Representing dementia:

A qualitative analysis of how people affected by dementia situate themselves in relation to different dementia discourses.

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Abstract

Dementia remains widely feared and stigmatised in contemporary society. Popular representations commonly reduce dementia to either concerns surrounding ageing, degeneration and death, or to an overly positive discourse of ‘living well’, both of which can present unrealistic expectations and socially distance people with dementia. Against this, individuals directly affected by dementia can provide more nuanced accounts that engage with multiple discourses and better reflect dementia’s complexity. Further qualitative exploration of these first-hand accounts is urgently required.

The present study explores the perspectives of 51 people who are all affected by dementia, either by having a diagnosis or being a carer or loved one of someone who does. Through focus groups and interviews, this thesis examines how participants situate themselves in relation to wider portrayals of dementia. It considers how individuals represent dementia and people with/without the condition, respond to examples of images and language used in relation to dementia, and overall, how participants interpret, reproduce and challenge a variety of dementia-related discourses.

This thesis draws on thematic, multimodal, critical and positive discourse analysis to examine how participants engage with a range of discourses. The approach combines a focus on overarching themes across the data with in-depth analysis of participants’ accounts and interpretations of the stimuli. This is considered in relation to broader social issues and the potential for positive change.

Analysis showcases the complexity and diversity of participants’ representations, with participants reproducing, challenging and adapting a range of discourses, including biomedical, psychosocial, structural, embodied and relational. Analysis begins by comparing how two participants with dementia differently represent their experiences and interpret the same images, demonstrating the subjectivity and nuance of people’s engagement with discourses. Subsequent chapters attend to all focus groups and interviews to explore participants’ experiences of dementia, particularly of diversity, change and approaches to biomedical versus social spheres. Alongside this is an exploration of participants’ responses to different visual and linguistic practices, which culminates in a discussion of current representations and areas for improvement. Overall, three recommendations for improving dementia portrayals emerge from participants’ contributions: 1) normalise dementia; 2) provide more nuanced representations; and 3) better enable advocacy for people with dementia.

This study foregrounds the importance of considering both individual and collective voices for dementia representations, alongside the role that people affected by dementia can play in countering problematic hegemonic discourses and providing more diverse, nuanced and experience-led accounts.

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Chapter 1: Introduction

During a discussion of word choices in my first focus group, a participant with dementia (Participant C) quoted Shakespeare's famous line from *Romeo and Juliet*: 'A rose by any other name would smell as sweet'. Implicit in this line is the concept that language does not have the power to change an experience of the world, here the smell of a rose. This thesis proposes the opposite, arguing that language, as well as discourse more broadly (which manifests in language but goes beyond that; see section 3.2.1), holds significant power in our interactions and perceptions of the world. Indeed, the same individual notes his hurt at words such as 'loony' to describe people with dementia, exemplifying that words and the meanings with which they are imbued hold very real consequences. It is therefore important to reflect on, critique and develop representations of dementia in collaboration with the people who are most impacted, namely people with dementia, as well as their carers, family and friends. This will facilitate real-world improvements that can empower, rather than disempower, people with dementia.

1.1 Representing dementia

Dementia is increasingly recognised as a public health priority; it is a major cause of disability, with both financial and human costs, and it requires much greater awareness and support overall (World Health Organisation, 2017). Indeed, existing research demonstrates the need to address both a lack of public understanding (Cahill *et al.*, 2015) and how dementia is portrayed, since many popular representations are reductive and establish social distance between those with and without the condition (Low and Purwaningrum, 2020; McParland *et al.*, 2017; Zeilig, 2014a). By 'popular representations', I refer to representations that are mediated in widely consumed texts, such as newspaper articles and televisual media. Recognising that such representations are overwhelmingly multimodal, scholars are increasingly considering visual as well as verbal modes of communication (Brookes *et al.*, 2018, 2021; Caldwell *et al.*, 2021; Harvey and Brookes, 2019).

Issues with representations include the dominance of a biomedical approach to dementia despite a range of alternative approaches to the condition, both in the UK and globally. This has been widely critiqued for eclipsing other important facets of a person's life, personality and environment (Milne, 2020). Relatedly, stereotypes of people with dementia are often disrespectful and dehumanising (Swaffer, 2014), and the voices of people with dementia themselves are noticeably lacking in popular media (Bailey, 2019; Van Gorp and Vercruysse, 2012). Such reductive and exclusionary portrayals contribute to both public and self-stigma, negatively impacting the lives of people with dementia, and those around them (Nguyen and Li, 2020).

There is a real need, then, for more qualitative research to recognise the unique expertise that is acquired through experience (Bryden, 2016) and to explore the perspectives of people with dementia (Carmody *et al.*, 2015). When addressing reductive popular representations, there is much to be gained from studying the nuance and multiplicity of people's dementia experiences (Hillman *et al.*, 2018; Hulko, 2009). Yet multimodal critical discourse analyses of representations traditionally privilege the analyst's perspective (Breeze, 2011). This presents a gap in knowledge regarding how other people interpret and respond to instances of visual and verbal dementia portrayals, which is 'an obvious next step for future research' (Caldwell *et al.*, 2021: 128). Although a range of non-profit communication guidelines do consult people with dementia on representations, individual voices are generally accumulated into a collective stance on what is good and bad practice, and the focus remains largely on language choices (Alzheimer's Society, 2018; Bould, 2018; DEEP, 2014; YoungDementia UK, 2020). This presents a partial picture, which this thesis tries to expand by working with people with dementia, carers and loved ones to consider how individuals affected by dementia respond to examples of linguistic *and* visual communication, and how participants themselves represent dementia and those with and without the syndrome. Such a focus presents unique and nuanced insights, led by people affected by dementia, into how dominant representations of dementia can be adapted, challenged and expanded.

1.2 Research questions and thesis outline

The thesis seeks to answer a central research question: how do people with experience of dementia (either lived or as a carer/loved one) situate themselves within popular discourses of dementia? This question is divided into three parts:

1. How do participants represent dementia for themselves and others?
2. How do people respond to visual and verbal representations of dementia?
3. Do participants' responses reproduce or challenge prevalent discourses of dementia?

To address these research questions, this study works with fifty-one individuals in and around Nottinghamshire, conducting seven interviews and eight focus groups between October 2019 and March 2020. Participants included seventeen people with a dementia diagnosis, one person with a mild cognitive impairment that she regarded as pre-dementia, and thirty-three participants without dementia, identifying as carers and/or family/friends. Four individuals were ex-carers, one of whom had since developed dementia. Following an initial discussion about experiencing and representing dementia, twenty images were shown to participants, alongside a range of phrases and headlines.

This thesis takes an inductive qualitative approach to the dataset, drawing on multiple discourse analysis approaches to do so. The data is organised principally through thematic discourse analysis, which enables me to attend to overarching themes alongside conducting close discourse analysis of participants' responses. In-depth analysis is underpinned by multimodal critical discourse analysis, particularly when examining how participants respond to examples of images and language associated with dementia, and how this relates to broader social issues and inequalities. I regard multimodality as the combination of different semiotic modes, such as language and images, in a communicative artefact or event (van Leeuwen, 2005: 281). Here, analysis incorporates participants' responses to visual and verbal stimuli and is thus concerned with multiple modes, although notably, the stimuli are themselves monomodal (either language or images). Following Caple (2018: 86), I use the term *semiotic mode* to refer to meaning-making systems (image, language, gesture), and *semiotic resource* to refer to features that constitute a semiotic mode. These can include both linguistic features (e.g., temporal reference, pronouns) and visual features (e.g., camera angle, colour, spatial organisation). This study's concern with the voices of a traditionally marginalised group and its aim of contributing to positive social change through exploring how participants engage with discourses additionally aligns it with the positive discourse strand of multimodal critical discourse analysis. The specifics of my theoretical stance and methodological choices are discussed in greater detail in Chapter 3.

This thesis is organised into nine chapters. Expanding on this introductory chapter, Chapter 2 provides the necessary background for the present study. Beginning with explanations of dementia, this chapter chronologically surveys key approaches to dementia, particularly focusing on biomedical, psychosocial, structural, embodied and relational approaches. It then considers how dementia is culturally represented, with an especial focus on language, image and metaphor, and three key sources of representations: the news media, not-for-profit organisations and people affected by dementia. The chapter concludes by defining prominent gaps in the literature that this thesis intends to address.

Chapter 3 outlines the methodological considerations and practices that underpin this thesis. It begins by defining my theoretical position, in which I detail the key concept of 'discourse' and position myself within the approaches of thematic discourse analysis, multimodal critical discourse analysis and positive discourse analysis. From here, I examine the rationale and practicalities of the study design, including the running of focus groups and interviews, stimuli, the recruitment process, participants, ethical practice, and data collection. I then outline my approach to the transcription, analysis, and presentation of the data, before reflecting on my subjective position as the researcher and the implications of this for the project.

Beginning the analysis, Chapter 4 focuses on two interviewees with dementia, Sheila and Jackie (pseudonyms). The chapter explores how these two individuals differently represent dementia and respond to images. Sheila navigates her identities as a nurse, carer and someone with mild Alzheimer's disease. Her account foregrounds love, family, care, coping, loss and suffering. In contrast, Jackie highlights her role as an advocate for people with dementia, focusing on the need for structural and social changes, including using the media to raise awareness and decrease stigma. Both women engage with different discourses to provide distinct depictions of their experiences of dementia, which is then shown to inform their unique interpretations and responses to the same images.

The four subsequent analysis chapters draw on the whole focus group and interview dataset. They are organised around prevalent themes that occur consistently across participants. Within themes, I examine how participants reproduce and counter different discourses, both in general conversation and when responding to specific stimuli. In its examination of different meanings of dementia, Chapter 5 highlights the diversity of people with dementia, and of dementia as a condition. This is showcased by a section on how people respond to two photographs depicting hands, from which differing interpretations and discourses emerge, including ageism and embodied approaches to personhood.

Building on this, Chapter 6 explores different biomedical and social representations. It considers how participants position dementia in relation to the brain and debate finding a cure versus better caring for people with dementia now. It also investigates how participants relate to biomedical experts versus their own peers, offering insights into different conceptualisations of 'expertise' and the need to bridge these.

While the above chapters allude to issues of change, Chapter 7 explicitly focuses on different types of change, as well as continuity with dementia. It begins by examining how participants differently navigate the past, present and future. This highlights a range of emotional responses and various coping mechanisms, such as humour. Debates of change and flux are then examined in relation to how participants differently respond to four decline-oriented visual metaphors of dementia, with a particular focus on a seasonal tree metaphor. Participants draw on biomedical and more psychosocial and embodied approaches to dementia to praise and critique the images, sometimes offering creative alternatives to better align the images with how they would represent dementia.

Since chapters 4 to 7 orient around responses to visual stimuli, much of Chapter 8 is dedicated to discussing different language choices related to dementia, which is generally initiated by the written stimuli in sessions. This covers debates surrounding how to refer to having dementia, including a discussion of 'suffering' and 'living well' discourses, into which popular portrayals tend to be dichotomised (McParland *et al.*, 2017). Following this is a consideration of different metaphors for dementia, both prominent ones (like life as a battle or journey with dementia) and more idiosyncratic ones produced by participants. Chapter 8 then draws together different analysis strands to present participants' evaluations and three recommendations for representing dementia moving forward. These recommendations prioritise greater nuance, normality and advocacy for people with dementia.

Chapter 9 concludes this thesis by discussing key findings in relation to the three research questions and wider literature. It considers the study's implications for academia, non-profit organisations, media institutions and the wider community. This includes considering important factors, guided by the theory of news values (Bednarek and Caple, 2017, 2019; Caple and Bednarek, 2016), for implementing participants' recommendations regarding how to improve dementia representations. This chapter then evaluates the study's limitations, and points to promising directions for future research.

1.3 Terminology

As will be discussed further in Chapter 3, the central term of 'discourse' must be clearly defined here, since despite its popularity as a term, it is used differently across a range of fields, with no agreed definition. Here, by 'discourse', I refer to a particular representation of reality (for example, that dementia is a biomedical disease versus a bio-psycho-social condition: Sabat, 2014) that is manifest in a set of resources (here, images, written text, metaphors and speech), and that not only reflects but helps to actually *shape* social realities (Burr, 2015; Foucault, 1972). Discourse, then, is a useful concept to explore how different people represent dementia and challenge prominent portrayals, alongside their social implications. Within this, this thesis uses 'discursive positioning' to refer to how participants draw on their personal histories to orient themselves (reflexive positioning) or others (interactive positioning) in relation to existing social discourses, for example whether a person with dementia identifies as a 'patient' (biomedical discourse) or rejects this (Davies and Harré, 1990).

Language has the potential to empower or devalue people with dementia (Swaffer, 2014). It is therefore important to outline the rationale behind the linguistic choices made here to refer to relevant social groups and dementia as a condition. Recognising that people's responses to language choices are personal and nuanced, this study follows the recommendations of communication guidelines, since these are produced by and in collaboration with people with dementia. As such, this thesis uses more neutral language to avoid assuming someone's experience, referring to 'people with dementia' and 'people living with dementia' as opposed to more evaluative terms like people 'suffering' or 'living well with dementia' (Alzheimer's Society, 2018; Bould, 2018; DEEP, 2014; YoungDementia UK, 2020). Similarly, in accordance with the Alzheimer's Society, I use 'people affected by dementia' to refer to both people with dementia and those important to them, which here includes carers, family and friends (Bould, 2018).

As this thesis demonstrates, 'dementia' is an umbrella term for a range of neurological conditions, of which Alzheimer's disease is the most common type. The present work tries to avoid the common mistake of conflating dementia with Alzheimer's disease (Zeilig, 2014a) by using it as an overall term and where relevant specifying a subtype, such as Alzheimer's disease or vascular dementia. When referring to dementia that affects people before the age of 65, I use the terms 'young onset' and 'working-age' dementia interchangeably, since both are synonymous and, while participants tend to use 'working-age', 'young onset' dementia is the norm elsewhere (YoungDementia UK, 2020). Although I use the singular form of 'dementia' to refer to multiple subtypes in accordance with social norms, Chapter 5 briefly considers that the plural, 'dementias', may help clarify the plurality incorporated within 'dementia'. It is worth noting that the term 'dementia' is subject to change. For instance, the fifth edition of the American Psychiatric Association's (2013) *Diagnostic and Statistical Manual of Mental Disorders* replaces the term dementia with the diagnostic categories of major and mild neurocognitive disorders. However, since at the time of writing, 'dementia' remains the most recognisable term, this thesis uses the term 'dementia', alongside 'syndrome' and 'condition' to provide stylistic variation where appropriate.

Dementia is 'an umbrella term […] there are different forms of disease, so everything's different'

- Participant N (Jackie)

Chapter 2: Background

2.1 Introduction

At the time of writing, dementia is popularly regarded as a neurodegenerative pathology distinct from natural ageing (World Health Organisation, 2020). It is an umbrella term for a range of progressive conditions that affect the brain, with over 200 subtypes, the most common of which are Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia and mixed dementia (Dementia UK, 2021). Dementia can affect someone's memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgement, social behaviour and motivation, but consciousness is not impacted (World Health Organisation, 2020). Dementia is a syndrome as it can be caused by multiple diseases; it consists of a collection of signs, which a professional detects, and symptoms, which are experienced by the person themselves (Sabat, 2018). The extent to which dementia is related to ageing is fiercely debated. It is clear that people of different ages can develop dementia, with estimates suggesting that about 5% of people with dementia in the UK are below the age of 65 (YoungDementia UK, 2020). Conversely, while age is the biggest risk factor for dementia, the syndrome is not an inevitable consequence of ageing, and most older people do not have dementia (World Health Organisation, 2020). Dementia, then, is not 'natural' ageing, but this exists on a continuum whereby, at the margins, it is unclear what constitutes dementia and what counts as normal ageing (Hughes, 2014).

A person's lived experience of dementia is individual and, as this chapter will demonstrate, is greatly influenced by their social environment (Sabat, 2018). In medicine and contemporary culture alike, dementia is 'conceptually slippery', as much remains unknown about this heterogenous syndrome, which is laden with cultural values that often evoke fear (Zeilig, 2014a: 260). Fear-inducing and reductive portrayals of dementia contribute to the widespread stigma that people with dementia and those associated with them face (Alzheimer's Disease International, 2012; Nguyen and Li, 2020). By stigma, I refer to what Goffman (1963) terms spoiled social identity, where people are regarded not as 'a whole and normal person' but as a 'tainted, discounted one' (31, 12). Corrigan and Watson (2002) propose that stigma can be categorised into two types: (1) public stigma, which is the general population's reaction, here to people with dementia, and (2) self-stigma, which is a person's internalisation of prejudice against themselves. As Table 2.1 shows, in both instances, stigma can manifest in beliefs (stereotype), evaluation and emotion (prejudice) and behaviour (discrimination).

Table 2.1 ***Definition of types of public and self-stigma***

	Stereotype	**Prejudice**	**Discrimination**
Public stigma	Negative belief about a group (e.g., dangerousness, incompetence)	Agreement with the belief and/or negative emotional reaction (e.g., anger, fear)	Behavioural response to prejudice (e.g., avoidance, withholding help)
Self-stigma	Negative belief about the self (e.g., character weakness, incompetence)	Agreement with the belief and/or negative emotional reaction to oneself (e.g., low self-esteem, hopelessness)	Behavioural response to prejudice (e.g., avoiding social events)

Adapted from Corrigan and Watson (2002: 16).

Public stigma for dementia is such that for some individuals, ‘the ugliest part of having dementia is probably the reaction of others’ (Swaffer, 2016: 66). Since self-identity is to a great extent relational and co-constructed (see section 2.2.2), the consequences of self-stigma are also multifarious, including shame, low self-esteem, depression, social isolation, avoiding help and/or diagnosis, and a lower quality of life (Alzheimer’s Disease International, 2012). Although there are some drug treatments available for people with dementia, there is no real evidence that these effectively delay decline (Dening and Babu Sandilyan, 2015). Considering the lack of a viable cure in the near future, attending to how society can better support people living with dementia must be prioritised (Kenigsberg *et al.*, 2016). This includes improving awareness and understanding of the syndrome (World Health Organisation, 2017).

This chapter provides an overview of the key research that informs the present study. It begins by dissecting the current context for dementia through a historical account of changing approaches to dementia over time, including the emergence of the biomedical approach (1970s), followed by a more psychosocial, person-centred approach (1990s), which has since expanded to incorporate a structural rights-based approach concerned with social citizenship (2000s), and a focus on embodied selfhood and relational citizenship (2000s-2010s) (Milne, 2020). After contextualising these changing approaches to dementia, this chapter summarises significant research into how dementia is socially represented, focusing on how various dementia discourses (see section 3.2.1 for more on the concept of ‘discourses’) manifest through language, images and metaphor. For this, I focus on three key sources of representations that are central to this thesis: the news media, not-for-profit organisations and people affected by dementia. The chapter concludes by drawing attention to underdeveloped areas within this otherwise comprehensive body of work, which this thesis aims to address.

2.2 Changing approaches to dementia

Something resembling modern dementia has accompanied humans for millennia, with shifting labels, explanations and associations over time (Boller and Forbes, 1998). The contemporary term, 'dementia', is derived from the Latin *de* (out of) + *mens* (mind) + *ia* (state of), making its literal translation 'to be out of or to have lost one's mind' (Herskovits, 1995: 148). Throughout history, old age has been seen to include cognitive decline. One of the earliest recorded instances of this is by the Greek lawmaker Solon, who, around 500 B.C., stipulated that inheritance could be divided amongst nonfamilial heirs, provided that the heir's judgement was not impaired by old age (Fox, 1989). It is only recently (the last 50 years) that definitions of dementia have become distinct from ageing. The position of authority for defining dementia has changed over time. For instance, taking a Western perspective, explanations of dementia have shifted from it being attributable to sin (when the Church held authority), to a form of insanity (when psychiatrists became the experts in the 19th century), to neurological changes in the brain (relating to the current authority of neurologists and medicalisation of dementia) (Albert and Mildworf, 1989). It is to the latter neurological focus that I now turn.

2.2.1 Biomedical approach

Approaching dementia through a biomedical lens positions it as an abnormal, pathological syndrome with progressive symptoms that are caused by physical processes (Innes and Manthorpe, 2012). The development of, and tensions within this now dominant approach are exemplified by dementia's subtype, Alzheimer's disease, which has received the most attention from society and researchers alike. Despite being discovered in the early 20th century, interest in Alzheimer's disease soared in the 1970s. This was due in part to technological advances (e.g., in electron microscopes), an ageing population, structural changes (such as the growth of national institutes for health and ageing), and the politicisation of dementia as a disease to garner funding, public support and improve care networks (Fox, 1989; Herskovits, 1995). At this point, a historical separation between dementia that was age related (senile dementia) and not (presenile dementia) was removed, establishing a 'unifying construct' that pathologised senility into a disease with specific characteristics and symptoms (Fox, 1989: 59). This heightened the numbers of 'potential victims' so that, across about twelve years, Alzheimer's disease was converted from a rare and obscure diagnosis into a major cause of death, being dubbed the 'disease of the century' by some (Fox, 1989: 58-59).

In contemporary society, Alzheimer's disease and other dementias are diagnosed through instruments such as clinical interviews, neurocognitive assessments and brain scans, which aim to differentiate between mild forms of dementia and normal ageing, and between different types of dementia (Innes and Manthorpe, 2012). Using diagnostic labels can help to structure, normalise and manage chaotic life experiences, scaffolding people to cope with dementia (Herskovits, 1995). The 'socially perceived authority' of the biomedical perspective (Zimmermann, 2017: 86) means that a dementia diagnosis can legitimise people's experience, both for themselves and others, by validating their symptoms as being 'real', with a physical cause, and as recognised by medical experts. Indeed, Gerritsen and colleagues (2018: 598) have suggested that distinguishing dementia from psychiatric conditions and ageing can give patients a degree of 'respectability' by attributing symptoms to 'abnormal' brain damage. Positioning dementia as abnormal justifies helping and treating people with dementia wherever possible, thus mitigating the 'therapeutic nihilism' that often accompanies complaints attributed to 'normal' ageing (Hughes, 2014: 39).

However, although medicalising a condition theoretically diminishes the shame of dementia by attributing it to biological causes, in reality, dementia remains stigmatised (Fletcher, 2019a; Nguyen and Li, 2020). With the advent of the prevention agenda for dementia (World Health Organisation, 2017), people may be blamed for not following the right guidance to mitigate risk, such as a healthy diet, exercise and brain activities (Peel, 2014). Equally, a biomedical approach overly relies on a 'hypercognitive' perspective of a person, which emphasises cognitive abilities above other facets, such as emotionality and empathy (Post, 2000a, 2000b). Thus, a narrowly artificial assessment rubric prioritises cognitive indicators rather than the many abilities that people use and display in the everyday social world (Sabat, 2018). Being clinically-oriented, people living with dementia are positioned as patients, which risks reducing individuals to 'damaged brains' rather than people with social relationships, interests, desires, identities and agency (Gerritsen *et al.*, 2018: 598). In other words, people may be 'identified as *being the disease* rather than *having the disease*' (Cahill, 2018: 16, original emphasis). Through this focus, a biomedical approach can lead to inaccurately attributing the actions of people with dementia to their syndrome, rather than to environmental factors that can be changed to better support people (Sabat, 2018). A related criticism of the biomedical approach is that it entails charting people's loss of abilities with dementia until death, which emphasises people's deficiencies over retained or enhanced abilities, and foregrounds degeneration and death over people's emotional worlds, relationships and lives (Taylor, 2008). Biomedicine can reinforce damaging discourses that position people with dementia as victims of a disease, who lose their core selves and become empty shells (see section 2.3.2). As will be explored further, the label resulting from someone's dementia diagnosis can thus 'amplif[y] any disabilities that may result from the pathology' (Hughes *et al.*, 2006: 4).

It is also worth noting that dementia diagnoses and treatments involve more uncertainty than is commonly believed (Whitehouse and George, 2008). Subsequently, excessive faith in the validity and reliability of these clinical and neurobiological instruments has significant ethical ramifications. Misdiagnosis is common and difficult for people to deal with, as is the disbelief that many people face from others if they do not exhibit expected dementia symptoms according to the biomedical framework (Swaffer, 2016). On a larger scale, a biomedical approach to dementia motivates the continued prioritisation of investing in research into drug therapies that can contribute to preventing, managing and curing the condition. Yet, evidence regarding the effectiveness of current treatments or viability of future cures is lacking (Dening and Babu Sandilyan, 2015). Similarly, there is a lack of evidence that supports the distinction between types of dementia (particularly Alzheimer's disease) and the process of ageing. Whitehouse and George (2008) argue that separating Alzheimer's disease from ageing is a myth that distorts expectations and understandings of our ageing brains, resulting in largely unfounded aspirations for a cure that overshadow the more realistic need to invest in prevention and care. Essentially, a biomedical approach emphasises medical innovations above holistic caring practices that could support people with dementia to be more than 'patients'. Clearly, despite still dominating the national and international stage, a biomedical approach to dementia is limited and needs to be used in conjunction with other approaches.

2.2.2 Psychosocial approach

A psychosocial approach moves beyond the biomedical conceptualisation of dementia by shifting the emphasis from 'person-with-DEMENTIA' to 'PERSON-with-dementia' (Kitwood, 1997: 7; original emphasis), and situating dementia as a subjective experience that is 'relational and co-created' (Latimer, 2018: 839). This involves embracing people's unique personal characteristics, histories, cultures, relationships and social environments, and considering how such factors interact to impact someone's experience of dementia (Brooker and Kitwood, 2019). As Davis (2004: 376) surmises, 'if a disease process causes an intellectual impairment, it is possible for social relations to prevent this becoming a disability'.

Particular focus, then, is on the 'personhood' (Kitwood, 1997) and 'selfhood' (Sabat, 2002) of people with dementia. In his seminal work, Tom Kitwood (1997: 8) explicitly ties personhood to social relationships, defining personhood as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust'. This focus expands the definition of personhood beyond cognitive abilities to instead emphasise the role of others (Kitwood and Bredin, 1992). Subsequent work builds upon this definition, including through transitioning from regarding personhood as a 'bestowed' gift to a human right (Dewing, 2019), which is examined further in section 2.2.3.

Relatedly, Steven Sabat (2002, 2018) draws on social constructionist theory to consider how dementia does and does not affect a person's selfhood, referring to three different aspects of self. Self 1 is the self of personal identity; it is the experience of being one and the same person with a continuous point of view in the world, conveyed through first-person pronouns (e.g., 'I' and 'mine') and gestures such as pointing to oneself. Being focused on expressing feelings and personal identity in the moment, it can remain intact even with advanced dementia. Self 2 is the self of mental and physical attributes, and a person's attitudes towards these. While someone may take pride in their kindness towards others, they may be ashamed of their dementia symptoms, making it important that others consider whether they focus on attributes that are a source of pride or shame for individuals. Finally, Self/Selves 3 refers to social personae, as everyone has multiple ways of being and acting with people, which vary according to our social relationships with others (Sabat, 2018: 141). For instance, the same person may act as a kind friend, firm teacher, good employee, polite customer, romantic partner, nurturing parent, and so on. As these social personae rely on the cooperation of others, they are particularly vulnerable for people with dementia.

Whether discussing personhood or selfhood, this psychosocial approach emphasises that identity loss is a potential risk, rather than an inevitable outcome of dementia (Bartlett and O'Connor, 2010). This has encouraged research into how personhood/selfhood can be interactionally supported or undermined. Supportive environments tend to recognise people with dementia for who they are, consulting and actively listening to their individual stories and needs (Sabat, 2018), being open to not only verbal but emotional and sensory meaning-making (Hughes, 2014), and acknowledging and accepting the contributions of the person with dementia rather than assuming a one-way relationship (Kitwood, 1997; Taylor, 2008).

Yet, even well-intentioned individuals can undermine personhood/selfhood through their interactions, due to what Kitwood (1997) terms a 'malignant social psychology', whereby we culturally inherit a social environment that disables and damages the health and wellbeing of people with dementia. This disempowering environment remains decades after Kitwood's initial research, requiring much further work to overcome (Sabat, 2019). Kitwood (1997) presents six psychological needs that all people require from interactions with others: love, inclusion, identity, occupation, comfort and attachment. These are consistently violated through social interactions, including through infantalisation, labelling, stigmatisation, invalidation, exclusion and disparagement (Kitwood, 1997; Sabat, 2002, 2018, 2019). Such actions undermine selves 2 and 3; for instance, positioning someone with dementia as a defective burden, rather than recognising other more admirable traits and social personae, restricts their identity to a dysfunctional, passive patient, with consequences for self-perception (Sabat, 2002). Focusing on social and psychological factors challenges the trend of attributing a person's experiences and behaviours to their diagnosis. For example, someone with dementia may act aggressively not because of their dementia but because of their frustration with their poor treatment by others (Sabat, 2018). As (Swaffer, 2016: 209) declares, 'Of course we will display "challenging behaviours" if no-one bothers to understand our frustrations, or our needs'.

While the psychosocial approach has heralded better recognition of people with dementia as fully rounded individuals who need respect and support to thrive, this approach also has weaknesses that subsequent work has tried to address. Namely, it remains entangled with issues of blame, agency and a restricted sense of dementia. As Bartlett *et al.* (2017) highlight, this approach fails to sufficiently recognise that dementia itself causes suffering and grief. For example, gaps in memory can result in frightening experiences, whilst moments of realisation evoke despair. Focusing on maintaining personhood can undercut people's ability to mourn what is lost with dementia (Davis, 2004). Equally, allocating responsibility for personhood to those without dementia removes agency from people with dementia and can overly attribute the blame for a person's ill-being to supporters, despite a range of factors being involved (Davis, 2004). Supporting personhood can be made difficult through its lack of specificity, which problematises its application to contemporary dementia care (Higgs and Gilleard, 2016). Relatedly, the problematic implication that personhood is bestowed by others, rather than being integral to an individual, requires critique and development, outlined in the subsequent sections (Dewing, 2019). A psychosocial approach used alone, then, simplifies and decontextualises the experience of dementia in its focus on how individuals' relationships support and undermine personhood. This includes overlooking how social inequalities impact relative agency and power, and how social structures can be targeted to bring about change (Bartlett and O'Connor, 2010).

2.2.3 Structural rights-based approach

A structural approach is concerned with the individual as a citizen situated within socio-political structures, and with how these impact experiences of health and disability. Notably, George and Whitehouse (2021) argue that everyone has the right to a social, psychological, political and ecological environment that supports (brain) health and cares for vulnerable members, situating dementia within the climate crisis, poverty and hyper-capitalism, amongst other pressing issues. Aligning with the social model of disability, which upholds that 'society must adapt to enable the participation of disabled people as equal citizens' (Mental Health Foundation, 2015: 6), a structural approach is primarily concerned with the unequal distribution of power, striving to improve the rights of members of marginalised groups and enact political change (Bartlett and O'Connor, 2010; Cahill, 2018;

Shakespeare *et al.*, 2019). This builds on the central argument of the social model of disability: that if a person has an impairment (as a result of a condition), they are disabled not by their impairment, but by a range of social, attitudinal, physical, economic, architectural and environmental factors (Mental Health Foundation, 2015: 15).

Such an approach extends the psychosocial conceptualisation of personhood by incorporating citizenship and sociological ideas about agency and structure to recognise people with dementia as agentive social actors (Bartlett and O'Connor, 2007). Underlying structural approaches, then, is the concept of social citizenship. In the context of dementia, this is popularly defined as:

> a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level.
>
> (Bartlett and O'Connor, 2010: 37)

This recasts the subjective and relative 'needs' of people with dementia as fundamental human rights and responsibilities (Hughes, 2019). This is significant since human rights are universal, objective, reciprocal (i.e. everyone has them and must also respect others' rights) and absolute, with not only moral but legal backing (Cahill, 2018). Rights can be classified as negative rights (civil and political rights, such as the right to life, which require protection against abuse) and positive rights (economic, social and cultural rights that place a claim on others for positive assistance to be fulfilled, such as the right to healthcare, education and social security) (Cahill, 2018).

As such, Bartlett and O'Connor (2010) explicitly extend Kitwood's (1997) six psychological needs, for love, comfort, identity, occupation, inclusion and attachment, to propose six associated rights (see Figure 2.1). Firstly, they argue that although love is of fundamental importance for humans, it is not a suitable concept for creating social change, especially when '"love" manifests as control' in many caring relationships (Bartlett and O'Connor, 2010: 46). Therefore, as well as being loved and respected, people with dementia are entitled to freedom from discrimination, at both a macro (e.g., transportation) and micro (e.g., speaking turns in a conversation) level. Secondly, since discrimination affects self-expression and development, an associated right is that of growth. Feeling secure and comfortable is insufficient, since humans need opportunities for personal growth too, whether political, spiritual, artistic or otherwise, which is especially important when other aspects of one's identity are changing or deteriorating with dementia.

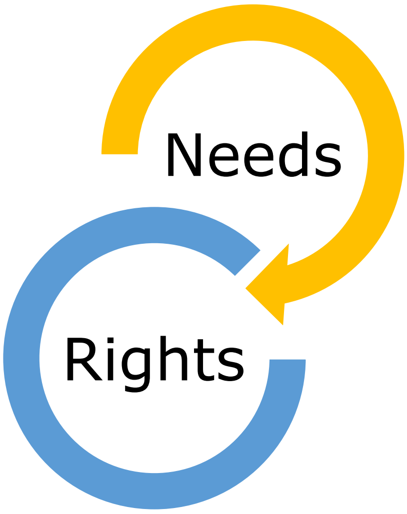
Figure 2.1 ***A comparison of psychosocial and structural conceptualisations of an individual's needs versus rights***[1]

Psychosocial

People (with dementia) need to have:

1. love
2. comfort
3. identity
4. occupation
5. inclusion
6. attachment

(Kitwood, 1997: 82)



Structural

People (with dementia) have the right to:

1. freedom from discrimination
2. growth
3. social positions
4. purpose
5. participation
6. solidarity

(Bartlett and O'Connor, 2010: 39-47)

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[1] Corresponding numbers signal equivalent concepts (e.g., inclusion and participation)

Thirdly, Bartlett and O'Connor (2010) advocate that people with dementia have the right to have their social positions recognised. This is more nuanced than identity, which is critiqued for failing to acknowledge the different statuses associated with various ways of being in the world (e.g., the difference between being a seventy-year-old white British man and a forty-year-old Malaysian woman in the UK). People also have the right to not only have occupation but *purpose*, since meaningful engagements provide people with reason for being in the world. Extending inclusion by foregrounding agency, individuals also have the right to participation, whether in political, medical or personal spheres. Finally, people have the right to solidarity, which again enables greater agency than the psychologically oriented and essentially submissive concept of attachment. Solidarity acknowledges that people may connect emotionally, as well as socially and politically by uniting with others to cause change. In such a way, a structural approach aims to 'broaden' the lens to contextualise the micro-level of personal relationships within the macro-level of broader socio-political structures (Bartlett and O'Connor, 2010).

A structural approach is useful for examining the psychological, physical, architectural, attitudinal and institutional barriers that people with dementia face (Cahill, 2018). It recognises that people experience dementia within the context of an ableist, ageist, sexist, classist, racist and heteronormative (often homophobic) society (O'Connor *et al.*, 2010). Factors such as age, gender, sexual orientation, ethnicity, socioeconomic status and other aspects of mental or physical health interact with different privileges and marginalisation to affect lived experience (Hulko, 2009;

Watchman *et al.*, 2019). Ageism, for example, pervades many contemporary societies. Unlike many other forms of discrimination, it is deemed socially accepted and so goes largely unchallenged, requiring global action to improve the wellbeing of everyone affected (Officer and de la Fuente-Núñez, 2018). Older people are popularly positioned as failing, frail and helpless, vilified as socioeconomic burdens, and are situated as objects of disgust for breaching social order and ideas of autonomous personhood (Latimer, 2018). In this way, senility becomes a 'monstrosity' (Herskovits, 1995: 152), and people are doubly stigmatised by being old and having dementia (Evans, 2018).

A body of evidence shows that the rights of people with dementia are violated in a myriad of ways. For instance, the right to freedom from discrimination (and freedom more broadly) is commonly violated for people with dementia through involuntary surveillance measures and physical or pharmacological restraints, with even residents in low-care facilities unable to go outside of their own free will (Cahill, 2018; Swaffer, 2016). More subtly, doctors frequently promote what (Swaffer, 2016) terms 'Prescribed Disengagement®', whereby people with dementia are encouraged to disengage from their role as active citizens in society and become passive, including through giving up driving and work before it is necessary, contravening Bartlett and O'Connor's (2010) identified right to participation. Galtung (1990) provides a useful framework for conceptualising how this sort of 'structural violence' (whereby social structures implicitly or explicitly infringe upon citizens' rights) is normalised and/or justified through aspects of culture, such as religion, art, language and education in a process that Galtung terms 'cultural violence'. This highlights the importance of attending to cultural representations as manifestations of discourses, explored further in sections 2.3 and 3.2.1. A structural approach, then, facilitates a focus on how language is used to create and maintain social barriers and oppression (Mental Health Foundation, 2015). This has led to a range of rights-based projects addressing dementia communication, including the Dementia Engagement and Empowerment Project's guidelines on language about dementia (DEEP, 2014).

Shifting the emphasis to how society must adapt to empower, rather than disempower, people with dementia through the lens of disability rights is a potentially significant driver for social change, which needs to be substantial, at both micro and macro levels (Mental Health Foundation, 2015). Through a structural approach, self-advocacy by people with dementia has risen dramatically, since the agency and expertise of people with lived experience is increasingly recognised (Bryden, 2016; Davies *et al.*, 2021). Dementia has become accepted as a disability rather than a terminal disease (Cahill, 2018; World Health Organisation, 2020), although this does not (yet) match the preferences of many people living with dementia, who are more likely to perceive dementia in terms of old age or as a disease (Mental Health Foundation, 2015). Advocates of the shift from disease to disability emphasise that this better protects the human rights of people with dementia through antidiscrimination laws, alongside facilitating a greater focus on people's assets and how best to adapt society to support people to 'live better' with dementia (Shakespeare *et al.*, 2019: 1083).

There are numerous weaknesses inherent to this approach that must also be addressed. Although there is much to be gained from self-advocacy, activism and connecting with like-minded people (Beard *et al.*, 2009b; Hagan and Campbell, 2021), it does come at a personal cost for people with dementia, including unnecessary pressure and exhaustion (Bartlett, 2014). There is also a tension regarding the extent to which people's rights rely on their ability to fulfil certain responsibilities as citizens, resulting in an overall shift towards a more passive form of citizenship, defined not by an individual's participation but by the recognition of their rights, upheld through care practices, policies, and institutions (Kontos *et al.*, 2017). Without developing this distinction, explored further below, this approach risks excluding and devaluing people with more severe cognitive impairments. Indeed, advocates are often younger, well educated people who are not living with the most challenging aspects of this syndrome (McParland *et al.*, 2017). This issue of exclusion is inherent to the application of the social model of disability to dementia, since, being designed for people with static physical impairments, it does not adequately contextualise impairments that are associated with pain, limitation, frailty and degeneration (Shakespeare *et al.*, 2019). A structural approach risks oversimplifying the complexity and fluidity of not only dementia but also of society. For instance, Parveen and colleagues (2014) highlight that although dementia is stigmatised across cultural groups, age itself is not a social barrier within some British minority ethnic communities, due to a greater cultural respect for elders. Equally, unduly focusing on ageist and other discriminatory structures as the cause of suffering overlooks other factors, including the reality that older age and/or dementia can itself be 'the site of distress, disgust and despair' (Gilleard, 2018: 29).

2.2.4 Embodied and relational approaches

More recently, scholars have expanded on the above approaches by foregrounding the relational nature of humans and the creativity, intentionality and communicative attributes of the body (Hughes, 2014; Kontos, 2004, 2006; Kontos *et al.*, 2017). Individuals are regarded as 'situated embodied agents', whereby personhood and selfhood manifest in our physical and emotional being, and in our engagement with the social and physical world (Hughes, 2014: 19-20). Selfhood is shown to (often subconsciously) manifest in both the body and relations with other artefacts, such as art, clothing and furniture (Downs, 2013; Hughes, 2014). Selfhood can be embodied through 'natural' (pre-social) bodily expressions and interactions with the world, like touching a pearl necklace or using a walker, or through socialised bodily interactions that reflect sociohistorical conventions, power dynamics and discourses (e.g., hairstyles can signify gender and class) (Kontos and Grigorovich, 2018). By regarding the body as having both intentional and creative capacity, rather than passively containing the brain, this approach stresses that agency and distinctive expression continue throughout the progression of dementia (Kontos and Grigorovich, 2018).

An embodied approach to dementia is inherently relational, as we are 'always intertwined with a shared world', interconnected through our bodies (Kontos and Grigorovich, 2018: 41). It builds upon previous psychosocial work by encouraging concern for how personhood and selfhood can be held by both other people and artefacts (Hughes 2014). This embodied-relational association provides the basis for a proposed new model of citizenship: relational citizenship (Kontos and Grigorovich, 2018; Kontos *et al.*, 2017). This model builds on the central tenets of relationship-centred care (interdependence, reciprocity and supporting people with dementia as active partners in their own care) and embodied selfhood theory (which focuses on natural and socialised bodily expressions as a source of agentive interactions and communications) (Kontos *et al.*, 2017: 184). The theory offers a more inclusive model of citizenship than the cognitively oriented social citizenship model, as it prioritises cultivating 'a relational environment that supports the capacity of individuals living with dementia for creativity, imagination, and other positive human potentialities' (Kontos and Grigorovich, 2018: 41). By recognising and supporting a person's citizenship status through their embodied and relational agency, relational citizenship can thus involve everyone, unconditionally, including people with more advanced dementia (Kontos *et al.*, 2017).

The need to draw on multiple approaches to provide a more nuanced discussion of such a complex and diverse syndrome is increasingly recognised. Notably, Shakespeare and colleagues (2019) advocate for a relational disability model of dementia that prioritises multiplicity, incorporating both biomedical research into deficits and treatments, and actions to remove social, attitudinal and architectural barriers. The model simultaneously strives to empower people with dementia and acknowledges that 'people with dementia will require support and protection when their disease makes it impossible for them to be active' (1082). Clearly, combining approaches, elsewhere demonstrated by Sabat's (2014) bio-psycho-social model, is necessary to more appropriately engage with the diversity, instability and complexity of dementia. We need to recognise that multiple facets — including biological, psychological, environmental, social and legal — 'interact to produce the experience of disability' (Shakespeare *et al.*, 2019: 1082). As a key component of attitudinal/social barriers and the overall experience of people with dementia, this chapter now turns to consider how dementia is popularly represented in the UK and other Western societies.

2.3 Representing dementia

A recent study by Heap and Wolverson (2020) found that exposing professional carers with a background in biomedical discourses to discourses of embodied communication and personhood shifted how they positioned the act of ‘being with’ people with dementia. ‘Being with’ refers to activities that affect someone’s psychosocial needs, like holding hands and talking, rather than the tasks typically recorded and prioritised in such settings, like eating and dressing. Carers shifted from depicting ‘being with’ people as a luxury separate to paid work, to being a part of it, demonstrating the impact that being exposed to different discourses can have on perceptions and the treatment of people with dementia. The importance of attending to how dementia is represented is widely recognised across the literature, including by people with lived experience who are calling for changes to the language practices surrounding dementia (DEEP, 2014; Swaffer, 2016). As such, this section examines existing research into how dementia is represented in contemporary Western societies, particularly attending to three key groups: the news media, not-for-profit organisations and people affected by dementia.

The news is widely regarded as ‘a window on the world’ (Tuchman, 1978: 1), since it both provides a platform for popularising knowledge about phenomena and helps determine what is seen and thought about (Harvey and Koteyko, 2013). This ‘window’ can change according to the type and focus of news media (e.g., print, televised or digital, mainstream, alternative or specialist, rural or metropolitan, local or national, free or paid-for) and is heavily influenced by, and equally able to influence, its economic and socio-political context (Bednarek and Caple, 2019). The news media has the power to influence governments and major social institutions (including non-profits), as well as to shape the ideas and behaviours of individual consumers (Bednarek and Caple, 2019). This is the case with health, where news media is instrumental in shaping public knowledge, opinions and reactions (Picard and Yeo, 2011). However, the media’s role is to attract and engage readers, not to tackle stigma or disseminate messages from dementia organisations (Kelly, 2019). It is therefore important to study how dementia is communicated in the news media, as certain events, social groups, solutions and courses of action will inevitably be prioritised here over others (Harvey and Koteyko, 2013).

Meanwhile, not-for-profit organisations are key sources of information, support and advocacy for people with dementia and their supporters, as well as for researchers, the news media and the wider public (Lawless *et al.*, 2018; Taylor and Yardley, 2014). By non-profits, or charities, I refer to established organisations that are run for the psychological and/or physical benefit of a particular community rather than to make a financial profit – indeed, the word charity is derived from the Latin ‘caritas’, meaning care (Malik, 2008). Non-profit organisations include local not-for-profit groups such as Memory Cafés, as well as national charities like the Alzheimer’s Society, and advocacy groups, such as the Dementia Engagement and Empowerment Project (DEEP), which is a rights-based UK network of dementia voices, consisting of approximately 80 groups of people with dementia aiming to enact change (DEEP, 2021). They also include international organisations, such as the World Health

Organisation (WHO), and international advocacy groups like Dementia Alliance International. That it is common practice to reference non-profits in the news media (Bailey, 2019), or in academic texts (this thesis included), exemplifies non-profits' positioning as experts on dementia. Not-for-profits are key drivers of dementia research, policy changes, advocacy and social interventions such as anti-stigma campaigns (Alzheimer's Disease International, 2012, 2019; Devlin *et al.*, 2007; World Health Organisation, 2017). However, not-for-profits have agendas; they must fund and justify their philanthropic work, much of which requires continued public and government support. As such, research has identified an increasing marketisation of the non-profit sector, with ever-growing competition for public attention and funding (Nikunen, 2016). In response to this socio-political context, Mautner (2005) argues that non-profit discourses are increasingly resembling the promotional discourses traditionally associated with the private sector, such as the news and advertising. There is thus an inherent tension between garnering public attention and concern to maintain financial sustainability, much like the news media, against improving understanding and helping people with dementia.

Finally, the voices of people affected by dementia are increasingly influencing how dementia is represented. This is seen through memoirs (Mitchell, 2018; Zimmermann, 2017), blogs (Castaño, 2020), social media (Talbot *et al.*, 2020), advocacy work (Bryden, 2016), contributions to research (Bryden, 2020; Swaffer, 2014) and advisory roles, such as on communication guidelines for dementia (Alzheimer's Society, 2018; Bould, 2018; DEEP, 2014). Although historically the voices of people without dementia, such as carers and family members, have been prioritised over people with dementia, there is an increasingly rich repertoire of work by and with people with dementia, who are being better recognised as experts through experience and emphasising that there should be 'nothing about us, without us' (Bryden, 2016, 2019). However, as this chapter will demonstrate, the full potential of people with dementia to contribute to how dementia is represented is yet to be realised, with the perspectives of people with lived experience commonly being ignored in popular media (Bailey, 2019; Clarke, 2006).

Representations are considered in relation to the current overarching binary between what McParland, Kelly and Innes (2017) term 'tragedy' and 'living well' discourses, which overwhelms contemporary discussion of dementia. Here, the 'tragedy' discourse refers to a biomedical approach to dementia that emphasises loss of function, decline and death, whereas the 'living well' discourse, as a challenge to the former, instead shifts the focus to supporting people's remaining strengths and appreciating enduring personhood throughout dementia (McParland *et al.*, 2017: 83). Before examining these representations in more detail, it is worth outlining a key theory for the framing of dementia representations: news values.

2.3.1 News values

News values, namely what makes an event, person or social phenomenon newsworthy, are a useful reference point for examining representations of dementia across media types, here the news and non-profits. Galtung and Ruge's (1965) seminal work theorised some of these factors (e.g., frequency, cultural proximity, intensity, unexpectedness and consonance) and emphasised that a threshold must be passed in order for something to be deemed sufficiently newsworthy to be recorded. This thesis follows the more recent multimodal discursive approach to news values as theorised by Monika Bednarek and Helen Caple, which builds on the above. Here, rather than events having a fixed or inherent newsworthiness, news values are regarded as existing in and being constructed through discourse(s), which the news media both draws upon and contributes to when constructing a topic or text's newsworthiness (Caple and Bednarek, 2016). As such, particular aspects of a news story and specific news values can be backgrounded or foregrounded in texts through a range of semiotic resources, including words, format and image features (Bednarek and Caple, 2014). The key news values proposed by Bednarek and Caple are outlined in Table 2.2 below.

Table 2.2 ***Summary of different news values***

News value	Definition
Negativity / Positivity	Negativity concerns the negative aspects of an event or issue. News regularly prioritises 'bad' happenings such as conflicts, damage or disasters. Its opposite, Positivity, concerns events constructed as positive (e.g., success, peace, heroic or kind acts).
Timeliness	An event/issue's relevance in terms of time (recent, ongoing, about to happen or seasonal).
Proximity	An event/issue's geographical or cultural nearness.
Superlativeness	An event/issue's scope or size (the larger, the more newsworthy).
Eliteness	The higher the status of the individuals (e.g., celebrities, politicians), organisations or nations involved, including as quoted sources, the more newsworthy.
Impact	The high significance of an event/issue in terms of its effects/consequences. Serious consequences or a national/global impact are more newsworthy.
Novelty	The new and/or unexpected aspects of an event/issue. Unusual, surprising or rare stories are more newsworthy.
Personalisation	The personal or 'human' face of an event/issue (including eyewitness reports) is more newsworthy than generalised concepts or processes. E.g., a science story is more newsworthy if it directly impacts people.

Consonance	The stereotypical aspects of an event/issue. Adhering to expectations about people, organisations, institutions or countries makes an event/issue more newsworthy.
Aesthetic Appeal	The aesthetically pleasing aspects of an event/issue (visual only). This can be through content (showing people, places, objects and landscapes culturally recognised as beautiful) and camera technique (using dynamic, asymmetric composition, alongside lighting, colour contrast and shutter speed for artistic effect).

Adapted from Bednarek and Caple, 2012, 2017, 2019; Caple and Bednarek, 2016.

News values provide a useful framework for examining social representations of dementia, here with a particular focus on newspapers and dementia non-profits. The news values of negativity and positivity map especially well onto the existing dichotomy issue in dementia representations, with an overall emphasis on portrayals that emphasise the negative aspects of dementia ('tragedy' discourse) that has resulted in a more recent push for portrayals highlighting positive aspects ('living well' discourse) (McParland *et al.*, 2017). This is the focus of the subsequent sections, within which I also draw on other news values, such as the role of stereotypes in relation to dementia (consonance), and the valuing of voices of individuals and organisations regarded as more elite, as opposed to the voices of people with dementia (eliteness). Often, these news values overlap, and below I particularly attend to the interrelationship of negativity and consonance. Namely, if negative portrayals are consistently presented, this contributes to negative stereotypes of dementia and the reinforcement of these by subsequent portrayals that adhere to this narrow stance, since observing these negative expectations can increase newsworthiness (Bednarek and Caple, 2019).

2.3.2 'Tragedy' discourse: victims and heroes

A biomedical approach remains the primary lens through which dementia is represented in contemporary society, with the emphasis on loss, degeneration and death driving what is commonly referred to as a 'tragedy' discourse (McParland *et al.*, 2017). This tragedy discourse dominates media portrayals (Van Gorp and Vercruysse, 2012), including newspapers (Bailey, 2019), with multimodal analyses demonstrating that this discourse is realised both linguistically and visually (Brookes *et al.*, 2018; Harvey and Brookes, 2019). While non-profit organisations tend to align themselves with the 'living well' discourse, multimodal analysis reveals that public health campaigns raising awareness about dementia can still perpetuate the tragedy discourse's emphasis on loss and degeneration, and disempower people with dementia (Brookes *et al.*, 2021). Equally, people affected by dementia draw on the tragedy discourse to express suffering and loss with dementia (Zimmermann, 2017), including expressing the impact of having dementia on psychological wellbeing (Castaño, 2020).

Being grounded in a biomedical approach to dementia, the tragedy discourse emphasises cognitive losses (especially memory loss), the disease process and degeneration until death (Beard *et al.*, 2009b). Popular media tends to elevate biomedical experts and technologies, whilst summarising their meaning for general audiences using metaphor and simplified language, such as reducing the many symptoms of dementia to memory loss (Bailey, 2019; Basting, 2009). Notably, images of brain scans are consistently used to represent dementia (Brookes *et al.*, 2018; Harvey and Brookes, 2019). Brain scans are popularly regarded as iconic and objective instruments of science, ignoring their inherent subjectivity, as multiple choices throughout the process influence the finished product (Dumit, 2004). Due to their expert status (eliteness news value), scans have immense persuasive power for viewers, but are very vulnerable to misinterpretations, especially when simplistic captions such as 'Scan of a person with Alzheimer's disease' insufficiently contextualise exactly what these highly specialised, technical outputs show (Brookes *et al.*, 2018: 387).

In response to the complexities of biomedical explanations of dementia, metaphors are frequently used. This reflects the importance of metaphors to how we understand and communicate complex and abstract notions, such as (ill) health, in a more imaginable and accessible way (Lakoff and Johnson, 1980; Semino, 2008). For example, British newspapers frequently envision the body as a failing machine, relating the processes of dementia to everyday ones by likening increasing plaques and tangles in the brain to waste in a pipe or a faulty computer system, which simplifies the complex neurobiology and supports science's ability to 'fix' what is 'broken', much like an engineer (Bailey, 2019). As Bailey and colleagues (2021) argue, this has multiple ideological implications, including attributing machine-like characteristics to humans and emphasising the individual above their socio-political context. Metaphors, therefore, are powerful framing devices, since they foreground certain aspects of a scenario while downplaying or ignoring others, shaping cultural responses to dementia through either naturalising or challenging specific worldviews, and encouraging certain behaviours, often without people even being aware of the metaphor's influence (Johnstone, 2013).

Dementia causing the body/machine to break down is just one of many metaphorical scenarios that position dementia as a threat. By 'scenario', I refer to a specific mental representation of a broader metaphorical concept; scenarios incorporate particular situations and associated settings, entities, goals and actions within a broader conceptual domain, here, threat (Semino, 2008: 10). Dementia can be positioned as a biological threat (a bacterial agent, an epidemic), an immoral physical threat (an invader/thief/monster), an unstoppable natural threat (tsunami, flood), a death threat (death sentence, killer) and a threat to self (people with dementia as the living dead) (Behuniak, 2011; Brookes *et al.*, 2018; Johnstone, 2013; Van Gorp and Vercruysse, 2012; Zeilig, 2014a). This metaphorical conceptualisation of dementia as a threat is so integral to popular understandings of the syndrome that Zeilig (2014a: 262) argues that dementia has itself become a metaphorical device, whereby 'Dementia = a complex, unknowable world of doom, ageing, and a fate worse than death'. Indeed, dementia is the most feared condition in the UK (Alzheimer's Society, 2016). Positioning dementia as such a frightening, powerful threat not only creates panic about dementia (Peel, 2014), but transforms people with dementia into diseased victims, with those without dementia dreading themselves or their loved ones developing it (Whitehouse and George, 2008: 102).

Scientific and medical breakthroughs, alongside the experts working on them, are commonly positioned as the heroes needed to fight against the threat of dementia (Van Gorp and Vercruysse, 2012). This battle metaphor reflects a common health communication trend of comparing illnesses to a war to be fought, both individually and collectively (Semino, 2008). Viewing dementias such as Alzheimer's disease as 'a physical disease, not some mystic curse', that 'will fall to a physical cure' facilitates a collective optimism by empowering humanity to rationalise and envisage defeating a condition that the individual 'can't battle' or be 'a plucky "survivor" of' (Pratchett, 2008: x). Although the collective fight can sometimes be for awareness and equality (Castaño, 2020), it more often positions scientific advancement as the hope of fighting, and eventually defeating, this enemy (Bailey, 2019; Van Gorp and Vercruysse, 2012). As discussed in section 2.2.1, such faith overlooks the uncertainty in the medical community regarding dementia as a syndrome and whether a cure is attainable, problematically prioritising a future cure above caring for people with dementia now (Lock, 2013). Individually, the idea of fighting one's dementia symptoms can be useful for people to respond agentively to their condition (Castaño, 2020), but when applied to this progressive and currently incurable syndrome, the metaphor may evoke feelings of inadequacy for ultimately being unable to 'win' (George and Whitehouse, 2014; Lane *et al.*, 2013).

It is the 'heroes' whose voices are most often heard in popular discussions of dementia. Scientific, political and medical elites, who are involved in financing, conducting and applying biomedical science are attributed the authority to explain, discuss and respond to dementia over those who are experiencing the condition (Bailey, 2019; Brookes *et al.*, 2018; Clarke, 2006). In line with the news value of eliteness (Bednarek and Caple, 2017), elite individuals from these groups (such as researchers, medical professionals, prime ministers, directors of research and leading figures for charities) are most frequently quoted in the news (Bailey, 2019). Increasingly, as part of the neoliberal turn of healthcare, whereby responsibility for health is shifted from the governing state to the individual citizen (Hunt and Koteyko 2015), elite spokespeople are sharing advice on how to reduce one's risk of developing dementia. This downplays the role of other social, systemic, and contextual factors for health (Lawless *et al.*, 2018) by foregrounding how the lay individual should act, according to the scientific and medical advice, to prevent (or at least manage and postpone) dementia, and thereby remain the ‘ideal’ person – ‘active, productive, fit’ (Latimer, 2018: 842). Peel (2014) identifies a ‘panic-blame’ framework in the British press, whereby representations of dementia as a catastrophic epidemic, firmly distinguished as a pathology separate from normal ageing, are juxtaposed against an emphasis on how individuals can ‘stave off’ dementia through particular behavioural practices and lifestyle changes, such as diet, physical and mental activity. Dementia is thus simultaneously overpowering and disastrous, yet preventable through following the advice of biomedical elites. The advice provided is questionable, with contradictory information emerging even in the one-year period Peel observes, with different articles recommending both low-fat and high-fat diets to help avoid Alzheimer’s disease. Emphasising responsibility for preventing dementia risks blaming people with the condition by implying that they have somehow failed to take the appropriate preventative measures advocated by experts (Peel, 2014; Swaffer, 2016). This can intensify stigmatisation and influence how people with dementia perceive themselves and are treated by others in their community, the medical field and at a government level (Lawless *et al.*, 2018).

This broad tragedy discourse, then, largely defines people with dementia as victims and passive patients who are reliant on the help of carers and biomedical experts, overwhelmingly ignoring the perspectives of people with dementia, as if they are ‘other’ to the general populace and do not have their own voices, needs and desires (Bailey, 2019; Brookes *et al.*, 2018; Clarke, 2006). Recent multimodal studies demonstrate that this positioning occurs both linguistically and visually in a range of sources, including newspapers, public health campaign posters, picturebooks and stock images (Brookes *et al.*, 2018, 2021; Caldwell *et al.*, 2021; Harvey and Brookes, 2019). In picturebooks, once grandparent characters have obvious memory problems, they are drawn as more passive and sedentary than before, often with a ‘blank expression’ and enhanced signs of ageing (Caldwell *et al.*, 2021: 121). Brookes and colleagues (2018: 384) demonstrate that photographs similarly direct viewers to ‘see the disease (or an aspect of its manifestation) before and perhaps instead of the person’. They identify particular visual tropes for representing people with dementia, which include brain scans, disembodied close-up shots of wrinkled hands, shots of people looking down with blank expressions, people who are subordinate to caregivers, and metaphorical images that connote loss of self (Brookes *et al.*, 2018; Harvey and Brookes, 2019). Notably, these are all stock images, an increasingly popular framing device, whereby an image bank, such as the industry leader, Getty Images, provides a database of millions of images that designers and text producers can search using key words and then purchase for a license fee (Harvey and Brookes, 2019). Their popularity makes image banks a leading force in shifting the world’s visual language from one that emphasises photography as a witness of reality, to one that emphasises photography as a symbolic system (Machin and van Leeuwen, 2007: 151).

According to Machin and van Leeuwen (2007), stock images are defined by their genericity, 'timelessness' and low modality. Rather than capturing 'specific, unrepeatable moments' (152), stock images are more 'timeless', as they denote general concepts, people, places and things through decontextualised backgrounds, props to connote attributes (such as a computer to signify work) and generic models and settings. Stock images tend to have a low modality; as the heightened colours and coordinated arrangements indicate, they favour abstract, sensory and emotive truths over a naturalistic one. Such genericity means that stock images tend to 'merely reflect or reinforce dominant [Western] ideologies' (Bednarek and Caple, 2017: 192). The danger is that such images come to represent 'the whole of a particular time, place and way of life', whereby 'we gradually come to accept them as showing us how the world really is' (Machin and van Leeuwen, 2007: 157). In the case of dementia, it is concerning that the top 100 images selected by Harvey and Brookes (2019) continually objectify and disembody people with dementia, as conveyed by a set of older actors in generic, isolating scenarios, taking disengaged and suffering oriented positions that evoke social distance from viewers.

