

AAGJE SWINNEN,
MARK SCHWEDA (EDS.)

POPULARIZING DEMENTIA

PUBLIC EXPRESSIONS
AND REPRESENTATIONS
OF FORGETFULNESS

From:

Aagje Swinnen, Mark Schweda (eds.)

Popularizing Dementia

Public Expressions and Representations of Forgetfulness

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How are individual and social ideas of late-onset dementia shaped and negotiated in film, literature, the arts, and the media? And how can the symbolic forms provided by popular culture be adopted and transformed by those affected in order to express their own perspectives? This international and interdisciplinary volume summarizes central current research trends and opens new theoretical and empirical perspectives on dementia in popular culture. It includes contributions by internationally renowned scholars from the humanities, social and cultural gerontology, age(ing) studies, cultural studies, philosophy, and bioethics.

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Popularizing dementia

Public expressions and representations of forgetfulness

AAGJE SWINNEN & MARK SCHWEDA

Owing to aging populations, the transformation of national welfare systems, and advances in biomedical research and diagnostics, late onset dementia is shifting to the center of current debates in bioethics, in social policy, and among the broader public. In these contexts, the condition does not just constitute a target of intensive neuro-scientific research and biomedical treatment approaches. It is, at the same time, experienced as a personal fate, negotiated as a challenge to established relationships and family ties, and discussed as a major problem for policy makers and society at large. Political statements and public campaigns postulate that “dementia poses one of the greatest societal challenges for the 21st century” (WHO 2012: 90), address Alzheimer’s disease as the “21st century plague” (Smyth 2013), or even declare a “war on Alzheimer’s” (for a critical analysis, cf. George and Whitehouse 2014). Countering such negative imagery and alarmist rhetoric, an increasing number of patient organizations, political initiatives, and academic approaches also advocate different understandings of dementia and a more open, inclusive, and accepting attitude towards those affected. Thus, many self-help groups are oriented toward the reality of ‘living with dementia’ and promote the creation of dementia-friendly environments and communities. Summarizing these kinds of endeavors, Alzheimer Europe hosted its 2013 conference under the banner of “living well in a dementia-friendly society.”

THE ‘DEMENTIA BOOM’

One effect of this development could be labeled as a cultural ‘dementia boom’: The concept of dementia is no longer limited to expert biomedical discourses, but gets integrated into public imagination and popular culture. That way, it also gains multiple new interpretations, evaluations, and functions in a variety of cultural domains, social spheres, and national contexts. ‘Dementia’ shows different qualities and appearances in film, literature, or art with their respective traditions, formal conventions, and aesthetics. It is also perceived and experienced differently in the political, economic, and socio-cultural contexts of countries such as Germany, India, or the United States, with their specific health care systems, political cultures, and legal frameworks (Williams, Higgs, and Katz 2012; Holstein 2000; Cohen 2000). Finally, being personally affected is believed to constitute a radically different perspective, one that may provide new contributions to popular culture, but also poses fundamental challenges with regard to its translation into common semantic idioms and conventional symbolic forms and orders (Gubrium 2000).

This volume is dedicated to the expressions and representations of dementia in contemporary popular culture. Its overall conception is aimed at summarizing and systematizing current research trends in the field of dementia studies. With the specific combination of humanistic, (bio-)ethical and socio-cultural approaches, we hope to provide insight into the state of the art and to promote theoretically and methodologically innovative perspectives. The central topic is approached from different angles: On the one hand, contributions investigate how individual and social ideas and images of dementia are – and should be – shaped and negotiated in film, literature, arts, and the mass media, thereby examining the range of cultural manifestations of dementia, their underlying formative factors, and their broader societal significance. On the other hand, the volume also explores how the symbolic forms provided by popular culture are – and can be – adopted and transformed by those affected in order to express and communicate their own perspectives and experiences. *Popularizing dementia* thus illuminates the scope and ambivalence of popular culture: its tendencies to reproduce and enforce reduced, distorted, or ethically problematic images and stereotypes that obscure or repress other viewpoints, but also its potential to initiate alternative and critical counter-discourses as well as to express a fuller range of perspectives on dementia.

