

Caregiver Identity Development and Mental Health in Care Partners of
Individuals with Mild Cognitive Impairment

by

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Abstract

As the number of Canadians diagnosed with cognitive impairment continues to increase, so will the demands on family members and friends who are providing them with care and support. Mild cognitive impairment (MCI) is one of the most prevalent forms of cognitive impairment, yet there is a dearth of literature focused on MCI care partners and their experiences, relative to dementia caregivers. Given that an MCI diagnosis is associated with a higher probability of progression to dementia, investing in support services to sustain MCI care partners is critical. The overarching objective of this dissertation (comprised of two distinct and separate studies) was to gain clarity on MCI care partners' caregiver identity and mental health to inform support services tailored to help address their needs. In Study 1, I conducted in-depth interviews (n=18) to explore how caregiver identity develops in family and friends of individuals with MCI, and analyzed the data according to constructivist grounded theory. The overarching themes influencing MCI caregiver identity development included: MCI changes; care-related experiences; "caregiver" interpretation; and approach/avoidance coping. These themes influenced how participants primarily identified, represented as: "I am a caregiver," "I am not a caregiver," or "liminality" (i.e., between their previous identity and a caregiver identity), and all conveyed thinking about their "future self," as providing more intensive care. These findings underscore that irrespective of how individuals identified, they were engaging in care, and would likely benefit from support with navigating these changes and their new, ambiguous, and evolving roles. In Study 2, my first objective was to compare MCI care partner and dementia caregiver (n=137) mental health. Results showed that both caregiver groups endorsed notable mental health symptoms, with dementia caregivers endorsing greater anxiety, depression, and burden. To meet my second objective, mediation results indicated that differences between MCI and dementia caregiver mental health were due to (i.e., mediated by) how distressed caregivers were by care-recipient behaviour disruptions and depression symptoms, but not memory symptoms. Lastly, results showed that distress regarding care-recipient behaviour disruptions and depression symptoms were equally important mediators in understanding caregiver mental health. These results underscore the importance of preventing or reducing poor mental health for individuals at the MCI stage of caregiving. Overall, findings from both studies provide important and additive insights to support MCI care partners along their caregiving trajectories, including implications for health care support services and future research.

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Dedication

I dedicate this dissertation to my parents, Debbie and Brent Beatie, who have provided care for many family members and friends through different seasons of our lives. Your care and kindness towards others instilled important values that have shaped me –and my work. Thank you for your unwavering support, patience, and love.

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Chapter 1: General Introduction

Preface

As the older adult Canadian population continues to increase at a rate that is four times faster than the population at large (Statistics Canada, 2020), the prevalence of people with chronic conditions who need some form of care will also increase (Eifert et al., 2015). Cognitive impairment is one of the most significant causes of disability experienced by Canadian older adults (Griffith et al., 2010), and often requires family-based care (Zarit & Femia, 2008). One of the most prevalent forms of cognitive impairment among older adults is mild cognitive impairment (MCI; Kim, 2011; Knopman et al., 2016; Petersen et al., 2014, 2018; Prince et al., 2013). MCI is characterized by a deterioration of memory, attention, and cognitive function beyond what is expected based on age and education level, yet it does not cause significant impairment in daily functioning (Petersen et al., 2014, 2018). MCI has also been viewed as the intermediate stage of cognitive impairment that is often, but not always, a transitional phase between normal cognitive aging and dementia (Blieszner & Roberto, 2010; Gauthier, 2006; Petersen et al., 2014, 2018). For example, although the risk of progression to dementia is heightened, some individuals' degree of cognitive impairment remains stable over time and a smaller portion will even return to a level of cognitive function that is normal for their age and education (Odawara, 2012; Petersen et al., 2018; Ward et al., 2012). Understandably, this diagnosis is associated with variability and ambiguity both for those diagnosed and the people caring for them (Blieszner et al., 2007; Gomersall et al., 2015).

Research on MCI care partners suggests that they too are a heterogeneous group. Although other labels (e.g., caregiver) are used within the literature to refer to family members and friends providing some form of support or care for individuals with MCI, I will refer to this group as "MCI care partners" and I provide additional rationale for this later in the literature review section. MCI care partners perform a variety of tasks that are largely dependent on the degree of impairment of the person with MCI (Seeher et al., 2013). The addition of care-related tasks in response to their family member or friend's decline, coupled with the high risk of MCI progressing to dementia, can contribute to significant levels of stress for individuals diagnosed and their care partners. Considerably less research has examined MCI care partners' mental health compared to care partners later in the caregiving trajectory (i.e., dementia caregivers). However, research to date demonstrates that MCI care partners' levels of stress and burden

exceed that of the general public, with an increased risk of developing depression and anxiety (Connors et al., 2019; Seeher et al., 2013; Werner, 2012). Relatedly, some studies highlight the importance of providing support services for care partners at the MCI stage to potentially prevent or reduce poor mental health by enhancing their ability to cope with challenges adjusting to the caregiving role (Johnston et al., 2011; Ryan et al., 2010; Underwood & Yost, 2016; Woolmore-Goodwin et al., 2016). Yet these resources continue to be underutilized by both MCI care partners and caregivers in general (Austrom & Lu, 2009; Bayly et al., 2019; Eifert et al., 2015, 2021; Garand et al., 2014). Several barriers to accessing such services have been identified, including insufficient availability of services, lack of perceived need for help, lack of service knowledge, and financial concerns (Keefe, 2011; Morgan et al., 2002; Peterson et al., 2016). One additional key reason may be that many of these individuals do not self-identify as caregivers (Andréasson et al., 2018; Eifert et al., 2015, 2021; O'Connor, 1999), which has not been explored as thoroughly.

To effectively support family members and friends providing care for individuals with MCI, I believe it is important to take a step back to examine what it means to be an “MCI caregiver,” and the extent to which they identify with this role. Relatedly, further research is required to better understand the potential impact of assuming additional caregiving responsibilities or adopting a caregiver identity on family members and friends’ mental health. Specifically, examining MCI care partners’ perceptions of changes observed in the individual living with MCI could offer insight into the impact of caregiving on mental health outcomes. Developing an in-depth understanding of factors that impact their caregiver identity development and mental health is critical as this information may provide insight on how to best support them as they navigate their evolving caregiver roles (Upton et al., 2015).

The overarching objective of this dissertation is to gain clarity on this unique population’s identity and mental health to inform appropriate support services to address their needs. I will meet this objective with two independent studies presented in a grouped manuscript format that are preceded in this “sandwich dissertation” by a general introduction, and followed by a general discussion. The objective of the first study (Chapter 2) is to explore how caregiver identity develops in family members and friends of people living with MCI. This study has already been published in the journal *Dementia* (Beatie et al., 2021). The objective of the second study (Chapter 3), which has not yet been submitted for publication, is to examine MCI care

partner mental health in comparison to dementia caregivers, including an examination of factors that mediate the relationship between caregiver type and negative mental health. I begin this general introduction by describing relevant background literature to underscore the importance of this research. This includes a review of literature on societal impacts of cognitive impairment in older adults, MCI as a diagnostic entity and its relationship to dementia, MCI care partners' experiences and mental health, and caregiver identity. I conclude the general introduction by providing an overview of the design of the two studies that comprise my dissertation.

Contribution of Authors

I, Ms. Brooke Beatie, M.A., am the primary contributor to Studies 1 and 2. With respect to Study 1, I was primarily responsible for the study conception and design, literature searches, data collection, analysis and interpretation of the data, and writing the first draft and editing subsequent drafts of the manuscript. This first study also included contributions from the following co-authors: Dr. Corey S. Mackenzie, C. Psych., Dr. Laura Funk, Mr. Dylan Davidson, M.A., Dr. Lesley Koven, C. Psych., and Dr. Kristin A. Reynolds, C. Psych. Drs. Mackenzie, Funk, and Koven provided input on the study design, analysis and interpretation of the data (particularly during theoretical coding), and reviewed drafts of the manuscript. Mr. Davidson provided input on analysis and interpretation of the data; he conducted line-by-line "initial coding" of the transcripts with me and provided written case summaries. Lastly, Dr. Reynolds provided input during the analysis and interpretation of the data (particularly during theoretical coding) and reviewed drafts of the manuscript.

Study 2 is based on data collected from November 2013 and June 2019 as part of a clinical service at the Early Cognitive Change Clinic in Winnipeg, Manitoba, Canada, run by Drs. Lesley Koven and Colleen Millikin. I was not, therefore, responsible for choosing the measures or collecting this data. For Study 2, I was primarily responsible for the study conception and design (specifically, analytic planning), literature searches, data entry and analyses, interpretation of the data, and writing the first draft and editing subsequent drafts. This study also included contributions from the following co-authors authors: Dr. Corey S. Mackenzie, C. Psych., Dr. Lesley Koven, C. Psych., Dr. Kristin A. Reynolds, C. Psych., and Dr. Jessica Cameron. Drs. Mackenzie and Koven provided input on the study design and analyses, and reviewed drafts of the manuscript. Lastly, Drs. Reynolds and Cameron provided input regarding the study design, and reviewed drafts of the manuscript.

Use of Copyrighted Material

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Literature Review

There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers.

—Rosalynn Carter, former First Lady of the United States

Societal Impacts of Cognitive Impairment in Older Adults

The number of family members and friends who assume caregiver roles is expected to increase coinciding with the numbers of older adults who are living with cognitive impairments (Eifert et al., 2015; Keefe et al., 2012; Nichols et al., 2019; Zarit & Femia, 2008). When an individual develops a cognitive impairment, members in their social network may assume caregiving responsibilities without necessarily knowing what those roles require or the impact the responsibilities may have on their identity and mental health.

Dementia is among the most common forms of cognitive impairment experienced by older adults and it is one of the major causes of disability and dependency worldwide (Nichols et al., 2019; World Health Organization, 2020). Dementia is considered an umbrella term for a number of progressive disorders (e.g., Alzheimer's Disease, Vascular Dementia, Frontotemporal Dementia, Lewy Body Dementia) sharing symptoms of memory loss and cognitive and functional impairments (e.g., difficulties with thinking, problem-solving, and language; Connors et al., 2020). Currently, one in five Canadians have experienced caring for someone living with dementia (Alzheimer's Society of Canada, 2021), which can bring about mental and physical health challenges and, at the same time, can also strengthen one's commitment to the relationship and confidence in their ability to provide care (Haley et al., 1995; Lloyd et al., 2016; Queluz et al., 2020; Roberto et al., 2019; Stall et al., 2019). Dementia caregivers provide an average of 26 hours of care per week and the total out-of-pocket costs incurred by dementia caregivers were 1.4 billion dollars in 2016 (Alzheimer Society of Canada, 2016). This number is estimated to increase to 2.4 billion dollars in 2031, yet out-of-pocket costs are only a small proportion of the overall contribution of caregiving (Alzheimer Society of Canada, 2016). Understandably, extensive research has been dedicated to dementia in an effort to better support not only those diagnosed, but also the family members and friends that are affected by this diagnosis, in addition to society at large. Given that there is currently no cure for dementia (Alzheimer's Society of Canada, 2021) and in light of the failure of drug trials in Alzheimer's disease

treatment, researchers have shifted their focus to delay the progression of dementia, which has included an emphasis on better understanding the relationship and progression of MCI, as this could reduce the prevalence and cost of dementia substantially (Anderson, 2019).

Relationship between Dementia and Mild Cognitive Impairment

Half a million Canadians aged 65 and older are currently living with MCI, although many may not know it as only a small percentage pursue a diagnosis (Andersen et al., 2012). MCI is characterized by a deterioration of memory, attention, and cognitive function beyond what is expected based on age and education level (Petersen et al., 2014). While MCI does not cause impairment in daily functioning, individuals presenting with this condition vary greatly in terms of type of impairment (e.g., memory vs. non-memory impaired cognitive domains) and severity of symptoms (Prince et al., 2013). MCI has also been viewed as the intermediate stage of cognitive impairment that is often, but not always, a transitional phase between normal cognitive aging and dementia (Petersen et al., 2018; Roberto et al., 2013). Current research states that MCI is associated with an increased risk of developing dementia, particularly Alzheimer's disease (Anderson, 2019). Approximately 10–15% of people diagnosed with MCI develop dementia within the first year, which increases to 80%–90% after approximately six years (Eshkoor et al., 2015). Additionally, some forms of MCI (e.g., amnesic MCI) are more likely to progress from MCI to dementia (Gauthier et al., 2006; Petersen et al., 2014; Roberts & Knopman, 2013). Although the conversion rate to dementia is high, not all people with MCI progress to dementia, and some eventually improve and return to a level of cognitive functioning that is normal for their age and education (Odawara, 2012; Petersen et al., 2018; Ward et al., 2012). As such, MCI is considered a heterogeneous diagnostic label, and individuals with this condition present with varying degrees of impairment (Petersen et al., 2011, 2014, 2018).

MCI was first introduced as a term in 1988 by Reisberg and colleagues, and was used to refer to stage 3 of the Global Deterioration Scale. As literature on MCI advanced, researchers realized that severity scale ratings did not account for the subtle differences between MCI and early dementia, and more detailed diagnostic criteria were warranted (Petersen et al., 2011). In response to this, new criteria for MCI were put forth in 1999, which included: memory complaint, objective memory impairment for age, normal general cognitive function, and generally preserved activities of daily living (Petersen et al., 1999). Petersen and colleagues (1999) focused on MCI as a prodromal condition for Alzheimer's disease and emphasized

memory impairment in the diagnostic criteria. However, researchers continued to observe that not all forms of MCI evolved into Alzheimer's disease, and decided that more expansive criteria were necessary to capture the different MCI presentations (Odawara, 2012; Petersen, 2004; Ward et al., 2012). Therefore, at a 2003 international conference on MCI, the criteria were expanded to include other forms of cognitive impairment, including attention, executive functioning, language, and visuospatial skills (Winblad et al., 2004). Finally, in 2013, the latest edition of the Diagnostic and Statistical Manual for Mental Disorders coined the term *mild neurocognitive disorder* (mild NCD) to describe MCI (American Psychiatric Association, 2013). The criteria for mild NCD include: (1) evidence of cognitive decline in one or more cognitive domains, obtained from reports from the client, an informant, or a clinician, or from objective testing; (2) preserved functional independence; (3) the cognitive impairments do not occur exclusively during episodes of delirium; (4) the cognitive deficits cannot be better explained by another condition (e.g., depression); and (5) criteria are not met for dementia. Although these are the most recent criteria, the term MCI continues to dominate in research and clinical settings (Anderson, 2019).

There are four subtypes of MCI: amnesic MCI single domain, amnesic MCI multiple domain, non-amnesic MCI single domain, and non-amnesia MCI multiple domain (Petersen, 2004). The subtypes are intended to recognize that not all forms of MCI progress to Alzheimer's disease, and instead may be a prodrome to other forms of dementia such as Vascular Dementia or Frontotemporal Dementia (Petersen et al., 2011). Amnesic MCI refers to patients presenting with memory impairment, whereas non-amnesic MCI refers to the absence of memory impairment with the presence of impairment in one or more non-memory cognitive domains (e.g., executive function/attention, language, and visuospatial skills; Petersen et al., 2014, 2018). These criteria are further refined by the number of impaired cognitive domains; single versus multiple (Petersen et al., 2014, 2018). The number of impaired domains has important implications for understanding underlying brain disease or pathology, disease severity, and probability of progression to dementia (Roberts & Knopman, 2013).

Further research on MCI can help both individuals diagnosed and their family members or friends who may be providing care for them, which may prepare them better for the likely onset of dementia (Bayly et al., 2019). Moreover, this information has important implications for the degree and form of care someone with MCI will require, and the possible increased risk of negative mental health outcomes, such as caregiver burden, for the individuals supporting them.

Yet despite the clinical and theoretical interest in MCI, much remains unknown about the people closest to those diagnosed, the “caregivers” of people with MCI.

Who Are “MCI Caregivers”?

Different labels are used when referring to family members and friends providing care for people with MCI (i.e., family caregiver, informal caregiver, caregiver role; Eifert et al., 2020; Paradise et al., 2015; Pine & Pine, 2018; Seeher et al., 2013). However, there are issues in using this terminology that are important to note. First, MCI does not cause significant impairment in daily functioning (Petersen et al., 2018), compared to more severe forms of cognitive impairment. Therefore, individuals with MCI typically do not require care or support with regard to activities of daily living (ADLs), which refer to basic self-care tasks such as bathing, dressing, and eating (Fisher et al., 2011; Petersen et al., 2018). Instead, people with MCI are more likely to require care or support with instrumental activities of daily living (IADLs), which are considered to be more complex skills needed to successfully live independently (e.g., managing finances, managing medication, and transportation (Bayly et al., 2019; Connors et al., 2019; Fisher et al., 2011; Garand et al., 2005; McIlvane et al., 2008). Yet, some researchers suspect that physical and sensory limitations may further burden people with MCI such that they need more support with ADLs than their cognitive impairment status alone would suggest (Anderson, 2019; Fisher et al., 2011). Second, researchers note that family members and friends who care for an individual with MCI may not necessarily identify as a caregiver, despite being labeled as such in studies (Paradise et al., 2015; Seeher et al., 2013). This discrepancy is consistent with research on caregivers in general (AARP, 2001; Eifert et al., 2015, 2021; Pruchno et al., 2008). Third, a further complication regarding the appropriateness of the term “caregiver” is that the defining features of what it means to be a family- or informal-caregiver varies across studies on MCI (Bastawrous, 2013). Although there is no clear objective criteria of what it means to be a caregiver in the literature (Gaugler et al., 2002; O'Connor, 2007; Schulz et al., 1995), most studies agree that a minimum criterion is that the person provides unpaid care and support to meet the needs of a family member or friend who is disabled, chronically ill, or frail (Keefe, 2011; National Alliance for Caregiving, 2020; Statistics Canada, 2020). Given these aforementioned complications with using the term “caregiver” in the context of MCI and for clarity and consistency with recent literature (Joosten-Weyn Banningh et al., 2013; Morris et al.,

2020; Pine, 2018; Roberto et al., 2011), I will continue to refer to family members and friends providing care for people with MCI as “MCI care partners.”

MCI Care Partners' Responsibilities

The experiences and responsibilities of MCI care partners vary greatly depending on the individual for whom they are caring, the severity of impairment, and the nature of the pre-existing relationship. Spouses are often the first to notice changes in their partner's cognitive functioning, which often requires them to assume more, or new, responsibilities and provide more emotional support (Pasymowski et al., 2013). Responsibilities with regard to providing care for people with MCI might include help with more complex IADLs such as transportation, shopping/running errands, cooking meals, housework, basic home maintenance, financial management, managing medications and managing medical appointments (Fisher et al., 2011; Garand et al., 2005; McIlvane et al., 2008). MCI care partners have reported engaging in these various care tasks for an average of 24 to 28 hours per week (McIlvane et al., 2008). As previously mentioned, although individuals with MCI typically should not require assistance with ADLs (i.e., basic self-care activities), some researchers suspect that they do because of physical and sensory limitations (Anderson, 2019; Fisher et al., 2011). Alternatively, support that individuals with MCI receive with regard to ADLs, and especially IADLs, may be more likely a reflection of previously established social roles within their relationship. Although performing a few of these tasks occasionally may be manageable, increasing and ongoing demands to care for a family member or friend with MCI can be extremely challenging (Paradise et al., 2015).

MCI Care Partners' Experiences

In addition to the aforementioned responsibilities, research exploring the experience of being an MCI care partner can include both positive and negative perceptions (Beach et al., 2000; Upton et al., 2015). Positive perceptions of caregiving, referred to as *uplifts* (Pinquart & Sörensen, 2003), that have been identified in the broader caregiving literature include: feeling useful and valued, experiencing additional meaning, learning new skills, feeling pride in one's own abilities to handle crises, a strengthened relationship with the care-recipient, and appreciation of closeness to the care-recipient (Pinquart & Sörensen, 2003; Schulz et al., 1997; Schulz & Sherwood, 2008). More specifically, one qualitative study examining 40 MCI care partners found that a positive reported outcome of caring for someone with amnesic MCI was feeling useful and needed (Woolmore-Goodwin et al., 2016). In line with this, another qualitative

study exploring couple dynamics ($N=11$) in the context of MCI found that some care partners perceived themselves positively, as effective and confident in their role (Pasymowski et al., 2013). Of the care partners who appeared to be struggling with adjusting to this role, even these participants self-reported that they remained committed to adapting and being open to trying new approaches to support their spouse (Pasymowski et al., 2013).

However, self-reports of positive experiences associated with MCI caregiving, do not appear to necessarily reduce or prevent potential negative or challenging experiences. One cross-sectional study examining the relationship between personal gain (i.e., increase in self-esteem and meaning added to care partners' lives) and depressed mood in 769 MCI care partners, found that all participants who reported a high level of personal gain also had an increased risk for depression (Lu et al., 2007). Therefore, some researchers argue that positive effects from caregiving (e.g., meaning added to caregivers' lives) do not necessary counteract stressful caregiver experiences (Lu et al., 2007). Researchers have also noted that the experience of caring for someone with MCI likely presents different challenges than caring for someone with dementia (Connors et al., 2019; Paradise et al., 2015). Unique aspects of MCI care partners' experiences involve challenges related to themes of anticipatory grief, future uncertainty, and caregiver identity, including role ambiguity.

