What The Eye Don't See, The Heart Don't Grieve: Social Workers' Understanding And Perception Of The Dementia Care Needs Of African Caribbean Elders In Wales

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Abstract

This thesis explores the intersections of three important contemporary issues in social work practice in Wales: race, ethnicity and dementia. There is limited evidence on the processes and structures involved in shaping social workers' understanding and perception of the dementia care needs of African Caribbean Elders (ACE). Drawing on a critical realist philosophical framework and informed by theories of critical race and intersectionality, this thesis addresses the gap in social work research by exploring how social workers understand and perceive the care needs of ACE with dementia. Fourteen semi-structured, in-depth interviews were conducted within a case study approach. Participants range from senior practitioners, social workers, social work assistants, to third sector leaders from local authorities across South Wales. Thematic analysis identified four key themes from the data: *The use and pursuit of an outcomes framework; Needs based on culture; The inclusion mirage; Anti-racist Praxis or Customised Universalism?* The use of an outcomes-focused framework negated consideration of race or ethnicity. Culture was perceived as unique to Black minority ethnic groups, suggesting that White practitioners did not examine aspects of their own culture as cultural expressions. Practice was perceived as inclusive because of approaches based on relationship building, multiculturalism and colour-blindness. Advocacy, social justice, and deconstructing stereotypes were perceived as necessary social work roles when supporting persons from Black minority backgrounds, but not as part of the universal social work mandate that can be tailored when supporting marginalised groups. There was no explicit linkage of these roles to anti-racist practice. This study contributes to the wider social work scholarship of practice with ACE with dementia by highlighting the importance of critical reflection and the adoption of an anti-racist lens to ensure practitioners are equipped to navigate the challenges of understanding and supporting the nuanced needs of ACE with dementia.

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Chapter 1

Introduction to the study

1.1. Context and relevance in the field

Alongside an ageing population, dementia poses a global public health challenge with over fifty-five million people living with dementia and an expected threefold increase by 2050 (Nicholas et al., 2019). Within this group, Black and Minority Ethnic (BME) persons with dementia are under-represented in dementia care, homogenised in research, making it difficult to determine which Black population is the subject of research (Saltus, Duval, and Vougioukalou, 2021). According to the Equality and Human Rights Commission (EHRC, 2015) in their report, *Is Britain Fairer?*', race and ethnicity are pervasive and sustained contributors to public service delivery inequalities across the United Kingdom (UK), particularly for persons from BME backgrounds.

A recurring finding across dementia research is that BME individuals with dementia face various challenges when accessing health and social care services (Bhattacharyya and Benbow, 2013; Roche et al.,2021). Although race has not been scientifically proven as a direct cause for dementia, and there are many issues around correlations to the disease based on ethnicity (Pham et al., 2018), research looking at disparities in dementia predominately focuses on race and ethnicity as key factors (Adamson, 2001; Adelman et al., 2011; Berwald et al., 2016).

Cohen et al. (2002) argue that to fixate on the race and ethnicity of minoritised groups in dementia research results in the 'deracialisation' of dominant White groups. This fixation, in turn, perpetuates difference in some whilst normalising others, without addressing deeper causes of inequalities in the context of dementia care and service provision. Frankenberg (2020), in their work *The Mirage Of An Unmarked Whiteness*, refers to the notion of 'the invisibility of whiteness'. This notion acknowledges that explicit references and public discourses on 'whiteness' have become less common over time. This has created the perception that 'whiteness' is invisible and the normative standard across society.

Identifying levels of inequalities by ethnic group is challenging, as the collection of ethnicity data across the UK and in devolved nations such as Wales is difficult. This is due to the ongoing changes in terminology to describe this population, as well as the way these terminologies are contested through self-identification. Additionally, a clear picture of health and social care in Wales is not always possible as social care is provided through a combination of public, private, and other commissioned providers (Sion and Trickery, 2020).

Captured in the terminology, BME are African Caribbean Persons (ACP). This group makes up 0.1% of the overall population in Wales, according to the Office for National Statistics (ONS, 2024). Whilst the number of African Caribbean Elders (ACE) with dementia in Wales is not clear, research highlights that they face significant disparities in dementia care, influenced by cultural, social, and systemic factors (Truswell, 2019; Roche et al., 2021). ACEs with dementia are less likely to access dementia services until symptoms become severe, often due to mistrust and previous negative experiences with service providers (Saltus, Duval, and Vougioukalou, 2021).

In the context of dementia care, social workers play a crucial role through the provision of person-centered services. Their unique skills and values make them well-suited to address the complex needs of individuals with dementia and their families (Kapman and Berkman, 2011). According to these authors, when social workers engage with diverse populations with dementia, social workers are required to demonstrate a nuanced understanding of cultural expressions of ageing, memory loss, and care preferences.

The Welsh approach to social work is characterized by a focus on partnership, collaboration, and sustainability, aiming to address social issues and economic disadvantages (Thompson, 2022). However, problems arise from the fragmented nature of service provision and the variability in post-diagnostic support, which often results in inconsistent access and unmet needs for people with dementia and their families (Tarrant, 2023; Carey, 2014). Existing literature, from contexts much broader than Wales, reveals a knowledge gap regarding how social workers specifically contribute to early intervention, care coordination, and sustaining relational care within community and residential settings (Milne et al., 2014; Manthorpe and Iliffe, 2009). Social Work practice in Wales is explored in more detail in chapter 3.

There is a paucity of research looking at social work practice with ACE with dementia. Where research does look at dementia in BME populations, research recommendations continue to call for cultural competence development in social workers (Dominelli, 1989; Jutla, 2015; Kenning et al.,2017 and Scourfield, 2022).

The ongoing drive for cultural competence in social work is based on empirical data that highlights that BME persons with dementia cannot access culturally appropriate services (Kenning et al., 2017; Lasrado et al., 2021). Additionally, cultural competence has been the profession's response to developing practitioner skill to provide person-centered services for people of all cultures and backgrounds. However, Garran and Werkmeister Rozas (2013); Williams and Lee (2024) argue that conceptual ambiguities, tokenistic practices, an overemphasis on individual skills, and a neglect of broader systemic issues limit the implementation and transformation capacity of cultural competence training.

Beagan (2018) argues that the current cultural competence model in social work practice, with older adults from ethnic minority groups with dementia, has been critiqued for its conceptual limitations, implementation challenges, and the lack of a nuanced approach to cultural diversity. Beagan (2018) further argues that current cultural competence models often reduce culture to race and ethnicity, neglecting other important aspects of identity such as gender, class, and religion. The model tends to present culture as static and uniform, failing to account for the dynamic and evolving nature of cultural identities. This can result in a one-size-fits-all approach that does not adequately address the unique needs of older adults from ethnic minority groups (Beagan, 2018).

Harrison and Turner (2010) suggest that social workers often face organizational and systemic constraints that hinder their ability to practice cultural competence effectively. These include limited resources, lack of training, and rigid institutional policies that do not support culturally responsive practices. Morris (2010) and Danso (2018) argue that the juxtaposition of "competence" and "culture" can lead to ethical dilemmas, as it implies a mastery of cultural knowledge that may not be attainable or appropriate. This can undermine the dignity and autonomy of individuals by positioning them as subjects to be understood rather than active participants in their care.

Some scholars advocate for a shift from cultural competence to cultural humility, which emphasizes ongoing self-reflection and critical engagement with power structures. This approach encourages social workers to listen to clients' narratives and understand their lived experiences, rather than relying solely on cultural knowledge (Beagan, 2018; Hollinsworth, 2013).

Cultural competence is a fundamental aspect of the social work knowledge base, significantly shaping practitioners' understanding and perception of diverse cultural contexts. The knowledge base in social work is a complex construct that is shaped and reshaped by theoretical, cultural, political, interdisciplinary, and organisational structures and mechanisms (Trevithick, 2008). This complexity is further compounded by knowledge biases that arise from the subjective application of knowledge, political influences, and the challenges of integrating practice and theory. Different understandings and perceptions of dementia, race, ethnicity, and culture can significantly impact service delivery and relationship building with diverse populations, such as ACE with dementia. Therefore, it is essential to have clarity of how social workers understand and perceive these concepts and what mechanisms shape those understandings and perceptions.

According to Heikes (2019), understanding involves the ability to recognise patterns, synthesise information, and appreciate the interconnectedness of experiences. Understanding goes beyond knowledge acquisition but involves deeper processes that facilitate the flexible application of information across different contexts. Understanding informs scientific inquiry and impacts interpersonal relationships as it enables individuals to grasp the needs and perspectives of others, make informed decisions, and foster meaningful connections. Perception is defined as one of the vital cognitive processes for accessing the external world through sensory feedback (Morales and Firestone, 2023). Perception shapes an individual's thoughts, actions, and interactions with others (Turtiainen and Anis, 2024).

Understanding and perception are fundamental concepts in social work practice, influencing how social workers engage with individuals, interpret their needs, and implement interventions. When social workers perceive and understand cultural complexities and injustices accurately, they are more likely to provide services that are just and appropriate for ACE with dementia. Conversely, simplified or inaccurate understanding and perception can lead to inappropriate service provision (Turtiainen and Anis, 2024).

These definitions are key to philosophical and scientific inquiry that focuses on perception and understanding. In the context of this thesis, these definitions also invite inquiry into the nature and purpose of social workers' perception and understanding. For example, to understand the usefulness of cultural competence training, it could be insightful to ask whether different social workers perceive the world in comparable ways or to what extent social workers understand their environment or the individuals they support.

Despite the importance of these concepts, there is no clear agreement on what "understanding and perception" in social work research or practice actually means. Additionally, there remains no consensus as to the role of 'understanding and perception' in shaping practice knowledge. Research around practitioners' understanding and perception has tended to focus on uncovering explanations for practice outcomes (Bundy-Fazioli, Quijano, and Bubar, 2013; Lee et al.,2024). Although these concepts encapsulate distinct processes that significantly impact social workers' practice knowledge and behaviours, these concepts are used across social work research and practice with implicit assumptions about their meaning, nature, and purpose in practice.

1.2. Research motivation and aims

Reflections on my experiences of 'caring'[1] for my great-grandmother in Trinidad and Tobago have highlighted differences between my historic lack of knowledge and understanding of dementia and my current perception, understanding, and knowledge of dementia. I never knew the term until I arrived in Wales sixteen years ago, as dementia was not a term I had heard in my family or indeed broader Trinidadian discourses. My great-grandmother displayed dementia symptoms such as forgetfulness, wandering, and accusatory behaviours (Alzheimer's Society, 2020). Through the Eurocentric lens that has since become part of my knowledge base, I

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[1] Caring for my Elder was seen as my duty and as a show of respect. The expectation that the family would be caring for my great-grandmother was a 'given' and not something we necessarily planned for. The family just 'knew' we had to look after our Elders. Whilst it involved personal care, it also entailed allowing my great-grandmother to live her life the way she wanted. My role and that of the rest of the family was to help her with anything she needed to fulfil this.

have come to accept the possibility that my great-grandmother had undiagnosed dementia.

My experiences as an older person's social worker in Wales conflicted with my experiences of providing care for my great-grandmother. The autonomous way in which she lived (rather than 'allowed to live' as no one ever considered infringing on her choices, as the Elder in the family), with possible undiagnosed dementia, reflected voice and control and person-centered care (Social Services and Well-Being (Wales) Act 2014), (SSWBA 2014). The risk-averse nature of older adults' health and social care (Kenner, 2008) would have resulted in a significantly different experience for my grandmother and the family. In my own professional practice, the presence of dementia symptoms propels individuals into a complex, fragmented system to access a diagnosis and any required care.

These contrasting experiences highlighted the paradoxes and conflicts within practices and discourses of empowerment, voice, and control, and person-centered care, which can be compounded where individuals have racialised identities (Saltus, Duval, and Vougioukalou, 2021). Whilst I understand the importance of getting a diagnosis, I also question the binary narratives that accompany getting or not getting a diagnosis. Such narratives imply that there is a linear, more positive pathway for those who receive a diagnosis compared to the chaos and despair of not having a diagnosis. These narratives ignore issues such as diagnostic criteria, service availability, impact on the person and family, as well as cultural complexities (Fox et al., 2013; Bamford et al.,2004).

ACE with dementia are often represented in research in reductionist ways, with aspects of their culture serving as the explanation of their negative experience of dementia and dementia services (Roche et al., 2021). Such representation fails to challenge deeper systems and structures that perpetuate ageism, ableism, and racism. This could be due to social work research in the UK having a history of being undertaken by White researchers for a White audience (Werkmeister Rozas, 2023). Additionally, the Eurocentric lens of research in the UK often ignores the UK's colonial past and its impact on the creation and legitimization of knowledge. Such epistemic dependency on colonial frameworks also limits the scope of academic inquiry (Lal, 2012).

My study also has a focus on race and ethnicity because health and social care inequalities in the context of dementia care are underpinned by systemic racism, which is often overlooked or not properly explored in dementia research (Moriarty, Sharif, and Robinson 2011; Nazroo, Bhui and Rhodes 2020). This thesis is undertaken within the boundaries of a devolved nation of the UK, Wales. The devolved context brings to the fore divergent approaches to social work policies, discussed in more depth in chapter two and three.

In this PhD, I seek to advance gerontological social work by heeding the call by Williams (2020) to expand the focus of social work research beyond children and mental health to include areas such as ageing. I also acknowledge the call by Willis (2007) that social work research must critically engage with issues of power and dominant discourses that exclude and disempower diverse groups. This thesis engages in the exploration of the processes and structures that shape and reshape social workers' perception and understanding of constructs such as race and ethnicity in the context of care needs of African Caribbean Elders with dementia. Such exploration seeks to challenge the perpetuating knowledge gap within social work practice with ACE with dementia.

1.3. Research questions

This study seeks to answer the overarching research question:

How do social workers understand and perceive the care needs of African Caribbean Elders with dementia, living in Wales?

More specifically, this study will explore and answer:

1. How do social workers understand and perceive race and ethnicity?
2. What approaches to dementia service provision do social workers use with African Caribbean Elders with dementia?
3. How are social workers supported when working with African Caribbean Elders with dementia?

1.4. Research aims

1. To explore how conceptualisations of race, ethnicity shape practitioners' understanding and perception when undertaking social work tasks with ACE with dementia.

2. To explore and understand to what extent critical race theory and intersectionality theory can be useful when undertaking social work tasks with ACE in the context of dementia care.

3. To understand the existing structures and mechanisms that support or hinder social work practice with ACE with dementia.

Having outlined the context and relevance in the field of social work research, the research motivations and aims, the next section of this chapter will present the structure of the thesis.

1.5. Thesis structure

The thesis comprises eight chapters, including this one, and I provide a sequential overview of the following seven chapters. The next chapter (Chapter 2) explores the literature that informs this research. In the literature review, I identify substantive fields: dementia, ethnicity, race and racism; culture; perception and understanding; and social work, which were further expanded as the literature review developed. The literature was critically explored in order to contextualise my work amongst the existing body of research.

Chapter 3 presents discussions and debates around the current state of social work. This chapter presents broad, global debates that culminate with the state of social work in Wales. Chapter 3 will also locate understanding and perception within social work and discuss them as foregrounding concepts across this study. Discussed in this chapter are the theoretical frameworks, Critical Race Theory (CRT) and Intersectionality theory, that underpin this study.

Within Chapter 4, the methodology is presented to illustrate the processes that were undertaken to conduct this study, including sampling and recruitment, introducing the fourteen participants, data collection and analysis, as well as reflexive and ethical considerations. This chapter also discusses in detail the philosophical underpinnings of this study, Critical Realism (CR). The next three chapters are the empirical chapters, which provide interesting responses to the research questions.

Chapter 5 (The Challenge of Cultural Outcomes) introduces the first of the three empirical findings chapters. This chapter presents critical discussions around outcomes-focused practice and the perceived cultural needs of ACE with dementia, as described by participants. There were connections made to chapter 3, and the analysis builds on the constructs presented in the literature review.

Chapter 6, (Working Hard or Hardly working: Approaches and Barriers to meeting the needs of ACE with dementia). Data analysis in this chapter gives insight into the approaches social workers use and the barriers they encounter when attempting to meet the needs of ACE with dementia.

Chapter 7 is the final empirical chapter in this study, (Anti-racist praxis or customised universalism?) This chapter provides insight into the roles that participants perceive as necessary if social work hopes to break barriers that negatively impact social work practice with ACE with dementia. Discussions draw on the complexity and challenges of meeting the needs of marginalised individuals such as ACE with dementia and the universalist ideals of the social work profession.

Finally, the conclusions and future directions that emerge from this study are detailed in Chapter 8. The research motivations and aims are revisited, and the research findings are summarised in relation to the research questions. Significant contributions to knowledge are identified, as well as the limitations of the study. The chapter also discusses ways the findings can have an impact by highlighting the targeted audience. The chapter concludes with words of hope for social workers.

Chapter 2

The Literature Review

2.1. Chapter Overview

This chapter explores the literature that informs this research. My approach to the literature review began with identifying substantive fields, which were further expanded as the literature review developed. These fields were: dementia; ethnicity; race and racism; culture; perception and understanding; and social work. The literature was critically explored in order to contextualise my work amongst the existing body of research. This required me to engage with literature from across several research and academic fields, namely, social work, nursing studies, psychiatry, race, and culture studies. The purpose of this chapter was to identify and consolidate the research already undertaken in the substantive fields, with a focus on social work with ACE with dementia in Wales, and to identify research gaps.

The focus of this study is positioned in the context of social work in Wales, a devolved nation within the UK. However, studies from other countries such as Canada and the United States of America (USA), as well as other nations within the UK, have been included as evidence for wider trends, patterns, beliefs, and as a way to develop debates and explore differences or similarities between Wales and other nations. Additionally, these countries have an African Caribbean (AC) diaspora, and social work is undertaken in a formal way, similar to the UK (Hackett, 2019).

This chapter is divided into nine sections and begins with a discussion of the development of the literature review, which includes the methodology of the literature review*,* the inclusion and exclusion criteria, and search terms. Next, it presents critical discussions around the terminology that is used across this thesis. This is followed by discussions on the significance of the title Elders and an in-depth discussion of African Caribbean Elders in the UK and specifically, Wales. Expanded presentations of the concepts of race, ethnicity, racism, and culture follow. The chapter ends with a presentation of the research gaps to be addressed by my study.

As a single researcher, I was unable to carry out or achieve the comprehensive level of review that systematic reviews offer (Petticrew and Roberts, 2008; Aveyard, 2010). However, I employed a clear and explicit search strategy, search terms, and inclusion and exclusion criteria (Kiteley and Stogdon, 2013) to ensure a level of quality to the literature used in this review (Grant and Booth, 2009).

2.2. Development of the literature review

The review of the literature was developed through two stages. The first stage aimed to develop an understanding of key concepts, theories, and authors in the subject field through the exploration of the extant literature that has been produced on the subject (Bryman, 2012; Pare et al., 2015). In this stage literature is broad; for example, the initial search looked at BAME and dementia, and social work and dementia.

The second stage of this literature review, which aimed at facilitating writing, entailed a more focused and systematic approach to searching. In this stage, the literature search was targeted to support the research objectives. For example, narrowing BAME studies to locate ACE. This stage also facilitated an enhanced articulation of the research problem and further development of the research questions, which helped me identify gaps in the literature in order to position my research within the field (Jesson, Matheson, and Lacey, 2011; Arksey and O'Malley, 2005).

Methodology of the literature review

The narrative or traditional way of reviewing extant literature was selected for this literature review as it supported a qualitative interpretation of prior knowledge, which maintains the qualitative approach of this study (Sylvester, Tate, and Johnstone, 2013; Onwuegbuzie and Frels, 2016). According to Werkmeister Rozas and Klein (2010), Willis (2007), narrative reviews enable critical evaluation of existing literature through the deconstruction of dominant discourses, which in turn can inform social work pedagogy. Additionally, a narrative literature review facilitates the re-conceptualisations of established research (Torraco, 2005). For example, I am able below to problematise and reconceptualize concepts such as race, ethnicity, culture, and being Welsh (Nadan, 2017; Lavalette and Penketh, 2014; Williams, Evans and O'Leary, 2015).

This type of literature review is critiqued for its potential to lack clarity around the criteria used for the selection of material, which can lead to biased interpretations or inferences (Green and Glasgow, 2006). However, despite this critique, Werkmeister Rozas and Klein (2010) argue that narrative literature review lends itself very well to the synthesis of social work knowledge, as narrative literature reviews allow for the easy incorporation of qualitative research findings, which can improve the empirical perspective on issues that are important to social work.

Literature search strategy

Studies from social work (Adamson, 2001); medicine (Prakash, 2011) and gerontology databases that were likely to include the relevant literature were searched. Additionally, I carried out reviews on reference lists from key papers to ensure no relevant studies were overlooked. Some studies were already known to me through previous learning, and some databases were discovered through key papers. I adopted a primary focus on UK-based sources as Welsh-specific sources were quite limited. A secondary focus on wider international literature from countries such as Canada, Australia, the USA, and Caribbean countries was also employed. Review of the literature also identified large AC diaspora populations in these countries, and despite differences in policy and practice, similar problems in terms of access to appropriate dementia services were identified.

In addition to subject-specific databases, I conducted searches of EBSCO, PubMed, Cochrane, Web of Science, ASSIA, Social Care Online, JSTOR, WILEY, Sage Publications, Campbell Collaboration, Official publications, and statistics such as ONS. SCOPUS, Social Care Online, and PsycINFO databases. I used the Google Site Search tool to access publications by the Welsh Government. Additionally, I also utilised print-based sources such as textbooks and Journals by BASW, Taylor and Francis Online Journals, and the Journal of Gerontological Social Work. Additionally, I considered grey literature, which included Age UK, Dementia UK, Race Equality Foundation, Diverse Cymru, and Alzheimer’s Society. These were also scoped to help overcome publication bias and to support the critical evaluation of studies that offered negative or neutral outcomes in the context of the topic being researched.

Search terms

Some search terms were developed at the initial stage of the study based on the area of research interest, for example, dementia, social work, and ethnicity. Some terms were developed based on my own knowledge and experience, whilst other terms were developed based on keywords located in the abstracts and titles of papers searched. Key search terms were: Caribbean, African Caribbean (AC), Afro

Caribbean, Caribbean people, African Caribbean People (ACE), Black Elders, African Caribbean Elders, Older Persons Social Work, Gerontological Social work, , People from the Caribbean, dementia, Alzheimers, Black, Black Minority Ethnic (BME), Black Asian, Minority Ethnic (BAME), ethnic, Ethnic Minority Group (EMG) Black African and Caribbean (BAC), social work, Welsh, Wales, devolution, Cymru, social care in Wales, elderly, ageism, adult care, vulnerable adult, human rights, racialised, minoritized, race, racism, culture, diversity, health inequalities, social services, health and social care, understanding, perception, knowledge. Within these searches, recurring terms emerged. Truncation and wildcards were used to create synonyms and alternative spellings, and forms for search terms. Words and phrases were also combined with the Boolean operators 'AND' and 'OR'. For example: African*Caribbean OR African Caribbean OR African Caribbean*OR Afro*Caribbean OR African Caribbean immigrant OR Minority ethnic* OR ethnic minorit* OR Black Asian Minority Ethnic* dementia AND BAME* African Caribbean AND dementia* social work AND BAME*, Social Work AND diverse groups*.

Inclusion and exclusion criteria

The inclusion criteria focused on papers reporting on dementia, social work with dementia, ethnicity, race, ethnic minority, and dementia, Caribbean people, and dementia. I also screened abstracts to determine if the full-text articles would meet the inclusion criteria. Although this study adopted a qualitative research methodology, quantitative and mixed methods studies were included in this literature review as current quantitative studies that looked at Black ethnic minority participants, provided empirical data on dementia prevalence and diagnosis rates (Adelman et al., 2011), which informed this study. There was no limit on the methodological approaches adopted by the studies used in this review, so that ethnographic and feminist papers were also included.

Grey literature, such as policy and legislation which integrated evidence relating to social work, dementia care, Black Ethnic Minority (BME), Caribbean people in the UK, services for ethnic minorities with dementia, gerontological social work, social work in Wales, and social care in Wales, was also used. There were no restrictions on dates of publication, as some aspects of this research are entwined with concepts deriving from the civil rights movement in the USA and the end of the Second World War in the United Kingdom. This allowed an engagement with literature that provided a historic context of race and ethnicity in the UK, whilst considering the contemporary relevance of sources to ensure contextual clarity and substantive focus. Media articles, reviews, and conference proceedings were also included. All papers were in English language only, as I did not have the resources to support translation services.

My study looked specifically at social work in Wales; as such, studies on social work, including social work training and education, were included. Health and social care are devolved in Wales (Williams, 2011), and the health and social care legislation in Wales (SSWBA 2014, s.15) requires joint working, particularly between health boards and local authorities in the provision of social care (Welsh Government, 2014). Therefore, health-based articles and research that focused on dementia care and dementia service provision were utilised as part of the literature that was reviewed.

Papers that reported on genetic studies for BME, ACE, or studies that focused on combined medical diagnoses, such as dementia and other medical diagnoses, were not included. Studies that did not report specifically on BME were excluded to maintain the focus on Black Minority groups. Papers that did not permit full access were excluded, as a full appraisal could not be carried out. Studies that reported on broad psychiatry or psychiatric intervention in dementia with no information on BME populations were not included. Studies reporting on the association of dementia and other activities, such as smoking, were also excluded.

Initial, broad searches yielded 895 hits with potential relation to the research topic and sub-topics that were searched. After removal of duplicates, inaccessible papers, due to pay walls and through in-depth inclusion and exclusion criteria, studies that did not clearly identify ACE or Black ethnic minority groups, such as studies on Roma populations, 895 was reduced to 350 articles, journals, and research papers for inclusion. Further review identified 95 papers that did not meet the inclusion criteria. These papers did not provide clear data around the number of participants from African Caribbean (AC) backgrounds, and in some cases, the participant numbers for (ACP) were so small compared to other ‘Black’ ethnicities that it was difficult to draw conclusions for ACE from such studies. Additionally, some papers were review articles themselves rather than original studies. This resulted in 255 studies that specifically identified ACE as included in the population of interest, and as such, these studies and papers make up the core papers that are included in this review.

Although not included in the core studies used in this research, several of the excluded 95 papers such as Sayer (1979) and Ballard (1996), were drawn upon to provide historical and theoretical context. These works supported broader arguments around race and ethnicity, which are explored in this review and throughout the thesis. The final number of included studies (255) was relatively low, reflecting the limited research on the intersection of ACEs, dementia, and social work. However, this smaller number allowed a more in-depth analysis of the existing literature and highlighted significant gaps in current research.

While there is a common assumption that academic references should be recent, this is not universally applicable or advantageous across all disciplines. The inclusion of older, foundational works can offer essential historical context, establish theoretical frameworks, and provide continuity within a field of study - elements that are critical for achieving a comprehensive understanding of complex topics (Verstak et al., 2014). As such, this research integrates several seminal and historically significant studies.

Additionally, the incorporation of classic and historical studies within my research underscores the continuity and progressive development of scholarship in the field. I believe key concepts central to this study, such as race, ethnicity, dementia, ageism and social work with AC populations, are enriched through engagement with historical perspectives (Webster and Watson, 2002). By serving as reference points, earlier studies enabled me to identify shifts in theoretical or empirical perspectives over time (Webster and Watson, 2002).

My approach to the literature review adopted some systematic methods in terms of establishing criteria for searching, including and excluding studies. However, I am aware that the lack of rigor compared to a systematic review means the findings of this review should be interpreted with caution. The following sub-sections will discuss the language and terminology that will be used across this study and the rationale for convergence or divergence from the language and terminology used in the studies within the review.

2.3. Language and terminology

Elder-Vass (2011) suggests that language is much more than semantic activity, as language plays a key role in how we perceive and understand the world around us. Vanidestine and Aparicio (2019) suggest that language shapes our understanding and perception of the world by providing cultural frameworks that allow us to receive and respond to societal knowledge. As a researcher, the choices I make in terms of language can reveal or reinforce how I perceive and understand the world, shaping my research and findings. I share deeper reflections on this in the reflexive section of the methodology chapter. In their study looking at social work in the context of child maltreatment, Ashton (2010) suggests that labels and categorising help social workers identify behaviours, cases, and the interventions that may be needed. This notion implies that, as a form of scientific inquiry, this thesis requires me to engage with categorisations, labels, and terminology that have become embedded in social, socio-political discourses.

In this section, I present in-depth discussions of the terminology used within this thesis and the rationale for such use. I am also aware that, as knowledge has developed, previously accepted terms have become offensive and derogatory, and I have taken extra care through reading and supervision to mitigate against this. I also discuss these terms, aware that they are often contested and applied in different ways across different contexts.

Social worker and social care

The terms social work and social care are used interchangeably within some of the literature reviewed and referenced in this study. However, this study had a specific focus on social work in Wales, which adheres to the definitions developed by the International Federation of Social Work (IFSW 2014), the Wales Local Government Association (WLGGA), and the Association of Directors of Social Services Cymru (ADSS Cymru). This states that ‘social work is a profession that supports, empowers and safeguards the most vulnerable adults and children in society’. Social Work is also a legally protected title, and as such, only persons with a social work professional qualification can practice as social workers (Social Care Wales, 2019).

The term social work is used to mean all the activities that social workers engage in and is used interchangeably with terms such as the’ profession’, the ‘broad field’, the ‘discipline’, and ‘social work practice’. Where other professions are referenced, this is made explicitly clear. This study uses the terms ‘social workers’, ‘practitioners’ interchangeably to mean persons engaged in social work activities. Wherever the term ‘professionals’ is used to mean persons engaged in social work activities, this is made clear. However, where the term ‘professionals’ is used to mean persons engaged in activities outside of social work, this is also made clear.

Individuals

People who use social services are generally referred to as service users, clients, and customers (Banks, 2012). These generic terms are the sites of debates, which argue that such terms ignore the experiences and relationships that are part of the individual’s identity (Cowden and Singh, 2007). Such homogeneous terms suggest that the needs and service requirements of individuals are the same. Additionally, such terms imply passive recipients, thus reinforcing negative sentiments about persons who access or may access a service, whilst ignoring issues such as power imbalances, particularly where participation is involuntary (McDonald, 2006).

Harris (1999) argued against the term consumer or customer, which implies that persons have choice or options when accessing services and that welfare is a commodity that can be bought or sold. Mc Laughlin (2009) further highlights the ongoing drive to develop appropriate terms to describe persons who access or may access social services, and that any term will encompass bias and challenges. For example, ‘experts by experience’, which places the individual as the expert, poses challenges to the accuracy of assessments done by practitioners, particularly where individuals do not agree with such assessments.

Through the Welsh model for social care, individuals who access or may access services are referred to as citizens (Drakeford, 2007). Wales' specific legislation (SSWBA 2014) highlights principles of voice and control and collaboration, suggesting a sense of belonging to a community alongside the idea of having rights and responsibilities and input in the development of services (SSWBA 2014). The concept of citizenship implies membership in a community; however, there are bureaucratic practices such as eligibility assessments, immigration and border controls, organisational cultures, lack of or very limited choice, and the fear of privatisation as potential barriers that may exclude some people from enjoying the benefits that citizenship conveys (Banks, 2006; Manthorpe, 2011 and Clements, 2016).

In an attempt to use terminology that aligns with social work notions of empowerment and social justice (IFSW 2014), I have used the term ‘individual’ as this is the predominant terminology used within the Code of Practice (Wales) for health and social care workers (Social Care Wales, 2021). Any other terms used will be due to references made in the literature or direct quotes from the research participants.

Language around race and ethnicity

This section undertakes the challenge of introducing discussions around the complexities of writing about race and ethnicity, regarding using the right terminology to describe the people they represent. These discussions are part of the ongoing reflections underpinning this thesis and are critically presented in more detail in section 2.8 of this chapter. In the UK, there is much variability and a lack of consensus on what terminologies are appropriate to use to describe people from Black backgrounds who are often assigned these labels, often without being consulted. Additionally, attempts to situate persons from ‘Black’ backgrounds also required me to situate persons from ‘White’ backgrounds, as these identities are interconnected through social, political, and historical meanings.

Ford (2015) highlights that various terminology is used to describe Black minority ethnic groups. In the UK, this is evident in the ongoing changes from Black, Asian Minority Ethnic (BAME), Black Minority Ethnic (BME), Ethnic Minority Group (EMG) to the current terminology, ‘ethnic minorities’, as recommended by the Commission on Race and Ethnic Disparities (2021). Most of the studies used in this literature review use the terms ‘BME’ or ‘BAME’ and ‘ethnic minorities’; therefore, these terms will be used as presented in those studies.

These terms raise debates around language sensitivity, appropriateness, and representation when referring to non-White populations. Gabriel (2021) argues that terms such as BAME homogenise ‘minoritized’ populations whilst reinforcing power imbalances and the privilege of White identities. The Commission on Race and Ethnic Disparities (2021) argued that terms such as BME, BAME fail to acknowledge the differences and similarities between and within groups. DaCosta et al. (2021)

posit that closer examination is needed to understand the purpose of these terms by questioning why and how these terms are adopted, for non-White populations, whilst there is an absence of a term for White populations, for example, there is no 'WME' (White Majority Ethnic) terminology.

Farkas (2017) calls for an examination of the persons and institutions who created, consented to, and legitimized these terms. Morning (2008) makes the argument that those who construct these terms and the meanings ascribed to these terms change and differ over time and place, with different outcomes for the populations that have been labelled. Puwar (2004) raises the argument that such terminology ignores the differences between populations deemed 'natural' inhabitants and those deemed 'outsiders', as in the case of Indigenous Australians (Flicker and Holdworth, 2014).

Expanding on these arguments, Schmachtenberg et al. (2020), in their work around people with a migration background and their access to dementia care, argue that a migration background can be considered a new form of ethnicity, which brings with it linguistic and cultural factors that play a major role in the health outcomes for persons with dementia. Many people with migrant backgrounds are further categorised as minoritised ethnicities on arrival in the host country. Such categorisations may differ from how those persons may have self-identified from birth. Additionally, terminology that categorises and reclassifies people has the potential to reconstruct identities and redefine group membership.

Such discussions are relevant to the context of this thesis, which has a focus on social work with persons of an African Caribbean ethnicity. The terminology used in this thesis to describe this population is African Caribbean (AC). I acknowledge the ethical complexities in using such terminology, as persons from the Caribbean may prefer other personalised or regional terminology to refer to themselves. I was born in Trinidad and Tobago, and I prefer to be called 'Trini' or Trinidadian'[2]. However, a lack of consensus on the desired terms of reference for each Caribbean country and

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[2] I have always been aware of my African ancestry whilst growing up in Trinidad. I did not feel the need to 'claim' my African roots as this was understood and demonstrated in much of the discourse in Trinidad which also acknowledged 'mixed' heritage as the norm due to our colonial history. There was a period of political shift that saw terms such as 'Afro' and 'Indo' Trinidadian being used, however, the difficulties of categorising groups became apparent as most Trinidadians claim some level of 'mixed' heritage. As such I have always accepted 'Trini' or 'Trinidadian' as an identity label that encompasses all of my 'mixed' heritage.

the ongoing changes of aggregate terminology within the UK Census make deciding on the best terminology very challenging. I discuss my own social positioning in more depth in the reflexivity section of the methodology chapter.

In contrast to the terminology Black Caribbean used in the UK's census, I have decided to use the term African Caribbean (AC). I believe that this terminology helps capture the unique heritage of this group that has been shaped by African roots, colonialism, and Caribbean cultural practices. I do not believe Black Caribbean acknowledges the distinct history of this group but rather presents a surface-level description based on skin colour. This terminology implies that persons from the Caribbean are a monolithic group, in contrast to the diverse ethnic composition of the Caribbean. Interestingly, whilst the UK Census has the option to identify as any other 'White', there is no explicit category for 'White Caribbean', although there are White persons who were born in the Caribbean or have Caribbean heritage, similar to White South Africans living in South Africa (Tate, 2021). Expanded discussions around broader aspects of race and ethnicity, such as racism and culture, are presented in section 2.8 of this chapter and feature across this thesis.

2.4. Elders

The terminology used to describe older individuals can significantly impact their perception and treatment within various cultural contexts. Amongst older African Caribbean People (ACP), the term 'Elders' is generally accepted as it connotes respect and value for their wisdom and life experiences (Brathwaite, 1989; Jacobus, 2022). I am aware that this is not a generalised view across all of the Caribbean, as cultural and societal differences influence the accepted or contested language and terminology around later life and ageing. Kelly (2005), in their work on *Growing old in St. Lucia,* highlights that the term 'Elders' is used in discourses around the care needs of the ageing population in St. Lucia and may evoke reductionist sentiments.

Sengani (2015) presents the notion that in African cultures, the term 'Elders' denotes persons who hold the histories, culture, and decision-making powers in the family. My decision to use the term African Caribbean Elders (ACE) in this thesis is underpinned by the different meanings presented by these authors. Revisiting discussions by Elder-Vass (2011), I argue that language and terminology can provide opportunities and alternative frames for elevating the status of older adults from societal perceptions of weak and frail to valuable assets within society. Such elevation is key to improving outcomes for persons from marginalised groups with a dementia diagnosis (ACE with dementia). The following section discusses and locates ACE with dementia in Wales.

2.5. African Caribbean Elders in Wales

The territories referred to as the Caribbean have been changed by colonisation in different ways. These differences are evident in their language, culture, and socio-political structures. Colonisation had also resulted in multiple and distinct subregional traditions such as the English-speaking Caribbean, the Hispanic Caribbean, the Dutch Caribbean, and the continental Caribbean (Briceño-Ruiz, 2013). Whilst there remain ongoing arguments around what regions should be considered the Caribbean, examination of these arguments requires a depth of historical analysis that is beyond the scope of this thesis. Therefore, my definition of the Caribbean is based on the descriptions of those regions that possess a historical African heritage linked to slavery, plantation, and European colonisation, primarily the British, French, Spanish, and Dutch (Briceño-Ruiz, 2013).

Williams and Bunkley-Williams (2021) in their work: *What and where is the Caribbean? A modern definition* provides critical arguments around the different definitions of the Caribbean. The authors argue that the Caribbean includes those islands that have proximity to the Caribbean Sea and have similar flora, fauna, and sea beds. Additionally, the authors argue that these countries share political histories of colonisation and transatlantic slavery. Whilst the scope of this thesis does not allow deeper inquiry into these arguments, in defining the ‘Caribbean’ as used in this study, I incorporate the definitions provided above as broad defining attributes of the Caribbean and African Caribbean People.

To provide clarity around the population referred to in this thesis, I draw on narrower, contextual definitions by looking to the history of those regions that were defined as British Caribbean colonies, from which people were recruited as the labour force needed to rebuild Britain following World War Two. These include, but are not limited to, people from Trinidad and Tobago, Jamaica, Barbados, the Leeward and Windward islands (Fryer, 1984).

The term African Caribbean is made up of two parts: African and Caribbean. However, exploration of this term reveals that it is complex and not easily defined for social or scientific clarity, even if taken in these two parts. As such, I use it in this study with much caution. There are considerable social and cultural differences between and within the nations that make up the African continent. So that the term African should be taken as a contested category.

Although the dominant story around the presence of AC populations in the UK starts with the Empire Windrush’s arrival in London in 1948, exploration of the historical, political, and social context of the presence of ACP in the UK reveals contrasting insights. From the 16th century until the early 19th century, European slave traders shipped African slaves across the Atlantic to various European colonies in the Americas. Persons identified as ‘Black’ have been in the UK since the 17th century (Walvin, 1973; Law et al., 2008). Black slaves were brought from plantations in the Caribbean colonies to become house slaves or to work across growing industrial Britain (Rawley and Behrendt, 2005). The development of White supremacist eugenic beliefs was a major influence on the justification of the transatlantic slave trade and the rise of abolitionism. These complex historical events involved the intersection and interconnection of the constructs of race and economics, deeply embedded in the colonial and post-colonial structures of power (Young, 2016).

Post-World War Two was also accompanied by the simultaneous decolonisation era and the dissolution of the British Empire. The abolition of slavery left many of the British colonies with poorly developed economies that could not meet the needs of growing populations (Morgan, 2007). This may have been a contributing factor to the willingness to answer the call to help fill post-war labour shortages in Britain. Citizens of Caribbean countries such as Jamaica, Trinidad and Tobago, Saint Kitts and Nevis, Barbados, Grenada, Antigua and Barbuda, Saint Lucia, Dominica, Montserrat, Anguilla, Saint Vincent and the Grenadines, Guyana, and Belize were encouraged to migrate to Britain to support the rebuilding of the UK economy and infrastructure (Piggot, 2018). Many persons who came from Caribbean countries at this time also settled in Wales (Goulbourne, 2002; Marwick, 2003; Rosen, 2003). The AC population in Wales remains concentrated in urban areas such as Cardiff, Swansea, and Newport (Williams, Evans, and O’Leary, 2015).

Whilst this study focuses on ACE, I acknowledge that the Caribbean diaspora in the UK includes Afro-Caribbean, Indo-Caribbean, and other subgroups, each possessing unique experiences, identities and cultural legacies. For example, the Indo-Caribbean community in the UK comprises individuals of Indian descent whose ancestors were brought to the Caribbean as indentured labourers during the colonial period. This group maintains a distinct cultural identity that synthesises Indian and Caribbean traditions (James, 1992).

Smaller Caribbean communities, such as those from St. Lucia and other Eastern Caribbean islands, have also established a presence in the UK. These groups often rely on kinship networks to facilitate social integration and provide mutual support, particularly in cities like Birmingham (Abenaty, 2003). The internal diversity of these communities reflects the broader heterogeneity of the Caribbean region itself, which includes English-speaking, Hispanic, and Dutch Caribbean subregions (Briceño-Ruiz, 2013).

Although other Caribbean communities often share cultural and social spaces with Afro-Caribbean communities, each preserves unique traditions and practices, thereby enriching the diversity of the Caribbean diaspora in Britain (James, 1992). The African Caribbean population in the UK, central to this research, possesses a distinct identity shaped by complex historical, social, and cultural trajectories.

The arrival of the Windrush generation marked a foundational moment, followed by subsequent generations who have navigated evolving challenges and opportunities (Stephenson, 2004; Adi, 2022). Far from being a monolithic group, African Caribbeans in Britain hail from various islands, each with distinct cultural and ethnic backgrounds. However, this internal diversity is often overlooked, leading to homogenized categorizations that fail to capture the nuanced experiences of African-Caribbean individuals (Malcolm and Mendoza, 2014).

These persons arrived in the UK as citizens of the United Kingdom and Colonies (CUKCs) in the 1950s and 1960s owing to birth in the former British colonies of the Caribbean and became known as the Windrush generation (Goulbourne, 2002). Despite the promise of citizenship, equal rights, these early migrants encountered hostility from the White population in addition to high levels of disadvantage in the housing and labour market, which is still evident today (Owens, 2006). The growth of

British nationalism amongst poor White British alongside growing ideologies around race, racial divides, and eugenics amongst the elite Whites presented as influential political forces that saw politicians adopt race-based and pro-British policies (Solomos, 2022).

The right of abode or indefinite leave to remain was granted to CUKCs who settled in the UK before 1973 under the Immigration Act 1971. Simultaneously, governmental policy changes stripped these persons of their citizenship and, in some cases, resulted in some persons being denied British citizen status (Piggot, 2018; Goulbourne, 2002; Marwick, 2003; and Rosen, 2003). In 2012, the then Conservative government implemented a strategy of a hostile environment to immigrants (Kirkup and Winnett, 2012).

The strategy included legislation and policy that mandated sectors such as banking, property leasing, marriage registrars, policing, health care, schools, and homeless services to report any suspicion of persons being illegal in the country (Griffiths and Yeo, 2021). Many of the Windrush generation and their offspring were targeted, arrested, and deported. Those who escaped deportation and remained undocumented, most of whom were elderly, were restricted from fully participating in society, through the labour market, housing, and healthcare. This strategy culminated in the Windrush scandal (Piggot, 2018).

The Welsh Government's position on the Windrush Scandal is not explicitly detailed in papers on this matter. This may be because immigration is not devolved and remains under the jurisdiction of the UK Home Office. However, the broader context of the scandal, which gave rise to anti-immigrant and anti-Black sentiments, did not escape Welsh society. In their work on ultra-nationalism in Wales, Alessio (2015) suggests that whilst discourses around nationalism in Wales tend to focus on anti-English sentiments, there has been a growing anti-migrant discourse which is often shared as synonymous with nationalist ideals.

As a nation of sanctuary (Welsh Government, 2019), alongside the ambitious Anti-racist Wales Action Plan, which aims to make Wales that is anti-racist by 2030 (Welsh Government, 2024), Wales is a paradoxical society. On the one hand, there is the claim that Wales is welcoming to all, but simultaneously, there is acknowledgement that racism exists in Welsh society. This has implications for ACE with dementia living in Wales who are already victims and survivors of various forms of oppression and injustices. The next section provides a discussion on dementia and the prevalence of dementia across the UK, Wales, and discourses around ACE with dementia.

2.6. Demographics and dementia prevalence

Dementia is an umbrella term for a decline in mental cognition that is severe enough to interfere with daily life. Dementia is the broad term used to describe a group of symptoms that exist when brain cells die and stop working properly (Alzheimer's Society, 2020). Dementia is a progressive disease, and the symptoms of dementia gradually get worse with age. Symptoms are likely to include cognitive impairment, progressive memory loss, changes in mood and behaviour, impaired mobility, difficulty in communicating, disorientation to time and place, and reduced abilities to perform familiar tasks (Alzheimer's Society, 2020). Other common symptoms include behaviours such as pacing, wandering, and restlessness. People may also experience hallucinations and have difficulty expressing themselves and understanding others. There are various forms of dementia, which include Alzheimer's Disease, Vascular Dementia, and Lewy Body Dementia (Alzheimer's Society, 2020)..

The most common form of dementia that is diagnosed in the UK is Alzheimer’s disease (Alzheimer’s Society, 2020). Dementia represents a global health challenge. The number of people living with dementia worldwide is currently estimated at 47.5 million and is projected to increase to 75.6 million by 2030, and to 115.4 million by 2050 (Wortmann, 2012). The number of people living with dementia is expected to increase in the years to come due to increased life expectancy in the older population in low, middle, and high-income countries, and because age itself constitutes a risk of developing dementia.

There were approximately 885,000 older people with dementia in the UK in 2019**,** of whom 84.7% live in England, 7.5% live in Scotland, 5.3% live in Wales, and 2.5% live in Northern Ireland (Wittenberg et al., 2019). Of the four countries, England has the highest overall prevalence rate of dementia (7.2%). It is projected that the number of people aged 65 years with dementia in the UK will increase to around 1.6 million in 2040. The projected increase in the number of people with dementia varies across the four countries. Northern Ireland is projected to have the largest increase, with the number of people with dementia rising by 95%, from 2019 figures. In comparison, the smallest projected increase among the four countries is in Wales, which is projected to rise by 70%, from 2019 figures (Wittenberg et al., 2019). This must be taken with caution as figures may be underestimated given that Wales has an older age structure than the rest of the UK, alongside the lowest diagnosis rates (Prince et al., 2014; Stevenson-Hoare, 2023).

The total cost of dementia in the UK rose from £34.7 billion in 2019 to £42 billion in 2024. This figure is projected to increase to £94.1 billion in 2040 (Prince et al. 2014). The cost of dementia is made up of all the aspects of care, not just the marginal costs of dementia. Therefore, included in this figure of £42 billion are costs linked to other health or social care needs and funding provided to and by the NHS. Additionally, funding to local authorities who fund social services and some community care, the costs for police time, research and advocacy, support by voluntary organisations, and unpaid-informal care, which is usually carried out by family or friends, are also included in this figure (Sion and Trickery, 2020).

Devolved policy on social care and its financing has developed in distinctive ways in Wales. This is in contrast to the English model, where the concept of personalisation is a basis for social care delivery (Davies, 2012). The current provision for social care services in Wales is a mixed economy offered through public, independent, private, and third sector funding flows. Older adult care in Wales is delivered through a combination of public and commissioned care providers. This complex mixed economy presents significant challenges in terms of policy and planning. The greatest cost pressure arises in Social Services. Local authorities are estimated to have incurred £29.1 million in additional costs for providing older adult social services during the first quarter of 2020-21 (Sion and Trickery, 2020). Research by Saltus, Duval, and Vougioukalou (2021) highlights that there are approximately 25000 people from ethnic minority groups living with dementia in the UK.

In 2021, 93.6% of the population aged 65 years and over living in England and Wales identified in the White ethnic group, 3.8% identified in the Asian, Asian British, Asian Welsh ethnic group, and 1.4% in the Black, Black British, Black Welsh, Caribbean, or African ethnic group. The remaining 1.2% of people aged 65 years and over were identified in the Mixed or Multiple ethnic groups and Other ethnic groups (ONS, 2021). Researchers looking at statistical data referencing AC populations warn about under-representation in data sources such as the census, as people self-identify and align to changing ethnic identities, particularly due to migratory histories, demographic positioning, and whether they are first or second generations (Race Equality Foundation, 2020). As such, figures for 'Black' ethnicities in the UK census may also include people who may at different times self-identify as Black and African Caribbean (Race Equality Foundation, 2020). Additionally, government data publication may also count members of the AC population as part of the BME, BAME groups, without specifically identifying which percentage belongs to the AC group.

The full ethnic breakdown of older people in Wales is difficult to estimate because older people who identify as non-White have been under-represented in population surveys. This implies that reliance on the census as the instrument for ethnicity data collection can be problematic. Simon, Piché, and Gagnon (2015) argue that the census is a categorisation instrument that can provide statistical evidence to challenge discrimination, whilst simultaneously creating racialised statistics which can lead to discrimination. This paradox indicates the need for more engagement and research with ethnic minority older people to improve understanding of the diversity within these communities.

Research has also shown that younger-onset dementia is more prevalent in ethnic minority populations (Seabrook and Milne, 2004), with 6.1% of all reported ethnic minority dementia cases deriving from young-onset dementia (Alzheimer's Society, 2020). This is an area that requires further research. Research by Adelman et al. (2011) also concluded that there is an increased prevalence of dementia in ACE compared to their White counterparts and that ACE were on average eight years younger than their White counterparts when dementia symptoms were observed.

Studies by Roche et al. (2021) and Baghirathan et al. (2018) provided lessons about African Caribbean people with dementia and their families, emphasising the unique challenges and cultural considerations faced by this community. These studies revealed insights into how cultural beliefs about mental health and ageing, family dynamics, stigma and community support structures as well as traditional practices and values, shaped responses to dementia by ACE with dementia and their carers.

These studies highlighted the need for further research to explore the diverse ethnic beliefs and practices within this community. Understanding these cultural nuances can help develop more effective interventions and support systems that are sensitive to the needs of African Caribbean families. Additionally, there is a need to address systemic barriers within healthcare services to ensure equitable access to dementia care for all ethnic minority groups.

Vascular dementia is thought to be more common among Asian populations and ACE because these populations are more prone to specific risk factors such as cardiovascular disease, hypertension, and diabetes (Adelman et al., 2011; Seabrooke and Milne, 2004). Truswell (2019) suggests that there is limited clarity as to the clinical implications of these vascular risks and that such broad claims have yet to be confirmed through large-scale studies.

Nazroo (2003) highlights the impact of social class and lower socioeconomic status of ethnic minorities as a key risk for developing chronic health conditions, and this should be included when considering the risk factors of ACE developing dementia. Kennedy (2012) suggests that diagnostic screening tools that are not culturally appropriate, which result in overdiagnosis or misclassification of dementia as mental illness, should also be considered as risk factors for dementia in this population.

References to Black, BAME, and BME include persons from other White minority groups, for example Gypsy and Irish Travellers (Commission on Race and Ethnic Disparities, 2021). Dementia research around minoritised ethnicities makes reference to BAME populations, with a limited number of studies that look specifically at dementia in ACE. Additionally, dementia research around ACE in the Welsh context is lacking, as most research tends to use aggregated data that covers England and Wales. This ongoing practice has resulted in little to no statistical data on ACE with dementia in Wales. However, research has indicated Black marginalised individuals with dementia are overrepresented in dementia disparity research, whilst at the same time, underrepresented in statistical data (Roche et al., 2021).

Such discrepancies alongside the historic and current oppressions and discrimination faced by this group suggest that research around this group is in the public interest, as well as health and public policy makers. In the context of social work, dementia is a progressive disease, which suggests there is a likelihood of social workers having to engage with this population, perhaps at a crisis stage. Despite being a small population within Wales, practitioners need to have sound knowledge of the complexities and histories that may shape the dementia care needs of this population.

Dementia and identity

Diagnosis is seen as a public health priority as dementia is a complex and progressive disease affecting the individual, families, communities, and impacting resources (Roche et al., 2018). Willig (2011) argues that a dementia diagnosis shapes or reshapes an individual's identity and the identity of those around them. Schaepe (2011) and Chaufan et al. (2012) suggest that a dementia diagnosis provides an instrument through which professionals enact social control, as it is usually only through a diagnosis can dementia services be accessed.

In the context of ACE, a dementia diagnosis matters as this can have far-reaching implications for ACE who already undergo various forms of categorisation around class, age, socio-economic status, as well as ethnicity and race (Bond, Corner, and Graham, 2004). A dementia diagnosis can further isolate members of a marginalised group across their multiple identities. Several studies report broadly on ethnic and cultural identities and the association of these in terms of poor access to dementia services and a dementia diagnosis (Brown and Murphy, 2018; Cheston et al., 2017; Baghirathan et al., 2018). However, these studies do not adequately address the implications of a dementia diagnosis on other identities that ACE navigate within their communities and the broader society.

Understanding the impact of a dementia diagnosis on the self, social, cultural, political, and intersecting identities of ACE who are positioned as a racialised, minority group can support the design and implementation of culturally appropriate services (Brown and Murphy, 2018; Tang et al., 2015). One weakness identified across most studies that look at dementia amongst African Caribbean people in

Wales is the failure to acknowledge the real impact of an immigration status and how this presents as a real barrier to accessing dementia support.

