

# **Dementia Stigma: From Theorisation to Language Use**

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## **Abstract**

Challenging stigma is a global priority for the dementia community, and the integral role of language (and discourse more broadly) in achieving this is widely recognised. Accordingly, this chapter aims to provide an overview of research into stigmatising discourses and debates surrounding best representation practices, with a particular focus on linguistic choices. To do so, we will discuss the theorisation of stigma in a dementia context and advocate for why discourse is a useful lens through which to explore the topic of dementia and stigma. We will then review the existing literature on representations of dementia and how these might be linked to perpetuating, and/or potentially challenging, stigma. Within this review, we consider how linguistic choices may create and sustain dementia stigma, including by foregrounding violence and fear in relation to dementia, while discursively distancing and delegitimising people with a dementia diagnosis. We also consider how dementia stigma might be challenged, notably through revising roles, resisting or reclaiming delegitimising representations and reframing dementia. The chapter will conclude by drawing together the above threads and by discussing potential future directions for researching representations of dementia.

**Keywords:** Dementia, stigma, representation, language, reframing

## 1. Introduction

Dementia is an umbrella term for a range of chronic and progressive conditions that affect the brain, such as Alzheimer's disease, vascular dementia, frontotemporal dementia and mixed dementia. People's experiences of dementia are subjective, with neurological changes intersecting with other aspects of a person's life and social environment. Stigma is widely recognised as a significant factor shaping experiences of dementia, both for people diagnosed with the syndrome and their close ones and caregivers, for whom it can result in exclusion, discrimination and psychological distress. While the concept of stigma has been theorised rather extensively across disciplines, the ways in which dementia stigma is constructed and maintained, as well as potentially dismantled, are comparatively less well-explored (Herrmann et al., 2018; Werner, 2014; Werner et al., 2022). This chapter aims to contribute to that growing body of research by bringing together sociocultural theories of stigma with a detailed analysis of language use, in order to examine how dementia stigma can be discursively constructed and resisted. The chapter's central aim is thus to show how linguistic choices across a range of contexts can both reinforce and challenge stigmatising representations of dementia and people living with it.

The chapter begins by outlining dementia stigma, notably attending to key theories, types and relevant social and cultural values. Building on this foundation, the chapter moves to its core focus: how language use might contribute to the creation, reinforcement and challenging of dementia stigma. To explore this, we draw upon our scoping review of language use and dementia stigma, which examined 44 publications from 2000-2022 (Putland and Brookes, 2024a), alongside incorporating further, more recent research. The chapter concludes by reflecting on the key trends emergent from our review, and by gesturing to areas for future research in this burgeoning area of language and mental health research.

## 2. Dementia Stigma

Erving Goffman (1963, p. 3) famously defined stigma in relation to “an attribute that is deeply discrediting”, which results in someone being “reduced in our minds from a whole and usual person to a tainted, discounted one”. A stigmatised attribute may include a person's appearance, age, cultural heritage, sexuality, employment, socioeconomic status, mental/physical health, beliefs or behaviour. Such attributes are not inherently discrediting; rather, stigma is a *social process* whereby members of marginalised groups become positioned as undesirable according to socially constructed criteria (Jones & Corrigan, 2014). In this chapter, we focus on dementia stigma, which has been shown to have severe repercussions for the positioning, experience, and treatment of people diagnosed with or otherwise affected by dementia. Amongst other things, dementia stigma is associated with social isolation, not seeking/receiving help, contributing to human rights violations and overall, having a lower quality of life with dementia (Bacsu et al., 2024). This chapter builds on an increasing number of dementia stigma (scoping, systematic and literature) reviews, many of which call for further work to better theorise and understand this complex

phenomenon (Bacsu et al., 2022, 2024; Herrmann et al., 2018; Low & Purwaningrum, 2020; Nguyen & Li, 2020; Putland & Brookes, 2024a, 2024b; Werner, 2014; Werner et al., 2022). As we have shown elsewhere, language is a key component of dementia stigma (Putland & Brookes, 2024a).

