

From the “Rising Tide” to Solidarity:
Disrupting Dominant Crisis Discourses in
Dementia Social Policy in Neoliberal Times

by

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Bachelor of Arts, University of Victoria, 1995
Bachelor of Social Work, University of Victoria, 2011

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of the Requirements for the Degree of

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Supervisory Committee

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Abstract

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As a social worker practising in long-term residential care for people living with dementia, I am alarmed by discourses in the media and health policy that construct persons living with dementia and their health care needs as a threatening “rising tide” or crisis. I am particularly concerned about the material effects such dominant discourses, and the values they uphold, might have on the collective provision of care and support for our elderly citizens in the present neoliberal economic and political context of health care. To better understand how dominant discourses about dementia work at this time when Canada’s population is aging and the number of persons living with dementia is anticipated to increase, I have rooted my thesis in poststructural methodology. My research method is a discourse analysis, which draws on Foucault’s archaeological and genealogical concepts, to examine two contemporary health policy documents related to dementia care – one national and one provincial. I also incorporate some poetic representation – or found poetry – to write up my findings. While deconstructing and disrupting taken for granted dominant crisis discourses on dementia in health policy, my research also makes space for alternative constructions to support discursive and health policy possibilities in solidarity with persons living with dementia so that they may thrive.

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Dedication

In memory of my Great Auntie Annie and for all people living with dementia and your families and friends . . . May the collective embrace you with loving, life-affirming, and generous supports so that you may live well in your communities.



dementia crisis looms

dementia a 'ticking time bomb'
huge wave of dementia cases coming
costs to soar as aging Canadians face
rising tide of dementia
province faces crisis
B.C. will be hit
a tidal wave of dementia patients:
are we ready for this dementia tsunami?



CHAPTER ONE: Introduction and Research Question

The above found poem¹ is a compilation of direct quotes – from recent news coverage about dementia and related social policies – that I have found distressing (Appendix A). As the niece of a truly great and spunky Great Auntie who lived with dementia, and as a social worker in dementia care, I am alarmed by discourses about dementia in the media and social policy that construct persons living with dementia and their needs as a threatening “rising tide” or crisis. I am particularly concerned about the material effects such dominant discourses, and the values they uphold, might have on the collective provision of care and support for elderly citizens in the present neoliberal economic and political context of health care. Overall, crisis and fear-based discourses

¹ A found poem is written by collecting existing text – from newspapers, books, road signs and beyond – and presenting it as poetry. Found poetry is a literary equivalent of collage.

about dementia seem to dominate the public imagination, and thereby distract from the possibility of more nuanced, multiple, and calm sociopolitical discussions embracing subjugated discourses about dementia and dementia care. As George (2010b) laments, “Shouldn’t a civilised society be able to summon public support for a health challenge that will affect us all and cost hundreds of billions of dollars without using severe language that foments fear, deepens stigma, and obviates meaningful contribution” (p. 1538)? By examining social policy and drawing on poststructural conceptualizations of discourse, which suggest discourse “not only reflects and sets limits on what can be known and said, it also constitutes knowledge, communication and practices” (O’Brien, 1999, p. 132), I have examined how dominant discourses about dementia work at this time when the country’s population is aging and the number of persons living with dementia is anticipated to increase.

**A Defining Moment:
Social Policy**

For the purposes of my research, I am using the term **social policy** broadly to include any document which refers to social arrangements aimed at distributing social resources and promoting the welfare of citizens (Gee & McDaniel, 1993, p. 139).

While approximately 500,000 Canadians currently live with some form of dementia, it is estimated 1.1 million Canadians will be living with dementia by 2038 (Alzheimer Society of Canada [ASC], 2010a, pp. 8, 17). Originating from the Latin word *demens* – meaning “without a mind” (Smith, 2008), dementia is understood by dominant Western biomedical models to be a “syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities” (World Health Organization [WHO] & Alzheimer’s Disease International [ADI], 2012, p. 2). Dementia is linked with many conditions including the

most common form, Alzheimer's Disease, as well as vascular dementia, dementia with Lewy bodies, and frontotemporal dementia (WHO & ADI, 2012, p. 19). Although individuals living with dementia are no longer explicitly labelled "mad" or "insane," dementia is classified as a "major or mild neurocognitive disorder" in the *Diagnostic and Statistical Manual of Mental Disorders: DSM-5* (American Psychiatric Association, 2013, Neurocognitive Disorders, para. 1). Furthermore, Western liberal society is rooted in Cartesian assumptions that privilege rationality in opposition to its binary irrationality (St. Pierre, 2000, pp. 486-87; Davies, 2000, p. 58). As Descartes stated: "I think, therefore I am." From this perspective, people with dementia are viewed as "not fully human" (Davies, 2000, p. 55) and as "'damaged goods,' no longer able to produce or compete" as autonomous individuals in a materialistic culture that measures human worth by productivity while seeming to forget that all citizens' brains are indeed aging (McFadden & McFadden, 2011, p. 57). In a society which also pathologizes old age as a social problem (Wang, 1999), persons living with dementia are thus doubly *othered* (McFadden & McFadden, 2011, p. 6). They are both aging and mentally ill which produces a category of *otherness* that is old and irrational:

After all, dementia invokes a heady combination of anxiety about old age and about mental illness. To be both older and mentally ill is to be doubly marginalized. An older person with dementia is at the extreme edge of mainstream society, which remains stubbornly youth oriented. (Zeilig, 2013, p. 5)

At the "extreme edge of mainstream society" then, people living with dementia are presented as overwhelming and expensive. For instance, Goldman (2011) observes that:

The media's take on Alzheimer's is very Gothic and apocalyptic . . . The typical presentation is: we have a huge baby boomer population and they'll be turning 65. . . They'll be zombies. And we'll have to pay for them. (as cited in Hall, 2011)

As a result, according to Kitwood and Bredin (1992), “the focus of attention is overwhelmingly on *them* [persons with dementia] as the problem, while *we* are not problematized at all” (p. 272, emphasis in original). My inquiry problematizes this pattern of problematization.

I have grounded my thesis research in an examination of two influential dementia social policy documents – one national and one provincial. Respectively, these are the *Rising Tide: The Impact of Dementia on Canadian Society* (2010) [RT] and *Improving BC’s Care for Persons with Dementia in Emergency Departments and Acute Care Hospitals: Findings and Recommendations* (2011) [IBCC] (Appendix B).² In the following chapters, I will consider my research question which asks: How do the RT and IBCC dementia policy documents work as exemplars of dominant crisis discourses on dementia – including the “rising tide” – in a neoliberal political environment? The next chapter, my literature review, draws on the ponderings of others to help theorise on why these crisis discourses appear at this particular place and

A Defining Moment: Neoliberalism

The contemporary neoliberal economic and political backdrop will be defined and explored in detail in the literature review. In a nutshell, however, **neoliberalism** discourages public funding for collective or government services, while “encouraging reliance on the private market and individual skill to meet social needs” (Baines, 2011, p. 30). Neoliberalism emphasizes economic efficiency. It establishes the market as the organizing principle for our daily lives as a norm against which decisions and actions across political and social spheres are measured to legitimize business approaches rather than care-based approaches (Smith, 2011, p. 204; Brown, 2005, p. 17; Baines, 2011, p. 33).

² Please note that the RT and IBCC acronyms will now be used throughout my thesis to refer to the two policy documents under study.

time. It examines literature about dementia discourses, the Canadian health care system, and the neoliberal political context. Chapter Three outlines my research design. It defines poststructural methodology and Foucault's archaeological and genealogical approaches to discourse analysis which consider how dominant dementia discourses work and their material effects. This chapter also describes the integration of poetic representation to display some of my findings with found poems, and reflects on the ethical considerations of my research as well as its merits and limitations. In Chapter Four, I share my data analysis of the RT and IBCC policy documents which describes and deconstructs dominant discourses about dementia and also considers their productivity vis-à-vis persons living without dementia, persons living with dementia, and family and health care staff caregivers. Chapter Five discusses my findings to further examine the material effects of dementia discourses that deresponsibilize the state and collective while also invoking moral panic. Overall, my research contemplates how the RT and IBCC policy documents engage with dominant discourses while negotiating the neoliberal context of health care in Canada. That said, however, I also examine how they might support alternative constructions of dementia so as to enable possibilities for solidarity that "[evoke] empathy for people more severely affected [by dementia] rather than just fear and sadness, while reminding us of our shared vulnerability to ageing processes and the essential unity this creates across the generations" (George, 2010b, p. 1538).

CHAPTER TWO: Literature Review

As a social worker with intersecting positions in health care practice and student research, I have chosen to deconstruct – or complicate – the “rising tide” discourse and other dominant discourses on dementia that appear in the media, political rhetoric, and social policy by examining two particular dementia policy documents. While my inquiry focuses on how dominant discourses work in the RT and IBCC policy documents, my literature review provides an overarching contextualization to help understand why these discourses are appearing at this particular time in Canada. That is, in order to situate dominant discursive themes on dementia – namely apocalyptic, economic, and biomedical – in the Canadian health policy context, I review scholarly literature in three key areas: dominant and disruptive dementia discourses; systems of health care delivery; and neoliberal politics in Canada. Because this is an academic project, I have drawn primarily on academic sources. However, because of the recent proliferation of grey sources on dementia and dementia care, I do draw on these to a limited extent as well.

Unpacking Discourses about Dementia

At this particular time many intersecting discourses on dementia abound, ranging from framing dementia as a tragedy or threat to upholding more positive perspectives that challenge biomedical assumptions and present possibilities for personhood and solidarity. This complicated mix demonstrates that dementia and the needs of those living with dementia are contested issues, and despite over two decades of scholarly research and dementia practice promoting solidarity with persons living with dementia, crisis discourses like the “rising tide” persist in the mass media and public imagination as dominant perspectives. As Gilmour and Brannelly (2010) note, “The term dementia is used

as an insult in western societies and is associated with a catastrophic illness in the popular imagination” (p. 242). McFadden and McFadden (2011) argue that “the way dementia is usually portrayed limits our imagination and magnifies our fears” (p. 16), while Behuniak (2010) similarly states that “such apprehension has strengthened the stigmatized view of individuals with dementia at the expense of both compassionate medical care and compassionate law” (p. 238). Dominant discourses metaphorically frame dementia, people living with dementia, and their care needs negatively and variously as a disease, tragedy, and/or threat to be managed and contained: “Dementia is not only a neurodegenerative disorder but a set of social anxieties about how to create discipline in chaos” (Brinjath & Manderson, 2008, p. 623). Examples of negative dominant dementia discourses that are critiqued in the literature include: dementia as a living death (Woods, 1989; Innes, 2002; Behuniak, 2011); dementia as social death (Herskovits, 1995; George, 2010a; McFadden & McFadden, 2011, p. 106; Brannelly, 2011); dementia as an epidemic (Basting, 2009, p. 32) and silent epidemic (Gubrium, 1986, p. 34); dementia as chaos (Brinjath & Manderson, 2008; Roberston, 1991, p. 142); dementia as catastrophe and burden (Gilmour & Brannelly, 2010; Basting, 2009, p. 3; Innes, 2002); dementia as “mushrooming” like a nuclear holocaust (Basting, 2009, p. 36); dementia as an attack and the “war” response to dementia (George, 2010b, p. 586; Gubrium, 1986, p. 121); dementia as an assault on adult status in industrial capitalist society (Herskovits & Mitteness, 1994, p. 337; Manthorpe, 2004, p. 137); and persons with dementia as zombies (Behuniak, 2011). Finally, even the “Dementor” threat in the popular Harry Potter series has been critiqued for ultimately working to misrepresent persons living with dementia (Gilmour & Brannelly 2010, p. 242; Clarke, Wilkinson, Keady, & Gibb, 2011, p. 87). For example, in the third novel, Professor

Lupin warns Harry about the “Dementors” whose very name suggests they are beings experiencing and causing dementia:

“Dementors are among the foulest creatures that walk this earth. They infest the darkest, filthiest places, they glory in decay and despair, they drain peace, hope and happiness out of the air around them . . . Get too near a Dementor and every good feeling, every happy memory, will be sucked out of you. If it can, the Dementor will feed on you long enough to reduce you to something like itself – soulless and evil. You’ll be left with nothing but the worst experiences of your life.” (Rowling, 1999/2010, p. 140)

In my analysis of the RT and IBCC dementia social policy documents I have endeavoured to be open to a multiplicity of discourses about dementia – dominant through disruptive – so I will now provide a brief overview of the literature that critiques apocalyptic, economic, and biomedical constructs of dementia, and then proposals for dementia discourses rooted in more solidaristic perspectives.

Critiquing dominant apocalyptic demography and economic views on dementia.

Dementia mainly affects older people (WHO & ADI, 2012, p. 12) so discourses on dementia must be considered within the broader context of ageist discourses which construct seniors as a “social problem” (Wang, 1999, p. 189), and the related “apocalyptic demography” discourses that present the aging population as a catastrophe and crisis for society (Robertson, 1991, p. 144). Examining the Canadian context, Gee (2000) states that apocalyptic demography implies “increasing numbers (or ‘hordes’) of older people will bankrupt a society, due to their incessant demands on the health-care system and on public pensions” (p. 5). However, while the aging Canadian population does create social policy challenges, such demographic changes in themselves do not create a policy crisis as they are intertwined with multiple socioeconomic forces which also have policy implications (Gee & McDaniel, 1993, p. 139). So while crisis discourse has “taken hold in the minds of

the public and policy-makers” (Gee & Gutman, 2000, p. 2), Robertson (1991) reminds us that we need not “believe ourselves to be at the mercy of blind forces, such as demographic and economic imperatives, as if these existed outside of the realm of public discussion and debate” (p. 147). The construction of a looming societal crisis holds individuals with dementia as responsible while “effectively obscur[ing] the diffuse networks of actors – including scientific researchers, medical clinicians, pharmaceutical company executives, legislators, paid caregivers and immediate family members – whose situated investments continually remake collective understandings of Alzheimer’s disease” (Asberg & Lum, 2009, p. 106). Marshall (1993) also examines the state of health policy in relation to aging in Canada and critiques the “rhetoric of demographic crisis” that focuses “too much on economics rather than social issues” (p. 153). In her deconstructive analysis, Gee (2000) argues further that the ideology of apocalyptic demography is used in Canada as a “tool for social policy reform that lines up with a neo-conservative political agenda” (p. 7) including the retrenchment of the old age welfare state (p. 5). Naiman (2004) states that while this agenda was at first referred to as neoconservatism – linked with its early proponents Margaret Thatcher and Ronald Reagan who were political conservatives – it is now “more commonly, and more accurately, referred to as neoliberalism” (p. 215).

In her case study of the politics of Alzheimer’s disease, the most common form of dementia (WHO & ADI, 2012, p. 7), in relation to apocalyptic demography, Robertson (1991) observes the emergence of Alzheimer’s disease as the “most publicized health problem in old age” (p. 135) in the United States. Furthermore, Dilworth-Anderson, Pierre, and Hilliard (2012) note that Alzheimer’s is the “most feared and most misunderstood” disease of later life (p. 26). Robertson (1991) examines its construction as “a fearsome

disease” (p. 143) associated primarily with loss – namely the losses of memory, intellectual function, language, bodily control, connectedness to other people, and ultimately the loss of that which defines “our humanness” (p. 143). Gullette (2009) argues that a dominant cultural fear of dementia and the “fake tremors of ‘population aging’” contribute to the growth of ageism which has concrete manifestations such that “we may withhold from the afflicted the thoughtful but difficult consideration that should be their due” (p. 58). Similarly, Basting (2009) asks “to what extent . . . our fears about dementia and aging contribute to the tragic conditions of living with dementia and the catastrophic economic story of dementia” (p. 3).

Critiquing dominant biomedical constructs of dementia.

Kitwood (1997) is credited with, and widely cited for, initially critiquing the dominant biomedical conceptualizations of dementia care and advocating for an alternative personhood or person-centred theorisation and practice that fully recognizes both the subjectivity and intersubjectivity of persons with dementia (Kitwood & Bredin, 1992, pp. 269, 270; Kitwood, 1997; Behuniak, 2010, p. 234; Gilmour & Brannelly, 2010, p. 245; Clarke, Wilkinson, Keady, & Gibb, 2011; Bartlett & O’Connor, 2007). Or as Tanner (2011) summarizes, “whereas ‘the standard [medical] paradigm’ focused on inevitable loss and decline, personhood affords the potential to transform the experience of living with dementia through changing the social responses to it” at least at the micro-level (p. 2). Robertson (1991) offers a broader political critique. She argues that dominant narratives frame the so-called problems of aging – like dementia – and their solutions, as primarily biomedical, and therefore effectively depoliticise them by overlooking the social, political, and economic determinants of the health of individuals and the collective (pp. 136, 138).

She suggests that privileging the biomedicalization of dementia creates an apparently stable diagnostic category to contain the uncertain boundaries of dementia without transparently acknowledging the “multiplicity of symptoms, the inconclusiveness of diagnosis, and the uncertainty of prognosis” (Robertson, 1991, p. 140). Behuniak (2010) has more succinctly referred to this as the “grey areas produced by the actualities of dementia” (p. 238). Furthermore, in their analysis of the evolution of the concept of Alzheimer’s disease and the related social movement in the United States, Chaufan, Hollister, Nazareno, and Fox (2012) contend that:

The hegemonic biomedical model leads to a ‘cult of expertise,’ where presumably objective, neutral and non-political problem definitions support decisions requiring professional or technical judgments that exclude laypersons from meaningful participation and decision over the distribution of resources. (p. 794)

They warn that the biomedical model persists at a social cost by implicitly establishing “a race against the demographic clock” (p. 789) that prioritizes finding a cure for Alzheimer’s disease over developing social policies to preserve the humanity of persons living with dementia and better address their needs (Chaufan et al., 2012, p. 789).

Disruptive discourses in solidarity with persons living with dementia.

In response to critiques of economic and biomedical models of dementia, and also building on Kitwood’s personhood theories, multiple alternative conceptualizations of dementia and dementia care appear in the literature in solidarity with persons living with dementia. These include relational discourses vis-à-vis persons living with dementia such as the dynamic co-construction of reciprocal relationships between persons with dementia and others (Graham & Bassett, 2006; Basting, 2009, p. 69); mentoring roles for persons with dementia (George, 2010a, p. 587); social citizenship (Bartlett & O’Connor, 2007;

Bartlett & O'Connor, 2010, p. 37); deconstructing the politics of self-care as a governing technology in the dementia context (Naue, 2008); and interdependency and connectedness (Kitwood & Bredin, 1992, p. 286; Barnes & Brannelly, 2008; Taylor, 2008, p. 333; Behuniak, 2011; see also Robertson (1997) on the interdependency of seniors and the moral economy). Additional solidaristic dementia discourses acknowledge and support the lived experiences of people living with dementia. These include: listening to people with dementia voice their subjective experiences (Herskovits, 1995, p. 148; Beard, 2004; Hulko, 2009; Gilmour & Brannelly, 2010, p. 245; Sabat, Johnson, Swarbick, & Keady, 2011); nurturing community and friendship with people living with dementia (McFadden & McFadden, 2011; Bastings, 2009; Hulko, 2009); and self-advocacy by persons with dementia as demonstrated by the Dementia Advocacy and Support Network International (DASNI) and in scholarly literature (Friedell & Bryden, 2002; Clare, Rowlands, & Quin, 2008; Bartlett & O'Connor, 2010). Despite these alternative, or disruptive, conceptualizations of dementia in solidarity with persons living with the condition, however, dominant discourses – including the “rising tide” – persist in the public imagination, media, political rhetoric, and social policy.

“Rising tide” discourse and its context.

The “rising tide” discourse on dementia draws on language of natural disasters like flooding, tidal waves, and tsunamis as well as the economic rhetoric of apocalyptic demography. Overall, it appears to be enmeshed in dominant discourses highlighting dementia as a crisis and threat to the health care system and the economy. I have found examples of the rising tide discourse being used uncritically in multiple sites to describe the increase in numbers of aging persons anticipated to soon be living with dementia;

namely in the media as exemplified in the found poem in my introduction, in social policy documents (Health Advisory Services, 1983; ASC, 2010a), and in academic literature (Larson & Langa, 2008; James, 2011, p. 7; Clarke, Wilkinson, Keady, & Gibb, 2011).

According to Zeilig (2013), who writes about the British context:

The danger of flooding has long been associated with dementia. . . . Rising tides continue to inform the language of contemporary politicians when discussing dementia. . . . The “silent tsunami” of dementia has also been a dominant watery image in many news stories. (p. 3)

One of the first instances of the rising tide discourse being used to describe people with dementia (at least of those I have found) appears in a British policy report produced by the Health Advisory Service in 1983 and entitled *The Rising Tide: Developing Services for Mental Illness in Old Age*. While I will discuss neoliberalism at length later, it seems important to note that this report appeared around the same time as the birth or manifestation of neoliberal ideology in British politics. By 1982 the British National Health Service was beginning to undergo neoliberal restructuring – as promoted by Prime Minister Thatcher and the Conservatives who were elected in 1979 – focused on economic efficiency, reduced public funding, and managerialism (O’Dowd, 2008). In fact, as *The Rising Tide* declared:

Unfortunately, *these are hard times* in which to develop any kind of new service but failure to do so is likely to result in most other kinds of health and social services being overwhelmed by the sheer weight of numbers. The situation is unprecedented. There have never been so many people surviving into great old age and the greater the age the higher the incidence of dementia and age related psychiatric disorders. (HAS, 1983, p. 3, emphasis added)

The Rising Tide set out to propose co-ordinated and comprehensive (HAS, 1983, p. 17) services to address the “full flood” (p. 1) of older persons with dementia and other mental illnesses through “thoughtful planning” (p. 7) because it was “no longer good enough to try

to muddle through with leftover buildings and disorganized unplanned services” (p. 4). The British report advocated that the needs of older adults with mental illness – including dementia – be determined, and suggested the state was responsible for “strategic policy, capital and manpower [*sic*] development” (HAS, 1983, p. 1) for a broad range of services while also acknowledging that informal care provided by families and friends was “the main source of support” (p. 17). Furthermore, the report desperately contended “the majority believe that far too little is spent on the elderly mentally ill and that much better services would be provided if society was more generous to helpless old people” (p. 28). Hilton (2010) observes, however, that while *The Rising Tide* (1983) report was “a model of good ideas,” the neoliberal government responded only “with time-limited, insufficient financial commitment,” which she argues continues to be the case for dementia care and policy in Britain (p. 293).

Larson and Langa (2008) claim that the contemporary “rising tide of late-life dementia is both a triumph of public health and an opportunity” (p. 431). Van den Noort and Bosch (2010) advocate for using heightened language to describe the dementia situation, arguing:

There is a serious risk that the use of the less severe terminology . . . will lead to a lower priority status on the agenda than the one dementia has now, resulting in cutting money from both the daily care of these patients and from scientific research on dementia. (p. 1538)

On the contrary however, Innes (2002), referencing Ineichen (1987) and the British context, cursorily mentions that the media’s constructions of older people as a burden and the “‘rising tide’ image, particularly as it is applied to people with dementia,” contribute to politicians’ unwillingness to support the improvement of dementia care (p.491). Similarly, in a short media interview on the release of the Canadian *Rising Tide* study that is one of my

selected policy documents, Zimmerman (2010), who is a gerontology research associate at Simon Fraser University, stated her major concern is that the alarmist report incites panic by shaping “a kind of crisis mentality where this is not absolutely required” (as cited by McMartin, 2010, p. A4).

Canadian media have used “rising tide” discourses to describe social issues besides dementia including child pornography (Dempster, 1997), crime (Ogilvie, 1993), Muslim radicalism (Bordewich, 1994), domestic violence (Josey, 2000), U.S. guns spilling into Canada (Editorial, 2012, p. A10), and single mothers (Evans & Swift, 2000). However, the only academic critique I have found of such rising tide discourses was that of Evans and Swift (2000) within their broader examination of the construction of single mothers as the subjects of “demonizing discourses” in newspaper articles in the 1980s and 1990s (p. 73). Relevant to my analysis of dementia discourses in Canadian social policy documents is their observation that the rising tide discourse was bolstered by “expert” discourse and the use of statistical data, and that it was also enmeshed with politically-driven restructuring discourse and the retrenchment of the welfare state (Evans & Swift, 2000, pp.73, 85, 88). Overall, Evans and Swift (2000) contend that the constitution of a homogenous population of single mothers as a supposedly never-ending and enormous problem, threatening the public purse and the social and economic fabric, worked to invite moral panic (p. 89). While Evans and Swift’s (2000) analysis is transferrable to my own inquiry, I have not found any detailed, scholarly analyses specifically deconstructing the rising tide discourse vis-à-vis dementia and the values it perpetuates. My research has endeavoured to address this gap. While undoubtedly intersecting with the aforementioned list of dominant threat discourses on dementia and the disruptive alternatives, I have been interested in examining how the

rising tide discourse about dementia works at this particular point in social policy in the Canadian context including first, health care delivery systems, and secondly, neoliberal politics.

Practices and Systems of Health Care Delivery

In order to examine dementia social policy in Canada, and British Columbia more specifically, the RT and IBCC policies must be set within the context of the delivery mechanisms of health care. Canada has a predominantly publicly funded and administered health care system at least with regards to the provision of “reasonable access to medically necessary hospital and physician services” (Health Canada, 2011, p. 1). This means citizens “have the right to care based on medical rather than financial need” (Armstrong, 2012, p. 322). The *Canada Health Act* is Canada’s federal health insurance legislation and defines the national principles governing the health insurance system (Health Canada, 2011, p. 1; Rockwood & Keren, 2010, p. 876). Romanow (2002) has observed that Canadians embrace the health insurance system dearly “as a public good, a national symbol and a defining aspect of their citizenship” (as cited in Mahon, 2008, p. 349).

Federal and provincial/territorial roles in the health care system.

The ten provinces and three territories are constitutionally responsible to administer the core principles of the health insurance system – namely, public administration, comprehensiveness, accessibility, universality, and portability (Health Canada, 2011, p. 1; Rockwood & Keren, 2010, p. 876; Armstrong, 2012). So while the federal government, under the *Canada Health Act*, establishes the criteria and conditions to be satisfied by the provincial and territorial health insurance plans for them to qualify for “their full share of the cash contribution available to them under the federal Canada Health

Transfer” (Health Canada, 2011, p. 1), the provinces and territories are responsible for the administration and delivery of health care services (Graefe, 2006). This includes determining local priorities through policy and managing their own health care budgets and resources (Health Canada, 2011, p. 1). Presumably, as well, the provinces and territories are responsible to interpret and declare what counts as “medically necessary” hospital and physician care. As a result, rather than one centralized system, there are multiple distinct health care systems across the country with significant variations in their interpretations of the *Canada Health Act* (Rockwood & Keren, 2010, p. 876; Graefe, 2006). Armstrong (2012) suggests that variation is even greater when it comes to services such as home care and long-term care – services that are often required by people living with dementia, but which are not clearly protected under the *Canada Health Act* (p. 322). Actually, as Cohen, Tate, and Baumbusch (2009) highlight, no national standards or minimum service levels regarding such home and community care are required of provincial governments: “In other words, there is no ‘right’ to community health care, and fees can be charged for publicly-funded services” (p. 3).

Within its varying provincial and territorial contexts, Cohen (2012) describes Canada’s health care system as consisting of three key intersecting elements: primary care (i.e. family doctors); acute care (i.e. hospitals and emergency services, the most expensive part of the system); and home and community care (i.e. residential care for seniors and home support services) (p. 9). People living with dementia and their families access all of these services. Notably, however, although the public health insurance system provides universal coverage for hospital and physicians’ services, this population is greatly impacted by the fact fees can be charged for long-term residential care, medications taken outside

hospital, home care, and even some hospital care that is not considered the most acute (Armstrong, 2012, pp. 326, 327; Finkel, 2006, p. 303). Furthermore, while primary care, acute care, and home and community care might represent the core services in the contemporary health care system, they are not necessarily designed to address the social determinants of health that also impact dementia. Ballenger (2006) states that dementia is:

... a dialectical process between the brain and the psychosocial context in which the aging person [is] situated. Factors such as pre-morbid personality structure, emotional trauma, disruptions of family support and social isolation [are] regarded as at least as important in explaining dementia as the biological processes within the brain. (p. 8)

As an example, Cohen (2012) draws on Lansdowne's (2011) research to demonstrate that social support is a determinant of seniors' health and that "social connectedness slows cognitive decline, the onset of dementia and the progression of disability (both mental and physical)" while also having a positive impact on longevity (p. 24). Compared to other wealthy nations, however, Canada "presents a mediocre population health profile and public policy environments increasingly less supportive of health" because, according to Raphael (2007), the "public health gaze is firmly - and narrowly - focused on lifestyle issues of diet, physical activity and tobacco use" rather than the structural and public policy factors that determine health (p. 76). In my research, I have considered "the economic and social conditions that shape the health of individuals, communities, and jurisdictions as a whole" (Raphael, 2007, p. 76).

The B.C. health care context.

In B.C., the Ministry of Health is responsible to provide leadership and set province-wide goals, standards, and expectations for health service delivery which in turn is primarily the responsibility of the province's six health authorities (MOH, 2012 February,

p. 6). The Ministry (2012 February) claims to enact its leadership role by funding transfers to the health authorities and developing legislation and social policy (pp. 6, 18) – including *Improving BC's Care for Persons with Dementia in Emergency Departments and Acute Care Hospitals* (2011), which I examine in my research. While the Provincial Health Services Authority is responsible for managing the quality and accessibility of services and province-wide health programs, the five regional health authorities deliver a range of health services within their respective geographic regions (MOH, 2012 February, p. 6). Locally, the five-year strategic plan for the Vancouver Island Health Authority (VIHA, 2009) in which I work states:

The most notable difference between VIHA's population and that of the rest of the province is age. An older population is one of the most significant challenges we face now, and will continue to face for at least the next twenty years. (p. 15)³

Furthermore, in its service plan, VIHA (2010) claims the “demand for health care services exceeds resources available” and that two of the four “most significant drivers of rising demand” are the aging population and the increasing need to provide care to the frail elderly (p. 2).

