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**A PHENOMENOLOGICAL INQUIRY OF THE EXPERIENCE OF
CARING FOR A LOVED ONE RECENTLY DIAGNOSED WITH
AMNESTIC MILD COGNITIVE IMPAIRMENT**

Sarah Margaret Woolmore-Goodwin

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A PHENOMENOLOGICAL INQUIRY OF THE EXPERIENCE OF CARING FOR A
LOVED ONE RECENTLY DIAGNOSED WITH AMNESTIC MILD COGNITIVE
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A thesis submitted in partial fulfilment
of the requirements for the degree of
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The School of Graduate and Postdoctoral Studies
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A Phenomenological Inquiry of the Experience of Caring for a Loved One Recently Diagnosed
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requirements for the degree of

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ABSTRACT

There are currently 500,000 people living with Alzheimer's disease (AD) in Canada. It is estimated that the total costs associated with AD are 15 billion Canadian dollars per year.

Informal caregivers across the nation provide an estimated 231 million hours of unpaid care annually. Individuals diagnosed with Amnesic Mild Cognitive Impairment (aMCI) have the highest rate of conversion to AD, with an average 5-year conversion rate from time of aMCI diagnosis. This study aimed to understand how carers of individuals recently diagnosed with aMCI experience the transition into their new role of care provider and what implications their new role has on carer well-being.

To explore the meaning of the experience of caring for a loved one with aMCI, a hermeneutic phenomenological investigation was used. Five carers created a narrative through in-depth interviewing which provided detailed and rich descriptions of their experiences. Data were analysed using van Manen's methodological structure for human science inquiry. The essence of the experience of caring for a loved one recently diagnosed with aMCI is the need for the carer to wear multiple masks in order to cope with the accumulated multiple losses they suffer as they continually adjust to their new and evolving carer identity.

Keywords: amnesic mild cognitive impairment, carer, carer burden, role strain, phenomenology

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LIST OF ABBREVIATIONS

| | |
|-----------|---|
| 18FDG-PET | 18F-fluorodeoxyglucose positron-emission tomography |
| ADL | Activity of Daily Living |
| ABMC | Aging Brain and Memory Clinic |
| aMCI | Amnesic Mild Cognitive Impairment |
| AD | Alzheimer's Disease |
| ADOD | Alzheimer's Disease and Other Dementias |
| AS | Alzheimer's Society |
| CDR | Clinical Dementia Rating |
| CIT | Caregiver Identity Theory |
| CSF | Cerebrospinal Fluid |
| CSS | Caregiver Stress Syndrome |
| fMRI | Functional Molecular Resonance Imaging |
| GFP | General Family Physician |
| IADL | Instrumental Activities of Daily Living |
| MIP | Memory Intervention Program |
| MCI | Mild Cognitive Impairment |
| MoCA | Montreal Cognitive Assessment |
| MMSE | Mini Mental Status Exam |
| RCT | Randomized Controlled Trial |
| SI | Symbolic Interactionism |

1. Introduction

1.1 Background

Mild cognitive impairment (MCI) is a diagnosis that differs from both normal age-associated memory loss and dementia (Petersen, 2011). Those diagnosed with MCI have cognitive difficulties, usually with memory, that are greater than expected for one's age and education, yet when compared to those with dementia, their independent activities of daily living are largely unaffected (Petersen et al., 2009). These individuals are at-risk for progression of cognitive difficulties, with approximately 80% of individuals with MCI progressing to dementia within five years (Petersen & Negash, 2008).

There are four sub-types of MCI (amnesic single domain, amnesic multiple domain, non-amnesic single domain, non-amnesic multiple domain) (Gauthier et al., 2006). Individuals diagnosed with single and multiple domain amnesic MCI (aMCI) have the highest rate of conversion to Alzheimer's disease (AD), with an average five year conversion rate from time of diagnosis (Gauthier et al., 2006; Petersen, 2011). In Canada, the estimated prevalence of MCI is 17% in people aged 65 and older (Rockwood, 2007). There are currently 500,000 Canadians living with Alzheimer's disease or a related dementia, which is costing the formal health care system 15 billion dollars. In addition, it has been estimated that informal caregivers across the nation provide 231 million hours of unpaid care annually. Twenty years from now, these numbers are expected to double (Canadian Alzheimer Society, 2010).

1.2 Theoretical Justification

Much of the literature on caregiver burden has focused on caregiving for people with AD and other chronic illnesses that are progressive and degenerative (Gallagher et al., 2011). The

focus has remained predominantly on later stage illnesses where caregivers are likely to be overburdened as they engage in multiple roles causing role strain and the inability to cope with stressors as interpersonal resources dwindle (Pearlin & Skaff, 1996). What is unknown at this time is at what stage in the dementia diagnosis caregivers form their new identity and begin to negotiate their new role with their existing ones. Individuals who are diagnosed with aMCI are considered to be at the greatest risk for progressing to AD. Hermeneutical phenomenology was used to investigate participants' experience and to supply a novel contribution to the research gaps in the existing knowledge base surrounding the beginning of this unique journey. The aim of phenomenology is to be able to understand how individuals experience a phenomenon which, in this case, is caring for loved ones recently diagnosed with aMCI.

The Alzheimer Society's 2010 document, *Rising Tide: The Impact of Dementia on Canadian Society* (Alzheimer Society of Canada, 2010), outlines four targeted interventions that could reduce the burden of dementia on Canadian society. Included in these four interventions is a recommendation for Caregiver Development and Support Programs. From these recommendations, the question emerges: what kind of programs and support do caregivers and individuals with dementia receiving care from informal care providers want? The report outlined the possible benefits of having caregiver support programs; however, it did not articulate what information would help facilitate positive change for caregivers.

1.3 Purpose

The purpose of this study is to use phenomenology to better understand the experiences and needs of family members caring for individuals newly diagnosed with aMCI. The aim of using phenomenology is not to make generalizations or recommendations to policy or programs because the sample size is inadequate to suggest that the findings will be applicable to other

people in similar situations. Rather, the strength of a phenomenological approach is its ability to shed insight on taken-for-granted experiences. This illumination helps provide a more meaningful understanding of an essence of the combined experience of the participants. From this, future research can be informed to consider the complexity of the human condition, the individual experience, and the meaning that we as individuals assign to the way they care for our loved ones diagnosed with aMCI.

1.4 Objectives

The first objective of this research project was to understand the lived experience of family members caring for loved ones recently diagnosed with aMCI using a hermeneutic phenomenological lens. The second aim was to examine the responses of participants in order to determine what the emergent experience of this new role is for carers, how carers negotiate their new roles, and what more they can illuminate on this new life transition. The final goal was to investigate the essence of 'caring for a loved one with aMCI' and compare this with existing caregiver literature.

2. LITERATURE REVIEW

2.1 Introduction and Review Strategy

As both Canada's and the world's population continues to age, there will be an ever-increasing strain on social, economic, and environmental resources (Oakie, 2011; Wolfs, de Vugt, Verkaaik, Verkade, & Verhey, 2010). The obligation to provide support to our aging population has begun to fall squarely on the shoulders of informal care providers because the health care system is steadily reaching a point of unsustainability (Oakie, 2011; Ryan et al., 2010). Informal caregivers are in a precarious position as the remuneration for their assistance and support goes unrecognized and unpaid at a societal level. There are few policies which reimburse informal caregivers for the multi-million dollar credit they are providing to the social welfare and health care systems. Currently Canadian care providers freely donate over 231 million hours of unpaid care to their aging parents, friends, spouses and other relatives (Alzheimer Society of Canada, 2010).

Informal care providers provide the majority of home care without formal assistance. As a result, they are at increased risk of caregiver strain or burden (Gallant & Connel, 1998). What is significant in the literature is the overwhelming agreement that receiving education and support early in the caregiving journey can be beneficial to a care provider's overall well-being (Ryan et al., 2010). The following chapter identifies three main research areas that pertain to caring for a loved one with MCI. The first section of this chapter will include a review of existing literature on aMCI, Alzheimer's disease and other dementias (ADOD). The second section will explore the theoretical models which describe the role of caregiver as well as the process of adopting multiple roles that may lead to caregiver burden and role strain. The final section will establish the current literature on providing care for a family member with aMCI.

Search criteria and limits were established to critically review the literature. I purposefully selected peer-reviewed journal article databases such as Scopus, CINHL, PubMed, and Medline which supplied the majority of articles for my literature review. When searching for articles related to aMCI, the following key terms were used: amnesic mild cognitive impairment, mild cognitive impairment, MCI, cognitive impairment, prodromal Alzheimer's disease/prodromal AD, mild dementia and mild Alzheimer's disease/mild AD. Only articles from 2006 to 2011 were included in the initial search. Articles predating this time frame were included only if they were foundational and cited multiple times in one or more of the 2006-2010 articles. Over 3000 articles were found after duplicates and non-English publications were eliminated.

A secondary search was conducted using the terms: carer, caring, caregiving, and caregiver. Over 6,800 articles were found after duplicate articles were eliminated and the same procedure outlined above was applied to refine the number of articles reviewed. The final stage of the search was to combine the final two groups of articles, aMCI and caregive(r/ing). This was done to reduce the number of articles to only those with the aMCI included in the full text or key words. Once these two search categories were combined and duplicates were removed, 24 articles remained dealing with MCI and caregiving. Of these 24 articles, five were qualitative studies and none of these were guided by phenomenology.

2.1.1 Amnesic Mild Cognitive Impairment

The diagnosis of MCI is representative of an intermediate stage of cognitive function situated between normal age-related cognitive decline and a diagnosis of dementia, usually AD (Petersen et al., 2009). The progression from MCI to AD is usually gradual, with noticeable deficits occurring in the memory domain. Petersen (2011) suggests that as few as 1 in 100 people

go through life with virtually no cognitive decline, and these individuals are often referred to as successful agers. However, age-associated memory loss is normal and is considered to be an acceptable and manageable part of the aging process. MCI is not a normal part of aging.

MCI has two different subtypes which are further subdivided into single and multiple domain MCI (Gauthier et al., 2006). The first subtype of MCI is amnesic mild cognitive impairment and the second non-amnesic mild cognitive impairment. The main differentiation between amnesic and non-amnesic subtypes is that individuals who receive an aMCI diagnosis experience clinically significant loss of memory that does not affect, or only minimally affects their level of independent functioning with other cognitive functions such as language, executive functions, and visuospatial abilities still largely intact (Petersen et al., 2009).

Single domain aMCI is a clinical subtype of MCI and is most closely correlated with conversion to AD. In longitudinal studies monitoring AD conversion, individuals who have this subtype diagnosis show poor performance on delayed recall and executive function tests (Gauthier et al., 2006). It is in these two cognitive domains that people with AD are also most impaired; therefore, this tends to be a robust indicator of a higher risk of progression to AD. Multiple domain aMCI indicates deficits in memory as well as the presence of behavioural and psychological signs, such as depression. Depression in older age tends to mask underlying cognitive impairments and often a diagnosis of MCI is delayed until signs and symptoms of advanced decline in delayed recall are obvious (Gauthier et al., 2006).

Non-amnesic MCI is characterized by non-clinically significant memory loss, yet, there is a noticeable decline in functions not related to memory, affecting attention, use of language, and/ or visuospatial skills. Non-amnesic MCI is less common and is usually associated with other dementias such as frontotemporal dementia, Lewy Body dementia and other dementias not

associated with AD (Petersen, 2011). Amnesic MCI on the other hand is very much related to conversion to AD within a five-year window from time of diagnosis (Brown et al., 2011; Di Ilio et al., 2010; Petersen, 2011; Reiman et al., 2011).

2.1.2 Diagnosis and Disease Trajectory

Scientists have begun to look at biomarker-based assessment of the neuropathological characteristics of AD in order to enhance the clinical detection of AD in early stages of the disease (Dubois et al., 2007). Biomarkers located in an individual's cerebrospinal fluid (CSF) have even been used to predict progression of aMCI to AD. Genetic screening for AD using the presenilin 1 gene is another recent form of early screening for at-risk groups, yet it is not a widely adopted form of disease detection (Oakie, 2011). Petersen and colleagues found that more than 90% of patients who had received an aMCI diagnosis converted to AD; that is, they displayed clinically significant signs associated with AD (Petersen et al., 2005). The actual diagnosis of AD cannot be made until an autopsy is completed and the postmortem brain is assessed for volumetric loss, lesions and CSF biomarkers of AD (Brown et al., 2011; Ewers et al., 2010; Reiman et al., 2011).

The most recent population estimates derived from American study samples project that the prevalence of aMCI ranges from 10 to 20% in individuals aged 65 and older (Manly, Tang, Schupf, Stern, Vonsattel, & Mayeux, 2008; Plassman et al., 2008; Petersen, 2011). Results published by Petersen and colleagues in 2009 from the longitudinal Mayo Clinic Study of Aging found that out of a sample of over 2,050 persons without dementia (age range 70-89 at time of enrollment), "prevalence of amnesic mild cognitive impairment was 11.1% and that of nonamnesic mild cognitive impairment was 4.9%" (Petersen et al., 2009, p. 1447).

One overwhelming finding in clinical trials research investigating aMCI in general is that individuals who receive the diagnosis have an increased risk of converting to AD (Brown et al., 2011; Ewers et al., 2010; Petersen, 2011; Reiman et al., 2011). According to statistics reported by the aMCI experts, in general, the incidence of dementia increases from the age of 65 by one to two percent per year (Petersen, 2011; Plassman et al., 2008; Schmidtke & Hermeneit, 2008).

2.1.3 Implications of Early Detection

Seniors who have concerns about their memory but do not have clinically significant memory loss (the worried well) can present with memory loss histories similar to people with aMCI. However, the worried well are clinically different from people with subtypes of MCI and this shows up in neuropsychological assessment (Petersen & Negash, 2008). This makes actual diagnosis of aMCI challenging if a family doctor does not have the correct tools at his/her disposal to be able to make a diagnosis.

The Mini Mental Status Exam (Folstein, Folstein, & McHugh, 1975) is often used as a diagnostic tool for ADOD but is insensitive to detecting the subtle memory changes in individuals with MCI. Tools such as the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2008) and the Short Test of Mental Status (Kokmen, Smith, Petersen, Tangalos, & Ivnik, 1991) are much stronger indicators of MCI (Petersen, 2011). Diagnosis of MCI occurs less often in a community family doctor's office and more frequently once a person is referred by his/her family doctor to a specialist memory clinic for a comprehensive geriatric assessment (Petersen, 2011; Visser & Verhey, 2008).

People who were diagnosed with aMCI reported a delay in seeking a diagnosis as the majority of individuals assumed that their memory decline was just a normal part of aging (Schmidtke & Hermeneit, 2008). The distinction between aMCI and other dementias is best

made by a specialist. The distinguishing feature that marks the progression from aMCI to AD is significant decline in function (Petersen et al., 2009). Being able to predict the likelihood of conversion to AD is not a perfect science and there are certain misconceptions about the disease process (Ewers et al., 2010). The degree of cognitive impairment a person presents with at time of diagnosis will certainly affect the length of time it takes a person with aMCI to convert to AD (Petersen, 2011). Greater impairment at baseline is associated with quicker conversion rate as the person is probably closer to the dementia criteria threshold.

The most robust methods for early diagnosis used in clinical research are in the form of functional imaging techniques, such as 18F-fluorodeoxyglucose positron-emission tomography (18FDG-PET), which provide an index of synaptic integrity (Petersen, 2011), and these are currently used as part of the diagnostic assessment when determining if a person has converted to AD. Another novel approach to detecting risk of conversion to AD is through use of functional molecular resonance imaging (fMRI), particularly of amyloid plaques in the brain (Ewers et al., 2011; Petersen, 2011). This form of detection is not common practice in clinical settings but is employed when conducting research and used in longitudinal studies monitoring conversion rates of MCI to AD.

2.1.4 A Challenging Diagnosis and an Uncertain Future

It has been estimated that those who receive the aMCI diagnosis in a specialty memory clinic often only comprehend about 25% of the information their health professional relays to them (McIlvane, Popa, Robinson, Houseweart, & Haley, 2008). The challenge is to explain to patients that there is an increased risk that they will develop AD without labeling them as having prodromal AD. Prodromal AD is defined as a pre-dementia stage, and it has three components that distinguish it from a diagnosis of aMCI: episodic memory loss (free-recall deficit with

cuing), intact instrumental activities of daily living, and biological evidence (the presence of at least one positive biomarker for the disease detected in CFS or through fMRI) (Dubois et al., 2007). The aim of health professionals who give their patient the diagnosis should be to inform them that aMCI is abnormal but that not everyone who has aMCI will eventually have AD (Petersen, 2011). Family physicians are also less likely to be able to determine the subtype of MCI and therefore unable to explain the potential trajectory of the disease process (Bai et al., 2011; Ewers et al., 2010; Petersen et al., 2009).

Although there is no known cure for aMCI, there is evidence to suggest that cognitive rehabilitation and memory strategies may assist individuals to cope in the home and can enhance wellbeing and functional ability. Training programs such as the Baycrest Memory Intervention Program have shown significant improvement in everyday memory in persons with MCI at the end of training and maintained improvement at a three month follow up (Fogarty & Murphy, 2009; Troyer, Murphy, Anderson, Moscovitch, & Craik, 2008). Evidence from two separate randomized controlled trials (RCTs) and two non-randomized controlled trials demonstrated that cognitive training in general is associated with long-term improvement in both episodic and working memory at two- and five-year follow-ups respectively in people diagnosed with aMCI (Chertkow et al., 2008). However, the memory intervention programs' results should be interpreted carefully because the improvements in cognition were only displayed in the cognitive domains specifically targeted by these studies (Chertkow et al., 2008).

While memory intervention programs have been associated with improvement in both short and long-term memory for people diagnosed with aMCI, there are other environmental, physiological, and lifestyle factors that are correlated with the development of aMCI and AD. Research suggests that individuals with hypertension and other cardiovascular risk factors have a

greater propensity of converting to AD (Di Carlo, Lamassa, Baldereschi, Del Parigi, Capurso, & Panza, 2007; Petersen, 2011). However, regular physical exercise has been shown to be not only preventative but also a neuroprotective therapy for cognitive impairment and AD (Ahlskog, Geda, Graff-Radford, & Petersen, 2011).

What is not well established is the impact MCI has on the family members who begin to take on caring roles to support these individuals. Even more deficient in the literature on MCI is the voice or point of view of individuals who care for family members with an aMCI diagnosis (Van Der Roest et al. 2009). Few quantitative or qualitative studies have developed carer assessment tools, in-depth assessments to determine carer needs for support, or explained the potential health risk that belonging to this group could have, as this is a population who could be providing care for a longest amount of time. The literature that does exist for caregivers of individuals with mild dementia is fairly well established and supports the notion of early caregiver support, education and intervention for this group, but few studies have focused specifically on people who care for family members with aMCI.

2.1.5 Alzheimer's Disease

AD is a degenerative neurological disease characterized by neuronal deterioration, gliosis, an accumulation of amyloid plaques and neuronal tangles (intracellular inclusions) in specific areas of the brain, primarily the basal forebrain, the association cortex and the hippocampus (Bilbul & Schipper, 2011). AD is a progressive dementing disease that affects approximately 500,000 Canadians and accounts for 75% of all dementia cases in people over the age of 65 years (Grand, Caspar, & MacDonald, 2011). What is so detrimental about the manifestation of AD is that it often afflicts 30-50% of those individuals who comprise the oldest old, that is, people over the age of 85 who also are at the greatest risk of living with multiple

complex co-morbidities (Bilbul & Schipper, 2011). These individuals lack the physiological, social, and psychological reserves to maintain high levels of independent function. The progressive decline in individuals who are diagnosed with AD ultimately always results in mortality as AD is a terminal condition.

In recent years, the study of AD has been primarily focused on early detection and treatment (Bilbul & Schipper, 2011; Grand et al., 2011, Oakie, 2011). While many risk factors for the development of AD have been identified (level of education, gender, family history, genetic factors, vascular risk factors, mood disorders, and psychosocial lifestyle factors), there is still no known cause or cure for the disease. By focusing on the early detection and treatment of AD, scientists, health professionals, and informal care providers believe that this will better prepare patients and their family members to cope as long as possible in their home without prematurely placing a person with AD in long-term care (LTC).

Early diagnosis may give the person afflicted and his/her family more time to discuss legal and financial issues such as advanced directives and the patient's specific wishes regarding medical treatment (Oakie, 2011). The primary caregiver may be able to manage longer and cope better if educated early on about behavioural changes, strategies for dealing with memory loss, and also how to care for themselves while caring for another with such extreme levels of dependence for ADL's (Carpentier, Ducharme, Kergoat, & Bergman, 2008). In a RCT where caregivers were provided with education, counseling, and instrumental support, LTC placement was delayed by an average of 18 months, which resulted in obvious cost saving to the client's family and also the health care system supporting these families (Mittelman, Haley, Clay, & Roth, 2006).

However, there may also be consequences associated with early diagnosis of AD. The moral dilemma of early diagnosis has been of recent interest to biomedical ethicists. Early diagnosis of AD has been linked to severe depression and suicide, especially among younger men (less than 65 years old) (Oakie, 2011). Early diagnosis may also have negative consequences for job retention, qualifying for life insurance benefits, revocation of driver's license, and poor self-esteem (Petersen, 2011). Another issue that arises from early diagnosis is the stigma AD patients can experience from their close circle of friends, family members and family doctor (Garand et al., 2007). Family physicians rarely record a diagnosis of AD in their patients' medical charts. This has been assumed to be due to a lack of education about AD as well as family physicians' personal feelings of fear and hopelessness due to their limited ability to help their patient who has AD. This feeling of hopelessness has been understood by ethicists as a stigmatic response (Oakie, 2011).

For the reason that there is no sufficient treatment to cure the disease, physicians may prescribe a cognitive enhancer (such as an acetylcholinesterase inhibitors) to their AD patients without ever mentioning the disease by name (Oakie, 2011; Petersen, 2011). This secrecy may stem from the fear that disclosure of the diagnosis may make their patient become suicidal. There is a lack of education and knowledge about AD among general practitioners and literature that exists that addresses the issue of stigma among family doctors is insufficient (Werner, Goldstein, & Heinik, 2011). Previous studies have looked at the psycho-social consequences of living with AD and the negative personal attributes people with AD associate with themselves such as feeling 'stupid', 'worthless', and 'in the way' (Burgener & Burger, 2008).

Few studies, however, have examined the stigma patients face from their family doctor, the health care system, or their personal social support system. The fear of being stigmatized

may affect both the caregiver and the person with AD and prevent them from seeking a diagnosis or formal support. The notion of stigma is manifested in different forms and perhaps most noticeable and detrimental to people with AD is in the paternalistic nature of the doctor-patient relationship (Oakie, 2011) or rather doctors wanting to protect their patients from harm. Further research is needed to examine the experience of stigmatization people with AD face and also to address this issue so that it does not prevent patients and their family members from getting the help they need early on in the disease process.

2.1.6 Gaps in Current Literature

Scientific research is getting closer to determining the subgroup of individuals with aMCI who are at greater risk of developing AD. However, RCTs and longitudinal studies are still only scratching the surface of being able to assess the effectiveness of pharmacological or lifestyle interventions with at risk groups (Bai et al., 2011; Ewers et al., 2010; Petersen et al., 2009). The most noticeable research gap in the aMCI literature is in the psycho-social implications the diagnosis has on both the person who receives the diagnosis and his/her loved ones.

Few studies address the barriers to care (Carpentier et al., 2008) in the early stages of cognitive impairment. Little is known about what may prevent or facilitate individuals and their loved ones from seeking help early on. It has been said that some care providers wait over two years before looking for a diagnosis for their loved one who is showing signs of cognitive impairment (Wackerbarth & Johnson, 2002). The research does suggest, however, that early symptom detection and intervention may be beneficial to the health of both caregivers and care receivers (Carpenter et al., 2008; Pearlin, Schieman, Fazio, & Meersman, 2005). When caregivers are unable to access the support they need while caring for a loved one with a cognitive impairment, caregivers are susceptible to becoming overtaxed and burdened. The

following section explores caregiver burden and the corresponding theories associated with the role strain care providers face as a result of acquiring the caregiver role.

2.2 Caregiving, Caregiver Burden and Dementia

Caregiving and caregiver burden associated with dementia have been well studied, and the complexity of these issues is well known. Informal care providers comprise the largest unpaid sector of the workforce (Oakie, 2011; Alzheimer's Society of Canada, 2010). As such, the economic impact associated with the time spent providing care to family members and friends is rarely documented or compensated. For this reason, a number of informal care providers are not only providing care in the home but are also employed in the formal working sector. The contrasting demands of occupying two working roles in addition to other ascribed roles such as parent, sibling, friend, church member, or volunteer, can often be stressful. However, there are multiple interconnected components which will affect how an individual experiences stress and what coping mechanisms a caregiver is able to access at any given time. The following section is an examination of the theoretical models which have been created to explain care provider stress and strain, more commonly referred to as caregiver burden.

2.2.1 *Stress Process Model and the Life Course Perspective*

In the late 1970's and early 1980's, Dr. Leonard Pearlin and colleagues created a model which captured the multifactorial and complex nature of the way individuals experience stress throughout their lives (Pearlin, Mullin, Semple, & Skaff, 1990). The experience of feeling stressed is a naturally- and normally- occurring endocrine reaction to external strains within an individual's environment. Stress, referred to as the 'fight or flight' response, recruits high levels of adrenaline when a person faces a situation where they are suddenly scared, upset, angry or physically stressed (e.g. exercise). When the body acquires an increased amount of adrenaline

over a sustained period of time, this can have negative effects on our overall health resulting from excess levels of cortisol (Marmot et al., 1991).

Pearlin's work did not focus on the physiological expression of stress but rather studied the environmental stressors and mediators which can predict different health outcomes for an individual within a specific population over a period of time (Pearlin & Skaff, 1996). The Stress Process Model was created to explain the range in the way people experience stress in their lives and the dissimilar manifestation of health-related stress effects in a given population (Pearlin et al., 1990). The life course perspective has been used to better understand the health outcomes related to stress. The life course perspective can be explained as "a sequence of socially defined events and roles that the individual enacts over time" (Giele & Elder, 1998, p. 354). In particular, this approach focuses on the connection between individuals and the historical and socioeconomic context in which these individuals lived. A life course perspective to caregiving may shed further light on this experience due to the heterogeneity that exists among the current population of care providers and care receivers respectively.

To study caregiver stress, certain factors such as employment status (the point in life at which caregivers retired or if they are still working), the type of relationship they have developed with their care receiver prior to diagnosis and their previous history of caring for a friend or family member, can help explain a caregiver's current experience of stress (Pearlin et al., 1990). Also important in this examination are the cultural and social contexts that are present for the caregiver. For example, individuals who provide care to a family member who is part of the baby boom generation will probably have a different experience than a baby boomer that provided care to a parent who lived through the First or Second World War (Pearlin et al., 2005).

