

UNMAPPING THE MINI-MENTAL STATE EXAM (MMSE)

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ABSTRACT

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This study is a critical discourse analysis of the Mini-Mental State Exam (MMSE), an assessment tool used to screen older adults for cognitive impairment worldwide. In it, I deconstruct and unmap two unofficial versions of the MMSE to reveal how its discursive practices are grounded in ageism, ableism, sanism, and other forms of oppression. I challenge the MMSE's status as a neutral container for knowledge by uncovering how it actively defines "cognitive impairment" and "cognitively impaired" identity formation through epistemic violence. I discuss five key issues: consent, scoring, claims-making, voice, and copyright. Lastly, I reflect on how hegemonic discourses about "dementia" keep older adults and people with cognitive impairments in their social place while maintaining the multi-billion dollar "care" industry. This study highlights how social workers are implicated in injustices against older adults that are often hidden. I hope it will be the impetus for transformative change in this field.

Keywords: Mini-Mental State Exam, short cognitive test, discourse analysis, unmapping, cognitive impairment, older adults, gerontology, anti-oppressive practice

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DEDICATION

To my husband and our family.

To those of us whose voices go unheard when spoken from “madness”. Please accept my apologies for all the times I unconsciously contributed to your suffering and oppression.

To older adults, people with cognitive impairments, caregivers, activists, and my colleagues in the field. Together, we can be the change. Hope this helps.

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CHAPTER 1. INTRODUCTION

Old age, by itself, is not a reason for social work intervention (Langley, 2001). The social construction of old age, on the other hand, is often harmful and oppressive (Cruickshank, 2013; Hulko, Brotman, & Ferrer, 2017; LeBlanc, 2016). Mainstream and social work discourses about “healthy aging” center a responsible, financially well-off, unimpaired, able-bodied, white subject (Hulko, 2009; LeBlanc, 2016). This can lead to unrealistic expectations and a one-size-fits-all approach to working with older adults (people over the age of 55). For example, social work interactions with older adults in clinical and community settings are organized around standardized assessments to measure cognitive, psychological and physical well-being, as defined by the healthy aging model (Hastings & Rogowski, 2015). Undetected cognitive impairment is positioned as the biggest issue facing older adults and a major threat to society today (Cruickshank, 2013; Johnstone, 2011). All older adults are suspect and, according to the healthy aging paradigm, should undergo regular cognitive screening. Being “at risk” of having a cognitive impairment often intersects with other marginalized identities, further disenfranchising individuals as they age (Ferrer, Grenier, Brotman, & Koehn, 2017; Hulko, 2009; Langley, 2001; Sandberg, 2018).

Cognitive impairment refers to changes in memory, thinking, orientation, comprehension, learning capacity, language, and judgement, as well as a decrease in social behavior and emotional control (Bosco, Schneider, Coleston-Shields, Higgs, & Orrell, 2019; Cruickshank, 2013; Davis, 2004; Gaines & Whitehouse, 2006; Hulko, Brotman, & Ferrer, 2017; Naue & Kroll, 2009; Simpson, 2014). These changes can be the result of many conditions, including Alzheimer’s disease, vascular dementia, and Lewy Body dementia (Dementia Engagement and Empowerment Project (DEEP), 2014; Simpson, 2014). These conditions are commonly referred

to as “dementia” or “neurocognitive disorder” (the new term introduced by the American Diagnostic and Statistical Manual of Mental Disorders (DSM-V)) (Simpson, 2014). Other causes include polypharmacy (Park, Park, Song, Sohn, & Kwon, 2017), institutionalization (Ong, et al., 2016), and psychiatric illnesses such as depression (Pachana, et al., 2016) or schizophrenia (Moore, Palmer, & Jeste, 2004).

In this MRP, I use the term “cognitive impairment” to refer to these conditions, except when citing authors who use a different word. Some people living with a cognitive impairment in the United Kingdom and Canada have expressed their preference for people to use this term (DEEP, 2014; George, 2010; Hulko, 2010; Sabat et al., 2014). The term “dementia” dehumanizes people living with a cognitive impairment (DEEP, 2014; Sabat et al., 2011). It is often sensationalized and misrepresented in media reports (Corner, 2017; DEEP, 2014; George, 2010; Gerritsen et al., 2018; Johnstone, 2011). In contrast, “cognitive impairment” carries less stigma and refers to the *type* of (dis)ability experienced by an individual without making assumptions about its cause. Furthermore, having a cognitive impairment is not always the same thing as having dementia (although the two are often conflated). While the term “cognitive impairment” is still deficit-focused, its ambiguity recognizes and holds space for alternative interpretations of cognitive, behavioral and emotional changes.

Cognitive impairment is usually screened for using an assessment tool called the Mini-Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975). The MMSE was created by two white, American geriatric psychiatrists in 1975 to be used as a quick, objective screen for cognitive impairment in older psychiatric inpatients “who were cooperative for only short periods of time” (Folstein, Folstein & McHugh, 1975, p. 190). It has since become the global gold standard of screening for cognitive impairment in older adults, as well as evaluating

changes in their cognitive function over time (Carnero-Pardo, 2014; Ford, Haley, Thrower, West, & Harrell, 1996; Godin, Keefe, & Andrew, 2017; Hawkins, Cromer, Piotrowski, & Pearlson, 2011; Kochhann, et al., 2008; McDonald, 2006; Monroe & Carter, 2012; Quan, et al., 2016). It is administered by doctors, clinical researchers, nurses, social workers, and allied health professionals (Cahill et al., 2008; Carnero-Pardo, 2014; Iracleous et al., 2010; Martin et al., 2015). In Ontario, it is an established part of clinical practice (Iracleous, et al., 2010) and its use is often mandated by law (Long-Term Care Homes Act, 2007, c.8).

I first learned to use the MMSE in an undergraduate university course about the social construction of aging and social work. I remember feeling surprised that a simple eleven-question test could screen for something as complex as cognitive impairment. *What makes these questions so special*, I wondered. I have used the MMSE dozens of times since then, and would be considered an MMSE “expert” by my colleagues. However, the more I use the MMSE, the more questions I have about this and other short cognitive tests.

Although the MMSE has been cited in nearly 30,000 studies in PubMed (Carnero-Pardo, 2014), there is significantly less research *on* the MMSE and its assumptions (Monroe & Carter, 2012). In 2000, its authors copyrighted the MMSE and licensed all publishing and distribution rights to a company called Psychological Assessment Resources Incorporated (PAR) (Fiore, 2015). This has discouraged research and innovation regarding this test (Fiore, 2015). In particular, a systematic review by Martin et al. (2015) found a gap in research that considered the actual experiences of the populations targeted by the MMSE. Of the few studies that have been done, one found that hospitalized older adults frequently did the MMSE under false pretenses and were not told the implications of getting a low score (Krohne, Slettebo & Bergland, 2011). Another found that healthy, community-dwelling older adults were four times more likely to test

positive for cognitive impairment on the MMSE if they were exposed to stereotype threat (Mazerolle, et al., 2017). These findings suggest that the MMSE is neither neutral nor objective.

In this MRP, I will explore how the seemingly harmless short cognitive test known as the MMSE is part of the incursion of the neoliberal, biomedical gaze into the lives of older adults. My analysis “unmaps” (Razack, 2002, p. 9) the claims made by the MMSE to make visible the problematic worldviews that rest upon it. My analysis will also reveal how the MMSE structures encounters between older adults and healthcare professionals, including social workers, through the construction of the “dementia space” (Macdonald, 2018, p. 290). My MRP highlights how Western social workers can become implicated in forms of injustice against older adults that are often hidden. On a practical level, I hope it will inspire healthcare professionals, researchers and policy-makers to work with people living with cognitive impairments and their caregivers to co-create a better way of screening for cognitive impairment, one that is grounded in their needs and socially-situated experiences. Before proceeding further, I present my theoretical framework to enable readers to better understand the lens through which I see the MMSE.

CHAPTER 2: THEORETICAL FRAMEWORK

Anti-Oppressive Practice

My theoretical framework for this MRP is grounded in anti-oppressive practice (AOP), which is a set of politicized social work practices constantly evolving to better challenge oppressive social structures and inequitable social relationships at the micro, meso and macro level (Baines, 2011). AOP rejects individual explanations for social problems and draws attention to their root cause: oppression in its many forms, which is defined as “a system’s capacity to deform the lives of many” (Jeffery, 2007, p. 134). As such, AOP is a politicized response to the impacts of neoliberalism and capitalism (Baines, 2011; Janzen, Jeffery, & Smith, 2015). Neoliberalism reduces all forms of social protection and promotes minimalist taxation, precarious work, and the virtues of individual responsibility, competition, and economic self-sufficiency (Voronka, 2019). However, it is important to recognize that “there is no such thing as ‘innocent’ space for social work” (Smith, 2011, p. 202). Social work’s low status and overt social control functions, particularly in relation to Indigenous nations, psychiatric survivors and people experiencing poverty, means that AOP research and practices do not always or automatically live up to their emancipatory aspirations (Wilson & Beresford, 2000).

Although AOP is becoming the cornerstone of the Canadian social work academe, service users continue to be excluded from theory and knowledge production (Wilson & Beresford, 2000). AOP research often includes the lived experiences of service users, which give it greater legitimacy. However, the power to construct social issues and to define what constitutes an “anti-oppressive” practice remains with social work academics and practitioners (Wilson & Beresford, 2000). Furthermore, AOP social work education still happens in a neoliberal context, which “eradicates the ‘radical imagination’ to dream the impossible which is

needed for creating an equitable society” (Pillay & Kathard, 2015, p. 209). As a result, there is often a gap between AOP theory and practice. This is particularly true for AOP social work with older adults (Hulko, Brotman, & Ferrer, 2017; LeBlanc, 2016).

My intention is not to take away from AOP’s emancipatory potential or the transformative work being done using this approach. I believe that these issues are important for any AOP social worker, researcher or academic to consider if they want to work with people in a good way. These concerns have shaped the direction of my MRP from the start, beginning with my decision to pursue research that brings AOP perspectives into a new context – social work with older adults – and is grounded in actual social work practices in this field. At the same time, I am still grappling with the challenges raised in Wilson and Beresford’s (2000) critical discussion of AOP “from a service user’s perspective” (p. 553) as I write this draft. I continue to reflect on how to engage in my work without appropriating the socially-situated knowledge and experience of people living with a cognitive impairment. This is especially important when writing about older adults and people with cognitive impairments, who regularly experience epistemic violence: “the process by which certain groups or persons in society are disqualified as legitimate knowers, culminating in institutional practices that deny their ways of being and construct them as less than human” (Liegghio, 2013, p. 123).

All research is political (Voronka, 2019). Throughout the process of writing this MRP, I have wondered if I am positioning myself as “too much of an expert” to be an AOP researcher, or as “too biased” to be an academic one. My husband, a clinical researcher and a chemist, had some surprising advice on this front: *all* research is biased. Even quantitative, double-blind, evidence-based research has bias – it’s just harder to see (Gray, Plath, & Webb, 2009; Voronka, 2019). This MRP is the start of a conversation. In it, I aspire to own my positionality and

perspective on the issue at hand. However, a re-evaluation of how health professionals do research and work with older adults and people with cognitive impairments is long overdue. Older adults and people with cognitive impairments need to be the ones who set the agenda and need to be treated as equal partners in health and social work research and practice. Furthermore, healthcare professionals need to make a political commitment to anti-agism, the disability movement, non-exploitative research methods, and research that “is widely disseminated for use against oppression” (Stone & Priestly, 1996, p. 715).