Although Canada does not have a coordinated “national strategy” for dementia care like England, Sweden, or more recently the United States (WHO & ADI, 2012, p. 34; U.S. Department HSS, 2012), reports like the RT are lobbying for one to address the “challenge of an aging population” and the related costs (Rockwood & Keren, 2010, pp. 879). Gee (2000) argues that the Canadian health care system is very expensive “despite, not because

³ On August 30, 2013, the Vancouver Island Health Authority (VIHA) announced that it would now be referred to as Island Health (VIHA, 2013, “Has your name changed,” para. 1). In my thesis, I cite the health authority according to how it is referenced in the particular document being referenced.

of, our demographics” (p. 20). She also notes that any attempts to reduce the costs of providing formal health care to the elderly will place an even greater burden on women who already are informally providing “the large bulk of health care to the elderly” (Gee, 2000, p. 20). That said, community care seems to be the way of the future for people living with dementia. For example, commenting on the current shortage of long-term care beds in Canada, Rockwood and Keren (2010) argue that “under no scenario” will enough new beds be provided to meet the predicted need of people living with dementia (p. 876). So unless ways to cure or prevent dementia are found, more care for severe dementia will occur in the community (Rockwood & Keren, 2010, p. 876), care which arguably will fall to families and women especially (Armstrong, 2012; Brodie, 2002). In the B.C. context, Cohen (2012) notes that “a decade of underfunding and restructuring has led to a home and community care system that is fragmented, confusing to navigate, and unable to meet seniors’ needs” (p. 5). Simultaneously, she observes media coverage continues to draw public attention to overcrowded hospitals and unacceptably long waitlists for emergency care and surgeries:

Taken together, these challenges can seem overwhelming, prompting dire warnings about the “financial sustainability” of Medicare, calls for private delivery of publicly-funded services, and fears that aging baby boomers are about to overwhelm the health care system, leaving few resources for younger British Columbians. (Cohen, 2012, p. 5)

Neoliberalism: The Political System Within Which the “Rising Tide” Discourse Appears

In order to better understand dominant discourses about dementia like the “rising tide” in the context of the RT and IBCC social policy documents, I consider briefly here the implications of the decline of the Canadian welfare state, and the contemporary neoliberal economic and political backdrop to the aforementioned examples of underfunding, restructuring, and calls for the privatization of health care. I examine this political context

to consider the power structures that influence and determine who will benefit from the use of the rising tide discourse – namely, as I will demonstrate, the corporate elite – and at what social cost. According to Baines (2011), neoliberalism is an approach to social, political, and economic life that discourages collective or government services while “encouraging reliance on the private market and individual skill to meet social needs,” which in the scope of social welfare has resulted in reduced funding for social programs, workplaces with fewer resources, and the incorporation of private sector management strategies (p. 30). These strategies include the prioritization of efficiency, competition, accountability through standardization, institutional need over human need, and profitability (Aronson & Smith, 2010, pp. 531, 538). And so, with the marketization of daily life, survival becomes an individual responsibility and “any form of dependence on the larger social fabric is removed” (Davies, 2005, as cited by Smith, 2011, p. 204).

Neoliberalism is rooted in classical liberalism which “saw government’s role as minimal, the market as the central determinant of social values, and the individual as the core unit of society,” and has the underlying goal to support a massive transfer of wealth and power to the corporate sector through the private accumulation of capital (Naiman, 2004, p. 215). As Naiman (2004) argues, the goal is to “create a lean state by privatization, contracting out, reducing state economic regulation, and slashing social welfare expenditures” (p. 216). Or, as Finkel (2006) more forcefully articulates, “the underlying argument of neo-liberalism was that Canadians had become too reliant on state handouts for their well-being and required the discipline of market forces to smarten them up” (p. 281). And so, like other welfare capitalist countries, Canada has engaged in neoliberal “reform” to reject the Keynesian welfare state and its social safety net by encouraging free-

market doctrines and practices (Naiman, 2004, p. 215; Aronson & Smith, 2010, p. 433; Brodie, 2002). The social safety net refers to federal and provincial social policy mechanisms established during the post-Second World War boom that intended to protect individuals from “the hazards of the inevitable ups and downs of the capitalist economy” (Silver, 2012, p. 112) and the “ubiquitous hazards of life” (MacGregor, 1999, p. 109) like illness and old age in order to prevent individual crisis and offer all citizens a certain level of well-being (Smith, 2011, p. 200).

Neoliberalism: Federally-speaking.

Neoliberalism has transformed the relationship between the federal state and the provinces. The once important role of the national government to protect Canada-wide social programs and ensure equity within the federation has been eroded, and provinces have more independence through which they may advance their own neoliberal agendas (Naiman, 2004, pp. 218, 219, 221). Such decentralization has also meant that the federal government has off-loaded the cost of social programs onto the provinces (Brodie, 2002, p. 103). The first neoliberal federal budget was introduced in the mid-1980s (Baines, 2008, p. 123). Since that time, federal cash transfers to the provinces for health care have been reduced, and for a period between 1996 and 2004 they were also combined with funding for post-secondary education and social assistance into a block payment called the Canada Health and Social Transfer (Brodie, 2002, pp. 104-105). This effectively worked to decrease federal responsibility in areas of provincial jurisdiction and made it difficult to determine just how much the federal government actually contributed to health care (Armstrong, 2012, p. 325; Finkel, 2006, p. 292). In 2004 health funding was once again provided separately as the Canada Health Transfer, and more recently, according to Armstrong

(2012), the federal government “significantly increased funding and suggested this new money go to several areas, including home care and wait times” (p. 325). Regrettably however, although provinces are required to report on their progress in these areas, “no enforcement mechanisms” are in place (Armstrong, 2012, p. 325).

Neoliberalism in B.C..

Until 2001, a social democratic government in B.C. tried to “respond to neoliberalism with moderate fiscal and social policies,” but then an “explicitly antiwelfare state, neoliberal government” was elected, which proceeded to implement the “deepest cuts to social programmes in Canada” (Baines, 2006, p. 22; see also Finkel, 2006, p. 308). Cohen (2012) states however, that in terms of expenditure, health care in B.C. has fared better than social service programs, and health spending actually increased slightly (p. 19). Compared to the rest of Canada, however, B.C. fell from the second highest level of health spending per capita in 2001 to the second lowest by 2011 (Cohen, 2012, p. 7). This is a result of restraint policies that reduced access to needed home and community services, and unfortunately, is not due to “genuine efficiencies” such as improved service integration or reduction in the ineffective and inappropriate use of emergency and hospital services (Cohen, 2012, p. 20). Furthermore, while examining the challenges in implementing individualized, person-centred dementia care practices in long-term care in B.C., Gnaedinger (2003) observes that health care practitioners’ workloads have increased steadily in recent decades because budgets are tighter for service delivery while simultaneously “residents’ average age at placement, level of acuity and complexity of care needs” have also increased significantly (pp. 362-363). I would also like to include Tanner’s (2011) work here. She writes from the perspective of a social worker in her analysis of

dementia care in the European Union where “dementia has been identified as a policy priority area” (Tanner, 2011, p. 1). While Tanner (2011) does not write about the Canadian context, she is one of the few authors to even cursorily refer specifically to dementia care in the context of neoliberal health care structures although she doesn’t name neoliberalism specifically. She argues:

At a time of major change and serious retrenchment in health and social services across Europe, the findings . . . are a salutary reminder of the time, energy, creativity, sensitivity, and advanced communication and interpersonal skills required if concepts of personhood and citizenship are to have meaning in social work practice with people with dementia. (Tanner, 2011, p. 12)

Neoliberal values appear at odds with the reality of implementing person and citizen-centred dementia care. Smith (2011) succinctly describes the institutionalized neoliberal processes in the aforementioned practice examples as the “intensified pressures to provide more with less” (p. 199).

Neoliberalism and the health care system.

I am mindful, however, that neoliberalism is “more than simply a set of economic principles” and goes far beyond dismantling health and social welfare such that the “market becomes the organizing principle for everything in our daily lives” (Smith, 2011, p. 204). The market has become a norm against which decisions and actions across the political and social spheres are measured to legitimize business approaches rather than care-based approaches (Smith, 2011, p. 204; Baines, 2011, p. 33). As Baines (2008) highlights, public social service organizations like health care operate on “nonmarket logics” and do not make a profit, but most have increasingly adopted “promarket approaches” (p. 124) that ground actions and policy decisions, as Smith (2011) similarly suggests, in considerations of commodification and profitability rather than moral or social

values (p. 199). For example, I see such neoliberal discourses echoed in the service plans of VIHA (2010) and the B.C. Ministry of Health (2012 February) which highlight the need to improve productivity, maximize efficiencies, and support “Lean Design” in health care as if it were a commercial commodity. Lean Design is a system design concept from auto manufacturing in Japan which is now applied to many other sectors including public health care:

One goal is to reduce waste and maximize value, and other goals include improving the quality of the design and reducing the time to achieve the final solution. . . . It relies on the definition and optimization of values coupled with the prevention of wastes before they enter the system. (Wikipedia, 2013, para. 1)

Thus, following this market-based logic and discourse, people living with dementia might be considered the so-called “waste” that needs to be removed from the hospital and health care system. This thought breaks my heart. McFadden and McFadden (2011) observe that dementia itself is also effectively commodified through the repeated refrain of how much it will cost the economy (p. 95). Following the ideologies of neoliberalism and also apocalyptic demography, the aging Canadian population is often constructed as a costly “major challenge to state welfare,” and the costs of seniors’ health care needs are seen as an “intolerable burden” (Wilson, 2006, p. 289). As a result, institutional needs, for example to balance budgets, become the focus over human needs and the right to health care (Aronson & Smith, 2010, p. 538). Overall, in the context of social policy, “neoliberalism discourages government programs and support, encouraging people to purchase care from private providers or turn to their families” (Baines, 2011, p. 30). For instance, Wilson (2006) argues, vis-à-vis her research on New Brunswick’s long-term care policies, that “this fear of unmanageable costs arising from population aging has been widely used as a justification

for restructuring,” reducing public services, and expanding privatization even though “the market for long-term care is a limited one at the best of times” (p. 289). Similarly, the B.C. government has implemented a process that requires all new publicly-funded residential care facilities to be tendered through a request for proposals which, according to Cohen, Tate, and Baumbusch (2009), “favours private corporations and a few large non-profits with the infrastructure to participate in the bidding process” (p. 7). As a result, most new residential care facilities are now private and for-profit. Furthermore, in 2002 the provincial government gave residential care employers “unlimited rights to contract out direct care and support services” (Cohen, Tate & Baumbusch, 2009, p. 7).

Armstrong (2012) indicates that the privatization of health care in Canada is demonstrated in multiple policy initiatives, beyond the above New Brunswick and B.C. long-term care examples, that “limit the role of the public sector and define health care as a private responsibility” (p. 321). Such initiatives include: opening health-service delivery to for-profit providers; shifting the burden of payment to individuals; transferring care work from public-sector health care workers to unpaid caregivers; and adopting the management strategies of private-sector businesses which means applying market rules to health service delivery as if health care were a market good (Armstrong, 2012, p. 321). She argues that “although there are those who openly promote privatization as a cure to what they define as a crisis [in health care]; a great deal of privatization is done by stealth and is absent from public debate” (Armstrong, 2012, p. 321). Brown (2014) similarly states that neoliberalism is “more termite-like than bear-like” in that it almost imperceptibly chews away, quietly destroying the foundations of the public sector. And just as the public realm is depoliticized in the neoliberal context (Aronson & Smith, 2010, p.531; Clarke, 2004;

McKeen, 2004), so is social policy debate and even the work of progressive advocacy groups by “inadvertently playing into neo-liberal agendas and, indeed, contributing to the further depoliticization of social policy” (McKeen, 2004, p. 88).

Neoliberalism and individual responsibility.

According to Lemke (2002), neoliberalism works by “shifting the responsibility for social risks such as illness, unemployment, poverty, etc. . . . into the domain for which the individual is responsible and transforming it into a problem of ‘self-care’” rather than a collective issue or state responsibility (p. 12). Drawing on the ideas of Ong (2006), Razack (2008) argues that “at the heart of neoliberalism is the idea and the practice of the exception, the notion that the government has the right to do anything in the interest of governance” (p. 11). Pratt (2005) comments on contemporary tendencies within neoliberalism “to judge moral worth in terms of self-care, such that a ‘mismanaged’ life is itself evidence of and grounds for abandonment” (p. 1055). “This logic lets governments retreat from social welfare obligations while simultaneously opening the door to the creeping advances of corporate interests and the imposition of new bottom-line calculations of what it means to care for others” (Smith, 2011, p. 198). Basically then, “disability and dementia become the problem of individuals and their families rather than a shared experience within the human community in which all participate” (McFadden & McFadden, 2011, p. 57). Drawing on the ideas of Foucault, Lemke (2002) further argues:

Discussion of neo-liberal governmentality shows that the so-called “retreat of the state” is in fact a prolongation of government, neo-liberalism is not the end but a transformation of politics, that restructures the power relations in society. What we observe today is not a diminishment or a reduction of state sovereignty and planning capacities but a displacement from formal to informal techniques of government. (p. 11)

The ideal neoliberal citizen is constructed as an entrepreneurial consumer-citizen (McCarthy, 2007, p. 25), who “carries the responsibilities for the consequences of his or her actions no matter how severe the structural constraints on this action” (Smith, 2011, p. 210). And, ultimately, the state is positioned to “[lead and control] subjects without being responsible for them” (Lemke, n.d., as cited in Brown, 2005, p. 43). Or as Davies, Browne, Gannon, Honan, and Somerville (2005) articulate, seeing something more sinister, “Neoliberalism is characterized by the ‘death of society’ and the rise of ‘individuals’ who are in need of a new kind of management, surveillance and control” (p. 344). Smith (2011) reminds us however that “neoliberalism is not simply imposed on us,” but requires our active, ongoing participation (p. 204). Wilson (2006) contends that we can choose “not to conform” and that neoliberal processes are “not monolithic” stating:

Global economic outcomes and financial beliefs are opposed by global ideologies of equal rights and citizenship. Global discourses of individual rights (for women, minorities and seniors among others) might be expected to strengthen citizenship entitlements, and to work against the financial and economic processes that increase individual inequalities. (p. 291)

Raphael (2007) calls on “agencies, organizations, and even government employees” to inform citizens about such “political and economic forces that shape the health of a society” (p. 88). Similarly, Clarke (2004) advocates for noticing resistances to neoliberal politics in social policy; he suggests that tracing the processes of neoliberalism, and also globalisation, “reveals that they have not been wholly successful – encountering resistances, refusals and negotiations that mean the outcomes (so far) do not match the world imagined in neoliberal fantasies” (p. 27). And so, in my research deconstructing dementia crisis discourses in Canadian social policy documents and a neoliberal political context, I too have made space for disruptive – solidaristic – “fantasies” that honour the voices of people living with

dementia, their needs, and humanity so that they, their families, and communities might thrive.

Purpose, Utility, and Social Justice

In considering possibilities for social justice for people living with dementia, I have drawn on Potts and Brown's (2005) definition of social justice as "transforming the way resources and relationships are produced and distributed so that all people can live dignified lives" (p. 284). My inquiry's political agenda is to hopefully help "impress on funding bodies and policy makers the importance of health related quality-of-life issues" (Todres, 2008, p. 1567). I feel though that I must account for my decision to examine discourse rather than the concrete redistribution of resources or practical dementia services. Marston (2004) argues that discourse must be understood as a "site of struggle" that is central to social policy change in contemporary welfare regimes (p. vi). In turn, social policy documents are one of the textualizations of such struggle between "differing discourses and ideologies contending and struggling for dominance" (Wodak & Meyer, 2009, p. 10) that reflect not only underlying social structures but also produce "the political parameters and social identities that are used to debate, develop and legitimate policy change" (Marston, 2004, p. 3). This has material implications including political choices and administrative decisions about the "appropriate division between public and private responsibility for our individual and collective wellbeing" (Marston, 2004, p. 1). However, just as the public realm has been depoliticized with the seemingly neutral language of neoliberal economic and managerial imperatives, as Marston (2004), Clarke (2004), and Aronson and Smith (2011) have articulated, social inquiry has also failed to give adequate attention to the discursive or "symbolic side of policy" (Marston, 2004, p. 1). For example,

“discursively, social policy and its implementation are rendered economic and technical matters, rather than contestable political questions” (Clarke & Newman, 1997, as cited in Aronson & Smith, 2010, p. 434). That said, however, dominant discourses in policy are contestable and I hope my research will contribute to efforts to “expand the social” (Newman, 2005, as cited in Aronson & Smith, 2011, p. 531) to disrupt neoliberal ideology that is penetrating the health care system, and advance progressive social policy agendas. I made a political choice to focus my thesis research on trying to complicate and better understand the present, local, discursive context in relation to dementia and dementia care social policy in complex multiplicity. Without this perspective, I cannot begin to articulate solidaristic alternatives that might begin to resist dominant discourses. As Todres (2008) articulates, researchers must “go beyond ourselves to be present to what is showing itself beyond that which we are constructing” (p. 1569) in order to:

... understand what it takes to change practice away from a “carrot and stick” culture that relies on targets and bottom lines to motivate change, to a culture of cooperative care that builds on practitioners’ existing heartfelt motivation for achieving quality of care. (p. 1567)

CHAPTER THREE: Research Design

Drawing on poststructural methodology, and particularly its conceptualizations of discourse, my thesis research approach is a Foucauldian-inspired discourse analysis, implementing both archaeological and genealogical methods. I also incorporate poetic representation, not for analysis per se, but as one way to share some of my findings.

Poststructural discourse analysis methods have supported me to explore, assess, and better understand how dominant discourses about dementia work in the two selected health policy documents and possibilities for resistance.

Rationale: Methodological Fit With Research Question

Sabat et al. (2011) state that “unlocking the potential of human beings who live with dementia rests, at one level, with a profound shift in public attitudes in order to . . . provide understanding of the (negative) power of language to define another person’s identity” (p. 291). In turn, I’d argue that the language used to describe people living with

dementia also impacts dementia policy and the dementia care a society provides. The ways we talk about dementia, specifically discursive practices in care settings, the media, and policy, matter (Hall, 2011). I believe that my research approach, drawing on Foucault’s archaeological and genealogical discourse analysis, rooted in poststructural methodology,

A Defining Moment: Archaeology, Genealogy, and Poetic Representation

I will elaborate on the differences between Foucault’s **archaeological** and **genealogical** approaches to discourse analysis in detail later. Briefly however, Foucault (1969/2011) defined an archaeological approach as describing the “group of rules proper to discursive practice” (p. 54), and a genealogical approach as examining “the effective formation of discourse” (Foucault, 1970/1981, p. 71). **Poetic representation** refers to a technique that involves writing found poetry using text from the policy documents under study.

has challenged me to disrupt taken for granted talk and discourses in the dementia policy documents. As Lahman et al. (2010) argue, this deconstructive approach to inquiry makes space “from which new meaning [can] emerge” (p. 40). My inquiry is both deconstructive by “disrupt[ing] and render[ing] problematic the themes, concepts and power relations embedded in everyday talk and writing,” and constructive by aiming “to expand people’s capacities to critique and analyze discourse and social relations, and allow a more equitable distribution of discursive resources” (Fairclough, 1992, as cited in Marston, 2004, p. 5). My goal is not to create a new dominant discourse, but to interrogate and complicate current discourse in an effort to make openings for alternatives. Overall, my methodology offers a way of “expanding the ‘social policy imaginary’” (Lewis, 2000, as cited in Marston, 2004, p. 2) vis-à-vis aging demographics and dementia care in Canada.

I have found only a few instances in the literature of poststructural discourse analysis methodology in dementia-related social science research. This reassures me there is much space for further, similar inquiry. For example, Adams (1998) writes from a clinical and practice perspective on mental health nursing, and although he does not explicitly present a discourse analysis, he does examine language and linguistic constructions of dementia and dementia care in the United Kingdom, particularly regarding community care policy. He draws attention to “the position of various family members in the provision of dementia care including the person with dementia” (Adams, 1998, p. 614). By examining a Department of Health social policy document entitled *Assessing Older People with Dementia Living with Dementia*, he observes that “‘partnership’ like the term ‘community care’, is an attractive word which suggests mutuality but makes no claims about the extent to which each party contributes to the provision of care or people’s position within the partnership”

(Adams, 1998, p. 615). Adams (1998) also refers to Kitwood (1993) who noted that nurses working in dementia care “are often placed in a conflict between two different discourses, the dominant medical discourse to which they are expected to adhere and what they know through experience” (p. 617). Secondly, Moran (2001) offers a very cursory discourse analysis in his consideration of three literary texts which present narratives about caring for a parent or spouse with dementia; he claims to place “the representation of dementing illnesses within a Foucauldian narrative of surveillance and control in the discourse of aging and death in modern Western societies” (p. 245). He observes overall that “because of the unspeakableness of dementia . . . The main characteristic of these narratives is therefore a real ambivalence in dealing with the awkward, unresolved issues surrounding dementing illnesses, in which both compassion and its limits are evident” (Moran, 2001, p. 259). Finally, Brinjath and Manderson (2008), while not using archaeological or genealogical discourse analysis specifically, draw on Foucauldian theory in their examination of representations of dementia in urban India, particularly in Indian-English media, clinical guidelines from the Indian Psychiatric Society, and a Bollywood film entitled *Black* (p. 608). Brinjath and Manderson (2008) are interested in considering the power relations in dementia care work in India, and state that “power relations are determined by three knowledge scripts— notions of acceptable public bodies, medical discourses of care and the individual context of the caregiver” (p. 622). Ultimately, they argue “the caregiver is the embodiment of these discourses and is charged with the task of mapping discipline onto inherently undisciplinable bodies” (Brinjath & Manderson, 2008, p. 607). From the above examples, it is clear that there is a fit between poststructural discourse analysis and questions about dementia care, and also plenty of room to build on these existing

explorations into popular culture and dementia care policies, both globally, and for the purpose of my study, more locally.

Poststructural methodology also asks that I be mindful of the ways I construct or present my research, which is why I have used poetic representation to display some of my findings. That is, in embracing poststructuralism, the necessarily uncertain researcher can appreciate her research is a mutable, sociohistorical construction (Richardson, 2000a, p. 5), and that it can blur positivist boundaries between literature and science in both the analysis and the writing up. Richardson and St. Pierre (2005) argue: “There is no such thing as ‘getting it right,’ only ‘getting it’ differently contoured and nuanced” (p. 962). Within a poststructural ontology then, Richardson (1993) argues that researchers are permitted, and in fact encouraged, “to doubt that any method of knowing or telling can claim authoritative truth. We have an historical opportunity to create a space for different kinds of science practice” (p. 706). I have done this in the writing up of my research. As Richardson (1997) declares, the production of research inquiry as “fields of play,” where writing genres – including academic texts like this thesis – are morphed and re-imagined, creates “new ways of reading/writing that are more congruent with poststructural understandings of the situated nature of knowledge making” (p. 3). It has been fun to dabble in the possibilities of considering my inquiry as “a social science art form” (Richardson & St. Pierre, 2005, p. 965) by writing and integrating found poetry from the text of the IBCC and RT policy documents. This has made space for my researcher self as bricoleur (St. Pierre, 2000, p. 507) – or ‘Jill of all trades’ who creates with whatever materials are at hand and with all the situatedness I bring (foibles, eclectic curiosities, and

hopefully some tools too) – to delve into issues around dementia care that matter both personally and collectively with open-mindedness, joy, and poetics.

Poststructural Methodology

In my research based in poststructural methodology, and particularly in Foucauldian interpretations, I have considered discourse and the materiality of discourse vis-à-vis the RT and IBCC policy documents; discourse and the politics of truth; and the often invisible, but nonetheless thwartable, power of discourse.

Materiality of discourse.

To begin, according to the poststructural ideas of Foucault, discourses are conceptualized as systems of power/knowledge where “knowledge both constitutes and is constituted through discourse as an effect of power” (Carabine, 2001, p. 275). Foucault (1975/1995) states that:

Power produces knowledge . . . that power and knowledge directly imply one another; that there is no power relation without the correlative constitution of a field of knowledge, not any knowledge that does not presuppose and constitute at the same time power relations. (p. 27)

Discourses are understood to be “structures of knowledge and systematic ways of *carving out reality* that characterize particular historical moments” (Chambon et al., 1999, p. 272, emphasis added). Discourses “have outcomes/identifiable effects which specify what is morally, socially and legally un/acceptable at any given moment in time” (Carabine, 2001, p. 274). More specifically, a discourse can be understood to include a group of statements – textual, spoken, visual, symbolic, and beyond – that appear consistently together (e.g. “rising tide” and “dementia”) following a certain type of rationality and ruling in a specific social and cultural context (Chambon et al., 1999, p. 272). Foucault (1969/2011) defines a “statement” as a building block belonging to a discursive formation just as a “sentence

belongs to a text” (p. 130). It is important to note that “within a Foucauldian viewpoint discourse may include, but is not reducible to, language” (Garrity, 2010, p. 196). Discourse, including language, does not simply reflect social reality, but rather produces it (Richardson & St. Pierre, 2005, p. 961). Foucault (1970/1981) has similarly stated that the production of discourse has “ponderous, formidable *materiality*” (p. 52, emphasis added) such that “no statement can be regarded as inactive . . . the least statement – the most discreet or the most banal – puts into operation a whole set of rules” (Foucault, 1969/2011, p. 163). In turn, discourses can be understood as “practices that systematically form the objects of which they speak” (Foucault, 1969/2011, p. 54). And so, social order is produced and reproduced by language, which is an exercise of power or a site of struggle between competing discourses (Richardson & St. Pierre, 2005, p. 961). Through discourse, “consent is achieved, ideologies are transmitted, and practices, meanings, values and identities are taught and learnt” (Fairclough, 1995, as cited in Marston, 2004, p. 1).

Discourse and the politics of truth.

Foucault (1980) also argues that while discourse produces knowledge and power, some discourses are positioned as more powerful than others: “Each society has its régime of truth, its ‘general politics’ of truth: that is, the types of discourse which it accepts and makes function as true” (p. 131). From this perspective, the way in which dominant discourse comes to present an issue such as dementia reflects the commonsense assumptions about the issue at hand, and also the *truth* about how it will be addressed (Dietz, 2000, as cited in Dewees, 2004, p. 348). Such hegemony – “the dominant discourse that shapes and reminds us of the views that we are supposed to hold” (Evans & Swift, 2000, p. 74) – asserts control not by force or coercion, but through consent (Fairclough,

2001, p. 232). In this way hegemony subverts “competing discourses in the interest of building consent for a single articulation of the social” (Marston, 2004, p. 47). That said, Foucault (1970/1981) warns against seeing discourses as essential or absolute: “We must not imagine that there is a great unsaid or a great unthought which runs throughout the world and intertwines with all its forms and all its events . . . Discourses must be treated as discontinuous practices” (p. 67). As an example, Chouliaraki and Fairclough (1999) argue that a state of hegemony for a market discourse is not an arbitrary reflection of economic realities, but a particular construction of them serving particular economic interests (p. 5).

Power within discourses and resistance.

However, while discourse is an inherent part of society implicated in social injustices and the struggles against them (van Dijk, 1997, as cited in Hastings, 2000), the power within discourses often “remains largely invisible” considering its taken-for-granted or normative nature (Wodak & Meyer, 2009, p. 10). As Brodie (2002) articulates, neoliberal-informed changes to the welfare state and health care in Canada, such as managerial structures, retrenchment of public services, marketization, privatization, decentralization, and so on, have been “accomplished largely, often insidiously, at the level of discourse and the way we come to understand the state, the public sphere, and our relationships to them” (p. 90). Foucault (1978/1990) contends, though, that discourses are not monolithic and that through reflection and political critique discourses can be rendered fragile and even thwartable:

We must make allowance for the complex and unstable process whereby discourse can be both an instrument and an effect of power, but also a hindrance, a stumbling-block, a point of resistance and a starting point for an opposing strategy. (p. 101)

According to Chambon (1999), Foucault's ideas suggest that "transformative work shows the present is not natural and need not be taken as inevitable or absolute. Change can come from the realization of the precarious nature of established ways and by inviting the development of alternatives" (p. 70). hooks (2003) cautions me that trying to address power while working towards social change "requires a commitment to complex analysis and the letting go of wanting everything to be simple. Segregation simplifies; integration requires that we come to terms with multiple ways of knowing, of interaction" (p. 78). Poststructural methodology supports possibilities for such multiplicity in truths and discourse by recognizing all knowledge as partial, local, and historical, and acknowledging the "situational limitations of the knower" (Richardson & St. Pierre, 2005, p. 961). Similarly, Strega (2004) states that poststructuralist researchers go beyond examining a specific discourse to consider "the all-encompassing nature of discourse, as the constructor and constituter of not just 'reality' but also of our 'selves'" (p. 54). So how am I complicit in perpetuating dominant dementia discourses? How does my research make space for disruptive and marginalized discourses? And if, as Fairclough (2003) suggests, discourses include not only representations of how things are and have been, but also "imaginaries – representations of how things might or could or should be" (p. 207), what imaginaries appear in these social policy documents?

