

SPECIAL ISSUE: NARRATIVE EMOTIONS AND THE SHAPING(S) OF IDENTITY

Oneself as Another: Intersubjectivity and Ethics in Alzheimer's Illness Narratives¹

Lucy Burke
Manchester Metropolitan University

This paper considers what is at stake in telling the story of another's illness and in taking on the history of another's dementia as part of one's own life narrative. Through a close analysis of Michael Ignatieff's *Scar Tissue*, it explores the ways in which writing about the experience of caring for a parent with dementia speaks to the intersubjective dimensions of selfhood but also complicates the ways in which the very concept of intersubjectivity is often evoked within scholarship on personhood. It argues that an engagement with this kind of narrative is illuminating in this context because it exposes some of the emotional, memorial, and ethical difficulties that attend the experience of writing for and about another person when he or she is no longer able to do so.

Introduction: Oneself as Another

Monday 25

We waited in the emergency room for two hours, with my mother lying on a stretcher. She wet herself. A young man had tried to commit suicide by taking pills. We went into the examination room and they laid my mother down on a table. The intern rolled up her chemise to reveal her stomach—the thighs, the white vagina, a few stretch marks. Suddenly, I felt I was the one who was being exposed in public.

¹ I would like to acknowledge the support of the Arts and Humanities Research Council UK (research leave scheme) in facilitating the research for this paper.

I thought back to the cat who had died when I was fifteen; she had urinated on my pillow before dying. And the blood and bodily fluids I had lost just before my abortion twenty years ago. (Ernaux, 2000, p. 15)

There are many things to say about Annie Ernaux's description of the treatment of her mother on her admission to hospital. The literal stripping of her mother's dignity by the nameless intern offers a painful account of her powerlessness and loss of autonomy in the face of an overstretched emergency department. One recalls Michel Foucault's (2003) description of the modern medical gaze in *The Birth of The Clinic*, in which "in relation to that which he is suffering from, the patient is only an external fact; the medical reading must take him into account only to place him in parentheses" (p. 8). Her mother is *produced* by this medical encounter as an aged, leaking, and malfunctioning body: passive, to be "laid out" and "worked upon." Her lack of bodily control bespeaks a loss of personal and social control over her situation and her treatment. She is cast here as the denuded, empty body of Alzheimer's, a living corpse. The de-realization of her personhood is nowhere so clearly signaled as in the comparison to the incontinent, dying cat.

Ernaux's description of her mother's exposure is ineradicably marked by gender. Rolling up her chemise to reveal a "white vagina," it is the signs of her motherhood that are noted: her stomach indelibly tattooed with the stretch marks of pregnancy. The shame of this unveiling reminds Ernaux of "the blood and bodily fluids" of her own earlier abortion. Her empathy with her mother is thus forged through the recognition of the bodily violations of pregnancy and abortion, and of their mutual vulnerability in these contexts, of their shared experiences as women.

Yet this is a troubling form of empathy, isn't it? To what extent does the text itself reproduce the violence that marks this medical encounter, by readmitting Ernaux's mother to the hospital and subjecting her this time to the critical and pathologising gaze of the reading public? Isn't it Ernaux who plays the intern in this textual scenario, removing her mother's clothes, unmasking her for a second time? Certainly in doing so, she also re-enacts the violence she experiences herself, in recalling her sense of public exposure and in the revelation of her abortion. This is brought to light *through* her narrative recollection. Second time around, not one but both women are exposed to public scrutiny, unmasked. The narrative rends the veil that separates a set of deeply intimate experiences—abortion, child birth, loss of bodily control, dying—from the public

gaze. As readers, we are taken into the emergency room and confronted with the exposure of both women.

Writing of the experience of oneself as existentially separate and alone, Arthur Frank (1995) notes that modern medicine “encourages monadic bodies in many ways” (p. 36). It does so institutionally in the arrangement of space on wards and in waiting rooms where we sit, staring straight ahead, avoiding eye contact, bags defensively lodged on our laps as if contact might be infectious or ill-omened. It also does so discursively in terms of the disease model that speaks to pathological signs and symptoms rather than to the whole person. Yet the experience of illness itself is often shared, reaching beyond the bodies of ill persons to saturate the lifeworld of those around them (Kleinman, 1988). And this is what we see in Ernaux’s description. In the face of the casual disregard shown to her mother as a consequence of her dementia, she asserts a shared, intersubjective experience in the recognition of her own shame in that of her mother’s loss of bodily control. Her account of this scene deliberately disturbs the usual distinctions between self and other, patient and carer, mother and daughter. To borrow John Wiltshire’s (2000) phrase, it is as if the narrative initiates a kind of “devolution of one selfhood into another” (p. 409).