A Foucauldian analysis of power informs this MRP. Foucault (as cited in Fook, 2016) suggests that power becomes power through the processes and structures of social interaction (Fook, 2016). For example, healthcare professionals who work with people recovering from brain injury often use their “changed, inert bodies against themselves. At one moment, they... order the patient to do their own care but then refuse to give them toothpaste because they were acting ‘helplessly’” (Fook, 2016, p. 71). A Foucauldian power analysis is applicable to understanding the MMSE because it can reveal how experiences of illness are actually experiences of social norms (Fook, 2016). It can reveal how various forms of knowledge about “dementia” function to maintain older adults and people with cognitive impairments in their social place. These include mainstream beliefs (widely-accepted ideas, stereotypes, biases, and generalizations, including all of popular culture), practical knowledge (specific behaviors and practices), theoretical knowledge (the ideas, rationalizations and conceptualizations that underpin these practices), and institutional norms (systemic organizations of practices and ideas, which ensure that institutions are maintained) (Fook, 2016; LeBlanc, 2016).

Spatial Theory

My theoretical framework is also informed by spatial theory, which is a critical way of looking at the material and symbolic constitution of physical and social spaces (Razack, 2002). Critical spatial theory rejects the notion that space is innocent and that it simply evolves over time (Razack, 2002). Instead, it explores how physical and social spaces are organized to sustain unequal social relations and how those social relations, in turn, shape spaces (Razack, 2002). For example, Razack and co-writers (2002) used a spatial analysis to explore how the social construction of race, space and the law sustains a White settler society in Canada. A spatial analysis asks us to reconsider the relationship between identity and geography by asking questions, such as: “What is imagined or projected on specific spaces and bodies? What is being enacted there? How much does identity dominance rely on keeping racial Others firmly in place?” (Razack, 2002, p. 5). As such, a spatial analysis is necessarily a critical, anticolonial and intersectional analysis (Hunter, 2002). Phillips (1997, as cited in Razack, 2002, p. 5) calls this “unmapping”. To unmap is to denaturalize geography by asking how spaces came to be and “to undermine the worldviews that rest upon it.” (Phillips, 1997, as cited in Razack, 2002, p. 5).

Older social orders are constantly being reshaped and revitalized (Jacobs, 1996, as cited in Razack, 2002, p. 16), so it is informative to consider space in conjunction with many systems of oppression in addition to race (Razack, 2002). These include colonialism, ableism and sanism (Bruce, 2017; Pillay & Kathard, 2015; Schott, 2017; Soldatic & Gilroy, 2018). For example, the creation of the rational subject and its converse, the cognitively impaired Other, are part of larger efforts to segregate, contain and limit the rights and opportunities of anyone who is not rational, productive and self-sufficient (Naue & Kroll, 2009; Rudy, 1987). In other words, anyone who does not advance capitalist interests. In this MRP, I consider how cognitive differences exclude

people from being Cartesian subjects – a requirement for human citizenship (Schott, 2017) – which translate to spatial differences that protect neoliberal and colonial state interests (Pillay & Kathard, 2015; Voronka, 2019). I refer to these spatial differences as the “dementia space”.

The Social Construction of the Dementia Space

The dementia space has come into being through biomedical, neoliberal, colonial, ageist, sanist, ableist, racist, and sexist discourses in our society. Although Macdonald (2018, p. 290) was the first to use the term the “the dementia space”, it and its component discourses have been around for a long time. The dementia space is part of our physical geography in the form of the long-term care home and the locked hospital dementia ward. These physical locations reduce people with cognitive impairments to the symptoms of their disease through psychiatrization and epistemic violence. This goes beyond denying people’s legitimacy as knowers. The person is broken down and reconstituted as incompetent, dangerous, and a risk to society and themselves (Liegghio, 2013). These powerful discourses justify the use of extreme interventions, including the use of restraints and physical force. Cognitive impairment then becomes a problem that is at once biological and political, and a problem of power (Voronka, 2019).

The dementia space is also a social space. It is a set of unequal social relationships stratified on the basis of age and cognitive (dis)ability. Older adults and people living with cognitive impairments are excluded from knowledge production and meaningful participation in society because of our “cultural and material aversion to impairment and difference” (Voronka, 2019, p. 82). At the same time, their social and economic disenfranchisement has created a multi-billion-dollar “care” industry (Sena, 2018). These unequal power dynamics have led to research, policies and practices which, in turn, legitimize the continued existence of the dementia

space. This ensures that institutions that manage and “care for” older adults and people with cognitive impairment – including social work – are maintained.

In this MRP, I expand on Macdonald’s (2018) definition and explore how the MMSE maps the boundaries and inhabitants of the dementia space. Existing research on the MMSE has looked at how well it screens for cognitive impairment. In contrast, I consider how this widely used tool actively *defines* cognitive impairment and constructs people living with cognitive impairments in particular ways. In what follows, I present a review of the literature that highlights, among other observations, the absence of a critical anti-oppressive approach, as described in my theoretical framework. Next, I will proceed to a discussion of my choice of methods (unmapping and deconstruction) and methodology (critical discourse analysis). I then present the findings of my analysis of the MMSE, and conclude with key implications for social work practice with older adults.

CHAPTER 3. LITERATURE REVIEW

There were three prominent themes in the literature: “cognitive impairment” is a social construct; the significance of cognitive impairment depends on its context; and the Mini-Mental State Exam (MMSE) is a scientific, clinical and legal tool that extends the biomedical gaze into the lives of older adults. The literature reviewed was comprised of quantitative and qualitative studies written in English from around the world, as befits a globally-adopted test. Disciplines present in the literature include: medicine, psychiatry, gerontology, nursing, psychology, linguistics, history, political science, sociology, anthropology, and social work.

Etymology of “Cognitive Impairment”

The Biomedical Model

The biomedical model is the most prevalent and well-established way of thinking about cognitive impairment around the world due to the combined efforts of the World Health Organization and the Alzheimer’s Society (Davis, 2004; Gaines & Whitehouse, 2006). In the biomedical literature surveyed for this MRP, cognitive impairment is exclusively defined using a deficit discourse. This includes the assumption that people are unaware of being impaired. Indeed, denial was seen as a symptom of dementia (Kochhann, et al., 2008). The majority of studies looked for links between biological markers, brain lesions and behavior (Gaines & Whitehouse, 2006). For example, medical researchers in the longitudinal Nun Study (Snowdon, 2003) looked for relationships between brain weight and histopathology, and the clinical expression of dementia over the lifecourse of six hundred and seventy-eight Catholic nuns.

Mehta (2011) traces the origins of the biomedical model to the mind-body Cartesian split in 17th century Europe. This established the body as a new geography for the pioneering field of medical research. People began to be seen as “biological organisms (materialism), to be

understood by examining their constituent parts (reductionism) using the principles of anatomy, physiology, biochemistry, and physics” (Mehta, 2011, p. 204). An increasingly technical medical gaze claimed that observable physical pathology was the objective, real and unquestionable foundation of all disease. However, dementia continued to be seen as a normal part of aging until 1906, when Alois Alzheimer discovered a new tissue-staining technique that revealed amyloid plaques and neurofibrillary tangles in a deceased person’s brain (Gaines & Whitehouse, 2006). This discovery was the first step towards making dementia a problem of the body (Macdonald, 2018) and extending the biomedical gaze into the lives of older adults (Davis, 2004).

Historical Dementia Discourses Are Recycled In Present Day

Contemporary Western discourses about dementia have been around since the sixth or seventh century BC (Bosco, Schneider, Coleston-Shields, Higgs, & Orrell, 2019; Papavramidou, 2018). The term itself is Latin: *de* means to depart from, *mens* – the mind (Corner, 2017). Dementia has been defined as: a normal part of aging, the result of a life devoid of active engagement and proactive thinking, divine punishment for sinful acts, a threat to society, a loss of agency, a social issue, a form of psychosis, the result of degenerative brain disease, and a social condition (Bosco, Schneider, Coleston-Shields, Higgs, & Orrell, 2019; Gaines & Whitehouse, 2006; Papavramidou, 2018). These discourses are revitalized and recycled in the present day. For example, the “use it or lose it” hypothesis dates back to the first century BC (Bosco et al., 2019). This discourse is recycled in highly profitable cognitive training programs today (Butler, et al., 2018; Lampit, Hallock, & Valenzuela, 2014). Studies about the impact of lifestyle and personality (Johansson, et al., 2014; Verghese, et al., 2003) get taken up by popular media outlets to blame individuals for their cognitive (dis)ability (Alzheimer's Research UK, 2014). The practice of forced isolation in long-term care homes (Rudy, 1987) dates back to the

Enlightenment, when people affected by cognitive impairments were put on trial and institutionalized so as not to infect the rest of society with their “degenerate” ways (Bosco, Schneider, Coleston-Shields, Higgs, & Orrell, 2019). The societal threat discourse has found new life in policies around driving, where older adults who fail short cognitive tests such as the MMSE lose their driver’s license, even if they have no formal diagnosis (Lee & Molnar, 2017). Society is protected from the “risky” individual at the expense of their mobility and freedom.

Becoming A Social Issue

The collective aging of the white settler state, advances in biomedical research, growing political and economic interest, and a medical consumer rights movement established dementia as a major social issue and a national research priority in the 20th century (Cruickshank, 2013; Gaines & Whitehouse, 2006; Naue & Kroll, 2009). The American National Institute of Aging (NIA) was founded in 1975, the same year that Folstein, Folstein & McHugh (1975) published their landmark paper on the MMSE (Gaines & Whitehouse, 2006). The NIA’s mission was to make Alzheimer’s disease a household word (Gaines & Whitehouse, 2006). In order to do so, the NIA presented cognitive impairment as an individual tragedy and a threat to society (Sabat, 2005). Present-day dementia biopolitics continue to make reference to demographic changes that pose an economic threat to society, which “make it necessary to reconsider health care priorities.” (Naue & Kroll, 2009, p. 292). For example, many research articles on cognitive impairment begin by reviewing the latest numbers of people affected. However, Cruickshank (2013) suggests that the idea of an aging population threatening the non-old is a cultural myth which perpetuates fear and ageism.

In a neoliberal society where personhood and citizenship are tied to rationality, independence and economic productivity, people with cognitive impairments are increasingly

being targeted for death (Naue & Kroll, 2009). A handful of studies draw attention to the ethical implications of how dementia is portrayed in popular culture and the scientific literature (Gerritsen, Oyeboode, & Gove, 2018; George, 2010; Macdonald, 2018). Others reveal the impact of dementia worry on how people interpret age-related cognitive changes, engage in screening and prevention, use the healthcare system, and interact with people with cognitive impairments (Kessler, Bowen, Baer, Froelich, & Wahl, 2012; Wray, 2017). For example, Johnstone (2011) suggests that the morally loaded epidemic metaphor, the military metaphor, the predatory thief metaphor, and the euthenasia metaphor are being used to stigmatize cognitive impairment in order to “mediate public opinion supporting the legalization of euthenasia as an end-of-life ‘solution’ for people with the disease” (p. 377). Despite the deadly consequences of this “Alzheimerization” of the euthenasia debate in Canada, biomedical research on cognitive impairment continues to be framed by these metaphors (Halewood, 2016; Lee & Molnar, 2017).

