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Introduction

Alzheimer's disease: A twenty-first-century first-world scare

She was not Inés any more, she was only a body in front of the doctor, a handful of inner organs, two lungs, a brain that was destroying itself.

Andrés Barba, *Ahora tocad música de baile*¹

We are, above all, human beings with strengths and weaknesses, highs and lows, and with a disease that touches an organ of our body: the brain.

Claude Couturier, *Puzzle, Journal d'une Alzheimer*²

When we think about dementia or Alzheimer's disease, we think about it in terms of loss: the loss of mental capacity, the loss of skills and agency, the loss of memory, identity and personhood.³ This book charts the development of this discourse from its origins in the nineteenth century to the present day and specifically considers concepts that have shaped the neurological and psychological understanding of dementia. It explores the extent to which the societal dementia discourse, which induces Andrés Barba to remove Inés's personhood and reduce her to mere bodily parts, is rooted in a science-led and medicine-adopted discourse. This discourse relates the broad-spectrum concept of loss of cognition, personhood and identity to the actual loss of cells in specific brain areas, as illustrated by the following extract from *Brain Facts*, a public information initiative of the Society for Neuroscience launched in 2012:

Initially, people experience memory loss and confusion ... symptoms of AD [(Alzheimer's disease)] gradually lead to behavior and personality changes, a decline in cognitive abilities such as decision-making and language skills ... AD ultimately leads to a severe loss of mental function. These losses are related to the worsening breakdown of the connections between certain neurons in the brain and their eventual death.⁴

I worked in experimental research related to Alzheimer's disease and other forms of dementia for fifteen years and have participated in this scientific discourse. Underlying it is what Nikolas Rose and Joelle M. Abi-Rached have termed a 'neuromolecular style of thought'. This way of reasoning argues that mental states express themselves in material processes in the brain, and that these processes can be anatomized at a molecular level.⁵ Applying this style of thought to reading literary texts could lead me to argue that a focus on unravelling molecular mechanisms of cell death in dementia has reduced patients to mere carriers of symptoms; and that this reductionism, as we hear it in the voice of Inés's husband Pablo, underestimates patients' need for and right to dignified care. But how well can Inés's objectification be explained by the appropriation within caregiver discourse of scientifically and medically sanctioned concepts of loss and reduction? Or is Pablo's objectification of his wife the result of overwhelming burdens of care placed on the caregiver? These questions bridge material-scientific and discursive-cultural understandings of Alzheimer's disease.

Concern with this nexus of issues has pushed my research interests more and more towards the intersection of literature, science and medicine. I began to focus on the context in which specific scientific and medical texts have been produced. I had to change my view of scientific work as being merely an isolated discipline of knowledge acquisition: science and its published products are clearly a form of culture.⁶ The process in part has turned me into a subject of my own enquiry, as I have come to understand my scientific research as historically situated. My initial work developed in the context of the early 2000s' fascination with biomarkers (which this book covers in Chapter 5), while later studies, in the framework of my *Habilitation*, evolved in response to growing doubts about the validity of specific disease hypotheses (discussed in Chapter 7). But this is not to say that this study is an auto-ethnographic work by a neuropharmacologist-turned-health-humanities researcher; nor is it evidence of lived two-culture splits that tell of the frustrations of a scientist healed by turning to literature. Science is neither weak nor wicked. It studies aspects of health and disease which the health humanities have no access to; and, vice versa, the medical humanities open additional perspectives onto health and illness.

But medical systems, especially in rich societies, have increasingly failed the patient. This is a phenomenon not unique to dementia: patients are objectified in the process of diagnosis and functional assessment of many diseases, and healthcare programmes continue to develop around the notion of the patient as burden and as having no voice.⁷ The patient's diminished capabilities, dependence and passivity are central to the cultural dementia narrative (i.e.

how the condition's nature and patient's identity are perceived and understood in Western societies today); and this narrative has become core to beliefs about dementia in the wider cultural and societal discourse. As this book will show, health humanities work, including literary scholarship, has greatly assisted the patient on the journey back to centre stage. Yet, this has come at the price of what I increasingly perceive to be an antagonistic mode that sets up the sciences against the humanities. This happens because the biomedical approach has become a hold-all for processes that remove the personhood from the patient, where the effects of the scientific and the medical are insufficiently separated out, either in terms of discourse developments or in terms of their preferred methodologies, goals and interest groups.⁸ This study, although it strongly aligns itself with the medical humanities, is not *a priori* intended as a 'challenge and corrective to the hierarchies of evidence that have come to define theoretical, practice-based and policy-oriented instantiations of the biomedical.'⁹ Rather, it will illustrate how current criticism of the biomedical approach could be more nuanced by drawing attention to the crucial difference between the process of methodological reductionism in science research and notions of objectification in medical and clinical practice.