Sharon Kaufman (2006) describes Alzheimer’s disease as “problematizing the subject in an unprecedented manner” (p. 23). She is referring here to the centrality of Alzheimer’s dementia to current bioethical and cultural debates around the value and the limits of meaningful life. Yet in familial and emotional terms, it is true also to say that Alzheimer’s problematizes inter-subjectivity in an equally unprecedented manner, in that it raises inescapable questions about the way we conceptualise the boundaries between self and other and about the ethical dimensions of memorial practices in this context. What, in other words, is at stake in telling the story of another’s illness and in taking on the history of this illness as part of one’s own life narrative? Reading Ernaux’s memoir, it is difficult not to feel some ethical unease about the relationship between the violations of the medical examination and those of memorial revelation. If privacy, as Jeffrey Reiman (1976) argues, is “a precondition of personhood” (p. 26), then surely the writing and indeed the reading of this description can be construed as a violation of Ernaux’s mother’s personhood. To the degree, then, that this piece asserts a shared, intersubjective experience in Ernaux’s recognition of her own pain and shame in that of her mother’s, the description of this scene also enacts a form of discursive violence upon her mother’s now silent

body, and a more complex and troubling dynamic between mother and daughter.

The “Alzheimer’s epidemic” of the last twenty years has produced a significant body of writing by the children of those with the disease.² These “filial memoirs” (Couser, 2009) construct the narrative of the illness experience in the context of the relationship between parent and child, and in relation to the perceived continuities and discontinuities of identity pre- and post-illness (Couser, 2009). Characteristically, the narrator’s relationship to the disease, and to the ill person, is experienced as a kind of trauma that disrupts his or her own sense of identity. For instance, Sue Miller (2004), in her account of her father’s final years with Alzheimer’s disease, describes herself as “altered ... in some of the very same ways” as her father is by his illness: “made bland and callous, *reduced*” (p. 137). This is typical of the form. The illness narrative, as Wiltshire (1998) puts it, characteristically suggests that “being a caregiver or relative, as well as a patient, is to be in a state of impaired, and contingent, subjectivity” (p. 197).

In relation to the contemporary experience of an Alzheimer’s diagnosis, this sense of impaired and contingent subjectivity is particularly intense. The impact of dementia upon memory, cognition, mood and behaviour makes an engagement with questions of the meaning and definition of personhood unavoidable. More particularly, recognition of the genetic components of the disease disturbs the conventional meanings of heritage, and any straightforward embracing of one’s familial history, as that which nurtures and sustains particular kinds of identity (Burke, 2008). That one may inherit more than stories, culture, and disposition from one’s parents is a recurrent theme in these memoirs. Ways of living become ways of dying. Genealogical heritage recast in genetic terms becomes a curse, the site of the undoing of identity as much as its foundation. Children are compelled to confront the possibility of their own cognitive and memory losses in those of their parents. The fiction of an inviolable or unitary identity is disturbed not simply in the organic damage wrought by the disease itself but in the dislocation of familial relationships that occurs when parents cease to recognise their own children and children are forced to re-orient their own sense of self in the face of this violation of foundational intersubjective relationships.

² I use “Alzheimer’s” here and throughout in recognition of the powerful effects of the biomedicalisation of dementia and the emergence of Alzheimer’s disease as the dominant category in relation to which dementia is popularly understood and arguably experienced.

To write of illness, in this instance, is far more than simply an act of writing back to the imperialising agenda of modern medicine, as Arthur Frank (1995) has described it. It is more complex, too, than simply a form of narrative reparation or compensation, although the impulse to make sense of what is often presented as an un-assimilable experience through writing is strong.³ “Why do you think that writing about it will make any difference?” asks the wife of the narrator of Michael Ignatieff’s (1994) *Scar Tissue*. Because “I need to do something, anything” is the reply (p. 8). Lives and selves become entangled in these Alzheimer’s memoirs—to write of another is necessarily to write of oneself. And this is an ambivalent undertaking: less an act of healing than a form of mourning, less an act of self-realisation than an elegiac reflection upon the fragility of all identity and its undoing. My aim, then, in this essay is to argue for the significance of this body of writing in relation to the ways we understand the meanings of intersubjectivity in the context of writing about dementia. I am thinking here particularly about the centrality of models of intersubjectivity and relational identity to the discourses of the personhood movement in dementia and its focus upon the ethical importance of the shared authorship of life narratives. I want to argue that an engagement with the literature of the Alzheimer’s epidemic is illuminating in this context, not only to the degree that it embodies the notion of relational selfhood, but also because it exposes some of the emotional, memorial, and ethical difficulties that attend the production of these narratives.

Recognition and Personhood

The concept of intersubjectivity, of the ways in which we come into being through the mutual recognition of another, is the central tenet of numerous ethical projects. We find various versions of the concept developed across the fields of social theory (Habermasian communicative ethics), moral philosophy (Emmanuel Levinas’s *Zwischen* and Martin Buber’s I-thou), psychology and psychoanalysis (Maurice Merleau-Ponty’s concept of perception, Jessica Benjamin’s account of recognition), philosophy of language (Mikhail Bakhtin’s theory of dialogism) and narrative theory (Paul Ricoeur’s formulation of narrative identity). This list is hardly exhaustive—clearly, there are many more

³ For a discussion of the characteristics of “filial memoirs”—specifically, the endeavour to compensate for the lost object in the shape of a distant parent—see Couser (2012, p.155).