Showcasing the contribution of conducting multimodal critical discourse analysis (see section 3.2.3), Brookes and colleagues (2018, 2021; Harvey and Brookes, 2019) unpack how these images realise this 'othering' of people with dementia. For example, they demonstrate how shots of people touching their heads and looking downcast, often sedentary and alone, visually foreground the concept of suffering from symptoms of dementia (including through the head→brain→memory loss link and people's pained expressions), alongside isolation and passivity (Brookes *et al.*, 2018). Directing the participants' gaze away from viewers discourages any social affinity with people living with dementia, instead impersonally 'offering' them as 'items of information, objects of contemplation', much like 'specimens [of people with dementia] in a display case', rather than as people with whom viewers can form relationships (Kress and van Leeuwen, 2006: 119). This perpetuates focusing upon the 'diseased brain' and its symptoms above the person who has dementia, creating a sense of an 'us' of people without dementia with normal/healthy brains, distanced from the 'them' of people with dementia, who are somehow damaged (Harvey and Brookes, 2019). As well as reinforcing stigmatisation through creating a social and psychological distance (McParland *et al.*, 2017), focusing upon a person's (damaged) brain risks indicating that 'everything a person with dementia does and feels is the outcome of brain damage and is abnormal in one way or another', therefore overlooking other social, psychological and structural factors (Sabat, 2014: 108).

Conflating a person with their brain reproduces the problematic discourse in which, rather than there being multiple ways of being human, the brain 'harbours all that defines the self' (Zimmermann, 2017: 81). Here, 'hypercognitive' values of rationality, independence, self-control, economic productivity, and cognitive enhancement define a person (Post, 2000a: 245). As such, people with dementia are perceived to inevitably experience a gradual loss or ‘unbecoming’ of self as a result of their cognitive deterioration (Fontana and Smith, 1989). This continues until people with dementia become ‘empty shells’ with ‘no identity’ (Van Gorp and Vercruysse, 2012: 1276-7), a conceptualisation that deprives people of any further agency as human beings (Zimmermann, 2017) and can cause people with dementia to be treated as if they are socially dead (Sweeting and Gilhooly, 1997). Extending the healthy/unhealthy ‘us’ versus ‘them’ narrative to a human versus inhuman one, people with dementia are often metaphorically positioned as the living dead, both linguistically (Aquilina and Hughes, 2006; Behuniak, 2011) and through visual tropes such as blankness and dull, lifeless tones (Brookes *et al.*, 2021; Harvey and Brookes, 2019). Behuniak (2011: 74) compellingly argues that when aspects of the biomedical model (such as a focus on abnormality, degeneration and the disease above the patient) are combined with the zombie metaphor, this ‘infuse[s] stigma with disgust and terror’ and delegitimises people with dementia as fellow humans. A similar effect is created by the association of dementia with ageing, as indicated by stock images of aged hands to portray dementia (Brookes *et al.*, 2018). Associations of ageing and the illnesses and death that it inevitably entails have become embroiled with dementia to the point that it has become a cultural ‘metaphor for fears of aging’ (Zimmermann, 2017: 88), epitomising the cognitive losses, behavioural changes and physical weakening that are seen to commonly accompany older age. Combined with the foregrounding of dementia’s terminal stages, which positions this as representative of the entire experience (Van Gorp and Vercruysse, 2012), representations risk ‘equating all forms of dementia with death’ (Taylor, 2008: 323). As such, people with dementia frequently portray their diagnosis as a ‘death sentence’ — although notably, people often rescind this view after realising the threat is not as imminent as representations convey (Castaño, 2020).

While it is important to acknowledge older age and dementia as a site of suffering (Castaño, 2020; Gilleard, 2018), popular media has been consistently criticised for unduly foregrounding such suffering over other aspects of life with dementia (Bailey, 2019; Brookes *et al.*, 2018; Van Gorp and Vercruysse, 2012). Equally, the devaluing of people with dementia manifests through overly focusing on the experiences of carers, family, friends and society, presenting people with dementia as a ‘burden’ and those around them as the ‘real victims’ (Gerritsen *et al.*, 2018; Taylor, 2008; Van Gorp and Vercruysse, 2012). Returning to the news value of consonance, it is concerning that the predominant representation of dementia is so negative; although there are some counter examples, research indicates that overall, dementia remains positioned as a biomedical and existential threat, imbued with fears surrounding ageing and death, that victimises and erodes the identities and social status of people with dementia (Low and Purwaningrum, 2020). The accumulative impact of these stereotypical representations is severe, since regarding people with dementia as sub-human due to their cognitive changes encourages fear and repulsion rather than sympathy and care (Aquilina and Hughes, 2006; Behuniak, 2011), greatly increasing the risk of violations to people's human rights (Cahill, 2018). Consequently, the counter discourse of 'living well' has become more prominent in recent decades, which I outline further below.

2.3.3 Communication guidelines and 'living well'

Although it is yet to significantly integrate into popular portrayals of dementia, the 'positive', or 'living well' discourse has become increasingly prominent in non-profit, advocacy, research and policy circles (McParland *et al.*, 2017). This discourse is inspired by the counter approaches to biomedicine discussed in section 2.2, as it foregrounds enduring personhood and people's strengths, aligning with a rights-based approach to dementia in its emphasis on the fact that people with dementia can live well, and that society needs to support people to do so. Importantly, this discourse recognises that people with dementia are experts through experience and have much to contribute (Bryden, 2016, 2019). The accounts and perspectives of people with dementia are integral to reinforcing that people with dementia can live well, whether in person, on social media or otherwise (Beard *et al.,* 2009b; Hillman *et al.*, 2018; Talbot *et al.*, 2020). Examples of this discourse in popular media include representing people with positive emotions (Kessler and Schwender, 2012) and showing people with dementia experiencing growth, exercising agency and contributing to society, whether by setting up a charitable foundation or, in later stages, expressing love through words, hugging and other physical signs of affection (Low and Purwaningrum, 2020).

That the living well discourse exists to directly challenge the disempowering implications of the tragedy discourse is exemplified by the attempt to replace overly negative and demeaning communicative practices. This tends to occur as a collaboration between people affected by dementia and not-for-profit groups. Multiple 'dos and don'ts' of representing dementia have been published to popularise 'words and descriptions that are accurate, balanced and respectful' (DEEP, 2014: 1) and that focus 'on our remaining abilities, not on our many and increasing deficits' (Bryden, 2016: 222). Terms that appeared throughout the above section are criticised for being depersonalising and othering, including phrases that are suffering-oriented and passivising (e.g., 'sufferer' and 'victim'), overly medicalising (i.e. 'patient' and 'service user' outside of a hospital or care service context), fear-inducing ('epidemic' and 'plague'), ageist ('senile'), undermining of personhood and selfhood ('demented', 'empty shell' and 'living death'), and that are otherwise demeaning (as with discussions of people with dementia as a 'burden' or 'dotty') (Alzheimer's Society, 2018; DEEP, 2014). Person-oriented alternatives are recommended instead, including the unabbreviated terms of people 'with dementia', 'living with dementia' or 'with a diagnosis of dementia' to better value individuals with dementia and reduce stigmatisation through language (Alzheimer's Society, 2018). More explicitly positive terms, such as 'people living well with dementia' (DEEP, 2014) or 'living beyond dementia' (Swaffer, 2016) are also proposed as alternatives to better empower people with dementia and counteract passivising stereotypes. Representations of 'living well' are deemed important, as they prioritise having meaning, agency, growth, social participation and life satisfaction, alongside considering the role of society in supporting this (Morgan, 2018). This builds on the rights of people with dementia, as outlined in section 2.2.3.

The importance of visual communication is also increasingly recognised, including the potential for images to be damaging if they create or reinforce a generalisation of who someone with dementia is and how they behave (Bould, 2018). Notably, generic stock images of isolated, older white women shown holding their head in their hands are challenged as a trope in stories about dementia (Bould, 2018). Similarly, DEEP (2014: 4) recommend that 'when talking about someone trying to live a positive life, use an image that reflects the whole person rather than a fading face or wrinkled hands'. There are many examples of more nuanced, person-oriented and empowering images, such as Cathy Greenblat's (2011, 2012, 2021) photography, which captures moments with people with dementia in a range of settings across the world, often showcasing aspects of ordinary life and 'moments of joy and connection' (Greenblat, 2011: 1363). Focusing on a positive ageing discourse, the Centre for Ageing Better (2021) has released a free image library of positive and diverse representations of older age, with people being active and socially engaged. These provide an alternative to commercial image banks, which are biased towards more negative, 'othering' depictions (Harvey and Brookes, 2019).

Countering these positive shifts, however, are examples even from organisations such as the Alzheimer's Society, which broadly aligns with a 'living well', rights-based discourse, that catastrophise dementia and disempower people with dementia. Brookes and colleagues (2021) show how a public awareness campaign, made in the 2010s by the Alzheimer's Society and the National Health Service (NHS) to encourage diagnoses, visually 'others' individuals with dementia and represents them as fading selves, while linguistically addressing people without - not with - dementia. Engaging with the news value of negativity, the posters overwhelmingly focus on negative experiences and potential consequences of memory loss (the only symptom discussed), such as 'nearly burn[ing] the house down' (Brookes *et al.,* 2021: 255). This example demonstrates an inherent issue with the dichotomy between 'tragedy' and 'living well' discourses for dementia: that the variance between tragedy-oriented scare tactics and the living well discourse is confusing, diluting and leaves many people trying to live well with dementia in a disenfranchised way, insufficiently supported by the systems surrounding them (Rahman, 2015: 51).

The living well discourse has itself received substantial criticism. Firstly, it can evoke self-stigma in people with dementia through what Fletcher (2019a: 6) terms 'benevolent othering', whereby in situating people with dementia as exceptional and needing special treatment, campaigns can inadvertently position people with dementia as a social 'other', separate from the general public. Moreover, the positive focus of 'living well' risks sanitising negative experiences (Fletcher, 2019a) and thus denying people the ability to express their pain, despair and moments where they do not, or cannot, 'live well' (Bartlett *et al.*, 2017). The pressure of normative expectations of what someone with dementia 'should' be like can be oppressing for individuals with dementia and cause 'dementia-related fatigue' for those advocating for 'living well', who may feel that they are 'putting on a show' (Bartlett, 2014). This is especially problematic when combined with an internalisation of the neoliberal responsibilisation of individuals for their health, as the emphasis is on the individual rather than existing inequalities and necessary social action to support 'living well' (Hillman *et al.*, 2018; Wu *et al.*, 2018). Reflecting on his experience of dementia, activist Keith Oliver highlights that 'this living well with dementia is very important and it is something we aspire to… but it's not easy. It can become almost a rod for your own back that you feel you're failing to live well with dementia therefore you're a failure' (Bartlett *et al.*, 2017: 178). As Gilleard (2018) highlights, ignoring suffering is likely to make it worse, and only attending to positive aspects of ageing and dementia can restrict social change by denying the seriousness of the issues. Equally, although a living well discourse prioritises the voices of people living with dementia, these are disproportionately younger, well-educated individuals experiencing less challenging stages of their condition (Fletcher, 2019a; Talbot *et al.*, 2020). As a progressive condition, the living well discourse risks dividing people with dementia into those who are living successfully with dementia and those who can no longer maintain society's notion of living well, perpetuating the rejection of the most cognitively impaired, frail and disadvantaged individuals (McParland *et al.*, 2017: 89).

Increasingly, people are calling to move beyond the simplistic dichotomy of either idealising or catastrophising dementia, towards more accurately reflecting and supporting the multiple realities of dementia, which includes facets of both the tragedy and living well discourses (McParland *et al.*, 2017: 91). As such, charities like YoungDementia UK (2020) emphasise that language must be realistic and able to reflect that person's experience at that time, such as 'life-changing', 'challenging', 'painful', 'debilitating', 'devastating', 'distressing' and 'stressful'. Communicative tropes need to be nuanced, flexible and prioritise the preferences of individuals with, and otherwise affected by, dementia (Alzheimer's Society, 2018; DEEP, 2014). As Gerritsen and colleagues (2018) highlight, very few representations can be considered entirely 'good' or 'bad', and the same metaphor, image or phrase can have entirely different meanings for different people. For instance, the term 'dementia friendly' may be celebrated as representing a move towards a more supportive society for people with dementia (Alzheimer's Society, 2021), or criticised as patronising and misleading (Shakespeare *et al.*, 2019; Swaffer, 2014). Equally, conceptualising dementia in terms of a battle may place undue pressure on individuals (George and Whitehouse, 2014), or provide an outlet for expressing agency and communicating the psychological impact of having dementia (Castaño, 2020).

2.3.4 Lived experience

Despite the pervasiveness of dementia in society, as indicated above, there remains a deficit of contributions from people with dementia themselves, especially in the popular media. As such, following Beard (2016: 6), this section asks: where are the perspectives of people with dementia and what can they contribute to the cultural dialogue that so influences experience? Increasingly, research is attending to the accounts of people with dementia, as well as carers and loved ones. This includes through blogs (Castaño, 2020), social media (Talbot *et al.*, 2020), forums (Bailey, 2020), memoirs (Zimmermann, 2017), poetry (Killick, 2017), surveys (Beard *et al.*, 2009b), and interviews (Beard, 2016; Buggins *et al.*, 2021; Fletcher, 2020b, 2020c; Hillman *et al.*, 2018). Some people with dementia and carers are also single or co-authors of papers, and thus directly contribute to the synthesis and presentation of their perspectives (Bartlett *et al.*, 2017; Beard *et al.*, 2009b; Bryden, 2020; Davies *et al.*, 2021).

Countering the reductive nature of many popular portrayals, the accounts of people with dementia tend to be more multifaceted, drawing on multiple discourses and demonstrating a complex interaction between positive and negative aspects of a person's lived experience (Beard, 2016; Buggins *et al.*, 2021; Hillman *et al.*, 2018). In a multitude of ways, dementia poses an existential threat to individuals' lives and sense of identity (Cheston *et al.*, 2015). As well as the impact of condition-related changes on people's lives, individuals' accounts commonly feature attempts to maintain some continuity in life and identity when faced with such change, and the role of contextual factors such as interpersonal relationships and the environment, both physical and sociocultural (Górska *et al.*, 2018). People with dementia report a range of emotional, cognitive and behavioural coping strategies for managing the 'ups and downs' of life with dementia (Beard *et al.*, 2009b), including focusing on the positives, humour, acceptance, denial, compensation, adapting routines and seeking help (Beard, 2016; Górska *et al.*, 2018). Humour is a prominent means of coping with and managing the identity threats that having dementia can cause (Birt *et al.*, 2020; Hickman *et al.*, 2020), although as Fletcher (2020a: 416) highlights, the success of humour is fragile, and it thus has the interactional potential 'for good or bad'. As well as strengthening social bonds and managing conflict during emotionally charged scenarios, humour can be used as 'an act of resistance against dominant paradigms', notably loss of self (Beard, 2016: 155).

There is a clear tension between continuity and change in both people's lives and identities (Caddell and Clare, 2011). People with dementia emphasise that their condition is something they 'happen to live with' rather than being defined by (Bryden, 2019: xii) and present more holistic self-presentations that incorporate dementia as one facet of self (Beard *et al.*, 2009b). Individuals with dementia regularly challenge the discourse of loss of self, with Bryden (2020: 79) offering a counter-discourse of her continuing sense of self that results from 'finding meaning in life and developing a sense of identity in the present moment, not based on events in the past'. Yet, there is simultaneously a concern about loss with this condition (Buggins *et al.*, 2021), which is demonstrated by bloggers with younger onset dementia expressing fears of losing themselves or undergoing an undesired transformation into another person over time (Castaño, 2020). Aside from dementia, a diverse range of factors affect an individual's sense of identity and positioning in the world, including gender, class, race, ethnicity and sexuality (Boyle, 2017; Hulko, 2009; O'Connor *et al.*, 2010). Hulko (2009) highlights that the extent to which dementia is viewed as problematic for a person's life and identity is related to the social location of the affected individual, suggesting that people with multiple privileges in gender, race, ethnicity and class are more likely to regard dementia negatively than people who are multiply marginalised, who will more likely dismiss dementia's significance and resist being viewed in relation to their condition.

Regarding how visible an individual makes dementia within their presentation of self, Fletcher (2020a) notes a direct conflict of interest between carers and people with dementia. Whereas people with dementia are more likely to conceal dementia-related impairments, likely due to a fear of being unfavourably perceived, many carers actively work to increase the visibility of dementia, as it legitimises their self-presentation as a carer and benefits them through institutional and interpersonal allowances. Such an example foregrounds the importance of distinguishing between carers and people with dementia, and attending to conflicts of interest when representing themselves, each other and dementia. Indeed, Beard *et al.* (2009a) observe supporters/carers to be generally more medicalised and negative in their expressed views on having dementia, compared to people diagnosed. More recently, when considering empowerment for people living with dementia, diagnosed individuals focus on individual needs and wishes, while carers prioritised the wider environment (van Corven *et al.*, 2021). Of course, carers also vary in their experiences, personalities, approaches and overall self-presentations (García-Castro *et al.*, 2021; Wawrziczny *et al.*, 2017), so it is important to foreground the heterogeneity of both carers and people with dementia. Simultaneously, many individuals with dementia cultivate a collective identity rather than focusing on a personal one (Bartlett, 2014; Talbot *et al.*, 2020). A sense of solidarity can emerge amongst people affected by dementia (people with lived experience and carers alike) through shared experiences and reciprocal support, which can contrast a sense of social distance from others, such as healthcare professionals (Hillman *et al.*, 2018; Keyes *et al.*, 2016).

When representing the condition itself, people affected by dementia tend to integrate multiple discourses to describe their personal understandings of dementia, which may reinforce, adapt or challenge the more hegemonic discourses discussed in the above sections (Beard, 2016; Fletcher, 2020b; Hillman *et al.*, 2018). Notably, many individuals with dementia reinforce a living well discourse through emphasising positive aspects of their lives (Beard *et al.*, 2009b; Talbot *et al.*, 2020), which is often evaluated as less problematic than a 'negative' discourse, even if not wholly accurate of 'this wretched disease' (Hillman *et al.*, 2018: 884). Yet a living well discourse can also be resisted, including by arguing that *not* living well should be okay too, or adapted, for instance, by foregrounding individual choices versus a person's social environment (Hillman *et al.*, 2018). Likewise, a range of adaptations result from people negotiating tensions between the hegemonic biomedical discourse and personal knowledge and experiences of dementia, including the role of relationships, environments and wider communities (Beard, 2016; Fletcher, 2020b; Hillman *et al.*, 2018). Tensions between 'positive' and 'negative' aspects of different discourses are also negotiated; individuals interweave elements of loss with growth, passivity with proactivity, and fear with pleasure, to establish multi-dimensional accounts that draw on the loss, fear and pathology aspects of the 'tragedy' discourse, alongside the strengths, support and growth of the 'living well' discourse (Buggins *et al.*, 2021: 1245). Overall, then, people with lived experience provide more nuanced accounts of dementia that incorporate biomedical, social, relational, embodied, emotional and spiritual understandings, alongside both positive and negative aspects of life with dementia (Beard, 2016; Hillman *et al.*, 2018). Such understandings are fluid and can be renegotiated throughout the progression of dementia, as they are both formed by and formative of a person's experiences, and greatly impact sense of identity (Beard, 2016; Fletcher, 2020b).

2.3.5 Responding to representations

Relatively little research directly addresses the interpretations and perspectives of people affected by dementia in relation to popular representations. Of course, numerous advocates with dementia have spoken out against demeaning language practices (Bryden, 2020; Swaffer, 2014, 2016), and communication guidelines have been created by or in consultation with people affected by dementia (Alzheimer's Society, 2018; DEEP, 2014). Notably, Devlin and colleagues (2007) consult people with dementia, carers and the general public to determine future directions for mass media awareness campaigns, raising the need to provide realistic images of people with dementia and avoid fear-inducing ones. However, their study orients around the perceptions, knowledge and attitudes of the general public, and the attitudes and lifestyles of people affected by dementia, rather than considering how individuals interact with particular representations. One Belgian study by Van Gorp and colleagues (2012) does directly address responses to fictional dementia awareness campaign posters, although they only consider how the general public respond to dominant and counter discourses, or frames, of dementia. In the study, survey respondents evaluate the headline referencing death and degeneration ('Helga, already buried by her friends and family, and yet she's still alive') as more attention-grabbing, comprehensible and credible than the alternative headline, which is concerned with the person's humanity and enjoyments ('Helga is losing her memory and her memories little by little, but she still cheats at whist'). It is worth noting that despite the importance of visual communication, only specific language examples are studied by Van Gorp *et al.* (2012). Their study uses images as a control variable, with all photos standardised as black and white close-up shots of people with Alzheimer's disease, none of whom make direct eye contact with the viewer. This reproduces the sense of social distance between viewers and represented participants critiqued in section 2.3.2 (Brookes *et al.*, 2018, 2021; Harvey and Brookes, 2019).

In other fields, the collective connotations of popular news images are demonstrated, as with Kitzinger's (1993) work with focus groups with varying knowledge of HIV/AIDS (namely, people with occupational interest, people deemed 'high risk' or politically involved, and people with no obvious interest). Groups recurringly reproduce similar messages, such as being unable to tell who has HIV/AIDS from a photo of a crowd, or of 'innocent victims' in response to a photo of a mother and child, supporting the strength of media stereotypes (consonance news value). However, there are always individuals who express contradictions, oppose dominant discourses (such as opposing the idea of 'innocent' versus 'guilty' 'victims') and provide alternative representations, including interpreting the crowd image as showing the world *ignoring* rather than helping people with HIV/AIDS. Such research showcases the heterogeneity of consumers, who are active participants in the construction of meaning in the face of multiple competing versions of reality (i.e. discourses) (Kitzinger, 1993: 300).

In the context of dementia, Rayment and colleagues (2019) have recently interviewed carers using photographs that carers have taken to illustrate their personal experiences supporting someone with dementia. They argue that using photographs is valuable for research, as images can constructively challenge participants, trigger memories, encourage new perspectives and explanations, and facilitate nuance. While the authors focus on these benefits in relation to exploring subjective experiences of caregiving, the strengths of using images equally apply to investigating subjective experiences in relation to popular media portrayals of dementia. When working with people with dementia, images are more often used as conversation aids (Hulko, 2009), including to help with recall (Boyle, 2017). Recently, researchers have begun to examine how people with dementia engage with artwork (Lea and Synnes, 2021; Morgner *et al.*, 2019). Such work focuses on the benefits of engaging with art exhibitions for people with dementia, including the artwork stimulating participants to make connections to their lives and experience, which enables them to take greater control of the conversational floor through their authority on the chosen subject (Morgner *et al.*, 2019). Despite being underexplored, working with visual representations clearly holds great potential for investigating the perspectives of people affected by dementia.

2.4 Summary

This chapter provides the necessary grounding for the present study. It summarises key approaches to dementia that inform contemporary representations, particularly attending to the dominance of the biomedical approach, which has in recent decades been augmented by psychosocial, structural/rights-based, embodied and relational approaches. The second half of the chapter focuses explicitly on representations, especially in relation to three key sources: the news media, not-for-profit organisations and people affected by dementia. A 'tragedy' discourse largely dominates popular representations, which is informed by biomedicine and its emphasis on loss, degeneration and pathology. This has been widely criticised as disempowering people with dementia, motivating its counter discourse of 'living well', which foregrounds people's enduring personhood and assets that, alongside social support, enable people to live well after diagnosis. Of course, the living well discourse has its own limitations, including sanitising negative aspects of dementia (Fletcher, 2019a). People with lived experience of dementia (and carers) navigate tragedy and living well discourses to present more multifaceted presentations of dementia and people with/without the condition. These include both negative and positive aspects, with accounts reinforcing, adapting and challenging dominant discourses. Throughout this chapter, the issues with the current 'tragedy' and 'living well' binary are outlined, alongside the need for representations to better reflect the complexities of dementia and take a more holistic approach to experiences of the condition.

Amongst this comprehensive body of research literature, there remain areas that need further exploration. Notably, although people affected by dementia clearly engage well with instances of visual communication like photographs and artwork, research is yet to directly discuss instances of popular visual representations with this group. The nuanced accounts that are demonstrated in focus group discussions that engage with multimodal media representations of other health concerns, such as HIV/AIDS (Kitzinger, 1993), demonstrate the significant potential in exploring how people affected by dementia engage with popular images and language choices. This thesis thus bridges existing analyst-oriented research into dementia representations with research into the perspectives and insights of people affected by dementia, which have been demonstrated here to be nuanced and able to reinforce, oppose and change dominant discourses of dementia.

Finding ‘ideas and questions [..] and answers to questions that Emma would never have thought of’

- Participant 25

Chapter 3: Methodology

3.1 Introduction

To examine how people affected by dementia position themselves in relation to varying social discourses, this thesis combines multiple methodological and theoretical approaches. The current chapter is dedicated to outlining these, beginning with my theoretical position, in which I explore the key concept of 'discourse' in much greater detail and position myself within the fields of thematic discourse analysis, multimodal critical discourse analysis and positive discourse analysis. From here, I examine the rationale and practicalities of the study, outline my approach to data analysis, and draw on everything in this chapter to reflect on my position as the researcher and what this means for the project.

3.2 Theoretical position

This thesis sits at the intersection of multiple approaches and methodologies, which enables a flexible, data driven approach, as each helps to tease something different out of the data. My main approach is thematic discourse analysis, since I aim to simultaneously showcase important themes across groups and interviews, while also attending to the linguistic details of specific interactions in order to ground the analysis of participants' responses. My background is in multimodal critical discourse analysis, which underpins much of my approach to discourse, particularly my concern with how participants respond to examples of images and phrases/headlines associated with dementia. Within this, I align with the positive discourse analysis research strand, being concerned with the discursive choices of a traditionally marginalised group and aiming to contribute to positive social change through such a focus. I outline these approaches in detail here and consider throughout the chapter how they inform the study's design, implementation and analysis. My theoretical position is integral to my overall position as the researcher, and I direct readers to section 3.5 for further reflections on this.

3.2.1 Discourse(s)

What draws my theoretical stances together is the concept of discourse(s). It is therefore important to begin with an in-depth discussion of what I mean by this key term. Broadly, there are three interrelated ways of envisioning ‘discourse’ (Hamilton *et al.*, 2015). The first is simply that discourse is language above the level of the sentence or clause (Stubbs, 1983). The second additionally emphasises the real-life context of discourse, that it is ‘language in use’ (Brown and Yule, 1983). In this way, discourse goes not only above but beyond the level of the sentence, to consider how language is produced and interpreted in the real world (Cameron, 2001; Schiffrin, 2014). This thesis principally adopts a third understanding of discourse, which builds on the previous two understandings to consider the social role of discourses (which manifest in language and other semiotic modes) in reflecting and shaping social understandings and action. It accepts that our understandings of the world are shaped by the ways of using semiotic resources that are available to us, making much of our reality discursively constructed (Cameron, 2001: 15), since discourses establish ‘parameters of a cognitive “window”’ through which to “see” people and events’ (Pan and Kosicki, 1993: 58-9). Discourses, then, have a dialectical relationship with the situations, stakeholders and structures that frame them – in other words, they are ‘socially constitutive as well as socially conditioned’, as discourses help to *constitute* situations, objects of knowledge, social identities and relationships as well as express them (Fairclough *et al.*, 2011: 394). That is, people’s discursive representations of dementia are informed by prior discourses that they have encountered, including in conversation and the media (socially conditioned). Individuals’ discursive representations function to reiterate and/or challenge existing discourses, and subsequently can influence understandings, interactions, identities and social structures in a multitude of ways (socially constitutive).

The theoretical shift in understanding discourse(s) here is reflected in a change from the singular ‘discourse’ to the plural ‘discourses’, since discourses become defined not simply as language use but as social practices that have plural and often competing possibilities (Cameron, 2001). This is inspired by a Foucauldian view that discourses are not just:

> groups of signs (signifying elements referring to contents or representations) but [...] practices that systematically form the objects of which they speak. Of course, discourses are composed of signs; but what they do is more than use these signs to designate things. It is this more that renders them irreducible to the language (langue) and to speech.
>
> (Foucault, 1972: 54)

Thus, although discourses are manifest in the choices that are made in concrete instances of communication, such as conversations and images, they cannot be reduced to such tangible entities (Fairclough, 2010: 3). Nonetheless, discourses can still be fruitfully analysed through these material forms, and can be usefully conceptualised as being manifest across a range of semiotic modes and resources, in a 'set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events' (Burr, 2015: 32).

Discourses are underpinned by ideologies, which can be defined simply as 'sets of beliefs and values belonging to particular social groups' (Flowerdew and Richardson, 2018: 23). Since discourses are socially constructed forms of knowledge, they inevitably serve or undermine the interests of particular social actors, whether these are institutions (e.g., news organisations) or more informal groups (e.g., researchers, people with dementia and carers) (Kress and van Leeuwen, 2001). It has been widely noted that dominant ideologies, and the discourses that convey them, disproportionately benefit groups with more power and are deeply entwined with normalising and validating particular social structures (Fairclough, 2010). Yet, discourses can always be challenged and changed to better represent the realities that people experience (Bartlett, 2018; Teubert, 2010).

Semantically, an instance of discourse is like an iceberg, as only a small proportion of its meaning is actually expressed — most remains implicit and must be inferred from explicit discursive features and the broader context (van Dijk, 2009). When analysing discourses, it is essential to note that, as Sunderland (2004) reminds us, this is a wholly interpretive project; there is no agreed, finite set of discourses to identify, since they are unbounded, interrelated and invisible, continually being produced and reproduced. There is therefore no 'right' discourse label, meaning that labels vary significantly, including from very general (e.g., 'tragedy discourse') to specific ('people with dementia are the living dead': Aquilina and Hughes, 2006; Behuniak, 2011). How I label something as a discourse will likely differ from another person, and will inevitably, and often unconsciously, be impacted by the discourses that we live with (Baker, 2006). As Foucault (1972: 146) observes, 'it is not possible for us to describe our own archive [of discourses], since it is from within these rules that we speak'. It must be emphasised that due to their fluid nature, the discourses discussed throughout this thesis cannot be authoritative nor concrete. To improve the reliability and relevance of my work, I therefore draw upon existing discourses in the literature, which have regularly been identified across individuals and countries. As well as indicating a certain level of reproducibility, this facilitates discussion through utilising a shared discourse repertoire.

3.2.2 Thematic discourse analysis

The explorative nature of this project suits thematic discourse analysis, which, as with any flexible approach with no set formula, requires a definition of how it is used in this context (Cheek, 2004). As the name indicates, thematic discourse analysis straddles thematic and discourse oriented analytical traditions. Thematic analysis is a wide-ranging method to identify, analyse, and interpret patterns of meaning, or 'themes', within qualitative datasets (Clarke and Braun, 2017). Discourse analysis is similarly broad, incorporating a range of approaches from different disciplines and theoretical traditions (Taylor, 2013). In sum, it is the study of discourse(s) through analysing semiotic modes such as language, either at a micro level of language practice, or the macro level of discursive patterns for particular topics (or both) (Braun and Clarke, 2021).

Combining thematic and discourse analysis enables key themes to be drawn from the data alongside attending closely to the contexts and implications of language use (Šestáková and Plichtová, 2020). Authors vary in the emphasis placed on each component, with some focusing closely on the structured coding of themes, attending to discursive features as an aid (Taylor *et al.*, 2012), while others prioritise discourse analysis to discuss how issues are constructed, and use looser themes to organise findings (Peel and Harding, 2014; Šestáková and Plichtová, 2020). This thesis ascribes to the latter tradition, taking an inductive, fluid approach to theme identification and using such themes to structure my discourse-oriented analysis. The specifics of how I utilise this approach will be outlined in section 3.4, as here I focus on the theoretical underpinnings to contextualise my methodology for readers.

3.2.3 Multimodal critical discourse analysis

Having broadly established my thematic discourse analysis approach, it is important to specify the details of how I approach the discourse analysis itself. Theoretically, this thesis takes a critical stance towards discourse, and, going beyond the usual remit of thematic discourse analysis, explicitly engages with visual and verbal representations, aligning with the tradition of multimodal critical discourse analysis (MCDA). MCDA is the multimodal branch of critical discourse analysis (CDA, also referred to as critical discourse studies), which interrogates macro aspects of society — particularly social inequality — through analysing how these aspects are locally expressed and enacted in instances of discourse, with the overall aim of supporting social equality and justice (van Dijk, 2009). Since CDA focuses on language, MCDA is distinguished through its 'multimodal' concern with not just language but a range of other semiotic modes, such as images, music and architecture.

Of the diverse multimodal and semiotic research that exists (for an overview, see Jewitt, 2014), this thesis is particularly informed by the work of Gunther Kress and Theo van Leeuwen (2001, 2006), and David Machin (2013; Machin and Mayr, 2012). Underpinning their research is a social semiotic theory of communication, which is concerned with how communicators use and change available semiotic resources to realise their interests (Machin and Mayr, 2012) and how this helps to shape social relationships and identities (Brookes *et al.*, 2021). A social semiotic approach is concerned with text producers' choice of signs, which 'signify' objects/concepts and are thus the 'conjunction, invisible and indivisible, of form and meaning' (Kress, 2010: 14). Here, I prefer the term *semiotic resources*, which are choices made in the process of text production (such as camera angle or pronoun usage) that carry meaning potential within particular semiotic modes (Caple, 2018). More broadly, semiotic resources can refer to the 'actions, materials and artifacts we use for communicative purposes' and how 'these resources can be organized' (van Leeuwen, 2005: 285). Taking a social semiotic approach in MCDA assumes that communicators are aware of the different meaning potentials of the choices that they make both within semiotic modes – such as different ways of visually representing a person with dementia – and between semiotic modes, for example, that an image can communicate broader ideas about the lives and identities of people with dementia more conveniently than language (Machin and Mayr, 2012).

Building on Halliday's work in systematic functional linguistics (Halliday, 1985; Halliday and Matthiessen, 2013), MCDA analysts regard communicators as navigating a rule-based system, or 'grammar' (Kress and van Leeuwen, 2006), when using or interpreting semiotic modes and resources such as images, font, colour and language. Famously, Kress and van Leeuwen (2006: 41-3) argue that visual texts can also fulfil Halliday's (1978) three communicative functions; they can represent the world (ideational), construct social relationships and express attitudes towards what is being represented (interpersonal), and be internally and contextually coherent (textual). For instance, similarly to sentences which begin with familiar information and end on new, Kress and van Leeuwen (2006: 180-1) propose that for cultures that read left to right, horizontally-arranged compositions can present elements placed on the left-hand side as 'given' (the already familiar and agreed upon point of departure for the message), and other elements on the right as 'new' (not yet agreed upon, and so requiring greater attention). Although of course textual, this can also fulfil ideational and interpersonal functions, for instance through who/what is presented as 'given' versus 'new'. Interpersonally, the authors chart how the camera angle and gaze of represented participants can establish different power dynamics and social closeness. For example, a distant side-shot and/or lack of eye-contact from a represented participant can convey greater social distance, while a higher camera angle positions viewers as higher, and thus more powerful, than those depicted. The authors detail each variable at length, making their work a useful reference point for visual analysis (for an application of their theory of gaze in relation to representing people with dementia, see section 2.3.2).

While undeniably useful, Kress and van Leeuwen's (2006) model nevertheless has some limitations. The appropriateness of imposing linguistic frameworks (here, Halliday's systematic functional linguistics) onto non-linguistic semiotic resources is debatable, as is the balance struck between empirical evidence and the authors' personal contextual knowledge when informing the framework (Machin, 2014). The authors themselves emphasise that their general theory is hypothetical, provisional and open to development, and that any 'general theory must look crude by comparison with the richness of the actual semiotic world (2006: 266). For instance, in an increasingly globalised world, we need to move beyond culturally specific models to incorporate the interactions of cultures when interpreting visual signs. It is therefore essential to regard this not as a fixed or comprehensive 'grammar', but as 'a flexible set of resources that people use in ever new and ever different acts of visual sign-making' (Kress and van Leeuwen, 2006: 266). Regardless, this grammar of visual design provides a productive and insightful framework for exploring how participants respond to visual representations of dementia in a British context.

As one of the means through which discourses can be expressed and multimodally analysed, my approach to metaphor merits a brief discussion here. Acknowledging the range of theories (see Semino & Demjén, 2016), this thesis draws primarily on Cognitive Metaphor Theory (Lakoff and Johnson, 1980; Semino, 2008). According to Cognitive Metaphor Theory, metaphor provides us with the tools to make complex, abstract, unfamiliar, subjective and/or poorly defined phenomena more intelligible and communicable. This is achieved by mapping features of a 'source domain', which is a more concrete, familiar, simple, physical and/or well-defined experience, onto a more complex or abstract 'target domain', such as dementia or aspects of dementia (Semino, 2008). Metaphors frame social phenomena in line with their associated discourse(s) by foregrounding certain aspects of a scenario while downplaying or ignoring others, thereby promoting 'a particular problem definition, causal interpretation, moral evaluation and/or treatment recommendation for the item described' (Entman, 1993: 52). Since much metaphor work orients around language, I find the work of Charles Forceville (1996, 2002, 2008; Forceville and Urios-Aparisi, 2009) particularly helpful when attending to visual metaphors shown to participants. Advocating for greater recognition of multimodal metaphors, Forceville (2002: 12) outlines three key questions for determining the presence of a metaphor: (1) What are the metaphor's two elements, and how do you know? (2) Which element is the metaphor's source domain and which the target domain, and how do you know? (3) Which features can/should be mapped from the source to the target domain, and how is this decided upon? This provides a clear and reflective starting point for identifying visual metaphor. I will return to Forceville's work in later chapters, particularly in Chapters 4 and 7, which examine hybrid visual metaphors.

Moving to the second word in multimodal critical discourse analysis, MCDA is 'critical' in the sense of being problem-oriented, interrogating social phenomena in a way that challenges, rather than accepts the status quo (for a more comprehensive discussion of the term 'critical', see Breeze, 2011). Although 'critical' does not necessarily mean negative, this is a common misconception for critical studies (Wodak and Meyer, 2009). CDA works are best known for critically deconstructing semiotic resources that reiterate the unequal distribution of social power, for instance through (re)producing racism, sexism or class inequalities (Flowerdew and Richardson, 2018b). However, when ‘critical’ is understood in a fuller sense, the CDA umbrella comfortably includes its sub-discipline, Positive Discourse Analysis, which highlights alternative discourses, often produced by marginalised groups, that address social inequalities and hold potential for positive change (Bartlett, 2018). Simply put, analysts study discourses they like, rather than wish to criticise (Macgilchrist, 2007). Positive discourse analysis seeks to offer more constructive analysis that engages with an ever-changing and increasingly global, technologically connected world, rather than continue to deconstruct the same types of texts without considering what can be, and is being done, to create positive change. Regarding the CDA literature as too narrowly focused on problematic interactions, many researchers are calling to instead examine how different members of society, especially minority or vulnerable groups, (re)interpret and resist mainstream discourses, and generate counter-discourses (Breeze, 2011; Luke, 2002). As Macgilchrist (2007: 75) highlights, counter discourses do not always remain so, since they change according to what is ‘predominant’ versus ‘dissenting’, as demonstrated by the now widely accepted feminist discourse regarding women’s equal right to vote.

This thesis falls somewhere between the two approaches. As will be demonstrated in the study design, I selected stimuli to reflect a broad spectrum of dementia discourses, and purposely drew multiple images and phrases from notable (M)CDA studies (Bailey, 2019; Brookes *et al.*, 2018; Harvey and Brookes, 2019), in order to explore people’s perspectives on representations that have already been critiqued by analysts other than myself. Many phrases, images and discourses are criticised in the analysis, reminiscent of traditional (M)CDA, but this occurs through the responses of people affected by dementia, which better balances the analysis by incorporating multiple perspectives (see below). Equally, through consulting people with their own experiences of dementia (lived, as a carer and/or loved one), I can move beyond analytical deconstruction, towards how particular members of society draw on their lives and discursive repertoires to interpret, align with and resist different ways of representing dementia. This produces both counter-discourses and some recommendations for how popular representations of dementia could improve. Therefore, despite drawing extensively upon MCDA critiques, my overall focus aligns well with the values of positive discourse analysis, with critiques of existing discursive practices being grounded in the input of a traditionally disenfranchised group, who are uniquely placed to generate experience-based alternatives in the hope of contributing to positive social change.

Through engaging with people affected by dementia, this thesis addresses another key criticism of (M)CDA: that it tends to ignore real consumers of semiotic resources, overlooking that there is always ‘a plurality of possible interpretations’ (Machin and Mayr, 2012; Widdowson, 1998: 150). Breeze (2011) reminds us that media studies research demonstrates that the reception and influence of semiotic resources is much more complex than is often indicated in CDA, where ‘reception is often naively assumed on the basis of the researcher’s interpretation of the text’ (520). In reality, as Kitzinger’s (1993) account of different groups responding to media representations of HIV/AIDS shows, people draw on a range of existing knowledge and interpretative techniques to produce a spectrum of readings, and may accept, reject or ignore discourses (Breeze, 2011). It is therefore valuable to also attend to people’s production of discourses since, as we adapt and change semiotic resources according to our own lived experiences, identities and contexts, we all hold the potential to reshape the semiotic resources (and associated discourses) that are available to us, on an individual and collective level (Kress, 2000). Heap and Wolverson (2020) present a fascinating analysis on just that, using CDA to examine how professional carers’ discursive positioning of themselves and people with dementia alters after being exposed to a more person-oriented (rather than medical) discourse. However, this interest within CDA is very underdeveloped, as emphasis remains largely on analysts’ critiques of semiotic choices for existing texts, as a proxy for problematic dominant social discourses, rather than on how such resources can be reshaped (Kress, 2000) ‘in close collaboration and solidarity with those who need it most’ (van Dijk, 2001: 63). Failing to address this by considering only the analyst’s interpretation heightens inherent issues in CDA, which, being politically rather than linguistically motivated, risks finding what the analyst expect to find (Stubbs, 1997). Widdowson (1998) argues that, ironically, this practice undermines CDA’s goal to expose inequalities and injustice, since imposing the analyst’s single view in turn controls audiences’ access to the semiotic resource.

Of course, there are other limitations that this study cannot address, such as a need to consider text consumption *and* production, which is more typical of other disciplines, such as media studies (Stubbs, 1997). Further, CDA works are often dismissed as too selective, subjective and qualitative in data selection and analysis (Machin and Mayr, 2012). Yet, researcher subjectivity is an inevitable aspect of any research, whether in the social or natural sciences (Mautner 2010), including in corpus-based studies working with a vast collection of texts (Baker *et al*. 2008). Smaller, qualitative samples enable deeper analyses that incorporate different semiotic modes and subsequently hold great value, since the aim is not to be ‘generalizable as descriptions of how things are, but as how a phenomenon *can* be seen or interpreted’ (Talja, 1999: 472, my emphasis). Inevitably, this thesis cannot escape that, as with any discourse analysis, the analyst is given great power to impose meaning onto another’s text (Cheek, 2004), since although I consult participants about visual and linguistic representations, ultimately I am charged with collating, analysing and presenting the interview and focus group data. This makes it vital that I explicitly outline my theoretical and ideological stance and reflect on this at all stages of the project. I hope that this practice will be evident throughout, and direct readers to section 3.5 for the greatest detail on this.

3.3 Study design and process

Having outlined my theoretical position when approaching this project, it is time to turn to my methodology and rationale for designing and conducting my focus groups and interviews. I am concerned with two aspects of discourses here: (1) how discourses manifest in visual and linguistic representations, namely how participants interpret and respond to examples of these; and (2) the discourses that participants themselves (re)produce and resist in our sessions. As will become evident, these two facets of discourse inform every stage of my research, from structuring the sessions to conducting analysis. This current section begins by outlining the study design, focusing on the rationale, structure and content of my focus groups and interviews. Following this is my recruitment of participants, ethical practice and greater detail on the process of data collection.

3.3.1 Study design

Both interviews and focus groups were included in the study design. This decision had multiple motivations: first, to better enable me to meet the individual preferences of participants, who may be more comfortable in a group or one-to-one situation; and second, to draw upon the different strengths of each method of data collection. Both means of data collection provide valuable insights into how participants construct their experiences and position themselves within different discourses surrounding dementia.

Interviews are simultaneously a familiar interaction that we consume via the radio, magazines and television (Dörnyei, 2007) and unusual to participate in within everyday life, since the interviewer shows unrivalled interest in someone’s views and experiences for an extended period while simultaneously holding greater power in the context of the interaction, as the interviewer determines the topic, questions and will report on their personal interpretation of the participant’s responses (Brinkmann and Kvale, 2018). In contrast, group discussions are seen to better emulate how people exchange opinions and navigate topics in everyday interactions (Flick, 2018). Of course there are still issues of power asymmetry, with the facilitator initiating and helping to direct the session, but researchers maintain that for focus groups of people who share an identity feature or experience, here of dementia, this more informal method can facilitate greater candour and help to discuss more sensitive topics, with a perceived safety in numbers and the stimulus of other group members (Barbour, 2018). It is this group interaction that is central to focus groups, making them invaluable for exploring ‘how knowledge, ideas, story-telling, self-presentation and linguistic exchanges operate within a given cultural context’ (Kitzinger and Barbour, 1999: 5). More than this, focus groups provide a ‘socially legitimated’ opportunity for group members to be introspective and reflect on assumptions and social narratives that are usually taken for granted, and rarely articulated in a critical space (Bloor *et al.,* 2001: 5). The same can be said on an individual level for interviews, with both offering the opportunity for participants to probe their perceptions and experiences, allowing the researcher to harness participants' own observations and insights in the process of generating, and then analysing and reporting, data (Barbour, 2007).

However, in a group context, multiple participants compete to tell their personal stories and viewpoints, which produces non-chronological and noisy data that is difficult to attribute to individuals (Barbour, 2018). In addition, there is a risk that some participants' voices dominate others, with the latter voices being interrupted or unexpressed in conversation (Smithson, 2000). This is where the key strength of interviews becomes important, as the one-to-one (or one-to-two) nature better facilitates a detailed and comprehensive account of an individual's experience and discursive practices. Of course, neither method offers 'the authentic Voice of the People', as that is in itself a myth, and these methods are always constrained by processes of recruitment, conduct and analysis (Bloor *et al.*, 2001: 15). Both artificial and naturally occurring data are influenced by discursive norms and perceived audience, here, group members and the researcher (Barbour, 2018). What combining focus groups and interviews offers, then, is a range of complementary insights into how people situate themselves in relation to popular discourses of dementia, and choose to represent themselves, their experiences, and others.

To make focus group and interview data more consistent, all sessions were semi-structured, using the same stimuli and overall structure throughout. Piloting both a focus group and interview enabled me to test my structure, delivery and stimuli, and make changes accordingly, resulting in the interview schedule shown in Table 3.1, which I have synthesised into eight main stages. I adapted this to participants' needs during data collection (see section 3.3.5 for more on this) and honed aspects of my phrasing as I gained experience in what participants responded well to. This is exemplified in stage 4, where I shift from asking what participants associate with dementia, which, being quite broad, generated uncertainty, to the more specific and interaction-oriented 'how would you explain dementia to others' that participants more readily engaged with.

Table 3.1 ***Interview and focus group schedule***

Stage	Summary	Breakdown of stage and researcher's framing
1	Introductions and explain the study	Set tone, including organising food and drink. Introductions for myself and participants (if not already familiar). Explain study's purpose: 'to collect your opinions on how we show dementia and talk about it in Britain, and how this affects you personally'. Position newspapers and charities as especially of interest. Explain the process of recording and the basic interview structure.

2	Consent and demographic information	Give all participants a folder with the following: (1) Full Privacy Notice for Research Participants (produced by the University of Nottingham) (2) Consent form (3) Questionnaire, asking for: age, gender, ethnic background, employment, experience with dementia Contextualise and explain the forms. Participants can work through them individually, in pairs, as a group or with me. I am always available for questions or concerns.
3	Turn on the recorder	Clearly establish that the audio recorder will now be turned on and that participants can ask to pause or turn it off at any point.
4	Initial questions about participants' experiences	Initial open conversation to gain context about: (1) Participants' engagement with charities and newspapers, including where they get their information about dementia from (2) What participants associate with dementia / how participants would explain dementia to others (the former quickly developed into the latter) (3) Participants' experiences of dementia (especially in interviews)
5	Discuss twenty images	Contextualise images as mostly from newspapers and charities, used in relation to dementia. Participants can discuss the images in chronological order or start with the most striking. Overall question: 'what do you think of the images and how do they make you feel?' Four starter questions also written on the front page: (1) What do you think the picture is trying to say? (2) How do you feel about the different photos? (3) What effect do you think these different images have? (4) Do any pictures stand out to you? Why? Also ask participants about which they would/would not use and why. [See Appendix 2 for more information on the images and their sources].
6	Discuss language	Show participants different phrases, a tagline and two headlines. These are presented in a written form and read aloud. Three starter questions: (1) How do you feel about each word or phrase? (2) Which words would you use and why would you use them? (3) Which words are more familiar/unfamiliar? [See Appendix 3 for the written stimuli and their sources]. At the end, ask participants how they would like to see dementia represented.

7	Concluding thoughts	Ask if there is anything else participants would like to add or discuss. Bring the conversation to a close. Stop recording.
8	Feedback, contact and payment	Ask participants for any feedback (verbal or in writing, either during or following the session). Establish future contact preferences and explain aim to provide a summary to interested participants. Thank people for taking part. Give everyone a thank you card containing a handwritten thank you, my contact details and £5 for participation.

As stages 2 and 8 will be discussed within my ethical practice (section 3.3.3), I focus here on my framing of these sessions for participants, before discussing the rationale and organisation of the visual and written stimuli in section 3.3.1.1. To introduce the study, I compressed my recruitment information (see Appendix 1 for an example) into a simpler explanation: 'to collect your opinions on how we show dementia and talk about it in Britain, and how this affects you personally'. I positioned participants' relationships with newspaper and charity portrayals as especially of interest, but noted that other forms of social portrayal, such as television, were welcome too. This explanation was intended to give participants context about the overall focus, while ensuring that I emphasised being interested in people's personal stance and experiences, in the hope of reducing preconceptions of a 'right' or 'wrong' answer. I then discussed the session's overall structure and audio recording, with the opportunity for questions.

The session began by gaining information about how participants engage with different sources of social portrayals and their own discursive practices (stage 4). This was achieved through first asking what experience participants had of newspapers and charities, and where they got their information about dementia from, which may include examples of specific organisations (often Alzheimer's Society) or other sources, such as the internet, doctors or peers. This was intended as a straightforward starting question to help participants relax into a discussion while considering their particular information sources and familiarity with newspapers and non-profits. Before influencing participants with stimuli, I then moved to explore what people chose to foreground about dementia when asked a variation of the question, 'what do you associate with dementia' (e.g., 'What kind of things would you associate with dementia? What would spring to mind for you personally, whether it's words, images, feelings?': Focus Group 1) or, more frequently, 'how would you explain dementia to someone who did not know anything about it?' (This question was used from Focus Group 3/Interview 3 onwards). The shift between an internal ('associate') and external ('explain') focus will have influenced responses, and an alternative phrasing that could maintain the original introspective focus is reported by Heap and Wolverson (2020: 2025), who opened their focus groups of professional carers with 'I just wondered what you thought of dementia(.) like what is dementia(...) to you'. Regardless of the internal/external framing though, my two question variations provide useful insights into the discourses that participants choose to reproduce (or challenge) about dementia. Often, especially in interviews, these questions would be accompanied by questions about the participant's experience of dementia, to enable a more personal (and often more narrative) account than was possible within the time constraints for a focus group, where accounts emerged more spontaneously, and were generally more fragmented due to the nature of group conversation.

Next, participants were shown twenty images (stage 5). Appendix 2 recreates the page layouts and content for visual stimuli, with the additional information of individual image sources for the benefit of the reader. In the sessions, no written material or sources were provided, so that participants could focus on the images themselves without being primed by associated written content. Participants were encouraged to briefly survey all images to gain an overview and then to either discuss images chronologically or start with a particularly striking personal choice. Images were contextualised as being used in relation to dementia and drawn primarily from charities and newspapers, with the overall prompt being 'what do you think of the images and how do they make you feel?'. Four starter questions were also provided (see Table 3.1) from which I drew verbal questions oriented around people's interpretations of what the images depicted and connoted, their feelings about each image (including what stood out), the images' effects on them (and others), and why participants reacted how they did. After a participant in Focus Group 1 asked other group members what they would use to represent dementia and why, I adapted and incorporated this into the schedule as an additional question, 'what images would you use or not use to represent dementia and why?', to further stimulate evaluative discussion.

Written stimuli (stage 6) were framed similarly to images. Here, I explored participants' responses to initially isolated phrases and then examples of headlines and a tagline (see Appendix 3 for the written stimuli). Beginning with isolated phrases enabled participants to focus on the words themselves and establish their own context. To help with this, I asked participants how familiar different phrases were, their opinions on each and whether they would use such language. Phrases progressed into three examples of real-world use for some of the terms or underlying discourses, which was intended to provide a next step, subject to time, where participants reflected on whole sentences and expanded on their previous discussion accordingly. To end, if it had not already been discussed, I planned to ask participants how they would like to see dementia represented, visually, verbally or otherwise. Finally, participants were invited to share any final thoughts (stage 7), to facilitate participant-initiated topics and closure.

3.3.1.1 Stimuli

Following an overall discussion of my sessions' structure and framing, I now turn to the stimuli used and the rationale behind these choices. I direct readers to look at Appendices 2 and 3 for an in-depth presentation of my visual and verbal stimuli respectively. Stimuli were developed in the summer of 2019 and drawn from sources between 2017—2019 to enable up-to-date examples. Both were inspired by existing literature on popular discourses and representations of dementia and were intended to contribute the responses of people affected by dementia to this body of knowledge (e.g., Brookes *et al.*, 2018; Gerritsen *et al.*, 2018; Low and Purwaningrum, 2020; Van Gorp and Vercruysse, 2012). Although written stimuli drew greatly on guidance materials for representing dementia, images could not because of a distinct lack of discussion on visual representations in this sphere, asides brief mention of images of people holding their heads, hands and fading faces (Bould, 2018; DEEP, 2014). The sourcing and design of visual stimuli therefore requires greater attention here.

Visual stimuli were obtained from charity websites (namely, Alzheimer's Society and Alzheimer's Research UK), newspapers/magazines and online 'dementia' image searches, through which stock images were found alongside relevant sources that used them. As discussed in section 2.3.2, image banks deserve attention as they are a pervasive, accessible and ever-expanding competitor of traditional photojournalism that supply a range of media organisations with images and videos, and therefore hold significant influence on the way that dementia is visually represented (Harvey and Brookes, 2019). Importantly, the same stock image can be used in a range of contexts, as with images 10 and 11, which feature in magazines/news media, a leaflet and books (see Appendix 2). Images were selected and arranged into five pages of four images, with each page engaging with different discourses and types of visual representation. Pages offer multiple details and points of contrast to better spark diverse discussion and debate. Figure 3.1 provides an overview of the images, in the order and layout that they appeared to participants.

Figure 3.1 ***The twenty images shown to participants, ordered by page and position.***

Page 1

1.

3.

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Page 2

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Page 3

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11.

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Page 4

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Page 5

17.

19.

18.

20.

As Figure 3.1 shows, page 1 contrasts two individuals in a home environment (one with a partner in the background) signalling some kind of a struggle and holding their heads, against two social settings where people are happily engaged in sharing a joke and a group activity. This juxtaposes isolation with social engagement, negative with positive emotions and home with community. It also engages with multiple visual tropes identified for people with dementia. Firstly, Kessler and Schwender (2012) argue that in their sample of German news magazines between 2000-2009, dementia is increasingly visually portrayed as a phenomenon affecting individuals (mostly women), rather than as a medical diagnosis, and that represented participants are more often shown in private individualised contexts (rather than more institutional settings), and 75% with a social partner. Whereas Kessler and Schwender found images to generally depict people with dementia with positive emotions while living an autonomous and socially integrated lives, others in the UK have highlighted the trend to show a 'head clutcher image' (Bould, 2018; Brookes *et al.*, 2018), namely 'stock images of older white women, isolated, holding their head in their hands', one of the only images I am aware of dementia guidelines explicitly discouraging (Bould, 2018: 31). Critically analysing this trope, Brookes *et al.* (2018) deconstruct how such images present people as suffering (illustrated by their pained expressions), passive (they are seated and immobile) and isolated (with downward gazes, they make no social connection with viewers or other participants). This page therefore draws on debates surrounding overly positive, socially engaged and happy representations (Kessler and Schwender, 2012) versus isolating, passivising and suffering oriented ones (Bould, 2018; Brookes *et al.*, 2018). Such broad dichotomies make page 1 a good entry point for discussion.

Page 2 raises questions surrounding who is represented and how. It juxtaposes two examples of more diverse faces (regarding ethnicity and age) for people with dementia against hands images, which reflect two trends: first, the overrepresentation of white older women when depicting people with dementia (Bould, 2018; Kessler and Schwender, 2012), and second, the pervasiveness of close-up shots of hands to signify people with dementia (usually older people, perpetuating the conflation of dementia with old age). The latter trend has been observed by Brookes *et al.* (2018) for newspapers, and Harvey and Brookes (2019) for stock images. These researchers observe that the composition of such photos is highly predictable. The hands are immobile, usually being clasped together or resting, and are shown close up, brightly lit and in sharp focus, foregrounding features such as creases, wrinkles and veins that are culturally associated with fragility, vulnerability and deterioration. Being disembodied, with no chance to see the person's face, these hands therefore 'direct us to see little more than atrophy and depreciation before and instead of the person' (Harvey and Brookes, 2019: 994). Contrasting faces with hands offers the potential to discuss the (de)personalisation of people with dementia, then, while other distinctions provide more nuance to the debate, namely whether a close-up of people holding hands is interpreted differently to an individual resting their hands, the latter being more typical of the aforementioned 'disembodied hands' corpus.

Page 3 orients around discourses of decline and loss of personhood, which, as discussed in the previous chapter, dominates much of the literature on dementia. Harvey and Brookes (2019) offer an insightful commentary on how image 12, showing the woman with a jigsaw piece missing, depicts the represented participant as defective (through the dark cavity in her head/brain) and lifeless (note the dull colour palette and her zombie-like vacantness). Image 10 harks back to the 'head clutcher' image of page 1, but additionally suggests the fragmentation of an individual, again from the area of the head containing the brain. Image 9 continues this disintegration but dehumanises the process by showing only the main organ featured in loss of self discourses: the brain. This is the only image not found across newspapers and charities in a dementia context, as it was added through an online search to replace an image of a paper head with its brain on fire (analysed in Brookes *et al.*, 2018), which was evaluated as being potentially too alarming or distressing when used in combination with the other three images on this page. Complementing the overall collection therefore took priority in this instance over the image's source. Finally, image 11 illustrates a slower paced deterioration through the seasonal loss of leaves from the brain area of a head-shaped tree, engaging with the use of plant metaphors to signal brain changes and decline with dementia (Caldwell *et al.*, 2021; Zimmermann, 2017). As my exchange of the fire image indicates, being the most loss-oriented and therefore potentially difficult, this page required extra consideration. As well as consulting others, such as participants in pilot sessions, I arranged this as the middle page so that participants could become accustomed to the task and other representations first, and view page 3 against the subsequent page, which emphasises a living well discourse. Through contextualising this page within diverse representations, I hoped to mitigate distress, as these types of images are important to include, not only because they are so prevalent but also because there would otherwise be a risk of overly sanitising dementia and its representations, which can be equally distressing for people (Bartlett *et al.*, 2017; Fletcher, 2019a).

Returning to the notion of 'giving dementia a face' through portraying individuals with dementia (Kessler and Schwender, 2012), page 4 orients around contrasting photos of ordinary people on the left, and celebrities on the right. As elites, celebrities with dementia are especially newsworthy (Bednarek and Caple, 2019), and are key to British newspaper reporting of dementia, with celebrity voices and experiences being showcased by the media far more than ordinary people, who are noticeably absent (Bailey, 2019). However, across society, ordinary people are increasingly speaking out about their experiences, as the advocacy movement gains momentum. Image 13 depicts such a couple who were in the UK news after they remarried in their garden when the husband, who had dementia, proposed again to his wife, as he did not recall that they were already married. His wife used this media attention as an opportunity to speak out against stigma, and one of the many headlines reporting this event is used as written stimuli (see below). For images 15 and 16, British icons Terry Pratchett and Barbara Windsor were chosen because both individuals had dementia and had undertaken significant advocacy roles, with extensive media coverage. Both follow the expected trajectory of celebrities with conditions: after publicly announcing their diagnosis, they share details of their experience and become visible, often optimistic, spokespeople (Lerner, 2006). In particular, Terry Pratchett has been associated with the living well discourse, as indicated in image 15, and has been presented, more than other celebrities with dementia, as 'an active, successful, articulate member of society', which relates to active citizenship discourses for people with dementia (Bailey, 2019: 187). Celebrities hold great influence and can be a source of inspiration, but can also be dismissed as exceptional and unrepresentative of ordinary people with dementia (Bailey, 2019). Of course, if participants are unfamiliar with these celebrities, the discussion does not have to incorporate this facet and can centre around the role of partners and family, living well with dementia, and anything else that participants raise. If people are familiar with Pratchett and Windsor, discussion could include advocacy and the controversial role of celebrities in representing people with dementia.

