

Dementia stigma: representation and language use

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Abstract. Linguistic choices are widely understood to have the potential to contribute to, but also to challenge, dementia stigma. This scoping review therefore aims to better understand: 1) the characteristics of language-oriented studies into representations of dementia and people with dementia, particularly regarding theoretical engagement with dementia stigma; and 2) what specific linguistic features have the potential to contribute to and/or challenge dementia stigma. Using Scopus, PubMed, PsychInfo and Google Scholar, 44 papers published between January 2000 and December 2022 were selected and thematically synthesized. We found that the number of publications addressing language and dementia stigma increased dramatically over the period covered. Most studies (75%) did not explicitly define their use of the term stigma, and those that did drew on a range of theories and sources. Linguistic features associated with stigma included catastrophizing metaphors and the personification of dementia as a cruel enemy. Distancing and delegitimizing strategies were popularly used for people living with dementia, including homogenization, negative group labels, dehumanizing metaphors, infantilization and passivization. Humor could be used to perpetuate dementia stigma, but also to resist and reclaim stigmatizing discourses. Dementia stigma could be challenged through redefining the roles attributed to social actors, directly critiquing harmful discourses, and by providing counter-discourses. Counter-discourses used normalizing, holistic, person-centered, rights-based, optimistic and affirmative language. Overall, a complex picture of language and dementia stigma emerges. Based on our review of the 44 papers considered, we argue that much language has the potential to perpetuate or resist stigma, and that this is shaped by and depends upon the broader discursive context within which such language use takes place.

Keywords. scoping review, dementia, stigma, discourse, language

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1 Introduction

People diagnosed with dementia must live not only with the syndrome, but also with the stigma surrounding it. Since we are concerned here with how other linguistic studies approach language and stigma, we refrain from providing our own stigma definition to avoid aligning ourselves with a particular theory (for comprehensive stigma-oriented reviews, see Nguyen and Li 2020; Pescosolido and Martin 2015; Werner 2014). What we do wish to emphasize here is that stigma is a complex social phenomenon that can manifest differently, most notably as stigma amongst the general public, self-stigma, stigma through association with the stigmatized person, provider-based stigma, and structural stigma (e.g., Goffman 1963; Link and Phelan 2001; Nguyen and Li 2020; Pescosolido and Martin 2015; Werner 2014). Dementia stigma can negatively impact the lives of people living with dementia (and those close to them) in a variety of ways, including by engendering feelings of shame, which makes individuals less likely to seek medical support or take part in research (Swaffer 2014). Dementia stigma can also distort service standards at all levels of healthcare, from funding decisions to service commissioning and frontline care (Swaffer 2014), adversely affecting the life chances of people with dementia. For the wider public, dementia stigma has been shown to create fear and misunderstanding of the syndrome, as well as negative attitudes towards those diagnosed with it (Alzheimer's Research UK 2023). The harm caused by dementia stigma can thus be widespread and deep, having implications not only for the health and quality of life of those diagnosed with the syndrome, but also for their relatives and carers, as well as for society as a whole (O'Connor et al. 2022).

The language we use to represent and communicate about health and illness has long been observed by researchers to have the power to shape societal attitudes towards those topics (see Brookes and Hunt 2021). We follow Hall (1997, 61), in viewing representation as “the process by which members of a culture use language [...] to produce meaning,” Hall elaborates that, “[a]lready this definition carries the important premise that things—objects, people, events in the world—do not have in themselves any fixed, final or true meaning. It is us—in society, within human cultures—who make things mean, who signify” (ibid.). The language we use to represent dementia is widely understood to play a role in the creation or challenging of stigma (Volkow, Gordon, and Koob 2021), including dementia stigma specifically (Swaffer 2014). What is perhaps less well understood—or at least less well documented—is the range of linguistic mechanisms by which these processes occur. Yet, understanding the language use that is associated with stigma is valuable for identifying and critiquing potentially stigmatizing representations of dementia and people with dementia, as well as for suggesting more positive alternative linguistic choices. Indeed, as Venkatesan and Kasthuri (2018, 76) put it, since “language mediates the personhood and subject-position of individuals in power relations, any stated attempt to reconfigure existing perspectives *necessitates the reconfiguration of available language*” (our emphasis).

Therefore, in this article we present a scoping review of literature that examines how language use contributes to the creation and challenging of dementia stigma. Ours is not the first review concerning dementia stigma (see, for example, Bacsu, Johnson, et al. 2022; Herrmann et al. 2018; Low and Purwaningrum 2020; Nguyen and Li 2020; Rosin et al. 2020; Werner 2014). However, it is—to our knowledge—the first to address dementia stigma from the perspectives of language use and represen-

tation (though for a frame-based review of dementia portrayals that does not focus specifically on language (see Low and Purwaningrum 2020). In particular, we take a thematic approach to research synthesis (see Popay et al. 2006; Thomas and Harden 2008; Tong et al. 2012), and seek to answer the following questions:

1. What theories of stigma have guided studies of representations of dementia and people with dementia?
2. What linguistic features of representations of dementia and people with dementia can contribute to and / or challenge dementia stigma?

By linguistic features, we refer broadly to all forms of identified language use, ranging from individual words and grammatical choices, up to higher-level phenomena such as metaphor and discourses (see Gwyn 2002). We do not seek to impose any particular theory of or approach to stigma (for an overview of types of stigma in dementia, see Nguyen and Li 2020). In recognition of the cultural conflation of dementia and Alzheimer's disease, our review considers research that examines the representation of either or both. While we acknowledge that Alzheimer's disease is a sub-type of dementia, for terminological clarity we will use the umbrella term *dementia*, delineating our discussion to Alzheimer's disease specifically where relevant.

2 Design and methods

In aiming to identify the discourses through which dementia stigma is created and challenged, our review is underpinned at the theoretical level by a broadly social constructionist view of discourse (Burr 1995). More specifically, we view discourses as ways of construing reality that are realized through particular linguistic articulations (Fairclough 2003). According to this view, it is possible for contrasting descriptions of any phenomenon to result in reality to being constructed in multiple (conflicting) ways, depending on which discourse(s) are invoked (124). As Burr (1995, 48) summarizes, discourses "each [have] a different story to tell about the world, a different way of representing it to the world." While the studies we review are not, as will be seen below, restricted by the view of discourse they take, the socially constructive view of discourse set out above guides our interpretation of the various representational discourses identified in the studies under consideration. In particular, and as noted, we are interested in the capacity of such representational discourses, which each offer a particular way of representing dementia, to contribute towards or challenge dementia stigma.

At the practical level, we follow Tong et al.'s (2012) 21-item guidance for enhancing transparency in reporting the synthesis of qualitative research (ENTREQ). In sum, ENTREQ requires: (1) outlining the study's aims and synthesis approach; (2) clearly detailing the process of searching for, screening and evaluating the included studies; (3) transparently explaining the analytical procedure, including how data was extracted and coded, studies compared and themes derived; and (4) closely grounding the synthesis in quotes from the primary studies and then going beyond these to provide new knowledge. Having addressed the first point in the introduction, we turn to the second and third aspects here, while the fourth focus underlies our results section.

2.1 Searching and screening studies

The flowchart (Fig. 1) visualizes our process for searching and filtering results. To develop a comprehensive search strategy, we piloted our search terms using Scopus (see Fig. 1 for the finalized terms), thus taking a pre-planned approach to searching the literature (Tong et al. 2012). The search terms are designed to maximize the heterogeneity of results, here by spanning various disciplines and theoretical models of communication. While the search terms incorporated a multimodal perspective on discourse (see Brookes, Putland, and Harvey 2021), in line with the theoretical view of discourse outlined above, this review focuses only on language-based findings.

The databases Scopus, PubMed and PsychInfo were selected to cover the social sciences, arts and humanities and health. Titles, abstracts and (where possible) keywords were searched in January 2023. We then searched Google Scholar to supplement these databases, sorting the approximately 17 800 results by relevance and screening the first 250, at which point the relevance of results waned. The inclusion criteria were:

- Contains original research on language use in relation to dementia representation;
- Relates some or all findings in relation to dementia stigma;
- Published between 01.01.2000 and 31.12.2022;
- Includes primary data (i.e., original empirical data);
- Can access the full publication;
- Written in English with either English language data or English translations.

Publications of interest were sorted in the referencing manager, Zotero, and new publications were checked against existing ones to avoid the inclusion of duplicates across databases. Sixteen publications were then added by hand through checking relevant reference lists and drawing on prior knowledge of the field. Eligible publications were read independently by both authors, who resolved borderline inclusions through discussion. Forty-two articles and two book chapters were included in the subsequent review.

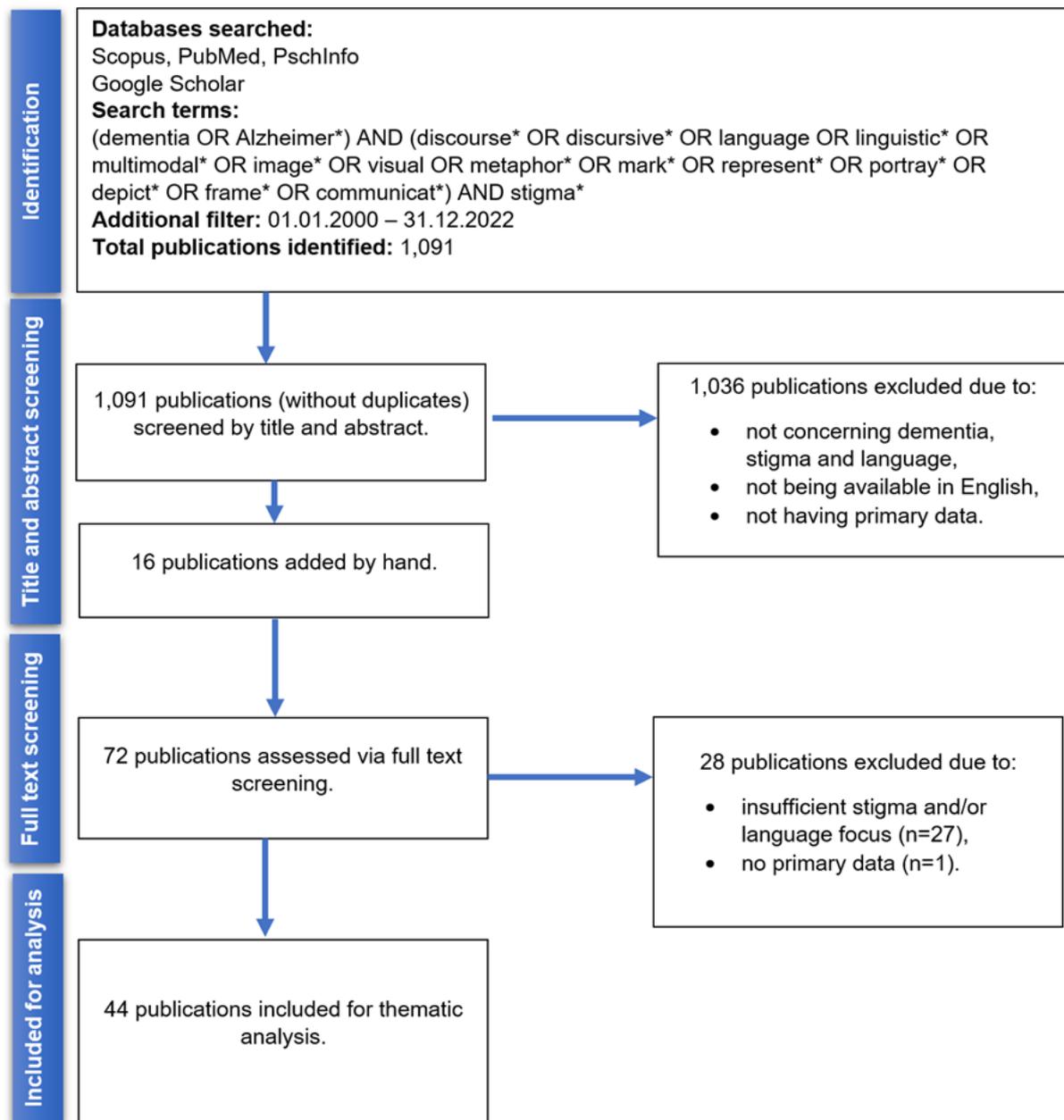


Figure 1: Summary of Screening process.

