

Fighting Symbolic Violence Through Artistic Encounters:
Searching for Feminist Answers to the Question of Life and Death With Dementia

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I was at the F ward in the nursing home. One of the residents was Tiffany Doggett, who played the part of an angel in the American series “Orange Is the New Black.” Tiffany saw how Gilbert [another resident] wanted to open a window, but no matter the effort, he couldn’t! He became afraid and stepped back. So Tiffany immediately went towards the window and opened it, stepping out on the balcony and gazing at Siri [a nurse in nursing clothes] who was standing across. Siri, calm and confident that the “patient” would listen, said: “Come on, Tiffany! Come on, do not go there!” But Tiffany did not obey. She looked at Siri in the eyes and thought: “No, I do not want to! Because you should learn how it is to be accused of something you feel no guilt for.” Suddenly she jumped over the banister and committed suicide. Her intention was to prove that she was present, that she knew what she was doing, and to demonstrate for Siri how it feels like to become a dementia patient. Siri would have to understand and take the consequences for what had happened; because now, it would be Siri’s fault that one “patient” jumped and that she lost control over her. It was her fault but also an institutional mistake. It was the system to blame for Tiffany’s jump, and for the ward’s lack of fresh air that had triggered the situation. The tension between the glass of window and Tiffany’s hands made creaking sounds, which then, suddenly, disappeared.

This dramatic situation took place in a dream the first author had during her fieldwork in a nursing home for people with dementia in May 2017. A claustrophobic atmosphere during some days at the nursing home overwhelmed her and affected her dreams. She felt a clear cut between “them” and “us” in dementia care—from “their” point of view. This problematic us-them binary within dementia care and research is the pivot of this chapter. *They* – people living with dementia – are those who do not pass as *one of us*. *They* do not comply with the neoliberal ideal of ageing well—the demand for a disembodied, self-contained autonomous individual—and hence cannot pass as fully “response-able” humans (Latimer 1999, 2018). In Dragana’s dream, Tiffany did not follow the scripted “them” but stepped back and jumped, and paradoxically produced herself as response-able.

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Suicide is a fatal act of agency, whilst at the same time an effect of the us-and-them binary that powerfully stigmatises “them”. In this chapter, we problematise how this binary in imaginations of dementia produces and reproduces suicide and euthanasia as the last response-able act for people who fail to be “fully human”. People with Alzheimer’s disease (AD) or other dementias (ADD) fall into this category. Worldwide, ADD is emerging as a health “epidemic” that affects more than 46 million people and will affect 123 million by 2050 (World Alzheimer Report 2015). There is no cure on the horizon. Even so, the bulk of research funds worldwide is devoted to biomedical and pharmaceutical research situating the disease within individuals’ brains as if isolated from the body and the environment. This biomedical understanding of ADD obscures the relational, material-semiotic, multisensorial human–non-human practices that challenge the dominance of such an understanding (Haraway 1997; Åsberg and Lum 2010; Lukić 2019). In concord with neoliberal ideals of the autonomous, response-able individual and a market-based logic of care as choice (Mol 2008 [2006]), the biomedical understanding of dementia is dominant both within healthcare and among the general public, producing the disease as deficiency and decay, potentially contributing to stigmatisation (Bond 1992). Suicide or suicidal thoughts are not uncommon effects of stigmatisation among people with ADD and next of kin alike (Purandare et al. 2009; O’Dwyer et al. 2015), and this is a feminist concern.

In 2015, a special issue of the journal *Feminism and Psychology* (Vol. 25:1), entitled *Suicide and Assisted Dying: Reflections on Sandra Bem’s Death*, addressed feminist contributions to the “right to die” debate in the case of the death of feminist scholar Sandra Bem. In this issue, Sue Wilkinson (2015) suggests that the right to suicide or assisted suicide is a feminist issue for people with ADD. Wilkinson argues that people who wish to end their lives before they lose their decision-making capacities and awareness of themselves, their loved ones, and the environment, should be allowed to do so. Elderly women, in particular, have been socialised to comply with paternalistic, masculinist traditions, therefore, they should not be compelled to subordinate their desire to die to desire of their doctors (or daughters) to keep them alive as long as possible (Wilkinson 2015). Davis (2015), supports the claim that health professionals should not monopolise the decision to die. In the editorial for this issue, Kitzinger (2015) suggests, in agreement with Parks (2000, 32), that women’s request to die may be dismissed as irrational due to their supposed self-denial and virtue of caring for others, not to be cared for. In contrast, in the

same issue, other feminists argue for improved dementia care as a better solution than institutionalising the right to die (Andrews 2015). From the standpoint of feminist ethics, Tulloch (2015) in turn, criticises the implicitly male Cartesian model of a rational, disembodied, independent self as a norm that advances masculine attributes and behaviours over feminine attributes and behaviours. Furthermore, Callahan (2015, 112) addresses how a naturalised symbolic power of male domination utilises violence that opens a space for suicidal decisions for people living with ADD “under the banner of increasing individual choice”.

We take this debate as our starting point, but argue that, with no way to cure the on-going and devastating brain damages, neither helping people to end their lives nor alleviating the burden of the disease through better care, fully problematises the biomedical understanding of ADD. We do not see in these solutions much room for appreciating a life together in difference: for “dwelling alongside and cherishing [...] difference” (Latimer 2018,16). Hence, despite good intentions, the positions in the special issue has the potential to contribute to the production and reproduction of stigma through picturing life with a dementia diagnosis as a life not worth living. Our worry is that the positions could inadvertently produce fear among those afflicted and strengthen the image of the person with the diagnosis as “the diagnosis only”.

By transcending the common biomedical foundation of the disease, and questioning the neoliberal logic of individualised autonomy, our aim is to offer new understandings of ADD. We approach this endeavour *first* via two previously-told stories about women with Alzheimer’s Disease. The first story is about Professor of Psychology and feminist pioneer Sandy Bem, who committed suicide in May 2014 (Henig 2015). The second story is about a fictitious Professor of Linguistics, Alice Howland, whom we get to know in the popular novel and film adaptation *Still Alice* (Genova 2015 [2007]; *Still Alice* 2014). Alice considered suicide, but did not succeed.

Second, we comparatively analyse the stories using a feminist understanding of Bourdieu’s (2001) theory of symbolic violence linked to Latimer’s (2018) concept of stigma. We draw on feminist materialist theories and feminist visual studies of technoscience (Åsberg and Lum 2010) that defy hierarchical binaries between mind and body, self and other, subject and object, human and non-human, and are attuned to study differences enacted in practices. We demonstrate how the biomedical understanding of dementia, underpinned by a neoliberal masculinist order of the autonomous response-able individual and a neoliberal logic of care as choice (Mol 2008), reinforces symbolic gendered violence, rendering suicide a rational choice.

Third, through a merging of the theoretical concepts and the stories, we actualise “being alongside” AD (Latimer 2013) proposing different enactments of ADD. We suggest that artistic entanglements in everyday life are helpful for the development of different understandings of what cognition and connectivity might be, not only for people with ADD, but for everyone.