Finally, page 5 is inspired by the conflict between biomedical discourses that emphasise obtaining a cure, versus social and structural discourses that foreground the need to care for people with dementia. Image 17 has been critiqued by Harvey and Brookes (2019: 996) for being inaccessible to non-specialists, but ideologically meaningful nonetheless, including by supporting the power of medical knowledge, reducing people with dementia to their '(seemingly aberrant) neurobiology' and segregating people with and without dementia into an 'us' with a healthy brain, and a 'them' without. Image 18 provides an interesting contrast to this specialist biomedical tool, as it metaphorically displays the brain itself as a jigsaw with a missing piece, and visually foregrounds the medical practitioner/researcher (indicated by the white coat) as the person who can solve the puzzle of dementia. Together, these images speak to concepts of medical authority and the role of biomedicine in the lives and futures of people with dementia. In contrast, two images of communities and volunteers supporting charities are displayed, to highlight the role of people and charities in supporting individuals affected by dementia. The two image's fundraising connotations also encourage discussions of financial support for cure and/or care oriented approaches.

Written stimuli can be divided into three types, the first being common phrases that are either supported ('living (well) with dementia', 'dementia friendly') or discouraged ('dementia sufferer', 'dementia patient') by prominent guidelines on dementia language use (Bould, 2018; DEEP, 2014; YoungDementia UK, 2020). Although people with dementia and others affected are consulted in these guidelines, they are generally presented as one voice, so the aim of including these phrases was to generate discussion to explore the possibility of different usage, views and reasonings. Following the prevalence of battle metaphors in dementia communications and research (Bailey *et al.*, 2021; George and Whitehouse, 2014; Lane *et al.*, 2013), I also included 'fight', 'beat' and 'defeat' dementia for group discussion (Appendix 3). Three real-life sentences followed the phrases, the first being an Alzheimer's Society fundraising envelope that offers an example of a battle metaphor which personifies dementia as 'the UK's biggest killer' that supporters are asked to help 'beat' through (financially) supporting research. The two headlines accompanied the news stories containing images 13 and 16, and were chosen partly because of this link, which was intended to facilitate engagement, but mainly for their use of language that is advised against by language guidelines for dementia (namely 'Alzheimer's disease agony' and 'sufferer'). The latter use of 'sufferer' is particularly interesting, as it is used in the context of a wedding and love, which would more typically be associating with a living well discourse. Here, dementia is personified as a powerful force that love manages to defy, creating a headline that is linguistically rich and draws on multiple competing discourses, notably suffering from, battling ('defied') and living (well) with dementia.

3.3.2 Participants and recruitment

To participate in this study, an individual needed to have experience of dementia. This could be through having a diagnosed type of dementia, previously/currently caring for someone with dementia, or being a close friend/family member. Participants also needed to be comfortable communicating in English. Convenience sampling was used to reach anyone who was willing to take part and could either travel to, or be visited for, an in-person session. Of the recruitment channels contacted, the most successful were local support groups, a care group, Memory café, choir for people with dementia (and carers), and a Patient and Public Involvement (PPI) group. Dissemination occurred via emails, newsletters, word of mouth and being invited to groups to discuss the study in person. In all contexts, interested individuals could access a promotional poster and an information booklet that outlined the study's focus, who could take part, what participation involved, an ethical statement, what would happen to the results, benefits for participants and how to participate. An example of the booklet can be found in Appendix 1. Participants were encouraged to digest the information provided before contacting me to arrange an interview or focus group, usually through emailing.

Fifty-one people from the Midlands, UK, were recruited and participated in sessions between October 2019 and March 2020. As Table 3.2 shows, eight focus groups and seven interviews were conducted. Participants' ages ranged significantly (from 21—87, mean age: 64.3) and there was a fairly even gender distribution (22 men: 29 women). As far as I am aware, with the exception of one carer, couples had heterosexual relationships. Regarding experience of dementia, 17 people had a dementia diagnosis, and one person had a mild cognitive impairment that she regarded as pre-dementia. Thirty-three participants without dementia identified as carers and/or family/friends, of whom three were ex-carers (a fourth ex-carer had since developed dementia). Although types of dementia and time since diagnosis were not explicitly requested, Alzheimer's disease, vascular dementia and types of working-age dementia were particularly discussed, while conversations indicated that time since diagnosis ranged from <1 to >8 years. Twenty-four participants attended sessions alone (5 people with dementia, 9 carers/previous carers and 10 family members/friends), while 27 attended as a pair (with one three) consisting of a person with dementia and their carer/supporter(s).

Table 3.2 ***Summary of participant demographics by group***

Group/ Interview	**Age range**	**Identified gender**		**Person with dementia** [a]	**Carer**	**Family/ friend**	**Previously a carer**	**Total number of people**
		Male	**Female**					
Group 1	21 - 83	5	3	3	4		1	8
Group 2	54 - 61		4			4		4
Group 3	69 - 80	2	2	2	2			4
Group 4	52 - 78	2	2	1	3			4
Group 5	26 - 31	2	1			2	1	3
Group 6	63 - 87	1	4	2	2	1		5
Group 7	73 - 87	3	2	3	1	1		5
Group 8	48 - 64	4	6	4	4	2		10
Interview 1	62		1			1		1
Interview 2	73		1		1			1
Interview 3	84		1	1			1[b]	1
Interview 4	27, 61	2		1		1		2
Interview 5	72		1		1			1
Interview 6	71		1	1				1
Interview 7	69	1					1	1
Total	21—87	22	29	18	18	12	4	51

[a] This includes one participant in Group 11 with a mild-cognitive impairment, which she regarded as pre-dementia.

[b] Following caring for her husband with vascular dementia, this individual now has Alzheimer's disease herself, and is therefore included in both categories.

Participants had a range of employment backgrounds, including: education (student, teacher, head, learning technologist), healthcare (nurse, speech and language therapist, carer, GP receptionist, NHS manager), construction (welder, builder, electrician, engineer), industry (coal miner, factory worker, lorry driver, production manager), retail (hairdresser, shop owner), the financial sector (tax accountant, clerk, bookkeeper), and the civil service (social services, police officer, merchant seaman, civil servant for the Ministry of Defence). Participants were predominately white British (49 of 51 participants, with one white Canadian and one non-specified mixed-race participant) and engaged with their local community. These are both typical demographics for individuals who participate in dementia research, especially when using traditional recruitment means, in this case convenience sampling through local networks (Fletcher, 2019b).

Equally, due to local recruitment, 25 participants already knew me before they agreed to participate (26 did not), while five of the eight focus groups consisted of people who were already familiar with each other. This reflects that I often organised a focus group before, during or after another group's meeting so that interested individuals could attend at a time and location that was convenient and familiar. This resulted in arranging focus groups around a local Memory Café (twice), choir (twice), Public and Patient Involvement meeting, and a working-age dementia support group, with three interviews also occurring this way. Another group was arranged with PhD students who responded to a call for participants that was made during a presentation, while the final focus group consisted of people who had not met but expressed a preference for a focus group.

3.3.3 Ethical practice and consent

Ethical approval was obtained from the University of Nottingham's Faculty of Arts full committee review. My participant information sheet was also informally reviewed by other academics and members of the community to improve its clarity and accessibility, which resulted in converting a multi-page sheet to a more concise booklet (see Appendix 1 for an example booklet). This appeared to be successful, with one interviewee telling me that '[participants] need to know what they're doing that's why I liked, your bit that came out, about the leaflets, they were clear, they were precise' (P33). The consent form and Full Privacy Notice for Research Participants were deemed the property of the University and were therefore not altered. As these were quite dense materials, where appropriate I offered these to participants ahead of our session to give people the opportunity to consider them in their own time.

Informed consent requires being able to voluntarily and consciously decide what to do based on sufficient information about the study, including the process, risks and benefits (Pesonen *et al.,* 2011). I recognise consent as an ongoing process rather than a one-off procedure (Dewing, 2008; Samsi and Manthorpe, 2020) and consistently made it clear that participants could withdraw or reschedule at any time. Two focus group participants withdrew beforehand due to an unexpected illness, and one interviewee rescheduled our session upon my arrival due to confusion with the days and not wanting to participate at that time. No one indicated any wish to withdraw during or after the sessions. On the day, the study was discussed before obtaining written formal consent and I was available to help with any questions or concerns. Participants also collaborated to help each other understand and respond to the forms. The consent process was tailored where possible to suit individual needs, in an attempt to include, rather than exclude, people with dementia with different communicative needs (Fletcher, 2021). No formal assessments of capacity were carried out, with informal conversation and non-verbal cues being used to determine that participants were happy to take part. Participants with dementia gave written and verbal consent when they clearly had the capacity to do so; otherwise, in the case of the latter, carers were present and could also be consulted on whether they thought the person was willing to participate. Capacity according to the Mental Capacity Act requires someone to meet four decision-making criteria: (1) to understand the decision and reasons to make it, (2) comprehend likely consequences of not/making the decision, (3) retain and use relevant information, and (4) somehow communicate their decision (Department for Constitutional Affairs, 2007). The reality is often slightly uncertain, necessitating subjective researcher evaluations *(*Fletcher *et al.*, 2019). My personal stance favours unobtrusive evaluation and inclusion where possible, especially in focus groups where other members are familiar, the atmosphere is collaborative, and exclusion can be detrimental (for more on the exclusionary consequences of current ethical procedures, see Fletcher, 2021). As the researcher and facilitator/interviewer, I was particularly attentive to any 'possible expressions of verbal, non-verbal and behavioural displeasure, disengagement and discomfort' and tried to respond to participants' needs throughout (Samsi and Manthorpe, 2020: 4).

3.3.4 Procedure

I prioritised facilitating a good experience for participants, including through creating a safe and enjoyable environment (Davies *et al.*, 2021). Following guidance (DEEP, 2013), locations were chosen to suit each participant, which largely entailed running groups in familiar community settings used for other groups that participants belonged to and visiting interviewees at home or in a café of their choice. A small grant from the Centre for Research in Applied Linguistics (University of Nottingham) provided financial assistance to book rooms and provide refreshments, which ranged from shop-bought squash, cakes and fruit to a professionally catered lunch, or buying participants drinks/lunch at their chosen café. This provided a way of thanking participants, building rapport and establishing a more familiar and friendly environment (McCabe *et al.*, 2018). For similar reasons, if visiting someone at home, I would always accept the offer of a cup of tea, since making time for this culturally significant exchange can greatly enhance comfort, trust and mutual respect in a research relationship (Ashworth, 2014).

Ending a research relationship is rarely discussed (Cowdell, 2006), yet is also important to participants' wellbeing. I thus carefully considered this facet of the study so that participants could leave the sessions feeling valued, with closure and a clear sense of what to expect next. As Table 3.1 shows, after the recorder was turned off, participants had the option to provide me with feedback on the session and any thoughts they had for the study. This could be done in person (verbally or in writing), or via email following the session. All three options were selected by different individuals, reinforcing the need for personalised choice. Feedback was overwhelmingly positive, with participants calling the sessions 'interesting and informative', finding it 'very valuable to me to be able to explore the issues raised during the course of the session', enjoying sharing views with 'likeminded people' and thanking me 'for the opportunity to voice my thoughts and opinions'. One group asserted that it was a good opportunity to discuss a topic that they care about but do not usually want to 'bother anyone' with, finding it 'really really nice to talk about […] it's not often you get to sit down and have that conversation'. Appraising the stimuli, a participant declared that 'Not too much writing, been dropped on our heads [laughs]', while another noted that they were 'interested by the reaction to people and pictures'. One comment evaluated me and the refreshments: 'Emma was extremely pleasant and patient and was interested in our answers. The lunch provided was a bonus'. I also received constructive feedback, including that 'I probably just needed a little bit more guidance as to what you were asking for when we were looking at the pictures – but maybe that would bias the responses!'. After receiving this, I reflected on the scaffolding I provided participants and further emphasised that I was interested in people's reactions and what they wanted to discuss, to help alleviate concerns. Equally, images were originally unnumbered to encourage participants to describe the pictures (and thus draw on particular discourses and foreground certain features) but after participants requested numbering, I amended this and numbered the images in the way shown in Figure 3.1. Participants were also given the opportunity to provide suggestions for future sessions and my research, and although uptake was low, responses were interesting, including 'how TV views dementia', 'passive versus active information acquisition' and showing people the stimuli who are not 'primed […] with talking about dementia'. Feedback therefore enabled participants to share their experience and ideas, and me to be responsive to participants' needs and suggestions.

Alongside this, I asked participants their contact preferences for follow up questions (if applicable) and for hearing back about the study's findings. Participants could opt in or out to either and showed especial excitement about receiving a summary of the study's findings. Finally, to thank everyone again for taking part, I gave participants a thank you card containing a handwritten note, a £5 note for participation and my contact details with an invitation to contact me if they had any further questions or ideas. This personal variation on payment and post-session contact was well received by participants as a sign of my respect and appreciation, although I quickly learned that I needed to accompany this informal touch with the clarification that the money came from the university, not me, so that participants felt comfortable accepting it.

3.3.5 Data collection

Data from focus groups has been kept confidential and securely stored throughout. Participants are anonymised through pseudonyms, with any other personal information being carefully screened to avoid making anyone identifiable. Letters are used to refer to participants with a form of dementia (e.g., PA), and numbers to participants without dementia (e.g., P1). These numbers and letters are chronological according to the order in which I spoke with participants. Such a system enables greater transparency for representing different participants' voices, without intending to unnecessarily label or create in/out groups amongst my participants.

Sessions ranged from 45–105 minutes in length. Individual needs, settings and time constraints necessitated a flexible approach to my interview schedule, in terms of content and questioning, which I adapted to the interests of participants. Although the opening questions and visual stimuli sections were always conducted, written stimuli were not always covered, either partially (e.g., the phrases were discussed but not the sentences, as with Group 3 and Interview 4) or at all (Groups 6, 7 and 8). This was generally due to a lack of time or participants' energy. Visual stimuli were prioritised over verbal stimuli because they were deemed more accessible and open to interpretation for participants, and also respond to a distinct lack of research into people's responses to visual representations of dementia.

As an interviewer and facilitator, I tried to 'take a back seat' and refrain from asking too many questions or commenting unless the conversation required it (Barbour, 2007: 106). I also ensured that I gave participants, especially those with dementia, sufficient time to pause 'to retrieve the thread of conversation' without distraction from me, even when this moved beyond the usual limits for conversation (Sabat, 2018: 64). This appeared to be appreciated, with one interviewee with dementia (PH) humorously telling me at the end that 'you've listened, and, and, been encouraging, as well, you know, so it's not been a "oh God not her again" [laughter]'. Of course, this approach meant that sometimes the conversation went off track, as it can be difficult to distinguish between someone developing a point that will become relevant, and going off on a tangent (Barbour, 2007). Indeed, a particularly tangential and self-reflective focus group (Group 7) raised this as we reflected on the session. Collaboratively, we navigated the conversation from a worry that participants '[took] too much of the focus off' (PK) to celebrating that tangents could be useful for coming up with 'ideas and questions [..] and answers to questions that Emma [the researcher] would never have thought of' (P25). We thus recognised the importance of flexibility to the research process to avoid pushing participants into a conversational 'cul-de-sac' (P24) and enable new questions and ideas to emerge, which expands the research scope by not limiting it to the researcher's preconceptions.

Dynamics across interviews and groups varied significantly. Generally, I found that the smaller the group, the better the balance of voices, although in some groups as small as four, when people with dementia attended with carers, I observed a tendency for carers' voices to dominate the conversation, a phenomenon that is certainly not unusual (Davies *et al.*, 2021; Dening *et al.*, 2013). However, my attempts to bring people with dementia into the conversation sometimes backfired by putting people on the spot and suggesting a lack of a contribution, which can make individuals uncomfortable and reluctant to participate (Sabat, 2018). This is exemplified in Focus Group 3:

Emma	Yeah, ok. Thanks. PE PD any thoughts or?
PD	Not really
P12	No
PE	No not really.
P13	Can't remember what he did yesterday can you love
PE	(Yeah) [laughter]

Subsequently, I changed my approach to nonverbally invite people to speak through my gesture and gaze. Of course, it is worth noting that this issue is not representative of everyone. Some people with dementia were confident contributors and occasionally the dominant voices, while other mixed groups actively prioritised the voice of the person with dementia, either through consulting them or immediately passing them the conversational floor if the person initiated a point. Equally, some people without dementia were also quieter in group discussions, reflecting that individuals have different conversational inclinations, which cautions against misattributing this to dynamics between people with and without dementia.

The audio recorder also influenced dynamics for interviews and focus groups. Participants revealed their awareness of the device when they reminded me that I could turn it off as we neared the end of the session. However, no one asked to pause the recorder during sessions. All sessions were audio recorded and transcribed verbatim by the researcher, totalling approximately 143,500 words. The University of Nottingham's Automated Transcription Service was used as a transcription aid because it is a secure platform that complies with data protection rules. Sections of transcripts that were to undergo close analysis and be presented in the thesis underwent more rigorous transcription, namely through additional screening and timing pauses for greater accuracy. The transcription conventions used throughout this thesis are outlined in Appendix 4, while the process of analysing the collected data is discussed below.

3.4 Analysis

I take a reflexive approach to thematic discourse analysis, which foregrounds inductive and iterative analysis, researcher subjectivity, and dedicated reflection on the data (Braun and Clarke, 2019). Reflections on my role as the researcher in relation to the data will be considered in the subsequent section, while the process of analysis is discussed here. Detailed transcription provided the first stage of data familiarisation. I listened repeatedly to each recording, then closely read and re-read each transcript, making detailed notes regarding how participants represented themselves and other people in relation to dementia. I used NVivo 12 Pro (QSR International Pty Ltd., 2018) to help organise quotes from transcripts into categories. These generally matched aspects of the interview schedule (for example, each page of images and linguistic stimuli) to facilitate cross-comparisons across groups and interviewees. As the analysis progressed, more specific folders were added, such as 'change (and flux)' and 'evaluations and recommendations for change'. Simultaneously, I visually mapped the main points for each focus group and interview and identified 'patterns of meaning' amongst them (Clarke and Braun, 2017: 297). These patterns, after multiple revisions, would develop into my themes and discourses.

By 'theme', I refer to a broad topic or issue (such as 'explanation of dementia'), within which there are different discourses (e.g., psychosocial versus biomedical discourses), each providing alternative ways of constituting the same topic/theme. In other words, this thesis structures analysis through broad themes, each of which contain multiple, often competing discourses. Although researchers inevitably approach data with preconceptions, it can be very fruitful to try to ground analysis within actual interactions with participants, especially for traditionally top-down (M)CDA approaches (Breeze, 2011). Here, data analysis incorporates topics and discourses that were planned in advance via the interview schedule (e.g., 'living with' versus 'suffering from' dementia, fighting/defeating dementia, biomedical versus more social discourses) with themes that emerged from the data, most notably diversity and change, which underlie Chapters 5 and 7 respectively. Structuring analysis around themes and discourses not only enables the direct address of my research questions but also for the responses of participants with dementia, carers and loved ones to be in dialogue together. Ideologically, this mitigates unnecessarily separating people with and without dementia, and practically, it enables richer, more nuanced analysis of discursive positionings within each theme. Of course, as section 2.3.4 demonstrates, people with dementia, carers and loved ones may have different motivations and preferences for representing dementia and people with the condition. Where relevant, this is recognised in the analysis, and the pseudonym system of letters and numbers (section 3.3.5) means I am transparent about whether a participant's contribution is informed by lived experience or not.

Analysis is structured to help balance 'an idiographic focus on the individual voice' with 'making claims for the larger group' (Smith *et al.*, 2009: 107). Thus, my first analysis chapter, Chapter 4, provides an in-depth exploration of how two interviewees represent their experiences of dementia and how their discursive preferences inform their responses to the same few images. One interviewee (Sheila) has been a carer for her husband with vascular dementia and is currently living with mild Alzheimer's, while the other interviewee (Jackie) is an active advocate for people with dementia. Both women reproduce alternative discourses in order to represent what dementia means for them, with Sheila taking a more family-oriented focus and considering love alongside suffering, whereas Jackie takes a structural rights-based stance. Closely focusing on two individuals provides a more personal opening for analysis, enabling a detailed exploration of how different life experiences and discursive preferences can manifest in individuals' interpretations and positioning of the same images.

The succeeding analysis chapters span all groups and interviewees. They are thus structured around prevalent themes that emerge consistently across the whole dataset, and different discourses within these. Sheila and Jackie are of course included in these chapters where relevant, although they are attributed their general pseudonyms, PF and PN respectively, for consistency across participants. Chapters 5 and 7 both orient around the two key themes to emerge from the data: diversity regarding what having dementia means and who a person with dementia can be (Chapter 5), as well as experiences of change and flux associated with dementia (Chapter 7). Building on the exploration of different meanings of dementia in Chapter 5, Chapter 6 considers different biomedical and social representations, and is the chapter based most closely on themes and discourses that were incorporated into the research design, although the analysis remains grounded in the responses of participants. Chapters 4 to 7 orient particularly around responses to visual stimuli, since this incorporates all participants and is significantly under researched. Subsequently, the first section of Chapter 8 is dedicated to discussing different language choices for dementia, which is generally initiated by the written stimuli in sessions. Then, the final analysis section builds on the preceding chapters to present participants' evaluations and recommendations for representing dementia moving forward. Overall, the analysis chapters are intended to provide not only an overview of key themes (and discourses within these) when representing dementia, but also in-depth insights into the individualities and nuances within this. However, being a discourse analyst, the data collected through focus groups and interviews are not the only data that should be analysed, since I must recognise that I myself generate data through the process of creating connections and telling stories within my analysis (Macgilchrist, 2020: 11). It is to this issue that I now turn.

3.5 Researcher positioning

Frequently, emphasis is on the role that participants want to play in the interview or focus group, how they want to be seen, and how their story can serve this purpose (Steeman *et al.*, 2007: 125). However, the researcher similarly wants to present themselves (and participants) in a certain way, which manifests in how they ask about and tell the stories of participants within their research. Research is thus jointly produced by the participants, the researcher, and their relationships (Finlay, 2002: 531). Moreover, as Macgilchrist (2020: 13) highlights, our communicative accounts (here, mine and participants') are entwined with ours and others' 'socio-material-economic-ecological-affective spaces', and with popular discourses which serve as 'the dominant plot lines in society' (Murray, 2000). To conclude my Methodology, I therefore attend more closely to my own position as the researcher, since my own 'socio-material-economic-ecological-affective' stance underlies the entire project, from study inception to data collection to the presentation of this thesis.

Notably, at the time of writing, I am a younger person without dementia who is a PhD student and volunteers in the community (for the Alzheimer's Society's Side-By-Side scheme and a local Memory Café). This influences not only my own standpoint but also my interactions with participants, who were in all but one case older than me, and generally had more direct experience of dementia, whether lived or otherwise. I found that my volunteering and family history of dementia were most often the credentials that participants I had not previously met sought, and that knowing I had some experience made me more acceptable as a respondent by providing some 'in-group' status (e.g., 'I mean you must have noticed Emma, when you go to the Memory Café': P13). Although my role as the researcher inevitably gave me power in our interactions since I determined much of the focus (Brinkmann and Kvale, 2018), in many contexts this oft-reported power imbalance was at least partly offset by my youth, student credentials and limited experience. Multiple participants took on more of a mentor role than would perhaps occur with other researchers, explaining aspects that they assumed I would be unfamiliar with (e.g., 'You won't know this, erm Emma because you've grown up in a different world […] but the Health Service came in the year after I was born': P26), joking about my youth ('the youngsters like Emma': PM) and helping to guide the conversation if they evaluated the group as having gone off-topic (e.g., 'I think though, folks, we're digressing in that we're meant to be talking about pictures' and 'is there any other questions you want answered Emma?': P5, PM). Of course, it is worth noting that group members often help to regulate the group, so the latter is not unusual (Barbour, 2007). Equally, my relative inexperience lends itself to the explorative nature of this study, which uses inductive qualitative analysis to be better led by the interests of the participants, rather than having overly restrictive pre-determined topics and goals. This flexibility is perhaps best exemplified by the significant changes in research scope, focus and questions that this thesis has undergone in response to the outcomes of interviews and focus groups, to evolve into the piece of work that you read now.

Yet, taking a more introspective turn, I inevitably bring to this project my own predispositions and agendas, which are important to outline. I regard dementia as a complex bio-psycho-social condition (Sabat, 2014) that will be experienced differently according to a person's environment, as well as care and support needs (McParland *et al.*, 2017). Dementia is better conceived of as a disability than a disease, in which a range of relational, social, political and economic variables can (dis)empower people who have dementia (Shakespeare *et al.*, 2019). I do not believe that cognitive abilities underlie personhood or selfhood, nor that this can be something that someone loses through having dementia (Kitwood, 1997; Kontos, 2006; Sabat, 2018). Much of my stance is influenced by the wider literature, which generally critiques the dominance of biomedical discourses and values person-centred, rights-based discourses. From both the wider literature and conversations with participants, I have come to increasingly advocate for nuance and multiplicity regarding representations. In other words, I seek to diversify our discursive repertoire instead of simply replacing what are currently problematic dominant discourses, such as biomedicine and loss of self, with similarly problematic ones like 'living well with dementia' (Bartlett *et al.*, 2017). Therefore, although this thesis advocates for incorporating less mainstream discourses, it aims to critically engage with the implications of *all* discourses, as it does not wish to reproduce the existing choice between tragedy or living well discourses (McParland *et al.*, 2017).

As has been discussed, my theoretical positioning within the fields of thematic discourse analysis, multimodal critical discourse analysis and positive discourse analysis is likewise influential. Not only does it determine my terminology (most notably, discourses) but also my assumption that the data generated is socially constructed. As such, the responses analysed here do not reflect participants' 'true' experiences or opinions but rather how individuals choose to represent their experiences, themselves and dementia, in the specific social context of our interviews and focus groups. My theoretical background also drives some of my aims, firstly, to contribute new insights into how individuals affected by dementia interpret and position themselves in relation to different visual and written representations, as this remains considerably understudied both in the (M)CDA and dementia literature. Moreover, through aligning with positive discourse analysis, I seek to foreground and prioritise participants' discourses and concerns wherever possible, while equally recognising the need to balance this with my own voice as the analyst. As the overarching narrator, I can draw upon the whole dataset, as well as other research and theories, to organise and extend participants' points throughout the analysis.

Finally, throughout this thesis, I recognise the role of language in reproducing ideologies, inequalities and power, and therefore attempt to use more accessible and less passivising or technical prose (elsewhere called 'pointless' 'fancy jargon': P33) in my writing to try to avoid reproducing the very issues that I and other (M)CDA analysts seek to expose (Billig, 2008). Unfortunately, this is not always possible. For instance, despite attending to the 'us' versus 'them' dichotomy that participants produce in their accounts, in order to evade undue noun repetition, I cannot avoid using third person pronouns to refer to social groups in my writing. As such, I attempt I share the distribution of 'they' relative to 'us' so that I do not consistently 'other' any particular social groups. Throughout, I seek to prioritise the voices and priorities of participants, while being cognisant of the role that I as the researcher play in generating, selecting and presenting the quotes, discourses and overall themes that will be explored in the succeeding chapters.

‘Unless you’ve had it, you can’t talk the language. It’s like any disease, experience. gives you an insight.’

- Sheila (Participant F)

Chapter 4: Sheila and Jackie

4.1 Introduction

This chapter is dedicated to just two participants, here named Sheila and Jackie but elsewhere referred to as PF and PN respectively. Both women have dementia and offer noticeably different stances on the subject which, due to both participating in one-to-one interviews, can be explored in greater detail compared to their counterparts in focus groups. Sheila draws on her experiences as a nurse and carer for her husband when he had dementia, as well as her current experience as someone with mild Alzheimer's disease, thus presenting a particularly multifaceted account that can draw on the perspectives of both a carer and person with dementia. In contrast, Jackie is an active advocate for people with dementia, volunteering in the local community and participating in multiple groups, such as DEEP, the UK network of dementia voices. While Sheila foregrounds the role of love, family and other sources of support, alongside drawing on discourses of loss and suffering to reflect on her past experiences and future fears, Jackie focuses on the need for structural and social changes, including using the media to raise awareness and decrease stigma.

As well as exploring unique self-presentations of experiencing dementia in the UK, this chapter compares how these two individuals respond to the same three images of people with dementia. This combination enables insight into how different life experiences and discursive preferences can manifest in individuals' interpretations and positionings of the same semiotic resources, here within a visual mode of communication. This chapter thus begins by attending to Sheila's account, then Jackie's, before comparing how the two women interpret and position themselves in relation to three different visual representations of people with dementia.

4.2 Sheila (PF)

While sat having a cup of recently brewed tea, Sheila commented on the first of the twenty images that I had brought (Figure 4.1), showing a couple distanced from each other, each with their head in their hands. Positioning the man in the blurred background as a supporter, she told me that 'he can't understand because unless you've had it, you can't talk the language. It's like any disease, experience. gives you an insight.'

Figure 4.1 ***Image 1***

I begin with this moment because, to extend the language analogy, Sheila is bilingual in dementia. She was a carer for her husband, here named Stephen, when he had vascular dementia and Parkinson's, and has herself also been diagnosed with mild Alzheimer's disease for approximately eight years. She therefore has a remarkable ability to draw on both her perspective as a carer and as someone with dementia.

4.2.1 A carer's account

Sheila has a long-standing history of caring for others. She worked as a nurse and midwife, shared caring responsibilities with her husband for their parents, and then cared for Stephen when he had vascular dementia and Parkinson's. When I met her, her older cousin had recently died and until then, Sheila had been actively involved in her care. She was currently helping another lady, with a non-specified disability, once a week. Meanwhile, Sheila's daughter and family support her, as will be discussed further in the subsequent section. Sheila's continuing to care for others despite being herself diagnosed with dementia reflects Boyle's (2017) observation of the tendency for women with dementia to maintain their caring roles, practically and emotionally. This challenges widespread associations between dementia and dependency by highlighting the interdependency within people's lives (Boyle, 2017), meaning that individuals can have the dual social personae of care giver and receiver (Sabat, 2018).

In response to me asking Sheila to describe her experience of dementia, she begins with her experience as a carer, starting her narrative at the point of Stephen’s diagnosis and the shock that they felt (see Appendix 4 for transcription conventions):

Sheila Well, initially, um, being told Stephen had dementia was a great shock.

Emma Mm.

Sheila And er, it made my daughter and I sort of go into to each other's arms and cry [laughs].

Emma Yeah.

Sheila So that was hard to take [clears throat] because he'd had a very, high-powered job and. You don't expect it to happen

Emma No

Sheila In any job or any status in life, you don't expect it to happen. But it did.

This account reflects the distress that many report upon diagnosis, although it is notable that rather than providing her own diagnosis story (Buggins *et al.*, 2021), Sheila narrates her response to her husband’s. Stephen’s reaction is not mentioned, with Sheila focusing on the grief that she and her daughter share. As will be explored further in section 5.3, Sheila grapples with the shock of someone with a ‘high powered job’ developing dementia, citing this as the reason for the unexpectedness and difficulty of a diagnosis. Indeed, research indicates that having a higher social status is associated with more negatively perceiving developing dementia (Hulko, 2009). This reflects the widespread devaluation of people with dementia (Steeman *et al.*, 2007), whereby a diagnosis negatively impacts people’s social personae (Sabat, 2018), here causing Stephen to shift from being a high-powered employee to someone associated with a range of disempowering stereotypes (see section 2.3.2). Reinforcing other participants’ accounts, here dementia defies expectations and can affect anyone, with any job or status.

Much of Sheila’s account of her experience of Stephen having dementia focuses on pragmatic details to explain how she coped with his physical and behavioural changes with dementia:

Sheila And, because I've been a nurse, I was able to cope, with his. Changes. Er. I’d done a bit of mental nursing and. I knew how to go along with it, so I was able to keep him at home.

Emma Mm.

Sheila Er. So when he was, I got the signs of him being violent. He would get hold off my hand and, squeeze it and squeeze it as hard as he could and I’d say, er “Let it go, you're hurting me" and then I learnt not to say that. I'd say, "oh keep squeezing me, keep on Stephen" and he'd let it go then, he did #the opposite.#

Emma #Aahh, ok.#

Sheila So, so sort of that was interesting. Um [clears throat]. He never hit me, he never became violent to that degree, if he was agitated. I would er, get him in the car, day or night, take him out for a ride.

Emma Mm yeah

Sheila Come back, and he'd be settled, he'd think he'd been on an outing it would, soothe him.

Emma Yeah, wow.

Sheila So that was how I used to cope when he was agitated. Er. I took him with me, wherever I went. We went out walked every day, because he had developed a stoop. [… due to Parkinson's] But, we coped, in our own way [laughs], and er, we were quite happy in that, coping with it.

The concept of coping runs throughout this account; indeed, Sheila repeats the word four times. She attributes her ability to cope with Stephen's 'changes' and care for him at home to her nursing background. Sheila certainly presents herself as more confident and pragmatic in adapting to and within this caring role than many partners and family members without this professional background (O'Shaughnessy *et al.*, 2010; Rayment *et al.*, 2019). Her above account is reflective, not emotionally but pragmatically, as Sheila foregrounds several learning points from her experience, such as using reverse psychology and that going for a ride could 'soothe' her husband. This pragmatic reflective tone is exemplified by her comment that the success of reverse-psychology 'was interesting', backgrounding any emotional impact of Stephen's changed behaviours, here of him hurting her hand by squeezing it too hard. Although 'coping' is a common feature of carer accounts, often this is more nihilistic and individualistic, presenting coping as the carer's only option (Fletcher, 2020c). Here, Sheila extends her individual coping to include Stephen in a couple identity ('we coped, in our own way'), taking a notably more optimistic and inclusive tone than many other carers by emphasising their happiness as a couple ('we were quite happy in that, coping with it') and 'shared togetherness' (Manthorpe *et al.*, 2011: 78).

After establishing that they could 'cope', Sheila shifts her focus from pragmatic to emotional when she considers what she positions as the 'hardest part' of caring for her husband: the change in their relationship.

Sheila The hardest part, is, I changed from being his wife, to being his, mother,

Emma Yeah

Sheila and carer. And [4.2] he needed me, as his focus all the time.
Emma Mm
Sheila But, he forgot to say things like he loved me or, he forgot to say my name. But, he obviously knew me right up to the end, so [2.0]

Renegotiating roles and behaviours within such a longstanding relationship is difficult for carers and people with dementia alike (Fletcher, 2020c). Many spouse carers, such as Sheila, must balance supporting their life partner with overcoming their own distress at no longer receiving the same level of support themselves (Manthorpe *et al.*, 2011). Sheila's metaphor of becoming Stephen's mother reflects their attachment relationship changing from one of equal partners to increasing dependency (O'Shaughnessy *et al.*, 2010). Sheila struggles with Stephen no longer saying her name or that he loves her, mirroring broader challenges of reduced communication and interaction skills impacting the social relationships of people with dementia (Górska *et al.*, 2018). This issue is repeatedly ascribed to Stephen forgetting to say this, with Sheila securely expressing her certainty through the modal adverb 'obviously' that despite this, he continued to know her.

Sheila later explicitly discusses her security in the love they felt for one another in response to looking at images of couples (images 13-16), where she discusses their own paralinguistic expressions of love:

Sheila And we've talked about that, how love [1.5] helps you through.
Emma Mm
Sheila [2.0] Because that's still [1.8] A recognisable bond between you.
Emma Yeah
Sheila I don't think, no matter how far it goes or it's, you see I'm talking of the experience with Stephen and I. Although he didn't, at the end tell me he loved me. he would still look at me as if he loved me and he would still hold my hand and when we went to bed he would still snuggle me.
Emma Mm
Sheila Erm. So it was still there.
Emma Yeah
Sheila Still there, the physical contact in that way and, just the knowledge [1.9] I never doubted
Emma Yeah
Sheila that he'd. lost the love of me.

It is made clear here that love remained 'a recognisable bond' between Sheila and Stephen, and that as Stephen's dementia progressed, embodied shows of love, such as hand holding, facial expressions and cuddling, became increasingly important. This emphasis on the body as a site for communicating and sustaining their identity as a couple speaks to the discourse of embodied selfhood, which, as explored in section 2.2.4, challenges equating the self with memory and cognition by highlighting the importance of the body in our identity, interactions with the world and relationships with others (Kontos, 2004). Here, Stephen's 'physical contact' communicated affection to Sheila, reinforcing her 'knowledge' that she was loved. Sheila's interpretation of Stephen's actions also demonstrates the role of others in our social identity (Hughes, 2014; Sabat, 2018), here for validating Stephen as a loving partner. This account supports the value of a more holistic, embodied approach to selfhood, as Sheila can appreciate the many ways that Stephen can and does express intimacy, rather than focusing on a narrower cognitive approach to recognition and relationships (Taylor, 2008).

Supplementing the above positive account of continued love and selfhood, Sheila elsewhere reflects on the despair that can be felt by both the person with dementia and their carer in response to change with dementia, discussing 'the despair, both of when Stephen had it, times, when he was failing and he was changing, from one man to another. I would see him holding his head, and, I know I held my head in despair.' This reflection is triggered by the first two images of people with their head in their hands (images 1 and 2) and engages with the metaphor of an undesired transformation into another person to explain the extent of Stephen's change (Castaño, 2020). Sheila explains that she was 'blessed with […] a good six years' of the eight that her husband had dementia, telling me that 'it was only [for] two years that it became noticeable to everybody else, outside, and that er, that I needed a break'. Through acknowledging her increasing need for support, Sheila reiterates the emphasis of many people affected by dementia of the necessity of outside support, including through aids, respite and support, here for Sheila as the caregiver (Bangerter *et al.*, 2021; Rayment *et al.*, 2019).

Sheila's engagement with external support draws on a structural approach to dementia (section 2.2.3) by exemplifying the importance of the environment in disabling or enabling people affected by dementia (Górska *et al.*, 2018). First, Sheila discusses how technology improved her home life with Stephen:

> they gave me [clears throat], a gadget, which, if you went through the door, it alarmed me, it told me he'd opened the door and gone out. And the other thing was that I had one, under my pillow. And that rumbled if he got out of bed. So, I had help, you know, these things were very helpful, or made it easier, to cope with it.

These subtle surveillance tools help her to cope by becoming a communicative partner ('it alarmed me, it told me', 'I had help') in keeping Stephen safe while at home, reinforcing the importance of aids for carers (Rayment *et al.*, 2019). As well as adapting the environment through technology, the couple utilise social support systems, including through a volunteer who took Stephen out for an afternoon a week, and a local hospice. Sheila reports that Stephen 'was, incredibly happy there [at the hospice]. So that was, a joy to me and a relief.' What Sheila terms 'joy' and 'relief' reflects a commonly noted improvement in carer wellbeing when day services provide support and respite (Bangerter *et al.*, 2021). Sheila recounts that Stephen would always take his briefcase with him and would often return home with spare slices of cake, and that 'some days, he would go and get his briefcase because, he liked going'. Revisiting the role of the body and other people in selfhood, here an object (Stephen's briefcase) plays an important role in conveying his identity (since Stephen always takes it) and in communicating his memory of attending the hospice and desire to return (Hughes, 2014). This implicitly recognises that such social supports can facilitate not only wellbeing but selfhood, exemplified here by Stephen's embodied self-expression (his briefcase) which communicates a relational and narrative self (here narrative is defined as finding meaning and narrative identity in the *present* moment), as at this moment he wishes to go to the hospice and see the people there (Bryden, 2020).

As well as supporting Stephen, Sheila foregrounds the importance of health and social care support services for her, especially during a period of depression while she was a carer:

> And so I could have which I wanted, and then for therapy, because you could have six. And then the other Monday afternoons, I went and I talked to a counsellor [2.6] But, I painted. We didn't just er, talk face to face I was painting because I like painting. Er. And. And she would talk and sometimes I might have a little weep and sometimes we'd have a laugh and [5.0] I think it perhaps shows in the painting. And then. there was a point. Maybe, I'll say maybe, six years into Stephen's, when I got depressed, and I couldn't understand it. I'd been, a ward sister, a district nurse, worked in hospitals. been night sister over a hospital you know, how could that happen to me? [Laughs]. But it did. And then I found that, I did take some medication, my doctor was excellent and said it was just, first aid. And erm, in that time. I started painting myself, erm, like a collage. And, as I was getting, started at one end when I was feeling really down, and as I was feeling better it got brighter and brighter and then when I was well, the end of it, it's, got butterflies and flowers and things [laughs]. [...] And that was very therapeutic.

That the service provision is finite is quickly established by Sheila, who remembers the exact number of therapy sessions people were entitled to ('six'). Most of the focus of her narrative is on her experience of art therapy, and the sharing of laughter and tears as they talked while she painted. The stigma of having depression is implicit in Sheila's listing of all of the responsible nursing roles she had held, climaxing with her rhetorical question 'how could that happen to me?' Her surprise at having depression is comparable to a dementia diagnosis, and indeed, Sheila's succeeding clause 'But it did' exactly parallels her earlier conclusion to the difference between expectations and reality for Stephen's diagnosis. Yet, caring is shown to increase the risk of depression, alongside anxiety and stress (Erol *et al.*, 2016). Although stressors will increase over time for spousal carers, family and community support enable continued resilience (Donnellan *et al.*, 2019). Sheila's narrative supports this, as with support from the doctor (whose analogy of 'first aid' helps Sheila handle having her depression treated) and art therapy, Sheila recovers, metaphorically representing this visually through 'brighter' colours and springtime symbols (butterflies and flowers), popularly associated with hope and optimism. In Sheila's account of her depression, then, we can see one of the many health issues that carers may face. That Sheila here foregrounds not her family but her doctor, counsellor and art therapy in her recovery process positions the support she received from health and social services as instrumental in helping her at a particularly low point of her life as a carer.

4.2.2 A person with dementia

Sheila's account of her caring experience often leads onto her experience of having dementia, meaning that she consistently negotiates these two contrasting perspectives throughout the interview. She begins her account as someone with dementia by foregrounding that she can continue her pre-diagnosis roles of caring for and driving herself, emphasising continuity (indicated by the repetition of 'still') and autonomy:

> So, about myself. [Clears throat]. Well I was diagnosed eight years ago. And, I started on donepezil, one, a day, which I know doesn't cure it, but it, retards it hopefully and I think that has worked, because, I'm having a long open window and I'm still caring for myself, I'm still driving.

Beginning accounts of dementia with an optimistic mood and emphasising a sense of productivity is common (Buggins *et al.*, 2021), and maintaining continuity, including a sense of agency and independence, is a key strategy for protecting selfhood and coping with dementia (Górska *et al.*, 2018). Through this, Sheila presents herself as adhering to dominant hypercognitive standards of a competent and meaningful person by being independent, rational and self-controlled (Post, 2000b). This reflects wider management strategies by people with dementia to address the cultural devaluation of this social group (Steeman *et al.*, 2007). Sheila attributes her abilities to her medication, mitigating her assurance of its effectiveness through 'hopefully' and 'think', which she later jokingly calls ‘my lifeline’ (this relationship to biomedicine is addressed further in section 6.3). However, Sheila clearly establishes that this state of continuing pre-diagnosis activities is finite and that there will be future change, later demonstrating her critical awareness through her driving, as ‘I make sure that my grandsons go out with me periodically, to make sure I'm driving ok, because when you drive alone, perhaps you wouldn't be aware of it’. Sheila explains that with her dementia, ’you do know what’s happening. As it’s gradual. And you're aware that, certain things you can't cope with.’

Following a popular trend to transition from the ‘high point’ above to reflecting upon current limitations (Buggins *et al.*, 2021), Sheila then details how her dementia affects her, and her response. She focuses primarily on forgetting short-term memories and the word she wants to find, tending to remember her earlier life in better detail:

Sheila I forget. I would forget, next week. probably our conversation, this week. Sometimes I forget [1.9] yesterday if it wasn't very important.

Emma Yeah

Sheila Then I have these lasps [lapses] where I can't find the word I want. And I tend to go back, we used to have horses. So I had stables. So I call my garage the stable

Emma Oh that’s interesting

Sheila very frequently and. And when they ask me where I live, I go back to [name of old home], which is where I lived before for 43 years, so that's firmer in my mind than [name of current house number and street]. But it doesn’t happen all the time, but it's these things that I know [1.6] that I'm gradually, very gradually [3.1] inverted commas ‘losing it’ [laughs]. Sadly. [Clears throat] So. Er. But God’s good, he knows, he's given me this trial. So [2.0] There’ll be, a reason to it, and I just have to trust. And when the time comes my daughter will look after me I know, because she looks after me now, she rings every single day.

Sheila’s example of substituting her target word (‘garage’) for a semantically related one (‘stable’) demonstrates her using long-term memory to circumnavigate issues with working memory word recall. This, alongside her emphasis that it is not consistent, contributes to the overall nuanced account of changes to memory seen in research (Sabat, 2018) and the accounts of other participants (see sections 5.2 and 8.3). Sheila positions these kinds of experiences as how ‘I know. that I'm gradually, very gradually, inverted commas ‘losing it’ [laughs]. Sadly.’ This moment exemplifies the complexities of participants’ engagement with hegemonic discourses. On one level, Sheila draws on language associated with loss (of self) to describe her experience of a progressive decline in abilities, which is widespread amongst the reflections of people with dementia (Castaño, 2020). Yet, the ‘inverted commas’ here mark Sheila’s resistance by indicating that this is not a perspective that she aligns with, corroborating that people with lived experience can simultaneously incorporate and challenge hegemonic discourses (Bryden, 2020; Hillman *et al.*, 2018).

In the face of her deteriorating abilities, Sheila turns to her relationships with others, particularly God and her daughter. Sheila positions her faith in God as fundamental to her navigation of having dementia, and that it provides comfort is indicated by her countering a ‘sad[dening]’ reflection with her faith (‘but’). She regards her dementia as a trial that will enable personal and spiritual growth, and her faith in God’s goodness and omniscience sustains her. Spirituality, whether religious or not, is ‘part and parcel of what it is to be a person’ (Hughes 2011: 205) and can greatly support individuals’ psychological wellbeing, resilience and meaning-making for dementia (Katsuno, 2003). During this interview, Sheila presents a shift in her health and subsequent social roles (as carer then cared-for). Countering this, her unwavering faith in God, alongside her other relationships, sustains Sheila’s ‘relational self’ which, alongside embodied and narrative selves, enables continuity of selfhood throughout the progression of dementia (Bryden 2020).

Indeed, Sheila is certain that when needed, her daughter, who is a palliative care nurse, will look after her, because she already is. Here we see Sheila shift from caring for others to being supported herself, something that she explicitly reflects on:

Sheila Wheels go round don’t they.
Emma Yeah
Sheila Stephen and I, we cared for my mother and dad. and we cared for his mother and dad.
Emma Yeah
Sheila And [my daughter] helped me care for Stephen, and, and you know.
Emma Circles, (as you say)
Sheila As the Bible says as you sow so shall you reap.

Contrasting her earlier emphasis on her independence, which takes an individualistic approach to care, here Sheila reproduces an alternative ideology to individualism, that of ‘familism’, which emphasises family commitment and obligation to care for loved ones (Ward-Griffin *et al.*, 2006). Sheila’s reference to the Bible’s teaching of cyclical care interweaves Christian morals of care with familism, an account that supports both her relational and narrative self (Bryden, 2020), since she finds meaning and identity in her place within the network of familial care, and substantiates this through her knowledge of Biblical teachings. Sheila’s account draws on multiple common motivations for caregiving, which include a combination of expectation and obligation, alongside love, religion and repaying care received as children (Erol *et al.*, 2016).

As the interview continues, Sheila’s reflections as a carer stimulate reflections on her fears for her future self and the care she can expect. Following observations that the boundaries that caring dyads initially establish are often later ignored or overcome, for instance regarding help with toileting (Fletcher, 2020c), Sheila explains that experiences ‘swing’ and you ‘think, you can't cope and then, you go on’. This account of resilience triggers a concern for what will happen when Sheila’s dementia progresses, particularly how she will change and whether her daughter will be able to ‘cope’:

> Now, I worry about myself, at times, I try to put it in the back of my mind. What is to become of me? What will I be like? [1.8] Would I become violent, and have to be taken away? [2.4] I know what it's like in those places. [1.8] And I wouldn't, want to be there. But [1.5] whether my daughter could <u>cope</u> with me. You see I had twenty-four hours with Stephen, I was retired, I’d got the time. but my situation will be different [1.5] So, I don't know. But I'm not going to worry about it, or try not to worry about it.

Sheila’s question of ‘what will I be like’ is of great concern to many people with dementia (Caddell and Clare, 2011; Castaño, 2020), as the progressive condition poses an existential threat for individuals (Cheston *et al.*, 2015). Here, Sheila particularly fears becoming violent, possibly because of the change to her character, and certainly because of the consequences of this behaviour. Returning to the disabling impact of a person’s environment, it is notable that Sheila’s future fear is that her daughter will not be able to cope with her, highlighting the distinct stressors within their mother and working daughter caregiving dynamic (Erol *et al.*, 2016). Here, not coping would lead to Sheila being ‘taken away’ to an institutional home against her wishes. Predicting her own future dependency and loss of agency, Sheila acknowledges that she may ‘have to’ end up at one of ‘those places’, her euphemistic language associating this kind of social institution with fear and taboo, which is furthered by the deictic demonstrative pronoun ‘those’, since it establishes a firm sense of distance (that she wishes to maintain) between herself and the ‘places’ that they send people to once the familial network that she favours can no longer ‘cope’. Elsewhere, Bryden (2016: 185) shares Sheila’s dread of ‘being put in dementia prison’, critiquing the lack of human dignity or care of such places, which is reinforced by frequent reports of human rights violations that can occur (Cahill, 2018; Swaffer, 2016). Sheila copes by avoiding thinking about future fears, a common coping strategy for dementia (Buggins *et al.*, 2021; Wawrziczny *et al.*, 2017). As her modality amendment in her final sentence indicates, she can only state that she will ‘try not to worry’, leaving a more ambiguous impression regarding distress levels that acknowledges the complexity and emotional toll of living with dementia (Bartlett *et al.*, 2017).

Sheila’s multifaceted account of both the positives and negatives of life as a carer and person with dementia culminates in a reflection on how ‘there is a suffering for both of you’. This is inspired by a discussion of using ‘suffering’ and ‘sufferer’ (see section 8.2.1 for a discussion of the distinction between these terms) and is a concept that Sheila has not previously considered, as indicated by her repetition that ‘I’ve never thought about [it] before’ and that ‘it’s giving me more thought’. The frequent lengthy pauses further support the impression that she is processing less familiar, more difficult thoughts, and trying to communicate some of these to me:

Sheila [1.8] You do suffer. You suffer the loss of them [2.4] You suffer [2.8] their [1.6] erm. lack of ability [6.0] They suffer. because for a long time, they are probably aware that they’re helpless.

Emma Mm

Sheila They’re dependant on somebody else [2.7] And that it’s [1.9] a grief of mind [1.5] Which is what suffering is isn’t it, grief.
[…] it's giving me more thought. And I would have said at the time I didn't think I was suffering.

Emma Yeah.

Sheila It's in hindsight, and talking about it now,

Emma Yeah

Sheila that I realise that. there is this process of suffering. because there’s the loss.

Emma Mm

Sheila The loss of the person that they were. [6.3] Which made me realise, there’ll be a loss, to what I was [2.0] A very competent, efficient, er. in the nursing world, fairly high powered. erm, to [2.7] not being that anymore [2.6] Just er. forgetful and [1.6] effort to function. Don't know how long I can go on driving.

As with care, Sheila’s reflections on suffering begin from the perspective of herself as the carer and culminate in herself as someone with dementia. Her stance on suffering is attributed to ‘hindsight’ and as different to her opinion while caring, indicating the continuous and contextual nature of people’s subjective constructions of their experiences, and that interviews can facilitate greater introspection (Bloor *et al.*, 2001). Due to its intensely personal nature, suffering is hard to define (Bartlett *et al.*, 2017). Here, Sheila defines suffering as ‘grief’, the emotional response to loss, explicitly linking its cause to a loss of abilities, independence and ‘the person that they were’ as dementia progresses. This reflects the sense of loss that can accompany dementia’s challenge to certain proposed psychological needs, such as independence, competence, relatedness and identity (Castaño, 2020; Cheston *et al.*, 2015)

Initially, Sheila positions herself as a carer, establishing an out-group ('they' and 'them') of people with dementia. After a longer pause (6.3 seconds), she transitions into the perspective of someone with dementia, indicating that her reflections as a carer have made her 'realise, there'll be a loss, to what I was' as well. Notably, Sheila focuses on the loss of hypercognitive attributes: competence, efficiency and accountability (being 'fairly high powered'), which echoes the socially assigned value of these abilities above more emotional, relational, expressive and/or experiential ones (Post, 2000b). By implying that she will lose power, Sheila ties social status and respect to her cognitive competencies, reflecting her 'loss' in value through shifting from the intensifier 'very' for her competencies to the reductive 'just', lowering her to merely forgetful and requiring more 'effort to function'. Through positioning this within the 'loss, to what I was', Sheila individualises this process, backgrounding the role of social relationships and broader structural inequalities in this shift (Bartlett and O'Connor, 2010; Sabat, 2018).

Our conversation was interrupted by my recorder beeping to signal a low battery, but Sheila returned to the questions around suffering when I asked her how she found the session. Since the recorder was turned off, the following response is taken from my detailed written notes, which are as close as possible to being verbatim:

> I was apprehensive at first as I didn't know how to help but I enjoyed it. It was good for reminiscing. I was interested by the reaction to people and pictures, it made me think about suffering which at the time I didn't realise we were suffering but because I now can talk the language of Alzheimer's I can push to be helpful for carers, but I don't know anyone at the moment.

Sheila foregrounds her retrospective reflection on the suffering that she and Stephen experienced with dementia here, the concept that appears to resonate most from this interview. Ending this interview where we began, Sheila continues the language analogy by positioning herself as someone who 'can now talk the language of Alzheimer's'. This metaphor (EXPERIENCE IS LEARNING A LANGUAGE) can be read as positioning Sheila as now being enlightened through lived experience (since Sheila is the partner with Alzheimer's disease), and thus able to act as a 'helpful' bridge for carers of people with Alzheimer's disease, reinforcing the wider recognition of people with dementia as experts through experience (Bryden, 2016, 2019). Alternatively, if this reflects the popular use of 'Alzheimer's' as a synonym for its superordinate 'dementia', then Sheila's *combined* experience as a carer and person with dementia may provide this understanding. Either way, this analogy reinforces the necessity of direct experience to being able to communicate about Alzheimer's disease and/or dementia, explored further in relation to peer support in section 6.6. It also continues Sheila's caring identity and agency as someone who can 'push' to help in the care of others, emphasising interdependency between carers and people with dementia.

4.3 Jackie (PN)

In contrast, Jackie approaches dementia primarily through a rights-based, structuralist lens, since she is consistently concerned with how socio-political structures affect citizens' experiences of dementia. Indeed, in many ways, Jackie is the quintessence of what Bartlett and O'Connor (2010) describe when they state the rights of people with dementia to be free from discrimination, seek personal growth, have recognised social positions, meaningful purpose, participation, and solidarity with others to create socio-political change. Jackie is greatly involved in her community and activist groups, from which she forms networks and critically engages with broader social issues. I first met Jackie through a patient and public involvement group at university, and beyond this, Jackie mentions being a member of DEEP (the UK network of dementia voices) and a dementia choir, as well as volunteering for the Alzheimer's Society, participating in research, doing radio interviews, being in pamphlets and on advisory boards. Our interview has a particularly outward-looking focus, with Jackie consistently positioning her experience of having dementia within wider representations and social structures, and offering her views on the role that media and society as a whole have to play within the context of dementia.

4.3.1 Dementia in society

In response to being asked about her experience of dementia, Jackie initially focuses on her diagnosis process and interaction with different service providers. She begins by describing seeking a diagnosis because she 'knew there was something [1.1] going on', since 'my daughter said I was double booking myself which meant I was having problems organising myself [...] And that, that to me is, is very important.' This account demonstrates that individuals and/or their family often notice symptoms first (Pratt and Wilkinson, 2001). That Jackie draws on her daughter's observations when presenting her changed behaviour to the doctor reinforces the important role of loved ones for recognising and validating changes (Brossard, 2017). Asides this nod to her daughter, Jackie instead foregrounds her interactions with a range of medical professionals and organisations, initially the GP practice and memory clinic. She tells me that she was informed of her diagnosis through a 'letter from the consultant', which she was then told in person at the memory clinic. Here, 'they give you the pills and then they check that the pills are [1.2] are comfortable with you [...] And then, that's it'. Expanding on this pharmacologically oriented intervention that swiftly ends, Jackie states that:

Jackie You are dropped back to the, GPs
Emma Yeah
Jackie Who don't know what to do with you because they haven't got the experience.
Emma Mm
Jackie And, and the time,
Emma Yeah
Jackie And, it's only when you get somebody that's really interested in dementia that you get to know a lot more.

The choice of 'dropped back' here is striking, since it provides a sense of Jackie's disempowerment through the sudden withdrawal of specialised support. This utilises the common orientational up-down metaphor, whereby GOOD (and power, control) IS UP, and BAD IS DOWN (Lakoff and Johnson, 1980), to present Jackie as involuntarily moving down the hierarchy, here back to non-experts. Critiquing the GPs' lack of experience and time, Jackie argues that learning more about dementia happens by chance, according to whether the person you see is 'really interested in dementia'. By shifting from the first person (used to outline her initiation of the diagnostic process) to the second person when discussing the subsequent processes, Jackie situates her experience as commonplace. Indeed, inconsistent and insufficient support and professional understanding is critiqued by multiple participants (see section 6.4), and other people affected by dementia, demonstrating a wider dissatisfaction with support for many individuals following diagnosis (Pratt and Wilkinson, 2001; Prorok *et al.*, 2013). Against this, Jackie presents herself as actively seeking information from the community about 'what was available' and 'what I could do', evaluating her local council and the Alzheimer's Society as the 'most helpful', as opposed to her GPs and the more general charity Age UK. That Jackie approached Age UK 'first [...] because of my age' but did not find it as helpful reinforces the diversity of the population that is consistently discursively and structurally homogenised as being 'over sixty-five' (Perel-Levin, 2019).

Although, as will become increasingly apparent, Jackie frequently aligns with other people with dementia to establish a collective group identity, she also emphasises the heterogeneity within this typically homogenised social group. This includes diversity regarding dementia, and a lack of understanding amongst its members regarding dementias different to their own. In response to seeing image 6 of a person with working-age dementia, Jackie tells me that 'it's nice to see that age' because she knows someone (Bill) through her choir, who has Alzheimer's disease and is aged thirty-two:

Jackie And [Bill] came and you could see that he was, fu-, progressing fur- quicker. Because they say that the working - it gives such as me a better understanding of the different types of dementia, because you're only talked about your, your diagnosis.

Emma Yeah

Jackie They don't tell you about. erm, the ones that are going to lose their voice, you know the speech, part of the brain, or that, and, so sometimes when you are in the Memory Café you don't know how to, deal with those people and you have to go through the carer first sometimes and that's wrong. You shouldn't have to you should be able to approach the person, but without the understanding of what, how the disease is taking it, away from them, it's very difficult, to start a conversation sometimes.

Here, Jackie reflects on the barriers that are created through ignorance, including between people with different dementias to your own. This is reflected linguistically in her choice of 'those people' that 'you don't know how to deal with' and therefore 'need to go through the carer first' for. Through the distancing demonstrative 'those', Jackie situates herself as apart from individuals with dementia that she doesn't understand how to communicate with, with the carer subsequently becoming the bridge between them. Jackie firmly evaluates this as 'wrong', emphasising that 'you should be able to approach the person'. However, she emphasises that 'without the understanding', it becomes 'very difficult'. Specifically, Jackie mentions understanding 'what, how the disease is taking it, away from them'. Dementia is simultaneously presented in biomedical terms as a 'disease' and personified as a thief. Although the ambiguity of 'it' as a referent raises questions about what exactly dementia takes, if Jackie's earlier discussion in this account of different symptoms (such as losing speech) are assumed to be the antecedents, then she would appear to be describing the loss of abilities rather than, as in much mainstream discourse, selfhood (Van Gorp and Vercruysse, 2012). These other people with dementia, then, are not separated due to a loss of self or status but rather an ignorance of how to communicate with them, since people are insufficiently educated on the diverse conditions within the 'umbrella term' dementia that means that 'everything's different' across individuals.

Relatedly, Jackie attends to broader attitudinal barriers, namely the double stigmatisation of being old and having dementia (Evans, 2018). Responding to two images of people socialising in groups (images 3 and 4), Jackie tells me of the need for marginalised people to connect and be listened to. She begins by stating the value of 'sitting two people together and letting them talk'. In the context of the stigmatisation and silencing of older adults (intensified for Jackie as a woman and someone with dementia; Proctor, 2001), the permissive connotations of 'let' imply the need to enable, rather than obstruct, such adults to speak for themselves. Indeed, although Jackie acknowledges that sometimes conversations do need 'directing', she quickly counters this with:

> but very often. people who have been. are, older in age. have got a lot to talk about, a lot of memories, a lot of expertise that, that, gets lost because we've become [2.4] not part of society so easily, it's, that we're sort of side-lined. [...] It's more for families and that sort of thing and, young, professionals.

