Representations of dementia in public discourse

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In J. Swallow and A. Hillman (eds.) *Elgar Companion to Dementia and Society*. Edward Elgar.

Introduction

It is important to begin this chapter by acknowledging the diversity and variability of dementia; across contexts, cultures, languages and time, how dementia is represented and understood varies (Boller and Forbes, 1998; Grande, 2018; Koncul, George Onyedikachi and Bartlett, 2024). This chapter focuses on contemporary representations of dementia in public spheres and, reflective of both the field of discourse-based studies and the UK-based authors, it has a particular (although not exclusive) focus on Western contexts and languages, particularly English. Before reviewing how dementia is discursively represented in different communicative contexts (e.g., newspapers, public health texts, etc.) and across different modes (i.e., linguistic and visual representations), it is useful to take a step back and consider what we mean when we discuss how dementia is *discursively* represented, and why this matters.

Dementia tends to be defined in the biomedical sense as a syndrome characterised by diseases and injuries that affect the brain and which progressively impair memory, reasoning, perception and communication, with Alzheimer's disease being the most common type (World Health Organization, 2023). This chapter takes a more holistic approach, regarding dementia as resulting from the interactions of biological, psychological, (inter)personal, environmental and structural factors (George and Whitehouse, 2021; Lock, 2013; Sabat, 2018; Shakespeare, Zeilig and Mittler, 2019). Despite having commonly recognised symptoms, each person's experience of dementia – even of the same type of dementia – is unique. Neurological changes intersect with other aspects of a person's life, personality, identity (which can include but is certainly not limited to race, gender and socioeconomic background), social roles and contexts, necessitating a consideration of a person's broader social environment (Milne, 2020). This includes recognising dementia as a subjective experience that is 'relational and co-created' through our interactions with others (Latimer, 2018, p. 839) as well as with broader socio-political structures (Bartlett and O'Connor, 2010). It is in this context that the discourses surrounding dementia can profoundly shape how people who are diagnosed with dementia, or who are otherwise affected by it (partners, relative-carers, etc.), experience life with the syndrome, including their relationships, opportunities (or lack thereof), sense of identity, and expectations for the future (Kitwood, 1997; Sabat, 2018).

As noted, our focus in this chapter is on how dementia is discursively represented. We refer to discourses here in a broadly poststructuralist sense as 'practices which systematically form the objects of which they speak' (Foucault, 1972, p. 54). This famous definition highlights the constructive potential of discourses to shape social realities through representations. This perspective is also articulated in the following definition of discourse, given by Burr, who refers to a discourse as comprising a:

> 'set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events [...] surrounding any one object, event, person, etc. there may be a variety of different discourses, each with a different story to tell about the object in question, a different way of representing it to the world.'
>
> (Burr, 2015, pp. 74–75)

Discourses, then, entail a particular worldview that is communicated by representational choices. This chapter follows Hall (1997, p. 61) in viewing representation as 'the process by which members of a culture use language [and other forms of communication...] to *produce meaning'* (our emphasis). Importantly, we regard discourses as being both *conditioned by* and as helping to *shape* society, since particular discourses can be 'used to represent, evaluate, argue for and against, and ultimately to legitimate or delegitimate social actions' (Cap, 2023, p. 156). For instance, in the context of representations of dementia, the dominance of the biomedical discourse as a supposedly 'value-free' 'medical fact' has been widely criticised for naturalising within society the notion that a 'cure remains the dominant goal, not care', which influences the allocation of money and other resources accordingly (Ward and Sandberg, 2023, p. 2). Discourses can also impact how individuals perceive themselves and their future – for instance, reproducing profoundly negative metaphors and stereotypes of older age has been associated with ageing anxiety and, at the extreme, with certain older individuals expressing a wish to die rather than continue to age (van Wijngaarden et al., 2019). Discourses also inform how people interpret and behave in particular social contexts. Notably, discourses can naturalise existing actions and (structural) inequalities, such as human rights violations associated with institutional care homes (Steele *et al.*, 2023), or on the other hand they can challenge these and thus contribute to social change. For instance, Heap and Wolverson (2020) worked with paid carers, who initially accessed biomedical discourses of loss, non-communication and lack of personhood (i.e., the status of being a person) when discussing working with residents diagnosed with dementia. After a training session that used alternative discourses, the carers reframed many of their interpretations to focus on more holistic ways of communicating (including nonverbal communication) and on recognising the personhood of people living with dementia.

This chapter focuses on discourse-based studies of public representations of dementia, by which we mean studies that engage with the concept of 'discourses' and that use data drawn from publicly accessible communicative contexts such as the news, rather than, for instance, private conversations in the home (see Table 1). The publications' engagement with the notion of discourse may be methodologically embedded, including through the traditions of discursive psychology (e.g., Lawless, Augoustinos and LeCouteur, 2018a, 2018b), (multimodal) critical discourse studies (e.g., Brookes, Putland and Harvey, 2021) and metaphor analysis (e.g., Castaño, 2020). Or it might be through the authors' discussions of dementia discourses in relation to their findings (e.g., O'Malley, Shortt and Carroll, 2022; Zeilig, 2014). Of course, terminology varies across fields, and there are relevant papers that discuss 'representations', 'narratives', 'constructions' and 'frames', some of which are referenced here (e.g., Herron, Funk and Spencer, 2021; Kessler and Schwender, 2012). This chapter includes a seminal paper on frames and counter frames, which is highly relevant to the notions of discourse and representation outlined above, since framing is essentially 'the manner in which the media and the public represent a particular topic or issue' (Van Gorp and Vercruysse, 2012, p. 1275). The studies included here span a range of communicative contexts and are drawn from the authors' pre-existing knowledge of the field. As Table 1 demonstrates, the majority of studies focus on the news. While at least in part reflecting a greater accessibility of newspapers as data, the news media is nonetheless an important contributor to public discourse. Indeed, the news can be regarded as 'a window on the world' (Tuchman, 1978, p. 1) since the news helps the public to see and understand the world while simultaneously determining what, exactly, is being seen. The discourse studies included here are all written in English and include data from America, Australia, Belgium, Canada, China, Germany, Ireland, Japan, Malaysia, New Zealand, the Netherlands, Norway, Slovakia, Sweden and the United Kingdom (UK).

