

***Conference Review: Dementia and Cultural Narrative Symposium***  
Universities of Aston and Huddersfield, December 8-9, 2017.

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The inaugural symposium of the Dementia and Cultural Narrative Network in December 2017 appeared at a critical juncture in not just health and medical discourse but also popular culture. As opening presenter Susanne Christ pointed out, in the week preceding the event, *The Late Show* host Stephen Colbert asked if it was “okay to say the ‘D’ word” about U.S. President Donald Trump yet. The comedic euphemism Colbert doled out on national television is indicative of dementia’s current place in the public imagination as a humiliating, delegitimizing mental impairment to be approached with apprehension, if not best wielded as a political slur.

The symposium sought to interrogate the myths and fantasies that have accumulated around Alzheimer’s disease and dementia in the twenty-first century. “A death sentence without an execution date,” “an apocalypse on the horizon,” “a silver tsunami”—such are the kinds of metaphors readily found across a variety of media, from news and health communication headlines to filmic and literary productions. Amongst symposium participants was a shared camaraderie and sense of purpose to provide counter-narratives to the stigma and fear these rhetorics produce.

A diverse participant roster showcased the interpretive possibilities emerging within this new subfield of dementia studies. Bringing together an audience from countries such as Sweden, Germany, Canada, the Philippines, and United States, the symposium’s conversations were international as well as multidisciplinary. Presenters included scientists-turned-health-humanities scholars, graduate students in fields such as social anthropology and creative writing, community activists, and professionals. Given the sheer breadth of approaches, each of the untitled sessions might have benefitted from an articulated theme to help focus conversation and delve deeper into shared issues. To that end, in lieu of a summary of panels, below are some of the symposium’s key lines and methods.

Literary studies was most heavily represented across genres of fiction and life writing, from first-person novels and poetic forms to children's picture books and graphic memoirs. Presenters' explorations of the ethical implications of dementia's thematic and narrative functions raised questions about rationality and memory as the basis of personhood, the limits and possibilities of language, and the politics of forgetting. In her analysis of dementia in Holocaust narratives, Sue Vice provocatively asked whether forgetting Auschwitz is a blessing or a curse. Often used as fodder for "existential thriller," dementia makes visible the tensions between historical and age-related forgetting in the face of irreparable trauma and injunctions to "never forget." Salud Mora Carriedo's literary-poetic portrait of her mother's living with Alzheimer's attempted to capture the "grace of forgetting" (in both the sense of its elegance and deliverance) and the importance of honoring the "here and now" to forge meaningful connections.

Aagje Swinnen's keynote set a strong tone for including the voices of "ordinary" readers in literary scholarship. Tracking the changing attitudes of age-sixty-plus reading and writing club members responding to the Flemish novel *Stammered Songbook*, Swinnen showed the power that discussing literature had in altering readers' fearful preconceptions of dementia and their beliefs in euthanasia. Swinnen illuminated the importance of literature's ability to cultivate an "ethics of resilience" by bringing about empathetic reflection on oneself and others.

A conversation about logocentrism emerged from these text-based analyses. By focusing on the person with dementia as a writer and the writerly expressions of dementia, might we be overlooking the richness of communication beyond the word, such as the haptic, kinetic, and musical? Refreshingly, a screening of Marlene Goldman's film, *Piano Lessons*, did offer a more sensory-based, person-centered perspective of Alzheimer's.

Beyond the literary, presenters also examined dementia in a variety of visual/verbal mediums from which a surprising number of interdisciplinary approaches emerged. Invoking life writing studies and performance theory, Janet Gibson argued the "unreliable" narrator living with dementia undermines

understandings of the “real” in verbatim theater, challenging the privilege placed on the truth-value of stories—a damaging expectation for those who cannot remember. In Singaporean cinema, the trope of the wandering person with dementia brings past into present to explore individual and national trauma, as MaoHui Deng argued in his postcolonial film analysis of Boo Junfeng’s *Parting*. In a close reading of pharmaceutical advertisements and media headlines at the intersection of aging studies, feminist theory, and queer theory, Linn Sandberg showed how heteronormative scripts of happiness predicated on able-bodiedness shape images of successful aging.

The importance of returning critical work to the ethical core of supporting caregivers and people with dementia directly was a concern resounding throughout the symposium. Dementia advocate June Hennell’s keynote about her late husband Brian Hennell staked out the importance of storytelling as witness and an act of care. Hennell’s stories resisted the end-of-life “zombie” narrative and attested to the richness and light, as well as the promise of imagination, that dementia brought to their lives.

By the symposium’s end, the politics of claiming and naming dementia remained an important topic. As participants asked, should we use the word *demented* if that is how someone self identifies? Is person-first language always more appropriate (i.e., “people living with dementia”)? And can the word *demented* be reclaimed as the terms *queer* and *crip* have been? These questions are best culturally situated, as scholars take heed from Christina Douglas’ concluding talk on “demented” as a political, rather than biomedical, diagnosis in Romania. Used to describe one’s support of “regressive” communist ideologies, *demented* is a nationally specific term; not all terms can be recuperated in the same ways.

Following the disability rights mantra, “nothing about us without us,” it remains necessary to continue the work of analyzing dementia in cultural narrative while also ensuring space for people with dementia in our conversations. What shape might the next symposium take if it more strongly prioritizes aging community members and those living with dementia? If participants more frequently prioritized modeling access in their presentations

(i.e., through multimodal interaction, large-print access handouts, audio descriptions of images, and closed captions)? Indeed, at the heart of the symposium is its contribution to enriching *both* theory and praxis surrounding dementia as well as experiences of disability, illness, aging, and embodied change so intrinsic to the human experience.