Research Articles

The Becoming Subject of Dementia

Katie Aubrecht & Janice Keefe
Mount Saint Vincent University

Abstract: In this paper we analyse the becoming subject of dementia, as it is made to appear within the contexts of nation-building and everyday life. Insights yielded from this analysis suggest the importance of time to recognition of normalcy, and to the meaning of being a person.

Keywords: dementia; population aging; normalcy; personhood

> "Futurity has often been framed in curative terms, a time frame that casts disabled people (as) out of time, or obstacles to the arc of progress. In our disabled state, we are not part of the dominant narratives of progress, but once rehabilitated, normalized, and hopefully cured, we play a starring role: the sign of progress, the proof of development, the triumph over the mind or body" (Kafer, 2013, p. 28).

> "It is not so much that dementia is different from normal ageing; it is that ageing itself is not normal, in the sense that it restricts people from participating in life as they did before. One of the consequences of this articulation of dementia is that it challenges societal life-course expectations. In this sense, it represents an extension of the conceptual shift that has accompanied the construction of AD [Alzheimer's Disease] as an illness distinguishable from normal old age" (Moreira & Bond, 2008, p. 363).

Introduction

In this paper we draw from disability studies, cultural gerontology and social philosophy, to critically examine the cultural production of the "becoming subject" of dementia within global policy reports and everyday life. Our analysis uses a social constructionist approach (Berger & Luckmann, 1991), and considers how ways of knowing dementia organize perceptions and experiences of dementia. For example, within contemporary global dementia discourse, dementia is routinely represented as an "umbrella term" that collects and describes symptoms, such as memory loss and disorientation, that can make it difficult for individuals to perform everyday activities, and that result from diseases and disorders that have been found to appear with greater frequency in older adulthood (Alzheimer's Association, 2016). This way of knowing dementia can be traced to Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV (1994) definition of dementia as:

> "Multiple cognitive deficits, which include memory impairment and at least one of the following: aphasia, apraxia, agnosia or disturbance in executive functioning. Social or occupational function is also impaired. A diagnosis of dementia should not be made during the course of a delirium. (A dementia and a delirium may both be diagnosed if the dementia is present at times when the delirium is not present.)"

The DSM-IV definition suggests that dementia is best understood as a multiplicity. Dementia is "multiple cognitive deficits" that manifest in varied ways, and in diverse assemblages with other impairments. It is cognitive, physiological, social and political – affecting functionality across multiple domains. Dementia is simultaneously continuous and discrete. Dementia can co-exist with delirium, an acute "disturbance" that resembles dementia, but is distinct from and endures beyond delirium. In dementia, the disturbance is normalized. The word "dementia" has been erased from the most recent edition, the DSM-V, published in 2013. What was once dementia is now known as a "neurocognitive disorder", and further divided into "major" and "minor" types. And yet, dementia persists. Despite dementia's removal from the DSM-V, dementia remains in national and international guidelines and diagnostic and assessment tools used for a range of diseases, including Alzheimer's disease; many of which are made publicly available online (Siberski, 2012).

In representing dementia as a biomedical problem solvable by medical diagnosis and intervention, the DSM-IV interpretation of dementia aligns with a medical model of disability (Barnes & Oliver, 1993). In contrast, our examination begins with the assumption that dementia, like other disabilities, is a socio-political phenomenon (Titchkosky, 2003). In doing so, we join others who use a social model of disability to expand understandings of dementia beyond an individual biomedical condition, towards recognition of dementia as a social and political identity shaped by disabling processes and social orders (Baldwin, 2005; Bartlett, 2014, 2000; Bartlett & O'Connor, 2010; Boyle, 2014; Burke, 2008; Chivers, 2011; Downs, 2002; Innes, 2009; Kitwood, 1997). A focus on relationality, and the co-production of disability and non-disability is central to a social model perspective, as articulated by Goodley and Roets:

> "The social model of disability has turned attention away from a preoccupation with people's impairments (and the associated 'consequences' on everyday activities), and instead focused on the ways in which disability is created – through the social, economic, political, cultural, relational – and psychological – exclusion of people with impairments" (2008, p. 241).

Goodley and Roets (2008) also note that within disability studies, the social model of disability and the language of impairment are themselves politically charged. Critiques of the social model suggest that it ignores the realities of impairment as they are lived and experienced by disabled people. Our analysis counter argues that medicalized constructions of impairment are

reshaping the meaning and experience of the social. This is evidenced in the DSM-IV definition of dementia, which lists impairment to "cognitive", "social" and "occupational" "functioning"; implying equivalence; and which frames them individually and collectively (in terms of their interactions and relations with one another) as biomedical subjects (specifically, subjects of psychiatry).

