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Multiple ontologies of Alzheimer's disease in *Still Alice* and *A Song for Martin*: A feminist visual studies of technoscience perspective

Abstract

The prevalence of dementia is increasing worldwide but there is still no hope of a cure. Huge resources go into biomedical research, whose reductive 'enactment' has severe consequences for women, who are predominantly affected by dementia. To challenge such tragic enactment, this article considers 'multiple ontologies' of the most common type of dementia – Alzheimer's disease (AD) – in the popular fictional film adaptations *Still Alice* (2014) and *A Song for Martin* (*En sång för Martin*, 2000). Using a post-humanist account of feminist visual studies of technoscience, this comparative film analysis reveals how gender supersedes AD oversteering the hierarchical dualisms between health and pathology, human and nonhuman, and biomedical and artistic modes of knowing about Alzheimer's. The author argues that these films stress the potential of the arts (dramatic arts and music)—as a multisensorial post-humanist embodied state of becoming with AD, to challenge hierarchical dualisms and innovatively contribute to dementia care.

Keywords

Alzheimer's disease, arts, dementia care, enactment, feminist visual studies of technoscience, fictional film adaptations, gender, multiple ontologies, women's bodies

Introduction

Even though the ontological status of Alzheimer's disease (AD) has been under constant scrutiny for some time (Commisso, 2015), it has been turned into a global 'matter of concern' built on the universal notion of the disease (Moser, 2008: 100). With common efforts from biomedical and pharmaceutical research, patients' associations, and political agencies within the international Alzheimer's movement (particularly in North America and Western European countries), the biomedical reality of AD has prevailed transnationally (Moser, 2008: 100). Epidemiological and political practices have consolidated the dominance of biomedical reality, naturalizing biomedical knowledges about Alzheimer's and other dementias (ADD) (Moser, 2008). Thus, AD has been 'enacted' (Mol, 2002: 33) as a fatal neurodegenerative brain disease that causes 60–70% of dementia cases but is not a normal part of ageing (WHO, 2017). Age is the main risk factor for AD, as most people get the diagnosis at the age of 65 or older (ALZ, 2016). Although already multiple, this enactment figures as universal, objective, and central scientific knowledge about AD. The most problematic aspect of such a dominant enactment is 'corporeal fetishization' practices that isolate one seemingly rational

independent object, such as a gene or a brain, as locus of AD (Haraway, 1997: 142; Åsberg and Lum, 2010)¹. Such an object becomes an ‘autotelic’ value-laden static ‘thing-in-itself’, isolated from the body and the environment, a sort of denial surpassing the material and semiotic human and nonhuman relational practices that sustain the imaginary of this techno-scientific biomedical enactment (Haraway, 1997: 147, 137). The biomedical enactment reduces people with dementia to individuals with deteriorating cognitive deficiency, contributing to stigma that may trigger suicidal ideation, as Erlangsen et al. (2008) exemplifies.

This enactment has severe consequences for women worldwide, who constitute the majority of people living with ADD and the majority of formal and informal dementia carers (GADAA). Women are under great psychological distress and pressure to leave or reduce paid work due to dementia care strain (GADAA). Åsberg and Lum (2010) find that the female brain in particular becomes a site for corporeal fetishist practices reinforcing hierarchical dualisms between sexes, ages, races, ethnicities, and species. Along with the involvement of nonhumans into biomedical AD research, these conditions figure AD a feminist materialist issue (Åsberg and Lum, 2010). However, Bartlett et al. (2016) have demonstrated that a feminist perspective on dementia is lacking in both research on dementia and national and international dementia policy guidelines.

Consequently, this article contributes to feminist engagement with AD within a new field spearheaded by Åsberg and Lum (2010: 328): ‘Feminist visual studies of technoscience’. The aim is to demonstrate how biomedical fetishist practices reproduce hierarchical dualisms and unequal gendered dementia care relations. The central focus of the analysis is the popular fictional film adaptations *Still Alice* (2014) and *A Song for Martin* (2000), which engage ‘multiple ontologies’ of AD, acknowledging multisensorial ways of living with AD mostly explored in the arts (dramatic arts and music) for dementia care (Mol, 2002: 6). The article highlights that multisensorial ‘intra-active’ encounters between people with dementia, their next-of-kin, and nonhumans (art objects and instruments) inspire connectivity and empower agency (Barad, 2007: 353). These post-humanist encounters dismantle biomedical fetishization practices (of the gene and the brain) oblivious to relational, embodied senses of becoming with AD.