NEW PERSPECTIVES ON DEMENTIA

Contrasting the dominance of naturalistic, neurobiological and biomedical discourses, dementia studies aims at a better understanding of dementia as a *cultural* phenomenon. In the Western context, the condition is increasingly used as a metaphor for the aging process itself as a stage in the human experience that needs to be fought by all means (cf. Zeilig 2013; Leibing and Cohen 2006). Understanding the multiple ways by which dementia, while biologically influenced, is at the same time culturally constructed contributes to the fight against stigma and can improve the wellbeing of people with dementia and their caregivers. In this sense, dementia studies has a normative dimension.

The so-called personhood movement in dementia studies (Leibing 2006: 242) was the first to draw attention to the ethical implications of positioning dementia as a disease of the brain and, consequently, its sufferers as ‘lost selves.’ It attempted to bring alternative philosophical models of personhood to the fore in order to stress that persons are more than their brains, that personal identity does not rest only on mental continuity, and that the story of dementia exceeds that of tragic loss and decline. Two such models have proven to be particularly influential in countering the dominant perspective that designates the mind as the locus of the person: the notion of embodied personhood and the concept of relational selfhood. Both have been instrumental in correcting overly individualistic and rationalistic understandings of the human condition and in challenging the value system of our ‘hypercognitive society’ (Post 2000). Over the years, the theoretical investment in these models has also increasingly and successfully been connected to the more empirical study of dementia care and dementia experiences. The model of embodied personhood, for instance, originating from the phenomenological writings of Merleau-Ponty, has been instructive for ethnographic research into how people with dementia can maintain their personal identity and productively engage in activities by relying on embodied memory rather than on cognitive capabilities (e.g., Kontos 2005; Moser 2010). The model of the relational self has been used for the reconceptualization of individual autonomy and the systematic assessment of institutional care practices, e.g., Kitwood’s (1997) approach to malignant versus personhood-upholding interferences, which has developed into the certified method Dementia Care Mapping, currently implemented in several countries.

These theoretical models continue to help build new bridges among different disciplines that have gained interest in dementia. Thus, science and technology studies now examines how technologies for frail elderly including people with dementia – still often designed without consulting the people the technology is meant for or evaluating their real care needs – interact with people with dementia and their caregivers (cf. Kamphof in this volume). The call for more dementia-friendly communities can take its cue from disability studies, which has longstanding expertise in and experience with both fighting negative stereotypes of disabilities and developing strategies for the inclusion and participation of people with disabilities. Also methodologically, disability studies can be inspiring in terms of how to ‘listen’ to the ‘voice’ of people with dementia by implementing approaches such as participant observation and photo voice. The study of dementia representations has scrutinized the incompatibility of traditional narrative forms with the account of dementia experiences (cf. Krüger-Fürhoff and Kruger in this volume), but also moves towards the analysis of care relations portrayed within novels and films as well as of affective components of ‘being in relations’ (cf. Burke, Wearing, and Folkmarson Käll in this volume). Creative arts interventions are called upon as a special type of person-centered care and have emerged as systematic and well-described approaches to care. Humanities and arts scholars (cf. Selberg in this volume) are increasingly getting involved in the study of these practices.

As its core ideas receive wide recognition and successful adoption in medical anthropology, gerontology, health care studies, aging and disability studies, science and technology studies, as well as media studies, the personhood movement seems to enter into a more self-reflective and self-critical stage. Scholars begin to take stock of what has been achieved so far and what new challenges lie ahead. Problematic aspects and applications of art interventions (cf. Selberg in this volume) or reminiscence therapy (cf. Bendien in this volume) are addressed and critically discussed. Moreover, the still-problematic ontological basis of current understandings of dementia and person-centered care is scrutinized (cf. Commisso in this volume). At the same time, the neuroscientific approach to dementia is redefining its position as well, modifying and complicating previous understandings of the condition. While consensus about the causes, diagnosis, and treatment of dementia is still not within reach despite enormous financial investments, new trends such as early detection (via genetic testing or imaging)

