MITIGATING THE IMPACT OF STRUCTURAL DISCRIMINATION FOR PEOPLE WITH DEMENTIA RESIDING IN LONG-TERM CARE FACILITIES: AN ETHICAL FRAMEWORK BASED IN VIRTUE ETHICS AND FACILITATED USING A CITIZENSHIP LENS

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Abstract

Over the past century dementia has undergone numerous iterations, from being perceived as part of the aging process to its current perception as a pathology. This thesis presents evidence that dominant dementia discourse is influenced by ageist and ableist perspectives, is laden with tones of tragedy and fear, and creates normative assumptions about the condition and the people who live with it. I argue that such discourse influences institutional and societal behaviours, and can prevent people with dementia from achieving the same rights and opportunities that are available to others due to structural discrimination. This thesis also presents evidence that dementia-specific practices in long-term care facilities result in restrictions on rights and freedoms. Through an ethical analysis of these practices, this thesis examines how an ethical response using a citizenship lens and having human flourishing as its end can help to mitigate the impact of structural discrimination in dementia care.

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"Nothing is hard to a man whose will is set on it, especially if it be a thing to be done out of love."- Saint Ignatius of Loyola

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List of Abbreviations and Symbols

AHD	Advance Health Care Directive
DSM-5	Diagnostic and Statistical Manual of Mental Disorders- 5
ICD-10	International Classification of Diseases- 10
MAiD	Medical Aid in Dying
PEOLC	Palliative and End of Life Care
WHO	World Health Organization

Chapter 1: Introduction and Background

Over the past century our understanding and treatment of dementia has shifted. In the early 1900s, dementia among older people was not viewed as pathological or as a disease, but rather as a manifestation of the cognitive degeneration that is associated with aging. The labeling of dementia as a disease was reserved exclusively for younger adults who exhibited the same signs of cognitive degeneration that was prominent among older populations. Beginning in the middle of the 20th century, dementia among older adults increasingly became viewed as a disease due to the fact that it began to contravene the socially constituted idea of health and normality. Consequently, biomedical frameworks of dementia began to emerge and dominant dementia discourse began to evolve. Over time, ageist and ableist perspectives began to influence this discourse, which became increasingly laden with tones of tragedy and fear. The result was the creation of normative assumptions about people living with dementia that rendered them susceptible to institutional and societal attitudes and behaviours that prevented them from achieving the same rights and opportunities available to others. This is known as structural discrimination.

In the context of long-term care facilities, residents with dementia experience structural discrimination by way of by dementia-specific policies, such as exclusionary practices and restrictions on rights and freedoms. While the term dementia is often used interchangeably with Alzheimer's disease in everyday and institutional parlance, it is worth noting that the two should not be conflated. Dementia is the name for a group of

brain disorders that impair memory, decision-making and control over one's emotions. Alzheimer's disease is the most common type of dementia and is characterized by a build up of proteins and fibers in the brain, blocking nerve signals and destroying nerve cells. Vascular dementia is the second most common and is characterized by insufficient blood going to the brain. For the purposes of this paper, no distinction is made between dementia and dementia of the Alzheimer's type.

The goal of this thesis is to develop an ethics-based framework that uses a citizenship lens to mitigate the impact of structural discrimination for residents with dementia living in long-term care facilities. But why employ this lens in lieu of another? Bartlett & O'Connor (2010) describe a citizenship lens as being used to "promote the status of discriminated groups of people as equal citizens, with similar entitlements and rights to everyone else" (p.12). As such, this thesis uses a citizenship lens to perform an ethical analysis of various dementia-specific practices in long-term care facilities that infringe upon the rights and freedoms of residents with dementia in long-term facilities. This will be accomplished by tracing the evolution of the social construction of dementia among older people as problematic, and then by following the implications of this evolution for medical and media discourse. The impact of dominant dementia discourse will then be explored in terms of the consequences it has for the rights and freedoms for people with dementia who reside in long term care facilities. Following this, a possible framework that can help to mitigate infringements on these rights and freedoms will be presented.

To accomplish this, the global and national prevalence of dementia is explored in Chapter 1. In Chapter 2, the various dementia-specific practices that are used in long-term care facilities are presented. The role of dominant dementia discourse in the framing of dementia and those living with it is presented in Chapter 3, while the role of ageism and ableism in the creation of this discourse is explored in Chapter 4. Assessing the impact that dominant dementia discourse has on dementia care and the ensuing structural discrimination that arises from this is examined in Chapter 5. Chapter 6 deliberates upon the ethical issues that occur in long-term care facilities because of the structural discrimination that results from dominant dementia discourse; Chapter 7 provides an ethical analysis of these practices. Chapter 8 provides insights into the potential implications that structural discrimination in long-term care facilities can have in discussions about medical aid in dying (MAiD) and end-of-life decisions among Canadians who have dementia. Chapter 9 concludes this thesis with a summary of the evolution and reconfiguration of dementia over the last century, how this evolution has impacted dementia care in long-term care facilities, and how an ethical response using a citizenship lens can mitigate the impact of structural discrimination in dementia care. This thesis will now begin with a cursory introduction to the prevalence of dementia globally and nationally and what this means for dementia care.

1.1 Dementia and its Prevalence Globally and in the Canadian Context:

The World Health Organization's International Classification of Diseases- 10 (ICD-10) defines dementia as a progressive or chronic condition wherein the individual experiences memory and intellectual impairments that cause significant social and

occupational impairment. The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders- 5 (DSM-5) has replaced the word dementia with the term major neurocognitive disorder. Semantics aside, both classification systems are referring to the umbrella term used to describe the cognitive symptoms of memory loss, mood changes, and difficulties with thinking, orientation, comprehension, calculation, learning capacity, language and judgment. Research indicates that dementia incidence increases exponentially with an increase in age, with rates doubling every five years once individuals reach the septuagenarian cohort (Jorm, 1998). One perplexing question is why this occurs. Is it, as dominant opinion would have us believe, a pathology, a mental disorder, a disability? Or is there another explanation for why dementia incidence increases with age?

In *The Alzheimer Conundrum: Entanglements of Dementia and Aging* (2013), Lock charts the evolution of the categorization of dementia in its many forms: from the 19th and early to mid 20th century term used to denote "any state of psychological dilapidation associated with chronic brain disease" (p. 13) excluding that which is expected to occur in old age, to the all-encompassing term currently used to denote any psychological deterioration including those resulting from the normal processes of aging. Lock explains the "partial eclipse of Alzheimer Disease" (p. 36) throughout the majority of the 20th century as occurring due to findings in the 1930s that almost 85% of people who died at the age of 65 or older had senile plaques on their brains, suggesting that what was once termed senile dementia was in actuality an inevitable part of the aging process. Lock notes that it was not until the mid to late 20th century that aging became medicalized

and, subsequently, that dementia became more politicized resulting in the current pathologization of dementia with which we are now acquainted.

This pathologization is due in part to the social construction of aging and how that construction has shaped the body of medical knowledge pertaining to dementia. Brown (1995) notes that the social construction of medical knowledge focuses on "ways of knowing that are based on the dominant biomedical framework…"(p.37). With dementia becoming progressively viewed as a pathological and degenerative condition, it becomes problematized due to the fact that it begins to contravene the socially constituted idea of health and normalcy (Davis, 2004). One outcome of the problematizing of dementia is the implementation of policies that create and sustain a knowledge that is focused on "service delivery and the management of behavioural symptoms" of dementia (Hunter & Doyle, 2014) to the exclusion of creating psycho-social supports.

In 2012, the World Health Organization declared that Alzheimer's and other dementias will be the number one societal health crisis by 2030 (World Health Organization, 2012). Alzheimer's Disease International (2015) recorded the worldwide prevalence of dementia in 2015 as 46 million individuals, representing 6.3% of the world's population, with a projected global prevalence of 131.5 million people by the year 2050, 68% of which will occur in middle to low-income countries. The report noted the worldwide incidence of dementia in 2015 sat at 9.9 million new cases per year. These 2015 numbers carried with them an $818 billion price tag that was expected to reach over two trillion dollars by 2030, should the rate of dementia incidence and disease duration remain the same. In Canada, the prevalence of dementia in 2016 was 564,000 individuals

with an incidence rate of 25,000 and an annual cost of $10.4 billion. By 2031, dementia prevalence in Canada is expected to rise to 937, 000 people at a cost of $16.6 billion per year (Alzheimer Society Canada, 2018).

Along with a need to address the financial costs of dementia, there will be a need to address the personal costs of dementia for individuals diagnosed with the condition. For instance, as dementia progresses individuals with the condition have a higher chance of being moved into a long-term care facility. This can be both incongruent with the wishes of people who have dementia (Quality End of Life Care Coalition of Canada, 2015) and has been characterized as a personal cost to the extent that it results in the loss of various rights and freedoms, one of which is the right and freedom to choose one's place of residence.

As demonstrated in this chapter, dementia has undergone a variety of iterations over the last century, each of which has influenced and continues to influence how people with dementia are perceived and in turn how people with dementia are cared for. In evaluating the care of people with dementia who reside in long-term care facilities, one component that should be examined is whether individual rights and freedoms are safeguarded. One way to accomplish this is to assess the impact of structural discrimination on dementia care in long-term care facilities in order to fully understand the extent to which the human rights and freedoms of people living with dementia are impeded. This would require becoming familiar with the ways in which residents living with dementia are treated differently from residents who do not have dementia.

Before doing so, it is important to note that the physical construction of these facilities can also be seen as discriminatory. Of interest is the design of long-term care facilities and how these facilities have typically be designed in a manner that is specific to the population that will be residing in the facility. In an article assessing the beneficial impact of reconfiguring traditional long-term care facilities into more immersive and creative spaces, Graham & Fabricius (2017) note that long-term care facilities are predominantly "medical geographies, but room can be made for more creative geographies within these communities of collective aging" (p. 2). Facilities fail to bring a home-like experience to residents with dementia in that residents are excluded from moving freely within and outside of their place of residence. In their ethnographic research into long-term care residential design in Canada, Adams & Chivers (2016) describe the physical build of long-term care facilities:

> Long-term care residences are easy to spot. From years of observing the building type, we know that most are set back from the road, made of brick, one or two stories high, and have a prominent entrance, rows of repetitive windows and pitched roofs. Typically, a long-term residential care (LTRC) building spreads horizontally across its site, justifying generous parking lots and expansive lawns. Invisible from the street is the ubiquitous inner courtyard, a chunk of landscape wholly contained by the walls of the facility and small enough to survey at a glance. Wheelchair ramps and orientation devise hint at the building's unique mandate to serve as a home away from home for people who, for one reason or another, can no longer live in traditional housing. This is our society's architectural expression of old age (p. 274).

