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Introduction: Alzheimer's disease as a gendered affliction – masculinities between dementia ventriloquism and symptomatic readings

Heike Hartung and Rüdiger Kunow

1. Alzheimer's disease and critical sociocultural constructions of old age

Dementia, and more particularly 'senile dementia of the Alzheimer's type' (American Psychiatric Association 2013), is not only a grim presence haunting senior residences and geriatric care wards, it has in many countries all over the world become part of the public conversation about diseases, care, and the prospects and challenges of late life. Since the 1990s, and thus incidentally the same time as HIV-AIDS, dementia has even become a pervasive cultural idiom and more specifically, dementia and its most visible variant, Alzheimer's, a.k.a. 'AD', has established itself as a descriptive shorthand for the condition of being 'old'.

Cognitive impairments can have many different causes and take on many different forms. *The Diagnostic and Statistical Manual* (DSM) of the American Psychiatric Association offers an evidence-based overview and a detailed description of the various neurocognitive disorders known to the medical profession. Since the present volume is interested less in the medical etiology of these disorders than in their cultural resonances, a certain generalization in terminology is possible, even called for. Hence, we will reiterate in our arguments the prevalence given to Alzheimer's disease as a suitable umbrella term while recognizing that other related disorders exist.

AD is a serious condition of the body, more especially of the mind, but at the same time it is a site of resistance. The etiology of Alzheimer's disease, like that of other forms of dementia, mounts serious challenges to normative concepts of the self which are crucial elements of the cultural history of the West. The losses of speech, memory, mobility, of control over bodily functions run counter to, in fact openly challenge, Enlightenment concepts of the self and its celebration of independent self-fashioning. At the same time, these neurocognitive disorders present multiple forms of resistance to our communicative, everyday routines in social interaction. AD patients behave in ways that other people may find erratic, because they run counter to what may be expected of 'normal' people and this seeming intransigence then adds to or reinforces the social and cultural marginalization of these patients.

While the social and cultural spaces of Alzheimer's are thus often tenuous, even troubled, the temporal coordinates of the disease seem stable, even obvious. AD is a disease of ageing. Old age, however understood specifically, has never been the most popular period of the life course, and the various forms of cognitive impairment occurring later on in life clearly feed into this dark vision. In other words, existing general fears of ageing have been superseded by fears of getting or being 'demented' in old age. Researchers are even speaking of an "Alzheimerization" of ageing' as an expectation of inevitable latest-life decline (Gilleard and Higgs 2000, 40). AD has in this sense become a widely shared historically new dystopia of the life course. In this 'Alzheimer's-obsessed era' (Gullette 2011, 169), the public conversation about AD is of course vast and varied. Aagje Swinnen and Mark Schweda are even speaking of a 'Dementia Boom' (2015, 10): the exponential growth of public and private representations. A Google search for 'dementia' yields 97 million hits, while 'dementia stories' produces a whopping 176 million. Representations of AD are a motley crew: that can occur in formal, expert contexts as well as in informal, mundane ones. They can take oral or written form, in traditional media as well as in the new digital ones. The proliferation of AD in a variety of media such as memoirs and blogs, expert papers, personal accounts, film and literary genres has nevertheless exhibited a remarkable concurrence in themes, images and stories told about the disease. This frequently takes the form of a *Bildungsroman* in reverse, recording the progressive un-learning of abilities and knowledge as the illness unfolds. These losses and the ways in

which they present challenges to patients and caregivers, together with the question of how these losses and challenges approach the limits of representation and question traditional views of selfhood and human development have been explored from the various perspectives in different cultural contexts and practices. They focus on: literature (Maginess 2018; Falcus and Sako 2019; Hartung 2016), film (Medina 2018), life writing (Zimmermann 2017; Kunow 2015, 2019) and a combination of these cultural representations and discourses (Swinnen and Schweda 2015; Bitenc 2020; Leibing and Schicktanz 2020).