Data Collection

The data for my inquiry consist of two dementia policy documents (Appendix B). The first has garnered significant ongoing academic, media, and political attention across Canada, while the second has been promoted by the British Columbia government as being key to framing acute care dementia practice in this province. The first policy document I

selected is the study entitled *Rising Tide: The Impact of Dementia on Canadian Society* (2010). The RT study was commissioned by the Alzheimer Society of Canada, a national dementia charity, and funded by the Canadian Institutes of Health Research, the Public Health Agency of Canada, Health Canada, Pfizer Canada, and Canada's Research-Based Pharmaceutical Companies (Rx& D) to make recommendations to the federal and provincial governments (ASC, 2010b, p. 1). Its publication sparked my interest in deconstructing dominant, crisis-based dementia discourses. The study also attracted considerable attention beyond my own critique and concern. For instance, the RT report has been multiply referenced in Canadian academic literature including that of Rockwood and Keren (2010) in the *International Journal of Geriatric Psychiatry*; Roger, Guse, Mordoch, and Osterreicher (2012) in the *Canadian Journal on Aging*; Schroeder, MacDonald, and Shamian (2012) in *Ageing International*; Estabrooks et al. (2011) in *BMC Medical Research Methodology*; Kondro (2010) in the *Canadian Medical Association Journal*; and Parke et al. (2012) in *Dementia*. Additionally, the report "made headlines across the country" (McMartin, 2010, p. A4) from national newspapers like the *National Post* (Duffy, 2010) and the *Globe and Mail* (Picard, 2010), to those in B.C. such as *The Province* (O'Connor, 2011) and the *Times-Colonist* (McCulloch, 2010). Furthermore, on the release of new dementia policy documents, the RT seems to keep resurfacing in the media. For example, when the World Health Organization and Alzheimer's Disease International recently published the report *Dementia: A public health priority* examining dementia globally, CTV News (2012) referenced the Canadian RT study in its news coverage.

As well, there is evidence that the Alzheimer Society of Canada and its provincial societies have been actively distributing the RT report to Canadian politicians. For instance,

the CEO of the Alzheimer Society of Saskatchewan stated: “I’ve presented it to the Minister of Health and I’ve just sent it out to every regional health authority, their CEO and their boards of directors” (as cited in Cowan, 2011, p. A8). Since the release of the RT in 2010, two opposition Members of Parliament have brought forward private members’ bills referencing the report. The first sought to “continue the fight against dementia” by establishing a national Alzheimer’s office within the Public Health Agency of Canada (Bill C-609, June 2010) (Government of Canada, 2010; ASC, 2011, p. 4), and the second hoped to introduce a *National Strategy for Dementia Act* (Bill C-356, November 2011) (Government of Canada, 2011; NDP, 2011).

In selecting my second policy document, I sought a text that frames provincial dementia care practice. To do so I solicited recommendations from staff at both the B.C. Ministry of Health and Island Health, as well as researchers in the B.C. dementia policy field, to determine influential and recent policy that is framing the direction of dementia care in the province. From the multiple policy documents that were mentioned related to aging, dementia, seniors, and health care in B.C. (Appendix C), I selected *Improving BC’s Care for Persons with Dementia in Emergency Departments and Acute Care Hospitals: Findings and Recommendations* (2011), which was produced by an advisory committee including many B.C. Ministry of Health and health authority staff. I chose it for many reasons. Firstly, unlike many of the other B.C. policy documents, but like the RT document, the IBCC text focuses specifically on dementia and dementia care which is the main scope of my inquiry. The IBCC policy is listed as a key accomplishment on the provincial “Families and Residents” webpage entitled “What we’ve done” regarding seniors under the topic of dementia (Province of British Columbia, 2013). As discussed in the introduction, the IBCC

report also provides an analysis of two particularly expensive and contested sites in contemporary health care vis-à-vis dementia, namely emergency and acute care. For instance, noting the 2012 annual report card released by the Wait Time Alliance, formed out of concern among Canada's doctors over delayed access to care for patients (Wait Time Alliance, 2008, para. 1), clearly the examination of discourses in policy documents related to dementia care in these settings is relevant and timely. More specifically, in the report card's analysis of wait times in the health care system, dementia is singled out for plugging up acute care such that even the Wait Time Alliance (2012) calls for:

... a national strategy to deal with illnesses such as Alzheimer's disease and to factor dementia into the management of other chronic diseases such as heart disease and diabetes. Doing so could help prevent those patients from ending up in hospitals in the first place. ... patients with dementia often go to hospital because of conditions like pneumonia or heart failure but destabilize in hospitals and can't be discharged home. ... "Right across the country, this is a systemic problem that all facilities, all institutions have," ... "It's a problem that's not getting better." (as cited by CBC News, 2012)

Finally, the IBCC report provides a contrast to the statistical and risk management emphasis of the RT study by drawing on a literature review and multiple focus groups that consulted with families and health care providers alike. Both policy documents are available to the public online and I printed hard copies for reading and re-reading, as well as for marking up with notes in the data analysis process.

I would like to note that two additional provincial dementia policy documents were released recently – namely, in October 2012, the *Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care* [BPSD], and, in late November 2012, *The Provincial Dementia Action Plan for British Columbia: Priorities and Actions for Health System and Service Redesign* [PDAP]. The BPSD

text claims to offer guidelines and an algorithm with “evidence-based tips and tools to deliver best practice, non-pharmacological approaches to person-centred dementia care” (MOH, 2012 October, p. 3). The algorithm is a nursing tool regarding the use of antipsychotic medications in the dementia context. The PDAP “outlines province wide priorities for improved dementia care through health system and service redesign work currently underway in British Columbia” (MOH, 2012 November, p. 4). The 24-page document presents a lot of general information about dementia and many full-page photographs, but the three priorities and actions of the actual “plan” are stated in a mere one and a half pages of text: support prevention and early intervention; ensure quality person-centred dementia care; and strengthen system capacity and accountability (MOH, 2012 November, pp. 18-19). The PDAP was released without fanfare or a commitment of funding, and, as far as I can see to date, has received virtually no media attention. Overall, the IBCC policy document stands out as an important policy at the provincial level that is thorough and specific in its approach, and concretely relevant to health care dementia practice.

Data Analysis Method: Poststructural Discourse Analysis With a Bike and Foucault’s Tools

Potter and Wetherell (1987) warn that the “analysis of discourse is like riding a bicycle compared to conducting experiments or analysing survey data which resemble baking cakes from a recipe” (p. 168). Discourse analysis, then, requires intuition, flexibility, and an iterative process. Similarly, Nicholls (2009) argues that, when embracing poststructural Foucauldian principles, researchers must resist “the trap of formalizing an approach that clearly eschews formalization” (p. 31). So in the spirit of presenting at least the rough map my poststructural bike ride took through the neighbourhood of data

analysis, I would like to share my somewhat-formalized-yet-not-formalized plan that had me moving back and forth throughout the research process and between the data (two policy documents), my literature review, found poems from the data, and my developing Foucauldian discourse analysis using archaeological and genealogical tools. Please note that this also included a rainbow of highlighters and sticky notes, and many unexpected analytic places and activities. That is, I followed St. Pierre (2011) who encourages her students to “explain what they did when they thought they were ‘doing analysis’” (p. 622). She reports that:

They describe a multitude of activities – washing the car and weeding the garden (*the physicality of theorizing*), making charts and webs, talking with friends, writing, listening to music, reading transcripts, reading more theory, dozing on the couch, and so forth. (St. Pierre, 2011, p. 622, emphasis in original)

And so quite naturally, perhaps, my analysis pattered endlessly in my intellectual and somatic self whether I was actively studying or not, and became enmeshed in my activities of daily life. Some of my best “a-ha!” data analysis moments occurred while riding my bike, literally, up and down the hill on Foul Bay Road to and from the university library. Inexplicably, activities like doing the dishes, or driving our family’s guinea pigs to the vet were also fruitful.

Journal Entry June 5

Swam in the outdoor pool at the university early this morning before heading to the library. Sky, planes, seagulls, sunshine . . . opening my shoulders and mind to read policies and just be gently curious.

Journal Entry September 6

I rode my bike up to the university library this fall morning, and, by the time I got here, the fog had actually collected on my sleeves making me look like I’d been through a lint machine. The material effects of fog which usually seems so intangible. A fitting metaphor for dominant discourse too.

Journal Entry September 25

Crisp, sunny morning. Riding up today, it suddenly occurred to me that the policies offer care, but with exceptions. Concern laced with fear; care with exclusion.

Next I will define my understanding of Foucault's archaeological and genealogical methods for discourse analysis.

The tool box: Archaeology of knowledge and genealogy of power/knowledge relations.

Foucault (1974) offered that his books be considered "a kind of tool box which others can rummage through to find a tool which they can use however they wish in their own area" (as cited in O'Farrell, 2005, p. 50). He stated that he wrote "for users, not readers" (Foucault, 1974, as cited in O'Farrell, 2005, p. 50). So, as a "user" who is definitely a rummaging bricoleur always open to a good deal and hard-working equipment, I grabbed into Foucault's discourse analysis tool box. I first wanted to take pause to notice and describe the dominant discourses as they appear in the RT and IBCC policy documents, and secondly I wished to consider the materiality of these discourses or what they do. I wanted to explore how these discursive regimes work to produce ways of thinking about people living with dementia and their needs at this particular time, and what counter-discourses appear in resistance. To this end, I implemented aspects of Foucault's archaeology and genealogy to complete a history – or problematization – of the present (Koopman, 2013, p. 17). In a nutshell, Foucault (1969/2011) defined an archaeological approach to discourse analysis as describing the "group of rules proper to discursive practice" (p. 54), and a genealogical approach as examining "the effective formation of discourse" (Foucault, 1970/1981, p. 71). Foucault's archaeologies and genealogies span a prolific body of his writing and lectures, and the scholarly debate on their purposes, similarities, and differences is rich, to say the least. For example, O'Farrell (2005) notes that "the difference between archaeology and genealogy [is] generally rather vague and confusing" (p. 129), while Stevenson and Cutcliffe (2006) observe that "Foucault's position is notoriously

difficult to pigeon hole” (p. 714). Scheurich and McKenzie (2005) contend that “archaeology and genealogy are much less different than is often assumed” (p. 858), and Koopman (2008) suggests that Foucault’s “mid-career historiographical shift” is best considered an “expansion” that invokes both genealogy and archaeology (p. 338). Visker (2008) observes that his two methodologies present similar topics, just from different positions (pp. 9-10). Foucault (1971/1986) himself argues that archaeology and genealogy are intertwined discourse analysis methodologies with similar objectives, but different approaches: “The difference between the critical [archaeological] and the genealogical enterprise is not one of object or field, but of point of attack, perspective and delimitation” (p. 161). To complicate things, Foucault also refers to his archaeological discourse analysis as critical analysis (White, 2009, p. 319).

I have considered academic literature from a variety of disciplines – including philosophy, nursing, and photography – to try to make some sense of this debate. Generally, there seems to be agreement that Foucault’s earlier works represent his archaeological methodology in the 1960s, including *The History of Madness* (1961), *The Birth of the Clinic* (1963), *The Order of Things* (1966), and *The Archaeology of Knowledge* (1969), whereas his genealogies came later in the 1970s, including “Nietzsche, Genealogy, History” (1971), *Discipline and Punish* (1975), and *History of Sexuality* (1976 & 1984). In a transitional piece entitled the *Order of Discourse* (1971), as well as a collection of lectures from 1973 to 1974 published recently as *Psychiatric Power*, Foucault explored his two methodologies and the emergence of his genealogical project (White, 2009, p. 318). Scholars have deliberated on the respective value of one of these methodologies over the other and vice-versa. For instance, Visker (2008) argues that “archaeology is the more attractive one” (p. 13),

whereas Habermas (1987) contends that Foucault “*subordinates* the archeology of knowledge to the genealogy that explains the emergence of knowledge from practices of power” (p. 268, emphasis in original).

Nonetheless, the bricoleur in me sees value in both and also that the two are interconnected projects which support my research. For instance, as Koopman (2008) articulates, Foucault’s archaeological analysis of discourse describes the structures of a momentary slice of knowledge or a system of thought (e.g. about people with dementia) by examining an historical archive of the present (e.g. contemporary dementia policy documents in my case) and the existence of a particular historical rupture (e.g. the rising tide or crisis discourses) (p. 355). Similarly, Habermas (1987) suggests that archaeology metaphorically examines a frozen iceberg in complex detail: “Under the *stoic* gaze of the archeologist, history hardens into an iceberg covered with the crystalline forms of arbitrary formations of discourse” (p. 253, emphasis in original). Overall then, archaeology offers a “descriptive picture of the ways in which statements about a problem [dementia, for instance] are regulated” (Stevenson & Cutcliffe, 2006, p. 715). However, archaeological analysis does not attempt to explain the “causes of the transition from one way of thinking to another” (Gutting, 2012, “3.2 Archaeology and Genealogy,” para. 2). With genealogy, though, my understanding is that Foucault brings his concepts of power/knowledge, power relations, and the productivity of power to his analysis while still looking at documentary evidence; he considers “where the grounds of the true and false come to be distinguished via mechanisms of power” (O’Farrell, 2005, p. 69). In this way, as Habermas (1987) states, the metaphorical iceberg “begins to move” (p. 253). Or, as Kendall and Wickham (1999) state, “genealogy is not so much a method as a way of putting archaeology to work, a way of

linking it to our present concerns” (p. 31). The objects of genealogical analysis are seen as being in “continuous change” which offers a lens of transformative and political possibility to the analysis of discourse (Koopman, 2008, p. 357). With genealogy we see that power is productive and consider the “interaction between power and knowledge” (Koopman, 2008, p. 343). While examining the RT and IBCC policy documents, genealogy supported me to ponder the ways the present system of knowledge or thought about dementia is productive and the nature of its appeal. Overall then, archaeology describes the rules that organize the statements of a discourse, and genealogy, in turn, describes the process by which these rules are enacted (Stevenson & Cutcliffe, 2006, p. 715). According to Foucault (1971/1986), his two methodological approaches to discourse analysis “alternate, support, and complete each other” (p. 162). He stated, “in truth these two tasks are never completely separable” (Foucault, 1970/1981, p. 71). Now, just what did I do with this pair of interconnected methodological tools?

Doing archaeological analysis.

In his book *The Archaeology of Knowledge*, Foucault (1969/2011) states that an archaeological approach to discourse analysis attempts to “reveal discursive practices in their complexity and density; to show that to speak is to *do* something – something other than to express what one thinks” (p. 230, emphasis added). He argues:

In analysing discourses themselves, one sees the loosening of the embrace, apparently so tight, of words and things, and the emergence of a group of rules proper to discursive practice. These rules define not the dumb existence of a reality, . . . but the ordering of objects. (Foucault, 1969/2011, p. 54)

He suggests an analytical process that tries to unpick the “systems that envelop discourse” and “grasp” the ordering or sanctioning of discourse (Foucault, 1970/1981, p. 73). An

archaeological lens to discourse analysis, then, “aims to *describe* discursive formations rather than to interpret them or look for a meaning beyond them” (Garrity, 2010, p. 201, emphasis in original). More specifically, the goal is to describe “an institutional field, a set of events, practices and political decisions” (Foucault, 1969/2011, p. 174) and to notice relations between “discursive formations and non-discursive domains” (Foucault, 1969/2011, pp. 179-80). This required me to describe the dementia discourses I examined within their broader contexts, in their plurality and specificity, and as set out in my literature review, “to show in what way the set of rules that they put into operation is irreducible to any other” (Foucault, 1969/2011, p. 155). What conditions make the discourse possible? This portion of my analysis of the RT and IBCC policy documents tried to notice and describe the dominant dementia discourses in and of themselves, not what they represent.

Archaeologically-inspired questions I asked during analysis.

- Which statements about dementia and people living with dementia make up the dominant discourses in the two policy documents?
- What are the relationships and connections between these statements? This includes analysing “the specificity, functions and network of dependences of a discourse and between discourses” (Foucault, 1969/2011, p. 214).
- What are the rules and conditions for these statements and discourses about dementia?

For instance, Foucault (1969/2011) argues that:

The unity of discourse on madness would not be based upon the existence of the object ‘madness’, or the constitution of a single horizon of objectivity; *it would be the interplay of the rules that make possible the appearance of objects during a given period of time.* (p. 36, emphasis added)

Furthermore, Foucault (1970/1981) considers exteriority stating “we must not go from discourse towards its interior, hidden nucleus, towards the heart of a thought or a signification supposed to be manifested in it; but . . . go towards its external conditions of possibility” (p. 67). What discursive practices, the “historically and culturally specific set of rules for organizing and producing different forms of knowledge [about dementia],” allow certain statements to be made (O’Farrell, 2005, p. 134)?

- What contradictions appear in the statements about dementia? As Foucault (1969/2011) states in the *Archaeology of Knowledge*:

To analyse discourse is to hide and reveal contradictions; it is to show the play that they set up within it; . . . For archaeological analysis, contradictions are neither appearances to be overcome, nor secret principles to be uncovered. *They are objects to be described for themselves.* (pp. 168-69, emphasis added)

For example, in his inquiry into the history of madness – which I believe is relevant to the discussion of dementia – Foucault (1970/1981) describes contradictions:

Since the depths of the Middle Ages, the madman [*sic*] has been the one whose discourse cannot have the same currency as others. . . . It is curious to note that for centuries in Europe the speech of the madman was either not heard at all or else taken for the word of truth. It either fell into the void, being rejected as soon as it was proffered, or else people deciphered in it a rationality, naïve or crafty, which they regarded as more rational than that of the sane. (p. 53)

Doing genealogical analysis.

While my archaeological analysis describes the statements of the dominant dementia discourses and their conditions of possibility, my genealogical analysis considers the ways these discourses are “produced, sustained, and revised over the course of a particular historical period” (Koopman, 2008, p. 362). Genealogy offers a tool to “rethink and call into question the given truths of our world” (Tamboukou, 1999, p. 208) by being

“attentive to details, many of them having remained unnoticed and recorded in the narratives of mainstream history” (Tamboukou, 1999, p. 207). Koopman (2013) states:

Genealogies are concerned . . . with submerged problems. The problems of genealogy are those problems found below the surfaces of our lives – the problems whose itches feel impenetrable, whose remedies are ever just beyond our grasp, and whose very articulations require a severe work of thought. (p. 1)

The analysis considers “what facts are regarded as uncontroversial and what discourse types are represented as ‘commonsense’” (Marston, 2004, p. 87). It also notices how discourses hook into normative ideas, which in turn produce “shortcut paths” into ideas that convey messages about the issue at hand (Carabine, 2001, p. 269). While Foucault’s (1980) genealogies reveal a “thoroughly heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements, philosophical, moral and philanthropic propositions – in short, the said as much as the unsaid” (p. 194), my genealogical analysis is much smaller in its scope.

In addition to accounting for the ways dementia discourses and knowledges – *truths* – are produced in the RT and IBCC policy documents, I also drew on the genealogical concept that considers “the constitution of the subject within a historical framework” (Foucault, 1980, p. 117). I considered the constitution of subjectivities, particularly for persons with dementia, family and friend caregivers, health care practitioners, and persons who do not have dementia (i.e. the ideal, healthy, homo economicus citizen) (Brown, 2005, p. 40). According to Chambon (1999), poststructuralism rejects the humanist notion of an essential self and tries to locate the individual subject within cultural and institutional systems of power (p. 59). That is, the subject is not seen as a “primitive atom,” but as “an effect of power,” and subjectivity is the way individuals perceive and understand

themselves in relation to the world (Mansfield, 2000, p. 54). Tamboukou (1999) states that genealogy starts “with a major interrogation of what has been accepted as the ‘truth’, any truth concerning the ways individuals understand themselves as subjects of this world” (p. 214). Subjectivity, then, is considered to be fluid and contradictory, continually being reconstituted through action, speaking, and thinking (Davies, 2000, p. 57). As Mills (2004) states, “discourses structure both our sense of reality and our notion of our own identity” (p. 15). When engaging with the IBCC and RT dementia policy documents, genealogical analysis required me to look for discursive strategies or the ways the dominant discourse was deployed and “given meaning and force, and through which its object is defined. It [*sic*] a device through which knowledge about the object is developed and the subject constituted” (Carabine, 2001, p. 288).

Genealogically-inspired questions I asked during analysis.

- How is power/knowledge constituted through discourse? That is, how are the dementia discourses productive?
- How are the rules of the dominant dementia discourses in the policy documents enacted? What practices, procedures, and institutions support this? “Which kinds of practices tied to which kinds of external conditions determine the different knowledges” (Tamboukou, 1999, p. 202)?
- What pictures of people living with dementia and their needs are produced in the RT and IBCC policy documents? What subjectivities are offered and how are these positioned? What do these tell people who do not have dementia? How might these subjectivities inform caregivers, health care practitioners, etc.?

- What is presented as truth about dementia and people living with it? What is at stake?

“Truth, genealogy teaches us, is never neutral, what counts as truth and claims to be above the parties, is always the result of a battle in which those who are slain, lose the right to speech” (Visker, 2008, p. 12). Genealogy involves:

... spotting contingencies, rather than accepting accepted wisdom in the form of causal explanations, especially those who hold power would prefer to forget ... Foucault’s (1975) research in ‘Discipline and Punish’ ... highlighted that the impetus towards a science of madness was filling the empty leper houses rather than a particular concern with the welfare of the ‘mad’ that is often presented in official histories. (Stevenson & Cutcliffe, 2006, p. 715)

- How is dementia constructed, or not, as a social problem? How is it framed and what solutions are proposed?
- What about resistance and counter-discourse? Genealogy attempts to trace:

... possible ways of thinking differently, instead of accepting and legitimating what are already the ‘truths’ of our world. The aim is to provide a counter-memory that will help subjects recreate the historical and practical conditions of their present existence ... opening possibilities for life. (Tamboukou, 1999, p. 203)

Writing Up: Sharing My Analysis With Poetic Representation

It’s a way of reframing an either/or perspective into one of both/and, of moving from dichotomous thinking to more divergent thought. It’s the transition from sauntering along dirt roads without thinking about one’s feet to the hop-swing on crutches where no movement is taken for granted. (Glesne, 1997, p. 206)

While the majority of my findings are written up in a fairly straight-up academic prose style, I chose to ‘think about my feet’ metaphorically in sharing my research process (which is particularly relevant to me given a back injury that delayed my research and asked me to be mindful of my body in new ways). And so, I implemented poetic

representation – specifically in the writing of found poems – as a way to share my discourse analysis of the two selected policy documents.

Defining poetic representation as writing found poems from policy documents.

Prendergast (2006) argues that “found poetry has a long history of practice in poetry as the imaginative appropriation and reconstruction of already-existing texts” (p. 369). More recently in the social science research context, found poetry has been referred to variously as poetic representation (Richardson, 1992), archival poetry (Lahman, 2011), and poetic transcription (Glesne, 1997), and it has been used to create “poemlike compositions” (Glesne, 1997, p. 202) from research data including interviews (Richardson, 1997; Glesne, 1997), newspaper articles (Lahman, 2011, p. 126), and academic literature (Prendergast, 2006). For my project, using actual text from the RT and IBCC dementia policy documents, I produced found poems to offer an additional, and hopefully evocative and accessible, view into the dementia discourses in the texts and the ways they construct people living with dementia and dementia care. These poetic constructions serve as bracketed “interludes” of sorts within my thesis text (Prendergast, 2006, p. 369). While overall such poetic representations of the content of the two dementia policy documents forms only a small portion of my research writing, I will now provide a solid philosophical rationale for its inclusion in my project, as well as the more technical details of how it infuses my thesis.

According to Leavy (2009), “the representation of the data in poetic form is not simply an alternative way of presenting the same information; rather, it can help the researcher evoke different meanings from the data” (p. 64). It is my hope that the inclusion of found poems from the RT and IBCC policy documents supports a creative engagement

with what might be seen as rather dry texts, but which I think are very powerful texts contributing to the future of dementia care in this province. In some ways including found poetry to present my findings is also a “pragmatic [decision] about how to present the large amount of data and construct the research text” (Ward, 2011, p. 357), and “a way of representing holistically what otherwise might go unnoticed” (Butler-Kisber, 2002, p. 5). In this way, poetic representation through found poems provides “a way to attempt to express the inexpressible” (Lahman, 2011, p. 129), and allows “the heart to lead the mind rather than the reverse” (Butler-Kisber & Stewart, 2009, p. 3). This strategy, states Butler-Kisber (2002), has the potential to “pull the reader/viewer into a world that is recognizable enough to be credible, but ambiguous enough to allow new insights and meanings to emerge” (p.1). As a bricoleur researcher, I am inspired by Lahman et al. (2011) who advocate for poetic “poking around” or “play[ing] . . . with words instead of being asked for ‘poetic credential’” so that researchers might be encouraged to experiment and take risks: “Poking around is one way that we all naturally learn something new” (p. 895). Hopefully my cobbling together of found poems offers “an opening, a clearing in the woods of research regularities” (Glesne, 1997, p. 218) and has brought me “closer to the data in different and sometimes unusual ways” (Butler-Kisber, 2002, p. 6). Finally, writing up my research at least partially with found poems helps highlight my role in the production of the research text, both for myself and the reader: “Representing the sociological as poetry is one way of decentering the unreflexive ‘self’ to create a position for experiencing the self as a sociological knower/constructor – not just talking about it, but *doing it*” (Richardson, 1992, p. 136, emphasis added).

Doing poetic representation.

This brings me to a discussion of how-to-do-found-research-poems. I kept the poetic process wide-open and drew on the experiences and tips of other poetic researchers. First, I followed “a free style format” (Lahman et al., 2011, p. 889) in compiling the found poems, while also recognizing the beneficial limits of writing found poems especially for the new poststructural researcher:

Because it relies on the words found in the data, found poetry is restricting. However, those limits can be comforting because the researcher is not compelled to find the ‘perfect word’ but rather plays with the existing words in ways that most closely portray a particular story and its emotional nuances. (Butler-Kisber & Stewart, 2009, p. 3)

To begin, I read and re-read the IBCC and RT policy documents highlighting the “most salient moments” while also trying to “retain the voice” of the texts (Lahman, 2011, p. 128). I used actual words from the policy texts, but like Lahman (2011) took “great liberty in rearranging phrases, use of punctuation, and poetry line” (p. 128). Or as Glesne (1997) models, I gave myself permission to further “convey the emotions that the interviews [policy documents] evoked in me” by perhaps repeating words, adding words, dropping or adding word endings, or changing verb tenses (p. 206). I acknowledge that overall this was a largely intuitive process of “sifting through data” (Prendergast, 2006, p. 370).

Summary of Research Process: Data Immersion and Data Analysis

As I embarked on a poststructural approach to discourse analysis, drawing on Foucault's conceptual tools of archaeology and genealogy, I applied an iterative process to data immersion, poetic representation, and data analysis. I began by reading the IBCC and RT policy documents through in completion while making copious notes, ponderings, and observations on copies of the texts themselves, and journaling in a computer document about initial issues that popped out at me while resisting the urge to analyse. In my original thesis proposal, I had not explicitly planned on journaling, but as I explored the nooks and crannies of the policy documents, I felt a need to store early impressions and pre-baked ideas in an informal and efficient way to let my thoughts flow onto paper without judgement, a need to know, or even deep thought. Clearly, just as Taylor (2001) reminds me, the nature of data immersion and even analysis is "relatively open-ended" such that the:

Journal Entry June 3

I attended a talk by Joy Kogawa this morning. She reflected on her novel *Obasan* and how the Canadian government and society interned Japanese Canadians during WWII. Hmm . . . these thematics of exclusion and exception. I wonder what we've learned as a collective.

Also, Kogawa's writing philosophy encourages me to be okay with this place of unknowing that I'm in vis-à-vis the liminal space between proposal and thesis. Between packing and going on the trip. She compared writing poems to an experience of a "spark" whereas novels are more like "swamp fire" – slow burning and warm. It seems I've landed myself in a space of spark and swamp fire for my thesis project.

... researcher is looking for patterns in the data but is not entirely sure what these will look like or what their significance will be. She or he must therefore approach the data with a certain blind faith, with a confidence that there is something there but no certainty about what. (p. 38)

While this “certain blind faith” stage of data immersion was extremely challenging and discomfoting as I felt myself resisting the uncertain, not-knowing state, I was interested in what stood out and demanded my intuitive attention. My initial journaling consisted primarily of writing reams of quick, found poems – poetic representation – from the policy texts (and a few from my proposal and activities of daily living). This proved to be a very liberating way to engage with data immersion to get really familiar with the RT and IBCC policy documents without committing to formal analysis. However, I also made general notes on themes and phrases that stuck out. I then repeated the entire process – re-reading the policy documents, journaling, and poem-ifying the policy texts. As I repeated this process, similar discursive statements and broad policy themes started to emerge again, confirming my earlier instinctual reads, and fewer poems came to me. I began to feel very familiar with the two policy documents including the tone and contents of the main texts and their appendices.

one poem found in my proposal

proposal to thesis
intuition: on? off? muddling
a commitment
to complex analysis
letting go of wanting everything
to be simple
bicycle tool box
bricoleur
problematization of the present
speech of madmen and students
a certain blind faith

Once my re-reads stopped producing new thoughts, I felt ready to move from data immersion to data analysis to start considering the archaeological and genealogical questions I had set out in my proposal (and as noted above). To do this I created a table

with four common columns for each question. The columns were: the question at hand (i.e. dominant dementia statements, contradictions, conditions of possibility, productivity of dominant discourses, etc.), examples and quotations from the IBCC and RT reports respectively, and a fourth column called “related comments/sources” for any random or more substantiated ideas from my work experience in dementia care or my literature review (Appendix D). In the end, I created a beast of a table that was over 120 pages. At this point, I met with my supervisor, showed her my stacks of paper (journal, data analysis table, and found poems), and she wisely said, “I think you need to stop reading and start writing,” which I did. As I wrote, I referred to the examples in my data analysis table while continually referring back to the original policy documents for clarification and additional examples.

thesis writing horoscope

this is not a day for deep thought
 you might not even be able
 to get a grasp
 on the essentials
 so just do your best
 and try to figure it all out
 later
 get a friend to help
 piece it together

Ethics of Research Project

While I must consider the ethics of my approach to the research inquiry I have chosen, I feel I must first address the ethics of what I have not chosen to study, namely the direct narratives of individuals living with dementia. As Wang (1999) contends, “what Foucault asked of us is to listen to the lived experience, the struggle and resistance of the elderly, and to foster their capacity *as well as ours* to resist the subjugation of subjectivity to the dominant discourses of old age” (p. 214, emphasis added). With my discursive critique, I hoped to ‘foster my capacity’ to resist dominant discourses about dementia in both social policy and my own social work practice so that I may continue to develop my role as an ally alongside those living with dementia, their families, and communities.