The life course perspective captures subtle differences in response to major life events such as transitioning into new roles while not fully retiring from previous social roles. For example, if a care provider is caring for young children, working, and caring for an elderly parent, their transition into the third roles was probably fairly sudden and the undetermined trajectory of time the carer will have to spend in any given role may, in turn, have an influence on the level of stress s/he experiences. Also worth noting is the social and cultural context within which this caregiver makes decisions (Pearlin et al., 1990). Western culture espouses that the responsibility to access health care and maintain well-being is that of the individual. This has significant implications on when and how caregivers begin to access support services (Carpentier et al., 2008).

2.2.2 Stress, Coping Mechanisms, Support and Mastery

The stress process model further builds on the life course perspective by looking specifically at how differences in population health outcomes can be explained by the inconsistent experiences people have when accessing internal and external support as well as the coping mechanisms people utilize when facing a stressful situation. There are four main components to the stress process model. The first, of course, is stress. Stress can come in various forms. Pearlin and Skaff (1996) explain that there are two types of stress resulting from chronic stressors and quotidian stressors.

Chronic stressors are defined by both ambient and interpersonal strains. Ambient strains are those tensions which we face as a product of interacting with our environments, such as missing a train, getting into a car accident, getting stuck in a snow storm, or stubbing a big toe. Interpersonal strains are those stressors which result from role conflict, often stemming from the difficulty one experiences in fulfilling the requirements of major social roles. Quotidian

stressors, on the other hand, arise from the context of one's individual obligations of self-governed responsibilities, or rather the hassles of daily life (Pearlin et al., 2005). These stressors are important to study because when an individual is unable to meet the challenge of the many small responsibilities in a day, they can become overwhelmed and unsatisfied, specifically if daily responsibilities are unmet as a result of fulfilling these same responsibilities for other people and not having enough time to complete one's own.

The second component of the stress process model is coping. The ability to cope is an adaptive behavior that is developed across the life course (Pearlin et al., 1990). Rather than change or rectify a stressful situation, individuals learn to cope with these stressors or rather manage the situation. The way people cope with stressful life events are contextually different for each person based on a number of factors such as group membership, previous experience with the stressor, sense of control (mastery), and personal values. Coping mechanisms are not the same for each person and there are very robust social determinants of health which dictate the adaptive or maladaptive coping mechanisms individuals draw on to minimize or dilute levels of stress (Marmot et al., 1991).

The third component of the stress process model is support (Pearlin & Skaff, 1996). Support operates on three different levels: micro, meso and macro. Micro level support is defined as the intrapersonal resources an individual draws on, such as sense of humour, spirituality and ingenuity. Meso level support is the informal social support networks individuals create and maintain over their life course. Macro level support is the farthest removed from the individual and can be thought of as the formal support system. This consists of everything from the political economic welfare state to the formal services to which an individual has access. Social support is defined by the different connections individuals make across their life course and to what degree

they are able to call on these linkages in times of need. Lack of social support or inadequate levels of both instrumental (assistance with instrumental activities of daily living such as banking, shopping, and household chores) and emotional support has been associated with deleterious health effects (Blazer, 2005).

The final component of the stress process model is 'mastery.' Like coping mechanisms and social support, sense of mastery is a resource that individuals draw on. Mastery, a perceived level of autonomy and control, can act to mediate or increase the level of stress an individual experiences. Intervening factors such as socioeconomic status, job satisfaction and social support network composition can influence an individual's sense of mastery (Pearlin & Skaff, 1996). One profound effect sense of mastery can have on an individual's perceived level of wellbeing is the extent of control a person feels over a stressful situation, especially if the situation is highly demanding. This experience has been defined (Karasek, 1989) as the high demand/low control model whereby lack of perceived sense of control and autonomy among workers who occupy highly demanding and stressful jobs are at risk of developing serious health conditions. The Whitehall Study I and II (Marmot et al., 1991) supports this. Workers in high demand/low control occupations displayed a greater incidence and prevalence of coronary artery disease, atherosclerosis, hypertension, hyperlipidemia, diabetes and obesity, than those workers who occupied low demand/low control positions.

The role of the caregiver is not usually thought of as an occupation because it is an informal task which happens in the unpaid labour force and is often undervalued because as it is considered to be domestic work (Gallagher et al., 2011). The role of informal caregiver can be seen as a high demand/low control position and could be used to explain the negative health effects that are common among informal caregivers. When taking a life course perspective, the

stress process model can help to explain how caregivers may experience elevated levels of stress while caring for a loved one with cognitive impairment. The following section explores the specific implications of caring for a loved one with dementia as the majority of the literature on caregiving comes from AD caregiver research.

2.2.3 *Caregiver Burden*

Caregiver burden is a complex and multifaceted concept that has a well-established literature base specifically dealing with dementia caregivers (Van Den Wijngaart, Vernooij-Dassen, & Felling, 2007). Caregiver burden is a widely accepted condition that can develop among people who provide the majority of instrumental and emotional support to family members with a degenerative disease (Brodaty, 1996). It has also been documented that individuals who provide care for family members with ADOD tend to experience high levels of clinical depression and psychological disturbances (Brodaty, 1996), increased levels of stress, and lower levels of life satisfaction (Marziali, McCleary, & Streiner, 2010).

Caregivers of people with AD have been assessed for levels of burden in many different settings (community, day programs, LTC) and what is worthwhile to note is that dementia caregivers have higher levels of psychological morbidity in each setting than caregivers who are providing care to people with different disease processes such as cancer, Parkinson's Disease and other degenerative conditions (Brodaty, 1996; Carpentier et al., 2010; Van Den Wijngaart et al., 2010). The majority of people with ADOD are cared for in the home, which means that for the most challenging stages of the disease, that is, once communication breaks down, informal caregivers assume the bulk of the caring burden (Gallant & Connell, 1998).

Caring for a disabled family member can be a source of physical strain, psychological distress, and social isolation (Dal Santo, Scharlach, Nielsen, & Fox, 2007). Caregiver health has

been widely studied and the overall consensus is that people who care for loved ones with ADOD experience greater levels of immune response suppression, cardiovascular disease, diabetes, depression, anxiety and poor self-rated health overall (Dal Santo et al., 2007; Gallant & Connell, 1998; Pearlin et al., 2005; Pearlin & Skaff, 1996; Tunajek, 2010). One in three caregivers meets the diagnostic criteria for depression and the most common expressions from caregivers whose loved ones have recently received a diagnosis of ADOD is that they are angry, resentful and feel guilty about having these feelings (Tunajek, 2010).

Caregiver burden or Caregiver Stress Syndrome (CSS) is not only the result of coping with the multiple stressors caregivers face while assisting a loved one with instrumental activities of daily living (IADL) but also refers to the grief carers feel attributable to the decline in their loved ones health (Tunajek, 2010). Caregivers also suffer multiple losses (Gallant & Connell, 1998). Some caregivers may have to take an unpaid leave of absence from work and suffer an economic loss while other caregivers grieve the loss of the relationship they have with the person with ADOD.

It is estimated that over 51% of people who are providing care to a spouse or relative with ADOD are still actively employed in occupations outside of their home (Dal Santo et al., 2007). Perhaps one of the most significant risk factors of experiencing caregiver burnout is that the greater level of stress a caregiver feels can result in premature or early institutionalization of their loved one with AD. This scenario often causes economic and psychological consequences for caregiver wellbeing (Gallagher et al., 2011).

The consistent finding when studying caregiver burden is that caregivers of individuals with dementia experience the most stress and burden when the person they care for displays challenging and responsive behaviours (Brodaty, 1996). Poulshock and Deimling's (1984)

foundational study of caregivers of people with dementia helped to further explain the various factors that affect levels of caregiver burden among caregivers of individuals with dementia while also explaining the disparate levels of burden within this population.

The level of behavioural disturbance a person with dementia experiences is directly correlated with the level of burden the caregiver experiences. Mediating the experience of burden is a number of exacerbating and protective factors. Factors thought to exacerbate the level of burden a caregiver experiences when their family member has behavioural disturbances are: social isolation, lack of knowledge, poor coping skills, feelings of guilt, poor marital relationship, and other personality factors such as ability to express emotion. Protective factors are those which mediate the experience of caregiver burden in a positive way when a care recipient displays behavioural disturbances. Protective factors are: practical support, emotional and instrumental support from family, occupational status and income, and ability to use problem-focused coping (Poulshock & Deimling, 1984).

Research into caregiver burden suggests that an individual's level of stress has much to do with his/her internal and psychosocial ability to cope with stressful events. Those who take on these roles often internalize society's concept of caregiving. This means that stress levels can be affected by the way that person feels about his or herself ability to fulfill the expectations society creates for the specific role of caregiver (Tunajek, 2010). If caregivers feel they have adequately fulfilled their social expectations, they seem to have lower levels of stress than caregivers whose self-concept is misaligned with the social obligations of caregiving for a loved one with ADOD.

The Stress Process Model (Pearlin et al., 2005) has been widely adopted to explain the complex nature of caregiver burden, specifically lending insight into the way caregivers react to multiple stressors. One fundamental component of the stress model is that an individual's

expression or reaction to an isolated stressful event is mediated by several factors such as internal and external resources (Van Den Wijngaart, 2010). An individual appraises to what extent they are able to control, cope and manage the stressful demands of caregiving.

While the literature on caregivers of individuals with dementia is robust and well-established as a research area, very little attention has been paid to the early trajectory of caregiving and at what point caregivers begin to assume their new role. The literature suggests that by the time their loved one receives the diagnosis, caregivers have been actively engaged in care provision activities for two to five years (Pearlin et al., 2005). Very recently the research question of interest to scholars working in cognitive impairment research is how beneficial support would be to caregivers early on in the disease process (Adams, 2006; Wheeler, 2010; Gallagher et al., 2011). While AD is currently not a preventable illness, education early on with regard to what to expect when someone is diagnosed and living with AD, and how to access support that could potentially reduce the levels of caregiver burden, would be very helpful. Further, the role of education and caregiver support in aMCI is not clear.

2.2.4 Gaps in Caregiver Burden Research

One of the most puzzling features exposed in the caregiving literature is that informal caregivers are reticent to seek out formal support services. Scholars have hypothesized that carers are reluctant to seek support for two main reasons. First, the caregiver may be unsure of how to ask for help and secondly, the caregiver may feel as though they can manage on their own given the existing support network they have available to them (Carpentier et al., 2008). Lack of support, awareness and limited time with the family doctor have been acknowledged by caregivers as key barriers to accessing the needed support services. Secondly, without referrals from a family doctor or other health care specialist to Alzheimer Societies and other

organizations, caregivers may not be aware of the services that are offered to help them cope with their loved one in the home (Adams, 2006). While lack of formal support is a significant component of caregiver stress, caregiver burden is a multifaceted and complex concept.

The on-going focus on caregiving after a diagnosis of AD may have reduced the scope of research to only concentrate on assessing interventions and adaptive strategies on caregivers of people with dementia specifically, rather than focusing on early intervention with caregivers who may be at risk for long-term caregiving. Within the last few years, the research focus has begun to shift toward understanding the psychosocial effects of the dementia diagnosis and the new caregiving role, and how this role is experienced. In a recent assessment of caregiving for a loved one with dementia, Adams (2008) advocated for more research on the early stages of the process to identify characteristics of family members who may be more prone to problems and may benefit from early intervention.

Researchers in this field have little insight into when caregivers transition into their new role and what opportunities there may be to support and educate care providers during this crucial identity formation and role adoption period (Adams, 2008). There is no general agreement regarding what is needed to support people who provide care to those with MCI due to the fact that MCI as a diagnosis not socially understood (Gallagher et al., 2011). There is very little empirical evidence available concerning interventions or even consensus on what defines the exact role a person is occupying when caring for a family member with MCI.

A study by Gaugler, Zarit, and Pearlin (2003) suggested that the role of caregiver is assumed when a person requires assistance with at least one activity of daily living (ADL). However, this is not helpful for those individuals who care for a family member with aMCI as this form of cognitive impairment is distinguished by no or only slight ADL deficits.

Researchers have also failed to address the effect of an uncertain or ambiguous MCI diagnosis or regression to normal cognitive function on the care provider. One question that emerges from the literature is to what extent the precarious nature of aMCI diagnosis creates a stressful or anxious response among caregivers and what the long-term consequences of the ambiguousness of the diagnosis are for carers. Similarly, existing research lacks the unique voice of individuals who care for loved ones with aMCI and has little insight into the lived carer experience.

Also missing in the literature are details regarding the extent to which caregivers are challenged by the long-term commitment that may be required for caring for a loved one who is diagnosed with MCI (Austrom & Lu, 2009). The average duration of the MCI diagnosis (depending on how far along in the trajectory the diagnosis was made) is five years. The average length of time a person lives with AD is five to 12 years (Petersen et al., 2009). The effect of long-term caregiving as well as the effect of receiving two diagnoses (aMCI and then AD) has not been explored in the existing literature (Austrom & Lu, 2009).

Perhaps the most glaring gap in the literature is the exclusion of the aMCI carers' lived experiences and the absence of qualitative methodological inquiry which explores the phenomenon of caring for a person with aMCI (Okura & Langa, 2011). Without an in-depth look at the immediate and long-term effects of caring for someone with aMCI, the beginning of the caring journey, what happens after a loved one is diagnosed, and to what extent carers form the carer identity is still largely unknown (Gallagher et al., 2011). Due to the lack of research and understanding about aMCI carers, no clear definition, social norms or expectations can be ascribed to the aMCI carer role, which could result in difficulty with identity formation and

feelings of belonging to a larger group (Carlander, Sahlberg-Blom, Hellström, & Ternstedt, 2011).

As 50 to 60% of the cases of dementia worldwide are of the Alzheimer's type (Hain, Touhy, & Engström, 2010), it makes sense to educate, engage and support care providers who will potentially be in the role of informal caregiver for a long time (Austrom & Lu, 2009). These individuals, in turn, will potentially face the greatest risk of developing caregiver burnout as well as the negative health outcomes associated with caregiving for a person with AD, thus costing the health care system even more. It is worth noting that, in the United States of America in 2009, caregivers of people with AD provided 12.5 billion hours of unpaid informal care, which would have cost around 144 billion dollars to the American health care system. Further, this high stress/low control unpaid job has considerable health consequences as more than 40% of caregivers experience high or very high emotional stress from caregiving with about a third of caregivers reporting clinical depression (Hain et al., 2010). For this reason alone, early evidence-based interventions should become the focus of research in the area of caregiver burden particularly in this population of potential long-term caregivers.

3. METHODOLOGY

Hermeneutic phenomenology was used to understand the experiences of individuals caring for a loved one with aMCI. The rationale for the hermeneutic phenomenological approach is outlined below. This is followed by a description of the study design, recruitment strategies, and the data collection and analysis process.

3.1 Phenomenology

Phenomenology is both a philosophical means of understanding lived experience as well as a methodology for human sciences research developed as an alternative to the widely accepted positivist paradigm (Dowling, 2007; Flood, 2010; McConnell-Henry, Chapman, & Francis, 2009; van Manen, 1997). Phenomenology can be used descriptively or inductively in order to investigate the meanings individuals associate with their lived experiences (Dowling, 2007; Finlay, 2002; Flood, 2010; Standing, 2009; Wilding & Whiteford, 2005). The central goal of phenomenology is to investigate “being-in-the-world,” that is, how the individual experiences a phenomenon in relation to a specific context. To understand the lived experience of individuals caring for loved ones recently diagnosed with aMCI, a phenomenological approach was considered the most appropriate choice.

There are many schools of thought that guide phenomenological inquiry and among them there are two philosophical foundations or ways of knowing. A primary one is Phenomenological Reductionism or Descriptive Phenomenology developed by Husserl (1931) and another is Hermeneutical Phenomenology developed by Heidegger (Heidegger, 1962; McConnell-Henry et al., 2009). Of these, this project adopts the latter because of the hermeneutic lens from which Heidegger views the world. Husserl dismisses Descartes’s mind-body dichotomy and “proposed

instead a science-grounded description of ordinary conscious experience devoid of presuppositions” (McWilliam, 2010, p. 230).

Husserl’s (1931) phenomenology is strongly informed by pragmatism and empiricism. His criteria for philosophical phenomenological discourse was that the phenomenologist’s view of “reality is constituted by our subjective conscious experience of the outer world, not objective facts” (McConnell-Henry et al., 2009, p. 230). Husserl maintained that phenomenologists should hold themselves separate from this subjective consciousness in order to maintain an unbiased examination of the phenomenon in question or rather, bracket oneself from preconceived notions in our attempt to capture the true human experience.

Heidegger on the other hand, in response to Husserl’s pragmatic quest for the truth of the lived experience, developed hermeneutic phenomenology. Hermeneutic, from the Greek word *hermeneusin*, means to understand or to interpret (Dowling, 2007; Flood, 2010; McConnell-Henry et al., 2009; van Manen, 1997). Heidegger was interested in moving from description to interpretation. With this approach, the researcher co-constructs meaning with the subject who experiences a phenomenon and, therefore, the researcher must acknowledge and draw on his or her prior understanding of a phenomenon (fore-structure). This means that the researcher becomes a legitimate part of the research process; the researcher becomes a “being-in-the-world” of the participant.

The concept of the ‘lifeworld’ (Husserl, 1931), encompasses the knowledge that a person gains through conscious awareness or mindfulness of the stimuli in the world around him/her. Heidegger (1962) took this concept one step further, maintaining that the researcher becomes a part of his/her participants’ lifeworld, and therefore is co-constructing meaning with the

participant (Crist & Tanner, 2003; Flood, 2010) and interpreting the phenomenon the participant experiences out of this tightly-knit relationship of understanding.

3.1.1 Hermeneutical Phenomenology as Methodology

Phenomenology, as a descriptive approach, focuses on the structures of experience, or rather, the organizing principles that give experiences of being form and meaning in the lifeworld (Heidegger, 1962). The development of understanding takes place through a dialectical process, moving from descriptive inquiry toward interpretive contextualization, referred to as 'hermeneutic understanding' (Flood, 2010). This is achieved when the inquirer concentrates on the philosophical and historical meaning of an individual's experience of a phenomenon and attempts to understand the meaning the individual gives to the experience while contextually situating the essence of experience in a social, historical and cultural epoch (Crist & Tanner, 2003; Polkinghorne, 1995). Heideggerian hermeneutical phenomenology as a school of inquiry moves away from description of a phenomenon toward an interpretation of the meaning individuals assign to a lived experience (McConnell-Henry et al., 2009). Hermeneutical phenomenology is particularly useful when there is a knowledge gap within the specific area one is interested in studying (Dowling, 2007; Holloway & Trodes, 2003; Koch & Harrington, 1998; van Manen, 1990, 1984).

Finlay (2002) suggests that to gain a deeper understanding of the individuals' experience of being in the world, the investigator must enter the hermeneutic circle where they are constantly reflecting on the participants and their own horizons of understanding, thereby creating a fusion of horizons between the subject and the phenomenon in question. Heidegger (1962) believed that because each person will experience a phenomenon differently and because as individuals we differ in our values and life histories, it is impossible for the investigator to

bracket their historical background or paradigmatic location. However, the researcher is urged to be reflexive about their fore-structure and be mindful of how this will shape and inform his/her interpretation of the participants' experiences with the phenomenon (Crist & Tanner, 2003; Wilding & Whiteford, 2005). The critical dialectical process of understanding attempts to span across culture, time and history.

3.1.2 The Hermeneutical Circle

The hermeneutic circle is a metaphor Heidegger uses to describe the experience of dialectically moving between "the part" and "the whole" (Crist & Tanner, 2003; Heidegger, 1962; Koch, 1996). Understanding the experience both the researcher and the participant bring to the interview process and the meanings both individuals are creating is a reciprocal process. As Heidegger does not believe in the ability to bracket a researcher's fore-conception or pre-understanding (Standing, 2009), the researcher needs to reflect on how these prior experiences and meanings influence the research process and be reflexively engaged in both the interview and in textual analysis. The researcher needs to have a firm location within the hermeneutic circle and it is the researcher's responsibility to determine how he/she fits within the circle and how he/she will influence the co-constructed meanings that are created throughout the research process.

3.1.3 Horizon of Understanding and Reflexivity

Heidegger believed, like van Manen, that hermeneutical consciousness evolves out of the types of questions the researcher asks of the participant (Koch & Harrington, 1998; van Manen, 1997). The questions that are powerful and evoke the most possibility for understanding are those questions that address 'taken-for-granted' experiences as there is meaning to be found in these places that may not have been recognized before (Standing, 2009). Dialogue between

researcher and participant must remain open-ended, narrative and non-directive so that individuals are able to relay the stories in a fashion that is best suited to the way they experienced a phenomenon (Crist & Tanner, 2003; Flood, 2010). While probes are used to critically examine those taken-for-granted experiences, the course, tone and duration of the conversation should remain largely determined by the participant's narrative.

Through engaging in the dialectical hermeneutical circle, I was able to assess the role that 'part meanings' (Holloway & Trodes, 2003) have in the larger body of my participants' narrative account of the experience of caring for a loved one with aMCI. I was able to observe how 'part meanings' were combined with other 'part meanings' to constitute the whole or essence of a phenomenon. Heidegger (Heidegger, 1962) recommends passive engagement with the participants' experiences through interaction with the text. I strove to be present as the phenomenon exposed itself through contemplation and reflexive writing about the essence of being (Wilding & Whiteford, 2005).

3.1.4 Fusion of Horizons

Heidegger believed that interpretation occurs through the 'fusion of horizons,' a horizon being a vantage point from which an individual experiences a phenomenon. Horizons are not static but ever in motion (Koch, 1996). When horizons are fused, it means that multiple vantage points are coming together. When a researcher's horizon of understanding is fused with that of their participant, they are open and receptive to meanings and experiences that are not their own. During the meetings with participants, and during the analysis, I repeatedly reflected on my pre-conceptions as they aligned or disagreed with those of the participants (Koch & Harrington, 1998; Flood, 2010).

While these horizons begin to fuse during the interview process, they are solidified during analysis and writing of results. This fusion of horizons is evidenced through the choices the researcher makes about including or excluding data and the way the participant's point of view is depicted through the selected quotes. The horizons can be thought of as fusing when the researcher's interpretation of the participants experience with the phenomenon resonates both with the participant and other readers. Fusion of horizons is experienced when the researcher is able to reconcile their own fore-conceptions, not by eliminating or dismissing them, but by allowing pre-understanding to give way to their participant's horizon of understanding (Thompson, 1990).

3.2 Study Design

The goal of this study was to understand the phenomenon of caring for a loved one who has recently been diagnosed with aMCI using hermeneutical phenomenology.

3.2.1 Sampling and Study Recruitment

Purposeful sampling was employed to gain an in-depth understanding of the caregiving experience for loved ones of those recently diagnosed with aMCI. Study participants were recruited through the Aging Brain and Memory Clinic (ABMC) at Parkwood Hospital, St. Joseph's Health Care, London. The ABMC is an outpatient assessment and treatment clinic that offers the services of specialized clinicians such as geriatricians, geriatric clinical neuropsychologists, and other allied health professionals who are experts in the care of older adults. Patients are referred to the clinic by either their family physician or a specialist. Patients attending the ABMC are typically offered the opportunity to be part of several outpatient programs, such as the Memory Intervention Program (MIP) (Troyer et al., 2008). Participants for this study were recruited from the MIP at Parkwood Hospital.

The MIP at Parkwood Hospital, based on a program developed at Baycrest Centre for Geriatric Care in Toronto, is an eight-week group session for both people with aMCI and their family members. The MIP is offered twice a year. Participants and their family members attend eight consecutive sessions and two follow-up sessions, the first at one month and the second at three months post-program. During this eight-week intervention program, participants are provided with education about lifestyle factors that affect memory (e.g., diet, exercise, mental and social activity, stress) and are taught by allied health professionals. Participants are also taught memory strategies that can reduce the impact of their memory difficulties on functional abilities.

Participants' family members are invited to join the education session for the first hour of the weekly two-hour sessions. However, not every participant has a family member who is interested in attending, so this is optional. For the second half of the sessions, family members are invited to attend a "family member only" group session facilitated by a social worker. During these sessions they are encouraged to discuss interventions that are helping and what challenges may be arising out of the new tools the participants are given. This forum offers the family members a unique opportunity to hear what their peers are experiencing and to share their own stories as well. Typically 10-12 participants take part in the MIP at any given time. This is consistent with recommended sample sizes for qualitative research which suggest that two to 10 research subjects (Boyd, 2001) and "long interviews with up to 10 people" (Creswell, 1998, pp. 65) are sufficient to reach saturation in phenomenological studies.

For the purpose of this study, participants were recruited from the MIP scheduled from March to May 2011. Twelve participants with aMCI were enrolled in the March to May 2011 MIP session. Of these twelve however, only six had family members who participated with

them. These six family members were invited to participate in this study. Dr. Fogarty, MIP Program Director, was the initial point of contact with family members. Dr. Fogarty provided potential participants with a letter of information outlining the study along with a consent form. Signed consent forms were forwarded to me by Dr. Fogarty.

Five of the six MIP family members agreed to take part in the study and provided signed consent forms. One family member withdrew her consent shortly after agreeing to participate due to personal circumstances and a change in her husband's status. This left a final sample of four participants for my study. Each of the four family members was contacted by telephone and interview dates and times were arranged. To reach a greater number of potential participants, recruitment was extended to include family members from the Fall 2010 MIP (September to December 2010). These family members were only eligible to participate if their loved one had not converted to ADOD. Of the 10 Fall 2010 participants, only four had family members. Of these four, three had converted to ADOD leaving one participant from the Fall 2010 MIP. This provided me with a total sample of five participants.

Both Spring 2011 and Fall 2010 letters of information and consent forms can be seen in Appendix A. In Appendix B is a telephone screening questionnaire which was used to determine family members' interest in participating, as well as the Clinical Dementia Rating Scale (CDR) located in Appendix C. The CDR is an interview administered over the phone which has been validated as an instrument for detection of altered level of cognitive impairment from baseline (Morris, 1993). This screen was given to determine whether the MIP participant's cognitive status had changed from their baseline CDR assessment score.

3.2.2 Interviews and Data Collection

One in-depth semi-structured interview was conducted with each participant. Interviews ranged from 55 to 140 minutes. Prior to each interview participants completed a demographic questionnaire (Appendix D). To guide the interview, a semi-structured interview guide was developed. Initially questions were created using Pearlin's Stress Process Model (Pearlin et al., 2005). Upon reflection, however, the questions were too directive to obtain unrestrained accounts of participants' lived experiences as caregivers. Thus, to obtain carers' pre-reflexive lived experiences, the narrative interview guide (Appendix E) was modified to focus on themes rather than specific questions. Probes such as "please tell me more about how you experienced that feeling/emotion/reaction" were included. During the interview, family members were asked to narrate their experiences of caring for a loved one recently diagnosed with aMCI.

All interviews were audio-recorded and each participant's narrative was transcribed. No notes were taken during the interview. This enabled me to be fully engaged in the narrative described by each participant. I did, however, create a field note guide which was used to journal experiences before and after each interview (Appendix F). This field note guide allowed me to reflect on the description of the environment, the observable characteristics of my participants, such as how they behaved, spoke, shifted their weight, where their attention was focused, the nature or tone of the conversation, non-verbal communication, and also my own experience prior to and after the interview. This included my personal reflections about my own experience of caring, the kind of day I was having and any insights or interpretations that were starting to form from the interview.

