Dementia, Death and Discourse

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1. Introduction

Dementia is one of the most feared health conditions in contemporary (Western) societies such as the UK (Alzheimer's Research UK, 2023) and many people have equated a dementia diagnosis with their life being over (Alzheimer's Society, 2016a). Such attitudes are exacerbated by the prevalence of overly negative, dehumanising and fear-inducing portrayals of dementia in popular culture, which both reflect and perpetuate the stigma associated with the condition (Low and Purwaningrum, 2020; Nguyen and Li, 2020; Putland and Brookes, 2024a, 2024b). The significant role of language – and of discourses more broadly – in influencing social attitudes and responses to people living with and otherwise affected by dementia is increasingly recognised, as exemplified by the array of communication guidelines aiming to challenge dementia stigma with more nuanced and humanising discourses (e.g., Alzheimer Europe, 2022; Alzheimer's Society, 2018; DEEP, 2014). Despite existing research recognising that fears of ageing, death and degeneration are integral to contemporary (Western) dementia discourses (Low and Purwaningrum, 2020; Van Gorp and Vercruysse, 2012), with the notable exception of analyses of the 'living dead' metaphor (see Aquilina and Hughes, 2006; Behuniak, 2011), the authors are not aware of a detailed examination of the discursive relationship between dementia and death specifically. In this chapter, we therefore explore more closely how dementia and people with dementia are represented in relation to dominant discourses of degeneration and death, alongside considering the implications of such discourses.

We divide this chapter into two parts, first providing necessary context, and then a corpus-assisted case study of UK newspaper discourses. To contextualise this issue, we first define the concepts of dementia and discourse (see section 2) and then examine major biomedical and social associations between dementia and death/dying (section 3). These sections are intended to introduce the complexities associated with both dementia and dying/death, which can then be compared with how these two social phenomena are discursively represented. In section 4, we present a narrative review of how dementia and death are depicted in popular discourses, attending in particular to three metaphors that are relevant to our case study: (1) dementia is the bringer of death, (2) dementia is (worse than) a death sentence, and (3) having dementia is death in life. Section 5 builds on this review by

presenting our case study: a recent corpus linguistic analysis of dementia metaphors in UK newspapers (Brookes 2023). For this, we focus on how dementia is metaphorically presented as causing the death of people with the syndrome through an array of violence metaphors. While dementia is consistently attributed agency as a killer or leading cause of death (rather than as a condition that people die with), people with dementia are often positioned as its victims, or as inevitably losing their battle against dementia. Moreover, some metaphorical choices equate having dementia with death in life, even as a living hell. We discuss the role of such metaphorical framings in contributing to dementia stigma, before concluding the chapter in section 6 by considering potential linguistic routes to change.

2. Defining dementia and discourse

Dementia's complexity and variability necessitate a nuanced approach that considers various biological, psychological, (inter)personal, environmental and structural factors (George and Whitehouse, 2021; Sabat, 2018; Shakespeare, Zeilig and Mittler, 2019). Experientially, dementia can be defined as a shift in how we experience the world (Johnson, Kelch and Johnson, 2017; Power, 2010). Medically, dementia is defined as a neurodegenerative syndrome distinct from natural ageing (National Health Service, 2020; World Health Organisation, 2022). 'Dementia' is an umbrella term for a range of chronic and progressive conditions caused by diseases that affect the brain, such as Alzheimer's disease, vascular dementia, frontotemporal dementia and mixed dementia (Dementia UK, 2021). Dementia may affect one or more cognitive functions, including learning and memory, complex attention, language, executive function, perceptual motor function and social cognition (Van Assche *et al.*, 2022, p. 3). In nearly all cases, dementia is incurable and progressive, meaning that people have dementia until death, with symptoms becoming increasingly severe over time (World Health Organisation, 2022).

Despite having commonly recognised symptoms, each person's experience of dementia – even of the same type – is unique. Neurological changes intersect with other aspects of a person's life, personality, 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) and with broader socio-political structures (Bartlett and O'Connor, 2007). Notably, on both an interpersonal and structural level, people with dementia can be negatively impacted by stigma surrounding the condition (and by related issues such as ageism), as they are positioned as undesirable, even as 'non-persons', according to socially constructed criteria (Jones and Corrigan, 2014). Consequently, as well as internalising stigma, people with dementia can be at risk of exclusion, sub-standard care and human rights violations (Cahill, 2018). Especially without a viable cure for the near future, attending to how society can better support people living with dementia is global priority

(Kenigsberg *et al.*, 2016). In the words of someone living with young-onset dementia: 'a cure would be nice but a better way to live with dementia is better' (Castaño, 2023, p. 118).