Drawing on this wealth of cultural critiques of dementia, we focus in this volume on Alzheimer's disease as a deeply gendered affliction. Whereas older women have been more in the focus of Age Studies because of the even more punitive cultural constructions of female old age, in general, male patients and male caregiving in the context of AD still has to be explored in its cultural repercussions. To address this blank spot in previous research, the focus chosen in this volume on the specifics of dementia as a disease of ageing masculinities aims at an analysis of the gendered difference in relation to the syndrome. Furthermore, specific aspects of male identity construction in the context of mental illness will be explored. From the perspective of cultural critique (to which we will return at the end of this introduction), dementia, like other biomedical pathologies, can perhaps best be understood as a figure of interruption: resisting normative constructions of the human self and its wonted range of behaviour. AD intrudes into the most 'normal' everyday routines and makes life in its wonted ways impossible; it intrudes into the fabric of relations between self and others, 'virtual' and physical reality, and in communication it interrupts the flow between linguistic signs and their signified.

Clinical data suggest that, as the disease progresses, dementia patients increasingly encounter considerable difficulties in matching the ideas in their mind with the conventional means of expression (Meteyard and Patterson 2009). The progressive loss of communication and comprehension skills manifests itself in a shrinking of vocabulary (dyslexia), losing one's place while reading, and poor comprehension of what is being read. Oftentimes, patients still know words but cannot connect them in ways to form comprehensible sentences, as in this recorded exchange:

Elinor How are you, Mother?

Lil Oh, in a fast muff, getting out of the wet ditches.

Elinor Wet ditches, well, that's interesting.

Lil Oh, I'm in a dedeford, they're, they're having a beurz. I mean, they're having a cressit. And would be considered hijardi. Would be picking dependent stuff. I mean they're showing up prepaes and other things.

Elinor That's good.

Fuchs 2005, n.p.

This passage from Elinor Fuchs's memoir of her mother's dementia, *Making an Exit* (2005), also foregrounds the performative function of language in AD discourses: as a successful business woman, Fuchs's mother Lilian Kessler was used to giving speeches in public. At a stage when most of her former capabilities are no longer available, she still goes through the routines of a speech in a small circle of relatives who encourage her emotional success in such a performance. In a kind of dramatic monologue, she gives a nonsensical speech reminiscent of Samuel Beckett's modernist minimalism, as Fuchs points out: 'Meanwhile, as Beckett would say, that wasn't "such a bad little canter"' (Fuchs 2005, 109).

As this example shows, literary criticism provides possibilities for making sense of what is usually perceived as the losses of AD in the medical framework. However, the position of cultural critique vis-à-vis dementia is complex and sometimes marred by generalizations and silences. Certainly, it is not circumscribed by the primary and pressing material problems of appropriate care or therapy options. Important as these are, cultural critique has little to offer here. Instead, and from a perspective concerned less with healing the cognitive pathologies associated with dementia than with its cultural pathologies, this critique can turn to the cultural archives and interrogate the resources they offer for the representation of determinate otherness.

The cultural presence of the disease is occasionally framed by various forms of organized creativity – creative engagement projects would be the technical term here – among them theatrical performances, sculpting and painting, life writing, also poetry. These performances are designed to open 'avenues for meaning-making between people who cannot communicate through traditional, rational language [and] can help put meaning back into what we

fear are meaningless lives' (Basting 2009, 164). These representations, and side by side with them professional portrayals, are of course extremely varied in content and form, ranging from award-winning movies such as *Still Alice* (2014) via self-help manuals to semi-private blog spots.

The entry of dementia into popular discourses, facilitated to no small degree by the new social media, may have popularized the disease; whether it has also popularized its victims remains an open question, and a crucial one for cultural critique. From this perspective, dementia is an example of what Aihwa Ong, in a different context, has called 'the cultural logics of subject making' (1999, 6) and all the distortions and omissions implied in these logics.

'Popular' seems an awkward term anyway in the context of a terrible disease which offers little hope for improvement and for which no cure is available. Nonetheless, the term is useful here because it points to a continuing process during which dementia has travelled from the clinical domain into the public sphere, while gerontological or geriatric experts have lost some, if not much of their former interpretive authority. As a consequence, the overall understanding of dementia is being modified 'from the bottom up', by the voices of the people directly involved – or so it might seem. So we should not forget here that the cultural embrace of dementia and here again, especially AD, can at times be smothering so that the disenfranchisement of patients in their everyday routines is reiterated and reinforced by well-meaning popular representations.