While not the purpose of this paper, it is worth noting that physical characteristics of these facilities is specific to residents with dementia and can lend to discriminatory practices inside these settings by framing the resident with dementia as one whose needs,

rights and freedoms differ from those of people who do not have dementia. Attending to the physical construction of these facilities and how these are influenced by our perception of aging and dementia can also influence how the rights and freedoms of people with dementia are safeguarded or infringed-upon, and forces us to explore how best to fulfill our moral obligations to this population.

In light of this, the following chapter will explore how people with dementia are treated differently from their counterparts by: (1) looking at the way the perceived phenomenon of wandering is interpreted by others; (2) exploring the notion of the "supervised body" and; (3) comparing the amount of medical interventions that people with dementia experience.

Chapter 2: Dementia Specific Practices in Long-Term Care Facilities

In Canada, facility-based long-term care is both a home for residents and a workplace for health providers and is comprised of three components: accommodation, hospitality services and health services (Canadian Healthcare Association, 2009). Long-term care residents are not a homogeneous population. People choose to or are moved into facilities for various reasons. As a result, there is a range of cognitive and physical capabilities across the residents. For the purpose of this thesis, practices that residents with dementia are susceptible to will be explored and will include: (1) the use of physical and chemical restraints to limit resident ambulation; (2) the use of instruments of surveillance and; (3) the overuse of medical interventions at end of life. This chapter will highlight how these practices have emerged in large part due to the impact of dementia framing and dominant dementia discourse.

2.1 Use of Restraints to Curtail Wandering

The propensity for people with dementia to wander within and away from their residence is a well-documented yet not well understood phenomenon that presents formal and informal caregivers with the challenge of how to safely and effectively manage it. Historically and currently, the biomedical community has condoned the use of chemical and physical restraints to curtail wandering in long-term care facilities. But by recognizing the purpose and meaning of the phenomenon of wandering among people with dementia as more than a mere manifestation of the pathology, research has demonstrated that there are more effective and less restrictive ways of addressing the

issue. Therefore, it is integral to look at differing conceptions of wandering among people with dementia in order to identify how framing and interpreting the phenomenon influences the way care is delivered and, subsequently, how this impacts various freedoms for these individuals.

Clinical understanding of wandering among people with dementia has been lacking (Algase, Moore, Vandeweerd, & Gavin-Dreschnack, 2007; Wigg, 2010) resulting in it being pathologised and biomedicalised as a problematic behavioual symptom of dementia requiring intervention to keep the individual safe from falling, from eloping, or from death (Hughes, Newby, Louw, Campbell, & Hutton, 2008; Neville, McMinn, & Cave, 2006). A different conceptualization of wandering as purposeful rather than wanton, however, also exists (Algase et al., 2007; Dewing, 2006; Wigg, 2010), where wandering is seen to have salutogenic effects on behaviour, agitation levels, fall levels, use of antipsychotics, resident quality of life and resident safety (Detweiler, Murphy, Kim, Myers & Ashai, 2009; Detweiler, Murphy, Myers & Kim, 2008;Rolland et al., 2007).

The use of restraints to curtail wandering is often deemed necessary for resident safety. However, wandering is not an independent factor in falls, fractures, injuries and death (Detweiler et al., 2009; Rolland et al., 2007); rather it is precisely the use of chemical and physical restraints that can serve as a key factor in an increase in both fall rates (Detweiler et al., 2009), and behavioural problems (Lovheim, Sandman, Kallin, Karlsson, & Gustafson, 2006; Neville, McMinn, & Cave, 2006; Robinson et al., 2007; Turner, 2005; Wigg, 2010).

In order to contain what is perceived as wandering among people with dementia, long-term care facilities have historically been designed to ensure the residents who have dementia remain within the confines of the building. Locked doors preventing residents from exiting the buildings or from entering other wings of the facilities, the prohibition of residents to go outdoors without supervision and monotonous hallway ambulation have typified the long-term care facility experience for people with dementia. With increasing evidence supporting the therapeutic effects of what is perceived as merely wandering (Detweiler et al., 2008; Ford Murphy, Miyazaki, Detweiler, & Kim, 2010) some institutions, such as the Baie Verte Peninsula Health Centre in Newfoundland and Labrador, have incorporated outdoor wander gardens into their facilities while others have reconfigured the interior of their buildings to be barrier free and more conducive to walking (Dickinson, McLain-Kark, & Marshall-Baker, 1995). Further in this thesis, the implications of physical and chemical restraints for the rights and freedoms of people with dementia will be discussed.

2.2 The Supervised Body

In long-term care facilities supervision and protection of residents with dementia can be in place for a variety of reasons, such as preventing risk to oneself, other residents and caregivers. It can be in the form of physical restraint, chemical restraint, manipulation of the physical environment via video monitoring, dementia lock down units, wearable technology and denial of access to the outdoors. Mealtime, medication administration time, bath time and bedtime are also subject to caregiver supervision for purported reasons of safety and expediency. In a paper assessing the preoccupation with

securing the elderly body in long-term care facilities, Kenner (2002) challenges the notion that the surveillance of people with dementia is exclusively for their safety and instead suggests that incessant monitoring of the elderly is reflective of ageism in our society. The author notes that dementia has come to be seen as a social, medical, political and economic crisis due to fearful discourse, which surmises that dementia will have an irrevocable negative impact on social services, health care systems, policy and ultimately the national economy. Hyde, Burns, Hassard & Killett (2014) contend that in long-term care facilities the aged body becomes colonized through bodily appropriation and imposed separation from an individual's previous identity. Activities of the body are organized and controlled by facility staff and their identity becomes subsumed by the concept of a "normative residential identity" (p. 1713), where the focus of care is to manage physical dependence. Moreover, the authors state that spatial autonomy and personal identity often take a backseat to organizational expediency, and private living spaces become public sites where the care staff performs the required duties.

Petinito &Muschert (2018) also address the discourse of fear that surrounds dementia. They claim that those with dementia are framed as belonging to an apocalyptic demography because their cognitive decline has economic and physiological impacts on family caregivers, health care institutions, economic policy and societal fabric. It is these claims of an apocalyptic demography that are used to justify interventions such as surveillance to protect not necessarily what *is* happening but what could *potentially* happen. According to the authors, this occurs because of the social construction of dementia as a problem; a concept that will be explored in Chapter 3.

Kenner suggests that surveillance is actually an example of "ageism in place", a play on the phrase "aging in place," insofar as it renders the person with dementia increasingly susceptible to unequal power and social relations and serves as a tool for appeasing the discourse of fear surrounding the impact of dementia on society. In an article looking at the meaning of aging in place to older people, Wiles and colleagues (2012) explore what it means to age in place. They refer to work by Davey et al. (2004), which defines aging in place as "remaining living in the community, with some level of independence, rather than in residential care" (p. 133). They explore the concept and suggest that it needs to extend past the dwelling home to include immediate neighbourhoods, society and economic and health policy. This, the authors contend, helps reflect the nuanced, varied and complex process of aging in place that is a continual renegotiation of the individual in relation to their surroundings, which can include transitioning to a long-term care facility.

While not to diminish the importance of maintaining the physical safety of the individual with dementia, one would be remiss to fail to acknowledge that surveillance is often imposed on people with dementia, not requested by them. This precludes a reciprocal interactional relationship between caregiver and care recipient to the extent that the shared decision making is absent in the implementation of surveillance practices and can exacerbate the negative effect of policies that result from structural discrimination, a concept that shall be explored further in this thesis. |Graham & Bassett (2006) note that reciprocal interactional relationships are rooted in the compassionate act of caring but are often negatively impacted due to the view of dementia care as a service

as opposed to an act of caring. Imposed surveillance, therefore, becomes less about caring and more about ensuring a service is being performed.

2.3 Medical Interventions and Palliative Care and End of Life Care for People with Dementia in Long-Term Care Facilities

People with dementia receive more invasive and aggressive treatments throughout the trajectory of their illness when compared with non-cognitively impaired individuals (Ahronheim, Morrison, Baskin, Morris & Meier, 1996; Evers et al., 2002). The use of feeding tubes, the overuse of antibiotics, the inappropriate use of physical restraint and lack of comfort care occur more frequently in this population (Hinkka et al., 2002; Evers et al., 2002). These individuals also experience more suffering as a result of these life-sustaining interventions (Aminoff & Adunsky, 2006; Evers et al., 2002; Sampson et al., 2006). In contrast to people without dementia, people at end-stage dementia experience under and non-control of pain at end of life, leading to longer phases of pain and suffering (Harrison Dening, 2016; Kovach, Wilson & Noonan, 1996; Lloyd-Williams, 1996; Middleton et al., 1997).

In a retrospective case note study, Sampson et al., (2005) noted that people dying with end-stage dementia received fewer referrals to palliative care and received less palliative care than cognitively intact individuals at end of life. Additionally, Evers et al., (2002) conducted an ante mortem study in a long term care facility and found that 14% of people with dementia received narcotic pain medication compared with 38% of people without dementia who received narcotic pain medication. Finally, a retrospective study by Di Giulio et al. (2008) described the last month of life for people at end-stage

dementia living in a long-term care facility. Fifty-eight percent of the residents were in some form of physical restraint. Of these residents, anywhere from 25-89% of them were always restrained with the specific restraint. Almost half of the residents had pressure sores and anywhere from 20.5%- 71.6% experienced some form of inappropriate intervention during the last 48 hours of life.

Before concluding this section it is important to note that end-of-life care and palliative care are not inherently one and the same. Too often, there is a failure to recognize that palliative care can be and should be delivered throughout the trajectory of a condition: during the diagnostic phase, the curative phase and the end-of-life phase. Krau (2016) describes the purpose of palliative care as to improve the quality of life for the patient and their family and does not have as its goal the hastening of death, but rather a focus on prolonging a life of quality, while he submits that end-of-life care strives to ensure that the patient dies with dignity. Understanding the differences between these types of care can have positive implications for this population. A Canadian Institute for Health Information report on palliative and end-of-life care (2014) notes that only 5% of people with dementia residing in long-term care facilities received palliative care while 20% of those residing in their own homes received it. The report attributes this disparity to a lack of dedicated resources, specialized skill and knowledge within long-term care facilities as one of the

When faced with dilemmas such as resident wandering, supervision and medical intervention, how do health care providers decide which course of action is the appropriate one to pursue? The purpose of this over view of dementia-specific practices

is not to suggest that the afore-mentioned practices occur out of malice, ill intent or disregard. Rather, it is to highlight the differences in practices that people with dementia experience in comparison to their counterparts and to gain a better understanding of what is informing these practices. It is to this discussion that we shall now turn.

Chapter 3: Dominant Dementia Discourse

After becoming acquainted with dementia prevalence and dementia-specific practices in long-term care facilities, attention can now be turned towards how dementia is framed. Framing of health care issues shapes health care policy, practice and scholarship (Koon, Hawkins & Mayhew, 2016) and can rely on social, cultural and political influences. It is for this reason that framing can be understood as being, in part, dependent on dominant discourse.