Discourses can differently impact how people interact with and approach the care of people living with dementia (Dildy and Largent, 2021; Heap and Wolverson, 2020; Johnson, Kelch and Johnson, 2017), as well as how individuals perceive themselves, their belonging to society and their future – at the extreme, ageist discourses are associated with a wish to die amongst some older individuals (van Wijngaarden *et al.*, 2019). Recognising the impact of discourses on how people experience dementia, this chapter contributes to the growing body of work on popular discursive representations of dementia (for recent reviews, see Low and Purwaningrum, 2020; Putland and Brookes, 2024a, 2024b). By discourse, we refer to a particular stance towards the world (e.g. that dementia is a 'killer', see below), which is manifest in a set of resources, including language but also other semiotic resources such as sound, images and texture (Burr, 2015). Importantly, discourses not only reflect but help to *shape* social understandings and actions (Fairclough, Mulderrig and Wodak, 2011). For instance, the socially dominant biomedical discourse on dementia is widely criticised for focusing on people's (primarily cognitive) losses above their abilities, and for foregrounding degeneration, disease and victimhood while backgrounding people's emotional worlds, relationships and lives (Milne, 2020; Taylor, 2008). Subsequently, people with dementia are often underestimated, excluded and ignored, with people's actions being (often incorrectly) attributed to their syndrome, rather than to environmental factors that can be changed to better support those people (Brooker and Kitwood, 2019; Sabat, 2018). We aim to contribute to positive social change by deconstructing some of these discourses, here specifically in relation to death, which, as we will now outline, is intricately linked with dementia in contemporary imaginations and is similarly subject to fear-inducing and potentially harmful discourses.

3. Death and dementia

To reduce death to a physical or biological end of life event would be to ignore the social and cultural meanings that death and the dying process hold (Cottrell and Duggleby, 2016). In contemporary UK mainstream culture, death is a sensitive and largely taboo topic, as demonstrated by the numerous linguistic strategies (namely metaphors and euphemisms) to avoid explicitly mentioning death itself (Fernández, 2011; Galal, 2014; Sexton, 1997). Death is also an increasingly medicalised event (Walter, 2017), as are dementia and ageing – all of which therefore assume a reductive model of decline across the lifespan (Hepworth, 2003). Social, medical and technological advances mean that dying trajectories are increasingly prolonged, as chronic and terminal illnesses last over months, years or decades; this is for many a source of dread (Walter, 2003). Frailty and dementia have been described as a major dying trajectory of 'prolonged dwindling', whereby body systems become increasingly fragile and at risk of even minor setbacks, and where it is difficult to predict when dying begins and

when death will come (Cottrell and Duggleby, 2016; Lynn and Adamson, 2003; Walter, 2017). If a 'good death' is conceived of in a culture that values independence, having dementia may be associated with a 'bad death' by impacting upon people's (perceived) awareness, acceptance and control over death, contributing to the fear of living and dying with the condition (Cottrell and Duggleby, 2016; Walter, 2003, 2017). In contrast, alternative conceptualisations of a 'good death' that emphasise compassion, comfort and familiar people/surroundings can incorporate people dying with dementia (Alzheimer's Society, 2016b; Takahashi *et al.*, 2021).

Currently, there is ambiguity surrounding whether people die *with*, or *from*, dementia. Increasingly, dementia is being presented as the cause of death for some individuals. It is generally agreed that deaths *with* dementia are far higher than deaths *from* dementia, since dementia commonly interacts with other conditions to predispose an earlier death (Gao *et al.*, 2018). People with dementia may die due to issues with eating and fluid intake, as well as from respiratory problems, cardiovascular causes and infectious diseases (Garcia-Ptacek *et al.*, 2016). However, dementia is increasingly being presented as 'a disease that you can die from' (Gastmans, van der Steen and Achterberg, 2022, p. 234). Notably, the Office for National Statistics's (2024) most recent records at the time of writing state that dementia 'continued to be the top leading cause of death in England and Wales in 2023', at 11.6% of all registered deaths.

It is important to consider socio-political factors that have contributed to dementia becoming the leading cause of death in the UK (Adair *et al.*, 2022). In accordance with guidance from the World Health Organisation, internationally recognised death certificates include the direct cause of death, contributing factors and the underlying cause, which may be a longstanding, chronic condition that predisposed the person to later fatal complications (UK Government, 2022). Dementia is increasingly reported on death certificates, including as the underlying cause of death, which is significant as this is the information reported in official mortality statistics (Adair *et al.*, 2022). Potential reasons for the increased number of deaths with an underlying cause of dementia are numerous. A report by Public Health England suggests three explanations: (1) an actual increase of people dying with dementia because people are living longer, (2) greater awareness and understanding of dementia, alongside key policy changes to encourage more frequent recording of the condition, and (3) changes in coding practices on death certificates (Khera-Butler, 2016). For example, using 'old age or frailty' alone on death certificates is increasingly discouraged (Gao *et al.*, 2018; UK Government, 2022), whereas the coding options for dementia have expanded in recent years, thus including more deaths that would have previously been attributed to another cause (Khera-Butler, 2016). Evidence supports that different certification practices greatly impact dementia mortality rates. For example, in Australia, dementia death rates for ages ≥85 are six times higher than those of Japan, despite no substantial differences in prevalence between the countries (Adair *et al.*, 2022).