Since Goffman's work, two theories have become particularly influential in conceptualising dementia stigma: Attribution Theory and Modified Labelling Theory (Werner et al., 2022). Beginning with the former, stigma is regarded as a complex cognitive-emotional-behavioural process, with stigma forming and manifesting in beliefs (stereotypes), emotions (prejudice), and behaviours (discrimination) (see Corrigan et al., 2005; Corrigan & Watson, 2002). A negative stereotype about a group (e.g., that people with dementia are incompetent and a burden) becomes prejudice when the stereotype arouses a negative emotional reaction, such as disgust, anger, or fear towards the stereotyped group, which "connotes agreement with a stereotype" (Jones & Corrigan, 2014, p.11). Prejudice becomes discrimination when it entails a behavioural response, such as avoiding people with dementia or withdrawing from society. In comparison, Modified Labelling Theory posits that stigma results from five interrelated components: labelling, stereotyping, separation, status loss and discrimination, and a power dynamic that facilitates this. First, people identify human differences that are deemed relevant and consequential, and label these accordingly. Secondly, these labelled differences are linked to "a set of undesirable characteristics that form the stereotype" (Link and Phelan, 2001, p. 369). Third, the group doing the labelling separates 'them' (the stigmatised group) from 'us' (everyone else in the dominant non-stigmatised group); in extreme instances, stigmatised groups may even be dehumanised. Fourth, people in the labelled group experience a loss of status within the social hierarchy and encounter discrimination. More specifically, "when people are labelled, set apart, and linked to undesirable characteristics, a rationale is constructed for devaluing, rejecting, and excluding them" (Link & Phelan, 2001, pp. 370–371). Finally, stigmatisation cannot occur without the fifth component: exercising social, cultural, political, and economic power over the stigmatised group.

As Werner et al. (2022, p. 30) note, "the forces perpetuating dementia stigma do not operate in a sociocultural vacuum – they influence and are influenced by social structures and systems". Focusing primarily on a Western context, dementia's characteristics flout cultural values and norms in hypercognitive societies that prioritise individual independence, rationality, cognitive abilities and economic productivity (Post, 2000). Stigmatising attributes associated with dementia thus include deteriorating cognitive abilities, needing support from others, and being economically 'unproductive' (Werner et al., 2022). Dementia stigma can manifest in many ways, with Alzheimer's Disease International's 2024 report on global attitudes to dementia noting five key types (pp. 16-17): (1) public stigma, (2) self-stigma, (3) courtesy stigma (stigma by association with the stigmatised person), (4) affiliate stigma (self-stigma felt by people close to the stigmatised person), and (5) structural stigma, namely social structures that discriminate against a stigmatised person through laws, cultural norms and policies.

Beginning with *public stigma*, research indicates that members of the public often have limited knowledge of dementia and report negative stereotypes (e.g., that people with dementia are dangerous and incompetent), negative emotions (e.g., fear, anxiety, disgust) and discriminatory practices, particularly avoiding people with dementia (e.g., by excluding them from social events or ignoring them in interactions) (Nguyen & Li, 2020). During the Covid-19 pandemic, public stereotypes included that people with dementia were unable to live fulfilling lives and might be ‘better off dead’, while stigma simultaneously manifested structurally in the inequitable access to life-saving equipment, medical care or support compared to other patients, alongside family carers feeling pressured to sign ‘do not attempt to resuscitate’ (DNAR) orders (Bacsu et al., 2024). There were also reports of abuse, overcrowding, understaffing and overmedication in institutional care for people living with dementia, which reflects a broader issue of human rights violations for people living with dementia – a recurring issue within structural dementia stigma (Bacsu et al., 2024; Steele et al., 2023). *Structural stigma* can also be seen in the overreliance on – yet undervaluing of – unpaid dementia care in many countries, which particularly affects relatives (and thus can also be considered a form of *courtesy stigma*; Oliveira & Musyimi, 2025).

Stigma can be devastating when internalised (*self-stigma*; for further discussion, see Price & Hill, 2021). For example, Swaffer (2015) and colleagues (Low et al., 2018) critique ‘Prescribed Dis-engagement™’, whereby health professionals present an overly bleak outlook that foregrounds later stages of dementia when they diagnose people with dementia; this encourages people to prematurely give up meaningful connections and activities, detrimentally affecting wellbeing and quality of life. Hypercognitive expectations and poor social treatment can damage the confidence of individuals living with dementia, which can be debilitating and contribute to frustration, grief, fear and despondency (O’Sullivan et al., 2014). Family/friends and carers may also experience negative stereotypes, such as being perceived as ‘neglectful’, alongside being socially excluded due to their association with someone with dementia (*courtesy stigma*), or they may internalise negative dementia stereotypes and thus feel fear, anger and shame, and isolate themselves (*affiliate stigma*) (Alzheimer’s Disease International, 2024). Denying or hiding dementia, delaying seeking support, distancing oneself and withdrawing from daily activities are common examples of self-stigma and affiliate stigma in people living with dementia and familial carers (Nguyen & Li, 2020).