people whose work I could cite, and these disciplinary attributions themselves are permeable precisely because of the centrality of the idea of the intersubjective realm to this body of work. All these theorists develop models in which subjectivity is predicated upon an encounter with another and in which a properly ethical identification is borne of shared recognition. As Benjamin (1988) puts it:

The intersubjective view maintains that the individual grows in and through the relationship to other subjects. Most important, this perspective observes that the other whom the self meets is also a self, a subject in his or her own right. It assumes that we are able and need to recognize that other subject as different and yet alike, as another who is capable of sharing similar mental experience. Thus the idea of intersubjectivity reorients the conception of the psychic world from a subject's relations to its object toward a subject meeting another subject. (pp. 19-20)

The emphasis here upon "meeting" recalls Martin Buber's (1937/2004) observation that "All real living is meeting" (p. 11). What Benjamin means is not simply any kind of encounter, but one which is open and alive to the feelings, actions, and intentions of both self and other: "such recognition can only come from another whom we, in turn, recognize as a person in his or her own right" (p. 12).

It is this sense of our essential connectedness to others that is placed in parentheses in prevailing biomedical models of dementia and in neuroscientific discourses that seek to locate increasingly subtle personal behaviours and dispositions in various chemical interactions and electrical impulses in the brain. The search to establish different types of brains (depressed, autistic, schizophrenic, demented) is redolent of the nineteenth century pathologisation of sexuality in which particular behaviours became ontological categories. As many scholars have argued, this kind of discourse produces rather than simply reflects an ill or disabled body, and it speaks to this body in isolation as if the meanings of disease are reducible to the functioning (or otherwise) of the grey and white matter enclosed within our skulls.

In the specific case of dementia, the focus upon the pathology of cognitive decline and upon the enumeration of various forms of deficit feeds into the strand of bioethical thought that Theodore Fleischer (1999) terms "personalism" (p. 309). Here, "a human being achieves a claim to life and medical resources only if he possesses certain capacities,

primarily cognitive abilities and self-consciousness” (p. 309). Thus for personalists such as the utilitarian philosopher Peter Singer (1995), personhood is something that we can test for by way of an assessment of cognitive function and self-awareness. It is defined by the capacity to “see [oneself] as existing in different times and places,” by having “wants and plans for the future,” “rationality,” and “self-awareness” (pp. 197-98). There is also, he suggests, “a powerful social and political reason for protecting the lives of those who are capable of fearing their own death” (p. 218). Buttressed by increasingly sophisticated medical technologies for the establishment of brain function, Singer’s argument is for the development of a new ethics of life and death founded upon these criteria. Separated from bare or biological life—the mere fact of our existence—personhood becomes an individual property to be established and a matter of judgement. It is perhaps no surprise that for Singer, the judges are primarily medical professionals armed with a battery of diagnostic instruments.

That being a person involves more than simply cognition and self-consciousness is one of the defining arguments of the personhood movement in dementia care. This body of work—theoretical and therapeutic—emerges out of a sense of the ethical shortcomings of biomedical discourse and of personalism within bioethics. Both are felt to condemn persons with dementia prematurely to a form of biosocial death, removing them from the realm of meaningful social interaction (Kitwood, 1997). The argument is that particular models of brain, mind, and person can lead to the perception that the person with dementia is a nonperson and that this, in turn, is iatrogenic, actively collusive with their impairment (Leibing, 2006, p. 243). Tom Kitwood (1997), for instance, one of the most influential voices in the personhood movement, identifies the ways in which particular attitudes towards dementia produce a “malignant social environment” that is “deeply damaging to personhood, possibly even undermining physical well-being” (p. 46). He develops a list of seventeen inter-related elements that characterise the malignant psychosocial environment, including labelling, infantilization, ignoring, stigmatization, social banishment, and objectification (p. 47). These modes of response, he argues, deprive persons with dementia of social selfhood, further disabling and disempowering them.

In this respect, an engagement with various theoretical accounts of intersubjectivity has been central to the project of the personhood movement. Models of narrative identity in particular have been deployed in two main and inter-related ways. First, they have been evoked as

descriptive frameworks for the conceptualisation of the relationship between brain, mind, and person and thus for the formation of personal identity in an intersubjective milieu. Second, they have been used in a prescriptive sense as the basis for an ethical argument about good dementia care that points to the importance of the social environment and nexus of relationships in which people live (Sabat, 2001; Kitwood, 1997). First then, narrative theories of consciousness—as opposed to physicalist models that reduce mind to cognitive function—enable one to conceptualise identity as something that exceeds the individual. As Grant Gillett (2004; quoted in Hughes, Louw, and Sabat, 2006), puts it:

we make discursive and narrative sense of ourselves as persons who live and move and have our being among others. The narrative is constructed out of the events that befall persons as detected by their information gathering systems and rendered meaningful by their conceptual skills. The resulting story shapes holistic patterns of brain activity and thereby affects the neurophysiological stream that constitutes the proximal effects of one's doings in the world. In making sense of the world, we apply discursive skills and norms of judgment to what is going on in that stream to produce the narratives of our lives according to the framework we have made our own (on the basis of the kinds of things that normally go on around here. (p. 13)

