“Everybody Has Different Levels of Why They Are Here”: Deconstructing Domestication in the Nursing Home Setting

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This chapter examines how assumptions about dementia mediate social understandings of the nursing home and organize relations between the people who live in it. It analyzes how dementia is imagined as an opportunity to affirm the legitimacy of social orders that privilege capacity and frame the meaning of personhood from the perspective of the “rational subject.” Although the analysis is guided by psychologist Tom Kitwood’s theory of the person in dementia care, which promotes recognition of individuals with dementia as persons first, it questions how the normative values that shape recognition of personhood “level” the lived experience of dementia. This chapter considers how this leveling is accomplished in at least two ways within the nursing home setting: by a flattening of the multiple and contested meanings and experiences of dementia and by ways of relating to dementia that treat dementia as an occasion for people

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without dementia to reflect on and reaffirm their place within the natural order of personal relations and interpersonal hierarchies. Our analysis uses a disability studies perspective to deconstruct the relationship between personhood and domestication, as this relationship has been made to appear in interviews with nursing home residents.

**Dementia, a Discourse of Vulnerability**

Historically, dementia has been regarded as a social, rather than medical, problem. Psychologists Alexander Kurz and Nicola Lautenschlager assert, “[F]rom the earliest of times dementia has been associated with reduced civic and legal competence on the one hand, but with entitlement to support and protection on the other.” While this may be the case, a public health perspective shapes current entitlements and supports for individuals with dementia diagnoses and their family and friend caregivers. A public health perspective on dementia, as embodied in the 2015 Organization for Economic Co-operation and Development (OECD) report *Addressing Dementia: The OECD Response* and the 2012 World Health Organization (WHO) and Alzheimer’s Disease International report *Dementia: A Public Health Priority*, represents dementia as a global economic and social burden that, as a result of global population aging, can only be expected to get worse. This is illustrated in the opening paragraph of the OECD report, which frames the OECD’s position on dementia as a debilitating condition of dependency and disability, a global cost with a negative value equivalent to the positive value of a prosperous Western country:

Dementia is a debilitating condition for which there is currently no cure. As the condition progresses, those affected can be left dependent on others for support in their daily lives. The human and financial costs of dementia are of a worrying magnitude. Globally, it is the second largest cause of disability among those over the age of 70, with an estimated 44 million people living with dementia worldwide. In terms of financial burden, the global cost of dementia is well over half a trillion US dollars each year—roughly equal to the GDP of Switzerland.

The proposed solution to the social and economic consequences of the projected exponential increase in the prevalence of dementia consists of globally coordinated national dementia strategies. Eight countries currently have strategies for dementia in place: Australia (2005), Denmark (2010), England (2009), France (2008), Norway (2010), Scotland (2010), United States (updated 2014), and Wales (2011).

Within Canada, the focus of this chapter, there is currently no national strategy for dementia and no consensus concerning effective treatment. However, efforts are currently underway in support of the development of a national dementia strategy by the federal government in consultation with the provinces. Strategic policy documents addressing dementia have been released in Alberta (2002 and updated in 2015), British Columbia (2012), Manitoba (2001), Newfoundland and Labrador (2001), Ontario (1999), Quebec (2009), Saskatchewan (2004), and one was recently released in Nova Scotia (2015). Within these strategies, a person-centered approach to dementia care is promoted. Person-centered dementia care is an emerging paradigm widely understood as having great potential to improve the lives of individuals with dementia diagnoses by privileging personhood over the disease process. The expressed aim of person-centered dementia care is to individualize treatment to meet the needs and preferences of the person living with dementia through the use of a biographical approach centered upon the person, rather than the disease. In his influential text *Dementia Reconsidered: The Person Comes First*, Tom Kitwood prioritizes the person via text, capitalizing each letter in the word “PERSON” and creating a visible distance between the “PERSON” and the all lower-case lettered word “dementia” using a dash, “PERSON-with-dementia.” A biographic approach uses the “life stories” of the person with dementia as a basis for care planning and as resources that can be used to encourage healthcare practitioners and residential care staff to perceive individuals living with dementia as people, with experiences, needs, and preferences—as a “self.” While person-centered dementia care is promising in its aims, it has been criticized on the grounds that its underlying concept of personhood has yet to be fully clarified and empirically developed.

