

# *Alzheimer Expressions or Expressions Despite Alzheimer's?*

## REFLECTIONS ON SELFHOOD AND EMBODIMENT

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ALZHEIMER'S DISEASE IS CONSIDERED TO BE THE MOST FRIGHTENING CONDITION that faces the aging population in the twenty-first century,<sup>1</sup> a much-feared stigmatizing label that carries with it a sentence of social death.<sup>2</sup> The lay media are replete with descriptions of Alzheimer's such as a "living death," "unbecoming" a self, and a "drifting towards the threshold of unbeing."<sup>3</sup> Even the US federal government's Advisory Panel on Alzheimer's Disease describes the person with the illness as one whose mind has been dissolved, leaving only a body from which the per-

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<sup>1</sup> Steven Schroeder, Marcus Krupp, Lawrence Tierney, and Stephen McPhee, *Current Medical Diagnosis and Treatment* (Norwalk, CT: Appleton and Lange, 1990).

<sup>2</sup> Ann Robertson, "The Politics of Alzheimer's Disease: A Case Study in Apocalyptic Demography," in *Critical Perspectives on Aging: The Political and Moral Economy of Growing Old*, ed. Meredith Minkler and Carroll L. Estes (Amityville, NY: Baywood, 1991), 135–50.

<sup>3</sup> Elizabeth Herskovitz, "Struggling over Subjectivity: Debates about the 'Self' and Alzheimer's Disease," *Medical Anthropology Quarterly* 9, no. 2 (1995): 153; Andrea Fontana and Ronald W. Smith, "Alzheimer's Disease Victims: The 'Unbecoming' of Self and the Normalization of Competence," *Sociological Perspectives* 32, no. 1 (1989): 36; Tom Kitwood and Kathleen Bredin, "Towards a Theory of Dementia Care: Personhood and Well-Being," *Ageing and Society* 12 (1992): 285.



son has been removed.<sup>4</sup> Richard Taylor, who writes of his own dementia, reflects on public perception: “I think that, for most people, Alzheimer’s disease means certain death before your ‘natural time,’ preceded by a period of time during which you have been stripped of your personality and your memories and have become someone you cannot imagine. You have no dignity and no sense of self, and eventually you just sit around waiting for your body to forget how to keep itself alive.”<sup>5</sup> Thus, while Alzheimer’s disease is usually described and analyzed in terms of the cognitive dysfunction it produces, “what seems to be at stake on a deeper level in . . . Alzheimer’s is our very notion of what comprises the ‘self.’”<sup>6</sup>

Social scientists and health science scholars have challenged in a significant way the presumed loss of self that is so widely associated with the cognitive deficiencies that lie at the core of dementia.<sup>7</sup> Emerging from this research are critical contributions concerning the impact of cultural definitions, care settings, and caregiving relationships on the experience of dementing illness that have been shown to damage care recipients’ fragile self-esteem, leading ultimately to the loss of selfhood that is so widely thought to be caused by neuropathology alone. Theories that reclaim and reframe the self in Alzheimer’s are influenced largely by a social interactionist perspective.<sup>8</sup>

Key to interactionist social theory is belief that selfhood is socially acquired and sustained, and that the body of the social actor is a largely inconsequential feature of the “self-in-society perspective.”<sup>9</sup> Thus, the self is understood not as a fixed attribute of an individual but rather as “emergent” and as crucially tied to interaction.<sup>10</sup> Yet to maintain that it is the socio-interactive environment alone that constitutes selfhood is to deny the significance of embodiment<sup>11</sup> or, more precisely, embodied selfhood<sup>12</sup>—the idea that bodily habits, gestures, and actions support

<sup>4</sup> William L. Keane, “The Patient’s Perspective: The Alzheimer’s Association,” *Alzheimer Disease and Associated Disorders* 8, suppl. 3 (1994): 152.

<sup>5</sup> Richard Taylor, *Alzheimer’s from the Inside Out* (Baltimore, MD: Health Professions Press, 2007), 114.

<sup>6</sup> Herskovitz, “Struggling over Subjectivity,” 148.

<sup>7</sup> *Ibid.*, 146–64; Murna Downs, “The Emergence of the Person in Dementia Research,” *Ageing and Society* 17 (1997): 597–607; Hava Golander and Aviad E. Raz, “The Mask of Dementia: Images of ‘Demented Residents’ in a Nursing Ward,” *Ageing and Society* 16 (1996): 269–85; Tom Kitwood, “The Dialectics of Dementia: With Particular Reference to Alzheimer’s Disease,” *Ageing and Society* 10 (1990): 177–96; Tom Kitwood, *Dementia Reconsidered: The Person Comes First* (Buckingham: Open University Press, 1997); Stephen Post, *The Moral Challenge of Alzheimer Disease* (Baltimore, MD: Johns Hopkins University Press, 1995); Steven Sabat and Rom Harré, “The Construction and Deconstruction of Self in Alzheimer’s Disease,” *Ageing and Society* 12 (1992): 443–61; Anne K. Vittoria, “Preserving Selves: Identity Work and Dementia,” *Research on Aging* 20, no. 1 (1998): 91–136.