2.2 Analytical procedure

For each publication, we were concerned with the research aim/questions, data type, cultural context and analytical approach (see Appendix, Table 1), alongside the studies' theoretical approach to stigma (Appendix, Table 2). Thematic synthesis was then conducted for linguistic features of stigma (Appendix, Table 1, reported in the next section), attending to any linguistic device (e.g., metaphor) that related to social actors (people affected by dementia, dementia etc.) or social processes (i.e., interactions) in a way that might contribute to and / or challenge stigma. Coding combined manual and software-assisted approaches (specifically, version 23 of ATLAS.ti). Following

Thomas and Harden (2008), relevant findings and arguments were first coded line-by-line, from which descriptive themes were generated, and then revised and added to throughout the 44 studies. Analytical themes were subsequently developed relating to how linguistic features might contribute to or challenge dementia stigma. These were loosely informed by our synthesis of the coding frameworks synthesized from existing studies (see Figure 2). The authors independently identified then discussed descriptive themes, and collaboratively developed analytical themes. Although theme generation was inductive, it was inevitably influenced by our prior knowledge of dementia, stigma and language research. The results of our analysis are described in the next section, which begins by summarizing the publications' overall characteristics, before considering how stigma is theorized across the studies and the language features that are identified as contributing to and challenging dementia stigma.

3 Results

3.1 Overview of the studies reviewed

The dataset shows a clear increase in coverage between 2000 and 2022. While one qualifying publication was found from 2000-2005, this increased to four in 2006-2011, ten in 2012-2017, and 29 from 2018-2022 (with 19 from the last two years). Most qualifying articles were published in aging, dementia, communication and / or health journals. No (co-)authors were reported to be living with dementia, and carers were co-authors in only one study (Hudson et al. 2022).

Methodologically, most studies take a qualitative approach to the data (34 publications). Five studies are quantitative, and five take a mixed approach. The most popular data type is newspapers and magazines (22 studies). Also prevalent are online and social media texts (websites, Twitter, forums, blogs), popular literature (novels, memoirs and picturebooks), and academic and / or professional literature (e.g., official records and medical journals). Eight studies conduct interviews and / or focus groups, while one analyses a questionnaire. The participants in such studies are people living with dementia, health professionals, carers and / or relatives (each in four studies) and members of the public (two studies). Analytically, publications often draw from (critical) discourse analysis, thematic analysis, content analysis and frame analysis, although some publications either use an alternative approach or do not specify one.

Although all publications are written in English and provide English translations, fifteen other languages are analysed in this dataset: Arabic, Chinese, Dutch, Flemish, French, German, Hebrew, Hindi, Norwegian, Polish, Slovak, Spanish, Swedish and Tamil. Over half of the publications are situated in (or include) a European context (24), of which eleven analyse data from the United Kingdom (UK). Six publications have a North American context (United States of America [USA] and Canada), four Australasia (Australia and New Zealand) and three Asia (India, Israel and China). Eight publications are based on a non-specific Western context.

3.2 Theorizations of stigma in the studies reviewed

While all publications mention stigma, the concept's inclusion ranges from fleeting to being theoretically and analytically integral. Seventy-five per cent of the studies do not

provide an explicit definition or theorization of stigma (see Appendix, Table 2). This reinforces Werner's 2014 systematic review finding that 73% of publications on dementia and stigma between 1990 and 2012 did not specify a theoretical background. It also accords with Nguyen and Li's (2020, 149), observation that, while the concept of stigma is "overused" in the social sciences, it remains "underdefined" or "not explicitly defined." Overall, stigma is used as a term to discuss intersectionality (most often of dementia stigma with agism), types of stigma (public, self-stigma and stigma by association / courtesy stigma), the consequences of stigma (e.g., social isolation), and, most prominently, to argue that certain discourses and types of representation might contribute to, or challenge, stigma.

While there are some attempts to theorize stigma, these are often limited by a lack of depth, missing references and inconsistent uses of models. Of the eleven studies that do explicitly theorize stigma, six do so in terms of spoiled social identity (Appendix, Table 2), whereby a discrediting attribute devalues the person. This theorization is largely informed by the seminal work of Goffman (1963), who is cited by all of these publications.¹ Also citing Goffman (1963) are Bacsu, Fraser, et al. (2022, 2), although with a different definition: "stigma (e.g., stereotypes, negative beliefs, and discriminatory behavior)." This does not clearly align with the language of their cited sources (Goffman 1963; Thornicroft et al. 2007), suggesting a broader theoretical stance that may incorporate other perspectives, namely affective and cognitive stigma processes (Corrigan and Watson 2002; Smith 2007)—however, these are not explicitly mentioned. Focusing instead on labelling, Heynderickx, Creten, and Dieltjens (2022) specify stigma as the attribution of negative labels and terms for members of a particular group, but having no citations limits further discussion of their positioning. Finally, three studies draw on Link and Phelan's (2001; 2006) modified labelling theory to situate stigma as the co-occurrence of five elements: labelling, stereotyping, separation of *us* from *them*, status loss and discrimination, and the exercise of power. However, Creten, Heynderickx, and Dieltjens (2022) only discuss the first four elements of this model, while Gove et al. (2016) add a sixth component: emotional reactions.

1. Although Behuniak (2011) and Xu (2021) only cite Goffman (1963) in relation to "courtesy stigma," their explanations of stigma do resemble Goffman's work, respectively discussing stigmatization as "the process of devaluing an attribute or condition, and through this, the individual who possesses it" (Behuniak 2011, 73), and as "a stigma denoting people living with [dementia] as discreditable or inferior in some way" (Xu 2021, 1).

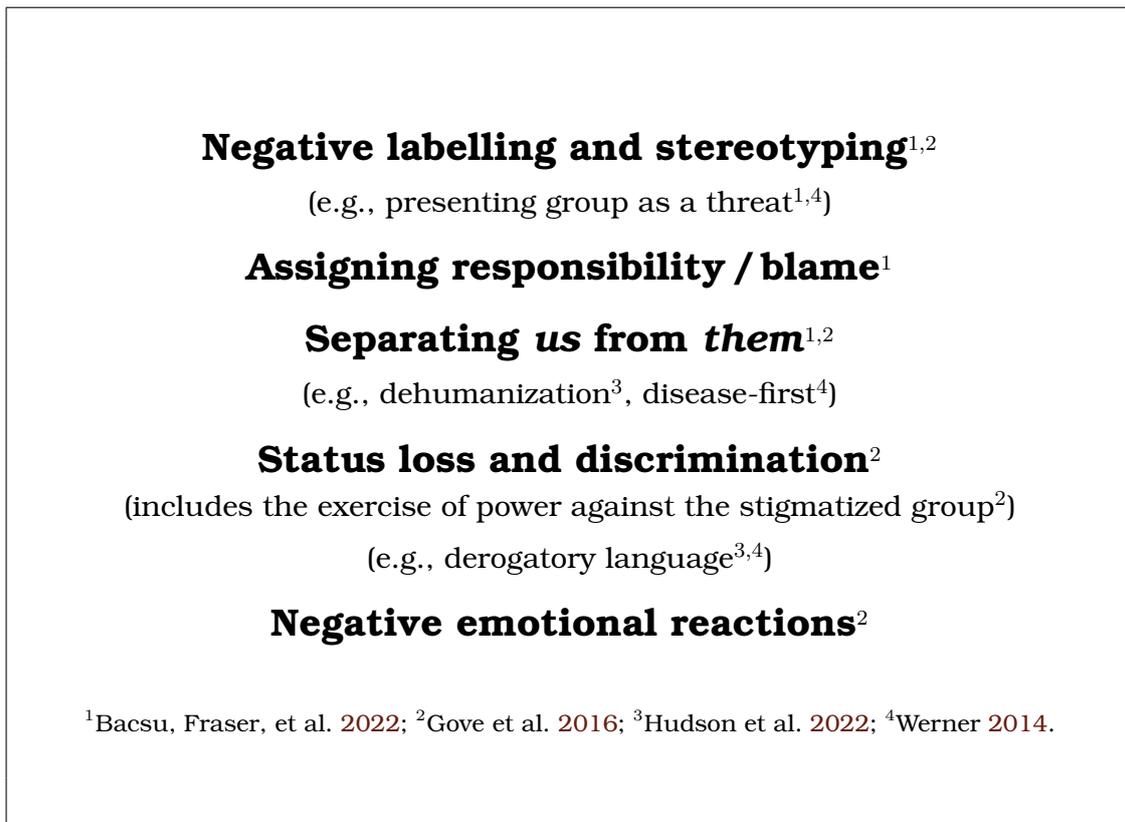


Figure 2: Theorizations of stigma components relevant to linguistic features

When analysing stigmatizing portrayals, most publications focus on specific questions about representations, and later discuss the implications of these for contributing to or challenging stigma. However, a few studies specify frameworks for coding for stigmatizing representations, which have been synthesized in Figure 2. Notably, Gove et al. (2016) directly draw on literature around stigma to combine Link and Phelan's (2001; 2006) model (labelling, stereotyping, separating us from them, status loss and discrimination, and exercising power) with Jones et al.'s (1984) contributing factors (concealability / visibility, course / progression, disruptiveness, aesthetic qualities, origin and peril). Taking a more language-oriented focus, Bacsu, Fraser, et al. (2022) refer to the four types of message content proposed by the stigma communication model (Smith 2007, 2014), namely: a mark to classify people in a stigmatized group, group labelling that creates separation, assigning responsibility / blame, and presenting the group as a threat to society. In contrast, Werner et al. (2019) draw on previous studies' approaches to representations of mental illness in newspapers and language guidelines developed by people living with dementia (DEEP 2014) to code for stigmatizing elements (the representation of people with dementia as dangerous to themselves or others and the personification of dementia) and stigmatizing language (e.g., derogatory, inflammatory, inaccurate language, reducing someone with dementia to the disease, and military metaphors). Meanwhile, Hudson et al. (2022) consult carers on terms that they regard as contributing to misconceptions and / or stigma, namely language that is minimizing, dehumanizing, weaponizing, outdated or

incorrect / questionable. Combined, these four studies present a useful and theoretically substantiated coding framework for stigmatizing portrayals. Any theorization for challenging stigma is noticeably absent in this dataset.

3.3 Linguistic features identified as contributing to stigma

As will be demonstrated throughout this section, many studies link stigmatizing discourses to the overdominance of a biomedical approach to dementia, in which “the person disappears behind the diagnosis” (van Gorp and Vercruyssen 2012, 1276). This may take the form of news coverage mostly focusing on dementia rather than individuals affected (sm-Rahman, Lo, and Jahan 2021) or of pathologizing people’s behavior by attributing it to dementia and ignoring individual agency or structural / interpersonal factors (Herron, Funk, and Spencer 2021). The dominance of the biomedical discourse is problematized for two main reasons. Firstly, biomedicine is observed as often being combined with harmful discourses, such as a hypercognitive model of personhood that suggests a loss of self with dementia, or with metaphors, notably of the living dead (Behuniak 2011). Secondly, an overreliance on the biomedical discourse, it is argued, “conceals alternative discourses and ideologies” (Bailey, Denning, and Harvey 2021, 373) that could challenge dementia stigma, as explored further in the subsequent section of this review. Here, we focus on linguistic features identified in the literature that can contribute to stigma in representations of dementia and people with dementia.