We retell the stories about the two women, Sandra Bem and Alice Howland, for three reasons: first, dementia figures globally as a feminised disease. Across the globe, women are disproportionately affected by ADD, both as people with the diagnosis and as next of kin (GADAA 2017). Since age is the strongest risk factor for developing ADD, and women live longer than men, more women than men will develop and live with ADD; they also more often bear the consequences of the disease alone (Bartlett et al. 2016). Worldwide, women account for more than two-thirds of the family carers and a majority of formal carers, performing feminised, devalued, overloaded, racialised, healthcare and lowest-paid social care jobs (GADAA 2017). In general, female next of kin experience a higher burden of care than male next of kin—also due to the aggressive behaviours of their male partners living with dementia (Lotherington et al. 2018) – whilst at the same time receiving less support than male next of kin (Gibbons et al. 2014). In addition, women with dementia receive less formal or informal support than men with dementia, and because women’s spouses are often not willing to care for them, they are institutionalised sooner (Bartlett et al. 2016). Consequently, women are more prone to stigmatisation (GADAA 2017). In spite of this, gender perspectives on stigma within dementia research are missing, and so are relational gender perspectives in policy guidelines and strategies worldwide (Bartlett et al. 2016; GADAA 2017).

Second, in the stories we relate, both Sandy and Alice strived to fulfil the neoliberal masculine ideal of being an independent, strong, active, free individual. Then they got AD. To continue to live this ideal, they chose suicide as a means of maintaining control over their lives, their loved ones, and the environment. Third, both stories provide knowledge about dementia, but in different ways. Whilst Sandy Bem’s story complies with the common understanding of dementia as deficit, Alice’s story offers new possibilities of dwelling alongside dementia in artistic encounters, cherishing differences and breaking hierarchical dualisms between biomedical and artistic knowledge of dementia (Lukić 2019).

Sandy Bem: Suicide as an Option and Assisted Suicide as a Possibility

“The last day” is a story about Sandy Bem, as told by Robin M. Henig in the *New York Times Magazine* of 17 May 2015. Sandy Bem was a feminist pioneer, Psychology professor, and director of the Cornell University feminist, gender, and sexuality studies programme, who published a number of books on gender identities. Sandy was married to professor of psychology Daryl, with whom she had a daughter, Emily, and a son, Jeremy. The Bems were known as an unusual couple, travelling worldwide to give public talks on gender stereotypes. They raised their children in a gender-neutral way, and shared household duties equally. However, when Emily and Jeremy grew older, Sandy felt that Daryl did not take enough responsibility at home. Therefore, the Bems went through a friendly separation after 29 years of marriage, while Daryl continued visiting the family. When Sandy was diagnosed with mild amnesic cognitive impairment—a condition that in most cases progresses to AD within 10 years—she decided to end her life:

She felt terror at the prospect of becoming a hollowed-out person with no memory, mind or sense of identity, as well as fury that she was powerless to do anything but to endure it. With Alzheimer’s disease, she would write, it is ‘extraordinarily difficult for one’s body to die in tandem with the death of one’s self.’ [...] The prospect of mental decay was particularly painful for Sandy, whose idea of herself was intimately entwined with her ability to think deeply and originally. (Henig 2015, 38)

Sandy first told Daryl about her decision, then the other family members. No one opposed her. The question was when. She wanted as much joy as possible without waiting too long. She discussed this problem with Daryl who, after the diagnosis, became closer to her than ever before. He accompanied her to doctors’ appointments, and Sandy was surprised at how attentive, gentle and emotive he had become. In spite of this “gift” of tenderness and attention—she would never have accepted living with dementia (Henig 2015, 39). On the other hand, Daryl was surprised that Sandy’s cognitive decline did not affect his feelings for her, and that their relationship rather heightened as the disease progressed. Daryl became, again, a central person in Sandy’s life.

When Emily gave birth to Felix—Sandy’s and Daryl’s grandson—Sandy was thrilled: “She told Emily that her ‘new brain’ might actually make her better suited to being a grandmother than her focused, hyper-analytical ‘old brain’” (Henig 2015, 41). Sandy babbled songs and stories to Felix, without bothering about her memory loss. Emily liked her “newer” mother. It had been hard

to grow up with a hyper-critical one. She hoped this “newer Sandy” would quit the suicide idea: “[W]ho should make the decision to die, the old Sandy or the new one?” (Henig 2015, 41). In this case, the “old one” did.

Sandy appreciated sentient pleasures, but prioritised her ability to think critically and believed that this ability was a reflection of her true autonomy. After having read two books on “dying with dignity” that Daryl brought her, she decided on a liquid substance controlled in the USA, called pentobarbital—a barbiturate that veterinarians use to euthanise animals and physicians for assisted suicides—to do the deed for her. She followed the instructions from one of the books and ordered the drug from a foreign supplier. Her younger sister Bev—who had been diagnosed with ovarian cancer a year before Sandy was diagnosed—offered the alternative that Sandy could have the drugs she might get from her doctor in Oregon, as Bev would not need them. For a long time, Sandy envied Bev’s option to have her request to die accepted.¹

Even though she had enough savings to prolong her treatment for AD, and be with Felix for one more year, her condition deteriorated, and she felt that she was losing control. Prolonging the treatment with expensive medications “for Felix’s sake” was not worth her savings (Henig 2015, 54). Therefore, she realised that time had come, and asked Daryl which date it should be. He chose 20 May. Nobody except Emily dared to challenge her decision. Emily was angry at everybody, particularly her father, because he was thinking “...so pragmatically about her mother’s death” (Henig 2015, 54). However, the day before Sandy died, Emily admired her mother for choosing the right moment. On her last day, five years after receiving the diagnosis, Sandy printed an email called “Ending” that she had written to Daryl nine months earlier, telling him why she wanted to die and stating that nobody was responsible for her death but herself. On the printout, she marked the date 20 May 2014, with the declaration: ““The time has come to end my life. I love you, Daryl”” (Henig 2015, 56). After 5:30 pm, she wanted only Daryl to be in the room with her. She poured a glass of pentobarbital and a glass of wine, and asked Daryl twice which glass is the wine, which is the drug and if she could combine the wine and the drug. ““That’s not a good idea,” Daryl answered. ‘You don’t want to fall asleep before you’ve drunk it all’” (Henig 2015, 56). She died peacefully in her home on 20 May 2014 at the age of 69.

Alice and Lydia: Artistic Entanglements

We learn about Alice Howland in Lisa Genova’s bestselling novel *Still Alice* (2015) and Glatzer’s and Westmoreland’s popular film adaptation, *Still Alice* (2014). Alice is a 50-year-old honoured

expert in linguistics and professor at Columbia University (*Still Alice* 2014). She is happily married to John, a professor in biomedicine, also at Columbia. They have three grown-up children: Anna, Tom, and Lydia. After some memory glitches and incidents of disorientation, Alice goes to the doctor and is diagnosed with early onset AD—a rare but familial disease probably also affecting her children. In a genetic test, it turns out that Anna carries the same gene mutation, while Tom’s test is negative and Lydia refuses to be tested.

