

Dementia becoming popular. Representations of a cultural phenomenon in contemporary fiction, the arts, and mainstream media

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Swinnen, Aagje; Mark Schweda (Hg.): Popularizing dementia. Public expressions and representations of forgetfulness. Bielefeld: transcript, 2015.

Abstract:

Editors Aagje Swinnen and Mark Schweda assemble a variety of expertise from different disciplines, and a range of methods and research designs to critically investigate the representation and the popularization of dementia in literary fiction, the visual arts, and the mass media. The volume sheds light on the communication processes at work and the images of dementia ranging from negative stereotypes to new and alternative discourses. It hints at the crucial and delicate role of mainstream media in the information society – especially when it comes to a phenomenon such as dementia – threatening the agency of those affected. With a very broad scope, this book continues to raise awareness and provides stimuli for research as well as activism.

Over the course of the last 25 years, the view of dementia as a purely medical syndrome has been challenged by a variety of disciplines outside of medicine. At the same time, concepts of dementia have also reached the general public - often enough they have produced fear and shame. Editors Aagje Swinnen and Mark Schweda describe the manifold political, social, and medial re-interpretations of dementia in popular culture as a “cultural ‘dementia boom’” (p.10). The ‘popularization’ of dementia in different media is looked at from different academic perspectives with an accordant variety of methods. “Literary fiction,” the first part of the volume, comprises five articles concerned with the representation of dementia in contemporary litera-

ture from Europe, the US, and Canada. The second section, entitled “Art, Artistic Approaches, and Film,” describes the potential of artistic expression in retaining selfhood in dementia. The third section, “Media Discourses and Public Understandings,” touches on recent perceptions of dementia in popular print media and takes a look ahead. The central questions are: How is dementia portrayed in popular culture? How do these perceptions alter existing images of dementia? And what ethical implications does this have? The young research branch of dementia studies takes (a first) stock.

In the realm of fictional literature, the profound changes that come with a dementia diagnosis for those affected and their caretakers lend themselves well to authors seeking to fathom the humane/human core values. In a political reading of Margaret Forster’s 1989 novel *Have the Men Had Enough?*, Lucy Burke criticizes how care is perceived as an obstacle to both caretakers’ individual development and a threat to family cohesion. Looking at the continued personhood of parent figures with dementia in Jonathan Franzen’s *The Corrections* and A. M. Homes’ *May We Be Forgiven*, Sadie Wearing argues that novels which normalize dementia “as a defining condition of the present” (p. 62) might help to reduce negative stereotyping. In the second part of this section, the aesthetic means, possibilities, and limits of narrating dementia are delineated. Marlene Goldman traces both the use and the emergent overthrowing of Gothic and apocalyptic language in Canadian dementia fiction. The writer Naomi Kruger highlights the “imaginative possibilities” (p. 110) of fictional literature concerning the allegedly ‘untellable.’ In contrast, Irmela Marei Krüger-Fürhoff criticizes how the fictional approaches to date have not tapped the full pallet of affected subjectivity.

The second section holds analyses ranging from the representation of dementia in contemporary film to the materialization of dementia in clothing design. The critique of dementia portrayal and the marginalization of those affected sometimes becomes productive in arts-based interventions for people with dementia. Andrea Capstick, John Chatwin, and Katherine Ludwin, for example, not only convincingly theorize this “epistemic injustice” imposed on people with dementia (p. 229) in cinema, but endeavor to find a remedy by collaborating with them on making their own film. Elena Bendien explores the possibilities of reminiscing through familiar objects in a museum, Oliver R. Hautz reports the positive effects of joint artwork on both people with dementia and students. Despite achievements, the tenor remains cautious: Art interventions, regardless of their beneficial character, need methodical assessment. Much in the same vein, Scott Selberg’s insightful article hails creativity, which those affected retain, as “a mode of social collaboration and play” (p.157) which they are often denied. As he deduces from the exhibitions of two painters with Alzheimer’s, Willem de Kooning and the lesser-known William Utermohlen, however, the relations between art and the condition are complex, and more research is needed.