Gaps in Research Attempting To Define Cognitive Impairment

An etymology of cognitive impairment is essential to critically understanding how it has become a social issue and to unmapping the MMSE. A major limitation of the literature available is its Eurocentric focus. This curtails our understanding of dementia, which is a complex, culture-bound phenomenon (Wray, 2017). For example, in Cohen’s 1995 extensive anthropological account of people with dementia in northern India, *dimāg*, “hot brain” emerged as a way of thinking about dementia that emphasized “anger rather than memory as a fundamental index of senile difference” (p. 314). A related shortcoming is that most research uses a biomedical framework, which is not always helpful to understanding cognitive impairment. A biomedical framework reduces life to keeping the body of the person affected by cognitive impairment functioning (Macdonald, 2018). Mehta (2011) calls this biomedicine’s

failure to understand the real health concerns of people, as well as a process of dehumanisation and disempowerment “shaped by the notion that the body is a machine devoid of self” (p. 205). Lastly, researchers are positioned as rational producers of knowledge, whereas the knowledge and lived experiences of research subjects become objects of consumption for the academic gaze. People with cognitive impairments are objectified by this process in excess, because dominant discourses around rationality and personhood already construct them as less-than-human and, thus, unable to speak (Soldatic & Gilroy, 2018; Stone & Priestly, 1996).

Significance of Cognitive Impairment Depends on Social Context

Personhood

The question of whether or not someone with a cognitive impairment is still a person emerged as a key concern in the literature (Davis, 2004; Dementia Engagement and Empowerment Project (DEEP), 2014; George, 2010; Gerritsen, Oyebode, & Gove, 2018; Halewood, 2016; Johnstone, 2011; Mitchell & Agnelli, 2015; Naue & Kroll, 2009; Naue & Kroll, 2011; Sabat, 2005; Sabat et al., 2011; Wray, 2017). A turning point in this discourse was Kitwood’s (1997) notion of personhood. Kitwood (1997) defined personhood as “a status that is bestowed upon one human being, by others, in the context of relationship and social being” (p. 8). Kitwood (1997) acknowledged dementia’s biological components, but drew attention to the ways in which the personhood of people with dementia is undermined by behaviors he called malignant social psychology. These include: treachery, disempowerment, infantilization, intimidation, labelling, stigmatisation, isolation, objectification, ignoring, imposition, accusation, disruption, mockery, and disparagement (Mitchell & Agnelli, 2015, p. 48). Kitwood (1997) hypothesized that many of the problematic behaviors of people with cognitive impairments could

be addressed through positive person work, such as: recognition, negotiation, collaboration, play, giving, stimulation, celebration, relaxation, validation, holding, creation, and facilitation.

Social constructionist researchers such as Sabat and cowriters (Sabat, 2005; Sabat, Johnson, Swarbrick, & Keady, 2011) used personhood to critique the biomedical model and support the idea that the behavior of people with cognitive impairments is driven by meaning. Personhood was also instrumental to the epistemological frameworks of person-centered studies that sought to “humanize” people with cognitive impairments (Cohen, 1995; Cruickshank, 2013; Davis, 2004; George, 2010; Gerritsen, Oyeboode, & Gove, 2018; Halewood, 2016; Johnstone, 2011; Mitchell & Agnelli, 2015; Sabat, 2005). A major limitation of this research is that it relies on normative ideas of personhood (Macdonald, 2018). In the literature, personhood a static attribute that can be lost with cognitive decline, depends on a capacity for social engagement, confers status, and is conflated with being human (Macdonald, 2018). As a result, person-centered research flattens difference and continues to see cognitive impairment an individual problem. Even more problematically, personhood normalizes a world where people can be dehumanized on the basis of age, (dis)ability, sane-ness, race, gender, or other differences.

(Lack Of) Partnership in Knowledge Production

A central theme in the critical and anti-oppressive literature on cognitive impairments and the MMSE is the importance of doing research *with* people with cognitive impairments (Hulko, 2009; Hulko et al., 2010; Hulko, Brotman & Ferrer, 2017). Such research has the potential to challenge our existing knowledge base, deepen our understanding of cognitive impairment, and inform policy and clinical practice (Hulko, 2009; Martin, et al., 2015). However, people with cognitive impairments rarely have a voice in research on cognitive impairment or on the MMSE. For example, in a recent literature review by Martin et al. (2015), only nine out of twenty-nine

studies on attitudes and preferences towards screening for dementia involved people with dementia in any way. None of these studies were done in Canada (Martin, et al., 2015). In my literature review, I only found five major studies that engaged people with cognitive impairments as equal partners in knowledge production (DEEP, 2014; Krohne, Slettebo & Bergland, 2011; Hulko, 2009; Hulko et al., 2010; Sabat et al., 2011). Two were written by the same author, and were also the only studies of this kind done in Canada (Hulko, 2009; Hulko et al., 2010).

Language

The Dementia Engagement and Empowerment Project (DEEP) (2014) was co-written with 20 people with dementia in the United Kingdom and seeks to support the involvement of people with dementia in research. Their key message is that the language we use to talk about dementia influences how we see people with dementia, and how they feel about themselves (DEEP, 2014). DEEP participants (2014) provided a list of words that should never be used to describe dementia or people with dementia, which were considered to be “curl up and die” words: “dementia sufferer, demented, senile or senile dementia, burden, victim, plague, epidemic, enemy of humanity, living death” (p. 2). These words create stereotypes, are negatively attached to the person instead of the condition and send the message that a life with dementia is not worth living (DEEP, 2014). Hearing or reading them made people with dementia “physically flinch” (DEEP, 2014, p. 2). Sabat et al. (2011), which was co-written by a person with dementia, would call this a vocabulary of denigration. A vocabulary of denigration can affect MMSE performance, since stigma and stereotype threat affect cognitive load and, in turn, impact a person’s ability to perform on tasks that rely on working memory and cognitive capacity (Mazerolle, et al., 2017; Wray, 2017). Nonetheless, literature on cognitive impairment

and the MMSE extensively uses “curl up and die” terms to refer to people with cognitive impairments.

In MMSE Research

Research on the MMSE constructs participants in particular ways. The MMSE was mostly used to assess “patients” (Chapman, et al., 2016; Ford, Haley, Thrower, West, & Harrell, 1996; Kochhann, et al., 2008; McDonald, 2006), “participants” (Dean, Feldman, Morere, & Morton, 2009; Godin, Keefe, & Andrew, 2017; Quan, et al., 2016), “the old-old or frail” (Dean, Feldman, Morere, & Morton, 2009; Godin, Keefe, & Andrew, 2017), and “subjects” (Chapman, et al., 2016). Certain studies pathologized and dehumanized participants further by referring to them solely by their diagnosis or MMSE score (Chapman, et al., 2016; Kochhann, et al., 2008). Two studies occasionally referred to “culturally Deaf senior citizens” (Dean, Feldman, Morere, & Morton, 2009) or “African Americans” (Hawkins, Cromer, Piotrowski, & Pearlson, 2011), constructing participants as people with a self beyond their cognitive (dys)function. However, this self was recognized only insofar as it served the interests of researchers, who sought to validate the use of the MMSE with Deaf and African American older adults. Most existing research constructed undetected cognitive impairment as the biggest issue facing all older adults, to the point that “older adult” and “demented patient” became synonymous (Chapman, et al., 2016; Kochhann, et al., 2008). In contrast, the only literature review that included the lived experiences of people with cognitive impairments and their caregivers found that stigma and ageism were more significant issues (Martin et al., 2015).

Intersectionality

“Dementia is not an identity, it is a label” (Ann Johnson, as cited in Sabat et al., 2011, p. 285). Research on the MMSE tends to collapse the multiple intersecting identities and subject

positions of participants into the single category of “person with dementia”. This may be why dominant “illness narratives” of people with dementia are remarkably similar (Hulko, 2009). For example, failure to conform to normative (white, heterosexual) standards of masculinity and femininity through maintaining appearance is constructed as disorderliness, disreputability, and, ultimately, evidence of incompetence (Sandberg, 2018). In this way, dominant discourses around dementia are framed by racism, classism, normative gender roles, and the assumption of binary gender and gender continuity over the life-course (Hulko, 2009; Sandberg, 2018).

In one of two studies I was able to find on intersectionality, Hulko (2009) explores the relationship between experiences with dementia and the intersection of race, ethnicity, class, and gender using a grounded theory approach. Participant experiences of dementia ranged from “not a big deal” to “a nuisance” to “hellish”, and were related to their social locations. (Hulko, 2009, p. 131). For some, resilience acquired through experiences of discrimination and disadvantage “proved important in interpreting these differences” (Hulko, 2009, p. 141) and dementia became “one more hurdle to overcome” (p. 141). Hulko (2009) concludes that dementia might actually not be a problem for people living with it on a daily basis, and suggests that we stop intervening in the lives of people with dementia. This radical conclusion challenges common portrayals of people with dementia as victims. However, it also risks minimizing the need for interventions at the structural level to address the multiple, intersecting hurdles to be overcome.

Hulko et al. (2010) also worked in partnership with First Nations Elders in Secwepemc Nation territory using Indigenous research methodologies, constructivist grounded theory and a decolonial lens to explore the views of First Nation Elders on memory loss and memory care in later life. Themes that emerged through conversations with First Nation Elders included: being Secwepemc and going through the full circle of life, growing older, losing memory, supporting

one another, and dementia as a white, settler disease (Hulko, et al., 2010). Thinking about dementia as a white, settler disease begins to reveal the ways in which colonialism, racism and oppression shape dominant discourses around cognitive impairment. Unfortunately, I was unable to find any research that followed up on this important finding from Hulko et al. (2010).

The MMSE as a Scientific, Clinical and Legal Tool that Extends the Biomedical Gaze

Neoliberal positivism underpins most research on the MMSE. Positivism is a paradigm characterized by the assumption that reality is static and the only way to understand it is through observation and empirical research (Chilisa, 2012; Gray, Plath, & Webb, 2009). Hunter (2002) re-politicizes this concept by calling it *neoliberal* positivism, drawing attention to how research practices, such as the assumption that underlying brain pathology is what produces the symptoms of cognitive impairment, make institutional oppression invisible.

The MMSE Fits With Neoliberal Agendas

In a recent survey, Canadian family doctors identified “validity/accuracy”, “ease of administration” and “time required” as the top three attributes of the ideal cognitive assessment tool (Iracleous, et al., 2010, p. 26). “Acceptability to patients” and “comprehensiveness” were the least important (Iracleous, et al., 2010, p. 26). The MMSE is inexpensive and only takes ten minutes to administer (Chapman, et al., 2016). It scores cognitive function out of a possible 30 points (Folstein, Folstein, & McHugh, 1975). Depending on the cut-off chosen, anything less than 26 or 24 points indicates cognitive impairment. This provides healthcare professionals with a simple script to follow and a quantifiable, confidence-inspiring diagnosis in a situation otherwise characterized by uncertainty, contradiction and grief (Macdonald, 2018; Martin, et al., 2015; McDonald, 2006). This may be why the MMSE is frequently misused to diagnose, instead of screen for, cognitive impairment (Chapman, et al., 2016; Martin, et al., 2015). Its geriatric

psychiatry origins lend an aura of clinical expertise and professionalism to those who use it (Chapman, et al., 2016). The use of the MMSE in the place of more nuanced, expertise-heavy evaluations fits with the neoliberal agendas of residual welfare states in the Global North, and corporate-sponsored charity organizations setting up camp in the Global South (Chilisa, 2012).

It is important to note that the MMSE's appeal often has little to do with objective merit in evaluating cognitive function. Many studies that suggest we continue using the MMSE also found that it was an inappropriate measure of cognitive function (Dean, Feldman, Morere, & Morton, 2009; Ford, Haley, Thrower, West, & Harrell, 1996; Godin, Keefe, & Andrew, 2017; Hawkins, Cromer, Piotrowski, & Pearlson, 2011; Monroe & Carter, 2012). I was unable to find any follow-up studies that critically examined how and why this contradiction came about. However, one systematic review (Martin et al., 2015) and three recent quantitative studies (Chapman et al., 2016; Krohne, Slettebo, & Bergland, 2011; Mazerolle, et al., 2017) explicitly conclude that the MMSE should be discontinued. Unfortunately, other short cognitive tests are based on the same assumptions that underpin the MMSE (Chapman et al., 2016; Martin et al., 2015). Replacing the MMSE with a different assessment tool does not necessarily address the underlying issues with screening for cognitive impairment using this test.

