities, especially as essential services such as healthcare, welfare claims and banking become increasingly digitalised. While living with disability presents challenges distinct from those of non-disabled older people, the situation becomes even more complex when disability intersects with social isolation.

The IRF framework reveals that digital exclusion is not merely an individual shortcoming, but a structural issue shaped by race, age, class, and disability. Participants' exclusion is structural, not just technical. Participants link the increased use of digitalisation in most of the UK services including health with the challenges they are facing since the COVID-pandemic. Hannah (72) explains:

Virtual consultations have now been normalised, but observations are important when it concerns health issues. We now spend many hours on the telephone waiting for a response, and we now spend more time with the receptionists instead of with the GP's. This is frustrating and too expensive, and sometimes I have no choice but to just cut the phone call.

Therefore, Hannah's difficulty in accessing a GP delays medical care, exposing her to worsening health risks. This supports the arguments in Chapter 4.5.1 (p.134-6), that removing vaccination centres from Mosques and community spaces after the COVID peak reduced access for some older minority ethnic individuals. Consequently, booster uptake declined as booking required digital access. Participant 1 in FGD6 said online booking *"is not easy",* and NHS calls involve 'staying on hold for a long time.' Elisheba (67), who also contributed to the discussion on the challenges with NHS says:

These days I sometimes go to the pharmacy to ask for help in getting a doctors' appointment. Then you sometimes get the doctor's surgery ringing you and asking you to take your BP and send the reading to them. What if I can't afford buying a BP machine and what if I can't read a BP machine? It means that they now want us to medically examine ourselves, no? It's awful. It's certainly not healthy.

Senzia (68), who is blind, lives alone, is asthmatic, has brain aneurysm and is managing cancer in remission, offered a vivid account of the everyday obstacles she faces in accessing digital healthcare:

Now that almost everything in the UK has gone online, what happens to me, who cannot see, and lives alone? I can't see so I can't go online to book an appointment or to respond to my doctor because he asks me a question online. I can't do it. I must wait for my assistant, son or my daughter to come and help me. I like to have somebody next to me whilst talking to me, reassuring me, and so online contact does not work for me. Everybody is now so busy. They just talk quickly, and you are not even understanding them, let alone getting that care and time that you need. That's all gone. Why? Why? Why? This whole country has become nothing! It's in shambles. They don't care, do they? They don't

> *prioritise us, but themselves and their stomachs. They just don't value the caring element. It's lacking. It's gone. There is no humanity left to talk about anymore.*

Senzia's vulnerability is exacerbated because further to living with disability, she also lives alone. She is therefore disabled by social barriers because she cannot get face to face medical support when she needs it. Furthermore, when her personal assistant or children are not with her, she is unable to access some services that she requires. For Senzia, digital exclusion is not simply a lack of internet access. Her blindness, coupled with her age and potentially limited access to assistive technologies due to socioeconomic factors, creates an intersectional barrier where digital healthcare is fundamentally inaccessible. Senzia's case aligns with the notion of triple exclusion as articulated by Zapletal et al. (2023). Zapletal et al.'s (2023) study sought to establish the impacts of the COVID-19 pandemic on older adults' use of digital technology in Ontario. The research concluded that, whilst before COVID-19 older adults faced double exclusion due to lack of digital literacy and social isolation, the pandemic fuelled digital divide, when most services became online. This led to the magnification of people to be increasingly digitally literate. The concept of triple exclusion therefore applies for older adults who are non-users of digital technology and are socialy isolated.

This highlights how seemingly neutral technological advancements can exacerbate existing inequalities. The social models of disability and vulnerability postulate that the interaction of living with disability and being exposed to other pre-existing inequalities (such as socio-economic disadvantages) exacerbate an individual's vulnerability and expose them to heightened risk of negative health outcomes (Parley, 2010; Oliver, 2013; Mladenov and Brennan, 2021; Wickenden, 2023). Therefore, living alone as an older minority ethnic person also has its own challenges in terms of getting support in accessing medical help. Elisheba (67), who also lives alone, described how her medical condition and post-COVID fatigue make accessing care especially difficult:

> *The long hours on hold on the telephone stress me a lot and I get exhausted, so I end up giving up seeking medical help. The quality of service by NHS has gone down and it is very frustrating and irritating. If I need to talk to my GP or even 111 emergency services, I must be able*

to stay on hold for one hour or more, which I quite often cannot because of my medical condition. I get more tired since I suffered from COVID.

Despite significant barriers, older minority ethnic individuals demonstrated notable resilience. They often navigated digital exclusion through a blend of intergenerational support and community networks. Rather than being passive, they employed creative coping strategies, such as seeking help from pharmacists or delaying appointments until their family could assist them. As highlighted earlier under section 7.2.2 (p.208), Wright (2022) conceptualises this as a form of “bounded resilience”, that is strength that is exercised in unequal social structure confines.

These glimpses of resilience, however constrained, highlight that older adults navigate their circumstances with resourcefulness, even as systemic barriers continue to undermine their wellbeing. Therefore, this research shows that being older, living with disability, living alone, and socio-demographic characteristics are determinant factors in health for the older minority ethnic people. Data from my study demonstrates the importance of carefully considering the older minority ethnic people’s perspectives regarding the use of digital technologies in health and social care. Socio-demographic factors such as digital illiteracy and digital exclusion must be considered to ensure meaningful engagement by the older minority ethnic people in health and social care. Therefore, despite the increasing availability and the advantage of digital technologies, their successful implementation in health and social care depends on the individuals’ accessibility and engagement with the technologies. Existing research has shown that when supported, older adults are able to engage with digital technologies. For example, Zhang et al.'s (2023) research established that during the COVID-19 pandemic older adults’ engagement with online technologies boosted their resilience and mitigated against loneliness. My study points towards the importance of further research which includes the specific needs and perspectives of older minority ethnic people on digital technology in health care, especially given the structural inequalities that these groups face in the health and social care system, and also given the fact that NHS is embracing digitalisation in all its services (NHS, 2025). Additionally, my study also points towards the importance of further research which includes the specific needs and perspectives of older minority ethnic people on AI, especially given the educational and age related differential in people's understanding of and willingness to see positive aspects to Artificial Intelligence (AI) (GOV.UK, 2024; Gilbert

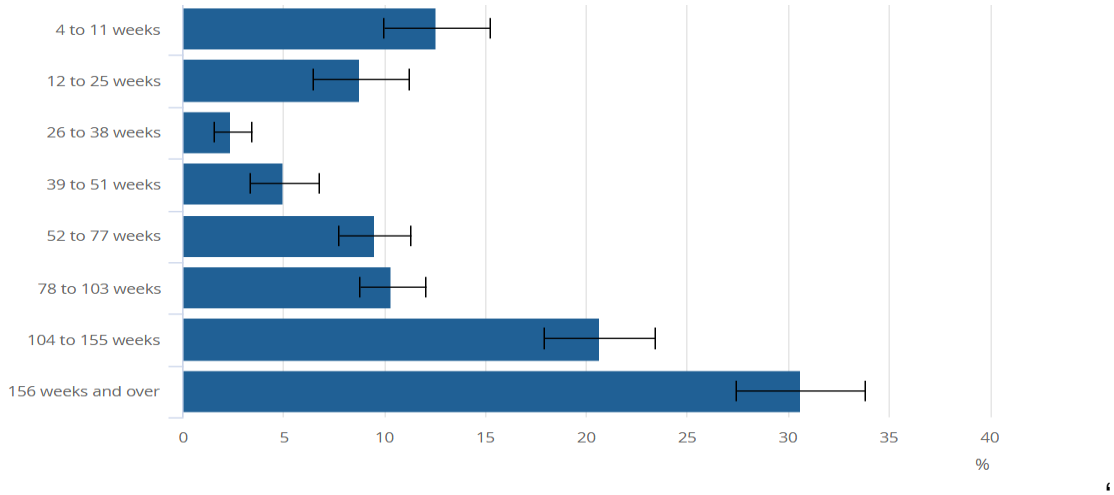
and Zandermann, 2025). People who are digitally excluded are far more likely to be underinformed and fearful of AI.