This book explores to what extent the current cultural dementia narrative is grounded in historical scientific and medical language related to brain diseases, beginning with its origins in the nineteenth century, when the condition was first described as an organic disease, to the present day, when it is viewed as a disorder of cognition. I pursue a historical approach, because I share the view of medical historian Jesse F. Ballenger that 'without a sense of history, without the ability to construct a coherent narrative linking the present to the past as well as the future, public discourse on Alzheimer's will itself be confused, disoriented.'¹⁰ I pinpoint changes in the scientific and medical understandings of dementia throughout the long twentieth century, and examine how these changes have influenced the wider cultural thinking about dementia over time. I take Ballenger's groundbreaking study as an invitation to historicize the literary approaches to dementia and Alzheimer's disease. Marlene Goldman has thought along these lines in her recent work on narratives about Alzheimer's disease in Canada. She turns to literature 'because fiction often explicitly or implicitly adopts a non-biomedical, historical approach to dementia', although she largely focuses on how current literary productions explore historically inflected notions of the condition.¹¹

The present study, by comparison, takes literary writing as an active contributor to discourse developments throughout the entire period under

investigation; in doing so, it critically negotiates the possibility that literary writings perpetuate and enhance biomedical discourse. It contends that whole-person approaches – approaches that acknowledge the patient as a feeling, thinking, communicating and engaging individual, with a mind and world of experience of their own – can integrate an understanding of Alzheimer's disease as a local pathological entity – an organic condition of the brain. Conversely, I argue that considering Alzheimer's disease as a whole-person phenomenon can equally subject the patient to a process of objectification ascribed to biomedical discourse. My overarching aim is to understand where the cultural path taken by the presentation and perception of dementia – since its respective definitions as an organic disease around 1900 and a cognitive, performance-limiting condition around 2000 – leads the illness and its sufferers to in the twenty-first century. Two processes interest me in particular: how have literary renderings of dementia been shaped by an evolving medico-scientific dementia discourse, and how has this cultural narrative fed back into the scientific and medical gaze at the condition? To address this, I will attend to four different kinds of text: fiction (including film), caregiver accounts, patient life-writing, and scientific and medical texts as well as their popular echoes in mass media reports and generally accessible scientific book publications.

Fictional representations can be understood in part as an expression of societal and cultural developments, and fictional depictions such as Andrés Barba's can be taken as both a product and an illustration of the current cultural dementia narrative. Caregiver life-writing, in turn, gives us a glimpse into how family members make sense of the illness; but the existence of these texts itself appears to objectify the patient. Such objectification has motivated individuals like Claude Couturier to reclaim identity and selfhood through their writing. Patient accounts convince me that dementia life-writing is well positioned to instigate a counter-discourse that focuses attention on patient experience and makes this experience central to both: the medico-scientific understanding of the condition and sociopolitical approaches to the illness.¹² Cultural renderings of dementia and ageing, indeed, do feature in more and more specialist clinical journals.¹³ These papers evince a clear interest by the medical and scientific professions in cultural representations of dementia. They also suggest that cultural images as well as the patient's and caregiver's own writing can reshape medico-scientific dementia discourse: I will explore this through analysis of a selection of scientific and medical research papers.

These different types of text already point to the fact that the condition is not only a scientific concept caught up in what Oliver Sacks termed neurology's

'deficit' language: language that denotes 'loss of speech, loss of language, loss of memory, loss of vision, loss of dexterity, loss of identity and myriad other lacks and losses of specific functions (or faculties)'.¹⁴ It is also an experience. And as such, the narrative of loss in relation to Alzheimer's disease reaches beyond what the biomedical model of the condition can explain. With the rise during the second half of the nineteenth century of cellular theories and the notion of mental life residing in a granular substance, the cell came to be understood as the locus of the disease. Wider cultural discourse began to link the integrity of the cell to that of identity.¹⁵ As William R. Clark puts it in his account of cell death as a creative principle, 'Human beings seem to have decided that cells of the brain are more important in defining life than other cells.'¹⁶ Once brain had acquired mind, wider sociocultural concepts equated the loss of cognitive skills and memory with the patient's loss of awareness and self; and concepts that link a sense of self to a sound mind (hence functioning brain) and intact memory link this sense of self also to the ability to narrate.¹⁷

In addition, there is a growing preoccupation with dementia as the synthesis of old age and illness.¹⁸ Ageing itself is equated with experiencing loss – the loss of family and friends, the loss of opportunities, power and prowess.¹⁹ Celebratory perspectives on ageing – notions of gain, growth and progress – hardly seem to feed into the current cultural dementia narrative. Instead, biological understandings of ageing appear to reinforce a dementia narrative that centres on loss; and a lot of gerontological research and geriatric practice integrates 'social values responsible for ageism and the declining status of old people'.²⁰ On top of all this, the perception of dementia has become yoked to 'loss of wholeness, loss of certainty, loss of control, loss of freedom to act, and loss of the familiar world' that is fundamental to any experience of severe illness.²¹