Theoretical approach, methods and materials

Feminist visual studies of technoscience (FVST) are post-humanist, non-representationalist, transdisciplinary studies that draw on intersections between cultural and visual studies, feminist cultural studies, and science and technology studies (Åsberg and Lum, 2010). Like feminist science studies, these studies criticize biological determinism, scientism, disembodiment, objectivization of bodies, and biological fetishism (Åsberg et al., 2011). The studies share the same onto-epistemological premises

with the new materialist feminist studies that resist hierarchical dualisms between mind and matter, fiction and reality, visual and textual, arts and sciences, epistemology and ontology, human and nonhuman, and are committed to study practices. For this reason, I am particularly inspired by ‘praxiography’, a term coined by Mol (2002: 31), for studying how a disease *multiplies* in practices. That is, a disease such AD is being ‘done’—‘enacted’ in practices—differently. In contrast to ‘perform’, which connotes a stage against which to view an action and its effects, ‘enact’ ‘leaves the actors vague’ and ‘...suggests that in the act, and only then and there, something *is*—being enacted.’ (Mol, 2002: 33). Thus, each enactment makes one definition of a disease possible. According to Mol (2002: 54–55), multiple enactments are not particularized, although they must hang out together to assure the unity of an organ, disease, and body.

Knowing a disease is a matter of intervening into practices as they unfold, producing definitions while ‘intra-acting from within, and as part of, the phenomena produced’ (Barad, 2007: 56). In contrast to ‘interaction’, an individualist term, ‘intra-action’ does not presuppose pre-existence of already defined human or nonhuman actors (Barad, 2007: 89); rather, actors and their properties emerge in situated material-discursive practices of becoming. These practices congeal agency as a materialized enactment of AD in particular space-time-matter (Barad, 2007). Thus, agency is not a property of human or nonhuman actors, but an intra-active open-ended performative process of becoming that reconfigures connectivity, constraints, and exclusions. Nobody

is standard or ‘ill-fitted’ at all times (Haraway, 1997: 38), as we are all continuously entangled in relations that articulate who we are: our properties, boundaries, and connectivity. Multisensorial artistic encounters may provide a space for growth of all people engaged, regardless of AD or other health condition (Dupuis et al., 2016).

Artistic encounters presuppose the involvement of multisensorial nonhuman agencies into our entangled state of becoming. To analyse such encounters, I find useful Bourriaud’s (2002: 84) ‘relational aesthetics’, which views art as a relational encounter between humans and art objects. In relational aesthetics, multisensorial embodied relations within art (dramatic art and music) collectively generate new knowledges and meanings about the world. Building on Guattari’s intentions, relational aesthetics moves human and social sciences away from hegemonic scientific paradigms towards ethical-aesthetic paradigms (Bourriaud, 2002). This is significant because artistic material and sensuous modes of knowing have been devalued in the western history of philosophy and education, within which the arts have not been regarded as a form of knowledge (Eisener, 2008). In addition, relational aesthetics follows Althusser’s materialist ‘trans-individual’ tradition (Bourriaud, 2002: 18), which fits well with post-humanist accounts of FVST, feminist materialist theories, and Barad’s understanding of agency (Lotherington, 2019). The non-representationalist approach, common to all these studies, allows the combination of visual and textual material into the analysis of film adaptations without a need to elaborate on distinctions between them.

Although *Still Alice* and *A Song for Martin* contributed to the establishment of AD as a global matter of concern—reinforcing the Western/Euro-American/biomedicalised/heterosexual/white/middle class/tragic vision of AD—they are valuable for analysis for several reasons. Both films emphasize the perspectives of women; as a people with AD (Alice in *Still Alice*) and next of kin (Barbara in *A Song for Martin*). The films depict life before and after AD diagnosis, in the first case of a fifty-year-old woman with early-onset AD (Alice), in the second of a sixty-year-old man with AD (Martin), allowing fruitful comparative discussions on gender and differences in dementia care. In each film, via standard Hollywood narrative techniques, we witness a successful professional protagonist brought down by AD: in linguistics (Alice) and in musical composition and conducting (Martin). In both films, art is a catalyst of knowledge about AD in a relational aesthetic understanding of the world: dramatic arts in *Still Alice* (the relationship between mother and daughter – Alice and Lydia) and music in *A Song for Martin* (the relationship between spouses – Barbara and Martin). The films are adaptations from literature, giving me the opportunity to draw on the corresponding literary narratives (the novel *Still Alice* and the memoir *The Book about E*) whenever they provide additional insight into different AD enactments. Even though the films are produced in different socio-cultural environments (*Still Alice* in the US and *A Song for Martin* in Sweden), they are both situated within the Western Euro-American AD movement.