Western research communities and news media share daily reminders of the rising global prevalence of Alzheimer’s disease and related dementias, and the projected burden that care for older adults living with dementia places on everyone. For example, some projections suggest that as many as one in 85 people will have Alzheimer’s by the year 2050. On their website, “Dementia Numbers in Canada,” the Alzheimer Society Canada states that “in 2011, 747,000 Canadians were living with Alzheimer’s disease and other dementias—that’s 14.9 per cent of Canadians 65 and older. By 2031, if nothing changes in Canada, this figure will increase to 1.4 million.” Typically, representations of dementia as a “global problem” are...
situated within a discourse of population aging, which depicts old age as a threat to national prosperity, and a danger to the health and well-being of older adults' families and communities. According to Ron Brookmeyer et al., "As a proportion, prevalence does not imply the risk or probability of a person becoming affected by the disease in question. Instead, prevalence portrays the potential burden—for care, services, and other things—that the disease places on the population." As compelling as the projections are, they may reveal as much as, if not more, about contemporary social ideals and political objectives, which view dementia as a social "burden" that can be "overcome" largely through an increasing medicalization of eldercare driven by neoliberal market forces.

Within current political and economic systems, modalities of care, including regimes of self-care, are marketed and purchased. For example, Andrew Lakoff advises that information regarding the increasing prevalence of psychiatric conditions should not be interpreted solely from the perspective of medical science. For Lakoff, "What is being constituted through numbers [of those labeled with psychiatric conditions], in this case, is not a population of living beings with certain biological regularities, but rather a market of consumers characterized by purchasing trends." While information on age- and disease-based projections plays a vital role in health and social services research and policy, it is important to bear in mind that such information is produced and circulated within Western sociopolitical and economic milieus that privilege a market mentality, and that sell this mentality through, among other things, the promotion of an eldercare system capable of supporting and even enhancing the health, well-being, and "quality of life" of individuals, while at the same time maximizing the efficiency of health and social systems, reducing labor costs, and increasing profit margins.

There are many ways of knowing, talking about, and treating dementia. Although commonly thought of as a disease, and routinely confused with Alzheimer's disease, dementia is better understood as a collection of symptoms. This, when considered with the fact that there are at least 45, and some suggest 70, different manifestations or types of dementia, has led many professional educational advocacy groups such as Alzheimer's Disease International to define dementia as an umbrella term. The lived experience of dementia has been compartmentalized and broken up into different stages, or levels, with capacity and competence being perceived as possibly impaired but still preserved in "early-stage" dementia, and less so in moderate or late-stage dementia (terms used to characterize the majority of older adults living with dementia in nursing homes). And yet this staged conceptualization of dementia is itself problematic and does not hold true for all types of dementia or even all individuals identified as living with any one type of dementia. Questions remain concerning the ambiguity and uncertainty with which dementia is diagnosed.

Local, national, and global dementia strategies advocate pre-screening for dementia, with the caveats that there is currently no known cure for dementia, and that a lack of capacity and effective coordination in dementia-specific research, policy, and practice can present barriers to effective care in response to early diagnosis. The increasing emphasis in social and health policy on pre-screening for dementia and cognitive impairment in older adults provides the impression that the diagnosis of dementia and related cognitive impairment is easily done, despite the heterogeneity of dementia. David Le Couteur et al. are suspicious of what they refer to as the "political drive" to initiate pre-screening due to the lack of evidence to support good outcomes. They caution that the expected benefits of a policy focus on dementia that emphasizes services and research, such as an ability to plan for the future and seek early treatment, typically in the form of pharmacological treatments, may not outweigh potential harms, including misdiagnosis/overdiagnosis. The result is a distorted understanding of the actual prevalence of dementia, and unnecessary interventions that may produce adverse side effects and outcomes, and lead to a diversion of resources and support from the people who need it most.

Within Canada, there is increasing recognition of the problematic use of psychopharmaceuticals as "chemical restraints" in nursing home care, and particularly, of antipsychotic medications prescribed despite widespread awareness of "black box" warnings and research that displays evidence of poor outcomes and increased mortality. A provincially commissioned report notes that over a two-month period, over 50 percent of nursing home residents in British Columbia were prescribed antipsychotic medications, many of which were atypical, or second-generation major tranquilizers and neuroleptics, which may not have received regulatory approval for use in older adults with dementia and which are described as more effective in treatment-resistant patients. In 2005, Health Canada reported that when taken by people with dementia, the side effects of drugs such as Risperdal are fatal and include stroke, heart failure/irregular heartbeat, and pneumonia, all of which are conditions that are routinely attributed to an unfortunate consequence of aging for older adults,
particularly those with chronic conditions that may or may not include dementia or other cognitive impairment. Such drugs are routinely prescribed and administered without the full understanding and consent of residents and their families, and while such drugs may be perceived as acceptable for use in “extreme cases” in which a perceived “high level of care” is required, the reality is that the exception is becoming the rule. This practice known as “polypharmacy” involves the use of medications that are not clinically indicated, that are used inappropriately, that lead to adverse reactions, such as death; and that can produce the very symptoms that are used to justify the need for treatment.