This is to suggest that the brain (the “information gathering system”) is part but not the whole of the story of selfhood. Jerome Bruner (1991) makes a very similar case when he argues that:

in understanding the nature and growth of mind in any setting, we cannot take as our unit of analysis the isolated individual operating “inside his or her own skin” in a cultural vacuum. Rather, we must accept the view that the human mind cannot express its nascent powers without the enablement of the symbolic systems of culture. (p. 20)

Both these accounts suggest that our identities are not simply interior properties reducible to brain function, but forged through the interaction of internal mental facilities and the external world of language, culture, and community. The brain is the organ of mindedness, but selfhood is not

reducible to the brain alone. Hughes, et al. (2006) describe the implications of these arguments as follows:

The idea is that narrative ... suggests the notion of our minds in some way reaching out into the community in order to provide the basis for an enduring sense of self. The idea of a narrative, that is, provides something public, something outside the head, even if connected to what might be occurring within, which can be shared and provide continuity beyond the necessity for the individual to be constantly self-conscious. (p. 15)

The concept of narrative identity thus allows one to envisage the construction of life narratives as a shared enterprise rather than as the province of a monadic entity. It also erodes the distinction between inner and outer selves pointing to a far leakier or permeable relationship between the two. Both these implications are used to develop arguments for the extension of personhood to those with dementia. First, the emphasis upon the development of identity through an interactive engagement with an interlocutory web of cultural, social, and familial narratives means that all forms of identity are contingent upon others. This is presented by Hughes, et al. as a fact about identity and about our lives (p. 35). Its ramifications for those with dementia are two-fold. It is a reminder of their interconnection with others and their place in a network of accrued life narratives and familial relationships. As such, it implies that should a capacity to tell their own stories diminish, then it falls to those around the persons with dementia to sustain their narrative identities. Indeed Jennifer Radden and Joan Fordyce (2006), drawing upon Marya Schechtman's (1996) work on characterisation identity, argue that this is a necessity:

To turn away from the task of sustaining the characterisation identity of the person with dementia suggests a failure to acknowledge the extent that the construction of the identity before the illness was a product of others as well as of the person themselves. Consistency suggests that what was begun by others should be continued by them. And this point would not so readily be lost from sight were the distorting ideology of individualism, which casts each person the master of their fate and captain of their soul, to be replaced with more realistic collectivist assumptions. (p. 82)

Here the fact of intersubjectivity becomes an ethical prescription. That we lead storied lives becomes the basis for an argument about our obligation to continue co-authoring the life narratives of those no longer able to do so themselves. It is an injunction that makes of us both expert readers and narrators, calling upon care-givers to make sense of fragments of speech, gesture, and behaviour in the context of what is known of that person's dispositions and "characterisation identity," which Schechtman (1996) defines as "the set of characteristics each person has that make her the person she is" (p. 74). I will return to this notion momentarily.

Second, the erosion of the boundary between inner and outer that is enabled by a model of narrative identity is taken up by Carmelo Aquilina and Julian Hughes (2006) as the basis for an argument about embodiment that relocates selfhood from the interiority of mental space to the shared social milieu of bodily display. Here, they draw upon Ludwig Wittgenstein's (1953) deconstruction of the distinction between inner and outer and, specifically, his claim that "The human body is the best picture of the human soul" (p. 178). Their argument is that the continuation of outward behaviours—of gestures, facial expressions, and so on—presupposes the continuation of an inner reality:

If we think of someone with dementia we may wish to focus on the inner and conclude that it is missing: the inner self is dead. Or we may conclude that the inner self is trapped in the outer shell: the defective body or dysfunctional brain. ... However, both conclusions are fatuous. In one sense, either conclusion might be true: we know what they are both getting at. But in a more important sense ... a human being with dementia is first and foremost a human being and, as such, is capable of characterisation in terms of both inner and outer. They will still have gestures and behaviours, to which we should continue to react in a human way. It will then be perfectly natural to think of the human being as having some sort of subjectivity, but that is because they act in ways that fit with our shareable practices. (pp. 153-154)

Subjectivity, this passage suggests, is expressed through outer gestures and behaviours which are rendered meaningful in a shared social milieu. These bodily expressions speak of intentions and agency that point to an "inner reality": "Our inner states are manifest by outer behaviour. Our shared understanding of outer characteristics is a prerequisite of

meaningful language. Outer behaviour, that is, requires shared (inner) understanding” (p. 154).

Aquilina and Hughes (2006) and Radden and Fordyce (2006) decentre the self in order to argue for its preservation. By arguing that the locus of subjectivity is not simply inner mental space, but the shared, intersubjective realm of social space and narrativity, they are able to argue for the extension of personhood to those with dementia on the grounds of the centrality of the role of others, and of relationships, to the formation of subjectivity *per se*. Dementia is simply that which demands our recognition of this fact to the degree that the role of others in the sustenance of the self becomes more pronounced. As Tom Kitwood (1997) puts it:

In dementia many aspects of the psyche that had, for a long time, been individual and “internal”, are again made over to the interpersonal milieu. Memory may have faded, but something of the past is known; identity remains intact, because others hold it in place; thoughts may have disappeared, but there are still interpersonal processes. (p. 69)

Whose Narrative Is It, Anyway?