7.3.3 Lack of empowerment programmes for those with long COVID

Although the severity of the pandemic declined post vaccinations (WHO, 2021) minority ethnic groups continue to face disproportionate challenges due to persistent COVID-19 related deaths and long COVID illness. Long COVID phenomenon remains a relatively novel condition, complex and not yet fully understood in the medical and social disciplines. WHO defines long COVID as the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include ongoing fever, pain, fatigue, shortness of breath, loss of smell, and cognitive dysfunction and over 200 other symptoms, and have been reported as impacting on everyday functioning (WHO, 2021a; Walker et al. 2023).

NHS (2024) reports that in March 2024, 2 million adults and children experienced Long Covid (LC) (3.3% of the population), with 69% and 41% experiencing it for at least 1 and 2 years respectively and 19% reporting that LC limits their ability to undertake day to day activities. Figure 6 below shows the estimated percentage of people living in private households with self-reported long COVID by duration since first experiencing long COVID symptoms, England and Scotland, during a four-week period ending 7 March 2024 (NHS, 2024).

Figure 6: The majority of people self-reporting long COVID experienced symptoms



Source: ONS (2024)

Existing research shows inequalities with long COVID experiences. Long COVID is associated with higher prevalence associated with being female, of older or middle age, having a higher body mass index (BMI), belonging to a minority ethnic group, and greater deprivation (ONS, 2021a; Thompson et al. 2022; Mullard et al. 2023, 2024; Shabnam et al. 2023). Research also shows that minority ethnic people face intersectional disadvantages relating to long COVID. These are the long-term consequences of the pandemic and future health risks. Excess mortality in the UK remains high beyond the peaks of the 2020–2021 pandemic period, with older adults disproportionately affected (Alicandro et al. 2023; ONS, 2023). Nonetheless, evidence regarding the relationship between age and long COVID remains inconsistent and varied, with symptoms reported as including fatigue, anxiety, depression, functional impairment, dizziness and impact on one's well-being

The absence of long COVID information specifically tailored to racialised older adults is a form of epistemic exclusion, limiting their ability to understand and/or manage their condition. Participants in this study also highlighted how this knowledge gap left them uncertain about their health status. Kenzo, a community leader questioned the

government's failure to raise awareness of long COVID noting its visible impact in the community.

> *There has been a lot of complications amongst people who suffered COVID. Some of our older people have worsened heart problems, strokes, developed pneumonia, mobility issues, fatigue, breathing problems and auditory problems. These symptoms seem permanent now. But there is not much awareness about long COVID, which means as communities we must find strategies to support these people.*

This study highlights the critical role of health literacy as an empowerment tool, as argued by Sørensen et al. (2012). As highlighted by Kenzo, it is important that communities be empowered about long COVID. Research shows that some individuals in the UK continue to suffer from or die due to COVID-19, while others endure persistent symptoms associated with long COVID-19. This study points towards the need for research on the effect of long COVID for older adults from minority ethnic populations. This research adds to Mullard et al.'s research which explored the barriers and impacts of living with long COVID and Smyth et al.'s research on minority ethnic people's experiences with long COVID. Mullard et al.'s research established intersectional disadvantage with minority ethnic people with long COVID experiencing high levels of emotional perseverance, accompanied by feelings of invalidation and the misrecognition of symptoms (Mullard et al. 2024). On the other hand, Smyth et al.'s (2024) research on minority ethnic people's experiences with long COVID concluded that health-related stigma intersected with ethnicity, gender, body type, and mental health status and contributed to hesitancy to seek medical support. As argued by Mullard et al. (2024), the intersectional disadvantage experienced by those with long COVID from minoritised ethnic and faith backgrounds could be reduced by staff who understand and empathise with their cultural identities, the intersecting needs of individuals, their wider contexts and backgrounds, in order to enhance their quality of life and longer-term wellbeing. Given the inconclusive medical information regarding diagnosis and treatment of long COVID, it remains a challenge for doctors to explain medical conditions to patients showing symptoms relating to long COVID, whilst maintaining a trustful relationship (Atherton, Briggs and Chew-Graham, 2021).

7.4 Vulnerability and bounded resilience

In addition to earlier-discussed adversities, older minority ethnic people face crises such as racism, climate change, and the increased use of AI. Evidence from this study shows they have endured various adversities throughout their lives and continue to face new ones. Their lived experiences and religious beliefs shape how they perceive these challenges.

Participants reiterated concerns about multiple crises including racism, climate change, contemporary wars, increased AI use, and mental health challenges among younger relatives. In FGD2, these worries were expressed emotionally:

> *The climate issues really worry me. During summer, the heat is too much, and breathing becomes a struggle especially with my health condition. And then in winter, it gets very cold, and keeping warm is expensive because gas and electricity is now too expensive.* (P2).

> *It's hard to know what animal will come next in this life. Today, its AIDS, next its COVID, next it's a big war. And then, they create AI, which some of us do not understand at all.* (P3)

> *I worry a lot about my grandchildren because they are struggling to cope in this world. As for myself, I have already lived a long life, so if God decides to call me home today, its ok. The young ones are always talking about stress. They stress over even small things. We were not like that when we grew up. We matured faster than them. However, we don't give up on them. We continue to give them the earthily wisdom. Everyday after school, they come to the Mosque, where they are taught to recite the Quran, which guides them in life.* (P1)

> *No, I lead a very confident life. I take every day as it comes. As a spiritual person, I take confidence in God's future and planning.* (P5)

> *I do not specifically worry about the COVID pandemic anymore, but I worry about the Russian-Ukraine war and its eventual impact on the rest of the world. What if the rest of the world joins in the war? Russia is exercising its superior power, and I am worried about that.* (P4)

Some participants described encounters with racism and their reliance on religious faith to cope. For example, Lindani, a community leader of a women's coffee group,

narrated how some White residents in their neighbourhood confronted her group, demanding they stop their meetings.

> *We come from far and our group has survived tough times. In the past, we have been confronted by some White young adults who first blocked entrance to our meeting room, before directly confronting us. But we don't fight with the swords. Prayer is our weapon, and firm we stand.*

In facing adversities, participants draw strength from their religious beliefs, using prayer to find meaning and courage. Lindani illustrates how prayer buffers against racism, while Participant 1 in FGD2 highlights trust in the Quran to help younger people cope with stress, also using its daily teachings to impart earthly wisdom. Earlier chapters (4 and 5) similarly show that religion helps buffer racism, discrimination, and other social risks. Yet, as compelling as these expressions of faith and collective resilience are, the IRF framework urges us to ask why such supports are necessary. These coping strategies emerge from long-term institutional abandonment, not one-off solutions. Lindani and Participant 1 in FGD2 are, in this respect, connected knowers (Collins, 2000) in the fullest sense. The resilience strategies they describe are not generic coping mechanisms but situated knowledge, generated from within the very intersections of marginalisation that state institutions have failed to address. It is precisely this connected knowledge as accumulated across Chapters 4 to 7, that the IRF model developed in this thesis is built to make visible. Without systemic investment, resilience becomes a moral burden placed on those least equipped to bear it.

While religious beliefs bring emotional solace and community solidarity offers practical support, these resilience strategies are often forged out of necessity, shaped by a history of structural exclusion and ongoing marginalisation. These strategies should not be misconstrued as evidence of community strength that negates the need for systemic reform; rather, they are adaptive responses to structural injustice. As highlighted earlier, contemporary societies are characterised by crises, which expose different groups to different modes of risks and vulnerabilities. In the UK, risks are unequally distributed between people because of inequalities based on various factors including class, race, disability, gender, and ethnicity (Olofsson et al. 2014; Hankivsky and Kapilashrami, 2020; UCL Institute of Health Equity, 2024). Resilience is shaped

by cultural and historical contexts and can manifest both individually and collectively; it varies across different social groups (Wright, 2022). It is thus important that resilience be understood in its contextual, subjective and constructivist embedding (Siller and Aydin, 2022; Hutcheona and Lashewicz, 2014). Baiasi (2020) argues that one's previous lived experience and encounter with resilience can build strength when new adversities emerge. Baiasi (2020) echoes Wilding's (2011, p. 27) metaphor of resilience as a muscle that strengthens through repeated use. On the other hand, Wright (2022) holds the view that resilience can diminish, be undermined or be weakened, for example when adversity and vulnerabilities repeatedly occur or through lack of support for the people experiencing adversities. Wright (2022) and Baiasi (2020) present arguments that align with the UK Covid-19 Inquiry (2024) Module 1 report, which notes that long-term risks, unlike acute risks, gradually undermine resilience and require special attention. Long-term risks disproportionately affect vulnerable groups (including older people) and contribute to persistent vulnerability.

