EXPERIENCES OF BLACK AND MINORITY ETHNIC PEOPLE LIVING WITH DEMENTIA IN RECEIPT OF DIRECT PAYMENTS

MARY NJOKI

Thesis submitted for the degree of Doctor of Philosophy

Faculty of Social Sciences University of Stirling

March 2022

DECLARATION

I declare that none of the work contained in this thesis has been submitted for any other degree at any other university. The contents herein have been written by Mary Njoki.

ACKNOWLEDGEMENTS

A huge thank you to all the people who have supported and encouraged me from the inception of this research, the application process and the whole research journey. Thank you, Dr Jane Robertson, who, in a brief encounter, paved the way for this path; I will be forever grateful for that and for continued support throughout the PhD journey.

To my three excellent supervisors: Dr Louise McCabe, Dr Fiona Sherwood-Johnson, and Dr Sian Lucas, thank you for all your guidance and SUPER-vision over the course of the project. All three of you have guided, supported, encouraged, motivated and challenged me throughout this mentally stimulating journey. You have always provided timely constructive feedback and allowed me to grow and develop as a researcher. Thank you for reading all my numerous ramblings and thoughts. I am grateful to Sian for stepping into the supervisory role in Fiona's absence and staying on, allowing me to have diverse expertise from three brilliant minds. The support and advice of all three supervisors throughout the research project have been invaluable.

A warm thank you to those who have been very supportive within the Faculty of Social Sciences Department, Prof Alison Bowes, Dr Kathryn Mackay and Dr Richard Simmons.

I want to thank my fellow cohort PhD students for their support. A big thank you to all my family, especially Mr Obado Obado, for believing in me and always encouraging me to achieve my goals. Thank you to my mum for all her love and support. I want to thank my friends, particularly my friend and sister Wahito Kangere, who has always been there without fail, listening and guiding me as I tried to conceptualise my thoughts into something meaningful. Thank you to Mary Thuo for always encouraging me to pursue my dreams and for her encouragement throughout the thesis. In addition, Claire Fottit, for the many PhD-related and well-being chatty walks and Norma Bain, for being very supportive towards the end of the race, gave me the boost I needed to finish.

Finally, I would like to thank all the participants, without whom this research would not have been possible. In particular, the people living with dementia; the willingness to share their stories and experiences so generously will forever be appreciated.

I dedicate this thesis to my grandfather and grandmother for all the life lessons the love and support they poured into me when they were still here.

I also dedicate it to all those people living with dementia all over the world and within my family. Also, to all those who work effortlessly to support them in improving their quality of life and reducing stigma towards dementia in society.

PREFACE

THE STORY I BRING TO MY PHD JOURNEY

My life experiences bring a unique perspective of skills, understandings and interests to my research area. Since childhood, engaging with older people has always been an area of interest. Having grown up in Kenya and moved to the UK as an adult, I started my career working as a health care assistant in residential and nursing homes for older people. While working there that I developed an interest in dementia. I observed that the staff had a limited understanding of dementia. This led to the needs of people with dementia rarely being met because staff misunderstood dementia care. Dementia training was not prioritised due to staff shortages despite having a high percentage of residents with the diagnosis.

Living in a collective society in Kenya that values elders for their wisdom and life experiences, I was brought up to respect them and prioritise their needs over my own. Therefore, my experience in the four care homes I worked in whilst in London challenged my core beliefs, values and prior learning. I found it challenging to adjust to this new way of treating older people. I would always try to do things differently, like offering more social support to the residents, especially those alone in their rooms and bedbound. Unfortunately, I was always criticised and informed that there was no time to waste; for example, sitting down to chat with residents was not considered part of our core caring responsibilities. I initiated talking and getting to know residents' interests and past stories of their lives as part of my work. I worked in a cat sanctuary during the weekends, where the contrast shocked me to the core. That was the last straw for me when I realised the cats were getting better care than that offered in the care homes I was working in. Even more baffling was that the salary at the cat sanctuary was higher than at the care home. As a new arrival in the UK, I assumed this was the value placed on older people in the UK. It felt like the residents had been locked away and forgotten and seen as a burden to society, a different way of looking after older people from my personal cultural experiences.

Having witnessed that practice, I decided to train as a social worker. Mistakenly, I thought as a social worker, I would be able to return to the care homes as an inspector and change the poor practice I had witnessed. My social work journey took me to adult care services, where I requested to be allocated mainly to people with dementia. As a path to increase my knowledge and awareness of dementia, I registered as the team's dementia ambassador with the Scottish Social Services Council, which entailed collating information on dementia from different

sources and attending conferences, then disseminating it to colleagues. In fact, it was during one of the European Alzheimer's conferences this PhD journey started.

I moved from the frontline social work team to Direct Payment (DP) team. This team specialised in offering DP advice to frontline staff, management, third party and DP recipients. I also worked as the link worker between the local authority and the Scottish Independent Living Fund, another form of a personal budget for people with higher needs. Working in this position, I noticed the very low uptake of DP for older people, especially those with dementia, and I started asking questions such as; 'what were the barriers? Was it DP management, capacity, awareness issues, or not valuing older people enough, as observed in the care homes?'

A case of a Black and Minority Ethnic (BME) older man living with an advanced dementia diagnosis was brought to my attention to advise what could be done. Every possible route to support this gentleman had been exhausted; Local Authority Commissioned Services were not working, and BME organisation were at capacity. His wife had been the primary carer but was unwell and at a breaking point. The gentleman's two adult children led busy lives with their own families and lived far away. Although he had spoken English all his life in the UK, this gentleman had reverted to his native language, 'Pashto', spoken by very few people in his community.

The family was offered a DP to recruit a Personal Assistant (PA) from the community, but six months later, they had not found anyone who spoke the language. I was allocated this case to support the practitioner in sourcing a solution. It was challenging because the wife had never learned English. The husband had learned English because he was the breadwinner while his wife stayed at home and cared for the children. Therefore, communication with a staff member, who did not speak his language, was challenging. Eventually, I advised that we request DP to employ a family member as a PA under exceptional circumstances. However, the daughter had a high-paying job and a busy life; therefore, it was not ideal to request her to reduce her working hours to take a minimum-wage job. The family also made it clear that a care home was not an option because it was against their culture, and they would not consider it. We agreed that the daughter is temporarily employed for a few hours, where language skills were critical as we sourced a long-term solution.

This case weighed heavily on me. I started wondering how many other BME people faced these challenges. I questioned if there were solutions for families in such situations. I wondered if we were asking the right questions. I also pondered what policymakers and service providers were doing to address BME people's unique challenges and what they were doing to improve access to services. I also wanted to explore if DP was a possible solution for

these challenges experienced by BME people with dementia in accessing culturally sensitive services. These questions and reflections are what led me onto this PhD journey. As a BME person and from my work experience, I felt that I was in a distinct position to engage in understanding BME people's stories who find themselves in marginalised spaces.

The culmination of my professional, voluntary work experiences working with BME communities, my personal experiences, my desire to improve services for older people, especially those living with dementia, and the fight for social justice informed my PhD research interests. Just as I 'wear many hats', so it is with the research area, considering the intersection of race and ethnicity, dementia and direct payments. I had witnessed the massive impact of budget cuts on care provision for those who use social care services. I wanted to understand the structural impact this was having on BME people with dementia after I witnessed the social-economic and deprivation BME people lived in.

Therefore, this thesis has provided me with personal fulfilment of producing work that could positively impact the BME people here in Scotland and, possibly further afield. It has been an honour researching something I am passionate about within a great faculty with an outstanding team.

ABSTRACT

Black and Minority Ethnic (BME) people with dementia have been shown to face various challenges when accessing health and social care services (Andrew, 2015; Moriarty, Sharif and Robinson, 2011; Ogliari et al., 2020; Wilson et al., 2020). The number of BME people with dementia in Scotland is increasing in line with the wider population. This research aimed to explore if Direct Payment (DP), one method of delivering support under the Social Care (Self Directed Support) (Scotland) Act 2013, is effective and culturally sensitive in meeting their needs.

Qualitative research methods were used based on interviews with 39 participants: four people with dementia, 10 carers, 12 practitioners and 13 stakeholders. Social constructionism provided a framework for understanding how their knowledge is shaped by the culture and context of society (Kukla, 2000; Prawat and Floden, 1994); narrative methodology was used to show how they construct meaning from their experiences.

The research findings revealed multi-faceted and intersecting structural, contextual, cultural and individual factors that make it challenging for BME people with dementia to access health and social care services. While BME people, in general, may face similar challenges with the wider population, they are further compounded by racism, discrimination, a lack of culturally appropriate services and language barriers, leading to increased marginalisation and isolation, which then intersect with dementia.

The SDS legislation appears to be progressive with good intentions. However, due to complex DP processes and limited funding, the extent to which DP offers personalised support to BME people with dementia is contextual; it was found to depend on individual needs, service availability and budget sufficiency. Whilst DP had a positive outcome for some BME people with dementia, extending this will require better working together by all involved.

This research has contributed and extended knowledge on exploring intersecting factors of race, gender, class, inequalities and dementia that affect BME people with dementia. It adds to the research on dementia using storytelling to collect data engagingly with BME people with dementia. The knowledge and insights gained will inform academic, practice, and policies on the needs of BME people with dementia on planning, delivery, and evaluation of DP for BME people.

TABLE OF CONTENTS

LIST OF TABLES:

Table 1, a- People with Dementia

Table 1, b- Carers

Table 1, c- Social Workers

Table 1, d- Stakeholders

CHAPTER ONE: INTRODUCTION TO THE THESIS

Background Context for Research

This research explores dementia, DP, and the experiences of BME people. The introduction is structured thematically to introduce the concepts and theories that recur across the literature relevant to the three distinct research areas. This chapter describes these three areas, starting with DP, dementia, and BME people's experiences. The research aims and objectives follow, and then a discussion on BME terminology before describing the thesis structure.

Dementia is an umbrella term for various conditions, with Alzheimer's disease, vascular dementia and Lewy body dementia as the most common, respectively (Alzheimer's Society, 2014). Dementia is a national priority in Scotland, as evidenced in Scotland's National Dementia Strategy first one was in 2009 and the third in 2017-2020 (Scottish Government, 2017a). The three main ambitions of the strategy were to raise awareness, facilitate the early investigation, diagnosis, and treatment, and improve services for people with dementia and their families. However, Greaves and Jolley (2010) argued that for the National Dementia Strategy to achieve its goals, the infrastructure of care and treatment of people with dementia is best informed and delivered by a collaborative model. They advocated a model that respects the knowledge of the person with dementia, the commitment of families, and better redirecting resources. The latest strategy builds on progress since 2009 in transforming services and improving outcomes for people with dementia and their families. It emphasises and recognises the need for flexible person-centred care that meets the needs of people with dementia (Scottish Government, 2017a).

Improving the services for people with dementia is important because dementia affects about 90,000 people in Scotland, and this number continues to rise (Scottish Government, 2021a). The number of BME people with dementia in Scotland is increasing in line with the general trend of people living longer and coming forward to be diagnosed. The estimated annual dementia diagnosis was approximately 20,000 by 2020, with roughly the same number of people dying with dementia each year (Health Scotland, 2021). Statistics highlight that in the UK, 3 per cent of people with dementia are from BME communities, about 25,000 people and the number is expected to double by 2026 due to an expected increase in older people in South Asian communities (Alzheimer's Society, 2019, a). Age is a major risk factor associated with developing dementia (Alzheimer's Society, 2021). Bothongo et al. (2022), in data from primary care medical records of a population of 1,016,277 from four inner East London boroughs collected between 2009 and 2018, found that both ethnicity and area-level deprivation were independently associated with dementia. They found that individuals of Black and South Asian ethnicity had a higher risk of dementia. However, Amele and

Katikireddi (2022) argued that research often under-represents people from BME groups and those that are socially disadvantaged, with studies in the UK focusing on affluent white individuals.

Accurate figures on the prevalence of BME people living with dementia are currently unavailable. Alzheimer Scotland (2013) had estimated there were 228 BME people with dementia living in Scotland. However, Alzheimer Scotland (2020) suggests lower numbers of BME population than those of the wider population due to fewer older BME people than the general population. However, aligning with the rest of the UK, dementia is predicted to rise relatively faster among BME communities than for the population as a whole (Alzheimer Scotland, 2021; Dodd et al., 2020; Ogliani et al., 2020; Wilson et al., 2020).

Pham et al. (2018) analysed health care records of 2,511,681 individuals aged 50–105 between 2007 and 20015. They found that Asian women were 18% less likely and Asian men 12% less likely to have a new dementia diagnosis than the white ethnic group. In comparison, black women were 25% more likely, and black men were 28% more likely to receive a new dementia diagnosis than the white ethnic group. Therefore, there is a variation in dementia prevalence among BME groups. However, this is English data and may differ in Scotland.

Data on the prevalence of dementia show variations by personal characteristics such as gender and ethnicity (Health Scotland, 2021). One of the suggested reasons prevalence is higher for the BME population in the higher incidents of chronic diseases and cardiovascular risk factors such as cholesterol, blood pressure, increased tobacco use, type 2 diabetes, obesity and stroke (Adelman et al., 2011; Botsford and Dening, 2015; Comegna, 2017). Another reason is that BME communities often face delays in dementia diagnosis and barriers to accessing services leading to worse outcomes than the wider population due to inequalities that affect their health. For example, research by Pham et al. (2018) analysed data from 2,511,681 people, including 66,083 who had a dementia diagnosis, from the Health Improvement Network primary care database between 2007 and 2015. They found that the rates of dementia diagnosis are higher among black African and black Caribbean groups compared to white and Asian groups in the UK. They found 25% higher dementia rates among black women than white women and 28% higher among black men than white men. Asian women and men were 18% and 12%, respectively, less likely than white women and men to have a dementia diagnosis. This highlights gender differences in how dementia affects the different BME groups. The researchers concluded that: there are inequalities in dementia care, or the BME communities were reluctant to seek services or name dementia where people are likely to experience stigma after disclosure.

In the recent Lancet Commission research, Livingston et al. (2020) have suggested adding three modifiable risk factors, excessive alcohol consumption, head injury and air pollution, which are likely to affect more people from low-income and middle-income countries. The previous 2017 Lancet Commission on dementia prevention had nine factors smoking, hypertension, obesity, depression, diabetes, lack of exercise, loneliness and isolation, hearing impairment and low level of education. These factors may have implications for BME people and public health policy decisions in Scotland. Livingston et al. (2020) assert that many of these risk factors cluster around inequalities, which occur particularly in BME groups and in vulnerable populations. Therefore, tackling these factors will involve health promotion and societal action to improve the situation and quality of life of BME people.

Extensive literature discussed in the next chapter highlights that many BME people have experienced racism and discrimination growing up in the UK. It is also argued that many BME people do not access health and social care services and are generally under-represented in dementia services (Andrew, 2015; Moriarty, Sharif, and Robinson, 2011; Ogliari et al., 2020; Wilson et al., 2020). They also often present to health services later in the illness than the wider population (Cooper et al., 2010; Dodd et al., 2020; Mukadam et al., 2011). There are multiple issues faced by BME people when accessing services; some are societal or political, others cultural and others personal factors.

The BME people who came to Britain in the 1950s and 1960s make up the ageing demographics (MECCOP, 2017). In addition, many BME older people were born outside the UK and, therefore, are growing old in a country with different cultures and customs from their own. They also face old age in a country where attitudes towards ageing differ from those in their country of origin. The UK Government is more aware of the impact of these changes in society and the rising health and social care costs in meeting the assessed needs of people with dementia. Thus, appropriate services are required to accommodate the predicted increase for BME people with dementia and their families to help improve their quality of life and access to health and social care services. There is limited research examining evidence of effective service delivery for BME people with dementia and the challenges they experience when seeking appropriate services. This research aims to fill some of those gaps.

DP is one method of delivery of self-directed support (SDS) under the Social Care (Self-Directed Support) (Scotland) Act 2013. SDS is the broad approach to personalisation which has been a major agenda in health and social care since DPs were initially introduced across the UK by the Community Care (Direct Payments) Act 1996. They aim to offer choice, control, autonomy and flexibility to the service users and their families (Harkes, Brown and Horsburgh, 2012; Scottish Government, 2014).

In Scotland, there have been several amendments to the Direct Payments Act. When the Community Care (Direct Payments) (Scotland) Regulations 2003 was introduced, it became a statutory duty for local authorities to offer DP to all those assessed to be eligible. It was amended in 2005, and a duty to offer DP was extended to all people over 65 who had been previously excluded. It was amended again in 2007, allowing the local authority to authorise the employment of close relatives to provide care to a family member under exceptional circumstances and if it is the best option. This is an area of interest in this research.

This qualitative research will approach the study from BME people's perspectives. This exploratory research project is underpinned by the social constructionist philosophy paradigm and uses interpretative narrative approaches to understand how meaning is constructed. It examines the experiences of BME people with dementia in receipt of DP and also explores some challenges, barriers, and benefits for BME people with dementia accessing DP.

Development of research questions

Aims and Objectives

As the literature will demonstrate, there is a gap in our understanding of the experiences of BME with dementia receiving DP, an underexplored topic in the Scottish context. Therefore, the main aim of this project is to critically interrogate if DP is an effective and culturally sensitive response to meeting the specific challenges currently faced by BME people with dementia, their carers, and families in Scotland. This research considers how people construct meaning in their narratives by exploring differing and subjective perspectives among people with dementia, carers, practitioners, and stakeholders. It is intended that the research findings will contribute to informing policymakers and practice in planning, delivery and evaluation of DP to BME people.

The project aimed that a narrative methodology would allow participants space to express their voice to provide valuable insights into how they experience, receive, and perceive personalised support.

This research aims to contribute new knowledge and move forward the current scholarly debates around the future of DP in relation to meeting the needs of BME people with dementia in Scotland.

To achieve these aims, this research will use qualitative research methods with a social constructionist, narrative/biographical approach to collect data that allows exploration of the participants' experiences. The narratives will then be analysed to gain insights and understand the individuals' lived experiences.

To achieve the identified aims, the following research questions were posed:

Questions

1.   What are the experiences of BME people with dementia in Scotland?

      a)   What are the specific challenges BME people with dementia and their families face?

2.   What is the potential for DP to provide personalised services for BME people with dementia?

      a)   What challenges do BME people with dementia, their families, and professionals experience when accessing DP?

      b)   What are the benefits of DP for BME people with dementia and their families?

3.   What are the perspectives and experiences of carers, practitioners, and stakeholders who support BME people with dementia in receipt of DP?

To study meaning-making processes, I use narrative as both a methodological and an interpretive approach. I interviewed 39 participants: people with dementia, carers, practitioners, and stakeholders. I analysed the data using thematic and narrative analysis. This is discussed further in chapters two and three, where I develop my social constructionism conceptual and theoretical approach.

Terminology

Black and Minority Ethnic (BME)

This thesis uses a term that has been regarded as problematic. Researchers have no consensus on the best term to use when describing people from minority groups; therefore, I will address this issue before progressing to the main thesis chapters. Many terms have been used to describe a non-white person or group, such as 'Ethnic Minorities', 'Racial Minorities', 'Racialised Minority', 'Visible Minorities, ' 'Ethnically Diverse Communities', 'Black and Minority Ethnic', 'Black Asian and Minority Ethnic', 'Minoritised other'. However, many of these terms have been criticised because they recognise some communities whilst ignoring others entirely, which does not allow for recognising and exploring ethnic and cultural complexities (Aspinall, 2002). For example, a survey published in November 2020 found that the term 'BAME' and 'BME' offended those it attempted to describe (MacInnes, 2020).

People identified as BME are diverse individuals from various geographical origins, races, ethnicity, and cultural backgrounds. There are many distinct differences within and between BME communities, including faith, diet, traditions and custom, and the construction of cognitive

impairment and mental health. Thus, referring to an 'Asian' community risks disregarding the profound differences in culture, religion, and language between people deemed to be from the same community. For example, Aspinall (2002) argues that official census categories ignore ethno-religious differences between South Asian groups, amongst other issues. Unambiguously attaching definitions to groups of people can lead to stereotypical systems of representation developing that could discriminate against those who do not fit into those definitions (Hall, Evans and Nixon, 2013).

This study uses the term BME to distinguish between black people or people from an ethnic minority living in a white majority country. I am aware that the term BME is debatable, emotive, sensitive, and sometimes controversial. Cree (2010) asserts that terms like BME/BAME are problematic and contested for their homogenising and depersonalising nature. It is seen as labelling a community or a group of people by using a blanket term to classify them, which then risks 'a blanket policy and practise response that does not consider diverse individual needs (Butt, 2006; 2).

I understand that there is not one homogenous BME community but many different communities requiring different approaches. Therefore, I use the term 'BME' to describe a group of people sharing similar experiences of racism and cultural differences and facing particular challenges in getting the support they need. As, Agyemang, Bhopal and Bruijnzeels (2005) argued, grouping minority people hide the huge heterogeneity within these groups, which weakens the value of ethnic categorisation to provide culturally appropriate health care services and understand the causes of ethnic differences in cause of disease.

BME or BAME classifications are the current terms used by the Scottish Government, policy documents, and most research publications to describe people of non-white descent. Therefore, this research adopts BME terminology for clarity and consistency of usage within a similar field of publication to avoid confusion with other terms and not alienate my research by adopting a new terminology that might also be unsuitable. Due to the ongoing debates on appropriate and inclusive terminology, more organisations and researchers are reviewing the language and terminologies they use to describe minority groups. I was mindful of changing language, which is ongoing. In this research, if a participant identified which BME community they belong to, for example, Arab, African or Asian or were explicit of their ethnicity, Chinese, Pakistani, or Indian, I aimed to use that identification where possible.

I, therefore, use the term but recognise it as problematic and highly contested (Commission on Ethnic and Race Disparities, 2021; Cree, 2010). I acknowledge the ethical complexities and lack of consensus on preferred terminology. The recent UK government report (Commission on Ethnic and Race Disparities, 2021) on the investigation of inequalities in the

UK opted to drop the terms BAME/BME due to this complexity favouring the term 'Minority Ethnic'. However, that term would not be specific enough to this thesis's focus on minority people of Asian, African and Arab ethnicities and those who identify as black. In this research, the term 'black' is used in the political sense to represent people of African, Caribbean and Asian descent who identify themselves as black.

This research encompasses UK-born ethnic minorities, immigrants, and asylum seekers who have needed health and social care services. It did not include white minority groups; however, it did include the views of white professionals and two people with dementia and two carers. Whether the official UK ethnic group classifications are useful for research and service provision is an ongoing debate. As a BME researcher myself, I recognise the need to write about and research this timely topic that highlights specific inequalities that affect BME people that might be different to white minority people and categorisation and labelling is one of them. Therefore, it is important to recognise this diversity or the multi-layered dimensions of oppression and not use these labels uncritically to avoid constructing everyone from the same race, ethnicity or country as the same.

Thesis Structure

Chapter 1: Introduction

This chapter provides an overview of the research topic and describes the current scope of research into the experiences of BME people with dementia accessing health and social care services, mainly DP. It also outlines the research background, aim and questions, and a reflection on key terminologies used in the thesis.

Chapter 2: Literature Review

This chapter evaluates and critiques literature from several related areas contextualising this research. It considers wider societal discourses and constructions of race, ethnicity, dementia and access to services for BME people. This literature review provides a basis for the historical, social and cultural facets of BME people's experiences with dementia. The literature review is structured thematically with the concepts and theories that recur across the literature relevant to the three distinct research areas mentioned above.

The structure moves from general to specific. It starts with a broader definition of the main research areas, then dementia and DP and then narrows it down to specific issues that impact BME people with dementia. It starts with details of the methodology utilised for the literature review.

Chapter 3: Methodology:

This chapter outlines the theoretical and methodological framework of the research explaining the links between the social constructionist paradigm and narrative approaches. This research uses a qualitative research design with interpretative narrative approaches to understand how meaning is constructed from people's experiences.

Before addressing the analysis, the narrative research process and data collection methods are discussed. The data was analysed using a 'hybrid' of narrative analysis and thematic analysis merged into Narrative Thematic Analysis to gain insights and understand the individual's lived experiences allowing some stories to remain intact and not disjointed. This chapter also describes the ethical and practical details of the research design processes, reflects on the researcher's positionality, and concludes with the study's limitations.

Chapter 4: Findings one

This chapter examines if DPs are an effective and culturally sensitive response to meeting BME people's specific challenges when living with dementia and their carers and families. It also reports findings from the entire data set analysed using thematic analysis. The findings reported here aim to answer research questions that focus on the experiences of BME people with dementia in Scotland. These are the perspectives and experiences of people with dementia, unpaid carers, practitioners and stakeholders who support people using DP.

This chapter discusses the key findings: BME people's perceptions and beliefs of Scotland's formal and informal health and social care. It highlights some challenges BME people with dementia face when accessing services, with racism reported as the main challenge. Racism then intersects with other factors such as ageism, gender, and class for BME people. The chapter discusses stigma, cultural stereotypes and their impact on people with dementia and how they do not want to be diminished by their support. The chapter concludes by discussing DP and the personalisation of care for BME people with dementia in Scotland.

Chapter 5: Findings two: Case Studies

This second findings chapter shares the life stories of three men living with dementia. Their narratives are presented in a case study format that investigates the three men's lives in detail, accentuating their struggles and the triumph of their journeys before and after a dementia diagnosis.

Presenting the narratives as individual case studies reflect the complexity and richness of the three participants' experiences but also situate them in the broader, cultural, social, and political context in which they are narrated. The stories reveal how each participant

constructed their present and past lives and made sense of their current circumstances living with dementia. The three stories are used to deepen our understanding of the multiple interviews from different categories of participants presented in chapter 4.

Chapter 6: Discussion

This chapter aims to analyse and interpret the meaning and significance of the findings presented in chapters four and five. It explores the meaning of the findings by situating them within a wider context and evidence base to answer the research questions. This is also linked to the research aims and identifies the study's significance and contributions.

The multiple structural, contextual, cultural, and individual factors determining BME people with dementia's access to DP is highlighted. BME people face similar challenges to the wider population; however, those problems are further compounded by racism, discrimination, a lack of culturally appropriate services, a sense of belonging, increased isolation, and language barriers.

Key findings, such as BME people's perceptions and beliefs of formal and informal care in Scotland, are identified. The chapter discusses how people with dementia want to be supported and concludes by exploring personalisation in care for BME people with dementia.

Chapter 7: Conclusions and Recommendations:

This final chapter summarises the research contribution to knowledge in furthering academic knowledge. It highlights the implications for practice and policy by considering key messages for practitioners and policymakers. Recommendations and suggestions for future research are made. The strengths and limitations of the study are discussed. The chapter concludes with the main argument if DP is an effective and culturally sensitive response to meeting the specific challenges currently faced by BME people with dementia, their carers and families.

CHAPTER TWO: LITERATURE REVIEW

Introduction

This study explores whether DP's claim of flexibility, creativity, choice and allowing more control might be beneficial and offer opportunities for BME people to meet their specific needs by recruiting their own staff. This chapter evaluates and critiques literature from several related areas contextualising this research. It considers wider societal discourses and constructions of race, ethnicity, dementia and access to services for BME people. This literature review provides a reflection on the historical, social and cultural facets of BME people's experiences with dementia. The three research areas are dementia, BME people's experiences and SDS focusing on DP and used to structure this chapter.

The literature review begins by considering different models of understanding dementia. It starts with a broader understanding of dementia and then to the specific meaning of dementia among BME people. In noting the lack of scope within medical models to fully understand the experiences of people with dementia, a bio-psychosocial model is adopted. This provides an opportunity to consider the relationship between the medical and bio-psychosocial models of dementia, their origins, criticisms, and their influence on contemporary constructions and conceptualisations of dementia and their relevance to the experiences of BME people with dementia.

The pattern of moving from broad understandings of personalisation to the specific experiences of BME people with dementia accessing DPs will also be followed for the DP section. It starts by looking at the history of personalisation and its philosophical positioning, looking at general challenges that affect people using DP and those specific to people with dementia.

Initially, it focuses on issues affecting BME people when accessing services and then those specific to people with dementia. This chapter also considers access to health and social care services and the implementation of SDS policy by professionals. The chapter begins with the search strategy method for the literature review and concludes by considering evidence to support the relevance of current research and the gaps in the literature.

Search Strategy method: Online databases used to search literature

I conducted a literature search to identify knowledge gaps in my chosen study area, which guided the research topic further and formulated research questions. Literature research was also carried out to provide the background of the study, support selected methodologies, provide context and comparisons for discussions.

The following search strategy was applied to ensure a comprehensive, rigorous and focused literature review was covered. I conducted a narrative literature review. This was a conscious choice over systemic and scoping review due to the broad nature of the research area covering three extensive areas in dementia, self-directed support and BME groups. I was also covering a wide range of grey literature due to the limited research in the combined area of study and not only peer-reviewed journal articles.

I read papers from different publications to familiarise myself with my research writing style and keywords of my research area. I built a concept map of related keywords and phrases related to my research. I consulted with supervisors and the subject librarian to develop key search terms. The key search terms were used, current and past papers were generated from initial database searches to ensure that BME people with dementia were the focal point of the review. Key terms around personalisation, BME communities and dementia were developed through scoping of abstracts and keywords within the literature to identify relevant references. I decided that the term 'Alzheimers' would be utilised within the search terms because Alzheimer's is the most common cause of dementia affecting 60-80% of people with dementia (Alzheimer's Research UK, 2020).

I also used the term Major Neurocognitive Disorder (MND) because some medical fields, care professionals and countries have stopped using the term dementia due to its negative connotation of its Latin root 'demens' meaning 'out of your own mind' 'mad' or 'insane'. Therefore, the introduction of the term neurocognitive disorder attempts to help reduce the stigma associated with the word dementia. MND term was introduced when the American Psychiatric Association (APA) released the fifth edition of its Diagnostic and Statistical Manual of Mental Disorders (DSM-5).

Due to multiple terminologies used to define minority groups, various commonly used terminologies were searched, such as BAME/BME/ME. In addition, specific ethnicities were searched, such as Asian, African, and Arab, to ensure all relevant minority groups were covered. I also explored previous research to determine what terminologies were in use, especially in the UK, given that different countries use other terms to define minority groups.

I searched peer-reviewed journals, books, policy documents, grey literature, conference proceedings, ongoing research at university websites, databases of high-quality pre-print material, online discussion forums and postdoctoral theses.

A narrative search review was conducted using the following electronic databases. This included subject-specific and generic databases to ensure a thorough selection process. Stirling University library catalogue, Social Sciences Citation Index, Web of Science, SSRN, JSTOR, PubMed, Medline, PsycInfo, CINAHL, Project muse and Google Scholar.

Keywords used for the search

Dementia, Alzheimer's, major neurocognitive disorder, medical model, bio-psycho-social model, social citizenship, personhood, person-centred care, Direct Payments, Personal Budgets, Personalisation, Black and Minority Ethnic people/groups/communities, racism, inequalities, ethnicity, health and social care, narratives, social constructionism, interpretivism.

I used Boolean operators to combine various keywords to narrow the search using AND or NOT. For example, dementia and BME service users or dementia and direct payments. When I combined the three keywords dementia, BME and direct payments, I received few or no results. I read the abstracts for relevancy before selecting articles to review and evaluate.

Selected papers were read and critiqued using inclusion and exclusion criteria to conceptualise the finalised set of papers. Most searches were initially restricted to Scotland. When insufficient research appeared, I searched the whole of the UK, other EU countries, the USA, Canada and Australia because they have equivalent personal budgets and much research on dementia. Years were restricted to recent depending on a specific interest, for example, 2017-present, when looking at policy implications of SDS or dementia prevalence in recent years. However, no limit was placed where interest was historical, for example, looking at race and ethnicity and understanding dementia or the history of DP. Only papers in English were included. I used these inclusion and exclusion criteria because there were many papers generated on the broader topic of the study, for example, dementia and personalisation; some were not directly relevant to this study. I also searched the references of selected papers, which led me to more relevant papers. The same process of reviewing the title and abstract of the full paper was utilised.

Different Approaches to Understanding Dementia

This section looks at different understandings of dementia through the use of the bio-medical and bio-psycho-social models. The different understanding of dementia among different BME communities impacts their access to services.

Bio-medical model

From a bio-medical perspective, dementia is described in terms of the cognitive and functional decline of the brain (Downs et al., 2006). The biomedical model states that cognitive changes result in a progressive, irreversible neurodegenerative decline in memory, reasoning, and decision-making, resulting in a need for medical treatment (Alzheimer's Society, 2014; Gubrium, 1986). Nonetheless, while this is still the most common way to people understand and define dementia, this research acknowledges the bio-medical model, contribution to the

diagnosis, rationalisation of required treatment, providing some level of understanding to people with dementia of what is happening to their brain (Spector and Orrell, 2010).

The bio-medical model has been critiqued for neglecting social factors involved in defining and interpreting dementia and affecting people with dementia (Lyman, 1989; Sweeting and Gilhooly, 1997). The bio-medical model reasoning can then result in viewing the person with dementia as a 'non-person' (Bond, 1992; Cotrell and Schulz, 1993), leading to the exclusion of people with dementia from their day-to-day lives (Ostwald et al., 2012), which is likely to deny them a good quality of life (Robertson, 2014). In addition, Robertson (2010) asserted that bio-medical focus on individual pathology in understanding dementia and its cure fails to reflect the social consequences of ageing and having dementia.

Turner and Kelly (2000) suggest that chronic and terminal illnesses should be considered within a broader context. Hence, a medical model would be inept in its capacity to account for how people with dementia respond to and cope with a diagnosis and its impact on their psychological well-being. Rudes and Guterman (2007) argue that humanising the medical model by supporting people with dementia to co-create new realities could empower them to generate new, preferred meanings about the diagnosis, pathology, and symptoms offered by medical professionals. This could shift from pathologising the individual as the problem but emphasise the sociocultural systems that are organised according to roles and structures characterised by hierarchy, power and control (Goolishian, 1988).

The social constructionism discourse of subjectivity represents a unique interaction of self and social experience (Young and Collin, 2004). Therefore, using the bio-medical model to describe and frame dementia may result in others' distorted views and perceptions of the person with dementia, including stigma, discussed later in this chapter. Decades ago, the behavioural changes observed in people with dementia were purely attributed to neurological impairment; however, it is now acknowledged that people with dementia also have a psychological response to cognitive decline and how they are socially treated by others (Sabat, 2008). Given that the bio-medical model fails to consider the social reality of dementia and the meaning attached to the persons' experiences (Vittoria, 2011), this study considers a different model for understanding dementia.

Bio-psychosocial model

The bio-psychosocial model was first introduced by Engel (1977; 1980) as a critique of the bio-medical model that was dominant at this time. Engel argued that the medical model was limited in providing a comprehensive approach to care. He defined a bio-psychosocial model as the interconnection and interaction of biological, psychological and sociological factors. He proposed that there is an interplay between these factors when understanding an illness.

Although his work was not dementia-specific, it is transferrable to a different understanding of different conditions and illnesses.

The bio-psychosocial model was later adopted to understand dementia in relation to the individual's biological, psychological, social and physical needs and understand the complex nature of a person's dementia experience (DiGasbarro, Whitaker and Mast, 2020; Edelman, 2000; Gagliese et al., 2018; Keady et al., 2012; Sabat, 2008; Spector and Orrell, 2010). This model allows us to understand the person's positive and negative cognitive functions, personality and social interaction, enabling us to see the person as having a social identity with innate value and worthiness (Edelman, 2000; Sabat, 2008). The bio-psychosocial model of dementia encourages us to focus on the persons' lived experiences, characteristics, relationships with others and the care they receive (Samsi and Manthorpe, 2020). Sabat (2011) asserted that with the bio-psychosocial model, focusing on the whole person is beneficial to carers because it highlights what the person with dementia can achieve regardless of the impact of dementia on them, whether mild or advanced. This is also whether they live at home or in residential care and the assessment outcome of their ability.

Hansen (2005) suggested that revaluing the inner subjective experiences of service users and patients presenting with various illnesses and conditions would humanise people and not lean too much on the medicalisation of health. Hansen (2005) also argued that the medical model "operates based on the external symptoms, without consideration for inner subjective experiences of clients" (p. 410). Translating this to dementia means that even though a person presents with a collection of external symptoms linked to dementia, their internal subjective experiences would be very different to another person with similar symptoms due to their individual personality traits and how they construct their own reality. Therefore, a bio-psychosocial approach enables a fuller understanding of dementia, allowing better practice and support for people with dementia (DiGasbarro, Whitaker and Mast, 2020).

Kitwood's (1993; 1997;1998) person-centred care approach is extensively implemented in dementia care and is grounded in the bio-psychosocial model. He criticised the biomedical approach to understanding dementia. He argued that it presented a narrow and limited understanding of the person's mental and emotional state. Kitwood (1997) asserted that some deterioration experienced by people with dementia was caused by how they were treated and not by the disease. Person-centred theoretical perspectives consider the interaction between psychosocial and neurological factors in dementia, the conceptual understanding of personhood and the concept of malignant social psychology.

The concept of personhood advocates autonomy, independence, reliability, flexibility and puts the service user at the centre of their care (Innes, Macpherson and McCabe, 2006). This

challenges professionals, families and society's perceptions of viewing the person with dementia as passive and incapable of independent functioning (Cowdell, 2010). Kitwood's approach of placing the person at the centre meant the illness did not become the centre of attention.

Kitwood (1997) argued that the link between the brain and behaviour should be understood in the context of the social environment around the person and the person's long-standing personality style and life story. He proposed that by improving the social environment, the person with dementia would feel comforted, loved, included, have reliable relationships, and maintain their identity, enhancing their overall sense of self-worth. Hence, locating dementia within the bio-psychosocial model and not the bio-medical model enables a better understanding of the person (Gilliard et al., 2005). Therefore, person-centredness interconnects ideas and ways of working with people with dementia lived experiences that accentuate communication and relationship (Kitwood, 1997:1993). Thus, this way of understanding dementia aligns with personalisation discussed later.

The bio-psychosocial model also encourages people to think of dementia as fluid and open to adapting to change and improvement where possible while still acknowledging that some factors are out of the person's control, such as the environment they find themselves in where they may not always be able to exert control (Spector and Orrell, 2010). The bio-psychosocial model has been critiqued for lack of consideration of the physical environment where the person with dementia lives (Keady et al., 2012). Previous findings have found that the physical environment for people with dementia needs to be stimulating, well designed with a good ambience, which positively influences the emotions of the person, staff and family members (Chaudhury et al., 2018; Harrison et al., 2017; Hung et al., 2017; Lee et al., 2021). While the physical environment for people with dementia is important, this study will not be exploring this. Therefore, Bio-psychosocial approaches that also look at the environment that the person with dementia lives in are important because they encourage others to look at the whole person and their needs and not only from the perspective of their diagnosis. Treating someone as a whole means attending 'not only to their biology, but also to their psychology, their social and ethical concerns, and the cultural and spiritual aspects of their lives' (Hughes et al., 2006. p.4). All of which are key in this thesis.

Downs et al. (2006) argued that not a single model could define dementia. Even so, they can represent attributes, explain why people behave the way they do and guide an appropriate response through understanding how people view themselves and dementia diagnosis.

Construction of self

To understand dementia from different perspectives, it is also important to understand how the person defines and recognises themselves. Personhood ideas links with Sabat and Harre's (1992) exploration of 'self' in dementia. Their self-hood theory was a conceptual shift from the biomedical model to understanding a 'person's cognitive and social experience of the world and the quality of interactions between the afflicted and the healthy' (Sabat, 2001, p.23). Moreover, Sabat (2019, p.165) argued that people with dementia 'should not be reduced to brains but to see the persons behind the dysfunctional symptoms and remember our shared humanity.' Hence, there is a focus on the person with dementia's self-hood, the nature of the person's lived experience, emotions, thoughts, social context and the impact of their social situation on their cognitive and social abilities (Innes, 2009; Keady and Gilliard, 2002; Kitwood and Bredin, 1992; Kontos, 2005; Lyman, 1989; Sabat and Harre, 1992).

Other theorists have understood self as a story about identity, character, and personality that individuals narrate to one another to understand self (Bakhurst and Shanker, 2001; Bruner, 2004; Gergen, 2000; Rudes and Guterman, 2007). Bruner (2004, p.4) has asserted that 'there is no such thing as an intuitively and essential self to know, one that just sits there ready to be portrayed in words' (p. 4). Instead, he argues that the self is a narrative phenomenon created and constantly recreated in a conversational domain and always changing (Bruner, 2004). This study uses narrative methodology and links well with this way of understanding a socially constructed self.

Sabat and Harre (1992) used social constructionist theory to argue that loss of self does not occur with dementia progression. Social constructionism is the chosen research framework, and it is discussed in greater detail in chapter three. Social constructionism is based on specific assumptions about reality, knowledge, and how people make sense of the world. Holzner (1972) asserts that cognitive activity and its effects on the social structure, including the construction of ideological knowledge, are all socially constructed. A social construct is an idea that has been created and accepted by the people in a society, not an objective reality, but as a result of human interaction and collaboration (Galanes and Leeds-Hurwitz, 2009). Therefore, it exists because humans agree it exists.

Sabat and Harre (1992) described a singular self-expressed through first-person 'I', 'me', 'mine' and 'myself' and 'selves' and used two in-depth case studies to evidence that self remains intact despite the severe cognitive decline. They highlighted that the threat of self is not directly linked to dementia progression but to the behaviours and reactions of others (Sabat and Harre, 1992, p.459). This includes how formal and informal carers, professionals and members of the public position dementia (Sabat, 2006), which contributes to the

construction or deconstruction of people with dementia selfhoods (Sabat and Harré,1992). Harre (1983, p.203) argued that a requirement for a sense of personal identity is the individual self-consciousness, their awareness that their experiences constitute a personal unity hence having a sense of personal identity. He added that 'consciousness as knowing' involves knowing what one is experiencing and knowing that one is experiencing it (Harré, 1983:28).

Social constructionism focuses on how the person constructs self over time and in context, including self-definition, self and agency, purpose, and subjectivity, how they construct their life story and the meaning they attach to it (Young and Collin, 2004). Therefore, social constructionism discourses are not specific or fixed perspectives but fluid and allow us to hold thoughts, dialogues, and actions in a meaningful way for a specific purpose at a particular time and context. However, social constructionism views the concept of self differently from other theories (Bruner, 2004; Gergen, 2000; White and Epston, 1990). For example, historically, psychology understood the 'self' in terms of some essential phenomenon that is 'just there' (Rudes and Guterman, 2007). At the same time, psychoanalysts believed that the self is deeply unconscious (Freud, 1971, cited in Mannoni, 2015).

Understanding dementia as a social phenomenon has been well-researched over the years (Cotrell and Schulz, 1993; Gubrium, 1986a; 1986b; 1988; Lyman, 1989; Lynott, 1983) and challenges stigma and ageist views such as the inevitability of dementia in old age (Lyman, 1989). Therefore, other concepts that try to address this stigma faced by people with dementia to ensure they live a full life and participate in whatever capacity is explored next.

Social citizenship, participation and empowerment of people with dementia

The person-centred care incorporates the personhood approach and people's lifetime experiences (Edgar, Wilson, and Moroney, 2020; Innes, Macpherson and McCabe, 2006; Kitwood, 1997; McCormick, McCance and Dewing, 2021; Stokes, 2000. However, personhood has been criticised for its focus on the individual, and it is considered lacking in political and social dimensions (Bartlett and O'Connor, 2007). The researcher's understanding of dementia is not centred on individual experiences but also recognises how socio-political practices and discourses shape the understanding of dementia (Bartlett, 2016; Bert, 2017). This is because broader social discourses can dehumanise and objectify people with dementia (Bartlett and O'Connor, 2010). O'Connor et al. (2018) argue that personhood fails to promote the notion of people with dementia as having agency and can assert power and influence. Therefore, they suggest extending the personhood lens with social citizenship to respond better to dementia.

Bartlett and O'Connor' (2010, p.37) define social citizenship as a status that protects people with dementia from discrimination and allows them 'to grow and participate in life to the fullest

extent possible.' Therefore, social citizenship provides a lens to explore social structures that may enable people with dementia to participate and belong to a community as decision-makers and with an equal position in social groups from workplaces to care facilities (Bert, 2017). Promoting social citizenship rather than personhood would enable a shift from needs and 'otherness' to universal rights and entitlement, which would place people with dementia into ordinary society without marginalising them and depicting them as powerless (Bartlett and O'Connor, 2007; Bartlett and O'Connor, 2010; Harding, 2012). Meaning it emphasises the right for people with dementia to remain active participants in their daily social lives and articulate the need for sustained advocacy focussed on their empowerment and social justice (Bartlett and O'Connor, 2010).

Social citizenship looks at the broader concept that integrates the principle of equality between people irrespective of gender, age and the need for support (Truchado et al.,2020). Kelly and Innes (2013) recognise that social barriers to inclusion and participation may undermine people with dementia's citizenship and human rights, which are necessary for improving practice and examining inequities. Approaches to citizenship are focused on empowering people with dementia in upholding their rights, autonomy, agency, and social and personal relationships (Bartlett and O'Connor, 2007; 2010; Gilmour and Brannelly, 2010; Kelly and Innes, 2013). This approach encourages viewing people with dementia as 'equal partners' in care provision as social citizens (Bartlett, 2014; 2016; Bartlett and O'Connor, 2007; Graham, 2004; Kelly and Innes, 2013; Payne, 2011). Doing so recognises that people with dementia have rights, history and are competent individuals who can still actively participate in a meaningful way in their lives even after diagnosis (Bartlett and O'Conner, 2010; Kelly and Innes, 2013). Social citizenship highlights that social-cultural practices shape people's experiences and societal assumptions, allowing more inclusion and understanding of people with dementia (Birt et al., 2017; Gilleard and Higgs, 2010; O'Connor, 2016). Moreover, the literature suggests that cultural definitions and social meanings attached to illness, disability, and ageing have a powerful influence on various services people may seek as support (Cotrell and Schulz, 1993; Mishler et al., 1981).

Many researchers have advocated moving dementia from deficit to active citizenship (Bartlett, 2014;2016; Bartlett and O'Connor, 2007; 2010; Bert, 2017). The social citizenship lens offers a conceptual framework for assessing the role of society and culture in moving away from the deficit model like a bio-medical model, to a discourse of agency and interdependence (O'Conner and Nedlund, 2016). An active citizen in the context of dementia is defined differently, outlining various participatory activities that include political engagement, community, and voluntary action (Truchado et al.,2020). Bert et al. (2017) propose that when diagnosed with dementia, people with dementia are viewed from a deficit lens, positioning

them as living as non-citizens threatening their social citizen status. Birt et al. (2017) suggest that people with dementia can move from the limiting and uncertain stages after diagnosis depending on their acceptance of the diagnosis, social networks, cultural and personal beliefs, and responses to other comorbidities affecting their lives. They, therefore, argue that narratives that focus on deficit do not reflect the agency of people with dementia in shaping their social worlds in ways that enable them to enact their citizen and participatory roles. A more inclusive understanding of dementia also moves away from the stereotypical public image of people with dementia as older people living in care and completely dependent on others (McParland et al., 2012). Such a view would only further marginalise and exclude people with dementia instead of creating the opportunity for social inclusion (McParland, Kelly and Innes, 2017).

Kitwood (1997) asserted that disempowering care practices such as failing to acknowledge people's lived experiences and dismissing their communication efforts worsen dementia symptoms. Bartlett and O'Conner (2010) asserted that assumptions, values and beliefs about dementia need to be challenged to avoid unintentionally diminishing the status of people with dementia. Moreover, many people with dementia want to be engaged within the community and their families. Furthermore, research has found that social engagements among people with dementia increases a sense of belonging, feelings of connectedness and personhood (Terkelsen, Petersen and Kristensen, 2020). However, some struggle with balancing the need for support against the need not to be diminished by this support (Baghirathan et al., 2020).

There are different ways people with dementia have increased their participation and involvement in the care sector, community, and research. Parveen et al. (2018) proposed that involving people with dementia and the public in health and social care services and research was driven by policy, people with dementia and carer advocacy groups and the academic community. They added that several dementia advocacy groups had adopted the motto '*Nothing about us without us*' to actively promote the meaningful involvement of people with dementia and carers in dementia research. Previous research has found that involving the people who use services in the design and intervention of support services is beneficial in sharing their life stories, motivation and what they considered meaningful in their lives (Backhouse et al., 2016; Burnell et al., 2015; Mockford et al., 2016). This research aimed to contribute to growing research that involves people with dementia in research and not only involve carers.

This section has briefly discussed different ways of defining dementia through the bio-medical and bio-psycho-social models. The focus was on the Bio-psychosocial model that looks at the interconnection and interaction of biological, psychological and sociological factors in

understanding an illness and self. The discussion highlighted personhood from Kitwood's approach to person-centred care to understand dementia from a bio-psycho-social perspective. However, it extended these concepts by looking at social citizenship to understand social-cultural practices that shape people's experiences and societal assumptions, allowing more inclusion and understanding of people with dementia. This study adopts the bio-psycho-social model with social citizenship lens in understanding dementia and uses social constructionism to understand the experiences of BME people with dementia.

Challenges Faced by BME People with Dementia When Accessing Support Services

This section discusses the experiences of BME people with dementia when accessing formal and informal support services. Identifying cultural factors specific to BME service users with dementia can be challenging because many of the challenges and barriers they experience are like those of other BME service users. These barriers are stigma, lack of knowledge and awareness of dementia, BME people's perceptions on accepting support and language barriers when accessing services. There are also some similarities to those faced by the white Scottish population when accessing services, for example, feeling that some services are not responsive to their needs, isolation, life stressors, lack of awareness, stigma and limited resources (Memon, 2016). However, despite the broader challenges faced by a wider population with dementia, some are specific to BME people and require a different response, which is explored below.

BME people, stigma and dementia

Stigma may affect access to services for BME people with dementia. Link and Phelan (2001:363) define stigma 'as the co-occurrence of labelling, stereotyping, separation, status loss, and discrimination and for stigmatisation to occur, power must be exercised.' This definition fits well with this thesis because people with dementia are labelled by their diagnosis and stigmatised when viewed through a lens of loss of self, dependencies, incapability and incompetency (Love, 2016; Zimmermann, 2017). In addition, stigma and discrimination against people with dementia complicate the cognitive problems that the person is already experiencing (Wood, 2001). Then this leads to an individual's behaviour and actions being judged through these negative stereotypes (O'Conner et al., 2017) at the risk of internalising stigma leading to feelings of shame and worthlessness (Swaffer, 2014). Therefore, it is not the functional challenges presented by dementia linked to stigma but the response from others (O'Conner et al., 2018), which means that society contributes to the difficulties experienced by people with dementia when navigating their environment (Bartlett, 2014).

BME people have been reported to present late for dementia diagnosis, linked to the stigma attached to having a dementia diagnosis and perceived social pressure to look after relatives without formal services (Cook et al., 2019; Mukadam et al., 2011; Mukadam, Cooper and Livingston, 2010). Therefore, high levels of stigma within some BME communities result in a tendency to minimise the need and a reluctance to report changes in behavioural and psychological functioning (Mukadam et al., 2011). However, the fear of being stigmatised after diagnosis can delay seeking intervention (Bamford et al., 2014). Dementia occurs over time and is not a single event, thus, people may be living with cognitive, physical, psychological and sociological changes for a long time before seeking help due to this delay.

Once a BME person is diagnosed with dementia, the family may keep the person hidden at home to avoid judgements from other community members (Baghirathan et al., 2020; Hossan and Mughal, 2021; MacKenzie, 2006; Parveen et al., 2014). Consequently, due to stigma, fear and shame within BME communities, BME people may suffer in silence because they are unlikely to seek support from dementia services when needed (Johl, Patterson and Pearson, 2016; West et al., 2021). However, Hossain and Khan (2020) found that the BME carers they interviewed, while they believed there was a stigma linked to dementia, did not consider it to prevent BME people from seeking dementia support. Therefore, stigma is not the only factor that might lead some BME people not to seek support.

Baghirathan et al. (2020) found that in Caribbean communities, people of higher economic status with dementia were hidden at home for a prolonged time as a way of protecting their dignity but did not link it to stigma towards dementia. They found that the Caribbean and Asian communities' had different reasons for hiding the condition. Both reasons resulted in not engaging with mainstream services and dementia-specific services such as 'memory cafes'. Therefore, BME people with dementia seeking specialist dementia care may experience greater levels of stigma, preventing them from seeking services (Dodd et al., 2020).

Stigmatising attitudes may exclude people with dementia from decision-making processes, choosing care options and accessing social spaces that they could benefit from (Batsch and Mittelman, 2012). Consequently, stigma can lead to devaluing someone by viewing them as purely defined by attributes and differences that do not exclusively define them as equal citizens enjoying the same rights and having the ability to make their own decisions. This may then affect how others assess their abilities. For example, previous research has highlighted that people with dementia may not be offered DP because they are assumed as incapable of deciding on a DP option (Stevens et al., 2016; Woolham et al., 2017), which may be linked to staff attitudes to dementia (Manthorpe and Samsi, 2016). The evidence reviewed here suggests a pertinent role of stigma impacting service access for people with dementia.

The person-centred approach acknowledges the dignity and quality of life of people with dementia, helping to challenge stigma (Terkelsen, Petersen and Kristensen, 2020). However, how dementia is understood among the BME communities may also contribute to stigma towards people with dementia.

Diagnosis, knowledge and awareness of dementia among BME communities

Research has evidenced that culturally specific constructs of illness can determine how people perceive their symptoms and the action they decide to take (Palmer and Ward, 2007; Tabassum et al., 2000). Fox, Hinton, and Levkoff (1999) asserted that cultural meanings of dementia arise within wider socio-political and historical frames that shape different groups' meanings of dementia. Some researchers have found that the term dementia was not known among BME communities and did not exist in most BME people's languages (Bowes and Wilkinson, 2003; Hossain and Mughal, 2021). Still, when it was known, the words used to describe dementia were negative. For example, Baghirathan et al. (2020) found that Chinese communities' words used to describe dementia had negative overtones, which translated to 'idiotic' or 'silly'. Likewise, Baghirathan et al. (2020) found that dementia was viewed as a superstition in some Asian communities. They found the word 'pagal' in Urdu was used to describe dementia, which denotes a 'madness' caused by evil spirits or previous bad actions. Other researchers have found similar findings where dementia has been linked to the evil spirit, punishment or karma for a past misdemeanours (Hossain and Mughal, 2021; Lee, Diwan and Yeo, 2010; MacKenzie, 2006; Mwakasi et al., 2019). Together these studies indicate that how dementia is understood within BME populations can be different from the wider Scottish population.

Some researchers have chosen to use different terminologies that may indicate cognitive impairment, such as 'memory problems' and 'disorientation in familiar places' (Baghirathan, 2020; Forbat, 2003; Hossain and Khan, 2020; Hossain and Mughal, 2021). However, Samsi and Mathrope (2020) suggest using the term 'memory problem' and not being explicit that it is dementia may raise many questions about the cause of the problem since there could be multiple causes of memory decline. They, therefore, call for clarity, especially when people are conducting research with people with a dementia diagnosis.

In some BME communities, dementia is thought to be a mental illness resulting in the person being subjected to the same stigma directed to people with mental health illnesses within the community (Baghirathan et al.,2020). Previous research has also found that dementia was assumed to be a normal part of ageing and health decline among some BME communities and therefore did not seek mainstream support but relied on family support (Johl, Patterson, and Pearson, 2016; La Fontaine et al., 2007; Mukadam, Cooper and Livingstone, 2010: Rauf,

2011; Subramaniam et al., 2020). Therefore, how people respond to dementia is also linked to their understanding of its causes.

To further complicate this, there is a variation in how dementia is understood among different BME communities. Hossain and Khan (2020) contrasted this with previous studies, where South Asian carers understood dementia as possession by evil spirits or God's punishment for previous life's sins. Their research revealed that Bangladeshi families' carers believed dementia was a medical condition needing medical intervention. They thought a possible explanation for the differences with previous research is the variation in beliefs of Bangladeshi people and other BME communities. They argued that overall, Bangladeshi people recognise and trust General Practitioners and medical doctors as experts on any health problem and have the authority in making decisions concerning their health and value their advice. They then concluded that religion and culture have a less negative influence on Bangladeshi family carers' understanding of dementia and, therefore cannot be represented homogeneously with other South Asians or BME communities

West et al. (2021) maintained that due to different understandings of dementia and cultural beliefs, BME people were less likely to seek support services compared to white people. Recurring findings from multiple UK research projects suggest that BME people also struggled to understand what dementia-related services they were entitled to (Ali et al., 2017; Collins, 2017; Loewenthal et al., 2012; Memon et al., 2016; Moriarty, Sharif and Robinson, 2011; Shah, 2010; Szczepura, 2005; Yasmin-Qureshi and Ledwith, 2021). Therefore, low awareness and knowledge about dementia among BME communities led them not to seek services and support (Baghirathan et al., 2020; Bowes et al., 2012; Giebel et al., 2014; Hossain and Khan, 2020; Jutlla, 2013; Moriarty, Sharif, and Robinson, 2011; Werner et al., 2014; Subramaniam et al., 2020; Venneri and Malik, 2014). Bowes and Wilkinson (2003) study found extensive negative experiences of dementia among older South Asian people and desperate need of support compounded by a lack of information and awareness of dementia. Similarly, a study that examined knowledge of dementia in South Asian older people, as compared with white older people, found that Asian older people had little knowledge about dementia, the researchers concluded that might be the reason they did not attend the local dementia treatment clinics (Purandare et al., 2007). Together, these studies highlight that low awareness and limited knowledge on dementia affect BME people's access to services.

Not knowing what dementia services are available has been a significant barrier for BME people with dementia and their families to access dementia referral processes (Johl, Patterson and Pearson, 2016; Kenning et al., 2017; West et al., 2021). This then led to delayed intervention or dementia diagnosis being overlooked (Devoy and Simpson, 2017; Dodd et al.,

2020; Hamilton-West et al., 2010; Hossain and Mughal, 2021; Pham et al., 2018; Wilson et al., 2020). Moreover, when La Fontaine et al. (2007) explored dementia among British people of Indian origin, they found that dementia symptoms were not recognised. Several studies have shown that many BME people presented later for assessment and were therefore diagnosed with dementia at an advanced stage (Baghirathan et al., 2020; Bowes and Wilkinson, 2003; Cook et al.; 2019; Cooper et al., 2010; Mukadam et al., 2011; Mukadam, Cooper, and Livingston, 2010). This made them prone to worse outcomes (Cook et al., 2019). An early diagnosis provides the family and the person with dementia with better future planning in managing dementia (Robinson, Tang and Taylor, 2015; Samsi and Manthorpe, 2011; World Health Organization, 2017). Collectively, the highlighted studies indicate that BME people not knowing about services affects their overall outcome.

Offering and accepting formal and informal support for BME people

Previous research has indicated that BME service users do not come forward for health and social care services (Katbamna et al., 2004; McMurdo et al., 2011; Iliffe et al., 2017; Liljas et al., 2017). This leads to BME older people being looked after within the family who are also likely to have noticed some of the changes and already supporting the person (Ali et al., 2017; Baghirathan et al., 2020; Davis et al., 2019; Hubert, 2006; Katbamna et al., 2004). However, this is not always the case, and it is an assumption that leaves BME people without access to support (Harries et al., 2019; Moriarty, 2014; Kokab et al., 2020; Nazroo and Kapadia, 2013). Darko (2021) argued that the assumption that BME looks after their family is a misconception of organisations avoiding engaging with BME communities. However, there is evidence to suggest that BME people are more likely to seek support from family, familiar networks such as community-based services and faith institutions (Baghirathan et al., 2020; Mukadam et al., 2011; Parveen, Peltier, and Oyebode, 2017; Tuerk and Sauer, 2015).

Mahmood et al. (2021) suggested that the government and health organisations need to engage with the BME community leaders to deliver targeted advice and key health messages that incorporate cultural and religious practices. Existing literature shows progress with examples of good practices whereby BME community leaders can support agencies with specific cultural knowledge (Craig, 2017; Race Against Dementia Alliance, 2015; Ware, 2017). Rauf (2011) advised that in Islam, Hinduism and Sikhism, the care of older people is seen as a duty and therefore using services is seen as a sign of shame. In some cases, other family members may prohibit the primary informal carer from seeking support to avoid bringing shame to the family (Blake et al., 2017; Ud-Din, 2010). However, Bowes et al. (2012) found that there were families who valued caring for their older relatives but were faced with

increased challenges from their own family life, employment and the increased needs of the person they supported.

Various studies exploring BME people's access to mainstream services found BME people had low expectations of meeting their specific cultural needs (Memon, 2016; Ray, 2003; Toofany, 2006). Mainstream services have been described as lacking cultural and religious sensitivity (Botsford and Dening, 2015; Bowes et al., 2012; West et al.,2021). Other studies have found a lack of access to culturally appropriate dementia services leads to isolation for the person with dementia and their family (Bowes and Wilkinson, 2003). Many BME people feel they have to fit into already established services and systems, which reinforces the view that services are often organised with the majority of white people's needs at the forefront and may not always be suitable (Vernon, 2002).

Bowes et al. (2012) highlighted that specialist BME providers were underfunded. Evidence suggests that this has not changed despite increased demand (Evandrou et al., 2016; MECCOP, 2017; Qureshi, 2020). Specialist BME organisations can become isolated and marginalised from mainstream services and can further isolate BME service users (Ali et al., 2017; Bhui and Sashidharan, 2003; Fernando, 2005; Vertovec, 1996). Intersecting factors may lead BME people to seek informal care instead of formal services. In some cases, perceived cultural and linguistic differences are seen as necessitating different services, and providing specialised services to BME service users has been a positive step.

Language as a barrier to health and social care services access

Studies exploring services for BME people have highlighted language as a major barrier to accessing health and social care services (Ali et al., 2017; Collins, 2017; Loewenthal et al., 2012; Memon et al., 2016; Nielsen, Nielsen, and Waldermar, 2020; Shah, 2010; Szczepura, 2005; Yasmin-Qureshi and Ledwith, 2021). Communication barriers among BME service users and professionals hinder timely access to services (Blake et al., 2017). Lack of resources has meant limited translation and interpreter services for BME people who find language a barrier to accessing the services they need (El Ansari et al.,2009; Evandrou et al., 2016; Mir et al., 2001; Samkange-Zeeb, 2021; Toofany, 2006). Balh (2001) argued that the lack of interpretation and translation services in BME service user languages means that individuals do not understand the medical and support information given to them and the available choices to meet their needs. Due to a shortage of translation services, service users may receive ineffective treatment and inappropriate support because of reliance on informal care and failure to seek professional support when needed (Memon et al., 2016). Together these studies highlight the key role language plays for BME people when accessing services.

Family and social networks within BME communities play a positive role in accessing services by providing information and interpretation, especially in crisis (Memon et al., 2016). However, those who have moved to the UK may not always have their families and social networks with them, requiring a more formal interpretation service. Various research studies have also highlighted the complexity of using family members as medical and social care interpreters (Bauer et al., 2010; Bradby et al., 2020; Samkange-Zeeb et al., 2021). This challenge included frustration to the service user when the family member adds extra information that they may not be ready to reveal to professionals or omits information they felt was culturally inappropriate to share (Samkange-Zeeb et al., 2021). Children have also been involved in translating for their parents, given they are more likely to be proficient in host countries' languages (Hughes, 2018). However, there are concerns about children's 'ability to translate technical and emotionally laden messages' (Lucas, 2021, p.673).

DP uses very technical language that is complicated for adults and likely more challenging for children, presenting extra challenges for BME people to understand DP processes and responsibilities. Thus, Lucas (2021) suggests that social workers have a duty to safeguard children and therefore need to assess the risk of harm when involved in interpretation. Health and social care policies advocate for formal interpretation for objectivity and confidentiality purposes, assuming that family and friends' interpretation presents an unmanageable risk (Pollock, 2021). Overall, these studies highlight that family interpreters need to be managed sensitively despite their significant role.

As dementia progresses, BME people with dementia may revert to their native language, complicating the matter further (Jenkins, 1998; Murphy et al., 2019). One explanation of why people with dementia have more vivid childhood memories than present ones is that dementia affects recent memories stored in working memory while childhood ones are stored in long-term memory (Keage and Loetscher, 2015). The language that is not deeply embedded tends to be lost (Alzheimer's Society, 2019b). A small study on bilingualism and dementia found that staff working in care homes in Ireland, Scotland and Wales found that bilingual people with advanced dementia and little to no linguistic skills transformed when care workers spoke to them in their mother tongue (Murphy et al., 2019). The researchers also suggested that first-generation migrants who develop dementia and revert to their native language may find themselves unable to communicate with their own children who did not learn their parents' first language growing up in the UK (Murphy et al., 2019). This may then leave them isolated within the household, unable to communicate. This is because language is a fundamental part of our human experience, if no one understands the person with dementia's native language, then they might begin to feel lonely, isolated, frustrated, confused and even depressed (Alzheimer's, 2019a).

Khan and Tadros (2014) suggest that it would be difficult for a person who has lost a learned language due to dementia to articulate their needs, symptoms, and care choices. Then due to this limitation in language, BME people with dementia may have difficulties understanding information and expressing themselves verbally (Machiels et al., 2017). Therefore, this unique problem affects bi/multilingual people with dementia, either born within the UK or outside, affecting their communication when accessing care. There is limited research on this area. Therefore, more research is required to understand the extent of this phenomenon and its impact on people with dementia and their families.

Various researchers have recommended that when working with BME people, the communication techniques need to be grounded in a person-centred approach to help in improving dementia care (Brooker, 2007; Fossey et al., 2012; Riachi, 2017; Whitaker et al., 2013). This is because better communication with people with dementia can improve their well-being and their carers' wellbeing (Brooker, 2007; Pritchard and Dewing, 2001). Podnieks (2006) recommended that professionals and agencies working with BME service users use an 'inclusion lens' rather than an 'ethnicity lens', which has led to a great focus on cultural differences, linguistic differences and religion as major barriers to lack of or poor access to services. She advised that this approach would improve communication and understanding of the situation and the experiences of BME service users by addressing pressing issues of feeling excluded when accessing services.

This section has demonstrated the language barriers that impact BME people when communicating with professionals as they access services, how this barrier may impact dementia assessment and diagnosis, and the challenges for accessing interpretations and translation services. Some of the language barriers, delays in diagnosis and access to post-diagnostic support dementia services have been linked to inequalities in service provision for BME people (Dodd et al., 2020; Mukadam et al., 2011). Having discussed language barriers, it is important to frame these communication challenges that BME people experience during services access within a broader context of culture, race, and ethnicity.

Impact of Racism and Inequalities in Service Delivery

This section reviews, critiques, and examines the impact of race and ethnicity on BME people when accessing services. Critical race theory is discussed as a way to understand racism and inequality. An intersectionality lens (Crenshaw, 1989) is adopted in understanding the intersection of race, gender, age, and dementia for BME people with dementia who may be marginalised and experience discrimination. Institutional racism in the UK within service provision, how racial categories have been constructed and legislated, and the impact on BME people living in Scotland is discussed.

Racism

My approach to understanding racism is based on the perspective that race is a social construction rather than a biological or genetic essence (Omi and Winant, 1986, cited in Obach, 1999). Solórzano and Yosso (2002) define race as a socially constructed concept created to distinguish racial groups and reinforce one group's superiority and dominance over a subordinated group. Social constructionism, the research framework, was introduced earlier and is discussed in chapter three. Social constructionism is based on specific assumptions about reality, knowledge, and how people make sense of the world. According to social construct theory, humans create constructs to understand an objective world (Lock and Strong, 2010). Therefore, social constructs are like heuristics that enable humans to quickly categorise and make sense of reality. However, not all social constructs are equally powerful or equally supportive of reality because the more people use the same frame of reference to understand the world, the more prevalent the social construct becomes (Lock and Strong, 2010).

At the genetic level, research has shown that there is as much variation among people within racial groups as there is between different racial groups (Adams, Bell, and Griffin, 2007). The multiple categories used to define people's identities, such as race, gender, age and sex, are socially constructed (Khalidi, 2015; Lohr, 2017). Hence, constitutively relying on subjective experiences about our social relations (DiazLeón 2015; Mallon 2014). Creating conceptually rich social categories enables people, researchers, organisations and governments to navigate the complex social world by allowing them to reason about others' likely thoughts, beliefs, actions, and interactions guided by group membership (Liberman, Woodward and Kinzler, 2017). Baciu (2020) cautions on the perils of categorising, labelling and stereotyping and their impact on BME people who are already marginalised and stigmatised. Therefore, labels are important but problematic, as discussed in chapter one.

Labelling theory suggests that peoples' self-identity and behaviour may be influenced by the terms used to categorise and describe them, leading to negative judgements and stereotyping (Kroska and Harkness, 2007; Skaggs, 2009). For example, Becker (1963) asserted that people's behaviour is defined by their social reactions and responses to that behaviour. Therefore, according to labelling theory, BME people may develop a self-identity and behave in ways that reflect how others label them. For instance, Skaggs (2009) argued that when people are assigned labels, society begins to treat the individuals based on their labels, and they begin to accept the labels themselves. Kenny (2002) called the labelling process a self-fulfilling prophesy in labelling theory because the individual internalises and accepts the labels put on them. Furthermore, Mwansa (2021) argued that grouping ethnicities together infers

whiteness as the status quo, with everyone else fitting neatly into the 'other' box, reduced to acronyms and generalisations regardless of the diversity in the group. Chavez et al. (2020) argue that the labels used to label others, just like racism, are socially constructed.

The Macpherson inquiry (1999) into the death of Steven Lawrence, which concluded that UK organisations, including health and social care agencies, were institutionally racist, raised awareness of how racism is embedded within organisations. Institutional racism or structural racism is when the whole organisation's procedures and policies disadvantage BME people (Delgado and Stefancic, 2001). Institutional racism occurs when an organisation's policies lead to discrimination of BME populations, regardless of the individual's motives (Mason, 2000). Therefore, institutional racism is the application of policies and procedures that ignore the diverse needs of BME communities (Weller, 1991). Atkin (2003) argued that such policies favour the majority white population, who are assumed to represent the 'norm' and services are organised around their needs. In doing this, the BME people are expected to adopt western attitudes, culture, values expected, understand how the organisation and public services operate and speak and understand English (Butt and Mirza, 1996). This may lead to diluting or losing their own cultures and languages. Researchers have argued that institutional racism and oppression are entrenched in various organisations and continue to affect BME people accessing needed services and support (Corneau and Stegiopoulos, 2012; Healy and Oikelome, 2017; Memon et al., 2016: Walter et al., 2017). Historical institutional racism and inequalities are also embedded in health and social care services and affect BME communities accessing those services (Ali and Atkin, 2004; Corneau and Stegiopoulos, 2012; Elias and Paradies, 2021; Paradies, 2015; Qureshi et al., 2020).