Dementia is associated not only with literal but also 'social death', where, although someone is socially alive, they are treated by others as if they are socially dead (Sweeting and Gilhooly, 1997). Historically, dementia and frailty have tended to be normalised within ageing as the final stage of human life (Fox, 1989). Lock (2013) observes that although not considered inevitable, dementia amongst older people was largely accepted as part of the ageing process until well into the twentieth century. In contrast, nowadays, as Higgs and Gilleard (2014, p. 15) compellingly argue, frailty and dementia have been pushed to the periphery of ageing within social life, so that 'frailty [including dementia] represents the outer boundaries of an alienated old age, ageing without agency'. This alienation reflects the threat that having dementia poses to Western 'hypercognitive' values, whereby rationality, independence, self-control, economic productivity and cognitive enhancement define a person, as opposed to facets such as empathy and emotionality (Post, 2000a, 2000b). Within such a discourse, dementia is widely positioned as entailing a loss or 'unbecoming' of self as a result of cognitive deterioration (Fontana and Smith, 1989). Thus, individuals with dementia can be positioned as a 'liminal or non-person' and be regarded by others as 'socially dead' despite their physical life continuing (Sweeting and Gilhooly, 1997, p. 99). This perceived 'death-in-life' for people living with dementia may become more extreme in the advanced stages, becoming instead, a form of 'life-in-death' (Kaufman, 2006, p.23). Králová (2015) proposes that social death entails the loss or severe compromising of social identity, social connectedness and the body disintegrating through mistreatment and loss of agency. Indeed, research indicates that people living with dementia risk losing their social identity as fellow citizens with agency, often lose their relationships with others, and that they may encounter bodily harm as a result of the above losses, such as pharmaceutical constraints or non-voluntary euthanasia (Cahill, 2018; Gastmans, van der Steen and Achterberg, 2022; Sabat, 2018).

Evidently, dementia has a complex and multifaceted relationship with death. Statistical measures of dementia death rates are controversial and reflect broader socio-political shifts regarding how dementia is understood and recorded in relation to death. Equally, the (bio)medical approach to dementia that underlies these death certificates is greatly influenced by a hypercognitive discourse that prioritises cognition and autonomy. For example, biomedical assessment rubrics for dementia prioritise cognitive indicators rather than the many abilities that people use and display in the everyday social world (Sabat, 2018). Overall, this hypercognitive bias can contribute to dementia being perceived as entailing a loss of self and 'social' death within life, and as being a 'bad' form of dying and death, which can cause significant harm to people living with dementia. Having introduced some of the more influential discourses and related social practices surrounding dementia, death and dying, we turn to how these discourses may manifest in contemporary discursive representations.

4. Death-related dementia discourses

The literal and metaphorical association of dementia with death pervades contemporary discourses. Notably, Low and Purwaningrum's (2020) systematic review found that books and films featuring dementia nearly always emphasise deterioration and death, including by using flashbacks of someone with dementia at an earlier time in life to emphasise decline, showing a desire to die, and by consistently ending with either institutionalisation or the death of the person with dementia. Such a focus reflects a situation in which the biomedical model remains the primary lens through which dementia is (discursively) represented (Bailey, Dening and Harvey, 2021; Milne, 2020), with its emphasis on charting loss and degeneration (alongside death) interacting with hypercognitive values to drive what is commonly referred to as the 'tragedy' dementia discourse (Castaño, 2023; McParland, Kelly and Innes, 2017).

Since metaphor is the focus of our case study, it is important to chart, in some detail, existing literature on the metaphorical relationship of dementia and death. This relationship is significant, since metaphor is essentially 'the phenomenon whereby we talk and, potentially, think about something in terms of something else' through a perceiving a shared similarity between two different things (Semino, 2008, p. 1). As such, metaphors help to frame social phenomena 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, p. 52). Metaphors that associate dementia with death thus draw on the connotations, fears and responses associated with this taboo topic. In this death-oriented narrative review, we organise this relationship into three types of interrelated metaphors: (1) dementia is the bringer of death, (2) dementia is (worse than) a death sentence, and (3) having dementia is death in life.