3.3.1 Dementia as powerful, catastrophic and fear-inducing

The literature suggests that language use surrounding dementia is overwhelmingly negative and fear-inducing. Dementia may be presented as a threat on a societal or individual level, namely by equating dementia diagnosis to a social and / or literal death sentence for individuals, and as a catastrophic disruption to society (Gove et al. 2016; van Gorp and Vercruyssen 2012; Zeilig 2014). There seems to be some disagreement about whether dementia is taboo (Hansen, Hauge, and Bergland 2016) or not (Heynderickx, Creten, and Dieltjens 2022), which likely reflects differing cultural and interpersonal contexts across studies and researchers’ differing analytical criteria.

What is consistent across the studies is the metaphorical association of dementia with disaster and violence. Dementia is frequently discussed as a natural disaster (*tsunami*), a weapon of mass destruction (*time bomb*) or an epidemic (Behuniak 2011; Johnstone 2013; Peel 2014; Zeilig 2014). Relatedly, dementia is consistently personified as an agentive enemy, whether as a malicious human (a killer, hostile intruder or thief) or a non-human threat (a demon, monster, parasite or alien) (Brookes et al. 2018; Clarke 2006; Creten, Heynderickx, and Dieltjens 2021; Johnstone 2013; Sestáková and Plichtová 2020; van Gorp and Vercruyssen 2012). This personification is achieved not only through noun but also verb choices, such as in the representation of dementia as an agent that “attacks,” “consumes,” “deprives,” “destroys,” “hits,” “invades,” “strikes,” or “robs” (Johnstone 2013, 378). Overall, dementia is attributed significant agency and power, and is often characterized as being undefeatable, as well as indiscriminate in selecting its victims. This portrayal can exacerbate the passivization and victimization of people living with dementia (addressed below); for instance, Zimmermann (2017, 84) argues that positioning dementia as an “omnipotent god” by

calling it the “Dark Lord” reinforces “the impression of the reduced and insignificant patient.”

Equally, dementia (or Alzheimer’s disease) is itself used metaphorically to refer to loss of self, dignity and autonomy (Johnstone 2013), human misdeeds and shortcomings (Zimmermann 2017), and “a complex, unknowable world of doom, aging, and a fate worse than death” (Zeilig 2014, 262). The fear-inducing portrayal of dementia likely contributes to stigma, as such fears can be “transferred” onto the people living with dementia (Johnstone 2013, 383). This argument reflects the role of threat and fear in stigma theories (e.g., Jones et al. 1984; Smith 2007) and the association of dementia stigma with reports of fearing people with dementia (alongside other negative emotions such as disgust) (Nguyen and Li 2020).

3.3.2 Othering people with dementia

There are many ways of representing people with dementia that are argued to contribute to stigma. Combined, these representations tend to encourage a separation between people without dementia (*us*) and people with dementia (*them*), whereby the latter group is stereotyped and distinguished as having negative, undesirable characteristics and a lower status than other citizens. Notably, all of these features are theorized to be central components of stigma (Link and Phelan 2001, 2006). Many authors observe the separation of people living with dementia (*them*) from the *us* of those without dementia, as well as of people with dementia from their previous identities (e.g., “I wanted him restored to himself. I wanted my father back. This old geezer made me mad,” Caspermeyer et al. 2006, 305). This may occur through only addressing people without dementia as the synthetically personalized *you* of campaign posters, which excludes people living with dementia as audience members (Brookes, Putland, and Harvey 2021). More often, this audience address is less explicit, and people with dementia are separated from *us* through a range of distancing and delegitimizing strategies.

Firstly, the homogenization of people with dementia can be used as a distancing linguistic strategy. People with dementia are often discussed collectively, as a generic group, which restricts empathy and might thus be regarded as a “dehumanizing tool” (Siiner 2019, 987). Occasionally, individuals living with dementia may also use group labels to disassociate themselves from the wider group of people with dementia (e.g., through referring to “such people” without including themselves) (Hansen et al. 2022). People with dementia may be grouped together as “all lunatics” (Talbot et al. 2021, 2551) or as “patients” or “sufferers,” anonymizing and homogenizing a diverse social group (Bailey, Dening, and Harvey 2021). Often, the experience of dementia is also homogenized, usually by being characterized in terms of its advanced stages. This overlooks the syndrome’s progressive nature, conflates the experiences of those experiencing the syndrome at distinct stages, and ultimately foregrounds negative and extreme stereotypes (Bacsu, Fraser, et al. 2022; Clarke 2006; Gove et al. 2016).

3.3.3 Delegitimizing group labels

Prominent group labels represent people living with dementia as losing their identity, personhood, autonomy and value. Broadly, individuals are defined as “being demented” rather than as simply having dementia (McColgan, Valentine, and Downs 2000, 97) and as non-reciprocal, which “represents a division between *us*

(we contribute / give back) and *them* (they don't)" (Gove et al. 2017, 956; Mackowiak et al. 2022; Medina 2017). People with dementia are thus positioned as an emotional, financial and social burden (Bacsu, Fraser, et al. 2022; van Gorp and Vercrusse 2012), or as a threat, with newspapers pathologizing aggressive or sexual behaviors to construct moral panic (Grigorovich 2020; Herron, Funk, and Spencer 2021). Perceived as unable to fulfil social roles, people living with dementia are often portrayed as a "non-person" (Gove et al. 2016, 395) or as socially dead (e.g., one care partner discusses their future with "a former life partner," Bös and Schneider 2022, 224).

Metaphors are therefore commonly used to dehumanize people with dementia, whether through positioning people as zombies (Behuniak 2011; Creten, Heynderickx, and Dieltjens 2021; Johnstone 2013) or as being invaded by an alien, being a vegetable, an animal, an empty shell, no longer being there, or already dead (Bailey, Denning, and Harvey 2021; Johnstone 2013; Medina 2017; van Gorp and Vercrusse 2012; Zimmermann 2017). Dehumanization can also occur through metaphors that envision people living with dementia as faulty machines, which risks pathologizing, backgrounding and passivizing individuals (Bailey, Denning, and Harvey 2021; Caldwell, Falcus, and Sako 2021).

People living with dementia are also frequently objectified and infantilized. This includes being categorized alongside wallets, keys, young children and pets in tracker technology advertisements (Vermeer, Higgs, and Charlesworth 2019, 2022) and being portrayed as childlike, vulnerable and dependent, for instance by likening someone with dementia's response to "the instinctive response of a baby to affection shown by a mother" (Grigorovich 2020).

Particular linguistic labels are reported to be stigmatizing in a dementia context, including *demented*, *senile*, *patients* (beyond a healthcare context), *victim* and *sufferers* (Bailey, Denning, and Harvey 2021; Hudson et al. 2022; Werner et al. 2019), the latter because it "implies that people living with dementia are helpless, thus reinforcing inaccurate stereotypes and heightening the fear and stigma associated with dementia" (O'Malley, Shortt, and Carroll 2022, 1356). Hurzuk et al. (2022, 2301) similarly argue that words such as *Paittiyam* (Tamil 'lunatic') and *Man Buddi* (Hindi 'half-witted') reflect and contribute to dementia stigma. Interestingly, Hansen et al. (2022) highlight that individuals living with dementia may also use stigmatizing language, for instance by referring to other people with dementia as *the demented*. Nonetheless, it can be problematic to equate particular linguistic terms with the propagation of stigma. Siiner (2019) exemplifies this by showing that, over time, the word *senile* has increasingly been used not only to stigmatize people with dementia but also as a more empowering *we* term, used by older people and people with dementia to resist the increasingly prevalent (and also potentially disempowering) *living / aging well* discourse.

3.3.4 Ridicule

Humor and ridicule may also be used to undermine people living with dementia. In the publications reviewed, this use of humor was identified specifically in the contexts of social media and newspaper texts. In some cases, humor is built on minimizing the actual experience of dementia, as in tweets about "selective dementia" (Hudson et al. 2022, 6) and a newspaper headline proclaiming that "Just walking the dog takes man 13 hours" (Kirkman 2006, 77), which position dementia and people with

the syndrome as the source of humor for others, with the potential impact being the ridiculing of the person being described and evaluated.

More overtly stigmatizing is the use of terms such as *dementia*, *demented* and *senile* to insult and ridicule others, particularly political figures and groups (e.g., *demented democrats*) or other individuals that the text's author disagrees with (Bacsu, Fraser, et al. 2022; Creten, Heynderickx, and Dieltjens 2022; Hudson et al. 2022; Kirkman 2006). In such cases, the notion of having dementia is invoked to suggest incompetence.

3.3.5 Passivization, exclusion and mistreatment

Relating to the above linguistic features is the widespread passivization of people with dementia. Grammatically, people with dementia are often cast in the passive role of object, in which they are acted upon by others (Bailey, Denning, and Harvey 2021; Sestáková and Plichtová 2020). This grammatical passivity reflects a broader passivization of people with dementia, rooted in a hypercognitive notion of "loss of self" with dementia, which may manifest in denying people agency over their actions (e.g., "She cannot control how she acts. It's part of the disease!" Behuniak 2011, 81), ability to consent ("Should Alzheimer's Patients Be Allowed to Have Sex?" Grigorovich 2020) or engage in an active form of citizenship (Leone, Winterton, and Blackberry 2023). Accordingly, people with dementia are also often presented as victims of dementia, of other social actors (through neglect and abuse) and of structures such as health services (Bailey, Denning, and Harvey 2021; Grigorovich 2020; Kirkman 2006), although sometimes, they may be depicted as the perpetrators (Grigorovich 2020; Herron, Funk, and Spencer 2021).

Associated with this passivization is an overwhelming lack, in contexts of public communication, of the perspectives and voices of people with dementia, who are "essentially voiceless" through discursive backgrounding or exclusion (Clarke 2006, 272). If the experiences, needs or rights of people with dementia are discussed, it is usually by other social actors, such as care partners, relatives, medical professionals and government representatives (Clarke 2006; Herron, Funk, and Spencer 2021; Leone, Winterton, and Blackberry 2023; Medina 2017). Moreover, O'Malley, Shortt, and Carroll (2022, 1358) find that, even when people with dementia are featured, newspapers rely on a restricted range of individuals, and editorial choices can still frame their contributions in a particular way (notably in catastrophic tones; e.g., "dementia sufferer tells of her ordeal"). Overall, such exclusionary practices further delegitimize the status of people with dementia as fellow citizens and significant voices in society.

When people living with dementia are delegitimized as fellow humans with rights, the mistreatment and discrimination against this social group can be normalized and justified by the above negative group labels, especially those that engender a sense of loss of agency and self. This includes medical professionals refusing procedures to people with dementia because "the person is gone" (Clarke 2006, 272) or their "quality of life [. . . does not] justify having this particular [expensive] treatment" (Gove et al. 2016, 396). It is also seen in news reports about violent incidents, in which authorities are quoted as demanding the removal and / or segregation of people with dementia from other residents (Herron, Funk, and Spencer 2021). This literal enact-

ment of *us* versus *them* promotes actions that degrade the citizenship of the *them* group (Herron, Funk, and Spencer 2021).

For people living with dementia, death is presented as reasonable, preferable or even as the solution, which Johnstone (2013, 388) links to widespread dehumanization, as this facilitates regarding people with dementia as being owed less in terms of moral obligations, as well as being less worthy of life. For instance, the loss of autonomy and dignity associated with dementia is used to justify choosing to die (Johnstone 2013) or claim that other types of death are preferable to dying with dementia (e.g., tweeting that “Covid is actually a better death than dementia” Bacsu, Fraser, et al. 2022, 4).

