

Dementia Discourse: From Imposed Suffering to Knowing *Other-Wise*

Gail J. Mitchell, Sherry L. Dupuis, & Pia C. Kontos

Abstract

The authors revisit the troubling discourse surrounding the diagnosis of dementia. A critique of the predominant words and images in health care literature, public discourse, and policy is considered from multiple angles. The authors link the dominant words and images with a form of inter-relational violence. Contrary images grounded in research and experience offer a different view of what it is like to live with a diagnosis of dementia—a view that is life-affirming and based in relationality and possibility. Concepts of embodied selfhood and knowing other-wise are portrayed as doorways to transforming a discourse of violence toward a discourse of compassion and ethical relating.

Keywords

dementia discourse, suffering, embodied selfhood, knowing other-wise

In our experience, the diagnosis of dementia, especially Alzheimer's Disease (AD), in Western society continues to initiate a totalizing process involving suffering, discrimination, isolation, and, in many situations a violence of inter-relating. Our purpose in this paper are two-fold. First, we will re-visit the troubling relationship between the dominant medical discourse and consequences for persons with dementia, family care partners, and healthcare workers. Second, we will build on the notions of relationality (Dupuis et al., 2012a; Greenwood, Loewenthal, & Rose, 2002), embodied selfhood (Kontos, 2004, 2005, 2006, 2012; Kontos and Naglie, 2007a, 2007b, 2009) and know-

ing *other-wise* (Olthuis, 1997) in order to heighten attention to the ethical responsibilities we all have to persons with dementia. To begin, we show how the discourse surrounding dementia is in large part responsible for reproducing the violent and *othering* (Olthuis, 1997, 2000a, 200b) processes that accompany the label of dementia and disclose how this discourse imposes a suffering of personhood that has yet to be deterred. An alternative discourse of possibility and knowing *other-wise* (Olthuis, 1997, 2000a,

Corresponding Author:
Gail J. Mitchell
Email: gailm@yorku.ca

2000b) is presented as a viable option to shift societal and professional assumptions and prejudices.

We concur with several other authors (see for e.g., Dupuis, Wiersma, & Loiselle, 2012b; Herskovits, 1995; Mintz, 1992; Sabat, Johnson, Swarbrick, & Keady, 2011) that the dominant discourse of dementia, coupled with the medicalization of aging, reproduces dementia and human suffering through a totalizing disregard for another's embodied personhood and the relationships that sustain one's sense of self-with-other. Critical scholars, such as Behuniak (2011) who tackled the social construction of persons with dementia as the walking dead or zombies, Kontos (2004) who challenges the cognitive foundation of personhood, and Dupuis et al. (2011, 2012a, 2012c) consistently dialogues with, and learns from, persons diagnosed with dementia and their families, and remind us of the power of words and how words shape actions in society. Language matters and, when used in certain ways, can be dangerous and harmful. Language shapes the way we see and frame the world. "What is named [is] noticed; what is not named is unlikely to be seen" (Davis, Sumara, & Luce-Kapler, 2008, p. 15). Thus, language has a profound impact on how we come to understand things, shaping our assumptions and perceptions. These assumptions influence how we act in different situations and how we are with others (Davis et al., 2008; Mintz, 1992). The language surrounding dementia has serious implications for how we see and engage with persons diagnosed with some form of dementia, especially Alzheimer's Disease (Dupuis et al., 2011, 2012b; Jonas-Simpson et al., 2012; Mitchell et al., 2011; Mitchell, Dupuis, & Jonas-Simpson, 2011; Naue & Kroll, 2008; Sabat et al., 2011). One of the most serious issues relates to how personhood of those diagnosed with dementia is represented.

In this paper, we bring forth images and representations from the health and lay literature about what it is like to live with dementia. We review what some outsiders think it is like to live with dementia and consider the dominant discourse that surrounds the dementia diagnosis. Serious attempts to counter the dominant discourse are considered as are the experiences of stigma from persons living with dementia. Our personal insights and understandings as informed by experience and complexity science are considered before introducing the idea of knowing other-wise and the call for new discourses based in hope and possibility.

Dementia and Personhood

What are the images of personhood for those diagnosed with dementia? Popular literature and social media portray frightening images of AD. In 2004, a published book titled, *Death in Slow Motion: A Memoir of a Daughter, Her Mother, and the Beast Called Alzheimer's* (Cooney) captures the gruesome portrayal of a medical diagnosis. The Canadian newspaper, the *Globe and Mail*, ran a story called *Doomed from Birth to Death* (A. Mcilroy, May 7, 2007) about a woman born with Down's Syndrome, who later developed AD. Other titles, such as *The Living Dead: Alzheimer's in America* (Lushin, 1990) and *That Cranky Old Cat May Have Alzheimer's* (Fujita, 2012) layer on the fearful and negative messages about dementia. These images, coupled as they usually are with the tragedy discourse of being doomed, gutted, ravaged, taken over by a beast, and turned into the living dead, perpetuate a deep and pernicious fear of, and disregard for, persons with dementia.

Legal and medical scholars have contributed to questioning the personhood of those diagnosed with dementia. Ponder the

views of medical philosopher Brock (1988) from his consideration of justice and dementia.

I believe that the severely demented, while of course remaining members of the human species, approach more closely the conditions of animals than normal adult humans in their psychological capacities. In some respects the severely demented are even worse off than animals such as dogs and horses who have a capacity for integrated and goal directed behavior that the severely demented substantially lack. The dementia that destroys memory...destroys a sense of personal identity across time and hence they lack personhood. (p. 87)

Twenty years later, an ethicist and advisor to the British government suggested that persons with dementia may have a moral duty to die, especially if they are wasting human and fiscal resources (Malpas, 2009). Debates continue over issues of personhood, human rights, and the meaning and awareness of self.

The assumed loss of self with cognitive impairment can be traced to the 17th century rise of the “modern self” where the self and brain became consubstantial, or identical in substance (Kontos, 2004; Kontos & Naglie, 2009). This ideology laid the foundation for the modern view of person as autonomous, rational, and cognitively determined. The equality of brain and self(hood) underpins the predominant biomedical approach of attributing personhood to a body part, the brain, and human actions to be disease-based behaviours (Dupuis et al., 2012b). We deeply appreciate the valued work of health professionals, but the practice of dividing humans and reducing human expressions and experiences to bodily functions and behaviours spread through multiple health care

disciplines in their languages, activities, and practice protocols. This spreading, a kind of colonization, also seeps into policies and government regulations in the languages and prescriptive codes used to assess quality and compliance. Finally, the seepage penetrates societal and marketing realms in its relentless domination, one that objectifies and problematizes lived experiences such as aging (Estes & Binney, 1989; Kaufman, Shim, & Russ, 2004) and grieving, to name just two.