Firstly, existing research indicates that dementia is often presented as bringing death, either in a military or criminal sense, as a 'killer' or 'invader', or in a disaster one, as with 'epidemic' and 'tsunami' (Low and Purwaningrum, 2020; Putland and Brookes, 2024a). Such metaphors grossly oversimplify the multidimensional relationship of dementia with death and dying outlined above. Although successful in making dementia a national and global priority, the disaster metaphor's focus on death and chaos 'subliminally cultivat[es] a public terror' of either contagion (as with the epidemic metaphor) or destruction (natural disaster), which can in turn contribute to the stigmatisation of people living with dementia (Johnstone, 2013, p. 390). Attributing such powerful agency to dementia is often accompanied by the passivisation and victimisation of people living with dementia (Putland and Brookes, 2024a). Although a military or criminal framing encourages individuals and society to "fight" dementia (George, 2010), oftentimes only science is positioned as having the ability to defeat this currently incurable enemy (Bailey, Dening and Harvey, 2021; Van Gorp and Vercruysse, 2012).

Relatedly, dementia is frequently positioned as 'synonymous with being condemned to death' (Van Gorp and Vercruysse, 2012, p. 1277). Foregrounding dementia's terminal stage risks 'equating all forms of dementia with death', including earlier stages of the condition (Taylor, 2008, p. 323). As well as being positioned as synonymous with impending

death, dementia is also sometimes represented as a fate *worse* than death, with Zeilig (2014, p. 262) arguing that dementia has itself become a metaphor for 'a complex, unknowable world of doom, ageing, and a fate worse than death'. Implicit in this metaphor is a fear of losing control, being socially marginalised and suffering to the point that death becomes not the source of fear, as with the above, but the only possible release (Johnstone, 2013; Putland and Brookes, 2024a).

Reflecting the discourse that equates cognitive degeneration with a loss of self (see section 3), people with dementia are popularly represented as experiencing a 'death-in-life' (Kaufman, 2006, p. 23). Indeed, a recent advert by Alzheimer's Society (2024), a leading UK dementia charity, asserted that 'With dementia, you don't just die once. You die again, and again, and again'. Within such a metaphor, people diagnosed with dementia risk being positioned as a 'liminal or non-person' (Sweeting and Gilhooly, 1997, p. 99) through a range of metaphorical associations, notably with the living dead/zombies (Aquilina and Hughes, 2006; Behuniak, 2011), inanimate objects (e.g., 'vegetables' and 'withered shells'), animals, sub- or non-humans ('self that unbecomes', 'nonpersons', 'not human') or even being 'already dead' (Low and Purwaningrum, 2020, p. 11). Crucially, the voices and perspectives of people with dementia themselves are consistently missing in such a positioning (Bailey, 2019; Putland and Brookes, 2024a). We found that the association with death was particularly evident in a recent study of AI-generated character descriptions, where characters with dementia were often described as corpse-like, decaying and inhuman, exemplified by lines such as 'my own body rotting from the inside out', 'as cold and dead as the grave' and 'There is no fragrance of life, no essence of humanity' (Putland, Chikodzore-Paterson and Brookes, forthcoming: 9, 13). Such a metaphorical positioning can occur not only linguistically but visually. With colleagues, we have shown that people with dementia can be discursively represented in relation to the living dead metaphor though visual tropes such as blank expressions, passive poses, no eye contact (which magnifies social distance) and a dull, lifeless colour palette (Brookes *et al.*, 2018; Brookes, Putland and Harvey, 2021; Harvey and Brookes, 2019; Putland and Brookes, 2024b; Putland, Chikodzore-Paterson and Brookes, 2025). That these types of discursive representations have been found across stock images, newspapers, AI-generated images and a non-profit campaign illustrates the metaphor's prevalence, whether it is explicitly or implicitly referenced.

These three types of 'dementia as death' metaphors subsequently position people with dementia as 'Other' to mainstream society, exacerbating both normative and social distance through increasing perceived differences between 'us' (my in-group) and 'them' (their out-group), and decreasing sympathetic understanding (Low and Purwaningrum, 2020). By combining a biomedical focus (e.g., on abnormality, degeneration and disease) with hypercognitive notions of personhood and cultural fears around ageing and death, such metaphors 'infuse stigma with disgust and terror' (Behuniak, 2011, p. 74).

Although the above emphasis on death and degeneration with dementia remains prevalent as part of a broader 'tragedy' discourse, it is important to note that a 'living well

with dementia' discourse has increasingly taken hold as its main counter-discourse in recent years (McParland, Kelly and Innes, 2017; Peel, 2014). This discourse focuses on supporting people to 'live well' with dementia, which includes emphasising remaining strengths, recognising enduring personhood, respecting the perspectives of people with dementia, positioning dementia as a manageable disability and being concerned with factors that can support people to 'live well' (Hillman *et al.*, 2018; McParland, Kelly and Innes, 2017). Increasingly, to 'live well' can be interpreted structurally as requiring better support within society, or neoliberally, being concerned with mitigating risk and managing symptoms at an individual level through healthy lifestyle choices, such as exercise and diet (Hillman *et al.*, 2018; Peel, 2014).