The UK Covid-19 Inquiry (2025) also heard reports from groups including The Patients Association (2024) who are seeking to ensure that lessons are learned to build a more resilient system that does not disregard the rights and needs of older and vulnerable people during future pandemics. Additionally, the Inquiry has also concluded that resilience depends on having a healthy, robust population; therefore, vulnerable groups require targeted support to strengthen overall resilience. Understanding how repeated adversities affect older people from minority ethnic backgrounds is crucial for safeguarding their wellbeing, especially since there are multiple crises simultaneously impacting on them.

7.5. Religion as a buffer in the face of adversities

Older minority ethnic participants described managing everyday struggles like the cost-of-living crisis, difficulties accessing NHS services and hostility as migrants-for example, the incident Lindani recounted where residents demanded that their networking group ceases activities.

Participants reiterated (as shown in Chapter 5, p.163-167) that religion remains central in their lives and that their faith strengthens during crises. Across Christianity, Islam,

and Hinduism, they turn to God and religion as vital coping mechanisms amid the polycrisis. The interchange with Delilah (76) airs her views.

> *Worrying about the current problems we are facing in today's world is one thing. But as human beings, what do we get from worrying? We fellowship and stand together in prayer. God loves us and He will see us through, and we will conquer, just like we survived COVID.*

Delilah's words reflect how strong faith fosters belonging, hope, and confidence a view shared by other participants. As discussed earlier (Chapter 5, p.159-169), their religious beliefs across Christianity, Islam, and Hinduism instil hope by framing current hardships as temporary, much like the transient nature of suffering symbolised in religious narratives. Religion therefore remains an important coping resource in participants' daily lives. As discussed in previous chapters, participants described surviving difficult past experiences that had fostered resilience, determination, and strength. For example, in Chapter 4 (p.130), participant 3 FGD5 recounted hardships such as '*hunger and illnesses in Africa, including HIV/AIDS and Ebola'.* After migrating to the UK, he also faced demanding employment conditions and '*worked long hours in the industries'*. These experiences appeared to strengthen participants' ability to cope with adversity. From the perspective of optimism bias, their lifelong exposure to hardship may have contributed to confidence in their ability to withstand the challenges of the COVID-19 pandemic. As participant 3 stated, *'...So COVID can't beat us!'* (Chapter 4, p. 130).

It is important to highlight literature which highlights that resilience can be learnt and strengthened (Baiasi, 2020; Wilding, 2011). It is also important to note that this research echoes Kim, Park and Lee's (2023) research which links successful ageing in older adults with resilience as a protective factor, thus emphasising its significance in thus demographic. When confronted with adversities, older adults build resilience as a coping strategy. MacLeod et al. (2016) present resilience and community participation as related with community involvement being associated with high resilience levels amongst older adults. In this research (Chapter 6), research participants spoke of missing their networking community groups during the government lockdowns, and how as communities they prayed for each other during illness with COVID.

In the UK, there is a growing body of research focusing on resilience, ageing and mental health (Netuveli et al. 2008; Zhang et al. 2023). However, while there is a plethora of research on resilience and the capacity to cope, most existing research considers adversities in isolation and not simultaneously. Based on arguments by scholars such as Crenshaw (1989), Collins (2000) and (Olofsson et al. 2014) of the IRS, who advocate for analysis of individuals' situations in the context of simultaneous intersecting of identities, not considering resilience in the context of various identities simultaneously, would therefore be problematic. Thus, consideration of the older minority ethnic people's resilience to the intersecting multiple crises is important. This study therefore points towards the need for further research to establish the resilience of marginalised individuals and populations during polycrisis, while taking into consideration the various identities (such as age, ethnicity, disability, class, gender and comorbidities).

Borrowing from scholars such as (UCL Institute of Health Equity, 2024; Wright (2022) and Mayrhofer (2025) who adopt critical approaches to vulnerability and argue from the perspective that vulnerability is not a pathology, personal limitation or deficit, the older minority ethnic people require support to cope with the daily challenges because their vulnerability which is primarily linked to structural or situational issues, is socially constructed and produced. The older minority ethnic people's vulnerability with the polycrisis including the COVID pandemic, the cost-of-living crisis, challenges with AI and digitalisation of most services, climate issues, contemporary wars, and mental health challenges amongst the young people also confirms research which reveals that vulnerability is not a fixed but dynamic concept. For example, most participants in Haggar et al.'s (2023) research on the cost-of-living crisis in the UK cited factors such as Brexit, the government's underinvestment in social housing and austerity policy as contributing factors to rising costs, pushing up the price of food and other goods by disrupting the labour market and global supply. Haggar et al.'s (2023) research established that the participants' vulnerability to the current cost-of-living crisis is linked to UK politics and policy decisions relating to responsibilisation as highlighted earlier in Chapter 7.1 and the welfare crisis.

7.6 Community networking and belonging

This study also reveals that the participants' groups are playing an important role in the older minority ethnic people's lives, through providing a sense of community social cohesion especially during times of crises. The participants' networking groups are key to maintaining relationships with friends and other members. Furthermore, it is through networking groups that they get support in their day-to-day challenges, and get a sense of belonging, hope, and courage. For example, through running the food banks to cater for the members' growing need for food, the groups are providing a strong sense of ethnic connection. This is consistent with scholarship which explains that a sense of belonging to a community can act as a buffer against adversities and increase resilience (Abrams et al. 2021). The participants solidarity through for example worshiping God together, and doing other various networking activities together confirm Siller and Aydin's (2022) position that connectedness, social support and collective action stimulate efficacy and resilience. According to Abrams et al. (2021) during crises, groups unite in spirit and cooperation, which is what the minority ethnic people are doing. However, it is important to reiterate that in the case of the participants in this study, the spirit of solidarity has always been thriving in line with their collectivist cultures (Joshanloo, Van De Vliert and Jose, 2021). In the light of increased adversities, their solidarity as minority ethnic communities strengthens, which is important for their wellbeing. Research has shown that increased social cohesion is associated with increased subjective wellbeing (Delhey and Dragolov, 2016). These coping strategies depict both the agency of the older minority ethnic individual in responding to adversity, but also the limits of collective and individual coping in the face of the absence of structural support. Resilience therefore must be envisioned not as an alternative to systemic change, but as a supplement to it in need of being underpinned by policy change.

Conclusion

The post-COVID world has highlighted how older minority ethnic adults in the UK are experiencing a polycrisis in the form of overlapping and mutually reinforcing challenges such as fears of global conflicts, persistent health inequalities and digital exclusion, socio-economic instability, and the growing impacts of climate change.

These are shaped by race, ethnicity, age, socio-economic status, and migration histories.

These crises also intersect with pre-existing structural problems, including austerity and sustained pressures on health and social care services, and exacerbate existing vulnerabilities. For example, the chapter has shown how economic insecurity experienced by older minority ethnic adults cannot be attributed solely to rising prices. It is also rooted in long-standing lived experiences, such as employment in low-paid and insecure work. Similarly, language barriers, digital exclusion, and limited health literacy do not operate in isolation but compound one another within the polycrisis, significantly restricting the older minority ethnic people's access to health and social care services. Long COVID emerges as a new health risk which is layered onto existing inequalities. Overall, the pandemic acted as a catalyst that intensified and deepened health inequalities among the older people.

