

Mourning me: An interpretive description of grief and identity loss in older adults with
mild cognitive impairment (MCI)

by

Jordan I. Ali

BA, Kwantlen Polytechnic University, 2010

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Supervisory Committee

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Dr. Colette M. Smart (Department of Psychology)

Supervisor

Dr. Holly Tuokko (Department of Psychology)

Departmental Member

Abstract

Dr. Colette M. Smart (Department of Psychology)

Supervisor

Dr. Holly Tuokko (Department of Psychology)

Departmental Member

Mild cognitive impairment (MCI) has long been associated with depression; however, few studies have addressed the presence of (prolonged) intrapersonal grief or its contribution to emotional distress in MCI. This may be a result of both an over-reliance on interpersonal models of grief (i.e. bereavement) and a systematic undervaluing of MCI individuals' perspectives. Thus, this study took a qualitative approach, using interpretive description, to understand the first-hand experience of persons with MCI, with the intent of 1) determining whether grief occurs for this group and, if so, 2) comparing this experience to well-defined grief constructs. Six themes were identified: Uncertainty and ambiguity, losses of self and role, disenfranchisement and disconnection, primacy of MCI, emotional distress, and coping. A relationship between themes was found, such that uncertainty and ambiguity, losses of self and role, and disenfranchisement and disconnection comprised the core dimensions of the MCI experience, with losses of self and role serving a central and binding role between the other two. These core dimensions then contributed individually and collectively to the primacy of the MCI experience and emotional distress, which in turn exhibited a reciprocal relationship with coping. The overall experience of MCI reflects features of several grief reactions to nonfinite loss, most notably chronic sorrow and disenfranchised grief. Implications for practice and further investigation are discussed.

Table of Contents

Supervisory Committee	ii
Abstract	iii
Table of Contents	iv
List of Tables	v
List of Figures	vi
Acknowledgments	vii
Chapter 1: Introduction	1
Chapter 2: Literature Review	7
Chapter 3: Research Design and Methods	38
Chapter 4: Results	60
Chapter 5: Discussion	104
References	128
Appendix A: Telephone Screening Protocol	141
Appendix B: Informant Questionnaires	145

List of Tables

Table 1. Types of grief	8
Table 2. National Institute of Health: National Institute on Aging MCI criteria.....	23
Table 3. Data collection schedule	44
Table 4. Summary of MMSE-2 and DRS-2 scores	61
Table 5. Summary of ECog ratings of individuals with MCI	63
Table 6. Summary of AMAS-E scores	64
Table 7. Summary of qualitative themes	68

List of Figures

Figure 1. Thematic structure of the MCI experience 102

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Chapter 1

Introduction

Bereavement, the loss of another, is acknowledged as a common experience for older adults (Bonanno, 2004), and as such, it has received a great deal of attention in the grief literature. However, there is another loss common among older adults that has received little empirical attention thus far: The loss of oneself. As the average life expectancy increases (Employment and Social Development Canada, 2014), there are a greater number of older adults experiencing non-normative cognitive decline and dementia. In fact, by 2031, it is estimated that 1.4 million Canadians will be diagnosed with Alzheimer's disease (Canadian Institutes of Health Research, 2013). Just as some experience anxiety around their own mortality and grief as a result of their narrowing possibilities, it is possible that many faced with the onset of dementia will be likewise affected with a fear of losing their connections, history and identity.

Grief over loss of the self may be an especially salient experience for those diagnosed with mild cognitive impairment (MCI), a presumed prodromal stage of dementia with forms commonly associated with Alzheimer's disease (i.e. amnesic MCI). Individuals with MCI exhibit non-normative cognitive decline with relatively preserved awareness of themselves and their surroundings, yet have a much higher likelihood of developing various forms of dementia (Albert et al., 2011); therefore, this group may uniquely confront the prospect of losing themselves (their sense of identity, roles, and relationships) while remaining aware of their losses (cognitive and otherwise) as they occur. However, grief and loss in this group may be complicated by the ambiguity and uncertainty inherent in an MCI diagnosis. MCI does not have a predictable or necessarily linear course, so diagnosed individuals may have as much chance of stabilizing or improving as they do of progressing to dementia. Further, since agreement on the

meaning of an MCI diagnosis continues to be refined, many extant studies and resources may be based on varying understandings of what MCI is or its implications. Therefore, in addition to presenting fears of annihilation, autobiographical disruption, and changes to oneself, MCI may also introduce a sense of unease and moratorium due to a lack of concrete information and medical direction.

Despite this unique and complex position, little research to date has been conducted on the emotional or psychological experiences of this population. Though some work has focused on coping strategies (Joosten-Weyn, Banningh, Vernooij-Dassen, Rikkert, & Teunisse, 2008) and existential themes (Frank et al., 2006; Roberts & Clare, 2013), the behavioural aspects of one's transition tend to be emphasized rather than emotional or lived experiences. To the author's knowledge, no work yet has examined grief as a result of the loss of one's hopes for the future, autobiographical disruption, or existential fears in those with MCI; of the few studies that have investigated grief in dementia or MCI, most focus exclusively on caregiver experiences, thereby not only discounting the experience of the primary individuals affected but also maintaining a cultural bias towards depersonalizing those with any form of cognitive deficit (Beard, 2004).

Issues in the Current Literature

There are three problems with the current body of research on MCI that the current study aims to address. Firstly, since the definition of MCI continues to develop and various forms of MCI-related impairment have only recently been recognized (Albert et al., 2011), the majority of research conducted on MCI may not represent current understanding of the disease or the MCI population. In acknowledgment, this study will build its inclusion criteria upon the current criteria adopted by the National Institute on Aging (NIA) (Albert et al., 2011) in order to provide

information relevant to those with a more contemporary diagnosis of MCI (i.e. including cognitive decline in domains other than memory). Secondly, most research on those with mild cognitive impairment or dementia (at any stage) largely neglects to take into consideration the experiences of the individuals directly affected. This trend may be in some part due to the erroneous conflation of MCI with dementia, in which it is anticipated that individuals cannot serve as reliable informants on their own experience. Unfortunately, applying the same standards as dementia research to those who retain some preserved cognitive function and awareness (i.e., those with MCI) performs a double disservice by overlooking important and unique first-hand information, as well as marginalizing those with MCI by undermining their senses of value and agency and exaggerating their perceptions of social disenfranchisement and stigma. Conversely, the current study recognizes the clinical value of the perspectives of those with MCI and aims to empower individuals with MCI by giving voice to their experiences. Thirdly, the qualitative research that has investigated the experiences of those with MCI more generally has primarily employed a phenomenological approach (Cheek, 2010; Roberts & Clare, 2013; Robinson, Clare, & Evans, 2005), which provides broad, idiosyncratic information. While the results of these phenomenological works have been important in highlighting the range of experiences in those with MCI, a more applied approach is now required to extend this understanding further to clinical utility. Therefore, this study will employ an interpretive description approach (Thorne, 2008) designed to build upon existing clinical knowledge and provide a robust description with the intent of expanding the clinical view of phenomena.

Research Objectives

The primary objectives of this study are to 1) provide a holistic description of the emotional experience(s) of MCI, and 2) compare these experiences to existing grief frameworks

to determine the extent to which they converge with and digress from the experiences of better-understood grieving populations. Auxiliary objectives of this study are to determine whether individuals with MCI experience a sense of identity change and/or loss, and to explore the meaning of MCI for those diagnosed. Lastly, this study aims to give voice to those with MCI, whose perspective and experience is currently underrepresented in the literature.

Clinical Implications

Though the current study will provide novel perspectives on MCI, the value of this research goes beyond merely filling gaps in the literature. Although a number of intervention programs and strategies are currently under review (Huckans, Hutson, Twamley, Jak, Kaye, & Storzbach, 2013) or have already been implemented (Banner Good Samaritan Medical Center, 2014), the evidence for their effectiveness remains inconclusive. A possible – and arguably probable – reason for the questionable efficacy of these programs may be their overemphasis on mitigating the cognitive impairments associated with MCI at the expense of attending to the whole person and their experience. Although interventions focused directly on managing impairments are likely economical in the short term, attending to the emotional and psychosocial sequelae (e.g. emotional distress, loss of self) of MCI may prove more fruitful in the longer term.

Concern for these experiences is warranted as both Carroll & Coetzer (2011) and Kuluski, Dow, Locoock, Lyons, and Lasserson, (2014) independently found that individuals recovering from stroke identified recurrent themes of identity loss, family disruption and loss of valued activities. Further, Alaszewski, Alaszewski, and Potter, (2004) demonstrated that stroke survivors participated in grief work processes as a natural part of their recovery. Though these studies examined the experience of stroke rather than MCI, they set precedence that individuals

who experience changes in lifestyle or ability as a result of health adversity – including cognitive losses – do experience emotional upheaval and intrapersonally-oriented grief.

Even given this evidence of the likelihood of emotional distress in those with MCI, it may remain unclear why this information is of value to clinicians and neurorehabilitation practitioners. Simply, addressing the grief experiences of those with MCI may have a direct influence on slowing the progression to dementia. In a recent review, Panza and team estimated up to 83% of individuals with MCI may suffer with depression (Panza et al., 2010). Depression, in turn, has been linked with accelerated cognitive decline in various clinical populations, including those with Parkinson's disease (Starkstein, Mayberg, Leiguarda, Preziosi, & Robinson, 1992), diabetes (Sullivan et al., 2013) and, indeed, MCI (Richard et al. 2013; Defrancesco, Marksteiner, Deisenhammer, Hinterhuber, & Weiss, 2009; Modrego & Ferrandez 2004). Similar patterns of cognitive decline have been suggested in those with grief-related depression (i.e. bereaved individuals) (MacCallum & Bryant, 2013; Xavier, Ferraz, Trentini, Freitas, & Moriguchi, 2002). Although it is possible that depression may result from any number of events and experiences, it is likely that one contributing factor among individuals with MCI is an experience of continuing loss and consequent prolonged grief. Thus, if grief is a component of the MCI experience, it is possible that efforts to mitigate its chronicity and associated distress may decrease the likelihood or intensity of depression and prevent/slow depression-related cognitive decline.

In light of this, it would seem necessary for an effective intervention to address the broader issues of emotional well-being and mental health in addition to cognitive functioning; yet, the design of such a program remains unfeasible without first gaining a greater understanding of the quality and nature of MCI individuals' experiences. Once this

understanding is developed, appropriate interventions (psychosocial or otherwise) may be identified and implemented. Therefore, the practical aims of this study are to 1) draw clinical attention to the importance of addressing the emotional and mental-health aspects of MCI, and 2) identify potential targets for psychological intervention in the hopes that this information will allow for the development of more comprehensive and effective treatment options for those with MCI.

Chapter 2

Literature Review

Grief and Loss in Later Life

Since aging is characterized by numerous transitions and losses, older adults are expected to encounter more frequent occasions for grief as they progress into older age. Loss may be comprised of the bereavement of any number of “objects”, such as parts of self, roles, security, styles of living, a sense of meaning, or visions of the future (Shuchter & Zisook, 1993). Grief, on the other hand, is the normal emotional reaction to loss (Griffin, 2001) characterized by an awareness that one has lost something that is irretrievable. Just as there are various targets of loss, there are various patterns of grief that tend to occur in response to particular situations (see Table 1).

Finite loss of another. A finite loss is a loss experience that results from a single, contained loss event. Finite losses are acute in that they do not persist beyond the immediate event and, though they may lead to a number of secondary losses (i.e. changes in social status or financial difficulties) the initial loss experience remains the root cause of grief and distress. Although this loss event is not necessarily constrained to interpersonal bereavement (i.e. the loss of an other), this has received the most attention as the qualities of this particular loss are commonly assumed to be the most representative and foundational of a range of loss experiences (Bruce & Schultz, 2001).

Despite being among the most common losses in older age (Bonanno, 2004), spousal bereavement may be a particularly difficult transition. In addition to coinciding with a number of age-related losses in other domains (i.e. health, physical ability, or financial independence), older

adults are often faced with finding new social roles (Cheek, 2010) and redefining themselves as a single entity (Naef, Ward, Mahrer-Imhof, & Grande, 2013) following the loss of a partner.

Table 1

Patterns of grief and characteristics

Grief Pattern	Characteristics
Finite Loss	Loss following a single loss event.
Loss of another (normative)	Loss of a loved one, immediate disruption followed by gradual abatement and return to pre-morbid levels of function (i.e. bereavement).
Complicated bereavement	Pathological, unremitting grief following the loss of a loved one. Distinct from depression, though may coincide.
Loss of oneself	Loss of previous ability or abrupt shift to self-concept. Coping processes similar to bereavement (e.g., stroke).
Nonfinite loss	Enduring loss following a negative life event. Cyclical and possibly progressive. Disrupted hopes for future and uncertainty regarding outcome.
Ambiguous loss	Uncertainty regarding whether another is lost when they are either a) physically present and psychologically absent (i.e. dementia), or b) physically absent and psychologically present (i.e. M.I.A. soldiers)
Chronic sorrow	Pervasive, cyclic, possibly progressive sadness due to need for repeated accommodating for a loss or repeated confrontation with reminders of the loss. (i.e. loss of a child).
Disenfranchised grief*	Grief that is not socially sanctioned due to societal disapproval of either a) the relationship with the grieved or b) characteristics of the grieved
Anticipatory grief	Preparatory grieving before the actual loss of a loved one occurs (i.e. cancer)

**Note.* Disenfranchised grief is not included as a heading in the main document, but rather is presented in this table as an informative concept. Anticipatory grief is listed among the other types of nonfinite loss within the main document.

This change in identity may cause self-perceptions of helplessness, inadequacy and incapacity. Due to this conflation of stressors, older adults are at increased risk for depression, anxiety, somatic issues, and suicide following the death of a spouse (MacCallum & Bryant, 2013). Supporting this, a qualitative analysis by Naef and colleagues (Naef, Ward, Mahrer-Imhof, & Grande, 2013) suggested that a major theme in bereaved older adults' grief experiences is "emotional turmoil", with loneliness, anger, numbness, shock, and betrayal among the specific experiences recounted. Despite the distress caused by grief, it is expected to abate over time to a level that no longer interferes with daily functioning (American Psychiatric Association, 2013). Further, following successful grieving, survivors resolve their role and identity changes to see themselves as more balanced and flexible (Shuchter & Zisook, 1993).

However, grief does not always resolve positively and, even when a loss is finite, one's grief reaction to loss may be prolonged. Approximately 10% of bereaved individuals experience complicated bereavement, which can be considered a "slower, hindered resolution to loss" (Lindgren, Burke, Hainsworth, & Eakes, 1992; MacCallum & Bryant, 2013) involving intense yearning for the deceased, intrusive thoughts, and avoidance of triggering emotional reminders (Shear & Shair, 2005). Complicated bereavement may result from an inability to integrate a loss into one's self-concept or worldview. In other words, the loss of a loved one can be so discrepant from one's expectations of the world or their future that they are unable to incorporate it into their personal narrative. This is a more likely outcome when the death is unexpected or due to trauma (MacCallum & Bryant, 2013). Where feelings of emptiness and loss characterize normal grief (American Psychiatric Association, 2013), complicated bereavement is characterized by

separation distress and yearning. Moreover, those experiencing complicated bereavement often demonstrate identity confusion, difficulty accepting the loss, denial, bitterness and emotional numbing (MacCallum & Bryant, 2013).

Though complicated bereavement shares some features with depression, anxiety and post-traumatic stress disorder, it is a distinct phenomenon (Boelen & van den Bout, 2005; Bonanno, Galea, Bucciarelli, & Vlahov, 2007). In addition, individuals experiencing complicated bereavement have an elevated risk of developing comorbid major depressive disorder, as well as anxiety disorders. Newson and colleagues found that older adults were at greater risk for complicated bereavement than other groups, however this may have been due more to their overrepresentation in the bereavement sample than an actual age effect (Newson, Boelen, Hek, Hofman, & Tiemeier, 2011). This interpretation is made more likely in light of research suggesting that loss of a partner late in life can be consider an “on-time” loss (Cheek, 2010). Since expected losses are less likely to elicit disruption (Gorman, 2011), it might be hypothesized that older adults are actually at a proportionately lower risk of complicated bereavement.

Regardless of their susceptibility to its occurrence, however, older adults may be at increased risk of adverse outcomes when complicated bereavement does occur. Complicated bereavement has been shown to interfere with information processing and impair the cognition of those affected (MacCallum & Bryant, 2010; Newson, Boelen, Hek, Hofman, & Tiemeier, 2011). Thus, it is possible that those experiencing complicated bereavement may be at greater risk of cognitive decline and, potentially, MCI. Likewise, and perhaps more relevant to the current study, if the prolonged stress and emotional upheaval associated with complicated bereavement are precipitating factors of cognitive decline, it is possible that those experiencing

chronic emotional turmoil and grief as a result of MCI may be similarly vulnerable to (accelerated) cognitive decline.

Finite loss of oneself. Finite loss may be most commonly viewed in terms of bereavement, but it is possible to experience finite loss of oneself as well. Though there are similarities between the two experiences, there are a number of marked differences due to the nature of the loss and the relationship to the lost person. For example, acquired brain injuries provide unique circumstances wherein an individual may be confronted with the loss of their self-concepts, relationships, roles, and identities at large in response to a finite event (i.e., the injury). This, in turn, is regularly associated with grief as well as an increased risk of depression (Carroll & Coetzer, 2011); that is, though depression is a potential outcome of spousal bereavement, it is an expected outcome for those who have experienced a loss of self due to the more drastic disruptions of self-concepts and competencies it entails (Carroll & Coetzer, 2011; Ellis-Hill & Horn, 2000). Correspondingly, coping with a loss of self may be more arduous and protracted than coping with the loss of another as, rather than adjusting one's social roles, one must instead reconstruct their own identity (Kosminksy, 2011).

Though the degree and nature of impact may differ, there is evidence to suggest that bereavement models of grief and coping may still apply to finite losses of self. Alaszewski, Alaszewski, and Potter (2004) found that stroke survivors consistently endorsed bereavement models to explain their process of loss and adjustment to their new circumstances. Further, a study by Roman (2006) showed that individuals with stroke engaged in an oscillating emotion- and reconstruction-focused process, similar to the dual-process model for coping with bereavement described by Stroebe and Schut (1999). Investigations into stroke in particular may offer insights into the experiences of those with MCI, as both stroke and MCI are often issues

with onset in older adulthood and stroke often entails cognitive impairments, which may approximate those in MCI. What is more, a study by Jin, Di Legge, Ostbye, Feightner, and Hachinski (2006) suggests that stroke and cognitive impairment may be reciprocally etiologically linked, in that those with cognitive impairment have a greater risk of stroke and those who have experienced stroke have a greater risk of cognitive impairment.

Nonfinite Loss. The discussion thus far around grief and loss has surrounded finite loss, a single, isolated loss event. As mentioned earlier, the reason for this is that finite loss (of another) has traditionally been viewed as the archetype for all grief experiences. However, though there may be some conceptual and behavioural overlap, this approach has unfortunately contributed to a distinct and pervasive form of loss being overlooked. Nonfinite losses are those which are continuing or progressive (e.g. chronic illness and disability) and whose associated grief remains constant without abating naturally. Bruce and Schultz (2002) define nonfinite loss as an “enduring loss that is usually precipitated by a negative life event or episode that retains physical or psychological presence with an individual in an ongoing manner”. Further, they emphasize that a hallmark of nonfinite loss is the disruption of a developmental trajectory and personal narrative that is cultivated from early in one’s life. Other contributing factors to nonfinite loss include a degree of uncertainty regarding outcome (Harris & Gorman, 2011), a feeling of disrupted hopes for the future (Roos, 2002), disconnection from normal experience, disempowerment, and a loss of identity (Harris & Gorman, 2011). Alternatively, Jones and Beck (2006) summarize nonfinite grief as comprising three parts: 1) a loss must be continuous and follow an event, 2) developmental expectations must be disrupted in such a way that they cannot be met, and 3) there is a sense of loss of one’s hopes and ideals. Unlike stroke, where there is an abrupt change that has ceased, nonfinite losses may entail frequent and persisting fluctuations or

changes that require constant monitoring and adjustment. In this way, nonfinite losses are not only long-lasting, but also salient aspects of individuals' daily experience.

Unlike finite loss, which is commonly conceptualized as a unitary construct, nonfinite loss serves as more of an umbrella term subsuming several prominent patterns. Although many of these patterns themselves overlap to some extent, the following discussion pertains to several of the most commonly referenced forms of nonfinite grief as distinct entities. While chronic sorrow and ambiguous loss are considered nonfinite losses proper, anticipatory grief is not nonfinite *per se*, but rather a form of disenfranchised grief that may persist over a longer term and share important characteristics with formal nonfinite losses.

Ambiguous loss. Ambiguous loss is a distinct form of nonfinite loss, defined as a loss wherein an individual is either physically absent but still psychologically present in the minds of loved ones, or *vice versa*, psychologically absent yet physically present. The former can be exemplified by considering individuals deployed for military action (Betz & Thorngren, 2006) where family may not have any knowledge of their wellbeing or continued survival, whereas the latter is well exemplified by an individual with Alzheimer's disease (Boss, 2012) where someone is physically present but psychologically changed or inaccessible. What binds these two situations is the lack of closure regarding whether someone is irretrievably lost and, to some extent, what constitutes an individual's identity or presence. Within the context of this discussion, the latter situation will be more relevant. Ambiguous loss is more interpersonal than chronic sorrow by definition (Harris & Gorman, 2011), as it is defined by the experience of the "survivors" of loss (i.e. caregivers, family members) rather than the lost themselves. Boss (2006) explains that when loss is coupled with this ambiguity, or lack of closure, the natural reconciliation of grief is disrupted. This disruption can lead to depression, anxiety, and a number

of negative social consequences. Another conflict inherent in ambiguous loss is that of boundary ambiguity (Boss, 2006). When faced with an ambiguous loss, determining whether an individual is still considered a participating member of a family or community may present both intrapersonal and interpersonal conflicts. The decision to exclude an individual may be additionally difficult given that doing so effectively requires an affirmation that said individual is irretrievably lost.

While ambiguous loss has most commonly been investigated in terms of physical absence or psychological absence associated with dementia, the core feature remains the inability to determine whether an individual's continuity persists or has been disrupted. In this way, aging itself may lend itself to some degree of ambiguous loss. Although the coherence of identity may not be threatened, the structure of one's roles and self-concepts may change dramatically throughout the lifespan (Teuscher, 2010). Afonso and colleagues (Afonso, Bueno, Loureiro, & Pereira, 2011) allude to this in their study of reminiscence; according to their work, (existential) despair in later life may result, in part, from the inability to integrate life experiences into a contiguous personal narrative. In terms of ambiguous loss, this lack of integration may translate to uncertainty about whether one remains the same individual as earlier in life, whether one has gained or lost value as a result of changes, and whether one is eligible to participate in their community to the same extent as before.