3.3.6 Responsibility and blame

Yet, somewhat contradicting the above passivization is an increasingly prevalent discursive practice of making people responsible for developing or managing dementia, particularly in a newspaper context. Verbs such as “fight, ward off, stave off, beat, save, stop, reduce, avoid and prevent [...] unambiguously present the onset of dementia as controllable through individual actions” (Peel 2014, 895). Individual choices, especially relating to diet or physical / cognitive activities, tend to be overstressed in the news (relative to the multiple individual and structural factors considered in the medical literature), and these actions can be framed using accusatory language (e.g., “Laziness Makes You Stupid,” Schicktanz 2021, 75). While this representation theoretically attributes greater agency to individuals, the focus on prevention emphasizes pre-dementia actions and risks blaming people living with dementia for past actions, likely exacerbating stigma (Lawless, Augoustinos, and LeCouteur 2018; Peel 2014; Petersen and Schicktanz 2021; Schicktanz 2021; Sestáková and Plichtová 2020). Relatedly, Xu (2021) argues that the broader positive / successful aging discourse risks establishing narrow, “perfect models” of individuals living with dementia that ignore differences in resources and symptoms, furthering the responsabilization (and thus potential blame) of the individual for (mis)managing dementia. Nevertheless, Gove et al.’s (2016) findings suggest that, unlike other conditions, people with dementia are stigmatized regardless of whether they are blamed for their condition.

3.3.7 Intersectionality with socio-demographic factors

That dementia stigma is intersectional is signalled by a few studies in relation to gender, race and age. Cullum, Simpson, and Gounder (2020) acknowledge intersections with colonialism and racism when they predict that, as with other chronic conditions, Mori and New Zealand Pacific Islanders with dementia will be particularly vulnerable to being blamed for perceived unhealthy lifestyle choices. Similarly, in a Canadian news context, imbalanced coverage has been linked to indigeneity, with indigenous persons being less favorably treated Herron, Funk, and Spencer (2021). Ageism may manifest as age-related stereotypes or insults (“You are a stupid old woman,” Medina 2017, 1402), a foregrounding of the cruelty of younger people having dementia (“The heart-breaking story of young Becky (32), at this young age she has been given a cruel diagnosis: DEMENTIA!” Sestáková and Plichtová 2020, 389), or positioning older people with dementia as less valuable than younger people (e.g., “my granny is 95, in a home, with full blown dementia. Quick Covid death clearly not a disaster there,” Bacsu, Fraser, et al. 2022, 4). Meanwhile, gendered cultural scripts contribute to

the news trend of presenting men with dementia as sexual predators and women as victims without any sexual agency (Grigorovich 2020). In this way, men with dementia are cast as a threat, whereas women tend to be passivized and infantilized; both representations can contribute to stigma through negative group labelling but do so in opposing, heavily gendered ways.

3.3.8 Complicating *us* versus *them*

Multiple, often intersecting, linguistic strategies can thus be associated with dementia stigma, including passivization, homogenization, infantilization, dehumanization, ridicule, blame, threat, negative group labels and the normalization or justification of mistreatment. Such strategies tend to contribute to the establishment of an *us*, without dementia, separated from a *them*, of people with dementia. Such othering is a central component of stigma (e.g., Link and Phelan 2001; Smith 2007).

However, some researchers suggest that this *us* versus *them* dichotomy is especially complex for people with dementia. Gove et al. (2016) compellingly argue that both separating and not separating people with dementia can contribute to stigma. As explored above, separating *us* from *them* through negative stereotypes can amplify perceived difference and thus facilitate devaluing and discriminating against people with dementia. Yet, blurring the boundaries between *us* and *them* may also contribute to stigma through heightening another factor: existential fear / threat of developing the syndrome. Such tensions between emphasizing similarity or difference can be seen amongst forum users with dementia, who disagree about whether people with earlier and later stages of dementia are “two different sets of folks” (Bös and Schneider 2022, 215). Relatedly, Creten, Heynderickx, and Dieltjens (2021, 62) argue that care partners transfer stigma from their loved one with dementia onto the syndrome by personifying dementia as a separate entity and thus establishing a variant of *us* (the person) versus *them* (dementia) and rendering the syndrome as the target of stigmatization rather than people with the condition. Clearly, stigma is a complex phenomenon and linguistic features may be used differently, either to contribute towards or, as we shall explore further below, challenge, stigma.

3.4 Linguistic features identified as challenging stigma

From 2012 onwards, increasing attention has been paid in the literature to how language might be used to challenge dementia stigma. Here, we examine what linguistic features this existing literature has identified.

3.4.1 Revising roles

First, challenging stigma involves foregrounding the perspectives and voices of people living with dementia and revising the disempowering, culturally inscribed social roles into which such people are routinely placed through language use (as we have seen above). Notably, people with dementia can “position themselves as experts in their own cause” and be recognized as such by others, including by giving advice to others, both with and without dementia (Bös and Schneider 2022, 224), and engaging in online advocacy (Talbot et al. 2021). Likewise, individuals living with dementia can showcase their unique skillsets (such as fluently speaking another language) and

social participation, as explored by Xu (2021) in relation to a TV reality show involving people with dementia running a restaurant.

In doing so, traditional power imbalances between doctors-patients and carers-cared for can also be challenged, as demonstrated by Bös and Schneider's (2022) analysis of a forum for people affected by dementia. Here, users with dementia may resist medical professionals' roles as "omniscient experts" (e.g., "asked for counselor that had more experience in helping those of us with dementia") and critique professional practices, such as unsuitable test conditions. People with dementia also advise care partners, and forum users report doing non-stereotypical activities together, such as writing. This more equitable partnership is reflected in the linguistic choice of *care partner* as a replacement for *carer* or *care giver*, as it foregrounds a non-hierarchical, cooperative relationship between *adults* instead of indicating a one-way provision of care (223). Traditionally disempowering labels can also be recontextualized, as exemplified by a forum user with dementia who identifies as a *patient*, yet simultaneously asserts their expertise: "I know what I am talking about" (222). Establishing a more agentive and socially involved identity for people living with dementia can thus be achieved through positioning such individuals as having insights to share and considering how existing terms can be either revised or recontextualized to provide greater empowerment.

To avoid the risk of presenting unrealistic "perfect models" of people living with dementia that ignores the disparity of experiences (5), personal accounts need to present a "multifaceted picture" of living with dementia (Bös and Schneider 2022, 229). Foregrounding different people's perspectives can highlight that dementia is a "personal journey, travelled differently by each individual," with personal narratives varying in the feelings, signs, challenges, relationships and responses discussed and thus providing more nuance to portrayals of life with dementia (O'Malley, Shortt, and Carroll 2022, 1356).

3.4.2 Resisting or reclaiming delegitimizing representations

Another strategy of challenging stigma is to directly critique harmful stereotypes, representations and practices, including by confronting systemic discrimination, derogatory language, agist and decline-oriented stereotypes, homogenization, passivization and the conflation of dementia with aggressive behavior (Bacsu, Fraser, et al. 2022; Herron, Funk, and Spencer 2021; O'Malley, Shortt, and Carroll 2022; Talbot et al. 2021). The voices of people living with dementia are important to such efforts, since such individuals are uniquely positioned to emphasize diversity amongst people with dementia in response to homogenization ("we're all true faces," Talbot et al. 2021, 2551) and agency in the face of passivization or victimization ("I had dementia, I was not going out like a victim!" Bös and Schneider 2022, 222), as well as to highlight the inaccuracy of agist stereotypes ("the typical image of the older person languishing in the nursing home sinking into a decline is not the whole picture [. . . people] normally say: 'But you do not look old enough,'" O'Malley, Shortt, and Carroll 2022, 1351). Other stakeholders can also achieve this, as exemplified by staff from the Alzheimer's Society being cited in newspapers challenging the "myth" that having dementia necessarily entails aggression and explaining why aggression by people living with dementia is often a reasonable response to experiencing anxiety, fear, and frustration (Herron, Funk, and Spencer 2021, 2084).

While humor has, as we have seen, been found to have the potential to contribute to stigma, it can also, conversely, be a tool to resist or reclaim potentially stigmatizing representations. Indeed, in a corpus-assisted critical discourse analysis of the use of *senile*, Siiner (2019, 991) argues that humor is “a tool of struggle,” as it enables individuals to draw on and exaggerate stereotypes to subvert social norms and power relations (e.g., “I am senile, but not old yet”). Elsewhere, some forum users have been found to index their dementia through humorous username references, as with *forget me not* or *who what* (Bös and Schneider 2022, 220). Authors living with dementia may engage either seriously or humorously with dehumanizing metaphors, as examined by Zimmermann (2017), who translates Claude Couturier’s running joke that “I will be a grilled vegetable,” including Couturier’s later statement that “life is only worth living when shared, otherwise one vegetates (look, I am again with vegetables)” (79). Here, vegetating is associated with social treatment rather than an inherent loss of self, and thus humor is combined with a serious point about the importance of not isolating people living with dementia.

3.4.3 Reframing dementia

Numerous counter-discourses have been identified as having the potential to challenge dementia stigma. Here we categorize key counter-discourses as normalizing dementia, person first, rights based, and optimistic / affirmative. We additionally explore less discussed counter-discourses and authors’ proposed routes to change.

The normalization of having dementia includes positioning it as a syndrome that many people experience and as a “disability” or “chronic illness” in order to argue that dementia requires greater acceptance (O’Malley, Shortt, and Carroll 2022; Xu 2021). Normalization may also include presenting the brain not as the locus of self but as an “organ,” so that dementia becomes “a disease that touches an organ of our body: the brain” (Zimmermann 2017, 92) or metaphorically envisioning dementia not as an enemy but as a strange travelling companion (van Gorp and Vercruyssen 2012). Some individuals argue that dementia should be normalized as a more extreme variant of the natural process of aging of the human brain, and that society should subsequently focus on improving support for living with dementia, rather than striving for an elusive cure (van Gorp and Vercruyssen 2012). Relatedly, life with dementia can be normalized through asserting that individuals “can lead meaningful and engaging lives” (Leone, Winterton, and Blackberry 2023, 167).

Perhaps the most familiar counter-discourse in the dementia literature is to focus on the person first, as advocated by Kitwood (1997). This foregrounds that “we are, above all, human beings with strengths and weaknesses, highs and lows” (Zimmermann 2017, 92). As such, ongoing personhood, identity and relationships are emphasized for people with dementia, whether in picture books that end with “She is still the best Grandma in the whole wide world” (Caldwell, Falcus, and Sako 2021, 125) or personal narratives showing that “we are still ourselves” (O’Malley, Shortt, and Carroll 2022, 1354). Presenting a “multifaceted picture” is important here (Bös and Schneider 2022, 229). This includes people living with dementia identifying themselves, or being identified by others, in terms of their individual personality, interests, professional or social roles, personal history and strengths (Bös and Schneider 2022). The self may be presented as dynamic, including as an interaction between past and present selves (Venkatesan and Kasthuri 2018). Even when discussing identities re-

lated to having dementia, the same person may identify as a care recipient but also as a physician and care partner / care giver, and participants living with dementia can be identified through positively connoted person-first terms, such as *peer volunteer*, *best advocate* or *mentor*, which foreground activity and expertise and signal roles that extend beyond simply having dementia and receiving care (Bös and Schneider 2022, 222).

Relatedly, a rights-based discourse focuses on the rights of people with dementia as citizens. This includes the right to be different, with people emphasizing that they have the right to act unconventionally (Siiner 2019) and to be valued and supported by society regardless, as illustrated in a letter to the editor of a newspaper from the daughter of someone with dementia: “I love him as he is . . . [we should all] say that just because someone is different and needs extra help it does not make them useless and a blight on society” (Leone, Winterton, and Blackberry 2023, 168). The discourse foregrounds how structural issues impact experiences of dementia. This includes people with dementia identifying “overarching barriers” and calling for greater “political will and leadership” to establish a more inclusive approach to care (O’Malley, Shortt, and Carroll 2022, 1352). From such a viewpoint, society is made responsible for supporting people living with dementia and meeting individuals’ diverse needs: “People with dementia want to connect and socialize. But they can be isolated if the right structures aren’t in place. Depending on the nature and stage of the illness a person will have certain needs. With some thoughtful planning, much of these can be met” (Leone, Winterton, and Blackberry 2023, 169). However, if anti-stigma social constructs such as “dementia friendliness” are insufficiently defined and understood, these too risk being disregarded or even negatively associated with labelling or excluding people living with dementia (Hansen et al. 2022).