<sup>8</sup> Kitwood and Bredin, “Towards a Theory of Dementia Care”; Golander and Raz, “Mask of Dementia”; Kitwood, “Dialectics of Dementia”; Kitwood, *Dementia Reconsidered*; Sabat and Harré, “Construction and Deconstruction of Self in Alzheimer’s Disease”; Vittoria, “Preserving Selves.”

<sup>9</sup> Bryan S. Turner, *The Body and Society*, 2nd ed. (London: Sage, 1996), 62.

<sup>10</sup> George H. Mead, “Development of Self through Play and Games,” in *Social Psychology through Symbolic Interaction*, ed. Gregory P. Stone and Harvey A. Farberman (London: Ginn-Blaisdell, 1970), 537–45; Charles H. Cooley, “The Looking Glass Self,” in *Symbolic Interaction*, ed. Jerome Manis and Bernard Meltzer (Boston: Allyn and Bacon, 1972), 231–33; Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Englewood Cliffs, NJ: Prentice Hall, 1963).

<sup>11</sup> Julian C. Hughes, “Views of the Person with Dementia,” *Journal of Medical Ethics* 27 (2001): 86–91; Pia Kontos, “‘The Painterly Hand’: Embodied Consciousness and Alzheimer’s Disease,” *Journal of Aging Studies* 17 (2003): 151–70.

<sup>12</sup> Pia Kontos, “Embodied Selfhood in Alzheimer’s Disease: Rethinking Person-Centred Care,” *Dementia: The International Journal of Social Research and Practice* 4, no. 4 (2005): 553–70; Pia Kontos, “Ethnographic Reflections on Selfhood, Embodiment and Alzheimer’s Disease,” *Ageing and Society* 24 (2004): 829–49; Pia Kontos, “Embodied Selfhood: An Ethnographic Exploration of Alzheimer’s Disease,” in *Thinking about Dementia: Culture, Loss, and the*

and convey humanness and individuality. Consequently, the body as a generative source of agency has largely been neglected in the discourse on selfhood in the dementia literature.<sup>13</sup>

In this paper I argue for an expansion of the discourse on selfhood to include embodied self-expression—encapsulated in the notion of embodied selfhood—as a source of interactive practices. The concept of embodied selfhood is intended to capture the ways in which selfhood is embodied and reproduced through our practical and corporeal actions. Literary accounts of the experience of Alzheimer's disease are explored here in the context of embodied selfhood in order to capture the corporeal dimensions of selfhood and the indeterminacy of the boundaries and experiences of Alzheimer's disease. My analysis suggests that corporeality is an active foundation of agency that sustains selfhood at a prereflective level and facilitates awareness of surroundings, engagement with the world, and interaction despite even severe dementia.

### EMBODIED SELFHOOD

Embodied selfhood is premised on a prereflective notion of agency that resides below the threshold of cognition and is manifest primarily in corporeal ways.<sup>14</sup> As an embodied dimension of human existence, selfhood persists even with severe dementia, as demonstrated, for example, in religious and artistic practices,<sup>15</sup> aversion to particular foods,<sup>16</sup> and bodily dispositions that convey the prior vocation<sup>17</sup> of persons with dementia.

Embodied selfhood takes its theoretical bearings from Merleau-Ponty's understanding of nonrepresentational or basic intentionality and from Bourdieu's concept of habitus, which links bodily dispositions to structures of the social world.<sup>18</sup> More specifically, I conceptualize Mer-

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*Anthropology of Senility*, ed. Lawrence Cohen and Annette Leibing (New Brunswick, NJ: Rutgers University Press, 2006), 195–217; Pia Kontos and Gary Naglie, “Expressions of Personhood in Alzheimer's: Moving from Ethnographic Text to Performing Ethnography,” *Qualitative Research* 6, no. 3 (2006): 301–17; Pia Kontos and Gary Naglie, “Expressions of Personhood in Alzheimer's Disease: An Evaluation of Research-Based Theatre as a Pedagogical Tool,” *Qualitative Health Research* 17, no. 6 (2007): 799–811.

<sup>13</sup> For exceptions, see Hughes, “Views of the Person with Dementia”; Kontos, “Embodied Selfhood in Alzheimer's Disease”; Kontos, “Ethnographic Reflections on Selfhood”; Kontos, “Embodied Selfhood: An Ethnographic Exploration of Alzheimer's Disease”; Kontos and Naglie, “Expressions of Personhood in Alzheimer's: Moving from Ethnographic Text to Performing Ethnography”; Kontos and Naglie, “Expressions of Personhood in Alzheimer's Disease: An Evaluation of Research-Based Theatre as a Pedagogical Tool”; Eric Matthews, “Dementia and the Identity of the Person,” in *Dementia: Mind, Meaning and the Person*, ed. Julian C. Hughes, Stephen J. Louw, and Steven R. Sabat (Oxford: Oxford University Press, 2006), 163–77.

