# OCCUPATIONAL PERFORMANCE AND MILD COGNITIVE IMPAIRMENT IN A

PRIMARY CARE MEMORY CLINIC.

By

LAURA TURNER, B.A., B.HSc.(OT)

A Thesis

Submitted to the School of Graduate Studies

in Partial Fulfillment of the Requirements

for the Degree

Master of Science

McMaster University

© Laura Turner, May 2014

MASTER OF SCIENCE (2014) McMaster University

(Clinical Health Sciences – Rehabilitation Science) Hamilton, Ontario

# TITLE: Occupational Performance and Mild Cognitive Impairment in a Primary Care Memory Clinic.

# 

AUTHOR: Laura Elizabeth Turner, B.A., B.HSc. (OT) (McMaster University)

SUPERVISOR: Dr. Mary Law, Ph.D.

SUPERVISORY COMMITTEE: Dr. Lori Letts, Ph.D.

Dr. Linda Lee, M.D.

NUMBER OF PAGES: x, 139.

**Abstract**

As Ontario faces a major shift in demographics, it is anticipated that the number of community-dwelling people living with cognitive impairment will increase significantly. Occupational therapists (OTs) may play a key role in ensuring timely diagnosis and/or informing a comprehensive plan of care for this population by assessing and reporting on functional abilities. The purpose of this study was to explore the impact of an OT home assessment on diagnosis and plan of care for persons with Mild Cognitive Impairment (MCI) in a primary care Memory Clinic setting using a before and after design. A toolkit of clinical measures was developed to assess self-perception of occupational performance, instrumental activities of daily living (IADLs), falls risk and home safety. Thirty-one participants who had been assessed by a Memory Clinic team completed a one-hour OT home assessment focused on these attributes. A change in the plan of care was proposed for 24 of 31 participants (i.e., 77%) after the assessment findings were reviewed by the lead physicians of three Memory Clinic teams. Clinical information from an OT home assessment was used by the Memory Clinic teams to change follow-up visit times, plan diagnosis and/or medication review and initiate additional community supports for persons with MCI. Women in this sample were more likely than men to experience changes to their plan of care and were also at a higher falls risk as indicated by scores on a screening tool of this attribute. Several time sensitive issues were identified during the OT home assessment including falls risk, home safety issues and participant concern with driving ability. The addition of an OT home visit to an existing Memory Clinic Model has the potential to change the overall plan of care and to identify issues that may impact overall health and wellness, and the ability to live well at home. While the context for this study was an existing Memory Clinic Model in primary care, the findings have implications for older adults in any health setting who are experiencing cognitive changes.

**Acknowledgements**

There are many people in my life who have made the completion of this thesis possible. My first heartfelt thank you is to my 'dream team' committee, Mary Law, Lori Letts and Linda Lee. It would be very difficult to find three more accomplished and inspiring women and it was an honour to work with each one of you. Mary, thank you for giving me an enthusiastic nod to this topic, for sticking with me, and for cheering me on. You have been a fabulous supervisor. Lori, thank you for bringing your content expertise to this study and for asking thought-provoking questions. I have grown in my research abilities and my understanding of older adults with MCI because of you. Linda, thank you for openly sharing your Memory Clinic with anyone who is interested, and for convincing an OT working in pediatrics to take a closer look at the functional abilities of older adults with MCI. Thank you to the Decadent Readers (you know who you are) for encouraging me when I stopped reading for leisure but kept coming to our gatherings for your support. Thank you to my friends and colleagues who have cheered me on every step of the way. Thank you to my participants for inviting me into your homes and so willingly discussing what it is like to be growing older with a diagnosis of MCI. Last but certainly not least, thank you to my family, and especially to Chris, Owen and Maeve. Owen and Maeve, Mommy has very good news. Her thesis is done and it's time to play!

**Table of Contents**

Abstract………………………………………………………………………… iii

Acknowledgements……………………………………………………..…….... v

Table of Contents………………………………………………………………. vi

List of Figures…………….……………………………………………………. ix

List of Tables…………………………………………………………………… ix

List of Appendices……………………………………………………………… x

**Chapter 1: Introduction**

Statement of the Problem……………………………………………… 1

The Present Study…………………………………………………….... 1

Research Question……………………………………………..…….… 2

Outline of Chapters………………………………………………….… 2

**Chapter 2: Literature Review**

A Primary Care Memory Clinic Model………………………………. 5

Memory Clinic Model Training Program………….….............. 5

Evaluation of Memory Clinic Training……………………….. 7

Memory Clinic Model Assessment Process.………………….. 8

Evaluation of a Primary Care Memory Clinic Model................. 10

Mild Cognitive Impairment (MCI)………………………………….... 11

Cognition in the Context of MCI and Dementia.….……........... 12

Incidence and Prevalence of MCI….………………………..... 14

Progression Rate from MCI to Dementia.................................... 15

The Occupational Therapy Role in the Context of the Present Study... 16

Occupational Therapy (OT) and Dementia................................. 16

Relevant Models.......................................................................... 17

The Occupational Therapy Role in Dementia............................. 19

Occupational Performance and MCI........................................... 22

Awareness of Disability............................................................... 23

Adapting Dementia Approaches to MCI...................................... 24

The Impact of Other Factors on Occupational Performance.................... 26

Chronic Health Conditions........................................................... 26

Falls............................................................................................... 27

Summary................................................................................................... 30

**Chapter 3: Assessment of IADLs**

ADLs and IADLs.................................................................................................. 33

Methods of Assessment........................................................................................ 35

Environmental Context............................................................................. 38

**Chapter 4: Development of a Clinical Assessment Toolkit**

Toolkits in the Occupational Therapy Literature.................................................. 41

The Process of Toolkit Development................................................................... 44

Attributes to be Measured during OT Home Assessment.................................... 47

Self-Perception of Occupational Performance............................. 47

IADLs........................................................................................... 49

Home Safety and Falls Risk......................................................... 52

**Chapter 5: Methods**

Overview.……………………………………………………….……............... 55

Research Question................................................................................................ 55

Design................................................................................................................... 56

Participants........................................................................................................... 56

Ethics.................................................................................................................... 57

Procedure.............................................................................................................. 58

Measures............................................................................................................... 60

Canadian Occupational Performance Measure (COPM).......................... 60

Texas Functional Living Scale (TFLS).................................................... 61

Home Falls and Accident Screening Tool (Home Fast)........................... 61

Timed Up and Go..................................................................................... 62

Reporting OT Assessment Findings..................................................................... 63

Analyses................................................................................................................ 64

Dissemination Plan................................................................................................ 65

**Chapter 6: Results**

Demographics........................................................................................................ 66

Findings Related to Plan of Care........................................................................... 67