The chapter also demonstrated how polycrisis reshapes both the meaning and the limits of resilience. Community networks, faith-based organisations, and religious practices provide essential support, enabling individuals to cope with overlapping crises through faith, solidarity, and resourcefulness. For older minority ethnic communities, faith and community groups function as social interaction platforms and as safeguards against systemic disadvantage. These groups offer vital spaces for connection, meaning, and mutual support. However, such coping strategies cannot replace the need for systemic support.

During the COVID-19 pandemic, social distancing measures and the shift to online provision inevitably constrained the capacity of community groups to offer support. The IRF highlights that this form of resilience is therefore inherently bounded, as it is repeatedly mobilised to compensate for systemic failures. Structural neglect, language barriers, and persistent gaps in healthcare and social services underscore the urgent need for policies that address these layered vulnerabilities that older minority ethnic people experience. The chapter also reveals the coexistence of the older people's agency and adaptability alongside enduring structural disadvantage, illustrating how narratives of resilience can obscure or mask systemic failure.

True resilience requires more than individual or community effort. It depends on equitable, culturally responsive interventions that ensure meaningful access to

healthcare, social care, and economic security. Policymakers and wider society must recognise and respond to the older minority ethnic people's lived realities, with a focus on co-creating solutions that support their wellbeing. Evidence from Finland demonstrates the potential of such approaches, where people with lived experience of homelessness successfully contributed to service design, resulting in housing programmes that were more accessible and effective (Meriluoto, 2018). Without a similar commitment, the most marginalised members of society including older minority ethnic people will continue to bear the burden of an increasingly complex and uncertain world.

CHAPTER 8: CONCLUSION AND RECOMMENDATIONS

Introduction

This thesis set out to understand how older minority ethnic people in the UK experienced the COVID-19 pandemic and its aftermath, and how these experiences were shaped by intersecting identities, structural inequalities, and overlapping crises. Rather than treating the pandemic as a discrete health event, the study approached COVID-19 as a moment that intensified and exposed pre-existing social risks, vulnerabilities, and inequalities. This concluding chapter consolidates the epistemological, theoretical, and empirical contributions of the thesis, reflects on its implications for policy and practice, and outlines directions for future research. Crucially, this chapter does not simply restate findings. Instead, it draws together the analytical strands of the thesis to demonstrate how centring the lived experiences of older minority ethnic people reconfigure dominant understandings of risk, resilience, and ageing in times of crisis.

Importantly, this thesis does not interpret contemporary experiences of risk and vulnerability as the outcome of a universal transition into a distinct historical stage. Rather, consistent with Povinelli's (2016) critique of linear accounts of social development, it recognises that experiences of crisis are shaped by historically embedded relations of power, colonial legacies, and institutional practices that continue to influence whose knowledge, suffering, and resilience are recognised.

A central and original contribution of this thesis is the application of Olofsson et al.'s (2014) Intersectional Risk Theory (IRT) to the experiences of older minority ethnic people navigating a major public health crisis. Olofsson et al. developed the IRT as a theoretical framework for understanding how risk and social inequality mutually constitute one another, yet their framework had not previously been applied to this population or this context. This study extends IRT into new empirical and theoretical terrain, generating what is termed here the Intersectional Risk Framework (IRF): a multi-dimensional analytical tool that integrates IRT with Everett's (2023) Intersectional Grief Framework (IGF). It foregrounds the epistemological contribution of the Connected Knower (Collins, 2000), and embeds Trnka and Trundle's (2014)

concept of competing responsibilities to explain why resilience in structurally marginalised communities is necessarily bounded rather than freely self-generating.

Ultimately, the journey of this research should be considered as an attempt to navigate the complex landscape where age, ethnicity, and structural inequality converged during one of the most significant crises of our time. As I bring this thesis to a close, it is clear that the COVID-19 pandemic was not a singular health event but a profound amplifier of the pre-existing social risks that have long marginalised older minority ethnic populations in the United Kingdom. By applying the Intersectional Risk Theory (IRT) lens, I have sought to demonstrate how the intersections of age, race, ethnicity, gender, class, and disability co-constituted a unique landscape of both suffering and resistance. Consequently, the narratives shared by the participants in the Thames Valley area provide a rigorous evidence base for understanding that their lived experiences were not characterised by passive victimhood. Rather, their lived experiences were marked by active sensemaking, a rational negotiation with systems that often failed to recognise their humanity, and a collective resilience rooted in deep-seated cultural and spiritual values. In this final chapter, as I synthesise the findings across the preceding chapters I argue that health equity in a post-pandemic world requires a fundamental restructuring of institutional trust. As a result, this synthesis moves beyond deficit-based models of “hard to reach” communities to call for a radical recognition of what I term the “connected knower” a term borrowed from Collins (2000), (an individual whose expertise is derived from the very intersections of marginalisation that the state has historically ignored) as articulated in Chapter 3 i.

8.1 Epistemological positioning and methodological reflections

This study’s methodological choices were guided by a commitment to capturing the nuance of lived experience while maintaining analytical rigour. Several qualitative approaches were considered but deemed unsuitable for this population. Interpretative Phenomenological Analysis (IPA), though well suited to emotionally complex topics, prioritises small, homogeneous samples and was therefore incompatible with this study’s large, diverse group of participants. The use of case study, while offering depth through a holistic lens, was limited by concerns about generalisability and structural rigour. Grounded Theory, which develops theory from emerging data, was also deemed inappropriate because this study was firmly grounded in existing

theoretical paradigms from the outset, specifically the Intersectional Risk Framework. My primary focus remained on giving a voice to the lived experiences of older minority ethnic people during COVID-19 and its aftermath, rather than generating a new theory from the ground up. Finally, although ethnography could have provided deep and rich insight, COVID-19 restrictions in the UK made prolonged in-person engagement and social immersion impractical.

By choosing an interpretivist-constructivist paradigm, I have been able to centre the "connected knower." Those situated at the intersection of multiple oppressions, like the participants in this study, offer critical insight into their lived realities often missed by "outsider" researchers. I have utilised Harding's (1986) concept of "strong objectivity" to explain that the perspectives of marginalised groups can facilitate more objective accounts of the social world because they help expose bias and reduce power imbalances in the research process. This situated knowledge provides a more robust and ethically grounded understanding of the pandemic's impact, in the process validating the expertise of those who have "come from far" to tell their stories. In doing so, this thesis challenges the Eurocentric hegemony of knowledge production by arguing that the "connected knower" understands knowledge through relationships and community, rather than the detached rationality often associated with traditional medical and sociological paradigms.

8.2 Intersectional risk and the epistemic foundations of mistrust

One of the most salient findings of this research challenges the prevailing public health narrative that attributes vaccine hesitancy primarily to "misinformation" or "conspiracy thinking." My analysis suggests a far more sophisticated epistemology of mistrust, one that is rooted in a lifetime of navigating structural violence. For example, participants like Abdul and Farai, skepticism toward government messaging was not an indicator of irrationality but a protective strategy developed over a life course marked by discrimination. This is what can be termed as 'situated rationality"; when participants spoke of their fear of being used as 'guinea pigs,' they were not reacting to rumors in a vacuum, rather they were referencing a historical timeline of unethical medical surveillance and neglect. This study integrates the feminist concept of situated knowledge (Collins, 2000), as discussed in Chapter 3.1, with Vandrevala et al.'s (2023) sensemaking paradigm, as outlined in Chapter 4.3, to conceptualise the older people's

choices and behaviours during the pandemic as ‘situated rationality’, emerging from their lived experiences, identities, and historical contexts.

The collective memory of events like the 1969 chapati research scandal serves as a persistent anchor for current risk assessments. This “weathering” effect of chronic racism means that for many older minority ethnic people, the state is perceived as a source of risk rather than a provider of safety. Through the “sensemaking paradigm,” participants used metaphors of tracking and depopulation to articulate a visceral sense of being devalued by the British state, a perception reinforced by the Windrush scandal and the Grenfell Tower fire I discussed earlier. For the study participants, these events unequivocally demonstrated that their lives were often treated as disposable, a reality further confirmed when COVID-19 mortality rates for Black and Asian groups were revealed to be significantly higher than for their White counterparts.