Within North American nursing home settings residents with dementia are often positioned in ways that can diminish their authority to refuse medication. This positioning occurs at the symbolic level, by way of infantilizing language that strips the person living with dementia of the insight to exercise control over their own care; as well as materially and physically, insofar as people living with dementia within nursing home settings also live within the present reality or constant threat of physical segregation within dementia care units. Even in the absence of segregated dementia care units, nursing homes are themselves segregated spaces (what Goffman refers to as “total institutions”) that create physical and communicative barriers between the people who live there and those who live in the “outside world.” Considering the fact that up to 80 percent of people living in nursing homes in Canada are viewed as living with some form of dementia, the real and present danger of physical segregation could be interpreted as a mode of regulating and policing resistance to pharmacological treatment regimes within nursing home populations, greatly diminishing the autonomy of aging populations and contributing to the ultimate negation of their personhood.

In many cases, communication plays a fundamental role in the elimination of nursing home residents’ capacity for personhood. Stripped of capacity and competence, the right to informed consent for residents with cognitive impairment is often revoked through a “de-authorization of personhood,” or positioning of the individual outside of knowledge exchange and as an object of care. This rhetorical (and often quite literal) repositioning of nursing home residents is justified on the grounds of perceived or lived impairment. The term perceived impairments refers to processes of pathologization of residents’ refusal or resistance to medication as a sign or symptom of cognitive or behavior disorder. Lived impairment, on the other hand, references a disjuncture in communication between the prescriber and resident, such that the resident is neither fully informed nor consulted regarding the treatment decision due to the expectation that the resident will make a nonautonomous or “an incompetently made choice.” In the first situation, a resident with cognitive impairment (dementia) is socially constructed as lacking the capacity to give voice to experience and speak out or against care. In situations of lived impairment, care is communicated in a way that fails to recognize and engage embodied difference from the perspective of the individual living with cognitive impairment. Perceived and lived impairment overlap. This overlapping, moreover, undergirds discourses of vulnerability that dominate current understandings of informed consent. Without dismissing the lived realities of cognitive decline, or the real and potential vulnerability of this population to exploitation and abuse, it is important to examine how assumptions about choice authorize the privilege and power of normative embodiment.

The remainder of this chapter further develops the meaning of capacity within the context of dementia care in nursing homes by way of an analysis of interviews with residents conducted as part of a Nova Scotia-based provincial research study (ca. 2011–2014) that assessed the impact of models of care on resident quality of life.

**Deconstructing Domesticity in the Nursing Home Setting**

Currently within Canada and across North America and much of the westernized world, “nursing homes,” or long-term residential care facilities, provide the primary domicile for an increasing number of older adults with multiple and complex care needs that cannot be met at home or in other community-based settings, due to lack of adequate and accessible social, interpersonal, and individual supports and services. Older adults make up the majority of nursing home populations; however, young adults whose care needs cannot be met within home- and community-based settings may also be residents. According to a 2010 report by the Canadian Institute for Health Information (CIHI), three in five people aged 65 and older receiving publicly funded residential care had a diagnosis of Alzheimer’s disease and/or other dementias, which as we have shown can often be a vague and capacious but ultimately powerful diagnoses.

