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STILL GLORIA: PERSONAL IDENTITY AND DEMENTIA

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1. Introduction

Beverly Beckham (2008) writes in the *Boston Globe* in praise of Lisa Genova's (2007) *Still Alice*: "You have to get this book.... I couldn't put it down...." After I read *Still Alice*, a book of fiction about an accomplished Harvard professor with early-onset Alzheimer's disease, I too wanted to tell everyone to get this book, but not because "I couldn't put it down." The first time I read it, I put it down several times to cry. It was too painful to read in one stretch. Years back, my mother, Gloria Baylis,[1] had been diagnosed with vascular dementia, and recently there had been findings suggestive of an atypical presentation of Alzheimer's disease. The story of Alice Howland, the Alice of *Still Alice*, was both too familiar (because of what I already knew), and too revealing (because of what I did not yet know).

Beckham refers to Alzheimer's as "the monster breaking down the door" and says "there's no place to run because there is no place to hide." One can try "to tame it and outrun and outwit it.... But the monster at the door does not go away." As these comments illustrate, Alzheimer's is, for many, a special kind of horror story from which there is no escape. Notably, the monster that is Alzheimer's is not only perceived as a threat to the person with the disease and a threat to all those who care about that person, but it is also perceived as

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a threat to all of us who might one day be living with dementia. Indeed, dementia is among the most feared diseases of our time.

The reality and the threat of dementia challenge us all in many ways, both at the level of practice and at the level of theory. In the latter case, dementia challenges our understandings of relational autonomy and relational identity. It requires us to evaluate carefully what it means to affirm that self-determination is inherently social, as is personal identity.

In this essay, I use my lived experience as the daughter of a woman with dementia to begin to think about how relational theory needs to work harder in considering what it means to be in relation with someone who is losing her mind and thereby losing some of the key capacities on which relationships are formed and upon which they rely.[2] In what follows, I suggest that persons with dementia are persons who need relational support to be seen as persons, and perhaps even to experience themselves as persons.

As persons with dementia change, so too do their relationships. Whether these relationships rupture, dissolve, or evolve depends on whether (and how) these relationships are valued by persons without dementia as they come to understand the ways in which the disease will change both them and their relationships. In my limited experience, many (if not most) friendships and some family relations will not withstand the crashing tides of dementia. As medical anthropologist Janelle Taylor (2008) writes of friendships in her work on recognition and dementia: "More like pleasure crafts than life rafts, they [friendships] are not built to brave the really rough waters—and these are rough, corrosive, bitter waters indeed" (319). As social and personal ties rupture, dissolve, or evolve, one's relational autonomy and relational identity shifts.

2. Reading *Still Alice*

I first read *Still Alice* in 2011 while living in New Zealand. Before I left my home in Halifax for Dunedin, I flew to Montreal to say goodbye to my mother, who was by then a resident of a nursing home with a special program for persons with Alzheimer's and memory difficulties. I took a taxi from the airport directly to the nursing home. I found my mother wandering the hall, a common behavior among persons with dementia. She looked somewhat confused when she saw me, and stared at my travel suitcase. She asked me if I was leaving. I told her I was leaving on a long trip, but not that day. That

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day, I had come for a quick visit with her. I reminded her that I was going to New Zealand for a year. I had explained this to her about two weeks previously in a face-to-face conversation during the Christmas holidays. She turned to me and said, "I don't know what you just told me, but all of a sudden I don't feel well." When it came time for me to leave later that evening, my mother asked me to spend the night with her. When I left the next day, I didn't know if I would see her again. As it happens, there were no dramatic events that year, and my mother is still alive today—more than five years after that goodbye, more than thirteen years after an initial clinical impression of "mild cognitive impairment of a vascular type," and more than sixteen years after an "MRI of the brain showing chronic ischemic changes of the white matter and discrete lesions in the frontal white matter."

Still Alice poignantly recounts the slow progression of debilitating symptoms characteristic of Alzheimer's disease punctuated, as they are, by staggering, life changing losses. This includes "memory loss that disrupts daily life; challenges in planning or solving problems; difficulty completing familiar tasks at home, at work or at leisure; confusion with time or place … new problems with words in speaking or writing; misplacing things and losing the ability to retrace steps …" (Alzheimer's Association 2015, 8). Persons with Alzheimer's "get lost in familiar places, fly into inexorable rages" (O'Brien 2015). They put things where they don't belong, and then can't find them because their short-term memory is gone. As their minds become increasingly unresponsive and disobedient (Genova 2007, 166), and their efforts at faking it begin to fail, others will see that they can't work, they can't read, they can't tell time, they can't dress themselves, they can't feed themselves, they can't walk, and eventually they can't talk.