A particular challenge unique to MCI care partners is their experience of ambiguous loss or anticipatory grief (i.e., phases of bereavement in advance of losing a significant person; Blieszner et al., 2007; Garand et al., 2012). Woolmore-Goodwin and colleagues (2016) conducted a qualitative phenomenology study found that MCI care partners' anticipatory grief involved multiple losses (e.g., of pre-existing relationship, control, hope), which shaped how care partners viewed themselves and made them question their ability to continue to provide care in the long-term. Additionally, previous studies suggest that anticipatory grief can negatively affect care partners' mood, as well as their physical health, productivity, and social relationships (Garand et al., 2012). Although anticipatory grief in MCI care partners has not been thoroughly examined, research thus far suggests that being female, reporting higher levels of caregiver burden, and higher levels of depression may be associated with a greater likelihood of experiencing anticipatory grief (Garand et al., 2012).

In addition to anticipatory grief, MCI care partners grapple with the uncertainty in their family member or friend. This future uncertainty is related to worries regarding how they would

be able to cope with potential changes (Beard & Neary, 2013). Additionally, the high risk of MCI progressing to dementia likely contributes to significant levels of stress not only for those diagnosed, but also for people caring for them (Gomersall et al., 2015, 2017). A recent qualitative study examining individuals with MCI and their family members' experiences of receiving a new MCI diagnosis found that uncertainty and fear emerged not only in response to current MCI symptom burden but also in relation to the future prognosis (Morris et al., 2020). Anticipatory grief and future uncertainty among MCI care partners are associated in some studies with a range of unpleasant emotions, including frustration, sadness, guilt, and anger (Betts Adams, 2006; Blieszner et al., 2007; Blieszner & Roberto, 2010; Lu & Haase, 2009). These experiences and emotions may also be signs of increasing tension MCI care partners may feel to "take on" a caregiver role or identity, as they continue to observe changes in their family member or friend.

Caregiver Identity

Although MCI care partners usually assume new roles and responsibilities (Blieszner & Roberto, 2010), likely impacting their identity, a more in-depth examination of what it means to be a caregiver, beyond the common sense, task-based understanding of caregiver responsibilities (O'Connor, 2007), is required. Previous researchers have theorized that identifying as a caregiver begins with an MCI diagnosis (De Vugt & Verhey, 2013; Woolmore-Goodwin et al., 2016), however, further research is required to explore the process of how, and if at all, MCI care partners come to identify as such. In part, the complexity of self-identifying as an MCI caregiver is related to the fact that people are faced with uncertainty in dealing with the symptoms, diagnosis, and prognosis of MCI (Lu & Haase, 2009). For example, the expression of impairment in people with MCI can vary (Roberto et al., 2013), which may create ambivalence in care partners regarding whether they fulfill or identify with this role. Therefore, as the literature on identity suggests, the process of caregiver identity development (even beyond the MCI context) may not be as simple as previously assumed (Eifert et al., 2015; O'Connor, 2007). Two influential identity theories that provide unique perspectives for understanding caregiver identity development include Positioning Theory and Caregiver Identity Theory, which will be explored in more detail below. It is important to note that these theories have been explored more extensively within the dementia literature and only to a lesser extent examining caregiver identity in MCI care partners.

Positioning Theory

A useful theory that has been used to examine the process of self-identification in caregiver samples (O'Connor, 2007), especially in qualitative research, is Positioning Theory (Harré & van Langenhove, 1999). Positioning Theory suggests that identity development is a dynamic and fluid process in which a “position” is constantly being renegotiated in relation to external influences and contexts (Harré & van Langenhove, 1999). According to Positioning Theory, an identity is discursively produced when an individual creates a new framework for understanding and constructing meaning about their actions (Harré & van Langenhove, 1999; O'Connor, 2007). One study using Positioning Theory to qualitatively examine caregiver self-identity found that recognizing oneself as a caregiver was constructed mainly through interactions with others (O'Connor, 2007). Without external influences, these 33 caregivers often viewed the work they did as an extension of their relational role (e.g., viewed work as a task related to being a wife, not a caregiver). Interestingly, positioning oneself as a caregiver might also occasionally compete with other social roles (e.g., wife position versus caregiver position), which can result in negative caregiver outcomes, including feelings of ambiguity, sadness, and anger (O'Connor, 2007; Roberto et al., 2013). Therefore, Positioning Theory provides unique insight into the relevance of integrating a caregiver positionality into one's identity, and the implications this has for whether caregivers will experience negative or positive outcomes in this regard.

Existing research on MCI caregiver identity is in line with Positioning Theory, which suggests that establishing an identity as a caregiver involves an ambiguous, dynamic, and evolving process of reconceptualizing other social role positions (Roberto et al., 2013; Woolmore-Goodwin et al., 2016). One qualitative study examining how 40 married couples responded to MCI over a three to four year period found that, as MCI symptoms worsened, caregivers were more likely to adopt a caregiver identity (Roberto et al., 2013). Transitioning to this new “position” helped caregivers to distance themselves emotionally from their partner's difficult behaviours and to cope more effectively with the increasing demands of dealing with MCI (Roberto et al., 2013). Similar to findings from O'Connor's (2007) study on caregiver self-identification, Roberto and colleagues (2013) found that participants' position as a caregiver occasionally competed with other positions they already fulfilled. For example, participants who adopted a caregiver identity self-reported feelings of ambiguity, sadness, and anger as they

attempted to sustain their identity as spouse, as their partners continued to decline (Roberto et al., 2013). Although MCI care partners are assumed to be at an early stage in their caregiving position relative to dementia caregivers, and may have had less time to adjust to the position (Dean & Wilcock, 2012), findings from this study suggest that identity development is occurring among MCI care partners (Roberto et al., 2013). However, as previously mentioned, other researchers have reported that MCI care partners do not necessarily identify as a caregivers (Paradise et al., 2015; Seeher et al., 2013). Based on Positioning Theory, a possible explanation for this is that the caregiver position is competing with other relational positions, and/or that caregiving behaviours are viewed as an extension of a relational position (Roberto et al., 2013). To further explore the complexities of why some individuals might identify as an MCI caregiver and others may not, a second theory on this topic provides useful perspectives.

Caregiver Identity Theory

Caregiver Identity Theory (CIT) is one of the most frequently used theoretical orientations in the caregiving literature, which has lent itself to the design and study of caregiver interventions (Montgomery & Kosloski, 2009). CIT is built on identity theory (Stryker, 1968, 1994; Stryker & Burke, 2000) and conceptualizes caregiving as a series of identity transitions that occur as a result of changes in the caregiving context (e.g., changes in symptoms of the care-recipient) and in personal and societal norms. A caregiver identity emerges from a pre-existing role relationship, often a familial role such as wife, husband, daughter, or son. Additionally, this theory suggests that similar to other social behaviours, caregiving identity is shaped by societal rules and cultural norms. In line with this, CIT suggests that a person's history and cultural background influence their expectations of caregiving responsibilities, and this lies within their own family ethos. Therefore, the caregiver role is influenced by the pre-existing relationship with the care-recipient and an idiosyncratic set of beliefs and expectations about their responsibility to provide care.

As the needs of the care-recipient continue to increase in both quantity and intensity, a "transition" has been theorized to occur; caregivers not only change their behaviours in how they provide care, they also tend to change the way they view their role in relation to the care-recipient, which Montgomery and Kosloski (2009) consider their "role identity." Essentially, a shift in identity occurs because care tasks that are required to maintain the health and well-being of the care-recipient are no longer consistent with the previous expectations associated with the

caregiver's initial relational role to the care-recipient. This incongruency causes distress for the caregiver, which must be reconciled. Distress may be manifested as a sense of objective burden (i.e., time compression), relationship burden (i.e., distress in the interpersonal relationship), and psychological burden (i.e., anxiety and depression). To provide relief and avoid distress, Montgomery and Kosloski (2009) theorize that a transition to a caregiver identity is necessary. CIT further posits that a change in identity is not a smooth and continuous process. Rather, it is a process that alternates between periods of stability (i.e., small adjustments in behaviour or changes in perception that do not result in an identity change) and periods where there are significant shifts in the caregiver's identity that are associated with the caregiver's acceptance of new norms for their behaviour.

Positioning Theory and CIT share a number of important implications in terms of caregiver identity development. First, caregiving is an idiosyncratic process, and therefore, the caregiver experience is personalized and unique to each individual. Second, there are differences among caregivers concerning the degree of tension, pressure, or distress they feel to "take on" a caregiver role or identity, and in the circumstances that ultimately determine whether and how they take on this identity. These differences speak to the diversity in background and history that shape individuals. Third, both theories speak to the idea that caregiver identity emerges from, and is influenced to some degree by, a pre-existing role relationship. However, CIT applies a developmental approach to identity development, whereas Positioning Theory suggests it is a more variable and fluid process.

Literature on caregiver identity suggests there is great variability in how and when people self-identify. Individuals may anticipate caregiving roles before ever beginning to provide such care (Sörensen, 1998) and other individuals may continue to hold a caregiver identity even after they are no longer providing care (e.g., bereaved caregivers becoming advocates for other caregivers; Larkin, 2009). Interestingly, some individuals may provide care without ever self-identifying as a caregiver (Funk, 2019; Hendersen, 2001; O'Connor, 1999), which may be true for MCI care partners for a few reasons. First, because MCI does not typically cause impairment in daily functioning (Petersen et al., 2014, 2018), care partners may not view the type of care they provide as significant enough to elicit an identity shift. Second, the expression of impairment in people with MCI varies (Roberto et al., 2013), which may create ambivalence in care partners regarding whether they fulfill or identify with a caregiver role versus their pre-

existing relational role (e.g., spouse). Third, self-identifying as a caregiver may signify that the care-recipient is dependent and needs help. Research shows that care partners may be worried about this, not wanting to intrude on the independence and autonomy of the care-recipient's identity (Eifert et al., 2015; Funk, 2019; O'Connor, 1999; Roberto et al., 2019). Relatedly, individuals may resist self-identifying as a caregiver because they are resisting the obligations that may be associated with that identity, as they may not be ready or willing for their role to be formalized in that way (O'Connor, 2007).

There is a noticeable gap in the literature aimed at understanding the experiences of MCI caregiver identity development, which warrants further exploration. Relatedly, examining MCI care partner mental health and how it may progress across the caregiving trajectory is needed to better understand the potential impacts on MCI care partners at this stage. A close interrelationship exists between identity related issues and mental health difficulties (Pearlin et al., 1990; Thoits, 2014), both of which are less understood in MCI care partners; this information is needed to inform ways to support them in their evolving role.

MCI Care Partners' Mental Health

Previous research, although limited, suggests that MCI care partners' responsibilities and experiences can sometimes lead to a decline in mental health, including burden, depression, and anxiety. Caregiver burden is the main theoretical construct used in the literature to examine negative effects associated with caregiving (Werner, 2012). Although no singular definition of caregiver burden exists, most researchers agree it is a multi-dimensional construct, including subjective and objective components of stress and burden that are associated with caring for someone with a chronic illness (Hall et al., 2014; Werner, 2012). A recent three year longitudinal study including 185 MCI care partners reported rates of clinically meaningful levels of burden ranging from 21.1% to 29.5% (Connors et al., 2019), which is consistent with previous prevalence rates (Seeher et al., 2013). Caregiver burden has also been associated with poor mental health, such as depression and anxiety (Garand et al., 2005; Paradise et al., 2015; Werner, 2012). A systematic review of cross-sectional research on 988 MCI care partners suggests that they are at an increased risk of developing significant symptoms of depression (Seeher et al., 2013). MCI care partners may also have an increased risk of developing anxiety symptoms, although there is significantly less research in this area and the existing cross-sectional research is based off of relatively small sample sizes (Garand et al., 2005, 2014; Lara-Ruiz et al., 2019).

Yet, qualitative studies have contributed rich accounts of anxiety related to care partners' worries about the diagnosis, life style constraints, and the future (Blieszner & Roberto, 2010; Carlozzi et al., 2018; Garand et al., 2012; Pasymowski et al., 2013).

A useful model to examine possible factors that contribute to negative mental health outcomes in care partners is the Stress Process Model (Pearlin et al., 1990). This model provides a comprehensive framework used to explain the diversity of the caregiving experience, and has been widely used to guide both research and practice related to caregiver stress. The Stress Process Model focuses on stressors (primary and secondary) at the individual, family, and community levels. Primary stressors are directly linked to the individual with cognitive impairment (e.g., neuropsychiatric symptoms and memory deficits) whereas secondary stressors arise from the demands of the caregiving role itself (e.g., constrictions of social life, family conflict). Relatedly, this model incorporates identity-related factors (e.g., role strains) as key contributors to the stress process that influence mental health outcomes. The model also notes that moderators (e.g., social supports, concepts of mastery or self-efficacy) determine how the same stressors affect people differently, which speaks to the diversity of caregiver experiences.

With regard to MCI care partners, their care-recipient's neuropsychiatric symptoms, a primary stressor, was the strongest predictor of caregiver burden in 185 participants over the course of a three year longitudinal study (Connors et al., 2019). A systematic review, and cross-sectional research studies have similarly shown that neuropsychiatric symptoms are strongly related to negative mental health outcomes such as depression and burden for MCI care partners (Blieszner & Roberto, 2010; Seeher et al., 2013). A recent cross-sectional study investigated the influence of the severity and frequency of different types of neuropsychiatric symptoms (e.g., dysphoria, agitation, disinhibition) on 108 MCI and mild Alzheimer's disease caregivers' emotional distress (Mavounza et al., 2020). This study found that both caregiver groups experienced an increased risk of developing emotional distress due to neuropsychiatric symptoms and that care-recipients' depressive symptoms induced elevated self-reported emotional distress among caregivers (Mavounza et al., 2020). Although this is an important finding, the authors were limited in their analyses by examining a general emotional distress variable without being able to examine more specific mental health outcomes. Examining the latter (i.e., depression and anxiety) is particularly needed among MCI care partners as this may provide important information to better address their support needs.

MCI Care Partners' Support Needs

Existing research suggests that there is currently a dearth of education materials and psychosocial supports specifically tailored for MCI care partners (Austrom & Lu, 2009) and research on support services for MCI care partners is limited. However, two important messages emerge from the literature. First, the majority of psychosocial (e.g., psychoeducation, support groups, psychotherapy) and indirect (e.g., memory training for the individual with MCI) support services have shown to be effective at reducing symptoms of depression, anxiety, and burden in MCI care partner samples (Garand et al., 2014; Greenaway et al., 2013; Joosten-Weyn Banningh et al., 2013; Lu et al., 2016). There is a strong rationale for providing MCI care partners with support services at this stage in the caregiving trajectory, as opposed to a later stage, when they are caring for someone with more severe impairment (i.e., dementia). Specifically, intervening at this early stage may provide longer-term preventative benefits to offset potential negative effects (e.g., burden) care partners may otherwise face as their care-recipients' needs increase (Garand et al., 2014). Additionally, at the MCI stage, care partners are experiencing challenges related to role ambiguity, anticipatory grief, and future uncertainty (Blieszner et al., 2007; Blieszner & Roberto, 2010; Carlozzi et al., 2018; Garand et al., 2012; Morris et al., 2020; Woolmore-Goodwin et al., 2016) and support services could help them in navigating their evolving role.

The second important message from the support service literature is that it is challenging to effectively reach and disseminate support services to MCI care partners (Dean & Wilcock, 2012; Woolmore-Goodwin et al., 2016). Most people in the community living with MCI are undiagnosed (Anderson, 2019); therefore, they and their family members may be unaware of the disorder, and of the potential resources from which they would benefit (Gildengers et al., 2016). It is only when the person with MCI's symptoms worsen, that family members and friends who are providing care are more likely to seek out support services for themselves (Woolmore-Goodwin et al., 2016). However, most of the available support services are tailored for "caregivers" and MCI care partners may not identify as such (Paradise et al., 2015; Seeher et al., 2013). Therefore, they may not think that they qualify for or could benefit from such supports. Yet, some MCI care partners are reporting a need for psychosocial support services (Ryan et al., 2010), which is consistent with researchers and clinicians advocating for support services for care partners at the MCI stage (Blieszner et al., 2007; Blieszner & Roberto, 2010; Carlozzi et al., 2018; Dean, 2013; Domingues et al., 2018; Woolmore-Goodwin et al., 2016). To develop a more

complete understanding of how to support MCI care partners, the interrelated constructs of caregiver identity and mental health require further exploration. In turn, this information can inform support services tailored to meet the needs of MCI care partners, and may help increase service utilization among this under-reached population.

Overview of Current Research Design

The current research is comprised of two distinct and separate studies, which were conducted concurrently. Yet, these studies are unified within the overarching aim to inform support services for MCI care partners based on information pertaining to their caregiver identity development and mental health. Study 1 employed a qualitative research design informed by constructivist grounded theory (ConGT) methodology, with the objective of exploring caregiver identity development in MCI care partners. Using quantitative methodology, the objectives of Study 2 were to compare MCI care partners' levels of anxiety, depression, and burden to dementia caregivers. A secondary objective was to examine whether care partners' reactions to care-recipients' symptoms (e.g., depression, memory deficits, behaviour disruptions) mediated the relationship between caregiver severity type (MCI vs. dementia) and poor mental health. Relatedly, my final objective was to investigate whether any of the three mediators were more critical in understanding caregiver mental health. While studies 1 and 2 answer specific research questions in line with their respective methodologies, they are related. Findings from both studies provide important and additive insights to better address how to support MCI care partners, including implications for improving access to services and potential strategies to meet the unique needs of MCI care partners. Following this introductory chapter (Chapter 1), Chapter 2 focuses on Study 1, exploring MCI caregiver identity development, and Chapter 3 focuses on Study 2, examining the mental health of MCI care partners compared to dementia caregivers. This dissertation concludes with Chapter 4, the general discussion, which provides a summary of the entirety of the current research and offers implications, including recommendations on support services for MCI care partners, and future directions.

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Chapter 2, Study 1: Caregiver Identity in Care Partners of Persons Living with Mild Cognitive Impairment

Abstract

Background and Objectives: Research on caregiver identity in the context of memory impairment has focused primarily on more advanced stages of the cognitive impairment trajectory (i.e., dementia caregivers), failing to capture the complex dynamics of early caregiver identity development (e.g., MCI; mild cognitive impairment caregivers). The aim of this study was to develop a nuanced understanding of how caregiver identity develops in family and friends of persons living with MCI.

Methods: Using constructivist grounded theory (ConGT), this study explored caregiver identity development from 18 in-depth interviews with spouses ($n = 13$), children ($n = 3$), and friends ($n = 2$) of persons recently diagnosed with MCI.

Findings: The overarching themes influencing MCI caregiver identity development included MCI changes, care-related experiences, “caregiver” interpretation, and approach/avoidance coping. These themes influenced how participants primarily identified, represented as “I am a caregiver,” “I am not a caregiver,” or “liminality” (i.e., between their previous identity and a caregiver identity). Irrespective of their current self-identification, all conveyed thinking about their “future self,” as providing more intensive care.

Discussion and Implications: MCI caregiver identity development in family and friends is a fluid and evolving process. Nearly all participants had taken on care tasks, yet the majority of these individuals did not clearly identify as caregivers. Irrespective of how participants identified, they were engaging in care, and would likely benefit from support with navigating these changes and their new, ambiguous, and evolving roles.

Introduction

Literature on caregiver identity in the context of aging and cognitive impairment has tended to focus on caregiving for persons living with dementia (Cross et al., 2018). However, there is growing interest in the experiences of people with mild cognitive impairment (MCI) and the family and friends who are supporting them (Joosten-Weyn Banningh et al., 2013; Morris et al., 2020; Petersen et al., 2011; Pine, 2018; Roberto et al., 2011). MCI is characterized by deterioration in memory, attention, and cognitive function beyond what is expected based on age and education. It is commonly viewed as a transitional phase between normal cognitive aging and dementia (Petersen et al., 2014). For example, roughly 10–15% of people diagnosed with MCI develop dementia within the first year, increasing to 80%–90% after approximately six years (Eshkoor et al., 2015). However, not everyone diagnosed with MCI develops dementia, and people with this condition vary greatly in terms of the presence or absence of memory impairment, the number of impaired cognitive domains, and symptom severity (Prince et al., 2013). Cognitive impairment(s) must be noticeable, but not severe enough to significantly impact daily functioning (Petersen et al., 2014). Understandably, this diagnosis is associated with variability and ambiguity both for those diagnosed (Gomersall et al., 2015) and their care partners.

Research on MCI care partners concludes that they too are a heterogeneous group, performing a variety of tasks that are largely dependent on the degree of impairment of the person with MCI (Seeher et al., 2013). Although different labels are used when referring to individuals in this group (e.g., family caregiver, informal caregiver, caregiver role), for clarity and consistency within the recent literature (Joosten-Weyn Banningh et al., 2013; Morris et al., 2020; Pine, 2018; Roberto et al., 2011), I will refer to this group as “care partners.” Despite diversity in responsibilities faced by MCI care partners, they commonly assume a number of caregiving tasks, (Fisher et al., 2011; McIlvane et al., 2008), which can sometimes lead to stress, burden, and negative effects on mental and cognitive health (Blieszner & Roberto, 2010). Yet, while this group could benefit from psychosocial support services (Ryan et al., 2010), they are unlikely to use them (Eifert et al., 2015). Although several barriers to accessing such services have been identified (e.g., insufficient availability of services, lack of perceived need for help, lack of service knowledge, financial concerns; Morgan et al., 2002; Peterson et al., 2016), a key reason may be that many of these individuals do not self-identify as caregivers (Eifert et al.,

2015). To best support MCI care partners, researchers must take a step back to examine what it means to be an “MCI caregiver.”