<sup>14</sup> See n. 12.

<sup>15</sup> Kontos, “Embodied Selfhood: An Ethnographic Exploration of Alzheimer's Disease,” 198–203; Kontos and Naglie, “Expressions of Personhood in Alzheimer's Disease: An Evaluation of Research-Based Theatre as a Pedagogical Tool,” 805–6.

<sup>16</sup> Pia Kontos, Gail J. Mitchell, Bhavnita Mistry, and Bruce Ballon, “Using Drama to Improve Person-Centred Dementia Care,” in “Outcomes from the Promotion of Personhood in Gerontological Nursing,” special issue, *International Journal of Older People Nursing* 5 (2010): 163; Pia Kontos, Karen L. Miller, and Gail J. Mitchell, “Neglecting the Importance of the Decision Making and Care Regimes of Personal Support Workers: A Critique of Standardization of Care Planning through the RAI/MDS,” *Gerontologist* 50, no. 3 (2010): 357.

<sup>17</sup> Kontos and Naglie, “Expressions of Personhood in Alzheimer's Disease: An Evaluation of Research-Based Theatre as a Pedagogical Tool,” 805; Kontos, Miller, and Mitchell, “Neglecting the Importance of the Decision Making and Care Regimes of Personal Support Workers,” 357; Pia Kontos and Gary Naglie, “Bridging Theory and Practice: Imagination, the Body, and Person-Centred Dementia Care,” *Dementia: The International Journal of Social Research and Practice* 6, no. 4 (2007): 558–59.

<sup>18</sup> Maurice Merleau-Ponty, *Phenomenology of Perception*, trans. Colin Smith (London: Routledge and K. Paul, 1962); Pierre Bourdieu, *Outline of a Theory of Practice*, trans. Richard Nice (Cambridge: Cambridge University Press, 1977);

leau-Ponty's elucidation of basic intentionality as providing the corporeal foundation of selfhood evidenced by the existential expressiveness of the body. Merleau-Ponty's basic intentionality is the body's concrete, spatial, and prereflective directedness toward the lived world. It refers to a field of possible movements, a kind of inner map of movements, that the body naturally "knows" how to perform without having to reflect upon such movements. In Merleau-Ponty's words, "a system of possible movements . . . radiates from us to our environment," giving us at every moment a practical and implicit hold on our body, a hold that situates us as subjects perceptually, linguistically, as well as through motor activity.<sup>19</sup> In this "system of possible movements," the body possesses, according to Merleau-Ponty, a coordinating capacity in relation to itself through what he refers to as the "primary perceptual" level that is prior to explicit intellection. I understand the primacy of perception as providing the foundation for selfhood and therefore argue that selfhood, at the most fundamental level, must be understood as inhering in the existential capacity of the body to engage with the world.<sup>20</sup>

In Merleau-Ponty's discussion of basic intentionality, he makes no reference to sociocultural modes of expression because his exclusive concern is with capacity per se. However, clearly there is a sociocultural style or content to bodily movements and gestures, the source of which cannot be attributed to a primary level of signification. Bourdieu's concept of habitus is pertinent here because it foregrounds the sociocultural sources of bodily practices.

Bourdieu's sociological approach to understanding the embodiment of social structures further informs my articulation of embodied selfhood in that I conceptualize habitus as instilling at a prereflective level the sociocultural dispositions of selfhood. Our social being derives from habitus, which Bourdieu defines as socialized inclinations that are associated with membership in a particular cultural group and that instill in individuals dispositions and generative schemes for being and perceiving.<sup>21</sup> Habitus comprises dispositions and forms of know-how that are learned by the body but cannot be explicitly articulated. It is a form of knowledge that does not pass through consciousness, for it is enacted at a prereflective level. As Bourdieu states, "the schemes of the *habitus* . . . owe their specific efficacy to the fact that they function below the level of consciousness and language, beyond the reach of introspective scrutiny or control by the will."<sup>22</sup> Just as dispositions are embodied and materialized in practice, so is selfhood embodied and manifested in socioculturally specific ways of being-in-the-world.<sup>23</sup>

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Pierre Bourdieu, *The Logic of Practice*, trans. Richard Nice (Cambridge: Polity Press, 1990). It is important to bear in mind that my theoretical articulation of embodied selfhood emerges fully by extending Merleau-Ponty's and Bourdieu's thought through my analysis of the literary representations presented here.

<sup>19</sup> Maurice Merleau-Ponty, "An Unpublished Text by Maurice Merleau-Ponty: A Prospectus of His Work," in *The Primacy of Perception*, ed. J. Edie (Evanston, IL: Northwestern University Press, 1964), 5.