Kemmis and McTaggart (1988) described the interdependent relationships between language/discourse, activities/practice, and social relationships/organisation in the process of institutionalization. The language we use, over time, gradually becomes institutionalized into accepted patterns of discourse, which shape our activities and practices (i.e., how we act) and our social relationships and organization (e.g., how we relate). These interdependent processes are reflected in Figure 1. The intermingling and interpenetration of values, words, and actions are undeniable. As Olthuis (1997) noted, “Knowledges cannot be and never were neutral, dispassionate, disinterested” (p. 2).

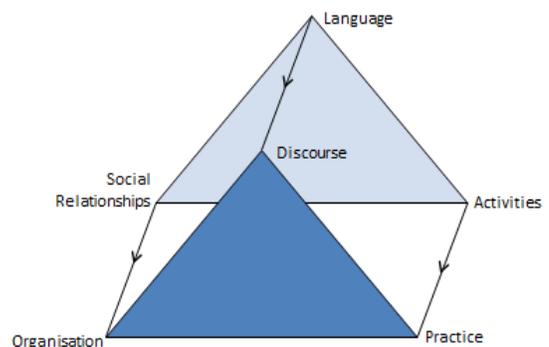


Figure 1: Interdependencies Between Words, Activities and Relationships (Kemmis & McTaggart, 1988)

There is an overabundance of compelling examples about how medical colonization and its discourse has infiltrated human

life and impacted human lives, especially for persons living with dementia (Dupuis et al., 2012b; Herskovits, 1995; Sabat & Harré, 1994; Sabat et al., 2011). Health professionals contribute to human health and well-being in many ways, but the consequences of biomedical colonization perpetuate dehumanized healthcare for persons with dementia - evidenced by such practices as infantilization, intimidation, stigmatization, and objectification (Herskovits, 1995; Kitwood, 1997; Mitchell, Dupuis, & Jonas-Simpson, 2011; Sabat et al., 2011). Policy documents and public health forecasters fuel this fear by conjuring up images of the *epidemic* taking over, the *tsunami* heading our way, the *rising tide* of dementia. In marketing with techniques that highlight the most debilitating, demeaning, and despairing fears of Alzheimer's disease and related dementias - the tragedy of it is emphasized and fear is commanded before compassion or even empathy.

Healthcare journals and texts represent persons diagnosed with dementia as dements, victims, diseased, disoriented, departing, devoid, irrational, disruptive, and uncontrolled. Consider these titles: "*Dementia and the Phenomenon of Social Death*" (Sweeting & Gilhooly, 1997) and "*Beyond appearances: Caring in the land of the living dead*" (Dunkle, 1995). Even authors advocating for revolutionary change in dementia care practices and policies, do not step away from the medical discourse. Consider the following description from authors advocating for social justice in dementia care (Dilworth-Anderson, Pierre, & Hilliard, 2012).

Alzheimer's disease is a progressive brain disease that destroys brain cells, causing problems with memory, thinking, and behavior, which affects the ability to work, socialize, and care for oneself. As the disease progresses, Alzheimer's pa-

tients increasingly need assistance with basic activities of daily living (ADLs), such as eating and dressing as well as functions that enable them to live independently, including shopping and managing money (i.e., instrumental activities of daily living [IADLs]). In the final stages of the disease, patients require 24-hour care. (p. 28)

Although these authors make an impassioned case for social justice in care and service for persons with dementia, and even though they address stigma and stereotype as forms of social injustice, they do not critique the medical discourse that strongly contributes to the stigma and stereotype of dementia.

Once diagnosed with dementia, persons and their feelings, actions, and expressions become symptoms within a problematized field of possibility. If persons with dementia express feeling healthy and well, they are judged as being in denial. If they are having trouble remembering details but fill in the gaps to save face, they are said to be confabulating. If they get angry with the way in which health workers are providing care, then they are labeled as aggressive and may end up being restrained and isolated. Other scholars have also noted this totalizing process of labeling and problematizing that engulfs a person's entire life and relationships with others (see for example, Dupuis et al., 2011, 2012b, Herskovits, 1995; Jonas-Simpson et al., 2012; Sabat et al., 2011; Whitehouse, 2008). Fazio and his colleagues (1999) describe the process of dehumanization in dementia that starts with predominant discourses and labeling and ends with the complete objectification that regards persons as no more than stages of disease and deficit. This dehumanizing process creates suffering by devaluing persons and rupturing relations with the social world; it is a process that

damages one's sense of self, leading ultimately to the loss of selfhood that is so widely thought to be caused by neuropathology.

Alarmingly, the medical colonization has seeped into the social and personal fabrics of contemporary society. The messages are clear and the impact profound. If we all live long enough, the odds are that we too will be diagnosed with dementia. There are strong advocates for diagnosing pre-dementia so that drugs can be started early but this raises ethical concerns and complexities (see Leuzy & Gauthier, 2012). Would we not all have pre-dementia? Medications too can be a form of violence—to both the physical body and one's selfhood and relationships. Moynihan and Cassels (2008) claim that the drug companies are selling sickness and making a fortune doing it. And, their predominant marketing tool is fear—fear that we too will get dementia, or depression, or some other dysfunction and become like *them* (Herskovits, 1995). But are we not already like them? “Do we not all have memory loss?” (Basting, 2009). Basting helps us see that forgetting is an aspect of being human. We all forget but it is only pathologized with a diagnosis of dementia. If we are the ones contributing to the social construction of Alzheimer's Disease, is this not irrational and degrading to humanity?

In our experiences, many family care partners also express the othering discourse about their parents or partners. Families have expressed to us that they do not believe there is anything left of their loved one - no feelings, no relationship, just a desire to get them in a home (see for example, Dupuis et al., 2011). This is consistent with a study of more than 100 caregivers for family members in Australia. Authors reported that less than 50 percent of participants believed life with dementia was worth living and many

considered the person socially dead and thought about or wished for the person's physical death (Sweeting & Gilhooly, 1997). And the medical colonization of old age and dementia is seen in the everydayness of life for many older persons residing in long term care homes, in our protocols and standards, our assessments, and policies. Wiersma and Dupuis, as an example, described five socialization processes of mechanical and regulatory procedures -- *placing the body, defining the body, focusing on the body, managing the body, and relating to the body* – used in long-term care homes to create “institutionalized bodies” or what Foucault (1977) termed “docile bodies”. Colonization is also seen in these settings in the overuse of medication, the use of geri-chairs, side rails and other physical restraints, in the violence of policies and surveillance that leave many direct care providers with moral residue (Webster & Baylis, 2000), fear, and guilt of knowing that health care should look a lot different than what is being delivered in Canada (Kontos, Miller, Mitchell, & Cott, 2011; McGilton, Sidani, Boscart, Guruge, & Brown, 2012).