Dementia, Personhood and Abnormal Aging

Dementia is a Latin word that means "away" or "out" of "mind" or "reason" (George, Whitehouse, & Ballenger, 2011, p. 419). Much of the current literature on dementia suggests that dementia is characterized by an impairment of the self that affects self-experience (Summa & Fuchs, 2015), self-reflection (Boyle & Lorna, 2015; Boyle, 2014), self-narration, and social self (Downs, 1997; Kitwood, 1997). What is imagined to be suffered in, and in-relation-with, dementia cannot be explained solely by medicine. What is also suffered is an expectation of living with what Sabat (2008) refers to as "spoiled selfhood", both of the person with the dementia diagnosis and this person's intimate others. For Sabat, "spoiled selfhood" occurs when interpretations of behavior emphasize pathology, and the individual loses control over self-representation.

The foreword to The World Alzheimer Report 2015 opens with the assertion that, "Today, over 46 million people live with dementia worldwide, more than the population of Spain. This number is estimated to increase to 131.5 million by 2050" (Alzheimer's Disease International, 2015, np.). The report proceeds to share facts that illustrate the scope and critical mass of dementia as a global issue by comparing dementia to both countries and corporations:

> "Today, the total estimated worldwide cost of dementia is US $818 billion, and it will become a trillion dollar disease by 2018. This means that if dementia care were a country, it would be the world's 18th largest economy, more than the market values of companies such as Apple (US$ 742 billion), Google (US$ 368 billion) and Exxon (US$ 357 billion)" (Alzheimer's Disease International, 2015, foreword, np.).

Projected increases in the prevalence and incidence of dementia are based entirely on projections of population aging (Alzheimer's Disease International, 2015, foreword, np.).

Population aging is now occurring in almost all countries in the world, and has been described by the United Nations as, "Poised to become one of the most significant social transformations in the twenty-first society" (2015, p. 1). Mullan (2002) observes that while current concerns about a "demographic time bomb" can be traced to the 1970s, it was only in the new millennium that the fear of population aging and its implications for individuals, societies and politics took root. The baby boomer cohorts had drawn attention to trends in aging, but at this point the focus was not primarily on the prevalence of older adults. Rather than a "time

bomb", declining fertility rates and aging populations were viewed favourably as an indicator of well-being and a sign that countries were headed in the right direction. As Mullan asserts, "Old age was seen as an opportunity rather than a penance" (2002, p. 80). Mullan also suggests that, "The main determinant for the rise of concern now is not population trends in themselves, but that the ageing preoccupation is a suitable manifestation for contemporary anxieties – fears with different, non-demographic roots" (p. 78). To understand the non-demographic roots of current concerns about aging, a as a 'becoming subject' we consider how ideas and images of dementia illustrate a shift in how the subject (or citizen) is understood within the Western political imaginary.

The first national dementia strategy was introduced in Australia, followed by the UK - England and Scotland, and one is currently in development in Ireland (Alzheimer's Society of Ireland, 2012). Seven of the Group of Eight (G8) highly industrialized nations have dementia strategies in place, the only exception being Canada. Such strategies include recommendations and approaches that appear to embody the principles of an emerging paradigm within dementia care: person-centred dementia care. This paradigm rests on Kitwood's (1997) theory of personhood as a relational accomplishment that can be distinguished on the basis of a perception of "human life as interdependent and interconnected" (p. 8), a "special form of intimacy", a "going out towards the other … a journey into uncharted territory" (p. 10). The focus on the interaction between people with dementia and their carers has been recognized as a significant contribution made by Kitwood's theory of person-centred dementia care (Baldwin & Capstick, 2007). However, a focus on interactions and relational approach does not protect against disablism, as we explore below.

Kitwood (1997) suggests that prioritizing personhood over dementia is a strategy care professionals can use to combat the dehumanization of "severe disability" – for people living with dementia diagnoses, and for themselves (1997, p. 14). The logic that supports this strategy makes the assumption that dementia offers an occasion for nondisabled people to reflect on their own anxieties concerning the probability that in time they too could become "demented". Within the person-centred philosophy advanced by Kitwood, anxieties concerning dementia that construct dementia as a reminder of the precarity of personhood are best understood as symptoms of a distorted experience of time. The logic of this philosophy parallels the logic of "temporary able-bodiedness" (TAB) (Breckenridge & Vogler, 2001). It rests on the assumption that within a context of population aging, in time anyone could become someone-with-dementia, and the call to promote self-determination for all, lest risk becoming someone who shares the fate of presently dehumanized others.