Findings by Clinical Measure................................................................................ 68

Canadian Occupational Performance Measure (COPM)........................... 69

Texas Functional Living Scale (TFLS)...................................................... 70

Home Falls and Accident Screening Tool (Home Fast)............................ 70

Timed Up and Go (TUG)........................................................................... 71

Correlational Analyses........................................................................................... 71

**Chapter 7: Discussion**

The Impact of OT on the Plan of Care.................................................................... 72

The Impact of a Clinical Assessment Toolkit......................................................... 76

Canadian Occupational Performance Measure (COPM)............................ 77

Driving............................................................................................. 78

Managing Finances.......................................................................... 79

Mobility........................................................................................... 80

Leisure............................................................................................. 80

Texas Functional Living Scale (TFLS)....................................................... 82

Home Falls and Accident Screening Tool (Home Fast).............................. 84

Timed Up and Go (TUG)............................................................................. 87

Environmental Context and Assessment.................................................................. 88

Implications and Future Directions.......................................................................... 90

**References**................................................................................................................. 106

**Appendices**................................................................................................................ 120

**List of Figures**

Figure 1: The Canadian Model of Occupational Performance and Engagement (CMOP-E)

Figure 2: The Person Environment Occupation Model (PEO)

Figure 3: The International Classification of Functioning (ICF)

**List of Tables**

Table 1: Attribute: Self-Perception of Occupational Performance

Canadian Occupational Performance Measure (COPM)

Table 2: Summary of Clinical Measures Eliminated Based on Exclusion Criteria

Table 3: Attribute: Instrumental Activities of Daily Living (IADLs)

Texas Functional Living Scale (TFLS)

Table 4: Attribute: Home Safety

The Home Falls and Accident Screening Tool (Home Fast)

Table 5: Attribute: Falls Risk

The Timed Up and Go (TUG)

Table 6: Summary of Proposed Changes to Plan of Care Following OT Home Assessment

Table 7: COPM Summary

Table 8: TFLS Summary

Table 9: Home Fast Summary

Table 10: TUG Summary

**List of Appendices**

Appendix A: Informed Consent Protocol

Appendix B: Information for Participants

Appendix C: Telephone Script for Participants

Appendix D: Data Collection Form: Part 1

Appendix E: Information Letter and Consent Form

Appendix F: OT Reporting Template

Appendix G: Data Collection Form: Part 2

Chapter 1: Introduction

Statement of the Problem

The healthcare landscape in Ontario is currently undergoing significant changes both in funding and in models of patient care. Ontario's Action Plan for Health Care (Ontario Ministry of Health and Long-Term Care, 2012) highlights three key areas of focus for Ontarians including: 1) support to become healthier; 2) faster access and a stronger link to family care (i.e., primary care), and; 3) the right care, at the right time, in the right place (p. 7). In a healthcare climate that is facing substantial fiscal challenges and a rapidly aging population, there is an emerging and evolving role for evidence-based occupational therapy focused on community-dwelling seniors who are experiencing cognitive changes. A Memory Clinic model has been developed to build capacity in primary care to address the needs of persons who have been diagnosed with MCI and dementia (Lee et al, 2010). The role of this clinic is complex and includes assessment, diagnosis, development of a comprehensive plan of care and ongoing treatment. A clinical gap in this process was identified by the Memory Clinic team related to the ability to adequately assess functional abilities in the clinic environment. Traditionally, OT has not been included in this model despite an excellent fit with primary care, and the training and skill set to assess functional ability.

The Present Study

The present study was designed in response to the clinical gap as described above. The research approach was two-fold, involving: 1) the development of an evidence-based and occupation-focused toolkit of clinical measures to be used during an OT home assessment visit, and, 2) the use of a before and after design to evaluate the impact of the OT findings on the existing plan of care.

Research Question

The research question to be addressed by this study is: "To what extent does a standardized occupational therapy home assessment protocol [or toolkit] of self-perception of occupational performance, IADLs, falls risk and home safety change the plan of care for patients with MCI in a Memory Clinic model in primary care?"

Outline of Chapters

This thesis is organized into seven chapters. Chapter one demonstrates the need for the current study and includes a statement of the problem, and the research question under consideration. Chapter two sets the stage for the reader by defining and discussing key concepts and ideas related to OT in primary care, MCI, the Memory Clinic model, and the OT role in MCI and dementia, including several issues worthy of consideration like the impact of chronic health conditions and falls. Chapter three introduces assessment IADLs and explores methods of assessment while highlighting the importance of environmental context. Chapter four describes and discusses the development of the clinical assessment toolkit used for OT home visits. Chapter five addresses topics related to study methodology including design, ethics, procedures, measures, reporting and analysis. Chapter six presents the results of this exploratory study, and chapter seven provides a discussion of the study findings and recommendations addressing next steps and future directions.

Chapter 2: Literature Review

The exploratory study presented in this thesis was developed in response to an identified gap in service for patients receiving assessment and intervention in a primary care Memory Clinic Model in Ontario. A critical piece of clinical information that is key in deciding whether a person is diagnosed with MCI or with dementia is functional ability (Gitlin, 2005). However, functional ability is difficult to assess with accuracy in a clinic environment, like a primary care setting. Occupational therapists can address this clinical gap by evaluating functional ability in the home environment. As occupational therapists continue to join primary care settings in Ontario, and focus on the development of role emerging areas of practice, an innovative strategy is to demonstrate the value and effectiveness of occupational therapy (OT) in an existing clinical model, such as a Memory Clinic. An opportunity exists for occupational therapists to develop evidence that demonstrates the positive impact of an OT assessment for persons with MCI, which is of benefit both to patient care and to system efficiency. While primary care was the setting for this study, the approach taken (i.e., the development and use of a toolkit of measures to address a gap in an existing model of care) is applicable to various clinical environments with the potential for adoption by other health care professionals. The purpose of the following section is to set the stage for the current study. Key topics to be introduced and discussed include a primary care Memory Clinic Model, MCI, and the occupational therapy role in the context of this research project.

A Primary Care Memory Clinic Model

A Memory Clinic model has been established (Lee et al., 2010) and is expanding in Family Health Teams (FHTs) and other primary care settings (e.g., Family Health Organizations and Community Health Centres) across Ontario. At present, there are 49 primary care Memory Clinics in Ontario, involving approximately 200 allied health professionals, 70 family physicians and 14 geriatricians, covering over 500 family practices. There are six additional Memory Clinics in training currently, and by December 2014, it is anticipated that there will be 67 Memory Clinics across Ontario (personal communication, Linda Lee, June 21, 2014). Representing an innovative and interdisciplinary approach to the management of MCI and dementia, primary care Memory Clinics provide patients with timely access to comprehensive assessment, represent a collaborative care approach and an enhanced ability to respond to the needs of patients with cognitive issues in primary care (Lee et al., 2010). Referrals to the Memory Clinic are generated by family physicians and patients are assessed by a team that includes a physician, nurse, social worker and pharmacist and potentially other disciplines.