Table 1. An overview of the main communicative contexts analysed in the studies that inform this chapter.

Communicative contexts	Example studies
News	Ang, Yeo and Koran, 2023; Bailey, Dening and Harvey, 2021; Brookes *et al.*, 2018; Brookes, 2023; Cullum, Simpson and Gounder, 2020; Grigorovich, 2020; Herron, Funk and Spencer, 2021; Johnstone, 2013; Kirkman, 2006; Lawless and Augoustinos, 2017; Leone, Winterton and Blackberry, 2023; MacLeod, 2019; O'Malley, Shortt and Carroll, 2022; Peel, 2014; Petersen and Schicktanz, 2021; Schicktanz, 2021; Šestáková and Plichtová, 2020; Siiner, 2019; Van Gorp and Vercruysse, 2012

Social media (includes blogs and forums)	Bacsu *et al.*, 2022; Bailey, 2020; Bös and Schneider, 2022; Castaño, 2020, 2022; Lawless, Augoustinos and LeCouteur, 2018a
Film and television	Drott, 2018; Kaplan and Chivers, 2018; Johnstone, 2013; Xu, 2021; Zeilig, 2014
Public health and/or non-profit texts	Brookes, Putland and Harvey, 2021; Chelberg, 2023; Johnstone, 2013; King, 2022; Latimer, 2018; Lawless, Augoustinos and LeCouteur, 2018b; Van Gorp and Vercruysse, 2012
Newspaper, stock image bank and/or AI-generated images	Ang, Yeo and Koran, 2023; Brookes *et al.*, 2018; Harvey and Brookes, 2019; Kessler and Schwender, 2012; Putland, Chikodzore-Paterson and Brookes, 2023
Academic/medical texts	Johnstone, 2013; Petersen and Schicktanz, 2021; Zeilig, 2014
Promotional texts (campaigns, adverts etc.)	Brookes, Putland and Harvey, 2021; Vermeer, Higgs and Charlesworth, 2022
Literature (books, magazines and AI-generated writing)	Caldwell, Falcus and Sako, 2021; Clarke, 2006; Van Gorp and Vercruysse, 2012; Zimmermann, 2017; Putland, Chikodzore-Paterson and Brookes, 2025
Consult stakeholders on publicly accessible texts	Ang, Yeo and Koran, 2023; Peel, 2014; Putland, 2022, 2025; Slocombe *et al.*, 2025; Vermeer, Higgs and Charlesworth, 2022

It is important to note that public discourses around dementia have the potential to reinforce, but also to challenge, dementia stigma (for reviews on dementia representations in the context of stigma, see Low and Purwaningrum, 2020; Putland and Brookes, 2024a, 2024b). Stigma is popularly defined according to the seminal work of Erving Goffman (1963, p. 3) as referring to 'an attribute that is deeply discrediting' (here, a dementia diagnosis), which results in a person being 'reduced in our minds from a whole and usual person to a tainted, discounted one'. Such aspects of one's person – or 'attributes', as Goffman puts it – are not inherently discrediting; rather, stigma is a social process whereby members of marginalised groups are positioned as undesirable according to socially constructed criteria (Jones and Corrigan, 2014). Dementia stigma is a global issue, with a recent international survey finding that 88% of people living with dementia reported experiencing discrimination (Alzheimer's Disease International, 2024). Especially without a viable cure on the near horizon, attending to how society can better support people living with dementia is a global priority (Kenigsberg *et al.*, 2016). In the words of a blogger living with young-onset dementia: 'a cure would be nice but a better way to live with dementia is better' (Castaño, 2023, p. 14). Attending to discourses, as this chapter will demonstrate, is fundamental to such an aim.

Representing dementia and people with dementia

Across the many discourses surrounding dementia in the public sphere, some certainly appear to be more prominent than others. This section therefore begins with a discussion of the most prominent of these: the biomedical discourse and some of its key intersections, notably with 'successful ageing' and hypercognitive discourses. A biomedical discourse is so-named because it foregrounds the biological and medical aspects of dementia, notably the physical disease pathways and medical responses. Multiple studies, spanning different countries and almost two decades, indicate that news reporting on dementia consistently foregrounds a biomedical discourse above alternative ones, notably by reporting on the pathology of dementia, clinical research into treatments, and strategies to reduce dementia risk (Bailey, Dening and Harvey, 2021; Clarke, 2006; Kirkman, 2006; Šestáková and Plichtová, 2020).

The complexities of the biomedical field tend to be (over)simplified in mainstream channels of communication. While making biomedical knowledge more accessible for audiences, this simplification carries ideological consequences. For instance, metaphors can relate pathological processes to everyday ones, as with the metaphor that *the body is a machine*, whereby increasing plaques and tangles in the brain are likened to waste in a pipe or a faulty computer system. As Bailey, Dening and Harvey (2021, p. 372) argue, such metaphors position the diagnosed individual as 'merely a passive vessel within which the syndrome progresses' while assuming science can 'fix' what is 'broken' despite strong uncertainties in the medical sphere (George and Whitehouse, 2021).