and prevention (cf. Leibing and Cuijpers and van Lente in this volume) are redirecting the priorities of research, medical practice, and the pharmaceutical industry. More recent categories such as ‘mild cognitive impairment’ complicate the picture and pose new theoretical and ethical challenges (Schick Tanz et al. 2014). With each new category of people who do not conform to dominant norms of being human, frequently backed-up and naturalized by allegedly objective scientific facts, it becomes more important to substantiate what it means to recognize those affected as persons: socially in terms of social participation (cf. Hautz, Iltanen, and Inthorn and Inthorn in this volume), culturally in terms of the production of meaning (cf. Kruger, Nizzi, and Capstick, Chatwin, and Ludwin in this volume), and politically in terms of citizenship (cf. Burke and Goldman in this volume).

THE CONTRIBUTIONS

One way or another, all contributions in this volume are concerned with the theoretical and critical implications of the popularization of dementia: How does it change public and professional perceptions of ‘(un-)healthy’ aging? Where does popular culture promote a de-medicalization of dementia and initiate critical counter-discourses that help to express a fuller range of perspectives? Where does it just reproduce and reinforce reduced, distorted or otherwise problematic stereotypes that obscure other viewpoints? What influence do different national cultures, health care systems, and socio-political traditions have on the ways dementia is culturally framed? And how can the perspectives of people with dementia be recognized and communicated in popular culture? These and other questions are discussed in 17 chapters divided into three main parts according to the respective fields of popular culture under investigation: literary fiction; artistic approaches, design, and film; as well as media discourses and public understandings.

The first part comprises analyses of dementia in contemporary literary texts. They offer insights into a variety of methodological approaches (i.e., affect theory, imagology, genre studies, and narratology) to different national literary traditions. At the same time, certain recurrent topics and tendencies emerge, especially regarding the cultural significance of literary portrayals of dementia as well as the aesthetic possibilities and limitations of narrative approaches to the subjective experiences of people with dementia and their relatives.

In her essay “The locus of our dis-ease,” Lucy Burke examines narratives of family life in the age of Alzheimer’s. Against the backdrop of recent British policy debates, she provides a close reading of Margaret Forster’s *Have the Men Had Enough?* (1989), exploring the conjunction between contemporary Alzheimer’s culture and the ideological discourses of neoliberal capitalism. Burke pays particular attention to the ways in which this conjunction produces new, often fraught reflections upon the meaning of family relations as well as tensions between care for the self and care for others. This interest in the way dementia fosters the reconfiguration of familial obligation and care also characterizes Sadie Wearing’s contribution, “Deconstructing the American family,” in which she compares the portrayal of parental figures with dementia in Jonathan Franzen’s *The Corrections* (2011) and A.M. Homes’s *May We Be Forgiven* (2012). Wearing focuses on the often neglected symbolic role that the characters of the parents with dementia play in these novels that offer contrasting accounts of the disintegration and remolding of the suburban family. She discusses their wider implications for considerations of the dynamics, aesthetics, and affects associated with dementia in contemporary culture. The analysis of the two US-American case studies is followed by Marlene Goldman’s close readings of three Canadian novels, Sheila Watson’s *The Double Hook* (1959), Michael Ignatieff’s *Scar Tissue* (1993), and David Chariandy’s *Soucouyant* (2007) in “Purging the world of the Whore and the horror.” In Goldman’s interpretation, the texts under consideration rely on portrayals of old age and age-related dementia to identify and symbolically expel what the contemporary Canadian nation-state still deems ‘evil.’ They do so by relying on tropes that are characteristic of the Gothic tradition in the Canadian novel and that heavily intersect with the identity categories age, gender, and ethnicity. Irmela Krüger-Fürhoff’s essay “Narrating the limits of narration” examines narrations of Alzheimer’s disease in Jonathan Franzen’s short story “My Father’s Brain” (2001), Arno Geiger’s novel *Der alte König in seinem Exil* (2011), the autobiography *Losing My Mind: An Intimate Look at Life with Alzheimer’s* (2002) by Thomas DeBaggio, and J. Bernlef’s novel *Hersenschimmen* (1984). Against the background of the central role of narrativity in Western Culture, she examines how these texts explore the tension between narrative selves and their looming post-narrative conditions, thereby distinguishing different genres of Alzheimer’s stories. As Krüger-Fürhoff argues, these genres stand for diverging ways of