Ballenger (2017) notes that historian Charles Rosenberg has gone so far as to suggest that disease only exists once there is an agreed upon perception, iteration and response to the condition: a frame. Ballenger admits that this does not negate the biological etiology of disease but rather draws attention to the fact that cultural frames help to define disease and influence our response to it. Moreover, Ballenger contends that the verbal constructs that form the biomedical definition of a disease: (1) reflect medicine's intellectual and institutional history, (2) ascribe social roles and, (3) become aspects of individual identity.

Because of the legitimacy granted to medical authority, dominant discourse about medical conditions often create one-dimensional normative assumptions. Dominant discourse is created by those in power and becomes the accepted way of looking at an issue, thereby creating normative assumptions. These normative assumptions become accepted as fact and further perpetuate and legitimize dominant discourse. As shall be

demonstrated, medical representations of dementia have impacted the dominant discourse associated with the condition. The phenomenon of social death and imposed suffering will be used to demonstrate how the symbiotic relationship between medical and media representations of dementia influence the dominant discourse and normative assumptions about the condition in everyday parlance. But first an overview of the evolution of the view of dementia in medical discourse and of how people with the condition are perceived by clinicians will be presented.

3.1 Medical and Media Representations of Dementia and their Impact on Normative Assumptions

In the early 20th century dementia was framed as a phenomenon unable to be disentangled from the aging process (Ballenger, 2017). Over the course of time it came to be framed as a brain disease, psychosocial problem or disability. While dementia was once considered a part of the human aging experience framing and reframing of the condition has separated it from the human experience and placed it in a category unto itself. It is now predominantly considered a disease or the product of a disease and, as a result, is primarily viewed through a negative lens, which culminates in a dementia discourse that has become laden with tones of tragedy (Reed, Carson & Gibb, 2017). The impact of dementia framing and discourse on media representations and public perception of dementia will now be addressed.

A World Health Organization report on dementia (WHO, 2012) has established as one of its goals the normalization of the dementia experience, meaning that the cognitive decline experienced by older people need not necessarily be pathologized. Achieving

this goal, however, is impeded by dominant discourse in medical representations. Robbins & Bernat (2017) point to a belief among clinicians that dementia care is futile because of the impossibility of changing the trajectory and outcome of the condition. Additionally, the authors highlight physician assumptions that people with dementia are unaware of their suffering and palliation, making physicians question whether efforts at palliation are worthwhile. Finally, they discuss the "spirit of nihilism" which results in the depersonalization of the person with dementia due to a perceived loss of intellect. All of these perpetuate the tragedy discourse of dementia in medical representations of the condition and further medicalize and pathologize the experience.

Historically, biomedical representations and frames have been accorded weight and legitimacy. Invariably, the discourse that surrounds dementia in other realms is influenced by these representations. Common stereotypes of people with dementia across disciplines include a perception of them as having no quality of life, no capacity for pleasure, no control over their life, and no identity. They are perceived as having unrewarding relationships, no communication skills, and are seen to be vulnerable, dependent and burdensome. Ironically, research into perspectives of people with dementia uncover that their own account of what it is like living with dementia differs from these representations (Mitchell, Dupuis & Kontos, 2012). Regardless of this dichotomy, representations and dominant discourses of dementia impact how people with dementia are perceived and the care they receive.

3.2 Dominant Discourse and Models of Dementia

In *Citizenship Social Work with Older People* (2012), Payne notes that "Existing care systems are part of a society that limits the opportunities and outcomes of social care for older people" (p. 107). Remedying this can be accomplished through critical thinking about accepted norms and power relations between people and institutions. As demonstrated, dominant discourse shapes perceptions of dementia, which in turn informs approaches to dementia-care. Dementia is primarily viewed in one of three ways: as a biomedical condition, as a mental disorder or as a disability (Gerritsen, Oyebode & Gove, 2016), each of which can carry its own stigma that can result in structural discrimination.

A biomedical view of dementia focusing on disease pathology, preventative measures and curative solutions can result in the identity of the person being subsumed by the pathology and risks, reducing the individual to a damaged brain (Sabat, 2008). In effect, dementia becomes the primary identifying characteristic of the individual. While this particular biomedical view focuses on dementia as its own entity, another biomedical view of dementia presents the condition as the result of individual choices. Individual responsibility, prevention and blame discourse are prevalent in medical and media representations of the biological genesis of dementia (Peel, 2014) and purport that a physically active and healthy eating lifestyle can prevent the onset of the condition (Lyons, 2000). Biological representations that focus on diet and active lifestyle assume that preventative measures can and should be taken to circumvent or stave off the onset of dementia. A biomedical view of dementia that focuses exclusively on preventative and curative aspects of the condition can result in the failure to acknowledge the need for

and the development of social supports (Swane, 1996). A one-dimensional biomedical view of dementia can result in unintended structural discrimination that can take the form of policies that exclude the utilization of multidisciplinary approaches to dementia care and policies that prevent them from gaining access to supports and services that are available to others, such as spiritual care, psychosocial care and psychiatric care.

The second dominant view of dementia—that of dementia as a mental health issue— can also foster structural discrimination by encouraging an approach to care that is over-protective, disempowering and restrictive (Kitwood, 1997). When approached from this perspective, consent and capacity often play a role in determining the extent to which individual choices should be accommodated. Structural discrimination in long-term care facilities can be both intentional and unintentional: intentional to the extent that the individual is precluded from health care conversations and decision-making, and unintentional to the extent that policies can preclude them from making everyday decisions regarding such things as mealtime, recreation time and bedtime. While regimented schedules can be part of everyday life for all residential dwellers, people with dementia are subjected to these regimens with more austerity and are not in a position to forego these regimens in the same manner as residents who are not living with dementia.

Finally, the view of dementia as a disability can inadvertently result in paternalistic care practices whereby, as opposed to encouraging and promoting inter-dependence, the individual is rendered completely dependent on care providers and institutions. Disability advocates have long fought against structural discrimination that precluded their ability to access and achieve the same rights and opportunities that are

available to able-bodied people. Individuals functioning at different cognitive and physical capabilities than the majority of the population are increasingly becoming more fully integrated into society and are enjoying more of the same rights and responsibilities that are afforded to the rest of the public. Disability advocacy has helped people with decreased cognitive and physical capabilities to become contributing members of the workforce and the volunteer community and has also advocated for increased independence in how this population chooses to live their lives. Sabatello & Schultze (2014) note that disability advocates have demanded "citizenship rights and participation, contested their incarceration in institutions, and drawn attention to the exclusion and discrimination they encounter in their daily life" (p. 14).

Yet, viewing dementia as a disability has not had the same effect. Unlike their counterparts with differing cognitive and physical disabilities, the person with dementia is often precluded from integrating fully into society. In long-term care facilities they are discouraged from performing daily routines. Rather than trying to improve health and functional abilities by promoting active participation in preparation of meals, making of beds, and other daily activities of living, long-term care facility personnel perform these duties for residents with dementia (Dobbs et al., 2005). Structural discrimination resulting from a disability view of dementia, therefore, can be seen in the imposed erosion of independence of individuals in their daily activities of life.

The influence of medical discourse, however, is not confined to the arena of academia and health care. It also finds its way into the consciousness of the general public via the uptake and promulgation of medical discourse by media outlets. In an

editorial about illness, health, and medicine in the media, Lupton (1999) explains that lay people receive most of their information about health and medicine from the mass media. Media portrayals create, reproduce, and perpetuate disease and illness knowledge and help craft the image of the ill person. Dominant media discourse frames dementia as "a national crisis", "a living death", "an epidemic", "crippling", "costly", "brain-wasting", "cruel", "merciless", and "catastrophic" (Peel, 2014). Van Gorp and Vercruysse (2012) analyzed the framing of media content related to dementia. In it, they note that the majority of media portrayals of dementia focus on the terminal stage of the condition, thereby portraying this phase as representative of the entire trajectory. Moreover, caregivers form the majority of the contributors to the conversation in media, not the people with dementia. Consequently, stories often focus on caregiver burden. It is also suggested that the portrayal of dementia in film perpetuates this discourse (Swinnen, 2012) by positioning the individual as incapable of maintaining their identity, self, and interpersonal relationships.

Imposed suffering and social death are two effects that can be experienced by people with dementia as a result of the various models of dementia. Examination of these concepts will demonstrate how, irrespective of the actual experience of living with dementia, representations and dominant discourse inform and dictate the dementia experience.

3.3 Imposed Suffering and Social Death

Mitchell, Dupuis and Kontos (2013) examined outsider representations, from the health and lay literature, of what it is like to live with dementia. They concluded that a dominant biomedical discourse that has shaped and been shaped by cultural norms imposes a suffering of personhood upon people with dementia; a characterization that is facilitated by the media and is promulgated by the language, mindset and behaviour of the lay public and health care professionals. According to the authors, however, this suffering of personhood lies in stark contrast to a life affirming discourse found in the research into the experiences of people living with dementia. They note that people with dementia are depersonalized, invalidated and perceived as dysfunctional, even though they do not feel this way themselves. They are objectified, infantilized, excluded, and silenced, yet still manage to express selfhood, desires, joy and suffering. In looking at media representations of Alzheimer's disease, Johnstone (2013) highlights the use of the Alzheimer's metaphor to represent the loss of dignity, capacity and selfhood, rendering the individual ineligible for "moral membership of the human social environment" (p. 388). The suffering of personhood is imposed because it is spectators- not the person with dementia- who are creating the discourse.

Ironically, research among people with dementia indicates that it is precisely the imposed suffering that causes actual suffering. An international literature review of the perspectives of people living with dementia by DeBoer et al. (2007) highlights the discrepancies between how people with dementia are perceived to suffer versus actual lived experiences. Mitchell, Dupuis & Kontos (2013) note that suffering occurs because

of the disparaging words and images imposed on people with dementia. They do not withdraw willingly but are rather forced to withdraw due to lack of meaningful opportunities to experience purpose and social engagement; both of which arise out of erroneous representations found in dominant discourse. Even though caregivers do not view being useful as being relevant to quality of life, people with dementia perceive the opportunity to contribute to society to be a protective factor in their perceived quality of life (Cahill et al., 2004).

One of the consequences of imposed suffering for the person with dementia is social death. Sweeting and Gilhooly (1997) trace the idea of social death as far back as 1907 through Robert Hertz. Hertz wrote that in addition to ending the biological life, death eradicates the social being bestowed upon the individual. By the 1960s, a refined concept of social death began to surface. Glaser and Strauss (1966) are credited with first coining the term *social death,* a term used to describe the social dying of people in hospital that can occur prior to their physical dying, thereby contributing to the loss of personhood while the individual is still alive (Gilleard & Higgs, 2013). Sudnow (1966) defined social death as occurring when "socially relevant attributes" no longer exist for the patient as a condition for treatment and they are perceived as already dead. Kalish (1966) speaks of social death as occurring when others view someone they once saw to be alive as now being dead or non-existent. Finally, Kastenbaum's (1967) description of social death is that someone experiences social death when (1) behaviours directed towards them are reflective of those behaviours that one would anticipate being directed

towards someone who is dead or non-existent, and (2) there is an absence of behaviours that one would expect to be directed towards someone who is living.