Likewise, when technical diagnostic images such as brain scans are used to visualise dementia in public contexts such as newspapers, these diagnostic tools are likely to be interpreted as tangibly *showing* what dementia looks like in the brain, ignoring the uncertainties in the biomedical field surrounding the relationship between symptoms and brain pathology, most discussed in the case of Alzheimer's disease (George and Whitehouse, 2021). These icons of neuroscientific authority are difficult for untrained viewers to interpret without appropriate context, and instead, the brain scans tend to be interpreted in the context of a hypercognitive society, whereby the brain 'harbors all that defines the self' (Zimmermann, 2017, p. 81) and rationality, independence, self-control, economic productivity and cognitive enhancement are key values (Post, 2000). When people are defined by their brains, the scans risk being conflated with the *person* themselves, thus potentially encouraging viewers to distinguish between a "healthy, normal" brain (and person) and a "pathological, diseased" one (Brookes *et al.*, 2018; Harvey and Brookes, 2019). Both the metaphors and brain scans exemplify that when the biomedical discourse overly dominates, people living with dementia risk being reduced to their "dysfunctional" brains, reinforcing the belief that 'everything a person with dementia does and feels is the

outcome of brain damage and is abnormal in one way or another' (Sabat, 2014, p. 108). This disease-first focus can also manifest in particular language choices, including medicalising people with dementia as 'patients' outside of a clinical context or positioning them as dementia 'sufferers' and 'victims' (Bailey, Dening and Harvey, 2021).

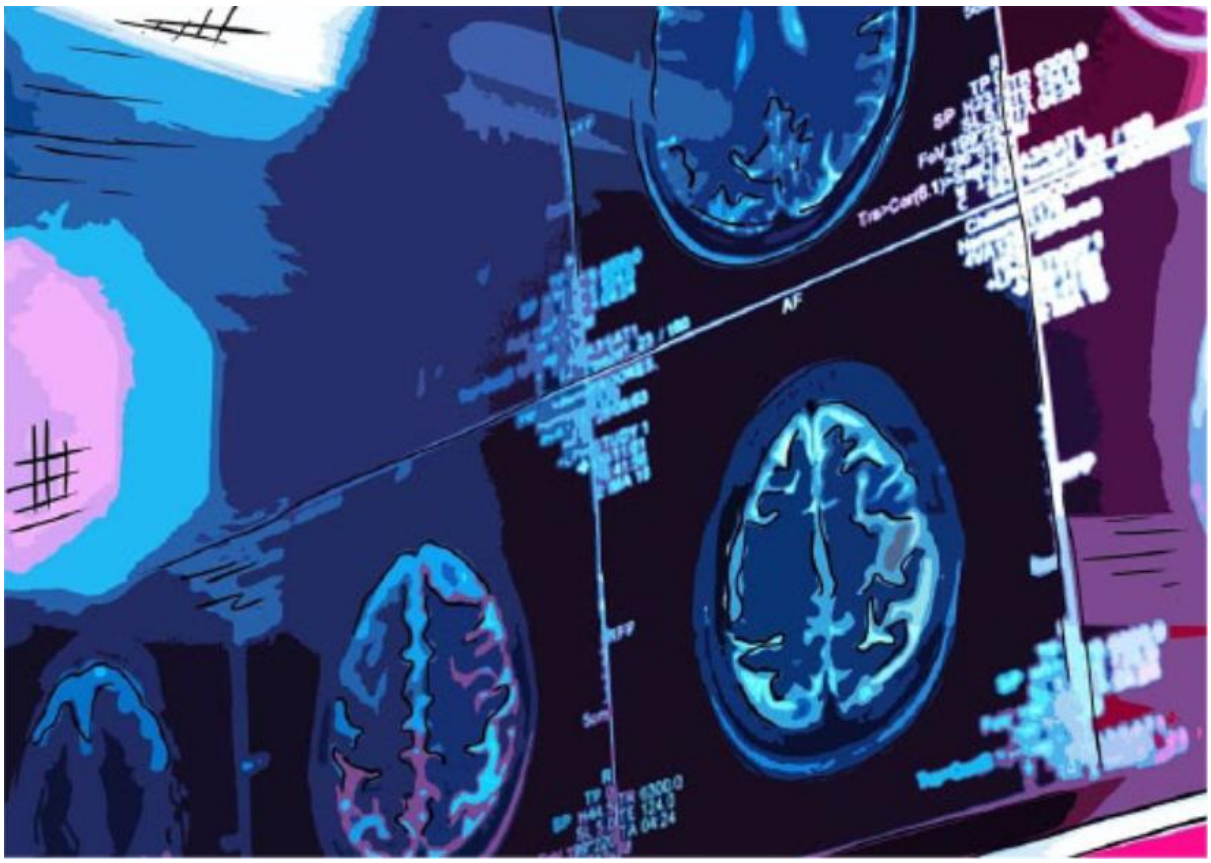

Figure 1. An artist's impression of a human brain scan in a neurology clinic, reproduced from Harvey and Brookes (2019, p. 996).