Caregiver identity is distinct from caregiving behaviour (Funk, 2019). Although MCI care partners help with tasks (e.g., managing finances and appointments, ensuring medication adherence; Fisher et al., 2011; McIlvane et al., 2008; Woolmore-Goodwin et al., 2016), how they identify is significantly less clear. Two useful theories contribute to our understanding of caregiver identity development: Positioning Theory (Harré & van Langenhove, 1999; O'Connor, 2007) and Caregiver Identity Theory (CIT; Montgomery & Kosloski, 2009). These theories align in suggesting that: 1) the caregiver experience is individualized, 2) caregivers differ in the degree of tension or distress around assuming a caregiver role or identity, and 3) caregiver identity is influenced by and emerges from a pre-existing relationship. However, CIT applies a developmental approach to identity development, whereas Positioning Theory suggests it is a more variable and fluid process. Further literature on caregiver identity suggests there is great variability in how and when people self-identify. For example, people may anticipate caregiving roles before ever beginning to provide such care (Sörensen, 1998). A caregiver identity may also continue even after an individual is no longer providing care (e.g., bereaved caregivers becoming advocates for other caregivers; Larkin, 2009). Interestingly, some individuals may provide care without ever self-identifying as a caregiver, which suggests a sense of discomfort with this identity (Funk, 2019; Hendersen, 2001; O'Connor, 1999). Overall, theory and prior research provide a solid foundation for exploring caregiver identity early in the caregiving process.

There is a noticeable gap in the literature aimed at understanding caregiver identity development in MCI. In fact, MCI care partners may not necessarily identify as caregivers, despite being labeled as such in studies (Dean et al., 2014; Morris et al., 2020; Paradise et al., 2015; Seeher et al., 2013). This may be especially true for MCI care partners for two reasons. First, because MCI does not cause impairment in daily functioning (Petersen et al., 2014), care partners may not view the type of care they provide as significant enough to elicit an identity shift. Second, the expression of impairment in people with MCI varies (Roberto et al., 2013), which may create ambivalence in care partners regarding whether they fulfill or identify with a caregiver role versus their pre-existing relational role (e.g., spouse).

I am aware of only one previous study addressing identity development within the context of MCI (Woolmore-Goodwin et al., 2016). Care partners symbolically wore “multiple

situational masks” to cope with accumulated progressive losses as they adjusted to their new and evolving identities. They reported “forbidden thoughts” (e.g., “sometimes I don’t want to be there for her”) - possible by-products of struggles accepting the social expectations involved in the new role. The authors highlighted the need to further explore the extent to which MCI care partners modify their self-concepts and identities. This aligns with previous research (Adams, 2006; Morris et al., 2020) which suggests that a deeper understanding of the early stages of caregiver identity development could provide insight into the attributes of persons who may be more prone to negative mental health outcomes and burnout. To address this gap, the current study examines how caregiver identity develops in care partners of people living with MCI. Insights into caregiver identity development in the context of MCI can inform the delivery of support services tailored to MCI care partners.

Methods

Research Design

This study was guided by constructivist grounded theory (ConGT) methodology (Charmaz, 2014). ConGT methodology is informed by the notion that knowledge is co-constructed through interactions with others and through historical and cultural norms that shape individuals’ lives to produce an interpretable understanding of the subjective meaning (Creswell, 2014). This methodological approach is suited to exploring understudied and complex social processes while generating theoretical insights with practical applications (Charmaz, 2014).

Constructivist Worldview

The constructivist worldview is based on the idea that individuals seek to understand the world in which they live and work by developing subjective meanings of their experiences (Lincoln et al., 2011). These meanings can vary from individual to individual, prompting researchers to rely as much as possible on the individual’s view of the situation being studied (Creswell, 2014). With this in mind, the interview questions, assessing participants’ caregiver identity development, were delivered in an open-ended format, which enabled participants to construct meaning from their experiences. Additionally, social constructivists tend to focus on examining the process of interaction among individuals (Creswell, 2014). They believe subjective meaning is formed through interactions with others and through historical and cultural norms that shape individuals’ lives (Creswell, 2014), which is in line with our conceptualization of the factors that shape identity development.

Constructivist Grounded Theory

In addition to coding, my research team and I (six members with professional and research backgrounds in geropsychology, clinical psychology, and sociology) used memo-writing and diagramming, to integrate and record theoretical directions during the analytic process (Charmaz, 2014). Memo-writing prompts researchers to analyze data and form codes early in the research process, capture important comparisons, and document questions for further analysis. Within memo-writing, clustering can be used to lay out the form and content of memos, which provides researchers with a flexible and creative technique to understand and organize the data. Clustering is intended to be a fast and fluid exercise, and it was especially useful to figure out how to begin writing about a certain construct (Charmaz, 2014). Diagramming is another useful method I used throughout analysis, which provided a visual representation of categories and subcategories, and helped my research team and I identify relationships, processes, and the direction of the emerging theory.

Study Setting

I recruited 18 participants from a memory clinic in a large health sciences centre of a major Canadian city. The memory clinic provides assessment and memory group intervention for older adults with cognitive impairment (including MCI and dementia) and their “program partners.” Program partners are spouses, children, or friends that people choose to bring with them to their initial neuropsychological assessment appointment.

Sampling and Participants

Consistent with grounded theory methodology, I used theoretical sampling to select participants according to emergent findings from ongoing data collection and subsequent analyses (Charmaz, 2014). Between February 2018 and November 2019, a geropsychologist approached 24 program partners to inform them of the study (see Appendices A and B) and 18 agreed to participate (response rate of 75 per cent). Program partners were eligible to enroll if: (a) their family member or friend received an MCI diagnosis within the past six months, and (b) they were fluent in English and had no obvious signs of cognitive impairment as determined by the geropsychologist. As themes began to emerge, additional participants were selected to enrich our theoretical understanding of caregiver identity development. My research team and I continued to examine emerging themes and adjusted the interview protocol as needed. I

continued to recruit participants until the data reached theoretical sufficiency, where few new ideas were emerging with additional interviews (Dey, 1999).

Data Collection

Consenting participants completed a semi-structured, approximately 75-minute interview with me in a location of their choice (e.g., their home or memory clinic). The interview protocol (see Appendix C) began with the central, open-ended question, "Can you start by telling me about your relationship with [care-recipient diagnosed with MCI]?" Depending on the response to this question, additional questions explored: details about their relationship before their friend/family member showed signs of MCI, societal and cultural norms (e.g., feelings of responsibility to provide care), contextual changes (e.g., the person with MCI's symptoms), changes in their own behaviour (e.g., care tasks), and how they view themselves since their friend/family member's decline. In line with ConGT, the interview questions evolved between interviews so as to build upon and generate theories through successive levels of data analysis and conceptual development. I documented field notes after each interview, which also helped identify preliminary themes and guide subsequent interviews. Interviews were audio-recorded, de-identified, and professionally transcribed.

Data Analysis

Consistent with ConGT (Charmaz, 2014), the interviewer, research team, and participants mutually co-constructed meaning regarding MCI caregiver identity development during data collection and analysis; the resulting theoretical diagram is an interpretation of this phenomenon. My research team and I used a constant comparative approach to analyze the data through three stages: initial coding, focused coding, and theoretical coding (Charmaz, 2014).

Transcripts, memos, and field notes were read, re-read, and my research assistant and I conducted line-by-line "initial coding" of the transcripts, which focused on preliminary concepts. Codes remained close to the data, with a particular focus on participants' use of language to generate codes as often as possible (e.g., "is this memory problems or is this the depression", "I am more of a teacher and a mother than I am as a wife," "caregiving is a lot of responsibility...we're not there yet.")). Our evolving list of initial codes, along with a selection of six transcripts, were reviewed and discussed with three additional research team members.

As additional interviews were conducted, each new transcript was coded and compared to previously analyzed interviews, which helped refine existing codes and generate new codes that

were more conceptual and described larger amounts of data (e.g., “my future self” code). I developed diagrams to further conceptualize and organize the initial and focused codes, which also provided theoretical direction during the analytic process.

Finally, during theoretical coding, my research team and I compared, refined, and related focused codes to each other, to develop main themes and sub-themes for the theoretical diagram. Consistent with ConGT, my team and I transitioned back and forth between these three phases of coding. We continued to compare incoming data with analyzed data to ensure we had a thorough understanding of participants' caregiver identity development, resulting in the final thematic categories.

Rigour

Throughout the analytic process, my research team and I maintained a rigorous audit trail, including coded interview transcripts and field notes, written case summaries for each participant, diagramming excerpts, and ongoing memos from the team to enhance analytic credibility and originality. Consolidated memos throughout the entire research process provided a visual trail of the various research stages, from formulating the research question to data collection and theoretical development. Additionally, given that under the constructivist paradigm, data collection and analyses are influenced by interactions between the researcher and participants (in addition to social, cultural, and structural contexts; Charmaz, 2014), I documented my personal reflections and how my background (e.g., my experiences as a clinical psychology doctoral student and clinician, and personal familial experience with caregiving) and presence affected my interactions with participants. Throughout the data collection and analytic process, these considerations were discussed with my research team and guided future participant interactions and analysis. Due to the rigorous analytic process, the constructed theoretical diagram offers a novel conceptual interpretation of MCI caregiver identity development.

Ethical Statement

This study received ethics approval from the University of Manitoba Research Ethics Board (P2017:136) and the St. Boniface General Hospital Research Review Committee (RRC:2017:1727) in Winnipeg, Manitoba, Canada. All participants provided written informed consent (see Appendix D) and received a \$10 gift card honorarium.

Findings

Sample Description

Participants were spouses (n=13), children (n=3), and friends (n=2) of persons recently diagnosed with MCI; including amnesic (n=16) and non-amnesic (n=2) MCI. The majority of participants (72%) lived with the person with MCI. Their ages ranged from 39 to 89 years old ($M=69.4$, $SD=12.8$), 61% identified as female, and 94% as White (one identified as Indigenous). Additional information on demographic characteristics is presented in Table 1 and the background information questions are provided in Appendix E.

Table 1

Participant Demographics

Characteristics	<i>n</i>	%
Relationship to Partner with MCI		
Spouse	13	72%
Child	3	17%
Friend	2	11%
Living with Partner with MCI		
Yes	13	72%
No	5	28%
Partner's MCI Subtype		
Amnesic	16	89%
Non-Amnesic	2	11%
Gender		
Males	7	39%
Females	11	61%
Ethnicity		
White	17	94%
Indigenous	1	6%
Marital Status		
Married/ Common Law	16	89%
Widowed	2	11%
Highest Education Completed		
Grade 12	7	39%
Undergraduate degree	7	39%
Graduate degree	4	22%
Occupational Status		
Retired	15	83%
Part-time	1	6%
Full-time	2	11%
Estimated Annual Household Income		
Under \$25,000	2	11%
\$25,001-\$50,000	5	28%

\$50,001-\$75,000	4	22%
Over \$75,001	7	39%
	<i>Range</i>	<i>M</i>
Age (in years)	39-89	69.4
		<i>SD</i>
		12.8

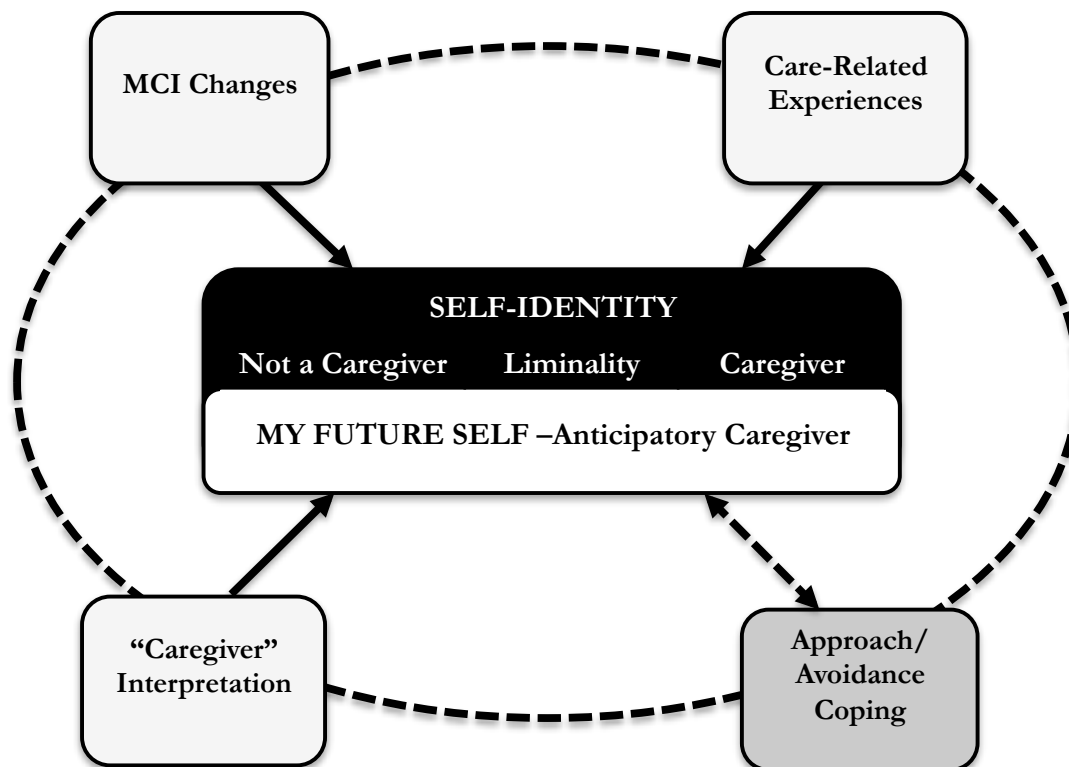
Note. *N*=18.

MCI Caregiver Identity Development

Our analysis generated four major thematic categories representing influences on MCI identity development: (1) MCI changes; (2) care-related experiences; (3) “caregiver” interpretations; and (4) approach/avoidance coping. An additional two thematic categories pertained to current and future identity. Specifically, these four themes appeared to influence how participants (5) currently self-identified, which were refined to: *I am a caregiver*, *I am not a caregiver*, and *liminality*. Related to participants’ self-identities were their reflections about how they envisioned their (6) “future self,” as an anticipatory caregiver. See Figure 1 for a visual representation of the themes generated from the data.

Figure 1

MCI Caregiver Identity Development Thematic Diagram



MCI Changes

MCI is Confusing, Unpredictable, and Sometimes Transient. Participants' descriptions of the cognitive symptoms of their family member or friend varied, consistent with the ambiguous and heterogeneous nature of MCI. Most frequently reported were memory problems that were not "extremely debilitating." Participants reflected that they were sometimes confused by observed changes, which were unpredictable and transient. Complicating matters further, some participants noticed co-occurring health problems (e.g., depression, anxiety, hearing difficulty), which "muddied the waters" in terms of how to understand or make sense of what was happening. Many participants discussed challenges trying to understand, "Is this the MCI, or is this something else?" As this husband explained:

"She doesn't only have a bit of memory issues but she also suffers from depression. And they sort of feed off each other as far as that goes...and it comes and goes. She still has some really good times where she's sharp as a tack, remembers pretty well everything. And then there's other situations which, you know, you can talk to her, and 10 minutes later she'll ask you the same question as though it's never been talked about."

Shifts and Imbalance in Roles Creates Tension. Participants reflected on how their roles began shifting as they observed MCI symptoms emerging, and in turn, influenced how they viewed their roles and identities. Many described feeling as though they were no longer on "equal terrain" with their family member/friend, an experiential shift from the norm of their pre-existing relationship roles, which contributed to the tension. They described sometimes feeling frustrated, resentful, and irritable toward their family member/friend and the MCI, often followed by guilt about these emotions. Some participants described resisting this "role shift" because they did not want the diagnosis (and what it represents) to be true. They struggled with accepting what was happening to their family member:

"So I sort of feel sometimes like I was kind of assuming this parent role almost with him...which I don't want to be. I'm not a parent right now, so don't want to be nagging my dad. And I have to be careful too because I don't want to... (participant became tearful). I get frustrated with him sometimes, and I sort of have to take a step back and just say, you know, I feel a little bit guilty about that almost."

Care-Related Experiences

In addition to MCI-related changes, caregiver identity appeared to be embedded within and influenced by two broader types of care-related experiences.

Past Experiences with Caregiving. Participants' prior histories and life courses appeared to shape their 'caregiver' self-identification. They recollected how social norms, cultural norms, gendered care expectations, and familial roles (e.g., providing care for ailing family members earlier in life as a teen/young adult) influenced their current self-concepts. Previous caregiving experiences appeared to be closely tied to current interpretations of the meaning of "caregiver," as discussed by this wife:

"It's just my life experiences. When I was young I was about 15 years old I looked after a woman with arthritis for two weeks one summer while her family went away on holidays. Like I started the caregiving early. It's inbred... and I think it was, I've always wanted to be a nurse, so I think that I was always like that."

Social Network Influences. Another contextual factor shaping caregiver identity was the influence of participants' social networks, including how participants were treated (i.e., symbolically viewed) by the health care system and other informal network members. Some participants reported direct feedback, as when the caregiver label was given to them by other family or healthcare practitioners, who would refer to them as the "caregiver." Additionally, many participants were indirectly influenced by their social network—hearing their friends or family discuss personal experiences with dementia. In turn, participants compared their experience with MCI to others' experiences with dementia, which shaped how they were currently viewing their role, and how their role could be affected in the future, as this husband illustrated:

"And her [wife with MCI] father has dementia. I mean he's now in a locked-down situation in a home. His wife was having trouble controlling him, and we've heard stories and watched it. And so I'm not sure whether that's been sort of an education if you want to call it that. But it has [been] for me because I'm looking at this from afar. And I'm hoping our relationship doesn't go there."

"Caregiver" Interpretation

Participants' interpretations of the meaning of being a caregiver shaped their self-identities and their thoughts about their future caregiving self. Four types of interpretations emerged from the data.

Caregiving is a Power Imbalance. The majority of participants' interpreted caregiving as signifying an observable or emotionally-felt imbalance. Some noted that caregiving involves more intensive behavioral tasks or responsibilities, beyond the norm for their role as a partner, child, or friend. Participants noted that these additional responsibilities create a power imbalance, which would not occur from 'normal' aging. As this wife explains:

"I think a partner you share and you talk about things and decide who's going to do what. A caregiver to me is in control. Makes the decisions. Tells you about big jobs, you know."

Role Ambivalence. Many participants conveyed confusion and uncertainty regarding what it means to be a caregiver. They voiced uncertainty about whether their new additional responsibilities were part of their previous roles (e.g., questioning whether being a spouse and a caregiver was in fact equivalent, or not). Expected norms were not always clear, as this husband described when asked about the difference between being a husband and caregiver:

"I guess there's certain things that have changed in our life that way. Just being the two of us, if there had been a subservient thing or an assertive thing, but it's always been an equal family thing, and so I can't really make any other distinction of it. It seems to be humming along really nicely until she forgets something that's all... I can't really describe it. I don't know. I guess it's from too many years of being together. I can't describe any difference."

Emphasis on Medical/Professional Definition. Some participants emphasized a professional or medical definition, describing caregiving as a professional job (i.e., synonymous with nursing or other health care work) with a clear, formalized set of tasks or responsibilities. For some participants, invoking this definition may be an active attempt to resist a caregiver identity, since this definition provides a stark contrast to their own self-identity. This husband, who did not self-identify as a caregiver, explained:

"There is an impersonality that a caregiver provides; it's a servant if I can say that. The 21st century, we don't have servants anymore. But when you think back and look at times gone by, the servants in the household would dress her and look after her. That's the caregiver. And that's acceptable from a caregiver. But not from your equal."

Caregiving as Both Burdensome and Purposeful/Important. Many participants interpreted caregiving with burden and strain. Asked whether he sees himself as a caregiver, this husband implicitly defines “caregiving” as something that is burdensome:

Yea, I think it does, but if you were rating it on a percentage scale, it would be 10, 20%.

It's not super taxing to me at this point in time.”

In contrast, others spoke of caregiving as an important, admirable, and powerful role that provided them with purpose. Occasionally, people vacillated throughout the interview, expressing both challenges and benefits of caregiving.

Approach versus Avoidance Coping

Participants responded to MCI changes in ways that my research team and I categorized into *approach* and *avoidance coping*. Nearly all participants (n=17) had taken on additional tasks (e.g., appointment and schedule management, reminders, financial decisions) since the onset of their friend/family member's symptoms. However, some participants appeared to do so in a more voluntary and active way, whereas others demonstrated a more avoidant coping style.