Long-term care policies do not help. As an example, the Ontario Long Term care Act (2007, 2011) is a lengthy document with hundreds of rules and expectations. Many relate to the facility, food preparation, plans of care, assessments, and so on. Neither the importance of personhood nor the idea of quality relationships are addressed in the Act, except for definitions of abuse that attempt to protect residents. However, even then, and we quote: “physical abuse does not include the use of force that is appropriate to the provision of care or assisting a resident with activities of daily living, unless the force used is excessive in the circumstances” (p. 1). It is extremely troubling to realize that the imposed suffering for persons with dementia in our health care system that is

unnecessary, unethical, and cruel is not addressed. The Act focuses on task completion, regulation, compliance, assessment, log-rhythms, evidence, and enforcement. This reality coupled with narrative accounts from those who provide direct care (see for example, DeForge, van Wyk, Hall, & Salmoni, 2011; Kontos, et al., 2011) paint a dark, and indeed alarming picture of how far we are from providing compassionate and loving care based in quality relationships. And other authors have raised similar concerns about the absence of relationships in our evidence-based world of healthcare (Mitchell, in press; Slife & Wiggins, 2009). It is our contention that we must shift this violent approach to the care of persons, and especially those with dementia. We must rebel against the suffering we are inflicting on others and the suffering it creates in our own lives (Malpas, 2012). Other countries, such as Denmark, have a totally different approach to dementia care that is far more humanistic and relational. A recent CBC production with leaders in dementia care in a Denmark facility reported that instances of problem outbursts were very rare and when they occurred, were considered a failure of relationship, not a disease process (Wells, 2012).

We would be remiss to not address the complex realities and losses that do accompany the diagnoses of dementia for individual persons and those closest to them. There are deep losses of familiar patterns, routines, ways of relating, and shared remembrances. Families often describe feeling trapped and fearful of the realities they see unfolding - realities that can increase isolation, loss of friendships, stress, and moments of sheer frustration. But, there is also the reality that the person with dementia is still an embodied being who expresses selfhood and desires, suffering and joy. Our concern is that the losses experienced are far more profound

when experienced within a totalizing culture that stigmatizes aging and dementia through the tragedy discourse and leads to dehumanizing practices such as objectification, exclusion, silencing and so forth. What would it mean to persons and families experiencing these realities and losses if their communities embraced difference and supported personhood and inclusion? For those of us who are involved in the care of persons with dementia, we have opportunities and obligations to try to make things more humane and compassionate, to work towards the creation of communities in which "all kinds of methods create all kinds of situations in which each of us finds relationships where our gifts are recognized and magnified" (McKnight, 2005, p. 117).

Countering the Dominant View: Calls for Dignity and Relationality

Some scholars have endeavoured "to restore dignity and resuscitate the humanity of individuals diagnosed with Alzheimer's" (Herskovits, 1995, p. 154) by focusing on the subjective experience of dementia, the nature of personhood and the self, and the socio-cultural context of disease definition, rather than on neuro-psychological deficits (see for example, Dupuis et al., 2011, 2012a, 2012c; Jonas-Simpson & Mitchell, 2005; Kitwood, 1995, 1997; Kontos, 2005, 2012; Naue & Kroll, 2008; Sabat et al., 2011; Sabat & Harré, 1994). The importance of Tom Kitwood's (1995, 1997) work cannot be overestimated in terms of the pioneering work he did in the area of personhood and dementia. Kitwood began with the assumption that the loss of self commonly associated with dementia was due more to a failure of understanding and care than to a structural failure of the brain. Focusing on the social environment of care, Kitwood described a host of ways in which persons with demen-

tia are depersonalized, invalidated, and treated as dysfunctional.

Our individual and collective efforts have focused on a re-visioning of the self in Alzheimer's disease and we strongly challenge the assumption that the loss of self is a direct consequence of a degenerative process in nervous tissue. Like others (see for example, Herskovits, 1995; Kitwood, 1995, 1997; Sabat et al., 2011), we purport that the debasement of personhood is more likely affiliated with the ways persons relate with those diagnosed with dementia. There is little agreement on what the diagnosis of dementia means beyond the neuropathology and there is remarkable diversity in how neuropathology is manifested in individual lives and patterns of living (Herskovits, 1995; Whitehouse, 2012). Further, neurologists now indicate that even persons who have the brain pathology, may not develop the symptoms of dementia (Black, 2013). In our re-visioning efforts, we have argued for an expansion of the discourse on selfhood in dementia to include *embodied* self-expression (Kontos, 2004, 2005, 2006, 2012; Kontos & Naglie, 2007a, 2007b, 2009), authentic partnerships, (Dupuis et al., 2012a), and a focus on the human being and his or her lived experiences and quality of life (Jonas-Simpson & Mitchell, 2005; Mitchell, Dupuis, & Jonas-Simpson, 2011).

Based on empirical research with persons with moderate-severe cognitive impairment, Kontos (2004, 2005, 2006, 2012) and Kontos and Naglie (2007a, 2007b, 2009) illustrate how the engagement of selfhood with the world consists primarily in their essential corporeality of being-in-the-world. The expressiveness of persons with dementia discloses a cultural particularity that is shaped by socialization, but the expressiveness is always embedded in situational unities that call forth bodily move-

ment and gestures. These situational and embodied expressions of self persist despite even severe cognitive impairment. In other words, many life patterns and ways of relating continue to be expressed in the presence of dementia because fundamental aspects of selfhood are embodied and not defined by cognitive function.

Kontos illustrated how persons with severe dementia continue to express themselves in significant ways through their bodies as demonstrated in social etiquette, affection, friendship overtures, concern for appearance, engagement in religious and artistic practices, expression of physical needs and discomforts, aversion to particular foods, and dispositions that convey one's prior vocation (Kontos, 2004, 2005, 2006, 2012; Kontos, Miller, & Mitchell, 2010; Kontos & Naglie, 2007a, 2007b, 2009). The importance of the body for these expressions is powerfully illustrated in the following example: a male resident with severe cognitive impairment living on an Alzheimer support unit who had lost the ability to talk and feed himself would hit other residents on the head before taking his seat at the table (Kontos & Naglie, 2007). Once a connection was made between the fact that he would always remove his hat before entering the dining room, and that the residents at his table whom he would hit were wearing a hat, it became clear that his 'aggressive behaviour' was related to his prior longstanding respect for the etiquette of removing one's hat before dining. Despite severe cognitive impairment, he still retained the ability to express himself through nonverbal behaviour.