The cultural profile of the condition is partly related to significant demographic shifts in Western societies and the politicization of these shifts. Alzheimer's disease has become the most common form of dementia among the elderly. And, representing the most feared neurological condition today, it has also turned into a trope for all forms of dementia. This anxiety is played on by the popular press in relation to the condition's epidemic proportions. Cultural figures about dementia include images of a 'rising tide' and 'millennium demon', and the condition has become a metaphor for all kinds of sociopolitical ills.²² This is also the case because plague-like terminology abounds which, as Susan Sontag explicated in relation to a quite different disease,

has long been used metaphorically as the highest standard of collective calamity, evil, scourge ... Although the disease to which the word is permanently affixed produced the most lethal of recorded epidemics, being experienced as a pitiless slayer is not necessary for a disease to be regarded as plague-like. [An illness] has been regarded as a plague ... not because it killed often, but because it was disgracing, disempowering, disgusting.²³

This book will delve into the historical grounding of objectifying patient presentations and explore how specific metaphorical language became affixed to condition and patient.

Dementia in history

Dementia has been conceived of as both an abstract and isolated molecular event and a condition related to an individual as a whole. Recent sociological work elaborates on these continued tensions: first, whether behavioural changes are the manifestation of a distinct pathology or are inherently related to ageing; second, whether specific organic changes in the brain cause behavioural changes or whether the process of ageing itself impacts on the mind and leads to changes that are pathological; and third, whether dementia is socially conditioned or genetically programmed.²⁴

While the second and third such tensions emerge successively from medico-scientific work at the end of the nineteenth and twentieth centuries, the first issue resonates with longstanding ideas about memory loss and ageing. Homer associated ageing with physical change, Juvenal coupled it with ideas of second childhood and foolishness and Horace described it as anticipating death.²⁵ In ancient Greece, figures of public life, such as Xenophon, ‘hesitated to live a longer time lest he be forced to pay the penalties of old age – to ... fail in intellectual capacities’; and literary representations feature characters like Strepsiades in Aristophanes’s comedy *The Clouds*, who ‘has a bad memory, is dull of comprehension, and is too old to learn.’²⁶ I agree with Pat Thane that we should not draw simplified cultural perceptions from classical Greek comedy.²⁷ But such literary stereotypes could not exist in a conceptual void, even if modern scholarship of classical texts can find almost no reference ‘specific to mental illness in old age.’²⁸

I do not claim that the present-day cultural dementia narrative has its roots in the Ancient World, nor do I read currently recognized symptoms of dementia into the cultural expressions of a society that thrived more than two thousand

years ago.²⁹ However, I agree with Helen Small 'that what philosophers and non-philosophers have had to say about old age has, in essence, changed very little since classical antiquity'.³⁰ Shakespeare's *King Lear* is perhaps the most frequently mentioned post-classical portrayal of ageing as a state characterized by memory loss and 'second childhood'.³¹ In common with Nina Taunton, I identify Lear as 'driven by anger and shame, two emotions associated with aged impotence', as acting under 'a misguided belief that he continues to wield power over his children and over nature itself'.³² Yet, Lear's behaviour is frequently linked to Alzheimer's disease. Work claiming parallels between Lear and the clinical case of a 'frail elder' and probable Alzheimer's, that 'Lear's increasing isolation results from a tragic combination of cognitive impairment, caregiver stress, and generational conflict', is one such example.³³ Shakespeare's interest in the development of character and familiarity with the human experience have been observed to invite continuous reinterpretation for a contemporary audience.³⁴ Still, I read such contemporary keenness to identify Alzheimer's disease in cultural representations of the Antiquities, Middle Ages and Early Modern Times first and foremost as a manifestation of the current societal concern with the condition.

From the end of the sixteenth century until well into the eighteenth, the term 'dementia' was employed as synonymous with 'melancholia' and 'madness'. By the late eighteenth century, the term held the meaning 'out of one's mind', around the time when the condition began to be treated as a mental illness.³⁵ This idea of the condition built on a growing interest in brain pathology, which emerged from the biological psychologies of Erasmus Darwin, Franz Josef Gall and other brain scientists, from the 1790s onwards, and played a crucial role in establishing the brain 'as the organ of thought'.³⁶ Methodological progress and technical advancements which became available towards the end of the nineteenth century supported the idea that the various morphological subdivisions of the brain consisted of discrete areas of particular function, which enabled development of a 'materialist science of the self'.³⁷ By the 1880s, biological explanations of physiological phenomena also included a changing conceptualization of dementia.

The structure of the modern sciences of memory became established between 1874 and 1886.³⁸ In particular, lesion theories began to fuel enquiries into potential links between bodily signs (symptoms related to a failing mind) and organic (cerebral) changes. The changing methods of clinical observation led, as Michel Foucault argued, to the 'projection of illness onto the plane of absolute visibility' and a 'gaze [that] dominat[ed] the entire field of possible knowledge'.³⁹

Alois Alzheimer's case of Auguste D. in 1906 is widely considered a landmark.⁴⁰ But it was part of a much larger shift in the discipline's approach to dementia, driven by new methodologies that created different conceptual perspectives.⁴¹ In this instance, the new methodologies included an expanding array of visualizing techniques, among them a nerve cell staining method developed in 1872 by Camillo Golgi (1843–1926).⁴² This staining technique enabled the study of the morphology of the brain, including pathological changes. And this, in turn, fuelled in the wake of Alzheimer's work a neuroscientific redefinition of the condition as an organic disease of the brain.