Here, through shifting to the plural personal pronoun 'we', Jackie positions herself as a spokesperson for older people, critiquing the marginalisation of older citizens, whereby 'a lot of memories' and 'expertise [...] gets lost' because people's voices are no longer heard in a society where older adults are 'largely invisible' and systemically discriminated against (Perel-Levin, 2019: 90). Many people with dementia share Jackie's frustration at their extensive life skills, work skills and experience being 'written off', being instead 'defined by dementia' and treated as lesser (Davies *et al.*, 2021: 17). In such a hostile environment, Jackie emphasises how 'important' it is to 'get people together, like-minded people together', a position on peer support that is shared amongst many participants (section 6.6). However, contextualising this within an unstable funding environment (another signal of older citizens being devalued), Jackie indicates that such groups rely on voluntary support or unpredictable council funding, meaning that it 'just gets started and then (is) stopped abruptly'. She focuses on how this impacts the individuals involved: 'it's awful for the people that have. built up relationships, and, you don't know where to go from there, do you?' A sense of powerlessness and abandonment is presented in the abruptness of the end of such support, as reflected in the more concrete, 'built' relationships giving way to uncertainty. Structural issues, namely the unreliable council funding, are given a human face by Jackie focusing on the people affected by structural shifts and explicitly drawing me into the experience of not knowing what to do through her tag question 'do you?'.

Throughout, Jackie foregrounds how the environment can enable or disable people with dementia. Above, she discusses attitudinal barriers (lack of understanding and stigma), but she also attends to social inequalities and structural issues within the social environment. This includes accessing more holistic support, whereby 'this social prescribing is taking so slow to get mo- [coughs] to move, that er, people are being left behind.' Social prescription is an increasingly influential aspect of healthcare that refers people to non-clinical activities to improve their wellbeing, usually delivered by community services and voluntary groups (Baker and Irving, 2016). Recognising the influence of social, physical and economic factors on health, schemes range from advice services (e.g., regarding benefits) to activities grounded in the arts or nature (Hamilton-West *et al.*, 2020). Social prescribing is increasingly popular, but researchers warn that these heterogeneous provisions require appropriate coordination and support, and that they are not a 'silver bullet' for austerity measures, with other services such as public transport and libraries remaining important for wellbeing (Hamilton-West *et* *al.*, 2020). Reflecting this broader discussion, Jackie highlights that she enjoys the independence of travel, which is facilitated by her bus pass:

> Jackie I seem to travel because I enjoy the independence and my bus pass. and that's one of the things I've been looking at in the erm political pamphlets. to see who's going to offer me, my bus pass because each time we have a general election that's one of my worries
>
> Emma That's a good point actually.
>
> Jackie Because it's not only for me is it, it's for all people, senior citizens.

Here, Jackie's continual concern about bus passes remaining a right for older citizens is conveyed through the simple present tense when discussing elections, which suggests a continuation between Jackie's past, present and future concern about this issue, due to the precarity of many social services. Through this, Jackie constructs a persevering identity that is related to her habitual activity (bus travel), the object that enables this (her bus pass) and her social persona as a politically engaged citizen concerned with the treatment of 'senior citizens' more broadly. This reiterates the interconnectedness of identity with our relations with people and artefacts within the social world (Hughes, 2014; Sabat, 2018). Jackie self-reflects on her positioning relative to other citizens, telling me that 'I'm lucky, I get two private pensions, erm. a, a state pension and an attendance allowance so [2.2] I'm comfortable. I can do what I what I want to do. […] And that's, that's important.' Situating her financial situation as one that enables, rather than disables her, Jackie positions herself as 'lucky', implicitly acknowledging the limitations that other people face. This mirrors her concern that 'people are being left behind' by services, and her further discussion that without 'a good doctor or a good welfare support worker', people 'on their own […] can miss out on a whole range of support'. Through her attention to structural and financial inequalities, Jackie emphasises that not everyone has equal access to support for dementia, focusing particularly on people 'on their own' who have less of a support network. Indeed, people with dementia who live in deprived areas and do not have a carer are at particular risk of having unmet needs and lower wellbeing (Wu *et al.*, 2018).

Throughout her interview, Jackie presents a personalised account of dementia that actively engages with the wider socio-political climate. She foregrounds the role of the environment in (dis)abling people with dementia, including through social attitudes, financial (in)stability and structural support, or lack thereof. This section has focused primarily on healthcare provision, broader non-profit community support, structural support (bus pass), the homogenisation of people with dementia due to insufficient understandings, and the marginalisation of older people, including those with dementia. As part of her engagement with society's role in experiencing dementia, Jackie foregrounds the role and potential of the media, considering current tropes in relation to lived experience. It is to this issue that I now turn.

4.3.2 Media and lived experience

Reflecting on the role of the media and consumers, Jackie positions the media as an important source for disseminating information and influencing its consumers' worldviews: 'the media is handy because it helps you to form. Not decisions, but opinions. [...] And it keeps your mind awake. [...] the media is good because it's thought-provoking, sometimes it's, problem-solving'. Here, Jackie establishes consumers, herself included, as actively constructing meaning when engaging with media (Kitzinger, 1993), since consumers are attributed the agency to deliberate and form opinions, while media content 'helps' inform this. Beyond influencing people's 'opinions' by being 'thought-provoking', Jackie positions the media as 'problem-solving', and thus as influencing real-world actions and social change. Expanding on this, Jackie establishes a problem-solution structure, whereby carers face insufficient structural support, for which the awareness that media can provide is instrumental to creating change:

Jackie carers can get so worn down by, erm their er usage of being used by the
person and, the care system, not helping them enough,
Emma Yeah,
Jackie So, the media needs to get to the care system too, and start waking their
ideas up by pointing the finger and saying excuse me, are you? Because that's
what the media is part of isn't it is
Emma Definitely
Jackie Questioning and, developing services and all sorts of things

Again, Jackie utilises an awakening metaphor ('waking' ideas up) that positions the media as an illuminating institution; here, rather than keeping 'your mind awake', the media must expose the issues in the care system and push stakeholders to face them. Through 'questioning' and 'developing' social issues, Jackie positions the media as an advocate for the public (here, carers), since media organisations are attributed greater agency than individuals to achieve change through critical coverage. This explicitly calls upon the media's broader socio-political power in its ability to frame public priorities, through which it can influence the political agenda and therefore push for change (Bednarek and Caple, 2019; Picard and Yeo, 2011).

Recognising the importance of the media, Jackie critiques current representations of people with dementia and advocates for a variety of improvements so that media representations can better reflect lived reality to improve the lives of people affected by dementia. Aligning with the other participants (see section 5.3), Jackie critiques the lack of diversity in media representations, including for dementia as a syndrome, which needs to be recognised as an 'umbrella term' with 'different forms of disease', meaning that 'everything's different'. She also criticises the negativity and narrow focus of representations (explored further in section 8.3), telling me that: 'a lot of it is, headline grabbing erm. Always the negative side, erm, usually it's just one-sided in that it's just dealing with the dementia'. Focusing on newspapers here, Jackie touches on the purpose of news media to garner readership through 'headline grabbing' (Kelly, 2019), critiquing their 'one-sided' rather than holistic depiction, and 'negative' focus. This recognises that news stories favour negative aspects when reporting on dementia (Bailey, 2019; Brookes *et al.*, 2018), as part of the broader news value whereby negativity makes an event more newsworthy (Bednarek and Caple, 2019). She supports her argument with a 'Dementia Friends talk' she attended, where they 'got loads of headlines, but it all seemed very negative. Er. They don't show a lot of the positives of dementia'. This positions the Alzheimer's Society, who run these sessions, as a trusted information source, something that Jackie questions for newspapers, suggesting that 'it's probably with somebody who doesn't know what they're talking about'. Indeed, most journalists will not be knowledgeable about dementia or recommended terminology, reflecting a broader lack of understanding amongst the public (Kelly, 2019).

In particular, Jackie promotes amplifying the voices of people affected by dementia in the media, arguing that this can provide expertise, nuance, diversity and a 'human side' to dementia. Jackie emphasises the value of people with dementia working with the media to improve awareness of the condition, telling me that:

> the media are important in doing that, to say there is life after the diagnosis. And that needs to be pointed out every time, […] I love, in [image] 15 where the guy is actually using the media. Because I think the more we can use the media, the more people realise that we, we are ok and and that we aren't to be feared. […] that's where the media is there, isn't it? It's, to lose that fear, to make people more aware of the pros and the cons of dementia,

Throughout the interview, Jackie aligns with the living well discourse's message that 'there is life after the diagnosis', elsewhere presenting the phrase 'living well' as a necessary counterweight to the negativity surrounding dementia by 'inspiring' people and reflecting that you can be 'enjoying life' while living with dementia (see section 8.2.1 for more on 'living well'). Image 15 depicts Terry Pratchett holding up a sign saying, 'It's possible to live well with dementia and write bestsellers "like wot I do"'. Jackie praises this advocacy and calls for more examples like this, arguing that greater visibility of people with dementia can reduce the fear and stigma surrounding those with the condition, as individuals with dementia will become less 'side-lined' (to use Jackie's previous criticism) and can improve awareness by addressing both the positive and negative aspects of dementia. Indeed, since fear, silence, misconceptions and stigma are all interrelated, improving communication via the media is instrumental to improving people's perceptions and thus experiences of dementia (Kelly, 2019). Here, Jackie establishes a collective group identity for herself and other people with dementia through the plural first person pronoun 'we'. This 'we' is contrasted against the generic, more distanced 'people' that need to become more knowledgeable ('realise', 'more aware') about dementia by learning from people with lived experience. This situates people with dementia as experts through experience, furthered elsewhere by Jackie's foregrounding of national advocates such as Agnes Houston and Wendy Mitchell who are 'doing, lots of sterling work'.

Thus, Jackie advocates showcasing the 'human side' of having dementia, through working with individuals with first-hand experience and showing what they and their life are like. Reflecting on her own experiences with television crews covering activities such as conferences, swimming and groups that she is involved in, she tells me that 'It's just such a good insight into how we are actually working, and reacting and talking. […] Why isn't it done more?'. This distinguishes between how people with dementia are 'actually' acting in real life versus how they are represented, indicating the need for this better 'insight' into reality. Notably, Jackie focuses here on responsivity ('reacting'), social productivity ('working') and voice ('talking'). These activities construct an image of the engaged, active citizen with dementia as found in the structural, rights-based discourse (Bartlett and O'Connor, 2010). Missing from Jackie's and other accounts that focus on active citizenship and 'living well' are people living with the most challenging aspects of this syndrome, who cannot participate in this cognitively oriented way (McParland *et al.*, 2017).

Expanding on her experience with television shows reporting on aspects of life with dementia, Jackie situates people with dementia within television programmes about disabilities and illnesses more broadly, promoting greater coverage of what it is like to live with a diagnosis and some of the ways that your environment can (dis)empower you:

Emma So, just to see if I've got the right erm, understanding, are you saying that it would be beneficial to kind of just show more ordinary life?

Jackie Yes, you don't see that, there isn't erm, a consistent programme each week. of, the hidden demen- of the hidden diagnosees [assumed to mean people with a diagnosis] or, the other side of living with a diagnosis and it's not just. it could be cancer, it could be a physical disability, it could be anything but, this Brexit's just taken over.

[…]

Emma Yeah, that's true. So when you say the other side, which sides do you think there are?

Jackie There's a human side because erm, there's a lot of people, getting through diversity with erm horrendous problems and, and solving those problems. There are television programmes that are highlighting those programs like the Nick Knowles program, where they go and sort out homes and that. Because, physically, there aren't enough, erm, the constraints of their home means that they can't have a proper life because they're forever, struggling, with their home life and until you've got your home life sorted you can't afford to get out and do other things can you?

This focus appears to be on normalising life with diagnoses by following the lives of individuals, all of which would help to show what Jackie describes as the 'human side' of dementia. It is here that Jackie explicitly raises 'highlighting' 'diversity' and some of the 'horrendous problems' that people face. She refers to a popular British show (named DIY SOS) hosted by Nick Knowles that improves the lives of ordinary people facing hardships through transforming their home, to exemplify that the media can actually contribute to improving people's lives through adapting their physical environments to enable, rather than disable them. Not only does this address individual and environmental barriers, but it can model ways of overcoming both environmental obstacles (for example, by changing the architecture and introducing aids) while simultaneously conveying 'various stigma-busting messages' when exploring the family's wider life, which contributes to breaking down attitudinal barriers for people affected by dementia (Kelly, 2019: 96). Here, dementia is very much situated within the larger context of disability activism and the need to improve structural support for people with disabilities, in part through collaborating to provide newsworthy human-interest stories that bring in revenue for media organisations, while simultaneously benefiting the individuals and community featured (here through home improvements) and overall, giving a relatable human face to dementia (Bednarek and Caple, 2019; Kelly, 2019). To facilitate such a relationship, Jackie insists that media representatives must 'be a lot more thoughtful in how you approach your subject', 'let[] people talk', and use more accessible 'language that the person would probably understand more', including by avoiding acronyms where possible. This again takes a rights-based approach that focuses on reducing power inequalities that are inherent in interactions between institutions, such as the media, and disenfranchised citizens like people with dementia.

As well as people with dementia, Jackie advocates for greater visibility of carers, arguing that it is: 'so important, for, you know, a lot of carers to be recognised and to know that they have a voice. Um. A lot of people with dementia have a voice and can't use it, and the, the carers use that voice but they then they have their own voice and their own thoughts'. This emphasis on carers' voices can be seen to challenge much of the social shift towards recognising the voices of people with dementia after decades of privileging carers and health professionals while silencing and discrediting people with dementia (Bailey, 2019; Clarke, 2006; Villar *et al.*, 2019). Yet, it also recognises the historic ignoring and undervaluing of carers, associated with a lack of support and the negative social, physical, psychological and economic effects of caring (Fletcher, 2020a). Jackie's contribution acknowledges the complexity of the dynamics between caregivers and people with dementia, with carers sometimes needing to advocate on behalf of their loved one, while simultaneously having their 'own voice' and 'thoughts' that must, too, be recognised.

In her concern for heterogeneity and more accurately reflecting people affected by dementia, Jackie also highlights the need for visual representations to be more diverse. Jackie establishes images as 'more important than the text' for many people, with images first drawing the eye, contextualising the piece and telling 'the story'. She references the popular saying 'a picture can say a thousand words' to describe the amount of information that images convey, and situates images and articles as 'the starter of a conversation', again situating the media as a means of stimulating social change. She explicitly critiques the collection of twenty images shown in the session, telling me that 'I think it's an interesting collection of pictures. I think you could have, more could be developed but, I think, that's the deficit of the, media, there's a lot of things written, but their illustrations, aren't always in line with the, the text.' In saying this, Jackie aligns herself with her DEEP network's criticism that 'sometimes the images selected to illustrate articles can serve to undermine the actual story' (DEEP, 2014: 4). It is within this ideological context that Jackie considers who is included in visual representations of dementia.

Telling me about her feedback for a local art gallery, Jackie recalls that the people they featured 'were all white' and 'all elderly or young children'. Here, in line with communication guidelines (Bould, 2018), Jackie clearly establishes different ages, skin colours and ethnicities as important features of visual representations that need diversification. In the context of evaluating the twenty images I provided for participants, Jackie similarly notes that: 'on the whole I think it's a good cross section of people, mainly white people. A couple of. I love the hands, I think that is so age related.' In an overwhelmingly white British majority group of participants, Jackie was the only participant to explicitly identify the overrepresentation of white people relative to minority ethnic groups. This reflects the normality of disparities in representations across popular culture and research (Bould, 2018; Hulko, 2009), indicative of broader structural inequalities (Culley, 2006). Clearly, different people and experiences with dementia beyond a white British perspective need foregrounding. Of course, individual identities are significantly more multifarious than using distinct, fixed ethnic group categories allow, whether for minority or mainstream groups (Culley, 2006; Khan, 2015; Mullay *et al.*, 2018). Jackie touches upon this when discussing the intersection of 'age, gender' and ethnicity for how people experience dementia, concluding that: 'it's all related how you cope with it. How your family copes with it. [...] And how you see it.' Throughout, whether for social demographics, types of dementia, positive and negative experiences or for people affected, Jackie situates diverse representations as fundamental to the role of media and as a way to improve the experiences of people with dementia and their loved ones.

Equally, Jackie acknowledges that in the context of such diversity, interpreting good practice in the media is subjective and depends on a person's 'upbringing [...] life experiences [...] family situations, and when you roll that into one, they're all different for everybody, you can't say that one, one thing suits everybody, and so it's very difficult when you write articles, to please everybody.' What she touches upon here is that, not only does the media influence consumers' worldviews, but an individual's 'life experiences' (social, cultural, economic, historical, physical and psychological etc.) affect how different consumers interpret media representations (Gamson and Modigliani, 1989). It is therefore vital to situate any discussion of media portrayals and discourses within individual contexts. Subsequently, this chapter concludes with an exploration of how some of Jackie and Sheila's personal 'life experiences' interact with their responses to particular representations.

4.4 Personal responses to images of dementia

Building on the above analysis of Sheila and Jackie's personal accounts, here the focus shifts to foreground some of the ways in which they each respond to three visual depictions of people with dementia. Despite a growing body of research into representations and recognition of the importance of attending to visualisations of dementia (Brookes *et al.*, 2021), a close consideration of how people other than analysts interpret and respond to visual representations is lacking (Breeze, 2011). The present section addresses this divide by comparing how Sheila and Jackie respond to three particular images, one literal and two metaphorical, which are used to represent people with dementia in charity and newspaper contexts. I consider how the two women's personal experiences and discursive preferences inform their responses, asking: what do they each choose to foreground when interpreting the same images?

Images 5, 10 and 12 are selected for analysis here for multiple reasons. Firstly, they are each used to represent someone with dementia, with image 5 reflecting a 'living well' discourse in its depiction of a man smiling in his garden, while images 10 and 12 reproduce a 'tragedy' discourse, explicitly denoting a loss-oriented fragmentation of the represented participants, either through a disintegrating head or missing jigsaw piece. Intriguingly, researcher-led analysis often differs from the points raised by these interviewees, with image 12 providing a particularly useful contrast, as it has previously been subjected to multimodal critical discourse analysis (Harvey and Brookes, 2019). A more pragmatic reason for selecting these three images is that both Jackie and Sheila comment on them in detail, enabling a more substantial comparison between the two women.

For context, it must be noted that the images that resonate most with Sheila depict the couples, hands and the women holding their head in their hands (images 1, 2, 7, 8, 13, 14, 16). While the head holding images are interpreted in relation to the despair that she and Stephen both felt from the challenges of dementia, the other images are associated with love and embodied forms of expression:

> Those, I thought, holding hands [7][8] went with these [13][14][16] which is, love. That, holding hands, often conveys a lot more than words, particularly if they're not fully understanding. Erm. To hold hands is a great thing, and um, probably. your love for each other gets you through some of the difficult times.

As such, the images Sheila foregrounds clearly reflect her experiences as a carer for her husband, both regarding their strong couple identity, embodied communication of love, and suffering. Her responses to these images, however, are used in the previous section to help illuminate her reflections on caring for Stephen, while Jackie's responses are either also interwoven into her above points or insufficiently detailed to feature. For example, Jackie's response to the images of couples is to emphasise that 'there is life after the diagnosis' and discuss the role of the media in supporting this message, a point that is more relevant to the above exploration of her discursive positioning. Jackie praises many images, including the hands images (7, 8) and tree image (11), but she declares that two of the images examined here 'represent dementia for me so much' (images 10 and 12). Although the images align more with Jackie's preferences, then, they have been selected for the interpretations and associations that both women respond with, which are distinct from the quotes discussed in the above sections and can provide useful insights into the subjectivity of interpretation.

4.4.1 Literal image

Beginning with an example of a literal image, which denotes a man smiling in a garden and resting on his broom (Figure 4.2), it becomes clear that the two women draw different connotations that relate to their own experiences.

Figure 4.2 ***Image 5***

As befits her earlier discussions, Sheila foregrounds the concept of ‘coping’ with dementia:

Sheila Erm. That just conveyed to me. that the man was coping?

Emma Mm.

Sheila Was making the best of things. Er. Perhaps you see a bit of anxiety, about his eyes. But. On the whole it's a cheerful, cheerful er face. And erm [2.9] the fact that it’s in his garden, and that he's, still sweeping up [laughs]

Emma [Laughs] yeah

Sheila Just making the best of it.

Underlying Sheila’s admiration that the man is ‘still sweeping up’ is an implicit assumption of deteriorating abilities, which implies that she interprets him as having dementia. She analyses his ‘face’ as ‘cheerful’ overall and repeats that he’s ‘making the best of things’, admiring that he’s being active in his garden (Sheila is herself a keen gardener), which presents a fairly optimistic account of ‘coping’. Yet, interestingly, Sheila also suggests ‘a bit of anxiety’ that shows ‘around his eyes’. The eyes are widely associated with revealing someone’s emotional state, usually signalling anxiety through a lack of eye contact (Waxer, 1997), which may here be indicated by the off-camera gaze of the represented participant. The suggestion that the man’s anxious emotional state contradicts his external display of cheeriness assigns a complex emotional identity to the figure, which reflects the external positivity that both people with dementia and carers can emanate, masking their actual, less optimistic emotional states out of concern for the wellbeing of others, a desire to present a positive self-image and the pressure to adhere to expectations of a person 'living well' with dementia (Bartlett, 2014; Manthorpe *et al.*, 2011).

While Sheila focuses on what she sees in the photo and in relating this to anxiety and coping with dementia, Jackie's response to the image reinforces her structural, rights-based focus. Namely, she highlights her personal growth through becoming friends with someone from the Caribbean, and considers some of the additional structural barriers that immigrants face. This is initiated through foregrounding the man's status as an 'ethnic minority':

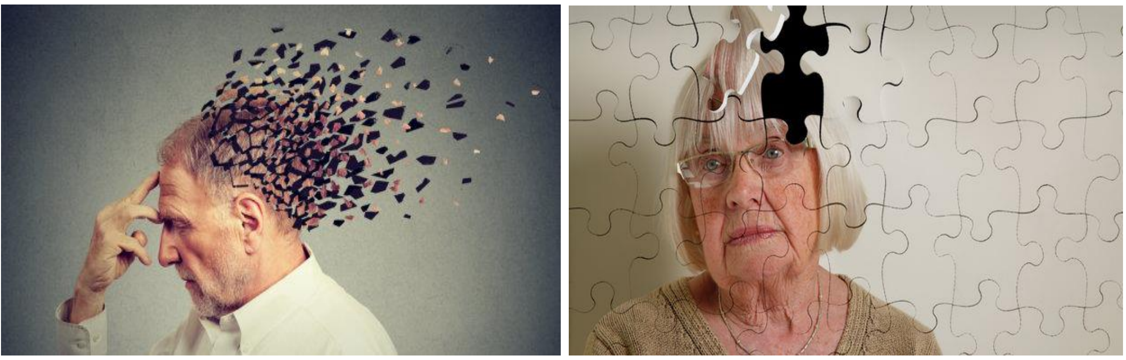
Jackie	Number 5 for the gentleman who's erm, of an ethnic minority. [...] I've already discussed because I love, I have a friend called [Vera] who lives in the [Willows], and she's woken me up to the differences. She talks about her childhood, she talks about her food, and, we've become quite close that way in that it shows me the differences. The way I think of white and, normal food and she thinks of Caribbean food as normal. We see a lot of differences but we see a lot of similarities.
Emma	Yeah
Jackie	Because she didn't come over in the Windrush she came over just after.
Emma	Ok.
Jackie	But she's still had problems with passports and, family, problems trying to get, nationality sorted out. Because it's, encompassing, as soon as the media starts on one thing. it makes you think of other things and and.

Again, through her friend having 'woken me up to the differences', Jackie uses an awakening metaphor for the greater awareness of the diversity of life experiences that she as a white British citizen gains from exploring Vera's alternate citizen perspective. This account is among Jackie's most self-reflective, and foregrounds her personal growth, which is a fundamental right proposed for citizens with dementia (Bartlett and O'Connor, 2010). Her individual growth supplements the broader, social awakening she previously suggested the media can achieve through foregrounding issues and diverse perspectives. That Jackie focuses on 'differences' in experiences and structural concerns (here, issues with nationality) reiterates her above emphasis on recognising the diversity of people affected by dementia, and situating people's experiences within the broader structural barriers that individuals can face. Notably, Jackie spends very little time on the image itself here, and indeed she acknowledges her associative thought process, with: 'as soon as the media starts on one thing. it makes you think of other things'. This example serves as a useful reminder to analysts that it is impossible to predict the many connections that individuals will make when presented with representations of a particular topic, here dementia, due to the countless intersections with a person's experiences and beliefs.

4.4.2 Metaphorical images

Whereas image 5 was drawn from an Alzheimer's Society webpage and adheres to a 'living well' discourse, the two images explored here (see Figure 4.3) are stock images that feature in newspaper articles and reproduce a 'tragedy' discourse. Both are examples of what Forceville (2008: 465) terms a hybrid metaphor, in that at least 'two phenomena are visually represented as occupying the same space in a manner that is physically impossible', consequently creating a new meaning that is more than the entities individually. Here, people are merged with the process of disintegration and an incomplete jigsaw, both of which are clearly impossible in the literal sense. This literal impossibility consequently encourages metaphorical interpretations, such as the BRAIN IS A DISINTEGRATING OBJECT and the BRAIN IS A PUZZLE. While this section focuses on Jackie and Sheila's responses to images 10 and 12, section 7.3 examines how all participants respond to the full page of decline-oriented visual metaphors. Being monomodal visual metaphors without any explanatory text, there are ambiguities regarding what these two images mean. This is furthered by their non-specific, blank backgrounds that remove the depicted participants from real-life scenarios, a characteristic that reflects their origin as generic stock images (Machin and van Leeuwen, 2007). Much is left, therefore, to the subjective interpretations of viewers.

Figure 4.3 ***Images 10 and 12***



10. 12.

As Figure 4.4 shows, Sheila and Jackie both identify the direction of movement of the fragments in image 10 as going 'away' from the man. They also both map their own experiences onto the image, reinforcing the ability of metaphors to resonate with and help communicate personal and intangible psychological, physical and emotional experiences (Castaño, 2020; Semino, 2008). For Sheila, this image initially resonates not with her Alzheimer's disease but with her spinal problem, specifically the movement of 'pain' through her body: 'up' her spine to her head where it 'goes out, there, and then it comes up again'. This cyclical flowing of pain has a clear locus (her lower spine) and direction ('up' and 'out'), which situates the head fragments as Sheila's spine-related pain, and as nothing to do with her thoughts, intellect and memories, which are more usually associated with the head (Harvey and Brookes, 2019). The difficulty of expressing pain is widely documented, due to its intensely personal, intangible and contextual nature, and a widespread inability to find the right words (Biro, 2010). As such, visual metaphors are a powerful resource for helping to visualise the invisible experience of pain (Padfield *et al.*, 2018).

Figure 4.4 ***Sheila and Jackie's responses to image 10***

	Sheila	I equated with that [10], funnily enough, not out of dementia, or Alzheimer's, but I have a spinal problem that causes me a lot of pain and it goes up my spine, and it comes out of my head and it goes out, there,
	Emma	Oh wow
	Sheila	And then it comes up again, and goes out, and [laughs] that made me think of that. […] Erm. [6.3] Because I put that to pain-related, erm, I suppose it's really saying, the man's got his hands on his forehead and, wishing it all away [laughs].
	Emma	Mm.
	Sheila	[3.5] (Or) saying "I can't bear it anymore", or "I know what's happening go away." Because, you do know what's happening.
	Emma	Yeah
	Sheila	As it's gradual. And er, you're aware that, certain things you can't cope with.
	Jackie	This, number 10 is so, erm. It's like an advert, for dementia, where. the guy's looking a bit perplexed, and everything's just flying away from him. and, I think, that happens to me quite often. It happened to me on a street corner erm, last year. And I do remember it, in that, erm, I stood on the street corner and I didn't know which way to go. And it was only about fifteen twenty yards away from my home. But I couldn't, organise my thoughts enough, and there was nobody around to say "are you alright?" [1.5]
	Emma	What happened?
	Jackie	I just stood still. And then I looked round and then I spotted somewhere that I recognised.
	Emma	That's good
	Jackie	I took a [breathes in] big deep breath [laughs]. And 12 is so amazing I'd say those two represent dementia for me so much.

Sheila revises her initial pain-oriented response to match the session's dementia context, suggesting that what 'it's really saying' is that the man is cognisant of 'what's happening', for which she hypothesises three reactions: that he 'can't bear it anymore', is 'wishing it all away' or saying 'go away'. Although Sheila distinguishes this from being 'pain-related', it could be argued that here she shifts from physical symptoms of pain for the spinal problem to psychological ones for dementia, such as despair and anger (Biro, 2010: 12). Indeed, noting the man's hand on his forehead, Sheila foregrounds the emotional experience that accompanies being 'aware' that you are changing when you have 'gradual' dementia. The fragments become, as with Sheila's pain, an aspect of yourself that you wish to lose; for instance, with knowledge comes despair and the wish for the unwelcome dementia to leave the body and 'go away'. Although implicit, assuming that the dementia is the intended recipient, Sheila's directive to 'go away' personifies the condition as an unwelcome, animate entity, therefore connecting this visual metaphor to the desire to remove an unwelcome intruder, itself a common metaphor used to describe dementia (Castaño, 2020; Van Gorp and Vercruysse, 2012). While Sheila's association with her spinal pain is obviously grounded in a personal experience, her interpretation of suffering with dementia, due to awareness that you cannot 'cope' with certain things and are gradually changing, mirrors her earlier discussion of suffering and her future fears for herself.

In contrast, Jackie positions image 10 as a visual metaphor for a different intangible experience, namely being unable to organise your thoughts, which Jackie experiences 'quite often'. Indeed, she utilises her own metaphor, that 'everything's just flying away from him' to express this common cognitive change with dementia (Górska *et al.*, 2018). Again, Jackie maps her personal experience onto the image, exemplifying this by telling me of a moment last year when, alone and nearby her home, she did not 'know which way to go'. This is presented as a short-term obstacle for Jackie, since after staying 'still' and looking around, she 'spotted somewhere that I recognised', took a 'big deep breath' and continued on. As such, the fragments 'flying away' in image 10 are not positioned as a permanent loss, but as a temporary cognitive experience associated with her dementia.

It is interesting that while both interviewees relate their own experiences to the man in image 10, and therefore to an extent identify with the represented participant, they both approach the woman in image 12 as observers viewing someone else with dementia (see Figure 4.5). Sheila focuses on 'physical signs' that 'you can see' (namely becoming 'more vacant'), which positions her as an external onlooker, rather than the person experiencing dementia. This socially distances Sheila from the represented woman, which notably contrasts her consideration of internal emotional experiences for the men in images 5 and 10. Similarly to image 5, Sheila uses the woman's eyes to point to the external 'physical signs' of internal processes (here brain 'tangles' getting worse and the person becoming 'more vacant'). Likewise, Jackie explicitly relates the woman to other people with dementia and positions herself as an observer ('you see so many people with that'), interpreting the woman as looking 'lost', with 'the piece of the puzzle [...] missing'.

Figure 4.5 ***Sheila and Jackie's responses to image 12***

Sheila	The lady with the piece of jigsaw [12] is, you can see, this look that, as you're getting worse, comes over your eyes and things you can become more vacant. And so the er. as the pieces of the tangles get, get worse, it, you get physical signs. At first nobody knows, and then it becomes obvious, gradually.
Jackie	I took a [breathes in] big deep breath [laughs]. And 12 is so amazing I'd say those two represent dementia for me so much.
Emma	Ok, 10 and 12
Jackie	In that, you know that the piece of the puzzle is missing [1.9] and wow, yes and she looks, sort of lost, and that's, you see so many people with that.
Emma	Yeah
Jackie	And when you go, I went to sing with a choir in the care home [1.8] and there was one lady that looked like that, and as soon as we started singing, her face lit up, and she started singing with us
Emma	Mmm, okay
Jackie	But until then she was in the care home sat in an armchair and it was the typical picture of a care home resident.
Emma	Mm. Yeah
Jackie	Just, sat there. no stimulation and I think stimulation is so, important in those care homes.
Emma	Definitely
Jackie	And it's taking a long time for the activities people to realise, or management, for people to realise.

A closer analysis of the two images may help to explain why both women align themselves with one representation and not the other. Concerning image 12, multimodal critical discourse analysts Harvey and Brookes (2019) argue that the woman is positioned as eroded and comparable to the living dead through this visual metaphor. They warn that although evocative, such a depiction potentially encourages fear and revulsion in viewers, rather than empathy and compassion. Neither person in these images makes eye contact with viewers, which arguably situates them as "offer" images of what dementia could look like, rather than demanding any social engagement with viewers through eye contact (Kress and van Leeuwen, 2006). However, with his finger pointing to his head, the man looks busy in thought (or at least in trying to gather his thoughts) while, sitting still and staring off-camera, the woman looks, as Sheila and the researchers (Harvey and Brookes 2019) note, 'vacant'. Perhaps these differences explain why Jackie and Sheila identify with the more active participant and distance themselves from the woman; despite Jackie evaluating image 12 as an 'amazing' representation of dementia, the representation is for other people with dementia, not her.

Again, Jackie associates a personal story with the image, recalling a specific person she met as looking like the lady in image 12. Notably, this is not someone close but simply 'one lady' that she sees when going with her choir to sing in a care home. Unnamed and unknown on a personal level to Jackie, she is situated as 'the typical picture of a care home resident', sitting 'in an armchair' with 'no stimulation'. Yet, Jackie states that 'as soon as we started singing, her face lit up, and she started singing with us'. Two aspects of Jackie's account are key here. The first is that the lady's state is not depicted as permanent, since upon the choir singing, her face lights up (the brightening metaphor connoting increasing happiness and engagement), and the lady herself bridges the initial separation by joining Jackie's 'us' through singing with them. Secondly, rather than attributing the lady's initial disengaged state to her dementia, Jackie foregrounds the role of the external environment, claiming that people such as the lady need 'stimulation' and that the 'management' need to realise this. For Jackie, the woman that she associates with image 12 is not herself a zombie – instead, her treatment and social positioning situate her as such (Latimer, 2018). Jackie concludes her narrative by advocating for broader social change in 'those care homes', again aligning with her overall structural, rights-based discourse by targeting environmental barriers to meaningful connections and wellbeing.

The above examples are powerful illustrations of the subjectivity of our interpretations. Of course, these responses occurred in a specific environment, and if there were accompanying text or a different arrangement of images, Sheila and Jackie may have responded very differently. Here, despite interpreting the same three images representing people with dementia, Sheila foregrounds emotional and physical aspects of dementia, particularly attending to the concept of suffering and coping, alongside how individuals change with dementia. In contrast, although Jackie recounts her confusing episode, providing a more personal insight into her own experience of living with dementia, she continues her structural rights-based discourse overall. This includes emphasising her personal growth through increasing awareness of diverse life experiences and promoting the right of people with dementia to an empowering, rather than disabling (here, unstimulating) environment. Sheila and Jackie's examples reiterate that responses to images are personal; we may agree on what the image literally shows (for example, the fragments moving away from the man in image 10), but the connotations that we draw are heavily influenced by our subjective experiences and discourses (Barthes, 1968).

4.5 Summary

This initial analysis chapter provides an in-depth consideration of how two interviewees represent their distinct experiences and stances towards dementia. Close analysis demonstrates the complexity of representations, with both women engaging with, and sometimes resisting, a range of discourses. Nonetheless, each clearly have their own signature stances, with Sheila drawing on 'familism', embodiment and Christian principles, prioritising her relationships with close others and God to present a self-identity grounded in relationships and caring for others. Throughout the interview, a discourse of suffering particularly resonates with Sheila, who positions it as a useful means of communicating her experience of the loss that dementia entails, both as a carer and person with dementia. In contrast, Jackie presents herself as an active citizen, advocating for the rights of people with dementia, which includes recognising the diverse range of people affected, addressing a range of attitudinal, structural and financial barriers, and working with the media to achieve this on a mass scale.

Comparing how the two women interpret and position themselves in relation to three different visual representations of people with dementia further supports the influence of viewers' personal preconceptions and history on interpretations (Breeze, 2011; Gamson and Modigliani, 1989). The rich complexity of the responses provided here showcases the potential of complementing existing researcher-led analysis with the perspectives of non-academics with lived experience, to provide a more comprehensive picture of how people differently engage with representations. Expanding this focus, the succeeding analysis chapters consider the contributions of all participants, comparing how different individuals and groups reproduce, resist and revise discourses of dementia, both in general conversation and when responding to visual and verbal stimuli. This begins by considering in greater detail what Jackie highlights in this chapter: the often-unrecognised diversity that the terms 'people with dementia' and 'dementia' entail.

‘There was I in the lane that was specially for the Alzheimer’s and [...] she said erm, “well, I'm sorry, but you can't go there. That's for the dementia group.” And I said, “how do you tell?”’

- Participant H

Chapter 5: (Mis)understanding dementia

5.1 Introduction

> I think, that if someone was to ask me, can you explain it? No I can't. And I don't think there's anybody else on the planet that can at the moment. […] But if you get different pers- […] read someone else's perception, of what it means to them, and then the next person, and then the next person. And you will then get a, a knowledge, of, what it's like to have dementia, and you're getting it from, all sorts of, things
>
> (Participant K)

The above declaration was made by a gentleman with Alzheimer's disease, hereafter referred to as PK, while I and five others sat around a table in a quiet University room, snacking on flapjacks and discussing exactly how you might try to explain dementia to someone who did not know what it was. It followed two other participants arguing over whether forgetfulness was entirely in the domain of dementia when even 'the youngsters like Emma [the researcher]' could forget things (PM), and PK's playful book promotion, in which he promised that I'd find the answers to my questions in the book he was currently writing about his experiences.

I begin with this moment because it speaks so well to this project's aim to expand 'knowledge' of dementia through bringing together multiple voices to debate current representations in relation to people's different experiences and 'perception[s]'. Complementing the close focus of my previous chapter on how two participants' personal life histories and discourses interacted with their responses to media representations, in this and succeeding analysis chapters, all participants' contributions are brought into dialogue with one another. Here, I examine how participants differently explain dementia and explore the diversity that the umbrella term incorporates. This diversity is set against participants' accounts of more homogenising popular portrayals that perpetuate misunderstandings of dementia.

5.2 What does dementia mean?

Considering the number of books, articles and other sources of information that open by defining dementia (as I did for Chapter 2), this analysis chapter begins with my participants' explanations of, and associations with, dementia. In other words, I explore what people who have experience of dementia select to say when asked variations of these two questions: what do you associate with dementia, and how would you explain it to others? Upon asking professional carers a similar question, Heap and Wolverson (2020: 2025) found that dementia was explained as an 'illness', 'awful' and like seeing a person 'disappear', with carers generally reproducing medical discourses of loss, non-communication and lack of personhood. Although participants affected by dementia in this study do draw on these discourses, the accounts they provide are far more varied, both reproducing and countering these 'tragedy' discourses.

In line with other studies, many participants initially focus on changes with dementia and frame these as losses (Beard, 2016). Memory, specifically a 'bad memory' (PJ) since it 'isn't functioning as it used to' (P12), emerges as a key feature of dementia across interviewees, reflecting the cultural emphasis upon memory loss as characterising dementia (Bailey, 2019; Brookes *et al.*, 2021). Participants emphasise 'short-term memory problems' (P6), whereby people remember 'things from way past' (P13) but are 'forgetting what you've just been told, forgetting where you put your coat forgetting. where the bathroom is' (P14). Short-term memory problems are clearly situated in people's everyday experiences, something that P33, who cared for his wife when she had young onset dementia, expands on: 'Memory is not, as somebody quoted to me "he keeps forgetting my address", it's not that. It's how to live your life. And I had to learn all that'. Here, P33 critiques the popular oversimplification of memory as factual recall (Basting, 2009), positioning dementia-related memory problems as a way of learning about memory's more expansive nature.

Relatedly, the working-age dementia support group offer an expansive list of changes with dementia experienced within everyday life:

PQ Yeah it affects everything, it affects the memory, it affects-
P30 -it's knowing how to eat, how to hold their knife and fork they lose that, the toilet, it's just everything it's not just memory, #you know#
P28 #Temperament#
P30 Yeah
P28 Walking
P30 Yeah, walking.
P28 Even finding a chair to sit in yeah

P30 Getting in and out of car yeah

Dementia is thus presented through its behavioural manifestations within daily activities, to show that it can affect 'everything'. Echoing the critiques of scholars (Lock, 2013; Whitehouse and George, 2008), numerous participants explicitly challenge the conflation of dementia with memory. Notably, P12, whose husband, PD, had been more recently diagnosed with dementia, explicitly revises her initial phrasing to shift the emphasis from changes to 'memory' to the 'brain' more broadly:

P12 I think when I said that your memory isn't working, as well as it used to do I think I should change that to you know your brain isn't working, #as well as it used to be?#
P13 #That's it, yeah#
PE #Mm mm#
P12 Because it's not just memory. It's everything. I think, you know, and everyone's different, every time

Accordingly, P12 replaces her reproduction of the 'crude formula' that 'dementia = memory loss' (Brookes *et al.*, 2021: 254), with the more holistic 'everything', allowing for a diverse range of effects according to the individual. This expansion reflects the iterative nature of expressing what dementia means and indicates that people 'learn' about its impacts through experience (P33).

For many people, discussions move to not only behavioural but personality changes. One couple suggest that:

P14 it's not just that [forgetting] it's been a huge change I've found in PG's personality he's become withdrawn. He wasn't like that at all. He was very outgoing. He was a Sergeant Major in the army very, very outgoing, yeah. Now he's. Totally different. It's like living with a different person.
[...]
PG No I. Er. What my wife says is, real. (Damn.) See my ay I've gone again now.

An alternative to the loss of self discourse is a transformation of self, whereby individuals struggle with feeling as if they have become an entirely different person with dementia (Castaño, 2020). Here, PG reinforces his wife's description of him as 'a different person', comparing him as he is now to his previous, more 'outgoing' personality (a self 2 attribute), which is exemplified by his social persona as a Sergeant Major (self 3) (Sabat, 2002, 2018; see section 2.2.2). The couple's interaction reflects that impression management is generally shared between couples, with carers often becoming more influential in their public-facing representations of their partner as dementia progresses (Fletcher, 2020a). Here, PG struggles to, as other people note, ‘communicate’ ‘the right words’ (PL, PK). He reacts with ‘I’ve gone again now’. Although a common phrase, PG’s exclamation reflects the cultural privileging of linguistic communication as a means of self-expression, since it suggests that PG can indeed ‘go’ anywhere when he loses his words but is still physically present and engaging with us in the room. As explored in sections 4.2.1 and 5.3.1, embodied forms of expression become increasingly important when living with a condition that makes verbal communication more difficult, thus challenging the conflation of self-expression with verbosity.

The overall narrative of loss and negative changes is resisted by some participants. Demonstrating the value of humour as a tool of resistance (Beard, 2016), one couple uses humour within a Memory Café group to challenge the assumption that dementia entails only negative behaviour and personality changes:

> PC I’ve cheered up [laughing] since having the dementia [laughs]
> Emma [laughing] you’ve cheered up you said?
> P5 Mm. Yeah you used to be a miserable old. curmudgeon [PC laughs] he’s quite, he’s quite chirpy now
> [group laughter]

Much of the humour here comes from the challenge to the emphasis of the dominant ‘tragedy’ discourse on a degradation in abilities, behaviour patterns and happiness. The couple explicitly situate themselves as a contrast to this, which encourages group laughter (as well as the idea that PC used to be anything other than the good humoured wit he is known as). Elsewhere, when explaining dementia, P18 highlights that his grandmother ‘had pretty severe dementia by the end, but then like she's always cracking jokes. She's happy [...] in some instances, you do get the, the sort of joyful bliss, even though they don't remember things’. Returning to the above accounts of memory, here, not remembering can be accompanied by ‘bliss’, rather than suffering. P18 resists the overall emphasis on losses by emphasising that his grandmother’s humour continues as her dementia progresses. Similarly, P18 argues that in his experience, dementia is ‘gradual’, so you can ‘forget it’s happening’. This highlights that your lives do not always revolve around dementia when you or a loved one develop it, challenging the trend to regard dementia ‘as if diagnosis is akin to falling off a cliff’ by acknowledging that you can have symptom-free seconds, minutes, hours or days (Basting, 2009: 156). P18’s use of ‘forget’ in a more general sense also serves as a reminder that, as numerous participants explicitly touch upon, forgetfulness is certainly not constrained to people living with dementia.

Moving beyond externally obvious changes, some individuals highlight that ‘it’s hard to describe what it’s like’, especially to those without experience of dementia (P28). When unable to fully express a personal, complex and intangible condition, many people turn to metaphorical language to express dementia (Biro, 2010). PH, a retired teacher with younger onset dementia, offers an insight into some of the ways that dementia is 'a right bugger' for him personally: 'Well, it's er, stops me doing a lot of things. That I would like to do. Erm. so, simple things like can't drive now. [...] I can't do DIY, in the way that I, used to, a lot [...] Mr Alzheimer's have got a, a lot to answer for.' By personifying his dementia as 'Mr Alzheimer's', PH positions the condition as an agentive individual with the power to stop him from undertaking everyday tasks that he considers 'simple', such as driving. Mr Alzheimer's is depicted as an antagonist here, reflecting the unwanted companion trope used by other people with dementia (Castaño, 2020), including Swaffer (2016) who nicknames 'Mr Dementia' as 'Larry'. Through his pronouns ('it' versus 'I') and by metaphorically positioning dementia as another person, dementia is separated from PH and his body in a way that contrasts many of the other participants' grounding of dementia in their minds and bodies. Notably, PF summarises the experience as 'a gradual confusion of your mind', while PN envisions her dementia as situated firmly within her brain cells ('the clogging up of the neurones er the, you know the cells that, that is why we, the Alzheimer's, disease develops'). Here, the concept of 'clogging' reproduces the common metaphor of THE BODY IS A MACHINE, which simplifies the biochemical processes to more relatable and concrete events for lay audiences (Bailey, 2019). In line with other people with dementia, here, PN adapts a biomedical discourse to suit her personal understanding (Beard, 2016; Fletcher, 2020b). Meanwhile, PH and PF provide alternate representations to a biomedical one, respectively attributing dementia agency as a separate (if interfering) entity and discussing an increasing confusion.

In another group, P19, who previously worked as a carer for a range of people with dementia, both in the community and care homes, foregrounds the need for a pluralistic depiction that balances positives and negatives. This aligns with the recent turn in scholarship and provides a more holistic counterpoint to the loss-oriented responses of professional carers in other research (Heap and Wolverson, 2020). P19 tells me that:

> I would want to put across the idea of, sort of a pluralism, like, there are <u>dementias</u>, and probably, sort of think different instances, so rather than going "dementia is this", not only are there different types of dementia but within that, you know it's a constant sort of like a tree. You know, it's going it keeps splitting off and splitting off into something else so within the different types of dementia there are different instances of how it, manifests, itself and er, that sort of thing. And also, there's obviously, the sad side to it, and at the same time, you know, there can be moments of, great humour, [...] I think to try and, allow it to be, erm, sort of this multi headed thing

Here, P19 advocates for using the plural term, 'dementias' to acknowledge the 'pluralism' of dementia(s), both regarding types and individuals' experiences, including 'sad' moments and times of 'great humour'. Dementia's complexity and conceptual slipperiness (Zeilig, 2014a) is reflected in P19's harnessing of multiple metaphors; dementia is envisaged as 'this multi-headed thing' that 'manifests itself' differently, being 'like a tree' in that it keeps branching off into an increasingly complex and diverse entity as opposed to being just 'one thing'. While the personification of dementia as a 'multi-headed thing' potentially draws on dementia's monstrous connotations in social narratives (Behuniak, 2011; Zeilig, 2014a), P19's dominant metaphor is that of a tree branching off, which instead situates dementia within a symbol of life and growth. This appears to be a more idiosyncratic use of the tree metaphor to conceptualise dementia itself as a diverse range of conditions. Normally, when trees are used, it is to situate people's experience of having dementia, notably through the metaphorical seasonal loss of leaves (Zimmermann, 2017; explored further in section 7.3.2). In P19's context, the plurality and multi-directionality within dementia is expressed through its association with a living entity with multiple branches or heads.

In the PhD student focus group, the members explicitly establish three key focuses when explaining dementia, namely biomedical, positive and negative:

P17 I guess you could go the route of explaining exactly what it, is in general terms, it's you know parts of the brain shutting down and things like that and so people? [Sighs] It's hard because like you say like it's so different for different people as to what happens. Erm.

P18 And I guess like it's, when you explain it do you put a positive spin on it, do you put a negative spin on it or do you just do this sort of #scientific objective answer?#

P17 #Yeah. Just like this is what it is.#

P18 Honestly, you could probably give all three. Here's what, here's what science says. Here's the, you know, worst case scenarios that I've experienced and here's, the best case scenarios I've experienced kind of thing and then, you give them a sort of broad idea of what it entails

Here, a scientific explanation is presented as 'objective' and 'general', since it provides a neurobiological account of dementia (although note again the BODY IS A MACHINE metaphor in '<u>parts</u> of the brain <u>shutting</u> down', which exemplifies how understandings of scientific concepts are influenced by social discourses). This impersonal biomedical 'route of explaining' comes first to the participants, before they expand to consider using their worst and best scenarios from their own experience to help give a 'broad idea of what it entails' on a day-to-day basis, introducing another type of expert voice, this time experience-led (see Chapter 6). These accounts are associated with 'spin', acknowledging the tendency for any discourse to 'spin' dementia a particular way through the details that are picked out, here dichotomised as 'positive' and 'negative', in line with existing research (McParland *et al.*, 2017).

Already apparent, then, is that despite some patterns of agreement emerging regarding behavioural and personality changes beyond the popular conflation of dementia with memory, there is a multitude of ways to represent dementia, even among a comparatively small group of people. Diversity is a prominent theme across participants; as PC later declares, when portraying dementia, 'it's got to be a personal thing, everybody's dementia's different like everybody's fingerprint is different'. This contradicts the widespread homogenisation of people with dementia, who are too often 'all put in the same bag, as if we were all the same' (Perel-Levin, 2019: 90). The issue of diversity thus warrants greater consideration below.

5.3 Diversity of dementia

Arguably the most unanimous discourse to materialise across the focus groups and interviews is the difference and individuality within the label 'dementia' — what P17 refers to as 'the diverse face of dementia'. As PH reflects, 'there's lots of difference, we come in all different shapes, sizes and, and all that. And, so. people are going to be different. There's going to be a lot – there's not, necessarily, a one track, for something like this'. Consistently, participants raise that despite stereotypes, there is no typical person with dementia. Instead, 'it's a lottery' (PH) and 'it happens to everybody' (P6), irrespective of status, age and other personal features.

Having said this, as Sheila indicates in section 4.2.1, a person's social status can greatly impact the reception of a dementia diagnosis. P6, who previously worked as a paid carer, explores this most explicitly when she reflects on the association between influence, attributed intelligence and dementia, stating that 'it seems somehow more shocking' that her 'locally respected' headmaster, previously so influential, is now 'unable to do anything for himself'. P6 compares this headteacher to a woman that she used to work with as a paid carer, who could not read and write:

> she used to say "well I've never been very bright anyway!" [laughs] […] I actually think, I think she had dyslexia I think that's what it was because I mean she was very good at playing cards and I think that, you know, she always thought of herself as not being very bright because she couldn't read and write you see […] and so when she got dementia she was just like "ah well, more of the same" [laughs]

Two things are particularly striking here. First is the link that the woman in P6's narrative makes between her low literacy levels and her intelligence, despite P6 noting other forms of intelligence (namely, that she was good at playing cards). This likely reflects the lower status afforded to illiterate individuals in hyper-cognitive society (Post, 2000a), which leads to the second point of interest, that the idea of not being 'very bright' is used to joke that having dementia therefore won't make much difference to her. Following Hulko's (2009) findings, a hierarchy is created in which dementia affects people more if they have greater pride in their cognitive abilities and written communication, and it is suggested that for someone accustomed to living life without such abilities being perceived as central to her identity, having dementia brings less of a change. Underlying this account is the discourse that people with dementia are inferior in intelligence and social standing, and that dementia is primarily a matter of intellectual decline rather than the behavioural and emotional changes noted by other participants above. Internalised and externalised social stigma are recognised as integral to individuals' self-concept and experiences, since more socially privileged individuals appear to encounter greater 'shock' upon being given the stigmatised label of dementia than people who are more marginalised (Hulko, 2009).

Two more frequently discussed contrasts between participants' experiences and public perceptions of dementia are being younger and/or having a type of dementia other than Alzheimer's. Since 'dementia doesn't always show' (PC, see section 6.2 for more), numerous participants depict their experience of existing outside of the cultural stereotype of someone with dementia as a point of tension between their 'reality' and the social 'preconception' of what dementia means (P20). Oftentimes, participants' own place of understanding is positioned as being due to their personal experience, which has enabled them to move beyond the popular social narratives that generally conflate dementia with Alzheimer's and older age (Low and Purwaningrum, 2020). Such discourses are embedded in British social structures, including in national organisations such as the Alzheimer's Society, which positions itself as the UK's leading dementia charity while being named after only the most common type, and a recently commissioned report on the cost of dementia care that only incorporates people with dementia aged 65 and over in its figures (Wittenberg *et al.*, 2019).

Participants consistently emphasise the need to stress the range of conditions within the term 'dementia', lamenting that 'people just don't understand all the different types' and that too often, the many types of dementia are simply 'put under an Alzheimer's umbrella' (P30). The personal impact of using dementia synonymously with Alzheimer's disease is elaborated on by P6, whose mother had vascular dementia:

> a lot of people [...] have got something different so as soon as you say she's got dementia or he's got dementia and then it's like they automatically think they've got

> Alzheimer's and actually, they're wrong and they're thinking it's going to follow the progress of Alzheimer's and of course with my mum it was like steps, because it was only when she had a stroke and then she'd go down, you know. And I didn't know that and I was her daughter […] I think there's misunderstandings, at the moment

Here, P6 shifts between the present state of unknowing for others ('they're wrong', 'there's misunderstandings') and her own progression, where she moves from also not knowing about alternative types of dementia, including her mother's ('I didn't know that and I was her daughter'), to her current more enlightened position through experience. Notably, she compares her mother's progression to 'steps' that she descends following a stroke. This provides an alternative, more fragmented representation of progression to the linear decline often associated with Alzheimer's (Wilkosz *et al.*, 2010), opening up other ways of visualising dementia pathways (here, stairways).

Participants with experience of young onset dementia similarly present a process of realisation that dementia is not constrained to older members of society. P28 reports that 'we were doing the same I guess before we got, involved in it. If you were watching the news and that you just assume that dementia's an old person's […] it's only when you get involved in it that you realise that [laughs] it's not'. Here, P28 attributes her realisation to personal experience interacting with younger people with dementia. It is 'being involved' in this aspect that allows her to see the nuance within dementia that is often missing in popular social narratives that conflate dementia with older age. Similarly, P19, who worked as a carer for a sixty-two-year-old man with dementia, considers the implications of such a realisation: 'we associate it with being elderly. So then you take that away suddenly, what does dementia actually look like? And that sort of took some getting used to'. Here, P19 interrogates his previously held assumptions of who a person with dementia is (in this case, 'elderly') when life experiences challenge this social stereotypes. Without such stereotypes, the question of what dementia looks like becomes much more complex, and as P19 suggests, can be difficult to adjust to.

A story by PH exemplifies both the personal impact of preconceptions for what a person with dementia looks like and the educational role that many people with experience subsequently take on in social scenarios where their presence challenges associations of dementia with older age. PH recalls:

> PH I go to [a local area] on a, on, once a week, and er, there's a swimming pool, to go swimming. And it's actually there's a, lane, set out for us. So that's for the dementia group, coz we did go there and we sort of have a, coffee and biscuits and all the other stuff you know. Erm. And, erm ah I'm losing the plot
>
> P20 Someone told you to get out didn't they
>
> PH Sorry?

P20 Someone told you that you're in the wrong place.

PH Oh yeah that was it. Erm. Yes, er, there was I in the lane that was specially for the Alzheimer's and they said erm, "I'm sorry", one of these you know little,

P20 Enough about that!

PH [Laughs] she'd not been there for long, but she said erm, "well, I'm sorry, but you can't go there. That's for the dementia group." And I said, "how do you tell?" coz she said you know you need to go to the other side and I said "how do you tell?" [Laughs]

[...]

P20 But it shows doesn't it-

PH -You can't tell-

P20 - that people have the preconception

PH Yeah

P20 And you understand that the preconception is not reality.

PH Yeah. Course I do [2.9] Yeah, so, that's a good way of putting it.

In a collaborative account with his son, 61-year-old PH positions himself as a challenge to preconceptions, asking the staff member who assumes he does not have dementia, 'how can you tell?' Yet, upon being diagnosed, PH remembers thinking 'I shouldn't have that, it's sort of for er, my Dad, instead', reproducing the widespread assumption that dementia is for older generations. Consistently, participants' place of knowledge regarding the diversity of people with dementia is attributed, whether explicitly or implicitly, to their less conventional personal experience of dementia. PH extends his argument that 'you can't tell' to his judgements of other people too, since when discussing the images I show him, he emphasises that all of the individuals depicted are 'just normal people' and asks, worried that I am asking him to evaluate whether they have dementia, 'how do I know?'

Throughout, the participants highlight the need to acknowledge the heterogeneity of people with dementia, consistently drawing on personal experience to do so. It is notable that here, participants foreground age, types of dementia and education/social status in their depictions of diversity, implicitly backgrounding other important aspects of a person's experience, including gender, sexuality and ethnicity (with the exception of Jackie in Chapter 4, who notes the lack of ethnic diversity in representations) (Hulko, 2009). Continuing the discussion surrounding age, I now turn to two images that became particularly pertinent to the discourses explored in this section, that of individuals' hands.

5.3.1 Responding to images of hands

A discussion of age in relation to dementia quickly materialises across groups in response to the two stock images of hands reproduced in Figure 5.1. Participants consistently critique the link between older age and dementia, but beyond this, interpretations diverge much more broadly, both between images and participants, exemplifying how image-specific semiotic resources (such as proximity, angle and colour) can intersect with viewers' personal experiences and worldviews. The images raise more questions than they answer. Who do the hands belong to? What are they doing? What is the emotional tone of each picture? The responses throughout this section demonstrate that for these two photos, there are many potential answers.

Figure 5.1 ***Images 7 and 8***

7. 8.

Participants with and without experience of younger onset dementia alike critique the conflation of dementia with older age that is established through these stock images of older people's hands in the context of dementia. While acknowledging that the 'statistics are that people with dementia are more elderly', participants argue that by 'enforcing' that dementia is confined to 'the elderly', such images misrepresent what is actually a more complex and 'mixed pattern' of people with dementia (P8). The process of interpreting such age-related images is presented in greater detail in the following focus group:

PK I looked at those, and my first impression would be, if I'd not, thingymabobs. Dementia, is, age related. It isn't. You look at the hands and say well, you know when you get to the stage where your hands are like that you're probably in your eighties, you're likely to have dementia. But you could be in your forties
PL #Mmm#
PM #Mmm#
PK #So, this is where your study what you're doing# with the media,
PM #because that's it yeah, this is just saying it's for elderly, very elderly#

PK they are, although they might be working or moving in the right direction, they ain't moving fast enough, and they are, still, projecting to the public with pictures like these, which are open to too much misinterpretation

Here, the hands are identified as the signifiers of the 'very elderly'. In both images, the actors' hands are the salient visual component and display the wrinkles, creases and prominent bones associated with ageing. This is noted as even more extreme for image 8: 'these look really old to me don't they, like <u>ancient</u>, I've never seen anyone with hands quite like that' (P6, speaker's emphasis). Consistently, participants use intensifiers to mark these hands as 'very' or 'really' old, situating them beyond the lexical benchmark of 'old'. This is perhaps best demonstrated through P6's emphasis of 'ancient', a word that appears to collocate more frequently with references to centuries-old historical civilizations and artefacts than with individuals in general British English (BNC, 2021). What PK highlights in the above extract is that, when these images that denote the physical signs of ageing are situated in the context of dementia, they give the false 'impression' that dementia is 'age-related' and are subsequently 'open to too much misinterpretation'. The concern, then, is with the connotations, or 'meaning potential' of the aged hands in a dementia context (Machin and Mayr, 2012).

Beyond the consistent age link, participants demonstrate a range of interpretative and emotional responses to the two images. Such variety is likely in part due to the decontextualised nature of these stock images, which feature anonymous individuals without stories, voices or indeed faces, which are the body part traditionally privileged as the conveyor of character and psychological insight (Archer *et al.*, 1983; Harvey and Brookes, 2019). Participants position the hands as some of the most ambiguous of the twenty images shown ('I'm not sure what the hands, are saying really': P7; 'I don't know what to say about the hands': P14). Of the two, image 8 is met with the most confusion ('Not quite sure what it's saying': P10). Without the more obvious cues that could be provided through showing whole bodies, the same pair of hands evokes conflicting readings of image 8's emotional tone, ranging from 'harsh' (P6) and 'very sad', to looking 'peaceful' (P10) and showing 'contentment' (P2).