Such a note of caution is even more important since the demotic character of dementia and especially of AD anchors the disease firmly in the popular culture of the Global North¹ at the same time that it also opens it to the analytic competence of cultural critique. The conjunction of mental impairment and cultural practices can be expected to offer useful information about both the status of such an impairment in contemporary culture, especially that of the United States, and also about the chances and limits of culturally available means of expression. This is especially true of what has sometimes been called a cultural 'master narrative' of dementia, a form of dementia storytelling which de- and prescribes how the entry of mental impairments into a person's life is

¹ It is important to make this distinction because, as Lawrence Cohen and others have shown, the reactions to cognitive impairments, especially in older people, are largely determined by social and cultural traditions and assumptions about later life, not all of which follow the patterns of the Global North.

to be scripted, what the intermediary steps are, how that person fights the disease, etc.² Taken together, these analytical steps would then point to the favourite and by now familiar diagnosis that dementia is – like so much else – culturally constructed.

Important as such work is, it is not enough. What is also necessary is a shift of terrain, not, as some might expect, from the medical-therapeutic domain to visions of empowerment offered by cultural practices such as painting, poetry, or performances. What we in this volume regard as the new terrain opened by cultural critique is one in which dementia is no longer seen as principally located in the individual patient, being ‘her’ or ‘his’ impairment, and by extension her or his problem. Instead, the purpose of this book project is to demonstrate how dementia is circulating incessantly in the public sphere, in formal and informal contexts, in conversations, written and filmic texts, etc. This change of terrain opens critical inquiry to a complex of analytical questions, among them how dementia is being (re)presented here in terms of gender, what the stories are that are being told about it, what types of narratives are used, who is speaking for whom and, perhaps most importantly, what the silences and lacunae are in the public conversation.

It is certainly tempting to understand such cultural critique as a form of ‘cultural therapy’, a critical praxis directed at alleviating some of dementia’s cultural burdens by exposing ‘the figures of power that operate in dominant discourses or ideologies’ (Hardt 2011, 19; Grossberg 2010, 93–6). Such a reading might well be called reparative because it is not held in thrall by hegemonic epistemologies of power (in this case, those of the geriatric or the medical profession in general) but instead looks for those cultural resources that may allow us to imagine alternative, better and empowering ways of life for dementia patients. Showing how social and cultural norms ‘reside in and find a concrete manifestation’ (Armour and St. Ville 2006, 6) in the human mind in its impaired stages can open up a space for reflection (and action) concerning not only cultural meaning but just as importantly also the civic meaning of human life in its frail, dependent and limited condition.

² For this discussion and the possibilities of a counter-narrative cf. Bitenc (2020, 16–17, 99–121), and with a more literary-critical focus England (2017).

The cultural readings of dementia proposed in the essays collected here are gesturing in this direction but at the same time are also seeking to move beyond this framework, and they do so especially in two directions: they give sustained attention to the gendered nature of the various forms of dementia and they also explore a phenomenon that we are calling here ‘dementia ventriloquism’.

2. Dementia ventriloquism: Speaker positions in AD

It is frequently assumed that since dementia patients can no longer speak for and of themselves – at least not in the ways ordained by our culture – others must take over the job³ – and there has to this day been no lack of such others as thousands of dementia stories and blogs show.

A good example of this kind of ventriloquism is a post from an Alzheimer’s caregiver about a Christmas situation with an Alzheimer patient:

‘The Greatest Gifts of All’ By Amy Goyer, 23 December 2015, 11:18 AM
 The way Alzheimer’s disease has ravaged my dad’s capabilities is especially hard to bear during holidays. . . . Linda [the blogger’s sister] and I looked at each other and teared up. My heart broke for him. But then he squeezed my hand and said, ‘But I like this one, too’ [that year’s Christmas tree] and gave me a little smile. . . . [dad has glaucoma which has affected his visual processing and verbal communication is getting more difficult for him.] . . . I helped him touch the tree and he looked up at the lights, and said, ‘I see it!’ . . . My heart overflowed. . . . We must always remember that deeply familiar things, such as holiday rituals and music, may bring up memories and very rich connections. We must never stop including loved ones; always reach out. Never give up. Even if we can’t see or hear it, something may be getting through. And we must never, ever get so caught up in sadness or self-pity that we miss the truly important moments of great joy and meaning.