For this chapter, we have conducted a secondary data analysis of interviews from the Care and Construction: Assessing Differences in Nursing Home Models of Care on Resident Quality of Life project with the aim of
examining the conceptualization of the person with dementia within current approaches to dementia care in the nursing home environment. A tension between situating dementia as an intersubjective relation, a significant connection experienced by and between people, and as the routinized task of documenting lived and felt experiences, often involving the creation of voluminous written documents—texts—animated the discussions researchers initiated with residents, their family members, and nursing home staff. The tension between dementia as relational and dementia as documentable, embodied, and experiential stemmed from contradictory assumptions about persons living with dementia that treated them as unique individuals with values, preferences, and life stories and as objects of care. The notion of the PERSON-with-dementia as work, as a site of effort and labor performed to fulfill a moral purpose, reconciled this tension. Residents “without” dementia described their co-residence with residents “with” dementia as work, both in the sense of “bed and body work” and “person work.” Where “person work” is intersubjective and prioritizes self-actualization through interrelationships, “bed and body work” describes a task-oriented form of medical custodial care that is informed by the intensification of labor and the assumption that dementia is a debilitating condition that cannot be cured and can only be expected to get worse. Residents shared accounts of the work involved in making others appear within public spaces in the everyday life of the nursing home. Imagining and articulating personhood within the context of dementia as performance made it possible for residents to imagine and articulate themselves as moral actors, and the nursing home as already and potentially more than a place of beds and bodies. But it did so by scripting the resident with dementia as a passive recipient of personhood.

Transcripts were critical in constructing the dementia patient. They, among other things, displayed residents’ negotiations of the meaning and significance of the affective work involved in the routinized performance of domestic life within the nursing home. Some descriptions of work revealed a desire to bear witness to the precarity of life from an “insider’s perspective” in ways that promoted the participation of the most marginalized members of nursing home communities. This was expressed by one nursing home resident study participant in terms that related the experience of co-residence to that of “family”:

Even though it’s a small family now, it’s a very close one and we do relate well in here. Sometimes you have to work at it because everybody has different levels of why they are here—I have to make the best of it, or I am just here sort of thing—and we had this in our own house. And if they don’t feel well or they have something which is not going to get any better or it is going to get worse, you still have to be a bit upbeat with them, otherwise it, they can’t change their own feelings about themselves or anything else and ... some of them won’t get any better, and they will get worse and of course you see them move to other floors and what not, and that’s not something you see when you are outside.

Working at maintaining their “small family” is important to nursing home residents. So much so that they take great care to maintain comforting and supportive relationships with them, noting that they remain “upbeat,” especially for those family members who “won’t get any better,” and “will get worse.”

Data analysis informed by social philosophical understandings of personhood has revealed an interesting contradiction in how preference is understood within nursing home settings: residents cannot fully realize preferences because of feelings of responsibility/accountability to other residents similar to those described above, and in other accounts as well. One resident discusses playing cards even though it is not her preference, on the grounds that she “knows” that if she does not, it will likely negatively impact the quality of life of the other residents with whom she lives. The decision to play cards is framed as more than a question of “saving face” or “impression management.” It rather evidences resident awareness of the need to appear happy and to participate in group activities, considering the reality that within this setting people once shared their life with are going to “other floors” and are not going to get any better. Within this setting, hierarchically divided by levels that materialize in the form of other floors, resident personhood is achieved through actions that recognize and reach out to other residents recognized as on their way up, or down, or out.

Within the interviews, residents identified doing things they did not want to do out of a sense of commitment to a shared community with other people that were not immediate friends or family. Responses revealed a sense of kinship tempered with a trace of remorse. They claimed to know that things were not going to get better, at least not in terms of normative understandings of “progress.” The ways residents reconciled the factual reality of separation and decline displayed recognition of proximity to illness and death (if not in the immediacy of their own lives through their co-residence with other people who do or might or could soon have
that the nursing home is a home, or thinking with Gaston Bachelard, a sense that the nursing home is an object of human dignity and thus holds a legitimate presence in the "human" community. Even if it may not always, nor ever, be experienced as home by one and all, it is a space of creation, a product of socially oriented action, and a site and scene of homemaking.

Not surprisingly, there is a distinctly gendered dimension to homemaking in the nursing home setting. This form of care that reaches out toward the co-resident, the neighbor, the stranger, this transformative process that both extends and encloses, and that does so in response to perceptions of a shared precarity of being, feminizes and infantilizes the people who live in nursing homes. It recalls patriarchal assumptions about a hierarchical "natural order of things" that (de)legitimates authority on the grounds of the demonstrable presence or absence of (white, bourgeois, masculinist) reason. Disability studies scholar, Robert McRuer remarks that "able-bodiedness ... still largely masquerades as a nonidentity, as the natural order of things."33 Displaying one's capacity, by acting and being "reasonable," involves recognizing that natural order and asserting one's place within it.