Still, overall differences in participants' interpretations of each image emerge, demonstrating how different semiotic choices in positioning, lighting and represented participants (namely showing one person versus two people interacting) can encourage divergent readings of what are fundamentally similar images of 'disembodied hands' (Brookes *et al.*, 2018: 384). Most notably, participants show an overall preference and alignment with image 7 over 8. P6 explains that although both images are 'harsh', image 8 especially is 'not a nice picture' because 'it looks like the hands of someone who is er, ill, in some way' and is 'not relaxed'. Another group describes image 8 as 'victim-y?' (P19) and 'very sad' (P18). P6 picks out the role of the camera angle in achieving this sad, victim-like reading: 'I think partly it's just the angle it's taken at [laughs]'. As Figure 5.1 shows, image 7 is shot from a slightly lower, close and front-facing camera angle in a way that viewers could almost reach out to touch the hands of the people; it is likely this close proximity combined with the moment of physical connection that makes image 7 'an intimate picture' for P10. In contrast, in image 8, a higher and slightly side-on camera angle, combined with a more distanced shot, places viewers in a position of relative social distance and superiority through looking down and across at an individual's hands; thus, instead of interacting, we are invited to observe the woman featured as a 'victim' of dementia (Ledin and Machin, 2018a). Arguably, the 'subject' and 'object' distinction that is usually identified through the presence or absence of front-facing eye contact with represented participants is here partly achieved through the positioning of their hands; viewers are encouraged to see the people in image 7 as subjects who could be interacted with as social equals, and the woman in 8 as an 'object' to observe and pity (Kress and van Leeuwen, 2006).

Moving beyond pitying the represented individual, three participants situate the hands in image 8 as 'frightening' (PJ) and 'scary' for being 'the, sign of things to come' (P22). Upon closer inspection, it appears to be the focus on physical markers of age — the 'crinkly', 'thin' skin and prominent 'veins' (P23) — that evoke such fear. P22 relates the reaction to image 8 to her own feelings towards similar age-related features on her hands, telling us that 'mine are like that [...] I hide mine sometimes when they (xxx) the veins just come up'. Her revulsion of physical signifiers of ageing, as indicated by her desire to 'hide' her 'bodily betrayals' (Featherstone and Wernick, 1995: 7), and her fear of 'things to come' signal the damaging effects of internalising demeaning cultural discourses on ageing. Popular discourses either associate ageing with irreversible mental/physical deterioration (and an associated declining social status), or promote defying ageing altogether (Laceulle and Baars, 2014), rather than respecting ageing as 'a process of learning to live a finite life' (Baars, 2017: 285). P22 is far from alone in her repulsion towards her own and others' ageing; van Wijngaarden *et al.* (2019) note the prevalence of profoundly negative discourses of old age (including metaphors of struggle, victimhood, breakdown and subhumanisation) amongst a group of socially disengaged and fearful Dutch older people who wish to die rather than continue ageing.

The bright, high-contrast lighting of image 8 relative to 7 contradicts the above desire to defy or 'hide' ageing, potentially helping explain the reaction of disgust and fear in participants PJ, P22 and P23. The camera angles interact with the images' lighting: partly due to the softer lighting and partly the lower angle, shadows are more prominent in image 7, obscuring much of the bottom right-hand side so that 'you can see one hand, but you can't really see the other one' (P7). In contrast, the brighter lighting of image 8 foregrounds the physical markers of age, since every vein, joint and skin crease is clearly defined, especially for the top hand, while the higher camera angle reduces the softening impact of shadows. Such a 'harsh' focus on displaying the physical frailties of an older person's body in image 8 over 7 likely encourages P6's association with being 'ill' and the fear that PJ, P22 and P23 report feeling towards it.

Consider, for a moment, what is missing from these two images due to the close-up shot of the participants' hands. No visual information is provided about the person as a whole, something that P7 reflects on: 'just seeing the hands and so close up, in a way it kind of separates it from the whole person for me actually'. Harvey and Brookes (2019) raise the same criticism of a similar hands image in the context of dementia, arguing that disembodied images diminish the 'whole person', both literally, as viewers are presented with a fragment of an individual (here their hands), and figuratively, since this fragment can be construed as the symbolic substitution for the incomplete individual. They propose that 'these participants are transformed and dehumanised to the point where, acutely excised from the frame as they are, it is impossible to personally or meaningfully relate to them' (994). The disgust and fear mentioned previously towards the represented participant in image 8 would certainly support the figure's treatment as being more symbolic of broader issues than of a person's experience. This is also suggested by P11's reading of 'old age and loneliness' for image 8, which depersonalises the person by foregrounding a society-wide perspective above an individual one. Notably, not all participants adhere to this; PI and P22 instead position the figure as a relatable person when they imagine that the woman in image 8 is doing something that 'we all do' (P22) – namely falling asleep: 'I bet you somebody's sitting there dropping off [laughter]' (PI).

Nonetheless, that participants generally appear to identify more with image 7 over 8 indicates that other features determine whether or not disembodied hands can be meaningfully related to on a personal level. The most important element appears to be the social interaction indexed by one person's hand being placed on top of another's clutched hands, which suggests greater action and agency than the inactivity of the hands passively resting in the woman's lap in image 8. Directly countering the fragmentation and dehumanisation noted by P7 and Harvey and Brookes (2019), P19 praises image 7 for its 'very human' representation of 'hand holding'. He tells me that 'I like that. It seems. It's not too sentimental, it's quite accurate, and I think it leaves enough open to interpretation [...] There's something very human about it, just sort of, fact. That's what happens.' Whereas PK previously criticised the images as too 'open' to 'misinterpretation', P19 commends the lack of context that enables individual interpretations of image 7 (at least in these sessions, where the image is not contextualised by any accompanying text). Often, participants' interpretations and/or associations are grounded in personal experiences, suggesting an ability to meaningfully project their own lives and emotions onto these disembodied figures in image 7. Due to the study context of representations of dementia, it is regularly assumed that one of the participants in image 7 has dementia, and that the other is a family member or carer. However, as P10 states, 'it could be either' of the participants who have dementia. The lack of specificity enables a range of imagined identities for the participants, as exemplified by the following interaction amongst the working-age dementia focus group:

> P28 -it could be a husband and wife, husband and wife holding hands-
> P30 -or could be daughter-
> P28 -growing old together, it's nice-
> P32 -It's old isn't it together-
> P30 -but that looks like a young hand so could be daughter and mother couldn't it really, do you think?
> [...]
> P30 And in actual fact you've got parents, supporting their own children with dementia

Here, the participants are always imagined as having a close familial relationship, primarily as spouses, or parents and children. As spouses, the idea of 'growing old together' is positioned as 'nice' rather than fear-inducing, but due to a lack of wrinkles, the other hand is interpreted as 'young', and as such, P30 advocates for his parent-child relationship reading. By claiming that either the parent or child could be the person with dementia, P30 presents an interpretation of image 7 that can challenge, as well as enforce, the conflation of dementia with older age.

Broadly, the interaction of the hands is interpreted as being one of 'support' (P8), 'nurturing' (P7), 'reassuring' (P16) and 'comfort/comforting' (P5, P22, P23). For P22, while the hands in image 8 are 'scary', the ones in image 7 are 'comfy and friendly'. An overall sense of supportive interactions is thus established, and many participants relate the hands' actions to their own relationships. For PI, this image encourages a reflection on her own relationship with her daughter-in-law, P21:

> PI I often get that don't I [laughs]
> P21 [laughter] You do
> PI She's my carer [laughs] aren't you P21 [laughs]
> PJ Nice to-
> PI -oh we have fun though don't we P21

Here, PI brings her sense of 'fun' and laughter with her carer to the interaction, offering a valuable reminder that the moment of 'hand holding' may be a regular, cheerful reminder of love and sharing of joy as much as it could be an attempt to soothe.

Touch is frequently foregrounded by participants as 'a way of making that kind of contact' and 'communication' with people with dementia (P10). Similar to Sheila's emphasis on embodied ways of being with each other and in the world (see section 4.2.1), P11 feels that 'the tactile aspect is important', while P33 emphasises that interactions are grounded not in words but a shared space and mutual engagement:

> communication, communication. You don't, need, to talk, to person with dementia. Hold their hand. Talk to them, face to face. Gobbledegook. I speak gobbledegook. If that person is talking "blergh blergh blergh is erm in" I'll repeat it back to them because they know what it means. I don't, but they - they're, they're face to face, they're having a conversation, that's communication. Holding hands, talking to people.

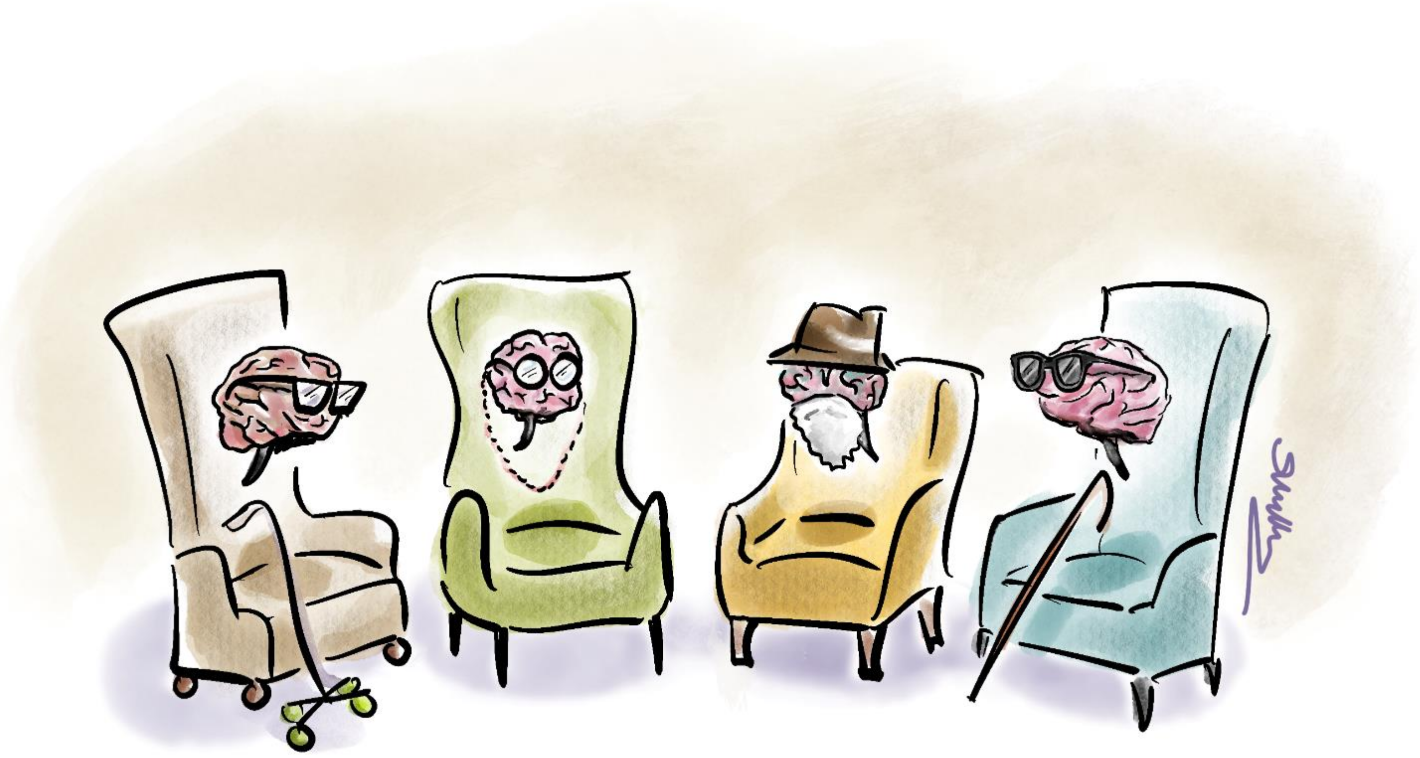
Communication is envisaged in its broader sense as being far more than the words spoken. As such, conversation does not need to be semantically comprehensible since it is the 'exchange itself' and 'way of being together' that is the point (Taylor, 2008: 327). As Kontos (2006: 207) explains, the body has an 'inherent ability to apprehend and convey meaning', including through pitch, facial expressions, gesture and turn-taking. A particular moment stands out for me here in relation to the inherent conveyance and interpretation of meaning through the body. During my focus group with people with working-age dementia, PP happily sings a string of vocalisations. While her husband P28 addresses us, she pauses to kiss her husband on the cheek, making him laugh as he thanks her, which he achieves as much with his gestures and smiling intonation as with his verbal response 'oh thank you oh that's nice'. Love is communicated through the culturally significant act of a kiss, and both individuals give and receive in this interaction, expressing their enjoyment through their tones and posture. Clearly, there is far more to a meaningful interaction than linguistic communication.

However, the holding of hands is not always seen to be an 'expression' of anything on the part of someone with dementia. For P1, who used to care for his wife when she had Alzheimer's, 'it can be an instinctive reaction for someone with Alzheimer's to grip and grip so hard that in reality it's not an expression it's an instinctive clutch and painful and there is no feeling with it in terms of the mind it's a physical reaction'. This raises an interesting point of tension regarding intentionality in non-verbal communication. P1's contrasting response to the hands is demonstrated in his semantically and phonetically harsher language; it is not 'hand holding' but 'an instinctive clutch' and 'hard' 'grip' by the person with dementia that can bring the recipient pain, rather than comfort. P1 presents such a 'grip' as a purely 'physical reaction' without conscious emotionality or intent. Part of what P1 seems to be drawing on here is the intent of the *body*, which does not need to align with conscious thought. Indeed, citing more positive moments, Kontos (2003: 166) explores how aspects of a person, such as their creativity, can actually be 'held in [the] hand'. This is exemplified by the ability of Willem de Kooning to paint during Alzheimer's disease (Kontos, 2003), and the observation that, despite being convinced she has forgotten, as soon as 'Ethel' holds a needle and thread, she can confidently and swiftly stitch (Kontos, 2006). Whether it sparks joy or pain in the recipient, our bodies can express and engage with others and the world in ways that go far deeper than the surface level of conscious cognition — this is true for people with and without dementia.

In the context of embodied forms of self, then, the hands take on new prominence; hands can express feelings through gesture, connect with others via physical touch and even create, all without needing conscious planning (Kontos, 2006). From this 'broader understanding of what it is to be a person' (Hughes, 2014: 19), these images of hands have the potential to become a more apt metonym for people, both with and without dementia, than representations of brains/heads, which will be explored in the succeeding chapter. After all, hands' abilities extend beyond cognitive impairment, and help to hold and express a richer, more fundamental self and engagement with the world than the traditional Western intellectual model that privileges the mind as the source of personhood (Hughes, 2014; Kontos, 2006). Although images 7 and 8 certainly engage with damaging and dehumanising discourses regarding people with dementia (Brookes *et al.*, 2018; Harvey and Brookes, 2019), discussions with a range of people with experience of dementia highlight that, when decontextualised from accompanying text, these images hold the potential for multiple readings, which range from 'harsh' and impersonal representations to depicting 'very human' moments and embodied ways of being in the world.

5.4 Summary

This chapter demonstrates the importance of acknowledging the diversity of people with dementia and of dementia as a syndrome. The participants explain dementia in a range of ways, focusing on external manifestations of cognitive changes, but also resisting loss-oriented discourses through humour and presenting a multifaceted depiction that incorporates both sad and fun moments, situating dementia as an aspect of life that is not always at the forefront. Metaphorical expressions offer a useful resource for expressing a condition that cannot be fully communicated through language. Participants whose experiences defy stereotypes of people with dementia explore the impact of living outside these stereotypes, particularly attending to people experiencing younger onset dementia and subtypes asides Alzheimer's disease. Debates surrounding ageing and diversity materialise in participants' responses to two images depicting the hands of older people, with the similarities and differences across participants exemplifying how image-specific semiotic resources intersect with viewers' personal experiences and worldviews to establish varying interpretations in relation to dementia.



‘You don’t go into a care home and just see brains, sort of, floating there [laughter]. You see people.’

- Participant 19

Chapter 6: Biomedical and social representations

6.1 Introduction

Complementing Chapter 5's focus on images of hands, this chapter explores debates surrounding heads and brains in relation to dementia. Building on existing research (Beard, 2016; Fletcher, 2020b), this chapter further demonstrates that people affected by dementia reproduce, adapt and resist dominant biomedical discourses to fit their experiences of dementia within their personal lifeworlds, where people's socially oriented activities, relationships and opportunities are key to their identities and lives. In this sense, psychosocial and structural approaches can offer ways of conceptualising the emotional and relational aspects of dementia in a person's lifeworld, establishing a counter discourse that emphasises these more 'social' aspects of dementia.

There is a clear tension between biomedical and more 'social' discourses in this chapter and in Chapter 7. The present chapter begins by examining how participants situate themselves in relation to biomedical technologies, figures and practices. While some participants are staunch advocates of biomedicine, others question its practices and expert status, particularly regarding the decontextualised knowledge on which clinicians' expertise is founded. The tension is exemplified by a debate regarding prioritising finding a cure versus better supporting and caring for people with dementia now. This leads onto examining how people experience dementia as a social being rather than a patient (Sabat, 2018), particularly attending to how participants construct relationships with other people affected by dementia through peer support, which is followed by a more individual exploration of experiencing dementia in Chapter 7.

Whereas Chapters 5 and 7 dedicate entire sections to how participants respond to relevant images, this chapter instead uses participant responses to images as a starting point for wider discussions relating to biomedical and social spheres, drawing on data that occurred at any point in the interviews and focus groups. This structure reflects that these discourses are embedded throughout participants' accounts, rather than being clustered around particular stimuli. Throughout this section, I draw together common threads, irrespective of when the contributions occurred, to enable a more focused consideration of these two prominent discourses.

Informing the ensuing discussion is the final page of images shown to participants (Figure 6.1), which were originally chosen for their research and medical connotations (images 17 and 18), alongside fundraising and charity depictions (images 19 and 20).

Figure 6.1 ***Page 5 images***

17.

19.

18.

20.

6.2 Dementia and the brain

When discussing 'loony' as a word that he dislikes, PC argues that: 'you don't get any sort of sympathy for dementia. If you've broke, if you've got say half your leg missing everybody's jumping up and all that but dementia doesn't always show'. PC is not alone in contrasting the oftentimes indiscernible dementia to the obviousness of missing or broken limbs—in another group, P13 declares that 'a lot of people with dementia don't look ill do they they're not ill it's not like having a broken arm.' It becomes clear that 'it's very difficult when people look alright' (P4), as understandings of health and sickness are often tied to external manifestations of (ill)health, motivating people to seek ways of visualising internal conditions (Cohn, 2010).

While the above participants compare dementia to a broken limb, many others look to medical images, such as brain scans, to make these internal biological processes in the brain visible, which in turn can validate people's experiences by 'mak[ing] the illness external' (Cohn, 2010: 74; Dumit, 2003). Brain scans, such as in image 17, hold immense persuasive power and are perhaps 'the most ubiquitous icon of neuroscientific power today' (Pickersgill, 2013: 326). They prioritise distinct boundaries above individual variances, exaggerate small statistical differences for viewers through stark colour contrasts, and compress a complex reality into a clear, aesthetically pleasing visual resource that is often positioned as objectively making visible, in a hyper-realistic way, what human eyes cannot see without technology: the brain and its processes (Beaulieu, 2002; Dumit, 2004; Harvey and Brookes, 2019). Participant narratives support the explanatory power of brain scans, with P2 positioning them as able to 'tell you whether the brain's been damaged', irrespective of external signs, as 'we didn't know PA had had two strokes but his brain scan showed us that he'd had two strokes so that's how his dementia started'. Elsewhere, P6 promotes the importance of being able to tangibly 'see' brain damage on a scan. She recalls that if her mother had 'a TIA [a transient ischaemic attack, also known as a mini stroke] she would often get, nasty, very nasty and say nasty things and, scratch and all this sort of thing', even though 'she was the sweetest person actually'. P6 therefore emphasises that 'it's important, that people understand, that's because her brain has been, damaged' rather than being angry with her for her behaviour during these times. According to P6, the insight that brain scans give can help promote greater tolerance and improve the treatment of people with (vascular) dementia by shifting the responsibility for behaviour from the person to their biological 'changes'. This indicates that defining dementia as a medical condition can lessen blame felt by the individual or their family by foregrounding decontextualised biological causes, such as 'a "mistake" of nature', pathogens, life cycle transitions and/or ageing, rather than the person themselves (Lock, 2013: 14).

Brain scans are highly technical and persuasive; they are what Dumit (1999: 173) terms 'expert images', since they are imbued with scientific authority and are difficult for non-experts to interpret and understand. Indeed, P12 declares that 'I don't think anybody without medical training would be able to tell what [the scans] portrayed anyway'. This is evident in the difficulty that numerous participants have in initially seeing that image 17 is showing brain scans:

P23 I don't [laughs] I don't understand it I'm sorry [laughs]
Emma No no a lot of people don't so this is one of the points is, do people know what this is about because I agree that it's a bit ambiguous
PI I don't know what this is
P23 I suppose you'd have to sit and study it and then you would understand it a bit more but immediately you don't
P22 What's it supposed to say?
PJ That's the brain that is. That's the brain
P22 Well I would say it's all to do with the brain
P23 Charts of-
PI -That's the brain isn't it there

P22	X-rays of a brain?

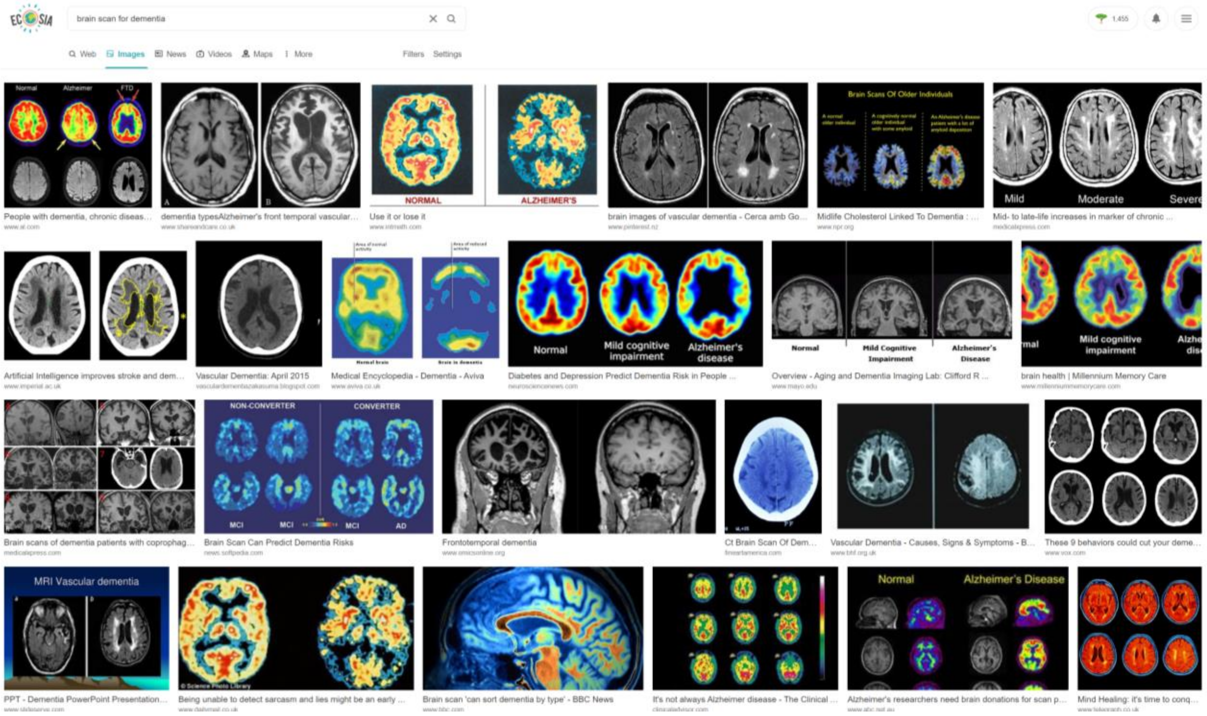
Admittedly, the stylised effect of the photo (see the prominence of the different coloured lens flare) provides what Harvey and Brookes (2019: 996) suggest is an 'ethereal quality' that is at odds with the scan's hyperreality; were we to look at the brain scans featured here in real life, they would not be bordered by the abstract shapes of the lens flare. This stylised presentation likely contributes to some participants' difficulty in interpreting the image ('I hadn't got a clue what it was to be honest, it looked like a disco': P6). In our interview, PF's description of the image foregrounds these stylistic features and format: 'Signposts, but, you see, clearly here and then it's fading. You can't read it there. And then, it seems to be oblivion there. Erm. These could be the cells, indicating the cells that. I don't know, you tell me what it's about'. Despite her difficulty in ascertaining what the image shows, PF still clearly relates the image to a biomedical context, substituting the brain for the much smaller level of the 'cell'. Even when participants are confident that the image shows brain scans, they suggest that 'the everyday general public' would not know what the scans actually show 'unless you're into technology and things' (P22). The brain scans' stylisation and inaccessibility is the subject of jokes in the PhD student focus group, who relate the image to a 'murder documentary' (P18) or science fiction films ('like a nineties Independence Day or Godzilla. It's like the battle plan': P19; '"They're using one hundred percent of their brains, what shall we do?"': P18).

Clearly, without the appropriate knowledge, these scans become meaningless as diagnostic tools. At best, participants identify that the image is 'obviously a scan' (P12) and that 'in this context, it could be, the the type of, a type of, dementia' (PH). In another focus group, P28 points out that the scans, despite being used here to represent dementia, could, for all they know, be portraying 'anything' related to the brain:

P28	Number 17 just looks like, they're doing scans for a tumour
Emma	Yes
PQ	Yeah
P28	that does, or it could be anything couldn't it that could be cancer of the brain, anything, that's not portraying dementia that's portraying everything-
P32	-Unless you know what a scan of a good brain looks #like# you won't know

Instead of representing specific processes and changes in the brain, a different, more general meaning emerges. This is exemplified by P32's contribution, which indicates the existence of a 'good'—and implicitly a 'bad'—type of brain. This is a key criticism of brain imaging techniques, as they consistently mark human differences, 'dividing us and measuring our deviation from "normal"' in a way that reinforces an 'us' versus 'them' discourse of people who are 'normal' (with a 'good' brain) versus those who are ‘abnormal' (Dumit, 2003: 36). These distinctions oversimplify reality, for instance, the density of amyloid plaques and neurofibrillary tangles in someone’s brain does not clearly correlate with normal or abnormal cognitive function, despite being considered a hallmark of Alzheimer’s disease (Lock, 2013; Whitehouse and George, 2008). Yet such brain images can greatly impact lay understandings, as indicated by a group member’s subsequent response to image 18, which visually realises biomedical discourses through icons of medicine such as the white lab coat, a surgical instrument (forceps) and the isolation of bodily organs (here a ‘fleshy’ (P10) brain). As will be further explored in section 7.3 in relation to similar stimuli, image 18 is clearly metaphorical, since the brain is patterned as a jigsaw, and one of its puzzle pieces is held by a hand in a white coat using a medical forceps. P29 challenges the brain’s fleshiness and apparent health, arguing that ‘to portray dementia you won’t have much of a brain there’, since ‘the brain is shrinking, from the core’. As Figure 6.2 shows, the visualisation of a greatly diminished brain (cerebral atrophy) is frequently depicted through brain imaging, especially through comparative brain scans contrasting ‘normal’ people against people with dementia.

Figure 6.2 ***Initial results of a search for ‘brain scan for dementia’, conducted on the platform Ecosia on 28.03.21***



In our hypercognitive society (Post, 2000a), conceptualising people with dementia as having a degrading, abnormal brain has significant ramifications, as brain images can be regarded as showing ‘a disembodied self’, offering viewers a narrow way to make sense of themselves, their thoughts and behaviours without considering context or social environment (Cohn, 2004: 71). Indeed, whether participants reproduce or challenge the incomplete jigsaw metaphor, it is clear that there is a conflation between a person's brain and their overall being, a phenomenon that Vidal (2009: 6) terms 'brainhood': 'the property or quality of *being*, rather than simply *having*, a brain'. Reflecting on her husband, who at the time of our focus group had had to move into a care home due to his working-age dementia, P30 states that 'But I mean number 18 has got one, one piece of the jigsaw missing. My husband's probably got three quarters of the jigsaw missing'. A sense of extreme loss is achieved through P30's inference that rather than missing one piece, her husband only retains a quarter of his personal jigsaw. Since only her husband is offered as a subject here, whether P30 is implicitly referring to his brain (likely, due to the comparison to the brain in image 18), or whether she is referring to her husband in his entirety is ambiguous. Either way, that there is not a clear distinction between her husband and his brain is telling. There is a similar ambiguity regarding the location of the missing piece(s) when participants from the Memory Café challenge the underlying metaphor of being incomplete:

P5 People used to say that years ago ooh there's a bit missing it's derogatory
P1 And, it's not true
P5 No
PC Of course not. I hope not! [laughs]

PC's response 'I hope not!' is a timely reminder that no one wishes to be seen as subhuman through somehow being less than a whole person (Aquilina and Hughes, 2006), whether through being compared to an incomplete puzzle or being segregated as 'other' than 'normal' brains. Perhaps the clearest instance of the conflation between brain and personhood is in P28's critique that image 18 is 'making it look like other people are taking pieces out of there and not, not the brain itself', preferring image 11 (which shows three head-shaped trees with increasingly bare branches where the brain is, analysed in section 7.3.2) since 'you're being degraded, on something like that, so, it's quite an effective picture there'. Here it is you, the person, who is being 'degraded', as opposed to the brain. This is another instance of the manifestation of hypercognitive values (Post, 2000a), in which 'the-mind-in-the-brain' (Beaulieu, 2000) is the locus of personhood, making your brain indistinguishable from your identity and status as a person.

The counter discourse that people are certainly not reducible to their brains is humorously explored in response to image 18 through the PhD student focus group, who expand on what they evaluate as a 'creepy' (P17) image by imagining the previously professional carer, P19, working in a care home filled with floating brains:

P19 -also let's be honest, brains are not the most attractive thing in the world [group agreement] and if you put, a face, to it, it's suddenly going to be a little. Like you don't go into a care home and just see brains, sort of, floating there [laughter]. You see people. I guess so, well.

P18 Yeah. Well, I gu- depends where you are I guess,

P19 Maybe in a weirdly themed care home

P17 This doesn't really happen then? [Laughs]

P19 No. we're constantly just like hoovering bits up off the floor [laughter] "Clive!" You know

P17 "Oh Clive"

P18 Just like taking some super glue and like carefully replacing little bits, yeah

P19 Like ceramic

P17 This is not, a representation of your job then, trying to fit, fit-

P19 -It's not. That's all we did. I didn't get a lab coat either.

Through creating a ridiculous imaginary scenario, in which the carers must constantly hoover up, or try to reattach, 'little bits' that a floating brain named Clive continually sheds, the students challenge the discourse that 'we are our brains' (Gillies, 2009: 74, in Zimmermann, 2017: 87), and by extension, that brain atrophy equals degradation of a person. Here, the brain damage associated with people with dementia is made literal, with the suggestion that, like ceramic, carers could attempt to reattach these lost 'little bits' if people really were losing pieces of themselves. Through this scenario, the students reinforce the fact that, in reality, you do not 'just see brains [...] You see people.' Their emphasis on personhood over people's biology reflects a wider movement to see beyond damaged brains and value the person above their dementia, which is widespread in accounts of people with dementia and their carers (Bryden, 2016; Hillman *et al.*, 2018; Talbot *et al.*, 2020).

When P19 jokes above that 'I didn't get a lab coat' (an iconic symbol of hospitals and laboratories), he separates his professional caring role from the clinical realm. This brings us to the other notable component of image 18: the hand of someone in a white coat, which, using forceps, holds the missing puzzle piece. Who does the hand belong to and what are they doing with the piece of the brain? This image is widely agreed to be 'ambiguous' (P7, P8) and something that participants are 'not sure about' (P22). From the 'white slither', P8 ponders: 'so is that a clinician, is it a research person is it a clinician?' The figure's action appears no less controversial, with people wondering if the person is 'removing' the piece (P7) or 'putting it in or?' (P9). PI raises that it might be both when she declares 'Took a piece out hadn't they. Putting it back in again.' Some participants suggest that it might be a 'surgical intervention' (P11), remarking that 'you can't put a piece of your brain back in so, it's silly' (P6). Meanwhile, others read the action metaphorically, aligning it with 'research into dementia and trying to get that final jigsaw, piece of the jigsaw put back in again' (P16). Participants indicate that this missing piece metaphor for research is an oversimplification of a very complex reality, wishing 'if it was only so easy' (PH) as 'it's not a matter of putting the missing jigsaw bit back in is it? It's more complex than that' (P12). Following his research interpretation, P16 acknowledges the uncertainty within his interpretive process, stating that 'well it could be picking it out but, suspect it's trying to fit it back in [PG laughs].' Context is likely playing a key role here, something that another group confirm explicitly:

P9 I thought if it was fundraising [group agreement], this side, it was about finding a cure or putting #(the missing piece back in)#
P7 But, yes but I would have only have thought that because of the #other ones#
P9 #Because you'd seen it# with the fundraising
P7 Yeah
Emma If you don't look at the other ones, what would you think of this bottom left [18]?
P8 What, on its own?
Emma Yeah
P7 I think it is very ambiguous [group agreement]

This is a very clear illustration of the influence of my framing as a researcher on participants' contributions. Here, the selection and layout of the four images is positioned as encouraging people to link image 18 with 'finding a cure' and putting 'the missing piece back in' because of interpreting the accompanying charity images as 'fundraising' (P9) and seeking a connection between the two sides. Putting the contextual influence aside, what is already emerging is the mixed reaction to the role and helpfulness of the figure in image 18. More broadly, beyond responding to these images, participants position biomedicine and medical practitioners differently; a trust in scientists/clinicians to offer the solution to dementia is contradicted by others' wariness of these experts and in the ability of medicine to help. It is to this issue that I shall now turn.

6.3 The impact of biomedicine

Participants present various stances on the impact of biomedicalisation and the extent to which dementia is and should be medicalised. While some participants indicate a desire to 'move away from the clinical, medical, stuff' (P19) and prefer non medicalised contexts (P6), in the working-age dementia group, the carers express frustration that dementia is not medicalised enough, directly linking biomedical explanations of dementia with more resources and support than what they currently receive. P30 passionately declares that:

> dementia is a disease, it's the same as heart disease. If your heart is, if your heart muscle dies, you will die. Dementia is the brain dying. So, what, what's the difference between your heart muscle dying and your brain dying because one's portrayed as medical, and one's portrayed as social. [...] it's a brain disease.

In contrast to the earlier participants' comparison of dementia to an externally obvious broken leg, here P30 positions dementia as the 'same as heart disease', a better known and treatable, but nonetheless internal, condition. Both are positioned as diseases caused by organs 'dying' and are used to argue that dementia 'should be the responsibility of the NHS and not the local authorities', who have 'got no money' (P32) and are depicted as 'not educated in' dementia (P30) and reluctant to 'fund anything' (P28). Returning to the issue of social stigma, P28 recalls that she and her husband 'went to the doctors and were told it were social they don't medicate', feeling amalgamated with 'alcoholics, drug abusers, because that's a social disease. My husband's never drunk in his life let alone took drugs'. P28 clearly separates her husband from people who exhibit socially undesirable traits to resist him being positioned in the same group by healthcare services, through the categorisation in this context of dementia as 'a social disease'. P28's account returns to the earlier point that medicalising dementia can help reduce social stigma by foregrounding a biological explanation (such as 'your brain dying') over individual responsibility (although of course, the two can also be combined through the prominence of individualistic dementia 'preventative' behaviour; Peel, 2014). This particular group of participants, then, position the medicalisation of dementia as a means of reducing stigma and achieving better financial and interpersonal support. Yet, as will be explored further in the subsequent section, the members also distrust the expertise of many healthcare professionals (such as the doctor who signalled that P28's husband needed a social pathway) and the efficacy of drugs, presenting a complex, tense and contradictory relationship with biomedicine.

For some participants, medical research, treatments and the biomedical discourse of working towards a cure offer hope, especially for people with a dementia diagnosis. Reflecting upon his experience of biomedicine, PJ foregrounds the importance of learning and researching for saving lives, including his own:

> PJ I think it's a good idea. People will get into this seriousness of looking into people's brains, inside their skulls. [...] you've got to learn, and look into these things. Because if we hadn't got these (xxx) people I don't think I'd be, here at

the moment, with the trouble I had. You know, a lot of people keep going in and (xxx) nurses, and students, looking into-

P23 -to, the research-

PJ -researching things. I think it's a good idea. Brilliant. Yeah.

Explicitly picking out 'nurses, and students', PJ presents himself as indebted to the people involved in research and medical care, as he would not 'be here' without them. Similarly, PF foregrounds the importance of medical treatments when she discusses her reliance on her medication (donepezil) for managing her Alzheimer's, which she positions as 'my lifeline'. Looking to the future, PF references the success of medication in her life to support a case for potential advances, hoping that one day society will 'find something that will say, there is a cure for it. Because donepezil had to be found.'

When asked what they think of the metaphorical battle language 'Fight dementia', 'Beat dementia' and 'Defeat dementia' (see section 8.2.2 for a more detailed discussion of this metaphor), many people position biomedical research as offering them hope for an improvement in their condition and, ideally in the future, a cure to ultimately 'defeat' dementia. In our interview, PH, a 61-year-old retired headteacher and self-identified 'physicist', argues that a hope for defeating dementia entails trusting 'very clever' biomedical experts to achieve this: 'I hope, that that is the case. And I hope that somebody who is very clever, will sort it out.' In the meantime, PH has signed up to local university research because 'You know, never know I might get a trial drug [laughs]'. He situates the 'actual chances' as 'minimal, probably almost lottery like [laughs]. But erm, I just think it's a good idea to. think about it and, do it, you know, so I signed up.' PH's account presents the very action of him thinking about and being involved in clinical research for an effective drug as 'good' for him, indicating the hope that he, as a person with younger onset dementia, takes from even 'minimal' chances of treatment that will improve his experience. PH draws on 'how much medical science has advanced, in the last, ten years' to argue that even if not in time for him, 'I'm sure it'll happen. By the time you're [referring to me as the 24-year-old researcher] my age you'll be er, you'll be able to ignore it'. This reflects the broader commitment of people with dementia to participating in research in the hope of benefitting science, future generations and their own lives (Beard, 2016). Throughout our interview, PH consistently emphasises that 'without [a cure], you can't go anywhere', positioning biomedical advances as the counter to his 'degradation' and 'gradually slipping back'.

While biomedicine is positioned by the above individuals as both life enhancing and lifesaving, other participants complicate the picture. This is exemplified by portrayals of drugs, since, contrasting PF's 'lifeline' medication, some participants highlight bad side effects, difficult transitions between drugs and their uncertainty about the effectiveness of certain treatments. Sometimes no medication is presented as better than dealing with the side effects, as for P7's father: 'I think my dad tried a couple of types of medication which had bad side effects so it really wasn't worth him pursuing it'. Reflecting on going through 'three different drugs' with his wife, P1 foregrounds the notion that not only can the medication 'cause more problems' than the dementia, but that when 'the side effects become so great that they decide to change [...] you've got a very difficult period of weaning one off and bringing the other one in'. Such is the impact on the person taking the medication that P1 likens the point at which 'it can settle after that period' to being 'in a different world altogether'. Yet, P14 raises the difficulty of telling, on an individual level, whether or not medication has been helpful, since 'it's six years now and we don't know what [PG] would be like if he hadn't had them'. If you cannot see a change or compare what you would be like without them, you can only trust that the medication is doing what it is 'supposed to', which for P14 is 'to slow down the memory loss'.

6.4 Representing medical 'experts'

Trust, and the related issue of social power, emerge as a consistent thread amongst participants' discussions of medical professionals and biomedicine at large. PM explicitly raises this when she discusses her diagnosis: 'I've got dementia, I've got impairment, prescribed, by a consultant, and you have to take his word for it, don't you'. Through her declarative clauses, PM presents the consultant's diagnosis that she has 'got' dementia and 'impairment' as being her present reality. PM's subsequent clause, that 'you *have* to take *his word* for it' (my emphasis), foregrounds that the consultant is the one person who has proclaimed this state of the world, whereby PM has dementia/impairment. Here, patients must trust and accept the consultant's perception of the world, reproducing the widely acknowledged unequal relationship between a medical professional as the voice of 'biomedical expertise' and their patient (Gwyn, 2002: 64).

Although many people accept this practitioner-patient dynamic and place their faith in the expertise of medical professionals, in the working-age dementia group especially, a dissatisfaction with and distrust of the voices of medicine emerges, as in the following conversation that contrasts the medical experts' claimed efficacy of drugs against the carers' experiences and opinions:

P28 They say the drugs, slow it down, but I feel,
P30 I don't think they do
[...]
P27 #and I think it only slows it# down then for so long anyway don't it, they say the first eighteen months like I read about that donepezil
P28 So, these drugs they're giving out, I'm not sure, one hundred percent what's in them but I don't think it's doing what they say, it's doing #because I've looked at other people#

P30 #they’re not sure themselves#

The carers in this group consistently establish two opposing voices in this exchange, the unspecified medical professionals (‘they say’ is repeated three times), versus the focus group participants. Almost every conversational turn disputes a claim from the medical professionals, who are distanced as a collective ‘other’ from the group of participants through the constant use of ‘they’. This delegitimisation culminates in P30’s statement that ‘they’re not sure themselves’, directly challenging the expertise of the experts through anecdotal observations in a way that is fairly atypical of many, but not all, participants. For instance, in another focus group PK provides a similar challenge, that ‘the professionals sometimes are not very professional’. He evidences his claim by telling us of an ‘experience’ last September when ‘my GP packed me straight off to a stroke clinic’ for an MRI (magnetic resonance imaging) scan but the consultant neurologist told PK that ‘“there is no evidence of a bleed, therefore you have not had a stroke”.’ PK’s issue here appears to be with the neurologist’s certainty that a stroke has not occurred, implicitly questioning the ability of technology and consultants to always provide a definitively correct answer. The tension between being both beholden to medical professionals, and dubious of them, is most extreme for P26, a self-proclaimed ‘free thinker’, who tells me in our interview that ‘You’ll always get people that live on the doctor’s words. I never have. […] I’ve been quite disappointed in the past’. Yet, despite consistently questioning individual practitioners and medicine as an institution throughout our interview (for instance with ‘Doctors don’t know’), P26 nonetheless relies on doctors to help her mother when she is unwell, chasing doctors to visit her mother and get second opinions when she is ‘poorly’.

By comparison, an individual such as PN, who supports biomedical research to the extent that she participates in studies, may also establish an ‘us’ versus ‘them’ narrative to indicate a dissatisfaction with current practice, here the distance between her and biomedical professionals’ understandings. Responding to image 17 of the brain scans, PN argues that as a research participant, ‘You only see your side of it. You don't see, medical side, they don't say come and have a look, in the office’ at the ‘MRI scan’. These two sides (the person’s and the ‘medical side’) are linguistically achieved through the separation of ‘you’ (here, someone with dementia) from the ‘they’ of medical professionals. The ‘office’ that ‘you’ cannot enter spatially establishes a hierarchy that privileges researchers and makes certain medical knowledge, here PN’s brain scans, off-limits to her. She would like to see her brain scan, as ‘I’ve had three now and yet I feel that. I’m being used as a guinea pig […] Not as a participant’. Instead PN wants ‘for them to tell me what I should understand and wha-, and why. And why. […] I think that would be interesting.’ Returning to the status of brain scans as ‘expert images’ (Dumit, 1999), PN reinforces the reliance of the lay public on medical experts to explain the meaning and implications of these scans. PN positions herself here as wanting to be an active, engaged ‘participant’ with a desire to learn new things, but as being disempowered through the normalised practices (as this occurs ‘three’ times) of medical research, in which she is a passive recipient of researchers’ actions and is consistently excluded from the conversations that would help her understand the ‘why’.

Presenting distinct areas of expertise, numerous participants articulate a need to bridge the divide between professionals and people affected by dementia by collaborating and sharing their different forms of knowledge. In our interview, P33 emphasises the need to ‘hear other people’s opinions’ because ‘the doctors, the specialists, for a long time were blinkered. They, had, the, idea, of, what, to, do. And not listen to the carers.’ Here, P33 resists the traditional unidirectional dynamic of a doctor-patient relationship, emphasising the need for reciprocity, here through listening to carers. Reflecting on hospitals more broadly after her recent hip surgery, PN highlights the lack of understanding that many medical professionals have: ‘the. staff and administrative staff at the hospital, didn’t know enough about dementia, and all they had was the experience of one patient that they had recently and, and I fear that, it wasn’t [2.8] it wasn’t a good representative of people living with dementia’. While PN challenges the homogenisation of people with dementia that stems from inexperience, P28 also critiques certain specialists’ knowledge of dementia as inadequate, despite providing guidance to people affected:

> But, half of these specialists, haven’t lived with the dementia. So they don’t really, understand it. It’s easier for them to say “look this is what can be done here’s a piece of paper follow this”. It’s rubbish there is no kind of guideline on a piece of paper that you can actually follow. So, they ought to, live with someone with dementia for a week, […] Two weeks, to get a better understanding of what dementia is all about. Because all they see is someone sat there, not responding to the questions but there’s other things that you can do to help someone through that, times of grief and everything, ’tis awkward, but they don’t understand it. Some of the specialists you look at them and you think, “nah. Waste of time”.

The ‘piece of paper’ repeatedly referred to in this account acts like a metonym, standing in for the specialists’ (lack of) expertise. By recommending the paper guidelines that P28 evaluates as ‘rubbish’ and inapplicable to actual life beyond the institution, these specialists’ advice is disregarded as thin, irrelevant and something to be ignored and thrown away. Medical knowledge is not the form of understanding that P28 is concerned with here; ‘understanding’ is repeated three times and is twice explicitly linked to understanding through actually *experiencing* living with someone with dementia. P28 is far from the only person to foreground experience as the means of gaining a true understanding of dementia; when discussing organisations being accredited as dementia friendly, P14 asks ‘do they actually understand though? I don’t think. Until you actually live with it I don’t think you ever do’, while PK similarly highlights to his group that, as people with dementia, ‘we understand, what it’s like to have dementia’, whereas other consumers of media do not. Throughout P28’s above account, he positions himself and other carers as ‘experts by experience’ (Parveen *et al.*, 2018) who can see more than the specialists, since ‘all they see is someone sat there, not responding to the questions’ (for a critique of inappropriate questioning methods in clinical assessments see Sabat, 2018). Twice, then, these specialists are metaphorically depicted as having narrow vision (‘all they see’ is one aspect; they are ‘blinkered’: P33), and as therefore being unable to understand other sides of having dementia without collaborating with carers and people with dementia, who are the experts through experience. Although P28 continues the ‘us’ versus ‘them’ narrative here, he directs his critique at only ‘half’/‘some’ of ‘the specialists’, therefore acknowledging that specialists are a diverse collective rather than one homogenous ‘they’ group; some, but not all, specialists are a ‘waste of time’ and need to better understand dementia.

Often, participants present their experiences with medical professionals and their support as inconsistent, frequently depending on the doctor you see or the area that you live in (‘what I found, is that every district as far as a healthcare in [this county] is totally different, and they have their own organisation and funding. […] So you'd get a different response’: P12). When comparing contradictory stories about vascular dementia (that people do or do not have scans and medication), P12 summarises this confusion with ‘Again. Different story again.’ Participants tell many stories of their encounters with biomedicine. At the extreme, medical professionals are cast in these accounts as ‘very clever’ (PH) heroes, who save lives, and at other times as a ‘waste of time’ (P28). Medicine can be positioned as a ‘lifeline’ (PF), or as causing more problems than the condition itself (P1). Clearly, participants’ stances on the role of biomedicine are conflicting and often contradictory. P26 emphasises that ‘I don’t think it’s always the medical route […] Because they don’t know about so many things’, foregrounding the impact of ‘all the toxins out that are there, all the plastic, all the, all the medication drugs that people are on and, they have an adverse effect’, asking ‘what are we doing to our bodies?’ Such critiques are shared by some members of the medical profession, with prominent critics, Whitehouse and George (2008) raising the uncertainties inherent within current medical knowledge, including for neurological assessments and treatments for dementia, and the need to look outwards, to other influences on health. What is the role of biomedicine when discussing dementia? How far should biomedical discourses extend and are we, as Whitehouse and George (2008: 14) suggest, currently ‘wast[ing] massive resources in quests for magic bullets to “fix” brain ageing — putting cure before care and prevention, and trying to achieve dominance over a domain that will continue to resist our control’? The section below considers the cure versus care debate by examining how different participants position a biomedically-oriented prioritisation of finding a cure, contrasted against a more social/structural emphasis on how society supports and cares for people with dementia.

6.5 Cure versus care

In some groups, I asked people directly what their thoughts were on the debate surrounding cure versus care. At other times, the issue emerged spontaneously or was implicitly touched upon during discussions, as with P33, who raises his desire for 'an even playing field' compared to the funding of other conditions such as cancer, declaring that dementia 'need[s] a lot more research money, but it's not just only research there is Admiral Nurses [...] hoping to increase'. Overall, whether implicitly or explicitly, participant accounts support achieving some sort of balance between an emphasis on cure versus care. This is exemplified by P16, a carer who set up his local Memory Café, when he tells us that:

> I know there's this conflict, isn't there, that's going off. About whether the money should be going into support or whether it should be going into, research. [...] I mean it's got to be a bit of both really, hasn't it. erm. It's just where, where do you put the balancing line on it all.

Drawing on the common metaphor of an argument being a 'conflict', P16 presents the obvious and necessary solution as being 'a bit of both'. P16 then raises that *how* exactly support and research should be balanced is the primary, and much more nuanced concern. Elsewhere, P11 raises the need for flexible and multiple approaches to supporting people affected by dementia, 'because there is no single answer'.

Of course, individuals exhibit different priorities. In my interview with PH and his son, P20, the subjective positionings and self-interests of participants are highlighted as an important influence on how individuals allocate attention to cure versus care:

> Emma Erm, if you were in charge of the government you know funding pot for dementia [PH laughs], how would you divide it up between cure and then support for people who have dementia?
>
> PH [3.9] I think, well the main bit is to get a cure. Would be (to get a cure) because, without that, you can't go anywhere.
>
> P20 But you have to declare an interest don't you
>
> PH But. Yeah but

P20 Because you’re not, I mean, you’re not very wealthy, but you’re not poor either, and we can, get you on the bus for instance. You’ve got money to get the bus, or, you’ve got your bus pass now but you see what I mean

Here, P20 foregrounds what has long been noted in research: people choose discourses that best reflect their interests (Kress and van Leeuwen, 2001). Considering that PH constructs an identity that is aligned with science (‘being a physicist’), and consistently presents finding a cure for dementia as his hope for living with the condition, his advocacy of finding a cure as the main way of creating meaningful change (‘without that, you can’t go anywhere’) is logical. His son shifts the focus from PH’s argument to his social position, attributing PH’s prioritisation of a cure to his financial security, which means that he could continue a similar lifestyle without the support structures currently in place, reducing their importance for PH.

In contrast, P5 responds to me asking what people think ‘about the whole cure versus care thing that’s going on’ by positioning the concept of a cure as being far removed from her everyday experiences and concerns:

P5 Well there’s not really any comparison is there between cure and care they’re two different things aren’t they. You know, I don’t think any of us sit and worry, or hope, or care about a cure appearing we just cope everyday with what we’re faced with so, you know, the research bit doesn’t really – I mean I’ll support it, financially, when appropriate, but it’s not something I feel I want to dive into or find out about because I haven’t got the brain power left after [laughter and group agreement]

PC I’ve (xxx) this one up

P5 And what bit of brain power I do have left I want to use doing something I enjoy

Here P5 establishes a clear role for herself in relation to research seeking a cure: she will financially ‘support it’ in ‘appropriate’ situations but does not want to waste her ‘brain power’ on understanding what is happening in that particular biomedical sphere. That the hypothetical cure is presented as ‘appearing’ reinforces P5’s presentation of research as abstract and unknown, since the cure appears much like an object does in a magic trick, where the behind-the-scenes workings are kept secret, and the public simply admire the end result. Through the collective pronoun ‘us’, P5 speaks on behalf of herself and other people affected by dementia as not worrying, hoping or indeed caring ‘about a cure appearing’ because ‘we just cope everyday with what we’re faced with’ and direct remaining energies towards enjoyable activities in life, a necessary component of wellbeing (Rayment *et al.*, 2019).

Research into a cure is thus presented as a peripheral concern that P5 wishes to remain distanced from to best preserve her limited supply of energy, since caring for each other in the face of the challenges that dementia presents is the necessary day-to-day focus for people affected. The subsequent section explores this more everyday lens further, particularly regarding how participants engage with social support and care for people affected by dementia. This complements Chapter 4's in-depth discussion of the role of care in a couple's life (section 4.2.1) and the implications of structural inequalities and changes for individuals accessing support services (4.3.1).

6.6 Experiencing dementia as a social being

Throughout these chapters, participants frequently indicate the need to acknowledge that humans are social beings and that we experience life with dementia accordingly. As such, agency is to a great extent relational — people can be empowered or disempowered by their environment, physically, through interactions, as well as through internalising particular attitudes, such as ageism (Pritchard-Jones, 2017). Within their social environment, participants consistently position peer interactions and support groups as being important sources of help, social connections and growth, reinforcing findings of the importance of peer support and friendships in existing work with people affected by dementia (Clare *et al.*, 2008; Harris, 2013; Keyes *et al.*, 2016; Ward *et al.*, 2012). It is worth noting that due to the nature of my recruitment, whereby information of my study was disseminated by local support groups, the majority of participants had regularly attended at least one of the following local sources of support: (1) a support group for any carers and the people they care for, (2) Memory Cafés, some of which included carer peer support groups, (3) a care group that provided, amongst other things, carer groups, training and supported day care with a range of activities, and (4) singing groups for people affected by dementia, with coffee and a chat afterwards. The participants represented here are thus especially engaged with and invested in social groups as part of their lives with dementia.

Several discussions around peer support are sparked by the first page of images shown to participants (Figure 6.3). As will be explored further below, people overwhelmingly position the left-hand side as more 'isolated', and the right-hand side as 'very social' (PN). Alongside this social focus, numerous people question who (if anyone) depicted has dementia and highlight that the images themselves are not directly related to dementia. For example, P13 immediately responds with: 'I don't think that defines dementia at all to me that's just elderly people', while PH declares that 'they're normal people'. P33 argues that 'it's got to be in context' to give viewers 'clarity', suggesting accompanying the image with text, such as 'how does wife deal with dementia, it's stressful and whatever' so that it clearly 'shows' something to do with dementia. Discussing the generic nature of the images (especially for 1 and 2), participants argue that 'you could interpret those in quite a few ways' (P9), since they 'could be anything.' (PM, P12).

Figure 6.3 ***Page 1 images***

1.

3.

2.

4.

Images 1 and 2 reproduce the ‘head clutcher’ trope, namely ‘generic stock images of older white women, isolated, holding their head in their hands’ (Bould, 2018: 31). Reflecting associations between the head and cognition, multiple participants provide cognitive oriented readings of these ‘head clutcher’ images, including that the women are ‘studying […] something and wondering what it is’ (PI), ‘trying to remember things’ (PJ) or are ‘confused’ (P4). Four people suggest that the women have headaches, or a migraine (P9, P12, PI, P24), while someone else suggests it ‘just looks like she’s, trying to do the crossword’ (P32). However, more often participants highlight the emotional, rather than cognitive aspects of these images. Readings can be broadly grouped into three types of emotions: frustration, unhappiness/despair and loneliness, although of course, there are overlaps between these. Readings of frustration range from being ‘grouchy’ because ‘you’ve had a bad night the night before’ (PH) to being ‘frustrated’ by ‘struggling’ with something (P13, P16), and being ‘under stress’ (P33). Other people read the women as being ‘sad’ (P14), ‘distressed’ (P6), ‘obviously unhappy’ (P11), showing ‘despair’ (PF) or as ‘depressed or, tired’ (P28). Meanwhile, for some, the pictures ‘could be more for, loneliness. Depression’ than dementia (PM). The experience of loneliness appears to especially resonate with a quieter member of the same focus group, PL, who lives alone and tells us that ‘I was crying out for someone to visit me, the other day, because I was lonely […] on my own’, reinforcing the impact of loneliness and isolation for people affected by dementia (e.g., Clare *et al.*, 2008; Holdsworth and McCabe, 2018). Regardless of the specific experiences identified, the common threads throughout responses appear to be that these individuals are struggling in some way and need support, and that it is the emotional experiences, of loneliness, and despair, that especially resonate with participants' own lives.

Against this, participants consistently highlight social engagement and happiness in response to images 3 and 4 of people in social settings with peers. The individuals are said to 'look happier' (P21, P23), even 'healthier' (P21), as they are 'making friends' (PI), whether it is the couple in image 3 'sharing […] joy' (P21) and 'a little laugh' together (P23), or the group 'having a game of cards' in image 4 (PI). Participants report a difference in their own emotional response; while the left-hand side images are evaluated as 'hard-hitting' and 'distressing' by P11, P6 reports that 'because these people are engaging that makes me, very happy, looking at that'. This is not always the case; P32 criticises the figures as 'too happy smiley' to be representative. A current Memory Café volunteer whose father had dementia, P7, suggests that the 'contrast' across the images could reflect the tension that she and other volunteers highlight between the 'good, and positive', 'living well in the moment […] philosophy' that groups such as the Memory Café promote and that images 3 and 4 'illustrate', against the 'reality' beyond this group setting, here that 'it can also be isolating' (images 1 and 2). Distinguishing between the 'philosophy' promoted by official sources of support, here the Memory Café, and the 'reality' of people's lives beyond this group, P7 indicates that both spheres of experience may co-exist in people's lives, and that the 'living well […] philosophy' is not always representative or attainable, echoing existing criticisms of the living well discourse as unrealistic (McParland *et al.*, 2017). Depending on their own experiences of peer support/interaction, participants interpret the images as showing 'dementia groups' (P33) or as 'quite an accurate representation […] Of that sort of hubbub that you can get in the communal room of a care home' during cake (P19) or a 'planned activity' (P18). Whether attributed to groups in the community or care homes, it is in response to these two images that many discussions of the value, and potential limitations, of peer interaction and support emerge.

Across accounts, peer groups and support networks emerge as a vital source of knowledge exchange and learning. People provide many sources when asked at the beginning of sessions where they get their information from, including sometimes healthcare services (such as GPs), media and the local council. However, charities (especially Alzheimer's Society) and peer support networks are the most frequently discussed and positioned as useful. Sometimes the need for peer groups is due to a perceived lack of information, and at other times to being 'bombarded with information', but the commonality is that such groups 'actually come along and explain, the things you need' (P16). For some participants, although charities and other organisations offer useful information through sources such as websites and booklets, other people are their most important source of knowledge about local services and support. P22 declares that 'it's word of mouth isn't it, all the time […] It's all coming from people', to which P23 jokingly responds that 'So you've got to join one to get your information from somebody else [laughter]'. In another group, P13 tells us that 'we started going [to the Memory Café] a year ago and I've learned everything from them'.

Peer groups are presented as about more than simply sharing resources, however; they are about collaborative, shared learning and community (Keyes *et al.*, 2016). This is something that PI raises when, discussing the choir, she says 'You learn each other if you know what I mean you pick something up from each other'. She continues to reflect on the enjoyment she gains from singing in the choir: 'You can't sing you soon learn don't you [...] I love to join in with the singing it's lovely isn't it if you all sing together'. Here, PI foregrounds the potential for learning and growth through engaging in this communal activity, an aspect of personal development that is too often denied to people with dementia (Bartlett and O'Connor, 2010; Sabat, 2018). Music brings back fond memories of PI's 'mam', as 'I loved it when she sang to us it were lovely'. The value of creating an environment that enables people with dementia to be themselves and enjoy what they can do, rather than regret what they cannot, is then discussed by the same focus group, with P21 reminding us that 'the Memory Café is a lot about reminiscing because they talk about what happened, years ago, and erm it just makes everybody feel brighter about what they're remembering, not what they've forgotten'. P21's metaphor of becoming brighter reinforces the value of an empowering social environment in which the impact of dementia does not matter (Ovenden *et al.*, 2019), therefore allowing everyone to take 'a bit of time out of the dementia' (P10). In P21's example, this involves enjoying sharing recollections, and as PJ reminds us just before P21 speaks, that's 'What life's all about isn't it [...] Different stories. And people build on the stories that they're from, especially the older generation of what they went through, to the present day'. From the perspective of a volunteer at a local Memory Café, P6 raises the importance of being 'careful' to facilitate this environment by avoiding actions that put people 'on the spot' and could make 'people aware, that they have lost their memory', situating this as an environment that needs to be properly cultivated, with great care. Meanwhile, in another focus group, P13 emphasises that these groups and activities are equally important to her as a carer: 'I get as much out of going to the Memory Café and all these other things as [PE] does. I mean, it's it's an outlet is to talk to other people. [...] We've got to be stimulated as well as you know'. Carers, as much as people with dementia, need spaces that can provide a release, stimulation, participation and the potential for growth (Górska, *et al.*, 2018; Rayment *et al.*, 2019).