With Alzheimer's, there are a few drugs that may slow the rate of cognitive decline, but there is no magic (cure) to stop it or reverse it. Current estimates on the prevalence of Alzheimer's, as reported by the United States Alzheimer's Association, suggest that, in 2015, there may have been as many as 5.3 million Americans living with the disease (16). In Canada, the most recent statistics, as published by the Alzheimer Society of Canada (2015), confirm that there were 747,000 Canadians living with Alzheimer's in 2011.

I don't remember who told me to read *Still Alice*, but I do remember that I wished I had read it much earlier. It helped me to understand better the fear and isolation experienced by persons with Alzheimer's as they slowly lose their minds because it is written from the perspective of the afflicted

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person, whereas so many other books are written from the perspectives of friends, family members, caregivers, or others.

I would like to believe that, with a better understanding of the disease, I might have had kinder, gentler interactions with my mother while she was in the early stages of dementia and merely suffering from "disorientation, mental confusion and memory lapses" (Genova 2007, 25). I might have had one or two fewer arguments with her about "facts." I remember one argument, in particular, when my mother and father were in Barbados and wanted to change the date of their return to Canada. The earliest flight on which I could book seats was a few days away. That wasn't good enough for my mother, who told me I was incompetent. She then told me to spend whatever was needed to get her home sooner. I explained that the issue was not the cost of the airline ticket but rather availability. As the argument and the tension escalated, she yelled at me, "Then I'll take a taxi." I replied, "You can't do that, Mom." Quick as a whip, she answered, "What, you think I don't have enough money?" "No Mom," I said. "I think there is a [expletive] ocean between Barbados and here."

This was a particularly dramatic exchange that has stayed with me over the years, but there were others. Another exchange, the exact details of which I do not remember now, prompted my mother to look at me, while standing in her bright yellow kitchen, and say in a pained voice, "I'm still a person." I don't know what I said then. I do know what I would say now: quite simply, "I know, Mom. I know."

In reading *Still Alice*, not only did I learn how frightening Alzheimer's is for the person with the disease, I also learned that there is a pattern to this ugly, unkind affliction. For example, early in the book, Alice is out jogging, and, for a terrifying moment, she stands at a familiar intersection, but she doesn't know where to turn to find her way home—a place she has lived for years and years. She experiences a "sea of anxiety swelling furiously inside her" (Genova 2007, 23). She is terrified "at being inexplicably lost" (23). I remember when my mother experienced similar disorientation in getting herself back home—a place she had lived for years and years.

At a later point in the story, Alice experiences frustration at not being able to make the white chocolate bread pudding that she has made "every Christmas Eve since she was a young girl" (65). As she relates, "I didn't make the pudding on Christmas Eve because I couldn't. I couldn't remember a single step of the recipe. It was just gone, and I've made that dessert from

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memory every year since I was a kid" (80). I remember the first Christmas my mother could not accurately remember the ingredients for her traditional Christmas trifle. It was December 2007. In time, she also would not remember how to make her pound cake with raisins, a cake she has made without a recipe for as long as I can remember.

In the throes of the dementia, Alice learns of her sister Anne's death. She asks her daughter Lydia where Anne is, and her daughter responds matter-of-factly, "Mom, Anne's dead. She died in a car accident with your mother" (155). Alice experiences gut-wrenching emotional pain: "Alice stopped breathing, and her heart squeezed like a fist. Her head and fingers went numb, and the world around her became dark and narrow. She took in a huge breath of air. It filled her head and fingers with oxygen, and it filled her pounding heart with rage and grief. She began to shake and cry" (155–56). Though her mother had died a long time ago, Alice did not remember this traumatic event. I remember visiting my mother at the Montreal General Hospital (after she had been removed from her home) and having her tell me that she was going home to her mother. I responded matter-of-factly, "But Mother is dead." My mom told me in no uncertain terms that I was wrong. I knew that I was right and was confused by my mom's adamance.