These arguments foreground the development of subjectivity in an interpersonal milieu in which others are called upon to act as co-authors or co-constructors of the identity of the person with dementia. We can see here the affinity between this narrative project and that of the dominant mode of Alzheimer’s memoir in which children take on precisely this kind of role as narrators of their parent’s illness experience. What characterises this body of writing, however, is a sense of the profound difficulties that attend such a calling. These difficulties are inextricably tied to the epistemological ruptures of dementia—the disturbances of memory and of identity that define the condition. Here, intersubjectivity as the concept that potentially salvages and preserves the identity of the person with dementia is also that which also stands in its way. I refer here specifically to the issue of recognition and to the notion of intersubjectivity as a “subject meeting another subject” (Benjamin, 1988). Largely unarticulated in the discourses of the personhood movement to which I’ve referred, one of the difficulties that resonates through Alzheimer’s life writing is the collapse of mutual recognition wherein the identities of both parties are thrown into crisis by the failure of one to

recognise the other. When Linda Grant (1998) asks in the title of her book about her mother's dementia, *Remind Me Who I am, Again?*, it is precisely the capacity of Alzheimer's to unsettle the identities of both persons with dementia and those around them of which she speaks. If we are to understand intersubjectivity as a concept that speaks to a reciprocal need for recognition on the part of parent and child, then it is precisely the impossibility of reciprocal identification that haunts these texts as a crisis of identity for both parties. This is something I will trace through a close analysis of Michael Ignatieff's (1993) *Scar Tissue*, a text that offers one of the most sustained and complex reflections upon dementia and intersubjective recognition.

Oneself as Another II

Although it is presented as a novel, *Scar Tissue* draws heavily upon Ignatieff's own experience of losing his mother to Alzheimer's and offers an uncompromising, if not pathological, perspective upon the impact of the disease upon the identities of both the person with dementia and those around her.⁴ Indeed, I've chosen to focus on this text not because it is straightforwardly representative of Alzheimer's lifewriting by children of parents with dementia, but because it offers an extreme version of the form of emotional violence to self and other that I identified at the beginning of this essay in Annie Ernaux's account of her mother's hospitalisation. It therefore encapsulates something I would argue we encounter in more latent or displaced forms in a range of less obviously distraught narrative accounts of parental loss. The novel traces the effects of Alzheimer's disease upon a family. The mother, displaying the signs of early memory loss, becomes dependent upon her husband, who then collapses and dies from a heart attack. Her care falls into the hands of her sons—one a philosopher, the other a neuroscientist—who make the decision to sell up the family home and place her in an institution. Written in the first person from the perspective of the unnamed philosopher son, the narrative is prompted by his desire to "redeem" this experience and to reconnect with a sense of his mother prior to her illness:

There must be some way back to unscarred beginnings, when she was in her painting clothes barefoot, sipping a beer, humming to

⁴For an account of the autobiographical content of the text and the rifts it caused in Ignatieff's close family, see Lederman (2012).

herself, happy and far away. That is how she should be remembered. That is what I must rescue from her dying, if such a thing can be done. (p. 1)

Despite this statement of reparative intent, the narrative itself traces the dismantling of both his and his mother's lives as a consequence of her disease. Unable to reconcile himself with his mother's cognitive decline, he struggles to find meaning in her every gesture and in the verbal fragments that remain of her speech. Obsessively visiting her in the care home, he becomes consumed by the progress of her disease, eventually at the expense of his own marriage, and then of his job. Teaching a course on "Philosophy and Shakespeare," he finds himself able only to teach *King Lear*, a text that he interprets not simply as a story of dementia but of the steady collapse of mutual recognition:

Look, I would tell my class, the mad king at first does not recognise his daughter, because he does not recognise himself. I never saw a performance of the play which managed to express the relation between losing yourself and losing everyone else. I had to act it out for them myself, in the middle of the class: the way the king pats his own body, running his hand over the hospital garments they have put on him. I would be up there in the middle of a class of undergraduates, patting my old tweed jacket, running my hands across my own arms, and I would see them looking at me, as my children did after the break-up of my marriage, asking themselves: Who is this? Why is he like this? (p. 164)

His performance of *Lear* points to the extent of his own psychological disturbance in the face of his mother's decline. The playing out of the role of the "mad king" suggests his own form of suffering as a kind of phantom dementia. This is borne out in the narrative of his progressive disconnection from the social worlds of his marriage, family, and job, a story that parallels that of the deracinating trajectory of his mother's illness. Like her, he becomes increasingly isolated, lost in the fracturing logic of her cognitive decline. The last sections of the novel, following his mother's death, see him holed up in his flat, spending his days seeking "oblivion" in daytime soaps and ads and his sleepless nights writing a "manic treatise" on selflessness (p. 180). He notes, "I didn't go out, didn't wash, looked at the world through the dusty, then rain-streaked windows

of this apartment, and felt the lunatic awareness and exaltation of the sleep deprived” (p. 179). His attempts to make sense of his mother’s illness manifest a kind of “entrapment,” as John Wiltshire (2000) puts it, in the crisis he seeks to understand (p. 419).