For a long time, Alice and John have disagreed about Lydia’s path as a stage actress in Los Angeles (*Still Alice* 2014). Alice admires Anna and Tom for choosing “real careers” in law and medicine and feels that Lydia is losing valuable time performing on the stage in LA (*Still Alice* 2014, 00:07:22). The tension between Alice and Lydia culminates when Alice finds out that John has been financially supporting Lydia’s theatre company without informing her (*Still Alice* 2014). However, with the progression of Alice’s disease, and Lydia’s inclusion of her mother into her drama practices, the relationship between Alice and Lydia flourishes. In particular, reviewing plays with Lydia buttresses Alice’s memory as she can talk over the scenes without having to compete, as she always does with John (Genova 2015). As they analyse the plays together, Alice comes to appreciate the strength of Lydia’s intellect and emotions, feel Lydia and love her in a different way than before. At the same time, Lydia practises her roles while anticipating Alice’s affection. As Alice’s ability to speak declines, her ability to track “body language and unspoken feelings” heightens (Genova 2015, 191). Lydia recognises Alice’s inability to speak as an “enviable skill” for an actor, who has to express actions and feelings without speaking (Genova 2015, 191). When Alice visits Lydia’s theatre for the first time while she is playing the piece Alice had helped her to practise (Genova 2015), she finds it easy to empathise with the character Catharine, whom Lydia plays (Genova 2015; *Still Alice* 2014). Moved by the play, Alice acknowledges Lydia’s acting skills off the stage, without realising that she is speaking to her own daughter (*Still Alice* 2014). No matter how defeating are the signs of her mother’s decline, Lydia appreciates that Alice sincerely recognises her talent.

Inspired by Lydia’s play, and following her encouragement, Alice writes a manuscript, hoping to deliver the most influential speech of her life at an Alzheimer’s Association conference (Genova 2015). In comparison to her previous and famous speeches about linguistics worldwide, this time Alice is the subject of her own speech. She stands at the centre of the stage, advocating for people living with AD, emphasising their agency, and that they always are more than the

disease, more than others' perceptions of them. She stresses that she is not a victim of AD, but that she is struggling to stay connected with the world and with her "old ambitious self", who was "fascinated with communication" (*Still Alice* 2014, 01:07:59).

As AD progresses, Alice's relationship with John declines. In her neurologist's office and without John as her closest advocate Alice feels guilty for becoming an unreliable AD patient (Genova 2015). However, Alice begins to wonder if John, and not AD, triggers her decline (Genova 2015), whilst John cannot accept the situation of Alice being seriously ill and in need of him. He hates that AD is happening to them (*Still Alice* 2014). Alice hates it too. She would rather have cancer because then she would not feel like a social outcast. Beside social support, with cancer she would also deserve John's attention, as in his job he is dedicated to find a cure for cancer (*Still Alice* 2014; Genova 2015). Instead of taking the opportunity to be with her on a sabbatical for one year, John chooses to follow his career and moves to another city, leaving Alice with caretaker Elena, and Lydia, who decides to move back home. With tears in his eyes, John admits to Lydia: "You are a better man than I am" (*Still Alice* 2014, 01:26:12).

Because of John's behaviour and Alice's own fear of burdening her family (Genova 2015), Alice decides to visit a nursing home for people living with dementia to see if this would be a place for her to live. She sees apathetic, elderly female residents in wheelchairs with no group activities and no loved ones around (*Still Alice* 2014). She realises that, for a young and physically fit person like her, a nursing home is not the answer. She imagines the fatal end with dementia: her body curled up in the fetal position, not able to swallow and, therefore, developing pneumonia (Genova 2015, 109). This is not the life she wants, so she secretly sets up her criteria for the timeliness of committing suicide (*Still Alice* 2014): when she is no longer able to do the things she enjoyed in life, like eating ice-cream – "when the burden of her disease exceeded the pleasure of that ice cream" (Genova 2015, 132) – she would want to die. She creates a memory test similar to the one her doctor and the neuropsychologist use (Genova 2015). When she is no longer able to pass that test, the time will have come. To be sure of fulfilling her plan, Alice records and stores a video of herself on her computer, addressing her future self:

Hi Alice, I am you and I have something very important to say to you. So, I guess that you've reached that point, the point that you can no longer answer any of the questions. So, this is the next logical step. I am sure of it. In your bedroom, there is the dresser with a blue lamp, open the top drawer, in the back of the drawer there is a bottle with pills in it. It says

take all pills with water. Now there are a lot of pills in the bottle but it is very important that you swallow them all. OK? And then, lay down and go to sleep. And do not tell anyone what you are doing. [After finishing the video, she types] ‘When you can no longer answer these questions, go to a folder on your computer labelled Butterfly.’ (*Still Alice* 2014, 01:19:51).

Alice calls the video “Butterfly” because she once told Lydia that like the life of a butterfly, life with AD is short, but may be beautiful and worth living (*Still Alice* 2014). One day, Alice accidentally opens the video “Butterfly”, but after several attempts to proceed with the instructions, she drops the box of sleeping pills and they spill all over the floor (*Still Alice* 2014). Her suicidal plan fails. However, this does not seem to worry her too much as life goes on and she appreciates the pleasures of life in the moment. The film shows Alice confidently holding Anna’s new-born twins, eating ice-cream with John, and discussing plays with Lydia. Even after her language is gone, she continues helping Lydia practise her theatre monologues. Both the book and the film conclude with a scene in which Lydia is reciting a part of the play to Alice, and Alice sees her as “the actress”, because she cannot remember Lydia’s name (Genova 2015, 326). Lydia’s interest is to figure out what Alice thinks about the play, focusing on her feelings and emotions, rather than narrative, coherence, and words:

Alice watched and listened and focused beyond the words the actress spoke. She saw her eyes become desperate, searching, pleading for truth. She saw them land softly and gratefully on it. Her voice felt at first tentative and scared. Slowly, and without getting louder, it grew more confident and then joyful, playing sometimes like a song. Her eyebrows and shoulders and hands softened and opened, asking for acceptance and offering forgiveness. Her voice and body created an energy that filled Alice and moved her to tears. (Genova 2015, 326)

In an immediate closeness to Lydia’s face and lips’ movements asking from Alice to express what the play was about, Alice articulates, searching for words that are mostly already lost for her, the word “Love” (*Still Alice* 2014, 01:30:29; Genova 2015). Lydia repeats, confirms to her mother: “Yes.. it was about love...” acknowledging a physically mutual feeling as well as their comprehension of the meaning of the play (*Still Alice* 2014, 01:30:37; Genova 2015).

