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Play and Possibility

Olivia Rosenthal's We're Not Here to Disappear and the Limits of Understanding Alzheimer's Disease

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Article abstract

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Play and Possibility: Olivia Rosenthal's *We're Not Here to Disappear* and the Limits of Understanding Alzheimer's Disease

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Cultural representations of Alzheimer's disease typically focus on the social and emotional burdens felt by family and friends, diluting or excluding the experience of the sufferer. This article demonstrates how narrative fiction may help us to engage with the experiences of individuals with Alzheimer's disease by imagining what it might be like to suffer from the disease ourselves. Demonstrating the humanized and subjective understanding of Alzheimer's disease articulated in Olivia Rosenthal's (2007) *On n'est pas là pour disparaître* [We're Not Here to Disappear (2015)] this article also exposes the limitations of narrative fiction as a means of highlighting our own ignorance in the face of others' experiences.

Keywords

Narrative; imagination; dementia; medical humanities; fiction; gerontology

Understanding Alzheimer's Disease

The most common form of dementia, Alzheimer's disease refers specifically to the presence of neurofibrillary tangles and beta-amyloid plaques in the brain that prevent the successful functioning of neurons or nerve cells and have a profound effect upon information-processing and behavior in an individual. Although most commonly associated with memory loss due to the initial degeneration of neurons in the hippocampus, Alzheimer's eventually results in the functional loss of a number of other areas of the brain and leads to unpredictable changes in mood and behavior, loss of physical co-ordination and orientation, rising anxiety and paranoia, and often aphasia, or the loss of language and communication. Alzheimer's Disease International (2015) estimates that by 2030, there will be nearly 75 million people living with the disease around the world, rising to well over 130 million in 2050. The concentration of the disease, focused in the last century on Europe and

North America, faces surging incidence particularly in Asia, in line with increased life expectancy and population numbers (Alzheimer's Disease International, 2015). Alzheimer's disease is now one of the leading concerns for policy makers across the world, with huge potential impacts upon political, social, and economic wellbeing, and with priority accorded to research and the reduction of recognized risk factors.

Despite significant advances in the diagnosis and treatment of the disease over the last three decades, Alzheimer's disease remains plagued by inconsistencies and misunderstandings. Sufferers or "victims" of Alzheimer's are often stigmatized, dehumanized, and infantilized; their disease is described as "a complex, unknowable world of doom, ageing and a fate worse than death" (Zeilig, 2015, p. 17). Alzheimer's, it is claimed, "obscures the distinction between life and death; [it is] a condition both of death-in-life and of life-in-death"; it is seen to be an excruciating process of "death in life, death before death, and never ending death" (Kaufman, 2006, pp. 23, 30). It is "Alzheimer's: No cure, no hope, no help" (Kitwood, 1997, p. 54). In cultural representation, this stigma typically translates into the invisibility of the one with the disease; priority is accorded to the social and emotional burdens of caregiving and caregivers, while the person suffering from the disease itself is often placed "under erasure" (Burke, 2015, p. 29). Sociologist Karen A. Lyman (1989) has noted ironically that the augmented "interest in the 'victims' of [Alzheimer's] generally does not include an interest in the perspective of the person with dementia," who is viewed as "burdensome," as a "stressor, not as one who is experiencing stress," and that sufferers are depicted merely as "disease entities, independent variables" (p. 603). Even when the sufferer is accorded significance within cultural representation, it is through acts of reconstruction that attempt to remember the individual as they once were, rather than to understand who they are now. In this article, I want to bring back into focus the experiences of the sufferer by demonstrating how narrative fiction can help us to engage with unknown and undesirable events, subjectivities, and feelings, and to discuss the possibilities and limits of understanding Alzheimer's disease.

¹ See Burke (2008, p. 68). See also Fraser (2018). Fraser's discussion of Paco Roca's (2007) graphic novel *Arrugas* [*Wrinkles*, 2011] places the subjectivity of the sufferer at the centre of the narrative to show how "even those who seem unable to tell stories are narrating themselves long after many suppose they have stopped doing so" (p. 169). Fraser does not discuss the ethics of Roca's work, however, placing the development of the narrative within a sequential, developmental framework of Alzheimer's to which patients are expected to conform.