Notably, existing research suggests a distinct lack of the living well discourse in popular representations, particularly news media (Bailey, 2019; Brookes *et al.*, 2018), with the exception being a neoliberal emphasis on risk prevention (Castaño, 2023; Lawless, Augoustinos and LeCouteur, 2018; Peel, 2014). Overall, although sections 2 and 3 demonstrate the need for a multifaceted approach to dementia and death/dying, here, the literature indicates that death-related dementia discourses are overly focused on tragedy, and attribute greater agency to dementia than to the people living with the condition, which may exacerbate the stigma surrounding having dementia (Low and Purwaningrum, 2020; Putland and Brookes, 2024a, 2024b).

5. Case study

Introduction

While insightful, the studies described in the previous section draw on relatively small datasets (as the exceptions, see Bailey, 2019; Bailey, Dening and Harvey, 2021, Castaño, 2020, 2023), and either focus on one small aspect of dementia-death discourses, such as the 'living dead' metaphor (e.g., Behuniak, 2011), or briefly consider death within broader analyses of representations of dementia (e.g., Low and Purwaningrum, 2020; Putland and Brookes, 2024a, 2024b). In this section, we describe, by way of a case study, a recent corpus linguistic analysis conducted by one of the authors (Brookes 2023; introduced in the next section) of dementia metaphors in UK newspapers. Rather than reproduce that study, we focus on select metaphorical patterns that were identified in it, (re)interpreting these in terms of how they might convey particular kinds of knowledge, ideas and attitudes around dementia and death.

Methodology

Corpus linguistics is principally a group of methods that use computer programs to analyse large collections of naturally occurring language (Brookes and McEnery 2020). Such datasets are known as 'corpora' (singular: corpus) and are assembled with the aim of representing a

language or linguistic variety on a broad scale. Corpora tend to be much larger and more representative than the types of data that are typically analysed in studies employing manual, purely qualitative analytical methods. Meanwhile, corpus analytical tools can provide unique insights into the language in a corpus, including relating to the frequency and statistical salience of linguistic phenomena such as words and collocations, which can in turn reveal broader phenomena such as metaphorical patterns.

The data analysed by Brookes (2023) was a purpose-built corpus containing UK national newspapers published over ten years (2010-2019). The online news repository, *LexisNexis*, was used to obtain all articles mentioning 'dementia*' in their headline and/or three or more times in the body of the articles (note: the asterisk acts as a wildcard to capture longer strings, e.g. 'dementias'). This resulted in a corpus of 6,751 articles (3,961,272 words), distributed across five UK national tabloids (*Express*, *Mail*, *Mirror*, *Star*, *Sun* – including print, online, Sunday and 'sister' publications). Table 1 provides a quantitative breakdown of the newspapers in the corpus.

Table 1. Newspapers in the corpus.

Newspaper	Articles	Words
Express	1,938	1,074,805
Mail	2,477	1,884,991
Mirror	1,476	686,832
Star	90	30,536
Sun	770	284,108
Total	**6,751**	**3,961,272**

Metaphorical patterns in dementia representation in this corpus were identified using collocation analysis. 'Collocation', as conceptualized in contemporary corpus linguistics research, refers to the association between words based on patterns of co-occurrence. Collocation is usually judged to exist using a word association measure that tells us how often two or more words occur within close proximity to each other within the corpus, and whether this association is notable as a sizeable effect (i.e., that the words in question have a measurably strong preference to occur together as opposed to being randomly associated). Brookes (2023) generated a list of collocates for the word *dementia* (frequency: 50,868) – the 'target' or 'recipient' of the metaphors. For words to be judged as collocates, they had to occur within a five-word window either side of *dementia* at least 10 times and be assigned a Mutual Information (MI) score of 3 or above.

Brookes (2023) then generated concordances for all resulting collocates and manually analysed their co-occurrences with *dementia* qualitatively, in order to ascertain whether or not they tended to be used metaphorically. This step was guided by the Metaphor

Identification Procedure (MIP; Pragglejazz Group 2007), summarised by Semino *et al.* (2018: 632) as follows: 'an expression is regarded as metaphorically used when its "contextual meaning" contrasts with a more physical and concrete "basic meaning", and where the former meaning can be understood via a comparison with the latter.' Simile and other figurative comparisons were also included (ibid.). Collocates judged to have metaphorical meanings in at least 50% of their uses were included in the analysis.

Findings

The analysis identified a range of metaphorical domains which contributed to the framing of dementia in terms of its prevalence, causes, symptoms and prognosis, lived experiences of it, and responses to it. The metaphorical collocates were allocated to one or more of the following categories, which reflect the specific 'targets' of the metaphors: (i.) prevalence; (ii.) causes; (iii.) symptoms and prognosis; (iv.) lived experience; (v.) responses. Brookes (2023) then qualitatively analysed all metaphorical uses of the collocates (or, if their frequency exceeded 100, took 100 metaphorical uses). This qualitative analysis set out to identify the frames (Goffman 1974) that are activated through the use of the metaphorical collocates. In particular, the analysis considers which aspects of dementia are foregrounded by the metaphorical framings (and which are backgrounded or elided), and what views or understandings of dementia are prioritised as a result. In the discussion following the analysis, these framings are interpreted in terms of their potential implications for the public's understandings, and indeed experiences, of dementia. Below, we focus on those metaphorical patterns which frame dementia as a cause of death. As will be seen, these permeate into discursive representations of dementia's prevalence, its symptoms and prognosis, and lived experiences of it. For a more comprehensive report of the wider range of metaphors used in this corpus, see Brookes (2023).