The large majority of participants demonstrated an “approach response” to MCI changes. They described acting as an advocate, initiating referrals or requesting doctor's appointments, and voluntarily performing additional tasks based on a sense of responsibility. Interestingly, more active and engaged approaches did not necessarily mean that participants identified as caregivers; this is represented by the dashed line between the *self-identity* and *approach/avoidance coping* themes in Figure 1. In contrast, a few participants described more of an “avoidant” response - not wanting to face what is happening and what it means for them, their relationship, and their lives. Not surprisingly, those participants who coped with avoidance tended not to identify as caregivers. These participants appeared closed off, minimizing the changes or their additional tasks. For example, a wife described how she was making more decisions which used to be her husband's responsibility, but then minimized this: “*It's not like they're big important decisions.*”

Self-Identity ('Who Am I' in Relation to the Person with MCI)

Participants were explicitly asked whether they identified as a caregiver near the end of the interview. A minority of participants self-identified as a caregiver, whereas some did not identify with this role at all. The majority of participants described existing in the “in-between” - identifying in a space of liminality.

I am a Caregiver. Of the few participants who self-identified as caregivers, this identity appeared to supersede their other role or pre-existing relational identities (e.g., wife, friend, or son). These participants illustrated a clear relational shift. They spoke of the loss of their pre-existing identity, often referring to it in past tense, with finality. Their identity shift, to seeing themselves as caregivers, appeared to be primarily shaped by the severity of the MCI changes, past caregiving experiences, and interpretations of caregiving as a “power imbalance.” These participants appeared to no longer view themselves as equals with their partners. Particularly, this was observed in how they believed they were depended on in distinctly different ways than in their pre-existing relationships. As this wife explained:

“Well, I have become a caregiver. Whereas before we were both very, although supporting each other, very independent, strong people. So that’s been a real change.”

I am Not a Caregiver. Several participants rejected the caregiver label; their pre-existing relational identities and other facets of their identities remained dominant. As one husband stated, *“I’m a guy. That’s it.”* Their firm stance - *not* identifying as caregivers - sometimes implied a sense of denial, rejection, and non-acceptance of the very idea of being a caregiver. In part, this appeared to be a sign of maintaining hope, attempting to avoid anxiety about impending decline and imbalance in the relationship, or maintaining boundaries around commitments and family obligations. Additionally, rejecting a caregiver identity was often coupled with efforts to preserve and protect dignity and respect for their friend or family member. For example, when exploring the term “caregiver,” many participants elaborated in detail about their family member or friend’s capabilities, independence, and special qualities. These care partners often emphasized how the current situation is not as bad as it could be with statements such as “we are not there yet.”

Liminality. Participants in this category conveyed a sense of ambivalence, or of being “in-between” their previous way of identifying and a newer sense of a caregiver identity, often contradicting themselves during the interview. Others described this “in-between” as a state of just beginning to see themselves as a caregiver, while not fully identifying as such. Identity liminality appeared to be influenced by the ambiguity and/or mild nature of their partner’s cognitive changes, often contrasting their partner’s MCI symptoms to more severe illnesses or impairments. Their caregiver interpretation of role ambivalence, including a sense of confusion and uncertainty with what being a caregiver means, also appeared to influence their identity

liminality. When asked if she considers herself as a caregiver in relation to her father, this daughter responded:

“I’m not sure. Like I do. I guess. I’ve sometimes (long pause) I must (long pause). In my mind, as you’re saying it, I associate caregiver with like he’s dying or like he’s really old. And I guess I don’t see him in that way yet. So I guess maybe that’s just how I associate the word as well a bit. So yes and no. Like I know I’m taking care of him. I guess I would say I’m taking care of him, I’m not his caregiver. But I know I’m doing a lot of that work so...I don’t know.”

Noticeably, this daughter struggles to make sense of how she sees herself, vacillating between identifying and not identifying as a caregiver, yet highlighting that she is in fact taking care of her father (i.e., an approach response). It is important to note, similar to many participants identifying in liminality, adopting a caregiver identity was not a prerequisite to provide care or support. Some described their approach response as entangled as part of both their pre-existing identity and beginning stages of a possible emerging caregiver identity, as noted above. In contrast, other participants in liminality felt the way they were supporting their partner was solely because of their pre-existing role (e.g., “To me it is my responsibility, it’s my job as her son”).

Future Self – The Anticipatory Caregiver

Irrespective of how participants currently identified, all conveyed thinking about their “future self” – most often, envisioning themselves providing more intensive care. We coded discussions of the future in the following three ways.

Worrying about Future (Uncertain) Decline. When reflecting on their future self, participants often described worrying about the clinical course and prognosis of MCI, a possible dementia diagnosis, and their own decline. As one husband illustrates:

“I really don’t want to get into that stage where she has to go somewhere, or I have to go somewhere. And if I had to go somewhere first for some physical reason or something, I would worry myself sick about her.”

Anticipatory Grief. Reflecting on the future, participants commonly conveyed a future sense of loss - of time and of what life was “supposed to be.” During these moments, it appeared that participants were already mourning the loss of what could have been, as depicted by this friend’s thoughts on what their future relationship might become:

“I think of that often. Or not often, once in a while. And it makes me sad. I’m sad because I’ll lose a friend.”

Maintaining Hope. Lastly, amid anticipations of their future self as a more intensive caregiver, including worries about their own future decline and grief, were glimpses of participants’ attempts to maintain hope, for the person with MCI, their relationship, and themselves. As one husband explained:

“I still hope there’s some kind of way of addressing that [wife’s MCI prognosis] a little better and dealing with it. I’m not sure if there’s, can’t say cure but, something changes for the better. Sometimes I just directly tell her that it’s going to get better. You know, don’t worry about it, it’s nothing to really worry about right now because we’re still moving ahead and there’s still a chance that things will turn right around in my mind. I’m trying to be very optimistic.”

Discussion and Implications

Study 1 contributes to a new and growing body of literature, providing novel insights into care partners for persons living with MCI, deepening our understanding of caregiver identity development in this understudied population. Central contextual lenses that appeared to influence how care partners’ self-identified included MCI-related changes, care-related experiences, “caregiver” interpretations, and approach/avoidance coping styles. Irrespective of how participants currently self-identified, all anticipated their “future self” would provide more intensive care. These findings highlight the complex process of caregiver identity development in MCI care partners and have implications for improving access to supports for these individuals.

MCI Identity Development: Connecting to the Caregiver Identity Literature

This study’s findings suggest that MCI caregiver identity is neither binary nor fixed. Rather, it is better understood as fluid and evolving across a continuum as depicted in Figure 1. Although in some respects CIT (Montgomery & Kosloski, 2009) and Positioning Theory (Harré & van Langenhove, 1999; O’Connor, 2007) may be perceived as contrasting theories of caregiver identity development (i.e., developmental change versus fluid and variable process), aspects of this study’s findings align with and provide insights relevant to both theories.

CIT conceptualizes caregiving as a series of developmental identity transitions that occur predominantly because of changes in the care context (e.g., onset of new symptoms;

Montgomery & Kosloski, 2009). CIT postulates identity development as comprised of five phases and suggests that during phase 2, individuals come to view themselves as caregivers when realizing their care tasks are beginning to extend beyond the scope of their pre-existing relational roles. In line with CIT, this study's findings highlight MCI changes as a primary theme influencing caregiver self-identification. These findings also add to CIT in suggesting other psychosocial factors (e.g., care-related experiences, "caregiver" interpretations) that may influence identity development.

Moreover, the majority of participants identified within liminality; the fluid and variable nature of this identity type is consistent with Positioning Theory. According to this theory, an identity is discursively produced, when one creates a new framework for understanding and constructing meaning about their actions (Harré & van Langenhove, 1999; O'Connor, 2007). One previous study used Positioning Theory to examine caregiver self-identification and found that recognizing oneself as a caregiver was constructed mainly through interactions with others (O'Connor, 2007), a finding confirmed in the present study. Indeed, I found that some participants' caregiver identities shifted throughout interviews as they were directly asked (perhaps for the first time), thought about, and discussed whether they considered themselves caregivers. This fluid sense of identity appeared to be related to the other themes that emerged, such as previous life experiences and shifting MCI symptoms and relational roles, highlighting the complexity of this issue.

Anticipatory Caregiving in MCI Care Partners

Anticipatory caregiving was a main theme among participants, irrespective of their current self-identification. Envisioning their future selves as more intensive types of caregivers elicited discussions of possible future loss and anticipatory grief. This aligns with previous research on MCI care partners' experience of ambiguous loss (i.e., phases of bereavement in advance of losing a significant person; Blieszner et al., 2007; Garand et al., 2012). Woolmore-Goodwin and colleagues (2016) found that MCI care partners' anticipatory grief involved multiple losses (e.g., of pre-existing relationship, control, hope), which shaped how care partners viewed themselves and made them question their ability to continue to provide care in the long-term. These worries were also common in my participants' accounts of anticipatory caregiving, which included worries about the future and uncertain decline of their friend/family member, and

how they would be able to cope with these potential changes, as is commonly reported in the MCI literature (Beard & Neary, 2013; Gomersall et al., 2015; Gomersall et al., 2017).

In addition to the loss of hope noted by Woolmore-Goodwin and colleagues (2016), several of my participants discussed ways they were trying to maintain hope as they navigate the MCI prognosis, and what it means for them and their relationship with their friend/family member living with MCI. The uncertain and fluctuating nature of MCI may be simultaneously comforting, an opportunity for hope for MCI care partners and those diagnosed. For example, some participants compared their experience to that of others' experiences with dementia or other more intense forms of caregiving, noting their situation was "not as bad." Nevertheless, if care partners at this stage of cognitive impairment already envision themselves as a more intensive type of caregiver in the future, and due to the increased risk of progression from MCI to dementia (Eshkoor et al., 2015), investing in support services to sustain the mental health and well-being of care partners during the MCI stage appears critical. Investing in such services must first be informed by addressing the current underutilization of caregiver support services that are already available.

Paradoxical Implications of Caregiver Identity

An overarching explanation for the underutilization of caregiver support services is that many individuals helping with care tasks do not identify as caregivers (Eifert et al., 2015). Nearly all of my participants (n=17) performed care tasks, yet only three clearly identified as caregivers. Encouraging caregiver identity may improve uptake of support services (Andréasson et al., 2018; Guberman et al., 2018), and may promote a sense of belonging to the broader caregiving community (O'Connor, 2007). Conversely, strongly encouraging care partners to identify might have the opposite effect, given the ambiguity and mild nature of MCI, which may complicate how care partners view themselves in relation to the person diagnosed (Gomersall et al., 2015). Pressuring individuals to adopt a caregiver identity may further promote caregiver need minimization as care partners work to protect the identity and dignity of those diagnosed (Moore & Gillespie, 2014). These potential consequences may be particularly true for MCI care partners, based on their interpretations of what it means to be a caregiver. For care partners who interpret caregiving more negatively (e.g., as a burden, power imbalance, confusion), enforcing a caregiver label may elicit difficult emotions.

Alternatively, it may not be necessary, or even beneficial, to encourage a caregiver identity in MCI care partners. Instead, simply recognizing this lack of self-identification can inform how we develop and advocate for such supports. For example, public service initiatives and support groups might be encouraged to use neutral terms (e.g. family and friends of people diagnosed with MCI) to attract care partners. This recommendation is consistent with research that calls for outreach strategies to attract caregivers who do and do not self-identify, for caregiver support programs (Corden & Hirst, 2011; Funk, 2019). Ultimately, amid debates about whether it is advisable to promote caregiver identification, it is important to reflect on the complex and potentially paradoxical implications of the label itself for those supporting someone with MCI. What does remain clear from this study's findings, as well as the MCI literature (Dean et al., 2014; Morris et al., 2020; Paradise et al., 2015; Seeher et al., 2013), is that irrespective of how care partners identify, they are engaged in care tasks, and would likely benefit from support with navigating these changes and their new and evolving roles.

Limitations and Future Directions

In addition to the strengths of this study, there are limitations of which to be mindful. The focus of this study was on participant experiences and interpretations; there is no expectation that the particular findings are generalizable. Nevertheless, I recruited a rather homogenous sample (e.g., most were White, middle SES, and all participants spoke fluent English) from a specific clinic in one geographic location. As such, I could not examine how diverse cultural frameworks may affect caregiver identity and service access. Neither did I explore identity development during the earliest stage of MCI that preceded participants' pursuit of assessment and support services via the clinic. There is also the risk of selection bias as it is possible that the experiences of people who did not wish to participate in this study differ from those who agreed to participate, albeit this is minimized due to the high response rate (75 per cent). Additionally, although it was not an aim of this study to compare the identity development of different types of care partners (i.e., children, spouses, friends), future research should explore whether caregiver identity emerges in similar or different ways depending on factors such as caregiver age, and the nature and intensity of the relationship with the care-recipient. Lastly, due to the risk of increasing decline in persons with MCI (Petersen et al., 2014), future work should also explore how the themes identified in this study may evolve to predict changes in caregiver identity development over time, as well as within different MCI types and stages of severity.

Nonetheless, this study provides a nuanced conceptual contribution to the understanding of the unique and evolving caregiver identity development in family and friends of persons living with MCI.

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Preface to Chapter 3

Chapter 2 illustrated the complex and evolving process of caregiver identity development in MCI care partners using qualitative methodology. Central contextual lenses that appeared to influence caregiver identity development included MCI-related changes in the care-recipient, previous care-related experiences, “caregiver” interpretations, and approach/avoidance coping. The majority of participants identified in liminality, followed by those that did not identify as caregivers, and a smaller group who did identify as caregivers. Yet, nearly all were providing care, and irrespective of how they currently identified, all envision they would provide more intensive care in the future. Amid worries about the future and anticipatory grief were also participants’ accounts of hope; for the person with MCI, their relationship, and themselves. These findings illustrate that care partners at the MCI stage may benefit from support services to navigate their evolving caregiving role.

Although Study 1 findings on caregiver identity development are separate and distinct from the focus of Study 2 –examining MCI care partner and dementia caregiver mental health– this research is unified in how these sources of information can inform support services for MCI care partners. Moreover, although I did not employ a mixed methods design, there are novel shared findings from these studies to consider, which will be reviewed in Chapter 4, the general discussion. First, Chapter 3 will review Study 2, a quantitative investigation to compare differences in MCI care partner and dementia caregiver mental health, including an examination of how distress reactions to care-recipient symptoms may impact poor mental health.

Chapter 3, Study 2: Mental Health Differences Between MCI and Dementia Care Partners: The Mediating Role of Distress Reactions to Care-recipient Symptoms

Abstract

Background and Objectives: Mild cognitive impairment (MCI) care partners have a high risk of becoming dementia caregivers, which increases risks of caregiver burden, anxiety, and depression. Research suggests that neuropsychiatric and memory symptoms in the care-recipient are a primary stressor predicting poor caregiver mental health, and that caregiver perceptions of the distress associated with these symptoms are may be a better predictor in this regard than symptom severity. My first objective was to compare MCI and dementia caregiver levels of burden, anxiety, and depression. My second objective was to examine whether any mental health differences between these groups are due to (i.e., mediated by) their levels of distress stemming from care-recipient symptoms – memory deficits, depression, and behaviour disruptions. My third objective was to investigate whether any of the three mediators were more critical in understanding mental health for caregivers.

Research Design and Methods: MCI care partners (n=53) and dementia caregivers (n=84) recruited from a memory clinic completed self-reported measures of their mental health (caregiver burden, anxiety, and depression) and distress arising from care-recipient symptoms (memory deficits, behavioural disruptions, and depression).

Results: MANOVA results revealed statistically significant mean differences for depression, anxiety, and burden in MCI care partners and dementia caregivers. Chi-square tests to examine differences in the clinical cut-scores for each mental health measure revealed significant differences in anxiety and caregiver burden. Multiple parallel mediation analyses indicated that differences between caregiver mental health were due to (i.e., mediated by) caregivers' distress reactions to care-recipient behaviour disruptions and depression symptoms.

Discussion and Implications: Dementia caregivers endorsed greater anxiety, depression, and burden than MCI care partners. Caregiver distress reactions to care-recipient neuropsychiatric symptoms (behavioural disturbances and depression), but not memory symptoms, may help explain why dementia caregivers have poorer mental health than MCI care partners. This information could inform prevention and intervention strategies aimed at reducing poor mental health for individuals at various stages in the caregiver trajectory.

Introduction

Caregiving for individuals with dementia is known to be stressful and burdensome, even though positive aspects may also be part of the role (Conner 2020 et al., Guberman et al., 2018; Queluz et al., 2020; Roberto et al., 2019). Yet, significantly less is known about the mental health of individuals providing care and support to individuals with mild cognitive impairment (MCI) who are earlier in the caregiving trajectory (Paradise et al., 2015; Woolmore-Goodwin et al., 2016). MCI is characterized by a deterioration in memory, attention, and/or cognitive functioning beyond what is expected based on age and education, yet without significant impact on daily functional ability (Petersen et al., 2014; Seeher et al., 2014). For example, unlike individuals with dementia whose basic activities of daily living are negatively impacted by their diagnosis, individuals with MCI typically only experience difficulty with instrumental activities of daily living and may require care and support in the form of transportation, medication adherence, preparing meals, managing households and finances, and future planning (Fisher et al., 2011; Lu et al., 2007; McIlvane et al., 2008). The literature is mixed on whether the term “caregiver” is even fitting within an MCI context, given that significant functional decline is not evident in care-recipients with MCI (Beatie et al., 2021). Additionally, different labels (e.g., family caregiver, informal caregiver, care partner) are used interchangeably when referring to family members and friends who are providing care or support to people living with dementia or MCI. For clarity and consistency, I will use the terms ‘care partners’ when referring to those supporting persons with MCI, and ‘caregivers’ to refer to those caring for persons with dementia. Although the level of functional impairment is significantly less severe for individuals with MCI, they are at an increased risk of developing dementia; 10–15% of people diagnosed with MCI develop dementia within the first year, which increases to 80%–90% after six years (Eshkoor et al., 2015). Thus, family members and friends providing care for people with MCI have a high likelihood of becoming dementia caregivers. Examining mental health among MCI care partners is critical to improve our understanding of the evolution of burden and other mental health difficulties in individuals providing care for people transitioning from MCI to dementia.

Caregiver Burden and Mental Health

Dementia caregivers are at risk of experiencing caregiver burden and other aspects of poor mental health, including depression and anxiety (Cooper et al., 2007; Haley et al., 1995; Paradise et al., 2015; Robinson et al., 2018; Seeher et al., 2014; Woolmore-Goodwin et al.,

2016). A meta-analysis, including 17 studies and 10,825 caregivers, reported prevalence rates of 34% for depression and 44% for anxiety disorders among dementia caregivers (Sallim et al., 2015). Additionally, a recent three year longitudinal study following 781 individuals with dementia and their caregivers found that caregiver burden rates increased over time from 47.4% to 56.8% (Connors et al., 2020). Although significantly less research has examined MCI care partner mental health, their levels of burden appear not to be as pronounced (Seeher et al., 2013). A previous systematic review that included information from five studies measuring burden among 517 MCI care partners reported rates of clinically meaningful levels of burden ranging from 10.5% to 31.4% (Seeher et al., 2013); these studies could not be pooled due to the heterogeneity of burden scales used. More recently, a three year longitudinal study following 185 individuals with MCI and their care partners reported caregiver burden increasing from 21.1% to 29.5% over the course of the study (Connors et al., 2019). MCI care partners also have an increased risk of developing significant symptoms of depression and anxiety (Garand et al., 2005; Lara-Ruiz et al., 2019; Seeher et al., 2013; Werner, 2012) which adds to their caregiver burden (Paradise et al., 2015; Werner, 2012).

Care-recipient Neuropsychiatric Symptoms and Caregiver Mental Health

In addition to understanding differences in mental health among individuals at different points in the caregiving trajectory, it is perhaps more important to understand why such differences exist. The stress process model (Pearlin et al., 1990) proposes that multiple primary and secondary stressors at the individual, family, and community levels contribute to poor mental health outcomes in dementia caregivers and MCI care partners (Seeher et al., 2013; Wang et al., 2016). Primary stressors are directly linked to the individual with cognitive impairment (e.g., neuropsychiatric symptoms and memory deficits) whereas secondary stressors arise from the demands of the caregiving role itself (e.g., constrictions of social life, family conflict). With regard to dementia caregivers, severity of care-recipient neuropsychiatric symptoms predicts caregiver burden, depression, and anxiety (Cheng, 2017; Lou et al., 2015), with greater anxiety associated with longer duration of caregiving, and greater depression associated with lower education and being a spousal caregiver (Lou et al., 2015). With regard to MCI care partners, a recent three year longitudinal study found that the severity of care-recipient neuropsychiatric symptoms was the strongest predictor of caregiver burden, followed by lower care-recipient functional ability, care-recipient driving inability, and caregiver employment (Connors et al.,

2019). Cross-sectional research has similarly shown that care-recipient neuropsychiatric symptoms are strongly related to poor mental health for MCI care partners (Blieszner & Roberto, 2010).

