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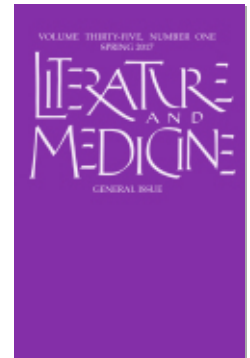
## Alzheimer's Disease Metaphors as Mirror and Lens to the Stigma of Dementia

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Literature and Medicine, Volume 35, Number 1, Spring 2017, pp. 71-97 (Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/lm.2017.0003>



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# Alzheimer's Disease Metaphors as Mirror and Lens to the Stigma of Dementia

Martina Zimmermann

[M]etaphors may be as necessary to illness as they are to literature, as comforting to the patient as his own bathrobe and slippers. At the very least, they are a relief from medical terminology. If laughter has healing power, so, too, may metaphor. Perhaps only metaphor can express the bafflement, the panic combined with beatitude, of the threatened person.

—Anatole Broyard, *Intoxicated by My Illness*<sup>1</sup>

In an attempt to create meaning during the autobiographical disruption experienced in illness, patients run to the healing powers of telling their story. The act of assigning meaning to specific events in an illness process has been shown to have healing effects.<sup>2</sup> In particular, metaphors “enable people to recreate a sense of continuity, . . . [providing] a transforming bridge between the image of the old life and the new one.”<sup>3</sup>

The present work is concerned with the additional complication posed by the narration of a disease defined by cognitive decline. This is of particular interest since writing is always also a process of making memory and, thus, creating and maintaining the self: how do individuals with impaired memory preserve their identity?<sup>4</sup> Self-preservation in this scenario must also confront culturally dominant images of dependence, decline, and passivity. But just as the act of writing per se is a statement against such images, Alzheimer's patients' telling becomes a platform for the creation of a dementia counter-discourse that emphasizes their continued agency.<sup>5</sup> I specifically want to understand

how patients define themselves in and through their narratives' form, content, and metaphors.

Alzheimer's disease is the most common form of dementia among the elderly in the developed world; it is a progressive, degenerative, and irreversible condition that has become a synecdoche for all kinds of dementia. Yet, its pathogenesis remains elusive despite much intensive research.<sup>6</sup> Patients receive the diagnosis of a cognitive disorder of terminal character, for which pharmacological treatments have only limited ability to control symptoms. The brain areas particularly affected are the hippocampus and cerebral cortex, which together harbor our ability to memorize and abstractly reason. Symptoms are largely of neuropsychological character: the loss of memory, the impaired ability to understand or produce speech, and the inability to recognize things or people. In the early stages of their condition, patients are aware that their mental acuity continually declines and their perception of the individual they used to be gradually disappears. Patients afflicted by the early-onset form of Alzheimer's disease are as young as forty-five at the time of their diagnosis and account for approximately two percent of patients diagnosed, while the more well-known late-onset form is defined as afflicting individuals aged sixty-five years or older. Regardless of their age of onset, patients usually have five to ten years between diagnosis and death, passing through different stages of the condition.<sup>7</sup> Early stages still allow for patients' self-articulation, while later stages strongly limit intellectual performance and make them dependent on caregivers for everyday tasks.

Set in the context of the condition's current medico-scientific outlook, this study has two aims. First, I want to give an overview of key metaphors that patients and caregivers use to put their experiences with a *chronic degenerative, cognitive, and incurable* disorder into words. Second, I want to analyze how these images mirror their views of the condition and, especially, their narration of cognitive decline. Some of the images discussed may not be new or unique to dementia. However, as they resonate (or not) with the depiction of other conditions (I am thinking of diseases like HIV/AIDS before effective pharmaceutical treatments were developed, terminal cancer, and other types of brain damage like stroke), their explanatory potential for the dementia patient is further highlighted by current disability studies discourse. Especially where patients and caregivers use the same metaphor but impose very different meanings on the image, the political intent of patients' writing becomes clear. While single aspects of the triad—chronicity, cognitive degeneration, and incurability—are

core characteristics of other conditions, their combination makes them key to understanding the dementia experience. This approach will help us appreciate whether patients and caregivers perceive the condition as similar to, or fundamentally different from, other diseases. It will also put Alzheimer's disease further in perspective, as we can better understand what it is about the condition that Western society, in particular, so fears.

The essay's first part explores the metaphors patients use to describe their condition, and analyzes how their narrative strategies fit with these images. It also looks at how caregivers depict their patients and attempt to narrate their stories. Since patient and caregiver have different agendas motivating their writing, I limit myself to looking into metaphors that directly refer to the illness itself, not the caring experience or other concerns of the caregiver. Comparing the patient's to the caregiver's telling will highlight the discrepancies between their perceptions of the illness and draw attention to the patient's assertions against a reifying discourse that is often found in caregiver stories. But metaphors are not only a mode of verbal articulation that mirrors the narrator's perception. They are also, as George Lakoff and Mark Johnson explain, a concept of thought and action.<sup>8</sup> They structure basic understandings of our experience, and can influence our actions in relation to this experience. Comprehending, for example, the human mind as a machine helps to grasp the systematic and methodical nature of thought processes; at the same time, this image may lead to conceptualizing and potentially treating an individual as "broken down" or "dysfunctional" when an illness is perceived to threaten that individual's mind. As such, metaphors can focus, like a lens, on the core concerns transported in the images related to the condition.<sup>9</sup>

My explorations of how patients and caregivers write *about* the condition are followed by a second section analyzing the images, metaphors, and concepts they are writing *against*. This approach will pave the way to better understand why they choose specific images for their condition in the first place. As I show, caregiver texts tend to feature concepts of loss, dependence, and passivity—concepts these narrators borrow from the scientific and medical texts from which they quote. This medico-scientific discourse reinforces caregiver presentations of the disease by supplying references supporting specific claims. But this support extends to the level of metaphor as well: caregiver texts draw on the metaphors used by scientific researchers, and both contribute to the larger societal conceptualization of dementia. This conceptualization is condensed in society's use of the term "Alzheimer's"

as a metaphor in its own right for larger biological and social ills. The situations and contexts in which this trope appears draw attention to the biomedical aspects of the condition that are most dreaded by society: the Alzheimer's-as-metaphor zeroes in on the patient's old age, inertia, and passivity, reinforcing exactly those concepts patients themselves resist most strongly.

The narratives analyzed here originate from countries on either side of the Atlantic and are meant to represent the Western world, where, due to changing demographic structures, Alzheimer's is diagnosed with increasing frequency. (While I limit my analysis to Western societies, I do not want to suggest that age-related cognitive decline does not also challenge more and more Eastern countries.) Publication dates range from the early 1990s, when first dementia memoirs were published, to today. This selection aims to reflect the panoply of dementia narratives. Even though most caregiver stories are authored by women, I include quotations from John Bayley's memoirs of his wife's illness.<sup>10</sup> His narratives have been widely analyzed, but, to my knowledge, never discussed in direct relation to patient accounts. In addition, his story presents—as an early and the most prominent caregiver account—a point of reference for later caregiver memoirs. Andrea Gillies, for example, explicitly writes about the inspiration she took from Bayley's narrative.<sup>11</sup> Since the majority of the patients who actually publish their stories write with the support of a family member or professional writer, I include Diana Friel McGowin's narrative as one of the earliest patient accounts in the field and Jeanne Lee's story as documents of collaborative life-writing.<sup>12</sup> As the only available diary I take Claude Couturier's records from the French language, and include Thomas DeBaggio's piece as the narrative of a professional writer and journalist.<sup>13</sup> I see these authors as having gained a prominence that compares to that of Bayley or Gillies.<sup>14</sup> DeBaggio, for example, was interviewed on National Public Radio and appeared on Oprah Winfrey's show, while Lee gained popularity as one of the founding members of the Dementia Advocacy Support Network.<sup>15</sup>

## I. Dementia Metaphors: Mirroring Patients' Fears of Alzheimer's

### *Counter-Narrating Chronic Degeneration: The Journey of No Return*

One metaphor frequently used by both patients and caregivers is the image of the "journey." But patients and caregivers deploy this

figure very differently. The title of McGowin's narrative *Living in the Labyrinth: A Personal Journey through the Maze of Alzheimer's* combines the metaphor of the journey with the image of the labyrinth, conveying her sense of a lack of direction and orientation as she faces Alzheimer's disease. She frequently uses the image of the labyrinth or maze when describing spatial or temporal disorientation. While the subtitle itself suggests that she experiences dementia in terms of a journey, her account instead places its emphasis on specific events. Individual chapters illustrate various aspects of living with dementia, such as "Early Retirement," "Sexuality," or "Fears," rather than a chronicle of her descent into memory loss; this structure may be an attempt to resist, or even deny, her fear of mental confusion, the fear that she would "deteriorate to the point of totally losing myself" (104).