After each interview was transcribed, I read through each participant's text and began to reflexively journal my own personal emotions, thoughts, and feelings that arose during in-depth

re-reading of the text with the intention of illuminating my own horizon of understanding. This interpretive process enabled me to reflect on my own part meanings and interpretations I was bringing to my readings of each participant's narrative. After multiple readings of the five participants' transcripts, theoretical saturation was reached as no new topics emerged and similar experiences were being echoed from the previous interviews.

To fully understand the emergent essence of the experiences, I conducted multiple readings of each transcript and listened to the audio-recordings numerous times, thereby immersing myself in the data and becoming more aware of the life world of the carer (Crist & Tanner, 2003; Wilding and Whiteford, 2005). By engaging in the dialectical hermeneutical circle, this allowed me to better understand the role that 'part meanings' (Holloway & Trodes, 2003) had in the larger body of my participants' narrative account of the experience of caring for a loved one with aMCI. This way I was able to observe how 'part meanings' were combined with other 'part meanings' to constitute the whole essence of being.

Heidegger recommends passive engagement with the phenomenon through interaction with the text. I strove to be present as the phenomenon exposed itself to me through contemplation and reflexive writing about the essence of being (Heidegger, 1962; Wilding and Whiteford, 2005). I remained fully immersed in the data once I completed all of the interviews. During both the transcription and data analysis, I kept a journal, created memos and took analytical notes.

3.2.3 Confidentiality and Ethics

Prior to study recruitment, research ethics approval was obtained from The University of Western Ontario's Health Sciences Research Ethics Board. This approval, the revised HSREB approval and Parkwood Hospital's Clinical Research Impact Committee approval are attached in

Appendix G. To maintain confidentiality, the digital recordings were kept in my locked office, in a locked suite of offices in the Aging, Rehabilitation and Geriatric Care Research Centre. The cleaned transcripts, stripped of any names, were kept on a password protected laptop. Data will be kept for five years and then both the hard copies of the transcripts and the digital recordings will be destroyed.

3.3 Data Analysis

Hermeneutical phenomenology employs an iterative analytic approach through the use of wholistic, selective, and line-by-line analysis (van Manen, 1997). Each phase of analysis guides a different way of interpreting the text and provides specific lenses in order to examine an experience or phenomenon. The strength of this approach for this study is that it provides a deeper way of understanding the multiple parts that help give meaning to the whole essence of the experience (van Manen, 1997).

3.3.1 *Wholistic Analysis*

Wholistic thematic analysis, a global approach to seeking overall meaning, was used as a first phase to construct a general theme that emerged from each participant's text (van Manen, 1997). This global theme highlighted both similarities and differences present in each participant's transcripts and allowed the formation of a starting point from which to gain insights into the lived experience of caring for someone with MCI. Similarities highlighted across each participant's transcripts during this initial phase of analysis are held constant during the next two phases of analysis (selective and line-by-line) with the aim of either providing robust experiential backing for this theme or dismissing it as a non-essential experience related to the phenomenon.

The aim of wholistic analysis is to begin to become aware of the multiple parts that help construct the whole essence of being, or rather how each global theme is reminiscent of the aMCI carer experience. To begin wholistic analysis, I read through each individual transcript then created a wholistic statement that I felt encapsulated the emergent experience of caring for a loved one with aMCI. Table 1 provides an example of the emergent experiences that began to take form and meaning during the wholistic analysis phase.

After completing wholistic thematic analysis, I met with my committee to present my initial interpretation of the experience of caring for a loved one with aMCI. What was determined in this first meeting was that the wholistic analysis had not yet fully captured the essence of the experience for all participants or level of reliability. This led me to further explore the separate parts of the experiences which helped me more fully understand the whole.

Table 1: Wholistic Thematic Analysis Examples by Study Participant

P₁ Linda: A spouse who is caring for husband recently diagnosed with aMCI; who needs to wear a mask in order to cover-up her guilt, resentment and anger that her husband has a problem and reconcile this with her knowledge that this is not his fault. She finds herself feeling accepted and validated in her experiences with her husband through the collective stories of other people who share a similar life world perspective. The experience is a form of anticipatory grieving, filled with uncertainty and ambiguity.

P₂ Mary-Anne: A spouse who is caring for her loved one recently diagnosed with aMCI experiences multiple losses. The loss of an equitable partner to share life with, the loss of a hope for the future together, loss of familial connectedness, loss of independence and autonomy and the loss of normalcy. She feels that her attention must always be focused on her spouse and can relate with other's in her situation who also feel that they must be constantly mindful of their spouse's actions. The experience is frustrating and she has a fear of the unknown; the future is a question mark.

P₃ Olivia: A spouse who is caring for her loved one recently diagnosed with aMCI feels isolation and embarrassment as a result of both the social stigma associated with her husband's diagnosis but also due to his dis-inhibition and inappropriate behaviour with family members and friends. She has to negotiate her relationship with him as well as the other people in her life in order for her to cope from day-to-day, maintaining a semblance of her normal life. The experience is the importance of the MCI diagnosis, the need to move forward, knowing that he has a problem and that her feelings are validated.

P₄ Lorraine: A daughter caring for a mother recently diagnosed with aMCI realizes that her mother is referring to her more often and this has created mixed feelings for her. Due to the constrained nature of their mother daughter relationship, the daughter welcomes her mother's new found needs for the daughter's opinions and appreciates that her mother needs her more than she once did as a result of the mother's failing memory. On the other hand, because the relationship is so strained, she questions her willingness to be there for her mother when her mother had never been there for her in the past. The experience is ambiguous, she resents that her mother needs her when she is at a point in her life where she is free to be her own person and live outside of her mother's powerful personality.

P₅ Shelly: A spouse who is caring for her loved recently diagnosed with aMCI approaches her husband's declining memory as a natural progression into older age and considers herself lucky that the diagnosis is not more severe. She does however have to remind herself to be patient and understanding of her husband's short comings and help him cope in the home. For her, coping is taking each day, the good with the bad from one day to the next. She experiences caring for her husband who is diagnosed with aMCI as an acceptable risk to loving someone and tries to celebrate the good days.

Note: The names in this table are pseudonyms

Table 2. Selective Thematic Analysis Examples with Participant 1

| Participants Text | Emergent Selective Thematic Analysis Theme |
|---|--|
| <ul style="list-style-type: none"> • P₁: uh, I find that it takes a lot of time. He will come, he will have a feeling where there will be something off and he will want to sit down and talk and we will need to talk through this and I find it takes a lot of time | <ul style="list-style-type: none"> • Shows that providing care to spouse takes a lot of time, resents time that it takes – shows a change, resistant to change |
| <ul style="list-style-type: none"> • P₁: But that's ok (she says slightly sarcastically) we are getting along pretty good. Um there are times when he can't quite see why I am doing something and it gets to the stage where, I have to leave... but so far he has been able to see what I was trying to do and acknowledge it afterwards, so we have been getting along pretty good. Um, I have to remember, I find it difficult (her tone changes) to have a smile on my face sometimes when I'd rather go Grrrr | <ul style="list-style-type: none"> • Shows the difficulty reconciling social expectations of caring for a sick spouse with the anger and resentment of him having a problem – having to wear a mask |
| <ul style="list-style-type: none"> • P₁: yeah, it's uh, a losing of part of your partner, and um, (lets out sigh), yeah, like I know that we're blessed, and I know it could be worse, but it's still losing part of a partner, part of what you were expecting and you need to deal with it differently | <ul style="list-style-type: none"> • Shows multiple losses, loss of hope for the future [unmet expectations], loss of a partner, loss of old roles as a result of taking on his roles |
| <ul style="list-style-type: none"> • P₁: Yes, you can't say it to him, and you have to say it to someone. I must admit, I had been very gently been starting to tell my daughters, to express some of the stress i feel, I don't want to over burden them, but I do want to let them know how I feel and that um, (with a sigh) I guess I want to prepare them to a certain extent. Now they accept this is not a problem, but not living with him, they don't understand and I am trying to, I don't want to put too much onto them and I'm trying to, bit by bit show them what's going on and uh, probably after so I can say the good results afterwards but yeah, and I think it's very important that they know | <ul style="list-style-type: none"> • Shows importance of having someone to talk to about your experience, looking for validation of feelings and current lived reality from family and friends, no support, no validation |

From the selective thematic analysis of participants' transcripts, multiple sub-themes emerged. During the selective analysis, I continued to create journal entries. This enabled me to be reflexive about my decisions and sensitive to the lenses I was using in collapsing sub-themes into larger themes. This prompted me to move into a deeper form of analysis, line-by-line analysis.

3.3.3 Line-by-line Analysis

The final stage of analysis was to look at each participant's entire transcript and analyze sentence clusters using line-by-line analysis. Line-by-line analysis takes a closer, in-depth look at the actual words of the participant as well as unspoken meanings, sentence structures, pauses and non-verbal expressions of participants recorded in my field notes. These hidden meanings were extremely important for drawing insights into the similarities and differences of each participant's experience of caring for a loved one with aMCI. Table 3 provides an example of the line-by-line analysis used in phase three of my analysis on P₁, Linda's text.

Table 3: Line-by-line Thematic Analysis Examples

| Participants Text | Line-by-line Analysis – Emergent Themes |
|--|--|
| <ul style="list-style-type: none"> • ...and I guess I was seeing things without seeing them if you know what I mean and he said, you know, there's something wrong, things are not going right here and we sat down and talked about it and ah we realized that, yes, there was a problem and his mother had had Alzheimer's, so we began to fear that this is what it was and um, the doctor sort of, well he didn't really, well you know he only sees him for a short time, and he said, "I think you are fine." But we felt we needed to go ahead and we did, we went first to the Alzheimer's society, they happened to be giving a course that was one day a week for 6 weeks out of the hospital and we took it. He didn't want to go but we thought it might make him better. We learned so much there. We learned, um, a more accepting attitude; we learned about the people, we become invested in them because some of the people there were so personable. It was great and um, that was good so we continued on through Alzheimer's (Society) and he was tested a couple of times and they kept saying you know he's not bad • ...he will now accept someone telling him what to do now for certain things. He is more apt to sit down and talk, uh, I find that it takes a lot of time. He will come, he will have a feeling where there will be something off and he will want to sit down and talk and we will need to talk through this and I find it takes a lot of time. But that's ok (she says slightly sarcastically) we are getting along pretty good. Um there are times when he can't quite see why I am doing something and it gets to the stage where, I have to leave • ...I have to remember, I find it difficult (her tone changes) to have a smile on my face sometimes when I'd rather go Grrrr (she raises her hands and shakes them vigorously and then laughs) but then again, I know it's not easy for him and we have to learn to deal with this and um | <ul style="list-style-type: none"> • Experience, knowing there was a problem before he realized it, family history of AD, anticipating the worst (multiple losses and anticipatory grief) • Family doctor not helpful, have to find help on your own, go searching for it (Validation of experience) • Getting help - helped understand that she wasn't alone, and other people are facing similar challenges (Validation of experience) • Not getting the answers you want, getting a diagnosis (Validation from formal setting) • Experience being isolated in rural Ontario, little access to services – Isolation, loss of connection to formal support (multiple losses and anticipatory grief) • Do not have any exposure to the term or understand what MCI is, ambiguous diagnosis (Stigma) • Hx of challenges communicating, learning how to open the lines of communication - Change in roles, acquiring new role that doesn't fit with traditional role (Wearing a mask) • Learning on your own, doing your own research to better understand the diagnosis, meaning that the information you are getting from the professionals is not sufficient for understanding, Validation from within (Validation of experience) • He is more open to communicate, or, he is learning that he needs to communicate in order to cope from day to day, she is sole support so he is becoming dependent on her – Loss of partner, loss of old roles (multiple losses and anticipatory grief) • Resents the amount of time it takes to talk with him but also appreciates that he is referring to her more – Wearing mask – resents time it takes, have to be supportive regardless of feelings (Wearing a mask) • loss of old roles, anticipation it will get worse (Multiple losses and anticipatory grief) • Social response vs actual sincere feeling, having difficulty modeling two opposing constructs - cultural, gender, age contextual representation (Wearing a mask) |

It was during the line-by-line analysis that the most prominent themes began to cluster. The most interesting aspect of line-by-line analysis was the opportunity to really interact with the text as it took on new shape and meaning during my interpretation. Sentence structure, pattern, and length became more apparent. From the line-by-line analysis, participants' reluctance to provide information through pauses, utterances such as "ums" and "uhs" and short staccato answers created a deeper and richer level of text that I was able to then analyze. These subtle unspoken meanings allowed the newly emergent themes to crystallize my own interpretation of the multiple sub-themes that materialized.

3.4. Quality Criteria in Phenomenology – Philosophy, Trustworthiness, and Resonance

Measures of quality in quantitative studies include reliability and validity.

Phenomenological research employs three parallel measures of quality: philosophical pedagogy, trustworthiness (study rigour), and representativeness or resonance. It is imperative when doing phenomenological research to maintain a strong philosophical grounding. To achieve this, I was constantly reflective about my own horizon of understanding, moving dialectically between part meanings and whole meanings that I and my participants held which allowed these horizons to fuse in a way that was reciprocal, as understanding is a dialogic process (Koch & Harrington, 1996).

By allowing other readers to engage in an interpretive conversation about the participants' texts, other readers can help formulate underlying meanings that the researcher may have missed or taken for granted. This allows the researcher to transcend the limits of their own horizon of understanding (van Manen, 1997). Through journaling, memoing, and analytical note taking, I maintained reflexivity and remained in the hermeneutic circle. It is within this circle that personal horizons can be described and interpreted.

Hermeneutic phenomenological research is thought to be representative when the inquirer is honest about how the findings they present are a representation of the meanings the informant and the researcher have come together to co-construct. The main aim of representativeness is to establish a space for pre-understandings, part meanings and interpretation of informant's narratives to enter into the research process transparently.

One way to ensure representativeness is to invite other researchers and study advisors to read the interview transcripts. Van Manen (1997) suggests that when other individuals are invited to participate in a conversation about the text, a common orientation to the phenomenon in question can be established. This is referred to as the 'art of testing,' or rather laying open the subject matter of the conversation. I provided each of my committee members with two to three different participant transcripts so that they could become immersed in the participant's data along with me. This allowed my advisors to help me have a deeper understanding and illuminate things that I might have taken for granted.

When conducting phenomenological research, one must strive to be trustworthy, meaning that a reader may be able to audit the work of the researcher through the researcher's theoretical framework, methodological choices, and analytical interpretation of the informant's experiences (Koch, 1996). To maintain trustworthiness, I created a decision and audit trail (Appendix H) about the way I came to create my themes and the choices I made when collapsing themes from the selective analysis into themes that emerged from line-by-line analysis. Included in my decision and audit trail are interpretations that formed during journaling and reflexive note taking. These journal notes were also another check for trustworthiness as I was able to be accountable for the way I was accessing my fore-structural knowledge. For an example of how I conducted my thematic analysis, please refer to Appendix I.

Phenomenological research is thought to be trustworthy and powerful when there is a high level of empathetic relatability (Smythe, Ironside, Sims, Swenson, & Spence, 2007). My advisory committee members utilized the art of testing the data (van Manen, 1997) by reading over the transcripts and producing their own themes through selective thematic analysis. This ensured that the themes I identified were acceptable and understood by the advisory committee which helped me transcend my own horizon of understanding. Allowing my committee members, who all come from different lifeworlds and have unique fore-structural knowledge, to participate in a discussion about the participants' experiences exposed new and unseen themes. I realized that I had achieved relatability when I reported my main themes and the essence of the caring experience to the committee and it resonated with them. At this point shared understanding was realized between myself and my advisory committee members.

3.5 Ontology and Epistemology: Researcher's Self

I am a Master of Science candidate in the Graduate Program of Health and Rehabilitation Sciences, specializing in the field of Health and Aging. My undergraduate degree was obtained in the Faculty of Sociology, where I achieved an honours specialization in Aging. I have had both personal and clinical experience with older adults, specifically those living with cognitive impairment. My grandmother was diagnosed with MCI in the fall of 2009. I have been interested in seniors' health issues as well as the social issues adult children and spouses experience when caring for an older adult for a number of years. I had the privilege of living in a family home with three generations: grandmother, parents and siblings. It is from my intimate experience with my unique family dynamics and also through my work as a research assistant at Parkwood Hospital in Geriatric Medicine that I have become aware of the complexity and challenges relatives of people with MCI face.

I selected this school of inquiry because I believe it to be most closely aligned with my ontological, epistemological and philosophical beliefs, but also because the hermeneutical interpretive approach to understanding is focused on the 'being' and the meaning the individual in the world gives to his/her experience, in this case, the meanings family members of individuals recently diagnosed with aMCI give to their experience. Epistemologically, I do not believe that there is one reality or way of knowing. I believe, like Heidegger, that we come to know things experientially through our interaction with our environment, our relationships, and ourselves. It is our ability to be reflective and question how we come to know things that we inherently learn what a truth is for ourselves.

Ontologically, I believe that reality is constructed and the way we interpret our reality as individuals is contextually, socially, and historically contingent on personal experiences. I believe that humans are autonomous agents, free to make choices within the confines of social barriers and obstacles that are imposed at a larger socio-cultural level.

4. FINDINGS

To begin this exploration of my analytic journey through participants' texts, the socio-demographic characteristics of the participants were examined as a way to locate their narratives contextually. The following are the demographic characteristics disclosed by my participants.

4.1 Participants

A total of five participants were included in the study. All five participants were female. The average age of the participants was 70 years (ranging from 57-80 years). Each participant had at least grade 12 education. The participants were all employed at one time or another, but four out of the five participants were currently either retired or unemployed. One participant was still working part time. Four out of the five participants were caring for a spouse with aMCI while one participant was caring for her mother who was diagnosed with aMCI. Participants' demographic characteristics are described in more detail in Table 4.

Participants had been married or in a relationship with the person with aMCI for an average of 50 years and each participant reported being a supportive member of an informal care team at one point or another in their lives, providing informal care to either family members or friends. The average length of time from the initial aMCI diagnosis was 11 months (range eight - 19 months). Four out of the five participants lived with the person with aMCI (all four of the spouses), while the remaining participant lived apart from her mother. Participants, on average, reported fair to good health and acknowledged that their self-assessed understanding of aMCI was probably above average, most likely, as a result of their participation in the MIP as well as their own personal interest to learn more about the diagnosis.

Table 4. Socio-Demographic Characteristics of Participants

| Characteristic | Study Participants (n=5) |
|--|--------------------------------|
| Mean Age (years) | 70 (range: 57-80) |
| Gender | Female (n=5) |
| Marital Status | |
| Married or Common-law | 80% (n=4) |
| Divorced or Separated | 20% (n=1) |
| Carer Relationship | |
| Spouse or Common-law partner | 80% (n=4) |
| Child (Daughter) | 20% (n=1) |
| Highest Level of Education | |
| Public School | n=0 |
| High School | n=4 (80%) |
| College (diploma) | n=1 (20%) |
| Other Post-Secondary Education | n=0 |
| Current Occupation Status | |
| Retired | n=3 (60%) |
| Unemployed (Seeking employment) | n=1 (20%) |
| Working (Part Time) | n=1 (20%) |
| Perceived Health* | |
| Excellent | n=0 |
| Very Good | n=0 |
| Good | n=4 (80%) |
| Fair | n=1 (20%) |
| Poor | n=0 |
| Previous Experience Caregiving | Yes (n=5) |
| Average length of time from diagnosis | 11 months (range: 8-19 months) |
| Average length of relationship (years) | 50 (range: 42-60) |
| Knowledge about MCI** | |
| Know everything there is to know | n=0 |
| Know very much | n=1 (20%) |
| Know a good deal | n=3 (60%) |
| Know some | n=1 (20%) |
| Know nothing at all | n=0 |

*Self-rated health ranged from 1 (poor) to 5 (excellent).

**Self-rated knowledge about MCI ranged from 1 (know nothing at all) to 5 (know everything)

4.2 Emergent Themes

The core essence of the caring experience that emerged from my participants' interviews was that of *wearing masks*. Masks were worn for protection, both for themselves and to protect their loved ones. Participants experienced needing to know what mask to wear given a particular lifeworld situation with their spouse/mother, family, friends and others in the formal support system. Within the core essence of wearing masks, three specific themes emerged (see Figure 1):

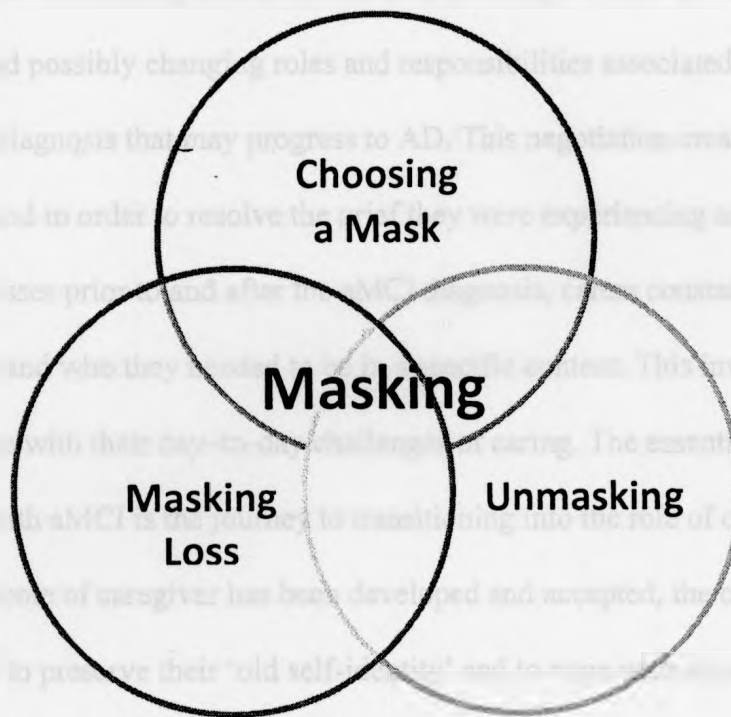
1. Choosing a Mask: Building Protective Identities
2. Masking Loss: Multiple Losses and Anticipatory Grief
3. Unmasking: Validation of Experience through Shared Understanding

Figure 1 is symbolic of the overlapping and interconnected nature of these themes which combine to reveal the essence of the caring experience, wearing masks, depicted as "Masking."

Within the theme of 'Choosing a Mask' four specific types of masks emerged:

1. Mask of Caregiver
2. Mask of Protector
3. Mask of Diplomacy
4. Mask of Normalcy

Figure 1. Experience of Wearing Masks



4.3 Core Essence: Wearing Masks

Through my journey to understand the essence of the aMCI carer experience, I found that participants in my study were forming new identities and, in doing so, were reconciling their old selves with their new and possibly changing roles and responsibilities associated with caring for someone with aMCI, a diagnosis that may progress to AD. This negotiation created conflict within the participants and in order to resolve the grief they were experiencing as a result of multiple accumulated losses prior to and after the aMCI diagnosis, carers constantly had to reinvent who they were and who they needed to be in a specific context. This involved putting on different 'masks' to cope with their day-to-day challenges of caring. The essential experience of caring for a loved one with aMCI is the journey to transitioning into the role of caregiver. However, until the new role of caregiver has been developed and accepted, the carer wears multiple masks in order to preserve their 'old self-identity' and to cope with an ambiguous diagnosis.

4.4 Choosing a Mask to Wear

Amnesic mild cognitive impairment presents an unknown future and an uncertain disease trajectory, therefore the experience of carers in this study was the uncertainty they felt in developing their new role and accepting it. Carers in this study experienced wearing four separate yet interconnected masks at different points in time. These four masks included: (1) *Mask of Caregiver*, (2) *Mask of Protector*, (3) *Mask of Diplomacy*, and (4) *Mask of Normalcy*. Choosing the appropriate mask to wear when new and unexpected situation arose was explained by carers as a need to always be watching to know how to shield both themselves and their loved ones from harm. Masks were also required to manage challenging relationships with their loved

one, interact with their informal support network, and to reconcile their anger and frustration about unmet expectations with their loved one going forward into an uncertain future.

As these carers had not yet fully assumed the role of being a caregiver, this negotiation of roles and responsibilities resulted in wearing multiple masks to bridge the experience gap they felt as these new roles and responsibilities were learned and adopted. Different masks were worn when carers experienced the need to provide new or different levels of support to their loved one who had not required this assistance in the past. Carers were challenged to adapt to status changes in their multiple lived roles while simultaneously shielding their loved one from the anger and sadness they often felt for having to take on this new role, or rather protect their loved one from their own blame and resentment. The following section further clarifies the themes of mask wearing when carers' current self conceptions are incongruent with current lifeworld experiences.

4.4.1 Mask of Caregiver: Quality of the Relationship with the Care Receiver

Participants in this study acknowledged how challenging it was for them to appear happy and content while caring for a loved one with aMCI when their actual experience of happiness was waning. Carers reported feeling a loss of identity and that their friends and family members did not validate their sadness regarding the multiple losses they were experiencing. In these instances, carers reported wearing different masks in order to cope with the multiple unwitnessed and unrecognized losses they encountered. The experience of wearing a mask and selecting what mask to wear was largely dependent on the type of relationship carers had with care recipients.

Carers who had a positive relationship with their loved one prior to receiving the aMCI diagnosis tended to have a different caring experience than those whose relationship with their loved one was strained or challenging. The quality of the relationship between carers and care

recipients also intersected with the way carers interacted and communicated with people in their informal and formal support network. The extent to which carers assumed the mask of the caregiver was essential to the quality of the relationship they had with their loved one prior to the aMCI diagnosis. The way carers experienced caring for their loved one with aMCI was complicated by the long history of distinctive lived experiences present in the relationship and the unique personality traits the carer and their loved one brought into the marital or parent-child relationship. This experience is depicted in Lorraine's comment:

Lorraine: Well it's frustrating because it takes more of my time...you know I'd like to be needed this much (*hold up her fingers to show a little bit, then chuckles*) but not a whole bunch. Um, she's had control of my life for so long that you know if she needs me that much than she's got more control again and I don't want to give her that control and it's a fighting issue.

Given that the previous nature of her relationship with her mother was strained, this participant experienced the need to wear a mask of caregiver as she did not yet feel like she was her mother's caregiver nor would her mother appreciate the fact that she was beginning to take on more of a supportive instrumental role in her day to day life. Even when Lorraine's mother did acknowledge that she was relying on Lorraine for more support, Lorraine was not sure she wanted to continue providing this support if it would not always be acknowledged by her mother going forward. Lack of acknowledgement or appreciation of support was one of the conditions that caused caregiver burden for caregivers of loved ones in advanced stages of AD (Brodaty, 1996).

The carers in this study who had a challenging relationship with their loved one diagnosed with aMCI felt ambiguousness around their caring role which often lead them to wear

the mask of caregiver as the role of caregiver did not fit with their own self concept. When carers were not actively providing instrumental support and only emotional or mental support to their loved one, they still experienced the need to wear a caregiver mask as this emotional support was not always easy to give to their family member, especially if their relationship was a challenging one. When the emotional support they were providing their loved one was not reciprocated, they felt that their own feelings were being neglected by their loved one. Interestingly, carers expressed feeling guilty about this as they also reconciled that lack of attentiveness on the part of their loved one was not purposeful and further reinforced their need to wear the supportive caregiver mask.