AD enacted as an enviable skill, a success, and painful progress: Alice and Lydia

Still Alice (2014) is an American drama written and directed by Richard Glatzer and Wash Westmoreland and based on Lisa Genova's bestselling novel *Still Alice* (2015). Genova wrote the novel from a third-person perspective, prioritizing Alice's point of view. She and a team of women from the Alzheimer's Association provided necessary knowledge on AD to Julianne Moore, who played Alice (NewsRx, 2015). With slight distinctions and in shorter form, the film adheres to the narrative of the novel.

The focus of the story is the internationally honoured expert in linguistics Alice Howland, who is happily married to John, a biomedical researcher with whom she has three grown-up children: Anna, Tom and Lydia. The film starts with the celebration of Alice's birthday, at which the whole Howland family is present except her youngest daughter Lydia. Alice is shining at the centre of the family while John toasts: 'To the most beautiful and most intelligent woman I have known in my entire life!' (SA 2014, 1:57). While Anna is discussing with her husband whether Lydia has an acceptable reason for being absent – she has yet another TV audition – Alice assumes that they are speaking about her sister Anne. Alice doesn't know why she has mismatched her deceased sister with Lydia, but this mistake appears to be one of the first signs of early-onset AD. Alice's type of AD is familial, and they are told that the probability her children will develop the

same disease is 100% if they have inherited the same gene mutation. While it turns out that Anna is positive and Tom is negative, Lydia never wanted to be tested: ‘Lydia always did things differently’ (Genova, 2015: 119). Lydia’s absence at the beginning of the film emphasizes her presence at the end, as she was the only family member to support Alice’s struggles with AD. AD comes to connect them and strengthen their relationship.

I argue that, due to AD, Alice learns to respect the dramatic arts as Lydia’s career choice because she understands the value of the arts for life. In the intra-active relational artistic encounters that generate Kushner’s drama play *Angels in America*, Alice feels Lydia and recognizes her talent, while Lydia perceives Alice’s inability to speak as an ‘enviable skill’ (Genova, 2015: 191). While Alice’s personal relationship with Lydia grows inspiring agency, her marriage to John falters. John embodies the biomedical enactment of AD and its failure (Falcus, 2014). The failure of the biomedical enactment is underlined by the circumstance in which Alice becomes affected by AD in her fifties. Although the film emphasizes the power of dramatic arts for differential becoming with AD, it also normalizes the biomedical ontology of AD as a dreadful communicable disease—caused by a mutant gene. This ontology, which excludes living matter and its perceptual and personal relations with the environment, reproduces stigma and feelings of guilt, pushing Alice to suicide.

After Alice forgets to say the word ‘lexicon’ during a guest lecture at California University, she meets Lydia, who is living separately from the rest of the family. While

Alice admires Anna and Tom for pursuing ‘real careers’ in law and medicine, she is convinced that Lydia is wasting her valuable time by acting in theatrical shows in LA (SA 2014, 7:23). Alice’s frustration grows when she realizes that John is financing Lydia’s acting. Alice and Lydia’s meeting culminates in the usual stony-faced silence: Alice wants Lydia to go to college, Lydia confidently resists. However, the camera ends the discussion focused on Lydia, supporting her point of view.

The major qualities that Alice cherishes in herself are her performances as a researcher and professor (Genova, 2015). Once affected by AD, she acknowledges sensuous ways of being in the world, mostly explored in arts that move beyond cognitive reasoning. Her ability to learn from AD is a courageous one, if we think about the ‘great fall’ that she experiences from internationally prized scholar in linguistics, teaching about the essence of language for communication (SA, 2014), to a dementia patient who loses her ability to speak. Genova (2015) describes this fall as causing Alice to feel less and less human, assuming that the ability to use language distinguishes humans from nonhumans. However, animal and disability studies oppose this distinction, revealing different, less rational ways of knowing, which function outside of logo-centric discourses (Åsberg et al., 2011). For instance, Weil (2006) describes how embodied feelings of touch and body language in human–nonhuman and animal–machine entanglements enable new sight built on compassion and communion. These material entanglements challenge the power of language and representationism to conduct