Further, according to Kitwood, anxieties regarding dementia are troubling primarily because of the way they can deplete an individual's "stock of learned [adaptive and experiential] resources for [future] action" (1997, p. 15), leading to a less developed personality (and by

implication, a person of an inferior type). Recognizing and prioritizing the personhood of individuals with dementia diagnoses are represented as techniques the nondisabled individual can learn and employ in the interest of securing a more highly developed personality and authentic sense of self.

Despite the on-going proliferation of new types of dementia, Alzheimer's disease remains the most common form of dementia (Alzheimer's Association, 2014). Basting (2008) contends that popular understandings of Alzheimer's disease as a "horrifying experience" (p. 212) are shaped by the national imaginary, and its ideological and mythologies concerning the natural citizen. Alzheimer's disease represents a threat to national identity, by projecting a future undoing of the nation's history and biography – its becoming story. As Basting asserts, "In a country that declared its 'independence' and that prides itself on its bootstrap success stories and rugged individualism, Alzheimer's disease is seen as the ultimate nightmare" (2008, p. 212). Globalization has meant that such assumptions are not restricted to Americans, and can be observed within global policy recommendations.

A notable example is found in the World Health Organization and Alzheimer's Disease International's Dementia: A Public Health Priority, which frames dementia primarily in terms of cost, stigma, suffering and loss (2012, p. 90):

> "The costs of dementia are estimated at US$ 604 billion per year at present and are rising more quickly than prevalence of the condition. The impact of dementia on socioeconomic conditions worldwide is enormous. Furthermore, dementia is highly stigmatized and universally feared, with studies suggesting that it is strongly associated with suffering, disability and economic loss at all stages of a person's journey through dementia."

In this report and others like it, rises in the number of older adults and in the prevalence of dementia are represented as co-constitutive problems. The nature of their relationship is constructed as self-evident, despite explicit claims that the physiological and psychosocial changes associated with dementia are distinct and ought not be confused from changes associated with "normal aging". Yet, nowhere is normal aging explicitly and unambiguously defined.

Within discourses of population aging, dementia is represented as a natural consequence of "abnormal aging". The meaning of "abnormal aging" operates across at least two registers: it signifies the aging-related pathologies that produce dementia as a physiological condition; and, on a more macro level, it also signifies current and projected demographic trends that challenge normative understandings of the life course. Although population aging is increasingly recognized as a global issue, it is most pronounced in developed countries. What is more, as is the case with a whole host of other psychiatric diagnoses, the diagnostic construct of dementia is

a Western invention, and not culturally universal (Timimi, 2014). Thus, abnormal aging can also be understood in a third way, as an effect of modernization and development. The concept of abnormal aging conditions the possibility of Western power's recollection, reflection and re-enactment of what is essential about being Western, its "self". Countries in which dementia is "on the rise" symbolize a nodal point in understandings of abnormal aging. The convergence of knowledge of abnormal conditions and non-normative trends produces something new: a conception of "normal aging" as a process that includes, is shaped by, and interacts with abnormalcy, without the abnormalcy becoming normalized.

A privileging of the uniqueness of persons, and a focus on eradicating the stigma associated with dementia are central to calls for the development of global dementia strategies and networks, comprised of partner organizations with community-based and international scopes. Under the auspices of improving the quality of life of persons living with dementia and their caregivers, dementia strategies and networks construct a divided image of dementia as a becoming-subject that is simultaneously natural and political; a biomedical condition and global economic burden pushing nations and their citizens to the brink of crisis. This divided image of dementia is productive of ways of knowing and relating to dementia as temporal thing – indicative of a phase, stage, or episode - that can be managed so as to promote assurance, optimize investments, maximize experience, and above all, minimize risk.

Representations of dementia as a temporal thing are evident in health and policy research population projections on the exponential growth in the prevalence of dementia. Such projections tend to be characterized by two common and interrelated themes. The first theme concerns the use of screening practices and technologies at the individual level, to identify dementia early in its progression, before persons with dementia become too different from persons without dementia. This theme is dominated by a staged understanding of dementia as a degenerative condition characterized by measurable cognitive decline. It is exemplified in Mild Cognitive Impairment (MCI), a clinical diagnosis that also serves as a means of formally classifying someone as being at risk for developing Alzheimer's disease or dementia.