Another example highlights the intersections between social class and gender, showing the ways in which embodied selfhood in dementia continues to express class habitus through habitual manners and gestures, including ones in relation to dress. Consider

the following observation from an Alzheimer support unit in a long-term care facility.

String of Pearls

Molly's wheelchair looked enormous next to her thin and shriveled body. Her legs had severely atrophied leaving a seemingly two-dimensional form. Were she able to stand, she'd be no more than five feet tall. Her face was heavily wrinkled but her skin soft, resembling a peach. Her hair was uniformly white which accentuated her China-blue eyes. The back of her hands was the most vivid testament to the near century she had lived. The skin was thin revealing a network of bones and purple veins. Her hands shook as if powered by an invisible gentle motor.

Despite her withered appearance there was an indescribable elegance to her. I noticed this in watching Molly as she was brought to the dining room. Once her wheelchair was positioned at the table a bib was fastened around her neck. Molly then carefully unfolded her napkin and placed it on her lap. Even though the use of the bib made the need for a napkin redundant, she nonetheless insisted in observing this table etiquette.

As a Health Care Aide was feeding her, cereal dribbled from Molly's mouth and coursed down her chin. When the Health Care Aide tried to give her another spoonful Molly wrinkled her forehead and gently pushed the woman's hand away. Molly then lifted her bib to her mouth to wipe the cereal. It was only after her chin was clean that she accepted another spoonful. One might expect indifference from a woman who has lost the ability to feed herself and yet Mol-

ly's insistence to adhere to a sense of social grace and her attention to neatness, suggested a strong and continuing presence.

She closed her eyes slowly and opened them again releasing a deep sigh. She then looked around the table as if for the first time noticing that there were others seated with her. She patiently waited to make eye contact with each of them to acknowledge their presence. Then reaching her wavering hand to the back of her neck, she struggled to pull something from underneath her bib. Extending her arm appeared to cause her pain and discomfort and yet she persisted. Molly eventually revealed a string of pearls she was wearing that had been covered by her bib. She allowed the pearls to pass through her long slender perfectly manicured fingers placing them ever so delicately atop her bib. With this simple gesture, Molly emerged from her world of decrepitude, incontinence, dementia and helplessness. (Kontos, 2006, pp. 197-198)

Relating with persons with dementia requires recognition and support of the existential expressiveness of the body in its relation to the world, and our unique and shared socio-cultural ways of being-in-the-world (Kontos, 2004). It is our experience, in bearing witness to persons with dementia, that a significant amount of suffering is linked with the way the tragic and the horror-filled words and images, that are common place in social and medical literature, get imposed on individuals living with dementia. We reflect our fears on persons and that fear disrupts relationships and opportunities for learning and knowing other-wise. In our work with families living with dementia (Dupuis et al., 2012a), one person with dementia described her experience in the following way:

The person that has the disease are sometimes treated like they're not here anymore....I think that's very bad because we definitely are still here. And we might not have all our capabilities up there as we used to have...., We might not have great days all the time but sometimes we do, and I think that should be encouraged and try and make people more aware of what goes on with people with Alzheimer's instead of just saying - - oh they've got Alzheimer's, so I guess they're not with the program anymore...., A lot of people I know will just walk by me or go the other direction if they see me now because they think I'm not the same person, which I'm not but I'm still here and I can still talk you know. (pp. 428-429).

Another stated: "Many think it is the disease that causes us to withdraw, and to some extent I believe this is true. But, for many of us, we withdraw because we are not provided with meaningful opportunities that allow us to continue to experience joy, purpose, and engagement in life" (Dupuis et al., 2012c, p. 240).

Persons living with dementia tell us about this suffering in their pleas for inclusion, respect, and love:

I want others to know and treat us as if we are whole people. We are not half full or half empty. We will never, ever be a shell of ourselves. Later in the disease you may knock on my door and I may not answer, but that doesn't mean I'm not home. I am still Richard. I am still wholly and fully a human being. I have a right to privacy, dignity, respect, and I am still able I believe perhaps in ways that you cannot appreciate because you don't have dementia. I am still able

to appreciate myself, to love, and need to feel love, I am in short no different than you except I have dementia probably of the Alzheimer's type. My world is full and complete, it fills my mind, it fills my days, and it's only the professionals and caregivers who remind me of parts of my old world that I cannot access, or I'm confused about. (Taylor, 2009, p. 47)

Malpas (2012) provokes us to think more deeply about suffering and to consider that suffering is "a form of distress that is directly related to one's sense of personhood" (p.11). Our sense of wholeness and of hope is linked with how we and others view and judge our personhood. Further, he reminds us that we are all interwoven tapestries that have formed over time and that continue to form through the relationships in now moments. Our embodied selfhood is an expression of our relationality with others, with our memories, our hopes, and in the places we find ourselves. Malpas says that places are not "containers but openings of actions and movement" (2012, p. 12) - places are where compassion dwells - where relationships dwell.

Deeper Understandings of Living with Dementia

We have many years of work, practice and research, with persons who live with dementia and their families. Over this time, we have learned some things that are not commonly known or acknowledged. First, we have seen that dementia is a very dynamic and fluid phenomenon that is not, as portrayed in the medical and societal discourses, a progressive, irreversible decline of one's humanity. In our experience, persons with dementia frequently fluctuate - moment to moment, day to day, and week to week-- among multiple realities interspersed with moments, sometimes shocking moments of

clarity in the present now. Even in the latest stages of dementia, persons have moments or times of clarity that cannot be explained by medical science.

Secondly, while our work has taught us that persons living with dementia do suffer with all the losses and restrictions that typically accompany the diagnosis of dementia, there are also continuing relationships and love, persisting patterns of one's values and activities, and moments of humor, joy, and peace. Further, there is also new learning and emergent possibilities that happen when living with dementia. The dominant discourse has done a thorough job of portraying the loss and decline, the bitter and the tragic. And, they have relatively ignored the continuity, love, and growth that also exists in life with a diagnosis of dementia. Some people and groups have advantage with the dominant discourse - as noted previously, political and financial benefits can accompany the tragic portrayals.