Through a discussion of Olivia Rosenthal's (2007) On n'est pas là pour disparaître (2007) [We're Not Here to Disappear (2015)], I suggest that narrative fiction may enhance our understanding of individuals with Alzheimer's disease by enabling us to imagine what it might be like to suffer from the disease ourselves, to consider the disease from the perspective of the person with dementia, and see the world through their eyes. Brute scientific facts and medicalized statistics do not, after all, offer any experiential insight that can help us to relate to the world around us, and it is only through artistic storytelling practices that we are able to gain a sense of experience as it is lived by ourselves and others. Narrative fiction, in other words, helps us to gain a sense of what political and cultural theorist Raymond Williams (1977) calls "structures of feeling," which comprise a sense of "what is actually being lived, and not only what it is thought is being lived" (p. 131). Rosenthal's We're Not Here calls attention to these structures of feeling, encouraging us to imagine Alzheimer's disease by demonstrating not how narrative can rebuild the past, but how it can show our own potentially shattered and diseased futures.

I begin by exploring how fiction can open up "spaces of possibilities" (Meretoja, 2018, p. 2) in which we can imagine ourselves and others as they could be otherwise. Through "exercises," the narrator invites the reader into the world of Monsieur T., a 74-year-old man thrown into the tangled cognitive disarray of Alzheimer's disease, inciting us to imagine the world through his eyes. In these comparative exercises, Rosenthal facilitates the reader's understanding of the disease by assimilating the unknown experience into our own comprehension of the everyday world. However, Rosenthal's work also navigates a fraught ethical limitation that inhibits the unassailability of narrative as a way of making sense of experience. Alzheimer's disease is a non-narrative experience, and to give it narrative form imposes an artificial framework grounded in concepts and language that resist translation from the healthy to the demented mind. Rosenthal's awareness of the limitations of imagination is reflected in the narrative's careful negotiation of the experience of Alzheimer's disease as essentially lacking in some way. Through this negotiation, Rosenthal informs our understandings of the complexities of representing dementia in literature. While narrative fiction may provide a valuable resource for understanding lives and experiences that are different from our own, it is important to consider its limitations and the ways in which narrative fiction may inhibit

understanding in order to highlight our own ignorance in the face of others' experiences.

Narrative Fiction and Narrative Imagination

In the epilogue to his memoir, *Anonymously Yours*, former teacher and young-adult novelist Richard Peck (1991) concludes with a poem written to inspire his young audience:

I READ: because one life isn't enough, and in the pages of a book I

can be anybody;

I READ: because the words that build the story become mine, to

build my life;

I READ: not for happy endings but for new beginnings; I'm just

beginning myself, and I wouldn't mind a map;

I READ: because I have friends who don't, and young though they

are, they're beginning to run out of material;

I READ: because every journey begins at the library, and it's time

for me to start packing;

I READ: because one of these days I'm going to get out of this

town, and I'm going to go everywhere and meet everyone,

and I want to be ready. (p. 120)

Reading novels, Peck believes, is not only important for young people but for us all: "a novel is never an answer, always a question. Only very young writers or cranks or practice teachers believe their words will change the world. Instead, a novel raises questions about the way things are and asks us to rethink our position" (p. xi). To lose oneself in a good book means departing from oneself and one's own world and entering—temporarily—into the world, the body, the life of another, leaving behind one's own worries and certainties and being transported into circumstances that we would never otherwise know. From an ethical perspective, storytelling does not simply fill the gaps in our hectic lives but feeds our "ability to imagine what the experience of another might be like" (Nussbaum, 2010, p. 97). It is this ethically important relationship between narrative fiction and what philosopher Martha Nussbaum terms "narrative imagination" that is at the heart of this discussion.

In Not for Profit: Why Democracy Needs the Humanities, Nussbaum (2010) contends that "citizens cannot relate well to the complex world around them by factual knowledge and logic alone" (p.

95), and that we must look to the humanities in order to cultivate a "humanistic and critical" (p. 94) understanding of the world. Learning facts and functions does not teach students how to interpret, assess, and appreciate information, and what Nussbaum terms "global citizenship" (p. 93) depends upon the development of children's—and adults'—narrative imagination.