Furthermore, according to Western academic standards, my thesis collects data from documents (social policy texts and academic literature), and thus does not have human participants. However, I recognize my research is not excused from the broad underpinnings of informed consent and confidentiality, namely respect and researcher integrity. So although I did not interview individuals living with dementia, families, health care policy-makers, health care practitioners, etc., I am mindful of the many persons living with the realities which I have had the privilege to write about abstractly. I am mindful that I have been immersed in social policy documents that have material effects in many Canadian households and I did not take my responsibility to commit to deep and considered reflection lightly. This also required me to be careful not to essentialize either dementia or people living with dementia as a homogenous group. My goal was to be accountable for my inquiry as if I were the entrusted holder of individual narratives and for

the fact my analysis of these social policy texts has produced only a partial truth in a dynamic situation of multiple truths.

Finally, as an aspiring self-reflexive researcher, I attempted to “come clean ‘at the hyphen’” by interrogating my relationship with this topic and acknowledging my responsibility to reflect on my identity and how I chose to direct my “scholarly gaze” (Fine, Weis, Weseen, & Wong, 2003, p. 195). As a social worker in dementia care, my very employment means I am complicit in neoliberal health care priorities in my day-to-day practice. My personal connections to this research question are also embodied in my memories of my Great Auntie Annie living her later years with dementia, clinging to her dignity in an ageist society while desperately fiddling with the locks of dementia care institutions. As well, this research stems from my daily witnessing of the challenges individuals with dementia face in accessing even the basics of care they need – never mind in a form they desire – as well as my own fears and questions around being able to respond more generously to their needs in a health care context where more must be done with less. I have tried to open my mind and heart (let’s not be all Cartesian and rational here!) to try to see and imagine ways that dominant discourses embedded in the IBCC and RT policy documents might be disrupted to inform how we could collectively conceptualize and provide dementia care that is flexible, generous, appreciative, creative, compassionate, and dynamic.

Reflections on Research: Merits, Limitations, Assessment, and Evaluation

I would like my research to be assessed according to how it engages with the social justice aims I outlined earlier; the extent to which I have been self-reflexive and transparent in my research choices and analyses; and whether my analysis contributes a

complicating view to dementia discourses and, ultimately, policy discussions. I understand poststructural analysis to be “nothing more than a rewriting . . . the systematic description of a discourse-object” (Foucault, 1969/2011, p. 156). I recognize this can be seen as a limitation, or what Hastings (2002) has noted is “a danger of discourse analysis being dismissed if it seems merely to retell familiar stories from a slightly different perspective” (p. 19). Overall, my goal was that my research be “reconstructive as well as deconstructive” and that it offer “imaginaries” by considering contradictions within the dominant discourses as well as possibilities presented by excluded discourses (Strega, 2005, p. 229).

A serious limitation with my research is that I am a forty-two year old person who is not living with dementia. I recognize that I do not have the direct, lived experience of older persons living with dementia. There is no doubt that this limits my perspective so I have tried to attend to any ageist and ableist assumptions and declare my biases throughout (Tracy, 2010, p. 842). As well, I have endeavoured to engage in what Potts and Brown (2005) refer to as “political listening” with the policy documents to “become aware of the construction of multiple interpretations and multiple truths” (p. 272). Secondly, by embracing poetic representation approaches to the RT and IBCC social policy texts, I tried to challenge assumptions about how academic research must be presented:

We must continue to ask ourselves why the field has privileged prose, and a very certain type of scripted prose, over other forms of representation and what knowledge this privilege has lost or obscured in relation to new research understandings. (Lahman et al., 2010, p. 46)

I am simultaneously aware that I am not a poet, although I enjoy reading poetry and very sporadically dabble in writing poems. However, as Lahman et al. (2010) contemplate, “poking around at research through lousy poetry may lead to *good enough research poetry* as the researcher grows and develops” (p. 47, emphasis in original). Nonetheless,

recognizing my serious poetic limitations, I have not relied solely on poetry to present my findings. Furthermore, Potts and Brown (2005) argue there is “no research without relationships” (p. 263). So while my study is limited by the absence of relationships between myself and active research participants with “epistemic privilege,” I recognize that I have had a relationship with the partial representations of people living with dementia, their families, and health care providers in the RT and IBCC policy documents (Potts & Brown, 2005, p. 263). I have tried to highlight rather than obscure my participation as a researcher. Additionally, while deconstructing dominant discourses about dementia and neoliberalism in health care, I acknowledged that these discourses are not “external monster[s]” entirely outside of myself, but in many ways are taken for granted and intricately enmeshed in my life and being which has made my task of troubling them that much more challenging (Davies et al., 2005, p. 347).

In terms of assessing the internal validity of my research, I have engaged in a very informal process of peer review and dialogue not only with my thesis committee, but also with colleagues and friends who are open to complicating understandings of dementia and dementia care in Canadian society. Secondly, I immersed myself in the data by reading and re-reading the two policy documents in a recursive manner, as well as journaling, writing found poems, and systematically making a detailed data analysis table. Thirdly, although I cannot claim to meet triangulation requirements as I only used two sources of data (policy documents and a literature review), I drew on Tracy’s (2010) concept of crystallization “to open up a more complex, in-depth, but still thoroughly partial, understanding of the issues” of dementia discourses in two Canadian policy documents (p. 843).

CHAPTER FOUR: Data Analysis

Archaeological Discourse Analysis: Statements Constituting Dominant Dementia Discourses

To begin my archaeological discourse analysis bike ride through the RT and IBCC policy documents, I first wind my way amongst the main statements articulated about people living with dementia and describe them. These interrelated statements constitute the dominant dementia discourses in the policy documents. And so, this is a meandering, sometimes lurching, and definitely iterative, sort of cycle tour through the statements.

STATEMENT: People living with dementia are absent-person objects.

Persons living with dementia are constructed as inactive, absent-person objects in the policy documents. That is, people living with dementia and their voices and perspectives are missing from the RT and IBCC reports. No direct quotations appear articulating the views of persons living with the condition around which the two policies have been developed. Of course, my research could be critiqued for this as well, but in a time when at least minimal evidence of consultation with stakeholders is seen as a requirement in most policy processes – consider for example the recent Enbridge Northern Gateway pipeline hearings – the complete absence of the voices of persons living with dementia in the IBCC and RT policy documents is striking. Their objectification works to deny their personhood and verges on relegating them to a category of non-persons. For instance, people with dementia are talked about, analyzed, tabled, graphed, cared for, provided for, problem-solved about, and generally acted upon. As shown in Table 1, repeated phrases throughout the two policy documents like “care received by,” “health care provided to,” and “beds occupied by” position persons living with dementia as objects – not

subjects – in the sentence structure, which in turn works to construct them primarily as recipients or objects of care. On the surface they are undoubtedly referred to as persons – varyingly as “persons,” “people,” “individuals,” and “patients” – and deserving of “person-centred care” (Donnelly et al., 2011, pp. 2, 9, 18, 55, 58, 64; ASC, 2010a, pp. 40, 51, 52). The IBCC report in particular states that the key to “successfully managing, treating, and caring for

persons with dementia depends upon knowing that person as an individual” (Donnelly et al., 2011, p. 9). However, the overriding implication is that care is done to these persons as if they are without agency or voice.

Interestingly, just as the IBCC policy document neglects to include voices of people living with dementia, buried deep in Appendix M near the end of the document, it quotes multiple family caregivers observing that emergency department staff similarly ignore the views of persons living with dementia during hospitalization:

“They would always speak to me as if she was not there.” (Donnelly et al., 2011, p. 99)

“I really did make sure that they at least gave him eye contact.” (Donnelly et al., 2011, p. 99)

“They [hospital staff] don’t know how to listen to what she’s actually saying. They don’t know how to speak to her and they just have the caregiver insert what’s needed. It’s like they treat the person with dementia as if they are not there.” (Donnelly et al., 2011, p. 99)

Table 1: Examples of Phrases Objectifying Persons With Dementia

In the IBCC report:

- “care received by” (p. 1)
- “health care provided to” (pp. 3, 5)
- “provide assistance to” (p. 14)
- “improving care for” (p. 2)

In the RT report:

- “beds occupied by” (p. 20)
- “care and treatment for” (p. 13)
- “care will be provided to” (p. 19)
- “provide care to” (p. 41)
- “services ... to” (p. 14)

Appendix C in the IBCC report states that consulted family caregivers recommended that the care of persons living with dementia in acute care hospitals could be improved by staff “not talking about the person in front of them as if they did not exist;” “do[ing] with’ rather than ‘do[ing] to’ the patient;” and “including [the] patient in as much of their care planning as possible” (Donnelly et al., 2011, p. 55). Notably, however, these basic recommendations about considering the possibility of relating to persons with dementia in hospital in a direct and relational way that recognizes their agency and humanity, and at least trying to communicate with them about their care wishes, remained in the appendix and did not make it into the main body of the IBCC policy. Instead, the “recommendations and strategies for improving acute hospital care” in the main text emphasize a more generalized, unspecified “person-centred care approach” that encourages staff to “focus on who the person is” by, for example, supporting the family caregivers and “seeking valid consent to health care from appropriate substitute decision makers” which, while important, again ultimately work to overlook the person in front of them (Donnelly et al., 2011, p. 16).

Similarly, the policy’s recommendation about communication highlights “communication approaches and approaches to behavioural issues” – not *with* people – and “appropriate approaches to dementia patients” – not *with* people living with dementia (Donnelly et al., 2011, p. 17).


Essentially, persons living with dementia become bodies and brains with their personhood, and psychosocial and spiritual needs overlooked. Even the recommended “48/5” care plan



differentiating the 3Ds

dementia
depression
delirium

death
decay
dealing with *them*



which presumably would be an opportunity to consider the whole person in their individuality beyond their illness and physical body, instead focuses solely on delirium/cognition, medications, functional mobility, nutrition/hydration, and bladder/bowel goals (Donnelly et al., 2011, p. 13). The “Sleep and Agitation Record” in Appendix I also limits the person living with dementia to three ticky box options – agitated, calm, or asleep – to note their state each hour (Donnelly et al., 2011, p. 92). In the RT text, 27 “exhibits” over 17 pages also disappear people living with dementia, objectifying them in graphs and tables with dots, lines, and billion dollar amounts accounting for the cost of their care. I find this language of “exhibits” particularly eerie and dehumanizing because it is evocative of museum displays where silent, trapped carcasses are the objects of active observers’ gazes.

STATEMENT: People living with dementia are dependent, incompetent, and incapable.

Linked to the statement that people living with dementia are objects of care is the notion that they are dependent on others to live because they are considered incompetent and incapable. The front cover of the IBCC report portrays this succinctly with a photograph of the wrinkled face of a woman in pink, gazing off into the distance, her brown hair graying at her brow. Her hand is the focal point of the photo and rests on the hand of a faceless person standing behind her who the viewer can identify as a male physician by his accessories, namely a stethoscope, white lab coat, and blue tie. The image reinforces both metaphorically and literally that this woman’s life – and care – rests in the hand of the physician and the health care system he represents. The woman, presumably living with dementia, is dependent on others to care for her. Furthermore, persons living with dementia are presented as dependent in the two policy documents because of the

assumption they can no longer communicate. Repeatedly in the IBCC report, the importance of family caregivers' role in communicating on behalf of the person with dementia is emphasized:

Families clearly want to be involved and believe that care will improve if they are able to communicate with health care providers and give direction (and consent) based on their knowledge of the patient and on their family members' wishes expressed for health care decisions while they were competent. (Donnelly et al., 2011, pp. 9-10)

Another example states, "As people with dementia may be unable to communicate *their own individuality* or express their needs and preferences, family and caregiver knowledge and the communication of that knowledge is central to quality care" (Donnelly et al., 2011, p. 9, emphasis added). While family and caregiver knowledge and communication are essential, this quotation suggests that not only is the person with dementia reliant on others to communicate their needs and preferences, but also "their own individuality" as if their current form of self-expression cannot support their humanness and personality at even a most basic level. I find this shocking. First of all, people with dementia are not a homogenous group, and a dementia diagnosis does not mean people immediately stop talking and expressing themselves. Furthermore, through my work I have known many people with advanced dementia who could still vocalize, hum their own tune, have a twinkle about them, express grief and joy, share their sense of humour, desire to eat or not eat, dance, express a wish for love, intimacy, and touch, and on. The implication in the IBCC policy document however, is that persons with dementia are formerly "competent" as if competence is a black and white binary without room for considering competence as a multidimensional continuum (Donnelly et al., 2011, p. 10).

Capability is similarly constructed in the discussion of consent to health care “on behalf of an incapable adult” (Donnelly et al., 2011, p. 11). “Patient autonomy,” then, refers to supporting “*pre-expressed* wishes for future health care, advance directives, [and] representation agreements” from when the person was supposedly autonomous, and not to supporting presently expressed wishes in whatever shape they take (Donnelly et al., 2011, p. 16, emphasis added). The text also works to separate persons with dementia from “cognitively intact patients” (Donnelly et al., 2011, p. 31). This distinction is made very clearly with the framing of the “primary issue” of the IBCC report declared on the first page: “when patients with dementia are admitted to acute care, they often have prolonged stays and worse outcomes than patients with intact cognition” (Donnelly et al., 2011, p. 1). Again, people with dementia are constructed as different from those who are supposedly cognitively intact and competent, but also as a homogenous group of identically incompetent individuals.

I have found two exceptions . . . sort of. In reviewing “what has been done [about dementia] in other countries” (ASC, 2010a, p. 39), the RT report lists “giving individuals living with dementia as much control over their care as possible, while recognizing limitations due to cognitive impairment” (ASC, 2010a, p. 39) and “the Dutch concept of building the national strategy on the foundation of problems identified, experienced and prioritized by individuals with dementia and their caregivers” (ASC, 2010a, p. 41). These supportive gestures toward recognizing the value, capacity, and expertise of persons living with dementia is ultimately dropped – dismissed – however, in the summary which states: “Most [national strategies] acknowledge the importance of investing in research,

supporting caregivers in their role and improving the skills of professionals who provide care to individuals with dementia” (ASC, 2010a, p. 41).

STATEMENT: People living with dementia are *other*.

People with dementia are constructed throughout the policy documents as *other* or *them*. As demonstrated in Table 2, they are not specifically included in the many *us* categories that appear in the texts including taxpayers, business community members, caregivers, and subject matter experts. As a result, people living with dementia are effectively excluded from their communities and denied personhood. More specifically, for example, in the list of stakeholders contributing to the IBCC report which is foregrounded in the early pages of the report, no people identified with dementia are included despite

Table 2: Categories Excluding Persons Living With Dementia

In the IBCC report:

- “taxpayers” (p. 82)
- “caregivers” (pp. 1, 2, 4, etc.)
- “readers” (p. 6)
- “stakeholders” (p. 3)

In the RT report:

- “labour force” (p. 22)
- “business community” (p. 10)
- “caregivers” (pp. 3, 4, 5, etc.)
- “Canadians” (cover)
- “Canadian society” (p. 9)
- “we” (p. 56)
- “Subject Matter Experts” (p. 5)

the declared goal of “hearing from a wide spectrum of stakeholders” (Donnelly et al., 2011, p. 5). Similarly, the lengthy list of “subject matter experts” acknowledged in the RT report, also in the initial pages of the report, does not include any individuals living with dementia, except for one general and brief nod to thank “the people with dementia . . . who have, over the years, shared their thoughts, experiences and provided guidance to the Alzheimer Society” – notably not to the report at hand (ASC, 2010a, p. 5). Once again, the voices of people living with dementia are excluded from the policy documents.

STATEMENT: People living with dementia are unproductive.

As I have observed above, people living with dementia are not included as contributors in the categories of the labour force (ASC, 2010a, p. 22) or business community (ASC, 2010a, p. 10). The RT report frames people living with dementia as unproductive in the market economy by concentrating on dementia's "effect on production" (ASC, 2010a, p. 25). For example, it argues that there is a "lower productivity level for Canadians living with dementia than for otherwise healthy individuals" and that "this reduced productivity translates into a reduction in output" (ASC, 2010a, p. 25). Furthermore, persons with dementia are constructed as responsible not only for their own "reduced productivity" or "lost production," but also that of their "informal caregivers" (ASC, 2010a, p. 25): "The amount of time which is spent on caregiving is indistinguishable from an economic disability" (ASC, 2010a, p. 63). In turn, the logic goes that this accumulated "lost production is translated into lost wages and reduction in corporate profits" (ASC, 2010a, p. 25) which yields "the Indirect Cost of disability associated with dementia and the provision of informal care" (ASC, 2010a, p. 25). In the economic model "disability . . . is assumed to correspond to one's reduction in productivity in the workplace" (ASC, 2010a, p. 63). And overall, dementia is quietly framed for messing with corporate profits.

Persons living with dementia are constructed as failing to produce in the market economy and therefore seen as failing to contribute to society in a valuable or meaningful way. The failure of people with dementia to produce and their need for care become their disability. Essentially then, persons living with dementia and their dementia are produced as an economic sickness. The RT policy document includes tables "exhibit[ing]" calculations

of lost production in dollar amounts due to dementia (ASC, 2010a, p. 25). The title of “Exhibit 15” reads, for instance: “Annual Lost Production Attributed to the Disability Due to Dementia and Informal Care . . . 2008-2038” (ASC, 2010a, p. 25). Exhibit 16 displays the “Cumulative Lost Production Attributed to the Disability Due to Dementia and Informal Care . . . 2008-2038” (ASC, 2010a, p. 26). Overall, the presentation works to make the supposedly “unproductive” individuals living with dementia responsible for the \$129, 849, 366, 889 – that’s almost \$130 billion – in lost production displayed in the table (ASC, 2010a, p. 26).

STATEMENT: People living with dementia need specialized care.

Both texts work to articulate that people with dementia are not only dependent and need care, but that they need “specialized” care (Donnelly et al., 2011, pp. 5, 13, 14, 18, 25; ASC, 2010a, pp. 14, 41, 44, 46). A distinction is made in the IBCC report that people with dementia often have “complex health issues and behaviour” (Donnelly et al., 2011, p. 1), “particular and unique needs” (Donnelly et al., 2011, p. 15), “multiple, interacting medical and social problems” (Donnelly et al., 2011, p. 15), and “many things wrong, all at once” (Donnelly et al., 2011, p. 15). In turn, this means “improving care for persons with dementia is equally complex with no single or simple answers” (Donnelly et al., 2011, p. 1). The complexity is emphasized throughout the text as is the need for a “specialized” care response to it. For instance, “All professional and non-professional health care personnel require *specialized* knowledge, skills, abilities and attitudes to facilitate

acute care

acute care
welcomes
one thing wrong at a time

persons with dementia
complex
many things wrong
all at once

timely and appropriate dementia care” (Donnelly et al., 2011, p. 18, emphasis added), or “explore options for *specialized* units, *specialized* staff and *specialized* programming for patients with dementia” (Donnelly et al., 2011, p. 64, emphasis added). The RT report articulates that there are “too few specialized providers” (ASC, 2010a, p. 14) and addresses this shortage with its own fleet of “subject matter experts” contributing to the study as portrayed in Table 3 (ASC, 2010a, p. 5). People with dementia are positioned to require care “supported with the expertise of geriatricians, neurologists, psychiatrists, nurses and other professionals with specialized knowledge of dementia and its treatment” (ASC, 2010a, p. 55).

Both policies advocate for increased training for these “specialized” dementia care professionals, as the RT articulates, to “Strengthen and Supplement the Dementia Workforce” (ASC, 2010a, p. 55) . The IBCC report asserts a need to “Improve training of all personnel in emergency regarding appropriate care for persons with dementia” (Donnelly et al., 2011, p. 14), and to provide “education for staff” in acute hospital care as well (Donnelly et al., 2011, p. 17). The RT study states “Canada must ensure basic dementia skills among primary care providers, emergency department staff, care facility nurses, assisted living personal support workers, and all others employed in care settings that are likely to serve individuals with dementia” (ASC, 2010a, p. 55). Notably, the assertion that people living

**Table 3: “Subject Matter Experts”
Contributing to the RT Report**

Doctor, Professor, Chair, Research Director, Geriatric Psychiatrist, Vice President, Therapeutic Area Head, President, Clinical Director, Interim Medical Director, Theme Lead, Adjunct Professor, Director of Programming, Administrator, Scientific Director, Evaluator, Consultant, Doctoral Student, Associate Professor, Staff Geriatrician, Senior Scientist, Research Director, President and Chief Executive Officer, System Planner, Research Scientist, Adjunct Scientist, etc. (pp. 5-7)

with dementia require specialized care is also taken up in a more recent international report about dementia:

People with dementia have special needs for care. Compared with other long-term care users they need more personal care, more hours of care, and more supervision, all of which is associated with greater caregiver strain, and higher costs of care. (Prince, Prina, & Guerchet, 2013, p. 4)

STATEMENT: People living with dementia need specialized care that is “appropriate.”

There is also a qualification – arguably a constraint although an admittedly subtle one – applied to the notion of specialized care. That is, while the IBCC and RT reports indicate that people living with dementia require specialized expert care, their proposed care is also continually described as “appropriate,” notably not as exceptional. I have seen the word “appropriate” similarly repeated without a definition offered in other health care documents as well including, for instance, the *Residential Care Regulation of the Community Care and Assisted Living Act* (2009), which mandates my work. While a dictionary definition states that appropriate means “suitable or proper *in the circumstance*,” this clearly leaves a lot open to subjective interpretation by health care practitioners (Oxford University Press, 2013, “Definition of appropriate,” para. 1, emphasis added). As exemplified in Table 4, the extensive repetition of the word “appropriate,” throughout the IBCC policy document, and to a somewhat lesser extent in the RT report, works to emphasize that people with dementia have particular needs for “suitable and proper” care. However, it also constrains expectations and possibilities by implying that the care be what is manageable “in this circumstance” or at this specific historical moment and context in health care and politics. Furthermore, once establishing the need that all care be “appropriate” for people living with dementia, the conclusion in the IBCC report states that “appropriate resources” are

“also necessary” to provide this so-called appropriate care (Donnelly et al., 2011, p. 18).

The shift from a focus on care to resources subtly connects dementia care to the economics and costs of dementia care which will be discussed at length shortly.

STATEMENT: People living with dementia need specialized care requiring time and patience.

Another aspect of specialized care repeatedly noted in the IBCC study is that caring for people living with dementia in emergency departments and acute care hospitals is “time-consuming” (Donnelly et al., 2011, p. 8) and requires extensive patience:

Family caregivers emphasized the need for gentle, patient, routine, and consistent care of persons with dementia . . . Taking time with patients emerged as a common theme. (Donnelly et al., 2011, p. 9)

Caring for people in this situation requires time and patience. (Donnelly et al., 2011, p. 8)

While the policy document does recommend to “improve training of all personnel in emergency [departments]” about a “patient-centred approach to caring for patients with dementia that features a positive, caring, slow approach” (Donnelly et al., 2011, p. 14), this

Table 4: Examples of the Emphasis on the “Appropriateness” of Dementia Care

In the IBCC report:

- “appropriate care” (p. 18)
- “the kind of care that is most appropriate for persons with dementia” (p. 9)
- “appropriate . . . assessment” (p. 10)
- “appropriate medication protocols” (p. 17)
- “security guards trained to deal with dementia patients appropriately” (p. 14)
- “the appropriateness of treatment” (p. 11)
- “appropriate triage for patients with dementia” (p. 13)
- “appropriate guidelines for managing behaviour problems in dementia” (p. 14)
- “appropriate approaches” (p. 17)

In the RT report:

- “services appropriate to people with dementia” (p. 14)
- “appropriate care and treatment for people with dementia” (p. 13)
- “treatments and care strategies are appropriate for different stages in the disease” (p. 45)
- “appropriate medication” (p. 50)
- “appropriate supply of dementia specialists and well-trained generalists” (p. 55)
- “appropriate . . . environments” (p. 44)

is undermined by the assertion that care also be provided in a “timely,” suggesting efficient, manner (Donnelly et al., 2011, p. 18). The report acknowledges the negative implications of the disconnection between the slowed-down pacing needs of people with dementia and the “rapid style” (Donnelly et al., 2011, p. 12) of the hospital environment:

This juxtaposition of the need for unhurried patient care for persons with dementia and the “fast-paced environment, the perpetual relocation of patients, the orientation to acute episodic and curative episodes” that are the hallmarks of emergency and acute care, suggests just some of the reasons that care of persons with dementia in these settings is often sub-optimal. (Donnelly et al., 2011, p. 8)

It is further stated that “emergency care of older adults requires more resources” than for younger people, suggesting that time and patience have a cost both in terms of human and financial resources (Donnelly et al., 2011, p. 12). Finally, in the IBCC report, even “Readers are strongly encouraged to *take time* to read the full accounts of the information on which this project’s results are based” (Donnelly et al., 2011, p. 6, emphasis added). Everything related to dementia takes time, but by reading the “full accounts” in the appendices, the IBCC report states the reader will get “a vivid picture of how dementia patients are cared for in emergency and acute care settings and how that care could be improved” (Donnelly et al., 2011, p. 6).

STATEMENT: Emergency and acute care hospital provide “suboptimal” service for people living with dementia.

While the stated goal and primary focus of the IBCC policy document is to improve emergency and acute care for people living with dementia, the RT report also weighs in arguing that “conventional health care systems were designed to manage short episodes of acute care and simply do not respond well to the challenges of chronic care [for conditions

like dementia]" (ASC, 2010a, p. 47). The ideal hospital patient is presented as someone with "specific acute health problems" (Donnelly et al., 2011, p. 1). Or, as the IBCC report notes:

On the one hand we have a system that is not designed to accommodate the particular and unique needs of patients with dementia and, on the other, the vulnerability of those same patients to increased distress or diminished health when those needs are not addressed. (Donnelly et al., 2011, p. 15)

The first problem specified regarding acute care in the RT report, notably, is that of economics: "the acute care model is expensive" (ASC, 2010a, p. 47). This is also articulated in the IBCC study: "the repercussions of the status quo can be costly" (Donnelly et al., 2011, p. 82). So, drawing on the earlier statement that dementia care requires extra time, presumably I can extrapolate that care for people living with dementia in the acute setting is more expensive than for other populations. Specific expenses for hospitals are presented in the IBCC report including: "the cost of avoidable complications associated with hospital care; prolonged lengths of stay; and

hospitalization offers older patients . . .

risks of
adverse events
functional decline
prolonged stays
worse outcomes
more likely to be restrained
with less morphine sulphate
than those with intact cognition

hospital cruise ship

offering hospital cruises
for persons with dementia

stay longer and
have a worse time
and with poorer outcomes
than while you were competent
or compared with cognitively
intact patients

repercussions can be costly
for hospitals
access and flow issues in the system
for patients
diminished quality of life

system problems

rooms with
no windows
no toilets
no place for family to be

access and flow issues in the system due to bed shortages” (Donnelly et al., 2011, p. 80). As well, the IBCC report outlines multiple problems or risks to the physical and emotional well-being of people living with dementia in acute care settings such as the “unnecessary stress and risk of iatrogenic illness [that’s hospital care making people sick]” (Donnelly et al., 2011, p. 11), and the higher risk of developing delirium and being restrained (Donnelly et al., 2011, p. 31). People living with dementia in hospital also experience “prolonged stays and worse outcomes than patients with intact cognition” (Donnelly et al., 2011, p. 1). And when they leave hospital, people living with dementia experience the “loss of independence” (Donnelly et al., 2011, p. 84) and “premature admission to residential care homes” (Donnelly et al., 2011, p. 82). Overall then, the hospital environment and the care provided there, are constructed as being “inappropriate or suboptimal” for people living with dementia (Donnelly et al., 2011, p. 10).

While the IBCC policy document does make multiple recommendations to improve hospital care for people living with dementia because “not all admissions can be prevented” (Donnelly et al., 2011, p. 12), the overarching goal is to **prevent** their admission to hospital in the first place whenever possible. For example,

Research literature and best practices in dementia care assert that an initial step to improving quality of life, maintaining function and decreasing mortality in dementia patients is to prevent unnecessary visits to the emergency department and admissions to hospital. (Donnelly et al., 2011, p. 11)

There is also good evidence to support the concept that preventing emergencies is the best care possible for patients with dementia and their families. (Donnelly et al., 2011, p. 18)

A transfer to hospital may not be in the patient’s best interest. (Donnelly et al., 2011, p. 11)

As a result, the report suggests that “gaps” in services beyond emergency and acute care – such as primary physician care, residential care, and home care – “may trigger unnecessary hospital admission” (Donnelly et al., 2011, p. 7).

STATEMENT: People living with dementia in hospital are “bed blockers.”