Sandy and Alice: Suicidal Agential Cuts

Our analysis of the two stories problematises hierarchical binaries in which we see locations of symbolic violence in “agential cuts”. Drawing on quantum physics, feminist philosopher Karen Barad (2007, 140) defines “agential cuts” as enactments of particular space-time-matters within phenomena that emerge as effects of material-discursive intra-actions. Barad (2007, 33, emphasis in the original) defines intra-action as “...*mutual constitution of entangled agencies*”. To be entangled is to lack individual self-contained existence (Barad 2007, ix). Hence, “intra-actions” presuppose inseparable agencies that emerge through mutual and dynamic processes of becoming, in contrast to “interactions” that presuppose pre-existence of individual self-sustained agencies. Cartesian cuts enact inherent hierarchical and static distinctions between an individualised subject and object and other hierarchical distinctions, in contrast to agential cuts that enact “...inherent ontological (and semantic) indeterminacy” not pre-existing as individual entities, but resolving as “*exteriority-within-phenomena*” (both quotes from Barad 2007, 140, emphasis in the original). Barad (2007, 140, 72) defines phenomena as “diffraction patterns” (Haraway 1997, 16), that is, iterative, material-discursive “patterns of difference that make a difference” in particular space-time-matters cuts.

In what follows, we analyse particular agential cuts in Sandy’s and Alice’s stories of living/dying with dementia. Doing so, we demonstrate how the symbolic gendered violence that is co-constituted within these cuts is also structurally maintained (Bourdieu 2001), with physical, harmful effects, one extreme of which is suicide. Finally, we propose a different understanding of ADD as not necessarily harmful but potentially vitalising, producing joy and connectivity within creative art encounters.

Both Sandy and Alice are white, middle-aged, married women (one previously married), with higher education, higher class status and an American background, tying the stories to Western Euro-American biomedical visions of ADD (Åsberg and Lum 2009) that make the contemplation of suicide possible. Public debates on euthanasia are in general a white-educated-privilege, where the opinions of subordinated groups by race, class, and gender are invisible and deviant. Jennings and Talley (2003), for instance, have demonstrated that people with racialised backgrounds are more likely to oppose euthanasia, because of both their collective history of abuse, and their lack of trust in the medical profession. Less-educated people and elderly women also tend to oppose euthanasia. Future research on euthanasia should, therefore, pay attention to

intersections between race, class, and gender, as well as other cultural differences (Jennings and Talley 2003). In different socio-cultural environments, ADD and suicide might not be issues at all (Hulko 2009).

Sandy and Alice also share a common background as worldly, honoured intellectuals cherishing their cognitive mastery as their main defining feature. They dread losing the ability to think and use their brains intellectually—a feature that Rooney (2017) describes as associated with the mind, in opposition to the body, in Western philosophical tradition. The mind figures as the centre of our thinking that “owns the body” and controls its movements through the environment (Vaaitinen 2017, 138). In the history of Western philosophy and modern political thinking, mind is commonly associated with masculinity and the body with femininity (Grosz 1994; Vaaitinen 2015). Likewise, the biomedical understanding of ADD situates the disease within the brain as an isolated, self-referential organ set apart from the body and the environment (Åsberg and Lum 2009). In contrast, indigenous worldviews, some religious worldviews, and feminist materialist theories subsequent to those views suggest an understanding of thinking as an entanglement of mind, body, and the environment (Mortimer-Sandilands 2008). As the most dominant in the environment of the contemporary West, the biomedical understanding of ADD thus shapes our thinking, potentially making us understand ADD as a deficit, overshadowing other realities of life with the disease (Moser 2008).

Here we see symbolic gendered violence as elaborated in Bourdieu’s *Masculine Domination* (2001). Masculine domination, Bourdieu argues, is a paradigmatic form of symbolic violence that acts as an insidious, omnipresent and subtle domination by masculine virtues, durably maintained via institutions as logical universal calculations. Masculine domination – the androcentric world order – revolves around the hierarchical primary opposition of male/female, followed by the secondary oppositions of top/bottom, public/private, outside/inside, big/small, strong/weak, mind/body. Such a world order prioritises masculinist virtues at the top of all hierarchies, while exposing vulnerable gendered human beings, women in particular, to symbolic violence. This means, effectively, erasure, silencing and de-valorisation of all that is coded as feminine – violence reminiscent to cultural violence (Reuterswård, this volume), and epistemic violence (Vaaitinen and Confortini; Féron, this volume). Within this order, the dominant is masculinised with symbols of virility, honour and duty, whilst the dominated is feminised. This naturalises the sexes and their relations, and potentially humiliates men who do not conform to the

symbolic power and authority of the dominant masculine ideal (Bourdieu 2001, 22; cf. Nuño; Féron, this volume). On the other hand, masculinised women may achieve intellectual independence but still be placed as objects into a “double bind” (Bourdieu 2001, 67). Acting according to a dominant masculine ideal necessarily *defeminises* these women, leaving them with the only options to participate in the masculine order or leave (Bourdieu 2001, 68) – perhaps by committing suicide.

Hence, symbolic violence is already material – it is, to apply Barad’s terminology, *material-discursive* violence. It acts “at the deepest level of the body” through “familiarisation” with established dispositions, in which the dominated may feel systematic self-denigration, taking the “form of bodily emotions – shame, humiliation, timidity, anxiety, guilt – or *passions* and *sentiments* – love, admiration, respect” (Bourdieu 2001, 38). Therefore, being in relationships of domination is not a matter of choice or constraint (Bourdieu 1992, 168). Rather, it is a mode of living (or dying) that is made possible upon the acceptance of structures of domination that are not imposed by force but taken as self-evident. Both Sandy and Alice accept the biomedical understanding of AD as an abject failure of personhood (cf. Latimer 1999). While for Alice a quickly deteriorating memory is the criterion for suicide, for Sandy it is a sense of losing control over her life. Both criteria adhere to the elusive neoliberal (white masculine) autonomous capitalist ideal (more on this later) of response-ability and able-bodiedness, which require constant body work and brain elasticity to age successfully (Latimer 2018). This biomedical understanding produces self-sustaining, autonomous subjects with an isolated brain as the centre for the formation of subjectivity (Åsberg and Lum 2010; Lukić 2019). In such a rationalistic hegemonic order, suicide becomes an option, and neglect of care a naturalised possibility. This is shown, for instance, by Purandare et al. (2009), who underscore that the risk of suicide is elevated in younger persons with dementia, as they are more aware of the disease and are still able to take care of, and make decisions for themselves.

The stigma associated with a dementia diagnosis is so strong that suicidal ideation often emerges shortly after a diagnosis has been disclosed (Erlangsen et al. 2008). Latimer (2018) explains stigma as an effect of complex entanglements of biomedical, political and cultural practices evolving from dementia’s relationship with ageing—perceived as the individual’s abject failure in the context of neoliberal world making. This ageing-dementia relation—the process of ageing entangled with the processes of becoming ‘the demented other’—figures as a “double

jeopardy”, particularly in Euro-American bio-medicalised culture (Greengross 2014, 6 in Latimer, 2018). This relation leads to a cultural and social magnification of becoming the hollowed-out person in a zombie state (Behuniak 2010), finally suffocating from pneumonia (which both Alice and Sandy fear).