Nursing homes are situated within, and informed by, broader historical, social, economic, cultural, and political contexts. Life in nursing homes in Canada is shaped by neoliberal governmentalities that prize self-sufficiency and flexibility.34 Under these conditions, appearing happy, healthy, and well and participating in household activities is one way that the capacity to reason is demonstrated, regardless of how one actually feels or whether one experiences the household as a home.35 It operates on the basis of an internal contradiction. This form of care affirms the inevitability of arrivals and departures (entry and exit), simultaneously acknowledging and negating transience, making it a permanent feature of the environment. It does this through the construction of an "us/them dichotomy" within the home, a way of caring that acknowledges and reinforces a common sense that, as one interviewee shared, "some of them won't get any better, and they will get worse."36 But what are the social and material conditions that organize perceptions of "some" residents as a "them" in need of the presence of residents who will journey out toward them, but who cannot change their life (and death) trajectories? Care that is oriented to the preservation of the personhood of lives lived beyond cure establishes a relation between neoliberal governmentalities and the natural order of things in which some of them (unlike us) are positioned as occasions to reaffirm the meaning and significance of co-residence through the performance
life of the nursing home. “Being moved,” or placed, somewhere else is treated as fate (and a fact) for “some of them,” but not those who retain the capacity to reason, as demonstrated through participating in household activities despite a lack of the desire to do so. In this way, the interviewee describing the pressures to play a game of cards also shows her bluff. Her words display consciousness of the nursing home as a divided space: a place of deterioration and death for some, but of life and growth for the rest who are in a position to recognize and respond to the significance of their positions within, and to the nature of the work that ought to be done. While this negotiation of life on the “inside” may prove life sustaining and even enhancing for the interviewee, it also comes at the cost of cementing an understanding of “some of them” living in the nursing home as statues subject to decay and ruin. “Some of them” (the residents) are reduced to objects that can either facilitate or get in the way of the work of making a home for the rest of us (the “people” living in nursing homes). Like furniture, they become fixtures in the environment that can be mitigated or capitalized on to make that environment more or less livable (“homelike”). Those on the inside have experiences that are distinct from the experiences that characterized their lives outside of the nursing home setting. As the interviewee says, “you see them move to other floors and what not, and that’s not something you see when you are outside.” At the same time, resident responses to questions about nursing home life (as well as current treatment regimes) could also be read as affirmations of the persistent force of the social conditions and cultural ideals that structure experience on the outside within nursing home settings.

What roles do images and ideas about dementia play in upholding and/or disrupting firmly entrenched assumptions about who lives in a nursing home and public understandings of the meaning and purpose of a nursing home? How is the “nursing home resident” made visible in public spaces, and how might such visibility shape what participation, and resistance, look like within nursing home settings? Articulations of experience on the “inside” serve as expressions of the public mind. As such, they communicate individuals’ interpretations and negotiations of popular cultural imaginaries about what it is like to live in a nursing home.

Although the aforementioned interviewee’s account makes it possible to imagine a meaningful life within the nursing home, the only perspective present is an ablest perspective. The imagined others that make life both meaningful and challenging (and perhaps even tedious in the sense of eliciting a sense of duty to participate in undesired activities) provide a
means for the resident to experience herself as different from the “some” since she can make the choice to participate where they cannot, to move while they are moved, which provides a means to experience herself as reasonable and purposeful, as a person. Reciprocity is limited to a question of how “they” do or do not make it possible to expand self-awareness. But who are “they?”

Thinking in terms of reasonableness and purposefulness, agency and volition exemplifies what McRuer, drawing from Adrienne Rich, describes as “compulsory able-bodiedness—the experience of the able-bodied need for an agreed-on common ground” in which everyone agrees that “able-bodied perspectives are preferable and what we all, collectively, are aiming for.” According to McRuer, “compulsory able-bodiedness functions by covering over, with the appearance of choice, a system in which there actually is no choice.” It becomes difficult and even dangerous to imagine value in disability perspectives. When disability experiences are present, they are typically framed and mediated by nondisabled cultural ideals of autonomy, and appear primarily in the form of a problem, usually in terms of dysfunction, deficiency, and disorder that must be eradicated or mitigated in some way. Reading the interviews (grouped into cases that include residents, their families, and the staff who worked with them) together, the concept of autonomy commonly appears across all of the cases and could be interpreted as the glue that binds each case together as one coherent story. This is not surprising considering the research objectives that shaped the study design and the nature of the questions participants were asked. However, it does have special relevance once we consider one of the dominant thematic tropes within discourses of dementia—the continuity of the self. And, some might say, what is a self but the story of a person?