I interpreted that carers feel the need to wear the mask of caregiver at different times as a result of their loved ones' increased dependence on them for things for which they had always been independent for previously. However, because their loved one was giving up certain roles and responsibilities, the carer was taking on this added burden with little acknowledgement from their loved one. This was experienced particularly by the participants whose relationship with their loved one was challenging. For the carers who had good relationships with their loved one prior to aMCI diagnosis, taking on new responsibilities was less of a burden as they felt that taking on new tasks was more of a learning curve as these were responsibilities they had not been responsible for in their relationship.

However, irrespective of the quality of the relationship prior to aMCI diagnosis, all the carers acknowledged that these new tasks for which they were becoming responsible for did not seem to fit well with their own self-concept, which subsequently resulted in a feeling of dissonance. This inner struggle resulted from carers' unmet expectations for their relationship with their loved one in the future. Most carers commented that they had not yet transitioned into

the role of caregiver as their loved ones were still largely independent in IADLs. However, carers still felt like the added tasks and responsibilities they were performing were not being acknowledged or validated by their loved one, their friends and family members or their family physician.

Mary-Anne: It's also a mighty big responsibility because I'm the one...saying well, you know, gee he did this...he did that...and it puts a lot of pressure (on you) and it's the people around you, for instance, last night his sister called and wanted to know how he was doing and what not and she said, "Well I've talked to him several times on the phone and he seems fine to me!" and I stopped her cold and I said, "you're right, you talked to him for 5 minutes, it's a lot different than 24/7"

4.4.2 *Mask of Protector: Building Protective Identifies*

Wearing a mask was seen as both protective for carers and their loved ones. The 'protector mask' was worn by all participants at one point or another and this experience was often referred to as the need to be mindful and attentive to their loved ones, often described as the experience of 'always watching.'

Linda: We seem to always be watching, not that they need us to be there all the time but we are always watching, just so if there is going to be something that comes up, that we are ready to save them... I find it difficult (*her tone changes*) to have a smile on my face sometimes when I'd rather go gouch (*she raises her hands and shakes them vigorously and then laughs*) but then again, I know it's not easy for him and we have to learn to deal with this... and there are times when I resent the time and uh, (*She is starting to get a bit teary eyed and her voice a bit*

strained) frustration, but, as well I know it's not his fault, so it's just, it's the way I feel.

The experience of always watching their loved one was shared by all participants. I interpreted that carers do this to know when to wear their 'protector mask' as this experience is protective for both the carer and the care receiver. The protective mask acts as armour, shielding both the carer and care receiver from pain and defending them from harm. When carers wear the mask of armour they are experiencing a need to be in control of their own emotions, being mindful not to get angry or upset with their loved one. In addition, this mask was worn to shield their loved one from the gaze or attack that others (acquaintances, friends and family members who do not understand or acknowledge the diagnosis) may inadvertently inflict on their loved one with aMCI.

Shelly: [*a challenge was*] trying to control my own shortcomings because I would feel, I guess, that James (*pseudonym*) was doing this on purpose, you know that he wasn't trying hard enough. You have to be understanding, you have to be patient because you do have shortcomings of your own and the person involved helps you...we care very deeply, one for the other. You know sometimes I think maybe I should just run away (*she laughs*), that's not ever anything to think about.

The spouses in this study experienced a challenge bringing their children into the caring relationship as they felt the need to protect both their spouse and their children from experiencing embarrassment or sadness as a result of their husbands' declining functional and cognitive abilities. Spousal care providers experienced internal conflict as they were reticent to relinquish their roles as mothers to their children, opting rather to protect their children from the potential harm their father's diagnosis could cause them, yet at the same time sacrificing the

level of support their children could provide if they were made aware of the help their mothers required.

Linda: I must admit, I had been, very gently been starting to tell my daughters, to express some of the stress I feel, I don't want to over burden them, but I do want to let them know how I feel and that um, (*with a sigh*) I guess I want to prepare them to a certain extent...not living with him, they don't understand and I am trying to, I don't want to put too much onto them and I'm trying to, bit by bit show them what's going on and I think it's very important that they know

Carers maintained that they were struggling to a degree to get their children and other family members to be as attuned to the subtle changes in their loved ones' cognitive ability. When this change was not seen by other family members, it reduced their level of involvement and put increased responsibility on the carer. The carers spoke about the challenges they faced when dealing with others including their social support network (family and friends), the formal health care system, and the general public. In some instances, when carers felt that outsiders were not accepting or knowledgeable about aMCI, they experienced an added need to wear the protector mask to shield their loved one from any judgment, pity or ignorance others may inflict.

4.4.3 *Mask of Diplomacy: Managing Relationship Challenges*

Carers also experienced having to be mindful of their interactions with their loved one and this experience varied by the quality of the carer and care receiver relationship. A mask of diplomacy was often worn in an attempt to diffuse arguments that could result out of carers' growing frustrations which stemmed from their loved ones' inability to remember something that had been previously discussed or repeated by the carer several times. The carers' fear would be to react negatively, in anger or annoyance, and subject their loved one, who they see as

vulnerable, to pain or distress. Carers recounted instances of biting their tongue, taking a deep breath, needing to leave the room and the need to get away from an argument in order prevent themselves from acting on angry feelings.

Lorraine: Last Friday, I could of, you know, I could have pulled my hair out and ranted and raved and I just, well, go with the flow. Me getting mad doesn't make anything get better, or anything...uuuhhh sometimes I don't want to be there for her, no, and then something happens and I am there like a dirty shirt. The old emotions, the hurt emotions, they say something but then the today emotions run and deal with it, you get over it, I mean I go and sit in a corner for a while and feel a little guilty a little bit about thinking that way and ultimately my actions speak louder than my thoughts, and I didn't act on angry thoughts.

Masks of diplomacy were worn by carers in order to keep the peace in their relationship with their loved one. For some carers, this mask was worn in order to keep the peace not only with their loved one with aMCI but also to keep the peace with other family members such as siblings and children. At times carers' initial reactions were to be angry and accusatory when their loved one forgot something as simple as an appointment. While forgetting "the little details" may appear benign to outsiders looking in, such actions serve as a reminder of how dependent their loved one had become on the carer "to fill in the blanks." It is my interpretation that because carers feel like they are no longer free to be separate from their loved one as a result of growing levels of dependence, they assume a mask of diplomacy to be the person who the care receiver as well as their other family members need them to be, while still trying to maintain a semblance of normalcy and shield themselves from their own ambivalent grief.

All at once carers were catering to the new demands of supporting their loved one with aMCI, protecting their family members and friends from feeling scared or worried about the aMCI diagnosis, educating people in their informal support network about the subtle changes and differences in their loved one's memory and trying to receive formal support from organizations who did not have aMCI caregiver programs. Carers for loved ones with aMCI felt like they were constantly caught in the middle of helping their loved one maintain a feeling of normalcy, presenting their loved one as normal to their friends and family yet, at the same time expressing their need for validation, encouragement, and eventual support from the informal support system.

Female spouses informed me that they were reluctant to place any additional burden on their children. However, they also acknowledged a desire that their children were more understanding of how troubling their own personal experience of caring had become and how different the children's father actually was. When children or siblings did not acknowledge that there was anything wrong with the family member who was diagnosed with aMCI, it made the caring experience even more challenging as the added burden the carer took on was not being recognized by their children/siblings. For Olivia, her caring situation is further complicated as her sons have a strained relationship with her spouse. Olivia is constantly trying to appease and placate both her sons and her spouse while negotiating the tension that exists between them. Olivia's experience of wearing the mask of diplomat is depicted below:

Olivia: But now he has a terrible relationship with both of them (his children).

They don't want to be around him, they don't want to see him. And they only see him because of me. They've told me that, which is very, very difficult. So I have told them that this is a possibility, that it may be a type of dementia...they don't see that as an excuse for his behaviour...I just wish that I could get them (*her*

sons) to accept their dad the way he is but it's hard ...they have accepted the fact that this is what it probably is (MCI), they can't accept his behaviour.

Olivia felt caught in the middle, as she wanted to protect her children from feeling burdened or upset, yet did not want to abandon her role of caring for her husband. Her children's inability to accept that her husband's personality changes could be a result of the aMCI diagnosis actually further alienated the family from her spouse, thereby decreasing the level of support from her informal support network which she would have expected to be there for her in the future. Olivia feels the need to wear the mask of diplomat to cope day-to-day as she at once wants to reassure her children and be supportive of her husband.

4.4.4 Mask of Normalcy: Acceptance and Denial of the aMCI Diagnosis

Acceptance of the diagnosis was a theme that emerged when looking at the similarities and differences that were present in the perceived quality of the relationship participants had with their loved one. Whether or not a loved one accepted his/her aMCI diagnosis had significant implications for the way the carer experienced taking on new roles and responsibilities and the masks that carers acquired. When the loved one accepted his diagnosis of aMCI, that is, acknowledged that he had a problem, carers remarked on how relieved and thankful they were that the lines of communication between them had opened and they were able to talk about it together. When loved ones with aMCI experienced frustration or anxiety as a result of forgetting, the carers maintained that being able to talk through this frustration with their loved one was both rewarding and reinforced the carer's importance in the world of their loved one with aMCI and allowed the carer to employ more positive coping mechanisms.

Mary-Anne: Oh that part is really, really good. He, that's a good thing. And there certainly are good things that have come out of the research, well number one is that we acknowledged it to each other and we can talk about it together.

Once a loved one had accepted that there was a problem, this allowed both the carer and care receiver to begin to talk about their feelings of fear, frustration and annoyance. However, all of the carers commented that until their loved ones were ready to admit that there was a problem, it was very difficult to appreciate that their loved one was not being confrontational and difficult on purpose.

Shelly: I knew before James (*pseudonym*) was diagnosed that he had some type of impairment, but until he would recognize that and be willing to become involved with medical help, nothing was happening...it helps to know how to cope because before I used to get angry, and blame him and say, "You know better than to do that." Well you just get two frustrated people don't you?

Perhaps the most profound experience that the respondents shared between them was that they were aware of their loved ones' decline before their spouse or parent was. For the carers whose loved ones accepted the diagnosis, acceptance was experienced once their loved ones demonstrated a willingness to seek medical attention and get a diagnosis. All carers acknowledged that they had been engaging in care providing and helping their loved one to cope at home for some time before acknowledging it to their family member or themselves. This was referred to by the participants as 'seeing things without seeing them.'

Linda: and I guess I was seeing things without seeing them if you know what I mean and he said, you know, there's something wrong, things are not going right here and we sat down and talked about it and ah we realized that, yes, there was a

problem and his mother had had Alzheimer's, so we began to fear that this is what it was.

For the carers whose loved one accepted the diagnosis, the diagnosis itself came as a relief to both the carers and care receivers. Yet, acknowledging the diagnosis to each other also appeared to be bittersweet. On the one hand, admitting there was a problem tended to preclude the carer from blaming their loved one for being forgetful and more dependent, yet the diagnosis also meant that there was a problem and that the expectations the carers and care receivers had for the future were suddenly changed. It is from this point I have interpreted that the carer chose to wear a mask of normalcy to diminish the impact loss of the future has on their day-to-day interactions with their loved one.

While all of the carers in the study acknowledged that their loved ones had cognitive impairment, not all of the care receivers in this study necessarily accepted they had a problem. Only two participants, a wife and a daughter, experienced this. Olivia's husband seemed to deny that there was anything wrong with him at all and denied the diagnosis outright, while Lorraine's mother accepted the formal diagnosis but did not accept that her diagnosis was a problem for herself or her daughter. For this reason, there are noticeable differences among the carers' experiences while caring for a loved one with aMCI. When a care receiver denied the diagnosis, the carer experienced uncertainty and ambiguity in her role.

When care receivers denied the diagnosis, they were also denying their need to be cared for. For the carers, this uncertainty about their own role caused resentment and frustration as the care receiver did not validate or acknowledge the extra roles and responsibilities the carer was assuming. For those whose loved ones accepted the diagnosis, the acknowledgement made a significant contribution to the carer's self-worth. For carers whose loved ones denied the

diagnosis, the lack of validation and appreciation of the carer's efforts caused sadness and anger. The pre-morbid (pre-diagnosis) quality of the relationship they had with their loved one largely influenced the way that these women experienced their new role.

Olivia: Don (*pseudonym*) doesn't think he has that problem...at all...he doesn't see that there is anything wrong. He thinks our life is just great. And sometimes I just want to give him a swift kick and make him wake up and smell the roses here...because right now I have to be very careful, well I always have to be careful what I say, um but I feel now, if this diagnosis is positive (*if he converts to Alzheimer's Disease*), it's going to be pure Hell, because he will not accept it.

Due to the unpredictable nature of the aMCI diagnosis, carers whose loved ones denied the aMCI diagnosis were fearful of the future and were concerned about their ability to support their loved ones in the long term. These women seemed to also suffer greater anticipatory grief as they felt their loved one was not assuming the loss equitably. Participants whose loved ones denied the diagnosis seemed to experience more stress, resentment, sadness and frustration with their loved one as well as a reluctance to continue caring if the extra support that they were offering continued to remain unacknowledged and taken for granted.

Olivia and Lorraine also experienced having less control and power within the relationship to make decisions on their loved ones behalf. Lorraine remarked, "You cannot help someone who does not think there is anything wrong." The respondents whose loved ones denied the diagnosis also experienced a more complicated relationship for quite some time prior to the care receiver was given the aMCI diagnosis. When loved ones continued to deny the diagnosis even after being formally diagnosed, carers felt that both they and their family member were in hiding or being secretive and that a mask of normalcy was being worn to cover up the things that

were not socially acceptable, that is, the mask becomes the public face masking the carers private feelings.

Lorraine: You know when a person starts losing it; they don't want to admit it... she's in denial about how bad it is, I get very, very angry with that. It's upsetting, it's upsetting because, I mean she's lying to herself, more so that she's lying to me, ultimately, so she's not ready to face things. Yeah, there's been a couple of times now where it has been rewarding to see that other people saw something, but I mean when they aren't within that close family realm, they wouldn't know what happened.

In addition, respondents whose loved ones denied the aMCI diagnosis felt that they were being lied to or deceived by their family member. Although some care receivers still denied their diagnosis, all made efforts to conceal their problem for as long as possible. One participant remarked that her spouse was like an alcoholic; friends and relatives were aware that there was a problem, but he believed he was hiding it so well that no one would notice. Another participant made an allusion to her husband 'being in the closet' and only 'coming out' once he was around other people who had a similar problem. Participants feared that both they and their loved one would be stigmatized if the truth about the aMCI diagnosis came out and for this reason the carer chose to wear a mask of normalcy to deter judgmental outsider gaze.

4.4.4.1 Fear of Being Stigmatized: Lack of Acceptance from Support System

On many occasions respondents made inferences that mental health issues were not something that was appropriate to discuss among acquaintances or friends and, as a result, felt that they were also remaining closeted along with their loved one about the aMCI diagnosis.

What was remarkable about this experience was that carers themselves admitted to not being

comfortable with the notion that their loved one could be perceived as being mentally ill or 'different.'

Mary-Anne: ... and that's the big thing, and that's why, that's why I hesitated so long to even really push to get help. I don't want anyone treating him any different, and we all know there's still a pretty big - stigma (*she pauses*). If he had a broken leg it would be ok, even if I said he had cancer, everybody would deal with it, but if I say its Mild Cognitive Impairment (*she makes a scrunched up face*), oh, and, and being able to accept that there's going to be a whole bunch of people who won't accept it, who will still judge me and so you have to keep the picture in your mind, who are you concerned about, the people, or your husband and you know, you have to be focused on that.

Participants were concerned not only about friends and acquaintances treating their loved one differently as a result of the diagnosis, but also about how they themselves would be regarded by others who were unfamiliar with the implications of the diagnosis or scared of the diagnosis. This prompted the carers chose a mask of normalcy until they were ready to bring other people outside of the caring relationship into the caring experience.

The fear of being stigmatized was present among the spouses in this study. However, through attending the MIP, both the person with aMCI and their carer were able to recognize that he/she was not alone in his/her problem with memory and functioning. By hiding the fact that there was a problem, carers hid behind a mask of normalcy for fear of being stigmatized. The experience of their loved one 'coming out of the closet,' words used by one of the participants, was shared among the respondent's whose loved ones had accepted the diagnosis of aMCI.

Linda: See to begin with, he didn't feel comfortable. In our days you didn't talk about 'mental illness.' It was something that was hidden away. At first, he didn't feel comfortable telling people about the diagnosis, probably because we were not really sure what it meant at first. I think it was after the first or the second session down here he met somebody who was just like him. He felt comfortable enough, he said, to come out and tell him.

Carers also mentioned how important it was to have a friend or family member as a non-judgmental support. This notion of judging seemed to be present among the carers in this study which I interpreted as the fear of being stigmatized because mental illness is not largely understood or accepted within the Canadian context (Canadian Medical Association, 2008). Fear of being judged is a condition from which carers felt they needed to hide and as a result, assumed a mask of both protection and normalcy at times. These masks serve to protect his/her loved one from the possible judgmental gaze of others, but also to preserve the carers own self-esteem, reinforcing their bravery or strength to care for someone with a mental health problem, even though they may not be in total agreement with the masks they are wearing.

Shelly: You know he has made a comment, um, my friends think I am different now, well he is. And not everyone adjusts to changes in people who aren't close to them, so you have to try to compensate for that...and then when he realized how helpful it was (*to tell people about his diagnosis*), he wanted to tell the world, which is good and it was only through someone telling us that we found out about the Aging Brain Clinic, and you should tell people about things like that.

Once the care receiver was able to recognize that he was not alone in his experience with the aMCI diagnosis, carers themselves were able to accept the diagnosis and began to feel less stigma associated with his/her loved one having cognitive impairment. Participants stated that they felt betrayed by other people who passed judgment or appeared to them as intolerant of their loved one's aMCI diagnosis yet understood where the judgment came from as they had been suspect of thinking that way themselves. To reduce the amount of stigma she felt, one participant made mention of trying to teach a group of peers at church about aMCI to reduce the fear and uncertainty others might have around the diagnosis.

I interpreted that the carers in this study were concerned with educating other people about the diagnosis in an attempt to reduce the likelihood that others would unfairly pass judgment on those affected, both the carer and the care receiver. Through teaching others, carers thought that they would eventually be able to take off their mask of protective armour and unmask around those who could accept and appreciated the implications of caring for a loved one with aMCI.

A common experience the respondents shared was the feeling that their family and close friends were not as accepting or supportive of the difficulty carers were having in assuming their new role. This experience was disconcerting because their informal support system, those individuals on whom he/she had always relied as confidants, were no longer perceived by the carer as providing the level of support they required from their close network of family and friends. Carers acknowledged that the lack of understanding, empathy and acceptance from people who they assumed would be there for them was jarring and, as a result, carers felt reluctant to be forthcoming with the diagnosis.

When carers felt stigmatized, judged or othered or saw their loved one experiencing these feelings, they constructed a suit of armour to protect themselves from the judgmental gaze from outsiders looking in. When a diagnosis such as aMCI is not well understood by the public, the carers themselves cannot identify with his/her place within this diagnosis as support and education is sufficiently lacking in order to guide them. When carers experience their role as being valid, the protective armour they have put on to repel gaze of others who do not understand is shed.

4.5 Masking Loss: Coping with Multiple Losses and Anticipatory Grief

All carers talked about some kind of loss. This loss was experienced in multiple ways, within temporal, corporal, spiritual and psycho-social contexts, and at different points of time, often at crucial transitions throughout the disease journey. The phenomenon of loss was pervasive and was experienced before, during, and after the loved one received an aMCI diagnosis. The following sections describe in detail the multiple losses experienced by carers in my study.

4.5.1 *Loss of Identity*

All of the women in my study experienced some loss of identity as a consequence of their family members' aMCI diagnosis. The notion of identity can be understood corporally or personally as it is an individualized experience that manifests itself internally, even though it is the result of a social interaction with another person (Erikson & Erikson, 1997). The experience of loss of identity can be understood when interpreting the comments carers made around not having enough personal time for themselves and an urge to get away from their present lifeworld/reality. Carers stated that assuming this new role took time and energy away from participation in their old life which translated into feeling a loss of self or identity. Carers also

acknowledged a desire to get respite or to get away from their caring role, which created a feeling of dissonance as they experienced remorse about needing this time away.

Mary-Anne: I'm probably resenting him because I'm having to give up a lot of my things because of course it takes time... You just all of the sudden feel like you don't have any life, and that could maybe just be part of when you retire, because you... *(she laughs)* I don't know that, I just know... sometimes you just think, "oh, if I could only just get away."

Respondents often spoke about the difficulty they had accepting the new caregiver role as well as the responsibilities their family members had given up as a result of the memory issues associated with aMCI, activities that the care receiver had occupied for a long time. Carers felt as though they had to make sacrifices, opting to put their family member's well-being and needs before their own.

Olivia: I stopped going to the Catholic women's league, because I was out too much and then a few years ago, I decided, no, I'm not going to give up my life. I know I married him and everything else but I cannot give up my life.

However, in doing this, carers found that when they gave up activities that made them happy or feel "normal" to appease their loved ones anxieties about being left alone, they started to resent occupying their caring role and that giving up personal time away from their loved one was not conducive to their own well-being. Carers selected instead to escape through utilizing brief moments away from the home, talking with close friends and family members or engaging in hobbies and leisure activities as a positive outlet for the experience of losing identity.

The experience of caring for a loved one with aMCI can be perceived as both a positive experience as well as a negative experience. For the carers in this study, the feeling of being

needed by their loved one with aMCI was a positive experience. However, participants also disclosed feeling overwhelmed or suffocated.

Linda: if I could get away just so I could be me (*she is getting teary-eyed*) without thinking, "Now is that the right way to do that, or is that the right way to answer that?"...I find he's referring to me and expecting me to come up with answers now, so I'm becoming more, how will I put this, I'm taking on more of the obligations perhaps that he used to look after...I am learning how to do a lot of things that I didn't do.

Respondents relayed that at times they did not know who they were when they were not caring for their spouse or mother. Carers communicated that the experience of occupying the carer role was at times an all-consuming identity. Each day, they began to assume different identities and donned new masks based on the life-world experiences that presented themselves. Carers also commented about not being comfortable with their feeling of anger and hurt feelings with their loved one and contemplated their ability to manage without the use of some kind of pharmaceutical or other intervention. This sentiment is depicted in the quote below.

Mary-Anne: I feel like I might need an anti-depressant. I don't know, I might need something because I'm not..., I'm the positive, organized person, and I'm not just so near positive right now (*she says with exhausted laughter*). So it's all a no win situation because I do want to be able to help Dan (*pseudonym*) and I guess if I have to take the antidepressant to keep myself, so, yes, very, very much, and then you feel so bad because it feels so self-centered when you're saying, geez, well you know, I'd like a little life of my own here, and you know...

All of the carers felt like they no longer had a life of their own and often chose a mask of normalcy to wear to fulfill the obligations of caregiving as these task and responsibilities were not in-line with their expectations they had for their loved one or themselves.

4.5.2 *Loss of Control*

For the carers in this study, loss of identity was closely aligned with loss of control. The theme of control is complicated by the complex nature of the existing relationship before a loved one receives an aMCI diagnosis. Respondents commented that they felt less autonomous in their decision-making abilities as the person with aMCI was often part of any decision carers made. For carers who had strained relationships with their loved one with aMCI prior to the diagnosis, the ability to gain control in the relationship appeared to be an important and powerful experience.

Experiencing a loss of control was profound for the carers in this study and perceived lack of control was embodied, manifesting itself through physiological stress responses. Participants experienced an increase in blood pressure as well as feeling fatigued and exhausted. Carers also experienced feeling helpless in their ability to control the trajectory of the disease and had difficulty comprehending the ambiguous nature of the aMCI diagnosis.

Linda: My blood pressure went up... my blood pressure was always high, I started blood pressure pills, but it's always been just a bit high, but the last time I was to the doctor, it's gone up so she upped my medication. She said we better just up it now for a while till you get...and I know, there are times that I'm really stressed, I am, I know that.

The respondents often commented that they wanted to help their loved one, to slow the cognitive decline or to keep their loved one functioning at an optimal level. When the carers observed

declining function, loss of control was felt intensely and the meaning they had given to the diagnosis changed.

One respondent commented that the stress she experienced as a result of her challenges in relating to her spouse resulted in elevated blood glucose levels, a possibly problematic response as she has diabetes. This participant felt a loss of control in the relationship as she was not able to predict her spouse's disposition and she commented that she must always be watching. I interpreted this heightened sense of remaining on guard as the need to watch so that she would know what mask to wear. In this instance the mask serves as armour, protecting her from an unwarranted outburst.

Olivia: He gets mad, you know if I say anything. He flies off the handle for no reason at all... It's terrible, it's really, really terrible. Really hard and of course it doesn't help my health either because with the strokes and heart problems, diabetes, I have a lot of things going on. So um, at times my sugars are completely out of whack and I can always put it down to why, it's always stress related.

I began to understand that the women in this study felt as though their carer role was not always appreciated by their loved one with aMCI, their closely related family members or friends. Loss of control seemed to be experienced as a consequence of occupying a role that was very demanding, yet offered little reward or agency. As noted previously, occupations that are classified as high demand/low control (Karasek, 1989) are typically the most stressful and are associated with the highest mortality rate as a result of stress responses that could lead to hypertension, diabetes, cardiovascular disease and cancer. Carers current self-reported health varied from poor to good health; however, they were also aware that the multiple losses coupled

with the role strain they were under could manifest as poor health. The women in this study commented how important it was for them to remain as healthy as possible as long as possible because of their loved ones' increased level of dependence on them.

Lorraine: I know finding a job would really help me deal, 'cause right now I deal with my mother, my daughter and my daughter's father, and, and they are all acting like children and they're users and abusers and I need something a little more constructive, stable and you know somebody else that will give, kind of equally, whereas these people all take from me, so I know I do need to find someplace where I could get a job and take some of my focuses off of them.

For some of the participants, reconciling the loss of control with an outlet was a coping mechanism that seemed to counter the physiological stress response they experienced. Participants used words such as 'distraction', 'outlet,' 'get my focus off,' 'escape' and 'get away' as a way to maintain well-being, or rather self-preservation. The essence of wearing a mask ties in well to loss of control as respondents create a mask to escape from their current lived-reality. In using the mask to distract from confrontation, grief and sadness, participants are able to manage from one day to the next. The mask helps the carer to reconcile their feelings of grief with their life-world experience.

4.5.3 Loss of Spouse/Parent

While participants are experiencing the loss of self and loss of control, they are also grieving the loss of a spouse or parent. As their loved ones are no longer able to fulfill their roles, carers are losing the connection they had with their loved ones from the past and anticipating a future loss of the relationship altogether. For the carers in this study, both spouse and parent relationships were redefined. Carers felt as if they were now no longer in the traditional dyads

they had come to understand; but rather, they were now caring for their loved one with aMCI in a manner similar to the way they would care for a child. This experience of shifting expectations from what the relationship would have been like to the way the relationship had become was very upsetting and irreconcilable for the respondents.