To be with other people experiencing dementia is regularly positioned as not only an opportunity to have 'a good social' (P21) with 'a nice lot' of people who 'all join in' (PI), but as being integral to the wellbeing of people with dementia and carers alike. P14 tells us that:

> You go to a group, especially like the Memory Cafés and things like that where people understand, erm and. They seem to come alive, you know, because they're

> with other people and. I think it's just human beings we like to be together. [...] We are a, pack. animal [laughs].

Reinforcing the widespread acknowledgement of the importance of supportive and understanding relationships for an enabling environment, P14 explicitly links being with others in this environment as the impetus for people with dementia to metaphorically 'come alive'. This language is noticeably similar to P21's above observation of people feeling 'brighter', P13's of being 'stimulated, and to the 'spark' that carers observe in people with dementia who are usually apathetic when they find a passion (Chang *et al.*, 2021). P14 sets this within a broader narrative of humans as a 'pack. animal', whereby positive relationships, including friendships, whether facilitated by a practitioner or spontaneous, are essential for maximising our quality of life (Ward *et al.*, 2012: 295). In particular, P33 reflects on the increase in the depth of his friendships through gaining this support network, as 'since [my wife] got dementia and I became her carer, I have more friends, and proper friends real friends coz friends disappear, families disappear'. Friendships gained through 'dementia groups' and 'carers' groups' replace the relationships that 'disappear' following a dementia diagnosis, and P33 situates these as more authentic ('proper' and 'real') than those that disappeared when his wife had dementia.

Consistently, participants foreground the importance of being in 'non-judgemental' (P9) and 'accepting' (P8) settings 'where people understand' (P14) 'what that daily grind is' (P9). Indeed, seven participants explicitly use the word 'understand' to discuss the shared understanding that comes from mutual experience of dementia (PF, PK, P9, P12, P14, P28, P33). This notably contrasts the lack of understanding attributed to people without dementia, particularly other friends and family, members of the public and health professionals. P33 explicitly distinguishes the understanding of peers from specialists, telling me that 'I'm a great believer' in peer groups, as 'these people, you can talk to, they'll, they know within five minutes that you know, how they feel, and they know how you feel. Because you're talking on the same wavelength. You don't "oh I understand" that's professional talk, right, no you don't'. Here, peers share an unspoken understanding and emotional connection as they 'know' how the others 'feel', so their communication happens on the 'same wavelength'. While authentic understanding is unspoken and felt, the sphere of 'professional talk' is characterised by P33 as pretending to understand, situating the latter as inauthentic. Another carer, P28, also explicitly distinguishes the support of peers from specialists: 'When we've got a group [...] I think that's a help, [group agreement] because everyone understands [...] we understand each other which, most of the time is a bigger help than the specialists'. Both accounts create an in-group of peers who understand, and an out-group of professionals, who do not. This builds on the same two carers' critiques of the lack of shared understanding between people affected by dementia and specialists (see section 6.4) and reflects that peer support involves different relationships, experiences and outcomes compared to interactions with health professionals (Hillman *et al.*, 2018; Keyes *et al.*, 2016).

However, a tension materialises between a sense of a collective group identity and acknowledging individual difference, especially when talking to people affected by younger onset dementia. A limitation of groups is that they can be exclusionary (Beard, 2016), at both a structural and an individual level. When reflecting on her grandfather's care home, P17 recalls 'there was a room that was decked out like the kind of forties fifties and they'd have events in there and obviously they're trying to kind of put the sort of majority demographic at ease in an environment that they're used to'. The working-age dementia group provides insights into the difficulties of being the minority age demographic, with carers raising that any reminiscence-based activities and 'wartime songs' are 'good for older people' but not their partners, who like 'a bit of heavy metal' (P30) and are 'a rocker' (P32). This is part of a larger conflation, as discussed in section 5.3, of dementia with older age, which perpetuates the failure to accommodate the true diversity of age groups who experience dementia. Beyond this, P29, whose husband has dementia with Lewy bodies and Parkinson's disease, indicates that even for a group of similar individuals such as the working-age dementia group, there is a tension between togetherness and individuality. In her capacity as a working-age dementia peer support lead at the NHS, P29 advocates for the need for resources that enable both a 'support network like these' and being able to be 'independent at home', indicating that 'it's about supporting you guys [...] together, but also sort of separate?' Summarising the totality of the participants views set out across this chapter, P29 presents people with dementia and their carers as simultaneously a collective group and as separate individuals, with their own unique experiences and needs.

6.7 Summary

This chapter examines the tensions between and within participants' engagement with biomedical and social discourses. The participants' discussions suggest that a biomedical explanation of dementia emphasising brain changes can help validate people's behaviours and experiences, but visualising people with dementia as abnormal brains can reproduce harmful hypercognitive discourses that marginalise people with dementia. Similarly, while some medical professionals and outcomes, such as medication, are situated as integral to certain participants' hope for the future, others dismiss or resist hopes of a cure and critique the problematic practices within medical institutions. Against this, participants unanimously praise the activities and shared understanding found in groups with peers, and many participants position people affected by dementia as the 'experts by experience' (Parveen *et al.*, 2018), indicating that both medical experts and non-experts could benefit from listening to people with experience of dementia to better understand what dementia means. Tensions between biomedical and social discourses in relation to participants' personal experiences are explored further in Chapter 7, particularly attending to change and flux with dementia.

‘like a tree […] it keeps splitting off and splitting off into something else […] there’s obviously, the sad side to it, and at the same time, you know, there can be moments of, great humour’

- Participant 19

Chapter 7: Change with dementia

7.1 Introduction

This chapter begins with a particularly striking image (Figure 7.1). Throughout focus groups and interviews, this picture was foregrounded, debated, and seemed to resonate with many participants, with P28 even asking to photograph the image so that he could show other people beyond the group. What is it about this image when it is placed in the context of representing dementia that makes it so compelling?

Figure 7.1 ***Image 11***

Of course, there are many potential reasons for this image's impact. One is its evocation of the seasons, speaking to the cycles of change inherent in life. Later in this chapter, I will more closely examine the image's metaphorical implications in relation to how participants differently interpret it.

I begin with this image because it encapsulates much of the discussion in this chapter regarding change, continuity, life, loss and renewal. As with the theme of diversity in Chapter 5, the theme of change emerged from participants as I did not explicitly ask about change in relation to dementia, although it certainly underlies the images that I will discuss in section 7.3. Change is integral to life with dementia (Górska *et al.*, 2018; Read *et al.*, 2017). There are, of course, behavioural, cognitive and lifestyle changes that accompany having dementia, ranging from the everyday fluxes to long-term changes that accompany the progression of the condition. Simultaneously, people face shifting social roles, relationships and identities (Sabat, 2018). As Sheila in Chapter 4 demonstrates, people navigate previous, current and future change. Recognising that 'these processes of transformation and change typically take place in collaboration with other persons' (Hydén *et al.*, 2014: 1), this chapter considers how participants situate themselves and others in relation to transformation and change. Beginning with a discussion oriented around participants' accounts of past, present and future experiences, and people's often collaborative impression management in the face of change (Fletcher, 2020a), this chapter then examines how participants reify and resist four images that provide a tragedy-oriented depiction of change with dementia.

7.2 Navigating the past, present and future

As Chapter 5 demonstrates, participants often cite changes in cognitive abilities, behaviour and everyday life when exploring what dementia means for them. This section examines the concept of change in more depth, beginning with how participants navigate their past, present and future relationships, identities and lives. While acknowledging that all 'people do change' (P33), many participants affected by dementia position the condition as initiating 'a total life change' (P28 and P30). Indeed, existing research highlights the substantial shifts in self-identity, relationships and abilities that experiencing dementia can generate for individuals, couples and loved ones (Boyle, 2017; Enright *et al.*, 2020; Holdsworth and McCabe, 2018; Spreadbury and Kipps, 2019). As a currently incurable condition that progresses over time, dementia poses an 'existential threat' and is a significant stimulus for ongoing transformation (Cheston *et al.*, 2015).

Change is identified at multiple levels. In stating to his wife that 'I know I vary day to day quite considerably don't I', PC situates himself as fluctuating in his behaviours and capabilities, emphasising the everyday changes that people must navigate. Larger, life-changing transformations materialise at varying rates; notably, P30 tells us that her husband has 'changed dramatically, in six months, he went from, me being able to live, at home with him, to having to go into care, and not through my choice'. Experiencing these changes can be deeply traumatic, as P30 shows when she discusses the consequences of now being unable to share decision-making with her husband:

> when you've got to make decisions for somebody you've loved, and you don't know whether they're right or not, it's awful. Sorry [P29 comforts P30 as she cries]. I can't

> talk without crying but, you have to make the decisions for them, and hope you make the right decisions, more or less.

Clearly, this is a deeply felt issue for P30, whose husband, at the time of the interview, is living in one of the only care homes that would accept him with younger onset dementia and 'challenging behaviour' (P30). The increased distance P30 currently feels from her husband in his current state is suggested by the past participle, 'loved', which foregrounds her past love for her husband while still tying it to the present moment. Her account signals their transformed relationship dynamics, here due to the imbalance in decision-making and ineffective communication. P30 is certainly not alone here; spouses of people with younger onset dementia frequently report a decline in the quality of their relationship, and struggle with significant shifts in their roles and responsibilities (Holdsworth and McCabe, 2018). This is not always the case; when reflecting on the impact of his wife's younger onset dementia, P33 declares that 'I got, as I say I probably got closer to [my wife] we was not had the perfect marriage [sic]. There was no serious problems it was just plodding along. And because I had to care for her and I had to do everything and whatever that was it'. Combined, these accounts indicate that changing roles and responsibilities may push people apart or bring them closer together, with existing research reinforcing that this sense of connectedness and separateness can oscillate over time (O'Shaughnessy *et al.*, 2010).

Many participants note the challenges that changes in communicative abilities pose, and the collaborative nature of subsequent transformations in social interactions and relationships (Hydén *et al.*, 2014). These may be facilitative or disempowering (Kitwood, 1997), with PK and PL arguing that carers may not recognise that people with dementia understand something, due to communicative barriers:

> PK When people. To some degree I suppose, detach themselves from the person they're caring for because they think or perceive that "they don't understand what I'm saying anyway". But they probably do. It's just that they're not able to project (it)
>
> PL Communicate mm

This exchange highlights the subjectivity of assessing another's understanding, especially without explicit verbal feedback, reminding people without dementia to avoid conflating (verbal) communication with comprehension. Building on the distinction between communication and comprehension, P28 emphasises the communicative change in his partner, PP, by comparing her previous social roles, when she 'was a fantastic nurse' and 'fantastic manager', to her present communicative state: ‘now, no she can’t even write her name, give her a pen she don’t know what a pen is’. P28 reflects on the communicative barriers that they currently work with:

> […] not being able to tell you what they want, as well. So, toilet needs I have to guess, so every two or three hours, we go, just in case. Food times, she don’t tell me she wants food but I think, it’s time we’re going to eat. She wants a drink, she can tell me sometimes she wants a drink, which is really nice, I know she’s not going to be dehydrated then. But other things, she can’t say “oh I want to go out and do this, can we go to the shops then we go to the park”. None of that. None of that comes out. And, so you have to be their mind, as well […] And hope, that you’re doing the right thing. It’s impossible to know if you are. I suppose, if she didn’t want to do something, then she’d probably tell me, in one way, or another so, I guess we’ve done the right thing, but we’re not perfect, so sometimes, I do make a mistake

P28 clearly establishes that his partner, PP, generally cannot now ‘tell’ him what she wants. Therefore, being unable to ascertain her needs, he must ‘guess’, and in doing so, take on the responsibility for expressing what is in her ‘mind’. PP is subsequently positioned as obviously having wants and needs and opinions, that can occasionally be expressed, while P28 situates himself as striving to hold for her the aspect of her ‘mind’ that she cannot communicate to him (Hughes, 2014). P28’s combination of the second-person inclusive ‘we’ with the clearly distinct person markers of ‘I’ and ‘she’ linguistically indicates this collaborative partnership, while his admission of occasional mistakes establishes that, regardless of this transformation, PP and P28 remain unique individuals as he cannot always guess what is in PP’s mind. Underlying both accounts, then, is the acknowledgement that people with dementia who cannot currently communicate their intentions are social beings who require the attentiveness and support of those around them to help hold aspects of their selfhood that newfound communicative barriers may otherwise prevent them from realising in the moment (Hughes, 2014).

As P28 demonstrates above, participants frequently situate themselves in relation to their past identities and lives. For PI, this manifests through sharing stories of her family and friends in response to conversational topics, especially of her ‘mam’, who ‘taught us a lot’ and would take her children ‘to another world’ with her songs on a Sunday afternoon, and PI’s ‘lovely lad’ of a late husband who, despite being as ‘quiet’ as she was ‘noisy’, seemed to love PI as much as she does him: ‘I was potty over him I loved him to bits!’. However, not all recollections are fond ones. Some participants, especially in my first focus group, contextualise their present state in relation to previously difficult times, in this case when they were first coming to terms with dementia. P4 tells us of the change in PB’s attitude towards forgetting:

P4 she accepts and laughs about it whereas at one time it was really, she would wake up, I wish I were dead, I'm useless, I can't, I don't know anything I know what's happening and she realised, very, in a brutal way what could happen or whatever. Don't help because we go to care homes and see family people and we see people go downhill very quick, […] it's scary and it upsets me but

PB Yeah. It upsets me as well

For PB and P4, watching the people they know 'go downhill very quick' (a metaphorical expression of decline, the focus of section 7.3) is scary and upsetting. Initially, P4 positions PB as reacting to her current and anticipated future self with dementia by feeling 'useless' and wishing she 'were dead' rather than have to experience 'what could happen'. Elsewhere, this is referred to as 'anticipatory helplessness', whereby people are paralysed by fears of the future, driven by the stereotype of the end stage of dementia rather than considering all that may lie in between (Bryden, 2016: 272). This may be further amplified for older people with dementia, since research suggests that feeling socially redundant contributes to a death wish in older adults (van Wijngaarden *et al.*, 2019). P4 suggests that, over time, PB has come to accept and laugh about her dementia, showcasing two common coping strategies in the face of great change (Górska *et al.*, 2018; Wawrziczny *et al.*, 2017). A point that will be returned to shortly is that PB's own retelling is largely missing from this account.

Similarly, P2 describes a time when her husband PA 'was really bad' but 'knew what was happening to him', reporting that he told her that 'I've had enough I want to kill myself'. PA adds that 'I'd got doctors and other people coming specially to see and none of them were talking the same'. PA's addition reiterates the instability of support from medical professionals indicated in section 6.4, and foregrounds his confusion and disorientation at this time, something that, as well as loss and grief, commonly accompanies a dementia diagnosis (Derksen *et al.*, 2006). The inclusion of the wish of two participants with dementia to die rather than experience the progression of their condition reinforces research that notes an increased risk of suicide for older adults with dementia (Serafini *et al.*, 2016). It is a sobering reminder of the importance of investigating the impact and (in)accuracies of discourses surrounding dementia, since these form an influential frame of reference for what life with dementia means (Bryden, 2016; Mitchell, 2018; Van Gorp and Vercruysse, 2012). Moreover, the prominence of the 'death sentence' metaphor to describe a dementia diagnosis reflects the broader conceptualisation of dementia as an unavoidable death in life (Zimmermann, 2017). Meanwhile, the increasing acceptance that Castaño (2020) observes within the blogs of people with early-onset dementia mirrors the shift from thoughts of death to an acceptance of life with dementia that participants portray here.

Building on the above exploration of PA and PB's 'low' (P2) points with dementia, P2 provides her own perspective regarding navigating her and PA's past, present and future experiences of life with dementia. She recalls a 'hard' time during which PA's initial medication made him feel 'really bad':

> I used to work as a carer with dementia but when he was really really bad I couldn't cope with PA and yet I'd worked with it. [...] So it made it really hard for me because I kept used to think I was useless "why can't you cope with it" do you know what I mean because you've been trained how to look after people and yet you can't cope with it. So at the time I was in despair especially when he was waking me up at night and getting dressed and getting undressed and getting dressed and he wouldn't listen to that it wasn't time to get up so I was losing my sleep there plus I'm disabled as well so it makes it harder to do anything when he decided to run away that's when I thought how am I going to get him back?

P2's 'despair' emerges in the increasing speed with which she delivers the story that climaxes with PA running away. She highlights the pressure of social roles and expectations in telling how she, as a 'trained' carer, 'can't cope' with her husband's dementia, causing her, like PB, to feel 'useless'. This exemplifies how a carer's sense of self can change when trying to support a loved one with dementia (Rayment *et al.*, 2019). Now, after changing PA's medication, P2 proudly positions PA as practically 'back to normal' and 'making cups of tea again aren't you whereas he couldn't do that he couldn't do anything'. Although this present state challenges the discourse of a linear decline (explored further in section 7.3), P2 does not communicate a happy ending. Instead, she uses her retelling of the past to exemplify her fears for their future: 'I'm just waiting waiting for it to change. At the moment it's marvellous he can do everything but I'm just waiting for that one day where he's going to get up, and he's going to go back to where he was before.' Through repetition, P2 emphasises her 'waiting' for this change, and indeed, P2's consistently high epistemic modality indexes her certainty that 'he's going to go back to where he was before', positioning PA's past abilities and mood as something they *will* return to. Many carers report similar resignation, behind which Wawrziczny *et al.* (2017) identify great sadness, a sense of fatalism and powerlessness.

Future fears materialise time and again, both across this study (see above and section 4.2.2) and in the field at large (Chappell *et al.*, 2015; Clare and Shakespeare, 2004). Accordingly, multiple discursive strategies for coping with change accompany participants' narratives. For instance, P5, who beyond this focus group leads a carer support group, berates P2 for being 'negative'. Instead, P5 advises P2 to enact 'Mindfulness. Enjoy today. Don't worry about what tomorrow's going to bring whatever it brings you'll deal with it'. This combines a common avoidance strategy, of deferring the future in favour of living in the moment, with one of acceptance, namely displaying self-confidence and trusting in your abilities (Wawrziczny *et al.*, 2017).

Throughout focus groups and interviews, many participants display or reference humour as an important coping mechanism, reinforcing the wider literature (Beard, 2016; Hickman *et al.*, 2020; Wawrziczny *et al.*, 2017), although, as P4 raises, humour is 'not always that easy', hence 'you have to keep the humour if you can' (P5). In these sessions, the function of humorous exchanges ranges from entertaining others and strengthening social bonds to making a point or mitigating the face-threatening potential of a disclosure (Norrick and Chiaro, 2009). In an interactive move that covers many of the above functions, PD uses humour to diffuse his wife's account about the 'difficult subject' of him having to stop driving due to dementia:

P12 it was becoming dangerous, but PD didn't understand why so it was quite a, a #difficult subject#
PD #It was something# to do with running over those railway lines [laughter]
P12 No [laughs]! You're joke- you've still got a sense of humour
P13 Yeah, [laughs] PE has
PE #[Laughing] we're together we are me and you are#

PD's joke may be read as a way of resisting his wife's face-threatening, problem-oriented account of his deteriorating driving and lack of understanding. The clash between P12 and PD's approaches to impression management here reflects a central issue, both to this thesis and interactions more broadly: often, carers and people with dementia have different motivations and approaches to how they represent dementia, with people with the condition preferring invisibility or managed visibility that leaves a positive impression, while carers may seek greater visibility of dementia's challenges, in part since this reinforces their own carer identity (Fletcher, 2020a). In many instances, as above with P28, P4 and P2, carers provide particularly extensive representations of their partners' changes and life, and this is oftentimes either supported or unchallenged by their partner with dementia, reflecting a broader imbalance in the voices representing dementia (Bailey, 2019; Davies *et al.*, 2021; Dening *et al.*, 2013). Yet, PD's resistance reinforces that people with dementia can and do reject their partner's negative positioning of them (Clare and Shakespeare, 2004). PD's technique appears to be effective, since P12 responds by observing a positive attribute of PD, notably his humour. That both wives appreciate that their husbands 'still' have 'a sense of humour' reflects the importance that sharing humour can hold for couples experiencing dementia (Hickman *et al.*, 2020). It also demonstrates that people's accounts can foreground continuity (here of humour) as well as change in the context of life-altering conditions (Whiffin *et al.*, 2019).

PE's response to the above conversation raises another notable means of coping with change with dementia, that of valuing togetherness. This is reflected in PE's combination of pronouns that situate his collective 'we' as 'me and you' (his wife, P13) 'together'. Their strong couple 'us identity' (Davies, 2011) materialises in their subsequent collaborative narrative of PE's changed relationship with driving:

P13 That was his life
PE Yeah that was my life
P13 Teaching
PE Yeah I started teaching, people, to drive a car properly [laughs]
P13 Well not people. Policemen
PE No well, #not people but er drivers yeah#
[...]
P13 Now, who drives you now?
PE You [laughter]
P12 #Who drives you crazy in the house# [laughs]
PE #She's a good driver# she's a very good driver.
P13 Yeah
PE I. I showed her a lot

Their joint telling of PE's 'life' as a driving instructor for police officers is demonstrated through mirroring the other's words and consistently expanding on their partner's previous turn. P13 then shifts their focus from the past to 'now', where she drives PE. His responses to this, complimenting his partner's skill ('she's a very good driver') and relating this to his role in her success ('I showed her a lot'), maintains his teaching identity and therefore attributes important roles to them both within their relationship. His pride in his partner's skill and their couple identity ('we're together we are') challenges the cultural privileging of individuality and independent action above interdependence, an imbalance that Boyle (2017: 1791) suggests contributes to the lack of agency commonly ascribed to people with dementia. Offering a carer's perspective, P33 similarly reports that as well as feeling 'closer' to his wife through caring for her, 'I've gained more. In myself. Through helping, through doing.' By presenting 'helping' as a means of personal growth and gains as a carer, P33 ties interdependence with action ('doing') and development. Evidently, the transformative experience of dementia can be presented as a source of (inter)personal growth for everyone involved, as well as of pain and struggle.

Of course, participants' accounts of change, identity and experiences with dementia are inherently subjective, something that is reflected on by P19, an ex-professional carer, and P18, whose grandparent moved into a care home. P19 highlights that ‘background knowledge’ impacts perceptions of the same individual with dementia to the point that it is ‘almost like a different person that you're seeing’. To him and the other paid carers, an individual ‘was just who they were when they came through the door’, and someone that you would gradually discover more about through ‘lucid moments’ and ‘relatives visiting’. In contrast, P18 positions relatives as ‘there to kind of interact with who that person, like was as well, in the past’. Notably, P18 argues that familiarity affects perceptions of change, suggesting that upon their loved one moving into care, families must adapt from a place of ‘constant contact’ to ‘now’ just getting ‘snippets’, where ‘each snippet is they’re changing and the family has to get used to this new baseline for this person, which is also changing constantly’, whereas the paid carer is ‘now constant contact. Erm, you know seeing this person getting to know them and everything as, as they are’. Just as time is relative, so is change. Length and frequency of time spent, relative to your familiarity in the past, is presented as inevitably colouring subsequent interactions and interpretations of the same individual with dementia and the concept of change.

7.3 Decline and flux

In the above discussion of change, participants differently position life with dementia. While P4 refers to going ‘downhill’, PC notes everyday variations in how he is, and two couples’ stories highlight large, if temporary, improvements in life with dementia due to a changing outlook and different medication. This section considers the nuances of discourses of decline and flux in more detail. It orients around participants’ responses to four images (Figure 7.2), which each act as visual metaphors of change, in particular of loss and deterioration when used in the context of dementia. Building on Chapter 4’s examination of how Jackie and Sheila respond to images 10 and 12, the present section considers participants’ overall responses to this page before focusing on image 11, as the most discussed and debated image of the group.

Figure 7.2 ***Page 3 images***

9.

11.

10.

12.

7.3.1 Reading visual metaphors

The four images are 'hybrid metaphors', since multiple phenomena are visually represented as interacting in the same space in a way that would be impossible physically — a brain blurs and disintegrates into pixels; a man's head turns to fragments; three face-shaped trees in different seasons stand together; and a woman loses a jigsaw piece from her head, leaving a dark void where it should be — combinations that subsequently establish new meanings beyond each individual component (Forceville, 2008: 465). The process of a hybrid metaphor is reflected in a focus group's discussion about the realism of the brain in image 9:

P7 I mean that's quite a realistic looking one actually
P10 I suppose it is yes
P7 But yes
P10 But maybe because it's disappearing it's less
P7 It's not a realistic thing is it

Here, combining different phenomena, namely the brain and the process of disintegrating, makes what is otherwise 'quite a realistic' brain unrealistic. Instead, the brain takes on metaphorical meaning, where, in a particular scenario of the broader conceptual domain HUMAN AS MACHINE, the brain with dementia is a data processor that is losing data, and therefore breaking down. Bailey (2019) observes the prominence of this discourse within newspapers' discussions of dementia and highlights the dangers of subsequently representing people with dementia as broken. It is generally immediately clear to participants that these are metaphorical images. As soon as P33 turns the page, he notes the symbolic quality of these combinations of phenomena, exclaiming that 'now we're going onto symbols, symbols yes'. Through this label, P33 separates these images from the more literal photographs that make up much of the visual stimuli shown to participants.

Cognitive Metaphor Theory (see section 3.2.3) helps explain the prominence of metaphor in the images used here to depict the target domains of progression, loss and/or change in Figure 7.2. All are 'relatively abstract, complex, unfamiliar, subjective or poorly delineated' experiences, meaning that mapping these onto more concrete and familiar source domains, such as a jigsaw or seasonal changes, provides a more tangible, experience-based explanation for these abstract phenomena (Semino, 2008: 6-7). Participants frequently remark on the source domain first, before elaborating to explore the metaphorical meaning by relating the source to the target domain. When justifying why she likes image 12, P21 draws on the cultural familiarity of the source domain: 'everyone knows a jigsaw don't you, and understands it, even children probably you know, understand that'. However, the mapping of the source to the target domain is not always clear for image 12:

PI And the piece missing out that one I wonder what that one's for. Why would that piece be missing like that.
P21 It's like, it's #portraying what dementia# so it's something about the brain isn't it
PI #this is the brain# Mmm
Emma What do you think about it? [4.9]
P21 Do you understand that what it's telling you about how to explain what dementia is? #Do you understand #
PI #Mmmm#
P21 what it is?
PI Ay?
P21 Do you understand what that's saying
PI [sighs] No

This exchange highlights that regardless of the familiarity of a jigsaw and missing piece, the metaphorical meaning is not always clear for individuals. It may also not be desirable; PH resists identifying a target domain for image 11, stating that 'being a physicist, it's a bloody tree'. Meanwhile, in response to being asked what he thinks of the four images, PA situates them as 'just a pretty picture, and if you don't know what it's about, and you can't read it, in the field or whatever, you just drive past.' Such reactions caution against assuming that everyone engages at the connotative level for metaphorical images. Sometimes a tree is just a tree.

Often, the more concrete aspects of the target domain, such as a brain or face, are noted by participants first since they are clearly shown alongside the source domain in the image. PI exemplifies this when she exclaims upon seeing the page: 'They're faces they are! That's the brain. They're faces they are. She looks how I feel.' PI identifies three aspects of the target domains that are literally shown in the images, that of the brain, faces and the woman's expression. In contrast to Sheila and Jackie in Chapter 4, who create a sense of distance between themselves and the lady depicted in image 12, PI explicitly aligns herself as feeling how the woman looks. This reiterates the subjectivity involved in relating to represented participants in images, regardless of the piece's composition. PI is not alone in initially foregrounding the woman's expression in 12; PD tells me that 'she looks a bit sad there' while P26 also suggests that she has 'sad eyes' and 'looks, lost'.

Equally, many participants discuss metaphorical connotations, going beyond what is literally depicted by each image. Remaining with image 12, participants consistently pick out the concept of the 'puzzle piece missing' (P17), often identifying a loss of brain function as the metaphor's target domain: 'obviously the mentality is that people are (losing) losing functions of the brain' (P8). For P6, it is this discourse that makes image 12 'possibly. better?' than the other three images, 'because it's like a piece, of your brain, that's gone, you know. I wouldn't have such a big piece [laughs]'. The location of the missing piece from the woman's head encourages participants' consistent associations with the brain, the organ situated there. Object size also matters: P6 does not resist the metaphor that you lose pieces of your brain with dementia—she instead resists the *amount* of loss that is signalled through the puzzle piece's size (it is approximately 1/9th of the area showing the woman's face). Sometimes the missing piece is interpreted in relation to the whole person, as with P33 who positions image 12 as 'the real one there that, says, you know, part of me is missing. And a carer would say that about mum, part of her is missing.' Although it may be a literal reading of the fact that the woman is missing a piece in the picture, that it is not the person's brain but their whole being that is incomplete can be seen to reify the popular discourse that dementia involves a loss of self, itself entangled with the prioritisation of the brain as the source of human identity (Van Gorp and Vercruysse, 2012).

Although some people, such as P6 and P33, align themselves with the representation in image 12, a notable number of participants resist the discourses that this image engages with. P8 criticises it as 'stark', while PJ tells me that 'I'm a bit dubious of this one' and that 'it affects me'. Within his explanation of its effect, PJ identifies the woman's 'blank' expression, and situates it as a frightening part of life, highlighting the negative impact of tragedy discourses for people with dementia (Bryden, 2016). The focus group of PhD students focus on the implications of the woman’s expression and missing puzzle piece for them:

> P19 It’s also it kind of implies that. I’m not saying she is, but I think it implies that she's stupid
> […]
> You don't suddenly become, gormless or you know, and I think that’s slightly implied, probably not intentionally I don’t imagine it would be intentional. But it is sort of, she looks like she's not quite sure?
> P18 Or like losing your mind in terms of like you go kind of, not crazy but you know what I mean, like erm
> P17 Lose your marbles that’s what we’re getting from that
> P18 Yeah, like that’s sort of what it's, like, just because you, forget something doesn't mean you're an idiot and it doesn't mean you're insane. It's just you forget things.

This conversation is remarkably similar to Harvey and Brookes' (2019) criticism of the same image. What P19 identifies as a ‘gormless’ expression is linked by Harvey and Brookes to the ‘living dead’ metaphor, in which the woman is positioned as a zombie, a ‘non-person’ through her vacancy (997). The PhD students instead link this image to denigration through low intelligence and insanity, factors that also accord people ‘less-than-full membership’ in society, partly due to a perceived lower conversational competence (Clare and Shakespeare, 2004: 213). They utilise common metaphorical phrases associated with the discourse of loss and madness (‘losing your mind’, ‘lose your marbles’) to explain their associations of insanity and stupidity from the image’s missing piece and the woman’s ‘gormless’ expression. Here we see a return to the stigmatising association of dementia with low intelligence (section 5.3) and insanity, and the students’ clear rejection of such discourses as separate from dementia. P28 takes a similar stance, arguing that: ‘someone could look at that and think, they’re loopy, because, a piece missing, this person’s a, a lunatic, you know, or something else. You couldn’t think “might have dementia” from that, you’d just think “oh, something’s missing from her”’. In this account, P28 makes the link between the missing piece and being ‘loony’ explicit through the causality of ‘because’, just as he firmly separates having dementia from having something missing. This leads P28 to declare that the woman in image 12 is ‘being misrepresented in society’, definitively rejecting this particular loss-oriented representation in the context of having dementia.

Deeper connotative levels are not always clear, and nor are the literal depictions in the images. Image 9 appears particularly confusing and is the least positively received. The relative unfamiliarity of the data source domain for dementia may contribute to such confusion and disregard;

indeed, elsewhere Getty Images (2019) situates it not in the realm of dementia but of digital data processing: 'human brain dissolving into squares representing data'. Few participants refer to it as showing 'your, brain dissolving' (P16) or 'disintegrating' (P17). The most evident issue appears to be the ambiguity of what is shown. My first interviewee, P6, exclaims that 'Ooh my goodness me [laugh] I don't know what that's supposed to be and I wouldn't like to speculate', later adding that 'it looks like a clump of clay I mean that one doesn't mean anything to me'. PF tells me that 'I don't understand this that, I'm not sure if it's a snail or something going down into water?' Here we see a breakdown between intended meaning and interpreted meaninglessness, as participants cannot clearly identify the components depicted in the image, let alone the wider discourses it engages with.

7.3.2 Seasonal decline: image 11

Overall, image 11 emerges as the clear favourite amongst participants, although the responses deemed favourable here range from image 11 being grouped with image 10 or 12 as the more favourable pair, being positioned as 'better' than the other three (P16), to being favoured above all other images shown. In part, the preference for image 11 can be linked to the use of more varied and saturated (brighter) colours, which are widely associated with a greater exuberance (Ledin and Machin, 2018b). Image 11's colours are positioned as 'nice', being evaluated as 'happier' and 'more gentle' than 'the dim, ones' (P22), which are critiqued for their 'quite cold […] stark background' (P19). However, much of the focus in evaluating the image revolves around the visual metaphor itself, and its perceived accuracy and clarity for representing change with dementia. Image 11 is positioned as 'meaningful' (P11, P28) and lauded as 'clever' (P11, P22) yet 'done simply' (P23). For PG, 'you can see what's happening' with dementia in this image, and for P22, it 'explains more to me than anything else in the book'. PJ makes explicit the underlying connection with processes in the brain when he declares that 'I'm going through it myself and. Every time you - looking at this, it explains what happens to your brain'. What is it about this visual metaphor that makes it such a widely accepted, even celebrated, analogy for dementia?

The tree, a 'symbol of life and image of seasonal change', is popularly associated with the brain (Zimmermann, 2017: 80). As Zeilig (2014a: 259) explains, the metaphorical connection is so strong that trees influence not only how the brain is discussed but how it is labelled, for instance, neuron 'dendrites' mean 'tree like' in Greek and are often referred to as 'branch-like structures' (National Institute on Aging, 2017). References to a 'brain forest' or 'neuron forest' can be easily identified in scientific papers and public-facing explanations of the brain alike, 'because a neuron is more or less similar to a tree' (Akram *et al.*, 2018; Prasantha, 2019: para.1). Tree metaphors are also an important feature of people's accounts of dementia (both fiction and non-fiction: Zeilig, 2014a, 2014b; Zimmermann, 2017), to the point that Christine Thelker's (2018) blog for Dementia Alliance

International is titled 'Walking through the Neuron Forest… called Dementia'. In an analysis of picture books, Caldwell *et al.* (2021: 124-5) highlight the use of weeds growing in a garden to represent dementia as tangles in the brain, the plant metaphor enabling a biomedical explanation of dementia that is grounded in the ordinary realities of a garden for children. For audiences of any age, then, linking trees with dementia can facilitate a biomedically-oriented depiction of complex changes in the brain during dementia.

Image 11 explains changes to the brain with dementia (the more abstract target domain) through the seasonal decay of deciduous trees' leaves in autumn (a familiar source domain). This is achieved through the 'different colours of the season' (P22) corresponding to the increasing loss of leaves located only in the faces' side-profile where the brain would be. By the third, red tree, the area that would be the brain has very few leaves remaining. The tree-face resemblance is so strong that some participants refer to them as 'faces' (PI, P20, P22), or 'heads' (PF) rather than trees, while occasionally, the two domains are conflated: 'the leaves are dropping off from the brain' (P26). Many individuals emphasise loss when explaining brain changes through the trees' seasonal cycle. For instance, PM likens a tree losing an increasing number of leaves in autumn/winter to a brain losing cells during dementia:

> That's why these pictures are good because you're suddenly normal, and then you start, to lose more, like a tree, when it's, it's losing its leaves in the winter time […] and then you lose some, like in the winter time your tree will lose some leaves, and then it will lose more, and then it will lose more, and that's just like your brain. It loses more, and more, brain cells.

That PM repeats 'lose/losing' seven times reflects the extent to which loss is foregrounded. The concept of loss is referred to throughout participants' accounts, both directly (P22, P23), and via a range of partially synonymous terms, including: 'it's deteriorating' (P22), 'everything's fading away, slowing down, degrading' (P28), 'it's […] dying off' (P28, P30) and 'the brain disappears' (P2). The terms 'fading away' and 'disappears' are particularly reminiscent of other metaphors that more explicitly associate cognitive losses during dementia with a loss of self, particularly dementia being a living death, through which people are positioned as fading/faded and lesser (Aquilina and Hughes, 2006; Behuniak, 2011).

Indicating that visual metaphors are less direct and specific than their linguistic counterparts, PF discusses this metaphor's target domain (the head/brain) without mentioning the source (the autumnal tree). PF tells me that:

> I take it or I feel, that that's [the green head], very imperceptibly starting, and then the goldie one is, the tangles are getting worse and the nerve endings are not going

> through and giving you the right coordination, and then the red one is when it's got destroyed a lot, the latter stages.

The visualisation of internal biological processes is still evident, with PF consistently linking increasing internal changes to their external manifestation. Initially, changes are imperceptible: the person is not showing signs of the subtle changes occurring, just as the tree's full, green foliage hides the biochemical processes occurring when, as sunlight reduces, leaves stop making food and the green-coloured chlorophyll molecule begins to be broken down (which will reveal yellow pigments as this process increases). As the 'tangles' get 'worse' and 'nerve endings are not going through' for the 'goldie'/yellow head, PF presents your 'coordination' as affected, an obvious external manifestation that notably contrasts the usual focus on changes to memory. The red face, with its near empty branches, is positioned as when the brain has 'got destroyed a lot' and is firmly situated in 'the latter stages', near the end of life with dementia.

As PF's discussion of destruction of the brain indicates, this image can evoke quite violent and disturbing descriptions of dementia, to the point that 'at the end your brain's gone' (P2). However, the metaphor is seen by some to soften the underlying discourse of loss and degeneration, as it is 'showing you without the kind of human expression' present in the others (P17). For P10, that 'it's not an actual human face' helps avoid the implication of a 'person's humanity […] disappearing'. Such responses would seem to suggest that, reflecting the broader literature that ties the tree metaphor to the brain, participants' responses emphasise biological changes and the manifestations of these, as opposed to the emotional, personal aspects of dementia. This is evident in the many evaluations of what the metaphor is useful for, with people such as P2 declaring it is 'ideal for saying what a brain does what's happening when you've got dementia'.

Weaving throughout the above responses to this visual metaphor is the concept of time, an inherent factor in trees' seasonal changes. Indeed, P22 explicitly highlights that 'it looks like it's deteriorated over time'. Participants consistently emphasise the slowness of the progression (often referring to 'gradual/gradually': PN, P2, P7, and 'slowly': PI, P28), while P14 interprets it as meaning a 'steady decline […] Because Alzheimer's is a steady decline'. This sense of time is achieved through placing three different stages alongside each other, since, as opposed to the one moment in time captured by the other images, here, moving from left to right, 'you can see how it's going along' (P21). This draws on the metaphorical relationship with time whereby humans move through moments in time (Lakoff and Johnson, 1980), here as three snapshots. As such, P28 declares that 'You trace it from the beginning, everything's fading away, slowing down, degrading. […] it's just slowly dying off, so that is one way, of portraying it'. To this, P30 adds that 'in some it's quickly dying off, like in [my husband]'. Clearly, P28 and P30 agree on the underlying discourse of 'dying off' over time, as it is the speed with which this process can occur that is debated, based on P30's experience of her husband's quick progression, until they concur that 'you can't put a time limit' (P28). Notably, the movement from left to right reflects the reading process in Western cultures across the page, and the associated trend noted by Kress and van Leeuwen (2006), whereby information on the left is deemed already familiar, or 'given', and information towards the right-hand side is less familiar, or 'new' (180). According to such a theory, the green head on the left is positioned as the 'normal' person (PM, PN) and moving right reflects not only time passing but a shift away from the familiar to the unfamiliar, abnormal state of increasingly progressive dementia.

The seasons metaphor is sometimes used to situate dementia within the overall life course, whereby A LIFETIME IS A YEAR generally positions springtime as youth, summer as adult maturity, autumn as old age and winter as death (Lakoff and Turner, 2009: 18). Elsewhere, individuals normalise their dementia within the life course using this metaphor: 'Like leaves fall to the ground from a tree, old people lose their memories' (Langdon *et al.*, 2007). Here, though, when P11 interprets image 11 as situating dementia as a natural stage of reaching 'winter', she resists this by arguing that 'not everybody who gets to the fall of their lives is going to [get dementia], but of course, a large proportion are'. Taking a broader perspective of health, P33 quickly identifies 'summer, autumn, winter', and positions winter as the last stage of life, explaining that 'unfortunately winter is when things don't start working right [laughs] in people's body'. Meanwhile, P2, whose partner with dementia is aged 73, explicitly locates dementia as the endpoint of older age: 'as the brain disappears that's when you're younger when you're all bright and (xxx) and as you get older your brain starts to go and as you get Alzheimer's or dementia your brain goes away.' She later adds that 'you start off young and vibrant and then gradually your brain starts to go and then at the end your brain's gone'. Mirroring the metaphor of decaying leaves and drawing on the discourse that dementia is a natural aspect of ageing, P2 establishes three stages: 1) green: being 'young' (which is marked by being 'bright' and 'vibrant'), 2) yellow: getting older, whereby 'your brain starts to go', and 3) red: where with dementia 'your brain goes away'. This speaks to a core aspect of the seasons metaphor when it ends with winter: there is no spring, no renewal. Instead, abilities, brains and/or lives, according to what is being discussed, degrade until, in time, they disappear.

The change portrayed in image 11 is not constrained to a dementia context. P33 jokes that it could be about hair loss, while PN initially declares that 'it's how. most. people get eroded I mean, it could be a child couldn't it. if the child is starved of imagination and. love and care.' Despite situating the image in non-dementia contexts, both accounts clearly engage with the image as a means of metaphorically conveying loss, with P33 positioning it as external (loss of hair) and PN as internal (a wearing down of a person through their environment). PN's interpretation is particularly striking, as she draws on another source domain, erosion, to position people of all ages as vulnerable to the effects of their surroundings, in which adverse exposure (here to a lack of care, love and imagination) can gradually wear away at individuals. When in a dementia context, the eroding force is attributed to internal changes from the condition, both in these interviews and in published written works (see Zimmermann, 2017: 80). By considering the image in a broader life setting, PN foregrounds another essential factor in people becoming 'eroded' or 'degrading' (P28): that of a person's social environment. This integral social factor is missing when this image is applied to dementia, whereupon it becomes a biomedically oriented metaphor for degeneration.

As well as accepting, praising and reproducing many of the metaphors communicated by image 11, participants show multiple moments of resistance, both to image 11 and its counterparts in Figure 7.2. For instance, P5 dismisses the four images as 'too stark' and reductive, emphasising that 'there's a lot more to dementia than they are portraying' (P5). The contention surrounding image 11 is epitomised by the following exchange between two members of a dementia-specific Public and Patient Involvement (PPI) group:

PK Dementia doesn't quite work like that does it, it's not a straight line. [...]
PM -That's why these pictures are good because you're suddenly normal, and then you start, to lose more, like a tree, when it's, it's losing its leaves in the winter time
PK But they point, as three stages
PM Yeah but it is #stages#
PK #You# could have a forest, of those trees-

Having examined PM's contribution earlier, the focus here is on PK's two main criticisms of the image's underlying discourses. First, recognising the linearity of the direction of time (left to right) in the image, PK emphasises that dementia is *not* a linear decline, as evident in his metaphorical conceptualisation that 'it's not a straight line'. Second, he resists the 'three stages' as an oversimplification of the reality of dementia, suggesting instead that a 'forest' of trees would better represent its diversity. Intriguingly, PK's arguments are remarkably similar to those of the other dissenters across the groups. Throughout, people present the multiplicity, individuality and changeability of dementia as their key counter discourse.

Participants consistently critique the linearity and finality of the images' depiction of progression with dementia. P1, whose wife used to have dementia, argues that image 11 'apparently shows a constant deterioration whereas if you've been with someone who has dementia you know that that's not the case', as there are 'moments of lucidity and those moments it's as if everything is restored, even the memory, and you can't cope because within a second it's […] gone.' Rather than a forest, he suggests altering the image to show 'leaves floating around because it can always come back'. The group supports this as a more accurate portrayal and later, P3 returns to P1's idea of incorporating changeability, adapting the tree metaphor accordingly:

> You know, it feels like ah I've got dementia I look at this – everything in my head is just going to dissipate you know but from my experience that's not true, and it's just like what P1 said about how the leaves, they do gravitate around the tree and sometimes they come back, you know and I think that's very true and I think these images kind of take away from that silver lining, you could say, that people with dementia. I think it's a very good point about the trees - the leaves do stay around the trees you know sometimes they settle back down, sometimes they blow away.

P3 touches on a flaw in the autumn to winter metaphor for trees here, in that leaves, once fallen, cannot reattach. To get around this, he extends the conceptualisation of what it means to be lost, highlighting that leaves 'do gravitate around the tree' and can 'come back' in the wind or 'settle back down', still with their tree, separating this from the permanent loss of 'blow[ing] away'. This possibility of things to return is the 'silver lining' that he suggests image 11's linear degeneration is currently missing. Focusing instead on the metaphor's emphasis on decay, a couple from the same group, PC and P5, argue that 'your brain's not decaying, it's just not working properly. in different areas' (P5). Subsequently, PC tells us how 'I can talk about all sorts of things, if you ask me about something I did yesterday I can't remember […] But er, I've done quite a lot of fairly interesting things in my lifetime and er (I remember all them)'. Rather than the finality of the degeneration implied by decaying autumn leaves, this group advocate for a focus on partiality and flux, as you certainly do not lose everything with dementia and many losses are not permanent.

In another focus group, P18, whose grandmother had dementia, recommends varying the areas experiencing leaf-loss to demonstrate that the effects of dementia for people can be unpredictable, changing on a day-to-day basis:

> I think like with the tree one, if they had it and, it's like, yes, things are missing, but like like different, like if the head sort of like if there was one and then part of it was missing and the other one was like that, another part, but not the same part was, missing you know what I mean, because we're saying like things do come back once in a while so it's like. You never know what you're going to get. Like when I go visit my grandma's like I'm either going to get the grandmother, I grew up with, I'm going

> to get the grandmother, my mother grew up with so it's like. But that's still them. You just get a different part of them when you visit.

Extending the changeability of life with dementia, where a 'missing' 'part' can return to people, P18's account positions the person themself as a constant ('that's still them'), and just as presenting 'a different part of them' depending on the day. This reflects the fluidity and relational nature of self (Sabat, 2018), something that P3 also recognises: 'the person that we all know or whatever isn't leaving, they're not disappearing as the pictures kind of portray in a very this is what's going to happen. It's not as simple as that, it's very hit and miss, come and go, very personal, very built within that relationship or that person not just that it's gone'. Here, P3 foregrounds the personal, embodied and relational aspects of identity, emphasising that identities are 'built within' our relationships and beings, and therefore cannot disappear. Both P3 and P18 strongly resist the images' underlying discourse of loss of self, instead presenting a more nuanced alternative conceptualisation whereby people have plural and fluctuating identities that are in part held by their relationships with the people around them (Hughes, 2014).

It is with these counter discourses that participants highlight that people with dementia are far more than their progressive biomedical condition (Bryden, 2020), and offer creative solutions to better match the visual metaphor to their experiences of dementia and identity. What becomes increasingly evident through the debates in this and other sections is the subjectivity of truth — it is through this phenomenon that for the very same image of the trees, PM asserts that 'they [are] true', while PK equally confidently responds to her that 'no it's not true'. In another group, P5 offers us an insight into her personal perspective and her subsequent emotional response to the pictures: 'they're kind of hopeless pictures to me and dementia in my case, I can only speak personally, it's not hopeless to me. It's difficult sometimes, it's funny sometimes and that's just portraying the brain decaying'.

7.4 Summary

Across accounts, experiencing life with dementia foregrounds change and continuity, and gains as well as losses, reflecting a growing need to consider more positive aspects, including of caregiving, alongside the more traditional emphasis on loss (García-Castro *et al.*, 2021). The range of perspectives on this issue are showcased by people's different interpretations and responses to the images in Figure 7.2, which metaphorically represent loss and linear decline with dementia. While many commend the simplified biomedical explanations of brain changes, particularly for image 11, other participants resist the underlying emphasis on loss and degeneration in the biomedical discourse. Such individuals counter this with a more nuanced presentation that emphasises the multiplicity, individuality and changeability of dementia, alongside a more holistic approach to selfhood that incorporates relational, embodied and contextual aspects. The next chapter supplements this chapter’s orientation around visual representations of loss and decline by exploring linguistic resources used to discuss life with dementia, debating language around ‘suffering’ versus ‘living well’, and metaphors, particularly journeys and battles. It will also expand upon the critiques and suggestions offered so far by participants in its concluding interrogation of current representations and participant-led recommendations for how to improve portrayals.

‘I think the more we can use the media, the more people realise that we, we are ok and and that we aren’t to be feared.’

- Participant N (Jackie)

Chapter 8: Evaluating representations

8.1 Introduction

How would you describe your life? This question lies at the heart of the next section, so I begin by asking you to consider your answer. Is your life a journey, and if so, what does this mean to you? Would you consider yourself to battle your obstacles, whatever or whomever they may be? What role has suffering played in your life and identity? Finally, what does it mean to live life 'well', and is it useful or detrimental to measure life in such a way?

As the penultimate chapter, Chapter 8 aims to consolidate and round off analysis by attending to discussions surrounding representations more broadly. Section 8.2 redresses the prior emphasis on visual stimuli by considering different language choices for representing life with dementia, which enables a nuanced exploration that builds upon existing contributions made by participants. In particular, the terms 'suffering', 'living' and 'living well' with dementia are debated, followed by the use of popular and idiosyncratic metaphors by participants. The discussion that these word choices evoke leads into a consideration of how participants evaluate and would like to alter popular representations of dementia in society. Within this, three key recommendations are established, namely: 1) normalise dementia; 2) provide more nuanced representations; and 3) expand the attribution of value and notions of personhood to enable better advocacy for people with dementia.

8.2 Language for life with dementia

Throughout the preceding four chapters, it is consistently demonstrated that, as with much in life, the experience of having dementia and of knowing someone who does is uniquely personal. Deliberating on the language used to represent such an experience offers a valuable exploration of the relationships between individual perspectives and semiotic resources, since, as has already been established for the visual stimuli, the same image can be interpreted and evaluated entirely oppositely by different people. It is worth noting that, due to time constraints, not all participants were shown the verbal stimuli explored below, meaning that explicit discussions are often drawn from a smaller pool of participants and from relevant conversations outside of the times when specific stimuli were being shown.

8.2.1 Living and suffering with dementia

As Figure 8.1 demonstrates, discussing life with dementia equally entails discussing the person living it. There are multiple guidelines in place to advise on appropriate language use for dementia-related topics that are made by or with people affected by dementia (Alzheimer Europe, 2013; Alzheimer's Society, 2018; Bould, 2018; DEEP, 2014). Section 2.3.3 outlines how these guidelines prioritise 'accurate, balanced and respectful' word and image choices that emphasise the person, such as people/person 'with dementia', 'living with dementia' and/or 'living well with dementia', rather than 'curl up and die' words such as 'dementia sufferer', 'victim', 'senile', 'living death' and 'burden' (DEEP, 2014: 1-2). PN (Jackie), herself a DEEP member, situates herself within this linguistic change: 'we had a long time er, talking to people, because they were saying that we suffered from dementia, whereas we try to say that we lived with, we live with dementia'. Her movement from past to present tense reflects the linguistic shift from 'suffering' to 'living' that has occurred in recent decades, as well as the greater prominence of the voices and desires of people with dementia, who have increasingly challenged externally attributed labels (Beard *et al.*, 2009b; Bryden, 2016; Swaffer, 2014). Overall, participants display similar linguistic preferences to those of the aforementioned guidelines. Nonetheless, there are many variations regarding the implications of 'suffering'/'sufferer', 'living with' and 'living well', which will be outlined below.

Figure 8.1 ***Stimuli that verbally relate to the 'living well'/'suffering' debate***

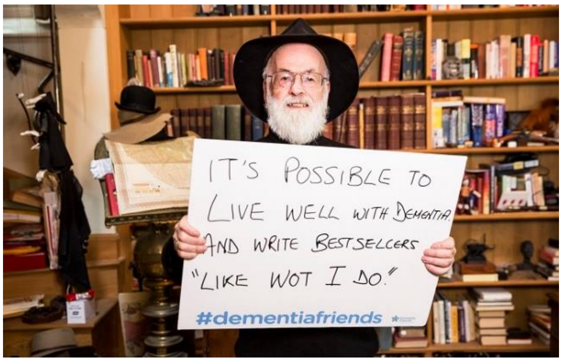
Suffer with dementia / suffer from dementia
Dementia sufferer

Living with dementia

Living well with dementia

Dame Barbara Windsor's heartfelt plea to end Alzheimer's disease agony
(The Express, 6 August 2019)

THE LOVE THAT DEFIED DEMENTIA; Most poignant of weddings after sufferer asks wife to marry him ...believing she's new love and falling for her all over again
(Scottish Daily Mail, 22 August 2019)



(image 15)

Participants take different stances towards suffering-related language. Some individuals intimate that the words used do not matter (PH), with PC quoting Shakespeare's famous line that 'A rose by any other name would smell as sweet', while others oppose these labels ('I don't like suffer': P7), often for being too 'negative' (PN, P11, P14). People generally distinguish between the experience of 'suffering' and the identity of being a 'sufferer'. As such, PF positions herself as willing to say that 'I suffer from dementia' to close friends, but resists being called a 'dementia sufferer', since 'it demeans me'. Indeed, very few participants use the term 'sufferer' themselves to refer to people with dementia. Two carers use 'sufferer' once outside of deliberating the word (P15, P16), and one when discussing the headline in Figure 8.1 that uses 'sufferer' (P26), whereas eight participants use variants of 'suffering with/from' dementia (PC, PF, P5, P6, P11, P23, P25, P26). Some of the tensions between suffering as an identity versus an experience are exemplified below, when a participant stops herself from saying 'sufferer', but then attempts to justify this censored word:

P5	Although actually they look like suff- people with dementia, nearly said the s-word then
Emma	What do you think of the s-word out of interest? Sufferers?
P5	I don't see it's as bad it's like you suffer from headaches, suffer from indigestion, why shouldn't you suffer from dementia?

There is clearly a tension here between 'sufferers' and the more socially acceptable replacement phrase, 'people with dementia', likely in part due to the social context being a Memory Café focus group in an environment that officially upholds a living well discourse and the language guidelines of the Alzheimer's Society. P5's self-censorship is expressed through her joke, 'nearly said the s-word then', which situates 'sufferer' as a taboo word. Yet, potentially in an attempt to save face, P5 then justifies the label, all while never explicitly referring to people as 'sufferers' and rationalising the term wholly in terms of the *experience* of suffering, since she changes the noun 'sufferer' to its verb 'suffer', thus shifting the focus from people themselves to the act of suffering. Through presenting alternative, non-stigmatising uses of 'suffer from', P5 constructs an argument for also suffering from dementia by normalising it within temporary, everyday conditions, effectively recontextualising the initial identity-oriented debate within an experiential one. By using 'suffer' while avoiding 'sufferer', P5 implicitly distinguishes between these two terms.

However, in other sessions, these distinctions become more explicit. In particular, 'sufferer' is often rejected for being 'horrible' (P10) as it undermines personhood: 'people with dementia are not sufferers, they <u>have</u> dementia, they are a <u>person</u>, and that is very important, a person with dementia. [...] It's politeness, it's, dignity. [...] Treat the person as a person' (P33). The emphasis within P33's account is strikingly similar to Kitwood's (1997: 7) oft-quoted call to recognise people with dementia ‘in their full humanity’ and shift the frame of reference from ‘person-with-DEMENTIA’ (as signalled by ‘dementia sufferers’) to ‘PERSON-with-dementia’ (original emphasis). Reflecting on his experience as a professional carer, P19 upholds this professional shift to person-centred language: ‘I mean usually you’d call them by their name, er, you know, shock! [Laughter] But er, when you couldn’t do that, you were working with people with dementia. […] never dementia, sufferers, ever’. In contrast, participants more frequently accept and use the verb ‘suffer’; for example, PC is reminded of ‘my mother and grandmother who suffered from it’. As justification, people point to the suffering that people with dementia and carers experience: ‘obviously it is a negative term but I mean, it’s [laughs] not a nice thing to have’ (P6) (see section 4.2.2 for further discussion). This reflects a wider move in the literature to acknowledge that dementia can be a ‘site of distress, disgust and despair’ (Gilleard, 2018: 29), with Keith Oliver making explicit what remains an implicit distinction amongst my participants: ‘I don’t see myself as a sufferer but I do suffer from dementia. I find dementia extremely challenging and frustrating but I am not a sufferer because if I become a sufferer that’s how I’m defined and that’s how I’m treated’ (Bartlett *et al.*, 2017: 177).

Against this, some participants, notably P19, caution against the blanket use of suffering to describe having dementia (‘you have to be pretty sure […] that suffer is the word’), suggesting that ‘suffer’ is too ‘black or white you're either suffering [or] you're not suffering’, when the reality of life with dementia is ‘a grey area’. For many people, shifting the focus to *life* with dementia is more helpful (‘the living with dementia is much better isn’t it’: P13). As P7 points out, ‘you are still living with it, you know, […] it's not killing you straight away or whatever’. Within this discussion of life with dementia, there are many distinct stances regarding what it means to live, or live well, with dementia.

For many people with dementia in particular, the concept of ‘living well’ is something they strongly identify with (‘living well with the dementia yeah I am’: PE) and aspire to, as it provides something ‘to aim for’ (PH) and ‘look forward to’ (PD), as ‘we all need that pressure […] That incentive, to live well’ (PN). The discourse ‘gives you help, and hope’, since it ‘conveys to you, you can do something, you can eat healthily, you can go out, you can walk. You can still do things, you can keep your life going’ (PF). In this context, the image of Terry Pratchett shown in Figure 8.1 is praised for its humour (‘I like the “like wot I do”’: PH) and depiction of a living well narrative (‘I love number 15 where he’s actually said it’s possible to live well with dementia’: PN). For PF, the image shows that ‘You can be happy and you can do things. This man's still writing, he’s written a bestseller! I keep thinking I want to try and write a, a little story’. PF makes a particularly personal connection with this image, identifying her own goal as, like the author shown, she too would like to write a story that could feature in a ‘lovely magazine’ she reads with ‘nice […] wholesome stories’. These responses indicate that the more positive outlook of the ‘living well’ discourse can be empowering (indeed, note PF’s repetition of 'can', to signal all that you are able to do) by promoting that 'life does not stop' (Morgan, 2018: 306), and that 'it is possible to continue to live and grow and to appreciate life' after a dementia diagnosis (Sabat, 2018: 136). Notably, these participant responses, particularly PF's discussion of actions that 'you can do' as an individual, such as go for a walk and eat healthily, tend to take a neoliberal approach to the living well discourse that foregrounds individual responsibility to 'live well' (Peel, 2014), rather than wider society's responsibility to provide a facilitative environment, including by respecting the human rights of people with dementia (Cahill, 2018). In this context, the individual focus appears empowering for participants, as they can evaluate their lives positively and express agency in how they choose to 'live well' with dementia.

However, the 'living well' discourse is also critiqued by participants (predominately those without dementia) for being inaccurate compared to the 'brutal' 'reality' of life with dementia (P8, P10). It is seen to carry an 'implication that like if you're not living well, you're not doing it properly' (P17) and are 'failing' if you are 'at screaming point' (P6). Declaring that 'I don't like Terry Pratchett's "live well"', P1 suggests a less pressurising alternative: 'live as well as you possibly can!', which is enthusiastically received by many of the other focus group members. The term itself, 'live well' is positioned as being vague and subjective, with P28 asking, 'how do you live well?' and other participants foregrounding the range of abilities and changing difficulties, which can make comparing people detrimental. For instance, Terry Pratchett (image 15) is distanced from other people with dementia as being an 'unusual guy' with an 'unusual form of [dementia]' (P7), with three carers contrasting his bestseller to the inability of their loved one with dementia to now write (e.g., 'PO can't even write his name': P27). PH also notes in relation to the image of Terry Pratchett that, 'you can still do things, some things, but, there are things that are, erm, much more difficult for me to do, now'. For some people, the addition of the evaluative 'well' to 'living with' is 'unnecessary', as it fails to acknowledge the nuance of daily life (P19). For P30, the term is 'one of my bugbears', as 'I know lots of people [affected by dementia] but I don't know anybody that's living well with it'. At its worst, 'living well' is evaluated by P28 as 'an evil way of putting it' because 'you can't live well with it', as 'it affects everyone's life […] dramatically'. P28 initiates a collaborative collection of alternative emotions experienced that challenge the 'living well' narrative:

P28 it's, frustration, it's annoying, upsetting, depressing, anything else?
P31 Anger.
P28 Anger, good game good game carry on yeah [laughter]
P30 Isolating?
P28 Yeah yeah, isolating, you are isolated.
P29 You are you are

Such a response reinforces arguments that by overly pushing the living well narrative, we 'risk sanitising negative experiences' of dementia that equally need to be acknowledged (Fletcher, 2019a: 2).