Her choice of presentation helps conceal the increasing disorientation that would become visible in a chronological account, and which would reveal her to be truly locked inside a labyrinth. This is especially relevant since she claims already in the "Introduction" that: "The Alzheimer's patient asks nothing more than a hand to hold, a heart to care, and a mind to think for them when they cannot; someone to protect them as they travel through the dangerous twists and turns of the labyrinth" (viii). Indeed, support in composing this eloquent narrative comes from McGowin's husband, whose contribution is only revealed in the narrative's epilogue. As also observed by Anne Davis Basting, Jack McGowin's help is certainly suggestive of his wife's need to be guided through the labyrinth. But it prevents us from perceiving McGowin's disease-related lack of orientation within her narrative, as she instead offers a well-structured and accomplished account.<sup>16</sup> Such an articulate presentation may well be aimed at convincing the reader of McGowin's continued self-sufficiency, with her narrative matching traditional forms of illness representation.<sup>17</sup>

The journey metaphor typically comprises the patient leaving her familiar environment, departing to a realm that is unknown to her, that is the illness itself, and then returning from this journey enriched by the experience.<sup>18</sup> It imagines the illness experience as one of change and otherness in relation to the normality of the healthy. Most importantly, this image traditionally implies that the patient will return from this journey (healed or in remission) feeling wiser, and will resume life accordingly. Therefore, the formulation of the illness experience as journey will only work partially for dementia patients, given that their medical condition precludes them from "coming back" from their illness experience. They are instead on a "journey of no return."

The journey metaphor works much better—if we remain in the area of conditions related to brain damage—for patients having undergone a stroke. It emphasizes the emotional stages of awareness during the patient's slow progress of recovery, which brings her/him back to a new, though altered, state of normality. The title of Robert McCrum's *My Year Off: Rediscovering Life after a Stroke* suggests such enrichment. The narrative embodies McCrum's return, which the forty-two-year-old journalist describes as follows: "The first year after illness struck was dominated by the struggle to become physically better. The second year . . . would be all about psychological well-being and the battle with the demons of despair and depression. But now, at least, I could begin to mix hope and optimism with sadness and gloom."<sup>19</sup>

However unlikely, the formulation of the journey myth works for dementia patients who describe themselves as wiser because of their illness experience. For example, they illustrate their insights gained in the confrontation with progressing degeneration, namely the deep understanding that they have to seize their lives now, while still aware of themselves and able to write. In this awareness they present narratives that are as accomplished as their author-narrators would like to remain. In her chapter "Doing What I Can" in *Just Love Me: My Life Turned Upside-Down by Alzheimer's*, for example, Jeanne Lee claims: "I certainly don't consider myself a hero, but I do know that I get a great deal of satisfaction when I do even simple work for others, knowing it was done to the best of my ability" (42). Further on, in her chapter "Living in the Moment," she contends: "The past is past, and because it no longer exists it is beyond our control to do anything about it . . . . Likewise, the future does not exist and so it also is not within our control and not worth giving any thought to. The only way to positively influence the future is by living this moment, right now, the best way we know how" (71). Lee openly admits that her book, which is, like McGowin's, organized by themes rather than a temporal sequence, could only come to life with the help of a professional writer. But as she fulfills her ambition to achieve the publication of a personal narrative in her condition, the book becomes the surrogate of her continued agency: her text supports fellow sufferers, even after she is unable to articulate this support herself.

Where those who stay behind—that is caregivers and family—use the metaphor of the journey, this image signifies very differently. Rather than presage the return of the narrator, it gives structure to caregivers' (or others') estrangement from the patient, particularly the fact that communication becomes so difficult. For example, during her

husband's decline, Nancy Davis Reagan memorably stated: "Ronnie's long journey has finally taken him to a distant place where I can no longer reach him," conjuring an image of the two of them spatially separated by mental alienation and of the patient as being swept along. The fact that the former President has traveled and, at the time of the quote, continues to travel to a far-away place, deflects attention from the preconceptions attached to an Alzheimer's patient, who is no longer in command of the nation or himself. Portraying him as on a journey avoids the need to spell out how pitiable is the distant place of regression the former President has reached. While terms such as "journey" and "distance" are neutral in themselves, they convey that Ronald Reagan is on the way somewhere far away from his wife and the American people. In suggesting both motion and change, the metaphor of the journey expresses Nancy Davis Reagan's distance and separation from her husband and, in this way, allows her to withhold any detail about her husband's cognitive, behavioral, and emotional state. This strategy achieves the dual aim of protecting Reagan's dignity and avoiding confronting the American people with the spelt-out truth.

How strongly a narrator's choice of metaphor is linked to her/his outlook becomes clear from an analysis of Floyd Skloot's *A World of Light*.<sup>20</sup> The forty-two-year-old poet and essayist suffered a viral infection that left him, within months, cognitively impaired. However, as early as the narrative's "Preface" he takes pains to distinguish his condition from his mother's dementia: "Over the last half dozen years or so, as I have moved closer to integrating myself and my world, my mother has been disintegrating, losing her self and its connection with the world as she slips deeper into the chasm of Alzheimer's disease" (xi). The narrative's construction brings out Skloot's understanding of the "light" in his situation and prospects. Its first part describes his mother's state, opening with a scene in the nursing home and the insight that, "memory is doing what it is designed to do, ridding itself of inessential matter, uncluttering. But as age-related dementia sets in, such forgetting intensifies and worsens, eradicating even the most essential matter, until nothing is left" (7).

As if wanting to sharply contrast the implications of his cognitive impairment to the worsening incurred by Alzheimer's disease, Skloot opens the second, central part of his narrative with the assertion that specific events "remain etched in my memory despite brain damage and long-term memory loss" (53). He offers vivid identity-defining memories from his past. The chapter eponymous to the narrative's title is placed in the formal center of the text and fluidly moves between



past, present, and future, anticipating the return to the present in the narrative's final part.

The story time significantly slows down as Skloot lingers on colorful images of his rich life for almost as long as on the introduction to the mother's limited life. He emphasizes once more that his "mother's mind is a meaningless dazzle of refractions and glimmers, winks of consciousness, cognitive chop," continuing that "her mind can neither be still nor organize itself, and there is no let-up from the chaos. Nothing coheres; nothing is stable" (190). He, instead, is in "A Stable State" (179), and has the prospect of "heading in a new and promising direction" (187), as the light metaphorically illuminates his mind.