Mary-Anne: And I've said that a good many times, and I've even said that to him, "I don't want to be your mother, AT ALL. I want to be your wife." And then he gets upset because he can't see it so... (*she lets out an exasperated laugh*), anyway, it's quite a, I just, for myself right now, I know I'm in a bad place right now because I'm, I'm, I'm really struggling, I'm really uh, you know, and probably part of it is, where am I gonna get some help, whether it's for him, or whether it's for me. Where am I going to find someone?

While it was not a theme that was present in all participants' narratives, the issue of loss of intimacy within the spousal relationship was one that came up and was very upsetting. Mary-Anne was the only participant who addressed the loss of this component of the relationship. However, her experience was similar to the others who described ways in which their relationships with their loved one had changed. I interpreted this to be that the meaningfulness of the relationship had changed. The carer role is no longer in congruence with the wife/daughter role due to the newly formed 'working' relationship that begins to develop among carer and care receiver.

Carers in this study noted that their loved ones with aMCI were looking to them more frequently for direction and reassurance on things that the carer would not have been invited to participate in previously. For the daughter whose mother had aMCI, her mother now referred to her for advice. This change in their relationship was welcomed as it gave the daughter a sense of

her mothers' respect for her. In this instance I have interpreted her feeling of gained respect from her mother as a shift in power dynamics. While the mother is taking on more of a child role, the daughter is continuing in her role as child but gaining her mother's respect, similar to the respect a child would give to a parent but at the same time is having to take on more of a parental role by providing guidance and advice.

Lorraine: She's slipping and I find I offer her more of my thoughts and opinions on things and she now accepts them a little more readily and as well as like when she had that accident, um, I was elated about certain emotions because she treated me with a certain respect. She needed me; um, she relied on me.

Participants who were spouses commented that they felt as if they were losing a partner. When considering the word partner, it can be thought of as a person who embodies an equal half, who shares openly, and provides a cooperative contribution. A partner gives and receives. The female spouses in this study experienced that the relationship was becoming more and more one-sided. They gave but did not receive much in return, and especially not on an emotional level. The ability to relate and communicate their wants and desires, because of the complex nature of these feelings, seemed to be lost in translation when relayed to their loved one.

Linda: yeah, it's uh, a losing of part of your partner, and um, (*lets out sigh*), yeah, like I know that we're blessed, and I know it could be worse, but it's still losing part of a partner, part of what you were expecting and you need to deal with it differently (*She clears her throat and tries to muster up a smile*). Like we start out in our married lives and we never expect our partner to be anything except what they were when we met them, when we married them and when they aren't, we

need to adjust to that and it's not always as easy to do as, "Oh well I'm going to adjust" it's not always that easy.

When communication remained open between the spouses, the loss was not as traumatic; however, the knowledge that they were going into the future without an equal partner with whom to share both the positive and negative aspects of a relationship, was frightening and overwhelming for these carers. Where the respondents experienced the loss most profoundly was when their expectations for the future were diminished by their acceptance that their partner would no longer be able to provide the elements that made their marriage successful.

4.5.4 Loss of Hope for the Future: Anticipatory Grief

In addition to experiencing loss on both personal and psycho-social levels prior to and after their loved one was diagnosed with aMCI, participants also experienced a loss for a future that was no longer obtainable for them given their current lifeworld experience. This demonstrates that loss can occur without having physically or explicitly experienced a loss and can be considered a temporal phenomenon. Loss of time is a theme that arose when discussing loss of identity as caring for a loved one monopolized a carer's personal time. The unique nature of anticipatory loss and grieving for losses that have not yet materialized is a fundamental attribute to caring for a loved one with aMCI.

Mary-Anne: Now all of the sudden there's grief because all of the sudden retirement wasn't what you thought it was going to be and now...I am the caregiver, this is my role and this isn't going to change. You'll have good days, you'll have bad days and there's a pretty big possibility it's going to get worse. And so, I'm probably at that point, I, I have to come to grips with that now, so I went from relief to, "gosh, this isn't really what I had in mind."

Respondents are not only grieving the loss of a spousal or parental relationship with the person who is diagnosed with aMCI, they are also anticipating that their future expectations will be unmet and unfulfilled. Participants often made comments that the gradual decline they experienced in their loved ones' ability served as a harbinger of continued decline and eventual transition into AD. Participants' unmet expectations were the hardest to reconcile as anger and disappointment were conjoined with the carers' want to be supportive and non-accusatory about their loved one's inability to change the outcome of their diagnosis. Participants indicated that they felt it was unfair to blame their loved one because they knew it was not their fault.

When participants experienced difficulty reconciling their emotions with their want to be empathetic to their loved one, that is, when they felt guilty, they donned a mask to cope with this disconnect. The mask worn in this specific instance is one of self-protection.

Linda: Sometimes it's just the frustration of, of (*long pause*) I suppose sometimes the frustration of an expectation that isn't there, now I have to deal with it not being there...but you have to figure out what to do by yourself. And it's not always easy figuring things out yourself...as I said I know that my expectations have to be less, but this is a husband I have lived with for almost 47 uh, 53 years and there are times when, although I know I don't quite accept it, there are times I resent extra time and it does, it takes a lot more time.

Fear of the unknown was an experience shared by all of the women in this study. Both spouses and children feared a worsening in their loved ones' ability to live a full life and the implications this would have on the future livelihood of the carer. Respondents questioned their ability to cope in the home, to look after the home on their own, and whether or not they would be able to manage the finances, driving, errands and other IADLs. Often the worry about the

future stemmed from the participant's apprehensiveness to discuss the future with their loved one for fear of upsetting them in their vulnerable state.

Shelly: to be strong enough as he is to face up to this and say ok, let's see how we can deal with this, knowing that we can't cure it, but we can live with it. And God help you if you can't live with it, what are you going to do?

For some of the participants, looking forward and anticipating the future was too frightening for them to contemplate and negatively affected their desire to care for their loved one at the present time. Carers often spoke of the need to take each day as it came, dealing with new issues or obstacles as they arose. I interpreted that a day-to-day approach to caring was one way that carers experienced being able to cope with their fear of the unknown and the uncertain trajectory of the disease process.

Carers often spoke about feeling selfish, petty, or irrational when being resentful of what they labeled as lost time. It is this resentment of the lost future spent together in a meaningful relationship that reinforced in them the need to be present and take each day one at a time. By remaining present in the moment, carers could be aware of their frustration levels and realize when they needed to take a break. When carers realized their frustration threshold through self-awareness, their carer identity began to crystallize and it is during these instances when carers felt compelled to get away temporarily and meet with people who were facing similar experiences or step out of their own lived reality momentarily.

Lorraine: I mean I know she's never going to go back to normal... I try to go with that from day to day, there's no point building a mountain... However, there are some bridges we haven't crossed. I'm a little chicken to have these discussions with her, like what happens if she can no longer make those decisions, I mean I

have thought of that, I know she's losing it mildly, but yeah, we've never crossed that bridge.

Participants who had challenging or strained relationships with their loved ones prior to receiving the aMCI diagnosis questioned their willingness to stay around and 'be abused' if a loved one's behaviour became aggressive in nature as a result of their worsening condition. All carers questioned their ability to access personal strength and resiliency to cope with caring for a loved one with aMCI for the rest of their lives. I have termed this experience 'anticipatory grief' for the reason that carers are anticipating continued loss of their relationship as well as loss of their independence or freedom. Multiple losses, coupled with the knowledge of the typical trajectory of cognitive decline, prompt carers to anticipate a worsening in a loved one's status irrespective of whether their loved one converts to AD.

Olivia: I'm not looking forward to it, at all. Definitely not looking forward to it... I don't know how I'm going to go through with another 10 to 15, 20 years, however long we have left in our lives... And the fact that it (*the MIP*) was ending was devastating, because it was like, what do we do now? Cause we had so much release with Sandy (*social worker pseudonym*), you know, what's going to happen?

Participants also grieved the cessation of the MIP. During the program, participants were able to experience validation and acceptance from other carers that had similar experiences caring for a loved one with aMCI. Losing the connections participants made in the program and no longer having an open forum for support was experienced as an acute loss with long-term consequences. During the program, carers were able to take off the masks they wore in front of their loved ones and display their true selves.

4.6 Unmasking: Validation from Support Systems Through Shared Experiences

The theme that carers shared among them was the experience of wanting to feel like their new role of carer was being accepted by their informal support system. The search for validation happened for these carers in hopes of being able to take off their masks and be their true selves. When family and friends accepted the aMCI diagnosis and acknowledged the impact this had on the carer's personal wellbeing, they experienced feeling validated. A theme that emerged out of each participant's narrative was how important it was for these women to experience validation from multiple levels of support. The carer role was perceived as precarious because the majority of individuals with whom carers and care receivers came into contact with, such as family and friends, were not as attuned to the subtle memory and functional changes which were obvious to the carer. When other people failed to see these changes as clearly as the carer, they had difficulty comprehending why the carer felt frustration and resentment about providing care to their loved one with aMCI.

I have interpreted that carers actively seek out validation in three different ways. The first is through finding a diagnosis, perceived as a form of formal validation. The second is through the search for meaning and shared understanding within the carers' informal support system. The final way carers seek out validation is through people who have had similar experiences caring for a loved one with aMCI.

4.6.1 Formal Validation: Getting the aMCI Diagnosis

The journey from initial signs and symptoms to receiving the aMCI diagnosis is not the same for every carer and this was certainly the case for the respondents in this study. However, all five participants experienced this journey as being disjointed, non-linear, and problematic. For the most part, respondents were intertwined with others in this process, corroborating

medical histories and providing context during the numerous visits to both the family physician and the specialist. The search for an explanation was undertaken to gain some form of justification for the anger and frustration carers were feeling as a result of the changing health of their loved ones as well as the changing and sometimes challenging nature of the relationship. Carers sought out validation for their feelings as a way to normalize their experience.

Formal validation for the carer's observations and feelings was received in the form of a diagnosis. However, the process to actually receive the diagnosis frequently caused both the carer and care receiver undue stress and strain.

Olivia: ... and I kept thinking, maybe that's why this is happening and why that happened, so it was a lot of things happening over the years that I kept thinking where on earth is this coming from? I walked out of here floating on a cloud because there may be a reason for this and I'm not crazy and it's not all in my head and... the first appointment I had here, it was like a weight lifted off my shoulders, and I think it was just the acknowledgment you see, the unfortunate thing is, your family doctor is dealing with so much, they don't have time to sit and listen to you, and I understand that because they can't, they have to see so many patients in such a short space of time.

Interestingly, for the carers in this study, actually receiving the aMCI diagnosis came as a relief. The negative emotions the carers experienced were validated because they were able to forgive themselves for the anger and resentment they were internalizing and not able to express to their loved ones. Carers mentioned that as a result of learning what they were feeling was not without reason, they felt validated. Consequently, once a formal medical authority established this diagnosis, they were able to reduce the level of blame they were placing on themselves.

Through receiving a formal diagnosis, participants began to stop blaming themselves and determined that the problem was not the fault of either person. The experience of receiving the diagnosis was both validating and a relief.

Shelly: Get all the help you can, find people in similar situations to share, but to come here was the best thing that could have happened because your own doctor is helpful but he or she is not as attuned to this as people in the field. But you have to have help, you can't do it on your own.

However, sometimes their family doctor did not validate their experience, at least initially, and they were forced to go searching for validation from less accessible avenues.

Lorraine: But your average Joe does not know where to get (*the diagnosis*), I mean and other than your family doctor's and then those are getting, you know, they're so busy that, "oh here, I'll write you a prescription, maybe that will work"...you know, go back in a year and you know your first approach with him didn't work so why do it again.

In addition, carers felt that they were not being heard by their general family physician (GFP). The concern they expressed to their GFP was not validated as the GFP maintained "I really can't see that there is anything wrong with him." One respondent expressed that she worried her family doctor would consider her to be a hypochondriac and a complainer resulting from her search to find an answer.

Mary-Anne: Well, that's exactly what it was like for us, we just have a new doctor that we've only seen for I suppose a year and a half, two years, so really didn't know us in the first place uh certainly it's exactly, she told him, "well you've done good on these tests, I don't think there's anything wrong." I'd push it

and she'd make me think I was a hypochondriac, and you know I should deal with it and he's fine... so once you have a diagnosis then you come to grips with it, and there was certainly so much relief, it was such a positive, the night we came home from the visit, the best thing was being able to talk about it.

The lack of resonance and validation of their lived experience following a visit to the GFP made the carer and the care receiver feel isolated and helpless. Sometimes the participants felt as though they had to force their family physician's hand to get the answers they needed. Once the diagnosis was made, however, the carers and care receivers felt an overwhelming wave of relief as the burden of not knowing and not being validated was lifted from both of them.

4.6.2 Informal Validation: Creating a Different Informal Support System

Only once the family doctor accepted that there was a problem, or rather validated the carers' request for help, a referral was made to a specialist. This was validating for the participants in this study as it opened up the doors that would allow the respondents to access the formal health care system in order to get answers to their question "what is wrong with him or what is wrong with me?" In addition to recognizing their need for education and the formal health care system, respondents also recognized that they needed a new informal care system. The old informal care system that carers had established for themselves over the course of many years was no longer perceived as sufficient to support their new and changing needs in the capacity they and their loved ones required.

Mary-Anne: You definitely need some support. Very important to actually get a diagnosis, so you can move on from there, and support is medical and emotional, it goes both ways. Uh, getting to the point where you can ask your family and friends for help. I don't know that we are totally there yet as far as that goes...It's

a little difficult too because of our friends, they are accepting but there is no one really that understands.

Carers conveyed that they were having difficulty relating to their friends who were not sharing a similar experience. Loss of time, freedom, and flexibility due to their carer role seemed to be misunderstood by their broader network of friends and acquaintances. Carers felt less able to engage in meaningful conversations with people who did not empathize with their current situation sometimes resulting in the dissolution of existing ties. Carers felt that they could not be comfortable or themselves around their old friends because they were not able to take off their multiple masks as their loved one demanded their attention even when the carer was spending time with friends away from their loved one.

I have interpreted that carers wear a mask of normalcy when communicating with old friends who are not sharing a similar life-world experience. Fear of alienating other people who do not empathize with their situation caused the carers to hide the difficulty they were facing from friends and acquaintances. It was only when the carer found another person who had experienced caring for a loved one with aMCI that the true self could be unmasked. Respondents in this study also made mention that other family members who they felt to be closely related to them, such as siblings, were not empathetic and could not validate the feelings carers were having.

One participant in particular experienced feeling completely abandoned to take care of her mother on her own as her brother did not accept or acknowledge that their mother had a problem with her memory. Lack of acceptance on his behalf meant that the carer would not receive the type of support she expected from her brother. As a result of this ambivalence from her informal support network, she felt she was in a precarious position. Not knowing if she

would be supported in the future by the people she would have expected to come to her aid made her question to what extent she would be able to provide care to her mother on her own.

Lorraine: We have a small family, just me and my brother. He, he's not much of a support system...he's not that helpful. So yeah, so for me to get even some support from him, it's not there, cause he sticks his head in the sand...I mean I definitely think I would be willing to look for help for myself you know if I, I know the frustration level gets there. I know I've been watching it with her and I think of it. And hopefully I would act and get help before I acted on it.

Other respondents also felt a lack of support from their informal care system although the context within which this was experienced varied. For one participant, relying on other people for support was not an experience to which she was accustomed. During the interview, she maintained that she received the guidance and support she needed from organized religion. While this respondent indicated that her children had been her support group in the past, similar to the other spouses in this study, she was reluctant to place any undue burden on her children, bearing the weight of the caring responsibility herself.

Shelly: Mmhmm, no, I don't have a support group, James (*pseudonym*) and I belong to the United Church and we thankfully have a strong faith, the two of us. Our children are our support group... um, I think they knew before either of us ever said anything to them but, well, noticing the changes in him you had to realize what was going on but we did tell the two of them and they were glad that we came here.

This carer felt that she received the most support from the new bonds that were made between other carers she met through the MIP caregiver support sessions. The benefits of this new informal support are explored in more detail in the following section.

4.6.3 Unmasking: Validation through Shared Experience

I have come to understand that for the carers in this study, the multiple masks they wore in order to conceal their true feelings from friends, family members and their loved one with aMCI were removed once they felt safe enough to allow their feelings to be validated. Where this validation was most profound was through meeting other people and sharing similar lifeworld experiences. By meeting other people who had been through a similar experience, concealed and masked feelings of isolation, loneliness, and fear were validated. As a result, carers felt less alienated and alone.

Mary-Anne: Yes, and I think just the reassurance by those other people, I'm not alone, I'm not making it up, this is real...and sometimes you might not have experienced a particular issue yet but that's not to say you aren't going to and so it's almost kind of giving you a little heads up and you know, like yeah...and you know that being able to feel that, yes...you know there will still be people that make you feel like, it's just me. And so when you can be with someone who's going through it, and they can tell you things, then it's like, "oh, that's ok," you know. The problem will still be there but at least it's taken off...it's not me. It's just not something specific like my attitude needs to change or whatever.

Carers felt that being able to talk with another person who understood what they were going through was not going to change the fact that their loved one had the aMCI diagnosis, but it did help them to feel supported and validated. Carers also made mention of what it was like to

know that their loved one was also experiencing a level of validation and acceptance from others who had received the diagnosis. When a loved one with aMCI accepted the diagnosis themselves, they were receptive to others who had also accepted their diagnosis and this fostered a unique bond between them. When seeing these bonds form, carers felt relief and were hopeful that this could be a potential outlet for their loved one, similar to the reprieve carers themselves felt when speaking to someone with a shared experience.

Shelly: Now coming here made the coping so much easier, because he realized that he wasn't weird, that there were other people in his situation. Here, James (*pseudonym*) had felt that they had bonded as a group and really they did, 'cause they would talk among themselves about what they were doing and uh laugh among themselves about their coping skills that would seem odd and funny, peculiar to someone who didn't have any problem. But, never to have come here would have been very unfortunate.

All of the spouses in the group, especially those whose loved ones had accepted the diagnosis, noted the benefits associated with care receiver bonding. In addition, the participants felt that their needs were met as a result of their shared experience specific to aMCI. Some participants recounted looking for support from the Alzheimer's Society (AS). However, after meeting with the AS support group, they felt more worried or apprehensive about their experiences rather than assured and validated.

Linda: If we got nothing (else) out of the course, (it) was meeting other people going through the same thing and being able to talk, not only for me, but for my husband. It's been wonderful. Absolutely wonderful (*she says smiling*)...Like the ladies here understood when I said something, they all understood exactly what I

was saying and what I meant...and how can they know unless they have gone through something? ... there are Alzheimer's groups, I know that and if there is nothing else you can go there but, and I know it's difficult, but if there is one, just for the one you are dealing with (*meaning an MCI support group*), it's so much easier to go and acknowledge the other people and them acknowledge you and accept what you have to say and listen.

Carers also noted that the stories they heard from other carers during the MIP provided insight to what they should anticipate while providing care. Sharing experiences helped carers have less fear about the future and provided a feeling of encouragement that they would be able to fulfill the responsibilities of the caring role. While the level of care being provided by the carer varied, the carers acknowledged that the support group allowed them to be honest and open about their frustration and anger. This feeling of frustration seemed to be pervasive among the group. Learning that anger was not a feeling unique to their own experience was validating. Unmasking themselves and exposing their anger helped carers to feel connected to the other women in this study.

Lorraine: I was thinking about that this morning, like the anger issues and stuff, and I mean I find after listening to them in the support groups that they all have anger issues, um or frustration levels I guess.

The participants felt validated when their stories were heard, acknowledged, and understood intrinsically by other people who had similarly experienced caring for a loved one with aMCI. Communication was easier when there was a shared, lived-world experience that resonated among the carers. This resonance allowed carers to feel a sense of belonging to a group and help to crystallize their carer identity.

4.7 Playing the Part: Summary

In summary, when taking a phenomenological lens to this experience of shared understanding, it seems worthwhile to note that the experience of caring for a loved one with aMCI could be understood as the experience of wearing multiple masks to conceal feelings associated with the changing relationship with the care receiver, dealing with anticipatory grief and multiple losses, and building a coat of armour to help deal with the challenges of the social world. Masks are worn and interchanged depending on what coping strategy is contextually appropriate. The masks are shed when the carer experiences validation from others caring for a loved one with aMCI.

4.8 Conclusions

The carers in this study all shared a similar experience while caring for their loved ones who had been recently diagnosed with aMCI. Before and after aMCI diagnosis, carers wore caregiver, protective, diplomatic, and/or normalizing masks to cope with multiple losses, challenging aspects of their relationship with their loved one and other members of their informal support group, social stigma, lack of validation of their experience from old friends and acquaintances and their own anticipatory grief about the future. This chapter described the phenomenon of caring for a loved one with aMCI and how these women coped with their transition into new roles through the experience of masking as a coping strategy. Masking is the carers' way of negotiating their old self with their new ascribed role of caregiver while protecting both their loved one and themselves from the guilt, fear and ambiguity they feel about moving forward into the future living with a potential AD diagnosis. The way that carers begin to unmask is through the validation they experience when co-creating shared understanding with other aMCI carers.

5. DISCUSSION AND FUTURE DIRECTIONS

5.1 Wearing a Mask and Existing Literature

Symbolic Interactionism (SI) is a theoretical framework which is used to understand the way people create meaning through their social interactions with one another and through these interactions come to construct their own identity (Blumer, 1969). Erving Goffman, a prominent German American sociologist subscribed to the tenants of SI and used this framework to develop his theory of dramaturgy (Goffman, 1959). Dramaturgical analysis is used to explain the way individuals form their identity through their interactions with social symbols, that is, their milieu (social environment) and the players (other people) on stage with the actor at a given time.

Goffman (1959) uses dramaturgical analysis, a theatrical metaphor, to explain the way an individual's identity is not fixed, but fluid, changing from one scene (social interaction) to the next (1959). In his book, *The Presentation of Self in Everyday Life*, Goffman, (1959) proposes that people engage in "impression management" meaning that actors convey their everyday actions, intentions, meanings and expressions through a series of performances. It is this self-monitoring that allows people to express specific aspects of themselves at a given time, thereby wearing a series of masks to interact with other actors. The concept of wearing a mask from a SI framework has been well established and accepted in sociological literature with regard to identity formation.

My findings are congruent with this theory and have the potential to illuminate novel aspects of the way people who care for loved ones with aMCI come to form their carer identity, an area in the literature that is innovative and in need of further examination. Building on my findings, other researchers could use dramaturgical analysis to understand role strain, carer burden, and role transition among aMCI carers.

The notion of role transition has been well explored in the caregiver literature. However, the attention paid to the early stages of caregiver role transition has only been investigated within the last five years (Carlander et al., 2011; Gallagher et al., 2008; Montgomery & Koleski, 2009). While the experience of 'wearing a mask' was not a common finding that came out of the caregiving literature, what was present and helped to further crystallize my understanding of new role formation the carers experienced in my study was the work done by Montgomery and colleagues (2009) on Caregiver Identity Theory (CIT). CIT views the career of caregiving as a series of transitions that result from the caregivers ever changing care context (changes in dependency level of the care recipient, changing levels of activity and responsibility for IADL's).

CIT proposes that caregivers not only change their behaviours but also change the way they see their role in relation to the care recipient (Montgomery & Koloski, 2009). What this means and how it relates to the experience of caring for loved ones with aMCI is that carers are constantly undergoing a change in their own identity and self-concept. This identity change happens because of increased levels of dependence a care receiver begins to display. The care tasks that are required to support and maintain the health of the care recipient become inconsistent with the expectations the caregiver had from their initial relationship with the care recipient. The theory also maintains that other changes in the care context, such as decrease in level of informal support and formal resources may also create a change in the caregiver's identity (Montgomery & Koloski, 2009).

CIT can be used to draw out important experiences that the carers in this study reported with regard to caring for a loved one with aMCI. The respondents in this study reported feeling that their spouses were no longer the person that they married or that their mother seemed to be

behaving like a child. They made comments referring to feeling like the expectations they had for the future could no longer be met. Respondents reported that their experience was not so much that the role of carer was difficult, but rather that it was a role that was hard for them to see themselves in because it was not what they had expected for themselves nor in congruence with their self-concept.

This transition in the definition of self has been captured frequently in literature on caregiving for individuals with chronic or terminal diseases such as AIDS and dementia (Carlander et al., 2011). In their study of family caregivers who provided support to people dying in the home, Carlander and colleagues (2011) discovered that experiencing different life events, which the caregiver had not anticipated experiencing, forced the caregiver to form an alternate self or a new identity in order to manage the unexpected. In this instance, one could assume that a person who is caregiving for his/her loved one at home is forming a new identity in order to shield him/herself from the fear of the unknown, similar to the notion I interpreted as wearing a mask of armour.

Erikson's *Identity Theory* further confirms this idea as he postulated that people are shaped by critical events and forced to view themselves in new ways (Erikson & Erikson, 1997). Each new transition can be understood as a defining moment in life that shapes individual experiences and memories that, in turn, will become attached to the caregiver's new self (Carlander et al., 2011). The modified self is continually reinvented in order to protect, transform and support the care receiver as well as the caregiver. Carlander proposed that forbidden 'thoughts,' or rather those things that people think but are afraid to say because they are socially unacceptable, are part of the process of self-modification (2011).

When considering the respondents in this study, forbidden thoughts seemed to be very close to the surface and once these thoughts were shared with me, the carers felt guilty and ashamed for thinking this way. Comments such as “sometimes I’d like to just run away” and “I wish I could just shake him” or even “sometimes I don’t want to be there for her” would be considered forbidden thoughts. This uncomfortable experience of thinking forbidden thoughts and feeling guilty about these thoughts is a bi-product of entering into a new role which has socially accepted rules that are not yet accepted by the caregiver. However, the modified-self steps in to overrule the forbidden thoughts or rather, a person wears a mask to prevent the care receiver from being hurt as a result of the disclosure of these thoughts. Future studies could focus on to what extent the carers’ modified self (or mask) is experienced while caring for a family member with aMCI and what social rules and norms are required for a carer to assimilate with this new role.

Interestingly, not all carers in this study considered themselves a caregiver. While they appreciated that they were performing some tasks which would suggest they were functioning as caregivers by the social definition, not all carers felt they could say they were actually caregivers. This finding is supported in the work of O’Connor (2007) who explored the self-identifying process carers go through to become a caregiver. She revealed that when a person self-identified as a caregiver before actually becoming a caregiver, he/she received little benefit from the formal support services available/offered. Another experience among MCI carers who attended support groups for caregivers of people with ADOD was to feel like an outsider looking in on the lives of other people who actually accepted the role of caregiver (O’Connor, 2007).