The ageing-dementia relation is a failure in the masculine, neoliberal symbolic order, because it represents an unavoidable downward spiral, subverting the ideal of the highly cherished youthfulness of modernity. This stigma affects everybody who fails to enact the active, vigorous and self-sustained ideal of ‘successful aging’, producing misfits with internalised feelings of guilt and weakness. According to Latimer (2018, 2), “growing old badly”, that is, failing to remain response-able, emerges as the biggest sin. The stigma that emerges with the ageing-dementia relation, then, operates as a series of *agential cuts*: They are enacted as effects of material-discursive intra-actions with ADD, sustained through media representations, public discourse, and healthcare institutions, while legitimising the use of medicalisation for reduced costs and enhanced profitability. Taken together, these political and cultural practices violently transform people with ADD into nonhumans (Latimer 2018).

Early on, in the doctor’s office, Sandy brings up her final decision about suicide, while Alice carries her decision secretly alone. Neither uses physical pain as a reason, but mainly each underscores the fear of losing her sense of identity (Sandy) and becoming a burden of care (Alice). Steinbock (2005) affirms that suffering and losing a sense of autonomy and control over one’s own life are the main reasons for suicide requests among people in general, rather than pain. Clear Lewis (2010), a disabled activist, points out that the usual response to suicidal people is not to help them die but to help them live better lives. From a disability studies perspective, if debility is the reason why a person may be granted assistance in dying, then it means that persons with disabilities and their lives are less valuable. The clear-cut distinctions between a healthy and diseased “self”, as between able-bodied and disabled individuals, are grounded in the linear “peak-and-decline ideology” (Gullette 2017, 4), in which gradual decline and ageing with a disease are inevitable. Gullette (2017) argues that the neoliberal rational order generates ageism, producing “incitements to suicide” as the norm for the elderly, particularly women, insofar as they are the majority. The neoliberal order pushes people with disabilities to “choose” death (Shildrick 2015). This, we argue, is symbolic violence at the heart of gendered symbolic orders of health and life.

Both Sandy and Alice make the clear-cut distinction between the “older self” and “self with AD”, where the “older self” – the more rational, liberal, independent self – is the one to make the suicide decision. However, the “older self” cannot predict when the diseased self will stop enjoying life and when the right moment to die will be. Alice thinks that no longer enjoying an ice-cream would be one important sign. However, she continues enjoying ice-cream even after her suicide attempt. Feeling that she is losing control and capacity to end life with AD, Sandy asks Daryl to decide a right date. Hence, the coherent self in which both Sandy and Alice believe – isolated from the environment and from others – does not exist. The “self” is never static, and agency is not an attribute of the body, or the rational mind. Rather, as Karen Barad (2007) emphasises, agency emerges in “intra-actions” *within* the environment, not in relation to an environment that is external to an individuated “self”.

The Neoliberal Structures of Symbolic Violence

The violence of the biomedical understanding of dementia is not only embedded in circulating terminology regarding life with ADD (e.g., dignity or not), but also in the rationalist logic of choice (Mol 2008). Therefore, the symbolic gendered violence in question not only reshapes our language, culture, and bodies, but also how we live and the decisions we make. Indeed, to return to Bourdieu (2001, 83), symbolic gendered violence is maintained via institutions (the state, nursing homes, family, etc.) that are de-historicising and permanently preserving masculine domination. Following neoliberal ideology, the state is presently dismantling welfare services for elderly citizens in Western, democratic ageing societies (Burke 2015; Andersson and Kvist 2015; Vaittinen 2017; Tronto 2017), thereby cutting off collectivity (Bourdieu 1998). Neoliberal ideology celebrates the abstract self-centric, self-realising, able-bodied, white male independent individual (Burke 2015), focusing on the accumulation of wealth and excluding all those who are seen as intruders disrupting (his) independence (Code 1991, 77).

Such individualist ideology values isolation, separation, and the formal sameness of individuals whose “...interdependence is at best *manageable* if carefully regulated; at worst it is straightforwardly menacing” (Code 1991, 80). Those who do not fit in these ideals are alienated as ‘others’. In such a reality, people living with dementias are always in deficit, in need not only of constant care but also of third-party mediation between their needs and the market logic of choice. They emerge as a burden doomed always to fail to become accountable as “human” and “normal” autonomous individuals according to a medical norm (Moser 2011). In contrast, a logic

of care is preoccupied with liveable, unpredictable bodies entangled with a more-than-human environment *interfering* with a disease, figuring out how to craft care to create a good balance and live better *with* a disease. The logic of care does not impose a limit, give up, or say no to “unprofitable” patients (Mol 2008).

To come back to our analysis of Sandy and Alice’ stories, both calculate the financial and emotional prospects of the disease. Sandy will not, even if she could, financially cover the cost of further treatment of her AD. She does not want to be *that* Sandy. Alice, on the other hand, cannot imagine herself ageing in a nursing home after she visits a stereotypical home that does not allow for connectivity and joy. What Alice saw was probably a nursing home in which the effects of work pressure and lack of resources only sustained the biological functions of life, which were potentially a result of constant neoliberal cuts (Hoppania and Vaittinen 2015). Having internalised the symbolic order of (neo)liberal individualism, she does not want to end her life in a nursing home that is founded on hierarchical relations and procedures, in which bodies with AD would not pass as full humans but as dependent ‘others’. Her rejection of the biomedical culture in the nursing home potentially positions a critique of the neoliberal masculinist symbolic order, whilst paradoxically strengthening agential individualisation. Hence, she rather produces herself as agential, as Tiffany did. Yet, as we emphasise towards the end of this chapter, life with dementia – also in nursing homes – can be otherwise (see also Vaittinen, this volume).

AD is surrounded with such a stigma that Alice and Sandy would rather have had cancer. Therefore, both prefer death to a life with AD. They both act as response-able citizen-consumers, choosing a medical product (pentobarbital for Sandy, sleeping pills for Alice) to attempt ending their lives. While Sandy shares her suicidal decision with family members, Alice develops her suicide plan secretly because she fears the reactions of her family. Sandy’s decision to die is “... both enabled through, and constrained by, the relational and legal contexts in which she live[s]” (Peel and Harding 2015, 38). Suicidal decisions are also effects of intimate relationships in which next of kin are deeply involved and need more time to learn to cope with ADD (Martin 2015), or to go through another exit, as John does. John continues to live a life that is in line with the dominant, masculine, independent, biomedical ideal of life, prioritising his own career in cancer research over life with Alice—and dementia. John’s choices are in line with the biomedical quest for a cure (Falcus 2014) that surpasses the relational and emotional dimensions of life. Hence, as

Falcus (2014) suggests, John’s crying at the end enacts the failure of this quest and the failure of the biomedical understanding of AD.