Chronic sorrow. Chronic sorrow may occur in response to finite loss, and may serve as an extension of complicated bereavement when it does; however, it is considered a more common response to continued and progressive nonfinite losses. Roos (2002) defines chronic sorrow as “a set of pervasive, continuing, and recurring grief responses resulting from a significant loss or absence of crucial aspects of oneself or another to whom there is a deep

attachment.” It should be stated that chronic sorrow is viewed as a normative, though not necessarily adaptive, response to ongoing or multiple losses, which includes elements of identity change, alienation, unpredictability, and loss of expected future(s). Though the term “chronic sorrow” was originally coined by Olshansky (1962) to describe the reaction of parents of developmentally disabled children, evidence suggests that it may be applicable to those with any permanent and impairing condition (Roos, 2002). Chronic sorrow has been found in individuals with a wide range of health issues, including cancer (Eakes, 1993), multiple sclerosis (MS) (Hainsworth, Eakes, & Burke, 1994; Isaksson, Gunnarsson, & Ahlstrom, 2007), and HIV (Lichtenstein, Laska, & Clair, 2002), as well as others affected by loss, such as dementia caregivers (Burke, Hainsworth, Eakes, & Lindgren, 1992; Collins, Stommel, Wang, & Given, 1994) and bereaved individuals (Burke & Eakes, 1999). In fact, chronic sorrow is so pervasive that some have argued that it may be a common experience among those normatively aging as well due to progressive losses of independence, social roles and partners (Lindgren, Burke, Hainsworth, & Eakes, 1992), and Roos (2002) goes so far as to argue that it is likely to develop in anyone with a sufficiently permanent and impairing condition.

At its core, however, chronic sorrow is not so much a response to disability as it is to shifts in self-image and the ongoing disparity between one’s present situation and hopes or expectations for the future (Bruce & Schultz, 2004; Roos, 2002). This parallels Goffman’s (1963) contention that one acquires a “spoiled identity” due to the mar of a disease diagnosis on their self- concept and personal narrative. Supporting this view of chronic sorrow, individuals with physical disability not only identified loss of bodily function, loss of relationships, and loss of autonomy as contributors to their distress, but also loss of the life imagined, loss of roles, loss of activities, loss of identity and loss of positive emotions (Ahlstrom, 2007). Isaksson,

Gunnarsson, and Ahlstrom (2007) add to this loss of hope for the future, loss of a healthy identity, loss of integrity and dignity, and loss of a “just world”.

An additional feature of chronic sorrow is its course. Chronic sorrow is continuous, cyclical and potentially progressive (Burke, & Eakes, 1999; Lindgren, Burke, Hainsworth, & Eakes, 1992). Although chronic sorrow does not interfere with activities of daily living (Isaksson, Gunnarsson, & Ahlstrom, 2007), reminders of the initial loss or confrontation with continued losses may trigger intense grief episodes that cause occasional functional disruption. Burke and Eakes (1999) interviewed bereaved individuals and individuals with chronic illness and disability to determine more specifically which experiences were likely to serve as triggers. They found that, for bereaved individuals, triggers consisted of anniversaries, confrontation with memories, confrontation with role changes, and confrontation with social norms that they no longer fit. In contrast, individuals with chronic illness and disabilities identified confrontation with social, developmental and personal norms that they no longer fit, health management crises (i.e. the prospect of additional losses) and anniversaries (i.e. the date of injury, etc.) as triggering events.

Though ostensibly similar to typical grief or depression, chronic sorrow is a distinct construct. Unlike typical grief after death that tends to abate after time, chronic sorrow has no predictable end (Lindgren, 1996) and may even intensify over time. Moreover, in regard to depression, chronic sorrow’s periodicity and general lack of interference with daily functioning do not fit with a clinical diagnosis of major depressive disorder (American Psychiatric Association, 2013). That being said, it is quite possible that depression may co-occur with chronic sorrow (Isaksson, Gunnarsson, & Ahlstrom, 2007).

Disenfranchised grief and anticipatory grief. Disenfranchised grief is that which occurs as a result of a loss that is overlooked, invalidated, or not socially accepted (Corr, 2002). Roos (2002) argues that chronic sorrow and disenfranchised grief are related such that chronic sorrow related to nonfinite loss is often disenfranchised due to a general lack of recognition for grief that is unrelated to (physical) death. By its nature, disenfranchised grief serves to isolate those experiencing it, which in turn may contribute to greater distress (Corr, 2002). On the other hand, anticipatory grief, a subtype of disenfranchised grief, refers to loss that occurs before the death of a loved one that is associated with disrupted expectations for one's future (Jones & Beck, 2006). While not considered a response to nonfinite loss *per se*, due to its often long course and unpredictable end, anticipatory grief responses may well fit into this category. Further, anticipatory grief may be associated with identified nonfinite loss experiences at different points in the progression of a loved one's decline.

Anticipatory grief has been found to occur in various settings, including among family of terminally ill patients, or, as in Jones and Beck's study of disenfranchised grief (2006), death row inmates. Like ambiguous loss, anticipatory grief is often determined by the caregiver's experience. A study on caregiver experience found that caregivers of individuals with AD experienced more anticipatory grief, as compared to caregivers of those with MCI who were more likely to endorse missing "the person they knew" (Garand et al., 2012). Thus it is possible that, at least in the case of chronic disability or degenerative disease, caregivers may experience an initial period of ambiguous loss at the early, undifferentiated stages of disease and progress to more of an anticipatory grief experience as their loved one's degeneration becomes more pronounced. Further, it is suggested that anticipatory caregiver grief may translate to chronic sorrow following the actual death of an individual (Lindgren, 1996)

Although anticipatory grief, like ambiguous loss, has traditionally been directed more towards the caregiver's perspective, there is evidence to suggest that individuals facing their own functional loss or death may experience a similar sense of grief (Hottensen, 2010). In patients with cancer, Cincotta (2004) describes anticipatory grief as a "range of intensified emotional responses that may include separation anxiety, existential aloneness, denial, sadness, disappointment, anger, resentment, guilt, exhaustion and desperation". This reaction appears to closely resemble that of death anxiety. Assuming that these constructs are related, it may be expected that contributors to death anxiety, such as physical and mental deficits, institutionalization, and loss of control (Fortner & Neimeyer, 1999; Hoelterhoff & Chung, 2013) may also exacerbate anticipatory grief. Further, as death anxiety has been associated with negative aging, anticipatory grief may also be an applicable construct to those struggling with the transitions of older adulthood.

Although there are more frequent and expected occasions to experience loss in old age, grief and loss are by no means relegated to the latter years of one's life. A variety of circumstances may comprise loss experiences and a variety of grief responses may result. That said, finite loss of another (bereavement) may be reported as the most common loss experience among older adults, however, it is quite possible that this determination is artificial; finite interpersonal losses may only appear more common than nonfinite losses of self or others because loss is often defined through a finite interpersonal lens. In fact, if changes to self and potential futures are hallmarks for nonfinite loss, it is quite likely that nonfinite losses are more ubiquitous among older adults than either finite or interpersonal losses. Unfortunately, with the exception of chronic sorrow, most nonfinite loss-related constructs continue to adhere to an interpersonal orientation. However, given the wide applicability of chronic sorrow, it is possible

that the exclusively interpersonal focus for other constructs may be due more to a lack of application to intrapersonal loss experiences than an actual lack of grief or distress in response to intrapersonal losses. Chronic sorrow is most likely to affect individuals with compromised competencies, as each obstacle encountered may serve as a reminder of their loss. This may be especially relevant to those with physical or cognitive deficits such as those that occur in both normatively and pathologically aging individuals. Ambiguous loss and anticipatory grief may also be relevant to individuals with health adversities; individuals diagnosed with progressive conditions are more likely to remain vigilant to changes in their functioning and, as a result, may be acutely affected by the oftentimes unpredictable, yet inevitable course of degeneration.

Grief and Loss in Mild Cognitive Impairment

Mild cognitive impairment – definitions and diagnoses. To provide a foundation for the discussion of grief in response to MCI, it is essential first to review the definition of MCI. MCI is typically considered to be a prodromal stage of AD, however, what it actually constitutes has been a point of contention since its conception. The notion of MCI grew out of various streams of research, including that on “benign senescent forgetfulness” (Kral, 1962), “age-associated memory impairment” (Crook et al., 1986), and “age-associated cognitive decline” (Bischkopf, Busse, & Angermeyer, 2002). Though many themes overlapped considerably, due to a poor conceptualization of the syndrome and numerous unique terminologies, it was not until decades later that the various threads were gathered into a single framework. That being said, common factors between each of these syndromes were memory impairments (though these were not primary in age-associated cognitive decline), a declining course to dementia, and an absence of present dementia.

In 1999, Petersen and colleagues (Petersen et al., 1999) first proposed MCI as a singular construct and put forth a hallmark definition of its presentation. They maintained that the chief difference between MCI and AD lies solely in the range of faculties that are afflicted; MCI includes only memory decline, whereas AD includes decline across a number of domains. They described MCI as cognitive decline, characterized by memory deficits, beyond that expected from normal aging. They went on to posit further requirements that individuals experiencing MCI have subjective complaints of their memory and that, despite their declining faculties, individuals with MCI should be able to continue activities of daily living unimpeded. This definition, though successful in drawing further research attention to the construct, was not universally accepted among those working directly with those with MCI. The so-called “Petersen criteria” (1999) were viewed as being too narrowly focused on memory complaints. This is likely due to the fact that the Petersen team recruited their sample from a memory disorder clinic, although many clinicians felt other forms of cognitive decline at this prodromal phase were underrepresented. Further, where the Petersen criteria described a singular presentation of MCI, many clinicians argued that MCI was, in fact, a far more heterogeneous condition. Lastly, while MCI may lead to AD, there was evidence to suggest that its course was less specific to AD and more variable than these criteria could account for.

Petersen et al. (2001) updated their definition shortly thereafter to account for several subtypes of MCI: amnesic MCI, multiple-domain MCI, and single non-memory domain MCI. They argued that amnesic MCI was uniquely associated with AD, whereas the other two subtypes were associated with a greater variety of dementias (i.e. frontotemporal, vascular, Lewy body, etc.), including the possibility of AD. While this updated definition addressed some of concerns surrounding the original, many still argued against the primary focus on memory

complaints. Further, evidence suggested that, even with the updated taxonomy, only 6 to 25% of individuals diagnosed with MCI actually did progress to AD (Bischkopf, Busse, & Angermeyer, 2002; Joosten-Weyn et al., 2008), though it should be noted that this is still significantly higher than the general population (Bischkopf et al., 2002; Busse, Hensel, Guhne, Angermeyer, Riedel-Heller, 2006). What is more, studies have demonstrated that individuals with MCI do not uniformly decline; while some may decline into dementia, others may remain stable or even recover (Winblad et al., 2004). As much difficulty as this ambiguous course causes clinicians, the unclear implications of an MCI label are more disconcerting for diagnosed individuals; a diagnosis of MCI may or may not warrant existential fears, help seeking, adjustment of future plans and alterations to self-concepts.

The construct of MCI continued to evolve into the early 21st century. For example, Winblad and colleagues (2004) addressed clinicians' concerns regarding the primacy of memory impairments with their recommendations for updated MCI general criteria. According to their scheme, MCI could be defined according to self and/or informant report of cognitive decline in a number of domains, much like the previous conceptualization of age-associated cognitive decline. Furthermore, Winblad et al. (2004) suggested explicit requirement of objective cognitive performance indicators. However, they did agree with Petersen's contention that MCI is not simply due to normative aging. Adopting many of Winblad et al.'s (2004) recommendations, Albert and colleagues (2011) recently created a more widely applicable (to both amnesic and non-amnesic MCIs) and clinician-supported definition for MCI, which has been adopted by the National Institute on Aging and Alzheimer's Association (National Institute on Aging, 2013) (criteria outlined in Table 2).

While perhaps not as straightforward as the previous “gold standard” of the Petersen criteria, Albert et al.’s definition (2011) allows for a greater range of presentation and further possibilities for study. Not only does this heterogeneous group present an opportunity for a more holistic enquiry into MCI’s course, it is likely also more representative of cognitively compromised individuals outside of the memory clinic. Moreover, these inclusive criteria, together with the endorsement of the NIA, have led to the inclusion of mild neurocognitive disorders in the DSM-5 (American Psychiatric Association, 2013), making reliable diagnosis a more realistic possibility for those with cognitive deficits other than memory. However, while necessary, a standard definition is not sufficient to ensure reliable diagnosis. Bondi and Smith (2013) demonstrate that diagnosticians themselves may be an important factor in determining the veracity of an MCI presentation. In contrast to those provided by medical practitioners, diagnoses provided by clinical neuropsychologists using standardized neuropsychometric tests with objective performance indicators were found to be the most reliable.

The definition of MCI has undergone numerous revisions; however, what has remained consistent has been an agreement that there is an identifiable pattern of decline heralding Alzheimer’s and other forms of dementia, and that the more complete our understanding of this prodromal period, the greater likelihood there is of effective preventative treatment and intervention. As the “Albert” criteria (Albert et al., 2011), has been adopted by the NIA and provides a more complete and broadband understanding of MCI, this study shall aim to be consistent with this system for determining and discussing MCI. That said, the primary aim of the current study was not to diagnose; existing diagnoses were respected, however, aspects such as functional impairment, dementia, and concern regarding cognitive change were corroborated and accounted for. Furthermore, in accordance with Bondi and Smith’s results (2013), the

current study accounted for the diagnostic source in order to ensure the most reliable sample of individuals with MCI according to the current criteria.

Table 2

National Institute of Health: National Institute on Aging MCI criteria (Albert et al., 2011)

Criterion	Description
1. Concern regarding cognitive change.*	There is concern regarding change in cognitive ability compared to previous levels by a patient, knowledgeable informant, or skilled clinician.
2. Impairment in at least one cognitive domain.	There is evidence of lower performance than expected given an individual's age and education level. Repeated assessments should demonstrate a decline in performance. Possible domains include memory, executive functions, visuospatial skills, attention, and/or language. Episodic memory deficits are most common in those progressing to Alzheimer's disease.
3. Preserved independence in functional abilities.	Individuals with MCI may be slower, less accurate, and/or less efficient while performing complex tasks they completed easily previously; however, individuals with MCI should still be able to complete instrumental daily tasks such as paying bills, preparing meals, etc. with little or no assistance.
4. Not demented.	Cognitive changes should be sufficiently mild that there is no significant disruption of an individual's social or occupational functioning.

**Note: Where repeated assessments are unfeasible, changes in cognition beyond what can reasonably be expected due to age or education should be inferred from history or evidence.*

The impact of mild cognitive impairment diagnosis. In light of the various historical definitions of MCI, the veracity of MCI diagnosed before the development of the current criteria may be questionable. While this has clear implications for clinicians and assessment, this ambiguity also affects those diagnosed. When asked to describe features of their MCI diagnoses,

older adults identified uncertainty of diagnosis, skill loss, change in social and family roles, embarrassment and shame, emotionality, insight, and (fear of being a) burden as relevant themes (Frank et al., 2006). In a qualitative study by Beard and Neary (2013), focus groups with older adults generated four major themes: Questioning whether or not MCI was a disease, struggling to define MCI, distancing their experience from AD, and grappling with the social implications of an MCI diagnosis. In yet another study, individuals identified fear and uncertainty and interdependence as key themes. Though there were varied understandings of what an MCI diagnosis meant, several common threads among the various studies are apparent; there is considerable confusion as to what the diagnosis means and what are its implications, there is a loss of independence, and, finally, there is an underlying fear of developing AD (or other dementia).

Understood to be a prodrome for AD, reactions to MCI are often determined by an individual's feelings towards AD. Unfortunately, AD is one of the most heavily stigmatized and feared conditions commonly known to older adults (Corner & Bond, 2006). Portrayals of dementia often present an extremely negative view of those affected, emphasizing a loss of personal narratives, extreme presentations, and perceptions of caregivers as victims (Beard & Neary, 2013). This view is pervasive, as can be seen by participants going to lengths to differentiate themselves from those with AD (Beard, 2004) and avoiding talking or thinking about the prospect of dementia because it is too threatening a possibility (Corner & Bond, 2004). Further, Beard (2004) suggests that acceptance of a diagnosis confronts individuals with their own aging, decline, and ultimately, mortality. Compounding this negative view of dementia, the ambiguity of the MCI label may cause more distress; as it does not necessarily represent future progression to AD, diagnosed individuals may be confused regarding whether they are

experiencing dementia or normal decline (regardless of MCI's definition as non-normative) (Corner & Bond, 2006). In a study by Roberts and Clare (2013), older adults did not use the term "MCI", suggesting that it is either too threatening for them or that it holds no particular meaning. That being said, after clarification many find succor in an MCI diagnosis as it indicates an absence of dementia, whereas others opt to consider it normative decline regardless of contrary information (Lingler et al., 2006). This latter response may represent emerging anosognosia or defensive denial – the tendency to deny personal inadequacies in order to avoid confrontation with the unpleasant reality of one's adverse situation (Ownsworth, 2005). While it is clear that AD is feared and association with an AD diagnosis is avoided, there are still questions about why and how someone with an unequivocal MCI condition may be affected. It is possible that identification with AD or MCI may formally disrupt one's personal narrative, their self-concept and hopes for the future (Corner & Bond, 2006).

Identity loss in dementia and mild cognitive impairment. Disruption in one's narrative serves not only to change one's own perception of oneself but, perhaps more importantly, affects how others perceive them. This coincides with one of the themes from Beard and Neary's study above (2013). Due to societal assumptions that there is necessarily a loss of self in AD, individuals are exposed to systematic, yet unintended, depersonalization and invalidation from caregivers and loved ones (Clare, 2002; Sabat, 2002). This, in turn, exacerbates disability due to feelings of low agency and efficacy. Holst and Hallberg's work (2003) echoes these sentiments, showing that a major contributor to withdrawal and disengagement was initial depersonalization from one's social surroundings. Therefore, in order to mitigate this social stigma, it is not unusual for individuals with AD to hide their deficits for as long as possible to preserve their sense of self (Beard, 2004).

In light of this stigmatization and depersonalization, Robinson, Clare and Evans (2005) argue that a dementia diagnosis early in the development of the disorder may be more harmful than beneficial. While early diagnosis may help one to describe and understand symptoms, it may also label the affected individual and accelerate the transition of loved ones to caregiver roles. Further, a diagnosis may alter the dynamic of romantic relationships by heralding the divergence of each partner's needs. As familial roles are the most robust aspects of identity throughout disease progression (Cohen-Mansfield, Golander, & Arnheim, 2000), the schism between partners presented by a diagnostic label may speed decline and perceived identity loss.

As this devaluation is often built upon the assumption that there is an absolute lack of awareness in AD, it may seem paradoxical that the majority of the literature suggests that identity in AD is intact – at least in some form – until the end-stages of the disease (Basting, 2003; Clare et al., 2013). In fact, a sense of identity does not appear to be affected by cognitive ability at all (Caddell & Clare, 2013; Naylor & Clare, 2008); however, this may be an artifact of our standard, stationary definition of identity. There is evidence to suggest that, when characteristic aspects of identity are threatened (i.e. memory ability, functional independence), individuals reconstruct their identity to place a heavier emphasis on unaffected traits (Beard, 2004). Caddell and Clare (2011) demonstrated this in another study, where individuals consistently described themselves according to those characteristics least threatened. Specifically, when describing changes, individuals focused on behavioural descriptions, as opposed to the more cognitive or emotional descriptions provided when focusing on stable characteristics. Another notable outcome of this study was that individuals tended to move fluidly between discussing their strengths in unitary terms and adopting more of an orthogonal approach to their identity when discussing challenges. In other words, rather than viewing

identity as a single, integrated entity with different aspects, individuals with compromised cognitive functions described themselves as a combination of separate, mutually exclusive aspects/abilities fluidly as best fit the circumstance.

This suggests that an active effort is put toward adjusting one's views of identity to maintain a sense of continuity despite changes in various aspects of oneself. As a result, Caddell and Clare (2011) argue that Neisser's (1988) model of orthogonal sub-selves may be of particular relevance in the discussion of identity in dementia. Neisser's model describes the structure of identity as consisting of cognitively different "selves" bound together by shared experience and chronology that, together, give rise to an emergent "conceptual self". In the case of MCI, as one "self" is compromised, another may merely be made more salient to compensate. This preferential weighting of particular "selves", however, may not be a unique reaction to MCI, but rather one common in aging. Baltes and Baltes' (1990) model of selection, optimization, and compensation (SOC), on the other hand, posits that individuals partake in these three distinct yet related processes as their ratio of gains to losses becomes more negative (as may occur in normative aging). "Selection" refers to the selection of personal goals and the amendment of said goals when internal or external resources change. "Optimization" refers to the preferential attention and allotment of resources to achieving goals that are achievable given the realities of one's means (growth-orientation), rather than the maintenance of goals that may no longer be feasible (loss-orientation). Lastly, "compensation" refers to the ability and willingness to adjust one's goals and priorities to match one's current internal and external resources. Where Neisser's (1988) model describes the possible structure of identity, Baltes and Baltes' (1990) SOC model may better explain why individuals with MCI demonstrate such a fluid self-concept. Since losses can be expected to be greater and internal resources (cognitive

ability) fewer in MCI than in normative aging, the more plastic identity described by Caddell and Clare (2011) fit well with the predictions of the SOC model.

Similar to literature on aging and chronic sorrow in those with chronic illness and disability, this striving for continuity can be construed as an effort to maintain independence and autonomy. MacQuarrie (2005) interviewed a number of individuals with probable AD and found a major theme in their narratives to be the tension between being an independent party and becoming an “object without agency”. Further, much like the variability in self-identified identity characteristics, individuals in this study tended to endorse opposing aspects of resistance to accepting and adjusting to their illness, and acknowledging and coping by limiting their activities. This conflicted approach to coping is described well by themes of “I’m still the same vs. I’m different from before”, “I’ll always stay the same vs. I don’t know what to expect”, “life is much the same vs. life is different”, and “always having a social support vs. being a social burden” found by Caddell and Clare (2011).

Thus, it may be concluded that MCI not only affects one’s cognitive abilities, but also one’s sense of self. Aside from gaining a “spoiled identity” (Goffman, 1963), individuals with MCI are confronted with the possibility of losing access to their autobiographical history and those qualities that define them. Beard and Neary (2013) suggest that this may be so threatening that individuals default to denial in order to maintain a sense of stability. This has also been evidenced by individuals with MCI’s tendency to define themselves fluidly in order to maintain a homeostatic self (Caddell & Clare, 2011). Though it may be unconscious, this active denial may hint toward an awareness of the discrepancy between self-concepts and present abilities. If so, it is possible that grief results to the extent that individuals can tolerate discrepant self-concepts.

A Case for the Examination of Grief in Mild Cognitive Impairment

Though grief of various forms has been discussed in terms of bereavement and chronic (physical) illness and disability, MCI has thus far remained unexamined in this respect. Instead, most research regarding grief in response to a diagnosis of MCI or dementia has focused on the experience of caregivers. While this is understandable in the case of dementia given issues with self-awareness, this may not be strictly applicable to individuals with MCI. In fact, by definition, an individual with MCI must have relatively well-preserved self-awareness. (Albert et al., 2011). What is more, it has been shown that unresolved grief of various forms can become long lasting and lead to mental illness, which in turn, may accelerate cognitive decline (MacCallum & Bryant, 2013). Thus, considering that approximately 1.4 million individuals in Canada are expected to be diagnosed with AD by 2031 (Canadian Institutes of Health Research, 2013), there is a large population that is not only being overlooked, but is being put at risk by the lack of attention to the emotional and psychological experiences of loss and transition due to MCI and early-stage dementia.

Features of grief and loss in mild cognitive impairment. Though a number of emergent themes throughout the MCI literature are suggestive of grief experiences, the first-hand experiences of grief and loss in MCI have not yet received specific attention. Despite this, a number of phenomenological themes and characteristics of the pathology are pertinent to this discussion.