In the third section, Annette Leibing retraces the development of dementia's new image in recent media coverage from an irreversible, desperate disease of the brain to a general health condition of old age – prevention and early detection thus become more important (p.284). This observation is shared by Yvonne Cuijpers and Harro van Lente in their framing analysis of Dutch newspapers. They detected various “interpretative packages” (p.308) making up a “cultural repertoire” (ibid.), a diversified understanding of dementia, moving away from the biomedical model towards a multi-layered phenomenon. The cross-cultural approach taken by Marie-Christine Nizzi further widens the picture. She shows that different cultural contexts, along with categories such as gender, age, and the degree of personal involvement, account for immense differences in people's image of dementia. The three analyses indicate that a new, more diverse thinking about dementia seems to be on the way. Innovations/Changes in (the focus of) medical research such as early detection endeavors bring up new, challenging questions for the non-medical study of dementia (in the realm of the humanities), some of which are astutely and with justifiable criticism posed here (p.289).

With a 400-page tome such as this, an overarching thesis at first is hard to find – even more so as there is no concluding chapter. Instead, many of the articles feature extensive lists of questions. This absence might hint to the fact that it would be too early for the young field of dementia studies to jump to hasty conclusions. The editors have not put up with the difficult task of defining popular culture. One could say “Popularizing dementia” assembles a multidisciplinary, multi-methodological, all-encompassing patchwork of concepts and ideas.

Its backbone is its political program. All articles criticize the way dementia has been and is often still/currently dealt with in popular culture: ruminating doom scenarios stigmatizing those affected, and thus wasting its potential to establish alternative forms of representation. Almost all the articles call for change: for more research, for the critical assessment of interventions, for inclusion of the people affected, for their voice in decision-making processes, and for collaboration. The question of how they can get involved and use “the symbolic forms provided by popular culture” (p.10) to make themselves heard is, however, only tentatively touched upon.

With its vast scope, “Popularizing dementia” demonstrates that many disciplines can fruitfully contribute to dementia studies. The volume provides pieces of exciting new research on the topic, and will probably spark much follow-up. It looks back into the history of media coverage concerning dementia, it gives an insight into what is happening at the moment, and it raises many reasoned questions for the future. Besides, it not only has a normative aspect to it, but strongly advocates for the rights of people with dementia. This makes it a very useful and productive groundwork for scholars and activists alike.

German Abstract:

Die Popularisierung der Demenz. Repräsentationen eines kulturellen Phänomens in zeitgenössischer fiktionaler Literatur, den bildenden Künsten und den Massenmedien

Die Herausgebenden Aagje Swinnen und Mark Schweda versammeln im vorliegenden Sammelband Expertisen aus verschiedenen Disziplinen, die mit einer Fülle von Fragestellungen und Methoden die Repräsentation und die Popularisierung von Demenz in Literatur, bildender Kunst und den Massenmedien kritisch hinterfragen. Dabei werden sowohl die zugrundeliegenden kommunikativen Prozesse als auch Demenzbilder von negativen Stereotypisierungen bis hin zu neuen, alternativen Diskursen beleuchtet. Der Band verweist auf die bestimmende wie heikle Rolle populärer Medien für die Informationsgesellschaft – gerade im Fall eines die Betroffenen marginalisierenden Phänomens wie Demenz. Dieser reichhaltige Band macht von neuem aufmerksam und gibt sowohl der Forschung als auch politischem Engagement wertvolle Anregungen.

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Zitationsempfehlung

Christ, Susanne K.: „Dementia becoming popular. Representations of a cultural phenomenon in contemporary fiction, the arts, and mainstream media [Review on: Swinnen, Aagje; Mark Schweda (Hg.): Popularizing dementia. Public expressions and representations of forgetfulness. Bielefeld: transcript, 2015.]“. In: KULT_online 46 (2016).

><http://kult-online.uni-giessen.de/archiv/2016/ausgabe-46/rezensionen/dementia-becoming-popular-representations-of-a-cultural-phenomenon-in-contemporary-fiction-the-arts-and-mainstream-media><

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