Both the RT and IBCC policy documents allude to persons with dementia occupying hospital services they do not need. While one health professional is quoted in the appendices of the IBCC report blatantly referring to people with dementia as “bed blockers” or “using up a very vital bed,” the same person is also quoted arguing that a related “attitudinal shift” needs to occur “to know them as people as opposed to bed blockers” (Donnelly et al., 2011, p. 111). Otherwise, the language in both reports is more neutral, but the notion holds. For example, “Taxpayers are faced with the burden of . . . longer waits in the emergency departments as beds are occupied by seniors who are medically stable but unable to manage at home” (Donnelly et al., 2011, p. 82) and hospitals have costs due to “access and flow issues in the system due to bed shortages” (Donnelly et al., 2011, p. 80). In the RT report,

The concept of “alternate level of care” (ALC) is a key hospital utilization and health system performance indicator. An ALC bed represents a bed occupied by a patient whose acute care is complete, but the patient has not been transferred to a more appropriate level of care. (ASC, 2010a, p. 46)

In contrast, however, the IBCC report advocates in its recommendations for an alternative perspective in support of people with dementia that emphasizes “quality of life in hospital, rather than length of stay or ALC” (Donnelly et al., 2011, p. 17).

STATEMENT: Admission to long-term care should be delayed for people with dementia.

Just as the IBCC policy document suggests that emergency and acute hospital care is suboptimal for people living with dementia and that admission is best avoided, the RT report advocates for delaying their admission to long-term care as well. It explicitly argues that “delay[ing] admission for the person with dementia into long-term care” (ASC, 2010a, p. 31) will “lessen the pressures placed on long-term care resources [to produce] significant savings in costs” (ASC, 2010a, p. 31) or “reduc[e] the heavy societal costs associated with institutionalization” (ASC, 2010a, p. 54). Unstated is the fact that delayed admission to long-term care will also presumably “lessen the pressures” on the collective and the government to provide excellent facilities that support people living with dementia to thrive. Furthermore, the RT report cites the work of Wodchis et al. (2008) to assert that “the cost per resident per day for individuals living with dementia is approximately 1.06 times the average cost of long-term care” (ASC, 2010a, p. 62). Clearly, once again, economics drive this particular statement that admission to long-term care should be delayed for people with dementia because dementia care is more expensive, and that there would be “substantial savings by delaying admission to long-term care facilities for individuals with dementia” (ASC, 2010a, p. 37). As well, in Appendix C, the reader learns that “long-term care bed utilization is constrained by the supply of beds” (ASC, 2010a, p. 62). So not only are long-term beds for people with dementia costly, they also do not actually exist in adequate numbers which of course makes the delay of institutionalization necessary, although this is not stated.

One indication is made that delaying institutionalization, beyond economic benefits, might also benefit persons with dementia by “enabling individuals to remain at home as

long as possible” (ASC, 2010a, p. 39). This seems reasonable on the surface, but does assume that people with dementia want to stay in their homes “as long as possible.” Exhibit 20 visually displays the so-called “benefit” of “Delaying Admission to Long-Term Care” both in reduced predicted numbers of people living in long-term care, and the associated dollar savings (ASC, 2010a, p. 32). It strikes me that this table provides a visual example of the merging or unifying of people with the dollars they purportedly cost which all works ultimately to keep people with dementia away from health care services, particularly long-term care and as stated above, hospital. These two statements suggest that while people with dementia may prefer to stay at home, this is also the desired option because it is the least costly for the health care system and taxpayers.

STATEMENT: Dementia is an “economic burden” for society.

According to the RT report, dementia – and by association people living with dementia – are and will be an economic burden. Quite simply, the word “burden” is used in relation to dementia and economics over 100 times throughout the report from the table of contents to the appendices. On page 22 alone, the word “burden” and its accoutrements are repeated 16 times. Examples include: “Economic Burden of Dementia,” “Total Economic Burden,” “Monetary Economic Burden,” “Total Annual Economic Burden of Dementia,” “annual Total Economic Burden of dementia,” etc. (ASC, 2010a, p.

burden of dementia

annual total economic
burden
cumulative total economic
burden
monetary economic
burden
total economic
burden
caregiver
burden
societal
burden

22). (For examples beyond page 22, see Table 5.) The “burden” is everywhere and it is really big; it appears throughout the text and in the titling of the tables displaying costs in billions of dollars. While the repetition starts to feel ridiculous, it also develops a mantra effect where the conceptualization of people with dementia as a burden assumes the status of truth. Furthermore, the notion of “the dementia burden” is often paired with a call for action which adds a sense of urgency to doing something to cope with the anticipated burden of dementia: “Canada requires a national action plan grounded in an up-to-date and comprehensive understanding of the dementia burden in Canada, in order to quantify, prepare for, and mitigate the impact of dementia” (ASC, 2010a, p. 8).

This burden is further constructed as “the health and economic burden of dementia on Canadian society” suggesting that dementia threatens not only the country’s economy, but also the health of its population and the health care system (ASC, 2010a, p. 8). Or, in summary of the apparent magnitude and far-reaching impact of the dementia burden, the RT report states: “dementia usually implies . . . severe strain and financial burden on family and caregivers, health providers, the health care system, the business community, and society in general” (ASC, 2010a, p. 10). Overall, dementia impacts everybody and everything, in the wallet and beyond. In a telling use of synecdoche – “Dementia places a long-term progressive burden on those who care for

Table 5: Additional Examples of the “Burden” of Dementia in the RT Report

- “Cumulative Economic Burden” (p. 3)
- “the cumulative economic burden will be \$872 billion” (p. 15)
- “population health and economic burden attributable to dementia” (p. 16)
- “substantial additional societal burden” (p. 23)
- “health and economic burden placed on informal caregivers” (p. 31)
- “burden placed on health care resources across all types of care” (p. 37)

them” (ASC, 2010a, p. 10), persons living with dementia – “them” – are referred to as “dementia,” losing their personhood and becoming their disease.

While clearly the RT report really emphasizes the burden metaphor vis-à-vis dementia, the IBCC text does not. Nonetheless, language of the economic burden does appear once. That is, in Appendix G, the IBCC policy document draws on the burden metaphor to detail the expenses borne by taxpayers due to elder care:

Taxpayers are faced with the burden of providing resources for older patients requiring more services in their home, increased demands for funding for residential care homes, home support services and longer waits in the emergency departments as beds are occupied by seniors who are medically stable but unable to manage at home due to the functional decline induced by hospitalization. (Donnelly et al., 2011, p. 82)

The implication is that seniors and persons living with dementia who require health care services are no longer considered to be “taxpayers.” So even though seniors arguably come from all economic stratifications and many continue to pay taxes, their health needs become a marker of their failure to cope or self-manage as individuals in a neoliberal society. In turn, their needs become framed as a burden on the wallets of more properly behaved taxpayer citizens.

STATEMENT: Dementia prevalence is increasing.

Both the IBCC and RT policy documents state that the prevalence of dementia is increasing. The IBCC report does this in a neutral way, referring generally to the 65 years plus population “growing” (Donnelly et al., 2011, pp. 1, 27); “the eve of this demographic shift” (Donnelly et al., 2011, p. 84); “increasing number of seniors in the general population” (Donnelly et al., 2011, p. 84); and the “urgent demographic imperative to step up to the challenge of improving acute care for older adults” (Donnelly et al., 2011, p. 84). Overall, the IBCC report acknowledges the issue of increased dementia prevalence gently

and diplomatically: “Both current and projected numbers of persons with dementia encourage the exploration of how well our health care system now serves these individuals and how prepared it will be to serve increasing numbers of them in the future” (Donnelly et al., 2011, p. 3). The RT report, however, refers to the increasing prevalence more dramatically and emphatically stating, for instance, that the “predicted surge in dementia prevalence threatens to overwhelm Canada’s health care system unless specific and targeted actions are undertaken. **Canada must act**” (ASC, 2010a, p. 14, emphasis in original). It argues that “the first of the baby boomers will enter their senior years (65+) in 2011, at which time the aging of the Canadian population and the dementia burden on Canadian society will begin to accelerate” (ASC, 2010a, p. 26). It also uses six pages of related statistics and accompanying graphs and tables to suggest that without intervention there will be 250,000 new “cases” of dementia per year (ASC, 2010a, p. 26) such that by 2038, “1.1 million Canadians will have dementia” (ASC, 2010a, p. 26) or “approximately 2.8% of all Canadians” (ASC, 2010a, p. 26).

STATEMENT: Dementia is an “epidemic.”

When describing the anticipated, increased prevalence in numbers of people living with dementia, the RT report equates dementia with an epidemic, both by repeating the words “dementia” and “epidemic” together throughout, and by illustrating the so-called epidemic visually. To start, similar to the repeated use of the word “burden” in the report (but to a slightly less frenetic scale), “epidemic” is continually linked with “dementia” – e.g. “the impending dementia epidemic” (ASC, 2010a, p. 52) and “Canada’s Dementia Epidemic – A Call to Action” (ASC, 2010a, pp.3, 8, 9). There is an overarching sense of doom requiring urgent action, and dementia and epidemic become synonymous – conflated – such that

readers are encouraged to apply their own preconceived notions about the word epidemic to the dementia situation. In particular, the commonsense conception of epidemic meaning “an outbreak of a contagious disease that spreads rapidly and widely” takes hold (Farlex, 2013, “epidemic,” para. 2). Zeilig (2013) concurs, noting that “An anxiety about ‘epidemics’ is often linked with dementia, implying that it is infectious and can be ‘caught’” (p. 4). So even though dementia is not contagious, the repeated use of the word epidemic partnered with dementia implies that it might be, and works to heighten the sense of risk and danger associated with the aging population. I find myself asking, does 2.8 percent of the Canadian population in 2038 really count as “widely” prevalent (ASC, 2010a, p. 26)? After all, we could just as accurately state that 97.2 percent of the population will likely not have dementia.

Consider the table entitled “Projected Incidence” (ASC, 2010b, p. 6), which claims to predict the number of new cases of dementia in relation to time – per year, and then, presumably by extrapolation, per minute. It declares that, in 2008, there was “one new case every **5 minutes**,” and by 2038 predicts there will be “one new case every **2 minutes**” (ASC, 2010b, p. 6, emphasis in original). As the reader, I can imagine the numbers flipping by in my mind, faster and faster, as more and more people presumably succumb to dementia. Additionally, by linking the so-called “Dementia Epidemic” with “Canada” (ASC, 2010a, pp. 3, 8, 9, 45, 49, 51, 52, 53, 54, 55, 56), the RT report constructs the predicted increase in dementia prevalence as a Canadian problem that requires a “pan-Canadian response” (ASC, 2010a, pp. 49, 51, 53, 54, 56) – sometimes capitalized within a sentence: “Pan-Canadian Response to the Dementia Epidemic” (ASC, 2010a, p. 51). Such capitalization heightens the significance of the phrase and serves to reify the construct that

urgent, formal action is needed to protect the country and its population from the supposed contagion of dementia. The RT study explicitly articulates that all “Canadians must call on their federal, provincial and territorial governments to take action now – to rise to the challenge of the dementia epidemic” (ASC, 2010a, p. 9).

The heightened language of mobilising Canadians works to invoke, and condone, an almost militaristic response to the supposed threat of a dementia epidemic. For example, Canadians are urgently rallied “to rise to the challenge” (ASC, 2010a, p. 9); “to take action now” (ASC, 2010a, pp. 8, 9); to recognize the “urgent need for a national dementia strategy to guide, manage and mitigate the health, economic and social impacts of dementia” (ASC, 2010a, p. 37); “to manag[e] the impending dementia epidemic” (ASC, 2010a, p. 52); and “to ensure that the dementia epidemic is met with an appropriate supply of dementia specialists and well-trained generalists working collaboratively” (ASC, 2010a, p. 55). The language of “the dementia epidemic” once again serves, like other statements noted previously, to disappear human beings living with dementia such that they become their disease, especially in contrast to the mobilized troops of human “dementia specialists and well-trained generalists” – which suggest to me dementia ‘soldiers’ and well-trained ‘generals’ perhaps – who are being rallied to “meet” the dementia epidemic as if in a battle at the Plains of Abraham. At present, the RT report claims, the “record of *tackling* this challenge in Canada has been uneven” (ASC, 2010a, p. 49, emphasis added). While clearly the articulated recommendations in the RT report do not specify taking up arms against people living with dementia, the heightened language of “Canada’s dementia epidemic” functions to highlight dementia as a threat to the nation and, ultimately, is a form of fear-mongering against people living with dementia: “Now that we have a clear sense of the

scale and impact of the dementia epidemic in Canada, inaction is not an option. Our economy, our health care system, [and] the lives of millions of Canadians will be affected” (ASC, 2010a, p. 56).

STATEMENT: Dementia is a “rising tide.”

As I discussed earlier, both policy documents state an increase in the numbers of people living with dementia. The “demographic shift” (Donnelly et al., 2011, pp. 81, 84) is also constructed as a natural disaster, particularly a “rising tide.” While this watery crisis metaphor appears explicitly only once in the IBBC report in the appendices, it washes throughout the RT report. The IBBC policy document quotes a “health care professional” conflating aging people with tsunami and flood imagery:

“I think with the tsunami of the elderly coming, I think we’re going to have to look at a better way of dealing with them. They are just going to flood the Emergency otherwise and really people will still be looking at the other emergencies as the priority and the elderly shunted off to the side unless we have an Emergency that is primarily interested in the elderly and primarily has their needs in focus.” (Donnelly et al., 2011, p. 103)

So while on the surface, the IBCC report seems to draw on neutral language to present concern about the “suboptimal” care people living with dementia receive in hospital and to offer reasonable and practical recommendations to improve their care, this one instance of over-the-top crisis language also makes sense because it aligns with overarching messages in the policy document. For example, the image of elders “flooding” emergency departments in the above quotation aligns with, and supports, the presentation of costly hospital expenses incurred as a result of “access and flow issues in the system due to bed shortages [because of beds being occupied by people with dementia]” (Donnelly et al., 2011, p. 80). As well, the notion that “A transfer to hospital may not be in the patient’s best

interest” (Donnelly et al., 2011, p. 11) is underscored with the image of floods of elders abandoned in piles at the sides of emergency waiting rooms.

The RT report runs with these metaphors much further, however, starting with the report title – *Rising Tide: The Impact of Dementia on Canadian Society*, the front cover, and continuing throughout. The front cover illustrations, notably, are super-imposed with a blue transparency suggesting a metaphorical submersion in water. Three bar graphs, claiming to scientifically portray the numbers of people with dementia and the related “costs to Canadians for dementia care,” reach like waves over a pixelated map of Canada which in itself suggests a nation in danger of crumbling apart because of the supposed dementia burden (ASC, 2010a, p. 1). Overall, between the title and the incorporation of flood-like graphics and apparently objective, scientific, and monetary facts, the front cover establishes the rising tide discourse that appears throughout the report implying that dementia is a concrete threat to an imagined Canadian population and the society, health system, and economy it cherishes. Similarly, the four section cover pages throughout the document are superimposed with blue, and all the tables are titled and shaded in blue, as are the main titles within the text. Water, water everywhere.

Additionally, the image of a rising tide is further constructed with words like surge and overwhelm: “The predicted *surge* in dementia cases will certainly *overwhelm* Canada’s health care system unless specific and targeted action is taken” (ASC, 2010a, p. 2, emphasis added). Even the repeated use of the words “impact” and “pressure” is evocative of a tsunami or rising tide crashing into the Canadian population, economy,

rising tide

predicted surge
threatens to overwhelm
place a tremendous strain
potentially overwhelming
the country’s
health care system

and health care system (ASC, 2010a, pp. 3, 5, 6, 8, 28, 31, 33, etc.). Finally, the policy document is also inundated with huge, billion dollar amounts in both the text and the multiple tables which further works to present dementia as a threatening rising tide because of its predicted, catastrophic expense. To sum up, the IBCC report states: “At no other point in the history of Canada has there ever been such an *urgent* demographic imperative to step up to the challenge of improving acute care for older adults” (Donnelly et al., 2011, p. 84, emphasis added).

STATEMENT: Dementia is a crisis for which we are not prepared.

An overarching theme in both the RT and IBCC policy documents is that the health care system is not prepared to cope with the forecasted, increased prevalence in dementia, and, as a result, the very “health” of the health care system and also the Canadian society and economy are at risk. The IBCC report indicates that the health and social service system will have difficulty “recover[ing]” from the dementia burden, while the RT policy document suggests the impact will be “crippling” if action is not taken immediately:

It will be difficult for our health and social care system to recover from the increased burden of illness and the concomitant care needs of older Canadians and it will be very, and unnecessarily, costly. While over the next 50 years the baby boomer generation will die out, the next generation may likely be healthier and live longer than current elders, consequently the problem will not completely go away. On the eve of this demographic shift, the appropriateness and quality of hospital care for older adults remains grossly inadequate. (Donnelly et al., 2011, p. 84)

If we do nothing, dementia will have a crippling effect on Canadian families, our health care system and economy. (ASC, 2010b, p. i)

More specifically, for example, current services in health care are presented as “not equipped to manage . . . people with dementia” (Donnelly et al., 2011, p. 1), “constrained” (ASC, 2010a, p. 19), “maldistributed, uncoordinated and, where available, delivered with

little standardization and continuity” (ASC, 2010a, p. 14). Similarly, health care staff are constructed as “busy, often unprepared” (Donnelly et al., 2011, p. 2, 18), “too few” (ASC, 2010a, p. 14), and “inadequately prepared” (ASC, 2010a, p. 14), with “limited” training (ASC, 2010a, p. 14). Overall, “The few provinces that have made earnest efforts are still largely unprepared for the impending societal impact of dementia” (ASC, 2010a, p. 49) and, according to the RT report: “Clearly, something must be done” (ASC, 2010a, p. 49). The IBCC policy document, in comparison, articulates the need for action in response to dementia in a more nuanced way. In fact, it seems to be walking on proverbial eggshells in its attempt to assert solidarity with people with dementia while gently acknowledging the limits of “the current situation,” presumably the economic and political context of health care:

While some of the report findings may appear critical of the current situation, it is important to remember that the identification and analysis of problems is a necessary first step in correcting them and that the focus of the report is on improving care and outcomes for patients with dementia. (Donnelly et al., 2011, p. 1)

not equipped

the system
not designed
to accommodate
not equipped
to manage
complex health, behaviour
particular and unique
needs
of people
with dementia

services

broad spectrum
maldistributed
uncoordinated
services
delivered with
little standardization
little continuity
training is limited

Canada must act
specific, targeted
actions

Archaeological Discourse Analysis: Conditions of Possibility for Statements and Discourse

According to a Foucauldian, archaeological approach to discourse analysis, the “conditions of possibility” are that which “give rise to knowledge” (O’Farrell, 2005, p. 69) – including statements and discourses – about a certain issue at a specific time. Or, as Foucault (1969/2011) articulates, “the set of rules” (p. 155) or the “interplay of . . . rules that make possible the appearance of objects during a given period of time” (p. 36). So with regards to the two policy documents under study then, which “external” conditions allow the dominant dementia discourse, as constituted in the above statements (Foucault, 1970/1981, p. 67)? Which contemporary, commonsense assumptions make it *normal* to consider people living with dementia as homogenous objects who are unproductive, as well as overwhelming and threatening by virtue of their care needs? I now examine how the current, neoliberal political climate in health care (and beyond) provides the “set of rules” that support the dominant apocalyptic demography (e.g. rising tide and epidemic metaphors) and economic dementia discourses.

Neoliberal political climate in health care.

In my literature review, I explored in detail the neoliberal political underpinnings to the health care system in Canada. In a nutshell, key priorities in neoliberal rationality include the primacy of promarket approaches to all aspects of social, political, and economic life; efficiency; reduced government; restraint policies; institutional need over human need; individual responsibility for well-being; privatization; and corporate profit. Clearly, these concepts proliferate in both the IBCC and RT policy documents such that neoliberalism is the main “condition of possibility” for the previously discussed statements constituting dominant discourse about people living with dementia.

Economics and policy decision-making.

Neoliberalism is most obviously taken up in the two policy documents, as I have observed throughout, with the assumption that economics should be, and are, the primary determining factor for policy decisions, even when they are related to health care and population well-being. Excellent dementia care in and of itself is not valued as an essential goal. Instead, the neoliberal context demands that economics subsume all social undertakings (Brown, 2014). For example, on its first page, the IBCC report declares euphemistically that the possibility of policy recommendations was determined – constrained – by “the current economic situation” (Donnelly et al., 2011, p. 1). That is, “this report offers ten specific recommendations . . . selected from the many actions possible to improve care for persons with dementia . . . these actions were considered achievable in the current economic situation” (Donnelly et al., 2011, p. 1). The report claims to recommend a particular set of actions out of “many possible actions” (Donnelly et al., 2011, p. 1) based primarily on their economic feasibility, despite the fact the policy document is ostensibly concerned utmost with the well-being of people living with dementia. Nonetheless, promarket values, rather than social policy “imaginaries” (Fairclough, 2003, p. 207) or human need, subtly govern the policy. For instance, the phrase “considered achievable in the current economic situation” repeats later in the text, highlighting the influence of financial considerations on the recommendations made in the policy (Donnelly et al., 2011, p. 8). I experience this in my work in residential dementia care too, where often the budget is implicitly the determining factor for any action, and if it is not, the action is understood to be “risky,” which implies irresponsibility and recklessness regardless of the potential positive human outcomes. The vague and euphemistic phrase “considered achievable in the

current economic situation” also functions to depoliticize the issue of dementia care and deresponsibilize the social collective and government. The phrase fails to contextualize the challenges of dementia care within contemporary neoliberal politics which assert individual responsibility over collective care and work to dismantle publicly-funded government health and social services. After all, the phrase could have more directly and accurately stated: *considered achievable within the current neoliberal priorities of the provincial government (and the B.C. electorate) and the decisions they make about taxation, health care spending/cuts, and care for people living with dementia*. In the RT report, the uber-emphasis on the “economic burden” of dementia in Canada examined earlier also demonstrates the centrality of market values in the development of the policy within a neoliberal rationality. Despite the fact the RT report is a health policy document presumably concerned primarily with the health and well-being of the social collective and people living with dementia, the document focuses on economics. In fact, health and the economy become one and the same such that the interventions in the RT study are “selected for their anticipated health and economic value” (ASC, 2010a, p. 28). This is neoliberal commonsense-making in action. The rendering of health as economics appears natural or accidental, but it is an intentional neoliberal construction serving particular, namely private, interests (Brown, 2014).

As well, I see the prioritization and primacy assigned to the economy in the minute ordering of concerns within the RT text. For example, notice the positioning of the economy first in the following phrase: “Our economy, our health care system, the lives of millions of Canadians will be affected” (ASC, 2010a, p. 56). Economics are the heart of the matter and outcomes other than economic benefit appear to be almost lucky, unintended

consequences: “Beyond the reduction in demand for long-term care resources, there are additional emotional and quality of life benefits” (ASC, 2010a, p. 37). Reduced “long-term care resources” might be more clearly stated as government and taxpayer savings, while “quality of life” benefits for people living with dementia and their caregivers are effectively constituted as an after-thought to economic priorities. Because the policy document is dominated by financial considerations, dementia, and by association, people living with dementia, become commodified. The report predicts the “cumulative economic burden” of dementia by 2038 will be \$872 billion including direct health costs, opportunity costs (foregone wages) of unpaid informal caregivers, and indirect costs (ASC, 2010a, pp. 5, 8). These sorts of cost analyses work to obliterate individuals living with dementia and the contexts of their lives, and they also privilege and perpetuate neoliberal capitalist values that permeate all aspects of social life including health care. This exemplifies Brown’s (2005) contention that: “Neoliberal rationality, while foregrounding the market, is not only or even primarily focussed on the economy; it involves *extending and disseminating market values to all institutions and social action*” (p. 40, emphasis in original).

Family caregivers bear the costs.


The RT report presents a marketized construction of family caregivers and the work they do, and simultaneously devalues them in comparison to government and social collective restraint goals. For instance, in the discussion of benefits from the proposed recommendation to delay admission to long-term care homes, the report acknowledges that “this would shift costs to caregivers,” but ultimately dismisses the impact on these individuals’ lives by asserting that “the savings in direct health costs [i.e. to government] *more than compensates*, thus producing a significantly lower Total Economic Burden” (ASC,

2010a, p. 31, emphasis added). Economic language – “compensates,” “savings,” “costs,” etc. – permeates the statement, subtly working to prioritize economic values in determining health care provision. And clearly, reducing the “economic burden” of dementia on government and taxpayers – Canadian society – is presented as more important than considering the economic burden, or any other challenge, experienced by



shift costs to caregivers

the savings
in direct health costs
more than compensate
producing
Lower
Total Economic Burden



families coping with dementia even though arguably these families are also taxpayers and members of Canadian society. There is no doubt that such neoliberal restraint ideology – producing savings to government through reducing government services – pervades the recommendations in the RT report. Considerable emphasis is placed on “produc[ing] significant savings to health costs” (ASC, 2010a, p. 24) – variations of this phrase are repeated throughout – even at the risk to the well-being of families caring for persons living with dementia.

As examined in my literature review, in a neoliberal political climate, individuals are positioned to bear the consequences of aging and health challenges – “the ubiquitous hazards of life” (MacGregor, 1999, p. 109) – on their own with only minimal state support at best. Accordingly, the RT policy document outlines, without question, the respective financial responsibilities of government and individual families euphemistically as “direct health costs . . . *within* the formal health system” and “direct health costs *outside* the formal health care system” (ASC, 2010a, p. 22, emphasis added). The assumption is that it is acceptable for families to bear the costs “outside” the formal health care system which

include over-the-counter medication, long-term care accommodation, and unspecified “out-of-pocket expenses” (which could indicate dental floss or private long-term care accommodation) for people living with dementia (ASC, 2010a, p. 22). No mention is made of the fact that B.C. hospitals can charge a fee for hospital stays when the person has been assessed as not needing acute or sub-acute care and is in hospital “awaiting admission for long-term placement in a residential care facility” (VIHA, 2012, p. 2). In her review of home and community care issues affecting seniors, the B.C. Ombudsperson (2012) states:

It is unfair for the Ministry of Health to permit health authorities to charge seniors for hospital stays that extend beyond 30 days after they have been assessed as needing residential care when they have to remain in hospital because of the unavailability of appropriate residential care beds. (p. 170)

Similarly, the RT report does not raise concerns about the financial burden these expenses may or may not create for families, nor is the responsibility of the public collective to care for all citizens across their lifespan and according to their level of need considered.

Corporatization of health care.

The RT report places an emphasis on the loss of “corporate profits” due to the so-called reduced productivity of people with dementia and their caregivers through the sheer repetition of this pair of words, which underlines that the primary goal of corporate endeavours is indeed to make a profit (ASC, 2010a, pp. 22, 25, 26, 29, 30, 32, 34). The fact that “corporate profits” are mentioned at all in a health care policy document reminds me that corporate needs are a key consideration in neoliberal rationality across all sectors of life. And, by implication, just as government is diminishing its role in supporting people, it does have an important role in supporting private profits. Obviously the primacy of corporate needs also works to legitimize the privatization of elder care, although notably this is not stated directly in either policy document. Neither do the two policy documents

acknowledge that the *Canada Health Act* and public health insurance cover hospital (except when awaiting an alternate level of care) and physician care, but not health services such as home care and long-term care which are required by people living with dementia (Armstrong, 2012, p. 322). Again, these unstated conditions subtly make room for the corporatization of long-term care, for instance, as a “solution” to the “problem” of expensive collective care by offering a way to produce “savings” for what has been constructed throughout the RT policy document as the strained public purse. Following neoliberal logic, the privatization of elder care would also presumably solve the stated problem of lost corporate profits and shortages in public long-term care beds. In these subtle ways, the RT report quietly functions to support the privatization of dementia care, evidence of Armstrong’s (2012) contention that “privatization is done by stealth” (p. 321).

The IBCC report alludes to the challenges of creating positive change for elder and dementia care in hospitals, but does so rather cautiously and deep within the appendices, separate from the main body of the report and its recommendations, and without naming neoliberal politics explicitly. The report argues that “growing evidence has emerged” in support of models of “elder friendly” care in hospital and emergency settings that offer “demonstrated clinical, economic and social




‘elder friendly’ care

in other words
appropriate and sensible
care
transformational change
challenging deeply ingrained
traditional ways of providing
poor and inappropriate care

financial and human
resource constraints
effective interventions
cannot be cost-effectively
implemented

no clear solutions
the problem will not
completely go away
on the eve
of this demographic shift



benefits,” but that these are “yet to be widely accepted and adopted” due to “financial and human resource constraints” (Donnelly et al., 2011, p. 83). The IBCC study references the research of Bradley, Schlesinger, Webster, Baker, and Inouye (2004), arguing that “The implementation of new acute care models directed at the care of older adults is largely influenced by evidence of effectiveness, organizational culture and structure, and financial costs and benefits” (Donnelly et al., 2011, p. 83). Once again, I see that sacred neoliberal values – financial cost and benefit – are the underlying conditions of possibility that determine what is conceivable in dementia care in the contemporary political context of British Columbia. Finally, the intentions of the RT report, which are arguably to do good for people living with dementia and “alleviate the personal and social consequences” of their illness by “champion[ing] *their* issues with government,” get lost in the depoliticizing effect of the report’s enmeshment in neoliberal rationality (ASC, 2011, p. 2, emphasis added).