The most explicit articulation of the 'dementia as a cause of death' discourse is in the metaphorical construction of dementia as a murderer that kills people diagnosed with it, as indicated in uses in the following collocates (frequency of collocation in parentheses): *kill* (54), *killed* (83), *killer* (108), *killers* (12), *killing* (45), *kills* (22).

> **DEMENTIA** <u>kills</u> more Brits than any other illness, new figures show.
>
> (*Sun* 2017)

> How we fail victims of our worst <u>killer</u> illness, **dementia**; There are now 850,000 dementia sufferers and that number can only increase as our population ages.
>
> (*Mirror* 2017)

This fatalistic framing of dementia is supported by the anthropomorphic characterisation of the syndrome in terms of qualities which imply dementia to be a violent actor who inflicts

such acts of violence, or murder, wilfully and deliberately (*brutally* (11), *cruel* (83), *cruellest* (16), *deadly* (44), *heartless* (17), *savage* (10)).

> **Dementia** is a <u>cruel killer</u>
>
> (*Express* 2017)

Consistent with such framings, lived experiences of dementia could also be discursively represented in terms of victimhood and conflict. People with dementia were explicitly referred to as a *victim* (115) or *victims* (143), as well as being described as in dementia's *grip* (18) or *hold* (79), as being *stricken* (176) and *struck* (95) by dementia, and as being *stripped* (26) of their cognitive function and sense of personhood. This continues the observed trend that attributing great agency to dementia is often at the expense of people with the condition (Brookes et al., 2018; Putland and Brookes, 2024a).

Attributing slightly more agency than this passive victim construction, people with dementia were also variously framed as battling, facing and struggling with dementia (*battle* (425), *battled* (22), *battles* (31), *battling* (167), *face* (152), *faces* (44), *fight* (370), *fighting* (49), *fights* (24), *struggle* (75), *struggling* (70)). Being encouraged to 'fight' dementia may empower people to feel a sense of agency and focus on what they *can* do, such as improve awareness (Castaño, 2020) or make lifestyle changes (some of which are controversial, see Peel, 2014). Death with dementia was frequently framed as a person losing a 'battle' or 'fight', which could be viewed as implicitly presenting dementia as the cause of the death in question, and winner of the 'fight'.

> MUCH-LOVED BBC weatherman Ian McCaskill has died age 78 after <u>battling</u> **dementia** for five years.
>
> (*Express* 2016)

The framing of people who die with dementia as *succumbing* (10) or having *succumbed* (14) to dementia arguably implies an initial struggle or resistance but an eventual failure or even surrender.

> Comedy writer behind Steptoe & Son dies aged 88; Ray, who partnered with Alan Simpson to create legendary comedies like Hancock's Half Hour, <u>succumbed</u> to his **dementia** battle, his family has confirmed.
>
> (*Mirror* 2018)

Clearly, individuals cannot ultimately win against the currently incurable dementia, which may contribute to harmful notions of inadequacy or (self-)blame (Lane, McLachlan and Philip, 2013).

The notion of dementia as a killer also extends to metaphorical representations of other aspects, including its prevalence. Notably, mixed metaphors bring together the domains of violence and sport/competition in order to figuratively present dementia's high

and rising prevalence, including when covering an Office for National Statistics report suggesting that dementia had become the leading cause of death in the UK. This metaphorical combination was indicated in uses of the collocates *leading* (242), *leader* (49), *overtaken* (19) and *overtook* (10), and in uses of the mixed metaphor in conjunction with the killer-related collocates described above. In such cases, dementia is depicted as leading or overtaking other conditions to become the *leader* or the *leading* cause of death in the UK.

      dementia has <u>overtaken</u> heart disease as the biggest killer

(*Express* 2017)

Violence metaphors could also be used to frame the prevalence of dementia and its associated death rates more directly, where the incidence of the condition was quantified in terms of the number of people who had been *hit* (162) by the condition, or what its death *toll* (53) was.