univocal constructions of reality that privilege word over matter and exclude ‘nonhumans’ from conversations. In contrast, ‘otherworldly conversations’ (Haraway, 2008: 157), which emerge in human–nonhuman animal encounters without appropriating and objectifying nonhuman animals, are respectful to differences, because none of the parties is ever the same after the encounter. In my adaptation of the ‘otherworldly conversations’ concept I also include other human–nonhuman relations that materialize connectivity in a multisensorial intertwinement of perceptual feelings. A photograph of Lydia with a dolphin illustrates that she has the ability to conduct such otherworldly conversations with nonhuman animals, using broad vocal and non-verbal signs for communication (SA, 2014). The film elicits otherworldly conversations between Lydia and Alice while discussing the play, in a material, intra-active process of remembering and forgetting. Flashing word mistakes do not really matter in their conversation where gesticulation and body expression convey feelings. We see how the play in a relational aesthetic encounter creates a world-in-themselves, and an environment of shared experiences and sorrow for friends who died from AIDS. (Latimer, 2012). Conversations during these encounters change Alice’s perception of AD. In addition, reviewing and analysing plays with Lydia buttresses Alice’s memory and enables her to see the depth of Lydia’s intellect and to love her (Genova, 2015). Simultaneously, Lydia can practice her roles, anticipating Alice’s affection:

As her ability to track what was said in complex conversations with many participants declined, Alice's sensitivity to what wasn't said, to body language and unspoken feelings, had heightened. ...[Lydia'd] said that she and other actors had to focus extremely hard to divorce themselves from verbal language in an effort to be honestly affected by what the other actors were doing and feeling. Alice didn't quite understand the distinction, but she loved Lydia for seeing her handicap as an enviable skill. (Genova, 2015: 191)

The film confirms that in her relationship with Lydia, Alice is 'differently abled' to articulate herself by other creative means than verbal language (Moser, 2000: 210). Their relationship remains reciprocal, unconditional, and personal, as Lydia decides to share her diary with Alice and have 'no secrets' from her. (SA, 2014, 56:24). Lydia is also the only one who asks Alice what it is like to have AD, and she accepts Alice's lived experience as a valid definition of the disease.

Their mutual becoming with AD inspires Alice's personal speech at the Alzheimer's Association conference, which enacts AD as a success (SA, 2014). In contrast to her previous frequent talks worldwide about language, Alice believes this is 'the most influential' speech of her life (Genova, 2015: 284), as she is at centre stage talking about her experience of living with the disease (SA, 2014). She reveals that she would not like to be regarded as a victim of AD; she is, rather, engaged in a constant struggle to 'stay connected' and appreciate the pleasures of life in moments that matter (SA, 2014: 01:07). Her speech is explicitly political because she insists that people with AD are profoundly more than the disease, how others see them, or how they see

themselves; ‘they’ are part of ‘us’, and who they become is co-constituted in an intra-active material-discursive process of becoming with us. The agency that emerges in this intra-active process never ends (Barad, 2007: 235). There are always new possibilities to matter, as Alice demonstrates in an entangled becoming with a marker and papers and audience waiting to be touched.

Towards the end of the film, as Alice’s short-term memory and ability to use verbal language declines, we see Alice and Lydia immersed in the play. They sit near each other. Alice absorbs silent movements of Lydia’s lips and eyewinks:

Nothing’s lost forever. In this world, there is a kind of *painful progress*. Longing for what we’ve left behind, and dreaming ahead.’ (*my emphasis*, 2014, 1:29:27; *Angels in America*, 2013: 300).

This monumental scene reveals that past and future are ‘enfolded participants’ larger than any individual (Barad, 2007: ix). There is no way to leave the past behind, as the past is writing the universe in its differential becoming, and the future is always present as an agential possibility. Lydia and Alice’s conversation enacts AD as a *painful progress* required also for other endeavours in life. In an ‘affective space’—presence of charged feelings of immediate closeness with Lydia—Alice feels and comprehends ‘love’ (Cataldi, 1993: 130). The intertwining of touch, vision, and hearing embedded in the environment demolishes the epistemic priority of vision as the dominant sense for reason and construction of reality (Cataldi, 1993).

