

CHAPTER SEVENTEEN

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, dehumanizing 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 recognized, as exemplified by the array of communication guidelines aiming to challenge dementia stigma with more nuanced and humanizing discourses (e.g., Alzheimer Europe 2022; Alzheimer's Society 2018; DEEP 2014). Despite existing research recognizing that fears of ageing, death and degeneration are integral to contemporary (Western) dementia discourses (Low and Purwaningrum 2020; Van Gorp and Vercruyse 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 contextualize 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 Organization 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: 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 Organization 2022).

Despite having commonly recognized 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 recognizing dementia as a subjective experience that is 'relational and co-created' through our interactions with others (Latimer 2018: 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 internalizing 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 a 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: 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). Recognizing 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 criticized 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 medicalized 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 conceptualizations of a ‘good death’ that emphasize 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: 234). Notably, the Office for National Statistics’ (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 per cent 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 Organization, internationally recognized death certificates include the direct cause of death, contributing factors and the underlying cause, which may be a long-standing, 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 previously have 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 normalized 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: 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: 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: 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 prioritizes cognition and autonomy. For example, biomedical assessment rubrics for dementia prioritize 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 emphasize deterioration and death, including by using flashbacks of someone with dementia at an earlier time in life to emphasize decline, showing a desire to die, and by consistently ending with either institutionalization 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, Denning 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 perceiving a shared similarity between two different things (Semino 2008: 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: 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 organize 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 stigmatization of people living with

dementia (Johnstone 2013: 390). Attributing such powerful agency to dementia is often accompanied by the passivization and victimization 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 unbeatable enemy (Bailey, Denning 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: 1277). Foregrounding dementia’s terminal stage risks ‘equating all forms of dementia with death’, including earlier stages of the condition (Taylor 2008: 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: 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 marginalized 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: 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: 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: 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 through 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: 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 emphasizing remaining strengths, recognizing 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, Denning 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.

TABLE 17.1: Newspapers in the corpus

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

The data analysed by Brookes (2023) was a purpose-built corpus containing UK national newspapers published over ten years (2010–19). 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 17.1 provides a quantitative breakdown of the newspapers in the corpus.

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 ten 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), summarized by Semino et al. (2018: 632) as follows: ‘[A]n 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 (Semino et al. 2018: 632). Collocates judged to have metaphorical meanings in at least 50 per cent 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 prioritized as a result. In the discussion following the analysis, these framings are interpreted in terms of their potential implications for the public's understanding, 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 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 kills more Brits than any other illness, new figures show.

(*Sun* 2017)

How we fail victims of our worst killer 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 characterization 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 cruel killer

(*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), *fight* (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 battling 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 *Step toe & Son* dies aged 88; Ray, who partnered with Alan Simpson to create legendary comedies like *Hancock's Half Hour*, succumbed 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 overtaken 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 stigmatizing 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 counter-argument 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 conceptualized 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 lose 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 descent 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 characterize 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 living well with **dementia** he should stay active, eat healthily and socialise.

(*Mirror* 2019)

Living 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 per cent 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 per cent 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 characterize 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 counter-arguments 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-humanizing 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: 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 aside that of tragically struggling with and succumbing to dementia-oriented dying/death.

Even if under-represented, there are alternative framings that instead emphasize 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 Vercruyse 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: 587).

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