P28's discussion of how everyone's life is affected 'dramatically' touches on an unanticipated trend in distinguishing 'living with' from 'living well with'. A few carers argue that carers are 'the person living with dementia' because 'they have to adapt to that person's life' (P33). Distinguishing between living with/well, P14 tells us that 'I'm living with dementia but want my mum to live well with dementia', thus positioning carers as providing the support needed for people with dementia to 'live well'. This noticeably diverges from language guidelines which, following the preferences of their interviewees with dementia, suggest that it 'is usually not useful' to say that people without the condition are living with it, instead encouraging the term 'affected by dementia' to refer to both people with dementia and anyone close or who offers support, such as carers (Alzheimer's Society, 2018: 15). Regardless of the linguistic choice, a key point that emerges in carers' discussions here is the importance of others in supporting, rather than impeding, someone's ability to 'live well' with dementia (Bartlett *et al.*, 2017; Sabat, 2018). Notably, P13 suggests that 'living with dementia to me is, not being stimulated' while 'living well is', explicitly tying the ability to live well to a facilitative social environment. This carer perspective presents a more interdependent, environment-oriented approach compared to the more individualistic envisioning of 'living well' by people with dementia, a distinction that has also been observed regarding priorities for empowerment more broadly (van Corven *et al.*, 2021).

Clearly there are many competing interpretations of what life with dementia means, and some participants, such as P6, suggest that 'you would need both' 'living with' and 'living well with dementia', as they are each appropriate in 'certain contexts'. Other participants would argue the need for 'suffering' to also be included in the language used to discuss dementia. Throughout, participants' responses clearly support the need for a nuanced representation of dementia, 'rather than understanding it as a dichotomised experience of tragedy or living well' (McParland *et al.*, 2017: 83). Returning to the focus on the person within these discussions of life and suffering with dementia, P17 highlights another type of nuance that is rarely discussed, memorably distinguishing between being a person who *has/had* dementia versus a person (living/suffering) *with* dementia:

> I would say my Granddad has, slash had, dementia. I'm not sure about 'with', because. That implies to me that they've got like a little gremlin on their shoulder? And it's something they have to cope with? I don't know. Maybe, maybe some people are comfortable with that but. Suffer with or from, living with. It's like a, a burden, it's like a thing you have to have when actually. It's just you. You have it, you are, you know.

> […] it’s just like, I’m living with this thing and it’s, separate to me, I don't know that's kind of what that implies to me anyway. And it's not because it's your brain, and it’s you and. You're just changing.

P17 challenges the preposition ‘with’ in suffering/living with dementia discourses. She draws on metaphors of dementia as a travelling companion (here, a gremlin that sits on your shoulder) and a ‘burden’ (Van Gorp and Vercruysse, 2012) to argue that for her, ‘with’ envisions dementia as an additional ‘separate’ entity whose weight people must bear. P17 argues that this does not reflect that ‘actually. It’s just you’, explicitly situating dementia within the person and their body (‘it's your brain, and it’s you’). Subsequently, P17 promotes that dementia is something that you ‘have’, advocating for a metaphorical conceptualisation of dementia as something you possess, rather than as an accompanying entity that a person must bear for life. In this sense, the importance of dementia is reduced from the prominent description of what/who you spend your life ‘with’ (‘It’s almost like it makes you part of a couple or something it’s like, “oh here comes Bridget and her dementia”’: P19) to one of many conditions and attributes that you ‘have’ (thus conceptualising dementia as a possession, as ‘everyone has something don't, they’: P17). Although this stance only occurred in this particular focus group, it is reflective of a broader trend of people opting to say that they ‘have dementia’ (Bailey, 2020). Of course, other participants share P17’s emphasis that dementia is one of many problems, albeit through different language choices. Notably, PN advocates for greater coverage of ‘Life. as a person living with a problem’, using ‘living with’ interchangeably with the possessive ‘have’ to make a similar point that ‘most people have more than one problem’.

8.2.2 Life as a battle with dementia

It is worth attending to P17’s choice of ‘a little gremlin on their shoulder’ more closely. A gremlin is widely associated with being an antagonistic character that causes problems for others, and elsewhere P17 again personifies dementia, this time as comparable to an abductor/thief: ‘it kind of takes people away’. P17 is not alone in drawing on the metaphorical envisioning of dementia as a harm-causing adversary. Elsewhere, P28 positions dementia as a malevolent, imprisoning force: ‘there’s another person in there, that’s fighting, frustrated, trying to get out, but can’t get out. And it’s not her fault, it’s not, it’s not. You don’t ask for it, you wouldn’t wish it on anyone. It’s evil, it is, it’s evil.’ Invasion metaphors that position dementia as a combative ‘evil’ enemy force, alien invader or predatory thief are widespread socially (George and Whitehouse, 2014; Johnstone, 2013; Van Gorp and Vercruysse, 2012), and, as with P28’s description, are often fatalistic and nihilistic, with no way out for people with dementia.

Although here P28 uses the metaphor to alleviate blame from his partner with dementia who cannot escape the imprisonment of dementia despite her 'fighting', elsewhere, the expectation for people to fight and 'stave […] off' dementia (P11) can stigmatise alternative ways of coping. This is exemplified by P14's comment, 'are you going to give into this thing and be a dementia sufferer or, you know, live with it', whereby the only acceptable route is for people to resist, which is not always attainable, especially for people with comorbidities (Lane *et al.*, 2013). More specifically, P26 suggests that 'you can fight dementia' through 'food' and 'your attitude', reproducing discourses of self-responsibility for preventative/mitigative responses to dementia in order to attribute agency to the individual to 'fight', which simultaneously conveys 'a moral identity' for how individuals should behave (Lawless *et al.*, 2018: 1547). Resisting this discourse, P6 describes this fight as unrealistic as 'you're not going to beat the dementia itself of course'. Notably, P33 distinguishes between the notions of 'fighting' and 'beating', arguing that 'you're not gonna beat it but yeah you can fight it'. It is therefore the day-to-day battles and small successes that matter here, not the overall victory, mirroring Castaño's (2020) findings for bloggers with early-onset dementia, who draw agency from a 'fighter' identity, despite simultaneously acknowledging that, ultimately, theirs is an unwinnable battle.

The social prevalence of combative metaphors makes it significant that in this research project, relatively few participants explicitly discuss dementia through these metaphors or even use them at all other than in response to my stimuli. Notably, PK presents an unconventional use of the alien invader metaphor, which supports a humorous shared understanding of the experience of dementia with his vicar. Elsewhere, a *Star Trek* alien's invasion of a character's body has been used to position having dementia as meaning that 'my body will have been taken over by another being with a disturbing but illusory resemblance to my former self' (Davis 2007: 61). This utilises the metaphor to reinforce loss of self, clearly attributed to mental capacities since the body remains. For PK, the same metaphor, also initiated by his vicar watching an alien invader *Star Trek* episode, is instead used to facilitate a representation of dementia that is grounded in the actual lived experience of the person with dementia, as, like the person taken over by the alien, 'you know things, you want to do something. You know things coming on, er go going on, but you can't do anything about it, and that is, can be what it's really like'. When the vicar asks PK 'how's the alien?' it makes him 'smile' and 'takes all the tension out of (what) might have been your mind because of? The Alzheimer's'. Rather than being helpless against the invader, which is a frequent consequence of military metaphors (Lane *et al.*, 2013), PK presents his Alzheimer's as a separate but accompanying entity that he has a two-way relationship with, as 'you've got to work with it'. He positions figures in his life, here the vicar, as allies who have the ability to alleviate 'all the tension' triggered by socially interacting with Alzheimer's disease, again highlighting the reactions of others as integral to a person's experience with dementia.

Similarly, while the media have been shown to establish dementia as ‘our biggest killer’ in response to changing regulations surrounding death certificates (Brookes *et al.*, 2018), participants challenge this sensationalist representation of dementia (see Figure 8.2 for the stimulus). The participants consistently position it as ‘misleading’ and ‘negative’ (PN), likening it to a ‘horror story’ rather than being ‘factual’ as dementia ‘doesn't actually kill you’ (P11). P19 emphasises its distance from everyday reality, telling us that ‘I don't think carers go in, in the morning and think like “oh here we go, dealing with the nation's biggest killer” [laughter]’. Even the biggest advocate of the term, P33, says that ‘it is a killer but it just brings death, sooner’, acknowledging that there are comorbidities ‘underlying’ death with dementia. Multiple participants link the term’s use on the charity envelope to a financial motive (‘it's obviously meaning, come on [rubs fingers together] we want we want your money’: P11), with PN highlighting the consequences of this language for ‘mental health’, since seeing something like this could make someone feel ‘awful about themselves’. As Peel (2014) found when comparing carer and media discourse, people affected by dementia here do not tend to reproduce hyperbolic media metaphors such as ‘biggest killer’, although it is evident above and below that combative metaphors still play a role in people’s utterances.

Figure 8.2 ***Section of an Alzheimer's Society envelope shown to participants***

Will you advance research to beat the UK’s biggest killer?

Moving beyond hyperbolic metaphors, it is worth further considering how participants use and extend combative metaphors in their representations of life with dementia. Numerous participants express a sense of and a need to fight, but the conditions and motivations of these fights vary. Taken together, these provide a more nuanced insight into the multiplicity of battle metaphors in relation to dementia. Firstly, some participants take a macro approach to fighting dementia as a society, for the benefit of others rather than themselves:

P16 I don’t know whether [a treatment/cure] will come or well it certainly won’t come to help, my wife, and such like

P14 Or my husband

P16 But, we've got to keep fighting for it

PG Yeah

This group explores the need to 'keep fighting' for a cause that is bigger than them, touching on the imperative to maintain faith in, and support for, future success, here in relation to a cure or treatment (see section 6.3). P33 extends the usual emphasis on a cure to include good care within the fight metaphor: 'it carries on when I've gone, the fight must carry on. You know. But it's not just the fight for the cure it's the fight, to help, the people 'til they get the cure'. Yet participants also articulate this fight in terms of individual battles, either against dementia or social structures. P33 reconceptualises the meaning of success when battling dementia, arguing that: 'It's a battle. Some you win, some you don't. […] [My wife] didn't win. I didn't win in that respect but, I've gained more. In myself'. That personal growth becomes a 'win' from experiencing dementia reflects that 'in some cases, our greatest leaps in personal growth occur when we are confronted with challenges of great magnitude' (Sabat, 2018: 134), which presents an alternative form of winning to the more familiar but less attainable goal of treating or curing dementia (Kenigsberg *et al.*, 2016).

Offering an alternative to fighting dementia altogether, some participants instead foreground their fight against a system and society that does not understand or provide what people affected by dementia need. P29, P26 and P11 talk about the 'fight' for benefits and support for people with dementia and their families, indicating a struggle for sufficient financial, medical and social care, while P29 further discusses battling against the preconception that dementia is 'about the old people', telling us that 'I go to meetings at work and I'm constantly fighting, against it, and it's like, it's like deaf ears'. Here, the perpetual battle is against misunderstanding, not dementia, demonstrating the variety of uses of combative metaphors in a dementia context beyond the primarily disease-oriented ones perpetuated by the media (Bailey *et al.*, 2021; Lane *et al.*, 2013). Reinforcing previous findings of both individual and collective fighter identities (Castaño, 2020), here battles can occur at both levels, and adversaries include not only dementia but wider society and social structures in need of change.

Having said this, fighting is not a useful metaphor for everyone. P6 dismisses it as 'army sort of language', also suggesting that 'it's not defeating the dementia is it it's more defeating the erm, say the stigma, or the implications, erm overcome would be better wouldn't it, overcome.' Similarly to above, P6 presents the social treatment of dementia as needing to be fought, but goes a step further than changing the enemy (here to 'stigma') by also exchanging the metaphor 'fight' for the less combative 'overcome'. Other participants also suggest 'better' alternatives to the combative metaphor. PN tells me that fighting dementia is:

> not part of the general public's life is it? It's part of the scientist's life, it's part of research life, it's part of medical life. but does it touch the general public? No, they want to live with it, don't they? They want to, learn how to survive with it. I think survive with dementia might be better.

Here, the sense of separation from researchers and medical staff previously expressed in section 6.4 is conveyed through keeping these spheres apart as distinct semantic categories, and metaphorically, through creating spatial distance, since the researchers and medical practitioners' fight does not 'touch' the public's experience of dementia. Subsequently, PN emphasises that it is learning survival skills for life with dementia that becomes important, as people cannot fight off dementia, but can 'learn' to adapt to a life that includes it. Personal development through learning, with the aim of enduring a progressive long-term condition, becomes the more meaningful goal for the individual than a collective 'fight' against a condition that is 'with' them for the rest of their life. Likewise, P13 tells us that 'You can't really can you, fight, fighting dementia is, doing the best you can. Er. While you can. [...] You #cope with it'.

Coping, overcoming and surviving are striking alternatives to combative metaphors. The verbs are united by the act of prevailing in the face of adversity, thus providing agency and hope for individuals much like combative metaphors, but without the emphasis on violence and adversaries. Dementia is positioned here as a source of adversity and challenge but is not personified as an animate enemy. The focus therefore remains on the people experiencing dementia, providing greater space for promoting change and adaptation as people assimilate the impact of dementia into their lives (Hillman *et al.*, 2018: 880), rather than the loss and deterioration that combative metaphors implicitly foreground through their winning/losing dichotomy for something that individuals cannot beat (Lane *et al.*, 2013). Presenting these alternatives to people affected by dementia in future research would provide valuable insight into the potential of such linguistic choices beyond these individuals since, as has already been established here, responses to the same word or metaphor are deeply personal (Gerritsen *et al.*, 2018).

8.2.3 Life as a journey with dementia

Another metaphor that emerges from participants' responses is that life, here with dementia, is a journey. Existing research indicates that this metaphor is a popular means of envisioning dementia in the written works of people with dementia (Castaño, 2020; Zimmermann, 2017) as well as for life and illness more broadly (Lakoff and Johnson, 1980; Semino *et al.*, 2017). Much like the combative metaphors, it is not useful for everybody (Gerritsen *et al.*, 2018). Since this metaphor was not a stimulus, it is worth noting that only people who reproduce the metaphor can be discussed here, necessarily excluding those who do not align with it.

About a tenth of participants explicitly situate life with dementia as a journey. As your dementia progresses, you are seen as moving ‘further along’ and ‘deeper into the journey’ (P7, PN). These do not have to be solitary travels; PF tells me that ‘you’re taking this journey together’, and P26 similarly reflects on ‘the friends you’ve made along the journey’, indicating a sense of community and togetherness within their dementia journeys that is elsewhere expressed by talking of other people affected by dementia as ‘fellow travellers’ (Castaño, 2020: 125). When asked why she uses the journey metaphor, PN explains that: ‘the course of the disease is a bit boring and a bit sort of err, negative [...] Whereas a journey means it can be, good or bad can’t it and it explains my journey, it explains how I'm dealing with the disease.’ Here, the journey metaphor is presented as more interesting and less imbued with ‘negative’ associations of decline than the medical equivalent PN provides (‘course of the disease’). It is worth noting that ‘course’ itself has metaphorical roots in the journey metaphor, which exemplifies how metaphors can become normalised within speech (Lakoff and Johnson, 1980). PN notes the flexibility of the journey source domain, as a journey can be good or bad, and is uniquely personal to the individual — ’my journey’ will be different to yours, in a way that a fight may not, as there are expected tactics and behaviours in a fight, such as obeying commands from superiors (Lane *et al.*, 2013). In contrast, there are many ways to ‘deal’ with dementia in your ‘journey’, which also has many routes and destinations, contrasting the win, lose or draw outcomes of a fight.

Previous studies have emphasised the potentially disturbing fact that a person with dementia cannot return to a life without dementia, making this a ‘one-way’ ‘journey of no return’ (Castaño, 2020; Zimmermann, 2017). This is acknowledged in one focus group, who discuss that:

PK But also there’s, there’s, the concept from the media I think is, or the thing that it points you in. there’s only one direction. #And to some extent# that’s true.
Emma #What’s the direction?#
PK It’s a terminal disease. You’re only going to go in one way. But you’re not going to go in one way, in a straight line.
P25 Yeah but we’re all going in that same direction generally
PK Yeah
PM Yeah, even if you’re well [laughs]

What sets this discussion apart is the alignment of the unidirectionality of the dementia journey with the life journey in general, as indeed, we all share the same destination of death, irrespective of the conditions we experience beforehand. The tension between being powerless to stop dementia's progression while having agency over your experience is evident in PK's later comment that: 'It is what it is, you know, you can't alter it. Or you can. But you can't change the direction you're going in so you've gotta live with it'. Here, building on PK's earlier envisioning of the dementia journey as going ultimately in 'one direction' but not 'in a straight line', PK indicates that you can 'alter' your path even as you still move in the same overall direction.

8.3 Representing dementia: evaluations and recommendations

Throughout this study, participants reproduce, challenge and change existing dementia discourses, within which they explicitly evaluate visual and linguistic representations. This final analysis section gives space to some key reflections and suggestions made by participants regarding dementia representations. The section begins by considering different discourses and audiences, before moving onto participants' evaluation of the media and its role. This leads onto three key recommendations for how to represent dementia in a way that better aligns with the perspectives and experiences of people affected. These recommendations have been compiled from participants' contributions throughout this and preceding chapters, particularly their critiques and suggestions for change. Within this are examples of how participants have altered existing stimuli and suggested alternative portrayals, which demonstrate the creative potential of working with people affected by dementia. Since these contributions generally emerged spontaneously through conversation, the voices of certain participants, particularly people without dementia, are overrepresented in this section, as the input of people who did not explicitly discuss these topics is unknown. Supplementing this multi-participant section, readers are directed to Jackie's discussion of the media in section 4.3.2, which is highly pertinent to the issues discussed here.

Within participants' contributions is a tension between living well and tragedy discourses. Many participants stress the importance of considering the intended audience for representations, as 'it depends who it's aimed at' (P9). Thus, the daughter of someone recently diagnosed critiques the decline and loss-oriented images (Figure 7.2), arguing that her mother would not like photographs that suggest 'she'd have bits of her brain missing' as 'it's not a positive message to a person with dementia. still at the early stages', since it can lead them to think 'is that what's going to happen to me' (P15). This echoes the initial fears discussed in section 7.2, reinforcing that tragedy-oriented discourses exacerbate fear and insecurity about a person's future with dementia (Bryden, 2016; Górska *et al.*, 2018; Zeilig, 2014a). In contrast, a focus group of Memory Café volunteers discuss their internal conflict from feeling that the living well discourse they publicly uphold does not reflect lived reality:

P8 Mm. It’s a very hard one because I'm like having like P7 had a parent and experienced dementia from that angle. But also be concerned to promote the Dementia Friends message and our philosophy for the Memory Café that is a bit of a push pull kind of thing [group agreement], you know, because it is really important that we’re positive and there's a lovely environment, and supportive, but, you know, I mean, we know it's brutal and, and that's, you know, the reality, so I'm kind of, conflicted at times [group agreement]

P7 Me too, me too

P8 I feel like putting on different hats [...] You know, because we're giving a different face to them.

P10 Yeah, I completely agree. Because you know the push is very much about living well with dementia isn't it [group agreement] and that's great. But the reality is so [laughs] very different [group agreement]. And the gritty day to day stuff that carers go through is a nightmare for most people.

Here, the living well discourse is consistently positioned as ideological (as a ‘message’ and ‘philosophy’), and as something that, being representatives of the initiative, they should ‘promote’, while the ‘brutal’ side of living with dementia is portrayed as ‘the reality’ that ‘we know’ through personal experience with their own loved ones with dementia. Their identities as volunteers that represent the Dementia Friends initiative are positioned at odds with their personal ideas regarding dementia’s ‘reality’, necessitating the repression of the latter through wearing ‘different hats’ and showing group attendees ‘a different face’. The underlying reference to changing guises is indicative of their sense of deception, where they purposefully change their portrayal, much like an actor, in order to adapt their ‘message’ to the situation and audience. Underlying this exchange appears to be a desire to be able to acknowledge both the ‘positive’ and ‘brutal’ facets of dementia, reinforcing previous discussions of balancing positive and negative aspects (section 5.2).

Although it is acknowledged that consumers do hold some responsibility to ‘challenge’ and ‘find out a bit more’ by reading multiple sources (PK), participants overwhelmingly recognise the media as a powerful influence on social understandings and attitudes towards dementia. P16’s stance, that ‘it’s the way it’s portrayed obviously. But you do need to keep it in the news’, appears to be widely supported, with people acknowledging the importance of media coverage but wanting to alter how dementia is portrayed, due to what they currently evaluate as the ‘wrong publicity’ (P22). Criticisms of current social representations include that the media ‘sensationalise’ (P7, P25), and ‘generalise’ (PK). This contributes to a ‘general, erm, perception [...] that everybody’s the same’ (PK), whether regarding age (‘watching the news and that you just assume that dementia’s an old person’s’:

P28), tone (‘when the media look at it it’s all quite very like low and, solemn, you know’: P21), or type of dementia (PK suggests that charities and the media often ‘push people’ towards a certain set of ‘symptoms’ for dementia, citing a popular Alzheimer’s Society booklet that foregrounds just ‘five, symptoms of dementia’).

Occasionally, the media are praised for an increasing level of nuance. PM advocates that ‘papers do, are trying their best, to highlight dementia, and the difference between dementia and Alzheimer’s’, subsequently initiating an exchange about social progress:

PM when I was growing up, […] they didn’t seem to know much about it, about what, the differences were, you were just put in a box and that were it #you know#
PK #You’re still# put in a box #as well#
PL #You were# labelled in other words
PK Yes
PM I don’t think you are as much – I think people are more aware now
PL Yes
PM Of the different types of dementia, and the fact that you don’t wake up one morning and you’ve got dementia. It comes and-
PK -it’s going in the right direction yeah
PL It is

Returning to the journey metaphor, social understandings are presented as moving ‘in the right direction’ towards greater awareness and less labelling, although PK counters that people with dementia remain a homogenised social group in the public imagination. Elsewhere, participants reflect on how perpetuating a ‘victim mentality’ through the media ‘means that people are scared to get diagnosed’ due to ‘stigma’ (P8), as dementia is seen as ‘dirty’ (P10). Such stigma is widely recognised as a pressing social issue (Alzheimer’s Disease International, 2012). Overall, despite recognising improvements in social representations and understandings, and acknowledging that the media are ultimately ‘trying to sell’ a product, so ‘you can’t blame them for that that’s their business isn’t it’ (P6), participants firmly express a need for media portrayals to develop further. Their suggestions can be divided into three key areas: 1) normalise dementia; 2) provide more nuanced representations; and 3) expand the attribution of value and notions of personhood to support better advocacy for people with dementia.

Firstly, participants emphasise that dementia needs to be normalised and familiarised for the public, in order to help people to connect with the issue and better integrate life with dementia into wider society. P16 highlights that people invest time, energy and money into ‘causes that they think [are] going to affect them’, acknowledging that the same applies to us all, since although people affected by dementia are very familiar with it, ‘we might know nothing about something else, another disease or whatever’. He thus advocates ‘getting the message across, that it will affect you in your lifetime or one of the members of your family or someone and er. Let’s try and do something about it, while we can’. P16’s attempt to expand the group of people invested in dementia is reflected in his pronoun shift from the generic second person ‘you’, which is more individualistic, to a collective ‘we’, by directly relating dementia to people’s lives. Similarly, P8 shares that ‘everybody is going to be affected by dementia in some way, they'll know somebody. […] So it's kind of normalising it in a way that's, you know, the press should play a powerful role in that’. Dementia’s increasing prevalence thus becomes a way to help reach out to more people who may not otherwise engage with the topic, for which the press is positioned as a ‘powerful’ institution through which dementia can and ‘should’ be normalised.

To normalise, rather than ‘sensationalise’ dementia (P7), participants advocate for better accuracy and normality through providing ‘more facts’ (P15) and ‘telling people, carers. What’s available’ in terms of support and activities (P13). This situates life with dementia within daily routines and broader support structures, as well as providing tangible help for people affected by dementia. Similarly, P28 declares that ‘they’ve just got to put a truer story out there, that reflects what’s happening, on the day to day challenges, of the carer, and, the person that’s affected with the dementia’, so that ‘people would understand it a little bit more, and they may be more, sympathetic, when they see you’. Mirroring Jackie’s call to foreground individuals’ experiences with dementia in section 4.3.2, normalising dementia through providing ‘truer’ person-oriented accounts of daily life and challenges is explicitly linked to improving public understandings, and subsequently interactions with people affected by dementia.

More broadly, participants encourage ‘toning things down’ in terms of ‘telling the story a bit more objectively’ (P7) in social representations. Bringing it back to this chapter’s earlier discussion of language, P9 suggests ‘keeping it just the living with dementia’, thus favouring the midpoint between living well, suffering and biomedical discourses for media representations, rather than extremes. Attending to ‘how, visually, dementia is presented’, P19 ‘would really like to see a move away from the clinical, medical, stuff’, suggesting that:

> It needs to be warmer, […] more familiar and I think stop being. this sort of cold, er, clinical doctor's waiting room thing and actually more of a, a story, more personal more approachable and. within that, then also be truthful so there are those positives and negatives and I think that's the pendulum and it’s sort of swinging between the

> two making sure you have a balance of, the two but certainly that is honest. […] Something that's a little more. familiar I think, would be good.

Again, P19 promotes shifting emphasis from the ‘cold’ ‘clinical’ side of dementia to the ‘warmer’ ‘personal’ side of life with dementia, in which you ‘balance’ the more positive and negative extremes. The latter is twice presented as being ‘more familiar’, which is evaluated as ‘good’ and ‘more approachable’. In sum, participants’ first recommendation is that dementia needs to be made more familiar and relatable for people, which can be achieved through providing a more balanced and person-oriented account of life with the condition.

Secondly, building on the discussion in Chapter 5, participants advocate for greater nuance when representing dementia, in order to reflect that people can have any experience and type of dementia, at any age and at any stage, and that while dementia is more than simply memory loss, life with dementia is far more than just the condition. P3, after asking other group members to draw on ‘your experiences’ to suggest ‘how do you think it should be portrayed’ and ‘illustrated in the media’, summarises people’s responses to emphasise the importance of considering both ‘the happy side’ and ‘when things are bad, when things are tough’ in portrayals. This overlaps with arguments for balance in the first suggestion of normalisation, but equally applies to discussions of nuance since representations need to provide space for a range of experiences of dementia. For instance, P21, reflecting on media representations, suggests that ‘I don’t think it highlights, the fun that people can have with – not because of their dementia but what is available to them’. Promoting a consideration of what life with dementia means beyond the condition itself, this account situates people’s experience of dementia within their opportunities and engagement with wider society, acknowledging the importance of social structures and responses to people’s experience of dementia. Such a point engages, albeit implicitly, with calls to consider the rights and social wellbeing of people with dementia (Bartlett and O’Connor, 2010; Cahill, 2018; Sabat, 2018), moving beyond the typical biomedical focus attributed to media (Bailey *et al.*, 2021). There is a need for emotional and personal nuance, but also for framing life with dementia as being rooted in a range of structural and social, as well as biomedical spheres.

Many participants also promote providing a more nuanced account of who can have dementia, rather than conflating a person with dementia with older age and particular stages and types. Some older people with earlier and mid dementia suggest that ‘the media, have concentrated too far up the line’ on ‘the later stages of dementia’, which can exacerbate ‘ignorance’, whereby people ‘say well you seem to be doing ok, when you’re not’ (PK). In contrast, carers of people with advanced younger onset dementia argue that when people with dementia feature on media, it’s people with ‘the earlier stage and it’s only just been diagnosed’, leading people to think ‘that’s what dementia is', when the reality is far more diverse. It is therefore important to represent every stage of dementia, rather than concentrating on extremes (McParland *et al*., 2017). Similarly, P6 raises the issue that many people have Alzheimer's 'stuck in their head' when they think of dementia, and that different types of dementia are conflated, creating 'false beliefs' such as there being drugs available, when this is not the case for all dementia types. She therefore upholds that 'we just need to be a bit sort of broader I think in understanding the different types'.

Extending the common metaphor of dementia being an umbrella term for a range of different conditions, P29 asserts that 'in the media [...] they need to look at it as an umbrella of people who, unfortunately have this disease dementia [...] instead of portraying it as an older person's disease'. Here, diverse individuals are incorporated within the dementia umbrella, as well as types. P29 hopes that then people will realise that 'actually there's no age attached to anything, and then we can start tackling and dividing resources, as individuals'. Again, the participants associate improved understandings of who can have dementia and what life with dementia involves with improved outcomes for people affected. Here, it is that resources can be allocated on a more individual basis rather than concentrating on older people with dementia, as the working-age dementia group consistently demonstrate how this often results in their exclusion from care and support because of their age. The group subsequently adapt images 10 and 11 (Figure 7.2) as examples of how to achieve better awareness, changing 10 to show 'one young and one old' person, and foregrounding what they celebrate in 11, that 'there's no age', through adding 'wording' such as 'Dementia can affect any age' (P28, P30).

Throughout, participants promote the need to expand what it means to have dementia. This includes challenging the focus on declining memory, with P30 declaring, 'media wise don't portray everything as being memory because it's not memory'. Simultaneously, participants provide a more nuanced account of memory than is popularly represented. In two different groups, the analogy of bookshelves is linked to an account of changes to memory with dementia. In one group, a carer recollects how the Alzheimer's Society explained dementia on a course, summarising it as: 'it's like a bookshelf and you've got books falling off the shelves you might get one or two just leaning a bit and as it, progresses, the books start tumbling off and end up with an almost empty bookshelf' (P21). Symbolising memory and knowledge through books, P21 presents a fairly typical, linear account of progressive memory loss here, with a steadily increasing loss of books until the bookshelf (brain) is 'almost empty'. Yet in the other group, the bookshelf analogy instead foregrounds a state of flux, as in section 7.3, when participants challenge the representation of dementia as a linear progression:

P17 sometimes it's not there, sometimes it is there and I'm sure that there are, some parts that aren't but like different kind of ways to get to those memories can help as well so?

P19 It's more like bookshelves, or something [group agreement]. You know, sort of sometimes, it's on the shelf, other times it's, it's out.

P17 Yeah exactly

P18 Or they've misplaced it and put on another bookshelf.

P17 Yeah, it's been miscatalogued [laughs]

Situating books as being sometimes 'on the shelf' and sometimes 'out' or 'miscatalogued' adapts P21's linear account of books falling off to allow for more transient changes. Rather than emphasising what is lost, this foregrounds how changes to the organising system can create unpredictable shifts in what memories a person can access at a particular time. Viewing memories as inaccessible rather than necessarily gone facilitates focusing on various 'ways to get to those memories' that can help recall. This broadens the discussion surrounding dementia from a linear loss to flux, whereby the latter both provides more nuance and enables strategies to help cope with the challenges of changes to memory. Reflecting a widespread association between music and memory (Rahman, 2015), P26 reinforces the latter model of memory in her anecdote that when a researcher interviewing her mother about her wedding day played her meaningful songs, 'the response was amazing. She could remember so much more about her wedding day'. Much as dementia affects more than memory, changes to memory are more than a linear loss. Dementia representations therefore need to better highlight the diversity within dementia as an umbrella term, not only regarding types but also people and their experiences.

Building on a more nuanced notion of dementia and memory, the third suggestion is to expand understandings of personhood and attributions of value in order to better support advocacy for people with dementia. When discussing media portrayals, participants emphasise the need to acknowledge that someone with dementia is 'still the same person' (P23), even if 'certain traits that happen aren't there' (P21), thus problematising the hegemonic conflation of cognitive abilities with an individual's value and personhood (Post, 2000a; Van Gorp and Vercruysse, 2012). Rather than images that perpetuate discourses of a loss of self, one group propose the following:

P19 it could be a quite an evocative picture. To have almost like a family photo, just sort of going with the typical sort of having an older woman for instance, then a thirty-year-old woman and a little girl and the implication being that, […] that's all going on in there because actually you. You see all those different layers er, sort of. Er. And there's no order to it, it sort of it flits between, each one […to] Promote the sort of idea of the […] layered individual

[…]

P18 And I guess before this sort of like, as individuals we are the make-up of whatever experiences. We've #had. But we don't.#

P17 #We are the sum of our experiences#

P18 But we don't separate them out

P17 Yeah

P18 But for them. It's like they're the sum of their experiences. But they like, but those experiences have now like sort of detached from one another.

This image of the same person at multiple points of their life promotes the concept of a 'layered individual', which becomes more fragmented and fluid with dementia. Such an image recognises that people with dementia can 'flit' between present and past selves, positioning the self as a temporal culmination of a person's life that can vary from one moment to the next. This has parallels with Sabat's (2002, 2018) theory of selfhood whereby a person's 'I/my' expression (self 1) remains constant as their attributes and social personae change (selves 2 and 3). Since memories of experiences can be held in the mind or the body (Kontos, 2003), this image has the potential to recognise a more holistic version of personhood than the hypercognitive model (Post, 2000a). This image thus exemplifies how, through being led by people affected by dementia, metaphorical visual portrayals could be expanded beyond loss-oriented ones (Figure 7.2) to better value and support the personhood and identities of people with dementia.

Relatedly, participants raise the issue of expertise and voice within media representations. People highlight the responsibility of the media 'to question themselves' and their notions of expertise, which tends to 'come from a specialist', so that they become 'less tunnel visioned' (PK). This aligns with the recognition in Chapter 6 that medical specialists are not the only experts, and that people with dementia (and carers) must be valued as experts by experience (Parveen *et al.*, 2018), not only in research and medical interactions but in the media, where the voices of people with dementia are still lacking (Bailey, 2019). As Jackie emphasises in Chapter 4, through utilising the media, people with dementia can show the public that 'we aren't to be feared' (PN), thus better advocating for people with and otherwise affected by dementia, while simultaneously bringing greater normalisation and nuance regarding dementia through sharing their perspectives and concerns.

Evidently, there is a collective will amongst participants to re-appropriate what it means to live with dementia through altering media portrayals (Hillman *et al.*, 2018: 884). Within this, it is important to acknowledge what semiotic modes (e.g., language, image, audio, gesture) are used to represent dementia in order to achieve the above suggestions. Each semiotic mode contains its own available semiotic resources to communicate meaning; for instance, an image includes the resources of colour, focus and the spatial organisation of elements, each of which communicate meaning, in a way that language does not. Notably, some participants critique the ability of images and written text to represent dementia, advocating for something more dynamic as a means of promoting a more multifaceted, nuanced understanding. While other focus groups praise the ability of video to provide a less 'startling' account of progressive dementia compared to the images in Figure 7.2 (P7), the following discussion offers the most explicit discussion of semiotic modes:

> P12 I think it's got to be. Some sort of interaction with a person with dementia or a film or a programme involving someone with dementia. Because then I think it comes over, erm, the variety of it all, and the effect on the people. I don't think anything like this [gestures to pictures] can ever. Convey what actually happens you know and the effect on that person
>
> P13 No. Got to be more physical hasn't it.
>
> P12 Yeah

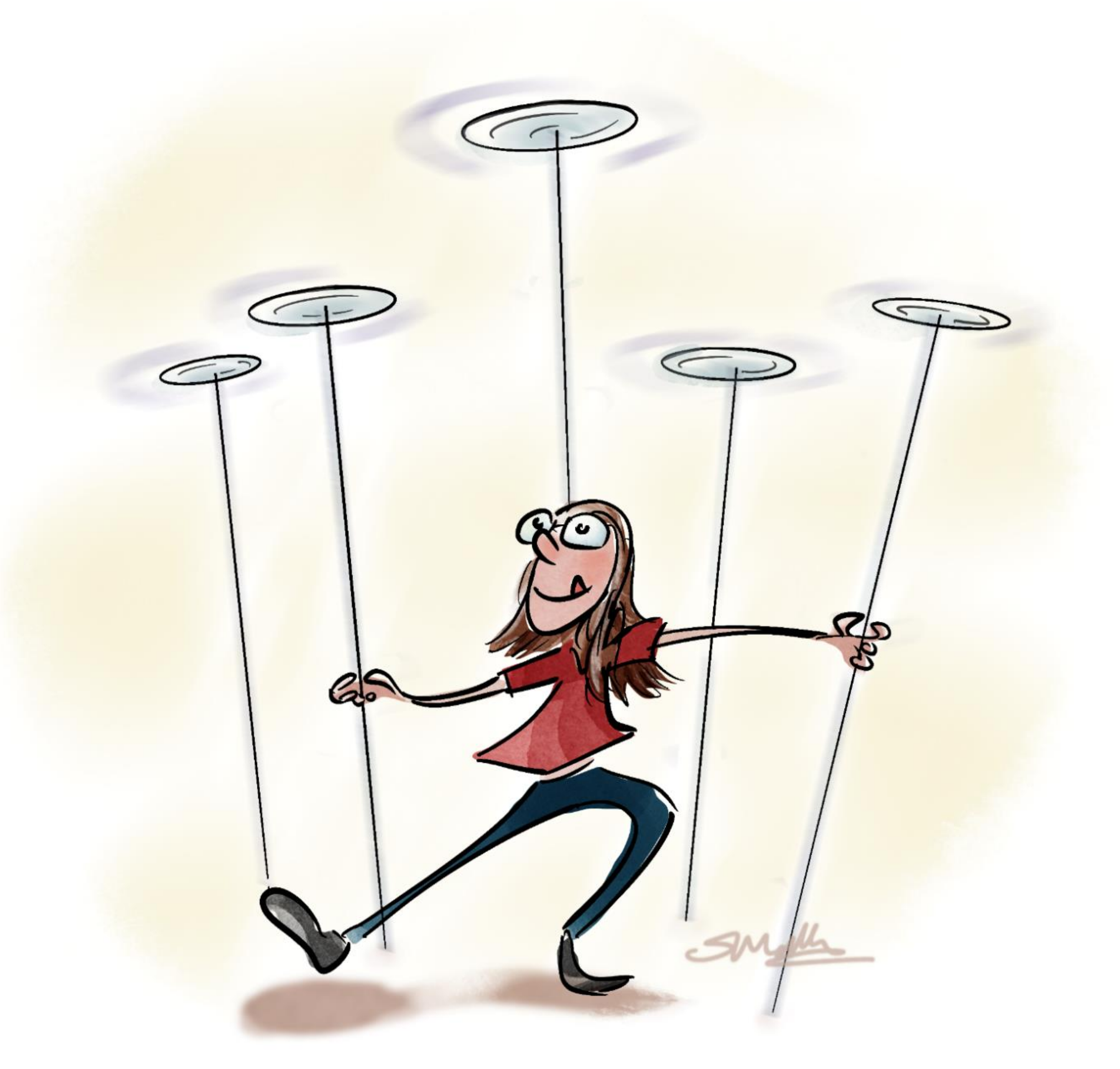
Ultimately, a static picture cannot 'convey' dementia. Nor can a newspaper article or charity blog post. It is an extended 'interaction', whether in real life or captured in a film/programme, that is necessary in order to communicate 'the variety of it all, and the effect' of dementia on people, as well as the fact that dementia is 'a process' (P12, P13). While images and language provide a valuable insight and route into influencing perceptions (Brookes *et al.*, 2018), what P12 and P13 highlight is the need to carefully select an appropriate means through which to communicate the ideas expressed here. On a small scale, the nuance and diversity that participants recommend is indeed better suited to a more expansive multimodal medium, such as film or personal interaction. Ultimately, though, all relevant avenues for communication ought to be considered, since it is the overall discourses that they collectively reproduce, reinforce or challenge that shape our understandings of dementia.

8.4 Summary

This chapter concludes my analysis by attending to how participants differently represent life with dementia through language. Overall, participants indicate a need to acknowledge suffering with dementia without reducing people with dementia to sufferers. Whereas people with dementia more often identify with and are inspired by an individual approach to 'living well' as an empowering concept, carers might focus more on relational and environmental factors in supporting people with dementia to live well. Many participants, notably those without dementia, position 'living well' as unrealistic, and thus as providing damaging expectations, which reiterates existing criticisms of the discourse (Beard *et al.*, 2009b; Hillman *et al.*, 2018; McParland *et al.*, 2017).

Popular and more idiosyncratic metaphors are also examined as a means of expressing complex and intangible experiences with dementia. Here, battle metaphors incorporate personal growth and more socially oriented battles, expanding the existing focus on primarily biomedical applications of this metaphor (Bailey, 2019; Lane *et al.*, 2013). Participants' individual engagements with both literal and metaphorical language showcase the personal, creative nature of linguistic representations, demonstrating that the language of people affected by dementia is a rich source of alternatives to, and adaptations of, dominant discourses.

Finally, bringing together key analysis threads, this chapter explores how participants evaluate popular discourses and ways of representing dementia. Within this, three key recommendations are established. First, make dementia more familiar and relatable for people through providing a more balanced and person-oriented account of life with the condition. Second, provide more nuanced representations that acknowledge the diversity of subtypes, people and experiences in relation to dementia. Third, better value people with dementia, who need to be recognised not only as fellow persons but as experts through their experiences with dementia. These recommendations build upon the overarching concerns with diversity, multiplicity and better supporting people affected by dementia that have been expressed throughout the analysis. The application of these recommendations will be considered further in the concluding chapter in relation to news values, within a broader discussion of the implications of this study's findings and avenues of future research.



‘It is hard to get a balance […] it’s that tension of, you don't want to be all doom and gloom all the time and pessimistic about stuff because people do have to get on with life but, but at the same time, you know, if you're painting it as all roses then that's not helpful either’

- Participant 10

Chapter 9: Concluding discussion

9.1 Introduction

In a society that consistently stigmatises and misperceives dementia (Nguyen and Li, 2020), it is vital that we attend to the role of popular representations in perpetuating and challenging current understandings in collaboration with people who are affected by dementia. Accordingly, the present study conducted seven interviews and eight focus groups with 51 people who were affected by dementia, either through lived experience, or as a carer or loved one, to explore the following research question, which is subdivided into three parts:

> How do people with experience of dementia (either lived or as a carer/loved one) situate themselves within popular discourses for dementia?
>
> a. How do participants represent dementia for themselves and others?
> b. How do people respond to visual and verbal representations?
> c. Do participants' responses reproduce or challenge prevalent discourses?

The current chapter addresses these research questions through outlining and reviewing key findings in relation to the wider literature in section 9.2. The first sub-question is examined in two parts — how participants represent dementia, and how participants represent people with dementia and those around them — to enable a nuanced discussion that reflects the distinction between these two interrelated topics. The key findings regarding responses to visual and written stimuli are then discussed, and throughout these three sections, I explore how participants reproduce and challenge prevalent discourses. Building on key findings, section 9.3 addresses this study's implications for academia, non-profit organisations, media institutions and the wider community. In particular, I build on participants' recommendations for how to improve dementia representations by considering some important factors for implementing these changes. This chapter then shifts its focus to evaluate the study's limitations (section 9.4), and point to promising directions for future research (section 9.5).

9.2 Key findings

9.2.1 Participants' representations of what dementia means

Participants' accounts corroborate that there remains a divide between the nuance and multiplicity of people's dementia experiences (Hillman *et al.*, 2018; Hulko, 2009) and society's simplistic, overly stigmatising portrayals of the condition (Alzheimer Europe, 2013; Low and Purwaningrum, 2020). Analysis furthers existing research into how people affected by dementia integrate multiple discourses to present their personal understandings of dementia, which may mirror, distort or counter hegemonic discourses (Beard, 2016; Fletcher, 2020b). The subsequent sub-sections summarise participants' representations of people affected by dementia and their varied responses to visual and verbal manifestations of dementia-related discourses, while section 9.3.2 examines the potential applications of participants' recommendations in greater depth. Here, I attend to how participants represent what dementia itself means. Specifically, I consider different ways of explaining an invisible, internal process, how dementia is conceptualised as a multi-faceted condition and experience, and how participants situate dementia in relation to different discourses.

When discussing dementia, participants consistently emphasise that it is an umbrella term for a range of different conditions, potentially making its plural, 'dementias' (P19), more apt. Particularly in Chapter 5, participants emphasise the reality of 'the diverse face of dementia' (P17), explicitly challenging the widespread conflation of dementia with its most prevalent subtype, Alzheimer's disease, and with older age (Low and Purwaningrum, 2020). Instead, participants encourage people to consider dementia as a 'lottery' (PH); in other words, it is an unpredictable event that is beyond individual control, since dementia can affect anyone, regardless of age, social status or other features, and will do so in different ways. Set against a trend of increasingly placing responsibility on individuals to reduce their risk of getting dementia *(*Lawless *et al.*, 2018; Peel, 2014), it is notable that no participants indicate that the person is responsible for developing dementia, instead only engaging with this neoliberal discourse to highlight how they are responding to dementia to maintain health and wellbeing (section 8.2.1). Here, dementia can affect anyone and manifests as a range of subtypes.

Reflecting the dominance of memory loss as the most cited symptom of dementia (Alzheimer's Research UK, 2018; Bailey, 2019), when participants are asked to explain dementia (see section 5.2), changes to memory emerge as key. However, this discussion provides much greater nuance than other sources, including public health campaigns (Brookes *et al.*, 2021), the news media (Bailey, 2019), and children's books (Caldwell *et al.*, 2021), which tend to conflate dementia with progressive memory loss, and memory with recall. Of course, participants do discuss memory in terms of recall, acknowledging that someone can experience short-term memory loss (for example, where the bathroom is), while long-term memory goes unimpeded. However, while some participants indicate a linear and lasting memory loss, others highlight that it is fluid. This tension materialises in two groups' different uses of the bookshelf metaphor in section 8.3; one presents a gradual loss of books from the shelves over time, while the other presents the books as moving on and off the shelves and occasionally being miscatalogued, to provide a more fluid account of memory that allows for changes to and strategies to reach memories. One participant explicitly positions memory as more expansive than recall, impacting 'how to live your life' rather than just entailing forgetting information, such as an address (P33). This reinforces what Basting (2009: 15) states, that memory is more complex than is often represented, and can be thought of in terms of:

1. short-term (including working memory) and long-term memory;
2. procedural (how we do things), episodic (specific people, events and information) and semantic memory (general knowledge);
3. implicit (subconscious) and explicit (conscious) memory.

A person with dementia might therefore be unable to recall an argument but still feel hurt through implicit memory, or be unable to dress themselves, yet happily reflect on what dementia means to them and how they are (or not) coping with its effects (Sabat, 2018). Overall, participants reinforce this more nuanced view of memory, rather than conflating explicit memory loss with a complete loss of memory. This shift is significant as it encourages people without dementia to consider ways of working with memory changes to better support and engage with people with dementia (Sabat, 2018).

While memory is acknowledged as important, participants move beyond defining dementia through memory loss by aligning themselves with more diverse cognitive changes, whereby dementia affects 'everything it's not just memory' (P30). Changes to a person's personality or behaviour are frequently discussed, and, as one couple humorously remind us, are not automatically bad (section 5.2). Navigating change will be discussed further in section 9.2.2; here, it is notable that participants discuss a range of abilities that can be impacted by dementia, including driving, walking, eating, communicating, doing DIY and finding a chair to sit in. This corroborates that dementia is experienced as not only altered memory but also changes to other cognitive functions, such as thinking, judgement, orientation, calculation, motor control and language, as well as emotional control, motivation and social behaviour (World Health Organisation, 2020).

Importantly, although rare when asked to explain dementia, elsewhere across their accounts, participants accompany discussions of lost abilities with those of regained or maintained abilities, such as making tea and sense of humour (Chapter 7), or nonverbally expressing love despite no longer saying it aloud (Chapter 4). Moreover, many people indicate taking up new activities and joining new groups since having dementia, including advocacy work (Chapter 4), research participation and peer groups such as choirs, swimming groups and Memory Cafés (Chapters 5 and 6). This reinforces what Sabat (2018: 37) highlights: that if, for instance, you struggle with conscious recall or recognition (explicit memory), you can still learn new information, retain this for long periods of time, and act on the basis of that new information or new experience – in other words, learn and grow as a person. As Bartlett and O'Connor (2010) argue, growth is a fundamental right that must be respected for everyone. Many people with dementia highlight activity and growth within their lives (Buggins *et al.*, 2021; Talbot *et al.*, 2020), which can offer a means of resisting being devalued by others (Steeman *et al.*, 2007). Despite some examples (Low and Purwaningrum, 2020), learning and growth are worryingly absent in popular and clinical representations of dementia, which overwhelmingly orient around the loss of memory and other abilities (Beard, 2016; Behuniak, 2011; Brookes *et al.*, 2021). Strikingly, participants' accounts of more constructive attributes and activities emerge during conversation rather than when participants are asked to explain dementia, which is indicative of the overall emphasis on deficits in definitions, diagnoses and discussions of dementia (Sabat, 2018; World Health Organisation, 2020).

Alongside discussing external manifestations, in Chapter 6, participants highlight that 'dementia doesn't always show' (PC), as internal cognitive changes are invisible to the human eye. Following previous accounts of people affected by dementia (Fletcher, 2020b; Manthorpe *et al.*, 2011), participants regularly refer to a simplified biomedical explanation of dementia as being caused by changes in the brain, sometimes reproducing biomedical terminology such as plaques, tangles and neurones to do so. As argued in Chapter 6, biomedical accounts and technologies such as brain scans can provide a way for participants to comprehend internal changes, and bestow a certain level of 'respectability' that shifts the blame from the person to their biology (Gerritsen *et al.*, 2018). Yet, analysis also demonstrates that the specifics of biomedical explanations, including the meaning of brain scans, remain largely reserved for medical experts rather than the public (Dumit, 2004; Harvey and Brookes, 2019), the implications of which are discussed in section 9.2.3. As such, participants may draw on more lay understandings of illness, including comparing the brains of people with dementia to having a broken limb, which externalises these internal changes in a more accessible way.

To explain this complex and varied condition, participants often supplement biomedically oriented accounts with metaphorical ones that draw on more tangible everyday objects and experiences as a source domain. This includes PH personifying dementia as a controlling companion, 'Mr Alzheimer's', who has 'a lot to answer for' in Chapter 5, and PK comparing having dementia to living with an alien that occasionally takes over that ‘you’ve got to work with’, with his vicar asking ‘how’s the alien?’ much as one would ask after a family member or pet (Chapter 8). Drawing on Van Gorp and Vercruysse's (2012) classifications of dominant dementia frames and their counter-frames, which are comparable to discourses and counter-discourses in this thesis, it is evident that participants counter dominant discourses when representing dementia. Notably, PH’s ‘Mr Alzheimer’s’ figure aligns with the ‘strange travelling companion’ counter-frame, which provides a less catastrophic and potentially more empowering alternative to the more popular ‘invader’ frame often used in a tragedy discourse, whereby dementia possesses people and destroys their lives. Moreover, PK demonstrates that participants may reshape dominant frames into counter-frames, as the typically monstrous alien invader is humorously converted into a companion that PK works with. This corroborates that the connotations of metaphors are not fixed and can vary according to contextual factors like attitude (Castaño, 2020).

Often, creative metaphorical choices such as that above counter more usual framings of dementia that are impersonal, loss oriented and disempowering (Van Gorp and Vercruysse, 2012), to present more personal, pluralistic portrayals. Sometimes, participants apply typically unrelated similes to explain dementia, for instance, when PC presents dementia in relation to fingerprints to show that both are unique to individuals. Other participants demonstrate original applications of popular source domains, such as a tree, with P19 comparing dementia to a ‘tree’ that keeps branching off into different types and experiences to emphasise ‘pluralism’, rather than the typical deficit-oriented plant metaphors of weeds growing in the mind or trees losing their leaves (Caldwell *et al.*, 2021; Zimmermann, 2017). Evidently, simply dismissing alien metaphors as damaging or tree metaphors as loss-oriented ignores the creative self-expression of people affected by dementia, as well as the potential for marginalised groups to re-interpret and reshape semiotic resources associated with a dominant discourse to present alternative counter-discourses.

In line with existing work, a tension emerges between biomedical and other discourses throughout participants’ accounts of dementia (Beard, 2016; Fletcher, 2020b). Some participants prioritise biomedical approaches to dementia, arguing that ‘without [a cure], you can’t go anywhere’ (PH). Indeed, the carers in the working-age dementia group push for greater medicalisation, associating biomedical explanations of dementia as a ‘brain disease’ with more resources and support than they currently receive when it’s portrayed as ‘social’ (P30). This draws on a structural concern with resources to advocate for a biomedical discourse, reflecting wider systemic issues with dementia care (Peel and Harding, 2014) and the use of a biomedical discourse to justify funding and medical intervention, boosting the resources available (Fox, 1989). Other participants indicate a desire to ‘move away from the clinical, medical, stuff’ when representing dementia, towards more ‘personal’ and ‘familiar’ approaches (P19), that give ‘a good insight into how we are actually working, and reacting and talking’ (Jackie/PN). This aligns with the psychosocial approach’s emphasis on the person and their subjective experience before the dementia, resisting the disease-oriented focus of biomedicine (Kitwood, 1997).

Equally, participants’ accounts recognise the intersectional nature of having dementia, engaging with a more structural approach to dementia. In particular, people focus on the role of age in someone’s dementia experience, with occasional nods to the impact of class (PH is not concerned about free services because he is financially secure, section 6.5) and overall social status (see P6 comparing the response to a headteacher versus someone who cannot read and write, section 5.3). As Hulko (2009) argues, many factors influence someone’s perception of dementia, including class, gender, ethnicity and race, with individuals ranging from being multiply marginalised to multiply privileged. Hulko’s study indicates that the more marginalised someone is, the more likely they are to dismiss the significance of dementia, which, although not the focus of this thesis, is reinforced by Sheila attributing her shock at her husband’s diagnosis to his high-powered job and P6’s observations of someone with low literacy dismissing dementia as just being ‘more [of] the same’. That age is most commonly presented as impacting participants’ experiences of dementia likely in part reflects that participants are predominately white British, making them multiply privileged regarding ethnicity and race.

Ageism materialises as an important factor, firstly through the ‘double stigma’ experienced by people who are older in age and have dementia (Evans, 2018: 272), with Jackie claiming that older people are commonly ‘side-lined’ in Chapter 4. Through advocating for the need to listen to the 'expertise' of older people (with dementia), Jackie resists ageist attitudes. However, some participants demonstrate internalised negative views of ageing, particularly in Chapter 5, with individuals expressing fear and repulsion at signs of older age when examining the hands images. As Latimer (2018) explores, dementia can be seen to embody some of the worst fears of growing old, including the hollowing out of personhood and an existence as a disintegrating body that is the subject of widespread revulsion. Such discourses can cause great harm to older people and/or people with dementia (van Wijngaarden *et al.*, 2019), which is demonstrated in the extreme by PB’s wish that she ‘were dead’ because ‘I’m useless’ (P4, in Chapter 7). Conversely, people with younger onset dementia emphasise that the ‘ageing-dementia relation’ (Latimer, 2018) is such that if people do not fit into the social category of an older person, they face a unique set of challenges when trying to navigate the world as someone with dementia, since existing support structures and understandings of dementia overwhelmingly exclude them. This may result in a person’s identity as someone with dementia being challenged, as PH reports when swimming (Chapter 5), or through inappropriate music and activities

(Chapter 6). Although the prevalence of dementia undeniably increases with age, participants' accounts highlight the need to complicate the dementia-ageing link, and to start to listen to the voices of both older people and people with dementia, as part of challenging some of these fear-inducing, ageist discourses to make the dementia-ageing relation less harmful moving forward.

Throughout, then, participants navigate biomedical terminology and explanations for dementia alongside their personal understandings and experiences, and work to destigmatise what dementia means by presenting a nuanced discussion of positives and negatives, in line with existing accounts by people affected by dementia (Beard, 2016; Fletcher, 2020b; Mitchell, 2018). Overall, participants establish dementia as diverse, highlighting different subtypes, life stages, impacts and social experiences that are affected by a person's sociocultural positioning. There are clear signs that participants may internalise disempowering discourses, or counter them, often through creative language use. Representations of dementia and an individual's sense of identity and experiences are deeply entwined, so I now turn to focus in greater detail on the 'people' side of dementia representations.

9.2.2 Participants' representations of people with dementia (and those around them)

Following previous research on identity work by people who have dementia, participants with dementia both acknowledge dementia as part of their identity, and resist being defined by it (Bailey, 2020; Beard, 2016). In Bryden's (2019: xii) words, '[w]e are people who happen to live with dementia'. This is evident throughout; people with dementia will discuss their experiences of dementia and refer to themselves as people with dementia, while equally emphasising other aspects of their identity, whether this is as a physicist (PH), activist (Jackie/PN) or author (PK). Indeed, when initially asked what he associates with dementia, PC mentions family members with dementia first, before displaying his sense of humour and resisting the tragedy discourse in his statement that 'I've cheered up [laughing] since having the dementia' (section 5.2). Following Hickman *et al.* (2020), Chapter 7 explores humour as an important means of coping with dementia and the stressors (such as identity threats) it entails. As well as a means of social bonding, humour can mitigate the face-threatening potential of a disclosure (Norrick and Chiaro, 2009), as when PD diffuses his wife's narrative about the 'difficult subject' of him having to stop driving due to his dementia. This exchange results in the group appreciating the sense of humour that the two husbands with dementia have, showcasing that people's accounts can foreground continuity for a person (here, their humour) as well as change in the context of life-altering conditions (Whiffin *et al.*, 2019). In line with existing research, then, participants with dementia highlight their identity *beyond* dementia and may challenge perceived threats to their identity through humour, which can be an important resource for social connection and identity work.

Navigating change is a central aspect of participants' representations of what it means to be someone with dementia. Adding to existing findings on change (Buggins *et al.*, 2021; Holdsworth and McCabe, 2018; Spreadbury and Kipps, 2019), here, it can manifest through changing abilities or personality traits with dementia, as well as changed attitudes and social positioning within the world, including experiencing stigma, relationship changes, new opportunities and the loss of old ones, such as driving. Whereas PC talks of cheering up (Chapter 5), in the same focus group, two other couples discuss an initial wish to die upon being diagnosed with dementia, due to feeling useless, overwhelmed and fearful of the future (Chapter 7). Being diagnosed with dementia is consistently shown to be traumatic, often unnecessarily so, with fear-inducing cultural conceptions (Sabat, 2018; Taylor, 2008) and specialists failing to offer sufficient hope or clarity, often treating individuals with dementia as an 'incompetent or at least soon-to-be incompetent person or "patient"' (Beard, 2016: 109). Combined with current and future changes, and the stigma associated with the condition, unfortunately my participants' accounts reflect an increased risk of suicide for older adults with dementia more broadly (Serafini *et al.*, 2016), who are commonly devalued, rejected and denied fundamental rights by others (Alzheimer's Disease International, 2012; Cahill, 2018; Latimer, 2018).

In this study, both participants who expressed a wish to die are represented by their partners as moving towards acceptance of the condition. Against these carer accounts, Sheila's interview in Chapter 4 offers a useful first-hand insight into some of the complexities of navigating your status as someone with dementia. Through much of the interview, Sheila positions herself as a carer, and as someone who is currently coping well with her dementia. However, later in the interview, Sheila draws on her account of her husband's change and increasing dependency when he had vascular dementia to also predict that 'there'll be, a loss, to what I was'. She contrasts her previous competency, efficiency and power against becoming 'forgetful and [pause] effort to function'. This loss-oriented list diverges from her previous discussions of abilities and activities, such as driving and caring for others. Here, Sheila reveals a more vulnerable and fearful side, highlighting the existential threat that dementia poses to individuals' lives and sense of identity (Cheston *et al.*, 2015). While this is frequently expressed by other people with dementia (Castaño, 2020), it can also be masked beneath overly positive self-representations (Talbot *et al.*, 2020), likely as a resistance to cultural devaluation (Steeman *et al.*, 2007). By focusing on the loss of socially assigned attributes, Sheila reinforces the valuing of hypercognitive abilities like efficiency above more emotional, relational, expressive and/or experiential ones in (Western) culture (Post, 2000b). Her distress reiterates first-hand the damage of exclusionary hypercognitive values. Moreover, that Sheila particularly fears being 'taken away' to an institution, despite not wanting to be there, indicates that many fears of loss and future treatment as a person with dementia are socially situated, being worsened by structural inequalities and the mistreatment, including human rights violations, of people with dementia (Cahill, 2018). Her story contributes an individual case to the increasing criticisms of hypercognitive approaches to human value and the greater attention being paid to other people's role in selfhood and experience of dementia (Sabat, 2002, 2018).