*Cognitive States and Prospects: The Living Inanimate*

The above quotations suggest that Skloot can write about the cognitive aspects of his condition in less negative terms because he does not perceive his cognitive impairment to be of a chronic degenerative type. In what follows, I will take a closer look at how Alzheimer's patients understand their cognitive challenges to be inseparable from the condition's chronic degenerative aspects. To confirm Skloot's "lighted" view by contrast, Claude Couturier, in *Puzzle: Journal d'une Alzheimer* (Jigsaw: Diary of an Alzheimer's patient), describes disappearing into a "trou noir" (black hole; 33) to illustrate the uncontrolled, inexorable vanishing of her self and personality in mental, emotional, and physical terms. Blackness is identified with concepts of darkness and downward orientation; "sickness and death are down," as Lakoff and Johnson explain.<sup>21</sup> In the context of the memoir, Couturier's "black hole" adds to the directional notion of her experience and links to the conceptualization of illness as a journey. As patients aim to remain in control in a situation of chronic degeneration, the question is then how they manage to depict, and continue depicting, the cognitive aspect of their predicament, as their loss of mental acuity will, eventually, deprive them of further control.

In *Losing My Mind: An Intimate Look at Life with Alzheimer's*, the patient Thomas DeBaggio muses on the fact that he has "only a few years before I become a hatstand" and, further on, sees himself "rattl[ing] my cage but no one comes to feed me" (58, 185). He uses metaphors that strip him of his humanity and personhood and reduce him to an animal, if not an inanimate object. Such imagery suggests that patients perceive themselves as losing their agency and

dignity through the loss of mental acuity. This perception culminates in the patient's fears of being "shovel[ed] . . . into the ashcan" (200) and considered, as McGowin words it, "human refuse, without merit, without feelings" (105).

These images do not leave much room for interpretations that would focus on the patient's remaining abilities. At the same time, however, DeBaggio feels that he is "flooded with early memories preserved in protected places of my brain where Alzheimer's does not reign supreme. These memories become the last remnants of my search for who I am" (42). In this awareness he preserves his memories in writing. His narrative becomes the grasping of his self—in the fear of ending in-animate, once he cannot remember and write any longer.

Couturier contemplates her loss of personhood, anticipated familial neglect, and undignified end of life in similar language: "ils vont bien finir par me jeter comme une vieille chaussette trouée" (they will surely come to throw me away like a sock full of holes; 97). She compares herself not only to an inanimate object here, but to one that is being trodden on. In further expanding on the object's damaged nature, she includes the condition's deleterious bearing on personhood as well as its impact on physical and psychological decline and related caregiver reactions. In particular, she is concerned about ending up in a vegetative state, an "existence . . . de légume" (vegetable existence), and would much rather "être incinérée" (be incinerated) under such circumstances.<sup>22</sup> Continuing "je serai un légume grillé" (I will be a grilled vegetable; 71), she pokes fun at such in-animate discourse. That said, Couturier's use of suspension points suggests her hesitance to enter into a discourse of dehumanizing symbolism. She confirms this assumption, when later claiming that "[l]a vie ne vaut d'être vécue que dans le partage, sinon on végète" (life is only worth living when shared, otherwise one vegetates), immediately adding in brackets "tiens, me voici à nouveau dans les légumes" (look, I am again with vegetables; 107), as if to draw attention to the harmfulness, but equally noteworthy the intuitiveness, of such imagery.

What I find most remarkable about Couturier's writing is that she finds imagery that does turn attention to her remaining abilities, while equally pointing to the horror of the disease. She compares herself to objects that are frequently associated with life-affirming symbolism, shifting our attention from the notion of the object's lifelessness to that of its hidden potential. For example, she has the impression "d'être un arbre en automne qui essaie désespérément de garder ses feuilles mortes, arrachées par un vent violent, et n'arrive plus à les remplacer

le printemps venu car ses racines ont été dénudées et ne peuvent plus se nourrir dans l'humus" (of being a tree in autumn, which desperately tries to keep its dead leaves that are being pulled off by violent wind, and no longer manages to replace them when spring comes, since its roots have been exposed and can no longer nourish themselves from the humus; 49). She transplants the tree, symbol of life and image of seasonal change, into the austere landscape of dementia, where the autumnal loss of leaves matches the patient's perception of decline. The image conveys Couturier's feeling of inescapable and increasing helplessness through the enforced passivity of the object (her self) and its exposure, including the leaves (her memories and qualities), to wind and weather (the illness).

Couturier's choice of images reflects her will to portray continued capabilities, while concomitantly acknowledging the condition's inescapable nature. The form and construction of her narrative follows the same principle. As G. Thomas Couser has observed regarding the form of the cancer patient's diary, it necessarily manifests Couturier's decline, with chapters becoming shorter over time as the reader moves forward in the story (just as the patient moves through her entries), fully aware that after one final date there will be no more entries witnessing the patient's esprit and humor.<sup>23</sup> Couturier's metaphor mirrors the form of her narrative: as the tree loses its leaves, the entries in her diary become shorter. And in living this metaphor, she shows the agency she still has: as long as the tree is standing, she tells her story. The water keeping this tree alive is her continued ability to put pen to paper, her doctor's encouragement to make the diary available in print, and the reader's recognition of her achievements.

A second metaphor pictures feelings of loss no less memorably, when the artist compares herself to "une bougie en train de s'éteindre à cause du courant d'air montant des profondeurs de l'abîme qui se rapproche inexorablement" (a candle about to burn out due to the draught rising from the depth of an abyss that approaches inexorably; 97). The candle (the person) consumes itself in shining (living); the light (the self), the very essence of the candle, is extinguished by the wind (the illness) without having any means to resist this process. While Couturier does not explicitly play on notions of the candle's flickering, I think it noteworthy that this metaphor can also convey ideas of motion, revealing the patient's feeling of being torn between the will to continue to be active and the perceived, cognitively enforced disappearance into passivity.<sup>24</sup>

Passivity figures centrally in caregivers' imagery describing patients' profound cognitive impairment and substantial erosion of memory. In *Keeper: Living with Nancy—A Journey into Alzheimer's*, Andrea Gillies, who looks after her mother-in-law Nancy, believes her relative to be "aware of the great buried store of memory, her past, her self, glimpsed under the tangles of Alzheimer's like a ruined house under the suffocating grip of ivy" (19). The brain is the home of the patient and her self; it harbors all that defines the self: Nancy's past and memories. While the "ruined house" image is the caregiver's attempt to imagine the quality of a life with dementia, it also portrays the patient as passive and defenseless, unable to take measures against the house falling down, her memories and self being lost. In fact, Gillies's narrative presents the story of her *own* grappling with caregiving rather than an attempt to record the parent's story that would hold on to Nancy's identity.<sup>25</sup>

Another powerful image describing the patient's passivity is the "empty shell" metaphor. In expanding the notion of emptiness to the patient's entire being, this image reveals how the caregiver understands the brain to be the core of the patient's self. Its emptying becomes equivalent to losing that self.<sup>26</sup> Caregivers' frequent use of metaphors that compare experiences to physical, hence tangible, objects highlights how difficult they find it to describe mental phenomena or grasp emotional issues. As Lakoff and Johnson explain, "[o]nce we can identify our experiences as entities or substances, we can refer to them, categorize them, group them, and quantify them—and, by this means, reason about them."<sup>27</sup> In picturing the mind as a machine, as an efficient and productive entity with an internal mechanism of its own, the caregiver conceives of the patient's incoherence and silence as a mechanical failure rather than, for example, as related to the patient's awareness of and upset about shrinking communication capabilities. In this context, Gillies imagines "the lights going out one by one" to simplify the far more complex reasons for and effects of her mother-in-law's silence (74).

Caregiver imagery of houses and shells refers to the patient's mind as the container of their memories and self. Its emptiness deprives patients of any further agency. This imagery is in stark contrast to how patients describe themselves: with images that convey animatedness and a still-rich memory. But although patients use imagery that conveys their continued agency, the question remains as to how they handle the fact that Alzheimer's disease continues to be an untreatable condition, which eventually will deprive them of the agency they seek to maintain. The following section addresses this question;

it will show that dementia patients use imagery very similar to that used by patients with other (non-cognitive) conditions to describe the incurability of Alzheimer's disease.