Importantly, dementia stigma is inherently intersectional, interacting with other aspects of social identity that may also be subject to stigmatisation, such as gender, age, ethnicity and socioeconomic status (e.g., Hulko, 2009; Oliveira & Musyimi, 2025). For instance, older people with dementia face the “combined jeopardy” of older age and dementia stigma (Milne, 2010, p. 231), while women experience greater socioeconomic and health disadvantages from unpaid care, and care inequities are worse for carers with multiple stigmatised identities (Oliveira & Musyimi, 2025).

Language is central to both the proliferation and the challenging of stigma. Linguistic choices help to represent dementia and people affected in particular ways, which can reflect,

reinforce, normalise and/or resist the kinds of stereotypes, prejudices and discrimination outlined above. We follow Hall (1997, p. 61) in viewing representation as “the process by which members of a culture use language [...] to produce meaning [...] this definition carries the important premise that things—objects, people, events in the world—do not have in themselves any fixed, final or true meaning. It is us—in society, within human cultures—who make things mean, who signify”. Recognising language’s importance, the subsequent section discusses how language use can create and sustain dementia stigma, which is followed by a discussion of how dementia stigma can also be challenged through language use. This builds on an increasing body of work that aims to destigmatise dementia, including through education (e.g., dispelling myths), increasing contact (i.e., increasing interactions with people with dementia) and a combination of the two (Bacsu et al., 2022). It is worth noting that stigma is far from all-encompassing for dementia, which is exemplified by positive responses that have been observed amongst the public, including showing empathy towards people with dementia (Nguyen & Li, 2020). The complexity of dementia, dementia stigma, and language use is such that any recommendations for challenging stigma must be made cautiously (Stites et al., 2025; Werner et al., 2022).

### **3. Creating and sustaining dementia stigma through language use**

Stigmatising discourses around dementia have been linked (at least in Western contexts) to an overreliance on the biomedical approach to dementia, whereby “the person disappears behind the diagnosis” (Van Gorp & Vercruysse, 2012, p. 1276). This may, for example, take the form of language that pathologises the actions of people with dementia by attributing these to dementia (e.g., behaviours that signal distress may be framed as symptoms), which ignores individual agency and the role of structural and interpersonal factors (Herron et al., 2021). The biomedical discourse’s dominance is problematised for two main reasons. Firstly, biomedicine is often combined with harmful discourses, such as a hypercognitive model of personhood that equates dementia with a loss of self. Secondly, this overreliance risks concealing alternative discourses and ways of seeing dementia, including those which could help challenge dementia stigma. Below, we describe linguistic features that have been interpreted as contributing to stigmatising representations of dementia and people with it, with a particular focus on contexts such as newspapers, books, social media, interviews and online fora (based on Putland & Brookes, 2024a).

#### ***3.1) Foregrounding violence and fear***

A recurring observation in studies of language use around dementia is that the syndrome is represented in a way that is likely to induce fear. Dementia may be presented as a threat to individuals, for example, by being equated to a social or even literal death threat (e.g., Van Gorp & Vercruysse, 2012). Meanwhile, as a threat to society, dementia is often framed as a catastrophic disruption (e.g., Zeilig 2014), including through the metaphorical association of dementia with disaster and violence. Notably, dementia is commonly framed as a natural disaster (e.g., a tsunami), a weapon of mass destruction (e.g., a time bomb) or an ‘epidemic’

(see Brookes et al. 2018; Brookes, 2023). Relatedly, dementia is often personified as a malicious actor (e.g., a killer, a hostile intruder or a thief), and less commonly as a non-human threat (e.g., a demon, a monster, a parasite or an alien). Personification is achieved through choices relating not only to nouns but also verbs – for example, dementia “attacks”, “consumes”, “deprives”, “destroys”, “hits”, “invades”, “strikes”, or “robs” (Johnstone 2013, p. 378). Such portrayals may exacerbate the passivisation and victimisation of people living with dementia (addressed further below), including by ‘robbing’ them of their personality or humanity (Marhánková & Honelová, 2024).