However, the research also highlights that while institutional trust was severely compromised, relational or “facework trust” remained a vital resource. The success of mosque-based vaccination clinics and the influence of community leaders in interpreting scientific guidelines demonstrate the power of “value similarity” (Siegrist, 2021) (see Chapter 1.2.7). I found that risk perception is essentially a collective process within minority ethnic households. Intergenerational dialogue with “proximate experts” such as children and grandchildren working within the NHS served as the primary mechanism for assessing state credibility. This highlights a major theoretical contribution of the thesis: namely that trust is not a static attribute but a relational achievement mediated through shared identity and values. The “Connected Knower” in this context is not just an individual, but a node in a network of trusted relationships that facilitate or hinder health engagement.

8.3 Intersectional grief and challenges faced by the Fourth Age

My investigation into dying, death, bereavement and grief reveals that the pandemic reconfigured the “fourth age” into a space of intense social and spiritual disenfranchisement for minority ethnic people. The evidence indicates that the universal trauma of loss was uniquely aggravated by the intersection of ageism and racism. Participants expressed a profound sense of “death-related ageism,” as they felt that their lives were viewed as less valuable than those of younger populations by

both the media and the state. Participants used metaphors of tracking and depopulation to express feeling devalued by the British state, a perception reinforced by the Windrush scandal and Grenfell Tower fire. This sense of them being treated as disposable was further confirmed by COVID-19 mortality rates, which were significantly higher for Black and Asian groups than for White counterparts.

This perception led to a “lonely death” fear, causing many to delay seeking hospital treatment even when critically ill. The enforcement of infection control measures resulted in “disenfranchised grief,” since mourning in these communities is not an individual psychological task but a communal and ritualised obligation. The prohibition of practices such as ritual body washing, the inability to host large communal gatherings, and the denial of viewing the body created a rupture in the social order.

Participants such as Gabriel and Mukhulis spoke of the lasting emotional burden caused by “distanced funerals.” For them, the burial place is essential because it is where the “umbilical cord” lies, referencing a connection to ancestors and ancestral soil that cremation or clinical disposal violently severs. Yet, despite this disenfranchisement, religious faith served as a profound buffer. In alignment with Terror Management Theory (TMT), participants utilised their worldviews to manage the terror of mortality. For these individuals, a “good death” was not defined by the Western medical focus on pain management but by ritual integrity and the recitation of holy texts. This highlights the urgent need for end-of-life care that transcends the biomedical and embraces the spiritual and cultural needs of a diverse population, ensuring that the “bird being released from a cage” is met with dignity and justice.

8.4 The reserve workforce and the invisible infrastructure of care

A significant empirical contribution of this thesis is the identification of older minority ethnic women as a “reserve yet hidden workforce” that sustained the UK’s front line economy during the pandemic. By assuming intensive childcare and domestic responsibilities, these women enabled their adult children to continue working as key workers in health, social care, and logistics. This informal care was motivated by cultural values of altruism and the communal philosophy of interconnectedness, even though it extracted a significant physical and emotional toll on the community.

The role of care giving was found to be highly gendered. While men often provided practical external support, women like Nadia and Fatima bore the burden of personal care for disabled relatives and active grandchildren, often exacerbating their own chronic conditions. The “weathering” of the caregiver became apparent as social identities of age, gender, and ethnicity intersected to accelerate physical decline. Furthermore, the rapid digitalisation of services inadvertently created a “triple exclusion” for those living with disabilities or alone. For participants like Senzia, who is blind, the shift to “digital-by-default” care was “ghostophobic,” as she was unable to access her GP or manage her appointments without help. This digital ageism, combined with language barriers, has resulted in a loss of the “third age”, the period of life characterised by fulfillment and social networking. The closure of community centers was catastrophic, as these “lifelines” provided the only space for social interaction outside the family home.

8.5 Navigating the polycrisis and the limits of bounded resilience

In the UK, there is a growing body of research focusing on resilience, ageing, and mental health. However, while there is a plethora of research on resilience and the capacity to cope, most existing research considers adversities in isolation and not simultaneously. Based on the arguments of scholars such as Crenshaw, Collins, and Olofsson, who advocate for analysis of situations in the context of simultaneous intersecting identities, I argue that failing to consider resilience in the context of various identities simultaneously is deeply problematic. My research indicates that older minority ethnic people do not experience crises as discrete events but navigate a state of “polycrisis” where the cost-of-living crisis, digital exclusion, and health disparities converge and mutually amplify one another.

This study points towards the need for further research to establish the resilience of marginalised populations during polycrisis, while taking into consideration the various identities such as age, ethnicity, disability, class, gender, and comorbidities. While participants displayed remarkable resilience through faith and community networking, I must emphasise that this is “bounded resilience”. This is so since this strength is exercised within the confines of an unequal social structure and cannot realistically

compensate for institutional abandonment. The reliance on community-led food banks represents a form of “responsibilisation”, where the state expects the marginalised to be experts in their own survival while simultaneously denying them the resources to do so. This dynamic is precisely what Trnka and Trundle (2014) identify as the tension between neoliberal responsibilisation and the competing moral frameworks of care and social contract obligation that actually shape people’s lives. Communities of older minority ethnic people in this study simultaneously bore individualised demands for self-management and deep relational obligations of their faith while the state withdrew the structural supports that would make either form of responsibility achievable. The systematic defunding of community groups by local authorities has undermined the primary mechanism through which older minority ethnic people maintain their wellbeing. Resilience, therefore, must be envisioned not as an individualised substitute for systemic change, but as a supplement to it that must be underpinned by radical policy reform.

8.6 Substantive contributions to knowledge

This thesis makes a substantive contribution to the sociology of ageing and health by centring the marginalised standpoint in crisis research.

8.6.1 Methodological contributions: Safe spaces and strong objectivity

The study provides a methodological blueprint for engaging “hard to reach” communities through “strong objectivity.” By operationalising the concept of “safe spaces”, I have demonstrated how reflexive positionality enables the elicitation of narratives often silenced by Eurocentric research paradigms. My identity as an “insider” facilitated a depth of disclosure regarding legal status and mistrust that could be less readily accessible to an outsider. Furthermore, I have modeled an “ethics of care” in qualitative inquiry that prioritises the emotional wellbeing of participants over data extraction, respecting the dignity of the “connected knower”.

8.6.2 Theoretical contributions: Integrating Intersectional Risk and Grief

The primary theoretical contribution of this thesis is the extension of Intersectional Risk Theory (IRT) into an Intersectional Risk Framework (IRF) that explains how older

minority ethnic people negotiate risk during a public health emergency and its aftermath. While this framework draws on theories of risk and individualisation associated with late modernity (Beck, 1992; Giddens, 1991), it also acknowledges Povinelli's (2016) critique that contemporary social conditions cannot be understood as a universal historical stage replacing earlier forms of social life. Instead, the IRF demonstrates how risk experiences are produced through the interaction between contemporary forms of governance and historically rooted inequalities.

Drawing on my empirical findings, I argue that the framework extends IRT in three distinct ways: by demonstrating the explanatory value of the Connected Knower (Collins, 2000) as an epistemological mechanism; by drawing on Competing Responsibilities (Trnka and Trundle, 2014) as a structural explanation of decision-making; and by integrating the Intersectional Grief Framework (IGF) to show how intersecting systems of power shape pandemic risk, resilience, and end-of-life experiences.

The development of this multi-dimensional Intersectional Risk Framework (IRF) moves beyond additive models of inequality by demonstrating that risk, identity, and structural power are mutually constitutive. Rather than treating intersecting identities as fixed categories of vulnerability, my research shows how they actively shape the production, interpretation, and negotiation of risk across the life course and at the end of life. Furthermore, by integrating IRT with the Intersectional Grief Framework (IGF), I offer an analytical framework for examining how structural power relations influence experiences of both life and death. In doing so, my research advances scholarship on responsibilisation by theorising resilience as an adaptive response to institutional abandonment rather than as a substitute for state support, thereby extending how IRT explains decision-making under conditions of structural inequality.