In contrast to the relationship with Lydia that enables growth, concealing the profound meaning of AD, the relationship with John articulates decline and the reductive

biomedical imaginary around the disease. The film shows John avoiding watching Alice taking her pill dispenser and, later, looking at her with his ‘clinical eye’, objectifying her as one of his rats in cancer research (Genova, 2015: 151). The clinical gaze embodies biomedical normalisation practices that turn lived bodies into patients and objects of research (Foucault, 2003) with fixed boundaries, and cut off relational human–nonhuman ‘naturalsocial’ intra-active practices, replacing them with one ‘seemingly objective thing’ (Haraway, 1997: 143; 142). In a neurologist’s office—where Alice and John learn Alice might have inherited a mutation gene from her father, and possibly transferred it to her children—the gene as a fixed, self-generated entity becomes the most dreadful ‘thing’ to ‘have’, concealing the monstrous communicable disease of AD. The gene obtains the power to decide which lives are liveable and worth bringing to life (SA, 2014; Genova, 2015).² Without questioning the biomedical ‘technobiopower’ and its urge to establish control over ‘life itself’ (Haraway, 1997: 161; 137), the film normalizes the biomedical reality of AD and the related stigma. Alice feels guilty ‘having’ the mutation gene, and hates her father for ‘transferring’ it to her. Her children might hate her too, particularly Anna, who distances herself increasingly from her mother. Alice would rather have cancer than AD, as she would not feel like a social outcast (SA, 2014). John hates that AD is happening to them too, as he cannot bear staying with Alice and facing her decline. He decides to take advantage of a job opportunity in Minnesota, leaving Alice at home with

Lydia and caretaker Elena. John's inability to handle AD concludes with his cry at the end when he admits to Lydia: 'You're a better man than I am' (SA, 2014: 1:26:09). Genova (2015: 263) hints that perhaps John's reaction to Alice's AD triggers her decline, as he leaves her before she leaves him. After visiting a nursing home, where she cannot imagine herself living, Alice sets up cognitive criteria for suicide. However, as the title of the film suggests, Alice remains present in physical and emotional relations with her family, especially with Lydia (Falcus, 2014).

AD enacted as creative force, kiss and touch: Martin and Barbara

A Song for Martin (2000) is a Swedish drama directed by Bille August based on Ulla Isaksson's memoir *The Book about E* (*Boken om E*, 1995). In her memoir, the well-known Swedish screenplay writer elucidates how AD shook the last five years of her marriage with literary critic Erik Hjalmar Linder. The film constructs the same narrative in a shorter form, following middle-aged music professionals, Barbara and Martin.

The focus of the story is orchestral concertmaster Barbara Hartman, who falls in love with the famous composer Martin Fisher and divorces her husband, with whom she has two grown-up children, to marry and live with Martin in creative symbiosis. Barbara mentions what a 'great experience' it is for her to play Martin's music (*ASfM* 2000, 6:32). As concertmaster, she improved Martin's compositions, giving him fruitful comments and revising mistakes. They enjoyed a mutual collaboration that was 'the basis of their

life' (Isaksson, 1995: 75). To feel secure in his love, Barbara asks Martin to promise that he will never leave her and that they will always be honest and sincere with each other. As Martin gets AD diagnosis, Barbara is the first one to break the promise. AD comes to change the dynamic of their relationship and put their love on test. Barbara's patronizing behaviour and feelings of distrust, defeat, and negligence separate Martin from Barbara under a 'comfort blanket' (livstäck) that he keeps just for himself: 'He feels all the time that the comfort blanket is going to slide off him and that he must grab it again and again and try to hold it still' (Isaksson, 1995: 141).³ Their collaboration ceases as Martin turns his resentment and anger on Barbara, whose life fades into the shadows because of pain and guilt that she feels. Although Martin does not allow Barbara to transcribe his opera, working on it brings Barbara back to life, keeping his presence still vivid.

I argue that, although AD causes both the emotional and, eventually, the physical separation of Martin and Barbara, this does not imply that their relationship is lost. Music strengthens their relationship and sustains their connections with the world. In an intra-active multisensorial encounter between Martin, the piano, and Barbara, AD is enacted as kiss and touch. In addition, the film shows how Mozart's opera *The Magic Flute* triggers Martins' participation as a conductor, enacting AD as a creative force. While violin playing helps Barbara to overcome AD and her dependence on Martin, playing the piano reminds Martin of loss, so as the AD progresses he stops composing. Nevertheless,

his opera is constructed as a ‘distributed achievement’ of collective care agencies: Barbara, Martin’s manager, Martin’s daughter, and a philharmonic orchestra (Ursin and Lotherington, 2018: 62). The film also showcases Barbara as more affected with AD than Martin, defeating the biomedical enactment of the disease.