Memory Clinic Model Training Program

The Memory Clinic model under consideration is unique in that an interprofessional training program has been developed to support primary care teams who have expressed an interest in, and the capacity to adopt this physician-led, interdisciplinary model of care. The training program involves three activities including a two day workshop, a one day observership, and a two day mentorship. The workshop is delivered by a multidisciplinary team from the Centre for Family Medicine (CFFM) in Kitchener, Ontario and is focused on knowledge translation using various learning activities including real-life cases of patients who have received assessment and intervention in this clinic setting, interactive lectures with multimedia content, small group activities and coaching and hands-on guidance from the workshop team. Built in to the workshop structure are networking opportunities and key resources to be used both to set up the clinic model, and during assessment and intervention.

The one day observership is hosted at the CFFM by the Memory Clinic team and involves teams travelling to the Kitchener, Ontario site to experience first-hand the structure and processes inherent in this model. Using remote video access with consent from patients and/or their caregivers, this approach allows for observation and learning without disrupting the patient-clinician interaction. Following the assessment activities, teams are invited to listen in and to participate in team discussions focused on reviewing assessment findings and developing care plans. The final step in this formal program is the two day mentorship in which the CFFM Memory Clinic team travels to the new team's clinic setting to observe the first two days of the implementation of the model with their patients who have been referred for cognitive issues. While the CFFM team is on-site, a presentation about the Memory Clinic model is delivered to the physicians and other members of the FHT to encourage appropriate referrals and implementation of care plans. In addition to the activities completed as part of this formal training program, ongoing mentoring is provided to individual teams, in addition to a yearly Booster Day where Memory Clinic teams gather and have the opportunity to learn about new and emerging research related to dementia care, engage in problem-solving related to more challenging topics and clinical scenarios, and to network with each other (Lee, Weston & Hillier, 2013).

Evaluation of Memory Clinic Training

This comprehensive five day training program has been evaluated using online surveys that were administered pre and post training program. The first survey (i.e., pre-training) included demographics and information about current practice related to cognitive impairment, and how prepared health professionals felt to address this clinical practice area based on the professional education that they had received. At the conclusion of the workshop, and again following the observership day, an additional in-person survey was completed. Of 124 potential respondents, the response rate was very high for the pre-training survey (i.e., 91.9%), and lower for the post-training survey (i.e., 66.9%) which was completed at least six months following the completion of the training program. The response rate was 100% for the two in-person surveys as described above (Lee, Weston & Hillier, 2013).

In general, participants responded positively to the training program, and there were statistically significant increases in a number of perceived changes as measured pre and post training. These perceived changes were related to self-reported knowledge and ability in the assessment and management of cognitive impairment and overall confidence and level of comfort when discussing memory issues with patients. The training program is an example of knowledge transfer and capacity-building in supporting an innovative Memory Clinic model for primary care settings (Lee, Weston, & Hillier, 2013). The next section of this thesis will outline the Memory Clinic process, and make the connection to an occupational therapy home assessment evaluating how patients who have been diagnosed with MCI manage in their home

environments day to day.

Memory Clinic Model Assessment Process

Patients who are experiencing cognitive issues are referred to the primary care Memory Clinic by a family physician working in the FHT. Prior to attending the Memory Clinic, patients are mailed the Functional Abilities Questionnaire (FAQ) (Pfeffer, Kurosaki, Harrah, Chance, & Filos, 1982), an indirect, self-report tool used to measure the ability to perform ten everyday activities including money management tasks, shopping, making coffee and meals and way finding in the community. Participants score their ability on a scale of zero to four, with zero equal to normal or never did activity but could do it now, one equal to has difficulty but does by self or never did activity and would have difficulty now, two requires assistance, three dependent. Scores range from zero to thirty where a cutoff score of nine i.e., dependent in three or more activities indicates impaired function and possible cognitive impairment. An information letter is included, encouraging patients to complete the FAQ prior to their appointment time, and to bring this information with them, in addition to the medications that they are currently taking. Patients are also instructed to have a family member or friend accompany them to the appointment.

During the Memory Clinic appointment, cognitive tests are administered by an allied health professional and may include the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005), Trail Making Test (TMT), Parts A and B (Reitan, 1958), CLOX, (Royall, Cordes, & Polk, 1998), Animal Word List Generation (WLG) (Barr & Brandt, 1996) and other tests of executive function as appropriate such as the Luria Fist-Edge-Palm test (Dubois, Slachesvsky, Litvan & Pillon, 2000). The pharmacist reviews all medications that are currently taken, including the method of administration and provides education to patients and recommendations to the team about potential medication changes and substitutions. While the team includes a social worker who assesses for depression, caregiver stress, and the need for a home safety assessment and community supports, an in-depth assessment of a patient’s ability to perform key everyday activities is absent from the current model. While several Memory Clinic teams now include occupational therapy, there are challenges associated with fully understanding patients' abilities to function day to day in their home environments in the context of this model for teams with and without OT. These challenges include the use of a self-report approach to assessing IADLs i.e., the FAQ, the clinic environment, and the current burden of measurement inherent in this office-based model of care.

An occupational therapy assessment of instrumental activities of living (IADLs) such as handling money and paying bills, meal preparation and medication management has the potential to provide key information to the physician and assessment team when there is uncertainty in making the distinction between a diagnosis of MCI and dementia. Furthermore, information gleaned during the OT home assessment may better inform referrals to community services and agencies to best support the patient with MCI living in the community. Information regarding a patient’s ability to perform IADLs in his/her home environment can be difficult to assess in the clinic setting but is important in understanding the extent to which impaired cognition is affecting a person’s ability to manage safely and effectively in their daily lives. OTs have the potential to bring their knowledge about cognition and dementia paired with a unique understanding of the impact of cognitive impairment on occupation to the Memory Clinic Model. In the context of this study, occupation refers to the everyday activities that participants need to do, want to do, or are expected to do related to enjoying life, looking after themselves and contributing to society (CAOT, 2002). MCI is discussed in the next chapter of this thesis to give the reader a better understanding of the complexity of this health condition.

Evaluation of a Primary Care Memory Clinic Model

An evaluation of the Memory Clinic model under consideration was completed through the use of a patient and caregiver satisfaction survey, a physician survey, a chart audit, and the collection of patient data from July 2006 to September 2009. During this time frame, 174 patients were referred, 151 completed the assessment process and 23 were waiting to be assessed. Of particular relevance to this exploratory study was the finding that 44.4% of this sample received a new diagnosis of MCI. (Lee et al., 2010).