MCI is characterized by observable changes in memory recall, language, attention and spatial navigation, which exceed what is expected of normal aging, but do not interfere with the activities of daily living. MCI is described in ways that suggest it too can be imagined as a stage in what some educational programs and advocacy groups refer to as the "dementia journey" (Alzheimer's Disease International, 2013), as "predementia" - a prologue or forerunner of a dementia to come (Chertkow, Feldman, Javoca, & Massoud, 2013). Although research evidence suggests that people with MCI are at a higher risk of developing dementia than the general population, it is inconclusive with respect to the actual extent of this risk, with significant differences noted across populations (Langa & Levine, 2014). Moreover, not only may people diagnosed with MCI not develop dementia, they may even experience improvements in cognitive

function (Smith et al., 2013). Considering that there is no effective medical treatment for MCI (Karakaya, Fuber, Schroder, & Pantel, 2013), its currently privileged status within clinical discourses of dementia may have more to do with the role that MCI plays in marking a transition towards dementia; of marking its becoming, and making it more amenable to being monitored. MCI provides a rationale for calls for screening and early identification for a condition that has no cure (dementia), and doing so in the absence of formal diagnosis. Whether or not dementia develops may be tangential to the broader goal of documenting the dementia journey and in the process, producing objective knowledge about normal aging.

Discourses of MCI organize interpretive relations to the appearance of dementia as an opportunity to narrate the 'origin story' of Western global power. People are living longer because of advances in science, technology and social order introduced in and by Western modernity. Although currently there is no cure for dementia, one needs only to look to the past successes of Western science to know this will not always be so, and that it is only a matter of time before there is a cure. Until then, in the meantime, we need to document our failures. Doing so will help us to understand future successes.

MCI is exemplary because it affirms the Western modernist commitment. It invokes the becoming subject of dementia haunting national and global reports on population aging. As such, MCI simultaneously activates and addresses aging-related anxieties, throwing the ameliorative power of modern science into relief. Further, its liminal status as marker of the "the edges of normalcy" (Titchkosky, 2014) and normal aging positions it as a driver of innovation, yet not responsible for any consequences of innovation. Thus, MCI serves as a harbinger of new taxonomies of difference that could be used to develop systematic understanding of normal aging. MCI is exemplary in one other way. It produces dementia and people with dementia as inessential to understanding dementia. MCI offers a way to develop knowledge about dementia using information from people who do not have dementia, but who could one day. As a result, people living with dementia in the here and now, especially people identified as having "moderate" and "late stage" dementia, become less essential to how dementia is known. Dementia, positioned in relation with MCI, makes dementia appear less timely and attractive as a subject.

The second theme concerns the use of screening practices and technologies to monitor trends - to document and follow what kinds of issues dementia is becoming within, and for, individuals, families, communities, industry, systems, and countries. This theme is embodied in recommendations that nations enhance data collection related to dementia, and monitor trends (Prince, Bryce, Albanese, Wimo, Ribeiro, & Ferri, 2013, p. 63).

Policy recommendations related to the early identification and documentation of dementia to track its development include the caveat of that monitoring will be challenging in non-Western

and "developing" countries where professional medical knowledge of dementia is lacking, or where the meaning of dementia may not yet have taken hold in the minds of citizens (WHO, 2012). This theme is dominated by a modernist understanding of development, which is defined using the World Bank's categories of low, lower-middle, upper-middle, and high income, to stratify countries according to their Gross National Income (GNI) per capita. Such recommendations can also be read as evidence of the ways, "Neoliberal economic and socio-political rationalities urge responsible individuals to control their health not only for their own sake but also for the socio-economic good of the nation" (Erevelles, 2011, p. 79).

What dementia means and how dementia is understood and experienced is also informed by national reports, such as the 2010 Alzheimer Society Canada's report, A Rising Tide. A Rising Tide opens with the assertion that the current 500,000 Canadians with Alzheimer's Disease or related dementias will grow to 1,100,000 within a generation. Despite an acknowledgement that health promoting lifestyle changes and preventive practices have been associated with a decline in the prevalence of a number of specific types of dementia, the report reminds readers that this does not change the course of population aging or the fact that dementia is "on the rise". It also forecasts that "within a generation" there will be a similarly exponential growth in financial costs to national economies - projected to increase from approximately $15 billion to $153 billion, and in the erosion of individual caregivers' time –231 million hours to 756 million hours (Alzheimer Society Canada, 2010). Within this report and other texts like it, facts about prevalence and demography shape more than the cost of dementia care and services. Strategic references to a rapid and global growth of loss that can be expected to be experienced within the reader's life time (i.e., "within a generation") inform what kinds of questions can be asked in the study of dementia – questions concerning the possibilities and limits of (inter)national prosperity, sustainable (self)governance, social and individual breaking points and points of no return.