In the primary analysis of the interview transcripts, the original research team observed that autonomy appeared in the form of a question of the extent and quality of continued participation in activities, where activities included the activities of daily life related to primary health needs such as being in a position to self-administer medications, but also managing finances, and hobbies such as knitting. For the purposes of this chapter, we are most concerned with the team’s finding that advocacy on behalf of oneself and/or others appeared as an activity that made autonomy visible in the lives of nursing home residents.

Cultural conceptions of autonomy privilege noncognitive impairment. Returning to Kitwood’s conception of “PERSON-with-dementia,” where the person is capitalized and abstracted from dementia, one can observe how the concept or construct “autonomy” foregrounds the person without dementia, with the effect of reinforcing taken for granted assumptions that whatever personhood means it involves being able to make decisions for self and on behalf, or in the best interests, of others. Formal and informal knowledge of dementia that treats dementia as a “problem that can only be expected to get worse” constructs the “PERSON-with-dementia” as a site for the production of autonomy as a concrete thing that is separate from (and that can be separated from) lived experience. Lived experience becomes a property of the self (private). Autonomy becomes sayable as a measure of an individual’s relation to, and control over, lived experience (private property). This way of thinking about autonomy is very much in line with cultural notions of the “rational subject,” which have been strategically deployed throughout history to marginalize, exploit, and disenfranchise groups—women, people of color, and disabled persons.

What are the practices that organize the appearance of dementia? The production of knowledge about people who live with dementia can be examined from the perspective of social relations to time as made to appear in histories of difference (marked by race, class, gender, and sex). Rather than simply another other, or additional exemplar of difference, dementia makes a distinct difference in terms of how lives and worlds are experienced and understood. The difference that dementia makes will now be discussed, in relation to paper and paperwork.

**Dementia and the Evidence of Experience**

An exclusive focus on personhood, at the expense of a more multidimensional understanding of the social, political, and economic changes that have occurred throughout history, and the power structures through which knowledge of dementia is established and institutionalized, shifts attention away from how dementia is what it is, and away from an examination of the methods through which people with dementia are produced and the role that texts play in what Clive Baldwin refers to as the narrative dispossession of people living with dementia.

The discourse of experience communicates the hegemony of the visible. Joan Scott’s critical interrogation of the “evidence of experience” can offer insights about the significance of social constructions of dementia in the reproduction of knowledge about what constitutes the validity of a distinctly human life. For Scott, “Experience is, in this approach, not
the origin of our explanation, but that which we want to explain. Scott contextualizes the evidence of experience within the history of difference. She states,

> When the evidence offered is the evidence of “experience,” the claim for referentiality is further buttressed—what could be truer, after all, than a subject’s own account of what he or she has lived through? It is precisely this appeal to experience as uncontestable evidence and as an originary point of explanation—that weakens the critical thrust of histories of difference.

Drawing from a study which made use of Max van Manen’s phenomenological method of researching lived experience and “understanding the ‘particular’ in light of the ‘universal,’” Alison Phinney casts a critical gaze on studies that question the awareness of people with dementia over their own lives, and specifically, over symptoms. In contrast to such studies, Phinney frames participants’ expressions of forgetfulness, loss, fear, and confusion as demonstrations of an enhanced reflectiveness, a reflectiveness that resists being reduced to the product of lessons learned over time. This reflectiveness, an inability to take things for granted, is steeped in corporeality and displays the limits of mind and being minded. Since stepping out of the routine or the usual can produce symptoms that lead to frustration, participants are more attentive to their environments, acting in intensely strategic and self-aware ways.

Phinney notes that people with dementia operationalized loss in terms of challenges to being in the world in an unreflective way. She says, “Feeling lost was experienced by many as a sense of being in unfamiliar terrain, feeling that the world around them did not make any sense.” Rather than reduce the meaning of the experiences of people living with dementia to evidence or originary points of explanation, Phinney treats articulations of dementia-specific experiences as occasions to dwell with how people reconcile questions about what needs to be done when they find themselves in “unfamiliar terrain.” Phinney makes it possible to imagine that dementia is not merely written but is also a way of writing and of making a home, and negotiating one’s way home.