Relatedly, rather than the multifaceted approach to dementia risk identified in medical literature (Petersen and Schicktanz, 2021), representations in public facing contexts (e.g., newspapers and charity webpages) seem to foreground individual risk and preventive action. This is exemplified by newspaper headlines such as 'Take a walk to keep dementia at bay', 'Beetroot can fight dementia' and 'How We Should Live to Protect Ourselves From Dementia' (Peel, 2014, pp. 889, 894; Petersen and Schicktanz, 2021, p. 2011). Such representations signal the intersection of a biomedical discourse with a neoliberal one of 'successful ageing'; this discourse values individuals 'keeping productive, independent, fit and healthy, including managing risk', against which, dementia typifies "ageing badly" (Latimer, 2018, p. 841). Thus, individuals are attributed a moral duty to take action to prevent or mitigate dementia (and may themselves construct self-responsible identities; Lawless, Augoustinos and LeCouteur, 2018a). This ignores the complex multifaceted interactions of dementia risk factors (much of which

is beyond human control) and thus risks blaming individuals for their dementia (Chelberg, 2023; Lawless and Augoustinos, 2017; Lawless, Augoustinos and LeCouteur, 2018b; Peel, 2014; Petersen and Schicktanz, 2021; Šestáková and Plichtová, 2020; Xu, 2021). Such blame may not be equally distributed, with Cullum, Simpson and Gounder (2020, p. 26) reflecting on the particular victim-blaming of Māori and New Zealand Pacific Islanders in New Zealand media coverage for chronic conditions and warning that 'dementia could become yet another chronic disease that is more common in socially disadvantaged peoples, who are then made responsible for developing the disease and morally judged for their assumed unhealthy lifestyle choices and health-related behaviours having an impact on society as a whole'.

The ethical concerns associated with this individualised risk discourse are being noted more broadly. For example, Knaggs and Siette (2025: p. 100718) have recently called, in a clinically oriented journal, for public health messaging about dementia prevention to 'empower individuals without inadvertently shifting undue burden onto them or overlooking the broader social determinants of health'. This recognises that coverage of dementia prevention/risk largely backgrounds the responsibility of wider society to support cognitive health, for instance, by reducing air pollution and supporting equal access to education (George and Whitehouse, 2021; Livingston *et al.*, 2024). This is not to say that coverage of such issues does not exist (see Cullum, Simpson and Gounder, 2020); for example, in the UK, newspaper campaigns have held footballing authorities accountable for needing to protect footballers from unnecessary traumatic brain injuries, another risk factor for dementia (Putland *et al.*, Forthcoming). Returning to the above example news headlines, it is notable that dementia is discursively constructed as something to 'keep at bay', 'fight' and 'protect ourselves' from. This reflects what Peel (2014) has termed a 'panic-blame framework', whereby representations of dementia as a catastrophic threat (which can cause 'panic') are juxtaposed by individualistic behavioural and lifestyle actions that enable people to 'fight' – or at least delay – the condition (which risks attributing 'blame' to individuals who do not succeed).

Indeed, dementia is often discursively constructed as a threat at both an individual and societal level. Metaphors are a powerful framing device here, with dementia often being positioned as a natural disaster (e.g., as a tsunami, an epidemic), a military threat (timebomb) an immoral physical threat (an invader/thief/monster), a death threat (death sentence, killer) and as a threat to the self (whereby people with dementia undergo a loss of the self and become the living dead) (Brookes, 2023; Brookes *et al.*, 2018; Castaño, 2020; Clarke, 2006; Johnstone, 2013; Šestáková and Plichtová, 2020; Van Gorp and Vercruysse, 2012; Zeilig, 2014). It is not uncommon to see phrases such as 'BRITAIN faces a dementia *timebomb* with one in three people born this year expected to develop the condition, research shows', 'DEMENTIA is a silent

epidemic' and 'Dementia is the *cruellest* of diseases. It *robs* you of your faculties, your dignity, your identity' (Brookes, 2023, pp. 220–221; original emphasis). The third example demonstrates the propensity to anthropomorphise dementia as an animate being with cruel intent, who is 'threatening, attacking, destroying lives and haunting modern society' (Šestáková and Plichtová, 2020, p. 387). In such representations, there is little room for agency for people living with dementia, who tend to be positioned as the personified dementia's helpless victims. Having said this, Bailey (2020, p. 256) suggests that for diagnosed individuals, positioning dementia as a monster that they are in conflict with can be a useful strategy to separate dementia from their identity, as exemplified by 'Sorry, I'm not forgetful, I have a disease that eats thoughts and memories not just hides them for a while. Aaaaaaaaaagghhhhh!!!!'. Likewise, there are examples of people living with dementia establishing more agentive fighting identities (Castaño, 2020, 2023) and refusing victimhood, as with one message board user who writes that 'I had dementia, I was not going out like a victim!' (Bös and Schneider, 2022, p. 222).

The metaphorical conceptualisation of dementia as a threat is so integral to popular understandings of the syndrome that Zeilig (2014, p. 262) asserts that dementia has *itself* become a metaphor, whereby 'Dementia = a complex, unknowable world of doom, ageing, and a fate worse than death'. Sometimes, the threat that dementia poses to society is economic, with statistics focusing on prevalence in relation to expenditure (Chelberg, 2023; Latimer, 2018). The burden of care for individuals may also be presented, including through statements such as 'the disease that is destroying him is also consuming his wife' (Johnstone, 2013, p. 385), or the implication that a caring relative is 'forced' to put aside their wishes, as with 'Linda wanted to leave her unfaithful husband: when she learned the cruel truth, it forced her to stay with him forever' (Šestáková and Plichtová, 2020, p. 393). Perhaps this may be related to the individualisation of responsibility for care in at least some cultural contexts, with family members being attributed the responsibility to care for people living with dementia (Šestáková and Plichtová, 2020; Xu, 2021). Figure 2 exemplifies another way in which dementia is associated with threat, namely by focusing on disaster scenarios that can occur when experiencing memory loss (here, leaving the bath running until it overflows). While memory loss is a common symptom of dementia, concerningly, it is the *only* symptom acknowledged by Figure 2 and its companion posters from a campaign promoting dementia diagnoses, which was run by the Alzheimer's Society and National Health Service (NHS) in the UK.