Issues Identified in the Literature

Most studies on the MMSE are concerned with problems of method, not the meaning or value of knowledge produced by the test. Researchers were primarily interested in finding the right cut-off score to validate the use of the MMSE with marginalized populations (Chapman, et al., 2016; Dean, Feldman, Morere, & Morton, 2009; Hawkins, Cromer, Piotrowski, & Pearlson, 2011; Monroe & Carter, 2012). MMSE scores were found to correlate with education (Ford, Haley, Thrower, West, & Harrell, 1996; Godin, Keefe, & Andrew, 2017; Hawkins, Cromer,

Piotrowski, & Pearlson, 2011), age (Godin, Keefe, & Andrew, 2017; Hawkins, Cromer, Piotrowski, & Pearlson, 2011), hearing aid use (Quan, et al., 2016), insomnia (Cricco, Simonsick, & Foley, 2002), alcohol consumption (Reid, Maciejewski, Hawkins, & Bogardus, 2002), and gender, race and disease burden (Hawkins, Cromer, Piotrowski, & Pearlson, 2011).

Some studies also investigate the impact of stereotype threat (Mazerolle, et al., 2017), improper MMSE administration and scoring (Chapman, et al., 2016; Godin, Keefe, & Andrew, 2017; Hawkins, Cromer, Piotrowski, & Pearlson, 2011; McDonald, 2006; Monroe & Carter, 2012), ableism (Dean, Feldman, Morere, & Morton, 2009; Godin, Keefe, & Andrew, 2017; Quan, et al., 2016), and ceiling and floor effects (Chapman, et al., 2016). Concerningly, Chapman et al. (2016) found that using an MMSE cut-off score of 26 resulted in a thirty-five percent chance that participants were misdiagnosed with cognitive impairment. Failure to do well on a short cognitive test has far-reaching legal, social, psychological, and emotional consequences, from losing your driver's license to being diagnosed with a cognitive impairment to being forcibly institutionalized (Krohne, Slettebo, & Bergland, 2011; Mazerolle, et al., 2017; Martin, et al., 2015; Sabat, 2005; Simpson, 2014). However, Krohne, Slettebo and Bergland (2011) found that healthcare professionals often misrepresented the purpose and implications of the MMSE, leaving patients to interpret the significance of this experience only after it was over.

Refusal to Engage in the MMSE

Refusal to answer part or all of the MMSE is problematized in the literature. Refusal was attributed to test difficulty (Godin, Keefe, & Andrew, 2017), (dis)ability (Godin, Keefe, & Andrew, 2017; Quan, et al., 2016), and mental illness or cognitive impairment (Monroe & Carter, 2012). Some researchers saw refusal as an individual failure (Hawkins, Cromer, Piotrowski, & Pearlson, 2011) or as a threat to the success of their study (Chapman, et al., 2016).

They remedied this issue by “excluding”, “removing” and “deleting” participants (Chapman, et al., 2016; Ford, Haley, Thrower, West, & Harrell, 1996; Hawkins, Cromer, Piotrowski, & Pearlson, 2011; Kochhann, et al., 2008; Monroe & Carter, 2012). Only one study actually asked participants why they did not want to do the assessment (Quan, et al., 2016).

Refusal to answer all or part of the MMSE may actually be a normal reaction (Barkaoui, Swain, & Lapkin, 2011; Dean, Feldman, Morere, & Morton, 2009; Godin, Keefe, & Andrew, 2017; Martin, et al., 2015; Quan, et al., 2016; Sabat, 2005). Some researchers saw it as a valid form of resistance against the incursion of irrelevant, infantilizing and pathologizing questions into people’s lives (Barkaoui, Swain, & Lapkin, 2011; Krohne, Slettebo, & Bergland, 2011; Martin, et al., 2015; Sabat, 2005). Refusal is not random (Godin, Keefe, & Andrew, 2017). Participants most often refused to draw interlocking pentagons, to spell the word “WORLD” backwards and to count backward from one hundred by sevens (Godin, Keefe, & Andrew, 2017; Hawkins, Cromer, Piotrowski, & Pearlson, 2011; Quan, et al., 2016). Researchers who saw refusal as evidence of pathology described these questions as the most difficult (Godin, Keefe, & Andrew, 2017; Hawkins, Cromer, Piotrowski, & Pearlson, 2011). Researchers who saw refusal as an indicator of agency, self-respect and semiotic being described these questions as the most infantilizing or irrelevant to participants (Barkaoui, Swain, & Lapkin, 2011; Quan, et al., 2016; Sabat, 2005). Importantly, refusing to spell or count backwards automatically deducts five points from total MMSE score, which is enough to label someone with cognitive impairment.

Not a Neutral or Objective Measure of Cognitive Impairment

The overall theme in the literature is that an MMSE score is not an objective measure of cognitive impairment. MMSE scores correlate somewhat with other measures of cognitive impairment (Chapman, et al., 2016; Dean, Feldman, Morere, & Morton, 2009), but are context-

dependent and open to interpretation (Barkaoui, Swain, & Lapkin, 2011; Godin, Keefe, & Andrew, 2017; Hawkins, Cromer, Piotrowski, & Pearlson, 2011; Mazerolle, et al., 2017; Monroe & Carter, 2012; Quan, et al., 2016; Tierney, Herrmann, Geslani, & Szalai, 2003). This may be because a person's wholistic embodied experience, recent health history, fear of dementia, relationship with the person administering the MMSE, and how the test is presented all affect their cognitive function and test performance (Barkaoui, Swain, & Lapkin, 2011; Cahill, et al., 2008; Krohne, Slettebo, & Bergland, 2011; Mazerolle, et al., 2017; Sabat, 2005; Wray, 2017). For example, unimpaired older adults doing the MMSE were four times more likely to test positive for a cognitive impairment if they were told that younger people were also taking the test (a state of stereotype threat) (Mazerolle, et al., 2017).

Barkaoui, Swain and Lapkin (2011), Krohne, Slettebo and Bergland (2011) and Mazerolle et al. (2017) were the only researchers to consider the impact of social, physical, psychological, and emotional context when administering the MMSE. Similarly, only three primary research articles (Cahill, et al., 2008; Krohne, Slettebo, & Bergland, 2011; Mazerolle, et al., 2017) and two review articles (Martin, et al., 2015; Sabat, 2005) considered the legal, social and psychological implications of getting an MMSE score below the cut-off. Crucially, these five studies all concluded that the MMSE is an intrusive, stigmatizing and poorly-administered test.

Limitations of Existing Research

Most studies are founded on the assumption that cognitive function and capacity (or lack thereof) are static attributes that can be quantified using the MMSE. Researchers also assumed that cognitive impairment was irreversible and independent of physical, social, psychological, and emotional context. With two exceptions (Krohne, Slettebo, & Bergland, 2011; Mazerolle, et

al., 2017), primary research studies used MMSE scores to infer the cognitive function of participants. Few studies question how the MMSE, which does not assess the domains most impacted by cognitive impairment (such as long-term memory and executive function), can possibly reflect true cognitive function or impairment. In other words, most MMSE studies fail to consider the meaning or value of the knowledge produced by this test.

Research is most concerned with establishing the validity of the MMSE for use with an ever-growing list of populations. Validity was conceived of in purely statistical terms in every study on the MMSE except for Krohne, Slettebo and Bergland (2011) and Sabat (2005). For example, upon discovering that using an MMSE cut-off value of 26 resulted in thirty-five percent of people being misdiagnosed with a cognitive impairment, Chapman et al. (2016) concluded that they needed to lower the cut-off “to do justice to the science at hand” (p. 6). Justice for people (mis)diagnosed with a cognitive impairment was not a concern. Similarly, Hawkins et al. (2011) were concerned with administering the MMSE properly because “replicable measurement is fundamental to science and clinical practice” (p. 650). However, positivist measures of internal validity often have weak external validity and generalizability (Gray, Plath, & Webb, 2009).

Research in favor of the MMSE actually often lacks academic rigour, as it does not emphasize the importance of “knowing responsibly” (Doucet & Mauthner, 2002, p. 2). McClintock (as cited in Doucet & Mauthner, 2002) defines knowing responsibly as a commitment to the uniqueness and contribution of each research subject throughout the research process (particularly during data analysis), “even when those subjects fundamentally challenged theoretical, ontological and epistemological perspectives” (p. 6). For example, the desire to produce quantitative, statistically significant findings led many MMSE researchers to throw out

incomplete datasets (Chapman, et al., 2016; Ford, Haley, Thrower, West, & Harrell, 1996; Hawkins, Cromer, Piotrowski, & Pearlson, 2011; Kochhann, et al., 2008; Monroe & Carter, 2012). When researchers twisted their data by rejecting aberrant patterns “in order to fit more acceptable mainstream scientific explanations” (Doucet & Mauthner, 2002, p. 7), they broke trust with participants and with their own epistemological frameworks. Abdicating epistemic responsibility in this way greatly undermines the validity of any and all results. This contradictory behavior sheds light onto two major limitations of positivist research: inflexibility and the inability to understand the impact of human behavior (Gray, Plath, & Webb, 2009).

Many researchers generalized findings from doing the MMSE with cognitively “normal” participants to all older adults from that population, thereby flattening individual differences (Dean, Feldman, Morere, & Morton, 2009; Hawkins, Cromer, Piotrowski, & Pearlson, 2011; Hawkins, Cromer, Piotrowski, & Pearlson, 2011; Quan, et al., 2016). By failing to consider the impact of intersecting social location and being diagnosed with a cognitive impairment on a person’s ability to do the MMSE, these researchers committed sameness error (Chilisa, 2012). For example, studies on whether or not race affected MMSE scores did not consider the impact of the race of the (white) researchers, who inevitably concluded that race and racism have no effect (Ford, Haley, Thrower, West, & Harrell, 1996; Hawkins, Cromer, Piotrowski, & Pearlson, 2011). However, a recent research study found that stereotype threat has a significant impact on MMSE performance, even for healthy older adults (Mazerolle, et al., 2017). Lastly, none of the researchers critically reflect on how their worldviews “influenced their conceptualization of dementia and attitudes towards those living with a cognitive impairment” (Hulko, 2009, p. 132).

Gaps and Research Question

A review of the literature revealed that existing research on the MMSE has largely disregarded the assumptions that went into making this test, the value of the knowledge produced, or the degree to which the cognitive impairment that it (re)produces is the result of “a social relationship, created by a disabling environment and disabling attitudes, socially constructed and culturally produced” (Stone & Priestly, 1996, p. 701). Crucially, I was unable to find any critical, anti-oppressive social work research on the MMSE. A recent narrative phenomenology study in Sweden found that older hospitalized patients experienced the MMSE as a blow to their self-respect (Krohne, Slettebo, & Bergland, 2011). Furthermore, “patients and clinicians almost never experience the screening as a benign procedure” (Krohne et al., 2011, p. 685). A follow-up quantitative study by Mazerolle et al. (2017) in France found that stereotype threat significantly impacts MMSE performance. These findings warrant further study, since the MMSE is an established part of clinical and community practice with older adults in Ontario and is often mandated by law (Long-Term Care Homes Act, Revised Statutes of Ontario, 2007, c. 8).

