Chapter 2

From History to Intervention
A Sociocultural Analysis of Dementia Stigma

Perla Werner, Pieter Vermeulen, Baldwin Van Gorp and Peter Simonsen

1 Introduction

Driven by the increasing number of persons with the disorder, dementia has been declared a major public health concern worldwide. In an effort to deal with this challenge, many countries have developed and adopted national dementia strategy programmes aimed at raising awareness and decreasing stigma. Accordingly, an increasing amount of research has been devoted to understanding the concept of stigma in the area of dementia and to examining its antecedents and revealing its consequences [1–2]. Despite these important advances, the literature on dementia stigma is still in its developing stages and is lagging behind the knowledge accumulated on the topic of stigma in the area of mental illnesses. An increased understanding of the concept will help answer the worldwide call to reduce dementia stigma and help turn the disease into a more liveable condition for people with dementia and their caregivers.

This chapter aims to make a modest contribution to the existing literature while trying to provide an explanation for *dementia stigma*, with special attention to *dementia public stigma*. We start with a brief summary of the knowledge accumulated in this area until today (Section 2). We follow by summarizing and critically discussing the historical roots of dementia stigma (Section 3), and then turn to a discussion of the mechanisms perpetuating it (Section 4). In the second half of the chapter, we turn to a number of different strategies to manage dementia stigma. We look at how literary engagements with dementia have expanded our imaginings and experiences of dementia (Section 5), which might open the way to a less stigmatizing approach to dementia. In a final section, we focus on existing efforts to address dementia stigma through education and contact and on how media might frame dementia in a more positive way (Section 6). We conclude by suggesting future steps to expand knowledge in this incipient area of study.

2 Dementia (Public) Stigma: Typology, Prevalence, Characteristics

Four main types of stigma are conceptually distinguished: self-stigma, courtesy stigma, structural stigma and public stigma. Self-stigma names the *internalization* of the stereotypes held by the general public towards people with devalued characteristics, such as people with mental illnesses. Courtesy stigma refers to the emotions and beliefs of those *surrounding* the stigmatized person, such as family members and professionals. Structural stigma, for its part, refers to the inequalities inherent in *social structures* that restrict the means and resources of stigmatized groups. Public stigma, finally, is defined as the cognitive, emotional and discriminatory attributions endorsed by the *general public* towards a group or a person with a disease or a disability [3].

It is this fourth kind of stigma that is central to this chapter, for three reasons (apart, of course, from the fact that the relation between dementia and society is the explicit focus of this book): it is the most common type of dementia stigma; it is the one that has attracted the most interest in stigma studies; and, finally, public stigma is at the core of the formation of the three other types of stigma, which means that reducing this type of stigma will help reduce the other types as well [4]. The strategies we survey in the second half of the chapter, which directly target public stigma, can then also be expected to have a more general beneficial impact on the complex interactions between different forms of stigma.

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

The (mostly quantitative) empirical literature shows that the prevalence of public stigma in the area of dementia is, surprisingly perhaps, moderate [5]. Regarding its characteristics, evidence shows that the most common *cognitive* beliefs or stereotypes attributed by the general public to a person with dementia are dangerousness and a lack of aesthetic propriety [6–7], while the most common *emotional* reactions are mostly positive and include principally sympathy, concern and a willingness to help. The main negative emotions are fear and uneasiness. Feelings of pity are also common, although its classification as a positive or negative emotion requires further examination. The main stigmatic behavioural reactions attributed by laypersons to persons with dementia are work-related and health-related discrimination, treatment coercion and institutionalization. Finally, studies indicate that laypersons belonging to cultural minorities and people having lower levels of education, lower levels of knowledge about the disease and limited contact with persons with dementia tend to report higher levels of dementia stigma [4].

3 The Historical Roots of Dementia Stigma

These empirical findings might differ from anecdotal accounts about dementia stigma. Especially the relatively moderate nature of public stigma and the prevalence of positive emotional reactions show that strategies to remedy stigma in this area are far from hopeless and can rely on positive emotional resources to achieve change. Elucidating the origins of the stigma concept as well as of the understanding of dementia across time throws further light on the phenomenon of dementia public stigma and allows us to gain a better grasp of the challenges facing efforts at destigmatization or stigma reduction. As this section shows, the concept of dementia stigma is strongly rooted in historical developments of the concept of stigma in general, as well as of historical changes in the understanding of dementia.

3.1 The Historical Development of the Concept of Stigma

The concept of stigma can be traced back to Greek and Roman societies, when the word was used to represent the physical marks put on specific groups to indicate their lower social status and deviance. During the second half of the twentieth century, the study of stigma in the area of mental illnesses evolved from descriptive investigations of laypersons' attitudes towards mental illnesses to the seminal conceptualizations developed by Erving Goffman, who provided a clear characterization of the concept. Defining stigma as a physical or figurative *mark* that deeply discredits its bearer and leads to discrimination, Goffman paved the way for the development of cognitive and sociological theories of stigma, such as attribution theory and modified labelling theory, which have guided researchers in the identification of the antecedents and consequences of stigma.

Attribution theory holds that stigmatic behaviour is determined by a complex cognitive-emotional--behavioural process, in which individuals' cognitive attributions or stereotypes about the person with a disease lead to negative emotional reactions (such as anger or fear), as well as to positive emotional reactions (such as sympathy and concern). Negative emotions are conceptualized in this theory as motivating hostility and rejection, leading to behavioural reactions such as increased discrimination; positive emotions, for their part, motivate positive behaviour such as a willingness to help. Expansions of the attribution model hold that increased familiarity with the mental disorder are associated with a decrease in discriminatory behaviour [8]. As we will see, this explains why a number of destigmatization strategies rely on familiarizing audiences with realities they may fear because of a lack of previous exposure. The *modified labelling theory* adds to this the insight that individuals *internalize* social labels in order to assess their disease diagnosis [9]. This leads to stigmatized people's withdrawal from social life and a weakening of their social network, making them even more vulnerable than a mere assessment of public stigma would suggest. Here again, it is clear that public stigma is deeply entangled with other forms of stigma – such as, most notably here, self-stigma.

Despite robust theoretical and empirical developments in the study and conceptualization of stigma, especially in the area of mental illnesses, its understanding in the area of dementia is emerging slowly, with the majority of the studies still

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

being descriptive and a-theoretical. Scrutinizing the historical roots of dementia is crucial for advancing this line of research.

3.2 The Historical Roots of the Understanding of Dementia

Several explanatory models have been advanced in an effort to understand dementia. Across time, the meaning attributed to the disease has changed from an irreversible, incurable and hopeless condition to a more positive risk-reduction approach (see Chapter 8). As the general development of the concept of dementia is covered by the first chapter of this book, in this chapter we restrict our discussion to the interactions between those conceptual changes and the prevalence of stigma.

While the Greek philosophers generally view dementia as having an organic origin and as being an inevitable part of old age, it is not until the beginning of the nineteenth century that dementia begins to be framed as instigated by a disease. Following this change, the *biomedical* model became the dominant framework for understanding dementia: it stresses the pathological aspects of the condition and sees the pursuit of a cure as the first priority of professionals, decision makers and society. While moving away from the perception of dementia as an extreme but ultimately *normal* part of ageing to a conceptualization of dementia as a *pathological* process of the brain, this altered perspective provoked feelings of hopelessness and fear about the condition, emotions that, as we have seen, are closely associated with stigmatic views. Other aspects of the biomedical understanding of dementia, such as it being a hereditary or genetically determined condition, might equally have contributed to the devaluation and social distancing from persons who carry the gene or who are supposed to be more vulnerable to the development of the disease. As we explain later in this chapter, this means that efforts to destigmatize dementia – be it in the media or literature or through education or contact – have to move beyond this still dominant biomedical model.

The *biopsychosocial* model this book puts forward provides a different explanation of dementia. Centring on internal-level indicators (such as biomedical, personality-based and emotional factors), as well as on external-level ones (such as environmental elements) as the basis for understanding dementia, this model provides a more holistic and person-centred approach [10]. However, it is not immediately clear to what extent or even whether this perspective contributes to decreasing laypersons' stigmatic beliefs. As we explore in more detail in the next section, several authors have mentioned that concentrating on the person with dementia as an individual rather than as a group does not decrease perceptions that might encourage stigma, such as a dualistic view between body and mind [11], or does not change the perception of the person with dementia as 'different' or 'strange' [12].