When Alice was confronted with facts about the death of her loved ones, "she could only hear her own voice in her head screaming for Anne and her mother" (156). My mother, shaking and crying on hearing me speak of her mother's death, screamed, "Don't you think I would know if Mother was dead?" My mother had no recollection of the death that had occurred years and years ago. In the moment, she experienced the pain of tragic loss thinking her mother had just died. To this point in our relationship, I had been convinced that respecting my mother as a person required truthfulness. Thereafter, I came to understand that respecting my mother as a person required kindness above truthfulness.

On my reading, *Still Alice* is a heartrending story about memory, belonging, and recognition. As such, it is also a sobering story about how personal identity and relationships are deeply imbricated. Alzheimer's robs the person of memory. In turn, this threatens belonging and recognition. Whether Alzheimer's also robs the person of belonging and recognition, and thereby of identity, is up to us—all of us.

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3. Identity

Elsewhere, I have outlined and defended a relational narrative account of personal identity that describes the ways in which persons "are constituted in and through their personal relationships and public interactions" (Baylis 2012, 117). This account of personal identity, which is deeply relational and social, recognizes and valorizes personal embodiment, as well as the social, political, and cultural embeddedness and interdependence of persons. It also makes transparent the many ways in which past and present, private and public relationships (clusters of meaning and belonging) shape a person's identity. On this view, personal identity is a dynamic, thoroughly relational narrative construct fashioned in concert with others, in both intimate and public spaces. It is the fruit of a dialectical process that critically depends upon affirmation by others.

Personal identity is different from personality, insofar as it cannot be reduced to inclinations and character traits. Personal identity is the narrative integration of a person's lived experience into a dynamic autobiographical story. So it is that a person creates her identity-constituting narrative over time, in concert with others, "through a series of actions, interactions, reactions, and transactions" (Baylis 2012, 110). The identity-constituting narrative is the one that satisfies the "equilibrium constraint"—a temporary and temporizing balance between self-ascription and ascription by others.

With relational narrative identity, identities are created by relational beings mutually engaged in the never-ending project of constituting themselves in and through personal relationships and public interactions. Through ongoing "(more or less conscious) interpretations of our values, memories, actions, experiences, and so on as well as the (more or less conscious) interpretations of these same characteristics by others" (Baylis 2012, 117), we come to understand who we are, who we want to be, and who we might become. We thereby instantiate our place in the world, as we continually strive for balance (equilibrium) between how we see and understand ourselves (self-ascription) and how others see and understand us (ascription by others). Accordingly, personal traits, significant and trivial memories, as well as lived experiences occupy a more or less prominent place in our identity-constituting narrative, depending upon our perceptions, reflections, and performances, as well as the perceptions, reflections, and performances of others.

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With relational narrative identity, personhood and personal identity rely crucially not only on an individual's inner life, but also on the attitudes of others manifest through instances of belonging and recognition. "Persons are (and can only be) dynamic complex co-creations informed by the perspectives and creative intentions of others" (Baylis 2012, 118). The viewing of personal identity as both relational and narrative is consonant with the belief espoused by moral philosopher Alistair MacIntyre (1984) that "we are never more (and sometimes less) than the co-authors of our own narratives. Only in fantasy do we live what story we please. In life … we are always under certain constraints" (213).

Recently, I had the pleasure of reading Paul Kalanithi's (2016) memoir *When Breath Becomes Air*. Kalanithi wrote this memoir during his final year of training as a neurosurgeon after having received a fatal diagnosis of stage IV lung cancer. In his reflections, he describes the brain as the crucible of identity because it mediates our experience of the world (71). He further acknowledges that our "brains give rise to our ability to form relationships and make life meaningful [but] [s]ometimes, they break" (38). These insights prompt the question: what happens to relationships that make life meaningful when the brain "breaks" as when, for example, memory steadily and inexorably declines to nothingness? As feminist philosopher Sue Campbell (2012) observed in her writings on relational memory, "Sharing memory is such a constant and vital attribute of being in relation to others that … the failure of its possibility … requires our critical scrutiny" (138).