Archaeological Discourse Analysis: Contradictions in Statements

As I noted earlier in my methodology chapter, in addition to examining the conditions of possibility of discourse, Foucault (1969/2011) contends that analysing discourse includes considering and describing contradictions that appear “to show the play that they set up within it [the discourse]” (pp. 168-69). I will now describe four key contradictions at “play” within the dominant dementia discourses in the RT and IBCC reports: dementia is a “rising tide” even though dementia and tides are predictable; person-centred care is advocated, but persons living with dementia are homogenized and disappeared; the stigma of dementia must be reduced, but dementia and its economic burden are stigmatized; and persons living with dementia need specialized care, but such care is not best provided by the health care system.

Dementia is a “rising tide” BUT tides are predictable.

While both policy documents state that dementia and care for people living with dementia are, at best, an approaching challenge to the health care system and society, and, at worst, a rising tide – or epidemic and financial crisis, clearly dementia only needs to be a problem if it is constructed as one. So for example, a contradiction lurking within the rising tide metaphor that pervades the RT report is that tides are actually quite predictable and therefore unthreatening. Similarly, the aging baby boomer population is predictable; it has been known since the end of the Second World War that there would be this significant group of aging people. Political choices have been made over the last decades about how to prepare or not. Nonetheless, the image of a rising tide that dominates dementia policy, and also media coverage, has become dangerous in dementia discourse, metaphorically linked with the language of natural disasters like tsunamis or flooding, which de-emphasizes the underlying politics of dementia care.

Person-centred approach advocated BUT people with dementia are homogenized and disappeared.

The IBCC policy document repeatedly refers to the importance of “person-centered” care that “is so important to people with dementia” (Donnelly et al., 2011, p. 18), that “depends on knowing that person” (Donnelly et al., 2011, p. 9), “to ensure that all carers understand the patient [notably not the person]” (Donnelly et al., 2011, p. 9), and “focus on who the person is” (Donnelly et al., 2011, p. 16). However, simultaneously, on a very basic level, and as

most important point

to successfully
managing
treating
caring
for persons with dementia
means
knowing the person

discussed above throughout the descriptions of the dementia statements, (see, for instance, STATEMENT: People living with dementia are absent-person objects) the report, by not including the perspectives or voices of people living with dementia, fails to demonstrate a person-centred approach within its pages. Furthermore, as seen in the RT report, persons living with dementia essentially lose their individual personhood and become conflated with their disease and the costs of their care. Overall, people living with dementia are homogenized into a lump group of incapable and incompetent people who cannot communicate and who have overwhelming and expensive care needs.

Reduce stigma vis-à-vis dementia BUT stigmatize dementia and its economic burden.

Both policy documents under study articulate the “stigma” associated with dementia (Donnelly et al., 2011, p. 16; ASC, 2010a, pp. 14, 39, 50) and the need to destigmatize dementia (Donnelly et al., 2011, pp. 16, 68; ASC, 2010a, pp. 43, 50). For example, the IBCC study recommends education “for health care providers and other staff to destigmatize dementia and encourage [a] clinical culture of caring” (Donnelly et al., 2011, p. 16). The RT report recommends that early diagnosis is important and advocates that individuals be supported to seek medical support without shame: “Access to diagnosis is limited by stigma . . . The Alzheimer Society works to offset the stigma associated with dementia so that individuals who need help seek it with guidance and support” (ASC, 2010a, p. 14). On the one hand, I have seen in my social work practice how the Alzheimer Society nurtures the destigmatization of dementia through support groups for people with dementia and their families that normalize the condition and encourage quality of life, and through handouts like the *Person-Centred Language Guidelines* which highlight the importance of using respectful and humanizing language in dementia care:

The Alzheimer Society has developed these language guidelines as a tool for anyone who lives with, supports or cares about a person living with Alzheimer's disease or another dementia. We hope that they will promote consistency in the use of respectful language throughout dementia support services.

Person-centred language helps tackle the fear and stigma surrounding Alzheimer's disease and other dementias, in effect, making the disease one that people are more likely to acknowledge and discuss. The preferred terms are meant to maintain dignity and respect for all individuals. (ASC, 2012b, p. 1)

On the other hand, however, I see an irony or contradiction here. That is, the RT policy document commissioned by the same Alzheimer Society, does not destigmatize dementia. It is hard to imagine how individuals concerned about their memory would feel encouraged to search out medical support if they had faced the report's constructions of dementia as a rising tide or epidemic that will cost – burden – their fellow citizen taxpayers billions of dollars. Similarly, persons with dementia are actively discouraged from going to emergency or an acute care hospital in the IBCC policy document, and discouraged from using long-term care services in the RT policy document. Unfortunately, rather than destigmatizing dementia and fostering a “culture of caring” (Donnelly et al., 2011, pp. 16) in dementia care, the overriding message in the policy documents is for people with dementia to stay away from health care services. Persons with dementia are thus constituted in a contradictory position that ultimately contributes to stigma and could make them reluctant to seek help for their dementia. The dilemma goes like this: people with dementia learn by implication that capable, healthy citizens do not need costly health service assistance, but they are also told that conforming dementia citizens should seek early diagnosis, but that “good” dementia citizens should also stay away from the health care system.

People with dementia need specialized care BUT such care is not best provided by the health care system.

Related to the above contradiction are conflicting notions presented in the two policy documents about the care needed by people living with dementia and where best it should occur. The first overriding notion is that, due to the complexity of their condition, people living with dementia require “specialized,” “expert,” and “time-consuming” care that presumably would occur within the vestiges of the formal health care system. The second notion, however, is that hospital care is not necessarily in the “best interests” of people living with dementia, and that long-term residential dementia care is not in the best interests of the Canadian economy, health care system, or society. As a result, people living with dementia are constructed as needing “specialized care” that somehow needs to take place outside of the formal health care system that is normally understood to be the site of medical expertise and complex care.

Archaeological Discourse Analysis: In Summary

Through my archaeological discourse analysis of the RT and IBBC policy documents, I have described the ways dominant dementia statements and contradictions produce a discourse or knowledge about dementia and people living with dementia within a neoliberal rationality. Overall, dementia is constructed as an overwhelming, growing problem due to the cost of specialized care for people living with dementia who are constituted as unproductive, incapable, and expensive. Nonetheless, while persons living with dementia are produced as requiring specialist interventions, both policies under study work to discourage their use of public health care services including acute and long-term care facilities. Now that I have described the dominant dementia discourses and their

inherent contradictions in the policy documents, I turn my attention – my dipsydoodling, poststructural bicycle ride – to the ways this knowledge or system of thought about dementia and people living with dementia emerges in practices of power within the conditions of possibility of a neoliberal sociopolitical context.

Genealogical Discourse Analysis: Introduction

A genealogical approach to discourse analysis asks: What do the dominant discourses about dementia, constituted by the statements about people living with dementia, do at this particular time and place? How are they put into practice – enacted – in the IBCC and RT policy documents? Clearly, a sense of urgency is presented in the policy documents to respond to the constructed problem of dementia – namely, the “impending economic burden” and associated health and social risks to the Canadian population and health care system. The contemporary construction of the so-called dementia crisis delineates the associated solutions.

Genealogical Discourse Analysis: Proposed Solutions to the Constructed Dementia Crisis

Both policy documents offer solutions – referred to as “interventions,” “recommendations,” and “strategies” – to the challenges presented by dementia and people living with dementia. I will start with the RT policy document because its proposed solutions are national in scope, at least on the surface, whereas those of the IBCC report are more localized. Throughout the RT report a broad, sweeping “call to action” (ASC, 2010a, pp. 8, 9, 28) is reiterated in the form of a “pan-Canadian response” (ASC, 2010a, pp. 49, 51, 53, 54, 56) or “national dementia strategy” (ASC, 2010a, pp. 37, 48, 49, 54) that is largely unspecified, but constructed as an “urgent need” (ASC, 2010a, p. 37). For example, “A

Canadian dementia strategy must be comprehensive in scope and designed to reduce the impact of dementia on Canadian families, businesses, communities and governments” (ASC, 2010a, p. 51). Notably, persons living with dementia are not explicitly included in the list of bodies potentially benefitting from “*our* national strategy” (ASC, 2010a, p. 54, emphasis added). At another point, promoting this one-size-fits-all approach, the RT report refers to “Canada’s National Dementia Strategy” (ASC, 2010a, p. 54). The capitalization of the phrase suggests a proper noun as if indicating a named program that already officially exists.

The more detailed solutions in the RT policy document appear in two chunks, namely proposed “intervention simulations” (ASC, 2010a, pp. 4, 28-37) and “recommendations for moving forward” (ASC, 2010a, pp. 4, 48-55). The four interventions suggested focus on prevention and support with prevention listed as the primary priority: prevention through increased physical activity (ASC, 2010a, p. 28); prevention with a program to delay dementia onset (ASC, 2010a, p. 28); support through caregiver support and development (ASC, 2010a, p. 31); and support with “System Navigator/Case Management” (ASC, 2010a, p. 33). In the RT study, each intervention is examined vis-à-vis the financial benefits it will hypothetically produce. Additionally, the recommendations “to improve care at every stage [of dementia]” (ASC, 2010a, p. 49) overlap widely with the aforementioned interventions and focus, in order, on:

1. Increasing the investment in dementia research.
2. Providing support for informal caregivers.
3. Emphasizing prevention and early intervention.
4. Building an integrated system of care.
5. Strengthening and supplementing the dementia workforce (ASC, 2010a, p. 51).

Overall, the RT report states, “It is the fervent hope of the Alzheimer Society that these ideas will foster further discussion and analysis, and find their way into policies that create real change” (ASC, 2010a, p. 56).

The IBCC policy document is a little more nuanced in its tone and makes recommendations specific to improving emergency department and acute hospital care for people living with dementia. Before exploring these recommendations in detail however, the IBCC report focuses on a dementia research literature review and focus group responses that support “Preventing Unnecessary Emergency and Acute Care Admissions” (Donnelly et al., 2011, p. 11). As a result, the structure of the study implies that preventing people with dementia from using hospital services is a priority although it is not explicitly named or articulated as a “recommendation.” In a nutshell, the suggestions for preventing unnecessary admissions to hospital include: “earlier interventions” at residential care facilities and in the community (Donnelly et al., 2011, p. 11); “primary care [physician] services at an earlier stage” (Donnelly et al., 2011, p. 12); “building community services to prevent crises and unnecessary admissions to emergency departments” (Donnelly et al., 2011, p. 11); and “education for proxy decision makers about the likely outcomes of hospitalization and the course of dementia as a disease” (Donnelly et al., 2011, p. 11). The IBCC report also suggests “policy changes may be necessary in the form of better funding for long-term care facilities and primary care physicians to improve early management of preventable conditions” (Donnelly et al., 2011, p. 12). Clearly, these interventions advocate for improved primary physician, home and community, and residential care to monitor and treat health complications for people with dementia outside of the hospital system. As well, families and health care providers are responsabilized to support advance care planning

with a “stabilization and comfort care” focus (Donnelly et al., 2011, p. 11). In the suggestion for “better funding,” the state is implicitly responsabilized, but notably is not named specifically, and the proposal is softened by the words “may be necessary.”

The five “recommendations and strategies for improving emergency care” (Donnelly et al., 2011, p. 13) are: “screen all patients for delirium who show indications of cognitive impairment” (Donnelly et al., 2011, p. 13); “provide appropriate triage for patients with dementia and involve specially-trained geriatric emergency nurses where possible” (Donnelly et al., 2011, p. 13); “focus on working well with caregivers as partners in care” (Donnelly et al., 2011, p. 14); “follow appropriate guidelines for managing behavioural problems in dementia, starting with non-pharmacological approaches and adding medications as needed” (Donnelly et al., 2011, p. 14); and “improve training of all personnel in emergency regarding appropriate care for persons with dementia” (Donnelly et al., 2011, p. 14). For acute hospital care, the IBCC policy document offers the following five recommendations and strategies: “focus on who the person is by following a person-centred approach” which includes education for health care providers and support to family caregivers (Donnelly et al., 2011, p. 16); “implement the 48/5 protocol” to develop care plans within 48 hours of admission (Donnelly et al., 2011, p. 16); “follow appropriate behavioural protocols for patients demonstrating behavioural or psychological symptoms of dementia” (Donnelly et al., 2011, p. 16); “have a policy of minimal restraints” (Donnelly et al., 2011, p. 17); and “get consumer feedback and consumer involvement” (Donnelly et al., 2011, p. 17). Overall, the recommendations for emergency and acute hospital care appear specific, reasonable, and practical, and generally seem to focus on activities that individual health care staff can initiate with only limited systemic support mostly in the

form of education. Ironically, deep within its appendices, however, the IBCC report argues for much more substantial system change rather than endlessly tinkering futilely at the edges:

Importantly, the implementation of new models of care is especially challenging to current acute care practices because it requires the commitment of teams of highly qualified personnel, and senior management across organizations and within organizations (Siu, Spragens et al. 2009). This calls for the adoption of a model of *transformational* change as opposed to *incremental* change that has failed in previous attempts to implement care guidelines. (Donnelly et al., 2011, p. 83, emphasis added)

I will now consider more specifically the implications of the key recommendations – solutions – proposed in the RT and IBCC policy documents to further examine the productivity of the dominant dementia discourses which construct people living with dementia as dependent, incapable, unproductive, and in need of specialized, time-consuming care at epidemic rates that are forecast to overwhelm and economically burden the health care system and Canadian society generally.

Genealogical Discourse Analysis: The Productivity of Dominant Dementia Discourses

Genealogical discourse analysis considers the ways dominant discourses have material effects that contribute to the constitution of subject positions, and also policy and institutional decisions. In considering the productivity of the dementia discourses in the IBCC and RT policy documents, I examine how subject positions are produced for people living with dementia, their caregivers (family and health care staff), and for the population of people not living with dementia. I focus in particular on the ways these individuals, as well as private and charitable institutions, are responsabilized in the provision of dementia care, while simultaneously state and collective care is de-emphasized.

On the surface, the RT policy document repeatedly urges the state to take action: “We hope this study will incite and guide our . . . federal and provincial governments in developing policies to improve the lives of people living with dementia, while ensuring the sustainability of our health care system and economy” (ASC, 2010b, p. i). Paradoxically though, the recommended interventions responsabilize individuals without articulating concrete government or collective roles. As a result, state responsibility effectively disappears. Similarly, the IBCC report tiptoes around state responsibility with vague and euphemistic phrases like “the current economic situation” (Donnelly et al., 2011, p. 1) and passive sentence structures that do not identify who is responsible for a certain action that would presumably be state-held. For example, who or what entity is responsible for the suggestion above that “policy changes may be necessary in the form of better funding for long-term care facilities and primary care physicians” (Donnelly et al., 2011, p. 12)? I would assume the absent state. Wang (1999) has also observed discursive practices vis-à-vis old age that socially construct “intergenerational conflict” while overlooking patterns of power behind the so-called crisis and “[diverting] attention from . . . demands for government responsibility and universal entitlement programs” (p. 207). In the case of the IBCC policy document, for instance, care for people living with dementia in the overwhelmed hospital setting is tightly scrutinized and restricted such that only “necessary” care is deemed “appropriate.” This language echoes the *Canada Health Act* which promises citizens “reasonable access to medically necessary hospital and physician services” (Health Canada, 2011, p. 1). However, as discussed in my literature review, clearly the definition of “medically necessary” is influenced by political values and priorities. The notion of restricting public health care for people living with dementia is consistent with the

neoliberal conditions of possibility which valorize economic considerations (i.e. government savings) while promoting reduced government and increased individual self-reliance and management.

Individuals responsabilized to dodge dementia with healthy lifestyle and diet choices.

In the RT policy document, the state is deresponsibilized from providing excellent dementia care while individuals are responsabilized to avoid dementia. For example, the report produces a subject position for people without dementia and holds them individually responsible for preventing dementia through healthy lifestyle and diet choices. Even though the highest risk factor for dementia is aging – a “non-modifiable risk factor” (ASC, 2010a, p. 11), the report nonetheless focuses on ways individuals might prevent dementia. This makes sense in a neoliberal political and economic context because “neoliberalism normatively constructs and interpellates individuals as entrepreneurial actors in every sphere of life. It figures individuals as rational, calculating creatures whose moral autonomy is measured by their capacity for ‘self-care’” (Brown, 2005, p. 42). The RT report frames the healthy lifestyle interventions as promoting desirable behaviour in individuals to address modifiable risks. It argues that “promoting brain health through lifestyle choices is the most effective way of reducing the risk of Alzheimer’s” (ASC, 2010b, p. 3), and that preventing or even delaying dementia by two years

delay onset by two years

impact of
hypothetical
prevention
program
healthy diet and lifestyle

fewer individuals
living with dementia
reduced constraints
on health care resources
and the health care system

would save \$219 billion (ASC, 2010b, p. 13). Two prevention interventions are proposed: “Increase in Physical Activity” (ASC, 2010a, p. 28) and “A Program to Delay Dementia Onset” (ASC, 2010a, p. 30). The first “prevention scenario” proposes that “all Canadians (65+) without dementia, who are already moderately to highly active” increase their physical activity by 50 percent (ASC, 2010a, p. 28). The intervention presumes that this population of active seniors has the time, energy, and resources to increase their exercise routines. It also silently excludes those seniors who are not already active which in turn suggests they are not worthy of dodging dementia. The intervention does nothing to address the social determinants of health which are also modifiable risks. Neoliberal values dominate once again, while any values of collective responsibility to nurture excellent health opportunities for all are ignored.

Similarly, the second prevention intervention is “a hypothetical prevention program” (ASC, 2010a, p. 30) that recommends lifestyle and diet choices to self-regulating citizens – “target[ing] the entire dementia-free 65+ Canadian population” – to stay “dementia-free” (ASC, 2010a, p. 30). The proposed healthy lifestyle choices include: eating a “healthy” diet (e.g. “Mediterranean style” as well as blueberries, raspberries, dark green leafy vegetables, cold water fish, flax, and walnuts (ASC, 2010a, p. 12); having “an active social life” (e.g. organized social leisure activities like playing cards and group theatre-going (ASC, 2010a, p. 13); engaging in “intellectual activity” (e.g. the “use it or lose it” principle behind such activities as crossword puzzles, reading, and playing chess (ASC, 2010a, p. 13); and “protecting your head” especially by using recreational/sporting safety helmets (ASC, 2010a, p. 13). These proposed interventions assume that “the rationally calculating individual bears full responsibility for the consequences of his or her action no

matter how severe the constraints on this action” in the localized specificity of his or her social context (Brown, 2005, p. 42). But healthy lifestyle interventions, like the increased physical activity intervention, presume an affluent subject with access to leisure time to resist dementia, and neglect to notice the social determinants of health that restrict choices and capacity to implement the recommended interventions on the self. Also, it ultimately neglects to propose how this “hypothetical prevention program” (ASC, 2010a, p. 12) might be implemented or supported by the state. Nonetheless, in Exhibits 19, 24 and 25, the RT policy document claims that the intervention to delay dementia onset offers the largest financial savings, compared to the other interventions, in terms of overall “Total Economic Burden” and “Total Direct Health Costs” savings (ASC, 2010a, pp. 30, 35). As a result, individuals are responsabilized to save the state money by reducing health care costs whether or not the “hypothetical” intervention actually works. In fact, the RT policy document fosters an air of certainty even while acknowledging what is actually unknown about this intervention:

It isn’t known whether the 2-year delay in onset would come from regular use of statins, anti-inflammatory agents, exercise or improvements in diet. *What is clear* is that the case for doing further research and applying the risk reduction knowledge already available is *beyond a doubt*. (ASC, 2010a, p. 54, emphasis added)

Clearly, the healthy lifestyle intervention is upheld as *truth*, whether it works or not, because it would cost virtually nothing for the state and the collective to implement while also hypothetically working to save them money which is the crux of the matter in a neoliberal political climate: “With fewer Canadians living with dementia, the burden placed on health care resources across all types of care would be reduced, producing substantial savings for Canadian governments and society” (ASC, 2010a, p. 37).

Individuals responsabilized to seek early dementia diagnosis and intervention.

If individuals are unsuccessful in preventing dementia through healthy lifestyle and diet choices, the RT policy document then holds them responsible for seeking early dementia diagnosis and intervention. And thus, for these undisciplined subjects, “greater emphasis on early intervention is needed” (ASC, 2010a, p. 54) because it “offers opportunities for early treatment, *more self-management*, greater education and support, all of which can improve quality of life for those directly involved while reducing the heavy societal costs associated with institutionalization” (ASC, 2010a, p. 54, emphasis added). While purportedly this solution to the dementia challenge seems to support quality of life for “those directly involved,” it does not explicitly name people living with dementia as beneficiaries in the vague category of “those directly involved.” It also champions the societal economic benefits garnered if individuals with dementia take it upon themselves to be “self-managing” to get help early and to stay out of state-funded institutions. The budgetary focus of the intervention may not feel very caring to people who are concerned about their memory health and future needs. Furthermore, there is a link made in the text between early diagnosis and the possibility of pharmaceutical corporate profits which further prioritizes private interests over individual well-being:

Once a diagnosis is made, the physician may prescribe a cholinesterase inhibitor to mitigate the symptoms associated with the decline in memory, language and thinking abilities. There are, as of yet, no therapies that have been proven to slow down, stop or reverse the decline. (ASC, 2010a, p. 14)

While it is not clear whether individuals with dementia would benefit from this intervention because “Major clinical trials of drugs to treat Alzheimer’s have failed” (Kolata, 2013, para. 7) and because it will likely cause them economic burden since cholinesterase

inhibitors can be expensive and are not always covered by state-funded, public health insurance, undoubtedly private pharmaceutical companies that produce the medications would benefit.

Individuals responsabilized to care for people with dementia outside of health care institutions.

According to the discursive and policy assumptions in the RT and IBCC policy documents, when individuals with dementia can no longer “self-manage” their own care, someone in their community must care for them. That is, informal caregivers – unpaid individual family members and friends – must step in to provide care. While evidence of support for informal caregivers appears in both policy documents, much of the so-called support also works to further responsabilize them to keep people living with dementia out of hospital and long-term care, with little public support. The IBCC report notes in Appendix B that “prolonged hospital stay . . . was increased by burden of care on caregivers. . . . It may lead to more frequent crisis situations . . . [and] make caregivers more reluctant about patient discharge” (Donnelly et al., 2011, pp. 30-31). Clearly, the caregiver is key to preventing hospital admission, and the IBCC policy document recommends the health care system support them using a “multidisciplinary approach to care of patients with dementia in the community . . . to decrease the burden of care on family members” (Donnelly et al., 2011, p 31). For instance, it proposes home visits by the primary care physicians, nurses, and care aids, and respite programs (Donnelly et al., 2011, p. 31). Notably, the IBCC report does not identify whether the state or individual families would pay for these caregiver support services. Funding, obviously, would be necessary for actual program implementation. Until then, informal caregiving can be quite a lonely, exhausting, overwhelming, and expensive enterprise.

The RT policy document similarly identifies “Support for Informal Caregivers” (ASC, 2010a, p. 53) or the “Caregiver Development and Support Program” (ASC, 2010a, p. 31) as a recommended intervention. Where the IBCC report acknowledges “caregiver burn-out” (Donnelly et al., 2011, p. 10) and the “burden of care” (Donnelly et al., 2011, p. 30) on caregivers, however, the RT report goes even further to define caregiving as an “economic disability” (ASC, 2010a, p. 63). Unsurprisingly then, the stated goals of the “Caregiver Development and Support Program” – to improve “informal caregiver competence, skills and communication strategies for supervision of activities of daily living; coping strategies for patient behaviours and the overall burden of care” (ASC, 2010a, p. 31) – have a significant underlying economic focus. The goal is to “[reduce] the amount of caregiving time and hence the health and economic burden placed on informal caregivers . . . [and] to delay admission for the person with dementia into long-term care” (ASC, 2010a, p. 31). Another instance of the associated economic priorities linked to the caregiver support intervention is evident in the tables entitled Exhibit 20 and 21. They display the “benefits” of the caregiver support intervention only in dollar amounts highlighting savings in direct health system costs, total informal caregiver opportunity costs, and total economic burden, as well as resulting corporate profits (ASC, 2010a, p. 32). And, as I examined earlier in the archaeological analysis, with fewer people living in long-term care and more living at home – euphemistically referred to as “within the community” – the “savings in direct health costs more than compensates” for the cost-shifting to informal caregivers (ASC, 2010a, p. 31). The report works to legitimize the financial and caregiving responsibilities placed on individual families such that any implication of state responsibility is effectively

disregarded other than perhaps in the undefined “community-based care” (ASC, 2010a, p. 31).

Finally, I would like to consider how individual families are responsabilized to take care of people with dementia through the repeated, incongruent use of “partnership” language in the policy documents. That is, families are presented as “care partners” (ASC, 2010a, p. 53) and “partners in care” (Donnelly et al., 2011, p. 14), and their role is constructed as essential to approaching the dementia challenge: “Support for caregivers, and clear recognition of the important role they play as care partners, is an essential component of any comprehensive strategy to deal with dementia” (ASC, 2010a, p. 53). However, the other half of the partnership – namely, people living with dementia, health care staff, and the health care system – is never articulated, which further works to isolate family caregivers as alone in their responsibilities. Only once does the RT policy document allude to state responsibility in supporting informal dementia caregivers: “It is incumbent on governments to demonstrate that the work of caregivers is valued and that society makes it easier to continue providing care” (i.e. to keep people with dementia out of health care institutions) (ASC, 2010a, p. 53). Such state support and esteem for family caregivers is difficult to substantiate, though, when instead the policy document consistently and emphatically emphasizes that cost-shifting to family caregivers is “more than compensated” by state savings in health care, and reduced burden on corporate profits.

Individual health care staff responsabilized for incremental changes.

I would like to examine briefly how individualized solutions rather than systemic changes are upheld in the two policy documents by considering the subjectivity and responsabilization of individual health care staff. First of all, both policy documents argue

that health care staff are not adequately prepared to respond to the needs of people living with dementia. For example, in the IBCC report, staff in residential care facilities “may . . . not have the necessary expertise, knowledge, skills, abilities, and attitudes to meet these needs” (Donnelly et al., 2011, p. 11). Or in the RT report, health care staff are described as “inadequately prepared” (ASC, 2010a, p. 14) and having “limited” training (ASC, 2010a, p. 14). As a result, both of the policy documents under study propose dementia care education for health care staff to improve their individual skills within the existing health care system. The IBCC report recommends “education for staff (all new hires) in dementia care including communication approaches and approaches to behavioural issues” (Donnelly et al., 2011, p. 17) and that staff – “care aides or LPNs working in transitional units, [and] security staff” (Donnelly et al., 2011, p. 17) be trained “in appropriate approaches to dementia patients” (Donnelly et al., 2011, p. 17). It is unclear whether or not the hospital environment will also be modified to support these efforts. In a way, health care staff are being asked to do more – provide specialized, person-centred, patient, non-pharmacological (Donnelly et al., 2011, p. 14), and generally time-consuming care – but without additional resources or time to do so. Instead “flexible nurse ratios” are suggested, which is presumably more acceptable in a neoliberal economic climate than requests for increased staffing hours (Donnelly et al., 2011, p. 17). In the depths of the IBCC report’s appendices, however, is the seemingly radical suggestion to “make sure the model of staffing is congruent with the person-centred model of care so that the needs of the patient will define the staffing needs” (Donnelly et al., 2011, p. 64), but unfortunately it does not appear in the main body of the policy.

Another intervention in the RT policy document, called “System Navigator/Case Management” (ASC, 2010a, p. 33), also responsabilizes individual health care staff as human band-aids to systemic problems: “Care is uncoordinated and it can be difficult to tell who, if anyone, is in charge. In short, the system is difficult to navigate” (ASC, 2010a, p. 46). To solve this systemic problem of “a disjointed maze of health care services” (ASC, 2010a, p. 46), the report recommends “assigning a system navigator (case manager) to each newly diagnosed person with dementia in order to provide care coordination to individuals with dementia and support to informal caregivers” (ASC, 2010a, p. 33). The title of “system navigator” diverts our attention from the “disjointed maze of health care services” by suggesting the health system is indeed navigable. Individual “system navigators” are then expected to single-handedly finesse complications and problems in the broader health care system in order to facilitate coordinated care for families in the community. Once again individuals, this time individual health care staff, are held responsible to “delay long-term care admission” and although it would result in increased community-care and “an increase in unpaid caregiver opportunity costs and indirect costs” (ASC, 2010a, p. 33), the report again claims “the savings in direct health costs would more than compensate, producing a significantly lower Total Economic Burden” for the Canadian state and society (ASC, 2010a, p. 33). Interestingly, no mention is made of the cost to pay “system navigators,” but considering the report’s obsession elsewhere with quantifying all costs, the overall expense to fund this proposed case management is presumably relatively small, or an out-of-character oversight. Or perhaps volunteers are expected to do it.

As the state is deresponsibilized in dementia care, charitable and private organizations step in.

Charity.

While the IBCC policy document alludes to the role of charity, particularly the Alzheimer Society which is a charitable organization, in the provision of dementia care, the RT report makes a stronger case. In the IBCC report, we learn that the Alzheimer Society has a significant vested interest in the research project such that the twelve caregiver focus group members were “chosen by the Alzheimer Society of BC” (Donnelly et al., 2011, p. 5). Similarly, the RT report claims that the “four intervention scenarios, [were] selected by the Alzheimer Society and a panel of subject matter experts” (ASC, 2010a, p. 28) demonstrating the Alzheimer Society’s influence on the research process. No explanation is given for the role of the Alzheimer Society in determining caregiver participation or the four intervention scenarios, but according to the RT report, which was commissioned by the Alzheimer Society with public and private funding support from the Canadian Institutes of Health Research, the Public Health Agency of Canada, Health Canada, Pfizer Canada (which makes the cholinesterase inhibitor for dementia called Aricept), and Rx & D (ASC, 2010b, p. 1):

The Alzheimer Society is the leading, nationwide health organization for people affected by dementia in Canada. The Society is a principal funder of Alzheimer research and training, provides enhanced care and support to people with the disease, their families and caregivers, and is a prominent voice within all levels of government. (ASC, 2010a, p. 2)

As an example of the Alzheimer Society’s provision of “support to people with the disease, their families and caregivers,” the IBCC report’s first recommendation for ways that hospital staff can “provide support to family caregivers” is by “linking them with the Alzheimer’s Society and its caregivers’ support groups” (Donnelly et al., 2011, p. 16).