Patient and caregiver satisfaction surveys were completed by 55 people with no significant differences noted in ratings between caregivers and patients and responses indicating a high rate of satisfaction with the services provided by the Memory Clinic teams. Surveys were completed by 8 physicians who were also very satisfied with the Memory Clinic model and process, and indicating greater confidence in assessment (n=4) and management (n=5) ability related to cognitive impairment, greater comfort in discussing dementia with patients and their families, and the provision of an improved quality of care (n=6). Thirty chart audits were completed by two geriatricians and the level of agreement with diagnosis and plan of care was 97.2% (Lee et al., 2010). Despite a small sample size, the results of this study would suggest that this Memory Clinic represents a promising model in primary care.

Mild Cognitive Impairment (MCI)

Mild cognitive impairment (MCI) is a diagnosis that is used to define and describe a population of older adults who present with cognitive changes beyond those which occur during the typical aging process (Peterson et al., 2009). The cognitive changes associated with MCI often have a gradual and subtle onset (Riley, 2009) and individuals with a diagnosis of MCI do not typically experience a decline in their ability to perform activities of daily living (ADLs) (Peterson, 2011; Peterson et al., 2009), such as bathing, eating and dressing. Furthermore, instrumental activities of daily living (IADLs), which include activities such as cooking, paying bills and driving, are either intact, or only minimally impaired in this population (Griffith et al., 2003; Healey, 2012). While cognitive slowing can occur over time, a decline in functional abilities is generally not a part of an expected aging process (Healey, 2012). The cognitive changes that occur during aging can be conceptualized on a continuum from normal, to MCI, to dementia (Healey, 2012; Peterson, 2011). Thus, MCI may represent a transitional state between typical age-related memory loss and a neurodegenerative disorder like Alzheimer's disease (AD) (Peterson, 2011; Peterson et al., 2009). Notably, while some individuals progress from MCI to dementia, there are others who either improve post-diagnosis, or remain stable over time (Patel & Holland, 2012). To better understand MCI in the context of this continuum, a brief discussion of cognition and age-related cognitive changes is warranted. The body of literature related to aging and cognition is extensive and a full discussion is beyond the scope of this thesis. However, understanding several key concepts about age-related cognitive changes will provide a context for the discussion of MCI.

Cognition in the Context of MCI and Dementia

Cognition can be defined as, "a means of acquiring and processing information about ourselves and our world" and includes not only memory, but other domains such as executive function, mental processing speed, language, visuo-spatial skills and attention (Patel & Holland, 2012, p. 857). The concept of 'normal aging' is used to make a distinction between older adults who are considered healthy i.e., not experiencing physical and/or mental health issues that are impacting cognition and those who are experiencing diseases and other impairments that may impact their cognitive function (Riley, 2009). It does not, however, take into consideration the extent to which people with cognitive changes are able to function, and to participate in their daily lives, despite the presence of cognitive issues. While older adults may report concerns related to their thinking skills as they age, the areas of concern and level of impairment differ when comparing normal aging, MCI and dementia. For example, people may complain of being more forgetful as they age, but if they are able to recall what they had forgotten with cues or slower processing speed, these reports may be considered in line with a typical cognitive aging process. In the early stages of dementia presenting symptoms may vary depending on type; short term memory may be preserved if executive function is primarily affected, such as in dementias due to stroke (Buckner, 2004). Additionally, a cognitive evaluation of the aforementioned skills that is unremarkable, and the absence of issues related to social interactions, ADLs or IADLs would suggest a typical aging process (Patel & Holland, 2012). In stark comparison to MCI is a diagnosis of dementia, when cognitive impairment impacts the ability to function day-to-day, and often results in a loss of independence and a corresponding need for caregiving and community supports (Peterson, 2011).

MCI first appeared in the literature over two decades ago, and has received an increasing level of attention over the past decade as the link between MCI and dementia becomes better understood and therapies are developed for primary disease prevention (Peterson et. al., 2009). As the benefits of early intervention in dementia are demonstrated, it becomes increasingly important to understand when MCI has progressed to early dementia (Peterson, 2011). Despite the research that has been done, and the increasing level of attention and representation in the literature, the entity of MCI is not clearly defined (L. Lee, personal communication, June 15, 2013) and there is agreement among experts that MCI as a condition is "not yet well understood" (Patel & Holland, 2012, p. 857). MCI may develop because of vascular or neurodegenerative changes, brain trauma, or metabolic, psychiatric or other underlying medical conditions. Ruling out reversible causes such as depression, vitamin B12 deficiency, hypothyroidism, sleep disorders and medication effects is an important first step in the diagnosis of MCI. Delirium, depression, and central nervous system conditions such as tumors, stroke, subdural hematoma, epilepsy, and traumatic brain injury are also in the differential diagnoses of MCI (Patel & Holland, 2012; Peterson, 2011).

MCI is categorized into two types, amnestic (i.e., subtle decline that affects memory and is considered clinically significant) and nonamnestic (i.e., subtle decline that affects attention, language or visuospatial skills but not memory and is considered clinically significant) (Peterson, 2011) but this distinction was not made for participants referred for an occupational therapy home assessment in the context of this study. A diagnosis of MCI is typically informed by the consideration of the following criteria: subjective memory complaints (preferably substantiated by a key informant such as a spouse, family member or close friend); memory impairment (age and level of education considered); functional abilities generally preserved; ADLs intact, and absence of dementia (Peterson et al., 1999; Peterson, 2011). The Alzheimer Society of Canada (2013) describes MCI as a condition involving issues in several areas, including memory and thinking. While these changes may be noticed by those who are close to the person and detected on tests, the level of impairment associated with MCI does not impact the ability to function day to day. However, Gitlin (2005) describes behavioural changes that can be associated with MCI, including anxiety, forgetfulness and confusion which may result in occupational performance issues. Occupational performance refers to the complex relationship between people, environments and their everyday activities, or occupations (Townsend & Polatajko, 2007) and has been defined as "the ability to choose, organize, and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after one's self, enjoying life, and contributing to the social and economic fabric of a community" (CAOT, 2002, p. 30). Griffith et al. (2003) compared people with MCI to their non-cognitively impaired peers and found that the former demonstrated a decline in some money management abilities (i.e., IADL) such as payment of bills.