The women in this study highlighted the importance of receiving both emotional, physical, and other types of support that are not generic but rather specific to the unique needs of the individual carer. One participant in particular commented that having a support group with other women who were also experiencing caring for a loved one with aMCI was much more beneficial to her than attending an AD caregiver support group. She stated that the other women in the MCI support group provided her with a feeling of relief, validation, and wellbeing which she did not receive when she visited the AD support group before attending the MIP. O'Connor (2007) also found that identifying as a caregiver was only beneficial when the support services an individual required were specific to their own needs.

5.1.1 Interpretation of Wearing a Mask

Despite the attempt of community centers, health care professionals, and other caregiver support programs to assist caregivers of people with dementia, the needs of informal caregivers caring for a loved one with aMCI are not being met in the community (Hain et al., 2010). Even more significant to this issue is that individuals who do not yet self-identify as a caregiver do not qualify for a number of services which are specifically aimed at caregivers caring for those with cognitive changes. The literature on caregiver service utilization points out that informal caregivers are not seeking out the support that is offered to them. However, the experience of the women in this study was that dementia support programs do not adequately meet the unique needs of individuals caring for loved ones with aMCI.

The findings from this study, supported by existing literature in caregiving research, highlight the precarious nature of caregiver role acquisition and the heterogeneity that is present among informal care providers. Based on the experiences of the women in this study, I have come to understand that carers assume multiple roles in the transition from being a spouse or

child to becoming a caregiver. Throughout their experience, pre- and post- their loved ones aMCI diagnosis, carers wear multiple masks to conceal their forbidden thoughts that are not socially acceptable given the social norms, values, and expectations society places on *being* a caregiver.

In response to the Alzheimer Society of Canada's, *Rising Tide: The Impact of Dementia on Canadian Society* Report (2009), future research, which may influence the development of programs and services for dementia carers, may consider the unique needs of individuals with aMCI as their needs and expectations are different from caregivers of individuals with ADOD who are referred to dementia support groups. Carers of individuals with aMCI are at-risk of developing caregiver burden because they may be responsible for providing prolonged long-term care to their loved ones in the home with minimal support as the care receiver transitions from aMCI to AD to death. It would be interesting to assess whether specialized education and support programs for aMCI carers reduce long-term impact of caregiver burden and delay or deter nursing home placement.

5.2 Multiple Losses and Anticipatory Grief and Existing Literature

The notion of multiple losses and anticipatory grief comes from the bereavement literature. However, neither of these two concepts are exclusive to a bereft family member. The experience of losing a spouse or parent was a theme that was pervasive among the women in this study. In addition, loss was experienced in different ways and at different points in time throughout the aMCI journey. When trying to interpret the experience and make references to previous scholarly literature on loss and grief among caregivers, the majority of the articles published deal specifically with caregivers of people with dementia. However, very recently, a novel research area has emerged looking at people who care for family members with a

diagnosis of MCI. The overall finding from this research area is that carers in this specific context experience ambiguous loss (Bliezner, Roberto, Wilcox, Barham, & Winston, 2007; Holley & Mast, 2009; Garand, Lingler, Deardorf, DeKosky, Schulz, Reynolds, & Dew, 2011)

Ambiguous loss is defined as “the process of experiencing the phases of normal bereavement in advance of the loss of a significant person” (Gerand et al., 2011, p. 1). This type of loss is experienced when a loved one is physically present but emotionally, psychologically or spiritually absent (Lu & Haase, 2009). As emotional, psychological and spiritual changes are frequently experienced among those living with ADOD and MCI, their carers may experience such a loss. The person with dementia or aMCI is still physically present, grief is static, but life does not go on in the fashion it once did. As a result, care providers suffer from the constant reminder that their loved one will most likely die before them (Holley & Mast, 2009).

When there is no validation of a point of death, a person caring for a loved one with aMCI or dementia is unable to reach closure and there can be no resolution of his/her grief until his/her loved one passes away. The usual social recognition of death, such as a funeral or wake which serve to commence the mourning of a loved one, are put on hold and the caregiver continues to grieve and mourn the loss of their relationship with their loved one prior to their passing (Bliezner & Roberto, 2010). In her study of married couples coping with ambiguous loss as a result of MCI, Bliezner and colleagues (2007) asserted that care providers have “great difficulty in identifying and using effective coping strategies because of the psychological incongruence and confusion some people experience” (p.15).

In addition to experiencing loss and anticipatory grief, the carer can experience ambiguity and confusion around the MCI diagnosis (Bliezner et al., 2007; Garand et al., 2011). The uncertain and fluctuating nature of MCI can simultaneously be comforting and disconcerting to

both care provider and receiver. Carers in this study celebrated the fact that their loved one had not been given a diagnosis of AD. However, the multiplicative effects of fear of conversion, the uncertain length of time to AD diagnosis, the possibility of regression and the lack of understanding from other people created perturbation among the carers in this study.

For the majority of the respondents in this study, the ambiguity of the diagnosis also was experienced prior to receiving a formal diagnosis as the carers admitted to knowing that there was a problem with their loved one's memory for quite some time. Carers responded that they were forced to seek out information on their own, looking to find an explanation in the form of some kind of answer that could cure their loved one. This was also a finding from Bleizner and Roberto (2010). In their study, care providers reported the experience of ambiguity prior to receiving the diagnosis as uncertain losses which was further described as a need to make sense out of the change in their loved one. Yet by looking for an answer, they were further losing the expectations they had for the future.

On numerous occasions, the respondents in this study made references to being resentful of their lost future together with their loved one, especially the spouses. This is a theme that has been well documented in the dementia caregiver burden literature (Brodaty, 1996; Dal Santo et al, 2006; Gallant & Connel, 1998; Pearlin et al., 2005; Tunajek, 2010). What researchers have begun to uncover is that the anticipatory loss for the future can be experienced very early in the caregiving journey. A powerful and upsetting experience that was revealed by a carer in this study was the loss of intimacy she felt with her husband that she attributed to his MCI. While not a global essence of the caring experience, intimacy and sexuality is an under researched and extremely important area which has far-reaching implications especially for people who are anticipatorily grieving the loss of a partner (Steadman, Tremont, & Duncan Davis, 2007).

When addressing the literature specifically looking at the impact of memory impairment on spousal relationships, especially around intimacy, the literature is rich with regard to dementia. However, there is a gap in the literature with regard to issues of intimacy among care providers of people with MCI. Premorbid marital quality and satisfaction seem to play an important role in the way a care provider engages in intimate acts with their loved one with dementia (Davies et al., 2010; Gallant & Connel, 1998; Garand et al., 2007).

Researching carer – care receiver intimacy has significant implications for supporting care providers over the long term. Because of the uncertain nature of MCI and possible conversion to AD, there is a chance that carers could be providing instrumental care for a prolonged period of time (5-12 years on average). Davies proposes that a “couple’s satisfaction with their emotional, sexual, and other forms of intimacy may not only affect psychological and emotional health, but may also have longer-term ramifications for decisions about caregiving and placement. Placement decisions also have economic implications for both individuals and the health care system” (2010, p. 619).

To understand the omission of a discussion on intimacy from the other spouses in this study, I had to take a life course perspective so that I could culturally and historically locate the possible reasons for this lack of disclosure in their narratives. This led me to understand that the women in this study, who belong to a similar age and generational cohort, may experience a heightened level of discomfort disclosing such sensitive and private information and this could be one of the reasons it was not discussed with three out of the four spouses.

The overall experience carers had in this study with regard to caring for their loved one long term was apprehension and ambivalence. Carers expressed concern about their ability to provide care on their own for an undetermined amount of time with the knowledge of what the

future could be like for them. Findings from a study of 80 caregivers of people newly diagnosed with MCI echo the concerns expressed by the respondents in my study. Carers were apprehensive of the future because they all intuitively held the knowledge of what losses they would face. They knew that the losses they had already endured would continue to be compounded going forward (Holley & Mast, 2009). Losses identified in Holley and Mast's study (2009) included loss of personal freedom, loss of finances, loss of meaningful communication, loss of family cohesion, loss of emotional closeness, and loss of the person with MCI's personality.

5.2.1 Interpretation of Anticipatory Grief

Anticipatory grief is a complex and multifaceted concept which captures the emotional response to an impending loss of a close friend or family member and the associated losses from the past, present and future (Holley & Mast, 2009). For the carers in this study, the multiple losses they experienced shaped their self-concept and made them question their ability to continue to provide support to their loved one long term.

This study highlighted the importance of shared understanding and communication with peers who occupy similar life-world experiences, thereby validating the phenomenological approach to the study. Future research on aMCI and individuals who will be potentially providing long-term caregiving to loved ones with AD could benefit from utilizing the unique expertise and recommendations from those individuals who have a clear understanding of the aMCI diagnosis and who can thoughtfully reflect on their experience. It is through co-construction of meaning that these carers and I were able to come to better understand the experience of caring for a loved one with aMCI.

5.3 Study Limitations

When conducting the literature review for this study it became apparent that phenomenology as a method for investigating the experience of those caring for a family member with aMCI is a novel research area. My findings were congruent with the literature as many themes overlapped and this served as corroboration and a further check for resonance. Because this research is qualitative and the focus was specifically on the experience of the participants in this study, the findings being generalizable. Nevertheless, the participants in this study were demographically homogenous and this could have accounted for some of the similarities the respondents experienced. Each participant was Caucasian, female, and over the age of 50. While study findings cannot be generalized to people who fit these demographic characteristics, future studies would benefit from exploring and interpreting the experience of different social groups, specifically individuals who do not have access to specialist memory clinic services and specialized geriatric health care professionals as well as those marginalized by ethnicity, socioeconomic status, language proficiency and people in rural communities.

Although this study group had the unique experience of attending the MIP, the study was able to explore the phenomenon of the caregiving experience for those caring for a loved one with MCI and subsequently the carers in this study probably had above-average insight compared to a person who had not attended either the MIP or the caregiver support session. What this study captured was that understanding and validation come from shared experience.

5.4 Future Directions

Understanding the essential experience of wearing a mask and anticipatory grief among caregivers of people with aMCI has great potential to supplement future research. As a field of research the 'aMCI caregiver' has not yet been well developed in the current literature. Further

research could benefit from exploring the acquisition and carer role attainment for people who care for individuals diagnosed specifically with amnesic MCI. Because this group has the highest risk of converting to AD, care providers are an at risk group for developing caregiver burden and the negative health effects that are associated with caregiving. Should future studies develop a better understanding of this phenomenon and should evidence-based strategies that mitigate the caregiver burden be identified, early placement into long-term care and the associated negative economic consequences for both the carer themselves as well as the health care system may be minimized. With the ever-increasing numbers of older adults over the next 20 years and with the increasing numbers of those with AD, finding a way to support carers over the long term so they can support their loved ones who convert from aMCI to AD is of the utmost importance.

Another challenge is how to deliver the support to an undefined group of carers. If there is not a sufficient base of support for the carers of individuals with aMCI, they will not go looking for the support programs and services until their loved one is much farther along in their disease trajectory. Future research could be conducted with the family doctor who often serves as the first line of contact for family members concerned about their loved one's memory. Future research could focus on the identification of strategies that could close the knowledge gap that seems to exist between the family practitioner and existing support services for aMCI care providers.

An area of research that could be helpful for this specific population of carers could identify aspects of peer support that are positive in reducing early LTC placement and reduce caregiver burden long term. Future studies could address what existing support groups are

offered, what adult learning strategies are the most accessible for this population and also how to deliver sustainable support programs in the community.

The majority of the literature on caregivers of family members with MCI came out of specialist memory clinics. However, those who attend such clinics tend to have highly attuned insight into how to navigate the health care system, how to get support, and when to ask for formal help. Future population-based studies may provide a fuller understanding of the experience of caring for a loved one with aMCI. In addition, learning more about the experience of the rural versus the urban MCI care provider could perhaps offer novel contributions to the existing body of literature.

Future research could begin to investigate the early stages of the caregiver trajectory, paying particular attention to point of aMCI diagnosis in order to develop strategies, resources, and support which could maximize carers' ability to support their loved ones as health status begins to deteriorate and they become more dependent on their care provider. The ability to intervene early on may be beneficial to care provider wellbeing and may even reduce the likelihood that carer will experience caregiver burden. Without investigating the experience of anticipatory grief, it would be very challenging to understand the essential experience of caring for a loved one with aMCI (Garand et al., 2011). Acknowledging caregiver grief early in their carer trajectory through multiple research designs and testing this experience may even lead to a new understanding of caregiver strain and the possible negative health outcomes associated with caregiver burden.

5.5 Conclusions

This hermeneutic phenomenological study explored the experience of caring for a loved one with aMCI. Through my journey to understand the essence of the carer experience, I have

come to know that the women in this study are forming a new identity and, in doing so, how they must negotiate the transformation from their old self to a new self with their new roles and responsibilities as a carer. This negotiation creates conflict within them and in order to reconcile the grief they are suffering as a result of multiple losses accumulated prior to and after the aMCI diagnosis, carers constantly have to reinvent who they need to be in a specific context. The essential experience of caring for a loved one with aMCI is the journey to taking on the identity of caregiver and the multiple masks carers wear in order to preserve their 'old self' until the new role of caregiver has been accepted.

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APPENDICES

The following appendices provide information on the various instruments that were used in the study. The appendices are: Appendix 1: Demographic Data; Appendix 2: Interview Schedule; Appendix 3: Interview Schedule; Appendix 4: Interview Schedule; Appendix 5: Interview Schedule; Appendix 6: Interview Schedule; Appendix 7: Interview Schedule; Appendix 8: Interview Schedule; Appendix 9: Interview Schedule; Appendix 10: Interview Schedule; Appendix 11: Interview Schedule; Appendix 12: Interview Schedule; Appendix 13: Interview Schedule; Appendix 14: Interview Schedule; Appendix 15: Interview Schedule; Appendix 16: Interview Schedule; Appendix 17: Interview Schedule; Appendix 18: Interview Schedule; Appendix 19: Interview Schedule; Appendix 20: Interview Schedule; Appendix 21: Interview Schedule; Appendix 22: Interview Schedule; Appendix 23: Interview Schedule; Appendix 24: Interview Schedule; Appendix 25: Interview Schedule; Appendix 26: Interview Schedule; Appendix 27: Interview Schedule; Appendix 28: Interview Schedule; Appendix 29: Interview Schedule; Appendix 30: Interview Schedule; Appendix 31: Interview Schedule; Appendix 32: Interview Schedule; Appendix 33: Interview Schedule; Appendix 34: Interview Schedule; Appendix 35: Interview Schedule; Appendix 36: Interview Schedule; Appendix 37: Interview Schedule; Appendix 38: Interview Schedule; Appendix 39: Interview Schedule; Appendix 40: Interview Schedule; Appendix 41: Interview Schedule; Appendix 42: Interview Schedule; Appendix 43: Interview Schedule; Appendix 44: Interview Schedule; Appendix 45: Interview Schedule; Appendix 46: Interview Schedule; Appendix 47: Interview Schedule; Appendix 48: Interview Schedule; Appendix 49: Interview Schedule; Appendix 50: Interview Schedule; Appendix 51: Interview Schedule; Appendix 52: Interview Schedule; Appendix 53: Interview Schedule; Appendix 54: Interview Schedule; Appendix 55: Interview Schedule; Appendix 56: Interview Schedule; Appendix 57: Interview Schedule; Appendix 58: Interview Schedule; Appendix 59: Interview Schedule; Appendix 60: Interview Schedule; Appendix 61: Interview Schedule; Appendix 62: Interview Schedule; Appendix 63: Interview Schedule; Appendix 64: Interview Schedule; Appendix 65: Interview Schedule; Appendix 66: Interview Schedule; Appendix 67: Interview Schedule; Appendix 68: Interview Schedule; Appendix 69: Interview Schedule; Appendix 70: Interview Schedule; Appendix 71: Interview Schedule; Appendix 72: Interview Schedule; Appendix 73: Interview Schedule; Appendix 74: Interview Schedule; Appendix 75: Interview Schedule; Appendix 76: Interview Schedule; Appendix 77: Interview Schedule; Appendix 78: Interview Schedule; Appendix 79: Interview Schedule; Appendix 80: Interview Schedule; Appendix 81: Interview Schedule; Appendix 82: Interview Schedule; Appendix 83: Interview Schedule; Appendix 84: Interview Schedule; Appendix 85: Interview Schedule; Appendix 86: Interview Schedule; Appendix 87: Interview Schedule; Appendix 88: Interview Schedule; Appendix 89: Interview Schedule; Appendix 90: Interview Schedule; Appendix 91: Interview Schedule; Appendix 92: Interview Schedule; Appendix 93: Interview Schedule; Appendix 94: Interview Schedule; Appendix 95: Interview Schedule; Appendix 96: Interview Schedule; Appendix 97: Interview Schedule; Appendix 98: Interview Schedule; Appendix 99: Interview Schedule; Appendix 100: Interview Schedule.

APPENDIX A

The following section presents the three separate letters of information that were created for this study. The initial phase of recruitment only produced four study participants from the Spring 2011 MIP. An HSREB revision was made in order to include carers from the Fall 2010 MIP whose family members still fit aMCI criteria. A letter of information was created for both the family member with aMCI and the carer who attended the caregiver support group sessions and who had also completed the three month follow-up session with advisor member Dr. Jennifer Fogarty.

Letter of Information Spring 2011



A study of individuals lived experience of loved ones recently diagnosed with Amnestic Mild Cognitive Impairment (aMCI)

Principle Investigator: Marita Kloseck, PhD¹²³

Co-Investigators: Sarah Woolmore-Goodwin, BA, MSc Candidate¹²³; Jennifer Fogarty, MSc, PhD, C. Psych,²³⁴; Iris Gutmanis, MSc, PhD¹²³⁵

¹ School of Health Studies, The University of Western Ontario

² Aging Rehabilitation and Geriatric Care Research Centre, Parkwood Hospital

³ Geriatric Medicine, Schulich School of Medicine and Dentistry, The University of Western Ontario

⁴ Department of Psychiatry, Schulich School of Medicine and Dentistry, The University of Western Ontario

⁵ Department of Epidemiology and Biostatistics, Schulich School of Medicine and Dentistry, The University of Western Ontario

Dear Participant,

You are being invited to participate in this research study because you have been identified as a family member of a person with mild cognitive impairment who is being followed at Parkwood Hospital and is participating in the Memory Intervention Program.

Background:

This study is aimed at investigating your experience with your loved one who has been diagnosed with a memory problem and the way this has impacted on your life and relationship. This research study will be recruiting between 10 participants who will answer questions about personal experiences. The purpose of this letter is to provide you with the information you require to make an informed decision on participating in this research study. It is important that you understand why this study is being conducted and what it will involve. Please take the time to read this letter carefully and feel free to ask any questions if anything is unclear or if there are words or phrases you do not understand.

What will happen in this study?

Should you choose to participate in this study you will be required to participate in one in-depth interview with Sarah Woolmore-Goodwin, The University of Western Ontario Masters student conducting this research. The interview will be approximately 1 to 2 hours in length and will ask questions about how you experience what it means to be a family member of someone who has

mild cognitive impairment and how you experience this relationship. The interview will be conducted in a private room at Parkwood Hospital. This interview will be audio-recorded. If you agree to participate in this study, you are also agreeing to have your interview recorded. If you choose to participate in this study and drive to Parkwood Hospital, all parking costs will be paid for you as a courtesy.

Types of Information to be collected:

If you agree to participate in this study, several sources of information will be recorded and analyzed by the researcher including your age, your gender, and your relationship and experiences with your family member. Information will be collected only during the course of the interview. Your interview will be audio-recorded. Sarah will listen to the audio-recording and type up word for word your interview. This interview will be transcribed into a hard copy (printed off of the computer) and will become valuable data. If you agree to participate in this study, you are also agreeing to have your interview recorded.

Risks:

There are no known risks associated with participating in this study. It is possible that during the course of the interview you may feel distress or upset if you choose to disclose information that is disconcerting to you or of a personal nature. You also may feel frustrated with the length of the in-depth interview. Should you feel the interview to be too long or invasive, you may refuse to participate, refuse to answer any questions or withdraw from the study at any time.

Benefits:

There is no known benefit to you associated with your participation in this research study. By choosing to participate, you may be aiding in the development of recommendations for programs and supports that may help others in similar situations. This research is being conducted with the aim of understanding the relationship between family members and individuals who are diagnosed with mild cognitive impairment. It is through this understanding that interventions can be implemented to help those family members who identify challenges in this caring relationship. You will also receive a copy of the results of this study. Please note that none of your identifiable information will be included in the results of this study. Results will be shared with you at the Memory Intervention Program 22 week follow-up in September 2011.

Voluntary Participation:

Your participation in this research is completely voluntary. You may refuse to participate or withdraw from the study at any time. Withdrawing from the study will not impact you or any future care you or your family member receives at Parkwood Hospital. If you withdraw from the study, please note that any data collected up to this point will still be used, however, no further data will be collected and your identifiable information will be completely erased from the master file.

Confidentiality:

It is important for you to know that your identity will remain confidential. All of your personal information will be de-identified once entered into a computer database. Your identifiable information will be stored in the following manner: locked in a cabinet in an office; files will be viewed only by members of the research team and they will be kept for five years after all information is collected. Each participant will be given a numerical code, and a list of participant names and their numerical codes will be kept in a locked cabinet and kept for five years after the data has been collected. Your name will not be used in any reports or publications arising from this study. You do not waive any legal rights by signing the consent form. It is important to note that representatives from the University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of this research. Only the primary and co-investigators will have access to the database file. Your identifiable information will not be taken off-site or accessed by another party who is not on this letter of information.

If you have questions about the study that were not adequately addressed in this letter or if you would like to speak with the Principal Investigator, Dr. Marita Klooseck, please call:

(xxx) xxx-xxxx, x. xxxxx.

If you have any questions related directly to the study, such as changing a scheduled interview date or time, you can contact Sarah Woolmore-Goodwin directly:

(xxx) xxx-xxxx, x. xxxxx.

If you have any concerns or questions about your rights as a research participant or the conduct of the study you may contact:

Dr. David Hill, Scientific Director, Lawson Health Research Institute (xxx) xxx-xxxx

This letter is for you to keep. Thank you so much for your time!

Letter of Information: Potential Participant – MIP Fall 2010



A study of individuals lived experience of loved ones recently diagnosed with Amnesic Mild Cognitive Impairment (aMCI)

Principle Investigator: Marita Kloseck, PhD¹²³

Co-Investigators: Sarah Woolmore-Goodwin, BA, MSc Candidate¹²³; Jennifer Fogarty, MAsc, PhD, C. Psych,²³⁴; Iris Gutmanis, MSc, PhD¹²³⁵

¹ School of Health Studies, The University of Western Ontario

² Aging Rehabilitation and Geriatric Care Research Centre, Parkwood Hospital

³ Geriatric Medicine, Schulich School of Medicine and Dentistry, The University of Western Ontario

⁴ Department of Psychiatry, Schulich School of Medicine and Dentistry, The University of Western Ontario

⁵ Department of Epidemiology and Biostatistics, Schulich School of Medicine and Dentistry, The University of Western Ontario

Dear Participant,

You are being invited to participate in this research study because you have been identified as a relative or friend of a person with mild cognitive impairment who is being followed at Parkwood Hospital and has participated in the Memory Intervention Program. In order to determine if you are eligible for this study, both you and your family member/friend may need to answer some additional questions about his/her memory and everyday function over the phone.

Background:

This study is aimed at investigating your experience with your loved one who has been diagnosed with a memory problem and the way this has impacted on your life and relationship. This research study will be interviewing 10 participants who will answer questions about personal experiences. The purpose of this letter is to provide you with the information you require to make an informed decision on participating in this research study. It is important that you understand why this study is being conducted and what it will involve. Please take the time to read this letter carefully and feel free to ask any questions if anything is unclear or if there are words or phrases you do not understand.

What will happen in this study?

Should you choose to participate in this study you will be required to participate in one in-depth interview with Sarah Woolmore-Goodwin, The University of Western Ontario Masters student conducting this research. The interview will be approximately 1 to 2 hours in length and will ask questions about how you experience what it means to be a family member or friend of someone who has mild cognitive impairment and how you experience this relationship. The interview will be conducted in a private room at Parkwood Hospital. This interview will be audio-recorded. If you agree to participate in this study, you are also agreeing to have your interview recorded. If you choose to participate in this study and drive to Parkwood Hospital, all parking costs will be paid for you as a courtesy.

In order to determine if you are eligible to participate in this research study, Sarah Woolmore-Goodwin would like to conduct a telephone interview with both you and your family member/friend. This telephone interview will take approximately 30-45 minutes. The reason for doing this telephone interview will be to determine whether you family member/friend continues to have mild thinking and functional difficulties. Two interview tools will be given to you and your family member/friend over the phone: the Telephone Interview for Cognitive Status (TICS) and the Clinical Dementia Rating Scale (CDR). Both of these tools have been commonly used over the phone with people aged 65 and older who live in the community and have memory problems. If Sarah and Dr. Fogarty determine that your family member/friend is still experiencing mild thinking and functional difficulties, you will be invited to participate in this research study. With your permission, Sarah will call and set up a time to do a telephone interview with you and your loved one that is most convenient. If there is a change in status from the initial study visit, a clinical visit will be scheduled in the near future.

Types of Information to be collected:

If you agree to participate in this study, several sources of information will be recorded and analyzed by the researcher including your age, your gender, and your relationship and experiences with your family member. Information will be collected only during the course of the interview. Your interview will be audio-recorded. Sarah will listen to the audio-recording and type up word for word your interview. This interview will be transcribed into a hard copy (printed off of the computer) and will become valuable data. If you agree to participate in this study, you are also agreeing to have your interview recorded.

Risks:

There are no known risks associated with your family member/friend participating in the telephone interview. The two research tools that will be administered to your family member/spouse have been approved for people who have trouble with their memory and these tools are not meant to cause frustration or upset. However, if your family member/spouse gets frustrated, Sarah will remind them that their participation in this interview is completely voluntary and that they can skip a question, not answer a question or refuse to participate at any time.

There are no known risks associated with participating in this study. It is possible that during the course of the interview you may feel distress or upset if you choose to disclose information that is disconcerting to you or of a personal nature. You also may feel frustrated with the length of the in-depth interview. Should you feel the interview to be too long or invasive, you may refuse to participate, refuse to answer any questions or withdraw from the study at any time.

Benefits:

There is no known benefit to you associated with your participation in this research study. By choosing to participate, you may be aiding in the development of recommendations for programs and supports that may help others in similar situations. This research is being conducted with the aim of understanding the relationship between family members and individuals who are diagnosed with mild cognitive impairment. It is through this understanding that interventions can be implemented to help those family members who identify challenges in this caring

relationship. You will also receive a copy of the results of this study. Please note that none of your identifiable information will be included in the results of this study.

Voluntary Participation:

Your participation in this research is completely voluntary. You may refuse to participate or withdraw from the study at any time. Withdrawing from the study will not impact you or any future care you or your family member receives at Parkwood Hospital. If you withdraw from the study, please note that any data collected up to this point will still be used, however, no further data will be collected and your identifiable information will be completely erased from the master file.