Immigration is not a devolved matter (Williams, 2015); therefore, following the UK government's legislative discharge of the inalienable rights of ACE who came to the UK post-World War two (Goulbourne, 2002), these individuals and many within their immediate family experience an additional challenge to their identities as they are neither legally British nor legally Welsh. Instead, these persons now have the identity of 'The Windrush Generation' (Piggot, 2018). The significance of such a reshaping of these people's identities as British citizens has a direct impact on their capacity and rights to access services such as dementia care.

Additionally, research by Willis et al. (2017) highlights the impact of ageist and homophobic assumptions and prejudice faced by older adults whose sexual orientation was different to the heterosexual norms. In this context, studies on ACE with dementia failed to acknowledge the additional jeopardies or disparities faced by ACE with dementia who may identify as LGBTQI+. This is important as homosexuality in ACE communities is a site of huge debates with pervasive homophobic sentiments steeped in religiosity (Beck et al., 2016).

Such perspectives within the ACE community indicate a barrier to help-seeking in the context of dementia. Willis et al. (2017) discuss the difficulties that LGBTQI+ older adults with dementia face in terms of service provision and appropriate care, particularly in care home settings. When this issue is situated within the AC community, it can be accepted that ACE persons with dementia who may also identify as LGBTQI+ may face additional disparities from within their own communities and through a lack of services that can sensitively meet these parallel needs.

Cultural beliefs can impact one's understanding and perception of illnesses such as dementia. This, in turn, can significantly affect an individual's attitude towards approaches or compliance with treatment and access to services (Remennick, 2006). During the review process, I identified recurring themes within the literature around the framing of dementia. The decision to discuss these themes is based on the fact that the populations identified in these themes are also categorised as ethnic minorities in their respective countries. Additionally, these themes highlight the similarities, differences, and unique aspects of how dementia is given meaning across cultures. These themes add breadth to the debates around ACEs and societies' understandings, perceptions, attitudes, and experiences of dementia, whilst evidencing that such framings are not unique to ACE. I have grouped these papers under different themes, which I refer to as frames and discuss them in the following section.

2.7. Framings of dementia

Throughout history and over time, dementia has been framed and reframed. From dementia, the brain disease, to dementia as a psychosocial problem and currently the framing of dementia as a global public health crisis (Ballenger, 2017). Rosenberg (1992) argued that until there is an agreed perception, an agreed naming and a response to disease, that disease does not exist. Rosenberg's intent was not to deny the biological reality of disease, but instead, through his cultural framing, Rosenberg attempted to explain disease as also being a verbal construct which in turn influences interactions between doctor and patient, the individual and social identities, and roles.

Sociocultural constructions of dementia emerged in the late 70s and 80s (Ballenger, 2006). Whilst medical research into dementia focuses on the biological pathology of dementia, on a conceptual level, the term dementia is open to interpretation and is culturally and historically subjective. Cultural framing is one of the ways of looking at dementia that allows for recognition of the role and influence that culture has on how dementia is understood (Rosenberg, 1992). Different cultures perceive old age, ageing, and dementia in variable ways, and these perceptions change across generations and locations (Cipriani and Borin, 2015; Lyons, 2009).

Dementia as a natural process of ageing

The various 'sufferings' experienced in old age were perceived as inevitable and as a natural part of ageing (George et al., 2011). By the late 19th century and early 20th century, ageing was explored through the increasing attention to brain ageing, by examining brain tissues to understand and define the loss of cognitive functioning in old age (Engstrom, 2007). This resulted in a medicalised understanding of brain ageing that was pathological and expressed as categories of disease, dismissing the vague concept of 'natural ageing'.

Research findings from Berwald et al. (2016), Cheston et al. (2017), Parveen, Petier, and Oyebode (2017) report that ACE with dementia and their carers understood dementia as a normal part of getting old, and that it was unrealistic to try to prevent dementia because it is unrealistic to try to prevent getting old. It can be implied that by seeking help to prevent or manage dementia, one is, in fact, in denial of getting old. Similarly, research by Henderson and Henderson (2002) found that American Indians also accepted dementia as a normal part of ageing. Research conducted by Smith, Flicker, Shadforth et al. (2011) in Australia highlighted that Aboriginal people regarded one of the causes of dementia as old age.

Political framing of dementia

Ballenger (2006) and Gubrium (1986) have argued that the conceptualisation of dementia as a brain disease rather than a consequence of ageing engendered a political agenda with huge global consequences for science and society. The increasing research and public awareness agendas promote dementia as a disease, which carries implications for further research, funding, and finding a cure. Marei Krüger-Fürhoff et al. (2021) highlight that the existence of discourses, legislation, and governmental policies around dementia care raises questions of social justice and therefore suggests that dementia is inherently political. Whilst this approach may progress the agenda to find a cure, it has the consequence of ignoring the lived experience of dementia and promoting a deficit approach to dementia.

Kenner (2008) highlights this political frame of dementia through American approaches to dementia care. Through the problematising of dementia alongside the commodification of ageing within the private health care system of the United States of America (USA). According to Kenner (2008), the commodification of ageing is the process by which aspects of ageing, such as care services, and even the perception of older individuals, are transformed into marketable commodities. This transformation is influenced by broader socio-economic trends, including the rise of neoliberalism and market-driven approaches to welfare and care. Dustin (2007), in their work on the *McDonaldization of social work,* argues in a similar vein that care in social work has become commodified with the transformation of care services into market commodities that prioritise profit over quality of care.

In the context of African Caribbean elders with dementia, the commodification of ageing can create financial barriers for African Caribbean elders, as market-driven care services may be more expensive and less accessible to those with limited financial resources. Additionally, such commodification can exacerbate the challenges they face in accessing culturally sensitive care due to the commodification of ageing, which often prioritises standardised care models over individualised approaches.

Kenner further connects the USA's political framing of dementia as negatively impacting the lives of Black persons in the USA. Through a UK study looking at monitoring and surveillance technology for elderly people with dementia, Martin et al. (2007) directed our thinking to notions of power and control by the state over people with dementia, as these individuals age in places they call home.

Zeilig (2013) identified the metaphoric framings of dementia. In the UK, dementia has been metaphorically framed through the use of descriptors such as 'flooding' and 'tsunami', often depicted as something that cannot be anticipated but as something sinister that must be overcome (Wiley, 2012). Critically, such metaphorical framing is not discussed as 'lacking knowledge' or 'denial of the disease', rather it feeds into the fear of the disease and urgency for a cure. Cultural framings of dementia in Western societies, such as the UK, have resulted in an overarching, commonly accepted understanding of dementia as a threat (Furness, 2012); as a freakish condition (Twomey, 2011) or something monstrous (Behuniak, 2011).

Dementia as a spiritual phenomenon

The deep-rooted belief in faith or religion often reframes dementia as either bestowed on the individual by God or by witchcraft, and the 'sufferer 'can only be healed or delivered if it is the will of God. As such, there is little or no reliance on science or western medicine as these are not deemed effective against the work of God or witchcraft (Regan, 2014, and Mukadam et al., 2010). Research by Khonje et al. (2015) into the knowledge, attitudes, and beliefs about dementia in an urban Xhosa-speaking community in South Africa found that although most participants believed that dementia was not a punishment from God, nor from the ancestors, there was a substantial proportion of participants who held the belief in dementia as a punishment. Additionally, several participants also believed that dementia was due to a curse or witchcraft, and about half of these people also believed that traditional healers could heal dementia.

American Indians ascribed ‘super normal’ attributions to dementia as they believed it represented communications with the supernatural world (Henderson and Henderson 2002). Chinese Americans have been reported to think that symptoms of dementia are caused by retribution for individual or family sins, and an imbalance of yin and yang in the body and possession of evil spirits (Low et al., 2010).

African Caribbean Elders with dementia have religious and spiritual beliefs rooted in cultural and historical traditions that also reflect similar narratives of dementia as ‘God’s will’ or ‘punishment’ (Regan, 2014). These traditions have grown and changed over time from African traditions that have changed following slavery to the adoption of Western Christianity and, in some instances, an amalgamation of different spiritual beliefs. Additionally, research has highlighted that religious and spiritual beliefs in ACE have been used as a form of personal and treatment control in place of medical interventions (Parveen, Peltier, and Oyebode, 2017). Moodley and Bertrand (2011) refer to African Caribbean spiritual practices such as Voodoo, Santeria, and Spiritual Baptist as practices grounded in resistance that serve to preserve the cultural identity of ACE in the diaspora.

Whilst this thesis does not have the scope to delve deeper into this specific debate, the literature reviewed highlights that religious and spiritual beliefs impact help-seeking behaviours amongst ACE and can positively impact the well-being of certain members of this group. However, this thesis also acknowledges the studies that highlight the negative consequences of such beliefs, which include the perpetuation of stigma, fear, and isolation for some members of this group within their own communities (Regan, 2014; Mukadam et al., 2010).

Cultural framing of dementia

In recognition that there are many truths about a phenomenon (Hookway, 2004), this study argues against the pervading reductive narrative of ACE as ‘denying dementia’. Instead, I argue for a recognition that ACE can have a ‘different worldview of the disease’ (Meng and Brown, 2025). Acknowledgement of this different worldview of dementia can facilitate a broader understanding of the needs of ACE in the context of dementia care. Additionally, such an approach can highlight the existing strengths and tacit knowledge amongst this group. The cultural framing of dementia by ACE may also challenge current narratives and understanding around ageing within Wales (Ray, 2008; Holstein and Minkler, 2007).

Cultural values, beliefs, and norms all shape and inform the meanings ascribed to dementia as well as how those meanings are assigned (Dilworth-Anderson et al., 2002). Clara, Johnson, and Christie (2019) suggest that whilst dementia is a medical condition, attempting to understand it purely through a physiological framework is very limiting. Zeilig (2014) and Dixit (2005) suggest that through the appreciation and understanding of the influence of cultural contexts, dementia itself can be better understood. Benbow and Jolley (2012) suggest that the cultural definition and understanding of dementia has an intrinsic relationship with the level of inclusion or exclusion persons with dementia have. Additionally, the authors suggest that cultural frames impact the well-being, the types and level of stigma and discrimination persons with dementia may face, and how dementia policy and dementia care are developed and provided. The social model approach to dementia has been criticised for portraying the experience of disease and disability as a linear, White experience, often ignoring factors such as ethnicity, gender, or age, sexual orientation (Thomas, 1999).

All framings of dementia come with problematic consequences and must be acknowledged with caution. Political framings invite discourses of hopes for cures, the need for further research, surveillance, and control. Additionally, frames that view dementia as a ‘normal part of ageing’ were at one point the accepted frame, thus demonstrating that framings around dementia are not stagnant but rather they change over time and place. In the context of faith and religion, it must also be noted that such beliefs may have an impact on how well individuals cope and live with dementia. In developing the focus of this thesis, three recurring themes in the literature came to form dominant concepts in this thesis, namely, ethnicity, race, racism, and culture. These will be explored in the upcoming sections.

2.8. Ethnicity, race and racism and culture

Ethnicity

Ethnicity is a complex, controversial concept. It is hard to define, and there is a risk that attempts to define and use this term may lead to inappropriate generalisations

(Botsford, Clarke, and Gibb, 2011). Cornell and Hartman (1998) warn against the tendency of researchers to conflate race and ethnicity, resulting in the interchangeable use of both concepts. Edles (2004) further warns that such conflation fails to acknowledge that race and ethnicity are distinct identity categories in which the privileges or oppressions of those categorised are experienced very differently.

Historic attempts to define the term ‘ethnicity’ invited debate as ethnicity is an ever-changing phenomenon, which changes and shifts throughout time and life course (Ballard, 1996; Lane and Hearsum, 2007). Hall (1993) suggests that the persistent flux of cultural identities is reflected in the changing terminology that is used to describe ethnic groups. However, Edles (2004) argues that within the UK, what has remained fixed over time is the acceptance of an ethnic majority that is White, of British origin, and English-speaking (ONS, 2021). Within research, ethnicity is usually described as a shared culture, language, religion, tradition, heritage, and geographical origins, and these are also intersecting, overlapping, and potentially conflicting at the point of the individual (Helman, 2000).

The UK has had an ethnicity question in the census since 1991 (Laux, 2019). In the 1960s, nationality was captured rather than ethnicity. In the 1970’s ethnicity was determined on assumptions made by the census officer, based on the appearance (colour of skin, attire, physical features) of the individual being interviewed. The 1980s saw ethnicity determined based on the Commonwealth category of the heads of households. 1991 had the first official question on ethnicity in England and Wales with a ‘Black Caribbean’ category. In 2001-2021, new categories, Arab, Roma, were added. Black or Black British was changed to Black/African/Caribbean/Black British (Laux, 2019). These vast changes highlight the arguments by Lane and Hearsum (2007) about the constant change in terminology.

Historically, ethnicity was not recorded by the National Health Service (NHS) as this was deemed discriminatory. However, there is increased interest in ethnicity within UK health care, and it is now mandatory for NHS Trusts to collect ethnicity data, so that health inequalities in terms of access and outcomes can be monitored and addressed (Johnson, 2008; Department of Health, 2007; Commission for Racial Equality, 2002)**.** Botsford et al. (2011) warn against using ethnicity as a shorthand way to gain an understanding of an individual’s attitudes, experiences, or needs. These authors highlight the danger of using ethnicity to make generalisations which place individuals in a homogenous group, resulting in non-recognition of individuality and a compromise on person-centred care (Kondrat, 2014, and Kitwood, 1997).

Race and ethnicity data are crucial for the development of effective social work in the context of practice with ethnic minority groups, such as ACE with dementia. The lack of comprehensive, current data prevents social workers from addressing the unique needs of this population. Social work remains poor at collecting and analysing race and ethnicity data (Woo et al., 2018; Williams and Soydan, 2005). (Murji, 2020) makes the argument that major historic events, such as those that occurred in Nazi Germany and Apartheid South Africa, which stemmed from categorising individuals based on their race, ethnicity, and religion, have created a reluctance to engage with these concepts. Rao et. al. (2021) echoes this fear of the potential for misuse of such data, through the argument that policies around data protection and concerns around the sensitivity of race and ethnicity data, as well as the ethics around privacy and consent, can deter organisations from collecting data on race and ethnicity.

Roa et. al. (2021) and Murji (2020) also argue that the lack of clear definitions for and the inconsistent use of race and ethnicity have also resulted in inconsistent integration of these concepts in social work research and practice. These authors further suggest that such inconsistencies negatively impact the profession’s ability to effectively respond to systemic racism, develop policies, or make practice changes that address racism or support practitioners to recognise and challenge racial or ethnic disparities in service development and delivery.

Tarrant (2023) suggests that ongoing resource constraints in health and social care in Wales promote a generic approach to service provision. Such genericism, according to Williams and Parrott (2013), deprioritises the needs of ethnic minority groups such as ACE with dementia, who may be a small percentage of the overall population. This can lead to an uncritical approach to universalism (Gray and Fook, 2004), resulting in a one-size-fits-all approach that does not adequately consider or address the unique dementia care challenges faced by ACE with dementia.

In contrast to the UK’s approach to counting persons by ethnicity, France, Germany, and Spain have not established population monitoring based on ethnic categories.

This stance is an attempt to avoid the horrors of the Nazi era, alongside the view that interactions between the state and individuals should be based on the acceptance that the individual is a citizen with equal rights, opposed to someone belonging to a group or community (DaCosta et al., 2021). Whilst historical events should serve to inform the future, continuous refusal to engage with race and ethnicity does not prevent racial or ethnic disparities. Boulila and Carri (2017) highlight the growing levels of unacknowledged racism in Germany and argue that race and racism denial serve to increase other forms of oppression for racialised groups, particularly where gender and migration status interconnect. Berdiyev and Can (2022), De Genova (2020) also argue that despite the widespread refusal to frankly confront questions of race and ethnicity across Europe, the growth of nationalism alongside anti-migrant discourses and Islamophobia demonstrates the need to ethically and responsibly engage with race and ethnicity, to promote equity and inclusivity.

Ahmed and Bradley (2000) highlight that the status of ‘ethnic minority’ often conveys that the individual migrated from elsewhere, despite the fact that some ethnic minorities are also Indigenous people. Williams et al. (2015) recognise the complexities and dilemmas of acknowledging ethnic minorities in Wales, within policy statements, and dealing with the marginalisation, racism, and widening inequality faced by those ethnic minority groups living in Wales. The term ethnic minority is often used to acknowledge people of colour, implying that White or other non-Black persons do not have an ‘ethnicity’ when the truth is each individual has an ethnic background (Da Costa et al., 2021).

It is beyond the scope of this thesis to engage in exhaustive debate around the definition of ethnicity. Having considered the complexities of terminology that categorise individuals, I have adopted the term ‘ethnic minority’ as this is the current preferred language used across government policy documents. In 2021, the UK government also decided to use the term ethnicity and not race in its publications, to create consistency of terms and to align with data collected by surveys such as the census, which asks people about their ethnicity rather than their race. Additionally, in line with Pawson et al. (2006), I believe that, given my own positioning as a member of the ACP, I will use this term with the caution it warrants. The following section will discuss some of the key debates that surround the concept of race.

Race and racism

Race refers to the rudimentary, basic, biological definition of those socially constructed meanings and interpretations. Race is constructed socially, culturally, and politically, and the meaning changes over time (Hall, 1993). Edles (2004) argues that the anatomical and physiological basis on which race has long been defined is no longer acceptable or adequate, as these attributes provide the narrowest construct of race.

Singh (2004) argues that theories of race were developed to legitimise colonialism and the slave trade. Salifu (2007) and Cavalli-Sforza et al. (1996) argue that the entire human race evolved from one common ancestry and therefore cannot be subdivided into different ‘races’. Goldberg (2008) and Hall (1993) suggest that race is an ordering mechanism, employed by governments and institutions across different times and places, to generate specific policy. Bhattacharyya (2018) posits that race is a mode of social categorisation, which, over time, creates categories with unpassable boundaries.

This varied approach to the concept of race and how and when race is used is also evident in the UK’s approach. Whilst the UK had opted for ‘ethnicity’ within the UK census, the main piece of anti-discriminatory legislation, the Equality Act 2010, refers to ‘race’ rather than ethnicity. However, when referring to disparities, for example, across pay, this is referred to as the ‘Ethnicity Pay-Gap’ despite the fact that persons from Black backgrounds are the ones receiving the lowest pay for the same work, compared with their White counterparts (UK Government, 2021).

This disparity across policy implies that the overall stance of the UK is that race is a biological, anatomical, and physiological construct, inherent to the individual or group, with ‘unpassable boundaries’ (Bhattacharyya, 2018; Edles, 2004). As such, the attributes of race are taken as inherent to the individual or group and require legislative protection. Despite the implementation of legislation, deep and complex challenges exist in terms of proving racism has occurred. An individual must be able to demonstrate they have been treated unfairly and establish that this treatment was specifically due to race. The difficulty in proving racism is further compounded by the differences in evidentiary standards within legal proceedings and the subjective interpretations of racial discrimination (Citizens Advice, 2021). As such, the boundaries of race truly become unpassable for the individual, within themselves and within society, perpetuating racist structures, thinking, and attitudes.

Racism in its various dimensions, such as state racism and institutional racism, significantly influences the professional practice of social work assistants and senior social workers. These forms of racism create systemic barriers that affect service providers and recipients, particularly those from marginalized racial groups. Such barriers result in systemic racism and become pervasive and deeply embedded across all sectors of society and encompasses both structural and institutional racism (Braveman et al., 2022).

Understanding these dimensions is crucial for social workers to effectively address and mitigate the impacts of racism in their practice. The following sections explore how these dimensions shape social work practice.

State racism refers to the systematic and institutionalized practices and policies enacted by government entities that result in the marginalization and discrimination of specific racial or ethnic groups. This form of racism is often overt and codified within the legal and political frameworks of a society, manifesting through laws, regulations, and institutional practices that disadvantage certain populations. Examples of state racism can include discriminatory immigration laws, biased law enforcement practices (Murji, 2020) and unequal access to public services, all of which can perpetuate cycles of inequality and exclusion.

Institutional racism encompasses the broader, more pervasive set of practices and norms within public and private organizations and institutions that result in unequal treatment and outcomes based on race. This form of racism is not always codified in law but is often reflected in the policies, practices, and cultural attitudes of institutions, such as schools, healthcare systems, and businesses. Institutional racism can manifest through unexamined biases and cultural norms that perpetuate inequality without explicit intent. For example, biased hiring practices, inequitable educational opportunities, and disparities in health outcomes.

Institutional racism may result from policy implementation and has much more profound implications for social work practice. These implications include poor service delivery for Black ethnic minority groups with dementia (Saltus, Duval, and

Vougioukalou, 2021) as well as through the shaping of organizational culture within social work agencies.

Both forms of racism work in tandem to reinforce systemic inequalities, creating a cycle where individuals and groups face compounded disadvantages. The impact of these often leads to a misalignment between professional values and institutional practices. For ACE with dementia, these intersecting forms of racism can impact their access to necessary resources, culturally appropriate care, and overall well-being.

In the context of my study, I note these definitions with caution as devolution means there are some 'state' laws, such as immigration, which are not devolved, or health and social care, which is devolved. This is an important factor that is threaded throughout the Welsh context focus of this study. Although there has been an absence of race-specific legislation in the UK since the Equality Act 2010, Kamasak et al. (2019) argue that whilst the existing law may provide a framework for protection against racism, focus should shift towards enforcement, public education and sector-specific interventions.

Whilst racism, the enactment of racism, and the experience of racism have been contested as embedded within collective ethnic groups and socially constructed (Anderson, 1983; Anthias and Yuval-Davis, 1996), what remains is the growing research interest to understand the concept of racism. Several studies reviewed for this literature review raised the issue of racism faced by those from Black ethnic minority backgrounds in the context of dementia care in the UK (Roche et al., 2018; Brown and Murphy, 2018; Saltus, Duval, and Vougioukalou, 2021). Arguments have also been made implying that Wales has a history of racism which often conflicts with the dominant narrative of a tolerant and welcoming Wales (Threadgold et. al., 2008; Williams, Evans and O'Leary, 2015).

This study also acknowledges and explores the notion of dysconscious racism (King, 1991). The term refers to an uncritical approach to behaviours, thinking, perceptions, and attitudes that justify inequality and exploitation. This acceptance of the existing order of things, as a given, promotes the ideology that there is no alternative vision. Singh (2004) highlights that the pervasive reluctance to acknowledge what he refers to as ‘race thinking’ also perpetuates dysconscious racism, as denial of racism is an indication of the existence of racism.

In the context of this study, Nash et. al. (2018) highlight that dysconscious racism exists within dementia services. Studies used in this literature review highlight the utilisation of the dominant White discourses around dementia and dementia care with no acknowledgement of alternative views other than through reductive arguments (Lasrado et al.,2021; Mukadam et al.,2011). Additionally, through dysconscious racism, ACEs have been offered dementia services that have been tested and developed for the White majority population. These services are often ‘adapted’ for other communities in ways that fail to recognise diversity, and as such, dementia care is not appropriate (Saltus, Duval, and Vougioukalou, 2021).

Participants in some studies used in this literature review also reported historic and negative experiences with services, racial discrimination, and an overall feeling that professionals were not listening to their concerns, and a lack of culturally appropriate services (Roche et al., 2018; Brown and Murphy, 2018). The literature reviewed also highlighted ACE with dementia experienced structural, institutional and systemic racism. Structural racism is manifested as overarching systems of racial discrimination that is embedded across multiple institutions and sectors of society such as housing and criminal justice (Gee and Hicken, 2021).

Such experiences provided insight into the lack of culturally appropriate resources, such as diagnostic screening tools and dementia care systems that were not designed or developed to meet the needs of diverse populations. Additionally, the literature highlighted the negative impact implicit biases and stereotyping can have on service provision for ACE with dementia (Reynolds et al.,2023; Lasrado et al.,2021; Roche et al, 2018). Dysconscious racism will be explored in more detail in the chapter that looks at social work, specifically at social work knowledge as steeped in inherently racialised, White dominant discourses (Heron 1999; Rossiter 2001).

My own stance on race and racism is that both the biological and social debates have merit and will be discussed throughout this thesis in the context of the biological and the socially constructed interpretations. I believe that this will add insight into the key focus of this research by presenting alternative world views.

According to Singh (2004), the continuous ‘racialisation’ of non-White populations has far-reaching implications for those populations. It is in this vein that Salway et al. (2011) argue that it is imperative that all research acknowledge and engage with ‘race’. Within my study, the overlap between ethnicity, race, and culture was evident. The next section will discuss a conceptualisation of culture that presents culture as a separate, yet intertwined concept.

Culture

Fletcher-Jansen et al. (2000) suggest that culture refers to those beliefs and behaviours that are ascribed to specific people. Scholars such as Kroeber and Klukhohn (1952; Durham,1991; Spencer-Oatey and Franklin, 2012) argue that culture is difficult to define and conceptualise. Raeff et al. (2020) argue that although it is important to demonstrate that culture and diversity matter when attempting to understand the world, it is necessary to go beyond this and look at *how* culture matters. The authors further argue that ways in which culture is evidenced in behaviours and development can inform the development of culturally sensitive programmes or services in order to address key global issues such as dementia. Causadias (2020) conceptualises culture through a ‘p-model’ to illustrate racism experienced by minority children in America. This model looks at the interactions of people, places, practices, and power. This conceptualization of culture is of particular relevance to this study as it defines culture through a systems lens (Overton, 2010).

This conceptualisation can offer support to arguments within this study as to the influence *of* culture and *on* culture when looking at dementia within the context of ACE living in Wales. An adaptation of Causadias’ p-model highlights that the combination of African Caribbean People (ACP) living in Wales, within ‘places’ of residential segregation as a result of ‘practices’ such as ageism, racial discrimination, creates a culture system. This culture system, in turn, exerts power *over* and *within* AC communities. Research by Williams (2011) examined the impact of immigration to Wales and how notions of nationalism can create residential segregation for ethnic minorities living in Wales. Research by Reynolds et. al. (2023) and Parveen et. al. (2017) highlights the significant ‘*practices*’ such as religion, caregiving, and traditional medication, and the role these play as part of the whole AC culture system. The authors also suggest that understanding that practices such as immigration, stigma, ageism, and racialised persons exert '*power'* over AC people is crucial to the development of fair and inclusive services.

While African Caribbean Elders (ACE) with dementia in Wales and the broader UK face significant challenges related to dementia, the literature highlights the importance of researchers and other stakeholders considering the broader context in which health and social care disparities occur. The literature calls for a deeper understanding of the socio-economic and cultural dynamics at play and an acknowledgement of the pervading forms of racism that hinder service development and delivery.

2.9. Gap in study and rationale

Significant to this research is the general pervading finding across all studies that ACE present to services at an advanced stage of dementia (Roche et al., 2018; Cheston et al., 2017). Given that social workers usually enter people's lives at a crisis stage, particularly in social work with older adults (Boyle, 2015), it is imperative that social workers and social work itself are duly prepared to engage with ACE with dementia. This study hopes to address the following gaps, which were identified across the literature review.

Gap in population

Although there is a growing body of research into dementia amongst racialized groups, African Caribbean populations are continuously aggregated with other Black ethnic minority groups. My study aims to bring research focus to African Caribbean Elders, to add to the knowledge base of the state of dementia support for this population in the context of social work and dementia. Additionally, where studies referred to 'professionals', it was not clear if social workers were included. By focusing on social work practitioners supporting older adults with dementia, my study aims to bring focus to the social work profession, in the context of dementia care, older adult care, and social work with a specific population, ACE with dementia.

Conceptual gap

Although several studies in the literature review reported on the understanding and perception of practitioners, there was no clear definition in any study as to what these concepts mean or how they were operationalised in the studies. I attempt to fill this knowledge gap by using these concepts within the disciplinary focus of social work with ACE with dementia in order to bring attention to the complexity and usefulness that underpin these concepts that are often assumed to be universally understood.

Contextual gap

Social work research identified in this review, from the UK, presented data from England and Wales. It was not clear which aspects of the findings were Wales-specific. This review did not locate any studies that combined ACE, social work, and dementia within a Welsh context. My study will address this gap by focusing on Wales-only practitioners to provide insight into social work with ACE with dementia through the Welsh context.

Also absent in the studies reviewed were clear definitions of the concepts understanding and perception. There was also a lack of deep analysis of these concepts, their influence on social work knowledge development, or practice. Additionally, these concepts were used in a ‘taken-for-granted’ way, implying that there is a universal acceptance of what these concepts mean. Further, this review did not locate any social work studies that conducted deep analysis of the structures that shape the understanding and perception processes of social workers.

Gap in social work knowledge

The combination of the research gaps above is a reflection of an overall knowledge gap in social work. My study hopes to add to the scholarly body of knowledge that informs social work practice with ACE with dementia, within the Welsh context.

To this end, my research seeks to answer the overarching research question:

‘*How do social workers understand and perceive the care needs of African Caribbean Elders with dementia, living in Wales?*’

More specifically, this study will explore and answer:

1. *How do social workers understand and perceive race and ethnicity?*
2. *What approaches to dementia service provision do social workers use with African Caribbean Elders with dementia?*
3. *How are social workers supported when working with African Caribbean Elders with dementia?*

The next chapter will situate social work within dementia care in Wales and present discussions around the usefulness of the concepts perception and understanding by connecting them to social work knowledge development. The chapter also includes in-depth discussions around the theoretical frameworks underpinning this study.

Chapter 3

Conceptually and theoretically situating social work

3.1. Chapter Overview

This chapter will present salient discussions around social work, specifically within the Welsh context. Discussions will link social work and dementia service provision, with discussions drawing on notions of universalism and how social work knowledge might be reconceptualised. Next, I will present philosophical debates underpinning the concepts understanding and perception and link them to social work knowledge and practice with African Caribbean Elders with dementia. Lastly, I elucidate the theoretical frameworks that I employ in this study: Critical Race Theory (CRT) and Intersectionality Theory.

3.2. Social work definition and Welsh context

The International Federation of Social Workers (IFSW 2014) defines the social work profession as a practice-based and academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility, and respect for diversity are central to social work. Underpinned by theories of social work, social sciences, humanities, and indigenous knowledge, social work engages people and structures to address life challenges and enhance well-being (IASSW and IFSW 2014, p. 224).

Whilst IFSW postulates global social work objectives, social work practice is contextualised. According to Cox and Parwar (2006), American social work is inclined towards addressing the needs of individual service users. In China, social work focuses on the mobilisation of the masses to address social problems. Latin American social work is social justice-oriented, whilst in Africa, social work is becoming increasingly focused on social and community development. These differences, therefore, reflect the profession’s responses to changing regional needs, profiles, or outlines and service users’ resource needs at regional, national, and local levels (Cox and Parwar, 2006). This diverse approach to social work, as presented by these authors, implies that attaining a global social work purpose is not linear.

Payne (2014) advises that there is no single definition for social work. Rather, social work is constructed through interactions between social workers, their organisations, other professionals, and people. Legislative changes can redefine the role of social work within society, often positioning it as a mechanism for managing social issues rather than addressing the root causes of inequality. This shift can lead to a transformation in how social work knowledge is perceived and utilized, emphasizing individualistic approaches over collective or structural solutions. Local policies establish the legal and regulatory framework within which social workers operate. These policies dictate the standards of practice, ethical guidelines, and the scope of services that social workers can provide.

Policies determine the allocation of resources, including funding for social services. When local governments prioritize certain areas, such as mental health or housing support, social workers may focus their efforts on these areas, impacting the breadth and depth of services available to clients. This can lead to disparities in service provision based on the political priorities of a region. Policies can influence the training and professional development opportunities available to social workers. Policies that emphasize evidence-based practices may encourage social workers to pursue specific training, thereby shaping the knowledge and skills they bring to their practice. This can affect how social work knowledge is generated and applied in real-world settings

Social work practice in Wales is described as distinct from practice across other parts of the UK, as practice in Wales is governed by legislation that has pursued a progressive universalism, thus rejecting the big society concept and market-led English model (Rees and Raithby, 2012; Drakeford, 2007). Instead, social work practice in Wales requires a collaborative, co-productive and strength-based approach where social workers work alongside people to meet their personal outcomes.

The Social Services and Wellbeing Act 2014 (SSWBA 2014) represents the efforts by the Welsh Government to have a distinctive policy identity in the context of adult social care (Evans, Smith, and Williams, 2021). The notion of ‘personal outcomes’ is particularly important to the Welsh context of this study as it reflects the ongoing divergence of Welsh approaches to social welfare in comparison to those of

England. Wales rejected approaches to the welfare state which characterised citizens as ‘consumers’ and instead campaigned for universal, equitable services, free at the point of use, facilitating equal outcomes as well as equal opportunities (Evans, Smith and Williams, 2021). In contrast, Burrows (2020) puts forward arguments that suggest that, despite the aspirations of the 2014 Act, a care management approach still dominates social work practice in Wales.

This study will draw on the notion of a post-colonial Wales, as it is relevant to contextualise ACE living in Wales. ACE have a post-colonial history with the UK, as belonging to former colonies owned by the UK and as a diaspora coming to the UK after the Second World War (Roche et al., 2021). This highlights examples of diversity amongst ACE, such as regional, cultural, ethnic, and racial backgrounds and language. Additionally, Wales has a contested England-Wales history (Thomas, 1999) that has resulted in Welsh regional diversity, which makes it difficult to identify a ‘pure’ or ‘distinct’ Welsh identity. Fanshaw and Skriskandarajah (2010) highlight that whilst the demographic profile of Wales is small, it is increasingly diverse, thus being classified as ‘super diverse.’ Such diversity extends to the range of needs that individuals seek social work support for. The next section will discuss and link social work in the context of dementia care.

3.3. The intersection of social work and dementia

Social work is defined as an empowering practice that must consider human rights and social justice (IFSW 2014). To fulfil this, social work is underpinned by anti-discriminatory (ADP) and anti-oppressive practice (AOP)values (Thompson and Thompson, 2008). These values involve recognising the impact that discrimination has on an individual’s life. Social workers need to be aware of the impact of racism, ageism, under stigma on the life of an ACE with dementia. Social workers should also be aware of their own personal values to ensure that their practice does not reinforce or add to such discrimination (Banks, 2012).

Whilst studies reviewed for this literature review did not highlight any role or task specific to social work with ACE with dementia, some papers did refer to social work tasks with older people with dementia, which include care management, advocacy and community development (Boyle, 2015; Mc Keown et al., 2010; Manthorpe and Iliffe 2009; Moriarty, Sharif and Robinson, 2011). This review will also discuss two specific tasks within the legislation that governs social work practice in Wales. These tasks are safeguarding and assessment, and they are significant to this study as they underpin an individual's eligibility for support.

Safeguarding

Within the (SSWBA 2014, s.126), the key duty defined is the protection of people from abuse, neglect, and harm. Whilst the protection of people is a vital duty, the Older People's Commissioner for Wales argues that the definition of adult at risk as held within section 126 of the Act has the potential to exclude persons who do not meet such criteria. This is particularly relevant as there may be older adults at risk, without pre-existing needs, who will not qualify for care and support. This is particularly important in the context of ACE and dementia care, as several studies report the notion of ACE 'looking after their own' and are often overlooked in service development. Participants in such studies argue against this notion, citing that they were in fact struggling to keep their relatives with dementia safe (Lawrence et al., 2011; Adamson and Donovan, 2005). This approach by services ignores the concept of Safeguarding as 'everyone's business (NHS Wales, 2021) and potentially can lead to harm to ACE with dementia.

Assessment

Through national occupational standards for social work practice and the Codes of Practice guidelines for social work practice in Wales, the Welsh government foregrounds the importance of the relationship between the social worker and the individual and their carer (Social Care Wales, 2017). Under the Welsh framework, social workers must adopt an approach that acknowledges that the individual is best positioned to determine what contributes to their own well-being. This is particularly important within the context of assessment. Social workers must have due regard for the individual's circumstances, their well-being outcomes, and any barriers or risks to achieving such (SSWBA 2014, s.19). Assessments must be appropriate and proportionate, allowing a balance to be found between people's strengths and the barriers to achieving outcomes. The Act also provides for the combined assessment of carers and cared-for people, subject to consent. (SSWBA 2014, ss.28 and 29).

This study has a focus on social work with older persons and specifically, those older persons who have a diagnosis of dementia and identify as African Caribbean Elders

(ACE with dementia). Milne et. al. (2014) and Kane (2008) suggest that there is a lack of specialist social work training through academic institutions, thus perpetuating the belief among social work students that social work with older adults has less value compared to social work with children and families. Social work with older people is affected by ageist attitudes that negatively impact assessments and intervention decisions for older people. Graham and Schiele (2012) argue that whilst anti-discriminatory frameworks are progressive steps in highlighting the impact of discrimination and oppressive structures and processes, this framework is still limited in its ability to highlight the continued significance of racism in contemporary social work education.

McDonald (2007) and Healy (2008) suggest that, as a human rights activity, social work must effectively use its roles and power to challenge all forms of discrimination. These include ageism and arbitrary decisions about older persons with dementia from marginalised and racialised groups. Social workers must recognise the human rights implications when working with marginalised persons and persons who have dementia. This human rights approach also takes on a social justice approach when working with persons who have multiple identities (Ife, 2012). Social work is well-positioned to challenge narratives of dementia that inadvertently promote ageism or solely focus on an individual’s pathology rather than including a focus on their social needs and influencing societal response. Only limited attention has been given to the sociocultural needs of ethnic minorities within dementia (Atkin,1998; Patel et al., 1998). The next section provides insight into the provision and development of services, which are a crucial element of social services support.

3.4. Service development and service provision in social work

Universalism

The concept of universalism in social work suggests a standardized approach that applies general principles across different contexts, while recognizing the unique challenges faced by ethnic minority groups. Universalism in social work is characterized by the application of general principles and practices across different cultural and ethnic contexts. This approach is often seen as a way to ensure consistency and fairness in service delivery.

Universalism in social work refers to the belief that certain rights, values, and services should be available to all individuals, regardless of their background or circumstances. This perspective is rooted in the idea that human rights are universal and should be upheld across all cultures and societies. Universalism posits that social work practices should prioritize the needs and rights of individuals, advocating for social justice and equality (Dominelli, 2002). It emphasizes a standardized approach to service delivery, where interventions are designed to be applicable to all, thus promoting inclusivity and equal access to resources.

The quest for a universal social work practice is driven by trends towards globalism, which seeks to establish common standards and practices across different countries. Additionally, the IFSW (2014) also established global mandates for social work. However, this is often set against localism and multiculturalism, which emphasize the importance of context-specific practices (Gray and Fook, 2004).

One of the significant benefits of a universalist approach is the standardization of services. This can lead to more efficient resource allocation and service delivery, ensuring that all individuals receive a minimum level of care. As noted by Healy (2005), universalism can streamline social work practices, making it easier for practitioners to implement interventions that are evidence-based and widely accepted.

The universalist approach in social work has been criticized for potentially undermining the capacity to deliver ethnically sensitive services. In Europe, the rise of neo-nationalist sentiments and assimilationist policies has put pressure on the inclusive values of social work, challenging the ability to provide appropriate services to ethnic minorities (Husband, 2007). Another critique of universalism is that it may lead to cultural insensitivity. By focusing on universal principles, there is a risk of overlooking the unique cultural and social dynamics of different communities, potentially leading to ineffective or inappropriate interventions.

Universalism has been critiqued for its inability to adequately address the complexities of intersectionality—how various social identities (such as race, gender, and class) intersect and influence individuals' experiences. Crenshaw (1989) argues that a universalist approach may inadvertently marginalize individuals with multiple, intersecting identities, as it often prioritizes a singular narrative that does not reflect the diversity of experiences within a population.

This study offers anti-racist social work as a response to the limitations of universalist approaches, and this perspective is discussed in-depth throughout chapters 7 and 8. However, I acknowledge that its prominence within practice has diminished over time, partly due to a shift towards anti-oppressive frameworks, which some scholars argue have diluted the focus on race-specific issues (Williams, 1999).

Institutional racism remains a pervasive barrier, with Black social workers and individuals from racially minoritised backgrounds experiencing persistent discrimination within the system (Tedam and Cane, 2022). Critiques of anti-racist approaches have highlighted concerns about their effectiveness, noting that they often lack a comprehensive understanding of Black perspectives and risk reducing the complexity of racial issues to mere opposition to racism (Banaji, Fiske, and Massey, 2021). Furthermore, anti-racist social work has been critiqued for its prescriptive nature, which can overlook deeper theoretical debates that might otherwise enrich and inform practice (Hanna, Arnold-Renicker, and Garza, 2021).

While universalism aims to provide equal access to services, the reality is that resources are often limited. This can lead to a dilution of services, where the quality of care provided to individuals may be compromised in the effort to serve everyone equally. As noted by Fraser (1997), this can create a paradox where the pursuit of universalism results in inadequate support for those who may require more tailored interventions. Both approaches to practice are embedded in debates around their usefulness and capacity to evolve to meet the changing needs of communities and social work practice. The following section aims to bring attention to debates around social work knowledge.

3.5. Reconceptualising social work knowledge

The main aim of this research is to understand and explore social workers' perception of race and ethnicity in the context of dementia care for ACP, situated within the broader debates around what constitutes as social work knowledge base for work with ethnic minority persons with dementia. The status of social work as a profession has also been challenged based on the nature of social work's knowledge base (Flexner 1915; Rogowski 2000). Social work is often the site of unfavourable comparisons to the medical professions, and many social workers report difficulty in having social work knowledge accepted above that of medical professionals within multidisciplinary teams, when working with people with dementia or mental illnesses (Frost, Robinson and Anning, 2005). Cropper and Hamalanies (2007) argue that social work lacks coherence and systematic structure in terms of the theories and knowledge used by social workers.

The positivist approach of medicine, acquiring factual, proven, and tested hypotheses to justify action in terms of diagnosis and treatment, is in contrast to social work, which acquires its knowledge from various sources and schools. For example, this study comprises knowledge from sociology, political and cultural studies, psychiatry, as well as knowledge from African Caribbean individuals, their carers, and service providers. Parker and Dael (2013) suggest that this approach by social work to include various sources of knowledge demonstrates the social and moral characters of the profession. This combination of different types of knowledge makes it difficult to define what social work knowledge is. In defence of social work’s approach to building its knowledge base, Thyer (2002) argues that knowledge itself does not recognise any specific discipline and, as such, should be utilised by all of science.

Tascon and Ife (2020) further argue that the promotion of White dominant discourses within social work makes social work knowledge inherently racialized. This is evident in what they refer to as the Whiteness of social work, also evident in Wales, where 94.9 percent of social workers in Wales are White (Social Care Wales 2017). This is not to say that White social workers may not be inclusive and consciously anti racist; however, without acknowledging the White dominance that they bring to social work practice, they will inadvertently perpetuate colonial and racist oppression and disadvantage, particularly when working with racialized groups.

Parton (2009) and Fawcett (2013) argue that the way social work knowledge is constructed, understood, and shared and used is from within a White Western paradigm and that there is a need to critique this social work so that other ways of knowing are acknowledged. They argue that knowledge itself is culturally constructed and that terms such as ‘professional knowledge’, ‘knowledge base’, and ‘practice knowledge’ add dominant Western world views that seek to commodify and package knowledge for the consumption of practitioners. The next section builds on these debates around social work knowledge by shining a light on often-taken-for-granted concepts, understanding, and perception.

3.6. Philosophical attributes of understanding and perception

Although several studies in the literature review reported on the understanding and perception of practitioners, for example, (Guterman, N. B. & Bargal, D., 1996; Beddoe, Staniforth, and Fouché, 2019), there was no clear definition in any study as to what these concepts mean or how they were operationalised in the studies. I attempt to fill this knowledge gap by using these concepts within the disciplinary focus of social work with ACE with dementia in order to bring attention to the complexity that underpins these concepts that are often assumed to be universally understood. I posit that understanding and perception are not mere abstract concepts; rather, they are continuously operationalised in social work through the philosophical underpinnings, epistemology, ontology, and methodology that shape social work practice and research.

Clear definitions of these concepts can support social work researchers and practitioners in improving communication with diverse participants and individuals from diverse backgrounds who are in need of care and support. Additionally, clear definitions can provide a framework for practitioners to reflect on their response to the needs of diverse populations, such as ACE with dementia, as well as reflect on how services or interventions might be developed to provide person-centered care.

I acknowledge the ongoing philosophical debates concerning ‘how’ perceptual knowledge of the external world can be made possible. Cohen (2021) argues that perceptions are not necessarily reflections of reality, and it is not possible to have genuine knowledge through perception. Lyons (2016) argues that there are too many variables at play to make the knowledge provided by perceptions reliable. For example, (Hérault, 1995) argues that the biological state of an individual can influence the perceptual knowledge they produce. Debates around perception have spanned decades and continue to grow. The challenge of developing a clear definition and consensus on the role and usefulness of perception in knowledge production across other disciplines and within philosophical arenas may explain social work's reluctance to create its own definition, despite ongoing use of this concept within social work research.

Perception starts with our senses. It involves sensory awareness and the ability to interact with our environment through our senses. As we process sensory information through sight, hearing, for example, we begin to interpret that information and create a mental image or understanding of what is being perceived, and we develop meaningful comprehension or action (Audi, 2018). In addition to our senses, memories, and past experiences, as well as the social and cultural contexts in which we are experiencing the phenomenon, are integral to the process of perception. In the context of this study, a social worker might 'see' an ACE (Black individual, grey hair), hear (a unique accent), and at the end of the sensory processing, the social worker may come to perceive the ACE as a Black Older individual who is perhaps not from Wales. If the social worker has (positive/negative) lived experience of interacting with ACE, the social worker also draws on these memories to further aid their understanding and choice of action.

As such, the perception-understanding-action link is important to social work practice with ACE with dementia and warrants a move that goes further than 'reflecting on one's values'. The structures and mechanisms that have the potential to shape a practitioner's perception, according to Audi (2018), ultimately shape the choices the practitioner makes. In the context of practice with a racially marginalised group that experiences oppression across several interconnected identities, how a social worker perceives them has the potential to impact the practitioner-individual relationship.

Studies drawn upon in the literature review that looked at how ACE /BAME individuals with dementia perceived the illness all reported on how individuals initially perceived the illness (natural process of ageing, 'denial'). Each perception resulted in action (help seeking or no action). The studies highlighted the subjective nature of perception and how this can impact the way individuals respond to the illness. (Cheston et al., 2017; Adamson & Donovan, 2005). In earlier discussions around the framing of dementia, individuals with strong religious or spiritual beliefs perceived dementia as an act of God, and such perceptions impacted their response to the illness. Perception is also shaped by an individual's cultural background and social factors such as class, socio-economic status, and gender. When individuals from different cultures interact, misunderstandings or new understandings can occur as their perceptions about the phenomenon differ or have shared meanings.

Epistemology significantly influences social work practice by shaping how knowledge is produced, understood, and applied (Hothersall, 2025). From an epistemological stance, understanding and perception can be operationalised to highlight the ways in which social work knowledge is acquired, legitimised, and applied in practice. In the context of this study, I am interested in how/where/through what mechanisms social workers gain knowledge about race and ethnicity, how their knowledge is validated and applied in practice with ACE with dementia.

Ontology in social work refers to the nature of reality and how practitioners perceive and understand these realities (Hothersall, 2025). The ontological stance of practitioners in the context of practice with ACE with dementia is important as this population, by way of multiple marginalised and racialised intersectionalities, face several disadvantages across society and in particular, across dementia care.

Brewer (2008) suggests that perception is not only a sensory experience but also a cognitive process that involves sensory input and interpretation to help us form understandings of the environment. Past experiences, cultural background, and societal norms can also shape perception. Perception is linked to epistemology as perception creates a foundational basis for knowledge acquisition. Sensory input and interpretation provide us with the initial information needed to form beliefs about the world around us. Audi (2018) goes further to suggest that, in addition to sensory input, we need conceptual capacity to analyse, interpret, and make sense of the world. For example, in the context of this study, a social worker supporting an ACE with dementia would require additional concepts, for example, inequalities, discrimination, to be able to move beyond the visual experience of seeing a (Black, elderly person) to recognising the other intersecting identities and how these might shape the support provided.

According to Janvid (2014), the concept understanding is subjective in nature. Individuals can have contrasting understandings of the same subject matter. Cultural, historical, and linguistic factors can influence understanding. Literature review of how understanding might be linked to epistemology, highlighted work by

Gordon (2017), who argues for the notion of ‘grasping’. This author suggests that through ‘grasping’, understanding can be defined as more than knowing and memorisation, requiring subjects to demonstrate deeper levels of cognitive processing and active engagement, and application of knowledge.

Research by Kudryavtseva (2013) and Hannon (2021) suggests that understanding supports individuals to critically engage with complex information and encourages deeper questioning and exploration of information so as to achieve more meaningful engagement with their environment. Gordon (2017) puts forward the argument that whilst an individual may possess knowledge about a subject, in terms of facts, understanding demonstrates the individual has a ‘grasp’ of the connections and relationships between those facts. In the context of my study, social workers demonstrating understanding of the needs of ACE with dementia would connect the knowledge they hold of ACE with dementia and ‘grasp’ that culturally appropriate care is required.

Summary of understanding and perception

According to (Hothersall, 2025), epistemology in social work refers to the study of, acquisition and application of knowledge. Ontology in social work refers to the nature of social realities and the existence of social phenomena, which are often constructed through shared beliefs and practices (Hothersall, 2025). These philosophical underpinnings shape the methodologies and practices within social work, influencing how practitioners engage with individuals and communities.

Understanding and perception are frequently used concepts in social work research. However, there is a lack of definition and consensus on how these concepts are interpreted, studied, and applied in research. By exploring the nature and value of understanding and perception as more than mere abstract concepts, social work researchers can gain insights into other epistemological issues, potentially leading to new theories and perspectives to improve all areas of the profession. The following section discusses the theoretical framework that underpins this study.

3.7. Theoretical frameworks

Critical race theory (CRT)

Lysaght (2011) suggests that selecting and using a theoretical framework in research is not arbitrary, as it reflects the beliefs and understandings of the nature of knowledge held by the researcher. A theoretical framework provided structure and vision of the research, and it guided my choice of philosophical, epistemological, methodological, and analytical approaches to the study (Mertens 1998). The social work profession places a strong emphasis on the utilization of theories in social work education and social work practice (Trevithick, 2000). This suggests that theoretical frameworks can bridge the gap between research, practice, and education by providing a deeper understanding of complex issues via research and informing the development of the social work curriculum and practice interventions.

Dominelli (2008) and Crenshaw (2011) argue that in order for social work research to address issues such as ethnicity, race, racism, and other intersecting axes of oppression, social work must go beyond anti-oppressive and anti-discriminatory approaches that fail to challenge such structures of power that produce or reproduce oppression. Williams and Graham (2016) and Coxshall (2020) put forward the arguments for a shift in social work education to adopt an intersectional and culturally competent framework that is underpinned by reflexivity, which would enable practitioners to engage with their biases and the ways these may affect their practice. In order to pay attention to this argument, this study is underpinned by an integrated theoretical framework incorporating tenets from critical theories that allowed me to explore the contextual nature of age, race, racism, ethnicity, and dementia in this study. Critical theoretical approaches to social work research are not new in the UK, as this was a mandatory requirement across social work education and training to address endemic racism of Black minority ethnic groups and the need for social work to understand the nature of structural discrimination (Coxshall, 2020).

Critical Race Theory was not developed for research, but rather as a move within the legal studies in the USA to expose the ongoing impact of racism on the lives of people of colour (Delgado, 1995; Bhopal, 2018). However, CRT has been employed in social work education as a conceptual framework for teaching about diversity (Quinn and Grumbach, 2015), and the (American) National Association of Social Work (NASW) suggests that CRT is a strong fit for social work research as it aligns with social work pursuits of social justice, competence and human relationships (NASW, 2017). Additionally, the use of CRT as a framework for research within the applied sciences is growing (Delgado and Stefancic, 2012). CRT has an interdisciplinary foundation and draws on ideas from social movements, philosophy, and disciplines such as history, sociology, gender studies, post-colonial studies, and ethnic studies. This makes CRT well-suited to several disciplines (Delgado and Stefancic, 2012).

Critical Race Theory (CRT) offers a valuable framework for examining the systemic racism and social injustices faced by ACE with dementia. It highlights how structural inequalities rooted in race can shape access to care, treatment outcomes, and broader social experiences. However, it has been critiqued for its emphasis on race and systemic oppression that may inadvertently marginalise and limit understanding of intersecting factors such as culture, religion, and socio-economic status (Aronson and Meyers, 2022). This narrower focus can limit the holistic understanding essential for effective social work practice with ACE living with dementia (Daftary, 2020).

Additionally, practitioners may struggle to apply its principles in ways that directly inform day-to-day interventions (Daftary, 2020). Another critique is the risk of essentialism – the assumption that members of a group share uniform experiences. This assumption can obscure intra-group differences (Fletcher, 2020; Milne and Chryssanthopoulou, 2005) as discussed in chapter 2. Regan (2014) suggests that standpoint theories, while offering valuable insights into subjective experiences of marginalized groups, may lack the explanatory power needed to understand complex issues like dementia that are influenced by a multitude of factors beyond race and ethnicity.