Clearly this is relatively inexpensive “support” from the state’s perspective considering “Volunteers are the most important resource for charitable organizations . . . At the Alzheimer Society, volunteer time and energy are essential to help . . . support people living with dementia” (ASC, 2013b, para. 1). Sample volunteer services with the Alzheimer Society of B.C. which hospital staff might refer families to include: First Link support, a dementia helpline, support groups, one-to-one support, and Minds in Motion (ASBC, 2010). Finally, the RT policy document argues that “scarce resources” of dementia care staff “must be supplemented by a well-resourced voluntary sector” (ASC, 2010a, p. 55). A “well-resourced voluntary sector” is essential to neoliberalism because it is cheaper for the government than a well-resourced dementia care workforce. Simultaneously, the establishment of high-profile, charity dementia services like the Alzheimer Society (which also seems to be entangled with private pharmaceutical corporations if considering the funders of the report) effectively works to further deresponsibilize the state for the provision of publicly-funded health care, while responsabilizing individuals to volunteer to fill the gaps.

Privatization of dementia care services and pharmaceutical corporate profit.

Earlier, in my discussion of the neoliberal conditions of possibility for the dominant dementia statements and discourses, I elaborated on the ways neoliberal market-driven priorities quietly made space for the privatization of dementia care services such as long-term care and home support. Clearly, one way the dominant dementia discourses are productive is in the way they legitimize the privatization of health care services. The neoliberal focus on corporate profit is also supported by the rising tide and epidemic burden dementia discourses. For example, with the recommendations for early

intervention, the RT policy document highlights the supposed benefit of early pharmaceutical intervention for individuals (ASC, 2010a, pp. 14, 54). However, as Katz and Peters (2008) argue, “cognitive enhancement as a goal of cholinesterase-based memory medicine is also a profitable goal” for private companies (p. 351). Another way in which private interests are supported in the RT report is with the extensive focus on the role of dementia research: “In response to the dementia epidemic Canada must, as a minimum, triple dementia research spending” (ASC, 2010a, p. 52). At the same time, the policy document asserts that “It is imperative that we leverage Canada’s dementia expertise to the fullest” (ASC, 2010a, p. 52) which notably includes “publicly and privately funded clinical trials” (ASC, 2010a, p. 52). So government funding of dementia research could potentially fill private research coffers: “In order to maintain Canada’s leadership role in dementia research, *to reap the commercial benefits* of discovery, and improve the quality of life of Canadians, Canada needs to dramatically increase funding it makes available to its dementia scientists” (ASC, 2010a, p. 52, emphasis added). Once again “commercial benefits” are positioned ahead of “quality of life.”

Genealogical Discourse Analysis: Responsibility for Health Care and Social Well-Being at Stake

Having explored the ways neoliberal priorities permeate both the IBCC report and the RT report, I see how economics are normalized as the foundational determining factor – constraint – in the development of the recommendations put forward in these dementia health care policy documents. Overall, the recommendations function to save the state (and thereby taxpayers) money, reduce state responsibility in health care, establish individual responsibility to self-manage one’s health, normalize informal caregiving as well as the

voluntary sector as the unpaid services responsible to protect the health care system, and quietly nurture opportunities for corporate profit. Ultimately, well-being and quality of life issues become secondary to market-related priorities. Overall, individuals are responsabilized to protect themselves, the economy, and the state from the so-called dementia epidemic, while expectations for the state or collective to provide care are subtly disappeared.⁴ As noted in my literature review, however, Canada has an historical narrative of a collective, social and health “safety net” intended to support individuals from “the hazards of the inevitable ups and downs of the capitalist economy” (Silver, 2012, p. 112) and to maintain a certain level of well-being across the citizenry. I have demonstrated that the implications of the dementia fear-mongering discourses and the recommendations in the policy documents function instead to undermine the safety net on a discursive and material level. For instance, in addition to valorizing economic and market-driven values, the policy documents also generally overlook the social determinants of health which could include safety net basics like access to healthy food, living wages, housing, recreation,

⁴ In contrast, in the *World Alzheimer Report 2013, Journey of caring: An analysis of long-term care for dementia*, the “overarching recommendation” explicitly articulates the politics of dementia care:

- All governments should initiate national debates regarding the future of long-term care, with all stakeholders and an informed public. For future generations of older people, the numbers of older people requiring long-term care, and their profile of needs is already predictable within narrow limits of uncertainty. Debate may focus upon:
- The balance of roles and responsibilities of the state, private companies, the third sector, and the families in providing care.
 - The structure of the long-term care system, the services that should be prioritised, and who should be eligible to receive them.
 - The financing of long-term care (with a focus upon the need to shift from ‘pay as you go’ to ‘fully-financed’ systems in which each generation of working adults pays, collectively, for their own future needs for care). (Prince et al., 2013, p. 10)

affordable post-secondary education, and on. So clearly, what is at stake is not only the responsibility for the provision of health and dementia care (i.e. public or private ownership and delivery), but also the well-being of the human population generally:

The essential question we must ponder is whether a lack of commitment to the elderly population affects the principles on which society is based. To consider care issues primarily – if not exclusively – as an economic problem will ultimately compromise our social values. We are all in the process of becoming “the elderly.” If we do not understand that the way we treat them reflects on our values and those we instill in our children, we will all ultimately suffer. . . . With major advances in medical science, the 21st century holds great promise for the elderly. If, however, the foundations and principles are not based on a committed system that values the elderly as integral and important even when frail and disabled, we will have sacrificed the principles of a society that truly respects and cares equitably for all of its members. (Gordon, 2000, “Caring for the Elderly,” para. 4)

Or, as local Victoria City Councillor Lisa Helps (2013) succinctly articulates on her Twitter board: “New economic principle: we need each other to flourish” (para. 1).

Genealogical Discourse Analysis: The “Uncontroversial” Fact Dementia is on the Rise

In my archaeological analysis, I examined the multiple ways both policy documents under study assume that dementia prevalence is increasing. I too have believed this to be true, an “uncontroversial” fact (Marston, 2004, p. 87). However, by happenstance, I have been encouraged to examine this assumption further. In the early fall of 2013, while attending a webinar presentation by Dr. Michael Gordon who works in the fields of geriatric medicine and medical ethics, I realized how easily I had accepted the discursive *truth* of the so-called rising tide or dementia epidemic. That is, Dr. Gordon’s timely talk drew my attention to two studies, in Britain and Denmark respectively, that were recently published in *The Lancet* and that disrupt the dominant dementia forecasts:

[The studies] soften alarms sounded by advocacy groups and some public health officials who have forecast a rapid rise in the number of people with

dementia, as well as in the costs of caring for them. The projections assumed the odds of getting dementia would be unchanged. Yet experts on aging said the studies also confirmed something they had suspected but had had difficulty proving: that dementia rates would fall and mental acuity improve as the population grew healthier and better educated. (Kolata, 2013, paras. 3-4)

This new research also supports the notion that nurturing the social determinants of health – education and good health over the lifespan – could also reduce the prevalence of dementia and reduce its economic impact on the health care system. So while the RT policy document recommends healthy diet and lifestyle choices on an individual level, a step further to ensure these healthy choices are available to all Canadians through collective means might make the recommendations even more effective. Interestingly, the Alzheimer Society of Canada webpage for the RT policy document – “this ground-breaking research study” (ASC, 2013a, para. 6) – now reads:

Is the prevalence of dementia declining?

Unfortunately, this is not the case.

It’s true that **some kinds of dementia**, which can be caused by lifestyle factors and environment, **are declining in percentage of growth**. This is because as we eat better and live healthier lives, the instances of heart attack and stroke, two factors that can cause cognitive impairment, are reduced. However, it’s important to note the **number of people across the globe with dementia is climbing**, and as baby boomers age, dementia is becoming a health crisis. (ASC, 2013a, paras. 1-4, assorted emphases in original)

Ultimately, the updated website for the RT report works to protect the discursive state of dementia crisis as an uncontroversial fact now constructed not only as a national threat, but also a global one. So while the European studies may “soften” the dementia alarm, the Alzheimer Society is ringing it loud and clear. For instance, the “Get Involved” webpage reads: “New staggering figures show that the dementia crisis in Canada is worse than we

thought. The story hasn't changed, but the numbers are alarming" (ASC, 2012a, "Impact of dementia in Canada," para. 1).

Genealogical Discourse Analysis: Resistance and Counter-Discourse to Neoliberal Priorities

As noted in my methodology chapter, a Foucauldian, genealogical approach to discourse analysis tries to examine "possible ways of thinking differently" from the dominant discourse to make space for resistance and disruption to open "possibilities for life" (Tamboukou, 1999, p. 203). As a child, reportedly, Foucault wanted to be a goldfish simply to see and understand the world differently (O'Farrell, 2005, p. 20). The poststructural researcher must also do this metaphorical goldfish work to try to problematize the present and notice expressions of alternatives to commonly held assumptions about the world. In the RT and IBCC policy documents, two disruptive discourses challenge dominant, contemporary discourses rooted in the neoliberal social values of economic restraint and individualized responsibility for dementia care. These counter-discourses advocate for the development of elder-specific care sites in hospitals and improved funding for long-term care services.

Elder-specific care sites in hospital.

The IBCC report cautiously resists neoliberal notions of individual responsibility and reduced government services by gently advocating for the introduction of "more transitional care units, Acute Care of Elders (ACE) units as model, and secure acute units to enable safe wandering" (Donnelly et al., 2011, p. 17). Another suggestion is made in the appendices not to build an ACE unit per se, but to mimic one in current facilities as best possible: "Group patients with dementia into a certain area of the hospital and develop staff

interest in those areas so that they are akin to ACE Units” (Donnelly et al., 2011, p. 60). So while presumably working within budgetary restraints, this somewhat watered-down ACE unit proposal nonetheless presents a disruption to the dominant discourse promoting the primary goal of preventing the hospital admission of persons living with dementia, and makes a small space for the consideration of creating something different and respectfully specialized within the acute care hospital. So in contrast to the statement that “emergency departments are not designed in a way that facilitates care of patients with dementia” and thus the recommended exclusion of this population from hospital care, the notion that a new design of architecture and service is necessary frames not dementia, but the health care institution, as a problem instead (Donnelly et al., 2011, p. 11). As an example, in the United States, Dr. Bill Thomas is credited with starting the first elder emergency department in 2008 (Martin & Rashidian, 2011, para. 7), in response to his “nation's rapidly growing population of older adults and overcrowding of emergency departments” where the “noise, chaos and crowding of typical emergency rooms have a negative impact on older patients” (Wikipedia, 2012, para. 1). Instead, geriatric emergency rooms are designed to reduce anxiety, confusion, and the risk of falling by incorporating handrails, non-skid flooring, pressure-reducing mattresses, soft lighting, and larger clocks (Martin & Rashidian, 2011, para. 2) as well as a health care team including “physicians, a geriatric nurse practitioner, registered nurses and a social worker, all specially trained in geriatric emergency medicine” (Holy Cross Hospital, 2014, para. 3).

Improved funding for long-term care.

Another way both policy documents resist the neoliberal priority to reduce health care spending is to promote – at least gently – improved funding for long-term care homes.

For instance, while acknowledging that “although residential facilities care for people with complex care needs, staff may be insufficient or not have the necessary expertise, knowledge, skills, abilities, and attitudes to meet these needs” (Donnelly et al., 2011, p. 11), the IBCC report suggests that “policy changes may be necessary in the form of better funding for long-term care facilities . . . to improve early management of preventable conditions” (Donnelly et al., 2011, p. 12). Admittedly, the stated goal is not to improve quality of life, but to prevent individuals with dementia from being admitted to hospital. Nonetheless, any recommendation to “better fund” health care is radical in the neoliberal economic context, which the IBCC policy document seems to recognize almost with remorse:

Although *community resources* were considered outside the scope of this project, the project proposal called for attention to be paid to the goal of reducing unnecessary trips to the hospital for persons with dementia as a lens to be applied through the course of the project. Therefore, some information and focus group comments are directed at how to achieve such purposes. (Donnelly et al., 2011, p. 7, emphasis added)

The RT report also addresses long-term care funding, but it is even more careful about managing expectations. Unlike the IBCC which recommended “better” funding, the RT report suggests to:

. . . ensure that long-term care is funded at a level that permits the availability of staff trained in understanding dementia, skilled in the management of the psychiatric and behavioural symptoms of dementia, and deployed to ensure that residents have days filled with social interaction, physical activity and nutritious meals. (ASC, 2010a, p. 51)

As a result, in the neoliberal climate, even when apparently imagining good care, expectations are limited to staff “managing” behaviour and “deploying” opportunities for social interaction and nutritious meals. Is this version of long-term care somewhere people actually want to live? To be fair, the RT policy document does also mention in passing that

long-term care should be “dementia-friendly” (ASC, 2010a, p. 54) and “as home-like as possible,” but only when long-term care is “required” (ASC, 2010a, p. 39). Overall, then, the RT and IBCC policy documents resist, although in a somewhat constrained way, neoliberal priorities to reduce government services in long-term care. In the spirit of greater resistance though, I would like to offer a more emphatic view on the urgency of taking the risk to envision elder-friendly dementia care:

What you're seeing right now is the end of the American nursing home. It is finished. And the big question that really ought to be on the lips of the politicians and the leaders and the academics is, what comes next? . . . the biggest problem is that nursing homes are anathema to most people . . . In long-term care, love matters. And the heart of the problem is, institutions can't love. When we rethink our mass institutionalization of elders, when we do these things, we're not just making a better life for the elderly, we're making life better for everybody in every part of society. (Thomas, 2002, as cited in Dentzer, 2002)

CHAPTER FIVE: Discussion

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. . . . Alternative discourses challenge what is known and provide new possibilities for being and relating. (Mitchell, Dupuis, & Kontos, 2013, p. 14)

Those who research dementia and those who work with people living with dementia may benefit from considering the powerful sway of the wider cultural narratives in which they are inscribed. (Zeilig, 2013, p. 9)

Thanks to Foucault's archaeological and genealogical tool boxes, and by pedaling through and contemplating the related questions outlined in my data analysis method section, I have been able to better understand the workings and materiality of the dominant dementia discourses in two particular contemporary policy sites, namely the IBCC and RT reports. As Zeilig (2013) suggests, I feel I have benefited from "considering the powerful sway of the wider cultural narratives in which [I am] inscribed." However, I find myself writing timidly now. I am aware of the inherent messiness of my research project into the insidious yet blatant discourses about people living with dementia and the neoliberal conditions of possibility. It suddenly seems rather bold and risky to start summing up and wrapping up all this messiness. I have a sinking feeling that what I have written "may appear critical of the current situation" (Donnelly et al., 2011, p. 1) in dementia health care policy in Canada and more locally in the health authority where I work in B.C.. Throughout the research process, I have been struck by the contrast in tone and approach in the two policy documents I examined, namely the urgency and heightened language of the RT report as opposed to the more nuanced nature of the IBCC report. As noted earlier, I chose these policy documents because they both address issues related to dementia and dementia care, but perhaps I now better appreciate how they each have a

distinct purpose and come from a particular context. The IBCC report was a collaboration between the B.C. provincial government and the B.C. Psychogeriatric Association, which is a “professional multi-disciplinary interest group” (BCPGA, 2014, para. 2). The IBCC policy document presents relatively hands-on recommendations about dementia practice to health care practitioners and administrators in the hospital setting with careful consideration of the current political restraint priorities. In contrast, the RT report was produced by the Alzheimer Society of Canada, a national dementia charity, which clearly is in an equivocal position to balance competing pressures while trying to strategically negotiate its advocacy goals to support people living with dementia and get political attention in a neoliberal context. I know mine is but one read of these two influential policy documents, just one critique which is very particular, personal, and situated. However, on a quick literature review update, I see that other critically-informed interpretations of dominant dementia discourses like the so-called rising tide and the dementia epidemic are appearing (Zeilig, 2013; Mitchell et al., 2013). Nonetheless I must be accountable for what I have learned. So just what have I learned and what use is it anyway?

From my poststructural time in the nooks and crannies of the IBCC and RT policy documents, I see that the ways that words and discourse are used to describe people living with dementia have material effects. That is, in a neoliberal context, when people living with dementia are framed as incapable, dependent, unproductive in the labour market, and unable to communicate even their personality, they become constructed as a social and economic problem – a threat to society. This is even more so because, as I have discussed in my analysis, people living with dementia are constructed as requiring – notably not deserving – care that is specialized and potentially expensive to the state and taxpayers. As

a result, and because neoliberal rationality permeates all social realities, people living with dementia and their friends and families are held accountable for their own care, and the possibility of a sense of collective responsibility to care lovingly and generously for our elder citizens gets lost and depoliticized. Let me now link my data analysis with my literature review as I review the descriptions of the dominant discourses in the two policy documents under study as well as their material effects. Finally, I will examine possibilities for transformation and resistance including personal implications for my social work practice and broader considerations for future research and policy development.

Archaeological Discourse Analysis: Describing Dominant Dementia Discourse

Both the IBCC and RT policy documents ultimately construct dementia and the needs of people living with dementia as a problem – as a crisis for the health care system, the economy, and the general population. This echoes the findings in my literature review which noted three key dominant dementia discourses, namely, biomedical, apocalyptic demography, and economic discourses, which problematize the condition. Clearly, biomedical discourses are evidenced in both policy documents in that people living with dementia are presented not only as requiring specialized health care, but also as being absent-person objects. They are effectively denied their personhood and not infrequently become conflated with their dementing disease itself. These medicalized descriptions of people living with dementia also favour the knowledge of “subject matter experts” – primarily medical experts – or what Chaufan et al. (2012) refer to as the “cult of expertise” (p. 794), over the experiences and voices of people living with the condition. Both policy documents exclude the voices of people with dementia. While discourses of person-centred care are invoked in the RT and IBCC policy documents indicating resistance to a simple

biomedical view, such person-centred views are repeatedly undermined denying the possibility of fully recognizing the subjectivity and intersubjectivity of persons with dementia as advocated in my literature review (Kitwood, 1997; Bartlett & O'Connor, 2007).

The apocalyptic demography and economic discourses about dementia flourish, and in a sense merge, in the two policy documents with statements describing people living with dementia as a growing, homogenous category of dependent, incompetent, and unproductive absent-person objects, requiring specialized and time-consuming care in an already stretched and impoverished health care system. Together with statements constructing dementia as an epidemic and rising tide, dementia is described as an economic burden on Canada, the ill-prepared health care system, taxpayers, corporations, and society: "Language around 'burden' and weight also recurs, as does the term crisis, and this is most often associated with financial imperatives" (Zeilig, 2013, p. 4). Dementia is described in the policy documents – explicitly in the RT report, and more implicitly in the IBCC report – as a concrete threat such that dementia, and by association people living with it, are to be feared. Zeilig (2013) concurs that "a range of emotionally charged metaphors about dementia pervades the popular imagination" (p. 1) and that dementia "which is so persistently associated with crisis, war, uncontrollable natural disaster, and death, has become synonymous with a general sense of calamity" (p. 4). Furthermore, as I noted in my analysis, the dominant apocalyptic discourse invokes a militaristic response to the constructed dementia threat as exemplified in the RT report with calls to mobilize all Canadians to participate in a "pan-Canadian response" or "national dementia strategy." Zeilig (2013) observes this framing of a supposed war against dementia in the British context as well: "Another recurring linguistic device in the cultural framing of dementia is

the reliance on military and war-like metaphors. So David Cameron . . . proclaimed: ‘We need an all-out fight-back against this disease; one that cuts across society’” (p. 4). Finally, researchers in the Canadian context, have, like me, observed the fear-mongering produced by apocalyptic descriptions of people living with dementia as an epidemic or rising tide crisis:

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. (Mitchell et al., 2013, p. 4, emphasis in original)

Genealogical Discourse Analysis: Materiality of Dominant Dementia Discourse

As I have demonstrated in my data analysis, the dominant dementia discourses in the two studied policy documents about people living dementia have material effects in terms of the proposed solutions to the implied dementia problem. Here I would like to discuss the explicit and implicit policy recommendations put forth in the IBCC and RT reports and the ways they support a neoliberal policy agenda.

Neoliberal agenda: Competition between citizens for care.

In my literature review, I drew on Gee (2000) who writes that the ideology of apocalyptic demography is used as a “tool” to promote neoliberal social policy reforms such as the retrenchment of the old age welfare state (pp. 5, 7). The dominant dementia discourses, including the epidemic dementia burden and rising tide, also perpetuate a sense of “intergenerational conflict” whereby younger generations are encouraged to see the elderly as a “rapidly growing” dangerous population whose “collective dependence is straining the economy while sustaining their self-interest and sacrificing the young” (Wang,

1999, p. 206). In turn, this supports the neoliberal value of market competition (Aronson & Smith, 2010) between citizens over health care services. As an example, in my data analysis, I noticed how the RT and IBCC policy documents actively work to discourage – even prevent – people living with dementia from using public health care services like the hospital and long-term care. Cynically, I wonder if this is in order to make restrained health care funds and services available for everyone else who is “dementia-free” (ASC, 2010a, p. 30). Furthermore, even the title, *Improving BC’s Care* (i.e. doing what we can considering economic constraints), signals less generosity and committed vision than the recent Ombudsperson Office’s (2012) report entitled *Getting it Right for Seniors* (i.e. doing the right thing based on morals beyond economics).

Private benefits: Deresponsibilizing the state and the collective.

Similarly, as I examined in the archaeological section about the contradiction in the RT and IBCC policy documents about people living with dementia being constructed as needing specialized care, but not in the health care system, I am also curious about the material effect of the epidemic metaphor. That is, while language of a dementia epidemic is used extensively in the RT report, it is simultaneously disconnected from the health care system – since both policy documents discuss preventing and delaying the admission of persons with dementia to hospital and long-term care – which presumably would actually be most appropriately positioned to respond to a medical epidemic. Instead, individuals with dementia and their families become responsabilized to self-manage and provide this specialized care in their homes for as long as possible. The responsabilization of individuals is normalized in a neoliberal economic and political context that values self-care over collective care and ultimately “[undermines] collective political and social solidarities” and

responsibilities (Smith, 2005, p. 79). As a result, the recommended solutions in the RT and IBCC policy documents direct unpaid caregivers to improve their capacity to cope while managing persons living with dementia at home who have been constructed as chaotic and expensive: “Caregivers must discipline not only the bodies of people with dementia, but also their own bodies to perform this work” (Brinjath & Manderson, 2008, p. 612). Furthermore, Innes (2002) reminds me that care work is gendered and the dominant assumption is that “women will care and do not desire or need to be rewarded for this” (p. 495). The responsabilization of individuals also works to produce an ideal, active female “citizen capable of self-government and capable of managing [her and the dementia subject’s] own risks” (McDonald & Marston, 2005, p. 381) with essentially no collective social or political support.

I can see how the recommendations in the policy documents are “designed to produce particular ways of behaving matched to the needs and purposes of society” (McDonald & Marston, 2005, p. 381), which prioritize protecting the national economy and producing a *homo economicus* population (Brown, 2005), over community and individual economic, social, spiritual, physical, and emotional needs. For instance, in a recent B.C. government news release, the Minister of Health is quoted proclaiming the benefits of the “Home is Best” philosophy, which clearly highlights cost-savings to the state as a significant impetus underlying the “Home First” program:

“Providing care to individuals in their home rather than hospital is one example of a suite of integrated primary and community care programs underway in health authorities to better support patients, their families and caregivers,” said Health Minister Margaret MacDiarmid. “Keeping people out of acute and residential care [long-term care] also benefits the health system as these are often our most costly forms of care.” (MOH, 2013, p. 1)

Clearly, the neoliberal “purposes of society” to reduce government spending and services are determining factors in the development of the Home First program, which also aligns with federal funding transfer priorities that highlight home care and hospital wait times as key health care policy development areas (Armstrong, 2012, p. 325). And, as I noted in my data analysis, ultimately individual family members, friends, and health care staff (i.e. the Home First team of “home and community care clinicians, a nurse practitioner and a community-based pharmacist”) are held accountable for saving the state and taxpayers health care related costs with relatively little public support (MOH, 2013, p. 7). So, if unable to negotiate care at home or to continue providing care at home, responsabilized individuals are likely well-versed in the discourse making it clear that space for people living with dementia is limited in long-term care facilities, and that hospitals are not safe for this population and admission must be prevented unless absolutely necessary. As a result, by implication, private care – in the form of home support, long-term care, etc. – is normalized as the responsible choice – often the only choice – at the neoliberal buffet regardless of whether this is affordable or desirable on an individual or collective level. Overall, business or promarket approaches to health care are legitimized over care or needs-based ones (Smith, 2011; Baines, 2011; Baines, 2008). As the collective and the state are deresponsibilized from providing public health care services, for-profit corporations benefit by stepping, apparently seamlessly, into service gaps created by neoliberal political restraint policies. Does the public realize this is happening to their supposedly public health care system and “the services they need and expect” (Morton, 2013, p.1)?

Moral panic: Care with exception and exclusion.

Through the process of individualization, demonization and stigmatization, moral panics publicly identify individuals or groups who do not conform to the new codes of behaviour expected of them, symbolically defining them as posing a risk to society, and legitimizing their regulation, control and social exclusion. (Young, 1999, as cited in Ajzenstadt, 2009, p. 71)

The socially constructed nature of dementia has led to the application of the label 'demented' to symptoms and behaviours not well understood by those who are not so labelled. By categorising individuals as demented . . . society can re-impose order onto the situation that is difficult to understand and, in the process, label the person with dementia as different and therefore potentially deviant. (Innes, 2002, pp. 484-85)

I would like to consider the ways the dominant dementia statements and discourses in the RT and IBCC policy documents – and beyond – unnecessarily fuel a “moral panic” (Altheide, 2009) about dementia that works to *other* or exclude people living with dementia from the collective community. Broadly defined, a moral panic is “the mobilization of strong social sentiment against perceived threats to the social order” (Odartey-Wellington, 2009, p. 26). The construction of moral panic works to “reinforce stereotypes, and perpetuate existing divisions, both societal and global, while simultaneously inciting fear” (Collins, 2012, p. 108). A brief literature review shows that moral panics have been produced in Canada about a wide range of perceived threats including obesity (Patterson & Johnston, 2012, p. 265); ecstasy use at Toronto raves (Hier, 2002, p. 33); the “Sharia law debate” in Ontario (Razack, 2007, pp. 7- 8); youth crime (Schissel, 1997, p. 10); single motherhood (Evans & Swift, 2000, p. 89); and “Muslim terrorism” and the racial profiling of Muslims, Arabs, and other visible minorities (Odartey-Wellington, 2009, p. 26). As Hier (2002) contends, moral panic serves a particular purpose such that the heightened discursive transformation of a social issue “into a set of risks and dangers . . . serve[s] political – and morally regulative – ends” (p. 36). As an example, Evans

and Swift (2000) note that the news media's construction of a moral panic about single mothers during the mid-1990s worked "to strengthen hegemonic discourses posing the proper role of the state not as support but as control, reshaping and repositioning 'problematic' social groups" (p. 89). It also worked to construct single mothers as "undeserving of public sympathy and help[ed] legitimize and entrench shrinking public provision and retrenching the welfare state" (Evans & Swift, 2000, p. 73).

Turning back to dementia once again, clearly "there is a growing social fear of a tidal-wave of older people with needs that exceed the capacity of a society to meet" (Clarke, Wilkinson, Keady, & Gibb, 2011, p. 87). The IBCC report takes up similar "capacity" language, although with a somewhat more neutral tone than Clarke et al. (2011), implying that while it is important to "improve health outcomes for seniors," the broader goal is to "increase the system capacity to provide care for everyone" (Donnelly et al., 2011, p. 84). And as I have indicated previously, while the RT report argues that the state's "meagre and uneven policy response to [dementia] leaves an enormous gap" (ASC, 2010a, p. 2) that needs to be addressed, the policy document's emphasis on constituting dementia as an economic threat to social functioning does more to fuel moral panic about seniors than incite the government to take social justice action. Politicians and the media also play into the production of economic moral panic through rhetoric and inaction. For example, in a recent news article, the federal Minister of Human Resources warns that "as the baby boomer generation retires . . . the total cost of benefits will be increasingly unsustainable for tomorrow's workers and taxpayers . . . and it's the next generations of Canadians who will have to shoulder the burden" (Finely, 2012, as cited in Curry & Baluja, 2012, p. A4). To heighten the panic, the neoliberal federal government's construction of seniors as a

problem “actually calls into question *the sustainability of everything else*” as well (Nanos, 2012, as cited in Curry & Baluja, 2012, p. A4, emphasis added). Similarly, Prime Minister Harper (2012) argues that Canada’s aging demographics constitute ““a threat to the social programs and services that Canadians cherish”” (as cited in Kennedy & Press, 2012). Or, consider the crisis tone in the federal NDP’s “Statement by Official Opposition Health Critic Libby Davies on World Alzheimer’s Day” in September 2013:

These alarming statistics are only going to get worse. . . . *Alzheimer’s wreaks havoc wherever it strikes. . . .* As a result, the NDP has proposed a national strategy for neurodegenerative diseases, to limit the impact of diseases like Alzheimer’s on our health, economy, and society. (NDP of Canada, 2013, para. 3, emphasis added)

The constitution of people with dementia as a threat to “our health, economy, and society” can also be seen to support fear-mongering that legitimizes their “social exclusion” (Razack, 2008, p. 178) from excellent health care in “our” system. What is most chilling from my time with the RT and IBCC policy documents is the insidious but nonetheless powerful implication that persons living with dementia may receive care, but that this care will not be exceptional or rooted in a collective desire to care well for our elders, but a barebones care with severe exceptions and exclusions.