<https://blog.aarp.org/author/amy-goyer>

Reading this report, one cannot miss the sense of control which the blogger exercises over both, ‘Dad’, the Alzheimer’s patient, and her own reactions. The

³ There is an echo of Marx’s *The Eighteenth Brumaire of Louis Napoléon* where he speaks of subaltern peasants. The reduced mode of being registers here also in an economy of representation: ‘They cannot represent themselves, so they must be represented’ (Marx 1963, 51).

memory evoked here is meant to bring home the lesson for which 'Dad's Christmas' is providing the example and occasion, namely the moral imperatives involved in caring for Alzheimer's patients. In this way, what is meant to pass as an AD memoir is less 'about' the ravages of the disease than about the ascendancy of the caregiver over the recipient of her care.

Many attempts have been made to counter or at least curtail some of the disenfranchising power of such ventriloquism. One of these is the 'Meet Me at MoMA', part of Francesca Rosenberg's MoMA Alzheimer's Project. In December 2011, people suffering from various degrees of AD were invited to look at van Gogh's painting *Starry Night* (1889) while their responses were recorded. Afterwards, these responses were assembled into a text by the project organizers acting as facilitators.

Ventriloquizing, 'a projected or simulated Other signification' (Banerjee 2008, 78), is a key factor shaping the cultural presence of dementia. Speaking of and for the afflicted, ventriloquism seems to secure a continued social and cultural presence for 'them', even if such a presence might exist only in memory. Oftentimes, informal stories about dementia patients are declared as memorials. Also, Jonathan Franzen's by now 'classic' dementia narrative, 'My Father's Brain: What Alzheimer's Takes Away' opens with the declaration: 'Here's a memory' (2001, 81). As the text chronicles Earl Franzen's gradual subjugation to the 'subtractive progress of Alzheimer's' (90), the memories recorded are getting invested with a double entendre. This is quite typical of the genre of the dementia memorial: there are events that happen in the life of the patient but these events also happen in the parallel universe of textualized memory so that the text gets to be speaking about two lives at one and the same time (or textual moment). And, even while Franzen avoids the openly ventriloquizing posture adopted in many other dementia memoirs written by next-of-kin, his text is curiously ambivalent about whose story this really is: 'My memories of my father's initial decline are vividly about things other than him. Indeed, I'm somewhat appalled by how large I loom in my own memories, how peripheral my parents are' (82).

Postcolonial critique has taught us that the cultural/textual praxis of 'speaking for' is never really innocent. Rather, it is one that involves us in a complex politics of representation: 'All speaking, even seemingly the most immediate, entails a distanced decipherment by another, which is, at best, an

interception, an interruption in the direct flow of communication between speaker and the persons or groups he/she is speaking for (Spivak 1999, 309). Dementia ventriloquism thus gives presence to and at the same time withholds the presence of those it speaks about while leaving them curiously 'un-gendered'.

Although Samuel Beckett has never spoken either for or about persons with dementia, his work has implications for representations of the illness. His later plays have been described as dramatizing the quandaries of the human mind (Takahashi 1982, 72). *Ohio Impromptu* (1981) is interesting for the question of dementia ventriloquism. The very short play displays a situation in which a generic listener (L) and a generic reader (R) are positioned at a table opposite each other. They are 'as alike in appearance as possible' (1984, 285), and thus suggest in their symmetrical poses two parts of a single, split consciousness. It is only the reader who speaks, reading out a third-person narrative from the book in front of him/her. The contents of this narrative concern the story of a man who has suffered a separation from his beloved. Unable to sleep, he encounters a stranger who has been sent to him by his lover, 'the dear name', to 'comfort' him (1984, 287). This minimal story is repeated and ritualized, while the narrative trajectory moves from 'Little is left to tell' (1984, 285) at the beginning to 'Nothing is left to tell' (1984, 288) at the end of the play. In this way, the play illustrates a problematic aspect of representing dementia in narrative, since the experience of dementia also disrupts the 'sense of an ending' or the illusion of wholeness, which a story with a beginning, middle and ending perpetuates.