Although collectively, severity of care-recipient neuropsychiatric symptoms poses the greatest difficulty for both MCI care partners and dementia caregivers, what remains unclear is how specific types of care-recipient symptoms affect caregivers, and whether such symptoms have similar or unique effects on MCI care partners versus dementia caregivers. A recent cross-sectional study investigated the influence of the severity and frequency of different types of care-recipient neuropsychiatric symptoms (e.g., dysphoria, agitation, disinhibition) on distress in 108 MCI and mild dementia caregivers (Mavounza et al., 2020). This study found that both caregiver groups experienced heightened distress due to neuropsychiatric symptoms and, specifically, care-recipients' depressive symptoms predicted elevated levels of distress in both caregiver groups (Mavounza et al., 2020). Additional research is needed to expand upon this work to examine more specific mental health measures, including depression, anxiety, and caregiver burden.

There is also a growing body of research suggesting that caregiver reactions to care-recipient symptoms (specifically, levels of self-reported distress associated with symptoms) may be a better predictor of poor caregiver mental health than the actual degree or severity of neuropsychiatric symptoms and memory deficits (Bruce et al., 2008; Lingler et al., 2016; Seeher et al., 2014). A cross-sectional study examining caregiver burden in 51 MCI care partners found that the subjective self-reports of the degree of distress related to care-recipient memory, behaviour, and depressive symptoms was associated with increased caregiver burden, whereas care-recipients' objective neuropsychological test performance (assessing their degree of cognitive impairment) was not (Bruce et al., 2008). Similarly, a larger cross-sectional study examining predictors of general distress in 714 MCI care partners found that although their level of general distress was generally low, their negative reaction to care-recipients' behavioural symptoms was associated with elevated general distress (Seeher et al., 2014), whereas objective impairment measures were not. With regard to dementia caregivers, their reactions to and appraisals of care-recipient behavioural and psychological symptoms have been associated with poor mental health outcomes (Black & Almeida, 2004; Goode et al., 1998). However, these previous studies only examined how MCI care partner and dementia caregiver reactions to care-recipient symptoms predicted general measures of distress or burden, and did not include other

common mental health measures such as anxiety and depression. Further examining the unique role of caregiver distress reactions to symptoms is warranted, and to my knowledge, there are no studies using a multiple mediation model to test for differences in MCI care partners and dementia caregivers' mental health due to their distress reactions to different types of symptoms associated with cognitive impairment (memory deficits, behaviour disruptions, depression symptoms). A multiple mediation strategy is particularly advantageous as it allows for the comparison of distress reactions to different types symptoms against one another through the examination of specific indirect effects (Hayes, 2018). This information could inform preventative supports or intervention services for both MCI care partners and dementia caregivers. In other words, by understanding how MCI care partners and dementia caregivers experience distress from these distinct symptom categories, I may be able to illuminate what clinicians and health service efforts should target with respect to delivery of support services.

Study Objectives and Hypotheses

To address these gaps within the literature, the current study examined a broad range of common mental health measures in MCI care partners and dementia caregivers and investigated whether their distress reaction to symptoms mediated or explained mental health differences between the two groups. My first objective was to compare MCI and dementia caregivers on measures of anxiety, depression, and caregiver burden. I hypothesized that dementia caregivers would have significantly poorer outcomes on each of these measures compared to MCI care partners (Hypothesis 1). My second objective was to examine whether any mental health differences between these groups are due to (i.e., mediated by) their subjective levels of distress from care-recipient symptoms (e.g., memory, depression, behaviour disruptions). I hypothesize that dementia caregivers will have poorer mental health, in part, because they are more distressed by care-recipient memory and neuropsychiatric symptoms than MCI care partners (Hypothesis 2). Relatedly, my final exploratory objective is to examine whether the three mediating variables vary in terms of their ability to explain group differences in mental health outcomes.

Methods

Participants

I explored my objectives using secondary data obtained between November 2013 and June 2019 from 137 participants recruited from a memory clinic in a large health sciences centre of a major Canadian city. The memory clinic provides assessment and memory group

intervention for older adults experiencing early cognitive changes (including MCI and mild dementia) and their “program partners.” Program partners are spouses, children, or friends that care-recipients choose to bring with them to their initial neuropsychological assessment appointment. Care-recipients complete a comprehensive neuropsychological assessment and diagnoses were provided by a neuropsychologist. During the assessment, their program partners complete a questionnaire package that includes the self-report measures, described below. This information was collected as secondary data from chart review. The resulting dataset contained information from participants identified as MCI care partners (n=53) and dementia caregivers (n=84).

Ethical Statement

This study received ethics approval from the University of Manitoba Research Ethics Board (P2017:117) and the St. Boniface General Hospital Research Review Committee (RRC:2017: 1721) in Winnipeg, Manitoba, Canada.

Measures

Sociodemographics

Participants completed a background questionnaire in which they self-reported their age, gender, race/ethnicity, marital status, relationship to person with memory concern, living arrangement, education, occupation, and household income.

Caregiver Mental Health

Depression and Anxiety. Depression was assessed with the Beck Depression Inventory (BDI-II; Beck et al., 1996), and anxiety was measured with a subscale from the 21-item Depression Anxiety Stress Scale (DASS-21; Lovibond & Lovibond, 1995), both of which have been validated for use with older adults (Gloster et al., 2008; Segal et al., 2008). The BDI-II (Beck et al., 1996) is a 21-item self-report questionnaire, which was designed to aid in the assessment of depressive disorders corresponding to DSM-IV criteria and measures severity of depression over the past two weeks. Items are rated on a 4-point scale and summed such that higher total scores indicate greater depression. Scores can be categorized as normal (total score = 0-13), mild depression (total score = 14-19), moderate depression (total score = 20-28), and severe depression (total score = 29-63). For this study Cronbach's α was 0.90. With regard to the DASS-21, the 21-item questionnaire assesses participants' depression, anxiety, and stress symptoms over the past week using a 4-point severity/frequency scale ranging from 0 “Did not

apply to me at all” to 3 “Applied to me very much, or most of the time.” I summed total scores for the 7-item anxiety subscale and multiplied by two, consistent with the short form scoring instructions, with higher scores indicating greater symptom severity. Anxiety subscale scores can be categorized as normal (subscale total score = 0-7), mild anxiety (subscale total score = 8-9), moderate anxiety (subscale total score = 10-14), severe anxiety (subscale total score = 15-19), and extremely severe anxiety (sub score =20+). In my sample Cronbach's α was 0.79.

Caregiver Burden. Caregiver burden was assessed with the Zarit Burden Inventory (ZBI; Zarit et al., 1980), the most widely used measure for assessing burden experienced by caregivers of persons with MCI and dementia (Hébert et al., 2010; Seeher et al., 2013). Total burden scores are obtained by summing all items and a score of 21 or greater is considered clinically significant burden (Zarit & Zarit, 1987). Cronbach's α was 0.93 for this study.

Caregiver Distress Reactions to Care-recipient Symptoms

The Revised Memory and Behaviour Problems Checklist (RMBPC; Teri et al., 1992) is a 24-item caregiver self-report measure of observable memory, depression, and behaviour disruptions in people with cognitive impairment during the past week. Participants self report the presence or absence of 24 symptoms observed in the care-recipient. For every symptom endorsed, participants are asked to rate their level of distress – specifically, how much they are bothered or upset by the symptom. Participants' distress reactions were rated on a 5-point scale ranging from 0 “Not at all bothersome” to 4 “Extremely bothersome.” The RMBPC provides two sets of subscale scores. The first set of subscales are *frequency of symptoms* scores that are sum totals of the number of symptoms participants observed in the care-recipient: memory, depression, behaviour disruptions, which range from 0-7, 0-9, and 0-8, respectively. The second set of subscale scores are the self-reported level of distress (being bothered or upset by) associated with each endorsed symptom. To obtain subscale *distress reaction* scores, the distress level rating for each symptom endorsed is summed such that subscale totals can range from 0-28 for memory, 0-36 for depression, and 0-32 for behaviour disruptions. For this study, Cronbach's α for RMBPC distress reaction subscales were not reported due to the variability in the number of symptoms endorsed by MCI care partners and dementia caregivers (i.e., some symptoms were only endorsed by dementia caregivers).

Statistical Analyses

Statistical analyses were performed using IBM SPSS version 26 (IBM, 2017). To address

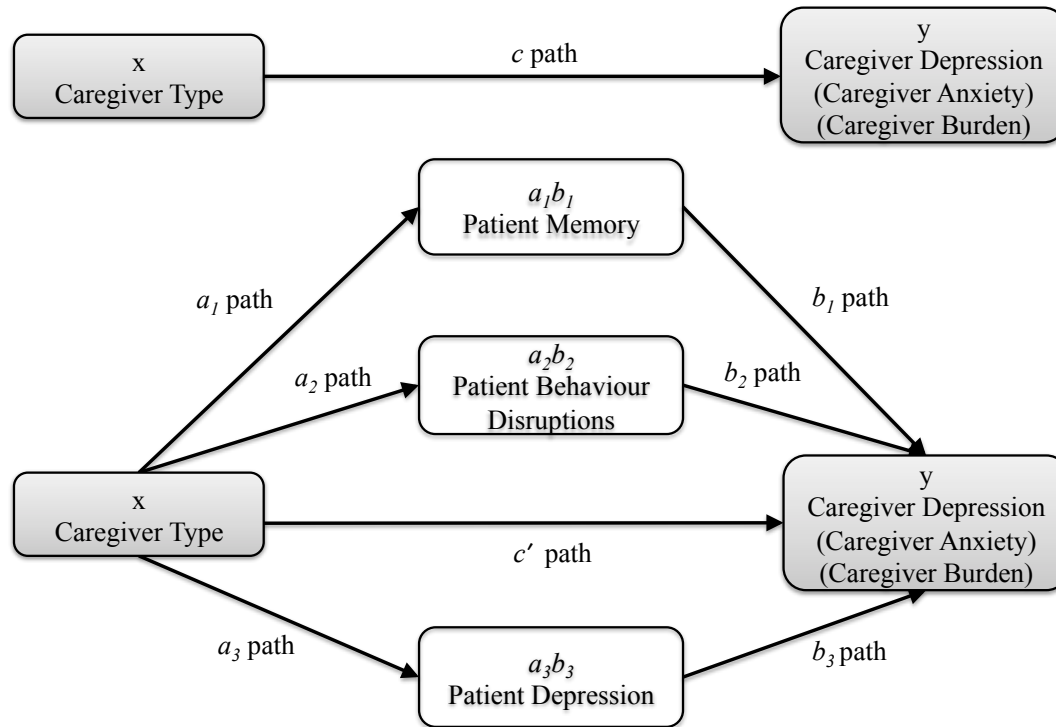
my first objective – comparing MCI care partner and dementia caregiver mental health– I conducted a one-way multivariate analysis of variance (MANOVA) to examine mean differences between the two caregiver groups on the three mental health outcomes (DV1: depression, DV2: anxiety, DV3: caregiver burden). I examined both the significance of group differences and the size of effects using partial eta-squared. Small, medium, and large effect sizes are associated with values of $\eta_p^2=0.01$, $\eta_p^2=0.06$, $\eta_p^2=0.14$, respectively (Cohen, 1988). I also used chi-squared tests to examine whether there were significant differences in the percentage of caregivers in each group who scored at or above clinical cut-scores of each mental health variable.

To address my second objective – whether MCI care partner and dementia caregiver distress reactions to care-recipient symptoms mediated or explained mental health differences between caregiver type (MCI vs dementia) – I tested three parallel multiple mediator models, one for each mental health dependent measure (i.e., caregiver anxiety, depression, burden). In each model, the three symptom distress reaction variables (i.e., level of distress in response to care-recipient memory, depression, and behaviour disruptions symptoms) are mediators of mental health differences in the two caregiver groups. I used the PROCESS macro in SPSS (Hayes, 2018) to test these models, controlling for gender and age. Multiple parallel mediation allows estimation of both the total indirect effect associated with all mediators and the specific indirect effect associated with each mediator. As such, to address my final objective – whether there are differences in the ability of the three mediators to explain mental health differences between MCI care partners and dementia caregivers – I examined the pairwise contrasts of the specific indirect effects for each mediation model. The PROCESS macro mean-centres variables for ease of interpretation, and uses a series of OLS regression analyses to estimate causal relationships between variables. PROCESS employs percentile bootstrapped 95% confidence intervals (with 5000 bootstrap samples) of the indirect (mediated) effect. I seeded the random number generator to 12345, which allows for exact replication of my analyses that is otherwise impossible due to the random nature of bootstrapping. The bias-corrected bootstrapping method does not assume symmetry or normality of the distribution of the indirect effect and offers better control of type I error rates than other mediation approaches (MacKinnon et al., 2004). As shown in Figure 1, mediation analyses include tests of path *a* (relationship between the independent variable and the mediator), path *b* (relationship between mediator and dependent variable), and the direct effect *c'* (relationship between independent variable and dependent variable,

controlling for the mediator). Additionally, pairwise contrasts of all the specific indirect effects were calculated for each mediation model. Mediation is supported if the percentile bootstrapped 95% confidence intervals of the indirect effect (ab) of the independent variable on the dependent variable through the mediator does not include zero.

Figure 1

Distress Reactions to Care-recipient Symptoms as Parallel Mediators of Mental Health Differences Between MCI and Dementia Care Partners



Note. c path = total effect, c' path = direct effect, a_1b_1 = indirect effect of care-recipient memory, a_2b_2 = indirect effect of care-recipient behaviour disruptions, a_3b_3 = indirect effect of care-recipient depression.

Results

Participants Sociodemographic Characteristics

MCI care partners ($n=53$) and dementia caregivers ($n=84$) identified as spouses (64%), children (26%), friends (4%), or another type of family member (6%), in relation to the care-recipient. The majority of participants were White (77%), female (66%), living with the care-recipient (65%), and 67 years old, on average. MCI care partners and dementia caregivers did not significantly differ on any of the sociodemographic variables. Additional information on sociodemographic characteristics is presented in Table 1.

Table 1*Sample Demographics and Distress Reactions*

	MCI Care Partners (<i>n</i> =53)		Dementia Caregivers (<i>n</i> =84)		Statistical Comparison	
	<i>n</i>	%	<i>n</i>	%	Chi-square	(<i>df</i>)
Relationship to Person with MCI/Dementia					1.09	(3)
Spouse	34	64.2%	55	65.4%		
Child	13	24.5%	23	27.4%		
Other family member	3	5.7%	4	4.8%		
Friend	3	5.7%	2	2.4%		
Living with Person with MCI/Dementia					0.12	(1)
Yes	35	66.0%	54	64.3%		
Gender						
Female	35	66.0%	56	66.7%	0.01	(1)
Male	18	34.0%	28	33.3%		
Ethnicity						
White	43	81.1%	62	73.8%	2.20	(3)
Indigenous	2	3.8%	2	2.4%		
Indian/Pakistan/Sri Lanka	0	0.0%	2	2.4%		
Black	0	0.0%	1	1.2%		
Education					2.72	(3)
< High school diploma	5	9.4%	12	14.3%		
High school diploma	14	26.4%	22	26.2%		
Undergraduate/College degree	25	47.2%	31	36.9%		
Graduate degree	4	7.5%	12	14.3%		
Occupation Status					2.27	(1)
Part-time/Full-time	10	18.9%	23	27.4%		
Retired	40	75.5%	48	57.1%		
Marital Status					1.39	(1)
Married/common-law	44	83.2%	72	85.7%		
Singe/Divorced/Widowed	9	16.8%	12	14.3%		
Household Income					1.29	(3)
0-19,999	2	3.8%	1	1.2%		
20,000-34,999	3	5.7%	4	4.8%		
35,000-59,999	15	28.3%	20	23.8%		
60,000+	24	45.3%	41	48.8%		
	<i>M</i>	(<i>SD</i>)	<i>M</i>	(<i>SD</i>)	T-test	(<i>df</i>)
Age (range 38-91)	67.9	(11.7)	65.9	(12.9)	0.92	(134)
Memory (RMBPCr)	2.72	(2.72)	5.54	(4.81)	-4.39***	(131)
Behaviour Disruptions (RMBPCr)	0.75	(1.30)	1.90	(2.61)	-3.42***	(129)
Depression (RMBPCr)	2.66	(3.27)	4.52	(5.41)	-2.51**	(135)

Note. *N*=137. RMBPCr =Revised Memory and Behaviour Problems Checklist distress reaction subscales.

p*<.05, *p*<.01, ****p*<.001.

MCI and Dementia Caregiver Mental Health

The MANOVA testing my first objective, comparing MCI care partner and dementia caregiver mental health, revealed a statistically significant multivariate group difference in mental health (i.e., depression, anxiety, burden), $F(3, 130) = 14.63, p < .001, \eta_p^2 = .252$, with a large effect. Table 2 provides follow-up tests of this difference, including univariate results revealing that dementia caregivers had significantly worse depression, anxiety, and burden scores. This table also provides information on the percentage of participants who had at least mild clinically significant symptoms. The majority of MCI care partners and dementia caregivers fell within the normal range on the depression and anxiety measures (indicating no clinically significant symptoms). Chi-square tests, however, revealed clinically significant differences in anxiety and caregiver burden. Dementia caregivers endorsed more clinically significant anxiety and caregiver burden (24.1%, 61.4%) than MCI care partners (9.8%, 17.0%, respectively). Although the chi-square test indicated no clinically significant difference in depression, the results trended in the same direction, with more dementia caregivers endorsing depression symptoms (36.9%) compared to MCI care partners (23.5%).

Table 2

MCI Care Partners and Dementia Caregivers Mental Health Mean Differences and Clinical Cut-off Score Differences

Dependent Variable	MCI Care Partners (<i>n</i> =53)		Dementia Caregivers (<i>n</i> =84)		Statistical Comparison	
<i>Continuous</i>	<i>M (SD)</i>	<i>95% CI</i>	<i>M (SD)</i>	<i>95% CI</i>	<i>F^a</i>	<i>η_p²</i>
Depression (BDI-II) (possible scores 0-63)	6.6 (6.4)	4.8, 8.4	10.1 (8.2)	8.3, 11.9	6.86**	.049
Anxiety (DASS21) (possible scores 0-42)	2.6 (4.1)	1.4, 3.8	5.4 (6.8)	3.9, 6.9	7.09**	.051
Caregiver Burden (ZBI) (possible scores 0-88)	13.1 (8.5)	10.9, 15.6	26.5 (13.7)	23.5, 29.5	39.80***	.232
<hr/>						
<i>Categorical</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	Chi-square ^{b,c}	
Depression (BDI-II)					2.62	
No	39	76.5%	53	63.1%		
Yes (mild to extreme)	12	23.5%	31	36.9%		
Anxiety (DASS21)					4.25*	
No	46	90.2%	63	75.9%		
Yes (mild to extremely severe)	5	9.8%	20	24.1%		
Caregiver Burden (ZBI)					25.94***	
No	42	83.0%	32	38.6%		
Yes (severe burden)	9	17.0%	51	61.4%		

Note. ZBI=Zarit Burden Inventory; BDI-II=Beck Depression Inventory; DASS21=Depression Anxiety Stress Scale-21 (short form). BDI-II: total score of 0-13=normal, 14-63= mild-severe depression; Anxiety-DASS21: sub-score of 0-7=normal, 8-42=mild-extremely severe anxiety; ZBI: total score >=21 suggests severe caregiver burden.

^a*F df* = 1. ^b $\chi^2 df$ = 1. ^c For BDI-II and DASS21, chi square tests were run by combining mild to extreme symptoms and comparing this to no symptoms endorsed.

p*<.05, *p*<.01, ****p*<.001.

Caregiver Type and Mental Health Mediated by Distress Reactions to Symptoms

I addressed my second objective by testing three parallel multiple mediator models for each mental health variable: depression, anxiety, and caregiver burden. Zero-order correlations between variables are provided in Table 3. Across all models (see Table 4), there were some notable similarities. First, in examining the *a* paths for each model, dementia caregivers consistently endorsed more distress from all care-recipient symptoms (memory, behaviour disruptions, depression) compared to MCI care partners. Second, in examining the *b* paths for each model, reporting more distress from care-recipient behaviour disruptions and depression symptoms was significantly associated with higher levels of anxiety, depression, and caregiver burden, but being more distressed by memory symptoms was not. As seen in Table 4, both distress reactions to care-recipient behaviour disruptions and depression symptoms significantly mediated the relationship between caregiver type and caregiver depression, anxiety, and burden. The specific indirect effect of distress reactions to care-recipients' memory symptoms was not a significant mediator in the relationship between caregiver type and mental health. Lastly, I addressed my third objective by examining the pairwise contrasts of the specific indirect effects computed for each parallel mediation model. There were no significant differences in the mediating power of distress reactions to care-recipient behaviour disruptions or depression symptoms in the depression (-1.41, 1.69), anxiety (-0.56, 1.72), and burden (-0.78, 3.05) models because the 95% bootstrap confidence interval for each pairwise contrast contains zero. This suggests they are equally important in explaining mental health differences between MCI care partners and dementia caregivers in the models.