*Admitting Surrender to the Incurable: An Unequal Battle  
and the Limits of Expression*

In Skloot's recording of his illness experience closer to the time of diagnosis, namely in a series of poems collected under the title "The Virus," we read that he perceives of himself:

in a state  
of siege, a protracted cold  
war, I am occupied by an unseen  
enemy. . . . I have lost control,  
order is shattered, pockets  
of resistance crushed one  
by one. . . .  
I have seen myself  
become a factory of disease  
spewing internal acid rain,  
then become the polluted  
stream.<sup>28</sup>

According to Hawkins, the battle myth or war metaphor "serves to enhance the ill person's sense of dignity, self-esteem, and active participation in therapy."<sup>29</sup> These images work well for Skloot, as he perceives himself as the victim of a "viral assault [having] eaten away parts of my brain, the resulting damage showing up as scattered punctate lesions in the cerebral cortex whose effects left me totally disabled" (ix). He can make out a well-defined virus as his enemy, and the image of the war becomes even more supportive for him as a victory, at least "a stable state," becomes possible.

But can an Alzheimer's patient use the metaphor of the battle to describe a condition that is degenerative and incurable? The most striking metaphor for the inexorable, destructive power of dementia in the words of a patient comes from DeBaggio, who refers to the disease process as "biological war" and "the holocaust of my brain" (169). These images allude to the remorseless dying of brain cells, express pain in the face of relentless loss, and convey the inescapable situation of the untreatably ill. Notably, Elaine Scarry classifies both

biological war and holocaust as torture, not as war or battle, expanding on how experiences of this kind lie beyond the victim's powers of verbalization—which further underlines the speechlessness to come for DeBaggio when dementia overtakes him.<sup>30</sup>

While the illness-as-war metaphor crops up a few times in DeBaggio's memoir, he more frequently compares his diagnosis to a "death sentence" (e.g., 1, 37, 45), a verdict that leaves little room for waging battle. How strongly patients relate to the image of the death sentence—the absolute absence of a future—becomes clear from narratives of other incurable illnesses, like HIV/AIDS prior to the development of antiviral cocktails.<sup>31</sup> In confirmation of the explanatory power of colors and in stark contrast to Skloot's light, the title of Harold Brodkey's *This Wild Darkness: The Story of My Death* emphasizes the patient's awareness that "the sentence to such death" leaves little room for a positive outlook.<sup>32</sup> Consequently, Brodkey does not—even though, like Skloot, he is infected by a virus—appropriate the image of war.

However, what Brodkey does discover is, as Oliver Sacks writes about Anatole Broyard in the foreword to the latter's essays relating to his terminal cancer: "a tremendous, unprecedented freedom in being ill, a freedom (perhaps for the first time in his life) to say exactly what he wants."<sup>33</sup> In fact, Brodkey states that "I have no shyness now," and continues that he can, despite the awareness of the condition's sexual stigma, "without hysterics describe the anal diddling that probably led to the transmission of this virus and to my death" (28). It is consequential that Brodkey chooses the form of a diary, making the narrative's structure the true platform of his testimony: shorter and shorter entries separated by longer and longer intervals hide nothing of his wasting and nearing death.

Like Brodkey and Broyard, DeBaggio—who had given up his profession as a journalist for that of a herb grower—seizes his last chance, professing: "I was nearer to death than I anticipated. A few days later I realized good might come of this. After forty years of pussyfooting with words, I finally had a story of hell to tell" (1). In living up to this aim, he composes an illness narrative that skillfully illustrates mental deterioration, which suggests (I am echoing here Couser's insights into HIV/AIDS life-writing) that he transformed his initial view of his diagnosis as "tantamount to a death sentence" to that of a *life* crisis, and thereby changed his outlook and quality of life.<sup>34</sup> Yet the form of DeBaggio's narrative does not actually trace his cognitive decline, even though, according to the "Author's Note," his book "is an attempt to show the parameters of long- and short-term

memory and how Alzheimer's works to destroy the present and the past. To do this I set up three narrative lines" (xi). The narrative presents as a collage of page-long sections telling about DeBaggio's childhood memories, italicized paragraphs of random aphoristic thoughts, and extracts from medico-scientific literature. While this construction may seem suggestive of an Alzheimer's patient's lacking mental coherence, we perceive it as strategically constructed. But this strategy can only partly work out, because we are aware of DeBaggio's imminent cognitive limitations. This is also true because the disease-imposed absence of happy closure contrasts with DeBaggio's effort to offer a rounded and fully elaborated narrative.

The tension between the trajectory of their disease and their will to portray themselves as continuously competent and productive explains why dementia patients are in urgent need of imaginative language as "explanatory models," to be able to "communicate, and thereby symbolically control symptoms," without necessarily following through with a comprehensive formulation of their images.<sup>35</sup> With the death sentence image, for example, patients using the metaphor should not be expected to surrender to this verdict, although it very clearly describes their prognosis. The need for imaginative models is perhaps especially acute for patients facing dementia, given the condition's current untreatability and its deleterious consequences for the patient's self-understanding. In this respect I disagree with Susan Sontag, who claims "that the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking."<sup>36</sup> But I follow her, as I will outline further below, when it comes to the use of metaphors that are of clear disservice to the patient.

Picturing themselves as being subjected to an anonymous verdict helps patients in their pursuit to keep as much agency and control as possible. After all, the threat is described as external, not internal, and the sentence is handed down to an as-yet-unchanged individual. Yet, as seen in their representations of the condition's cognitive or chronic degenerative aspects, caregivers readily sacrifice their family members' activity in their own illustrations of the untreatable nature of Alzheimer's disease. They frequently personify the condition, as if they needed to be able to grasp and face the opponent more clearly. In *Iris*, John Bayley writes about the disease as "Dr. Alzheimer," picturing him as the "Dark Lord." In drawing an omnipotent god from whose powers his wife cannot possibly escape, he reinforces the impression of the reduced and insignificant patient. His metaphor highlights the

unequal match between patient and illness, and embraces—reminiscent of the journey metaphor—her departure to the realm of the dead. Similarly, Gillies imagines dementia as a sneaky robber and a “forest fire . . . [causing] havoc” to further her own understanding of her mother-in-law’s defenselessness (77).

This latter image comes closest to DeBaggio’s biological war and death sentence, suggesting that patient and caregiver perceive the burden of incurability in similar terms. I see this unison most clearly reflected in Ruth Schäubli-Meyer’s narrative *Alzheimer: Wie will ich noch leben—wie sterben?* (*Alzheimer: How will I continue to live—how will I die?*), a piece of collaborative writing between patient and caregiver.<sup>37</sup> The Swiss caregiver presents her husband as an independent personality. She offers fragments of his personal writing to illustrate the patient’s autonomous choice to “sterben, solange ich dich noch kenne” (die, while I still know you; 35), with the help of the Swiss organization Exit. Her narrative is symbol of the patient’s agency and a literal answer to his death sentence.