This entrapment moves through various stages in the narrative, reflecting an increasingly pathological blurring of the boundaries between his identity and that of his mother. Early in the text, his sense of the crisis of identity that Alzheimer’s brings begins with a reflection upon the extent to which his mother’s memory acts as a kind of guarantee of his own life narratives:

Sometimes at night, lying by her side, I think about all the memory that must remain inside her, trapped within the circuits, denied speech yet still present in her mind. She is the silent custodian of the shadow zone of my own life. She is the only one who can tell me what I was like before I began to remember, the only one who can decipher those first senseless scenes when memory begins. (p. 50)

Here, the narrator simply acknowledges the intertwining of the story of his life with that of her own. Yet as his mother’s illness progresses, he becomes increasingly fixated on the question of where and whether these memories remain—as if the question of her personhood is inextricably tied to that of his own. This is played out through a range of visual metaphors in which her capacity to “see,” and thus to know him, is gradually diminished and broken up. Early in the text, the narrator tells the story of the time his mother painted a portrait of him as a teenager. He describes the finished painting as both that which enables him to see himself “through her eyes” and that which takes him “about as deep into” himself as he is “ever likely to get” (p. 17). This passage foregrounds the extent to which his sense of self is contingent upon her recognition. I am reminded here of Mikhail Bakhtin’s (1990) description of inter-subjectivity in which selfhood can only be fully realised through the mutual exchange of glances between self and other: “As we gaze at each other, two different worlds are reflected in the pupils of our eyes” (p. xxii). Ignatieff’s narrator requires his mother to “see” him in order fully to see himself. As her dementia progresses, he describes her failing cognitive powers and withdrawal from him in explicitly visual terms as the breaking up of his own reflection in her mind. In turn, her inability to

recall the whole of his image is experienced as the fracturing of his own identity and personal breakdown:

By this stage, I was all in pieces inside her; name, face, texture of skin, shape of my eyes, all tumbling over and over in the darkness of her mind. Upon occasion, she could catch a piece of the broken mirror and hold it up long enough to know who I was. Then that shard would slip loose and sink back into shadows and she wouldn't give a flicker of recognition ... if she failed to recognise you, you ceased to exist. No longer her son, no longer anyone. Acknowledge that I exist. Acknowledge your son. (pp. 163-64)

This sense of being broken up is replicated at the level of the narrative itself, in which the story is interrupted by various narrative fragments. These include his reading of *King Lear*, an analysis of Willem de Kooning, his own philosophical reflections upon selfhood contained in his "manic treatise," a brief paragraph on Melanie Klein, a discussion of the case of Janet Adkins, and finally, a reflection upon the logic of neuroscientific models of subjectivity. In this manner, the psychological problems he experiences around his mother's failure fully to recognise him are linked to an epistemological crisis around how we should "see" dementia. Through the text, the narrator's philosophical disposition is contrasted with what his father describes as his brother's "propositional" scientific intelligence. Whereas neuroscience provides his brother with a meaningful epistemological frame through which to make sense of her illness, the narrator struggles with the implications of his sense of Alzheimer's as an "illness of selfhood." This is rather ponderously explored in a range of fraught conversations between the two brothers and in a meeting with a neurologist in which each attempt the narrator makes to assert his mother's personhood is rebutted with a clinical description:

"Take the business about her language," I say. "She can't maintain a conversation, but the way she listens, and laughs when you say something that amuses her, nods to let you know she's following what you say."

The doctor seems interested. "Her semantic and syntactic memory functions have collapsed, but prosodic variation is still intact." (pp. 57-58)

To the extent that this exchange presents the doctor, and by implication medical discourse, as displaying what Tom Kitwood (1997) might describe as a “malignant” disregard of the person, the novel itself presents the narrator’s desire to preserve his mother’s personhood as a difficult and damaging choice, at least so far as his own sense of identity is concerned. His desire to understand her dementia and the crisis it precipitates is explicitly contrasted with the contained response of his brother:

My brother isn’t bothered by what he doesn’t know. The answers will surrender themselves eventually. There is a serenity in his science which makes me envious and unhappy. “I wish I knew how to change my life,” I say.

He acts as if he hasn’t heard and counts off on his fingers the things science will be able to do for this kind of patient one day: implantation of DNA to correct the genetic defect; chemicals to retard the production of protein; or chemicals to help the enzymes to break down and remove the protein; other chemicals to improve neurotransmitter function. Tragedy is thus transformed into a manageable condition. (p. 132)

“Does understanding *anything*,” he eventually asks, “make a difference, if there is nothing you can do to stop it happening?” (p. 197).

The twin crises of recognition and of knowledge, of ways of seeing dementia and of failures to see, come together at the end of the text in an Oedipal moment of violent self-revelation. The narrator relates an anecdote about his attempt to pin a photograph of himself as a child on the notice board in his mother’s room:

I wanted to pin this picture up on the bulletin board beside my mother’s bed. I had already laid the pin in the centre of the top margin of the picture when I placed the photo in her hand. She held it there for a second and stared carefully at this image of a child who was once her son. Then with sudden, savage deliberation, she removed the pin and jabbed at the picture, puncturing both of my eyes.