The main rationale for utilising CRT in this study is an acknowledgement that race is part of the fabric and demographic of Wales and is a contested and fluid construct, but one that is recognised by the Welsh Government as a site of inequality. This has resulted in the Anti-Racist Wales Action Plan (Welsh Government, 2024). Coxshall (2020) suggests that CRT is based on the premise that many Western societies are fundamentally racially stratified and unequal, and there is an ongoing, systematic disenfranchisement of racially oppressed people. Hickman et al. (2005) argue that across the UK, racial categorisation serves to place individuals into groups for various forms of race and ethnicity monitoring. Such arguments suggest that race is central to social and political life in Wales, and therefore, social work practice in Wales is not excluded from the impacts of the construct of race. This can be seen in assessment plans that require social workers to collect racial, ethnic, cultural, and religious data. Although collating such data is done in an attempt to address the problems associated with racial discrimination, without understanding the broader implications, there is the risk of perpetuating those problems. For example, such data can be misinterpreted in ways that reinforce stereotypes. Race is also significant to my research as I am exploring elements of social work practice with a racially marginalised ethnic group with dementia. Daftary (2020) and Jeffers (2019) suggest that CRT is a vital tool that can be used to advance understandings of how race and racism might shape social work practice.

CRT allowed me to consider to what extent race shaped social workers' understanding of the dementia care needs of ACE with dementia, as well as the approaches they adopted when working with this service user group. Through the promotion of intersectionality theory, CRT provides a way of challenging structures of power that perpetuate or create oppression and discrimination, thus making CRT a good fit with intersectionality theory.

Intersectionality theory

Intersectionality theory (Crenshaw, 1989) was intended to address the failure of White feminist discourses to recognise and address the distorting and lack of acknowledgement of the experiences and struggles of Black women. According to Collins (1991), when utilised as a critical, theoretical, or analytical framework, intersectionality can reveal interlocking systems of privilege and oppression, such as racism, sexism, heterosexism, and classism at the macro social-structural level. Such systems have developed at the points where different social identities, such as age, race, gender, sexual orientation, socioeconomic status, and disability, intersect at the micro level of individual experience. May (2015) suggests that intersectionality theory allows for a matrix perspective over a single-axis perspective when investigating the simultaneous operations of power and privilege.

Ageism and the social stigma attached to dementia intersect with racism to create compounded challenges for individuals with dementia, particularly those from minority ethnic groups (Wong, Johnson, and O'Connor, 2024). The intersectionality of these factors is rooted in social determinants of health, such as social support and healthcare access, which further compound health disparities (Steward et al., 2024).

This complex interplay of ageism, stigma, and racism necessitates a nuanced understanding to inform effective interventions and policies.

Wong, Johnson and O'Connor (2024) suggest that cultural and racial backgrounds significantly shape the experience of stigma and discrimination. Older adults from ethnic minority groups with dementia often experience "triple stigma," which includes ageism, dementia-related stigma, and racial discrimination. This triple burden leads to increased vulnerability and invisibility, as individuals face compounded discrimination from multiple sources (Wong, Johnson and O'Connor, 2024). Bacsu et al. (2023) argue that experiencing oppression compounds disadvantage throughout life, so that an individual who has experienced racism throughout their lives will find it even harder when ageism and dementia stigma are thrown in.

In line with the notion of interlocking systems of power and privilege at the macro social-structural level (Collins, 1991). I adopted intersectionality theory as part of the combined theoretical framework that underpinned this study. I was mindful of the warning by Moradi and Grzanka (2017) to ensure responsible stewardship of intersectionality. To do this, I paid attention to the rich history of intersectional activism that preceded and attempted to use intersectionality theory to support a reflection and extension about epistemology in research by acknowledging possible interlocking systems of privilege and oppression (racism, ageism, ableism) and explored how these might be implicated in the processes of knowledge production within social work practise with ACE with dementia.

My research had a focus on social work practice with a marginalised group, ACE with dementia. Additionally, the participants for my research were social work practitioners; therefore, I reflected on the usefulness and implications of intersectionality theory for both practitioners and practice. In research by Hudson and Mehrotra (2021), who looked at the implications of utilizing intersectionality theory on practice and practitioners, the findings highlighted that knowledge of intersectionality theory allowed practitioners to address issues around power, privilege, and acknowledge the impact of their own social locations. In the context of practice, the findings highlighted the use of intersectionality theory to bring focus on individual identities rather than on systemic or structural interlocking systems of oppression.

In contrast, Moradi and Grzanka (2017) have argued against the individual-level, identity-based framing of intersectionality and call for a deeper focus on interconnected dynamics of power. Grzanka (2018) suggests that more work that addresses intersectionality at systemic and structural levels is needed if social work scholarship is to attend to its social justice aims. Additionally, intersectionality theory can be operationalised to highlight the political intersectionality of social work and how this may impact practice with ACE with dementia. Social workers have significant powers that they use on behalf of the state (Gray et al., 2002; Lipsky, 2010), and such powers have direct implications for both civil and human rights of citizens. Social work is underpinned by policies, legislation, and benefits from the often taken for granted socio-political project (Parker, 2020) that social workers are engaged in with the state.

The utilisation of intersectionality theory (Collins, 1991) allowed me to interrogate the structural intersectionality of social work as a practice-based profession and academic discipline (IFSW/IASSW, 2014). Social work institutions such as universities and local authorities, which are responsible for the education, training, and employment of social workers, consciously or unconsciously perpetuate the barriers that ACE with dementia encounter when seeking dementia care, through systemic barriers. Intersectionality theory also had the potential to highlight systemic, institutional, and structural barriers, challenges, or support that social workers encountered in their work with ACE with dementia.

Combining or blending theories is a common thread within social work practice and learning (Biggs, 2018; Thompson, 2020). This facilitates an ethical approach to social work practice and social work education that reflects the interdisciplinary nature of social work and recognises the simultaneous and parallel approach to social work practices. For example, a blended theoretical approach to social work practises considers that assessment, direct casework, and intervention may all be occurring at the same time when an ACE with dementia seeks social work support. Social work action to these tasks would require the social worker to draw on various theoretical principles to promote a specific outcome for the ACE with dementia (Rapaport and Baiani, 2017). Through this combined theoretical framework, I was able to be true, intentional, and representative of my intersecting social locations as an AC female, social worker, and trade unionist, as these critical theories embedded calls to action and activism. I am also aware of the potential biases that these positionalities may have on the research, and I have addressed these in the reflexivity section of this chapter.

The main critique of adopting a blended or combined theoretical framework in social work research is that scholars or practitioners may not have sufficient understanding of theories, which could result in a muddled theoretical eclecticism (Thompson, 2010; Leskosek, 2009). To avoid this, I engaged in ongoing reading, reflecting, and evaluation of the aims and objectives of my research alongside supervision to ensure my understanding and rationale for my chosen theories and theoretical framework aligned with the research aims and objectives and the required research protocols.

3.8. Conclusion

This research explored four very distinct concepts, namely race, ethnicity, and dementia as a disability and age, and how the interconnectedness of these manifests within social work practices and social work itself. One of the key recurring themes that was identified across the literature review for this study is racism. Researchers undertaking dementia research with ACE with dementia, highlighted that ACE identified historic and ongoing experiences of racism as a barrier to accessing appropriate dementia services (Lasrado et al., 2020) This meant that my research had to be undertaken within strong theoretical frameworks, that could attend to this inherent racism and inequality as part of understanding how social workers account for race and ethnicity when engaging in social work with ACE with dementia.

An intersectional framework, combined with CRT, supported the centralising of the layered marginalisation of ACE with dementia by highlighting that race and ethnicity discrimination does not happen on a single categorical axis (Crenshaw 1989). Through this framework, I explored the understanding and perception processes of social workers that may perpetuate or challenge discriminatory policies, patterns, practices, and structures that result in unequal access to appropriate dementia care for ACE with dementia.

In the next chapter, I will present the methodology and philosophical framework that underpins this study.

Chapter 4

Methodology Chapter

4.1. Chapter Overview

This study explored the subjective understandings and perceptions of social workers around the dementia care needs of African Caribbean people (ACE) with dementia in South Wales.

To facilitate this exploration, the following research aims were developed.

1. To explore how conceptualisations of race and ethnicity shape practitioners' understanding and perceptions when undertaking social work tasks with ACE with dementia.

2. To explore from the perspective of the social worker to what extent their work with ACE with dementia is informed by critical race theory and intersectional theory.

3. To understand the existing structures that support or hinder social work with ACE with dementia.

This chapter sets out the methodology and design for this research. This chapter begins with an in-depth discussion on the reflective and reflexive practices I engaged in to critically assess my own biases and perspectives throughout the research journey. Discussion moves into the philosophical position that framed and guided this research. This is followed by presentation of the research design, the participant sample, the recruitment process, and ethical considerations. Discussion moves to the rationale for the use of qualitative methods and data collection processes. The final section discusses how the data were analysed and quality assurance considerations for this study.

4.2. Reflexivity and researcher positionality

This section discusses how I engaged in reflexivity throughout my research, reflections on my positionality. This section was emergent and iterative (Berger, 2015; Finlay, 2002; Gilgun, 2010) and was ongoing until the thesis was submitted. Throughout the research process, I returned to this section and recorded how my thinking, experiences, and knowledge development influenced the research. I attempted to capture my thought and decision-making processes alongside the dilemmas I faced during my research journey. I conducted this research to fulfil the requirements for a doctoral degree, and the decision-making responsibility around the design, method, and analysis, for example, rested with me. As such, the first person singular (I) is used in this section to reflect the primary agency of myself as the investigator.

As a guide to the reader, this section is presented as follows: Part 1- a definition and purpose of reflexivity within the context of this qualitative research, underpinned by a critical realist philosophical approach. Part 2 will present personal reflexivity, which will present my history, background, positionalities, and their influence on the research.

Part one- Reflexivity defined in the context of this study.

According to Barry et al. (1999), reflexivity is an intrinsic component of the production of knowledge in qualitative research. Reflexivity facilitates the evaluation and enhancement of the quality and rigour of qualitative research (Cohen and Crabtree 2008). Reflexivity has also been defined as a methodological tool to account for the situated and embodied nature of knowledge production (Etherington, 2004; Le Grand, 2014; Pillow, 2003). Simmonds and Gazley (2018, pp. 140–159) suggest that ‘reflexivity that is underpinned by critical realism helps researchers reflexively critique and examine their assumptions and current trajectories by paying attention to the power within structures, agents’. Therefore, the practice and reporting of reflexivity within research has become an expectation (Koch and Harrington, 1998; Pillow, 2003).

In qualitative research, reflexivity has been conceptualized and defined in different ways (Finlay, 2002; Pillow, 2003). Davies (2008) and Probst and Berenson (2014) suggest that in qualitative research, reflexivity is the generalized practice in which researchers seek to explicitly discuss their influence on the research to themselves, and often to their audience. Glas and Soedirgo (2019) further suggest that reflexivity supports researchers to move beyond positionality statements within their research and rather, interrogate the potential effects their biases can have on what they research and how their research is conducted.

Although reflexivity is by definition a critical tool, as it specifically involves paying heed to power relations; I have chosen to use the longer term “critical reflexivity,” which explicitly foregrounds my attentiveness to power within social work systems and structures and broader society in the context of ACE with dementia (Sayer, 2000; Thompson, 2022; Wacquant, 2004; Gray et al., 2002; Lipsky, 2010 and Lasrado et al.,2020). Additionally, the iterative and emergent nature of my research required me to adopt active, ongoing reflexivity (Soedirgo and Glas, 2020) that supported my interrogations of my positionality, how my positionality was read by others and the assumptions I have of these. This will be illustrated in part two.

Despite reflexivity being discussed as crucial to good research, there have been critiques of reflexivity within research. Finlay (2002) and Pillow (2003) argue that a focus on reflexivity increases the focus on the researcher, which can lead to self-indulgence and shift the focus of the research to the researcher. Pillow (2003) further questions the overall usefulness of reflexivity to produce better research. Cutcliffe (2003) argues that reflexivity prevents the development of creative insights within research as it hinders those free interpretive processes that are required for this to occur. Even as I engaged in reflexivity, I acknowledged that the subjectivity in my choice of how I engaged with reflexivity and what aspects of my research I chose to consider as significant or crucial and how this choice has been influenced by my experiences, my thoughts and different events happening around me. However, having evaluated the arguments for and against reflexivity, my own position is that there is value in interrogating and sharing my thought processes, history, and experiences, as I believe that these have a crucial influence on the choices I made across this research. Reflexivity, underpinned by a CR lens, helped me take a critical stance towards my historical location, the various positionalities I occupy by bringing to the fore the potential effects the ontology within each position can have on the research.

Reflections on my positionality

Discussion in this section is underpinned by the typology of the indigenous insider (Banks,1998). This typology suggests that researchers are positioned along a continuum of closeness to, or distance from, the indigenous community. In this typology, the researcher can be an insider as long as they share the same knowledge, values and attitudes of the studied community, no matter whether they have been socialized inside or outside the community.

I also acknowledge the ethical and epistemological complexities and debates that arise from using terminology such as ‘Black woman’ and ‘colonise’ and whilst I would like to present myself as simply an ‘academic’, I have found myself, throughout this research, moving in and out of my different positionalities, in conscious and sometimes subconscious ways. For example, during the participant recruitment stage of the research and specifically during the development of the interview schedule, I found myself entangled in notions of being an insider/outsider/ not belonging (Holmes, 2020; Chhabra, 2020). I explore this movement in more depth in the section on sampling and recruitment.

Although I do not possess unquestionable authority about ACE and do not share the experiences of older ACE with dementia, I do share the same AC background, similar beliefs, values, behaviours, and knowledge of the AC community. In a similar vein, as a qualified social worker, I also have that typology and believe that I can speak with some authority on social work, as I share some of the experiences that participants have experienced and share similar values and beliefs. So, at the start of my research, I recognised my insider-outsider status (Holmes, 2020; Chhabra, 2020) and that in some contexts I might occupy an unseen space between being an insider-outsider (Dwyer and Buckle, 2009). For example, I am a qualified social worker, conducting social work research. Whilst I do not feel I possess sufficient skill and experience to call myself a ‘fully fledged researcher’, I am also not a social worker in the sense that I am no longer practising. I am both a social worker and researcher, whilst at the same time I am not fully either, thus occupying a space in between these two locations, becoming both insider and outsider in both these locations. To what extent such positionings have afforded me privileges or disqualified my knowledge claims, or whether or not these positionalities are cohesive, has been explored and acknowledged across this section and throughout the thesis.

I was born and raised in Trinidad and Tobago, a former British colony (Piggot, 2018; Goulbourne, 2002; Marwick, 2003; Rosen, 2003). I make this point as this has not been something I initially considered as having any influence on my research; however, I discovered that this historical fact about myself had a significant bearing on the academic pathway I chose. Before my move to the UK, I never spoke of myself in terms of my race or ethnicity. I was simply me, a 'Trini' or Trinidadian. However, due to a lack of consensus on the desired terms of reference for people like me, from the Caribbean islands, former colonies, alongside the ongoing changes of aggregate terminology within the UK Census, I am sometimes seen as just a 'Black woman', despite being much more than this. However, my move to the UK, which involved a complex immigration process, meant I had to come to terms with new ways of 'identifying' myself (Dickens, Womack, and Dimes 2019; Yuval-Davis, 2019). These new terms did not fit who I thought I was and to some degree, I still think I am.

Having been exposed to what (Baines, 2018) referred to as the western lens of class, status, (as these were not concepts I grew up with. I acknowledge that these concepts may have existed but perhaps not been used in my family or proximate community or used in ways I did not recognise or understand. I place myself somewhere along the middle-class spectrum. I say this as I do not neatly fit into either upper or lower class, as I certainly do not meet the criteria for such status (Crenshaw, 2011 and Wilson et al., 2019). I grew up in a middle-class home in an extended family setting, led by a very matriarchal grandmother, in contradiction to the Western concept of the nuclear family (Baines 2018). At the same time, I did not know my father, who had died when I was a baby and my mother had emigrated to the USA to build a better life for my sister, my brother and me. My grandmother sold clothes in a market but also owned several properties and collected rents from these. We had a car, running water, an indoor toilet, a washing machine and I attended prestigious schools. I qualified as a teacher at the age of nineteen and again enjoyed somewhat middle-class privileges.

My family has always seen education in all its forms as crucial to life and has been involved in grassroots politics (Mills, 2022), activism and social justice struggles. As such, I am not surprised that I find myself heavily involved in trade unionism, anti-racist activism, social work, and doctoral research. My historical background has influenced the many positions I now occupy and these in turn influenced my research approach, the subject of my research and the evolution of my research.

My acknowledgement and interrogation of my former colonial roots and my experience living in the state that once colonised the country of my birth, has meant that I deal with the dilemma of knowing I am independent at the same time, knowing I am living under systems and structures that have promoted and continue to promote various types of discrimination that affect a Black woman such as me as well as other people from Caribbean countries, for example, the Windrush scandal (Piggot, 2018; Goulbourne, 2002; Marwick, 2003; Rosen, 2003). These forms of discrimination are further compounded as I pursue an academic career. As a doctoral researcher, looking at disability (dementia) and race and ethnicity, I have been educated at universities within the UK, via a Western/White lens (Clarke, 2022). This means part of my knowledge construction is steeped in the knowledge gained growing up in Trinidad and living and studying in the UK.

This varied knowledge base was often at odds throughout my career as a social worker and during my academic journey. Tascon and Ife (2019), in their work *Disrupting Whiteness in social work,* discuss epistemicide and epistemic injustice as the process through which Western epistemologies are privileged and legitimised over indigenous knowledge. Whilst claims of epistemic injustice may appear strong, I often had to accept that my knowledge of older person's care from my experiences in Trinidad was viewed as 'third world' views and I struggled to present them in ways that would legitimise them based on the academic standards of UK universities. For example, from a practice position, my knowledge around supporting the autonomy of older persons with dementia was often tempered with questions around 'safeguarding'. Additionally, my knowledge of the God/witchcraft attributes some ACE placed on illnesses such as dementia, had to be described through western terms such as 'denial of dementia', 'a belief in the supernatural', which tend to claim implicit hierarchical assumptions whilst disregarding local and Indigenous knowledge. However, I was able to draw on Western academic concepts to create space for my ‘Indigenous’ knowledge whilst maintaining the required assimilation for academia via insider/outsider perspectives (Holmes, 2020; Chhabra, 2020).

As I reflected on the interplay between my own experiences and broader societal narratives around race, I battled with the notion that this might be me playing the ‘race card’ (Gilbert and Rossing, 2013) unconsciously. The concept of the "race card” emerged as a significant term within sociopolitical discourse and invokes discussions around the interplay of race relations and systemic inequality. The term ‘race card’ can be used in reference to the strategic use of race or racial identity to gain advantage in various contexts, such as social interactions, political debates, and legal proceedings. Additionally, the term ‘race card’ possesses a duality where it can be seen as serving to highlight legitimate instances of racial injustice or perceived by others, both Black and non-Black persons, as an attempt to manipulate perceptions and divert attention from substantive issues. This duality was a point of reflection for me as it raised critical questions about how my claims related to race, interplayed with the dynamics of power and privilege, and the broader societal impact of race discourses, understandings and perceptions. This notion of the ‘race card’ highlights the sensitivities that arise as individuals navigate issues of race, particularly when such discussions may inadvertently lead to self-doubt or the questioning of one's motives.

However, I realised, even in my other roles, as a trade unionist, I was advised by a senior White male trade unionist to never mention or ‘appear Black’ in the presence of White colleagues, if I wanted to get anywhere in the union. In another experience, I attended a conference, where I spoke in my capacity as an antiracist activist and one of the opening remarks by the first speaker, a White female academic, was on the fact that Afghan refugees who had asylum in Wales needed to learn Welsh to demonstrate their true desire to integrate into Welsh society. These experiences have led me to accept that I am not defaulting to the ‘race card’; rather, this type of assimilation (Williams, 2011) is perhaps an unspoken prerequisite that Black persons/ethnic minority persons should meet to be socially accepted as ‘a true member of the society’. For me, engaging in reflexivity and reflection has brought this to light, as I never really fully interrogated all these experiences I had, putting them down to isolated events.

My insider experience and knowledge provided me with useful, comprehensive knowledge and awareness of some of the potential problems, issues, and responses that participants may present (Mannay, 2010). However, this also presented the issue of having to or being unable to make the familiar strange (Gunderson, 2020). This also extended to how I utilised feedback from my supervisors, who are also social workers. I examined my value positions, taking on board that researchers who research their own culture (Coffey, 1999) are always researching with an advantage and a drawback (Lofland and Lofland, 1995). I managed these issues and added to the overall knowledge development of this study through ongoing reflection, supervision, review of the existing literature and questioning these issues through a critical lens. Reflexivity and ethics in research are intricately linked, as both emphasize the significance of self-awareness and ethical responsibility throughout the research process. The following section is an account of the ethical considerations employed in this study.

4.3. Ethical considerations

This section discusses the complex ethical landscape that I had to navigate as a novice social work researcher throughout the research process.

Informed consent was a critical aspect, requiring clear communication about the study's purpose, procedures, and potential risks. This ensured that participants were fully aware of what their involvement entailed. Additionally, my role as the interviewer was pivotal, as I had to navigate the dual responsibilities of being a researcher and maintaining a professional relationship with the interviewees, some of whom I had worked with previously or participated in trade union and anti-racist activism. I was aware that familiarity with the participants could influence the research material, analysis, and presentation and raise questions about potential biases and the ethical implications of my influence over participants. To mitigate this, I had one-to-one meetings with participants at the same time I provided the information sheet, assuring participants that they were not under any pressure to participate. Participants were also given the freedom to withdraw from the study at any point, up until I had conducted the final interview, to avoid their responses being used in the analysis.

Maintaining confidentiality and anonymity were important ethical considerations in this study. Particularly as participants came from very small teams and could be easily identified. It was crucial to protect the participants from potential repercussions in their professional lives. Particularly as the subject matter of my research meant that a participant could have shared sensitive information. I used pseudonyms to ensure anonymity and protect the privacy and identities of individuals involved in the study. By anonymizing participant data, I was able to mitigate risks associated with privacy breaches and ensure that the information shared by participants was used responsibly and ethically. This approach aligns with ethical guidelines that prioritize the protection of participants from potential harm, including the risk of being identified through their responses. This practice not only protected participants but also enhanced the credibility and ethical standing of my research (Wiles et al., 2008).

Interestingly, I attended a trade union conference where delegates were making strong arguments about the mispronunciation of their names or the exclusion of their names by employers and how this made them feel unseen. I reflected on this in terms of my own research and my approach to anonymity as described above. I questioned the ethical intent of my use of pseudonyms (Riese, 2019) argues that altering names might inadvertently affect the authenticity and richness of the data, as the personal and cultural significance of names can be lost, potentially impacting the interpretation of the data. Additionally, while changing names can protect participants from potential harm, it may also lead to a sense of detachment or alienation from the research process, as participants might feel their true identities and stories are not fully represented. This detachment can be exacerbated by the power dynamics inherent in the researcher-participant relationship, where participants might already feel like mere data sources rather than active contributors to the research. Following deep reflection on this, I believe I had justifiable reasons for my approach to anonymity.

I reflected on the subject matter of my research and believed that the use of participants' names was not a requirement to meet my research objectives, as well as no participant disagreed with the use of a pseudonym as my chosen approach to anonymity. Additionally, I used 'neutral' pseudonyms such as 'Participant 1 -P1-QSW', which meant I was not ascribing names that may be culturally inappropriate or names that would imply that participants were from a specific demographic. I believe this also demonstrated my deeper understanding of the ethical responsibilities of researchers in balancing the need for confidentiality with the imperative to maintain the integrity and authenticity of the data.

Additionally, guided by the theoretical and philosophical underpinnings of this study, namely, critical realism, critical race theory and intersectionality theory, my approach to ethics in this study considered the concept of power imbalances in research (Aluwihare-Samaranayake, 2012). Research ethics has a focus that assumes that research subjects are relatively powerless, however, I reflected on the possibility that the research participants for this study, by virtue of their roles within the local authority, could be considered elite research subjects as they had the organisational capital and structured positions of privilege, perhaps on the same level as I did in my role as a qualified social worker and academic researcher. I discussed this ethical dilemma in more detail in the reflexivity and researcher positionality section.

Another key area that presented with ethical dilemmas was negotiating access for the study. There were long periods of waiting to hear back from gatekeepers at the research site and the ethics committee within the university. This required me to make contact in a tactful but persistent way, which highlighted the power of large organisations and bureaucratic bodies such as ethics committees to impact (willingly or unwillingly) aspects of research. Additionally, high service demands and staff shortages at the research site had an impact on the initial time frame I projected for the data collection. I discuss issues around participants in more detail in the recruitment and sampling section.

My ethical considerations extended to the dissemination of my research findings. I was very cautious about transmitting unfavourable stereotypes or damaging representations of participants and considered the impact of null or negative findings on publication likelihood and professional reputation. This balancing act required me to approach discussions and presentations of my findings in broader and deeper ways to ensure that I acknowledged the experiences of ACE with dementia that have been reported across research, as well as the constraints and efforts participants were navigating as they made meaning of the needs of ACE with dementia.

Following ethical approval from the university's ethical committee, permission to undertake this study was sought from the relevant local authorities in South Wales. This study was underpinned by ethical requirements from three main stakeholders:

The university where I am undertaking this doctoral research, https://www.cardiff.ac.uk/research/our-research-environment/integrity-and-ethics

I am funded by a studentship from the Economic and Social Research Council (ESRC) and therefore need to meet their ethical requirements,

https://www.ukri.org/councils/esrc/guidance-for-applicants/research-ethics-guidance

The local authorities, as research sites, have their own stipulated policy and governance framework for engaging in research but also need to ensure social work staff adhere to the ethical requirements within the code of practice for social care staff as set out by the Welsh Government. https://socialcare.wales/cms-assets/documents/Code-of-Professional-Practice-for-Social-Care-web-version.pdf.

The ethics approval for this study is attached as Appendix F and discusses in detail the ethical considerations I undertook for this study, which included: informed consent, withdrawal from the study, confidentiality, and anonymity, General Data Protection Regulations (GDPR 2018 and Data Protection Act 2018). The participant information sheets, Appendix I and Appendix J, provided potential participants with information about the research and also information about my responsibilities in regard to data protection, confidentiality, and safeguarding. To maintain confidentiality and anonymity, participants and the research sites were given pseudonyms. I also use codes (numbers) for participants when transcribing the data.

4.4. Research methodology within a critical realist (CR) framework

A research paradigm is the philosophical assumptions, beliefs, or worldviews that a researcher employs to think about and make sense of the complexities of the real world (Creswell and Clark, 2011; Patton, 2002). Orme and Shemmings (2010) argue that when a researcher chooses a research paradigm, they do so with ethical goals for maximizing rigour, as a way of guiding their choice of research methodology and as a basis of the research questions. Marshall and Rossman (2010) highlight the importance of researchers providing a philosophical grounding for their study by explicitly addressing their epistemological positions so as to demonstrate that there is consistency across the study in terms of the researcher’s approach to knowledge formulation, the methodologies and methods applied.

I chose critical realism (CR) as the most appropriate ontological approach for this study because it demonstrated better potential to address the research questions and account for those generative mechanisms (Guba and Lincoln, 1994; Bhaskar, 2008). CR posits that there is a real world and the ways through which we interpret this world are under ongoing development and improvement. The central task of critical realism is to demonstrate that what is real is not necessarily perceptible to us in the moment that we are trying to study it. Indeed, social structures regularly obscure our ability to comprehend what is real (Collier, 1994). CR seeks to engage the researcher in deep consideration of the interaction of human agency with power structures and social life to both constraining and enabling effects (Gorski, 2013; Houston, 2010). CR is not a value-free mode of academic inquiry (Houston, 2010); rather, it seeks to inform collective action by understanding how social injustices function beyond our immediately comprehensible thoughts and perceptions (Houston, 2001).

Although there is a paucity of social work research that incorporates CR, my position is that of (Houston, 2001) that CR is relevant to social work practice as CR attends to the role of social structure and individual agency similarly to social work’s own definition of engaging with people and structures to address problems and create a changes (IFSW/IASSW 2014; Bhaskar, 2008; Sayer, 1992). CR provides a strong, ideological, philosophical, and conceptual case for its use and benefits to social work research as it provides a framework that can inform anti-oppressive and emancipatory action, which are part of the social work mission (IFSW/IASSW, 2014).

Society is complex in nature, susceptible to change, and is characterised as an open system, which means it is impossible to directly isolate or control all the mechanisms that may be at play in any given situation or event (Oliver, 2012; Bhaskar, 1989). Danermark et al. (2002) suggest that our inability to isolate all such mechanisms is due to the influence of human agency, social structures, and the fact that social scientists seeking to study social phenomena bring their interpretations of other people’s interpretations of those social phenomena, thus adding to the complex and unpredictable nature of society as an open system.

From an ontological standpoint, CR holds very strong ontological claims. Bhaskar (2008) suggests a stratified and emergent ontology for CR. This ontology argues that phenomena at one level of reality are to be explained in terms of structures or mechanisms located at a deeper level that generate or produce these phenomena (Bhaskar, 1975). Within this stratified ontology, Bhaskar contends that reality can be divided into three main layers or domains. At the top of the stratification is the most superficial, the *empirical* domain, which sees knowledge as observable and experiential. In the middle, the *actual* domain, where events that actually happen and can be observed, independent of our identification of them. At the third level is the *real or deep* domain, which entails less observable or even hidden processes and events that form a necessary precondition for the *actual* and the *empirical*. CR argues that the structures, processes and entities within these domains (observable and invisible) have properties that endow them with powers that, when activated, can result in harm or good. CR also posits that an absence of immediate evidence for such entities does not mean they do not exist or are endowed with powers to do harm or good (Bhaskar, 2008; Sayer, 1992).

In the context of this study, I hold the position of a relativist ontology, which posits that social realities (e.g., race and ethnicity, dementia) are observed and seen by multiple people who interpret the phenomenon differently, leaving multiple perspectives of race and ethnicity and dementia. Therefore, I believe that the social workers engaging with ACE with dementia hold multiple realities of race, ethnicity and dementia. A relativist ontology also implies that I believe these realities can be explored and reconstructed or meaning can be made from them through the interactions I would have with the social workers as research subjects (Creswell et al., 2007).

The theoretical assumptions of CR acknowledge that social structures can enable or constrain human action and human action in turn can reproduce or transform the old structures. To gain an understanding of the social phenomena under study in this research (how social workers understand and perceive race and ethnicity in the context of dementia care for ACE), a theoretical analysis of the nature of the structure at play within this context is essential.

Therefore, cause and effect descriptions or subjective interpretations cannot, on their own, fully explain these social phenomena. According to (Bergin et al., 2008) and (Oliver, 2012), the stratified ontology of CR provides CR with explanatory and emancipatory powers not located within positivism or interpretivism. CR encourages the questioning of structural conditions and the analysis of social problems and social issues. According to CR, social phenomena are the result of the plurality of structures (Bhaskar, 1989). The structures cannot be conceived, and their existence can only be identified through an examination of their effects.

Maxwell (2012) suggested that a recognition that 'understanding' is fallible means that use of a CR methodology supports reconceptualization, which in turn allows explanations of the phenomena under study to be revised and tested during the lifespan of the research. In the context of my research, adopting a CR methodology means my position is that social workers' understanding and perception of race and ethnicity in the context of ACE with dementia is in itself fallible. Additionally, my own understanding of this is also fallible and initial conceptualisations of such understandings need to be revisited throughout the research process.

It was important for me to be able to capture such structures because the literature review for this study identified racism as a key recurring theme with ACE with dementia. Research with ACE with dementia identified structural, systemic, and institutional racism as key barriers to ACE with dementia accessing appropriate dementia care (Lasrado et.al., 2020; Berwald et al., 2016; Parveen et al., 2017; Cheston, 2017; Tang et al., 2015). This acknowledgment steered my research towards a paradigm that could incorporate the multiple world views of myself as the researcher, the participants, as well as associated subjective meanings and perspectives within the structural, organisational and institutional contexts.

Understood in the context of this study, a dementia café (*observable entity/empirical level*) that does not provide Afro Caribbean food or have other ACE with dementia attending can become an entity endowed with powers to exclude or appear exclusionary to an ACE with dementia whose social worker may recommend it. Likewise, a policy (*invisible entity/real/deep domain*) that requires all dementia care plans to account for race and ethnicity has the power to enhance rights. According to CR (in the absence of an entity), for example, the lack of a policy that upholds rights, ACE with dementia will still be affected (*actual level*) by the suffering that occurs where human rights are ignored.

From an epistemological standpoint, critical realism contends that our knowledge and understanding of reality are subject to change. Given that the construction of knowledge cannot be infallible, sometimes this change is based on the construction of misconceptions or our recognition that long-held theories about the phenomenon have been rejected or further developed. CR argues that all knowledge will be imperfect, specific to the context, subject to revision and finite. CR further argues that knowledge can turn out to be wrong when the depth of reality is not recognised, when unsuitable methods are used, or when the nature of a phenomenon being researched is not appreciated (Danermark et al.,2019).

The critical realist notion that it is impossible to access reality in itself leads to a relativist epistemological position, meaning that it is recognised that there are multiple ways of knowing and that, by implication, no single method or science can produce adequate and complete knowledge of reality. For example, social work has gone through changes and is still undergoing change based on the development and rejection of theories and ways of practice. So, where anti-racist social work was a mandatory programme requirement for social work qualification, government policies, over time, have replaced this with theories of anti-oppressive and anti-discriminatory practice (Lavalette and Penketh, 2013). This, in turn, may have an impact on how social workers come to know and make meaning of race, ethnicity and racism.

From an axiological standpoint, CR aligns with the ethics and values embedded within social work. CR is focused on a concern for social justice and equality and posits that we can better understand and explain these tendencies through the identification of structures and mechanisms at the level of the real, and that this understanding will help to bring about change and social justice. Although CR has only recently been used in social work research (Houston, 2001; Pease, 2010), public health and human rights scholars have been using CR for some time (Price, 2017; Harris et al., 2014; Danemark, 2002).

From a qualitative methodological standpoint, CR contends that the primary purpose of research is the theorizing of explanations for recurrent relationships between phenomena or the absence of any relationships that have been observed or experienced (Danermark et al.,2019). For example, some ACE with dementia explained from their perspectives that they believed the lack of culturally appropriate dementia services was due to racism (Lasrado et al., 2020). These explanations focus on generative mechanisms between processes and structures as well as the properties of such structures that empower them with such mechanisms (Bhaskar, 1975, p.47). The layered nature of reality (stratified ontology) means that critical realists adopt a pragmatic approach to methodology and methods. This means multiple disciplines and methodological approaches may be needed to understand the multilevel relationships between social work, race, ethnicity, and ACE with dementia.

The empirical testing of theories about the nature of social structures and their effects upon human action needs to occur. However, testing becomes complicated due to the conceptual nature of social science subject matters. According to Bhaskar (1989), this complexity within social science subject matters limits the explanatory power of quantitative measurement. Similarly, Bergin et al. (2008) and Danermark et al. (2002) argue that positivism and interpretivism are philosophically constrained and therefore those structures that are often invisible or not easily measured are often missed or not fully explored during the research process.

I acknowledged arguments by (Craig and Bigby, 2015) that critical realism does not commit to a specific methodology, and it has been difficult to translate it to my own research methodology, however, my research is seeking to add to the discussion on the understandings and perceptions of social workers around race and ethnicity in the context of social work with ACE with dementia. I believe that a quantitative approach would reduce findings to descriptive summaries of correlations between variables, and these cannot uncover evidence on the causal mechanisms that generated the actual events that may be observed in social work practice with ACE with dementia. The aim of my research is not primarily to describe the interactions of social workers with ACE with dementia, but rather it is to explore the understanding and perception process (related to the dementia care needs of ACE with dementia) of social workers. The critical realist underpinnings of the study mean attention is directed to identifying and exploring the workings of ontologically deep mechanisms within social workers working with ACE with dementia, beyond what is seen or known.

Sayer (2000) suggests that research can either be intensive or extensive. Extensive research looks for patterns, similarities and usually employs large-scale surveys and statistical analyses. Intensive research has a focus on individual agents in context, using interviews and qualitative analysis. Adopting a quantitative methodology, underpinned by positivism (Denzin and Lincoln, 2011), would result in either cause and effect descriptions (social workers understand race and ethnicity as such, therefore the effect for ACE with dementia is such). Additionally, a qualitative methodology philosophically underpinned by interpretivism (Denzin and Lincoln, 2011), although useful for analysing and capturing the individual experiences of social workers and their understanding and perception of race and ethnicity, would fail to attend to issues of false consciousness around social workers' understanding and perception of race and ethnicity in the given context.

Sayer (1992) suggests that false consciousness is a concept that refers to the potential for individuals to be misled about their true interests and social conditions, often due to prevailing ideologies or societal norms that obscure their understanding of reality. This can result in individuals supporting systems or practices that perpetuate inequality. Acknowledging and understanding false consciousness is crucial for social workers whose mission is to challenge oppression and social change. As a result, I felt these approaches would fail to meet the aims of my study as they would limit the understanding of reality to an empirical domain or to the domain of the individual social worker, without acknowledging the power relations and influences of the structures at play (Sayer, 1992).

Therefore, I have adopted a qualitative methodology that is underpinned by CR and engages with qualitative methods such as interviewing and document analysis. Tsoukas (1989, p.556) argues that such qualitative methods are epistemologically valid and capable of identifying structures and interactions between and across complex mechanisms. Price and Martin (2018) argue that whilst CR can achieve metatheoretical unity by acknowledging the value of the empirical within positivism, to achieve what Bhaskar (2016, p.51) refers to as the 'inside' or 'interior' of social life, research methodologies that attend to the use of language and meaning and more suitable. Hu (2018) suggests that in order to gain a better understanding of social events, an engagement with hermeneutically based methodologies is preferred.

4.5. Research design

As discussed earlier, this study was initially designed and developed within an interpretivist-constructivist paradigm, seeking to answer the research questions through qualitative methods: semi-structured interviews, group interview and document analysis. Although I have changed the philosophical framework of this study, the initial qualitative methods remain, as I believe they reflect my attention to advice provided by Danermark et al. (2002) and Sayer (1992) on aligning the choice of methods to the purpose of research. This section discusses the nuances of undertaking these methods through a CR framework.

Danermark et al. (2002, p. 150) state, '*If we assume – as Critical Realism does – that social science studies are conducted in open systems, that reality consists of different strata with emergent powers, that it has ontological depth, and that facts are theory-laden, then these are some factors that affect the choice of design and method'*.

Case Studies differ from other qualitative research methods like ethnography, as they focus on contemporary cases and aim to answer specific questions over a shorter period, often to inform decision-making or uncover causal links in complex settings. Flyvbjerg (2011) suggests that case study research is a powerful tool for understanding complex, real-world issues from the perspective of those involved, offering a holistic view that is often unattainable through other research methods. Yin (2014) suggests that it is very difficult to define the term case study and offers the definition of a case study as an in-depth research of a phenomenon intertwined with a particular context using different sources of data.

Gerring (2007, p.20) defined a case study as the intensive study of a single case where the purpose of that study is to shed light on a larger class of cases (a population). However, Yin (2014) argued that this definition limits case study to the study of the single case, while there can be both single and multiple cases depending upon the purpose of the research. Whilst acknowledging the varied, sometimes conflicting definitions of case study research, this study aligns closely with the definition offered by Yin (2014), who posits that a case study is a research design and an empirical inquiry which investigates a phenomenon in its real-life context. In the context of this study, I wanted to explore the process through which social workers understand and perceive the care needs of ACE with dementia within the real-life context of social work practice with ACE with dementia in South Wales.

This research adopted a case study approach, which is often used interchangeably with 'case study research', 'case study design'. Although my approach does not hold to the rigorous nature of 'classical' case studies (Yin,2018; Miriam, 1998; Stake, 1995), I adopted key tenets of case study research and discuss them in the following sections.

Epistemological commitments

Case study research design is underpinned by various philosophical positions, each offering distinct perspectives on reality and knowledge generation (Baxter and Jack, 2008; Yazan, 2015). According to Bhatta (2018), philosophical assumptions shape the nature of any research, including case study research, as well as how the various approaches to case study research are understood and interpreted. The choice of philosophical position determines the ontological and epistemological characteristics of the research, which significantly influence the research design and methodology. Bhatta (2018) argues that the philosophical position of case study research has been a challenge due to philosophical duality, as both positivists and interpretivists employ case study research. This philosophical duality has resulted in much debate and differences in understanding case study research.

For example, different authors hold different perspectives on case studies. Yin (2014) follows the post-positivist tradition of research. Stake (1994) adopted a constructivist position in his epistemological understanding of the case study approach. To mitigate the challenges of philosophical duality as well as to ensure I have acknowledged my own epistemological understanding and approach to case study research in this study, I have adhered to advice by (Bhatta, 2018) and through an iterative process supported by my supervisors, I have clarified and refined the objectives for the study which helped in deciding on an appropriate philosophical position. I align with the depth over breadth stance of qualitative methodologies and therefore, this study adopted a qualitative case study research, framed within a critical realist philosophical position.

According to Dore (2019) and Houston (2010), the multifaceted nature of social work requires practitioners to navigate complex human interactions across various levels of reality to effectively address the needs of individuals and communities. Whilst CR does not prescribe methods for the researcher (Fletcher, 2020), CR- based methodologies and methods are particularly appropriate for exploring these interactions and their consequences. According to Wynn and Williams (2012), a CR case study is a suitable approach to uncover the interaction of structure, events, human agency and context. The exploratory nature of my research and the flexibility towards methods that critical realism supports allowed me to choose a research design that would answer the research questions. Gilgun (1994) argued that the case study has been a neglected and maligned approach to social work research, although they have been utilised in other professions such as medicine, law and business. Case study research is appropriate for social work research, due to the complex and variable nature of human experiences, which necessitate a method that can capture such nuances (Gilgun, 1994).

Identifying and bounding the case

This process involved first identifying the case, or unit of analysis, as part of an iterative process during the literature review (Harrison et al., 2017). As discussed in the literature review chapter, my initial research interest was around ACE with dementia and social workers' response to the dementia needs of this population. However, the knowledge gap highlighted unexplored areas around the understanding and perception processes employed by social workers to make meaning of the needs of ACE with dementia. Through an iterative approach, I utilized sensitizing concepts (Gilgun, 2019) such as 'anti-racist social work', 'anti-oppressive social work' 'cultural competence', which provided a framework for identifying and constructing the case.

Stake (1995) suggested bounding a case so that the scope of the study remained focused, clearly framed, and data collection and analysis could be managed. Bounding the case initially seemed to go against the key tenet of CR that reality is an open system that is beyond our ability to directly control (Danermark, Ekström and Karlsson, 2019). However, by treating preliminary definitions as sensitizing concepts, I was able to navigate the complexities of bounding a case, which also supported a more nuanced and innovative approach to the findings. Theory provided a guiding framework that helped me determine what aspects of the case were relevant and should be included. By aligning the case with theoretical constructs around political interests, intersectionality and power dynamics (Yuval-Davis, 2016), I was able to focus on elements that I believed to be significant to the case. Yin (2018) suggests that the drive by case study design to utilise multiple sources of data is significant for CR's 'open system' as it allows the researcher to identify (subjectively) the possible systems that may be present within the different sources of data and explore how they may interconnect, cancel or oppose each other.

Although the process of bounding this case was difficult as there were many intersecting points of interest based on the fact that social work practice is multifaceted and occurs across multi-disciplinary settings, I established boundaries based on time, location and participant relevance. Data collection took place between January 2023 to August 2024. The case was also bounded geographically as it would be beyond the remit of this study to look at all the social workers in Wales; therefore, I focused on South Wales as this locality had the largest population of first and second generation ACE who may be living with dementia and require or are being supported by social services. The case was also bounded by the inclusion and exclusion criteria for participants so as to ensure participants who could provide answers to the research questions. Therefore, I purposively selected adult social workers, social work assistants and third sector staff who supported older adults with dementia via local authority settings. This is discussed in more detail in the sampling section.

Deciding on the type of case study

Case study designs offer distinct approaches to research, each with unique strengths and applications (Stake, 1995; Yin, 2018). The holistic case study method in social sciences involves designing research around specific contexts, employing triangulation for data collection, and building theories that offer a complete view of the subject matter. In social work, holistic approaches are particularly valuable as they align with the profession's eclectic nature, requiring close collaboration with other professionals to meet clients' complex needs. Holistic research, aligned with fields such as social work, which involves a global perspective (IFSW 2014) that integrates various disciplines, supported deeper insights into the phenomena under study. Additionally, a holistic case study approach was an appropriate alternative to traditional, reductionist approaches, facilitating in-depth exploration of the stratified layers of participants’ understanding and perception of the dementia care needs of ACE with dementia.

Holistic case study design is particularly effective in contexts where the integration of various elements, such as race, ethnicity, age, and disability in social work practice with ACE with dementia, is relevant. A holistic design allowed for a detailed exploration of the complex system of social work practice with ACE with dementia, provided insights into the interplay of different factors that shaped participants’ understanding and perception of the dementia care needs of ACE with dementia and their potential collective impact on social work practice and dementia service provision and development with and for this population.

4.6. Introduction and rationale to methods, care plan analysis, and recruitment

Qualitative methods were chosen to explore the nuanced and complex human experiences involved in social work practice. This approach, which included interviews and document analysis, was appropriate for capturing the subjective meanings and underlying mechanisms that shape social workers’ perceptions. Grounded in critical realism, this approach provided a philosophical foundation for examining observable practices such as institutional norms and less visible structures such as racialised assumptions that may shape practitioner practice in dementia care.

The study collected data through semi-structured individual interviews and group interviews with practitioners. These interviews aimed to gather insights into how practitioners perceived and understood the care needs of ACE with dementia. Particular attention was paid to their conceptualizations of race and ethnicity, and the relevance of frameworks such as critical race theory and intersectionality in shaping their practice.

My study also included an analysis of an anonymized care plan for ACE with dementia. This was intended to provide insights into the motivations behind social workers' actions, how race and ethnicity were acknowledged, and how outcomes were identified and recorded. Although the aim was to analyse at least five care plans, only one met the inclusion criteria. Further details on the methods and analysis process are discussed later in this chapter.

Participant recruitment

This section describes and reflects on the process of participant recruitment and access in the context of this study. I started this process hoping to strictly adhere to the discussions of (Patton, 1990; Guba and Lincoln, 1994) on case study research and the need to purposefully select information-rich cases that can provide a comprehensive understanding of pertinent and critical issues under investigation. However, achieving this was not as straightforward as I hoped and my PhD project adopted a combination of the recruitment strategies; namely, convenience recruitment and an adapted small-scale version of snowballing recruitment (Brewis, 2014). These strategies supported my outcome of purposive participant recruitment (Bryman, 2016).

Participants included social workers, social work assistants, and third-sector staff from local authority areas across South Wales who supported older adults with dementia. According to O'Malia, Hills, and Wagner (2014), the expectations and responsibilities for social workers, senior social workers, and social work assistants vary significantly based on their qualifications and seniority. These expectations are shaped by the evolving nature of social work, sector-specific roles, and the professional competencies required at each level.

South Wales was selected due to the concentration of the ACE population in certain localities, increasing the likelihood of social workers engaging with this group. Recruitment of third sector participants was purposive. I conducted an online search to identify third sector organisations that met the inclusion criteria, emailed them with the details of the study and requested a meeting. Only one of the three organisations approached responded and participated in the study. I was also purposive from the start in the selection of care plans that were used in this study. Eight case files were initially provided, many of which contained rich and potentially insightful data. However, only one met the inclusion criteria and was included in the final analysis.

Debates around convenience sampling include arguments that it can be cost-effective and facilitate faster data collection. However, other critics argue that convenience sampling reduces diversity in the sample. I would not have encountered this issue as the sample of participants I interviewed previously was diverse along the lines of professional positions in the team, sat within different adult teams, race, gender and age. I approached the local authority where I had previously worked and conducted research with social workers. Access was also convenient as I knew the gatekeepers and participants. I believed this approach to participant recruitment was justifiable because the participants met my inclusion criteria. However, following the COVID-19 pandemic, many local authorities were still experiencing staff shortages. As a result, the response to my initial request to undertake research at this local authority was delayed.

This outcome made me reflect on my recruitment approach and that I had not really considered how grave the staffing shortages were, following the pandemic. I also reflected on the assumptions I held that access and recruitment would be easy. Supervision supported this reflection, and I was able to revisit my recruitment approach. For example, the next local authority I reached out to, I requested an initial meeting before sending out my participant information sheet. I met with gatekeepers and discussed my research aims and purpose. These discussions developed into a snowballing recruitment (Parker, Scott, and Geddes, 2019) because the main gatekeepers agreed to discuss my research with team leaders whom they felt would be suitable participants. This approach was acceptable to me because the team leaders met the participant criteria. Whilst this yielded positive outcomes as I was able to meet with several team leaders, I had to reflect on some key ethical points in this approach.

Firstly, I had no control over how the main gatekeeper described my research to the team leaders, and this may have been the reason some team leaders did not wish to participate after speaking with me and reading the information sheet. Secondly, I reflected on the power dynamics that may have been at play between the main gatekeepers and the team leaders and whether that may have influenced their decision to participate in my research. To mitigate these ethical issues, I offered participants an additional week to come back to me with a decision around their willingness to participate. Two participants cited time constraints and feeling unable to contribute to my research. I did not pursue these participants. This version of snowballing yielded five participants.

Reflecting on the strategies I had used so far and the outcomes, I revisited my research aims and research questions and engaged in more reading on purposive sampling. I attempted recruitment online via the social media platform, Facebook, with a clear description of my research aims, and I shared an adapted participant information sheet (Appendix I). The information sheet was adapted to reflect additional ethical requirements around recruiting social work participants online and to advise potential participants that they may require employer approval to participate in my research. For example, to ensure online recruitment met the participant inclusion criteria, participants had to share their Social Care Wales registration number. I had online meetings with those respondents, discussed my research in more detail and answered any questions. Participants went back to their local authority employers to confirm if they needed approval to participate in my research in their own time.

The first local authority site reached out to me and, following a meeting, agreed that any staff who met my participant criteria and wished to participate in my research to do so during their working hours. This online recruitment strategy yielded seven participants, five from the first local authority site and two from two different local authorities. Each participant was also given an extra week to ensure I met the ethical requirement of informed decision-making (Long, 2018). Informed decision-making is discussed in more detail in the section on ethical considerations.

Drawing on Bryman (2016), purposive sampling enabled me to select appropriate informants in reference to my research questions. I recruited social workers and social work assistants from across adult social work teams within local authorities in South Wales, as well as a third sector participant. The purpose of recruiting participants from different teams across the local authority was to provide different contexts that would allow deeper insights into the phenomena under study within this research. Another rationale for choosing this locality as the research site was that the population of ACE in Wales is quite small and concentrated in certain localities in South Wales (as discussed in the literature review section of this study). This suggested the possibility that social workers were more likely to engage with ACE with dementia from these communities, which have a population of ‘The Windrush Generation’ (Piggot, 2018; Goulbourne, 2002), who may be coming into or seeking input from social services.

During the participant recruitment stage, I found myself moving between confidence and worry. On the one hand, I was an insider (Holmes, 2020) as I am also a qualified social worker seeking to interview social workers. On the other hand, I am a Black researcher, and this positionality made me feel like an outsider (Chhabra, 2020), particularly during the recruitment. I found myself paying close attention to wear my hair in what I felt were styles that did not make me appear 'too Black'. I am aware that not only am I researching race and ethnicity, but I am doing so as a very visible Black woman. I am acutely aware of the challenges that I and other Black women face in trying to do 'Black' the right way (Davis et al., 2019) and therefore, I wanted to ensure I did not come across as 'threatening' (Davis et al., 2019) in any way to potential participants. I felt that appearing conscious of my 'Blackness' through my dress or hairstyle (afro/braids) (Watson et al., 2019) might make participants wary or uncomfortable that my research was seeking out racism. Upon reflecting on my unconscious movements, I recognised that I often used terms as 'we' and 'us' when talking with potential participants to assure them I was a social worker who also shared their values and that I was not there to do anything sinister but rather to talk as peers.

When I reflect on this stage in my research, I consider whether such movements were ethical, deceptive, or simply a coping strategy as a Black researcher, looking at race and ethnicity amongst predominantly White participants. I question if this type of assimilation had been learnt, and I found myself returning to the fact that my history comprises growing up in a country that was once a British colony, and I am currently living in the land of the 'colonizer' (Virdee and McGeever, 2018; Williamson and Khiabany, 2010). These realities made me realise how much I had changed since arriving in the UK and how I had learnt to assimilate not just for my research but that most of my interactions were underpinned by this sub/unconscious assimilation.

There were key areas of reflection in terms of sample size. The scope of the study and time limitations were ongoing considerations that continued to influence the study. For example, I began this research seeking to recruit up to 25 social work participants; however, out of the six local authorities I contacted, only two responded favourably and participants were recruited through the strategies discussed above. Severe staff shortages and high service demand, as well as the possible sensitivity of my research topic, resulted in fourteen participants. However, despite this low number, I was able to conduct thirteen individual interviews and one group interview. These are discussed in detail in the section on data collection.

Access

Social services departments within local authorities provide statutory support to vulnerable populations. They integrate services such as mental health support, housing assistance, adult and community services and children and family services to meet diverse needs. Access to these departments for research can be fraught with challenges, including bureaucratic hurdles, confidentiality concerns, and the need for ethical considerations when handling sensitive data related to vulnerable populations. Negotiating access was complex and required me to navigate the evolving landscape shaped by COVID-19, organizational pressures and heightened sensitivity surrounding data confidentiality.. Navigating these complexities required an understanding of both the legal frameworks governing data, such as the Data Protection Act 2018, which is a UK law that updates data protection laws and extends the General Data Protection Regulation (GDPR).

Gaining access to participants within such tight layers of bureaucracy required me to first establish trust and connections with primary gatekeepers. This was quite evident as I attempted to gain access to a local authority where I had previously worked and had undertaken research. Due to the ever-changing landscape of local authority management, the previous gatekeeper was no longer there, and I had to build trust and rapport with the new gatekeepers. My discussions with gatekeepers centered mainly on articulating the mutual benefits of my research and how data would be protected.