Schäubli-Meyer’s supposedly fictional narrative of “Anna and Gustav” reveals itself, on the last page, as the author’s “authentic account of her and her husband’s final years together, from the husband’s diagnosis to death.” The story’s problematic status—the caregiver’s searching for a suitable way to communicate the husband’s highly controversial decision (and her supporting it)—is already manifest in its form.<sup>38</sup> The text’s simple language and continuous present tense suggest fictionality, while the frequently interspersed, paragraph-long quotations from the patient clearly claim the report’s authenticity. Schäubli-Meyer dedicates half of the originally published text to the documentation of their final year, and a third of this very section to their final day together, highlighting her husband’s decline by quoting him saying, “ich bin nicht mehr der, der ich war” (I am no longer the one who I was; 38). The patient’s metaphorical language expresses his pain over the fact that “Vergessen heisst, langsam zu Tode gequält werden” (Forgetting means being slowly tortured to death; 11). Gustav pictures the condition as a murderer, which, conversely, enhances our appreciation of his active decision to preempt forgetting. I do not mean that Gustav is able to halt this aspect of the disease process, but rather that he chooses to end his life before the disease has advanced to a stage in which he does not recognize himself anymore. Existence of the narrative itself persists to remind people of him, and keeps readers from forgetting the sociopolitical discussion regarding assisted suicide. The narrative’s 2010 addendum emphasizes, not least in formally amount-



ing to a third of the new edition's total text, Schäubli-Meyer's need to justify her husband's decision. She adds further quotes from her husband; their selection remains the author's domain, but in serving the final purpose of advocating the ethicality of assisted suicide, she follows her husband's legacy.

## II. The Myth of Alzheimer's: A Lens on Societal Fears

### *The Medico-Scientific Narrative: Dementia as the Synthesis of Illness, Aging, and Death*

Schäubli-Meyer's account portrays a patient who remains an active partner beyond the narrative time and frame, making a case against the Swiss government's recent efforts to tighten laws regarding assisted suicide.<sup>39</sup> Both contents and construction of her narrative advocate the patient's autonomy and agency, which strongly resonates with the messages individuals afflicted by Alzheimer's disease convey in their narratives. The Swiss caregiver's text deserves to be singled out further, as it gives voice and a platform to a patient and his cause against the usual assessment of passivity and emptiness.

In the context of the above elaborated tension between patient and caregiver discourse, and with the understanding that metaphors are not only a concept of thought but also action, I now turn to the source of the images patients write against, and which caregivers rely on so heavily. This analysis will lift the patient's counter-discourse onto a much broader level—beyond that of “a voice in solitude” in disagreement with a caregiver's assessment to an articulation in the process of sociopolitical opinion formation.<sup>40</sup> I posit that patients choose their images of animated-ness in response to the metaphorical language from scientific and medical dementia discourses, on whose socially perceived authority caregiver presentations thrive.

Gillies's narrative, for example, seeks literal and figurative support from medico-scientific insights in the chapters that constantly interrupt her telling about living with Nancy. These chapters dwell on scientific facts regarding brain, mind, and memory. While the first of these chapters (chapter 4 in the narrative) eases the reader into an understanding of the brain, specifically its anatomy and biochemistry, the second such chapter (chapter 6) offers scientific and epidemiological data, quickly drawing the link between this condition and the loss of self. In particular, Gillies alleges that “[w]e don't have brains; we *are* our brains” (74; original emphasis), continuing: “Lose the use of your

brain by degrees and the self is stripped away, layer by layer" (74). This assertion about Nancy's loss is further highlighted by additional chapters (8, 10, and 12) that ponder Alzheimer's original research paper on the patient Auguste D., who had stated "I have lost myself" (106); the condition's elusive pathogenesis; and the merely symptomatic treatment options. Against this bleak backdrop, Gillies believes that it "isn't possible to have identity without a history" (150; chapter 16), corroborating her claims in the following chapters that consider the relationships between brain as well as mind and memory (18 and 20). The remaining twelve chapters are no longer interrupted by scientifically inspired deliberations: Gillies has her own story of loss of self to tell.

It might seem surprising that patients similarly quote from this discourse. DeBaggio, for one, initially fills entire pages with quotes from scientific and medical literature spelling out Alzheimer's patients' decline, loss, and involution. In particular, he cites from the "Progress Report on Alzheimer's Disease" by the National Institute on Aging, "The Johns Hopkins White Papers," and his own "Neuropsychological Evaluation." These quotations direct, as well as reflect, DeBaggio's perception of loss: "Alzheimer's disease . . . results in memory loss, unusual behavior, personality changes, and a decline in thinking abilities. These losses are related to the death of brain cells and the breakdown of the connections between them" (6). When his citations from scientific and medical literature become less and less frequent, they are replaced first by material published by or for caregivers. Like the medical passages, these are similarly centered around aspects of loss, such as when a caregiver is cited by the Duke University Alzheimer Support Group as saying, "It is like losing a part of your history" (90). The home safety notes DeBaggio cites from the Alzheimer's Disease Research Center also entirely rely on notions of loss: "Alzheimer's patients . . . may experience confusion, loss of judgment, and difficulty finding words . . ., they may become more agitated or irritable, or very passive . . . and become lost . . . . They may suffer from loss that affects vision, smell, or taste" (112).

DeBaggio's choice to progressively replace clinical statements with extracts from caregiver manuals underlines his perception that the caregiver discourse strongly relies on the medico-scientific representation of the condition. But citations from either of these categories appear far less often in the second half of the narrative. DeBaggio's story and rich memories end up filling that perceived "emptiness" and replace the initially prevailing scientific and caregiver-focused account. In some ways, DeBaggio offers several models for other Alzheimer's

narratives: Gillies's choice to turn from her mother-in-law's to her own story emphasizes caregiver strain, while Schäubli-Meyer's decision to place her husband's words and will into the narrative's center within and beyond his illness emphasizes patient autonomy.

Floyd Skloot's references to medical and scientific literature are especially revealing, as he speaks as both patient and caregiver. Very early on he cites, in order to grasp his mother's condition, the memory researcher Daniel Schacter: "[O]verall brain mass steadily shrinks. . . . Blood and oxygen flow to the brain diminishes; the frontal lobes shrink; the hippocampus, cornerstone in forming explicit memories and developing our sense of self, atrophies; the basal forebrain, implicated in most amnesias, loses neurons and lessens the production of essential memory chemicals" (6). But Skloot pushes the conceptualization of dementia as loss even further, because he stresses its connection to old age, stating (as quoted above) that "as age-related dementia sets in, such forgetting intensifies and worsens, eradicating even the most essential matter, until nothing is left" (7).

This discourse is, again, amplified by the biomedical concept of aging. Aging is associated with "an increasing probability for the individual to contract one of the degenerative diseases," as a "progressive and irreversible" process, a "gradual decline." The scientific discourse regards cognitive aging as biological senescence, describing changes in cognitive processes in older age in terms of failure, loss, inefficiency, and impaired performance.<sup>41</sup> If society has increasingly come to see aging as a synonym for illness, then, Alzheimer's comes to epitomize the sum of illness, aging, and dying. It has become a metaphor for fears of aging.<sup>42</sup>

#### *Societal Predetermination: Myths about Alzheimer's Disease*

The conceptualization of dementia as loss belonging to old age is core to the patient's counter-discourse. This centrality becomes clearest when we look at the demographic characteristics of those telling their story. All cited (and available) patient-authored texts are written by early-onset patients who have been diagnosed with the condition in the midst of their professional life, when the societal expectation of productivity sharpens their sense of loss and inadequacy and spurs their desire to make themselves heard. In addition, the early-onset patient's awareness that the disease will prevent them from living the many years they biologically still "should" have further links the perception of Alzheimer's to a condition of premature aging. Caregiver-authored

texts, by comparison, typically tell about late-onset Alzheimer's patients: members of society who have already entered retirement age. These patients, as the caregiver's presence suggests, have typically already reached a more advanced stage of their condition. The demographic as well as the clinical characteristics of these individuals match the very image of the patient against which early-onset sufferers assert themselves.