Aging and mild cognitive impairment. As MCI is a disease of old age, it is reasonable to assume that a number of difficulties that afflict those with MCI may coincide with those of typically aging adults. As discussed above, the diagnosis of MCI may elicit a “spoiled identity” (Goffman, 1963) as someone with impending dementia or, at the least, (pathological) cognitive decline. This, in turn, may elicit a disruption of one’s expectations for the future and

confrontation with one's mortality. The theme of distancing from AD found among those with MCI diagnoses (Beard & Neary, 2013), as well as themes of uncertainty and fear (Roberts & Clare, 2013) may suggest some level of existential angst and fear of annihilation; dissimilarly to death anxiety proper (Fortner & Neimeyer, 1999), however, the projected end of one's selfhood in dementia or MCI (due to the expectation of later dementia) may not coincide with physical death.

Nevertheless, despite support for this fear of AD (Beard, 2004), it is not clear what AD in particular represents to these individuals and why other forms of dementia and, perhaps, even death are not perceived as threateningly. One possibility is suggested by themes Roberts and Clare (2013) identify as "fear of becoming a burden on others" and "losing one's autonomy". Though these themes closely compare to those expressed by normally aging adults, the onset of pathological cognitive decline is likely to exacerbate the concerns regarding autonomy and independence that are normative for this age (Langer, 2011). Unfortunately, due to the risk of depersonalization that comes with a dementia diagnosis (Beard, 2004), individuals with MCI are at even greater risk of losing any agentic roles available to them. As independence has been found to be a central component of positive identity at this age, those with MCI are consequently at increased risk of identity threat and resulting depression compared to typically aging older adults (Langer, 2011). On the other hand, AD may merely be a familiar concept to many older adults and erroneously conflated with dementia.

Although MCI may present an additional degree of identity threat, aging itself may be threatening to the self-concepts older individuals have nurtured throughout their lives. Caddell and Clare (2013) argue that the expression of malleable self-concepts in those with early-dementia may represent an inability to acknowledge one's changing abilities, but some degree of

this identity plasticity may be normative for older adults in general; indeed, identity plasticity may be more the rule than the exception (Baltes & Baltes, 1990; Tate, Swift, & Bayomi, 2013). With that said, it remains likely that those with MCI may be more changeable in their self-concepts than normatively aging others purely due to the elevated threat posed by unexpected changes in cognition, unpredictable prognosis, and fear of incipient dementia.

An additional issue for those with MCI is how to cope with the aging process in general. Research suggests that reminiscence prepares individuals for increasing change and loss and helps to integrate one's past experiences with one's current condition (Afonso et al., 2011). Further, Van Hiel and Vansteenkiste (2009) suggest that what one finds through this process can determine the success of their aging. However, for those with MCI, this task may be increasingly difficult; though individuals with MCI are mainly self-aware, declarative memory declines are common (Petersen et al., 2001). If one's past is wholly or partially inaccessible, it is likely to disrupt autobiographical continuity and, consequently, their achievement of ego integrity in older age (Erikson, 1982). Moreover, Naylor and Clare (2008) suggest that those with greater awareness are at greater risk for depression, which can be cognitively impairing in itself. Therefore, those with MCI may encounter more difficulties achieving ego integrity compared to normatively aging older adults due to autobiographical disruptions and, likewise, may have a greater susceptibility to depression than demented older adults on account of having largely intact awareness.

Although a general consensus has recently been reached regarding MCI's veracity and definition (Albert et al., 2011), there remains ambiguity among those diagnosed. Though this is partially due to the aforementioned difficulties in defining MCI, a larger part may be a lack of clear prognosis. This ambiguity itself may cause increased distress as individuals are effectively

put into a moratorium, where they do not know what to do to manage their condition – or even if it is necessary – and simultaneously feel unable to plan for their futures and pursue goals due to the potential of developing dementia. Further, many older individuals actively downplay their symptoms (Frank et al., 2006), construe their decline as normative and/or distance their experiences from that of AD due to the ego threat of incipient dementia. This existential fear, paired with an unclear outcome and trajectory may well combine to create anxiety and grief in individuals with MCI.

Finite loss and mild cognitive impairment. While bereavement, as a finite loss of another, may not in itself share many obvious similarities to MCI, work by Alaszewski, Alaszewski, and Potter's (2004) identification of bereavement models of coping in other health-related intrapersonal losses suggests that such models may also serve as a framework through which to understand grief in MCI. Stroebe and Schut's dual process model of coping (1999) suggests that an individual oscillates between active grieving and more instrumental coping in order to balance their emotional experience with the management of secondary losses. While this pattern has been found to apply to stroke (Alaszewski, Alaszewski, & Potter, 2004), a finite loss, it is unclear whether this would apply to MCI. Where finite losses consist of a single loss experience and stability thereafter, MCI is characterized by an insidious onset and, for approximately a third of those afflicted, continued decline. Further, it is not clear whether secondary losses would require management, as individuals with MCI are still largely capable of performing instrumental activities of daily living. An additional difficulty applying a bereavement model to MCI is that those afflicted are more likely to attempt hiding their deficits (Frank et al., 2006). Since many bereavement models rely heavily on acknowledgement and support seeking, they may not be appropriate for use with those utilizing defensive denial.

Nonfinite loss and mild cognitive impairment. Nonfinite loss may be the most applicable framework with which to view the MCI experience; MCI is continuous, has no reliable resolution, requires repeated accommodations and elicits a sense of uncertainty about the future (Bruce & Shultz, 2001).

Chronic sorrow and mild cognitive impairment. Chronic sorrow, in particular, has been applied to a number of intrapersonal losses, including neurodegenerative disorders such as MS (Hainsworth, Eakes & Burke, 1994). The constant confrontation with reminders of the discrepancy between one's self-concepts and one's abilities in reality characteristic of chronic sorrow may be especially relevant to the MCI experience. Specifically, individuals with MCI are often confronted with the inability to remember certain aspects of their day or history. This may be doubly disconcerting as, not only is one's sense of self undermined, but also their functionality is simultaneously brought into question. Another feature of chronic sorrow that may be prominent in those with MCI is the loss of expectations for the future. The course of MCI is unclear and may progress, remit or stabilize at any stage of the disease (Albert et al., 2011). Further, for many diagnosed, MCI is an ambiguous term which may or may not be linked to AD (Beard & Neary, 2013). As a result of this ambiguity, individuals diagnosed with MCI may find it difficult to plan for the future given the lack of a concrete timeline of progression or guarantee of further degeneration or remittance. In this way, MCI may present a quandary; one may be effectively stopped from moving forward on their planned trajectory, and may also increasingly lose connection with their current self-concepts.

Despite many of these potentially applicable aspects of chronic sorrow to MCI, however, the extant literature on chronic sorrow has not yet provided a strong basis for these assumptions. Though much attention has been paid to chronic illness and disability, the majority of these

studies have focused on terminal diseases, such as HIV (Lichtenstein, Laska, & Clair, 2002) and cancer (Eakes, 1993), or the experiences of caregivers and survivors (Burke & Eakes, 1999; Collins, Stommel, Wang, & Given, 1994). Though MS is a neurodegenerative disease, Hainsworth and colleagues' work (1994) focuses primarily on chronic sorrow in relation to physical symptoms. To the writer's knowledge, only one study thus far has provided support for chronic sorrow in individuals with AD (Burke, Hainsworth, Eakes, & Lindgren, 1992), though none have yet examined its application to MCI. Therefore, it appears the research on chronic sorrow is also overdue for a first-hand perspective of potentially incipient dementia.

Ambiguous loss and mild cognitive impairment. Aside from the ambiguity in the meaning of MCI for diagnosed individuals (Beard & Neary, 2013), there is also ambiguity in terms of whether individuals are really losing their selves or not. Though it might be expected that there is a loss of identity (Sabat, 2002), research supports the view that an identity, if not the same identity, remains throughout one's disease progression (Caddell & Clare, 2011; Clare et al., 2013). Despite this, however, some aspects of ambiguous loss may still occur in MCI. While identity may remain, individuals with MCI may still grapple with the question of whether they are the same as before and, if not, whether the magnitude of change is sufficient to constitute a different identity. This may be further complicated by the ambiguity of prognosis and the difficulty for those with MCI to determine whether their previous abilities/roles/selves are irrevocably lost or recoverable.

It is important to clarify, however, that ambiguous loss has been defined in the literature as an interpersonal experience (Boss, 2012). While features of this construct may overlap with features of grief in MCI, aspects of ambiguity and questions regarding continuity are more likely to relate to issues of of identity (re)construction or role adjustment in those with MCI. Since

ambiguous loss has thus far only been applied to interpersonal losses, it is unclear whether it will still be applicable to the more intrapersonal context of MCI. In fact, given the traditionally interpersonal focus of this construct, if features of this pattern are identified in an intrapersonal context, such as MCI, it may suggest the adoption of a dual perspective as both griever and grieved. As the question of grief in MCI is self-referential by nature, the endorsement of an interpersonal pattern may be indicative of a schism between one's current self-concept and one's past.

Anticipatory grief and mild cognitive impairment. Anticipatory grief is another grief response pattern to long-term interpersonal loss. Anticipatory grief can be considered as preemptive grieving in preparation for an expected loss. Though this has been defined interpersonally, it is possible that an individual expecting to lose their abilities and sense of self would undergo a similar experience. Individuals with MCI may be more vigilant in monitoring their abilities and, consequently, may be aware of their continued decline. In this way, an individual with MCI may experience feelings of loneliness, anxiety, and desperation similar to that of caregivers for terminal patients (Hottensen, 2010).

Much like ambiguous loss, anticipatory grief has thus far been approached from an interpersonal perspective. Therefore, endorsement of this pattern by those experiencing the intrapersonal losses of MCI may suggest a dual role and possible confirmation of identity change. Further, if the applicability of either of these constructs to MCI is supported by the current study, this may suggest the broadening of either concept or the merging of several constructs into a novel pattern to describe intrapersonal experiences. However, while anticipatory grief provides a possible framework for understanding the experience of those with MCI, it is unclear at which point anticipating a loss would become experiencing a loss. Unlike

bereavement, where the loss is sudden and identifiable, the onset of MCI or dementia may take years before it is pronounced enough to recognize. Thus the construct of anticipatory grief may be more instrumental when taken into account together with other forms of nonfinite grief response. If grief does occur in those with MCI, and if it is comparable to the experiences of other groups studied, it is possible that there is a chronological progression between the various types of nonfinite grief experiences. At least hypothetically, it is possible that an individual with MCI may experience anticipatory-like grief directly following a diagnosis, transition to a more ambiguous loss-like pattern as they experience early impairments and consider what the loss experience might mean for their selfhood or social functioning, and then convert to chronic sorrow once/if their deficits become more pronounced and functionally disruptive (dementia). That being said, the current study is exploratory and it remains to be seen whether any confirmation for this speculation exists.

To conclude, grief is a natural response to loss and transition, and older adulthood is characterized by a number of these experiences. As a result of losses of social status, physical ability, and independence, older adults may have more opportunities to grieve than those in other age groups. Unfortunately, though these sources of loss are normative, older adults are also susceptible to certain unique forms of loss, such as the pathological cognitive decline of MCI. Although research has not yet been directed to the question of grief related to MCI, there are hints throughout the literature to suggest that individuals with MCI experience emotional turmoil. Beard and Neary (2013) demonstrate that individuals with MCI experience fear of AD and possibly engage in denial. Further, a number of studies have identified emergent themes suggesting conflict in defining one's identity, fears for the future, and unpredictability (Beard & Neary, 2013; Frank et al., 2006; Joosten-Weyn et al., 2008). Notably, these themes of identity

change and uncertainty are not specific to MCI, but rather appear to be the central characteristics of nonfinite loss suggesting the that this construct may be applicable to MCI.

Summary and Aims of the Current Study

Despite indications of a grief experience throughout the literature, grief in MCI has not received direct attention for several reasons. Firstly, until recently, the definition of MCI was quite controversial. As a result, the diagnostic label of MCI was applied to a vastly heterogeneous group, making research necessarily obtuse. Secondly, a fallacious tendency to equate MCI with AD – the two of which differ markedly in terms of the degree of personal insight available – has led to a majority of the literature emphasizing either concrete behavioural aspects of coping or the experiences of caregivers. Those studies that have attempted to investigate the more obscure aspects of MCI have taken an undirected approach, which has provided little focus for follow up. Thirdly, the various patterns of nonfinite grief that are well-characterized have not been applied to MCI. Although chronic sorrow has been applied to other chronic disabilities and illnesses, MCI has been overlooked, likely due to misguided concerns regarding the intactness of self-awareness. Thus, the objectives of this study were to 1) provide a holistic description of the emotional experience(s) of MCI with a particular focus on those related to loss and grief, and 2) to compare said experience(s) to existing loss and grief frameworks. An additional objective was to 3) explore whether identity change/loss occurs for those with MCI and, if so, to determine whether this contributes to their experience(s) of loss and grief. Finally, as those with MCI are largely overlooked and unheard in the literature, an auxiliary goal was 4) to represent the experiences of those with MCI and add their voice to the discussion of its management.

Chapter 3

Research Design and Methods

Pilot Study

A pilot study was conducted in order to determine the best items to include in the primary study's interview protocol and to test the study format and duration. The goals of this pilot study were to 1) create an interview protocol that was non-threatening and that elicited a high degree of disclosure from interviewees; 2) to identify those items that best addressed role transition, identity change, concern and satisfaction, growth and stagnation, relationship quality, and both positive and negative emotions that result; 3) to select items that were clear and coherent to interviewees; and 4) to ensure that the interview protocol was not overly fatiguing and that all items could be addressed fully within a 60-minute period.

Recruitment. The author distributed information posters widely throughout Victoria, focusing on community centres, older adult activity groups, medical clinics, as well as organizations affiliated with the University of Victoria focused on older adults.

Participants. A sample of older adults was drawn upon in order to pilot test the structure, format, and content of interviews for the study's principal sample, persons with MCI. Eligible participants 1) were between the ages of 65 years and 80 years of age, 2) were fully retired, 3) lived independently in the community, and 4) had not been diagnosed with any degree or form of cognitive impairment. The pilot study sample ($n = 9$; women $n = 7$, men $n = 2$) ranged from 70 years to 79 years of age ($M = 69.33$ years, $Mdn = 71$, $SD = 4.72$ years). All pilot study participants currently resided in the Greater Victoria Area. Participants did not receive any compensation for their participation in this study.

It was understood that those with MCI would differ in some respects from the normatively aging pilot sample, however, the use of a non-MCI pilot sample was important for several reasons. Given the small MCI population in Victoria, pilot testing on individuals with MCI would have reduced the already limited size of the sample eligible for the primary study. Further, pilot testing the interview on individuals of a similar age to those with MCI allowed the researcher to become familiar with communicating and rapport-building with the relevant age group. Finally, a sample of normatively aging older adults was readily available and retirement represented a shared, normative, age-related transition that could be conceptually compared and contrasted with MCI.

Measures and materials. The pilot study was intended to test the utility of a semi-structured interview protocol with questions derived from the Transition Interview for Person's with Alzheimer's Disease (TIPAD) (MacQuarrie, 2001). The protocol developed by this pilot study was identical to that used for MCI participants with the exception that any mention of MCI was instead replaced with "retirement". It was felt that retirement provided a similar sense of transition while contrastingly being a normative life experience and, therefore, more relevant and accessible to the normatively aging pilot study sample.

Procedures. Interested participants were informed that the study would constitute an hour-long interview about their experiences with retirement and was intended to pilot questions for another study on a different population. Appointments for a telephone conversation were then arranged with interested participants. At the appointed time, the author called participants and reviewed verbal consent according to a prepared script. Once consent was obtained, participants were asked a short series of questions to determine their eligibility in the pilot study. Further corroboration or confirmation of their responses was not sought.

Once eligibility was established, the author conducted the interview. Notes were taken throughout the interview, both reflecting the content of participants' narratives, as well as the author's impressions of the narrative and the interview process itself. Upon completion of the interview, participants were thanked for their participation and debriefed as to the goals of the pilot study and its relation to the primary study of "a clinical population of older adults". Each were asked how they felt following the interview and offered a list of community supports if they felt distraught as a result of the study. No participants reported distress or asked to receive the list of community supports.

Analyses. Pilot study data consisted of the author's notes regarding the interview process, and the quality and depth of individuals' responses to given questions. Following the interview, the notes compiled throughout the interview were reviewed, appropriate changes were made to the interview protocol, and the notes were summarily destroyed. The demographic/eligibility data collected prior to the interview was de-identified and retained for later descriptive analysis.

Primary study

Recruitment. The author distributed information posters widely throughout medical, neurology, and neuropsychology clinics throughout the Greater Victoria Regional District, as well as organizations affiliated with the University of Victoria focused on older adults. All MCI participants were referred directly by a local clinician (i.e. neurologist, neuropsychologist). MCI participants recruited informants who they determined to be reliable and able to corroborate their reports of functional ability. Therefore, while purposive sampling was conducted to recruit participants with MCI, informants were recruited via chain sampling instead.

Participants.

Individuals with MCI. The primary participants of this study were older adults with MCI. However, as is standard in neuropsychological research and practice with cognitively compromised individuals, each participant with MCI also selected a (presumed) cognitively intact friend or family member to serve as an informant and help corroborate descriptions of their (concerns about) functioning. Initial eligibility criteria for participants with MCI were that they were 1) between the ages of 65 years and 80 years of age, 2) had received a diagnosis of mild cognitive impairment (MCI) from a qualified professional (i.e., geriatrician, psychiatrist, neurologist, neuropsychologist), 3) were neither demented nor significantly functionally compromised, and 4) had either a partner, family member, or close friend willing to provide an informant report on their behavioural and cognitive functioning.

Demographics. An initial sample of seven individuals with MCI were recruited, screened, and determined to be eligible for inclusion in this study. However, subsequent to the eligibility screening, one participant chose to withdraw. Therefore, the final sample of participants with MCI comprised six individuals ($n = 6$; women $n = 3$, men $n = 3$) ranging in age from 63 years to 72 years ($M = 67.67$, $Mdn = 68$, $SD = 3.33$). One participant's age did fall below the lower limit of the 65-year age criterion; however, their data was included as they could still be addressed appropriately with available norms and study measures, and the participant had fully retired and was, therefore, in a role and life stage comparable to other study participants. The sample was relatively homogenous, though representative of the local population; all MCI participants self-identified as "Caucasian" or as being of Western European ancestry, spoke English as a first language, and were fully retired. MCI participants were well-educated overall ($M = 14.833$ years, $Mdn = 16.5$ years, $SD = 3.87$ years). The majority of participants ($n = 5$) lived within the Greater Victoria Regional District of Vancouver Island, British Columbia, Canada.

Diagnosis and medical history. All participants had received a diagnosis of MCI from a qualified professional (neurologist $n = 5$, neuropsychologist $n = 1$) within the last two years ($M = 1.04$ years, $SD = 0.64$ years). All participants reported being concerned about their cognitive changes and feeling that their cognition had worsened over time. Participants varied in how long ago they noticed cognitive changes ($M = 5.42$ years, $Mdn = 3.25$ years, $SD = 6.09$ years), however, this may be inflated by different conceptions of what MCI entails; one participant claimed that she had always had some degree of MCI and another associated MCI with an acute episode of psychological “burnout” experienced 17 years earlier. None of the MCI participants reported any personal history of psychiatric disorder, though half the sample ($n = 3$) reported a previous history of diagnosed anxiety and/or depression. Half the sample ($n = 3$) reported a family history of psychiatric disorder (e.g. bipolar). Half the sample ($n = 3$) also reported a family history of dementia. Two participants reported head injury and possible neurological injury in the past, however, neither of these cases were diagnosed. Other medical conditions reported were past cancer ($n = 2$), past alcoholism ($n = 2$), diabetes ($n = 1$), restless leg syndrome ($n = 1$), irritable bowel syndrome ($n = 1$), sleep issues ($n = 2$), and possible arthritis ($n = 1$). All but one participant ($n = 5$) reported using at least one medication regularly.

Informants. Eligible informants were partners, family members, or close friends of individuals in the MCI group who 1) spent six to ten hours per week with them, 2) were willing to provide independent reports of MCI participants’ behavioural and cognitive functioning, and 3) had no premorbid or comorbid history of traumatic brain injury, stroke, or other potentially impairing condition.

Demographics. All informants in this study were opposite-sex spouses of participants with MCI ($n = 6$; women $n = 3$, men $n = 3$) ranging in age from 63 years to 74 years ($M =$

69.33, $SD = 4.72$). Informants were generally similar in age to their MCI participant counterparts, though slightly older on average ($M = 1.67$ years difference, $SD = 2.66$ years difference). All informants spoke English as a first language, and reported similar ethnicities (Caucasian or of Western European descent) and similar levels of education ($M = 14.33$, $SD = 1.67$) to participants with MCI. No informants had received a diagnosis of dementia or had been diagnosed with any degree or specific type of cognitive impairment. Surpassing the minimum cut-off of six hours of contact per week with the MCI participant, informants reported spending the majority of their time during the week with their MCI counterpart/spouse ($M = 144.50$ hours, $SD = 20.35$ hours).

Measures and materials. As informant reports were intended only to corroborate individuals with MCI's reports of their functioning, those measures related to corroborating diagnosis were administered to both groups. However, due to the different roles of individuals with MCI and informants in this study, and due to the primary interest on the emotional experiences of individuals with MCI, several other measures did differ between the groups (see Table 3 for a summary).

Individuals with MCI.

Telephone screening. A telephone screening questionnaire was designed expressly for use in this study with the principal aims of corroborating an existing MCI diagnosis and collecting demographic information. Screening items addressed sociodemographic variables (i.e. age, sex, ethnicity, level of education), health information (i.e. number and nature of medications, history of neurological trauma, family history of psychiatric illness), and diagnostic information (i.e. source, years since, and nature of diagnosis). Screening items were derived, in part, from the Memory and Aging Telephone Screen (MATS) (Rabin et al., 2007); however,

additional items pertaining to MCI diagnosis and concern regarding decline were added in order to determine whether current criteria were met (Albert et al., 2011). Moreover, a number of items from the MATS were excluded from the screening for the sake of concision and relevance to the study question and procedures. The telephone screening form is provided in appendix A.

Table 3

Data collection schedule

Day: Focus	MCI Group	Informants
Day 0: Telephone Screening	Telephone Screening	
Day 1: Measures	Lawton-Brody IADL Scale MMSE-2:SV DRS-2 ECog AMAS-E GDS, short form TCSC:2	Demographics questionnaire MCI questionnaire Lawton-Brody IADL Scale* ECog* AMAS-E GDS, short form
Day 2: Interview	Interview	
Day 3: Member Check	Member Check	

Note: Items marked with an asterisk () are completed by informants, but with respect to the experience of their respective MCI participants, not the informants themselves.*

Lawton-Brody Instrumental Activities of Daily Living (IADL) Scale (Lawton & Brody, 1969). This eight-item scale provides insight into the ability of older adults to complete common daily activities independently and is arguably the most widely used screening tool for determining functional impairment in rehabilitation settings. The Lawton-Brody IADL Scale asks individuals to indicate the extent to which they can independently complete common activities such as shopping, using the telephone, and banking. As individuals with MCI are largely functionally intact by definition – and those who have progressed to dementia are not –

the Lawton-Brody IADL Scale provides a gross measure of the veracity of MCI diagnosis by manner of excluding persons with dementia. This measure has been found to have a high inter-rater reliability with other measures of functional ability, such as the Physical Self-Maintenance Scale ($r = .85$) and significant correlations with the Behavior and Adjustment rating scales, the Physical Status scales, and the Mental Status Questionnaire (Hokoishi et al., 2001).