Additionally, many large public bodies, such as local authorities, are bound by policies such as research governance frameworks and legislation which aim to ensure ethical research practices but also add layers of bureaucracy that can delay or hinder research access. For example, I had to speak to several different heads of governance before I could meet with team managers, who then, through discretion, facilitated my engagement with practitioners. Such layers of bureaucracy also highlighted the way power dynamics, combined with issues such as staffing and resources, interconnect to impact access to undertake research.

4.7. Critical realist qualitative interviews

Kvale (1996) suggests that interviews are contextual, messy, complex social interactions where meaning is collaboratively created by both the interviewee and interviewer. Burgess (1984, p. 102) describes qualitative interviewing as ‘conversation with a purpose’ with a flexible and fluid style. Rubin and Rubin (2005) wrote about interviews as co-constructed through the active engagement of the interviewer and interviewee around the specific topics or relevant issues. This approach is in contrast to the formal, structured, uniform design of the questionnaire survey for data collection.

In keeping with the philosophical framework underpinning this study, I employed a critical realist approach to the development and conduct of the interviews. A critical realist interview is a qualitative research method that aims to move beyond surface-level descriptions to explore the underlying mechanisms and structures that shape individuals' understandings and perceptions of social phenomena (Brönnimann, 2022). Critical realist interviews are designed to delve deeper than mere descriptions of events or individual experiences.

This approach acknowledged that social realities are complex and observed differently by multiple people, leading to various perspectives on phenomena like race, ethnicity, dementia and ageing. Critical realist interviewing explicitly foregrounded my attentiveness to power dynamics within social work systems, structures, and broader society. This was particularly relevant as the study included a focus on a marginalized groups, ACE) with dementia (Brönnimann, 2022).

Individual interviews

Undertaking interviews with different groups of participants was important and meant that I could triangulate (Flick, 2018) different stakeholders’ perceptions of the same or similar events. Senior social workers or team managers had been invited to participate in a group interview as well as one-to-one interviews. Social workers and social work assistants had been invited to participate in one-to-one interviews. Within the Local Authority where the research will be undertaken, the title of ‘social work assistant’ is given to practitioners who carry out ‘social work-type’ roles but who have not undergone a formal social work qualification.

Due to the iterative nature of the research as well as the difficulties faced during recruitment, I invited different categories of practitioners to participate in the research and therefore developed appropriate consent forms and interview schedules to reflect their roles. For example, I recruited from the third sector as well as staff from the governance department of the local authority. Written consent was obtained from all participants prior to interview (see Appendix G, K, L, M for details of consent forms).

To undertake critical realist interviews, I initially drafted a set of questions and following additional reading and a pilot interview (Malmquist et al., 2019) with my supervisor, who previously worked as a social worker, allowed me to recognise the implications of interviews as ‘sites of power’ and ‘negotiated text’ (Denzin and Lincoln, 2008, p.47). I refined these questions to better reflect a critical realist approach. This reframing helped me reflect on how my experiences and my expectations of others and the knowledge I hold around race and ethnicity and racism within my different social locations shaped the way I developed the questions for the interview schedule. Additionally, a more discursive space was created for participants to reflect their relationships and interactions with structural forces in their practice, enabling the collection of rich and contextually grounded data.

I include two examples of questions below to show how the changes to some questions from the initial interview schedule made them more in line with a CR approach (Mukumbang et al., 2020; Brönnimann, 2022). The interviews were carried out using an online platform, Microsoft Teams, as this was the preferred medium for participants, most of whom were still working from home following home working mandates during the COVID-19 pandemic. This online platform allowed audio and video recording and automatic transcribing. Interviews lasted an hour and a half (see Appendix E and N for interview schedules).

Initial interview schedule

17. Have you had any training on working with diverse communities? If yes, when did you have the training and has it been useful? If the training has not been useful, why do you feel this way? If you have not had any training, would you like to have training and how will this help you?

18. What can social workers do to increase or improve the engagement or take-up of dementia services by persons from the African Caribbean population?

Interview schedule version 2

1. Can you share your experience of any formal training on working with diverse populations that you may have had? This can be pre- and post-qualifying. What were some of the key learning points from that training?
2. If you did not have any formal training on working with diverse populations, can you share some of your experiences or encounters, or informal learning that helped your understanding of the dementia care needs of persons from diverse populations?
3. What sort of steps can social workers take to try and overcome cultural barriers within dementia care?

Group interview with vignettes

One group interview was conducted with four participants: three senior social workers and one manager overseeing adult services within the local authority. The rationale for focusing on senior practitioners was due to their dual roles in frontline practice and strategic oversight, including policy development, governance and service delivery across adult services in the local authority. Additionally, senior practitioners might have been more aware of systemic and structural barriers, and their insights could have informed how organizational policies and resource constraints impacted practitioners' ability to provide culturally appropriate care for ACE with dementia.

Vignettes were short stories that present a hypothetical but plausible situation that is relevant to the research and can provide a useful way to expand the interviews, with a narrower focus (Jenkins et al., 2010). I utilised vignettes to guide a group interview with senior practitioners only (Denzin and Lincoln 2011). Whilst the interview schedule asked broad, open-ended questions, the vignettes have specific focuses, namely looking at ACE with dementia and inviting discussion on the role of social workers in those contexts (see Appendix H for the complete vignette, Fig. 1 for a photo of vignette 1).

There are analytical challenges that come with utilising vignettes. O’Dell et al. (2012) argue that there is the risk that vignettes can be too far-fetched and may cause participants’ focus to move from the fictional characters to their own views, particularly where the likelihood of participants encountering. This inward gaze can skew the research data as participants may project their biases and personal experiences onto the scenario, which can impact the validity of the data. The hypothetical and static nature presents notable limitations. The lack of contextual detail can lead to oversimplified or biased responses, as participants may fill in gaps with personal assumptions or experiences. This can distort the data and reduce the reliability of the insights generated (Brönnimann, 2022). I have addressed this in more detail in the quality assurance section of this chapter.

However, arguments by Jenkins et al. (2010) highlight that vignettes enable people to articulate the thinking with which they would engage with a scenario and the people within it in more personalised and open ways, as vignettes are not bounded by implicit restrictions that may be present in interview questions. To ensure the vignettes were not ’far-fetched’, I used anonymised segments of real-life cases that had practice outcomes (O’Dell et al., 2012), and participants could accept them as real-life scenarios.

Through CR the use of vignettes provided participants with a sort of focused breadth in which to unpack some of those hidden-unseen interactions between structures and social worker agency in the context of their understanding and perception around race and ethnicity, that may not necessarily come to the fore during their day to day practice due to structures present in their day to day practice but absent in the group interview setting, for example time constraints. Social workers, particularly seniors who have additional responsibilities, are often constrained by time, which can limit their engagement with ACE service users. I also observed that in the group setting, the use of vignettes allowed for a balancing of the power dynamics between myself as the researcher and the participants, as well as amongst the participants who were senior practitioners in different areas of governance within the local authority. The use of vignettes also allowed participants to demonstrate the extent of their engagement with reflexivity; this is explored in more detail across the findings chapters. I believe this usefulness justified my use of vignettes as tools that supported my efforts to address the research topic.

Documentary analysis

The research involved an analysis of an anonymised care plan for ACE with dementia, which was completed by social workers. The expected number of care plans was at least five; however, only one local authority provided care plans. Although eight care plans were provided, only one met the criteria. Reflections on this highlighted the complexities associated with recording data around ethnicity and race, as well as the issues that arise when homogenous terms are used across complex systems such as social services departments. The other care plans that did not meet the criteria were identified as ‘African’ and ‘Black British’. I purposely did not include these terms in the care plan criteria due to the embedded dilemmas around terminology that tend to aggregate different ethnic groups. (I discussed this in detail in the literature review).

It was anticipated that an analysis of the documents produced by social workers and care managers would not only offer insights into the meanings and motivations underpinning the actions taken by social workers but also highlight how practitioners acknowledged race and ethnicity. The care plan would also produce insights into how the local authority, as the overarching organisation in which participants worked, perceived race and ethnicity in the context of dementia care, social work actions and interventions (see Appendix A and B for details of a blank care plan and the request form to access care plans analysed within the empirical chapters of this study.

Additionally, analysis of care plans aimed to identify how the outcomes for ACE with dementia were identified and recorded and if there was any variance with this across local authorities. Further, identified differences could also lead to deeper exploration of service provision and service delivery, as well as provide useful feedback to practitioners and organisations on the extent to which practice was aligned with policy and specific areas of care planning were challenging for practitioners and may require additional training.

The analysis of the single care plan in the study involved a manual, iterative process. I chose to manually analyse the care plan because it was easier to read in Word format. My tacit knowledge as a social worker, facilitated immersion in the document. The analysis involved an iterative process of re-reading and highlighting interesting phrases, and looking for themes guided by thematic analysis, (Braun and Clarke

2006), as discussed in-depth below. This ensured a thorough understanding of the care plan's content. I found the re-reading stage interesting as I found new data that either supported or challenged data already found and this encouraged me to develop my knowledge in broader areas whilst promoting discipline allowing me to remain focused on the subject matter of my thesis.

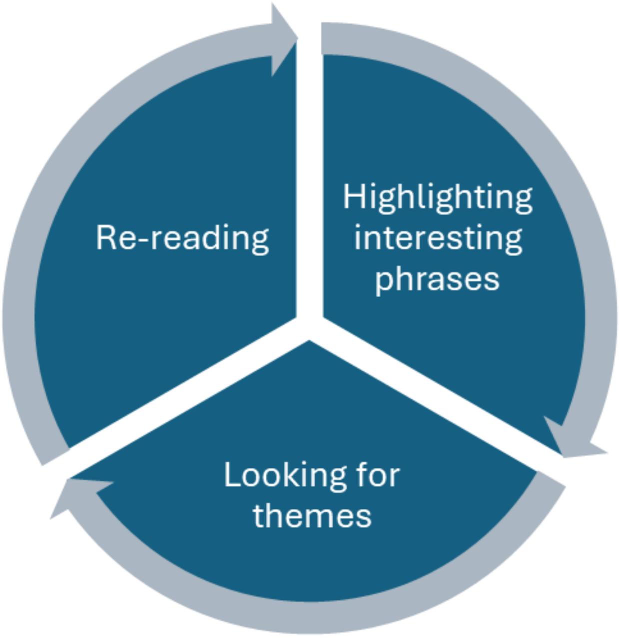

Figure 4: Care plan analysis process

4.8. Data analysis

According to Braun and Clarke (2006), thematic analysis (TA) is a method for identifying, analysing, organizing, describing, and reporting themes and unanticipated insights found within the data. One of the arguments for thematic analysis in social work research is the potential for TA to facilitate opportunities to connect the themes in current social work practices with ACE with dementia to the literature (Labra et al., 2020).

From the context of my research, the rationale for employing TA as the data analysis tool came from the flexible characteristic of TA, which allows it to be used across various frameworks and research questions. This was important as this study employed a combined theoretical framework of critical race theory (CRT) and Intersectionality theory, a CR philosophical framework, and a case study approach.

My research sought to understand from the perspective of social workers in South Wales, how the needs of ACE with dementia are understood and perceived. TA is suitable for this type of research that is looking for meanings across data sets, rather than individual meanings (Braun and Clarke, 2012)

Another rationale for utilizing TA is its systematic way of analysing qualitative data through data-driven insights, which in turn reduces potential researcher biases and increases the reliability of the findings. Braun and Clarke (2023) warn researchers to be aware of pitfalls that can occur where the flexibility of TA makes it difficult for researchers to maintain analytical depth and there can be inconsistencies with coding and theme development, particularly where multiple researchers are involved. My research was a single researcher-led study and to mitigate against issues with analytical depth, I employed quality assurance measures, discussed in section 4.6 and I also employed NVivo 12 (Lumivero, 2024), which is a coding software that managed and organised the data and made the analysis process easier.

Before installing NVivo, I considered my skills and ability to effectively use the software. I engaged in training via the university and online to improve my skills (Adu, 2019). I was able to mitigate the common disadvantages of using coding software, as there were no costs attached, as I was able to use a free version from my university, and my computer system was compatible. NVivo was an effective tool through which I conducted the six stages of TA (Braun and Clarke, 2006).

Researchers such as Adu (2019) argue that computer-assisted qualitative data analysis software (CAQDAS) such as NVivo 12 is a powerful tool for assisting researchers in identifying themes during the thematic analysis process by providing a structured approach to data management, coding, and analysis (see Appendix C for a sample codebook developed with NVIVO). NVivo 12 allowed me to be efficient as the scale of data; a two-hour group interview and thirteen individual interviews at ninety minutes each meant that manual analysis would be extremely difficult and time-consuming as a single researcher.

I chose to manually analyse the care plan as I was able to read it easier in Word format, and I was familiar with the layout of care plans from my experience as a social worker, and this tacit knowledge made immersion easier. The following sections discuss how I employed NVivo 12 and critical realism (CR) within the six phases of Thematic Analysis (TA) (Braun and Clarke 2006).

Kiger and Varpio (2020) argue that the adaptability of TA across various theoretical and epistemological frameworks suggests that TA can be philosophically neutral. This neutrality allowed me to apply TA within a critical realist framework, which allowed me to enhance the depth and theoretical richness of my analyses, moving beyond surface-level descriptions to explore the underlying mechanisms and structures shaping the understanding and perceptions of social workers. However, to ensure I mitigated against the challenges of maintaining rigor and clarity due to such philosophical neutrality, I ensured I explicitly articulated my chosen theoretical frameworks and engaged in ongoing reflexivity.

Phase 1: Familiarization with data

Following the guidance of TA at this phase, I immersed myself in the data to gain a deep understanding. During the interviews, I made notes of any points from participants that I found interesting. I had begun manually cleaning the transcripts of filler words; however, NVivo 12 allowed me to continue with the cleaning of the transcripts at a faster rate. This cleaning process was ongoing throughout the analysis process, as there were filler words I missed, as well as the process of rephrasing participants' words required ongoing engagement with the data to ensure any rephrasing maintained the integrity of the data (Ide and Beddoe, 2024). There was no cleaning to be carried out on the care plan as all anonymising was done by the local authority (see ethics application Appendix F). However, I engaged in the same process of re-reading and highlighting interesting phrases as part of the familiarization phase.

I read and re-read the transcripts and recorded initial ideas or interesting quotes alongside the participant who provided the quote or phrase manually in a notebook. I had generated pseudonyms (Wang et al*.,* 2024) for participants, such as (P1-QSW; SNR 2), during the interview stage, which I documented in a manual memo book and discussed in detail in the ethical consideration section.

Phase 2: Generating initial codes

In this phase, I used data identified in phase one to generate initial codes. Based on the exploratory nature of my research, which featured what and how questions within a case study approach, I employed an interpretation-focused coding strategy (Adu, 2019). This coding strategy helped me identify data within the transcripts and care plan that had the potential to answer the research questions. NVivo facilitated this through a coding feature that allowed me to highlight text and assign it to nodes (codes). I carried out two levels of coding simultaneously. On the first level, I used the interesting phrases I noted during interviews and phase one to create initial codes. I also assigned 'anchor codes' to these initial codes and to my three research questions.

For example: RQ2- What approaches to dementia service provision do social workers use with ACE with dementia? - The anchor codes were: *'Approaches used by social workers' and 'Expectations. '* Transcripts were then searched using the text search in NVIVO to find any data that matched. This search also improved my knowledge of the data as well as my understanding of the context of participants' narratives. I also utilised concepts from critical realism (participant agency), critical race theory (power, empowerment, racism) and intersectionality theory (diverse, intersecting, ethnicity) to create initial codes and anchor codes. I did not use words such as dementia or social work as initial codes, as I expected these would be quite prominent, as they formed the basis of the interview questions and would not add new insights in this phase. This streamlined process was crucial for organizing data into meaningful groups and NVivo's ability to handle large datasets and provide easy access to coded segments of the data made this phase efficient and consistent (Zapata-Sepúlveda et al., 2012; Singh and Jones, 2007).

Phase 3: Searching for themes

To develop themes, I put the data through an open-ended process of identification, recombination and grouping and re-grouping. I reassessed the relevance between the codes and the transcript and care plan extracts. I looked for patterns, and I used the anchor codes to either recode data or group the data under one broad theme. NVivo supported this process through the function that allowed the creation and management of nodes hierarchically. This helped me organize codes into broader themes. The software's visualization tools, which included charts and graphs, assisted me in exploring relationships between codes and themes (Buchanan and Jones, 2010; Gibbs, 2003).

Phase 4: Reviewing themes

This phase involves refining the themes by checking if they work in relation to the coded extracts and the entire data set. Within this phase, I checked that the data grouped under a theme was accurate and relevant, as well as representative of the transcript to which it was linked. NVivo allowed me to easily go back and forth across the transcripts to confirm this accuracy. I revisited themes and sub-themes, checking that they were in the right hierarchical order and whether the themes are relevant for answering the research questions. NVivo's functions were able to help me link back to the original data to ensure that themes accurately reflect the data (Braun et al., 2014).

Phase 5: Defining and naming themes

In this phase, I carried out a revision of the themes and subthemes to assess whether the designated names given to themes were appropriate and had sufficient evidence to support such designations. To arrive at definitive names for themes and sub-themes, I asked questions of the data within the anchor codes. For example, in the anchor code 'Approaches to social work', I asked the question: 'What specific 'approach' is this participant referring to?'. To answer these questions, I revisited the broader literature underpinning the study. This was a very iterative process, as even at this stage, I discovered there were sub-themes that could be grouped with other sub-themes and that some themes were not themes but perhaps interesting excerpts, as there was insufficient or irrelevant data.

Phase 6: Producing the report

NVivo12 was very useful in this final phase as well as it enabled the extraction of coded data and themes into reports via a codebook. This feature supported the presentation of findings in a structured and coherent manner, which made it easy for me to describe each theme, sub-theme and to locate the data from the transcript and identify the participant. The iterative process, alongside the use of supervision to discuss, explore and refine my ideas as they arose from my data analysis, allowed me to take the discussions of the themes into the findings section of the study with confidence and depth that went beyond mere description (Jones, 2007).

4.8.1 Quality assurance in critical realist research

Fuchs (2022) argues that quality assurance is an often taken-for-granted concept in qualitative research, and the need to adapt quality-associated measures to the chosen research paradigm and methods is crucial. Ensuring quality assurance in qualitative research that integrated critical race theory (CRT), intersectionality theory, and critical realism within a case study design involved a multifaceted approach. Given the paucity of social work research utilising a CR philosophical framework, I had to be creative and look to other disciplines, such as business (Zachariadis, Scott, and Barrett, 2013) and education (Stutchbury, 2022), so as to gain some insight into CR's contribution to research quality. As a guide, I also considered quality criteria utilized in qualitative research. I believe the following criteria ensured that the research quality was sufficiently met, particularly around rigour, reliability, validity and generalizability.

To demonstrate rigour, I engaged with critical reflexivity as discussed in the section on reflexivity. To ensure that I acknowledge the implications of my own positionalities on the research. Through the implementation of a systematic framework, such as thematic analysis as well as the use of NVivo software, I demonstrated methodological rigour by ensuring that the findings were robust and potentially applicable to other settings.

Saunders et al. (2009) suggest that reliability is concerned with the degree of consistency of research findings and the extent to which they can be replicated. Within critical realism, the principle of reliability refers to the cognitive path that the researcher takes to move the research from the empirical level to the findings or real level. Avenier and Thomas (2015) suggest that, for research to be deemed reliable, CR contends that the researcher must be clear and transparent about the cognitive processing undertaken to move along this path. In light of these ideas, I engaged in deep ongoing reflection and reflexivity and supervision to ensure transparency throughout my research. At times, it was challenging, and this was particularly due to my own positionalities and experiences, as well as balancing the requirements of academic writing. These reflections were iterative and are discussed in-depth in the reflexivity section of this chapter but also feature as an ongoing thread in this study.

The principle of validity within CR research speaks to the processes utilised by the researcher to establish whether the uncovered generative mechanism is involved in the observed events, in other words, the extent to which the data can support the claims that are being made within the research findings (Smith and Johnston, 2014). There are different frameworks for determining research validity. I am seeking to achieve internal validity through the use of different data sources (interviews, document analysis. According to Labra et al. (2020), the criterion of generalizability is often met with mixed views. To mitigate this, I presented the findings of my study within the broader literature and demonstrated why the findings were meaningful within the context of previous research.

4.8.2 Conclusion

This chapter presented the development and rationale for the chosen philosophical, theoretical and methodological underpinnings for the study. Specifically, this chapter attempted to present a justification for my philosophical turn to CR as the underpinning philosophical framework that guided this study. This chapter also provided a discussion of the chosen methods for data collection and data analysis. I also presented an in-depth discussion about my positionality and how I engaged with reflexivity and the ethical issues I considered in this research. An outline of how I negotiated and obtained access to the local authority services departments was also presented. The chapter concluded with a discussion of the components of quality assurance considered for this study. The following chapter is the first of three empirical chapters in this thesis and begins the critical discussion of the findings of this study.

Chapter 5

The Challenge of Cultural Outcomes

5.1. Chapter Overview

This chapter is the first of three chapters that present and critically discuss the findings of this research. The findings of this qualitative exploratory study are reported within contextual frames and represent the locally defined knowledge of the participants (Holliday, 2007). These findings are presented with caution and restraint around implied generalisability and an acknowledgement of the potential of the different tiers of social work represented across participants to shape the findings.

Through thematic analysis, the participants' responses have been organised into two distinctive themes and associated sub-themes. Theme one: *the use and pursuit of outcomes as defined by policy* and with sub-themes: *social workers' constructions of outcomes* and *the construction of outcomes within multi-disciplinary team (MDT) working*. Theme two: *needs based on culture.* Four sub-themes were identified: *social workers' constructions of culture, culture as food and religion, culture as music* and *culture as language*. Direct quotations from participants and excerpts from a care plan have been used as the organising principles to situate debates and discussions within context.

5.1.2. The use and pursuit of outcomes as defined by policy

When asked to share their perceptions of the needs of ACE with dementia, compared to White persons with dementia, all participants referred to outcomes-focused working as guiding how they identified the needs of ACE with dementia. National eligibility criteria provide guidelines for defining and assessing care needs within an outcomes framework (SSWBA 2014). Whilst these needs are not specific to dementia, they are applied across health and social care in Wales, which means that social workers across Wales are guided by these criteria when working with persons who may have dementia care needs (SSWBA 2014, Section 145). Outcomes, outcomes-focused, and personal outcomes were used interchangeably by participants and were a recurring theme in this study. The following excerpts demonstrate this.

P5-SNR
‘The starting point is always what would you want to achieve? What is the outcome you were looking to achieve?’

P6-QSW
‘We're meant to be working with people to identify outcomes in order to alleviate the issues.’

Participants did not refer to outcomes as anecdotal or a discretionary way of working, but rather as a fundamental way of working. Additionally, participants did not relate an outcomes-focused approach as specific to ACE with dementia, but rather as a broad, universal way of working with all individuals. Participants did not make specific reference to this way of working as specific to persons with dementia, but rather as the prescribed way of undertaking assessments within their practice.

This consensus amongst participants suggests participants may have genuine buy-in to the principles of the *Code of Practice and National Outcomes Framework* and the SSWBA and the centrality of ‘what matters conversations’. P5-SNR and P6-QSW acknowledged that outcomes are a crucial part of their work with people with dementia by placing outcomes as integral to initial engagement with individuals, ‘*the starting point is always what would you want to achieve’*. P6-QSW makes the interesting point of the role of outcomes as a method for supporting people ‘..*in order to alleviate the issues’,* which is part of the social work mission (IFSW 2014).

Interestingly, participants talked about outcomes and appeared to be using ‘outcomes’ language to communicate with individuals, ‘*What is the outcome you were looking to achieve?’* Shapiro et. al. (2009) argue that an outcomes focus can be problematic as social workers can be pressured to articulate their practice in outcomes-based language to meet requirements by funders. This can lead to misalignment of practice values and organisational evaluations. In the context of this study, an outcomes-focused approach to practice with ACE with dementia that does not acknowledge intersecting identities that shape individual experiences and systemic disparities that contribute to and perpetuate inequalities is not inclusive and cannot be said to be supporting voice and control or collaborative relationships.

5.1.3. Social workers' construction of outcomes

Although there can be other unseen mechanisms at play, the data inferred that the local (Welsh)and global (IFSW 2014) contexts also shaped participants' perception, understanding and construction of outcomes. Legislation, policies and global mandates underpin social work practice in Wales and, through a critical realist lens, can be understood as those unseen mechanisms that shape the observable (participants' construction of outcomes for ACE with dementia). ACE with dementia are a racially marginalised group, with intersecting identities, and practitioners' understanding of these attributes can shape their construction of outcomes for individuals with this background. The extracts by P4-SNR and P7-SNR below highlight participants' perceptions of outcomes as more than practicalities; rather, participants construct outcomes as individualised and specific to the person.

P4-SNR

'*Understanding of what people's outcomes are. So, forget about the washing, dressing and all those things that you know have to be done. You know, do you want a bath on a Thursday? Do you have a shower every day? All of those things need to be taken into consideration. So, I'm not minimizing the fact that those are outcomes as well.''*

Through a critical realist lens, P4-SNR appears to demonstrate a deeper understanding of the subjective and complex nature of personal care amidst other possible objective realities. For example, another individual may prefer showers only, with no preference for the days. Through the questions '*Do you want a bath on a Thursday? Do you have a shower every day'?* P4-SNR demonstrates a good use of conceptual knowledge (Audi, 2018) around personal care, which produces an understanding that personal care is more than physical hygiene and that outcomes are more than activities of daily living.

The data infers that perhaps P4-SNR acknowledges that the individual receiving personal care also has agency to determine how and when they receive such care. This inference aligns with the principle of voice and control within the (SSWBA 2014). This is an important principle, particularly for persons who have a dementia diagnosis and may have difficulties making their wishes and feelings known, or where professionals assume these persons cannot make their wishes and feelings known because of a dementia diagnosis. P7-SNR gave some insight into their approach to identifying the personal outcomes for individuals with dementia by sharing the questions they reflected on when engaging with individuals who have dementia.

P7-SNR

'Again, it's about trying to build up a close, communicative, good relationship with someone and just being clear about, you know, what's important to them. What do they want? What would they expect from us? What's their personal experience? You know the outcomes for that person.'

Through this dialogue, P7-SNR infers that there are processes that practitioners engage with in order to arrive at an individual's outcomes. P7-SNR suggests relationship building and communication as important approaches to the identification of personal outcomes.

Interestingly, P7-SNR refers to the individual's personal experiences, which contrasts with the guidance in the *code of practice for assessing needs*, which stipulates the necessity to differentiate and separate outcomes from experiences (SSWBA 2014 Part 3). This reference suggests that practitioners have discretionary powers (Evans, 2020) within their 'street-level bureaucracy' (Lipsky, 1980). Such powers determine the extent to which practitioners perceive an individual's historical experiences to be important within the outcomes dialogue.

This is particularly important for social work with ACE with dementia, whose historical experiences of racism or inappropriate services may shape their engagement or lack of engagement with services (Lasrado et al., 2021). P7-SNR further makes the point that personal outcomes also include an individual's expectation of social workers, '*What would they expect from us?'.* This question suggests that social workers also engage in managing the expectations of service users whilst simultaneously *'trying to build up a close, communicative, good relationship'*. This further promotes the complexities of the 'street level bureaucracies' (Lipsky 1980), which are involved when social workers are attempting to establish and support individuals to identify and meet their outcomes.

Whilst the two participants above alluded to a personalised approach to identifying outcomes by placing the individual at the centre, here P1-QSW acknowledges the influence of the underpinning policy, the SSWBA, on how social workers record an individual's personal outcomes.

P12-QSW

'One of the important things about the well-being assessment is the requirement that people, their voices, their actual words, are written down on the forms. So, we will ask people about, you know, what are your outcomes? People will usually often say want to stay at home and then you start working about what does that actually mean? What are you prepared to compromise on because it might be, for example, you can only live in one room because you can't go up and down stairs.'

P12-SNR identifies a drive of the policy to capture the individual in ways that facilitate authenticity, '*their voices, their actual words, are written down on the forms.*' Through the question, '*What are you prepared to compromise on?'* P12-SNR gives further insights into the negotiations and compromises that occur when social workers attempt to support an individual to meet their personal outcomes, highlighting that personal outcomes are not fixed or given, but rather they can be contested.

In this example, it would be that the individual must be prepared to '*only live in one room'.* On the one hand, P7-SNR reflects on the question around service user expectations of social workers, and P12-SNR talks about service users' willingness to compromise. These two conversations made me question what social workers expect of service users in these situations and what social workers are prepared to compromise when working with ACE with dementia to identify and meet their personal outcomes.

Research by Ylvisaker & Rugkåsa (2022) found that social workers are constantly having to balance between implementing policy and helping people, thus engaging in constant compromise and management of expectations from service users, organisations and their own professional and ethical responsibility. Allen-Meares (2013) argues that understanding an individual's culture is important to social work practice, especially where compromises occur.

The author further argues that cultural competence in social work is not simply a skill; rather, it is an ethical imperative that ensures compromises do not inadvertently perpetuate inequalities. Compromises also occur where practitioners are part of multi-disciplinary teams, specifically, health-based teams, such as community mental health teams, or where social work teams are situated within hospital teams. The following section presents data from participants and discusses the sub-theme around multi-disciplinary (MDT) working and the construction of outcomes.

5.1.4. The construction of outcomes within multi-disciplinary teams (MDT) working

In their research on social work practice and outcomes in rehabilitation settings, Freymüller, Knoop, and Meyer-Feil (2024) suggest that specific activities such as social workers' interactions with health professionals, local and global contexts and the circumstances and context of the individual shape how social workers perceive, understand and construct outcomes. In the context of my study, some participants work within and across multi-disciplinary teams and outcomes are often negotiated, contested and shaped by social and medical constructions of outcomes, similar to arguments made by the (Freymüller, Knoop, and Meyer-Feil, 2024).

A recurring theme throughout this study was the complexities and constraints of MDT working, particularly where social workers engaged with health practitioners. The following extracts from P1-QSW and a case file resonate with some of those tensions highlighted by Dustin (2007), specifically, the fine line between supporting people to meet their outcomes, whilst managing risks within the bureaucracies of care management.

P12-SNR

'I've also seen in perhaps people with a dementia in the West Indian community, where people, especially men, have lived life in a much more relaxed freeway that their outcomes are poor because people just want to lock them away. We had a man who lived on a boat, and I think he was, you know, he clearly enjoyed the odd bit of dope, and he was having a very nice time. The hospital didn't like it at all because they were always worried he was going to fall in the water. I'm, you know, fair enough. I can see that, but frankly, there was a judgment being made, a big judgment, you know. Well, he's not safe on his own. And I think the outcome for him was that they wanted him to be locked up because then they felt safer."

In unpacking this case recalled by P12-SNR, I observed that elements of the story feed into several debates around ACE with dementia and service engagement. In their research about the experiences of BAME persons with dementia, Saltus, Duval, and Vougioukalou (2021) found that ACE with dementia have poorer outcomes due to several factors, such as culturally inappropriate services. Similarly, P12-SNR refers to ‘poor outcomes’, going further to suggest that not only are outcomes poor for ACE with dementia, but that men from this community experience poorer outcomes than women from the same community.

Through a critical realist lens, it can be inferred that there may be unseen mechanisms at work that might shape such outcomes for men from this community. Additionally, P12-SNR talks about observing these poor outcomes but does not discuss further their perspective on the role of social work in challenging this, implying that perhaps P12-SNR may not think there is a role for social work or that the role is difficult to define. I explore the role of social workers in more detail in chapter seven.

Additionally, the notion of ‘poor outcomes’ for ACE with dementia also underscores the notion that the concept of good and poor outcomes is contested and under constant negotiation, depending on context. Bullock (2004), in his work ‘*How do we evaluate outcomes’,* discusses the difficulty for practitioners in not only establishing what outcomes are but also evaluating outcomes, due to various influences from professional, political and organisational requirements that promote their own outcomes.

The account by P12-SNR of their experience of MDT working with healthcare professionals to support this ACE with dementia, also provides an imagery of how practitioners can feed into the stereotypical perceptions of Black men as associated with drug use, ‘*he clearly enjoyed the odd bit of dope’* and needing monitoring, ‘*he's not safe on his own’*. These statements feed into arguments made by Seffrin and Teeple (2025); Jesson et al. (2011) that Black men are often associated with drug use, and even where they may be facing mental health or other traumas, their drug use overshadows their need for mental health support. Whilst I am not arguing against known evidence that people take recreational and other illegal drugs, my inquiry leans towards exploring how P12-SNR’s perception of this individual may have been shaped by societal discourses that associate Black men with drugs. These statements invite questions around the extent to which P12-SNR considered other factors that may have contributed to this individual's use of '*the odd bit of dope'.* This man has been presented by P12-SNR as a drug user, a Black man and a vulnerable adult. The overlapping of multiple social identities may combine in unique ways to contribute to discrimination.

This excerpt also highlights ongoing challenges of multi-disciplinary working between social work and health services, given that both disciplines are underpinned by incongruent models of work, the social model and the medical model, which bring inherently different values and ways of working (Phillipowsky, 2018). P12-SNR ends the story by highlighting, '*And I think the outcome for him was that they wanted him to be locked up because then they felt safer.'* This invites reflection on a critical point I made earlier, and a point supported by Clapton (2021) as to who defines outcomes and how outcomes are defined. This final line from P12-SNR suggests the professional rather than the person defined the outcome, through a risk-averse approach to meet the needs of the organisation, which was the management of a perceived risk.

An interesting observation, within P12-SNR's story, is that whilst P12-SNR offers a critical opinion of the views of health professionals in this case, P12-SNR refers to the service user in question as from the 'West Indian' community. This terminology and the way it shapes the identity of ACE have been explored in depth in the literature review. However, the point of revisiting it here is to demonstrate that, whilst my own subjective truth is that it is a term that has deep roots in oppression, the participant, knowing that the researcher identified as an ACE, did not check the correct terminology.

When looking at the context of engaging with ACE with dementia, who may hold certain terminology as oppressive, this can be a factor that promotes non-engagement. The use of this terminology by P12-SNR demonstrates the way language can become embedded in society (Hall 2018). It further highlights how social work and social workers can become unconscious of their complicity in servicing and perpetuating deep-rooted oppressions that are built by the groups in power and reinforced by the dominant discourses (Stanfield, 1984; Van Den Bergh, 1995).

The following excerpt from the care plan consolidates the theme and sub-themes discussed so far. The excerpts presented here are from the care plan of an ACE with dementia who is a resident of a care home. According to P12-SNR above, *'one of the important things about the well-being assessment is the requirement that people, their voices, their actual words, are written down on the forms'.* These excerpts illustrate how one particular local authority captured the voice and actual words of an ACE with dementia.

This illustration also demonstrates discussions I made earlier around the way policy shapes how social workers construct personal outcomes and presents further arguments that outcomes are contested and that social workers have discretionary power to determine which personal outcomes are supported. Interestingly, records in the care plan (see blank care plan in Appendix A for reference) analysed in this study are not clear as to whether the statements have been made explicitly by Mrs X or have been constructed by the practitioner who completed the assessment. This is significant as it will be in contrast to earlier statements made by P12-SNR, *'One of the important things about the well-being assessment is the requirement that people, their voices, their actual words, are written down on the forms.'*

'*Agreed Needs:*

Mrs X experiences low mood/Depression and this will need close daily monitoring, as this impacts on her wish to eat/drink, which in turn impacts on her overall health and well-being. Care home staff to alert GP with any concerns about Mrs xxxxx low mood.

Eligibility: Needs can only be met by C&S Plan (Eligible)'

'Agreed Needs:

Mrs X needs daily monitoring of skin integrity, as she is at high risk of skin breakdown, due to immobility, incontinence and poor nutritional intake. Mrs xxxxx needs regular application of prescribed creams to appropriate areas, to minimise discomfort and skin breakdown.

Eligibility: Needs can only be met by C&S Plan (Eligible)'

Whilst P5-SNR shared, '*'The starting point is always what would you want to achieve?',* this case file record shows that the starting point is based on the guidance of policy, specifically*,* the *Code of Practice and National Outcomes Framework,* through which, Welsh Government set out specific criteria as to what constitutes a care need by prescribing a national eligibility criteria for determining eligible care needs (Social Care Wales, 2023).

Mrs X's needs for nutrition, skin care and mobility fit the national eligibility criteria for eligible needs, as such Mrs X is eligible for local authority support. A critical question that arises from the above excerpt comes from the heading '*Agreed Needs'*. It is not clear who agreed these needs as the needs of Mrs X, if there was any agreement made, or if this is just a bureaucratic design within the care plan that is a policy requirement.

The significance of this is to demonstrate that dementia care planning by social workers is undertaken within ambiguities. The actual design of this care plan, whether on purpose or by chance, shows that the starting point is the consideration of needs so as to determine eligibility, followed by identifying personal outcomes, which are in line with the policy guidance. The design of the care plan also demonstrates the arguments made by Shapiro et al. (2009) around the problems that arise when practitioners have to articulate their practice in the language of outcomes.

The care plan for Mrs X showed eight sections for 'Agreed Needs' before the section for Personal Outcomes. This seems to be in contrast to what P5-SNR said about outcomes always being the starting point. The following excerpt of Mrs X's personal outcomes adds to earlier discussions around the tensions that arise when an individual's personal outcomes are perceived as a risk to be managed by social workers.

'Personal Outcome Description: Mrs X said, her outcome is "Just dying, want to go quickly". "Tell her when I pass away, just cremate me here. No funeral" (Mrs X was referring to her daughter). "I lost my appetite, and I can't eat. I see my daughter sometimes, downstairs. I hope I go quickly and don't give you all trouble.'

Personal outcomes describe what a person wants to achieve. Personal outcomes must be identified through the process of proportionate assessment, and although individual to each person, will reflect national well-being outcomes (SSWBA 2014, s.5). According to the record of the casefile, Mrs X identified her personal outcome as '*Just dying, want to go quickly'*. Whilst it is not stated if Mrs X has a history of making statements such as this and has been receiving specialist mental health support, I argue that, given the context, it may be that this is a cry for help and perhaps should be understood by the practitioner as an unmet need.

If seen this way, there is the possibility for new or different conversations to establish Mrs X's true outcome. The context is that Mrs X has been unable to have frequent visits with her daughter due to COVID-19 restrictions that were in place at the time. Research by Shaw and Csikai (2023) around the impact of COVID-19 restrictions on the psychosocial well-being of nursing home residents found that the attempts to maintain social connections through phone or video calls, and 'window' visits between residents and family/friends, were insufficient to replace physical face-to-face connections.

Their research also found that COVID-19 restrictions had detrimental effects on the overall mental health of nursing home residents and negatively affected the attachment relationships with spouses/partners. According to the care plan, '*Mrs X experiences low mood/Depression'* and this could have been exacerbated as a result of COVID-19 restrictions on family visits, as she expressed, *'I see my daughter sometimes, downstairs'.* From my experience as a care home social worker during COVID-19 restrictions, I believe Mrs X's needs around mobility and skin integrity may have made getting her out of bed often challenging and perhaps not always possible, during COVID-19, due to space restrictions within care homes as a result of social distancing rules and staff shortages.

The following excerpt illustrates the actions taken in light of Mrs X's identified personal outcome.

'Carers will support and enable Mrs X to maintain a good diet/fluids'

'Carers will support Mrs X with assisting her to wash daily'

‘Carers will support Mrs X with to engage with activities within the care home and encourage her to engage with conversation and company to continue to increase her mood’

The excerpts demonstrate a combined biomedical-social approach by staff. It can be argued that such an approach will not support Mrs X to achieve her identified outcome; however, this is an example of the tensions that social workers have to navigate when service users identify personal outcomes that go against policy. Social Workers are mandated by professional, organisational and national policies to safeguard vulnerable adults and ensure such adults do not experience neglect or abuse (SSWBA 2014).

To keep Mrs X safe, her identified personal outcome was [re]constructed and new outcomes pursued and used on her behalf. Whilst it can be argued that in the case of Mrs X, the approach by care home staff and the social worker to ensure Mrs X did not die, was the right, moral or humane approach, I make the point that where ‘personal outcomes’ challenge or go against organisational and societal agendas, such ‘outcomes’ become ‘risks’ that need to be managed.

I further argue Mrs X’s words indicate an emotional, or even existential need, that seems inadequately addressed here. Cheston and Christopher (2019) suggest that existential needs are fundamental to the emotional and psychological well-being of humans. These needs are exacerbated for persons with dementia, who may no longer be able to articulate wanting to have purpose and meaning to their day or the importance of making or maintaining social connections. Therefore, dementia care providers must acknowledge and address these needs, as if left unmet, can result in feelings of anxiety and hopelessness.

Mrs X, expressing her personal outcome as *"Just dying, want to go quickly",* may have been due to her depression being exacerbated by not being able to have frequent visits with her daughter. The excerpt below is from a note on the ‘Personal Outcomes’ section of the care plan states that her mood was reported as improved following the lifting of restrictions:

‘*Update: Visiting restrictions have been lifted, and Mrs X has been able to see her daughter at least on 2 occasions. Her mood is reported to have lifted. Mrs X has been prescribed Citalopram, short-term.’*

The data excerpts show that following Mrs X's expression of her outcomes, which would have been perceived as a risk to be managed, professionals involved pursued a different outcome for Mrs X: 'reducing her symptoms of depression'. Here, the outcome used was not that of Mrs X, but that of the care home and social services: 'meeting their duty of care according to the law' (Social Care Wales, 2023).

As a result, *'Mrs X has been prescribed Citalopram, short term'.* Mrs X had a diagnosis of depression, and medical intervention was sought, and antidepressants were prescribed, which is a common approach (Dudas et al., 2018). It can be argued that Mrs X's own care and support needs, by way of a diagnosis of dementia, may have facilitated a path for staff to [re] construct what her outcomes should be. Perhaps it would have been more difficult for staff to justify a prescription for anti-depressants if Mrs X did not have a prior diagnosis of depression.

Having a diagnosis as well as not being diagnosed opens up several critical questions around the epistemic powers at play (Kurs and Grinshpoon 2018), and the vulnerability of ACE with known mental ill health when they engage with social workers and other health care professionals. Research conducted by Banerjee et al. (2017) and Johnell et al. (2017) highlights that whilst antidepressants are commonly used in dementia, as depression is a common co-morbidity in dementia, and antidepressants are often used to treat depression and more widely, the evidence for antidepressants having a positive role in dementia is weak.

An interesting observation is that the note about the prescription was recorded in the section for 'Personal Outcomes'. Whilst it can be argued that this is perhaps an administrative error or it was done to link in to the outcome of Mrs X as discussed above, the other notes around support were recorded in the 'Actions to be taken' section of the care plan. I note this observation as it alludes to the idea that Mrs X identified having an antidepressant prescription as one of her outcomes. If it is the case that Mrs X did not identify this as her outcome, then this record in the care plan contrasts with the suggestion by P12-SNR above, *'One of the important things about the well-being assessment is the requirement that people, their voices, their actual words, are written down on the forms'.* This then raises the question of who determines personal outcomes for service users?

A deeper look at this situation with Mrs X suggests the potential to understand the social worker's construction of personal outcomes as time-specific and situational. This is significant as it may suggest that an individual may only require short-term support to meet a short-term personal outcome or that a personal outcome may only be identified as such, due to a specific circumstance.

Consideration of these notions may further impact what gets defined as an outcome. For example, Wilson (2020) highlights that during COVID-19, care and support assessments were scaled back. Where care plans were required, a new design for proportionate assessment was developed and these assessments were difficult to undertake by telephone, particularly where the individual's dementia was advanced. On many occasions, staff and relatives were responding 'on behalf' of residents. Social needs such as visits with family and even interaction amongst residents were fraught with challenges and although accepted as important, unmet social needs were seen as a temporary and situational issue, which meant the personal outcomes of many residents were not attended to, similar to Mrs X.

5.1.5. Summary of the use and pursuit of 'outcomes' as defined by policy

Theme one of this chapter, presented participants as actively using their professional agency, (Lipsky, 1980), to pursue and shape the implementation, of an outcomes-focused policy, inferring practitioner 'buy-in'. For example, social workers [re]constructed the outcomes of ACE with dementia within the care plan. The account by P1-QSW showed that where the personal outcomes of an ACE with dementia were perceived as risks to be managed, social workers and other involved professionals reconstructed those outcomes, or pursued different outcomes that aligned with the organisation.

Participants also demonstrated an awareness of some of the underpinning tensions, competing factors and complexities when supporting ACE with dementia to identify and achieve their outcomes, particularly within multi-disciplinary settings. However, participants did not explicitly demonstrate using their agency to address these tensions (Pascoe, 2025; Prior and Barnes, 2011).

Most participants were able to identify eligible care and support needs as defined in the *Code of Practice and National Outcomes Framework* and the SSWBA, such as 'washing and dressing' and 'remaining at home.' Although one participant gave an explicit account that demonstrated some understanding that ACE with dementia had poor outcomes, which is congruent with research findings (Saltus, Duval, and Vougioukalou, 2021), the participant did not provide insight as to what good outcomes for ACE with dementia might look like.

Despite bold claims of the Welsh approach to well-being, it has been argued that there is no consistent approach to assessing and measuring the well-being of older people in Wales (Older People's Commissioner, 2016). The data also invited reflections on who determines outcomes, the subjective and bureaucratic processes employed by social workers and health care practitioners when supporting ACE with dementia to meet their personal outcomes.

The data also illustrated that personal outcomes are the caveat that gatekeeps care and support services by requiring individuals seeking support to be assessed to determine eligibility for care and support before identifying outcomes. For example, participants expressed outcomes as the 'starting point', the 'key factor in alleviating people's problems'. However, both the literature (Clapton, 2012) and the data highlighted that the use and pursuit of 'outcomes' is subjectively [re]constructed, contested, and not always in harmony with the personal choice of the ACE with dementia. Whilst this section argues that social workers utilise an outcomes-focused framework underpinned by policy as a means to identify and understand the needs of ACE with dementia, the next section will present and critically discuss what participants perceived as the needs of ACE with dementia.

5.2. Needs based on culture

The data showed that when asked about the needs of ACE with dementia, a recurring theme amongst all participants was: *Needs based on culture.* This need will be critically discussed alongside identified sub-themes: *cultural needs as food and religion*, *cultural needs as language, cultural needs as music, cultural needs as understanding behaviours and cultural needs as challenging to social work perception and knowledge.* Fletcher-Jansen, et. al. (2000) suggest that culture refers to those beliefs and behaviours that are ascribed to specific people.

Scholars such as Spencer-Oatey and Franklin (2012) argue that culture is difficult to define and conceptualise. Malik (2006) argues that culture is multifarious and presents in a myriad of ways and therefore, there can be no static definition of culture. I acknowledge and agree with aspects of these arguments around culture and present the data on the perceived cultural needs of ACE with dementia with caution, as participants may perceive cultural needs as meaning different things, at another time, place and context.

My definition of culture has changed over time since emigrating from Trinidad and Tobago to Wales. I once held culture as a simplistic identity marker based on the food, dialect, carnival, Soca and steelpan and celebrations of the different religions and celebrations that I grew up with. My move to Wales, alongside engagement with higher education, has caused me to view culture as a broad, multifaceted, social and political construct with embedded power to categorise people, include and exclude some.

I now view culture as a construct that can be contested, subjective and changed. At the same time, I see culture as a construct that can be subjectively fixed by an individual or even by a group. For example, my grandmother gave back her American citizenship to return to Trinidad so that she could ‘eat Trinidadian food’ and hear the ‘real Trini’ accent around her and live like a ‘Trinidadian’. As I reflect on this, part of me feels robbed of my innocence.

Since living in Wales, I have found myself having to self-manage when, how and to whom I share my Trinidadian culture. I question whether I have enough ‘Welsh culture’ for certain spaces. However, I often reflect on how fortunate I am to be able to ‘pick and choose’ which ‘culture’ I want to adopt at specific times, in specific spaces, and I have found ways for my different cultures to co-exist. In my own reflections, culture is a big aspect of my identity, my history. For me, my culture is reflected in my accent, my food preferences, my values, and my beliefs about the world.

According to Park (2005), the concept of culture has become more significant over time in social work as it has a central role in the development of interventions with minority populations. The narrative from SNR3 from the group interview and from P11-QSW from the one-to-one interview gives some insight into their views on culture.

SNR3
‘We are required to make sure we understand what people's cultural backgrounds

are and it is a part of the whole person because people's cultural needs, their faith-based needs, all of those make them what they are. And that's why when we're doing any form of assessment, that's something that you would naturally talk about as a social worker. I mean, you can't make assessments of people without understanding a bit about what their life is like, where they've been, how did they get to Wales.'

P11-QSW

'It's different for White people, for British people. They have everything they are used to. They have the same language, they have the same food, they have the same music, they have the, the things they are used to, people from other cultures, they don't have.'

Interestingly, SNR3 starts by stating that understanding the cultural backgrounds of people is a mandatory requirement for social workers. SNR3 does not elaborate on where they got this mandate; however, they link this to assessment, which is a statutory part of social work practice, alluding to this mandate as a requirement of organisational policy. SNR 3 expresses that finding out about a person's cultural needs is 'natural' to social work,' *that's something that you would naturally talk about as a social worker',* suggesting that cultural inquiry is a natural aspect of social work assessment.

It may be that talking about culture is 'natural' when social workers engage with ACE with dementia because the social worker perhaps perceives the interaction as being with someone from a different ethnic background to White persons with dementia and therefore talking about cultural needs is the 'right' approach rather than the 'natural' way of social work. The (IFSW 2014) principles on social justice and diversity require social workers to attend to the culture of the people they engage with.

Additionally, social work research continues to make recommendations for supporting social workers to become culturally competent, which implies social work is not great at engaging with culture (Dominelli, 1989; Boyle and Springer, 2001; Marsiglia, Kulis and Lechuga-Peña, 2021). However, the drive for social workers to achieve 'cultural competence' challenges the notion by SNR3 that cultural inquiry is 'natural' to the social worker.

The narrative from P11-QSW suggests an acknowledgement that White persons with dementia have a 'culture', but this is acknowledged in a way that makes very interesting assumptions that White British residents get their cultural needs met, without complexities and contest. However, arguments by Perry (2001) highlight that even within predominantly White culture, there are nuances and differences. Additionally, some individuals within this culture may, as a result of different religious beliefs, dietary preferences and even music preferences, be denied their cultural needs. Unmet needs may be the result of a lack of resources or a lack of understanding of these needs. The excerpt shared by P11-QSW implies that this participant's perception of White culture, the 'natural' way of inquiring about the cultural needs of White people with dementia, may be based on possible stereotypes.

Interestingly, both participants provide insights into how an awareness of 'culture' not only brings to the fore a realisation of 'other' but that this 'other' can be interrogated to determine rights and entitlements. P11-QSW alludes to having a perception of a difference between White British and ACE, *'It's different for White people, for British people'.* This is significant for ACE with dementia from the context of the role of 'citizenship' in informing identity, entitlements and responsibilities that may come with the title 'British people'. I have explored this in depth in the literature review.

Responding to the vignette on Mildred, an AC woman with dementia who would like support from the local authority to move to Brixton, where she grew up as a child when she arrived in the UK, SNR 3 expresses that an assessment should inquire *'how did they get to Wales'.* This is a significant question in light of the changing role of social workers to attend to immigration issues surrounding service users, as well as working with service users with a migration history (Lymperopoulou, 2020). Perhaps SNR3 is aware of some of the complexities, such as immigration status, which might have a bearing on eligibility to statutory support, for ACE like Mildred.

This observation highlights the arguments made by Park (2005) that whilst culture is constructed as a helpful approach to acquiring knowledge to inform the development of social work interventions, culture is an instrument that reinforces subjugation by categorising specific groups as other and as having a deficit, compared to the dominant White groups. This suggests that social workers do not inherently attend to the culture and cultural needs of minoritised individuals and groups and raises questions as to what social workers understand as the skills and values required when supporting ACE with dementia. These concepts are explored deeper in chapter seven.

Responding to the vignette of Mr Leroy, an AC man with dementia, whose daughter would like him to be placed in long-term care, SNR2, who participated in the group interview, shared an interesting account of their perspective on the cultural needs of ACE with dementia.

SNR2
'You know that has a lot of implications in terms of the cultural dos and don'ts. How can you provide for him to meet his outcomes in a way that is culturally sensitive.'

Here, SNR2 suggests that the way social workers attend to the cultural needs of Mr Leroy will be shaped by 'rules' around acceptable and unacceptable action for social work with ACE with dementia. Although SNR2 does not expand on what they perceived or understood as the 'do's and don'ts,' they have demonstrated a perception that meeting the cultural needs of an ACE with dementia is not linear and requires a level of knowledge about the 'dos and don'ts.' Interestingly, SNR2 has linked outcomes for Mr Leroy as requiring attention to his culture, which is in line with P5-SNR's notion about 'the starting point is always outcomes'. It appears that the approach is one that first identifies outcomes but is required to go further when engaging with an ACE with dementia to address the 'cultural' aspect of the identified outcome. However, it is not clear what processes social workers engage in to determine if, how, or when 'cultural sensitivity' is used or required.

Cultural needs were a recurring theme offered by all participants throughout the one-to-one interviews and the group interview. Interestingly, the data showed that whilst participants spoke about different cultural needs, participants presented nuanced understandings of culture, and some participants attached deeper meaning to cultural needs. This is a significant finding as, according to Song (2009), the ways in which culture is defined or classified inform us about the claims that are being made within those definitions. For example, the data showed that some participants defined culture as food and religion.

The possible claims within this definition can be claims to certain foods, to specific calendar dates and times, or claims to have access to certain spaces and places for worship or religious practices. According to Park (2005), the usage of the concept of culture in social work and the meanings social work assigns to "culture" are profoundly political and biased and can shape the way social workers engage with individuals, particularly those seen as ‘other’ or different to the norm. Participants shared similar perceptions of a culture-food-religion synonymous relationship. There was a shared perception amongst participants that an ACE with dementia has a culture that is linked to food and religion. The extracts below from P9-QSW and P5-SNR introduce this sub-theme.