Invariably, dementia results in dramatic changes in cognition, mood, behavior, and memory—changes that may be ameliorated or exacerbated through the use of medications. Not infrequently, these changes have a negative impact on personality. Consider, for example, persons with dementia who become overwhelmingly frustrated, angry, paranoid, fearful, accusatory, and sometimes even verbally or physically abusive. Such changes in personality, whether disease induced, drug induced, or both, can have a dramatic, negative impact on personal relationships of belonging and recognition. Not surprisingly, this can be expected to have lasting, damaging effects on the personal identities of both the persons with dementia and those in their circles of belonging and recognition—family members, friends, neighbors, colleagues, coworkers, members of community or faith groups, and so on. Below, I reflect on the experiences of belonging and recognition that I take to be essential features of relational narrative identity.

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4. Belonging

In very general terms, as persons with dementia manifest negative changes in personality, they are at risk of losing relationships of belonging. Peripheral relationships/connections (e.g., acquaintances), as well as more proximate relationships/connections (e.g., coworkers or neighbors) may slip away as the disease progresses and opportunities for meaningful, rewarding interactions (e.g., two way conversations) lessen. Alternatively, these relationships/connections may become strained and eventually rupture if the interactions become increasingly aggressive or frustrating. Closer relationships (e.g., friends and extended family), and intimate relationships (e.g., spouses, siblings, children, and grandchildren) may suffer one or other of these fates, but these relationships might also move in different directions, sometimes positively. This is to be hoped for, as the person with dementia becomes all the more dependent on others not only for activities of daily living, but also (and perhaps more importantly) for shoring up her identity-constituting traits: the "desires, beliefs, values, emotions, intentions, memories, actions and experiences that make up a person's self-narrative" (Baylis 2013, 517).

For example, my mother's identity as a wife is maintained by regular visits from her husband, weekly excursions to go shopping or to go to church, and nightly prayers. There are birthday cards, anniversary cards, and Valentine's Day cards, many of which are accompanied by flowers. My mother's identity as a mother is sustained by regular visits from her children who live in the same city. Of necessity, my visits are less frequent as my mother and I live in different cities. We "speak" on the phone more or less regularly. In our conversations (in person or on the phone), I have much vested in shoring up her identity as a successful mother, and I work hard to provide her with frequent verbal reminders of successes she has inspired, and not only among her biological children. My mother's identity as a grandmother is supported by visits from her grandchildren and a wall covered in pictures for all to see. Her identity as a family member is reinforced by her inclusion in family holidays and celebrations, despite the many challenges this entails. Beyond this, there are many ways in which her identity as a competent nurse and successful businesswoman are celebrated.

Having and maintaining personal and social relationships is key to belonging, and belonging is key to relational narrative identity. As persons with dementia lose their relational capacity and become less and less able to

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participate meaningfully in maintaining relationships of belonging—relationships that are essential to the activity of coauthoring one's life narrative—what was once a shared authorial responsibility with the protagonist as an author becomes the primary responsibility of others. They can choose to anchor the person in relationships of belonging through relational remembering (Campbell 2012), or they can let her drift away.

5. Recognition

In *The Course of Recognition*, philosopher Paul Ricoeur (2005) reflects on the many usages and meanings of the word "recognition" and draws the reader's attention to "its use in the active voice: to recognize something, objects, persons, oneself, another, one another… [and] in the passive voice: to be recognized, to ask to be recognized" (19). Ricoeur then describes a progression from the active voice ("I recognize") to the passive voice ("I am recognized") with reference to three thematic understandings of recognition. There is recognition as identification/distinction (of something or someone), self-recognition (typically understood in terms of identity and based on procedures of identification), and mutual recognition, which Ricoeur describes as "our most authentic identity, the one that makes us who we are, that demands to be recognized" (21). In this work, Ricoeur not only draws the reader's attention to the ways in which "the self becomes what is at stake in the second and third stages of our progression [i.e., self-recognition and mutual recognition]" (22), he also highlights the ways in which the focus shifts from the cognitive and the intellectual to the ethical and the political. As paraphrased by Janelle Taylor (2008), who drew my attention to this work, "What begins in the sovereign self's active intellectual 'recognition' of external objects ends in the socially and politically embedded subject's passive receipt of 'recognition' granted by others" (314).