Incidence and Prevalence of MCI

While it is difficult to pinpoint incidence and prevalence of MCI due to variation in definitions in the literature, populations studied, sample heterogeneity, and techniques used for evaluation and diagnosis (Patel & Holland, 2012), a number of sources were consulted, with variation in percentages reported. In 2009 Peterson reported a worldwide prevalence of MCI of 14% to 18% for those aged 70 years of age and older, and more recently, a 10-20% prevalence in persons 65 years of age and older (Peterson, 2011). A 1991 Canadian Study of Health and Aging described approximately 17% of people aged 65 and older as having 'mild impairment'. In a systematic review of the literature, Ward et al. (2012) identified four dominant terms in the literature: age-associated memory impairment (AAMI), cognitive impairment no dementia (CIND), MCI and amnestic MCI (aMCI). Across 42 publications included in this review, incidence and prevalence varied greatly both between definitions and within each definition. Prevalence of MCI ranged from 18.8% to 28.3% among older adults with a mean age range of 65-80.5, increasing among older age groups. Incidence was reported in person-years, i.e., the number of people followed over a specified amount of time; for MCI, incidence was reported as ranging from 21.5 to 71.3 per 1000 person-years (i.e., 1000 people were followed for one year).

Progression Rate from MCI to Dementia

Another topic of great interest to clinicians and to researchers is the progression (or conversion) rate from MCI to dementia. One of the factors that impacts progression is advancing age, as progression rate is approximately 10% per year. There also appears to be an increased rate of progression for people who have risks factors related to the cardiovascular system. Research is currently underway to better understand key biological mechanisms (e.g., presence of apolipoprotein, hippocampus measurements using MRI) which may also predict a more rapid progression from MCI to dementia (Peterson, 2011).

When considering MCI in the context of the current research study, we can be certain that the Canadian population is aging (Statistics Canada, 2011) and people are living longer lives (Novak & Campbell, 2010). The prevalence of MCI increases with age, there is a marked rise in the incidence and prevalence of diabetes and cardiovascular disease, and therefore an increased risk of developing MCI, and having MCI may impact the quality of life in those who experience this condition (Gitlin & Corcoran, 2005). MCI has received little attention in the occupational therapy literature, and the impact of an occupational therapy home visit and subsequent findings on care plans in a primary care FHT Memory Clinic model has not been previously studied. Clinical decision making appears to be key in distinguishing MCI from mild dementia (Albert et al., 2011) and occupational therapists bring a unique skill set related to the ability to identify occupational performance issues that are impacting the ability to function safely and independently in a community setting. The author acknowledges the complexities and unanswered questions related to MCI. The OT role in MCI and dementia is discussed in the next section of this thesis.

The OT Role in the Context of the Present Study

The present study is focused on assessment of functional ability in the home environment for persons who have been diagnosed with MCI in a primary care Memory Clinic Model. In this section, the OT role in the context of this study is explored, starting with a discussion of dementia. The impact of chronic conditions and falls on occupational performance will also be discussed.

Occupational Therapy and Dementia

The occupational therapy role in dementia has received some attention in the literature. This role, which includes assessment and intervention, varies greatly depending on a number of variables, including the disease process and level of functional impairment, occupational performance issues related to both dementia and to other chronic health conditions, the environment in which a person lives and the number and types of family, social and community supports available. Assessment and intervention may focus on the person with dementia and/or their caregivers, the environment (i.e., supports and barriers) and/or occupation and occupational performance. The OT role in MCI, however, is emerging both in the literature and in clinical practice (e.g., Malinowsky, Almkvist, Kottorp & Nygard, 2010; Ohman, Nygard, & Kottorp, 2011) and therefore this study is timely. OT assessment in the context of MCI will be addressed in subsequent chapters and focus on both cognition and occupational performance. The following section provides background information and a framework outlining the OT role with a population of older adults who are experiencing cognitive changes.

Relevant Models

A discussion of several major models of occupation will provide a context for the occupational therapy role in MCI and dementia. As aforementioned, occupational therapists focus not only on the person, but also on the environment and occupation, and the complex relationship between all three of these variables. The Canadian Model of Occupational Performance and Engagement (CMOP-E) (CAOT, 2002 & Townsend & Polatajko, 2007) (see Figure 1) and the Person-Environment-Occupation Model (PEO) (Law et al., 1996) (see Figure 2) are of particular relevance to this research project and guided both the development of a toolkit of clinical measures to be used with participants diagnosed with MCI in a primary care Memory Clinic, but also in the development of the template used to report assessment findings back to primary care Memory Clinic teams. The toolkit development and reporting template will be discussed in subsequent sections, but first, these models are considered in the context of this exploratory research project.

The CMOP-E represents an expanded version of the Canadian Model of Occupational Performance (CMOP) (CAOT, 1997) and builds on the original model by making engagement explicit (see Figure 1). Engagement can be defined as "something that engages," and "being involved in activity, occupied or busy." (Merriam Webster online dictionary, accessed September 8, 2013). The CMOP-E is a three-dimensional depiction of occupational performance and engagement and the interconnectedness of person, environment and occupation. At the centre of this model is the person, having three performance components (i.e., physical, cognitive and affective), with spirituality at the core. The contribution of the CMOP-E to this research project is an overall understanding of the complexity of a person, his/her spirituality, and the occupations in which he/she engages.

The PEO model (Law et al., 1996) is depicted by three overlapping circles representing the person, the environment and occupation. With occupational performance at the core, this model illustrates the fit between person, environment and occupation, and how occupational performance ebbs and flows over the lifespan. Like the CMOP-E, the PEO model endorses the transactional nature of the relationship between these three variables, and engagement is implied. In the context of this exploratory research project, the PEO model provided a framework for considering occupational performance within the context of MCI. Development of the toolkit for the OT home visit was influenced by the PEO model, through the selection and use of measures that captured attributes in all three categories. The PEO model offers a means to both analyze and to discuss the factors related to the person, environment and occupation and the interaction among all three which in turn influence the occupational performance of older adults with MCI.

The final model worthy of discussion and of significant relevance to this research project is the International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001). The ICF is a rehabilitation model that conceptualizes a framework that includes body function and structure, activity, participation, and factors related to both the person, and to the environment (WHO, 2001). Law, Baum & Dunn (2005) stress the importance of occupational therapists focusing at the level of the person-environment interaction to ensure that occupational performance issues are at the forefront of assessment and intervention within the context of this framework. Focusing at the level of the person-environment interaction translates to activity (i.e., the individual's function) and participation (i.e., the individual in his or her environment and the ability to engage to the fullest in society) (WHO, 2001). The CMOP-E, the PEO and the ICF provided a framework through which this researcher gained insight into the participation and occupational performance of older adults who have MCI, and how to build a clinical assessment toolkit that was both evidence-based, occupation-focused and able to capture the complexities of being an older adult living with MCI and most often, other chronic health conditions. The following section provides a brief discussion of the OT role and dementia, while making connections to the CMOP-E, the PEO and the ICF as discussed and the emerging role in working with a population who are beginning to experience cognitive issues (i.e., MCI).