5.2.1. Culture expressed as food and religion

P9-QSW

‘ I think it's very specific information you need to get, like for example, religion can be one of the things, diet, the culture, the things they eat.’

P5-SNR

‘It's sometimes the basics that are completely different, and so down to the likes and dislikes of food preferences could be completely different. We have also got to accommodate religious practices.’

When talking about food, participants did not provide any insight as to what they understood and perceived as ‘the food preferences of an ACE with dementia’. Guerrero et al. (2009) suggest that traditional food is food that is frequently consumed in relation to specific times of the year or celebrations, and it is normally passed down through generations and made in a precise manner, linked to specific countries or regions. For example, from my own knowledge and experience, most African Caribbean people have their regional, familial way of cooking curry dishes.

Research by Gaviola et al. (2024) and Rand et al. (2024) highlights the challenges faced by care homes in meeting the unique food preferences of ethnic minority residents. In many instances where dietary preferences are specific to a culture outside the British norm, people rely on their family to provide them. Hanssen and Kuven (2016) put forward the argument that culturally sensitive food provides more than physical nutrition, often being a source of reminiscence, well-being, and a way to improve and maintain appetite for individuals with dementia.

P9-QSW talks about culture as something that exists in its own right, alongside diet/nutrition and religion, rather than culture as comprising cultural food and religion. P5-SNR expresses a perception that all service users, White with dementia and ACE with dementia, have the same needs, which can be considered as ‘basic needs’ with food as one of them. However, there is the potential for the food preferences of ACE with dementia to be different from those of their White counterparts. P5-SNR does not go further to explain what their understanding of the religious practices of ACE might be and how these might or might not be ‘accommodated’.

No participant made any reference to religious beliefs that are specific to ACE, for example, Rastafarianism, Obeah, Orisha, or Santeria (Clark and Howard, 2005; Bilby and Handler, 2004; Forde, 2019; Paravisini-Gebert and Olmos, 2011). This lack of reference may be due to a lack of knowledge around these specific religious beliefs. Interestingly, no participant offered Christianity as a possible religious belief or faith for ACE with dementia, even when prompted to share any similar religious beliefs they may expect to find between ACE with dementia and White persons with dementia. This may be due to participants' own lack of interest in religion or due to an unconscious belief that Christianity is a ‘White’ religion. Watson and Twomey (2024) suggest that professionals can assume that ethnic minority people as less likely to be practicing Christianity, and such unconscious beliefs should be addressed through reflexive practice and cultural competence training.

Interestingly, no participant linked food and religion as being shaped by each other (Houk, 2024). No participant talked about food requirements based on religious practices (animal sacrifices, chicken and goat sacrifices are common amongst Orisha practices) or how ACE may use food within their religious practices, for example, offerings to ancestors within the Orisha religion (Houk, 2024). Similarly, no participant linked bread and wine as foods synonymous with Christianity (Albala, 2011). Again, this lack of knowledge can be a reflection of the non-religious aspects of participants’ lives, as religion is a personal choice and not a requirement of the profession.

I acknowledge that it can be challenging for social workers to gain a deep and complete understanding of all the different foods and religious beliefs that ACE or their White counterparts may hold. However, I also posit that due to high caseloads and limited time, practitioners may have adopted an ‘as and when needed’ approach to their knowledge development on diverse populations such as ACE with dementia, or where individuals with ‘unconventional’ needs present.

However, such an approach to learning about ACE with dementia suggests practitioners may not be equipped to support members of this population who might present to services at points of crisis. Additionally, an as-and-when-needed approach suggests that there may also be an absence of organisational drive to develop culturally appropriate services. A lack of knowledge around this food-religion connection can also lead to cross-cultural tensions.

For example, an ACE with dementia, who might require food offerings for an ancestral altar in their room, within a care home setting, might be refused due to health and safety reasons or a lack of understanding. However, this refusal can severely impact the well-being of the ACE with dementia, who may have done ancestral veneration most of their life. Additionally, food and religion play an integral role in palliative care and maintaining identity (Rosendahl et al., 2016). Song (2009) argues that acknowledgement of an individual’s or group’s claim to a specific culture or aspect of their culture invites reflections as to what elements of that culture get legitimised or challenged. P1-QSW shared a narrative that highlighted how specific aspects of ACE religion may get challenged when it conflicts with the White norm of religion:

P1-QSW

‘I can remember working with a young lad. And he was from African Caribbean background he was very religious, and the young lad was talking about how God speaks to him. The psychiatrist felt that was a sign of mental illness and that he was having hallucinations. This MDT, all these White people sitting around talking about how this was also a sign of mental illness. And then I said, well, I talk to God every day, so does that make you think I need to be sectioned? And for me, that was really interesting. Just because that wasn't a norm for them, whereas Asian people, Afro Caribbean people are quite religious and do see a sign from God or, you know, their

lifestyle, their cultural lifestyle can be very different to what the White society norm is.'

Although this story shared by P1-QSW is not about an ACE with dementia, it does highlight the experiences of a young AC man who engaged in an aspect of his culture that was deemed outside the White norm by the professionals in the room. This story by P1-QSW brings several discussion points to the fore. First is the notion of how professionals interpret religion and religious beliefs and asks the question 'when do religious beliefs become mental ill health, which requires medical intervention?'

A second point for consideration is similar to that raised earlier by P1-QSW around the tensions that arise when outcomes are constructed by disciplines such as medicine and that 'outcomes are poor specifically for men' from this group. Here, it is highlighted once again that within multi-disciplinary working, professionals engage in what Ortner (1998) refers to as an ideological construction of culture. This construction of this ACE's religious beliefs as 'hallucinations' situates this aspect of his culture in ways that aligned with the modes of power operating in the Multi-disciplinary setting.

Additionally, by sharing their own religious belief, '*I talk to God every day',* P1-QSW highlights that religion is not exclusive to AC service users, and there is the potential for the personal religious beliefs of practitioners to shape their attitudes to the service users' religious beliefs. P1-QSW's challenge to the MDT, '*I talk to God every day, so does that make you think I need to be sectioned?*' alludes to the role of advocacy in social work practice, particularly with marginalised groups. I discuss the role of advocacy in more depth in chapter seven.

Through the statement, '*their cultural lifestyle can be very different to what the White society norm is',* P1-QSW also demonstrated the importance of social workers' awareness around the nuances within the religious beliefs of ACE, and what this might mean for social work with this group. Additionally, this statement invites the need for social workers to reflect on their own cultural and religious beliefs and practices in terms of how they align or do not align with the White norm or with the ACE 'norm'. It can be argued that if P1-QSW did not challenge the MDT, this AC young man's claim to the aspect of his religion, '*talking to God,'* may not have been legitimised. Discussions presented by participants highlighted the complex interconnection of food, religion and culture.

Cultural identities are shaped, legitimised and delegitimised within these interconnections, which can be quite challenging to practitioners who may lack the appropriate training and time to engage in self-directed learning to support ACE with dementia to meet their religious needs and have their food preferences met, particularly in care home settings. Another cultural need that was identified by participants was the importance of having culturally relevant music. Ashida (2000) suggests that music can evoke memories and feelings, provide a sense of accomplishment, bring comfort and increase social interaction and physical movement.

5.2.2. Culture expressed as music

Excerpts from P4-SNR and P11-QSW have been used to explore how they understood and perceived music as a cultural need of ACE with dementia.

P4-SNR

'All the things that he would like, they [care home] know what music he likes, you know, they [care home] involve his culture'.

P11-QSW

'They [Care homes] give the same to everyone and that is what makes me mad because people have different music needs and they put like Elvis for everyone, and people don't need to like Elvis. They (people who are non-White ethnicity and culture) just have to go with what everyone else gets and that makes them more confused.'

Both participants here are sharing narratives about their experience of how care home staff attended to the musical needs of residents from a 'non-White' background. P4-SNR appears to applaud the efforts made by this particular care home, highlighting how the care home staff paid attention to this individual's cultural needs. It can be said that the care home staff demonstrated a certain level of knowledge gathering about 'the person', which aligns with the wellbeing and co-production principles of the SSWBA (Campbell, 2014). Interestingly, P4-SNR does not expand on how this knowledge was used to meet this individual’s need for cultural music.

The narrative by P11-QSW is in contrast to P4-SNR’s and suggests that this particular care home adopts a ‘one size fits all approach’, *they put like Elvis for everyone, and people don't need to like Elvis.’* According to P11-QSW, non-White residents in care homes are being made to listen to music that is not representative of their culture. P11-QSW further demonstrates an understanding of the usefulness of culturally appropriate music in terms of dementia symptoms. Research by Tanaka, Nogawa, and Tanaka (2012), which looked at the effects of traditional music on Japanese patients with dementia, found that music has the potential to be a non-pharmaceutical method for treating dementia and that the combination of life story approaches and music improves interactions between persons with dementia and their family or carers.

This is particularly important to ensuring well-being for both the person with dementia and their carer as the illness progresses. The statement *‘just have to go with what everyone else gets’* also suggests issues around agency and voice and raises questions around advocacy and how/if such persons can make their choices known and what happens if and when they do. Additional issues around possible lack of resources also come to the fore, as it could be the case that some care homes do not have resources to provide music that is culturally specific to non-White residents.

An interesting point from this data was that although participants demonstrated an understanding of the importance of culturally appropriate music, none referred to examples of culturally appropriate music specific to ACE with dementia. My own subjective experience made this a surprising observation, as I believed AC music to be well known, as AC music has been part of international popular music trends for quite some time, from reggae, calypso to dancehall (Hebdige 2003; Duany, 1996; Rommen, 2020).

Whilst I agree with P11-QSW that ‘*people don't need to like Elvis’,* I reflect on my own experience of not hearing Trinidadian music on the radio when I recently arrived in Wales and the effect that had on my mood and even on activities that I engaged in, such as Saturday house cleaning. This led me to think that music, like food, is associated with other cultural activities and this might place greater meaning and value on culturally relevant music in settings such as care homes, where residents' cultural engagement and activities may be limited.

Barton and Barton (2018), in their work *The relationship between music, culture, and society: meaning in music*, highlight the multipurpose role of music in facilitating ceremonies, traditions, social gatherings, rituals and activities of daily life. Discussions in this section highlighted that whilst music is beneficial to persons with dementia, culturally relevant music must also be provided to meet the needs of diverse individuals, such as ACE with dementia. The next section presents discussions on participants' perceptions of the culture-language link. According to (Kramsch, 2014), language is an expression of culture which reflects beliefs, values and traditions.

5.2.3. Culture expressed as language

Data from P10-QSW and P11-QSW were used to explore language as an aspect of culture that was expressed as a cultural need. Participants shared their perspectives and understandings on the importance of meeting the language needs of an ACE with dementia.

P10-QSW
'Maybe somebody with dementia will prefer to speak in their first language, sometimes they revert to their first language. Umm, in terms of cultural background and needs, somebody from the Caribbean, look in more on their family backgrounds, their cultural background just to find out what's important for them.'

Interestingly, P10-QSW demonstrated an understanding that reverting to one's first language is symptomatic of dementia (Tipping and Whiteside 2015). However, P10-QSW was not able to identify what language an ACE with dementia might have. Notably, P10-QSW suggests that they would seek information from the ACE's family to ascertain their wishes and feelings. Whilst it is commonplace to engage with family where an individual has dementia, where there is a language barrier, independent interpreters are employed by social workers.

However, the social worker must be able to identify the language that the individual has reverted to. Cooper, Hill, and Powe (2002) highlight that a lack of knowledge about the dialects or patois spoken by ACE, Saunders (2005) and particularly ACE with dementia who have reverted to dialects or patois can negatively impact interventions for this group. This lack of knowledge by P10-QSW is perhaps an indication of the knowledge gaps in social work with ACE with dementia.

P11-QSW

‘Research again says that they (people who are non-White ethnicity and culture) revert to their own language. And how can you do a mental capacity assessment? If you don't have someone who knows the language and the culture, it's not just the language; it’s the culture as well. They [care home staff] need to know that the way they (people who are non-White ethnicity and culture) speak, the way they look, if it means something.’

Whilst both participants refer to language as another facet of dementia care, as well as part of an individual’s culture, P11-QSW goes further and demonstrates a deeper knowledge of language, as much more than spoken words and makes specific reference to a service user whose culture incorporates non-verbal language as a form of communication. Research by Mclean, Campbell and Cornish (2003) and Keating (2009) argue that in the context of mental health, communication styles impacted how ACE engaged with mental health practitioners.

Social workers engaging with persons with dementia need to have an understanding of the role of non-verbal language, such as body language and other forms of gesticulations and what they might signify for the person. This is important in building trust but also prevents misunderstandings or communication breakdowns. Interestingly, in Wales, we have the Welsh language active offer (Social Care Wales, 2018), which makes it a legal requirement to provide the support needed for persons who wish to communicate in the Welsh language, but there is no such provision for ACE with dementia, who may revert to speaking patois or dialects. African Caribbean elders with dementia often face significant barriers in accessing appropriate care due to language discordance and cultural differences (Bhattacharyya, and Benbow, 2013). Language discordance in social work can lead to misunderstandings and reduced quality of care, highlighting the need for culturally and linguistically appropriate services (Gustafsson, 2023). The challenges faced by African Caribbean elders are compounded by the lack of structured legal frameworks similar to the active offer for Welsh language in Wales, which could ensure the provision of services in their native languages.

This may be due to the small size of the AC population as well as the unavailable resources. However, this may have a negative impact on ACE with dementia who may have reverted to dialect or patois and not have family available to translate during life-changing social work interventions such as mental capacity assessments, hospital discharge and best interest decisions.

5.2.4. Summary of needs based on culture

The discussions provided by participants highlight a general acknowledgement that ACE with dementia will have cultural needs. However, from the data, it can be inferred that participants drew on forms of tacit knowledge and wider perceptions of ACE, as ‘other’, to provide responses. Whilst participants appeared to ‘know’ that ACE with dementia have cultural needs, critical analysis of participants’ responses reveals there is a lack of understanding around those needs that would translate into meaningful practice.

5.3. Conclusion

The data and literature provided a basis for critical discussions around outcomes-focused practice and the perceived cultural needs of ACE with dementia, as described by participants. Participants engaged in a ‘pursuit’ of outcomes, which featured in the way they articulated their practice with ACE with dementia. Participants used tacit and experiential knowledge to construct ‘culture’ and ‘cultural needs’ as unique to ACE, ignoring aspects of their own culture, whilst implicitly acknowledging White culture. There were three perceived cultural needs: *cultural needs expressed as food and religion*, *cultural needs as music* and *cultural needs as language.*

To critically reflect on the assumptions I may hold about participants’ responses, I acknowledge that while many did not demonstrate a deep understanding of the cultural needs of ACE with dementia, or how these needs translated into person-centred care, their interpretations may be shaped by generational and cultural differences within the ACE community. These differences are rooted in a complex interplay of historical, social, and cultural factors, including migration histories, experiences of racism, and varying degrees of integration into Welsh society. These in turn, shape the experiences and understanding of dementia and social work support.

Saltus and Folkes (2013) highlight in, *Understanding dignity and care,* older, first generation African Caribbean individuals often view dignity and care through a communal lens, placing emphasis on respect and personal relationships in healthcare interactions. This perception may shape their engagement with formal dementia care services, particularly when past experiences of racism have eroded trust in institutional care. Consequently, even when social workers are willing to engage with cultural needs on a deeper level, this service user group may choose not to participate, leading to ‘unmet’ needs that reflect disengagement rather than service failure.

In contrast, younger generations – those born or raised in the UK - may hold different health beliefs and expectations. Second- and third-generation African-Caribbeans often exhibit greater familiarity with UK health and social care systems and may possess higher levels of health literacy (Moore et al., 2022). These generational shifts can result in divergent understandings of dementia and different levels of willingness to engage with formal services.

Whilst I acknowledge the important aspect that culture plays in the lives of everyone, not just ACE with dementia, an interesting point was that participants did not list other needs, such as housing or social interaction. Research has shown that ACE with dementia face disproportionate negative impacts from socioeconomic and sociodemographic factors such as poor housing, gentrification and lower household incomes (Tsamakis et al., 2021). ACE with dementia also face high rates of isolation and loneliness (West et al., 2021), which is known to exacerbate dementia symptoms and affect well-being.

I also accept that participants genuinely may not know or see these needs, highlighted above, as specific to ACE with dementia or as specific to White persons with dementia, as they can be perceived as broader societal needs. Loneliness and social isolation may very well be perceived by participants as an older person or an older person with dementia problems, rather than an ACE with dementia problems.

The fact that these issues were absent from the narratives of participants might be an indication that participants' perception of needs in the context of ACE is developed through their limited conceptual knowledge of culture. The data analysed in this chapter infers that participants draw on 'culture' as a catch-all response to non-White persons. Holding such a perception implies that participants do not have a deep understanding or a 'grasp' (Gordon, 2017) of the necessary knowledge to fully support ACE with dementia. The following chapter is the second of the three empirical chapters and will present discussions on the Approaches and Barriers to meeting the needs of ACE with dementia.

Chapter 6

Working Hard or Hardly working: Approaches and Barriers to meeting the needs of ACE with dementia

6.1. Chapter Overview

In Chapter Six, I continue to present and discuss the findings of this study. Data presented in this chapter give insight into the approaches social workers use and the barriers they encounter when attempting to meet the needs of ACE with dementia, as identified by participants and discussed in Chapter 5. The data has been organised into one distinctive theme: *The inclusion mirage*.

6.1.1. Approaches to meeting the needs of ACE with dementia

Participants talked about approaches they utilised when they attempted to meet the needs of ACE with dementia. Participants did not provide clear rationales for how these approaches became part of their practice. However, some participants implied that these approaches were shaped by the practices within the team and their subjective understanding and perception of social work practice with ACE with dementia.

Some participants made explicit claims to relationship building as key to working with ACE with dementia. These excerpts provided different perceptions of relationship building with ACE with dementia and are discussed below.

6.1.2. Building relationships

According to Ruch et al. (2010), social work is relationship-based, and the relationship is a vital tool that enables social workers to gain a deeper understanding of their own beliefs and how these are shaped by the relationships they form or are involved in with service users, the organisation and society. Although not all participants explicitly used the term ‘relationship building’, the data highlight that most participants acknowledged aspects of relationship building, which include trust and knowledge of the community. Through this data, it can be inferred that participants shared different perceptions of what relationship building in social work practice with ACE with dementia entailed.

Such difference could in turn have different outcomes for the quality of the relationship that is formed between ACE with dementia and the social worker. Additionally, these differences have the potential to shape the level of understanding practitioners develop and apply to addressing the needs of ACE with dementia. For ACE with dementia, such differences in understanding and perception of relationship building can result in varied experiences of social work, service delivery and opportunities to collaborate on development. When asked about how they would overcome challenges to working with ACE with dementia, participants offered the following responses:

P7-SNR

'*If you've got something in common you could share during that interaction but if I had an Afro Caribbean service user obviously I wouldn't have that ability to share something and build a relationship, but then you know, just because you've got some things in common with a person doesn't mean that there's a magic wand. I suppose one of the other issues is if that person has had a long life experience and some of that was an experience of racism, I don't know whether they would share any of that with me as a White professional social worker, you know, in a position of power, relatively speaking over them. I mean, we got that power difference either way, with the service uses that we have, but that's a potential added layer to it'.*

P7-SNR begins by identifying that commonality can be a starting point for relationship building. Notably, P7-SNR did not make reference to the race or ethnicity of the individual they may share commonality with. Rather, it can be inferred that P7-SNR would be open to exploring what commonalities exist and building relationships through this exploration. However, P7-SNR did not adopt this approach when considering relationship building with someone who was from an AC background. This can be seen through the statement: '*if I had an Afro Caribbean service user, obviously I wouldn't have that ability to share something and build a relationship*.' In the context of this study, this could be taken to mean cultural or ethnic difference. Interestingly, this statement suggests that whilst P7-SNR is aware of these observable and assumed differences, P7-SNR does not consider other commonalities that may exist and support relationship building, such as love of sport or travel, or music.

From the data, it can be inferred that despite individuals having intersecting identities, where race is identified or assumed as ‘Black’, in the absence of an acknowledgement that ‘White’ is also a race (Frankenberg, 2020), other identities held by the ‘Black’ individual can be relegated to the background. In the context of relationship building and wider practice with ACE with dementia, the centering of racial identities (Rodriguez and Freeman, 2016) suggests the need for practice that is prepared to challenge and mitigate the negative implications of such race-centering. I posit that race-centering can ‘other’ ACE with dementia in ways that limit opportunities for relationship building and, in turn, limit wider areas of social work, such as service development.

P7-SNR goes on to offer the reflection that commonality or the absence of it does not, on its own, support or hinder the building of relationships between individuals and social workers. McMullin (2017) argues that relationship building in social work also hinges on active listening, respect, and a genuine commitment to understanding the service user's unique perspective. Research by Ojikutu et al. (2022) and Hupcey et al. (2001) suggests that a lack of trust or mistrust can negatively impact the development of relationships between practitioners and service users. Reflecting on relationship building with ACE with dementia, through the statement: *‘I suppose one of the other issues is if that person has had a long life experience and some of that was an experience of racism..’* P7-SNR also acknowledges the existence of racism and that an ACE with dementia may have had experiences of racism and the potential that such experiences may negatively impact relationship building. This acknowledgement by P7-SNR aligns with the insight by Stafford (2017) that relationship building in the context of ‘interracial relationships’, personal or professional, requires respect for and acknowledgement of each other’s racial identity and how these might impact the relationship building process.

Research by Daftary (2020) suggests that for ethnically diverse persons such as ACE with dementia, it is important that practitioners acknowledge that experiences of racism across society and possibly within services may negatively impact the development of a social worker-service user relationship. According to Lynch (2022) trauma trauma-informed social work in the context of racism would support a critical understanding of the psychological and emotional harm experienced by individuals due to racism and discrimination.

This trauma can present as low self-esteem, anger, and internalized racism, which may be passed down through generations. A trauma-informed approach to relationship building recognizes the historic and ongoing role of social work in contributing to systemic racism. This approach emphasizes safety, humility, trustworthiness, and empowerment, which are essential for effective practice, particularly with this group.

P7-SNR goes on to make interesting statements, acknowledging that even within the relationship-building process, there exist power imbalances. Significant to this study is P7-SNR's acknowledgement of their positioning *as a White professional social worker*' and how this might shape relationship building with an ACE with dementia. In their paper *Social Work as a Product and Project of Whiteness,1607–1900*, (Gregory, 2021) argues that Whiteness is a pervasive element in social work that, if left unexamined, can perpetuate systemic inequities and influence the power dynamics between social workers and Black service users. Also significant to my study is P7-SNR's explicit acknowledgement of their 'whiteness'.

Whilst my study is not looking at individual practice, it is worth noting the explicit way P7-SNR makes their 'whiteness' visible by drawing on conceptual knowledge around the link between 'whiteness' and power. This statement by P7-SNR demonstrates a move from the perception (Audi, 2018); of professional 'interracial relationship' building as social worker and Ace with dementia, to the use of conceptual capacity to critically engage with broader concepts around such relationship to demonstrate a 'grasp' and true understanding (Gordon, 2017; Kudryavtseva, 2013; Hannon, 2021); of the complexities involved in such relationships.

Through critical race theory and intersectionality theory, I argue that power imbalances between a White social worker and an ACE with dementia occur across several interconnected domains in addition to race and ethnicity. These domains include age, gender, ability, class, sexual orientation, and socio-economic status. A critical realist lens can support further exploration of the power dynamics between P7-SNR and '*the service users that we have'.* P7-SNR is a senior practitioner within an older persons team and supports and manages social workers in the team. Such positionality allows P7-SNR to shape and reshape the practice of individual practitioners as well as the practice within the team.

Additionally, P7-SNR's role may in turn be shaped and reshaped by local authority policies and goals, which in themselves may be under ongoing reshaping through governmental policies. These levels of power dynamics are not without negotiations, suggesting that the power imbalances that might be observed between practitioner and ACE with dementia (empirical level) result from ongoing contesting and reshaping of power at the actual and deep levels.

The following excerpt from P4-SNR provides discussion around the perceived nature of relationship building with ACE with dementia and builds on the points presented by P7-SNR around the importance and challenges of relationship building in social work practice with ACE with dementia.

P4-SNR
'If you get known by the community. If you become part of the community, you will always find some allies. So, it is about building those relationships. When we first have that first communication, because if you don't get it right in the beginning, you're on the back foot to build in a relationship with somebody'.

In this account, P4-SNR's use of metaphors creates the imagery that relationship building is fraught with potential conflicts and that it is not a linear process. Beckett (2003) suggests that metaphors shape our thoughts and enable or constrain practice. It is with the cautionary words of Hawkins, Fook, and Ryan (2001) that I present this discussion on the use of language by practitioners. I am reminded that as the researcher, my subjective interpretation of the data is shaped by several factors, particularly my own social location and positionality as a qualified social worker and as a member of the African Caribbean community. Therefore, I acknowledge that the talk produced in the interviews and subsequently used as data in this study does not indicate certainty of social workers' actions or thoughts. As such, I do not present these metaphors as indicative of how social workers practice, but rather these metaphors form part of how they perceive practice.

P4-SNR's discussion places relationship building in social work within a conflict-centered frame (Beckett 2003). P4-SNR describes a starting point that is uncertain but requires building rapport and familiarity, *'If you get known by the community',* followed by this notion of integration, again this is uncertain and not guaranteed, '*If you become part of the community'*. Although P4-SNR does not discuss their perception or understanding of ‘*the community’* or how one might ‘*become part of the community’*, these statements direct my focus to arguments made by Williams, Evans, and O'Leary (2015), who argue that in Wales, in the context of ‘community’ there is a stark difference between a sense of belonging that is based on acceptance and mutual respect for ethnic, racial and cultural difference.

The authors contrast this with tolerance and assimilation, where tolerance is seen as one group granting the other group ‘permission’ to be diverse, but there is little to no engagement with such diversity. Expanding on tolerance, assimilation requires one group to adopt the cultural norms and values of the other [dominant] group to be accepted. Through these reflections, I consider how P4-SNR perceives community and to what extent P4-SNR understands the notion of community and becoming part of a community and how P4-SNR’s perception and understanding of community and wider notions of becoming part of a community shape their own practice with ACE with dementia living in and having their own ‘communities’ in Wales.

Once the social worker has managed to complete these tasks, then certainty looms on the horizon: ‘*you will always find some allies’.* The use of the word ‘allies’ suggests that building a relationship with ACE with dementia is challenging and unwelcoming and that one has to navigate these activities, which are not guaranteed to end in success but if they do, there will be some ACE with dementia who will be supportive and welcoming.

This excerpt by P4-SNR also demonstrates the often ignored possibility that marginalised communities such as ACE with dementia can push back against systems, reshape those systems through their own agency. Through a critical realist lens, this discussion by P4-SNR can be reframed from a situation where relationship building is fraught with conflict and challenges to one where ACE with dementia employ strategies of resistance (Craig and Bigby, 2015). ACE with dementia are empowered to grant or deny access to their community through the leveraging of their agency, which in turn can challenge and transform how social workers engage with them.

P4-SNR also goes on to imply that building relationships with ACE with dementia is a one-chance situation and that the social worker must be prepared for the first meeting, as there may not be a second chance to build that relationship and getting it wrong the first time can set things back. On the one hand, this can be taken to suggest that for P4-SNR, there may be the idea that for social workers to build a relationship with ACE with dementia, the social worker should have an understanding of the ACE with dementia, which sits within social works' own agenda of self-directed learning (Zuchowski et al., 2022). On the other hand, this statement can be taken to suggest that relationship building with ACE with dementia is steeped in judgement and there are 'no second chances' and a social worker who gets it wrong on the first try will have difficulties forming that relationship in the future.

The excerpts from P4-SNR and P7-SNR both highlight challenges and points for deeper reflection within the relationship-building process in social work practice with ACE with dementia. Interestingly, the excerpt below by P11-QSW describes a creative approach to relationship building that is focused on establishing trust.

P11-QSW

'I have games that I use with them so I can build the trust and when you are doing those games, they just open up and share things that normally they wouldn't speak about'.

According to Lymbery et al. (2007), trust plays a crucial role in relationship building in social work with older adults. Trust serves as the foundation for effective communication, service delivery, and emotional well-being. Trust facilitates the social worker's ability to engage effectively with clients.

Some of the central discussions in this study point to the bureaucratic constraints faced by practitioners when attempting to build relationships with ACE with dementia. The emphasis on care management and resource allocation can overshadow the relational aspects of social work, making it difficult to prioritize trust-building activities (Lymbery et al., 2007). However, P11-QSW shares their use of games as an approach to relationship building in the face of these constraints.

This is significant as it demonstrates the possibility that P11-QSW may have the skills needed to navigate these constraints in ways that do not limit their autonomy and discretion in practice (Kaplan and Andersen, 2013). Contrastingly, this opportunity for using a creative approach to establishing trust within the relationship-building process may be an organisational goal and P11-QSW is supported to explore such approaches. Whichever of these circumstances is true, P11-QSW demonstrates an awareness of the importance and usefulness of establishing trust, '*they just open up and share things that normally they wouldn't speak about'.* This statement also aligns with the notion of getting it right at the beginning of the relationship-building process, as discussed by P4-SNR.

Lymbery et al. (2007) suggest that where trust in the social worker-client relationship is established, it can lead to improved outcomes by enhancing the quality of interactions and interventions. In their work, *Strengths-based social work with older people,* (Nelson-Becker et al., 2020) suggest that when trust is established, older adults are more likely to engage with services and participate actively in their care plans, leading to better health and social outcomes.

In the context of this study, research has highlighted that the relationship between African Caribbean communities and social services in the UK is complex and often characterized by mistrust (Lasrado et al., 2021; Vickers, Craig, and Atkin, 2012). This mistrust can be attributed to historical, cultural, and systemic factors that have influenced the experiences of African Caribbean people with social services (Singh, 2019; Hackett, 2019).

Although P11-QSW does not share the nature of the games or how games came to be part of their practice. Research by Chambers (2002) highlights that games can be powerful tools in social work for building relationships, encouraging open communication, reducing anxiety, facilitating reflection, and building empathy among participants. This is particularly beneficial in social work with ACE with dementia, who may be hesitant to share their thoughts and feelings.

Li et al. (2022) in their work on play intervention for dementia, advise that practitioners utilising games as part of trust building with ethnic minority elders with dementia, need to pay attention to key areas. These include ensuring the games are culturally sensitive and that the games are designed in ways that are personalised to the individual. In the context of this study, the use of games should consider the unique histories and experiences of ACE with dementia and evoke positive memories. Additionally, games should consider the cognitive abilities, personal interests and physical limitations of the individual. Such considerations mitigate against exclusion or reinforce or challenge existing inequalities and stereotypes.

The creative use of games by P11-QSW to build trust as part of the foundation for relationship building highlights important issues for practice with ACE with dementia. P4-SNR and P7-SNR also reaffirmed the challenges practitioners must navigate as they engage in relationship building. Addressing these challenges requires a comprehensive understanding of the value and purpose of relationship building in social work with ACE with dementia.

The following section presents a discussion around another approach to meeting the needs of ACE with dementia. Several participants discussed an awareness of diversity and described ‘diversity approaches’ as ways in which they engaged with ACE with dementia to support them to meet their outcomes. The data identified two diversity approaches discussed by participants. Namely: Multiculturalism and Colour blindness.

6.1.3. Diversity approaches: Multiculturalism

The Welsh government’s approach to diversity is influenced by historical, cultural, and political contexts, which shape its policies and practices. This understanding of diversity encompasses gender, ethnicity, disability, socio-economic status, professional backgrounds, and language (Awan-Scully et al., 2018). This approach to diversity suggests that diversity is not solely about ethnic or linguistic differences but encompasses a broader spectrum of social identities and experiences. crucial for fostering an inclusive society that values and respects differences while promoting social cohesion and development.

Research by Sayers et al. (2017) suggest that whilst the Welsh Government emphasizes equality and universality as fundamental aspects of its social service policies, there is tension between competing priorities. The focus on efficiency is often on competition with equality. This leads to a neglect of the needs of underserved groups, which can impact social work practice by limiting the scope of services available to diverse populations, such as ACE with dementia.

Social workers' understanding and perception of diversity are shaped by a multitude of factors, which significantly impact their practice. These factors include educational background, cultural competence, socio-political climate, and personal experiences and organisational policies. Each of these elements contributes to how social workers perceive and engage with ACE with dementia, ultimately influencing the effectiveness and inclusivity of their practice with this group.

Hahn et al. (2015) and Plaut (2002) argue that multiculturalism calls for the acknowledgement and celebration of the ways racial and ethnic differences enrich society. Song (2009) suggests that multiculturalism is a key component of the struggles for religious, ethnic, and racial justice. Critics such as Tempelman (1999); Chin and Levey (2023) have argued that multiculturalism should be understood as a symbolic politics of recognition and that multiculturalism is a distraction from the pursuit of equality, as it focuses on valuing cultural diversity while ignoring economic inequality.

Kew (2023), in their work on the tokenistic impact of multiculturalism in the Midlands UK, used the phrase ‘steel bands, samosa and saris.’ The phrase suggests that multiculturalism is often viewed through a narrow lens. This limits the focus to superficial aspects like food and music. Such reductionist perceptions fail to capture the deeper social, political, and historical contexts that shape ‘multicultural’ identities, thus limiting practitioners’ understanding of the individuals they support. This argument aligns with earlier discussions in chapter 5 around participants’ perceptions of culture and the cultural needs of ACE with dementia. The data highlighted that participants relied on various definitions of multiculturalism to demonstrate their awareness of difference and their drive to promote their practice as based on equality. The following extracts are examples of this.

Here, P5-SNR uses the notion of the local authority as being a ‘multicultural’ space, where practitioners engage with service users from diverse racial and ethnic backgrounds.

P5-SNR
‘This local authority is multicultural. So, we are dealing with a varied background of clients. We assess people of different races, ethnicities. That's a normal part of our practice and you know it's not the odd case. It's not something that's unusual to the team and it's something that we deal with a lot, and we use the relevant services a lot to support our assessments with various cultures and languages. Everybody in the team is very accepting of all different cultures, ethnicities, you know, religions. The team is not all White, Welsh and we are a mixed cultural team as well’.

Interestingly, P5-SNR claims that working with diverse groups is '*a normal part of our practice'* and *'it's something that we deal with a lot',* alluding to the team's experience and perhaps competence in working with racially and ethnically diverse groups. By locating social work with diverse groups as a normal part of practice, P5-SNR adds to the narrative by SNR 3 in chapter 5 that there are universal activities that social work undertakes, and that such activities are not just add-ons when working with diverse groups. This is interesting because, on the one hand, it can be taken to mean that the nature of social work makes the profession prepared to work with diverse populations.

On the other hand, it can be seen to indicate a false belief in the capacity of social work to work with diverse populations, given that research suggests an unpreparedness of the profession for working with diverse populations and specific to this study, ACE with dementia (Pollock, McCaughan and Scholar, 2024). Additionally, given what the research suggests, it may also be inferred that there may be some disconnect between the aims or capacity of the profession and that of individual practitioners or groups of practitioners. This could indicate the need for a deeper look at social work as a profession to ascertain where the disconnect might be.

These claims are significant to this study as research around the experience and competence of social workers to support ACE with dementia is quite low. P5-SNR also makes a point to highlight that the team is comprised of diverse staff, '*The team is not all White, Welsh and we are a mixed cultural team as well'* and that all staff are, '*very accepting of all different cultures, ethnicities, you know, religions'.* P5-SNR's discussion of multiculturalism aligns with arguments made by Garran and Werkmeister Rozas (2013) around the varied interpretations and applications of multiculturalism in practice. Here, P5-SNR does not appear to engage with the deeper complexities within multiculturalism, such as power imbalances or homogenising of groups (Husband, 2007). In contrast to practitioners 'denying aspects of their own culture', as discussed in chapter 5, through the statement, *we are a mixed cultural team as well',* P5-SNR appears to be acknowledging that practitioners have culture.

The following extract by SNR4 also demonstrates the use of multiculturalism as an acknowledgement and celebration of difference. Similar to P5-SNR, SNR 4 does not demonstrate an understanding of how multiculturalism shapes their practice.

SNR4
' I have a very multicultural team, with really diverse backgrounds and ethnicities, religions, races and I'm pretty sure whenever I've been out on visits with many of them. I've been out and shadowed White Welsh, White British social workers and I've not seen any difference in their practice towards anyone.

This discussion by SNR4 is significant as it highlights a perception that 'multiculturalism' negates the existence of racial discrimination. However, the statement, '*I've been out and shadowed White Welsh, White British social workers'* can be seen as two-fold. In the first instance, SNR4 acknowledged an awareness that there may be an assumption by me as an ACE that White practitioners may be discriminatory to ACE with dementia and SNR4 felt it was important to reassure me that this was not the case, as they had shadowed 'the usual suspects' of discrimination.

Secondly, positioning the White social workers as the ones from the 'multicultural team' who have been shadowed suggests an assumption that social workers from Black, Asian and other minority ethnic groups do not engage in discrimination, as discrimination in social work is seen as the action of White social workers. Additionally, through their statement around observing the practice of others and "*not seen any difference in their practice towards anyone'* SNR4 acknowledges that despite having '*a very multicultural team'* differences in practice can occur. This may also be an indication of the use of a colour blind approach to practice (Bonilla-Silva, 2015), which is explored in detail in the following section.

SNR4 does not critically reflect on 'which individuals may require practitioners to engage with them differently because of culture, age, or ability. This reaffirms earlier presentations of arguments by (Garran and Werkmeister Rozas, 2013). In the context of this study, the reliance on multiculturalism as the response to challenging racial discrimination against ACE with dementia could result in ongoing dyconscious racism (King 1991). This could manifest in practice through culturally inappropriate services, reliance on dominant discourses about ACE with dementia, denial of racial issues, and inadequate development of services to meet the needs of ACE with dementia.

Such assumptions run the risk of creating or reinforcing stereotypes about practitioners. In contrast to SNR4 and P5-SNR, discussion by P2-SWA brings to the fore one of the limitations of multiculturalism as suggested by Song (2009).

P2-SWA
‘As a mainstream person [White person], you could be living in in a multicultural country for all your life and not have the understanding or knowledge. Even though you have these people [ACE]around you, you only go on what you see or what you hear. I know someone who's been a care assistant in London for over 20 years, and her knowledge about, you know, BAME, Caribbean was very small; it's like she was quite ignorant about stuff and not know. I believe we don't have enough BME social workers. We don't have enough BAME social worker assistance. We don't have enough BAMEs in this field’.

The context of this discussion with P2-SWA is interesting as P2-SWA identifies as Black Asian Minority Ethnic (BAME) and shares these views from that standpoint, as well as all the other intersectional identities they occupy. P2-SWA begins their discussion by acknowledging that they consider ‘White’ to be the dominant racial group in the UK and that the UK is, at the same time, a ‘*multicultural country’*. However, the ‘*mainstream person’* in P2-SWA’s discussion, even after living in such a multicultural space as London, and working as a care assistant, had very little knowledge about BAME cultures, including African Caribbean.

The 2021 census of England and Wales identified London as the most ethnically diverse region in the UK, with 46.2% of residents identifying as BAME (ONS, 2025). It is as though P2-SWA is suggesting that there is no reason or excuse for a ‘*mainstream person’* who lives in a multicultural space such as London, to not know about different races, ethnicities and cultures, particularly ACE with dementia.

Through their discussion, P2-SWA raises the point that is argued by Song (2009) that multiculturalism does not equate to deeper understandings of diverse groups or different cultures. P2-SWA’s story demonstrates that time and exposure to different racial and ethnic groups did not improve this individual’s knowledge about the diverse populations they were exposed to. This story also suggests that perhaps exposure to a multicultural environment may only be beneficial to social workers if there is deliberate learning and knowledge acquisition in such environments. This suggests that claims by SNR4 and P5-SNR about working in multicultural teams and in a multicultural local authority cannot be taken as evidence of practitioners' knowledge and understanding of ACE with dementia. Liu (2014) argues that exposure to multicultural spaces or environments does not indicate a perceived level of cultural competence.

The BAME social care workforce in Wales is 21.2 percent in relation to the BAME population in Wales, which was less than 6 percent in the 2021 census (ONS, 2021). This data contradicts P2-SWA's claim around underrepresentation; however, Williams and Parrott (2014) argue that efforts to diversify the workforce can sometimes be perceived as tokenistic, particularly when there is a lack of genuine engagement with the issues of race and culture. This can lead to a superficial approach that fails to address the underlying power dynamics and privileges associated with whiteness. A social care workforce report highlights that despite workforce diversity, BAME social care staff are under-represented in managerial positions and were more than twice as likely to report a lack of additional training to support career progression compared to their White counterparts (Social Care Wales, 2024).

Relying on a multicultural workforce can lead to superficial changes that do not address systemic discrimination where marginalized individuals are in low-pay positions, reinforcing a subordinate status rather than redistributing power. (Baines, 2001) argues instead for comprehensive strategies that include structural changes, critical engagement with power dynamics, and a focus on social justice and anti-racist practice. Additionally, Pollock, McCaughan and Scholar (2024) argue that diversity approaches that do not consider intersectionality fail to address the compounded challenges of intersecting identities, such as race, gender, and sexual orientation. This oversight results in the exclusion of these individuals from leadership roles and decision-making processes.

Through a CR lens, exploration of the potential structures that may shape the' *lack of knowledge about BAME and AC'* may not solely reflect a systemic failure within the social work sector. It may also highlight that human agency is at work, and this care assistant has made the personal choice not to know or lacked the initiative to engage with different cultures outside of a professional setting. Moreover, the argument for increasing the number of BAME social workers and support staff presupposes that representation alone guarantees cultural competence and effective service delivery.

P2-SWA is not clear on what the role and purpose of more BAME social workers would bring to practice with ACE with dementia. However, the expectation for Black social workers to lead anti-racist efforts is critiqued by Obasi (2022) as a form of tokenism. Sush tokenism can lead to feelings of isolation and undermine the professional and personal experiences of racism. A collective responsibility and structural change are essential for effective anti-racist practices in social work. Obasi (2022) further argues for the acknowledgement of the dynamics of invisibility and hypervisibility, where Black social workers may feel invisible in their contributions to anti-racist practice, while simultaneously being hypervisible as representatives of their race.

This duality can result in backlash and additional pressures for a social worker from an African Caribbean background, challenging discriminatory practice within a team or advocating for an ACE with dementia. This backlash may also be from the organisation and from the AC community and can manifest in the form of unmanageable expectations. Additionally, a focus on representation may overlook the broader need for a holistic approach to cultural competence that includes ongoing education and engagement for all social workers and the organisation.

Chin and Levey (2023) argued that multiculturalism as an approach to challenging discrimination does not go far enough in questioning the structural factors that propagate racial oppressions and discrimination. The following excerpt by P4-SNR was discussed through a critical realist lens (Fletcher, 2017) to explore the factors that might shape how this social worker responded to this particular case. P4-SNR was responding to a question on how they dealt with challenges when supporting ACE with dementia. Interestingly, similar to their discussion on building relationships, P4-SNR utilised metaphors to describe their experience. Whilst I adhere to the warnings of (Hawkins, Fook and Ryan, 2001) and I am not declaring certainty about P4-SNR's thoughts and actions, this use of metaphors again by P4-SNR might be an indication that part of this practitioner's practice is formed by these metaphors.

P4-SNR

‘And you know, we can set something up for them. We can set services up for them and but that's not what they wanted. They didn't want that. They didn't want to have any integrated services whatsoever. We want a special service here. We want a special service there. When our whole ethos as an authority was to have an integrated society. So, you know we've got this battle all the way along the line between, you know, people wanting to have their own little bits with only their own cultures and traditions and what have you. And then the rest of us going. It's a lovely big melting pot and we're all going to be in together. And so, you know, this lovely integrated community. So, we're now we're never going to win, but we can just, you know, we just need to try to do our best and I think we do because we look at the person as an individual.’

Pithouse (1998) suggests that by unpacking the language used by social workers, insight can be gained into what might be considered ‘invisible activity’, by social workers. Looking to the tenets of critical realism, the use of metaphors suggests this social worker’s practice and perhaps the types of metaphors they use, may be shaped by other visible or invisible factors, for example, years in the role, experience and culture within the team and wider organisation and society.

P4-SNR talks about the challenges of trying to align the goals of the organisation, the local authority, with the goals of a particular population group and describes these challenges through the use of metaphors: ‘*battle*’, ‘*melting pot’* and ‘*win*’. According to Thompson (1993), language used in social work plays a critical role in challenging discrimination or reinforcing it. Beckett (2003) suggests that metaphors shape our thoughts and enable or constrain practice. Pithouse (1998) argues that the language of social work is not just a means of communication but also reflects the underlying conceptual frameworks that can reveal practitioners’ attitudes and beliefs about the profession and its clients.

Utilising the arguments by (Pithouse, 1998), and a CR lens, the invisible activity’ within the metaphor ‘*this battle’* could comprise policy development or grant funding application, given that P4-SNR had indicated that the team was developed out of Welsh Government funding. This military metaphor, ‘*battle’* (Beckett, 2003), suggests a long and sustained fight. This use of a military metaphor (Beckett, 2003) suggests a struggle between powers, with one side attempting to achieve something against the resistance of the other side. In this context, the possible powers could be taken to be the power of the local authority or Welsh Government to give or withhold funding, or the voice and agency of the service user group who refused the offer of the integrated service.

Integrated services in social work are crucial for addressing complex social issues by ensuring collaborative working across different sectors to provide comprehensive care. This way of service provision in Wales is promoted through legislative frameworks and social policies (Gwilym, 2023). Although integrated services aim to improve access, they can inadvertently create barriers for certain groups. The complexity of navigating multiple services may disadvantage those with limited resources or understanding, such as individuals with disabilities or those from minority backgrounds (Rees and Raithby 2012). In the context of this study, an integrated service may not consider the unique cultural needs of ACE with dementia, if they are not the majority 'service user' group supported by the service. This can result in exclusion, further marginalisation and needs being unmet.

Whilst the dynamics within the group (which member/s of the group decided to reject the offer of the integrated service or how such decision was determined) is unknown, the reference to the metaphor '*battle*' suggests that this group wanting their own service was not interpreted by the social worker as a collective approach by a marginalised group, or an opportunity for the local authority to co-produce a culturally specific service with the opportunity to develop strengths and community organising as expressed in the global definition of social work IFSW (2014). Similar to points discussed earlier around situations where personal outcomes differ from organisational goals, a negative interpretation of the actions by the service user group is presented.

The metaphor of '*melting pot'* conveys the notion that the local authority has a structure that incorporates different ethnic groups into one. Such a structure may have required this ethnic group, in the account provided by P4-SNR, to quietly enter the 'melting pot' disband their 'culture' or perhaps they may be allowed to bring 'acceptable' elements of their culture with them and once in the 'melting pot' the transformation of '*being part of this lovely integrated community'* will occur.

The assumption that integrated communities are non-contested spaces is particularly interesting and important as it suggests a linear approach to integration. Such an approach does not consider the gains and losses, such as identity loss or the acquisition of new identities. Additionally, the power imbalances, such as one group gaining or losing power over another group, are not acknowledged or mitigated. The claims and consequences of intersectionalities that can occur within cross-cultural interactions and that these gains and losses must be agreed and developed within strong contracts of trust, are also ignored (Gleason 1964).

The '*us*' and '*them*' categorization, '*People wanting to have their own little bits with only their own cultures and traditions*' versus '*the rest of us*' followed by notions of defeat '*we are never going to win*' not only reaffirms the imagery of a battle, it also does not align with the 'meeting people in their environment' ideology within the definition of social work (IFSW 2014). In contrast, P4-SNR ends by expressing what (Gary, 2005) refers to as paradox processes. The contradiction '*we look at the person as an individual'* following the expression of wanting the group to join the '*melting pot'* demonstrates the dilemmas that unfold in paradoxical ways as social workers attempt to align local voices, local context, with the much wider context of organisational demands.

In the context of the ACE, research by (Archibald, 2011) found that ACE tend to view community as living amongst other ACE whilst at the same time living within the broader society with a 'freedom' to embrace their own culture, and 'dip in and out' of the dominant culture as they, (ACE) deem necessary. It can therefore be suggested that the notion of a 'melting pot' may bring many restrictions to this way of life for ACE.

This was an interesting narrative by P4-SNR, which brought to the fore the implicit biases of the culture within the social work profession (Thompson et al.,1996) and the social workers who become entangled in elements of people's lives. P4-SNR highlighted the tensions that can be manifested when social workers, who become acculturated to the values and culture of the organisation, are faced with ethnocultural differences between their values and culture and those of their ethnoculturally different service users. P4-SNR's narrative gave rise to challenges around the often simplistic argument that these tensions arise as a result of cultural differences or because of '*People wanting to have their own little bits with only their own cultures and traditions*'. Instead, as chapter 5 of this thesis suggests, a deeper reflection on the culture of social work needs to happen. It is critical to the well-being of marginalised groups such as ACE with dementia that reflections are undertaken around the impact a practice steeped in a culture of fear, blame, uncertainty and bureaucratic processes might have on other cultures.

The reliance on multiculturalism to challenge discrimination is fraught with challenges. Analysis of the excerpts from participants highlights that understanding and perception of the usefulness of multiculturalism can be inconsistent. The lack of clear guidelines for its use in practice and measurable outcomes leads to varied applications in practice. Practitioners did not engage with the complexities of multiculturalism in deep, critical ways, which can negatively impact service development and delivery for ACE with dementia. The following section will present data and discussion around the second diversity approach identified within the data

6.1.4. Diversity approaches: Colour blindness

Colour blindness is an ideology that can be understood as the belief that race should not and does not matter. It is based on a system of ideas that purports that by ignoring race, everyone is treated equally (Bonilla-Silva 2015). In contrast to multiculturalism, colour blindness attempts to 'not see' difference and therefore adopts a pursuit of equality that ignores difference along the line of race.

Interestingly, whilst these two diversity approaches appear to assume opposite positionalities, with multiculturalism, acknowledging and celebrating difference and colour blindness attempting 'not to see' difference, both approaches were used alongside each other by the same participants, across the same local authority. This suggests that social workers may not have a full understanding of the benefits and limits of these approaches, whilst engaging with these approaches.

The data used in this section were derived from the group interview with senior social workers. Practitioners were presented with two vignettes (Appendix H) and were invited to discuss their views based on guided questions. Participants' accounts highlighted a conflation between colour blindness and 'being fair and equal'. It is with caution that I present these findings as I am aware that factors such as me being a visible ACE in the social locations of social worker and researcher, may have evoked a level of social desirability bias (Grimm, 2010) with participants perhaps feeling the need to ‘prove’ to me that they treated everyone ‘equally’ (Krysan, 1998).

SNR4

‘It doesn't matter what race they are; we do it exactly the same way. In terms of the person's wishes, whether that's feasible, safe, equitable. The only time that their race, ethnicity will come into that conversation is when you're looking at what’s important to them. It's certainly not going to influence how we practice it might influence some of the elements of the care or support in relation to their needs, but it’s exactly the same for everyone. We deal with so many of these and I can't say that any of them are ever dealt with any differently just because of somebody's background. This is just about our processes, isn't it? Because it doesn't matter what Mildred’s rationale is for wanting to move to Brixton. She's clearly got a reason. It wouldn't make any difference if I had a White woman who was originally from Carmarthenshire, who says I'd like to go back and live in Carmarthenshire’.

In this account, SNR4 makes contradictory statements that highlight deeper institutional constraints. First, by the denial that race matters, *‘it doesn’t matter what race they are’* and then by identifying the organisational policies of ‘*feasible, safe, equitable’*. This contradiction aligns with arguments by Pithouse (1998) that the language used by social workers can conflict with the underlying values of the profession. In the context of this discussion by SNR4, the values of the profession, which speak to person-centered care and what is important to the person (ACE with dementia), are misaligned with a colourblind approach. Through a CRT lens, the taken-for-granted power of social workers is highlighted. Despite the intent of being neutral and fair, SNR4 has defined the bounds within which an individual’s race should be considered. This is particularly significant for practice involving individuals from racially marginalised and minoritised groups, as colourblind approaches can perpetuate racial inequalities (Abrams and Moio, 2009) rein whilst at the same time attempting to be equitable but constrained by resources and risk-management, creates an image of tension, where rights and obligations will be competing.

By implying that there is a place for ‘*race and ethnicity’* when talking to the person about ‘*what’s important to them’* SNR4 demonstrates some ‘knowing’ about race and its possible impact but perhaps believes that by making race invisible (Hayes, 2017) and only acknowledging race if the service user ‘brings it up’ demonstrates that they are not prejudiced and want racial harmony (Babbitt, Toosi and Sommers, 2016).

This act of placing race and ethnicity in a ‘holding space’ that appears to be in Mildred’s control, as SNR4 states that Mildred can discuss these when looking at what is important to her, does two things. Firstly, it suggests that SNR4 perceives race as an extrinsic attribute (Lett et al., 2022) and ACE with dementia has moments when their race and ethnicity could be important to them and other times when these are unimportant. This perception is problematic for social work relationship building, as discussed earlier in this chapter.

As a member of the AC community, I argue that my race and ethnicity are always important to me. Whilst there may be times when I do not readily present them as crucial to the particular situation, they are intrinsic aspects of my identity. Hackett (2017) argues that race is an intrinsic attribute for African-Caribbean people. Race is deeply rooted in their historical experiences of colonization and migration. Understanding race as intrinsic to ACE with dementia is crucial for relationship building and addressing poor service provision and systemic racism.