I see the difference in presentations between patient and caregiver particularly rooted in the patient's urgency to write against age-related stigma. Still, the number of patients voicing this view—or any view—is small. Some reasons for this phenomenon are certainly inherent to the condition, i.e., patients' lack of time and energy to compose narrative in the light of an ailment that will soon prevent them from competent articulation—DeBaggio explicitly writes against his memory “crumbling into obscurity” (199), while Lee already had to rely on a collaborative writer to convert her “mumble-jumble . . . to paper in a manner that is readable” (ix). At the same time, patients might find themselves in the position to recount a narrative that is already written in the mind of society.<sup>43</sup> Given that caregiver narratives far outnumber those written by patients, the caregiver version of the Alzheimer's narrative easily reinforces the scientifically grounded, culturally dominant picture of the dementia patient's passivity, dependence, and old age.

In fact, as Alzheimer's has become synonymous with fears of aging, the disease has reached an everyday presence that strongly influences our response to this particular illness narrative. As a consequence, a narrator's admission that she or he suffers from dementia overdetermines the interpretation of the narrative that follows.<sup>44</sup> To my mind, this predetermination also guides the reader's interpretation of specific metaphors. Upon encountering the patient's reductionist metaphors, the reader hunts for relevant properties of the source (the image being used) that apply to the presumed characteristics of the target (the patient using that image).<sup>45</sup> For example, we might read Couturier's candle image under the impression of chronic degeneration, picturing it as one being extinguished (and leading to darkness) rather than as a source of light and warmth. Likewise, we read Skloot's narrative “in the light” of his own age. While Skloot may well be in “A Stable State,” it is in the nature of nervous system viral infections that they can lead to renewed infection and decline at any time. Yet decline is instead assigned to the nonagenarian mother's Alzheimer's disease by the narrator—and by the reader. As Rita Charon puts it, “the meaning of a narrative . . . arises from *and is created by* the meeting between teller and listener.”<sup>46</sup>

The core fears society harbors in the confrontation with dementia are, eventually, laid bare in an analysis of contexts and situations where the term Alzheimer's is used as a metaphor in its own right.<sup>47</sup> Susan Sontag severely condemned the use of "metaphors to enliven charges that a society [is] corrupt or unjust."<sup>48</sup> Yet, in the light of the illness's increasing daily presence, Alzheimer's has not remained exempt from use as a metaphor to deliver a moral judgment against society or highlight historico-political atrocities. Three examples illustrate how the condition, having reached the peak of popular awareness during the last two decades of the twentieth century, has been appropriated by public figures as well as scholars to denounce forgetful conduct. That public figures use Alzheimer's as a metaphor for misdeeds reinforces a vicious circle that will make it more and more difficult to lift the societally ingrained stigma around the condition. These examples further emphasize that society sees the core stigma attached to Alzheimer's as centering on the patient's dependence, inertia, and loss of self.

In 1994, shortly after Germany's reunification, the historian Christian Maier employed the term "dementia transitoria" to describe the reunited country's state "zwischen der Bonner und der Berliner Demokratie" (between the Bonn and Berlin democracies), referring to its need for a "Neugründung deutscher Demokratie" (new establishment of German democracy) and re-awakening of German historical consciousness that would help to provide confidence in the light of changed roles and expectations within Europe.<sup>49</sup> It remains questionable why Maier employs the term dementia, instead of simply stating the facts and positively claiming the nation's need to remember. His oxymoron suggests the condition's reversibility, which painfully belittles the patient's exposure to a chronic degenerative and incurable disease. It also ignores the fact that patients like DeBaggio continue to remember richly. When considering that patients have used the metaphor of a holocaust to capture the illness's incurable nature, Meier's reference seems acutely misplaced. He stigmatizes the illness by linking it to a concept of inertia that bears no relation to the patient's activity in early stages of the disease.

The second example is that of Sonja Vukicevic, once Serbia's most celebrated ballerina and during the Milosevic regime its most famous opposition artist. Vukicevic produced a highly critical theater trilogy, presented at the Institute for the Decontamination of Culture, in 1999. Entitled "Alzheimer," the trilogy explores the reasons and motivations for the "collective dementia" that enables the compulsive repetition of political patterns throughout history.<sup>50</sup> Using the disease to signify

a refusal to learn from historical events ascribes to the patient an unteachable or unpersuadable disposition, a concept that will become even clearer in the following example.

In his controversial biography that touches on the highly debated question as to whether his father, the German philologist and writer Walter Jens, had actually been a member of the national-socialist party NSDAP, the journalist Tilman Jens claims that the heated debate emanating from this issue may have led to his father's dementia. Walter Jens was diagnosed with vascular dementia one year after having been questioned about his potential NSDAP membership.<sup>51</sup> Specifically, Jens brands his father's claim not to have any recollection of such membership as "fatale Schweigekrankheit" (fatal illness of silence), going so far as to write that his father's "Symptome politischer Demenz" (symptoms of political dementia) were conveniently timed as they comfortably excused the philosopher's memory loss relating to the issue.<sup>52</sup>

Jens interprets dementia as a psychosomatic expression of mental distress. But scientific evidence that would justify this perspective continues to be patchy. Regardless, in the light of the condition's chronic, degenerative, and incurable character, such an interpretation appears most unethical. As Sontag puts it, such "psychological theories of disease assign to the luckless ill the ultimate responsibility both for falling ill and for getting well."<sup>53</sup> In the light of the patient's desperate search for an ascribable pathogenic cause that would allow for the use of much more enabling metaphors, if we think about Skloot's image of war, Jens's assertions must seriously upset patients. These examples show how the general idea of dementia as an illness of "only" memory loss prevails in the public opinion. In addition, such misuse of dementia or Alzheimer's loads the condition with negative associations as to the patient's unconstructive, even malevolent behavior, which will not enhance society's positive attitude towards the ill and their need for empathetic accompaniment on their journey.

### III. Alzheimer's Disease Metaphors Illuminate the Fear of the Nearness to Death

That Alzheimer's disease is exclusively used in the context of negative associations, human shortcomings, and failures makes this metaphor a sharp lens with which to focus on society's underlying fears: of loss and of aging. These disease-related concepts are universally present and culturally sanctioned. But they hardly match what patients

set out to tell us, even though they themselves employ several of the stereotyped metaphors against which they write. Such ambivalence is a testament to the pervasiveness of this discourse and patients' lack of alternative vocal models. Foremost, however, patients see themselves on a journey, and perceive themselves as being enriched by this journey. They breathe animated-ness into lifeless objects, and identify themselves as being alive even in the prospect of loss. They are aware of their bleak outlook—condensed and accelerated aging—and see themselves sentenced to a premature death. Yet they maintain their agency in telling their stories, asserting themselves as individuals in and beyond the ability to remember.<sup>54</sup>

Their narratives emphasize the potential in an aged human being that is accounted for in metaphorical expressions such as completeness, fulfillment, and wisdom—and it is these characteristics that individuals with early-onset dementia fall back on, as Couturier does here: “Nous sommes avant tout des êtres humains, avec des qualités et des défauts, des hauts et des bas, et avec une maladie qui touche un organe de notre corps: le cerveau” (we are, above all, human beings with strengths and weaknesses, highs and lows, and with a disease that touches an organ of our body: the brain; 143). In insisting on the physical nature of her condition, Couturier puts it on the same level with other terminal illnesses, thereby removing it from the preconception-loaded notion of an incapacitating cognitive disorder. Her move suggests that, for her, imminent cognitive impairment by itself is not the condition's core threat. This insight is amplified when we read this passage alongside DeBaggio's, Lee's, or McGowin's writings. Considering, for example, Brodkey's emotional urgency in the face of terminal illness, or Skloot's need to set his condition apart from the mother's illness of old age, we come to understand that it is the patients' awareness of their nearing death and dying that underlies most directly their selection of specific images and modes of presentation. The perceived core threat of Alzheimer's disease is the death of the self and, relatedly, the fear of how people who are losing their selves will be treated.