More recently, Mulkay & Ernst (1991) described social death as occurring once an individual ceases to be an active agent in the lives of other people. Those most prone to experiencing social death include those at the end of a terminal illness, the very old, and those whose personhood is compromised (Sweeting & Gilhooly, 1997). People living with dementia fall into at least one, and potentially all three, of these groups. Irrespective of the fact that person-centred care is becoming the preferred approach to care for people with dementia, George (2010) believes the "totalizing" language of dementia shapes dominant understandings of the condition as a "blanching of selfhood", thereby creating a non-person out of the individual. As shall be explored fully in Chapter 6, exclusionary practices, involuntary isolation, ghosting, elder-speak and decreased ability for self-advocacy are examples of social death that are experienced by against residents with dementia.

Accordingly, dominant dementia discourse shaped by medical and media representations results in the social construction of not only the condition but also the person with dementia. People with dementia are portrayed as being in a perpetual state of emotional, psychological and physical suffering due to a loss of personhood and self; this, despite the fact that the perspectives of people living with dementia fail to validate the assumption that they live in a constant state of suffering (de Boer et al., 2007). Dominant discourse has resulted in imposed suffering and social death for people with dementia and, as shall be demonstrated later in this thesis, is in part responsible for

influencing and perpetuating structural discrimination unique to dementia-care in long-term care facilities.

3.4 The Social Construction and Problematizing of Dementia

Waitzkin (1989) suggests that medical ideology and the role that health professionals play in social control is fueling medical discourse. The author draws upon work by Lukacs (1971) to illustrate how focus is concentrated on the concrete problem being addressed as opposed to the totality of social relations and social causes that contribute to the concrete problem. The result is a medical and societal response to the identifiable problem at hand— the pathology and the pathologized individual— as opposed to a response to the larger and more nuanced influences that contribute to it. The author also refers to work by Habermas (1971) in order to illustrate how medical discourse becomes legitimized and translated into public discourse. At the heart of it, suggests Habermas, is the ability of science to legitimize current patterns of domination by de-politicizing them and by turning critical attention away from the larger societal issues. In essence, the larger societal problem is negated and the gaze turns in towards the pathologized and identifiable problem resulting in the medicalization of social problems. Waitzkin suggests that because historically powerful social classes have dominated the professional occupations, such as medicine, legitimacy is granted to the medical discourse. As a result, medical discourse becomes perpetuated by media discourse, transforms into a dominant discourse, and becomes an accepted truth that in turn structures individual experiences.

Yet within the field of critical gerontology, there is a shift towards approaching dementia from more than exclusively a biomedical perspective. Innes & Manthorpe (2012) criticize an exclusively biomedical approach to dementia in that it necessitates that the medical community define exactly what constitutes normal ageing. They note that critical gerontology, however, allows for a reconceptualization of dementia by examining the structural inequalities and dynamics of power that serve to create and perpetuate dominant dementia discourse and how social and structural factors impact how people experience living with dementia. Zielig's (2014) research into representations of dementia explores the social construction of dementia as a cultural phenomenon. The author notes that critical gerontology delves into the historical and cultural influences that have shaped not only our understanding of the condition but also the priority accorded to scientific and medical perspectives of dementia, often to the exclusion of other perspectives. The resulting medical discourse can structure individual experience. Maton (2008) illustrates this by noting that while individuals may have unique experiences, the experiences are shared in terms of their structure with others of the same group due to the coalescing of "objective social structures and subjective personal experiences" (p. 53). In the context of dementia and long-term care, the interaction of structure, power and agency is further explored by Rhynas (2004). The author notes that the manner in which incoming nurses relate to and care for people with dementia is predominantly influenced by observations they have of other nurses' interactions with the same population which, as shall be demonstrated, can be influenced by ageist and ableist frameworks.

Chapter 4: Ageism, Ableism and the Creation of Dominant Dementia Discourse

As has been demonstrated, people with dementia experience structural discrimination that is shaped by dominant dementia discourse. But what is informing this discourse? As previously noted, dementia is classified as a cognitive impairment that increases in incidence among older populations. This renders those who are living with the condition particularly susceptible to two forms of prejudice: ableism and ageism. A brief overview of each will be presented followed by a description of how they contribute to current dominant dementia discourse. Then, in Chapter 5, I will turn to the implications of this for structural discrimination.

4.1 The Influence of Ageism and Ableism

In 1969, psychiatrist Robert Butler developed the term ageism to capture the systematic stereotyping and discrimination of people based on their age. Butler used the term to describe the prejudicial attitude of valuing younger lives over older lives and noted that it is predicated on three interrelated and mutually reinforcing elements: (1) prejudicial attitudes towards older people, old age and the aging process; (2) discriminatory practices directed towards older people, and; (3) policies that perpetuate stereotypes about older people (Butler, 1969). Butler describes these elements as coalescing to develop a dominant discourse of ageing that views it not as a natural process but rather as a social problem that permeates multiple levels of everyday life including politics, public policy, the workplace, media, education, and entertainment. But he was especially concerned with the proliferation of ageism into the arena of medicine, health care and medical education (Perry, 2012).

Ageism in health care is evidenced by: (1) the lack of sufficient geriatric training in medical school; (2) the underuse of preventative care for treatment of the older adults (3) the inappropriate and incomplete treatment of the elderly via beneficial and effective interventions, screenings or tests; (4) negative perceptions of elderly patients and; (5) the shortage of geriatricians (Perry, 2012). The inequitable distribution of health care and public health resources for the elderly (Salway et al., 2017), over-protective and paternalistic attitudes that create dependency and marginalization (Dobrowolska et al., 2017) are also examples of medical ageism. Ouchida & Lachs (2015) note that ageism in health care is not reflected exclusively in the action or inaction of medical providers, but is also fostered by the mindset of older patients[1] themselves and the structure of health care systems. The prevailing idea that acute health care use among the elderly is overwhelmingly higher than among younger populations, the exclusion of the elderly from clinical trials, lower remuneration for geriatricians, age-based rationing of resources, and the discharge of the frail elderly to long-term care following an extended hospital admission or stay in acute care are some examples of ageism in health care that Ouchida & Lachs present. Effectively, ageism translates into the unintentional yet embedded practices that carry over from the societal level into the systems level to culminate in structural discrimination in health care settings.

Similar to how ageism defines a person based on their age, ableism defines people based on their physical or mental ability. In *Contours of Ableism: The Production of*

[1] Throughout this paper, residents of long-term care facilities who have dementia are referred to as residents: not as patients. In instances where the word patient is used, it is in specific reference to a hospital setting, an acute care setting, or because a primary author uses this term.

Disability and Ableness (2009) Campbell suggests that ableism constitutes a "network of beliefs, process and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species typical and therefore essential and fully human" (p. 5). Campbell also references Chouinard's definition of ableism as those "ideas, practices, institutions and social relations that presume able-bodiedness, and by so doing, construct persons with disabilities as marginalized…and largely invisible 'others' " (p. 5) . For the person with dementia, this would be the cognitive disability ascribed to them via the biomedical model of the condition. Not only, then, is the older adult with dementia open to ageist discrimination but they are open to ableist discrimination as well. Wysocki (2017), for example, notes that aging is often framed as a deviation from the normal state of the body and is implicitly and explicitly linked to disability and disease.

It is beyond the scope of this thesis to delve into the theoretical underpinnings of ageism and ableism. However, a cursory overview of the two concepts can highlight why ageist and ableist practices can occur in dementia care. Othering and activity theory are two processes that impact the aged and those whose cognitive abilities are compromised due to the contribution they make to aging and disability discourse. By addressing these, it will become evident why using a citizenship lens to develop an ethical framework for dementia care in long-term care facilities is applicable and appropriate and how it can help mitigate the impact of structural discrimination in dementia care.

4.2 Activity Theory and the Phenomenon of "Othering"

As previously noted, some behaviours that are exhibited by individuals living with dementia have become pathologized when in fact similar behaviours exhibited by individuals who do not have dementia would be considered acceptable responses under similar situations. Pacing while nervous, being restless while agitated, and experiencing aggression when faced with confrontation, are responses that can be considered appropriate responses in given situations when exhibited by people without a diagnosis of dementia. As indicated earlier in this thesis, behaviours such as wandering, restlessness, agitation, and aggression among people living with dementia are typically viewed as problematic and necessitating an intervention. As discussed in Chapter 3, critical gerontology suggests that the problematization of these behaviours among people with dementia is largely due to the historical and cultural influences that have shaped the understanding of what these behaviours mean, and the influence of structural inequalities in classifying these behaviours as pathological. What is it that contributes to these behaviors being viewed as pathological? Of particular salience to the present discussion is the phenomenon of "othering," which involves labeling individuals as belonging to a subordinate social category to whom social norms do not apply. Ageism has an undeniable influence on othering and shall now be explored.

Recalling that Robert Butler viewed ageism as a form of prejudice, it is important to look at ageism from the same vantage point that we look at other forms of prejudice. Butler contended that ageism is predicated on the same principles found in sexism and racism. In their work on the othering of the elderly, Higgs & Gilleard (2014) call the

reader's attention to Weis' (1995) definition of the process of othering as that which demarcates and names that which is considered different from oneself. The authors contend that there is an increasing schism between the old and what they call the deep or real old. The former can maintain similarity with working aged adults through delayed retirement and elder volunteerism while in comparison the collapse of agency and identity for the latter exacerbates the difference between themselves and other adults. The deep old are not the product of successful social, cultural and economic achievements; rather because they are no longer perceived as fully engaged citizens contributing to the social, cultural and economic fabric of society, the deep old are considered to be at the inescapable end of life.

Similarly, van Dyk (2016) contends that the old are viewed as capable and are valued for their sameness, as long as they continue to contribute to society. Conversely, the very old are othered, marginalized and stereotyped as objects of care. For van Dyk, this binarism represents a hierarchical structure separating the universal from the other one or the deviant. For Zimmerman (2016) the othering found in ageism is predicated not only on binarism but also on essentialism to the extent that the characteristics and behaviours of old people are essentially pre-determined by the process of decline. So what one sees is a polar or binary distinction between those who are not the real old and those who are the real old, which constitutes a clear and distinct othering.