narrating the limits of narration that Alzheimer's disease entails. Her comparative analysis is paired with the essay "'The terrifying question mark'" by the fiction writer Naomi Kruger. The piece explores the aesthetic possibilities and limits of creative writing by testifying to the struggle to evoke a literary character with dementia without reiterating doom scenarios and projecting agony onto both persons with dementia and their caregivers. Kruger weaves the story of a fictional character with dementia, parts of a fictional manual for 'writers of dementia,' and self-reflexive comments on the writing process into a multilayered collage. The aim is to suggest that fictional narratives may enable us to become more aware of our fears and expectations as well as that they could allow us to revisit the way we view people living with the condition.

The volume's second part comprises analyses of expressions and representations of dementia in artistic approaches to dementia care, design, and film. The contributions explore a whole range of different fields of artistic production and its aesthetic reception, from avant-garde painting over clothing design to box-office mainstream cinema. They discuss the didactic or therapeutic potential of visual and applied arts in the context of dementia, and also investigate their broader socio-cultural framing and function.

In his chapter "Dementia on the canvas," Scott Selberg points out new approaches to creativity and Alzheimer's, recognizing the need to celebrate the value of art interventions while moving toward a more complex account of their place in representational culture. By examining the cases of William Utermohlen and Willem de Kooning, both artists famous for the art they made when living with Alzheimer's, Selberg shows how presumed connections between art and dementia, as well as between the work and the personhood of the artist, influence the way the art is received and framed in the museum context. Elena Bendien's contribution "Cultural projections of dementia in the Reminiscence Museum" sets out to show how the extrapolation of the prevailing cultural image of dementia towards the entire older generation can change our attitudes and actions in practical settings where older people with and without dementia live. The piece is based on ethnographic research conducted in the residential care facility of the Humanitas Foundation in Rotterdam which has set up a Reminiscence Museum to create an environment for older people to remember their past. Bendien describes how older people interact with the familiar domestic environment

from the past and how this interaction can affect and fine-tune our perception of what can be called a dignified life with dementia. In “Opening minds through Art,” Oliver Hautz examines how students who participated in a creative arts project for people with dementia in the Midwestern United States constructed the artists they were interacting with as persons. Following the approach of Interpretative Phenomenological Analysis, his study supports claims about the benefits of interactions between people with and without dementia through service learning projects for students, volunteer opportunities for non-students, or simply through collaborative projects. Sonja Iltanen’s essay, “Dementia materialized in clothing Design,” turns to a different field of popular culture: the social construction and materialization of dementia in the design of dress. By analyzing garments specifically made for people with dementia in Finland as well as interviews with their designers, Iltanen makes clear that clothing design has the potential to enhance the functionality of the person with dementia, but can also include elements that are stigmatizing or even restrain agency. The study raises important questions on the ethical implications of design and shows an urgent need to work towards change in its development and marketing. In their chapter “Challenging representations of dementia in contemporary Western fiction film,” Andrea Capstick, John Chatwin, and Katherine Ludwin address the epistemic injustice of dementia representations in box office films such as *Iris* (2001) and *The Notebook* (2004), as well as in TV dramas such as *Boss* (2011) and *Frankie* (2013). In an attempt to move away from this epistemic injustice, in Capstick et al.’s collaborative documentary film project, *Bay Tree Voices* (2012), people with dementia emerge as knowledgeable and creative commentators, not only on the experience of dementia, but on a range of subjects including social history, moral values, and practicalities of everyday life. Contrasting this critique of mainstream film, Lisa Folkmarson Käll turns to cinematic portrayals of dementia as a way of reflecting ethical relations and decision-making in “Intercorporeal Relations and Ethical Perception.” Examining *Away from Her* (2006) and *En sång för Martin* (2001), she illustrates how alterations of self and self-experience in dementia are embodied and intercorporeal and cannot be understood in simple terms of diminishment or loss. While the two films differ in their portrayal of dementia, both show how embodiment and intercorporeality affect relations between persons with dementia and their relatives.