We learn from Sandy’s story that AD strengthens her relationship with Daryl, but even so, suicide triumphs. Drawing on Bourdieu’s (2001, 109–112) understanding of love within the symbolic violent order—the supreme and most subtle and invisible form of masculine domination based on trust and disinterestedness—we suggest that their love relationship co-constitutes symbolic gendered violence. As AD progresses, Sandy takes on a position of the dominated female in her relationship with Daryl, as she leaves it to him to decide the last day of her life, and relies on his help to end her life. Alice’s relationship with John also co-constitutes symbolic gendered violence as Alice inevitably falls into the dominated position of a dependent AD patient, with internalised feelings of guilt as imposed on both Alice and her intimate others by the surrounding biomedical culture. Feelings of guilt are an effect of stigma, the symbolic and material ageing-dementia relation that affects both Alice and Sandy. This stigma makes them “choose” suicide, a “choice” that is amplified within relationships of domination, and the symbolic gendered violence that circulates through them.

Enactments of Being alongside Dementia(s)

Bypassing suicide as a matter of concern, Sandy and Alice’s stories demonstrate how AD is *enacted* differently in particular space-time-matter cuts of “being alongside” the disease. Here, we find Mol’s (2002, 32) term “enactment” useful, as it connotes the disease “being done” differently within different situated practices. “Enactment” disrupts the binaries of subject/object, epistemology/ontology, culture/nature, and goes well with Barad’s ontology of agential realism, particularly the intra-actions of space-time-matters in agential cuts.

We read Sandy and Alice’s stories of living with dementia and seeking to control death as an enlightening series of different situated agential cuts – that is, specific resolutions of *indeterminacy* between the subject and object, and other hierarchical distinctions (Barad 2007) – which delineate meanings of AD. Here, each space-time-matters cut emerges as an enactment of AD as a phenomena intertwined with other enactments that go “beyond choice” (Mol 2002, 178). Enactments of AD then intra-act and are never a coherent whole – AD is never a coherent whole, but in *constant ongoing processes of becoming*. With this understanding, we see the potential to disrupt the biomedical comprehension of ADD as timeless, spaceless, fixed, and universal. To do

this and propose different – and hence liveable – AD enactments in particular space-time-matter cuts, we utilise Latimer’s understanding of “being alongside” dementia which breaks the dualistic humanist visions of the autonomous individual, allowing entities to emerge differently through multisensorial artistic encounters situated in time and space (cf. Vaitinen, this volume).

Latimer (2013) formulates “being alongside” as a human-nonhuman animal relational encounter, in which both parties are being partially connected and partially divided, each preserving a sense of difference and mutuality. The parties are not becoming “better humans”, but are becoming differently through the encounter (Barad 2007). Hence, the relation enacted cherishes differences and differential becomings. Although Latimer uses this concept for studying human-nonhuman animal relations—sensitive to multisensorial post-humanist ways of living together respectful of differences, we adapt this concept to demonstrate how AD is enacted differently in Alice’s and Sandy’s stories within particular agential cuts.

For instance, in Sandy’s story, the relationship between Sandy and Emily is strengthened after the Alzheimer’s diagnosis. Using babbling sounds and emotions with her grandson, Felix, enables Sandy to communicate differently and hence *become differently* alongside Felix, transforming her from the critical “old” Sandy to the “new” Sandy which ultimately enacts AD as a mutual delight in an agential cut. Thus, using Barad’s terminology, the encounter between Sandy and Felix delineates inherent ontological and semantic indeterminacy between them as the subjects of the encounter, and AD as the object that enables the encounter. In contrast to a/the Cartesian cut that enacts absolute separability (and independency) between subject and object (i.e. individual independence of Sandy and Felix from AD situated in Sandy’s brain), this situated agential cut enacts “local”, “contingent separability” *within* the encounter which creates conditions for objectivity (Barad 2007, 348, 350).

However magical they are, these moments are not enough for Sandy to endure the disease. Such very present perceptual moments are undermined in the context of a neoliberal rationalist ideology that values reflection over perception and requires a coherent, autonomous self, capable of rational comprehension and expression (Mortimer-Sandilands 2008). Therefore, not even the ‘gift’ of a renewed relationship with Daryl persuades Sandy to endure the disease. Her life with AD ends in an agential cut while being alongside Daryl. This agential cut resolves indeterminacy between the subjects (Sandy and Daryl), the object (AD), and the instrument (pentobarbital). We

interpret this last cut in Sandy's life as "choice" within a neoliberal masculinist individualist order, which perpetuates symbolic gendered violence.

However, Alice's story is more complex. We learn that the relationship between mother and daughter (Lydia) strengthens. In her artistic drama encounters with Lydia, Alice becomes Lydia's most reliable audience, and AD is enacted as an "enviable skill" that evolves into a most influential speech at the Alzheimer's conference (Lukić 2019). The artistic intra-active encounters create a world in themselves (Latimer 2012) and the environment, while becoming differently alongside each other. In her artistic drama entanglements with Lydia, thanks to AD, Alice becomes differently abled to communicate beyond language and the meanings of words. Simultaneously, Lydia becomes the professional actress, whom Alice helps her to acknowledge. In the final space-time-matters cut, Alice *feels* what Lydia expresses by using her body, gesticulation, and different voice tonalities, becoming emotionally touched. Beyond the words, she realises and articulates the meaning of the play physically, inviting Alice to articulate the word love at a point when she has mostly lost the ability of verbal communication. They are together in a joint intra-active artistic drama entanglement, partially connected with different accomplishments. In this intra-active entanglement of which Alice and Lydia are subjects, AD – an object intertwined with the subjects – is enacted as enviable skill–professional actress.

All these different enactments within the two stories intermesh, and, eventually, the emergent entanglements determine the choices to be made (Mol 2002). In Sandy's case the biomedical enactment of ending one's life to survive dementia dominates, whilst in Alice's case, artistic entanglements of being alongside Lydia defeat the understanding of her life as the life of a misfit. Lydia and Alice's relationship demonstrates that life with AD can be valuable to live, as we argue – also in nursing homes (see Vaittinen, this volume) – if we are tuned into multisensorial aspects of life that do not stigmatise "them" as distinct from "us". Having done field work in a nursing home for a long time, Dragana also experienced lovely and joyful moments through artistic as well as care encounters. Luckily the prologue that began this chapter was just a dream. Yet, we have seen how Tiffany's fatal act of response-able agency repeats in Alice's fictional and Sandy's factual stories.

Conclusion

In this chapter, we have argued that the symbolic gendered violence of a biomedical understanding of ADD, amplified by a stigmatised ageing-dementia relation, produces suicide and assistance in suicide as choices. This violence affects all gendered human beings, particularly women. We find that the feminist “right to die” movement is grounded in this biomedical understanding of ADD, prescribing life with dementias as un-liveable. We build on a feminist debate on assisted suicide in *Feminism and Psychology*, to examine the symbolic gendered violence in dominant understandings of ADD, and analyse how this violence affects Sandy and Alice, two women living with AD and seeking to control death. We propose that different enactments of AD emerge in multisensorial encounters of “being alongside” dementia. We offer the examples of a multisensorial entanglement between Sandy and Felix – and their “irrational” babbling, as an agential space-time-matter cut—and of the last liveable emotional entanglement between Sandy and Daryl—which ultimately dies the last day of Sandy’s life.