Confidentiality:

It is important for you to know that both yours and your family members/spouses identities will remain confidential. All of your personal information will be de-identified once entered into a computer database. Your identifiable information will be stored in the following manner: locked in a cabinet in an office; files will be viewed only by members of the research team and they will be kept for five years after all information is collected. Each participant will be given a numerical code, and a list of participant names and their numerical codes will be kept in a locked cabinet and kept for five years after the data has been collected. Your name will not be used in any reports or publications arising from this study. You do not waive any legal rights by signing the consent form. It is important to note that representatives from the University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of this research. Only the primary and co-investigators will have access to the database file. Your identifiable information will not be taken off-site or accessed by another party who is not on this letter of information.

If you have questions about the study that were not adequately addressed in this letter or if you would like to speak with the Principal Investigator, Dr. Marita Kloseck, please call:

(xxx) xxx-xxxx, x. xxxxx.

If you have any questions related directly to the study, such as changing a scheduled interview date or time, you can contact Sarah Woolmore-Goodwin directly:

(xxx) xxx-xxxx, x. xxxxx.

If you have any concerns or questions about your rights as a research participant or the conduct of the study you may contact:

Dr. David Hill, Scientific Director, Lawson Health Research Institute (xxx) xxx-xxxx

This letter is for you to keep. Thank you so much for your time!
Letter of Information: Previous Participant - MIP Fall 2010



A study of individuals lived experience of loved ones recently diagnosed with Amnestic
Mild Cognitive Impairment (aMCI)

Principle Investigator: Marita Klooseck, PhD¹²³

Co-Investigators: Sarah Woolmore-Goodwin, BA, MSc Candidate¹²³; Jennifer Fogarty, MAsc, PhD, C. Psych,²³⁴; Iris Gutmanis, MSc, PhD¹²³⁵

¹ School of Health Studies, The University of Western Ontario

² Aging Rehabilitation and Geriatric Care Research Centre, Parkwood Hospital

³ Geriatric Medicine, Schulich School of Medicine and Dentistry, The University of Western Ontario

⁴ Department of Psychiatry, Schulich School of Medicine and Dentistry, The University of Western Ontario

⁵ Department of Epidemiology and Biostatistics, Schulich School of Medicine and Dentistry, The University of Western Ontario

Dear Participant,

You are being invited to participate in this telephone interview because you have been identified as a participant from Dr. Fogarty's Memory Intervention Program that took place in the Fall of 2010. Your answers to the questions in this telephone interview will help determine if your family member or friend is eligible to participate in a student research project looking at what it is like having a loved one receive a diagnosis of Mild Cognitive Impairment

Background:

This study is aimed at investigating how family members of people diagnosed with a memory problem experience this diagnosis. This research study will be interviewing 10 family members of people with Mild Cognitive Impairment. These family members will answer questions about personal experiences. The purpose of this letter is to provide you with the information you require to make an informed decision on participating in this telephone interview. It is important that you understand why this interview is being conducted and what it will involve. Please take the time to read this letter carefully and feel free to ask any questions if anything is unclear or if there are words or phrases you do not understand.

What will happen in this interview?

Should you choose to participate, Sarah Woolmore-Goodwin, The University of Western Ontario Masters student conducting this research will call both you and your family member/friend and ask questions about your memory and your everyday function. These questions come from two standard memory questionnaires that have been commonly used for people with memory problems. These questionnaires are called the Telephone Interview for Cognitive Status (TICS) and the Clinical Dementia Rating Scale (CDR). These questionnaires will ask questions like, "Can you recall an outing you had with your family member/friend in the past week?" and "Can you count backwards from 100 by 7." You may have answered some of these questions previously while participating in the Memory Intervention Program.

Types of Information to be collected:

If you agree to participate in this interview, several sources of information will be recorded and analyzed by the researcher including your age, your gender, and your answers to the TICS and CDR. Information will be collected only during the course of the interview. Your answers to the two questionnaires will help Sarah and Dr. Fogarty determine if your family member/friend is eligible to participate in the research study. With your permission, Sarah will call and set up a time to do a telephone interview with you and your family member/friend that is most convenient. One outcome of this phone call might be a clinical visit with a clinician at Specialized Geriatric Services.

Risks:

There are no known risks associated with your participation in this telephone interview. The two research tools that will be administered to you have been commonly used for people who have trouble with their memory. However, if you do find the interview to be upsetting or uncomfortable, please be assured that your participation is entirely voluntary and you can refuse to answer any question that you do not wish to answer. Some people also may get frustrated with the length of the telephone interview. Please remember that you may take a break at any time and if you wish to stop for any reason this will in no way effect your care at Parkwood Hospital.

Benefits:

There is no known benefit to you associated with your participation in this telephone interview. This research is being conducted with the aim of understanding the relationship between family members and individuals who are diagnosed with mild cognitive impairment. It is through this understanding that interventions can be implemented to help those family members who identify challenges in this caring relationship. Your family member will receive a copy of the research study results but not any information about your scores on either telephone questionnaire. Please note that none of your identifiable information will be included in the results of this study.

Voluntary Participation:

Your participation in this telephone interview is completely voluntary. You may refuse to participate or withdraw at any time. Withdrawing from the interview will not impact you or any future care you or your family member receives at Parkwood Hospital. If you withdraw from the interview, please note that any data collected up to this point will still be used, however, no further data will be collected and your identifiable information will be completely erased from the master file.

Confidentiality:

It is important for you to know that both yours and your family members/friends identities will remain confidential. All of your personal information will be de-identified once entered into a computer database. Your identifiable information will be stored in the following manner: locked in a cabinet in an office; files will be viewed only by members of the research team and they will be kept for five years after all information is collected. Each participant will be given a numerical code, and a list of participant names and their numerical codes will be kept in a locked cabinet and kept for five years after the data has been collected. Your name will not be used in any reports or publications arising from this study. You do not waive any legal rights by signing the consent form. It is important to note that representatives from the University of Western

Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of this research. Only the primary and co-investigators will have access to the database file. Your identifiable information will not be taken off-site or accessed by another party who is not on this letter of information.

If you have questions about the study that were not adequately addressed in this letter or if you would like to speak with the Principal Investigator, Dr. Marita Kloseck, please call:
xxx-xxx-xxxx, x. xxxxx.

If you have any questions related directly to the study, such as changing a scheduled interview date or time, you can contact Sarah Woolmore-Goodwin directly:
xxx-xxx-xxxx, x. xxxxx.

If you have any concerns or questions about your rights as a research participant or the conduct of the study you may contact:

Dr. David Hill, Scientific Director, Lawson Health Research Institute (xxx) xxx-xxxx

This letter is for you to keep. Thank you so much for your time!

CONSENT FORM

A study of individuals lived experience of loved ones recently diagnosed with Amnestic Mild Cognitive Impairment (aMCI)

Principle Investigator: Marita Klooseck, PhD¹²³⁴

Co-Investigators: Sarah Woolmore-Goodwin, BA, MSc Candidate¹²³; Jennifer Fogarty, MAsc, PhD, C. Psych,²³⁴⁵; Iris Gutmanis, MSc, PhD¹²³⁴⁶

¹ School of Health Studies, The University of Western Ontario

² Aging Rehabilitation and Geriatric Care Research Centre, Parkwood Hospital

³ Geriatric Medicine, Parkwood Hospital

⁴ Geriatric Medicine, Schulich School of Medicine and Dentistry, The University of Western Ontario

⁵ Department of Psychiatry, Schulich School of Medicine and Dentistry, The University of Western Ontario

⁶ Department of Epidemiology and Biostatistics, Schulich School of Medicine and Dentistry, The University of Western Ontario

I have read the letter of information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Participant Name: _____

Participant Signature: _____

Date: _____

Name of person obtaining consent: _____

Signature of person obtaining consent: _____

Date: _____

APPENDIX B

Telephone Script: Potential Study Participant - MIP Fall 2010

Hello Mr./Mrs. _____

My name is Sarah Woolmore-Goodwin. I am a Masters student from The University of Western Ontario, Health Sciences, Health and Aging program. You may remember me from your family members/spouses participation in Dr. Fogarty's Memory Intervention Program last Fall. I am calling you today because I am conducting a study looking at how people who have relatives or friends with Mild Cognitive Impairment experienced the diagnosis of Mild Cognitive Impairment and how this has impacted their life and relationships. This research study will be recruiting about 10 participants who will answer questions about personal experiences. The study will take place at Parkwood Hospital and would take about 1-2 hours of your time. You will not be required to perform paper or pencil tests, this is a one-on-one in-depth interview exploring your personal experiences with your family member's diagnosis of Mild Cognitive Impairment. If it has been more than nine months since your friend or family member took part in the memory intervention program, he/she may need to answer some additional questions about his/her memory before you take part in the study. One outcome of this interview with your family member might be a follow up clinical visit at Parkwood with the person who referred your family member to the Memory Intervention Program.

Are you interested in hearing more about this study?

If NO: Thank you for your time. Your decision not to participate in this study will have no impact on any current or future care you or your family member or friend might receive at Parkwood Hospital.

If YES: Let me tell you a little more about the study so you can decide if you are interested in participating.

Participants should have a functional use of the English language and have a family member/friend who was a participant in Dr. Fogarty's Memory Intervention Program. In order to determine if you are eligible to participate in this research study, I also may request to speak with your family member/friend to assess whether his/her thinking and functional difficulties still meet study inclusion criteria.

If you are interested in participating, both you and your family member/friend may be asked to complete a telephone screening interview that may take up to 45 minutes of your time. This interview will include questions about his/her memory and everyday functioning. The answers to this phone screen will help us determine whether or not you meet the eligibility requirements.

Prior to completing the telephone interview, however, we would ask you to read over an information sheet about the study and have you sign a consent form. With your permission, this information sheet can be mailed to you along with a stamped addressed envelope to mail the consent form back to us. After the signed consent form is received back at Parkwood Hospital, we can set a mutually agreeable time to proceed with the telephone screen.

Are you interested in participating? If YES, take full name and mailing address.

Can I speak with your family member about whether they would be willing to be asked some additional questions about their memory and daily functioning prior to your taking part in the study?

Telephone Script: Previous Study Participant - MIP Fall 2010

Hello Mr./Mrs. _____

My name is Sarah Woolmore-Goodwin. I am a Masters student from The University of Western Ontario, Health Sciences, Health and Aging program. You may remember me from your participation in Dr. Fogarty's Memory Intervention Program last Fall. I am calling you today because I am conducting a study looking at how family members and friends of people with Mild Cognitive Impairment experienced their loved one's diagnosis. In order for me to determine if your family member or friend is still eligible to participate in this study, I would like to ask you some questions about your memory and your independent activities of daily living. One outcome of this telephone interview might be a follow up clinical visit at Parkwood with the person who referred you to the Memory Intervention Program.

Are you interested in hearing more about this study?

If NO: Thank you for your time. Your decision not to participate in this study will have no impact on any current or future care you might receive at Parkwood Hospital.

If YES: Let me tell you a little more about the study so you can decide if you are interested in participating.

If you are interested in participating, both you and your family member/friend may be asked to complete a telephone screening interview that may take up to 45 minutes of your time. This interview will include questions about you memory and everyday functioning. The answers to this phone screen will help us determine whether or not your family member/friend meets eligibility requirements.

Prior to completing the telephone interview, however, we would ask you to read over an information sheet about the study and have you sign a consent form. With your permission, this information sheet can be mailed to you along with a stamped addressed envelope to mail the consent form back to us. After the signed consent form is received back at Parkwood Hospital, we can set a mutually agreeable time to proceed with the telephone screen.

Are you interested in participating? If YES, take full name and mailing address.

| | | | | | |
|-------|------|--------|-----------|---------|------|
| NAME | LAST | FIRST | MIDDLE | ADDRESS | CITY |
| | | | | | |
| PHONE | AREA | NUMBER | EXTENSION | | |
| | | | | | |

Thank you for your time. If you have any questions, please call the research office at Parkwood Hospital. We are located at 333 Windermere Road, London, Ontario, Canada N6A 5S8. Phone: 519-833-1100. Fax: 519-833-1101. Email: research@parkwoodhospital.com

APPENDIX C: THE CLINICAL DEMENTIA RATING SCALE

| | NONE 0 | QUESTIONABLE 0.5 | MILD 1 | MODERATE 2 | SEVERE |
|-------------------------------------|---|---|---|--|--|
| Memory | No memory loss or slight inconsistent forgetfulness | Consistent slight forgetfulness; partial recollection of events; "benign" forgetfulness | Moderate memory loss: more marked for recent events; defect interferes with everyday activity | Severe memory loss, only highly learned material retained: new material rapidly lost | Severe memory loss only fragments remain |
| Orientation | Fully oriented | Fully oriented but with slight difficulty with time relationships | Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere | Severe difficulty with time relationships; usually disoriented to time, often to place | Oriented to person only |
| Judgment and Problem Solving | Solves everyday problems and handles business and financial affairs well; judgment good in relation to past performance | Slight impairment in solving problems, similarities and differences | Moderate difficulty in handling problems, similarities and differences; social judgment usually maintained | Severely impaired in handling problems, similarities and differences; social judgment usually impaired | Unable to make judgments or solve problems |
| Community Affairs | Independent function as usual in job, shopping, volunteer and social groups | Slight impairment in these activities | Unable to function independently at these activities though may still be engaged in some; appears normal to casual inspection | No pretense of independent function home; appears well enough to be taken to functions outside the family home | Appears too ill to be taken to functions outside the family home |
| Home and Hobbies | Life at home, hobbies and intellectual interests well maintained | Life at home, hobbies and intellectual interests slightly impaired | Mild but definite impairment of functions at home; more difficult chores, and complicated hobbies and interests abandoned | Only simple chores preserved; very restricted interests, poorly maintained | No significant function in the home |
| Personal Care | Fully capable of self-care | | Needs prompting | Requires assistance in dressing hygiene and keeping of personal effects | Requires much help with personal care; frequent incontinence |

Score only as decline from previous usual level due to cognitive loss, not impairment due to other factors.

Morris, J.C. (1993) The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology*, 43, 2412-4.

APPENDIX D

DEMOGRAPHIC QUESTIONNAIRE

General Information:

1. In what year were you born? _____
2. Gender: Check one Male Female
3. What is your occupation, or if you are retired, what occupation did you retire from?

4. How many years of formal education have you had?
 Public School High School College University (+Grad)
5. What is your relationship to your family member
 Spouse Relative (Specify) _____
 Common Law Partner Daughter/Son (in-law)
 Other (Specify) _____
6. What are your current living arrangements?

7. What city do you live in? _____
8. If London, what part of London do you live in? _____
a. How long have you lived in London? _____
b. How familiar are you with London Hospitals _____
9. Have any of your closely related family members ever had a serious health condition before?

10. Have you ever provided care to a family member before? (If yes, can you please tell me a little more about this?)

11. On a scale from 1 to 10 where 1 means terrible health and 10 means exceptional health, how would you rate your health? _____
12. How much do you feel you know about Mild Cognitive Impairment? On a scale where 1 means "I know nothing at all" and 5 means "I know everything there is to know about the diagnosis," how would you rate your understanding?

APPENDIX E

Narrative Guide

A study of individuals lived experience of loved ones recently diagnosed with Amnestic Mild Cognitive Impairment (aMCI)

- Greet Participant
- Thank participant for coming and explain that we will be discussing their personal experiences as family member of a person recently diagnosed with aMCI
- Remind participant that the interview will be tape recorded and that the tape recorder can be turned off at any time if they would like to share something they do not want recorded
- Remind participant that they can refuse to participate at any time without consequences

TURN ON THE TAPE RECORDER

EXPERIENCE OF aMCI DIAGNOSIS

How long ago was your family member diagnosed with mild cognitive impairment?.

1. What did you experience when you first learned of this diagnosis?
2. Please tell me what it is like to care for a loved one recently diagnosed with mild cognitive impairment

Prompts:

What was that like for you?

Please tell me more about how that made you feel...

How has that been positive/negative...

If you can, please expand on that feeling/thought/experience...

Please tell me about what you think would be beneficial for other people who are in a similar situation to you, that is, providing support to a family member with MCI.

Thank participant for coming and set up time for follow-up interview

TURN OFF TAPE RECORDER

APPENDIX F

Guide for recording field notes**

Code (participant/household):

Date/Time:

3. Description of the environment
4. People Present (how they behave, interact, dress, move, where their attention is focused)
5. Description of activities
6. Description of dialogue/informal conversation
7. Description of nonverbal behavior (eg. Tone of voice, posture, hand gestures)
8. Content of interview (e.g. overview, focus, topics that stand out)
9. Personal reflections (e.g. going into the field, own life experiences that may influence observations)
10. Insights, interpretations, beginning analysis, working hypotheses
11. Notes/suggestions for future follow-up

** Adapted from

Morse, J. & Field, P. (1995). *Qualitative research methods for health* (2nd ed.) (p.115). London: Sage

Mulhall, A. (2003). In the field: Notes on observation in qualitative research, *Journal of Advanced Nursing*, 41(3), 311.

APPENDIX G



Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Marita Kloseck

Review Number: 17934E

Review Level: Delegated

Approved Local Adult Participants: 10

Approved Local Minor Participants: 0

Protocol Title: A study of Individuals lived experience of loved ones recently diagnosed with Amnesic Mild Cognitive Impairment

Department & Institution: Medicine-Dept of, University of Western Ontario

Sponsor:

Ethics Approval Date: April 12, 2011

Expiry Date: September 30, 2011

Documents Reviewed & Approved & Documents Received for Information:

| Document Name | Comments | Version Date |
|---------------------------------|----------|--------------|
| UWO Protocol | | |
| Letter of Information & Consent | | 2011/03/28 |

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research

Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The UWO HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer to Contact for Further Information

| | | |
|--|--|-------------------------------------|
| Janice Sutberland (jsutberl@uwo.ca) | Elizabeth Wambolt (ewambolt@uwo.ca) | Grace Kelly (grace.kelly@uwo.ca) |
|--|--|-------------------------------------|

This is an official document. Please retain the original in your files.

The University of Western Ontario
Office of Research Ethics

Room 5150, Support Services Building • London, Ontario • CANADA - N6A 3K7
PH: 519-661-3036 • F: 519-850-2466 • ethics@uwo.ca • www.uwo.ca/research/ethics



Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Marita Kloseck
 Review Number: 17934E
 Review Level: Delegated
 Approved Local Adult Participants: 10
 Protocol Title: A study of Individuals lived experience of loved ones recently diagnosed with Amnesic Mild Cognitive Impairment
 Department & Institution: Medicine-Dept of, University of Western Ontario
 Ethics Approval Date: July 12, 2011 Expiry Date: October 31, 2011
 Documents Reviewed & Approved & Documents Received for Information:

| Document Name | Comments |
|---|--|
| Revised Letter of Information & Consent | Spring 2011 |
| Revised Letter of Information & Consent | Fall 2010 |
| Revised Letter of Information & Consent | MIP Fall 2010 |
| Other | Telephone Script |
| Other | Telephone Script - Fall 2010 MIP Participant |
| Other | Telephone Interview for Cognitive Status |
| Other | Clinical Dementia Rating Worksheet |
| Revised UWO Protocol | Recruitment has now changed to include family members of participants who have completed screening purposes. |
| Addition of Co-investigator | Dr. Aleksandra Zecevic has joined the research team. |
| Revised Study End Date | The study end date has been revised to October 31, 2011 due to the recruitment of additional |

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB. The Chair of the HSREB is Dr. Joseph Gilbert. The UWO HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer to Contact for Further Information

| | | |
|--|-------------------------------------|--------------------------------------|
| Janice Sutherland (jsutherl@uwo.ca) | Grace Kelly (grace.kelly@uwo.ca) | Shantel Walcott (swalcolt@uwo.ca) |
|--|-------------------------------------|--------------------------------------|

This is an official document. Please retain the original in your files.

The University of Western Ontario
 Office of Research Ethics

Support Services Building Room 5150 • London, Ontario • CANADA - N6A 3K7
 PH: 519-661-3036 • F: 519-850-2466 • ethics@uwo.ca • www.uwo.ca/research/ethics



*Aging, Rehabilitation &
Geriatric Care*



**Parkwood Hospital Clinical
Research Impact Committee**

MEMO

Aging, Rehabilitation & Geriatric Care

DATE: May 17, 2011

Lawson Health Research Institute

TO: Members of the CRIC:

Parkwood Hospital

D. Wolfe

801 Commissioners Rd. E.

I. Gutmanis

London, ON N6C 5J1

C. Forchuk

519-685-4292 extension 42983

D. Keast

Facsimile: 519-685-4060

R. Petrella – Ex-Officio

FROM: Bonita Stevenson

bonita.stevenson@sjhc.london.on.ca

SUBJECT: Research Protocol – Mail In Vote

Re: A study of individuals lived experience of loved ones recently diagnosed with amnesic mild cognitive impairment – REB 17934

I have received the attached CRIC submission from Marita Kloseck. Please advise me whether or not you approve the abovementioned. Thank you for your assistance.

Please provide your response by Tuesday, June 7, 2011. Thank you.

I approve the protocol Y Yes No Abstain

Signature

COMMENTS TO CHAIR:

COMMENTS TO INVESTIGATOR:

Study approved.

In addition, FYI only

- The investigator is reminded that data security, privacy, transfer, storage and destruction must be according to SJHC policies. Information on all relevant SJHC policies is provided below:
 - Access to Personal Health Information for Research, Education and Quality Assurance:
https://intra.sjhc.london.on.ca/policy/search_res.php?polid=MMI002&live=1
 - Security of Confidential Information policy:
https://intra.sjhc.london.on.ca/policy/search_res.php?polid=GEN003&live=1
 - Confidential policy:
https://intra.sjhc.london.on.ca/policy/search_res.php?polid=MMI004&live=1
 - Privacy policy:
https://intra.sjhc.london.on.ca/policy/search_res.php?polid=GEN002&live=1
 - Privacy website at SJHC:
<https://intra.sjhc.london.on.ca/refer/privacy/index.htm>

APPENDIX H

Thematic Analysis Decision and Audit Trail

Emergent Themes

Once I completed the line-by-line analysis and reflexive journaling associated with the three separate levels of analysis just described, I created a diagram that demonstrated the emergence of six initial themes and the decision trail that led me to this phase of analysis. The following are the initial emergent themes from the line-by-line analysis:

1. Multiple losses and anticipatory grief
2. Struggling with an ambiguous diagnosis
3. Wearing a mask (escaping from current lifeworld)
4. Importance of shared experience
5. Sense of mastery/low sense of control
6. Searching for validation

Once I had created these themes, I went back and re-read through each participant's original transcript (without my added comments) keeping the initial evolving themes in mind. From this final reading I was able to determine that there was a great amount of overlap among the initial themes and more importantly I realized that there was a gap existing in the emergent themes. Multiple losses and anticipatory grief was a theme that remained constant across each participant, as was the need to wear a mask.

What emerged out of the final reading of the transcripts was that the interpretation I had originally given to the theme 'wearing a mask' was changing its meaning for me. I realized that the experience of wearing a mask had more to do with protection of the person they were caring for rather than what I initially interpreted as self-preservation. Participants experienced needing to know what mask to wear given particular situations with their spouse/mother, family, friends or formal care settings.

1st Decision on Themes

The theme of multiple losses was pervasive and seemed to be experienced deeply by all respondents. Participants experienced loss as being multilayered, operating in the person or as van Manen (1997) would describe it, corporally (ex. loss of identity, loss of control/ sense of mastery). Loss also took place at a social-personal level (ex. loss of meaningful friendships, loss of sense of community, loss of ascribed role within the family) and also in temporal contexts (ie. loss of hope for the future/unmet expectations; loss of the way things were). The experience of multiple losses on different levels created for the participants a shared experience of anticipatory grief. In looking at the theme of grief, I decided that the ambiguousness of the diagnosis was an antecedent to anticipatory grief, a consequence of the multiple losses carer's experienced.

What was also interesting to note was the theme I had originally labeled 'sense of mastery/low sense of control,' fit with the theme of multiple losses and anticipatory grief. Respondents experienced feeling like they were losing control and felt great responsibility to fulfill the roles that the person with aMCI could no longer be in control of. This experience I labeled as loss of control (high demand/low control).

2nd Decision on Themes

The next decision that I made after reading through the transcripts for the final time was to collapse the themes 'searching for validation' and 'importance of shared experience' into one global theme. Respondents experienced a feeling of validation when others could relate or be empathetic to their situation. Participants experienced validation when meanings were accepted and shared with peers who had lived similar life-world experiences. In keeping these themes separate, I was not able to gain a meaningful understanding of the need for validation across all participants until these two constructs were held in tandem. While analyzing the transcripts with

the theme of validation in mind, sub-themes such as stigma and the importance of formal diagnosis emerged as a part of this thematic concept.

3rd Decision on Themes

After collapsing the six initial themes into three main emergent themes, I felt that there was still an aspect of the experience caring for a loved one with aMCI that I had not captured. The three themes were descriptive of the experience, yet they were not capturing the essence. It was at this point in the analysis that I turned back to my reflexive journals and discovered an emergent theme that I had not included in my initial six themes, 'the quality of the relationship.' This theme accounted for a number of the differences and similarities in the experience my participants shared. One participant in particular had had a very tumultuous relationship with her mother and this had implications on her current and possible future level of willingness to care for her mother. Another person, a spouse, who shared a very equitable, loving and meaningful marriage with her husband for over 50 years, felt that she could not be resentful of the diagnosis, as she so eloquently stated, "to care for someone is risking that you will someday lose them." While this theme accounted for subtle differences, it did not however seem to capture the essence of the experience.

Final Decision on Themes: The Essence of 'Masks'

The final theme that emerged out of the search for the essence of the experience was 'acceptance of mild cognitive impairment diagnosis.' Participant's whose loved one had accepted their aMCI diagnosis seemed to share a very deep connection with one another, a notion that can only be described as the essence of caring for a loved one who has accepted their aMCI diagnosis. Participant's whose loved one did not accept the diagnosis (denied diagnosis) experienced caring in a more ambiguous and unpredictable light. It is after this final theme

emerged that I felt comfortable to stop the analysis and present my findings to the research committee. I felt that I had interpreted each theme to be experiential to the meanings carers attach to their new role.

All research committee members had read between 1 and 3 transcripts that were in their original format. In order to have an informed and open discussion about the emergent themes, committee members were encouraged to come up with their own interpretation of the transcripts. Again, the goal of the meeting was to determine if the themes resonated with the committee (reliability).

During the committee meeting, advisory members felt that the themes resonated deeply with their prior understanding. They felt that the theme of 'wearing a mask' was the most robust and determined it a novel contribution to their existing knowledge of the phenomenon of 'caring for a loved one with aMCI.' After having a discussion around the themes with the committee members, I realized how powerful and pervasive the need to wear a mask was for all of my participants. Carers experienced difficulty reconciling the grief and disappointment they faced as a result of suffering multiple losses, with their want to protect and continue caring for their loved one.