Another counter-discourse foregrounds optimism and affirmation. This counter-discourse is highly comparable to van Gorp and Vercruyse (2012) *Carpe diem* counter frame in that it emphasizes making the most of life with dementia and seeking opportunities for fulfilment where they arise. Extending this further, dementia can be reconceptualized in terms of healing and wonder. Notably, reconceptualizing the mainstream narrative of dementia as a loss of self, one individual presents dementia as offering people “a unique opportunity” to “become just you, the you [that] you came into this world as . . . pure, whole, and complete. A shedding of sorts, an unencumbering . . . in preparation for heaven” (Bös and Schneider 2022, 229). Rather than loss, changes with dementia are conceptualized here as valuable opportunities to “shed . . . fake and pretend” parts of one’s personality and thus not lose but regain one’s true essence of self. This is similar to notions of returning to one’s origins and freeing oneself from the constraints of adult society that are part of van Gorp and Vercruyse’s (2012) *Each in turn* counter frame. Relatedly, Venkatesan and Kasthuri (2018) propose that Dana Walrath’s graphic novel, *Aliceheimers*, develops a positive language repertoire for describing her life with her mother (Alice) who had Alzheimer’s disease. This repertoire focuses on hope, compassion and finding meaning in having dementia. Alice’s *hallucinations* become *visions* because Walgrath proposes that “the beatification-incarceration spectrum all depends upon frame of reference” and thus, while a *hallucination* may encourage incarceration in a ward, *vision* beautifies Alice as having a connection that others do not (77). More broadly, words such as *anxiety*, *forgetting*, *dying* and *disgust* are replaced by *flying*, *healing*, *peaceful* and *beautiful* (78). Having dementia is reimagined as an “altered magical state” with its own mean-

ings, and as able to help affected individuals to recognize their “deepest self” and heal prior relationships and ways of being in the world (74, 80).

Having identified the main counter discourses put forward as ways of challenging dementia stigma, it is also worth noting less discussed ones. Schicktanz (2021, 74) highlights the value in taking a multifactorial, holistic approach to factors that contribute to dementia, which integrates “bodily, psychological, social, and biological views.” van Gorp and Vercruyssen’s (2012) other counter frames reframe the burden discourse by arguing that each person in turn looks after and is looked after by others and that love and respect for one another is a moral duty. Finally, Zeilig (2014) avers that dementia can—and should—be metaphorically positioned as a lens through which to see more clearly and emphasize shared humanity, not used simply as a shorthand for human fears.

Turning to the challenges that authors themselves issue after analysing their data is also useful for considering how dementia can be reframed to challenge stigma at the levels of text production and reception. Focusing on the production of social texts, some authors argue that the genuine inclusion and participation of the “authentic voices” of people living with dementia needs to become normalized in popular media (including social media) through addressing barriers (Talbot et al. 2021; Leone, Winterton, and Blackberry 2023, 172) and seriously considering the intersectionality of stigma (Xu 2021). Turning to language use and framing, calls include encouraging “non-elitist, uncomplicated and non-judgemental” language (Hurzuk et al. 2022, 2302), and establishing new metaphors that more constructively portray this complex issue and encourage greater care (Johnstone 2013). For instance, Behuniak (2011) argues that the zombie trope for people living with dementia should be actively resisted by instead valuing the connectedness, commonality and inter-dependency of humans. Limitations and suffering should be balanced against portrayals of living a good life (Mackowiak et al. 2022), which includes recognizing people living with dementia as multifaceted and sexual beings who have many relationships and rights (Grigorovich 2020; Herron, Funk, and Spencer 2021). Finally, attending to text reception, audiences have the potential to re-read existing representations without the preconception of loss of self; for instance, the metaphor of a person with dementia as a flickering candle may be interpreted as facing extinguishment (death / loss) or as providing warmth and light (continuation and hope with dementia) (Zimmermann 2017).

4 Discussion and conclusions

This article reviews research exploring the relationship between stigma and linguistic representations of dementia and people with dementia. We have seen that the number of publications examining this topic has increased considerably in recent years. However, the under-theorization of stigma observed in previous reviews remains (Werner 2014), with three-quarters of these studies not defining stigma or explicitly articulating a theoretical position in relation to it, making it difficult to establish a theoretical stigma framework. The remaining quarter drew upon a range of theories and approaches to stigma, and just four provided sufficiently detailed coding frameworks for us to synthesize five components of stigma that may relate to linguistic portrayals: negative labelling / stereotyping, assigning responsibility / blame, separating *us* from *them*, status loss / discrimination, and negative emotional reactions. While drawn

from the studies in the dataset, it is worth noting that these components draw heavily upon Link and Phelan's (2001; 2006) modified labelling theory, which situates stigma as the co-occurrence of five elements: (negative) labelling; stereotyping; separation of *us* from *them*; status loss and discrimination; and the exercise of power. No studies theorized ways of potentially challenging stigma. Clearly, there is a need for linguistic studies to more comprehensively theorize stigma as a concept. Within this, it may be useful to engage with different types of stigma (e.g., public stigma, self-stigma, stigma by association and structural stigma) and anti-stigma strategies in relation to representations.

There are clear mappings between our synthesis of theorized stigma components (Figure 2) and the distancing and delegitimizing linguistic strategies identified in these studies. Firstly, both dementia and people with the syndrome are negatively labelled and stereotyped. Dementia is presented as a powerful and fear-inducing threat, often through catastrophizing metaphors and personifying dementia as a cruel enemy, to the point that dementia itself can function as a metaphor for negatively appraised phenomena in society. Meanwhile, people living with dementia are attributed negative (and often homogenous) group labels that present such individuals as losing their identity, personhood, autonomy and value, and as a threat to society (e.g., as aggressors or an emotional, financial and social burden). Such negative stereotypes are partly achieved through dehumanizing metaphors and infantilizing comparisons to babies and pets. There appears to be a tension between the passivization and / or victimization of people with dementia with assigning responsibility and / or blame for individuals' actions, whether for failing to prevent dementia or inappropriately behaving while experiencing the condition; either has the potential to contribute to stigma.

These linguistic strategies all contribute to positioning people living with dementia as an undesirable *them*, separated from the *us* of people without dementia. The status loss associated with having dementia is most evident in the widespread passivization of such individuals, both grammatically (being positioned as the object acted on by other subjects) and in the texts' construction, with the voices of people living with dementia tending to be excluded. Instead, the focus is often on how their existence negatively impacts other individuals and society, and discriminatory practices such as segregating or refusing treatment are normalized for people with dementia. Implicit throughout is an emphasis on discursively encouraging negative emotional reactions to dementia and people with the syndrome, with fear and emotional distance being two particularly prominent examples. Turning to a broader social context, the studies indicate that the dominant biomedical and hypercognitive discourses can combine with the linguistic features noted above to provide a loss- and disease-oriented representation of dementia and people with the syndrome, while simultaneously suppressing alternative counter-discourses.

This review also considers language use that has been identified as potentially challenging dementia stigma. Specifically, such language use involves redefining the roles attributed to social actors (and necessarily foregrounding the perspectives of people living with dementia), directly critiquing harmful discourses, reclaiming particular terms and providing counter-discourses, which use normalizing, holistic, person-centered, rights-based, optimistic and affirmative language. The counter-discourses identified across this review could usefully inform communicative guidelines and other efforts designed to challenge dementia stigma in society (see Bacsu, Johnson, et al. 2022), as has indeed been suggested by multiple studies in this review.

Importantly, though, the success of any anti-stigma initiative is likely to depend on a number of contextual factors. Considering the lack of theorization of ways of challenging stigma in this dataset, it is useful to turn to other scholars working in the field of stigma more broadly. Notably, in relation to challenging psychiatric stigma, Corrigan and Penn (1999) advocate for direct contact with members of the stigmatized group as a way of challenging (negative) public attitudes, but caution that more successful contact may depend on the participants sharing equal status, interacting cooperatively, and having institutional support. In public and structural destigmatization, Clair, Daniel, and Lamont (2016) similarly highlight the importance of counter-discourses being regarded as credible, which is tied to their conclusiveness and the status of social actors advocating for them, alongside counter-discourses interacting constructively with existing understandings and ideologies, such as hypercognitive values and agist stereotypes. The authors also argue that perceiving a linked fate between the stigmatized group and the dominant group makes destigmatization more likely, supporting the initiative to challenge the *us* versus *them* separation by normalizing dementia and the propensity for anyone to be affected, while managing the risk that perceived similarity may instead contribute to stigma (see Gove et al. 2016).

Alone, the various forms of language use that have been attributed to the creation or challenging of stigma might be rather ineffective in these regards. Instead, it is likely that the effects of such linguistic choices are cumulative—working in concert with each other within and across texts and contexts—as well as incremental, taking effect over time (Fairclough 2001). Moreover, many of the linguistic features discussed in this review are used in ways that are too complex to be regarded as straightforwardly (and consistently) creating or challenging stigma. Evidence indicates that humorous language can be used to perpetuate stigma (through ridicule, insults and undermining the experience of dementia), but conversely also to resist or reclaim stigmatizing discourses. Equally, a given word or discourse could have the potential either to contribute towards or resist dementia stigma, as exemplified by the diverse uses of the word *senile* observed in the literature. Regarding the positioning of dementia as an overpowering enemy, we could note that it is not always the case that this passivizes people with dementia, as people living with dementia may also draw on the metaphors discussed to establish a more agentic “fighting” identity (Castaño 2020, 2022). Indeed, as one of the forum users in Bös and Schneider (2022) study put it, “I had dementia, I was not going out like a victim!” (222). With all this in mind, it is essential for any study seeking to examine language use in relation to dementia stigma to interpret the possible effect of any linguistic choices in view of their contexts, both at the macro (i.e. socio-political, historical) and micro (i.e. contexts of text production and reception) levels.

Inevitably, we have not been able to provide an entirely comprehensive picture of research on language use and dementia stigma. Some reasons for this are procedural; our search strategy and inclusion criteria might have led us to miss publications that provided additional or contrary insights to those we have gleaned from our data. The same can be said for our decision not to include so-called grey literature (e.g., doctoral theses, conference contributions, posters). Another practical obstacle concerns language. We have only been able to focus on studies published in English and that analyse (translated) English textual data, which may contribute to the dataset’s bias towards Western (especially Anglo) contexts. Other challenges were more theoretical in nature, and perhaps reflect disciplinary differences between ourselves and

the authors whose work we were reviewing. As noted, in some cases it was difficult to ascertain how data was selected, collected and analysed. The publications reviewed also exhibited differing degrees of linguistic focus, and so sometimes we had to infer the identification of particular linguistic patterns based on the representative data examples provided and occasionally disagreed with a coding decision.