The title of the Alzheimer Society Canada (2010) report evokes the (in)famous Wall Street proverb, "The rising tide lifts all the boats," which coincidentally US President Kennedy also used in a speech to mobilize support for US intervention in Europe during the Cold War. This expression highlights the need to focus on macroeconomic growth (raises in a nation's Gross Domestic Product/market valuations over a given period of time) as good for everyone, and threats to the status and prosperity of the group as a whole as detrimental to each and all. One of the major criticisms of this view is how, in absence of appropriate, targeted policies some may flourish while others run aground. In his narrative of the development of Rising Tide report, former Chief Executive Officer of the Alzheimer Society of Canada (2007-2009) Dudgeon (2012) suggests that recognition, regulation and the exercise of restraint on the part of governments and individuals are required if the rising tide of dementia is to be an opportunity and not an obstacle to Canadian society. Canadians need to take notice of dementia, and do so in a productive way, lest others (Europe, the United States, but also other countries that do aging well) may profit while Canadians are run aground or amuck. A central premise of Rising Tide is

that while Canadian governments, communities and individuals need to do better than well, they also have to be careful not to rock the boat.

Shifting our focus from the national to the global, one observes a similar logic in the Organization for Economic Cooperation and Development (OECD)'s 2013 brochure, Addressing Dementia: The OECD Response, developed for the G8 Summit held in London in 2013 with the "goal to place dementia at the fore of international collaboration". It opens by citing the history of the OECD and its connection Marshall Plan or European Recovery Program, an American initiative comprised of "34 member countries committed to democratic government and the market economy" developed to aid and rebuild Europe following WWII in order to prevent the spread of Soviet Communism via collaborative projects that focused on modernization, free trade and stabilizing/securing European prosperity. The focus of the brochure is on modernization, free trade and stabilizing/securing European prosperity. In the brochure dementia is described as a "major health burden with high social and economic costs"; a degenerative and deadly condition that "hospitals are still unprepared to deal with"; difficult to diagnose and treat effectively – a risk; a challenge and an opportunity - to promote modernization and advances in information and technologies (Big Data); global surveillance (sustainability of data sets, exchange and access to data, linkage, quality and efficiency, capacity building). Although Europe and its allies had apparently triumphed over total death and dissolution, new threats emerged from within Europe that threatened democratic self-actualization.

In the remainder of this paper, we turn our attention of a consideration from the macro to a narrative analysis of a micro-interaction: a joke once told as a truth. In doing so, we trace how assumptions about normalcy what some public health commentators and demographers have referred to as the "grey tsunami" (Simpson, 2014) organize relations to dementia within interpersonal relationships and everyday life.

Pulling the Plug on Normalcy

> During a visit to my doctor, I asked him, "How do you determine whether or not an older person should be put in an old age home?"
> "Well," he said, "we fill up a bathtub, then we offer a teaspoon, a teacup and a bucket to the person to empty the bathtub."
> "Oh, I understand," I said. "A normal person would use the bucket because it is bigger than the spoon or the teacup."
> "No" he said. "A normal person would pull the plug. Do you want a bed near the window?"

You can find this joke on the Internet when searching for resources related to the topic of dementia (see for example, Josline Diabetes Centre, 2008). When we came across it, it was not our first encounter. A woman who lived with her mother, who had a dementia diagnosis, first told it to us. This daughter was struggling with siblings to keep her mother at home. Her struggle

was conditioned by her current status as a co-resident in the family home, which stayed in the family as long as her mother stayed at home. The daughter said a doctor had subjected her mother to the bathtub test, and her mother gave the right answer – "pull the plug". One could suppose it did really happen, although one could also suppose that it may have been the daughter's way of making a connection. Perhaps she also read it on the Internet when she was seeking information and support; something to hold on to and use to make sense of where she found herself, with her mother; and what her mother might have said, had someone had asked her what she would have done. In describing this exchange between her mother and the doctor, this woman also shared that her mother is a wonderfully funny lady who was always telling jokes. That was why it was so easy to believe the truth of this joke, this brainteaser that could be someone's experience and lived reality. It really could have happened, it even might have. In sharing this story, this woman told us that normalcy is something that has to be recognized for it to be real. Given the chance her mother would know the answer, and make the right choice. She would pull the plug, and the professional putting her mother's normalcy to the test was the one who actually needed the bed near the window.