Table 3

Zero-order Correlations Between Variables

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.
1. Caregiver type ¹	--													
2. Relation to care-recipient ²	-.08	--												
3. Live with care-recipient ³	.03	-.21*	--											
4. Gender ⁴	.01	.14	-.33**	--										
5. Age	-.08	.10	.65**	-.26**	--									
6. Marital status ⁵	.10	-.33**	.46**	-.14	.14	--								
7. Education ⁶	-.01	-.02	-.16	-.04	-.26**	-.02	--							
8. Occupation status ⁷	.07	-.11	-.54**	.07	-.69**	-.04	.24**	--						
9. Income ⁸	.10	.01	.04	-.04	-.03	.30**	.20*	.13	--					
10. Dep-BDI-II	.22**	-.06	.01	.24**	-.14	-.01	-.01	.02	-.20*	--				
11. Anx-DASS21	.23**	-.07	.09	.23**	-.01	.03	-.07	-.04	-.12	.66**	--			
12. Burden-ZBI	.48**	-.10	-.11	.18*	-.24**	-.04	.14	.17	-.07	.63**	.42**	--		
13. Memory-RMBPCr	.32**	.08	.15	.01	.14	.08	-.11	-.10	.04	.26**	.19*	.40**	--	
14. Depression-RMBPCr	.20*	.01	-.12	.13	-.34**	-.05	.13	.19*	-.03	.46**	.29**	.43**	.28**	--
15. Behaviour-RMBPCr	.25**	.02	.18*	.13	.08	.06	-.10	-.05	-.07	.39**	.37**	.47**	.55**	.22**

Note. $N = 137$; ZBI=Zarit Burden Inventory; DASS21=Depression Anxiety Stress Scale-21 (short form); BDI-II=Beck Depression Inventory; RMBPCr=Revised Memory and Behaviour Problems Checklist distress reaction subscales.

¹Care type: MCI care partner=1, dementia caregiver=2; ²Relation to care-recipient: family member=1, friend=2; ³Live with care-recipient: no=1, yes=2; ⁴Gender: male=1, female=2; ⁵Marital status: single/widowed/divorced=1, common-law/married=2;

⁶Education: <high school=1, high school diploma=2, undergraduate/college degree=3, ≥graduate degree=4; ⁷Occupation status:

retired=1, PT/FT work=2; ⁸Income=\$0-\$1999=1, \$2000-\$3499=2, \$35000-\$5999=3, \$6000+=4. Correlations are Pearson

correlations. Correlations containing a dichotomous variable (1–4, 6, 8) were computed using point-biserial correlations.

* $p < .05$; ** $p < .01$.

Table 4

Multiple Parallel Mediator Models: Caregiver Type (MCI, Dementia) and Mental Health Mediated by Distress Reactions to

Symptoms

	Path <i>c</i> (SE)	Path <i>c'</i> (SE)	Path <i>a</i> (SE)	Path <i>b</i> (SE)	Indirect Effect (Bootstrap SE)	Bootstrap 95% CI	R ²	F
							(<i>df₁</i> , <i>df₂</i>)	
Model 1: Depression (Y)	3.45** (1.32)	1.33 (1.25)					.32	9.84***
Indirect effect of distress reactions to care-recipient symptoms:								(6, 126)
<i>Memory</i>			2.94*** (0.74)	0.04 (0.17)	-0.11 (0.66)	-1.39, 1.28		
<i>Behaviour Disruptions</i>			1.23*** (0.39)	0.93** (0.31)	1.14 (0.64)	0.09, 2.61		
<i>Depression</i>			1.85* (0.80)	0.59*** (0.14)	1.09 (0.59)	0.08, 2.37		
Model 2: Anxiety (Y)	2.93** (1.04)	1.82 (1.04)					.24	6.67***
Indirect effect of distress reactions to care-recipient symptoms:								(6, 126)
<i>Memory</i>			2.94*** (0.74)	-0.17 (0.14)	-0.49 (0.39)	-1.37, 0.19		
<i>Behaviour Disruptions</i>			1.23*** (0.39)	0.85*** (0.26)	1.05 (0.48)	0.25, 2.12		
<i>Depression</i>			1.85* (0.80)	0.30** (0.11)	0.55 (0.36)	0.02, 1.35		
Model 3: Burden (Y)	12.78*** (2.04)	8.79*** (1.91)					.47	18.76***
Indirect effect of distress reactions to care-recipient symptoms:								(6, 128)
<i>Memory</i>			2.94*** (0.74)	0.33 (0.26)	0.97 (1.20)	-1.20, 3.58		
<i>Behaviour Disruptions</i>			1.23*** (0.39)	1.68*** (0.47)	1.99 (0.83)	0.58, 3.83		
<i>Depression</i>			1.85* (0.80)	0.60** (0.21)	1.03 (0.53)	0.08, 2.15		

Note. *SE* = standard error. The independent variable in all mediation models was caregiver type (MCI=1, dementia=2). Distress reactions to how bothersome and upsetting care-recipient memory, behaviour disruptions, and depression symptoms were measured using distress reaction subscales from the Revised Memory and Behaviour Problems Checklist. Depression (Y) was measured with the Beck Depression Inventory-II; Anxiety (Y) was measured with the Depression Anxiety Stress Scale-21 anxiety subscale; Burden (Y) was measured with the Zarit Burden Inventory; path *c* = total effect; path *c'* = direct effect; paths *a*, *c'*, *a*, *b*, and the indirect effect (*ab*) are reported as unstandardized regression coefficients; 95% CI = bias-corrected 95% confidence intervals of the indirect effect with five thousand bootstrapped samples. Gender and age were controlled for in each model.

p* < .05, *p* < .01, ****p* < .001.

Discussion

A number of MCI care partners will likely become future dementia caregivers (Eshkoor et al., 2015), which can be associated with poor mental health outcomes (Connors et al., 2020; Sallim et al., 2015). Therefore, investigating specific mental health outcomes in these distinct but related caregiver groups, and factors that may contribute to differences in their mental health, is warranted. The main purposes of this study were to (1) examine differences in MCI care partner and dementia caregiver mental health, (2) examine the multiple mediating role of participant distress reactions to care-recipient symptoms in the association between caregiver type and poor mental health, (3) and to investigate whether any of the three mediators were more critical in understanding caregiver mental health.

Consistent with previous research, which suggests that dementia caregivers are further along in the caregiving trajectory and thus, more likely to experience adverse mental health (Cheng, 2017; Mavounza et al., 2020; Seeher et al., 2014), the dementia caregivers in this study reported poorer mental health relative to MCI care partners. However, participants from both caregiver groups endorsed notable mental health symptoms. Just under 25% of MCI care partners and 37% of dementia caregivers endorsed mild but clinically meaningful depression. Mild and clinically meaningful symptoms of anxiety were also endorsed by 10% of MCI care partners and just under 25% of dementia caregivers. Notably, more than half of the dementia caregivers and 17% of the MCI care partners endorsed severe caregiver burden. These results are in line with previous longitudinal research, which reports severe caregiver burden ranging between 47.4% and 56.8% for dementia caregivers and 21% to 30% for MCI care partners over the course of three years (Connors et al., 2019, 2020). It is important to note that caregiver burden is both a consequence of caregiving and a predictor of poor mental health, including depression and anxiety (Connors et al., 2019, 2020; Razani et al., 2014). Although the majority of MCI care partners and dementia caregivers in this study fell within the normal range for depression and anxiety, their notable elevations on caregiver burden increase their risk for developing depression and anxiety symptoms as they continue their caregiving roles.

A primary factor identified both within the literature and a key determinant in the stress process model that increases the risk of poor mental health for both MCI care partners and dementia caregivers is the care-recipient's degree of cognitive impairment (e.g., memory deficits) and neuropsychiatric symptoms (Pearlin et al., 1990; Seeher et al., 2013; Wang et al.,

2016). A growing body of research suggests that caregiver subjective reactions to symptoms (i.e., distress; perceptions of symptoms as bothersome or upsetting) may be a better predictor of poor caregiver mental health (Black & Almeida, 2004; Bruce et al., 2008; Goode et al., 1998; Lingler et al., 2016; Seeher et al., 2014) than the actual objective severity of symptoms. In response to this, I examined the mediating role of how distressed participants were about care-recipient symptoms to explain, in part, differences between MCI care partner and dementia caregiver mental health. I focused on distress reactions to three types of care-recipient symptoms: memory deficits, behaviour disruptions, and depression. A noteworthy finding from this study was that the greatest difference between the care groups in terms of my mediating distress variables was for memory symptoms (the *a* paths in Figure 1 and Table 4). However, this difference did not explain dementia caregivers' poorer mental health; distress about care-recipients' memory symptoms was not related to caregiver mental health (the *b* paths). In contrast, there were significant but weaker group differences in terms of levels of subjective distress from care-recipient behavioural disturbances and depression symptoms, and it was this distress that was strongly related to mental health. These results suggest that MCI care partners and dementia caregivers may be at risk of adverse mental health in part due to how upset or bothered they are by depression and behavioural symptoms in their family member or friend; this finding was most prominent in dementia caregivers who noticed more of these symptoms and were more bothered by them. A possible explanation for why distress reactions to memory symptoms were not related to mental health is that memory deficits are the most obvious and well known symptom of MCI (amnesic) and dementia (Alzheimer's Society of Canada, 2021). Therefore, those symptoms are expected and perhaps tolerated better by family members and friends who are providing care and support. Conversely, other neuropsychiatric symptoms may be less understood and more difficult and upsetting to observe in the person with MCI or dementia. Thus, although there has been a large focus on memory deficits in MCI and dementia in both research and clinical contexts, the results of this study, in line with recent advances in the literature, suggests that caregivers' distress reactions to neuropsychiatric symptoms are primary risk factors for poor mental health in both caregiver groups (Bruce et al., 2008; Connors et al., 2019; Ikeda et al., 2015; Mavounza et al., 2020).

The results of this study have important implications for how both caregiver groups may benefit from preventive or intervention supports. For example, given that there is currently no

cure for MCI or dementia (Alzheimer's Society of Canada, 2021; Petersen et al., 2014, 2018), it is promising to know that the degree or severity of symptoms may not be the most important factor to address in programs targeting caregiver mental health. Instead, targeting caregivers' reactions or responses to neuropsychiatric symptoms through well-developed and empirically supported preventive and intervention strategies (e.g., psychoeducation, cognitive-behavioural therapy, acceptance and commitment therapy) may off-set or reduce the risk of poor mental health. It may be particularly important to provide psychoeducation to normalize the presence of neuropsychiatric symptoms in MCI and dementia (e.g., that these symptoms are common and co-occur with the more well-known memory symptoms associated with these diagnoses) and provide individuals with coping skills to manage these changes. Preventive strategies aimed at helping MCI care partners better understand and manage their concerns related to their family member or friend's symptoms, such as psychoeducation, support groups, and early cognitive behavioural intervention, have been found to improve adaptive coping and reduce depression, anxiety, and caregiver burden (Domingues et al., 2018; Garand et al., 2014; Lu et al., 2016; Vogel et al., 2004). Providing supports early in the caregiving trajectory (i.e., at the MCI stage) could prevent or reduce more adverse mental health outcomes in the event that MCI care partners transition to dementia caregivers.

Limitations and Future Directions

This study must be considered in light of some key limitations. First, the data were collected from a relatively homogeneous sample (e.g., predominantly White, middle SES background, access to a hospital memory clinic), which can affect the broader generalizability of the results. Second, consideration must be taken in interpreting causal inferences from the results of the mediation models, as the data were cross-sectional. Although, the causal direction of effects –that caregiver distress reactions to care-recipients' symptoms can lead to poor mental health– is based on previous research and theory (i.e., the Stress Process Model; Pearlin et al., 1990; Seeher et al., 2014; Sheehan et al., 2020; Wang et al., 2016). Yet, an important consideration when interpreting the indirect effect mediation results is the risk of epiphenomenal or confounding associations. For example, the indirect effects in my models could be due to an epiphenomenal association between distress reactions to care-recipient symptoms and the objective severity of care-recipient symptoms, which could be the “true” mediator. With regard to confounding and spurious associations, although I was able to control for background

variables that have been previously identified in the literature as impacting the risk for poor mental health (e.g., MCI care partners' and dementia caregivers' age and gender), I did not have access to other potential confounding variables (e.g., caregiver support or pre-existing mental health status). For example, it is possible that caregivers' pre-existing mental health difficulties could influence their perception (i.e., distress reactions) of care-recipient symptoms. Future research using a trained mental health professional to assess for mental health symptoms in MCI care partners and dementia caregivers would be helpful. There is also a need for longitudinal research to follow MCI care partners transitioning to dementia caregivers over the course of a caregiving trajectory to better assess how their mental health is impacted. Further, different subtypes of MCI and dementia have different symptom profiles, and given my findings that perceptions of symptoms are key factors in determining MCI care partner and dementia caregiver mental health, future research should explore this to better understand how caregivers of different subtypes of MCI and dementia are affected in unique or similar ways.

Conclusion

Despite these limitations, this is one of the first studies to not only demonstrate differences between MCI and dementia caregiver mental health using a broad range of indicators, but to go one step further in examining potential reasons for mental health differences between these caregiver groups. This study highlights how distress related to care-recipient depression and behaviour problems, but not memory, might help explain why dementia caregivers are more likely to be anxious, depressed, and burdened by their care experiences. This information could further inform prevention and intervention strategies aimed at improving mental health for family members and friends at various stages in the caregiver trajectory.

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Chapter 4: General Discussion

The objective of my dissertation research was to deepen our understanding of what it means to be an MCI care partner, including an exploration of the distinct, yet interrelated, constructs of caregiver identity development (Study 1) and mental health (Study 2). The results of these two studies suggest clinically meaningful directions for addressing the support service needs of MCI care partners. In this general discussion, I first provide a summary of the distinct and shared findings from Studies 1 and 2, followed by a discussion of how key findings from these studies are related and integrated within the literature on identity and mental health. Finally, I review the clinical implications of my findings, which I hope can help inform MCI care partners' support service needs.

Research Summary

Using a qualitative approach informed by constructivist grounded theory methodology, the objective of Study 1 was to explore how caregiver identity develops in family and friends of individuals living with MCI. In this study, 18 care partners whose family member or friend was recently diagnosed with MCI were interviewed in their homes, at their local hospital, or at a university research lab. Semi-structured interviews explored themes related to how care partners self-identified. In this study, caregiver identity was affected by MCI-related changes, previous care-related experiences, "caregiver" interpretations, and approach/avoidance coping. The majority of participants (n=17) described being engaging in care tasks in support of their family member or friend living with MCI, yet only three clearly identified as caregivers. Interestingly, most MCI care partners (n=9) identified in liminality (i.e., existing between two identities), followed by those that did not identify as caregivers (n=6). Irrespective of how closely their current identity aligned with being a caregiver, all participants envisioned their "future self" as a more intensive type of caregiver. These findings illustrate how caregiver identity development in MCI care partners is a complex, fluid, and evolving process.

Study 2 examined differences in MCI care partner and dementia caregiver mental health and explored potential explanations for mental health differences between these caregiver groups. This study examined the multiple mediating roles of participant distress reactions to three types of care-recipient symptoms (i.e., behavioural disruptions, depression, and memory deficits). Although dementia caregivers endorsed significantly higher levels of depression, anxiety, and caregiver burden, MCI care partners also endorsed notable mental health symptoms

at this stage, even though the majority of them fell within the normal range. Specifically, some MCI care partners endorsed mild but clinically meaningful depression (24%) and anxiety (10%) symptoms and severe caregiver burden (17%). A noteworthy finding from the mental health mediation models was that, although there were significant differences in the caregiver groups' distress from care-recipient memory symptoms, these differences did not explain dementia caregivers' poorer mental health; distress from memory symptoms was not related to any of the caregiver mental health measures (depression, anxiety, caregiver burden). Instead, differences in the mental health of MCI care partners and dementia caregivers were due to (i.e., mediated by) how distressed participants were by care-recipient behavioural disruptions and depression symptoms.

Shared Findings from Studies 1 and 2

The findings from studies 1 and 2 are separate and distinct, yet unified within the overarching aim to inform support services to address the unique needs of MCI care partners. Although I did not employ a mixed methods design (i.e., a design in which the qualitative and quantitative studies were explicitly interconnected; Creswell, 2011), there are also shared findings to consider.

In reflecting on the integration of Studies 1 and 2, there are three noteworthy findings to further inform our understanding of MCI care partners and their support needs as they navigate their complex and evolving roles. First, MCI care partners' perceptions matter, both in terms of how they view themselves and how they are experiencing and reacting to the changes happening in their family member or friend, including the impact this may have on their own mental health. Second, findings from both studies underscore the importance of offering support services for MCI care partners at this stage. Even at what most consider the 'mild' stage of the caregiving trajectory, findings from Study 1 show that a complex and dynamic caregiver identity development is already in flux. Further, irrespective of their current self-identities, MCI care partners are providing care and support. Relatedly, findings from Study 2 demonstrate that some MCI care partners are endorsing mild yet clinically significant mental health symptoms and severe caregiver burden even during this stage. A final shared finding from Studies 1 and 2 is that MCI care partners would likely benefit from access to ongoing supports throughout their caregiving trajectory. Care partners described envisioning themselves as more intensive types of caregivers in the future, and they also face the increased risk of their own mental health

worsening if care-recipient cognition continues to decline. Taken together, findings from Studies 1 and 2 not only provide novel insights on caregiver identity development and mental health in MCI care partners, but also underscore the importance of addressing their support needs in a way that takes into consideration that many people do not consider themselves caregivers at this point.

Contextualizing the Relationship Between Identity and Mental Health

The results of my dissertation suggest the clear interrelationships of mental health and identity issues. Thus, it is necessary to incorporate identity-related issues into stress and mental health research. In fact, it is widely accepted in clinical psychology and psychiatry that mental health is at least partially influenced by self-concepts, self-esteem, and in the context related to this dissertation research, social identities (Thoits, 2014). In line with this, poor mental health has been at least partly attributed to hindered or inadequate identity development (Erikson, 1963; Freud, 1933), threats to one's self-concept (Abramson et al., 1989), and identity loss (Thoits, 1986; Brown & Harris, 1978). Moreover, identity factors are thought to play an important part in stress appraisals and in the processes of coping and support giving (Pearlin et al., 1990; Thoits, 2014).

Consistent with this, with regard to a caregiving context, the stress process model illustrates how dynamic interactions among background and contextual factors (i.e., demographic characteristics, caregiving history, and interpersonal dynamics), primary stressors (i.e., neuropsychiatric symptoms and memory deficits and subjective indicators of role overload and relational deprivation), secondary stressors (i.e., role strains and intrapsychic strains such as low self-esteem and changes in one's sense of self), and protective factors (i.e., coping strategies and social support) can affect mental health (Pearlin et al., 1990). This model has been used extensively within the dementia caregiving literature (e.g., Campbell, 2009; Cheng, 2017; Gallant & Connell, 1998; Goode et al., 1998; Haley et al., 2003; Judge et al., 2010; Lou et al., 2015; Roberto et al., 2019; Sheehan et al., 2020; Stevens et al., 2004) and a smaller body of research has also used this model to explore the experiences of MCI care partners (Blieszner & Roberto, 2010; Roberto et al., 2011; Savla et al., 2011; Seeher et al., 2013; Seeher et al., 2014; Wang et al., 2016).

Novel findings from Studies 1 and 2 highlight key elements of the stress process model related to MCI care partners. This model alludes to identity-related factors as key contributors to

the stress process that influence mental health outcomes (e.g., caregiving history, role strains; intrapsychic strains). Study 1 further illustrates how caregiver identity is not firmly established in an MCI context. Rather, caregiver identity development in MCI care partners is a dynamic, evolving, and individualized process, influenced by key relational themes (e.g., MCI symptoms and changes, observed shifts and imbalance in roles, past experiences with caregiving and current social network influences, “caregiver” perceptions, and approach/avoidance coping). This finding is supported by a number of prominent identity theories such as Positioning Theory (Harré & van Langenhove, 1999), Caregiver Identity Theory (Montgomery & Kosloski, 2009), and Identity Theory (McCall & Simmons, 1987), which are founded in symbolic interactionism and suggest that one’s identity (including role identities) and society mutually shape and influence each other (Thoits, 1991). Specifically, role identities, such as a caregiver identity, are self-concepts informed by one’s position in a social structure, which have been formed and based on relationships with others. Thus, caregiver identity is informed and influenced by relationships and experiences with others and one’s position in a social structure. Additionally, Study 2 highlights the relevance of care-recipient neuropsychiatric symptoms as primary stressors in the stress process model when applied to MCI care partners and dementia caregivers. Importantly, this study demonstrates that reactions to memory symptoms, which would also be considered primary stressors, may not be important in contributing to poor mental health outcomes. Rather, perceptions of behavioural and depression symptoms in family members or friends living with MCI or dementia were better predictors of mental health differences between MCI care partners and dementia caregivers. In summary, findings from Studies 1 and 2 highlight key factors in the stress process model related to identity and mental health stressors, and the shared findings offer clinical implications for supporting MCI care partners.