A third and final modern perspective on dementia is the *sociocultural* one, which considers the meaning of dementia to be embodied and shaped by social and cultural contexts [13]. This framework has been used mainly to explain dementia in non-Western cultures. As mentioned in Chapter 1, research focusses on religious beliefs such as the disease being a 'divine punishment', a supernatural curse or the result of the 'evil eye', as well as on cultural values such as filial piety or individualistic (as opposed to collectivistic) tendencies. Here, it is important to remark that factoring in cultural frameworks might put a further 'mark' on the person with the disease and thus encourage laypersons' stigmatic beliefs. Even though this framework is not generally applied to Western societies, there is no reason to assume that sociocultural dynamics do not determine the stigma of people with dementia in these societies also, and that sociocultural changes might not become a main driver of destigmatization, as the second half of this chapter explores.

In addition to these three conceptualizations, a fourth perspective for the understanding of dementia is currently emerging. Driven by an enablement and equality-based approach, a *relational* model of disability is increasingly being applied to dementia [14]. Stressing the principles of self-determination, human rights and involvement in decision-making, this view of dementia is at the basis of two important policy and public health initiatives. The first advocates the development of social, environmental, organizational or virtual communities – so-called *dementia-friendly communities* – as a strategy for empowering, supporting, respecting the rights of and recognizing the full potential of persons with dementia and their caregivers. The notion of dementia-friendly communities is supported by the World Health Organization and by Alzheimer's Disease

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

International as a path to the normalization of dementia. It has been incorporated in the national dementia plans of many countries, even if, as we discuss in what follows, its ability to decrease stigma is uncertain. A second approach is based on the emerging knowledge about modifiable dementia risk factors such as adequate diet, physical activity, smoking and hypertension. It underscores the benefits of adopting healthy behavioural patterns as a way to reduce the risk of developing dementia. This is a proactive approach to the maintenance of cognitive functioning that places responsibility directly with the individual person. This might lead to an increase in stigmatic perceptions of blame and responsibility towards persons with dementia, who can be condemned for failing to change their lifestyles, and therefore to increased discrimination, as occurs in sociocentric societies (see Chapter 1). As with the other three conceptions of dementia, there is no clear-cut relation to destigmatization.

Regardless of the views and conceptualizations of stigma and dementia across time, dementia stigma continues to be at the core of public health discourse. If we want to confront that challenge, it is vital to gain insight into the mechanisms that perpetuate it.

4 Socio-structural Mechanisms Perpetuating Dementia Stigma

Social structures are a crucial factor in reducing or perpetuating stigma in a variety of conditions. In the case of dementia, language, media and sociocultural structures play a central role in the permanency of negative stereotypes about persons with dementia. This section discusses these three elements in turn.

4.1 Language

Language is, among other things, a system of symbols bridging the social world with the inner world; it is a medium through which interior states of mind, emotions and thoughts can be externalized, but it is also a medium that allows public stigma to be internalized and that can lead to self-stigma. *Linguistic relativity philosophy* holds that language may shape and frame the way the public perceive and feel the world in general and persons with a disability in particular. This means that it is important to use appropriate terminology. This need has been recognized for a long time in the area of mental illnesses, with the *person-first movement*, for instance, calling for replacing the phrase 'a mentally ill person' with 'a person with mental illness' [15]. This position recognizes that language can do real harm in perpetuating stigma, but it also stresses the hope that linguistic change may be an effective strategic move in a destigmatizing direction. Here, as we will see, literature and media have a role to play.

Indeed, in recent years we have witnessed several steps in this direction. As mentioned in Chapter 1, first, in 2013, the term 'dementia' was replaced in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) with the term 'major neurocognitive disorder'. This is a welcome change, as the term 'dementia', literally meaning 'being out of one's mind', brings connotations of madness and insanity, which undoubtedly increases stigmatic beliefs. Still, because the term 'dementia' is already widely established and much easier than 'major cognitive disorder', it is likely that it will continue to be used by laypersons, the media and presumably professionals also.

Second, following the interventions of the person-first movement in the context of other mental diseases, guidelines suggesting the use of adequate language to refer to persons with dementia have been published in Canada, the UK and Australia. These relate to the use of derogative or pejorative language (such as 'demented', 'madman' or 'dull brain'), as well as to the use of militaristic metaphors (such as 'the battle against dementia', 'dementia as an enemy' or even 'combating stigma'), and metaphors associated with natural disasters (such as dementia as a 'rising tide' or 'an emergent silent tsunami'). Again, in spite of these welcome developments, it should be noted that these metaphors are still common in professional publications as well as in the media.

4.2 The Media

Traditional media as well as online and social media are important sources of potentially stigma-enhancing information and images. Since media play a central role in shaping and perpetuating stigma, they can also do the opposite – that is, reduce stigmatic beliefs. In all media, including films, TV documentaries, news reports, theatre plays, memoirs, novels and policy documents, dementia is often presented as a burden and as

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

particularly threatening both to the individual and to society. This prevalent so-called tragedy discourse is reflected, for example, in the imaging and use of metaphorical language, which contributes to the perception that dementia is a real horror [16]; it is, according to this way of speaking, a fate worse than death [17]. Dementia is like a monster that lurks in wait, strikes unexpectedly and kills its victims. Additionally, there are references to the plague or other infectious diseases, leading to associations of dementia with contagiousness and pandemics. Even stakeholders who fight the disease by investing in scientific research or making donations to charities and non-governmental organizations (NGOs) exacerbate this 'tragic' representation of dementia in the competition for scarce research resources and in fundraising: they also tend to use threatening language, and to invoke the vast proportions and the overwhelming and unstoppable force of a 'tsunami'.

The use of war imagery is also common in media coverage of dementia. Although not unique to dementia, it is uniquely stigmatizing in the case of this disorder. For instance, while equally common with other diseases such as cancer and HIV, the difference is that the use of this stigmatic imagery in dementia is reinforced by the framing of at least three related themes: mental illnesses, old age and care institutions. Because all of these themes are already given shape in the media in a strongly stereotypical and stigmatizing way, they reinforce each other when they are addressed simultaneously, as is the case of people with dementia (and this is not to deny the prevalence of early-onset dementia).

First, dementia has in common with other *mental disorders* that diagnostics are not self-evident. To the average media consumer, it is not directly visible what is going on, as they may lack the knowledge or ability to assess what is happening to a person with dementia. The seemingly capricious and incalculable nature of the disorder might therefore create anxiety and uncertainty.

Second, the stigma surrounding *old age* in many cultures reinforces dementia stigma. Although recent studies show that the stigma attributed to older persons with dementia is lower than the stigma attributed to a younger person with the disease [18], the media tend to keep cases of young-onset dementia out of sight. Moreover, some authors argue that media portray older people of the fourth age frequently as weak and repulsive and as outsiders. This perception of 'real' old age is aggravated by contrasting it with competing narratives about the 'third age', which is described as a period of low risk of disease or disease-related disabilities, of high cognitive and physical functional capacities and of engagement in interpersonal relations and activities that create social value [19–20]. In a society where many issues are looked at from a cost-benefit perspective, the perception that the economic usefulness of the elderly is minimal and replaced with huge costs constitutes a problem for older persons with dementia, resulting in a further strengthening of the stigma.

Third, stereotypical ideas about *residential care centres* are both a source and a consequence of the stigma of old age. Nursing homes are the last living place before death. This makes it easier to share, in the news and on social media, stories about poor care, misuse and abuse. In literature and films, nursing home narratives typically depict nursing homes as places of fear and terror, and it is much rarer to see them depict nursing homes as places where new opportunities and relations arise.

Paying attention to studies assessing the portrayal of dementia in different media sources reveals a complex picture. For instance, a longitudinal study (1984–2008) of news and talk shows in the United States shows that facts regarding symptoms, causes and the diagnosis of Alzheimer's disease remain underexposed compared to personal stories about the disease [21]. Overall attention, in general, did increase over time, as was also shown by a study of German photographs accompanying news articles magazines in the period 2000–9 [22]. This research shows that the characters in the photos are mostly shown in an individualized context: people are portrayed in their home environment and with their personal belongings. Moreover, although the majority of the photographs depict older people, they mainly portray them with positive emotions.

Inconsistent findings emerge regarding the portrayal of persons with dementia in films. For example, studies that contrast the image of dementia in feature films with the lived reality of the condition have concluded that the cinematic representation is misleading in certain respects: it suggests, for instance, that moments

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

of complete lucidity occur and moments of agitation do not [23], which does not fit the medically attested manifestations of dementia. Despite this finding, Cohen-Shalev and Marcus analyse three films released between 2008 and 2010 and conclude that instead of portraying only negative sides, these films in fact do pay attention to personhood [24].