BME people experience more disadvantages, such as social-economic conditions compared to the wider population leading to social exclusions, unemployment, poor and overcrowded housing, poverty, low wages and poor health and access to health care, which influence health outcomes (Aldridge et al., 2020; NHS, Health Scotland, 2016; Killoran et al., 2006; Khunti et al., 2020; Marmot, 2005; Wilkinson, 2005; Yaya et al. 2020). Knifton et al. (2010) proposed that access to health and social care services could be made difficult by limited opportunities to meet BME people's needs or receive inappropriate services to the individual's needs. There has been recognition from both the UK and Scottish governments and researchers about institutional racism and the need to develop appropriate policies, legislation and initiatives to improve health and social care services access to BME people who continue to be underrepresented in their uptake of health and social care services (Botsford and Dening, 2015; Hoppitt et al., 2012; National Health Service-NHS Guiding Principles, 2016; NHS Scotland, 2016; Scottish Government, 2017b).

The amalgamation of policies, practices, and procedures rooted in a bureaucratic structure systematically leads to BME people's unequal opportunities and differences being viewed as the norm instead of being investigated and challenged (Social Work Policy Institute, 2014; Walter et al., 2017). In previous research, Chinese people were fearful of taking their older relatives to a care home in case they were treated differently and became isolated, especially if they were unable to communicate in English (Irvine et al., 2016). Moreover, some service providers struggled to understand BME people's lived experiences and experiences of racism, leaving them feeling frustrated and misunderstood (Brathwaite, 2018; Jeraj, 2021; Khan, 2021; Masko, 2005). Therefore, individuals who face racial prejudice and discrimination from services may affect their service experiences and may choose not to use it again or disengage with the service. Furthermore, older BME people, in particular, may feel reluctant to complain because of perceived expectations of how minority groups 'should' behave and the historical experience of many older migrants who arrived in the UK at a time when racism was much more normalised (Harries et al., 2019).

BME people's fear of racism, discrimination, marginalisation, and previous negative experiences of service providers have added barriers to poor service access (Cattell, 2001; Evandrou et al., 2016; Memon et al., 2016; Nazroo, 2003; Netto et al., 2011; Patel, 2006: Szczepura, 2005). It is documented that BME people with dementia experience difficulties not only because of dementia, cultural barriers, poor access to many health and social care services, but also racial discrimination (Age Concern, 2002; Botsford and Dening, 2015: Finney et al., 2016; Irvine et al., 2016; Livingston, 2006). The Equality Act 2010 provides a legal framework to protect the rights of individuals and promote equal opportunities for all. However, Bhopal (2007) argues that providing 'a blanket service' for all does not mean everyone receives equal services. This may result in their needs being largely unknown or understood and how best to meet them and address any inequalities, especially for those with added needs due to dementia. Therefore, understanding how racism intersects with other factors, including dementia, would enable a better understanding of BME people's needs.

Critical Race Theory and intersectionality

This research uses Critical Race Theory (CRT) and the concept of intersectionality to explore racism experienced by BME people. CRT examines social, cultural and legal issues relating to race and racism. CRT argues that racism and different racial outcomes result from complex, changing and often subtle social and institutional dynamics and not explicit and intentional individual bias and prejudices (Burrell-Craft, 2020). Therefore, CRT examines the racism embedded in the systems, institutions and policies. This enables our understanding of how racism is embedded into daily aspects of BME people's lives in health care, housing,

economics, education, employment, the criminal justice system and more (Delgado and Stefancic, 2001).

CRT is multidisciplinary and helps understand how power based on racial hierarchies can be deconstructed and challenged (Baciu, 2020; Hurtado, 2019; Lee and Tapia, 2021; Parker and Lynn, 2002). CRT emerged in the literature of legal scholars in the USA in the 1980s. The majority of whom were black women who had experienced exclusion and marginalisation under legal theory within the wider white and male-dominated institutions (Austin, 1989; Bartlett and Brayboy, 2005; Bell, 1980; Crenshaw, 1989; Delgado, 1989; Matsuda, 1987; Williams 1991). These CRT legal scholars argued that racism is pervasive and entrenched in the foundation of the US legal system and society as a whole. Eunsong and Khoshgozaran (2017) argued that researchers considered the law to support inequalities rather than a tool for justice. They aimed to confront conscious and unconscious racial bias in legal research and policymaking and highlight how and why laws continued to produce structures and practices that disadvantaged black people (Crenshaw et al., 1995).

Ortiz and Jani (2010) consider CRT and social work to be highly compatible because of their commitment to equality and non-discrimination in their pursuit of social justice. CRT seeks to understand and tackle structures and mechanisms that create or maintain social disadvantage, while social work aims to improve the social functioning of people from various disadvantaged backgrounds and promote their well-being. Therefore, CRT is well placed with this research because the CRT framework is helpful for social work research in developing practice approaches that are culturally sensitive and understanding the position of the socially constructed 'other' (Campbell, 2014). Baciu (2020) found that using CRT proposes a race-based critical to understanding the power relations between different groups in the society, especially those labelled as 'others' by the dominant group, a concept explored later.

CRT theorists argue that unchallenged assumptions can hide and promote structural inequalities embedded in the functioning of social institutions (Abrams and Moio, 2009). Hence, it is committed to challenging and disrupting racism and its associated social, legal, political, and educational consequences (Patton et al., 2011). Cabrera (2019) argues that racism should be conceptualised as prejudice and analysis of oppression. To achieve this analysis, some scholars have combined CRT and intersectionality concepts to understand how systematic racism intersects to form a more complex experience for people from minority groups (Harris and Patton, 2018; Lynn and Dixson, 2013).

Crenshaw (1991) applied intersectionality to explore how black women experienced oppression based on their race, gendered and classed experiences. Intersectionality recognises that racism intersects with other subordinated identities such as gender, class,

religion, disability, sexual orientation, and forms of oppression such as sexism, ageism, classism, homophobia, ableism and others to influence Black people's lived experiences (Bartlett and Brayboy, 2005; Harris et al., 2019; Solórzano and Yosso, 2002). Intersectionality as an analytical tool moves the CRT study of racial bias to consider other oppression when multiple systems of social identity-based oppression operate instantaneously to produce complex combinations of power and disadvantage (Crenshaw, 1989). Experiences of racism are inherently complex, being part of a set of potential factors that intersect and affect people differently (Hancock. 2007). This research adopts an intersectionality lens to understand how different experiences of BME people intersect. Cabrera (2019) argued that race is gendered but that we need to move beyond framing oppression as race and gender only but look at other forms of oppression beyond patriarchy that influence systemic racism.

Intersectionality has been preceded by literature on the impact of multiple disadvantages on older people, some researchers called it 'double jeopardy' (Dowd and Bengtson, 1978: Ferraro and Farmer, 1996) and others 'multiple jeopardy' (King, 1988). These terms were used to indicate the added disadvantages experienced by older people from the BME groups. Ferraro and Farmer, (1996) used 'double jeopardy' to examine health outcomes between black minority groups and white majority groups in America later in life. They found important racial differences for change in health outcomes, and African Americans had poorer health but found no evidence for 'double jeopardy'. 'Multiple jeopardy' was later used to highlight that factors linked to one's identity, such as age, gender, race, religion and social-economic status, may lead the person to experience multiple discrimination and oppression (King, 1988).

Employing an intersectionality lens illuminates links between individual subjectivities and wider social structures and power relations, bringing our attention to the intersection of race and gender discrimination (Cabrera, 2019). However, Harris and Patton (2018) argue that intersectionality should not be conflated with analysis of two or more social identities but critically examine multiple forms of social oppression and how they are mutually reinforcing. This is because the exclusive focus on the intersection of social identities misses Crenshaw's (1989, 1991) call to connect everyday identity and specific experiences to intersecting structures of oppression. Therefore, every part of an individual's identity fundamentally interacts with others. For example, it might be difficult for an older, black, working-class woman with dementia to say which social identity is most important to them or which one is causing the most disadvantages. Therefore, to address their needs, one might need to examine how all these factors intersect and complicate their experience rather than address each identity one by one.

In addition, Crenshaw (1991) asserts that oppression can be multi-dimensional within a marginalised group of people. Therefore, there are various degrees of oppression for different people, even within a minority group. For example, BME Muslim women may experience discrimination linked to their faith (Baird et al., 2021; Yasmin-Qureshi, 2021). Khattab and Hussein (2017) found that despite the multiple intersecting identities, education, and employment status, Muslim women with dementia faced worse outcomes than other minority groups who did not ascribe to the same faith.

Recent findings have reported fears from BME Muslim people, with some feeling that there has been an increase in racism and Islamophobia in the UK, going from bad to worse (Abbas, 2019; Beck, 2019; Chantler et al., 2019; Singh, 2021; Zaheer, 2021). Although, this does not appear new in the UK, as highlighted by Bulmer and Solomos (2004), who asserted that Islamophobia had transcended the traditional Black-White binary theorising of racism in the UK. Other research has also indicated this institutional and structural dimensions of anti-Muslim racism (Kundnani, 2007). Sivanandan (2006) argued that these sentiments increased after the 9/11 American bombing and 7/7 London bombing, which increased nationalist attitudes and othering of other groups. Therefore, religion may intersect with other forms of discrimination. These intersecting identities are further compounded by society and how BME people are viewed.

Belonging and othering

Berry and Sabatier (2011) assert that a sense of belonging is a deep-rooted feature of one's identity, and it requires substantial psychological investment to develop and change. This idea is emphasised by Baumeister and Leary (1995), who equally argue that a sense of belonging is inseparable from identity and the need to belong is essential for human motivation in taking action. They also argue that "*human beings have a pervasive drive to form and maintain at least a minimum quantity of lasting, positive, and significant interpersonal relationships*" (Baumeister and Leary 1995; 497). This is the understanding of a sense of belonging adopted for this discussion.

The Commission on Ethnic and Race Disparities (2021) asserts that systemic, institutional and structural racism can leave BME people feeling a lack of belonging and 'othered' by organisations leaving them not wanting to seek support. The ideological notions of 'other' and the 'othering process' are central to understanding racism. Philo (1992) describes this 'othering process' as an unwarranted focus on the interests of powerful groups resulting in the active exclusion of many different social groups from what he refers to as the zone of sameness. The excluded groups stand outside of the mainstream of western society because of their race, ethnicity, skin colour, class, age, gender, sexuality, (dis)ability, political affiliation,

religious persuasion and others (Bulmer and Solomos, 2004; Philo, 1992). These processes of exclusion positions BME people as outsiders.

Bulmer and Solomos (2004) argued that there is a tendency to group BME people according to geographical and political contexts. They are then racialised and continuously 'othered' by racist ideologies. Furthermore, Abrams and Mojo (2009) describe racialisation as a process in which the dominant, powerful group assigns specific attributes to the BME population. These attributes may include various expectations, roles, behaviours, norms, language or meaning, and labels that lead to 'othering' the BME groups. However, racialisation can differ historically, depending on the dominant group's concrete social, economic, political needs and agendas (Campbell, 2014). Therefore, a person may then be viewed as belonging or not belonging to a society based on these characteristics. Similarly, McGarry (2017) asserts that identity and sense of belonging are influenced by debates and attitudes from different levels of social hierarchy, which relies on the power dynamics within society. Therefore, the othering of BME people through the processes of racialisation can leave them feeling that they do not 'belong'.

Ouseley (2001) argues that self-segregation is driven by the fear of others who are more powerful than themselves, the need for safety from racial harassment, and the belief that it is the only way to retain their cultural identity. This links to what Allport (1979 p.37) referred to as 'in-groups' and reference groups '*where the majority white population positively adhere to the principles of in-group loyalty and, in doing this, reject those deemed to belong to a reference group or out-group*'. Lala et al. (2021) have suggested a clear tradition of the institutional dimensions of racism embedded within key organisations of the state, such as education, health and employment established within this creation of in-groups and out-groups within mainstream UK society. Kundnani (2007. p5) referred to it as state-sponsored racism, which seeks to limit cultural differences and suppress the diversity of those seen as 'other'.

Naz et al. (2019) found that policy changes in Britain linked to the rise in anti-immigration, nationalistic and racist sentiments have had a massive impact on BME people because many were afraid of reporting incidents for fear of losing their services or livelihood. Similarly, Beck (2019) asserted that there was evidence to suggest that BME communities in the UK have been experiencing more racial harassment since the beginning of the Brexit campaign, with a five-time increase in incidents. Miles and Brown (2003) argue that racism was conceived as an ideology and is interdependent on nationalism. They add that such ideologies mean that the national 'self' must be protected from 'others' whose 'real' nationality must lie elsewhere. This may lead to nationalistic purism, an ideology that 'we' must not be contaminated by 'them' (Miles and Brown, 2003. p10). Such ideologies may lead to more BME people experiencing

exclusion and feeling they do not belong due to experiencing 'us' vs 'them' perception. Hence, many have called for radical changes to tackle institutional racism within services. At the same time, others have advocated for more personalised services that listen to the individual needs of the people they support to tackle institutional and structural racism.

Personalisation

This section will discuss personalisation in health and social care services, starting with historical context. It also discusses how DP option one of Self Directed Supported has been implemented in Scotland, highlighting various challenges such as DP being viewed as part of cost-cutting and marketisation of care. Austerity and the impact on offering DP to service users will be discussed. This is followed by DP management for people with dementia and concludes with DP outcomes.

Background of personalisation

Personalisation means recognising people as individuals with strengths and preferences and then putting them at the centre of their own care enabling them to become participants in the design and delivery (DOH, 2006; Leadbeater, 2004). It emphasises the importance of choice, flexibility and control to service users (DOH, 2008). In addition, it introduces the idea that personalisation is relevant for all service users accessing social care services regardless of their needs, background and circumstances (Barnes, 2011). Needham (2011, p.55) characterises personalisation as a 'way of thinking about services and those who use them, rather than being a worked-out set of policy prescriptions.' Furthermore, evidence suggests that care is less effective if the people receiving it do not feel in control (Jepson et al., 2016). Therefore, it is this ideology and ambition that lies behind personalisation.

Disability rights activists criticised traditional welfare systems in constructing disabled people as passive welfare recipients of controlling and paternalistic professionals (Morris, 1993; Oliver, 1990, 1996). They began framing the experience of disabled people in terms of their human rights and demanded that society address their right to independent living (Duffy, 2010). Independent living is the ability to determine one's life and live like everyone else, having opportunities to make decisions that affect one's life (REACH, 2021). This includes having the right to choose and pursue a course of action and activities of interest and is only limited in the same ways non-disabled people are limited. However, for individuals with specific mental impairments that may affect their ability to make complicated decisions or pursue complex activities, independent living for them may mean having every opportunity to be as self-sufficient as feasible (REACH, 2021).

Multiple researchers viewed personal budgets as encouraging user empowerment, social justice, and more flexible services that allow a wider range of choices and control (Duffy, 2010; Ellis, 2007; Laybourne et al., 2016; Leece, 2004; Pearson, 2000; 2004a; Rummery, 2006; Scourfield, 2007; Stainton, 2002). Many considered individualised funding or personal budget schemes such as Independent Living Funds (ILF) and DP were regarded as a significant way forward in the struggle for disabled people who wanted to control their lives and have more freedom in choosing their support. Therefore, disabled people ceased to be passive consumers and became agents of care (Duffy, 2010).

The disability rights movement was greatly influenced by the social model of disability, which identifies systemic barriers, attitudes, and social exclusion, making it difficult for people living with disabilities to attain independence (Pearson et al., 2005). The model was derived from the direct experiences of people living with various disabilities and framed disability as socially produced by environmental, economic and cultural barriers rather than individual pathology (Barnes, 2003). This way of understanding disability informed the philosophy of independent living founded on the assumptions that all human life has equal value, regardless of the complexity or severity of impairment (Morris, 1993). Another assumption is that despite any impairment, the person has the capacity to make decisions and should be supported in doing so and have greater control over their life and be able to participate fully in all areas of mainstream life (Morris, 1993). This way of framing disability aligns with my framing of dementia using the bio-psycho-social model discussed earlier because it emphasises how it is not the illness that makes it difficult for the person with dementia but the treatment from others in society.

In 1998, New Labour published its White Paper on the future of social services in England: Modernising Social Services: Promoting Independence, Improving Protection and Raising Standards (Department of Health, 1998). This paper advocated for innovation and improvement of services by responding to the needs of citizens by offering what they needed in the way they wanted it. Therefore, the principle of 'person-centredness' is key to modernisation because services are expected to be person-centred. This links with the above discussion on Kitwood, person-centred care. In order to achieve the modernisation of services, there were increased demands on partnership working, integration and joined-up services. Innovative and collaborative cultural change at the policy-making and operational levels was also demanded, moving away from the 'risk averse' culture inherent in the government and social services (Cabinet Office, 1999, p.55).

Personalisation in social care has been the subject of various critiques relating both to its principles and practical implementation (Ferguson, 2007; Glendinning et al., 2008; Lymbery,

2014, a,b). One of the personalisation's aims in shifting the emphasis from professionally driven assessment to self-assessment has been challenged (Barnes, 2011). Ferguson (2007) argued that such changes could lead to the de-skilling of the social work profession and that the '*philosophy of personalisation is not one that social workers should accept uncritically*' (Ferguson, 2007: p.337). He argued that personalisation also neglected poverty and wider inequality issues and could stigmatise those who depend on welfare. Ferguson also argues that the state holding a reduced role in its service provision and service users taking on greater responsibilities and risk for their care as promoted by personalisation agenda is central to neo-liberalism and therefore needs to be scrutinised.

Like Ferguson's argument, other researchers have debated that personalisation is the marketisation of health and social care services (Holloway, 2007; Pearson and Ridley, 2017). For example, Scourfield (2007) asserted that Labour's modernising care project assumed that modern citizens should be autonomous, managerial and entrepreneurial, hence viewed as responsible for managing their own care and receiving it. Modernisation is a process in which private and public areas of society are subjected to the 'technologies' of managerialisation and entrepreneurialisation (Scourfield, 2007). Therefore, for the individual citizen, personhood is expressed through being entrepreneurial, innovative, and taking and managing risks (Rodrigues and Glendinning, 2015). The extent to which market consumerism could empower social services user groups is highly contested (Baldock, 2003). This approach to personhood and citizenship also raises questions about the place in society for those considered 'vulnerable' or with health conditions that render them unable to manage their own care or because they are not as innovative and entrepreneurial. Thus, the idea of using independence and choice as central organising principles Scourfield (2007) asserted was putting people dependent on care at risk of not getting secure and reliable support.

Pearson et al. (2005) assert that the resistance to the consumerism of welfare services was heightened more strongly in Scotland, which prevented social work staff from actively promoting the policy leading to lower uptake of DP compared to England. This is linked to a stronger allegiance to state-provided services and professional power featured in many social policy areas (Riddell et al., 2001). The advantages of encouraging the uptake of DP against a background of prolonged financial and resource constraints have been the subject of intense critical debate (Brookes et al., 2015; McNeill and Wilson (2017). At the same time, others have viewed personal budgets with suspicion as a cost-cutting activity (Daly, 2002; Needham, 2011).

The personalisation approach aligns with Reshaping Care for Older People 2011-2021 (Scottish Government, 2012; Audit Scotland, 2016). This is a Scottish government policy that

aims to redesign and support services for older people to ensure they are sustainable for the future and meet their outcomes in a person-centred manner. DP is part of the wider personalisation agenda and vision for social care services to be tailored to individual needs and preferences. It is part of the broader view that the state should empower its citizens to shape their own lives, improve their choices and have individual control over services (Glasby and Littlechild, 2010; Leadbeater, 2004: Lundsgaard, 2006; Williams et al., 2014; Xie, 2012).

Duffy (2010, p.253) proposed the citizenship theory of social justice to explore the meaning of personalisation for social workers. This theory is based on two fundamental moral beliefs: '(a) the equal dignity of all human beings; and (b) the positive value of human diversity and difference'. Duffy believed that the theory of social justice offers an inclusive model of citizenship and is necessary for organising society so that everyone can be treated as equal citizens. In his theory, Duffy defines citizenship as someone who possesses the qualities necessary to call forth an attitude of respect and not people who hold the same passport' (p.261). Furthermore, Duffy believed that citizenship was the motivating factor behind SDS, DP, Individual Budgets, Personal Budgets and person-centred planning, presenting new ways of assessing, planning and delivering support.

Duffy (2006;2008) argued that the SDS model was consistent with citizenship principles because being in control of your life is part of being a citizen. This links with early discussion on social citizenship and person-centred care central to dementia care and how people with dementia want to be treated and involved. Duffy (2010) advocated that achieving justice, fairness, and equality goes hand in hand and therefore, there needs to be a recognition of human beings' diversity in mind, body and situation. He argued that not doing this creates disadvantages, stereotypes, prejudice, and excluded and oppressed groups. Therefore, Duffy's theory aims to include marginalised groups due to a disability, illness, race, gender, or other factors and aligns with this thesis' idea of personalisation and inclusivity of BME people with dementia.

The personalisation agenda on ensuring person-centred response to diverse needs has been viewed positively by some professionals in reaching service users with varied needs that are not readily met by other mainstream services (Barnes, 2011; Heslop et al., 2009). Therefore, it fits well with Kitwood's (1997) personhood theory and Batlett and O'connor (2010) social citizen model discussed earlier because of its emphasis on the individual's needs and preferences.

Self-Directed Support

In Scotland, personalisation is implemented through the Social Care (Self Directed Support) (Scotland) Act 2013 and its underpinning principles of the act are informed choice, flexibility

and control. This legislation placed a mandatory duty on local authorities to provide four options to service users who have been assessed as needing service per section 12A of Social Work (Scotland) Act 1968, which places a duty on the local authority to provide a service to those with assessed needs. Option one is DP, option two is the Individual Service Fund (the service user chooses their own support, but the local authority or third party organises it), option three is traditional council commissioned services (the local authority assesses and organises for the appropriate support) and option four is a mixture of the three (Scottish Government, 2015).

The Scottish government adopted the term Self-Directed Support (SDS) in developing different policy approaches from the rest of the UK, declaring SDS as part of its ambition to create a 'healthier nation with stronger and safer communities' (Scottish Executive, 2007, p.2: Scottish Government, 2010). In Scotland, the focus on SDS has greatly been on the relationship between the citizens and the state regarding health and social care based on values and principles (Mitchell, 2015). Carr (2008) defines SDS as a flexible system for organising support services in ways that give the 'citizen' the maximum degree of control over their support (Carr, 2008). Moreover, Audit Scotland concluded that SDS was '*based on the human rights principles of fairness, respect, equality, dignity and autonomy for all. This means that people should be equal partners with relevant professionals in determining their social care needs and controlling how their needs are met*' (Audit Scotland, 2014, p5).

In the Scottish route of SDS, there was a greater emphasis on co-production than in England. Personalisation provides the opportunity for the co-productive involvement of people who use services in designing, commissioning, and delivering the social care services they receive (Bracci and Llewellyn, 2012). Flemig and Orsborne (2019) argued that co-production as a set of approaches to working in partnership with service users offers a natural fit with the person-centred ideals of personalisation. They offer an integrated policy and service delivery framework that enhances the role of co-production in personalisation settings and bridge the gap between different variations in implementation and the policy ideals in personalisation. Co-production requires service users to be the 'experts' in their own circumstances and capable of making their own decisions, while professionals work collaboratively to facilitate service delivery (Flemig and Orsborne. 2019). Thus, co-production requires a shift of power from professionals to the service users to be transformative (Boyle, 2004). Therefore, this ideology aligns with the person-centred care, personalisation and constructionism philosophy adopted in this research by advocating that service users should be involved in all the processes of planning, designing, delivery auditing of health and social care services (Boyle, Clarke and Burns 2006; Needham and Carr, 2009).

The most common and well-known self-direct support personal budget is DP, the focus of this thesis, although some people use the two terms interchangeably. Personal budgets are the money or resources allocated to an individual, while DP is the mode of delivery. DP are local authorities' cash payments for anyone who has been assessed as needing care from social services and who would like to arrange, organise and manage their own care and support services instead of receiving LA directly commissioned service (DOH, 2006). Personal budget holders can take their budget as a DP, ask the council to commission services on their behalf, or use a combination of the two. Council Commissioned Services mean services provided directly by the local authority, such as care at home, day services in day centres and respite in care or nursing homes. DP recipients can use them to employ PAs or buy services from an agency of their choice. Therefore, DP allows the recipient the freedom to commission and arrange the support they want within the terms and conditions of their support plan. However, Scourfield (2007) calls it 'audited freedom' because although recipients are told they are free to make their own decisions, DP is granted based on an assessment and a care plan that details how the money should be spent and subjected to annual review.

Evandrou et al. (2016) found that the amendment of the Community Care (Direct Payments) Act 1996 authorising a family member to be employed was significant for some people with dementia from BME backgrounds who may struggle to recruit staff with the required linguistic abilities and cultural understanding in providing care. In some circumstances, only a family member can provide the required care as part of family honour and preserve respect and status within the community (Evandrou et al., 2016). Although, there are concerns with the distribution of power within a family context when family relationships change to that of employee and employer (MECOPP, 2017). Therefore, employing family members is not entirely unproblematic, especially given the different DP responsibilities the family member must manage in recruiting staff (Care and Health, 2004).

Direct payments eligibility, responsibilities and management

DP follows the same eligibility criteria as other council commissioned services. However, research into the implementation of DP policies and legislation has shown greater frontline discretion in determining who gets access to DP (Clark and Spafford, 2002: Hasler and Zarb,2000; Spandler and Vick, 2005, Stainton and Boyce, 2004). This ambiguity may have been created due to the demand for limited resources (Holloway, 2007: Manthorpe and Samsi, 2013).

Ellis (2007) argued that practitioners had been placed in a dilemma that she called 'double-bind' by being expected to apply strict eligibility criteria and encourage increased DP uptake. She then applied the theory of 'street-level bureaucracy to suggest that practitioners had the

discretion to resolve this difficult situation by deciding who met the criteria for DP. Lipsky's (1980) theory of 'street-level bureaucracy suggests that professionals have the discretion to interpret policies, guidelines and organisational procedures to decide who gains access to resources (Lipsky, 1980). This practitioner's way of practising can be viewed as staff behaving, deciding who is deserving of service and who is not based on their assumptions and stereotypes. Lipsky's theory is still relevant today in analysing practitioners' DP policy and legislation responses. The dilemma of strict DP eligibility and encouraging uptake is likely to cause uncertainty and hostility to frontline staff (Ellis, 2007). Such contradictions could significantly compromise the professional role, judgement and values in their job (Lipsky, 1980).

On the one hand, it is possible to say that the staff would like to maintain their professional discretion, power, and skills, but, on the other hand, the government wishes to promote empowerment, choice, and control of DP recipients, causing a professional dilemma. However, taking away staff discretion to make decisions during assessments could undermine the professional judgment that staff are trained to make (Clark and Spafford, 2002; Ferguson, 2007). Furthermore, there are contractual responsibilities and obligations placed on DP recipients to encourage them to manage their money responsibly. This includes opening a DP dedicated bank account. The recipient takes the role of an employer and decides to fulfil this role or arrange to receive support from a third-party organisation. According to employment law, the person managing DP is responsible for recruiting staff, payroll, HMRC cost, insurance, pension, and other legal responsibilities.

In addition to the above challenges, another major barrier to implementing DP is the ongoing climate of austerity and the fear that an increase in DP take up would undermine council commissioned services leading to poorer choices and effective provision of services (Brookes et al., 2015; Lymbery, 2014a; McNeill and Wilson, 2017; Netten et al., 2012; Patterson, 2010). Practitioners also have reported a lack of knowledge and training in DP alongside ambivalence and scepticism about the value of DP in promoting personalisation affecting SDS successful implementation (Ferguson, 2007; Leece and Leece, 2011).

The person receiving DP directly or through a nominated person is accountable to the local authority on how the money is spent (Scottish government, 2017b). The assessor needs to be fully satisfied that the person understands what is involved in managing a DP. During a DP annual review, the recipient must produce bank accounts for inspection and demonstrate they have utilised the money according to the care plan objectives. If there is any underspend should be returned to the LA. Scourfield (2007) argues that these obligations mean there is no shift in political power, and DP only offers recipients a chance to be 'managers' and

'entrepreneurs', not necessarily offering them choice, control and independence. Therefore, it is questionable whether DP offers the freedom it proposes to offer the recipients.

In their study, McNeill and Wilson (2017) reported that DP recipients continued to experience anxieties when managing DP. The long and complicated DP processes, paperwork, and support planning are barriers for many individuals (Laybourne et al., 2016; Leece, 2008). Some recipients also experienced difficulties after commencing using DP due to a lack of ongoing support and advice from the practitioners who closed their involvement after the DP process was finalised (Arksey and Baxter, 2012). Many DP recipients face various challenges, such as recruiting and retaining qualified staff care staff to meet their assessed needs (Carmichael and Brown, 2002; Scourfield, 2005; Spandler, 2004). However, some research evidence suggests that DP recipients tend to have varied experiences and hold both positive and negative views about the value and effectiveness of DP in addressing their needs (Arksey and Baxter, 2012; Duffy, 2010; Netten et al., 2012).

DP management for people with dementia

People with dementia face added obstacles, making it more challenging to access DP. They are also underrepresented from those benefitting from DP, with decision-making and DP management acting as a major challenge (Laybourne et al., 2016; Woolham et al., 2017). This has then resulted in low uptake of DP by older people, with some social workers expressing reservation in offering them (Clark, Gough and Macfarlane, 2004; Ellis, 2007; Glendinning et al., 2008; Leece and Leece, 2006; Lundsgaard, 2006; Stevens et al., 2016) and especially to those with dementia (Bartlett, 2009; Woolham et al., 2017). Lower uptake of DP from older people is also due to a lack of brokerage support services, anxieties and fear of getting it wrong (Pearson et al., 2005; Ridley and Jones, 2003). Additionally, older people also experienced shortages of PAs to employ (Ellis 2007; Fernández et al. 2007). However, Clark, Gough and McFarlane (2004), in their qualitative study that explored the experiences of forty-one older people using DP and various front-line staff and managers, found beliefs that older people would not want the stress of recruiting their own staff with all the paperwork involved and tightening eligibility criteria discussed earlier, hindering easy access to PAs. These studies indicate that different factors cause the underrepresentation of older people with dementia.

Other obstacles are professionals' views and judgements of people with dementia. Some studies have found that many older people were encouraged to use commissioned services and not DP for fear that they could not manage DP or lacked the capacity to decide they wanted a DP (Hatton and Waters, 2011; Newbronner et al., 2011). Social work practitioners may also assume that people with dementia do not want the responsibilities of managing DP or see them as incompetent, especially if their judgement is impaired (Carr, 2013; Ellis, 2007;

Leece and Leece, 2006). Other researchers have expressed concerns that DP may not benefit people with dementia, and council commissioned services and Individual Service Funds may achieve better outcomes (Moran et al., 2014; Woolham et al., 2017). Laybourne et al.'s (2016) study explored the experience of managing a DP for someone with dementia from the perspectives of suitable people and adult social care practitioners; some of the practitioners assumed that DPs were not intended for older people with dementia.

The practitioner's attitude towards older people's use of DP may be linked to the general assumption about age, ability and stigma for dementia discussed earlier. Ellis (2007) suggested that some social workers might view older people as dependent, passive, and with low expectations of autonomy and entitlement to good quality care (Ellis, 2007). Not offering DP specifically to people with dementia could also be due to some practitioners' belief that people with dementia have fixed, basic needs that social care services can meet without the challenges of DP (Laybourne et al., 2016, Ettelt et al., 2018). Lewis and West (2014) challenged commissioning services based on time and tasks, they felt this excludes the cost of the emotional labour needed to build a good working relationship between the staff and service user.

Capacity and decision-making issues are important to consider in this study because people with dementia may have high social care needs and be assessed as lacking the capacity to consent to use a DP (Laybourne et al., 2016). Capacity is the ability to understand and use the information to make an informed decision by providing appropriate information (NMC 2008). In Scotland, formal assessment and understanding of capacity are framed by legislation. The Adults with Incapacity (Scotland) Act (2000); (AWIA) provides a legal framework to help safeguard the individual's welfare and financial affairs for those assessed as lacking capacity (Scottish Government, 2015). AWIA promotes the principle that each person should be assumed to have capacity unless assessed as having impaired capacity. There is a difference between deciding and implementing a DP decision (Boyle, 2008; Leece and Pearce, 2010). This means individuals may decide that they want a DP even if they cannot manage the DP themselves and may require support from someone else. The capacity to make various decisions in one's life may be diminished temporarily or permanently, partially or totally, and some people with dementia can retain the capacity to make decisions until the late stages of their illness (NHS, 2012). Therefore, capacity is not an all-or-nothing notion. Capacity is concerned with how other people, mainly professionals, assess whether people with dementia should be making specific decisions and the types of decisions they are allowed, supported, or prevented from making. Therefore, there needs to be a robust consideration for capacity assessment during the DP assessment.

Previous studies have suggested that DP is only possible with the support from unpaid carers and other family members willing to manage DP on behalf of the person with dementia (Hamilton et al., 2017; Larkin and Dickinson, 2011; Moran et al., 2012). One of the key roles of unpaid carers is to enable the person they support to be a full and equal citizen and allow greater participation in their care (Barnes, 2011; Carr, 2013). That suggests that unpaid carers for people with dementia play a significant role in supporting them with accessing DP, decision-making, and promoting their autonomy, especially if they lack capacity. The Scottish government also recognises the important role of unpaid carers. This is evidenced in the Carers (Scotland) Act, 2016, which advises that carers have a right to a separate carer's assessment and service provision if needed. The carer act suggests that when offering DP to people with dementia who cannot manage and a carer is the DP manager, their ability to cope with their caring role and the added DP responsibilities need to be considered.

The administrative burden of managing DP with service users becoming employers can be too tasking for older people and their carers (Carers UK, 2008; Moran et al., 2014; Priestley et al., 2010; Steven et al., 2016; Ridley and Jones, 2003; Ridley et al., 2011). This can be problematic for people with dementia who may struggle to understand DP responsibilities and obligations (Laybourne et al., 2016). While sometimes the government policies tend to assume that the interests of carers and the people they care for are intertwined, there can be a conflict of interest (Keywood, 2003; NHS, 2012). This can happen during a DP assessment if the person with dementia does not want the carer handling the finances. Similarly, Marczak et al. (2021), drawing from evidence from in-depth interviews in three local authorities in England investigating if they were meeting their obligation in the Care Act 2014, found that the assessment of needs and finances could lead to a conflict of interest between carers and the people they care for. Therefore, all these need careful consideration when assessing people with dementia for DP.

The Adult with Incapacity Act 2000 emphasises that people with dementia need to be supported with decision-making, promoting a concept of 'assisted autonomy' by the carers (Morris, 2005). Tyrell et al. (2006) suggest that although unpaid carers may be willing to support their relatives with decision-making, they may have difficulty assessing capacity and may be unsure how to seek formal support. They also highlighted that unpaid carers' perceptions of the person with dementia may not always reflect the views of their relatives. This could be due to different lived experiences and frames of reference and sometimes not understanding the impact of dementia on the person.

Dunning (1997) and Burton (1997) assert that advocacy plays an important role throughout the life of people with dementia, especially in a decision regarding their care. An advocate

speaks on behalf of the person with dementia, facilitates their views and acts as a mediator between the person and professionals to ease communication between them. Therefore, an advocacy service may be considered when working with a person who lacks capacity or a conflict of interest exists with their relatives. Cheston, Bender, and Byatt (2000) advise that advocacy for people with dementia assumes that they have similar rights as other citizens, with equal entitlement to services and interventions. Therefore, it is important to consider capacity issues for people with dementia and ensure they do not miss out on DP if appropriate.

Direct payments outcomes

Although the initial take-up of DPs has been low, the messages from research about the beneficial effects for DP recipients have almost all been positive (Clark et al., 2004; Davidson and Luckhurst, 2002; Glendinning et al., 2000; Hasler, 2003; McNeill and Wilson, 2017). A considerable amount of literature has highlighted that if DP implementation difficulties can be overcome, DPs have the potential to promote: choice, control; flexibility in how services are provided and deliver better quality services (Clark et al., 2004; Dawson, 2000; Glasby and Littlechild, 2010; Hamilton et al., 2017; Irvine et al., 2016; Leece and Bornat, 2006; Moriarty, 2014). For example, in their longitudinal survey, Arksey and Baxter (2012, p.160) found that many respondents reported DP had 'offered them increased choice, flexibility and control which gave them and their families an improved quality of life'. Laybourne et al. (2016) suggested that DP enabled flexible lifestyle choices, such as accessing stimulating activities like singing groups, swimming clubs and visiting local cafes and pubs within the local community enabling the recipient to maintain a flexible and engaging routine.

DP has been known to effectively fill the gaps between service provisions that are not addressed by formal care (Rummery, 2009). For example, people can choose to have more flexible day services and more unconventional respite options such as getaways, although they may have to subsidise with their own money. DP has helped improve the well-being of older people by allowing them to choose who supports them, how, and when enabling them to exercise control in their lives as independent citizens (Brown, 2010; Ettelt et al., 2018; Rummery, 2009). Rodrigues and Glendinning (2015) study found that older people who opted for DP was after previous unsatisfactory experiences with local authority-commissioned home care. The older people complained that they struggled to get the service they wanted, the providers were inflexible and there lacked continuity in their packages. They advised that DP offered them greater flexibility and control over their time schedules, range of tasks, and greater responsiveness in making adjustments. Likewise, Moran et al. (2014) reported that people with dementia receiving DP experienced greater choices, control, care continuity with the same worker and the ability to employ some family carer. Rodrigues and Glendinning

(2015) also found that DP recipients could alter their daily routines and have fluid, informal arrangements, and DP recipient was also flexible with PA needs, such as if they needed to leave earlier or arrive later.

Other potential benefits from DP for people with dementia include choosing to remain in their own homes and receiving person-centred care tailored to individual support needs offering continuity at home, and sustaining established relationships (Clark, 2006). DP also enabled people with dementia to pursue their own interests and maintain social networks and psychological well-being without adding costs to the care package (Jones et al., 2014; Laybourne et al., 2016). Netten et al. (2012), in a randomised control study with older people, people with a learning disability and mental health issues, reported that the use of DP was associated with enhanced quality of life. This aligns with the DoH (2003) vision of DP, offering a means to improve the quality of life of people who wish to manage their own support and promote independence and aid social inclusion by offering flexible leisure and employment opportunities for people in need of community care.

Unpaid carers supporting people with dementia have highlighted DP benefits such as increased independence through choice, flexibility and tailored support (Rosenthal et al., 2007). Unpaid carers have also advised that by choosing the type of support and designing it, they can fulfil their ambitions, such as having a job and pursuing some social activities, giving them a sense of normality and inclusion (Ridley and Jones, 2003). Laybourne et al.'s (2016) study that explored carers' experiences of managing a DP for someone with dementia reported that DP had a positive financial impact and positively influenced their ability to remain as a carer. They concluded that DP indirectly benefited the person with dementia by benefitting the carer. This was through improved quality of life by having time to take care of their physical and mental well-being.

In 2006, the Scottish government suggested that DP could be an essential method of delivering better services to BME individuals. DOH (2003) suggested that DP offered greater independence and flexibility in delivering culturally sensitive services to BME communities. They also added that DP could facilitate inclusive social support by providing access to mainstream activities that are not stigmatising. Despite the scant literature in Scotland, research from England highlights the potential for DP and SDS to transform positively the care provided to BME service users and carers in providing timely and culturally sensitive services (Carers UK, 2011; Irvine et al., 2016; Pearson, 2004b; Stuart, 2006; Terashima, 2011). A qualitative study by Irvine et al. (2016) that looked at the impact of personalisation on people from Chinese backgrounds found that personalisation had the potential to transform the lives of people from Chinese backgrounds. They found that if the support was tailored for Chinese

people to understand and access DP and put them to creative use, they could meet the social and cultural needs that mainstream services were struggling to meet.

Spandler and Vick's (2005) mixed-method research using semi-structured interviews and focus groups evaluated DP benefits among people with mental health needs across five local authorities across England. They found that DP offered BME people in the sample greater choices and control, more flexible and culturally responsive support that aimed to promote inclusion and resulted in a better quality of life. Spandler and Vick (2005) gave an example where DP employed a PA of similar background to the service user to provide culturally sensitive support to a Southeast Asian family. The family needed someone who could relate to and understand their culture because the service user was extremely isolated and needed social support. They were looking for a PA who could build a good relationship with the service user with a shared language to encourage him to engage in social activities. While it took a long time to build trust and a good relationship before the service user agreed to go out, the family felt that without an Asian PA, it would not have worked.

Therefore, with the introduction of DP through personalisation, despite the implementation challenges and responsibilities compounded by austerity, DP has made some progress in offering a different option in how care was provided (Barnes, 2011; Brookes et al., 2015; Ferguson, 2007; Spandler, 2004; Stevens et al., 2011). Increasing DP take-up by people from BME communities relies on developing resources and approaches specific to those communities to benefit from any positive DP outcome (Newbigging and Lowe, 2005).

Conclusion

This chapter has explored literature relating to dementia and BME people's experiences of accessing health and social care services, mainly DP. It has identified a key tension in the literature, relating to more people developing dementia alongside diminishing resources and the need for more effective and flexible strategies, and examining if DP could be one avenue for this. The chapter has explored research about BME people with dementia and how their families may wish to access formal services, especially when the family is no longer coping. It has also examined why some BME family members may look after the person with dementia due to a lack of alternatives and a desire to safeguard the family's honour and status within the community and meet cultural expectations, and service providers may assume that BME people do not require support. However, cultural factors may prevent them from doing so, compounded by fear and retribution from other family members and the community. This has highlighted that some challenges BME people experience are context-specific and lie partly with BME service users, such as family norms, beliefs, values, linguistic and family structures. Other factors are out of their control, such as social-economic status, institutional racism,

discrimination, inequalities and structures of the services. While culture plays a role in decisions made by BME service users when assessing services, caution is needed in assuming its major significance and not considering other factors and their implications and how different factors intersect. The tension between specialist versus mainstream services is one that this study aims to explore by investigating if DP can bridge the gap and contribute to addressing the culturally specific needs highlighted.

It has outlined and critically reviewed various bodies of theories and concepts. They all promote seeing people with dementia as individuals with rights, autonomy and agency. This includes the person-centred approach and social citizenship lens with the bio-psychosocial model of defining dementia as the guiding principle in this study. This chapter has highlighted that, unlike the bio-medical model, the bio-psychosocial model can challenge the stigma of dementia by not viewing the individual through their illness but through their personhood and social citizenship. This would allow consideration of both positive and negative factors affecting someone with dementia's life and well-being. Therefore, dementia is framed as a multifaced condition with social and psychological aspects in this research.

This chapter has summarised current policy with relevance to self-directed support and capacity assessment for people with dementia. An important issue raised by the literature review is whether DP represents the state shifting its responsibilities to its citizens or whether the provision of DP shifts the balance of power in the relationship between the state and local authority services to meet the needs of those who most need care. The argument that DP requires social services and service users to become managers and entrepreneurs is important since DP has extensive responsibilities, excluding service users who do not possess the required skills. DP may better suit people who worked in entrepreneurial, management, accountancy or finance positions in their career or people who are comfortable with the employment laws and DP responsibilities. If a service user is already struggling with health issues such as dementia, thinking about recruitment, HMRC, and pension for staff might be too demanding. Therefore, the shift of the local authority commissioning care to service users and making them responsible for the money, quality of care they receive, and taking on the risks could be cumbersome for some. Although some might welcome it as a good challenge if they think the benefits outweigh the responsibilities. The literature has highlighted that if older people and people with dementia are to benefit from DP, professionals need to challenge their stereotypes and ageist attitudes and not assume service users are dependent, unable to decide and manage DP, but can assert autonomy in how their care is provided.

The literature has identified a gap in understanding the experiences of BME people with dementia using DP. Having searched the literature from all over the UK since DP

implementation in 1996 to date, much attention has been given to DP and other service user groups, such as people with learning and physical disabilities. However, there has been very little research on BME people with dementia receiving DP. There is growing research on dementia and personalisation, but insufficient attention has been paid to BME people within this group. No research was found on the intersection of dementia, DP and BME service users in a Scottish context. The literature available on the BME population and access to services in the Scottish context is patchy. Literature is largely confined to England, resulting in a major knowledge gap in Scotland that this research contributes to. Like the rest of the UK, as highlighted in the introductory chapter, Scotland has a growing population of BME communities with dementia projected to increase among these communities.

This research is timely in understanding how BME people access and experience different service delivery, specifically DP. DP may have the potential to meet individuals' needs in a more personalised manner with people directing and managing their care. However, the potential of DP to transform, improve and deliver better services to BME people is generally under-researched, and many of the challenges that hinder uptake remain unsettled. Therefore, this research aims to interrogate policy aspirations, practice realities and practicalities and make recommendations.

CHAPTER THREE: THEORETICAL FRAMEWORK AND RESEARCH METHODOLOGY

Introduction

This thesis draws on social constructionism as a theoretical framework to structure and inform the analysis of the findings. This chapter starts by situating the narrative research approach, also known as narrative inquiry, within the framework of social constructionism, starting with an overview, then focusing on how it allows an understanding of participants' social and cultural worlds. This also includes understanding the self and racism, and inequality as socially constructed problems. The alignment of social constructionism's theoretical and conceptual framework with this research's aims and methodological processes in epistemological and ontological terms is discussed.

The next section presents the narrative research methodology used in this research that adopts a qualitative research design with interpretative narrative approaches in understanding how meaning is constructed from people's experiences. The narrative methodology is also known as the narrative inquiry or biographical approach. The underpinnings of the narrative approach, the narrative research process, ethics and data collection methods are examined before finally addressing the analysis. The data was analysed using a 'hybrid' of narrative and thematic analysis to gain insights and understand participants lived experiences allowing some stories to remain intact and not disjointed.

Reflections on narrative research and the researcher's positionality in conducting this study are discussed. The final part of this chapter examines some of the limitations of the research methods.

Background on social constructionism

As discussed in the previous chapter, social constructionism is based on specific assumptions about reality, knowledge, and how people make sense of the world. Holzner (1972) asserts that cognitive activity and its effects on the social structure, including the construction of ideological knowledge, are all socially constructed. A social construct is an idea that has been created and accepted by the people in a society, not an objective reality, but as a result of human interaction and collaboration (Galanes and Leeds-Hurwitz, 2009). Therefore, it exists because humans agree it exists.

Social constructionism and social constructivism are sometimes used interchangeably, but they differ. Social constructionism, which this thesis adopts, focuses on how people come together to negotiate jointly constructed understandings of the world. In contrast, social

constructivism focuses on how individuals learn in group settings. Social constructionism claims that humans and society socially and culturally construct knowledge and reality which cannot be discovered because it did not exist before its social invention (Ernest, 1999; Gredler, 1997; Kukla, 2000; Prawat and Floden, 1994). Therefore, social constructionism accentuates the importance of understanding society's culture and context and constructing knowledge guided by this understanding. Social constructionism views research as a social process. It does not occur only within an individual, nor is it a passive development of behaviours shaped by external forces (Kafai and Resnick, 1996). Therefore, individuals create meaning through their interactions and environment, as do researchers and research participants.

Postmodernism, to which social constructionism supports, rejects modernist conceptions of certainty, truth, and objectivity (Lyotard, 1979). It is based on a relativist epistemology positing that all knowledge is relative to one's location within a set of social norms (Potter, 2003), making the ontological position of social constructionism anti-essentialist, anti-realist (Burr, 1995), and it is seen to challenge positivist assumptions of absolute truth and objectivity (Cruickshank, 2012; Hibberd, 2001). Social constructionism focuses on social reality and views 'man as a social product' and society as a subjective reality (Garfinkel, 1967). On the contrary, the positivist approach sees society as shaping the individual, believes that 'social facts' shape individual action and researchers tend to look for relationships or 'correlations' between two or more variables, adopting quantitative research methods (Maxim, 1999).

Social constructionism derives from multidisciplinary sources such as sociology (Berger and Luckmann, 1966; Mead, 1934), philosophy (Lyotard, 1979), psychology (Collin and Young, 2000; Gergen, 1982; 1985; Guichard, 2005; Harre, 1981; Savickas, 2002), and postmodern approaches (Derrida, 1982, 1998; Foucault, 1970). It has influenced various disciplines, for example, economics (Cullenberg, Amariglio, and Ruccio, 2001), anthropology (Geertz, 1973), art (Heartney, 2001), literature (Ruland and Bradbury, 1992), and social work, the discipline that this research is based within (Flynns, 2021; Michailakis and Schirme, 2014; Parton, 2003; Payne, 1999). More relevant to this thesis, constructionist approaches in social work have been used to analyse discursive power orders between ethnic majorities and minorities, insiders and outsiders, social workers and service users, and gender norms (Michailakis and Schirme, 2014).

Scholars have increasingly asserted that human beings live in socially constructed realities, and meaning is not inherent, but it is central to social life and social interaction (Best, 2017; Cunliffe, 2008; Harris, 2006). Therefore, in research, individuals are understood by their identities, personalities, roles, and mode of communication based on the ability of the participants to convey meaning and intention and the ability of the researcher to grasp this

meaning (Cunliffe, 2008). Moreover, Berger and Luckmann (1996) suggest that knowledge is socially constructed, and facts are social products. Consequently, individuals are socialised in the world as they interpret the meanings of events and other subjective experiences. In doing so, we take on the world, the identity of others and, therefore, our own place and identity (Cunliffe, 2008), meaning who we are and who others think we are is not innate because people's identities are attained through social interaction (Holstein and Gubrium, 2000). In this thesis, the interaction and building rapport with participants was important in gaining their trust to share their stories freely.

Social work, power, and socially constructed problems

Many researchers have argued that numerous issues experienced by BME people, including those related to race and inequalities, are connected to power. By framing the research within a social constructionist framework, possibilities exist for challenging current understandings of BME people living with dementia's experiences of accessing DP by looking at its influence in wider society and BME communities. This framework also enables exploration of the role of the socially produced and governed self and how individuals negotiate and enact both individual and collective community identities.

Racism and inequalities discussed earlier are considered social problems that are socially constructed (Best, 2017; Holstein and Miller, 1993; Loseke, 2003; Loseke and Best, 2011; Spector and Kitsuse, 1977;1987). Ferber (2009) argues that racial categories are assumed to be 'natural' and 'essential', oppression, and inequalities are socially constructed and were created within racialised power relations. Therefore, a social constructionism perspective suggests that existing inequalities are neither unavoidable nor unchangeable. Furthermore, the social constructionism viewpoint is concerned with the meaning created by defining and categorising groups of people, experience, and reality in cultural contexts, which is all-important in this research. BME categories are always shifting, redefined, and contested in different historical and political periods across different societies, times and spaces, highlighting these social constructs. Therefore, social constructionism works well with social work and this thesis because social work is concerned with social problems to generate knowledge about causes, consequences, and solutions (Michailakis and Schirme, 2014).

Adopting social constructionism to understand power distribution allows me to explore power imbalance within health and social care services and the structures within social work. Constructionist approaches are relevant in current research in understanding BME people's experiences in a country where they are the minority and are sometimes viewed as outsiders. The ideas of Foucault (1980) form the foundation of social constructionism. He argued that knowledge was connected to power. Hence, a dominant perspective suppresses competing

ones, as it is seen with minority people who are often disempowered by dominant members of the society (Hansen, 2004). Chapter two highlighted how this power dominance continues to oppress minority groups today and negatively impacts their lives. However, given the relationship between knowledge and power (Foucault, 1980), particular theoretical positions are likely to be suppressed by the dominant voices and ideologies.

Societies are structured differently, with distinct power structures regulating how members behave. Therefore, social and cultural understanding limits the range of cultural meanings and knowledge about society and its institutions (Segre, 2016). Michailakis and Schirme (2014) proposed that modern societies are divided into different classes, subcultures, minority cultures, and others, therefore possessing different powers. Hence, they claimed that there are no agreements on causes and solutions for social inequalities and other social problems, hypothesising that it would be hard to establish if a problem is caused by the unfair distribution of wealth and resources or a lack of individual incentives and motivations. This research explores some of these complex and intersecting factors, such as if BME people's poor access to services discussed earlier is due to inequalities, limited resources, or personal and cultural reasons. This may lead to further questions about who is responsible, whether it is those in power, the individual, or a collective problem, and who should take action.

Social constructionist approaches have been used in studying the labelling and social categorisation of service user groups in social work identified as 'problematic identities such as criminals, substance abusers, refugees, immigrants…' (Michailakis and Schirme, 2014, p. 432). The group is portrayed as problematic, challenging or troublesome, and it is blamed for its social problems instead of critically examining the root cause. The problem does not exist socially until it has been defined as a troublesome social issue that needs to be resolved (Spector and Kitsuse, 1977). For instance, MIND (2011) recognised the dynamic and complex process by which dominant groups socially produce racial categories in ways that imbed social inequalities and marginalisation. They argued that organisations located the problems within BME groups and blamed them rather than the systems that oppressed them, resulting in social injustices and institutional racism. What is considered a social problem for particular groups, like minority groups, is defined by others, such as social movements, researchers, policymakers, politicians, scientists, and not necessarily the individuals themselves (Loseke, 2003). This suggests that labelling BME groups identify them as the problem groups, marginalising them further.

Flynn (2021) asserts that social care practices can be viewed as socially constructed alongside competing stakeholders' priorities. This is because a social constructionist lens would imply that social processes such as advocacy, lobbying, and raising awareness

alongside a critical stance on knowledge production may aid practitioners in negotiating the difficulties ahead (Burr, 2015; Gergen, 1985). Flynn (2021) argues that by this very nature, and as a historically and culturally specific moment in time, social care provides a valuable window of opportunity for practitioners seeking to bring change in the service they provide.

Culture is a social system of shared symbols, meanings, perspectives, and social actions and norms that people mutually negotiate in their relationship with others (Stead, 2004). Therefore, different cultures, societies, and people may have different ways of conceptualising dementia. Social constructionism is another way to examine how people understand and experience dementia as a socially constructed concept (Harding and Palfrey, 1997). Besides, this research does not aim to uncover new truths about the realities of BME people living with dementia but to understand how they make sense of their experiences, underlying power relations, and the influence of the environment and society they live in, making social constructionism a suitable framework for exploring this.

Research Methodology

Aims and objectives

This research aimed to explore if DP is an effective and culturally sensitive response to meeting the specific challenges faced by BME people with dementia, their carers and families. The knowledge gained aims to inform academic, practice and policy on the needs of BME people with dementia. It is intended that the research findings will contribute to ongoing scholarly debates discussed in the literature review chapter and provide insights to policymakers and practice in the planning, delivery, and evaluation of DP for BME people.

Research questions

1.   What are the experiences of BME people with dementia in Scotland?

    a)   What are the specific challenges BME people with dementia and their families face?

2.   What is the potential for DP to provide personalised services for BME people with dementia?

    a)   What challenges do BME people with dementia, their families, and professionals experience when accessing DP?

    b)   What are the benefits of DP for BME people with dementia and their families?

3.   What are the perspectives and experiences of carers, practitioners, and stakeholders who support BME people with dementia in receipt of DP?

Methodological approach

The qualitative research method was selected due to the exploratory nature of the research questions and to present a detailed perspective of the research problem. It also fits with social constructionism and narrative approaches discussed next.

Narrative methodology

This research uses a narrative methodology that adapts the interpretivist approach. Interpretivist epistemologies attempt to understand the complexities and meanings of interactions within social situations (Riessman, 2003). Narrative research studies how human beings experience and construct meaning in their world, and narrative researchers collect these stories and write narratives of experience (Gudmundsdottir, 2001). It provides an opportunity to generate insights that can be hard to gain from other methodologies (Polkinghorne, 1995; Riessman, 2003). The term 'narrative' refers to knowledge structures and storied ways of knowing (Cortazzi, 2001; Polkinghorne, 1995). Narrative research acknowledges that telling stories is conceivably the most natural way for humans to understand events in their lives (Polkinghorne, 1988). Muller (1999) suggests that stories are used to define who we are, to claim an identity. Other researchers have asserted that stories have the potential to validate the knowledge of 'ordinary' people (Coates, 1992; Reinharz, 1992). Moreover, for a growing number of years, personal storytelling is now seen as a valid means of knowledge production (Cotterill and Letherby, 1993; Fraser and MacDougall, 2017; Haydon et al., 2018; Riessman, 1990, 1993; Skeggs, 2002). Like some researchers, this study has focused on the narrative approach as a method of inquiry (Carter, 1993; Connelly and Clandinin, 1990; Gudmundsdottir, 1997, 2001). Therefore, the narrative approach as the phenomenon and the method (Connelly and Clandinin, 1990).

I sought to understand access to services and cultural worlds of BME people with dementia and their families. My research focused on answering specific questions related to their experiences of using DP. In this aspect, compared to more extensive unstructured narrative studies, it was a focused narrative study (Riessman, 1990;1993;2003). I took this approach because it suited both my research aims and questions and conceptualised human experience and the meanings people give to their experiences. The small sample narrative researchers work with to obtain rich free-ranging discourse (Roberts, 2002) suited my aim to interview a small number of people with dementia. This aligns with Cortazzi (2001), who proposes that in narrative inquiry, the emphasis is on storied participants' experiences through interviewing around the topic of interest. I also chose narrative methodology because of its ability to explore the construction of personal meaning and identity (Muller, 1999), fitting well with the social constructionism framework.

Social constructionism and narrative inquiry

In narrative inquiry, it is posited that experiences and reality are socially constructed, and people make sense of their world based on their social interactions (Ernest, 1999; Kukla, 2000; Prawat and Floden, 1994). The use of narratives is a way of thinking and organising thoughts typical to human beings and, therefore, closely reflects people's experience in everyday lives (Bruner, 1990), which is greatly emphasised in constructionism epistemology. A narrative methodology can be applied to access social and cultural conventions, emotions, attitudes, and motives that construct meaning for the storyteller (Cortazzi, 2001). This can then provide a deeper understanding of the individuals' lives and life experiences (Brunt, 2001; Johnson, 2001), which was of interest in this research. Social constructionism asks questions, often critical, political, and pragmatic, regarding people's choices in its generation of social and cultural knowledge. This is key in this research as it aims to engage participants in a dialogue that gives them greater freedom in exploring their stories.

In order to understand BME people's experiences without labelling and alienating them, as discussed in chapter two, Delgado and Stefanic (2017) advise that engaging stories can help the audience understand what life is like for BME people. They suggest that many victims of racism suffer in silence or blame themselves; however, stories can give them a voice and reveal that other people have similar experiences. They also argue that if race is not real or objective but socially constructed, racism and prejudice should be capable of deconstruction. Therefore, the narratives provided in this study may provide a language to bridge the gaps in imagination and conception that give rise to the difference among people and help reduce the alienation of excluded groups while offering opportunities for members of the majority group to meet them halfway. Moreover, CRT discussed in chapter two emphasises that without the voices of minority people and contextualising their everyday experiences of racism, a clear and critical understanding of their daily struggles with racism and inequalities would not be understood (Yull et al., 2014). Therefore, social constructionism is useful when working with marginalised groups or for cross-cultural work because narrative inquiry offers a different perspective for understanding, questioning and resisting inequality (Brunt, 2001; Indira, 2020; McCabe and Bliss, 2003). Indira (2020) argues that the narrative approach humanises knowledge. This humanising aspect makes it suitable for this research to interview BME people who experience intersecting discriminatory factors and people with dementia who tend to be stigmatised by society.

As highlighted earlier, we understand the self as largely a product of ongoing exchanges that transpire between people. Therefore, adopting a social constructionism position might contribute to a deconstruction of traditional conceptions of self, especially through

understanding people's stories. Hadden and Lester (1978, p354) asserted that 'we do not merely add to previous identifying activities but continually construct and reconstruct who we are, how we became who we are and who we might be in the future'. Self is a cultural phenomenon from a social constructionist perspective, and through narratives, we help individuals create and recreate preferred stories about self (Bruner, 2004). Therefore, social constructionism may help understand the construction of self of those with cognitive difficulties and, as such, is relevant to this thesis.

Numerous researchers (Barnett, 2000; Gibson, 2004; Robertson, 2010:2014; Surr, 2006) have found narrative approaches beneficial when conducting research with people with dementia because it allowed participants space and time to tell their stories. This is because narrative approaches can recognise people's strengths and engage them in active, meaning-making dialogues that may help the researcher move beyond a strict problem focus to a more social exploratory stance (Fraser, 2004).

Narrative research does not claim to be neutral, objective, and factual. It has been linked with non-scientific metaphors, with narrative researchers likened to chefs who see cooking as an art and do not try to stick to traditional recipes (Hollway and Jefferson, 2000). This greatly resonated with my way of thinking and working, whereby I do not view the world as factual and objective with one reality but that we create and recreate our experiences as we gain more knowledge and insight. Researchers' subjectivity is well acknowledged in narrative research (Ellerman, 1998; Lawler, 2002; Plummer, 2001), and calls for reflexivity are greatly emphasised. Anderson and Jack (1991) assert that a reflective journal may describe this subjectivity by taking notes during the research process on feelings that emerge and anything that may affect the subsequent interpretation of the data. Cunliffe (2008) calls for researchers to be aware of the power imbalance by becoming more thoughtful, careful, and reflexive in how they conduct the conversation and to offer insights into how they negotiate meaning about the experience of both the interviewer and interviewee. I, therefore, kept a reflective diary, which I will discuss in greater detail towards the end of this chapter.

In conclusion, considering a narrative methodology adapting interpretivist approaches was well suited for this research and fitted with social constructionism on the aspect that we create meaning to the experiences of our lives. Considering race and inequalities as socially created problems and dementia as a socially constructed concept, an interpretivist epistemology approach placed within the ontological position of social constructionism is best fitted to ground my research. The postmodernist basis of social constructionism that knowledge is socially constructed seems particularly aligned with understanding BME people with dementia

narratives of how they make sense of their experiences and circumstances as they access DP.

Viewing knowledge production as a social rather than an objective factual process makes social constructionism suitable for understanding not only the experiences of BME participants from a historical, cultural, and personal perspective but also how BME people living with dementia are positioned within society and how they interact with the organisations that support them.

Sampling strategy

This research examined the experiences of BME people living with dementia using narrative and semi-structured interviews to gather the data. Narrative interviews were used to collect data from people with dementia, while semi-structured interviews were used to collect data from carers, practitioners, and stakeholders, although they also had narrative interviewing elements.

Since my research drew on qualitative design, the sampling was not random but purposeful to encompass a range of cultural, migration, economic and social care services experiences. This was undertaken by visiting places where BME people frequent or seek services and organisations they were likely to engage with. As Denzin and Lincoln (2011) suggest, the researcher seeks out groups and individuals where the studied experiences are likely to occur in purposive recruitment. Purposeful selection can elicit rich data that gives in-depth insights into the subject of study (Creswell, 2003; Freeman et al., 2007; Glesne, 2006; Maxwell, 2005; Patton, 2002). Freeman (2000) argued that purposeful selection is a technique to access data and frame what matters as data. I was aware that the selection of participants also determines the data collected, the analysis of that data, and the interpretation. As Reybold, Lammert and Stribling (2013) suggest, I acknowledge that participants' stories were embedded in my choices and subjective judgements as a researcher, as well as the research questions, selection criteria, the interviewing and analysis skills.

The original inclusion criteria were interviewing 10 practitioners, 10 stakeholders, 10 carers, and 10 BME people with dementia. Later this was altered for lack of sufficient numbers. The initial logic of recruiting 40 participants from four distinct groups, each category having 10 participants, was grounded in the value of rich, balanced information and the emergent, in-depth understanding of BME peoples' experiences from different viewpoints and perspectives. However, the final numbers interviewed were four people with dementia: two BME people, one with DP, one without; then two white Scottish people with dementia, both with DP. One BME person with dementia met the three aspects of the inclusion criteria described below. I interviewed him three times to get a detailed description of his story.

The other participants were 13 stakeholders, 12 practitioners, and 10 carers. Eight were BME carers, not all managing a DP, and two were white Scottish carers who managed a DP. A total of 39 participants. See participants' descriptors in figure 1.

Participant Recruitment

Participants were recruited from both local authorities and voluntary organisations through gatekeepers, essential personnel who mediate between potential participants and the researcher and hold the power to grant or withhold access to the setting (Andoh-Arthur, 2019). The gatekeepers I approached were the managers of the organisations and the owners of care agencies. I already had established networks with various organisations and local authorities from previous employment. Initially, gatekeepers were sent all necessary information, including consent forms and information sheets, to be passed on to potential participants. Initial contact with organisations was made via email correspondence. See Appendices (2, 3, 6) for recruitment letters, consent forms, debrief and information sheets. Once participants had informed the gatekeepers of their willingness to participate, I was passed their contact details to get in touch. Others contacted me directly via my contact details in the information sheet and arranged interviews. However, researchers have challenges relying on gatekeepers for access to potentially vulnerable participants like people living with dementia. For example, Kay (2019) asserts that there are some personal and wider contextual influences of gatekeepers' decision-making, some are problematic and may result in a negative outcome for researchers in their request for authorisation for research. Prolonged negotiation may lead to significant delays in conducting the research or the abandonment of the research due to the challenges of acquiring informed consent (Kay, 2019).

I made deliberate research choices during the design of the research process. For example, informal access was negotiated at the beginning of the PhD with an organisation that works with BME people with dementia, especially those using DP and their carers. Unfortunately, the organisation went through major changes and could not honour my request due to capacity issues. Therefore, I had to try to reach participants through other methods. I designed a leaflet that was circulated through emails and organisations' newsletters and was put on notice boards. I contacted community centres and places of worship and attended several events targeting BME people, where I discussed my research with the attendees. As the above efforts became futile, I contacted two Asian radio channels that agreed to advertise my research and invite potential participants. I also contacted and emailed many organisations, visited some managers for introductory meetings, and explained my research in greater detail.

I was, therefore, placed in a spontaneous adaptation of my criteria due to the small number of BME people who volunteered for the research. This aligns with Reybold, Lammert and

Stribling (2013), who assert that some research choices are spontaneous and provoked by circumstance. I needed to make inclusion criteria more flexible to increase the potential for successful recruitment. Denzin and Lincoln (2005) refer to this flexibility as a mosaic of piecing together and editing parts into a whole with its own meaning and significance. These changes included a change of location to include the whole of Scotland. Also, participants no longer needed to meet all three criteria; for example, they were interviewed if someone was from a BME background and had dementia but was not using DP. This was because they could still contribute to the aims of this research. Also, a decision was made to include white carers who were DP managers for someone with dementia to contribute to the research objectives.

Despite all the efforts, it became apparent that there were various challenges in recruiting BME people with dementia and BME carers. It is a small population in Scotland to recruit. However, some organisations explained that it was due to stigma towards dementia. Others said it was due to a lack of trust. This links with some of the issues raised in the literature review chapter. Researchers have found greater levels of stigma, making it harder for BME people to come forward for dementia-related services and research (Berwald et al., 2016; Co et al., 2021; Hossain and Khan, 2020; Khan et al., 2015; La Fontaine et al., 2007; Mackenzie, 2006; Moriarty, Sharif and Robinson, 2011). Several gatekeepers said BME people with dementia and their families would not want to talk about it because it could be perceived as bringing shame to the family and community.

Due to this stigma, a neutral expression, 'memory problems', was also used in the leaflets and information sheet targeting people with dementia. This meant avoiding assumptions that people understood what dementia meant if it was unknown within the community. For example, when interviewing a BME person with dementia, I asked when he was diagnosed with dementia. He appeared very confused. His daughter rephrased 'your illness', to which he replied, '*oh my illness, my bad memory*'. Reid et al. (2001) highlighted that people with dementia might get upset or distressed if the researcher informs them that they have dementia. Therefore, initially, I relied on the gatekeepers' or carers' information and then met the people with dementia on their own terms without asking for any evidence or confirmation of the diagnosis.

Some BME people expressed that they get asked to contribute to research, and then no actions are taken, and they do not see any benefits in their participation. Jutlla and Raghavan (2017) found similar frustrations and dissatisfaction among BME participants. This difficulty was only experienced when recruiting carers and people with dementia from BME backgrounds. BME population have occasionally been referred to as 'hard to reach' for recruitment (Liljas et al., 2017; Manthorpe, 2009), although others have disagreed and

asserted that they might just be '*easy to ignore*' (Parveen et al., 2017). I found it complex and not simply hard to reach or easy to ignore, but there were many intersecting factors why BME people did not put themselves forward for research, making the recruitment more challenging. Some BME carers said they had responded to my request because they were aware that very few BME people would respond, and they felt BME communities needed to speak up strongly about dementia and care services.

Due to these challenges, I conducted two in-depth life-story narratives with the two available BME people with dementia. In addition, another life story was selected due to the richness of the data and narration provided by the primary carer, a daughter, unlike other carers' interviews that were services focused. The three stories complemented the findings from stakeholders and practitioners. The majority of those who volunteered were white and easy to access, and all had experiences working with BME people with dementia using DP.

BME participants with dementia inclusion criteria:

•   A diagnosis of dementia as confirmed by the gatekeeper organisation, family member, or self-disclosure.

•   In receipt of DP (this altered to include BME people who had dementia but did not use DP).

•   Identified themselves as being of BME background (added white people with dementia in receipt of DP to the sample).

•   Ability to speak and understand English (one participant's daughters offered to interpret).

•   Ability to give informed consent to participate in the research.

Unpaid carers' inclusion criteria:

•   Carer needed to be supporting a BME person with dementia and have some knowledge about their DP arrangements. (This was altered to include a carer supporting anyone with dementia in receipt of DP).

•   A carer was whomever the person with dementia identified as the main carer.

•   Ability to communicate in English

Stakeholders' and practitioners' inclusion criteria:

•   They needed to have supported a BME person with dementia in receipt of DP in the past 12 months or be providing support at the time of the interview.

The different stakeholders were from the voluntary and third sectors and were involved at various stages of advising, managing, and implementing DP. Some stakeholders' role was advocating for people with dementia or older BME people in accessing SDS. The practitioners worked for local authorities as DP assessors, DP reviewers, DP consultants, and managers.

Interpretation and translation

It was important to consider the potential language barriers and ways to overcome them in advance. I decided to address this by requiring the participant to have the ability to understand and speak English. However, this skewed an already small sample further, excluding many older BME people and migrants who do not speak English. Hussain-Gambles et al. (2004) argued that this could be viewed as a form of institutional racism. However, with the limited duration of my PhD study and without extra funding for translation and interpretation, it was impossible to recruit non-English speakers unless a family member was willing to be an interpreter.