Clinical Implications: Support for MCI Care Partners

Caregiver support services (e.g., psychoeducation, support groups, psychotherapy, respite, memory and cognitive training for the care-recipient) are intended to mitigate the stress associated with caregiving that often lead to poor health outcomes (Connors et al., 2019, 2020; Garand et al., 2014; Haley et al., 2020; Paradise et al., 2015; Seeher et al., 2013). It is important to note that not all MCI care partners may experience difficulty and there are positive aspects to caregiving that are not often discussed in the MCI literature. For example, Study 1 findings showed that in addition to the more dominant view of interpreting ‘caregiving’ as a power

imbalance and burdensome, a few MCI care partners described it with purpose, admiration, and importance. This is in line with research that demonstrates there are *uplifts* associated with a caregiving role, including feeling useful and valued, experiencing additional meaning and purpose, and experiencing pride in one's own abilities to handle crises (Lloyd et al., 2016; Pinquart & Sörensen, 2003; Roberto et al., 2019; Schulz et al., 1997; Schulz & Sherwood, 2008; Woolmore-Goodwin et al., 2016). Additionally, Study 2 findings demonstrated that although some MCI care partners endorsed poor mental health, the majority were not experiencing clinically significant mental health difficulties. This is consistent with research demonstrating that care partners experience lower rates of mental health problems at the MCI stage compared to individuals at the dementia stage (Connors et al., 2019, 2020; Paradise et al., 2015; Seeher et al., 2013, 2014) and those further along in their caregiving trajectory (Haley et al., 2020). Yet, these positive aspects of providing care will not necessarily offset or reduce the potential negative or challenging aspects associated with the role as they continue along their caregiving trajectories.

Although most MCI care partners in this dissertation research were not be experiencing significant mental health problems, research shows they are at risk of developing poor mental health as they continue to provide more substantial and sustained care (Connors et al., 2019, 2020; Haley et al., 2020). In line with this, Study 2 results suggest that caregiver mental health difficulties may worsen by distress elicited from care-recipient neuropsychiatry symptoms – behavioural disruptions and depression symptoms. Both longitudinal and cross sectional studies have similarly highlighted that neuropsychiatric symptoms are strongly related to poor mental health for MCI care partners (Bruce et al., 2008; Connors et al., 2019; Ikeda et al., 2015; Mavounza et al., 2020; Wang et al., 2016). Moreover, there may be less visible, albeit unique and impactful challenges individuals face that are inherent to the MCI care partner experience. Study 1 findings and past research highlight the challenges associated with being an MCI care partner, including the complexities associated with caregiver identity and role ambiguity, anticipatory grief, and future uncertainty (Blieszner & Roberto, 2010; Blieszner et al., 2007; Carlozzi et al., 2018; Garand et al., 2012; Morris et al., 2020; Woolmore-Goodwin et al., 2016). Additionally, irrespective of caregiver identity, MCI care partners in Study 1 described engaging in numerous care-related activities. Research shows that MCI care partners provide support in the form of instrumental activities including providing transportation, ensuring medication adherence, and cooking; and the time associated with these activities can be substantial at

approximately 24 to 28 hours per week (Carlozzi et al., 2018; Fisher et al., 2011; McIlvane et al., 2008; Paradise et al., 2015; Roberto et al., 2011). Thus, support services implemented for care partners at the MCI stage could help them to better cope with these challenges and prevent mental health symptoms from developing over the course of their caregiving trajectory (Bayly et al., 2019; Garand et al., 2014). However, MCI care partners, and caregivers in general, underutilize support services (Austrom & Lu, 2009; Eifert et al., 2015; Wiprzycka et al., 2011).

Implications for Improving Access to Support Services for MCI Care Partners

There are several factors that contribute to the underutilization of support services for caregivers, including insufficient availability of services, reduced time and energy to seek supports, lack of service knowledge, and financial concerns (Keefe, 2011; Morgan et al., 2002; Peterson et al., 2016; Wiprzycka et al., 2011). Not self-identifying as a caregiver is another key factor that has been recognized as contributing to the underutilization of support services for caregivers in general (Eifert et al., 2015; Eifert et al., 2021). For individuals who are early in a caregiving trajectory, such as MCI care partners, caregiver identity related factors appear to further complicate their access to support services. Coinciding with this is the “early needs paradox” issue (Boots et al., 2015). For example, care partners may not fully recognize that they are experiencing what others might view as caregiving stress. Thus, they may find it challenging to accept help or support at the MCI stage but then retrospectively identify the critical importance of having early stage support (Boots et al., 2015). The present work demonstrates the complexities with identity and the early needs paradox may be especially true for some MCI care partners, most of whom identified in liminality and not as caregivers. Moreover, healthcare professionals may also underestimate the challenges associated with being an MCI care partner, as most caregiver supports related to cognitive and memory impairments are advertised to individuals further in the caregiving trajectory with a diagnosis of dementia (Alzheimer’s Society of Canada, 2021).

Research suggests that encouraging individuals to embrace a caregiver identity could result in greater support service uptake (Bayly et al., 2019; Eifert et al., 2021). Yet, as discussed in Study 1, there are paradoxical implications regarding whether it is necessary, or even beneficial, to encourage MCI care partners to adopt a caregiver identity to improve their access to support services. Given the negative associations with caregiving (e.g., as a burden, power imbalance) identified in Study 1 and in the literature (Cohen et al., 2002; Horrell et al., 2015;

Moore & Gillespie, 2014; Werner et al., 2010), encouraging MCI care partners to adopt a caregiver identity may complicate how they view themselves and elicit difficult emotions (Funk, 2019; Gomersall et al., 2015). It could also promote caregiver need minimization as MCI care partners may work to protect the identity and dignity of those diagnosed, referred to as the “caregiving bind” (Moore & Gillespie, 2014). In other words, if an individual is strongly encouraged to take on a caregiver identity, this inadvertently can imply that their family member or friend is dependent on them to some degree. MCI care partners may not be ready to accept these changes, and it may not be appropriate for their circumstances (e.g., depending on the care-recipient’s severity of cognitive impairment). In response, they inadvertently may try to conceal or downplay the extent of care they actually are providing. Thus, reducing the likelihood that they will seek support should they need it now, or in the future, as they try to protect the identity and independence of their family member or friend. Instead, access to support services for MCI care partners could be improved by encouraging the use of neutral and inclusive terms (e.g. family and friends of people diagnosed with MCI) to attract care partners, irrespective of where they might be in their caregiver identity development. This is supported by research that advocates for outreach support strategies to attract individuals who do and do not self-identify as caregivers (Corden & Hirst, 2011; Funk, 2019).

Additionally, healthcare professionals interacting with MCI care partners, such as their own family physician or professionals in relation to the care-recipient, represent an important point of contact to connect them to support services. Therefore, it is important that healthcare professionals are informed about the difficulties care partners can experience at the MCI stage, to ensure they are screening for possible distress and recommending support services that could be beneficial.

To aid with this, caregiver assessment tools have been developed, such as the USA-based *Tailored Caregiver Assessment and Referral* (TCARE), which can assist healthcare professions in connecting care partners to appropriate resources available in their community (Kwak et al., 2011). This protocol is also intended to help care partners recognize their distinct role and needs, which may help with alleviating stress and tension related to caregiver identity and role ambiguity, as identified in Study 1. A longitudinal randomized controlled trial including 97 caregivers found that the TCARE resulted in lower identity discrepancy and reduced caregiver burden (Kwak et al., 2011). However, these participants were further in their caregiving

trajectory compared to MCI care partners. A similar Canadian caregiver assessment tool was developed, the *Caregivers' Aspirations, Realities, and Expectations Tool* (The C.A.R.E. Tool; Keefe et al., 2008). The C.A.R.E. Tool is designed to identify and understand aspects of a caregiver's circumstances, including challenges they may be experiences, as well as identifying their strengths, and needs. A large qualitative study examined its usefulness in working with 100 dementia caregivers (Guberman et al., 2018). Findings suggested that the assessment process helped caregivers reflect on their current situation with an increased awareness, and they appreciated the relationship with the healthcare professional to validate and normalize their experience. The researchers speculate that this assessment tool may help caregivers take further action in their caregiving situation to pursue support services for themselves. They also noted that this assessment tool may help increase healthcare professionals' knowledge and awareness of caregiving experiences. However, no previous studies have examined the effectiveness of assessment tools such as these with healthcare professionals in relation to assessing the needs of MCI care partners, which could be beneficial.

Additionally, given that most participants in Study 1 endorsed a liminality identity, characterized by fluid and variable changes to one's identity that even occurred in the context of an hour interview, monitoring MCI care partner needs for support services over time appears warranted. For example, it would be important for healthcare professionals to check in with MCI care partners on a few different occasions to assess for distress and explore their interest in support services. Lastly, it is important to note that MCI care partners will likely vary in their resources and ability to cope. Thus, not all MCI care partners will need all of the information or possible support recommendations in the same way or at the same time. Thus, utilizing a caregiver assessment with MCI care partners could be particularly effective to help healthcare professionals tailor their recommendations, including what supports, if any, will be most beneficial (Austrom & Lu, 2009; Guberman et al., 2018; Keefe et al., 2008)

Implications for Strategies to Best Support MCI Care Partners Who Access Services

Caregiver support services have been developed to assist people in coping with the changes and demands of providing care as they navigate their caregiving roles (Eifert et al., 2015). Researchers have highlighted how the stress process model may be used as a guide to develop, implement, and evaluate support service interventions for caregivers (Mittelman et al., 2004; Schulz et al., 2000). Psychosocial supports (e.g., psychoeducation, support groups,

psychotherapy), indirect supports (e.g., cognitive and memory intervention for the individual diagnosed), and respite may be particularly important at intervening in the stress process by strengthening coping strategies, social support, and other resources, thereby reducing or offsetting potential mental health difficulties (Mittelman et al., 2004).

Psychoeducation

At the time of an MCI diagnosis, an important first line of support for MCI care partners is for healthcare professionals to provide psychoeducation about living with MCI (Austrom & Lu, 2009; Domingues et al., 2018; Lu et al., 2016). Psychoeducation is the evidence-based delivery of information to help individuals understand a particular medical or mental health condition, including possible strategies to cope and improve treatment adherence and efficacy (Bayly et al., 2019). Psychoeducation can be helpful in providing a better understanding of MCI, including normalizing the variable and transient nature of MCI symptoms (described in Study 1), and the common neuropsychiatric symptoms associated with MCI (described in Study 2), which may not be as well understood as memory and cognitive deficits. Additionally, given that most MCI care partners in Study 1 did not identify as caregivers, psychoeducation could help provide more of a context for navigating the caregiver role. This could include possible next steps to be taken, both in support of the individuals diagnosed and for themselves. This also may include future planning for care needs should more severe symptoms develop in the future (Domingues et al., 2018; Roberto et al., 2011). Specifically tailored psychoeducation interventions are potentially very useful to better prepare MCI care partners for possible increases in behavioural disruptions and worsening mood symptoms in the care-recipient (Lu et al., 2016; Roberto et al., 2011; Vogel et al., 2004). *Living with Mild Cognitive Impairment: A Guide to Maximizing Brain Health and Reducing Risk of Dementia*, by Drs. Anderson, Murphy, and Troyer (2012) is a particularly useful psychoeducation resource developed for individuals with MCI and their care partners. This book provides information on how MCI affects individuals diagnosed and their family members. It also provides information about the prognosis and strategies for coping with MCI, albeit most of the strategies are for the individual diagnosed (e.g., memory training). An updated edition of this book would be helpful, given the growing research in MCI over the last decade. Yet, despite the importance of providing psychoeducation to MCI care partners, there are, unfortunately, limited education and support materials for MCI care partners, which requires further attention (Dean, 2013; Joosten-Weyn Banningh et al., 2015).

Support Groups

Peer support groups, which provide an opportunity to gather and share experience, information, and mutual support among individuals with a shared lived experience, have also been cited as an important service for MCI care partners (Dean & Wilcock, 2012; McIlvane et al., 2008; Ryan et al., 2010; Underwood & Yost, 2016). Previous researchers have highlighted the need to develop support groups for care partners specifically dealing with MCI because support groups for caregivers of those with dementia may not be appropriate to meet their unique needs (Blieszner et al., 2007). For example, the discussion topics and advice from Alzheimer's disease caregiver support groups may be addressing significantly more severe challenges that are not yet relevant to the needs of MCI care partners (Blieszner et al., 2007; Carlozzi et al., 2018). A qualitative study examining the experiences of MCI care partners found that attending an MCI support group enabled them to be more open and honest about feelings of frustration and anger, which helped them feel more connected to others in the study and less alone in their experience (Woolmore-Goodwin et al., 2016). However, an ongoing challenge with enrolling MCI care partners in this type of support is that they are unlikely to look for support groups until their family member or friend is farther along the cognitive impairment trajectory (Woolmore-Goodwin et al., 2016). Again, this underscores the importance for psychoeducation as a precursor to the initiation of other psychosocial support services.

Psychotherapy

Psychotherapies such as cognitive behavioural therapy (CBT) are a more intensive type of psychosocial intervention for those experiencing challenges adjusting to their caregiving role, and those more susceptible to poor mental health outcomes. CBT focuses on helping individuals understand the relationship between their thoughts, emotions, and behaviours, and provides strategies to change maladaptive thoughts and behaviours that may contribute to mental health problems (Greenberg & Padesky, 2015). CBT is an effective psychotherapy intervention used to treat a number of mental health problems, and has been adapted to be used specifically in caregiver populations (Gallagher-Thompson & Coon, 2007; Sorensen et al., 2002) including MCI care partners (Domingues et al., 2018; Garand et al., 2014; Joosten-Weyn Banningh et al., 2011; Joosten-Weyn Banningh et al., 2013; Joosten-Weyn Banningh et al., 2015). Findings from Study 2 highlight the relevance of MCI care partners' perceptions and reactions to MCI-related changes, which could be addressed with a CBT approach. Furthermore, in Study 1, many MCI

care partners described trying to make sense and understand the confusing and unpredictable nature of MCI symptoms, which sometimes led to feelings and acts of frustration, resentment, and irritability, often followed by guilt. A CBT approach could help MCI care partners understand their experience and develop coping strategies to better manage the challenges they are facing with their family member or friend.

A specific form of CBT that has recently been used with MCI care partners is problem-solving therapy (PST; Garand et al., 2014). Based on a problem-solving model of stress, PST for MCI care partners focuses on developing and improving adaptive coping strategies over the course of six sessions and three telephone follow-up sessions. Results from one randomized controlled trial examining the effectiveness of PST for 43 MCI care partners and early dementia caregivers found that it significantly reduced depression and anxiety; these results were maintained one-year post intervention (Garand et al., 2014). The authors note that the timing of the intervention may be important, given that the PST appeared to have a protective effect that prevented MCI care partners' mental health symptoms from worsening. They also noted that this form of intervention was feasible and acceptable for MCI care partners. Most importantly, the long-term maintenance of treatment gains over a one-year follow suggest that the skills learned over the course of PST will help MCI care partners to effectively cope with increasing stressors in the future. However, these results are not consistent throughout the literature.

Another study examining the effectiveness of CBT for MCI care partners did not find significant differences between care partners and wait-list controls with respect to sense of competence, well-being, distress, acceptance, and helplessness, although this may have been due to the small sample size (Joosten-Weyn Banningh et al., 2013). The authors further examined the longer term (i.e., six and eight months post-intervention) effects after program completion and found that helplessness and well-being in MCI caregivers were worse at follow up, however, sense of competence increased, suggesting a need for extended support and follow-up interventions after completing the program. The scarcity of research in this area is, perhaps, an indication of the difficulty researchers and clinicians experience trying to recruit MCI care partners for more intensive interventions, as they may not perceive the need for it at this stage. Alternatively, care partners may have limited time to take advantage of more intensive forms of support services (i.e., psychotherapy) if they are struggling to fit additional care demands into

already busy schedules. More research is needed examining the effectiveness of CBT for MCI care partners.

In line with this, exploring possible advantages of third wave CBT approaches with MCI care partners could be beneficial. Unlike traditional CBT approaches that emphasize decreasing distress and mental health difficulties, third wave CBT approaches emphasize strategies to improve overall health and well being (Hayes & Hofmann, 2017). Third wave approaches, such as Mindfulness Based Cognitive Therapy (MBCT) and Acceptance and Commitment Therapy (ACT), emphasize the importance of mindfulness (e.g., attending to the present moment), accepting ones thoughts (as opposed to labeling them as good or bad), and exploring how an individual relates to their internal experiences (i.e., thoughts, urges, sensations) without judgment to improve their overall well-being (Hayes & Hofmann, 2017). Although there is a dearth of research examining third wave CBT with MCI care partners, there is growing support for MBCT and ACT with dementia caregivers (Han et al., 2020; Liu et al., 2017; Losada et al., 2015). A recent systematic review and meta analysis examined the effectiveness of ACT with family caregivers, including dementia caregivers (Han et al., 2020). This study found a large effect on increased psychological flexibility (i.e., the ability to face challenging experiences in an open conscious manner and engage in value-based living; Hayes et al., 2012) at three and six months follow up with caregivers. As demonstrated in Study 1, MCI presents many challenging experiences for MCI care partners and many of them described envisioning, worrying about, and even grieving their future self as a more intensive type of caregiver. Thus, third wave approaches, such as ACT, could be especially beneficial at helping MCI care partners attend to their present experience with psychological flexibility to enhance their overall well-being and increase their confidence in facing whatever challenges may lie ahead.

Indirect Support Services

In addition to psychosocial support services directed toward MCI care partners, indirect support services for individuals diagnosed with MCI, such as memory and cognitive rehabilitation programs, show promise in reducing caregiver burden (Cuc et al., 2017; Lu & Haase, 2009). These interventions help individuals with MCI develop self-management skills that may lead to improvements in quality of life for them and their care partners (Cuc et al., 2017). For example, a previous randomized control trial, including 40 individuals with MCI and their care partners, showed that individuals with MCI who were trained to use external memory

supports were better able to perform memory-related daily living activities than those not trained (Greenaway et al., 2013). In turn, this had a positive effect on MCI care partners, who did not need to perform as many care-related tasks, which was also reflected in improved mood and a reduced sense of caregiver burden. Similarly, a pilot randomized control trial of two cognitive rehabilitation interventions for 64 individuals with MCI and their care partners found that at six months, MCI care partners from both treatment groups showed improvements in depression, compared to those in the control group whose depression worsened (Cuc et al., 2017). However, most of the limited research on indirect supports focuses on memory training and supports. As previously discussed, Study 2 findings suggest that care-recipient memory difficulties may not be as important in impacting caregiver mental health compared to other neuropsychiatric symptoms associated with cognitive impairment, such as behavioural disruptions and depression symptoms. Incorporating these considerations in supports developed for the care-recipient (e.g., strategies to cope with mood difficulties) may be particularly beneficial. Nevertheless, it is promising to see that interventions intended to improve functioning in individuals with MCI can also indirectly benefit MCI care partners by alleviating some of their responsibility and contribute to improved mental health.

Respite

Respite services involve temporary care provided by another individual or service to provide the primary care partner a break (Alzheimer Society of Canada, 2021). Literature examining the utility of respite care among MCI care partners is quite limited, however some researchers suggest that it may be helpful at the MCI stage (Blieszner & Roberto, 2009). As previously discussed, MCI care partners provide support in the form of numerous instrumental activities such as transportation, medication adherence, and cooking (Fisher et al., 2011; McIlvane et al., 2008). As a result, having access to respite from these supportive activities may reduce feelings of burden and stress. Study 2 results demonstrated that even at the MCI stage, 10% to 25% of care partners endorsed mild yet clinically meaningful symptoms of anxiety, depression, and severe caregiver burden. Thus, respite might be helpful for MCI care partners who are experiencing mental health symptoms, which could worsen as their family member or friend's cognitive functioning continues to decline (Cheng, 2017; Mavounza et al., 2020; Seeher et al., 2014; Tonga et al., 2020). A cross-sectional study examining current and future service needs of 29 MCI care partners found that 67% reported a need for respite care in the future but

not at the MCI stage (McIlvane et al., 2008). Interestingly, a phenomenological qualitative study examining the experiences of MCI care partners reported that they had a desire to acquire respite, yet endorsed feeling a sense of dissonance and remorse about needing time away from the individual with MCI (Woolmore-Goodwin et al., 2016). In line with this, a recent meta-review and meta-analysis, which included over 500 intervention studies for dementia caregivers, found that using respite was associated with feelings of caregiver guilt (Cheng & Zhang, 2020; O'Shea et al., 2017). Moreover, although respite appeared to reduce caregiver burden in some studies, meta-analysis results suggest respite is generally ineffective (Cheng & Zhang, 2020). Thus, if respite is not very effective for reducing mental health difficulties in individuals further along in the caregiving trajectory, it would appear unlikely that it would be effective for MCI care partners. Further research is needed to assess the desire and utility of respite for MCI care partners.

Multimodal Approach

A promising type of intervention developed for individuals with MCI and their care partners is the *Learning the Ropes for Living with MCI*, a 6-week multimodal intervention-education program, which incorporates psychoeducation, indirect support (i.e., memory training for the individual with MCI), and a CBT psychosocial intervention for care partners (Murphy, 2014). Although research examining the effectiveness of this group is focused on the improvements of individuals with MCI (Fogarty et al., 2016; Nalder et al., 2018; Troyer et al., 2008), researchers suggest that MCI care partners benefit from this multimodal intervention-education approach but also may require additional support (Underwood & Yost, 2016). For example, the clinician-researchers associated with the Alzheimer's Society London and Middlesex reported that group participants who completed this program identified the importance of accessing ongoing support. In response to this, they began offering an alumni support group and MCI/early-stage spousal support group to 'graduates' of the program. Research examining the utility of the alumni support group found that care partners endorsed an increased ability to cope and support their partner. The combination of supports provided in this multimodal approach, coupled with the optional ongoing support groups may show promise in meeting MCI care partners support needs over the long-term. Previous reviews examining interventions for early dementia caregivers suggest that multimodal approaches that incorporate psychoeducation may be the most beneficial (Bayly et al., 2019), although a recent meta-review

and meta-analysis suggests that multimodal interventions do not have a greater impact than single-component interventions (Cheng & Zhang, 2020). Further research is needed to examine the utility and effectiveness, specifically for MCI care partners.