As we discussed earlier in this chapter, metaphor can have the power to foreground certain elements of the phenomena they represent while backgrounding or eliding others. Notably, violence metaphors (also termed 'war', 'martial' and 'militaristic', etc.) are pervasive not only in coverage of dementia but in the language associated with health and illness in general. Criticisms of these metaphors are, by now, long-standing. One of the earlier commentators on such tropes, Susan Sontag, cautioned against the use of violence metaphors, arguing that they can have stigmatising effects for those affected by the illness in question (Sontag, 1978). In particular, Sontag argued that violence metaphors have the potential to frame people affected by illness as the 'enemy' of the 'war', and their bodies as the metaphorical 'battlefields'. She also argued that a further issue with violence metaphors is that if the disease prevails and the person fails to recover from it, that person could then be viewed as having 'lost' the battle. This is especially problematic in the case of dementia; given, as noted, that dementia is a chronic syndrome with no known cure, this is a battle that people diagnosed with the syndrome will inevitably lose. A prominent counterargument is that some people can find violence metaphors empowering, as these have the potential to grant individuals a greater sense of agency in their illness experience, helping them to feel like they have greater influence over their prognosis. In the case of dementia, people with the condition might use violence metaphors to express their efforts to achieve greater social awareness and rights, or to ascribe themselves greater agency in managing their dementia than the role of a passive victim allows (Castaño, 2023). However, such uses are noticeably lacking in these news representations.

Alongside violence metaphors that establish dementia as the bringer of death, the experience of having dementia is also associated with decline, dying and of death through other metaphors within this corpus. Notably, having dementia is metaphorically conceptualised in terms of loss, descent and hell. The loss of memory and cognitive function (and related loss of self) is a well-established metaphor in dementia discourse. The articles in this corpus appear to reproduce the loss metaphor through the collocates *lose* (72), *loses*

(18), *losing* (111) and *lost* (125), as these attribute grammatical agency to the person with dementia, who is framed as having metaphorically lost the particular functions under focus.

> Many people with **dementia** gradually <u>lose</u> their ability to walk and perform simple tasks as their condition progresses.
>
> (*Mirror* 2016)

While more grammatically agentive, such an emphasis on losing abilities even for 'simple tasks' foregrounds the more advanced stages of dementia, at which people experience greater deterioration and are closer to death. Relatedly, the use of the collocate *descent* (12) indicates a spatial metaphor that frames life with dementia as a downward movement into the condition until death. As the below example shows, this draws on the broader down equals bad metaphor to negatively evaluate experiences of dementia in terms of decline and feelings of 'anguish'.

> Yesterday in her heart-breaking series about her husband's <u>descent</u> into **dementia**, Nula Suchet described her anguish as she watched his health deteriorate.
>
> (*Mail* 2019)

Another frequent collocate of dementia was that of *live* (377) and *living* (1,198), which was used to metaphorically characterise the relationship between dementia and the person with the condition as one of companionship. As the below examples indicate, this companionship may be fairly harmonious and enable the person with dementia to focus on 'living well', or it may be used to position having dementia as hellish.

> Doctors advised him that to keep <u>living</u> well with **dementia** he should stay active, eat healthily and socialise.
>
> (*Mirror* 2019)

> <u>Living</u> with **dementia** is hell, and I wouldn't wish it on anyone else.
>
> (*Mail* 2012)

Likening living with dementia to living in *hell* (18) is also implicitly evoked by metaphors of a *horror* (13) movie or a *nightmare* (10). Since to enter hell traditionally necessitates death and is eternal punishment for wrongdoing in life, this suggests that dementia entails not only death in life but also punishment of the worst kind. Combined, these metaphors of loss, dying and hell implicitly position dementia as (worse than) a death sentence and thus can indicate that people with dementia are experiencing death – or hell – in life.

Clearly, the above violence, loss, descent and hell metaphors have the potential to frame dementia in a way that contributes to dementia stigma. Stigma remains a salient feature of the experience of living with dementia (Swaffer 2014) and its effects on people's lives and society can be severe. Dementia stigma may contribute to a societal view of people

with dementia as 'Other', as well as a sense of spoiled identity in which dementia is seen first, with all of an individual's traits and behaviours being attributed to dementia, and other aspects of their identity being backgrounded or overlooked altogether. Taken together, these kinds of societal representations of dementia and people with it can lead to them being negatively labelled and stereotyped, which can in turn lead to discrimination and a loss of power (Link and Phelan 2001). As well as drawing on our understanding of the impacts of stigma in general terms, recent research has highlighted the impacts of dementia stigma in particular. For example, dementia stigma has been found to engender feelings of shame in people with dementia and to prevent them from seeking diagnosis and medical support, as well as making them less willing to get involved in research (Burgener and Berger 2008). Dementia stigma has also been found to distort service standards at all levels of UK healthcare, including frontline provision and resource allocation (Benbow and Jolley 2012). Dementia stigma can also contribute to fear, misunderstanding and negative attitudes around dementia among the general public. For example, approximately one in five adults in the UK mistakenly believe that dementia is an inevitable part of ageing while 49% agree that dementia is the health condition that they fear most (Alzheimer's Research UK 2023). More globally, a report by Alzheimer's Disease International (2019) suggested that 80% of people are fearful of dementia.