<sup>20</sup> Kontos, "Embodied Selfhood in Alzheimer's Disease"; Kontos, "Ethnographic Reflections on Selfhood, Embodiment and Alzheimer's Disease"; Kontos, "Embodied Selfhood: An Ethnographic Exploration of Alzheimer's Disease."

<sup>21</sup> Bourdieu, *Outline of a Theory of Practice*; Bourdieu, *Logic of Practice*.

<sup>22</sup> Pierre Bourdieu, *Distinction: A Social Critique of the Judgement of Taste*, trans. Richard Nice (Cambridge, MA: Harvard University Press, 1984), 466, emphasis in original.

<sup>23</sup> Kontos, "Ethnographic Reflections on Selfhood, Embodiment and Alzheimer's Disease."

## ALZHEIMER EXPRESSIONS OR EXPRESSIONS DESPITE ALZHEIMER'S?

I have organized the literary representations of Alzheimer's disease into the thematic categories of the painterly hand, familial recognition, and immutable gentilities. Each theme will be analyzed in turn with reference to pertinent precepts of embodied selfhood. The perspective on embodiment advanced here provides the framework to articulate the richness and complexity of selfhood as manifested in creativity, love, storytelling, conversation, social norms, and customs. I shall argue that embodied selfhood underscores a prereflective form of agency that provides an important foundation for how persons with dementia interact meaningfully with the world through activity and engagement.

### *The Painterly Hand*

Michael Ignatieff's novel *Scar Tissue* is a story about a woman suffering from Alzheimer's disease, recounted by her son. The son describes his mother's passion for painting, as she would spend much of her time, before becoming ill, working at her easel. Following the death of his father and the worsening of his mother's disease, the son had no other option but to place his mother in a nursing home. He recounts that shortly after his mother's admission to the nursing home, she became unable to feed herself and spent most of her time staring out of the window; the advancing illness allowed her only a small margin of maneuver. The son visited his mother daily, observing with admirable but painful honesty her decline while contemplating crucial questions about science, genetics, art, and personhood.

One afternoon, while in the nursing-home dayroom together, the son asked his mother to sketch him.

I put the charcoal into her left hand and I put a fresh sheet of paper down, and I sat there holding her right hand, posing so that she would understand what was wanted of her.

For a moment, she remained motionless, not looking at the pencil or the paper, just smiling faintly. Then, as if the pencil placed between her fingers and my expectant face triggered a forgotten power and a forgotten scene, she began to draw. The first charcoal line appeared. Her eyes rose to take in the fall of my eyebrows, my jaw and the shape of my head. She brought her free hand up towards my face, as if to estimate distance and proportion and shape.

. . . Then just as quietly as she began, my mother stopped. The charcoal remained in her hand, poised above the last line, but it would move no further. Such connection as had been made was now broken and my mother stared off once again into space.<sup>24</sup>

At the time that this incident takes place, the son indicates that the mother had reached the stage of Alzheimer's disease where she needed assistance with washing, dressing, toileting, and feeding. This incident, given the severity of his mother's cognitive impairment, leads the son to ponder questions about the self and creativity: Did he witness in the nursing-home dayroom an unleashing of a spontaneous and subconscious source of creative energy? Does art come from the intentional self or from the primal self? With these queries the son implicitly raises the issue of what precisely constitutes "the active presence" of the artist.<sup>25</sup> Central to this issue is a distinc-

<sup>24</sup> Michael Ignatieff, *Scar Tissue* (London: Penguin Books, 1993), 152.

<sup>25</sup> Mariam Fraser, "The Face-off between Will and Fate': Artistic Identity and Neurological Style in de Kooning's Late Works," *Body and Society* 4, no. 4 (1998): 6.



tion between instinct and intent, a dichotomy that does not allow for the possibility that the body can be imbued with a life-force that has its own intentionality, inventiveness, and creativity.

Does the ability to paint, in the face of the progression of Alzheimer's disease, reside somewhere deeper than cognition? Can the body itself be a source of intention? Merleau-Ponty's redefinition of perception is critical here, for it offers an alternative to the simple distinction between conscious will and unconscious intuition. Merleau-Ponty insists that perception should not be amalgamated with cognitive consciousness, because the body itself has a primordial capacity for movement and gesture, a capacity that he describes as a power of signifying or expressing.<sup>26</sup> By locating agency also in the body and not just in the mind as distinct and separate from the body, we can begin to make sense of the mother's creative impulse to draw.