One way to provide support to MCI care partners over the course of their caregiving trajectory as their needs evolve is through stepped care. Using this model, brief and flexible interventions could be provided remotely (e.g., via telephone or computer format) prior to progressing to more intensive interventions, if needed (Gallagher-Thompson & Coon, 2007; Mittelman, 2008). Another way of providing individualized care to MCI care partners would be to adapt the model used in the well-known *Resources for Enhancing Alzheimer's Caregiver Health II* (REACH II) intervention (Belle et al., 2006; Elliott et al., 2010). The REACH II protocol is a structured multimodal intervention that incorporates an individualized assessment of caregiver needs. Each intervention includes various strategies that are selected to address the certain needs identified in the assessment, which can include psychoeducation, problem solving, stress management, and telephone support. Considering such methods to address MCI care partners evolving needs throughout their caregiving trajectory is a necessary and important area for research.

Future Directions

In light of the novelty and dearth of research in the caregiving literature on MCI care partners, further research in this area is warranted. First, longitudinal research is needed examining how caregiver identity development and mental health in MCI care partners changes over the course of their family member or friends' diagnosis, including the possible transition to dementia. It may be particularly advantageous to carry out this research using a measurement burst design (Stawski et al., 2015). Such designs would help capture a more detailed account of identity and mental health changes through frequent assessments within a short time frame (e.g., weekly) that can be repeated longitudinally.

Second, future research aimed at increasing our understanding of the unique experiences of MCI care partners would benefit from utilizing rigorous mixed methods. Mixed methodologies would allow for a more in-depth exploration of the dynamic interplay between caregiver identity and mental health, which would be particularly important as our understanding of MCI care partners continues to develop. For example, given the different variations of caregiver identity that emerged from Study 1, it would be interesting to explore possible

differences in mental health for MCI care partners who identify as caregivers, in liminality, or who reject the caregiver identity. A promising measure is in the process of being developed to assess the extent to which individuals identify as caregivers (i.e., Family Caregiver Identity Scale; FCIS; Eifert et al., 2021). Preliminary testing of the FCIS showed initial evidence of validity and it is undergoing the next stages of validity and reliability testing. Future research could use quantitative methods with this promising measure, mixed with qualitative approaches, to further our understanding of how identity development and mental health are inter-related in MCI care partners. Additionally, mixed methods could be particularly helpful in exploring MCI caregiver identity and mental health with diversity and intersectionality considerations.

Diversity, particularly racial and ethnic differences, has been explored more within the dementia caregiver literature (e.g., Liu et al., 2020); as research in MCI care partners continues to grow, this will be an important area to examine. Furthermore, research exploring diversity with respect to MCI care partners should be expanded to examine a broader range of factors (e.g., cultural and societal influences, gender diversity, individuals living with disabilities). This broader intersectionality lens will be important moving forward to better understand nuance in terms of how individuals caring for those with MCI develop caregiver identities, and how they navigate mental health challenges (Goldsen et al., 2019).

Finally, future research should assess support service needs and the effectiveness of assessment and interventions to support those caring for individuals with MCI. Study 1 and 2 provided novel information on caregiver identity and mental health, which informed ways to address support needs of MCI care partners. However, it would be worthwhile to directly examine MCI care partners' perceived need for supports and whether and how perceived need changes throughout the course of an MCI diagnosis. Additionally, more research examining the effectiveness of interventions (e.g., psychoeducation, support groups, psychotherapy, respite) aimed at reducing or offsetting poor mental health both in the short and long-term would be particularly helpful. This information could further inform the need for additional assessment and intervention supports to address the unique and complex challenges experienced by MCI care partners.

Concluding Remarks

There is an increasing awareness that family members and friends play a pivotal role in providing care for individuals living with cognitive impairments (Alzheimer Society of Canada,

2016). Yet, MCI care partners may find themselves occupying a particular grey zone of liminality; they are often providing the type of care associated with caregiving, yet many do not view themselves as caregivers. This dissertation research illustrates the complexities MCI care partners face as they navigate their evolving roles and what this means for their identities, relationships, and futures. Relatedly, there are mental health considerations to be mindful of at this stage; there is merit to providing support services for MCI care partners to offset or reduce poor mental health. Perhaps of equal importance is that support services for MCI care partners can promote psychological flexibility, resilience, and foster the uplifts of caregiving as they continue providing care. Efforts to further understand the unique experiences of MCI care partners and how best to support them will be to the benefit of our families, communities, the health care system, and society at large.

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Appendix A: Study 1 St. Boniface General Hospital Recruitment Script

Description of script: As part of the ECCCOA neuropsychological assessment services, Dr. Koven will meet with the patient and the program partner for a feedback session to provide them with a diagnosis, which may include a diagnosis of Mild Cognitive Impairment (MCI). Dr. Koven will then contact the MCI affiliated program partners/eligible participants approximately one week later, to provide them with information about this study. Dr. Koven will call ECCCOA program partners/eligible participants and she will read the following description of the research study to them:

Hello [client name],

Brooke Beatie, a doctoral candidate in clinical psychology at the University of Manitoba, is conducting a research study under my co-supervision to understand the experiences of people like you who support people with memory difficulties. She also hopes to understand how changes in your family member's or friend's memory has impacted you. You are eligible to participate in this research study. Participation in this study involves sitting down with Ms. Beatie to complete a brief self-report questionnaire and for an approximate 60-minute interview. The interview will be audio-recorded, and can be completed here at the St. Boniface Hospital or at an office at the University of Manitoba, Fort Gary campus. Ms. Beatie will give you a \$15 gift card to a coffee shop or grocery store as a thank you for your time. I want to emphasize that your participation in this research study is in no way linked to the services that you or family member/friend are receiving at the Early Cognitive Change Clinic at St. Boniface Hospital. Whether you decide to participate or not participate in this research study, their and/or your treatment will not be affected. However, given my involvement with ECCCOA and my role as a co-supervisor on this project, there is a risk that I may be able to identify participants from the clinic, despite names and identifying information being removed or altered in the study. Does this study seem like something that you are interested in learning more about? [If no, Dr. Koven will thank the program partner for the time they took to listen to this information].

[If yes]

Since you are interested in learning more about this study, can I give Ms. Beatie your name and telephone number so that she can contact you to discuss this study in more detail and arrange an in-person interview, if you decide to participate?

[If yes, Dr. Koven will leave potential participants' contact information in a file folder that will be kept in a locked filing cabinet on the 4th floor of the McEwen Building]

Thank you very much. Ms. Beatie will be in touch with you shortly.

Appendix B: Telephone Recruitment Statement

Description of recruitment statement: I [Brooke Beatie] will introduce myself and briefly go over the details of this study. After I have discussed this study and answered any questions the potential participant may have, I will ask if they are interested in participating in this study. If they are interested in participating, I will schedule a meeting time and location to conduct my interview with them.

Hello [name],

My name is Brooke Beatie; I am a PhD student in clinical psychology at the University of Manitoba. I am calling you because you indicated to Dr. Koven that you would like to learn more about this study. Is this a good time to tell you more about it?

[If no]: If you are still interested to learn more about it, is there a better time I should call you back?

No: Thank you for your time. Have a nice day.

Yes: Ok, I will give you a call then [time they request to be called back]. Thanks!

[If yes]: This research study is looking at the experiences of people like you who support people with memory difficulties. Participation in this study involves sitting down with me for a semi-structured individual interview and completing a brief questionnaire. The questionnaire includes questions on your background (i.e., your age, your ethnicity, marital status etc.), mental health, burden, and your relationship satisfaction with the person with the memory concern. I will then begin the interview. I will ask you questions about your personal experiences and your relationship with the person who is having difficulties with their memory. You will also be asked about changes they've experienced since they began having difficulty with their memory and how this has affected you. It will take approximately 60 minutes to complete the interview. Your participation in this study is completely voluntary. Should you choose to withdraw from the study at any point or feel that you would rather leave some question(s) unanswered, you may do so. It will take approximately 1 hour to complete the interview. You will receive a \$15.00 gift card to a local coffee shop or grocery store as a thank you for your participation in this study.

Before I continue telling you more about this study, did you have any questions so far?

No: Ok.

Yes: [I will answer any questions they have thus far.] Now I'll finish telling you about this study.

After I complete all of my interviews, I may contact you again to invite you to meet with me for a follow-up interview. The purpose of this second interview is to ask follow-up questions and discuss my interpretation of the previous interview. The follow-up interview should take approximately 30-60 minutes. You will have an opportunity to decline this second interview, if you chose. If, at the end of either of the interviews, you decide that you would not like the information you've provided to be used in this study, please let me know and I will remove it from my analysis.

Your interview will be audio-recorded, and will be completed privately in a location of your choice, which may include an office in the McEwen Building at St. Boniface Hospital or at the University of Manitoba. Your participation in this research study is in no way linked to the treatment that you are receiving at St. Boniface Hospital. I will not disclose to your doctor whether you decide to participate in this study or not. Whether you decide to participate or not, your treatment will not be affected. However, given Dr. Koven's involvement with ECCCOA and her role as a co-supervisor on this project, there is a risk that she may be able to identify participants from the clinic, despite names and identifying information being removed or altered in the study.

Did you have any questions?

No: Ok.

Yes: [I will answer any questions they have thus far.]

Would you like to participate in this study?

[If no]: Thank you for your time. Have a nice day.

[If yes]: Where would you like the interview to take place?

O St. Boniface

O University of Manitoba?

What day/time is best for you?

Date: _____

Time: _____

Thank you for your time. If you need to cancel or reschedule our meeting, please do not hesitate to call me at (204) 770-6617. I look forward to seeing you on [meeting date/time].

Appendix C: Interview Guide

Preamble statement: Thanks for taking the time today to meet with me. The questions I will be asking you today are to help me understand the experiences of people like you who are here to support people with memory or thinking difficulties. Additionally, when individuals experience memory/thinking changes, it can present challenges for people in their life, so I'm also going to ask questions about how you are doing. Today, I'll be spending the next hour or so talking about this, feel free to talk as much as you like. I really just want to understand your experience the best way that I can. If there are some questions you don't feel comfortable answering, or if you would like to stop the interview at any time, that is ok, just let me know. Feel free to let me know if you have any questions at any time.

1. Can you start by telling me about your relationship with X? *[probe for how they identify their relationship; are they the primary caregiver, or do they refer to themselves as a son/wife/daughter etc.]* I'm interested to know what the relationship is, how long you've known X, how much time you spend with her/him, etc.

- a. How has their memory difficulties affected your relationship? *[some folks may answer this question with just tasks. If so, probe for how this have impacted other dimensions of their relationship. E.g., how you relate to each other, how you feel about him or her?]*

2. Tell me about the cognitive changes that X has been experiencing.

- a. How long has this been going on?
- b. What kind of changes have happened
- c. When did you notice something was wrong, etc.

3. Now that I have a good sense of your relationship, and of the reasons that brought you to ECCCOA with X, I would like you to tell me how your relationship has changed since X started experiencing memory problems.

- a. What was your relationship like before you noticed changes in X's memory/thinking? *[probe for prior relationship quality vs now.*
 - i. If no change: What do you think has contributed to this? Has anything not changed? *(try to get a picture of their daily life. The more changes the more likely their identity will change)*
 - ii. If changes: What kind of changes? What did these changes mean to you? How did feel about it, what do these changes look like? Did they change you?

4. It's often the case that the focus of attention is on people who are going through health challenges. What about you – have you noticed any changes in yourself since X started experiencing memory problems?

- a. What about you has remained the same? *[probe for societal, cultural, familial influences]*

5. How have you been coping with these changes?

- a. What do you do to manage these changes?
- b. Have they been difficult?

- i. Were there times when you've felt more distressed?
 - ii. What about times when you felt less distressed?
- 6. Have you had earlier life experiences that have helped prepare you to care for or support X in the way you do?
- 7. Have you heard of the term "caregiver"? – yes/no What is your understanding of the this word?
 - a. What does that term mean to you?
 - b. Do you think that applies to you in any way?
- 8. Has anyone used the term "caregiver" to describe you in relation to X before?
 - a. If yes:
 - i. When was the first time you heard it?
 - ii. How did you react?
 - b. If no:
 - i. What is your reaction to that term now? [probe to see if they may be avoiding this term/resisting the label]
 - ii. Do you think that you might consider yourself a caregiver to X at some point in the future?
 - iii. What would it mean if you were a caregiver?
- 9. Would you consider yourself a caregiver for X?
 - a. If yes:
 - i. How does it feel, when you think of yourself as a caregiver for X?
 - ii. How is it different from being a [daughter/etc]?
 - iii. When did you start to think of yourself in that way? [probe for previous history of caregiving, how did they internalize that role, how did other people treat them]
 - b. If no:
 - i. How do you primarily identify then in relation to this person?
 - ii. Can you talk about how you view the roles as different (or not)?
- 10. Is there anything else that you would like to say before we end the interview?

Appendix D: Study 1 Informed Consent Form**Hôpital St-Boniface Hospital****UNIVERSITY
OF MANITOBA**

Exploring The Experiences Of People Who Support Family Members And Friends With MCI

Principal Investigator: Brooke Beatie, M.A., Department of Psychology, University of Manitoba

Ph. (204) XXX-XXXX/ E-mail: umbeatie@myumanitoba.ca

Research Co-Supervisors: Dr. Corey Mackenzie, Ph.D., C. Psych., Associate Professor, and Director of Clinical Training, Department of Psychology, University of Manitoba

Ph. (204) XXX-XXXX/ E-mail: corey.mackenzie@umanitoba.ca

Dr. Lesley Koven, Ph.D., C. Psych., Assistant Professor, Clinical Health Psychology, Max Rady College of Medicine, University of Manitoba

Ph. (204) XXX-XXXX/Email: LKoven@sbgh.mb.ca

Human Ethics

Email: humanethics@umanitoba.ca.

This consent form, a copy of which you may keep for your records, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. Please take your time to review this consent form and discuss any questions you may have with the researcher. Please take the time to read this carefully and to understand any accompanying information. If there is something that you do not understand, please ask the researcher to explain any words or information that you do not clearly understand.

Purpose:

Brooke Beatie is conducting this study as part of her dissertation research, under the supervision of Dr. Mackenzie and Dr. Koven. The purpose of this research is to explore the experiences of people who support family members and friends diagnosed with MCI. This study will inform researchers, clinicians, and public policy initiatives aimed at contributing to the development of support services.

Participant's Initials: ____

Participation:

Your participation in this study is completely voluntary. Should you choose to withdraw from the study at any point or feel that you would rather leave some question(s) unanswered, you may do so. If you decide to participate in this study, you will participate in an interview conducted by the principle investigator, Ms. Brooke Beatie. Prior to taking part in the interview, you will complete a brief questionnaire focusing on your background (i.e., your age, your ethnicity, marital status etc.) mental health, burden, and your relationship satisfaction with the person with the memory concern. The questionnaire should take approximately 20 minutes to complete. This information will be reviewed and used during the interview and in this study with your consent. Ms. Beatie will then begin the interview. During the interview, you will be asked questions about your personal experiences and your relationship with the person who is having difficulties with their memory. You will also be asked about changes they've experienced since they began having difficulty with their memory and how this has affected you. It will take approximately 60 minutes to complete the interview. After I have completed the interview, I may contact you again by telephone to schedule a brief follow-up in-person interview. The purpose of this second interview is to ask additional follow-up questions and discuss my interpretation of your previous interview to ensure I have an accurate description of your experience. The follow-up interview should take approximately 30-60 minutes. You will have an opportunity to decline this second interview, if you chose. You will receive a \$15.00 gift card to a local coffee shop or grocery store as a thank you for your participation in this study. Should you decide to withdraw from the study at any time, you will still receive the \$15.00 gift card as a thank you for your time. If, at the end of the first interview, you decide that you would not like the data you've provided to be used in this study, please inform the researcher and it will be removed from the study.

Legal Rights:

Your decision to participate does not waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities.

Results:

The summary results of this study (not your individual results, which will never be shared) should be available by August 2019. If you would like to receive a summary of the results, please provide your contact information below.

Confidentiality:

Only the principal investigator, her supervisors, and members of Dr. Mackenzie's Aging and Mental Health laboratory will have access to the three types of data: the questionnaires, the audio recordings, and the transcribed interviews. The questionnaires will be de-identified when entered into a secured SPSS computer program. The audio recordings will be de-identified when they are transcribed into typed word documented by a private transcriber. The transcribed interview documents will be password protected. The questionnaire SPSS dataset and the transcribed interview documents will be kept in a secure location on a password-protected computer. The researchers will not share the identity of participants with any psychologists or service provider at St. Boniface General Hospital or elsewhere. Whether you decide to participate or not participate in this research study, the services you receive from ECCCOA at St. Boniface Hospital will not be affected. However, given Dr. Koven's involvement with ECCCOA and her

Participant's Initials: ____

role as a co-supervisor on this project, there is a risk that she may be able to identify participants from the clinic, despite their names and identifying information being removed or altered in the transcripts. Medical records that contain your identity will be treated as confidential in accordance with the Personal Health Information Act of Manitoba. Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. The plans for dissemination are to present findings at seminars, conferences, and to submit the findings for publication in a peer-reviewed publication. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed.

Limits to confidentiality:

If you disclose information that you are an imminent threat to someone else or to yourself, we are required to break confidentiality to ensure the safety of the person at risk. If you disclose information that a child or other vulnerable person is being abused or neglected, we are required to break confidentiality and report the information to the appropriate authority.

Benefits:

Although this study will have no direct benefits for you, we hope the information learned from this study will be used to help health care practitioners better understand and support the unique role of family members and friends of people diagnosed with MCI.

Risks:

Although the risks of taking part in this study are minimal, you will be asked to provide information that you could find difficult or distressing to talk about. If you become distressed you can stop at any time without consequence. We will also provide you with a list of mental health resources or service providers should you need to talk with someone.

University approval:

This research has been approved by the Psychology/Sociology Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at (204) 474-7122.

Security:

All questionnaire and interview data will be stored on password-protected laboratory computers and in locked filing cabinets at the Aging and Mental Health Laboratory at the University of Manitoba. University administrators may check the data to see that the research has been ethically done. The University of Manitoba Psychology/Sociology Research Ethics Board and St. Boniface Hospital may review research-related records for quality assurance purposes.

Contact:

If you have any additional questions about this study or your rights as a research participant, please feel free to contact the principal investigator, Ms. Beatie, doctoral candidate in Clinical Psychology, University of Manitoba. You may also contact Ms. Beatie's supervisor, Dr. Mackenzie. Contact information for these individuals can be found at the top of this form.

Participant's Initials: ____

Statement of Consent:

I have read this consent form and I understand my role as a participant. I have had the opportunity to discuss this study with Ms. Beatie and I have had my questions answered. The risks and benefits have been explained to me. I have not been influenced by any study team member to participate in the study by any statements or implied statements.

I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I permit the inspection of my records that relate to this study by The University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Participant signature: _____

Participant printed name: _____

Date _____
(day/month/year)

Permission for future contact: I agree to be contacted by Ms. Brooke Beatie by telephone, mail, or email for future follow-up in relation to this study, if any of the content from the individual interview is unclear to her.

Yes ____ No ____ Participant Initials _____ Telephone: _____

Email: _____

Would you like to receive a summary of the results of this study?

____ No

____ Yes, I would like to receive the summary results.

If yes, please provide your contact information below:

Email: _____

Phone number: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

Printed Name: _____

Date: _____

Signature: _____

Role in the study: _____

Participant's Initials: ____

Appendix E: Background Information Questionnaire**Today's Date:** _____**Age:** _____**Gender:** _____**Highest level of education:** _____**Current occupational status:**☐ Full-time ☐ Part-time ☐ Retired, from what:☐ Other: - _____**If you are currently retired, how long have you been retired?** _____**Estimated Annual household income:**☐ Under \$25,000 ☐ \$25,001 - \$50,000 ☐ \$50,001 - \$75,000 ☐ Over \$75,001**Marital status:**☐ Single ☐ Common law ☐ Married ☐ Widowed ☐ Divorced☐ Separated**Please indicate the type of relationship you have with the person with the memory concern.****Are you his/her:**☐ Spouse ☐ Child ☐ Sibling ☐ Friend☐ Other-please specify: _____**Do you live with the person with the memory concern?**☐ Yes ☐ No**Race/Ethnicity:**

_____ White

_____ Black

_____ Indian/Pakistani/Sri Lankan

_____ Japanese/Korean/Chinese

Other: _____

_____ Indigenous

_____ Middle Eastern

_____ Hispanic/Latino

_____ Filipino/Malaysian/Indonesian

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