In the context of long-term care, the othering of people with dementia is seen in different contexts. Gove et al. (2017) note that general practitioners perceive a clear distinction between people without dementia— "us" (contributors to society)—and

people with dementia—"them" (those who take/ don't contribute). Functional dependency, loss of selfhood and ability, attributing aggressive behaviour to the dementia diagnosis, social exclusion and the pathologization of normal behaviour (such as wandering) are some examples of othering practices that are commonplace in long-term care facilities, including those that are rooted in person-centred dementia care (Doyle & Rubinstein, 2013).

Activity theory has also reinforced ageism and, by extension, ableism. Positivist aging models assert that optimal aging occurs when disease, disability, cognitive impairment, disengagement and dependency are avoided (Martinson & Halpern, 2011). Normal aging is increasingly being touted as being exemplified by good health, engagement and vibrancy, whereby the elderly are transformed from a burden to an asset. The dominant discourse surrounding optimal aging, therefore, views it as synonymous with physical activity, social engagement, success and productivity. For the authors, this purpose-focused narrative of the older adult is ethically problematic in that it creates a normative model for aging that places the onus on elders to prove their worth and purpose to society through productivity and contribution.

While not the intention, activity theory also perpetuates ableist ideals of aging in that models of aging such as activity theory and successful aging are predicated on a concept of the "normal" aging of an able bodied individual. In a systematic review of social gerontology literature regarding successful aging, Martinson & Berridge (2014) explore the criticisms leveled against the successful aging model first promoted by Rowe & Kahn (1987). In referencing social gerontologist Matilda Riley (1998), they contend

that normative models of successful aging are exclusionary and incomplete as they focus explicitly on individual successes and omit the influence of structural and societal factors on aging. Putnam (2002) suggests that in an attempt to counter the tendency to view disability as potentially one component of aging, successful aging models strive to sever any suggestion of concomitance of aging and disability. This can further pathologize and isolate the older person with dementia. According to Martinson & Berridge, aging models that define successful aging as "the avoidance of disability and disease, maintenance of cognitive and physical function, and engagement with life fails to capture the full experiences and contexts of aging" (p. 65) create a normative concept that fails to recognize the influence of structural and social inequities that create and sustain illness and disability while at the same time creating a normative concept of how everyone should age. However, successful aging does not need to be framed as being contingent on the absence of disease or disability, but rather should assessed in the context of individual circumstance. In summation, ageist and ableist positivist aging models create a new ageism that dictates how the aging process should ideally occur. Martinson & Berridge thus postulate that dominant models of successful aging suggest that successful aging is void of disease and disability and is exemplified by the older person who continues to remain a contributor to society economically, and through volunteerism and community engagement.

For the person with dementia, the effects of ageism and ableism are amplified. They are in the precarious position of being simultaneously exposed to ageist and ableist discrimination not only within the fabric of society but also in the context of health care.

They are more susceptible to the inequitable distribution of resources, and the incomplete or inappropriate use of interventions because their opportunity to self-advocate is undermined, an issue which will be further explored in Chapter 7. Now that the influence of ageism and ableism on the creation of dominant dementia discourse has been presented, the relationship between this discourse and structural discrimination as it relates to people with dementia will be explored. In order to accomplish this, the elements that contribute to and constitute structural discrimination must first be examined.

Chapter 5: Dominant Dementia Discourse, Structural Discrimination and the Implications for Dementia Care

As demonstrated, the way dementia is perceived and socially constructed is influenced by medical and media representations of the condition and perpetuated by ageist and ableist dominant discourse. People with dementia are viewed as shells of who they once were, devoid of agency, personhood and self. Suffering is imposed upon them by dominant discourse and they are no longer seen as socially alive. In this section, the relationship between dementia discourse and structural discrimination will be explored by examining the public perception of; (1) long-term care facilities; (2) residents with dementia, and; (3) dementia care. But first, an overview of structural discrimination will follow.

5.1 Structural Discrimination

Mirjana Najcevska (2015) defines structural discrimination as the "rules, norms, routines, patterns of attitudes and behaviour in institutions and other societal structures that represent obstacles to groups or individuals in achieving the same rights and opportunities that are available to the majority of the population". The concept of structural discrimination is rooted in civil rights and sociological dialogue and was originally used to describe the discrimination experienced among people of colour that was not the result of individual behaviours directed towards them but rather institutional discrimination perpetuated by governments and policies. Similar to what was previously suggested by Butler (1969), Corrigan, Markowtiz & Watson (2004) note that structural discrimination can be intentional—as exemplified by rules and policies—or unintentional

—as exemplified by the unintended consequences of rules and policies. The effect of both, however, is the restriction of opportunities for those who are subjected to the policies (Angermeyer, Matschinger, Link & Schomerus, 2014). Dementia-specific long-term care facility policies and practices are not immune to the effects of structural discrimination. What makes these policies susceptible will now be addressed.

5.2 Perceptions of Long-term Care Facilities

In his research into autonomy and dependence among elders living in long-term care facilities George Agich (2003) surmises that it is not death but rather long-term care that, in Western culture, is abhorrent. He concludes that this outlook is due primarily to the images that these facilities conjure up: of arduous work for staff, of prison-like, malodourous surroundings for residents and workers, and of inhumane treatment of residents. How, then, do these images become part of the dominant narrative in public consciousness?

A 2013 systematic analysis of media coverage in the United States found that stories about long-term care facilities from 1999-2008 were predominantly negative (Miller, Tyler & Mor, 2013). They focused primarily on patient neglect, sub-standard care, patient fraud and staff attrition, which resulted from and contributed to further stereotyping, bias and discrimination of elder residents in the general population (Miller, Tyler & Mor, 2013; Miller, Tyler, Rozanova & Mor, 2012). The question that needs to be answered is how media coverage contributes to stigmatization and eventual structural discrimination.

Stigmatization rests on three interrelated components: (1) dominant cultural beliefs associate unwanted characteristics to labeled people; (2) labeled people become categorized as "other" and; (3) those who are labeled experience unequal outcomes due to discrimination and loss of status (Link & Phelan, 2001). Therefore, negative stereotyping of long-term care residents with dementia enters the consciousness of people even prior to interacting with or providing care for them. A review of student nurse perceptions of community care uncovered that perceptions were shaped by media representations of this type of work, rendering it unattractive and unappealing even prior to entering the program (van Iersel et al., 2016), mostly due to the assumed nature of the type of care delivered in these settings as being chronic, arduous, and lacking any real skill. These perceptions can contribute towards the creation of interpersonal interactions, policies and practices that can prevent residents with dementia from achieving the same rights and opportunities available to other residents. This is not to suggest, however, that these perceptions do not result in the stigmatization of people living in long-term care who do not have dementia. What is of particular note to this discussion is the way in which these perceptions compound the problem of a person with dementia not being able to enjoy the same rights and opportunities that are available to the rest of the residential population.

5.3 Perceptions of Residents with Dementia

Agich's (2003) research into nursing home experiences uncovers themes of loss (including loss of identity, control over daily life, and financial independence), isolation and rejection. Agich presents the reader with a dominant image of the resident of long-

term care facilities as a "blabbering, incoherent, disheveled elder strapped into a geri-chair, withdrawn or beckoning for attention, but invariably ignored by staff" (p. 2). Vulnerable, dependent, obsolete and frail were dominant descriptors that were used in media coverage of residents of long-term facilities in the United States (Rozanove, Miller & Wetle, 2016). As evidenced by self-stigmatization, residents with dementia can unwillingly become the stereotype. In a study by Dobrowolska et al. (2017) it was uncovered that providers of medical care were not the only perpetrators of negative stereotyping of people living in care facilities. Residents, students, and the elderly who were living at home also perpetuated negative ageist stereotypes. Self-stereotyping and projected self-stereotyping was found to include images of the self as having lost autonomy, dignity and the ability to make their own decisions.

These stereotypes were manifestations of the societal perceptions of older adults in general and older adults living with dementia in particular. For example, a study into nursing home staff attitudes towards residents with dementia revealed that the most prevalent perceptions of residents with dementia were that they are: (1) anxious, (2) have little control over their difficult behaviour; (3) unpredictable; (4) lonely; and (5) frightened (Brodaty &Draper, 2003), resulting in lower job satisfaction and higher levels of stress among staff. Caregiver stress can result in higher levels of resident aggression (Rodney, 2000), resident abuse and neglect (Goergen, 2001), and a desire for caregivers to distance themselves from these residents (Draper et al., 2000).

5.4 Perceptions of Dementia Care in Long-Term Care Facilities

Those who provide dementia care are said to experience stigma by proxy, exemplified by the undervaluation of their work. In long-term care facilities, care nurses' knowledge and competency is perceived as being inconsistent and variable (Page & Hope, 2013). Unmet training and education needs in the area of health care ethics and human rights, lack of familiarity with national dementia strategies, unfamiliarity with multi-disciplinary approaches to dementia care, and the inability to create a dementia friendly environment are additional perceived shortcomings of professional care givers (Page & Hope, 2013). In addition to the perception that dementia care in long-term care facilities will be inadequate, there is a perception that there will be imposed restrictions on personal care practices (such as eating, bathing and sleeping), personal health practices (medication, exercise, and doctor appointments) and physical freedom (Agich, 2003, p.75).

Ageism and ableism have contributed to a dementia discourse that creates and perpetuates societal attitudes and behaviours that have resulted in the creation of negative images of life in long-term care facilities for people with dementia. The consequence of these images is the creation of barriers by way of institutional policies and procedures that prevent individuals with dementia from achieving the same rights and opportunities afforded to others. Structural discrimination is often unintentional as it represents institutional actions carried out in accordance with societal norms. To illustrate this, the following chapter will demonstrate how dementia-specific practices in long-term care facilities contribute to the creation of these barriers.

Chapter 6: Ethical Issues Associated with the Influence of Structural Discrimination in Dementia-Specific Practices in Long-term Care Facilities

As indicated, the way in which people with dementia are treated by society and the type of care they receive in health care settings is influenced by the different models used to categorize dementia. To recap, dementia is primarily described using a biomedical, mental health or disability model. Ethical implications of how dementia is perceived arise because each model creates normative assumptions about the correct course of action when delivering care or when an ethical dilemma arises in the delivery of care. Consequently, professional caregivers can experience ethical dilemmas when adhering to dementia-specific practices in long-term care facilities, which in turn can contribute to moral distress for the person providing care and can contribute to anguish for the person receiving care. This section will address various dementia-specific practices and policies that impose restrictions on the rights, liberty and self-determination of the person receiving care that can contribute to moral distress and anguish.

6.1 Exclusionary Practices

There are many exclusionary practices that occur in long-term care facilities that are dementia-specific. Because the purpose of this research is to demonstrate how a citizenship lens can mitigate the impact of structural discrimination in dementia care, the discussion will be limited to four general exclusionary practices: (1) marginalization of people with dementia to excluded status in access to health care services; (2) isolation; (3) directed dismissive attitudes and; (4) decreased permission for self-advocacy.