The first argument is illustrated in a scene in a neurologist’s office in which she shows Barbara an image of Martin’s ‘deteriorated’ brain juxtaposed with a ‘healthy’ brain. In the medical imaginary, the brain becomes a self-sufficient organ for the naturalization of “‘appropriate’ human subjectivity’ (Åsberg and Lum, 2010: 333). The healthy brain is commonly an embodiment of white, middle-class, Western, male humanness, an authoritative rational subject in control of own body and of relations with distanced others and the environment (Åsberg and Lum, 2010). This imaginary reinforces hierarchical dualisms between body and mind, subject and object, human and nonhuman, and excludes all who misfit the ‘able-bodied’ world. Åsberg and Lum (2010: 331) demonstrate how the brain as a fetish ‘obscures the other ongoing material processes and the cultural work that it takes to sustain this racialized and gendered understanding of human identity’. The neurologist advises Barbara: ‘I think it’s best if you try to see that Mr. Fisher is no longer your husband. Not the man you’ve been married to’ (*ASfM* 2000, 1:36:36). The camera emphasizes her amazement with a close up on her face that reveals disapproval and accusation. Her husband and the man she has always admired, Martin, is reduced to impairment: frail, elderly, and a burden (Latimer, 2012). In the next shot,

Barbara invites Martin to sit in front of his piano and his handwritten compositions in their house. She plays the symphony from the concert when they met and fell in love. ‘Play, Martin’, she says, placing his hands on the piano (*ASfM* 2000, 1:38:34). In this intra-active multisensorial encounter, Martin pronounces Barbara’s name. Barbara’s touch and kiss awakens its meaning—that she is his wife.

Field (2014) remarks that touch is the first of all the senses developed through human evolution and it is disproportionally allocated throughout the whole skin, but increased in the lips and fingertips. Although acknowledged as the first and most general sense, touch never held the privilege of a ‘superior intellectual’ sense like sight and hearing – and its meaning was gendered (Korsmeyer, 2004: 86). Together with taste and smell, touch belongs to the ‘lower bodily animal’ senses that are embodied physically in the environment, in contrast to sight and hearing, which function in proximity, at a distance from the environment (Korsmeyer, 2004: 87). Therefore, touch disrupts the dominant, reflective, masculinist ‘economy of gaze’ that favours detachment, clearness of sight, and completeness (Shildrick, 2001: 393, 2); a scientific, disembodied, infinite, and fixed vision characteristic of ‘male supremacy’ (Haraway, 1991: 188). In contrast, situated vision and mutual touch acknowledge processes of becoming-together as changeable bodies and minds, always fluid, leaky and in partial differential connections (Shildrick, 2001). Therefore, the five senses never function in isolation, they constantly intra-act with each other and the environment in synergy; so Martin remembers Barbara

in the multisensorial embodied experience of touching, seeing, hearing, smelling, and even tasting (Fürst, 2014). Their relationship rests on reciprocal and lucid moments when they ‘communicate with each other beyond words and habitual caresses...’ (Isaksson, 1995: 130). Even though Barbara has packed away all her memories of their past life from her everyday life, ‘everything still remains’ (*ASfM* 2000, 1:45:50). Memories are not written in individual brains, but in ‘enfoldings of space-time-matter written into the universe’ (Barad, 2007: ix).

How we learn to enact our everyday practices, and how we remember ourselves entangled in those practices, is not just registered in the brain, but also in our skin, hands, fingers, legs, and other parts of the body and environment (Mortimer-Sandilands, 2008). This claim is supported in a scene in which Barbara takes Martin to see the Mozart’s opera *The Magic Flute* (*ASfM* 2000, 1:12:10). On the way there, Barbara reminds Martin how he was fascinated by a certain passage in the opera played in a minor key. Martin does not know what Barbara is talking about, drawing attention to the moose-crossing sign that appears on the road for a moment. However, in the opera hall, he hears the passage in question:

PAMINA: Wherever you go, I shall be at your side. – I myself shall lead you – Love is my guide ...[
Pamina hands the magic flute to Tamino to help them pass all trials]... She will strew the way with
roses, for roses are always found with thorns. Play on your magic flute; it will protect us on our way.