The Occupational Therapy Role in Dementia

While a full discussion of the role of occupational therapy in dementia is beyond the scope of this thesis, several approaches are highlighted, demonstrating the focus on complex interactions between person, environment and occupation, as supported by the CMOP-E and the PEO. The focus of this discussion is limited to assessment and intervention with people who have dementia and are living in their homes. Doble (2009) has identified several broad categories describing the occupational therapy role in dementia, including designing therapeutic environments, supporting occupational performance, and supporting and coaching caregivers. The following interventions represent a focus on one or more of the aforementioned categories.

Occupational therapists most often focus on occupation and environment when working with people who have dementia, and their caregivers. Gitlin and Corcoran (2005) developed the Home Environmental Skill-Building Program (ESP) designed to provide education and coaching to caregivers, with a focus on environmental modification. This program has recently been renamed Skills2Care (Rosalynn Carter Institute for Caregiving, 2012). The education component of this intervention approach assists families to build their understanding of the impact of physical and social environmental features on people who are experiencing changes in their cognitive abilities. These features include both how a home is set-up physically, and how caregivers are communicating with a loved one who has dementia. Through the use of coaching and skill-building, this intervention promotes a problem-solving approach for caregivers, enabling them to address three specific environments: physical (i.e., how objects are used), task (i.e., how daily activities and routines are orchestrated), and social (i.e., how family members and supports both formal and informal, can be organized and involved in daily care). The hands-on skill training characteristic of this intervention is related to five key areas including problem-solving, communication, task simplification, stress management and the modification of both physical and social environmental factors. The overall goal of ESP according to the authors is to focus on both the family caregiver and the individual with dementia to enhance quality of life and occupational performance (Gitlin & Corcoran, 2005).

The approach that has been outlined above includes aspects of supporting occupational performance as a key focus for occupational therapists. Interventions related to IADLs and to leisure involving social interactions may also be worthy of consideration for a population of older adults with Alzheimer's Disease (AD) based on a systematic review of the literature completed by Letts et al. (2011). The review considered interventions focusing on the following occupations: ADLs, IADLs and leisure with outcomes related to health, well-being and client and caregiver satisfaction. While the population was persons with dementia and their caregivers, it is feasible that interventions demonstrating promise with this population would also have relevance to persons with MCI. As part of an OT home-based community intervention, using environmental and compensatory strategies to address occupational performance issues with IADLs appeared to have a positive impact on the quality of life and health of this population, and their caregivers. Additionally, leisure that involved social interactions positively impacted the outcomes under consideration. As occupational therapists have the opportunity to focus on the health and well-being of people who have been diagnosed with MCI, enabling engagement in occupation is a natural fit.

Despite the clinical differences between MCI and dementia, one can look to the dementia literature and draw parallels to this emerging area of practice. Gitlin and Corcoran (2005) have categorized dementia by stage (i.e., mild, moderate and severe), and have included MCI in comparing corresponding information about memory, cognitive and behavioural changes, functional changes and impact on caregiving. The information presented illustrates the chronic and degenerative nature of dementia and inferences can be made about how the occupational therapy role changes with the progression of this disease. Of relevance to this research project is the MCI stage in comparison to mild dementia. At both stages, the overall goal of occupational therapy is to enable people to live their lives as fully and as independently as possible, engaging in valued occupations. At the MCI stage however, the occupational therapist may be focused on memory loss and behavioural changes such as anxiety, forgetfulness and mild confusion and the impact on perceived occupational competence and occupational performance. There may or may not be subtle functional changes and potentially a need or desire for client and caregiver education as clients and families seek to understand the day to day implications of having MCI. With regard to the provision of education however, caution may be prudent about how MCI is portrayed and the amount and detail of information provided given a lifetime conversion rate from MCI to dementia of approximately 60-80% (Busse, Angermeyer & Riedel-Heller, 2006). Therefore, not all people who are diagnosed with MCI will go on to develop dementia and ongoing assessment and intervention must be planned according to this unknown and potentially evolving clinical picture.

This approach to assessment and intervention is in comparison to mild dementia which involves a new diagnosis of a progressive and degenerative disease, additional changes to memory and cognition such as difficulty with word-finding, concentration, and problem-solving skills, and impairment in IADLs where assistance may be required to manage finances, medication, and way-finding. At the mild dementia stage, there may also be impairments in the ability to work, and to socialize with others and discussion of, and initiation of medication in an attempt to slow the disease process As dementia progresses to the moderate and severe stages, people generally experience difficulty engaging in ADLs independently, may move from a home setting to a facility setting, and the occupational therapy role shifts to focus on equipment needs, mobility issues, self-care, and eventually matters related to palliative care (Gitlin & Corcoran, 2005). While the OT role in assessment and intervention is different when comparing MCI and dementia, what is in common is the focus on the person, the environment and occupation as portrayed in the PEO, and an ongoing interest about how people are able to engage and to participate in their day-to-day lives.

Occupational Performance and Mild Cognitive Impairment

Occupational therapists have had a long-standing interest in understanding how people perceive their ability to manage in their everyday occupations. While there is a body of literature related to occupational therapy and dementia, understanding occupational performance in the context of MCI is a newer area of clinical and research interest. Historically the model of care has focused on remediation of, or compensation for impairment, and not on intervention at early stages of the disease process (e.g., at the onset of MCI) but this focus may be shifting as occupational therapists in Ontario continue to join FHTs providing primary care focused on wellness, health promotion, disease prevention and chronic disease management. Intervention at the MCI stage could have major positive implications on participation, quality of life and occupational engagement.

The role for occupational therapy in the context of MCI may not be immediately apparent as individuals with this diagnosis typically function independently in their occupational roles. (Kearney, Shaw & Gitlin, 2005). However, Lyketsos et al. (2002) studied 320 individuals with MCI in the context of a larger longitudinal study and reported the following statistics reflecting the presence of mental health issues: depression symptoms (20%), apathy symptoms (15%) and irritability symptoms (15%). Furthermore, Bierman et al. (2007) have demonstrated a non-linear relationship between depression and cognitive decline worth noting in the context of this project. The researchers discovered that people experienced more anxiety and depression in the early stages of cognitive impairment, and noted decreases as the disease process progressed. Whether mental health issues were present before participants were diagnosed with MCI, became more apparent following diagnosis or are somehow linked to MCI, it is important for occupational therapists to be aware of, and to address the potential for such issues. Furthermore, this clinical picture may become more complex with the presence of other chronic health issues.