One participant met other criteria but did not meet the language part, but his two daughters offered to translate. Literature cautions using family members as translators because they may not use language in the way that the researcher intends and may omit, add, condense or substitute information (Atkin et al., 2009; Mir and Tovey, 2003). Therefore, I ensured I asked for clarity, especially when the participant spoke longer than the interpreted information. It is also feared that using any interpreters may undermine the richness of qualitative data (Jutlla and Raghavan, 2017), and conversation might not flow in a three-way as expected in the narrative approach (Riachi, 2017). However, this did not have a major implication because the participant was very expressive, and I also have a basic understanding of his language, Arabic.

Table 1: Participants Characteristics (39)

Table 1, a: People with Dementia (4)

PWD: Person with Dementia

GENDER	PSEUDONYM	AGE	YEARS SINCE DEMENTIA DIAGNOSIS	HAS DIRECT PAYMENT	ETHNICITY
Male	Yosef – PWD 1 Not present, the participant was his daughter, the main carer. Therefore, Yosef is not included as person living with dementia because he was not interviewed, but his story is included as narrated by his daughter.	85	13 years	No	BME - Jewish American
Male	Kareem – PWD 2 Three interviews	82	5 years	Yes	BME - Arab
Male	Daniel – PWD 3	71	14 months	No	BME- Chinese
Male	James – PWD 4	53	5 years	Yes	White Scottish
Female	Anna – PWD 5	72	15 Years	Recently moved to DP from Individual Service Funds.	White Scottish

Table 1, b: Carers (10)

C: Carers

GENDER	CODE IDENTIFIER	CARED FOR PERSON	MANAGED DP	ETHNICITY
Male	C 1	Wife	Yes	White
Female	C 2	Mother	Yes	White
Female	C 3	Father	No	BME
Female	C 4	Father	No	BME
Female	C 5	Father	Yes	BME
Female	C 6	Father	Yes	BME
Female	C 7	Father	No	BME
Female	C 8	Father in-law	No	BME

| Female | C 9 | Aunt | No | BME |
| Female | C 10 | Grandmother | No | BME |

Table 1, c: Social Workers (12)

SWM: Social Worker manager and DP consultant

SW: Social Worker

SWR: Social Worker DP Reviewer

DSW: Duty Social Worker

CSW: Crisis Social Worker

OT: Occupational Therapist

GENDER	CODE IDENTIFIER	JOB ROLE	YEARS OF EXPERIENCE	ETHNICITY
Female	SWM 1	Social work manager and DP Consultant	42 years	White
Female	SWR 1	DP Reviews Social Worker	16 Years	White
Female	SWR 2	DP Reviews Social Worker	26 years	White
Female	DSW 1	Duty Social Worker	11 years	BME
Female	CSW 1	Short-term Crisis Hub Social Worker	24 years	White
Female	SW 1	Social Worker, Community Care	18 years	White
Female	SW 2	Social Worker, Community Care	5 years	White
Female	SW 3	Social Worker, Community Care	12 Years	White
Female	SW 4	Social Worker, Community Care	16 years	BME
Female	SW 5	Social Worker, Community Care	13.5 years	White
Male	SW 6	Social Worker, Community Care	10 years	White
Female	OT 1	Occupational therapist	27 years	White

Table 1, d: Stakeholders (13)

ILSM: Independent Living Support Manager

ILO: Independent Living Officer

SDS-C: Self Directed Support co-ordinator

PAM: Personal Assistant Organisation Manager

DIM: Diversity and Inclusion Manager

CEO: Chief Executive Officer and Managing Directors

GENDER	CODE IDENTIFIER	JOB ROLE	YEARS OF EXPERIENCE	ETHNICITY
Male	ILSM 1	Independent Living Support Manager	4.5 Years	White
Female	ILSM 2	Independent Living Support Manager	13 years	White
Male	ILO 1	Independent Living Officer and Personal DP recipient for 12 years and employs a PA	7 years	BME
Female	ILO 2	Independent Living Officer	1.5 years	White
Female	ILO 3	Independent Living Officer	11 years	White
Female	ILO 4	Independent Living Officer	1.5 years	BME
Female	SDS-C 1	Self-Directed Support Co-ordinator and Personal DP manager for her son for over 10 years	5 years	White
Female	SDS-C 2	Self-Direct Support Manager for people with dementia within an organisation that works with people with dementia	8 years	White
Male	PAM-1	Manager for an organisation that supports Personal Assistants	2 years	White
Female	DIM 1	Diversity and Inclusion Manager for 60+ BME people seeking social work and housing support, some of which is Self-Directed Support	20 years	BME
Male	CEO 1	Chief Executive Officer in support organisation that supports people receiving DP	7 years	White
Male	CEO 2	Managing Director and founder of care agency and that provides personalised	10 years	White

		support mainly to people using Independent Living Funds, Individual Service Funds and DP		
Male	CEO 3	Managing Director and founder of a care agency that specialises in providing personalised care to people with dementia using DP or other personal budgets	9 years	White

Ethical Considerations

I completed the University of Stirling General University Ethics Panel approval process, which was granted in December 2018. I also completed internal ethical clearance with a local authority to interview practitioners, see Appendix 1. One gatekeeper's organisation had extensive internal ethical clearance that I completed before gaining access to recruit people with dementia. Due to the length and for confidentiality purposes, this form is not in appendices. In both organisations, the additional processes were explicitly stating the participants' requirements, gaining consent, any identified risks, and how the information would be used and stored. The forms were sent to managers in charge of research, who approved the research to proceed.

I adhered to the British Sociological Association (2017), the Economic Social Research Council, and the University of Stirling's ethical guidelines and framework on confidentiality. I also abided by the General Data Protection Regulation (GDPR) 2018 and Data Protection Act 2018. This ensured that data on individuals was ethically collected, securely stored, protected, and participants' confidentiality maintained throughout the research.

Involving people with dementia in research

Section 51 of the Adults with Incapacity (Scotland) Act 2000 aims to protect people with dementia who lack the capacity to consent to research. The law states that 'no research should be carried out on any adult who is incapable in relation to a decision about participation in the research unless research of a similar nature cannot be carried out on an adult who is capable in relation to such a decision.' Therefore, I only aimed to involve those able to consent to this research. Since dementia is progressive, and people's ability to give informed consent may change and decline over a prolonged period or in subsequent visits (Dewing, 2007: Moye et al., 2006; Wilkinson, 2002), I was aware that a person's ability to consent could change during the fieldwork.

When researching people with dementia, they may be classified as 'vulnerable' to exploitation and abuse due to cognitive impairment, affecting communication and decision-making skills (Herrona and Rosenberg, 2017; Vandrevala et al., 2017); hence ethical considerations need careful attention. The Economic and Social Research Council (ESRC) (2017) advises that one may be considered 'vulnerable' due to age, disability, potential marginalisation, and disadvantageous power relationships within personal and professional roles. The older BME participants with dementia had an added intersection due to their age and race as protected characteristics under the Equality Act 2010. However, this does not mean that people considered 'vulnerable' should not participate in the research. ESRC's guideline advises that the researcher assess the participants' 'vulnerability' within their research setting and the potential consequences of their participation (ESRC, 2017). Robinson (2002, p.107) highlights that it can be powerful for people with dementia to know that they contribute to an understanding of dementia, as one participant in my study said, '*no one but us knows what it's really like to have dementia*', making me acutely aware of the ethical complexities of researching people with dementia and the potential benefits of including them in research.

Many researchers over the years have called to involve people with dementia in research and to focus on the individuals' lived experiences (Bamford and Bruce, 2002; Barnette, 2000; Bartlett, 2012; Bartlett and Brannelly, 2019; Clark and Keady, 2000; Dewing, 2007; Downs, 1997; Goldsmith, 1996; Hellstorm et al., 2007; Kapp, 1998; King et al., 2016; Kitwood, 1995; Leorin et al., 2019; Moriarty, Sharif and Robinson, 2011; Rivett, 2017; Samsi and Manthrope, 2020). In Scotland, some researchers have actively involved people with dementia in research and sometimes as community researchers (Bowes and Wilkinson; 2003; Clark et al., 2020; Kennedy et al., 2019; McKillop, 2002; Robertson, 2010; 2014; Rokstad et al., 2019; Ward et al., 2018). Some researchers have included people with dementia as co-analyst of the data (Clarke et al., 2018).

Informed consent

This section considers informed consent for people with dementia before discussing consent for the rest of the participants.

Informed consent for people with dementia

Interviewing people with dementia poses several ethical, methodological and practical challenges such as consent, considering the impact of dementia on the person, gaining access, and analysing data (Keady et al., 2017; Samsi and Manthrope, 2020). I had to carefully plan and consider how to conduct interviews with people with dementia ethically without causing any harm.

To give informed consent, a person must have enough understandable information about the research and be free to consent or decline voluntarily (Polit and Hungler, 1995). I designed the information sheet and consent form using large font and included some pictorial information. See appendix 2. One person with dementia found it helpful. She said:

'I am neurologically and visually impaired due to my dementia. I need this kind of information like your information sheet. I need pictures like this to guide me through it. It was very easy to read about your' research.' PWD-3.

Dewing's (2007) notion of 'process consent' is grounded in a person-centred approach in seeking consent from people with dementia. I was aware that people with dementia, while they may consent to the research, may experience certain difficulties with memory, communication, comprehension and retention of information (Alzheimer's Society, 2014). Therefore, I opted for Dewing's (2007) process consent to ensure that the participants understood the information from the beginning and throughout the interviewing process.

Dewing (2007) suggests that meeting the person with dementia in a favourable environment and in their best state of mind helps build trust with the researcher. Therefore, when planning, I asked the person about the most comfortable environment for the interview, a home visit or a neutral meeting point, like a local organisation office. I inquired about the best time of the day to meet when the person would be most alert and least disruptive to their routine. I was attentive to the fact that people with dementia do not like changes to their routine for easy navigation of their environment and to reduce anxiety (SCIE, 2020). I always asked the person where they wanted me to sit to respect their home environment. Samsi and Manthrope (2020) suggest that taking into account of setting is important when interviewing people with dementia. Ideally, I wanted to sit facing the person and maintain good eye contact, as this can enhance communication and interaction during an interview (Keady et al., 2017; Trevithick, 2005).

Dewing (2007) asserts that although the process follows five steps, it relies on the skills and expertise of the researcher to be able to engage and communicate with the person with dementia and continually be reflective during the process. Therefore, when interviewing and engaging with participants, I drew on my own professional experiences working with people with dementia as a care assistant, social worker, and on community projects. This included adopting a sensitive approach during the research process with good communication, interviewing and interpersonal skills. Also, critical reflection skills allowed me to reflect in action as I tried to determine if the person could consent to the research and during the interview. McKillop and Wilkinson (2004) advise that the researcher needs to be authentic, warm and genuine when conducting the interviews. If they are not, the person with dementia may notice

and be uncomfortable in an interview. Therefore, I ensured the person felt at ease before the interview by building a rapport. Building rapport is important to make the participants feel comfortable talking to the researcher, and it is considered a necessary skill for effective interviewing (Creswell, 2003; Trevithick, 2005). Thus, I allowed extra time before the interview to have an informal conversation.

During the interview, I outlined my intention to achieve process consent and clarified the purpose of my involvement and the research aims. I established the basis for capacity with an initial conversation and considered the person's personal well-being. I confirmed that all four people with dementia could consent because they were independent and already made most decisions in their lives. They all agreed to sign the consent form. For one participant, the daughter verbally translated the form before he signed.

Affirming consent was a process throughout the fieldwork (Dewing, 2007) and did not end when the participants signed the consent form. There was ongoing consent monitoring, and consent was revisited at every meeting and sometimes within the same interview. I assessed the consistency of the consent provided and that the person was willing to continue by observing the person's behaviour and body language. I also ensured that I communicated at a pace that matched the individual's abilities by monitoring their verbal and non-verbal cues for signs of lethargy, frustration, discomfort or needing to stop, as suggested by Slaughter et al. (2007).

Verbal consent

Sometimes written informed consent can be a barrier for BME people with dementia (Mukadam et al., 2011). I had considered verbal consent because some people from the BME background have had bad experiences reviewing and signing forms and may be hesitant. There were some cultural issues that I had to consider when asking BME people to sign any document because it could be viewed as official and risky (Emmel et al., 2007). It is also viewed as a western way of gaining research consent that many people from outside the UK may treat with suspicion (Brijnath, 2014). I observed that almost all the BME participants read everything on the papers, commenting that they wanted clarity on what they were signing, while some even asked follow-up questions. On the other hand, most white British participants quickly scanned the information sheet, with some commenting 'I believe you' and quickly signed. In my interpretation, this signalled the trust issues between BME people and professionals highlighted in the literature review, especially if they have been through complex immigration processes involving much paperwork.

The choice between verbal and written consent was explained, but all participants agreed to written consent. If verbal consent was preferred, I intended to read aloud the consent form to

the participants and ask them to say yes/no to each section with permission to audio record this. See appendix 3 for a consent form.

Written consent

The written information was accessible, without jargon or too much information on the piece of paper to allow easier understanding and processing of information. I verbally informed the participant of the purpose of the research and gave them time to absorb the information and ask any questions. Then participants were invited to sign the consent form. The printed information sheet was left with the participant for future reference and as a reminder of the purpose of the study. See Appendix 2.

Informed consent for other participants

All carers were requested to give written consent. However, BME carers were also made aware of verbal consent. I verbally summarised the information on the written consent form and information sheet, and then handed it over to the participants. They read it before agreeing to the statements and then signing and dating.

The practitioners and stakeholders were requested to give written consent. They were provided with both the information sheet and consent form in advance via email, but copies were also available during the interview. Time was allocated for reading, absorbing the information and signing consent forms before each interview commenced.

Anonymity and confidentiality

Pseudonyms have been used for participants in the case study findings chapter and codes for other participants to ensure they are not identifiable. Participants were informed of this measure during the consent process. Since the BME community is a smaller group of people, information that can easily identify individuals has been omitted, as have any identifiers of service settings. These are family composition, community status, specific details of the local area, their services providers and country of origin where there is a risk of identifying the person. However, participants will be unlikely to be identifiable after analysis and reporting the findings. I conducted member checking by sending the complete case studies back to the participants. This was to check the accuracy, the resonance with their experiences and whether they were satisfied with the level of anonymity. One case study was not sent for member checking for compassionate reasons, but all efforts have ensured the person is not identifiable. Birt et al. (2016) assert that member checking is used to improve the trustworthiness and credibility of the findings in qualitative research.

Participants were informed that their contribution would be confidential and I would not be sharing it with third-party organisations and service providers. However, they were pre-warned this guarantee could not be maintained if there was concerning information about the risk of harm to themselves or other individuals. Still, we would discuss such information in the first instance before consulting with anyone else. I reassured the participants that they would not lose their services by participating in the research.

If the interview took place at home, practical and ethical concerns regarding confidentiality were considered. I explored who could overhear the conversation and whether the participant was comfortable with the carer or PA's presence. This could be other family members, guests or staff members disrupting the interviewing process. Bassett et al. (2008) asserted that distractions and the presence of other family members during a home-setting interview have implications for confidentiality. All stakeholders, practitioners and one carer were requested to book a private room for the office interviews to avoid others overhearing the interviews or interrupting.

Risk of harm to marginalised groups

While recognising power and positionality in cross-cultural research (Merriam et al., 2010), I hoped to present an authentic and insightful understanding of the participants' experiences that would not further marginalise or disempower them. Salway et al. (2009, p.3) highlighted that 'Untheorised or insensitive inclusion of data on ethnic groups can lead to negative consequences including the creation of damaging stereotypes; exaggeration of differences between "groups"; and the production of culturalist explanations that ignore socioeconomic and political factors.' This was an ethical consideration I needed to adhere to: not to reproduce prejudiced misinformation that could damage and stigmatise the participants and other BME groups. Etherington (2002) emphasises the importance of developing trust and openness with the participants. I allowed enough time to establish rapport, trust, and respect. I also did this by being reflective, transparent, and sincere in the collaboration, clearly explaining the research objectives.

I ensured that my approaches and research tools were culturally appropriate to the participants and did not demean their identity. Therefore, I was mindful of the language I used. I explained to the participant with clarity what I meant by the term BME and allowed them time to express any thoughts they had about the terminology. Papadopoulos (2006) calls for research to be 'culturally competent'. He asserts that the researcher must accurately convey meaning for the broader context to be understood to avoid unintentionally causing harm or offence to the participants and the BME group they belong to.

Audio recording

With consent from participants, all interviews were audio-recorded because notetaking can interfere with the flow of the conversation, especially in less structured interviews (Creswell, 2003). It could also be challenging to remember everything while paying attention to non-verbal communication and how the participant expressed themselves, which is vital for narrative analysis (Reissman, 1993).

Safety

Working with the selected groups of participants was not anticipated to be high risk, and all participants had a choice of where they felt safe to have the interview. The university lone working safety policy was my guiding principle to reduce any risk of working in an unknown lone environment. A risk assessment was completed before commencing fieldwork, and safety measures were put in place, such as letting one of my supervisors know of my whereabouts if needed. I am a registered member of the Protection of Vulnerable Groups (PVG) scheme that ensures all vulnerable adults are protected from abuse and neglect.

Sensitive information and emotional risk

I was aware it is a sensitive area of study, with some participants talking about their health or close relatives' health and the challenges experienced. One participant said they had disclosed experiences they had previously not shared and narrated more than they intended to reveal. This may occur when using a narrative approach that encourages participants to tell their stories (Etherington, 2000; Reissman, 1993). Gabriel et al. (2017) call for researchers to be reflective when conducting in-depth qualitative research that is likely to be emotive for the participants. This called for a high level of reflexivity, awareness, and sensitivity during the fieldwork and analysis stage. As highlighted earlier, I drew on the associated knowledge and skills to manage the interviewing process and emotions and respond sensitively and professionally.

Some participants spoke of their memories of war, immigration, racism, discrimination, and antisemitism. For someone with dementia revisiting such difficult previous memories could be distressing and scary. Furthermore, psychological trauma is painful when it happens and causes continuing distress to the person (Flannery Jr, 2002). Flannery Jr added that someone with dementia might have coped well in the past with the painful memories, however, after dementia, these memories may become distressingly vivid and discussing the traumatic event may evoke the painful feelings associated with the original incident. Nonetheless, they appeared to have enough reflective grasp on their life experiences and narrated them as past

experiences without appearing traumatised by the re-telling of their stories. Narrative interviewing allowed participants to decide what stories they wanted to tell and in what depth.

Killick (2001) believes that direct questioning of people with dementia can lead to anxiety and increased confusion. He suggests that researchers allow time and offer encouragement to explore their perspectives. I allowed plenty of time for people with dementia to answer the questions. If the participant looked confused or upset, I enquired if they had heard me properly, and I repeated or rephrased the question. Where there were notable silences, pauses or gaps, I tried to distinguish if they were thinking pauses, boredom or distress and decided when I needed to interject. McKillop and Wilkinson (2004) call for greater flexibility and urges researchers to recognise if a person is becoming tired and re-schedule the interview for another date.

Some carers became emotional and distressed. I needed to give them space and time to recompose themselves, especially three carers whose parents were at the final stages of Alzheimer's disease. One carer's accounts of her father's life were sometimes painful and had to be handled with sensitivity while allowing her space and time to process the emotions. She said she found the process therapeutic. This aligns with Haynes (2006), who found that qualitative research used methods that enabled participants to tell life stories that had potential therapeutic effects. Keady et al. (2017) advise that researchers consider distress management in advance. Therefore, I checked with each participant how they felt at the end of the interview. When a person became distressed during the interview, I asked if they wanted a break or to stop the interview and continue another day.

Sometimes, practitioners and stakeholders became visibly agitated, frustrated, and angry with work processes. One practitioner banged the table out of frustration for feeling unsupported, and she said: '*they really don't care about us or DP*' SWR-1. Another, talking about LA, said, '*I get really mad sometimes, the service users are just a figure and a number to them*' ILO-4. While understanding some of their frustrations and emotions, I needed to maintain a researcher's role and not a therapeutic advisory social worker's role. Remaining mindful of this was necessary; otherwise, there was a risk of being left emotionally drained with feelings of helplessness since I could not help the person beyond the researcher's role. However, I also had to skilfully steer the participant back to the interview before diving too deep into their work stressors, even if they were partly connected to the research topic.

Samsi and Manthrope (2020) call for the researcher to establish a safeguarding protocol. To manage participants' distress, I scheduled any potentially sensitive questions later in the interview to build trust and rapport with participants (Trevithick, 2005). To reduce the chances of high emotional distress, I made participants aware they could skip any question that they

found distressing or uncomfortable. Participants interviewed at workplaces had access to other people they could talk to if they needed any support after the interview. Most of those interviewed at home had access to support staff or a family member nearby if required after my departure. However, I had support information for carers and people with dementia if they needed extra help. I also had Alzheimer Scotland dementia 24-hour free helpline (0808 808 3000) for anyone with dementia who wanted to talk confidentially to a dementia advisor following our interview.

I ensured that I ended the interviews positively by finishing with an informal talk to check if any participant needed further reassurance or support. This aligns with Samsi and Manthrope's (2020) suggestion that the researcher should manage farewell and exit sensitively. I was extra cautious with the person with dementia we held three interviews to ensure he understood when my role was ending, especially after he suggested we meet weekly. We marked the last interview with a cup of tea and biscuits as per his culture. This was important as Hillman et al. (2020) call for recognition that the engagement of participants with dementia and researcher occurs in social and cultural contexts, shaped by the interview and the meanings attached to it, and wider socio-cultural and political framings.

Methods of Data Collection

This research used both narrative interviewing and semi-structured interviews to gather qualitative data. I decided on one-to-one interviews because I was interested in individuals' perspectives without the influence of others, like in a group setting. By talking to the individuals and taking a narrative approach, I could fully explore answers that might otherwise be underdeveloped if answered in other methods.

Narrative interviewing

Narrative interviews were chosen for interviewing people with dementia to explore their lived experiences of accessing services and living with dementia. This approach was the most appropriate for the research because it was interested in how people with dementia make meaning of their experiences. Previous research has highlighted that narrative interviewing approaches are more likely to produce stories (Hatch and Wisnieski, 1995; Polkinghorne, 1988; 1995; Riessman, 1990; 1993) because they allow the participants to give more unrestrained responses (Mishler, 1986) that were needed in this study. This method allowed the participants to decide what narrative they wanted to share from the open question (see appendix 7). For example, when I asked a participant, 'tell me about your early childhood', the participant was free to choose what stories of their childhood they wished to share, easing them into the interview.

I used the open questions as a guide in case participants got stuck before the story started flowing. After the initial question, the order of the questions was not rigid because the interview process was determined by the stories or responses from the participants. Coates (1996) advises that narrative research interviewing takes up a conversation or dialogue style, encouraging participants to communicate their underlying attitudes, beliefs, and values in sharing their experiences. Narrative researchers advise that by entering a dialogue with the research participants, narrative interviews may unearth hidden or exceptional ideas that other interviewing methods may miss (Anderson and Jack, 1991; Berg, 1998; Borland, 1991; Harrison, 1996). I tried to achieve this by being flexible and taking the participants' lead. For example, some people with dementia started narration from their past while others started from the present.

The initial question triggering this was 'tell me about yourself'. This question was deliberately broad to allow the participant to start their story where they felt most comfortable before asking specific questions about services and dementia. The interviewer needs to be flexible and allow the stories to flow, as something that may not appear relevant initially may turn out to be related during analysis (Coates, 1996; Laird, 1994). Thus, it was important not to rush the participant (McCabe and Bliss, 2003) but to take the time to listen even if the story may have felt slightly off-topic at the time, which may happen in narrative approaches (Anderson and Jack, 1991; Hey, 1997). I was open to new understandings and different angles to the participant's story narrated by them, as encouraged in the narrative approach (Roberts, 2002).

This meant that even though I had the interview schedule (see appendix 7), I was not governed by it, which worked well during the interview by not breaking the narrative with more questions. Reinharz (1992, p.38) refers to this type of schedule as 'interviewee-oriented other than instrument oriented'. Despite the flexibility, the data was gathered carefully and systematically, focusing explicitly on those phenomena identified at the outset as interest, such as experiences of accessing services such as DP, dementia, and their cultural backgrounds. Lieblich (1998) refers to this approach as a focused narrative when the research looks at parts of the story rather than holistically, looking at the whole story with no limits.

Semi-structured interviews

Semi-structured interviews were utilised to obtain data from all carers, stakeholders, and practitioners to highlight the broader aspects of the topic. However, I used a narrative approach when I asked participants to give examples in short stories of the presenting issues and intervention using DP. During this mode of questioning, the interview was participant-led, but I occasionally prompted the person with follow-up questions about the case they were narrating to encourage the flow of the narrative account (Bauer, 1996).

I developed an interview guide with semi-structured questions see appendix 7. The guide had broad, open-ended questions related to the research aims and objectives that ensured that the participants were not responding with a yes or no (Creswell, 2003), which would not gather enough data to answer the research questions. Mishler (1986) has emphasised the importance of asking the right questions in the interview to generate the data needed. I only asked open-ended questions that were more likely to produce rich data (Reissman, 1993; Trevithick, 2005). I asked the same major questions in the interview schedule, but I still had the freedom to change the questions' sequence and probe for more information depending on the participants' responses. Reissman (1993) proposes that probes in a narrative methodology are often necessary to initiate the narration. This is known to elicit rich, detailed data used for qualitative analysis (Creswell, 2003), and my own data collection evidenced this. The interview guide consisted of some 'icebreaker' questions to ease participants into the process.

Data storage

Data was collected on an encrypted audio recorder, and all recordings were deleted after all information was transcribed and anonymised. Transcripts were stored in an encrypted password-protected drive on a personal laptop to which only I had access. Only I had access to the raw data for the study period. I stored the consent forms in a locked cabinet for the duration of the research, and they will be destroyed after my PhD thesis is submitted and corrections are done. They will not be kept past two years post submission.

Data Analysis

Data analysis was not a one-off exclusive stage but commenced during the fieldwork stage. I reflected analytically on my thoughts, impressions, and feelings about the interaction in the interview and wrote a reflective diary. I reflect on any possible biases and prejudices later in this chapter. This enabled me to generate ideas about what might be essential in the research and what might relate to literature later in the discussion stage. As I wrote findings drafts, I continued to do data analysis from the feedback I received from the supervisory team. They encouraged me to dig deeper into the data and think analytically and critically as I elicited more meaning from the presented data. This is the nature of qualitative research in which analysis is not a discrete stage of research but an ongoing process (Creswell, 2003; Hammersley and Atkinson, 1997; Roberts, 2002; Strauss and Corbin, 1998).

Transcribing

The data were transcribed manually verbatim. The extracted excerpts have been cleaned without changing words by removing filler words, pauses, and non-verbal communication. Not

all asides and short non-lexical markers (hm, nuh-uh, um, OK, yeah, eeeeh, mhhm, uh-huh) were transcribed. I adopted Oliver et al.'s (2005) transcription process that corrects grammar, removes existing noises and thinking pauses during the interviews, and standardises non-standard speeches and accents. Nascimento and Steinbruch (2019) assert that this transcription results in "clean" data, free of socio-cultural characteristics and information, and may improve the study results while it still seeks to be complete and faithful transcription (Cameron, 1995).

Some of the participants' repetitions and false starts were removed to make the presentation clearer and less repetitive unless to emphasise a point. I was committed to preserving the meaning of the text. Square brackets have been used to identify when words have been removed or replaced for anonymity.

Fraser (2004) advised that the narrative analysis approach allows the researcher to get close to the stories as compared to a third party doing the transcription. Doing my own transcription was time-consuming, but it allowed me to immerse myself in the data to gain detailed insights and start making connections (Nascimento and Steinbruch, 2019). Transcribing it myself also had the advantage of starting to elicit meaning from the data because transcribing is a form of interpretation and analysis as well as a technical process (Mishler, 1991; Riessman, 1993). Transcriptions are also beneficial because they offer a more accurate interview record than memory alone or field notes (Fraser, 2004). It was also expensive for a student to subcontract to a third party, making it financially more realistic to do it personally.

The interviews ranged from 30 to 120 minutes in length, with the narrative approach taking longer with people with dementia and some carers' interviews, generating 164,140 words of text for analysis.

Justification for selected hybrid data analysis method

A hybrid data analysis method was used. Narrative analysis and thematic analysis were combined to form Narrative Thematic Analysis as described by some researchers who have used a similar technique (Green et al., 2015; Held et al., 2019; Jones and Lynn, 2018; Ronkainen et al., 2016).

Both narrative and thematic analysis are distinct but compatible and can even complement each other (Shukla et al., 2014) and therefore worked well together in this study. They both lend themselves to constructionist paradigms that view people's experiences, meanings, and social structures as mutually constitutive by attending to what is said in the interviews (Held et al., 2019; Shukla et al., 2014). However, they differ in that narrative analysis focuses on how the personal stories are co-constructed between the participant and the researcher and

participants are encouraged to narrate their stories freely (Phoenix, 2008). In comparison, the thematic analysis looks across the data for repeated patterns of meaning associated with the study (Boyatzis, 1998; Braun and Clarke, 2006; Lincoln and Guba, 1985). It worked for the entire data set in analysing the emerging themes linked to wider social and cultural structures to achieve the level of analysis that I intended to answer the research questions. Although I will discuss them separately, I will also show how they merged.

Thematic Analysis

Thematic analysis is a method for identifying, analysing, and reporting patterns within data' (Braun and Clarke, 2006, p.79). I followed the thematic analytic process of Braun and Clarke (2006) because they considered it an effective way to organise and collate codes into broader sub-themes and themes. I followed their updated thematic analysis coined reflexive thematic analysis (Braun et al., 2019; Braun and Clarke, 2019) because it is theoretically flexible, organic, evolves throughout the coding process, and aligns with the narrative methodology constructionist paradigm adopted in this research. Braun and Clarke (2019) assert that the theoretical freedom offered by reflexive thematic analysis provides a flexible and valuable research tool which can potentially provide a rich, detailed, and complex account of data.

Since the theoretical understanding of BME people with dementia and using DP is limited, this approach worked well. It would have been inappropriate to conceptualise codes and themes too early in the analytical process, especially inductively. In the inductive approach, the researcher begins the analysis with a completely open mind with no preconceived ideas of what will be found (Creswell, 2003). However, I used my research questions to narrow down the scope of the research. The review of the literature also enabled me to start conceptualising my ideas. Braun and Clarke's (2006) approach provided the flexibility required to fully explore the extensive data and answer the identified research questions.

I used reflexive thematic analysis to analyse the entire data set from all four participant categories. I started with data familiarisation. This process began at the transcription stage, followed by several readings of the transcripts. Then I listened to the audio recording a few times before generating the initial codes and then coding the entire dataset.

Coding and organising data

The collection of rich qualitative data brings its own challenges in managing it (Bryman, 2008). I opted to use the NVIVO QSR 11 computer software to manage and organise the data for deeper analysis and insights into the data patterns. I developed a data coding system on NVIVO that allowed linking codes and categories to form overarching themes and concepts reported in this study. A case node is used to store, manage, and categorise themes, creating

an accessible coding system. Nvivo enabled me to easily hold and identify participants' information and retrieve it quickly through search options. I could also encode and move data conveniently or add annotations or memos.

Saldana (2013) defines coding as a method that enables us to organise and group similarly coded data into categories because they share some characteristics. Throughout the analysis, a flexible coding framework was developed to provide a clear trail of evidence and a record of how the analysis developed and continued to change throughout the process. A code was given to a sentence or a paragraph. I used InVivo code at the beginning of the coding process, which means descriptively naming a code directly from what the participant said. Many of the same codes were used repeatedly for different participants throughout the coding process, which was deliberate as the repetitive patterns and consistencies emerged. Some codes had 30 plus references from the 40 participants. However, some codes had less than 10 references. Different colours on NVivo were used to highlight these patterns. Saldana (2013) advises that when searching for patterns in coded data to categorise them, one needs to be aware that codes may be grouped together not because they are exactly alike but because they might have something in common, even if that commonality may consist of differences. This aligns with the way I categorised similar codes.

To identify patterns, I followed Hatch's (2002, p155) categorisation process that does not view patterns as stable regularities but constantly changing. Therefore, I looked for similarities and differences in the data, the frequency of what was said often or rarely. I also looked at the sequence in which things happened. All these enabled me to look for relationships and underlying concepts based on the combination of codes. Saldana (2013) asserts that coding is not a precise science but primarily an interpretive act. Therefore, what I coded depended on my interpretation based on my epistemological, ontological, theoretical and conceptual frameworks discussed earlier. Saldana (2013) maintains that codes can attribute more evocative meanings when a framework interprets data, meaning that 'all coding is a judgment call' since we bring 'our subjectivities, our personalities, our predispositions, and our quirks' to the process (Sipe and Ghiso, 2014, p.482–3).

Lincoln and Guba (1985, p. 347) maintain that during coding for patterns, we use classification reasoning plus our 'tact and intuitive senses' to determine which data 'look alike' and 'feel alike' when grouping them. Similarly, Braun and Clarke (2019) emphasise the researcher's role in the analysis and argue that they are not passive. They advocate that themes are actively generated through the researcher's active involvement with the data (Braun and Clarke, 2019). They strongly reject the idea of themes emerging from the data like they are

sitting there waiting to be discovered. Therefore, during the analysis period, I was very aware of my thoughts and always noted them down.

As suggested by Saldana (2008) and Braun and Clarke (2006), I coded and continuously reviewed and refined codes and categories, and first-cycle codes were later merged with other codes, relabelled, or dropped altogether. This stage involved systematically coding interesting data features. I continued rearranging and reclassifying coded data into different and even new categories. I generated 72 codes that were reduced to 36 codes, then 14 categories, and finally, five themes with 11 subthemes. In the final analysis stage, the major categories were compared, consolidated, and redefined where necessary until I was satisfied with the final categories and progressed toward a thematic and conceptual framework reported in the Findings chapter. Silverman (2005) suggests using this constant comparison for the validity of the study.

The more I analysed the data, the more questions emerged, which pushed me deeper to seek connections. I continued re-examining the data and returning to raw data when needed. Once coding had been finalised, I looked for vivid and compelling excerpts to report in the findings and counter extracts to support the themes and emerging understanding. I remained engaged with the data through the analysis and writing stage. The notes and memos I kept helped trace my thinking and guide me to the final conceptualisation that answered my research questions. Miles and Hubert (1994) assert that memos support all activities of qualitative data analysis.

Thematic analysis, however, has some limitations. According to Braun and Clarke (2006), it has the potential for not analysing the themes or producing a weak analysis because of too much overlap between themes or a lack of consistency. Another limitation is failing to adequately capture most of the data or failing to provide a rich description and interpretation of one or more aspects of the data (Braun and Clarke, 2006). Therefore, I tried to spend sufficient time analysing to fully understand the data's story. To have methodical scrutiny of the data, I took enough time to familiarise myself with it during transcription by reading and re-reading and noting initial ideas, thoughts, reflections and then reviewing and merging similar themes. After transcription, I also listened to all audio a few times, ensuring transcripts were accurate, gaining a deeper understanding of the data and generating more conceptualised themes.

Narrative Analysis

Narrative analysis was utilised to analyse narratives and stories from three BME people with dementia to maintain their wholeness. They were also included in the thematic analysis, but this meant reducing them into small segments and losing their richness. Polkinghorne (1995)

asserts that narrative analysis takes the story as its object of investigation to analyse how the participants made sense of the events and experiences in their lives. Narrative analysis fits well with reflexive thematic analysis because the narrative analysis is loosely formulated as it aims to understand lives in a social context and not through prefigured and narrowed lens (Josselson and Lieblich, 1993).

I adopted Reissman's (1993) narrative analysis, a paradigmatic approach to narratives, which moves from stories to similar elements or themes that can cut across the stories, characters, or settings to produce general concepts. I did this inductively, generating and developing themes and concepts from the stories instead of pre-defined ones. This approach combined well with thematic analysis that looked for patterns and themes across the three narratives.

The first task in the narrative analysis was putting the raw data in a coherent story that flowed by scanning for chronology, which has been deemed an effective method (Chanfrault-Duchet, 1991). This is called 'restorying', which is the chronological sequencing of personal accounts to create a context for a participant's connection to the research while prioritising the voice and input of the participant (Creswell, 2003; Polkinghorne, 1995). The participants' stories were not told coherently but moved from present to past and vice versa and from one subject to another. Sometimes parts of a story were narrated repeatedly to emphasise a point. There are multiple ways of doing narrative analysis, but organising the narratives in a case study was suited for this research, where the conversion of raw data into case studies was part of the analysis. This involved condensing the amount of the data without losing the meaning of the stories and disregarding some content that was considered irrelevant to answering the research questions. It was a lengthy and difficult process to convert the raw data into case studies because one storyline ebbed seamlessly to another.

As Riessman (2008) encouraged, I considered each narrative in its entirety. I examined how participants drew on their own cultural and societal positioning and constructed their responses, weaving detail from their past, present and future. Robertson (2014) considers this form of narrative research as a type of case-centred research, which has been used to understand the creation of meaning within an individual's account of their everyday life.

Using narrative approaches allowed me to consider context, commonalities, differing perspectives, assumptions, identity, and specific narratives linked to the aims of this research. Robertson (2014) advises that examining narrative connections across interviews strengthens the significance of themes and ideas, especially where there are competing interpretations or ambiguity. For example, if a participant expressed joy, sadness, disappointment, or satisfaction, Fraser (2004) advises that it can help decipher the particular meaning of the stories told. Occasionally, during the interview, I noted any non-verbal, visual gestures and

tone of voice that I thought were significant. For example, I noted down, '*I could see the light in his eyes fade*' PWD 2 when he moved on from narrating his happy childhood stories to his difficult political career.

The three narratives were then presented as case studies to ensure the participants' thoughts and opinions remained together and in context. I then generated significant and interesting texts related to the research questions and supported them with raw data excerpts. The case study structure ensured that the voices of the people with dementia were not drowned by the voices of practitioners, stakeholders and carers, where I have utilised thematic analysis. It also gives a more in-depth insight into an individual's life, which narrative inquiry offers (Etherington, 2000; Reissman, 1993). Through re-telling the three narratives, I aimed to create a written account of the individual's life from the stories to illuminate the meaning of their life experiences in ways that help us understand the complexities of BME people with dementia through storytelling. Following Riessman's (2008, p.57) interpretative use of narrative analysis, my intention with the participant data was to offer space for the stories that they told to be considered in both an individual context and in terms of making use of wider social and cultural values and discourses, grounded in everyday understandings. I was particularly interested in how participants positioned themselves and their values, how this translated into the services they received and how they coped with dementia.

The outcome of narrative research is a researcher-generated story (Reissman, 2001). My role as a researcher was not to produce a historical record but to capture the voice of people with dementia, their stories and offer a collection of overarching themes and subthemes. My challenge was defining the elements of the person's story to be told, identifying themes, uncovering important patterns, and re-telling these stories to provide insights and meaning.

A limitation of narrative analysis is that personal stories may contain overlaps and 'slightly chaotic' narratives, making it more difficult to organise them (Coates, 1996, p.56). Fraser (2004) asserts that this does not mean stories narrated this way are inferior to more literal and linear 'questions and answers' interviews**.** I tried to be sensitive in the way I explored the meaning created by participants narrating the story and how they expressed the fragments of their ideas. Sensitivity enables narrative researchers to navigate the stories' fragmentation, especially when discussing personal matters (Coates, 1996; Harrison, 1996).

Thematic identification of case studies themes

Riessman (2001) recommends unpicking further the themes that emerge when re-telling the stories and for the researcher to move from 'surface' to 'deeper' levels of meaning. The case studies were moved to NVivo, and the reflective thematic analysis (Braun and Clarke, 2006; 2019) discussed earlier was followed. The reflective and analytical process pulled together

the individual narratives and combined the main themes in each story or the main ideas the participants raised while maintaining the individual story's essence. Thus, participants' meaning of their story and the interpretation drawn from them was built within and across the three cases. This allows the exploration of connections between the stories (Etherington, 2000). Two overarching themes were presented in the main findings following the three case studies.

To familiarise myself with the data, each case study was read repeatedly and occasionally returned to transcripts and audio, noting any points of interest across all case studies. I generated the initial 55 codes, which were then reduced to 18 categories. I continued coding, reviewing, and rechecking the codes in the three case studies. I searched for similarities and disparities among the case studies. The process involved organising and collating the codes into broader themes and subthemes. In the first findings chapter, the two final themes and two sub-themes were defined, named, storied, and identified as having connections with the data's broader narratives. I identified extracts from raw data, re-read case studies and analysed to ensure the final themes reflected the data set as a whole. The compelling and vivid extracts were extracted from the transcript to report in the final analysis. This also helped to demonstrate the connection between the original transcripts and the developed themes.

The themes were embedded in the social constructionism framework, which was then interpreted with theoretical understanding discussed in the literature review and generated understanding from patterns in the data. Chapter four presents the themes from the complete data set, and chapter five the three case studies and themes drawn from them.

Limitations

Some researchers, especially those who use quantitative methods that adopt positivist approaches grounded in scientific evidence (Hansen, 2006; Pole and Lampard, 2002), question the subjectivity, reliability, and validity of qualitative research because they view it as theoretically flawed (Howe and Eisenhart, 1990; Scheurich, 1994). However, in a qualitative study, the researcher is often the study tool, drawing on their skills to receive information in a natural context, such as interviewing and uncovering meaning by the descriptive and exploratory procedure (LeCompte, 2000). Therefore, as discussed earlier, I relied on my previous experience interviewing service users and working with people with dementia to elicit thick descriptions and narratives that I have used throughout in reporting data in chapters four and five.

The generalisability of this research is limited due to its methodological nature, the small sample size, and its homogeneity in focusing on a small specific group from the wider population. However, the validity of qualitative research is often referred to as trustworthiness

or credibility and the use of coherent data (LeCompte, 2000), and the focus is not on generalisability. In this research, the sampling was purposive, meaning there was less emphasis on generalising from the small sample to the wider population but purposely recruiting participants who had the potential to produce rich, insightful information, as described by Patton (2002). This reveals the historical processes, the interactive features of the experience, and the researchers' interpretations (Creswell, 1998). However, purposeful sampling may have sampling bias due to the researcher's subjective judgement (Patton, 2002). Therefore, I applied ideas across concepts to interpret and understand the social construction of meaning from participants' experiences. I also appreciated the complexity and multiple realities of the generated data, aware that different interpretations exist. I sought different insights from the data. I also conducted member checking with two case studies, asking participants if it represented their experience and accurately captured their stories' essence.

Reflections On Researcher's Positionality

Reflexivity is the process of critical self-reflection through which researchers consider their positionality in relation to the research's cultural, social, and political context (Coghlan and Brydon-Miller, 2014). The researchers then need to evaluate how this may impact the research process and outcomes (Bradbury-Jones, 2007; Guillemin and Gillam, 2004; Stronach et al., 2007). The concept of reflexivity challenges the idea that knowledge creation is objective and independent of the researcher producing it (Berger, 2015). Denzin (2017) argues that there is no objective truth, and all research enquiry reflects the researcher's stance; therefore, there is no possibility of theory or value-free knowledge. Moreover, Meyrick (2006) emphasises that the qualitative data analysis process needs to demonstrate transparency and rigour. Therefore, it is critical for me to reflect on the research process.

The narrative methodology involves social interaction during fieldwork as the researcher interviews participants. Therefore, it was unavoidable that my physical presence and interaction with the participants would have some impact. A positivist approach that aims to be objective might view this as a limitation and a problem that should have been avoided. However, a constructionist views knowledge as co-constructed by participants and the researcher and data collection is shared by both parties (Silverman, 2001). Moreover, researchers bring their own theoretical assumptions and life experiences to the research, guiding their fieldwork and analysis (Braun and Clarke, 2019). Therefore, I needed to be critically aware and transparent about the assumptions I was bringing to this research. I needed to reflect on how my identity as an African black woman, my previous professional background as a social worker and adviser on direct payments, and my familiarity with race and inequalities issues influenced this study. I had also worked with some practitioner

participants as a colleague and some of the stakeholders as a link worker and an advisor. These identities came with a different set of responsibilities, perspectives, and dynamics.

I maintained a reflective diary throughout the research process, both written in notes, memos, and voice notes, to monitor my personal experiences and perceptions of the research process and any potential source of bias. This enabled me to reflect on the impact that I was having on the research and vice versa, from the choice of research questions, methodology, fieldwork, and interpretation of the findings. These reflective notes reminded me of my thoughts and feelings at different analysis points and why I made specific decisions and judgments. Glaze (2002) encourages using reflective diaries for PhD students to record reflections and observations during fieldwork to reflect on their research's subjectivity. Banister et al. (2001) argue that a reflexive approach to data collection and analysis should be viewed as essential and a resource rather than problematic. Therefore, I acknowledge and value the influences in this research as part of the research process.

Insider status

Research has illustrated that individuals' lived experiences, personal characteristics, and the professional background of researchers can affect the way they design the research, ask questions, use language, and adopt lenses to make sense of data, which, in turn, shapes the findings and conclusions of the study (Berger, 2015; Kacen and Chaitlin, 2006). Therefore, it is important to acknowledge my insider status as a BME researcher. There were some advantages to this position, such as understanding some shared experiences in a white-majority country and some similarities in cultural experiences, which can help establish a rapport and build trust. However, there can also be several disadvantages, such as a tendency to assume shared understanding and not probe deeply enough to familiarise some experiences and concepts. Although we were of BME background, we could have very distinct experiences. Some BME participants acknowledging our shared identity tended to say, 'As an African person yourself, you will understand this…' (SW-4), 'you are also BME, you know what I mean…' (C-6, C-7, DSW-1), especially when talking about issues on racism and discrimination. However, I ensured I asked for clarity and examples of what they were talking about and not always agreeing, I knew what they meant.

Although I had work-related knowledge of dementia, I had limited personal experience and could be seen as an 'outsider' to those with dementia (Mullings, 1999). One participant with dementia pointed this out, and I acknowledged her expertise in the area and my willingness to learn. I was also an outsider to white participants, former colleagues, however, could have viewed me as an insider to some extent, regardless of our ethnicity. Therefore, my insider and outsider status was fluid and contextual.

Self-evaluation and self-awareness were essential, especially in researching a topic I was very passionate about. In the reflective diary, I would contemplate my own feelings, biases, subjectivity, stereotypes, and even prejudices and question how I arrived at my interpretations. For example, when one BME participant discussed the 'caste system', a class classification still persistent in her country, I remember being surprised and a judgement creeping into my thoughts but trying to remain neutral, not to discourage her from sharing. At the outset, I wondered how it was linked to my research. However, allowing her time and showing interest, she explained the link of the 'caste system' and its impact when people from her community in Scotland are selecting PA to be employed through DP and wanting to employ people of similar castes. A stakeholder gave an example where a DP recipient considered a lower caste by a potential PA who was of a higher caste refused to accept the job after this discovery despite meeting all other requirements.

I also tried to be fully present when conducting the interviews, establishing I heard what participants said through actively listening (Trevithick, 2005). I ensured I probed further when a participant assumed my knowledge. A few practitioners inferred I knew what they meant because I knew the nature of the job. I would remind them it was over three years since I left my role, there could have been significant changes, and urged them to give me fuller details of what they meant. Some participants felt they were explaining processes and concepts that I understood well, mainly when they talked about DP, because I used to be their DP advisor and trainer, and it was awkward for some.

Those practitioners who did not feel confident about DP were hesitant to talk about DP processes because they feared that I might know the process better than them and they might contradict themselves. A few practitioners commented on their lack of confidence in talking about DP to me. Others used the awkwardness to point out how they had been abandoned with no DP team for advice and no DP training and resources. This made me feel like they were slightly blaming me for leaving my post and therefore had to deal with feelings of guilt as I listened to them. However, those who were confident in their DP knowledge did not appear threatened by my own knowledge. They wanted to highlight how things had changed in the last few years since the disbandment of the DP team, how they had needed to take on more DP responsibility, and for that reason, they were better informed.

It is important to acknowledge that some of the information I got from some participants was due to this insider identity. For example, some of the practitioners who knew me well and held multiple debates on inequalities, ethnicity, immigration, discrimination, and British imperialism in the past felt very comfortable exploring how these issues impact BME people's access to services. One white practitioner, in particular, challenged her positionality as a white worker,

trying to advise what BME people needed. When I asked her about BME people's use of DP, she said:

'*I think you are better off asking BME people. I do not want to speak for them with my white privilege. What I think as a white worker might benefit them might not be what they want, so the best thing is to speak to them and ask them.*' OT-1

While it could have been a tactical way to avoid the question, I was aware of how she was presenting her views and opinion because, as a colleague, we had created this platform where we spoke openly about race, the impact of imperialism and other structures of powers that continue to oppress BME people, especially when accessing resources and services. Another former white colleague with whom we had never engaged in race and ethnicity conversations was very anxious talking about BME people and their challenges. She felt it might be viewed as singling BME people out and treating them differently and should just be referred to as British. This is what I entered in my reflective diary:

'*T was not confident in articulating the identities of BME clients. She struggled to say where people were originally from and only said someone was British. But it was important to know if she was referring to an EU minority person, a white British person or a second-generation BME person to know if they met the research criteria. I felt that she did not feel confident in exploring sensitive issues affecting BME communities least I judged her being of BME background myself. She probably did not want to offend me or get it wrong. I wonder if it was a white researcher interviewing her, she would have struggled this much, or my race had an impact on how she felt.*'

In conclusion, critical reflection on my personal and professional background is an important part of qualitative research to identify the researcher's positionality within the research process and improve transparency and credibility.

Conclusion

This chapter has linked my epistemological and theoretical positions with my choice of a narrative methodology. I have discussed how narrative methodology using an interpretivist approach can be used to provide a deeper understanding of the individuals' lives and life experiences which worked well with the social constructionism approach in answering research questions.

Social constructionism is a helpful approach for understanding the subjective meaning individuals attach to their experiences by examining wider society's belief systems and how they contribute to the construction of self-identity. This socially constructed knowledge may then impact how they act and perceive their environment, social relationships, and different

events. Situating the narrative research approach within the social constructionism framework allowed me to understand participants' social and cultural worlds in their everyday lives. The postmodernist basis of social constructionism that knowledge is socially constructed seems particularly aligned with understanding the diversity and intersection of BME people with dementia experiences of accessing DP. This has also allowed me to explore social problems, race, dementia, self as social constructs and how social constructionism could enable researchers to apply a different lens in understanding how these issues impact individuals.

The main ethical issues discussed were gaining informed consent from people with dementia, and Dewing's (2007) process consent was adopted to establish continued consent throughout the fieldwork. I have also highlighted the importance of reflecting on the research process, participants' emotional risks, the researcher's positioning as an insider or outsider, and the biases or assumptions I may have had when conducting the research and analysing the data. The use of reflection and drawing on my skills as a social worker in interviewing people enabled me to elicit thick descriptions, allowing me to overcome some of the shortcomings of qualitative research on subjectivity.

Some of the recruitment challenges I experienced when gaining access to participants through gatekeepers were linked to BME people's belief in dementia and engaging in research, and others were the small population of BME people in Scotland.

A reflexive thematic narrative and narrative analysis were used to analyse data. They both lend themselves to constructionist paradigms that view people's experiences, meanings, and social structures as mutually constitutive by attending to what is said in the interviews. Thematic analysis was successful in looking across the entire data set for repeated patterns of meaning associated with the study, which helped in understanding. This was then complemented by narrative analysis that dived deeper into the three narratives to tell non-segmented stories highlighting the different transitions and challenges BME people with dementia face.

In the next two chapters, four and five, I report on the findings of the major themes, highlighting the challenges BME people with dementia experience when accessing DP and exploring if it is an effective delivery mode of meeting their specific cultural needs.

CHAPTER FOUR: FINDINGS ONE

Introduction

Using a social constructionist paradigm, the research utilises an interpretative narrative approach to understand how meaning is constructed from peoples' experiences. This approach has led to a deeper understanding of participants' social and cultural worlds.

This chapter focuses on research questions that explored the experiences of BME people with dementia in Scotland. The questions were also used to examine if DPs are an effective and culturally sensitive response to meeting the specific challenges BME people face living with dementia, together with their carers and families. In this chapter, data is drawn and analysed using thematic analysis from interviews with people living with dementia, carers, practitioners and stakeholders to reveal several themes that elucidate DP's barriers and potential benefits for BME people with dementia. Refer to table 1 for participants' codes and Appendix 8 for extracts from the reflective diary on data analysis.

The chapter starts with a discussion on BME people's perceptions and beliefs of formal and informal care in Scotland. The findings reveal how racism intersects with other factors, such as ageism, gender and class for BME people, impacting their access to services. The chapter highlights the many challenges BME people with dementia face when accessing services. Another main theme is how stigma and cultural stereotypes affect BME people. The chapter concludes by discussing DP and the personalisation of care for BME people with dementia in Scotland.

A distinction is made between different participant categories (people with dementia, carers, practitioners and stakeholders) where deemed necessary. Extra contextual information about participants is provided where the information is linked to who they are or other personal roles, for example, a BME practitioner or white carer. Excerpts from the interviews are used to illustrate participants' perspectives and positions. Longer verbatim quotations are included where it was relevant to keep the unfolding story intact and illustrate the broader point being made. Narrative interviews were used for people with dementia, while semi-structured interviews were used for carers, practitioners and stakeholders. One BME person with dementia had multiple interviews (three), while all other participants were single.

BME People's Perceptions and Beliefs of Formal and Informal Care in Scotland

This section explores BME peoples' cultural and religious beliefs about care for older people and perceptions that may lead to BME communities looking after their own families instead of seeking mainstream services support. First, this section highlights participants' cultural beliefs

and perceptions about care as a duty and obligation for women within the household, making it difficult for BME families to seek external support. Second, the section discusses participants' perceptions about the lack of cultural sensitivity in mainstream services.

Care is perceived as a duty and obligation

Several practitioners and stakeholders believed that the strong sense of duty and obligation from BME families meant that many BME families only sought care in a crisis, limiting their chances of receiving a DP. One stakeholder said:

'If BME people do not seek support, they seek it in crisis when they go to the hospital, and that is not the time to talk about DP or consider it.' CEO 1

All eight female BME carers believed that it was their 'duty and honour' as daughters to look after their parents. They said this duty had been instilled in them from a young age because caring was regarded as a woman's role within the family. A few carers said it was a cultural expectation that was never questioned but accepted. Three carers said:

'*Care is seen as predominately a woman's role.*' C-3

'In Jewish culture, you are kinda expected you will provide care to your parents when they need it. It falls much on the women in the family.' C-7

'I have to look after my dad. In our culture, it is expected that you look after your parents, especially daughters.' C-5

A few carers said that many families lived in a multi-generational household in their countries of origin, simplifying the sharing of duties with the extended family. Most of the women did not work outside the family home, and therefore caring for older family members was seen as their work. One carer (C-4) advised that in Pakistan, in addition to the extended family support, there were cheap casual labourers employed as home helps, drivers and gardeners, affordable to most households, particularly middle and high-economic-status families. This made life more comfortable and manageable to support family members who needed support. The carer compared this with life in Scotland, where people mainly live in nuclear families, with no cultural gender restrictions in seeking employment. One carer said:

'*Here, everyone has to work to make ends meet. I cannot afford to just stay at home and look after dad and my children with no husband to support us. It is extremely hard, and I am so stressed, and dad won't see it another way. I am his daughter, and he expects me to do my part*'. C-5.

Therefore, BME families try to balance this duty and obligation to look after their parents and meet the demands of daily life in a country with different support networks and systems that are more individualised and not collective, as in their countries of origin. Several carers reported feelings of guilt for failing to do what they considered a cultural and religious duty. One carer said:

'*There is a part in the Quran which says, do you not know God is all-powerful and do you not know there is a time when you were a child, and you were totally dependent, and you became strong, and you will return to the childlike state. This is very powerful, and it puts it into perspective that it is part of God's plan. My personal faith means a lot to me. Dad took care of me when I was totally dependent on him, and this is not returning the favour, but it is doing the same for him and looking after him as he looked after me*'.C-4

A few BME carers and two BME stakeholders (ILO 1, ILO 4) said that the pressure to look after parents is not only within a household but also comes from the community. Due to this sense of duty, as some BME people's religion and culture have emphasised, families may object to external services even when they desperately need them. For example, most BME carers felt that a care home signifies a failure in their duty. Two carers (C4, C7) felt they had failed as daughters when their fathers were admitted to a care home and asserted it was never their decision. One carer said:

'*In my culture, when it comes to care home, it is taboo because I remember my mum saying we can't send your father to a care home because people are going to think we can't look after our own people. There is a big big taboo about people from BME communities going to a care home because it shows that the children were disobedient as they are expected to care for their parents in their own homes. They just think you don't care.*' C4.

The expectations from other BME community members create tension and dilemmas for the family needing support, which is compounded by feeling obligated by their cultural and religious duty. Thus, the concept of BME people looking after their own families is intricate. BME participants expressed a cultural and religious expectation to look after their families and elaborated on the challenges of meeting this obligation. This positioning of need and obligation was picked up by professionals who felt that the issue's complexity has led to an assumption and misperception that most BME people prefer looking after their own families. Some said:

'*In Muslim families, it's considered that the family should look after their loved ones. It's a duty for people to care, especially when you're looking at it from the perspective of older family members, including those with dementia. So, with that generation, it is expected that you would look after the elderly when they need your care and support.*' ILO-1

'*It is difficult because BME people you go to will say we support our older people and say no to services. We say we can provide personal care for your mum every day, and they will say, 'no I do that', and it is what we can offer them'*. SWM-1

'Y*ou know how white [*CITY*] is, and the BME population is very tiny, and there is a strong culture of families looking after families, so they are less likely to come to us anyway.*' OT 1

Many BME participants said that the perceptions that BME people support their own families derive from the older BME people who see their family members as solely responsible for taking care of them. A stakeholder (DIM-1) highlighted that many older BME people did not plan their future care provision and house adaptation. She found this to be common with older, independent people living in affluent areas and with home accessibility already done privately. They struggled to envision future changes, suggesting a relationship between social-economic status and their choices.

There were notable differences in perceptions and attitudes towards the care of older people between the younger and the older people in this participant group. Although it is acknowledged that these cultural expectations may differ through generation, as expressed by two younger BME participants (C-10; ILO-1) and a BME person living with dementia (PLWD-3). One younger BME carer said:

'*My gran is very violent, and she needs a lot of personal care. The social workers in the hospital wanted to take her to a care home. They say she will be safer there, and they have tried to convince my dad it's the best thing for my gran, but my dad and my uncles did not want that. They wanted to look after her. I saw their thinking as the culture, the fear of shame and judgement from the community. I argued with them, and I said that a care home was safer for her and granddad, but they were against it and also, I am a youngster, so they couldn't listen to my views. I couldn't argue with them anymore. It is their mum, it is something they are doing in their own way, and what they think is the best for their mother even though I don't think the same way.'* C-10

Like this quote, many participants suggested that BME people feel responsible for looking after their family members, and they usually want to do it. Consequently, the challenges and assumption that BME people look after their families and do not want formal intervention leads to expectations within the family and community that care will be provided within the family and not by health and social care services. Moreover, they usually find that these wishes to look after their own families are further reinforced by negative experiences and perceptions of care services.

Lack of cultural sensitivity in mainstream services

Many participants across the different groups perceived mainstream services as lacking cultural sensitivity and delivered services in a 'one size fits all' model that further excluded BME communities. They felt that both community and residential services did not consider BME people's culture, religion, beliefs and traditions, including food selection and preparation such as 'halal' (per Islamic law) or 'kosher' (per Jewish law). Participants argued that this might lead to BME people not engaging with services due to their expectation of services being unable to meet these needs. Two participants said:

'*For us, our life and religion are not something separate. When we talk about halal food, it is not an option for us. There was no halal meat option in the care home; my father was forced to be a vegetarian by circumstance. People don't understand halal, and therefore they do not want to be involved, but it's our religious requirement.*' C-4

'*The traditional services are not structured to provide the time required to cook cultural food from scratch, which is important to many BME older people.*' ILO-3.

Several participants highlighted that some older BME people prefer family support because they fear mainstream services would not understand their religious beliefs and practices. One stakeholder (ILO-4) said many Hindu, Muslim and Jewish service users expressed concern that the services would not understand their religious observations on personal care and hygiene. Cleanliness was considered an essential requirement in Islam, and one has to be in a state of 'taharah', meaning they must be clean 'ethically, physically, and morally' (C3). Another carer said:

'*There are religious barriers, we are Muslims, and our ways of cleaning ourselves is different because we pray five times a day, and we have to clean ourselves five times a day, and we have a certain way to clean ourselves. Scottish carers don't know; for example, they will use the same cloth for the whole body. As Muslims, we can't do that. We use separate face cloths for different body parts. That is why it is difficult for us Asian people to get the carers in because we need our personal care provided in a certain way.*' C-10.

Still, when formal care was provided, a few participants observed that BME families did not trust paid carers to provide culturally appropriate care. Two practitioners (SW-1, SWM-1) noticed that some paid carers had been chaperoned by a family member when providing care due to this lack of trust. On some occasions, the family had already completed the required personal care tasks, defeating the purpose of the mainstream service offered. Some BME carers said they were anxious about leaving their family member to be supported by an unfamiliar person. One carer said:

'*There is a trust thing, that is us as a family not trusting that a stranger or an outsider will provide the required care in the way that we would want it sensitive to our cultural and religious needs. We hear all sorts of bad scary stories about personal assistants or carers, so we are hesitant to go down a route where [NAME] is left with a stranger.*' C9

Carer (C-10) also advised that despite her grandmother needing full-time care, the family were concerned about the treatment she would experience based on the poor care they had witnessed on a television program. They feared she might not express herself to the care staff without spoken English if she needed help or be treated differently because of her ethnicity. In addition, several participants felt the fear of being treated differently based on ethnicity, which led to some BME people deciding not to seek mainstream services for a person living with dementia. Therefore, the fear of mainstream services lacking cultural sensitivity was both actual and perceived due to things heard from others in the community and seen in the media. This actual and perceived fear links to participants' wider experiences of racism.

The Impact of Racism on Service Provision

Within this research, it was clear that broader societal and structural barriers were faced by BME people when accessing services. The findings highlighted that BME people experience racism at a personal, individual and institutional level, impacting their decisions about accessing various services. Several participants felt that health and social care did not adequately recognise and respond to BME people's individual needs because of this discrimination. A BME carer said:

'*People from BME are also scared to ask for help due to experiences of discrimination. I think racism and prejudice may play a part. When dad was in the hospital, I found this to be the case: one nurse kept referring to 'people like you'. My dad was declining in the hospital, and we felt we were not getting much support. As a family, we decided we would have him discharged, and we look after him ourselves.*' C-3

This view of BME people as 'other' may leave them feeling uncomfortable about seeking services. Several participants highlighted that sometimes it was not the actual treatment of BME people by services but their perception of how they are likely to be treated. A few BME carers and stakeholders thought that BME people felt judged based on general stereotypes, prejudice and assumptions about BME people when viewed as not contributing to society. A BME practitioner and BME carer said:

'*BME population still feel like second-class citizens in this country, so there is that biased treatment. For people with dementia and the older generation might feel they are not even entitled to ask for support, that self-understanding and awareness you are an immigrant and*

should be grateful for being here. So, they feel they are asking for too much, asking for a service, and we must be in our place. This is self-discrimination. We are discriminating against ourselves too. But also, society plays a part, so it's both us and society, especially with the populism that we are in, Brexit and everything, nationalism coming onboard more, people are more wary of that and cautious that they must not ask for too much.' SW4

'*It's the presumption of the service providers when you go there, and they see you are from a BME background, they just assume you are there to abuse the system. It is really bad. I face that when I really do not have dementia or disability; imagine those who need a service. As a BME person, you are scrutinised more if you need service due to underlying assumptions we are here to take and not give. If something goes wrong, they just assume it is you who have done it even without investigating it. I feel that as BME, you always have to prove yourself and your worth. While a white person doesn't need to prove themselves*. C-6

The above idea of 'self-discrimination' and 'proving your worth' highlight how BME people might perceive their position in the UK. Furthermore, the findings highlighted that BME people might be disenfranchised due to their position within society and how others view them from the social, political, and economic spheres.

Many practitioners and stakeholders discussed institutional racism in service delivery. They felt systematic barriers linked to discrimination and inequalities made it harder for BME people to access services. They did not think services were deliberately racist but conceptualised it as 'structural racism', where services were only designed to consider the needs of the majority. A white practitioner said:

'*One of the barriers is institutional racism; it is especially white people accessing services. Because of that, the families from BME are not comfortable accessing services because they do not feel that those services are for them. People without equality do not feel services are targeting them. They feel unwelcome. I wouldn't say that organisations are racist or anything. They are open to receiving any client, but you find when BME people go, they do not feel they fit in, and therefore they will stop going; that is what my client did.*' SW-6.

In this quote, there is an element of 'othering' BME people and homogenising their needs when the participant says that organisations are not racist because they are open to receiving everyone, minimising any possible racist practice. In comparison, a white stakeholder reflected on inherent institutional racism in her organisation. She said:

'*Some of the racism is systemic. I don't know if it is fair to say that we are inherently racist as an organisation because the country we are in is systematically racist. I just think we are not prioritising it high enough as an organisation, and there is not enough drive.*' SDS-C2.

Several white practitioners expressed a lack of confidence when working with BME service users and struggled to understand their experiences of discrimination. They feared that not being familiar with historical injustices, conflicts and tensions between BME groups from different countries that impact them today could result in misunderstanding of race and ethnicity-related issues. A few practitioners said they had tried to seek culturally appropriate advice from a BME organisation or BME colleagues before visiting BME service users. One white practitioner shared:

'Trying to be culturally aware, I arranged to go with one of the workers from [BME ORGANISATION] *and see what they could offer. Then the son wrote a letter of complaint saying that I had just turned up in their house with an Indian woman, and that was inappropriate and basically saying I was denying them a service because I was a racist. The family were Pakistani Muslim, and she was Indian Muslim, and there are political, cultural and racist tensions between the two countries and communities- all that drama to do with partition and the war that Britain started removing itself from the empire.' OT-1*

The quote above demonstrates the challenges workers experience trying to be culturally aware and considering service users' backgrounds. Instead of finding it helpful, this family were aggrieved and felt it was unacceptable.

A few BME stakeholders felt that limited time, or workers lacking the required skills and knowledge, were used as an excuse not to tackle racism in practice and reach out to BME people to offer appropriate services. One BME stakeholder said:

'*Workers do not look for a solution to tackle racism; they say too much, too hard, I see inequalities all the time. The fear of getting it wrong becomes the justification for doing nothing. It's too complex, too hard work, and too time-consuming. Let us just leave it and let them get on with it themselves. I keep reading about hard-to-reach. It is such a small country they are not aliens you are trying to reach. So, people are left living in a very difficult situation; it's just horrendous.' DIM-*1.

Therefore, racism is a sensitive and multi-faceted issue that is challenging for staff to tackle, especially when it intersects with different socially constructed sources of power and oppression. Also, consulting with key people and agencies and preparing before visits to avoid making mistakes does not equate to understanding all the different cultural differences among BME communities.

Racism intersections with age, gender, class and DP

A few practitioners and stakeholders argued that an older BME person living with dementia might experience challenges when accessing services because of their diagnosis, ethnicity,

and age. Therefore, racism may intersect with other factors like sexism, ageism and disability, adding another layer of intricacy for individuals living with dementia. One practitioner said:

'BME people come across other barriers, such as discrimination due to their skin colour in addition to the illness and disability they may have. Some people in the community may target them, and having someone with shared experience may help the client overcome wider society challenges and discrimination.' SW-5.

Therefore, several participants felt that BME people being targeted in the community would make their experience of living with dementia more difficult, compounded with fear of racism. Furthermore, participants found it hard to determine if racism contributed to older people being disproportionately offered DP or whether it was due to ageist attitudes towards older people from the DP assessor. Several stakeholders argued that practitioners did not value and recognise how DP could support older people with dementia. Several participants said:

'*It is difficult to know when people not getting DP is linked to their race, their age or other factors. So, if someone says they think they were discriminated against, we need to examine that by listening to them asking about their experiences, then we see how we progress. But the cultural narrative is that we ask all the time how we can help and then do nothing, and that is why BME people are not engaging.' CEO-1.*

'*If you are a younger person and your DP is in lieu of day centre, and you want to use that to go to the gym, fine we can sort that for you, but if you are an older person with dementia, and your package is personal care, there is a limit to how you can be creative and flexible with that.*' OT-1

'*I think there is something discriminatory in not offering DP to older people with dementia because if we were looking at peoples' outcomes, then social workers wouldn't ignore them*.' SDS-C2

However, some participants argued that these attitudes could be partially based on DP legislation. For example, when DPs were first introduced by Community Care (Direct Payments) Act 1996 for people below 65 years, DP was not an option for older people assessed as needing community care services until its amendment in 2000. Therefore, this age limiting enacted legislation could have contributed to the attitude that DP was not meant for older people, as mentioned by one stakeholder:

'*I think in terms of people with dementia, if you were over 65, you were not offered DPs. There was no access, and it was the way they implemented it from the legislation. It was also* [CITY] *policy.'* ILSM-2.

Two decades later, many participants still highlighted this inequality, that older people continue to be disproportionately not offered DP.

Some BME carers' participants highlighted that their experiences of racism, sexism, gender roles and how BME people are viewed in society as not contributing to the economy might cause them not to seek services when needed for fear of discrimination. Several participants described circumstances where BME women living with dementia might be differently impacted when racism intersects with their gender and social-economic position. One BME carer said:

Care is seen as predominately a woman's role. Men came here to the UK to work and arrived first then brought their wives over who tended not to work… the majority stayed at home looking after the home and children, very traditional outlook'. C4

Staying at home reduced women's financial independence and integration into the broader society. Some practitioners felt this left some BME women living in poverty, powerless, and unable to learn English, making it harder to access services independently. If they had dementia, practitioners felt they would be further marginalised when accessing services and disadvantaged when accessing DP in a climate where topping up extra funds to the DP budget was becoming the norm. One practitioner said:

'*I know through research; working-class black women are the worst paid and have the worst terms and conditions in this country. Poverty and inequality affect a lot of BME women, and their voices don't get heard, which then impacts their care in later life. People with the biggest voice are the ones who get heard, and they are wealthy.'* SW-6.