> [Narrative imagination is] the ability to think what it might be like to be in the shoes of a person different from oneself, to be an intelligent reader of that person's story, and to understand the emotions and wishes and desires that someone so placed might have. (pp. 95–96)

Nussbaum argues for the centrality of literature and the arts in the education of our empathetic sensibilities; consequently, narrative fiction is not distinct from the real world but bound up with our everyday actions and reactions. Literature challenges our approaches to the world as we know it by raising questions and helping us to envisage how things could be otherwise, and academic discussion increasingly points to the value of literature in influencing how we perceive and react to the world around us and the people in it. In particular, literary scholar Hanna Meretoja (2018) argues that narrative fiction influences what she calls our "sense of the possible" (p. 2) by enlarging and diminishing the "spaces of possibilities" in which we "think, experience, feel, do, and imagine" (p. 183). By simulating experiences beyond our own lives, the worlds we encounter in narrative fiction may even influence and transform our actions in the "real" world. Mary Warnock (1972), in her introduction to Jean-Paul Sartre's (1940/1972) The Psychology of Imagination, writes that our power to act in the world is a result of our ability to "envisage a given situation as possibly being otherwise than how it is" (p. xvii). If one could not imagine that

his life might be different, he would have neither motive nor capacity for remedying his situation. Merely to experience something as given is not enough. One must have the power of imagining it as well as perceiving it; that is, of imagining it otherwise. (p. xvii)

In developing our ability to imagine the otherwise and the not-yet, narrative fiction awakens us to possibilities that influence how we think and act in the "real" world, and it is particularly useful for imagining not only potentially beneficial, optimal, or ideal scenarios, but also undesirable events, experiences, and futures.

Although the appeal of narrative fiction arrives, typically, from the positive and self-aggrandizing possibilities that are opened up to us as readers—we become the celebrated hero or heroine of the story who overcomes adversity to reach his or her "happily ever after"—narrative fiction is also an invaluable tool to imagine negative or unpleasant possibilities, such as war, loss, heartbreak, or illness. Nussbaum (2010) suggests that reading narrative fiction may help us to address what she terms "cultural blind spots," lives and experiences that are completely foreign or unknown to us and that are "likely to be dealt with ignorantly and obtusely" (pp. 106–107). Dementia and Alzheimer's disease are such cultural blind spots, hemmed into our cultural imagination by stereotypes of aging, old age, and cognitive impairment. We have already seen how the experience of the Alzheimer's sufferer him- or herself is often sidelined, with narrative priority given to the social and emotional devastation of family and friends so that "the consequences of caring for someone with dementia and its impact upon familial relationships is placed at the center of the narrative rather than at its periphery" (Burke, 2015, p. 33). However, narrative fiction may provide a point of entry into a disease that is fast becoming a primary concern for policy makers around the world by helping us to imagine dementia from the inside, "to see the world through the eyes of others" (Blackman, cited in Cain, 2014) and walk in their shoes for awhile.² From both an ethical and an epistemological perspective, narrative fiction potentially promotes a productive engagement with Alzheimer's disease because it helps us to address areas of experience to which we are typically ignorant. In Rosenthal's We're Not Here to Disappear, the reader is invited to imagine the experience of Alzheimer's disease as an experience that could be—or could become one's own.

Let's Play a Game: Play and Possibility

² Nussbaum's philosophical approach can be seen in the work of teen and young-adult author Malorie Blackman, who has been criticized for her over-representation of underrepresented minorities. Blackman argues that "Books [allow] you to see the world through the eyes of others... Reading is an exercise in empathy; an exercise in walking in someone else's shoes for a while. So this is not about writing certain books for certain people, they should be read by everybody" (see Cain, 2014).

Rosenthal (2015) qualifies her work as fiction that reinvents and reimagines the lives and experiences of real people (p. 170). She tackles the disintegration of language, identity, and chronology that are archetypal of Alzheimer's disease within the form and structure of the narrative itself, writing fragments of memory, slipping from one identity to another without warning, and telling stories that overlap and go backwards and forwards in time and place, all the while intersecting autobiography, biography, and fiction. The narrative begins with a clear indication of date, location, and identity and situates the surprising turn of events in which Monsieur T. has been found in the garden of his neighbours' house after stabbing his wife. This precision soon deteriorates as Rosenthal enters the scattered psyche of an Alzheimer's sufferer as relationships between father and daughter, husband and wife, and even between past and present selves fall apart.