I must be explicit about how this study extends the original IRT on which the IRF builds. Olofsson et al. (2014) conceptualised the mutual constitution of risk and social inequalities across intersecting identities but did not examine older populations, racialised minority ethnic communities, or the complexities of crisis navigation within a polycrisis environment. This is so, furthermore, because the original framework did not fully account for the role of community-based knowledge, competing relational obligations, or the ways in which intersecting inequalities shape experiences of dying

and bereavement during public health emergencies. My empirical findings demonstrate that these dimensions are essential for understanding how risk is perceived, negotiated, and acted upon by older minority ethnic people.

Accordingly, my research extends the original framework in three analytically distinct ways. First, I demonstrate the explanatory value of the Connected Knower (Collins, 2000) as an epistemological complement to IRT. As I have shown across Chapters 4 to 7, the risk knowledge of older minority ethnic people grounded in lived experiences of structural inequality, cultural obligation, and intergenerational trust networks constitutes a legitimate and influential form of expertise that shaped pandemic decision-making. Pammy and her fellow Muslim participants, for example, did not arrive at their decisions about the vaccine through ignorance of medical guidance; they arrived at them through a sophisticated religious epistemology that public health communication consistently failed to recognise. This extends the original framework by recognising community-based knowledge as a central, not peripheral, component of risk negotiation.

Second, I draw on Trnka and Trundle's (2014) concept of Competing Responsibilities to explain the structural conditions within which bounded resilience emerges. Rather than interpreting participants' actions as failures of individual responsibility or self-management, my findings demonstrate that they were navigating often irresolvable tensions between neoliberal expectations of personal responsibility, deep obligations of relational care, and the consequences of constrained or inadequate state support. This is so since resilience, as my data shows, is not a freely available personal resource but a structurally conditioned process whose limits are set by institutional abandonment, not individual character.

Third, by integrating the Intersectional Grief Framework (IGF) with the extended IRF, my research expands the analytical reach of IRT beyond risk-in-life to encompass risk-in-death. The findings show that the same intersecting systems of inequality that shaped exposure to pandemic risks also determined whose grief was publicly recognised, whose cultural and religious mourning practices were protected, and whose dying occurred with dignity and social accompaniment. Furthermore, as I evidenced in Chapter 5, the prohibition of ritual body washing and communal gathering

did not fall equally on all; it fell hardest on those whose grief was never designed to be absorbed by a biomedical system. My research therefore demonstrates that pandemic risk cannot be fully understood without considering the intersecting inequalities that shape experiences across the continuum from living through crisis to dying within it.

Taken together, these theoretical developments extend the explanatory scope of IRT and establish the IRF as an integrated analytical framework for understanding how intersecting identities, structural inequalities, community knowledge, and competing responsibilities shape risk, resilience, and end-of-life experiences among marginalised populations during public health crises. In doing so, the IRF contributes to debates on risk by demonstrating that marginalised communities do not simply encounter contemporary risks as isolated individuals. Their interpretations and responses are shaped through historical experiences, collective memories, institutional relationships, and unequal social positions. This reflects Povinelli's (2016) argument that contemporary social relations remain embedded within overlapping histories and power structures rather than representing a complete break from earlier forms of inequality.

8.6.3 Empirical findings: Challenging the deficit narrative

Empirically, the study provides original data on the specific health needs and coping strategies of older minority ethnic people in the Thames Valley area. It identifies the rational basis for vaccine hesitancy, the critical role of grandmothers in the frontline economy, the long-term impact of disrupted funerary rituals on mental health, and the specific mechanics of "triple exclusion" for those with sensory impairments. These findings challenge the deficit-based models that frame these communities as "hard to reach" or "non-compliant."

8.7 Recommendations for policy and practice

The findings of this study necessitate radical change as the UK government must adopt an intersectional approach to policy that moves away from majoritarian, single-axis frameworks. Specifically, the NHS 10-Year Health Plan must include a statutory guarantee for face-to-face appointments for individuals over 75 and those with limited English proficiency to end the "digital-by-default" exclusion that renders services "ghostophobic" for the most vulnerable. Furthermore, Neighbourhood Health Centres

must be established as “one-stop shops” for culturally competent care, open at least 12 hours a day, 6 days a week, starting in areas where healthy life expectancy is lowest.

In addition, there is need to prioritise the recognition and financial support of informal carers within the National Health Service. This includes acknowledging the reproductive labor of older minority ethnic grandmothers and ensuring funding is distributed fairly to avoid the current set up of care that currently leaves many without support. This should be implemented as a national assessment system with standardised grading to ensure consistent support across all local authorities. Simultaneously, local authorities must be mandated to provide ring-fenced, long-term funding for minority ethnic networking groups and integrating them as primary sites for social prescribing and preventative care. Finally, the UK Commission on Bereavement should implement “Intersectional Grief Literacies” training for support workers to address the complexities of disenfranchised grief and ritual disruption, ensuring specific outreach to bereaved older men who are at high risk of social isolation.

8.8 Limitations of the study

Some participants faced language barriers and relied on their children for support with communication during interviews. In some cases, older participants requested the presence of their children, as this made them feel more comfortable and safer. While this facilitated participation, reliance on family members as informal interpreters may have influenced how some experiences were expressed. Family members are often used as interpreters in healthcare to address language barriers, but this practice is criticised due to potential bias and reluctance to convey sensitive information (Hadziabdic et al. 2014). In addition, the study was unable to include participants in the ‘old-old’ category (advanced old age) due to physical immobility and ill health, which rendered them home-bound. As a result, the study could not fully explore the intersection of advanced age, ethnicity, and comorbidities.

8.9 Final word: Toward an ethics of recognition

In bringing this research to a close, I am reminded of the legacy of my late father, Michael Makande, and the resilient voices of the participants in the Thames Valley area. Their narratives offer a profound vision of a more compassionate and collective future. This is so since true resilience is not found in individual endurance but in the "muscle" of a society that recognises the dignity of all its members. This recognition also highlights the importance of moving beyond understandings of inequality as the result of individual circumstances alone. As Povinelli (2016) argues, contemporary social worlds remain shaped by historically produced relations of power that influence whose lives, knowledge, and experiences are valued. An ethics of recognition therefore requires not only inclusion within existing systems but critical attention to the structures that have historically determined who is heard, protected, and cared for.

As the UK moves toward the implementation of the National Health Service and the 10-Year Health Plan, the voices of older minority ethnic people must be central to the co-creation of solutions. To ignore their expertise is to repeat the failures of 2020. The ultimate call of this thesis is for an "ethics of recognition", a society where the "bird being released from a cage" is met with justice, care, and the promise that they will never again have to grieve in silence. Only through collective structural change can we ensure health equity for those who have "come from far".

8.10 Dissemination and ethical closure

Consistent with the study's epistemological commitments, dissemination of findings has been approached as an ethical responsibility rather than an academic afterthought. Ongoing engagement with participants and community organisations ensures that findings are shared, validated, and situated within the communities that produced them. This approach reinforces the study's commitment to respectful knowledge production and challenges extractive research practices.