What is it that makes this choice the right choice, and the mother recognizable as a "normal person"? To understand, let us return to all of the options we have available to us and begin with the teaspoon. There is an agony to the image of a person using a spoon to empty a tub. The time and expenditure of energy involved in emptying a tub of water with a spoon makes this approach appear not only laborious and excessive, but even as a self-defeating task. This alone would logically lead to the exclusion of the spoon as the tool to get the job done in the best way. The choice of the spoon embodies the relationship to uncertainty characteristic of a spoiled self. This relationship is epitomized in the infirmed cogito of Descartes' Second Meditation that understands it thinks and exists, but lacks insight concerning its limitations and finitude. As Ricoeur says, "Left to itself, the 'I' of the cogito is Sisyphus condemned, from one instant to the next, to push up the rock of its certainty, fighting the slope of doubt" (1992, p. 9). Imagining our choice in this way also makes it possible to imagine the tub as a spatiotemporal schema that reveals a relational order. Everyone knows no one should choose the spoon. And yet, the spoon remains as a choice, which also serves as a diagnostic tool. Like the spoon, current diagnostic practices demarcate relations of truth and/or error. They serve as constitutive marks of the limits of human agency.

Our second and third choices are the bucket, and pulling the plug. The bathtub test reveals that what is at issue in human agency is evaluation: how humans evaluate a situation and act in the face of uncertainty. What makes pulling the plug the best choice is its time-efficiency[1]. The bucket is not only more time consuming, but also more labour intensive than pulling the plug. It won't get all of the water out of the tub; there will be traces of water left. Where will the water moved using the bucket go? The plug solves the problem cleanly and completely.

Following Taylor (1985), one might say that there is a utilitarian logic at work in normative diagnostic evaluations of dementia. We want to be able to calculate the right evaluations and "reduce practical reason to calculation" (Taylor, 1985, p. 17). To do so, we need to get rid of the strong and weak evaluations (the spoon and the bucket), and take a big picture view of the situation in its totality. Knowing to pull the plug rests on the assumption of a pre-existing infrastructure that can support the water's removal.

The bathtub test suggests that the realness of dementia comes into view in situations where people need to weigh alternatives. It also suggests more. The joke illustrates a normative understanding of rationality as something that can be measured in terms of losses and gains. While pulling the plug appears as though it is the radical choice, it could also be understood in terms of preference. Although it was not proffered in a list of choices, pulling the plug resides in the common stock of knowledge. The criteria for knowing how to respond are present as part of the horizon of experience that makes tests of normalcy a sensible and worthwhile human engagement. From within this horizon, the assertion to pull the plug does not necessarily have to be creative. It can be caustic, dismissive. Of course you pull the plug.

The difference between the spoon and the bucket elicits the desire for a third way, and an implicit recognition of what Ricoeur (1992)[2] refers to as the third person, yet unarticulated but no less present. In lieu of framing the choice to pull the plug as a radical choice, a choice made without criteria, we could think with Taylor's (1985) conception of "radical re-evaluation" (p. 40), which he understands as a mode of evaluating that calls undefined or inexplicit values into question. Radical re-evaluation is a responsibility, a practice and a privilege that the diagnostic category of dementia works to exempt individuals from. According to the logic of interpretation for persons with dementia, any radical re-evaluation is best understood as a demonstration of a loss of self, and the existence of cognitive decline – a change in personality. The very condition of dementia, represented as vulnerability, a space of disorientation, confusion concerning where and when and how and perhaps even who one is, could be the prima facie condition of becoming otherwise.

Destabilizing Sovereignty

Questions of personhood cannot be divorced from what Turner refers to as the "problem of the body" (1984, p. 81): i.e., its possession. Who owns the body? Or put otherwise, who has legitimate power and authority over the body? This question animates much of the current discourse on biopolitics, and is particularly salient in issues concerning the value and/or dangers of psy-interventions and professional medical expertise currently espoused by global mental health regimes. Personhood provides a pragmatic, rational and ready-made solution to the problem of the body; which is to say, that person's own their own bodies. Understanding personhood in this way is both unsatisfactory and problematic once personhood is situated within

broader historical, cultural and socio-political contexts. For as Turner reminds us, legal definitions of persons recognize collective entities such as cities and trading corporations as persons universalis, "One person composed of many" (1984, p. 79). Turner recalls political conceptions of sovereigns as having two bodies, "One real and corruptible, one fictive and immortal" (p. 79). This, he says, makes sense sociologically given recognition of the body as both material thing and sign.