Reflecting on some of the main features and limitations of the research reviewed here, future studies on language use and dementia stigma should aim to more comprehensively engage with stigma as a theoretical construct, attending to both how features might contribute to and challenge dementia stigma. Such engagement would also provide insight into the—as yet, unestablished—relationship between given forms of language use and particular types of stigma. As noted earlier, a number of different types of dementia stigma have been identified in the vast literature on this topic, so understanding whether certain forms of stigmatizing language use attach to any particular kinds of stigma could be helpful in terms of developing analytical frameworks for identifying the entextualization of different kinds of stigma. Greater diversity would be welcome in terms of cultural contexts (with the acknowledgment that such a focus might be better represented in non-English language publications), text types (including more multimodality), and the perspectives that are represented in the interpretation of the data (e.g., by involving in the research process people living with dementia or who are otherwise directly affected by dementia). Another promising avenue of inquiry could be to adopt a more granular perspective on some of the variables in the foci of the studies we have considered. This includes comparing insights based on data from distinct linguistic and cultural contexts, different text types (e.g. comparing findings about news texts with those about social media texts), and considering whether particular language features are associated with different types of stigma (public stigma, self-stigma etc.). At present, we did not feel that there was sufficient representation across these variables to carry out any meaningful comparisons, but this situation may change in the future as this area continues to develop. With the rise of social media as a source of health information, an important theme for future research to consider is misinformation / disinformation. Misleading representations range from conflating dementia with memory loss to claiming that vaccines cause dementia (Bacsu, Fraser, et al. 2022; Sestáková and Plichtová 2020), and future research could interrogate the extent to which such inaccurate portrayals might contribute to the further stigmatization of dementia.

Ethics statement

As a review of published papers, ethics approval was not necessary and all of the data is available for readers to access.

Conflict of interest

The authors have no conflict of interest to declare.

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Appendix

Table 1: Characteristics of the publications in the review

Authors, Date, Research aim / questions Analytical approach	Cultural context Data analysed	Linguistic features that contribute to and / or challenge stigma
<p>Bacsu, Fraser, et al. (2022). To examine social media discourse on stigma against people with dementia during the pandemic. Thematic analysis of global tweets.</p>	<p>English language. 1743 stigma-related tweets between 15.02.2020 and 07.09.2020</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> Negative and homogenizing group labelling emphasizing difference and features of advanced dementia. Presenting dementia / people with dementia as a threat to society's resources. Using <i>dementia</i> as an insult. Presenting death or risk of death (from Covid) as preferable to dementia.
<p>Bailey, Denning, and Harvey (2021). What are the most dominant discourses drawn upon to depict dementia in the British news media? How do these discourses construct the syndrome, and those living with it? What are the implications for cultural understandings of dementia? Corpus-assisted critical discourse analysis.</p>	<p>UK; English language. News articles about dementia published in the British press in the years 2012-2017</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> Dominance of biomedically oriented metaphors (machinery, warfare, waste disposal and infection) that reduce dementia to pathological processes and attribute agency to the condition, not people. Excluding perspectives of people with dementia. Positioning people with dementia as a homogenous and anonymous group of social actors. Reductive and derogatory group labelling which emphasizes victimhood and dehumanizes people with dementia.
<p>Behuniak (2011). To examine how the zombie metaphor is referenced in both the scholarly and popular literature and show how this contributes to stigma. Approach data through seven specific characteristics of the contemporary zombie trope.</p>	<p>USA-oriented; English language. Popular and scholarly literature (e.g., medical journals, popular books, charity handbook, T.V. show).</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> Dehumanizing and marginalizing people with dementia and presenting them as a threat to social order by metaphorically representing them as the living dead through three popular zombie characteristics: zombie-like appearance, loss of self and inability to recognize others. Implying three zombie characteristics for dementia: epidemic threat, widespread cultural terror, and death as preferable to becoming an animated corpse. Applying cannibalism trope both to people with dementia and to the effect of their dementia on others (e.g., eating away at caregivers' time and selves).

Bös and Schneider (2022). To explore processes of self-positioning on a public message board for persons living with dementia provided by a non-profit health organization.
Analysis of discursive identities, influenced by membership categorization analysis, critical discourse analysis and Sabat and Harré's work on "joint productions" of Self-2.

Western societies; English language.
15 threads from a message board for people living with dementia, comprised of 318 comments of 99 users. 69 users identify themselves as people living with dementia at and 20 self-identify as care partners.

Challenge stigma:

- Rejecting disempowering role ascriptions (e.g., passive victim) and discourses (dementia as loss of self).
- Referring to other / multiple category memberships, rejecting being reduced to a person with dementia only. Users prefer positively connotated person references (e.g., foregrounding expertise and activity).

Brookes et al. (2018). To critically examine how the British press reported the findings of the 2016 Office for National Statistics' bulletin that dementia is the leading cause of death in England and Wales.
Multimodal Critical Discourse Analysis.

UK; English language.
11 articles by 10 national newspapers in the UK published on 14-15th November 2016.

Contribute to stigma:

- Using militaristic or violence metaphors: dementia as an actor that kills and inflicts other forms of violence on those who have it. Dementia often given grammatical agency, which passivizes and victimizes people with dementia.
- Omitting perspectives of people with dementia; spokespersons from charities etc. are quoted but not people with dementia.

Brookes, Putland, and Harvey (2021). Investigate how dementia is constituted through discourse, including through linguistic and non-linguistic means, in an awareness-raising campaign.

Multimodal Critical Discourse Analysis.
UK; English language.
Three parallel images produced as part of an awareness-raising campaign by the UK charity, Alzheimer's Society, and the National Health Service (NHS).

Contribute to stigma:

- Conflating dementia with disaster.
- Equating dementia with a loss of self.
- Addressing people without dementia as *you* and positioning people with dementia as *they*. Socially distancing and disregarding people with dementia, with other people being made responsible for their care and well-being.

Caldwell, Falcus, and Sako (2021). To examine what picturebooks for young children communicate about dementia, both visually and textually.
Close visual and textual critical discourse analysis. Adapts Caldwell and Wilbraham's (2018) methodology for qualitative visual analysis.

Western countries: UK, Australia, New Zealand, USA, Canada, Belgium;
English language.
The images and text in 10 randomly selected picturebooks about dementia (from a corpus of 46). Published between 2002 and 2017.

Contribute to stigma:

- Using body-as-machine metaphor which medicalizes dementia as a brain pathology and positions people with dementia as faulty brains.
- Challenge stigma:*
- Focusing on ongoing personhood despite changes, such as through maintained social roles (e.g., grandma) and supporting identity or memory with activities and relationships.

<p>Caspermeyer et al. (2006) To analyse US newspaper coverage of neurologic diseases to determine whether stigmatizing language is used in describing patients and examine its sources where found, as well as to examine stories for medical errors. Content analysis (stigma and accuracy codes)</p>	<p>USA; English language. 1203 news stories on 11 neurologic conditions from <i>The New York Times</i> and 8 regional newspapers in 2003. When combined, Alzheimer's disease and other types of dementia covered 400 articles (33%) and meant 10 categories in total.</p>	<p>No explicit features identified. Stigmatizing language found in 16% of dementia news stories and dementia coded as having inaccurate and exaggerated reporting.</p>
<p>Clarke (2006) To describe and analyse the portrayal of dementia in mass print articles published in the USA and Canada over a decade. Consider the portrayal of the person with dementia, the syndrome itself, and the significant others in the articles. Interested in the dominant discourse / frame used to portray Alzheimer's disease. Inductive analysis, with especial attention to frames and discourses.</p>	<p>Canada and USA; English language. 25 articles from the highest-circulation mass print magazines available in Canada and / or America for 1991 (n=3), 1996 (n=5), and 2001 (n=17).</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Describing dementia almost entirely in terms of its latter stages, in a medical frame and using language that exacerbates fear. Frequently using of military and catastrophic language, with dementia personified as fearsome, relentless, and aggressive. • Rendering people with dementia as "essentially voiceless," since virtually nothing is said about their perspectives, needs or desires. • Presenting people with dementia as the social "Other" by foregrounding bizarre behaviors and assuming deterioration and loss of self. Implying that people with dementia may not need to be treated according to common ethical principles or human rights because they are "gone" or incompetent.
<p>Creten, Heynderickx, and Dieltjens (2021) To analyse the representation of dementia in care discourse, here in the blog posts of people who are in direct contact with people with dementia. Corpus analysis of all blog posts and discourse analysis of a random sample of 26 blog posts, using conceptual metaphor theory.</p>	<p>Flanders, Belgium; Dutch language. 225 blog posts from 3 personal-journal type blogs, two by a family caregiver of a person with dementia, and one by a health professional in direct contact with a person with dementia.</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Representing people with dementia as the living dead. • Conceptualizing dementia as a separate and threatening entity, whether as a natural threat or a personified one (often a thief or monster). • Conceptualizing dementia as an attack or something that needs to be fought.
<p>Creten, Heynderickx, and Dieltjens (2022) To what degree is the stigma of dementia present in Dutch language tweets? Which factors are more likely to contribute to the presence / absence of stigmatic tweets? Sentiment analysis, approached as a classification task.</p>	<p>The Netherlands-oriented; Dutch language. 969 tweets posted over 148 days (01.11.2019–08.12.2019; 25.03.2020–12.07.2020).</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Ridiculing people with dementia by using dismissive language, using <i>dementia</i> as an insult and establishing an <i>us</i> versus <i>them</i>. Tweets containing ridicule were mostly political without an informative message and with negative emotions.

<p>Cullum, Simpson, and Gounder (2020). To evaluate how New Zealand newsprint media shapes discourse about dementia through its framing of the causes, effects and solutions, and who bears responsibility for the disease. Content analysis.</p>	<p>New Zealand; English language. 361 articles from New Zealand's three largest metropolitan daily newspapers between 2012 and 2016.</p> <p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Reporting individual effects of dementia as a loss of personhood, judgement and autonomy. Individual effects also described in negative, even catastrophic terms. • Associating modifiable medical causes of dementia with adverse consequences for society, suggesting a shift towards blaming dementia's impact on society on people with dementia for their lifestyle choices for dementia's impact on society.
<p>Gove et al. (2016). Content analysis (open coding then applying a literature-informed framework).</p>	<p>England; English language. Telephone interviews with 23 GPs from England.</p> <p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Emphasizing both separation or similarity between people with and without dementia can contribute to stigma. Separation of <i>us</i> and <i>them</i> (positioned as a non-person at the extreme) is one aspect of stigma. But emphasizing similarity can expose people to existential fears about getting dementia, with this sense of threat being another stigmatizing factor.
<p>Gove et al. (2017). How do GPs perceive people with dementia as failing to reciprocate and / or consider such perceptions to be present among the general public / wider society? "Following a thread" of lack of reciprocity from the Gove, Downs, Vernooij-Dassen and Small (2016) study above.</p>	<p>England; English language. Telephone interviews with 23 GPs from England.</p> <p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Representing people with dementia as non-reciprocal in relationships and society. Representations contribute to stigma through negative labelling, loss of social status, threat (existential or physical) and a separation of <i>us</i> and <i>them</i>.
<p>Grigorovich (2020). To examine representations of dementia and sexuality across recent North American, European and Australian news media sources. A discursive textual analysis in the tradition of cultural studies.</p>	<p>North America, Europe and Australia; English language. News articles, features, editorials, columns and opinion pieces published between 2013 and 2017 in North American, European and Australian news media (includes metropolitan and regional dailies, and national magazines and newspapers).</p> <p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Constructing moral panic by representing people with dementia as either having a pathological, dangerous sexuality or as endangered by others' sexualities. • Stigmatizing portrayals can also be gendered and heteronormative: Portraying men with dementia as violent sexual predators, using sensationalist and stigmatizing language (e.g., <i>rape case time-bomb</i>). In (presumably) consensual residential cases, articles focus on the financial and emotional consequences for people without dementia. Depicting women with dementia as having no sexuality and as being vulnerable victims of men's sexual desires, often being infantilized and passivized.