The nineteenth-century *fin de siècle* has attracted scholarly attention not only because of the 'new technologies that became available ... the new sites of scientific enquiry thereby opened, and the new forms of knowledge they facilitated'.⁴³ It was also a time when 'biological explanations of psychological states held sway', and 'ideas about the functioning of the mind and body seeped from science into broader cultural discourses'.⁴⁴ In the context of the memory sciences, literary notions of memory impairment throughout the nineteenth century became increasingly related to concepts of lesion as a form of loss. Nicholas Dames, for example, establishes a clear link between the researched understanding of memory and the literary representation thereof, and Sally Shuttleworth shows how fictional representations of memory changed during the second half of the nineteenth century.⁴⁵ Also from a wider cultural perspective the *fin de siècle* makes a suitable beginning for this study. The concept of identity in dementia has shifted in response to changes in the meaning of terms such as 'idiocy', 'retardation', 'senility' and 'madness'.⁴⁶ These shifts happened, towards the end of the 1800s, in response to changing societal preoccupations, scientific understandings and wider cultural concerns about health and disease.⁴⁷ And related to this, socio-economic, political and legal language at the *fin de siècle* assumed a decidedly degenerative aspect.⁴⁸ This suggests there existed, at the end of the nineteenth century, a range of dimensions to the cultural counterparts of the evolving medico-scientific discourse of dementia.

This study is not meant to foreground ageing, but there is consensus that 'the quality of our ideas about the meaning of aging has considerable implications for medical ethics and practice, psychotherapy and the education of older people, research on the biology of aging and the prolongation of human life, public policy, and religious and spiritual life'.⁴⁹ These insights directly feed into social, cultural, political and economic implications of dementia. In addition, attending to the close connections between ageing and memory loss will help to explore questions of identity within dementia. 'When we think about old

age', emphasizes Helen Small, 'our thinking rests on larger, but usually tacit, assumptions about what a life is, what a person is, what a *good* life is, what social justice is, and much else besides'. Small explores questions of identity and agency within Alzheimer's disease, arguing that the experience of decline and ageing depends on personal, political as well as historical circumstance.⁵⁰ The same is true for how ageing is negatively viewed in Western culture and how ageism is gendered, that is, how old men and women are treated differently within a wider presumption of ageism. Discourses of ageing and gender both influence how individuals with dementia are stereotyped negatively – in the wider societal discourse as well as in cultural productions.

Methodology: Literature and science

The core procedure of my research is to read literature alongside science and medicine in a way that takes into account the emphasis placed by scientific as well as medical research on dementia as being, first, mental, behavioural and psychiatric; second, bodily, organic and biochemical; and third, cognitive and performance-limiting in nature.

I distinguish science from medicine based on how their practices relate to the patient. For the purpose of this study, I take science to denote medical science: an applied discipline, whose 'goals are interventions to produce health'.⁵¹ Medical science research takes place in the laboratory and uses, for instance, tissue samples; in its procedures and approaches it comes close to what Bruno Latour terms 'technoscience'.⁵² It relies on simplified model systems or focuses on individual molecular events. This practice is necessary so that the conclusions drawn can remain objectively true within the methodological framework employed. Where this practice directs understanding that the whole system can be explained by causalities and connections between the individual molecular events investigated, it may become problematic and reductionist. It overlooks that, with each hierarchic level, 'entirely new laws, concepts, and generalizations are necessary, requiring inspiration and creativity to just as great a degree as in the previous one'.⁵³ Such reasoning is especially important where medical science involves the patient, for example, for the collection of imaging data. Here, I see an overlap with medicine. This area of overlap technically concerns the sphere of scientific medicine. It is in this area of overlap that scientific research procedures have been applied to studying, for instance, molecular pathways in the living patient; and from here approaches 'generated by the microperspectives of

biomedicine' make their way into the area of medicine.⁵⁴ My use of the term 'medico-scientific' in this book acknowledges the blurred nature of this area of overlap. But medicine is much more than applied medical science.⁵⁵

I use the term 'medicine' in the context of clinical work, a practice in which the healing of, and the care for, the individual patient is the primary concern. It is in these settings that cognitive assessment takes place, behavioural observations are made and psychiatric research is carried out. Where thinking within the framework of reductionist scientific research procedures filters into such clinical encounters, objectification of the patient may ensue as the practitioner aspires to intervene in the molecular process gone awry – without embracing the further dimensions relevant to any illness experience, including considering the patient as the ultimate authority of and within their condition. What my investigations will not aim for is to describe how knowledge articulated in a single case report becomes part of a body of scientific learning. The process of experimental work itself and how research results become part or not of a specialist journal publication is not my focus. Nor am I primarily interested in what Bruno Latour termed 'the disorderly mixture revealed by science in action' in relation to Alzheimer's disease.⁵⁶