Although we draw our analysis of symbolic violence using the factual narrative on Sandy’s and her family’s life with AD, our intention is neither to moralize about suicide nor judge about actual people, as we do not have an individualist approach. The intention of exploring Sandy’s “choice” to die due to AD— and thereof possibilities of other agential suicidal choices of people living with AD to end their lives, is not to dismiss or reject these possibilities, but to problematize individualization of these choices within a neoliberal masculinist symbolic order. The point is that *we do not own our choices* even though we *do them*, and choices are individually enacted. As we do not have an individualistic approach, our analysis focuses on symbolic gendered violence that we encounter within the neoliberal order that we are part of. Therefore, our hope is that the analysis rather enlightens multiplicity of situated “choices” that each space-time-matters cut enacts.

We discuss the more profoundly multisensorial artistic entanglement between Alice and Lydia. Given the latter example, as a conclusion, we propose that in the artistic encounters that extend connectivity beyond the cognitive abilities and able-bodiedness of the people involved, different possibilities for lives with dementias emerge. The world that Alice and Lydia create while being alongside AD, situates AD in-between the limits of life and death for a moment, where having AD is just one of the meaningful experiences in life that is unfolding in-between the dreams of tomorrow and longings for the past (*Still Alice* 2014; Lukic 2019). In contrast to Sandy, Alice fails

to commit suicide but lives on and continues to appreciate life in moments, making us see the value of arts in life—and perhaps value the art of life. The entangled, if sometimes conflicting, enactments of ADD that we have described suggest that a life with the disease might be prosperous and worth living, even towards the end, and that artistic modes of knowing and producing new knowledge about ADD should have legitimacy and validity, in feminist debates on global health and beyond.

References

- Andersson, Katarina, and Elin Kvist. 2015. “The neoliberal turn and the marketization of care: The transformation of eldercare in Sweden.” *European Journal of Women’s Studies* 22 no. 3: 274–287.
- Andrews, June. 2015. “II. Keeping Older Women Safe from Harm.” *Feminism and Psychology* 25, no. 1: 105–108.
- Åsberg, Cecilia, and Jennifer Lum. 2009. “PharmAD-ventures: A feminist analysis of the pharmacological imaginary of Alzheimer’s Disease.” *Body and Society* 15, no. 4: 95–117.
- Åsberg, Cecilia, and Jennifer Lum. 2010. “Picturizing the scattered ontologies of Alzheimer’s Disease: Towards a materialist feminist approach to visual technoscience studies.” *European Journal of Women’s Studies* 17, no. 4: 323–345.
- Barad, Karen. 2007. *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning*. Durham, NC: Duke University Press.
- Bartlett, Ruth, Gjernes, Trude, Lotherington, Ann-Therese, and Obstfelder, Aud. 2016. “Gender, Citizenship and Dementia Care: A Scoping Review of Studies to Inform Policy and Future Research.” *Health and Social Care in the Community*, 1–13. [https://doi: 10.1111/hsc.12340](https://doi.org/10.1111/hsc.12340).
- Behuniak, M. Susan. 2010. “The Living Dead? The Construction of People with Alzheimer’s Disease as Zombies.” *Ageing & Society* 31, no. 1: 70–92.
- Bond, John. 1992. “The Medicalization of Dementia.” *Journal of Aging Studies* 6, no. 4: 397–403.
- Bourdieu, Pierre, and Loïc J. D. Wacquant. 1992. *An Invitation to Reflexive Sociology*. Cambridge and Malden, NJ: Polity Press.
- Bourdieu, Pierre. 1998. *Acts of Resistance: Against the New Myths of Our Time*. Cambridge: Polity Press.
- Bourdieu, Pierre. 2001. *Masculine Domination*. Cambridge: Polity Press.
- Burke, Lucy. 2015. “The Locus of Our Dis-Ease: Narratives of Family Life in the Age of Alzheimer’s.” In *Popularizing Dementia: Public Expressions and Representations of Forgetfulness*, edited by Swinnen, Aagje and Schweda, Mark, 23–41, Bielefeld: Transcript Verlag.
- Callahan, Sidney. 2015. “III. A Feminist Case Against Self-Determined Dying in Assisted Suicide and Euthanasia.” *Feminism and Psychology* 25, no. 1: 109–112.
- Code, Lorraine. 1991. *What Can She Know? Feminist Theory and the Construction of Knowledge*. Ithaca and London: Cornell University Press.
- Davis, Kathy. 2015. “IX. Dying, Self-Determination, and the (Im)Possibilities of a ‘Good

- Death?." *Feminism and Psychology* 25, no. 1: 143–147.
- Erlangsen, Annette, Zarit, Stevan H., and Conwell, Yeates. 2008. "Hospital-Diagnosed Dementia and Suicide: A Longitudinal Study Using Prospective, Nationwide Register Data." *American Journal of Geriatric Psychiatry* 16, no. 3: 220–228.
- Falcus, Sara. 2014. "Storying Alzheimer's Disease in Lisa Genova's *Still Alice*." *EnterText* 12: 73–94.
- GADAA (Global Alzheimer's and Dementia Action Alliance). 2017. "Women and Dementia: A Global Challenge." Published February 2017. Accessed January 6, 2018, https://www.gadaalliance.org/wp-content/uploads/2017/02/Women-Dementia-A-Global-Challenge_GADAA.pdf.
- Genova, Lisa. 2015, [2007]. *Still Alice*. London: Simon and Schuster.
- Gibbons, Carrie, Joy Creese, Mun Tran, Kevin Brazil, Lori Chambers, Bruce Weaver, and Michel Bédard. 2014. "The Psychological and Health Consequences of Caring for a Spouse With Dementia: A Critical Comparison of Husbands and Wives." *Journal of Women and Aging* 26, no. 1: 3–21.
- Greengross, Baroness S. 2014. "Foreward." In *A Compendium of Essays: New Perspectives and Approaches to Understanding Dementia and Stigma*, edited by Sally-Marie Bamford, George Holley-Moore, and Jessica Watson, 6–7. London: ILC-UK.
- Grosz, A. Elizabeth. 1994. *Volatile Bodies: Toward a Corporeal Feminism*. Bloomington and Indianapolis: Indiana University Press.
- Gullette, M. Margaret. 2017. "How Does Incitement Work When the Target Is Not an Adolescent, But Old People?." *International Network for Critical Gerontology*, Published August 4, 2017. Accessed December 30, 2017, <http://criticalgerontology.com/incitement-suicide/>.
- Haraway, J. Donna. 1997. *Modest_Witness@Second_Millennium: FemaleMan Meets_OncoMouse*. New York and London: Routledge.
- Henig, R. Marantz. 2015. "The Last Day." *The New York Times*, May 17, 2015.
- Hoppania, Hanna-Kaisa, and Vaittinen, Tiina. 2015. "A Household Full of Bodies: Neoliberalism, Care and 'the Political'." *Global Society* 29, no. 1: 70–88.
- Hulko, Wendy. 2009. "From 'Not a Big Deal' to 'Hellish': Experiences of Older People with Dementia." *Journal of Aging Studies* 23: 131–144.
- Jennings, K. Patricia, and Clarence R. Talley. 2003. "A Good Death?: White Privilege and Public Opinion: Research on Euthanasia." *Race, Gender and Class* 10, no. 3: 42–63.
- Kitzinger, Celia. 2015. "I. Feminism and the 'Right to Die': Editorial Introduction to the Special Feature." *Feminism and Psychology* 25, no. 1: 101–104.
- Latimer, J. Elizabeth. 1999. "The Dark at the Bottom of The Stairs: Performance and Participation of Hospitalized Older People." *Medical Anthropology Quarterly* 13, no. 2: 186–213.
- Latimer, J. Elizabeth. 2012. "Home Care and Frail Older People: Relational Extension and the Art of Dwelling." In *Perspectives on Care at Home for Older People*, edited by Christine Ceci, Kristín Björnsdóttir, and Mary Ellen Purkis, 35–61. New York and London: Routledge.
- Latimer, J. Elizabeth. 2013. "Being Alongside: Rethinking Relations amongst Different Kinds." *Theory, Culture and Society* 30, no. 7/8: 77–104.
- Latimer, J. Elizabeth. 2018. "Repelling Neoliberal World-Making? How the Ageing-Dementia Relation is Reassembling the Social." *The Sociological Review*, 1–21.