Metaphors are a concept of action. This action is most apparent where caregivers, in the pain of losing a parent, do not concede the remaining control their patients so urgently need; where they instead emphasize the emptiness of the shell and the ruined house, quote from medico-scientific material, and offer their own story. The underlying idea that regards dementia patients as a senile, disengaged, or unproductive burden will not support a purposeful ethical discourse

about their aging and dying with dignity. The counter-discourse that is instigated by patients publicizing their life-writing is very much needed—on a societal, cultural, and individual level. In particular, the similarities seen between their metaphors and the metaphorical language used for terminal cancer or HIV/AIDS invite a reconsideration of the sociopolitical conceptualization of the disease. They remove from dementia the aura of cognitive failure, demanding metaphorical concepts that really offer, to speak with Broyard, “a relief from medical terminology.”

It is obvious that dementia pathographies cannot be truly representative, in that patients can only articulate their decline while still in an early stage of the condition, and the metaphors they use “are created to express the feeling of subjective self, unitary, human, and unique.”<sup>55</sup> All the same, these images come from individuals who wish to remain in control, who are not handing themselves over to the scientifically suggested and societally retained images of passivity, dependence, and emptiness. They mirror the patients’ illness perception, and faithfully illustrate their needs. And it is these images that must be read with a fresh perspective, free from the societal predetermination of memory decline as loss of self.<sup>56</sup>

## NOTES

The research for this paper was supported by the Wellcome Trust [099351/Z/12/Z] and the Lesmüller Foundation. I am indebted to Brian Hurwitz for his insightful comments on an earlier version of this manuscript, to two anonymous reviewers, one of whom pointed me to Floyd Skloot’s and Harold Brodkey’s narratives, and to Anna Fenton-Hathaway for her thoughtful editing of this piece.

1. Broyard, *Intoxicated by My Illness*, 18.
2. Bury, “Chronic Illness”; Frank, *Wounded Storyteller*, 1–20; Brody, *Stories of Sickness*, 12–16.
3. Becker, *Disrupted Lives*, 60.
4. Eakin, *How Our Lives*.
5. Ryan, Bannister, and Anas, “Dementia Narrative.”
6. See, for example, Herrup, “The Case.”
7. Grønning et al., “Does Alzheimer’s Disease . . .?”
8. Lakoff and Johnson, *Metaphors*, 3–6.
9. My view of dementia metaphors as both “mirror” and “lens” to the cultural understanding of dementia takes inspiration from Guy Deutscher’s *Through the Language Glass* that introduces language as both mirror and lens to the culture and society of its users.
10. Bayley, *Iris Trilogy*; all references incorporated in the text.
11. Gillies, *Keeper*; all references incorporated in the text.
12. McGowin, *Living in the Labyrinth*; Lee, *Just Love Me*; all references incorporated in the text.



13. Couturier, *Puzzle* (Jigsaw); references incorporated in the text; I offer working translations of this and the later mentioned German language texts in parentheses following the original; DeBaggio, *Losing My Mind*; references incorporated in the text.

14. Bayley's narrative gained international visibility not least through Richard Eyre's movie adaptation *Iris*, and Gillies was awarded prizes for her narrative (Wellcome Prize 2009, Orwell Prize 2010).

15. "Tom DeBaggio."

16. For an analysis of McGowin's narrative as describing rather than performing the author-narrator's condition, see Basting, "Looking Back," 89–91.

17. See Ballenger, *Self, Senility and Alzheimer's Disease*, esp. 174–76; in chapter 6, Ballenger offers a sociocultural analysis of several patient narratives, including McGowin's, Lee's, and DeBaggio's accounts.

18. Hawkins, *Reconstructing Illness*, 78–87; Frank, 115–36.

19. McCrum, *My Year Off*, 209; for a detailed analysis of stroke narratives, see Zimmermann, "Narrating Stroke."

20. Skloot, *A World of Light*; all references incorporated in the text.

21. Lakoff and Johnson, 15.

22. "Incinéré" can be translated as "incinerated" or "cremated"; the latter refers to subjects, while the former is used in relation to objects.

23. Couser, *Recovering Bodies*, 55.

24. On the power of metaphorical language even to engage the reader physically, see Gibbs, Jr., "Feeling Moved."

25. For a detailed analysis of Gillies's narrative, see Zimmermann, "Journeys."

26. For the caregiver's use of the shell metaphor, see Gubrium, "Narrative Practice."

27. Lakoff and Johnson, 25; on the mind as machine metaphor, see esp. 27–28.

28. Skloot, *Music Appreciation*, 73–74.

29. Hawkins, 66.

30. Scarry, *Body in Pain*.

31. Couser, 81–92; Robbins, "Death Sentences."

32. Brodkey, *This Wild Darkness*, 5; subsequent references incorporated in the text.

33. Broyard, xiv.

34. Couser, 82–84.

35. Kleinman, *Illness Narratives*, 48–49.

36. Sontag, *Illness as Metaphor*, 3.

37. Schäubli-Meyer, *Alzheimer*, originally published in 2008; all references incorporated in the text.

38. These considerations echo deliberations on Michael Ignatieff's *Scar Tissue*, where the supposedly anonymous narrator reports on the mother's cognitive symptoms and inheritable condition; see Wiltshire, "Biography," 419.

39. Britschgi, "Neue Vorschläge" (New suggestions).

40. Stanley, "Patient's Voice."

41. Davidson, "Metaphors," 175.

42. O'Rourke, "Alzheimer's Disease."

43. These have been suggested as reasons for the small number of patient-authored HIV/AIDS narratives; see Couser, 81–92.

44. For deliberations on the reader's predetermination in relation to narratives of terminal illness, see Robbins, "Death Sentences."

45. For an explanation of metaphor-related feature matching as developed by Amos Tversky and Andrew Ortony, see Hogan, *Cognitive Science*, 89–94.

46. Charon, *Narrative Medicine*, 52 (original emphasis).

47. See also Zeilig, "Dementia."

48. Sontag, 73.

49. Meier, "Deutschland" (Germany).

50. Crawshaw, "Play Reveals."  
 51. Consider, for example, Aly, "Was wußte Walter Jens?" (What did Walter Jens know?) as compared to Spiegel, "Sprachlos" (Speechless).  
 52. Jens, *Demenz* (Dementia), 73, 87.  
 53. Sontag, 59.  
 54. Anne Davis Basting's *Forget Memory* shows many ways in which patients can continue to live their identity beyond the ability to remember, inviting the caregiver's and society's acknowledgement of patients' continued agency, and Jens Brockmeier elaborates on the concept of pre-narrative personal identity construction in "Questions of Meaning," there also referring to Basting's work.  
 55. Olney, *Metaphors of Self*, 34; for the non-representativeness of pathographies see, e.g., Couser, 170, 183, 227.  
 56. Linton, "Reassigning Meaning."