Popular science contributes to the public understanding of what is going on inside research laboratories. But especially where popular science is concerned with medical science, it is a genre prone to blurring medical science, scientific medicine and clinical and healthcare practice, for example, by telling its story through the prism of medical cases. Although not always possible, my intention is to separate these entities, which is reflected in my choice of primary research materials, as I will read scientific research papers and popular scientific publications side by side. The research papers included relate to core scientific questions and medical concepts that were developed during the long twentieth century. I specifically address the central early papers related to Alzheimer's disease, between 1907 and the 1960s (Chapters 2 and 3), and discuss the seminal publications appearing in the high-impact journals *Science* and *Nature* once research picked up from the 1980s onwards (Chapter 5). From the 1990s onwards, biomedical research accelerated with the number and diversity of scientific journals drastically increasing and publication in high-impact journals becoming more and more competitive. For covering the final three decades (Chapters 6 and 7), I therefore choose representative research articles, whose citation frequency is suggestive of their scientific relevance as much as the impact factor of the journal in which they appeared. My reading of the medico-scientific literature, lay press and popular science texts will attend to the

figurative language used in the context of patients and illness. But it also includes the language related to biomolecular and cellular events as well as behavioural and psychiatric symptoms and descriptions.

Scientific specialization since the 1950s does complicate this procedure. Ever more compartmentalized expert knowledge and professional language have made biomedical research nearly inaccessible to the general reader. My analysis puts these publications not only into their historical but also their scientific context. But such scientific contextualization is not intended as a running commentary on recent research projects or an assessment of state-of-the-art treatment strategies. Similarly, popular scientific texts cannot serve as a more easily accessible substitute for primary scientific papers. I use popular scientific outputs as primary research materials in themselves rather than as an objective source of information on scientific findings, because the selective emphasis of popular scientific texts reflects fascination with particular methodologies or insights symptomatic of a specific cultural context. I have made every attempt to explain scientific ideas in generally accessible ways in the running text, without introducing new metaphorical concepts. For clarity, I follow the abbreviations used in each research paper, but since these abbreviations vary from paper to paper, I do not employ abbreviated terminology throughout the running text; I also offer lay definitions of current medical and scientific understandings in the glossary at the end of this book, although these definitions cannot be free of the metaphorical understandings that this study aims to investigate.

Metaphoric language is key to this study. Metaphors are, as Andrew S. Reynolds puts it so well, 'a central element of the scientific process, every bit as important as the material instruments and microscopes with which [scientists] investigate and create understanding of the world'.⁵⁷ But they also represent a challenge to interdisciplinary conversation.⁵⁸ I employ the relevant terms as they are used in each context: metaphoric or non-metaphoric. More generally, I take images and metaphors as 'rhetorical tools in the construction of a public meaning', but also as 'intermediaries, establishing a link between nature and society, science and culture, reality and representation'.⁵⁹ I want to understand why specific images related to Alzheimer's disease are so persistent, and why certain research concepts maintain a dominant position in both the medical sciences and health humanities, at the expense of the patient's individuality and personhood. Nearly all the contributions on patient life-writing published to date concentrate on how these accounts capture changing notions of selfhood and identity.⁶⁰

This means that I am not invested in drawing ‘arrows of influence’, as G. S. Rousseau would have it.⁶¹ With the exception of a few cases of recent life-writing, I do not claim their authors were directly engaged with Alzheimer’s disease research. Rather, I take literary texts to be representative examples of certain moods and discourses or phenomena at a given time. I do not contend that literary writing serves as an access point of information about the condition per se, not least since a fictional plot might require ‘a measure of idealization or vilification’ of character or condition.⁶² But I agree with writer and literary critic Stefan Merrill Block, who, with reference to dementia fiction, intimates: ‘I’m left with urgent questions that only fiction can answer: What do those late stages *feel* like? What is it like to lose oneself and still live? Could there be some essential kernel of selfhood that survives until the end? Mid- to late-stage sufferers, lost in their aphasia, can’t explain it to us.’⁶³ Therefore, I ask what models, and perhaps alternatives, fictional accounts develop. More generally, I argue that the fascination with specific narrative themes and strategies coincides with selected research interests or medical concerns, that certain narrative trends have given us the terms in which we have come to understand dementia, consciousness and the mind.

I especially focus on prose, mindful of ‘the essentially *narrative* nature of human consciousness.’⁶⁴ I am interested in how, for example, modernist and postmodernist approaches to consciousness developed ideas of dementia, and what conceptual overlaps there are with wider medico-scientific and sociocultural concerns during specific periods. Like David Herman, I take such approaches to be ‘a window onto changes and innovations in the wider sociocultural context.’⁶⁵ But this is not to say that I exclude either poetry or drama. The latter offers additional perspectives on interactional challenges (to which I return in Chapters 6 and 7); a specific example of the former allows for an analysis of the density of nouns linked to the condition during the initial popularization of Alzheimer’s disease (Chapter 4). I also include film, taking entertainment culture to be a key indicator of broader sociocultural concerns especially since the last third of the twentieth century.