4.3 Sociocultural Structures

The forces perpetuating dementia stigma do not operate in a sociocultural vacuum – they influence and are influenced by social structures and systems. *Structural stigma*, defined as the intentional or unintentional discrimination of persons with a disease by cultural norms, societal systems, social institutions' rules, guidelines and norms, has not been widely examined in the area of dementia. This lack of attention to intangible, supra-individual forces is not surprising since several characteristics of dementia seem to contradict values and norms that are central to many cultures, not least in the West. Firstly, there is increased *individualism*: people are socialized by stressing that they need to learn to stand on their own two feet and ultimately strive for self-fulfilment. The prospect in dementia of being dependent on others, losing autonomy and slowly deteriorating contradicts this norm and strengthens the stigma. Secondly, there is the importance and high value attached to *ratio and cognitive abilities* in contemporary society. Because dementia impairs the very ability to reason, the stigma is reinforced again. Humans are distinguished from animals and other living organisms by their cognitive abilities; as soon as these disappear, the human dimension fades away too, according to this reasoning. Thirdly, and relatedly, there is a long-standing *Cartesian dualism*, in which body and mind are seen as separate identities, and in which the body is perceived as subordinate to the mind. This dualistic perspective is propagated and cultivated in different religions, in which the individual is represented by the spirit or the soul, which is valued at a higher level than the body. Dementia is often portrayed negatively as taking away the mind or soul, as if what makes a person unique and valuable disappears behind the diagnosis, leaving a deformed body, an empty shell, a plant. This state of affairs explains why different images and discourses about dementia, in literature and the media, that unsettle dualistic, individualistic and ratio-centric stereotypes can play an important role in destigmatizing dementia, as we will see in Sections 5 and 6.

Economic norms and expectations may similarly increase stigmatic beliefs towards persons with dementia, especially in societies where some form of return on investment seems a requirement in all circumstances (quid pro quo), stigmatic beliefs towards elderly people may increase. This is especially true in economic systems, such as the one currently reigning in the West, where manual labour is estimated to be of less value than cognitive labour. In a knowledge society, a condition marked by cognitive diminishment is prone to stigma.

Despite the undeniable importance of sociocultural structures to the understanding of dementia stigma, there is a dearth of studies examining this topic. Recent studies in Israel found considerable stigma towards persons with dementia engrained in the welfare system as well as in the legal system [25–26]. Moreover, Stites and colleagues in a study examining laypersons' discriminatory beliefs towards persons with dementia found that half of the participants consider that health insurance should be limited for persons with dementia, and that 25% of participants believe that research resources should not be devoted to this population [27]. Here again, it seems likely that a lack of direct experience (as a person with dementia or a caregiver) had stigmatizing consequences. As welfare states operate in a context of scarcity, and difficult decisions about allocation of resources and policy priorities are unavoidable, stigma makes it hard for dementia research and care to acquire a prominent place on research and welfare agendas (see Chapter 14).

When evaluating sociocultural contexts, dementia stigma poses an important concern. Foregrounding destigmatizing interventions can have a real impact on the way stigma is addressed at the social and individual levels. The rest of this chapter zooms in on such interventions, and points to different strategies used to bring about stigma reduction: first in literature, which can be considered a 'free zone' where social stereotypes can be negotiated and changed, and then in the context of intervention programmes that invest in education and contact and in the development of alternative images and discourses.

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

5 Literature and the Destigmatization of Dementia

Much art and literature has dealt in recent years with the topic of dementia from a variety of perspectives and in many different forms and genres. A general tendency in this body of work over the past half century is to increasingly emphasize that a dementia diagnosis is not necessarily an end-of-life-diagnosis, but that it is possible to imagine living with dementia and even under certain circumstances deriving new meanings and positive values. Interestingly, in some ways, some of the features that make dementia prone to stigma are also what make it attractive to artistic practitioners: its relative invisibility and inscrutability; its challenge to received ideas of selfhood, rationality and identity; and its irremediable, terminal nature. In a sense, the way art and literature attend to dementia in itself may contribute to destigmatization. By imagining what it might be like to live with the disease, whether as the person with the disease or as a caregiver, art and literature make audiences perceive individuals living with dementia as fellow humans. The following subsections present and evaluate three potentially destigmatizing literary strategies: empathy, complexity/ambiguity and forms that generate direct and sudden insight.

5.1 Literary Fiction: Empathy and Dementia

Remarkably often, works of fiction invite their readers to imagine a highly educated and highly rational character to have a diagnosis of dementia. In Matthew Thomas' novel *We Are Not Ourselves*, a neuroscientist receives a dementia diagnosis; in Alice LaPlante's *Turn of Mind*, a retired orthopaedic surgeon suffers from dementia and is accused of killing her best friend. The most famous example is Lisa Genova's bestselling novel *Still Alice* and its award-winning Hollywood movie adaptation featuring Julianne Moore. The novel offers the reader an empathetic identification with the brilliant and beautiful Alice Howland, who lives an enviably successful life both as a private person (wife and mother in privileged affluence) and as a professor of cognitive linguistics at Harvard University. As this character at age 50 experiences early-onset dementia, audiences come to a new and perhaps richer awareness of dementia as something that could potentially affect them as well, but that may not necessarily be only catastrophic. Based on the author's (who holds a PhD in neuroscience from Harvard) expert knowledge, the novel does more than circulate scientific ideas: it offers the intimate perspective of a character who lets the reader share her gradual loss of cognitive functioning, control of memory and language especially, but also vicariously experience the approximation and renewed intimacy between Alice and her family.

The question whether works of literature and art can effectively contribute to the destigmatization of dementia is a speculative one: empirical studies of the effects on readers' opinions are rare and remain contested within the scholarly community. Tracking the engagement with a book like *Still Alice* on Goodreads.com – the leading social media site for sharing reading experiences – shows that ordinary readers report a destigmatizing effect. Of the 287,256 readers who have rated the novel, 47% gave it five stars out of five possible and 39% gave it four stars. More than 27,000 readers have left reviews of it. The most liked five-star review, by 'Annalisa' (469 likes as of 8 April 2020), opens: 'After you read this, you will never look at Alzheimer's the same again. Nor will you ever forget it. Oh the irony.' 'I lived Alice's story right along with her, crying when she cried and smiling at her accomplishments.' 'Genova has done a fabulous job bringing attention to this debilitating disease.' It is evident that the novel functions to create an affective community for readers (all of whom use female names) who have or fear to have personal contact with the disease, and for whom the novel is seen as providing unique insight into this condition. In comparison to other kinds of media representations of the disease, art and literature offer a more internal – and potentially more transformative – encounter with the reality of dementia.

A more direct way that literature and the arts can potentially aid the destigmatization of dementia is by impacting key players in the social systems that, as the previous section showed, all too often perpetuate stigma. Fictional texts can play a role in the training of doctors and nurses. The interdisciplinary field of the medical humanities (or the health humanities) has ample experience exposing doctors and health professionals to fictional texts that enrich and challenge their engrained ideas about particular diseases,

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

which will carry over into their relation to patients and the care profession as a whole [28]. In the case of medical doctors, an appreciation of diverse positions and the complexity of the lived reality of disease has been shown to counter mis- and overdiagnosis, and to allow doctors to adopt different postures than that of the infallible expert [29]. We can mention a novel like *Elizabeth Is Missing* by Emma Healey, which is being used in nurses' training in the UK. The novel is partly narrated from the perspective of Maud, an ageing woman with dementia, and these parts of the novel invite the reader to adopt the same uncertain, limited and destabilizing perspective as the narrator. Other parts of the novel focus more on the perspective of the caregivers, most notably Maud's daughter, and evokes the plight of family members living with people with dementia. The novel has been credited with increasing nurses' empathy for and understanding of people with dementia. Because of the complex and multiple narrative perspectives, it also helps nurses reflect on and update their own engrained ideas about the experience of living with dementia [30].

However, the destigmatizing efforts of *Still Alice* and *Elizabeth Is Missing* risk missing their goals and reinforcing the stigma they want to undo. Goodreads reactions show that a considerable subset of readers object to the privileged social position of *Still Alice*'s protagonist, while *Elizabeth Is Missing*, in having Maud contribute to the solution of a decades-old crime, risks having its destigmatizing efforts spill over into an uncalled-for idealization of dementia [31]. As we argue in Section 6.3., a combination of a(n often negative) frame and a (more hopeful) counter-frame may lead to more convincing results. An alternative strategy that has been embraced by literary work is to destigmatize the contiguous elements, such as the care facility, that, as the previous section showed, exacerbate the stigma of dementia. Nursing homes are traditionally depicted as sites one wants to run away from (as in Jonas Jonasson's wildly popular novel *The Hundred-Year-Old Man Who Climbed Out of the Window and Disappeared*) because they enforce a dependency that is incompatible with values such as control and self-determination. Still, some novels and short fictions provide more nuanced and sometimes even hopeful representations of the care work carried out in and by these institutions which enable new forms of living for both the elderly and their adult children [32].