The third thing we have learned is that people with dementia often live in a world without the boundaries of time, place, and sometimes person. The boundaries that we construct and rely on to separate things like time, place, and person shift with dementia, the boundaries and barriers become more fluid, and less defined such that the person before you, is all at once, in the instant of the now moment; the person before you is a unity of everyone they have been over a life span. Past, present and future are experienced together. A woman recalled from one of our practices showed this great expanse of being as she spoke about being a child waiting to sit in her dad's dentist chair, a mother with growing children, an aging and loving widow, and an old woman waiting to be called home. She moved effortlessly in her speech from one scene to the next with no boundaries or limitations of who she was.

She was all she had been and all she was becoming there in one instant of being and expanding.

This phenomenon of disappearing borders and boundaries may actually herald a different and more transformative process of human aging. There is at least one theory, gerotranscendence (Tornstam, 1996, 2005; Tornstam & Tornqvist, 2000), that suggests some qualities of aging as described by older people in Sweden, sound something like the disappearing boundaries with dementia. Older persons in Sweden also describe a greater connection with the cosmos; connecting and reconnecting with loved ones and memories; and redefinitions of time, space, life, and death. The point we are trying to make is that the process of aging and death is not yet understood; beyond physical changes aging is still a mystery. There is the possibility that the disappearing boundaries of time, place, person currently designated as symptoms of brain disease and dementia, may in fact be markers of a natural transformation that occurs with aging. Another theoretical frame offers important insights about the complexity and relationality of human being and the universe.

Complexity Science and Relationality

Complexity science with its core idea of relationality is changing how we think about and relate with persons with dementia. We offer a sketch of how complexity science is helping us to understand dementia and then we turn to several philosophers who have advanced the relational nature of selfhood and the opportunities that many health providers are not yet realizing. We will then explore more fully the notion of the relational self and dementia.

Complexity science is a conceptual frame that is informing research and practice

in multiple disciplines, including education, healthcare, physics, and biology (Uhl-Bien, Marian, & Mckelvey, 2007; Westley, Zimmerman, & Patton, 2006). There are many sources of complexity thinking that expand understanding of relationality, and possibility in healthcare and education in particular (see for example, Davis & Sumara, 2012; Davis, Sumara, & Luce-Kapler, 2008; Doll, 2012; Doll, Fleener, Truit, & St. Julien, 2008; Mason, 2008; Ricca, 2012). “The central ideas of complexity science are that human beings and the universe we inhabit are living systems, complex adaptive systems where mutual process, non-linear change, networked connections, and transformations continually bring forth new realities and new possibilities” (Mitchell, Jonas-Simpson, & Cross, 2012). Concepts informed by complexity include: emergent growth, mutuality, relationality, non-linearity, and unpredictability (Ricca, 2012). Complexity science helps us see that there are multiple nested realities emergent over time that co-exist and co-influence through relationships. In Figure 2 we offer an image of how nested realities might be conceptualized for persons living with dementia.

As portrayed in this Figure, a person experiences dementia within a particular family, community, culture, and history. People have relationships with particular memories and dreams, with favourite foods and people, with preferred routines, habits, and life patterns, with familiar and often comforting music and images. The opportunities to engage with persons with dementia have yet to be fully articulated and mobilized into practice arenas. Indeed, instead of attending to ways of relating with persons with dementia, in order to preserve and extend their relational selves, regulatory bodies and clinical assessments and protocols are compressing all forms of relating and reducing life in long term care homes to tasks and duties, “bed and body work” (Gubrium, 1975), creating “institutional bodies” (Wiersma & Dupuis, 2010). Indeed, recent literature suggests that some direct care providers who care for persons with dementia in long term care are either afraid to care for residents, fearful of doing what people want them to do (DeForge et al., 2011) or workers break the rules to do what residents want and live with the fear of being caught and punished (Kontos et al., 2010).

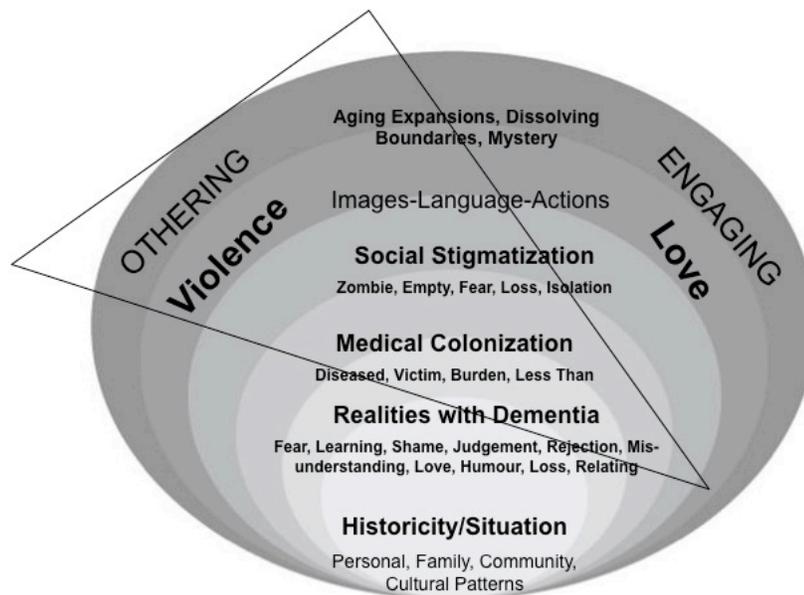


Figure 2. Dementia & Other-Wise: An Emergent Opportunity for Wisdom and Ethical Relating

Dementia and the Relational Self

We believe that the consequences of the rampant medicalization of later life is a form of violence. The violence is expressed and lived out through image, language, and action in all aspects of our contemporary world. We refer again to Figure 2 as a way to think about and see this cone of violence that dominates dementia care in the West, and to also show that there are other alternatives to consider and create. We can attend to relationships in all their complexity and mystery with persons who live with dementia. The question before us is how to move the predominant cone of violence portrayed in the diagram toward the opposing realm of compassion and knowing other-wise?

Olthuis (1997) proposed that being other-wise is a commitment to being-with and

ethics is the responsibility we bear to love another. The question of whether one needs to love to practice knowing other-wise is perhaps debatable. At the very least a core of deep compassion for other human beings is foundational. Knowing other-wise is an opportunity to see difference as potential wisdom instead of something to be changed or fixed. If we truly believed that difference is a space of potential growth, an opportunity for engagement and expansion of our own understanding, then how might we approach others? For Olthuis (1997), we would approach with a humble curiosity, an open and non-judgmental invitation for the other to reveal who they are in the moment of their own unfolding. One can imagine that such an approach with persons diagnosed with dementia would stand in sharp contrast with contemporary practice protocols and policies. Post (2000) conquers: “Rather than allowing declining mental capacities to divide humanity into those who are worthy or unworthy of full moral attention, it is better to develop an ethics based on the essential unity of human

beings and on an assertion of equality despite unlikeness of mind” (p. 5).