Throughout, participants' (self-)presentations of people with dementia reinforce, resist and replace hypercognitive discourses that value cognitive efficiency, and the related 'loss of self' discourse. In Chapter 6, some participants conflate the brain with the whole person, while others resist equating the self with the brain (Vidal, 2009) by emphasising that you 'see people' not 'brains' (P19). In the same chapter, while some carers of partners with more advanced dementia suggest that there are pieces of their loved one missing, other people without dementia reject this discourse. Participants with dementia appear less likely to comment, aside from PC who, like P5 and P1, challenges the derogatory phrase of 'a piece missing' as false. Accompanying these moments of resistance are multiple counter-discourses. These align with advocates such as Bryden (2020), who convincingly argues that people with dementia continue to have a sense of themselves as an embodied, relational self, with a narrative of meaning that is grounded in the present moment, rather than past events. Indeed, participants more frequently discuss *changes* to a person rather than suggest that they have lost their original self, and indicate the importance of relational and embodied aspects of the self. Accounts such as PE and P13's, featuring their couple identity in Chapter 7, challenge the cultural privileging of individuality and independent action above interdependence, an imbalance that Boyle (2017) suggests contributes to the current lack of agency ascribed to people with dementia. Equally, meaningful interactions are shown to include more than linguistic communication, particularly in Chapters 4 and 5, with the body being recognised as an important site of intent and engagement (Kontos, 2004, 2006). Clearly, then, participants engage with a range of hegemonic and counter-discourses, overall aligning with approaches that emphasise continued personhood and sense of self for people with dementia, and an expanded sense of what it means to engage with the world (Brooker and Kitwood, 2019; Bryden, 2020; Kontos, 2006). These counter-discourses parallel the disability movement more broadly, where disabled people and their allies are challenging society to rethink what it means to be human, and find 'more human and humane possibilities' for how we treat one another (Goodley, 2020: 13).

Participants' accounts indicate a tension between diverse individuality and a sense of an overall collective of people united by their experiences of dementia. On the one hand, participants consistently resist the homogenisation of people with dementia, which, as Bailey (2019: 186) observes for news media, assembles people into an undifferentiated, anonymous mass, obscuring any sense of individuality or selfhood. As discussed in section 9.2.1, participants continually promote a discourse of difference and individuality within the label 'dementia'. They emphasise that stereotypes of older age and a conflation of dementia with its most common type, Alzheimer's disease, constrain the image of who a person with dementia can be, resulting in misunderstanding (as with P6's mother's vascular dementia), microaggressions (see PH in the swimming pool) and exclusion (e.g., in care homes and music/activity choices) for people who do not fit either or both of these stereotypes. In Chapter 6, PN/Jackie critiques the homogenisation of people with dementia by medical staff due to insufficient understanding, and in Chapter 4, she discusses how she sometimes struggles to engage with other people with dementia as she is not knowledgeable about how different types affect individuals. That this lack of understanding extends to people with different types of dementia highlights the diversity of individuals who are so commonly homogenised as a collective.

Simultaneously, participants establish a sense of community amongst people affected by dementia, contrasting shared understanding within this group against others' lack of understanding. Chapter 5 charts the evolution of participants' understanding, with multiple individuals overcoming their initial misconceptions of people with dementia through experience. Following this, Chapter 6 examines the perceived lack of understanding of those without experience of dementia, including organisations (e.g., the media and business) and members of the public. Participants especially focus on certain specialists, who need a 'better understanding of what dementia is all about' through actually living with someone with dementia (P28). Against this, participants construct a group identity oriented around shared understanding (e.g., 'we understand, what it's like to have dementia': PK). That seven participants explicitly use the word 'understand' to discuss the shared understanding that comes from mutually experiencing dementia highlights the importance of this concept. As such, peer support is regularly praised as a source of collaborative, shared learning that boosts the sense of connection and wellbeing of people affected by dementia, and that involves alternative (often better) relationships, experiences and outcomes to interactions with health professionals (Hillman *et al.*, 2018; Keyes *et al.*, 2016). Indeed, it is in the context of peer groups that many participants discuss having fun and feeling brighter. People with dementia and their supporters are positioned as being the 'experts by experience' (Parveen *et al.*, 2018), reflecting a broader social shift towards recognising the integral role of people with dementia within research and social responses to dementia (Davies *et al.*, 2021; Hillman *et al.*, 2018). The participants in this study further support the need to consult and listen to people with dementia and supporters, consistently demonstrating their unique expertise, which can improve social understandings of all that it can mean to be a person who has dementia (and those who support them).

Clearly, being a person with dementia is complex, and identities are fluid rather than fixed (Bailey, 2020; Beard, 2016). Of course, the same is true for people without dementia, but people with this condition must additionally navigate changing positions in the world and sense of future self through the existential threat that dementia poses (Cheston *et al.*, 2015). Participants provide a nuanced presentation of what it can mean to be someone with dementia, which incorporates despair, distress and fear alongside growth, connection and happiness. Overall, participants support models of selfhood that respect the individual as a fellow human being and consider more ways of being in the world than cognitive engagement, most especially relational and embodied aspects of the self. Equally, a focus on the value of togetherness and interdependence challenges the existing prioritisation of independence, marking more inclusive and 'human' ways of relating to one another moving forwards (Goodley, 2020: 13). Participants negotiate a tension between the need to emphasise the diversity and individuality incorporated within the term 'people with dementia', against an overall sense of community and shared understanding with others affected by dementia. Such understanding is positioned as a means of bridging the current disconnect between the experience-led knowledge of people affected by dementia and the lack of understanding amongst other members of society, including healthcare professionals, journalists, family, friends and the overall public. The notions of diversity and nuance, which thread throughout this and the above section, are explored further below, paying particular attention to visual and verbal manifestations of discourses surrounding dementia.

9.2.3 Engaging with (visual and verbal) manifestations of discourse

As shown above, participants reinforce, challenge and reshape a range of discourses relating to dementia and people affected by dementia. This section complements the preceding ones by attending to key findings surrounding participants' responses to specific instances of discourse. Analysis further corroborates that popular discourses often do not match the discursive preferences of people with dementia (DEEP, 2014; Swaffer, 2014, 2016). This thesis extends existing work through considering how different participants affected by dementia respond to specific examples of visual and verbal representations. I outline how individuals' interpretations of images are informed by their discursive preferences (Chapter 4) and interact with different semiotic resources, such as camera angle and represented participants (Chapter 5). Drawing on Chapters 6 and 7, I consider issues of accessibility, accuracy and the ideological consequences of different images used to represent dementia. Then, referring to Chapter 8, I explore how participants differently relate to phrases used to describe people with dementia and experiences of the condition.

Across chapters, interpretations and responses to the same images and words vary greatly, reinforcing the subjectivity of people's responses to images (Breeze, 2011; Kitzinger, 1993). Chapter 4 provides a focused exploration of how two interviewees with dementia, Sheila and Jackie, differently represent their experiences of dementia, and how their personal experiences and discursive positionings materialise in their unique responses to the same three images. Overall, Sheila draws on more psychosocial discourses, being concerned with relationships and her subjective experience, while Jackie takes a more structural, rights-based approach to dementia in her focus on inequalities and advocating for people with dementia through the media. Although the women similarly recognise what each image shows, such as the movement of fragments away from the man represented in image 10, both draw on different personal experiences to contextualise their interpretations, here back pain versus disorientating moments. Sheila is more likely to emphasise emotions, change and identity when interpreting the images, and Jackie to link her interpretations to structural points, such as the need improve care homes. Evidently, people may similarly interpret what the image literally denotes, but the connotations drawn are heavily influenced by our subjective experiences and discourses (Barthes, 1968). By comparing Sheila and Jackie's responses to image 12 to an analysis of the same image by MCDA analysts, Harvey and Brookes (2019), Chapter 4 models how dialogue can be raised between academics and people with differing perspectives and experiences to provide a more comprehensive picture of engagement with discourses than is usually provided in (M)CDA-oriented work (Breeze, 2011).

Particular semiotic resources also inform participants' interpretations, which Chapter 5 exemplifies with the two photographs of hands (images 7 and 8). In these close-up shots, signs of ageing such as wrinkles are foregrounded; subsequently, the majority of participants comment on the hands as signifying old age, regularly critiquing the conflation of dementia with older age, as discussed in section 9.2.1. Beyond this clear agreement on signifying age, the ambiguity of a decontextualised close-up of only hands causes confusion regarding meaning, with many contradictory interpretations. In general, though, while some individuals consider semiotic choices such as the angle and differences in lighting, many participants distinguish between the two photos of hands through the represented participants (Kress and van Leeuwen, 2006). Here, participants are more likely to relate to the image of two people holding hands than of one person's hands. The two hands tend to be associated with relationships and non-verbal communication, alluding to the embodied nature of the self (Kontos, 2006). Conversely, without anything to engage with, the solitary hands more frequently evoke interpretations of victimhood, depersonalisation and sadness, in line with existing analyses of solitary hands, which are a common visual trope (Brookes *et al.*, 2018; Harvey and Brookes, 2019). This contrast between one and two pairs of hands reveals the importance of attending to specific semiotic resources within the same broader trope, here of close-up, decontextualised hands.

Furthermore, participants' responses to the brain scan (image 17, Chapter 6) and tree metaphor (image 11, Chapter 7) raise issues of accessibility, perceived accuracy and the ideological implications of images that are often used to visually explain dementia. Conversations with participants about image 17 reinforce existing criticisms of brain imaging, as although participants position brain scans as a means of showing internal brain changes, without being specialists, no one can confidently read what the scans show (Cohn, 2010; Dumit, 2004). Despite the obscure and inaccessible nature of the scans, participants overwhelmingly trust their accuracy. Indeed, the only criticism of brain scans is implicit, when PK challenges a medical professional’s diagnosis based on not seeing a bleed, thus implying that scans cannot show everything (section 6.4). Instead, participants draw generalised conclusions, such as the scans in image 17 showing ‘a type of, dementia’ (PH). Being imbued with social as well as scientific meaning, the brain scan exemplifies how image and language choices have ideological implications that can extend far beyond what the image itself denotes or is intended for. Notably, participants infer the existence of a ‘good’ (P32) and bad/ill type of brain, reinforcing Cohn's (2004: 69) assertion that '[v]isual styles and conventions can serve as non-linguistic constructions that can contain and shape discursive elements without ever having to refer to them explicitly'. Here, through being used to diagnose conditions, brain scans can indirectly convey a dichotomy between ‘healthy’ and ‘unhealthy’ individuals, which becomes inherently divisionary and stigmatising when combined with the widespread conflation of people with their brains (Harvey and Brookes, 2019; Vidal, 2009).

The tree metaphor in Chapter 7 offers an alternative visualisation of dementia through drawing on a more tangible source domain (deciduous trees) to metaphorically depict people with dementia as losing brain cells the way trees lose their leaves in autumn. Although not everyone reads the image metaphorically, most do, and many participants praise the metaphor for its ability to meaningfully show and explain what is happening in the brain with dementia. This underlines the ability of metaphors to resonate with people’s psychological, physical and emotional experiences, offering a valuable means of self-expression and understanding (Castaño, 2020; Padfield *et al.*, 2018). Interestingly, the visual metaphor is more likely to be criticised than the brain scan, perhaps as it is more accessible and not imbued with any ‘expert’ status or scientific authority (Cohn, 2004; Dumit, 2004), despite both images having similar ideological connotations. For instance, multiple participants resist the tree metaphor’s implications of a linear loss and conflation of personhood with a deteriorating brain. Participants suggest a forest to present the multiplicity of dementia rather than reducing it to three stages, as well as including floating leaves and varying the areas experiencing leaf-loss to acknowledge changeability and flux, in both abilities and identity, with dementia. That participants employ metaphor to illustrate their counter-discourses demonstrates its importance as a semiotic resource for expressing intangible and complex phenomena (Semino, 2008). The debates surrounding the ideological implications of the brain scans and tree metaphor in this study reinforce the subjectivity and plurality of individuals’ responses to manifestations of discourse, with people drawing on different existing knowledge and interpretative techniques to accept, reject or reframe visual manifestations of a biomedical discourse (Breeze, 2011; Kitzinger, 1993).

That participants express a range of linguistic preferences and interpretations throughout underscores the need for multifaceted uses of semiotic resources to enable diverse representations of dementia. Metaphor emerges as a key semiotic resource with which participants creatively engage to not only reproduce but reshape existing discourses of dementia to better align with their individual experiences (note PK's alien and the many ways that people draw on battle and journey metaphors). The variety of participants' responses to 'suffering', 'living' and 'living well' with dementia reiterates the importance of acknowledging multiple facets of experiencing dementia, rather than overly sanitising or vilifying it (Bartlett *et al.*, 2017; Fletcher, 2019a; McParland *et al.*, 2017). Intriguingly, participants with and without dementia take different stances towards 'living well with dementia'. Whereas people with dementia tend to identity with 'living well', presenting it as a means of empowering themselves as individuals to 'be happy' and active while living with dementia (PF), carers are more likely to position 'living well' within a social environment whereby the actions of others (dis)empower people with dementia to 'live well'. This distinction encourages future research into how people with and without dementia differently relate to semiotic choices, contributing to existing research that explores nuances between people with dementia and supporters/carers (Baber *et al.*, 2021; Beard *et al.*, 2009a).

9.3 Implications of this study

9.3.1 Contributions to research

This project's central contribution is its exploration of how people affected by dementia situate themselves in relation to pervasive representations of dementia, including how individuals respond to a selection of images and language choices. This adds to an increasing recognition of the integral role that people with dementia, as well as their supporters, need to play in improving understandings and social treatment (Bryden, 2016; Hillman *et al.*, 2018). With researchers such as Carmody *et al.* (2015) calling for more qualitative research to address the experiences of people with dementia and carers, this thesis is part of a shift in academia towards redressing the historic exclusion of the voices of people with dementia and acknowledging this social group as experts through experience (Davies *et al.*, 2021). Including explicit discussions about dementia representations adds another perspective that supplements the rich wealth of research into how people affected by dementia use language in other contexts, such as books, online forums, blogs, and interviews that do not foreground language practices (Bailey, 2020; Castaño, 2020; Peel and Harding, 2014; Zeilig, 2014b; Zimmermann, 2017). My approach builds on previous work, including the *Dementia Talking: Care, conversation and* *communication* project, within which carers were interviewed about how dementia is represented and talked about in society, which included contrasting carer and news discourses (Peel, 2014). With projects that involve people with dementia, explicit discussions of dementia representations remain rare, with the focus usually being on how people represent their experiences and identities (Beard, 2016; Buggins *et al.*, 2021; Fletcher, 2020a, 2020b; Hillman *et al.*, 2018). When language practices are included, it is briefly. For instance, Langdon *et al.* (2007) ask participants with dementia about terms such as 'dementia' and 'Alzheimer's' before focusing on participants' experiences of other people's reactions to their changed condition and social status. To the author's knowledge, then, this is the first qualitative study to orient around participants' responses to visual and verbal stimuli for dementia discourses (for a quantitative analysis of the general public's response to verbal stimuli, see Van Gorp *et al.*, 2012).

This multimodal focus adds to a small but growing body of literature that attends to both verbal and visual representations of dementia (Brookes *et al.*, 2018, 2021; Caldwell *et al.*, 2021; Harvey and Brookes, 2019). Multimodal analysis recognises that in a society that is increasingly saturated by, and literate in, visual communication, it is important to interrogate non-verbal manifestations of discourses, since these influence much of our engagement with the world (Ledin and Machin, 2018a, 2018b). By consulting people affected by dementia, this thesis diverges from existing multimodal work and addresses some key limitations of (multimodal) critical discourse analysis, in the hopes of modelling a more grassroots-led application of this approach. Like Heap and Wolverson's (2020) CDA study on changes to professional carers' discourses following exposure to a person-oriented discourse, I break with the traditional (M)CDA focus on the researcher's reaction to a text. This enables an empirically grounded examination of the range of interpretations and responses to discourses that individuals can give, including accepting and reiterating, challenging and rejecting, or adapting and reshaping dementia discourses (Breeze, 2011). Notably, responses to the degenerative images in Chapter 7 demonstrate how non-semiotic specialists can not only deconstruct ideologies connoted by semiotic resources but also suggest changes so that these resources (particularly the tree visual metaphor) can better align with their own experiences and discursive positionings. By including stimuli that are identical or similar to those analysed by other MCDA researchers (namely Brookes *et al.*, 2018; Harvey and Brookes, 2019), this thesis has compared the responses of academics specialising in semiotics, and participants with experience-led expertise in dementia. Working with people affected by dementia, then, enables me to explore how individuals from a traditionally disenfranchised social group, with extensive experience themselves of dementia, (re)interpret and resist mainstream discourses, and generate counter-discourses (Breeze, 2011; Luke, 2002). Attending to not only problematic but also potentially more empowering practices holds great potential for positive social change. This aligns my work with the principles of a positive discourse analysis strand of (M)CDA, which explicitly aims to construct, as well as deconstruct, instances of discourse (Bartlett, 2018). Considering the need for more scholarship that aligns with this positive strand, this study provides a comprehensive example for other researchers.

9.3.2 Recommendations

As well as contributing to existing dementia research, the present study has multiple implications for society more broadly, especially for media, non-profit and advocacy organisations. These are summarised here, with particular attention paid to participants' recommendations, which I explore in relation to the theoretical landscape of news values (in particular, the work of Bednarek and Caple), to consider ways forward beyond this thesis.

Firstly, the discussions here extend existing language guidelines produced by non-profit and advocacy organisations (Alzheimer's Society, 2018; Bould, 2018; DEEP, 2014; YoungDementia UK, 2020). Two key features are addressed: (1) to date, even if guidelines acknowledge the importance of images, they focus overwhelmingly on words; (2) guidelines consult people affected by dementia but amalgamate participants' voices to produce a clear directive for language use. Instead, this project prioritises individual voices, nuanced accounts, and in-depth debate that includes responses to visual as well as verbal depictions. I achieve this through combining thematic and (multimodal critical) discourse analysis, to examine key themes in the data while simultaneously closely attending to individuals' discursive practices (Šestáková and Plichtová, 2020). Acknowledging the different purposes of charity guidelines, which balance clear language directives with person-oriented advice (e.g., 'find out how the person identifies themselves'; DEEP, 2014: 3), this thesis may form a useful resource that guidelines can signpost readers to for a more in-depth exploration of how individual differences can manifest. This project also emphasises the importance of addressing visual representations in detail, and offers a model of how to do so, building on guidelines' sparing examples of inappropriate image types, namely 'head clutcher' images (Bould, 2018: 31) and 'a fading face or wrinkled hands' (DEEP, 2014: 4). As the tree visual metaphor (image 11) demonstrates, even images that are not as obviously stigmatising can reinforce loss-oriented and disempowering discourses. The finding builds on previous work in which we demonstrate that within a public health campaign, the Alzheimer's Society visually infringes many of the person-centred recommendations' found in their language-based guidelines (Brookes *et al.*, 2021: 262). This highlights the need for in-depth explorations of the implications of different visual choices, in addition to examining the connotations of language choices, not only for the guidelines' readers but for the non-profit organisations themselves.

Pertinent to non-profit, advocacy and media organisations are the recommendations that are established from participants' contributions in Chapter 8. In sum, these are: 1) normalise dementia; 2) provide more nuanced representations; and 3) expand the attribution of value and notions of personhood to enable better advocacy for people with dementia. These recommendations echo calls across research and dementia advocates for more holistic, empowering representations (Bailey, 2019; Bryden, 2016; Talbot *et al.*, 2020). To strive for meaningful social change, however, it is important to consider these recommendations within the broader media context. Since the literature extensively covers news media, I will be focusing primarily on this genre as an example, for which the theory of news values, as introduced in Chapter 2, is particularly influential (Bednarek and Caple, 2012, 2017; Caple and Bednarek, 2016). As Chapter 2 details, many of the same values, such as negativity, are evident across communication genres, including charity campaigns, speeches and film (Brookes *et al.*, 2021; Low and Purwaningrum, 2020; Zeilig, 2014a). Likewise, media, non-profit and other organisations face comparable structural, social and economic factors, which impact the discourses they align with (Fox, 1989; Lock, 2013; Macgilchrist, 2007). Such parallels ensure that the below discussion is relevant beyond news media. Beginning with obstacles to the uptake of these recommendations, the discussion then shifts to consider potential enablers for enacting change.

The participants' recommendation to normalise dementia responds to their criticisms of the media for sensationalising dementia. In other words, normalising dementia contradicts multiple key news values that inform media content, inevitably restricting the uptake of such a recommendation. These values are primarily superlativeness (high intensity or large scope = more newsworthy), impact (serious national/global consequences = more newsworthy), negativity (negative events = newsworthy) and eliteness (higher status = more newsworthy) (Bednarek and Caple, 2017). Indeed, following an analysis of news representations of dementia, Bailey (2019: 193) concludes that '[i]f the news media depicted dementia as a commonplace, unexceptional change in daily life and showed people with dementia continuing to work and contribute to society [...] the topic would become inherently less newsworthy'. The same standard applies to non-profit communications, which rely on emphasising the impact, negativity and intensity of dementia to garner financial support (Fox, 1989; Lock, 2013). Visual trends also offer barriers to the uptake of ordinary, everyday visual representations. Stock images increasingly dominate publications, and are 'changing the world's visual language' from photographs being records of reality to being symbolic conveyors of dominant ideologies (Machin and van Leeuwen, 2007: 151). As explored in Chapter 2, stock images can be defined through their genericity, timelessness and low modality, thus favouring actors in non-specific settings who can be used to represent a range of concepts (Machin and van Leeuwen, 2007). To show normal people in an everyday, specific setting contradicts this influential (and convenient) trend for visually representing dementia in more abstract, non-specific terms using pre-made stock images (Brookes *et al.*, 2018; Harvey and Brookes, 2019).

Similarly, increasing nuance in representations is problematised by text producers having limited space to convey their messages, which often leads to cutting anything that undermines or confuses the central argument(s) (Macgilchrist, 2007). Here, successfully rendering the issue more complex requires balancing the news values of consonance, which entails connecting to pre-existing understandings and stereotypes about the topic and people involved, with that of novelty, which refers to the new and/or unexpected aspects of an issue (Bednarek and Caple, 2012). Macgilchrist (2007: 88) envisions this through the 'curiosity gap' model, arguing that 'if the article is too far from the reader's current knowledge of the world, it will be ignored; if the article tells readers what they already know, it will be deemed uninteresting. The key is to meet the readers where they are and add a manageable amount of new information'. In other words, complicating an issue by challenging hegemonic discourses (novelty) requires sufficient alignment with these discourses (consonance) that audiences are comfortable enough to engage with new counter-discourses.

This novelty-consonance balance informs the uptake of all three recommendations. For instance, increasingly nuanced representations of personhood will need to use the currently dominant hypercognitive discourse as a bridge towards normalising more holistic models, similar to how researchers build on existing personhood work to progress over time. In this way, what are initially counter-discourses, such as Kitwood's (1997) theory of personhood, can become central, encouraging new areas of focus as a result (Brooker and Kitwood, 2019). The same may be true for the third recommendation of advocacy. It is increasingly recognised amongst academics and advocacy/non-profit groups that listening to the perspectives of people with (and affected by) dementia is 'an obvious and viable way to explore new, alternative representations and eventually draw a richer, more comprehensive and multifaceted picture of living with dementia in the public sphere' (Schweda, 2019: 7). This shift indicates that popular portrayals, too, can transition from undermining the personhood of people with dementia (Low and Purwaningrum, 2020), to also acknowledging a diverse range of people with dementia as being experts through experience (Parveen *et al.*, 2018). Accordingly, people with dementia could join social groups already valued as 'elite' by media, such as researchers, politicians and medical professionals (Bailey, 2019; Bednarek and Caple, 2017), by being celebrated for providing unparalleled access into what it is like to experience life with dementia.

One image from this dataset offers a useful example of how normalisation, nuance and advocacy may be incorporated into mainstream portrayals through addressing this novelty-consonance balance, alongside the news value of personalisation (the personal or 'human' face that explores how an event/issue impacts real individuals). This is image 13, which is drawn from *The Times* newspaper and depicts an ordinary couple getting (re)married in their garden, clearly photographed by a guest. The photograph showcases another trend observed in news media that counters the prominence of stock images: that of using photos taken by ordinary witnesses of news events (Bednarek and Caple, 2017). The article is one of many that featured this national human-interest story in August 2019, which orients around the novelty of a married couple holding a wedding-like ceremony following the partner with dementia forgetting their original marriage and proposing again to his wife. Although the article aligns with overly negative, disempowering discourses (e.g., 'his illness robbed him of all memories of their relationship'), it simultaneously complicates these through representing a loving partner with dementia, who clearly has agency, selfhood and meaningful relationships (e.g., 'He's still my Bill'), thus aligning with more holistic and nuanced depictions of people with dementia. *The Times*' headline captures this tension, reading 'End dementia stigma, says Anne Duncan who 'remarried' sufferer'. While 'remarried' indexes novelty, 'sufferers' is a long-held term that despite being discouraged by language guidelines is still popularly used and familiar to readers (consonance) (Bailey, 2019). Despite using such terms, this story elevates advocates' voices, who call to 'end dementia stigma', and, as the article later explores, to increase 'visibility' for people with dementia, highlight that life with dementia can have 'rubbish' but also 'completely magical' moments, and promote ways of improving the wellbeing and connection of people with dementia. Conspicuously missing from this article, though, are any voices of people with dementia, with supporters being left to speak on their behalf. This article, then, can be seen as a stepping-stone; although using outdated terminology and ignoring the voices of people with dementia, it simultaneously builds on dominant, disempowering discourses to explore alternative ones that foreground continuance of self, relationships and happiness with dementia, the multiplicity of life with the condition, and social responses to support people with dementia.

This example illustrates that appealing to personalisation offers an important route to making representations more normalised, nuanced and empowering for people with dementia. As journalist Kelly (2019: 95) notes, 'the media and dementia sectors can benefit each other. The media need powerful, newsworthy human-interest stories and it's up to those in the dementia community to understand what these are and provide them, quickly and accurately'. What is important, however, is for these human-interest stories about individuals affected by dementia to represent 'the diverse face of dementia' (P17) in terms of people, types, experiences and social/structural factors. Equally, people with dementia need to become acknowledged as the expert voices that they are, rather than others being consulted on their behalf (Bryden, 2016). While balancing novelty with consonance offers a clear way to shift discourses over time, it is also worth considering how news values initially envisioned as obstacles can be repurposed to fit participants' recommendations. Notably, the newsworthiness of negativity can be drawn on to foreground systemic issues such as institutional human rights violations (Cahill, 2018) and the intersectionality of discrimination, including ageism, sexism and racism (Boyle, 2017; Evans, 2018; Hulko, 2009). Such issues are inherently negative, but their coverage can help to push forward improvements to the support provided for people with dementia through raising public awareness and understanding. By presenting participants' recommendations alongside theoretical explanations, this thesis demonstrates that it is possible for organisations to normalise dementia, increase nuance and advocate for people with dementia without detracting from the 'newsworthiness' of their message (Bednarek and Caple, 2017).

9.4 Methodological evaluation

As discussed above and in Chapter 3, this thesis combines multiple methodological and theoretical approaches to explore how people affected by dementia situate themselves in relation to popular dementia discourses. By working with people with dementia and their carers/loved ones, this study addresses key criticisms of both multimodal critical discourse analysis (see section 3.2.3) and dementia research more broadly, which has traditionally side-lined the everyday lived experiences and perspectives of individuals affected by dementia (Beard, 2016; Carmody *et al.*, 2015). Inevitably, though, there are several study decisions and limitations that must be recognised and critically commented on, particularly regarding the study's design, conduct, and analysis. Underlying all of these is the issue of voice. In a review of studies that engage people with dementia in research, Cowdell (2006: 91) asks: 'Has the voice of the participants been heard?' To this, I further question *whose* voices are heard, and how I as the researcher affect what is said and heard, both in the sessions and the subsequent write-up.

Multiple factors shape whose voices are heard in this study. As discussed in section 3.3.2, my recruitment strategies resulted in a group of predominately white British participants in heterosexual relationships (as far as I am aware), who lived in and around Nottingham. Unfortunately, the national Covid-19 lockdown in March 2020 permanently halted recruitment at a point where I was reaching out to different networks and research groups to try to improve sample diversity. This is a limitation of my study, as heterosexual white people are overrepresented in dementia imagery (Bould, 2018; Tilsed, 2019), making it crucial that researchers also explore the perspectives of people who are regularly excluded from representations, as well as research. That mine is the typical participant sample for research projects reflects broader structural inequalities within academia and society (Fletcher, 2019b; Innes, 2009). Often, members of society such as people of colour, the LGBTQ+ community, neurodivergent individuals, people with minority cultural backgrounds and those in rural locations, low socioeconomic situations or without a support network, are categorised as 'hard to reach', when the reality is that such individuals are 'easy to ignore' and thus 'seldom heard' (Tilsed, 2019). As Fletcher (2019b) points out, however, the fluidity, approachability and adaptability that is necessary for researchers to improve their reach is often undermined by the procedures that govern projects, making this an ethical and practical priority for academia moving forward.

Another central limitation is that, once recruited to the study, the running and analysis of focus groups/interviews overly relied on participants' verbal communicative abilities. This restricted the involvement of people with more advanced dementia, for whom paralinguistic oriented analysis would be more appropriate to consider embodied forms of communications (Hydén, 2013). When people who had little verbal communication were included in focus groups (primarily in the working-age dementia group), I was generally unable to consider their responses as my analysis orients around vocalisations (with the exception of PP's kiss in section 5.3.1). As this moment was particularly striking and partly captured by her partner's reactions on the recorder, I could document it following the session. However, many more interactions were lost due to audio-only recording and being unable, through lack of resources and time, to properly attend to them. This particularly impacted people with more advanced dementia, but also applies to the paralinguistic communications of all participants, marking a promising area that research is already beginning to explore (Morgner *et al.*, 2019). Focusing on verbal-only communication also meant that certain voices dominated focus groups. As I discuss in section 3.3.5, although carers' voices often dominated, in line with existing research (Davies *et al.*, 2021; Dening *et al.*, 2013), the reality was much more complex and individualistic. This reflects that dementia is just one of many factors, including personality and group dynamics, that can influence the broader issue of dominant voices in focus groups (Smithson, 2000). Relatedly, practical constraints particularly influenced the eventual imbalance of perspectives surrounding verbal stimuli, as this section was frequently excluded due to insufficient time.

Of course, these focus groups and interviews only depict one specific context and point in time. Neither method can claim to provide any 'authentic Voice of the People', being insurmountably constrained by not only processes of recruitment, conduct and analysis (Bloor *et al.*, 2001: 15), but also by the fluctuating discursive identities of individuals and contextual influences on the expression (or suppression) of certain viewpoints during sessions (Barbour and Kitzinger, 1999). Moreover, as the researcher, I act as the overarching narrator who filters and organises participants' complex perspectives and 'multiple truths' to produce the work you see before you (Macgilchrist, 2020: 5). This can only ever be a simplified retelling that foregrounds certain aspects above others and which is inescapably influenced by my own sociopolitical and affective standing (see section 3.5 for details). Of course, this is true across academia, and qualitative research in particular 'embraces subjectivity', which is crucial to a researcher's ability to interpret participants' engagement with social phenomena empathetically and reflexively, thus transforming data into meaningful findings (Haven and Van Grootel, 2019: 234). By transparently dissecting my researcher positioning in section 3.5, I attempt to constructively address the role of subjectivity in my research by contextualising 'my voice' for readers.

All study decisions have implications, and often there are viable alternatives that are worth considering. For instance, when collecting participants' demographic data, I did not ask people to detail the type of dementia that they or loved ones had, nor give an idea of timeframe or stage. As discussed in section 3.3.2, such details often emerged spontaneously in conversation, with the rationale being to explore how people would choose to identify themselves rather than providing pre-determined categories, which are themselves disputed within the research and medical community (Lock, 2013; Whitehouse and George, 2008). However, my generalised demographic dataset is in tension with the key emergent theme of recognising diversity within the term dementia, since I cannot consider stage, timeframe nor type of dementia in relation to participants' responses unless they make this explicit in conversation.

Equally, my specific selection and arrangement of visual and verbal stimuli determined much of participants' responses and conversations, and therefore the study findings. This is made explicit in section 6.2 with: 'I would have only have thought that [about this image] because of the other ones [on the page]' (P7). Although selection was informed by existing guidelines and research, stimulus representativeness would be better ascertained through a more systematic, corpus-assisted selection process. However, whereas linguists can work with millions of words when conducting language-only dementia research (Bailey, 2019), multimodal corpora are yet to become large-scale, still relying greatly on smaller datasets like 11 articles or 100 images (Brookes *et al.*, 2018; Harvey and Brookes, 2019). Large-scale multimodal corpus assisted analyses provides a promising avenue for future research that could inform the selection of more representative stimuli to discuss with participants.

Finally, this project would benefit greatly from involving people affected by dementia, not just as participants but as co-producers. Through shared decision-making in the project's conception, development, management and analysis, the study's scope would expand beyond my own positioning to better address the needs and perspectives of individuals affected by dementia. To do so would require navigating current study barriers, namely resources and time, and focusing on enablers for co-production (Bethell *et al.*, 2018). This is a central recommendation for future research, reflecting the increasing recognition of the abilities and rights of people with dementia to lead and direct research (Davies *et al.*, 2021).

9.5 Future research directions

Building on the preceding recommendations, this section considers how both the design and findings of this project present promising directions for future research. Firstly, there are many ways to expand the study's scope, including regarding stimuli and perspectives. As participants highlight at the end of Chapter 8, more dynamic representations of dementia exist, and future researchers could explore people's responses to video representations of dementia, since films, programmes and adverts increasingly explore dementia and can help shape public awareness of the condition (Schweda, 2019). There are also other facets of dementia that current stimuli do not address, such as situating dementia within disability and human rights discourses, which currently appear to be used primarily by advocates and researchers (Cahill, 2018; Davies *et al.*, 2021; Shakespeare *et al.*, 2019).

As mentioned, the present study focuses on the perspectives of a particular group of people affected by dementia, yet nonetheless clearly demonstrates how intersectional and diverse people's experiences of dementia are. Accordingly, it is vital to listen to the perspectives of a broader range of people, including individuals from different cultural and socioeconomic backgrounds, with differing sexual orientations, ages, ethnicities and types of dementia (Boyle, 2017; Evans, 2018; Hulko, 2009; Pritchard-Jones, 2017). Not only will this help address historic exclusions of certain social groups within the already marginalised group of people with dementia (Innes, 2009; Tilsed, 2019), it will also expand the conversation begun here to one that is more representative of different perspectives within society. Through this, more counter-discourses may emerge that intersect with differing amounts of privilege and oppression, better recognising that people with dementia are 'intersectional beings' (Hulko, 2009: 142). This should enrich representations accordingly, shifting from overrepresenting older heterosexual white people to more nuanced and diverse portrayals that better reflect reality (Bould, 2018; Tilsed, 2019). It is also important to consider the perspectives of other members of society, including medical professionals and members of the public, in order to explore (mis)perceptions and fears surrounding the condition (Alzheimer's Research UK, 2018, 2021), which drive the stigma that participants and other people affected by dementia experience (Alzheimer's Disease International, 2012). Some research has begun to consider public responses to representations (see Van Gorp *et al.*, 2012), but comparative studies that include in-depth, qualitative explorations of how participants situate themselves can further illuminate divergences between people with and without the opportunity to learn and challenge stereotypes (as participants here discuss) through experiencing dementia.

Future research can also more directly influence representations by building on the creative suggestions made by participants to collaboratively create alternative portrayals of dementia. This thesis demonstrates the potential of working with people affected by dementia to explore how such individuals (re)interpret and counter current dementia discourses, including through the changes that people suggest to visual and verbal depictions. Much more work can be done regarding counter-discourses to produce new or revised imagery that is led by people with dementia and their supporters. This visual focus will supplement the numerous language guidelines that have been created by, or with, people affected by dementia (Alzheimer's Society, 2018; Bould, 2018; DEEP, 2014), better reflecting our diverse and increasingly visual society. There are many promising case studies that can be drawn on for such work. Cathy Greenblat's (2011, 2012, 2021) photography showcases aspects of ordinary life, activity and connection for people with dementia, thus offering a more normalising, person-oriented and diverse alternative to popular images that aligns with participant recommendations. Equally, after the Centre for Ageing Better's (2020) report recommended more diverse depictions of older adults, it responded by launching the first free age-positive image library to provide realistic and diverse alternatives to reductive visual stereotypes (Centre for Ageing Better, 2021). Elsewhere, Padfield and colleagues (2018) highlight the value of co-created photographic images that visualise invisible pain, which can strengthen agency for people in pain and help others without such experience to discuss pain. While their focus is on clinical encounters, such work shows how metaphorical co-produced images can help navigate rifts in understanding between people with and without lived experience.

Modelling how visual guidelines may work, Cochrane's (2020) 'Choosing images for sharing evidence: a guide' provides a breakdown of the types of images they do and do not recommend using, with explanations for each. This includes advice on avoiding images that could stigmatise, reinforce stereotypes, or dehumanise people, such as avoiding images that crop out people's heads without clear reason, and providing diverse representations. Alongside photographs, artwork created by people with lived experience of health conditions is recommended as a 'highly impactful and relatable' choice (Cochrane, 2020: 20). Although the value of supporting the creative self-expression of people with dementia is well documented (McFadden *et al.*, 2008; Swinnen, 2016), the educational potential of disseminating pieces by people with lived experience of dementia for supporters, professionals and members of the public requires much greater attention. As Swaffer (2014) highlights, to be meaningful, such work must prioritise people with dementia and overcome some of the barriers that have thus far restricted the take-up of language guidelines by professionals and media organisations alike. Clearly, stigmatising and demeaning imagery is still used, often in conjunction with pejorative language, despite a wealth of language guidance (Brookes *et al.*, 2018, 2021). Future research, then, needs to go beyond providing visual and linguistic alternatives, to also examine the social uptake and impact of such imagery and language choices.

9.6 Concluding remarks

This thesis has worked with people with dementia, carers and loved ones to explore how individuals affected by dementia situate themselves in relation to popular dementia discourses, particularly instances of visual and verbal representations. To do so acknowledges that 'without people with dementia, it is not really possible to assess things from their perspective, either anecdotally or through evidence-based research' (Swaffer, 2014: 712), a stance that has previously been lacking in analyst-oriented research on dementia representations. Through thematic multimodal critical discourse analysis (specifically taking a positive discourse analysis stance), I examine the plurality and subjectivity of our interpretations and note potential routes for positive social change. As experts through experience of dementia, participants provide new insights into how current discourses, which are widely critiqued for being reductive, demeaning and stigmatising (Low and Purwaningrum, 2020; Zeilig, 2014a), can be (re)interpreted and countered. This current chapter considers the implications of such work, outlining promising areas for future research and social change that build on the findings presented here.

As Sabat (2018: 58) states, there is no 'one size fits all' approach to understanding people's experiences of dementia. The same can be said for representations, which participants show need to better reflect the diversity and multiplicity of people with dementia and their experiences. With dementia remaining prevalent and incurable, the focus needs to be on how better to support people who are affected by it. As participants highlight, this includes normalising dementia within society, providing more nuanced representations, and better supporting advocacy for people with dementia. Achieving these recommendations requires actively listening to the perspectives of people with lived experience in order to develop social understandings that are grounded in experience-led expertise. This shift will have multiple benefits for people affected by dementia and society more broadly, with, for instance, people with dementia being able to challenge reductive portrayals and encourage more holistic models of personhood that will benefit all of humanity, both with and without dementia.

‘it’s like a bookshelf’, and ‘sometimes, it’s on the shelf, other times it’s, it’s out’ or ‘miscatalogued’

- Participants 21, 19 and 17

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Appendices

Appendix 1: Example of promotional materials for recruitment

The below leaflet was revised and personalised according to the context. For instance, when trying to recruit more people with dementia, I emphasised this demographic, and if I had arranged a session already that people could attend, I provided details of this.

University of Nottingham
UK | CHINA | MALAYSIA

Dementia and the media focus groups

Midlands4Cities

Emma Putland
Doctoral Researcher

Email:
emma.putland@nottingham.ac.uk

1

What is this study?

Dementia is often in the news these days, and many charities are working to promote the public's awareness and support people experiencing dementia.

What do you think about how dementia is presented in society?

How do newspapers and charities affect **you**?

This is what my research is interested in. Through talking to lots of different people, I hope to build up the best picture I can about social portrayals of dementia and their effects. I would love to hear about your experiences and views on this.

2

Who can take part?

I'm currently looking to hear from **people with experience of dementia** (at any stage). This includes:

- people with dementia
- Current or former carers
- family/friends/colleagues of someone with dementia

Important points:

You're welcome to withdraw at **any** point!

I'll audio record the session so I can accurately transcribe what's said. It'll be clear when the recorder is turned on and off. You're welcome to tell me to exclude any (or all) of your responses, either on the day or afterwards.

What does taking part involve?

The group will last about an **hour** (although you can leave whenever you like). It will include:

- **Introduction and consent process** (to check that you're happy to take part on the day)
- **Demographic questions** (e.g. age, experience with dementia)
- **Group discussion** of dementia and its representations
- Looking at some **images and word choices** from newspapers and charities to see what you think
- Your **feedback** and any final points
- Refreshments are provided, and everyone will get £5 to thank you for your time

Will my taking part in this study be kept confidential?

Yes. Ethical and legal practice will be followed. All your information will be handled in confidence and the project data will be stored securely. Any information you share will be confidential and anonymised.

3

4

What will happen to the results?

This study's results will be presented in my PhD thesis and associated talks and publications.

I want this project to be as useful as possible beyond my PhD, so if you have any suggestions for what you'd like me to do with my findings I'd love to hear them!

You can contact me at:
emma.putland@nottingham.ac.uk

From Depositphotos

5

What can I get from this study?

- Refreshments and £5 for your time
- A chance to explore your thoughts and feelings on this subject, and give your recommendations for change
- The opportunity to help shape research into our collective and individual understandings of dementia

How do I take part?

Please talk to me if you're interested!

We can arrange a time and place to suit you.

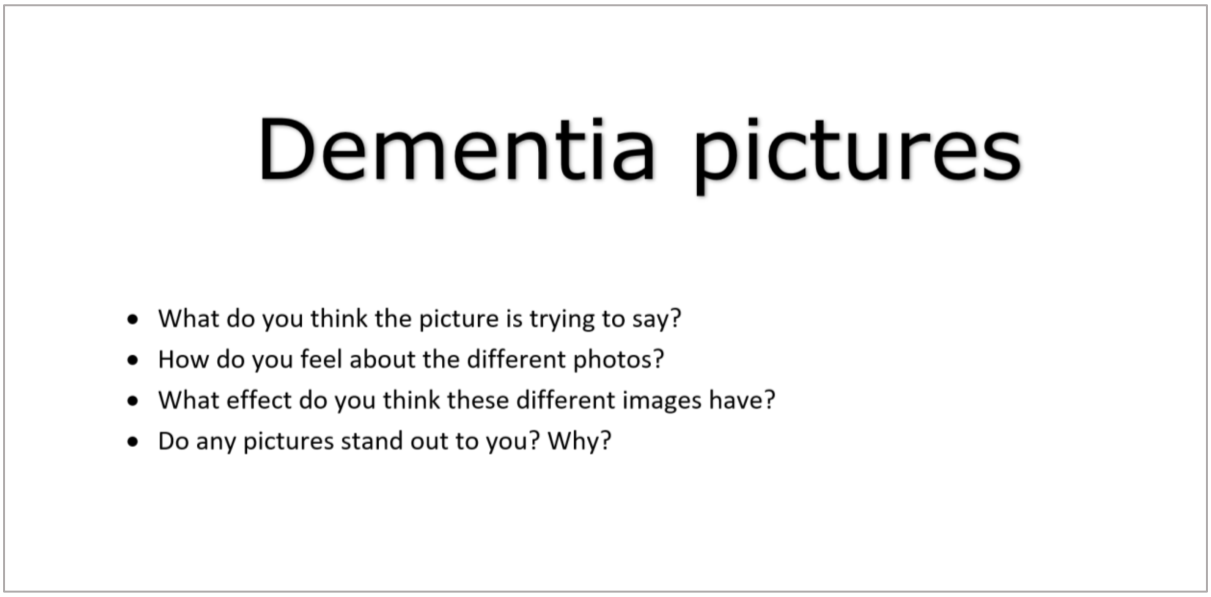
You can contact me at:
emma.putland@nottingham.ac.uk

6

Appendix 2: The organisation and sourcing of visual stimuli

These images are presented in the order and layout of the booklet presented to all participants. Each image is accompanied by information about its source(s), which is for the benefit of the reader and was not information that was provided to participants. Image credits are included if provided by the source.

Front page:



Dementia pictures

- What do you think the picture is trying to say?
- How do you feel about the different photos?
- What effect do you think these different images have?
- Do any pictures stand out to you? Why?

Page 1

1.

3.

2.

4.

Images on page 1 are sourced from newspapers.

1. *The Daily Mail*

> B. Spencer (2018) ‘People who have survived a stroke are TWICE as likely to develop dementia’. https://www.dailymail.co.uk/health/article-6117779/People-survived-stroke-TWICE-likely-develop-dementia.html
>
> B. Spencer (2019) ‘One in five people wrongly believes dementia is 'part of getting old' and almost half don't know how it could be prevented - so what ARE the eight lifestyle changes that cut the risk?’ https://www.dailymail.co.uk/health/article-6670013/One-five-people-wrongly-believe-dementia-getting-old.html
>
> (Image credit: Shutterstock)

2. L. Connor (2019) ‘Debunking some common myths surrounding Alzheimer's disease...’ *Belfast Telegraph*. https://www.belfasttelegraph.co.uk/life/health/debunking-some-common-myths-surrounding-alzheimers-disease--38503030.html (Image: Getty Images/iStockphoto)

3. P. Gallagher (2019) ‘Restaurants and cafés with confusing signs, loud noises and impatient staff are ‘failing people with dementia’’, *i*. https://inews.co.uk/news/health/restaurants-cafes-failing-people-dementia-noisy-alzheimers-494500 (Image: Alzheimer’s Society)

4. A. Hill (2019) ‘How football can spur reconnections for people with dementia’, *The Guardian*. https://www.theguardian.com/society/2019/aug/31/how-football-can-spur-reconnections-for-people-with-dementia (Image: Alicia Canter/The Guardian)

Page 2:

5.

7.

6.

8.

Images on page 2 are sourced from newspapers and charity websites.

5. Alzheimer's Society (2018) 'What is mixed dementia?' https://www.alzheimers.org.uk/blog/what-is-mixed-dementia

6. Alzheimer's Society (2019) 'Younger people with dementia'. https://www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia

7. P. Gallagher (2019) 'Make all new build homes 'dementia friendly', experts say', *inews*. https://inews.co.uk/news/health/new-build-homes-dementia-friendly-legislation-540562 (Image: Getty Images)

8. C. Read (2018) 'Dementia BREAKTHROUGH: Alzheimer's will be treatable like HIV, says top expert', *Express*. https://www.express.co.uk/news/science/928348/Dementia-news-Alzheimer-s-treatable-HIV-Michel-Goedert (Image: Getty Images)

Page 3

9.

11.

10.

12.

Images on page 3 are sourced from a newspaper and stock image banks. Used in news articles, books and a leaflet.

9. Getty Images (2019) 'Human brain dissolving into squares representing data'. https://www.gettyimages.co.uk/detail/photo/brain-data-royalty-free-image/460689423?adppopup=true

10. Shutterstock (2019) ‘Memory loss due to dementia, senior man’. https://www.shutterstock.com/image-photo/memory-loss-due-dementia-senior-man-754295458 Used in:

> Earth.com (2018). ‘Lower socioeconomic status linked to increased risk of dementia’. https://www.earth.com/news/lower-socioeconomic-status-dementia/
>
> Medical Board (2018). ‘Unlocking the Mystery of Memory Loss—The Mind You May Be Missing’, *Health Today*. https://www.hrt.org/unlocking-the-mystery-of-memory-loss-the-mind-you-may-be-missing/

11. iStock (2019) ‘Head shaped trees in fall progression. Memory loss concept stock photo’. https://www.istockphoto.com/photo/head-shaped-trees-in-fall-progression-memory-loss-concept-gm469723628-61723318 Used in:

> Warwickshire County Council Localities team (2017). *Activities and support in North Warwickshire for people with dementia and their carers* (Leaflet). https://www.bedworthhealthcentregps.co.uk/website/M84011/files/Activities%20and%20support%20in%20North%20Warwickshire%20for%20people%20with%20dementia%20and%20their%20carers.pdf
>
> J. Hughes (2014). *How We Think about Dementia: Personhood, Rights, Ethics, the Arts and What They Mean for Care*. London: Jessica Kingsley Publishers.
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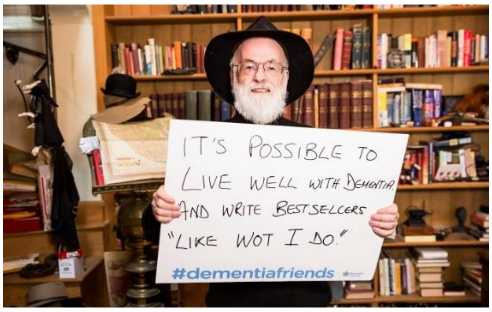
> [Later addition]: D. Weaver (2021) ‘Why don’t we have a cure for Alzheimer’s disease?’ *The Conversation*. http://theconversation.com/why-dont-we-have-a-cure-for-alzheimers-disease-156473

12. S. Cooper-White (2018) ‘What is dementia? Everything you need to know about the symptoms, diagnosis and how to try to avoid it’ *Mirror*. https://www.mirror.co.uk/lifestyle/health/what-dementia-everything-you-need-7262642 (Image: Getty Images)

Page 4

13.



15.

14.

16.

Images on page 4 are sourced from newspapers and charity news.

13. M. Horne (2019) ‘End dementia stigma, says Anne Duncan who ‘remarried’ sufferer’, *The Times*. https://www.thetimes.co.uk/article/end-dementia-stigma-says-anne-duncan-who-remarried-sufferer-rvkbt2sg5

14. Alzheimer’s Research UK (2019) ‘Dunfermline woman steps up to support dementia research in memory of dad’, *ARUK news*. https://www.alzheimersresearchuk.org/dunfermline-woman-steps-up-to-support-dementia-research-in-memory-of-dad/

15. N. Khomami (2017) ‘Terry Pratchett docudrama reveals moment author realised he was 'dead'’, *The Guardian*. https://www.theguardian.com/books/2017/feb/03/terry-pratchett-docudrama-author-dead-alzheimers (Image: Jeff Moore/Dementia Friends/PA)

16. G. Sheldrick (2019) ‘Dame Barbara Windsor’s heartfelt plea to end Alzheimer’s disease agony’, *Express*. https://www.express.co.uk/news/uk/1162179/Alzheimers-disease-Dame-Barbara-Windsor-government-funding (Image: Alzheimer’s Society)

Page 5

17.

19.

18.

20.

Images on page 5 are sourced from newspapers and a charity blog.

17. A. Hill (2019) ‘Alzheimer’s and dementia leading cause of death in England and Wales: Experts call for urgent action to tackle ‘biggest health crisis of our time’’, *The Guardian*. https://www.theguardian.com/society/2019/aug/06/alzheimers-dementia-leading-cause-death-england-wales (Image: Alamy)

18. A. Packer (2019) ‘Dementia is the UK's biggest killer - here are the facts and the big myths’, *Mirror*. https://www.mirror.co.uk/lifestyle/health/dementia-uks-biggest-killer-here-13855319 (Image: Getty Images/Blend Images)

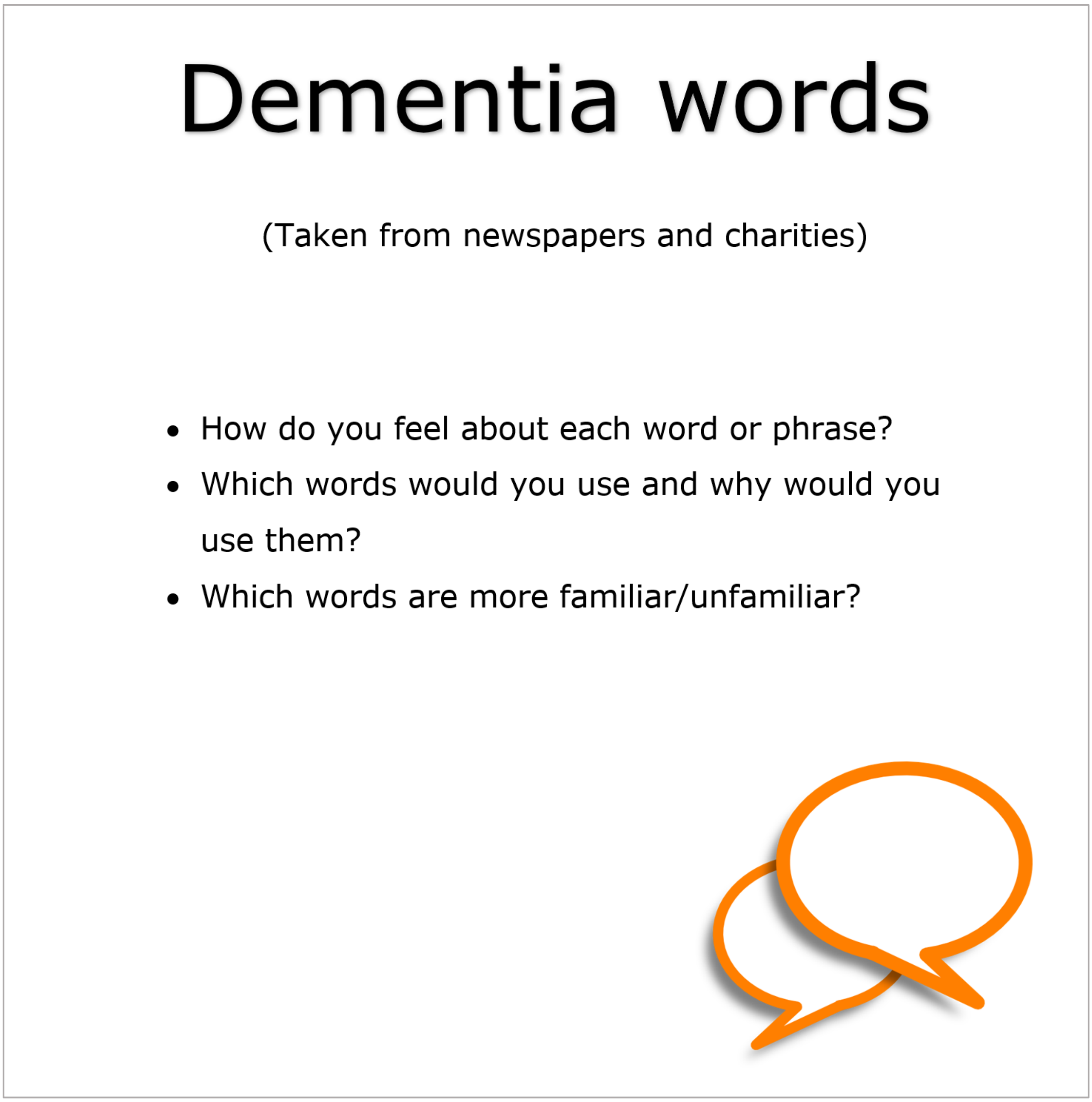
19. J. Gardiner (2019) ‘Hundreds step out to raise awareness and funds in quest to find a cure for dementia’, *Belfast Telegraph*. https://www.belfasttelegraph.co.uk/news/northern-ireland/hundreds-step-out-in-belfast-to-raise-awareness-and-funds-in-the-quest-for-a-cure-for-dementia-38478693.html (Image: Alzheimer’s Society)

20. Alzheimer’s Research Society (2018) ‘Call for determined volunteers to join fight against dementia in Preston and Fylde’, *ARUK news.* https://www.alzheimersresearchuk.org/call-determined-volunteers-join-fight-dementia-preston-fylde/

Appendix 3: Written stimuli

The below stimuli are presented in the order of the page about dementia language. In the sessions, as I presented phrases to participants on individual cards, the order varied. Phrases were always shown first, followed by the three headline/tagline examples.

Front page:



Dementia words

(Taken from newspapers and charities)

- How do you feel about each word or phrase?
- Which words would you use and why would you use them?
- Which words are more familiar/unfamiliar?

Phrases

Suffer with dementia / suffer from dementia

Dementia sufferer

Living with dementia

Living well with dementia

Dementia patient

Dementia friendly

Fight dementia
Beat dementia
Defeat dementia

Sourced from:

Alzheimer's Society. (2018) *Positive language: An Alzheimer's Society guide to talking about dementia*. London: Alzheimer's Society.

Bailey, A. (2019) *Discourses of dementia in the British press: a corpus linguistic approach*. PhD thesis. University of Nottingham, Nottingham.

Bould, E. (2018) *Dementia-friendly media and broadcast guide: A guide to representing dementia in the arts, culture and popular discourse*. Alzheimer's Society.

Brookes, G., Harvey, K., Chadborn, N. and Dening, T. (2018) '"Our biggest killer": multimodal discourse representations of dementia in the British press', *Social Semiotics*, 28(3): 371–395.

DEEP. (2014). *Dementia words matter: Guidelines on language about dementia*. The Dementia Engagement and Empowerment Project.

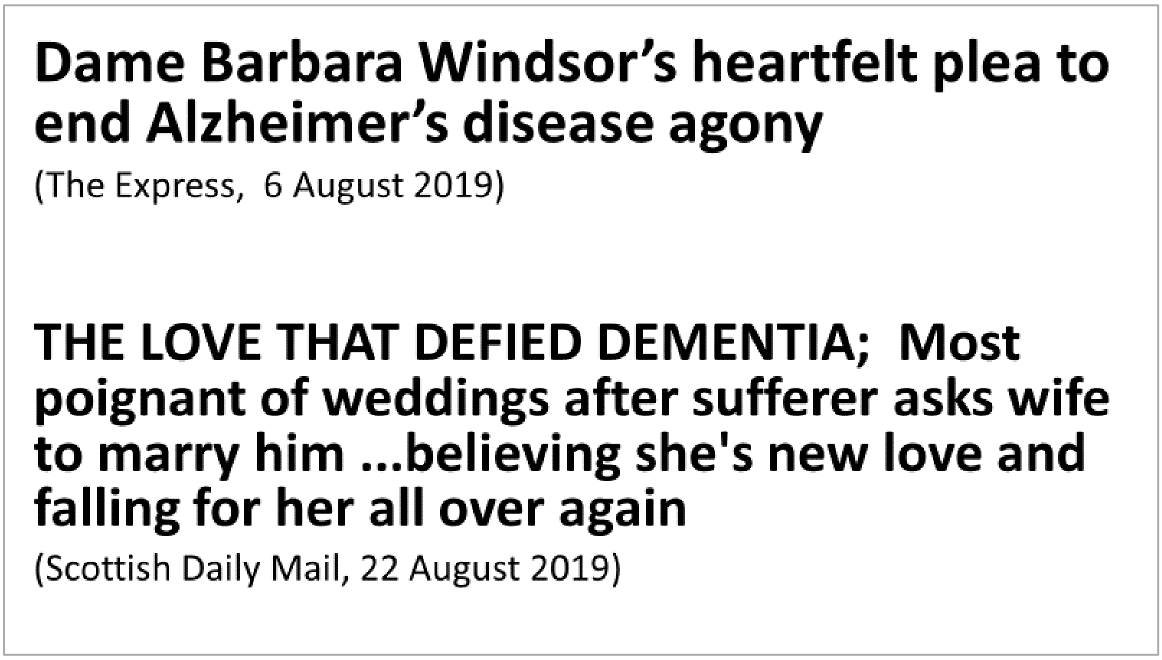
Swaffer, K. (2016). *What the hell happened to my brain? Living beyond dementia*. London: Jessica Kingsley Publishers.

Charity Tagline

Will you advance research to beat the UK's biggest killer?

Sourced from: an Alzheimer's Society fundraising envelope that was posted to a family member while I was collecting stimuli. I took the physical envelope into sessions, which included the Alzheimer's Society logo, and presented the above tagline to participants.

Headlines



Dame Barbara Windsor's heartfelt plea to end Alzheimer's disease agony

(The Express, 6 August 2019)

THE LOVE THAT DEFIED DEMENTIA; Most poignant of weddings after sufferer asks wife to marry him ...believing she's new love and falling for her all over again

(Scottish Daily Mail, 22 August 2019)

These two headlines were selected to provide context for some of the above words, with the aim of sparking debate.

Sourced from:

G. Sheldrick (2019) 'Dame Barbara Windsor's heartfelt plea to end Alzheimer's disease agony', *Express*. https://www.express.co.uk/news/uk/1162179/Alzheimers-disease-Dame-Barbara-Windsor-government-funding

A. Butterworth (2019) 'THE LOVE THAT DEFIED DEMENTIA: Poignant wedding after sufferer asks wife to marry him, believing her to be new love and having fallen for her all over again', *Scottish Daily Mail*. https://www.pressreader.com/uk/scottish-daily-mail/20190822/textview

Appendix 4: Transcription conventions

Below are the transcription conventions used for the interviews and focus groups.

Participants:

Emma	the researcher
P + letter (e.g., PA)	participant with dementia (or pre-dementia) diagnosis
P + number (e.g., P1)	participant without dementia

Pauses:

To make for easier reading, where exact timings are not necessary, I have used punctuation to note increasing pauses:

, (comma)	a pause for breath
. (full stop)	a slightly longer pause of <1 second
[2.0]	any pause of > 1 second is timed (this one is 2 seconds)

Other conventions:

[words]	inserted by researcher
[…]	removed by researcher
(xxx)	unsure of word(s) said
Word- / -word	interruption
# words #	section of simultaneous talk
“words”	participant has put on a voice (e.g., to imitate someone else in speech)
<u>Word</u>	participant has placed emphasis on this word