6.1.1 Exclusionary access to health care services

One of the key features of structural discrimination is that it is largely unintentional. If the exclusionary practices were more overt or perceived as being more intentionally exclusionary, the fact that they were discriminatory would be more apparent. However, they are not perceived as discriminatory because the various models used to frame dementia foster these practices, have influenced societal patterns of attitudes and have shaped our collective behaviour towards people with dementia. Two basic health care services that the general population and the cognitively unimpaired living in long-term care facilities have access to are dental care and primary health care. From a distributive justice perspective, access to these services for people with dementia is unjustly impeded and, consequently, ethically problematic.

A review of the literature by Torales et al. (2017) into the oral and dental health of people with mental disorders uncovered that they are at greater risk for oral disease due to side effects of medication, lack of self- care, difficulty in accessing health care services, negative attitudes towards health care providers and lack of patient co-operation with dental treatments. They point to research by Rejnefelt, Andersson & Ranvert (2006) and Zuluaga et al. (2012) which notes a high prevalence of untreated oral health problems among people with dementia which are manifested by self-beating in the face, restlessness and verbal outbursts (Ghezzi & Ship, 2000; McNamara et al., 2014). Similarly, a Swedish longitudinal study of almost 60,000 people with varying forms of dementia (Fereshtehnejad et al., 2017) notes a decrease in dental care utilization upon a diagnosis of dementia rendering the person susceptible to infection, pneumonia and death

by aspiration. What can account for the lack of dental care provision to this population? In Canada, a 2008 survey of British Columbia dentists' perceptions of providing care in long-term care facilities uncovered that residents in long-term care facilities are vastly underserved by dentists (Chowdrhy, Aleksejunien, Wyatt, & Bryant, 2011). Moreover, their reasons for not providing dental care in long-term care facilities was based on the perception that treating the elderly is both financially and professionally unrewarding and unsatisfying.

Marginalization to excluded status in access to primary health care also occurs among people with dementia. An investigation into the primary health care records of almost 70,000 people with dementia residing in long-term care facilities the United Kingdom uncovered disparities in delivery and access to preventative health care (Cooper et al., 2017). Results indicated that people with dementia living in long-term care facilities received more anti-psychotic, psychotropic, and hypnotic medication, had fewer physical health checks and primary health care contacts, and had lower rates of surgery consultation, blood pressure monitoring and weight monitoring when compared with individuals with dementia who were not living in long-term care. Only half of the records of people with dementia documented that an annual physical review was conducted. When compared to individuals with dementia who did not live in a long-term care facility, influenza and pneumonia among people with dementia who were living in a long-term care facility was more prevalent yet under-diagnosed, resulting in more severe conditions and worse outcomes. (Naumova, 2009). The increased mortality rate is thought to be related to the late diagnosis of conditions. A systematic review and meta-

analysis of outcomes of dementia based on hospital databases suggests that outcomes are so poor because there are no set standards of treatments, prognostication is inadequate and there are fewer life-saving interventions (Rao et al., 2016). Once discharged from hospital settings to long-term care facilities patient mortality, recurrent re-hospitalization and frailty have been noted to increase while functional health is noted to decrease (Rao et al., 2016).

These are merely two examples of how access to health care services for people with dementia residing in long-term care facilities is impeded by structural discrimination. It is important to bear in mind that there is also a lack of access to other health care services such as palliative care, rehabilitative therapies, surgical and diagnostic procedures, but it is beyond the scope of this thesis to address these issues.

6.1.2 Involuntary isolation

The second dementia-specific exclusionary practice in long-term care facilities that is ethically problematic is involuntary isolation. Theurer et al. (2015) note that reciprocal relationships and social productivity are absent for people with dementia residing in long-term care facilities and that isolation is felt across the continuum of care, irrespective of attempts to combat isolation through social gatherings. The authors contend that institutionalized recreation for people with dementia can further marginalize and stigmatize residents. As the authors note, this is because institutionalized recreation for people with dementia focuses on distraction and entertainment rather than on activities that foster personal growth, that are meaningful and that promote interaction. For

residents without dementia, however, distraction is not the target of recreational activities and the opportunity to engage in activities that can be fulfilling is more readily accessible. The result is a process of gradual self-imposed isolation by people with dementia who sometimes find such activities un-engaging and demeaning (Theurer et al., 2015). Moreover, such activities isolate them from interaction with people without dementia, effectively becoming an acceptable, unconscious and unintentional practice of segregation. To see how this can affect policy, one has to understand that two negative repercussions of isolation and unmet social needs are agitation and aggression (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015; Ferreira et al., 2016) both of which are susceptible to institutional policies that dictate what course of action (predominantly chemical and physical restraint) will be used to address these behaviours.

6.1.3 Dismissive attitudes towards people with dementia

A third ethical issue that arises from the influence of structural discrimination into long-term care facilities is the dismissive attitudes on the part of some caregivers towards people with dementia. Two ways dismissiveness is exemplified in long-term care facilities is through institutionalized "ghosting" and "elder-speak". In a paper looking at the impact of language in terms of "ghosting" the dementia speaker, Davis and Pope (2010) demonstrate how professional caregiver conversational interactions in long-term care facilities "render her or him less visible and speak over the voice of the AD [Alzheimer's disease] speaker" (p.30). The authors explain that institutional ghosting is exemplified by caregivers talking over, across and for the person with dementia who consequently becomes increasingly silent. Caregiver talk becomes dominant while

interpersonal discourse subsides thereby placing the person with dementia in a position where they need to solicit attention and interaction as opposed to attract it by virtue of being. Institutional ghosting occurs because the individual has become subsumed by stereotypes, including the inability to engage in what some caregivers would consider purposeful, meaningful and coherent conversation.

Similarly, elder-speak (the practice of using infantilizing communication in conversation) is a prevalent occurrence in everyday interactions between people with dementia residing in long-term care facilities and their caregivers. Aside from being patronizing and depersonalizing, elder-speak has been proven to precipitate aggressive, withdrawn, and wandering behaviours as well as to contribute to resistance to care (Herman & Williams, 2009; Williams et al., 2008; Williams et al., 2003). Both institutional ghosting and elder-speak have ethical implications for dementia care in that they place the individual at risk of emotional and physical harm they contribute to neglect and they compromise identity, autonomy, and personhood. Davis and Pope (2010) take this a step further and suggest that institutional ghosting in particular borders on elder abuse but can be mitigated through the implementation of a language policy that is specific to the needs of people with dementia..

6.1.4 Decreased ability for self-advocacy

The final ethical issue to be addressed regarding the impact of structural discrimination in dementia-specific practices in long-term care facilities is that of decreased permissibility for self-advocacy. The ability to advocate for oneself is intimately tied to concepts of

capacity. Self-advocacy helps one to achieve positive health outcomes, is a protective factor for self-worth and identity, and has shown to be effective for people living with an array of health concerns, including people with mental disabilities (Hagan et al., 2016). However, a systematic review of literature published between 1960 and 2012 conducted by Hagan & Donovan (2013) uncovered that self-advocacy is dependent upon one's ability to seek information independently in order to evaluate and use information to advocate for oneself. Awareness of one's needs, communication skills, and the ability to access resources are deemed to be the antecedents of self-advocacy. Unfortunately, dominant dementia discourse portrays the person with dementia as lacking these antecedents and therefore being incapable of self-advocacy. Ultimately, attempts by people with dementia who live in long-term care facilities to ameliorate their physical and psychological well-being is often times met with dismissiveness and abandon (Hagan & Donovan, 2013).

6.2 Restrictions on Rights, Freedoms and Self Determination

Structural discrimination is also responsible for imposing restrictions on residents with dementia that constrain rights, liberty and self-determination. Drawing upon Goffman's work on total institutions (1961) makes it possible to see how such infringements are legitimized. Goffman suggests that total institutions are comprised of like people who are cut off from wider society, who live administered and surveyed lives that are controlled by others, who have minimal or no agency in care decisions, and who behave in manners consistent with conforming to the expectations of caregivers in order to prevent revocation of privileges. Residents are treated this way, according to Goffman,

because primary frameworks that are used to inform decision-making are based upon "culturally bound cognitive schemas that can be understood as a way of organizing and interpreting the situations around us into meaningful information" (Marson & Powell, 2014, p. 150). In dementia care, stereotypes, stigma and dominant discourse frame how situations are interpreted and shape the institutional responses to them. In Goffman's characterization of total institutions, rights are granted when individuals exhibit appropriate behaviour. Behaviour that falls short of what is expected results in the restriction of rights, freedom, and self-determination. In long-term care, residents with dementia experience a lack of opportunity for self-determination because they are viewed as incapable of making informed decisions (Rhynas, 2004) and are at risk of having their rights and freedoms compromised.

6.2.1 Minimized opportunity for self-determination

Health care and personal care decisions are often made for people with dementia. Initial placement in a long-term care facility is often done at the request or suggestion of someone other than the prospective resident. Routinely people with dementia have their decisions questioned and over-ridden because their capacity is undermined by others in their circle of care, and they are often forced and manipulated by care providers to ensure adherence to decisions made for them that contravene their initial desires (Corvol et al., 2013). Opportunity for self-determination is diminished due to perceived decreased capacity and competency to make decisions for oneself. Not only is the ability to determine where one will reside overridden, but everyday choices— such as what one will eat, when they will sleep, who they will socially engage with, what health practices

they will follow, when they will bathe, how they will entertain themselves, where they will walk— are constrained. If, as the authors suggest, self-determination has historically been viewed as being contingent upon an awareness of oneself and others then there are implications for the perception of whether a person with dementia is capable of self-determination. This being the case, attempts by a person with dementia to make decisions about even the most simple of everyday experiences is at risk of being thwarted from the outset.

6.2.2 Behaviour contingent freedoms

In long-term care facilities, the freedom of movement is partly contingent on not being a liability. This can include being able to: (1) ambulate without falling; (2) refrain from entering other residents' chambers; (3) refrain from leaving the facility; (4) refrain from impeding organizational efficiency; and (5) refrain from walking about during bedtime hours (Graham, 2017). Walking within the facility becomes, for the person with dementia, a behavioural symptom that needs to be assessed and managed. As such, residents with dementia whose ambulatory behaviour conforms to institutional regulations enjoy the same freedom of movement that their cognitively healthy counterparts do. Similarly, the right not to be subjected to administration of psychotropics against one's wishes is contingent on exhibiting desired behaviours. Sawan and colleagues (2018) concluded that the use of psychotropic medication in long-term care facilities for residents with dementia was generally not aligned with ideal standards and occurred when administrators of the medication believed they were helpless to do the right thing by the resident, and when it was necessary for efficiency.