The memory difficulties characteristic of Alzheimer's disease undermine recognition, potentially in all three stages of progression. As persons with Alzheimer's lose the ability to recognize things, they lose practical abilities required for daily living, such as the ability to tell time, to cook, to read. Further, as the disease progresses, they may lose the capacity to recognize others and perhaps also the capacity for self-recognition. In turn, mutual recognition may be threatened. As persons with dementia are no longer able

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to recognize others who were once part of their many and varied circles of belonging, these others are apt to insist that likewise they do not recognize the person they once knew (as assuredly the person they knew would have recognized them). "She's gone" and "she's no longer there" are familiar assertions that carry with them a certain ring of inevitability. They do not, however, ring true for me as I embrace a dynamic understanding of the self as a cocreated subject in a complex web of interconnections where beliefs and values change through lived experience involving series of actions, interactions, reactions, and transactions. On this view, persons with ever-diminishing capacities for recognition (of objects and subjects) can still be granted recognition by others even as their actions, interactions, reactions, and transactions become less frequent, less coherent, less directed, and so on. What was once acquired in the realm of mutual recognition need not be lost provided that *others* continue to grant recognition.

A person with dementia may no longer recognize her family members as such, but may yet recognize them as friends, or merely as friendly. As the relational bonds become less clear for the person with dementia, it doesn't follow that these bonds are any less clear (or binding) for those whose memory is intact. Ultimately, the granting of recognition by others is about living in the company of others who both acknowledge and instantiate another's presence. In such circumstances, recognition is more about being remembered and less about remembering. Recognition is more about having connections than it is about making connections.

Whereas persons with dementia eventually will not be able to recognize others, those without dementia can choose otherwise. Specifically, they can choose to recognize the person with dementia as a person, as a family member, as a member of a community, and so on. What matters are the criteria considered essential for granting recognition. The person with the sharp wit, the person with the mind like a steel trap, the master of crossword puzzles or Sudoku, the successful businessperson, and so on may not be recognizable, as typically these identities are grounded in cognitive abilities. However, the wife, the mother, the sister may be recognizable, as these identities are typically grounded in emotive relations and are not equally dependent on the ability to remember objects and subjects. It follows that someone looking for the person with the sharp wit may not be able to find her, whereas someone looking for the social person should have no difficulty in finding her.

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6. Gloria Baylis (née Clarke)

Persons with memory impairment and memory loss are necessarily less and less able to contribute actively to the dynamic coauthoring of their identity-constituting narratives. Over time, they become more and more dependent on their coauthors (persons who share some of their personal and social memories) for belonging and recognition. And, as time passes and some personal relationships rupture or wither, the coauthoring becomes less personal.

My mother began experiencing memory difficulties (eventually attributed to vascular dementia and dementia of the Alzheimer type) in early 2000. Since then, family, friends, coworkers, and others have witnessed a steady, stepwise deterioration in orientation, affect, processing, judgment, and memory. In addition to the losses of emotive and analytical skills, there have been losses of ambulatory and verbal skills. My mother is now confined to a bed and a wheelchair, and transfers between them require several people and the use of a repositioning sling.

More recently, my mother has experienced difficulty swallowing and speaking. Now, she is on pureed foods, and her speech is mostly reduced to mumbles and occasional discrete syllables. As well, there is lots of grinding of teeth. It has been years since my mother has enunciated words and longer still since she has spoken my name. To my mind, the only person she still recognizes is my father, her husband of close to sixty years. Every now and then, however, when she reaches out to touch my face or my hand, I flatter myself with the hope that she may yet still recognize something of me. But, in her mind, I may just be a friend or even just a friendly face, and that is just fine. She is still a person. And, more importantly from my perspective, she is still my mother.

In the earlier stages of deterioration, well-meaning friends and caregivers started to say things to me like “this isn’t your mother [speaking or acting], it’s the disease,” or “she isn’t the same person anymore,” and “you lost your mother some time ago.” These comments were invariably offered when my mother scowled at me, insulted me, threatened me, or hit me. This person, others assured me, was not my mother. After all, my mother was a person who loved me, cared for me, enjoyed my company, and took pride in my accomplishments.

Though well-intentioned, those who sought to comfort me in this way failed to appreciate how their confident assertions robbed my grief of meaning.

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My deep sorrow only made sense because the woman scowling, screaming, insulting, threatening, and lashing out wasn't just some demented woman in a wheelchair or a bed; she was my mother. She was the woman who birthed me, took care of me through infancy and adolescence, read umpteen drafts of my school essays, celebrated every one of my graduations, planned my wedding, came to help when I was birthing my children, and thereafter found myriad ways to support me and nurture her grandchildren.