In Nobel Prize–winner Alice Munro's story 'The Bear Came over the Mountain', for instance, a woman with dementia's move to late-life housing allows her to escape a stifling marriage and to engage in new, meaningful relationships [33]. Not only is the caring home imagined as something other than a place of terror; in another destigmatizing move, dementia is credited with the ability to neutralize a surfeit of troubling memories. Similarly, research on Canadian and Scandinavian literature has established that contemporary fiction is increasingly intent on a more hopeful imagining of institutionalized late life [34].

5.2 Fiction and the Complexity of Dementia

The destigmatizing effects of efforts to portray the experience of dementia in an intimate way are never guaranteed, and the empathetic experience of dementia that fiction offers always threatens to reinforce rather than challenge stigma. For this reason, some approaches to literature and the arts have situated their destigmatizing potential elsewhere: not in a straightforward empathetic experience, but in an appreciation of complexity. A difficult, disorienting and morally complex work like Samuel Beckett's *Waiting for Godot*, for instance, has been seen as providing its audience with the disorientation and complexity of dementia – even if it remains contentious whether the author intended the work to be *about* dementia [35]. An increasing amount of scholarship investigates literary texts to use them as 'catalysts for deepening our understanding of the human condition and for challenging negative stereotypes and for critiquing the neglect and "othering" of those who are consigned to be a "burden"' [36–37]. Literary representations of dementia also have the capacity to highlight aspects of the dementia syndrome that are difficult to capture in accessible media frames.

The insight that people with dementia, until a fairly advanced stage of the condition, retain an experiencing self that continues to struggle to reflect on its situation is arguably best reflected in a novel like Dutch author J. Bernlef's *Out of Mind*, which is a first-person narrator's account of his own declining cognitive abilities, including his loss of language. Or, as stated previously, a novel like *Elizabeth Is Missing*, which alternates between

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

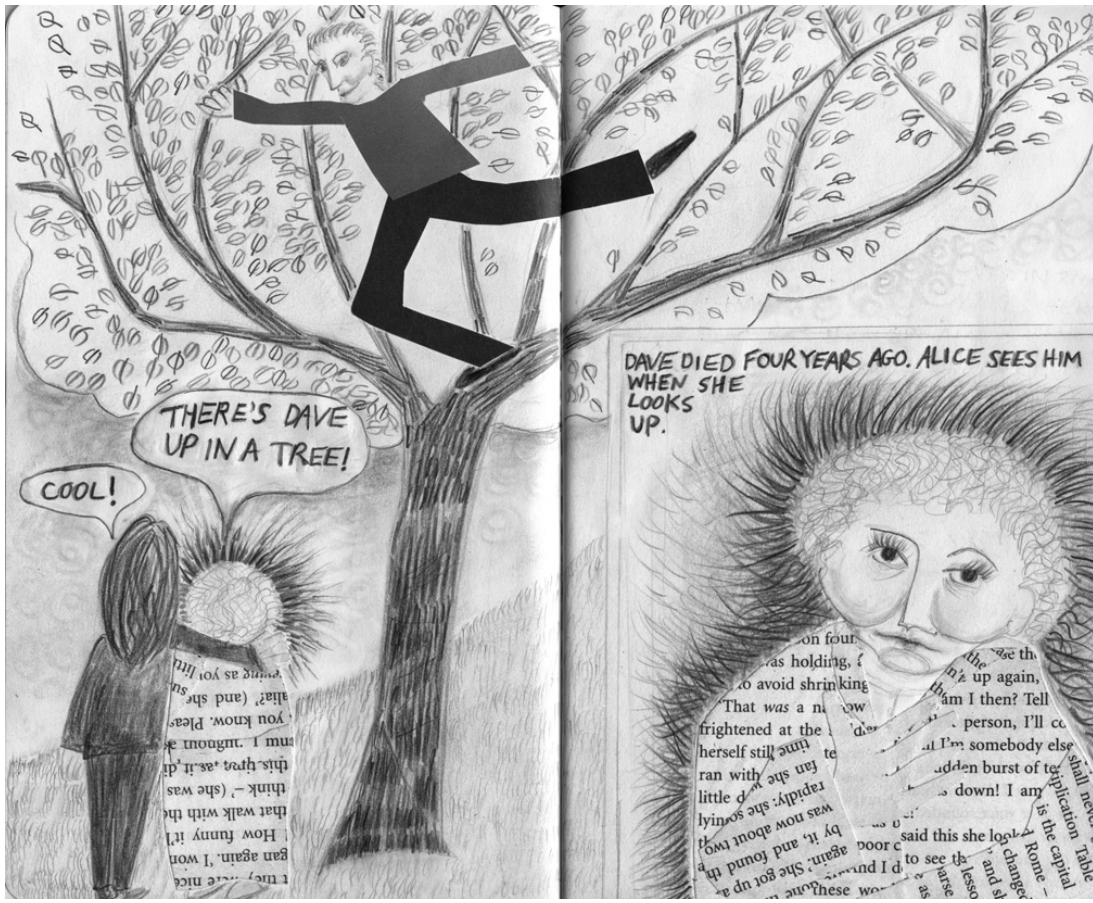
the perspective of a narrator with dementia and the perspective of a caregiver, offers repetitions, frustration, misdirection and disorientation that end up telling us more of what it means to care for a person with dementia than scientific or mass media discourses could. By making the complexity of dementia palpable, literature can contribute to overcoming reductive stigmatizing and stereotypical images of it.

In general, dementia narratives have developed from negative and stigmatizing depictions that focus on loss of functionality to accounts that imagine dementia as a challenging but non-exceptional part of life. An example of the earlier 'stigmatizing approach' is B. S. Johnson's *House Mother Normal* (1973), which provides a thoroughly negative and stigmatizing image of people living with dementia as sufferers at the mercy of a ruthless and un-empathetic welfare system. This view of people with dementia as deeply scary and hardly human informs early dementia novels such as Margaret Forster's *Have the Men Had Enough?* (1989), Michael Ignatieff's *Scar Tissue* (1993), Mordecai Richler's *Barney's Version* (1998) and Jonathan Franzens' *The Corrections* (2001). Increasingly, however, fiction has come to diversify the representation of dementia. As medical doctor Gayatri Devi argues in *The Spectrum of Hope: An Optimistic and New Approach to Alzheimer's Disease and Other Dementias*, there is a 'spectrum' of dementia enabling many people to live perfectly ordinary and satisfying lives with their disease, but their stories rarely get told and instead public discourse (and that of arts and literature) tends to equalize late-stage dementia with dementia itself. Examples of novels attentive to different stages of dementia include, apart from *Elizabeth Is Missing* and *Still Alice*, Ian McEwan's *Saturday* (2005) and Matthew Thomas' *We Are Not Alone* (2014) [38].

5.3 Flashes of Insight: Graphic Novels, Memoirs, Poetry

Different genres have different affordances for contributing to the destigmatization of dementia. Especially *graphic novels* and *memoirs* have become an important artistic medium: the interaction of word and images offers opportunities to operate on the border of the speakable, imaginable and the knowable in experimental ways, which is especially relevant for a liminal condition like dementia. Examples include Roz Chast's *Can't We Talk about Something More Pleasant?* (2014), which is an autobiographical narrative about Chast's father's dementia and the difficulties facing an adult child who must increasingly begin to take on parenting responsibilities for her own parents. Spaniard Paco Roca's *Wrinkles* (2007/15) explores a character's developing dementia, but complicates the customary emphasis on loss: increasingly, the reader gains access to the lives and imaginations of other characters in the dementia ward of the nursing home, whose dementia is different and not only associated with loss and anxiety, and who find themselves changing for the better in the meeting with the main character's dementia. Medical anthropologist and artist/writer Dana Walrath's graphic memoir of her mother, *Aliceheimer's: Alzheimer's through the Looking Glass* (2016), puts the powers of graphic literature to enrich and destigmatize dementia on full display. The inevitable decline narrative is countered by the daughter's story of regaining a meaningful relationship to a mother she had never felt close to. Walrath sees her book as offering a counter-frame to the dominant biomedical narrative of Alzheimer's disease. Instead of 'a horror story: people with the disease are perceived as zombies, bodies without minds, waiting for valiant researchers to find a cure', *Aliceheimer* presents the cohabitation of daughter and mother as 'a time of healing and magic' (p. 4). The work is explicitly imagined as capable of countering stigma: 'Stigma, silence, and social death surround rejected ways of being and echo through the hallways of hospitals, medical school lecture rooms, and textbooks. This is where stories and comics come in. They can rewrite the dominant narrative' (p. 5). The book presents enriching, surprising and often humorous experiences in short prose pieces, typically one page long, accompanied by visual artwork combining collage and drawings using *Alice in Wonderland* cut-outs. (see Figures 2.1 and 2.2). The brevity and humorousness of these elements is, for Walrath, what makes them especially effective: 'showing the faces, the lived experience, and the daily reality of those with Alzheimer's and other altered, different states removes the stigma and restores their humanity' (p. 6). Such short flashes of insight and connection offer a destigmatizing strategy that complements the empathy and the appreciation of complexity explored in the previous two subsections.