From a narrative hermeneutics approach, Rosenthal's work is ethically and epistemologically valuable because it seeks to direct the reader towards an understanding of Alzheimer's disease by actively manipulating our awareness of the subjectivity of perspective.³ Invited to follow the actions of the narrative from several different perspectives, we are encouraged to cultivate an empathetic response to the suffering of Monsieur T. while being simultaneously alerted to the unsurmountable alterity that divides the perspective of the demented sufferer from the perspective of the healthy mind. The chaotic narrative strives to highlight how the perspective of the one with Alzheimer's disease is not only different from the perspective of those who do not have the disease, but how the perspective of the one with the disease changes over time. Rosenthal's exploration is developed through her imaginative investment in the thoughts and understandings of the events from the perspective of Monsieur T. that shows how one singular event—the stabbing of Madame T.—must be reinterpreted from different perspectives if we are to make sense of the event and of the thoughts, actions, and feelings of those involved. In other words, the narrative highlights how facts alone do not tell us anything about the experience of Alzheimer's disease; the text is engaged in exposing the cultural blind spot of Alzheimer's disease by investing in the perspective of the sufferer and opening our eyes to the subjectivity of experience.

The narrative begins with the presentation of basic facts to the reader—"On July 6, 2004, Monsieur T. stabbed his wife five times with a

³ See Brockmeier and Meretoja (2014) for an introduction to narrative hermeneutics, particularly in a medical context.

knife" (p. 5)—and with a disorienting police interrogation of the accused that plunges us into the "senselessness" (Malabou, 2012, p. 5) of Alzheimer's disease:

> What's your name? Not me. What's your first name? It doesn't belong to me.... What's today's date? I don't know. Where are you? Next to you. In which city? Next to the river. Do you know the name of the river? Yes, it flows. $(pp. 5-6)^4$

In this initial introduction to the events and the characters, the subjectivities of demented and healthy minds are so disconnected that the narrative fails to reconcile any such understanding: the reader, like the policeman, is confused. If we are to consider narrative as a "practice of sense-making" that situates experience "as part of a meaningful, connected account" (Meretoja, 2018, p. 48), or as an intentional and agential representational process that structures events to imply "coherence, meaningfulness, and evaluative and emotional import" (Goldie, 2012, p. 8), then the narrative has only reinforced our belief that Alzheimer's is non-sense. The perspectives of the policeman and of Monsieur T. are so disconnected that no clear temporal or spatial structure can be established: Alzheimer's has "messed up" the narrative. 5 As We're Not Here progresses, however, we are invited to engage with the world and with the actions of Monsieur T. from his perspective and encouraged

⁴ It is worth noting that Rosenthal's representation of the disease is highly informed. In many of these question-and-answer couplets between the police and the accused there is a clear sense that meaning is being portrayed indirectly rather than entirely at random, and that Monsieur T.'s communicative challenges involve frustrated processes of recall rather than of understanding as his responses continue to flesh out themes despite his fragmented recall of appropriate nouns (see Sabat, 2001, pp. 24-90).

⁵ I refer to Peter Goldie's (2012) The Mess Inside: Narrative, Emotion, and the Mind with this phrase, and to the process of "narrative thinking" as one which salvages or imposes order upon the chaotic and messy "happenstance" (p. 165) of our everyday lives.

to participate in his non-sense-making in our own process of making sense of Alzheimer's. Within the safe space of the narrative, we are invited to imagine the performance of Monsieur T.'s actions as if they were our own and to reinterpret the events from his perspective without the ominous and terrifying reality of living with the disease ourselves.