Mini-Mental State Examination, 2nd Edition Standard Version (MMSE-2:SV) (Folstein, Folstein, White, & Messer, 2010). The MMSE-2:SV is a commonly used dementia screening tool used by practitioners in various disciplines, including psychology and medicine. As a screening tool, the goal of the MMSE-2:SV is to detect various types of cognitive impairment rather than to provide any particular diagnosis. Therefore, this measure provides an indication of the degree of impairment (none, mild, severe), rather than a clinical profile *per se*. The MMSE-2:SV has been shown to have high internal consistency (.36 to .57 for normative samples, .66 to .79 for dementia samples) and test-retest reliability (.79 to .98).

Dementia Rating Scale, Second Edition (DRS-2) (Jurica, Leitten, & Mattis, 2001). The DRS-2 is a standard dementia screening tool for older adults and has been used extensively with MCI samples. The DRS-2 is intended for individuals with cognitive impairment aged 56 to 105 years. It consists of five subscales that provide information on specific cognitive domains, including attention, memory, initiation/perseveration, construction, and conceptualization. The DRS-2 takes approximately 15 to 30 minutes to complete, making it a suitable choice for cognitively compromised individuals who may fatigue more quickly. The DRS-2 is highly convergent with other well-established mental status exams (MMSE: $r = .82$) and has high test-retest reliability ($r = .97$ for total scores). The inclusion of the DRS-2 provides the dual benefits

of a cognitive screening tool that is relatively comprehensive, as well as whose results are readily accepted and easily understood by clinicians across disciplines.

Measurement of Everyday Cognition (ECog) (Tomaszewski Farias et al., 2008). The ECog is a 39-item scale measuring perceptions of everyday cognitive ability in relation to same-age others across six domains, including memory, language, visuospatial ability, planning, organization and divided attention. Raters are asked to indicate the extent to which they agree with statements on a 5-point Likert scale, with response options ranging from “usually worse than other people” to “usually better than other people”. A strength of the ECog is that self- and informant-report forms are identical, allowing for easy comparison between raters. The ECog has excellent test-retest reliability ($r = .82$) as well as strong convergent and discriminative validity when compared to other measures (Tomaszewski Farias et al., 2011). Specific to the current study, the ECog has not only been shown to reliably discriminate between normally aging, MCI, and demented samples, but also between amnesic MCI and multi-domain MCI (Tomaszewski Farias et al., 2008).

Adult Manifest Anxiety Scale, elderly version (AMAS-E) (Reynolds, Richmond, & Lowe, 2003). The AMAS-E is comprised of 44 items and measures anxiety in individuals aged 60 years and above. The scale includes several subscales designed specifically for this population, including “worry/oversensitivity”, “physiological anxiety”, and “fear of aging.” Further, the AMAS-E also contains a lie (i.e., impression management) scale to assess the presence, degree, and nature of potential response biases. The AMAS-E was standardized on a sample of 636 men and women approximating US census data in terms of regional representation. The AMAS-E self-report takes approximately 10 minutes to complete, which may help to prevent undue fatigue in older adults with MCI. The AMAS-E has been found to be temporally stable over a three-

week period ($r = .74$ to $.89$), suggesting that it is a good indicator of longer-term or trait-level anxious mentation and behaviour and not unduly affected by day-to-day mood perturbations. Further, the AMAS-E subscales have been found to have moderate to good correlation ($r = .28$ to $.67$) with other established anxiety measures (Lowe & Raad, 2006) and to be invariant with gender (Lowe & Reynolds, 2006).

Geriatric Depression Scale (GDS), short form (Sheikh & Yesavage, 1986). The GDS is a self-report depression scale designed specifically to address the unique presentation of depression in older adults. As physical symptoms of depression are not as salient with this age group, the GDS focuses primarily on cognitive-emotional symptoms of depression. In a recent study by Imai et al. (2014), it was shown that the GDS has predictive validity in terms of quality of life, independent activities of daily living, and depressive mood. The GDS has been shown to have a Cronbach's alpha of $.90$ with elderly populations and has been used with individuals with cognitive impairment (i.e., stroke). The GDS short form consists of the 15 most valid items from the long form and is considered the optimal choice for those with mild cognitive impairment or others who are easily fatigued. The GDS short form takes approximately 5 to 7 minutes to complete.

Tennessee Self-Concept Scale, Second Edition (TSCS:2), adult form (Fitts & Warren, 1996). The TSCS:2 is a widely-used self-report measure of self concept across the lifespan. This measure provides information on how individuals view themselves in several domains, including physical, moral, personal, family, and occupational areas. Further, the TSCS:2 offers supplementary scores, such as sense of identity and satisfaction, and validity scores indicating faking good or self-criticism to name a few. The TSCS:2 was standardized on a sample of 3,000 people from 7 to 90 years of age. The TSCS:2 consists of 82 items and takes approximately 10 to

20 minutes to complete. Although the TSCS:2 was not designed with cognitive impairment in mind, it has been used previously in studies of MCI and early dementia (Naylor & Clare, 2008).

Interview. A semi-structured interview was created for use in this study. The questions for this interview were adapted to better apply to MCI from the Transition Interview for Person's with Alzheimer's Disease (TIPAD) (MacQuarrie, 2001). The interview consists of four main questions: 1) how has MCI affected your life?; 2) what does MCI mean to you?; 3) how has MCI affected your relationships?; and 4) how has MCI affected your goals for the future?. The aim of these questions is to allow for a deeper exploration of various emotional experiences related to MCI, various aspects of individuals' lives and self-conceptions, and various potentially grief-inducing role transitions. Care was taken not to reference grief directly in order to avoid unjustifiably imposing meaning onto individuals' experiences. A variant of this interview focused on retirement was presented to pilot study participants in order to gauge the effectiveness of questions in eliciting discussion, and to confirm that the format and timing were suitable for use with MCI participants.

Informants.

Demographics questionnaire. A demographics questionnaire was created to collect informants' demographic information and determine their eligibility for the study. Items pertained to informant age, education level, and health status (e.g. whether they have a diagnosis of MCI or dementia) (see appendix B).

MCI questionnaire. The MCI questionnaire was an author-created measure including several items intended to corroborate individuals with MCI's provision of a diagnosis and physical health status. Further, the MCI questionnaire contained additional items regarding

informants' perceptions of changes in individuals with MCI's personalities and cognitive/behavioural functioning (see appendix B).

Lawton-Brody Instrumental Activities of Daily Living (IADL) Scale (Lawton & Brody, 1969). This measure was identical to that administered to individuals with MCI; however, rather than providing a self-report, informants rated the functional ability and independence of their MCI counterparts. The goal of this exercise was to determine whether there was agreement regarding MCI participants' functional ability and to corroborate MCI diagnosis by means of ruling out significant functional impairment that would more likely be associated with dementia (Albert et al., 2011).

Measurement of Everyday Cognition (ECog) (Tomaszewski Farias et al., 2008). The ECog administered to informants was identical to that administered to individuals with MCI; however, informants were asked to rate their concern regarding MCI participants' abilities rather than their own. Once again, this measure was employed to ensure that the criterion that either oneself or an informed other was concerned about an individual with MCI's decline was met.

Adult Manifest Anxiety Scale, elderly version (AMAS-E) (Reynolds, Richmond, & Lowe, 2003). The AMAS-E administered to informants was identical to that administered to individuals with MCI. It has been shown that the magnitude of impairment reported by informants can often be coloured by informants' own mental health (Nygaard, Naik, & Geitung, 2009). Therefore, the value of administering this measure to informants was to identify any characteristics that may inflate or otherwise affect their reports of individuals with MCI's impairment.

Geriatric Depression Scale (GDS), short form (Sheikh & Yesavage, 1986). The GDS administered to informants was identical to that administered to individuals with MCI. As with anxiety (above), it has been shown that depressed individuals endorse specific cognitive

distortions that may affect the veracity of their report (Nygaard et al., 2009). Therefore, the goal of administering this measure to informants was to identify the likelihood of cognitive distortions or emotional distress that could potentially affect their reports of MCI participants' impairment.

Qualitative approach: Interpretive description. Though psychological research often defaults to quantitative standardized methods in favour of generalizability, replicability and predictive power, experiences like grief, that are subject to and contingent on individual interpretations, are not well-addressed by such approaches. Quantitative approaches subscribe to a post-positivist epistemology, which assumes that there is an objective truth that may be arrived at through experimentation and the application of scientific method. While valuable for the investigation of many phenomena, this epistemological claim of objective truth cannot be easily applied to experiences embedded in and defined by personal meaning. Qualitative methods, on the other hand, provide a more diverse array of epistemologies, including “constructivist/interpretivist”, which claims that truth is contextual and (socially) created or negotiated. While this epistemological stance may suit the topic of grief better than traditional post-positivist positions, it is susceptible to providing results that are non-replicable or generalizable; naturally, this presents difficulty for those attempting to apply research outcomes to clinical populations. This risk may be especially salient for exploratory research pertaining to issues like intrapersonal grief that are not highly recognized and, therefore, do not have a robust knowledge base against which to compare new findings and build further understanding.

Interpretive description (ID) is a noncategorical qualitative approach conceived expressly for use in applied health care fields (Thorne, Kirkham, & O'Flynn-Magee, 2004). The aim of ID is to describe the experiential aspects of health (adversities) in order to provide a more contextual understanding of clinical phenomena and inform future health practices and decisions (Thorne,

2008). A successful ID should provide a coherent description that identifies common themes, as well as the range of individual variations within themes, with the goal of shifting the existing clinical view of an issue rather than creating a new understanding from the ground up (Thorne et al., 2004). Further, by identifying greater themes that permeate a given sample and connect the experiences of individuals within said sample, ID allows for some degree of replicability and generalizability; although the particular experiences of each individual may be unique, the themes derived from an ID may be applied more broadly. It is granted that the exact structure and content of themes are liable to differ according to researcher (due to ID's interpretivist nature), however, through iterative sampling, theoretical/purposive sampling, and pursuing saturation (the point at which further sampling does not provide novel information), ID is likely to provide a robust and dependable thematic structure.

Interpretive description is not prescriptive by nature, and the actual practice of ID depends on one's field of study, subject of study, and research questions. The current study relied on interviews as the primary source of information, though quantitative measures and informant reports were also used to support the interview data. Much like in grounded theory, elements of data collection and analysis were conducted simultaneously and in concert with one another through a process of constant comparison within and across levels of data (within participant and across cases). To the extent that collected data deviated from the predetermined framework of grief, our current understanding was limited and new perspectives were identified.

Procedures. Data collection activities spanned several days (see Table 3 for a list of activities per day).

Day 0: Telephone screening. Upon receiving referrals from local clinicians, the author contacted participants to arrange a 30-minute telephone screening. Participants were informed

that this screening was to determine their eligibility to participate in the study proper, the goal of which was to understand the experience of MCI from the first-person perspective. If interested, the telephone screening commenced on a subsequent day. Following completion of the screening, eligible participants were informed of the study schedule/activities and asked to attend an initial administration session with an informant of their choosing.

Day 1: Measures. Upon obtaining consent from MCI participants and informants, each were placed in separate rooms within the author's supervisor's lab space. Informants were administered a packet with several paper-and-pencil measures immediately. In contrast, as the informant began filling their measures, the author administered the MMSE-2:SV and the DRS-2 to MCI participants. Following completion of these measures, MCI participants, too, were provided a packet with the remaining paper-and-pencil measures to complete. Upon completion of their respective measures, informants and MCI participants were thanked for their participation and informed that their responses would be reviewed to ensure that the eligibility requirements for further participation (i.e. MMSE-2:SV and DRS-2 scores indicating that individuals are not demented) were met. Participants were provided a list of local community supports should they feel distressed and were reimbursed for their parking cost. Participants' responses were reviewed and all eligible participants were contacted to arrange an interview date within three days of their participation.

Day 2: Interview. The author fully reviewed the consent agreement with MCI participants. A one-hour interview duration was predetermined in order to prevent undue fatigue for participants and to minimize attrition due to inconvenience or time burden. Interviews followed a semi-structured format led by four primary questions regarding participants' experiences of intrapersonal change, interpersonal change, their understanding of MCI, and

changes to their future goals or goal setting practices (appendix B). Notes regarding interview content and observations were kept during each interview and each interview was audio recorded to ensure accurate transcription. Upon completion of this interview, the session was concluded and participants were thanked for their participation.

Day 3: Member check. After interview notes and transcriptions were compiled, reviewed, and summarized, individuals with MCI were contacted to arrange a follow-up telephone conversation. Consenting participants were contacted and presented a brief summary of their interview data with the aim of ensuring that their experiences were faithfully represented and well-understood. Telephone interviews were limited to approximately one hour to prevent excessive fatigue for participants and were conducted in a private room over speakerphone to allow for audio recording. Participants were asked to clarify and correct any information that they felt was incomplete or inaccurate. Aspects of their experience(s) that were not clear during the initial interview were also discussed further during the course of this conversation. Finally, following review of the summarized initial interview data, the author asked participants to comment on whether they experienced a sense of loss or grief in relation to themselves as a result of MCI. In order to further contextualize their responses to this query, some participants were also asked to provide a definition of grief in their own words.

Analyses

Measures.

Statistical comparisons between participants were considered untenable due to the low statistical power any comparisons on this small a sample would provide. Instead, the quantitative measures employed in this study were intended to demonstrate eligibility for participation (MMSE-2:SV, DRS-2, Lawton-Brody IADL Scale, ECog), as well as to characterize the sample

on key constructs of interest (i.e., individual difference measures: GDS-Short, AMAS-E, TSCS:2). Quantitative measures were scored according to age- and education-appropriate norms, where available. Individual difference measures were analyzed according to whole scores (i.e. means and standard deviations). Informant reports were compared against MCI individuals' self-reports to determine the degree of convergence between the two accounts. All quantitative data were entered into a data frame and results were calculated using SPSS Statistics Version 22.

Interview and member check.

All recorded qualitative interview data (in-person and telephone) were transcribed verbatim by trained undergraduate research assistants. Following this, the author checked each transcript against their respective audio recording for accuracy and formatted the text to maximize clarity. Data for each participant were then reread, examined, and reviewed thoroughly. The author coded the data inclusively, making special effort to identify data that disconfirmed the initial conceptual frameworks of loss and grief. Coded data were then grouped according conceptual categories. A constant comparative process (Thorne, 2008) was employed to compare participant data within and between interviews, as well as to compare data between participants. As more robust categories emerged, underlying relational themes were identified and labeled. Said categories and themes were then compared to extant literature on grief and loss to determine the extent to which these conceptual frameworks were relevant to participants' reported experiences. This coding and categorization/theming process was repeated as new information (participants) became available and as further theoretical knowledge was gained.

Procedural rigour. The determination of procedural rigour in qualitative research is based on different criteria and assumptions than those often used to determine the validity and reliability of quantitative studies. Lincoln and Guba (1985) describe the goal of pursuing

qualitative rigour as achieving “trustworthiness”, which in turn is comprised of credibility (confidence in the “truth” of results), transferability (demonstrating the generalizability of results to other contexts), dependability (replicability of results), and confirmability (the degree to which the results are derived from the data and are independent from author biases and assumptions). As ID adheres to an interpretivist epistemology, confirmability was only partially relevant to this study; in an interpretivist epistemology, author experiences, assumptions and biases are considered part of the data, though should not overshadow or unduly influence the study outcomes. Likewise, dependability may not be strongly applicable to this study given its exploratory and small-scale nature, though expansion on this initial exploration may provide more robust themes that have greater potential for replicability.

The techniques selected for use in this study were an amalgam of those suggested by Lincon and Guba (1985), as well as those recommended by Creswell and Miller (2000) for both post-positivist paradigms and interpretivist. Given the applied nature of the research topic (MCI) and the qualitative approach (ID), the author felt it prudent to include those techniques specific to the interpretivist lens used in this study, but also to utilize those validation techniques that may be more readily comprehensible and/or acceptable to the predominantly post-positively oriented target audience of medical and mental health professionals.

Member check. The most apparent means by which rigour was achieved was through member checking. The author compiled a summary of the main points provided by each participant during their initial interview (day 2) and reviewed this summary with each individual over the phone (day 3). Participants were encouraged to provide clarification or correction as necessary. Further, the author used this opportunity to investigate unclear aspects of participants’ initial recounts further. Following this review and check, participants were asked whether they

felt the concept of grief applied to their experience(s) with MCI. Although this is not a typical approach to member checking, Thorne (2008) recommends presenting the initial conceptual framework directly in order to elicit feedback about participants' perceptions of the degree of fit with their experiences. Care was taken to present this grief framework as a possibility only after participants' initial interview information had been fully summarized and the review completed.

While both Lincoln and Guba (1985) and Creswell and Miller (2000) state that member checking is a powerful method by which to establish credibility, Creswell and Miller (2000) consider member checking as a particularly post-positivist method due to common criticisms that the practice relies upon an assumption of objective and fixed reality (Angen, 2000). One argument against member checking in interpretivist studies is that participants' interpretations may differ from authors' and that the act of checking may imply that one interpretation is less valid than another. Although this is a fair concern, the author does not feel this was a major issue for this study as the details provided in the summary were derived directly from the interview data and further interpretation was not provided to the participant. This was due to a conscious decision to limit the member check to the manifest content of individuals' experiences rather than an interpretation of the underlying meaning. Another argument against the use of member checking in interpretivist research is that participants may not have an accurate recollection of what they shared previously. This is true, though the author did not feel that this impacted the member check or study negatively. Participants were asked to comment on whether the summarized information was an accurate summary of their experiences; they were not asked to verify what had been shared previously. Therefore, all participants used the opportunity to consider unremembered information carefully and, at times, felt comfortable sharing that this information was no longer relevant to their situation. Their feedback did not rely on their

memory of the initial interview and, where inconsistent with initial interview data, provided further insight into their experiences and development. Overall, this member check did not undermine the interpretivist epistemology of this study, but rather provided more comprehensive and “thicker” data to interpret.

Prolonged engagement. Typically, prolonged engagement refers to anthropological fieldwork; however, at its core it refers simply to spending enough time in contact with an individual or issue to develop rapport and understanding. Prolonged engagement is another means by which to achieve credibility (Lincoln & Guba, 1985), particularly in interpretivist research (Creswell & Miller, 2000). Although naturalistic observation and immersion were not part of this study, the author did develop strong rapport with the study participants. Participants participated in two hour-long telephone interviews, one hour-long in-person interview, and one face-to-face assessment session with the author. Further, at each session, participants debriefed and discussed their concerns and questions. Although this falls far short of the prolonged engagement involved in ethnographic studies, the author did have opportunity to build ample trust and rapport over the course of interactions with participants that allowed for frank and honest disclosure.

Triangulation. Triangulation is another method by which credibility may be established. In line with this study’s interpretivist epistemological stance, no aspects of participants’ experiences were triangulated with external data sources. However, informants were used to corroborate individuals with MCI’s reports of whether they had or had not received a diagnosis of MCI and their current functional and cognitive difficulties. With respect to the interpretivist stance, it was necessary to determine that participants had indeed received a diagnosis of MCI to ensure that the appropriate population was being sampled for this study’s purposes. Further

corroboration of diagnosis was not sought, however, each participant was referred to the study by his or her diagnosing clinician.

Negative case analysis. Negative case analysis is a method of establishing credibility that consists of searching data for items/information that may disconfirm or contradict one's initial expectations or assumptions. This is especially important in interpretivist approaches (Creswell & Miller, 2000), particularly those founded on a predetermined framework such as ID.

Considering the natural tendency to seek and find instances that corroborate one's preexisting conceptions, performing a deliberate search for the inverse is a crucial step in ensuring that one's interpretations emerge from the data rather than purely from one's own assumptions. During the coding/theming process, the researcher ensured that as much, if not more, attention was paid to the data that did not correspond with the initial conceptual framework of grief and loss. These contradicting codes, categories, and themes were consequently included in the final results of the study as important and unique aspects of the MCI experience.

Audit trail. An audit trail is considered an important means to establish confirmability (Lincoln & Guba, 1985) in a post-positivist paradigm (Creswell & Miller, 2000). This study was interpretivist in nature and, therefore, not replicable in the traditional (objective) sense, however, an audit trail was created in service of maintaining methodological transparency. Notes were prepared throughout phone and in-person interviews, measures were anonymized and kept on record, audio recordings were retained, a reflexive journal was kept and updated throughout the process, and a log was prepared outlining the dates and natures of each session with participants. Although it is unlikely that the results of this study will be entirely replicable due to their subjective and interpretive nature, the availability of an audit trail may make clearer the process and help to establish the systematic nature of this inquiry.

Reflexivity. Lincoln and Guba (1985) list author reflexivity as a method by which to establish confirmability and Creswell and Miller (2000) recommend it primarily for those conducting critical research, however, reflexivity is an important aspect of any research undertaking. Although an interpretivist author's own experiences influence the final outcome of any study, it is important that the outcomes emerge from and reflect the participants' data faithfully. Reflexivity allows authors to gauge the level of rapport and dynamic of interviews, as well as affords insight into one's own assumptions and biases that may influence the study outcomes. In other words, researcher reflexivity allows qualitative researchers to not only be more effective in their engagements, but also more transparent with external audiences about how interpretations and results were generated. Throughout the process of this study, the author maintained a reflexive journal that was updated with the author's personal impressions and the products of his introspection following each interaction with clients and each wave of coding.

Chapter 4

Results

Eligibility Measures

Although each individual accepted into this study had received a diagnosis of MCI, the time since diagnosis varied and, for several, the actual time since the onset of their difficulties was unclear. Given this range of experiences and the potentially progressive nature of MCI, it was important that MCI participants and their informants complete several measures to ensure that current MCI criteria (Albert et al., 2011) were still met.

Corroboration of diagnosis. Participants with MCI were administered the MMSE-2 together with the DRS-2 to determine whether they met criteria for dementia (see Table 4). Total impairment scores on the MMSE-2 ranged from 21 to 27, with a mean score of $M = 24.67$, $SD = 2.58$. The MMSE-2 authors (Folstein et al., 2010) state that scores ranging from 18 to 24 indicate a mild level of impairment, though it is not stipulated whether this usage of “mild” corresponds to MCI. Moreover, studies using the first edition of the MMSE demonstrate that the measure is a good indicator of cognitive impairment in highly educated samples when the cutoff score was set to 27 or below (sensitivity = .69, specificity = .91) (O’Bryant et al., 2008). Based on these criteria, this sample was not considered demented though may be reasonably considered to fall within the mild to moderately cognitively impaired range.

The DRS:2 provides a score of total cognitive impairment, as well as an indication of impairment in various dimensions of cognitive functioning. All scaled scores were normed according to age-corrected MOANS norms. Individuals with MCI were moderately to severely impaired in memory ($M = 3.83$, $SD = 2.71$), mildly impaired in initiation/perseveration ($M = 7.33$, $SD = 3.88$), below average in construction ($M = 9.50$, $SD = 1.22$), below average to

average in conceptualization ($M = 10.67$, $SD = 1.21$), and average in attention ($M = 12.00$, $SD = 1.55$). Overall, MCI participants were mildly impaired (total score: $M = 6.50$, $SD = 2.59$), though fell into the moderately to mildly impaired range when scores were corrected for education in addition to age ($M = 5.50$, $SD = 2.43$).