Class may then intersect with these factors, with those in the working-class impacted more in accessing DP than those who are wealthy. Several participants viewed middle-class older BME people with dementia as having better DP outcomes because they could afford more expensive care and had experience employing staff privately. One stakeholder said:

'*Affluent people and professionals are the main ones who opt for DP, especially older people and those with dementia. I have worked with a few who are BME but all very wealthy families who were doctors, lawyers and other professions. It works better for them because they can top up. The system seems to favour those who can navigate the system, so then you find DP are very inequitable, and it's those who are wealthy, educated, and articulate get them.'* ILSM-2

Wealthy middle-class BME people's cultural and linguistic barriers were not as pronounced as indicated by this practitioner:

'*I had a BME lady with dementia. She is of a wealthy background. The family had already employed a PA privately when they came to us. So, I don't think there were barriers. The cultural issues are different when the person is middle-class. A BME middle-class person has these standards they want to keep and can pay a top-up of the DP to stay at home, while a BME working-class person may only have what the council offers. We need to address all the inequalities so that egalitarian rights to services are not just for middle-class men. Class is alive and well in this country.*' SW-6

This indicates that when class intersects with race, there are different outcomes for BME people, favourable for those in higher socio-economic status than those lower. The idea of service 'topping up' the extra cost could be viewed as creating a tiered class system where only the wealthy can access a DP, highlighting the lack of equality within the DP. Therefore, there are complex structural barriers that BME people have to navigate as they access services. Some are actual barriers, and others are attitudes and perceptions of how they feel treated. For those living with dementia, their diagnosis intersects with racism and other factors such as age, gender and class, making it even more difficult to understand an individual's circumstances and access to services.

Dementia, Stigma and Cultural Stereotypes Within BME Communities

This section explores cultural factors linked to dementia diagnosis and stigma within BME communities. It examines the understanding of dementia from the perspective of BME participants, adding dementia as another point of intersection in BME peoples' experiences. Different BME communities understand and talk about dementia differently. In some BME communities, dementia is rarely recognised or spoken about. Therefore, several participants highlighted that it was seen as a shameful condition to disclose. They added that the perceived fears and shame connected to dementia discouraged some BME people from seeking support when needed.

Almost all participants felt there was little knowledge and awareness of dementia among different BME communities. All eight BME carers interviewed had not heard of dementia prior to their family member's diagnosis. They reflected that this was likely a common experience for many BME communities. Some participants discussed culturally specific constructs of dementia. A few said some BME communities viewed dementia as a 'normal' ageing process. Two participants said:

'*I think there is a perception within our communities that dementia is old age and it's a normal part of ageing, rather than seeing it as a condition.*' C4

'There is a stigma attached to dementia. BME people think it is an age thing, and it happens to everybody.' DIM-1.

Several participants said dementia was viewed as a mental health illness by some BME communities and not discussed openly due to the stigma attached to mental health illness. Others said dementia might be viewed as a terminal disease with nothing that could be done at the point of diagnosis. Two participants said:

'*I think if a Chinese person is diagnosed with dementia will just say, I am doomed, I am incurable, and even then, they would be very reluctant to admit help from social workers and medical people.'* PLWD 3

'We find there is a stigma towards disability and dementia from some BME communities. The culture doesn't acknowledge these people. Or, if anything, it is seen as related to mental health, which happens with dementia; then families will not come forward to seek support.' CEO-1

Several participants highlighted that once a BME person is diagnosed, they may avoid going out in the community due to stigma, or the family may keep them hidden at home. Carer (C3) explained that coming from a small Pakistani community, it was easy for others to hear about the diagnosis, and they viewed it as bringing shame to the family. Some practitioners and stakeholders suggested that cultural background and identity defined acceptable responses to dementia diagnosis and appropriate responses to services offered by the local authority. Therefore, accessing dementia services was perceived as socially and culturally unacceptable within some BME participants' communities. As discussed in the first section, some practitioners explained that BME community members might judge and ridicule BME people seeking formal care for someone living with dementia, resulting in a major dilemma for the family needing support. One carer said:

'*In the Asian community, if someone has dementia, there is stigma. They will keep it within the family and won't let other people know, so they don't get the support they need. Keeping it hush-hush means they do not access any services. Part of the difficulty in accepting council care is the shame and judgement from the community; so not accessing services there is a BME community and societal element but also a cultural thing.*' C-9

Several participants suggested that stigma and judgement may result in people with dementia missing out on vital services and their families struggling alone until they reach a breaking point. One stakeholder (DIM-1) feared that the person might not receive good quality care if the family could not provide it and are afraid to request it. Others felt that BME families become

estranged from community support, leaving them and the person living with dementia lonely and isolated, with people of higher standing faring worse. One carer said:

'*My dad was a well-respected man in the Pakistani community, we did not know it was dementia, but he sort of lost his filter a bit and was rude. He would say things that he wouldn't normally say, and people would stay away; they wouldn't come to visit. Those of high status in the community suffer more, and their families keep them at home to avoid shame. There is still a lot of awareness needed. I think my dad got lonely towards the end because people did not visit.*' C4.

Several BME carers advised that their community was highly patriarchal. Therefore, men developing dementia was viewed as a threat to their masculinity and critical role within the household and community. If the man could not participate in his expected duties, he would likely experience further stigma and be shunned from the community, deepening their isolation. One carer said:

'*There is a role that you play as a male in our society; a man is a provider and protector, and to be seen as vulnerable is not seen as a good thing. You feel it's shameful, but as time goes on, it's hard to hide a condition like dementia. Outside that, there is the pride aspect. In my dad's example, he always thought he was indispensable, so approaching support services is a NO NO, and he thinks we can deal with this by ourselves.*' C3

Therefore, stigma may diminish social networks and connections, leading to greater social isolation and loneliness for BME people with dementia. Some stakeholders and practitioners suggested that DP discussed in the next section could provide less stigmatising support in dealing with the dilemma of wanting services and feeling judged for accepting them. They argued that if BME people knew about the DP option, they could employ family PA discreetly. One stakeholder said:

'*Maybe if BME people were aware of DP, they might use it, but how do we reach out to them to tell them about DP in the first instance when they are afraid to talk to us because of stigma in the community.*' CEO-1.

This section has shown that participants viewed the consequences of cultural stigma attached to dementia as leading to families not seeking support. They also recognised that the impact reaches beyond the individual and may affect the entire household when viewed as bringing shame. Thus, they perceived stigma as part of a complex web that led BME families to decide not to engage with formal services. Therefore, participants identified that offering DP to BME people to recruit their own care staff may enable them to meet the assessed cultural and linguistic needs in a personalised way.

Retrieval of earlier cultural, religious and geographical memories

Another intersection for BME people with dementia challenges in accessing services was linked to complex personal, social and linguistic factors. Many participants highlighted that it was common for BME people with dementia to regress or return to their native or first languages as dementia progressed, complicating the recruitment process further. Participants described that the person may have been proficient in English before dementia, and DP was offered due to this language barrier with carers. Carer's (C-4) father had lived in Scotland for 61 years and was fluent in English; after dementia advanced, he reverted to his first languages, Urdu and Punjabi. Another carer's (C-3) father lived in Scotland most of his life and primarily spoke English. However, when dementia progressed, he completely stopped speaking English and reverted to Punjabi. One practitioner shared a similar experience:

'*…because the dementia was quite advanced and also because he was reverting back to his native language, and the dad was getting very confused, that was the main reason for offering a DP to employ someone who could communicate.*' SWM-1

Several participants explained that some BME people with dementia, after they stopped speaking in English, also lost other less familiar and not deeply embedded second and third languages making it harder to recruit a PA. One participant said:

'I*t can be quite challenging, especially for people with dementia who may have gone back to using their first language. They may have reverted back to a language that may not be common even among the BME communities. I have come across that it is easier to get PA's who speak the main Asian languages such as Urdu, Punjabi, Gujarati, Hindi, but if people revert back to the smaller, less unknown language, it might be that only family can speak it.*' CSW-1

Several participants perceived that reverting to languages unknown to the family, because only a small population spoke it in their childhood, left families without many recruitment options.

Participants described circumstances in which the previous memories of BME people with dementia became more vivid, especially their childhood memories. Despite having integrated and assimilated within the Scottish culture, some BME people also reverted in behaviour, cultural and religious practices. For example, a carer (C-10) explained that her grandmother repeatedly talked about Pakistan as her dementia progressed. She stopped wearing black and urged family members to do the same in respect for 'Kabba', the sacred Islamic Mosque in Mecca, as she had done when young with her parents. They felt that not wearing black was a more ingrained memory that she returned to.

In contrast, according to her religion, she had always used her right hand to eat. However, after her dementia progressed, she started using her left hand, which was not aligned with her religion because it was considered 'unclean', and the right hand was considered 'honourable'. The family concluded she may have been born left-handed but may have been forced to be right-handed for religious reasons. They thought that after developing dementia, she may have forgotten the Islamic teachings on left and right hands and reverted by default to what was physically more accessible for her. This demonstrates how dementia impacts BME people's early memories, and retrieval is not straightforward.

A few participants said that some BME people with dementia preferred the same personal food choices they had grown up eating. Others reverted to eating food from their childhood that they had stopped eating, as highlighted by these quotes:

'*Dad stopped eating what I had left out for him; there would be a plate of food for him, and he would push it aside and make a sandwich. He got into this strange routine where he would only eat sandwiches for every meal. I asked him if I could make his sandwiches, but he wanted to make his own, and it was the same sandwich all the time. I remember he would put a lot of mayonnaise on his fish sandwich like he is an East European Jewish guy again; he ate a lot of fish, and anchovies just like they did in his teenage years in East Europe. It was so unappealing, but he would eat that.*' C7

'*BME people do not want sandwiches for lunch. They have grown up eating hot food for lunch. A sandwich is not the food they would opt to eat in their old age.*' DSW-1

It was complicated how family members understood or interpreted the person with dementia's storage and retrieval of old memories, living in a different country from their childhood. They also occasionally struggled in helping the person make sense of their experiences because they did not understand it themself. For example, one BME carer said:

'*I think reverting to own language is also reverting back to familiar childhood memories. I think my dad thought he was in Pakistan. He was talking about 'Tanga', a small carriage used in Pakistan in his younger days before cars were popular. He would say that he has taken a 'tanga' and is now stuck there in the village and can't move. We would explain to him that, dad, you are not in Pakistan; you are in* [CITY] *in Scotland. I don't think he took notice. He was convinced he was stuck and needed to get a 'Tanga' to return home. He was very much reverting back to his childhood home.*' C-4

While this carer's father was in Scotland, but conveying he was in Pakistan, he may have been expressing an emotional state, such as not feeling safe, rather than physically needing public transport to return home. However, some of these long-term memories from the country of

origin would make more sense to family members than care staff born and brought up in Scotland, who might be unlikely to relate to 'tanga' or understand what the person is referring to. Therefore, participants identified that offering DP to BME people to employ a community or family PA may benefit some BME people in meeting cultural and linguistic needs.

DP and Personalisation of Care

This section explores the experiences of BME people when offered DP to meet their specific needs that mainstream services are not able to offer. It also looks at specific cultural reasons discussed by participants that make it necessary to offer BME people DP. This section will also discuss DP implementation. The participants highlighted the broader structural resources and legislative barriers that affect DP's implementation for anyone accessing DP. This section starts with BME people's offer of DP, followed by implementation processes and then the outcome of DP. It explores broader DP issues first, followed by issues specific to BME people and those living with dementia.

BME people's accounts of using DP

Many stakeholders and practitioners perceived that BME people were offered DP as a compromise due to the inability of mainstream services to meet their specific cultural, religious and linguistic needs. Practitioners also described circumstances in which BME people were offered DP when it was not the best option or objected to DP responsibility. Sometimes their capacity to manage DP funds was not assessed. Two practitioners said:

'Some BME people are just dragged to DP, oh we don't know what to do with you, so they are offered DP, but it was never explored with them if they could operate with DP properly. It can be used to fob them off. We don't know what to do with you; here is DP, go sort your care, kind of thing.' SWR-2.

'BME people are forced into DP, which has more complicated responsibilities. DP gives them a vehicle to have their services provided, but it doesn't always cater to their needs. You see what I mean; it is a catch-22 situation.' SW-4.

Therefore, this can present a dilemma for BME people who want their assessed needs met but without the complications of managing a DP. Moreover, several practitioners and stakeholders perceived that for some BME people, it was not always a choice they were making as specified in SDS legislation. One stakeholder manager said:

'DP, it's about choice and control for people, but I feel that a lot of BME people are being forced down that route to source their own support. Instead of the council funding agencies that can meet the language or cultural needs of BME people.' ILSM-1.

Several practitioners argued that offering DP to BME people was a strategic and economical approach from local authorities to absolve the responsibility of funding the BME-specialised organisations that provided culturally sensitive care for people with dementia. Many were closing or scaling down their services for lack of funding. Several participants asserted that the majority were smaller services with insecure funding. This meant BME people who relied on a specialised organisation for information, DP processes support and culturally appropriate services missed out. One practitioner manager said:

'*We have no alternative when BME organisations close, and BME people are being given DP and asked to get on with it, kind of attitude. It is really bad, it is really shocking, there is funding around, it's just how it is spent, and it could be used to develop a remit for BME organisations; otherwise, it is a poor show.*' SWM-1

Many practitioners and a few stakeholders described specialised BME services as a conduit that offered BME people information about formal care services. Four carers (C1, C2, C5, C6) managing DP for a person living with dementia argued that without third-party organisations supporting carers and BME people, they would struggle with securing DP and making it a success. One BME carer said:

'*It was* [BME ORGANISATION] *who filled the forms for requesting a DP and were supportive in giving me information. I really struggled to understand during social work assessment, and when they talk to you, they assume you know. Too much to figure out, so much paperwork, but I will be honest, the BME organisation helped me a lot. I also had* [CARERS ORGANISATION] *they do an amazing job. They drafted the contract and then did a lot of confidentiality things I did not know. I didn't know where to get insurance, but they gave me a list of insurance companies that cover PA. The* [SDS ORGANISATION] *drafted a contract between me and PA; they advertised the job, and, after that, they followed up; they are very good. I couldn't have managed to sort DP without the three companies that helped.*' C-6.

Some practitioners argued that the lack of resources and the shortage of council-commissioned services pushed more people to DP, not only BME people. They described how DP recipients compete with a limited pool of staff, because hospital discharge and LA waiting lists in the community were a priority and argued that the government was not doing enough. Two practitioners said:

'*After the assessment, it was sent to the service matching unit for option three* [COUNCIL COMMISSIONED SERVICE]*, but it had been sat there waiting for a long time. The social worker involved at the time had been phoning around to find an agency that could pick it up, and she found* [NAME OF AGENCY]*, which was not one of the council funds, so it was more expensive. So, she suggested they get DP and top up the cost.*' SW-2.

'*The Scottish Government can't say in all honesty that they are supporting people with dementia and BME communities if they are not funding BME and third-party organisations that support them. People cannot manage DP appropriately without the support they need. The buck stops with the government.*' SW-5.

Stakeholders, who supported DP recipients to manage DP, and several practitioners advised that when BME people were offered DP, they struggled to recruit the right workforce who met the specific cultural and linguistic criteria. One DP reviewer practitioner (SWR-2) thought the lack of appropriate recruitment staff might be the reason for large amounts of unspent DP funds from BME recipients and accounted for their needs not getting met. For example, one practitioner (SW-3) expressed how she 'felt awful' offering DP to BME people knowing that they would struggle to employ staff unless they already had someone in mind. Equally, a stakeholder (SDS-C 2) felt service users were being set up to fail by promoting DP to them without the availability of a workforce for recruitment. One practitioner said:

'*There were several issues because the family wanted someone who was culturally appropriate. It was hard for us to find because there is a shortage of care anyway, let alone finding a devout, Urdu-speaking, Muslim female carer. We really struggled with that. We tried for months and months, and we could not find someone.*' OT-1

Some participants felt BME staff recruitment would worsen with the reduced availability of immigrant care workers. Some stakeholders and practitioners argued that Britain had become more hostile towards immigrants, impacting BME people's recruitment of culturally appropriate staff. One stakeholder said:

'*There is the current political climate, and there are a lot of people coming into Britain who take up personal assistants role, but with Britain becoming more hostile to immigrants, that could result in fewer people doing caring roles. People are starting to worry what will happen to them with all the political turmoil if their personal assistants have to return to their countries of origin.*' CEO-1

Therefore, the perceived negative climate towards immigration demonstrates how structural issues impacted BME people's access to DP and PA recruitments. It connects to the earlier discussion on structural racism and BME people's challenges in accessing mainstream services. Participants suggested employing family PAs could mitigate some of the challenges.

Employing family and community PA

Many stakeholders and practitioners suggested that many BME DP recipients mainly recruited PA from family members, friends, or other BME people within their community, to source culturally, linguistically and religiously appropriate services rather than using a care agency.

Several participants viewed this concept of using DP to employ a family member as having both advantages and disadvantages. Some viewed it as a possible solution of enabling BME people to continue looking after their family members without fearing being judged or shamed by their community. They also felt that families were better positioned to understand the specific needs of the person with dementia. Two participants said:

'*DP is a better option for BME people. That is my impression of it, and you can tailor it to someone able to meet your racial and cultural needs.*' SWM-1

'*With Asian communities, it is not uncommon to identify a PA within the family who could actually provide support for an older family member. I am working with someone, and we are trying to recruit a PA to provide support for an older Chinese person with dementia. It is a challenge, and it is fundamental for that person to have a Chinese speaker because the service user doesn't speak English.*' SW-2

Many participants highlighted that BME people come from small communities, raising anonymity dilemmas when recruiting for a PA. They said that PAs are recruited from a small pool of people who might already know each other, making it hard to protect the privacy and identity of individuals. One stakeholder manager expounded on this by explaining how it can be problematic for BME staff who might meet BME DP recipients at cultural events. He said:

'*A BME staff was unable to offer a DP service because she already knew the family through her local Asian community, so there was a conflict of interest. This highlighted the fact that Indian, Pakistan and Bangladeshi communities are quite small communities. This raises privacy concerns because people can meet service users professionally, but they also meet them in social gatherings, which can cause various challenges. It can get quite complicated, especially in the Asian community, where there may also be issues about honour and status. So, if their PA knows another side of the family that they don't want to be known within the community, then that can be a problem.*' ILSM-1

Some stakeholders and practitioners thought confidentiality issues might be why some BME people prefer recruiting PAs outside the community. However, several practitioners and stakeholders highlighted a predicament for some BME people who want anonymity but not through receiving mainstream services. Left with few options, one BME stakeholder found that they chose to seek support within their community to remain connected and have a sense of belonging and safety despite the risk of anonymity. She said:

'*I have had a lot of people complaining to me about gossip within the community, but still choose to stay within their community. They say if I go outside the community, I do not know what will happen; they think they will be ridiculed or there will be a level of racism, so they stay*

within the community even if there is still gossip. Many tell me that I am so glad you speak my language, but you are not from my community. So they feel safe I am not going to spread the news. It is rather a strange mentality, and it's complicated.' ILO-4

This quote demonstrates that community networks are beneficial but can also present a barrier when anonymity cannot be upheld, compounded by fear of racism when seeking support outside the community. Furthermore, people who did not grow up in Scotland may not always have family and social connections.

This section has considered how the LA might absolve themselves of responsibility by offering DP to people whose needs they are struggling to meet. This might leave some service users at risk when they cannot recruit staff with the DP offered or face extra challenges discussed next.

Challenges affecting DP implementation

Various stakeholders and practitioners viewed the Social Care (Self-directed Support) (Scotland) Act 2013 as well-intentioned and effective in delivering health and social care services. They felt it was transparent in its aims and objectives and could make a real difference in providing personalised service to the people they support. They highlighted that it provided clarity to the Community Care (Direct Payments) Act 1996 and put it in the Scottish context. However, they also believed that due to the lack of funding, DP had been poorly and inconsistently implemented in all the 32 LAs, resulting in different outcomes for different service users. Many practitioners and stakeholders felt the Scottish government had not provided enough resources to implement the Act successfully. One stakeholder said:

'*The SDS 2013 Act is very broad, it is great and very clear in its principles, yet folks are blaming SDS, but I don't think the problem is the legislation. It is the fiscal environment we are in. It's been implemented in a time of austerity. We identified the problem but linked it to the wrong source.*' ILSM-1.

Austerity was perceived to have a considerable impact on SDS implementation and the size of DP care packages. Many practitioners expressed challenges in securing support for service users. Two participants said:

'*The DP nowadays doesn't work around many things for people, let alone BME people and especially those with dementia; the way it is just now, it's very rigid. It is losing its meaning and what it used to be, and it will become just another option three, but far more complicated. So, it's getting smaller and smaller monetary-wise, or it gets tighter and tighter in hours, and then you can't recruit, so if you are only assessed for 3 hours a week, what can you do for that? Nothing much. It needs to be more flexible.'* ILO-1.

'I have argued for families where they are really struggling. The situation is very challenging, but it is very hard to get a DP increase. The funding has been systematically reduced. There is a crisis in care and getting a package of care is like gold dust.' SW-6.

Similarly, two care providers' stakeholders (CEO-2, 3) have witnessed a significant funds decrease. They felt enormous pressures to provide good quality care, with a minimal level of DP funding straining their business. They felt families had to decide the needs to be met from their limited allocated DP and what was to be funded privately.

A few carers believed austerity had impacted their caring role and DP obligations. The reduced budget for the person they cared for meant providing more unpaid support. Some practitioners asserted that this extensive lack of resources has led to greater reliance on families. One practitioner said:

'*If informal carers stopped what they are doing, we would be in a worse crisis. We would be on our knees. No way we could do what they are doing.*' (SW-3).

This highlights the significant contribution from the informal sector, bridging the gap left by reduced resources. Several participants thought austerity led many service users to associate DP implementation with budget cuts, making DPs more restricted and less flexible. A stakeholder said:

'*DP gets a very bad reputation for cutting current cuts costs because it does cost less; but it does give you choice, flexibility and control to choose whom you want in your own home*' SDS-C-1

Several stakeholders and many practitioners commented on the impact of reforms to integrate health and social care:

'*The fact that integration stuff came so quickly on the back of SDS, it means that became the priority, and it has not been handled very well either. We have just been swamped by the culture of NHS. I think this in itself is causing a lot of issues and affecting the implementation of SDS'*. SW-5.

 '*…everybody took the eyes off the ball, and people were busy trying to put two big institutions together with limited funding.'* SDS-C2.

This section has argued that austerity and health and social integration were viewed by participants to have significantly interfered with an already complex DP implementation process.

Complex and bureaucratic DP processes

All participants who had been involved in any DP processes complained they were 'complex', 'problematic', 'bureaucratic' and 'messy'. They considered this a significant barrier to DP accessibility for most people regardless of background or health condition. However, they stated that BME people and those with dementia are likely to face added hurdles. Additionally, they expressed that the DP's assessments and approval process were problematic, tedious, inconsistent, time-consuming and unstreamlined, going through many resource allocation panels. Many also criticised the 'bureaucratic' banking systems some Local Authorities use. One frustrated stakeholder manager said:

'*When we make a DP referral for a client, the local authority might take six months for someone to pick it up, they have 28 days to complete an assessment but can take longer, then it goes to the resource allocation group, then to practice allocation group and finally a local enabling group. It is overly bureaucratic. A service user trying to get through that process with us and even with an advocacy service, it is not unusual for that process to take a whole year.'* ILSM-2.

The complex processes left many practitioners feeling frustrated, anxious, demotivated, and unenthusiastic about DPs. They identified a lack of clear guidance and mandatory DP training and felt under-resourced to offer DP confidently. One practitioner said:

'*We have just been dumped with DP basically the same way as some DP recipients have been dumped with it. The council don't care. There is no training of any kind, and managers haven't got a clue. It's the council that has been woefully inadequate rolling out DP and made such a mess.'* SWR-2

Many practitioners expressed that staff were under tremendous stress and viewed DP as added pressure. This then impacted how they felt about promoting DP to the service users as an option because they were 'spread too thinly' (SW-1). Another practitioner said:

'*The current situation is very sad. We have had people leave within the team, staff in tears, stressed to the blink, and redundancies and teams disbanded. Staff are never replaced. Our caseload is higher than it has ever been. All these have an impact on DP processes. Staff also avoid DP, even me, I run a mile; I don't want it.'* SW-3.

Many stakeholders and practitioners suggested that the lack of resources had affected BME communities disproportionately because of the extra funding needed within their DP packages, such as translation and interpretation. They said that social workers lacked resources to dedicate to DP, and, with the strict guidelines and tight eligibility criteria, it was harder to meet specific BME needs. One practitioner manager said:

'*Language is a big barrier, but it requires extra resources. How do you go to someone and say you are here to provide personal care if you can't even introduce yourself in a language the person can understand? You need to be compassionate and use words that are consoling, but how do you do that with someone who would not understand? So, BME people wouldn't receive a service if there is a language barrier.*' SWM-1.

Therefore, the way the DP is currently set up presents challenges for many recipients and practitioners alike, making it hard to implement despite any positive identified outcomes. However, participants highlighted additional obstacles for people with dementia accessing DP.

Dementia and DP decision making

Two participants with dementia (PLWD, 2,4), a family member was managing their DP, and one participant (PLWD, 5) was in the process of seeking support from a third-party organisation.

Participants identified the capacity to consent to DP as a major barrier for people with dementia. Many participants felt that people with dementia were disenfranchised when it came to DP assessment and allocation of funds because they were assumed unable to decide on the DP option. They added that even if people with dementia could decide on receiving DP, they would be unable to manage. One stakeholder said:

'*The person still needs to understand what a DP is and make an informed decision when choosing what option suits them, for example, why they want a DP? What would it be used for? What does DP entail? What are their responsibilities? And that is a challenge if you have a diagnosis of dementia, depending on the severity of course.*' ILO-3

Two participants (PLWD-4,5) strongly felt that the challenges of managing the DP when living with dementia were used as an excuse to deny them DP access. Their initial DP request was rejected because they were assessed as unable to manage, and services in place were seen to meet their assessed needs. They felt a power imbalance between the DP recipients and their social workers' relationship, given that practitioners decided whom to offer or deny the DP. They also wondered if practitioners feared they were putting someone living with dementia at risk by offering a DP. They said:

'*I called my daughter, and I said, you know I can get self-directed support and get a PA to help me with understanding the paperwork and the practical things. So, I told the council I wanted to go for Self-Directed Support. They said No No No you won't qualify, and I went, oh, so I can't get it? They went, we give you the best service the one you have. So, you feel they are out to persuade you not to go down that route. I don't know if they do this with everyone or*

just people with dementia whom they worry are putting themselves at risk, taking on DP.' PLWD-5.

'*The biggest obstacle to receiving SDS is social work because they seemed to think I was not happy with what social work could offer, and they thought using SDS to allow me to choose my own options meant I was putting social work at risk or social work staff. Social workers felt we were unrealistic. To use a self-appointed service, that we were insulting the social services by saying the direct service they were offering us isn't what was needed. We had to get an advocate to push for a DP. I even involved the leader of the council. I knew what I was entitled to, but social work had different views and thought I was being uppity and trying to use my previous position of power to further my chances of a DP grant. It was not until we involved a local councillor that we started getting somewhere, and it was then that the local authority granted DP. 2.5 years we had been fighting for DP.'*PLWD 4.

The above quotes highlight dilemmas the professionals face when trying to empower people with dementia by assessing them for DP while maintaining a duty of care. However, some participants thought that professionals had distorted views and perceptions of people with dementia's level of independence. They saw these views as impacting professionals' decisions on offering DP to people with dementia. Participants (PLWD-4,5) said that the struggle to get DP left them feeling disempowered due to professionals' prejudiced views and perceptions of their abilities in managing DP. One said:

'*When you get a diagnosis of dementia, you are always disempowered and kinda told you will lose this, and you will lose that you start to feel hopeless. The way professionals treated me during the direct payment enquiry, I just felt more disempowered. Like what is my purpose for being here? I am breathing and taking oxygen that really I am not earning it because I have always worked and always felt purpose, and I just felt this is awful; I did withdraw.'*PLWD-5.

Many stakeholders and practitioners suggested that people with dementia struggled to access DP because of the professionals' stereotypes and attitudes towards dementia. Some of these attitudes towards dementia were linked to a practitioner's role when assessing someone with a high level of needs and viewing DP as a risky option. However, several stakeholders thought the biased treatment towards people with dementia was due to practitioners' tendency to prioritise different outcomes, such as physical and personal care. Others linked it to the stigma and negative frame of dementia. A stakeholder said:

'*There is a low expectation of what life could be for people with dementia or what folks deserve or would need to live a good life. Home care is a life and limb support type model that is largely incompatible with people with dementia, small budgets, unfamiliar faces, and people being in and out of a person's home, leaving them confused. There is this knee-jerk reaction; you have*

dementia, so you need personal care. That is not the first thing people with dementia need. You get people with dementia who, yes, their cognition is affected, but they are physically very fit. They might need some support and guidance when out and about, which a DP would work well for them getting a social support buddy PA.' SDS-C 2.

Similarly, a person living with dementia said:

'W*ith my home care package, I had people coming in physically doing things for me, and I said that is not what I wanted.   They were used to someone older who needed help with washing and dressing and brushing their teeth and what have you, and I was saying no, I need prompting. I told them that this was not working. I have a busy life. I don't want people coming to my house and not being of benefit to me. I was beginning to resent that they were keeping me back; it wasn't two-way working as a team.'* PLWD-5.

These two quotes demonstrate what practitioners prioritised when assessing people with dementia. They fail to consider the need for interaction and connectedness within their social network. Therefore, participants PLWD-4 and 5 considered a need to address the bias they felt was inherent in the social work system towards people with dementia. They argued that people with dementia were perceived as passive recipients of care, and their expert knowledge of their needs and condition was overruled by professional expertise and judgment. Both participants were involved in dementia activism and felt that their personality, knowledge, and networks enabled them to access DP.

One said: '*I am a very stubborn, independent person with a strong personality*' (PLWD-5),

While the other one said: '*I could talk for Britain, I was the chief executive* [NAME], *I talk well, I am assertive, I know my rights and entitlements too.'* (PLWD-4).

They feared that other people with dementia may not be as vocal and persistent as them when dealing with professionals and had less likelihood of DP allocation.

Participants (PLWD-4,5) felt that they would not have managed to secure the DP funds without the support of an advocate. One said:

I think this is where having an advocate really helps. How can I put it politely? He did not allow the local authority to bamboozle me. My advocate knew how to write my support plan so that it was clear. He took in my visual impairment, he took in my dementia, and he listened. So, they were telling me you do not want to be doing payroll, what if your PA was sick? What about this and that? All things that would put you off DP. I just thought I couldn't cope with this, but the advocate told them that [ORGANISATION] *could do it. Then the social worker said they don't do all that. The social worker kept going on and on, and I did not understand what he*

was saying to me. I could hear the words and the pitch, but I couldn't make sense of it. Then my advocate said, you need to go back to the beginning; I do not think [PARTICIPANTS NAME] *has caught what you have said.*' PLWD-5

The above quote highlights the importance of advocating for people with dementia and their families during the DP process. Both participants felt that the advocate had been pivotal in their allocation of DP after the challenges they had experienced navigating independently.

This section has highlighted multiple challenges that a person living with dementia has to navigate when accessing DP. Some are communication barriers, the complex DP processes, diminishing resources and assessors' attitudes towards people with dementia. With DP assessment, practitioners may experience tension, with the person living with dementia, as the service user, being in control of DP and employing their staff. This arrangement raises fears of exploiting those living with dementia and opting for DP being viewed as adults at risk and putting them at greater risk of a poor care arrangement. This may result in an ethical dilemma of empowering people with dementia by promoting DP for assessed outcomes while maintaining a duty of care.

DP Outcomes for BME People with Dementia

This section explores how DP has been perceived to offer a personalised service to meet the needs of BME people with dementia. This included receiving support tailored to their individual needs, wishes and preferences. The first section will explore the benefits of DP for people with dementia. The second part will explore those that are specific to BME people with dementia. Despite DP challenges discussed earlier, many participants still believed DP was the most flexible option and likely to deliver personalised care. One stakeholder stated:

I have met people who have said they have lost seven years of their lives to a care agency. They say I have taken on a DP as a last result, and I wish I did that seven years ago. We don't have that kind of time to lose in our lives.' CEO-1

Consistency and continuity in relationships using DP

Several participants advised that having the same worker allowed the service users to get to know the person and form a good working or therapeutic relationship, enhancing a better quality of care. For example, a carer supporting his wife living with dementia and final-stage cancer found that traditional services did not meet her needs. He felt they lacked flexibility and consistency. While two participants living with dementia said that having familiar faces reduced anxiety that multiple carers may cause, and PA felt like companions, not staff. The importance of relationships is highlighted by the three quotes below:

'Oh, there was a huge advantage of DP in providing continuity. Let's face it, we are talking sometimes of end of life, but DP can still offer a better quality of this life and some level of enjoyment. The relationship is very important, and DP arrangement allowed that, rather than different people coming each day. There can't be another area of more importance other than that of relationship. It is dementia we are talking about. If we had multiple carers turning up today, tomorrow, and the next day there would be hell. I had trouble sometimes getting in my own home because that is the nature of the illness. I slept in my car a few times because my wife thought I was a stranger. Dementia has many arms and legs and affects people differently; sometimes, there is aggression, confusion, shouting and noise, but when you are frail like my wife was, she needed a gentle approach. The PA is an art therapist and music therapist, and they bonded well over these activities because my wife and I love music and art. So, DP can allow a better match between a support worker and cared for person and pursue a similar interest, so they both get enjoyment from the activity. That is the advantage of DP; they allow people to form a more genuine relationship with the people they support, and that is really important.' C-1

'*Flexible budget when you have dementia is amazing. It is magic. I can't explain it to you. You have the routine of knowing the person well. When I know* [STAFF] *is coming in, there is that feeling of relief, I can relax, this is good, and you know in the Victorian time you used to pay to have a pal or companion who helped you. That is what it is; it is like having a companion and not a support worker. So, a companion to go shopping with. It doesn't feel like you are being supported. Other people around you won't know that is your support worker because they do not wear uniforms. They get to know your family. They really become part of your family or your friend; DP is really a good option*.' PLWD-5

'*I don't think it would be useful for someone with my condition for a stranger to be coming at their door flashing a badge and saying they have come to take you out. I think the benefit of DP is the fact that I am seeing one person and having a relationship with one person while if it's a social work carer, they are sending in different people, which can be difficult, especially for someone with dementia*.' PLWD-4

These three quotes demonstrate the importance of relationships, especially when supporting someone with dementia. They highlight that a PA can support a genuine friendship, mutual understanding, and trust between the service user and the PA in these contexts. In return, the PA can utilise other skills and shared interests and provide more personalised services providing greater stimulation and enjoyment. Participants viewed PA companionship as appealing because it allowed service users to feel like they were out with friends or family, enabling them not to feel stigmatised like with uniformed staff. A stakeholder said:

'*The uniforms and the agencies approach de-personalises someone. So, you are another uniform. PA's are coming in they are wearing their own clothes, they are on your own time, so they will do what you want them to do.*' CEO-1.

Several stakeholders viewed the lack of PA uniforms as a possible solution in providing a more discrete service to BME people afraid of shame and judgement from their communities. However, this issue of uniforms illustrates that what might be viewed as a DP benefit might be mainstream service delivery shortcomings. Including the mandatory staff policies that may lead DP to appeal to those wanting to keep receiving care covertly.

Many participants expressed that DP allowed the PA to know the person's routine and how they liked things done, creating greater consistency in their care. One stakeholder gave an example of a daughter who opted for a DP because she was frustrated demonstrating tasks to multiple carers. He said:

'*It is the silly things that upset people. I worked with a couple who were managing DP for their mum with dementia. In two weeks, she taught 7-8 care agency workers how to poach an egg for her mum because that is how she liked her eggs. I don't mind teaching you once to poach an egg, but doing it 8-10 times with different workers it's easier doing it myself. With DP, you get the same person. You don't need to teach them a task over and over again. They know things that really matter to people. There is that closeness with the people, which adds to their quality of life.*' CEO-3.

This illustrates the benefits service users and families experience when recruiting and retaining staff long-term that offer continuity to the service user and family.

DP flexibility and choice

Many participants viewed DP as offering more flexible choices and better outcomes for people with dementia during personal care. Two care agency stakeholders (CEO 2,3) advised that LA commissioned services' allocation of 15-30 minutes slots were unrealistic to deliver a flexible service because they were too task-oriented. They found that DP allowed them to work flexibly with the person. Two stakeholders said:

'*We were hearing stories like, 'my mum takes 1 hour to go to the toilet', I asked what happens with the home care, and they would say 'nothing because first 10 minutes are used up arguing with my mum trying to get her to stand up.' So, if you have someone who will spend an hour there, they will have time to understand what is going to work. So, there is that aspect of DP allowing that.*' ILSM', 2

'*…if carer only has 20-30 minutes, then the carer has no choice but to wash this person who is confused and embarrassed about a stranger washing them. We are not too focused on someone having a bath every day, it is a generation who all their life had a bath once a week; traditional care assessment says if you get care, you get it seven days a week. You can't get it three times a week because it doesn't work with their rota system. Whereas, typically with our clients, using DP we will visit 3-4 times a week for a longer period rather than seven days a week for a shorter time.'* CEO 3.

The above quotes indicate that achieving flexible time availability was key and a mindset change in thinking about providing care.

Many participants identified that maintaining staff using DP offered service users flexibility by co-designing the care packages and being creative in how they were supported around the choices they made. They asserted that many DP recipients felt more in control of how their care was delivered. One participant said:

'*With Self-Directed Support, the first two words, SELF-DIRECTED are most important because it is self-directed. I can say to my PA do you fancy going for a coffee, do you fancy going for lunch, do you fancy going for a Guinness, do you fancy going to the shops, or we go for a walk or go to the theatre it can be whatever I fancy doing.*' PLWD-3

Some participants advised that by allowing families more scope and flexibility to decide how to spend their DP budgets, they developed unconventional, imaginative and cost-effective solutions that were attuned to their needs and personality that professionals may not have considered. For example, two participants said:

'*One lady with dementia we agreed she could buy a wheelbarrow she was working in a community garden. She really loves that and really enjoys having her wheelbarrow. She doesn't need to carry a heavy load, which is painful for her joints, and I think it is using it in a creative way that makes DP really good.*' SW-6.

'*There is no one size fits all for respite. I remember a client who had used his DP to build a shed because that was his wee man cave, and that was his escape or break from his wife, who had dementia. It was giving him respite*'. SDS-C1.

Therefore, LA having across-the-board rules for DP budgets might not always work because people have a different perception of care at home, respite or day service.

Many practitioners and stakeholders shared short stories and scenarios where DP had allowed greater flexibility, with some families opting to merge allocated time to have extended visits. Some of these stories are summarised here. They describe that DP allowed PAs to

have enough time to prompt someone to complete tasks and promote independence. For example, a stakeholder (SDS-C2) gave an example of a daughter who stopped LA commissioned service and applied for a DP for her mother with dementia. The PA would take her to the kitchen and support her in making a cup of tea, while with the commissioned service, a cup of tea was brought to her because it was a quicker option.

The flexibility also allowed the PAs to explore the person's hidden interests or talents. For example, one stakeholder (SDS-C2) said that one PA found that the service user enjoyed having her nails done, which she found therapeutic. They set up a weekly mini nail bar in the house. The service user was non-verbal and responded well to the human touch, making this activity well-suited to her needs.

Several stakeholders reported that DP flexibility also allowed PA to do reminiscing work in a personalised manner rediscovering hobbies and past times. One stakeholder (ILSM-2) gave an example of a lady living with dementia who had always been interested in crafts, knitting, and making cards but had stopped. Her PA re-ignited this interest. Another stakeholder (SDS-C1) said the PA and the person living with dementia put together a photo memory book, enabling them to talk about those memories connecting with who they were. The PA said she found the process very therapeutic and meaningful to the person and family. A stakeholder (ILSM-2) said a PA worked with a former footballer with an extensive memorabilia collection, and they spent his support hours organising them. The PA reported that this triggered many happy memories. This way of reminiscing was viewed as having a positive impact on people with dementia, and the extra time allowed by DP was perceived as enabling this.

Many practitioners and stakeholders viewed DP flexibility as offering more social opportunities to people with dementia in a way that suited them. They said DP allowed people to visit museums, theatres, cinemas, cafés, restaurants, language classes, horticultural gardens, the seaside and take day trips instead of residential day services. Others used DP to attend dementia-related meetings and support groups. Many participants advised that this flexibility in using social hours helped reduce social isolation and loneliness. One carer said:

'*DP can help people with dementia socially and be out more and get more stimulation which is fantastic for someone with dementia because PA can work at the person's pace. They can take the person out for coffee or an activity they enjoy to keep social connections going. It could even be to visit old friends and families or places of worship. It could be very positive and life-changing for some people and help reduce isolation and loneliness for people with dementia.*' C2

Thus, a DP might offer an alternative, more meaningful activity to people keeping them connected with friends and their community depending on their ability, interests and assessed

needs. A few practitioners and stakeholders highlighted that the flexibility of DP had been very successful in meeting the needs of people with dementia in rural areas. They were able to employ a local person or a friend. The community is small, and therefore, they encouraged DP recipients to contact local colleges, universities, clubs and churches to find people with similar interests. A stakeholder said:

'*We had a man living in* [VILLAGE*] very rural area, and he had dementia. There were only three shops, three houses and a post office; that was about it. It is very, very small, with hardly any people who live there. In a sense, DP worked very well due to the rural locality. There was no care agency that could send someone there, but there was a family friend the daughter used DP to employ to go and support him. He was very isolated and secluded, but DP helped a lot.*' SDS-C 1

Therefore, DP flexibility can enable people to make different choices to support people living in remote areas without access to mainstream services and local support networks, reducing social isolation.

Responding to BME people with dementia's diverse needs using DP

As discussed earlier, many participants presented successful examples of using DP to meet some of the challenges experienced by BME people with dementia. Several participants advised that DP offered BME people a more personalised service allowing them to recruit a PA who had shared experiences of racism. They argued that the person was likely to feel understood and less marginalised because the PA would be more familiar with navigating various barriers that BME people face. Two practitioners said:

'*Having a personal assistant with a shared experience may help the client overcome wider society challenges and discrimination.*' SW-5.

'*I worked with a couple who received a DP and employed someone from the mosque. They said they experienced a lot of racism in their lives. It is a difficult time for people, and there have been mosques that have been attacked. DP could give people support in a way they feel comfortable with and supported. Having people who understand you, your anxiety and your experiences of history of racial abuse would be good. Things don't seem to be great at the moment for BME people. You look at America with Trump and horribly racist policies, especially to Muslim people; so, this would lead people to feeling excluded, and we need services that are flexible and inclusive.*' OT-1.

Similarly, some participants advised that DP allowed BME people's cultural, food and religious needs to be met by recruiting a PA from a similar background. One Muslim stakeholder (ILO-1) noted that he knew places in his city where he goes for prayer per Islamic faith five times a

day. He suggested that a Muslim PA knows how best to support a Muslim service user with their faith requirements. One practitioner said:

'*It is very important as workers to make an effort in understanding BME people's needs. It is about respect and breaking down barriers. Food and religion are fundamental in some BME communities; imagine, as a worker, you took the client to Morrisons without knowing their background and religion and ordered two full English breakfasts with sausage and bacon. It is coming from something unclean according to their religion. But having PA from the same religion, they would know straight away that it is not appropriate, especially if it is someone with dementia and may not be able to say that is not appropriate for me. But with the support worker who shares a religion, they could even pray together and find a quiet room for prayers in the community centre; he would also know where to get culturally appropriate food.*' SW-6

This quote illustrates various points that highlight why a PA who understands a service user's religious practices might be well suited. Many participants considered recruiting a PA who understood the service user's cultural requirements during personal care significant. A practitioner said:

'*There were cultural issues, such as she wanted only female carers to provide personal care. With council policy, we couldn't meet that request via a direct provision of care. It is about who is providing the care and how are they providing it. Do you need female-only carers or male-only carers? It's people understanding cultural expectations, family dynamics, what are the religious beliefs, norms and traditions that a worker needs to be aware of, and I think people would feel much more able to accept care, especially intimate care. DP offers more scope for that, and with the same person offering personal care, they get to know the person better.*' SW-3

Therefore, it is not only the actual delivery of care but also who provides it and the expectation and dynamic within a family in accepting that care.

Several participants viewed DP as allowing BME people to employ a PA who spoke a similar language to their family members to guide them through personal care routines. One BME carer said:

'*My dad liked long showers. It was one of his little joys of life left at the end stage of his life. So, I felt the tasks were too rushed. He likes sitting in his shower, and they would be shouting at him in English to get out, and he would just be applying soap. He didn't understand them. Then they would just turn the shower off, so he would be so confused and would still have soap on him, but they would get him out anyway and get him dressed. I did feel without proper language communication, he did not have the care he would have liked.*' C4.

While the above quote may also indicate poor practice and limited resources, it highlights the miscommunication that can occur for BME people who fail to understand the care prompts from the carer in a different language.

Unconventional, imaginative and cost-effective DP use

Several practitioners highlighted circumstances where DPs have successfully re-connected people with dementia with their country of origin, either for a short respite visit or a permanent move. A few participants considered this beneficial for BME people with dementia who had reverted to their native language, cultural and religious practices that they had previously abandoned. A practitioner manager believed that if workers were willing to explore different outcomes, there were individualised outcomes that BME people could use DP to meet and still comply with the legislation. She gave this example:

'*A BME person might be authorised to buy a laptop as a one-off as part of their day service for social support because they are using it to interact with other people in their community online because they do not live nearby. It is an option that meets an outcome of not being socially isolated. It could be speaking to people in their own country or to get in touch with other groups. There are many alternatives to providing a service if people are willing to explore more and think outside the box.*' SWM-1

Some practitioners and stakeholders discussed when BME people with dementia had used their DP respite budget to purchase flight tickets to visit their home country. While there, the extended family had supported the person. It had worked out cheaper than 24/7 care in the community with a PA or going to a care home respite where their cultural needs might not be met. A few stakeholders advised that the person with dementia thrived and did not return on some occasions because they appeared much happier, settled and alert. Two stakeholders said:

'*We had people going off to Pakistan for respite and was all approved. DP could be amazing if this creativity was used well. If someone would spend £600 on a care home but can spend the same £600 for a flight to Pakistan, and the carer still gets a break, what difference does it make? The alternative is putting someone in a care home where no one speaks their language and there is no appropriate cultural food. It's a better experience going to your family in Pakistan, and dementia may not be that apparent because you are using familiar language in a familiar environment and will have the extended family to look after the person.*' CSW-1.

'*DP really does make such a difference to people. We had two gentlemen in* [CITY] *who had married Thai brides. DP was used to facilitate the wives' return by paying for flights to go to Thailand, and when they were back there, the support would be from family. It does work, and*

I think it is a cheaper option and a better outcome for the person, especially if you have dementia; you are back to a familiar environment of your childhood and your family. I have heard people with dementia thrive on their return trip, and it's a better use of money too.' SDS-1

DP was also seen as an alternative for those BME people when travelling abroad was not an option, and they did not want to move to a care home due to barriers already discussed. A few practitioners explained that respite allocation is calculated in nights annually. The family could request an entire annual allowance or six months and organise 24/7 care in the person's home in Scotland. They can also choose to top up the shortfall if they can afford it. However, the families are made aware it works out as less respite for the carer than commissioned residential respite. Still, some practitioners said it should not matter if some BME people choose a shorter respite that works and meet the carer and the person with dementia's needs than a longer one that does not work.

Several stakeholders and one practitioner (SWM-1) discussed the voluntary return of older people with dementia who want to return to their country of origin as something that DP could facilitate. One stakeholder (ILO-3) advised that she had worked with a lady from India who had been extremely isolated. With DP, they recruited an Indian PA to do social activities that linked her with her community. Once she was confident, they organised a holiday for her. However, once she was in India, she realised she did not want to return to Scotland and had felt a greater sense of belonging there and returned permanently. One stakeholder who had seen older African people return to their country of origin said it works for some people but not everyone. She said:

'*There are very few older African people we come across because most go back to their countries of origin. So maybe that could be facilitated and supported with DP for older African people who want to return home. It is cheaper, and they are not stuck in the house and socially isolated. But, some have been very involved and are very mainstream and integrated within the Scottish culture, and it would be very difficult to go back. It is a difficult balance because they go back expecting the home they left behind, but everything has changed, the life there and the friends they left have moved on, and the children have grown. So, you have to build a new network. It's not an easy choice either.*' DIM 1.

While this idea of returning to a country of origin may be considered controversial, it was highlighted as a possible positive short-term DP intervention for those eligible for LA services. However, it did raise some concerns because once the person left the UK, the LA would no longer be responsible for their welfare. Thus, this use of DP would raise serious ethical issues, given that some participants already viewed DP as LA passing on their care and

responsibilities to the individuals. Also, a few participants feared that using DP to facilitate international respite could be viewed as LA funding a holiday when there is a significant financial constraint in the care sector.

This section has discussed the consistent and therapeutic relationships participants thought people with dementia may experience when using DP to enhance quality care with greater continuity. Participants discussed some benefits of matching BME people with dementia with someone who understands their experiences and needs. Having extra time to use the DP flexibly was considered a good outcome for people with dementia in allowing more personalised social support.

Conclusion

The findings have suggested that BME people navigate structural, cultural, personal and even historical barriers when accessing services. These barriers are compounded further by stigma towards dementia and fear of retribution from BME communities people who might not approve of those who seek formal services. This is because care is perceived as a duty and obligation mainly provided by women. The challenges faced by BME people with dementia are multifaceted, with intersecting factors such as racism, ageism, sexism, classism, illness and disability that can make accessing services, especially DP, difficult. The findings illustrated that BME people were offered DP to recruit PA to meet the specific needs that other mainstream services unable to provide. This led to LA being viewed as passing its responsibility to the DP recipient while still asserting its power with restrictive eligibility criteria and control. The structural barriers compounded already complex, problematic DP and LA processes challenged by diminishing resources and an overstretched workforce. BME people with dementia then struggled with securing DP and relied on advocates and third-party organisations for support. Despite all these barriers and limitations, DP potentially offered some positive outcomes in some contexts for people with dementia and BME people. A range of things were viewed as contributing to good care, such as genuine relationships, consistency, continuity in care, cultural understanding and enough time to spend with the person.

Participants viewed DPs as one of the tools that could provide more personalised support for BME people with dementia in meeting specific needs not met through mainstream services. However, the specific nature of that connection needs further exploration. It might be that other options could achieve similar outcomes if there were available resources, especially for those who do not wish to have a DP to meet their assessed needs. Therefore, to some extent, from the findings, it appears the poor experiences people have with LA commissioned services may be linked to the delivery model, while structural barriers and inadequate resources cause

others. Many participants viewed DP as an intervention to bridge the gaps between mainstream services not meeting BME peoples' needs and limited specialised BME services. Thus, DP satisfaction and usefulness depended on various contextual factors, the individual and their imaginative use of DP to achieve their intended outcome and successfully navigate the challenges highlighted.

CHAPTER FIVE: FINDINGS TWO CASE STUDIES

Introduction

The previous chapter highlighted the challenges BME people navigate when accessing services and DP, including structural, cultural, personal and resource-related issues. This chapter aims to deepen the understanding of existing themes in chapter four by exploring the three stories in depth. Findings in chapters four and five will be discussed in chapter six, and conclusions will be drawn in chapter seven. In this chapter, data is drawn from the narrative interviews with people living with dementia and analysed using both narrative and thematic analysis to reveal several themes. This chapter shares the life stories of Kareem, Daniel, and Yosef, who are all living with dementia. They shared their beliefs, values, fears, hopes, plans and experiences that guided their interpretation of what had happened in their lives from childhood to adulthood. The three stories demonstrate the chronological notion of their experiences, recognising that understanding of people and events changes and continues to change during their lifetime.

Their narratives are presented in a case study format that investigates the three men's lives in detail, their struggles and the accomplishment of their journeys before and after their diagnosis of dementia. Presenting these narratives as individual case studies reflects the complexity and richness of the three participants' experiences but also situates them in the broader cultural, social and political context in which they are narrated. The case studies reveal how each participant constructs their present and past lives and makes sense of their current circumstances living with dementia. This provides a nuanced account of the challenges, obstacles and historical injustices that BME people may face that may intersect with a dementia diagnosis.

Kareem and Daniel narrated their own life stories. However, Kareem's daughters, Mina and Khadija, assisted him with interpretation. Yosef's story was narrated by his daughter Catriona. Therefore, Yosef's story is from Catriona's perspective, including her thoughts, feelings and how she understood and interpreted her father's experiences. Catriona's perspective could include assumptions and biases from her interpretation of Yosef's life and may not correctly reflect Yosef's thoughts. Catriona does not become the story's protagonist and focuses on Yosef, although one cannot entirely separate them. However, she ensured that Yosef remained at the centre of the narrative and distinguished when sharing her own story as a carer and daughter. This perspective from a close family member allows us to see Yosef's life from a different point of view.

The methodology chapter detailed how aspects of the narrated stories were selected, processed, and organised into a case study, including my role as the storyteller. The first section presents the three case studies, then analyses the stories organised thematically.

Case Study One: Daniel

Early Years

Daniel is a 71-year-old man living with dementia who identified ethnically as Chinese. He is fluent in English and Chinese languages. He was born and brought up in South East (S.E) Asia. Daniel's parents came from different S.E Asian countries, where most of his relatives still live. Daniel comes from a family of six children, two boys and four girls, and he is the youngest. Daniel's family are Roman Catholic, and he only attended Catholic schools when he lived there. Daniel's teenage years were spent in S.E Asia with his family and friends. Friends were a crucial part of his life. He reminisced about enjoying going to restaurants, cafés, parks or movies. At the age of 18, Daniel moved to Scotland to attend university and relatives originally from S.E Asia hosted him. Daniel has lived in Scotland for 53 years and felt well integrated within Scottish culture. He is also rooted in his Chinese culture and has had regular contact with his extended family, visiting and taking his children to S.E Asia to embrace both cultures.

Daniel described that Chinese people in S.E Asia are widely spread and mixed through intermarriage, resulting in conflicts due to historical divisions. For example, he said his father was anti-Japanese because the Japanese government imprisoned him for working for an American firm as an accountant during the Second World War. His father would get offended if he were mistaken for a Japanese person. Daniel's mother was a housewife but ran a small jewellery business from home.

Adulthood, Marriage and Family

Daniel married a white Scottish woman, and they had two children, a daughter now aged 37 and a son aged 35. Daniel said they had embraced their dual identity, Chinese and Scottish. Daniel advised that settling in Scotland was easy because his host relatives were very supportive, and Scottish people were welcoming. Daniel's wife died two decades ago, and he later remarried another white Scottish woman. His second wife has two children from a previous marriage. Daniel's daughter has two daughters, and Daniel enjoys spending time with his grandchildren. Daniel spoke proudly of his children's success, having had a good education and now being professional. He felt he had given them the best possible life and experiences of two cultures.

Career

After Daniel completed his first university degree in Biology, he was unsure what to pursue, primarily because there are culturally defined careers for many S.E Asian students and Biological Sciences was not one. Preferred careers are law, medicine, and accounting. Therefore, Daniel had not followed what his parents had considered the expected path. Daniel did not like any of those careers and loved working with children. After reflection, he returned to the university and pursued a secondary education teaching qualification. Daniel was a teacher for 41 years until his retirement. He taught in many schools around Scotland, taking on different roles, including senior positions in various schools. Daniel fondly described how much he loved his job, especially the children and colleagues. He particularly loved working with children who needed extra help and were from deprived backgrounds. Daniel was also very involved with extra-curricular activities, such as coaching children in various sports such as football and badminton. Daniel advised that he had a fulfilling career and '*loved every minute of it.*'

Dementia Diagnosis

Daniel was diagnosed with dementia 14 months before I met him. Initially, he was shocked and did not accept the diagnosis, mainly because he felt he was still young and had many retirement plans and goals. The family had noticed that Daniel's behaviour had been changing for some time; his short-term memory had declined, and he struggled with finding words. Daniel described the diagnostic processes as straightforward because he understood the neurological processes and testing very well, given his biological and psychological background. He also understood the nature of dementia and how it impacts the brain. Daniel described MRI, lumbar puncture and blood tests for the genetic tests at length. He advised that understanding dementia had enabled him to move from a low mood and feeling sorry for himself to acceptance and positivity. However, he acknowledged that other Chinese people without similar backgrounds and a good command of English might struggle with the diagnostic process.

Daniel felt that to live and participate in the world with dementia, he needed to keep his mind occupied by staying active with different opportunities. He is very proactive in seeking those opportunities. Daniel felt that he still had a lot to offer, especially with technology. Therefore, he took a consultancy job with a university to help with online learning packages.

Daniel also wanted to remain sociable, meeting with friends for social events like attending the cinema and theatre. He also enjoyed playing his favourite sports, such as badminton and football, although these sports were on hold when I spoke to him due to an injured knee. Daniel

articulated energetically that he would not want to '*lock himself up at home and just watch the television'*; he would like to remain independent for as long as possible. Daniel values spending time with his wife, children and grandchildren. He loves cooking and does most of the cooking at home; he loves experimenting with different cuisines from different countries, although Chinese cuisine is his speciality. Daniel loves travelling and wanted to travel more with his wife, but he was worried about how dementia will affect his travel and independence.

Daniel decided he wanted to '*join the fight against dementia'* through contributing to research and had contacted various medical facilities, academic institutions, and third-party organisations to get involved. He felt his personal experience might help advance dementia research. He is currently very committed to this and delighted to be part of a dementia research group. Daniel has joined different local groups to share his experiences and skills. He said this offers a new meaning to his life after the dementia diagnosis, keeping him busy and occupied. Daniel also enjoys connecting with others online who live in very remote parts of the country. Connecting with others with dementia makes him feel less alone because he felt they were '*in the same boat'*.

Support

Daniel's focus is on living well with dementia. He concentrates on improving his lifestyle by eating healthy balanced meals, doing exercises such as aqua-aerobics, going to the gym three times a week and taking short walks. He keeps socially active to avoid isolation and loneliness. Daniel feels that this helps maintain his stability and reduces fast cognition deterioration. He felt it was easy to get socially isolated after retirement, especially if dementia inhibits his usual social activities.

At the time of the interview, Daniel did not require formal services and hoped he would not need them for ages. However, if a time comes when he may need services, he would like personalised services, whereby he chooses his care staff, his hours, and his choice of activities. Daniel was aware of DP because his mother-in-law had dementia and his wife managed her DP. He reflected that he is likely to apply for DP when he needs care because they appeared to offer more flexibility and choice, and his wife had experience in DP management.

Daniel was deeply aware that a time would come when he would need extra support, including physical support. However, he preferred not to think too far down the line because it might make him feel 'depressed'. He, therefore, chose to focus on the present. Daniel uses various technological gadgets to reach out to others, for shopping, meditation, for prompts, and to keep a pictorial diary to look back at the pictures and commentary when his memory deteriorates. He finds a digital personal assistant integrated into his phone beneficial in

prompting him by setting reminders, answering his questions, checking the weather, sending messages, calling, and completing many other actions.

When asked what would be important for Chinese people when accessing services, Daniel perceived that language and understanding the Chinese culture would be a significant barrier. Daniel said that he knew many older Chinese people who do not speak English and struggle with written or verbal information on dementia or services and need translated information. He said DP is complicated to understand, even without the language barrier. Daniel believed that Chinese people are 'proud' as a nation and individuals and do not seek help even when they need it. He said:

> '*Looking at the bigger picture, if China was in trouble as a country, they do not go and knock on America, the UK, France etc. and say they need help and a good example is the Coronavirus outbreak. China kept a lid on it for some time, trying to deal with it without external help.*'

Daniel said that the Chinese government believes in self-governance and self-reliance, which is their motto and principles. He linked this to Chinese history: a country that has been self-sufficient for thousands of years. Daniel's perception of the older Chinese people is that they are very suspicious of foreigners. Daniel believed that many of the older Chinese generations would not trust social workers who did not look like them because they have been brought up to distrust non-Chinese people. He asserted that Chinese people with dementia would be very reluctant to seek any social work or medical intervention due to this suspicion of outsiders. He believed they would refuse to talk openly about any challenges they experienced or dementia symptoms. Having integrated into the Scottish culture and having arrived as a teenager, Daniel did not position himself the same way as he felt older Chinese people who moved to Scotland in adulthood would. Despite having lived most of his life in Scotland and having a Scottish accent, people always ask Daniel if he moved to Scotland recently from China which he found unsettling.

Daniel felt that when reaching out to people living with dementia in the Chinese community, communication would be the key to building trust and tackling the stigma attached to dementia. Daniel also acknowledged that limited council funding would be a barrier to meeting Chinese people's specific cultural needs.

Daniel expressed that when Chinese people move to Britain, they firmly maintain their culture and traditions. He gave an example that Chinese people rely on families for help, aligning with their culture. Additionally, Daniel believed that Chinese people would also struggle to eat 'non-Chinese' foods in care homes or day centres. However, Daniel thinks that these views and attitudes will change over time with the younger generation of Chinese people.

When Daniel discussed these perceptions of Chinese people, while he positioned himself as Chinese, he said his experiences are different and would be different in accessing services because he has adapted to the Scottish way of life in many ways. Daniel felt he was advantaged by his education level, command of the English language and the affluent neighbourhood he lived in. Daniel also acknowledged that he was not living in poverty like some BME people who have no access to good education and employment who were more likely to struggle in accessing services. Daniel added that he could afford private care, while he felt that some Chinese people have to accept what is offered to them, even though it may be inappropriate for their needs. However, he explained that he had maintained his Chinese identity through his cuisine, holding on to some Chinese traditions and ways of thinking and he remains strongly connected to his family in S.E Asia. However, Daniel felt he lived between two cultures; his country of origin and his host country. Daniel also felt he had successfully integrated into the Scottish culture through participation in different areas of the society, such as the economic, political, social and cultural life, maintaining a balance between the two cultures.

Case Study Two: Kareem

Mina and Khadija- Kareem's daughters and interpreters for three interviews with Kareem.

Early-life

Kareem is an 85-year-old man from a Middle Eastern country. He identified as an Arab and speaks Arabic and very little English. Kareem was born in a small village and came from a big family. His father had three wives, and therefore Kareem had many brothers and sisters. Kareem said that he is the 'head of the family' as the firstborn and per their traditions. The family had a piece of land where they worked and employed other people. Kareem described families in his country as very close, with so much love and respect between them. They live in close communities, and everyone knows, supports and visits each other regularly. They also hosted feasts and ceremonies together, strengthening family bonds and connections. Kareem described village life as beautiful and simple, and he loved it.

Kareem has been living in Scotland for the last seventeen years and misses his childhood life immensely as, having a diagnosis of dementia, these are his most vivid memories. He called them the '*good old days*.' Kareem fondly reminisced about happy memories of walking to school beside a river in the village. He also excitedly shared how they would swim in the rivers and climb trees to pick wild fruit, such as plums and figs. Kareem recounted short stories. For example, he remembered how he used to climb a date tree and would pick so many dates for a girl he loved as he sang to her. He reflected that boys and girls played together, unlike today.

There was no segregation or repercussions. There were no televisions or any technological gadgets, and, therefore, they spent much time in nature. Kareem's daughter, Mina, remarked how her father was excited, like a '*little boy*', bringing these memories back to life as Kareem stood up to demonstrate in actions.

Kareem explained that food in his culture occupied a central part of the community spirit. It was not just for nourishment but also to connect with family and the community. He also emphasised that everything was grown organically, but now this has changed. Kareem described his mother's delicious cooking and fresh homemade foods, such as bread, yoghurt, cheese, and cream, from the milk they got from their cows and goats. They also reared chickens and sheep and went fishing, which Kareem enjoyed. Kareem described some food rituals in his culture, such as how men would slaughter a sheep in the fields, cook it there and then bring the meat home for the rest of the family, but women and children were not allowed to participate.

Adulthood, Marriage and Family.

While at university, Kareem met his wife. They married and had seven children: five daughters and two sons. After finishing university, Kareem got involved in politics and started campaigning for human rights, social justice and equality, which was not encouraged. He was captured, tortured, and imprisoned for several years and still bears physical and mental scars. The torture he experienced resulted in losing his hearing in one ear, partial hearing in the other and other health complications. Kareem demonstrated how the authorities tortured him and still relived this trauma. He called it the 'dark time' in his life. The enthusiasm and joy he recalled from his childhood faded at this part of his story.

Kareem was initially a teacher but was not allowed to teach because of his beliefs, as it was assumed that he would indoctrinate the students. He retrained as an accountant and also managed various departments. Kareem highlighted that he has always been very open-minded and that his workplace was very diverse, with multiple nationalities with different beliefs, religions, cultures, and ethnicities.

Kareem sadly described the war that broke out in his country. Many restrictions were placed during the war due to destruction, high levels of unemployment, mistrust and widespread demonstrations. Kareem missed ways of life before the war. He was outspoken against the war, which put him and his family at risk of government-instigated assassination and further persecution. This led Kareem and his wife to flee to a neighbouring country to seek refuge. After 11 years, his then host country became unstable. Kareem's children, already settled in the UK, advised him to migrate to Scotland with his wife so that his two daughters could

support them. Mina and Khadija explained that in their culture, the '*highest honour and privilege*' is to look after one's parents when they are older, even though it can be a demanding role. It is a duty expected to be undertaken by women in the family.

Religion

Kareem grew up as a staunch Muslim, but he no longer practices. He does not believe in organised religion. However, Kareem believed in God and humanity and that all human beings are equal. From his experience, he viewed religion as divisive rather than unifying. He reminisced how Muslims and Christians lived in harmony in his country and celebrated different religious festivals together, such as Christmas and 'Idd el Fitr'. He described himself as 'very liberal', a 'socialist' and a 'rebel' who already drank and smoked at age 20. He emphasised that this was despite coming from a strict Muslim family with a long lineage of devoted Muslims of high status and respect in the community.

Kareem argued that this change resulted from colonialism, imperialism, capitalism and greed for natural resources. He contemplated that this created divisions and different faiths no longer mixed due to segregation for fear of retribution.

Life in Scotland

When Kareem was 65 years old, he and his wife moved to Scotland. Kareem describes Scottish people as '*nice, friendly, and welcoming'*. He felt Scotland had provided him with a safe environment where his basic needs were met. Kareem also felt that there was less racism than he had expected. Nonetheless, Kareem and his wife faced various challenges, especially the language barrier, a new culture and a new way of life that differed from their own. Kareem found learning English hard at his advanced age and following retirement.

Kareem adapted to new food, although he preferred his traditional food, which his daughter batch cooked. Kareen described his traditional dishes as rice, meat, and vegetables with added dried herbs like turmeric, cinnamon and cardamom. They enjoy different salads and eat varieties of bread. Mina explained that the kitchen was viewed as a woman's place in their country, and therefore, Kareem has always relied on the women in his life for his meals.

Kareem struggled to connect with the new community and to make new friends. People were kind, but he found it hard to make lasting connections without speaking the language. As a result of this language barrier, he could not attend social gatherings and events because he needed the family to translate and support him with the transition but did not want to 'burden' them. Kareem realised most Arabic speakers were settled in bigger cities. He said he would have been delighted to meet his agemates from his country who shared similar interests, going to the public houses for a drink and talking about the politics of his country. However, most

143

Arabic speakers are practising Muslims and do not drink. Kareem also tried to befriend some African and Asian people who spoke Arabic. Still, he found it equally challenging to form lasting relationships because they differed culturally and politically.

Dementia Diagnosis

After a few years in Scotland, Kareem's wife was diagnosed with cancer and later died. Two years later, Kareem was diagnosed with dementia. Dementia has impacted his memory, decision-making, planning and routine. Kareem needs support with cooking, housework, laundry, shopping, managing his mail and small tasks around the house. Kareem said he had a simple routine: spending most of his time alone or with his family. Kareem has had to learn and adapt to new interpersonal communication methods because his day-to-day life is preoccupied with the streaming and consumption of transnational Arabic news to connect and follow the on-going in his country of origin. While Kareem is physically in Scotland, his mind is constantly back in his country of origin, engulfed with worry and concerns over his extended family. However, he enjoys window shopping, walking around the city centre or perusing in the clothes shops. Kareem enjoys a bus ride, sometimes touring around the city or further afield. He sometimes spends his day at the seaside or goes by the river and watches the ducks and swans. Kareem goes out by himself, although he has become confused on a few occasions and gotten lost.

Kareem is not involved with any community projects and described his loneliness since his wife died. He enjoys his daughters' company, and they visit him every day, sometimes with the grandchildren. Kareem greatly misses the company of male friends and extended family relatives in different parts of the world. He tries to stay in touch with extended family abroad through modern technology.

Employment of Personal Assistant through Direct Payments

When Mina and Khadija started struggling to meet all their father's needs, they sought support from a BME organisation which advised them to contact the Local Authority (LA). Kareem was first assessed for direct council services and received home care twice daily. The carers only spoke English and therefore struggled to communicate with Kareem. The family decided they needed someone who spoke Arabic to have social hours together. The BME organisation advised the family to request a DP and recruit an Arabic-speaking PA of their choice.

The LA offered them a DP with Khadija managing it. She advised that DP was a complicated, lengthy process, especially recruiting a PA, organising insurance, a pension, holiday pay, sick pay and a backup plan if the PA is sick, which was stressful for her. Without the BME and a carers organisations' support, she advised that she would not have fulfilled her responsibilities.

Using DP was successful, and Khadija said she would never consider commissioned services again because DP gave them control over who visited their father. Kareem said he would not like the responsibility of dealing with money and the complicated English paperwork.

The family recruited multiple PAs, most of whom spoke Arabic, but none worked for an extended period, and many did not get on with Kareem. Kareem said they were '*lazy, not diligent workers and not honest'* because they failed to deliver the full service for which they were contracted. This infuriated Kareem, who said it was against his ethos and values. Therefore, Khadija had to dismiss many PAs after Kareem refused to allow them back to his house. Kareem's qualities in his former employees are the same he sought in a PA. Eventually, he got a hard-working, dedicated white Irish PA. While she did not speak Arabic, she was committed to her role, and Kareem appreciated that. He said:

> *'She creates a job from nowhere; she even dusts the photos, pulls out the sofa and cleans behind it. Cleans the fridge, bathroom, and tables. She is very funny, for example, yesterday I told her there is nothing to clean, so she cleaned the windows.'*

Kareem liked his house very clean and tidy and disliked when other PAs refused to clean and said, '*it was not their job'*.

The current PA tried to teach Kareem English, and he taught her Arabic, making him feel like a teacher again. They had a good working relationship, and Kareem referred to her as a friend. They also found a way of communicating. The PA wrote in English on Kareem's phone, and then google translated it into Arabic. The family were surprised at how well they got on as they had been very focused on getting a Muslim, Arabic-speaking PA, thinking they were better placed to understand Kareem's needs. The family were reassured as they no longer had to worry about multiple carers attending to their father; sometimes, there had been up to 16 different carers a week. Kareem viewed them as strangers, and occasionally he would be so scared and confused he refused to open the door. His daughters thought this fear stemmed from his country's past experiences and were very conscious about getting the right support. Kareem said he was in good health despite having dementia, and he is a very positive person who likes to laugh and appreciates life.