The narrative ends where it began, but this time through the narrator's imaginative investment in the thought processes of Monsieur T. himself undertaking the act of stabbing his wife. It is an event enacted without premeditation or aggression, but appears to be the resolution of some unknown internal dilemma that spills out only distress, misunderstanding, sadness, and anger:

> it's complicated... to be human... to understand or to hide when we don't understand to be ingenuous or to hide when we aren't to adjust or to hide when we don't adjust to be furious without showing it to be sad without showing it to be alone without showing it to be here rather than elsewhere to be a prisoner it's so complicated he picks up a knife on the table and since she keeps talking with words he doesn't understand he erases her and erases himself with her to be a man it's too complicated. (pp. 168–169, translation modified)

Rosenthal's narrative concludes where it began: via significant departures that engage in cultivating an imaginative encounter with a singular experience from multiple perspectives, including Monsieur T.'s wife's, his consultant's, and the narrator's, but it is by imagining the thoughts and actions of Monsieur T. from his perspective—and in so doing humanizing and subjectively personalizing them—that the narrative invites us to reconceptualize "person-with-DEMENTIA" "PERSON-withdementia" (Kitwood, 1997, p. 7).

We're Not Here corresponds, therefore, to what Nussbaum (2010), following pediatrician and psychoanalyst Donald Winnicott, calls a "play space" that nourishes and extends our capacity for empathy:

Through the imagination ... we are able to develop our ability to see the full humanness of the people with whom our encounters in daily life are especially likely to be superficial at best, at worst infected by demeaning stereotypes. And stereotypes usually abound when our world has constructed sharp separations between groups, and suspicions that make any encounter difficult. (p. 107)

The notion of play in narrative fiction is ethically and epistemologically valuable because it helps to reduce the experiential distance between "us" and "them," or in this case between "healthy" and "demented," that allows the reader to imagine otherwise. Rosenthal's narrative fiction has the potential to change our views towards individuals with Alzheimer's disease by challenging our stereotypical attitudes towards dementia and helping us to engage with the singularity of each subject's experience of the disease in its individuality. This approach to Alzheimer's disease and its sufferers is an attempt to illuminate the humanness of the demented other in order to engage in an ethical understanding of self as other that will facilitate the uncomfortable encounter with our own potentially demented future selves.

We're Not Here is not only engaged in this humanized and subjective understanding in an attempt to reassess our approaches to sufferers of Alzheimer's disease, but in an attempt to familiarize ourselves with a possible unwelcome future in which we too are affected—directly or indirectly—by the disease: "The goal of this book is for me to get used to the idea that I could one day be suffering from A.'s disease, or that, even more terrible, the person with whom I live could suffer from it" (Rosenthal, 2015, p. 9). Rosenthal's investment in the humanness of people with Alzheimer's is not only aimed at furthering our empathetic understanding of the disease but in drawing the disease into a possible future that has a direct and inextricable link with our present. Philosopher Catherine Malabou (2012) writes that "A person with Alzheimer's disease ... is not ... someone who has 'changed' or been 'modified,' but rather a subject who has become someone else" (p. 15). Throughout Rosenthal's text, the narrative voice alternates among first-, second-, and third-person, so that the disease is experienced from different perspectives. The central event returns in the narrative, mediated through different voices and perspectives that tend to transform without warning: "I pierce her, she screams, why is she screaming like this, the noise hurts, I don't stop" (p. 18, emphasis added); "That morning, he knew he was going to / either kill her or sell the house / kill her or sell the house / I'm going to kill her or sell the house" (p. 25, emphasis added). In the act of reading, we are constantly thrown from one perspective to another, and this disorientation is not only ethically significant in cultivating our capacity to imagine otherwise but has epistemic significance in reproducing the self-fragmentation common to Alzheimer's disease. Indeed, the narrator herself alternates between firstand second-person voice, failing to reconcile certain events as part of a continuous and unified life: "You'd never have thought that one day your father could mistake you for his wife" (p. 24, emphasis added). The narrator's own confusion over her identity is a mark of the ways in which she attempts to come to terms with a possible future in which the disease will have truly made its impact upon her ability to connect past and present selves.