From what has been presented, it is evident that structural discrimination can manifest itself in long-term care facility dementia-care through the development of exclusionary practices and restrictions on the individual. An ethical analysis will now be presented in order to highlight how an ethical response that uses a citizenship lens and has human flourishing as its end can help to mitigate the impact of structural discrimination in dementia care in long-term care facilities by safeguarding rights and freedoms.

Chapter 7: Ethical Analysis of Dementia-Specific Practices in Long-Term Care Facilities

Analyzing dementia-specific practices in long-term care facilities through an ethics lens can assist in mitigating the impact of structural discrimination on policy and practice in these settings. Gibson & Upshur (2012) note that in chronic, non-communicable diseases bioethical expertise is notably lacking. Referring to work by Jennings, Callahan & Caplan (1988), they point out that bioethics has largely neglected the ethical dimension of chronic illnesses, such as dementia, due to a bioethics discourse that is autonomy-based, comes from an individualistic moral perspective and is predominantly concerned with problems of acute care. In *The Moral Challenge of Alzheimer Disease* (2000), Post suggests that dementia care which fosters an enhanced quality of life and that destigmatizes the person with dementia should be the goal. Safeguarding citizenship is one way to accomplish this and can be supported using a different conceptualization of autonomy for the person with dementia.

7.1 Counter-dependence and Loss of Autonomy

Beauchamp and Childress (2001) view autonomy as the state of being free from interference by others and free from limitations that prevent meaningful choice. For people with dementia who reside in long-term care facilities, this often does not occur. Individuals are precluded from performing their daily activities of living, such as cooking, cleaning and self-care, and the practice of elder-speak and ghosting foster an environment that decreases the ability to self-advocate. Combined, these render the

individual almost exclusively dependent upon their caregivers. Dominant cultural attitudes demonstrate an aversion to dependence known as counter-dependence (Agich, 2003). As indicated previously, ageism and ableism have been responsible for creating and perpetuating these attitudes. In long-term care facilities, the conflation of counter-dependence with autonomy is a barrier for self-determination among people with dementia and contributes to the erosion of autonomy. For implicit in attitudes of counter-dependence is the commendation of independence; and underlying the concept of independence is the ability to be seen as a person capable of reason. It is precisely the influence of structural discrimination on the creation of who is perceived and who is not perceived as capable of reason that contributes to the erosion of autonomy in long-term care settings. However, it is possible to foster autonomy in people with dementia through a reconfiguration of how autonomy is framed.

7.2 Autonomy as a Positive Right

The concept of autonomy is often subsumed by the concept of rationality. Agich (2003) argues that political liberal theory has perpetuated a concept of autonomy which frames the autonomous individual as an independent, self-sufficient, rational actor who is at the centre of decision making. While it is beyond the scope of this thesis to delve into an elaborate delineation between positive and negative rights, it is worth highlighting the difference between the two. Positive rights are those rights which are accorded to individuals via the imposition of an obligation on others to ensure that these rights are attainable; negative rights impose no such obligation onto others. The dominant frame of autonomy is that it is a negative right; individuals have the right to be free from

interference, but there is no obligation on the part of others to ensure that this right is met. In everyday decision making, for example, the autonomous individual is permitted to make decisions free from any interference of others. However, their perceived ability to make decisions is contingent upon whether they are deemed as having the capacity and competency to make such decisions.

As noted previously, dominant dementia discourse frames the individual as having impaired capacity and competency. Because the ability to reason is deemed requisite for autonomy and because autonomy is framed as a negative right, the person with dementia increasingly experiences this right being infringed-upon. They are viewed as no longer being able to meet the criteria necessary to be considered an autonomous individual who is an independent, self-sufficient, rational actor at the centre of decision making and they are no longer able to claim the right to be free from interference. It is evident that structural discrimination that results from the framing of dementia as a biomedical, mental health, or disability condition erodes autonomous decision making in this population.

One way to mitigate this type of structural discrimination is by making autonomy a positive right for people with dementia. Doing so safeguards citizenship rights and places the onus on caregivers to ensure that the ability for individuals to self-determine and make decisions related to everyday activities of living is not denied to them but is rather afforded to them. The following section will outline how it is possible to integrate a framework for dementia care that allows this to occur.

7.3 Ethical Response: Using a Citizenship Lens to Promote the Flourishing Life

An ethical analysis of dementia-specific practices in long-term care facilities has exposed the development of exclusionary practices and restrictions on freedoms that are imposed on residents due to structural discrimination. It is possible, however, to mitigate the impact of structural discrimination by promoting a response that focuses on citizenship and rights, and promotes human flourishing.

Kelly & Innes (2011) suggest that integrating a rights-based approach offers caregivers a way to understand their obligations, allows them to deliver care in a manner that relates to human and civil rights, and encourages them to challenge inequities. In a similar vein, Jones (2004) argues that rights-based approaches are grounded in the moral standing of humans as individuals and, accordingly, do not accord different standing to different groups of people. Additionally, Baldwin, Greason, O'Connor, & Nedlund (2016) suggest that moving from an individualist, personhood-based model towards a citizenship approach highlights the influence of power relations in care delivery. This section will illustrate how a rights-based citizenship approach to dementia care can mitigate instances of structural discrimination in long-term care facilities found in exclusionary practices and restrictions on rights, liberty and self-determination.

7.4 Mitigating Exclusionary Practices by Attending to Rights and Citizenship

Throughout this thesis, I have sought to demonstrate how dementia has increasingly become problematized due to the influence of dominant medical and media discourse, cultural perspectives, and ageist and ableist discourse. This has made it possible for the

rights and freedoms of people with dementia who reside in long-term care to be infringed-upon. However, by attending to rights and freedoms, attention is drawn to those aspects of everyday living that constitute citizenship. Incorporating a citizenship lens in the development of an ethical framework for dementia care in long-term care facilities, therefore, can encourage critical examination of policies and practices that preclude members of our citizenry from achieving the same rights and freedoms accorded to the rest of our society.

Citizenship has conventionally been understood as a status that is afforded to self-governing, autonomous individuals who have claims to tangible rights to resources and services, and claims to intangible rights to agency, participation and the practice of power (Baldwin et al., 2016). However, a re-genesis of the understanding of citizenship as a practice in everyday situations in relationship to others has begun to emerge (Brannelly, 2011) and focuses on engagement, participation, inclusion, rights, dignity and respect. As seen earlier, a variety of exclusionary practices that occur in long-term care facilities are dementia-specific. In particular, instances of marginalization to excluded status in access to health care services, involuntary isolation, directed dismissive attitudes, and decreased ability for self-advocacy were some examples of exclusionary practices that often occur in these settings. Additionally, a description of the impact of structural discrimination in terms of its ability to create and sustain dominant dementia discourse was presented. It illustrated the way by which the perception of people with dementia at the societal level can transcend into policy and practice in long-term care

facilities. Therefore, before discussing citizenship within long-term care facilities, it is vital to discuss citizenship for people with dementia at the broader societal level.

Bartlett (2016) looked at two emerging notions within the concept of citizenship studies to support the advancement of social citizenship in dementia studies: citizenship within the practice of the ordinary and citizenship within the domestic sphere. Bartlett draws upon citizenship research by Neveu (2015) which explores the role of the ordinary in politicizing experiences of individuals. Neveu suggests that moving away from a traditional conceptualizing of a politicized citizenship of 'political people' towards one that examines the everydayness of ordinary citizens allows the opportunity to witness how the "mundane spaces of daily sociability" impact citizenship. Daily interactions in public spaces are opportunities where citizenship can be either promoted or infringed-upon. In a similar vein, Bartlett uses research by Garcia-Del Moral & Dersnah (2014) into micro injustices experienced by people with dementia living at home to illustrate the interconnectedness between relational inequalities both within and outside of the home. Curtailing of opportunities and freedoms by way of confinement to the house and preclusion of social interaction outside of the home are examples of such injustices. While the intent is not necessarily to purposefully preclude people with dementia from being engaged citizens, these actions nonetheless have the same effect. Bartlett suggests that espousing a social citizenship lens allows the person with dementia to be free from discrimination and despair while providing opportunities to grow.

Citizenship can be fostered for people with dementia by permitting them to continue to fulfill roles and activities they may have undertaken within their communities

(Clarke & Bailey, 2016), such as going for a walk and engaging with others in a meaningful way. The authors explore research by Beard and Fox (2008) which suggests that a dementia diagnosis often leads to social disenfranchisement, resulting in infringements on rights, social inclusion and citizenship. Brannelly (2016) suggests that citizenship for people with dementia is challenged because; a) people with dementia are not perceived as having social worth; b) they are not perceived as active citizens and; c) they experience exclusion from their communities. Developing a rights-based approach to care, according to Wiersma et al., (2016) can help to mitigate challenges to citizenship for people with dementia. As the authors point out, a citizenship framework posits a rights-based approach as opposed to a needs-based approach. But they caution that developing such an approach requires the recognition of the dementia experience as one that is framed by social and cultural structures. Therefore, as this thesis has sought to demonstrate, the role that ageism and ableism plays in creating a dominant dementia discourse that fosters structural discrimination in the practice of the ordinary and in the domestic sphere, needs to be addressed in tandem with the development and implementation of policies that aim to mitigate such discrimination.

How, then, can this be accomplished? An approach to dementia care that recognizes the interconnectedness and interdependence of those providing and receiving care can help safeguard the cognitive, social and corporeal citizenship of people with dementia. Similarly, recognizing access to health care as a positive right would help to minimize inequities in access to primary health care for people with dementia that are born out of structural discrimination. Developing an ethical framework that utilizes a

citizenship lens can help mitigate the impact of structural discrimination in long-term care facilities by facilitating social, cognitive and corporeal citizenship. To demonstrate, an illustration of how each of these citizenship rights is often infringed-upon will be presented followed by a suggestion as to how an ethical lens can help to prevent the occurrence of such infringements.

Bartlett and O'Connor (2007) define social citizenship for people with dementia as "a status, practice or relationship in which a person with dementia is free from discrimination and despair and has opportunities to grow." But people with dementia experience challenges to their social citizenship. Brannelly (2016) suggests that current overvaluation of individuality, productivity and youth impedes the recognition of the social worth of older people, especially elders with dementia. Accordingly, the right to choose one's place of residence is compromised among people with dementia, as they are often forced to live in the social segregation of a facility as opposed to live socially integrated into their community. As previously noted, dementia-specific exclusionary practices result in the involuntary isolation of people with dementia residing in long-term care facilities, resulting in infringements on the social citizenship rights of this population through the imposition of restrictions upon an individual's ability to continue to play an active social role in the public and domestic sphere. Consequently, residential policies and procedures that fail to ensure that residents have access to meaningful association, activity and engagement actively restrict social citizenship. However, an ethical framework that is grounded in virtue theory and has as one of its aims human flourishing,

would encourage social citizenship by promoting policies that focus on safeguarding individual citizenship rights in addition to attending to individual needs.