Secondly, through this discussion, SNR4 appears to place the onus on Mildred to express that her race and ethnicity are important to her and should be considered. This can be seen as the social worker ‘empowering’ Mildred to advocate for herself (Goodley, 2005) or an attempt by the social worker to not appear as stereotyping Mildred by assuming that every ACE with dementia wishes to discuss their race and ethnicity.

However, this discussion by SNR4 suggests that in this scenario, SNR4 has not ignored or may not be aware of the possible power imbalances that exist between most social workers and the service users, as discussed earlier by P7-SNR, and how these power imbalances may impact Mildred’s confidence to express that her race and ethnicity are important to her. Additionally, SNR4 does not demonstrate reflection on the possibility that building a relationship with Mildred might involve particular knowledge and approaches different from the knowledge and approaches needed with a White Welsh person. SNR4 could be thinking this way due to the ongoing ‘pursuit of outcomes’ that practitioners are always engaged in, as discussed in chapter 5. This relegates ‘practice’ to ‘producing outcomes’ rather than the skilled relational work that has to be done to produce the right outcome for the individual. she notion of power imbalances between Mildred and Leroy and the social worker is acknowledged by SNR1 and discussed later in this section.

Interestingly, the statement, '*We deal with so many of these and I can't say that any of them are ever dealt with any differently just because of somebody's background'* whilst it is not clear if 'so many of these' refers to relocation requests or ACE with dementia, this statement infers practitioners have experience in one or both of these situations. Given the uncritical use of colour blind approaches, it can also be inferred that practice is embedded in colour blind approaches and the use of such approaches in not as subconscious as it first appears.

Further, by suggesting that Mildred's race and ethnicity is *'certainly not going to influence how we practice'* but that *'it might influence some of the elements of the care or support in relation to their needs',* SNR4 suggests that the colour-blind approach is perhaps not subconsciously used but that there are predetermined times when a social worker might consciously decide to use it. In this case, SNR4 implies that a colour-blind approach will be used in decision-making, perhaps due to social work decisions being more binary as they signify eligibility or non-eligibility for care and support.

However, the assessment process can be influenced by 'colour' as it considers the outcomes of individuals, and these outcomes may be connected to culturally specific needs as discussed in chapter 5. Additionally, SNR4 makes a clear comparison of a '*White woman who was originally from Carmarthenshire*' to Mildred, an ACE born in Trinidad and Tobago who lived most of her life in Brixton. This infers that colour is 'seen' but practitioners choose when and how to 'see colour', suggesting that perhaps, practice may not be as subconsciously colour-blind as it first appears.

The following extract from SNR2 appears to echo the views of SNR4. This extract by SNR2 also appears to suggest that the pursuit of completing care plans has brought about an orientation to the future and what service users want to do in the future.

SNR2
'But that's still about her outcomes, not about her ethnicity. It's about what we can do to support her, to live life as she wants to live. So, it's about her outcomes. We see everybody as the same. So, if I wanted to go somewhere, where I was out in the

country because that's where I'd always lived, and I wanted animals all around me, I'd expect the social worker to be able to take that into consideration. So, what is it about Mildred that needs to be provided for? It's not about where she's from.. It's about where does she want to live because that's where she feels comfortable. What does she need to achieve? And how can we support her to achieve it? But it's the same for everyone. So, it wouldn't be because she's from, Trinidad, It wouldn't'.

By suggesting that their approach to Mildred's case is '*about her outcomes, not about her ethnicity'* and that *it wouldn't be because she's from Trinidad'* highlights two issues. Firstly, the conflation of race, ethnicity and nationality implies that practitioners may miss the impact on Mildred's well-being, her rights and entitlements as these three identity categories intersect. The conflation of race, ethnicity, and nationality by social workers can have significant implications on their practice and the communities they serve.

This conflation can lead to misunderstandings and misrepresentations of clients' identities, potentially resulting in ineffective or even harmful interventions. Additionally, conflation can lead to a lack of clarity in policy and practice, as these terms are not interchangeable and carry distinct meanings and implications. The tendency to use these terms interchangeably can result in a one-size-fits-all approach, which may not adequately address the unique challenges faced by minority and migrant communities (Williams and Soydan, 2005)

Secondly, by attributing their colour blind approach to 'processes and outcomes', SNR2 and SNR4 demonstrate a 'refusal to know', which, according to Applebaum (2019), allows the perpetuation of those systematically privileged to continue to misunderstand or misinterpret the world. On the other hand, it can be argued that practitioners are not refusing to know but rather deciding when they 'need to know' about an individual's race or ethnicity and the usefulness and purpose of such information. This may be due to time constraints or specific outcomes to be achieved. However, I argue in line with (Hackett, 2017), that race and ethnicity are intrinsic attributes of an individual's identity and social workers' acknowledgement of these attributes is crucial to relationship building, particularly with racialised groups.

Through a CRT and Intersectionality lens, I also revisit the argument made earlier, that by choosing when to engage with an individual's racial or ethnic identity, a social worker is utilising their power within the relationship, to steer the relationship in the direction that is perhaps easier or more convenient for the practitioner, rather than facilitating ‘what matters’ to the individual.

The following account by SNR1 brought an interesting and important element of reflection-in-action (Schön, 2017) to the group interview by asking reflective questions to the group participants around social work practice with ACE with dementia.

SNR1
‘With Mildred, we have got someone who is not White British, I would imagine, unless something came up that was pertinent to Trinidad and Tobago or that Mildred said was important to her, would it matter that she's not White British? It's all about what matters to Mildred as opposed to her being from Trinidad and Tobago if that makes sense. Would we proactively ask Mildred, ‘I know that you're from Trinidad and Tobago is there anything in relation to your heritage that is also really important?’ With Leroy, there was nothing that we necessarily discussed about Jamaica, but we did discuss about what matters to Leroy, but I suppose if what matters to Leroy is about his Jamaican heritage and everything that can come with that, then that's what would be supported. I think I would feel quite vulnerable if I was from Trinidad and Tobago and had a group of White social workers. I think I would feel quite vulnerable because I would know that they weren't from the same culture as me. I would be the kind of person that would be quite passive, so I wouldn't want to make anything difficult for anyone, I would be happy to just go with the majority. I couldn't bring myself to tell them that they're have not asked’.

SNR1 brought focus again to the notion of nationality by alluding to a difference between ‘*White British’*, ‘*White social workers’* and Mildred ‘*being from Trinidad and Tobago’.* This highlighted two important issues in the context of the colour-blind approach discussed in this section. Firstly, SNR1 ‘saw’ colour and spoke about colour. Perhaps this was due to ‘White’ being accepted as the norm and therefore it was ‘easier’ to discuss and there may be a take-for-granted perception that ‘White’ is synonymous with being ‘British’, so there is no need to differentiate race and ethnicity when referring to a ‘White’ individual.

However, SNR1, within their discussion around nationality, did not refer to Mildred as British, despite being aware that Mildred had spent most of her life in the UK. This omission may be due to the terminology used to label and identify Mildred (ACE). Perhaps the use of 'Black Welsh' may have mitigated against this. Another argument is that in the absence of 'colour' attached to Mildred's ethnicity, SNR1 may not have been sure of the appropriate racial category to place Mildred. This possible lack of knowledge and fear of getting it wrong, as well as the various labels that are used to categorise individuals, make talking about an individual's identity problematic.

Another inference is that SNR1 did not want to make assumptions around Mildred's nationality or that there was still an ongoing conflation with race, ethnicity and nationality. This is important as it gives insight into social workers' understanding and knowledge around nationality, particularly for persons from the AC population who like Mildred may have come to the UK in the 1950's and may be part of the Windrush Generation (Wardle and Obermuller, 2019) and may or may not have claims to 'British' nationality and how such claims may shape social workers' engagement with ACE with dementia from this group.

Interestingly, as SNR1 reflects on how the group discussed both cases, SNR1 questioned whether enough attention and importance were given to Mildred's and Leroy's African Caribbean heritage and raised questions around whose responsibility it would be to ask such questions. SNR1 referred to the power imbalances and vulnerability that operate between Mildred, Leroy and the social worker.

6.1.5. Summary of approaches

The above section presented data and literature that discussed the two main approaches employed by participants as they support ACE with dementia to meet the perceived needs identified in chapter 5. Interestingly, participants did not explicitly discuss anti-oppressive or anti-discriminatory approaches. Instead, participants presented discussions and rationales for their chosen approach. Participants discussed relationship building as a foundation for engagement with ACE with dementia. Relationship building is the cornerstone of social work and can be seen as crucial to social work with all groups (Dustin, 2007). Participants went on to discuss diversity approaches, namely multiculturalism and colour blindness.

Whilst participants explicitly discussed multiculturalism, it was not clear if participants were aware that they were engaging in colour blindness. At times, it was not clear whether participants understood the benefits or limits of such approaches and where or how they came to the decision to utilise such approaches. The discussion from participants highlighted the constraints of the system in which social workers practice and the role of systems in sustaining epistemic injustice at the practitioner and structural levels (Applebaum, 2019).

The following section will present data and discussion around the barriers participants cited as having to navigate as they attempt to support ACE with dementia to meet the perceived needs identified in chapter 5.

6.2. Barriers to meeting the perceived needs of ACE with dementia

The data from this study highlighted that social workers experienced several barriers whilst attempting to support ACE with dementia to meet perceived needs. Interestingly, one of the barriers, namely managing expectations, appeared specific to senior practitioners as they were the only participants who reported on this barrier. This may be an indication that across social work practice with ACE with dementia, certain issues exist more acutely at certain levels of practice. Overall, all participants made reference to barriers around administration, policy and multi-disciplinary working, resources, a culture of fear and blame.

6.2.1. Administrative, multi-disciplinary working and policy barriers

Although paperwork has been a necessary part of social work's drive for professionalism through accountability and record-keeping, Pascoe, Waterhouse-Bradley, and Mc Ginn (2023) argue that the growing levels of administration within social work as a result of increased managerialism can have negative impacts on the profession, hinder social workers' effectiveness and negatively impact service users.

Participants discussed their perspectives on how a paperwork-oriented culture, the loss of autonomy within multi-disciplinary working and the difficulties and complexities encountered due to constraints and ambiguities within government policy.

The following extracts by P8-QSW highlight the level of paperwork that practitioners undertake when working with any individual with dementia and suggest that there may be additional challenges faced by ACE with dementia when dementia care is provided via multi-disciplinary settings.

P8-QSW

‘You know, we have our social work assessment, we have our care and support plan. We have a mental capacity assessment. We have the best interest paperwork. We have service order form. We have property and finance referrals. We have all that stuff just sort of this constantly’.

P8-QSW describes the expected administrative tasks of social workers within a multi-disciplinary team, and how managerialism within this type of setting can become a site of conflict (Dustin, 2007). Such levels of bureaucracy and administrative burden have the potential to limit the time social workers have to build relationships and contribute to the adaptation or creation of services to meet the needs of ACE with dementia (Pascoe, Waterhouse-Bradley, and Mc Ginn, 2023).

Additionally, such levels of bureaucracy threaten the opportunities social workers have to use their professional discretion, as forms are often standardised and systems are rigid. This raises issues around unmet needs and the associated risks (Dunatchik, Icardi, and Blake 2019). P8-QSW concludes with the statement, *‘We have all that stuff just sort of this constantly’,* suggesting a never-ending demand on practitioners. This brings attention to warnings from research by (Pascoe, Waterhouse-Bradley and Mc Ginn, 2023), who argued that social work practice that is dominated by bureaucratic systems and paperwork-heavy cultures results in burnout, stress and poor job satisfaction for social workers. P8-QSW continues to discuss how the entanglement of such a bureaucratic system within a multi-disciplinary setting further impacts their practice.

P8-QSW

‘Health wags social services, so if they're the dog we are the tail basically. I think the biggest challenge for me is that change from being able to manage my caseload, to being told when I've got to go and see somebody’.

Through the use of personification (Melion and Ramakers, 2016), P8-QSW personifies ‘health’ as a ‘dog’ that ‘wags’ its metaphorical tail, ‘social services’. The use of figurative language conveys a perspective by P8-QSW, whose role sits within the multi-disciplinary team, based in a hospital setting, that health is the driving force, the accepted authority and social services have to follow. In the context of social work practice with ACE with dementia, this suggests that there is the potential for practice with this group to be entangled in multi-disciplinary conflict (McLaughlin, 2016) around decision-making or resource allocation. Such conflicts can result in delayed packages of care or adaptations of services that are culturally appropriate to meet the needs of ACE with dementia.

P8-QSW goes on to discuss another disadvantage of multi-disciplinary working, which centres around loss of autonomy as a practitioner. The sense of disempowerment from P8-QSW echoes arguments by Probst (2012) around the difficult situation that social workers in health-dominated settings are placed in, when they are expected to use assumptions from health professionals to justify their actions. In this case, P8-QSW refers to *‘being told when I've got to go and see somebody’*, suggesting an absence of autonomy and independence for P8-QSW alongside a struggle to maintain and develop professional identity. Such tensions around which profession has decision-making power (Foucault, 1982) add to the complexity of social work practice itself.

Michel Foucault's work on power dynamics emphasizes the pervasive nature of power across various professions. Foucault suggests that power is not centralized but dispersed through various mechanisms and practices within professional contexts. These mechanisms include practices specific to the discipline, for example, assessments and care planning in the context of social work and health services. Power relations are central to the production of knowledge, affecting how professions like social work operate and make decisions amidst the often hegemonic power that exists in healthcare settings.

This notion of repression, as discussed by P8-QSW, highlights how power dynamics within multi-disciplinary team settings are contested. In the context of this study, Foucault’s theory around how different professions assert and challenge power, this ongoing challenge suggests implications for social work practice with ACE with dementia. Healthcare practices that are underpinned by a medical model (Farre and Rapley, 2017) could conflict with social work practices that are underpinned by a biopsychosocial model (Farre and Rapley, 2017). This can further impact relationship building and the development of culturally appropriate services to meet the needs of ACE with dementia, as P8-QSW may often be faced with having to balance the contextualised, humanistic values of social work with the dissonant values of the medical field (Probst 2012).

According to Lippman, Moore, and McIntosh (2009), where social work practice is undertaken amidst competing practice models from different disciplines, specifically health care services, different definitions of ‘outcomes’ are also in competition. In the context of ACE with dementia, this discussion by P8-QSW implies the potential for social work practice with this group, which is already complex, to become even more complex as social workers in multidisciplinary settings navigate additional challenges that come with multidisciplinary working.

Discussions from P8-QSW highlighted possible tensions and negative impacts on social workers and potentially ACE with dementia, due to the disadvantages of administrative burdens and multi-disciplinary working. Below, P3-SWA shares their perspectives on the barriers created by policy. P3-SWA was responding to questions around issues related to specific tasks and cases they undertook as part of their day-to-day work with persons with dementia. P3-SWA does not make a specific reference to this issue as directly related to social work with ACE with dementia, but rather as a barrier to social work with any person who has dementia. As such, I believe this discussion can provide insights as to how practice with ACE with dementia might be impacted.

P3-SWA
‘A few years ago, when they started talking about the Well-being Act and, you know, putting the onus on strengths- based and people doing more for themselves and it being less service-led and more individual-led, I had the feeling that it was like passing the buck onto people. I felt like it was just like a way to sort of reduce what we spend and sort of shirk responsibility a little bit. I imagine auditing says it's working really well, and it probably is in terms of finance and stuff, but I don't know if on an individual level it is working for people.’

Here, P3-SWA engages in what (Jansson, 1984) refers to as policy practice, where social workers engage with policy at different levels of design, implementation, or change. Discussion with P3-SWA gives insight into their perspective on various polices, namely,' *the Well-being Act'*, government policy (Welsh Government 2014), '*strengths- based'* (Saleebey, 1996), which is both a practice policy and a directive of the Welsh Government.

P3-SWA appears critical of these polices, suggesting that in the context of dementia service provision, they negatively impact resource allocation and engagement with people with dementia who may have needs and outcomes that they cannot meet on their own, meet. This is interesting as social work practice within local authorities is governed by the 'Act' as described by P3-SWA, which has provisions for persons who require support to meet their outcomes.

P3-SWA's discussion suggests that this provision may not be working as well as it is meant to, *'I don't know if on an individual level it is working for people'* and that perhaps there is a lean by practitioners or the local authority to adopt a 'strengths-based' policy even in situations where persons with dementia cannot meet their outcomes, in a bid to '*reduce what we spend and sort of shirk responsibility a little bit.'* This suggests that policy can be used by organisations to privilege organisational outcomes over those of service users (Clapton, 2021). In this case, reducing costs and responsibilities are organisational outcomes that are privileged over the outcomes of persons with dementia.

In the context of this study, this extract by P3-SWA gives insight into the possible ways in which policy practice can become a barrier to dementia service provision and suggests even further negative consequences where those services need to be tailored to meet the outcomes of ACE with dementia. Such consequences include specialised services being de-prioritised, a lack of support to take up services, such as with direct payments, due to the time constraints of practitioners.

These already difficult systems are made less accessible to ACE with dementia, who may require additional support or adaptation of services to meet their cultural needs. Interestingly, whilst P3-SWA does not go on to discuss what efforts they might be able to make to alleviate the negative impact of these policies, this critical stance taken by P3-SWA is perhaps a form of policy practice (Jansson,1984) and 'street level bureaucracy' (Lipsky, 1980).

This section discussed and reaffirmed the points raised in chapter 2 around the tensions that exist and need to be navigated by social workers as care management increases (Dustin, 2007). Participants discussed how ongoing administrative burdens alongside the constraints of working within the medical model of health practitioners (Mason and Evans, 2020) and policies that appear to privilege organisational outcomes over the outcomes of persons with dementia, have now created a situation where the tail is wagging the dog.

The very processes that were intended to support and improve social work practice have now become sites that threaten the humanistic aspect of social work practice (Burrows, 2020). This is particularly problematic for ACE with dementia as a marginalised group, as it limits the opportunity and time that may be required for establishing trust and building those foundational relationships.

This study does not seek to make generalisations around the possible impact of managerialism on participants' practice, or around other factors that might shape the impact of managerialism, as not all participants reported on this. However, Munro (2019) also argued that by reducing managerialism and its impacts, social workers get back the necessary time to improve their knowledge and skills. The following theme discusses participants' perspectives on how a lack of knowledge about ACE with dementia, within a blame culture, limits their confidence to engage with this group and can present as a barrier to social work practice with ACE with dementia.

6.2.2. Fear of getting it wrong in a blame culture

Despite the notion that blame culture is prolific across social work with children (Munro, 2019), this culture of blame exists across all social work practices, inclusive of adult services (Manthorpe and Stanley, 2004). According to Hardy (2020), the impact of blame culture on social work practice is an important issue that affects both social workers and service users, as this creates an environment where practitioners are afraid of making mistakes or where the decisions they make are heavily judged.

In the context of this study, where sensitive issues such as race and ethnicity are entangled, the impact of blame culture can be more pronounced for both practitioner and ACE with dementia. When responding to questions around the challenges they faced when undertaking social work tasks with ACE with dementia or what challenges they expected to face if they were undertaking social work tasks, this participant provided the following discussion:

P3-SWA

'We have an allocation spreadsheet where we can go in if we're not allocated a case by our manager and we've just got some spare capacity; we can go in and pick our own cases. I always find it interesting that people tend to leave the cases that have an ethnic sounding name. I find that the ones where, the spelling, or the surname suggests that they're Asian or they're maybe like Caribbean, they get left. I think it's because people see it as more work and because you likely to need an interpreter because you're potentially going to need to do a bit more searching, whereas you know Mary Jones is going to be an easier case because it's more familiar and there are more of these cases, and they fit into the cookie cutter version of the clients that we've had. I feel almost guilty saying it because I feel that like I'm sort of passing aspersions on my team and I don't feel like anyone is avidly doing it on purpose. I think it is just out of ease and out of familiarity and I think there is a big fear, people are afraid to say the wrong thing'.

This is an interesting finding because it highlights that even where practice autonomy exists, '*we can go in and pick our own cases',* according to P3-SWA, some practitioners in this team did not have the willingness or confidence to 'choose' a case that suggested that a potential service user might not be White. This alludes to a possible knowledge gap in social work in the context of practice with ethnically diverse people, as well as a possible fear of getting things wrong when working with people from ethnically diverse backgrounds. Where there is an indication that a need might be cultural, some practitioners shy away from these service users.

There may be several reasons for this, such as a lack of confidence, fear of getting it wrong, or, as Casey and Singh (2019) suggest, the fear of being labelled a 'racist' is very real and is associated with inexperience and a lack of exposure to people from minoritised groups. Gibson (2019), in their paper, *The Role of Pride, Shame, Guilt, and Humiliation in Social Service Organisations,* suggests that when practitioners do not feel safe to make mistakes, they turn towards what they are familiar with. This can manifest in strict adherence to organisational norms and rules, being less creative, and shying away from change.

Another key issue raised within the excerpt presented by P3-SWA is the assumption that persons from a White or non-minoritised background do not possess ethnicity, race, or indeed culture and cultural needs. Perry (2001), in her paper, '*White means never having to say you're ethnic: White youth and the construction of "cultureless" identities',* contends that there are social processes that White people engage with and in that facilitate a perception that White people are 'culturally empty'. The concept of 'having a culture' is viewed through a Eurocentric lens that constructs 'White' as the norm and all 'others' as 'cultural'. Through Perry's arguments, I suggest that the process of choosing 'Mary Jones' as P3-SWA pointed out is still an engagement with culture, specifically, White culture or White Welsh culture or White British culture.

Practitioners choose '*Mary Jones*' because of the familiarity of associating their own culture with that of '*Mary Jones'* culture, either through identity or acquired knowledge. This may in turn result in practitioners choosing the familiar, or a case from their own culture, because subconsciously, they 'recognise' their own culture. The assumption that '*Mary Jones*' will be easier also points to practice that might be based on homogenising White service users by ignoring that they are individuals with individual needs and outcomes, despite sharing similar racial, cultural and ethnic backgrounds. This approach is particularly dangerous in the context of ACE with dementia, as it risks reinforcing stereotypes and limits the development of culturally specific dementia services. It is important to address this ideology argued by Perry, as practitioners run the risk of making professional judgements that are underpinned by hegemonic assumptions, stereotypes and biases which can affect both practitioners and service users in negative ways.

Through the statement, '*they fit into the cookie-cutter version of the clients that we've had* 'suggests that this type of stereotyping that (Perry, 2001) warns against, is perhaps already part of how practice is undertaken in this team. Interestingly, P3-SWA offers possible reasons for practitioners choosing the 'Mary Jones' type cases over cases with ethnically diverse service users, when they have the choice to do so: '*I think it's because people see it as more work and because you're likely to need an interpreter because you're potentially going to need to do a bit more searching'.* This suggests that perhaps practice may not be entirely underpinned by hegemonic assumptions. There is an indication of other factors, such as a lack of time, knowledge and resources, which may be shaping the choice made by these practitioners. Therefore, there is scope for practitioners to build their confidence to choose ethnically diverse cases when they have the opportunity to 'choose' their own cases.

Below, excerpts from participants' responses to the same question as P3-SWA suggest that, amidst the possible lack of time, knowledge and resources, the fear of blame and the 'punishment' that comes when their decision-making is deemed wrong, is heightened.

P1-QSW

'I'm always worried that, I might say the wrong thing. I might upset people, and you really don't want to, but it's the culture. Gaps are wide in places but I'm covering bases all the time'.

Whilst P1-QSW talks about their fear of getting things wrong and upsetting people, it is not clear if reference is being made to the organisation or to ACE with dementia. Addressing race and ethnicity in social work amidst a blame culture requires the fostering of environments that promote ongoing professional learning and supportive organizational structures (Lavalette and Penketh 2013). This type of holistic approach can encourage social workers to engage safely and effectively with these critical issues.

However, what can be taken from this statement is that for P1-QSW, there is potentially a missing link regards knowledge about ACE with dementia, and perhaps knowledge building is required to improve their confidence to work with this group. The ongoing fear and worry expressed by P1-QSW is also an indication of how unsafe practitioners feel. This P3-SWA and P4-SNR share their perspectives on social work practice as being undertaken in a blame culture.

P3-SWA

'We hear about some of the accusations that get made against social workers, you know the severity of the repercussions that can come from, you know if you do something wrong'.

Here, P3-SWA is referring to their perspective that there is a general blame culture within social work practice and that a wrong decision is judged harshly. The fear of such judgements brings with it notions of shame, the fear of disciplinary actions and indicates the murky waters social workers must navigate within their decision-making and suggests that these fears and stresses may be exacerbated when they are working with ethnically diverse persons, as there are potentially more areas from which practitioners may be seen to '*do something wrong'.* P4-SNR reinforces this notion:

P4-SNR
'And then you have, you know, all the blame culture and the recriminations. So, it's difficult and complex work to do'.

For P4-SNR, the blame culture and the punishments that come with such culture make social work practice with ACE with dementia '*difficult and complex work to do'*. In the context of this study, P3-SWA and P4-SNR show an acute awareness of the blame culture in social work (Hardy, 2020). Through these excerpts, participants suggested that practice with ACE with dementia evokes worry and fear, '*always worried'* and '*covering bases all the time'*. This suggests that whilst social work with ACE with dementia can be *'difficult and complex work to do',* practice is hindered by a blame culture that exists in social work practice. This, in turn, can have a negative impact on social workers' willingness to engage with this group. Additionally, these excerpts suggest the need for possible approaches to practice that will improve social workers' overall confidence and knowledge for working with this group. Another area that may shape social work practice with ACE with dementia is resources, which will be discussed in the next section.

6.2.3. Resources

Social care in Wales continues to face resource constraints (Murphy, 2023). Such constraints have significant and lasting effects on both practitioners, in terms of what support can be offered to service users and on service users themselves in terms of what support they may be able to access. When responding to challenges they faced or expected to face when working with ACE with dementia, participants referred to a range of resources, namely, dementia services, time and staffing. P3-SWA and P6-QSW discussed issues around the shortage of culturally appropriate services for ACE with dementia.

P6-QSW
'We're always up against the fact that the services that people may need or require actually are not there in huge numbers.'

P6-QSW creates an image of work that is constantly hindered by shortage, positioning social work with this group on an economic spectrum of demand and supply, where demand is always outweighing supply. Seen through this lens, alongside ongoing financial cuts to public services, it can be suggested that where culturally tailored dementia services are required, local authorities may also have to negotiate budgets and where organisational outcomes might include the reduction of costs, such services may not be purchased, invested in, or developed. This may lead to practice that leans towards a ‘melting pot’ approach in a bid to provide ‘a service’ rather than be seen as not providing the right service. For groups such as ACE with dementia, this results in unmet needs as well as feelings that social services cannot support them to meet their outcomes. P3-SWA alludes to the impact of this shortage in culturally appropriate dementia services.

P3-SWA

‘I don't think that there's anything[services] culturally specific to African Caribbean or if there is, we, [social workers] just don't know about. Maybe it's something that's just not specific to dementia, because I guess, obviously being an Afro Caribbean, you're already in minority and then to have dementia, you're in a minority of the minority’.

This discussion by P3-SWA points to the notion of community provision (Vernon and Qureshi, 2000), where public services are unable to meet needs. In the context of dementia service provision, it highlights the challenge social work practice faces when attempting to work collaboratively with communities, despite this approach being a key principle in Welsh government policy and a key principle within the definition of social work (Welsh Government 2014; IFSW 2014). Further, this excerpt by P3-SWA highlights an old-school care management approach. Under the new act, social workers are meant to get to understand people’s community resources and help them to think about ways of achieving their outcomes besides just receiving packages of care

Another interesting point made by P3-SWA is that there is a gap in communication and engagement between ACE with dementia and social workers. Social workers are not always aware of those services that are developed and produced by marginalised communities. Such a lack of awareness demonstrates the challenges to social work practice to develop and maintain engagement with communities, as stated in the international social work definition (IFSW 2014). Additionally, this draws attention to the potential for informal carers to be left with unmet needs (Vaingankar et al., 2013) as well as potential issues around support for informal carers, particularly as this is an area of significance on a Welsh government policy level. P1-QSW reiterates the view that a lack of resources is a barrier to working with ACE with dementia:

P1-QSW
‘I think one of the biggest problems that the staff who work in the area I cover is that they don't have the time. We haven't got the resources and they're doing their very best to manage really complex scenarios’.

Here, P1-QSW not only shares similar views around the lack of resources, but they also refer to the lack of time that practitioners have to work with persons with dementia. Research has shown that social workers are limited by how much time they can spend with service users, as the level of managerialism within the profession means practitioners are managing high caseloads alongside high levels of bureaucracy. This issue of lack of time is crucial in the context of this study, as persons with dementia may require more time with social workers to build relationships of trust, as well as they may also be impeded by their cognitive impairment and require more time to respond.

For some ACE with dementia, the amount of time needed to foster those relationships of trust may even be more due to historic experiences of discrimination and lack of trust in social services (Lasrado et al., 2021). The combination of an overall lack of resources and a lack of time gives the impression of social workers attempting to do the most with the least. This, in turn, raises concerns around how social work practice with ACE with dementia might be impacted in the context of interpreting and managing risks, meeting needs and mitigating harm where needs remain unmet. P1-QSW brings to the fore the issue of staffing as another resource that they view as lacking.

P1-QSW
‘We just haven't got the resources. I mean, we've gone abroad to recruit social workers because we haven't got enough in this country’.

Similar to other participants, P1-QSW refers to a broad take on ‘resources’ but also highlights a crucial area in the context of social care policy in Wales. The Welsh Government faces ongoing challenges in maintaining adequate funding for social care. Wales has historically benefited from European Union (EU) funding, which supported social care and regional development. The cessation of these funds post-Brexit poses challenges for sustaining social care services, particularly in the context of austerity and economic constraints (Gwilym, 2023; Parken, 2022). Additionally, the social care sector in Wales employs a significant portion of the workforce, yet faces high turnover rates and staffing shortages, which impact service delivery (Thomas, 2023). Further, (Social Care Wales 2023) has highlighted the ongoing decrease in the number of social workers registered to practice in Wales. This, in turn, can have a significant impact on how local authorities support persons with dementia, as well as give some insight into the possible workload pressures for social workers. Recruiting social workers from abroad also comes with issues around differences in values, ways of working and knowledge gaps. The following section discusses another area raised by participants as a barrier to working with ACE with dementia.

6.2.4. Training

When responding to a question on formal training around working with diverse populations and dementia and where they may get support if they had to work with an ACE with dementia, participants expressed that they did not have such training and did not really know where to go if they needed support to work with an ACE with dementia. I discuss these data extracts with caution as I am unable to refute or confirm what participants might be referring to as ‘formal training’ or what the nature of the training might have been. However, these data extracts might give some insight into the type of training that social workers feel they need in order to work effectively with ACE with dementia and other diverse populations. P2-SWA highlights that whilst there is training, it is at the discretion of senior management who attends.

P2-SWA

‘There's a lot of training, but when training comes out they [senior management] will suggest which team should go for it. And they'll say they highly recommend that

social workers should do this, or they recommend another team. They'll list who will benefit the most'.

The above extract by P2-SWA gives some insight into what could be deemed a resource issue as local authorities have to make difficult choices on which team '*will benefit the most'.* Using an economics lens as suggested by (Murphy, 2023) not only does this situation suggest possible high demand and limited supply in terms of training opportunities and the number of practitioners who would like to have the training, it also brings attention to what might be the opportunity costs to social work practice with diverse groups such as ACE with dementia, when training for practitioners is determined by senior management. P5-SNR moves the discussion from how much training is on offer to highlighting that specialist training is not available.

P5-SNR
'There's lots of training specifically about dementia and cognitive impairment, but nothing specific to diverse cultures'.

P7-SNR

'Obviously people have other forms of anti-discriminatory practice training anyway. But it's not necessarily geared towards sort of a cultural understanding. I don't remember seeing or having done any training whatsoever about anything to do with dementia and diverse ethnic minority populations. There's not a pathway of different training and knowledge that's been offered. You've got our social work training covering communication, person-centred training and about the core social work values and codes of practice. I've never had or seen or been offered anything like a training course to understand Afro Caribbean culture and dementia'.

Here, P5-SNR confirms that in their workplace, there is no shortage of training around dementia. However, the perceived absence of training around dementia and specific cultures suggests that there may be an organisational thinking that a generic awareness of dementia is sufficient for effective social work practice with anyone with dementia. Arguments have been made by Williams and Parrott (2013) that the integration of race and ethnic diversity into a generic curriculum lacks specific learning outcomes and fails to maintain visibility on these critical issues. P7-SNR goes further with this argument, highlighting that there is no training pathway for those practitioners who may wish or may need to learn about diverse populations because this is their service user group. Interestingly, P7-SNR acknowledges that although anti-discriminatory training (Thompson, 2020) is available, it does not fulfil ‘*cultural understanding’.*

This thinking by local authorities points to a perception that the experience and needs of a person with dementia are the same for everyone with dementia. This type of homogenous approach goes against social work values around person-centred practice (Washburn and Grossman, 2017). For ACE with dementia, this type of approach to training and, in turn, practice, can result in a skewed understanding of the care needs of different persons with dementia. Additionally, a generic approach to training becomes a structure or mechanism within the system that promotes colour blind practice, which perpetuates racial discrimination. A negative impact on the profession from this generic approach to training is that it limits opportunities for social workers to be at the fore of the development of culturally appropriate dementia services for ACE with dementia.

6.2.5. Conclusion

Participants in this study discussed using a variety of approaches to meet the perceived needs of ACE with dementia. The discussion highlighted the ongoing tensions within social work and how these are exacerbated when social workers engage with race and ethnicity in the context of dementia care. Social work practice with ACE with dementia occurs within a complex political and social landscape. Practitioners are involved in ongoing balancing activities to meet the goals of Welsh government policies as well as organisational goals whilst meeting the needs of diverse populations such as ACE with dementia.

As a member of the African Caribbean community, a social worker and a researcher, my position on these approaches resonates with that of Song (2009). I posit that simply acknowledging and celebrating difference or attempting to ignore difference are inadequate approaches to tackle deeply rooted problems of inequality, oppression and racism. Adopting a critical lens, underpinned by critical race theory (Razack and Jeffery 2002) and intersectionality theory (Mattsson, 2014), can provide social workers with a pathway for reflecting on how ideologies such as multiculturalism and colour blindness might mask structural inequalities by appearing to ‘accept everyone’ whilst at the same time, ignoring ‘others’.

Discussion of the barriers to social work practice with ACE with dementia, as presented by participants, highlights that barriers exist at practice levels and at senior management levels, and across multi-disciplinary working. This suggests that perhaps a broad examination of social work as an academic profession is necessary to tackle the identified barriers to providing specialist social work practice to service users from ethnically diverse backgrounds, such as ACE with dementia. The following chapter is the final empirical chapter of my study, and it will present data and discussions around the roles that participants perceive as necessary if social work hopes to break barriers that negatively impact social work practice with ACE with dementia.

Chapter 7

Anti-racist praxis or customised universalism?

7.1. Chapter Overview

This chapter is the final empirical chapter for this study. I present and discuss data that gives insight into the roles that participants perceive as necessary if social work hopes to break barriers that negatively impact social work practice with ACE with dementia. The data has identified three distinctive roles, namely: Promoting Social Justice in Social Work, Deconstructing Stereotypes and Advocacy. Participants did not provide a clear rationale for their choice of roles to the question asked. Interestingly, participants talked about these roles as necessary for working with ACE with dementia but not as universal social work roles that would be required for any individual.

In contrast to the findings by Williams and Soydan (2005), around universalist approaches to social work with ethnic minority service user groups, discussed in chapter two of this study, some participants acknowledged the existence of systemic inequalities, racism and injustice. However, these were talked about in a voyeuristic way, without deeper discussions around action that was required (Murray-Lichtman and Elkassem 2021). This type of voyeuristic talk by participants highlighted that participants adopted a customised approach to universalist social work rather than engage with an anti-racist praxis, even when they are aware of racism.

Voyeurism in social work practices manifests in various forms, often reflecting deeper systemic issues within the profession. It can be seen in the way practitioners observe and assess people without considering the power dynamics or ethical implications. This tendency is not limited to individual practice; it is embedded within the institutional and academic structures of social work. The concept of voyeurism in social work can be understood through multiple lenses, including academic voyeurism and the observational gaze in assessments (Murray-Lichtman and Elkassem, 2021).

Academic voyeurism refers to a form of non-performative observation and analysis, primarily through the lens of White supremacy and colonialism. This phenomenon is characterized by the study and exoticization of Black, Indigenous, and other racialised populations without enacting substantive anti-racist actions. It reflects a broader dissonance within the social work profession, which simultaneously espouses social justice while being ambivalent towards racism and White supremacy (Murray-Lichtman and Elkassem, 2021). These authors further argue that academic voyeurism is also present within social work research and academic discussions where individuals from Black and ethnic minority groups are treated as subjects of study rather than active participants in the discourse, leading to their experiences of being eroticised.

The observational gaze in social work assessment further illustrates how power operates through seemingly neutral practices. This gaze, informed by Foucault's concepts of disciplinary power and panopticism, shifts the focus from understanding the care needs of individuals to managing risk, especially within the context of neoliberal governance and marketisation (Dustin 2007; Murray-Lichtman and Elkassem, 2021). This ‘gaze’ challenges the assumption that observation is objective and highlights its role in reinforcing or contesting power asymmetries between social workers and individuals (Bloor & McIntosh, 2019).

Voyeuristic practices in social work raise significant ethical concerns regarding professional integrity and trust. Their prevalence and impact vary across cultural contexts, influencing the effectiveness of interventions and shaping regulatory responses over time (Byrne et al., 2019). Recognising these implications is crucial for enhancing ethical standards and improving social work outcomes globally.

In the context of this study, "voyeuristic practice" refers to instances where practitioners acknowledge systemic inequalities, racism, and injustice without engaging in meaningful actions or concrete proposals for change. This form of passive recognition indicates a disconnect between recognizing a problem and actively working towards its solution. It underscores the need to explore the barriers and enablers to enhance social workers’ capacity to challenge oppression in practice.

7.2. Promoting social justice in social work

O’Brien (2010) argues that whilst there is no universally agreed definition for social justice or how social justice can be applied in the context of social work, the IFSW / IASSW (2014) suggest that social justice is fundamental to social work. Social justice is underpinned by the tenets of critical race theory CRT (Pulliam, 2017). These include empowering the voices of marginalised groups, and acknowledging the historical contexts whilst considering power, racism and other forms of oppression. (I discussed CRT in-depth in chapter 3). I acknowledge evidence of social justice principles within the code of practice (COP) in Wales. For example, respecting the views and wishes of individuals and promoting the rights of individuals and carers (COP1), promoting their well-being and voice and control (COP3) and respecting their rights (COP4).

However, the absence of an explicit mandate and definition of social justice for social workers in Wales highlights the potential for gaps between the COP values emphasised in social work education and their practical implementation. This gap may be attributed to the influence of neoliberal policies, the focus on clinical practice over systemic change, and the need for a more integrated approach to social work education and practice (Smith and Ferguson, 2016). Without an explicit social justice framework, social work risks reinforcing systemic oppression and inequality by focusing on individual treatment rather than addressing structural causes of inequality (Norris, 2024).

However, Ferguson (2008) argues that social justice is a diminishing and less visible aspect of social work practice. Dominelli (2004) and Payne (2006) argue that globalisation, a push to individualisation and case management activities have driven the less apparent presence of social justice within social work practice.

In their book, *The McDonaldization of Social Work* (Dustin, 2007), discuss how the adoption of managerialism has redistributed resources and redefined the role of social workers in ways that have transformed service delivery systems. Such discussion suggests that managerialism has brought an emphasis on efficiency in social work. This emphasis on efficiency is evident in the implementation of care management models that prioritize cost-effectiveness and resource allocation over individualized care, thus increasingly defining the role of social workers by managerial objectives rather than professional expertise.

This managerialism shift has, in turn, resulted in a misalignment between the objectives of the organisation and the social justice mandate underpinning social work. For example, time constraints due to heavy workloads, as discussed in the previous chapter, negatively impact the capacity of practitioners to build relationships with individuals and communities. It can be argued that relationship building is even more crucial, where practitioners are supporting marginalised individuals such as ACE with dementia, who will require more time for practitioners to understand the nuanced aspects of their culture. Such restrictions to relationship building can limit practitioners' ability and capacity to promote social justice as a challenge to oppression and discrimination.

My understanding of social justice was also informed by arguments made by Fraser (1997), who argues for a dual approach to social justice that incorporates expanded notions of redistribution and recognition. This expansion challenges the traditional social justice focus, which is on achieving economic redistribution. Additionally, Fraser (1997) emphasizes the need for a transformative approach to social justice that addresses economic inequalities as well as cultural and political injustices. This perspective is particularly relevant in addressing the complex practice dynamics of the social work profession, which is continuously shaped by growing capitalist ideologies (Dustin, 2007) and where issues of identity and cultural recognition are increasingly prominent.

For Fraser, political recognition and political redistribution are interconnected and must be understood together. For example, the political influence on categorising and homogenising ACE within terms such as BAME and how such aggregation can lead to inadequate resource allocation to meet the specific needs of ACE with dementia. Fraser (1997) argues that it is insufficient to recognise injustice without engaging with the broad meanings of resources within a political economy. In the context of access to culturally appropriate dementia care for ACE with dementia, such engagement would consider the broader systems, such as governmental policies that drive social work practice to adopt universal approaches to dementia service development and delivery, which are not inclusive or equitable.

Similarly, arguments made by Song (2009) that approaches such as multiculturalism (discussed in chapter six), which recognise diversity, do not go far enough to engage with issues around social justice. I hold the position that social workers who engage in social justice should demonstrate an awareness of different forms of inequalities and disparities. I posit that practitioners must move beyond the recognition of injustices to ACE with dementia in the context of dementia service provision and include an understanding that redistribution cannot happen without transformation. Transformation refers to changes in the discriminatory ideologies, policies underpinning social work practice at all levels. In the context of this study, all three aspects have been argued for by researchers in explicit and implicit ways. For example, (Gorski 2013), (Houston 2010), recognise the impact of the Windrush Scandal on some ACE, in terms of their access to services and rights as citizens.

Through the narratives provided by participants, it can also be inferred that the emphasis on managerialism, alongside resource barriers as discussed in the previous chapter and various forms of tacit knowledge have shaped social workers' understanding and perception of their role and more specifically, their role when supporting ACE with dementia. Despite the negative impact of managerialism on social work, narratives from some participants suggest resistance and collaborative efforts to mitigate its negative impacts by adopting a focus on social justice within their practice with ACE with dementia.

I interpreted the data with caution as I recognise my own subjectiveness in this process. I also acknowledge the subjectiveness of participants' responses. Additionally, these descriptions give some insight into how social workers understand and perceive their role within the broader context of dementia service provision for ACE with dementia.

The following excerpts from participants highlighted that some participants perceived and understood their role with ACE with dementia to be underpinned by social justice. Participants also implied that they understood that their social justice role should include recognition, redistribution and transformation.

P7-SNR
'There's not like a White experience and a Black experience that people automatically share. But neither at the same time should people be blind to issues of

discrimination or unknowledgeable. However you want to put it, you can't pretend we live in an equal world I think, there is a minor role for social workers. Yeah, you're not going to change the world, or change society, particularly by your individual practice with individuals. But I think fundamentally people want care and support and they want services that are actually fit for them, whatever their circumstances are, you know, whatever their origins are, if we can't provide that, you know that's what people come to us for, isn't it?'

Here, P7-SNR shares insights on their perspective on the importance of not homogenising groups because they may share similar skin colour. Although P7-SNR did not specify what 'experience' they meant, in the context of this study, research by Roche et al. (2021) warns against homogenising the experiences of all persons with dementia and of all ACE with dementia, as this can result in poor service development as well as leaving some service users with unmet needs. P7-SNR brings to the fore an argument around the importance of practitioners being aware of discrimination and inequality. *'You can't pretend we live in an equal world'* suggests that P7-SNR holds a position of what they believe to be true, that the world is unequal and that anyone who suggests otherwise is denying a truth. P7-SNR also puts forward the idea that they are aware not everyone may use the term 'inequality', but they cannot suggest that there is equality.

Interestingly, P7-SNR takes the position that social workers have '*a minor role*' in changing this 'unequal world'. Using a critical realist lens to interrogate the discussion by P7-SNR allowed me to unpack some of the complex interplay of individual agency and unseen structures, such as organisational or governmental policy. By looking at social work as an individual practice, rather than a collective approach, P7-SNR attends to what they believe each social worker might be capable of within their individual practice. This challenges the assumption that social work practice exists as this movement that brings about change by its very nature (IFSW/IASSW 2014). Instead, P7-SNR suggests that the change in society that is required to make the world equal requires much more than the efforts of individual practitioners.

This statement by P7-SNR is also interesting as it does not appear to acknowledge the policy development power of social work practice (Maylea, 2021) and the significant role that social workers can play in changing policy. For example, work by Sen et al. (2022), *Social work under COVID-19,* highlighted that practitioners utilised digital technology and engaged in what the authors referred to as ‘digital activism.’ Social workers undertook a legal challenge to the then UK Conservative government policy, known as *S1445*. This policy temporarily removed 65 legal protections and safeguards for children in care. Practitioners also challenged the removal of local authority duties to disabled individuals under the Care Act in England.

The collaborative efforts of social workers resulted in a Court of Appeal judgment declaring the policy illegal because of the lack of proper consultation. Whilst this example promises hope in the collective activism of social work practitioners, policy change occasionally happens, but it has not been the norm in social work practice in Wales and the wider UK for some time. This may be due to factors such as workloads or the ongoing redefinition of social work (as discussed in chapter three). Additionally, policy change takes time and campaigning against a policy injustice may not have any immediate benefit to the person presenting with a need.

In the context of social work practice with ACE with dementia, this perspective infers that social workers may perceive themselves as having very little influence in bringing about change that would improve dementia service provision for ACE with dementia. Interestingly, the development of specialist services in social work with dementia has been the result of individual practitioners or groups of practitioners. For example, Piercy et al. (2018) discuss how social workers employed various techniques to support the development of specialist dementia services. Social workers supported integration of services to address fragmentation in care provision and developed partnerships and collaborations with organisations such as Age UK.

Through engagement with policy within their positioning as agents of change, social workers do have the potential to realise the transformative potential of social work (Houston, 2023), suggesting that, on an individual level, social workers do have the power to make changes within society. Although P7-SNR is not arguing for a big, complete change, their perception of ‘*minor role*’ may be a big change for ACE with dementia, as well as social work practice itself.

The following extracts from three participants: P8-QSW, SNR3 and P1-QSW3 align with the arguments by Vasquez Heilig, Brown, and Brown (2012) who coined the term ‘*the illusion of inclusion*’. Their research employed a critical race theory lens to explore how standards that are meant to address issues around race and racism appear to do so, whilst at the same time, these standards marginalise race, thus resulting in an illusion of inclusion.

P8-QSW
‘When they were working on co-production a few years back, there was a meeting with staff and service users and I said ‘There's only one problem, we're all White. There's not one person in this room from within the council who's from another origin. So, our diversity is very limited.’

Anderson and Wiggins-Carter (2012) suggest that there are several definitions for diversity, namely: ethnic heritage, cultural background, group affiliation, identity, gender, age and status. These definitions highlight that diversity can mean different things in different contexts. Through the phrase, ‘*we’re all White’,* it appears that P8-QSW uses the term ‘*diversity*’ to mean persons from different racial backgrounds. P8-QSW’s extract suggests that they recognise the importance of having ACE voices or the input of ACE in the development of social work policies or services.

The practice of co-production is intended to support the overarching well-being principle of the (SSWBA 2014) through the recognition of people as assets who can contribute to the development, design and shaping of services (Welsh Government 2023). Looking at the principles of co-production as stated by the legislation (SSWBA 2014), the absence of non-White voices in a co-production meeting implies non-White persons are not seen as assets and the potential contribution they can make is not valued. Instead, non-White individuals appear to be subjects for observation or tokenistic gestures, rather than active participants in the development of dementia services (Murray-Lichtman and Elkassem, 2021).

Critically, when viewed in the context of this study, an absence of ACE with dementia in a co-produced meeting by social services and senior management would mean that the shaping, designing and development of dementia care services would be carried out without the input of persons for whom such services are meant. Research by Saltus, Duval, and Vougioukalou (2021) in their work on BAME with dementia found that persons with dementia and those caring for relatives with dementia believed that they were not included in the development of dementia services or policies.

Interestingly, engaging with this extract from P8-QSW through the stratified ontology of critical realism (Bhaskar 2008). At the *empirical level*, P8-QSW talks about a co-produced meeting they experienced and observed, which included social workers, service users and senior management within the local authority. This meeting was guided by legislative directive, SSWBA 2014 and P8-QSW observed that there were no racially diverse persons participating in the meeting.

At the *actual level*, embedded cultures that have excluded (consciously or subconsciously) non-White participation may be at play, as well as the possibility of a different understanding of co-production that resulted in the absence of 'diverse' voices, as well as P8-QSW's own subjective understanding of 'diversity'; in this case, P8-QSW refers to race. Additionally, invitations may have been sent out to racially diverse individuals who were unable or unwilling to attend. All these unobservable events entangle in unseen ways and may have shaped the meeting that P8-QSW observed.

Whilst at the *'real'* level, generative or overlapping mechanisms such as a history of poor engagement by the local authority with 'diverse' persons or groups, or historic experiences of racism by the 'diverse' groups or persons from the local authority, or some of the activities undertaken by the local authority in the past. Such deep systemic, structural inequalities, biases and power imbalances may be embedded in policies and practices that underpin the local authority's processes or underpin the values of persons acting on behalf of the local authority, when setting up meetings such as the one discussed by P8-QSW.

Seen through critical theory and critical realism, the narrative by P8-QSW not only highlights the usefulness of a critical lens within the context of this study, but also highlights the complexities that exist within social work activities and the importance of social workers consciously taking on a social justice role that recognises not only the absence of racially diverse voices but also the impact this can have on service development for these groups and closing the knowledge gap between practitioners and practice.

Interestingly, whilst P8-QSW talks about the absence of non-White voices, and this acknowledgement can be taken as a call for social justice, P8-QSW does not offer any substantive proposals for change. The following extract by SNR3 expands the points inferred by P8-QSW. SNR3 also acknowledged the absence of Black representation alongside a lack of disruption of the status quo.

SNR3
'I think what I'm concerned about is that we tend to look at dementia through the eyes of White Welsh people and families and not through the eyes of different cultures, different genetic backgrounds. What is difficult is to find a way of this predominantly White Welsh organization reaching out and making people feel comfortable in telling us about what they need and finding a meaningful way of delivering that. And that's quite a big challenge, but one I'm very interested to take on.'

Through a critical lens, SNR3 discusses what they perceive as the shortcomings of dementia services in meeting the cultural needs of ACE with dementia. SNR3 makes an interesting statement that acknowledged that the 'White lens' used by social work when looking at dementia, impacts negatively on the support offered to persons from different cultures, alluding to the call made by Tascon and Ife (2019) to disrupt Whiteness in social work. SNR3 talks about the use of a 'White lens' as hindering practitioners from fulfilling their duties under the law. Additionally, in talking about not being able to offer support or meet the expectations of different communities, issues around the impact on wellbeing for both the individual with dementia and their carer/s, the gap in service provision and potential risks around unmet needs are brought to the fore (Bhattacharyya, Benbow and Kar, 2012).

Interestingly, SNR 3 acknowledges the existence of White culture: '*we tend to look at dementia through the eyes of White Welsh people and families and not through the eyes of different cultures'.* This is in contrast to the overarching denial of White culture by participants in chapter five. Interestingly, P8-QSW highlighted the absence of non-White voices and SNR3 highlighted the presence of White culture.

Whilst both participants and P1-QSW3 highlight the marginalisation of BAME persons with dementia within a policy document.

SNR3 also demonstrates a critical awareness of '*this predominantly White Welsh organization*. Such awareness suggests that SNR 3 may also be aware of the role of the local authority in sustaining this White lens. According to Care and Tedam (2022), social justice is affected by sustained racism. Choonara (2021) argues that whilst social workers may be more aware of racism, following events such as the murder of George Floyd, there remains a lack of acknowledgement of institutional racism (as discussed in the literature review), as well as the lack of resources to tackle institutional racism. Similarly, P1-QSW3 highlights an ongoing pattern of absence in the context of Black voices in dementia care policy development.

P1-QSW3

'People write and view populations as generic, and we [BAME] seem to be on the margins. When the dementia strategy came out [BAME] people were in the appendix. Who reads the appendix? It says nothing about us without all of us'. How can you say that when you haven't even included us the pictures? Even the pictures in there were of White people'

The account by P1-QSW3 highlights the complexities and tensions between the development of policy and the impact on those individuals the policy was designed to support. In their research on how persons with a migration background are mentioned and addressed in national dementia policies across Europe, Canevelli et al. (2021) found that the dementia strategy for Wales does not have comprehensive objectives for meeting the needs of ethnic minorities with dementia. Similarly, research by Saltus, Duval, and Vougioukalou (2021) found that Welsh Government policy falls short of addressing the needs of BAME individuals with dementia.

Here, P1-QSW3 is making reference to the Dementia Action Plan 2018-2022. Through the statement '*[BAME] people were in the appendix',* P1-QSW3 highlights the absence of BAME as a gap in representation but also as a broader systemic issue where the experiences and needs and identities of marginalized communities are relegated to the periphery of the Welsh Government's policy on dementia care. This is significant as the absence or marginalisation of already marginalised groups within dementia policy has far-reaching implications for service development.

Critical realism posits that our understanding of reality is socially constructed (Houston, 2001; Danermark, Ekström and Karlsson, 2019). Therefore, the limited presence of BAME within the dementia policy, as described by P1-QSW3, has the potential to construct a reality that privileges certain voices while marginalizing others. This marginalised presence can lead to a distorted understanding of the types of dementia care services that need to be developed. This can negatively impact social workers' ability to support ACE with dementia, as there may be limited or inappropriate services.