It is possible to suggest, therefore, that the narrator plays the part of the Alzheimer's sufferer, experimenting "with the idea of otherness in ways that are less threatening than the direct encounter with another might often be" to develop "invaluable practice in empathy and reciprocity" (Nussbaum, 2010, p. 99). This imaginative power is not without forfeit, however, as the narrator's playful entry into the mind of Monsieur T. begins to warp her sense of self, blurring the boundaries between fiction and reality, self and other, present and possible future. As the narrative comes to life, the disease spreads, a self-fulfilling prophecy for the superstitious narrator whose own body revolts against her writing: "Writing on A.'s disease hurts me" (Rosenthal, 2015, p. 33). At various intervals, the readers, too, are invited to enter into this dangerous game and to enlarge their own "sense of the possible ... of how things could be otherwise" (Meretoja, 2018, p. 4) through guided exercises in imagination. For example:

Do an exercise.

Imagine that old and sick, you are put in a retirement home, that nobody ever comes to see you, those who might have being already dead and buried.

Granted, the exercise isn't great. (p. 60, translation modified) And later:

Do an exercise.

Imagine yourself in the place of the one whose life story has been swallowed up.

Imagine yourself at the dinner table, unaware of what you're eating, of where you are, of the objects around you, of the strangers chatting to you like friends. (p. 109, translation modified)

These exercises play with our "sense of the possible" by positioning us as the one with the disease, entering into the perspective of a person with Alzheimer's disease and seeing the world through his or her eyes:

> It's by doing exercises like this that we end up getting interested in A.'s disease and almost manage to enter into the minds of those affected. In fact, anxiety decreases as we enter, as we enter into their minds. (p. 60, translation modified)

The playful familiarity of these childlike role-play exercises connects "the experiences of vulnerability and surprise to curiosity and wonder, rather than to crippling anxiety" (Nussbaum, 2010, p. 101). As readers, we are engaged in the exploration of our own possibilities through playful interactions that reduce the intimidating encounter with one's own otherness by assimilating the experience of Alzheimer's disease into our everyday realities.

However, one wonders if in "playing" the part of the person with Alzheimer's disease we are not overstepping the ethical boundaries of imagination. Can the healthy mind really imagine the thoughts, actions, and experiences of the demented mind? Are we not merely reproducing and re-enacting established stereotypes of cognitive impairment? Rosenthal's comparative exercises aim to help us imagine otherwise, grounded in the language and experiences with which we are familiar, but Alzheimer's disease unsettles this familiarity. Can we even say that it is possible for the healthy mind to imagine the demented mind? Moreover, in the case of Alzheimer's disease, a disease notoriously labelled unspeakable, inconceivable, and taboo, is it truly ethically or epistemologically viable to "narrate" at all? And if the experience cannot be narrated, how can narrative be used to help us imagine? While narrative fiction may help us to imagine the world from the perspective of another and to empathetically respond to experiences as if they were our own, our ability to imagine and to understand may not depend upon the

fulfilment of traditional narrative structures but rather upon the interruption of narrative and imagination at the limits of understanding.

"An Experience without Words": Narratives of Non-Sense

In Dementia Reconsidered: The Person Comes First, psychologist Tom Kitwood (1997) observes that

It is impossible ... to enter fully into the experiential frame of another person, simply because each person is unique. In relation to dementia there are additional problems No one has returned from this particular journey of cognitive impairment in order to tell us what it is like. We are far more dependent on inference than in most ventures in intersubjectivity. Also, there is an essential contradiction. If we try to describe the experience of dementia in ordinary prose, we are using the calm, detached and highly ordered vehicle of language in order to convey impressions of a state of being that is often fragmented and turbulent. Furthermore, we are attempting to capture in concepts what it may be like to live in a subjective world where concepts are not holding up any more. The further we go into the domain of severe cognitive impairment, the more serious does this problem become. (p. 71)

This, I would argue, is the ethical challenge facing Rosenthal's work and any work that treats dementia and Alzheimer's disease. In We're Not Here, the narrator's exercises translate the unknowable world of Alzheimer's disease into everyday concepts that aim to facilitate the reader's comprehension of the unfamiliar experience, but we cannot know that these everyday concepts still pertain to the perspective of the one with the disease. Our attempts to understand Alzheimer's disease are caught between the distinct subjectivities of healthy and demented minds, and a realistic portrayal of dementia must depart from comprehensible narrative traditions in such a way that it will inevitably alienate the reader's attempts to understand. To realistically and empathetically portray Alzheimer's disease means to use language that has been fragmented, that is falling apart, that is, by its very nature, unreadable and incomprehensible, and that will invariably problematize our processes of understanding. Or, to rephrase Elie Wiesel's famous dictum about the