Figure 2. An artist's impression of a UK campaign poster by Alzheimer's Society and the National Health Service (NHS), reproduced from Brookes, Putland and Harvey (2021, p. 251).

The poster in Figure 2 is a compelling example of how people diagnosed (or in this case, soon-to-be diagnosed) with dementia are oftentimes depicted: as passive and fading social "others". Linguistically, the campaign directly addresses people who know someone who might have dementia, but *not* people who identify as potentially having dementia themselves, as exemplified by the statement that 'Spotting the signs early means *you* can get *them* the right treatment and support. And *you* get to keep the person *you* know and love a bit longer' (our emphasis). A similar disregard of people living with dementia has been observed in surveillance technology advertisements, where individuals living with dementia tend to be ignored as potential technology users, and are even sometimes positioned as objects and listed alongside possessions, children and pets as objects to be tracked (Vermeer, Higgs and Charlesworth, 2022).

Ignoring the perspective of people who have (or will soon have) a dementia diagnosis reflects a wider occlusion of the perspectives and voices of people living with dementia from public discourse, wherein such people have historically been made 'essentially voiceless' through discursive backgrounding or exclusion (Clarke, 2006, p. 272), even in news coverage of their social and spatial rights (Leone, Winterton and Blackberry, 2023). Grammatically, people with dementia are often cast in the role of object, in which they are acted upon by others – oftentimes, doctors, scientists, supporters and dementia itself (rendered metaphorically as a social actor)(Bailey, Dening and Harvey, 2021; Šestáková and Plichtová, 2020). Alongside being positioned as dementia's victims, people living with dementia can be victims of other social actors (through neglect and abuse) and of inequalities within structures such as health services (Bailey, Dening and Harvey, 2021; Grigorovich, 2020; Kirkman, 2006). This is not always the case; an alternative to the vulnerable victim is the "'violent dementia patient" perpetrator' in media reports that position people living with dementia as threats, namely as the perpetrators of sexual crimes or aggression against others, often fellow residents, staff or family carers (Grigorovich, 2020; Herron, Funk and Spencer, 2021, p.2081). A dual identity can thus be created, with such individuals being 'at once a victim of dementia and aggressor of violence' (Herron, Funk and Spencer, 2021, p.2082).

If the experiences, needs or rights of people with dementia *are* discussed, these have tended to be expressed by other social actors, such as care partners, relatives, medical professionals and government representatives (Clarke, 2006; Herron, Funk and Spencer, 2021; Leone, Winterton and Blackberry, 2023). Moreover, O'Malley, Shortt, and Carroll (2022, 1358) find that, even when people with dementia are featured, newspapers may quote only the same few individuals, and editorial choices can frame their contributions to fit dominant dementia discourses (e.g., 'dementia sufferer tells of her ordeal'). Moreover, dementia discourses also intersect with *other* dominant discourses to represent (certain) people living with dementia in distinct ways within

public discourse, including in relation to gender, sexuality, age, socioeconomic status and race (for greater discussion of the concept of intersectionality, see Crenshaw's seminal 1991 work). Recognising an imbalance in media portrayals, Kaplan and Chivers (2018: 2) observe that 'prominent circulating [...] images [of dementia] portray white, middle-class women and men, typically cared for by heroic family members with the occasional, backgrounded, appearance of racialized care workers'. MacLeod (2019) further highlights the absence of Indigenous perspectives in Canadian news articles and an overall failure to consider the link between systemic issues (including dementia care, healthcare and policing) and colonialism. King (2022) critiques the heteronormative framing of an Alzheimer's Society video advertisement, while Grigorovich (2020) finds that when reporting on dementia and sexuality, the news is more likely to construct men with dementia as sexual predators and passivise women as asexual (and sometimes infantile) victims. A recent study of gendered AI-generated character descriptions of people with dementia similarly finds that, although dementia is the primary identity feature, the bodies, social roles and threat ascribed to men and women with dementia aligns with traditional Western gender norms (Putland, Chikodzore-Paterson and Brookes, 2025). Focusing instead on intersections with race, MacLeod's (2019: 69) analysis of the media coverage of an Indigenous man, Joe, argues that the news stories 'evoke and sustain the racist stereotyping of Indigenous people as violent criminals'. Meanwhile, age can also impact how people living with dementia are represented, including newspapers foregrounding of the cruelty of dementia diagnoses for younger people (Sestáková and Plichtová, 2020) or social media posts positioning older people with dementia as lesser (e.g., 'my granny is 95, in a home, with full blown dementia. Quick Covid death clearly not a disaster there', Bacsu *et al*. 2022: 4).