Martin immediately stands up, singing loudly and conducting excitedly:

In a magic hour, my father cut it from the deepest roots of a thousand-year-old oak amid thunder, lightning – storm and rain. – Come, now, and play the flute! It will guide us on the dread path (ASfM 2000, 1:13:50; The Magic Flute, 32, my emphasis)

The irony is that his participation and joy, his awakening, breaks the illusion of the play on-stage. Martins' artistic elation is a 'matter out of place', so Barbara tries to calm him down (Douglas, 2003: 36). She drags Martin out of the auditorium, confused like a child, as a flash of painful remembrance arises in which he held the central place on the stage. We are invited to empathize with Martin and his struggle to stay connected. The audience in the auditorium is not aware that another love scene between Tamino and Pamina is happening right among them. The magic flute in Mozart's opera embodies the power of music to keep Martin and Barbara's relationship alive. The opera passage demonstrates the 'aliveness' of matter, active in its materialisation (Barad, 2007: 33). Mortimer-Sandilands (2008) notes that, in particular, kinesthetic memory and perceptual relations between people with dementia and their environment (i.e., bodily motions and rhythm) remain active even when cognitive memory and reflexive relations undermine them. In this way, Martin's further participation in the opera is constrained by cultural context and norms, and Barbara feels they are not 'normal people' anymore (ASfM 2000, 1:14:55). They must leave the last place Martin could still truly feel connected, as his enabled connectivity contributes to stigma around AD. The passage from the opera enacts AD a creative force, demonstrating the power of a 'needy body' to 'open up for political

relatedness' (Vaaitinen, 2015:113). This opening-up 'breaks down' the illusion of 'normal able-bodied' embodiment, revealing its co-constitutive political relatedness with the 'disabled' body in need (Barad, 2007:158). However, such co-constitutive relations may end up in care, neglect, or exclusion, as in this case.

Although violin playing helps Barbara to overcome AD, as writing does for Isaksson (1995: 15), '[i]t was never like "writing" – it was like vomiting or screaming'. When Isaksson (1995: 15) finished writing, she would 'flush it down the toilet' and immediately forget what she had written, because it was shameful to remember such 'excrement'. Likewise, the penetrating and shrill sound of Barbara's violin imitates Isaksson's painful writing in an attempt to express her despair. In contrast, Martin could not continue to play. In self-defence, deprived of work and the joy of composing music, he destroys their transcripts and breaks the neck of Barbara's violin – 'her fingers' (*ASfM* 2000, 1:25:35). Barbara beats Martin and runs out barefoot to a nearby forest. She stretches her arms upwards against a hard pine trunk, tearing her palms against the rough bark while screaming into the sky (*ASfM* 2000, Isaksson, 1995).

Barbara's fear of speaking out about violence is due to her internalization of guilt in the normalization practices of symbolic domestic violence, in which the dominance of men is legitimized (Bourdieu, 2004; Thapat-Björket et al., 2016). Her resistance is an adaptation to the situation, and self-harm is a way for her to establish control over her body or even reduce the anxiety that could lead to suicide (Thapat-Björket et al., 2016;

Enander & Holmberg, 2008). Her subservient role, apparent throughout, further strengthens the progression of AD. Barbara sacrifices her life to one man at the centre of her universe, who accuses her of deceit and inadequate care. ‘You are the biggest and the most beautiful man on this earth, Martin!’, she says at the very end (*ASfM* 2000, 1:48:32). She puts her career on hold to care for Martin and work on his opera. She sees his success as her own success. She returns to playing violin in the orchestra only after Martin is hospitalized. Nonetheless, Martin does not acknowledge Barbara’s care, as if care is self-evident for women (Allen, 1996). Martin physically confronts Barbara in front of witnesses and leaves for further investigation. On the way to hospital, he accuses her: ‘You betrayed me’ (*ASfM* 2000, 1:29:13). He relies more on institutional care than on Barbara’s care at home because in the nursing home he is relieved of her expectations. He also wants Barbara to continue with a new life: his gesture is, as Martin’s daughter Elisabeth comforts Barbara – ‘the last care for her’ (*ASfM* 2000, 1:33:46).

Comparative analysis and discussion

Both films showcase that Alice and Martin are dealing with their disease more confidently than John and Barbara. However, while Martin and Barbara share feelings of isolation and stigma, Alice mostly experiences those feelings alone. In contrast to Martin, Alice feels the financial and emotional burden of caring and cannot imagine life in a nursing home (Genova, 2015; SA, 2014). One reason might be the high feminization of care at

home and in nursing homes that both films depict. Furthermore, Martin does not consider suicide an option as Alice does, but he does almost drown Barbara during her attempt to save him on their holiday in Morocco. Martin is aggressive towards Barbara—he breaks her violin, her only way of fighting AD; Alice is aggressive towards herself. Nevertheless, neither Alice nor Martin can enact their practices efficiently after being affected by AD—Alice stops teaching, Martin stops composing. Via multisensorial relational encounters with and through dramatic art (Alice, *Angels in America*, Lydia) music (Martin, *The Magic Flute*, Barbara), and instruments (piano, violin, marker) they became differently abled to communicate. Yet, in contrast to Alice’s reciprocal, unconditional relationship with Lydia, Barbara’s relationship with Martin remains uneven, perhaps explaining why they do not manage to finish his opera together.