Simultaneously, dementia may be used metaphorically to refer to loss of self, dignity and autonomy (Johnstone 2013), human misdeeds and shortcomings (Zimmermann, 2017), and “a complex, unknowable world of doom, aging, and a fate worse than death” (Zeilig, 2014, p. 262). Fear-inducing portrayals of dementia are likely to contribute to stigma, as such fears can be “transferred” onto people living with the syndrome (Johnstone, 2013, p. 383).

### ***3.2) Discursive distancing***

Representations of people with dementia frequently contribute to stigma by reinforcing a divide between ‘us’ (i.e., those without dementia) and ‘them’ (i.e., those with dementia), casting the latter as possessing undesirable traits and having diminished social value, which are central components of stigma (Link & Phelan, 2001). This separation is evident not only between people with and without dementia, but also between individuals with dementia and their prior identities. For example, one caregiver laments, “I wanted my father back. This old geezer made me mad” (Caspermeyer et al., 2006: 305). Returning to the distinction between those with and without dementia, public health campaigns have been found to address only those without dementia, for example by using synthetically personalised references to the reader (as ‘you’) in a way that excludes those with dementia as the intended audience (Brookes et al., 2021). Discursive distancing is achieved through a range of linguistic strategies, some of which are explored further in the next three sub-sections (3.3-5).

### ***3.3) Homogenisation, passivisation and exclusion***

Another representational strategy that has been linked to the stigmatisation of dementia is homogenisation, whereby people with dementia are discussed as a uniform category, which in turn limits scope for empathy and can serve as a ‘dehumanising tool’ (Siiner, 2019). Even people living with dementia have been observed to reproduce this kind of representation, for example by referring to the wider group of people with dementia as ‘such people’, rather than using a form of reference that includes themselves (Hansen et al., 2022). Meanwhile, anonymising labels (e.g., ‘patients’ and ‘sufferers’) may obscure the diversity and complexity of individual experiences (Bailey et al., 2021). Dementia itself is often portrayed in ways that further this sense of homogenisation, as the focus in mass media representations is typically on the syndrome’s later stages, eclipsing the progressive nature of the condition and conflating distinct experiences into a single, extreme trajectory (Bacsu et al., 2022), which risks silencing those in earlier or more variable stages of the syndrome (Clarke, 2006).

Discursively, people with dementia are often cast in passive roles, being cast as objects rather than agents of processes; this includes denying people with dementia agency in relation to their actions, alongside portraying them as passive victims – not only of the syndrome itself, but also of mistreatment by caregivers, neglectful services or abusive systems (Bailey et al., 2021). Occasionally, people with dementia are positioned as perpetrators, in which case such depictions have been found to have the potential to reinforce stereotypes of danger and deviance, as outlined in the next sub-section (Herron et al., 2021). Closely linked to such processes of passivisation is the more general absence of people with dementia from public discourse. Their voices are frequently backgrounded or excluded, with others (e.g., caregivers, professionals, journalists) speaking on their behalf (Clarke, 2006). Even when people with dementia feature in contexts like newspapers, the range of individuals quoted is narrow, and news articles may frame their experiences in sensationalist terms (e.g., “dementia sufferer tells of her ordeal”; O’Malley et al., 2022, p. 1348).

### ***3.4) Delegitimising group labels***

Stigmatising labels can also contribute to the erosion of identity and social standing. For example, people with dementia have been observed to often be described using condition-first, as opposed to person-first, language, such as ‘dementia patients’ or, historically at least, as “being demented” (McColgan et al., 2000, p. 97), which implies a permanent, all-encompassing identity that revolves around the syndrome. They are also portrayed as non-reciprocal, again reinforcing a moral boundary between ‘us’ who contribute and ‘them’ who do not (Gove et al., 2017). This framing positions people with dementia as burdensome – emotionally, financially and socially – or even as threats, with sexual or aggressive behaviours being pathologized for people with dementia in ways that are liable to provoke moral panic (and which can intersect with gender and ethnic stereotypes, see Grigorovich, 2020; Herron et al., 2021). Relatedly, people living with dementia may also be labelled as “bewitched”, “possessed” or “crazy” (Mfene & Pillay, 2023).