In thinking with different narrative themes and trends, this book relies on close readings across a range of genres, including the family novel, detective fiction and children’s literature, each of them emerging and dominant at different times. Following John Frow, I take genre, albeit dynamic and elastic, as given by three structural dimensions, namely formal organization, rhetorical structure and thematic content.⁶⁶ Genres can change in response to cultural shifts, and, given the possibility for change, I am particularly interested in two

things: which narratives were told at particular times, and how these narratives were conditioned by the genre through which they were told. In addition, I explore how genre predetermines representational expectations and what we learn about shifts in cultural climate and discourse developments where such expectations remain unmet.

Different genres produce (but also delimit) different kinds of representations of clinical encounters, agency and subjectivity, depending on cultural and historical context.⁶⁷ There also is an enormous difference in purpose and tone of life-writing as compared to fiction. This is why I read patient and caregiver life-writing – memoirs, autobiographical accounts and diaries – against contemporary illness narrative theory, which to date has only to a limited extent touched upon cognitive and neurological disorders. I will focus on questions of the different concerns of the patient as compared to those of the carer, and those of the spouse as compared to those of the adult child. But in comparison to my earlier work on life-writing which attended to agency and independence, I particularly concentrate on the author-narrator's emphasis on scientific evidence, treatment strategies and attention to the loss of performance as compared to remaining abilities. Aware that life-writing is limited in how much it can depict the dissolution of the self, I will read these narratives against memory-related concepts of identity, and specifically focus on how representations depend on cultural and historical connotations of memory, cognitive performance and self-sufficiency. Dementia life-writings are limited in number. I expand my reading by including life-writings, *inter alia*, by Huntington's and Parkinson's disease dementia patients and even fictional accounts that centre on them. My premise is that comparing these narratives to those on Alzheimer's disease will help me address how memory-related brain diseases are considered to threaten identity, not least since motor neuron diseases like amyotrophic lateral sclerosis, and Parkinson's disease, by comparison, predominantly feature impaired motor function.

In view of the central role taken by German, French, Italian and British scientific research during the nineteenth century and the first two decades of the twentieth century, to begin with, this study centres on European developments. It will emphasize how a dementia discourse – how the medico-scientific and clinical establishment defined, and terminologically referred to, the condition – developed across Europe. The impact of Alois Alzheimer's research on twentieth-century science and medicine will become clear from including transatlantic research and politics: sociopolitical awareness of ageing and related research into old-age diseases arose much earlier in the United States than in Europe, during

the first decade of the twentieth century.⁶⁸ My literary and cultural consideration therefore echoes this pattern.

The choice of narratives discussed is the fruit of broad reading across British and other European, North American and Australian literatures, and the resulting selection is representative of the key themes of the century-long cultural dementia discourse. I take early-twentieth-century narratives from the British context, while my selection of 1980s and 1990s fiction focuses (though not exclusively) on American and German contexts. I also look at life-writing of the 2000s and take into account the French, Italian and Spanish situation. This approach is complicated by the fact that a country's cultural inheritance produces specific images. But the narratives chosen reflect themes and cultural developments that I have identified in parallel works of other national contexts, and I will position them in relation to primary texts that already have a strong readership.

This approach is supported, for instance, by Raquel Medina's recent work. In an intersectional study of non-mainstream filmic portrayals of dementia, the Spanish scholar reveals how Alzheimer's disease is approached metaphorically to explore issues of gender and ageing across world cinema. In other work, Medina has studied how biomedical discourses of ageing and dementia are negotiated within Spanish documentary; I find largely the same principles of medicalization and politics of memory at work in Dutch fiction (which I read in English translation) and American life-writing. Intergenerational challenges of caregiving feature in Spanish cinema in a way that is comparable to my reading of Italian narratives and German films.⁶⁹ Similarly, dementia caregiver and patient mobilization in France has been identified as echoing the American movement.⁷⁰ By engaging with material from different cultural and national backgrounds within their respective contemporary medico-scientific and sociopolitical contexts, I suggest that cultural concerns about Alzheimer's disease and dementia have varied only in degree, not kind – that today there exists a common global concern about the condition. That said, as my archive suggests, this study focuses on the global North. For the global South, the tale of the meshing of science and culture has not been told in the same depth and detail. In addition, unlike in the global North where 'aging followed industrialization', in Africa, India and other Asian countries the timelines of development, urban migration and improving standards of living (at least for a growing proportion of society) have been compressed together.⁷¹ As such, I would not want to extrapolate my findings indiscriminately to developing nations, although I will point to different conceptualizations of ageing and illness in countries especially of the global South.

As this work seeks to trace cross-cultural discourse developments, I have relied, wherever possible, on original language texts, and offer my own working translations in citations. This approach also avoids reliance on present-day translations of earlier, key scientific papers, because these translations carry the intellectual assumptions of a century-long discourse it is the purpose of this work to examine.