The volume's third part comprises contributions that investigate the images and understandings of dementia in the media and among the general public. They cover a whole range of different media discourses and areas, from newspapers and magazines to popular science journals and internet platforms. A recurring topic is the ambivalent role of new technologies, such as assistive robotics or monitoring systems, in the domestic sphere and care setting, as well as the uptake and negotiation of scientific and professional expert conceptions of dementia among the general public.

Annette Leibing's essay "Dementia in the making" explores the first manifestations of a 'new dementia' found in popular culture. Publications for the general public as well as advertisements are analyzed to trace two major shifts: a new focus on physical, behavioral, and psychological aspects of dementia, which is transcending its former definition as a merely cognitive disorder, as well as a strong movement in favor of early detection and prevention. Leibing discusses in how far these trends change the way individuals with dementia are perceived and perceive themselves. In their article "The framing of early diagnostic instruments for Alzheimer's disease in Dutch newspapers," Yvonne Cuijpers and Harro van Lente examine the meaning of early diagnostics by considering their framing in recent newspaper articles in the Netherlands. According to their analysis, the way in which early diagnostic instruments are provided with meaning through different framings matters. Many frames present early diagnostics as part of a bigger problem or a higher goal, thus giving it a specific meaning and legitimacy. In a similar vein, the contribution of Sanna and Julia Inthorn, "A different way of talking about dementia," examines the discussion of dementia in three British magazines. The article combines perspectives from medical ethics and media studies, exploring to what extent magazines have the potential to show the personal experience of those living with dementia, to suggest their autonomy, and to connect readers on an emotional level with the interests of people with dementia. In her paper "Representations of Alzheimer's disease among Non-Specialists," Marie-Christine Nizzi presents results from a survey in Paris and Boston. She investigates how representations of Alzheimer's vary between different cultural contexts and as a function of nationality, gender, age, and personal contact with people with dementia. The author suggests that the representation of Alzheimer's evolves along the lifespan, with younger respondents being more receptive to information campaigns via the media and older respondents

more in touch with a personal experience of aging via their own parents and relatives. In her article “In the company of robots,” Ike Kamphof traces the reiteration of malignant mechanisms and the potential for new, creative views on people with dementia in the context of assistive robotics. Employing a postphenomenological perspective on the ways technology and human beings shape each other, she explores the potentials and dangers of this emerging technology. Comparing public debates on assistive robotics with the vision developed in the film *Robot and Frank*, she argues that the latter can be read as an ironic commentary on and productive overcoming of recurrent stereotypes in the public discourse. In her essay “The zero-degree of dementia,” Elana Commisso discusses new approaches to re-thinking the subject and ontological basis of dementia. Traditionally, dementia and the experiences of persons with dementia have been conceptualized either from materialist/empirical (neurobiological) or idealist/socio-symbolic (transcendental, phenomenological, or semiotic) theoretical perspectives. Commisso argues that contemporary dialectical-materialist theories of subjectivity formulated by Catherine Malabou, Adrian Johnston, and Slavoj Žižek can offer new directions for rethinking and reconciling the dominant biomedical and social science discourses dedicated to thinking about and/or representing dementia.

The idea for this volume first took shape at the workshop Bioethics and Sciences of Aging: The Case of Dementia in October 2012 at University of California, Berkeley’s Center for Science, Technology, Medicine, & Society. There the two editors – an aging studies scholar and a philosopher and bioethicist – first met and exchanged views on public expressions and representations of forgetfulness. A lot has happened in the meantime. Today, probably more than ever before, the topic of dementia engages political agendas, popular media, and public discourses around the world. Demographic disasters have been predicted, national dementia strategies have been devised, battles and whole wars have been declared, hopes and hypes have come and gone, as the struggle for understanding and recognition of those living with the condition continues. We hope this volume can provide both insights into and stimuli to the ongoing debates evolving around dementia in contemporary popular culture.

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