Nazi camps: a narrative of Alzheimer's disease is either not a narrative or not about Alzheimer's disease.⁶

I would suggest, however, that this is precisely what Rosenthal's self-conscious narrative tries to show. Rosenthal is fully aware of the inherent incompletion that pervades any attempt at sense-making in the context of Alzheimer's disease, and although the narrator endeavors to transform her understanding—and ours—by adopting the perspectives of those around Monsieur T., and even of the sufferer himself, she concedes that "We can't really recount Monsieur T.'s life in full. His testimony is missing" (p. 166). To understand the experience of Alzheimer's disease is to realize that it cannot be understood and to carefully negotiate the potential of narrative to challenge our belief in this understanding:

The experience of meaninglessness is absolutely mute, it's an experience without words. No one can give an account of it, at least no one who is actually in a position to do so, I mean the people blessed with speech. Sick people can't talk about their illnesses because they don't have the words, and the healthy because they do have them. Writing about A.'s disease is by nature doomed to failure. (p. 70, translation modified)

Alzheimer's disease cannot be reconciled with coherent narrative, but in this failure to portray and represent we learn something about the incommunicability of the disease and of the impossibility of ever fully entering into the subjective experiences of others. Rosenthal's narrative sense-making practice is a *non-sense*-making practice that attempts to reveal something of the incomprehensibility of Alzheimer's disease by frustrating our engagement with the other and his or her experience. The experiential void that separates healthy from demented minds may be insurmountable, but by pointing to this gap in our understanding we learn more about the disease as an experience that lies beyond our powers of imagination. Meretoja (2018) argues that "it is easier to take the perspective of someone whose experiences are richly articulated in a language that sets our imagination alight, and considerably more difficult to take the perspective of someone whose experiences remain inexpressible" (p. 128), and in the case of narratives of Alzheimer's

⁶ A number of variations on this dictum are in circulation, including—but not limited to—"A novel about Auschwitz is not a novel, or else it is not about Auschwitz" (Wiesel, cited in Rosenfeld, 1980, p. 14), and "A novel on Majdanek is either not a novel or not about Majdanek" (Wiesel, cited in Sicher, 2005, p. x).

disease, the inexpressibility of the perspective of the one with the disease translates into a disruptive block to our understanding that can be used to convey a sense of our enduring incomprehension. These challenges to narratives of Alzheimer's disease, both ethically and epistemologically, are also their most valuable substance.

I have suggested that Rosenthal's work is useful in two ways: first, in its attempts to help us imagine the world from the perspective of someone different from ourselves through the cultivation of our narrative imagination, and, second, in the ways it obstructs the reader's definitive understanding by failing to present a full narrative that would make sense of nonsense. Narrative fiction has ethical and epistemological value in the ways it not only helps us to make sense of the world but in the ways in which it helps us to realize that the world, life, and all its associated experiences, events, and feelings cannot always be made sense of, that nonsense abounds, and that life does not conform to the structure of a good book.⁷ Irmela Marei Krüger-Fürhoff (2015) has noted the differences that separate autobiographical writing on Alzheimer's disease from fictional writing, arguing that autobiographical writing, such as Thomas DeBaggio's (2000) Losing My Mind: An Intimate Look at Life with Alzheimer's, aims not at "exploring the breakdown of language but rather at documenting the survival of [a] coherent narrative self" (p. 96). For the one with the disease, autobiographical narrative presents a means of holding on to a sense of self, of resisting the self-effacing threat of becoming "de-storied" when we can no longer remember or articulate who we are (Eakin, 2004, p. 123). Narrative fiction, on the other hand, can "go beyond" autobiography by allowing us to enter into the world of the afflicted characters in all their frailty and vulnerability to imagine their experience as it could one day be our own (Krüger-Fürhoff, 2015, p. 96). Narratives of Alzheimer's disease, such as We're Not Here, should not fill us with optimism or give structure to the unstructured internal experience of the disease but rather articulate the fragility of the human condition, exposing the reader to the vulnerabilities and non-senses that may lie in our future encounters.