Table 4

Summary of MMSE-2 and DRS-2 scores

Measure/Domain Score	Mean (SD)	Descriptor
MMSE-2		
Total	24.67 (2.58)	Mildly – moderately impaired
DRS-2		
Memory	3.83 (2.71)	Moderately – severely impaired
Initiation/Perseveration	7.33 (3.88)	Mildly impaired
Construction	9.50 (1.22)	Below average
Conceptualization	10.67 (1.21)	Below average
Attention	12.00 (1.55)	Average
Total	5.50 (2.43)	Mildly impaired

Lawton-Brody Instrumental Activities of Daily Living scale. The Lawton-Brody IADL scale was administered to individuals with MCI as a self-report and to informants as a report on the observed abilities of individuals with MCI. Scores garnered through self- and informant reports were in line with one another and indicated little to no impairment in IADLs (self: $M = 7.83$, $SD = .41$; informant: $M = 7.67$, $SD = .82$).

Measurement of Everyday Cognition. The ECog was administered in order to determine whether individuals with MCI or their informants recognized (were concerned about) impairment or decline in MCI participants' cognitive abilities (see Table 5). In regard to memory, individuals with MCI indicated that, on average, they perceived their performance as ranging from "usually worse than other people" to "sometimes worse than other people" ($M = 13.33$, $SD = 5.12$). Informants, on the other hand, provided a higher score of MCI participants' memory abilities, indicating that they perform "sometimes worse than other people" to "similar to other people" ($M = 21.17$, $SD = 8.47$). When asked about planning ability, individuals with MCI indicated that they perform "similar to other people" ($M = 15.20$, $SD = 1.10$). Informants rated individuals with MCI's planning abilities similarly, though with considerably more variation ($M = 17.33$, $SD = 5.78$). In regards to organizational ability, individuals with MCI endorsed that they perform "usually worse than other people" on average ($M = 17.50$, $SD = 4.80$), whereas informants were more likely to endorse that individuals with MCI perform "similar to other people" ($M = 19.33$, $SD = 8.29$). Finally, when asked to rate themselves on their performance on abilities requiring divided attention, participants with MCI indicated that they perform "sometimes worse than other people" ($M = 8.83$, $SD = 2.04$); informants, however, tended to rate individuals with MCI's divided attention ability as being nearer to "similar to other people" ($M = 11.33$, $SD = 4.59$). Taken together, these results bear out that there was some concern or recognition of impaired functioning, and that this concern was more highly endorsed by individuals with MCI themselves. Also notable, was that there appeared to be more variation among informant reports than self-reports in general.

Table 5

Summary of ECog ratings of individuals with MCI

ECog Domain	Mean (SD)	Descriptor
Self-report		
Memory	13.33 (5.12)	Usually worse than other people – Sometimes worse than other people
Planning	15.20 (1.10)	Similar to other people
Organization	17.50 (4.80)	Usually worse than other people
Divided attention	8.83 (2.04)	Sometimes worse than other people
Informant-report		
Memory	21.17 (8.47)	Sometimes worse than other people – Similar to other people
Planning	17.33 (5.78)	Similar to other people
Organization	19.33 (8.29)	Similar to other people
Divided attention	11.33 (4.59)	Similar to other people

Descriptive Measures

Individuals with MCI.

Adult Manifest Anxiety Scale, elderly version. The AMAS-E was administered to MCI participants to not only determine whether there was an anxiety experience associated with MCI, but also to determine whether these individuals' reports were likely to be affected by response biases due to anxiety, avoidance or defensiveness. All raw scores were converted to T-scores and compared to manual-provided norms for this analysis (see Table 6). Scores on the lie (impression management) scale fell within the mildly elevated range ($M = 55.83$, $SD = 6.71$), suggesting that

the profiles were valid (interpretable) overall, though this sample of MCI participants may have been somewhat morally rigid, naïve, or in a minor degree of denial. Total anxiety is divided into several domains, including worry/oversensitivity, physiological anxiety, and fear of aging. In regard to worry/oversensitivity, MCI participants as a whole scored within the expected range ($M = 45.17$); however, there was a considerable range between responses ($SD = 21.64$). Further investigation showed that while three MCI participants did indeed fall within the expected range, half the sample ($n = 3$) scored within the mildly elevated range, which suggested that these individuals may have been common worriers or mildly hypersensitive as a rule. With respect to physiological anxiety, the sample scored within the mildly elevated range, but once again with a considerable range ($M = 54.00$, $SD = 10.58$). Fear of aging showed a similar pattern in that the group scored within the expected margin ($M = 54.00$), but with a large range ($SD = 10.30$). Finally, overall, individuals with MCI showed a mildly elevated total anxiety score ($M = 54.33$, $SD = 8.91$), suggesting that they experienced an expected to mildly elevated level of anxiety for their age group; however, given the wide range and variety of anxiety domain endorsement, it was difficult to characterize the group as a whole based on manifest anxiety levels.

Table 6

Summary of AMAS-E scores

AMAS-E Subscale	Mean (SD)	Descriptor
Lie Scale	55.83 (6.71)	Mildly elevated (Probably valid)
Worry/Sensitivity	45.17 (21.64)	Expected
Physiological anxiety	54.00 (10.58)	Mildly elevated
Fear of aging	54.00 (10.30)	Expected
Total anxiety	54.33 (8.91)	Expected – mildly elevated

Geriatric Depression Scale – short form. Scores on the GDS were totaled and checked against a cut-off score to indicate the likelihood of depression. MCI participants as a whole exceeded the cut-off score (5), suggesting that they experienced some degree of depression ($M = 5.67$, $SD = 3.14$); however, this may be relatively mild given the small margin by which the overall mean score exceeded the cut-off.

Tennessee Self-Concept Scale, Second Edition. The TSCS:2 provides several summary scores of self-concept, as well as scores on specific domains of self-concept. Raw scores were converted to T-scores and compared to manual-provided norms for this analysis. The TSCS:2 provides three validity scales to help determine potential response bias. There was no evidence of inconsistent responding ($M = 48.00$, $SD = 10.28$), suggesting that participants were answering thoughtfully. However, scores on the self-criticism scale tended to be lower ($M = 38.50$, $SD = 10.91$). Three participants in particular scored low on this scale, indicating a tendency to self-enhance. On the other hand, scores on the final validity scale, faking good, fell within the normal range ($M = 53.33$, $SD = 8.80$). Scores on response distribution, a measure of certainty about the way one views oneself, fell within the normal range as well ($M = 46.00$, $SD = 6.60$). Taken together these validity scales suggest that the majority of the profiles were valid. Unfortunately, the combination of one participant's low self-criticism score and extremely elevated faking good score indicated that this profile was likely invalid. Further, another participant's profile was incomplete making it impossible to calculate the majority of subscale scores and the total profile score. Therefore, these participants' profiles were removed and all subsequent scale analyses were performed only on the remaining four complete, valid profiles. Overall, the sample demonstrated a flat profile, indicating no notable disturbances or strengths on any of the self-concept scales: Physical self-concept ($M = 47.75$, $SD = 5.56$), moral self-concept ($M = 52.75$,

$SD = 6.08$), personal self-concept ($M = 48.00$, $SD = 6.22$), family self-concept ($M = 52.50$, $SD = 4.80$), social self-concept ($M = 46.00$, $SD = 3.37$), academic/work self-concept ($M = 48.50$, $SD = 7.94$). The summary scores were relatively flat as well. Total self-concept for this group was within the normal range ($M = 49.50$, $SD = 5.51$), indicating a healthy self-concept and a reasonable level of self-esteem. Conflict, the extent to which individuals assert themselves via agreement with positive statements or negation of negative statements, was also within the normal range but bordered on high ($M = 58.00$, $SD = 6.83$). This suggests that MCI participants tended to define themselves as generally competent and that they felt they have worth. Finally, the supplementary scores were also found to fall within the normal range: Identity ($M = 45.25$, $SD = 4.50$), satisfaction ($M = 52.25$, $SD = 5.25$), behaviour ($M = 48.75$, $SD = 5.12$). Taken together the self-concept scores, summary scores, and supplementary scores indicated that this sample of MCI participants were reasonably well adjusted, functional, and had an intact sense of self. That said, it is possible that the two participants excluded from these analyses may have shown a different, more distressed pattern, had their profiles been valid and interpretable.

Informants.

Adult Manifest Anxiety Scale, elderly version. The purpose of administering the AMAS-E to informants was to determine whether their reports of individuals with MCI's impairments could be expected to be influenced by their own anxiety and associated response bias. All raw scores were converted to T-scores and compared to manual-provided norms for this analysis. Scores on the lie (impression management) scale were mildly elevated ($M = 56.00$, $SD = 9.80$), indicating a tendency to be rigid, moralistic, and possibly naïve or in some degree of denial. Scores on both worry/oversensitivity ($M = 37.50$, $SD = 6.56$) and physiological anxiety ($M = 40.00$, $SD = 7.12$) fell within the low range, indicating that informants were generally well-

adjusted individuals with appropriate coping abilities and few worries overall. Scores on fear of aging were slightly elevated by comparison, but still within the expected range for this age group ($M = 47.25$, $SD = 2.87$). Overall, the total anxiety score for informants was low ($M = 38.5$, $SD = 6.14$), indicating this sample was confident, centred, and that report of MCI participants' impairment was unlikely to be inflated due to informant anxiety.

Geriatric Depression Scale – short form. The GDS was administered to informants for similar reasons as the AMAS-E. Scores on the GDS were totaled and checked against a cut-off score (5) to indicate the likelihood of depression. Overall, informants scored uniformly low on depressive symptomology ($M = .83$, $SD = .98$).

Qualitative Themes

The qualitative interviews conducted with participants with MCI provided a diverse range of experiences of, concerns regarding, and reactions to MCI. Despite this, however, participants' recounted experiences were well summarized by six overarching and related themes: Uncertainty and ambiguity, changes to self and role, disenfranchisement and disconnection, primacy of MCI, emotional distress, and coping. Most themes, in turn, subsume several sub-themes (see Table 7). As the central construct of interest in this study, a theme of intrapersonal grief was explored as well, however, most participants did not explicitly endorse this experience. Consequently, this potential theme was not included in the thematic/relational structure that follows. Nevertheless, despite this lack of explicit support, various aspects of individuals' experiences indicated the presence/applicability of at least one extant grief construct. This is explored further in the sub-section entitled "grief" and the discussion.

Table 7

Summary of qualitative themes

Theme	Sub-themes	Example
Uncertainty and Ambiguity	The meaning of MCI	<i>"... I feel like I'm in one of those baskets where no one knows what it is there for – they're going to call it MCI... No one can really define it or say what it is."</i>
	Indeterminate prognosis	<i>"I have no idea what's going to happen."</i>
	Lack of information and direction	<i>"I mean, I've been diagnosed with it but, you know, what are the next steps?"</i>
Losses of Self and Roles	Perceived loss of self	<i>"... 'oh Jesus!... Now you've taken away... the most significant parts of me....'"</i>
	Loss of core competencies or characteristics	<i>"[MCI has] taken your security of doing things away. And your confidence of doing them, you don't have anymore."</i>
	Changes to social status or role	<i>"...I just had to retire for one thing, because I knew I wasn't – I knew that if I stayed much longer I probably would have a breakdown...."</i>
	MCI and mortality	<i>"Life is beautiful and I'm not going to be able to experience probably nine-tenths of it, you know."</i>
Disenfranchisement and Disconnection	Minimization of concerns	<i>"...nobody will listen to me!... you try to tell them, 'no. I think there's something going on.' 'No, no there isn't. You're fine.' So it's like nobody listens to you!"</i>
	Isolation and withdrawal	<i>"...and inside I'm so frustrated with what's happening to me, and why I can't get it across, and why I have to hide it, which is what I'm doing from my family members..."</i>
	Keeping up appearances	<i>"I know it's not a joke. But I'll laugh with them and pretend..."</i>)

Primacy of MCI	--	<i>“Daily! It doesn't go away. It's there every day, every part of the day.”</i>
Emotional Distress	Depression and despair	<i>“...really, there's a deep river of sadness inside me.”</i>
	Fear and anxiety	<i>“I have a fear that it's Alzheimer's and I am going to be a terrible burden on my family, or end up in a home.”</i>
	Frustration and anger	<i>“Mad. Mad at myself. Just genuinely mad, because I can't do it as well as I did.”</i>
	Loss of control and resignation	<i>“And that's been my life.... I was in control of it, and I'm not anymore.”</i>
Coping	Acceptance versus resistance	<i>“I'm just not going to fold up and accept it. That's not going to happen. I won't allow myself to do that.”</i>
	Exercising control	<i>“We're doing everything proactively that we can; diet, exercising, and doing everything we can. So I don't think I'm leaving any stone unturned.”</i>
	Emotion regulation	<i>“I am so busy focusing on protecting myself from being depressed that I don't know if I am using all of my energy on that.”</i>
	Goal adjustment	<i>“We, you know, we can't go and do the things that we would have wanted to do now.”</i>

Uncertainty and ambiguity. Although individual opinions regarding the meaning of MCI differed, all individuals with MCI uniformly expressed confusion over what MCI is, its value as a diagnostic label, its implications for the future, and how best to address the issues it presents with scarce information and medical direction.

The meaning of MCI. Individuals with MCI demonstrated considerable diversity in their understanding of MCI. Where some had sought information and held views generally in line with current clinical knowledge, most had little formal understanding of MCI. Participants largely believed MCI to be pathological, though some felt that the deficits associated with MCI were more normative.

“I’m not that old, you know. If I was 80, I’d say ‘okay’, this is pretty well a consequence of that age, but this is too young.”

“It’s, just say, ‘that’s the way it is when you get older. Get used to it!’

Throughout each of these narratives, however, it was clear that individuals felt that the label of MCI did not add substantially to their understanding of their own condition. One participant felt that MCI as a diagnosis served little purpose other than to describe what his situation was not – in other terms, that MCI is a default diagnosis when other possibilities had been ruled out. Likewise, many shared that, despite receiving a diagnosis, they were uncertain of what physical and cognitive symptoms were associated with MCI versus other comorbid or preexisting issues.

“... I feel like I’m in one of those baskets where no one knows what it is there for – they’re going to call it MCI.... No one can really define it or say what it is.”

“I guess it’s just there’s [sic] things I just don’t understand well – whether it’s part and parcel of it....”

With that said, the label may have provided validation that individuals' perceived difficulties were not imagined as well as some, if slight, direction for follow up. What is more, one participant was thankful for the diagnosis as she felt it helped to distance her experience from that of Alzheimer's disease, which was particularly threatening for her; however, it should be noted that she interpreted her diagnosis of MCI as more of a description of a cognitive impairment that is mild than a syndrome as we currently understand it.

"I've been thankful for it, because people have started to have stopped talking about Alzheimer's..... 'it's just MCI, it's no big deal.'"

Indeterminate prognosis. A distinct, yet related sub-theme was that of uncertainty regarding outcome. Although all participants acknowledged the possibility of their cognitive function declining further into dementia, there was considerable uncertainty as to how much more decline one could expect, whether further decline was likely, or what the time frame of said decline might be.

"I have no idea what's going to happen."

"[If I don't intervene] I think it would get worse. I do."

Lack of information and direction. A concern frequently cited by all participants was a lack of information about MCI. While only one individual had made efforts to learn more about MCI independently, all participants felt frustrated that their medical service providers could not

provide clearer information about what to expect, what MCI might entail, or what could be done to prevent further decline.

“I mean, I’ve been diagnosed with it but, you know, what are the next steps?”

“...nobody can really explain it.... Doctors, no one can give you an answer.”

Due to this lack of direction and information, several participants held reservations about the validity of their diagnoses. Furthermore, some participants felt that MCI was uniquely difficult to cope with, as, in their view, it is a medical issue without any semblance of medical recourse.

“...it seems so much more onerous [than cancer] I don’t know how I can beat this really... whereas, with the other [cancer], it was radiation and drugs and all these other things that was [sic] given me by a third person.”

“[There] doesn’t seem to be any magic pill that you can take to make it go away....”

Given these concerns and the anxiety associated with them, several participants noted the lack of available resources and sought information directly from the interviewer. Indeed, for several, this study represented an opportunity to gain information about MCI that they felt was unavailable through other means.

“...do you believe I fit in that category? That I’m ‘mild’? I thought you might be a resource for that.”

Losses of self and roles. When asked explicitly, individuals with MCI were divided on whether they felt their identity had changed as a result of MCI, however, deeper exploration showed that this was perhaps due to the difficulty of defining one's identity or the component parts of self. Despite this abstruseness, however, it was clear that individuals did endorse a change to one's typical and expected self as a whole (though not necessarily a negative one), as well as changes to their core characteristics and social roles. Although it may be expected that these changes to the whole were a result of changes to individuals' defining features and roles, participants were unclear on which changes specifically contributed to this overall feeling of change. Therefore, perceived loss/change of (total) self, changes to core competencies or characteristics, and changes to social status or role are addressed as sub-themes at the same level. Although several of the following sub-themes may appear commensurate with grief experiences, grief was not explicitly reported and, thus, was not included in these accounts.

Perceived loss of self. Several individuals remarked that they had lost who they were previously, though they could not clearly isolate what moment or change in particular contributed to this loss. Instead, the loss of self was seen as an outcome of incremental changes over time in a variety of domains, including work roles, social perceptions, and competencies. This is not to say that individuals with MCI endorsed a "lack of self", but rather that their current self was not that which they had cultivated, identified with or to which they were accustomed.

"sometimes I feel like I'm not me anymore, that I got lost somewhere and a different person has taken me over."

"... it's not who I am – or was."

In most cases, the current “self” was seen as being inferior to the former as a result of the cognitive changes associated with MCI and consequences thereof though, in few cases, participants advocated that the shift was either value-neutral or positive and that the current “self” was merely a new form to which one was in the process of adapting.

“...this isn’t the man I want to be – and I keep using that phrase because this isn’t who I am, and losing that ability to be that person is really, ultimately, very frustrating for me.”

“... ‘oh Jesus!... now you’ve taken away... the most significant parts of me....’”

“Yeah, I’m not the same [me] I was before, but I’m not a worse person.”

It is, however, unclear whether this latter, more positive view was born of denial or a desire not to engage with negative emotions (this was a common response pattern throughout the proponent’s respective interviews and quantitative measures). Additionally, contrary to reports of change, some participants felt that they remained consistent in the most important aspects of themselves.

“I find myself saying the same things and having an outlook on life and at things that doesn’t really change too much... beliefs and values.”

Loss of core competencies or characteristics. A common theme throughout narratives was that of losing one’s core defining competencies or valued characteristics. Examples of these were reliability, diplomacy, control, social fluency, mood, and memory.

“All my life I have been very determined and I’ve set my score...I was in control of it and I’m not anymore. It’s horrible.”

“... that was one of my strongest pieces of my character: Being accountable.”

Many individuals remarked that their social roles and interactions, self-concepts and pride were deeply interwoven with these characteristics. It was, therefore, also common for participants to endorse a loss of confidence in their abilities and anxiety when engaging in affected activities.

“[MCI has] taken your security of doing things away. And your confidence of doing them, you don’t have anymore.”

Notably, one participant viewed this change as positive instead, as she viewed her previous social dominance as being a more negative trait. That said, this particular account may require more cautious interpretation as this participant demonstrated a stronger tendency toward denial (as per scores on her quantitative measures) and frequently avoided engaging with negative aspects of her experience during interviews.

“Now I’ve thrown that away, you see. I’m just a friendly person who cares about other people’s feelings and wants to live and let live.”

Changes to social status or roles. A pervasive result of individuals’ cognitive impairment was a change in social roles and status. For several, the consequences of MCI motivated their

decision to retire from work. Although, several participants cited their inability to maintain their usual performance standards as a reason for their decision, a motivating factor for all MCI-related retirement decisions was that participants' difficulties had become apparent to their colleagues and coworkers.

"... I just had to retire for one thing, because I knew I wasn't – I knew that if I stayed much longer I probably would have a breakdown...."

"... when it started being noticeable, my assistant sort of waved to me and made sort of movements with the fingers like, 'you've already said that.' That's... when I started to notice it...."

Role changes were not relegated to occupational settings, however. Most participants stated that they previously held somewhat of a leadership position in their social circles: Participants stated that they served as the collective memory for their group or family, that they led social interactions, or that they served as the facilitator in group discussions and conflicts. Invariably, participants stated that these positions had changed and that they had become less active contributors to social interactions overall.

"I'm not leading a conversation; I am a follower."

"... if my wife asks me a question about something... I used to be able to kind of explain how things happen... and now I can't get the words out...."

Although some adopted this less active role intentionally as a reaction to feeling silenced by their peers (see disenfranchisement and disconnection), most argued that their cognitive impairments served as an obstacle to engaging effectively.

“... [if others] change channels on me... now I’ve got to step back and rethink and think and focus in on that issue or theme or whatever just to get my thought process going.”

“I am trying to explain an answer [and] I get kind of frustrated and it’s almost getting to the point now where I would rather not talk.”

Overall, most participants felt that their current social role was less active and generally less fulfilling than their previous roles. One participant in particular stated that this role transition, from authority to observer, was especially difficult at those times where she adopted an authoritative position and found herself to be mistaken in her recollection. Likewise, several participants felt it particularly distressing when their memory deficits interfered with what they viewed as their familial roles or obligations.

“...she says, ‘no, Mom, that’s not what happened.’ And inside I’m sure that’s what happened.... [B]ut I don’t have the facts right.... I think what I’m saying is what happened, but usually it’s not. I get it wrong!”

“And then you feel the guilt because you can’t remember it. You feel frustration. You feel mad at yourself for, ‘why can’t you remember this? This was your Mom!’”

These role changes extended to the home as well. For example, one participant expressed that he had relinquished certain household responsibilities to his wife and that he expected to surrender more in the future. Contrary to this experience, another participant reported that her family members often did not allow her the opportunity to undertake household tasks due to a lack of confidence in her abilities. Although the context of the role transitions may differ (i.e. surrendering one's role voluntarily or being barred from participation by others), MCI was commonly associated with a surrendering of position, either voluntary or otherwise.

“... sometimes I get angry and someone who treats me as if I am not going to know what to do or I don't know what I'm doing.”

“... fiscally, you know, I'm very responsible... that's something that along the line I may have to turn over and say, 'you know, you be fiscally responsible for us.'”

On the other hand, not all participants viewed all role changes as negative. One participant reported that the shift to a more passive role had served her well and that the quality and number of her social engagements had increased as a result of her becoming less socially dominant. Other participants viewed their disengagement and role change with more equanimity, though this was often due to beliefs that MCI was a normative part of aging.

“I said, 'alright, I'll just go and I'll sit and I'll smile.' And I did! And, oh, nobody noticed any difference; and in addition to that, a lot of people were drawn to me because I was listening to them.”

“...in a way, it doesn’t bother me that much.... I can sort of see it as something like getting old....”