"Alzheimer's disease is ultimately fatal" (Alzheimer's Association 2015, 5). I know this. I know that my mother is dying. But until she dies, I choose to recognize her as my mother and to cherish our relationship even as it disintegrates. Yes, it is true that my mother's personality has changed dramatically, and her capacities are extremely limited, but I have not "lost my mother." Her life story is not over. In the throes of her illness, my mother has struggled to be my mother, and I choose to honor that. I do so by instantiating her identity—by keeping her in my web of interconnections. My mother is not "gone," she is not "no longer there," and, most importantly, she is not "no longer a person."

One day in 2010, well into the illness but still living at home, my mother learned that I had resigned my position as a member of the Board of Directors of Assisted Human Reproduction Canada (Blackwell 2010). She gleaned this information from a newspaper article at a time when she had considerable difficulty reading. She asked my father to call me as she no longer knew how to use the phone. My father called and handed the phone to my mother. She asked me about my resignation, and I provided a cursory overview of the situation. My mother worried that I was in trouble, and she offered to get me a lawyer. She did not understand the events in play, but she understood that something bad had happened. It was her job as my mother to look after to me, and she was doing this to the best of her ability.

Now, at a time when my mother's abilities are minimal, her mothering is manifest not in her efforts to protect, but in her incidental teaching. As I bear witness to her daily living and her anticipated dying, I confront my own mortality. I revisit existential questions about the meaning of life and death, about my purpose on this earth. For me, it is through relational connections that we can make sense of our world. I am working hard to make sense of the person changing before my eyes and not to dismiss her as someone other than my mother and thereby negate the basis of my relationship with her.

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In my view, to say such things as “this isn’t your mother [speaking or acting], it’s the disease” is to conflate erroneously changes in personality with personal identity. There is no denying the profound personality changes that my mother has experienced, and that others have witnessed. But my mother is still my mother. Her behaviors and her vocalizations may be strange, but she is no stranger to me or to others who remain in her ever-shrinking circle of belonging.

7. Closing remarks

When the protagonist in the life story has dementia, she contributes less and less to the coauthoring of her identity-constituting narrative. That is, she engages less meaningfully (and perhaps eventually not at all) in the cyclical and iterative process of identity formation that typically occurs through a series of actions, interactions, reactions, and transactions. This has happened with my mother, as she has lost the ability to animate personal and social relationships. Her contributions to her life story are minimal, but they are no less important for being less frequent and less coherent. When my mother is not too tired, she is able to establish meaningful eye contact. As well, my mother still takes comfort in touch, and, on occasion, she will purposefully reach out to stroke someone’s hand or face. Sadly, she does appear to have lost the ability to smile. Nonetheless, in the ways she is able, my mother affirms her presence, thereby instantiating her dynamic identity as mother, spouse, and dependent person—once confident and strong willed, now weak and vulnerable. Though my mother’s agency is diminished, and some of her interactions with others are utterly impersonal, her identity is instantiated in webs of interconnections. As she loses her ability to shape her life narrative consciously, others (myself included) do so for her—we animate her life. We hold on to what is deeply personal and do not allow it to slide into the impersonal.

Before my mother lost the ability to speak, she looked me in the eye, and, as the mind was struggling, she said to me aloud, “You belong to me.” She was very right about this. And, just as I belong to her, she belongs to me. What is needed for persons with dementia to retain a meaningful place in the world is that they belong and that they be recognized. As the disease progresses, and the life trajectory is more a matter of circumstance than choice, it is important

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for others to hold on to the person and thereby to instantiate both her personhood and her personal identity.

To echo Beverly Beckham (2008), *Still Alice* "isn't only about dementia. It's about Alice, a woman beloved by her family and respected by her colleagues who, in the end, is still Alice, not just her disease." My mother is still Gloria, not just her disease. Indeed, all persons with dementia are themselves, not just their disease. And, as they lose the ability to hold on to themselves, it is increasingly the responsibility of others to cradle them by actively contributing to their ongoing life narratives as they shift from autobiography to biography.