Visually, it is notable that the woman in Figure 2 appears to be paused, in the act of forgetting, with half of her head fading into a disaster scenario (an overflowing bath), and that she looks away, rather than directly at viewers. This visual formula, which is replicated across the campaign (see Brookes, Putland and Harvey 2021), reflects multiple visual tropes for people living with dementia, who tend to avoid eye contact with viewers or other represented participants by looking down, looking vacantly elsewhere, or having their eyes closed (see also: Caldwell, Falcus and Sako, 2021; Harvey and Brookes, 2019; Putland, Chikodzore-Paterson and Brookes, 2023). This lack of eye contact is likely to discourage viewers from feeling social affinity with the represented individuals by 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, 2021: 118). Further distancing people with dementia, such individuals are often visualised in ways that may encourage viewers to see manifestations of dementia 'before and perhaps instead of the person' (Brookes *et al.*, 2018, p. 384). The brain scans discussed earlier (see Figure 1) are one such example, as are close-up shots of

disembodied hands (see Figure 3). These hands tend to emphasise markers of older age (including wrinkles and prominent veins) and work to depersonalise the individual by removing their face. Notably, decontextualised hands may be used to signal distress and isolation (especially when shown alone), dependency (e.g., if using a medical aid), or comfort and support (e.g., through holding hands) (Ang, Yeo and Koran, 2023; Brookes *et al.*, 2018; Harvey and Brookes, 2019). When faces are shown, hands may also be used to foreground dementia, either by pointing to or otherwise touching the brain area, often with a pained expression (Ang, Yeo and Koran, 2023; Brookes *et al.*, 2018; Putland, Chikodzore-Paterson and Brookes, 2023).

Figure 3. An artist's impression of examples of images of hands, reproduced from Brookes *et al.* (2018, p. 385).

Also underpinning Figure 2's promise to 'keep the person you know and love a bit longer' is the hypercognitive assumption that a neurodegenerative condition such as dementia entails a gradual loss of self (e.g., 'I will slowly, subtly lose me': Castaño, 2020, p. 120) since 'lose the use of your brain by degrees and the self is stripped away, layer by layer' (Zimmermann, 2017, p. 87). A trajectory of increasing loss is created, whereby increasing cognitive decline is envisioned as people eventually becoming 'empty shells' with 'no identity' (Van Gorp and Vercruysse, 2012, pp. 1276–1277) and being in a state of living death (Johnstone, 2013; Van Gorp and Vercruysse, 2012; Putland, Chikodzore-Paterson and Brookes, 2023, 2025). As such, dementia can be regarded as a death sentence (Castaño, 2020; Kirkman, 2006). These dehumanising and death-oriented representations were found to be particularly extreme in a recent study of AI-generated character prompts, where characters living with dementia were described as being 'without warmth, without life, as cold and dead as the grave' and as having 'no fragrance of life, no essence of humanity' (Putland, Chikodzore-Paterson and Brookes, 2025, p. 194). This discourse manifests visually, too, including through depicting individuals as fading away or disintegrating, and by showing individuals in a zombie-like state (e.g., vacant expressions, immobile bodies) exacerbated by dull, lifeless colour palettes (Brookes, Putland and Harvey, 2021; Harvey and Brookes, 2019). Metaphorical visualisations of loss and (neuro)degeneration are also popular, including jigsaws with a missing piece, head-shaped trees losing leaves, growing tangles of weeds in a garden and tidal erosion of a sand-built face (Figure 4; Ang, Yeo and Koran, 2023; Brookes *et al.*, 2018; Harvey and Brookes, 2019; Caldwell, Falcus and Sako, 2021; Putland, 2022; Putland, Chikodzore-Paterson and Brookes, 2023).

Figure 4. A visual metaphor showing three seasonal tree heads, reproduced from Putland (2022, p. 1474).

There are, of course, alternative discourses of dementia in the public sphere, which this section ends by focusing on. Offering an important counter to the discourse of a loss of self are discourses that take a more relational and embodied approach to the self. Notably, Drott (2018) argues that Japanese films tend to be more concerned with emotional, physical and social aspects of dementia relative to American film's emphasis on cognitive changes. Overall, dementia in a Japanese context is depicted 'not as a loss of self, but as a transformation. Not obliteration, but change' (Drott, 2018: 22). Moreover, within America itself (and resonating more broadly), 'settler logics' of dementia as a disease that needs medical care may clash with traditional Indigenous understandings of dementia as 'a spiritual state of being elsewhere' (Grande, 2018, p. 174).

Relatedly, a key counter-discourse that has emerged in recent decades is broadly termed 'living well with dementia', which foregrounds the enduring personhood of people living with dementia and positions dementia as a manageable disability (Castaño, 2023). This discourse may manifest in images of people living with dementia showing positive affect (e.g., smiling), agency and being socially connected (e.g., showing affection) either with other represented participants or viewers (Figure 5; Ang, Yeo and Koran, 2023; Harvey and Brookes, 2019; Kessler and Schwender, 2012). Even in the AI-generated text and images, which tended to align with the tropes discussed above, there were images of people smiling and interacting, and descriptions of characters with dementia connecting with others (e.g., 'when she saw me, her eyes lit up with surprise and warmth. She reached out with her hand and gently shook mine') (Putland, Chikodzore-Paterson and Brookes, 2023, 2025, p. 199). The right to be different and to engage meaningfully in society is also portrayed, as is being able to enjoy life and to be supported by others to do so (Bös and Schneider, 2022; Leone, Winterton and Blackberry, 2023; Xu, 2021).

Figure 5. A stock image of a senior woman and a caregiver (artist's impression, reproduced from Harvey and Brookes (2019, p. 995)).