MCI and mortality. Although participants were aware that MCI was not a fatal diagnosis, several participants mentioned an awareness of their mortality when asked about the future and responded in a manner suggesting that MCI had triggered a life review or retrospection with little expectation for future growth; several discussed their lives in the past tense, while others spoke about a future in which they were notably absent. This was more common among those participants who reported a positive history for mental health adversities. This may suggest that MCI – or the future dementia most expected to result – was equated with one’s own (symbolic) death in participants’ minds, though none made any conclusive statements regarding this connection.

“We thought we were immortal, too. So, if I’ve now been given the opportunity to stop and assess what’s going on, I think I’m very lucky.”

“Life is beautiful and I’m not going to be able to experience probably nine-tenths of it, you know.”

Disenfranchisement and disconnection. A common thread of feeling silenced and discouraged from sharing one’s concerns was clear throughout each participant’s recount. Interestingly, there was little explicit mention of stigma related to their MCI. Instead, participants relayed experiences of having their concerns invalidated by loved ones and feeling ill-equipped or unwelcomed to participate openly and fully in conversations with those closest to them.

Minimization of concerns. The failure of friends, family members, and others to acknowledge the seriousness of MCI participants' concerns was a major contributor to distress throughout much of the sample. Many reported feeling dismissed as a result of having family members "explain away" their concerns as due to normative aging or high anxiety, while others felt that their experiences were belittled by same-age peers' claims to have similar (normative) experiences. In both cases, individuals received the message from those close to them that their concerns were normal and, by extension, that their worries were unfounded and unimportant.

"... nobody will listen to me!... [Y]ou try to tell them, 'no. I think there's something going on.' 'No, no there isn't. You're fine.' So it's like nobody listens to you!"

"I was absolutely shattered when I started describing [it]... every single one of them said, 'oh! I do that, too,' and then they went and strolled off and they dismissed it!"

Despite the frustration (see emotional distress) this caused participants, however, most acknowledged that their friends and family members likely did not intend to minimize participants' experiences so much as manage their own anxieties related to the potential of their loved one (MCI participants) eventually developing dementia. Perhaps paradoxically, understanding that their own diagnoses were threatening to others, MCI participants often adopted responsibility for managing others' anxieties by censoring their disclosures and redirecting conversations about their impairments.

“Even [husband], but I think he’s got an underlying fear or motive or something, because I don’t think he can bear the thoughts of me not being me – me that was.... I think he’s kind of just building a protective wall for himself.”

“I’m trying to make it easier on them by not saying anything and... I’m hiding it and making it now like a joke - and that’s very hard to do. Very hard.”

In contrast, one participant’s experience deviated from this general trend in that it was reportedly her family, not herself, that was primarily concerned about her cognition. Her experience was further anomalous compared to the rest of the sample as, rather than feeling belittled by others’ claims of similar experiences, she found succor in the camaraderie and felt less anxious as a result of feedback that her difficulties were more normative than pathological.

“I’m beginning to feel that I’m not the only one and that it’s more common, perhaps.”

Both of these divergences, however, may be accounted for by contextual factors unique to this participant. This participant had a family history of dementia, so it is possible that she and her family were naturally more vigilant for signs of decline. Moreover, this participant had a history of anxiety issues. With her higher genetic likelihood of dementia and her potentially more intense anxiety in response to her diagnosis and the related threat of AD, she may have been more amenable than others to interpretations that distanced her experience from a pathological construal.

Isolation and withdrawal, Individuals with MCI unanimously reported a withdrawal from conversations and, often, prolonged social engagements with individuals outside their most intimate circles. Many participants reported censoring what they shared with others or withdrawing from conversations entirely. Although many stated that this withdrawal was undertaken intentionally to avoid having to encounter further invalidation or resistance to the legitimacy of their concerns, others stated that their withdrawal was due more to an inability to keep up in conversations, frustration with their own performance, or being treated as incapable.

“I’m sort of finding myself saying to them the things they want to hear. And so I’m just doing that now. I’m not pointing anything out anymore.”

“Give me a chance. Otherwise, I get hurt and sort of draw in on myself, and just thinking that I’m not going to talk or I’m not going to whatever.”

Regardless of the reason, however, most participants stated that this was an isolating experience, as they felt solely responsible for shouldering the burden of their concerns.

“... and inside I’m so frustrated with what’s happening to me, and why I can’t get it across, and why I have to hide it, which is what I’m doing from my family members....”

“You know your memory’s not fine and you do worry about it, but nobody will believe you so why bother keep talking about it? Just be quiet.”

However, not all participants felt that this withdrawal was distressing, or even negative. One participant viewed her gradual withdrawal from more agentic social roles as facilitating deeper connections than she had previously, while another felt that his withdrawal had not taken away from his life in any meaningful way.

“I’ve come to value people who will take just a little bit of time to listen to me – and nobody ever listened to me before. But of course, now it strikes me that perhaps I was doing so much talking there was no room for them to get in, you see.”

Keeping up appearances. As a result of feeling discredited and being less inclined and/or able to participate fully and freely in conversations, many participants with MCI shared that they felt obligated to maintain an appearance of composure and levity around those close to them despite their internal turmoil.

“... it becomes a joke and something that’s just – you forgot about, you know. But this is where the frustration comes in: I know it’s not a joke. But I’ll laugh with them and pretend....”

Moreover, several participants mentioned that they had developed strategies to avoid engaging with others about their cognitive difficulties, which served to both safeguard others from discomfort related to participants’ difficulties, as well as to prevent individuals with MCI from incurring stigma or becoming engaged in anxiety provoking, invalidating or hurtful interactions.

Alternatively, others shied from disclosing their cognitive challenges out of fear of alienating others.

“You learn with something like this to get very crafty, and very smart, and know how to skirt around different conversations so it doesn’t come back to you.”

“It feels like I’m always trying to cover up, because I feel they don’t understand and they probably wouldn’t want to hear that.”

Unfortunately, the very act of “hiding” caused its own anxiety to participants who felt effectively silenced.

“It seems the more you keep it to yourself, the more you worry about it. So you’re really not accomplishing anything.”

“Especially when you’re trying to hide things because you don’t want to bring it out because nobody wants to hear it. It becomes like it’s strangling you, and that’s pretty well how it feels.”

Primacy of MCI. Participants generally endorsed that MCI was not only a chronic issue, but that a preoccupation with their MCI and associated concerns were a central and salient part of their everyday experience.

“This is in my face all the time: 24/7.”

“Daily! It doesn't go away. It's there every day, every part of the day. It's not something that you forget, you know. You can be doing a chore, watching TV, but your mind is still focusing on, 'you're not right.'”

The chronicity of MCA-related concerns – and the frustration and distress related to them (see emotional distress) – was reinforced by unexpected and unpredictable triggering events, such as difficulties performing routine tasks or communicating with others.

“Things that are routine or automatic, now you forget to do them as well.... ‘Why did I do that? Why didn't I remember.’”

Indeed, several participants shared that even their interpretation of others' intentions and perceptions had become dominated by an awareness of their own deficits and a concern for how they may be perceived by others.

“... you're always questioning other things and, you know, 'are they just trying to make me feel better?' or 'they're noticing something different, but they're not saying it because they're trying to make me feel better.'”

Perhaps the most pronounced example of the primacy of MCI was that of one participant who not only reported that his MCI had become a prominent feature of his present, but that managing his MCI had now become the primary focus for his future as well (see goal adjustment).

“The only goal I really have, that’s in my face, is ‘what can I do to stop this from getting worse?’ ... It would overshadow any other goal I have.”

Emotional distress. Emotional distress may be viewed as the combined product of the themes listed above; the degree of distress individuals experienced as a result of MCI was dependent on the degree to which their cognitive difficulties disrupted their valued activities, relationships or roles (e.g. MCI-related retirement), and/or the extent of uncertainty individuals felt about their condition and future. Though differing in quality, degree, and explicitness, indicators of emotional distress clearly permeated each participant’s narrative.

Depression and despair. Depression, sadness, and general despair were clear throughout the narratives of most participants, though some more overtly than others. For those participants with a positive history of depression, it was difficult to determine the extent to which their previous/comorbid depression impacted their emotional experience of MCI in particular. However, regardless of mental health history, most participants endorsed sadness as a core feature of their MCI experience.

“I mean, the sadness will always be at the bottom of it.”

“... really, there’s a deep river of sadness inside me.”

Interestingly, even when individuals acknowledged sadness, they tended to disengage from discussing their low moods fairly quickly to provide several reasons why these feelings were not warranted (see coping: Emotion regulation).

Another emotional response that participants seemed to equate to their sadness was “self-pity”, though they commonly viewed this reaction with more contempt.

“I’m not going to talk about ‘poor me and my memory’ and ‘what am I going to do?’ and ‘oh, God!’ and ‘blah, blah, blah.’”

“... okay, I can’t be ‘poor me’ anymore. You know, you’ll always want to be the man you want to be. Well, be the man you want to be. You’ve got something. Get over it and move on.”

As with depression, participants actively avoided engaging with this response deeply as they felt it counter-productive to positive coping (see coping: Emotion regulation).

Although the emotions themselves are of obvious interest, participants’ reactions to sadness, depression, and “self-pity” were also important aspects of their experience. The apparent discomfort – and occasionally, contempt – associated with reflecting on these emotions may suggest that individuals with MCI felt particularly vulnerable to them and, consequently, were threatened by the prospect of close introspection. Support for this interpretation may be provided by participants’ accounts that they invested substantial effort in staving off negative emotions (see coping: emotion regulation).

“I am so busy focusing on protecting myself from being depressed that I don’t know if I am using all of my energy on that.”

“I didn’t want to go back to being depressed. That was the alternative as far as [I] could see. There’s only two ways to think when you’re in this state: Either you’re up or you’re down. I don’t want to go down.”

Fear and anxiety. Participants discussed a number of fears related to their MCI and the ambiguity of their eventual outcomes. As may be expected, the predominant fear for most individuals was that of progressing to dementia or Alzheimer's disease; however, participants' fears of dementia were not linked to concerns for their own well-being, but rather, were mainly associated with their desire not to burden their loved ones.

“That total reliance and burden on somebody else would [scare me]. That’s scary I think, for me.”

“To put that burden on my family is my biggest fear.”

Potentially contrary to the desire not to burden loved ones, MCI participants voiced a fear of institutionalization as well. It was not made clear what about this prospect was fear-inducing, however, participants' responses suggest that, to them, institutionalization may represent a loss of agency and, again, additional burden on others.

“I remember thinking... when I said ‘horrors’ was of the homes.... You know, and they come in and give them care and washing and all that stuff. And, oh God, I can’t stand the thoughts of it!”

“I have a fear that it’s Alzheimer’s and I am going to be a terrible burden on my family, or end up in a home.”

Frustration and anger. Frustration and anger were the most clearly endorsed emotional experience for individuals with MCI, however, their causes and targets were multiple. Individuals reported frustration with themselves when they experienced lapses in memory or word finding, frustration with others for not understanding or accepting their status, and frustration in general for having MCI at all and not having access to clear answers or solutions. Most prominently, participants were frustrated by their cognitive difficulties and their inability to perform activities to the same standard as before. Self-directed frustration and anger were most frequently cited as responses to unexpected cognitive lapses, such as forgetting events, word finding difficulties, or difficulties with expressing oneself.

“I will have some low points where I’m frustrated, particularly when I’ve forgotten something that was important or that I should have done.”

“How can I even explain how it makes me feel? Very frustrated. That’s, I think, the big thing - is the frustration of not being able to remember.”

This self-directed frustration was often associated with anger as well, however, several stated that the intensity of these reactions waned as they became more accustomed to their deficits.

“Mad. Mad at myself. Just genuinely mad, because I can’t do it as well as I did.”

“... at first I was angry – and I would be really angry – and I’m getting away from that now.”

Frustration and anger were also key emotions in individuals' interpersonal interactions, and were often tied to feeling isolated in their experience of MCI or feeling helpless to overcome their deficits (see loss of control and resignation).

"I find it terribly frustrating. It's like nobody will believe me."

"[It] becomes very frustrating, very hard, because you've got no one really you can share with."

"... frustration because there's not a darn [sic] thing you can do about it."

Participants were also quite concerned about the possibility of frustrating and alienating others as a result of their cognitive difficulties.

"I mean if she was getting angry and starting to push back or push away, um, I don't know what I would do. I don't know what I would do."

"... she is trying to help me out and piece this together, but someone else would not. And they would just get frustrated with me and annoyed...."

Loss of control and resignation. Loss of control appears to be an essential experience in MCI as it overlapped with ambiguity and fears for the future, and contributed to frustration and anger. Despite these overlaps, – or more specifically, because this theme is consistent and crosses multiple thematic boundaries – it is listed here as a distinct entity unto itself. Participants acknowledged that they felt disempowered and ill equipped to affect their MCI directly and several shared a feeling of resignation that they would progress to dementia.

“You're kind of floating in the middle and don't know how to control it.”

“I'm starting to try and tell myself to be a person who would be helpful for others in [dementia], right.”

“I feel like it's kind of hopeless, like down deep....”

Even in those who did not endorse this resignation, there appeared to be an assumption that dementia would necessarily result if further action was not taken. Therefore, many made the pragmatic decision to focus their energy on controlling more easily modifiable aspects of their health in the hopes that the positive effects of doing so would influence their MCI prognosis (see coping).

Coping.

Acceptance versus resistance. One of the most pervasive patterns apparent in across narratives was that participants' attempts to cope with MCI were divided among two seemingly contradictory approaches: Accepting MCI and the possibility of further decline, and battling the effects of MCI in the hopes that it may undo their current impairment or at least ward against or slow further decline. Although acceptance was viewed as an ideal state for many individuals with MCI, participants were most likely to value acceptance as the only pragmatic position to hold given their lack of agency over their outcomes.

“... just sort of that acceptance thing; that I don't know what's coming down the line but there's not much I can do about it....”

“When you accommodate yourself to reality, you accept it if you want to live happily. And I do want to live happily, so I’m accepting it.”

While some appeared to have achieved this state with relatively little internal conflict, most participants reported more of an ongoing process of accepting their MCI.

“I certainly haven’t come to terms with, ‘okay. I’m okay. This is the way it is,’ but I believe I’ll get there.”

“... I haven’t quite made that shift [to], ‘I’m okay with this now... and you’re okay.’ I’m still fighting that.”

One element that appeared to smooth this process was an endorsement of spiritual beliefs. Those who had attended Alcoholics Anonymous (a program with Christian foundations), or who identified themselves as spiritual, appeared to experience significantly less distress and difficulty in accepting their condition. Notably, although these participants still endorsed a lack of personal agency, this was not particularly disruptive to their views of themselves or the world.

“God grant me the serenity to accept the things I cannot change, to change the things I can change, and the wisdom to know the difference.”

“... that’s God’s will for me and I can’t do anything about it anyhow. So what’s the point of fussing?”

Others strongly equated acceptance with resignation and hopelessness and viewed the possibility of accepting their position as threatening to their selfhood. For these individuals, continued efforts to fight against their MCI were seen as an affirmation of their strength and, possibly, hope that it may yet resolve itself (see emotion regulation).

“I’m just not going to fold up and accept it. That’s not going to happen. I won’t allow myself to do that.”

“I am not the type that gives up easily on anything and I’m not going to give up easily on this – not without a hell of a fight.”

It is likely, however, that several participants adopted more of a combined approach, wherein they balanced a sense of acceptance of their current impairments and losses with active efforts to prevent further decline.

“What I realize is I have to learn how to compromise and, as opposed to, ‘oh, I’m losing [myself],’ because that’s a poor me place.... I’m going to fight this.”

“... if I can understand what I’m going through, fight against it in a sense, ... if I’m not going to give into it, I can maybe expand the beginning part.”

Exercising control. MCI participants uniformly engaged in activities that they felt would help them prolong their cognitive functioning. By far, the most common proactive coping methods undertaken by MCI participants were those pertaining to the maintenance of good physical health through keeping a regular exercise regimen and switching to a healthier diet.

Participants also engaged in many activities traditionally thought to “exercise” the brain, such as reading and crossword puzzles.

“...I have some control in the sense of eating, diet, and all these things I can control.”

“I’ll play, like, word games or mahjong... I try to make sure I do a couple of these every day just to keep my mind – making it work.”

Although there appeared to be an understanding that these methods may have limited utility in staving off dementia, participants reported that engaging in any sort of preventative action provided them a greater sense of security and control.

“Even though it doesn’t seem to be a miracle cure, it certainly makes me feel better for trying.”

Further, although only one participant made explicit efforts to research MCI, all were eager to learn more about MCI and sought opportunities to advance this goal (e.g. joining this research study, attending dementia information seminars).

Yet another means by which participants exercised control was by surrendering it in deliberate measures. Participants all reported recruiting the help of their partners to provide support in keeping track of appointments and instituting compensatory strategies to help them remain optimally independent. Participants’ partners were considered an essential part of their

coping and many expressed concerns that they would not be able to manage/function fully without their partner's support.

“...if [husband] dies, I can't go on. I can't. I'll have to go be in one of those shelters.”

Although this may ostensibly seem like a loss of control, most participants made the decision to surrender control themselves and were able to set boundaries as to how much support they received. In this way, they appeared to maintain their sense of agency, continue engaging as fully as they felt possible, and limit the burden they felt they presented to their loved ones.

Most individuals with MCI participated in numerous proactive coping activities, though they reported that few— if any — of these were recommended expressly by their medical service providers. Instead, many participants resorted to informal sources of information, such as alternative medical practitioners, self-help books, or Internet blogs to find information on activities thought to help prolong and strengthen cognitive functioning. Although ostensibly positive, this multi-pronged approach may have been fueled by a (perceived) lack of concrete medical recommendations and high levels of anxiety related to the possibility of MCI progressing to dementia if left unattended.

“I'm just, I think, grabbing at anything I can get that will keep my brain active.... All I care about is making it work and keeping it working and not getting worse, because I don't think I could handle that.”

“We’re doing everything proactively that we can; diet, exercising, and doing everything we can. So I don’t think I’m leaving any stone unturned.”

Emotion regulation. Participants engaged in several methods to allay their anxieties and remain within a functional and positive emotional state. Most reported spending a great amount of effort to remain positive and avoid engaging with negative thoughts or situations that may trigger them.

“I am so busy focusing on protecting myself from being depressed that I don’t know if I am using all of my energy on that.”

Occasionally, this comprised actual physical avoidance of triggering situations or negative thoughts.

“So you stick away from the things, you avoid the things that are going to have an effect on you, that you know will have an effect on you. So you try not, try not to do those things. So I spend a lot of my time avoiding situations, avoiding things that will make me feel bad.”

However, avoidance was also apparent in individuals’ response styles. Upon mentioning a potentially negative or threatening aspect of their experience, such as a sense of loss of self, some individuals switched their topic of discussion to a tangentially related topic. Though it is possible that some did this without conscious intent, others reported deliberately counteracting

negative thoughts and experiences with more positive content to prevent despair, or argued that they did not have the right to be upset given the other positive aspects of their lives.

“... how I counteract that – around how good my life is and how rich it is in so many other ways. I’m pretty lucky with it.”

“Now I feel embarrassed saying that, because I’ve done so many things, that I’ve had more than my share; I really have.”

Interestingly, those participants who disclosed a history of anxiety demonstrated a unique, potentially avoidant, response style in which they focused much of their attention on other individuals in their lives, or other topics entirely, rather than engage with discussion about MCI and its implications.

“... sometimes it’s just the words I can’t remember, and I think it’s – I’m [a] very bad influence on him because I think he’s getting that way now, too.”

“‘Let’s plan a trip. Let’s go to Europe or somewhere.’ ... I think that’s what we’re supposed to be doing at my age, apparently.... But that’s not MCI.”

Another common way participants regulated their fears was through maintaining hope that their MCI was either wrongfully diagnosed, had potential to resolve itself or that our understanding would progress quickly enough that they would be cured before the onset of dementia. Indeed, it was this latter hope that motivated some to participate in this study.

“I want the brain to change back where I can reprogram it.... [S]ome brain cells die, you've still got plenty left , from what I've heard, and you should be able to reprogram, or program those to take over from the others, and that's what my hope is.”

“Maybe, in time, there will be better treatments, there will be better diagnosis, there will be better help to us – if I am one of those ‘us’.”

Although maintaining hope for a positive outcome was a pervasive experience, it was also a precarious one. Several participants stated that they feared that their MCI would worsen and that, if this happened, they would likely lose hope entirely and surrender to what they viewed as the inevitability of dementia.

“... like there's nothing seems is helping so, then I would, I think, I would go into a depression about it, but I can't see myself that I would continue to fight - I think I'd be very disillusioned about it and be inclined to think, ‘what's the point?’”

Goal adjustment. When asked about their goal setting activities and hopes for the future, MCI participants uniformly reported a primary focus on maintaining their current functioning and an investment in upholding their current social roles.

“But, the only goal I really have, that’s in my face, is, ‘what can I do to stop this from getting worse?’ ... It would overshadow any other goal I have.... [M]y other goals are to be a good husband, you know, and still support my children...”

Further, participants reported an almost exclusive interest in the present and immediate future, with little regard for the longer term. Though some stated that this was due purely to their stage in life, others stated that this narrowing of focus was due partially to the unpredictability of the future or negative expectations of what may come (i.e. dementia).

“If I had more ambitions, I’m sure I’d be quite a bit bothered by it. You know, if I had some goals. But I’m just kind of getting into the twilight there.”

“I’m only looking at the immediate future right now.”

To this effect, several participants expedited previously longer-term goals out of a sense of urgency and a fear that they would soon be unattainable entirely, where others chose instead to relinquish their goals entirely as they did not expect them to be achievable after all.

“... if this happened over ten years, I wouldn’t be worried. But, because the time frame is quite small, I would say, yeah, there’s a sense of urgency to do this.”

“We, you know, we can’t go and do the things that we would have wanted to do now.”

Grief. MCI participants did not explicitly support the experience of grief in an intrapersonal context. However, as the central construct of interest in this study, the theme of grief warrants some further attention. Following the member check, participants were asked specifically whether they felt feelings of grief or loss in regards to themselves (as they were

before MCI). Although one participant agreed that there may be an aspect of intrapersonal grief involved in his experience of MCI, most had considerable difficulty conceptualizing grief outside of a bereavement (i.e. interpersonal and finite) context.

“There would be a component of grief. Definitely. [It] would be stupid... [if] I just blow it off.”

“Well, I think that, to me, real grief is when I’m standing [and] looking down at a coffin or an urn.”

Although one participant did describe grief in terms that could potentially be construed in an intrapersonal context, his subsequent discussion evidenced that this was intended in a purely interpersonal context.

“...it’s a loss of something that has been a substantial part of your life or your being... So it’s a void or a minus or loss or removal of a positive in your life; [it] could be someone, a neighbour or a relative, that was somebody you could go to and talk to and share things with.”

Since few participants acknowledged grief as a possible reaction to their own losses, grief as a qualitative theme was not supported and, accordingly, was excluded from the thematic structure and description of participants’ MCI experience (see thematic relationships and structure). With that said, given the experiences of MCI shared by the participants in this study, it is possible that grief may still be an applicable construct, only one that participants did not endorse or recognize

explicitly either out of a lack of familiarity with the concept, defensive denial, or a lack of insight into their experience. This possibility will be further expounded in the discussion.

Thematic Relationships and Structure

The totality of emotional MCI experience is complex and multi-layered; the themes identified and outlined in this study are merely a reflection and clarification of the most prominent and distinct aspects of this experience. However, though these themes were selected in part because of their distinctness, they were not entirely discrete. Rather than prove problematic to the interpretation of the MCI experience, however, the relationships between themes allowed for the development of a thematic structure that further clarified the experience as a whole (see figure 1).