### *The Primordial Depths of Painterly Practice*

Merleau-Ponty's phenomenology of perception offers a model of painterly practice that is premised upon the notion that painting is an activity of the body. He writes, "it is by lending his body to the world that the artist changes the world into paintings."<sup>27</sup> For Merleau-Ponty, vision is not conceptual; "indeed," he writes, "we cannot imagine how a *mind* could paint."<sup>28</sup> Vision is instead understood as "occasioned" by what happens in the body, or as "incited" by the body.<sup>29</sup> Thus, for Merleau-Ponty, the animation of a painter is not a mental process but is instead an embodied process, founded upon a prereflective grasp of the world, that occurs when "his vision becomes gesture."<sup>30</sup> Merleau-Ponty uses Valéry's remark "the painter takes his body with him" to stress the embodiment of vision.<sup>31</sup> This is in striking contrast to Descartes's understanding of perception as an inspection of the mind: "Perception . . . is neither a seeing, nor a touching, nor an imagining. . . . Rather it is an inspection on the part of the mind alone."<sup>32</sup>

The resilience of artistic expression can thus be understood in terms of embodied know-how and practical sense, that is, a perspectival grasp of the world from "the point of view" of the body. The mother's artistic expression described in *Scar Tissue* is founded upon bodily intentionality that is distinct from the self-transparent activities of a reflexive subject; intentionality, according to Merleau-Ponty, is not a thought, in that "it does not come into being through the transparency of any consciousness, but takes for granted all the latent knowledge of itself that [our] body possesses."<sup>33</sup> Painting then is not the function of a cognitive form of consciousness that carries the body to a given space by way of a strategic plan formulated beforehand. Painting is a bodily form of consciousness, what in Merleau-Ponty's terms is the body's prereflective ability to direct itself toward the world.

The mother's sketching in *Scar Tissue* powerfully illustrates the primacy of practical over reflective forms of being, underscoring Merleau-Ponty's philosophical premise that corporeality is

<sup>26</sup> Merleau-Ponty, *Phenomenology of Perception*.

<sup>27</sup> Maurice Merleau-Ponty, "Eye and Mind," trans. Carleton Dallery, in *The Primacy of Perception*, 162.

<sup>28</sup> *Ibid.*, emphasis in original.

<sup>29</sup> *Ibid.*, 175.

<sup>30</sup> *Ibid.*, 178.

<sup>31</sup> *Ibid.*, 162.

<sup>32</sup> René Descartes, *Meditations on First Philosophy*, trans. Donald A. Cress (Indianapolis: Hackett, 1993), 22.

<sup>33</sup> Merleau-Ponty, *Phenomenology of Perception*, 233.

the ground of agency. By extension, artistic creativity inheres “deep within.”<sup>34</sup> This is compellingly demonstrated by the abstract-expressionist artist Willem de Kooning, who produced many paintings while he was suffering from Alzheimer’s. As Fraser writes: “de Kooning’s actions are informed by ‘humanity and feeling.’ This sensibility is not linked to consciousness . . . but instead inheres in de Kooning’s body, at the cellular level. It resides in ‘those old nerve cells,’ cells in which de Kooning’s ‘ancient memories’ are lodged.”<sup>35</sup> The case of de Kooning powerfully illustrates how aesthetic and artistic feeling is fundamental, suggesting a notion of creativity that displaces the primacy of cognitive consciousness and underscores the significance of bodily, or embodied, consciousness.<sup>36</sup>

The persistence of creativity despite advanced Alzheimer’s disease exemplifies the existential expressiveness of the body that I argue is a fundamental source of selfhood.<sup>37</sup> Selfhood as an expression of creativity should be understood as the unique synthesis of movement and embodied perception that, according to Merleau-Ponty, is dependent upon the body’s ability to seize and transform the perceptible into something meaningful.<sup>38</sup>

### *Familial Recognition*

Elinor Fuchs, in *Making an Exit*, writes of her mother’s Alzheimer’s disease. She describes familial recognition that persisted in her mother, Lil, despite her advancing cognitive impairment. Fuchs suggests that her mother’s recognition of her indicates a bond between them that is founded upon much more than cognition:

In early August I make my first visit to Mother since installing her in the Special Care Unit. When I arrive, she looks at me with slow astonishment, some kind of recognition rippling across her face. It’s not exactly that she knows who I am. By any known measure of the term, she has forgotten. To “know” who someone “is,” I have learned, is not a simple move of cognition. Mother would have to know what a daughter is, for a start, and that “Elinor” and this idea of a daughter belong together, and that this woman hugging her is both “Elinor” and a “daughter.” But she knows me at another level and bursts into joyful sobs and hugs and kisses me.<sup>39</sup>

Even when Lil has declined to the point at which she “look[ed] so—lost to herself, sans teeth, sans breast, sans lipstick, sans earrings, sans everything,”<sup>40</sup> the recognition that Fuchs describes as inhering deep within persists. She recounts a call she received from her mother’s brother to say that Lil is “coming back.”

I return in mid-April and see for myself that her legs have become sticks, her ankles like wrists. There is food under her cracked fingernails. Her hair hangs in long strings. She wears

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<sup>34</sup> Fraser, “The Face-off between Will and Fate,” 15.