We wish to build on the ideas of knowing other-wise proposed by Olthuis (1997, 2000a, 2000b) and Hart (1997), by suggesting that embodied selfhood provides a foundation for an ethics of mutuality. Embodied selfhood extends Olthuis’ sensory knowing through the articulation of a synthesis of bodily and social being. We are embodied, complex beings who co-evolve with others in the universe. Bringing persons with dementia into this space of embodied co-evolution deepens and enriches the moral imagination and thereby enables possibility for relationality and compassionate care. Although not yet acknowledged as fully participating partners in Olthuis’ (1997, 2000b) symmetry of mutuality, if difference is the space of emergent wisdom, then persons with dementia create even more potential space and opportunity for developing wisdom and for knowing other-wise. A commitment to knowing other-wise, of embracing dementia as a place of difference and space for learning can provide one pathway toward a more compassionate, wise, and ethical world.

The places we live and the relationships that form there either contribute to and respect our personhood, or they deny our personhood and inflict suffering of the deepest kind. And one further point, for staff who work in long term care and who witness the suffering imposed by a culture of care that objectifies and denies the selfhood of others, staff too become depersonalized and distanced in their work. Work that should be about nurturing embodied selfhood and relationships, becomes work about bodies and tasks (Gubrium, 1975; Wiersma & Dupuis, 2010).

Calls for Re-Thinking Complexity and Other-Wise

There are gifted scholars and geriatric specialists who are now questioning the boundaries between normal aging and this process that medicine has labeled a disease. Peter Whitehouse (2008) is one such scholar and he has published a controversial book called the *Myth of Alzheimer’s Disease*. Some cultures view dementia as a natural part of the life journey (Ikels, 1998). The call for action is certainly to ease the pain and unnecessary suffering for persons diagnosed with dementia, or any mental illness for that matter. As a society we need to be more open, more compassionate, more curious about the differences that surround us when persons age or experience different realities. Instead of violating others, we could be learning, and growing, and loving others in far more ethical and compassionate ways.

Transformation of how we care for those living with dementia is needed and must begin with interrogating and changing the language and discourse surrounding dementia. Because of the harm and suffering evoked by the current powerful fatalistic and destructive discourses, Fazio and his colleagues (1999) emphasized the need for positive alternatives to describe the experience of dementia. They emphasized: “As words change, so do perceptions, and as perceptions change, so do actions” (p. 5). Alternative discourses challenge what is known and provide new possibilities for being and relating. As Kemmis and McTaggart (1988) noted “To change the culture of our groups (let alone whole institutions or society more broadly), we must change ourselves, with others, through changing the substance, forms and patterns of language, activities and social relationships which characterize groups and interactions among their members” (p. 17).

Cathie Borrie (2010a, 2010b), an advocate for both people with Alzheimer's and their care partners, herself cared for her mother with Alzheimer's disease for many years and wrote about how she came to reframe dementia for herself (see Borrie, 2010a). She became intrigued with her conversations with her mother and began to tape record their interactions. Although in the beginning she saw her mother's speech as garbled talk, nonsense, she began to see the poetry in her mother's words.

In reframing how she saw her mother's words, she learned to be truly present with her mother rather than correcting and judging. In thinking differently about her interactions with her mother she learned to listen attentively rather than dismiss. She learned that all actions are imbued with meaning and are a means of communicating. Her mother's words became an unexpected gift and Cathie has recently published her mother's words so that others can see the poetic and celebrate the eccentric realities of dementia (see Borrie, 2010b).

I felt free, free and undivided, free as a bird!
That I done, free and undivided,
I feel refreshed.

Free to flap my arms like a bird.

Go where I want to go.
Do what I want to do.

We close with an appeal for a more critical stance toward our practices and discourses. The predominant discourse surrounding dementia is entrenching those diagnosed in a cone of violence and fear. We need a more critical examination of our policies and standards and to rebel against those that diminish personhood for others and ourselves. We all need to promote a more curious and open frame of thinking about aging and life with dementia. Recent develop-

ments in understanding complexity concepts, relationality, and embodied selfhood can inform different ways of thinking, feeling, and acting with persons with dementia. Finally, we need to create language that inspires and enables respect, love, creativity, and compassionate relating. We need to fill in the spaces of knowing other-wise with what we come to know when embracing difference with persons with dementia.

Biographies

Gail J. Mitchell, RN, PhD. Professor, School of Nursing; Director/Chair YORK-UHN Nursing Academy. York University.

Sherry L. Dupuis, PhD. Director, Murray Alzheimer Research and Education Program; Professor, Department of Recreation and Leisure Studies, Faculty of Applied Health Sciences, University of Waterloo

Pia C. Kontos. PhD. Research Scientist, Toronto Rehabilitation Institute, University Health Network. Associate Professor, Dalla Lana School of Public Health, University of Toronto.

References

Basting, A.D. (2009). *Forget memory: Creating better lives for people with dementia*. Baltimore, MD: Johns Hopkins University.

Behuniak, S. M. (2011). The living dead? The construction of people with Alzheimer's Disease as zombies. *Aging & Society*, 31, 70-92.

Black, S. (2013). *Your head and heart - more connected than you think*. Alzheimer's SocietyCanada.