The second citizenship right that is commonly impeded in long-term care facilities is cognitive citizenship. Cognitive citizenship in this sense refers to the freedom to make decisions in accordance with personal preferences and values. In long-term care facilities, the focus on attending to needs in favour of attending to rights makes it possible for the cognitive citizenship of people with dementia to be overridden. Again, it is crucial to recall that for all intents and purposes such impediments to cognitive citizenship are not necessarily intentional and, as such, fit the operational definition of structural discrimination. Cognitive citizenship rights are violated at the time of admission to a long-term care facility in so far as it is most often not the individual's choice to leave their home. The freedom to decide upon where to reside is circumvented. Once within the new environment, cognitive citizenship is further eroded. Mandated regimens pertaining to personal care, health care, dietary intake, sleep and socialization preclude residents with dementia from making decisions with regards to any of these activities. But if dementia care is reframed as an interdependent shared decision-making process and if care is informed by virtue theory using a citizenship lens, then cognitive citizenship can be restored and protected.

The final infringed-upon citizenship right that will be addressed is what shall be called corporeal citizenship. By this I mean those practices which impose restrictions on ambulation, bodily movement and bodily expression. As illustrated in earlier sections, there are numerous ways that long-term care facilities accomplish this. Physical,

chemical and environmental restraints to discourage wandering, facilitate sleep, discourage interaction with others and prevent individuals from leaving the facility serve as restrictions on decisions regarding one's body. If a virtue theory approach is integrated into an assessment of how to manage these perceived dementia-specific manifestations, then it is possible to create a response to these behaviours that promotes flourishing and citizenship rights even in light of associated risks. Ethically problematic situations with regards to deciding upon which course of action to take can take into consideration the attention not only to the physical needs and safety of the individual but the necessity to safeguard their dignity and citizenship rights as well.

The ethical implications of the infringement on the citizenship rights of people with dementia residing in long-term care facilities are numerous. It has been illustrated that exclusionary practices, marginalization to excluded status in the context of health care, social isolation, decreased ability for self-advocacy, minimized opportunity for self-determination, behaviour contingent rights, and restrictions on the freedom to decide where and how to live evolve from a denial of citizenship rights for this population. But what has not been addressed are the ethical implications surrounding the impact of dementia specific practices on the specific citizenship rights of residents with dementia who are women, minorities, non-heterosexual or members of other vulnerable populations. It is beyond the scope of this thesis to do so, but nevertheless necessitates acknowledging that infringement on the citizenship rights of these groups may be varied. Ultimately, the compromising of rights and citizenship of people with dementia who reside in long-term care facilities is tied into dominant dementia discourse and the

perceptions of people with dementia. In order to understand why it is necessary to re-evaluate dementia care policy and practice in long-term care facilities the implications of not addressing them requires perusing.

Chapter 8: Implications for Dementia Care in Canada

Structural discrimination has far reaching implications for people living with dementia on a variety of levels. The purpose of this thesis was to bring to light how this plays out in long-term care facilities through policy and practice and to illustrate how an ethical framework using a citizenship lens can mitigate help to mitigate the effects. The reasons for addressing this issue are numerous from practical, ethical and human rights perspectives. But as a final thought, this thesis will look at potential implications that structural discrimination in long-term care facilities has for Canadian discussions surrounding the future of palliative and end of life care for people with dementia and medical aid in dying (MAiD).

8.1 Palliative and End-of-life Care

From a national perspective, the state of palliative and end of life care (PEOLC) is woefully inadequate. In the mid-1990s, the Canadian government took some initial steps to address the PEOLC needs of its citizens, beginning with a Special Senate Committee on euthanasia and assisted death. By 2000, a standing Senate committee identified quality end of life care as a right for all Canadians and established a blueprint for achieving this outcome. A set of themes and priorities arose out of these strategies. It was determined that, in Canada, the desire for an assisted death was primarily due to the fear of a painful, lonely and degrading death. As a result, five priority areas were set which included: (1) availability and access to PEOLC, (2) professional education, (3) research, (4) family and caregiver support, and (5) public education and awareness. A

progress report in 2010 uncovered that PEOLC for people whose illness had no predictable trajectory was lacking, that there was little to no research into PEOLC for people with dementia, and that 70% of Canadians who require PEOLC do not receive it (Carstairs, 2010), regardless of it being an enforceable human right under sections 7 and 15 of the Canadian Charter of Rights and Freedoms. As of 2014, PEOLC in Canada had still not improved (CSPCP, 2014) and by 2015 the Quality End of Life Care Coalition determined that PEOLC for people with dementia residing in long-term care facilities was virtually non-existent due to financial, temporal and educational constraints.

Granted, diagnosing when an individual with dementia should receive PEOLC is fraught with difficulties. Communication barriers, misinterpretation of signs and symptoms, and a lack of knowledge about the importance of PEOLC along the entire trajectory of the condition all contribute to creating barriers to access. But structural discrimination in the delivery of PEOLC for people with dementia underlies these barriers, beginning at the research level and traveling to the clinical level. Research into dementia focuses primarily on pathology, costs and care-giver burden; co-morbidities or indicators of impending death are overlooked, under assessed or erroneously treated; people with dementia receive more invasive and aggressive interventions. Structural discrimination has an undeniable influence over what is being researched, who is being researched and how research is carried out. The degree of importance we collectively afford to issues and groups of individuals influences what gets researched and impacts care delivery. The influence of ageism, ableism and dominant dementia discourse in determining what, who and how research is carried out cannot be overstated. As will be

illustrated, the impact of structural discrimination on palliative and end of life care for people with dementia has direct implications for medical aid in dying in Canada.

8.2 Medical Aid in Dying and Dementia

In 1997, John Hardwig suggested that individuals need to consider whether or not they have a duty to die. He postulates that only the competent have this duty; not the incompetent. But if the competent individual can foresee eventual incompetency in their future, then they have a duty to preemptively ensure the fulfillment of this duty prior to a deterioration in competency. This duty, Hardwig contends, is grounded in the notion that once individuals are no longer capable of caring for themselves, they have a moral obligation to die so as not to burden family and society.

As previously indicated, dominant dementia discourse has resulted in structural discrimination not only at the policy and practice level of long-term care institutions but also at the research level. If research consistently focuses on the deleterious effects of dementia and fails to delve into researching how to foster human flourishing by attending to citizenship rights, then the image of the person with dementia as a burden to family and society is perpetuated and reinforced. If, as national reports into assisted death indicate, the fear of a painful, lonely and degrading death are catalysts for seeking MAiD, and if people with dementia are framed as being burdensome, then the potential questions regarding requests for MAiD include a discussion surrounding advance health care directives (AHD) for people with dementia to include a request for MAiD in the future. While AHDs are not part of the current landscape of MAiD in Canada, requests for

medical assistance in dying can be included as part of an AHD in other countries where assisted dying and euthanasia are permitted. Therefore, it is worth considering the potential implications of AHDs in requests for MAiD.

The perceived fate of the person with dementia is imposed upon individuals by ageist and ableist influenced media and medical representations and reinforced by structural discrimination. There is a need not only to challenge these representations, but to assess the impact of these representations on the mental health of people with dementia and on prospective decisions made by people who anticipate developing dementia. In 2015, the Canadian Coalition for Seniors' Mental Health (2015) stated that, in Canada, more than 60 seniors die per week due to suicide and that over 100 seniors were admitted to hospital due to intentional self-harm. Thoughts and acts of suicide were often precipitated by feelings of purposelessness, anxiety, hopelessness, helplessness, isolation, withdrawal and anger. These feelings are not exclusive to individuals without cognitive impairment and, as such, should be researched and addressed among people with dementia. The diagnosis of dementia is often accompanied by a pathologization of the individual, framing them as incapacitated and incapable of maintaining their independence. Can dementia, then, be categorized as a grievous and irremediable condition for which MAiD is permitted if issues of consent and capacity are able to be skirted around via an advance health care directive? It is questions like this that underscore the need to examine the way that dementia is framed and the way people living with dementia are perceived.

Chapter 9: Conclusion

The purpose of this thesis has been to demonstrate how a citizenship lens based in virtue theory can be used to mitigate structural discrimination for people with dementia who reside in long-term care facilities. To accomplish this, this thesis has tried to ascertain what makes this particular group of people susceptible to institutional discriminatory policies and practices. As indicated, dementia has undergone several iterations over the course of the last century, resulting in the pathologization of what was historically seen as a chronic deterioration of the brain due to the process of aging. This reconfiguration of dementia demonstrates that current models of dementia are based in the social construction and problematizing of the condition. As a result, people living with dementia become susceptible to various forms of structural discrimination in the social and domestic sphere, and are vulnerable to dementia-specific practices in long-term care facilities that infringe upon their rights and freedoms.

Within long-term care facilities, structural discrimination has culminated in the creation of policies and practices that are specific to residents with dementia that prevent them from enjoying the same rights and opportunities as people without dementia. Some dementia specific practices that occur in long-term care facilities include the use of physical and chemical restraints to curtail what is perceived as wandering, superfluous supervision and inappropriate medical interventions at end of life. Informing these decisions are normative assumptions about dementia based on medical and media discourse, permeating not only the arena of academia and health care but also the

consciousness of the general public. Historically, biomedical representations and frames have been accorded weight and legitimacy due to the authority that has been granted to medical discourse. As a result, dementia discourse created in a biomedical silo becomes the basis upon which the social role is ascribed. Two consequences of the constructed representation of dementia are imposed suffering and social death. Individuals with dementia suffer because of the disparaging words and images imposed upon them and the lack of meaningful opportunities to experience purpose and social engagement; they experience social death because they cease to be an active agent in the lives of other people. This thesis demonstrated that medical and media representations of dementia are influenced by ageism and ableism, both of which have the effect of stigmatizing the person with dementia and preventing them from achieving the same rights and opportunities that are available to the majority of the population.

As demonstrated, structural discrimination experienced by residents with dementia in long-term care facilities can be in the form of rules and policies or in the form of the unintended consequences of rules and policies. However, it is possible to mitigate structural discrimination by developing inclusionary practices that safeguard rights and freedoms. An approach to dementia care that uses a citizenship lens and attends to human flourishing can help to accomplish this.

Undeniably, structural discrimination has implications for the quality of life and, potentially, end of life decisions for individuals diagnosed with dementia. We have seen that cultural representations of dementia are created by ageist and ableist influenced

medical and media representations of the condition and that these in turn impact dementia care in long-term care facilities. Various ethical issues are associated with the influence of structural discrimination in dementia-specific practices in long-term care facilities that result in the development of exclusionary practices and restrictions on rights, liberty and self-determination for the person with dementia. However, by attending to social, cognitive and corporeal citizenship rights of people with dementia, dominant dementia discourse can create an image of life with dementia less laden with tones of tragedy that in turn can positively impact dementia care, and ultimately how we engage with those living with dementia.

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