This study seeks to answer the following research questions: How are the discursive practices used by the MMSE grounded in ageism, sanism, ableism, colonialism, racism, patriarchy, and other forms of oppression? How does the MMSE actively define cognitive impairment and construct older adults and/or people living with cognitive impairments? How does the MMSE employ these oppressive discourses to construct the boundaries and inhabitants of the dementia space? In answering these questions, I endeavour to unmap the claims made by the MMSE to make visible the problematic worldviews that rest upon it. I also aim to uncover how using the MMSE can implicate healthcare professionals in forms of injustice against older adults and people with cognitive impairments that are not obvious or readily apparent.

CHAPTER 4. RESEARCH DESIGN

Methods and Methodology

This study used a critical discourse analysis methodology to unmap the claims made by the MMSE and reveal the problematic worldviews that rest upon it. Undetected cognitive impairment is presented as one of the biggest threats to society today. This has set into motion powerful mechanisms that justify increasing biomedical surveillance and intervention in the lives of older adults and people with cognitive impairments, including the use of coercion and force (Liegghio, 2013). We have attached a lot of significance to the importance of screening and diagnosis, without first considering how (if) the assessment tools we use to screen for cognitive impairment work. Documents such as the MMSE often enter and leave the field of health research in silence, because they are seen as mere containers for content (Prior, 2010). For example, existing research has only considered how well the MMSE's content serves its function as a short cognitive test. However, documents are part of patient identity formation and define pathologies in specific and particular ways (Prior, 2010). The MMSE has been a hegemonic part of clinical and community practice with older adults for forty-four years. It can be difficult to see it anew, or to imagine a radically different way of screening for cognitive impairment. To my knowledge, no researcher has explored how the MMSE actively defines our understanding of cognitive impairment and the identities of older adults and people with cognitive impairments.

Healthcare documents form a field of research in their own right. Furthermore, content is not the most important feature of a document (Prior, 2003). Intertextuality and the *arrangement* of words, sentences and things allow us to understand how documents manufacture meaning (Martin, 2011; Prior, 2003; Prior, 2010). These socially-situated schemas produce knowledge and meaning, and are what Foucault (1984; 1986) called discourses. The MMSE is also a

generative document: “a document that lays down rules about how other documents should be constructed” (Prior, 2003, p.34). Best practices, diagnostic entries in the DSM-V, healthcare policies, other short cognitive tests, and research studies on cognitive impairment are based on the conventions laid down by the MMSE. Importantly, power is exercised through all of these methods of knowledge production to create and sustain the dementia space (Fook, 2016).

Critical discourse analysis brings together language and social analysis, and how both are relational with power, ideologies, institutions, and social identities (Fairclough, 2013). Critical discourse analysis is a post-structural approach to inquiry that allows us to unmap how we have come to know what we know about cognitive impairment through the MMSE (Arribas-Ayllon & Walkerdine, 2011). It makes the discursive objects and practices that make up this test problematic and, therefore, visible and knowable (Arribas-Ayllon & Walkerdine, 2011). In doing so, it acknowledges the ways in which power and language are interrelated (Fook, 2016). Critical discourse analysis considers the whole set of experiences of knowing about a phenomenon and acknowledges multiple ways of thinking and knowing (Fook, 2016). This methodology is consistent with my theoretical framework and is an epistemically responsible way of approaching the subject of my MRP. Deconstruction (Fook, 2016) and unmapping (Razack, 2002; Schott, 2017; Smith K. , 2011) are the two specific methods that I used.

Discourse analysis brings with it its own set of challenges. It is often done alone, and thus wrought with tension and complexity (Doucet & Mauthner, 2002). Who can speak for whom (Denzin, 2017)? What happens when I speak for older adults and people with cognitive impairments, whose voices “go largely unheard when spoken from ‘madness’” (Gray J. , 2007, p. 411)? My research is a critical response to oppression that I have witnessed in social work practice with older adults, but it is someone else’s pain and someone else’s vulnerability that

allow me to speak. Stone and Priestly (1996, p. 702) suggest that able-bodied researchers can still do emancipatory research if they surrender objectivity in favor of an agitator's function, make themselves vulnerable and commit "to a social analysis of disablement and to the development of the disabled people's movement." Part of this process is rejecting the totalizing gestures of enlightened helpers (Gray, 2007). If you asked a hundred people with cognitive impairment what they thought about the MMSE, you would get a hundred different responses, each based on that individual's socially-situated experiences. My analysis is framed by my own lived experiences and worldviews. These include an appreciation for the importance of evidence-informed practice, a respect for elders ingrained in me since birth, and placing greater value on meaning and relationships over processes and following the rules.

As I reach the end of this research journey, I wish to hold space for the fact that I do not really know what a cognitive impairment is, or what it feels like to live with one. Furthermore, what I do know is filtered through my subjective positionality, embodied experience, memories, emotions, and worldviews (Denzin, 2017). Deconstruction and unmapping have the potential to reveal these tensions inherent in critical discourse analysis. Both methods question and search for contradictions, different perspectives, and different interpretations throughout the process of data collection and analysis (Fook, 2016; Schott, 2017). They also prompt the researcher to engage in critical reflexivity (Heron, 2005; Fook, 2016). This makes visible the ethical issues inherent in data analysis and encourages epistemic responsibility (Doucet & Mauthner, 2002).

Document Selection

I originally planned to conduct my research using the official version of the MMSE (Folstein, Folstein, & McHugh, 1975) in order to make the results as valid and reliable as possible. This version has been copyrighted since 2000, and all licensing and distribution rights

are owned by PAR (Powsner & Powsner, 2005). In April 2019, I filled out a request to use the MMSE for research and educational purposes through the company's "Permission Request Form Online Submission" (PAR, 2019). My request was denied on the grounds that any research on the content of the MMSE would constitute a violation of copyright law (V. McFadden, personal communication, April 10, 2019). I was cautioned that if my research contained any content analysis of the items on the MMSE, I would not be allowed to publish it at my University or anywhere else (V. McFadden, personal communication, April 10, 2019).

This was surprising, since the MMSE has been "widely distributed in textbooks, pocket guides, and Web sites and memorized by countless residents and medical students" (Newman & Feldman, 2011, p. 2447). In the past decade, dozens of published research papers about the MMSE's content replicated part or all of the test (Chapman, et al., 2016; Dean, Feldman, Morere, & Morton, 2009; Godin, Keefe, & Andrew, 2017; Hawkins, Cromer, Piotrowski, & Pearlson, 2011; Monroe & Carter, 2012; Quan, et al., 2016). In a subsequent phone conversation, PAR's Permissions Specialist conceded that the company only controls publishing and distribution rights to the original 1975 version of the test and a revised 2010 version called the MMSE-2. (V. McFadden, personal communication, April 11, 2019). PAR "could not speak to the existence of unofficial versions, as they did not control their publishing and distribution rights" (V. McFadden, personal communication, April 11, 2019).

Due to the issues around reproducing the content of the official version of the MMSE, I used two unofficial versions of the test in this MRP (Kurlowicz & Wallace, 1999; Veterans Affairs Canada, 2004). Since I have never seen or used the official version of the MMSE in research or clinical practice, I cannot speak to how similar or different it is from the unofficial versions. Both unofficial versions were found using a Google search in April 2019 (see

Appendix A: Document Inclusion Guide for details). One version is specific to the Canadian context (Veterans Affairs Canada, 2004). The other explicitly grants users permission to reproduce it for non-for-profit educational purposes, and is most similar to the unofficial versions that I saw used in social work practice with older adults (Kurlowicz & Wallace, 1999).

Critical Reflexivity

In addition to the two unofficial versions of the MMSE described above, I kept a critically reflexive research journal throughout the entire research process. Please see Appendix B for a list of questions that guided and structured my research journal entries. Questions were derived from Fook's (2016, p. 128-129) instructions for critical incident analysis.

Data Analysis

Deconstruction

Documents were first analyzed using Fook's (2016, p. 121-122) method for critical deconstruction, with some modification to the questions to allow for a textual (rather than critical case scenario) analysis. Please see Appendix C for the complete list of questions that guided my deconstruction. Deconstruction is a critical social work approach for analyzing the ways problem people, social issues and helpers or social workers are constructed (Fook, 2016). Deconstruction reveals how each part of a document, such as the MMSE, has been put together, which allows us to understand how it manufactures meaning (Prior, 2003). Deconstruction also investigates how the document engages in the process of claims-making to get a condition recognized as a social problem (Prior, 2010). A social problem is both a condition that threatens the well-being of a significant segment of society, and a process by which members of that society come to see the condition as a problem (Tepperman, Curtis, & Kwan, 2007). I repeated the deconstruction process twice for each document in May 2019, with a particular focus on arrangement,

intertextuality, and the differences and similarities between the two documents. First, I took preliminary notes in Microsoft Excel in response to each of the deconstruction questions (Appendix C). Next, I critically reflected on how my positionality and worldviews shaped my responses (Appendix B). I then sought insights from existing academic literature, striving to address the gaps that I had identified through critical reflection. Lastly, I reviewed my notes, looking for patterns in the discursive strategies employed by the MMSE. A major limitation of this process is that it relies heavily on academic literature published in English, which is overwhelmingly written by privileged, unimpaired academics and brings with it its own set of biases. As a result, certain deconstruction questions could not be answered without compromising epistemic responsibility. In particular, I could not speak to how the issue might be interpreted differently by older adults or people with cognitive impairments, whose voices are largely missing from the academic literature.

Unmapping

Next, I analyzed the results of my deconstruction using an unmapping framework as described in Razack (2002), adapting the questions to allow for a textual analysis. Please see Appendix D for a complete list of questions that guided unmapping. Points of entry into unmapping included how the MMSE defined the boundaries of the dementia space through the creation of social norms, how older adults and people with cognitive impairments were constructed in the dementia space and how the dementia space produced cognitively impaired bodies, and transgressions and journeys through the dementia space (Razack, 2002).

The next chapter discusses my findings from the deconstruction and unmapping analysis, and concludes with implications for social work practice with older adults and people with cognitive impairments.

CHAPTER 5. FINDINGS AND DISCUSSION

Jacques Rivette once said that every film is a documentary of its own making (Rivette, 1950). Similarly, the MMSE is a record of the decision-making processes that led to the creation of this test, and a map of the problematic worldviews that rest upon it (Prior, 2003). In this chapter, I unmap the MMSE to reveal how its discursive practices are grounded in ageism, sanism, ableism, colonialism, racism, patriarchy, and other forms of oppression. I challenge the MMSE's status as a neutral container for knowledge by revealing its hegemonic power to define cognitive impairment and (re)produce older adults and people living with cognitive impairments as incompetent and a risk to society and themselves. Lastly, I discuss how the MMSE is used to maintain the multi-billion-dollar "care" industry – of which social work is a part of – through the creation of the dementia space. In doing so, I uncover how using short cognitive tests such as the MMSE can implicate social workers in forms of injustice against older adults and people with cognitive impairments that are not obvious or readily apparent.

This chapter begins by outlining key themes, binaries and contradictions in the content of the two unofficial versions of the MMSE (Kurlowicz & Wallace, 1999; Veterans Affairs Canada, 2004). Next, I discuss how these documents actively define cognitive impairment and contribute to "older adult" and "cognitively impaired" identity formation. I reveal how these discourses perpetuate epistemic violence towards older adults and people living with cognitive impairments. Lastly, I reflect on how various forms of knowledge about "dementia" built upon the MMSE function to maintain older adults and people with cognitive impairments in their social place.