I am in contact with the participants who took part in this research. Plans are in place that I go back to the community centres to meet the participants who took part in this research and disseminate the data findings. Additionally, It is planned that findings will

be submitted for publication in and peer reviewed journals as well as book chapters. Knowledge has already been disseminated at the following conferences:

- UCL Qualitative Health Research Network Conference (02/2024), Paper presented was: *"Centring and engaging marginalised communities in qualitative research in times of crisis."*
- 20TH Biennial Conference of the European Society for health and medical sociology (ESHMS), Intersectionality and Inclusion in Health, Antwerp (3-5 July 2024), Paper presented was: *"I felt we were being used like guinea pigs": COVID-19 vaccine hesitancy among older minority ethnic people in the United Kingdom"*
- Death and Ageing. British Sociological Association's Death, Dying and Bereavement. Annual Symposium. University of Liverpool (12 December 2024), Paper presented was: *"Dying, death and bereavement during the COVID-19 pandemic and its aftermath: Reflections from older minority ethnic people in the UK"*
- Inequalities and Health Summit: Call for Action Liverpool Hope University (12 October 2024), Paper presented was: "*The role of trust in the experiences of UK older minority ethnic people during COVID-19"*
- The international 'Social Work and Society' Academy (TISSA), Online and run by University of Ghent, Belgium, Paper presented was: "*Intersectionality and older people: Understanding the complex needs of marginalised communities in qualitative research"*
- The BNU Research Conference 2025: Empowering Inclusive Research. Buckinghamshire New University, (25 June, 2025), Paper presented was: "*Dissecting the anatomy of social risk: disentangling the health inequalities in the UK through the Intersectional Risk Lens"*

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APPENDICES

BUCKINGHAMSHIRE NEW UNIVERSITY

APPENDIX A

Demographics Questionnaire

Name	**----------**
Contact details	**----------**
Age	**----------**
Gender	□ Male □ Female □ Other Specify ----------
What is your ethnicity?	□ Black African □ Black Caribbean □ South Asian □ East Asian If other, specify**: -------**
Were you living in the United Kingdom at the start of COVID-19 in 2019 and during the pandemic?	□ Yes □ No
Where were you living during the pandemic? **Which town were you living?**	**----------**
Were you living alone or with family? **-If you were living with family, how many were you in the household?**	**----------** **---------**
What is your highest educational qualification?	----------
Were you working (formally or informally)? **-If yes, what job did you occupy?**	□ Yes □ No **----------**
What was your household's average income per year in 2019?	□ Below £12 000 □ Between £12 000 and £15 000 □ Between £15 000 and £20 000 □ Between £20 000 and £30 000 □ Above £30 000
What was your household's average income per year in 2020?	□ Below £12 000 □ Between £12 000 and £15 000 □ Between £15 000 and £20 000 □ Between £20 000 and £30 000 □ Above £30 000

What was your household's average income per year in 2021?	□ Below £12 000 □ Between £12 000 and £15 000 □ Between £15 000 and £20 000 □ Between £20 000 and £30 000 □ Above £30 000
Have you been diagnosed with any of the following health conditions: **Tick all that apply.**	□ High Blood Pressure □ Cancer ☐ Obesity ☐ Diabetes ☐ Anxiety ☐ Depression □ Other ------- (specify)

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APPENDIX B

Interview Grid for community service providers

Aim	Questions and probes
Context and background	Can you give a brief insight into your organisation's aims and objectives? What sort of activities do your members engage in? -Which areas do you cover and what is your target group? -Since when has your organisation been in operation?
Management	-How did the COVID-19 outbreak affect the running and management of activities of your community groups? -Did you increase, decrease or close services or did you change and adapt your services in line with the government guidelines? -Were you able to stay in contact with members? If yes, how? What were the challenges of staying in contact? -Could you please elaborate? -Did the community group's priorities change as a result of the pandemic? -If yes, in which way/s and how did you manage or how are you managing the changed priorities so as to achieve future goals?
Financial implications	What financial implications did the COVID-19 outbreak have on the community groups?
Support and intergroup solidarity	What practical and emotional challenges did your community group encounter as a result of the impact of COVID-19? -How did the COVID-19 outbreak affect the level of need within the community group you work with? -How did you respond to and cope with the challenges and pressing needs by the community group? -What forms of support could you continue to give? -Where group members able to support each other? If yes, how?

Re-engagement, recovery, empowerment and expectations	How did you respond to the pausing of face to face networking activities in the community as a result of the government lockdown and social distancing measures? -To what extent are your group members still impacted by the effects of COVID-19? How is the current attendance rate or engagement rate and what efforts are you making to encourage re-engagement? -Now that the government lockdown and social distancing measures have been removed, how are you managing the empowerment of the community groups in view of the impact that COVID-19 caused? -What support does your community group need for its recovery? -Do you foresee the revival of your group's engagements as before, prior to COVID-19? -In future, what support would you expect from policy makers and other institutions during a public health crisis to enable you to best attain your clientele's desired outcomes or more effective interventions?

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APPENDIX C

Interview Grid for Focus Groups

<u>Preamble:</u> I will start the interview by showing the participants some newspaper cuttings with headlines and pictures about COVID-19 to remind them. I will also show them a short video on COVID-19.

Aim	Questions and probes
Impact in Neighbourhood	1. What is the impact of COVID-19 pandemic on your neighbourhood? • Has anything changed in your neighbourhood?
Engagements and inter-group solidarity	2. How has the COVID-19 pandemic affected your social networking and interacting activities in your community groups?
Response to changes and adjustments	3. In view of the government lockdown and social distancing measures, what was the impact of the disengagements on your community groups? • What were the main changes in your daily living? • How did you cope with the disengagement of face to face social networking activities of your group in the community? - How have you managed re-engagement? Do you feel safe ? 4. How did you feel when everything went online? • How did you manage with the shopping? • Did you move onto online shopping? • Did you access the services you needed such as General Practitioner, Pharmacy...? • How did you support each other? 5. What about religious and spiritual activities? • How did you feel about not being able to attend these activities? • Were you able to receive support from elsewhere? • How did your religious and spiritual groups respond to the changed reality and challenges brought about by COVID-19 pandemic in your community groups?

Feelings (fears, uncertainties, worries, hopes) and resilience	6. How would you describe your feelings during the peak of COVID-19? • How did you manage the unwelcome feelings and challenges? - Did you seek help or support? • Did you seek help from other individuals? From organisations? From local authorities? 7. How did you manage COVID-19 illnesses and/or deaths of family members or friends? • How did you support each other? 8. What is your views towards the future recovery and revival of your engagements in community groups? 9. What is your biggest fear or worry about the future? 10. What is your biggest hope about the future? 11. Is there anything else you would want to share?

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APPENDIX D

Interview Grid for individual interviews for older minority ethnic people

Aim	Questions and probes
Background and context	What were your experiences with the COVID-19 pandemic?
Life prior to COVID-19.	What did an average weekday look like for you before COVID-19? -work, leisure activities, religious or spiritual activities etc? -How did COVID-19 impact your average weekday? -Where there any difficulties you encountered before COVID-19? eg. financially, mobility-wise, comorbidity-wise, etc. -How did COVID-19 impact these difficulties? -How did you personally cope with these changes? -Did anyone, or any organisations, help you cope with this? If so, how? -Were there political decisions that were taken that helped you cope with this? Both from a local and state level.
Weekend life	What did an average weekend look like for you before COVID-19? How did COVID-19 impact your average weekend? -How did you personally cope with these changes? -Did anyone, or any organisations, help you cope with this? If so, how? -Were there political decisions that were taken that helped you cope with this? Both from a local and state level
For Daily living	What challenges or difficulties, if any, did you encounter in your daily living during COVID-19 pandemic? What was the impact caused by COVID-19 in the following areas: -your physical health and getting medical or other health care support -nutrition -financial situation -groceries, prescriptions, accessing spectacles and/or hearing aids… -your relationships, social life and interactions, voluntary activities (with family, friends, networking groups) -communication -your mental health and well-being
Communication	What mode of communication did you use during the lockdown? -mobile phone -landline phone -computer/laptop via internet How did you access the news and government lockdown measures? -via radio -via television -via mobile phone -if other, specify Did you face any challenges in using these modes of communication? Could you explain.

Government lockdown measures and adherence	To what extent was it hard for you to follow and stick to the government lockdown measures? -Did you encounter any challenges in accessing the information or regulations regarding COVID-19? Did you encounter any challenges in understanding the information or regulations regarding COVID-19? How did you feel about the lockdown measures, mask wearing etc? -What was the impact of reduced mobility on you? -Did the reduced mobility affect your physical well-being?
Feelings	**Loneliness and isolation** -Were you able to be with your family? -Did you feel lonely and isolated? -What other feelings did you have during the peak of COVID-19, and what caused those feelings? -How would you describe your feelings now? **Risk and worries** -To what extent did you feel at risk of infection by COVID-19? -To what extent do you still feel at risk? -Do you feel safe now? -You indicated that you live with several family members in your household. How did you ensure you were not risk of coronavirus?
Illness and bereavement	Did you or any of your family members become ill with COVID-19? -What happened? -What was your experience? -Did you lose any close family member or friend due to COVID-19? -How did you manage and cope with the experience? -How did you cope with grieving and bereavement? -Where you able to get support? -Have you heard of long COVID? -Are you experiencing long COVID or are there anyone close to you?
Coping and resilience	-How did you cope with the various challenges that you encountered during the COVID-19 pandemic? -What gave you strength?
Outlook and perception towards life	**Worries and desired outcom** **-** Has the COVID-19 pandemic made you have worries about the future? -What worries do you have? -Looking back now, what do you think would have made your life easier or better during the pandemic? -Have you been vaccinated? Would you like to give more details about it? **-**Has your experience of COVID-19 changed your view towards life? -Is there anything else you would like to say or share?