The last variation in this short play's reflection on storytelling can be read as an approximation of dementia, or as dementia ventriloquism:

What thoughts who knows. Thoughts, no, not thoughts. Profounds of mind.
Of mindlessness. Whither no light can reach. No sound. So sat on as though
turned to stone. The sad tale a last time told.

1984, 288

The movement in the play's embedded narrative is from a position of closeness to the first character's – the lover's – thoughts to one of externalized speculation, so that in addition to the mistrust in narrative there is also a progressive denial of interiority. Nevertheless, this analytic of regression is balanced by the play's

focus on relationship: the love relationship, the linguistic repetitions evoking familiarity, the 'comfort' of the reading voice. In bringing both these perspectives of familiarity and distance together, Beckett's play illustrates important aspects of the representation of dementia.

3. AD, gendered care and ageing masculinities

We return to the question of how representations of AD relate to ageing masculinities. Like all diseases, dementia is deeply gendered. Clinical data from various countries tell us that the incidence of dementia is higher in women: 'Two-thirds of clinically diagnosed cases of dementia and AD are women, according to U.S. and most European reports. The primary reason offered for this gender difference is women's greater longevity' (Beam et al. 2018, 1017).

This is also the reason why women have been more in the focus of dementia studies, also in their role as the primary caregivers to dementia patients. And while women have been, and continue to be, in that role, male caregiving for spouses or parents with Alzheimer's disease still has to be explored in its cultural repercussions. Therefore, the focus chosen in this volume on the specifics of dementia as a disease of ageing masculinities aims at an analysis of the gender difference in care as well as specific aspects of male identity construction in the context of mental illness from the perspective of cultural critique. Bringing together insights from Masculinities Studies and Age Studies for the first time, this volume focuses on the gendered perspectives in cultural representations of AD. Such a focus is meant to initiate a new and more complex approach which looks at dementia as a disease affecting more than one person, invoking and challenging traditional as well as unconventional views of ageing masculinities.

Care has historically been associated with women and femininity, a focus that remained strong even in Carol Gilligan's feminist ethic of care, in which she argued for the necessity of a 'mode of thinking that is contextual and narrative rather than formal and abstract', and conceived the activity of care as centred around 'the understanding of responsibility and relationships' (1982/2003, 19). Arguing against a different morality for men and women in

Gilligan's gender-based psychological theory, Joan Tronto has situated care in a contextual metaethical political theory that retains the relational aspect of care but foregrounds questions of inclusion and boundaries as well as aspects such as relativism, utopianism and (individual) rights (1987, 660, 663). Nevertheless, she has shown that traditional modes of male care have been associated with the public realm and with hegemonic masculinities. In this framework, male care encompasses protecting society and engaging in economic activity and men are thus 'granted a pass from caring' in the domestic sphere (2013, 92). However, as Tronto also points out, both gender conceptions and those of care are shifting in contemporary societies. The 'Care Collective', for instance, has formulated a vision of 'universal care' that is related to a 'politics of interdependence' and embraces more inclusive models of kinship than those of the traditional nuclear family. As the authors of *The Care Manifesto* point out, dependence and care continue to be 'devalued and even pathologised' because 'autonomy and independence have historically been lionised in the Global North and gendered "male"'. Indeed, notions of unfettered male autonomy and independence remain symbolic of 'manhood', defined primarily in opposition to the 'soft', caring and dependent world of 'domesticity' (2020, 23).