Mbembe opens his essay "Necropolitics" with the assertion that, "To exercise sovereignty is to exercise control over mortality and to define life as the deployment and manifestation of power" (2003, p.12). Mbembe also notes that while "modernity was at the origin of multiple concepts of sovereignty" (p. 13), the concept of reason is vital to normative theories of democracy privileged by late-modern political criticism. Referring to Hegel's articulation of a relationship between death and the "becoming subject", Mbembe asserts that "the human being truly becomes a subject – that is, separated from the animal – in the struggle and the work through which he or she confronts death." The truly human life (and history) is "that life which assumes death and lives with it" (Mbembe, 2003, p. 14).

How do we live with versions of life that challenge normative assumptions about death and with them, privileged conceptions of sovereignty that associate reason with freedom? Situated in relation with dementia, the becoming subject is discursively and materially produced as the shadowy figure of what Mbembe refers to as the "death-in-life" (2003, p. 21). Mbembe also draws our attention to Bataille's conception of sacrifice not simply as a manifestation of freedom – an expression of personhood – but comedy, what Bataille refers to as "voluntary self-trickery" (p. 336, as cited in Mbembe, 2003). Guided by Mbembe and Bataille, we may now return to the narrative of the tub and the plug, and question how expert and anecdotal understandings of the inescapable tragedy of dementia (death-in-life), and institutionalization as the final frontier of human relationality (a room with a widow), restrict the performance of the self as the property of an individual fully aware of his or her death, and thus fully a person. In questioning the normative grounds of privileged understandings of dementia, assertions of a claim to the status of being "full subjects capable of self-understanding, self-consciousness and self-representation" (Mbembe, 2003, p. 13) become present in the form of semi-scripted rehearsals that carve out space within which non-disability can symbolically enact the death of disability, it's a significant other.

Mbembe examines sacrifice through the body of the suicide bomber, which he describes as "the spectacular putting to death of the self" (2003, p. 38). The sacrifice in the story of the dementia caregiver manifests in the symbolic death of dementia as a central artery in an intersubjective and intercorporeal becoming otherwise. With-dementia the humanity of the becoming subject is constructed as a thing that can be recovered and preserved through demonstrations of yet unarticulated, but no less expected, normative values. Humanity appears in

negative form – as a thing that is liquid and slippery (Burke, 2014b); a form of capital that can slide over edges and through cracks, off the sides of spoons. Humanity, as the product and project of modernity, is a temporal thing, an occasion, to rediscover the power of practical reason to liberate individuals from their cultural containers, whether they be institutionalized settings, patriarchal economies or ageist assumptions, to devise better, more timely (i.e., culturally relevant) ways of understanding these containers; a thing, the true knowledge of which, can be used to separate and reify relations of care into events that both give life and are draining.

In framing resistance to diagnostic evaluation in humanistic terms, as an expression of individuality, and living proof of the perseverance of the self, the daughter laboured to communicate her understanding of her mother as retaining a claim to "human" life, and as being a person who is aware of the situation she is in and who can respond with reason. While the aging woman with dementia, the mother, was one protagonist in this story, she didn't speak, and truth be told she wasn't there for the telling. And while the story told was moving in its evocation of an important part of who she is, or at least how her family perceives her to be, a playful and agentive, very funny lady; its telling also legitimized the authority a singular and very narrow notion of sovereignty; one that, coincidentally, had also conditioned the possibility of searching the Internet for answers to the problem she is perceived to be becoming, and of routinely speaking of her life, thoughts, experiences and aspirations as though she wasn't there. The power of the punch line relies on an affirmation of normative conceptions of awareness, of "insight" into death, as a question of knowing when to say to pull the plug.

This particular exchange illustrates a fundamental limitation to reclamation narratives told by people who may live with dementia, but who are as yet, still on the periphery of becoming recognizable as suffering from a loss of self. The same Western rationality that locates the self in the mind is also a condition of its dislocation, the dissolution of the mind and dispossession of the body. What is ontologically disruptive (and productive) about the bodily being of cognitive impairment within the context of dementia, and particularly, dementia understood as a condition of abnormal aging, concerns a destabilization of previously accepted and normatively assumed frames of reference. Without romanticizing this destabilization, as Mbembe (2003) suggests political criticism has done of sovereignty, and working to be present to the variegated nature of lived experiences of it, there is an undeniable generative power to the introduction of profound, and is often the case with dementia, unexpected, changes in language and communication.