Such delegitimising framings can be further reinforced through metaphor. Notably, people with dementia are likened to zombies (Behuniak, 2011), aliens, vegetables, empty shells, and machines – tropes which imply absence, malfunction or even death (Bailey et al., 2021; Johnstone, 2013; Van Gorp and Vercruysse, 2012). Such metaphors render individuals with dementia as passive and backgrounded, or may even serve to erase their humanity altogether. The identities of people with dementia as adults have also been observed to be delegitimised through the process of infantilisation, by which people with dementia are equated with children. This occurs, for example, when the person with dementia’s responses to affection are likened to those of a baby with its mother (Grigorovich, 2020).

Overall, delegitimising depictions contribute to the perception of people with dementia as lesser, even as “non-persons” (Gove et al., 2016, p. 395) or as socially dead, for instance when care partners refer to a spouse currently living with dementia as a “former life partner” (Bös & Schneider, 2022, p. 224). AI-generated descriptions of people with dementia risk amplifying this by not only evoking social death (e.g., “We no longer recognized her as a human being”) but also by foregrounding physical death and decay (“my own body rotting

from the inside out”; bodies “without warmth, without life, as cold and dead as the grave”) (Putland et al., 2025, p.194).

### ***3.5) Ridicule***

Humour, especially in social media and newspapers, can be used as a way of trivialising dementia. Tweets about ‘selective dementia’ (Hudson et al., 2022) or headlines like “Just walking the dog takes man 13 hours” (Kirkman, 2006, p. 77) risk transforming individuals’ experiences of the syndrome into a form of entertainment. This ridicule positions people with dementia not as co-citizens, but the punchline of a joke to be enjoyed by others. Relatedly, terms such as ‘demented’ or ‘senile’ – widely regarded as being among the most stigmatising labels – have been used in language intended to insult politicians by both the media and politicians targeting political opponents (Tommaso, 2024). Such verbal attacks contribute to dementia stigma in the sense that they can only function, both as face threats and as a form of entertainment, by drawing on associations between dementia and confusion/incompetence.

### ***3.6) Responsibility and blame***

Somewhat paradoxically, alongside portrayals of people with dementia as passive and helpless, there is a seemingly growing discourse of individual responsibility in relation to the development of dementia. For instance, news coverage often uses verbs such as ‘fight’, ‘ward off’ or ‘stave off’ in framing dementia as avoidable through personal effort (Peel, 2014). In such contexts, the potential influence of individual lifestyle factors (especially diet and exercise) in developing dementia is often over-emphasised, while broader structural and biological determinants, and the intersection of multiple risk factors, remain downplayed (Schick Tanz, 2021). Such a discourse, which foregrounds personal responsibility in preventing dementia, risks retroactively blaming people with dementia for not having done enough to mitigate their personal risk of developing the syndrome (Slocombe et al., 2025). Meanwhile, the broader narrative of ‘successful ageing’ in contexts such as newspapers and television risks establishing unrealistic ideals that ignore disparities in resources and individuals’ capacities (Xu, 2021).

## **4. Challenging dementia stigma through language use**

Clearly, the language used to represent dementia and people with the condition plays a significant role in creating and sustaining stigma. Yet, more sensitive language use can also offer a means of counteracting dementia stigma, and in recent years, determining what such language use ‘looks like’ has become a growing and interdisciplinary preoccupation for research on dementia representation. We consider some of this work in more detail below. Language use is complex, and as a society, we require approaches that are more nuanced than simply instructing people to avoid contested terminology. For example, Siiner (2019) describes how historically stigmatising terms such as ‘senile’ have, in some cases, been reappropriated by older people and those with dementia as ironic or resistant identity markers



against purportedly more positive (yet also potentially restrictive) counter discourses such as that of ‘living well’.