# Awareness of Disability

A recent area of research involved the investigation of the individual awareness of disability in a sample of 35 community-dwelling older adults with a diagnosis of either MCI or dementia. The authors of the study (Ohman, Nygard, & Kottorp, 2011) argued the importance of evaluating individual awareness of disability in this context when planning interventions for individuals with MCI, and their families. For example, when individuals demonstrate a low level of awareness of disability, interventions may focus on supporting caregiver(s). With a high level of awareness, interventions may focus on individual education and teaching and implementation of compensatory strategies and assistive technology. Using the Assessment of Motor and Process Skills (AMPS) (Fisher, 1995) and the Assessment of Awareness of Disability (AAD) (Tham et al., 1999) developed to be used in conjunction with the first measure, the researchers examined the discrepancy between the level of skill observed during the performance of two ADL tasks and the level of skill reported. In general, participants with a diagnosis of MCI had better ADL performance and a higher mean awareness of disability than participants with dementia. This finding is in keeping with a clinical presentation of an intact ability to manage most if not all daily living tasks. It was unclear which ADLs participants chose to complete, and assessment happened in either a kitchen clinic setting or in the home environment. This research has implications for occupational therapists working with people who have MCI and dementia as individual awareness of disability may be an important consideration when planning occupational therapy intervention and ties in with assessment of self-perception of occupational performance.

Adapting Dementia Approaches to MCI

When considering the emerging role of occupational therapy in the context of MCI, there is potential to apply and adapt existing intervention approaches used with people who have dementia, and their caregivers. For example, Doble (2009) has outlined four strategies to support the occupational performance of people with dementia and their caregivers as follows: 1) supporting family in their role as caregivers, 2) identifying meaningful occupations, 3) training caregivers to use compensatory strategies, and 4) training caregivers to manage 'problem behaviours.'

As previously discussed, caregiving issues are generally absent at the MCI stage as people with this diagnosis are able to engage independently in their occupational roles (Gitlin, 2005). Perhaps an important idea to consider, however, is one of encouraging family and others in their role in supporting ongoing engagement in meaningful occupation despite a diagnosis of MCI and the inherent cognitive changes. In addition, the role of the occupational therapist at the MCI stage can be both coaching people to identify meaningful occupations, and taking a baseline measurement of occupational performance, using the Canadian Occupational Performance Measure (COPM) (Law, Baptiste, Carswell, McColl, Polatajko & Pollock, 2005). Instead of training caregivers to use compensatory strategies which would be a potential focus appropriate for the dementia stage, occupational therapists could be involved in providing education and training to people with MCI in the generation and use of strategies to compensate for the cognitive issues that they are experiencing. The fourth strategy outlined is training caregivers to manage 'problem behaviours.' A parallel idea for intervention with a population of people who have MCI is to focus on managing 'problem behaviours' such as those related to anxiety and negative self-talk.

The Impact of Other Factors on Occupational Performance

When developing this exploratory study and considering the attributes to be measured during an OT home assessment, it was important to think about factors other than MCI that could impact occupational performance in this population of older adults. The next section discusses chronic health conditions and falls related to the impact on occupational performance.

Chronic Health Conditions

When considering the clinical picture of people with MCI and dementia, what has not yet been discussed in any detail but is of great importance to this population is the impact of other chronic health conditions on occupational performance. When considering the health of older adults aged 70 and older, a sizeable percentage have one or more of the following chronic conditions or diseases: arthritis, cancer, cerebrovascular accident, diabetes mellitus, heart disease, hypertension and/or respiratory disease (Wilkins, Letts & Richardson, 2009). Of particular relevance to this project is a study of Canadian seniors receiving intervention for chronic health conditions in primary care settings. The sample consisted of

11,582 Canadian people of which 3,132 were community-dwelling seniors 65 years of age and older. Of those seniors surveyed, 76% aged 65 and older reported having one or more chronic health conditions, with an almost equal number of respondents reporting either 3 or more chronic conditions (i.e., 24%), or no chronic conditions (i.e., 26%). 50% of seniors surveyed reported 1-2 chronic conditions. The presence of chronic conditions increased with age as older seniors surveyed were more likely than younger seniors to have three or more chronic conditions (i.e., 36% versus 20%). Not surprisingly, participants' self-rating of overall health status decreased as the number of chronic conditions increased, and a greater number of chronic health conditions was linked to increased health care utilization in the primary care setting. This information highlights the need for occupational therapists to understand a diagnosis of MCI in the context of comorbidity. As occupational therapists interact with people who have MCI, it is likely that occupational performance issues identified as important may or may not be related to the cognitive changes that are experienced and instead to physical or psychological issues related to other chronic health conditions, or a combination of both. One additional topic of significant relevance to this research project is falls and how OTs have traditionally addressed this issue in a population of older adults.

Falls

One final topic worthy of consideration related to the health and well-being of older

adults who have been diagnosed with MCI is falls. Falls are a well-researched topic with extensive literature available across health disciplines, including medicine, nursing, and occupational therapy and physiotherapy, among others. There is no disputing the serious impact of falls, which are considered a major cause of fractures and other injuries, loss of mobility, psychosocial issues, placement in a long-term care setting and most seriously, early death (Tideiksaar, 2009). For adults over the age of 65, it is estimated that one third will experience a fall each year, and one half will experience multiple falls (WHO, 2007) in the same period of time. Within the context of this research study, it is important to note that greater than 70% of falls in older adults occur in the home while doing normal, everyday activities such as walking, engaging in ADLs and moving from one position to another (Soriano, DeCherrie, & Thomas, 2007). The environmental factors that are most commonly associated with falls in the home include poor lighting, slippery floors, carrying heavy and/or bulky objects and wearing poorly fitting shoes (Stevens, Holman, & Bennett, 2001). Stairs seem to pose a particular hazard, accounting for 10% of all falls (Soriano, DeCherrie, & Thomas, 2007). As the demographics in Canada shift to include a growing population of older adults, the cost of falls to the healthcare system is of major concern to policy and decision makers. When older adults are hospitalized as a result of a fall, costs are incurred based on length of stay, surgery related to fractures, rehabilitation, complications that may arise due to other comorbid health issues or complications, and blocked beds while patients wait to either go home or be placed in an alternate living arrangements, such as a long-term care facility. In Canada in 2005, approximately 1.4 million seniors fell at least once. With the projected shift in demographics, this number is anticipated to increase to 3.3 million in 2036 (Scott, Wagar & Elliott, 2010). Hip fractures are a common outcome of falls, and of those who experience this outcome, 20% will die within a year the fracture (Public Health Agency of Canada, 2005), and those who survive may experience decreases in both mobility and independence, post-fall syndrome (i.e., loss of confidence, change in activity level and potential for deconditioning and a greater risk of falls), and even depression (Scott, Wagar & Elliot, 2010). Furthermore, 20% of seniors who are hospitalized because of a fall never walk again which has a significant impact on overall health and well-being, occupational performance, and accessibility within home and community environments.