Notably, while the 'living well' discourse is an important counter to the above discourses (aptly collectively named a 'tragedy discourse'; McParland, Kelly and Innes,

2017), when combined with other discourses it can have very different ideological implications. First, if combined with a rights-based discourse, society is made responsible for supporting people to live well with dementia by meeting individuals' diverse needs (Leone, Winterton and Blackberry, 2023); this includes people with dementia identifying 'overarching barriers' and calling for greater 'political will and leadership' to establish a more inclusive approach to support (O'Malley, Shortt and Carroll, 2022, p. 1352). But a 'living well' discourse can also be associated with the focus on maintaining brain health as a strategy to 'live well' (Peel, 2014). This individualised and hypercognitive focus on 'living well' adds pressure to "age successfully" by maintaining independence as a cognitively "productive" member of society (Xu, 2021), which further marginalises individuals unable to achieve this (McParland, Kelly and Innes, 2017). Equally, while a 'living well' discourse has become more prominent over time, it has not necessarily been accompanied by a greater emphasis on the voices and perspectives of people living with dementia (Leone, Winterton and Blackberry, 2023; Siiner, 2019).

Rather than being defined by their diagnosis, people living with dementia themselves tend to express multifaceted identities and may reject both being labelled by dementia ('I am me not the illness. I am not a label'; Castaño, 2023, p. 8) and the discourse that dementia entails a loss of self. Notably, one user of a message board for people affected by dementia claims that:

> 'Dementia offers you a unique ability to purify yourself. It destroys the ego … and all the made up parts of one's personality (all the fake and pretend things). Until you become just you, the you you came into this world as … pure, whole, and complete. A shedding of sorts, an unencumbering … in preparation for heaven'
>
> (Bös and Schneider, 2022, p. 229).

Here, then, while dementia is still positioned as destructive, the neurodegenerative process usually associated with loss is instead associated with a (spiritual) purification and thus with becoming not a lesser but a *purer* form of yourself: 'just you'. Elsewhere, people may emphasise the continuation of self (as with 'I am still the same person inside'; Caldwell, Falcus and Sako, 2021; Castaño, 2023, p. 8) or a transformation of self, as with 'I'm still me, or at least a version of me' (Castaño, 2020, p. 120). Sometimes, a more socially oriented approach to maintaining identity is explored, as with some children's picturebooks, whereby child characters can support their grandparents by being 'the holder of memory', often sitting on their grandparent's lap and sharing memories or meaningful items (Caldwell, Falcus and Sako, 2021, p. 125). A range of non-destructive metaphors for experiencing dementia can also be used, including positioning dementia as an annoying visitor or companion, and presenting life

with dementia as a journey (e.g., 'I will travel this path with honour and integrity'; Castaño, 2023, p. 8).

Increasingly, studies are also considering how different groups might respond to examples of public discourse, moving beyond just the researchers' interpretations to consider those of people living with dementia, carers and family/friends, and people with professional links to dementia, such as doctors and dementia non-profit employees (Ang, Yeo and Koran, 2023; Peel, 2014; Putland, 2022, 2025; Slocombe *et al.*, 2025; Vermeer, Higgs and Charlesworth, 2022). For instance, Slocombe *et al.* (2025) found personal experience to impact how people respond to preventative media messages, with carers and people with dementia resisting media claims that dementia can be delayed/prevented, while those with less personal experience evaluated the messages as educational and able to promote positive lifestyle changes. Overall, such studies highlight the subjectivity of interpretations and may contradict researchers' analyses; for instance, Ang, Yeo and Koran (2023, p. 635) interviewed employees of the Alzheimer's Disease Foundation Malaysia and found that they had more positive interpretations of metaphorical brain degeneration images (such as a missing jigsaw puzzle piece being removed), evaluating it as 'an accessible way to explain these complex abstract processes in the brain to the public'. A similar interpretation was observed for Figure 4, with many interviewees affected by dementia (either by a diagnosis, a caring role or being close family/friends for someone diagnosed) positioning the tree-head image as clearly explaining what happens in the brain with dementia, while other participants either found it meaningless, or criticised it for being unduly loss-oriented, linear and hopeless (Putland, 2022, 2025). While small in number, such studies offer a powerful reminder of the importance of considering audience reception *as well as* analysing social texts when discussing public discourse. The perspectives of text producers are also important to consider, with Ang, Yeo and Koran (2023)'s interviews with non-profit employees foregrounding that while showing real-life people with dementia and their carers in a personal way would be ideal, this must be balanced with the need for confidentiality and privacy.

Looking forward

In this chapter, we have sought to provide a review of some of the key discourses about dementia in the public sphere. While not exhaustive, we have charted some of the major visual and linguistic tropes – tropes that, it must be said, are often reductive, exclusionary, and contribute to the stigmatisation of people living with dementia (for an extensive discussion of dementia stigma and discursive representations, see Putland and Brookes, 2024a, 2024b). Notably, a biomedical discourse risks reducing people living with dementia to their disease, as if facing a 'person-with-DEMENTIA' rather than a 'PERSON-with-dementia' (Kitwood, 1997, p. 7; original emphasis). Combined with hypercognitive and 'successful ageing' discourses, people are encouraged to prevent or

to ‘live well’ with dementia through individual actions, in order to aim for the “ideal” of a cognitively productive and self-responsible citizen. Against this ideal, dementia poses the ultimate threat to individuals and societies, often being catastrophised and anthropomorphised as an agentive and destructive social actor (e.g., a ‘killer’), whereas people living with dementia become its ‘victims’ and ‘sufferers’. Relatedly, there is a trend of passivising individuals living with dementia, who tend to be excluded as both speakers and addressees. Oftentimes, individuals diagnosed with dementia are represented in terms of loss and degeneration and, at the extreme, are presented as experiencing a living death. Such representations contribute to what has elsewhere been termed a ‘tragedy’ discourse (Castaño, 2023; McParland, Kelly and Innes, 2017). Overall, such representations tend to negatively label and stereotype both dementia and people living with the syndrome, separate people diagnosed with dementia from everyone else by creating a “normal us” and an “abnormal them” and contribute to the status loss and discrimination experienced by so many diagnosed individuals (and those affiliated with them), all of which can be associated with the perpetuation of dementia stigma (Link and Phelan, 2001).