Case study three: Yosef

Morag- Wife

Catriona-daughter, primary carer and narrator of this story

Early Years

Yosef is an 83-year-old man born and raised in Eastern Europe to a Jewish family. His family was of mixed race and ethnicity, and some were of South-East Asian descent. Some of Yosef's close family died in the Nazi Germany concentration camps during the holocaust. The survivors migrated to the United States of America (USA) with their extended families, including Yosef, his parents, and siblings. There, they faced stigma, prejudice and antisemitism. This led most family members to change their names to English ones, including Yosef. They also cut their hair and eliminated their 'Jewish look' to assimilate into American culture. Catriona described how the family had to keep their religion and identity hidden and that *'those with pale skin tones could pass as White Americans'*. Catriona thought that this led to Yosef's interest in campaigning against social injustice for marginalised groups of people in the community later in life. Once Yosef was older, he became more aware of his history. He started using his Jewish name and became very committed to practising his faith; he also grew back his hair and beard and started wearing a 'Yarmulke' (Jewish hat).

Yosef was a bright student and earned places in some of the world's most prestigious universities. He pursued an undergraduate degree and master's degree, acquiring the highest grades and earning him a full scholarship to pursue a doctorate. He was very interested in medieval Christianity, which led him back to Europe as a researcher.

Adulthood, Marriage and Family

Yosef settled in Scotland where he met his wife, Morag. They married and had two daughters. Catriona found some romantic letters her parents had exchanged. Morag expressed concerns that her family would never accept him, their relationship or marriage because he was Jewish. This presented some challenges for Yosef and his in-laws, who lived on a remote Scottish island and were not exposed to 'foreigners'. Catriona described how the family was treated with suspicion, and her grandfather openly discussed his discontent with his daughter marrying an American Jew. Catriona said the relationship was 'stand-offish' but not intentionally racist.

Catriona expressed feeling extremely judged and uncomfortable in the church as people whispered, '*she is the daughter of the Jewish man*'. Yosef felt rejected by the church and unwelcomed by the community and therefore stopped attending. This left him feeling

segregated, and eventually, with his family, they moved to a city hoping for greater diversity. He was offered a lectureship at the university and became an accomplished academic.

Catriona described Yosef as very liberal and preferred to engage with a more progressive congregation. Yosef attended a few LGBTQ marches with the Rabbi because he was always interested in inequality and social justice. While in the USA, he also joined the black civil rights marches in the 1950s and 1960s. He also campaigned for women's rights and believed in gender equality.

When Yosef got older, religion became more and more important to him. He also became 'ritualistic' and was 'stricter' about things he would have ignored when he was younger. For example, he ensured the whole family only ate 'kosher' food per Jewish law. Yosef also ensured his two daughters had Hebrew and Scottish names, and he took the time to teach them about their culture and religion. Yosef practised his Jewish faith with his family and celebrated Jewish holidays. He would wear the 'Yarmulke', take his 'Torah' (Jewish holy book) and attend services in the synagogue. Every Friday night, he would prepare a blessing, called 'Shabbat', observed before sunset on Friday evening until the appearance of three stars on Saturday night. It is a ceremony of gratitude. Catriona remembered that it was always a wonderful experience that brought them together as a family or community when done with others.

As Yosef got older, the Jewish 50+ community became much more important to him. He spent more time with them at the synagogue than with his academic colleagues as he had previously done. He also volunteered in the synagogue, led some talks and dialogues and wrote for the Jewish newsletter about Jewish history. Yosef continued to work as a lecturer and author until his retirement.

Life After Retirement

Yosef kept busy after retirement doing all the things he enjoyed. It was in his 70s that he started showing cognitive decline. His wife, Morag, was taking care of him, but she began to struggle. Catriona and her sister had moved back to the USA to join their extended family. However, Catriona moved back to Scotland with her two young daughters and husband to support her mother and care for her father. Catriona explained that older people are revered in Jewish culture due to their knowledge and wisdom and are highly respected community members. Children, mainly females, are expected to provide care when their parents need it. Unfortunately, Morag was diagnosed with end-stage cancer not long after Catriona's return. Catriona expressed that her priority switched to her mother's care, but it also became apparent that Yosef needed more care than she had anticipated. Morag was going through her

treatment, and she deteriorated after a few months. During this time, Yosef's memory also started deteriorating. His decision-making and behaviour were changing. He declined fast: he left the house on numerous occasions, and strangers returned him home. This was a constant worry for his daughter and wife, who, at this point, was extremely unwell.

Catriona thought that taking her father to go and see his wife in the hospital would help. Sometimes, he would agree to go but would insist on public transport instead of going in her car. Then he would catch the wrong bus and get lost. Occasionally, he would make it to the hospital, but he would leave abruptly without informing anyone. Catriona said that her father's decisions were not rational: he would go shopping at 11 pm. It was hard to convince him otherwise because he was a '*very independent, strong-willed man.*' Yosef still tried to retain a level of social life and would even attend lectures, meet up with friends or go out to explore.

The home arrangement became unsustainable. Previously, Morag had dealt with household tasks, cooking, gardening and all the 'DIY tasks'. Yosef spent most of his time writing at his desk, so he struggled with his wife not responding to his 'demands'. Eventually, Morag moved to a hospice and later died. After Morag's death, Yosef's symptoms worsened, his cognitive abilities and personality changed considerably, and there was an apparent decline. At this point, Yosef had not been diagnosed with dementia, although the family suspected it was dementia. He always refused to go to the doctor for an assessment. If his daughter persisted, Yosef would get '*physically and verbally aggressive'* towards her. Catriona assumed that Yosef was aware of dementia but was scared to confront the reality. As an academic, Yosef had expressed that his biggest fear was cognition and memory decline, as these had been significant to his long successful career. Catriona remembered that her father once said, '*to lose your mind is the worst nightmare'* after visiting his own father in the USA, who had Alzheimer's.

Catriona advised that her mum's funeral was the turning point for her father's illness. Yosef became incontinent daily, his speech became incoherent, he stopped following his routine, and he stopped eating with the rest of the family and would eat alone. He also ate random food items at very unusual times. They found him having what he called breakfast in the middle of the night, and he started drinking at every meal and sometimes opened a bottle of wine at 8 am because he thought it was dinner time. Yosef started falling asleep at the dining table and failed to understand his daughter when she corrected him. He started making a sandwich for every meal with the same unusual fillings. Catriona said he did not eat sandwiches before and considered them non-Jewish food, mainly because they contained many food items or combinations that Jewish people do not eat. Catriona thought that he had returned to his

childhood as an East European Jew where they ate many sandwiches with different fillings, mainly tinned and pickled fish.

Dementia Diagnosis

Finally, Yosef agreed to go and see a psychiatrist for an assessment. However, because his wife had just died and he had a history of alcoholism and had started drinking more than usual, they decided his behavioural change was due to grief and could not diagnose dementia. Yosef continued to deteriorate. He stopped self-care completely and would stay in his pyjamas all day. Regularly he left the house in his pyjamas and would be brought back by the police.

Yosef had always been very smartly dressed and always preferred suits. This change of behaviour indicated to his daughter that it was not only bereavement but something more serious. His mobility also reduced significantly. He developed an awkward gait that led to falls. Catriona insisted that she did the shopping. However, he continued shopping most days for things they did not need, such as milk, bread, and cat food. On numerous occasions, Yosef attempted to go to the bank to deal with his finances which was an area of concern for the bank staff and Catriona.

Eventually, they returned to the hospital, and Yosef was diagnosed with advanced Alzheimer's, and a psychiatric nurse was allocated to offer support. Unfortunately, six months after Morag's death, Catriona's husband was diagnosed with cancer and died eight months later. Those eight months were incredibly challenging for Catriona because she looked after her father, husband, and young daughters. Despite the tremendous stress, she felt it was her duty as a daughter, wife, and mother to meet all her obligations. During Yosef's son-in-law's funeral, he refused to sit with his family and sat alone. Catriona remembered feeling alone, helpless and overwhelmed, mainly because she had just attended to her father's personal care needs in extremely challenging circumstances, which meant she was late for the funeral. She realised she needed to disregard her cultural expectations and seek help before a complete breakdown.

Catriona felt guilty and thought she had failed her father, and that the extended family would not understand the situation. However, the home situation was risky for Yosef, with multiple falls. The psychiatric nurse raised her concerns with the General Practitioner, who referred Yosef to the social work department. After social work assessed the situation as critical, a care home placement was sought the same day.

Life in a Care Home

Catriona described the first six months as challenging, and Yosef attempted to escape numerous times. He was considered 'very aggressive' towards the staff and 'disruptive' to other residents. Yosef was uncooperative during personal care tasks: he refused to be washed and dressed and 'hit out' at staff. While Catriona believed part of it was to do with dementia, she also felt another reason was that staff were not promoting Yosef's independence. She felt they did not allow him time and opportunities to do things he could physically do.

Catriona was dissatisfied with Yosef's care and made an official complaint to the Care Inspectorate. She said that Yosef would be left in bed for a long time and got '*bedsores; he was unclean and smelly'*. He had occasionally ended up in the hospital with a urine infection that was not detected in good time. After investigation and recommendation, the situation greatly improved. However, she felt her daily visits and constant follow-up with staff were driven by the guilt of not fulfilling her duty and obligation as a daughter as per Jewish customs and expectations.

Jewish cultural foods and religious practice implementation in a care home

High staff turnover made it challenging for Catriona to explain Jewish customs. Therefore, she ensured detailed information in Yosef's care plan. For example, she provided staff with a list of pork products, but the staff struggled to understand and always asked if Yosef was allergic. Catriona would then explain it was not 'Kosher' and pork is considered unclean in Jewish law. Mixing dairy and meat is prohibited in Jewish law; for example, a Jewish person would not eat a cheeseburger because it contains both milk and meat. Although the staff were willing to accommodate these requests, they struggled to meet these needs, especially because they are well incorporated into British cuisine. Occasionally, Catriona would get a call from staff asking, '*could we give your father a ham sandwich since it is not pork?*' which was always shocking to her.

Religion, traditions and customs had always been important to Yosef, and Catriona wanted to ensure that he still experienced some aspects of these, even in a care home. The care home accommodated the Rabbi's visits and the Jewish ceremonies such as 'Hanukkah' and 'Passover'. They would have a meal in the dining room where other residents could join in. Some members of the synagogue congregation visited him in the care home and took him out. However, after dementia progressed, Yosef could no longer participate because he was bed-bound; but the Rabbi would still visit infrequently. Catriona found that staff from the Philippines who had a strong faith were more willing to accommodate Yosef's spiritual needs. She felt it was probably because their own faith was important to them, and therefore, they

had a better understanding of others' need for spirituality. Catriona felt more could have been done to support her father's faith within a care home setting after his dementia progressed.

As Yosef's health deteriorated, he became very frail. Catriona now focused her energy on checking that Yosef was dry, free from bedsores and fed. Catriona said all those things that had seemed important such as maintaining his religion and cultural food seemed irrelevant. She no longer asked if they were giving him 'Kosher' food or not, as she felt staying alive was what mattered and that he got the love and comfort he needed.

Case Study Analysis

This section presents findings from a thematic narrative analysis of the three case studies. The experiences embedded in the three life stories bring together layers of understanding of different life transitions. Analysis of the participants' meaning and interpretation of their stories has been undertaken within and across the three cases to explore the stories' connections. The reflective and analytical process pulled together the individual narratives and combined the themes while maintaining the essence of each individual's story.

The use of thematic narrative analysis led to three overarching themes. Theme one explores the intersection of historical events in an individual or community and later in life. Theme two explores racism, BME people's position within society and their sense of belonging. Theme three discusses participants' unique experiences of living with dementia and their understanding of the diagnosis, highlighting similarities and differences within the cultural context of their life stories. It explores the concept of social citizenship and not wanting to be diminished by the care they receive either from the family or services. The themes in this chapter are connected with the themes in chapter four. They are not entirely new themes but aim to deepen the existing categories by exploring the three stories in greater depth.

The intersection of Past and Present Experiences for BME People with Dementia

Kareem, Daniel, and Yosef's stories highlight how the impact of historical events such as wars, colonisation and the holocaust can intersect with their current lives and continue to influence their identity and decisions in later life. These decisions include accessing health and social care services and dementia-specific services. Kareem and Daniel discussed the tension and complexity with external political powers in their countries of origin and how the aftermath affects the individual or their BME communities today. Kareem narrated his personal experiences during a civil war in his country of origin and described how the conflict affected him. Daniel represented historical political events as external to his experience that he believed continue to influence the cultural beliefs and affect some Chinese people. He said:

'*If you are a social worker and go to see a 70-year-old Chinese woman with dementia, she probably wouldn't trust you and tell you everything that is wrong with her. The Chinese people are very suspicious of everybody, and so is the country because of the opium war and other wars. Chinese people are also suspicious of services and even more suspicious of foreigners. We have a nickname for western people: we call them the western devil. China is a very independent country and likes to keep everything to itself. Also, I think Chinese people are too proud to admit they need help. They are very traditional and stubborn in their thinking.*'

Daniel thought this self-pride, independence, and self-reliance were significant in the older Chinese community. However, from his personal perspective as a younger Chinese man, he highlighted a generational change explaining his willingness to accept support when needed. Daniel attributed this openness to mainstream services to his arrival in Scotland at a young age, obtaining Scottish education, being fluent in English and adapting to the Scottish way of life, making integration into Scottish society easy.

Unlike Daniel, Kareem arrived in Scotland after retirement. His history had a major impact on his self-image and identity and continued to affect him. Kareem had changed from being self-sufficient and well-positioned within society to feeling like a burden to his family and Scottish society. I interpreted that the value of Kareem narrating his life story allowed him to make connections between aspects of his life that were previously disconnected. Kareem linked the torture he experienced in his mid-years to dementia later. While he was unsure whether this was the case, he made these connections when recounting the story. It was like fitting a jigsaw puzzle together through the links he was making with the structure of narrative interviewing, allowing this to happen. It enabled Kareem to view events in his life or country as part of a bigger picture and how different parts relate. From this position, Kareem could step outside his story of pain, torture, displacement and ill health and view things differently by looking at the relationship of his political career and the impact it has had on his well-being and family life while appreciating his secure life in Scotland. Kareem reflected:

'*I tried to fight the regime myself to fight for the good people of* [COUNTRY*] as an activist but see how much I suffer. They imprisoned me, and they tortured me. I was in fear of my life. So, I left all my family because the government wanted to execute me because of my beliefs. Life was not easy there.* But *Scotland gave me a place to feel safe and secure and have my basic life needs met. I believed in the equality of all people regardless of race, ethnicity, class, and country of origin. For this, I paid the price. They did not like what I said, and they hung me from my ears upside down and beat me. Sometimes I forget where I put things. I lose my memory. I forget where we park the car. It could be related to age, but I also have a disability with hearing. They are all connected. I want no association with those religious people of the*

ruling party. They caused me disability and mental trauma. Maybe they caused this illness of mine, who knows.' [REFERRING TO DEMENTIA].

Kareem's linking of dementia and hearing impairment with his past and those he perceived as responsible has affected how he viewed Muslim support workers. He said Muslim people supported the government oppressing civilians during the civil war and tortured and imprisoned him. These experiences led Kareem to re-evaluate his position and opinions as a Muslim. His feelings were reflected when discussing PA, who previously worked with him. He said:

'*Muslims are the worst. They do not do the job they get paid for, yet they take wages. Their wages is 'Haram'.* [FORBIDDEN IN ISLAM] *Even Allah doesn't accept this. They are cheating, complete 'Haram'. They don't work for two hours and still take the money. Yes, they are Muslim, wearing a scarf and speak my language, but if their work is 'Haram', I do not want them working in my house. It is not right at all. The Irish woman [PA] works her two hours she doesn't stop her wages are 'halal'* [ACCEPTED IN ISLAM].'

The quote above highlights how his past experiences may have influenced Kareem's thoughts and perceptions about PAs employed to support him. Kareem's daughter thought his fear of strangers, such as multiple carers arriving at his home, stems from the fear he lived with when politically active in his country. This is partly why the family needed a familiar, regular carer, not multiple carers whom Kareem viewed as strangers. Kareem's PA expectations were based on his past experiences, values, attitudes, beliefs, and what he saw as specific to him and his needs. Kareem reflected that the qualities he expects from PA are the same ones he looked for when he worked as a manager for a large co-corporation. When asked about PA, he said:

'*They need to be faithful to their job and committed. I like decent, honest human beings, Irish, Scottish, African, Arabs doesn't matter so long as they are honest. I don't care about their ethnicity if they are a minority or not. I don't care for their religion, they work hard, and they get rewarded. I only treat them with humanity and respect, and they need to do their work*'.

Kareem's experience highlights the complexity of an individual's identity and how past experiences intersect with current decisions and choices. His narrative demonstrates that other values and skills might be relevant to some BME people when recruiting a PA other than shared culture, language and religion. Kareem's story also gives a different perspective that not everyone from a predominantly Muslim country is a practising Muslim and prefers a Muslim Arabic-speaking support staff. However, Kareem and his daughters explained that religion and being a practising Muslim are considered extremely important within their community. Therefore, the lack of religious faith or not practising the faith they were born into was considered highly deviant. In Scotland, Kareem distanced himself from religion, which meant

he missed any support and information offered through Muslim communities and mosques, leaving him isolated. Being cut off from support reduced his chances of making the connections he desired of meeting like-minded people with a shared language. Kareem felt being a non-practising Muslim hindered making friends because he was likely to find Arabic-speaking people in the mosque or community projects linked to Islamic ceremonies, not the public house, which he preferred.

All three stories highlighted that religion is not only about faith and worship but also access to various resources preserved for those who possess similar faith. The community hubs, mosques, temples and synagogues where BME people come together for religious ceremonies, festivities and information about services, or what is happening among the communities are shared. In return, this provides extended social networks and support that may help the person cope with isolation and loneliness. Daniel highlighted that when in S.E Asia, he only attended Catholic schools preserved only for catholic people and highly sought for their high academic achievement and discipline. Therefore, religious organisations and places of worship have social significance for some BME groups.

In Yosef's story, the holocaust experiences were significant stressors for him and his extended family. While they escaped its horrors and persecution, they lived in its shadow. When his family uprooted themselves from one country to another, they lost part of their culture, deepening their loss of identity. While Catriona did not give a detailed account of Yosef's personal experiences, history tells us it was a challenging and dehumanising experience for those involved. These experiences will have shaped some of Yosef's life and his decisions in later life.

Yosef felt burdened by the legacy of the holocaust; he felt the need to remain strongly grounded in his Jewish identity and teach others in the synagogue. Yosef viewed his family's suffering from a group's perspective, creating a communal responsibility other than that of an individual. Catriona described Yosef's relationship with the Rabbi and people at the synagogue as a responsibility of allegiance and closeness to the Jewish group. This way of looking at these challenging early life experiences promoted the need to find meaning in the suffering of the Jewish people and the need to cope with the group's loss of identification. Yosef did this by embracing his Jewish heritage and promoting it to other Jewish people in the synagogue through his writing and talks, providing a feeling of continuity from one generation to the next without losing their history. Yosef's story provided a sense of affirmation of his Jewish identity in Scotland, reflecting the importance of community and people's identity. This was partly why Catriona was proactive in maintaining Yosef's Jewish identity both in a care home and at home.

Racism

Kareem and his daughter Mina argued that historical experiences of colonialism continue to affect how minority groups are treated in Britain because they are not viewed as equals, affecting their uptake of services and employment. Mina said:

'They don't see us as one of them but coming here to take their jobs. We came from countries that are much further behind than the UK, but those coming here are not always after free services provided by the government.'

Kareem and Mina felt that such views might prevent some BME people from seeking services for which they were eligible. They also thought that some BME people experienced discrimination from the wider population because some still held similar views to the British people who invaded their country. Kareem said:

'It is the colonialism and capitalism; all they [WESTERN COUNTRIES] do is divide people to take over our resources and rule us. They divide us by making us hate each other and create divisions where there were no divisions.'

Kareem and Mina felt that professionals working with BME people might be unaware of the many different conflicts, prejudices and stereotypes based on historical injustices that may lead BME to hesitate to seek services or integrate within British society.

Kareem and Daniel linked some of their personal experiences of feeling like outsiders to broader issues of racism experienced by immigrants but less on personal experiences of racism. For example, Kareem said that the warm welcome in Scotland changed his perception and attitude towards the Scottish people. He said:

'Scottish people are nice and less racist. It is a good normal life. We had good relations, people are decent, we go to the shops, and people are nice they talk to you, and you feel they are welcoming.'

Daniel shared a similar experience to Kareem and found Scottish people welcoming. However, while Daniel positioned himself as ethnically Chinese, he felt able to navigate the system due to his education and economic class. Although he believed that structural racism and other barriers might exist for Chinese people when trying to access services. He said:

'I was educated in Scotland. Not sure if I fit your BME category in terms of having lived here very long and being well integrated in Scotland. I am Chinese by race. I am well placed with the council over here. I am aware of the local authority that could supply social workers. Financially we are ok. If you look at our home and surrounding, we are ok. But other Chinese people may face language barriers and fear of being treated differently as Chinese people.'

The prejudice, discrimination, antisemitism, non-acceptance and exclusion Yosef and his family experienced are examples of 'othering'. one group and then treating it differently. In Yosef's story, they decided to assimilate into American culture and abandon their Jewish identity outwardly to stop being stigmatised. This resulted in losing part of their Jewish identity to fit in with the new society. Catriona said:

'Being a Jew was kinda kept very quiet and swept under the carpet. There was a stigma, and they changed their names to sort of assimilate into American culture. They had a Christmas tree and everything. Why could they not be both Jewish and Americans?'

The antisemitic attitudes and viewing of Yosef and his family as 'other' continued even after his move to Scotland. Catriona expressed feeling self-conscious about her Jewish identity and that of her father. She said:

'*I hated going to my grandparents… I hated going to church. I felt like every sermon was directed at me. They would talk about Jews all the time and how un-Christian they are. I felt uncomfortable even as a child. I knew they all knew I was the daughter of the Jewish man. My father did not go to church; he felt he wasn't accepted*.'

Yosef experienced multiple rejections, discrimination and challenges as a Jew. Still, he navigated these barriers and settled in Scotland, becoming a successful scholar who educated others about culture and religion. When Catriona narrated Yosef's story, she tried to make sense of the different transitions he navigated, moving from Europe to North America and then to Scotland and how the broader population treated him. Catriona positioned herself and her family as the 'other', treated with suspicion because of her father's background. Catriona argued that these would be similar challenges other Jewish people face moving to settle in a foreign country.

Although Kareem had lived in Scotland for 20 years, he still referred to his country of origin as 'home', similarly to Daniel. Kareem felt like an outsider in Scotland and commonly referred to the Scottish people as 'they' or 'them', showing a separation between himself and the Scottish people. Daniel described himself as well integrated into Scottish culture and a naturalised British citizen. However, he felt that while his lifestyle and Scottish accent were like the wider population, he was still made to feel he did not belong and was viewed as an outsider because of his Chinese heritage. People regularly enquired where he was from, leaving him feeling that he was not accepted as a Scottish person by some white Scottish people who viewed him as other. He said:

'People are always asking me, are you Chinese? Yes, I am, but when they hear me talking, they ask me, have you been here for a long time? I say I have been here for over 53 years. So, you can never fully belong.'

Daniel's experience raises questions on what constitutes 'Britishness' or 'Scottishness' which could be seen as originating from interpretations of who belongs and who does not belong, who is the 'insider' and who is the 'outsider'. This then highlights underlying assumptions of 'us' and 'them' within society, including or excluding those considered outsiders. It also highlights that living in another country for a long time and even intermarrying in the host country and integrating does not mean one will experience a full sense of belonging and full citizenship, especially when one looks different outwardly. Daniel hinted at prejudice and stereotypes based on his nationality and ethnicity, which impacted his sense of belonging. The overemphasis on Daniel's country of origin overshadows the multi-faceted aspects of identity and experience at the core of his sense of belonging. Daniel appears not to be exclusively bound by one culture or nationality, but his identity is dynamic, and he embraces multiple identities. Therefore, Daniel finds a sense of belonging from different groups, not necessarily BME groups or those linked to his country of origin.

Furthermore, one may feel or think they belong, and others may not see it the same way because different people have different ideas about who is an 'insider' and who is an 'outsider'. This differing perspective allowed a more complex understanding of Daniel's identity and sense of belonging, or not, to emerge. Thus, Kareem, Daniel, and Yosef's experiences in Scotland and accessing services are shaped by feeling like outsiders, having moved from a different country and trying to integrate within Scottish culture. Moreover, they might have felt more or less like outsiders or insiders, depending on context. Therefore, they could position themselves as 'insiders' or 'outsiders' in different situations and circumstances despite how they are viewed by the wider society based on their identity. Hence, the ideas of belonging and citizenship are fluid and multi-layered, and this is explored in greater detail next.

BME people with dementia positioning impact on the sense of belonging

The stories explored the three men belonging to particular BME communities through shared beliefs, values or practices. As discussed in chapter two, a sense of belonging is defined as having an affinity for a place or situation and fitting in with the community, group, family, or friends. In the narratives, the three men's choices (such as their religion, professions, and networks) and the services they accessed served to position them as part of the groups, categories, and communities that make up our society. Therefore, exploring how BME people self-identify their sense of belonging enables us to understand their decisions when selecting what services to use or not. Feelings of belonging brought comfort and stability in Kareem,

Daniel and Yosef's lives, while experiences of discrimination and rejection made them feel they did not belong or fit in with the host country. This links with the above discussion on feeling like an outsider or being viewed as the 'other', as the three men shared different stories of cultures, traditions, values, connections and backgrounds that have remained important to them over the years.

There were discussions on feelings of belonging, or not belonging, connected to one's identity. Culture, especially in Yosef and Kareem's story, was an important factor in shaping their identity and sense of belonging through highlighting various ceremonies they did together as a family and with their respective communities. Kareem's childhood narrative described a great sense of belonging as he nostalgically recollected about time spent with his big, close-knit family. Kareem described how they coped together as a family with different hardships. He said:

'*Families are very close, very much respect to each other, they give kisses and hugs to each other as customary. We live in close communities, and everyone close, we visit each other, very nice. I miss my old life a lot, especially when I was young. I loved it. I miss normal life, farming; I used to do horse racing. I was the fastest. All these things brought me such joy.*'

Dementia diagnosis further complicated Kareem's memory retrieval process as his past life experiences became more vivid than his current lifestyle, intensifying his longing to be with extended family. Symbolic reminders, such as photos of his extended family, revived his memories of his earlier life in his home. Kareem said:

'*I miss my life in* [HOME COUNTRY] *a lot, especially when I miss my old days. You know with my illness I remember old days but not day to day, so what I have is my old memories. I remember when I was a child walking to school, walking beside the river in the village where we swam. Before, we did not have TV, we were outdoors a lot. It was the good old days. I miss living in a very close family unit.*'

While Kareem indicated that Scottish people are amicable, he still longed for a sense of community and belonging. Kareem had not found a community to connect with where he could truly feel he belonged.

During those difficult periods, Yosef felt rejected and discriminated against in Europe, the USA and Scotland, he may not have felt he belonged. However, he had a strong sense of identity as a Jew and connected with other Jewish people in the synagogue, giving him a sense of belonging in this smaller community, even if he felt rejected by the wider society. Following his experiences of discrimination and antisemitism, being actively involved in the synagogue may have helped him cope with the hostility and rejection from the wider population, building

158

a safe community away from discrimination and offering him a greater sense of belonging. Catriona touched on her sense of belonging, saying:

'*Ethnically and culturally, I consider myself Jewish, because that is how I was raised, and that is the culture that I was raised in, and I understand it; but I am not religious at all; I am an atheist. But I like a sense of feeling tied up with an old church and the rituals and feeling that I belong to some community. It is nice, like having this sense of familial history.'*

Therefore, the sense of belonging may be based on how they were raised and the community and faith they were raised in, even though they may choose not to follow it later in life. For Yosef, the synagogue he belonged to was an important source of his social identity, interacting with others who had shared faith and history. Conducting the Jewish ceremonies with his family also had great meaning to him, as described by Catriona, keeping him linked and grounded in his faith and sharing it with his family.

Daniel spoke of developing friendships and social networks, which defined a different sense of belonging and lifestyle he wanted to lead, his social capital, social status, and shared values. As Daniel joined and left different social networks and groups, he repositioned himself with others, developing new connections and discarding others in a continuous social interaction and integration process. He discussed how after developing dementia, he had joined groups of people living with dementia that made him feel understood and that he belonged. He said:

'*It's a case of sharing experience and others learning from it. Since I joined the dementia group, I have met other people with dementia spread all over Scotland and can connect. Some areas are as far as remote parts of Scotland. It is a great platform that ensures you are not isolated and have people you are in the same boat and can share experiences not to feel alone.'*

Therefore, Daniel created a new community of belonging with other people living with dementia with mutual understanding and providing him with strategies to cope. He viewed people living with dementia as 'insiders' while others, like his family, whom he felt misunderstood his symptoms and provided unnecessary intervention, were 'outsiders'. The opportunity to volunteer to give back to the community and others in need was an essential social resource for Daniel and Yosef. Yosef enjoyed volunteering in his Jewish community, especially educating members about Jewish culture and religion, enabling them to feel more connected and understood. Daniel enjoyed volunteering, contributing his knowledge and supporting others living with dementia. Therefore, the lack of a sense of belonging and feelings of separation from others in the community may lead to loneliness and isolation.

Daniel also left more physically demanding groups like football, where he felt his affinity was weakening for not managing to keep up with the group activities. He highlighted that his social interactions had become more complex and intertwined as he defined his new identity, living with dementia and his new sense of belonging. This meant he could shift between different groups of belonging, social networks and communities and select those with whom he experienced a sense of social bonding with like-minded individuals. Thus, Daniel chose the interest groups, values, and beliefs he wanted to identify with. In contrast, Kareem expressed a yearning for a social club to connect with people from his community who might have shared experiences of historical events in his home country and celebrate national holidays and festivals together. Therefore, a sense of belonging is not static. It is constantly changing and not only categorised through better-defined routes like class, race, religion and nationalities. Hence, being a BME person does not mean you will have so much commonality with other BME people within that group, giving you a sense of belonging.

In the three stories, a sense of belonging was also linked to professional identity and having meaning and purpose in life. The three men took a great sense of pride and satisfaction in their careers, shaping their identity and making them feel they belonged within their employment environment and colleagues. Kareem was very articulate on what mattered to him when he was younger, which remained influential in his life today, such as equality and justice. Kareem particularly emphasised how he loved feeling accepted and belonged among his Christian colleagues and friends, finding a sense of belonging in a different group outside his own identity due to other universal shared values, which Kareem referred to as 'brotherhood'.

Similarly, Yosef worked hard in his academic career and experienced belonging among fellow academics. During these sessions, he enjoyed talking about his work with like-minded individuals. His academic career gave him a sense of purpose to contribute and influence others intellectually. Catriona said:

'Dad was a university lecturer. He was a very clever and intelligent man. He went to [TOP-RANKING UNIVERSITY] *on a full academic Scholarship. He did his PhD at* [ANOTHER HIGH-RANKING UNIVERSITY]. *He is well-published in his academic career. His speciality was medieval Christianity. I always thought it was interesting he was Jewish but was very interested in Christianity. He loved sharing his knowledge with others.'*

Yosef's sense of belonging was within his Jewish community and in different marginalised groups where he felt accepted and could contribute, such as the civil rights movement and LGBTQ communities. Similarly, Daniel working with children from underprivileged

backgrounds gave him a sense of purpose and job satisfaction that enabled him to have a sense of belonging with a greater focus on his intellectual capacity and not his nationality or BME categorisation. This was reflected when Daniel spoke about his respect from other teachers and the different promotions as a valuable staff member. Therefore, it is interesting to consider how closely Kareem, Daniel and Yosef associated their own personal and group identities with the professional organisations and educational institutions they belonged to. It was clear that their work and choice of careers influenced a significant part of their identities and belonging.

All three men were members of various groups, such as political parties, spiritual groups, sporting teams and job-affiliated groups that extended their feelings of belonging. In the narratives, Kareem calls himself a 'rebel' 'activist' 'socialist' 'non-practising Muslim', while Catriona used similar terms to describe her father 'rebel' 'activist' 'traditional Jewish man'. They also agreed to participate in this research because they identified as BME, with Catriona basing that identification on Yosef's Jewish identity. This illustrates that many aspects of our lives are organised around belonging to something or a place, which was not exceptional for Kareem, Daniel, or Yosef, despite living with dementia.

In Kareem, Daniel, and Yosef's stories, we cannot separate the importance of a sense of belonging from social, physical, and mental well-being because their social and family ties acted as protective factors in keeping them connected within their communities in the UK and abroad. This enabled them to feel supported and not alone. All three individuals made efforts to build a sense of belonging by choosing to engage with others and remaining connected with issues that mattered to them. They continued to have ties in two countries and found ways of maintaining these two parts of their lives.

Globalization has created a greater interconnection to social, political, and economic networks through technology. This allowed Kareem and Daniel not to be bound by their physical space and move beyond the ideas of physical communities here in Scotland. Kareem is not firmly anchored in his physical environment, where he feels he has little in common with those around him. Hence, he spends a considerable quantity of time following news in his country and communicating with his siblings spread across the globe, giving him a virtual sense of belonging through global connection. Therefore, through digital technology and globalisation, Daniel and Kareem have developed different ways of interacting with their networks that help to shape how they perceive and relate to others, not in their physical environment. This may enable them to feel they belong in a wide variety of different cultural settings, especially when they cannot physically visit their families abroad either due to war, in Kareem's case, or dementia making it challenging, as described by Daniel. Therefore, a connection to cultural

identity and tradition appears to help maintain a sense of belonging and reduce isolation and exclusion.

Social Citizenship vs Feeling Diminished by Care

This section explores Kareem, Daniel, and Yosef's individual and cultural influences on their response to a dementia diagnosis and not wanting to feel diminished by care or their social citizenship affected. Their individual experiences of living with dementia differed despite some shared characteristics and related cultural expectations of service provision. For example, Catriona thought her father was living in denial of dementia. She said:

'*My mother had told my father we needed to go and visit the GP, especially because of his memory loss, but he would get very aggressive, and he would say there was nothing wrong with him, he was fine. Either he was not aware, or he did not want to be aware of cognitive and personality changes. So, either he knew, and he was in denial, or he was genuinely unaware.'*

Yosef's fear of developing dementia since witnessing his father's struggle with Alzheimer's may have resulted in his resistance to seeking medical help. However, it could also be a lack of insight into his symptoms, even though his family assumed he was deliberately avoiding acknowledging the changes that were obvious to them. When Yosef was diagnosed at an advanced stage of Alzheimer's, it limited his chances of accessing community social care services, including DP. Yosef's frustrations and challenges of adjusting to dementia, his wife's terminal illness and later her death were described as 'aggressive' and 'disruptive' both at home and in the care home. Daniel described how, initially, he was in denial and questioned why it had happened to him. Daniel went through various emotions, including initial shock and disbelief at the loss of what his life could have been. However, he also experienced relief through the tests and diagnosis by understanding the symptoms. He said:

'*When I first got the diagnosis, I was like, oh my God, why? Why is this happening to me? I did not ask for this, but after thinking about this, I thought if I can't beat it, I need to join it. I was happy to do tests* [DEMENTIA DIAGNOSTIC TESTS] *because I would better know who the devil is than to kid myself that everything is normal.'*

One of Daniel's coping strategies was to focus on supporting others living with dementia. He was aware of his strengths and what he could offer to remain active and involved. He strived for self-empowerment and self-improvement through volunteering, inquisitiveness and learning about dementia and the latest research to gain more insights. Daniel said:

'*I just want to make things better, not just for myself but also for other people. You don't realise how many people are affected by dementia, not just in the UK but all over the world. It affects*

people from all walks of life, rich, poor, working-class, middle class. It doesn't matter what background you come from or the environment you live in. It doesn't discriminate. In the meantime, while I am in good health, I want to prolong that period when my dementia is stable and not declining. That is my motto. After retirement, I did not want my brain wasted, so I wanted to continue using it.

Kareem's response to his diagnosis was positive. He focused on living in the present moment, which brought contentment to him. Also, following the suffering of citizens in his home country made him appreciate having a safe place to live in Scotland. He saw the liberation of his country as a more significant issue than his personal challenges with living with dementia. His daughter Mina said:

'My dad is a very positive man, which helps; he has a good energy to be around, so you enjoy spending time with him. He has a very cheerful character.'

Yosef sought solace in his faith to cope with his dementia diagnosis and continued involvement within his Jewish community. He also sought opportunities to remain connected with the academic community by attending public lectures at the university. Catriona viewed it as Yosef's strategy of ignoring his deteriorating health and loss of his independence.

Catriona and Kareem's daughters also experienced challenges adjusting to their fathers' dementia and supporting them. Catriona felt some of the responses from her father were culturally influenced by the traditional role of family members, while others were related to dementia. Catriona said:

'He wouldn't listen to me. He did whatever he wanted, and also the relationship between us because I am his daughter and the youngest daughter. I think that even though I was making sense to him, there was that pridefulness where 'why should my kids tell me what to do. I will not listen.' So, he saw me as being beneath him and unable to make decisions, so what I said did not matter. He also got more sexist as he got older. He would have just seen me as a woman telling him what to do. It was strange, a complete regression because he was very liberal and into gender equality. It is like he changed his personality.'

There were different strategies that Kareem, Daniel, and Yosef undertook to cope with dementia symptoms. They received some level of support from their families, although it was not always viewed as necessary. Daniel highlighted that while the family supported his needs, it was a challenge convincing them that he was still capable of managing his life and living independently. He felt his family behaved in an overprotective manner which sometimes felt condescending to Daniel, with his efforts being undermined and undervalued. This resulted in frustrations that are not dissimilar to Yosef's when he felt he was getting unnecessary

intervention from his daughter and professionals. Kareem wanted to continue living alone with support, deciding what he did, where he went and who supported him. Meanwhile, Yosef hated feeling confined both at home and in the care home. Catriona said:

'*First six months were hellish; he would ask the nurses to call me, and he would yell at me saying, 'you put me in prison, I am a prisoner. I can't leave they call it a care home, but I call it I couldn't care less home,' and he was really aggressive with the staff, and he was always trying to escape.*'

Although demonstrated differently, the three men's desire to be self-reliant and not be diminished by care by remaining active was something they had in common. They also relied on their thoughts, views, and ability to remain interdependent with their family and support.

Conclusion

Daniel, Kareem and Yosef's narratives provide a greater understanding of the themes explored in chapter four, indicating some relationship with the themes in both chapters. This chapter has explored the three men's cultural beliefs, customs, society, and politics to understand how some aspects of their past experiences impacted or influenced their present lives living with dementia. While Kareem, Daniel, Yosef and their families may face similar challenges to other people living with dementia in Scotland when accessing services, they may experience additional worries about fears of racism, discrimination and inequality. This intersection adds a specific dimension to their lives, resulting in a more complex pattern of disadvantage that they need to reduce loneliness and isolation. Although interdependent, their narratives show that they do not want to be diminished by care and want to be active citizens. Needing to belong and feeling one belongs, whether to a specific group, family, community, network, nationality, class, career or religion, seems to remain important in one's life. The stories of Kareem, Daniel and Yosef highlight a choice belonging not necessarily defined by nationality, ethnicity and race but can be a career, social group or people with a similar health condition. Therefore, people may possess multiple identities when placed in different situations and environments.

While Kareem, Daniel and Yosef's cases share similarities, they also have huge disparities and echo some of the wider experiences narrated in chapter four. To some extent, their stories could be similar to other BME people with similar life circumstances, social class and culture. However, importantly, the three stories represent a subset of BME people. They are men from middle-class families, well-educated, and held high-level professional jobs. Kareem also comes from a high social-standing religious family, affording him different opportunities in his home country despite the challenges he experienced. The individual accounts of their life stories cannot be generalised because multiple contextual, structural, cultural and individual

factors may determine social disadvantages and affect access to services for BME people living with dementia. However, these narratives are not entirely separate from other BME people who have migrated to Scotland and help us to understand and form meaningful cultural connections in understanding their lived experiences. This enables us to use these stories to make sense, evaluate and understand the complexity of BME people's experiences living with dementia when accessing mainstream services, specifically DP.

CHAPTER SIX: DISCUSSION

Introduction

This research aimed to explore whether DPs are an effective and culturally sensitive response to meeting the specific challenges currently faced by BME people with dementia, their carers and families. This chapter places these findings within the broader academic and practice context. This section links the research aims, identifies the significance of the findings interpreted, and lays the foundation for the conclusions in chapter seven.

This chapter analyses and interprets the findings presented in chapters four and five. Chapter four focused on the entire data set, exploring the experiences of professionals, carers, and people with dementia in Scotland. Thematic analysis was used to develop four main interconnected themes. Chapter five consisted of three case study interviews with people with dementia, and three major themes connected to chapter four were developed using thematic narrative analysis. This discussion chapter collates information from the two chapters and the literature review to demonstrate how the research findings extend existing knowledge and fulfil the overarching aim of the research

This chapter is divided into four sections using four major themes. Three similar themes from the previous chapters have been re-absorbed as sub-themes. These four key themes represent a chronological approach and are discussed in turn in this chapter: Theme one discusses BME people's perceptions and beliefs of formal and informal care in Scotland. The second theme explores how experiences of racism impacted BME people's decisions to seek formal services. The third theme deals with understanding dementia and how people do not want to be diminished by the support they receive. The fourth and final theme explores the personalisation of care for BME people with dementia.

This chapter demonstrates how narrative methodology has answered the three main research questions and three sub-questions set out below:

Research Questions

1.   What are the experiences of BME people with dementia in Scotland?

   a)   What are the specific challenges BME people with dementia and their families face?

2.   What is the potential for DP to provide personalised services for BME people with dementia?

a) What challenges do BME people with dementia, their families, and professionals experience when accessing DP?

b) What are the benefits of DP for BME people with dementia and their families?

3. What are the perspectives and experiences of carers, practitioners, and stakeholders who support BME people with dementia in receipt of DP?

The findings highlighted the multiple structural, contextual, cultural and individual factors determining BME people with dementia's access to DP. The findings also revealed that BME people face similar challenges to the wider population. However, those challenges are further compounded by racism, discrimination, a lack of culturally appropriate services, a lack of a sense of belonging, isolation and language barriers, all discussed in this chapter. The intersectional nature of BME people's experiences is discussed before considering the potential for DP to offer potential benefits and the significant shift required to facilitate this, especially in streamlining processes and funding.

BME People's Perceptions and Beliefs of Formal and Informal Care in Scotland

The main theme in this section is BME people's understanding of dementia and the care of older people within BME communities. It also discusses stigma towards dementia and how participants viewed mainstream services. The research questions about the experiences of BME people with dementia in Scotland and the specific challenges they face with their families contribute to the discussion of this theme.

Understanding dementia and care provision for people with dementia within BME communities

The current study contributes to research that has found that the term 'dementia' is not well known or understood among BME communities and may have different meanings in different communities. Similarly, Hossain and Mughal (2020) found that most BME carers lacked knowledge and awareness of the symptoms of dementia to support the family member with dementia. The term 'dementia' was also not easily translatable in most Asian and Arabic languages, and sometimes words with negative connotations in local languages were used to describe dementia (Baghirathan et al., 2020). Other researchers have reported the lack of equivalent meaning of dementia in different BME languages (Baghirathan, 2020; Forbat, 2003; Hossain and Khan, 2020; Hossain and Mughal, 2021). For example, in this research, one participant with dementia understood memory problems but not the term dementia.

The findings highlighted that differences in understanding and perceptions of dementia within BME communities impacted their decisions about accessing dementia and social care

services. This suggested that cultural factors contribute to meaning making about dementia diagnosis, underpinned by past experiences, religion, and cultural understandings. For example, dementia was perceived by some participants as a normal ageing process and not a medical condition needing medical intervention or formal services. This resonates with previous research, which found dementia was linked to ageing, and health decline among BME communities and therefore did not seek mainstream support but relied on family support (Johl, Patterson, and Pearson, 2016; Subramaniam et al., 2020; Turner, Christie and Haworth, 2005). In line with previous research (Baghirathan et al. 2020), the current research found that some BME people linked dementia with mental health illness, and people with dementia were consequently negatively treated by their communities. Therefore, BME people and their communities may not engage with services because of their understanding perceptions of dementia.

Caring may be viewed as a cultural or religious duty and an obligation. This thesis illustrated that families play a key role in supporting people with dementia in seeking dementia support. In the three case studies, the families were viewed as the catalyst in persuading the person to seek professional support after noticing the different symptoms. This aligns with previous research that BME people are more likely to seek support from family and familiar networks (Baghirathan et al., 2020; Mukadam et al., 2011; Parveen, Peltier, and Oyebode, 2017; Tuerk and Sauer, 2015). Participants reported that many families thought it was culturally unacceptable and taboo to place people with dementia in a care home. This aligns with a study that found a group of older Chinese people said they feared taking their relatives to a care home in case they were treated differently, discriminated against, or their behaviour was misunderstood because they could not communicate in English, leading to isolation (SCIE, 2015). The current findings are consistent with previous research, as Ahmed (2020) asserts that care home placements for BME people go against common religious teachings, customs and traditions. While people from the wider population enter into residential care at a crisis point, BME people may delay assessments due to feeling obligated to look after the person and the fear of judgement from their community. This is then compounded if they feel that the care home will not meet their cultural needs.

This research identified that practitioners might make assumptions about BME families caring for family members with dementia; this inhibits their needs from being properly identified and receiving culturally appropriate support. Various research studies show BME communities do not always choose to look after their families, and such assumptions then leave BME people suffering in silence with no access to support (Harries et al., 2019; Kokab et al., 2020; Nazroo and Kapadia, 2013). However, the findings also broadly support the view that BME people choose to look after their own families within extended familial networks and fail to seek formal

services (Davis et al., 2019; Hubert, 2006; Katbamna et al., 2004). This may lead to health and social care professionals assuming that everyone in BME communities has strong family support, which will provide the care needed. The situation is complex and nuanced- it is not simply about a family choosing to provide the care or not wanting to seek formal support.

The ability of BME families to provide care within the family unit has been impacted further by structural changes within their households. Participants explained that many had moved from traditional multi-generation to smaller nuclear families without extended family support, which impacted older family members' care. Some changes are demographic and involve younger people leaving the family home to seek greater economic and personal independence or to seek work to support their own families. This change in BME family structure and ability to provide care within the home environment without external support is shown in research (Harries et al., 2019; Hubert, 2006; Memon et al., 2016, Simpson and Parsons, 2016). One of the issues that emerge from this thesis is the tension between family members wanting to fulfil the cultural and religious duty of care when living in a country with different expectations, challenges and networks. This is heightened by the understanding of dementia and stigma towards dementia, which may lead to feelings of shame and judgements from other community members.

Stigma, fear and shame among BME communities

The findings illustrated that people's cultural background and specific understanding of illness defined acceptable responses to dementia diagnosis and appropriate responses to services offered by the LA. People with dementia from the broader population may experience stigma towards dementia. However, this research revealed that stigma towards dementia in BME families was part of a complex web that led to a lack of engagement with formal services even when they were needed. Some feared being shamed and judged by members of their communities for seeking external formal help. Some families looking after a family member with dementia chose to stay away from community involvement, becoming estranged, isolated and lonely. In the current findings, stigma was recognised as reaching beyond the individual and may affect the entire household.

These findings align with other studies focusing on BME people diagnosed with dementia, in which the family may keep the person hidden at home to avoid judgements from other community members (Baghirathan et al., 2020; Hossan and Mughal, 2021; MacKenzie, 2006; Parveen et al., 2014). BME people were least likely to seek support from dementia services due to the significant stigma towards dementia within BME communities (Dodd et al., 2020; Johl, Patterson and Pearson, 2016; West et al., 2021). In contrast, Hossain and Khan's (2020) research found that the BME carers they interviewed, while they believed there was a stigma

linked to dementia, did not consider that it prevented BME people from seeking dementia support. Therefore, not all BME people fail to seek dementia support for fear of being stigmatised within the community.

Current findings suggested that stigma was worse for those with high economic or social status within the community because of embarrassment or shame about a dementia diagnosis and loss of respect. Similarly, Baghirathan et al. (2020) found that in Caribbean communities, people of higher social status with dementia were hidden at home for a prolonged time as a way of protecting their dignity. This suggests that BME people with dementia have to cope with both their diagnosis and the community response, which in turn affects their decisions about seeking support outside the family.

Lack of cultural sensitivity and trust in mainstream services

The idea and, for some, the reality that mainstream services were not equipped to meet BME people's specific cultural, religious and linguistic needs led to BME people not seeking services. They felt that they were not designed for their needs. This corresponds with other research findings (Bergstresser, 2015; Codjoe et al., 2019; Frearson et al., 2013; Health in Mind, 2013; Whittaker, 2006) that found that BME people did not trust that mainstream services would meet their needs in the way they wanted to be supported. Previous research has also found that BME people are generally less satisfied with and have a poorer understanding of the UK health and social care systems than the population as a whole (Greenwood et al., 2016). This thesis found that some BME people did not access services because they feared being treated differently due to their race and ethnicity; for some, this was due to personal experiences; for others, it was based on perceptions of others' treatment or what they had seen in the media. This aligns with Bergstresser (2015), who argued that 'under-served' communities like BME people and immigrants are rightly distrustful of public health institutions because, historically, they have been undertreated or experienced racism through the medical and health system.

The findings indicated that the closure of BME specialised organisations had a devastating impact on BME people using their services, and participants blamed the Scottish Government for not resourcing them adequately. They thought of BME organisations as being better placed to meet BME people's cultural, religious, and linguistic needs. The participants observed that as a result, BME people were forced to receive DP to source alternative care, but this was not a choice they would have made had the specialised services continued being funded. The broad coalition of BME charities and anti-racist organisations in Scotland argued that only 1% of the overall charity grant had gone to services designated explicitly for BME communities despite the growing number of BME people in Scotland (Qureshi, 2020). They argued that the

Scottish Government's rhetoric of welcoming immigrants and refugees should be reflected in funding services for BME people. Without these BME, communities may be further marginalised. As highlighted in the findings, a possible explanation for the underfunding of specialised services is institutional racism. Camera (2021) argued that mainstream organisations have been constructed and protected over generations in ways that give white people advantages compounding disadvantages to BME people.

Previous research has labelled BME communities 'hard to reach' (Iliffe et al., 2017; Liljas et al., 2017; Katbamna et al., 2004; McMurdo et al., 2011). Participants in the current research also used this phrase to indicate BME communities were difficult to assess for provision of DP because they did not come forward and engage with health and social care services. Darko (2021) argued that 'hard to reach' is a misconception of organisations that are avoiding engaging with BME communities. Similarly, Begum's (2006) research identified the 'hard to reach' label as an assumption about BME communities' participation. He argued that when organisations used that label, they were not engaging with BME people and were making excuses such as, 'we don't know what they want,' 'they are not interested in participating' (Begum, 2006, p.7). Therefore, the term 'hard to reach' appear to describe communities and groups who present challenges to conventional and mainstream ways of providing services. When the term is used, it homogenises the needs of communities, viewing them as the problem rather than the organisations. Thus, when trying to engage with a group labelled 'hard to reach', the onus is placed on them to reach out to the services. Many participants felt that local authorities should work closely with community leaders and religious institutions to pass on council services and DP information.

The language barrier was viewed by many participants as an ongoing challenge for many BME people when accessing services. This was especially so for DP, whose complicated language and processes can disadvantage BME people. This aligns with multiple research findings that have highlighted language as a major barrier to accessing health and social care mainstream services for BME people (Ali et al., 2017; Collins, 2017; Loewenthal et al., 2012; Memon et al., 2016; Nielsen, Nielsen, and Waldermar, 2020; Shah, 2010; Szczepura, 2005; Yasmin-Qureshi and Ledwith, 2021). However, many participants felt that language barriers could be overcome through accessible translation and interpretation services, including for DP. The main challenge was not the language barrier itself but the willingness to find a solution; this in turn, was connected to resources and structural racism in designing the services.

The findings build on previous research showing BME people's limited uptake of services., This was linked to their lack of awareness of their availability, entitlement to services, and

language barriers. Therefore, if services are to reach out and involve BME people, there need to be greater efforts to engage with them and allocate resources for services to build trust.

The Impact of Racism on Service Provision

This section discusses structural racism and how it intersects with other factors to impact on BME people's access to mainstream and specialised services. It also discusses the experiences of BME people feeling excluded when 'othered' and how this may affect their sense of belonging. This research supports some existing theories on racism, such as Critical Race Theory (CRT), intersectionality, and labelling theory which have been utilised in understanding BME peoples' experiences of racism.

As discussed in the literature review, this section adopts Solórzano and Yosso's (2002) definition of race as a socially constructed concept created to distinguish racial groups and reinforce one group's superiority and dominance over a subordinated group. This stance is also compatible with the thesis epistemology of the social constructionism framework. This section addresses the research question on the specific challenges BME people with dementia and their families face, with racism being one of them.

The structural racism that affects BME people when accessing services

The current study highlighted that racism is prevalent, with many participants describing that BME people continue to experience racism when accessing health and social care services. As discussed in the literature review, the situation is complicated and partly reflects British society's deep-seated discriminatory structural barriers. The findings indicated that racism was experienced both at an individual and institutional level, impacting the person's decisions and choices about accessing health and social care services. Some were not direct or overt experiences of racism but what participants perceived to be racist attitudes and perceptions from health and social care professionals.

The current research provided some evidence on how racism can manifest itself in everyday life of BME people; it can produce social identities and power relations that maintain oppressive structures and inequalities and affect access to services. Current inequalities and racism were also linked to cultural stereotypes and historical injustices such as imperialism and civil wars. In line with the findings of this study, the Commission on Ethnic and Race Disparities (2021) found that for some minority groups, historical experiences of racism still haunt the present, and they did not think the UK had become a more open and fair society. However, the Commission on Ethnic and Race Disparities (2021, p.8) reported that they 'no longer saw a Britain where the system was deliberately rigged against ethnic minorities.' While their report acknowledged racism still exists in the UK, their evidence indicated that family

influence, social-economic background, geographical location, culture and religion had a greater impact on an individual's life chances than racism. Though the current thesis illustrated a need to consider social-economic factors, it also highlighted the need to dig deeper and acknowledge the influence of historical injustices that continue to impact BME people today.

As discussed in chapter two, Baciu (2020) found that using CRT proposes a race-based criticality to understanding the power relations between different groups, especially those labelled as 'others' by the dominant group. Parallel to many participants' opinions, CRT views racism as something embedded in the systems, institutions and policies and not blamed on individuals (Burrell-Craft, 2020). Like some participants' arguments, CRT asserts that racism and different racial outcomes result from complex, changing and often subtle social and institutional dynamics and not explicit and intentional individual bias and prejudices (Burrell-Craft, 2020). CRT theorists argue that unchallenged assumptions can lead to promoting structural inequalities embedded in the functioning of social institutions (Abrams and Moio, 2009). Therefore, understanding how racism manifests itself would enable us to challenge our assumptions, given Mota's (2020) argument that everyone needs to understand how systemic racism oppresses BME people when accessing services. The findings here enable an understanding of how racism is embedded into daily aspects of BME people's lives when accessing health and social care services.

CRT may explain some participants' thinking; for example, a stakeholder questioned whether her organisation was inherently racist, due to the systemic racism in the wider UK, without deliberately causing unequal access to the services for BME people with dementia. While the current findings identified some difficulties that BME people experience due to internal cultural factors, these challenges were compounded by what they described as ingrained institutional racism within various organisations such as health and social services. Lala et al. (2021) have suggested a clear tradition of the institutional dimensions of racism embedded within the key sectors such as education, health and employment established in-groups and out-groups within mainstream UK society. Kundnani (2007, p.5) referred to it as state-sponsored racism, which seeks to limit cultural differences and suppress the diversity of those seen as 'other'. Qureshi et al. (2020) have argued that inequalities that BME people experience when accessing services are underpinned by historical and institutional racism. They emphasised that racism should not be limited to prejudiced interpersonal encounters but consider structural racism and the multiple forms of racism that BME people face. They also argued that failure to do this might give the impression that inequalities experienced by BME people are due to factors internal to them and inherent in their different cultures and would ignore the widespread institutional discrimination that lies at the root of the inequalities they experience.

The current findings added to these debates and illustrated how some BME people fail to seek services they feel are not for them. In this thesis, racism was raised by most participants as a major issue that continues to impede BME people in Scotland when accessing services.

Intersectionality of racism and other factors

Like other scholars (Harris and Patton, 2018; Lynn and Dixson, 2013), this research has combined CRT and intersectionality theory to understand how systematic racism intersects to form a more complex experience for BME people. A key finding here was the importance of contextualising experiences of racism in relation to a range of factors, including other sources of potential discrimination. Hancock (2007) highlighted that experiences of racism are inherently multi-faceted. McKenzie (2017) and Meer, Akhtar, and Davidson (2020) found that BME communities across Scotland are over-represented compared to the broader population regarding deprivation, unemployment and poor housing conditions. In the current research, practitioners and stakeholders highlighted that many BME people were disadvantaged in terms of education, employment opportunities, and poverty.

The findings in this research illustrate intersecting factors that may compound the negative experiences of BME people with dementia. Intersectionality recognises that racism intersects with other forms of oppression, such as sexism, ageism, classism, homophobia, ableism and others, to influence BME people's lived experiences (Crenshaw, 1991, Bartlett and Brayboy, 2005; Solórzano and Yosso, 2002). The current study provided some evidence of intersectionality by highlighting the multiple identities BME people with dementia may have and that need to be examined simultaneously when assessing them for DP. Cabrera (2019) argued that we need to move beyond framing oppression in terms of race and gender only but look at other forms of oppression. This research adds to this framing by looking at other factors such as age, disability, social-economic class, family structure, culture and geographical location and how they intersect with dementia producing a more intricate combination of power and disadvantage for people with dementia.

Research findings showed racism was seen to intersect with disability and ageism towards older people with dementia, adding another layer of complexity when accessing DP. This made it more difficult to understand individuals' circumstances. Many people with dementia were assessed as lacking the capacity to manage DP. Various participants highlighted that wealthy older people and wealthy BME people with dementia were more likely to be offered DP. Many had prior experience managing and employing staff and could afford to top up the budget shortfall. This supports previous research (Ferguson, 2007; Leece and Leece, 2006; Woolham and Benton, 2013), which argued that DPs were viewed as privileging the well-educated families who are more articulate, fluent in English and able to manoeuvre the SDS

processes. Leece and Leece (2006) viewed it as creating a two-tier system and disadvantaging people from lower economic status. Therefore, this thesis has important implications for understanding how both social-economic status and age can lead to disadvantages.

An intersectionality lens helps illuminate links between individual subjectivities, wider social structures, power relations and the intersection of race and gender discrimination. Participants commented that BME women navigated more barriers than men when accessing services. For example, many older BME women, who never learned English, like their working husbands, stayed at home to support the family, leading to expectations they would become carers. These women then relied on their husbands for translation and interpretation, which could cause confidentiality issues and inaccurate translation, especially dementia-related struggles linked to stigma and shame., Harries et al. (2019) found that BME people with limited English were more likely to have their needs unmet for a lack of translation and interpretation. When women relied on men as interpreters, information was deliberately filtered if deemed embarrassing or against cultural norms. Therefore, this could disadvantage BME women in understanding dementia diagnosis and available interventions and services.

Another intersecting factor that affected BME people is that of religious beliefs and nationalist notions. The findings highlighted increased Islamophobia in Scotland, which may affect Muslim BME people approaching service providers. Participants viewed the re-emergence of extreme right-wing politics as leaving Muslim BME people more vulnerable to attack, which increased their fear of accessing mainstream services. One report describes a seven-fold increase in the number of anti-Muslim incidents reported in the UK the week after the New Zealand Christchurch Mosque far-right terror attack in March 2019 (Tell Mama, 2020). Previous research has reported similar fears from BME Muslim people, with some feeling that there has been an increase in racism and Islamophobia in the UK (Abbas, 2019; Beck, 2019; Chantler et al., 2019; Singh, 2021; Zaheer, 2021). The findings suggested that one's religion, if not viewed in a favourable light by others, may add another angle of intersection, highlighting how some BME people might be more marginalised than other minority groups. Similarly, researchers such as (Baird et al., 2021; Khattab and Hussein, 2017; Yasmin-Qureshi, 2021) found that Muslim women faced worse outcomes, irrespective of other factors such as education status, than other minority groups of a different faith. This finding may help us understand the globally interconnected world we live in, where incidents in different parts of the world may significantly impact minority communities living in the UK.

The findings broadly support the work of Crenshaw (1991) in her argument that oppression can be multi-dimensional within a marginalised group of people. It is unclear if negative service

delivery is about race, class, gender, religion or perceived cultural factors. Hence, investigating and understanding discrimination in organisations is highly subjective due to these intersecting factors. My research builds upon the limited studies that currently exist and tries to look at racism and the Intersectionality of BME people with dementia experiences. It indicates the importance of critically examining multiple forms of social oppression and how they are mutually reinforcing, and intersectionality should not be conflated with analysis of two or more social identities (Harris and Patton, 2018).

Impact of 'othering' on belonging

The research highlighted that racism leads BME people to feel 'othered', resulting in 'us and them'. This further marginalises them and leaves them feeling they do not belong, adding a layer to their difficult experiences. Naz et al. (2019) found that when people who have felt part of UK society were made to feel like the 'other', this elicited difficult emotions. As illustrated in the case studies, these feelings of 'otherness' affected BME people's sense of belonging and made them re-evaluate their identity when living as a minority in Scotland. The Commission on Ethnic and Race Disparities (2021) argued that 'othering' behaviours at an organisational level make BME people feel they do not belong. In addition, systemic, institutional, and structural racism could leave BME people feeling like outsiders. They also added that we are susceptible to differentiating between those groups we belong to and those we do not, and then intentionally or unintentionally favouring those to which we belong.

An interesting concept raised by one participant was 'self-discrimination', whereby BME people discriminate among themselves through their own perceptions that they do not deserve services. By contrast, other BME people were described as feeling privileged to be in Britain and therefore did not want to ask for more, reflecting on their families' struggles back in their countries. Ouseley (2001) argues that self-segregation is driven by the fear of others who are more powerful than themselves, the need for safety from racial harassment and the belief that it is the only way to retain their cultural identity. This links to what Allport (1979; p.37) called in-groups and reference groups discussed in the literature review 'where the majority white population positively adhere to the principles of in-group loyalty and, in doing this, reject those deemed to belong to a reference group or out-group'.

The findings further support the idea that the different terminologies used to identify BME people could be divisive and deepen this 'us' versus 'them' divide. The current research contributes to the labelling theory by highlighting why the classification of BME people is problematic. Skeggs (2009) argued that when people are assigned labels, society begins to treat the individuals based on their labels, and they begin to accept the labels themselves. Grouping ethnicities together infers whiteness as the status quo, with everyone else fitting

neatly into the 'other' box and being reduced to acronyms and generalisations regardless of diversity in the group (Mwansa, 2021). Therefore, the labels we use, like racism, are also socially constructed concepts (Chavez and Rocheleau, 2020).

The ideological notions of 'other' and the 'othering process' are central to understanding the racism described in the findings. BME people were described as feeling 'othered' by organisations, leaving them feeling discouraged from seeking their support. Sometimes, this 'othering' can have detrimental consequences, like in the story of Yosef on the extermination of the Jewish people. Philo (1992) argued that excluded minority groups stand outside the mainstream of western society because of their race, ethnicity, class, age, gender, sexuality, (dis)ability, political affiliation, religious persuasion and others. These processes of exclusion position BME people as outsiders.

The findings highlighted that nationalistic discourses had increased in the UK and other parts of the world, resulting in BME communities feeling anxious about not belonging. In support of Miles and Brown (2003), the findings found that racism was perceived as an ideology interdependent with nationalism, meaning that the national 'self' must be protected from 'others' whose 'real' nationality must lie elsewhere. This may lead to nationalistic populism, an ideology that 'we' must not be contaminated by 'them' (Miles and Brown, 2003, p.10). The findings highlighted that such ideologies might lead to more BME people experiencing exclusion and feeling like they do not belong in the UK.

Practitioners' skills and knowledge in tackling racism in practice

The current study found that some white practitioners felt they had limited skills and confidence in working with BME service users. They felt that discussions on racism sometimes triggered difficult emotions for white workers, such as uncertainty, guilt and anxiety. These feelings then affected their engagement with the BME service users for fear of being accused of racism or getting it wrong. They deliberately avoided talking about racism, ethnicity or culture since they felt unsure of how to approach these topics. This finding was consistent with that of (Spanierman, Clark, and Kim, 2021), who suggested that white people may use feelings of guilt as a defensive tool to avoid being accused of racism and escape the personal and collective responsibility of challenging racial injustices. They argued that it reframes whiteness and the white person who feels guilty instead of tackling racism through listening and sympathising with the BME person (Spanierman, Clark, and Kim, 2021).

Keum (2021) argues that guilt and fear of engaging with other races seemed to be barriers to promoting advocacy and responding to racism. Thus, white workers' feelings of guilt are complex and nuanced, as suggested by this criticism, and appear unhelpful in practice. Therefore, tackling racism within the practice may not happen if workers feel uncomfortable

177

discussing race-related issues. This finding has important implications for tackling racism within the practice. The evidence from this study suggested that service providers' fear of getting it wrong has meant service users were not receiving a service or were left in challenging home environments. In other instances, findings indicated that BME people were offered DP when it was inappropriate because workers had struggled to understand their cultural needs. Naz et al. (2019) concluded that practitioners lacked the confidence to ask questions about service users' ethnicity, culture, or experiences of racism in case they made mistakes or offended them.

Burgos (2021) argued that by not discussing the issues that BME people experience and interrupting racism, people remain complicit in systems of white superiority. They could also be viewed as adopting a colour-blind approach (Neville et al., 2013). For example, a practitioner stated that she did not see colour; she just saw a service user needing a service and therefore focused on the service needed, not the colour of their skin. The worker used this phrase to explain she was not prejudiced and welcomed diversity. However, this ignored or diminished the varying needs of service users connected to their race. When people say they do not see an individual's skin colour, they may disregard the privilege and power of the dominant racial group of society. This is likely to reduce feelings of prejudice, bias, and racism experienced by BME people seeking services.

The 'colour blind' approach is damaging to diversity and inclusion efforts; it is inaccurate since sighted people can see and recognise different skin tones. It is hard for practitioners to tackle and fix something they claim not to see or do not believe is a problem. As Morin (2015) asserts, most people hold some racial bias. To deconstruct racism and a system of power and privilege based on race, practitioners need to discuss the deep-seated racial bias people hold about other racial groups. Morin (2015) suggests that a powerful catalyst for change in tackling racism in society is acknowledging and accepting our own biases and prejudices.

In the current research, the idea of staff being culturally competent to understand BME people's needs was raised numerous times by different participants. Culturally competent in this context means workers with awareness and knowledge of BME people's diverse needs. One of the strategies to facilitate and promote social workers' cultural competence has been matching service users with social workers of similar cultural backgrounds (Leung, 2021). One interesting finding was that professionals desire greater diversity in their teams to reflect their diverse service user groups. Out of the 12 practitioners interviewed, only two were of BME background, and they felt like representatives for BME staff within their teams. Different studies have indicated the lack of diversity in social work staff in Scotland and assumed that this results in BME people's racial, cultural and religious needs not being met (Hothersall and

Bolger, 2020; Käkelä, 2020), indicating further exploration is needed to ensure that BME people are not missing out on support.

The current finding has demonstrated that the numerous intersecting challenges cannot simply be addressed by matching BME service users and practitioners of similar backgrounds. The findings indicated that some BME practitioners and stakeholders took on the role of educating white colleagues as the latter expected it. Many practitioners and stakeholders argued that all services and professionals needed to be culturally competent to engage with service users of different backgrounds and challenge structural racism and inequalities experienced by BME people. They argued that their BME colleagues should not be expected to educate non-BME colleagues on race issues or be allocated to BME service users because they are assumed to meet their needs by default. Consistent with these findings, Burgos (2021) argues that black people are not responsible for educating white groups about anti-blackness and racism because doing this perpetuates the systems of oppression.

Two BME stakeholders advised that they carried 90% of the team's BME service user's caseload because they were considered able to understand their cultural needs and spoke their language. The stakeholders' manager said these two workers were an asset, and they relied heavily on them for translation and interpretation services. The two workers spoke eight Asian languages between them, ones that are widely spoken by their BME service user group. The two workers were not only doing their day job but also saved the company money and time needed for translation and interpretation.

This study provided stronger evidence of matching service users with paid carers than with professionals. Many BME service users preferred care staff of a similar background, assuming a shared understanding of their religious and linguistic needs. PAs of similar backgrounds were found to be able to engage and comfortably discuss racism with the service user and found it easy to share their experiences of oppression with someone similar to themselves and support the service user more effectively. This mirrors Memon et al. (2016) study, in which BME service users said that they had been treated differently because of their skin colour and preferred receiving a service from people of their own race who would understand and sympathise with the realities of their lived experiences.

Bhopal (2010) cautioned against ethnic matching based on implicit assumptions of the importance of shared identities, such as race and language, while other differences might be just as significant, such as age, class, gender, and immigration status. As seen in Kareem's case study, the family had used the similarity of background, language, and religion as criteria for employing a PA. However, these were not important to Kareem because he considered other qualities more important. Therefore, there are complex positionalities and dynamics

involved when matching service users and staff, and a personalised approach to each individual might be most appropriate.

Social Citizenship vs Feeling Diminished by Care

This section discusses how some ways of thinking about care, support and independence can diminish the dignity, social citizenship or perceived value of those requiring care and support. This section discusses the struggles faced by people with dementia to assert their autonomy and personhood while professionals and families wish to protect them. It explores the research question on challenges experienced by BME people living with dementia when accessing services.

Many participants favoured the concept of person-centred care and felt it would effectively meet BME people with dementia's personalised and culturally sensitive needs. This echoes Kitwood's (1997) arguments about the importance of placing the person, rather than the illness, at the centre of attention when planning and delivering care. Sabat (2002) also argued that addressing people by their diagnosis and not through personal and socially situated attributes may result in the person with dementia being viewed as dysfunctional. Therefore, personal and broader social structures may lead people to react differently to the diagnosis. In the current study, the four people with dementia expressed a range of psychological and emotional responses to living with dementia. They felt that the way their families, friends, professionals, and society treated them affected their self-hood, identity, and independence.