⁷ Goldie (2012) writes that "the simple fact about life is that 'stuff happens.' Life is messy" (p. 167) that many things in the world and even in our own lives remain unexplained and incomprehensible, that experience cannot always be understood, and that the temptation "to seek a narrative that neatly ties all the ends together" risks oversimplifying the intricate complexities and imprecisions of life and the mind (pp. 167-173).

References

- Alzheimer's Disease International. (2015). World Alzheimer report 2015: The global impact of dementia. Retrieved from https://www.alz.co.uk/research/WorldAlzheimerReport2015-sheet.pdf
- Brockmeier, J., & Meretoja, H. (2014). Understanding narrative hermeneutics. *Storyworlds*, 6(2), 1–27.
- Burke, L. (2008). "The country of my disease": Genes and genealogy in Alzheimer's life-writing. *Journal of Literary Disability*, 2(1), 63–74.
- Burke, L. (2015). The locus of our dis-ease: Narratives of family life in the age of Alzheimer's. In M. Schweda & A. Swinnen (Eds.), *Popularizing dementia:* Public expressions and representations of forgetfulness (pp. 23–41). Verlag.
- Cain, S. (2014, August 23). Interview with Malorie Blackman: "Children's books still have a long way to go before they are truly diverse." *The Guardian*. Retrieved from https://www.theguardian.com/childrens-books-site/2014/aug/23/malorie-blackman-teen-young-adult-fiction-diversity-amnesty-teen-takeover-2014
- DeBaggio, T. (2002) Losing my mind: An intimate look at life with Alzheimer's. The Free Press.
- Eakin, P. J. (2004). What are we reading when we read autobiography? *Narrative*, 12(2), 121–132.
- Fraser, B. (2018). Sequencing Alzheimer's dementia: Paco Roca's graphic novel Arrugas [Wrinkles (2008)]. In Cognitive disability aesthetics: Visual culture, disability representations, and the (in)visibility of cognitive difference (pp. 136–169). University of Toronto Press.
- Goldie, P. (2012). *The mess inside: Narrative, emotion, and the mind*. Oxford University Press.
- Kaufman, S. R. (2006). Dementia-near-death and "life itself." In A. Leibing & L. Cohen (Eds.), *Thinking about dementia: Care, loss, and the anthropology of senility* (pp. 23–42). Rutgers University Press.
- Kitwood, T. (1997). Dementia reconsidered: The person comes first. Open University Press.
- Krüger-Fürhoff, I. M. (2015). Narrating the limits of narration: Alzheimer's disease in contemporary literary texts. In M. Schweda & A. Swinnen (Eds.), *Popularizing dementia: Public expressions and representations of forgetfulness* (pp. 89–108). Verlag.
- Lyman, K. A. (1989). Bringing the social back in: A critique of the biomedicalization of dementia. *The Gerontologist*, 29(5), 597–605.
- Malabou, C. (2012). The new wounded: From neurosis to brain damage [Les nouveaux blessés (2007) (S. Miller, Trans.)]. Fordham University Press.
- Meretoja, H. (2018). The ethics of storytelling: Narrative hermeneutics, history, and the possible. Oxford University Press.
- Nussbaum, M. (2010). Not for profit: Why democracy needs the humanities. Princeton University Press.
- Peck, R. (1991). Anonymously yours. Messner.
- Rosenfeld, A. H. (1980). A double dying: Reflections on holocaust literature. Indiana University Press.
- Rosenthal, O. (2007). On n'est pas là pour disparaître. Gallimard.
- Rosenthal, O. (2015). We're not here to disappear (B. Mousli, Trans.). Otis Books.

Sabat, S. (2001). The experience of Alzheimer's disease: Life through a tangled veil. Blackwell.

Sicher, E. (2005). The Holocaust novel. Routledge.

Warnock, M. (1972). Introduction. In J. P. Sartre, The psychology of imagination (pp. iv-xvii). Methuen. (Original work published 1940)

Williams, R. (1977). Marxism and literature. Oxford University Press.

Zeilig, H. (2015). What do we mean when we talk about Dementia? Exploring cultural representations of "dementia." Working with Older People, 19(1), 12–20.

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