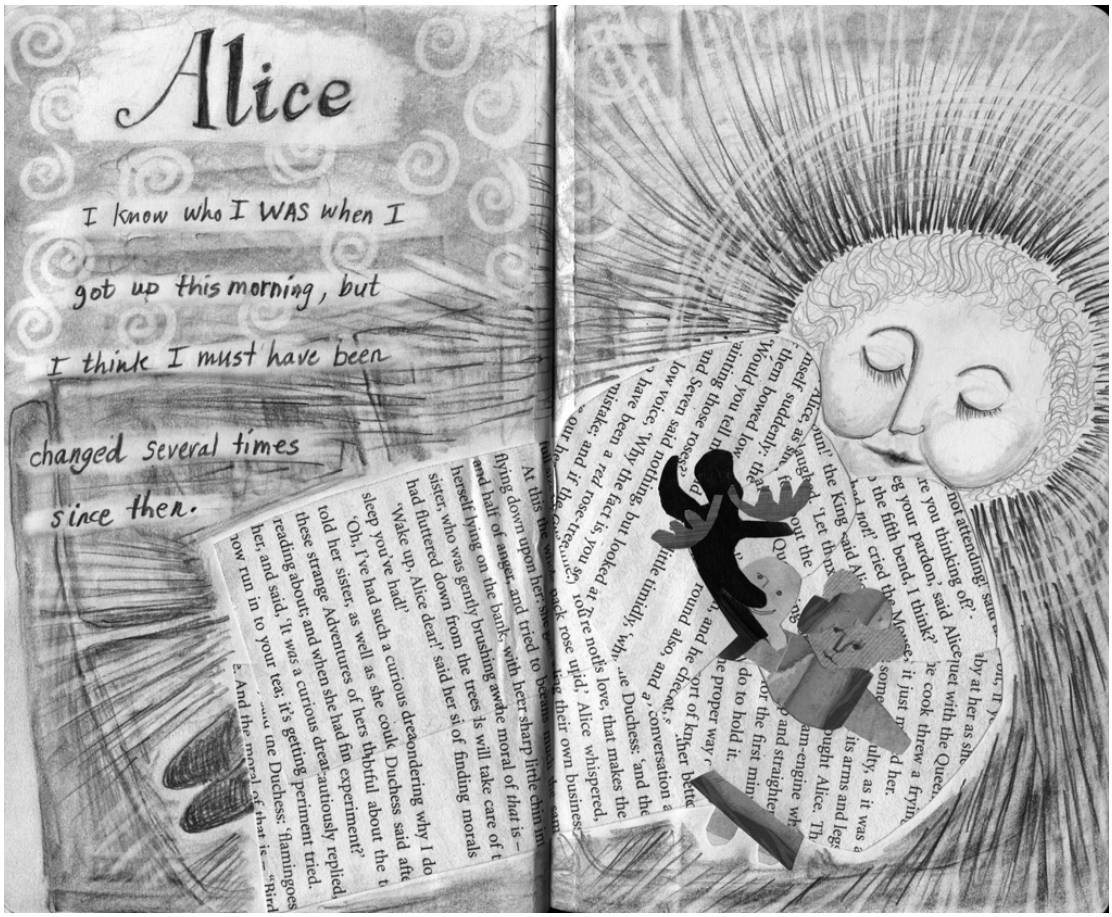
https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press



Figures 2.1 and 2.2 Illustrations from Dana Walrath's *Aliceheimer's: Alzheimer's through the Looking Glass* (used with permission)

The emphasis on short forms, fragmentariness and sub-semantic effects also characterizes *poetical* attempts to engage with dementia. Here, the development of the work of Tony Harrison is paradigmatic of a destigmatizing shift. Harrison's first poem about dementia, 'The Mother of the Muses' (1989), still unequivocally focusses on loss, fear and confusion, and on the final phase of the condition rather than the full spectrum. Harrison's much-quoted lines 'If we are what we remember, what are they / Who don't have memories as we have ours' come close to suggesting that 'they' are non-beings insofar as they have no memories. Harrison's *Black Daisies for the Bride* (1993) offers a more enabling picture of dementia, and like *Aliceheimer*, it not coincidentally does so by mixing different media: it is a film/poem mixing song, lyric, acting and documentary film-making. The work combines actors with people with dementia, staging with documentary, and it makes visible the proximity between seemingly insignificant nursing rhyme poetry with radical avant-garde language experiments: both disrupt conventional ways of meaning-making and invite attention to non-traditional sites of significance (sounds, rhythms, movements). Harrison insists that there is a human being behind the (seemingly nonsensical) language, which does not have to be intended as poetry to count and matter as poetry, and which does not have to mean anything to be understood as possibly an indication of some form of joy and pleasure. The work features a key scene in which the actors who play the nurses dress up as young brides, as younger versions of the people with dementia, to underline the tension between

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press



Figures 2.1 and 2.2 (cont.)

continuities and discontinuities of identity. *Black Daisies for the Bride* bestows a destigmatizing humanity on these individuals, even if this means bestowing, imagining and hypothesizing signs that are not readily discernible; this combination of imagination and recognition, it suggests, is key for dealing with literature, and also when it comes to interacting with and caring for people with dementia. Harrison's work displays a transition from a seemingly unthinking stigmatizing representation to a new attempt to use literature to explicitly destigmatize individuals living with dementia by showing them as individuals with resources, including creative and poetic resources. In that way, as this section has shown, it is exemplary of broader literary and artistic developments. Even if the real-world impact of these destigmatizing efforts remains hard to assess, they complement the endeavours we foreground in the next section.

6 Addressing Stigma: Education, Contact, Alternative Discourses

In the area of mental illnesses, we find advocacy, government and community service groups leading the development of strategies to reduce public stigma. These efforts are based on the willingness to improve the quality of life of persons with mental illnesses and include three main types of interventions: education, contact and protest. *Educational* interventions are based on the assumption that increasing awareness and overcoming misinformation and ignorance through the provision of factual and evidence-based knowledge about the stigmatized condition will

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

help challenge stereotypes. *Contact-based* interventions are founded on the rationale that exposure to persons pertaining to a stigmatized group might reduce laypersons' stigmatic beliefs by clarifying and erasing stereotypes, decreasing anxiety and increasing positive emotions such as empathy and understanding. Finally, *protest or social activism* strategies are rooted in the conviction that stigma can be discouraged by stressing its immoral grounds and by clearly criticizing the consequences of holding on to stigmatic stereotypes [39].

In the area of dementia, education and contact-based initiatives to reduce public stigma are scarce, and their impact is still limited and inconclusive, as we discuss next. To the best of our knowledge, there have not been any protest interventions yet. This might be related to the fact that, as we noted earlier, the importance of highlighting the human rights and the capacity for self-determination of people with dementia has only emerged in the past few years. This new understanding of dementia, together with increased knowledge about its early diagnosis and prediction, might soon increase the number of dementia organizations and advocacy groups, as today, in many countries, these are limited to caregivers' groups. As these developments occur, we might witness the flourishing of stigma-reduction interventions based on protest activities such as letter writing and public demonstrations.