Describing an interview with Jacques Derrida published under the title of “Le paper ou moi, vous savez… (nouvelles spéculations sur un luxe des pauvres),” Kevin McLaughlin considers what Derrida means by his reference to ours as “an epoch in the history of technics and in the history of humanity” delimited by the ‘hegemony’ of paper. McLaughlin assures his reader that he does not mean to mistake paper for a metaphor, and that in fact, paper appears as an unobserved subject rather than a sign of the time. For McLaughlin, paper comes to appear as something missed (whose recollection allows for the mourning of the subject). Like paper, dementia appears in the form as an unobserved subject in ways of talking and writing that treat dementia as a sign of the times (a “now” distinguished by an aging population), and as a symptom or metaphor of modernity (where modernity is understood as a break from tradition that can be accompanied by disorientation, nostalgia, and anomie). But, what kind of subject is dementia? In considering this, one could return to the material and symbolic significance of paperwork. Like the resident who plays cards even though she would prefer not to, people invest time and energies in paperwork because of the influence it is assumed to have over people’s capacity to be recognized as belonging to the group of “those” who are flexible and can adapt to “unfamiliar terrains,” “those” who are perceived as capable of reaching out toward the others with whom they live, and in so doing avoid or delay being “moved to other floors.” Paper provides the material for an archive of experience, and as such, represents a condition of possibility for modern understandings of memory.

Paperwork is central to the social accomplishment of personhood in a nursing home setting. Policy documents and reports coordinate relations to dementia and those perceived to be it or have it, making it possible to recognize and respond “appropriately” often through the administration of psychotropic drugs, but also through “person-centered” approaches. Despite this, the social significance of paperwork within such settings is routinely reduced to a task that duplicates efforts and produces redundancies, and as a surplus of modern bureaucratic organization and practice.

Harrigan and Gillett assert that “each of us is constantly a being-in-the-process-of-becoming who has to adapt to the world in new ways, and one is not along in this task but is held in personhood by relationships which support us and enhance our abilities.” As McLaughlin notes, a simple question about paper turns Derrida to trace the specter of the subject of his life’s works—of who he is and who he understands his self to be. Discourses of person-centered dementia care rarely occasion such a turning. Dementia tends, rather, to materialize as an apparition of the subject that both manifests as and gives rise to an uncanny sense of “ambiguous loss.” Who, or rather what this subject is, is the PERSON-WITHOUT-DEMENTIA. Like paper, and dementia, PERSON is not a metaphor. It does not stand for a historical period, despite Western associations
between the ascendency of the person, the self-actualized individual of fully realized potential, with moments in enlightened thinking, science, progress, colonialism, and global imperialism.  

Despite dominant institutional discourses on personhood in residential dementia care, families, residents, and staff seem to share the impression that being in places and situations that one does not want to be in can cause mental, emotional, and physical discomfort or distress. Yet those situations and those places can be bearable, as long as one is given the impression that despite one’s “level of being there,” one’s personhood, is acknowledged. There is a will to recover and recapture the present that accompanies a longing for impression. This will to the present, to be present, is made legible in constructions of the present as a potential past or future. Like paper, personhood is operationalized in ways that represent it as the mind or subject. And like paper, it can be very difficult to question the actual meaning and significance of personhood because we become accustomed to thinking about personhood as a condition of human action, some “thing,” and a tool that can be used to make visible the work that needs to be done.

CONCLUSIONS

In interviews with older adults living in a nursing home, dementia appeared in at least three ways: as a means of making sense of vulnerability, as a question of capacity and competence; as a mode of performing capacity and competence by participating in domestic activities; and as affirmation of presence and being with others. Assumptions about dementia shaped how residents understood what it means to be a person, why being a person is important (what being a person does), and what is at stake when personhood becomes questionable (e.g., the imposition of uninformed or unwanted interventions). Interestingly, interview participants’ expressed relations to dementia paralleled the assumptions of global policy and institutional practice texts. In such texts, dementia is imagined as a global problem. Conceived as a global problem, dementia represents an occasion to reflect on national and international vulnerability, what domestic policy means within an increasingly globalized world (what effects it can have at home and abroad), and what is at stake for countries that do not possess the expert knowledge and wherewithal to adequately address a problem of such magnitude. Our parallel analysis of interview transcripts alongside texts such as the WHO and Alzheimer’s Disease International’s Dementia:

A Public Health Priority yields new insights regarding the multiple levels of assumptions that structure the meaning and experience of nursing home life.