<p>Hansen et al. (2022). To explore how people with dementia and their relatives ascribe meaning to and discursively construct dementia-friendliness. Critical Discourse Analysis.</p>	<p>Denmark (language not specified). Participant observation, conversations and 13 semi-structured interviews with people living with dementia (7), relatives (3) and couples where one person was diagnosed with dementia (3).</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • People without dementia referring to people with dementia as <i>them</i> and positioning people with dementia as needing to be acted upon. • Individuals with dementia may also use stigmatizing language (e.g., <i>the demented</i>) and distancing language (e.g., <i>such people</i>).
<p>Hansen, Hauge, and Bergland (2016). To explore how staff who assess and allocate healthcare services to older people living with dementia at home describe challenges in communicating about dementia with those with the syndrome and their relatives. To also explore staff's justifications for their choice of words. Interpretive approach for focus group data. Qualitative content analysis for administrative decisions.</p>	<p>Norway (language not specified). 246 administrative decisions and 4 focus groups with 19 healthcare services staff (mostly registered nurses). Data collected between September 2012 and June 2013.</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Using certain euphemisms for dementia (e.g., <i>forgetful</i>) or omitting dementia entirely (e.g., by focusing only on physical needs). This reflects and exacerbates dementia as a taboo and stigmatized condition.
<p>Herron, Funk, and Spencer (2021). To analyse how mainstream news media frames violence in relation to dementia and the consequences of different frames for people living with dementia and their carers. Conceptually, to bring literature on citizenship and aggression into dialogue with each other. Coded by how violent incidents, victims, and perpetrators were described, using Baldwin's (2009) approach. Initial codes reviewed using a relational citizenship lens.</p>	<p>141 articles from regional and national English-language mainstream Canadian news media (print and online) between 2008 and 2019. Canada: English language.</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Employing trope of <i>violent dementia patient perpetrators</i> (contrasted against <i>vulnerable older adult victims</i>) which risks essentializing people with dementia as violent and problematic non-citizens who must be managed. Trope complicated by disease framing that victimizes people with dementia. • Concern with systemic issues focuses only on the experiences of staff, not people with dementia. • Rarely presenting the voice, identity or perspective of anyone with dementia. Articles tend to quote medical, legal, charity and research experts instead.
<p>Heynderickx, Creten, and Dieltjens (2022). To analyse the obituaries of well-known people diagnosed with dementia, to determine if the mention of dementia is avoided, thus indicating a stigmatic attitude. Also consider which aspects of dementia are included in the obituaries and analyse their linguistic representation. Qualitative bottom-up approach focusing on content and language.</p>	<p>Flanders, Belgium; Flemish language. 77 obituaries for 33 people, spanning two decades (1999–2020). The corpus contains 29 487 words.</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Using stigmatizing language, e.g., sometimes <i>dementerend</i> (<i>dementing</i>), which is unacceptable to the dementia community. • Some euphemistic language used, but not to circumvent mentioning dementia, which was expected as a marker of stigma. Instead, it is to soften the description of dementia's progression (e.g., "the writer's condition quickly went downhill").

<p>Hudson et al. (2022). To identify and analyse types of dementia conversations on Twitter using participatory methods. Specifically, to co-develop a thematic framework with carers to understand the forms that dementia misconceptions take on Twitter.</p> <p>Coding of tweets as negative or neutral by carers. Negatively coded tweets examined by service user researchers using a thematic framework approach.</p>	<p>Global tweets; English language. Three carer focus groups to develop a framework and categorize tweets. 48,211 tweets collected in 4th - 7th February 2020. Samples of equally negative and neutral tweets (n=1497) and negative only tweets (n=863) later taken.</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> Using dehumanizing, weaponizing, or outdated words / statements (e.g., <i>demented</i>) that ridicule dementia or people with dementia, often for political insults. Minimizing the experience of dementia by making it a joke, which may still present a negative picture (e.g., as just waiting for death).
<p>Hurzuk et al. (2022). To explore perceptions, beliefs and experiences of dementia across a number of stakeholders in India, with an effort to understand stigma towards people with dementia. Inductive thematic analysis approach.</p>	<p>India (cities of Chennai and Delhi); Tamil, Hindi and English languages. Focus groups and individual interviews with a range of key stakeholders, including people with dementia (n=8), caregivers (n=19), health care professionals (n=16) and the general public (n=15).</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> Infantilizing people with dementia. Some words for dementia discussed as stigmatizing, including in Tamil, <i>Nyabaga maradhi</i> 'memory loss' and <i>Paittuyam</i> 'lunatic,' and in Hindi, <i>pagalpan</i> 'madness, insanity, lunacy,' <i>Bhulakad Bawla</i> 'dementia, mad, pippy' and <i>Man Buddi</i> 'half-witted.'
<p>Johnstone (2013). To critically examine how Alzheimer's disease and other dementias are portrayed in public discourses and possibly used as a linguistic framing device to influence public opinion on the euthanasia / physician-assisted suicide question.</p> <p>Content and thematic analysis. Draws on theorizations of "moral policy" drivers and processes characteristic of catalytic social movements.</p>	<p>Australia-oriented; English language. Five main databases: professional and academic literature (n=436); media (news, documentary and film) (n=140); public opinion polling (n=61); law reports (n=11); and the homepages of partisan groups (n=59).</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> Using Alzheimer's disease as a metaphor for loss of self, dignity and autonomy. Used to support legalizing euthanasia as a "solution" for people diagnosed with dementia. Using epidemic, military (i.e., enemy and alien invader) and predatory thief metaphors which exacerbate fear of the "Alzheimer metaphor."
<p>Kirkman (2006). To identify and analyse the contexts in which Alzheimer's disease is portrayed in the New Zealand print media. Qualitative interpretive analysis.</p>	<p>New Zealand; English language. 1327 items from 15 newspapers between 1996 and 2002 (included articles, notices, obituaries etc.).</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> Discussing literal, social and anticipatory deaths of public figures with dementia. Personal stories / first person accounts are by carers or family members, not people living with dementia. Referring to dementia in the active voice and with military metaphors. Using <i>dementia</i> to refer to people (especially politicians) who appear to have forgotten the lessons of past experiences. Presenting wandering as a humorous event (e.g., "Just walking the dog takes man 13 hours"). Biomedical discourse intersects with agism, e.g., having dementia positioned as expected with older age but a tragedy if younger.

Lawless, Augoustinos, and LeCouteur (2018). To examine how information about dementia risk prevention is presented on the websites of the most prominent English-language, non-profit dementia organizations.
Discursive psychology.

Australia, New Zealand, Canada, USA, UK and Ireland; English language. The websites of eight non-profit dementia organizations in different Western countries.

Contribute to stigma:

- Representing participation in certain lifestyle practices as normative and emphasize personal responsibility for managing dementia risk. Foregrounding individual responsibility (implicitly) attributes responsibility / blame to individuals for their condition and can facilitate victim-blaming.

Leone, Winterton, and Blackberry (2023). To understand media constructions of people living with dementia and carers in relation to their socio-spatial rights. Foucauldian-inspired discourse analysis, referring to Lefebvre (1967) "right to the city" as a conceptual framework to define socio-spatial rights.

The City of Greater Bendigo, Victoria, Australia; English language. 126 news stories from local online news media publications and websites relevant to the City of Greater Bendigo from 2003 - June 2020.

Challenge stigma:

- Representing people living with dementia as social beings who can lead meaningful lives with appropriate community understanding and support. Advocating for the right to be treated as a citizen regardless of difference.

Contribute to stigma:

- Excluding voices of people living with dementia.
- Some words associated with stigma (i.e., *sufferers* and *patients*, which construe people with dementia as victims and sick people).

Maćkowiak et al. (2022):

To investigate the understanding of the word *otępienie* 'dementia' in the Polish language among the general public in Poland in relation to the concept of the prototype disease.
Frame semantics approach (drawing on Fillmore's theory of frame semantics).

Poland; Polish language. 100 instances of *otępienie* being identified as a disease in the National Corpus of Polish (1 500 million words). 52 responses of members of the public to a question in a linguistic survey, asking "What is dementia (*otępienie*)?"

Contribute to stigma:

- Depicting people living with dementia as having lost their self, being irreversibly changed and as big children.
- Suggesting that people with dementia cannot experience emotions in a normal way, as dementia either narrows the range of emotional states or prevents the person from being empathetic towards the outside world.

<p>McColgan, Valentine, and Downs (2000). To identify the stories that were told about Iris's life with and without dementia. Approach not specified.</p>	<p>Scotland; English language. Thirteen obituaries or news reports in broadsheet newspapers published on 9th February 1999, the day after Iris Murdoch's death.</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Presenting dementia in essentialist terms, defining Iris in terms of being demented rather than as having dementia. The former positions dementia as her whole character. The obituaries suggest a social death may have occurred before Iris' actual death.
<p>Medina (2017). To examine the ethics of representation of violence against vulnerable subjects and the ethics of care in <i>Ahora tocad música de baile</i>. Approach not specified.</p>	<p>Spain; Spanish language. A book, <i>Ahora tocad música de baile</i>, by Barba (2004)</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • The character with dementia (Inés) is voiceless and defined by other narrating characters in terms of accumulated deficits, losses and impact on her family. • Inés is repeatedly infantilized, depersonalized, animalized and depicted as a zombie — as someone incapable of having meaningful relationships. • Treating aging as grotesque. • Normalizing verbal and physical violence, which in this case culminates in Inés being pushed into traffic and killed by her son. <p>Ambiguous moral message of Inés' death; it may be interpreted as an animalistic sacrifice to liberate those around her, as murder or as being assisted to die with dignity.</p>
<p>O'Malley, Shortt, and Carroll (2022). To explore what personal narratives in Irish broadsheet and tabloid newspapers reveal about the lived experience of people with dementia. Inductive analysis and thematic analysis.</p>	<p>Ireland; English language. Irish broadsheet and tabloid newspaper articles of personal narratives of people with dementia between 2011 and 2017. Of 3 669 search results, 20 narratives were collected.</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Excluding perspectives of people with dementia. • Articles that include the person's voice and lived experience of dementia often mediated by biased editorial lexical choices, e.g. "dementia sufferer tells of her ordeal." • Narratives of people with dementia largely rely on the same small group of people, indicating a lack of diverse perspectives.
<p>Peel (2014). To explore the nuance of contemporary media representations of dementia and the salience (or not) of media coverage to those caring for people with dementia. Thematic discourse analysis.</p>	<p>UK; English language. 350 articles from British print media between 01.10.2010 and 30.09.2011. Interviews with 12 informal carers of people with dementia.</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> • Use of "Panic-Blame" framework: • Panic: Dementia constructed as an insidious and indiscriminate threat or imminent catastrophe (<i>epidemic, time-bomb</i>) in personal, social and / or economic terms. • Blame: Individual lifestyle recommendations can encourage blame and personal culpability for the development of dementia.

Petersen and Schicktanz (2021). To examine medical science, nursing science, and media discourses in Germany between 2014 and 2019, with a focus on the social and moral implications of the new understanding and public representation of dementia.
 Discourse analysis.

Germany; German language.
 130 articles from a range of medical journals, nursing science and media (newspapers, magazines and websites) between 2014 and 2019.

Contribute to stigma:

- Responsibilizing people with / at risk of dementia for managing their risk and symptoms through lifestyle choices. Implicit moral obligation to do so.
- (Self-)responsibilizing of cognitive aging and the presentation of cognitive decline as a preventable disease (no longer an inevitable fate) could further stigmatize dementia and contribute to new forms of agism, replacing general angst about aging with a specific fear of frailty, inability and loss of cognitive abilities, and devaluing those who cannot meet the ideal of self-reliant, successful aging.

Schicktanz (2021). To examine how preventing dementia is positioned in German medical professional and media discourse. Is dementia regarded as preventable and, if yes, how and how not? How are addressed actors, social groups or individuals targeted? How is dementia prevention assessed as a form of knowledge, normative aim or research justification?
 Critical discourse analysis.

Germany; German language.
 65 articles from German medical and professional journals and 44 media reports from five leading newspapers and weekly journals. Data between 2000 and 2019.