Key Themes, Binaries and Contradictions in the MMSE

We begin our journey of unmapping the MMSE by outlining key themes, binaries and contradictions in two unofficial versions of this test (Kurlowicz & Wallace, 1999; Veterans

Affairs Canada, 2004). The MMSE is made up of eleven questions arranged into five categories: orientation, registration, attention/calculation, recall, and language (Kurlowicz & Wallace, 1999; Veterans Affairs Canada, 2004). The questions pre-date the MMSE, and were described in earlier papers as “a motley assemblage, apparently sustained by habit rather than by any consistent process of standardization and validation” (Hinton & Withers, 1971, p. 13). Questions include orientation to date and place, arithmetic, reading and writing exercises, a Babcock sentence, and a pentagon-drawing test. The Kurlowicz and Wallace (1999) version additionally contains a one-page introduction to the MMSE. The Veterans Affairs Canada (2004) version contains additional instructions for the person administering the test and space for them to write comments. Key themes that emerged from discourse analysis of these documents are: consent (and lack thereof), power becomes power through scoring, “undetected cognitive impairment is the problem”, loss of voice, and copyright.

A Brief Note on Meaning

What the questions on the MMSE actually mean depends on “whose meaning we are to study, and whose meaning is at stake” (Prior, 2003, p. 122). For example, from a clinical perspective, the MMSE assesses the cognitive process involved in short-term memory, the visuospatial/constructional praxis, orientation, attention/calculation, and language (Woodford & George, 2007). In contrast, a critical, poststructural perspective suggests the MMSE assesses willingness to submit to biopower: a set of techniques employed by the state to subjugate bodies and control populations in order to advance capitalist and colonial interests (Foucault, 1990). The meaning of the questions is bound up in relation to other documents, epistemology, and social context (Prior, 2003). I was unable to find academic literature that explores what MMSE questions mean to older adults or people with cognitive impairments, whose lives are most

affected by this test. Since I cannot speak to these socially situated experiences, my analysis focuses on discourses and intertextuality instead of what individual MMSE questions mean.

Consent (And Lack Thereof)

Consent (and lack thereof) is a key theme in both MMSE documents. The Veterans Affairs Canada (2004) version instructs the healthcare professional administering the test to ask, “May I ask you some questions about your memory?” (p. 1) and records the answer. Asking for consent in this way is misleading. It misrepresents the purpose of the MMSE and does not inform the individual about the implications of getting a lower score. The MMSE is a clinical assessment tool, and subjective experiences and concerns about memory are not factored into the score. Participating in this screening test has been found to negatively impact older peoples’ dignity and can be strenuous due to the pressure to perform (Krohne, Slettebo, & Bergland, 2011). Getting a lower MMSE score can result in the loss of certain rights and freedoms, such as having your driver’s license taken away (Lee & Molnar, 2017). A lower score can also disqualify people from participating in potentially therapeutic interventions, such as physiotherapy or clinical trials for medications that could slow down the progression of Alzheimer’s disease (Chapman, et al., 2016). Equally concerning is Dziedzic et al.’s (1998) finding that emergency department physicians change patient care plans after being informed that a patient has a lower MMSE score, even if it has no bearing on the health issue at hand.

Asking for consent to do the MMSE is somewhat of a contradiction. The decision to administer this test is based on a healthcare professional’s suspicion that an individual may have a cognitive impairment (Cahill, et al., 2008). The person is considered impaired enough to warrant doing the test, while at the same time being capable of giving consent. This may be why consent is oversimplified to the point of being treated as a formality. The assumption is that the

person doing the test would not understand the information necessary to make an informed decision. This defeats the purpose of obtaining informed consent in the first place. This practice is what Ahmed (2018a) calls dynamic non-performativity: “when naming something does not bring it into effect, or when something is named in order not to bring something into effect.” Currently accepted criteria for a person to demonstrate the capacity to consent are: an understanding of the issues, an appreciation of how this information applies to them and its implications for the future, the ability to explain the reasoning for their choices, and the ability to communicate their decision voluntarily and without internal or external coercion (Kiriaev, et al., 2018). Politely asking people if they can answer some questions about their memory gives them the *appearance* of being autonomous, consenting participants to the MMSE while circumventing the processes necessary for making an informed decision and ensuring people’s cooperation in their own disenfranchisement. Asking for consent also implies that people can afford to refuse to do the test. This is not the case. Older adults are often required to complete the MMSE in order to receive healthcare treatment and social services, even if cognitive impairment has no bearing on the issue that caused them to seek out service (Krohne, Slettebo, & Bergland, 2011; Sabat, 2005).

In contrast to the Veteran’s Affairs Canada (2004) version of the MMSE, consent is most conspicuous by its absence in the Kurlowicz and Wallace (1999) version. This may be because the MMSE was created for use with people “who were cooperative for only short periods of time” (Folstein, Folstein & McHugh, 1975, p. 190). In other words, it was created with the assumption that, given the option, people would *not* give consent to do this test. The original study participants were psychiatric inpatients who were neither asked for, nor gave, their consent (Folstein, Folstein, & McHugh, 1975). They were not even told that they were participating in a

research study. Instead, the MMSE was presented as a normal part of psychiatric patient evaluation and care planning. Study participants were not debriefed afterwards, nor were they given a chance to voice their experiences. The use of deception and the absence of debriefing continues today. For example, older adults in the Krohne, Slettebo and Bergland (2011) study said that healthcare professionals' initial presentation of the MMSE was not fully understood, leaving them to interpret the experience in light of the questions and tasks involved. For many, this was a distressing experience (Krohne, Slettebo, & Bergland, 2011).

The use of deception reflects the MMSE's origins in psychiatry, where deception was once considered a best practice (Sieber, Iannuzzo, & Rodriguez, 1995). Many patients, consumers and survivors of the psychiatric system would argue that deception and coercion are still common practices in clinical social work and psychiatry today (Lee, 2013; McKeown, Scholes, Jones, & Aindow, 2019). For example, institutional deception is presented as a compassionate and officially-recognized therapeutic intervention with people with Alzheimer's disease (Alter, 2012). However, such treatment may actually exacerbate the symptoms and speed up the progression of the disease (Alter, 2012; Kitwood, 1997; Sabat, 2005).

Power Becomes Power Through Scoring

Scoring is a key theme and source of contradiction in both MMSE documents (Kurlowicz & Wallace, 1999; Veterans Affairs Canada, 2004). Scoring is grounded in reductionism and positivism. The assumption in both documents is that cognitive function can be broken down into easy-to-score questions pertaining to orientation, registration, attention/calculation, recall, and language. Healthcare professionals administering the MMSE interpret answers and translate them into a binary: correct (worth one point) or incorrect (worth zero points) (Folstein, Folstein, & McHugh, 1975; Kurlowicz & Wallace, 1999; Veterans Affairs Canada, 2004). Both

documents assume that being able to measure something (cognitive function or impairment) in this way makes it real. Problematically, neither version of the MMSE contains instructions for how to differentiate between correct and incorrect responses on the test. In the Kurlowicz and Wallace (1999) version, only scores are written on the MMSE form. However, Kurlowicz and Wallace (1999) caution healthcare professionals that “patients that are hearing and visually impaired, intubated, have low English literacy, or those with other communication disorders may perform poorly even when cognitively intact” (pg. 1). In contrast, the Veterans Affairs Canada (2004) version has space to write down the actual answers of the person doing the test next to each question. It refers healthcare professionals to a separate document copyrighted by PAR, the “Instructions for Administration and Scoring Manual” (Veterans Affairs Canada, 2004, p. 1), to guide scoring decisions. This version also records level of education, native language, and the presence of depression, anxiety, poor vision, poor hearing, head trauma, family history of dementia, stroke, alcohol abuse, and thyroid disease (Veterans Affairs Canada, 2004).

Each question on the MMSE is scored differently. Orientation to date and time are scored out of ten. The arithmetic question in “attention and calculation” is scored out of five. The “registration” and “recall” questions are each out of three. The “language” section has six questions, of which the Babcock sentence, reading, writing, and pentagon-drawing test are each worth one point. Naming two objects is worth two points, and following a three-stage command is worth three. Scoring rarely corresponds to the number or complexity of cognitive processes involved (Woodford & George, 2007). For example, the pentagon-drawing test involves visuospatial capacity and planning skills (Woodford & George, 2007). When scored using a six-point scale, the pentagon-drawing test has been found to distinguish between people with and without Alzheimer’s dementia with high sensitivity and specificity, without being affected by

level of education (Fountoulakis, et al., 2011; Martinelli, Cecato, Martinelli, Ribeiro de Melo, & Aprahamian, 2018). In contrast, the MMSE scores this question using a binary method. Similarly, the Babcock sentence in the language section of the MMSE assesses hearing, attention, the ability to learn new information by rote, the ability to repeat phrases (which is particularly impaired in conductive aphasia), and fluency in English (Hinton & Withers, 1971; Woodford & George, 2007). This question is also only scored out of one on the MMSE.

Scoring on the MMSE places the greatest emphasis on orientation and attention/calculation. These sections account for fifty percent of the total possible MMSE score. However, orientation and attention/calculation questions are often answered incorrectly for reasons other than cognitive impairment. For example, orientation to place on the MMSE asks for the exact address (including floor) of where someone is writing the test. However, older adults brought to hospital by ambulance usually do not know the address of the hospital, or the floor that they are on (Krohne, Slettebo, & Bergland, 2011; Sabat, 2005). Furthermore, many people rely on Google maps, GPS and our phones to “remember” addresses and directions. Similarly, people with less years of formal education may incorrectly answer the arithmetic question in attention/calculation, even if they do not have a cognitive impairment. This disproportionally affects older adults who are Indigenous, Black, have a disability, or are poor. These populations have historically encountered barriers in the education system and may have less arithmetic skills or feel less confident answering arithmetic questions on an assessment (Dean, Feldman, Morere, & Morton, 2009; Hawkins, Cromer, Piotrowski, & Pearlson, 2011). The arithmetic question also takes on a different grammatical and structural meaning when translated. For example, Dean et al. (2009) found that eighty-four percent of Deaf participants were unable to correctly recall all five consecutive numbers, despite not having a cognitive

impairment. This was because the task was more difficult to comprehend and tapped into different cognitive domains once translated into American Sign Language (Dean, Feldman, Morere, & Morton, 2009). Such discrepancies produce “excess disability” (Sabat, 2005, p. 1031).

Both versions of the MMSE used in this study stress the importance of always using a score out of 30 and discourage making question substitutions (Kurlowicz & Wallace, 1999; Veterans Affairs Canada, 2004). At the same time, both documents acknowledge that MMSE scores are affected by level of education, English language literacy, having impaired hearing or vision, having a stroke, having a communication disorder, alcohol abuse, depression, and anxiety. Although healthcare professionals are instructed take note of these factors, they ultimately have no bearing on total MMSE score. For example, the total possible score for someone with a vision impairment is 25, since they would likely be unable to answer the reading, writing, naming an object, and pentagon-drawing test questions. However, they would still be given a score out of 30. Depending on the cut-off chosen, this would immediately label them as having a cognitive impairment (Chapman, et al., 2016). In this way, experiences of cognitive impairment are experiences of social norms – in this case, ableism. Similarly, older adults with hearing impairments or hearing loss are expected to do the MMSE the same way as everyone else: by answering questions that the healthcare professional reads out loud. This intersection of cognition and sensory perception significantly increases false-positives on the MMSE (Quan, et al., 2016; Roalf & Moberg, 2016). There is strong evidence that polypharmacy (Park, Park, Song, Sohn, & Kwon, 2017), length of hospital stay (Ong, et al., 2016), insomnia (Cricco, Simonsick, & Foley, 2002), stereotype threat (Martinelli, Cecato, Martinelli, Ribeiro de Melo, &

Aprahamian, 2018), and abuse (Navalta, Polcari, Webster, Boghossian, & Teicher, 2006) also increase the likelihood of “discovering” cognitive impairment using the MMSE.