### ***a) Revising roles***

Rather than simply rejecting negative representations, challenging stigma may involve actively reconfiguring the social roles into which people with dementia are often placed. Foregrounding the perspectives and voices of those living with dementia is central to this effort, as it allows such people to disrupt disempowering discourses and reclaim agency (Castaño, 2023; Pinzon-Pulido et al., 2025). For instance, people with dementia can position themselves as “experts in their own cause”, offering guidance not only to others with the syndrome, but also to those without it, including through advocacy and public engagement (Bös & Schneider, 2022, p. 229). This kind of role revision can productively destabilise traditional power dynamics, including between healthcare professionals and people receiving care. Interactions in online fora show how individuals with dementia may question professional authority, critique inadequate care practices, and resist being positioned as passive recipients of care (Bös and Schneider, 2022). For example, they may advise care partners, engage in collaborative activities like writing, and emphasise more reciprocal relationships—indeed, use of the term ‘care partner’ over ‘carer’ or ‘caregiver’ reflects this shift, signalling a non-hierarchical, mutual form of support between adults, rather than a one-way model of dependency.

Even traditionally disempowering terms, such as ‘patient’, can be recontextualised to express authority. Indeed, one forum user self-identifies as a patient while simultaneously asserting, “I know what I am talking about”, in that way reclaiming both experience and epistemic legitimacy (Bös & Schneider, 2022, p. 222). Through such discursive acts, people with dementia can resist stereotypes while establishing themselves as socially involved and having valuable insights. This kind of role revision is not without its potential pitfalls, though. One risk is that such counter-representations may inadvertently normalise idealised or unrealistic portrayals of people with dementia, and ignore the syndrome’s progressive nature, which makes such involvement increasingly difficult. To mitigate this risk, it is advised that when including accounts of experiences of dementia, especially in contexts like mass media, these are contextualised in a way that acknowledges their subjective nature and, with that, the variability in such individuals’ feelings, relationships, symptoms, and coping strategies (O’Malley et al. 2022).

### ***b) Resisting or reclaiming delegitimising representations***

Another strategy for challenging dementia stigma involves directly critiquing or subverting delegitimising representations. For example, personal accounts of experiences of dementia in online fora/blogs – and less commonly, in the media – have been observed to have the potential to confront such portrayals by rejecting reductive labels and exposing the limitations of culturally dominant stereotypes (Bös and Schneider, 2022; Castaño, 2023; O’Malley et al., 2022). In this respect, people with dementia themselves play a crucial role in resisting stigma, as their testimonies can highlight personal agency and individuality in response to

stereotypes. For example, returning to the forum analysed by Bös and Schneider (2022, p. 222), one of the users declares, “*I had dementia, I was not going out like a victim*” – thereby directly contesting the passive or tragic framing often imposed on those diagnosed with the syndrome. Similarly, bloggers diagnosed with early-onset dementia have challenged the use of “demeaning terms”, such as “victim”, “fading away” and “empty shell”, calling for people to remember “that it is still a whole human being inside that shell, one with a soul and one with feelings even though they may not show outwardly very much anymore” (Castaño, 2023, p.118). Individuals diagnosed with dementia have been observed to challenge (among other things) the homogenisation, infantilisation and dehumanisation of people with dementia, the misleading conflation of dementia with old age, and representations of dementia as a burden or epidemic (Bös and Schneider, 2022; Castaño, 2023; O’Malley et al., 2022).

Humour can also be used as a rhetorical tool to resist stigma, despite its potential to reinforce it. For example, humour enables people to exaggerate or parody stereotypes in order to subvert dominant norms, with self-referential jokes like, “*I am senile, but not old yet*” allowing people to maintain control over how they are perceived (Siiner, 2019, p. 991). Similarly, some users in the fora analysed by Bös and Schneider (2022) chose usernames which playfully acknowledge memory loss while refusing to be defined by it (e.g., ‘forget me not’). Authors living with dementia may also rework stigmatising metaphors to critique negative social attitudes around the syndrome. Zimmermann (2017, p. 79), for example, translates and discusses Claude Couturier’s recurring joke about becoming “a grilled vegetable”, which Couturier expands into a serious observation: “life is only worth living when shared, otherwise one vegetates”. Here, humour and metaphor are used not to trivialise dementia, but to expose the harmful effects of social isolation and to highlight the need for meaningful relationships.