Participants' interpretations of why they were denied DPs align with a deficit model of dementia discussed in the literature review chapter. Findings suggested that the DP assessor focused more on the dementia diagnosis than on what the person was still capable of doing, including deciding how they wanted their care delivered and managing a DP. However, it could also be due to stigmatising attitudes from professionals that people with dementia were excluded from decision-making, care planning options and accessing social spaces (Batsch and Mittelman, 2012; Steeman et al., 2007). Nevertheless, people with dementia may depend on others to provide care and compassion for them because people have varying degrees of dependence and interdependence (Gilligan, in Bailey and Cuomo, 2008). Therefore, while people with dementia may want to be independent, there is an interdependence on others to support them in meeting their everyday needs.

As discussed in chapter one, several laws aim to enable decision-making and protect the rights of people considered at risk of harm, including older people and people with dementia. These are the Adults with Incapacity (Scotland) Act 2000, the Mental Health (Care and Treatment) (Scotland) Act 2003 and the Adult Support and Protection (Scotland) Act 2007. People with dementia in the current research expressed strongly their desire to be respected,

have more control of their lives and make decisions. Similarly, previous research (Martye et al., 2018; O'Rourke et al., 2015; Stewart-Archer et al., 2015) highlighted the need to support people with dementia in maintaining their independence and providing the information they need to make the choices, such as how services are delivered. Sherwood-Johnson, Mackay and Greasley-Adams (2021) suggested that older people wanted to be viewed as autonomous and not 'vulnerable' and that some practitioners' interventions may not be considered essential by the older people in keeping well and safe and may have a negative impact. They argued that safeguarding interventions that fail to consider the person's views, circumstances, and strengths are unlikely to promote their quality of life.

It was clear in this study that people with dementia resisted becoming socially disenfranchised by the limitations placed on them by others. The findings suggested that people with dementia wanted support from family and formal services but were worried it would affect their independence and agency. Baghirathan et al. (2020) referred to this dilemma as balancing the need for support against the need not to be diminished by this support. While this feeling of diminishment might be the case for many people with dementia, it was exacerbated further for BME people who felt they would be further diminished if the service provided was not culturally appropriate. The fear of losing independence risked the BME person with dementia and their families getting lonely and isolated within what was perceived to be a predominantly white service. Additionally, the feelings of diminishment were triggered if people with dementia thought the wider society lacked understanding of dementia and had no compassion towards their everyday challenges.

The findings of this study lend weight to claims that social citizenship is a useful lens through which to explore social structures that may enable people with dementia to participate and belong to a community as decision-makers and with an equal position in social groups (Bartlett, 2016; Bert, 2017). Participants with dementia in this research were very articulate and wanted to remain at the heart of decisions made by professionals about a care package. Their expressed desires are consistent with Bartlett and O'Conner (2010, p.39), who suggested that social citizenship '*recognises the person with dementia as an active agent with rights, history, and competencies*'. This research actively sought the views of people living with dementia and ensured that their voices were not hidden behind those of practitioners, stakeholders and carers.

This thesis has demonstrated that when people with dementia are not allowed to participate and engage within family and community life, they feel devalued; family, professionals, and societal views on dementia stigmatise them further. Thus, some ways of thinking about care, support and dependence can diminish the perceived value of those requiring care and support.

This broadly supports Bartlett and O'Connor (2010), who argued that broader social discourses could dehumanise and objectify people with dementia. Bartlett and O'Connor (2010) examined social citizenship as a framework for dementia care and advocacy and explored dementia as a socio-political issue, as discussed in chapter two. They emphasised the right for people with dementia to remain active participants in their social lives and articulated the need for sustained advocacy focussed on their empowerment and social justice. This was an area that participants with dementia felt very passionate about and did not want to be side-lined in their communities and home environments. They expressed the view that people with dementia should be included in all areas of society, politics, and policy work and help design dementia care. Their desires are consistent with many researchers who have advocated shifting dementia from deficit to active citizenship (Bartlett, 2014; 2016; Bartlett and O'Connor, 2007; 2010; Bert, 2017).

The social citizenship lens offers a conceptual framework for assessing the role of society and culture in moving away from the deficit model of dementia to a discourse of agency and interdependence (O'Connor and Nedlund, 2016). People with dementia in this research were very aware of their cognitive and behavioural changes and acknowledged that their lives had changed with a dementia diagnosis. Some of the personal challenges they experienced were due to neurological decline, but the rest arose from the societal response and stigma linked to dementia. However, they did not want this to inhibit them from living a full life as independent citizens with agency. Therefore, the experiences of people with dementia need to be heard and considered during service assessment and delivery; professionals need to consider individuals' social and cultural contexts to deliver care that is tailored to their needs.

Personalisation of Care for People with Dementia

This section explores personalisation in care in greater detail. It starts by discussing the complex processes and lack of resources that significantly impacted the implementation of DPs. This section interrogates how much choice, flexibility and autonomy DP offers in providing person-centred care. It concludes by discussing the possible DP outcomes for BME people with dementia as reported by the findings. This section addresses the two main research questions: first, the challenges of providing DPs to people with dementia, especially those from BME communities, by discussing the different perspectives of carers, practitioners, stakeholders and people with dementia; second, the potential for DP to offer specialised services for BME people with dementia.

The underfunded, complex DP processes and systemic challenges

Current findings contribute to the burgeoning literature in the field of personalisation and SDS discussed in chapter two; this found that DP processes are complex, bureaucratic and underfunded. In the current study, these challenges were viewed to have greatly impacted DP implementation within the 32 local authorities in Scotland. The system introduced to calculate SDS individual budgets is complex and constraining and thwarted room for practitioners' creativity. This is despite social workers being urged to actively embrace integrated systems of quasi-market-based care in delivering SDS (Carey, 2021; Petrie, 2015; Webb, 2006), as highlighted by some participants in the current study. Similarly, (Brooks et al., 2017, p.155) found 'fragmented and inconsistent' practices within 16 adult social care departments in England when interviewing lead officers. Miller and Barrie (2020) argue that tensions arise when choice and control concepts are compounded by funding restrictions and bureaucratic means of determining access. The systemic challenges described were intensely felt by practitioners who, by law, have to offer SDS options to the people they assess for health and social care services but with limited funding.

The findings highlighted that staff were under enormous stress and perceived DP as an added pressure that impacted their implementation due to a lack of monetary and human resources. This could be understood using resource dependency theory which looks at human services organisations and how resources may define the behaviour of service providers in carrying out their duties on service delivery (Hansenfeld, 1983). The principle function of these human organisations are viewed as protecting, maintaining and enhancing the personal well-being of those who use them. However, Hansenfeld (1983) advises that they present a dilemma in trying to meet those roles if there are under-resourced and with competing interests, as seen in the delivery of DPs with practitioners trying to deliver quality service but felt spread 'too thinly' for lack of funding and staff turnover.

Another important finding was concern about the economic and political environment in which SDS was implemented. Austerity and health and social care integration were viewed as interfering with how DP was assessed and delivered, with SDS policy not being seen as a priority. Like Pearson, Watson and Manji (2017), this thesis found that SDS had been affected by policy overload and overshadowed by legislation for health and social care integration. This may have led service users to view SDS as cutting costs or an opportunity for LA to scale down existing DP packages to cover budget cuts. This supports Daly's (2002) and Needham's (2011) views that personal budgets were viewed with suspicion and as a cost-cutting activity. This thesis found that service users feared DP reviews because they expected practitioners to reduce their personal budgets. Many practitioners described feeling anxious when carrying

out DP reviews due to the resulting hostility they faced from service users. Manji (2018), in her research, concluded that implementing the SDS policy at a time of significant LA financial constraint cast doubt on the potential for achieving significant change in the organisation of health and social care in Scotland. Therefore, in agreement with Pearson, Watson and Manji (2017) and Pearson and Ridley (2017), the current study found that SDS implementation during extensive financial constraints for LA may have further reduced the policy's potential to meet its aims and objectives.

The practitioners in this thesis did not view DP as a cost-cutting activity but an untimely introduction of SDS legislation during a time of austerity. Reduced funding added a layer of difficulty for BME people, who required extra funding for translation and interpretations within their DP budget. It remains unclear whether, if implementation had been well funded, SDS policy would have fulfilled its promises of providing flexible and person-centred support to service users. However well-intentioned the policy may be, without the necessary support, BME people will still struggle to achieve the outcomes they seek of culturally appropriate care.

The closure of dedicated DP teams to support the workforce had left staff feeling unsupported by management, who appeared to know less than the staff about DP. The lack of funding also affected DP training and the availability of staff dedicated to dealing with DP. These challenges, fears and concerns are similar to those raised over the years that personalisation was about the marketisation of health and social care services and was not offering greater choices to service users (Ferguson, 2012, Holloway, 2007; Pearson and Ridley, 2017). Current findings also mirror Eccles and Cunningham's (2018) research on enablers and barriers to providing personalised support through SDS in Scotland. Their research found gaps between the ambitious promises of SDS support and the lengthy and complicated implementation aspects that DP recipients had to deal with.

Despite the time that has elapsed since the introduction of DP, its implementation has remained problematic, underfunded, and lacking in training and management for the workforce. This has left some service users feeling anxious about their services, and they have linked DP to a reduction in their support. At the same time, the practitioners reported increased frustration, anger, and anxiety.

Transfer of responsibility from LA to DP recipients

The findings were directly in line with previous studies (Glasby and Littlechild, 2010; Leadbeater, 2004: Lundsgaard, 2006; Williams et al., 2014) found that DP was failing as a vehicle for delivering personalisation of care. The aim had been to empower people to shape their own lives, improve their choices and have individual control over the services they used, and this was not happening. In the current study, there was fear DP placed an enormous

responsibility on the person with dementia and their family; it transferred to them some responsibilities from the LA with whom they were already struggling. This supports Ferguson (2012), who argued that personalisation increased service users' responsibilities, extending further 'the privatisation of risk' from the state to older people and their families. This raises questions about the extent to which DP could empower DP recipients. It appeared that in practice, this was not the practitioners' priority, especially for people with dementia, where meeting their basic personal needs took precedence. Previous research has highlighted that in a market-infused care provision, priority should be given to autonomy, choice, performance, user empowerment and participation (Baines, 2016; Jordan and Drakeford, 2012). However, this thesis found that this is not always the case and that DP does not always empower service users to receive the service they want.

Glendinning and Bell (2009, p.9) feared that personal budgets risked 'institutionalising low-paid or unpaid informal carers' if appropriate services were unavailable for them to purchase care. Practitioners involved with DPs reviews feared that might be a reason for DP underspending, and some DP recipients may be missing out on care. Therefore, DP could be deemed ineffective without workforce availability for DP recipients to recruit. Current findings concur with Barnes (2011), who argued that if DP recipients are going to be commissioners of their own care, then LA should develop markets to ensure there are enough care providers for them to have choices.

The findings demonstrated that tendering changes complicated services unnecessarily. For example, one BME organisation that the LA contracted to provide care to older people with dementia was decommissioned. BME service users, who had already been receiving satisfactory service, were then requested to apply for DP and employ the same BME organisation privately in order to retain the service. This failed to make sense to many BME service users since the LA would still provide the DP money. Specialised BME organisations are both care providers and social gathering places with other people with a shared language and cultural experiences for many BME people. Many BME service users using specialised BME organisations come from a collective culture and make good use of them which may help tackle isolation among BME communities. On a similar note, Ferguson (2012) found that the decommissioning of services forced people to seek DP in order to retain their existing and satisfactory services; it was also frustrating for practitioners. Moriarty (2014) suggested that BME organisations were important in enabling BME communities to benefit from personalisation and the impact of budget cuts on them needs to be monitored.

The findings showed that transferring responsibility to DP recipients meant people were taking on complex administrative and recruitment tasks they did not want. On the one hand, by failing

to accept DP to recruit their own staff, they risked their culturally specific needs not being met. On the other hand, some BME people were offered DP because of a lack of mainstream services to meet their needs. One BME practitioner referred to this dilemma as 'catch 22' for BME people. This is another example where DP is not a choice but a result of LA services restructuring due to austerity. This raises questions about whether DP is really a real choice or used because there is no alternative.

DP and choice

The literature review and the previous research also dealt with the question of whether personalisation offers real choices to DP recipients. Inadequate budgets can mean that offering a choice is seen as an illusion if there are few choices available. The findings suggested that the nature of choice, the conditions of these choices, and how they are delivered appear to depend not only on the individual's needs but also the flexibility of the care provider. Hence this choice is not free of limits and conditions. For example, a stakeholder care provider saw DP as one way of affording older people a choice between daily or twice weekly baths, and any saved hours could be banked for longer social visits. He argued this could not be done with many care agencies that are task-oriented and unable to work flexibly with the DP budget. Therefore, people might be forced into receiving multiple short visits every day that do not fully meet their needs. Hart (2014) made a similar argument about offering older people the choice of a shower every day or two baths a week. Therefore, in this example, the extent to which DP offers a choice is contextual and depends on the DP recipient and the provider working together to provide a flexible outcome.

The current study adds to the debate by highlighting the challenges in making DP work: people with dementia try to assert their independence and agency, and practitioners try to offer choices but are constrained by policies and procedures. The narratives shared by people with dementia highlighted the personal, emotional, and societal hoops they have to jump to secure DP. Some had needed to appeal, and it was only through the use of advocacy that this was possible. Rabiee (2013, p.883) highlighted the intricacies involved: independence is multi-faceted and context-specific, and the relationship between choice and independence is 'not always as simple and linear as choice policies assume'. The consumer model of personalised care minimises the diverse needs and uncertain circumstances often experienced by most community-based older service users. Therefore, when people take on DP responsibility, they take on the risks that come with its management. Carey (2021) saw this as a paradox for people with dementia; on the one hand, they want to have DP so they can have more freedom and choice, and on the other hand, DP makes them dependent on others for organising and managing their care, and this increases risk if the care cannot be sourced. In the current study,

this risk was heightened for people with dementia if cognitive decline and memory problems meant reduced ability to manage a DP unless a carer was willing to take on the role.

The findings identified that some people with dementia chose DP to provide continuity with long-standing relationships with carers who understood their routines and preferences. They then sought DP and employed the care staff as a PA privately because the agency rota system did not allow the consistency they sought: If agencies worked more flexibly in meeting such requests, there would be no need to switch to DP. Therefore, while the use of DPs in this way was reported as a positive outcome, it also highlights the poor delivery mode of some care agencies.

DP outcomes for BME people with dementia

The findings reported that DPs had the potential to deliver personalised and improved care to people with dementia in specific contexts with more flexibility and control. This is one aim of the SDS; however, it has not been realised for many service users. Co-production was at the heart of SDS legislation, but current research did not find evidence of it during implementation. Many practitioners felt they were under enormous stress and pressure to work productively withservice users to assess them for DP and to have a fully co-produced action plan. They felt that more training and support from management was crucial if positive outcomes for many service users were to be achieved. Pearson, Watson, and Manji (2017) drew a similar conclusion in their study that explored changing social care culture in Scotland. They highlighted that personalisation had the potential to bring transformative change but was compounded by acute austerity in health and social care; as a result, service users were offered limited choices rather than increased opportunities for independent living. Similarly, Manthorpe et al. (2010) study examining support for BME older people's mental well-being in social care practice found that DPs were viewed as offering a variety of choices and a more personalised way for BME older people to organise their care in a way that it promoted their wellbeing. Similarly, Moriarty (2014) suggested that personalisation had the potential of offering BME people better options that align with their values, cultural and religious preferences.

The current findings contribute to the literature and research about the positive outcomes of DP. However, the majority of studies have focused on younger groups of DP recipients and older people in general, and very few have looked at the use of DP among BME people with dementia. Despite the scant literature in Scotland, research from England highlights the potential for DP to transform positively the care provided to BME service users and their families in providing timely and culturally sensitive services (Carers UK, 2011; Irvine et al., 2016; Pearson, 2004; Stuart, 2006; Terashima, 2011). Other work showed beneficial effects

for DP recipients after overcoming the initial hurdles of setting up DPs (Barnes, 2011; Clark et al., 2004; Davidson and Luckhurst, 2002; Glendinning et al., 2000; Hasler, 2003; McNeill and Wilson, 2017).

Despite the many personal budget challenges, the current study identified various benefits of DPs for people with dementia and those from BME backgrounds. Some of the benefits align with Barnes (2011), who suggested that DP could promote independence for service users. Barnes advised that the personalisation agenda has been viewed positively by reaching DP recipients whose varied needs are not readily met by other mainstream services. Similarly, Netten et al. (2012), in a randomised control study with older people, reported that the use of DP was associated with enhanced quality of life. Other researchers found DP helped improve the well-being of older people by allowing them to choose their support and exercise control in their lives as independent citizens (Brown, 2010; Ettelt et al., 2018; Rummery, 2009).

The findings provided examples where DPs were perceived as providing consistency and enhanced genuine working relationships. They were seen to work better for people with dementia who struggled with changes in routines and unfamiliar faces coming to provide care. DPs were also thought to offer longer time slots, permitting more meaningful relationships and exploration of the person's specific interests and needs. In the current study, building a good relationship based on trust and understanding of the person's needs, especially those unable to communicate due to dementia or lack of English, was viewed as paramount in providing personalised care. Various research has identified the importance of good working relationships in care provision. For example, Miller and Barrie (2020, p.4) asserted that 'relationships are the mechanism for establishing trust and rapport, reaching a shared understanding, careful consideration of what constitutes reasonable risk, negotiation of what is possible, and appreciation of the contributions that everyone involved can make to achieving health, well-being and quality-of-life outcomes.' In support of Fisher and Tronto (1990), the current research found that a good relationship includes being listened to, valued and treated with respect. Similarly, Miller and Barrie (2020) recognised that we are interdependent, relational beings and that authentic care is founded in positive relationships.

DPs were also seen as offering continuity in care by allowing extra time for reassurance, encouragement, and empowerment for service users to do more for themselves; there was no need to rush through tasks due to limited time. This was especially important for BME people needing carers with an understanding of cultural and religious requirements. This finding supports Giebel et al. (2018) argument that continuity in care should be considered when designing an intervention for someone with dementia. Miller and Barre (2020) asserted a need for attentiveness and subtle modes of engagement in understanding the needs and

preferences for someone with a cognition decline. More time is required for this to happen, but it is limited in the LA commissioned services.

The SDS and DP guidelines aimed to offer more flexibility, independence, choice, control, empowerment, and more opportunities for diverse leisure activities for people using health and social care services (SCIE, 2012). These terms were heavily used by participants in this research who believed DP offered this to some extent to BME people with dementia. However, the DP challenges discussed earlier made them fall short of the initial expectation. The findings provided various examples of how DP had allowed greater choices, control and autonomy to DP recipients. For example, care packages could be designed that enable activities such as reminiscing or going out and about in the community, and so a better outcome within the allocated budget. The current research supports the evaluation (Glendinning et al., 2008) that DP recipients reported more feeling in control of their daily lives than the control group receiving LA traditional services.

Participants considered social networks and family support important for people with dementia. They argued that maintaining a good quality relationship with friends, family and new networks was essential in living well with dementia and enabling them to preserve their 'self' and their identity. Current research adds weight to research that has found that DP enabled people with dementia to pursue their hobbies and maintain social networks and psychological well-being without adding costs to the care package (Needham and Glasby, 2014; Jones et al., 2014; Laybourne et al., 2016). Research such as (Terkelsen, Petersen and Kristensen, 2020) found that social engagement among people with dementia increased feelings of connectedness and personhood; meaningful relationships in local communities enhanced their sense of belonging. This is consistent with the current study and Burgener et al. (2015), who advocated for families to support the person with dementia in maintaining their social networks and other activities.

DP was also seen as a good option for providing less stigmatising support for some BME people who might otherwise withdraw from the community because of the stigma and shame linked to the dementia diagnosis. In some circumstances, a family member can be employed to provide the required care as part of family honour and to preserve respect and status within the community (Evandrou et al., 2016). Previous research has indicated that DP has sometimes effectively filled the gaps between service provisions not addressed by formal care (Rummery, 2009). For example, matching service users and PA was seen as beneficial in meeting the person's diverse needs because they were likely to understand their cultural, food, and spiritual needs. Others added that they might find it easy to share their experiences of oppression with someone similar to them.

The findings indicated that DP could be utilised to allow people with dementia to participate in more active roles within society, such as attending dementia activism meetings and linking with other people with dementia. If people with dementia were to benefit from DPs, their families and professionals needed to see them through a strength-based lens and not a deficit lens, and as individuals with the ability to design their care and needs. Bert (2017) emphasises that narratives of deficit fail to reflect the agency of people with dementia to shape their social worlds in ways that enable them to participate as citizens. Two people with dementia felt that without DP, they would not have afforded PAs to accompany them to meetings and events. However, they acknowledged it was not easy because many professionals still assessed their needs using loss and deficit models without focusing on what they could do.

Some interesting findings were on successful ways BME people used DP in place of respite to reconnect with family in the country of origin, permanently or temporarily. Some people decided to settle back in their country of origin, and participants felt this could be a DP option for those who wished to return. While this idea may work for some people, others may view it as Britain deporting or repatriating older people with dementia from Britain so as not to burden diminishing resources. Therefore, it would need to be explored sensitively with those who want to return. No literature was found exploring this use of DP. Thus, it is unclear whether this is suitable or not and would need further investigation.

One unanticipated finding was the use of DP to fund technological gadgets for people with dementia. For example, one person with dementia relied heavily on assistive technology that she was able to summon for help at any time of the day, especially in an emergency. She used her DP budget to pay the annual costs. She considered it a lifesaver because it saved her life when she had a medical emergency and thought she was dying but could press a button just on time to get help. The technical team clicked the camera, saw what was happening, sent an ambulance, reassured her, and called her daughter to attend to her home. She said she could not afford it without DP funding. This participant's experience resonates with Giebel et al. (2018), who found that assistive technology was considered a vital element in care intervention. They also found that more people with dementia wanted to learn how to use technological devices. This is another underexplored area of DP highlighted by this research.

This study found that technology can help maintain existing and new social networks, especially with families abroad. This corresponds with Metykova (2010), who found that media and technology play a vital role in the migrants' identity, sense of belonging and political participation. Another interesting suggestion was that BME people could use DP instead of day service to purchase laptops to enable international connections with friends and families.

Previous research, such as Davies et al. (2020) and Holthe et al. (2018), also found that technology was important for people with dementia and their carer; it promoted social interactions, communications with health professionals, contacting family members in hospitals, care homes, safety indoor and outdoor and ordering groceries. Zamir et al. (2021) focus group study on designing video call technology with care home residents found that including people with dementia in the study illustrated that with assistance, people with dementia can benefit from modern technology to interact with others and even contribute to technology's future designs. Therefore, technology provided through DP was seen as having a key ability to help people retain their independence, and it was viewed that it would play a key role in the future in assisting people with dementia to remain connected.

Conclusion

The cultural meanings BME people attached to dementia are contextually situated and arise from their wider social, political, cultural and historical contexts. This then shapes the meaning they attach to dementia, influencing their decisions in seeking or not seeking formal interventions. These decisions and experiences are then compounded by perceived fears of racism, discrimination, previous negative experiences, and mainstream lack of cultural sensitivity.

Tackling racism in service delivery requires both change in individual attitudes and system-level change. BME people continue to navigate complex broader societal and structural barriers when accessing DP. There are power relations inherent in the mainstream health and social care systems, and BME people continue to struggle to assert their needs in the face of persistent race, gender, and class stereotypes and discrimination. BME people are often left feeling they do not belong and feel 'othered' by the wider society. The individual experiences of racism compound this.

CRT and intersectionality theories have illustrated the multiple layers of intersecting disadvantages that create how BME people experience racism. It has been challenging to untangle where one factor starts and where the other ends; for example, knowing whether failure to offer DP to a BME person is linked to their ethnicity, to ageist attitudes from staff or to stigma towards dementia. However, as illustrated in this chapter, the challenges may not always be with service providers; they could be embedded in the culture and attitudes of BME communities themselves and how they perceive care for people with dementia.

People with dementia may feel excluded in the DP process, and care planning by family and professionals may result in them feeling devalued. Social workers were viewed as having lower expectations of people with dementia and prioritising their care needs and not the social and emotional support they felt was well suited to be offered via a DP. Therefore, some ways

of thinking about care, support and dependence can diminish the perceived value of those requiring care and support.

There are many difficulties in offering DP in austerity to BME people with dementia. This scarcity has a knock-on effect on the service user's choice, control, and autonomy. This also affects the potential for DP to offer a more personalised service to BME people in meeting their specific cultural, religious and linguistic needs. Discussion on the implementation of DP highlighted the impact of diminishing resources on the implementation of DP, illustrating the complex interplay between supporting people using DP with understaffed, demotivated teams as well as balancing choices and risk and responding to diverse needs

DPs were also suggested to offer more personalised support to BME people with diverse needs, allowing them to employ care staff to meet their cultural, linguistic and religious needs. It also offered more unconventional respite, such as returning to the country of origin. However, the idea of DP offering personalised support in a person-centred manner is contextual and dependent on the specific individual needs and the availability of a service or a PA and enough budget to meet the assessed outcome. Overall, this thesis cannot draw a solid conclusion that DP is the best way to resolve the many challenges BME people experience when accessing services; this is due to many intersecting factors that need further understanding. However, from the discussion above, DP is one way of delivering culturally sensitive care to some BME people with dementia.

CHAPTER SEVEN: CONCLUSION, RECOMMENDATION AND LIMITATION

Conclusion

This research explored if DP is an effective and culturally sensitive response to meeting the specific challenges currently faced by BME people with dementia, their carers and families. The research utilised a qualitative research method with an interpretative narrative approach to understanding how meaning is constructed from peoples' experiences using a social constructionist paradigm. The research used the narrative inquiry methodological approach to gain a deeper understanding of participants' social and cultural worlds.

Contribution to knowledge

The original contribution of this thesis is to add to the existing body of knowledge on DP and experiences of BME people with dementia using an intersectionality lens and narrative methodology. The research teased out underlying challenges experienced by BME people with dementia when accessing services. This research contributes to a further understanding of the intersectionality between individual experiences, social structures and positioning, especially those linked to structural inequalities. A key finding was that race appeared to be the biggest factor for most people over and above gender, age, class and dementia. This research has contributed to the basis for future explorative research on intersecting factors of race, gender, class, inequalities and past experiences that affect BME people with dementia.

One of the methodological contributions of this research is using a narrative approach in the form of case studies to explore participants' everyday lives. This produced rich, extensive data for analysis to gain deeper insights into living with dementia and accessing services. The methodology allowed rapport building and trust for participants, especially those with dementia, to tell their stories at their own pace, adding to the dementia research. Moreover, Delgado and Stefanic (2017) suggest that engaging stories can help the audience understand what life is like for BME people and invite the reader into a new and unfamiliar world that enables them to bridge the gap between their worlds and others. Therefore, this research included an extra layer by exploring the stories of BME people with dementia, adding to the scant dementia research that has utilised narrative methodology. The thesis has clearly indicated that people with dementia want acknowledgement and respect by professionals and society and be enabled to contribute to society. The use of case studies helped keep the unfolding story intact, highlighting the different transitions before and after dementia. The

theoretical contributions have implications for practice for extending knowledge on cultural sensitivity when working with BME service users and building on existing knowledge.

Finding summary

The findings highlighted multiple structural, contextual, cultural and individual factors determining BME people with dementia's access to DP. The findings also revealed that BME people face similar challenges to the wider population. However, those challenges are further compounded by racism, discrimination, a lack of culturally appropriate services, lack of a sense of belonging, isolation and language barriers.

The current review of health and social care services provides a timely opportunity to engage the policymakers, LA, stakeholders, BME people with dementia and their families in conceptualising an approach to personalisation that combines the quality of life, well-being and better outcomes for them. This research has demonstrated that people with dementia want to be heard and remain active citizens with their person-hood promoted and respected. They also want to have control of their lives, maintain their independence and agency and have services designed to deliver their individual needs.

This thesis has argued that an intersectionality lens would allow looking at all the different factors that affect BME people. Many participants acknowledged the pervasiveness of stereotypes and prejudice of BME people and the importance of adopting certain positive attitudes and practices to mitigate discrimination. To understand racism, we need to be aware that prejudice or sexism focused on an older white woman because of her gender or age would differ from the intersecting prejudice focused on an older BME woman. She would be affected by stereotypes related to being a woman, older, her ethnicity, cultural and religious practices. Therefore, these intersecting factors would need to be considered simultaneously when assessing her needs.

The research findings reveal a complex and multi-dimensional landscape of structural racism that profoundly impacts the BME people trying to access LA services. Addressing these structural issues and inequalities by providing front-line care staff with adequate resources, support and training should be a priority if care provision for those who need it most will be sustainable. This will require a review of the under-resourced, market-based model of provision of personalisation via DP. DP has been highlighted that might be part of the solution to some of these structural issues identified in some specific circumstances. This research supports previous studies discussed in the literature review that structural racism and inequalities in organisations and society need to be addressed to meet BME people's need

The austerity and tighter eligibility criteria are far from enhancing personalisation, choice and control, making it hard to implement DP with the diminished individual budgets. DP success depends on various factors such as context, individual needs, and the political environment. Therefore, the findings suggest that the choice, control, and flexibility DP aims to offer are contextual because it depends on the budget available to the individual, the agency's flexibility, and the assessor's willingness to explore all options available. This makes it harder to say with confidence that DP would be the most efficient way to meet the culturally specific needs of BME people that mainstream services struggle to meet.

The findings also highlighted that great emphasis is placed on drawing up support plans and not enough on whether the specified outcomes are being met and if people's life chances and circumstances are improving. For example, the arguments made by participants on using respite DP to go abroad argued that the outcome is for the carer to have a break. Therefore, so long as the assessed outcome and needs of the person with dementia and the carer are met, it should not matter if they opt for residential care respite, care in the community, or a return to their country of origin.

In the current study, a few participants argued that the Scottish Government was not doing enough to tackle inequalities within the health and social care mainstream services. They asserted a dire lack of funding for the specialised services that support BME people and blamed the Government budget cuts. Unless there is adequate funding in the health and social care sector, they fear that the situation will only worsen for BME people with dementia and others in need of support. The Scottish Government has highlighted its commitment to tackling race inequalities through the Race Equality Framework 2016-2030. The Race Equality Framework aims to ensure that this vision of a healthier, happier and where opportunities, wealth and power are distributed more equally is achievable for people from all ethnicities, helping to build a Scotland where BME people feel they too belong (Scottish Government, 2021, b).

The Scottish Government (2021, c) focuses on actions that will deliver greater improvements while still ensuring that their processes and structures can efficiently deliver equality systematically and sustainably, which is promising. This vision aligns with current research findings that BME people want to have a sense of belonging, but when they are treated as outsiders, it hinders it. We also need to move beyond the narrative of 'us' vs 'them' and view the problems we are facing in health care provision as 'our' problem that needs to be resolved systematically to benefit all and not only some groups of people.

This research is timely with current policy considerations and contemporary issues worldwide on inequalities and discrimination. This includes the COVID-19 pandemic that broke out in

early 2020 and the events in May 2020 when a police officer murdered an African American man named George Floyd during an arrest. This murder led to protests and the resurgence of the Black Lives Matter Movement. Floyd's murder also brought attention to institutional racism in the UK (Priniski et al., 2021). Both events have brought racial injustices, ethnicity and discrimination to the forefront of many people and organisations. The Scottish Government (2021, c) has recognised the significant issues of racism and discrimination in Scotland, as indicated within the action plan in Race Equality Plan 2017-2021. It highlights the actions taken to tackle race inequalities in response to COVID-19, which has disproportionately affected BME communities bringing this issue to greater attention (Abuelgasim et al., 2020; Aldridge, 2020; Esegbona-Adeigbe, 2020; Kirby, 2020). Smith et al. (2020) indicated that there is already a significant mental health inequality among BME groups, and COVID-19 exacerbated this. These studies have indicated that while COVID-19 has had a negative impact on many people, it has had adverse outcomes on the BME population economically and mentally, with historical inequalities being highlighted as one of the reasons.

Having dementia deepens the structural issues experienced by a BME person further. The underfunding in health and social care also became more pronounced in the aftermath of the COVID-19 pandemic because it had a more significant devastating impact on older people, especially those with dementia in care homes and the community. During the first wave of COVID-19, the number of deaths of people with dementia rose by a quarter, with evidence showing that dementia is the most common underlying condition in people dying from COVID-19 in Scotland (National Records of Scotland, 2021). Magnus et al. (2021) acknowledged the significant impact of the pandemic on people with dementia, their families and carers. They suggested that people with dementia and their carers often felt alone, 'vulnerable' and anxious during COVID-19. Therefore, it is crucial to develop policies and support plans that support people with dementia and their families to receive adequate care and support without delays. The issues discussed in the findings are also relevant and timely in the current climate when many other individual organisations and agencies across Scotland are reviewing their internal race and inequalities policies and labels given to BME communities.

This thesis has explored the extent to which DP effectively meets the needs of BME people with dementia. Despite the positive DP outcomes reported in the rhetoric of DP offering more choice, control and flexibility to BME people, extensive challenges of delivering DP, the complex processes, and structural barriers were found to inhibit their effectiveness. This research has highlighted that, if properly funded, supported and with the availability of advocacy services, self-directed support could be one way of meeting BME people with dementia personalised needs according to their culture and customs by employing their own staff. DP may also give BME people with dementia a degree of control and flexibility that they

feel mainstream services cannot provide. However, DP is only one of the various options and not all BME people want all the challenges of managing DP and recruiting staff. Some BME people with dementia and their family require to be provided with a service that meets their individualised needs but do not necessarily want DP.

Thus, if DPs are going to work and have better outcomes, real benefits and choices for BME service users with dementia, then practitioners, LA, care providers, third-party organisations and the Scottish Government need to work together. This joint effort would ensure adequate funding to implement the policy, ensure that everyone is working in partnership, and guarantee that necessary structures are in place to engage with BME people. Without this support in place, it is unlikely that DP will be very efficient in supporting BME people with dementia.

This research aligns with Feeley's report, The Independent Review into Adult Social Care (IRASC) report (2021), which recommended the establishment of a Scottish National Care Service by 2026. The Scottish National Care Service aims to have equality, dignity and human rights at its heart and will empower people to make the right choices for them. This links with SDS legislation's emphasis on co-production and empowering people who use services and putting them at the heart of service delivery. Feeley, the independent review chair, asserted that the Scottish National Care Service would tackle systemic barriers that inhibit people from accessing services equitably by providing equality of outcomes. Feeley added that SDS legislation is ground-breaking, but the implementation falls short of what is needed, and not everyone in Scotland is benefiting from SDS. Therefore, his findings are much in line with this thesis's findings.

Recommendations

This study makes various practice and policy recommendations based on the research findings and conclusion.

Practice and policy recommendations

In this section, various recommendations for practice are made that professionals could utilise to improve services for BME people with dementia. Practitioners could tackle racism through awareness and self-reflection. DP processes could be mainstreamed and made easier for the service users' access. Other recommendations are improved well-being for people with dementia, and some are policy related.

Tackling racism within the workforce

The findings highlighted a willingness to tackle racism and inequalities within service provision. Significant work is needed to address inequalities, starting with professionals discussing

racism with their service users and acknowledging that racism still exists. As discussed in chapter six, staff need to recognise that they may have preconceived ideas, biases and expectations of different racial and cultural groups. Hence, practitioners need to be sensitised towards individuals limiting beliefs, stereotypes and generalisations they may hold about other groups and then take a conscious and compassionate approach to change them. This approach would need to be incorporated into staff training on racism, cultural sensitivity, diversity and working with BME communities to move away from potential racial biases.

Practitioners felt they lacked knowledge and confidence in responding to service users when they shared experiences of racism apart from listening empathically. However, staff training is not the only recommendation required to tackle racism. After all, there have been many diversity training offered to social work teams and mainstream organisations over the years. Therefore, having done the individual work tackling their own racial biases might be a good start. Training could then enhance that as practitioners reflect on their personal journeys of understanding race and inequalities that affect the people they work with. Training success would also depend on managers' willingness to implement lessons learnt, supporting staff and individual staff change in attitudes and perceptions towards the diversity-related training. Diversity training could frame racism differently by humanising the training more with real-life stories from people with lived experiences sharing stories, other than only abstract theories.

Findings also suggested that more diverse work environments, to reflect the communities staff work with, could be a positive outcome through improving staff knowledge and relating to people from different backgrounds on a day-to-day basis. This may help in boosting the confidence within teams and reassure workers who might be afraid of being accused of racism. However, being heavily reliant on BME staff could be viewed as expecting BME staff to be the 'experts' on BME people's needs instead of making an effort for every staff to be culturally aware. Therefore, systemic and structural changes are needed so that even white workers can feel comfortable tackling racism without relying on BME staff.

The findings highlighted the need for diversity among paid care staff. However, care agency providers interviewed have found that BME people do not apply for carers posts even when they have exclusively sought them; none applied. Therefore, there can be a willingness to make care teams diverse but may still struggle to recruit BME people to fill those gaps resulting in a dilemma of trying to make teams diverse and the shortage of BME people to employ. Therefore, as the findings have revealed, the issue of racism and inequalities are sensitive, multi-faceted and need to be solved structurally and from society and governmental level and not only within practices because it could be a reflection of the wider society.

Improving the quality of life for people with dementia

The findings highlighted that some people with dementia want to develop new networks with other people with dementia who will understand their experiences and create a new sense of belonging. They also felt networking with other professionals would enhance their mental, social, physical and emotional well-being by sharing their experiences about living with dementia and contributing to dementia research and awareness. Thus, DP could enhance these aspects for people with dementia and not view personal care as the only priority but a more person-centred approach exploring other needs of connectedness to things that matter to them. This may include activism, social and spiritual needs and other creative outcomes.

For BME people, findings suggested that many were unaware of where to access services and dementia and DP were not well known or understood. Therefore, more access to information in accessible languages to promote awareness, knowledge, and well-being could ensure they are not left suffering under challenging circumstances.

The research demonstrated how having a DP allocated as a mode of service delivery does not guarantee choice and control, but the amount of that budget and market availability to purchase support matters greatly. This is more pronounced when DP is viewed as adopting more economical practices aligned with neo-liberalism of seeing service users as consumers who can seek their own services and recruit and employ workers in business-style managerial practice. Despite the marketisation of care being problematic and not encouraged, if the BME people are going to be pushed down the DP route for lack of alternative care, then the availability of a market to recruit PAs or agency staff is required if they are going to benefit. This would ensure that people in need of services are not being left in risky situations for lack of appropriate care. This research has identified BME families' PAs provide critical care when mainstream has failed to provide it. Therefore, family PA employment should be encouraged other than viewed as needed in exceptional circumstances; still, the scrutiny that is in place safeguards the DP recipient, which should remain in place.

The support from third-party organisations like centres for inclusive living and specialised BME organisations were viewed as providing invaluable support for DP recipients navigating the recruitment processes per employment law should be well funded and maintained.

This research found considerable anxiety among practitioners regarding the effects of DP implementation on their already large caseload and mental health. Therefore, practitioners need greater emotional and case management support.

There is a need to streamline DP procedures to reduce the complex administrative processes highlighted by many participants and previous research. Thus, the workforce needs greater support in assessing and managing all SDS processes.

The findings also revealed that advocacy support was needed to support some people with dementia to navigate the complex DP application. This appeared to be the main intervention that enabled the participant with dementia to access DP on the second attempt. Therefore, during DP assessment, advocacy services should be afforded to people with dementia and older people.

Findings highlighted that DP tends to benefit people with dementia with a high economic status where they or their family already have experience employing staff privately. Hence, practitioners need to ensure DP is equitably allocated and not advancing a two-tier system for those financially able and those economically disadvantaged.

All participants interviewed highly discussed the impact of austerity on services in general on how it affected BME service users. As highlighted in the literature review, BME people with dementia are increasing. Thus, it is necessary to continue making these arguments despite the austerity. Some participants argued there were funds available but not prioritised for Older or BME persons. Others argued that funds were not well managed or budgets did not include BME people due to inequalities. There was notable stigma towards dementia and older people, as evidenced by low priorities on resource allocation due to ageist attitudes. This research recommends a need for equitable resource distribution within health and social care services and allocation of funds among different service user groups. Although funding of health and social care arguments have been raised over the years without much action and changes, service commissioners and policymakers need to keep hearing them even when difficult and without clear solutions and outcomes.

The findings have also indicated that besides language skills and the need for interpreters, professionals need to consider BME people's life history and past traumas that may be affecting their current choices and decisions. Exploring the life history of immigrants provides a deeper understanding of the conditions that restrict their ability to access health and social care services and information. Focusing only on dementia may not be enough, and therefore a more personalised approach to BME communities is needed.

Future Research

Many changes are needed in practice before a full understanding of the extent of DP benefits to BME people with dementia is established as an efficient and effective way of meeting their specific needs. Funding in health and social care remains an important issue, and if the funding situation changes, future research could review how this has impacted DP delivery and access. However, this research has clearly established that DP remains unlikely to achieve its full potential without proper funding and support.

To develop a complete picture of the barriers experienced by BME people with dementia use of DP, additional studies on the nature of the intersecting factors explored in this study would further understand the challenges this group of service users faces. This would allow addressing the barriers to reflect the interconnections other than addressing one layer by one. For example, BME groups may vary in socioeconomic status, geographical regions, resulting in deprivation, economic indicators, and inequalities that are not evenly spread. It is possible that the BME people interviewed may not be economically deprived as BME people in other parts of Scotland, for example, the three men in the case studies. BME people in more deprived areas, less educated and more marginalised may have worse outcomes. Therefore, repeating this study in different areas may reveal different patterns and different intersecting factors not covered in current research that might be of interest. Intersectionality knowledge could be extended with a more diverse sample of participants. This could include other minority populations not included in this study, such as white-minority people, travelling communities, and LGBTQI communities.

A further study could investigate if SDS and DP staff training that integrates a self-hood approach into the already established person-centred approach could promote more positive staff engagement with BME people with dementia seeking personalised care that is more person-centred and culturally appropriate. This could then be reviewed to determine if the practice could be improved by integrating Sabat's (2001) self-hood approach and Kitwood's (1997) person-centred philosophy within the DP training and raising awareness about dementia

Research Limitations

There are some potential limitations in this study. The challenges of recruiting BME people discussed in the methodology chapter and the constrained timescale for the study impeded my ability to hear from more BME people with dementia and in receipt of DP. Similarly, I relied heavily on recruiting participants through gate-keepers and previous work networks, which may have meant that I did not hear from more isolated people of BME origins who do not attend those organisations. I also did not hear from BME women living with dementia due to

recruitment challenges, limitations using gatekeepers, and maybe due to the English language requirement making this research less generalisable to all BME people. Other participants highlighted that many older BME women did not speak English because they mainly stayed at home to look after the children while men went to work, learned English, and were more integrated. Therefore, I am aware that the sample is not representative of all BME people with dementia, carers, stakeholders and practitioners. It is skewed to those who can participate in research and were interested in the topic through self-selection, family or gate-keepers. Some BME carers informed me that they deliberately took part in this research, hoping that it would yield benefits for BME people living with dementia whose families are unlikely to volunteer for research. Therefore, given these limitations, caution is needed in interpreting the findings and generalising them. BME groups, by their nature, are heterogeneous and are always changing due to cultural, immigration or political influences. Also, BME people experience services provision differently; therefore, any generalisation of these findings needs to consider the varied contexts within the participants' lives and this heterogeneity among BME communities.

Social constructionism that frames this research has been critiqued as a social construction concept itself (Hansen, 2005) that 'does not offer an ultimate authority from which to justify knowledge' (Rudes and Guterman, 2007, p.391). Churchill (2002) suggests that this positioning of everything as a social construction leads to relativism. While Hansen (2004, p. 134) argues that 'if what we call reality is always a social interpretation, and there is no conception of true reality against which to judge these interpretations, we have no criteria to evaluate various constructions.' Therefore, to be aware of the subjectivities of the research, I kept a reflective diary throughout the fieldwork and analysis stage of the data to understand my own positionality, thinking patterns and any biases as discussed in methodology chapter three.

Young and Collin (2004) argue that social constructionism is inconsistent in its main claims that many scholars do not use it in the same way. However, many researchers agree that the central principle of social constructionism is that meaning is not inherent and that the central concerns of constructionist inquiry are to study what people "know" and how they create, apply, contest, and act upon those ideas (Berger and Luckmann 1966, 15; Best 2000, p.4; Gubrium and Holstein 1997, p.38). A rigorous approach was followed in data collection and analysis, and member checking was done with some case studies to ensure accuracy.

Despite these limitations, the present study has contributed to the growing literature on BME people's experiences of care in Scotland, their use of DPs and their experiences of living with dementia. It has enhanced the understanding of BME people with dementia and the different intersecting factors that affect them. This study has demonstrated that people with dementia

could provide rich, detailed accounts of their life history, hopes, fears, and obstacles in service access, which professionals could use to produce a collaborative DP care plan. It has also highlighted the power of storytelling and taking account of personal biographies for BME people living with dementia throughout the diagnostic and services intervention process. This research contributes to the body of knowledge that suggests that cultural, political, historical and structural issues continue to affect BME people in day-to-day lives that need to be acknowledged and find individualised care solutions.

This research has suggested that ample support is required to make DP a reality for BME people with dementia, but it can be a great option for some people. However, the study has highlighted that the best interest and focus should be on those receiving services and their needs and then seek the best way to support them in a person-centred manner. This does not necessarily have to be through DP could be through improved practice, funding BME organisations that might provide culturally specific services and increased awareness of dementia and structural racism among professionals and society. Therefore, practitioners should explore service users' desires and aspirations regarding how they wish their care to be delivered to allow more personalised care offering greater choices and flexibility.

REFERENCES

Abbas, T. (2019) 'Implementing, prevent in countering violent extremism in the UK: A left realist critique '*in Critical Social Policy'* vol. 39 (3), pp. 396-412.

Abbe, A. and Brandon, S. E (2014) Building and maintaining rapport in investigative interviews, Police Practice and Research, *An International Journal,* vol.5, (3), pp.207-220, https://doi.org/10.1080/15614263.2013.827835.

Abrams, L. S. and Moio, J.A. (2009) Critical race theory and the cultural competence dilemma in social work education. *Journal of Social Work Education*, vol. 45, (2), pp. 245-261.

Adams, M., Bell, L. A. and Griffin, P. (1997) *Teaching for Diversity and Social Justice: A Sourcebook*, edited by and Pat Griffin, pp. 82-109. London: Routledge.

Adelman, S., Blanchard, M., Rait, G., Leavey, G., and Livingston, G. (2011) Prevalence of dementia in African-Caribbean compared with UK-born White older people: two-stage cross-sectional study. *The British Journal of Psychiatry,* vol, 198, pp. 1–7.

Age Concern. (2002), *Black and Minority Ethnic Elders' Issues*, London: Age Concern.

Agyemang, C., Bhopal, R. and Bruijnzeels, M. (2005). "Negro, Black, Black African, African Caribbean, African American or what? Labelling African origin populations in the health arena in the 21st century". Journal of Epidemiology & Community Health. 59 (12): 1014–1018. doi:10.1136/jech.2005.035964. PMC 1732973. PMID 16286485.

Ahmed, M. H. (2020) Black and Minority Ethnic Alliance Against COVID-19: One Step Forward. J. *Racial and Ethnic Health Disparities*, vol. 7, pp. 822–828. https://doi.org/10.1007/s40615-020-00837-0.

Aldridge, R. W., Lewer, D., Katikireddi, S. V., Mathur, R., Pathak, N., Burns, R., Fragaszy, E. B., Johnson, A. M., Devakumar, D., Abubakar, I. and Hayward, A. (2020) Black, Asian and Minority Ethnic groups in England are at increased risk of death from COVID-19: Indirect standardisation of NHS mortality data. Wellcome Open Research. Vol. 5, pp 88-99. Available at: https:// doi.org/10.12688/wellcomeopenres.15922.2. (Accessed: 12th May 2021).

Ali, N., McLachlan, N., Kanwar, S and Randhawa, G (2017) Pakistani young people's views on barriers to accessing mental health services, *International Journal of Culture and Mental Health*, vol.10 (1), pp. 33-43.

Ali, S., and Atkin, K. (2004) Primary Healthcare and South Asian Populations: Meeting the Challenges: Institutional racism, policy and practice (1st ed.). CRC Press, Available at: https://doi.org/10.1201/9781315376561. (Accessed: 28th September 2021).

Allport, G. W. (1979) *The Nature of Prejudice*, New York: Basic Books.

Alzheimer Scotland (2020) Dementia Epidemic: Prevalence of dementia, Available at: https://www.alzscot.org/dementia-epidemic, (Accessed: 2nd December 2021).

Alzheimer Scotland (2021) Preference of Dementia. Available: https://www.alzscot.org/dementia-epidemic.(Accessed: 2nd January 2022).

Alzheimer's Research UK (2020) Alzheimer's disease: Available at:
https://www.alzheimersresearchuk.org/dementia-information/types-of-dementia/alzheimers-disease/ (Accessed: 3rd January 2022).

Alzheimer Scotland (2013) Dementia Epidemic. Available: https://www.alzscot.org/dementia-epidemic#:~:text=There%20are%20an%20estimated%20228,the%20population%20as%20a%20whole. (Accessed on: 23/07/2022).

Alzheimer's Society (2014) Changes in Behaviour, available at:
https://www.alzheimers.org.uk/info/20064/symptoms/87/behaviour_changes (Accessed, 13th August 2021).

Alzheimer's Society (2019) Losing your English: 'Reverting' to your mother tongue as dementia progresses. Available at: https://www.alzheimers.org.uk/dementia-together-magazine/june-july-2019/losing-your-english-reverting-your-mother-tongue-dementia. (Accessed: 27th January 2022).

Alzheimer's Society (2021) Risk Factors for Dementia. Available at:https://www.alzheimers.org.uk/sites/default/files/pdf/factsheet_risk_factors_for_dementia. (Accessed: 28th July 2020).

Alzheimer's Society (2019) Black, Asian and minority ethnic communities and dementia research. Available at: https://www.alzheimers.org.uk/for-researchers/black-asian-and-minority-ethnic-communities-and-dementia-research, (Accessed: 10th January 2022).

Anderson, K. and Jack, D. C. (1991) 'Learning to Listen: Interview Techniques and Analyses', in Gluck, S. B and Patai, D (eds) *Women's Words: The Feminist Practice of Oral History*, pp. 11–26. New York: Routledge.

Andoh-Arthur, J. (2019) Gatekeepers in Qualitative Research [Edited by] Atkinson, P., Delamont, S., Cernat, A., Sakshaug, J.W and Richard R.A: Available at: DOI:http://dx.doi.org/10.4135/9781526421036854377 (Accessed: 14th April 2021).

Andrew, J (2015) *Dementia: The one-Stop Guide- Practical advice for families, professionals, and people living with dementia and Alzheimer's Disease*. Profile books, London.

Arksey, H. and Baxter, K. (2012) 'Exploring the temporal aspects of Direct Payments', *British Journal of Social Work*, vol.42, pp. 147–64.

Armistead, N. (Ed.). (1974) *Reconstructing social psychology*. Harmondsworth: Penguin.

Aspinall, Peter J. (2002). "Collective Terminology to Describe the Minority Ethnic Population: The Persistence of Confusion and Ambiguity in Usage". *Sociology*. 36 (4): 803–816. doi:10.1177/0038038502036004401. S2CID 143472578.

Atkin, K. (2003) *Health care in South Asian populations: making sense of policy and practice*. In: Sayyid B, Ali N and Singh VK (eds) Asian Nation: postcolonial settlers in Britain. Hurst, London.

Atkin, K., Ali, N. and Chu, C.E. (2009) The politics of difference? Providing a cancer genetics service in a culturally and linguistically diverse society, *Diversity in Health and Care*, vol.6(3), pp.149–157.

Audit Scotland. (2014) *Self-Directed Support*, Edinburgh: Audit Scotland.

Audit Scotland. (2016), *Reshaping Care for Older People: Impact Report*, Edinburgh: Audit Scotland.

Austin, R. (1989) Sapphire bound. *Wisconsin Law Review*, vol 1 (3), pp. 539–578.

Baciu, L. (2020) Reading beyond the Label: Implications of the Critical Race Theory for the Social Work Practice with Roma People. Revista de Asistenţ\ Social\, anul XIX, nr. pp. 79-98. Available at: http://eds.a.ebscohost.com.ezproxy-s2.stir.ac.uk/eds/pdfviewer/pdfviewer?vid=1&sid=b9247588-8eb0-4ad6-917c-c7f826d39ec3%40sessionmgr4008. (Accessed 15th July 2021).

Backhouse, T., Kenkmann, A., Lane, K., Penhale, B., Poland, F., and Killett, A. (2016). Older care-home residents as collaborators or advisors in research: *A systematic review. Age and Ageing*, vol.45(3), pp.337–345.

Baghirathan, S., Cheston, R., Hui, R., Chacon, A., Shears, P., Currie, K., (2020) A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: Balancing the need for support against fears of being diminished. *Dementia*, vol.19(5) pp. 1672–1691. DOI: 10.1177/1471301218804714.

Bahl, V. (2001) Improving access and quality for ethnic minority women. Women's. *Health Issues*, vol, 11, pp. 348–54.

Baines, D. (2016) Care, austerity and resistance. In Williams C (ed.), *Social Work and the City*. Basingstoke, UK: Palgrave Macmillan, pp. 193–214.

Baird, J., Yogeswaran, G., Oni, G. and Wilson, E.E. (2021) What can be done to encourage women from Black, Asian and minority ethnic backgrounds to attend breast screening? A qualitative synthesis of barriers and facilitators, *Public Health*, vol 190, pp.152-159.

Bakhurst, D. and Shanker, S. G. (2001). *Jerome Bruner: Language, culture and self*. Thousand Oaks, CA: Sage.

Baldock, J. (2003) 'On being a welfare consumer in a consumer in a consumer society', *Social Policy and Society,* vol. 2(1), pp. 65–71.

Bamford, C, and Bruce, E. (2000) Defining the outcomes of community care: the perspective of older people with dementia and their carers. *Ageing Society*, vol.20, pp. 543-70.

Bamford, S., Holley-Moore, G. and Watson, J. (2014) *New perspectives and approaches to understanding dementia and stigma*. London: ILC-UK.

Barnes, M. (2011) Abandoning Care? A Critical Perspective on Personalisation from an Ethic of Care, *Ethics and social welfare*, vol. 5(2), pp. 153-167.

Barnett, E. (2000) *Including the Person with Dementia in Designing and Delivering Care: "I Need to Be Me"* London, Jessica Kingsley.

Bartlett, J. (2009) *At your service. Navigating the future market in health and social care*. London, England: DEMOS.

Bartlett, L. and Brayboy, B. M. J. (2005) Race and schooling: Theories and ethnographies. *Urban Review,* vol.37(5), pp. 361-374.

Bartlett, R. (2012) Modifying the diary interview method to research the lives of people with dementia. *Qualitative Health Research*, vol. 22(12), pp. 1717–1726.

Bartlett, R. (2014) Citizenship in action: the lived experiences of citizens with dementia who campaign for social change, *Disability and Society*, vol. 29, (8), pp. 1291–304.

Bartlett, R. (2016) Scanning the conceptual horizons of citizenship, *Dementia*, vol.15, (3), pp. 453–461.

Bartlett, R., and Brannelly, T. (2019) On being outdoors: how people with dementia experience and deal with vulnerabilities. *Social Science and Medicine*, vol.235: 112336, https://doi.org/10.1016/j.socscimed.2019.05.041.

Bartlett, R., and O'Connor, D. (2007) From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, vol. 21, pp. 107–118.

Bartlett, R., and O'Connor, D. (2010) *Broadening the dementia debate: Toward social citizenship.* London: Policy Press.

Bassett, R., Beagan, B.L, Ristovski-Slijepcevic, S., and Chapman, G.E. (2008) Tough Teens: The Methodological Challenges of Interviewing Teenagers as Research Participants. Journal of Adolescent Research, vol.23(2):119-131. doi:10.1177/0743558407310733.

Batsch, N.L. and Mittelman, M.S. (2012) World Alzheimer report: *Overcoming the stigma of dementia. London*: Alzheimer Disease International.

Bauer, A. M. and Alegria, M. (2010). Impact of patient language proficiency and interpreter service use on the quality of psychiatric care: a systematic review. *Psychiatrist Services,* vol. 61, pp. 765–773. 10.1176/ ps.2010.61.8.765.

Bauer, M. (1996) *The narrative interview: comments on a technique for qualitative data collection.* Methodology Institute.

Baumeister, R F., and Leary. M. R. (1995). "The Need to Belong: Desire for Interpersonal Attachments as a Fundamental Human Motivation." *Psychological Bulletin,* vol. 117 (3) pp. 497–529.

Beck, A. (2019) "Understanding Black and Minority Ethnic service user's experience of racism as part of the assessment, formulation and treatment of mental health problems in cognitive behaviour therapy," *The Cognitive Behaviour Therapist. Cambridge University Press*, vol. 12, pp. E8. doi: 10.1017/S1754470X18000223.

Becker, H. (1963) Outsiders: Studies in the Sociology of Deviance. Glencoe: *Illinois*. The Free Press.

Begum, N. (2006) *Doing it for Themselves: Participation and Black and Minority Ethnic Service Users.* London: SCIE/REU.

Bell, D. A. Jr. (1980). Brown v. Board of Education and the interest-convergence dilemma. *Harvard Law Review,* vol. 93(3), pp. 518-533.

Berg, B. (1998) *Qualitative Research Methods for the Social Sciences.* Boston, MA: Allyn and Bacon.

Berger, P. L., and Luckmann, T. (1966). *The social construction of reality: A treatise in sociology of knowledge.* Harmondsworth: Penguin Books.

Berger, P., and Luckmann, T. (1966) *The social construction of reality*.

Berger, R. (2015) Now I See It, Now I Don't: Researcher's Position and Reflexivity in Qualitative Research. *Qualitative Research*, vol.15(2), pp.219-234.

Bergstresser, S. M. (2015) Health Communication, Public Mistrust, and the Politics of "Rationality", *The American Journal of Bioethics*, vol. 15(4), pp.57-59, DOI: 10.1080/15265161.2015.1009570.

Berry, J. W., and C. Sabatier. (2011). "Variations in the Assessment of Acculturation Attitudes: Their Relationships with Psychological Well-being." *International Journal of Intercultural Relations,* vol. 35: pp. 658–669.

Bert. L., Poland, F., Csipke, E. and Charlesworth, G (2017) Shifting dementia discourses from deficit to active citizenship, *Sociology of Health and Illness*, vol. 39, (2), pp. 199–211.

Berwald, S., Roche, M., Adelman, S., Mukadam, N., and Livingston, G. (2016). Black African and Caribbean British Communities' perceptions of memory problems: "We don't do dementia.". PLoS One, vol. 11(4), e0151878. doi:10.1371/journal.pone.0151878.

Best, J. (2000) The apparently innocuous "just," the Law of Levity, and the social problems of social construction. *In Perspectives on social problems*. vol. 12, ed. J. A. Holstein and G. Miller, 3-14. Stamford, CT: JAI Press.

Best, J. (2017) *Social problems*. 3d ed. New York: Norton.

Bhopal, K. (2010) "Gender, identity and experience: researching marginalised groups", *Women's Studies International Forum*, vol. 33(1), pp. 188–195.

Bhopal, R. (2007) Race, Ethnicity and Health in Multicultural Societies, *The European Journal of Public Health*, vol. 17(3), pp. 238-241.

Bhui, K. and Sashidharan, S. P. (2003) Should there be separate psychiatric services for ethnic minority groups? *The British Journal of Psychiatry*, vol, 182 (1), pp. 10-12.

Birt, L, Scott S, Cavers D, Campbell C, Walter F. (2016) Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? *Qualitative Health Research*, vol,26(13), pp.1802-1811. doi:10.1177/1049732316654870.

Blake, M., Bowes, A., Gill, V., Husain, F., and Mir, G. (2017) A collaborative exploration of the reasons for lower satisfaction with services among Bangladeshi and Pakistani social care users, Health and Social Care in the Community, vol. 25 (3), pp. 1090-1099.

Blumer, H. (1969) *Symbolic interactionism*. Englewood Cliffs, NJ: Prentice-Hall.

Bond, J. (1992) The medicalization of dementia, *Journal of Aging Studies*, vol.6(4), pp. 397-403.

Borland, K. (1991) 'That's Not What I Said: Interpretive Conflict in Oral Narrative Research', in S. Berger Gluck and D. Patai (eds) *Women's Words: The Feminist Practice of Oral History*, pp. 63–76. New York: Routledge.

Bothongo, P., Jitlal, M., Parry, E., Waters, S., Foote, I.F, Watson, C.J., Cuzick, J., Giovannoni, G, Dobson, R., Noyce, A. J., Mukadam, Naaheed., Bestwick, J.P and Marshall, C. R. (2022) Dementia risk in a diverse population: a single-region nested case-control study in the East End of London. Lancet Reg Health Eur. 2022;15: 100321. https://doi.org/10.1016/j.lanepe.2022.100321

Botsford, J. and Dening, K. H. (2015) *Dementia, Culture and Ethnicity: Issues for all.* London. Jessica Kingsley.

Bowes, A. and Wilkinson, H. (2003), 'We didn't know it would get that bad': South Asian experiences of dementia and the service response. *Health and Social Care in the Community*, vol. 11 (5), pp. 387–396.

Bowes, A., Avan, G. and Macintosh, S. (2012) Cultural diversity and the mistreatment of older people in black and minority ethnic communities: some implications for service provision, *Journal of Elder Abuse and Neglect*, vol. 24 (3), pp. 251-74.

Boyatzis, R. (1998). *Transforming qualitative information: Thematic analysis and code development.* Thousand Oaks, CA: Sage.

Boyle D (2004). 'Is this how to end public service failure?'. *New Statesman*, vol 133, pp2–21.

Boyle. D., Clarke, S. and Burns, S. (2006) *Aspects of co-production: the implications for work, health and volunteering.* London: New Economics Foundation.

Bracci, E. and Llewellyn, S. (2012), 'Accounting and accountability in an Italian social care provider: Contrasting people-changing with people-processing approaches', *Accounting Auditing and Accountability Journal*, vol, 25, pp.806-834.

Bradbury-Jones, C. (2007) Enhancing rigour in qualitative health research: Exploring subjectivity through Peshkin's I's, Journal of Advanced Nursing, vol.59(3), pp.290-8. DOI: 10.1111/j.1365-2648.2007.04306. x.

Bradby, H., Lindenmeyer, A., Phillimore, J., Padilla B. and T. (2020) 'If there were doctors who could understand our problems, I would already be better': dissatisfactory health care and marginalisation in superdiverse neighbourhoods. *Sociology Health and Illness*, vol. 42, pp.739–757. 10.1111/1467.

Brathwaite, B. (2018) Black, Asian and minority ethnic female nurses: colonialism, power and racism. *British Journal of Nursing*, vol. 27(5), pp. 254-258.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, vol. 3 (2). pp. 77-101.

Braun, V., and Clarke, V. (2019). Reflecting on Reflexive Thematic Analysis. *Qualitative Research in Sport, Exercise and Health*, vol.11(4), pp.589-597.

Braun, V., Clarke, V., Hayfield, N., and Terry, G. (2019). Thematic Analysis. In P. Liamputtong (Ed.), *Handbook of Research Methods in Health Social Sciences* (pp. 843-860). Singapore: Springer.

Brijnath, B. (2014) *Unforgotten: Love and the Culture of Dementia Care in India. Oxford.* Berghahn Books.

British Sociological Association (2017) BSA Statement of Ethical Practice. Available at: https://www.britsoc.co.uk/media/24310/bsa_statement_of_ethical_practice.pdf. (Accessed: 23rd April 2020).

Brooker, D. (2007) *Person-centred dementia care: Making services better*. London: Jessica Kingsley.

Brookes, N., Callaghan, L., Netten, A., and Fox, D. (2015). Personalisation and innovation in a cold financial climate. *British Journal of Social Work*, vol. 45, pp 86-103.

Brown, L. (2010) Balancing Risk and Innovation to Improve Social Work Practice. *The British Journal of Social Work*, vol. 40, (4), pp. 1211–1228.

Brown. D. and Associates. (1973) (Eds.) *Career choice and development* (4th ed., pp. 149–205). San Francisco, CA: Jossey-Bass.

Bruner, J. (1990) *Acts of meaning*. Cambridge, MA: Harvard University Press.

Bruner, J. (2004). The narrative creation of self. In L. E. Angus and J. McLeod (Eds.), *The handbook of narrative and psychotherapy: Practice, theory, and research* (pp. 3–14). Thousand Oaks, CA: Sage.

Brunt, L. (2001) 'Into the Community', in P. Atkinson, A. Coffey., S. Delamont, J., Lofland and L. Lofland (eds) *Handbook of Ethnography*, pp. 80–91. London: Sage.

Bulmer, M. and Solomos, J. (2004) *Researching Race and Racism,* London: Routledge.

Burgener, S.C., Buckwalter, K., Perkhounkova, Y. and Liu, M.F. (2015) The effects of stigma on quality-of-life outcomes in persons with early-stage dementia: longitudinal findings: Part 2, *Dementia*, vol.14, (5), pp. 609–32.

Burgos, A. (2021) Am I Black or White? A Lifelong Quest to Define Myself in the Binary of Race, *The Vermont Connection,* vol 42, pp. 61-72.

Burnell, K.J., Selwood, A., Sullivan, T., Charlesworth, G.M., Poland, F., and Orrell, M. (2015) Involving service users in the development of the Support at Home: Interventions to Enhance Life in Dementia Carer Supporter Programme for family carers of people with dementia. *Health Expectations*, vol.18(1), pp.95–110.

Burr, V. (1995). *An introduction to social constructionism*. New York, NY: Routledge. doi:10.4324/ 978023299968.

Burr, V. (2015) *Social constructionism* (3rd ed). London: Routledge.

Burrell-Craft, K. (2020) Are (We) Going Deep Enough? A Narrative Literature Review Addressing Critical Race Theory, Racial Space Theory, and Black Identity Development. Taboo: *The Journal of Culture and Education, v*ol 19 (4), pp. 9-25.

Burton, A. (1997). *Dementia: A case for advocacy? In Susan Hunter (Ed.), Dementia: Challenges and New Directions.* London: Jessica Kingsley.

Butt, J. (2006) *Are we there yet? Identifying the characteristics of social care organisations that successfully promote diversity*. London: Social Care Institute for Excellence.

Butt, J. and Mirza, K. (1996) *Social Care and Black Communities*. HMSO, London.

Cabinet Office (1999) *Modernising Government*, Cm 4310, London, The Stationery Office.

Cabrera, N. L. (2019) Critical Race Theory v. Deficit Models, *Equity and Excellence in Education*, 52 (1) pp. 47–54. https://doi.org/10.1080/10665684.2019.1630342.

Camera, L. (2021) What Is Critical Race Theory and Why Are People So Upset About It? Most Americans are not familiar with term critical race theory, but that hasn't stopped some from getting upset about attempts to reckon with the sprawling repercussions of slavery. *The Report*. pp, 8-12. Available at: http://content.ebscohost.com/ContentServer.asp?EbscoContent=dGJyMNXb4kSeqa44yOvs OLCmsEmep7JSrq24S7GWxWXS&ContentCustomer=dGJyMPGnskmzqLNIuePfgeyx43zx1 %2B6B&T=P&P=AN&S=R&D=bth&K=150718703, (Accessed: 15 July 2021).

Cameron, D. (1995) *Verbal hygiene*, London, United Kingdom: Routledge.

Campbell, E. (2014) Using Critical Race Theory to Measure "Racial Competency" among Social Workers. *Journal of Sociology and Social Work*, vol. 2(2), pp. 73-86.

Care and Health (2004) Letters regarding "direct" and "indirect" payments', Care and Health Magazine, 7–12 December 2004.

Carers UK, (2008) *Choice or Chore? Carers' Experiences of Direct Payments*, London, Carers UK.

Carers UK. (2011) *BAME Families and Personalisation A Person-Centred Approach*: Making personalisation successful for Black Asian Minority Ethnic (BAME) families and communities Policy Briefing. Available at: https://raceequalityfoundation.org.uk/wp-content/uploads/2018/02/Health-Briefing-34.pdf. (Accessed: 12th August 21).

Carey, M. (2021) "The neoliberal university, social work and personalised care for older adults," *Ageing and Society*. Cambridge University Press, pp. 1–15. doi: 10.1017/S0144686X20001919. Available at: https://www.cambridge.org/core/journals/ageing-and-society/article/neoliberal-university-social-work-and-personalised-care-for-older-adults/76B7F46A59E5C99E5F5C5888C68A774F. (Accessed: 24th October 2021).

Carmichael, A. and Brown, L. (2002) 'The future challenge for direct payments', *Disability and Society*, vol.17(7), pp. 797–808.

Carr, S. (2008), *Personalisation:* A Rough Guide, London: Social Care Institute for Excellence.

Carr, S. (2013). *Improving personal budgets for older people*: A research overview. Adults' Services Report (Vol. 63). London, England: Social Care Institute for Excellence.

Carter, K. (1993). The place of story in research on teaching and teacher education. Educational Researcher, vol. 22(1), pp.5-12.

Cattell, V. (2001) Poor people, poor places, and poor health: the mediating role of social networks and social capital. *Social Science and Medicine*, vol. 52 (10) pp. 1501-1516.

Chanfrault-Duchet, M. F. (1991) 'Narrative Structures, Social Models and Symbolic Representations in the Life Story', in S. Berger Gluck and D. Patai (eds) Women's Words: *The Feminist Practice of Oral History,* pp. 77–92. New York: Routledge.

Chantler, K., Gangoli, G. and Thiara, R.K. (2019) Muslim Women and Gender-Based Violence in India and the UK '*Journal of critical social policy'* vol.39 (2), pp.163-183.

Chaudhury, H., Cooke, H. A., Cowie, H., and Razaghi, L. (2018) The influence of the physical environment on residents with dementia in long-term care settings: A review of the empirical literature. *The Gerontologist*, 58(5), pp.325-337. DOI: 10.1093/geront/gnw259.

Chavez, J. M, and Rocheleau, G. C. (2020) Formal Labelling, Deviant Peers, and Race/Ethnicity: An Examination of Racial and Ethnic Differences in the Process of Secondary Deviance. *Race and Justice*, vol 10 (1), pp 62-86. doi:10.1177/2153368717727122.

Cheston, R., Bender, M. and Byatt, S (2000) Involving people who have dementia in the evaluation of services: A review. *Journal of Mental Health*, vol 9 (5), pp.471–479.