Social workers, family doctors and allied health professionals receive little to no training in understanding and critically evaluating the empirical literature and clinical context of cognitive assessment tools (Martin, et al., 2015; McDonald, 2006; Pachana, et al., 2016). What happens when these individuals have final say over scoring on the MMSE? Taking note of known factors that may affect scores, using a different cut-off, or even changing total score does not address the fundamental issue at hand. In fact, these practices constitute a rush to innocence. At the end of the day, healthcare professionals score the person doing the MMSE. The score takes over the narrative, irrespective of what kind of narrative the person or healthcare professional was trying to explain beforehand. This violently rearranges the person’s story and erases their socially-situated experiences, conveniently removing the ableist, sanist, ageist, racist, and colonial dimensions to the “problem” of their MMSE score (Raju & Penak, 2019). Furthermore, this change allows no return to previous forms of identity (Naue & Kroll, 2009).

“Undetected Cognitive Impairment Is The Problem”

The MMSE communicates messages about the cause of the problem being addressed and the solution that this intervention is meant to provide (Kurlowicz & Wallace, 1999; Veterans Affairs Canada, 2004). The Kurlowicz and Wallace (1999) version explicitly locates the problem in the failing bodies and brains of older adults. According to this document, the issue is undetected cognitive impairment due to aging, illness and injury (Kurlowicz & Wallace, 1999). Furthermore, “older adults are at higher risk” (Kurlowicz & Wallace, 1999, p. 1). The MMSE’s preoccupation with risk assessment and management is part of managerial discourse, which is currently the dominant model for providing health services to older adults (Clancy, Happell, &

Moxham, 2014). The focus on early detection and diagnosis originates in mainstream adult healthcare, from where it was introduced with limited supporting research or regard for the unique requirements of older adults (Clancy, Happell, & Moxham, 2014). Unlike cancer or high blood pressure, there is no “cure” for diseases such as Alzheimer’s, nor is there a pill that you can take to reliably make the symptoms of cognitive impairment go away. Early detection has limited therapeutic value if it is not accompanied by structural and cultural changes to support people with cognitive impairments in living well after diagnosis.

The solution put forth by the MMSE is “prompt and aggressive action by nurses” (Kurlowicz & Wallace, 1999, p. 1) to “identify early changes in physiological status, ability to learn, and evaluating responses to treatment” (Kurlowicz & Wallace, 1999, p. 1). This language justifies the incursion of the neoliberal, biomedical gaze into the lives of older adults. At the same time, it creates psychological distance (Sabat, Johnson, Swarbrick, & Keady, 2011). The military metaphor reinforces power differentials and dehumanizes people with cognitive impairments, which negatively impacts therapeutic care (Bosco, Schneider, Coleston-Shields, Higgs, & Orrell, 2019; DEEP, 2014; Gerritsen, Oyebode, & Gove, 2018). This statement also implies that the MMSE can be used to assess the capacity to consent, which is false (Fassassi, Bianchi, Stiefel, & Waeber, 2009; Kim & Caine, 2002; Kiriaev, et al., 2018; Pachet, Astner, & Brown, 2010).

The MMSE positions itself as a tool that can “separate patients with cognitive impairment from those without it” (Kurlowicz & Wallace, 1999, p. 1). It fulfills the desire for “a clear demarcation between... the fully engaged, active adult and... the passive, to be cared for older person” (Naue & Kroll, 2009, p. 29) by highlighting and essentializing aspects of test performance in binary opposition to existing theories of normal cognition. However, cognitive

impairment is far more complex than that. Heron (2005) suggests that “desire is integral... to discourses, and thus produces individual investments in particular subject positions” (p. 347). Narrowing the subject to a series of binaries, such as correct versus incorrect answer, gives the appearance of greater knowledge and control over cognitive impairment than exist in reality (Gaines & Whitehouse, 2006). This maintains the medical institution as powerful expert and contributes to the appearance of progress and hope in “curing” cognitive impairment.

By making undetected cognitive impairment the problem, the MMSE allows for institutions to disappear (Ahmed, 2018b). This maintains the patriarchal and neoliberal status quo. For example, the cultural and structural devaluation of care work in Canada is a major barrier to living well with a cognitive impairment. Inadequate healthcare and social services, food and transit deserts, and inaccessible infrastructure undermine the health and wellbeing of older adults. By solely focusing on early detection and diagnosis of cognitive impairment, the MMSE disregards these psychological, social and environmental factors. In doing so, it mislays its subject matter and gives up moral responsibility toward the real health concerns of older adults and people living with cognitive impairments (Mehta, 2011). Similarly, the Veterans Affairs Canada (2004, p. 2) version of the MMSE asks whether or not someone can independently handle money, bills, medication, transportation, and using the telephone. This implies that dependency on others is the problem. For older adults and people with cognitive impairments, “our interdependency as humans is negated, and those that fail to live up to neo-liberal tenets inevitably become subjects that need to be managed” (Voronka, 2019, p. 82).

Loss of Voice

Loss of voice is a key theme throughout the MMSE (Kurlowicz & Wallace, 1999; Veterans Affairs Canada, 2004). The Veterans Affairs Canada (2004) version reminds healthcare

professionals that only clients can answer the questions on the test. Nevertheless, the questions are written for the benefit of healthcare professionals, and they are the ones who fill out the form. The voice of the client gets reinterpreted and re-storied into the professionalized formulations of the MMSE. This process imposes passivity onto older adults and people with cognitive impairments. Similarly, there is no space for the person writing the test to sign off that they have seen and agree with the healthcare professional's interpretation of their answers, or to comment on circumstances that may have affected their score. The writing task is the only space where people doing the MMSE have a voice. One of the participants in the Barkaoui, Swain and Lapkin (2011) study used this space to comment, "This test stinks" (p. 68). I have read similar comments over the course of my social work practice with older adults, and was expected to then turn them into a binary one (correct) or zero (incorrect) score.

The MMSE also constrains the voices of the healthcare professionals, albeit to a lesser extent. Both versions of the MMSE in this study prescribe a detailed script for administering the test (Kurlowicz & Wallace, 1999; Veterans Affairs Canada, 2004). The healthcare professional asks the questions, but cannot cue the client or substitute questions based on context. The person doing the MMSE supplies the answers, but cannot ask any questions of their own. This creates psychological distance and reinforces the binary of expert practitioner and passive, impaired Other in need of expert intervention (Pillay & Kathard, 2015). The MMSE effaces the moral person, because it makes epistemic violence towards older adults and people with cognitive impairments inevitable. Free will become irrelevant (Razack, 2004). Epistemological concerns, such as who can speak for whom, become secondary to the logistics of carrying out the test. On the surface, administering the MMSE becomes less of a totalizing gesture and more about following convention. Furthermore, the MMSE reassures healthcare professionals that it "should

not replace a complete clinical assessment of mental status” (Kurlowicz & Wallace, 1999, p. 1). As a result, issues around scoring, false-positives and voice appear to carry less moral weight. In this way, the MMSE produces “thoughtlessness”, which Razack (2004, p. 162) defines as the repetition of simple “truths” meant to convince us that we are doing the right thing and that there is no alternative course of action.

Changing the script does not change the power dynamics inherent in the MMSE. For example, I was taught to integrate MMSE questions into a more “normal” conversation with clients. Administering the test this way felt less oppressive and I was a lot more comfortable doing it. This, precisely, is the problem. As a social worker, my comfort comes at the expense of someone else. Trying to make the MMSE questions seem more “natural” so that they were less distressing to older adults was paternalistic and a rush to innocence. Although I *felt* less oppressive administering the MMSE in this way, it did not challenge my epistemic privilege and epistemic authority in the situation. Nor did it require me to re-evaluate the inequitable distribution of power between social workers and clients who are older or have a cognitive impairment. This dynamic is accentuated by the unequal power relationship which exists between people with and without disabilities in the wider world (Stone & Priestly, 1996).

Copyright

Lastly, copyright is a significant theme and source of contradiction in the MMSE (Kurlowicz & Wallace, 1999; Veterans Affairs Canada, 2004). At the top of the Kurlowicz and Wallace (1999) version is an eight-centimeter banner that reads, “try this: Best Practices in Nursing Care to Older Adults” (p. 1). This implies that this version of the MMSE can be used freely in clinical practice. In a different part of the document, the authors say that it may be reproduced “for not-for-profit educational purposes only, provided The Hartford Institute for

Geriatric Nursing, Division of Nursing, New York University is cited as the source” (Kurlowicz & Wallace, 1999, p. 1). At the end of the document is a citation for the original 1975 Folstein, Folstein and McHugh article, accompanied by the phrase “Used by permission” (Kurlowicz & Wallace, 1999, p. 2). However, the copyright notice for the *Journal of Psychiatric Research* – which published the original Folstein, Folstein and McHugh (1975) article – explicitly forbids unauthorized reproduction of the MMSE (Powsner & Powsner, 2005). Similarly, the Veterans Affairs Canada (2004) version states “copyright in the Mini-mental State Examination is wholly owned by the MiniMental LLC, a Massachusetts limited liability company” (p. 2). However, anyone can freely download this version of the MMSE from the Veterans Affairs Canada website and use it.

The uncertain legal terrain of accessing and using the MMSE creates fear. As a researcher doing a critical discourse analysis on the MMSE, I felt at times as if I was balancing on a knife’s edge when talking about the content of the test. Feldman and Newman (2013) suggest that instilling fear is the point of copyright discourses on the MMSE, since this fear “could easily become a self-fulfilling prophecy if it prompts the creation of an industry norm for licensing medical tests” (p. 625). Since the MMSE was copyrighted in 2000, fear has certainly discouraged research and innovation in short cognitive testing. For example, in 2011, the Sweet 16 – a more sensitive, freely-available assessment tool – was removed from the internet because PAR claimed that it used some of the same questions as the MMSE (Rosati & Rosati, 2012).

Copyright discourses have repercussions for clinical practice as well. The Veterans Affairs Canada (2004) version is “protected information when completed” (p. 1). PAR’s position is that healthcare professionals who use their tests “may not release copyrighted and confidential material to individuals not professionally qualified to obtain, review, and/or interpret them”

(PAR , 2019, para. 7). What this means in practice is that people who have written the MMSE are denied access to their own results (Feldman & Newman, 2013). This violates the “nothing about us without us” (Wehbi, 2011, p. 140) principle, which is fundamental to working with people with disabilities, including people with cognitive impairments. In this way, the copyright discourse excludes older adults and people with cognitive impairments, as well as their caregivers, from full and direct participation in decision-making.

Copyright discourse appears to be applied selectively. Clinical experience suggests that unauthorized copies of the MMSE continue to be routinely used by healthcare professionals (Feldman & Newman, 2013; Newman & Feldman, 2011; Powsner & Powsner, 2005; Rosati & Rosati, 2012). Feldman and Newman (2013) attest that it may be impossible for PAR to stop unauthorized use of the MMSE, given the shakiness of their copyright claim and the prevalence of unofficial copies of the test. Similarly, PAR has not prosecuted large institutions like Veterans Affairs Canada for copyright violation. Who, then, does the copyright discourse benefit?

The copyright discourse protects the privilege of healthcare professionals who use the MMSE. If you use this tool, you are an expert (Smith, 2011). By allowing some institutions and researchers to use the MMSE while prosecuting others for breach of copyright law, PAR has created a hierarchy of “experts” who can speak about cognitive impairments and this test. For example, Veterans Affairs Canada is an “expert”. The person being assessed using the MMSE is not. This hierarchy allows PAR to control knowledge production around the MMSE and is self-sustaining. Forms of resistance are also part of the hierarchy. Academic research, such as this MRP, is more permissible than giving someone a copy of their MMSE, because this puts it into the hands of a “risky”, potentially “impaired” individual. This maintains institutions that are part

of the “care” industry by providing them with an endless supply of “impaired” individuals who cannot contest this identity.