- <http://eprints.whiterose.ac.uk/121840/>.
- Lewis, Clair. 2010. "Clair Lewis: Disabled People Need Assistance to Live, Not Die." *Independent*, February 28, 2010. Accessed 28.12. 07, <http://www.independent.co.uk/voices/commentators/clair-lewis-disabled-people-need-assistance-to-live-not-die-1911313.html>.
- Lotherington, Ann Therese, Obstfelder, Aud, and Gøril Ursin. 2018. "The Personal Is Political Yet Again: Bringing Struggles Between Gender Equality and Gendered Next of Kin onto the Feminist Agenda." *NORA – Nordic Journal of Feminist and Gender Research*, 1–13. <https://doi.org/10.1080/08038740.2018.1461131>.
- Lukić, Dragana. 2019. "Multiple Ontologies of Alzheimer's Disease in *Still Alice* and *A Song For Martin*: A Feminist Visual Studies of Technoscience Perspective." *European Journal of Women's Studies*. <https://doi.org/10.1177/1350506819831718>.
- Martin, Norah. 2015. "VI. From the Theoretical to The Personal: Weighing Further Feminist Concerns on Physician-Assisted Suicide and Euthanasia." *Feminism and Psychology* 25, no. 1: 124–130.
- Mol, Annemarie. 2002. *The Body Multiple: Ontology in Medical Practice*. Durham, NC: Duke University Press.
- Mol, Annemarie. 2008 [2006]. *The Logic of Care: Health and the Problem of Patient Choice*. London and New York: Routledge.
- Mortimer-Sandilands, Catriona. 2008. "Landscape, Memory, and Forgetting: Thinking through (My Mother's) Body and Place." In *Material Feminisms*, edited by Stacy Alaimo, and Susan Hekman, 265–287, Bloomington: Indiana University Press.
- Moser, Ingunn. 2008. "Making Alzheimer's Disease matter: Enacting, Interfering and Doing Politics of Nature." *Geoforum* 39: 98–110.
- Moser, Ingunn. 2011. "Normalitetens grenser, pris og alternativer – funksjonshemming som levd realitet." ["Limits, Price and Alternatives of Normality – Disability as Experienced Reality."], *Tidsskrift for Den norske legeforening* 9, no. 10: 962–964.
- O'Dwyer, T. Siobhan, Wendy Moyle, Melanie Zimmer-Gembeck, and Diego De Leo. 2015. "Suicidal Ideation In Family Carers of People with Dementia." *Aging and Mental Health* 20, no. 2: 222–230.
- Parks, A. Jennifer. 2000. "Why Gender Matters to the Euthanasia Debate: On Decisional Capacity and the Rejection of Women's Death Requests." *The Hastings Center Report* 30, no. 1: 30–36.
- Peel, Elizabeth, and Rosie Harding. 2015. "VII. A Right to 'Dying Well' with Dementia? Capacity, 'Choice' and Relationality." *Feminism and Psychology* 25, no. 1: 137–142.
- Purandare, Nitin, Richard C. Oude Voshaar, Cathryn Rodway, Harriet Bickley, Allstair Burns and Nav Kapur. 2009. "Suicide in Dementia: 9-Year National Clinical Survey in England and Wales." *The British Journal of Psychiatry* 194: 175–180.
- Rooney, Phyllis. 2017. "Rationality and Objectivity in Feminist Philosophy." In *The Routledge Companion to Feminist Philosophy*, edited by Ann Garry, Serene J. Khader, and Alison Stone, 243–255. New York and London: Routledge.
- Shildrick, Margrit. 2015. "Death, Debility and Disability." *Feminism and Psychology* 25, no. 1: 155–160.
- Steinbock, Bonnie. 2005. "The Case for Physician Assisted Suicide: Not (Yet) Proven." *Journal of Medical Ethics* 31, no. 4: 235–241.

- Still Alice*. 2014. Glatzer, Richard, and Westmoreland, Wash. Stockholm: BSM Studio.
- Tronto, Joan. 2017. "There is an alternative: Homines Curans and The Limits of Neoliberalism." *International Journal of Care and Caring* 1, no. 1: 27–43.
- Tulloch, Gail. 2015. "IV. Sandra Bem, Feminism, Assisted Suicide and Euthanasia." *Feminism and Psychology* 25, no. 1: 113–117.
- Vaittinen, Tiina. 2015. "The Power of The Vulnerable Body: A New Political Understanding of Care." *International Feminist Journal of Politics* 17, no. 1: 100–118.
- Vaittinen, Tiina. 2017. *The Global Biopolitical Economy of Needs: Transnational Entanglements Between Ageing Finland and the Global Nurse Reserve of the Philippines*. PhD diss. (published), Tampere Peace Research Institute and Tampere University Press: <http://urn.fi/URN:ISBN:978-952-03-0505-5>.
- Wilkinson, Sue. 2015. "X. Refusing to Live with Advanced Dementia: Contemporaneous and Prospective Decision-Making." *Feminism & Psychology* 25, no. 1: 148–154.
- World Alzheimer Report. 2015. "The Global Impact of Dementia: An Analysis of Prevalence, Incidence, Cost and Trends." Republished with corrections October 2015. London: Alzheimer's Disease International. Accessed June 1, 2018. <https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf>.

¹ Physician-assisted dying has been legal in Oregon since 1997, but for people living with AD is subject to different regulations (Kitzinger 2015) and therefore Sandy may not have had her request to die accepted even if she would have lived in Oregon (Henig 2015). In the state of New York, where Sandy lived, terminally ill people do not have the right to physician-assisted dying.