Of course, efforts to resist stigma are not (and should not be) limited only to people with dementia. For instance, advocacy organisations such as the Alzheimer’s Society have used media to counter the myth that dementia causes innate aggression, instead framing such behaviours as understandable responses to anxiety or distress (Herron et al., 2021). People with professional experience (e.g., healthcare, psychology and social care professionals) and the families of people living with a dementia diagnosis and have also been shown to challenge language practices and call for anti-stigma initiatives, including by calling to avoid terms such as ‘sufferer’ and ‘patient’ and to instead regard people with dementia as adults who deserve respect (Pinzon-Pulido et al., 2025).

### ***c) Reframing dementia***

Challenging stigma also involves reframing dementia itself. We identified in the literature several relevant counter-discourses, including those which seek to normalise dementia, adopt person-first and rights-based perspectives, and promote more (socially) transformative framings. Normalisation strategies portray dementia as a chronic condition, disability, or natural part of ageing that should be socially accepted rather than feared (O’Malley et al.,

2022). Such strategies can also challenge the view of the brain being the seat of personhood by framing it as a simple bodily organ (Zimmermann, 2017).

Person-first approaches (Kitwood, 1997) centre on the ongoing identity and humanity of people with dementia. Such depictions highlight the importance of recognising the full person, instead of foregrounding their status as someone with a dementia diagnosis. In practice, this can involve describing people with dementia not only as ‘care recipients’, but also as ‘doctors’, ‘volunteers’, ‘mentors’ or ‘advocates’ – all of which are identities that complicate the prevailing notions around agency and dependency that surround dementia (Bös and Schneider 2022). This may also entail recognizing the sexualities of people living with dementia (Grigorovich, 2020) or reframing dementia as a condition that changes how an individual perceives the world around them, requiring those around the person to seek to understand their alternative approach to the world (Marhánková & Honelová, 2024).

A rights-based discourse asserts the civil and human rights of people with dementia. This includes the right to act unconventionally, be respected, and receive appropriate support regardless of one’s cognitive condition (Siiner, 2019). From this perspective, structural barriers to inclusion (e.g., inaccessible public spaces or lack of political will) are called out explicitly (O’Malley et al., 2022). Relatedly, rather than individualising dementia risk, population-level interventions can also be foregrounded (Slocombe et al., 2025), for instance, regarding the right to clean air, education and social involvement.

Transformative discourses can further resist loss-based discourses around dementia. From this standpoint, dementia may be reinterpreted as a process of revelation or transformation – a shedding of socially imposed expectations to reveal a more authentic self (Bös & Schneider, 2022). At a societal level, dementia also has the potential to constructively challenge existing (Western) social norms, including the expectation of a consistent self across time and a fear of dependency (Marnfeldt, 2026). For instance, individualism may be rejected in favour of mutual care and interconnection (Behuniak, 2011; Van Gorp and Vercruysse, 2012). Relatedly, Zeilig (2014) argues that dementia should be seen as a lens through which shared humanity becomes visible, and not used as a shorthand for social breakdown or fear.

In addition to these counter-discourses, others have proposed more holistic approaches. Schicktanz (2021), for example, calls for a multifactorial understanding of dementia that integrates biological, psychological, social, and existential dimensions. Castaño (2023, p.119) highlights the value of reflecting ‘the complexity and, in some cases, conflicting facets of dementia’ by balancing an acknowledgement that ‘living a fulfilling life after diagnosis is possible’ with recognising that this ‘does not preclude people from experiencing a range of functional and social losses and negative emotions’.

Other scholars have called for shifts at the level of text production and reception. As noted, considering that people with dementia are largely absent from public (media) discourse, it is important to resolve this ethically (Talbot et al. 2021). In addition to media production, the reception of media, i.e., how audiences understand such texts, requires greater attention, since familiar representations may be interpreted differently by audiences (see Putland, 2025;

Slocombe et al., 2025). For example, Zimmerman (2017) notes how describing a person with dementia as a ‘flickering candle’ could evoke either looming extinguishment or enduring warmth. The potential for re-reading such imagery unlocks new possibilities for resistance and reframing, reminding us that stigma is not fixed but continually negotiated in and through language.

Alternative metaphors for dementia have also been proposed as means of counteracting damaging tropes. Metaphorical language, as we have seen, looms large in the kinds of discourse that create and propagate dementia stigma. In response, it has been argued that metaphors that frame dementia as a journey or companion, rather than an adversary, can reduce fear, and promote, respectively, greater awareness of dementia’s progressive and variable nature, and more contented and positive evaluations of life with the syndrome (Brookes, 2023; Van Gorp & Vercruysse, 2012). Yet, it is important to highlight that metaphors cannot be generalised as stigmatising (or not); for instance, while violence and combat metaphors have been linked to dementia stigma (Brookes, 2023), there are some contexts in which they may be used in more empowering ways (Castaño, 2023).