APPENDIX I

Example of Thematic Analysis

Wholistic Thematic Analysis: The point of a wholistic thematic analysis is to develop a global statement about each participant's text (transcript that sums up what the experience means to them and how I have interpreted this experience)

Selective Thematic Analysis: selective thematic analysis is used to further flush out the theme that arose in the wholistic approach. Here I must find statements and sub-themes that are representative of the experience the participant is discussing and then interpret what this means as a construction of my understanding of the participants experience with the phenomenon

Line-by-line Thematic Analysis: By employing a line by line or sentence cluster specific analysis to the participants text, I am better able to pick up on themes that were not apparent in the first two waves of analysis. As I go through each sentence cluster, I am interpreting, discussing and memoing what each sentence says about the participant's experience. Here I can see if the wholistic theme that emerged is significant to the participant and if the meaning I have interpreted is consistent across the three forms of analysis.

Pt1 – Wholistic Analysis

A spouse who is caring for her loved one recently diagnosed with aMCI needs to wear a mask in order to cover-up her guilt, resentment and anger that her husband has a problem and reconcile this with her knowledge that this is not his fault. She finds herself feeling accepted and validated in her experiences with her husband through the collective stories of other people who share a similar life world perspective. The experience is a form of anticipatory grieving, filled with uncertainty and ambiguousness.

Pt1 - Selective Analysis:

P: he will now accept someone telling him what to do now for certain things. He is more apt to sit down and talk, uh, I find that it takes a lot of time. He will come, he will have a feeling where there will be something off and he will want to sit down and talk and we will need to talk through this and I find it takes a lot of time. But that's ok (she says slightly sarcastically) we are getting along pretty good. Um there are times when he can't quite see why I am doing something and it gets to the stage where, I have to leave... but so far he has been able to see what I was trying to do and acknowledge it afterwards, so we have been getting along pretty good. Um, I have to remember, I find it difficult (her tone changes) to have a smile on my face sometimes when I'd rather go Grrrr (she raises her hands and shakes them vigorously and then laughs) but then again, I know it's not easy for him and we have to learn to deal with this.

P: yeah, it's uh, a losing of part of your partner, and um, (lets out sigh), yeah, like I know that we're blessed, and I know it could be worse, but it's still losing part of a partner, part of what you were expecting and you need to deal with it differently (She clears her throat and tries to muster up a smile).

Just the fact that you can talk; you can say what's been bugging you

S: because you can't say it to him

P: Yes, you can't say it to him, and you have to say it to someone. I must admit, I had been very gently been starting to tell my daughters, to express some of the stress i feel, I don't want to over burden them, but I do want to let them know how I feel and that um, (with a sigh) I guess I want to prepare them to a certain extent. Now they accept this is not a problem, but not living with him, they don't understand and I am trying to, I don't want to put too much onto them and I'm trying to, bit by bit show them what's going on and uh, probably after so I can say the good results afterwards but yeah, and I think it's very important that they know

Pt1 – Line-by-Line Analysis

P: Um, I suppose that I had realized that there was something going on but then again as we get older we do lose the ability for some things, I had been finishing sentences for him for a while. He used to be a very good speaker, he would be a chairperson and that sort of thing, but he discovered that words were not coming as easily, he also, we had a farm and he also worked in heavy construction, before then they didn't use ear plugs, so therefore he has some loss of hearing and it had gotten to the stage where I was saying very often, " won't you ever listen to me" (she says with her voice elevated and a bit of a laugh) and I guess I was seeing things without seeing them if you know what I mean and he said, you know, there's something wrong, things are not going right here and we sat down and talked about it and ah we realized that, yes, there was a problem and his mother had had Alzheimer's, so we began to fear that this is what it was and um, the doctor sort of, well he didn't really, well you know he only sees him for a short time, and he said, "I think you are fine." But we felt we needed to go ahead and we did, we went first to the Alzheimer's society, they happened to be giving a course that was one day a week for 6 weeks out of the hospital and we took it. He didn't want to go but we thought it might make him better. We learned so much there. We

- Experience, knowing there was a problem before he realized it, hx of Ad in family, anticipating the worst
- Family doctor not helpful, have to find help on your own, go searching for it –validation
- Getting help helped understand that she wasn't alone, and other people are facing similar challenges – Validation

learned, um, a more accepting attitude; we learned about the people, we become invested in them because some of the people there were so personable. It was great and um, that was good so we continued on through Alzheimer's (Society) and he was tested a couple of times and they kept saying you know he's not bad, but then we got the opportunity for the last test from our, we live in Grey Bruce and they couldn't come, they were very busy, backed up with a back log so we got somebody from Huron Township to come and she did the comprehensive test with him and I think she felt perhaps there was a little something. She said at the end, you know, he's not bad (she laughs a bit). There's a Dr. Hurtsitz?

S: Hurwitz

P He comes to Zurich, and uh, we had an appointment. I think it was two or three days before we left for Australia for 6 weeks.

S: oh wow

P: and he said at the time, it was quite comprehensive, that "I think this is what it is (meaning MCI)." Neither one of us knew what it meant but we went on and we spent our six weeks in Australia and because of him, he contacted Dr. Fogarty and we came down and he was tested again (she says with a bit of exhaustion) and then there was the opportunity to take the course (Memory intervention program) and that's what we did. So that's the way we went through to find out, and um, (she stops and takes a heavy sigh) he was always a person who did not like anyone to tell him what to do, he wanted to be, um, I'm not sure, he didn't want someone to tell him what to do and if you wanted something done you had to work around that. He was not someone who enjoyed talking, I mean he would not discuss a problem unless I really, ahh (breaths out heavily) insisted that we needed to discuss this was ... that was a problem. So we sat down together and went

- Not getting the answers you want, getting a diagnosis – Validation from formal setting
- Experience being isolated in rural Ontario, little access to services – Loss, anticipatory grief

- Do not have any exposure to the term or understand what MCI is, ambiguous diagnosis - Stigma
- Hx of challenges communicating, learning how to open the lines of communication

through what could be if this was Alzheimer's and we went through what this is (meaning MCI?) and we needed to find out a little bit more about it and so on and so forth so we went on to the computer and I found that (pause) he is less, he will now accept someone telling him what to do now for certain things. He is more apt to sit down and talk, uh, I find that it takes a lot of time. He will come, he will have a feeling where there will be something off and he will want to sit down and talk and we will need to talk through this and I find it takes a lot of time. But that's ok (she says slightly sarcastically) we are getting along pretty good. Um there are times when he can't quite see why I am doing something and it gets to the stage where, I have to leave... but so far he has been able to see what I was trying to do and acknowledge it afterwards, so we have been getting along pretty good. Um, I have to remember, I find it difficult (her tone changes) to have a smile on my face sometimes when I'd rather go Grrrr (she raises her hands and shakes them vigorously and then laughs) but then again, I know it's not easy for him and we have to learn to deal with this and um, i think he's far enough, or hasn't gone far enough yet that he can still drive, uh, there has been a couple of times where he has had to stop, take a deep breath and look at it and figure it out um..

S: is he getting lost?

P: For a while we had known that if he is getting tired, he had triple bypass surgery a number of years ago and at that time he was allergic to something, we thought he had a small stroke, because he lost the facilities of, he was very good with his brain, he could do math in his head and he finds it much more difficult now and we were thinking that was it, um so when he gets tired he finds that he is not able to cope as well but he, if he gets tired and he is driving, he'll say, " I can't do

- Learning on your own, doing your own research to better understand the diagnosis, meaning that the information you are getting from the professionals is not sufficient for understanding – Validation from within
- He is more open to communicate, or, he is learning that he needs to communicate in order to cope from day to day, she is sole support so he is becoming dependent on her – Loss of partner, loss of old roles
- Resents the amount of time it takes to talk with him but also appreciates that he is referring to her more – Wearing mask – resents time it takes, have to be supportive regardless of feelings – wearing mask
- Shows it takes a lot of time, this is a change, needs to make an adjustment – loss of old roles, anticipation it will get worse

it anymore, I'm too tired, you'll have to drive" cause he's learned to do that. There's been a few times when he's had, he's looked at a certain situation and is not sure how to deal with it but he's competent enough that he can say "I don't know, you had better drive." He knows how to find his way around in places that he knows, he has no problem driving down to London and around. He used to be a volunteer driver. I can drive too but he, and I let him drive as much as I can because we both know he's not going to be able to continue so we've decided that as long as he can drive, he'll drive and I'll drive when he asks me. So we are dealing with that. Um..

S: This is great. I'm just going to turn the conversation at this point. You are giving me a lot of background history on him and his diagnosis which is fantastic, I need that, I need that back story,

P: but now you want to know how I am dealing with it

S: yes

P: well,

S: I want to know what this diagnosis means to you? And on the other side of what it means to you, how are you experiencing it. Is your experience aligned with your expectations of what you thought this would be like, do you feel like your expectations and experience is at a disconnect? Tell me about this experience.

P: I find it, (pauses to think) hard to (pause), I guess as things come up, I don't know how to deal with them. I have to learn so I'm striving always to figure out the best way to do things, to talk to him, to, I don't know what else, I just, I'm always looking for the right way. I find (she chuckles quietly) I find sometimes when I'm, I try to be as positive as I can, we look for small victories, I find that there are times I know I need to smile and say, "that's good" when I would just like to go

- Social response vs actual sincere feeling, having difficulty modeling two opposing constructs - cultural, gender, age contextual representation- wearing mask

- Experience needing to get away, needing respite – need to get away; support/validation from others who have shared experience

- She says they are getting along 'pretty good' but she just spoke about how frustrated she is, contradiction - social justification vs her actual experience – Wearing mask

goushhh (makes similar clenched fist shake again, and laughs)

S: what's that experience like?

P: I would like to almost shake him because, come on, because much of it is I know there are times that I have trouble, ahm, excuse me

S: would you like me to get you a drink of water

P: When I um, as I said I know that my expectations have to be less, but this is a husband I have lived with for almost 47 uh, 53 years and there are times when, although I know I don't quite expect it, there are times I resent extra time and it does, it takes a lot more time. I have to adjust what I am doing to make sure that I'm there and I think one of the things too, and I've talked to some of the other ladies, we seem to always be watching, not that they need us to be there all the time but we are always watching, just so if there is going to be something that comes up, that we are ready to save them.

S: Hmm, can you talk to me more about the experience of feeling like you need to save him, being a saviour?

P: Clears throat. Maybe..

S: sorry, am I putting words in your mouth..

P: No, not at all, I just don't feel like a saviour, it's not really quite as black and white as that, it's um, we don't want them to get into a situation that they can't get out of themselves. So we need to be watching. Like he's quite competent to drive, yet I find I am watching more carefully, all the time, because I know there will be signs and I need to see them. He's very competent with his tools. He's been working on his truck and it's been wonderful and he's been doing things he hasn't done for a while and it's been great, there's no problem with that. It's with the other things. I have no problem with him walking but I still need to watch. I make him make his own appointments. He doesn't like to tell anyone but I make him do it.

- Feels like she has to wear a mask
- Shows that she understands that this diagnosis is not his fault but can't help being resentful of the change or loss of her spouse
- Shows anticipation of a loss in his ability to drive, possible realization of isolation his loss of the ability to drive will create
- Shows she is trying to let him figure things out on his own when she would like to do it for him – loss of control
- Shows a significant change in his cognitive function, a loss of ability, loss of spouse
- Shows changing roles, no longer occupying traditional gender roles, social significance - loss
- Shows the change has been gradual and is not all-encompassing, however, there is an

So I am always listening to make sure that he's said the right thing (she chuckles, slightly embarrassed). When he was telling our one son about the Mild Cognitive Impairment but he didn't, he has also had an infection in an artery on the side of his head, he had a biopsy and so on and so forth, the son had been away and he came home and he (participants husband) was talking about it, and I find myself listening to make sure that he's saying the right information. Most of the time I don't need to but I am still watching, umm...

S: so are you anticipating that he's going to make a mistake and then if he does make a mistake...

P: it's ok

S: are you going to try and fix it? Is the experience that you want to fix or correct the mistake or that you want to start calculating how many mistakes he is making so you can gage how he is progressing

P: I suppose, I suppose when he's driving, what I want to do is, I want to anticipate if there is going to be a problem

S: because he no longer has that foresight

R: right. We were up to Owen Sound one day and he, uh, I don't know why, ran up on the curb and later we came up to this divide in the road and I could see in a minute he wasn't sure what to do or which way to go so I said pull over here, take your deep breathing, and that was all it was, just the fact that it was something new, he had never done anything like that before., and to do that stressed him out enough that he wasn't sure he could do the next step. But if I can see or anticipate these, then we can keep going over this deep breathing and you know when you come into situations you are not sure of, and I guess this is what I keep trying to do is to (pauses) have him go over thing enough that it becomes second nature rather than me having to have to tell him and as I said, there are times when I resent the time and uh, (She is starting to get a bit teary eyed and her

ambiguousness to the future – loss of hope for the future

- Shows and anticipation for his loss of ability, the carer will have to take on responsibilities husband gives up
- Dealing with, shows an unwelcome, uncomfortable change they are 'dealing with' but also shows that it is something she is willing to live with – wearing the mask

- Shows she hasn't been to reflective about how the experience is effecting her – wearing a mask
- Shows the challenge in communicating with a person who has been one way for 53 years of marriage and then changes rather rapidly over a short period of time – resistant to change, want things to remain the same – loss of partner
- Shows that if she can find the right way, maybe she can bring things back to the way they used to be, or maintain them at some level of normalcy – wants to fix him/ accepting he has a problem
- Shows the need to find a reason, to be validated for the time and energy she is putting into her new role
- Shows the way she is feeling and her actions

voice a bit strained) frustration, but, as well I know it's not his fault, so it's just , it's the way I feel.

S: and you are entitled to these feelings

P: and there are days that I have had the frustration of, I think one of the things is, I need to, I have to remember to put things into smaller brackets when it comes to jobs, I understand that, I've got that down. But when I'm talking about someone or telling him some information, I have to learn, and I haven't learned yet, to reduce it to shorter sentences, and get the same point across but to do it in smaller pieces because I find that he's not comprehending ah, lengthy ...if it's something quite familiar, but if it isn't then I have to remember that, and yeah, i do sometimes and yeah there are other times I think I do go, "I've got to go, I've got to get away, but then we have good days and its okay again.

S: Would you say that you are now experiencing your relationship differently?

P: yes

S: can you tell me how this experience has changed the way you see yourself and then also tell me the way this experience has changed the way you see your relationship together?

P: well, um, when we were bringing up our kids, I was the person who did the caring for them and I also did, um, when there was any problems, I did, I looked after that. I, I find now that he refers to me more, and he was a very competent person as I said, he didn't want anyone to tell him things, and I find he's referring to me and expecting me to come up with answers now, so I'm becoming more, how will I put this... I'm taking on more of the obligations perhaps that he used to look after, um, he still does his own banking, as long as it's just straightforward. If it isn't, I have to go with him. And um, we have gone to the insurance agent and told him what was going on and I am learning how to do a lot of things that I didn't do, um... and

are not aligned, wearing a mask to preserve his feelings

- Shows real frustration and difficulty understanding her reality with him, her expectations for their future and relationship together are not being met – loss of hope and expectations for the future
- Shows resentment of new role, resentment of absorbing all of her time, shows her expectations are no longer being met, hard time reconciling her hopes for the future with her current reality, anticipatory grieving
- Shows a need to change herself in order to care for him, not an easy thing to change yourself

a lot of our bills now are paid out of the account so that it frees him up and it doesn't put more on me

S: That's good

P: and he had started doing that before so I appreciate that. I think the thing that I like the best is the fact that he, mind you the time it takes sometimes annoys me, but I think the fact that he is willing to talk about how he feels is really a big thing, um, because that was not something he did. It was just not something a man did for goodness sake.

S: No

P: and the fact that he will do this, I have to remind myself and actually I need to hear it. I need to hear it, because I need to know how he's feeling. I have to deal with these things and I need to understand. It makes me tired. Smiling when I'd rather not be but, uh, well, it's ok. We really are blessed. When you think of it because it's much less than we'd have expected (referring to his memory loss), we know it's going to get worse, but he's accepting of it and has been able to tell other people. So you know, there's not a lot of understanding for people who don't have this problem but at least they're willing to accept, and I mean what else can you expect?

S: that's all you can ask of people

P: Like the ladies here understood, when I said something, they all understood exactly what I was saying and what I meant, and I don't believe Mr. M has gone as far in this disease as some of them and I feel sorry for them because I know how hard it must be, but I also know that it is coming, so I need to be prepared for that.

P: So you feel like given the MCI diagnosis, you are anticipating something that is next to come? You feel like you are kind of getting ready for it?

S: yes, but the fact that we got the diagnosis to begin with was a relief; and yes, now we need to plan ahead to a certain extent. We live out in a

- Shows the new role of caretaker, saviour – justification of role

- Saviour, caretaker, why me? to make me a better person, can't be angry if it's God's way, according to her religious belief, she shouldn't be angry or resentful of his diagnosis, but she is, the why me question gets answered through her faith, because god tests us – validation from higher power

- Shows a need to observe the person with amci because it is a representation of the change in them, this representation, once more frequently occurring, signifies the entrance into new role of caregiver - loss and wearing mask, need to know what mask to wear or what role to take on

subdivision in the country. There will be a time, and we hope that we will know when we need to move out into town. If all of the driving is to be mine, then we need to go closer to all of the doctors and the dentists and all of those sort of things. So far we've been able to discuss this and this, as I said, is a big thing that we have been able to do this, but ya, maybe I guess I, you know when you're...no you probably won't, (she chuckles) when our kids are little, we spend a lot of time steering them away from things that are dangerous for them, and I think possibly my, now some of my attitude is this, but towards my husband and sometimes I have a little trouble equating that, cause this isn't suppose to happen you know, course it does, we know but (she laughs softly)

P: You mean you feel like the experience is that you are becoming a mother to him, and you are trying not to take on the role of a mother to him?

S: yes, a certain amount of things have always been what I did. There are certain things that I did for him that he could have done by himself, but this was just the way things were. There are certain things, I have also realized that I cannot be an enabler, and I have been an enabler throughout most of our married life in certain areas and now I have to realize that I cannot be that enabler and like, when it came to the strategies for learning, I started by trying to teach him these things and it took a lot of time to get this through to the fact that he has to take it on himself and now he realizes it works and it's ok, but there are still little things where I have to remind myself, "do not do that, let him follow through, if he doesn't follow through, mention it" and then let him do it. And that's one of my big problems.

P: Would you say you have experienced a hard time letting go of control?

S: no, I have a hard time not doing it altogether

- Shows a need to be vigilantly aware in order to be ready to step into role, wearing mask
- Shows that once his hobbies and interests decline, caregiver role will need to be filled, anticipatory grief
- Show's changing of gender expectations – loss of old way of life
- Anticipating that he is going to make a mistake, shows her anticipatory grief, fear for the future and what to come – loss and grief
- Anticipating his disease has changed his abilities to do things he once did, shows she is trying to anticipate when to move into new role – loss and wearing mask
- Shows that she is having to change her interactions with him
- Shows that she wants things to go back to the way they were before when she didn't have to tell him how to do things, when he could do them on his own and this is why she is starting to get emotional
- Shows resentment and anger of a change in him, their relationship, multiple losses
- Shows how frustrated she is about him having this diagnosis but also how guilty she feels about it, experience is she is guilty for the way she feels as a result of her not being able to reconcile that this is not his fault – wears mask to conceal her grief as a result of the multiple losses
- Shows that she is not in agreement with her feelings and what she is saying, socially, she knows what she should be doing, emotionally she is feeling frustrated, angry and scared of the unknown –wearing mask
- Shows inertia, reluctance to change, because this means accepting he has a problem
- Shows that she is having a hard time reconciling her current experiences with her expectations, needs to get away from her

because I have been doing it for 53 years. I make him make his appointments now and he's always had trouble turning on the oven, now we have a new stove and it's down where he can't see it well, and well I would do it for him before and now, we discussed it and I've gone through it enough times, he can do it. If he forgets to turn it off, alright, that's just another thing that's a problem but I have to stand back and let him do it. You have to let them take their own steps, and I feel very much like that sometimes, um, like I said we are blessed but there are things that are hard

S: What are those things?

P: well I think the things is just the fact that this is not exactly the husband that I married and I cannot depend on him for certain things, I must remember that I need to be there for him for certain things now that he looked after before. I need not to yell (she laughs breathlessly) and be impatient and I find that's hard, becoming patient for things that ordinarily, if it was too much I would have just left the room and gone out for the afternoon, but I can't do that now because he's a bit fragile yet, learning all these things and I need to be in control of myself so I can help him and I don't always like it but ok, we're going to get there (she laughs again)

S: so you are experiencing having to create sort of a hospitable environment for him to learn and grow and relearn things in

P: exactly, exactly, without stepping in and doing them, which is doing him no good at all

S: that must be so hard

P: It is hard, especially when we have had discussion about something I won't do and he thinks I should, and afterwards when he understands it's ok, but I have to remember to just go out and leave the room, just go away because it's so easy to, to, for that outburst and it's not doing either one of us any good. It's a little difficult

experience

- Shows a change in the traditional familial structure, loss of traditional ascribed roles
- Shows a change in her responsibilities, a change in her traditional role and discomfort in the new role as it is not yet well defined
- Shows having to learn new roles and responsibilities loss of sense of control – high demand low control
- Shows taking up her time,, resents its stealing her time away – accepting there's a problem loss of time/loss of personal identity
- Shows breaking down of traditional gendered roles and his new found need to be heard by her, his need to talk with her about his feelings because this is something he still has a sense of mastery over and it makes her feel appreciated to have him come to her, although she still resents the time it takes – accepting he has a problem, loss of time= loss of personal time/identity
- Shows that she is trying to be more open and accepting of the fact that he has a problem and he needs help, that he is not the husband she married – loss of partner
- Shows expectation of decline, anticipatory grief, trying to reconcile this idea with expectations for a normal future together
- Shows that he has accepted it and started 'coming out'- acceptance from spouse
- Shows the diagnosis is felt to be misunderstood and ambiguous to the general public, mental health problems are stigmatized
- Shows that having peers who are going through a similar experience is validating, relief from being understood by peers – Validation – shared experience
- Anticipating things will get worse, need to start preparing, getting things in order – loss of

too because of our friends, they are accepting but there is no one really that understands. I do go to, uh, I took a course for caregivers, I wasn't a caregiver at that time but I took the course when they offered it and our group has continued to meet once a month

S: that's great

P: and I find it's wonderful because there are ones who have parents or friends with Alzheimer's, there's one with Pick's, but it's okay, we can talk, we can cry, and we laugh a lot, and that's good, I appreciate this very much. Just the fact that you can talk; you can say what's been bugging you

S: because you can't say it to him

P: Yes, you can't say it to him, and you have to say it to someone. I must admit, I had been very gently been starting to tell my daughters, to express some of the stress i feel, I don't want to overburden them, but I do want to let them know how I feel and that um, (with a sigh) I guess I want to prepare them to a certain extent. Now they accept this is not a problem, but not living with him, they don't understand and I am trying to, I don't want to put too much onto them and I'm trying to, bit by bit show them what's going on and uh, probably after so I can say the good results afterwards but yeah, and I think it's very important that they know

S: because their experience will be that, through their infrequent visits, that if he does transition, they will be unprepared

P: yep, that's right

S: so not only are you trying to create an environment for him that is hospitable, but you are also trying to recreate the environment for your family as well, and your friends. You are helping to teach them.

P: yep, and I have, I had to before he *came out*, I had to start

S: you said *came out*

hope for the future

- Shows the importance of the diagnosis to move forward, no diagnosis, no acceptance of problem, diagnosis is also scary and an unknown – acceptance of problem
- Shows anticipation of the loss of old life, loss of traditional roles, loss of connection to current community,
- Shows that her relationship with him has changed from equal partners to a mother child relationship, where she feels she has to keep him out of harm's way, but this is not a change she had anticipated on – loss of partner, loss of identity
- Shows understanding of previous gendered roles, feels guilty that she did so many things for him previously – loss
- Shows that she sees her role as a teacher or a mother to him and less like his wife, adopting new roles and responsibilities – wearing mask
- Shows having all of the responsibility with little control – distorted sense of mastery = stress – loss of sense of control

P: (she chuckles) well this is how he said he felt. See to begin with, he didn't feel comfortable. In our days you didn't talk about 'mental illness.' It was something that was hidden away. At first, he didn't feel comfortable telling people about the diagnosis, probably because we were not really sure what it meant at first. I think it was after the first or the second session down here he met somebody who was just like him. He felt comfortable enough, he said, to come out and tell him, he told our bible study group to begin with, but then from there it built on, and on, and I know some of them still don't quite understand but before that started (she pauses to think), I had begun, well, we had a friend, he's got a (she pauses again as though what she is about to say is very difficult) 'mental problem,' but he also has dementia, and he came home recently, he had been in the hospital, down here for 6 months and by using him and talking about certain things, I was able to introduce this just a little bit you know, "This is not something he understands, and it is something that is just as hard on him as it is on her" and you know, it seemed to work pretty good. They still don't get it completely. Small steps, baby steps. And even for us it's been a learning curve, so everybody else has to have time to learn too. How can they know unless they have gone through something?

S: You have told me a lot about changes in your new role, you haven't ever referred to yourself as a caregiver yet

P: I don't feel I've quite reached that. I know that's what I will be, but I feel that he is competent enough with so many things. He volunteers at the thrift store in Port Elgin once a week and he goes into town by himself and he does that and does his business. We try, and it doesn't always work, we try to each have a day a week that we can be out on our own and he's comfortable enough, and the

- Shows that she is trying to be accepting of his shortcomings but still resents the reason for these changes in his ability – wearing the mask
- Shows she is wearing the mask again
- Shows difficulty reconciling her need to move into new caregiver role, her guilt for feeling this way and her need to overcome her negative feelings and be a support system for him by assuming responsibilities for things he once did – wearing mask/ grief from multiple losses
- Shows that she is acknowledging that he has a problem and that her anger at his diagnosis is not fair to place back on him especially because he is losing the faculties to cope with her being upset with him – wearing mask
- Resistant to change – anticipatory grief

people there know what's going on, I don't know how well they understand but they know and they accept and uh, it gives him that control and so I don't feel yet that I'm a caregiver. I know I will be, but not yet

S: So is the experience of him losing control when you think you will see yourself transitioning into a new caregiver role?

P: probably, it, it, like I know to a certain extent I am now but I don't feel it's the full, to me a caregiver perhaps take on more roles that I am currently doing. I am taking part of the roles of caregiver but I haven't completely accepted all of them because he is still able to do many of those things by himself. I have no problem helping him if it is necessary and I know that there will be times that I will need to help more, um, but I personally feel that it is very important that he remains as independent as possible. And we have talked about it and the fact is that these memory strategies are helping him to deal with this now and he's quite confident now if he's, if someone comes to talk to him and he doesn't know their name he'll go, "say, I can't just recall your name, would you tell me your name" and people don't seem to mind, but he's much more comfortable doing that now, which is a big step!

- Shows her need for respite, need to get away temporarily or else there may be consequences – need for escape/respite
- Shows that the diagnosis is hard for people who are not living with it to understand, importance of peers who have shared experience – Shared understanding from peers
- Wasn't a caregiver at the time, shows she is taking on more roles now that would put her into the caregiver role – loss of previous self