Churchill, S. (2002). Stories of experience and the experience of stories: Narrative psychology, phenomenology, and the postmodern challenge. *Constructivism in the Human Sciences*, vol.7, pp. 81–93.

Clark, A., Campbell, S., Keady, J., Kullberg, A., Manji, K., Rummery, K. and Ward, R. (2020) Neighbourhoods as relational places for people living with dementia. *Social Science and Medicine,* vol. 252, pp. 1-7.

Clark, C and Keady, J. (2002) Getting down to brass tacks: discussion of data collection with people with dementia. In: Wilkinson H (ed) *The Perspectives of People with Dementia: Research Methods and Motivations*. London.

Clark, H. (2006). ''It's meant that, well, I'm living a life now'': Older people's experience of direct payments. In J. Leece, and J. Bornat (Eds.), *Developments in direct payments* (pp. 79–94). Bristol: The Policy Press.

Clark, H. and Spafford, J. (2002) 'Adapting to the culture of user control?', *Social Work Education*, 21(2), pp. 247–257.

Clark, H., Gough, H. and Macfarlane, A. (2004) '*It Pays Dividends': Direct Payments and Older People*, Bristol, Policy Press.

Clarke, C., Wilkinson, H., Watson, J., Wilcockson, J., Kinnaird, L. and Williamson, T. (2018) A Seat Around the Table: Participatory Data Analysis With People Living With Dementia. *Qualitative Health Research,* vol. 28 (9), pp.1421-1433.

Co, M., Couch, E., Gao, Q., Mac-Ginty, S., Das-Munshi, J. and Prina, M. (2021) Access to Health Services in Older Minority Ethnic Groups with Dementia: A Systematic Review. *Journal of the American Geriatrics Society*, vol, 69 (3), pp 822-834.

Coates, J. (1996) *Women Talk: Conversation between Women Friends*. Oxford: Blackwell.

Codjoe, L., Barber, S., and Thornicroft, G. (2019) Tackling inequalities: a partnership between mental health services and black faith communities, *Journal of Mental Health*, vol. 28 (3), pp. 225-228, DOI: 10.1080/09638237.2019.1608933.

Coghlan, D., and Brydon-Miller, M. (2014) *The SAGE Encyclopaedia of Action Research*. London: Sage Publications Ltd.

Collin, A. and Young, R. A. (2000) The future of career (pp. 276–300). In A. Collin & R. A. Young (Eds.). *The future of career* (pp. 163–180). Cambridge, UK: Cambridge University Press. doi: 10.1017/ CBO9780511520853.018.

Collins, T. (2017) The experience of black and ethnic minority service users with dual diagnosis and those who support them. *Mental Health Nursing*, vol. 37 (3), pp. 6-15.

Comegna, S. (2017) Prevalence of Obesity in the UK According to Sex, Age and Ethnicity: A Literature Review. *Sports Nutrition Therapy*, vol. 2: pp.121-131. doi: 10.4172/2473-6449.1000121.

Commission on Ethnic and Race Disparities (2021) Commission on Race and Ethnic Disparities: The Report. Available at: https://www.gov.uk/government/publications/the-report-of-the-commission-on-race-and-ethnic-disparities. (Accessed: 12th July 21).

Connelly, M. F., and Clandinin, J. D. (1990). Stories of experience and narrative inquiry. *Educational Researcher*, vol. 19(5), pp. 2-14.

Cook, L., Mukherjee, S., McLachlan, T., Shah, R., Livingston., G. and Mukadam, N. (2019) Parity of access to memory services in London for the BAME population: a cross-sectional study. *Aging and Mental Health,* vol.23, (6), pp. 693–697. https://doi.org/10.1080/13607863.2018.1442413.

Corneau, S. and Stegiopoulos, V. (2012), More than being against it*: Anti-racism and anti-oppression in mental health services*, vol. 49, (2), pp. 261-282.

Cortazzi, M. (2001). Narrative analysis in ethnography. In P. A. Atkinson, S. Delamont, A. Coffey, J. Lofland, & L. H. Lofland (Eds.), *Handbook of ethnography* (pp. 384–394). London, UK: Sage.

Cotrell, V. and R. Schulz. 1993. "The Perspective of the Patient with Alzheimer's Disease: A Neglected Dimension of Dementia Research. *The Gerontologist*, vol. 33, pp. 205–11.

Cotterill, P. and Letherby, G. (1993) 'Weaving Stories: Personal Auto/biographies in Feminist Research', *Sociology*, 27(1), pp. 67–80.

Cowdell, F. (2010) The care of older people with dementia in acute hospitals. *International Journal of older people in nursing*, vol. 5, pp. 83-93.

Craig, G. (2017) *Community Organising Against Racism 'Race' ethnicity and community development.* Bristol. Policy Press.

Cree, V. E. (2010) *Sociology for Social Workers* (Second Edition). Abingdon; New York: Routledge.

Crenshaw, K. (1989) Demarginalizing the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine, feminist theory, and antiracist politics. *University of Chicago Legal Forum*, pp. 139–67.

Crenshaw, K. (1991) Mapping the margins: Intersectionality, identity politics, and violence against women of colour. *Stanford Law Review*, vol. 43(6), pp. 1241-1299.

Crenshaw, K., Gotanda, N., Peller, G., and Thomas, K. (1995) *Critical Race Theory: The Key Writings that Formed the Movement*. (Eds) New York: The New Press. ISBN 978-1565842717.

Creswell, J. W. (2002) *Educational Research: Planning, Conducting, and Evaluating Quantitative and Qualitative Research*. Upper Saddle River, NJ: Merrill.

Creswell, J.W. (2003) *Research Design: Qualitative, Quantitative and Mixed Methods Approaches* (2nd eds), Sage: London.

Cruickshank, J (2012). "Positioning Positivism, Critical Realism and Social Constructionism in the Health Sciences: A Philosophical Orientation: Assessing Realism and Social Constructionism." *Nursing inquiry*, vol.19 (1) pp. 71–82.

Cullenberg, S., Amariglio, J., and Ruccio, D. F. (2001) *Post-modernism, economics and knowledge: Economics as social theory.* New York: Routledge.

Cunliffe, A. L. (2008) Social Constructionism: Relationally Responsive Social Constructionism and its Implications for Knowledge and Learning. *Journal of management learning*, vol. 39(2), pp. 123–139. DOI: 10.1177/1350507607087578.

Daly, M. (2002) 'Care as a good for social policy', *Journal of Social Policy*, vol. 31(2), pp. 251–70.

Darko N. (2021) *Engaging Black and Minority Ethnic in Health Research 'Hard to Reach' Demystifying the misconceptions.* Policy Press. Bristol.

Data Protection Act 2018; Available at: https://www.legislation.gov.uk/ukpga/2018/12/contents/scotland, (Accessed: 23rd July 2021).

Davidson, D. and Luckhurst, L. (2002) *Making Choices Taking Control: Direct Payments and Mental Health Service Users/Survivors*, London, National Council for Independent Living.

Davis, S. F., Silvester, A., Barnett, D., Farndon, l. and Ismail, M. (2019) Hearing the voices of older adult patients: processes and findings to inform health services research. *Res Involve Engagement*, vol. 5 (11). https://doi.org/10.1186/s40900-019-0143-5.

Dawson. C. (2000) *Independent Successes: Implementing Direct Payments,* York Joseph Rowntree Foundation.

Delgado, R. (1989) Storytelling for Oppositionists and Others: A Plea for Narrative. Legal Storytelling. *Michigan Law Review*, vol 87 (8), pp. 2411-2441, Published By: The Michigan Law Review Association https://doi.org/10.2307/1289308.

Delgado, R. and Stefancic, J. (2017) *Critical Race Theory* (Third Edition) An Introduction, New York; The New Press.

Delgado, R., and Stefancic, J. (2001) Critical race theory: *An introduction*. 1st edn. New York, NY: New York University Press.

Denzin, N. K., and Lincoln, Y. S. (Eds) (2000) *Handbook of qualitative research*, (2nd Ed). Thousand Oaks, CA: Sage.

Denzin, N. K., and Lincoln, Y. S. (Eds.). (2011). The Sage handbook of qualitative research (4th ed.). Thousand Oaks, CA: Sage.

Denzin, N.K (2017) *Critical Qualitative Inquiry, Qualitative Inquiry*, vol. 23(1), vol. 8–16.

Denzin, N.K, and Lincoln, Y.S. (2005) *Introduction: the discipline and practice of qualitative research*. In: Denzin, NK, Lincoln, YS (eds) The SAGE Handbook of Qualitative Research. Thousand Oaks, CA: Sage, 1–32.

Denzin, N.K. (1984) *On Understanding Emotion*. San Francisco: Jossey-Bass.

Department of Health (1998) *Modernising social services* (London, HMSO).

Department of Health (2003) *A guide to receiving direct payments from your local council – a route to independent living*. London: Available at: Department of Health. www.doh.gov.uk/directpayments/index.htm. (Accessed: 12th July 2020).

Department of Health (2006) *Our Health, Our Care, Our Say: A New Direction for Community Services.* HM Government White Paper. Department of Health, London.

Department of Health (2008), *Putting People First: a shared vision and commitment to the transformation of adult social care*, London: Department of Health.

Derrida, J. (1982). *Margins of philosophy* (A. Bass, Trans). Chicago, IL: University of Chicago Press, (Original work published in 1967).

Derrida, J. (1998) *Of grammatology* (G. C. Spivak, Trans.). Baltimore, MD: John Hopkins University, Press (Original work published in 1967).

Devoy, S. and Simpson, E. E. A (2017) Help-seeking intentions for early dementia diagnosis in a sample of Irish adults. *Aging and Mental Health*, vol. 21(8), pp. 870-878. http://dx.doi.org/10.1080/13607863.2016.1179262.

Dewing, J. (2007) Participatory research: a method for process consent with persons who have dementia. *Dementia*, vol. 6, pp. 11–25.

Diaz-León, E. (2015) What is social construction? *European Journal of Philosophy*, vol.23(4), pp.1137–1152.

DiGasbarro, D., Whitaker, C., and Mast, B. (2020). Positive Behaviors and Strengths of People With Dementia. *Innovation in Aging*, *4*(1), pp. 276. https://doi.org/10.1093/geroni/igaa057.883.

Dodd. E., Pracownik, R., Popel, S., Collings, S., Emmens, T., and Cheston, R. (2020) Dementia services for people from Black, Asian and Minority Ethnic and White-British communities: Does a primary care-based model contribute to equality in service provision? *Health and social care in the community*. Vol. pp, 1-9. DOI: 10.1111/hsc.13167.

Dowd, J. J., and Bengtson, V. L. (1978). Aging in minority populations: An examination of the double jeopardy hypothesis. Journal of Gerontology, 33(3), 427–436. https://doi.org/10.1093/geronj/33.3.427.

Downs, M. (1997) "The Emergence of the Person in Dementia Research", *Ageing and Society*, vol.17, pp.597-607.

Downs, M., Clare, L. and Mackenzie, J. (2006) "Understandings of dementia: explanatory models and their implications for the person with dementia and therapeutic effort", in

Hughes, J., Louw, S. and Sabat, S. (eds.) *Dementia: mind, meaning and the person*, Oxford, Oxford University Press.

Doyal, L. and Gough, I. (1991) *A Theory of Human Need, Basingstoke*, Basingstoke: Palgrave Macmillan.

Duffy, S. (2006) *Keys to Citizenship*, Paradigm, Liverpool.

Duffy, S. (2010) 'The Citizenship Theory of Social Justice: exploring the meaning of personalisation for social workers', *Journal of Social Work Practice*, vol. 24(3), pp. 253–267.

Dunning, A. (1997). *Advocacy and older people with dementia. In Mary Marshall (Ed.), State of the Art in Dementia Care*. London: Centre for Policy on Ageing.

Dunning, J. (2011) 'Social workers say personalisation will fail most service users', Community Care, 25 May, Accessed at: http://www.communitycare.co.uk/Articles/25/05/2011/116868/ social-workers-losing-faith-in-personalisation.htm (Accessed: 30th September 2020).

Eccles, A. and Cunningham, I. (2018) *The Enablers and Barriers to Voluntary Sector Organisations Providing Personalised Support Through Delivery of Self-directed Support*. Glasgow, UK: University of Strathclyde.

Edelman, R. J. (2000) *Psychosocial aspects of the health care process*. Essex: Prentice-Hall.

Edgar, D., Wilson, V. and Moroney, T. (2020). Which is it, person-centred culture, practice or care? It matters. *International Practice Development Journal*, vol.10 (1), pp.8-17.

El Ansari, W., Newbigging, K., Roth, C. and Malik, F. (2009) *The role of advocacy and interpretation services in the delivery of quality healthcare to diverse minority communities in London*, United Kingdom, Health and Social Care in the Community.

Elias, A, and Paradies, Y. (2021) The Costs of Institutional Racism and its Ethical Implications for Healthcare. *Journal Bioethics Inquiry*. Vol.18(1), pp.45-58. doi: 10.1007/s11673-020-10073-0. PMID: 33387263; PMCID: PMC7778398.

Ellerman, A. (1998) 'Can Discourse Analysis Enable Reflective Social Work Practice?', *Social Work Education,* vol. 17(1), pp.35–44.

Ellis, K. (2007) Direct payments and social work practice: The significance of 'street-level bureaucracy' in determining eligibility. *British Journal of Social Work*, vol. 37, pp. 405–422.

Emmel, N., Hughes K., Greenhalgh., J and Sales, A. (2007) Accessing socially excluded people—trust and the gatekeeper in the researcher–participant relationship. *Sociological Research*, vol. 12(2), Available; http://www.socresonline.org.uk/12/2/emmel.html (Accessed: 10th October 2021).

Engel, G. L. (1977) The need for a new medical model: a challenge for biomedicine. *Science*, vol. 196, pp. 129–136.

Engel, G. L. (1980) The clinical application of the biopsychosocial model. *American Journal of Psychiatry*, vol. 137, pp. 535–544.

Equality Act 2010. Available at: http://www.legislation.gov.uk/ukpga/2010/15/contents (Accessed: 2nd June 2021).

Ernest, P. (1999). *Social Constructivism as a Philosophy of Mathematics*: Radical Constructivism. New York: State University Press.

Esegbona-Adeigbe, S. (2020) COVID-19 and the risk to black, Asian and minority ethnic women during pregnancy, *British Journal of Midwifery*, vol 28, (10), pp. 718-723.

ESRC (2017) Research with potentially vulnerable people [online] ESRC. Available at: http://www.esrc.ac.uk/funding/guidance-for-applicants/research-ethics/frequently-raised-topics/research-with-potentially-vulnerable-people/ (Accessed: 8th August 2020).

Etherington, K. (2000) *Narrative approaches to working with adult male survivors of childhood sexual abuse.* London: Jessica Kingsley.

Ettelt, S., Williams, L., Perkins, M., Wittenberg, R., Lombard, D., Damant, J. and Mays, N. (2018). Explaining Low Uptake of Direct Payments in Residential Care: Findings from the Evaluation of the Direct Payments in Residential Care Trailblazers. *Journal of Social Policy,* pp.1-18. Available: https://eprints.lse.ac.uk/85765/1/Wittenberg_Explaining%20low%20uptake.2018.pdf. (Accessed 21st June 2021).

Eunsong, K., Khoshgozaran. G. and Matsuda, M. (2017) Founding critical race theorist, activist and artist. Contemporary. Available at https://contemptorary.org/mari-matsuda/. (Accessed: 21st December 21).

Evandrou, M., Falkingham, J., Feng, Z. and Vlachantoni, A. (2016) Ethnic Inequalities in Limiting Health and Self-Reported Health in Later Life Revisited. *Journal of Epidemiological Health*, vol. 1, pp 1-10.

Ferber, A. 2009. "Keeping Sex in Bounds: Sexuality and the (De)Construction of Race and Gender." Pp. 136-142 in *Sex, Gender, and Sexuality: The New Basics*, edited by Abby L. Ferber, Kimberly Holcomb and Tre Wentling. Oxford, UK: Oxford University Press.

Ferguson, I. (2007) 'Increasing User Choice or Privatizing Risk? The Antinomies of Personalization', *British Journal of Social Work*, vol. 37(3), pp. 387-403.

Ferguson, I. (2012) Personalisation, social justice and social work: a reply to Simon Duffy, *Journal of Social Work Practice*, vol. 26, (1), pp. 55-73, DOI: 10.1080/02650533.2011.623771.

Fernández, J. L., Kendall, J., Davey, V. and Knapp, M. (2007), Direct payments in England: factors linked to variations in local provision, *Journal of Social Policy*, 36, 1: 97–121.

Fernando, S. (2005) Multicultural Mental Health Services: Projects for Minority Ethnic Communities in England, *Journal of Psychiatry*, vol. 42 (3), pp. 420-436.

Ferraro, K.F, Farmer, M.M. Double jeopardy to health hypothesis for African Americans: analysis and critique. Journal Health Social Behaviour. 1996 Mar;37(1):27-43. PMID: 8820309.

Finney, N., Lymperopoulou, K., Kapoor, N., Marshall, A., Sabater, A., and Simpson, L. (2016). Local ethnic inequalities: Ethnic differences in education, employment, health and

housing in Districts of England and Wales, 2001-2011. Manchester: The University of Manchester in association with the Runnymede Trust.

Fisher, B. and Tronto, J. (1990) Towards a feminist theory of caring. In Abel E and Nelson M (eds). *Circles of Care Work and Identity in Women's Lives*. Albany, NY: State University of New York Press, pp. 36–54.

Flannery Jr, R. B. (2002) Addressing Psychological Trauma in dementia sufferers, *American Journal of Alzheimer's Disease and Other Dementias*, vol. 17(5), pp. 281-285.

Flemig, S. R. and Osborne, S. (2019) "The Dynamics of Co-Production in the Context of Social Care Personalisation: Testing Theory and Practice in a Scottish Context," *Journal of Social Policy*. Cambridge University Press, 48(4), pp. 671–697. doi: 10.1017/S0047279418000776.

Flynn, S. (2021) "Social Constructionism and Social Care: Theoretically Informed Review of the Literature on Evidence-Informed Practice Within the Professionalisation of Social Care Professionals Who Work with Children in Ireland." Child care in practice: *Northern Ireland journal of multi-disciplinary child care practice*, vol.27 (1), pp 87–104.

Forbat, L. (2003) 'Concepts and understandings of dementia by "gatekeepers" and minority ethnic "service users"', *Journal of Health Psychology*, vol 8, no 5, pp 645−655.

Fossey, J., Ballard, C., Moniz-Cook, E. and Murray, J. (2012) Improving the quality of life for people with dementia in care homes: Making psychosocial interventions work. *The British Journal of Psychiatry*, vol. 201(5), pp. 344–351.

Foucault, M. (1970) *The order of things: An archaeology of the human sciences*. London, England: Routledge.

Foucault, M. (1980). *Power/knowledge. Selected interviews and other writings* 1972–1977. New York: Pantheon Books.

Fraser H, and MacDougall C. (2017) Doing narrative feminist research: Intersections and challenges. *Qualitative Social Work*, vol. 16(2), pp. 240-254. doi:10.1177/1473325016658114.

Fraser H. (2004) Doing Narrative Research: Analysing Personal Stories Line by Line. *Qualitative Social Work*, vol.3(2), pp. 179-201. doi:10.1177/1473325004043383.

Frearson, S, Henderson. J, Ravat, B. et al. (2013) End of Life Care for the British Asian Hindu Community; Preferences and solutions. *End of Life Journal,* vol, 3(3), pp. 1–8.

Freeman, M. (2000) Knocking on doors: on constructing culture. *Qualitative Inquiry*, vol.6, pp.59–369.

Freeman, M., DeMarrais, K. and Preissle, J. (2007) Standards of evidence in qualitative research: an incitement to discourse. *Educational Researcher*, pp.36(1), pp. 25–32.

Gabriel, L., James, H., Cronin-Davis, J., Tizro, Z., Beetham, T., Hullock, A. and Raynar, A. (2017) Reflexive research with mothers and children victims of domestic violence. *Counselling and Psychotherapy Research*, vol (17) 2, pp.157-165.

Gagliese, L., Gauthier, L. R., Narain, N., Freedman, T (2018) Pain, aging and dementia: Towards a biopsychosocial model, *Progress in Neuro-Psychopharmacology and Biological Psychiatry*, vol 87, Part B, pp. 207-215, https://doi.org/10.1016/j.pnpbp.2017.09.022.

Galanes, G.J. and Leeds-Hurwitz, W. (2009) *Socially constructing communication*. Cresskill, NJ: Hampton Press.

Garfinkel, H. (1967) *Studies in ethnomethodology*. Englewood Cliffs, NJ: Prentice-Hall.

Geertz, C. (1973) *The Interpretation of Cultures*, New York, Fontana Press.

General Data Protection Regulation (GDPR), Available at: https://gdpr-info.eu/, (Accessed: 23rd July 2021).

Gergen, K. J. (1982) *Toward transformation in social knowledge*. New York, NY: Springer Verlag. doi: 10.1007/ 978-1-4612-5706-6.

Gergen, K. J. (1985). The social constructionist movement in modern psychology, *American Psychologist,* 40, 266–275. doi:10.1037/0003-066X.40.3.266.

Gergen, K. J. (2000) *The saturated self: Dilemmas of identity in contemporary life*. New York: Basic Books.

Gergen, K. J. (2001a). *Psychological science in a postmodern context*. The American Psychologist, vol.56, pp.803–813.

Gibson, F. (2004) *The past in the present: using reminiscence in health and social care*, Baltimore, MD: Health Professions Press.

Giebel, C. M., Zubair, M., Jolley, D., Bhui, K. S., Purandare, N., Worden, A., and Challis, D. (2014). South Asian older adults with memory impairment: Improving assessment and access to dementia care. *International Journal of Geriatric Psychiatry*, vol.30, pp.345–356.

Giebel, C.M., Challis, D., Hooper, N.M and Ferris, S (2018) A step-by-step translation of evidence into a psychosocial intervention for everyday activities in dementia: a focus group study, Aging and Mental Health, vol, 22, pp. 323–329,http://dx.doi.org/10.1080/13607863.2016.1262819.

Gilleard, C. and Higgs, P. (2010) Aging without agency: theorizing the fourth age, *Aging and Mental Health,* vol. 14, (2), pp. 121–128.

Gilliard, J., Means, R., Beattie, A., and Daker-White, G. (2005) Dementia care in England and the social model of disability. Dementia: *The International Journal of Social Research and Practice*, vol. 4(4), pp. 571–586.

Gilligan, C. (2008) "Moral Orientation and Moral Development." In Alison Bailey and Chris J. Cuomo (eds.). The Feminist Philosophy Reader. Boston: McGraw-Hill, 2008. N. page. 471 Print.

Gilmour, J. A., and Brannelly, T. (2010) Representations of people with dementia—Subaltern, person, citizen. *Nursing Inquiry*, vol. 17(3), pp. 240–247.

Glasby, J. and Littlechild, R. (2010) *Direct Payments and Personal Budgets: Putting Personalisation into Practice,* 2nd edn, Bristol, Policy Press.

Glaze, J. (2002) Ph.D. Study and the Use of a Reflective Diary: A Dialogue with Self. Reflective Practice, vol.3 (2), pp. 153-166.

Glendinning, C. and Bell, D. N. F. (2009) *Rethinking Social Care and Support: What can England Learn from Other Countries?* Joseph Rowntree Foundation, York.

Glendinning, C., Challis, D., Fernandez, J., Jacobs S., Jones K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M. (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report,* York Social Policy Research Unit, University of York.

Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K. and Tyer, J. (2000) 'New kinds of care, new kinds of relationships: How purchasing affects relationships in giving and receiving personal assistance', *Health and Social Care in the Community*, vol.8(3), pp. 201–11.

Glesne, C. (2006) *Becoming qualitative researchers: an introduction* (3rd ed.). New York, NY: Pearson Education, Inc.

Goldsmith, M. (1996) *Hearing the Voice of People with Dementia: Opportunities and Obstacles*, London, Jessica Kingsley Publishers.

Gordon, L. E. and S. A. Abbott. (2002) "A Social Constructionist Essential Guide to Sex." In Robert Heasley and Betsy Crane, Eds., Sexual Lives: *Theories and Realities of Human Sexualities*. New York, McGraw-Hill.

Graham, R. (2004) Cognitive citizenship: access to hip surgery for people with dementia, *Health*, vol. 8 (3), pp. 295–310.

Greaves, I., and Jolley, D. (2010). National Dementia Strategy: well-intentioned but how well-founded and how well-directed? *The British journal of general practice: the journal of the Royal College of General Practitioners*, *60* (572), pp.193–198. https://doi.org/10.3399/bjgp10X483553.

Gredler, M. E. (1997) *Learning and instruction: Theory into practice* (3rd ed). Upper Saddle River, NJ: Prentice-Hall.

Green, S., Kearbey, J., Wolgemuth, J., Agosto, V., Romano, J., Riley, M., and Frier, A. (2015). Past, Present, and Future of Assessment in Schools: A Thematic Narrative Analysis. *The Qualitative Report*, vol. 20(7), pp.1111-1124. Available at: http://nsuworks.nova.edu/tqr/vol20/iss7/11. (Accessed:2nd May 2021).

Greenwood, N., Holley, J., Ellmers, T., Mein, G., and Cloud, G. (2016) Qualitative focus group study investigating experiences of accessing and engaging with social care services: perspectives of carers from diverse ethnic groups caring for stroke survivors. *British Medical Journal, open*, vol. 6(1) e009498.

Gubrium, J. (1986a) *Oldtimers and Alzheimer's: The Descriptive Organization of Senility Greenwich*, CT: JAI Press.

Gubrium, J. (1986b) "The Social Preservation of Mind: The Alzheimer's Disease Experience. *Symbolic Interaction*, vol. 9, pp. 37–51.

Gubrium, J. F., and Holstein. J. A. (1997) *The new language of qualitative method*. New York: Oxford University Press.

Gudmundsdottir, S. (1997). Introduction to the theme issue of "narrative perspectives on research on teaching and teacher education." *Teaching and Teacher Education*, vol. 13(1), pp.1-3.

Gudmundsdottir, S. (2001) *Narrative Research in School Practice.* In V. Richardson (Ed.), Fourth Handbook for Research on Teaching (pp. 226-240). New York: Macmillan.

Guichard, J. (2005) Life-long self-construction. *International Journal for Educational and Vocational Guidance*, 5, 111–124. doi: 10.1007/s10775-005-8789-y.

Guillemin, M., and Gillam, L. (2004) Ethics, Reflexivity, and "Ethically Important Moments" in Research. *Qualitative Inquiry*, vol.10(2), pp.261-280.

Hadden, S. and Lester, M. (1978) "Talking Identity: The Production of 'Self' In Interaction", *Human Studies*, vol.1, pp. 331-356.

Hall, S., Evans, J. and Nixon, S. (2013) *Representation*. 2nd Ed. London: Sage.

Hamilton, S., Szymczynska, P., Clewett, N., Manthorpe, Tew. J.J., Larsen, J. and Pinfold. V. (2017) The role of family carers in the use of personal budgets by people with mental health problems, *Health and Social Care in the Community*, vol. 25(1), 158–166. doi: 10.1111/hsc.12286.

Hamilton-West, K., Milne, A., Chenery, A., and Tilbrook, C. (2010). Help-seeking in relation to signs of dementia: A pilot study to evaluate the utility of the common-sense model of illness representations. Psychology, *Health and Medicine*, vol.15, 540-549.

Hammersley, M, and Atkinson, P, (1997) *Ethnography: Principles in Practice*, London: Routledge.

Hampson, C. and Morris, M. (2017) Dementia: Normal Ageing, Political Cause or Social Construction? *Journal of Gerontology and Geriatric Medicine*, vol (1) 4, pp. pp.1-4.

Hancock, A.M. (2007) When multiplication doesn't equal quick addition: Examining intersectionality as a research paradigm, *Perspectives on Politics*, vol. 5 (1), pp. 63–79.

Hansen, E. C. (2006), *Successful Qualitative Health Research: A Practical Introduction,* Maidenhead, Open University Press.

Hansen, J. T. (2004). Thoughts on knowing: Epistemic implications of counselling practice. *Journal of Counselling and Development,* vol. 82, pp.131–138.

Hansen, J. T. (2005). The devaluation of inner subjective experiences by the counselling profession: A plea to reclaim the essence of the profession. *Journal of Counselling and Development*, vol.83, pp.406–415.

Harding, N.H. and Palfrey, C. (1997) *The Social Construction of Dementia Confused Professionals*? Jessica Kingsley, London.

Harding, R. (2012) Legal constructions of dementia: discourses of autonomy at the margins of capacity, *Journal of Social Welfare and Family Law*, vol. 34, (4), pp. 425–442.

Harkes, M.A., Brown, M., Horsburgh, D. (2012) Self-directed support and People with Learning Disabilities: a review of the published research evidence, British Journal of

Learning Disabilities, Vol. 42, pp.87-101, Available at:
http://www.nationalelfservice.net/social-care/personalisation/direct-payments-are-they-working-well-for-people-with-learning-disabilities-or-dementia-who-lack-mental-capacity-to-consent.dpf(Accessed: 10th August 2020).

Harre, R. (1981) Expressive aspects of descriptions of others. In C. Antaki (Ed.), *The psychology of ordinary explanations* (pp. 139–156). London: Academic Press.

Harré, R. (1983) *Personal Being: A Theory for Individual Psychology*, Oxford, Basil Blackwell.

Harre, R. and Secord, P. (1972) *The explanation of social behaviour*. Oxford: Blackwell.

Harries, B., Harris, S., Hall, N. and Cotterell, N. (2019) Older BAME people's experiences of health and social care in Greater Manchester; Lessons for practice and policy. Available at: http://www.oldham-council.co.uk/jsna/wp-content/uploads/2018/11/BAME-peoples-experiences-of-health-and-social-care. (Accessed: 14th July 2021).

Harris, J. C., and Patton, L. D. (2018). Un/Doing intersectionality through higher education research. *The Journal of Higher Education*, vol. 90(3), pp. 247-372. doi:10.1080/00221546.2018.1536936.

Harris, S R. (2006) "Social Constructionism and Social Inequality: An Introduction to a Special Issue of JCE." *Journal of contemporary ethnography*, vol. 35 (3), pp.223–235.

Harris, S. R. (2000). The social construction of equality in everyday life. *Human Studies*, vol.23: pp.371-93.

Harris, S. R. (2001) What can interactionism contribute to the study of inequality? The case of marriage and beyond. *Symbolic Interaction*, vol. 24, pp. 455-80.

Harris, S. R. (2006) "Social Constructionism and Social Inequality: An Introduction to a Special Issue of JCE." *Journal of contemporary ethnography*, vol. 35 (3). Pp.223–235.

Harrison, L. (1996) 'Distant Voices, Still Lives: Young Women, Research and (Em)power(ment)',in D. Colquhoun and A. Kellehear (eds) Health Research in Practice, Personal Experiences, *Public Issues*, vol. 2, pp. 71–93. London: Chapman Hall.

Harrison, S. L., Dyer, S. M., Laver, K. E., Milte, R. K., Fleming, R., and Crotty, M. (2017). Physical environmental designs in residential care to improve the quality of life of older people. *Cochrane Database of Systematic Reviews*, vol.12, pp.1-14. DOI: 10.1002/14651858.CD012892.

Hart, V. (2014) A view from social work practice. In Needham C and Glasby J (eds). *Debates in Personalisation*. Bristol, UK: Policy Press, pp. 111–119.

Hasenfeld, Y. (1983). Human Service Organizations. Englewood Cliffs, NJ:

Prentice-Hall.

Hasler, F. (2003) 'Making choice a reality', *Care and Health*, Magazine, vol.34, 23, pp.22-23. Publisher: Care and Health.

Hasler, F. and Zarb, G. (2000) 'Direct payments and older people: The principles of independent living', *Research, Policy and Planning*, 18(2), pp. 7–12.

Hatch, J. A. (2002) *Doing qualitative research in education settings.* Albany, NY: SUNY Press.

Hatch, J. and Wisniewski, R. (1995) *Life history and narrative.* London: Falmer Press.

Hatch, M. J. (1997) 'Irony and the Social Construction of Contradiction in the Humour of a Management Team', *Organization Science*, vol. 8(3), pp. 275–88.

Hatton, C. and Waters, J. (2011) The National Personal Budget Survey 2011, Lancaster University/In Control. Available at: www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Personalisation_advice/201 1/POET_surveys_June_2011_-_EMBARGOED.pdf (Accessed: 15th December 2021).

Haydon, G., Browne, G and Riet, V. (2018) Narrative inquiry as a research methodology exploring person-centred care in nursing, *Collegian*, vol. 25(1), pp.125-129, https://doi.org/10.1016/j.colegn.2017.03.001.

Haynes, K. (2006), "A therapeutic journey? Reflections on the effects of research on researcher and participants", *Qualitative Research in Organizations and Management*, vol.1 (3), pp. 204-221, https://doi.org/10.1108/17465640610718798.

Health Scotland (2021) Improving Health: Dementia and Health Inequalities. Available at: http://www.healthscotland.scot/health-topics/dementia (Accessed: 12th July 2020).

Healy, G. and Oikelome, F. (2017), Racial Inequality and Managing Diversity in the United Kingdom and United States, in Mustafa F. Özbilgin, Jean-François Chanlat (ed.) Management and Diversity, *International Perspectives on Equality, Diversity and Inclusion*, vol 3 Emerald Publishing Limited, pp.33 – 62.

Heartney, E. (2001) *Postmodernism: Movements in modern art.* New York: Cambridge University Press.

Held, P., Klassen, B. J., Hall, J. M, Friese, T. R., Marcel, T., Bertsch-Gout, R. M., Zalta, A, K. and Pollac, M. H (2019) "I Knew It Was Wrong the Moment I Got the Order": A Narrative Thematic Analysis of Moral Injury in Combat Veterans, Psychological Trauma: *Theory, Research, Practice, and Policy*, vol. 11(4), pp. 396 – 405.

Hellstrom, I. Nolan, M. Nordenfelt, L. and Lundh, L. (2007) Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14(5), pp.608-619.

Herrona, R. V. and Rosenberg, M. W. (2017) "Not there yet": Examining community support from the perspective of people with dementia and their partners in care, *Social Science and Medicine*, vol, 173, pp. 81-87.

Heslop, P, Williams, V. and Spandler, Helen (2009) *Personalisation in mental health: A review of the evidence.* Mind. ORCID: 0000-0002-0970-5141.

Hey, V. (1997) *The Company She Keeps: An Ethnography of Girls' Friendships*. Buckingham: Open University Press.

Hibberd, F. J. (2001) "Gergen's Social Constructionism, Logical Positivism and the Continuity of Error: Part 1: Conventionalism." *Theory and psychology*, vol. 11. (3), pp 297–321.

Holloway, M. (2007) Caring for People: Social Work with Adults in the Next Decade and Beyond, *British Journal of Social Work,* vol, 37, pp. 375-386.

Holloway, W. and Jefferson, T. (2000) *Doing Qualitative Research Differently: Free Association, Narrative and the Interview Method.* London: Sage.

Holmes, P. (2015) Chapter: Intercultural encounters as socially constructed experiences: Which concepts? Which pedagogies? *In Companion to Cross-Cultural Management.* Edited By Nigel Holden, Snejina Michailova, Susanne Tietze. London. Routledge.

Holstein, J. A., and J. F. Gubrium. (2000) *The self we live by: Narrative identity in a postmodern world.* New York: Oxford.

Holstein, J. and Miller, G. (Eds.). (1993) *Reconsidering social constructionism: Debates in social problems theory.* Hawthorne, NY: Aldine de Gruyter.

Holthe, T., Jentoft, R., Arntzen, C. and Thorsen, K., (2018). Benefits and burdens: family caregivers' experiences of assistive technology (AT) in everyday life with persons with young-onset dementia. *Disability and Rehabilitation: Assistive Technology*, vol,13(8), pp.754-762.

Holzner, B. (1972) *Reality construction in society*. Cambridge: Schenkman Publishing Company.

Hoppitt, T. Sha, S. Bradburn, P. Gill, P. Calvert, M. Pall, H. Stewart, M. Fazil, Q. and Sackley, C. (2012). Reaching the 'hard to reach': strategies to recruit black and minority ethnic service users with rare long-term neurological conditions. *International Journal of Social Research Methodology*, vol. 15, (6), pp.485-95.

Hossain, M. Z and Mughal, F. (2020) Dementia and revivalist Islam: New perspectives to understanding dementia and tackling stigma, *Journal of Evaluation in Clinical Practice*, 10.1111/jep.13412, vol.27(2), pp.213-217.

Hossain, M.Z and Khan, H.T.A (2020) Barriers to access and ways to improve dementia services for a minority ethnic group in England. Available at: https://doi.org/10.1111/jep.13361, (Accessed: 14th April 2021).

Hothersall, S. and Bolger, J. (2020) *Social Policy for Social Work, Social Care and the Caring Professions* (EDS) Ashgate. Farnham.

Howe, K., and Eisenhart, M. (1990), 'Standards for Qualitative and Quantitative Research: A Prolegomenon', *Educational Researcher*, 19 (4), pp. 2-9.

Hubert, J. (2006). Family carers' views of services for people with learning disabilities from Black and minority ethnic groups: a qualitative study of 30 families in a south London borough. *Disability & Society,* vol. 21 (3), pp. 259-272.

Hughes, J.C., Louw, S.J. and Sabat, S.R. (2006) *Dementia: mind, meaning, and the person*. Oxford: Oxford University Press.

Hughes, Z. (2018) *Family Caring and Minority Populations*, Carers Alliance, Ireland, Guiding Principles for Carers. Available at: https://www.researchgate.net/profile/Zoe-Hughes-6/publication/327982525_Family_Caring_and_Minority_Populations/links/5bb202a9a6fdccd3cb80b49a/Family-Caring-and-Minority-Populations (Accessed: 12th December 2021).

Hung, L., Phinney, A., Chaudhury, H., Rodney, P., Tabamo, J. and Bohl, D. (2017). "Little things matter!" Exploring the perspectives of patients with dementia about the hospital environment. *International Journal of Older People Nursing*, vol.12, pp.12153-12160.

Hurtado, A. (2019) Critical Race Theory and Questioning Whiteness: Young Feminists Speak Out Against Race and Class Privilege. *A Journal of Women Studies*, vol 40, (3), pp. 90-116.

Hussain-Gambles, M., Atkin, K. and Leese, B. (2004), Why ethnic minority groups are under-represented in clinical trials: a review of the literature. *Health and Social Care in the Community*, 12: 382-388. https://doi.org/10.1111/j.1365-2524.2004.00507.x

Iliffe, S., Walters, K., Manthorpe, J., Goodman, C. and Kharicha, K. (2017) "Health and well-being promotion strategies for 'hard to reach' older people in England: a mapping exercise," Primary *Health Care Research and Development*. Cambridge University Press, 18(6), pp. 563–573. doi: 10.1017/S1463423617000378.

The Independent Review into Adult Social Care (IRASC) (2021) Adult Social Care Independent Review led by Derek Feeley. Available: https://www.gov.scot/publications/independent-review-adult-social-care-scotland/, (Accessible: 17th July 2022)

Indira, R. (2020) Lending Voices to the Marginalised: The Power of Narratives as Alternative Sociological Discourse. *Sociological Bulletin*, vol. 69(1), pp. 7-16. doi:10.1177/0038022919898999.

Innes, A. (2009) *Dementia Studies*, Sage: London.

Innes, A., Macpherson, S., and McCabe, L. (2006) *Promoting person-centred care at the front line*. York: Joseph Rowntree Foundation.

Irvine, F., Yeung, E.Y. W., Partridge, M. and Simcock, P. (2016) The impact of personalisation on people from Chinese backgrounds: qualitative accounts of social care experience. *Journal of Health and Social Care,* vol,25 (3) pp, 878-887.

Jenkins, C. (1998) 'Bridging the divide of culture and language', *Journal of Dementia Care*, vol 6, no 6, pp 22−24.

Jepson, J., Laybourne, A., Williams, V., Cyhlarova, E., Williamson, T., and Robotham, D. (2016) Indirect payments: when the Mental Capacity Act interacts with the personalisation agenda, *Health and Social Care in the Community*, vol. 24(5), pp. 623–63.

Jeraj, S. (2021) Doing the work to end health inequalities caused by systemic racism, *British Medical Journal*, vol. 373, n821 doi:10.1136/BMJ.n821.

Johl, N., Patterson, T., and Pearson, L. (2016). What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings. *Dementia*, vol.15, pp.721–742.

Johnson, J. M. (2001). In-depth interviewing. In J. F. Gubrium, and J. A. Holstein (Eds.), *Handbook of interview research*: Context and method (pp. 103–119). London, UK: Sage.

Jones, C. W. and Lynn, M. R (2018) Blogs Written by Families During Their Child's Hospitalization: A Thematic Narrative Analysis. *Journal of Pediatric Nursing*, vol. 41, pp. 110-116, https://doi.org/10.1016/j.pedn.2018.03.011.

Jones, K., Netten, A., Rabiee, P. and Glendinning, C. (2014) Can individual budgets have an impact on carers and the caring role? *Ageing and Society*, vol 34 (1) pp.137-175.

Jordan, B. and Drakeford, M. (2012) *Social Work and Social Policy under austerity*, Basingstoke Palgrave Macmillan.

Josselson, R. and Lieblich, A. (1993) (eds) *The Narrative Study of Lives*, 3. London: Sage.

Jutlla, K. (2013) Ethnicity and cultural care in dementia: A review of the research. *Journal of Dementia Care*, vol. 21(2), pp.33–39.

Jutlla, K. and Raghavan, R. (2017) Improving the recruitment of Black, Asian and Minority Ethnic (BAME) communities in health and social care research: A review of the literature. Available at: https://dora.dmu.ac.uk/bitstream/handle/2086/13221/Improving%20recruitment%20BAME%20communities%20in%20health%20and%20social%20care%20research.pdf?sequence=1&isAllowed=y. (Accessed:14th April 2021.

Kacen, L., and Chaitin, J. (2006). "The Times They are a Changing": Undertaking Qualitative Research in Ambiguous, Conflictual, and Changing Contexts. The Qualitative Report, vol.11(2), pp.209-228.

Kafai, Y., and Resnick, M. (1996) *Constructionism in practice: Designing, thinking, and learning in a digital world*. Mahwah, NJ: Lawrence Erlbaum Associates.

Käkelä, E. (2020) Narratives of power and powerlessness: cultural competence in social work with asylum seekers and refugees, *European Journal of Social Work*, vol. 23(3), pp. 425-436, DOI: 10.1080/13691457.2019.1693337.

Kapp, M. B. (1998) Persons with dementia as 'liability magnets': ethical implications. *The Journal of Clinical Ethics,* vol.9(1), pp.66-70.

Katbamna, S., Ahmad. W., Bhakta, P., Baker. R. and Parker, G. (2004) Do they look after their own? Informal support for South Asian carers. *Health Soc Care Community*, vol. 12(5), pp. 398-406. doi: 10.1111/j.1365-2524.2004.00509.x. PMID: 15373818.

Kay, L. (2019) Guardians of research: negotiating the strata of gatekeepers in research with vulnerable participants, *Practice*, vol. 1 (1), pp.37-52, DOI:10.1080/25783858.2019.1589988.

Keady, J., and Gilliard, J. (2002). Testing times: The experience of neuropsychological assessment for people with suspected Alzheimer's disease. In P. B. Harris (Ed.), *The person with Alzheimer's disease: Pathways to understanding the experience* (pp. 3–28). Baltimore, MD: The Johns Hopkins University Press.

Keady, J., and Hydén, L. C., Johnson, A. and Swarbrick, C. (eds.) (2017) *Social Research Methods in Dementia Studies*: Inclusion and Innovation, Routledge, London.

Keady, J., Campbell, S. Barnes, H and Ward, R. (2012). Neighbourhoods and dementia in the health and social care context: a realist review of the literature and implications for UK policy development. *Reviews in Clinical Gerontology*, vol. 22, pp. 150–163.

Keady, J., Jones, L., Ward, R., Koch, S., Swarbrick, C., Hellstrom, I., Davies-Quarrell, V, and William, S. (2012) Approaches to Patient Care: Introducing the bio-psycho-social-physical model of dementia through a collective case study design. *Journal of Clinical Nursing*, vol.22, pp. 2768–2777, doi: 10.1111/j.1365-2702.2012.04292.x.

Keage, H. and Loetscher, T. (2015) Passage of time: why people with dementia switch back to the past. Available at: https://theconversation.com/passage-of-time-why-people-with-dementia-switch-back-to-the-past-45159. (Accessed: 27th January 2022).

Kelly, F. and Innes, A. (2013) Human rights and citizenship in dementia care nursing, *International Journal of Older People Nursing*, vol. 8 (1), pp. 61 –70.

Kennedy, L., Wilkinson, H., and Henstridge, C. (2019) Buddy Pairs': A novel pilot scheme crafting knowledge exchange between biomedical dementia researchers and people affected by dementia – Innovative practice. *Dementia*, vol 20 (1), https://doi.org/10.1177/1471301219885543.

Kenning, C., Daker-White, G., Blakemore, A., Panagioti, M. and Waheed, W. (2017). Barriers and facilitators in accessing dementia care by ethnic minority groups: A meta-synthesis of qualitative studies. *BMC Psychiatry*, vol. 17(1), pp.316-330. https://doi.org/10.1186/s12888-017-1474-0.

Kenny, J. S. (2002) victims of crime and labelling theory: a parallel process? Deviant Behaviour: *An Interdisciplinary Journal,* vol. 23, pp. 235-265.

Keum, B. T (2021) Does Witnessing Racism Online Promote Individual and Institutional Anti-Racism Advocacy Among White Individuals? The Role of White Empathy, White Guilt, and White Fear of Other Races. *Cyberpsychology, Behavior, and Social Networking,* vol. 24(11), pp 756-761.

Keywood, K., 2003. Gatekeepers, proxies, advocates? The evolving role of carers under mental health and mental incapacity law reforms. *Journal of social welfare and family law*, vol.25 (4), 355–368.

Khalidi, M. A. (2015) Three kinds of social kinds. *Philosophy and Phenomenological Research*, vol. 90 (1), pp.96–112.

Khan, F. and Tadros, G. (2014) Complexity in cognitive assessment of elderly British minority ethnic groups: *Cultural perspective*, vol. 13 (4), pp. 467 – 482.

Khan, O., Shah, A., Escudero, S. L. Z., Moriarty, J., Jutlla, K., Goodorally, V., ... Wahab, S. (2015). *Dementia, culture and ethnicity: Issues for all*. London: Jessica Kingsley Publishers.

Khan, Z. (2021) Ethnic health inequalities in the UK's maternity services: a systematic literature review. *British Journal of Midwifery*, vol. 29 (2), pp. 100-107.

Khattab. N, and Hussein, S, (2017). Can religious affiliation explain the disadvantage of Muslim women in the British labour market? *Work, Employment and Society*, 32(6): pp. 1011–28.

Killick, J. (2001) 'The best way to improve this place'– gathering views informally. In Hearing the User's Voice: Encouraging People with Dementia to Reflect on their Experiences of Services (C Murphy, J. Killick. and K, Alan eds). *Dementia Services Development Centre*, Stirling, pp. 6– 9.

King, D. K. (1988). 'Multiple Jeopardy, Multiple Consciousness: The Context of a Black Feminist Ideology'. *Signs*. 14 (1): 47, 69–70, 51. doi:10.1086/494491. JSTOR 3174661.

King, A., Hopkinson, J., Milton, R., (2016) Reflections of a team approach to involving people with dementia in research. *International Journal of Palliative Nursing*, vol. 22(1), pp.22-27.

Kirby, T. (2020) Evidence mounts on the disproportionate effect of COVID-19 on ethnic minorities. *The Lancet Respiratory Medicine*, vol. 8 (6), pp. 547-548. https://doi.org/10.1016/S2213-2600(20)30228.

Kitwood T (1998) Toward a theory of dementia care: ethics and interaction. *The Journal of Clinical Ethics*, vol. 9, pp. 23–34.

Kitwood, T. (1993). Towards a theory of dementia care: the interpersonal process. *Ageing and Society*, vol.13, pp. 51-67.

Kitwood, T. (1995) Exploring the ethics of dementia research: a response to Berghmans and Ter Meulen: a psychosocial perspective. *International Journal of Geriatric Psychiatry*, vol.10, pp. 655-657.

Kitwood, T. (1997) The experience of dementia, *Aging and Mental Health*, vol.1 (1), pp.13-22.

Kitwood, T. and Bredin, K. (1992) Towards a Theory of Dementia Care: Personhood and well-being, *Journal of Ageing and Society*, vol 12 (3), pp. 269-287.

Knifton, L., Gervais, M., Newbigging, K., Mirza, N., Quinn, N., Wilson, N. and Hunkins-Hutchison, E. (2010), Community conversation: addressing mental health stigma with ethnic minority communities. *Sociological Journal of Psychiatry Epidemiology*, vol. 45, pp. 497-502.

Kokab, F., Greenfield, S., Lindenmeyer, A., Sidhu, M., Tait, L., and Gill, P. (2020) Social networks, health and identity: exploring culturally embedded masculinity with the Pakistani community, West Midlands, UK. BMC *Public Health*, vol. 20(1), pp. 1432-1442. doi: 10.1186/s12889-020-09504-9. PMID: 32957934; PMCID: PMC7507824.

Kontos, P. (2005) Embodied selfhood in Alzheimer's disease: rethinking person-centred care. Dementia, vol. 4, pp.553–570.

Kroska, A. and Harkness, S. K. (2007) Exploring the Modified Labeling. Theory of Mental Illness Using Affect Control Theory Simulations. Conference Papers. *American Sociological Association. Annual Meeting,* vol 6 (1), pp. 35-46.

Kuhn, T. S. (1962) *The Structure of Scientific Revolutions*. Chicago: University of Chicago Press.

Kukla, A. (2000) *Social Constructivism and the Philosophy of Science*. New York: Routledge.

Kundnani, A. (2007) *The End of Tolerance: Racism in 21st Century Britain*, London: Pluto Press.

La Fontaine, J., Ahuja, J., Bradbury, N. M., Phillips, S. and Oyebode, J. R. (2007) Understanding dementia amongst people in minority ethnic and cultural groups. *Journal of Advanced Nursing*, vol. 60, pp. 605–614.

Laird, J. (1994) '"Thick Description" Revisited: Family Therapist as Anthropologist Constructivist', in C. K. Reissman (ed.) *Qualitative Studies in Social Work Research*, pp. 175–89. Thousand Oaks, CA: Sage.

Lala, R., Baker. S.R., and Muirhead, V. E. (2021) A Critical Analysis of Underrepresentation of Racialised Minorities in the UK Dental Workforce [Special issue of Community Dental Health, to be disseminated at the 'Racism and oral health inequities' International Association for Dental Research symposium, *Community Dental Health*, vol. 38, pp. 1–8.

Larkin, M. and Dickinson, H. (2011) *Personalisation: What Will the Impacts Be for Carers*? Working Paper 64. Third Sector Research Centre, University of Birmingham, UK.

Lawler, S. (2002) 'Narrative in Social Research', in T. May (ed.) *Qualitative Research in Action*, pp. 242–58. London: Sage.

Laybourne, A. H., Jepson, M.J., Williamson, T. D. and Williams, V. (2016) Beginning to explore the experience of managing a direct payment for someone with dementia: The perspectives of suitable people and adult social care practitioners. *Dementia,* vol. 15(1) pp. 125–140.

Leadbeater, C. (2004) *Personalisation through Participation.* A New Script for Public Services, London: Demos.

LeCompte, M. D. (2000) *Analysing qualitative data. Theory Into Practice*, vol.39(3), pp.146–154.

Lee, S. Y, Hung, L, Chaudhury, H, Morelli, A. (2021) Staff perspectives on the role of physical environment in long-term care facilities on dementia care in Canada and Sweden. *Dementia.* 20(7), pp. 2235-2247. doi:10.1177/.14713012211003994.

Lee, S.E., Diwan, S. and Yeo, G. (2010) Causal Attributions of Dementia Among Korean American Immigrants, *Journal of Gerontological Social Work*, 53:8, 743-759, DOI: 10.1080/01634372.2010.515290.

Lee, T. and Tapia, M. (2021) Confronting race and other social identity erasures: the case for critical industrial relations theory. *ILR Review*, vol. 74(3), pp. 637–662 DOI: 10.1177/0019793921992080.

Leece J. and Peace S. (2010) Developing new understandings of independence and autonomy in the personalised relationship. *British Journal of Social Work*, vol. 40, pp. 1847–1865.

Leece J., and Bornat J. (2006) *Developments in Direct Payments*, Bristol Policy Press.

Leece, D. and Leece, J. (2006) Direct Payments: Creating a Two-Tiered System in Social Care? *British Journal of Social Work*, vol, 36, pp.1379–1393.

Leece, J. (2004) 'Money talks, but what does it say? Direct payments and the commodification of care', Practice: *The Journal of the British Association of Social Workers*, 16(3), pp. 211–21.

Leece, J. (2008) Paying the Piper and Calling the Tune: Power and the Direct Payment Relationship, *The British Journal of Social Work*, vol. 40, (1) PP. 188–206.

Leece, J. and Leece, D. (2011) 'Personalisation: Perceptions of the role of social work in a world of brokers and budgets', *British Journal of Social Work*, vol.41(2), pp.204–23.

Leorin, C., Stella, E., Nugent, C., Cleland, I. and Paggetti, C. (2019). The Value of Including People with Dementia in the Co-Design of Personalized eHealth Technologies. *Dementia and Geriatric Cognitive Disorders*, vol. 47(3) pp.164-177.

Leung, V. W. Y., Tan, W., Chuang, D. M., Tsang, K.T. and Lai, D. W. L. (2021) A Multidimensional Approach to Explore the Experiences with Ethnic Matching amongst Chinese Social Service Practitioners in the Greater Toronto Area, *The British Journal of Social Work*, bcab 122, https://doi.org/10.1093/bjsw/bcab122.

Lewis, J. and West, A, (2014) Re-shaping social care services for older people in England: policy development and the problem of achieving 'good care' *Journal of Social Policy, vol.* 43 (1) 1-18.

Liberman, Z., Woodward, A. L., and Kinzler, K. D. (2017). The Origins of Social Categorization. Trends in cognitive sciences, vol.21(7), pp. 556–568. https://doi.org/10.1016/j.tics.2017.04.004.

Lieblich, A., Tuval-Mashiack, R. and Zilber, T., (1998) *Narrative Research: Reading, Analysis and Interpretation.* London: Sage.

Liljas, A. E. M., Walters, K., Jovicic, A., Iliffe, S., Manthorpe, J., Goodman, C. and Kharicha, K. (2017) 'Strategies to improve engagement of 'hard to reach' older people in research on health promotion: a systematic review', *BmC Public Health*, (2017), 17:349. DOI:https://doi.org/10.1186/s12889-017-4241-8.

Lincoln, Y., and Guba, E. G. (1985) *Naturalistic inquiry.* Newbury Park, CA: Sage.

Link, B. and Phelan, J. C (2001) Conceptualizing Stigma, *Annual Review of Sociology*, vol.27(1), pp.363-385. https://doi.org/10.1146/annurev.soc.27.1.363.

Lipsky, M. (1980) *Street-Level Bureaucracy: Dilemmas of the Individual in Public Services*, New York: Russell Sage.

Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H.C., Kivimäki,M., Larson, E. B., Ogunniyi, A., Orgeta, V., Ritchie, K., Rockwood, K., Sampson, E.L., Samus, Q., Schneider, L. S., Selbæk, G., Teri, L., Mukadam, N (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission, vol.396, available: https://doi.org/10.1016/ S0140-6736(20)30367-6. Accessed: 6th July 2022).

Lock, A and Strong, T (2010) *Social Constructionism: Sources and Stirrings in Theory and Practice.* Cambridge, New York: Cambridge University Press. pp. 12–29. ISBN 978-0521708357.

Loewenthal, D., Mohamed, A. Mukhopadhyay, S., Ganesh, K. and Thomas, R (2012) Reducing the barriers to accessing psychological therapies for Bengali, Urdu, Tamil and

Somali communities in the UK: some implications for training, policy and practice, *British Journal of Guidance and Counselling*, vol.40:1, pp.43-66.

Lohr, Guido. (2021) "Social Constructionism, Concept Acquisition and the Mismatch Problem." *Synthese (Dordrecht)* vol. 198 (3) pp. 2659–2673.

Loseke, D. and Best, J. (Eds.). (2011) *Social problems: Constructionist readings*. Hawthorne, NY: Aldine Transaction.

Loseke, D. R. (2003) Thinking about social problems. 2d ed. *Social Problems and Social Issues. Hawthorne*, NY: Aldine de Gruyter.

Love, K. (2016). Living well with dementia: The Pygmalion effect. Dementia action alliance. Available at: https://daanow.org/living-well-with-dementia-the-pygmalioneffect/. (Accessed:13th April 2021).

Lucas, S.E (2021) Social Workers' Management of Child Interpreting: A Qualitative Study, *The British Journal of Social Work*, vol 51(2), pp. 673–691, https://doi.org/10.1093/bjsw/bcaa204.

Lukes, S. (1973). *Emile Durkheim: His life and work*. Standford, CA: Stanford University Press.

Lundsgaard, J. (2006). Choice and long-term care in OECD countries: Care outcomes, employment and fiscal sustainability. *European Societies*, vol. 8(3), pp. 361–383.

Lyman, K. (1989) "Bringing the Social Back in: A Critique of the Biomedicalization of Dementia", *The Gerontological Society of America*, vol.29(5), pp. 597-605.

Lymbery, M. (2014, a) Austerity, personalisation and older people: the prospects for creative social work practice in England, *European Journal of Social Work*, vol. 17 (3), pp.367-382.

Lymbery, M. (2014, b) 'Social work and personalisation: Fracturing the bureauprofessional compact?', *British Journal of Social Work*, vol.44, pp. 795.

Lynn, M., and Dixson, A. D. (Eds.). (2013). *Handbook of critical race theory in education*. New York, NY: Routledge.

Lyotard, J. (1979) *The postmodern condition: A report on knowledge*. Minneapolis: University of Minnesota Press.

MacAlpine, M. and Marsh, S. (2005) 'On Being White: There's Nothing I Can Say', *Management Learning*, 36(4), pp. 429–450.

Machiels, N., Metzelthin, S.F., Hamers, P. S. and Zwakhalen, M.G. (2017) Interventions to improve communication between people with dementia and nursing staff during daily nursing care: A systematic review. *International Journal of Nursing Studies*, vol. 66, pp. 37-46.

MacInnes, P. (2020). "'BAME' term offends those it attempts to describe, sporting survey finds". The Guardian. Available: https://www.theguardian.com/sport/2020/nov/12/bame-term-offends-those-it-attempts-to-describe-sporting-survey-finds-sporting-equals, (Accessed: 20th December 2021).

Mackenzie, J. (2006), 'Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK', Dementia: *The International Journal of Social Research and Practice*, vol.5 (2), pp. 233–247.

Macpherson, W. (1999) The Stephen Lawrence Inquiry: Report of an Inquiry Presented to Parliament by the Secretary of State for the Home Department by Command of Her Majesty. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/277111/4262. (Accessed: 4th Jan 2022).

Mahmood, F., Acharya, D., Kumar, K. and Paudyal, V (2021) Impact of COVID-19 pandemic on Black, Asian and Minority Ethnic (BAME) communities: a qualitative study on the perspectives of BAME community leaders. *British Medical Journal*. Available at: https://www.medrxiv.org/content/10.1101/2021.03.03.21252286v1.full.pdf+htm. doi: https://doi.org/10.1101/2021.03.03.21252286. (Accessed: 1st October 2021).

Mallon, R. (2014). Naturalistic approaches to social construction. *The Stanford Encyclopedia of Philosophy*. Edward N. Zalta (eds.), Available at: https://plato.stanford.edu/archives/win2014/entries/ social-construction-naturalistic/ (Accessed:15th July 2021).

Mallon, R. (2017) Social construction and achieving reference. *Noûs*, vol.51(1), pp. 113–131.

Manji, K. (2018) 'It was clear from the start that [SDS] was about a cost-cutting agenda.' Exploring disabled people's early experiences of the introduction of Self-Directed Support in Scotland, *Disability and Society,* vol.33(9), pp.1391-1411, DOI: 10.1080/09687599.2018.1498767.

Mannoni, O. (2015), Freud: *The Theory of the Unconscious*, London: [1971], pp. 49–51, 152–54.

Manthorpe, J., Moriarty, J., Stevens, M., Sharif, N. and Hussein, S. (2010) Supporting Black and Minority Ethnic Older People's Mental Wellbeing: accounts of social care practice. Knowledge and research report 38, London: Social Care Institute for Excellence. http://www.scie.org.uk/publications/reports/report38.pdf

Manthorpe, J. and Samsi, K. (2013) 'Inherently Risky?': Personal Budgets for People with Dementia and the Risks of Financial Abuse: Findings from an Interview-Based Study with Adult Safeguarding Coordinators. *British Journal of Social Work,* vol, 43, pp. 889–903.

Manthorpe, J. and Samsi, K. (2016) Person-centred dementia care: current perspectives, Clinical Intervention Aging, vol. 11. pp. 1733–1740.

Manthorpe, J., Iliffe, S., Moriarty, J., Cornes, M., Clough., R., Bright, L., and Rapaport, J. (2009) 'We are not blaming anyone, but if we don't know about amenities, we cannot seek them out': black and minority older people's views on the quality of local health and personal social services in England. Ageing Society, vol,43(1), pp.36–44.

Marczak, J., Fernandez, J. L., Manthorpe, J., Brimblecombe, N., Moriarty, J., Knapp, M., and Snell, T. (2021). How have the Care Act 2014 ambitions to support carers translated into local practice? Findings from a process evaluation study of local stakeholders' perceptions of Care Act implementation. Health and Social Care in the Community. https://doi.org/10.1111/hsc.13599.

Marmot, M. (2005) Social determinants of health inequalities. Public Health, The *Lancet*, vol. 365, (9464), Pp.1099-1104.

Martyr, A., Nelis, S. M., Quinn, C., Wu, Y. T, Lamont, R. A, Henderson, C, Clarke, R., Hindle, J.V, Thom J. M., Jones, I.R., Morris, R.G., Rusted, J.M., Victor, C.R., and Clare, L. (2018) Living well with dementia: a systematic review and correlational meta-analysis of factors associated with quality of life, well-being and life satisfaction in people with dementia. *Psychol Med*. vol. 48(13), pp. 2130-2139. doi: 10.1017/S0033291718000405.

Masko, A. L. (2005). ''I think about it all the time'': A 12-year-old girl's internal crisis with racism and the effects on her mental health. *The Urban Review*, vol. 37(4), pp. 329–350.

Mason, D. (2000) *Race and Ethnicity in Modern Britain*. Oxford University Press, Oxford.

Matsuda, M. J. (1987) Looking to the Bottom: Critical Legal Studies and Reparations, 22 Harv. C.R.-C.L. L. Rev. 323.

Maxim, P. S (1999) *Quantitative Research Methods in the Social Sciences*, New York. Oxford University Press.

Maxwell, J. A. (2005) *Qualitative Research Design*, (2nd edn), SAGE Publications, London, England.

McCabe, A. and Bliss, L. (2003) *Patterns of Narrative Discourse: A Multicultural, Life Span Approach*. Boston, MA: Pearson Education.

McCormack B., McCance, T. and Dewing, J. (2021) (edited) *The Person in Person-centred Practice*. Oxford. John Wiley and Sons.

McGarry, A. (2017) *Romaphobia: The Last Acceptable Form of Racism*. London: Zed Books Ltd.

McKenzie, E. (2017) A qualitative study exploring the experiences of access and pathways to health care among BME community groups residing in Ayrshire, no. 193. Available at: https://eresearch.qmu.ac.uk/handle/20.500.12289/7731. (Accessed: 23rd August 2021). McKillop, J. (2002) Did research alter anything. In: Wilkinson, H. (ed.) *The perspectives of people with dementia: Research methods and motivations*, London: Jessica Kingsley Publishers, pp. 109–114.

McKillop, J. and Wilkinson, H. (2004) Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed. *Dementia,* vol. 3, pp.117– 125.

McMurdo, M.E., Roberts, H., Parker, S., Wyatt, N., May, H., Goodman, C., Jackson, S., Gladman, J., O'Mahony, S., Ali, K., Dickinson, E., Edison, P. and Dyer, C. (2011) Improving recruitment of older people to research through good practice. *Age Ageing*. 2011;40(6), pp. 659–65.

McNeill, S. and Wilson, C. (2017) Use of Direct Payments in Providing Care and Support to Children with Disabilities: Opportunities and Concerns. *British Journal of Social Work*, vol. 47, pp.1903–1922 doi: 10.1093/bjsw/bcw159.

McParland, P., Devine, P., Anthea, I. and Vernon, G. (2012) 'Dementia knowledge and attitudes of the general public in Northern Ireland: an analysis of National Survey Data', *International Psychogeriatric*, vol. 24 (10), pp. 1600-1613.

McParland, P., Kelly, F. and Innes, A. (2017) Dichotomising dementia: is there another way? *Sociology of Health and Illness*, vol. 39 (22), pp. 258–269.

Mead, G. H. (1934) *Mind, self and society*. Chicago: University of Chicago Press.

MECOPP (2017) Self Directed Support and Scotland's Black and Minority Ethnic Communities, Available at: https://www.mecopp.org.uk/files/documents/MECOPP%20publications/mecopp_briefing_sheet_05.pdf. [Accessed, 23rd August 2021].

Meer, N., Akhtar, S., and Davidson, N. (2020) *Taking Stock: Race Equality Scotland. Runnymede: Intelligence for a Multi-ethnic Britain.* Available at: https://www.race.ed.ac.uk/wp-content/uploads/2020/07/Taking_Stock_Race_Equality_in_Scotland.pdf#page=17. (Accessed 26th November 2021).

Memon., A, Taylor., K, Mohebati., L. M, Sundin., J., Cooper,. M, Scanlon., T. and De Visser R. (2016) Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: a qualitative study in Southeast England. *British Medical Journal Open*, vol 16. 6(11):e012337. doi: 10.1136/bmjopen-2016-012337. PMID: 27852712; PMCID: PMC5128839.

Mental Health (Scotland) Act 2015: Available at: https://www.legislation.gov.uk/asp/2015/9/contents, (Accessed: 23rd July 2021).

Merriam, S.B., Johnson-Bailey, J., Lee, M.Y., Kee, Y., Ntseane, G. and Muhamad, M. (2010) Power and positionality: Negotiating insider/outsider status within and across cultures. *International Journal of Lifelong Education*, vol, 20 (5), pp. 405–416.

Metykova, M. (2010) Only a mouse clicks away from home: transnational practices of Eastern European migrants in the United Kingdom, *Social Identities,* vol. 16 (3), pp. 325-338.

Meyrick, J. (2006) What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality. *Journal of health psychology*, vol.11(5), pp.799-808.

Michailakis, D, and Schirmer. W. (2014) "Social Work and Social Problems: A Contribution from Systems Theory and Constructionism: Social Work and Social Problems." *International journal of social welfare*, vol. 23(4) pp. 431–442.

Mik-Meyer, N. and Villadsen, K. (2013) *Power and welfare: Understanding citizens' encounters with state welfare.* New York, NY: Routledge.

Miles, R. and Brown, M. (2003) *Racism*: Second Edition, New York: Routledge.

Miller, E. (2011) *Getting Back to What Matters*. Edinburgh: Dunedin.

Miller, E. and Barrie, K. (2020) "Ethical dilemmas: balancing choice and risk with a duty of care in extending personalisation into the care home," *Ageing and Society*. Cambridge University Press, pp. 1–22. doi: 10.1017/S0144686X20001737.

Milne, A. (2010). The 'D' word: Reflections on the relationship between stigma, discrimination and dementia. *Journal of Mental Health*, vol.19 (3), pp.227–233.

MIND (2011) Rights of Well-being and Racialised Groups: The End of Delivering Race Equality? Perspectives of frontline workers and service-users from racialised groups. Available at: https://www.mind.org.uk/media-a/4397/the-end-of-delivering-race-equality. (Accessed: 30th September 2021).

MIND (2013) Mental health crisis care: commissioning excellence for Black and minority ethnic groups A briefing for Clinical Commissioning Groups March 2013, Available at: https://www.mind.org.uk/media/494422/bme-commissioning-excellence-briefing.pdf, (Accessed: 2nd July 2020).

Mir, G, and Tovey, P. (2003) Asian carers' experiences of medical and social care: the case of cerebral palsy, *British Journal of Social Work*, vol. 33, (4), pp.465–479.

Mir, G., Nocon, A., Ahmad, W. and Jones, L. (2001) Learning Difficulties and Ethnicity, Report to the Department of Health: Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4002991, (Accessed 20th October 2021).

Mishler, E.G. (1986) *Research Interviewing: Context and Narrative*. Harvard University Press, Cambridge, MA.

Mitchell, W. (2019) *Somebody I Used to Know*. London: Bloomsbury Publishing.

Mockford, C., Murray, M., Seers, K., Oyebode, J., Grant, R., Boex, S., … Suleiman, R. (2016). A SHARED study – the benefits and costs of setting up a health research study involving lay co-researchers and how we overcame the challenges. *Research Involvement and Engagement*, vol. 2, pp.8–19.

Moran, N., Glendinning, C., Wilberforce, M., Stevens, M., Netten, A., Jones, K., … Jacobs, S. (2014). Older people's experiences of cash-for-care schemes: Evidence from the English individual budget pilot projects. *Ageing and Society*, vol. 34 (1), pp. 157–175.

Moriarty, J. (2014) Personalisation for People from Black and Minority Ethnic Groups. A Race Equality Foundation Briefing Paper. Available at: www.better health.org.uk/DP%20and%20Personalisation%20articles/basw_personalisation%20for%20BME.pdf. (Assessed: 15th July 21).

Moriarty, J., Sharif, N., and Robinson, J. (2011) SCIE Research briefing 35: Black and minority ethnic people with dementia and their access to support and services. Social Care Institute for Excellence. Available at: https://kclpure.kcl.ac.uk/portal/files/13501330/SCIE_briefing.pdf (Accessed: 27th September 2021).

Morin, R (2015) Exploring Racial Bias Among Biracial and Single-Race Adults: The IAT. PEW Research Centre. Available at:https://www.pewresearch.org/social-trends/2015/08/19/exploring-racial-bias-among-biracial-and-single-race-adults-the-iat/. (Accessed: 15th September 2021).

Morris, J. (1993) *Independent Lives? Community Care and Disabled People*. Basingstoke, Palgrave.