6.1 Educational Dementia Stigma-Reduction Interventions

While several small-scale educational interventions have been developed, the most important and thorough initiative based on the principles of education to overcome dementia stigma is undoubtedly the Dementia Friends programme. Based on the principles of increasing awareness and knowledge about the disease, the Dementia Friends programme recruits volunteers and provides them with information about the disease with the aim of motivating them to spread it to other groups and thus reduce stigmatic beliefs [40]. Currently adopted by many countries with national strategic programmes, Dementia Friends initiatives have been implemented mainly with college students as the target population, and by providing information either through offline or online talks [41]. However, it should be noted that up till today, these initiatives have not attained significant reductions in participants' stigmatic beliefs about dementia, although they have undeniably improved knowledge levels. These fairly sobering findings stem from two main reasons: the lack of structured valid instruments to assess empirically the concept of dementia stigma among laypersons, as well as the low to moderate levels of stigmatic beliefs about dementia, as stated earlier in this chapter.

6.2 Contact-Based Interventions

In the area of dementia stigma, the use of contact-based interventions was implemented mainly with intergenerational groups including young populations such as college students. The use of video or other media to bring audiences into contact with a person with dementia was adopted by several dementia anti-stigma campaigns in Japan, the UK, Australia and Israel [42]. Although there is little knowledge of how exactly they function, media campaigns are a viable method of putting a stigma-reducing approach into practice [43]. An Australian study shows that both national and local campaigns emphasize personhood and underscore that persons with dementia have rights and deserve dignity and respect [44]. Local campaigns also aim to normalize living with dementia more than national campaigns do, as they try to strengthen the social commitment of those directly affected.

While the hope informing these campaigns is that a greater exposure to and a deeper and more personal identification with persons with the disease will at least approach them in a more open and unprejudiced way, evidence accumulating from these interventions shows modest improvements in laypersons' stigmatic beliefs at best. This is not surprising, especially as the most successful component in contact-based interventions to reduce mental illness stigma is the direct live contact with a person with mental illness sharing personal life experiences. In the case of dementia, this is possible only with persons who retain their language and communication abilities and who probably find themselves at a relatively early stage of the disease. In a disease that, as we explain in the next subsection, is mainly framed by discourses stressing the loss rather than the preservation of cognitive abilities, exposure to a person

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

with the disease might reinforce stigmatic stereotypes instead of reducing them. And moreover, as we stated earlier in the chapter, dementia public stigma is typically characterized by high levels of positive feelings towards the person with the disease. Exposure to such a person might erase such positive feelings and increase rather than decrease negative emotions, especially fear.

Thus, reducing laypersons' stigma in the area of dementia is a complex and challenging task. Knowledge accumulated until today shows that two of the most recommended strategies for other diseases – education and contact – might have a merely moderate or even a negative effect, as they might increase feelings of pity, helplessness and victimization towards persons with dementia. Called 'benevolence stigma', this phenomenon reinforces stigmatized persons' inability to make decisions by themselves and perpetuates their need to rely on authoritative figures [45]. Investing in the development of an alternative discourse for the understanding of dementia might provide an alternative strategy for reducing dementia public stigma.

6.3 Interventions Providing Alternative Discourses and Images

As stated earlier, the prevalent 'tragedy discourse' emphasizing the 'worst case' aspects of the disease, such as the progressive loss of cognitive abilities and the gradual but irrevocable process of deterioration in which people no longer recognize their loved ones, is very likely strengthening the stigma surrounding dementia [46]. The question then arises whether there are alternative discourses available that may reduce stigma. A possible alternative to the 'tragedy' discourse is the 'living well with dementia' discourse. In this discourse, personhood is emphasized, and encouraging the support from others makes it possible to deal with the condition. This is in line with policies that focus on early care planning, the promotion of 'ageing well', and the concept of dementia-friendly communities.

There are many examples of initiatives that want to promote and express these values. For instance, the 'living well with dementia' project in Stillorgan, Blackrock, in Dublin (Ireland), aims to build 'a community that respects, supports and empowers people with dementia; a community in which people with dementia are socially and culturally valued'. In the domain of art and literature, such values are pursued through forms of interactive creativity. The TimeSlips project, for instance, develops a technique for collaborative storytelling, in which a visual cue (such as a painting or a photo) leads to responses that allow the group leader to construct a story with the participants. As the TimeSlips website puts it (under the slogan 'connect through creativity'): 'TimeSlips opens storytelling to everyone by replacing the pressure to remember with the freedom to imagine.' Other examples include Gary Glazner's Alzheimer's Poetry Project (APP), in which a call-and-response model is used to unlock hidden forms of creativity that may result in strengthening the dignity of the people with dementia involved, and John Killick's *Poetry and Dementia: A Practical Guide* (2018), which demonstrates that through poetry people with the condition can help others to look at different aspects of life from an unexpected angle [47]. From this perspective, identity and selfhood are situated more in playfulness, social interactions, embodied activities and forms of community than in rationality or self-consciousness. McParland, Kelly and Innes point out some pitfalls in this type of alternative approach. Sometimes, it seems to be a matter of just doing your best to maintain third-age (rather than fourth-age) status and continue to participate in a normal, active life [48]. This risks obscuring the undeniable negative aspects of the disorder.

The major risk of the 'living well' perspective is that the most vulnerable will be seen as the 'failed ones', and as a result, stigmatization is strengthened rather than reduced for this group. As McParland, Kelly and Innes note, 'dementia means different things to different people depending on their social context' (p. 259). To achieve a more nuanced image, they state, it is necessary to accept the paradoxical nature of this very complex condition. It is therefore important to break open the dichotomy between 'tragedy' and 'living well' and to *combine* several frames in the representation of dementia.

Van Gorp and Vercruysse distinguish a number of counter-frames that can counterbalance the dominant stigmatizing views on dementia [49]. A nuanced image of dementia, first of all, does not focus exclusively on the last stage of the disease. It covers aspects of life from the moment the

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

Figure 2.3 Advertisement designed by Tramway21 (tramway21.be) combining different frames and tested in an experimental study design (photo taken by Laura Baudoux, used with permission)

diagnosis is made. Depending on the age at the time of diagnosis, life expectancy is on average seven to ten years (three years or less if the patient is 90 years or older), so time is still available to gain in quality of life. A useful counter-frame might then be 'seize the day'. Although there is an undeniable gradual decline in the number and nature of activities that are still possible, one could learn to enjoy the little things that make life still worth living, even with a diagnosis of dementia. Alternative forms of communication can be sought with people with dementia, which is, as in the poetry examples presented earlier, mainly non-verbal yet meaningful. In this way, caregivers can get to know their loved ones during the process of illness in different and unexpected ways.

The deployment of a number of framing and counter-framing strategies, as discussed earlier, have been tried out in experimental research that explores to what extent these strategies can be used in awareness-raising campaigns. A combination of a frame that focusses on the problem with a counter-frame that offers a more positive and hopeful alternative perspective turns out to be the best choice to get the audience thinking and evaluating the campaign positively. Figure 2.3, for example, uses a combination of the heading

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

'Helga, already buried by her friends and family, and yet she's still alive' and the baseline 'Behind every person with Alzheimer's is a living person' [50].

Furthermore, the 'Unity' frame (which does not distinguish between body and mind) has proven useful and has led to positive attitudes towards people affected by dementia [51]. A frame that distinguishes between body and mind, in contrast, brings about emotions such as sadness and anger. Visual stimuli, especially the depiction of people with dementia, draw attention to the campaign image, as demonstrated by the use of eye-tracking technology. The image of an elderly person ensures that more attention is paid to the accompanying text on a campaign image. A younger adult holds the attention for a longer time, but directs the attention away from the text. The results of this type of research make clear that each building block of a message matters, as it can generate different effects with different target groups. Communication should therefore be tailored as closely as possible to the living world of the different target groups.

One example is the story of a woman who got to know her father through dementia as someone who liked to cuddle, whereas before he was always very distant from her. The ability to discover previously occluded aspects of a parent's character is also underlined in the literary genre of the filial dementia memoir, in which (often female) authors report on new physical and emotional intimacy with fathers who, because of reigning ideals of masculinity, were previously often aloof or simply absent (although one of the famous cases, Arno Geiger's *Der alter König in seinem Eksil*, in which a son gets to know his father through dementia, is written by a male author). As such, a ray of light appears in a life with dementia that is very often presented as pitch-black. Therefore, the German nationwide awareness-raising campaign Konfetti im Kopf (Confetti in the Head) tries to bring colour to the lives of people with dementia by making use of the motivating power of art, culture and direct encounters.