APPENDIX D1 Demographics data

NAME	E	G	AGE	SO	R	LA	CV	B	HC	D	AI	EQ	O
ABDUL	Pakistani	m	85	h	Christian	MGL	yes	no	high blood pressure, heart condition	no	A	primary	unemployed
ABID	Yemen	m	80	h	atheist	MGL	no	no	high blood pressure, pain in legs	no	B	uneducated	unemployed
ADAM	Indian	m	77	h	Islam	MGL	yes	no	diabetes	no	B	secondary	retired interpreter
ALI	Pakistani	m	86	h	Muslim	MGL	yes	no	high blood pressure, diabetes	no	A	primary	unemployed
AMINA	Indian	f	86	h	Islam	with daughter	yes	yes	diabetes, osteoporosis	no	A	uneducated	unemployed
ARIEL	Jamaican	m	75	h	Muslim	with daughter	yes	no	arthritis	no	A	secondary	unemployed
ASSITA	Kenyan	f	72	h	Muslim	with husband and her m	yes	no	none	no	B	college diploma	community support worker
AYMAN	Afghanistan	f	67	h	Hindu	MGL	yes	yes	diabetes	no	B	secondary	unemployed
BENNY	Indian	m	78	h	Hindu	with wife	yes	yes	diabetes, high blood pressure,	no	D	Msc EngineeringE	retired engineer
CALEB	Black Caribbean	f	68	h	Christian	with wife, son	yes	no	asthma	no	B	college diploma	unemployed
DEBORAH	Black Caribbean	f	66	h	Christian	with husband, son	yes	no	high blood pressure	no	B	primary	unemployed
DELILAH	Black Caribbean	f	76	h	Christian	alone	yes	yes	2 pace makers, heart condition, false knees	yes	B	sixth form	unemployed
ELISHEBA	Jamaican	m	67	h	Christian	with husband	yes	yes	high blood pressure	no	B	secondary	unemployed
EVE	Sri Lankan	f	73	h	Christian	with husband	yes	yes	diabetes	no	B	secondary	unemployed
FADZI	Black Caribbean	f	70	h	Christian	alone	yes	yes	diabetes, sickle cell	no	B	primary	unemployed
FARAI	Bangladesh	f	80	h	Muslim	MGL	yes	no	none	no	B	uneducated	unemployed
FATIMA	Black Caribbean	m	73	h	Muslim	alone	yes	no	none	no	A	primary	unemployed
FELICIA	Somalia	f	65	h	Muslim	MGL	yes	no	none	no	B	uneducated	unemployed
GABRIEL	Cameroonian	f	68	h	Christian	alone	yes	no	high blood Pressure	no	B	college diploma	retired prison support worker
HAMZA	Pakistani	m	70	h	Muslim	MGL	yes	no	high blood pressure	no	A	primary	taxi driver
HANNAH	Indian	f	72	h	Christian	alone	yes	yes	is on immuno suppresant medication	yes	A	nursing diploma	retired nurse
HAZEL	Black Caribbean	f	80	h	Hindu	with husband	yes	yes	high blood pressure	no	A	typist Diploma	retired typist
JEREMIAH	Bangladesh	m	79	h	Christian	MGL	yes	yes	6 diseases including diabetes, by-pass, wheelchair user	no	B	secondary	unemployed
JERRY	Indian	m	77	h	Hindu	with wife	yes	yes	theldimite, thyroid, arthritis	no	A	primary	retired industry labourer
JOMO	Pakistani	m	84	h	atheist	with wife	no	no	none	no	A	BSC degree	retired construction labourer
JONAS	Pakistani	f	74	h	Christian	MGL	yes	no	high blood pressure	no	B	primary	taxi company, funeral undertaker
KETTINA	Indian	m	74	h	Hindu	MGL	yes	yes	none	no	B	nursing diploma	retired nurse
KIRI	Jamaican	m	69	h	Muslim	MGL	yes	no	high blood pressure	no	B	uneducated	unemployed
KUMBI	Jamaican	m	66	h	Christian	alone	yes	yes	none	no	B	secondary	unemployed
MAKEEN	Bangladesh	m	77	h	Muslim	family (4)-son, daughter	yes	yes	asthma	no	B	secondary	retired industry labourer
MOMO	Jamaican	f	82	h	Hindu	alone	yes	yes	diabetes, high blood pressure,	no	A	secondary	retired shop assistant
MUKHULIS	Bangladesh	m	83	h	Muslim	MGL	yes	no	high blood pressure, diabetes	no	B	primary	retired industry labourer
NADIA	Pakistani	f	79	h	Christian	with daughter	yes	yes	high blood Pressure	no	B	uneducated	unemployed
NOMA	Sri Lankan	f	77	h	Christian	with husband	yes	yes	high blood Pressure	no	B	secondary	unemployed
PAMMY	Afghanistan	f	71	h	Christian	MGL	yes	no	none	no	B	primary	unemployed
PENCY	Jamaican	f	83	h	Christian	with husband	yes	no	none	no	A	primary	unemployed
RUDO	Somalia	m	68	h	Christian	MGL	yes	yes	high blood pressue, diabetes, arthritis, asthma	yes	A	primary	unemployed
SAKHILE	Indian	f	64	h	Hindu	alone	yes	no	high blood pressure	no	D	teaching diploma	retired teacher
SENZIA	Indian	f	68	h	Muslim	alone	yes	yes	cancer on remission, asthma, brain aneurysm	yes	A	college diploma	community support worker
SIPHO	Chinese	m	66	h	Christian	alone	yes	yes	chronic knee pain	no	A	college diploma	community support worker
TENDAI	Saudi Arabia	m	77	h	Muslim	MGL	yes	no	high blood pressure	no	B	secondary	unemployed
THULA	Black Caribbean	m	65	h	Hindu	alone	yes	no	none	no	B	secondary	unemployed
VIMBAI	Black Caribbean	f	77	h	Christian	with husband	yes	no	neorological disorder, chronic fatigue, sleeping disorder	yes	A	primary	retired quality controller
WADA	Indian	f	74	h	Christian	MGL	yes	yes	migraines, chronic fatigue	no	D	BA Honors	retired hospital administrator

NB: these are pseudonyms of the older minority ethnic people participants

KEY FOR APPENDIX D1

E=ethnicity

G= gender

F= female

M= male

SO=sexual orientation

H=heterosexual

R=religion

CV= Covid vaccination status

MGL=multigenerational living

LA=living arrangement

B=boosters

HC=health condition

D=disability

EQ=educational qualification

AI=average income

O=occupation

KEY FOR AVERAGE INCOME COLUMN

A=less than £12 000

B=£12 000 to £15 000

C=above £20 000

D=above £30 000

APPENDIX D2

COMMUNITY LEADERS

NAME AND SEX	DESCRIPTION OF NETWORKING GROUP
Lindani, F	coffee meeting group for women
Laiza, F	Networking group for women
Kerina, F	Networking group for women and men
Jaya, F	daycentre
Yoyo, F	artistic group for women
Danai, F	spiritual group for men and women
Sabelo, F	interacting group for men and women
Mustaf, M	muslim group for women and men
Kenzo, M	muslim lunch meeting group
Xaba, M	networking group for men and women
Sipho, M	Gigong and yoga group
Moses, M	Muslim women and men

NB: these are pseudonyms of the community leaders