Aside from the more manifest content of emotional distress and coping techniques, disenfranchisement and disconnection, losses of self and roles, and ambiguity were the most salient and readily identified latent themes throughout each individual's experiences. Although there was variation in the context in and extent to which MCI affected participants, these dimensions were endorsed unanimously. Consequently, disenfranchisement and disconnection, losses of self and roles, and ambiguity may be considered core dimensions of the MCI experience. Moreover, these core dimensions were conceptually linked as well.

Disenfranchisement and disconnection related directly to losses of social roles, which in turn were associated with losses of sense of self. Further, invalidating feedback from peers and loved ones introduced additional ambiguity for MCI participants and created additional confusion to those with MCI struggling to resolve whether they had changed as a person, or to what degree. Likewise, uncertainty and ambiguity informed losses of self and roles as well. Those individuals who viewed MCI as possibly normative or less certain to herald dementia exhibited a more

secure sense of self and less emotional distress than those who expected to develop dementia. On the other hand, most participants experienced a disruption of expected futures and goals due the unpredictability of MCI and the lack of a clear prognosis. This, in turn, contributed to participants' perceptions of personal impact and sense of mortality. Therefore, losses of self and roles may serve a central, binding role among these core themes as feeling invalidated and isolated by others, and lacking certainty about the diagnosis or its implications both informed at least some of the reported experiences of loss of/changes to self.

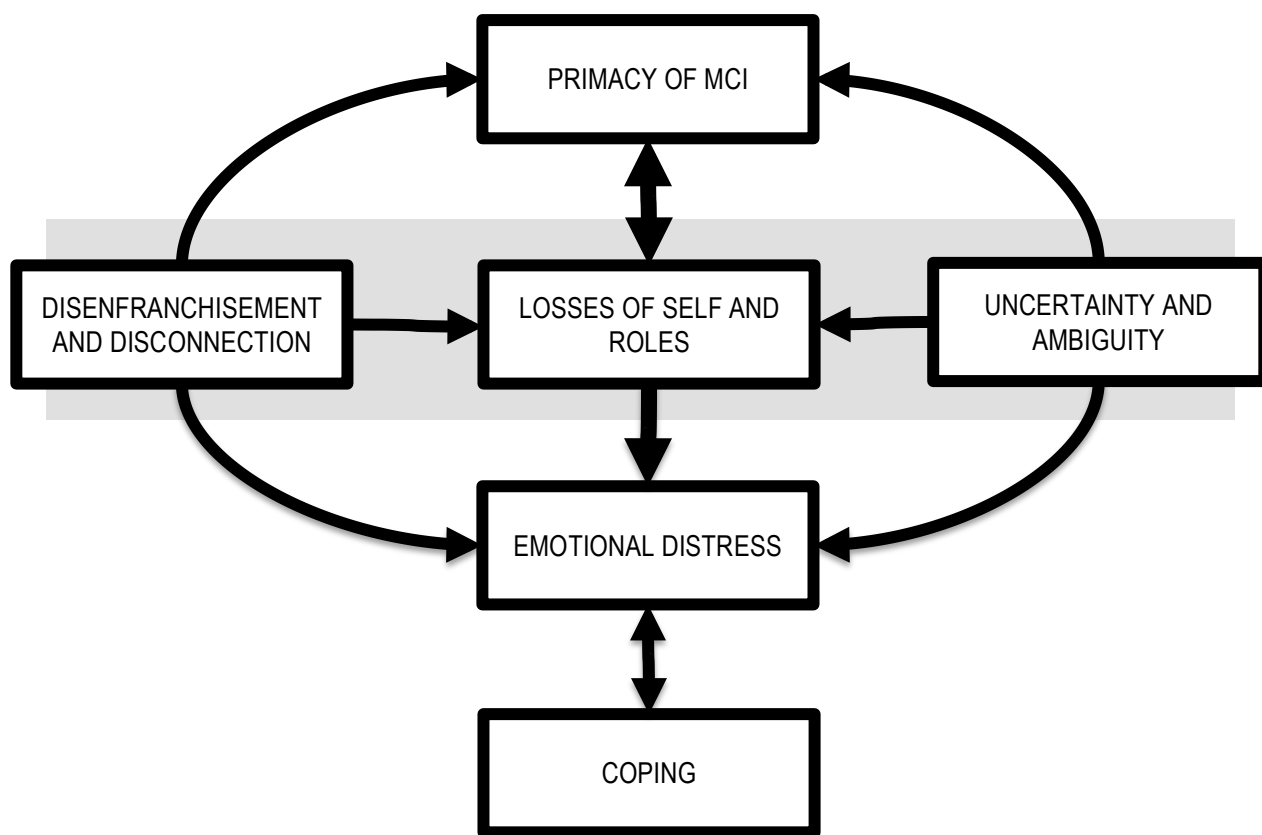


Figure 1. Thematic structure of the MCI experience.

The primacy of MCI, on the other hand, may be viewed as more of a reflection of the impact of the aforementioned core themes. Once again, although all core dimensions contributed

to the salience and omnipresence of MCI-related concerns independently, the degree to which individuals felt losses of self and roles seemed to most strongly affect the primacy of MCI-related concerns. Moreover, the relationship between primacy of MCI and losses of self and roles may be reciprocal. While those who perceived more of a loss of self were more preoccupied with MCI and how it affected their abilities, identity, and roles, those who felt the effects of MCI frequently or who devoted more time and energy to managing their MCI tended to feel more of a loss of self.

Each core dimensions also contributed independently to emotional distress, though it may be argued that losses of self and roles contributed more heavily to distress than the other core dimensions given its central role in the MCI experience. Despite the unanimous endorsement of emotional distress across narratives, however, it was not considered a core dimension of MCI as it was reported as an outcome rather than a facet of the MCI experience *per se*. Finally, coping and emotional distress were integrally tied in a reciprocal relationship: How individuals coped was determined (in large part) by the nature and intensity of their emotional distress, and individuals' levels of distress were likewise affected by the nature and efficacy of their coping responses.

Chapter 5

Discussion

The primary goals of this study were to provide a description of the MCI experience and determine whether and to what extent this description reflects existing grief paradigms. The themes identified in this study correspond closely to those in the existing MCI literature, suggesting that this sample may be a sound representation of those with MCI as a whole. Replicating themes found by Beard and Neary (2013), participants reported questioning the pathology and meaning of MCI, difficulty defining MCI, and social isolation and potential stigmatization as a result of MCI. For some, conceptual distancing from Alzheimer's disease was also apparent, though this was not as consistent across this sample as for Beard and Neary's. Similarly, participants' coping responses were akin to those identified throughout the literature on chronic illness and Alzheimer's disease (Clare, 2002; Hainsworth, Eakes, & Burke, 1994), suggesting the possibility that those with MCI may view their position as commensurate to transition into dementia. The degree of corroboration between this sample and those in previous MCI and Alzheimer's research is encouraging as it contributes to the confirmability of this study; however, the main contribution of this study remains the novel consideration of grief in MCI.

Of the three core dimensions of MCI identified in the results (losses of self and roles, disconnection and disenfranchisement, uncertainty and ambiguity), losses of self and roles serve an essential role as the theme which binds the other core dimensions and that which corresponds most directly to both the primacy of MCI and emotional distress. Therefore, losses of self and roles may be considered the central and most emblematic aspect of MCI. With that said, it remains unclear whether losses of self and roles, and the associated emotional distress, characterize a grief reaction in line with other better-understood loss experiences.

Loss and Grief in MCI

Several important models will be addressed in turn, noting their congruence (or lack thereof) with the MCI participants' reported experience of MCI. In order to determine which grief framework(s) may apply to MCI, it is necessary to first determine the nature of the loss experience.

Determination of the nature of loss in MCI.

Classical bereavement models. Though it is likely that identity change occurs for those with MCI, and that they relate to their premorbid selves as different, if not entirely distinct, from their current selves, whether their former self is construed as being "lost" requires clarification. At first glance, bereavement frameworks may appear to apply to MCI to the extent that perceived changes in self reflect an "othering" of premorbid selves/identities; however, there are various points of dissonance between the reported experience of MCI and bereavement models that make this unlikely. The most apparent mismatch between bereavement and MCI is that MCI constitutes a nonfinite loss, complete with disruption of expectations for the future, progressive losses over time, and the need for continuous adjustment and coping. Further, most participants were unable to identify an incident or single point in time that served as the singular point of their loss. Further, the coping responses found among other groups experiencing finite losses of others or self were not evident in this group; MCI participants did not describe coping with their loss in an oscillating fashion suggestive of the dual-process model of coping (Stroebe & Schut, 1999), nor did any discuss more existential or emotional coping responses characteristic of bereavement, such as redefining one's relationship to the lost (Bowlby, 1980) or relinquishing one's world view (Parkes, 1988). Instead, participants appeared to cope primarily through maintaining a sometimes-conflicting balance between seeking acceptance of their condition and

potentially negative future, resisting further progression, and resignation to the perceived-to-be-inevitable progression to dementia. Based on the current data, a bereavement paradigm narrowly construed is not supported for application to MCI, however, this may warrant further investigation in future.

Nonfinite loss. Though finite loss paradigms (e.g. bereavement) do not apply well to MCI, it is not altogether clear whether nonfinite loss paradigms characterize MCI better, or if MCI represents a novel loss paradigm altogether. In order to resolve this issue, the characteristics of nonfinite loss may be considered within the context of participants' reports. Individuals with MCI universally reported a discrepancy between their previous and current statuses, and between their premonitory hopes for this life stage and expectations for the future following diagnosis. Moreover, each individual reported some measure of loss of control over their outcomes and unpredictability regarding what their futures may hold (Bruce & Schultz, 2001). Each of these features of the MCI experience are characteristic of nonfinite loss and correspond to the experiences of those with other protracted or progressive health adversities.

Ambiguous loss, a specific type of nonfinite loss, may be especially relevant to the experiences of those with MCI. Ambiguous loss refers to loss experience where it is difficult to resolve whether a loss has actually occurred, preventing survivors from either initiating mourning or continuing with their daily lives. A sense of immobilization, or moratorium, was clear in the recounts of individuals with MCI. A primary contributor may have been the lack of clear prognosis and information about MCI, as participants were uncertain whether their previous level of functioning was recoverable. As a result, participants encountered difficulty accepting their changes, but also felt powerless to resist them. Additionally, participants reported that they felt unable to pursue valued goals out of an expectation of future dementia, but also felt

compelled to engage in as many preventative measures as possible in the present (at the expense of other valued activities). As evidenced by the primacy of MCI, much of their lives were committed to maintaining hope of recovery and warding off despair while being careful not to become too hopeful lest recovery be impossible and dementia inevitable. It was clear that this ambiguity was a cause of stress for most participants and that each felt restricted to their present with a dwindling connection with their past and little control over their future. Moreover, without a clear indication that they would progress, or at least, that they would not recover, participants encountered difficulty resolving whether attachment to their previous roles, abilities, and identities was warranted. Thus, there is strong evidence to suggest that the experience of MCI may reasonably be described as a nonfinite loss with features of ambiguous loss in particular. In light of this determination, grief frameworks such as disenfranchised grief, chronic grief, and anticipatory grief may be reasonably considered for the MCI experience.

Grief response in MCI.

Disenfranchised grief. Similarly to their loss experience(s), participants' grief responses also aligned with some expected grief paradigms. The most apparently applicable grief paradigm was disenfranchised grief. As traditionally conceived, disenfranchised grief may result from a failure to recognize the legitimacy of either of the loss, the griever themselves, or the relationship to a lost person or object. It may be argued that disenfranchisement occurs in all three of these domains for those with MCI; however, as those with MCI grieve themselves, in some sense there may be a limited distinction between the three. Participants perceived that the losses they felt were either viewed as unimportant, or were considered over-reactions to normative changes. Likewise, given social invalidation of the losses incurred by those with MCI, the individuals with MCI themselves perceived that they did not have the right to grieve. Finally, since identity

change appears to be due more to subjective changes in personal narrative and self-concepts, and because those with MCI are largely viewed as being the same person as before, the relationship between an individual and their previous, valued selves was not readily recognized. Since the losses of MCI may be difficult for others to recognize, there is no socially sanctioned way to mourn and individuals with MCI and their peers alike may be ill equipped to find emotional resolution. In line with participants' narratives, this multi-level disenfranchisement may serve to isolate those with MCI from any mitigating social supports and exacerbate the emotional distress resulting from losses (Corr, 2002).

Chronic sorrow. In addition to experiencing grief that is disenfranchised and isolating, it is possible that those with MCI experience chronic sorrow as well. Chronic sorrow may be summarized as a response to a finite or nonfinite event that includes pervasive, permanent, periodic, and potentially progressive sadness that may be exacerbated by reminders of the loss (Ahlstrom, 2007). Chronic sorrow is expected to be more likely to occur when losses are disenfranchised, unexpected, and ambiguous as MCI was for the study participants. Further, the loss of valued and expected futures described by participants is argued to be central in chronic sorrow (Roos, 2002). Participants' approaches to coping are also in line with what would be expected for those experiencing chronic sorrow: Those experiencing chronic sorrow often remain functional and opt to accept their condition out of pragmatism. Roos (2002) describes this pragmatic acceptance as the "best face" norm. The alignment of participants' reports with these features, together with evidence that chronic sorrow appears to be a common experience among many chronic health conditions (Burke & Eakes, 1999), it is probable that those with MCI experience chronic sorrow.

With that said, however, several defining features of chronic sorrow were notably absent in participants' experiences. Chronic sorrow is potentially progressive and periodic, in that confrontation with reminders of one's losses triggers an intensification of negative affect (Roos, 2002). Instances of forgetting or confrontation with lost competencies did trigger emotional distress for those with MCI; however, participants were more liable to feel anger and frustration directly related to the incident rather than sadness or sorrow related to MCI as a whole. Moreover, these responses were reported to last for a moment only, and to lessen in intensity over time. While it is possible that MCI participants' angry responses were grounded in grief or sadness over their losses, it is difficult to make that conclusion definitively without further evidence. Therefore, while some aspects of chronic sorrow were present within the MCI experience, it was an incomplete expression and, therefore, warrants further investigation before chronic sorrow can be said to conclusively apply to those with MCI.

Anticipatory grief. Perhaps the most difficult grief paradigm to apply meaningfully to MCI is anticipatory grief. Anticipatory grief is preemptive grieving for individuals who are expected to die but have yet to, with the intention of emotionally preparing oneself for the loss when it occurs (Saldinger & Cain, 2004). Although there is a sense of expectation of dementia for those with MCI, and dementia is likely to represent a symbolic death for these individuals, anticipatory grief is difficult to apply to an intrapersonal loss context. Anticipatory grief is undertaken with the aim of being emotionally prepared to mourn effectively and move on after loss and, therefore, it necessarily requires consideration of one's own survival following a loss. Those participants most expectant of later dementia were also those most likely to speak of a future in which they were absent; in other words, these participants did not foresee their survival – at least not as themselves – following the loss experience of dementia. In light of this, death

anxiety may be a more apt paradigm to consider than anticipatory grief as this includes the existential considerations demonstrated by some participants without necessitating an expectation of continuity.

The anxious anticipation and existential “dread” characteristic of death anxiety were most markedly present for those with a positive history of depression and/or anxiety. Given that death anxiety has been shown to exacerbate both existing anxiety symptoms (Strachan et al., 2007) and depression (Maxfield, John, & Pyszczynski, 2014), this may explain the additional distress experienced by these individuals. Further, Maxfield and coworkers describe that death anxiety may be mitigated by interpersonal supports, personal meanings, and worldview (Maxfield et al., 2014); given that the experience of MCI is disenfranchised and includes changes to self-concepts and world views, this suggests that death anxiety may not only apply to MCI but that it may be uniquely and intensely triggered by it. If death anxiety is present in those with MCI, and if it is known to exert a stronger effect on those with preexisting anxiety and/or depression, this may help explain the reticence of participants with previous mental health adversities when asked to describe changes to self, experiences of loss, or negative emotional responses. It is likely that, if discussion of MCI elicited a strong sense of death anxiety for these individuals, that they would engage in some degree of defensive denial to manage their anxiety and distance themselves from their feared outcomes as was observed (Ownsworth, 2005).

Summary of MCI characterized within existing grief frameworks. Thus, in reference to current understanding of grief and loss, MCI presents a nonfinite, disenfranchised, and ambiguous loss of self. The diagnosis of MCI and its associated impairments signify a waning connection with one’s past, the loss of expected and valued futures, and ultimately, a change in identity. As a result, individuals with MCI may be at an elevated risk of experiencing chronic

sorrow, feeling isolated, and developing depression. For those with comorbid or preexisting depression or anxiety, MCI may be particularly threatening and may exacerbate their symptoms. Given that grief is an emotional response to loss (Griffin, 2001) and those with MCI clearly endorse emotional distress in response to pervasive losses in several domains, this study concludes that grief does occur for those with MCI. Though this conflicts with other literature that states that grief is uncommon in response to medical illnesses (Parker, Paterson, & Hadzi-Pavlovic, 2015), these studies continue to rely upon narrow interpersonal and finite definitions of grief.

Identity Change in MCI

All individuals with MCI endorsed a change in social roles, capabilities, and core characteristics; however, there was less agreement regarding what these changes represented in terms of identity as a whole. While several participants reported that they felt generally consistent with their premorbid selves despite their changes, many clearly endorsed that they felt that they were different people and that their MCI had fundamentally altered who they were. However, several participants' reports were inconsistent within and/or between interviews (initial interview and follow up), as they alternately described that they were the same person as before *or* that they had fundamentally changed. These responses parallel the conflict themes of "change versus consistency" outlined by Caddell and Clare (2011) in those with early-stage dementia. While it is possible that this ambiguity regarding change is partially due to ambiguity regarding the nature and implications of MCI, it is likely further complicated by the difficulty of conceptualizing identity. It was difficult for all participants to describe what it was that constituted their identity and to what extent this was influenced by their various characteristics and capabilities. Indeed, when asked to describe what made an individual who they were, various

participants referred to descriptions of their ability to perform certain tasks, social roles, or, less frequently, their feelings of “selfness”. Given that participants themselves were unclear on the nature of identity and, consequently, were often unable to describe whether they felt they had changed or remained the same, it is prudent to consider several models of identity and what they may suggest regarding the structure of identity.

Neisser’s multiple selves. Neisser (1988) describes five related, yet distinct “selves”: The ecological self (self in relation to the environment), the interpersonal self (socially-defined self), the extended self (continuous self founded on memory of the past and projection into the future), the private self (personal and internal experiences), and the conceptual self (the meaning of self and self-concepts influenced by roles, valued characteristics, and world view). He argues that each of these selves not only develops independently from one another, but that each may also be uniquely susceptible to disruption or pathology.

The loss/change of self-concepts, roles, and abilities and the ambiguity regarding the future reported by those with MCI correspond clearly to changes in most, if not all, the selves outlined by Neisser. The conceptual self constitutes the emergent self that is most commonly recognized as the seat of identity; however, as an amalgam and extension of lower-order selves, it is the most sensitive to disruption. Therefore, it should not be surprising that participants’ changes in self-concept, personality traits, and competencies most heavily implicate changes to this self. However, MCI may cause disruption to interpersonal selves, extended selves, and private selves that underlie the conceptual self as well. The interpersonal self includes one’s social identity: Their relationships, their social status, their social roles, and their patterns of interacting and social scripts. Either due to the adoption of a diagnostic label and associated “sick role” (Goffman, 1963), or due to the interference of cognitive impairments with social activities,

MCI clearly causes changes to this self. Further, MCI appears to affect individuals' personal selves as well, introducing more negative self-thoughts, more uncertainty and doubt of one's abilities, and more emotional distress than participants experienced before. Lastly, the changes in participants' plans for the future, the discontinuation of previous goals, and the new concerns regarding independence in later life and mortality initiated by MCI suggest changes to the extended self. The extended self is a projection of the future based on one's past up to their present. Theoretically, the unexpected changes of MCI cause a schism between the past "me-that-was" and present "me-that-is" resulting in the invalidation of a future that was valued, expected, and pursued.

If identity is conceptualized according to Neisser's model (1988), regardless of whether identity change as a whole is defined as changes to those selves that are/were most valued, changes to more selves than remain unchanged, or changes to the holistic and unifying conceptual self, those with MCI clearly experience a change in identity. Neisser's model may also explain participants' confusion regarding their identity change, as they may be more aware of changes in one "self" than in others due to personal values or particular events.

Narrative identity. Yet another model that may apply well to MCI is that of narrative identity. Narrative identity is grounded in an individual's autobiographical memory. Manczak and coworkers describe narrative identity as one's defining story that serves to integrate past experiences with their present situation and expected future in a continuous and cohesive manner (Manczak, Zapata-Gietl, & McAdams, 2014). What is more, one's narrative identity provides a sense of causality and stability (akin to just worldview) that supports a sense of purpose and overall good mental health (McAdams & McLean, 2013). As narrative identity is founded upon autobiographical memory and an uninterrupted continuity of experiences, it is likely that

memory impairments would cause a disruption to an individuals' sense of self and stability and, consequently, would negatively impact mental health and quality of life.

Within the context of this study, participants with MCI's reports suggest that both their access to their past story and their expected futures may have been disrupted and that their defining story had changed as a result. Participants who reported the loss of important autobiographical memories reported severe emotional distress and loss of valued roles, and all participants reported prognostic ambiguity that impacted participants' connection to their expected and valued futures. Individuals' narratives create and expect a sense of causality, purpose and predictability, however, the onset and diagnosis of MCI was reported several times to be unexpected, unfair, and to not make (existential) sense. Further, MCI-related losses and concerns caused participants to alter or surrender their planned futures by adjusting plans, discontinuing valued goals, and opting not to plan further than the immediate moment. Thus, if identity is defined as one's uninterrupted story, MCI may serve to disrupt the known arc. To the extent that both the past and future must be restructured to accommodate the present situation, those with MCI may experience identity change.

With that said, however, the connection between autobiographical memory and sense of identity has been argued in the literature. In a study by Naylor and Clare (2008) individuals with impaired autobiographical memory did not report lower scores on a self-concept measure. It should be noted, however, that the measure used in this study was designed for use within a different context and population. Cohen-Mansfield and coworkers (2000), on the other hand, claim that autobiographical memory is not necessary for a sense of continuity. They argue that the confabulation common to those with dementia may be a means by which individuals create a sense of continuity and cohesion regardless of the accuracy of their memories. However, this is

speculative, and other research suggests that those with autobiographical memory loss (e.g., due to traumatic brain injury) display impairments in self-perception and auto-noetic consciousness (the ability to project oneself to the lived past and hypothetical future and reflect on one's thoughts and actions) (Piolino et al., 2007). Narrative identity is contingent on auto-noetic consciousness and the disruption of this function in those with autobiographical memory loss may suggest that identity defined narratively may be disrupted by autobiographical impairments.