<http://www.alzheimer.ca/en/We-can-help/Stories-of-hope/Sandra-Black>

- Borrie, C. (2010a). *The long hello—the other side of Alzheimer's*. Vancouver, BC: Nightwing.
- Borrie, C. (2010b). *Looking into your voice – The poetic and eccentric realities of Alzheimer's*. Vancouver, BC: Nightwing.
- Brock, D.W. (1988). Justice and the severely demented elderly. *The Journal of Medicine & Philosophy*, 13(1), 73-99. doi: 10.1093/jmp/13.1.73
- Cooney, E. (2004). *Death in slow motion. A memoir of a daughter, her mother, and the beast called Alzheimer's*. New York: NY: Perennial, an imprint of HarperCollins.
- Davis, B., & Sumara, D. (2012). Fitting teacher education in/to/for an increasingly complex world. *Complicity: An International Journal of Complexity and Education*, 9(1), 30-40.
- Davis, B., Sumara, D., & Luce-Kapler, R. (2008). *Engaging minds: Changing teaching in complex times*. (2nd ed.) New York, NY: Routledge.
- DeForge, R., van Wyk, P. Hall, J., & Salmoni, A. (2011). Afraid to care; unable to care: A critical ethnography within a long term care home. *Journal of Aging Studies*, 25, 415-426.
- Dilworth-Anderson, P., Pierre, G., & Hilliard, T.S. (2012). Social justice, health disparities, and culture in the care of the elderly. *The Journal of Law, Medicine, & Ethics*, 40(1), 26-32, doi: 10.1111/j.1748-720X.2012.00642.x
- Doll, W. (2012). Complexity and the culture of curriculum. *Complicity: An International Journal of Complexity and Education*, 9(1), 10-29.
- Doll, W., Fleener, M. J., Trueit, D., & St. Julien, J. (Eds.) (2005). *Chaos, complexity, curriculum and culture*. New York, NY: Peter Lang.
- Dunkle, R.M. (1995). Beyond appearances: Caring in the land of the living dead. *Journal of Christian Nursing*, 12(3), 4-6.
- Dupuis, S., Gillies, J., Mitchell, G. J., Jonas-Simpson, C., Whyte, C., & Carson, J. (2011). Catapulting shifts in images, understandings and actions for family members through research-based drama. *Family Relations*, 60, 104-120.
- Dupuis, S.L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., & Sadler, L. (2012a). Moving beyond patient and client approaches: Mobilizing authentic partnerships in dementia care. *Dementia*, 11, 427-452. doi: 10.1177/1471301211421063
- Dupuis, S.L., Wiersma, E., & Loiselle, L. (2012b). Pathologizing behavior: Meanings of behaviors in dementia care. *Journal of Aging Studies*, 26(2), 162-173.
- Dupuis, S.L., Whyte, C., Carson, J., Genoe, R., Meschino, L., & Sadler, L. (2012c). Just dance with me: An authentic partnership approach in understanding leisure in the dementia context. Submitted to a special issue on Leisure, Health and Disability of *World Leisure Journal*, 54(3), 240-254.
- Estes C.L., & Binney E.A. (1989). The biomedicalization of aging: Dangers and dilemmas. *The Gerontologist*, 29, 587-597.
- Fazio, S., Seman, D., & Stansell, D. (1999). *Rethinking Alzheimer's care*. Baltimore, MD: Health Professions Press.

- Foucault, M. (1977). *Discipline & punish: The birth of the prison*. New York, NY: Random House.
- Fujita, A. (Oct 5, 2012). That cranky old cat may have Alzheimer's. ABCNews. <http://abcnews.go.com/blogs/headlines/2012/10/that-cranky-old-cat-may-have-alzheimers/>
- Gough, N. (2012). Complexity, complexity reduction and 'methodological borrowing' in educational inquiry. *Complexity: An International Journal of Complexity & Education*, 9(1), 41-56.
- Greenwood, D., Loewenthal, D., & Rose, T. (2002) A relational approach to providing care for a person suffering from dementia. *Journal of Advanced Nursing Studies*, 36(4), 583-590.
- Gubrium, J.F. (1975). *Living and dying at Murray Manor*. New York, NY: St. Martin's Press.
- Hart, H. (1997). Conceptual understanding and knowing other-wise: Reflections on rationality and spirituality in philosophy. In J. H. Olthuis, (Ed.). *Knowing other-wise. Philosophy at the threshold of spirituality* (pp. 19-53). New York, NY: Fordham University.
- Herskovits, E. (1995). Struggling over subjectivity: Debates about the "Self" and Alzheimer's disease. *Medical Anthropology Quarterly*, 9(2), 146-164.
- Ikels, C. (1998). The experience of dementia in China. *Culture, Medicine and Psychiatry*, 22, 257-283.
- Jonas-Simpson, C.J., & Mitchell, G. J. (2005). Giving voice to expressions of quality of life for persons with dementia through story, music, and art. *Alzheimer's Care Quarterly*, 6(1), 52-59.
- Jonas-Simpson, Mitchell, G.J., Carson, J., Whyte, C., Dupuis, S., & Gillies, J. (2012). Phenomenological shifts for healthcare professionals after experiencing a research-based drama on living with dementia. *Journal of Advanced Nursing*, 68, 1944-1955.
- Kaufman, S., Shim, J., & Russ, A. (2004). Revisiting the biomedicalization of aging: Clinical trends and ethical challenges. *The Gerontologist*, 44(6), 731-738.
- Kemmis, S., & McTaggart, R. (1988). *The action research planner* (3rd ed.). Geelong: Deakin University.
- Kitwood, T. (1995). *The new culture of dementia care*. London, UK: Hawker.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Philadelphia, PA: Open University Press.
- Kontos, P. (2004) Ethnographic reflections on selfhood, embodiment and alzheimer's disease. *Ageing & Society*, 24, 829-849.
- Kontos, P. (2005) Embodied selfhood in Alzheimer's disease: Rethinking person-centred care. *Dementia: The International Journal of Social Research and Practice*, 4(4), 553-570.
- Kontos, P. (2006) Embodied selfhood: An ethnographic exploration of Alzheimer's disease. In L. Cohen & A. Leibling (Eds.) *Thinking about dementia: Culture, loss, and the anthropology of senility*. New Brunswick, N.J: Rutgers University.
- Kontos, P.C. (2012) Rethinking sociability in long-term care: An embodied dimension of selfhood. *Dementia: The International*

Journal of Social Research and Practice, 11(3), 329-346.

Kontos, P. Miller, K-L., & Mitchell, G. (2010). Neglecting the importance of the decision making and care regimes of personal support workers: A critique of standardization of care planning through the RAI/MDS. *The Gerontologist*, 50(3), 352-362. doi: 10.1093/geront/gnp165

Kontos, P.C., Miller, K-L., Mitchell, G.J., & Cott, C.A. (2011). Dementia care at the intersection of regulation and reflexivity: A critical realist perspective. *Journals of Gerontology*, 66B, 119-128.

Kontos, P., & Naglie, G. (2007a) Bridging theory and practice: Imagination, the body, and person-centred dementia care. *Dementia: The International Journal of Social Research and Practice*, 6(4), 549-569.

Kontos, P., & Naglie, G. (2007b) Expressions of personhood in Alzheimer's disease: An evaluation of research-based theatre as a pedagogical tool. *Qualitative Health Research*, 17(6), 799-811.

Kontos, P., & Naglie, G. (2009) Tacit knowledge of caring and embodied selfhood. *Sociology of Health & Illness*, 31(5), 688-704.

Leuzy, A., & Gauthier, S. (2012). Ethical issues in Alzheimer's disease: An overview. *Expert Review on Neurotherapeutics*, 12(5), 557-567.