Contribute to stigma:

- While academic discourse emphasizes a multifactorial approach to prevention, the media tends to over-stress the role of individuals' single actions and may frame their news with provocative or accusatory language. *Contribute to and / or challenge stigma:*
- Using a prevention discourse which suggests that dementia's underlying disease processes start in the second stage of life (40+) and then become explicit in later life. This could challenge stigma by expanding who can be affected and attributing people with or at risk of dementia more agency to act, or it could further stigmatize people with dementia by adding blame for previous lifestyles and behaviors.

Šestáková and Plichtová 2020. To analyse (1) which representations of dementia are created and shared by the Slovak media, (2) which topics are thematized and which are omitted, (3) how the themes are mutually related, (4) how objectification and anchoring are accomplished by the media and (5) to suggest the potential implications of the identified media representations.
 Thematic discourse analysis, informed by critical discourse analysis.

Slovakia; Slovak language.
 227 headlines of TV, radio, print and web sources that mentioned the words Alzheimer and dementia between 2015 and 2018.

Contribute to stigma:

- Biomedical perspective (and associated agism) dominates at the expense of a socio-psychological one. Dementia catastrophized (e.g., *catastrofhe*) and personified as a powerful, insidious being (e.g., an invisible enemy, killer, and monster that threatens, attacks, destroys lives and haunts modern society). Emphasize symptoms, decline, and tragic aspects of dementia, with people with dementia positioned as its victims.
- Giving people without dementia (e.g. scientists) an active role and people with dementia a passive one, labelled in terms of their diagnosis: "Experts will demonstrate how to work with Alzheimer sufferers."
- Individualizing responsibility for care and prevention.

Siiner (2019). To understand how views on dementia have changed in the Norwegian public space and culture, and to extend the timespan covered by combining qualitative and quantitative tools. Corpus-assisted critical discourse analysis.

Norway; Norwegian language. A 6960 000 word corpus of articles published in the period 1995–2015 in the Norwegian national and regional paper press.

Contribute to stigma:

- Using collectivization as a dehumanizing tool, as people with dementia and relatives are overwhelmingly presented in collective terms.
- Using nomination to evoke horror. Individuals' stories told by municipal authorities such as the police or social authorities, for whom the individuals are a danger to the existing (moral) order. Individuals with dementia depicted in terms of loss (of both face and dignity) and as a burden for society.
- Excluding voices of people living with dementia.

Contribute to and / or challenge stigma:

- Shifting focus from disease and loss to personhood and successful aging, which can also disempower people. By 2015, the traditionally humiliating term *senile* is used as a *we* term to (often humorously) resist the normative view of aging gracefully, thus facilitating both stigmatization and empowerment.

sm-Rahman, Lo, and Jahan (2021). Are there changes in news content related to dementia over time? What are the differences in news stories between the two newspapers across time? What is the overall tone in presenting topics related to dementia in the newspapers? Descriptive and content analysis.

UK and USA; English language. 291 articles featuring dementia published in two online newspapers (*The New York Times* and *The Guardian*) from November 2014 to November 2019.

Contribute to stigma:

- Focusing more on dementia and care need / burden than the diagnosed individuals. The few discussions about having dementia are told by people without dementia (e.g., carers).
- Using negative language (e.g., *tragedy*) associated with dementia. Lack of positive portrayals reflects and influences stigma. Did observe a declining trend in negative tones over time though.

Talbot et al. (2021). Why do people with dementia use Twitter? What challenges do people with dementia face when using Twitter? Thematic analysis.

UK; English language. Interviews with 11 younger people with dementia.

Challenge stigma:

- Sharing nuanced accounts of lived experience that are framed by the person living with dementia, not others (e.g., through personal Twitter account).
- Directly challenging stigma through Twitter posts and by normalizing the diversity of people living with dementia.

Contribute to stigma:

- Rejecting or harassing people living with dementia for not presenting themselves as “sufferers” / “victims” or not fitting stereotype of (late-onset) dementia.

van Gorp and Vercruyse (2012). To understand the dominant images related to dementia by means of an inductive framing analysis. Inductive framing analysis.

Sample of 552 newspaper articles from six Belgian newspapers from 2008-2010 (58% in Dutch and 42% in French). A convenience sample of movies, documentaries, books and healthcare communications. Belgium; Dutch and French languages.

Contribute to stigma:

- Positioning the mind as the locus of identity and personhood and thus people with dementia as “empty shells.”
- Demoting dementia and victimizing people with dementia.
- Reducing people with dementia to patients with a biomedical condition and placing science as the only hope.
- Positioning dementia as a fatal prognosis whereby the person’s life is over. At a demographic level, presenting dementia in apocalyptic terms (e.g., “tsunami of dementia”).
- Infantilizing people with dementia and presenting them as abnormal and a burden.
- Positioning people around the person with dementia as the “real victims,” focusing both on the burden or care without reciprocity and the loss of their once shared past.

Challenge stigma:

- Emphasizing continued identity and humanity regardless of cognitive deterioration (“unity of body and mind”).
- Normalizing metaphors for dementia, such as it being a travelling companion that you live with.
- Naturalizing aging and dementia as a part of life.
- Emphasizing making the most of life, which is short for everyone, and showing that people with dementia still have good experiences and things to look forward to.
- Normalizing and celebrating caring for and being cared for in turn by others, and being able to experience a return to your beginnings.

Venkatesan and Kasthuri (2018). To examine how Walrath’s *Aliceheimer’s* cultivates alternatives to the biomedical and cultural figurations of Alzheimer’s disease through the use of collage form, positive lexical choices, and a creative appropriation of *Wonderland*. Approach not specified.

USA; English language. Walrath (2016) graphic Memoir. *Aliceheimer’s: Alzheimer’s Through the Looking Glass*.

Challenge stigma:

- Emphasizing hope, meaning and compassion to counter clinical and cultural discourses. Challenging and replacing medical terminology (e.g., *vision not hallucination*). Repeats that her mum, Alice is “always” and “still” beautiful, resisting monstrous trope. Dying, forgetting, anxiety and disgust replaced with *flying, healing, peaceful, and adorable*.
- Presenting process of losing memory as becoming “ungrounded,” emphasizing transformation not loss. Focus on new / old and multiple selves.
- Author presents their world together as “wonderland” to represent an alternative reality with its own meanings and logic, which is caused by the changes associated with dementia.

Contribute to stigma:

- Using infantilizing language.

<p>Vermeer, Higgs, and Charlesworth (2019). To review marketing materials of surveillance products for people with dementia and their carers in three aging countries, as part of a dementia-technology media analysis. Online environmental scan.</p>	<p>UK, Sweden, and the Netherlands; English, Swedish and Dutch languages. 242 eligible product websites from the UK, Sweden and the Netherlands.</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> Positioning people with dementia as a problem to be managed and objectified (placed in the same class as wallets, keys, young children, dogs and / or prisoners).
<p>Vermeer, Higgs, and Charlesworth (2022). To examine the interplay between surveillance technology advertisements and audiences, and to reflect on what it means for this discourse and market. A tripartite approach to media literacy. Data analysed using qualitative content analysis and a critical discourse approach to semiotic analysis.</p>	<p>UK, Sweden, and the Netherlands (languages not specified). Six websites with adverts for surveillance technology. Two focus groups that responded to the adverts; (1) four women carers, and (2) four men and one woman living with dementia.</p>	<p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> Objectifying people with dementia (technologies simultaneously target tracking pets, babies and possessions). Do not acknowledge people with dementia as human technology users. Excluding viewpoints of people living with dementia and people from marginalized cultural groups.
<p>Werner et al. (2019). To examine the objective characteristics and the portrayal of Alzheimer's disease and of persons with Alzheimer's disease in Hebrew and Arabic online newspapers across time. Literature-informed coding of objective article characteristics and the portrayal of Alzheimer's disease and people with the condition. Statistical analysis.</p>	<p>Israel; Hebrew and Arabic languages. 180 articles that report on dementia from seven Israeli online newspapers (4 Hebrew and 3 Arabic). Data collected between 2010 and 2011; 2014 and 2015.</p>	<p>No explicit features identified in analysis. Coding includes depicting people with dementia as dangerous to themselves / others, personifying Alzheimer's disease, using militaristic language, reducing the person to the disease and derogatory / misleading / disrespectful references to people living with dementia (e.g., <i>he is crazy, dementia sufferer, victim, plague, living death</i>). Found stigmatizing features to be infrequent.</p>
<p>Xu (2021). To explore how the <i>Forget Me Not Café</i> reality show cast talk (or write) about dementia in older people. What discursive themes about dementia in older people are formed in the show? What views do the cast express in discourse about dementia in older people? Thematic analysis.</p>	<p>China; Chinese language. Ten 75-minute episodes of the reality show, <i>Forget Me Not Café</i>, which brought together five older people (aged 65 and older) living with dementia to run a pop-up restaurant and intended to reduce the stigma of dementia.</p>	<p><i>Challenge stigma:</i></p> <ul style="list-style-type: none"> Normalizing dementia as a chronic condition people live with. Including voices of people with dementia, who in this case explain and demonstrate that they can contribute, effectively communicate (even in a second language), lead meaningful, happy and sociable lives and take actions to improve their circumstances (e.g., stay socially connected, seek medical advice). <p><i>Contribute to stigma:</i></p> <ul style="list-style-type: none"> May indirectly contribute to stigma by positioning the five people with dementia as "perfect models." This ignores diversity and perpetuates pressure to adhere to positive aging and living well discourses, which reinforces neoliberal self-responsibility and risks blaming people for getting dementia and / or not "living well."

Zeilig (2014). To consider: (a) the social and political dimensions of dementia, (b) how the metaphors persistently used to explain dementia shape our consciousness about this condition, and (c) the extent to which dementia is an inherent part of contemporary life.
 Critical gerontology.

Global but USA and UK oriented; English language.
 Films, TV documentaries, medical and scientific literature, news reports, theater, memoirs, novels and poems.

Contribute to stigma:

- Stereotypes associating dementia with extreme events and disaster, distancing us (without dementia) from *them* (with dementia).
- Metaphorically generalizing dementia as a vast, natural or monstrous force that must be fought, or individualizing dementia as a condition that affects people in extreme ways. Both framings engender fear and helplessness.
- Using dementia as a fear-inducing metonym for calamity.

Challenge stigma:

- Metaphorically using dementia as a lens through which we can more clearly see society and emphasize shared humanity.

Zimmermann (2017). Examine key metaphors used by people with dementia and carers to represent their experiences. Analyse how these mirror individuals' views of the condition and cognitive decline. Approach not specified.

Western societies; English, German and French languages.
 Dementia narratives by people with Alzheimer's disease and carers. From 1990s to time of writing.

Contribute to stigma:

- Using hypercognitive biomedical metaphors which emphasize loss and passivity (e.g., empty shell).
- Personification of dementia (in this case, by care partners) passivizes people with dementia.
- Using *dementia* as a metaphor for larger biological and social ills, reinforcing stigmatizing tropes such as inertia and passivity.

Contribute to and / or challenge stigma:

- Dehumanizing metaphors can be engaged with seriously or humorously by people with dementia (becoming "a hatstand," "I will be a grilled vegetable"). They can be used to reflect social treatment or explore fears about having dementia.

Table 2: Summary of publications' theorizations of stigma

Theorization of stigma	N. Publications
No explicit theoretical position / definition.	33
Stigma as a discrediting attribute that spoils a person's social identity.	6 Behuniak (2011), Brookes et al. (2018), Caspermeyer et al. (2006), Gove et al. (2017), Hurzuk et al. (2022), and Xu (2021)
Stigma as stereotypes, negative beliefs and discrimination.	1 Bacsu, Johnson, et al. (2022)
Stigma as the attribution of negative labels, associations or terms to identify individuals in a particular group.	1 Heynderickx, Creten, and Dieltjens (2022)
Stigma as labelling, stereotyping, separating <i>us</i> from <i>them</i> , status loss and discrimination, and the exercise of power.	3 Creten, Heynderickx, and Dieltjens (2022), Gove et al. (2016), and Hansen et al. (2022)