How do these gendered concepts affect the situation of people with dementia? The position of the feminist philosopher Eva Feder Kittay seems most adequate to this situation, who argues that dependency is a fundamental human relationship, both for men and women, and should, therefore, be the foundation for theorizing the subject. Reflecting her own position as a moral philosopher and as mother of a cognitively disabled child, she promotes an inclusive sense of subjectivity and care: 'We human beings are the sorts of beings we are because we are cared for by other human beings, and the human beings' ontological status and corresponding moral status need to be acknowledged by the larger society that makes possible the work of those who do the caring required to sustain us' (2010, 412). To bridge the gap between concepts of gender, masculinity and the person with dementia, her way of depicting the human in its broadest sense, brings us back to the function of art and literature in representing dementia: '[T]here is so much to being human. There's the touch, there's the feel, there's the hug, there's the smile . . . there are so many ways of interacting. I don't think you need philosophy for this. You

need a very good writer. . .' (2010, 408; emphasis in text). An example for such a very good writer who has embraced the 'limitations' of both old age and mental illness, is Samuel Beckett. At the age of seventy-five, he famously summarized his poetic practice of diminishment:

It's a paradox, but with old age, the more the possibilities diminish, the better chance you have. With diminished concentration, loss of memory, obscured intelligence – what you, for example, might call 'brain damage' – the more chance there is for saying something closest to what one really is.

qtd. Shainberg 1987, n.p.

In spite of one monograph on the topic (Jeffers 2009), the relation in Beckett's work to notions of masculinity still needs to be further explored. By contrast, its engagement with old age and (mental) illness has been widely acknowledged and researched. Beckett is an extremely useful reference in the present context, because his work addresses in fundamental and undaunted ways the central issue that lies at the heart also of a cultural critique of Alzheimer's disease, namely the question of the relation between the human subject in its most frail condition and the cultural inventory of representations.

4. Conclusion as departure: AD and cultural critique

In the beginning, we characterized Alzheimer's as a site of resistance, of intransigent refusal of conforming to the normativities vested in the Enlightenment self. In these concluding remarks we want to offer brief reflections also on AD as a site of resistance to the routines of cultural critique.

In this perspective, we would do well to acknowledge that there is no inside of AD that would be fully accessible to outsiders, and this includes critics. This is not to say that no such inside exists – this would be a demeaning view of people suffering from the disease. Instead, what we want to solicit attention to is the idea that the oftentimes broken pieces of communication – linguistic, gestural, or otherwise – from the patients themselves cannot and perhaps should not be read mimetically, as being somehow expressive of intersubjectively shared meanings.

Such an acknowledgement would seem to suggest a different approach to these expressions, one that might be called symptomatic.⁴ This would involve a focus on and commitment to what the text is unable to say. A symptomatic reading does not stop at recognizing surface features of a given text, nor does it seek to ‘normalize’ it, making it conform to established protocols of expression, such as genre or use of symbols and metaphors. Instead, it concentrates on the gaps, contradictions and non-sequiturs and reads them as traces or symptoms of a larger unresolved problem. The text as symptom also places readers and critics at a distance from expressions which they acknowledge they cannot fully comprehend.

Such a symptomatic reading of people with Alzheimer’s and their expressions has energized reparative cultural activities such as ‘Meet Me at MoMA’ or the Alzheimer’s Poetry Project. They seek to give a voice to those who are silenced by the standards of everyday communication without ventriloquizing them, speaking for them. Examples of similar such readings can be found throughout this collection.

Symptomatic readings of texts associated with Alzheimer’s disease open up a space for reflection (and action) concerning not only their linguistic or communicative meaning but just as much the status in public conversation of human life, especially in contexts where the normative assumptions about what makes life human are up for debate.

With this in mind, the question of how much mental malfunction a society and a culture will accept in old people (and not only there) without regarding them as irretrievably Other is fast becoming an increasingly important ethical issue which the present collection is committed to exploring further.

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⁴ There is no space here to enter into a full elaboration of the concept and its ramifications. The term itself has entered critique through the work of Louis Althusser where it is meant to designate a reading that focuses on what the text in question represses or fails to express fully. Cf. Althusser and Balibar’s *Reading Capital* (1970). Althusser’s ideology-critical commitments do not guide our use of the term. Cf. also Eve Kosofsky Sedgwick’s *Epistemology of the Closet* (1991).

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