<sup>35</sup> *Ibid.*, 13.

<sup>36</sup> Kontos, “Painterly Hand.”

<sup>37</sup> *Ibid.*; Kontos, “Embodied Selfhood in Alzheimer’s Disease”; Kontos, “Ethnographic Reflections on Selfhood, Embodiment and Alzheimer’s Disease”; Kontos, “Embodied Selfhood: An Ethnographic Exploration of Alzheimer’s Disease.”

<sup>38</sup> Merleau-Ponty, *Phenomenology of Perception*.

<sup>39</sup> Elinor Fuchs, *Making an Exit* (New York: Metropolitan Books, 2005), 175–76.

<sup>40</sup> *Ibid.*, 185.

white elastic stockings up to her thighs for circulation. Her teeth are lost, her lips sunken. She sits for long hours with her eyes closed. How is she “coming back”?

But when I walk in, she suddenly opens them and greets me with a little whoop of recognition—that ho-ho-ho of hers—and joyful tears.

“Is that the . . . the . . . baby?” she cries hoarsely, picking up my hand and covering it with kisses. “Is that . . . is that . . . the one I love?”<sup>41</sup>

In Lisa Genova’s novel *Still Alice*, about a cognitive psychology professor in her early fifties who learns she has early-onset Alzheimer’s, the depths of familial recognition are similarly captured in the following exchange between Alice and her daughter:

“You’re so beautiful,” said Alice. “I’m afraid of looking at you and not knowing who you are.”

“I think that even if you don’t know who I am someday, you’ll still know that I love you.”

“What if I see you, and I don’t know that you’re my daughter, and I don’t know that you love me?”

“Then, I’ll tell you that I do, and you’ll believe me.”

Alice liked that. *But will I always love her? Does my love for her reside in my head or in my heart?* The scientist in her believed that emotion resulted from complex limbic brain circuitry, circuitry that was for her, at this very moment, trapped in the trenches of a battle in which there would be no survivors. The mother in her believed that the love she had for her daughter was safe from the mayhem in her mind, because it lived in her heart.<sup>42</sup>

How do we make sense of Lil’s recognition of Fuchs? Is recognition founded upon cognitive memory alone? What is the basis for Alice’s belief that love is much deeper than cognition? A discussion follows of how these accounts displace the primacy of cognitive consciousness and underscore the significance of an ontological continuity between consciousness, body, and world that is essential to understanding the recognition between mother and daughter.

### *The Primordial Depths of the Mother-Daughter Bond*

Merleau-Ponty uses notions of depth, reversibility, and “coiling over” to describe his concept of flesh and the powerful nexus it implies between bodies, connecting individuals over time and space.<sup>43</sup> He understands mother and infant as one flesh<sup>44</sup> that binds each to the other and forms an “inexhaustible depth.”<sup>45</sup> There is an intercorporeality to the mother-infant relationship that enables a primordial attunement to each other, an understanding that is intertwined with touch, sight, and movement.<sup>46</sup> The overlapping and sedimenting of past touch, sight, and movement return to Lil, Fuchs’s mother, with the presence of her daughter, evoked through the senses, and incite in Lil maternal associations and feelings that are manifest in her recognition of her daughter. Her past experiences with her daughter persist in the body as a matrix of perceptions and ac-

<sup>41</sup> Ibid.

<sup>42</sup> Lisa Genova, *Still Alice* (New York: Pocket Books, 2007), 230–31.

<sup>43</sup> Maurice Merleau-Ponty, “The Intertwining: The Chiasm,” trans. Alphonso Lingis, in *The Visible and the Invisible*, ed. Claude Lefort (Evanston, IL: Northwestern University Press, 1968), 140.

<sup>44</sup> Francine Wynn, “The Embodied Chiasmic Relationship of Mother and Infant,” *Human Studies* 19, no. 2 (1997): 253–70.

<sup>45</sup> Merleau-Ponty, “The Intertwining: The Chiasm,” 143.

<sup>46</sup> Wynn, “Embodied Chiasmic Relationship of Mother and Infant.”



tions. They are embodied in the sense that memory of them is not confined to the brain but is actually encoded in the muscles, nerves, and sinews of the body. Lil's recognition is not a kind of knowledge that she has by virtue of her *social identity* as a mother—as Fuchs argues, “Mother would have to know what a daughter is, for a start, and that ‘Elinor’ and this idea of a daughter belong together, and that this woman hugging her is both ‘Elinor’ and a ‘daughter.’”<sup>47</sup> Rather, it is recognition in a more existential sense. This existential recognition is captured as a potentiality in Alice's belief that her love for her daughter is rooted not in the mind but in the heart and will thus persist even when her dementia advances. This is not to suggest that irrespective of the severity of dementia such recognition will always manifest itself. Yet the absence of manifestation should not necessarily lead us to conclude that recognition itself becomes extinguished; rather, it may be that the *expression* of recognition is what becomes impaired with advancing dementia.