There was not a shadow of doubt as to what she intended. It had been a blinding. Now, of course, I understood. If you hold the picture up to the light, radiant illumination streams through the

eyes. It is the light streaming from the terrain beyond the gates of truth. (p. 198)

This moment of understanding is one that speaks to the sublime and terrible impossibility of understanding, of what he describes as an encounter with “a pure and heartless reality beyond anything a living soul can possibly imagine” (p. 199). This is a reality that is literally unthinkable, a violent evacuation of meaning. At this point, his earlier recognition of his intersubjective bond with his mother, and of the intertwining of their stories and memories, collapses into a loss of all boundaries. By the end of the text, he not only identifies with, but seeks to devolve himself into his mother. Convinced he is in the early stages of dementia, he visits an old friend, Dr. L, for neurological tests: “I asked him to read the report and not spare me the details. When he finished, I said, ‘So it’s too early to tell.’ And he nodded and then he said, ‘You almost look disappointed’” (p. 192).

Unable to find a way of living with the reality of his mother’s dementia, he ultimately seeks it out as a way of dying, and as an integral constituent of his identity. The text concludes with his walking out, bare footed, into the night:

I will walk out to end of the railway line. I will listen to the Chatham freights. I will feel the night breeze on my face. I will hear the road just beyond the orchard. I will see the lights of Alton and hear voices beckon. I will see the car lights, streaming through the night. No one will stop me now. The good Dr. L. is mistaken. The scans are mistaken. The cells are too small to see. But I know, I feel them inside me. My fate has come to meet me. My voyage has begun. (p. 199)

There are various ways in which this denouement can be read. There is something of Lear here in the barefooted journey into the night, and something, too, of the night wanderer, one of Alzheimer’s stock characters. Yet it also references the familiar conclusion of the male *Bildungsroman*, in which the hero flees the nets of social obligation, separating himself from the world of home and family that stand in the way of true self-realisation (always outside the bounds of the text, always outside the bonds of the family). Here, though, the narrator’s journey out of the city and away from the apartment that overlooks his mother’s care home is marked by the embracing of a way of death, a journey into the

heart of dementia. Self-realisation then comes with the recognition of the collapsing of his own story into that of his mother, a story of the inescapable and shared fate of the family disease.

Conclusion

Scar Tissue is, in many respects, a deeply self-indulgent text in its obsessive and prolonged exploration of the narrator's *cri de coeur* in the face of his mother's dementia. It is striking that his mother's personhood is persistently effaced by the narrator's focus upon his own crisis of identity; she effectively functions as a cipher or screen upon which he projects his own existential crisis. There are moments in the narrative that gesture towards other modes of response that fall between his brother's Platonic rationality and his own psychological collapse: his wife encourages him "just to live," and his mother's nurse (with whom he has an affair) simply gets on with the job of caring for his mother's practical and emotional needs. However, what the narrative brilliantly exposes is the way in which the narrator's desire to sustain his mother's identity is disturbed by her inability to recognise and thus to affirm his own sense of self. In this text, the consequences of the erosion of reciprocal or mutual recognition upon which the concept of intersubjectivity is founded is played out both masochistically and narcissistically; the narrator engages in increasingly self-destructive behaviours, culminating in the enactment of his own social death and isolation from friends and family.

In works such as Annie Ernaux's *I Remain in Darkness*, there is an explicit violence in the descriptive language she uses to convey her mother's cognitive losses and decline. It is hard not to read this as an act of violence towards her mother for no longer being the mother she once was, but equally hard not to read it as a form of violence towards the self. This is evident in the passage with which I began, in which Ernaux compares her mother's treatment in hospital to her own experience of abortion. In the context of the significance accorded to the concept of intersubjectivity within the personhood movement, what an engagement with these narratives indicates is the degree to which the task of sustaining another's identity is problematized by the rupturing of mutual recognition as that which constitutes and supports narrative identity. The fact of intersubjectivity may be that which enables us to sustain personhood in dementia but it is also at the centre of the identity crises explored in many of these narratives. To acknowledge this is not to turn away from the task of telling another's story, but it is to recognise that

such a task is more complex and potentially more difficult than a simple evocation of intersubjectivity implies.