Another strategy to identify alternative perspectives consists in greater awareness that the perception of dementia is not determined solely by the actual symptoms of the condition; it is not simply a biological, but also a psychological, social and cultural condition. For example, in the context of informal care, reference is regularly made to the role reversal between parents and children ('reverse parenting'): parents should care for their children, but not the other way around. However, this is not a natural fact but a socially constructed norm. It is equally possible to look at informal care from the perspective of reciprocity. Parents take care of their young children, and later in life it is the children's turn to take care of their parents. Similarly, people with dementia who play with a doll or use the tablecloth to wipe their mouth in the restaurant are a source of shame only to the extent that they are viewed from a normative perspective. It is also possible to see a person with dementia playing with a doll as the liberating falling away of social inhibition. The adults, then, can return to the carefree and playfulness of their childhood. Wanting to prevent this type of situations in public at all cost can increase the social isolation of people with dementia. In other words, how dementia is perceived and conceived has real impacts on the lived experiences of citizens with dementia. This also means that changing perceptions matters.

7 Conclusion: Future of Dementia Stigma

The aim of this chapter was to familiarize the reader with the historical and sociocultural origins of dementia public stigma, its conceptualization, perpetuation mechanisms and interventions to reduce it. Undoubtedly, we are at a unique turning point. Promoted by initiatives of leading worldwide bodies in the area of dementia, such as Alzheimer's Disease International, Alzheimer's Europe and the World Health Organization, public health attention on the topic is at its peak. Still, conceptual, methodological and strategic limitations continue to obstruct the successful translation of this interest into productive research and intervention initiatives. Some of the questions remaining are: First, do we have a clear understanding of dementia public stigma, or are we sticking to conceptualizations developed in relation to other conditions? Are we, in other words, missing the uniqueness of dementia stigma? Second, to what extent will recent, socially oriented and positively inclined views of dementia affect dementia stigma?

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

Third, do we even have reliable and valid instruments to assess dementia stigma? And fourth, why is the impact of interventions to reduce dementia stigma so modest?

Our approach to dementia stigma needs to walk a fine line between assuring the problem is urgent without representing it as hopeless, and valorizing it as a distinct way of life and underlining the very real challenges it involves. Because the stigma surrounding dementia might partly be due to the dramatization of the disorder, it might be tempting to opt for a more extensive form of deproblematization of the disorder. This is, however, not a panacea either. In the contested book *The Myth of Alzheimer's*, the authors state unequivocally that dementia is a normal far-reaching form of natural ageing of the brain [52]. Searching for a cure for Alzheimer's would therefore be a futile quest for a 'cure' for ageing in general. Because the search for this holy grail is pointless, the authors argue for a radical shift in attention: away from the stubborn desire to find a cure for the disease to prevention and especially caregiving. For all the good intentions powering this destigmatizing effort, it again risks exacerbating the stigma and trivializing the condition. In any case, there is a paradox that needs to be taken into account – namely, that dramatizing the condition contributes to the stigma, whereas deproblematizing can result in the disorder being disguised in such a way that it seems no longer necessary to pay attention to it. As a result, the limited resources available for scientific research might go to, for instance, research into cancer, a disease that is less easily perceived as being primarily age related.

This is only one of the challenges future engagements with dementia stigma will need to reckon with. Another key challenge is to involve people with dementia more in ethically responsible ways in research into dementia perceptions. A further challenge is to develop more sophisticated and dementia-specific methods to understand both the causes and the mechanisms behind stigma. Further, and as we underlined in the sections on literature and media, the cognitive processing of text and image remains to a large extent a black box. All of these challenges remain, and if efforts at destigmatization insist that dementia is not a hopeless and meaningless condition, they should never fool us into believing that living with dementia is easy.

References

1. Herrmann LK, Welter, E, Leverenz, J, et al. A systematic review of dementia-related stigma research: Can we move the stigma dial? *The American Journal of Geriatric Psychiatry* 2018; **26**: 316–31.
2. Nguyen T, Li X. Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia* 2018; **19**: 148–81.
3. Corrigan PW, Kosyluk KA. Mental illness stigma: Types, constructs, and vehicles for change. In Corrigan, PW, ed. *The Stigma of Disease and Disability: Understanding Causes and Overcoming Injustices*. Washington, DC, American Psychological Association, 2014; 35–56.
4. Werner P. Stigma and Alzheimer's disease: A systematic review of evidence, theory, and methods. In Corrigan, PW, ed. *The Stigma of Disease and Disability: Understanding Causes and Overcoming Injustices*. Washington, DC, American Psychological Association, 2014; 223–44.
5. Werner, P, Kalaitzaki AE, Spitzer N, et al. Stigmatic beliefs towards persons with dementia: Comparing Israeli and Greek college students. *International Psychogeriatrics* 2019; **31**: 1393–1401.
6. Stites, SD, Rubrighr JD, Karlawish J. What features of stigma do the public most commonly attribute to Alzheimer's disease dementia? Results of a survey of the U.S. general public. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* 2018; **14**: 925–32.
7. Corrigan PW, Green A, Lundin R, et al. Familiarity with and social distance from people who have serious mental illness. *Psychiatric Services*. 2001; **52**: 953–8.
8. Link B, Cullen F, Struening E, et al. A modified labeling theory approach to mental disorders: An empirical assessment. *American Sociological Review* 1989; **54**: 400–23.
9. Kitwood T. *Dementia Reconsidered: The Person Comes First*. Buckingham, Open University Press, 1995.
10. Van Gorp B, Vercruysse T. Frames and counter-frames giving meaning to dementia: A framing analysis of media content. *Social Science & Medicine* 2012; **74**: 1274–81.
11. Gerritsen D, Oyebode J, Gove, D. Ethical implications of the perception and portrayal of dementia. *Dementia* 2016; **17**: 596–608.
12. Hillman A, Latimer J. Cultural representations of dementia. *PLoS Medicine* 2017; **14**: e1002274.
13. Young JA, Lind C, Orange JB, Savundranayagam MY. Expanding current understandings of

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

epistemic injustice and dementia: Learning from stigma theory. *Journal of Aging Studies* 2019; **48**: 76–84.

14. Granello DH, Gibbs TA. The power of language and labels: 'The mentally ill' versus 'people with mental illnesses'. *Journal of Counseling & Development* 2016; **94**: 31–40.
15. McParland P, Kelly F, Innes A. Dichotomising dementia: Is there another way? *Sociology of Health & Illness* 2017; **39**: 258–69.
16. Zeilig H. Dementia as a cultural metaphor. *The Gerontologist* 2013; **54**: 258–67.
17. Werner P, Raviv-Turgeman L, Corrigan PW. The influence of the age of dementia onset on college students' stigmatic attributions towards a person with dementia. *BMC Geriatr* 2020; **20**: 1–6.
18. Higgs P, Gilleard C. Frailty, abjection and the 'othering' of the fourth age. *Health Sociology Review* 2014; **23**: 10–19.
19. Rowe JW, Kahn RL. Successful aging. *The Gerontologist* 1997; **37**: 433–40.
20. Kang S, Gearhart S, Bae, HS. Coverage of Alzheimer's disease from 1984 to 2008 in television news and information talk shows in the United States: An analysis of news framing. *American Journal of Alzheimer's Disease & Other Dementias* 2010; **25**: 687–97.
21. Kessler EM, Schwender C. Giving dementia a face? The portrayal of older people with dementia in German weekly news magazines between the years 2000 and 2009. *The Journals of Gerontology: Series B* 2012; **67**: 261–70.
22. Gerritsen DL, Kuin Y, Nijboer J. Dementia in the movies: The clinical picture. *Aging & Mental Health* 2014; **18**: 276–80.
23. Cohen-Shalev A, Marcus E. An insider's view of Alzheimer's: Cinematic portrayals of the struggle for personhood. *International Journal of Ageing and Later Life* 2012; **7**: 73–96.
24. Strier R, Werner P. Tracing stigma in long-term care insurance in Israel: Stakeholders' views of policy implementation. *Journal of Aging & Social Policy* 2016; **28**: 29–48.
25. Werner P, Doron I. Alzheimer's disease and the law: Positive and negative consequences of structural stigma and labeling in the legal system. *Aging & Mental Health* 2016: **21**: 1206–13.
26. Stites SD, Rubrighr, JD, Karlawish J. What features of stigma do the public most commonly attribute to Alzheimer's disease dementia? Results of a survey of the U.S. general public. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* 2018; **14**: 925–32.
27. Whitehead A, Woods A. Introduction. In Whitehead A, Woods A, eds. *The Edinburgh Companion to the Medical Humanities*. Edinburgh, Edinburgh University Press, 2016; 1–31.
28. Bleakley A. *Medical Humanities and Medical Education: How the Medical Humanities Can Shape Better Doctors*. Abingdon, Routledge, 2015.
29. Bladon H. Using fiction to increase empathy and understanding in dementia care. *Nursing Times* 2019; **115**: 47–9.
30. Vermeulen P. *Homo sacer/homo demens*: The epistemology of dementia in contemporary literature and theory. In Krüger-Fürhoff I, Schmidt N, Vice, S, eds. *The Politics of Dementia: Forgetting and Remembering the Violent Past in Literature, Film, and Graphic Narratives*. Berlin, De Gruyter, 2020; 39–54.
31. Simonsen P. The terror of dementia in Ian McEwan's *Saturday*. In Chivers S, Kriebernegg U., eds. *Care Home Stories: Aging, Disability, and Long-term Residential Care*. Bielefeld, Transcript, 2017; 175–90.
32. Jamieson S. Reading the spaces of age in Alice Munro's 'The bear came over the mountain'. *Mosaic: An Interdisciplinary Critical Journal* 2014, **47**: 1–17.
33. Simonsen P. *Livslange liv: Plejehjemsromaner og pensionsfortællinger fra velfærdsstaten*. Odense, Syddansk Universitetsforlag, 2014.
34. Casey B. Dementia and symbiosis in *Waiting for Godot*. In Maginess T, ed. *Dementia and Literature: Interdisciplinary Perspectives*. Abingdon, Routledge, 2018; 37–52.
35. Maginess T. *Dementia and Literature: Interdisciplinary Perspectives*. Abingdon, Routledge, 2018.
36. Swinnen A, Schweda M, eds. *Popularizing Dementia: Public Expressions and Representations of Forgetfulness*. Bielefeld, Transcript, 2015.
37. Swaffer K. Foreword. In Maginess T., ed. *Dementia and Literature: Interdisciplinary Perspectives*. Abingdon, Routledge, 2018; xi–xiii.
38. Devi G. *The Spectrum of Hope: An Optimistic and New Approach to Alzheimer's Disease and Other Dementias*. New York, Workman, 2017.
39. Rüsch N, Xu Z. Strategies to reduce mental illness stigma. In Gaebel W, Rössler W, Sartorius N, eds. *The Stigma of Mental Illness: End of the Story?* Cham, Springer, 2017; 451–67.
40. Phillipson L, Hall D, Cridland E, et al. Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project. *Dementia* 2019; **18**: 2679–94.