Following the contemporary scientific and/or medical discourse, I employ the term 'dementia' in relation both to a diseased brain and a failing mind, a local pathological entity or a condition related to the whole person. The terms 'Alzheimer's' and 'Alzheimer's disease' are interchangeable, and I adopt 'Alzheimer' (disease) only where original work employs this form. I use the term 'Alzheimer's disease' where the condition is referred to as such in the medico-scientific context; where it relates to an experience; and where the sociocultural or popular discourses employ it, whether as a synecdoche or construct for types of dementia other than Alzheimer's disease, such as vascular dementia, dementia with Lewy bodies, frontal lobe disorder and Parkinson's and Huntington's disease. I prefer the terms 'sufferer' and 'patient' where the individual with dementia is the object created by the scientific, medical, healthcare, popular or societal discourse of the 'healthy'.⁷² I avoid such terminology when exploring the life-affirming presentations of individuals living with dementia and where changes in discourse take place.⁷³ I define the caregiver as the person who writes about the patient, although her or his role might not primarily be to look after the patient.⁷⁴

Overview

This book is divided into four parts. Part I (Chapter 2) provides an account of how the work of clinicians before 1920 changed the definition of dementia from a psychiatric condition to an organic disease, which sanctioned sociocultural perceptions of dementia as a form of degeneration. Part II (Chapters 3 and 4) analyses the dynamics between literary images of the elderly with memory loss and the socio-medical awareness of the ageing population since the 1940s, which eventually led to an exponential increase in research funding for Alzheimer's disease. Part III (Chapters 5 and 6) investigates how, during the 1980s and 1990s, reductionist research methodologies began to be used in scientific medicine, and how this impacted on the objectification of patients and reformulated the illness as one of limited cognitive performance. It also analyses how detective

fiction, while reflecting the period's fascination with cognitive performance, helped to claim back authority for patients. Part IV (Chapter 7) illustrates how recent medico-scientific research has focused on disease prediction and prevention, while concurrent patient advocacy has led to the redrafting of a biopsychosocial approach to patient care. Fiction and life-writing has begun to show a growing sociocultural and healthcare appreciation of the continued personhood of people with dementia. Such literature challenges the concepts of loss and degeneration that continue to dominate socio-economic thinking.

Part I (Chapter 2) explains how the conversation between science, medicine and literature related to dementia first arose in the second half of the nineteenth century when psychology began to take shape as an academic discipline organized around the science of memory. This instigated the systematic neurological study of the dementias at the fin de siècle. The microscopic observations of tissue loss by Alois Alzheimer and other researching clinicians during the first two decades of the twentieth century were taken to corroborate a psychiatric definition of dementia as a form of degeneration. Reflections of this can be found in literary works of the period: the ailment of John Galsworthy's Timothy in *The Forsyte Saga* (1906–21) – one of ageing, decline and loss – is a micro-cultural image of macro-cultural concepts of degeneration at the fin de siècle.

Between the 1910s and 1930s, brain inspection was carried out in younger as compared to old-age patients, who increasingly were all conceived to be in stages of involution. By the 1940s, this way of looking at the brain had narrowed dementia down to a biomolecular process of shrinkage and loss. In *There Were No Windows* (1944), the Irish novelist Norah Hoult explores notions of disorientation in space and time as well as issues of care. The fate of the central character Claire Temple illustrates the growing general awareness of ageing mid-century, and it brings out the link between ageing and memory loss, a societal challenge that by the 1960s would be recognized internationally. Hoult's narrative, like William Faulkner's *The Sound and the Fury* (1929), also explores the uncontrolled intrusion of memory. I take Hoult's inward turn as an example of how modernist mimetic approaches developed during a period marked by post-Freudian psychiatric interest in the patient's illness experience, which became increasingly important to sociological research from the 1950s onwards.

Part II focuses on conceptions of dementia as pertaining to old age. Research interest in ageing and old-age diseases first arose during the first third of the twentieth century, with gerontology and geriatrics established as disciplines by mid-century. Chapter 3 covers the socio-medical studies that followed from these developments. These studies played an important role in the conversation

between science, medicine and literature related to dementia, because by using interviews, their focus was the patient's experience and inner world. But comprehending dementia as a mental condition did not aid the patient: it underwrote a healthcare discourse centred on images of the patient as dependent, passive and failing. This discourse began to take shape in the 1960s. By that time, as I will also explore in Chapter 3, socio-medical concerns about population ageing were reflected in cultural productions which established the elderly as sufferers of memory loss and as a task for care management. One example is British writer Paul Bailey's lonely and isolated old woman Faith Gadny in the short novel *At The Jerusalem* (1967).