“Cognitive Impairment” Is A Category with Wheels

In their revolutionary paper, “Decolonizing Audiologist Education in South Africa” (2015), Pillay and Kathard outline how the notion of disorder “has developed into its present status, richly imbued with... biological meanings, via intimate association with colonialism” (p. 201). Our understanding of cognitive impairment has developed through intimate association with discursive practices used by the MMSE to create and manage “cognitively impaired” people through epistemic violence. These include paternalism, deception, coercion, managerialism, thoughtlessness, and dynamic non-performativity. Cognitive impairment as defined by the MMSE originally evolved to fulfill the neoliberal desire for a clear demarcation between rational, productive, self-sufficient subjects, and those who pose a threat to capitalist interests. By this, I mean individuals and communities who rely on interdependency for survival.

The MMSE perpetuates several hegemonic beliefs about cognitive function and impairment. According to the MMSE, cognitive function is a normative concept that can be broken down into easily quantifiable parts. It is a finite resource that can be lost due to old age, illness or injury. Crucially, once lost, it can never be regained by older adults. Cognitive processes that are not suited to short, easy-to-administer assessments are not important. Similarly, complex concepts such as cognitive impairment can be translated into a score, which then informs patient evaluation and care planning. Identifying and interpreting the significance of cognitive impairment is best done by a detached, objective healthcare expert. Intersectionality, subjective experiences and caregiver concerns are not important, and including them can hinder diagnosis. Cognitive impairment is not affected by social or environmental context. Undetected

cognitive impairment poses a risk to society. Lastly, prompt and aggressive action on the part of healthcare professionals and experts is necessary to identify and manage this risk.

The formation of cognitive impairment and the cognitively impaired identity morally justify the withdrawal of the social protections and the welfare state from older adults, who do not contribute to the economy by working and whose potential dependence on others threatens the economic productivity of caregivers. Although mortality rates have decreased, the prevalence of disease and morbidity have increased in the Western world (Crimmins & Beltran-Sanchez, 2011). Advances in modern medicine have also blurred the line between life and death (Teresi, 2012). Increases in life expectancy challenge “mid-life’s emphasis on work and productivity” (Cruickshank, 2013, p. 170). Like racism, cognitive impairment is used to stratify the population, making distinctions between productive and regressive bodies (Voronka, 2019). At the same time, the label of cognitive impairment also prevents older adults from participating in society or the economy to become self-sufficient. In other words, it imposes passivity and produces dependence. In this way, the MMSE creates a liminal space (Scott, Prior, Wood, & Gray, 2005) between being a rational, productive, self-sufficient subject and being dead. This “dementia space” is inhabited by people who are “already not quite living, that is, living in a state of suspension between life and death” (Butler J. , 2006, p. 36). Neglect, mistreatment and violence against these people “leaves a mark that is no mark” (Butler J. , 2006, p. 36).

It is important to note that the social and economic disenfranchisement of people living in the dementia space has generated a multi-billion-dollar “care” industry (Sena, 2018). The ordinary living of older adults and people with cognitive impairments is only deemed a crisis insofar as it poses a problem to the withdrawal of the welfare state. The “problem” of cognitive impairment offers economic opportunities for professionals to grow research, knowledge, and

service industries based on the abjection of the “cognitively impaired”. Care industries have a vested interest in the production of excess cognitive impairment, and cognitive impairment in excess. In response, cognitive impairment has emerged as a “category with wheels” (Prior, 2001). This is most evident in the MMSE’s approach towards scoring.

Keeping Older Adults and Cognitively Impaired “Others” In Their Social Place

Agreeing to do the MMSE amounts to agreeing to the possibility of being diagnosed with cognitive impairment, thereby losing the status of Cartesian subject, which is a requirement for human citizenship in our neoliberal society (Mehta, 2011). However, one does not need to be diagnosed with cognitive impairment in order to enter the dementia space. The MMSE has been described as a “quite distressing... invasive test (Cahill, et al., 2008, p. 666). This may be because it is an interface between older adults and the discursive practices that characterize the dementia space. In that moment, the older adult is immobilized. Their story is violently rearranged, their socially-situated experience is erased, and their concerns are reinterpreted and re-storied into the professional formulations of the MMSE. Transgression of the social norms dictated by the MMSE, such as refusal or breaking the script by asking questions, results in epistemic violence ranging from being ignored to being automatically diagnosed with a cognitive impairment. Afterwards, older adults are unable to return to civilized space because this journey through the dementia space has evicted them from human citizenship through ageism, sanism, ableism, and other forms of oppression. Their feelings of frustration, loss, shame, sadness, and anger at being treated this way are labeled “decreases in social behavior and emotional control”, which are then interpreted as evidence of cognitive impairment. In this way, journeys through the dementia space produce excess disability (Alter, 2012; Kitwood, 1997; Lee, 2013; Sabat, 2005).

In contrast, healthcare professionals are able to traverse the dementia space and return to “civilization” unscathed. Many healthcare professionals build their entire careers on such journeys. For example, Osterholm and Hyden (2018) found that healthcare professionals appropriate autobiographical stories about clients with cognitive impairment to justify why care services are needed, describe experiences about previous care and provide a good working climate. These stories often position the person with cognitive impairment as dependent on others (Osterholm & Hyden, 2018). At the same time, these stories substantiate healthcare professionals’ claims to knowledge and expertise in managing older adults and people with cognitive impairments.

Concluding Thoughts

The MMSE is a window into the problematic worldviews of the dementia space. However, discursive practices that perpetuate epistemic violence towards older adults and people with cognitive impairments are not limited to the MMSE. Consent, paternalism, deception, coercion, managerialism, loss of voice, thoughtlessness, dynamic non-performativity, and copyright are issues inherent in other assessment tools and in research on older adults in general. This has significant implications for social workers, whose interactions with older adults in clinical and community settings are often organized around standardized assessments (Hastings & Rogowski, 2015).

The MMSE is just one example of how Western social workers can become implicated in forms of injustice against older adults that are often hidden. Canadian social work is characterized by a long history of benevolent “improvement” projects meant to “help” that, in reality, organize and manage subjugated peoples (Voronka, 2019). A re-evaluation of how social workers do research and work with older adults and people with cognitive impairments is long

overdue. Older adults and people with cognitive impairments need to be the ones who set the agenda and need to be treated as equal partners in health and social work research and practice. Furthermore, social workers need to make a political commitment to anti-agism, the disability movement, non-exploitative research methods, and research that “is widely disseminated for use against oppression” (Stone & Priestly, 1996, p. 715).

APPENDICES

APPENDIX A: DOCUMENT INCLUSION GUIDE

For this research study, I will be evaluating an unofficial version of the Mini-Mental State Exam (MMSE) (Folstein, Folstein & McHugh, 1975). I have elected to analyze an unofficial version of the MMSE because the publication and distribution rights to the official version are held by Psychological Assessment Resources (PAR), who has denied my request to use their official version in my research. The unofficial versions of this test are not copyrighted, and PAR does not own their publishing and distribution rights. The unofficial version will be chosen from a Google search using the following keywords: “MMSE form” OR “Mini-Mental State Examination form” AND “Canada”.

The document will be the first result from the Google search that satisfies the following criteria:

1. Is not a Standardized Mini-Mental State Exam (SMMSE), since this version is different from a regular MMSE.
2. Is either a) not copyrighted or b) says that it can be reproduced for not-for-profit educational purposes.
3. Preferably, is specific to Canada.

APPENDIX B: CRITICALLY REFLEXIVE JOURNALLING QUESTIONS

Research Journaling Questions (adapted from Fook, 2016, p. 128-129)

1. What main themes or patterns emerge from the data analysis and appear important to me?
What terms, phrases or patterns of communication do I use frequently? What labels or categorizations do I apply? Is there evidence of binary opposites?
2. Who are all the potential players involved in the situation or potentially affected by it?
Where do I sit in relation to them and how do I see myself in relation to them?
3. Whose perspectives are represented and whose are missing? How do I present my perspective in the story? What does this say about power? Whose position or perspective is privileged? Where does my own sit?
4. What interpretations or explanations did I make? Were they all mine or was I influenced by someone else or from elsewhere? Did I present them as mine? How did I represent and how did my interpretations influence the situation?
5. How might I have interpreted the situation differently? How many different interpretations could I have made, and how might it have been interpreted by different players in the situation?
6. What knowledges and assumptions do I imply and use in my account? What do these assumptions have to do with: practice theory, value and belief systems, paradigms, human behavior, moral and ethical codes, social and political systems and change, power, gender and cultural considerations? Are they relevant to the situation at hand?
7. Where do these assumptions originate? Where do they come from? What roles or positions do these assumptions support? What roles or positions of mine do they support? What players stand to gain or lose from holding them, and what social and power functions does holding these

assumptions perform, particularly for me? What practices, systems or structures are upheld by these assumptions?

8. What holes, gaps or biases are there in the document? What perspectives are missing, distorted or devalued? What actions or assumptions of mine support these biases?

9. What is my 'theory of power' arising from my account? Where does this come from and why have I developed it or taken it on board?

APPENDIX C: DECONSTRUCTION QUESTIONS

Deconstruction Questions (adapted from Fook, 2016, p. 121-122)

1. What main themes or patterns emerge from this document? What terms, phrases, or patterns of communication reoccur frequently? What labels or categorizations occur? Is there evidence of binary opposites?

2. Who are all the potential players (individuals, groups or organizations) involved in the situation, or potentially affected by it?

3. Whose interpretations or explanations are missing?

4. What are the underlying messages the document communicates about the cause of the problem that is being addressed, and the solution that the intervention is meant to provide?

5. What interpretations or explanations are made in this document? Whose are they? How are they represented? How do they influence the issue or person?

6. How might the problem be interpreted differently? How might it have been interpreted by different players in the situation?

7. What knowledges and assumptions are implied and used in this account?

How do they relate to: practice theory, value and belief systems, paradigms, human behavior, moral and ethical codes, social and political systems and change, power, gender and cultural considerations? Are they relevant and appropriate to the situation at hand?

8. Where do these assumptions originate? What roles or positions do these assumptions support?

9. What players stand to gain or lose from the way the problem and its solutions are framed? What social and power functions does holding these assumptions perform? What practices, systems or structures are upheld by these assumptions?

10. What holes, gaps, or biases are there in the document? What perspectives are missing, distorted, or devalued? What actions or assumptions support these biases?

11. What are the ways in which **MY** social positions/intersections in the world (gender, sexuality, race, class, religion, ability, age, significant life experiences, and so on) intersect and inform my analysis of the document? In terms of these positions and their intersections, what is my privilege? How does my analysis of the document maintain or resist this privilege?

12. What are the implications of this document for the relationship between social workers and clients?

APPENDIX D: UNMAPPING QUESTIONS

Unmapping Questions (adapted from Razack, 2002).

1. What do the results of my deconstruction reveal about the MMSE as a cartography of epistemic violence that extends the neoliberal, biomedical gaze into the physical, social, psychological, and emotional lives of older adults?

2. What do the results of my deconstruction reveal about the MMSE as a cartography of epistemic violence that defines the dementia space? (Using discourses grounded in ageism, sanism, ableism, racism, colonialism, sexism, and other forms of oppression)

- Dementia space as a social product
- How does the dementia space produce bodies?

3. What do the results of my deconstruction reveal about the MMSE as a cartography of epistemic violence that (re)produces the bodies of people with cognitive impairment in the dementia space?

- How are bodies (re)produced in the dementia space?
- What is imagined or projected onto specific bodies?
- What is being enacted there?
- How much does identity dominance rely on keeping Others (intersectional) firmly in place?
- Transgressions of the dementia space?
- Journeys through the dementia space?

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