A defence of the use of the metaphors identified in this analysis is that such tropes might offer useful linguistic and conceptual apparatus with which to communicate about what is – in dementia – a complex and difficult-to-understand syndrome, in the process conferring a sense of 'symbolic order' over it. Indeed, many people have a poor understanding of and continue to fear dementia more than they do other serious diseases. Yet, we might question the extent to which the metaphors which characterise the tabloids' coverage are indeed likely to improve public understanding of dementia. For example, the metaphors used to represent dementia's prevalence as wide and growing to disastrous effect – including the framing of dementia as a killer, and a 'leading' one at that – risk (mis)representing dementia itself as a cause of death when, as we have seen, this is not the case (i.e. people die *with* dementia, rather than *of* it). Furthermore, such depictions were seldom accompanied by any discussion of the epidemiological niceties, discussed earlier in this chapter, which are likely to give us an inflated impression of dementia's prevalence. Indeed, recent research indicates that the prevalence and incidence rates of dementia in high income countries such as the UK may have actually fallen (Prince *et al.,* 2016; Wolters *et al.,* 2020). However, such optimistic counterarguments run contrary to the news value of negativity (and would thus make for less sensational headlines). Moreover, the news agencies studied here might contend that their priority is to sell newspapers and generate traffic to their websites. Although it is true that the news organizations included in this study are also commercial outfits, and hence are not strictly responsible for raising genuine awareness of health issues like dementia, we ought nevertheless to reflect critically on the likely trade-off between raising profits and awareness, and the ramifications this might have for the lives of people living with dementia, as well as the public more generally.

6. Conclusion

Throughout this chapter, we have shown that the complex relationship between dementia and death is widely simplified in popular discourses. Focusing on metaphors, we have demonstrated through both our case study and review of the existing literature that dementia is popularly presented not as a chronic condition that people die with but as the *cause*, or bringer, of death. Dementia is thus presented as a death sentence, and life with dementia is either a living death or a fate worse than death – a living hell. The prominence of such framings reflects wider discourses surrounding what it means to be alive and to have a "good death". Notably, the threat that having dementia presents to the hypercognitive notions of personhood and a "good life/death" informs (and is in turn exacerbated by) metaphors that associate dementia with horror and with death in life.

Discourses such as those explored in this chapter must be critically engaged with, as they can impact on (self-)perceptions, interactions and wider social practices (Heap and Wolverson, 2020; Johnstone, 2013; van Wijngaarden *et al.*, 2019). Notably, metaphors that present life with dementia as a living death or fate worse than death can subsequently be used to support the discourse of euthanasia as the logical way of regaining control and "saving" people from dementia through death (Johnstone, 2013). While it is important to acknowledge individual preferences, to regard death as preferable to living with dementia on a societal level risks de-humanising and limiting the moral worth of (and thus obligations to) people living with dementia, with people with dementia then potentially being viewed by some as 'life unworthy of life' and 'better off dead' (Johnstone, 2013, p. 388). As Castaño's (2020) analysis of bloggers with dementia shows, there can be a discrepancy between the expectations expressed by the 'death sentence' metaphor and people's lived realities, with individuals with dementia distancing themselves from this metaphor over time (e.g., 'I thought I was given a death sentence but it does not have to be, many people live for a long time with their diagnosis'). It is therefore important to consider what other roles are available to people with dementia in popular discourses asides that of tragically struggling with and succumbing to dementia-oriented dying/death.

Even if underrepresented, there are alternative framings that instead emphasise life and opportunities with dementia, including of being happy, contributing to society and experiencing personal growth (Low and Purwaningrum, 2020; Putland and Brookes, 2024a; Van Gorp and Vercruysse, 2012). While not the focus of the present chapter, analysing counter discourses in greater detail is a promising avenue for future research, and offers potential routes to linguistic and social change. Notably, a more diverse range of semiotic resources, such as alternative metaphors, could better reflect people's subjective realities and the overall complexity of dementia and death (Johnstone, 2013; Putland, 2022). To achieve

linguistic change, people with and otherwise affected by dementia must be at least consulted, and ideally, lead the agenda (Castaño, 2023; Davies *et al.*, 2022; DEEP, 2014; Hillman *et al.,* 2018). Equally, as Kelly (2019) proposes, redefining relationships between the dementia community and journalists could help to provide more awareness-raising and nuanced accounts of dementia, and of people affected by the syndrome, moving forward. Acknowledging the limitations of the current 'tragedy' versus 'living well' discursive binary (McParland, Kelly and Innes, 2017), the aim should be not to uncritically shift towards positivity but to establish a 'more humane approach' that can reframe personhood, interdependency and frailty in a way that resists, rather than propels, the 'social death' of people with dementia (George, 2010, p. 587).

7. References

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