The comparative analysis reveals that gender supersedes AD. It is not just that John’s treatment of Alice, which embodies biomedical fetishist practices, is gendered and gendering, but also that these practices are not present in Barbara’s *carrying* of Martin (Vaittinen, 2017). Barbara invites Martin to see *The Magic Flute* and engages to finish ‘his opera’ (*ASfM* 2000, 1:47:23). Johan leaves to take on a new job opportunity. Barbara stops working as a concertmaster. Devaluing sensuous relational becoming with AD under cognitive mastery—something her husband appreciates most—Alice wants to kill herself. Barbara too is unable to express her despair —would self-harm relieve her pain?

Even so, Alice and Barbara are keen to maintain their relationships with John and Martin, who conversely avoid sharing feelings with their spouses. Both John and Martin retain authority in their relationships and stand in an ambiguous relation to *care* as a corporeal relation (Vaaitinen, 2017). Martin does not acknowledge care from Barbara—John refuses to care for Alice. Their stereotypically gendered approach to care has severe material consequences for Alice and Barbara's bodies.

Hence, both films reveal how gendered binaries and practices of dementia care repeat themselves iteratively, co-constituting uneven spousal gender relations and reproducing societal norms and expectations, consistently affecting women's bodies more than men's, both as people with dementia and as next-of-kin. This coincides with research finding that female next-of-kin feel a greater burden of care than male next-of-kin (Pöysti et al., 2012) while men with dementia show more aggressive behaviours (Gibbons et al., 2014). Consequently, both films demonstrate structurally the performative repetition of hierarchical modes of knowing AD, whereas artistic modes of knowing AD do not matter to neoliberal economies as the biomedical ones. This is consequential for how we think about ADD and live or die with the disease.

Conclusion

Both *Still Alice* and *A Song for Martin* represent living with AD as dreadful and damaging to relationships but also defeasible in artistic encounters. The films illuminate

the embodied and situated nature of the disease and its power to connect and strengthen but also dissolve relationships. The biomedical enactment of AD as a dreadful neurodegenerative disease is embedded in the narratives, yet it does not have to be.

The mutated gene and the deteriorating brain as fetish appear as just one possible enactment of AD: unliveable ontologies that lead to a dread path. The film demonstrates that different socio-material relations, combining nonhuman and human agencies in concrete time-space-matter, participate in the ‘mattering’ of the disease.

Biomedical ontologies do not come to ‘matter’ in relationships that entail relational, multisensorial encounters between human and nonhuman agencies in the embodied state of becoming with the disease. In particular, nonhuman–human multisensuous intra-actions in artistic encounters acknowledge multiple post-human modes of becoming with AD that challenge binaries of body and mind, passive and active, human and nonhuman. These encounters may innovatively contribute to dementia care, expanding space for agency and connectivity.

Notes

1. Haraway’s (1997: 142) concept of ‘corporeal fetishism’ that Åsberg and Lum (2010: 342) utilize stresses the biomedical focus on the examination of the brain and its internal ‘micro-biological puzzle-solving’ processes in search of a cure (Moser, 2008). From Marxist theories, Haraway draws on ‘commodity fetishism’, the objectification and investment of value into one thing, such as money. From psychoanalytical theories, she incorporates fixation on one object of desire and

disavowal, which requires balancing between knowledge and beliefs. The object of desire becomes a master of ‘life itself’ while a fetishist is aware of (his) false investments—he both desires and fears losing control over the ‘switch’ (Haraway, 1997: 144, 146). In her elaboration of ‘corporeal gene fetishism’ in comparison to commodity fetishism, Haraway (1997) includes nonhuman actions (not just actors involved), and in comparison, to psychoanalytical fetishism, gives a feminist critique from the standpoint of a woman.

2. Alice asks herself if she would have conceived her children if she had known that she was caring the ‘deformed gene’ (Genova, 2015: 115). Anna ‘saves’ her babies from the dreadful gene through pre-insemination genetic testing of the embryos (SA, 2014; Genova, 2015)
3. Both memoir and film are originally in Swedish and all translations are mine.

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