Conclusion – From Personhood to Posthuman

We conclude our analysis by turning to Braidotti's (2013) conception of the "posthuman", which she understands as an off-shoot of the death or "de-centering of Man, the former measure of all things" (p. 3)[2]. According to Braidotti, "The posthuman condition introduces a qualitative shift in our thinking about what exactly is the basic unit of common reference for our species,

our polity and our relationship to the other inhabitants of this planet" (2013, pp. 2-3). She also says, "I believe that the posthuman condition can facilitate the task of defining a new role for Europe in an age where global capitalism is both triumphant and clearly deficient in terms of sustainability and social justice" (2013, pp. 52-53). There is something problematic about Braidotti's conceptualization of the significance of posthuman condition as a tool for redefining Europe and which focuses on cartographies for different subject positions. In defining a new role for Europe, as well as for the daughter caregiving for her mother with dementia, are we moving to the next meditation? Is this just about recognizing that we think and exist but are also finite and limited? Is the posthuman condition more authentic than humanism for its recognition of the other's resistance, with the qualitative distinction that this other is recognized as a significant other, a co-resident? Braidotti's rather functionalist conception of posthumanism in her reference to its role of facilitator in "the task of redefining a new role for Europe" reproduces the Eurocentric commitment to a universal consciousness, its practice of beginning the search for the truth of the structure of that consciousness by attending to a localized deficiency, and a belief in Europe's responsibility to care for the world.

To borrow from Rose and Abi-Rached (2013), one might say this conception of the posthuman represents, rather, a "new register or dimension of selfhood, alongside older ones." With the exception that here we can "understand and take care of ourselves" by "discerning" (Titchkosky, 2014, p. 125), as well as mapping and acting on "transversal connections" (Braidotti, 2013, p. 93), those invisible connections between subject positions beyond the centre. As crucial as such a move may seem to the vitality of relationalities and the possibilities of recomposition through affirmative bonds, the basic tenets of Western reason and politics persist, albeit in the form of the yet unarticulated correct choice; correct to the extent that it displays rational insight regarding matters of significance to the current historical moment (what can be done). As in the narrative of the tub that must be emptied, communicating a sense of the becoming subject involves a thought experiment that plays with the death of the significant other – the Human – as a means of coming to terms with the true nature of the process of becoming, now figured in terms of an assemblage of relations that can and should be mapped. Perhaps the time has come for a genealogy of history that de-centres the dominant conception of sovereignty Mbembe discusses, and that re-centres the current fascination with the subject within the political paradox of normal aging.

Katie Aubrecht is a Canadian Institutes of Health Research Postdoctoral Fellow. Her research uses critical disability studies theory and phenomenological and interpretive sociological methods to trace and historically situate the relations between institutional organization and subject formation. Current research explores the meaning of the experience of dementia, and how individuals' social identities and status as human beings are produced within the context of institutionalized dementia care. Dr. Aubrecht has published numerous peer-reviewed book

chapters and articles in *RDS*, *Studies in Social Justice* and *Seniors Housing & Care*, and has guest edited a special issue on translations of happiness in *Health, Culture and Society.*

Janice Keefe is Professor of Family Studies and Gerontology, Mount Saint Vincent University, Lena Isabel Jodrey Chair in Gerontology and Director, Nova Scotia Centre on Aging. Selected as the Mount's first Canada Research Chair in Aging and Caregiving Policy (2002-2012), her research areas are caregiving policy and practice, continuing care policy and projecting the needs of older Canadians. In the past decade she has published over 60 articles and technical reports and has received numerous awards for her scholarship and leadership. She teaches courses in social policy and aging and provides mentorship and supervision to a number of graduate students and postdoctoral fellows.

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Endnotes

[1] For an artful analysis of narratives of Alzheimer's Disease which makes use of Ricoeur's concept of oneself as another please see: Burke, L. (2014a). Oneself as another: Intersubjectivity and ethics in Alzheimer's illness narratives. *Narrative Works, 4,* 28-47.

[2] See also Erevelles' "Materializing Normalcy at the Intersections of Difference: Theoretical Impasses" presented at the *Theorising Normalcy and the Mundane* conference in 2014 at University of Sheffield.