Assumptions about choice, made present in research on medical interventions for people living with dementia in nursing home settings, the interviewed residents expressed commitment to a notion of the person as “rational subject,” and textual representations of dementia as a global problem, are organized by a discursive dichotomy. Dementia is perceived as either a threat to personhood and to being and feeling at home or an opportunity to reaffirm personhood and recreate home through responsible home making. Our analysis illustrates how the assumption that there is choice can affect the self-perceptions, everyday lives, and aspirations of residents. For example, for some residents it promoted activities oriented to reaching out to others, and working with others to make the space more homelike, despite differences in condition and changes in with whom and how that space is shared. Thinking with the textual organization and activation of the rational subject, through an examination of paperwork, may shift how personhood is recognized within the nursing home away from an imagined quality of life that can be preserved through the administration of psychotropic drugs, and even contribute to what van Manen refers to as a “broadened notion of rationality,” which he understands as a faith in reciprocity and a shared life.

NOTES


8. For a detailed description of a biographical approach to dementia care and example of how this approach is understood from a public health perspective, see Amanda Clarke, Elizabeth Hanson, and Helen Ross, “Seeing the Person behind the Patient: Enhancing the Care of Older People Using a Biographical Approach,” *Journal of Clinical Nursing* 12, no. 5(2003):697–706.


15. Ibid.


18. OECD, p. 3.


20. Ibid.

21. No drugs have been approved for treating dementia’s psychiatric symptoms. The “black box warnings” by drug regulators (such as the FDA in the USA) warn prescribers of increased risks of cerebrovascular events and mortality in the use of antipsychotic medications for the treatment of dementia symptoms. For more on “chemical restraints,” see Erick Fabris and Katie Aubrecht examine the use of chemical restraints in “Chemical Constraint: Experiences of Psychiatric Coercion, Restraint and Detention as Carceratory Techniques,” in *Disability Incarcerated: Imprisonment and Disability in the United States and Canada*, edited by Liat Ben-Moshe, Chris Chapman and Allison Carrey. New York: Palgrave Macmillan; Kim, H.M., C. Chiang and H.C. Kales. “After the Black Box Warning: Predictors of Psychotropic Treatment Choices

32. The description of the nursing home as a hotel is from the interviews and is discussed by Stephanie Chamberlain in her master of arts thesis “Silent Partner in Care: Impact of Physical Environment on Quality of Life for Residents with Cognitive Impairment in Long-Term Care.” MA Thesis. Department of Family Studies and Gerontology, Mount Saint Vincent University, Halifax, Nova Scotia, 2014.


34. Armstrong, Pat and Susan Bradleyn (Editors). *Troubling Care: Critical Perspectives on Research and Practice*. Toronto: Canadian Scholars’ Press Inc., 2013.

35. See Robert McRuer’s *Crip Theory: Cultural Signs of Queerness and Disability* (New York, 2006) for a poignant exploration of the social, cultural, and economic conditions that shape ablest and heterosexist assumptions about the “natural order of things” and the role of these assumptions in shaping the experience of subjective wholeness (which could alternately be interpreted as a feeling of being at home in the world).


40. In his essay "The Person" in *The Category of the Person: Anthropology, Philosophy, History*, edited by Michael Carrithers, Steven Collins, and Steven Lukes, Michael Carrithers, Charles Taylor makes the following observation: “So generally philosophers consider that to be a person in the full sense you have to be an agent with a sense of yourself as an agent, a being which can thus make plans for your life, one who holds values in virtue of which different such plans seem better or worse, and who is capable of choosing between them.” (1985, 257).
41. McRuer 2006, 8, 9.
42. Ibid., 8.
44. The mixed-methods project examined to what extent and in what ways differences in the nursing home model of care impact resident quality of life. Research objectives focused on “quality of life” as variously experienced and described by residents, their families and nursing home staff across Nova Scotia. Twenty-two nursing homes participated as study sites, but all facilities in the province were invited to participate in a research ethics board approved survey. Interview questions elicited accounts of individuals’ perceptions and experiences of choice within the nursing home environment, and explored possible constraints and facilitators to the exercise of choice.
45. For a description of the importance of the stories of disabled people and their significant others to understanding the meaning of care within a Canadian context, see Anne Martin-Matthews and Janice Keeffe’s “Work and Care of Elderly People: A Canadian Perspective,” In Working Carers: International Perspectives on Working and Caring for Older People, edited by Judith Phillips (Aldershot, UK, 1995).
50. Ibid., 777.
52. Ibid., 56.
53. Ibid., 56.
57. McLaughlin, 2005.
58. Van Manen 1990, 16.