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

41. Buckner S, Darlington N, Woodward M, et al. Dementia friendly communities in England: A scoping study. *International Journal of Geriatric Psychiatry* 2019; **34**: 1235–43.

42. Werner P, Schifmann KI, David D, AboJabel H. Newspaper coverage of Alzheimer's disease: Comparing online newspapers in Hebrew and Arabic across time. *Dementia* 2019; **18**: 1554–67.

43. Werner P, Schiffman, KI. Exposure to a national multimedia Alzheimer's disease awareness campaign: Assessing stigmatic beliefs towards persons with the disease. *Int J Geriatr Psychiatry* 2918; **33**: 336–42.

44. Haapala I, Carr A, Biggs S. What you say and what I want: Priorities for public health campaigning and initiatives in relation to dementia. *Australas J Ageing* 2019; **38**: 59–67.

45. Fominaya AW, Corrigan PW, Rusch N. The effects of pity on self- and other-perceptions of mental illness. *Psychiatry Research* 2016; **241**: 159–64.

46. Herrmann LK, Welter E, Leverenz J, et al. A Systematic review of dementia-related stigma research: Can we move the stigma dial? *The American Journal of Geriatric Psychiatry* 2016: **26**: 316–31.

47. Killick J. *Poetry and Dementia: A Practical Guide*. London, Jessica Kingsley, 2018.

48. McParland P, Kelly F, Innes A. Dichotomising dementia: Is there another way? *Sociology of Health & Illness* 2917; **39**: 258–69.

49. Van Gorp B, Vercruysse T. Frames and counter-frames giving meaning to dementia: A framing analysis of media content. *Social Science & Medicine* 2012; **74**: 1274–81.

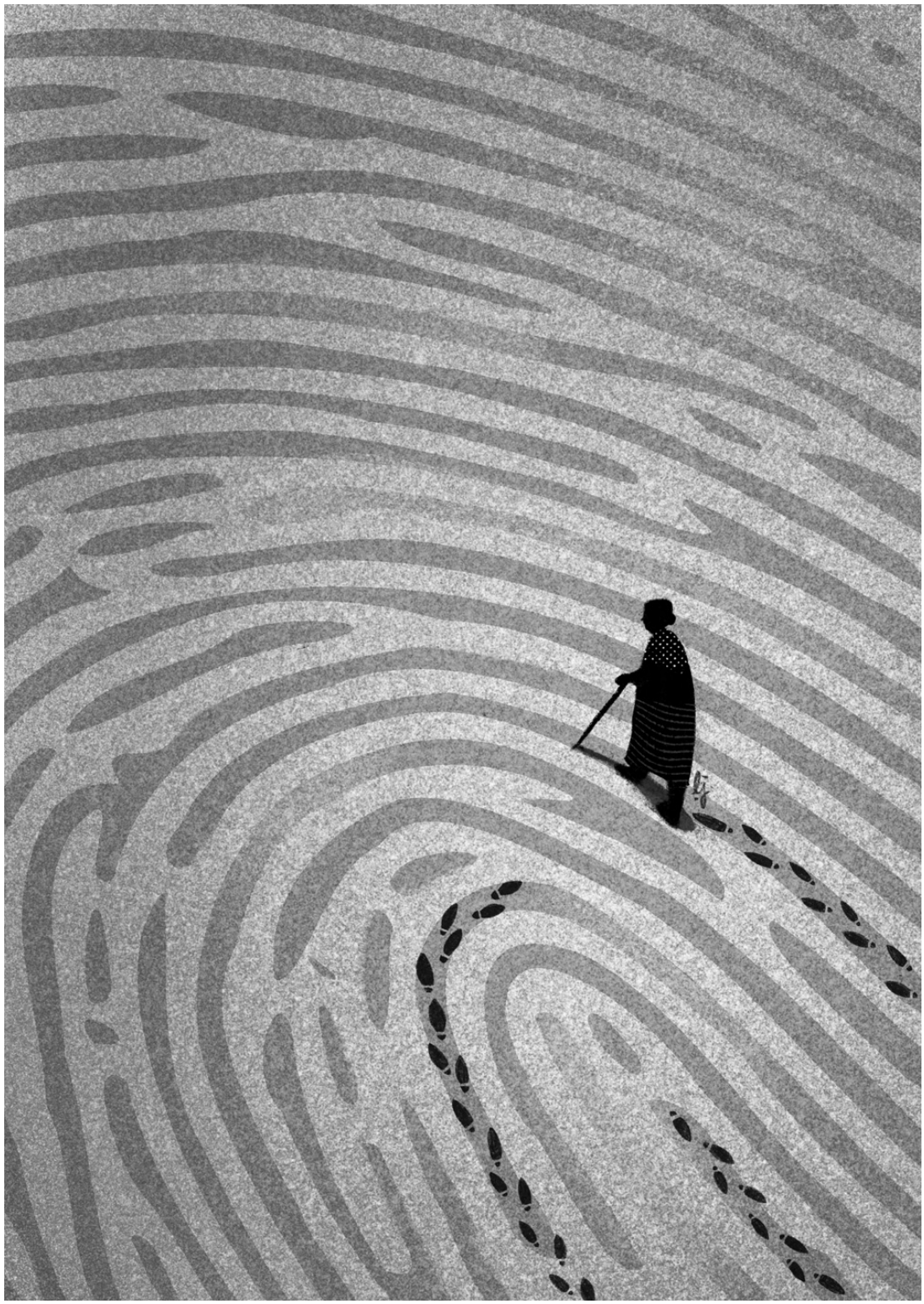
50. Van Gorp B, Vercruysse T, Van den Bulck, J. Toward a more nuance perception of Alzheimer's disease: Designing and testing a campaign advertisement. *American Journal of Alzheimer's Disease and Other Dementias* 2012; **27**: 388–96.

51. Cuadrado F, Antolí A, Rosal-Nadales M, Moriana JA. Giving meaning to Alzheimer's disease: An experimental study using a framing approach. *Health Communication* 2020; **35**: 447–55.

52. Whitehouse PJ, George D. *The Myth of Alzheimer's*. New York, St. Martin's Press, 2008.

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press

https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press



https://doi.org/10.1017/9781108918954.003 Published online by Cambridge University Press