## BIBLIOGRAPHY

- Aly, Götz. "Was wußte Walter Jens?" (What did Walter Jens know?) *Die Zeit*, January 15, 2004. [http://www.zeit.de/2004/04/W\\_Jens](http://www.zeit.de/2004/04/W_Jens).  
 Ballenger, Jesse F. *Self, Senility and Alzheimer's Disease in Modern America: A History*. Baltimore, MD: Johns Hopkins University Press, 2006.  
 Basting, Anne Davis. *Forget Memory: Creating Better Lives for People with Dementia*. Baltimore, MD: Johns Hopkins University Press, 2009.  
 ———. "Looking Back from Loss: Views of the Self in Alzheimer's Disease." *Journal of Aging Studies* 17, no. 1 (2003): 87–99.  
 Bayley, John. *The Iris Trilogy*. London: Abacus, 2003.  
 Becker, Gay. *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley: University of California Press, 1997.  
 Britschgi, Hannes. "Neue Vorschläge zur Sterbehilfe" (New suggestions regarding assisted suicide). *Blick*, November 1, 2009. <http://www.blick.ch/news/schweiz/editorial-neue-vorschlaege-zur-sterbehilfe-id35190.html>.  
 Brockmeier, Jens. "Questions of Meaning: Memory, Dementia, and the Post-Autobiographical Perspective." In *Beyond Loss: Dementia, Identity, Personhood*, edited by Lars-Christer Hydén, Hilde Lindemann, and Jens Brockmeier, 69–90. New York: Oxford University Press, 2014.  
 Brodkey, Harold. *This Wild Darkness: The Story of My Death*. New York: Metropolitan Books, 1996.  
 Brody, Howard. *Stories of Sickness*. 2nd ed. New York: Oxford University Press, 2003.  
 Broyard, Anatole. *Intoxicated by My Illness*. New York: Ballantine Books, 1992.  
 Bury, Michael. "Chronic Illness as Biographical Disruption." *Sociology of Health and Illness* 4, no. 2 (1982): 167–82.  
 Charon, Rita. *Narrative Medicine: Honoring the Stories of Illness*. New York: Oxford University Press, 2006.  
 Couser, G. Thomas. *Recovering Bodies: Illness, Disability, and Life Writing*. Madison: University of Wisconsin Press, 1997.  
 Couturier, Claude. *Puzzle: Journal d'une Alzheimer* (Jigsaw: Diary of an Alzheimer's patient). Paris: Josette Lyon, 2004.  
 Crawshaw, Steve. "Play Reveals Bitter Truth to the Serbs." *The Independent*, July 16, 1999. <http://www.independent.co.uk/news/world/play-reveals-bitter-truth-to-the-serbs-1106905.html>.  
 Davidson, Warren A. S. "Metaphors of Health and Aging: Geriatrics as Metaphor." In *Metaphors of Aging in Science and the Humanities*, edited by Gary M. Kenyon, James E. Birren, and Johannes J. F. Schroots, 173–98. New York: Springer Publishing Company, 1991.

- DeBaggio, Thomas. *Losing My Mind: An Intimate Look at Life with Alzheimer's*. New York: The Free Press, 2002.
- Deutscher, Guy. *Through the Language Glass: Why the World Looks Different in Other Languages*. London: Arrow Books, 2011.
- Eakin, Paul John. *How Our Lives Become Stories: Making Selves*. Ithaca, NY: Cornell University Press, 1999.
- Eyre, Richard, dir. *Iris*. UK and US: Miramax and BBC, 2001–2002. DVD.
- Frank, Arthur W. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press, 1995.
- Gibbs, Jr., Raymond W. "Feeling Moved by Metaphor." In *The Language and Literature Reader*, edited by Ronald Carter and Peter Stockwell, 209–218. London: Routledge, 2008.
- Gillies, Andrea. *Keeper: Living with Nancy—A Journey into Alzheimer's*. London: Short Books, 2009.
- Grønning, H., A. Rahmani, J. Gyllenborg, R. B. Dessau, and P. Høgh. "Does Alzheimer's Disease with Early Onset Progress Faster than with Late Onset? A Case-Control Study of Clinical Progression and Cerebrospinal Fluid Biomarkers." *Dementia and Geriatric Cognitive Disorders* 33 (2012): 111–17.
- Gubrium, Jaber. "Narrative Practice and the Inner Worlds of the Alzheimer Disease Experience." In *Concepts of Alzheimer Disease: Biological, Clinical, and Cultural Perspectives*, edited by Peter J. Whitehouse, Konrad Maurer, and Jesse F. Balenger, 181–203. Baltimore, MD: Johns Hopkins University Press, 2000.
- Herrup, Karl. "The Case for Rejecting the Amyloid Cascade Hypothesis." *Nature Neuroscience* 18, no. 6 (2015): 794–99.
- Hawkins, Anne Hunsaker. *Reconstructing Illness: Studies in Pathography*. West Lafayette, IN: Purdue University Press, 1999.
- Hogan, Patrick Colm. *Cognitive Science, Literature, and the Arts: A Guide for Humanists*. New York: Routledge, 2003.
- Jens, Tilman. *Demenz: Abschied von meinem Vater* (Dementia: Farewell to my father). Gütersloh: Gütersloher Verlagshaus, 2009.
- Kleinman, Arthur. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books, 1988.
- Lakoff, George, and Mark Johnson. *Metaphors We Live by*. Chicago: University of Chicago Press, 2003.
- Lee, Jeanne J. *Just Love Me: My Life Turned Upside-Down by Alzheimer's*. West Lafayette, IN: Purdue University Press, 2003.
- Linton, Simi. "Reassigning Meaning." In *The Disability Studies Reader*, 3rd ed., edited by Lennard J. Davis, 223–36. New York: Routledge, 2010.
- McCrum, Robert. *My Year Off: Rediscovering Life after a Stroke*. London: Picador, 1998.
- McGowin, Diana Friel. *Living in the Labyrinth: A Personal Journey through the Maze of Alzheimer's*. New York: Elder Books, 1993.
- Meier, Christian. "Deutschland zwischen der Bonner und der Berliner Demokratie" (Germany between the Bonn and Berlin democracies). *Zeitschrift für Politikwissenschaft* (Journal of political science) 41, no. 3 (1994): 261–79.
- Olney, James. *Metaphors of Self*. Princeton, NJ: Princeton University Press, 1972.
- O'Rourke, Norm. "Alzheimer's Disease as a Metaphor for Contemporary Fears of Aging." *Journal of the American Geriatrics Society* 44, no. 2 (1996): 220–21.
- Robbins, Ruth. "Death Sentences: Confessions of Living with Dying in Narratives of Terminal Illness." In *Modern Confessional Writing: New Critical Essays*, edited by Jo Gill, 154–65. London: Routledge, 2006.
- Ryan, Ellen Bouchard, Karen A. Bannister, and Ann P. Anas. "The Dementia Narrative: Writing to Reclaim Social Identity." *Journal of Aging Studies* 23, no. 3 (2009): 145–57.
- Scarry, Elaine. *The Body in Pain: The Making and Unmaking of the World*. New York: Oxford University Press, 1985.

- Schäubli-Meyer, Ruth. *Alzheimer: Wie will ich noch leben—wie sterben?* (Alzheimer: How will I continue to live—how will I die?) Zurich: Oesch Verlag, 2010.
- Skloot, Floyd. *Music Appreciation*. Gainesville: University Press of Florida, 1994.
- . *A World of Light*. Lincoln: University of Nebraska Press, 2005.
- Sontag, Susan. *Illness as Metaphor* and *AIDS and Its Metaphors*. London: Penguin, 1991.
- Spiegel, Hubert. "Sprachlos: Germanisten als Hitlers Parteigenossen" (Speechless: German scholars as Hitler's party members). *Frankfurter Allgemeine Zeitung*, November 24, 2003. <http://www.faz.net/aktuell/feuilleton/geisteswissenschaften/biographien-sprachlos-germanisten-als-hitlers-partegenossen-1132549.html>.
- Stanley, Patricia. "The Patient's Voice: A Cry in Solitude or a Call for Community." *Literature and Medicine* 23, no. 2 (2004): 346–63.
- "Tom DeBaggio." *The Economist*, March 3, 2011. <http://www.economist.com/node/18275908>.
- Wiltshire, John. "Biography, Pathography, and the Recovery of Meaning." *The Cambridge Quarterly* 29, no. 4 (2000): 409–422.
- Zeilig, Hannah. "Dementia as a Cultural Metaphor." *The Gerontologist* 54, no. 2 (2014): 258–67.
- Zimmermann, Martina. "Narrating Stroke: the Life-Writing and Fiction of Brain Damage." *Medical Humanities* 38, no. 2 (2012): 73–77.
- . "'Journeys' in the Life-Writing of Adult-Child Dementia Caregivers." *Journal of Medical Humanities* 34, no. 3 (2013): 385–97.