P1-QSW3 highlights that putting BAME in the 'appendix' [referred to as the annex in the policy document, page 32] results in the further marginalisation of already marginalised groups within policy, namely: ACE and ACE with dementia. P1-QSW3 goes on to say that ACE are not even represented in the photos that are used in the document. Haney (2002) and Lawrence et al. (2003) argued that a country's concept of need is a reflection of its historical and cultural interpretations of need and social work is a reflection of its historical, political, economic and cultural context.

Interestingly, through the data from SNR3 and P8-QSW, it can be inferred that social workers are aware of the problem (the absence of Black voices or representation from marginalised groups), but awareness that there is a problem is not an acceptable response, as awareness on its own does not elicit change (Vasquez Heilig, Brown and Brown 2012). It can be implied that White social workers are ill-equipped to disrupt Whiteness and its impact on social work (Ife and Tascón, 2019). This argument aligns with Gramsci's theory of cultural hegemony (Flynn, 2021; El Aidi and Yechouti, 2017), which suggests that dominance is maintained in capitalist societies by promoting ideologies that appear well-meaning, but are designed to maintain the dominance of the ruling group. Seen through a critical theory lens, the narratives by P8-QSW and P1-QSW3, highlight that even where legislation provides guidance to practice, social work as a profession, which has historically centered White experiences, struggles to overturn this ingrained culture. As such, despite co-production being a legislative requirement of public bodies such as local authorities, P8-QSW pointed out, there remained an absence of non-White voices (Headley, Wright, and Meier,2021).

7.3. Summary of promoting social justice in social work

Participants appear to be caught in a space of dissonance when engaging with ACE with dementia. On the one hand, there appears to be an endorsement of social justice, whilst on the other hand, participants appear to have an irresolute approach to addressing racial inequalities. This may be due to a number of factors, such as time to engage in the type of activism that is required of social work to challenge racial inequalities or a lack of knowledge to confidentially move beyond observations and challenge the systems that perpetuate such inequalities.

Additionally, it may be that participants believe that awareness of the context in which they practice is sufficient and their response would reflect the needs of the individual they are supporting at that specific time, as SNR4 discussed in chapter six. In addition to promoting social justice, some participants also discussed the importance of challenging often-held stereotypes that may further marginalise those diverse, marginalised voices. The following section presents and discusses data around the stereotypes some participants identified as negatively shaping social work practice with ACE with dementia.

7.4. Deconstructing stereotypes and assumptions about ACE with dementia

Research by Dominelli (1989) and Forbat (2004) highlight the dangers of stereotyping and homogenising of Black service users in both Children's and Adult social services across the UK. Stereotyping and homogenising can lead to over simplified understanding of the unique needs of individuals, resulting in a one-size-fits-all approach. Such results are not specific to ACE with dementia but across many Black Ethnic Minority groups, negatively impacting service users and service delivery.

Discussion with participants on their role in breaking cultural barriers between social workers and ACE with dementia, participants talked about challenging assumptions of ACE with dementia based on stereotyping. The data highlighted practice that is shaped by an often taken-for-granted use of stereotyping and homogenising. Such stereotyping and homogenising were identified in some of the held beliefs by practitioners around the level of familial support that is available to ACE with dementia, and the assumed behaviours by an individual with dementia.

Stereotyping and homogenising were also acknowledged as shaping a perception amongst social workers around the role of Black social workers, where service users identified as ACE or other Black identities. Two participants referred to held assumptions around the level of familial support that is available to ACE with dementia, through the use of the stereotype, ‘they look after their own’.

P1-QSW
‘I think the one thing that sticks straight into my mind is a phrase I've heard so many times, and please excuse me for saying it because I consider it very racist. ‘Ohh well, they always look after their own’. What really gets me about that statement, which I've heard quite recently, is that it completely ignores the fact that the person who has the dementia may not be getting the best support they could.’

This discussion by P1-QSW is interesting as, within their discussion, they raise what Adamson and Donovan (2005) argue is a common stereotype amongst many professionals who may be supporting persons from Black and Minority backgrounds. Whilst this is an assumption that is not specific to social work practice only, it does suggest that social work practice matters, such as safeguarding and best interest decision-making, may produce disproportionate results for social work practice with ACE with dementia when compared with their White counterparts.

For the ACE with dementia, this could mean, they have needs that cannot be met by the level of support they receive from family and due to the assumption, ‘*they always look after their own’* these needs are not brought to the attention of the social workers, or where those needs are identified, assumptions are made by practitioners that family will meet those needs. This can have a negative impact on the well-being of the ACE with dementia, as well as inadvertently result in carer burnout.

Interestingly, P1-QSW described such narratives, ‘they look after their own’ as racist. Whilst P1-QSW did not provide more details as to why they believed this to be so in the context of social work practice, such a narrative can shape practice in ways that limit the creativity of practitioners to engage with communities, to ‘meet people in their places’ and support people to find solutions to their problems, thus failing to meet the principles of the (IFSW/IASSW 2014) definition of social work.

Additionally, the stereotype, ‘*they look after their own’* in reference to ACE with dementia, is underpinned by hegemonic assumptions that informal, familial caregiving is a ‘cultural’ practice, and that the notion of ‘culture’ belongs to ‘others’ (Perry, 2001). Giroux (2014) argues that assumptions and stereotypes that centre culture are a form of cultural racism as they create and legitimize moral differentiation through culture, and this has its roots in colonialism and post-colonialism.

Through a critical realist lens, this discussion by P1-QSW can also be explored to determine how they express and use their own agency (Houston, 2001) and how this might shape their own understanding of stereotypes and their impacts on practice with ACE with dementia. According to Bhaskar's stratified ontology, events observed at the empirical level are shaped by unseen and often unobservable events at the actual level, which in turn are shaped by those events at the real or deep level.

In the context of this excerpt from P1-QSW, I argue that at the actual level, P1-QSW is using their own agency to define this stereotype as '*racist'*, whilst highlighting that '*the person who has the dementia may not be getting the best support they could.'* Through this lens, it can be suggested that P1-QSW may be able to use their agency as a social worker to shape or reshape their own practice or practice within their team, or that of another social worker, thus reshaping what might be observed at the empirical level when a practitioner engages with an ACE with dementia and is presented with this stereotype.

Whilst this may not be a straightforward reshaping that involves ongoing negotiations and power struggles, a critical realist lens is useful in shaping a picture of what might be possible for social work practice, where practitioners utilise their own agency to deconstruct stereotypes. For example, practitioners may engage in recognition without action, as discussed earlier, or they may seek alternative, creative ways to bring about change.

P3-SWA also makes reference to the same narrative as P1-QSW. However, P3-SWA goes further by making suggestions as to how practitioners might challenge this narrative.

P3-SWA
'I think it is important not to make the assumption that people from Black and Asian families have the family support system because it's not necessarily the case, even though it's a widely held belief. I think asking questions and, listening to what people want and being prepared to do a little bit more digging and looking around and it's tricky because we have to address it. If we don't flag it on our own, if we don't know how to be antiracist… you have to look at the things that make you uncomfortable.'

P3-SWA begins by challenging the stereotype of BAME individuals having family support. This narrative is similar to the one made by P1-QSW. Such an assumption as described by P3-SWA is important in the context of ACE with dementia, as not all ACE with dementia will have the same level of support. Failings by practitioners to critically attend to this can result in exacerbated distress for the individual with dementia and their carer, as well as disregard for the impact of this type of discrimination. Additionally, this stereotype can potentially cause practitioners to ignore issues around gender-based caregiving, such as carer abuse (Hulko, 2009).

There is also the potential to miss possible harm to the ACE with dementia due to inappropriate or unsafe care, as carers may not be trained or have adequate knowledge around dementia symptoms, particularly as the disease advances. Understood through the lens of critical race theory, caregiving is not a practice that is carried out by ACE with dementia only. White individuals with dementia also have families who provide informal care and support.

By suggesting '*asking questions and listening to what people want and being prepared to do a little bit more digging'* P3-SWA is suggesting that challenging such a narrative requires relationship building and continuous learning on the part of practitioners to improve their own understanding and knowledge about the ACE with dementia. One of the biggest barriers to engaging in such '*digging*' is time constraints faced by social workers, which may be even more difficult when supporting ACE with dementia, who may present with needs that practitioners are not familiar with or where resources to meet those needs are few or non-existent.

For example, research by Chibaya (2018) highlights the challenges practitioners face with having opportunities for reflective and reflexive practice due to high caseloads and time constraints under care management systems (Dustin, 2007). Such challenges may be more noticeable where practitioners have to do their own research and learning about a different culture from the dominant group.

Through the statement, '*If we don't flag it on our own'* Ps is suggesting that challenging such assumptions is the responsibility of social workers. Whilst P3-SWA does not clarify if this is the responsibility of individual social workers or the organisation, their argument implies that there can be a key role for social work in challenging stereotypes. Additionally, calling for practitioners to become anti-racist suggests that P3-SWA acknowledges that racism exists within social work. Through the phrase '*things that make you uncomfortable',* P3-SWA implies that there are aspects of social workers' practice and perceptions that through critical reflexive practice, biases may be revealed (Baker et al., 2018).

P1-QSW and P3-SWA demonstrate the challenges that exist for social workers across different understandings and perceptions of caregiving and care receiving. P1-QSW and P3-SWA highlight the need for practitioners to interrogate and understand the impact of care receiving on the person receiving the care. Through an intersectional lens that acknowledges the nuanced challenges of the intersection of race and dementia support, practitioners can respond appropriately to the needs of ACE with dementia. The following narrative by P6-QSW lends support to arguments made by (Larsson and Englund 2004) around the impact of colonialism and post-colonialism on the development of stereotypes and their perpetuation across social work practice.

P6-QSW
'I think that racism is a bigger problem than is probably accepted generally and it comes out in so many different ways. People saying they are not racist but then they come out with stereotypes or assumptions, all the things that would usually come out when people are being racist. I think councils have every responsibility to say it is racism, and practitioners should be taught not to discriminate in that way and to challenge people who do. If you live in XXXX and you've got a statue of somebody who's now famous for the way he treated his slaves, I can't see how that Council can say it's anti racist without saying something about that statue.'

Here, P6-QSW raises several areas that they perceive as requiring change to tackle the cultural barriers that hinder social work practice with ACE with dementia. Firstly, P6-QSW suggests that it is important for social workers to reflect and be reflexive of their values and behaviours and recognise when these are aligning with racist values and behaviours and to call out such behaviours when they are observed and recognised. Research by Cane and Tedam (2022) highlights that challenging racist behaviours in the workplace is difficult, complex and requires confidence and a safe working environment in which colleagues feel supported by senior management to do so.

Next, P6-QSW discusses corporate responsibility in challenging racial discrimination (Cane and Tedam, 2022) by highlighting what they perceive as the role of the local authority in challenging racial discrimination by examining its own role and ability in shaping anti-racist policy and practice. Similar to arguments by Ife and Tascon (2020), P6-QSW appears to call for social work practice and the local authority to actively and consciously embed the historical context of these groups into its practice or knowledge development.

King-Jordan and Gil (2021) argue for the importance of social work institutions where social workers work, such as local authorities, to recognise the ingrained elements of racism, as some social work institutions may be located in regions that have benefited from the slave trade. Such acknowledgement can support critical thinking around the possible impact of these histories on policies that shape social work practice and its response to racism, as well as shape ideologies of communities and practitioners who may live in such localities.

The data also highlighted that participants acknowledged broader areas of stereotyping based on age and expected behaviours by persons with dementia. P1-QSW highlights the stereotyping that occurs due to someone’s age and goes further to illuminate that an acute type of stereotyping occurs at the point where age and ethnicity intersect.

P7-SNR
‘You know, if people from an Afro Caribbean background, you know, maybe have, I think someone gave an example of someone who was going through some rice and picking out the bad grains of rice, you know, from a bowl in front of them. If you saw that in a context here you might think oh well they've developed some kind of obsessive behaviours or some compulsive behaviours and there's this terrible thing because of their dementia. But if that's something you've already done for the last 40 years and you're continuing to do it, are they retaining a skill? Yes, of course they are, you know, or but that could easily be interpreted as something, well, you know, they've got these odd behaviours, you know, and they seem to have this. You know, this seems to be this repetitive, obsessive behaviour. So, it's a, you know, something that's quite normally one’s culture like if I was going to a Muslim household, you know or a Jewish household, there's, you know, things around, you know, you know

what's normal, what's culturally acceptable, what's culturally unacceptable. So, there's all those kind of areas of that's what I would be concerned about missing something of significance because of that lack of knowledge of, you know, culture and norms'.

The response by P7-SNR was particularly interesting as this was the only participant who raised the issue of 'behaviours' by looking at culture as broader than food, dress and faith, to include behaviours. Stampley (2008) suggests that through socialised definitions of 'good' or 'proper' behaviours, social workers who work with diverse populations often find themselves entangled in cultural tensions and that these tensions arise due to laws and societal norms that act as (invisible or visible) authoritative references for social workers. Through these authoritative references, social workers can reaffirm the norms of the dominant culture. Exploring the account provided by P7-SNR through a critical race theoretical lens, P7-SNR brings to the fore the importance of practitioners having an awareness of the power within the invisibility of 'Whiteness' and 'White' notions about 'normal behaviour' and the reductionist impact of failing to address such power imbalances (Foucault, 1980). P7-SNR has creatively reframed the scenario, and this reframing has placed the ACE with dementia in a positive position that promotes agency.

Interestingly, a search of the literature for 'behaviours and dementia' produced a range of studies that described the behaviours of persons with dementia in negative, reductionist, medicalised terms such as aggressive, troublesome and disruptive and challenging (Swearer et al., 1988; Schnelli et al., 2023). However, Hansen (2012) argues that such labels ignore the influence of culture on behaviours as dementia progresses and that these behaviours may be linked to a 'rhythm of life' which may have developed over time, based on the type of work the individual did, the times they had meals, baths, or socialised with others.

An understanding of the cultural frames and meanings of dementia and its associated experiences and behaviours may support practitioners' understanding of behaviours in ACE with dementia that do not seem to fit the 'norm'. For example, cultural framings of dementia as a normal part of ageing or in the context of faith and religion may have an impact on how well individuals cope and live with dementia. I have discussed the cultural framings of dementia in more detail in the literature review chapter.

Additionally, this narrative by P7-SNR brings attention to the argument put forward by Matsumoto (1996), which highlighted the importance of understanding the socio-cultural factors such as customs, beliefs, symbols and behaviours that have a wide influence on how culture is conceptualised. This understanding can provide key information to social workers when assessing or developing care and support plans for ACE with dementia. It can also support practitioners in reflecting on how their own socio-cultural factors shaped their understanding of the experience and needs of ACE with dementia (Gibson 2002; Brooke et al.,2017).

7.5. Summary of deconstructing stereotypes and assumptions

Deconstructing stereotypes of ACE with dementia requires social workers to engage in uncomfortable reflexivity to address ingrained biases. To have meaningful change, practitioners need to move beyond the voyeuristic approach of acknowledging racial inequalities caused by stereotyping and engage in transformative, anti-racist action. The following section discusses the role of the social worker as an advocate and the importance of advocacy in meeting the needs of ACE with dementia. All participants responded to a question around the roles they felt were required to break barriers between social work and ACE with dementia.

7.6. Advocacy

The code of practice in relation to Part 10 of the (SSWBA 2014) clarifies local authorities' duty to arrange advocacy services for people with care and support needs. Advocacy practices undertaken by social workers and independent advocacy services differ in their objectives, approaches, and the degree of autonomy from service systems. Social work advocacy tends to be integrated within the service delivery framework and seeks to balance the needs of individuals with organizational goals. Independent advocacy is focused on representing the interests of individuals, often operating outside the constraints of service providers, with little to no conflict of interest. This distinction supports a better understanding of the advocacy practices employed by participants in my study.

Advocacy has an important role to play in relation to voice and control and underpinning the wider requirements of the (SSWBA 2014) in terms of well-being, safeguarding and prevention. It can greatly assist people to express their views and make informed choices, thereby ensuring they have access to relevant services. According to Sewpaul (2016), advocacy has been at the core of social work practice right from its inception. Social work values and principles suggest that practitioners would engage in advocacy as part of the profession's objectives to achieve social and political change for individuals and groups who cannot undertake such advocacy for themselves (IFSW 2014). The following excerpt adds to the discussion of social workers' understanding of how the role of advocacy might be demonstrated within their practice.

P3-SWA
'The first thing you do is arrange to go out and see the person and possibly invite family and make sure that either they can advocate for themselves or would need advocacy. We can get outside advocates, but most of the time they don't tend to need anyone or request one. Family or a friend or someone that they feel happy to join them or most people can advocate for themselves'.

Here, P3-SWA is going through the steps they would take if they had to support an ACE with dementia. P3-SWA acknowledges that in the ACE culture, family and friends are usually the first point of advocacy support for ACE with dementia. P3-SWA also recognises that having dementia does not mean an inability to self-advocate. The following extract statement by P2-SWA and P9-QSW suggests an acceptance that advocacy is a key role of social workers.

P2-SWA
'*You know you're there to be their voice. That's why you do your job. That's what the role is all about, you know, to advocate and to make sure that they're being heard'*.

P9-QSW
'The service user may be able to advocate for themselves, if they can't and I see they are in need of advocacy, I can advocate for them or seek to find additional advocacy if it is required.'

When asked about what they thought was a necessary role for practitioners if social work hopes to break barriers that negatively impact social work practice with ACE with dementia, P2-SWA and P9-QSW allude to an idea that ACE with dementia may not have a voice when it comes to seeking dementia support from social services.

Interestingly, many people with dementia are disempowered along their interconnected identities of age, abilities, sexual orientation and socio-economic status (Hulko, 2004; Willis et al., 2016).

Participants did not offer rationales for why or how they decided that the role of advocate was necessary for breaking barriers between ACE with dementia and social work. However, the data and discussions across my study infer that practitioners have varying levels of awareness of systemic inequalities, racism and the need for social work to do more.

Therefore, it may be that participants have based their responses on held perceptions and understandings of the role of advocacy and perceive this role as useful in breaking those barriers. Another interesting aspect of this discussion by participants was that they did not discuss these roles as necessary for social work with all persons with dementia, inferring a perception that barriers only exist between social work and Black marginalised individuals, such as ACE with dementia. This implies that there may be an underlying perception by participants that there are some social work roles that are necessary only with Black individuals, bringing to the fore notions of a type of customisation of the universal social work roles.

Research by Saltus, Duval, and Vougioukalou (2021) supports this belief, highlighting that the impact of ongoing racism and even low expectations from services has resulted in many ethnic minority persons, such as ACE with dementia, not feeling empowered to make their wishes and feelings known. This approach by P2-SWA and P9-QSW is also in line with health and social care policy in Wales. The (SSWBA 2014) has placed a duty on public bodies such as local authorities to support individuals to make their wishes and feelings known through advocacy. The MHA and MCA also have provisions for independent mental health advocates to support persons who may not have the mental capacity to make their wishes and feelings known.

In the context of this study, by adopting an integrated lens of critical race theory and intersectionality theory, practitioners can create opportunities to work collaboratively with ACE with dementia to challenge discrimination in dementia service provision and development, as well as address complex needs. Additionally, such an integrated lens has the potential to encourage social workers to acknowledge the intersectional identities of ACE with dementia and address the intersectional needs that may arise in culturally sensitive ways. For example, a recognition of the intersection of gender, race, disability and immigration status can help social workers understand an ACE's reluctance to engage with services or interrogate how their caring role might be shaped by their gender, as in ACE culture, care is usually provided by females (Hulko 2009). Or in the case of an AC man with dementia and a disability, how these intersecting identities may shape his choice of carer.

P10-QSW
'When I think about dementia, if somebody has got no family, next of Kin and big decisions have to be made for them, we will look straight for advocacy. I think the advocate should be somebody from a Black ethnic minority background and they should have knowledge of Black issues to advocate for that person.'

Interestingly, P10-QSW starts by inferring that the role of advocacy may only happen where someone has no family. P10-QSW does not demonstrate awareness of the possibility that the ACE with dementia may which to self-advocate or that even in the face of family, advocacy should still be offered as family may not be appropriate, willing, or able to advocate for that individual. This further implies a surface-level understanding of the role of advocacy. This is in contrast to the argument put forward by P3-SWA around the assumption of family support for ACE with dementia, in earlier discussions on stereotyping. P10-QSW's emphasis on the advocate being from a Black ethnic minority background infers that perhaps P10-QSW is aware of the significance of representation and cultural competency in advocacy roles (Kirmayer, 2012). This perspective aligns with critical realism's recognition of the importance of social context in shaping individual experiences and needs (Archer 1995).

Whilst P10-QSW suggests that ACE with dementia should have a Black advocate, P10-QSW does not acknowledge the possibility that an ACE with dementia should be able to make that choice. P10-QSW is assuming that a Black advocate is best for an ACE with dementia, perhaps based on homogenised perceptions of this population. P10-QSW does not demonstrate an awareness that Black people are not a monolith and there may be nuances that impact the level of advocacy that can be provided based on the individual needs of an ACE with dementia. P10-QSW also does not engage with deeper issues around practitioner development and practitioner burden (Kirmayer, 2012). By designating advocacy to ACE with dementia to the responsibility of a Black advocate, P10-QSW implies that White social workers may not have a role in advocating with /for ACE with dementia. Such perceptions can have implications for cultural competency development as well as impact staffing, where local authorities do not have adequate Black social workers to take up advocacy roles.

Although P10-QSW does not explicitly discuss what is meant by ‘Black issues’, their discussion implies that P10-QSW is aware that ACE with dementia face the structural inequalities, and that these inequalities may exist within social services. Critical realism posits that societal structures can constrain individual agency, and in the case of dementia care, systemic biases may limit access to appropriate advocacy and support (Collins 2000). P10-QSW is suggesting that advocates who are aware of these structural barriers can better represent the interests of those they serve.

7.7. Summary of advocacy

Overall, participants described advocacy as a key role when working with ACE with dementia. Participants demonstrated varied perceptions and understandings of advocacy for this service user group. Additionally, participants appeared to include a strengths-based approach to advocacy, ensuring that ACE with dementia were empowered to advocate on their own behalf, whilst also recognising the importance of culturally appropriate advocacy support.

7.8. Conclusion

The data in this chapter were analysed through the use of critical race theory, intersectionality theory and critical realism. These were useful in identifying potential activities at the empirical, actual and real levels in different contexts as well as illuminating the intersectionalities of several power relations that are relevant to this study, such as race, age, ethnicity and dementia diagnosis.

Whilst participants did not explicitly categorise themselves in the roles discussed and it may be that my own subjectiveness interpreted their narratives as such, most participants had varied perceptions and understandings of the role of advocacy. Although participants demonstrated awareness of systemic inequalities and racism, participants did not appear to perceive the role of advocacy as a tool for challenging those structures or mechanisms that perpetuate such inequalities. This may be due to participants holding on to a surface-level perception of advocacy or participants may not see their role as engaging in anti-racist praxis, as well as not having an awareness or understanding of what anti-racist praxis might entail.

Analysis through a critical lens suggests that participants were aware of different identity categories that intersect in the context of ACE with dementia and demonstrated an understanding of how such intersectionalities can affect ACE with dementia. Interestingly, participants did not just look at their individual roles but also demonstrated critical awareness of the role of the organisation and organisational policy in shaping their own practice with ACE with dementia.

The data also suggest that social justice is an element of practice for these social workers and whilst they demonstrated this in different ways, there appears to be a sense of critical awareness amongst participants as to when social justice is absent from practice. This is particularly interesting as it suggests that social workers can identify shortcomings in their practice and potentially recognise the impact on ACE with dementia, as well as offer potential solutions. However, these acts of social justice were expressed on an individual level; for example, social justice was not a theme that was evident in the group interview or in the case file analysis. This suggests that there is much more work to be done across social work practice with ACE with dementia, as well as the possibility that social justice is indeed diminishing from social work practice, or that there is an acceptance that ‘*you're not going to change the world, or change society, particularly by your individual practice with individuals’.*

Whilst participants demonstrated awareness of the impact of stereotyping on ACE with dementia, participants did not go further to express the impact on service development or offer ways in which they would challenge stereotyping. The data implied that although participants were aware that stereotyping is wrong, there was a lack of know-how in translating this to social work action. A similar approach was observed through participants’ perception of advocacy. There were varied understandings of advocacy, its purpose and how and when advocacy may be required for ACE with dementia. Whilst participants suggested these three roles as necessary for social workers to break the barriers between ACE with dementia and social work practice, participants did not explicitly discuss what those barriers may be.

Instead, participants engaged in a voyeuristic acknowledgement of inequalities and racism, with no discussion on how social work might challenge these. Interestingly, no participant demonstrated an awareness that the roles discussed were part of the universal social work mandate. Participants appeared to offer a customised universalism in contrast to the anti-racist praxis that is being called for by researchers such as Singh (2021) and Obasi (2022). Participants did not discuss how these roles might transform their own practice with ACE with dementia, nor did they offer deeper discussions of how the roles they identified would break barriers between ACE with dementia and social work. This lack of clarity may be an indication that participants may just be engaging with surface-level understandings of inequalities, whilst simultaneously feeling unable or unwilling to engage with those structures and mechanisms that are embedded in racism, which perpetuate the inequalities they might acknowledge in social work with ACE with dementia. Participants may also not perceive their role as having deeper transformative potential. The chapter that follows is the final chapter in this thesis and presents conclusions and future directions

Chapter 8

Conclusions and future directions

8.1. Chapter Overview

This final chapter discusses the conclusions that emerged from this study and is made up of six sections. Section one reminds readers of the research aims, the research questions and summarises the key findings. In section two, I highlight the theoretical and philosophical contributions of this thesis in the fields of critical realism, critical race theory and intersectionality theory. Section three discusses the implications for social work as a professional and academic practice within the wider fields of social work research and equality and diversity policies. Section four discusses the study's strengths and limitations. In section five, I present discussions around the future directions for social work research based on the findings of this study and how the research findings have been and can be communicated to targeted audiences. Finally, I conclude this thesis with some reflections on how social workers can contribute to a more equal world.

8.2. Research aims

Review of the literature revealed that existing research on social work with respect to race, ethnicity, culture, and dementia predominantly focused on the discourses surrounding cultural competence of practitioners. To my knowledge, there are no studies with a focus on social workers' understanding and perception of these concepts in relation to the care needs of African Caribbean Elders (ACE). My study sought to bring attention to this by exploring those structures and events that shape practitioners' understanding and perception in relation to the care needs of African Caribbean Elders with dementia. My study had three key aims:

1. To explore how conceptualisations of race and ethnicity shape practitioners' understanding and perception when undertaking social work tasks with ACE with dementia.

2. To explore and understand to what extent critical race theory and intersectionality theory can be useful when undertaking social work tasks with ACE in the context of dementia care.
3. To understand the existing structures that support or hinder social work with ACE with dementia.

These aims were addressed through the following three research questions:

Research Questions

1. How do social workers understand race and ethnicity?
2. What approaches to dementia service provision do social workers use with African Caribbean Elders?
3. How are social workers supported when working with service users from African Caribbean backgrounds?

8.3. Summary of research findings

This section will present a summary of the key findings from fourteen semi-structured, in-depth interviews and a group interview with research participants from across different local authorities in South Wales. Participants comprised social workers, senior practitioners, social work assistants and a third sector leader. The study was framed within a critical realist philosophy and underpinned by theories of critical race and intersectionality. Data were analysed thematically. This summary is presented in relation to each research question.

How do social workers understand race and ethnicity?

Whilst participants demonstrated awareness of race and ethnicity as part of an individual's identity, with a few participants linking race and ethnicity to racial discrimination, there was an overall reluctance to use and engage with race and ethnicity as terminology, as well as concepts that embodied deeper meanings for practice and ACE with dementia. Notably, participants engaged in a process that highlighted the paradoxical challenges they face as they attempt to simultaneously understand race and ethnicity as essential, neutral, and unproblematic categories. Race and ethnicity were perceived as and used interchangeably with culture, food and religion.

There appeared to be an unspoken preference amongst participants to use the term ‘culture’ over ‘race’ or ‘ethnicity’ as identifying markers for ACE with dementia. This may have been due to the fear of saying the wrong thing and the overall unwillingness of social workers to engage with race, particularly within a blame culture (Munro, 2019). This led to a narrative that ACE with dementia had needs based on culture. The findings indicate that social workers did not move beyond perception (Audi, 2018) to demonstrate true understanding or ‘grasping’ (Gordon, 2017) of the concepts race, ethnicity. Instead, participants often adopted a simplified approach to understanding culture, which led to a lack of recognition of injustices faced by minorities. This oversimplification can be an indication that participants’ learning did not provide them with adequate conceptual capacity (Audi, 2018) to support the development of an understanding of the encompassing and interconnected nature of ‘culture’ in the context of minority groups such as ACE with dementia. This can be problematic as it can hinder effective advocacy and support for ACE with dementia (Vanidestine and Aparicio, 2019).

Culture was perceived as unique to Black minority ethnic groups, again demonstrating that participants perhaps lacked knowledge of the broader conceptual knowledge around culture. This ‘lingering’ in the perception stage can also be an indication that participants lacked the cognitive processing skills that can support active engagement and application of knowledge around culture (Gordon, 2017). I am aware of the subjective nature of perception and understanding (Janvid, 2014) and accept that this lack of deeper engagement with culture can be a deliberate choice by participants, shaped by their own histories, cultures and beliefs.

This study reveals a paradox in participants’ narratives: while some participants implicitly acknowledged the existence of White Welsh culture, they simultaneously denied or failed to explicitly recognise it as a distinct cultural entity. This contradiction was evident in discussions around cultural needs and identity within social work practice. Participants often framed cultural needs in ways that assumed a normative baseline. For example, P11-QSW, stated "they have everything they are used to. They have the same language, they have the same food, they have the same music, they have the things they are used to, people from other cultures, they don't have". While referring to others, this statement implicitly defined a default cultural framework -presumably White Welsh – against which other cultures are measured.

Similarly, participants' awareness of 'other' cultures often surfaced only in contrast to this unspoken norm. The absence of explicit reference to White Welsh culture suggests it functions as an invisible standard, against which these 'others' are compared. SNR3 directly acknowledged this dynamic, stating, "I think what I'm concerned about is that we tend to look at dementia through the eyes of White Welsh people and families and not through the eyes of different cultures, different genetic backgrounds". This recognition of a dominant "White lens" in dementia care highlights the influence of a specific cultural perspective that shapes practice.

However, the perception of culture as unique to ‘Black’ groups also suggests that White practitioners did not examine aspects of their own culture as cultural expressions. Further, this implies that participants did not engage in reflexivity that considered how personal or societal cultural aspects may shape their understanding and perception of the needs of ACE with dementia as well as their White counterparts. Where interview questions invited participants to engage with race and ethnicity, the responses were steeped in fear, uncertainty and a lack of confidence. Through processes of avoidance, aided by the use of organisational policy and underpinned by fear of getting things wrong or being labelled racist, resulted in a lack of confidence to engage with race. Practitioners perceived race and ethnicity as ‘special’ identities that were challenging to their practice, controversial and best avoided. The data infers that similar to culture, participants perceived ‘race’ as relevant to Black minority groups. Such perceptions reflect discussions made in chapter 1 around the arguments made by Frankenberg (2020) that not engaging discourses around ‘whiteness’ perpetuates an invisibility of ‘whiteness’ and a belief that ‘whiteness’ is the norm and does not require interrogation.

Organisational policy focused on legislative definitions of outcomes and performance targets, reinforcing this lack of deeper engagement with culture, race and ethnicity. Participants engaged in a pursuit of outcomes that they perceived as negating the consideration of race or ethnicity. Notably, participants showed an entrenched faith in an outcomes-based approach. It was not clear if this was a genuine buy-in to an outcomes framework or if this was a safety net for practitioners, who were afraid of getting things wrong or being labelled racist. Bureaucratic templates and guidelines do not necessarily enhance professional awareness of ethnic and cultural diversity.

Instead, they can contribute to a proceduralised approach that overlooks the complexities of individuals (Benedict et al., 2024).

What approaches to dementia service provision do social workers use with African Caribbean Elders?

Despite the avoidance and fear around race and ethnicity, participants perceived their practice as inclusive because of approaches based on relationship building, multiculturalism and colour-blindness. These approaches were used by practitioners to suggest that their practice with ACE with dementia was based on fairness and equality. Building a reciprocal relationship can lead to better outcomes for individuals as it fosters trust and understanding (Ruch et al., 2010). However, participants did not demonstrate any acknowledgement or knowledge of the opportunities for reciprocity, such as knowledge exchange through relationship building with ACE with dementia and the wider AC community. Participants presented varied levels of understanding of the broader concepts that are interconnected with relationship building. I acknowledge that participants work within systems that are prohibitive of the work that is required to build relationships. At the same time, participants rigidly follow processes that lead to narrowly defined outcomes, resulting in a lack of skills and knowledge to support them to work with any individual outside the 'norm'.

I also argue that the data implied that due to the blame culture embedded within social work (Munro, 2019); P1-QSW *'I'm always worried that, I might say the wrong thing.';* P3-SWA '*the severity of the repercussions that can come from, you know if you do something wrong';* practitioners 'hide behind' the safety of organisational processes to keep themselves safe. This in itself is exhaustive; P1-QSW '*I'm covering bases all the time'* and leaves practitioners without a safe space for building their confidence, skills, knowledge and understanding of diverse communities. This can have a profoundly negative impact on ACE with dementia in terms of building trust, accessing culturally appropriate support and having a voice in the development of services.

Interestingly, by drawing on notions of multiculturalism, relationship building and colour-blindness, practitioners were making implicit confessions (Aarsand and Aarsand, 2018) that they are aware of difference. Further, they are aware of the possibility that discriminatory practices exist, and this can exclude some individuals and there is a need to attend to such differences in ways that do not perpetuate exclusion. It was not clear if participants saw this level of challenge as part of their role. As such, I argue that participants are often engaged in ethical dilemmas of keeping themselves safe amidst a blame culture, and perhaps wanting to, but not knowing how to challenge forms of injustice or discrimination that they may be aware of within dementia service provision.

Practitioners used their proximity to diverse, cultural, racial and ethnic groups by way of the local authorities in which they worked to suggest that their practice with ACE was based on equality and fairness (Dreisinger, 2008; Stafford, 2017). Whilst participants engaged in some use of tacit and experiential knowledge, there appeared to be an overall lack of deeper critical reflection on the usefulness of these approaches. Understanding of the inadequacy of these approaches to address systemic inequalities or how they perpetuated marginalisation was not demonstrated. Such uncritical use of these diversity approaches implies a disconnect between and a lack of movement from; participants' perceptions of equality, fairness and inclusion and their understandings of these concepts in relation to how they shape and are applied in their practice with ACE with dementia. This disconnect can negatively impact practice with ACE with dementia as practitioners may not possess the conceptual capacity, professional skills or personal willingness to challenge systemic forms of discrimination that disadvantage ACE with dementia.

There was no evidence of critical reflection on how these approaches became part of practice. This lack of evidence highlighted a gap between perceived inclusivity and the realities of practice with ACE with dementia, creating an *inclusion mirage*. There was no explicit linkage of approaches based on relationship building, multiculturalism and colour-blindness to anti-racist or anti-oppressive practice. Expressions such as **'***melting pot', 'integrated society'*, as discussed in chapter 6, although well-meaning, were used in uncritical ways. Social work engagement with arguments made by Williams, Evans, and O'Leary (2015) in their work, *A Tolerant Nation?: Exploring Ethnic Diversity in Wales,* can support practitioners to reflect deeper on their perceptions and understandings of Welsh society, and how these might shape the realities for individuals they support, particularly those from racially marginalised groups. These findings highlight a gap between practitioners' perception of inclusivity and the realities of practice with ACE with dementia.

According to Harrisson and Turner (2010), social workers exercise a high degree of discretion, which can lead to varied interpretations and actions based on personal biases and cultural understandings. There was a notable inconsistency in how social workers responded to cases involving (Black) ethnic diversity. The thesis concludes that the complexities and nuances of social work practice with ACE with dementia, not only suggests ongoing challenges for practitioners to achieve alignment between the goals of social work and the processes they employ to achieve them but also calls for a deeper look at the impact on already marginalised individuals, service delivery and service development where the synergy between social work purpose and the methods employed to achieve this purpose, fails.

How are social workers supported when working with individuals from African Caribbean backgrounds?

While training and support are essential to enhance professional competence, the findings suggest that simply having standardized frameworks and mandatory training around anti-discriminatory practice does not guarantee improved awareness of ethnic and cultural diversity in practice, nor do they facilitate the necessary move from perception to understanding (Husband 2007; Gordon, 2017). Additionally, organisational criteria, budgets and what organisations perceive as the needs of the service, determine who is entitled to receive training. Training is a limited resource and staff have to justify their attendance based on their roles within the organisation.

Overall, participants stated that they received little or no support from their workplace. Participants who identified as having a (Black) minority background also stated that they received little support from their organisations when they experienced or witnessed racism. This lack of support was from the organisation and the university, suggesting a perception by participants that universities that qualify social workers and local authorities that employ social workers share responsibilities in addressing racism. Research by Friedline et al. (2023) suggests that collective action by social work educators and employers of social workers can advance the profession’s progress toward becoming anti-racist.

This is significant for social work practice in Wales as the Welsh government continues the drive to make Wales anti-racist by 2030 (Welsh Government, 2022). The government’s anti-racist action plan requires all public bodies in Wales, such as local authorities and institutions such as universities, to develop and implement anti-racist action plans as part of their commitment to an anti-racist Wales. Participants reported that there was a reluctance by their institutions to take action against racism because no policy was in place and an absence of knowledge as to what the best response and support could be. Also significant to this study is the often immeasurable, seen and unseen impact of racism, particularly where the perception of the victim and the institution differ. This difference highlights the arguments made across this thesis that whilst perception is subjective, a lack of knowledge about racism produces perceptions that cannot/do not connect the impact and the potential of the action or inaction.

Notably, participants who identified as Black talked about not feeling like they belonged in social work and that the organisation cared more about performance indicators than supporting staff to work competently with ACE or any other Black minority service users. Participants often relied on their own resilience and agency to guide them. Others relied on the tacit and experiential knowledge of team members to support each other.

In the absence of a support pathway, participants utilised their discretion and took on specific roles they believed were necessary for working with ACE with dementia.

Advocacy, social justice and deconstructing stereotypes were perceived as necessary social work roles for breaking the barriers between social work and individuals from Black minority backgrounds. However, participants did not talk about these roles as part of the universal social work mandate that can be tailored when supporting marginalised groups. Whilst this implies that some participants hold perceptions that ACE with dementia face specific challenges that require targeted support, participants did not demonstrate conceptual capacity (Audi, 2018) around the linkage of these roles to anti-racist or anti-oppressive practice. This suggests a possible gap in understanding of the universal mandate of social work (IFSW 2014) and how this universal mandate might be tailored to support marginalised groups (Ladhani and Sitter, 2020).

8.4. Philosophical and theoretical contributions

Critical realism

Critical realism offered a robust framework for understanding the complexities of social work research through its unique epistemological and ontological contributions. By emphasizing the interplay between structure and agency (Bhaskar, 2008), critical realism supported an exploration of the mechanisms that shape how social workers perceive and understand the care needs of ACE with dementia. Critical realism encouraged me to question dominant paradigms and engage with alternative perspectives. I believe critical realism supported the production of knowledge in the field of social work that adds to the wider knowledge base of critical social science.

This perspective encouraged me to seek out and explore the broader socio-political contexts that may not be easily observed but subtly or profoundly affect social workers' understanding and perception of the care needs of ACE with dementia, ultimately shaping practice with this group. As such, critical realism has the potential to offer social work researchers much scope for deep exploration of practice across different service areas, as well as the potential to enhance reflexive practice.

Critical race theory, intersectionality theory

Critical race theory (CRT) allowed me to openly explore the pervasiveness of racism in society, including in social work, providing a space for a reflexive and transparent approach to the study. I was able to undertake a deep interrogation of the data without attributing blame to individual practitioners, which in turn facilitated awareness of possible events and structures that shaped practitioners' understanding and perception of the care needs of ACE with dementia. I have integrated CRT and Intersectionality theory to improve understanding around the processes and structures that shape how social workers understand race and ethnicity in the context of care needs for ACE with dementia.

I incorporated a greater number of factors as the antecedents of these theories, compared to former work, which looked at dementia and ethnicity (Lasrado et al., 2021); dementia and social work (Manthorpe and Iliffe, 2009); social work and ethnicity/race (Lavalette and Penketh, 2013). My study has incorporated race, ethnicity, dementia and social work within the parameters of the Welsh context. By extending the original application of critical race theory beyond sex, gender and race, I offer a modest contribution to the purchase of CRT. I demonstrate the usefulness and potential of both CRT and Intersectionality theory, as critical theories useful for social work research, dementia research, ACE with dementia research and research within a Welsh context.

Intersectionality theory significantly contributes to social work research by providing a nuanced framework for understanding the complexities of identity and systemic inequalities by emphasizing the interconnectedness of various social identities and the complexities of power dynamics (Almeida et al.,2019). This theoretical lens allowed me to examine how various social categories, such as race, age, dis/ ability, and class, interact and shape individual experiences and outcomes within social work contexts. Critical examination of how these dimensions are shaped, reshaped, problematised and contested in social work contexts provided a deeper understanding of some of the challenges involved in addressing the care needs of ACE with dementia.

Intersectionality theory supported the identification of structures that can potentially impact social work practices with ACE with dementia. Intersectionality theory promoted a thematic and methodological agenda that supported the interrogation of inequalities at micro, meso, and macro levels (Rothman and Mizrahi, 2014), facilitating a comprehensive analysis of social issues.

8.5. Implications for social work the profession

One of the significant implications for the social work profession from my thesis is the acknowledgment that years of practice, seniority, or being qualified or unqualified were not influential factors for improved cultural confidence in the context of practice with individuals from marginalised communities.

According to participants, senior social workers typically managed more complex cases and provided guidance and supervision to less experienced colleagues. They played a critical role in bridging frontline practice and senior management, (Ravalier et al.,2025). Social work assistants were seen as support staff, who required structured and supportive supervision to develop their capacities to effectively contribute to service delivery.

My study acknowledged that different levels of seniority could have shaped findings and responses in several ways. Senior social workers, due to their experience often carried additional responsibilities and faced time constraints. Their responses reflected a broader understanding of organizational policies and systemic issues, as they were involved in decision-making and managing expectations. For example, the theme of "managing expectations" appeared specifically among senior practitioners.

Senior social workers, by virtue of their roles within the local authority, could be considered "elite research subjects" due to their organizational capital and structured positions of privilege. This power dynamic was a consideration during recruitment. To mitigate this, the group interview was conducted with senior practitioners and did not include social work assistants or third sector staff.

From the findings, I acknowledge that whilst the impact of a blame culture, might be more acute at different levels of practice most participants expressed a fear of "getting it wrong" or upsetting people when discussing sensitive topics like race and ethnicity, indicating a potential gap in knowledge or confidence in engaging with these issues, at all levels. Senior practitioners and qualified social workers appeared more aware of systemic and structural barriers that impacted their practice with ACE with dementia. This was evidenced through their discussions around administrative burdens, multi-disciplinary working, organizational policies and resource constraints.

These findings have broader implications for an ever-changing profession such as social work, alongside the increasing expectations that those engaging in social work activities demonstrate an ever-changing level of competency. Additionally, it is essential to recognise that anti-racism requires ongoing education, self-reflection, and a commitment to challenging systemic inequalities, regardless of the length of one's professional experience, seniority and qualification. Most practitioners, including those who openly expressed anti-racist and trade union values, expressed worry and uncertainty about supporting individuals from Black minority backgrounds. A lack of cultural knowledge and confidence to enquire, as well as a practice culture steeped in fear and blame and limited resources within a bureaucratic system, means social workers are not equipped to work with ACE with dementia in deep critical ways that would challenge broader inequalities.

Additionally, a belief that culture is an abstract thing belonging only to Black minority groups or that race and ethnicity are only relevant to Black minority groups means practitioners are making hegemonic assumptions about White Elders with dementia, which can also have negative impacts for this group in terms of service development and delivery. Discussion of the perceived barriers to social work practice as presented by participants also highlights the need for a holistic examination of social work practice, education and research. Such examination can develop pathways for practitioners to be adequately supported to meet the needs of individuals from ethnically diverse backgrounds, such as ACE with dementia.

8.6. Strengths and limitations

Public impact strength

Public impact scholarships in social work research emphasise the integration of academic inquiry with community engagement to address pressing social issues such as eradicating poverty, social justice for marginalised communities and climate change (Bromfield and Duarte 2022). This approach aligns with the United Nations Sustainable Development Goals (SDGs), advocating for social justice and human rights. By centering public impact scholarship, social work scholars can enhance their contributions to societal well-being and sustainable development. I believe my study promotes public impact scholarship as it engages with stakeholders such as social workers within public bodies, such as local authorities. My study also adds scholarly insights around social work with ACE with dementia within the Welsh context to the social work knowledge base. Additionally, my study challenges social injustice related to dementia service provision for ACE with dementia.

Methodological strength

Qualitative research in social work offers several strengths. These include an ability to provide deep insights into the experiences and perspectives of individuals, allowing for a richer understanding of complex social issues. This methodological approach allowed me to engage in a deep exploration of the subjective meanings offered by participants around the research topic. This depth was crucial for my study, as I was interrogating sensitive and contested concepts. The inherent flexible and iterative nature of a qualitative approach enabled me to adapt my methods (semi-structured interviews, vignettes) as the study progressed. This adaptability is beneficial in social work research where the context can change over time. Additionally, an iterative and flexible approach enhanced the quality of the research, supporting the production of findings that I believe can help bridge the gap between academic research and practical application in social work, specifically in the context of practice with race, ethnicity and dementia.

Limitations

Despite ongoing reflexivity, I am aware that my own positionalities and background may have influenced the direction of the study and analysis of the data. As a member of the African Caribbean population, a qualified, experienced social worker and an upcoming academic, there may be subconscious thinking patterns and beliefs that shaped this study in ways that may not be reflected if this study were undertaken by another researcher. I have addressed the impact of my various positionalities in the reflexivity section in chapter 4, as well as incorporating reflexivity throughout this thesis. However, as I conclude this study, I reflect on some nuanced limitations of this study.

Contextual limitations

This study focused on the Welsh context of social work with ACE with dementia and this required engagement with Welsh legislation. Devolution means there are differences in the implementation of policies and how social work practice is governed and resourced in Wales, compared to other nations in the UK. Since 2016, social work in Wales has been operating under a very distinct legal framework from that in England, which joined children, family and adult social work under one framework, underpinned by principles of well-being, voice and control (Evans, Smith and Williams, 2021). Public bodies such as local authorities have some discretion in how legislation is implemented, and how practice is resourced and governed. The data from this study also reflected this variability as different participants within the same local authority interpreted and applied legislation and policies in different ways. The findings do not fully capture the unique experiences and challenges faced by social workers in different regions or settings, such as multi-disciplinary working and home working post COVID-19 (Owens et al., 2024).

Limitations of methods, sample size and sample diversity

Interviews

Additionally, my research primarily focused on social workers. This means my research did not fully capture other elements of social work, including social work education, social work training. Although participants shared their subjective insights around available training, I did not interview social work educators or review social work curricula. This could have provided rich data to aid in supporting deeper exploration and understanding of the extent to which such structures shape social workers' understanding and perception of the care needs of ACE with dementia.

Document analysis

I had hoped to analyse up to five care plans from across local authorities to explore how social workers understood and perceived the care needs of ACE with dementia. However, I was only able to gain access to one care plan. Some insights were gained in terms of the wider impact of COVID-19 on the ways individuals and families may have been affected in terms of visitation. Reflection on this method highlighted the real and ongoing difficulty and time-consuming nature of undertaking research in busy organisations such as local authorities. I may have underestimated the challenges to the local authority in terms of time and staff resources when I asked local authorities to be responsible for the main ethical aspects of sharing care plans with me, namely: anonymising and consent. Two questionnaires; one targeted at social workers supporting individuals with dementia and another for ACE with dementia and their carers around the completion of care plans, may have yielded data that supported triangulation and provided more insights into how and to what extent race and ethnicity featured/should feature in care and support plans for ACE with dementia.

Vignette

The study employed a vignette method to explore social workers' understanding and perception of the care needs of ACE with dementia. While this method can provide interesting insights, it may not have fully captured the complexities of real-life situations. The reliance on hypothetical scenarios could have inadvertently encouraged oversimplified conclusions about social workers' perception and understanding processes. This was discussed in more detail in chapter 4; however, it is a significant area of reflection for me as I conclude this thesis.

Sample size and diversity

The research involved 14 participants, most of whom were from predominantly White ethnic backgrounds. Due to the sensitive nature of the research subject matter, I did not actively engage with participants around their own racial and ethnic backgrounds, or other identities such as age, sexual orientation or nationality and how these may have shaped their understanding and perception of race, ethnicity or the needs of ACE with dementia. This reluctance to do so was partly down to the initial fears expressed by gatekeepers during the recruitment stages of the research. I had to choose between the potential depth of the study with actually being able to undertake the study. This highlighted arguments by (Vanidestine and Aparicio, 2019) around the fear social workers have of wrestling with race. Consideration of these individual-level factors, such as participants' race, ethnicity, or nationality, may have added a more balanced exploration of both systemic and individual influences and could have provided a more holistic understanding of the subject matter of this study. Whilst the data from their interviews provided some insights, a larger sample size and the inclusion of the voices of social work educators and social work policymakers may have produced more comprehensive data and a wider range of perspectives.

8.7. Future directions and dissemination

Building competencies

In contrast to what participant SNR3 in chapter 5 said about culture being something that is natural to social work, the findings of my research suggested that talking about and understanding the culture of ACE is not 'natural' to social work, despite an awareness that an understanding of culture is necessary. Additionally, practitioners' understanding of the needs of ACE with dementia often remained superficial. This superficiality highlighted potential knowledge deficits and systemic and linguistic gaps through the lack of legal provisions for language needs of ACE with dementia, similar to the active offer for the Welsh language. These suggested that cultural competence, as currently practiced, is inadequate in equipping social workers with the in-depth knowledge required for effective practice.

In line with arguments by Beagan, (2018) and Hollinsworth, (2013), to make the cultural competence model more effective, it is essential to incorporate culturally anchored approaches, community partnerships, a recognition of the broader systemic issues that affect dementia care provisions and a focus on the lived experiences and realities of ACE with dementia. The findings also highlighted that without explicit guidance on defining, assessing and measuring cultural competence, social workers may struggle to provide effective support, leading to disparities in care. Addressing these challenges requires a concerted effort from policymakers, researchers, and community stakeholders to create a more inclusive and equitable healthcare system.

This lack of knowledge, as well as an inability to ‘grasp’ and connect deeper conceptual knowledge around ACE with dementia, can also mean that practitioners may be unable to identify specific training needs that could help them navigate the complexities of ethnicity and race. There is a need for social workers to reflect on their own biases and the impact of their identities on their practice. This self-reflection can lead to personal and professional growth and a deeper understanding of how race and racism influence social work interactions. By fostering a culture of introspection, the profession can work towards dismantling internalized biases and promoting equity.

Additionally, the findings in this study suggest that participants demonstrated knowledge around processes, policies and some social work theory. However, in the context of supporting ACE with dementia, only a few participants were able to move from ‘perception’ through deep conceptual engagement to demonstrate ‘understanding’ of race, ethnicity and dementia. Those participants who were able to move from perception to understanding did so amidst a blame culture and uncertainty of getting it wrong.

A lack of definition and consensus on how understanding and perception can be interpreted, studied and applied in research has resulted in poor measurement of the epistemological and ontological value of these concepts in relation to the wider social work profession, specifically, social work education. Definitive engagement with understanding and perception as useful concepts for social work research and practice has the potential to help practitioners recognize and correctly interpret cultural signals, thereby improving their overall understanding in intercultural contexts.

A return to community social work

To be effective, social workers must be knowledgeable of the different communities they work in and with, the external and internal factors impacting cultural norms and beliefs, socio-economic factors, history, and overall needs of individuals (Delgado, 1999). Whilst the number of participants was small, they had years of experience working in localities with the highest numbers of ACE in South Wales, yet most participants had not worked with or had personal experience of the AC community. Some participants expressed that I was the first person from an AC background that they had ever met or engaged with.

This may be an indication of how changes to community-based social work have limited social work presence in communities, particularly within Black populations in urban communities, as well as those in the rural localities of South Wales (Delgado, 1999). The social work profession is entrenched in the traditional social work practice within office settings, or home working, post-COVID-19, further limiting opportunities for community engagement. The social work profession must improve on educating and preparing social workers for community-based social work practice. Additionally, this study suggests that by developing and strengthening partnerships with AC communities, practitioners can enhance the relevance and effectiveness of social work education, social work practice and social work research (Williams and Parrott 2013).

Adopting an anti-racist praxis

The findings indicate that race, ethnicity and cultural diversity were often integrated into unexamined narratives of colour-blindness and treating everyone the same. This generic approach can dilute the focus on race issues, which could lead to social workers being less equipped to handle racial and ethnic diversity in practice. An anti-racist praxis that includes critical theorising recognises that racism is pervasive in society and social work also shares in this, historically and currently (Tedam and Cane, 2002; Williams and Graham, 2016). A focused anti-racist approach is required to address these persistent challenges. Adopting an anti-racist praxis can provide social workers with a pathway for reflecting on how ideologies such as multiculturalism and colour-blindness might mask structural inequalities by appearing to 'accept everyone' whilst at the same time, ignoring 'others'**.**

The findings also highlighted the tensions and contradictions of adopting an anti-racist praxis, particularly when practice was shaped by unchecked dyconscious racism, where practitioners held an uncritical acceptance of beliefs of ACE with dementia that appeared to justify inequality (King, 1991). Practitioners also faced the dual task of addressing racism while respecting cultural differences, which sometimes led to conflicting priorities and practices. This dynamic was further complicated by the historical and ongoing impact of racism on Black and minority ethnic communities in Wales, necessitating a nuanced approach to anti-racist practice. These tensions necessitate critical reflexivity and a reconsideration of the profession's claim to neutrality and the need for genuine engagement with anti-racist and decolonial discourses (Yan, 2008; Ye, 2022).