When I read *Still Alice,* I heard my mother saying to me, "I'm still *Gloria, Gloria in Excelsis Deo."* My mother loved this refrain, and, during the Christmas holidays, she would often introduce herself as "*Gloria, Gloria in Excelsis Deo*."

Addendum

My mother is not capable of giving me permission to share her story. I do so in the firm belief that she would approve. I believe this, in part, because she did read and approve my very first publication on identity, "Black as Me: Narrative Identity" (Baylis 2003), which includes personal anecdotes about her. More generally, my mother was always supportive of my writing. Out of respect for the privacy of my father and my siblings, I have not included their stories even as these stories intertwine with my mother's story (and mine).

Notes

1. My mother, Gloria Baylis, was a strong, independent, accomplished woman. She left Barbados in 1945 at the age of sixteen and trained in England as a nurse. She then emigrated to Canada in 1952. In 1964, she was refused employment because she was a "Negro." She launched a successful lawsuit against the Queen Elizabeth Hotel. In 1983, she founded Baylis Medical Company Inc., and, in 1999, was given the Jackie Robinson Award for the Business Person of the Year by the Montreal Association of Black Business Persons. Her biography was included in the 1st and 2nd editions of *Who's Who in Black Canada* (Williams 2002) and is also available on the Black in Canada website (http://www.blackincanada.com/2010/09/02/gloria-baylis/).

2. I owe this wording to my colleague, feminist philosopher Sue Sherwin.

References

Alzheimer's Association. 2015. "2015 Alzheimer's Disease Facts and Figures." *Alzheimer's & Dementia* 11 (3): 332–84. http://dx.doi.org/10.1016/j.jalz.2015.02.003. Medline:25984581

Alzheimer Society of Canada. 2015. "Dementia Numbers in Canada." http://www.alzheimer.ca/en/About-dementia/What-is-dementia/Dementia-numbers

Baylis, Françoise. 2003. "Black as Me: Narrative Identity." *Developing World Bioethics* 3 (2): 142–50. http://dx.doi.org/10.1046/j.1471-8731.2003.00070.x. Medline:14768646

Baylis, Françoise. 2012. "The Self *In Situ*: A Relational Account of Personal Identity." In *Relational Theory and Health Law and Policy*, ed. Jocelyn Downie and Jennifer Llewellyn, 109–31. Vancouver: University of British Columbia Press.

Baylis, Françoise. 2013. "'I Am Who I Am': On the Perceived Threats to Personal Identity from Deep Brain Stimulation." *Neuroethics* 6 (3): 513–26. http://dx.doi.org/10.1007/s12152-011-9137-1. Medline:24273621

Beckham, Beverly. 2008. "Despite Monster, She Is 'Still Alice.'" *Boston.com*, March 16. http://www.boston.com/news/local/articles/2008/03/16/despite_monster_she_is_still_alice/?page=full.

Blackwell, Tom. 2010. "Third Board Member Quits Fertility Industry Watchdog." *National Post*, May 31. http://www.geneticsandsociety.org/article.php?id=5244

Campbell, Sue. 2012. "Memory, Reparation, and Relation: Starting in the Right Places." In *Relational Theory and Health Law and Policy*, ed. Jocelyn Downie and Jennifer Llewelyn, 132–60. Vancouver: University of British Columbia Press.

Genova, Lisa. 2007. *Still Alice*. New York: Gallery Books.

Kalanithi, Paul. 2016. *When Breath Becomes Air*. New York: Random House.

MacIntyre, Alasdair. 1984. *After Virtue: A Study of Moral Theory*. 2nd ed. Notre Dame, IN: University of Notre Dame Press.

O'Brien, Greg. 2015. "What Alzheimer's Feels Like from the Inside." *Nautilus*, December 10. http://nautil.us/issue/31/stress/what-alzheimers-feels-like-from-the-inside.

Ricoeur, Paul. 2005. *The Course of Recognition*. Trans. David Pellauer. Cambridge, MA: Harvard University Press.

Taylor, Janelle S. 2008. "On Recognition, Caring, and Dementia." *Medical Anthropology Quarterly* 22 (4): 313–35. http://dx.doi.org/10.1111/j.1548-1387.2008.00036.x. Medline:19189720

Williams, Dawn P. 2002. *Who's Who in Black Canada: Black Success and Black Excellence in Canada: A Contemporary Directory*. Toronto, ON: D.P. Williams & Associates.

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