### *Immutable Gentilities*

In *Untold Stories*, an anthology of autobiographical sketches, Alan Bennett writes of his mother, Mam, who resides in a nursing home, and although he is not certain she has Alzheimer's disease, her cognitive impairment is suggestive of some form of dementia. He writes:

Words pour out of her as they always have and with the same vivacity and hunger for your attention. But to listen to they are utterly bewildering, following the sense [is] like trying to track a particular ripple in a pelting torrent of talk.

Still, despite this formless spate of loquacity she remains recognisably herself, discernible in the flood those immutable gentilities and components of her talk which have always characterized her. . . . So that now, with no story to tell (or half a dozen), she must needs still tell it as genteelly as she has ever done but at five times the speed, her old worn politeness detached from any narrative but still whole and hers, bobbing about in a ceaseless flood of unmeaning; demented, as she herself might have said, but very nicely spoken.

And as with her speech, so it is with her behaviour. Surrounded by the senile and by the wrecks of women as hopelessly, though differently, demented as she is, she still clings to the notion that she is somehow different and superior. Corseted in her immutable gentilities she still contrives to make something special out of her situation and her role in it. “He'll always give me a smile,” she says of an impassive nurse who is handing out the tea. “I'm his favourite.”

. . . Her life has been made meaningful by frail, fabricated connections, and now, when the proper connections in her brain are beginning to break down, it is this flimsy tissue of social niceties that still holds firm.<sup>48</sup>

Elinor Fuchs writes of similar loquacity and immutable gentilities in her account of her mother's experience with Alzheimer's disease. Not long after Fuchs moved her mother into a special care unit, she called her mother, and this is the conversation she recounts:

“How are you mother?” I begin.

“Oh, in a fast muff,” she says briskly. “Getting out of the wet ditches.”

“Wet ditches, well, that's interesting.”

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<sup>47</sup> Fuchs, *Making an Exit*, 175.

<sup>48</sup> Alan Bennett, *Untold Stories* (London: Faber and Faber, 2005), 87.

She's off and running. "Oh, I'm in a dedeford. There they're having a bedurz. I mean, they're having a cressit. And would be considered hajardi. Would be picking dependent stuff." Her tone of authority is undiminished.

"Well," I ask, "are you recovered now from your fall where you had to have stitches in your forehead?" I always gave her the words she might need to flip back a response. . . .

"We basent had any consedery other than a bull," she chats on, "which we're not getting. They've got the meat in the vettery, so they feel things aren't by any means all wet."

". . . Do you have some friends there?" I ask.

She is dismissive. "Oh, they have the thogs here with the wolfit beef. But they're still rather concerned about the westerd stuff being westerd. They feel rather patz to that."

"Uh-huh. And how's the Professor, that nice man in the wheelchair?"

"Oh, the one in the fossilic? He's in habalik."<sup>49</sup>

In this exchange Fuchs allows us to witness the disease "performed," what Basting argues is missing from most autobiographical and, I would add, biographical accounts of the experience of living with the disease, since in such accounts any evidence of the disease is cleansed from the writing itself.<sup>50</sup> Leibing agrees with Basting and further argues that because these accounts "write about, and not from within, dementia," coherent text is upheld as the only way to address readers, which in turn confines personhood to periods of "normalcy."<sup>51</sup> In contrast, Fuchs breaks from this tradition and permits meaning to emerge from *incoherence* evidenced by her observation that her mother's tone of authority is undiminished. There is also meaning in the notable exchange of speaking turns in that Lil does not interrupt Fuchs when they are speaking. In addition, the nature of the dialogue allows one to sense the intonation changes, the rise and fall of pitch level, and pauses, all of which are laden with meaning, so full of life.

In John Bayley's memoir, *Elegy for Iris*, a graceful exploration of the author's marriage to Iris Murdoch, he similarly observes that memory may have wholly lost its mind function, but it retained some "hidden principle of identification," even after the Alzheimer's had long taken hold.<sup>52</sup> For example, according to Bayley, Iris's social reflexes were in a weird way still very much in place. For example, if someone came to the door, such as the postman, Bayley describes how Iris

receives him with her social smile, then calls for me in those unhurried, slightly "gracious" tones which married couples automatically use with each other in the presence of a stranger. . . . In the same way, she deals instinctively with more complex social situations, seeming to follow the conversation and smiling, prepared to bridge a silence by asking a question. Usually, the same question: "Where do you come from?" or "What are you doing now?"—questions that get repeated many times in the course of a social event.<sup>53</sup>

Are storytelling, conversation, social norms, and customs cognitive forms of expression? If so, how do we explain their persistence when the mind is not in command? Can inventiveness and spontaneity be persuasively explained without recourse to reflective deliberation? I shall argue that understanding these sociocultural practices requires a shift from the current preoccupa-

<sup>49</sup> Fuchs, *Making an Exit*, 179–80.