The findings identified the need for effective anti-racism education and training involving social workers, students and individuals with lived experiences and realities of racism. There is a need to revisit the social work agenda and promote active engagement of social workers with anti-racist practices within their organisations and communities. This includes advocating for policies that address systemic racism and implementing programs that support marginalized populations. Social work organisations must commit to addressing racial issues at an institutional level. This includes creating policies that prioritise diversity, equity, and inclusion within the workplace.

Interestingly, whilst there is no standalone or explicit anti-racist legislation in Wales, the IFSW (2014) and the SSWBA (2014), which are drawn upon for social care and social work training in Wales, do not explicitly include anti-racism or social justice as core principles. Conclusions drawn from my research suggest that an absence of such explicit frameworks in Welsh social work contributed to voyeuristic practice, where marginalised lives were observed and documented without meaningful intervention. Practitioners often neglected the broader socio-political context that contributed to the challenges faced by ACE with dementia. This oversight led to practices that inadvertently reinforced existing power dynamics and inequalities, rather than challenging and transforming them. This reflects a deviation from the core values of social work, which emphasize social justice and empowerment.

There was a lack of clarity on how the roles identified by participants (such as promoting social justice or deconstructing stereotypes) might transform their own practice or dismantle systemic barriers. Their understanding remained surface-level, limiting the potential for transformative change. Adopting an anti-racist praxis grounded in critical race theory, alongside an acknowledgement of the professions' complicity in systemic racism and commitment to active resistance, is essential for addressing systemic inequalities and fostering social justice. This approach not only aligns with the profession's ethical standards (Banks, 2020; Rogowski, 2021) but also enhances the effectiveness of interventions aimed at marginalized communities.

Further exploration of critical race theory, intersectionality theory and critical realism as useful for social work research

I advocate for more extensive application of critical race theory (CRT) and intersectionality theory in social work research. Future research should focus on deeper integration of these two theories into social work education, practice, and research. This integration has the potential to develop a deeper awareness of racial inequalities and the experiences of marginalized people. Future studies could delve deeper into how CRT and intersectionality theory can inform social work policy. Research into the usefulness of these theories in the development of a framework for understanding and addressing systemic racism in social work settings.

Despite its usefulness, I found it quite challenging to locate social work research examples to reference as guides for employing critical realism and ensuring methodological alignment. According to Craig and Bigby (2015), there is a need for further exploration of robust methodological approaches that align with critical realism and support researchers to effectively incorporate critical realist principles into social work research.

8.8. Dissemination

As a recipient of a PhD studentship from the Economic and Social Research Council (ESRC), I began thinking about the impact pathways for my research at the point of application for the studentship. In thinking about impact, I also considered the target audience by reflecting on who will benefit from my research and how this benefit will be realised (McKenna, 2021). I also reflected on the findings by (Gray et al., 2024) in their paper, *Shooting in the dark*, how I might be able to improve the relevance and accessibility of my research amidst where there is no evidence, where evidence challenges existing practice, or where the evidence base is still emerging. I acknowledge that the complexity of dementia care, the interconnected stigmas and the diverse needs of stakeholders can make it difficult to create a standardised approach to dissemination.

To meet these challenges, my thesis will be available via Cardiff University’s Open Access Portal and I will foster inclusive and respectful communication with my target audiences (Walter et al., 2024; McGovern, 2015). In line with the aims of my research, my target audience comprises social workers, academic institutions where social workers are trained, and organisations where social workers are employed. As my research developed, my perception of research impact developed into an acknowledgement that dissemination was not just about my findings but that every aspect of my research had a potential audience and there was an opportunity for knowledge exchange in this way of thinking.

Academic Seminars, Workshops and Conferences

In 2023, I engaged with several dementia care and dementia service stakeholders, such as dementia hubs across Wales, to disseminate emerging findings. As a team member of a research group at Cardiff University, the Migration, Ethnicity and Diversity (MEAD), I have presented my research methodology at one of our annual workshops in 2023. The audience comprised academics from across the social science and business schools, undergraduate and postgraduate students. I have presented early and final findings of my research at workshops for the Master's Social Work students at Cardiff University from 2023-2025.

In 2024, I presented my research to researchers and academics at a workshop at Cardiff University Centre for Adult Social Care Research (CARE). This was very insightful, provided excellent feedback and supported a knowledge exchange around the usefulness of critical realism and intersectionality theory for social work research. I also had the opportunity to present early and emerging findings to practitioners at a workshop organised by the Evidence Community for Social Care Wales.

In 2024 and 2025, I presented aspects of my research focusing on intersectionality and the usefulness of critical reflection in policy development at Public Health Wales conferences. The audience comprised policy makers from across the Welsh Government, Social Care Wales, Local Authorities and Local Health Boards.

In March 2025, I presented the findings of my research at the European Conference for Social Work Research in Munich. The audience comprised social work researchers, practitioners and social work educators. Following this, I have been invited by social work educators from the Open University to share my research with their Wellbeing, Education and Language Studies (WELS) faculty and at the University of Bedfordshire as part of their open day activities.

Community Engagement Events

As a member of the MEAD team at Cardiff University, I have participated in the joint dementia week public engagement workshops with Alzheimer's Society, 2023- 2025. At these workshops, I have presented on the role of social workers in supporting persons with dementia.

In 2023-2024, have presented to students and educators at Cardiff and the Vale College and King's College London on the role of educators to support an anti-racist agenda in education through decolonisation approaches and supporting Black aspiring researchers.

I have utilised opportunities at the UNISON Black Members Annual Conference 2024 and 2025 to present on the role of the trade union in supporting social workers to challenge racism across society and in their workplaces. I have linked this discussion with dementia awareness raising for Black workers and the role of the trade union in supporting organisations to become dementia friendly.

Sharing Findings with Social Work Participants

I aim to share the research findings with social work participants during lunchtime seminars. Given that participants worked at four different local authorities, I will aim to hold a lunchtime seminar at each site. At each site, once arrangements have been agreed by gatekeepers, I will hold an in-person or online/ hybrid lunchtime seminar. This will allow staff working from home or remotely to join in. Given that the number of participants from each site was low; to maintain participant anonymity, I will send invitations to participants directly but extend the invitation to all staff in adult services. Given that there was only one third sector participant, I will discuss with them the option of having a seminar with their relevant staff members and possibly extend the invitation to their partner organisations, who also provide similar dementia services.

8.9. Final thoughts

As I reflect on the challenges I navigated in completing this thesis, the biggest challenge for me was the ongoing engagement with race and ethnicity. Whilst I deal with these identities every day in various contexts of my daily life, the emotional labour of engaging with them academically made me feel quite vulnerable at times. My preparation during the recruitment and interview stages involved a hypervigilance that I was not coming over too ‘Black’. I was constantly aware that my positionalities of African Caribbean, Immigrant, Black woman, were more prevalent than my other positionalities, such as qualified social worker, researcher.

At times, I felt disappointed that the profession I had placed on a pedestal as the holders of justice appeared to be downtrodden, steeped in fear and engaged in a voyeuristic approach to racism, unable to challenge the very thing that was hurting me and people who shared the same race as me. There were moments of hope where some participants demonstrated a willingness to challenge the status quo and despite organisational bureaucracies, they were exercising agency in creative ways.

The key messages underpinning this thesis include the need to consider the wider context in which social work practice with ACE with dementia occurs and to acknowledge that the interconnections of race, ethnicity and dementia pose deep challenges for practitioners. These challenges are rooted in historical colonialist approaches to research and practice that ignored race and ethnicity or reduced race and ethnicity to ethnocultural differences. Social work has engaged with anti-racist praxis before and needs to revisit this, as racism has not gone away; instead, it is more sophisticated. Without an anti-racist praxis, the profession remains a revolving door that promotes cultural competence whilst simultaneously gripped with the fear of being labelled racist, where practitioners prefer not to have to ‘wrestle with race’ (Cane and Tedam, 2022). This fear and reluctance to engage with race and the associated challenges such as racism are not unique to social work practice but also acknowledged in fields associated with social work practice with dementia, such as nursing (Bell,2020); dementia health, and dementia policies and social care systems (Lasrado et al., 2021; Saltus, Duval and Vougioukalou 2021; Vickers, Craig and Atkin, 2013).

The thesis argues that the epistemology of social work is connected to the identity of the profession itself. This means that social workers’ understanding and perception of individuals and their needs are continuously shaped by complex structures, which produce or reinforce knowledge that directly impacts their practice and the effectiveness of their interventions. The conclusions drawn from this study resulted from an iterative exploration of the subject matter, reflecting the complexity of social work and act as a reminder of the need for a flexible approach to understanding practice. Understanding and perception of needs play a crucial role in social work practice, influencing how services are delivered and how practitioners engage with individuals. The concept of need is multifaceted, encompassing both objective and subjective dimensions, which can lead to varying interpretations and applications in social work settings. This complexity necessitates a nuanced approach to understanding needs in practice. The conclusions indicate that understanding is not a static outcome but a dynamic process that evolves through continuous inquiry and reflection.

'*The need for sustained scholarly analysis and knowledge building on issues of race/ethnicity (R/E) in social work research is as compelling as ever given the intensification of global racial inequalities, issues associated with the 'migrant crisis', the spread of populist racialised political discourse and the ongoing downward pressure of neo-liberal imperatives'*. (Williams, 2020, p. 1058).

Charlotte Williams, in her discussions of the current state of race and ethnicity in social work research made the above statement. In my study, I aimed to take up this call and make further contributions to the necessary re-evaluation of how race, ethnicity and racism are presented, discussed and analysed in social work research. My research seeks to stimulate discourse and encourage all professionals involved in social work to work collectively to address the pervasive presence of racism in society and in social work. Through my PhD study, I posit that if social work wishes to truly hold a claim of being a profession governed by social justice values, it must embrace an anti- racist mandate which acknowledges the existence and impact of prejudicial concepts such as race and ethnicity.

Social work policymakers and service providers in Wales need to develop and implement robust policies and structures that acknowledge the ways race and ethnicity can shape service development and practice with Black minority groups, such as ACE with dementia. These stakeholders must ensure such policies are underpinned by an anti-racist praxis and social justice and are purposed to challenge and eliminate the underlying drivers of disparities in social work service development and delivery in the context of dementia care. I believe in the subversive knowledge within social work and hold fast to the optimism that, although social work is part of the larger system, possessing a dual identity as a form of resistance whilst also being an upholder of power structures, it still has the potential to challenge and change that system. This makes it both a tool for empowerment and a mechanism that can perpetuate existing power dynamics.

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Glossary of terms

AC-African Caribbean
ACE-African Caribbean Elders
BAME- Black, Asian and Minority Ethnic
BME- Black and Minority Ethnic
CR-Critical Realism
CRT- Critical Race Theory
EHRC- Equality and Human Rights Commission
ESRC- Economic and Social Research Council
IASSW- International Association of Schools of Social Work
IFSW- International Federation of Social Workers
NASW- American National Association of Social Workers
RQ-Research Questions
UK-United Kingdom
UN- United Nations
US/USA- United States

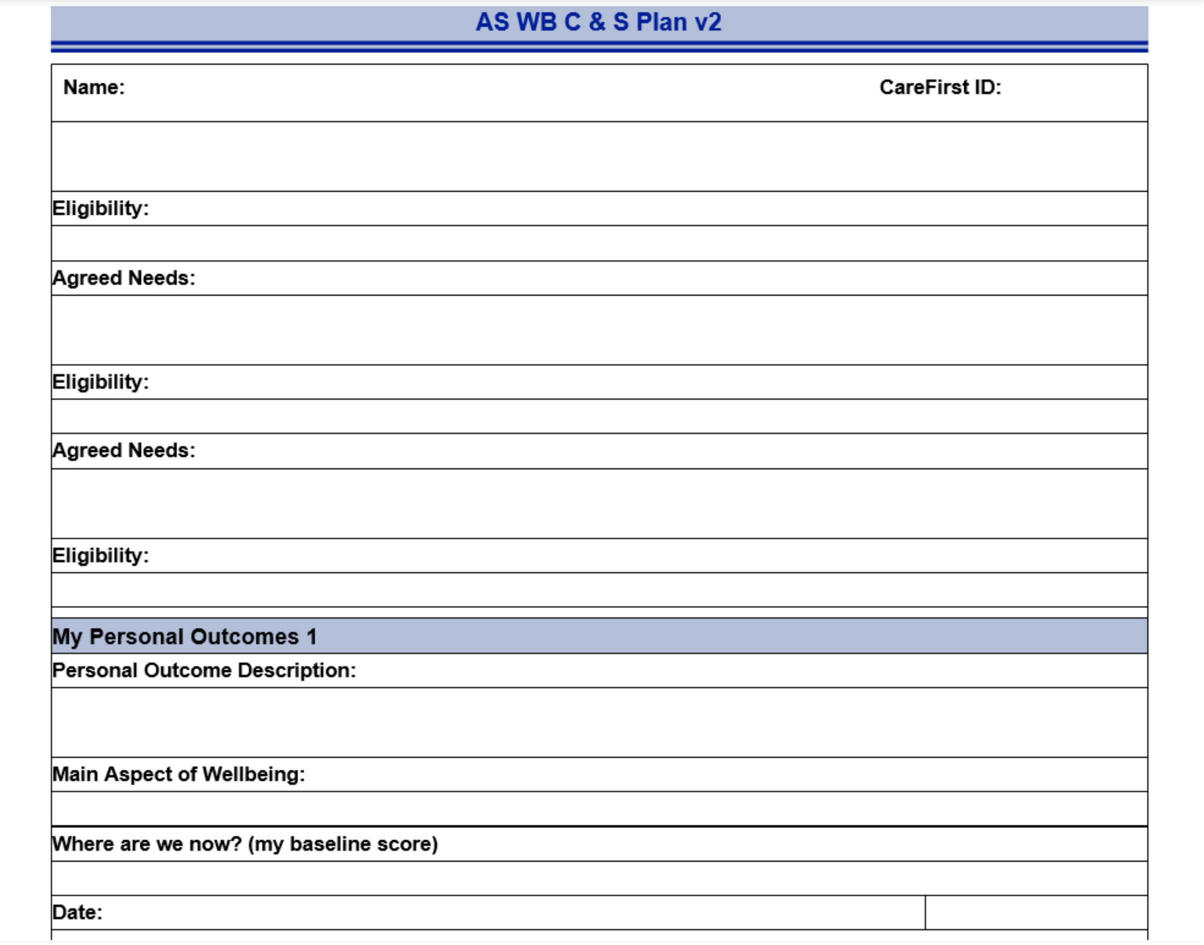
Linguistic devices

Black is written in Uppercase B to signify I am referring to people with a deep history, interconnected identities that are much more that than skin colour.

White-the ‘w’ in White has purposely been capitalised throughout the thesis (but not in quoted work, for example references from research using the term ‘whiteness’ remains in lowercase w.) ‘W’ acknowledges that I am making reference to people who also embody more than skin colour.

Appendices

Appendix A- Photo extract of blank care plan



AS WB C & S Plan v2

Name:	**CareFirst ID:**
Eligibility:	
Agreed Needs:	
Eligibility:	
Agreed Needs:	
Eligibility:	
My Personal Outcomes 1	
Personal Outcome Description:	
Main Aspect of Wellbeing:	
Where are we now? (my baseline score)	
Date:	

Appendix B- Care plan access request

Cardiff University

School of Social Sciences
Glamorgan Building
King Edward V11 Avenue
Cardiff
CF10 3WT
Email:
Hadaway-MorganK@cardiff.ac.uk
Tel:07909410512

INFORMATION SHEET TO THE LOCAL AUTHORITY'S RESEARCH GOVERNANCE BOARD /TRAINING AND LEARNING DEPARTMENT
FOR
CASEFILES ACCESS

RESEARCH PROJECT TITLE: Race, Ethnicity and Dementia: A qualitative study to explore the ways African Caribbean People's dementia care needs are perceived and understood by social workers in Wales.

I am submitting a request for access to social work casefiles- (social work assessment for care and support AND/OR care and support plans completed by social workers) for persons who identify as African Caribbean and have a diagnosis of dementia. Before you decide whether or not to approve my request, it is important for you to understand why the research is being undertaken and what it will involve. Please take some time to read the following information carefully and discuss it with others if you wish.

What is the purpose of this research project?

This study hopes to explore and understand from the perspective of social workers how understandings and perceptions of race, ethnicity and dementia are employed when providing dementia care services for persons from African Caribbean backgrounds with a diagnosis of dementia, living in Wales.

About the Researcher

My name is Kemba Hadaway-Morgan, and I am undertaking Doctoral Research at Cardiff University. This research will be used for me to complete my PhD. I would be very grateful if you would agree to take part in my research. If you do, I can assure you that all your information will be kept confidential. This research project has been reviewed and given ethical approval by the School of Social Science School Research Ethics Committee, Cardiff University, Reference number (XXXXX).

Why have I approached the Research and Governance Team (RGB) OR Training and Learning Department (TLD)?

You have been approached because you provide research governance to your organisation and can make decisions on sharing data such as Social Work Records. My research aims to present social workers' perspectives and understandings around race and ethnicity in the context of dementia care for African Caribbean people. As such, I am interested in exploring the way social workers record and write about race and ethnicity and dementia and how such written records are interpreted (service provision).

Additionally, I believe that my research meets the public interest qualifier as I am conducting research into a field (social work with African Caribbean people with dementia) where very little is known and as such having access to social care records (casefiles) is in the public interest. Cardiff University is a reputable university, and I have been funded by the ESRC with the expectation that my research benefits the wider public, not just academia.

What are the inclusion and exclusion criteria for the casefiles I wish to access and review?

Inclusion-
Must be clearly recorded on casefile that the individual identifies as African Caribbean.
Individual must have a diagnosis of dementia.

Case file must be completed/ has been completed by a qualified, registered social worker.

Given the expected low number of casefiles, there will be no time restriction on casefile recording. However, due to the data collection end date of September 2023, I would not accept any casefiles after this date.

Exclusion-
Casefiles where it is not clear if the person the person identifies/identified as African Caribbean, for e.g.: BAME/BME.

Casefiles that were completed by NHS staff or other non-qualified social care staff who may be/have been supporting persons with dementia.

Casefiles where consent criteria have not been met under the local authorities' research governance guidelines. For e.g.: a practitioner obtaining consent to share a casefile directly from the service user, without referral to the local authorities' research governance team.

Confidentiality and Data Management?

I am aware that the person's whose casefiles I may get access to, may not have mental capacity under the Mental Capacity Act 2005, therefore, I expect that as the data source, the local authorities will only provide me with casefiles where consent requirements meet their research governance guidelines and that they would have sought consent from service users or their relative, power or attorney or relevant person to share anonymised casefiles with me for the purpose of the research.

The expectation is that the local authority (as the data source of the casefiles) will anonymise the casefiles before sharing them with me. I will further anonymise any identifiable or sensitive data. Due to the research focusing on African Caribbean people with dementia, race and ethnicity and dementia diagnosis will not be removed from the data analysis.

The LA would be responsible for ensuring anonymity and all readily identifiable features of service users are removed, **before** allowing me access to the casefiles. Additionally, the local authority would be responsible for obtaining relevant permissions from service users to share their care and support plans.

I will provide the local authority with participant information sheets of my research to share/discuss with those persons or their representatives, whose casefiles will be shared with me. I will ensure that I use only those casefiles that have been identified as having met appropriate consent criteria under the local authorities' research governance guidelines.

Data would be retained for no less than 5 years or at least 2 years post-publication and then destroyed in accordance with GDPR. Direct identifiers such as your name, email, workplace, job role will be removed.

Although absolute anonymity cannot be guaranteed, pseudonyms will be used in place of real names and replacement terms, e.g.: X and X Local Authority, X and X Social Services Team. Your Job role will be replaced with a coded replacement, for example, code of (2) to mean senior practitioners, and a code of (1) to mean non senior practitioners.
A copy of the original data will be archived in accordance with the University's archiving policy together with a log of any replacements used.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection and GDPR legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

I expect that discussions with the LA will include agreement with LA as to the best process for accessing and reviewing casefiles. For e.g.: if accessing or reviewing online via LA's IT systems. I understand that I may require clearance in relation to current DBS (which I have) and possibly undergo LA's internal security clearance and data protection training and agreements. Other considerations for both myself and the LA would be appropriate location in terms of office/building and confidentiality agreement with any staff who may have to support me accessing this data. This would also mean that I would not have a hard copy of casefiles and therefore no consideration from me, in regard to data storage for the casefiles, would be required. However, this arrangement may cause issues such as having to record (written) information from the casefiles and this record would need to be stored in accordance with the University's data storage policy. This process may be time consuming and if I need access to casefiles at another time, I may have to undergo procedures of clearance again. This can be avoided if there is an agreement between myself and the LA in terms of time frame for accessing and reviewing casefiles.

Should the agreement (preferably) be via secured (encrypted and password secure) zip file via email, I would be able to receive this data (anonymised casefiles, which meet research governance guidelines and appropriate consent from service user, where relevant) and store in on Cardiff University's One Drive.

How will I manage risks associated with accessing and reviewing social services' casefiles?

I am aware that local authorities and third sector organisations, seeking consent to allow me use of service users' casefiles, may inadvertedly cause distress to the individual or to their relatives, particularly, if that person has passed away. This will be discussed with gate keepers/ research governance managers to ensure that local authorities and third sector organisations are reminded of their responsibility.

I am aware that anonymizing or de-identifying the data may introduce bias or error by way of changing context or alter its interpretation. For e.g.: not identifying a casefile as the casefile of someone who is part of the Windrush generation. Although this is an important debate within my broader research, the data analysis is focused on the way the social work practitioner recorded and acted upon the recording within the casefile, therefore 'Windrush identity' is not required for data analysis.

Given the small population of African Caribbean people in South Wales, pseudonyms and gender neutral pronouns will be used to ensure easily identifiable features are not presented in the data analysis. Through ongoing supervision, I will ensure that casefile analysis maintains research integrity.

What will happen to the results of the research project?

It is my intention to publish the results of this research project in academic journals and present findings at conferences and share the findings with participants, the Local Authority and third sector organisations that work with African Caribbean people with dementia. Participants will not be identified in any report, publication, or presentation. The findings/data analysis will also be presented in an aggregate and summarized format rather than on an individual basis. This will reduce the likelihood of a service user, whose casefile was used, being identified.

What if there is a problem?

If you have any questions or concerns, please feel free to contact me on Hadaway-MorganK @cardiff.ac.uk or on the mobile number at the top of this page. If you are unhappy about any aspect of the study, have any concerns or wish to make a formal complaint, you may contact my university supervisors, Dr Daniel Burrows, School of Social Sciences (SOCSI), Cardiff University, Glamorgan Building King Edward VII Avenue, Cardiff. CF10 3WT. Email: burrowsdr1@cardiff.ac.uk Telephone: 029 2087 5501 or Prof Sin Yi Cheung School of Social Sciences (SOCSI), Cardiff University, Glamorgan Building King Edward VII Avenue, Cardiff. CF10 3WT. Email: cheungSY@cardiff.ac.uk Telephone: +44 (0)29 2087 5179.

Thank you for considering my request. Please contact myself and/or my supervisors on the contact details included to arrange a meeting at your convenience.

Appendix C- NVIVO Codebook Sample for this Study

Name	Description	Files	References
Approaches to dementia service provision used by social workers with ACE w D		14	230
Barriers	What actions, activities, structures prevent social workers from working well with ACE w D	14	106
Building trust	The role of trust in working with ACE w D and ways in which social workers/social work can build trust with this community	8	37
Expectations	The expectations social workers have from families in the context of dementia support for a relative	12	70
Family	What expectations do social workers have of family/relatives when providing dementia services	11	22
Organisations, universities and local authorities and health boards	What expectations do social workers have of these organisations in the provision of dementia services	13	44
Self	What expectations do social workers place on themselves when providing dementia services	9	23
Society	What expectations do social workers have of society in the provision of dementia services	7	21
Generic approaches to dementia service provision	These are the standard, general approaches to dementia service provision used by practitioners, without special attention to any specific group.	6	16
Cultural Penalty	Situations where participants highlight how the system in which they work disregards cultural backgrounds as a rationale for certain attitudes, beliefs and behaviours of service users and instead 'penalises' service users through placement, medication or sectioning	3	29
Factors that influence social workers' human agency	What are the factors that influence how social workers perceive themselves, their lived experiences and how these might shape their sense of agency	13	68

Name	Description	Files	References
Confidence as a key factor in utilising human agency	How does confidence or lack of confidence affect social workers when working with ethnic minority groups	6	16
Knowledge development	How has knowledge development influenced social worker's ability to engage with their own human agency when working with ethnic minority groups	12	105
Social Justice Equality	Participants expression of how a sense of or an awareness of social justice, equality or anti racism influence their work with ACE/ethnic minority persons with dementia	3	15
Job Roles	The complex, multidisciplinary approaches to social work. Also presents the various pathways ACE w D may come into services	10	39

Appendix D- Participant consent form

Participant Consent Form

Group Interview for Senior Social Workers/Senior Social Work Practitioners

Following individual, one-to-one interviews with the researcher, those holding the title Senior Social Work Practitioner/ Senior Social Worker will be invited to participate in a group interview, comprising **only** Senior Practitioners.

Please read the statements below. If you are happy **with all of the statements**, please copy and paste them into an email and send it to me at **Hadaway-MorganK@cardiff.ac.uk**. This will be considered to constitute giving your consent to participate in the study.

If you have any questions about the research or the statements below, please do not hesitate to contact me.

I confirm that I have read and understand the information sheet for the study **Race, Ethnicity and Dementia: A qualitative study to explore the ways African Caribbean People's dementia care needs are perceived and understood by social workers in Wales.**

1. I have had the opportunity to consider the information, via the participant information sheet, to ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences or penalty.
3. I understand that if I withdraw after the cut off point as stated in the participant information sheet, my interview data will remain as part of the analysis of this study.
4. I understand what will happen to my data.
5. I give the researcher permission to interview me and that my interview will be recorded and transcribed.
6. I give permission for the researcher **to quote me directly using a pseudonym.**
7. I give permission for the researcher to re-contact me to clarify information.
8. I agree for anonymised research data collected in this study to be used in other research studies.
9. I accept the shared responsibility for maintaining confidentiality of the information shared in the Group Interview.
10. I am happy to take part in the research.

I confirm that I am a Senior Social Work Practitioner and **consent/do not consent** to participation in the Group Interview.

Signed---

Date---

Appendix E Social Worker Interview Schedule Version 2

1. Can you tell me what a typical day looks like in terms of some of the tasks you undertake as a social worker working with persons who have dementia?
2. In your day to day work with persons who have dementia, do you see persons from a variety of backgrounds? If yes, can you tell me about some of the differences you see in terms of background. If no, can you tell me about the similarities that you observe amongst the persons you work with?
3. What do you think is the biggest challenge to working with dementia?
4. Can you tell me about a case (anonymously) that you found challenging and how you overcame those challenges?
5. Have you ever worked with someone from the African Caribbean community who had/has dementia? If yes, what were some of the issues you remember about the case? If you have not worked directly with someone from this community, have you had any other encounters with the African Caribbean community- these may not necessarily be work related.
6. When you worked with that individual from the AC community who had dementia, did you encounter similar or different challenges to work you have done with someone from a White British background with dementia? If yes, can you tell me what some of those similarities and difference were/are?
7. What support did you have to overcome those challenges?
8. Where social workers have answered no to ques 5- I know you said you have not previously worked with someone from the African Caribbean community with dementia, but thinking about working with someone from a White British background who has dementia, in terms of challenges, what do you think some of the similarities and differences might be?
9. What support would you need to help you overcome those challenges?
10. How easy or difficult is it for you to discuss race and ethnicity in a professional setting, for example if you felt that it mattered during a residential placement? What issues make/would make doing so easy or difficult?
11. Can you share your experience of any formal training on working with diverse populations that you may have had? This can be pre and post qualifying. What were some of the key learning points from that training?
12. If you did not have any formal training on working with diverse populations, can you share some of your experiences or encounters or informal learning that helped your understanding of the dementia care needs of persons from diverse populations?
13. What sort of steps can social workers take to try and overcome cultural barriers within dementia care?

Appendix F- Ethics approval

SOCSI - Ethics Office

To:Kemba Hadaway-Morgan

Wed 2023-05-24-11:34 AM

Dear Kemba Hadaway-Morgan,

Research project title: Race, Ethnicity and Dementia: A qualitative study to explore the ways African Caribbean People's dementia care needs are perceived and understood by social workers in Wales.
SREC reference: 264

The School of Social Science Research Ethics Committee reviewed the above application on the .

Ethical Opinion

The Committee gave a favourable ethical opinion on the basis described in the application form, protocol and supporting documentation.

Supporting Documents Received

Document Title, Date and Version Number

- Casefiles Information Sheet 21.7.22 version1.docx
- Group Interview Consent 21.7.22 version1.docx
- Interview schedule Version 2.docx
- Kemba ethics - Version 3.0 (TS) [11321]. docxlatest.docx
- Kemba ethics - Version 3.1 (TS)11321.docxlatest DB [13240].docx

- Kemba PhD Ethics Application updated version 4.0 DB_SYC [19960].docx
- Kemba PhD Ethics Application updated version 4.1 DB signed.docx
- Participant Consent Form-Voluntary Organisation.docx
- Participant Information Sheet 21.7.22 version2.docx
- PhD Group Interview Schedule Vignettes Version 2.docx
- PhD online recruitment participant information sheet.docx
- PhD Participant Information Sheet version 2.docx
- PhD Research Participant Information Sheet 21.7.22 version 3.docx
- Programme Manager Participant Consent Form.docx
- Social media participant recruitment consent form for social workers.docx
- Social Worker Consent Form 21.7.222 version1.docx
- Social Worker Consent Form 21.7.222 version2.docx
- Social Worker Consent Form version3.docx
- Third Sector Voluntary Organisations Participant Information Sheet.docx
- Web capture_7-12-2021_16852_learningcentral.cf.ac.uk.jpeg

Please ensure that you have uploaded all final versions of your research tools, information sheets and consent forms, if not already done so, before starting your data collection. When uploading documents, please ensure it's saved by name, date and version number.

Appendix G- Participant Consent Form-Voluntary Organisation

Participant Consent Form-Voluntary Organisation

One-to-One Interview

Please read the statements below. If you are happy **with all of the statements**, please copy and paste them into an email and send it to me at **Hadaway-MorganK@cardiff.ac.uk**. This will be considered to constitute giving your consent to participate in the study.

If you have any questions about the research or the statements below, please do not hesitate to contact me.

1. I confirm that I have read and understand the information sheet for the study **Race, Ethnicity and Dementia: A qualitative study to explore the ways African Caribbean People's dementia care needs are perceived and understood by social workers in Wales.**
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw **at any time**, without giving any reason, and without any adverse consequences or penalty.
4. I understand that if I withdraw after my interview data has been collected, **past the deadline stipulated in the information sheet**, this data will remain as part of the analysis of this study.
5. I understand what will happen to my data.
6. I give the researcher permission to **interview me and that my interview will be recorded and transcribed.**
7. I give permission for the researcher **to quote me directly using a pseudonym.**
8. I give permission for the researcher to re-contact me to clarify information.
9. I agree for anonymised research data collected in this study to be used in other research studies.
10. I am happy to take part in the research.
11. I confirm that I have checked with my employer regards any permissions that I may need to participate in this research in my own time as a professional.

I confirm that I work for a voluntary third sector organisations within the South Wales, and I work directly with ethnic minority communities who have dementia and within my role I have responsibility for planning and coordinating dementia services, (information, advice or support-advocacy) and **consent/do not consent** to participation in the Interview.

Signed---

Date---

Appendix H- Group Interview Schedule Senior Social Workers

Group Interview Schedule

Senior Social Workers

Vignette 1.

Mr Leroy is an 82-year-old man who was born in Jamaica. He came to the UK in the 1950s with his wife and settled in Cardiff. The couple went on to have three children. When his wife passed away, Mr Leroy went to live with one of his daughters. Mr Leroy has a diagnosis of dementia. Following a fall at home, his daughter contacted social services expressing that she was struggling to safely care for her dad.

Questions for discussion

1. Thinking about your current roles as seniors, how well are social work teams equipped to deal with Leroy’s needs?
2. What would you hope to see discussed in the social worker’s assessment of needs and addressed in the care plan?
3. What sort of issues might social workers need to discuss with you during supervision, when dealing with Leroy’s case?

Group Interview Schedule

Senior Social Workers

Vignette 2.

You have been asked to lead on a Multi-disciplinary Team meeting (MDT) regarding an 80-year-old lady, Mildred. Mildred spent most of her life in Brixton in London after coming to the UK to work as a nurse in her early 20s. Mildred was born in Trinidad and Tobago. Mildred also has a diagnosis of Vascular dementia. Following the recent passing of her husband, Mildred moved to Newport to stay with her daughter. However, Mildred has told her daughter that she would like to go back to Brixton.

Mildred’s daughter is worried about her living on her own and discussed this with Mildred, who is happy to have support in her home. Your colleagues on the MDT are suggesting a long-term residential placement for Mildred in Newport.

1. As seniors, can you tell me how your role as a social worker impacts the decisions of an MDT when looking at dementia care planning?

2. Can you share your experience of MDT care planning where the individual with dementia comes from a background that is not White British? What would you say were the similarities and differences in terms of issues raised?

3. If you do not have any experience of this can you share what differences and similarities you might expect an MDT to discuss when care planning for someone with dementia, who was not White British?

4. What has your experience been when part of an MDT responsible for dementia care planning for someone from the African Caribbean community who has dementia? Can you share any similarities and differences that were raised compared with White British persons with dementia and other non-white British persons with dementia?

5. If you do not have any experience of this can you share what differences and similarities you might expect an MDT to discuss when care planning for someone with dementia, who was African Caribbean?
6. What challenges or opportunities have you encountered or might encounter in your role as a social worker on an MDT responsible for dementia care planning for an African Caribbean person?

Appendix I- participant information sheet online recruitment

Cardiff University
School of Social Sciences
Glamorgan Building
King Edward V11 Avenue
Cardiff
CF10 3WT
Email:
Hadaway-MorganK@cardiff.ac.uk
Tel:07909410512

PARTICIPANT INFORMATION SHEET

RESEARCH PROJECT TITLE: Race, Ethnicity and Dementia: A qualitative study to explore the ways African Caribbean People's dementia care needs are perceived and understood by social workers in Wales.

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Thank you for reading this.

What is the purpose of this research project?

This study hopes to explore and understand from the perspective of social workers how understandings and perceptions of race, ethnicity and dementia are employed when providing dementia care services for persons from African Caribbean backgrounds with a diagnosis of dementia, living in Wales.

About the Researcher

My name is Kemba Hadaway-Morgan, and I am undertaking Doctoral Research at Cardiff University. This research will be used for me to complete my PhD. I would be very grateful if you would agree to take part in my research. If you do, I can assure you that all your information will be kept confidential. This research project has been reviewed and given ethical approval by the School of Social Science School Research Ethics Committee, Cardiff University, Reference number (264).

Why have I been invited to take part?

You have been invited because you are a qualified, registered social worker, undertaking social work tasks with older persons, some of whom may have a diagnosis of dementia and identify as African Caribbean.

Do I have to take part?

No, your participation in this research project is entirely voluntary and it is up to you to decide whether to take part. If you decide to take part, I will discuss the research project with you [and ask you to sign a consent form]. If you decide not to take part, you do not have to explain your reasons and it will not affect your legal rights. [If You are a Cardiff University student, please be assured that the University maintains that involvement in this research project will have no effect on your education or progression through a degree course].

You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing the consent form. However, there will be a cut-off point of up to two months after the final interview has been conducted, at which point, you may express your wish to withdraw from the research and have the data collected from you withdrawn. If, however, you withdraw after this cut-off point, your interview data will remain as part of the analysis of this study.

What will taking part involve?

I will ask qualified, registered social workers, (Social Care Wales Registration required) to participate in a One-to-One Interview with me. This interview is expected to last up to one and a half hours. Due to current working restrictions in some organisations, interviews will take place via an online/virtual platform (Microsoft Teams) and interviews will be recorded to facilitate transcription. Only voice data will be transcribed and used in analysis, this means that you can have your camera off during the virtual interview, if you prefer. Although only voice data is being transcribed, if your camera is on during the interview, video footage will be captured, this will be recorded and stored securely according to the university's data storage policy as voice and video footage cannot be separated.

If you prefer, in line with your organisations working guidelines, a face to face interview can also be conducted in an agreed location. This can be a private office in your organisation or at Cardiff University. The interview will be recorded by Dictaphone and manually transcribed by me. If there is a question that you feel uncomfortable you can decline to answer that question.

As a social worker, I will ask you to participate in a One-to-One Interview. Due to current working restrictions in some organisations, interviews will take place via an online/virtual platform and interviews will be recorded to facilitate transcription. Only voice data will be transcribed and used in analysis, this means that you can have your camera off during the virtual group interview, if you prefer. Although only voice data is being transcribed, if your camera is on during the interview, video footage will be captured, this will be recorded and stored securely according to the university's data storage policy as voice and video footage cannot be separated.

All of the research will be done by me, and I will only discuss it with the people supervising me at Cardiff University. This will mainly be my two supervisors, Dr Daniel Burrows, and Prof Sin Yi Cheung. If you agree to take part in this study, you, and anyone you talk to me about will be given a false name to ensure anonymity and confidentiality. All interviews will be recorded and stored on Cardiff University's secure one drive in accordance with Cardiff University data protection rules and in accordance with the requirements of GDPR.

What are the possible benefits of taking part?

I am hoping that this study will tell us more about the skills and knowledge that social workers who may undertake or have undertaken social work tasks with persons who identify as African Caribbean. This can potentially influence social work education prior to qualifying and influence continuous professional development for social work practitioners as well as potentially improve social work with African Caribbean People with dementia and their carers.

What are the possible risks of taking part?

During the interviews, you may discuss or share something with me that upon reflection may cause you to feel upset or question your practice. If this is the case, please inform me during the debrief session, following the interviews and speak to your supervisor during supervision. As a qualified social worker, I am aware of the Code of Practice for social work and Safeguarding policies and as such, if I am given information that potentially indicates an issue of concern, or you disclose practice I consider unethical or harmful I am obligated to report this concern to the manager.

Whilst professionals can engage in research in their own time (outside of working hours) it is your responsibility to check with your employer regards any permissions that you may need to participate in this research in your own time as a professional.

There is the potential that we may be exposed to prolonged screen time, and this can have potential adverse impact to health. Interviews will be conducted in keeping with Health and Safety Screen time policies.

Confidentiality and your Personal Data?

Data (actual interview recordings, not just transcripts) would be retained for no less than 5 years or at least 2 years post-publication and then destroyed in accordance with GDPR. Direct identifiers such as your name, email, workplace, job role will be removed.

Although absolute anonymity cannot be guaranteed, pseudonyms will be used in place of real names and replacement terms, eg: X and X Local Authority, X and X Social Services Team. Your Job role will be replaced with a coded replacement, for example, code of (2) to mean senior practitioners, and a code of (1) to mean non senior practitioners.
A copy of the original data will be archived in accordance with the University's archiving policy together with a log of any replacements used.
In the case of video recordings and voice recordings, these will also be archived in accordance with the University's archiving policy. If you do not consent to the archiving and or sharing of video recording, you have the option of a recorded voice only interview.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection and GDPR legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

What will happen to the results of the research project?

It is my intention to publish the results of this research project in academic journals and present findings at conferences and share the findings with participants, the Local Authority and third sector organisations that work with African Caribbean people with dementia. Participants will not be identified in any report, publication, or presentation.

What if there is a problem?

If you have any questions or concerns, please feel free to contact me on Hadaway-MorganK @cardiff.ac.uk or on the mobile number at the top of this page. If you are unhappy about any aspect of the study, have any concerns or wish to make a formal complaint, you may contact my university supervisors, Dr Daniel Burrows, School of Social Sciences (SOCSI), Cardiff University, Glamorgan Building King Edward VII Avenue, Cardiff. CF10 3WT. Email: burrowsdr1@cardiff.ac.uk Telephone: 029 2087 5501 or Prof Sin Yi Cheung School of Social Sciences (SOCSI), Cardiff University, Glamorgan Building King Edward VII Avenue, Cardiff. CF10 3WT. Email: cheungSY@cardiff.ac.uk Telephone: +44 (0)29 2087 5179.

Thank you for considering to take part in this research project. If you decide to participate, you will be given a copy of the Participant Information Sheet and a signed consent form to keep for your records.

Appendix J- Participant information sheet

Cardiff University
School of Social Sciences
Glamorgan Building
King Edward V11 Avenue
Cardiff
CF10 3WT
Email:
Hadaway-MorganK@cardiff.ac.uk
Tel:07909410512

PARTICIPANT INFORMATION SHEET

RESEARCH PROJECT TITLE: Race, Ethnicity and Dementia: A qualitative study to explore the ways African Caribbean People's dementia care needs are perceived and understood by social workers in Wales.

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Thank you for reading this.

What is the purpose of this research project?

This study hopes to explore and understand from the perspective of social workers how understandings and perceptions of race, ethnicity and dementia are employed when providing dementia care services for persons from African Caribbean backgrounds with a diagnosis of dementia, living in Wales.

About the Researcher

My name is Kemba Hadaway-Morgan, and I am undertaking Doctoral Research at Cardiff University. This research will be used for me to complete my PhD. I would be very grateful if you would agree to take part in my research. If you do, I can assure you that all your information will be kept confidential. This research project has been reviewed and given ethical approval by the School of Social Science School Research Ethics Committee, Cardiff University, Reference number (264).

Why have I been invited to take part?

You have been invited because you are a qualified, registered social worker, undertaking social work tasks with older persons, some of whom may have a diagnosis of dementia and identify as African Caribbean.

Do I have to take part?

No, your participation in this research project is entirely voluntary and it is up to you to decide whether to take part. If you decide to take part, I will discuss the research project with you [and ask you to sign a consent form]. If you decide not to take part, you do not have to explain your reasons and it will not affect your legal rights. [If You are a Cardiff University student, please be assured that the University maintains that involvement in this research project will have no effect on your education or progression through a degree course].

You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing the consent form. However, there will be a cut-off point of up to two months after the final interview has been conducted, at which point, you may express your wish to withdraw from the research and have the data collected from you withdrawn. If, however, you withdraw after this cut-off point, your interview data will remain as part of the analysis of this study.

What will taking part involve?

I will ask qualified, registered social workers to participate in a One-to-One Interview with me. This interview is expected to last up to one and a half hours. Due to current working restrictions in some organisations, interviews will take place via an online/virtual platform (Microsoft Teams) and interviews will be recorded to facilitate transcription. Only voice data will be transcribed and used in analysis, this means that you can have your camera off during the virtual interview, if you prefer. Although only voice data is being transcribed, if your camera is on during the interview, video footage will be captured, this will be recorded and stored securely according to the university's data storage policy as voice and video footage cannot be separated.

If you prefer, in line with your organisations working guidelines, a face to face interview can also be conducted in an agreed location. This can be a private office in your organisation or at Cardiff University. The interview will be recorded by Dictaphone and manually transcribed by me. If there is a question that you feel uncomfortable you can decline to answer that question.

If you are a Senior Social Worker/ Senior Practitioner, I will ask you to participate in a Group Interview **AND** the One-to-One Interview.. The group interview is expected to last up to two hours. Due to current working restrictions in some organisations, interviews will take place via an online/virtual platform and interviews will be recorded to facilitate transcription. Only voice data will be transcribed and used in analysis, this means that you can have your camera off during the virtual group interview, if you prefer. Although only voice data is being transcribed, if your camera is on during the interview, video footage will be captured, this will be recorded and stored securely according to the university's data storage policy as voice and video footage cannot be separated.

All participants of the Group Interview will have to agree on a location, virtual (Microsoft Teams) or face to face (a secure, private office in your organisation or at Cardiff University).

All of the research will be done by me, and I will only discuss it with the people supervising me at Cardiff University. This will mainly be my two supervisors, Dr Daniel Burrows, and Prof Sin Yi Cheung. If you agree to take part in this study, you, and anyone you talk to me about will be given a false name to ensure anonymity and confidentiality. All interviews will be recorded and stored on Cardiff University's secure one drive in accordance with Cardiff University data protection rules and in accordance with the requirements of GDPR.

What are the possible benefits of taking part?

I am hoping that this study will tell us more about the skills and knowledge that social workers who may undertake or have undertaken social work tasks with persons who identify as African Caribbean. This can potentially influence social work education prior to qualifying and influence continuous professional development for social worker practitioners as well as potentially improve social work with African Caribbean People with dementia and their carers.

What are the possible risks of taking part?

During the interviews, you may discuss or share something with me that upon reflection may cause you to feel upset or question your practice. If this is the case, please inform me during the debrief session, following the interviews and speak to your supervisor during supervision. As a qualified social worker, I am aware of the Code of Practice for social work and Safeguarding policies and as such, if I am given information that potentially indicates an issue of concern, or you disclose practice I consider unethical or harmful I am obligated to report this concern to the manager.

There is the potential that we may be exposed to prolonged screen time, and this can have potential adverse impact to health. Interviews will be conducted in keeping with Health and Safety Screen time policies.

Whilst I will adhere to full anonymity and confidentiality, I cannot guarantee full anonymity and confidentiality for the Group Interview as any member in the Group may deliberately or accidentally report, share, or discuss information shared during the Group Interview, outside the group, therefore, I ask you to consent to shared responsibility for maintaining confidentiality and anonymity if you are participating in the Group Interview.

Confidentiality and your Personal Data?

Data (actual interview recordings, not just transcripts) would be retained for no less than 5 years or at least 2 years post-publication and then destroyed in accordance with GDPR. Direct identifiers such as your name, email, workplace, job role will be removed.
Although absolute anonymity cannot be guaranteed, pseudonyms will be used in place of real names and replacement terms, eg: X and X Local Authority, X and X Social Services Team. Your Job role will be replaced with a coded replacement, for example, code of (2) to mean senior practitioners, and a code of (1) to mean non senior practitioners.
A copy of the original data will be archived in accordance with the University's archiving policy together with a log of any replacements used.
In the case of video recordings and voice recordings, these will also be archived in accordance with the University's archiving policy. If you do not consent to the archiving and or sharing of video recording, you have the option of a recorded voice only interview.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection and GDPR legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

What will happen to the results of the research project?

It is my intention to publish the results of this research project in academic journals and present findings at conferences and share the findings with participants, the Local Authority and third sector organisations that work with African Caribbean people with dementia. Participants will not be identified in any report, publication, or presentation.

What if there is a problem?

If you have any questions or concerns, please feel free to contact me on Hadaway-MorganK @cardiff.ac.uk or on the mobile number at the top of this page. If you are unhappy about any aspect of the study, have any concerns or wish to make a formal complaint, you may contact my university supervisors, Dr Daniel Burrows, School of Social Sciences (SOCSI), Cardiff University, Glamorgan Building King Edward VII Avenue, Cardiff. CF10 3WT. Email: burrowsdr1@cardiff.ac.uk Telephone: 029 2087 5501 or Prof Sin Yi Cheung School of Social Sciences (SOCSI), Cardiff University, Glamorgan Building King Edward VII Avenue, Cardiff. CF10 3WT. Email: cheungSY@cardiff.ac.uk Telephone: +44 (0)29 2087 5179.

Thank you for considering to take part in this research project. If you decide to participate, you will be given a copy of the Participant Information Sheet and a signed consent form to keep for your records.

Appendix K- Programme Manager Participant Consent Form

Programme Manager Participant Consent Form

Group Interview

Please read the statements below. If you are happy **with all of the statements**, please copy and paste them into an email and send it to me at **Hadaway-MorganK@cardiff.ac.uk**. This will be considered to constitute giving your consent to participate in the study.

If you have any questions about the research or the statements below, please do not hesitate to contact me.

1. I confirm that I have read and understand the information sheet for the study **Race, Ethnicity and Dementia: A qualitative study to explore the ways African Caribbean People's dementia care needs are perceived and understood by social workers in Wales.**
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw **at any time**, without giving any reason, and without any adverse consequences or penalty.
4. I understand that if I withdraw after my interview data has been collected, **past the deadline stipulated in the information sheet**, this data will remain as part of the analysis of this study.
5. I understand what will happen to my data.
6. I give the researcher permission to **interview me and that my interview will be recorded and transcribed.**
7. I give permission for the researcher **to quote me directly using a pseudonym.**
8. I give permission for the researcher to re-contact me to clarify information.
9. I agree for anonymised research data collected in this study to be used in other research studies.
10. I am happy to take part in the research.

I confirm that I am a Programme Manager at the local authority within Adult Services and **consent/do not consent** to participation in the Group Interview.

Signed---

Date---

Appendix L- Social Media Recruitment Participant Consent Form

Social Media Recruitment Participant Consent Form

One-to-One Interview

Please read the statements below. If you are happy **with all of the statements**, please copy and paste them into an email and send it to me at **Hadaway-MorganK@cardiff.ac.uk**. This will be considered to constitute giving your consent to participate in the study.

If you have any questions about the research or the statements below, please do not hesitate to contact me.

1. I confirm that I have read and understand the information sheet for the study **Race, Ethnicity and Dementia: A qualitative study to explore the ways African Caribbean People's dementia care needs are perceived and understood by social workers in Wales.**
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw **at any time**, without giving any reason, and without any adverse consequences or penalty.
4. I understand that if I withdraw after my interview data has been collected, **past the deadline stipulated in the information sheet**, this data will remain as part of the analysis of this study.
5. I understand what will happen to my data.
6. I give the researcher permission to **interview me and that my interview will be recorded and transcribed.**
7. I give permission for the researcher **to quote me directly using a pseudonym.**
8. I give permission for the researcher to re-contact me to clarify information.
9. I agree for anonymised research data collected in this study to be used in other research studies.
10. I am happy to take part in the research.
11. I confirm that I have checked with my employer regards any permissions that I may need to participate in this research in my own time as a professional.

I confirm that I am a qualified, registered Social Worker and **consent/do not consent** to participation in the Interview.

Social Care Wales Registration---

Signed---

Date--

Appendix M- Participant Consent Form One-to-One Interview for Social Workers and Social Work Assistants

Participant Consent Form

One-to-One Interview for Social Workers and Social Work Assistants

Please read the statements below. If you are happy **with all of the statements**, please copy and paste them into an email and send it to me at **Hadaway-MorganK@cardiff.ac.uk**. This will be considered to constitute giving your consent to participate in the study.

If you have any questions about the research or the statements below, please do not hesitate to contact me.

1. I confirm that I have read and understand the information sheet for the study **Race, Ethnicity and Dementia: A qualitative study to explore the ways African Caribbean People's dementia care needs are perceived and understood by social workers in Wales.**
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw **at any time**, without giving any reason, and without any adverse consequences or penalty.
4. I understand that if I withdraw after my interview data has been collected, **past the deadline stipulated in the information sheet**, this data will remain as part of the analysis of this study.
5. I understand what will happen to my data.
6. I give the researcher permission to **interview me and that my interview will be recorded and transcribed.**
7. I give permission for the researcher **to quote me directly using a pseudonym.**
8. I give permission for the researcher to re-contact me to clarify information.
9. I agree for anonymised research data collected in this study to be used in other research studies.
10. I am happy to take part in the research.
11. I confirm that I have checked with my employer regards any permissions that I may need to participate in this research in my own time as a professional.

I confirm that I am a qualified, registered Senior Social Work Practitioner/Social Work Team Leader and **consent/do not consent** to participation in the Interview.

Signed---

Date--

I confirm that I work directly in an Adult Social Work Team and I am a Social Work Assistant/ qualified, registered, Social Worker and **consent/do not consent** to be interviewed.

Signed--

Date--

Appendix N- Third Sector Interview Schedule Version 2

Third Sector

Interview Schedule Version 2

1. Can you tell me what a typical day looks like in terms of some of the tasks you undertake/undertook within a third sector organisation that provided dementia support/information/advice?
2. In your day to day work do you provide dementia support for persons or other organisations, sectors?
3. What do you think is the biggest challenge a third sector organisation faces when working with dementia?
4. What was/is the mission/purpose of your organisation in terms of dementia care?
5. Does your organisation provide dementia support to persons from the African Caribbean community who had/has dementia? If yes, what were some of the issues you remember about the case? If your organisation does not, can you tell me if there are any other instances where your organisation might encounter the African Caribbean community- these may not necessarily be work related.
6. When your organisation worked with individuals from the AC community who had dementia, did you encounter similar or different challenges to work you have done with someone from a White British background with dementia? If yes, can you tell me what some of those similarities and difference were/are?
7. As an organisation what has been the key source of information and knowledge around dementia in the BAME community?
8. What are some of the barriers you encounter as an organisation in raising awareness of dementia within the BAME community? How have you/are you overcoming those barriers?
9. If the organisation delivers dementia training/cultural training- What are the training outcomes of the programmes offered by your organisations and who are the target audiences?
10. How easy or difficult is it for your organisation to discuss race and ethnicity in the context of dementia care/dementia service provision? What issues make/would make doing so easy or difficult?
11. Does your organisation work with social services? If yes, in what context? (referrals/signposting/ IAAA/ training). What impact do you think your work with social services can have on social work practice in the context of dementia care?
12. Based on your experience within the organisation, have you encountered stereotypes such as ‘Black communities are hard to reach/ Black communities look after their own/ one size fits all’? If yes, how has your organisation managed these?
13. What sort of steps can third sector organisations take to try and overcome cultural barriers within dementia care?