Threaded throughout this chapter is the issue of *imbalance*. While there are some examples of public-facing content by people living with dementia (e.g., Castaño, 2020, 2022) far more often, the sources of the representations discussed here are institutions, such as the news media, medicine/academia, non-profits and companies (e.g., stock image banks). Institutional pressures may favour certain discourses (and perspectives) above others; notably, biomedical and ‘tragedy’ discourses have been used for decades to justify financially supporting medical research. Meanwhile, the goal of mainstream news media and social media is to make a profit by capturing readers’ attention, which may encourage the use of sensationalised language. Non-profits, too, must navigate gaining public financial support with supporting people affected by dementia, and can draw on a range of discourses to do so. Notably, a controversial Alzheimer’s Society advert in 2024 asserted that, ‘With dementia, you don’t just die once. You die again, and again, and again’. Dominant dementia discourses also intersect with other dominant social discourses to naturalise existing social structures and norms. MacLeod (2019) offers a particularly compelling example of this in her analysis of how Canadian news media’s use of a ‘dementia crisis’ discourse homogenises the Canadian population, perpetuates racist stereotypes and ignores both Indigenous perspectives and the impact of colonial healthcare and justice systems. MacLeod’s work is an important reminder that the diversity of people affected by dementia is often not reflected in public discourse. The same critique can also be applied to academia; the Global North is clearly overrepresented in this chapter, as are the perspectives of people without dementia. This in part reflects the restricted choice of data in the academic literature examined here, as well as (structural) barriers that

can restrict the prominence of people with dementia in research (ethical procedures being a key example).

This chapter has also shed light on alternative discourses, which can be related to (but are not confined to) the 'living well' discourse, a major counter-discourse to the 'tragedy' discourse discussed above (McParland, Kelly and Innes, 2017). Representational tropes associated with this discourse include showing people living with dementia as engaged, connected and active participants in society, and as able to enjoy life. The assumption that dementia entails a loss of self is challenged, and the neurodegenerative process is reimagined as a continuation or transformation of self. When the voices of people living with dementia are foregrounded, such individuals often present multifaceted identities that can include, but are not defined by, their dementia diagnosis. Such discourses can be used to challenge dementia stigma by emphasising social connection and presenting dementia as a manageable chronic condition. Having said this, stigma is a complex and multifaceted social phenomenon, and Fletcher (2021) has convincingly argued that campaigns that aim to destigmatise dementia through the 'living well' discourse can inadvertently stigmatise people living with dementia. Notably, a 'living well' discourse tends to have exclusionary criteria for who is shown to be 'living well' with dementia (predominately younger and more articulate people) and risks overly sanitising dementia, at the expense of ignoring the many people who *do* suffer due to dementia. Equally, 'there is a danger that well-meaning initiatives to destigmatise dementia through awareness-raising unwittingly contribute to felt stigma through repeatedly asserting the severity of enacted stigma and implicitly attributing a certain notoriety to dementia' (Fletcher, 2021, p. 422). Perhaps the same criticism could also be applied to this chapter and to academic research more broadly. It is important to critique potentially harmful and stigmatising portrayals, but this must be balanced with focusing on more constructive representations, which is a key recommendation for future research.

Looking forward, it is worth thinking about other gaps in the literature reviewed in this chapter. Of course, we cannot promise a comprehensive overview, being limited to English-speaking and peer-reviewed publications drawn from our existing knowledge of the field and prior scoping reviews. A key recommendation, then, is a more expansive coverage of public discourses in different cultural and linguistic contexts, which may be better reported in languages other than English. Equally, a more diverse approach to data collection could facilitate the examination of other information sources in public discourse, such as popular social media platforms (e.g., *Instagram* and *Tiktok*) and, importantly, more public-facing media produced by or in collaboration with people with lived experience, including public-facing books authored by people living with dementia

or more collective texts, such as the 'Dementia Diaries'[1] in the UK, where a range of authors living with dementia contribute audio and written pieces. Searching for alternative discourses that go beyond those examined here is also important, as is greater engagement with both text producers and audiences, to provide a more comprehensive consideration of how social texts are created, shared and interpreted in the public sphere. While research has considered how dementia discourses intersect with other discourses, this could be taken further to provide more multifaceted accounts of both dominant and counter discourses. Such a research agenda for the study of dementia discourse also calls for great reflexivity on the part of researchers, particularly regarding how their personal beliefs, experiences and priorities may influence their interest in and analysis of social texts. Equally, reflecting a broader shift in dementia research, this chapter calls for a reimagining of how research teams could be built to incorporate different forms of expertise, notably of academic, lived and professional experience (e.g., communications and health professionals) moving forward.

Funding

This research was supported by the UKRI-funded project, 'Public Discourses of Dementia: Challenging Stigma and Promoting Personhood' (grant reference: MR/V022954/1).

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[1] See https://dementiadiaries.org/.

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