Normative identity change in aging. According to several models, identity change is likely to have occurred for those with MCI; however, it may be argued that identity change is a constant process and one that is more likely and normative in older adulthood. With consideration to this, the salient question of whether changes to identity beyond those that are expected in older adulthood occur in those with MCI. Older adulthood is defined in many ways by losses in roles, abilities, and independence (Langer, 2011), with independence playing a particularly important role in older adults' sense of self, quality of life, and general wellbeing (Secker et al., 2003). Those with MCI described many of these same changes and several noted that these changes would be of little concern were it not for their magnitude, abruptness, and surrounding circumstances. Therefore, where normatively aging older adults experience gradual transitions and losses to independence, participants felt that threats to their independence were "off-time", immediate, and extreme, causing distress and disruption beyond that which may be expected from older adults without MCI. Moreover, MCI participants felt that the potential for dementia presented a greater threat to their independence than they would expect otherwise. As may be expected, this was distressing in itself, and several participants went so far as to state that they would prefer an earlier death to experiencing the infirmity of late-stage dementia. Expanding on this, several participants cited their ability to drive as symbolizing their agency,

and claimed that the loss of their license and associated independence due to MCI would be “devastating” for their lifestyles and “ego”. Thus, while older adults may expect to lose independence in a number of ways, MCI participants felt that their condition accelerated this transition and that their sense of agency and various aspects of identity were threatened more frequently and intensely as a result of MCI than would be expected otherwise.

As shifts in individuals’ developmental trajectories and expected futures is a core consideration in both models of identity discussed above, this point is germane to address in the context of normative aging. Older adults adjust their activities as they age and, though there is a general tendency to withdraw from previously enjoyed activities, Baltes and Baltes (1990) argue that this is normative and positive. Baltes and Baltes (1990) propose the selective optimization and compensation model of aging. This model states that, as older adults become less able to pursue valued activities and goals, they devalue these goals and more heavily weight and invest in activities that are more achievable. This is normative and does not cause distress, as it is not always purposive. Rather, older adults view these shifts as a natural result of aging. Although some participants with MCI did report that their adjustments to their activities and future plans were normative and not distressing, most reported that their changes were precipitated by MCI, were pathological, and were not conducive to their quality of life. Chief considerations in whether individuals were distressed were their views of whether MCI was normative, whether they felt that their losses occurred quickly, and whether their losses prevented them from living in a way that was consistent with the person they felt themselves to be. It should also be noted that those who did not report distress due to their MCI-related losses had positive mental health histories and potentially were more avoidant and defensive in response to threatening topics. This may be contrasted with the responses of the normatively aging retired participants in the

pilot study, who reported little distress associated with their transition to retirement and associated losses of previously held social roles. Moreover, normatively aging pilot participants did not feel that their cognitive or physical decrements (due to age) proved an obstacle to their living in a manner consistent with their self-concepts and values, whereas those with MCI reported this as a chief complaint.

Therefore, although MCI occurs in older adulthood, a time of change and loss by default, participants did not report issue with aging *per se*, but rather with the unexpected losses over and above those of aging specifically presented by MCI. Stated differently, participants did not recognize the expected changes of adulthood as identity change but role transition. In contrast, reports of identity change were associated specifically with MCI-related changes that were perceived as inconsistent with participants' development and expectations for aging. This coincides with the narrative disruption model of identity change suggested by McAdams and McLean (2013). Therefore, it is argued that MCI is associated with a perception of identity change beyond that expected of normative aging, and that those with MCI experience an existential threat to self and emotional distress as a result.

Identity consistency in MCI and early dementia. Though the experience of MCI does appear to reflect a change/loss of identity, and despite the common report among this sample of changes in self as a whole and losses of self and roles, the majority of the literature suggests that some sense of identity persists until the late stages of dementia (Clare et al., 2013; Cohen-Mansfield et al., 2000). With that said, most of this literature pertains to individuals with dementia and may not be applicable to those with MCI. While better cognitive functioning is generally associated with more accurate self-knowledge, Caddell and Clare (2013) report that lower scores in some cognitive domains may be protective and may contribute to a more stable

sense of identity; this may be especially true for those experiencing marked changes in function. In addition, those with dementia may acknowledge deficits in particular cognitive domains without perceiving any global change (Clare et al., 2013). Since those with MCI have more intact cognitive functioning as compared to persons with frank dementia, they may have more insight into their changes and, consequently, may recognize (and be threatened by) more global changes to their identity as a result of impairment in multiple domains. Unfortunately, this critical distinction between those with MCI and dementia has been largely overlooked, as no work to the author's knowledge has been conducted on identity in those with MCI to date.

Yet another potential reason for the discrepancy between reports of identity consistency between those with MCI and those with dementia may be the degree of threat to self a condition evokes. It is likely that individuals with MCI and dementia have aspects of identity that both change as a result of their respective diseases and remain consistent throughout. However, identity is inherently an ambiguous concept and individuals may interpret change or consistency preferentially, in light of which aspects of self are invalidated or threatened. Evidence suggests that dementia may not only elicit defensive denial (MacQuarrie, 2005) and identity fluidity (Caddell, & Clare, 2013) in those diagnosed due to the threat to self it represents, but also that those diagnosed with dementia are commonly dehumanized, overlooked, and disenfranchised as individuals (Beard, 2004). In response to this disenfranchisement and the default assumption of identity change, those with dementia may be more likely to reiterate those aspects of themselves that have remained consistent, compared to those with MCI, who may feel that they are changing but are discounted as remaining the same.

Clinical Implications

Providing the MCI Diagnosis. A primary question evoked by this study is whether individuals should be explicitly told that they have a diagnosis of MCI in the early stages of the condition. Though the label of MCI may serve a purpose for clinicians, for those with MCI, the current lack of information, resources, and clear prognosis make this label confusing at best and anxiety- and fear-inducing at worst (Corner & Bond, 2006). Many participants reported that the impact of their MCI diagnosis was unclear and that, rather than adding to their understanding or security, it interfered with their plans for their future and introduced a measure of fear and ambiguity into their lives that they had no way of resolving. Further, as MCI remains a broad category with uncertain consequences, the diagnosis contributed to those with MCI feeling misunderstood and devalued by those around them. Whether the provision of an MCI diagnosis is harmful or helpful may be further complicated by an individual's mental health history. Those with positive mental health histories in this sample reported less distress overall, but also demonstrated more avoidance, denial, and potential death anxiety. If the diagnosis itself is causing distress and is negatively impacting mental health, clinicians need to weigh the costs and benefits of providing a diagnosis and attending to the relative psychological impact of such information. For psychologists in particular, this becomes an ethical issue of balancing beneficence versus non-maleficence – the desire to respect the autonomy of the individual by providing accurate information, while not causing undue harm by disclosing such information (Canadian Psychological Association, 2000).

Interventions to Support Individuals with MCI. As noted previously, the mental health of individuals with MCI may be overlooked as a target for intervention or formal support. This is unfortunate given the known association of MCI with depression and, in turn, depression with accelerated cognitive decline (Richard et al. 2013). This study's results suggest that

individuals with MCI likely feel a significant change in identity, a sense of loss, and invalidation. In response to these experiences, participants reported emotional distress, including anger, frustration, despair, loss of control, and isolation. Together, it is likely that these experiences contribute to the depression commonly reported among those with MCI. Somewhat perplexingly, although such upset would often warrant psychological attention, these issues seem to be regularly overlooked in the MCI population. Though this may be due to systematic ageism that undervalues the wellbeing of older adults more generally or underestimates their needs (Degn Pedersen & Mehlsen, 2011), it is more likely that grief is not commonly recognized in this group due to the inappropriate application of finite and interpersonal grief and loss paradigms. Alternatively, MCI individuals' emotional turmoil may be overshadowed by their more apparent cognitive impairments. Nevertheless, provided that loss does occur and individuals feel disenfranchised and less agentic in their own lives, these aspects of the MCI experience require clinical attention. Psychotherapeutic interventions may help to delay progression to dementia and prolong functioning through fostering emotional wellbeing. Providing an open and supportive environment for those with MCI to share their experiences may help to validate their experiences, provide social support, reduce resentment in their relationships, and generally raise their quality of life.

The implication of a chronic sorrow framework may provide some direction in terms of effective intervention approaches for those with MCI. Gordon (2009) presents that approaches that favour empathy, provide encouragement and praise for individuals' coping, and allow for "emotional ventilation" were rated as the most effective by parents experiencing chronic sorrow due to the loss of their child. Indeed, companionship and the pursuit of acceptance are viewed as being more fruitful aims in chronic sorrow intervention than achieving closure, as may be more

relevant to traditional finite losses (Imao, 2004; Rossheim & McAdams, 2010). Langridge (2002) adds to this that the provision of clear and accurate medical information may decrease ambiguity and, thereby, reduce chronic sorrow. Another consideration that is integral to any chronic sorrow intervention is an understanding of the long-term nature of chronic sorrow. With this in mind, Imao (2004) cautions clinical practitioners to respect that the mourning process for those with chronic sorrow is likely to span a longer period of time than for those experiencing more traditional grief. The application of traditional models of grief to chronic sorrow experiences may not only be unsuitable, but iatrogenic. In fact, one study found that health care professionals often served to make parents with chronic sorrow feel more hopeless, and that parents' optimism was often construed as a symptom of distress (Griffin & Kearney, 2001).

However, considering that the majority of research conducted on chronic sorrow interventions continues to focus on interpersonal losses, the efficacy of previously identified chronic sorrow interventions for individuals with MCI remains unclear. Further, MCI presents unique threats to self and fears for the future that may benefit more from the application of other psychotherapeutic approaches – though which approaches may be most appropriate requires consideration. Cognitive-behavioural therapy remains a dominant approach in psychotherapy and its focus on cognitive restructuring and benefit finding has been shown to decrease the severity of grief and depression in traditional bereavement (Harper, O'Connor, & O'Carroll, 2014), however, its utility in treating prolonged or complicated grief – which is arguably more comparable to chronic sorrow and grief in MCI – remains debated (Bhattacharya, 2015; Nagy & Szamoskozi, 2013). Additionally, cognitive restructure requires a degree of cognitive flexibility and access to episodic memories of thought experiences (Petersen et al., 1999; Traykov et al., 2007). Given that those with MCI regularly experience difficulty in these domains, whether this

approach proves effective for MCI may be contingent on the degree and nature of individuals' particular constellation of cognitive impairments and their residual cognitive abilities.

Alternative to cognitive restructuring, Bryant and coworkers (2014) suggest that the active ingredient in effective cognitive-behavioural approaches to prolonged grief may be exposure to memories of the lost; however, it is unclear how this may be accommodated to the contexts of nonfinite loss and identity change in individuals with MCI.

Interpersonal therapy, on the other hand, is specifically designed to address issues of grief, role transition, and social relationships (Markowitz & Weissman, 2004; Weissman, Markowitz, & Klerman, 2000). This may be a more suitable choice and may help those with MCI adjust their social roles and navigate grief with less emotional turmoil. Further, interpersonal therapy's focus on relationships may benefit those who feel isolated or alienated by their loved ones due to disenfranchisement of their loss and grief. With that said, interpersonal therapy focuses more on interpersonal loss and may not address the nuances of nonfinite, health-related losses as well as bereavement-related issues.

Yet another possibility is the application of mindfulness-based therapies. Bruce and Schultz (2001) state that the only feasible goal when working with many chronic health adversities is to help individuals achieve a sense of acceptance, paralleling the reported coping goals of those with MCI. Mindfulness-based therapies – such as mindfulness-based cognitive therapy for depression (Segal, Williams, & Teasdale, 2002) and acceptance and commitment therapy (Harris, 2006; Hayes, Luoma, Bond, Masuda, & Lillis, 2006) – share a common thread of advocating for less attachment to a single inflexible self-concept, an acceptance of change and release of (the illusion of) control, and the adoption of a less value-polarized (e.g. good vs. bad) view of one's situation and the world. Additionally, many approaches may also extend these

tenets of equanimity and inconsistency to individuals' fears of mortality. Thus, mindfulness-based approaches may have the most utility in helping individuals with MCI accept their changes, and the likelihood of further changes, without existential distress. This is supported by a study by Paller and colleagues demonstrating that mindfulness-based interventions led patients with cognitive decline to report greater quality of life and fewer depressive symptoms (Paller et al., 2015).

Existential therapies, too, may be a viable option, as they focus on managing internal conflict through reconciling individuals to the "givens" of meaninglessness, existential isolation, and the inevitability of one's own mortality (Macquarrie, 1972; Vos, Cooper, Correia, & Craig, 2015). Reminiscence therapy may prove useful in this vein as well, as it helps older adults to integrate their pasts with their present and future. Reminiscence therapy has been shown to have a positive impact on mental health and to help individuals come to terms with their eventual mortality in normatively aging older adults (Afonso et al., 2011; Dempsey et al., 2014).

Finally, and perhaps most simply, grief counseling or psychotherapy based upon a Rogerian approach may be beneficial (Capretto, 2015; Gordon, 2009). Rogerian approaches do not seek to repair dysfunction or provide insight, but rather, validate, empathize, and listen to individuals. Given the isolation and silencing experienced by those with MCI, this approach may very well be sufficient to reduce anxiety and ameliorate individuals' loneliness. This approach also corresponds most closely with those approaches advocated for use with chronic sorrow (Gordon, 2009). These approaches may be further augmented through the inclusion of aspects of MCI individuals' spiritual beliefs if any are endorsed (Capretto, 2015; MacKinnon, 2013).

Aside from individual therapeutic approaches, and in light of the centrality of disenfranchisement and ambiguity in the MCI experience, persons with MCI may also benefit

from support groups in the community. Several participants stated that they sought such opportunities and that they attended dementia-related lectures when possible, but that they ultimately felt the available options did not pertain to their condition. Further, almost all participants stated that they felt that they were unique and alone in their experience, and that they did not know where to find information. The organization of an MCI support group in the community may be a powerful resource for those with MCI, not only to connect socially and share their experiences, but also to benefit from others' knowledge and experiences. A support group may be additionally beneficial if family members were to attend as well. Most participants in this study stated that their family members felt that their perceptions of impairment were related more to personality than any actual change or decline despite receiving a diagnosis. It is possible that exposure to others with MCI may help those with MCI demonstrate to their families that their experiences and concerns are not unique to them and are deserving of validation. Moreover, if family members are resistant to accepting the reality of MCI-related distress and loss due to their own fears of dementia, a support group including other families may help provide succor to them as well, thereby helping them to be more available to their own family member with MCI (Paun et al., 2015).

Caveats and Limitations

Though this study aimed to provide general themes that may permeate the experience of those with MCI, there are several caveats to the results provided. Notably, there was a marked difference in content and response style between those individuals with no prior mental health history and those with preexisting or concurrent anxiety, depression, and/or substance abuse issues. Those with comorbid or preexisting mental health issues were overall more resistant to engaging with the negative aspects of MCI and endorsed more apparent acceptance of their

diagnosis (though the degree of their acceptance varied throughout their accounts). Furthermore, these individuals were also those who reported the most confusion regarding the normativity of MCI. This may be partially due to a misunderstanding of which experiences were due to MCI and which were due to their mental health adversities. Though the experiences of these individuals are an important addition, the majority of the disconfirming evidence found for the themes and thematic structure was derived from these participants' accounts. It is therefore likely that the results of this study may better describe the experiences of those without a positive mental health history than those with.

An additional consideration is that, based on the authors' observations, several participants may have engaged in defensive denial throughout the study due to the potentially threatening nature of MCI or high anxiety. This coping response would not be surprising given that it has been found in MCI individuals before (Joosten-Weyn et al., 2008; Roberts & Clare, 2013). Where one participant spoke primarily about her retirement rather than discussing MCI at length, another spoke almost exclusively about how developing MCI was one of the best experiences of her life. This latter participant rated highly on all measures of defensiveness (rendering the quantitative measures invalid) and was visibly uncomfortable speaking about any negative MCI-related events or emotions. This participant also acknowledged the possibility of her own denial following her interview. Thus, the information derived from this participants' interviews in particular may have been influenced by impression management concerns and emotional distress and, consequently, should be interpreted with caution. Although it may be practically difficult to distinguish between defensive denial and the possibility of anosognosia, the fact that this participant acknowledged her cognitive deficits freely and that her occasional reports of distress were discontinued quickly in favour of elaborate reports of positive impacts,

lead the researcher to speculate that anxious avoidance and denial were more likely explanations for this report than anosognosia.

This study also used a relatively small sample and did not achieve theoretical saturation. As an initial exploration of grief in those with MCI, this study may have served as a valuable proof of principle; however, further study will be required to provide a comprehensive account of the MCI experience. Specifically, further sampling from MCI populations both with and without mental health histories will be required in order to reach saturation. What is more, a comprehensive interpretive description will benefit from including samples from other grieving populations (e.g. spousally bereaved, other chronic illness) to better determine the extent to which the grief experienced in MCI is comparable.

The results of this study may also warrant cautious application to individuals with MCI from different cultural or socioeconomic populations. The sample used in this study was relatively highly educated, middle to upper-middle class individuals of Western European descent. Although this sample is representative of the local population in Victoria, BC, the results derived from this sample may not apply entirely to those of different cultures or socioeconomic status (due to potential differences in access to resources or health-related knowledge). Further, given the known influence of years of education on rate of cognitive decline (Zahodne, Stern, & Manly, 2015), it is possible that individuals with less education may have a different experience of MCI or distress resulting therefrom. The degree of emotional distress and identity change experienced by “working class” individuals with MCI may be attenuated by social roles unrelated to or heavily impacted by cognitive impairment.

Further, although all participants in this study had received a diagnosis of MCI from a qualified professional, it was unclear what criteria were used for their diagnosis, which subtype

each individual represented, or what the nature and degree of each individuals' impairments were. As a result, it is possible that the study participants may have represented several subtypes of MCI (e.g. amnesic MCI, non-amnesic MCI, MCI multi-domain, MCI single-domain). Future investigations would benefit from more comprehensive neuropsychological assessment to better characterize the sample and provide a more nuanced description based on diagnostic categories. Moreover, by taking these variations into account, future studies may be better able to determine whether and which interventions are effective for different MCI classifications and presentations. Finally, future iterations of this study would benefit from a longitudinal design in order to allow for determination of grief responses and emotional outcomes over time, as well as their impact on actual progression to dementia.

In conclusion, this study identified losses of self and roles, disconnection and disenfranchisement, and uncertainty and ambiguity regarding their diagnosis and its implications as key facets of the MCI experience. Together with emotional distress, these facets suggest that those with MCI experience a nonfinite, likely ambiguous, loss related to changes in identity and self-concepts. In response to this loss, participants experience a grief reaction best characterized as probable chronic sorrow informed by disenfranchised grief. Further, it is possible that those with MCI may experience death anxiety due to a perceived equation of progression to dementia with dying. Although these results were robust, these themes should be only applied with caution to individuals with comorbid/preexisting mental health adversities and low education or socioeconomic status.

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Appendix A
Telephone Screening Protocol

Demographics

- Date of Birth (year/month/day): _____
- Age: _____
- Sex: M F Other
- Ethnicity: _____
- English First Language?:
Yes No
- If no, at what age did you learn English?: _____
- If no, what is the primary language spoken at home?:

- Years of Education: _____
- Highest Level of Education Completed:

<i>High School</i>	<input type="checkbox"/>	<i>Master's Degree</i>	<input type="checkbox"/>
<i>Diploma/Certificate</i>	<input type="checkbox"/>	<i>Doctorate Degree</i>	<input type="checkbox"/>
<i>Bachelor's Degree</i>	<input type="checkbox"/>		
- Occupation:
 - *I am retired*
 - *I am working* (please describe): _____

MCI & Mental Health

- Have you been told you have mild cognitive impairment (MCI)?
Yes No
- If yes, who told you that you have MCI? (i.e. neurologist, family doctor, etc):

- If yes, when were you told you have MCI? (year): _____
- Have you been told you have Alzheimer's disease or any other kind of dementia?
(please check one):
No

-
-
- If yes, who told you that you have Alzheimer's disease or other dementia? (i.e. neurologist, family doctor, etc):

-
- Is there a family history of Alzheimer's disease, dementia or other memory problems?

Yes No

- Have you been told you have a psychiatric disorder?:
No

-
-
- If yes, who told you that you have a psychiatric disorder? (i.e. neurologist, family doctor, etc):

-
- Have you ever struggled with depression or anxiety?
No

-
- Is there a family history of psychiatric problems?
Yes No

- Were you ever diagnosed with a learning disorder?
Yes No

Physical Health

- Do you have any other health issues?:
No
-

- Do you have double vision or problems reading print?
Yes No
 - Have you ever had a neurological disease or injury (epilepsy, stroke, Parkinson's disease, brain injury)?
Yes No
 - Do you take any medications? What are they for?:
No
-

Cognitive concerns

- Are you concerned that your thinking abilities have declined more than you would expect for your age?:
Yes No
 - If yes, how long ago/when did you start to notice changes in your thinking abilities (Age, year, years ago): _____
 - Do these changes in your thinking abilities affect daily activities (i.e. cooking, shopping, managing your bills)?
Yes No DK
 - Have these changes gotten worse over time?
Yes No DK
 - How would you rate your understanding of what mild cognitive impairment (MCI) is?:

1	2	3	4	5
I do not know what MCI is at all		I think I have a fairly good idea what MCI is		I completely understand what MCI is
 - 15. In your own words, what is mild cognitive impairment (MCI)?:
-

Informant

- Do you have a person who knows you well and with whom you have at least 10 hours per week of direct or phone contact, and who could answer questions about your mental ability and general health?

Yes No Name: _____

Relationship: _____

Administer the Lawton-Brody Instrumental Activities of Daily Living***(IADL) Scale (Lawton & Brody, 1969)***

DEBRIEFING:

Thank you so much for answering all of my questions. As I explained, we are looking for specific individuals to participate in this study. The phone screen is the first step in the process of determining eligibility, however, if you are accepted into the study, your eligibility will also be assessed following the first day of data collection. Please be aware that none of the information gathered during this study can or will be used to make a medical diagnosis. As such, if you are found to be ineligible for inclusion in this study, this does not imply any medical issues. However, if you do have any concerns about your health, you are encouraged to follow up with your primary health provider (i.e. family doctor). Further, if participation in this study has caused you any undue distress, please feel free to follow up with any of the excellent supports in the community.

Do you have any questions for me at this time?

Yes No Don't know

1b. If yes, which type of professional diagnosed them? (i.e. neurologist, family doctor, etc):

1c. When were they diagnosed? (please write year):

2. Has the study participant been diagnosed with Alzheimer's disease or any other kind of dementia? (please check one):

Yes No Don't know

2b. If yes, what diagnosis have they received?:

3. Has the study participant been diagnosed with any other health issues? (please list or check No or Don't Know):

No Don't Know

4. Has the study participant ever had a head/brain injury? (please check one):

Yes No Don't know

5. Has the study participant been diagnosed with a psychiatric illness (including depression or anxiety)? (please list or check No):

No Don't Know

6. How would you rate your own understanding of what mild cognitive impairment (MCI) is? (please circle one):

1	2	3	4	5
I do not know what MCI is at all		I think I have a fairly good idea what MCI is		I completely understand what MCI is

7. In your own words, what is MCI?

8. How much would you say your friend/family member with MCI has changed since being told they have MCI?

1	2	3	4	5
Not at all. They are the same as before.		Somewhat. Certain things have changed, but many have stayed the same.		Entirely. They are a different person

9. Have you noticed changes in the study participant's mood or behaviour since they were told they have MCI? (please describe, or check *No*):

No

10. Have you noticed changes in the study participant's energy or motivation since they were told they have MCI? (please describe, or check *No*):

No

11. Have you noticed any other changes in the study participant since being told that they have MCI that I have not asked about yet? (please describe, or check *No*):

No