References

- Aquilina, C., & Hughes, J.C. (2006). The return of the living dead: Agency lost and found? In J. C. Hughes, S. J. Louw and S. R. Sabat (Eds.), *Dementia: Mind, meaning, and the person* (pp. 143-162). Oxford, England: Oxford University Press.
- Bakhtin, M. (1990). *Art and answerability: Early philosophical essays*. (V. Liapunov, Trans.), M. Holquist & V. Liapunov, Eds. Austin, TX: University of Texas Press.
- Benjamin, J. (1988). *The bonds of love: Feminism and the problem of domination*. London, England: Virago.
- Bruner, J. (1991). The narrative construction of reality. *Critical Enquiry*, 18(1), 1–22.
- Buber, M. (1937/2004). *I and thou*. (R. G. Smith, Trans.). London, England: Continuum. (Original work published 1937)
- Burke, L. (2008). “The country of my disease”: Genes and genealogy in Alzheimer’s life-writing. *The Journal of Literary Disability Studies*, 2(1), 63-74.
- Couser, T. (2009). Memoir and (lack of) memory: Filial narratives of paternal dementia. In C. S. Todd, *New essays on life writing and the body* (pp. 223-240). Newcastle upon Tyne, England: Cambridge Scholars Publishing.
- Couser, T. (2012). *Memoir: An introduction*. Oxford, England: Oxford University Press.
- Ernaux, A. (2000). *I remain in darkness*. New York, NY: Seven Stories Press.
- Fleischer, T. (1999). The personhood wars. *Theoretical Medicine and Bioethics*, 30(3), 309-318.
- Foucault, M. (2003). *The birth of the clinic*. London, England: Routledge.
- Frank, A. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago, IL: University of Chicago Press.
- Gillett, G. (2004). Cognition, brain pain, psychotic cognition, hallucinations and delusions. In J. Radden (Ed.), *The philosophy of psychiatry: A companion*. Oxford, England: Oxford University Press.
- Grant, L. (1998). *Remind me who I am, again*. London, England: Granta.
- Habermas, J. (1987). *The theory of communicative action: Vol. 2. Lifeworld and system: A critique of functionalist reason* (T. McCarthy, Trans.). Oxford, England: Polity Press.
- Ignatieff, M. (1994). *Scar tissue*. London, England: Vintage.
- Hughes, J. C. (2006). The return of the living dead: Agency lost and found? In J. C. Hughes, S. J. Louw, & S. R. Sabat (Eds.), *Dementia: Mind, meaning, and the person* (pp. 143-161). Oxford: Oxford University Press.
- Hughes, J. C., Louw, S. J., & Sabat, S. R. (Eds.). (2006). *Dementia: Mind, meaning and the person*. Oxford, England: Oxford University Press.
- Kaufman, S. (2006). Dementia-near-death and “life itself.” In A. L. Cohen, *Thinking about dementia: Culture, loss and the anthropology of senility* (pp. 23-42). New Brunswick, NJ: Rutgers University Press.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Milton Keynes, England: Open University Press.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition*. New York, NY: Basic Books.

- Leibing, A. (2006). Divided gazes: Alzheimer's disease, the person within and death in life. In A. L. Cohen (Ed.), *Thinking about dementia: Culture, loss and the anthropology of senility* (pp. 240-28). New Brunswick, NJ: Rutgers University Press.
- Lederman, Marsha. (2012, April 10). A new life for Ignatieff's powerful Alzheimer's novel. *The Globe and Mail*. Retrieved from <http://www.theglobeandmail.com/arts/theatre-and-performance/a-new-life-for-ignatieffs-powerful-alzheimers-novel/article4099682/>
- Miller, S. (2004). *The story of my father: A memoir*. New York, NY: Random House.
- Radden, J. & Fordyce, J. R. (2006). Into the darkness: Losing identity with dementia. In J. C. Hughes, S. J. Louw, & S. R. Sabat (Eds.), *Dementia: Mind, meaning, and the person* (pp. 71-88). Oxford, England: Oxford University Press.
- Reiman, J. (1976). Privacy, intimacy, and personhood. *Philosophy and Public Affairs*, 6(1), 26-44.
- Ricoeur, P. (1992). *Oneself as another*. (K. Blamey, Trans.) Chicago, IL: Chicago University Press.
- Sabat, S. (2001). *The experience of Alzheimer's disease: Life through a tangled veil*. Oxford, England: Blackwell.
- Schechtman, M. (1996). *The constitution of selves*. Ithaca, NY: Cornell University Press.
- Singer, P. (1995). *Rethinking life & death: The collapse of our traditional ethics*. Oxford, England: Oxford University Press.
- Wiltshire, J. (1998). The patient writes back: Bioethics and the pathography. In J. Adamson, R. Freadman, & D. Parker (Eds.), *Renegotiating ethics in literature, philosophy and theory* (pp. 181-198). Cambridge, England: Cambridge University Press.
- Wiltshire, J. (2000). Biography, pathography and the recovery of meaning. *Cambridge Quarterly*, 24(4), 409-422.
- Wittgenstein, L. (1953). *Philosophical investigations*. (G. Anscombe, Ed. & Trans.) Oxford, England: Blackwell.

Lucy Burke, PhD, is Professor of English at Manchester Metropolitan University. Prof. Burke's research primarily focuses on cultural representations of cognitive disability and the ethical significance of literary discourse in this context. She is also interested in the ways in which contemporary literary and cinematic texts explore bioethical problems, from organ transplants to the termination of life support. As such, her research encompasses two inter-related fields: Literary and Cultural Disability Studies and the Medical Humanities. Burke has been at the forefront of the development of the former area in the United Kingdom through her involvement in the editorial board of the *Journal of Literary and Cultural Disability Studies*. She also has two monographs on the subject: *Representing Alzheimer's* (Liverpool University Press, 2009) and *The Idiots* (Palgrave).