## 5. Conclusion

This chapter has explored how dementia stigma is not only a product of social attitudes or structural inequalities, but is, significantly, something that is constructed, reinforced and potentially resisted through language use. Our central focus in this chapter has arguably been on the discursive *production* of dementia stigma. We have shown how certain linguistic strategies – such as metaphorical framings of dementia as a violent threat, the discursive distancing of people with dementia from the general population, and the use of delegitimising or homogenising labels – can function to reinforce stigma (e.g., by casting people with dementia as somehow ‘less than’ fully human or as burdens on society). Such representations are, of course, not neutral; they both reflect and in turn further shape public understandings of dementia and related policy decisions, as well as the interpersonal relationships and even self-perceptions of those living with the syndrome. For instance, the above language choices can serve to legitimise discriminatory treatment, including denying medical care because “the person is gone” (Clarke, 2006, p. 272) or because their quality of life is deemed to be insufficient to justify costly treatment (Gove et al., 2016). Meanwhile, calls for the removal of people with dementia from care homes following incidents, which are often aired in news media, reinforce a logic of separation (Herron et al., 2021), constituting a literal enactment of the aforementioned division between ‘us’ and ‘them’. In extreme cases, death is framed as preferable, as in the claim that “Covid is actually a better death than dementia” (Bacsu et al., 2022, p. 4).

Language can also serve as an important site of resistance against such harmful, even discriminatory, discourses. Whether through the rejection of or strategic reappropriation of stigmatising labels, the amplification of lived experiences, or the adoption of person-first, rights-based and transformative framings, there are indeed ways in which we can all

challenge dominant discourses around dementia in the service of promoting more genuine awareness of the syndrome and more compassionate attitudes towards those diagnosed with it. Of course, any attempt to challenge dementia stigma must be carefully considered to mitigate the potential for unintended negative consequences, such as creating unrealistic expectations for people living with dementia and their carers.

Studies of dementia representations, including those which relate such representations to the notion of stigma, seem to be growing not only in terms of number but also scope regarding the range of genres, contexts, communicative modes (note an increasing interest in visual representations; Putland & Brookes, 2024b), methodologies and disciplinary perspectives. Yet, considerable potential for advancement in this area remains, including attending to cultural contexts beyond Western countries and English-language publications. Another area requiring further attention is intersectionality. Stigma does not, as noted, operate uniformly, but intersects with aspects of identity, including age, race/ethnicity and gender. A small but growing body of work has considered the intersectional dynamics of dementia stigma, including concerning ethnicity (e.g., Herron et al. 2021), age (e.g., Medina 2017) and gender (e.g., Grigorovich, 2020; Putland et al., 2025). However, further research is needed to better understand the intersectional dynamics of dementia stigma and how it can variously manifest in language use. A key area for future work in this respect involves interrogating how different stereotypes and biases may be reproduced and combined in AI-generated outputs (Putland et al., 2025).

As in most other areas of discourse-based research, another area for further development concerns the production and reception of discourses. The majority of studies on dementia representations are based on analysts' interpretations. Such interpretations may be enriched, and the representations in question further contextualised, through more systematic engagement with how audiences (including those with lived experience of dementia) may receive, and even challenge, dominant tropes (e.g., Putland, 2025; Slocombe et al., 2025) and how different framings may influence audiences' attitudes and behaviours (e.g., Cooper & Harwood, 2024; Van Gorp et al., 2012). Research is also increasingly attending to how different texts can be produced by or in collaboration with people living with dementia, whether short films or AI-generated images (Davies-Abbott et al., 2025; Vrancken et al., 2026). More participatory – and indeed, experience-led (e.g., Davies et al., 2022) – work is an important step in striving for a more inclusive and innovative research environment that centres, rather than excludes, the voices of people living with dementia. Alongside this, greater reflection on how different discourses and linguistic norms influence the design, conduct and dissemination of research itself is needed, with consideration of (co)researchers and participants' positioning alike (Bormans & Van Gorp, 2025).

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