<sup>50</sup> Anne Basting, "Looking Back from Loss: Views of the Self in Alzheimer's Disease," *Journal of Aging Studies* 17 (2003): 89.

<sup>51</sup> Annette Leibing, "Divided Gazes," in Leibing and Cohen, *Thinking about Dementia*, 253, emphasis in original.

<sup>52</sup> John Bayley, *Elegy for Iris* (New York: St. Martin's Press, 1999), 48.

<sup>53</sup> *Ibid.*, 75.

tion with assessing the extent to which agency is a product of reflex or reflective thought to treating the body as itself having creative and intentional capacity. Bourdieu's concept of habitus, which foregrounds the sociocultural sources of bodily practices, facilitates this shift.

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Bourdieu argues that social history and culture, acquired through the process of socialization, are objectified in habitus, which is the source of an individual's way of being and perceiving. Of paramount importance to the concept of habitus, and of relevance to my analysis here, is that the power of habitus derives from the nonconsciousness of habituation rather than consciously learned principles and rules.<sup>54</sup> In this sense, the practices of storytelling and conversation, as captured in the texts of Bennett, Fuchs, and Bayley, remain intact because dispositions and forms of know-how are internalized, function below the threshold of cognition, and are enacted as practical sense at a prereflective level.

According to Bourdieu, social practice does not derive from conscious obeisance to external rules or principles, which would have no application, for example, in Bennett's narrative about his mother, Mam, given her "ceaseless flood of unmeaning." Yet despite the incoherence of her speech, recognition of storytelling persists, as does Mam's distinct style of storytelling. Reflective thought is further excluded as the genesis of her storytelling by the fact of advanced dementia in all of the examples provided. Neither should these social interactions be understood as mechanistic. The interactions are suggestive of spontaneity, evidenced by Mam's "formless spate of loquacity" and "pelting torrent of talk" and by the fact that none of the conversations that Fuchs recounts with her mother are the same. Such spontaneity resonates with Bourdieu's argument that habitus should be understood not as mechanically constraining action but rather as permitting an element of inventiveness and creativity, albeit within the limits of its structures, which are the embodied sedimentations of the social structures that produced it. Habitus is "a generative spontaneity which asserts itself in the improvised confrontation with endlessly renewed situations," and it "follows a *practical logic*, that of the fuzzy, of the more-or-less, which defines the ordinary relating to the world."<sup>55</sup> It is this fuzzy and vague but no less masterful capacity to relate to the world that makes it possible for Iris, for example, to respond in "complex social situations."

## CONCLUSION

The literary accounts of the experience of Alzheimer's disease explored here invite a rethinking of conventional notions of selfhood. These accounts call for the understanding of selfhood, not as the exclusive privilege of the sphere of conscious will, but as also emanating from our corporeal depths. This entails a shift from the current preoccupation with assessing the extent to which selfhood is a product of reflective thought or social interaction to treating the body's creative and intentional capacity as being fundamental to selfhood. The notion of embodiment, more precisely embodied selfhood, sets an important agenda for critical gerontological inquiry into the complex phenomenon of Alzheimer's disease. It is a critical approach that invites a carefully con-

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<sup>54</sup> Bourdieu, *Logic of Practice*.

<sup>55</sup> Loïc Wacquant, "Toward a Social Praxeology: The Structure and Logic of Bourdieu's Sociology," in *An Invitation to Reflexive Sociology*, ed. Pierre Bourdieu and Loïc Wacquant (Chicago: University of Chicago Press, 1992), 22, emphasis in original.

textualized discussion and exploration of the localized symbiosis of prereflective intentionality and structures of the social world. It is a symbiosis that is “enacted at every instant in the movement of existence,” rendering the animated, living, experiential body of paramount importance for understanding embodiment, selfhood, and dementia.<sup>56</sup>

This is not to suggest that embodied selfhood encapsulates all aspects of body-self and body-world relations. However, by not paying attention to embodiment in relationship to human agency, in the case of Alzheimer’s disease we ignore a vital source of selfhood that is present in the sufferer. In this sense, rethinking selfhood is not merely a philosophical exercise; recognition of the larger human dimension of individuals with Alzheimer’s disease has important implications for improving their quality of life and quality of care.<sup>57</sup> A

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<sup>56</sup> Merleau-Ponty, *Phenomenology of Perception*, 89.

<sup>57</sup> Kontos and Naglie, “Expressions of Personhood in Alzheimer’s Disease’: An Evaluation of Research-Based Theatre as a Pedagogical Tool”; Kontos et al., “Using Drama to Improve Person-Centred Dementia Care”; Kontos and Naglie, “Bridging Theory and Practice”; Pia Kontos and Gary Naglie, “Tacit Knowledge of Caring and Embodied Selfhood,” *Sociology of Health and Illness* 31, no. 5 (2009): 688–704.