In Chapter 4, I show how the first caregiver narratives tended to emphasize caregiver burden, such as American Rosalie Walsh Honel's *Journey with Grandpa* (1988), and perpetuated the idea of the patient as passive, something also seen in public healthcare campaigns. And rather than developing counter-narratives to these representations of dependence, fiction of the 1970s and 1980s propagated the idea that a functional self relies on intact memory and narrative capabilities. As part of a surge of post-war memory discourses, these narratives also enmeshed dementia with notions of extermination and the Holocaust, as in Dutch writer J. Bernlef's *Out of Mind* (1984), laying the ground for Alzheimer's as metonym for all types of memory loss and forgetting and as underwriting pessimism about ageing more generally.

Part III explores the dominance of biomedical research in establishing a shared discourse of dementia as cognitive loss. This dominance can be traced back to the mid-1970s, as sociopolitical awareness of demographic changes pushed Alzheimer's disease into research laboratories. This happened through a sharp increase in funding from the National Institute on Aging, which was founded as an agency of the US Department of Health, Education and Welfare in 1974. In Chapter 5, I attend to salient research papers from the 1980s and 1990s and their neurochemical and genetics focus detached from the patient's experience – which additionally endorsed a healthcare discourse that dehumanized patients. By the end of the 1980s, the scientific rush for cause and cure as well as caregiver-focused healthcare campaigns induced readers to overlook the patient's plight in a growing literary marketplace for caregiver accounts that told of the patient's social death. Literary scholarship played its part in this discourse. This was the case, because, until recently, the Oxford don John Bayley's account about his wife Iris Murdoch from 1998 has dominated literary studies about dementia. In this account, Murdoch's previously fulfilled and youthful life is shown as destroyed by dementia.

A growing fascination with intellectual performance and healthy cognitive ageing towards the end of the twentieth century further demoted the standing of the patient, as I explore in Chapter 6. In exchange with a growing cultural interest in the visual, both imaging studies of atrophying brains and pharmaceutical efforts to achieve cognitive enhancement additionally stressed the patient's losses, also furthered by popular scientific accounts, like neurogeneticist Rudolph E. Tanzi's *Decoding Darkness* (2000). Yet, despite this century-long conceptual adversity, the patient finally began to be credited with authority towards the turn of the twenty-first century. As I also bring out in Chapter 6, the fascination with cognition, together with many other elements that contributed to this conversation between science, medicine and literature since the 1970s, eventually supported the releasing of the patient from being typecast so negatively. Linguists studied the patient narrative; and patients began to hold centre stage in popular detective novels, such as British crime novelist Michael Dibdin's satirical *The Dying of the Light* (1993), and eventually contributed to the conversation through their own writing and institutionalized advocacy.

The final part of this study (Chapter 7) covers discourse developments since the turn of the century. Immunological approaches to Alzheimer's disease introduced notions of flexibility and spontaneity into the medico-scientific writing about the condition. These scientific ideas strengthened budding cultural concepts of the patient as active and resistant. Disappointing drug trial outcomes related to these immunological approaches, however, left patients all the more vulnerable, pushing them back into a position of passive objects of pity waiting for a cure. Given that enterprise societies assume cure to be superior to care, with access to care frequently being conditioned on a formal diagnosis, the dementia patient inevitably takes on victim status in these societies. As such, appreciation of the patient's individuality appears to be tragically short-lived in today's prosperous societies. Such societies don't have space or place for the ageing and cognitively challenged; and, paradoxically, as patients finally took measures to assert their continued agency, their condition became the object of economic interests. The market made them cardboard figures yet again. Since the turn of the century, the condition has dominated bestseller lists and made for controversial hit movies like German director Til Schweiger's *Honig im Kopf* (2014). But it is not only a market for accounts of dementia that has arisen; there is also a market of people afflicted by dementia, and their condition guarantees the profit of the cognitive health industry. At present, patient individuality remains confined to niche children's books, like Italian primary school teacher Alessandro Borio's *La guardiana di Ulisse* (2006), and caregiver

texts like French psychologist Cécile Huguenin's *Alzheimer mon amour* (2011). Such depictions challenge the concepts of degeneration, decline and loss that continue to dominate socio-economic thinking in rich societies, as my reading of Matthew Thomas's *We Are Not Ourselves* (2014) in the final section of this book will bring out.

Over the long twentieth century, two approaches to understanding and representing dementia have crystallized: on the one hand, as a disease of the brain, and on the other hand, as a condition of the mind. Both evolved in parallel, not always in tension, and intertwined with literary representations; and both perpetuated notions of the patient as elderly and in decline – with far-reaching consequences for how, today, Alzheimer's disease signifies the synthesis of illness, ageing and dying. Literary explorations have developed important counterweights to a more fatalistic view of Alzheimer's disease as a condition that strips patients of their humanity. But contrary to the often invoked dualism between the psycho-sciences and the neurosciences, understanding the condition as an illness of the mind did not aid the patient. It underwrote images of dependence, dispossession and failure, and this conditioned a remarkable characteristic of literary writing about Alzheimer's disease: compassion focused on the caregiver rather than the sufferer. This prepared the ground for how today dementia is the most prominent condition for representing the burden of care, the passivity of the patient and the death of the self. I begin this study with an early and perceptive literary representation of dementia as a form of material and social dispossession in old age, as living death.