Morris, J., (2005). Citizenship and disabled people. report to the Disability Rights Commission [online]. [Online] http://www.leeds.ac.uk/disability-studies/archiveuk/morris/Citizenship_and_disabled_people_final.pdf (Accessed, 12th July 2020).

Mota, J. (2020) *On deconstructing and unlearning anti-Blackness in the Latinx community.* Available at: Remezcla. https://remezcla.com/features/culture/ unlearning-antiblackness-latino-latinx-community. (Accessed: 15th September 2021).

Moye, J., Karel, M.J., Gurrera, R.J. and Azar, A.R. (2006). Neuropsychological predictors of decision-making capacity over 9 months in mild-to-moderate dementia. *Journal of General Internal Medicine*, vol.21, pp.78-83.

Mukadam, N., Cooper, C., and Livingston, G. (2010). A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry*, vol.26(1), pp. 12-20. http://dx.doi.org/10.1002/gps.2484

Mukadam, N., Cooper, C., Basit, B., and Livingston, G. (2011, September). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics*, vol. 23(7), pp.1070–1077.

Mukadam, N., Cooper, C., Kherani, N., Livingston, G. A (2015) systematic review of interventions to detect dementia or cognitive impairment. International Journal Geriatric Psychiatry, vol. 30, pp. 32–45.

Muller, J. H. (1999) Narrative approaches to qualitative research in primary care. In: Crabtree B, Miller W, eds. *Doing qualitative research*. Thousand Oaks, CA: Sage, pp. 221–38.

Mullings, B. (1999). Insider or Outsider, Both or Neither: Some Dilemmas of Interviewing in a Cross-Cultural Setting. *Geoforum*, vol.30(4), pp.337-350.

Murphy, D, Loingsigh, Birnie, I., Bak. T. H. (2019) Bilingualism and dementia: how some patients lose their second language and rediscover their first. Available at: https://theconversation.com/bilingualism-and-dementia-how-some-patients-lose-their-second-language-and-rediscover-their-first-126631. (Accessed: 27th January 22.

Mwakasi, C. C., Hayes, C., Fulton, J., and Roberts, A. R (2019) A pilot qualitative study of dementia perceptions of Nigerian migrant caregivers, *International Journal of Africa Nursing Sciences*, vol. 10, pp.167-174.

Mwansa, N. (2021) Should we still be saying 'BAME' in 2021? Available at: https://www.standard.co.uk/insider/bame-acronym-poc-b73997.html. (Accessed on 17th July 2021).

Nascimento, L.D.S. and Steinbruch, F.K. (2019), "The interviews were transcribed", but how? Reflections on management research", RAUSP, *Management Journal*, vol. 54(4), pp. 413-429. https://doi.org/10.1108/RAUSP-05-2019-0092.

National Records of Scotland (2021) Deaths involving coronavirus (COVID-19) in Scotland. Online. https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/weekly-and-monthly-data-on-births-and-deaths/deaths-involving-coronavirus-covid-19-in-scotland. (Accessed: 21st Jan 22).

Naz, S., Gregory, R. and Bahu, M. (2019) "Addressing issues of race, ethnicity and culture in CBT to support therapists and service managers to deliver culturally competent therapy and reduce inequalities in mental health provision for BAME service users," *The Cognitive Behaviour Therapist*. Cambridge University Press, 12, p. e22. doi: 10.1017/S1754470X19000060.

Nazroo, J and Kapadia, D. (2013) *Ethnic inequalities in labour market participation. Dynamics of Diversity: Evidence from the 2011 Census*. ESRC Centre on Dynamics of Ethnicity, University of Manchester.

Nazroo, J. Y. (2003) The structuring of ethnic inequalities in health: Economic position, racial discrimination, and racism. *American Journal of Public Health*, vol. 93, pp.277–28.

Needham, C. (2011) *Personalising public services: Understanding the personalisation narrative.* Bristol: Policy Press.

Needham, C. and Glasby, J. (Eds.) (2014). *Debates in personalisation*. Bristol: Policy Press.

Needham. C. and Carr, S. (2009). SCIE Research briefing 31: co-production: an emerging evidence base for adult social care transformation. London: Social Care Institute for Excellence. Available from: **Error! Hyperlink reference not valid.**: 27th August 2021).

Netten, A., Jones, K., Knapp, M., Fernandez, J. L., Challis, D., Glendinning, C., Jacobs, S., Moran, N., Stevens, M. and Wilberforce, M. (2012) 'Personalisation through individual budgets: Does it work and for whom?', *British Journal of Social Work*, 42, pp. 1556–1573.

Netto, G., Sonko F. and Branley F. (2011) Poverty and Ethnicity in Scotland: Review of Literature and data sets. Available at: https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/poverty-ethnicity-Scotland-full.pdf. (12th June 2021).

Neville, H. A., Awad, G. H., Brooks, J. E., Flores, M. P., and Bluemel, J. (2013) Colorblind racial ideology: Theory, training, and measurement implications in psychology. *American Psychologist*, vol. 68, pp.455–466. doi: 10.1037/a0033282.

Newbigging, K. and Lowe, J. (2005) *Direct Payments and Mental Health: New Directions; Research into Practice*: Published for Joseph Rowntree Foundation by: Brighton; Pavilion Publishing Ltd.

Newbronner. L, Chamberlain. R, and Bosanquet. K. (2011) SCIE Report 40: *Keeping personal budgets personal:* Learning from the experiences of older people, people with mental health problems and their carers, London: Available at: SCIE www.scie.org.uk/publications/reports/report40/. Accessed: 15th December 2021).

NHS (2012) Think Capacity Think Consent: Supporting application of the Adults with Incapacity (Scotland) Act (2000) in Acute General Hospitals. Available at: https://www.nhs.uk/Capacity/dementia/NHS/Interactive/think/capacity/think/consent. (Accessed: 28th November 2020).

NHS Guiding Principles (2016) Principles and Values that Guide NHS Available at: http://www.nhs.uk/NHSEngland/thenhs/about/Pages/nhscoreprinciples.aspx accessed. (Accessed 10th July 2021).

NHS Health Scotland (2016) Health Inequalities: What are they? How do we reduce them? Available at: http://www.healthscotland.scot/media/1086/health-inequalities-what-are-they-how-do-we-reduce-them-mar16.pdf accessed (Accessed: 10th March 2021).

NHS Scotland (2016) Human rights and right to health: Health Inequalities, Available at: http://www.healthscotland.scot/publications/human-rights-and-the-right-to-health (Accessed, 19th July 2021).

Nielsen, T.R., Nielsen, D.S and Waldermar, G. (2020), Barriers in access to dementia care in minority ethnic groups in Denmark: a qualitative study. *Aging and Mental Health*, vol. 25(8), pp.1424-1432. DOI: 10.1080/13607863.2020.1787336.

Norberg, A. (2019) Sense of Self among Persons with Advanced Dementia. In: Wisniewski T, editor. Alzheimer's Disease [Internet]. Brisbane (AU): Codon Publications; Chapter 13. Available: https://www.ncbi.nlm.nih.gov/books/NBK552152/ doi: 10.15586/alzheimersdisease.2019.ch13. (Accessed: 23rd May 2020).

Nursing and Midwifery Council NMC-(2008) Nursing and Midwifery Council Code: *Standards of conduct, performance and ethics for nurses and midwives.* NMC, London.

O'Conner, D. and Nedlund, A. (2016) Editorial introduction: special edition on citizenship and dementia, *Dementia*, vol.15(3), pp.285–88.

O'Connor, D. (2016) Editorial introduction: Special issue on Citizenship and Dementia, *Dementia*. 15(3) pp. 285–288.

O'rourke, G. (2016) "Older People, Personalisation and Self: an alternative to the consumerist paradigm in social care," *Ageing and Society. Cambridge University Press*, 36(5), pp. 1008–1030. doi: 10.1017/S0144686X15000124.

Obach, B. K. (1999) Demonstrating the Social Construction of Race: Teaching Sociology. *American Sociological Association*, vol. 27 (3), pp. 252-257. https://doi.org/10.2307/1319325.

O'Connor, D., Mann, J., Wiersma, E. (2018) Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship, *Journal of Aging Studies*, vol, 44, pp. 45–51.

Ogliari, G., Turner, Z., Khalique, J., Gordon, A. L., Gladman, J.R.F, Chadborn, N.H. (2020) Ethnic Disparity in access to the memory assessment service between South Asian and White British Older Adults in the United Kingdom: A Cohort Study, *Inter. J. Geriatric. Psychiatry*, vol. 30 pp. 507-515. Doi:10.1002/gps.5263.

Oliver, D. G., Serovich, J. M., and Mason, T. L. (2005) Constraints and opportunities with interview transcription: Towards reflection in qualitative research. *Social Forces*, vol. 84, pp.1273–1289.https://doi.org/10.1353/sof.2006.0023.

Oliver, M. (1990) *The Politics of Disablement*, Basingstoke, Macmillan.

Oliver, M. (1996) *Understanding Disability from Theory to Practice*, Basingstoke, Macmillan.

Ortiz, L. and Jani, J. (2010). Critical Race Theory: A transformational model for teaching diversity. *Journal of Social Work Education*, vol. 46(2), pp.175-193.

Ostwald, S., Duggleby, W., Kenneth, R.N. and Hepburn, W. (2012) The stress of dementia: View from the inside, *American Journal of Alzheimer's Disease and Other Dementias*, vol, 17(5) pp, 303-312.

Ouseley, H. (2001) *Community Pride not Prejudice*, Bradford: Bradford Vision.

Palmer, D. and Ward, K. (2007) 'Lost': listening to the voices and mental health needs of forced migrants in London. *Medical Conflict Survival*, vol, 23, pp. 198–212.

Papadopoulos, I. (2006) Culturally competent research: a model for its development, in Nazroo J (ed.) *Health and Social Research in Multi-ethnic Societies*, Routledge, Abingdon.

Paradies, Y., J. Ben., N. Denson., Elias., A, Priest., N, Pieterse., A, Gupta., A, Kelaher., M. and Gee, G. (2015) Racism as a determinant of health: *A systematic review and meta-analysis. PLOS One* 10(9): e0138511.

Parker, L. and Lynn, M. (2002) What's race got to do with it? Critical race theory's conflicts with and connections to qualitative research methodology and epistemology. *Qualitative Inquiry*, 8(1), pp.7-22.

Parton. N (2003) Rethinking Professional Practice: The Contributions of Social Constructionism and the Feminist 'Ethics of Care' *British Journal of Social Work*, vol. 33, pp. 1-16.

Parveen, S., Barker, S., Kaur, R., Kerry, F., Mitchell, W., Happs, A., Fry, G., Morrison, V., Fortinsky, R. and Oyebode, J.R., (2018). Involving minority ethnic communities and diverse experts by experience in dementia research: the caregiving HOPE study. *Dementia*, vol.*17*(8), pp.990-1000.

Parveen, S., Oyebode., J. and Down, M. (2014) Exploring cross-cultural and country responses to dementia in new perspectives and approaches: A multifaith and cultural view. In (Eds. Bamford SM et al.). *A compendium of essays: New perspectives and approaches to understanding dementia and stigma.* London: ILC-UK (pp.37-41).

Parveen, S., Peltier M. A. and Oyebode, J. R. (2017) Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise, *Health and Social Care in the Community*, vol. 25(2), 734–742. doi: 10.1111/hsc.12363.

Patel, N. (2006) *Old Agenda, New Areas and Directions in Research and Development of Health and Social Inequalities faced by Europe's Growing Minority Ethnic Older Population*. Lancashire: Centre for Ethnicity and Health, University of Central Lancashire.

Patterson, M. (2010) 'Personalisation: What it means for providers', *Journal of Care Services Management,* vol. 4, pp.217–28.

Patton, M. Q. (2002) *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Payne, M. (1999) Social construction in social work action and practice. In A. Jokinen, K. Juhila, and T. Pösö (Eds.), *Constructing social work practices* (pp. 25–65). Aldershot, UK: Ashgate.

Payne, M. (2011) *Citizenship social work with older people*. Bristol: Policy Press.

Pearson, C, Watson, N, Manji, K. (2018) Changing the culture of social care in Scotland: Has a shift to personalization brought about transformative change? *Social Policy Administration*, vol. 52: pp.662– 676. https://doi.org/10.1111/spol.12352.

Pearson, C. (2000) 'Money talks? Competing discourses in the implementation of direct payments', *Critical Social Policy*, 20(4), pp. 459–77.

Pearson, C. (2004a) Keeping the cash under control: What's the problem with direct payments in Scotland? *Disability and Society,* 19(1), pp. 3-14. DOI: 10.1080/0968759032000155596.

Pearson, C. (2004b) The implementation of direct payments: issues for user-led organisations in Scotland, in Barnes, C. and Mercer, G. (eds.) (2004) *Disability Policy and Practice*: Applying the Social Model. Leeds: Disability Press.

Pearson, C. and Ridley, J. (2017) 'Is personalization the right plan at the wrong time? Re-thinking cash-for-care in an age of austerity', *Social Policy and Administration*, vol.51, pp.1042–1059. https://doi.org/10.1111/spol.12216.

Pearson, C., Barnes, C., Jolly, D., Mercer, G., Priestly, M., and Riddell, S. (2005). Personal Assistance Policy in the UK: What's the problem with direct payments? *Disability Studies Quarterly*, vol.25(1). Available at: Doi.10.18061/dsq.v25i1.525.http://www.dsq-sds.org/login.asp? referer /_articles_html/2005/winter/Pearson.asp. (Accessed 21st November 2021).

Petrie, S. (2015) 'Commodifying' children: the impact of markets in services for children in the United Kingdom. *International Journal of Child, Youth and Family Studies,* vol. 62, pp.275–294.

Pham, T. M., Petersen, I., Walters, K., Raine, R., Manthorpe, J., Mukadam, N. and Cooper, C. (2018). Trends in dementia diagnosis rates in UK ethnic groups: Analysis of UK primary care data. *Clinical Epidemiology,* vol.10, pp.949-960.

Philo, C. (1992) "Neglected Rural Geographies: A Review", *Journal of Rural Studies*, vol. 8 (2), pp. 193-207.

Phoenix, A. (2008) 'Analysing narratives in contexts', in Andrews, M., Squire, C. and Tamboukou, M. (eds) *Doing the narrative research*, London: Sage.

Plummer, K. (1995) *Telling Sexual Stories: Power, Change and Social Worlds*. London: Routledge

Plummer, K. (2001) 'The Call of Life Stories in Ethnographic Research', in P. Atkinson, A. Coffey, S. Delamont, J. Lofland and L. Lofland (eds) *Handbook of Ethnography*, pp. 395–406. London: Sage.

Podnieks, E. (2006). Social inclusion: An interplay of the determinants of health— New insights into elder abuse. *Journal of Gerontological Social Work*, vol, 46(3), pp. 57–79.

Pole, C. and Lampard, R. (2002), *Practical Social Investigation: Qualitative and Quantitative Methods in Social Research,* Harlow, Pearson.

Polit, D. F. and Hungler, B.P. (1995) *Nursing Research: Principles and Methods*. Philadelphia: Lippincott.

Polkinghorne, D. E. (1988) *Narrative Knowing and the Human Sciences*. Albany: University of New York Press.

Polkinghorne, D. E. (1995) Narrative configuration in qualitative analysis, in J. A Hatch and R. Winiewski (eds) *Life History and Narrative*. London: Falmer Press.

Pollock, S. (2021) More than words can say: Why health and social care policymakers should reconsider their position on informal interpreters. *Critical Social Policy*, vol. 41(1), pp.128-147. doi:10.1177/0261018320911819.

Potter J. 2003. *Representing reality: Discourse, rhetoric and social construction*. London: Sage.

Prawat, R. S., and Floden, R. E. (1994) Philosophical Perspectives on Constructivist Views of Learning. *Educational Psychologist*, vol.29 (1), pp. 37-48.

Priestley, M., Riddell, S., Jolly, D., Pearson, C., Williams, V., Barnes, C. and Mercer, G. (2010). Cultures of welfare at the front line: Implementing direct payments for disabled people in the UK. *Policy and Politics,* vol. 38, pp. 307–324.

Priniski, J. H., Mokhberian, N., Harandizadeh, B., Morstatter, F., Lerman, K., Lu, H. and Brantingham, P. J. (2021). "*Mapping Moral Valence of Tweets Following the Killing of George Floyd*". Available at: arXiv:2104.09578 [cs.SI. (Accessed: 16th September 2021).

Pritchard, E. J., and Dewing, J. (2001) A multi-method evaluation of an independent dementia care service and its approach. *Aging and Mental Health*, 5(1), pp.63–72.

Purandare, N., Luthra, V., Swarbrick, C. and Burns, A. (2007), Knowledge of dementia among South Asian (Indian) older people in Manchester, UK. International. Journal. Geriatric. *Psychiatry*, vol. 22, pp. 777–781.

QSR international (2016) WHAT IS NVIVO? Available at: http://www.qsrinternational.com/what-is-nvivo. (Accessed: 11th November 2019).

Qureshi, K., Hill, S., Meer N. and Kasstan, B. (2020) 'Covid-19 and BAME inequalities- The problem of institutional racism'. Available at: https://chpi.org.uk/blog/covid-19-and-bame-inequalities-the-problem-of-institutional-racism. Accessed: (29th September 2021).

Qureshi, R. (2020) Broad coalition of BME charities and anti-racist organisations: Cuts to BME charities in Edinburgh will have a devastating impact. Available at: https://www.thenational.scot/politics/18275574.cuts-bme-charities-edinburgh-will-devastating-impact/ (Accessed: 4th December 2021).

Rabiee, P. (2013) Exploring the relationships between choice and independence: experiences of disabled and older people. *British Journal of Social Work*, vol.43, pp.872–888.

Race Against Dementia Alliance. (2015) *Race against dementia: a call to action: good practice guidance*. London.

Rauf, A. (2011). *Caring for dementia: exploring good practice on supporting South Asian carers through access to culturally competent service provision*. Bradford: Meri Yaadain Dementia Team.

Ray, K. (2003) 'Constituting "Asian women": Political representation, identity politics and local discourses of participation', *Ethnic and Racial Studies*, vol,26(5), pp. 854–78.

REACH (2021) Resource Centre for Independent Living: What is Independent Living. Available at: https://www.reachcils.org/what-independent-living/ (Accessed: 4th Jan 2022).

Reid, D., Ryan, T., and Enderby, P (2001) What Does it Mean to Listen to People with Dementia? *Disability and Society*, vol.16(3), pp.377-392.

Reinharz, S. (1992) *Feminist Methods in Social Research*. Oxford: Oxford University Press.

Reybold, L. E, Lammert, J. D. and Stribling, S.M. (2013) Participant selection as a conscious research method: thinking forward and the deliberation of 'Emergent' findings. *Qualitative Research*. vol.13(6), pp.699-716. doi:10.1177/1468794112465634.

Riachi, R. (2017) Person-centred communication in dementia care: a qualitative study of the use of the SPECAL method by care workers in the UK, *Journal of Social Work Practice,* available at: DOI: 10.1080/02650533.2017.1381948. (Accessed: 16th November 2021).

Riddell, S., Baron, S. and Wilson, A. (2001). *The Learning Society and People with Learning Difficulties*. Bristol: Policy Press.

Ridley, J. and Jones, L. (2003) Direct What? The Untapped Potential of Direct Payments to Mental Health Service Users*, Disability and Society*, vol. 18, (5) pp. 643–658.

Ridley, J., Spandler, H., Rosengard, A., Little, S., Cornes, M., Manthorpe, J., and Gray, B. (2011). *Evaluation of self-directed support test sites in Scotland.* Edinburgh: Scottish Government Social Research.

Riessman, C, K. (2008) *Narrative methods for the human sciences*, London, Sage.

Riessman, C. K. (1990) Strategic uses of narrative in the presentation of self and illness: *A research note, Social Science and Medicine*, vol. 30 (11), pp. 1195-1200.

Riessman, C. K. (1993) *Narrative analysis.* London, UK: Sage.

Riessman, C. K. (2003) 'Performing Identities in Illness Narrative', *Qualitative Research,* vol.3(1), pp. 5–34.

Rivett, E. (2017), "Research involving people with dementia: a literature review", *Working with Older People*, vol. 21(2), pp.107-114.

Roberts, B. (2002) *Biographical Research: Understanding Social Research*. Buckingham. Open University Press.

Robertson, J. M. (2010). Making sense and finding meaning: comparing narratives of older people with dementia and carers about the quality of an ordinary life. PhD Thesis, School of Applied Social Science, University of Stirling. Available at: https://dspace.stir.ac.uk/handle/1893/2530. [Accessed, 18th August 2021].

Robertson, J. M. (2014) *Finding meaning in everyday life with dementia*: A case study. Dementia, vol. 13(4) pp. 525–543.

Robinson, E. (2002) "Should people with Alzheimer's disease take part in research?", in Wilkinson, H. (ed.) *The Perspectives of People with Dementia*, London, Jessica Kingsley Publishers.

Robinson, L., Tang, E., and Taylor, J.P. (2015). Dementia: Timely diagnosis and early intervention. *British Medical Journal*, vol.16;350:h3029.

Rodrigues, R. and Glendinning, C. (2015) Choice, Competition and Care – Developments in English Social Care and the Impacts on Providers and Older Users of Home Care Services. *Social policy and administration,* vol. 49(5), pp. 649–664. ISSN 0144–5596 DOI: 10.1111/spol.12099, John Wiley and Sons Ltd.

Roger, W. (2010) Revealing Socially Constructed Knowledge Through Quasi-Structured Interviews and Grounded Theory Analysis, *Journal of travel and tourism marketing*, vol, 5 (1) pp. 21-40.

Rokstad, A.M., McCabe, L., Robertson, J. M., Strandenæs, M. G., Tretteteig, S. and Vatne, S. (2019) Care for People with Dementia: A Qualitative Study Comparing Experiences from Norway and Scotland, *Dementia journal*, vol 18(4), pp.1393-1409.

Ronkainen, N. J., Watkins, I., and Ryba, T. V. (2016). What can gender tell us about the pre-retirement experiences of elite distance runners in Finland?: A thematic narrative analysis. *Psychology of Sport and Exercise*, vol.22 (1), pp.37-45. doi:10.1016/j.psychsport.2015.06.003.

Rosenthal, C.J., Martin-Matthews, A. and Keefe, J.M. (2007) Care management and care provision for older relatives amongst employed informal caregivers. *Ageing and Society*, vol, 27, pp. 755–778.

Rudes, J, and Guterman, J.T (2007). "The Value of Social Constructionism for the Counseling Profession: A Reply to Hansen." *Journal of counseling and development.* Vol. 85 (4), pp.387–392.

Rummery, K. (2006) Disabled citizens and social exclusion: the role of direct payments, *Policy and Politics, vol.* 34(4) pp. 633–50.

Rummery, K., (2009). A comparative discussion of the gendered implications of cash-for-care schemes: markets, independence and social citizenship in crisis? *Social policy and administration*, vol. 43 (6), pp. 634–648.

Sabat, S. R (2011) A Bio-Psycho-Social model enhances young adults' understanding of and beliefs about people with Alzheimer's disease: A case study. *Dementia.* Vol. 11(1), pp. 95–112.

Sabat, S. R. (2001) *The Experience of Alzheimer's Disease: Life Through a Tangled Veil.* Wiley-Blackwell, New Jersey.

Sabat, S. R. (2002) Surviving manifestations of selfhood in Alzheimer's disease: a case study, *Dementia*, vol. 14 (1) pp. 11–9.

Sabat, S. R. (2006) "Mind, meaning and personhood in dementia: the effects of positioning", in Hughes, J., Louw, S. and Sabat, S. (eds.) *Dementia: mind, meaning and the person*, Oxford, Oxford University Press.

Sabat, S. R. (2008) A bio-psycho-social approach to dementia, Available at: https://www.researchgate.net/publication/283413651_A_bio-psycho-social_approach_to_dementia, (Accessed: 22nd September 2021).

Sabat, S. R., and Harre´, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, vol.12, pp.443–461.

Sabat, S.R. (2019) Dementia Beyond Pathology: What People Diagnosed Can Teach Us About Our Shared Humanity. *Bioethical Inquiry, vol.* 16, 163–172. https://doi.org/10.1007/s11673-019-09899-0.

Saldana, J. (2013) *The coding manual for qualitative researchers*. London: Sage.

Salway, S. Allmark, P. Barley, R. Higginbottom. G. Gerrish, K. and Ellison, G. (2009), *Researching ethnic inequalities, Social Research Update*, vol. 58, pp. 1-4, University of Surrey, Guildford.

Samkange-Zeeb, F., Samerski, S., Doos, L., Humphris, R., Padilla, B. and Bradby, H. (2020) "It's the First Barrier" - Lack of Common Language a Major Obstacle When Accessing/Providing Healthcare Services Across Europe. *Frontiers in sociology*, 5, 557563. https://doi.org/10.3389/fsoc.2020.557563.

Samsi, K. and Manthorpe, J. (2011) 'I live for today': a qualitative study investigating older people's attitudes to advance planning', *Health and Social Care in the Community*, vol 19(1), pp. 52−59.

Samsi, K. and Manthorpe, J. (2020) Interviewing people living with dementia in social care research. Method Review. Available at: https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-methods-review_MR022. (Accessed: 26th January 2022).

Savickas, M. L. (2002). Career construction: A developmental theory of vocational behavior. In D. Brown and Associates (Eds.), *Career choice and development* (4th ed., pp. 149–205). San Francisco, CA: Jossey-Bass.

Scheurich, J.J. (1994), Validity. International Journal of Qualitative Studies, *Education*, vol. 9, pp.49-60.

Scholl, J. M, and Sabat, S.R. (2008) Stereotypes, stereotype threat and aging: Implications for the understanding and treatment of people with Alzheimer's disease. *Aging Society*, vol. 28(1), pp.103–30.

SCIE (2015) Social Care Institute of Excellence: Black and minority ethnic (BME) communities and dementia. Available at: http://www.scie.org.uk/dementia/living-with-dementia/bme/ (Accessed: 7th July 21).

SCIE. (2020) *When people with dementia refuse help*: Available at: https://www.scie.org.uk/dementia/living-with-dementia/difficult-situations/refusing-help.asp. (Accessed: 5th July 2021).

Scottish Executive (2007) *National guidance on self-directed support.* Edinburgh: Author.

Scottish Government (2010) *Self-directed support: A national strategy for Scotland*: Consultation. Edinburgh: Author.

Scottish Government (2014) Self-Directed Support four options. Available at: https://www.gov.scot/Topics/Health/Support-Social-Care/Support/Self-Directed-Support, (Accessed, 21st July 2020).

Scottish Government (2015) Adult with Incapacity. Available. http://www.gov.scot/Topics/Justice/law/awi. (Accessed: 23rd October 21.

Scottish Government (2015) Mental Health (Scotland) Act 2015 - Key provisions, Available at: http://www.gov.scot/Topics/Health/Services/Mental-Health/Law/2015Act-provisions, (Accessed: 21st May 18).

Scottish Government (2017) Self Directed Support. Available at: http://www.gov.scot/Topics/Health/Support-Social-Care/Support/Self-Directed-Support. 13/11/17. (Accessed: 21st July 2020).

Scottish Government (2017a) Scotland's National Dementia Strategy 2017-2020, Available at: http://www.gov.scot/Publications/2017/06/7735, (Accessed: 14th July 2021).

Scottish Government (2017b) My support My choice, Self- Directed Support. Available at: http://www.selfdirectedsupportscotland.org.uk/self-directed-support, (Accessed: 14th July 2021).

Scottish Government (2017c) Self Directed Support. Available at: http://www.gov.scot/Topics/Health/Support-Social-Care/Support/Self-Directed-Support. (Accessed, 16th July 2021).

Scottish Government (2017d) Equality Outcomes and Mainstreaming Report 2017. Available at: https://www.gov.scot/Publications/2017/04/4384 (Accessed: 28th July 2021).

Scottish Government (2021) Race Equality Action Plan: Final Report 2017/2021. Available at: https://www.gov.scot/publications/race-equality-action-plan-final-report/pages/7/. (Accessed: 21st July 2020).

Scottish Government (2021a) Dementia - health and social services staff: framework – Promoting Excellence 2021. Available: https://www.gov.scot/publications/promoting-excellence-2021-framework-health-social-services-staff-working-people-dementia-families-carers/. (Accessed: 9th September 2021).

Scottish Government (2021b) Mental Health Policy from Director-General health and social care. Available at: https://www.gov.scot/policies/mental-health/dementia/#:~:text=Consensus%20on%20overall%20estimated%20dementia,population%20in%20Scotland%20and%20growing. (Accessed: 9th September 2021).

Scottish Government. (2012), 'The reshaping care for older people: a programme for change 2011-2021', Available: http://www.gov.scot/Topics/Health/Support-Social-Care/Support/OlderPeople/Reshaping Care. (Accessed: 21st July 2021).

Scourfield, P. (2005) 'Implementing the Community Care (Direct Payments) Act: Will the supply of personal assistants meet the demand and at what price?', *Journal of Social Policy*, vol.34(3), pp. 1–20.

Scourfield, P. (2007) Social Care and the Modern Citizen: Client, Consumer, Service User, Manager and Entrepreneur, *British Journal of Social Work*, vol.37, pp.107–122 doi:10.1093/bjsw/bch346.

Segre, S. (2016) Social Constructionism as a Sociological Approach, *Humanities Studies*,vol 39, pp.93–99. DOI 10.1007/s10746-016-9393-5.

Shah, A. (2010) Access to services for older BME patients. *British Journal of Healthcare Management,* vol. 17 (12) pp. 274-282.

Shakespeare, Tom. 2006. "*The Social Model of Disability.*" In The Disability Studies Reader, ed. Lennard Davis, New York: Routledge, (2d ed.), pp.197–204.

Sherwood-Johnson, F., Mackay, K. and Greasley-Adams, C. (2021): Negotiating safety and vulnerability in everyday life: perspectives of UK older people from participative research, European Journal of Social Work, DOI: 10.1080/13691457.2021.1882397.

Shukla, N., Wilson, E. and Boddy, J. (2014) Combining thematic and narrative analysis of qualitative interviews to understand children's spatialities in A. P, India. *Working Paper*. National Centre for Research Methods, Southampton.

Silverman, D. (2001) *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*, (2nd ed.), London, Sage.

Silverman, D. (2005) *Doing Qualitative Research*, (2nd ed.), London, Sage.

Singh, S. (2021) Independent Investigation into Alleged Discrimination Citing Protected Characteristics within the Conservative and Unionist Party in England, Wales and Northern Ireland. Available at: https://singhinvestigation.co.uk/wp-content/uploads/2021/06/Singh_Investigation_Report (Accessed: 15th July 2021).

Sipe, L.R and Ghiso, M.P (2014) Developing Conceptual Categories in Classroom Descriptive Research: Some Problems and Possibilities. *Anthropology and Education Quarterly,* vol, 35 (4) pp. 472-485. Published By: Wiley.

Sivanandan, A. (2006) Race, Terror and Civil Society 'in *Race and Class'*, vol.47 (3), pp.1-8.

Skaggs, S. L. (2009) Labeling Theory: Sociology. *Britannica*. Assistant Professor. Available at: https://www.britannica.com/topic/labeling-theory. (Accessed: 07th September 21).

Skeggs, B. (2002) '*Techniques for Telling the Reflexive Self', in T. May (ed.) Qualitative Research in Action*, pp. 349–74. London: Sage.

Smebye, K. L., and Kirkevold, M. (2013). The influence of relationships on personhood in dementia care: a qualitative, hermeneutic study. *BMC nursing*, vol.12(1), pp.12-29. https://doi.org/10.1186/1472-6955-12-29.

Smith, S., Gilbert, S., Ariyo, K. Arundell L. L., Bhui, K., Das-Munshi, J., Hatch, S., and Lamb, N. (2020) Multidisciplinary research priorities for the COVID-19 pandemic. *The Lancet Psychiatry*, vol 7 (7): pp. 40-52.

Social Work (Scotland) Act 1968: Available at: https://www.legislation.gov.uk/ukpga/1968/49/contents, (Accessed: 23rd July 2021).

Social Work Policy Institute (2014) *Achieving racial equity: Calling the social work profession to action.* Washington, DC: National Association of Social Workers.

Solórzano, D. G. and Yosso, T.J. (2002) Critical race methodology: Counter-story-telling as an analytical framework for education research. *Qualitative Inquiry*, vol. 8(1), pp. 23-44.

Spandler, H. (2004) 'Friend or foe? Towards a critical assessment of direct payments', *Critical Social Policy*, vol. 24(2), pp. 187–209.

Spandler, H. and Vick, N. (2005) 'Enabling access to direct payments: An exploration of care co-ordinators' decision-making practices', *Journal of Mental Health*, 14(2), pp. 145–55.

Spanierman, L. B., Clark, D. A, and Kim, Y. (2021). Reviewing racial microaggressions research: Documenting targets' experiences, harmful sequelae, and resistance strategies. Perspectives on Psychological Science, 16(5), pp.1037-1059.

Spector, A. and Orrell, M. (2010) Using a biopsychosocial model of dementia as a tool to guide clinical practice, *International journal Psychogeriatrics*, vol.22(6), pp.957–965.

Spector, M, and Kitsuse, J.I. (1977) *Constructing social problems.* Menlo Park, CA: Cummings.

Spector, M. and Kitsuse, J. (1987) *Constructing social problems.* Hawthorne, NY: de Gruyter.

Stainton, T. and Boyce, S. (2004) '"I have got my life back": Users' experience of direct payments', *Disability and Society*, 19(5), pp. 443–54.

Stead, G. B. (2004). Culture and career psychology: A social constructionist perspective. *Journal of Vocational Behavior,* vol.64, pp. 389–406. doi:10.1016/j.jvb.2003.12.006.

Steeman, E., Godderis, J., Grypdonck, M., De Bal, N. and Dierckx de Casterle, B. (2007) Living with dementia from the perspective of older people: is it a positive story? *Aging and Mental Health*, vol. 11(2), PP. 119–30.

Stevens, M., Glendinning, C., Jacob, S. et al. (2011) Assessing the role of increasing choice in English social care services. *Journal of Social Policy*, vol. 40 (2), pp.257–274.

Stevens, M., Woolham, M., Manthorpe, J., Aspinall, F., Hussein, S., Baxter, K., Samsi, K. and Ismail, M (2016) Implementing safeguarding and personalisation in social work: Findings from practice, *Journal of Social Work*, vol, 18, (1), pp. 3 –22.

Stewart-Archer, L. A, Afghani, A. Toye, C. M. and Gomez, F. A. (2016) Subjective quality of life of those 65 years and older experiencing dementia. *Dementia*, vol. 15: pp. 1716–36.

Stokes, G. (2000) *Challenging behaviour in dementia. A person-centred approach*. Oxon: Winslow.

Strauss, A., and Corbin, J. (1998) *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.

Stronach I, Garratt D, Pearce C, and Piper, H. (2007) Reflexivity, the Picturing of Selves, the forging of method. Qualitative Inquiry, vol.13(2), pp.179–203.

Stuart, O. (2006) *Will community-based support services make direct payments a viable option for Black and Minority Ethnic service users and carers? Stakeholder Participation.* Race Equality Discussion Paper 1 Social Care Institute for Excellence SCIE.

Subramaniam, B. (2014). *Ghost Stories for Darwin: The Science of Variation and the Politics of Diversity*. Urbana-Champaign: University of Illinois Press.

Subramaniam, H., Mukaetova-Ladinska, E.B., Wilson, A., Bankart, J. (2020) Representation of Black, Asian and minority ethnic patients in secondary care mental health services: analysis of 7-year access to memory services in Leicester and Leicestershire. *British Journal Psych Bulletin*, vol. 44, pp.145–152, doi:10.1192/bjb.2020.

Surr, C.A. (2006) 'Preservation of self in people with dementia living in residential care: a socio-biographical approach', *Social Science and Medicine*, vol. 62(7), pp.1720−1730.

Swaffer, K. (2014). Dementia: Stigma, language, and dementia-friendly. *Dementia*, vol.13(6), pp. 709–716.

Sweeting, H. and Gilhooly, M. (1997) Dementia and the phenomenon of social death, *Sociology of Health and Illness*, vol.19 (1), pp.93–117.

Szczepura, A. (2005) Access to healthcare for ethnic minority populations, *Postgraduate Medical Journals,* vol. 8 (953) pp. 141-147. The University of Warwick.

Tabassum, R., Macaskill, A. and Ahmad. I. (2000) Attitudes towards mental health in an urban Pakistani community in the United Kingdom. *International Journal Socio Psychiatry*, vol 46, pp.170–81.

Tajfel, H., Turner, J. C., Austin, W. G., and Worchel, S. (1979). *An integrative theory of intergroup conflict*. Organizational identity: A reader, 56-65.

Taylor, E. (1998) A primer on critical race theory. *The Journal of Blacks in Higher Education*, vol.19, pp.122-124.

Tell MAMA. (2020) The Impact of Christchurch Terror Attack; Interim Report. Available at: https://www.tellmamauk.org/wp-content/uploads/2020/03/The-Impact-of-the-ChristChurch-Attack-Tell-MAMA-Interim-Report-2019. (Accessed: 15th July 2021.

Terashima, S. (2011) Personalisation of care for people from South Asian communities Learning, *Disability Practice*, vol (14), pp. 2-17.

Terkelsen, A. S., Petersen, J. V., and Kristensen, H. K. (2020) Mapping empirical experiences of Tom Kitwood's framework of person-centred care for persons with dementia in institutional settings. A scoping review. *Scandinavian Journal of Caring Science*, vol. 34; pp. 6–22. doi: 10.1111/scs.1270.

The Adult Support and Protection (Scotland) Act 2007, Available: http://www.gov.scot/Publications/2007/07/04093127/22 , (Accessed: 10th May 2021).

The Adult with Incapacity Act (Scotland) 2000, Available at: https://www.legislation.gov.uk/uksi/2005/1790/contents/made, accessed, (Accessed: 11th August 21].

The Carer (Scotland) Act 2016, Available at: https://www.legislation.gov.uk/all?title=carers%20act, (Accessed: 10th May 2021).

The Community Care (Direct Payments) (Scotland) Amendment Regulations 2007, available at: http://www.gov.scot/Publications/2007, (Accessed, 10th May 2020).

The Community Care (Direct Payments) (Scotland) Amendment Regulations 2005, online, http://www.gov.scot/Publications/2005, (Accessed, 10th May 2020).

The Community Care (Direct Payments) (Scotland) Regulations 2003, online, http://www.gov.scot/Publications/2003. (Accessed, 10th May 2020).

The Direct Payments Act 1996, Available at: https://www.legislation.gov.uk/uksi/1997/756/contents/made, (Accessed: 5th May 2021).

Toofany, S. (2006) Cultural Competencies, *Journal of nursing older people*, vol 18 (7), pp. 14-18.

Trevithick, P. (2005) *Social Work Skills: A practice Handbook*, (2nd ed), England, Oxford University Press.

Truchado, B. E., Pulido S, P., Sancho, M. and Peña, G. F. (2020) Being an active citizen and the elderly: Old concepts, new approaches. A systematic review and qualitative meta-synthesis. *Revista Española de Geriatría y Gerontología*, vol. 55(5), pp. 289-299. Spanish. doi: 10.1016/j.regg.2020.01.001. Epub 2020 Apr 8. PMID: 32278536.

Tsang, K.K and Kwong, T. L. (2017) Teachers' emotions in the context of education reform: labor process theory and social constructionism, *British Journal of Sociology of Education*, vol.38(6), pp.841-855, DOI: 10.1080/01425692.2016.1182007.

Tuerk, R. and Sauer, J. (2015) Dementia in a Black and minority ethnic population: Characteristics of presentation to an inner London memory service. *British Journal of Psychiatry*. Bulletin, vol. 39, 162–166.

Turner, K. and Kelly, B. (2000) Emotional dimensions of chronic disease. *Western Journal of Medicine*, vol. 172 (2), pp. 124-128.

Turner, S., Christie, A. and Haworth, E. (2005) 'South Asian and white older people and dementia: a qualitative study of knowledge and attitudes', *Diversity in Health and Social Care*, vol 2(3), pp.197−209.

Tyrrell, J., Genin, N. and Myslinski, M. (2006) Freedom of choice and decision-making in health and social care Views of older patients with early-stage dementia and their carers.

Ud-Din, A. (2010) *Black and Ethnic Minority Older People Changing Care Needs*: A case study on lifestyle changes affecting access to care in Bradford. Available at: http://www.futureyears.org.uk/uploads/files/FINAL%20-%20BMEOlder%20Peoples%20Changing%20Care%20Needs%20-%20Adnan__s%20report%20-%20Nov%2010%20PDF.pdf. (Accessed: 11th July 2021).

Vandrevala, K., Samsi C., Rose, C., Adenrele, C., Barnes, H. and Manthorpe, J. (2017) Perceived needs for support among care home staff providing end of life care for people with dementia: *A qualitative study*, vol,32 (2), pp. 155-163.

Venneri, A., and Malik, B. (2014). Assessing mental status in Pakistanis living in the UK: A comparison of two different Urdu versions of the MMSE. Alzheimer's and Dementia: *The Journal of the Alzheimer's Association*, vol. 10, pp. 433–P434.

Vernon, A. (2002) *Users' Views of Community Care for Asian Disabled People*. York, Joseph Rowntree Foundation.

Vertovec, S. (1996) 'Multiculturalism, culturalism and public incorporation', Ethnic and Racial Studies, vol, 19 (1), pp. 49–69.

Walter, A.W., Ruiz, Y., Welch, R., Tourse, C., Kress, H., Morningstar, B., MacArthur, B and Daniels, D (2017) Leadership Matters: How Hidden Biases Perpetuate Institutional Racism in Organizations, Human Service Organizations: *Management, Leadership and Governance*, vol, 41 (3), pp. 213-221.

Wang, B. (2016). "The Social and Historical Construction of Social Constructionism: Prof. KJ Gergen in Dialogue." *Culture and psychology*, vol. 22 (4) pp. 565–573.

Ward, R., Clark, A., Campbell, S., Graham, B., Kullberg, A., Manji, K., Rummery, K. and Keady, J. (2018) The lived neighbourhood: understanding how people with dementia engage with their local environment. *International Psychogeriatrics*, vol.30, pp.867–880.

Ware, P. (2017) Capacity Building with BME groups in Craig G (2017) *Community Organising Against Racism 'Race' ethnicity and community development.* Bristol. Policy Press.

Webb, S. A. (2006) *Social Work in a Risk Society*. Basingstoke, UK: Palgrave Macmillan.

Weller, B. (1991) Nursing in a multi-cultural world. *Nursing Standard*, vol. 5 (30), pp. 31–2.

Werner, P., Goldstein, D., Karpas, D. S., Chan, L. and Lai, C. (2014) Help-seeking for dementia: A systematic review of the literature. Alzheimer Disease and Associated Disorders, vol. 28(4), pp. 299–310.

West, E., Nair, P. Barrado-Martin, y., Walters, K.R., Kupeli, N., Sampson, E.L. and Davies., N (2021) Exploration of the impact of the COVID-19 pandemic on people with dementia and carers from black and minority ethnic groups. *British Medical Journal*; 11: e050066. doi:10.1136/bmjopen-2021-050066.

Whitaker, R., Ballard, C., Stafford, J., Orrell, M., Moniz-Cook, E., Woods, R. T. and Fossey, J. (2013). Feasibility study of an optimised person-centred intervention to improve mental health and reduce antipsychotics amongst people with dementia in care homes: Study protocol for a randomised controlled trial. *Trials*, vol.14 (13), pp. 1–10.

White, M. and Epston, D. (1990) *Narrative means to therapeutic ends*. New York: Norton.

Whittaker, S, Hardy, G, Lewis, K, Buchan L. (2005) An exploration of psychological well-being with young Somali refugee and asylum-seeker women. *Clinical Child Psychology Psychiatry*, vol. 10(2), pp. 177–96.

WHO (2017) Global action plan on the public health response to dementia 2017–2025. Available: https://www.who.int/publications/i/item/9789241513487, (Accessed: 23rd Nov 2020).

Wilkinson, H. (2002) *Including people with dementia in research. The perspectives of people with dementia: Research methods and motivations*, pp.9-25. London: Jessica Kingsley.

Wilkinson, R.G. (2005) *The impact of inequality: how to make sick societies healthier*. Routledge, London.

Williams, P. J. (1991) *The Alchemy of Race and Rights*: Diary of a Law Professor.

Williams, V., Porter, S. and Marriott, A. (2014) Your life, your choice: support planning led by disabled people's organisations. *British Journal of Social Work*, vol. 44, pp.1197–1215.

Wilson, A., Bankart, J., Regen, E., Phelps, K., Agarwal, S., Johnson, M., Raghavan, R. Sitaram, B., and Subramaniam, H. (2020) Ethnic variations in referrals to the Leicester memory and dementia assessment service, 2010 to 2017. *British Journal Psych Open*, vol. 6, e83, pp.1–6. doi: 10.1192/bjo.2020.6.

Woods, R. (2001) Discovering the person with Alzheimer's disease: Cognitive, emotional and behavioural aspects. *Aging and Mental Health*, vol. 5 (1) pp. 7-17.

Woolham J and Benton C (2013) The costs and benefits of personal budgets for older people: evidence from a single local authority. *British Journal of Work*, vol. 43, pp.1472–1491.

Woolham, J., Daly, G., Sparks, T., Ritters, T and Steils, N. (2017) Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment. *Ageing and Society*, 37, pp. 961-984.

Yasmin-Qureshi, S. and Ledwith. S (2021) Beyond the barriers: South Asian women's experience of accessing and receiving psychological therapy in primary care. *Journal of Public Mental Health*, vol 20(1), pp.3-14.

Young, R. A, and Collin, A. (2004). "Introduction: Constructivism and Social Constructionism in the Career Field." *Journal of vocational behavior*, vol, 64 (3). pp. 373–388.

Young, R. A. and Collin, A. (2004). Introduction: Constructivism and social constructionism in the career field. *Journal of Vocational Behavior*, vol,64, pp. 373–388. doi:10.1016/j.jvb.2003.12.005.

Young, R. A. and Popadiuk, N. E. (2012) social constructionist theories in vocational psychology (chapter 2) in P. McIlveen, D. E. Schultheiss (Eds.), *Social Constructionism in Vocational Psychology and Career Development*, 9–28.

Yull, D., Blitz, L. V., Thompson, T., and Murray, C. (2014). Can we talk? Using community–based participatory action research to build family and school partnerships with families of color. *The School Community Journal*, vol.24(2), pp. 9–31.

Zaheer, M. (2021) Defining Islamophobia Is the First Step Toward Addressing It In the United Kingdom, Islamophobia is on the rise, but existing anti-racist measures are not equipped to deal with it. Available at: https://foreignpolicy.com/2021/01/29/islamophobia-united-kingdom-anti-racist-definitions/ (Accessed: 15th July 2021).

Zimmermann, M. (2017) Alzheimer's Disease Metaphors as Mirror and Lens to the Stigma of Dementia, *Literature and Medicine*, vol.35 (1), pp. 71–97.

Zamir, S., Allman, F., Hennessy, C.H., Haffner, A, Taylor, A.H and Jones, R. (2021) Aesthetically Designing Video-Call Technology With Care Home Residents: A Focus Group Study. Frontiers Psychol. 12:540048, https://doi.org/10.3389/fpsyg.2021.540048. Available at: https://www.frontiersin.org/articles/10.3389/fpsyg.2021.540048/full, (Accessed: 12th Dec 2021).

APPENDICES

APPENDIX 1: ETHICS FORM

Mary Njoki
Faculty of Social Sciences
University of Stirling
FK9 4LA
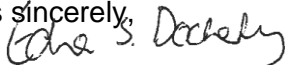
26 November 2018

Dear Mary

Re: Experiences of black and minority ethnic people with dementia in receipt of direct payments – GUEP537

Thank you for making the requested revisions to your submission of the above to the General University Ethics Panel. I am pleased to confirm that your application now has ethical approval.

Please note that should any of your proposal change, a further submission (amendment) to GUEP will be necessary.

Please ensure that your research complies with the University of Stirling policy on storage of research data http://www.stir.ac.uk/is/researchers/data/afteryourresearch/

If you have any further queries, please do not hesitate to contact the Committee by email to guep@stir.ac.uk

Yours sincerely,
Pp

On behalf of GUEP
Dr William Munro
Deputy Chair of GUEP

FACULTY OF SOCIAL SCIENCES

UNIVERSITY OF STIRLING

STIRLING

FK9 4LA

Hello, my name is Mary Njoki. I am a PhD student at the University of Stirling. You are being invited to take part in a research study. Before you decide to participate, it's important you understand why the research is being done. Please take your time to read the following information.

Aims and Objectives

In this research, I aim to talk to people from a Black or Minority Ethnic background with dementia or memory problems.

I also aim to talk to anyone with dementia and receiving direct payments regardless of background.

I would like to hear your story and experiences of the benefits and challenges of receiving support and especially if you receive Direct Payments. I am interested in your reasons for choosing this method of service delivery for example direct payments or a direct service from the council or family providing support.

I am hoping that what I find out could contribute to informing those who make decisions within the government and within the local services in order to contribute to the improvement of services to other people like yourself.

I hope that by sharing your experiences it will provide a valuable understanding to services for people with dementia.

This research also aims to contribute to new knowledge in this area

The project involves interviews with:

1.   People from Black and Minority Ethnic background with dementia or memory problems.

2.   Anyone from any background with dementia receiving Direct Payment
3. Carers supporting someone with dementia or memory problems from BME background.
4. Staff members who are involved in organising and providing Direct Payment support to someone like yourself.

What will happen if I take part?

The interview will take approximately 1 hour. The interview will take place at your home or another setting of your choice such as the care provider's office. All the information provided will be kept anonymous and your real name will not be used in the final report. If you feel at all uncomfortable to answer any question, please feel free not to answer without giving any explanation. If you want to discontinue the interview at any point that would be perfectly fine and you can withdrawal from the study without explaining your reasons.

All participants are required to sign the consent form provided or give verbal consent that will be recorded. This is to show that you understand the purpose of the study, your right to withdraw and that the information provided is not passed to any other person without informing you. However, if you disclose

any information which may cause concern, for example, the possibility of causing harm to yourself or another individual this will be passed on to my supervisor and further action could be taken if required, but I would make you aware of this if this was to happen.

The interview will be audio recorded, and I am requesting your permission for this to take place. If you prefer for this not to happen, please let me know and I will take notes instead. The recording is to help me understand what you are saying without missing anything. The audio-recorded information will be destroyed after I have written it down.

Any services you receive will not be affected by participating in this study.

This research will be written up for the purpose of my PhD thesis which will be read by examiners from the University of Stirling and an external examiner. A copy will also be held in a public domain in the Stirling physical and e-library. There may be further publications and presentations from this research. All names and identifiable details will be anonymised in any published output. However, I will be asking for your permission to use direct quotes in the thesis and future publications.

This research is funded by ESRC and they may require that all data derived

from a research project that they have funded be archived in the UK data archive so that it can be used for secondary data analysis. The data collected may be achieved but will all be anonymised before this happens.

If you would like to obtain further information about the study you may contact me through the e-mail mary.njoki1@stir.uk and I will be happy to answer any questions you may have. You can also call me on Tel: 07958195375: If you have any concerns or issues about my work, you can contact my supervisor: Louise McCabe, Tel: 01786 466317, email: louise.mccabe@stir.ac.uk

Yours grateful,

Mary Njoki- Research Student

APPENDIX 3: A SAMPLE OF WRITTEN CONSENT FORM: PRACTITIONERS AND STAKEHOLDERS

WRITTEN CONSENT FOR PRACTITIONERS AND STAKEHOLDERS

UNIVERSITY of STIRLING

**E·S·R·C
ECONOMIC
& SOCIAL
RESEARCH
COUNCIL**

FACULTY OF SOCIAL SCIENCES

UNIVERSITY OF STIRLING

WRITTEN INFORMED CONSENT

RESEARCH TOPIC: EXPERIENCES OF BLACK AND MINORITY ETHNIC PEOPLE WITH DEMENTIA IN RECEIPT OF DIRECT PAYMENTS.

This consent form is to reassure the researcher that you understand the purpose of the research is about and what your participation involves. By signing the consent form you understand that the statements below refer to the current research and potential future publications and presentations.

CONTENT	PLEASE INITIAL
I understand what the research is about and what my participation involves from the information provided by the researcher.	
I have had the opportunity to ask the researcher any question regarding the information provided.	
I agree that the researcher will use some of the interview content or direct quotations from the interview in writing her thesis, in academic publications or other outputs such as summary reports and presentations	
I agree to my interview being audio-recorded.	
I understand that the researchers will destroy any recordings of my interview after writing it down and will keep this written record of what I said for the duration of study.	
I understand that the researchers will follow the University of Stirling's policies for storing information about me and keeping it safe.	
I understand the consent forms will be stored in a locked cabinet for the duration of the research and will be destroyed after PhD thesis is	

submitted and any correction done. They will not kept past two years post submission.	
I agree that the researcher can take notes if needed	
I understand that my participation is voluntary, and I can withdraw at any stage without explanation.	
I understand that my information will be kept confidential unless I disclose any information that might be concerning or likely to put anyone at risk of harm she is obliged to discuss this disclosure with her supervisor and take any necessary further action, but she will notify me before this happens.	
I understand that my work will not be affected by participating in this study.	

Participant Name: _____

Signature:_____

Date: ___/___/___

Researchers Name: _____

Signature:_____

Date: ___/___/___

APPENDIX 4: RECRUITMENT POSTER

My name is Mary Njoki, I am a PhD student at Stirling University.

I am currently looking for people to interview for my research.

Research Invitation

DO YOU

- HAVE MEMORY PROBLEMS OR DIAGNOSIS OF DEMENTIA? AND
- DO YOU IDENTIFY AS BLACK AND MINORITY ETHNIC COMMUNITY? ALSO, PEOPLE FROM EAST EUROPEAN, MIDDLE EAST. OR
- DO YOU RECEIVE DIRECT PAYMENTS FROM THE COUNCIL AND HAVE DEMENTIA REGARDLESS OF BACKGROUND? OR
- SUPPORT SOMEONE WITH DEMENTIA?
- HAVE SOMETIME TO TALK TO ME FOR 30MIN-1HOUR?
  REASONS FOR THIS RESEARCH

My research is exploring the experiences of people from Black and Minority Ethnic (BME) communities with dementia or memory problems who use Direct Payments. Also, anyone with dementia using Direct Payments. I am interested in why people choose Direct Payments and the benefits and challenges of this for people with dementia. I hope that the research will help improve how Direct Payments are delivered. If you are BME person and have dementia but do not have DP its fine

If interested, please get in touch with me with contact details below

_____

Interview will take about 45 mins-1 hour

_____

The information you provide will be kept anonymous

_____

Thank you very much

CONTACT DETAILS

Mob: 07958195375

Mary.njoki1@stir.ac.uk

UNIVERSITY of STIRLING

E·S·R·C
ECONOMIC
& SOCIAL
RESEARCH

APPENDIX 5: LOCAL AUTHORITY ACCESS LETTER

Dear (Local Authority Research Representative),

I am a doctoral researcher from the University of Stirling and my research is titled: Experiences of black and minority ethnic people with dementia in receipt of direct payments.

My research is motivated by my experiences from practice when I realised that people from BME communities sometimes struggle in finding services that meet their specific needs especially those needs that are culturally sensitive. Some had tried Direct Payments with great results while others it did not work for them. This motivated me to research this area with the aim of better understanding and bringing in insights from people's experiences since it is under researched area here in Scotland.

This project aims to explore if DP is an effective and culturally sensitive response to meeting the specific challenges currently faced by BME people with dementia. It is intended that the research findings will contribute to informing policy makers and practice in planning, delivery and evaluation of DP to BME people. It is also aimed that by giving the participants a space to express their voice it will provide valuable insights into how they experience, receive and perceive personalised support. This research aims to contribute to new knowledge and move forward the current scholarly debates around the future for DP in relation to meeting the needs of BME people with dementia in Scotland.

In order to achieve these aims, this research will use qualitative research methods with a narrative approach to collect data that allows exploration of the experiences of the participants. The narratives will then be analysed using narrative and thematic analysis to gain insights and understanding of the individual's lived experiences.

I am writing to request permission to approach practitioners mainly social workers in your local authority for participation in this study. The practitioners must have been involved in either assessing, setting up or reviewing a direct payment package in the last 12 months. Subject to your approval and individual social workers contacting me I will provide them with a letter of informed consent, informing them of what the research is about and what their participation would involve. See the attached information sheet and informed consent that will be passed on to the staff member.

Great efforts will be made to interview the staff at a time that is convenient for their caseload to reduce any disruption to their duties, for example, if a staff member is on duty they wouldn't be expected to be taking part. All data generated in this study will be completely confidential and anonymous and I will not be requesting to see any confidential information from the council system or server. Feedback from the research will be given to any member of staff who would like to know the outcome which will be completely anonymous. The member of staff will be drawing from experience and therefore the person in reference will not be asked to meet me. This study has already been subjected to the University of Stirling Ethics Panel.

If you would like further information about the research, I would be pleased to answer any questions and can be contacted on phone number or email provided. I look forward to hearing from you.

Telephone: 07958195375

Email: mary.njoki1@stir.ac.uk

Yours sincerely,

Mary Njoki

APPENDIX 6: DEBRIEF

PARTICIPANT DEBRIEFING SHEET FOR PEOPLE WITH DEMENTIA/ MEMORY PROBLEMS AND CARERS.

Thank you for participating in this research project

1. **Research Project Title**: Experiences of black and minority ethnic people with memory problems in receipt of direct payments.
2. **Background aims of the project**: This qualitative research will examine the experiences of Black and Minority Ethnic people with memory problems who are receiving Direct Payments.

Direct Payments is one method of delivery of self-directed support. They are aimed at offering choice, control, autonomy and flexibility. This is a major Scottish Government agenda in meeting people's diverse care needs.

The Scottish Government recognises the need for person-centred care that is flexible and meets the needs of people with memory problems as the numbers of people experiencing this problem continues to increase and there are demographic changes too with Black and Minority Ethnic people living in Scotland.

This research will approach the study from Black and Minority Ethnic people's perspective. Many do not access services and are generally under-represented in services for all sort of different reasons. The research aims to explore some challenges, barriers and benefits for Black and Minority people with memory problem accessing Direct Payments.

3. **The legal basis for processing personal data**
As part of the project, I collected personal data relating to you. This will be processed in accordance with the General Data Protection Regulation (GDPR). Under GDPR the legal basis for processing your personal data will be public interest/the official authority of the University.
All your personal data will be anonymised.

4. **What happens to the data I provided?**
The research data will be kept anonymously using pseudonyms.
Your personal data will be kept for the duration of the study which is due to be completed by 30/09/21 and will then be securely destroyed. Any information archived is what will be published in the PhD thesis and journal articles, but you will not be identifiable from any of these publications. All recorded information will also be erased from the digital recorder and from any encrypted device it is saved on.

Will the research be published?
The University of Stirling is committed to making the outputs of research publicly accessible and supports this commitment through their online open access repository STORRE. Unless funder/publisher requirements prevent the university, this research will be publicly disseminated through university open access repository. The funder may require the anonymised transcripts to be uploaded on an online data storage facility and this data be re-used by me or other researchers. Let me know if you object to this.

5. **Your rights**
You have the right to request to see a copy of the information we hold about you and to request corrections or deletions of the information that is no longer required.
You have the right to withdraw from this project at any time

6. Contact Details

Once again, I would like to thank you for your participation and remind you that if you have any questions about the research or any queries you wish to raise, please feel free to contact me via email at mary.njoki1@stir.ac.uk or telephone me on 07958195375

You have the right to lodge a complaint against the University regarding data protection issues with the Information Commissioner's Office (https://ico.org.uk/concerns/).

The University's Data Protection Officer is Joanna Morrow, Deputy Secretary. If you have any questions relating to data protection these can be addressed to data.protection@stir.ac.uk in the first instance.

APPENDIX 7: RESEARCH QUESTIONS SCHEDULE

QUESTION GUIDE FOR THE PARTICIPANTS WITH DEMENTIA

1. Tell me about yourself? Tell me a bit about your childhood?
2. How do you spend your time on day to day/What sort of things do you do?
3. How long have you had dementia/memory problems?
4. How does dementia/memory problems affect your life?
5. What support do you receive to help you manage on day to day?
6. What do you know about Direct Payments?
7. What made you decide to choose Direct Payments as a form of your service delivery?
8. How much did you know about Direct Payment prior to receiving them?
9. What support do you have in place for managing the Direct Payments?
10. What benefits have you experienced using Direct Payments?
11. What has been the difficulties for using direct payments?
12. What are the specific benefits do you think Direct Payments offer people with dementia from Black Minority Ethnic background?
13. What do you think could improve the option of Direct Payments for you and others?

QUESTION GUIDE FOR CARERS

1. Who do you support has dementia? How do you find your role?
2. Who is managing the Direct Payment for them?
3. What prompted the person you support to opt for Direct Payments as a form of their service delivery?
4. What did you know about the Direct Payment prior to the person receiving them?
5. What support do you provide the person with managing the Direct Payments package?
6. What benefits have you witnessed in using Direct Payments?
7. What has been the difficulties or barriers for using direct payments?
8. What are the specific benefits do you think Direct Payments offer people with dementia from Black Minority Ethnic background?
9. What do you think could improve the option of Direct Payments for people with dementia from Black Minority Ethnic backgrounds?

QUESTIONS FOR PRACTITIONERS

1. Tell me about your role?
2. What are your views on Direct Payments?
3. What support of Direct Payment have you offered someone with dementia from a Black and Minority Ethnic background?
4. How well do Black and Minority Ethnic Communities know about the Direct Payment option?
5. What are the reasons that lead BME people to seek DPs?
6. What support do local authorities offer to recipients of Direct Payments?
7. What benefits have you seen for clients with dementia from Black and Minority Ethnic using Direct Payments? Please give me an example of when it worked?
8. What has been the challenges and barriers for using direct payments for Black and Minority Ethnic people with dementia? Do you have any examples?
9. What are the specific benefits do you think Direct Payments offer people with dementia from Black Minority Ethnic background?
10. What do you think could improve the option of Direct Payments for people with dementia from Black Minority Ethnic backgrounds?

QUESTIONS FOR STAKEHOLDERS

1. Tell me about your role?
2. What are your views on Direct Payments?
3. What support of direct payment have you offered someone with dementia from a Black and Minority Ethnic background?
4. How well do Black and Minority Ethnic Communities know Direct Payment options?
5. What are the reasons that lead BME people to seek Direct Payment?
6. What support does your organisation offer to people with dementia from Black and Minority Ethnic backgrounds who receive direct payments?
7. What benefits have you seen for clients with dementia from Black and Minority Ethnic using Direct Payments? Please give me an example of when it worked?
8. What has been the challenges and barriers for using direct payments for Black and Minority Ethnic people with dementia at the level you are involved in? Give me an example?
9. What are the specific benefits do you think Direct Payments offer people with dementia from Black Minority Ethnic background?
10. What do you think could improve the option of Direct Payments for people with dementia from Black Minority Ethnic backgrounds?

APPENDIX 8: EXCEPTS FROM REFLECTIVE JOURNAL ON DATA ANALYSIS

REFLECTIONS DURING DATA ANALYSIS STAGE.

The coding process examples not included in main body of the thesis.

I developed a flexible coding framework throughout the analysis to provide a clear trail of evidence and a record of how analysis developed and continued to change throughout the process. A code was given to a sentence or a paragraph. Here is an example of coded data from the transcript. The capitalised word is the descriptive code used which summarises the primary topic of the excerpt.

'With DP, you get the same person you don't need to teach them a task over and over again they know how to poach an egg they know things that really matter to people there is that closeness with the people, and that adds to their quality of life. You are here to provide me with a service. I don't mind teaching you once to poach an egg but doing it 8-10 times with different workers, so it is easier doing it myself.' CEO 3. Coded 'CONTINUITY IN CARE'

I occasionally used InVivo code at the beginning of the coding process, which means naming a code directly from what the participant said. An example of InVivo code,

'We are also living in times of austerity essentially even if you jump through the hurdles to get a package of support; it may not allow you to have that kind of quality of life you would hope to achieve.' ILM 2. Coded 'AUSTERITY'

Many of the same codes were used repeatedly for different participants throughout the coding process, which was deliberate as the repetitive patterns and consistencies emerged. For example, all participants agreed that DP access and delivery needed radical improvement. However, the recommendations on how to do this significantly varied, although descriptively coded IMPROVEMENT/RECOMMENDATIONS.

Some extracts were coded in different codes for example,

'It is home care literally. Keep them at home literally not keep them out of the care home don't get them out of the house, wash them, dry them, feed them, there is no much social element build in the traditional care for the elderly'. CEO- 2. Coded both under AGEISM and STIGMA

Reflecting on Saldana (2008) who asserts that coding is not a precise science but primarily an interpretive act. Therefore, what I coded relied on my interpretation depending on my epistemological, ontological, theoretical and conceptual frameworks discussed earlier. Saldana (2008) advises that in doing this, codes can attribute more evocative meanings to data.

Here is an example of how I arrived at categories and themes.

'But I think also racism and prejudice may play a part when dad was in the hospital, I found this to be the case one nurse kept referring to 'people like you.' C3.

'There is still discrimination and racism; there still those barriers. People from BME are also scared to ask for help due to experiences of discrimination.' C4

'BME people may come across other barriers such as discrimination due to their skin colour in addition to the illness and disability they may have.' SW6

Initial theme was DISCRIMINATION AND INEQUALITIES,

Codes that fell into this category were racism, prejudice and antisemitism with sub-themes of poverty, class and ageism.

COMPLICATED DP PROCESSES

The participants felt that there was a high level of bureaucracy with the DP process, and it was unnecessarily complicated. They argued it was mostly driven by austerity and feared that it would only get worse. Most participants felt that many workers and in particular the social workers lack confidence in DP information and therefore service users did not have enough information about DP processes and responsibilities, one said '*if you do not know or do not have the right information on DP how can you then advise someone else*?' in reference to social workers. It appears that navigating the process is hard for most people regardless of background although the complexity is more pronounced for BME people when trying grasp the DP concepts in a foreign language and maybe even harder for people with dementia. It was interesting what the manager said discussing DP multiple complex process he said, that '*no one sets out to be an employer, saying that, I want to be an employer and I want to employ 6 PAs, so that I can manage them, draw up their contracts, buy liability insurance for them, think about their pensions.*' Many people just need a service that works and meet their needs and not faced with multiple obstacles and un-streamlined even more difficult for BME people with dementia finds harder to navigate.

Workers expressed a lot of frustration regarding payroll service which was complex to navigate. Previously the council funded third party to provide support and payroll service for people using DP. This had worked well for many years, but council no longer funded full payroll service and DP recipient were referred to ordinary accountancy firm that charged cheaper. DP is meant to be person-centred and meeting individuals needs therefore it is unlikely that an accountancy firm that mainly works in large numbers would be using a person-centred approach. One participant expressing her frustration when she said, '*the service users are just a figure and a number to them*'. She said it is lacking the personalised service they offer with empathy, respect and compassion because they get to know their service users personally as individuals. The difference in cost was not massively different. Not sure if it was worth saving that little money if it disrupted a service and made it more inconsistent and complicated.

Participants advised that they spend most of their time in supporting people to comply with employment law looking at the pension, paying HMRC, purchasing liability insurance all which can be challenging to explain to people as they do not realise there is so much to deal with when managing a DP. The manager interestingly said that they are always shocked by all the terms and conditions and responsibilities of DP on top of their own circumstances while all they want is care and support.

It shows that while language and cultural barriers may be an issue for BME service users the complexity of the process compounds any effort to support people using DP.

LANGUAGE BARRIER

The language barrier was identified by all participants. They advised that this is one of the main reasons that people from BME may opt for DP to enable them to recruit a PA who spoke their language. They also added that this is more pronounced for older people and especially people with dementia who may lose their learned languages.

Language can be complicated; we know that language is important for our communication, but I wonder when it comes to caring for someone with dementia what is more important? Someone who speaks the same language as the person with dementia or someone who is empathic, compassionate, understands the needs of someone with dementia, someone who understands how dementia affects the individual's feelings, thoughts and behaviour? While we might say both are important what happens when recruiting a PA who meet the language requirement is a barrier?

BME population is not large here in Scotland and among the BME population very few want to apply for PA jobs, so it leaves a very small pool of people to be recruited.

Human beings want to feel that they belong, they are loved and can connect with others and if there is no language does that mean that this cannot happen? We may have BME people with dementia who are also visually impaired so might require braille translated leaflets. We may also have people who are not able to speak or have lost their speech or someone at advanced stages of dementia and not able to communicate. Therefore, I think sometimes we need to think beyond language as a tool of communication and think of other non-verbal communication to reach out to people and connect with them during their care provision. For example, touch might be important for some people as a way of reassurance, pictures could also be another way, I know talking mat is another tool developed although I have not used it. I also wonder if people with dementia revert to mother tongue languages because they forgot learned languages or the part of the brain that learns a language is affected by dementia or the mother tongue becomes the readily available language. I think it is an interesting phenomenon that I need to read and explore more. Since it is the older generation that moved here in Britain that does not speak English it appears in future this might not present many challenges like today as the second and third generation of Asian BME people will have been born in Britain.

RELIGIOUS BARRIERS

Some DP recipients have advised that they prefer recruiting someone who understands their religion. For example, they would want to recruit a Muslim person who understands that practising Muslim people need to pray five times a day, go to the mosque every Friday, importance of cleanliness and food handling in Muslim ways, food items not to be eaten such as pork plus others.

The debate on religious needs is an interesting one and one to be had with families because how do you distinguish who is practising and who is not? Also, it is only through a dialogue with the family members that one can understand what is more important for a family, for example, someone whom they share a religion, a culture or a language. For instance, there might be a PA from a different culture, race or country who is Muslim and may be able to meet the religious need if that is what is important for the cared-for person and family as opposed to meeting only language need. As discussed above it can be difficult to find PAs who can meet all the language, cultural and religious needs and a compromise may be required. However, it is good to know that if a compromise cannot be reached a family carer can be approved in exceptional situations if that is a better outcome for the service user and the family. Understanding family dynamics and how they operate as a unit appears to be an important task for the assessor because the intricacies of the culture may lead people to various preferences. One participant emphasised that a package has to work for the whole family and has to fit within their culture otherwise it breaks down very quickly.

The traditional view of woman as a carer and nurturer may push some women further into poverty and greater inequalities. The PA rate is very low and some family members may be leaving a well-paying job to be employed as PA so maybe the financial impact on family member PA needs to be discussed openly with the family before they commit to taking up DP.