Lushin, G. (1990). *The living dead: Alzheimer's in America*. Potomac, MD: National Foundation for Medical Research.

Malpas, P. (2009). Do those afflicted with dementia have a moral duty to die? A response to Baroness Warnock. *Journal of the*

New Zealand Medical Association, 122, 1296.

<http://journal.nzma.org.nz/journal/122-1296/3635/>

Malpas, J. (2012). Suffering, compassion, and the possibility of a humane politics. In J. Malpas & N. Lickiss (Eds.), *Perspectives on human suffering* (pp. 9-21). London, UK: Springer. doi: 10.1007/978-94-007-2795-3_2

Mason, M. (2008). Complexity theory and the philosophy of education. *Educational Philosophy and Theory*, 40(1), 4-18.

McGilton, K.S., Sidani, S., Boscart, V.M., Guruge, S., & Brown, M. (2012). The relationship between care providers relational behaviours and residents mood and behavior in long term care. *Aging & Mental Health*, 16(4), 507-515.

Mcilroy, A. (May 7, 2007). *Doomed from birth to death*. Globe and Mail.

McKnight, J. (2005). Community and its counterfeits. In B. Lucht (Ed.), *Ideas: Brilliant thinkers speak their minds* (pp. 112-128). Fredericton, NB, Canada: Goose Lane Editions.

Mintz, D. (1992). What's in a word: The distancing function of language in medicine. *The Journal of Medical Humanities*, 13(4), 223-233.

Mitchell, G.J. (2013). Implications of holding ideas of evidence-based practice in nursing. *Nursing Science Quarterly*, 26(4), 143-151.

Mitchell, G.J., Dupuis, S., Jonas-Simpson, C., Whyte, C., Carson, J., & Gillies, J. (2011). The experience of engaging with research-based drama: Evaluation and expli-

cation of synergy and transformation. *Qualitative Inquiry*, 17, 379-392.

Mitchell, G. J., Dupuis, S., & Jonas-Simpson, C. (2011). Countering stigma with understanding: The role of theatre in social change and transformation. *Canadian Theatre Review*, 146, 22-27.

Mitchell, G. Jonas-Simpson, C., & Cross, N. (2012). Innovating nursing education: Interrelating narrative, conceptual learning, reflection, and complexity science. *Journal of Nursing Education and Practice*, 3(4), 30-39.

Moynihan, R., & Cassels, A. (2008). *Selling sickness: How the world's biggest pharmaceutical companies are turning us all into patients*. Vancouver, BC, Canada: Grey-stone.

Naue, U. (2008) 'Self-care without a self': Alzheimer's disease and the concept of personal responsibility for health. *Medicine, Health Care and Philosophy*, 11, 315-324.

Naue, U., & Kroll, T. (2008). 'The demented other': Identity and difference in dementia. *Nursing Philosophy*, 10, 26-33.

Olthuis, J. H. (Ed.). (1997). *Knowing otherwise. Philosophy at the threshold of spirituality*. New York, NY: Fordham University.

Olthuis, J.H. (Ed.). (2000a). Towards an ethics of community. Negotiations of difference in a pluralistic society. Waterloo, ON, Canada: Wilfred Laurier University.

Olthuis, J.H. (Ed.). (2000b). Exclusions and inclusions: Dilemmas of difference. In J. H. Olthuis (Ed.), Towards an ethics of community. Negotiations of difference in a pluralistic society (pp. 1-10). Waterloo, ON, Canada: Wilfred Laurier University.

Post, S.G. (2000). *The moral challenge of Alzheimer disease* (2nd ed.). Baltimore, MD: The Johns Hopkins University Press.

Ricca, B. (2012). Beyond teaching methods: A complexity approach. *Complicity: An International Journal of Complexity and Education*, 9(2), 31-51.

Sabat, S.R., & Harré, R. (1994). The Alzheimer's disease sufferer as a semiotic subject. *Philosophy, Psychiatry, & Psychology*, 1(3), 145-160.

Sabat, S.R., Johnson, A., Swarbrick, C., & Keady, J. (2011). The 'demented other' or simply 'a person'? Extending the philosophical discourse of Naue and Kroll through the situated self. *Nursing Philosophy*, 12(4), 282-292.

Slife, B.D., & Wiggins, B.J. (2009). Taking relationships seriously in psychotherapy: Radical relationality. *Journal of Contemporary Psychotherapy*, 39, 17-24. doi: 10.1007/s10879-008-9100-6

Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health & Illness*, 19(1), 93-117.

Taylor, R. (2009, July/August). Crossing bridges when you come to them: The biggest mistake? *Assisted Living Consult*, 5(4), 46-47.

Tornstam, L. (1996). Gerotranscendence - a theory about maturing into old age, *Journal of Aging and Identity*, 1, 37-50.

Tornstam, L. (2005). *Gerotranscendence: A developmental theory of positive aging*. New York, NY: Springer.

Tornstam, L., & Tornqvist, M. (2000). Nursing staff's interpretations of "Gerotranscendence"

dental Behavior" in the elderly, *Journal of Aging and Identity*, 5(1),15-29.

Uhl-Bien, M., Marion, R., & McKelvey, B. (2007). Complexity leadership theory: Shifting leadership from the industrial age to the knowledge era. *The Leadership Quarterly*, 18(4), 298-318. doi 10.1016/j.leaqua.2007.04.002.

Webster, G.C., & Baylis, F. (2000). Moral residue. In S. Rubin & L. Zoloth (Eds.). *Margin of error: The ethics of mistakes in the practice of medicine* (pp. 217-232). Hagerstown, MD: University Publishing.

Wells, K. (Sunday, November 18, 2012). *Dementia Care in Denmark*. CBC Radio. <http://www.cbc.ca/player/Radio/The+Sunday+Edition/ID/2304600853/>.

Westley, F., Zimmerman, B., & Patton, M.Q. (2006). *Getting to maybe*. Toronto, ON, Canada: Vintage Canada.

Whitehouse, P. (2008). *The myth of Alzheimer's: What you aren't being told about today's most dreaded diagnosis*. New York, NY: St. Martin's Griffin.

Whitehouse, P. (December 10, 2012). War, water, mountains: Myths and metaphors of Alzheimer's Disease. Jackman Humanities Institute Working Group on Aging, memory, & Aesthetics. University of Toronto, ON, Canada.

Wiersma, E., & Dupuis, S. (2010). Becoming institutional bodies: Socialisation into a long-term care home. *Journal of Aging Studies*, 25(1), 278-291.