Resisting Dominant Dementia Discourse

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. (Mitchell et al., 2013, p. 14)

Language and discourse in solidarity with people living with dementia.

As I have shown, the dominant discourses about people living with dementia constructing them as a rising tide and threat to the health care system, economy, and society have negative material effects on the lives of people living with dementia, for example, by ignoring their voices and experiences, and excluding them from public health care services. Referring to the literature, I am heartened by advocacy for resistance to such dehumanizing, objectifying, and *othering* dementia discourses not only in solidarity with people with dementia, but with the human collective as a whole. For example, like Mitchell et al. (2013) who advocate for the “critical examination” of social policy and for a rebellion against discourses that “diminish personhood for others and ourselves” (p. 14), George (2010a) also champions a solidaristic approach to dementia discourse:

Choosing new language patterns can reshape our thoughts, attitudes, and actions towards our ageing neighbours and our own ageing brains, giving rise to a slightly different and more life-affirming reality that connects us to those who are ageing instead of hastening their social death. (p. 587)

According to Mitchell et al. (2013) such “life-affirming” language “inspires and enables respect, love, creativity, and compassionate relating . . . when embracing difference with persons with dementia” (p. 14). In this frame of mind, difference is not a threat, but something to be acknowledged and honoured. Instead of exclusion, the social collective might work to support solidarity with people living with dementia in our home places to

“heighten attention to the ethical responsibilities we all have to persons with dementia” (Mitchell et al., 2013, p. 1).

Knowing persons with dementia as unique individuals and acting on their knowledge.

Another way to resist objectifying, homogenizing, and exclusionary dementia discourses is to treat people living with dementia as people and unique individuals within community. There are glimmers of person-centred approaches and discourse in the RT and IBCC policy documents, at least in appearance but they are not fully developed or enacted. For instance, consider the practical and relational “Look at Me” tool in Appendix I of the IBCC report which encourages health care staff to walk in the shoes of the person with dementia by considering what the person feels (e.g. itchy, bored, lonely, angry); what the person is doing (e.g. fidgeting, singing, pacing); and what the health care staff can do for the person (e.g. do a pain assessment, help me connect with my family, help me feel needed) (Donnelly et al., 2011, p. 93). Written in the first person from the perspective of the person living with dementia, this tool asks health care staff to deeply see and consider the self-expression and needs of the person with dementia in front of them; to humanize the person in a relational way and appreciate that their behaviour has meaning. On a broader level, and as I noted earlier, an alternative to dominant exclusionary dementia discourses is mentioned in passing in the RT report, noting the Dutch practice “of building a national strategy on the foundation of problems identified, experienced and prioritized by individuals with dementia and their caregiver” (ASC, 2010a, p. 41). Clearly, this would center persons with dementia and their caregivers as “subject matter experts” whose opinions and experiences deserve not only to be known and heard, but acted upon.

The literature similarly advocates for including rather than excluding the knowledge of people living with dementia as a disruptive act to the fear-mongering of dominant dementia discourse:

There is an imperative to explore the subjective experience of dementia if researchers and practitioners are not to impose their own pervasive concerns with the meaning of dementia . . . [and] efforts to grapple with the nature of the relationship between those who are already old . . . and those who will yet 'become old in the future.' (Innes, 2002, p. 491)

Listening to the “subjective experience of dementia” might also support the possibility that persons with dementia are not in our communities to be feared, but “here to teach us something” (Alonzo, 2013, as cited in Mead, 2013, p. 94). Kitwood (1997) suggests that people living with dementia invite us “to return to aspects of our being that are much older in evolutionary terms: more in tune with the body and its functions, closer to the life of instinct” (as cited in Mead, 2013, p. 98). And while teaching the value of human experience beyond memory and thinking, dementia can also be perceived as having a spiritual purpose that offers alternatives to neoliberal social priorities of independence and economic productivity: “Valorizing dementia as a higher state of being may strike many people as bizarre, . . . yet our society does tend to prize cognition and executive function at the expense of other essential human qualities: sensuality, pleasure, intimacy” (Mead, 2013, p. 102). Alonzo (2013) articulates this spiritual perspective further:

“[People living with dementia are] closer to the higher being. This is who they are: real, honest, and sometimes raw. There is no ability to reason, or to cover up who you really are. And so, for much of the time, you see the loveliness of the soul – it is bare for everyone to acknowledge.” (as cited in Mead, 2013, p. 102)

I wonder hopefully if such an openness to the “loveliness of the soul” of persons living with dementia might make space for possibilities to not only know them as individuals but also in relationship as members of the social collective?

Challenging neoliberalism: From moral panic and individualism to collective social morality.

We need a protest against the limitations of consumerism and positivist reasoning, which carries us away in a maelstrom of calculus thinking. We need to be alert, and we need to have a concern for the uniqueness and fragility of each and every human life. (Adlandsvik, 2007, p. 668)

To resist the construction of a moral panic in response to dementia and the care needs of people living with dementia, social values beyond self-management and economic bottom-lines must be nurtured. Brown (2005) states that, “a governmentality of neoliberalism works to [eviscerate] nonmarket morality” (p. 52). I see an opening for conversation about developing policy that embraces this threatened “nonmarket morality,” that taps into collectivity and our desires “not for wealth or goods but for beauty, love, mental and physical well-being, meaningful work and peace – manifestly unmet within a capitalist order and to appeal to those desires as the basis for rejecting and replacing the order” (Brown, 2005, p. 57). Perhaps this could also extend to acknowledging human interdependence and nurturing possibilities for a “moral economy” where “people do not feel they have to sacrifice their values, harm human dignity or compromise ecological health in order to achieve economic security” (Boyle & Klein, 2013, “Defining a moral economy,” para. 2). For example, the vision of moral economics prioritizes “social good” – the well-being of all, young through old – such that:

The health and security of each family is mainly protected by enhancing the well-being of the entire society, a principle at the heart of public health care. In such an economy, many of our core needs – for housing, childcare, education, healthcare, retirement security – are provided collectively. . . . In

a moral economy we seek to uphold a social contract based on mutual responsibility, sharing and cooperation, rather than competition, hoarding and accumulation. (Boyle & Klein, 2013, "Jobs," para. 1)

Instead of constituting people living with dementia as a rising tide or epidemic burden that threatens the economy and society, we might calmly acknowledge our fears about dementia but also our desires to provide care collectively that is creative, generous, flexible, and in community; care that any of us would be happy to receive and the reassurance that we are welcome to it. Just knowing that a multiplicity of exceptional dementia and elder care supports are available through collective efforts and desires might make the diagnosis of dementia less scary:

Every human being begins life utterly reliant on kindnesses he can neither remember nor repay, and many of us will end our lives in a similar state. . . . It is only as members of communities that any of us can hope to transcend forgetfulness and death. Why then should a person be cast out and abandoned, condemned to social death, and denied recognition as a friend, a person, a fellow human being, just because she shows signs of succumbing to the same forces that we know will eventually claim each one of us? (Taylor, 2008, p. 333)

Implications for practice, future research, and policy development: Getting to know people living with dementia and nurturing community.

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). (Mitchell et al., 2013, p. 6)

Admittedly, neoliberal politics are a mighty force to contend with, but they are not just external to me, they are also within me. I have taken on the subject position of a responsabilized social worker in dementia care who is well-aware of the financial implications of my tasks. For instance, the health authority "loses money" due to "bed loss

days” when delays occur in “filling beds” after resident deaths. These delays can occur because we are trying to ensure the move-in for the person with dementia will be as smooth as possible and that the new environment is a good fit for them and all the people who already live there. It is easy to feel a need to rush the human, relational, and solid process aspects of move-ins to save the health care system dollars. In my day-to-day practice in long-term care for people living with dementia, a radical, resistant act to the materiality of neoliberal economic burden discourses, then, is just to slow down the move-in process, even a bit, to nurture values beyond economics such as humanity, connection, and getting to know a person’s needs, wishes, and that which they find meaningful. Another gentle disruptive act might be to simply spend more time listening to and being with the people who live where I work. While this might not be considered “productive” in a neoliberal promarket sense, it is “productive” if we value compassion, gentleness, relationship, and being in community. It is true that I feel relief when I have worked down my “to-do” list, especially when facilitating someone’s move into an empty room. I am glad they are receiving support, but also feel like a good social worker because the room is not sitting empty “wasting” the health care system money. It is also true, however, that my best days, the days when my heart really bursts with light, are the days when I have felt a connection with one of the residents or a family member and their life story, in their sorrow, joy, fear, humour, boredom, and beyond – in the moment. I need to see this as productive for me and hopefully for the person living with dementia as well regardless of what the neoliberal voices in my head are saying. As I noted earlier, Wang (1999) suggests that poststructural analysis nurtures transformation by supporting resistance both in the

object of the research (e.g. people living with dementia and dementia care policy) and the researcher – myself (p. 214).

It is essential that future research and policy development also nurture the participation of people living with dementia so that their voices and ideas are included in imagining, planning, and preparing dementia supports and care. The dominant apocalyptic and economic crisis discourses like the rising tide and epidemic burden evidenced in the RT and IBCC policy documents invoke calls for disaster planning through individual responsibility for well-being and only barebones public services as if in response to an actual natural disaster. On the west coast of B.C., for example, we are similarly responsabilized to prepare for 72 hours of independent survival in the wake of an earthquake and the language is not dissimilar from dominant dementia discourse:

Strong earthquakes may trigger tsunami.
If you are near the ocean during an earthquake, DROP, COVER,
and HOLD ON. When the shaking stops quickly walk to high ground . . .

Are you prepared?
Do you have an emergency kit stocked with enough food, water
and supplies for everyone in your home? . . .

Thank you for taking part in the Great British Columbia ShakeOut! (Southern California Earthquake Center, 2013, p. 1)

Fortunately, however, and despite dominant crisis discourses, dementia is not a natural disaster. Dementia comes with aging and all citizens – taxpayers, politicians, and corporate CEOs alike – are going to age and many of us will likely become forgetful. In preparation, instead of minimalist disaster planning, I would like to propose that future research and policy development champion exceptional dementia supports and care planning so that people living with dementia may live in community as valued members now and in the future. Furthermore, future research must also articulate the ways that providing such

exceptional and generous support and care will benefit not only people living with dementia and their families, but all of us – the collective. We must not compete for care, but share care. After all, the opportunities created by dementia are not reducible to “*us versus them,*” but to “*them is us.*”

CHAPTER SIX: Conclusion

In the previous chapters, I have unpacked dominant crisis-focused discourses about dementia – e.g. the “rising tide,” the dementia “epidemic,” the lack of preparedness to provide “specialized” dementia care, and the “economic burden” of dementia – in two contemporary dementia policies. My literature review explored the discursive, structural, and neoliberal political context of the Canadian health care system with a particular focus on the provision of dementia care. I then outlined my research design to define and demonstrate how I implemented poststructural discourse analysis tools, namely Foucault’s archaeology and genealogy, as well as poetic representation, to examine dementia discourses in the IBCC and RT policy documents. My data analysis and discussion chapters explored the construction of dominant dementia discourses within a neoliberal rationality by examining the constituting statements and contradictions which produce persons living with dementia and their needs as an overwhelming crisis that threatens not only the health care system, but also the Canadian economy. I also considered practices – such as a diminished collective and state role in health care, individual responsabilization for dementia care, increased privatization, and moral panic, which serve to enact dominant dementia discourses. Finally, I discussed openings for resisting these crisis discourses by promoting language in solidarity with people living with dementia and challenging individualistic and promarket neoliberal assumptions by supporting collective social responsibility and nurturing communities.

As I have demonstrated in my poststructural discourse analysis of the RT and IBCC reports, neoliberal rationality that prioritizes individual autonomy at any cost denies the realities of human interdependence and seeds doubts about possibilities for collective care.

A neoliberal focus on economics and marketization also distracts us from imagining and envisioning the dementia care we might actually want for ourselves. While such dementia care imaginaries may cost more or less than current supports and services, the point is that we – in solidarity with people already living with dementia – must start imagining them. We must also acknowledge, and generously address, the social determinants of dementia to help reduce the prevalence. We must understand though that people living with dementia are not *other* or *them*; they are *us*. All humans age and forget and if we are blessed with old age, we may well develop dementia. I want people living with dementia to be part of my community at work, at home, and in my neighbourhood. Here is to interdependence and compassion over fear.

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Appendix A: Found Poems with Citations

dementia crisis looms (Duffy, 2010)

dementia a 'ticking time bomb' (CTV News, 2012)
 huge wave of dementia cases coming (CTV News, 2010)
 costs to soar as aging Canadians face (Picard, 2010, pp. A1-A2)
 rising tide of dementia (Picard, 2010, pp. A1-A2)
 province faces crisis (Crawford, 2013)
 B.C. will be hit (Bermingham, 2010, p. A6)
 a tidal wave of dementia patients: (Bermingham, 2010, p. A6)
 are we ready for this dementia tsunami (O'Connor, 2011)?

one poem found in my proposal (MacLeod, 2013)⁵

proposal to thesis (MacLeod, 2013)
 intuition: on? off? muddling (MacLeod, 2013)
 a commitment (hooks, 2003)
 to complex analysis (hooks, 2003)
 letting go of wanting everything (hooks, 2003)
 to be simple (hooks, 2003)
 bicycle (Potter & Wetherell, 1987) tool box (Foucault, 1974)
 bricoleur (St. Pierre, 2005)
 problematization of the present (Koopman, 2013)
 speech of madmen (Foucault, 1970/1981) and students (MacLeod, 2013)
 a certain blind faith (Taylor, 2001)

thesis writing horrorscope (MacLeod, 2013)

this is not a day for deep thought (Yahoo Lifestyles Network, 2013)
 you might not even be able (Yahoo Lifestyles Network, 2013)
 to get a grasp (Yahoo Lifestyles Network, 2013)
 on the essentials (Yahoo Lifestyles Network, 2013)
 so just do your best (Yahoo Lifestyles Network, 2013)
 and try to figure it all out (Yahoo Lifestyles Network, 2013)

⁵ Please note that "MacLeod, 2013" indicates text that I have taken the liberty to add to the otherwise "found" poem.

later (Yahoo Lifestyles Network, 2013)
 get a friend to help (Yahoo Lifestyles Network, 2013)
 piece it together (Yahoo Lifestyles Network, 2013)

differentiating the 3Ds (Donnelly et al., 2011, p. 78)

dementia (Donnelly et al., 2011, p. 74)
 depression (Donnelly et al., 2011, p. 74)
 delirium (Donnelly et al., 2011, p. 74)

death (Donnelly et al., 2011, p. 36)
 decay (Donnelly et al., 2011, p. 103)
 dealing with *them* (Donnelly et al., 2011, p. 103, emphasis added)

acute care (Donnelly et al., 2011, p. 15)

acute care (Donnelly et al., 2011, p. 15)
 welcomes (Donnelly et al., 2011, p. 15)
 one thing wrong at a time (Donnelly et al., 2011, p. 15)

persons with dementia (Donnelly et al., 2011, p. 15)
 complex (Donnelly et al., 2011, p. 15)
 many things wrong (Donnelly et al., 2011, p. 15)
 all at once (Donnelly et al., 2011, p. 15)

hospitalization offers older patients . . . (Donnelly et al., 2011, p. 80)

risks of (Donnelly et al., 2011, p. 80)
 adverse events (Donnelly et al., 2011, p. 80)
 functional decline (Donnelly et al., 2011, p. 80)
 prolonged stays (Donnelly et al., 2011, p. 1)
 worse outcomes (Donnelly et al., 2011, p. 1)
 more likely to be restrained (Donnelly et al., 2011, p. 31)
 with less morphine sulphate (Donnelly et al., 2011, p. 31)
 than those with intact cognition (Donnelly et al., 2011, p. 1)

hospital cruise ship (MacLeod, 2013)

offering hospital cruises (MacLeod, 2013)
for persons with dementia (MacLeod, 2013)

stay longer and (Donnelly et al., 2011, p. 9)
have a worse time (Donnelly et al., 2011, p. 9)
and with poorer outcomes (Donnelly et al., 2011, p. 11)
than while you were competent (Donnelly et al., 2011, p. 10; MacLeod, 2013)
or compared with cognitively (Donnelly et al., 2011, p. 15)
intact patients (Donnelly et al., 2011, p. 15)

repercussions can be costly (Donnelly et al., 2011, p. 80)
for hospitals (Donnelly et al., 2011, p. 80)
access and flow issues in the system (Donnelly et al., 2011, p. 80)
for patients (Donnelly et al., 2011, p. 80)
diminished quality of life (Donnelly et al., 2011, p. 80)

system problems (Donnelly et al., 2011, p. 10)

rooms with (Donnelly et al., 2011, p. 10)
no windows (Donnelly et al., 2011, p. 10)
no toilets (Donnelly et al., 2011, p. 10)
no place for family to be (Donnelly et al., 2011, p. 10)

burden of dementia (ASC, 2010a, p. 22)

annual total economic (ASC, 2010a, p. 27)
burden (ASC, 2010a, p. 27)
cumulative total economic (ASC, 2010a, p. 23)
burden (ASC, 2010a, p. 23)
monetary economic (ASC, 2010a, p. 22)
burden (ASC, 2010a, p. 27)
total economic ASC, 2010a, p. 22)
burden (ASC, 2010a, p. 22)
caregiver (ASC, 2010a, p. 19)
burden (ASC, 2010a, p. 19)
societal (ASC, 2010a, p. 23)
burden (ASC, 2010a, p. 23)

rising tide (ASC, 2010a, p. 14)

predicted surge (ASC, 2010a, p. 14)

threatens to overwhelm (ASC, 2010a, p. 14)

place a tremendous strain (ASC, 2010a, p. 26)

potentially overwhelming (ASC, 2010a, p. 26)

the country's (ASC, 2010a, p. 26)

health care system (ASC, 2010a, p. 26)

not equipped (Donnelly et al., 2011, p. 1)

the system (Donnelly et al., 2011, p. 15)

not designed (Donnelly et al., 2011, p. 15)

to accommodate (Donnelly et al., 2011, p. 15)

not equipped (Donnelly et al., 2011, p. 1)

to manage (Donnelly et al., 2011, p. 1)

complex health, behaviour (Donnelly et al., 2011, p. 1)

particular and unique needs (Donnelly et al., 2011, p. 15)

of people (Donnelly et al., 2011, p. 1)

with dementia (Donnelly et al., 2011, p. 1)

services (ASC, 2010a, p. 14)

broad spectrum (ASC, 2010a, p. 14)

maldistributed (ASC, 2010a, p. 14)

uncoordinated (ASC, 2010a, p. 14)

services (ASC, 2010a, p. 14)

delivered with (ASC, 2010a, p. 14)

little standardization (ASC, 2010a, p. 14)

little continuity (ASC, 2010a, p. 14)

training is limited (ASC, 2010a, p. 14)

Canada must act (ASC, 2010a, p. 14)

specific, targeted (ASC, 2010a, p. 14)

actions (ASC, 2010a, p. 14)

shift costs to caregivers (ASC, 2010a, p. 31)

the savings (ASC, 2010a, p. 31)
 in direct health costs (ASC, 2010a, p. 31)
 more than compensate (ASC, 2010a, p. 33)
 producing (ASC, 2010a, p. 31)
 Lower (ASC, 2010a, p. 31)
 Total Economic Burden (ASC, 2010a, p. 31)

'elder friendly' care (Donnelly et al., 2011, p. 83)

in other words (Donnelly et al., 2011, p. 83)
 appropriate and sensible (Donnelly et al., 2011, p. 83)
 care (Donnelly et al., 2011, p. 83)
 transformational change (Donnelly et al., 2011, p. 83)
 challenge deeply ingrained (Donnelly et al., 2011, p. 84)
 traditional ways of providing (Donnelly et al., 2011, p. 84)
 poor and inappropriate care (Donnelly et al., 2011, p. 84)

financial and human (Donnelly et al., 2011, p. 83)
 resource constraints (Donnelly et al., 2011, p. 83)
 effective interventions (Donnelly et al., 2011, p. 83)
 cannot be cost-effectively (Donnelly et al., 2011, p. 83)
 implemented (Donnelly et al., 2011, p. 83)

no clear solutions (Donnelly et al., 2011, p. 83)
 the problem will not (Donnelly et al., 2011, p. 84)
 completely go away (Donnelly et al., 2011, p. 84)
 on the eve (Donnelly et al., 2011, p. 84)
 of this demographic shift (Donnelly et al., 2011, p. 84)

most important point (Donnelly et al., 2011, p. 9)

to successfully (Donnelly et al., 2011, p. 9)
 managing (Donnelly et al., 2011, p. 9)
 treating (Donnelly et al., 2011, p. 9)
 caring (Donnelly et al., 2011, p. 9)
 for persons with dementia (Donnelly et al., 2011, p. 9)

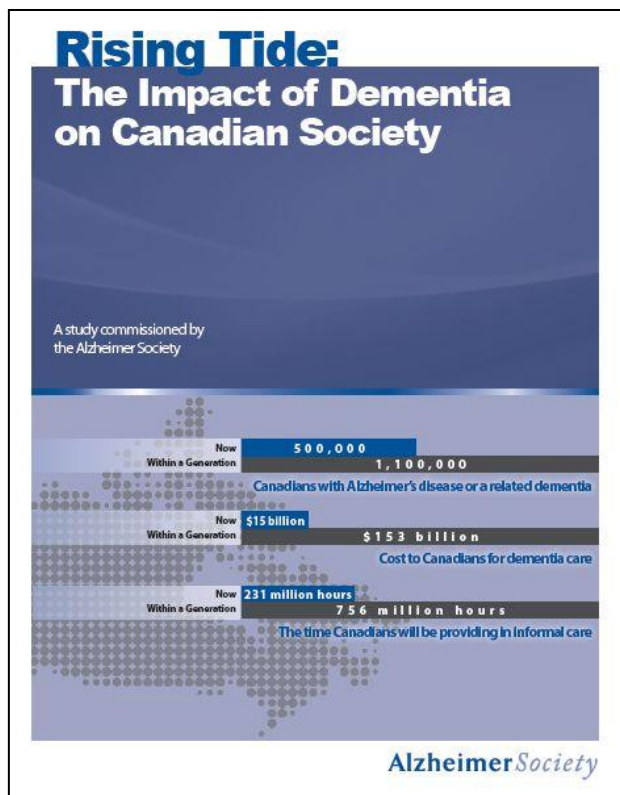
means (Donnelly et al., 2011, p. 9)
knowing the person (Donnelly et al., 2011, p. 9)

delay onset by two years (ASC, 2010a, p. 30)

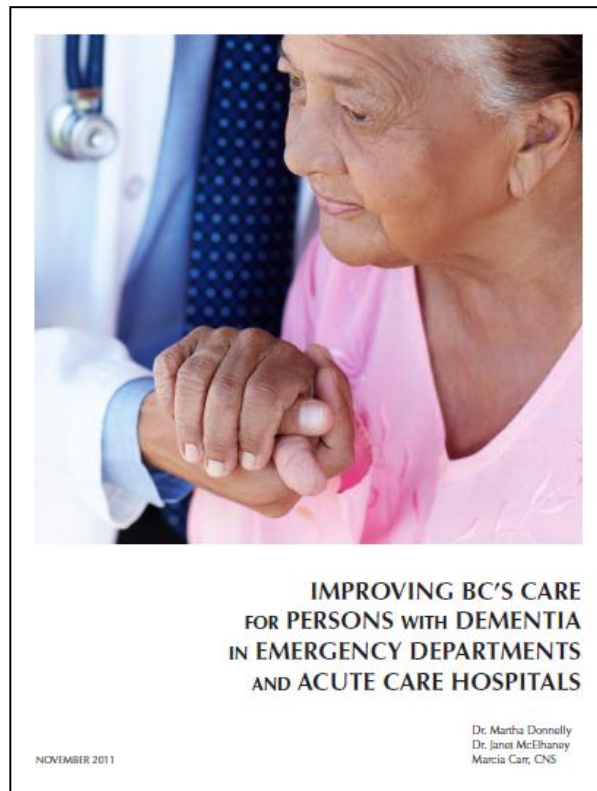
impact of (ASC, 2010a, p. 30)
hypothetical (ASC, 2010a, p. 30)
prevention (ASC, 2010a, p. 30)
program (ASC, 2010a, p. 30)
healthy diet and lifestyle (ASC, 2010a, p. 30)

fewer individuals (ASC, 2010a, p. 30)
living with dementia (ASC, 2010a, p. 30)
reduced constraints (ASC, 2010a, p. 30)
on health care resources (ASC, 2010a, p. 30)
and the health care system (ASC, 2010a, p. 30)

Appendix B: Policy Documents for Data Collection



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Appendix C: Selection of B.C. Policy Document

Many social policy documents have been produced in B.C. related to dementia and dementia care, at least tangentially, over the recent years which often reference each other, but without significant state action on the ground. For example, the British Columbia Office of the Ombudsperson (BCOO, 2012) released a report reviewing provincial senior care noting that the Ministry of Health had worked with stakeholders to produce the *B.C. Dementia Service Framework* in 2007 to develop “a comprehensive set of recommendations of practice, to guide the provision of dementia care” (p. 112). The BCOO (2012) also observes, however, that “despite the time and work invested in developing the framework [and money too presumably] . . . the ministry has not established standards, policies, services and training” (p. 112) specific to dementia care. Dementia-related policy documents in B.C. over the last two decades include by date order:

- B.C. Ministry of Health Services and Ministry Responsible for Seniors. (1992). *Services for elderly British Columbians with mental health problems: A planning framework*. Victoria, Province of British Columbia. [cited in BC Psychogeriatric Association, 2012];
- Centre for Applied Research in Mental Health and Addiction, Simon Fraser University, (September 2006). *Dementia Projections for British Columbia*;
- Provincial Dementia Service Framework Working Group. (September 2007). *BC Dementia Service Framework*;
- MacCourt, P. (March 2009). *Dementia Policy Lens Toolkit*;
- B.C. Ministry of Health & MCFD. (November 2010). *Healthy Minds, Healthy People: A 10-Year Plan to Address Mental Health and Substance Use In British Columbia*;
- B.C. Ministry of Health Services, Health Authorities Division. (January 2011). *Supporting the shift to integrated primary and community care: Priorities for Home and Community Care services*;

- **SELECTED B.C. POLICY DOCUMENT FOR THESIS:** Donnelly, M., McElhaney, J., & Carr, M. (November 2011). *Improving BC's Care for Persons with Dementia in Emergency Departments and Acute Care Hospitals: Findings and Recommendations*;
- B.C. Ministry of Health. (December 2011). *A review of the use of antipsychotic drugs in British Columbia residential care facilities*;
- British Columbia Office of the Ombudsperson [BCOO]. (February 2012). *The best of care: Getting it right for seniors in British Columbia: Overview (part 2)*. Public report no. 47 to the Legislative Assembly of British Columbia;
- B.C. Ministry of Health. (February 2012). *Improving Care for B.C. Seniors: An Action Plan*;
- B.C. Ministry of Health. (February 2012). *2012/13 – 2014/15 Service plan*;
- BC Psychogeriatric Association [BCPA]. (March 2012). *Meeting seniors' mental health care needs in B.C.*;
- B.C. Ministry of Health. (October 2012). *Best practice guideline for accommodating and managing behavioural and psychological symptoms of dementia in residential care*;
- B.C. Ministry of Health. (November 2012). *The provincial dementia action plan for British Columbia: Priorities and actions for health system and service redesign*.

Appendix D: Data Analysis Table (Template)

Dementia Discourse Analysis			
Archaeological DA: Statements about dementia/people living with dementia that make up dominant discourses in policies			
Statements	Examples in IBCC	Examples in RT	Related Sources/ Comments
Archaeological DA: “Conditions of possibility” or “interplay of rules” for statements & discourses			
Conditions of possibility	Examples in IBCC	Examples in RT	Related Sources/ Comments
Archaeological DA: Describe contradictions in statements			
Contradictions	Examples in IBCC	Examples in RT	Related Sources/ Comments
Genealogical DA: Power/knowledge constituted through discourse – how are dom discourses productive?			
Productivity	Examples in IBCC	Examples in RT	Related Sources/ Comments
Genealogical DA: What practices, procedures, institutions enact discourses? (determine knowledge)			
Practices Enacting Discourse	Examples in IBCC	Examples in RT	Related Sources/ Comments
Genealogical DA: What is at stake?			
At Stake	Examples in IBCC	Examples in RT	Related Sources/ Comments
Genealogical DA: What is presented as uncontroversial ‘fact’?			
‘Fact’	Examples in IBCC	Examples in RT	Related Sources/ Comments
Genealogical DA: How is dementia constructed as a social problem?			
Problem	Examples in IBCC	Examples in RT	Related Sources/ Comments
Genealogical DA: What is presented as solution to ‘problem’ of dementia?			
Solutions	Examples in IBCC	Examples in RT	Related Sources/ Comments
Genealogical DA: What subjectivities offered for persons living with dementia, etc. and how positioned? What does this tell people without dementia?			
Subjectivity	Examples in IBCC	Examples in RT	Related Sources/ Comments
Genealogical DA: Resistances? Counter-discourses? Ways of thinking differently re: dementia?			
Resistance	Examples in IBCC	Examples in RT	Related Sources/ Comments