The perception of falls among older adults is an interesting one that warrants some discussion. While falls are a common occurrence among in this population, falls are often underreported, and may only be reported if the result is an injury and/or the need to go to the doctor, or to the hospital. While some older adults consider falls a normal and expected part of the aging process, falls are often related to a disease process or changes in overall health and well-being. With regard to reporting falls, there may be concern among older adults that this practice may lead to a change in life circumstances such as restrictions in participation and/or placement in a care setting (Tideiksaar, 2009). Furthermore, older adults with MCI may not report falls as reliably as those who do not have MCI.

Occupational therapists have been discussing falls and the impact on health and well-being for two decades. Within the context of the PEO model (Law et al., 1996), OTs understand the complex interaction of factors related to the person, the environment and the occupation, and thus the multi-factorial nature of this health issue. While there is extensive information available about falls prevention programs an in-depth review is beyond the scope of this project. In the context of the research that was completed, the focus related to falls is on person and environment through the identification of risk. The clinical measures that were selected and used related to home safety and falls risk will be discussed in more detail in a later section outlining the development of a toolkit of clinical measures that was used during OT home assessments with people who had been diagnosed with MCI in a primary care Memory Clinic setting.

What is of particular relevance however, is the link between MCI and falls. The risk of falls related to dementia is well-documented (Tideiksaar, 2009), but this has not been the case for MCI. In a study of older women with MCI living in the community (n=72), Liu-Ambrose, Ashe, Graf, Beattie and Khan (2008) were able to demonstrate a higher risk of falls in this population, as compared to older community dwelling women without MCI (n=86). The researchers looked at both physiological factors and cognitive domains related to falling and the older women with MCI had significantly higher fall risk profile scores, including significantly increased postural sway, and lower scores on three tests of executive functioning. While this study looked at risk factors for falls and not the actual incidence, identifying increased risk in older women with MCI is an important finding that has implications for the clinical management of this population, related to falls risk screening and falls prevention. The next chapter of this thesis will discuss the assessment of IADLs and issues related to methods and environmental context of relevance to this research study.

Summary

MCI has received very little attention in the occupational therapy (OT) literature; however, OTs are knowledgeable both about cognition and the impact of cognitive impairment on occupational performance (Gitlin & Corcoran, 2005). As the demographics in Ontario and Canada shift to include a growing proportion of people over the age of 65, it is anticipated that MCI will occur in increasing numbers (Findlay, Bernier, Tuokko, Kirkland, & Gilmour, 2010) and impact the quality of life experienced by those who are living day to day with this condition. One model that has emerged and is expanding in primary care settings in Ontario to address MCI and dementia is a growing primary care Memory Clinic Model (Lee et. al., 2010). To date, occupational therapy services have typically not been included in this Memory Clinic Model. Therefore, evaluation of the potential role of occupational therapy in this existing clinical framework is worthwhile. The identified gap in service that inspired this research project was the OT role in the provision of a streamlined assessment of functional abilities for people who have been diagnosed with MCI in this primary care Memory Clinic Model. Current practice involved a screening process of functional abilities involving self and surrogate reports but what was missing was a more in-depth assessment of how patients were functioning day-to-day in their home environments. With this gap in service in mind, and in consultation with this author's thesis committee, the following research question was generated: To what extent does a standardized occupational therapy home assessment protocol [or toolkit] of self-perception of occupational performance, instrumental activities of daily living (IADLs) falls risk and home safety change the plan of care for patients with MCI in a Memory Clinic model in primary care? The information gathered during an OT home assessment has the potential to assist the Memory Clinic team in the earlier diagnosis of dementia, or confirm an existing diagnosis of MCI, trigger timely referrals to the most appropriate community supports and programming, flag the need for further medical investigation and/or changes to the existing plan of care, support and enable continued participation in valued occupations, ease caregiver stress and prolong community living therefore delaying placement in long-term care. With the potential to influence a current plan of care and enable people who have been diagnosed with MCI to live well despite having this condition, evaluating the role of occupational therapy in this context appears to be an important endeavour in demonstrating the value of OT for this population.

The research strategy used was two-fold and the first step involved developing a toolkit of clinical measures to be completed by participants during an OT home visit. The tools that were included needed to be both accessible and readily available to OTs working in the community. Building the toolkit involved a structured process involving consistency of approach and selection of tools that were both evidence-based and occupation-based. Following the development of the toolkit, 31 OT home visits were completed with patients who had been diagnosed with MCI in three primary care Memory Clinics in Southwestern Ontario. The results of the home visits were provided to the Memory Clinic lead physicians and teams who considered the information in the context of the clinical picture and then indicated whether this additional data would influence the existing plans of care. The next section of this thesis is the literature review and will explore the following topics in greater detail: MCI and the Memory Clinic Model under consideration, the OT role in MCI and dementia, and the assessment of instrumental activities of daily living (IADLs), self-perception of occupational performance, falls risk and home safety in the context of MCI.

As discussed in this literature review, there is a key role for OTs related to assessment of functional ability in a population of older adults with MCI. The next chapter of this thesis will explore assessment in more detail, in the context of the present study. ADLs and IADLs will be discussed, in addition to methods of assessment and the importance of environmental context when considering the assessment of older adults who have been diagnosed with MCI in primary care.

Chapter 3: Assessment of Instrumental Activities of Daily Living (IADLs)

The assessment of IADLs is an important area of consideration for OTs working with people who have been diagnosed with MCI. As previously discussed, the Memory Clinic identified a gap in their ability to adequately assess functional abilities (i.e., IADLs) in the clinic environment. A change in the ability to perform key IADLs is an indicator of the potential progression from MCI to dementia and warrants further investigation (Doble, 2009). This chapter defines and differentiates between the terms ADL and IADL and reviews methods for assessing IADLs. Relevant issues discussed consist of environmental context and methods of assessment including self and surrogate reports, direct observation and performance-based measures. Clinical and outcome measures evaluating IADLs are reviewed in the fourth chapter of this thesis which outlines and discusses the development of the assessment toolkit used during OT home assessments of functional abilities.

Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs)

Distinguishing between ADLs and IADLs is an important consideration in the context of this research project, and as the attributes relate to the diagnoses of MCI and dementia. Activities of Daily Living (ADLs) can be defined as "an area of occupation that includes activities oriented toward taking care of one's own body" (Bonder & Dal Bello-Haas, p. 656). Also referred to as basic activities of living (BADL), and personal activities of daily living (PADL) included in this definition are basic everyday activities such as bathing, eating, dressing, toileting and personal hygiene. In comparison to ADLs, Instrumental Activities of Daily Living (IADLs) or complex ADLs (Perneczky et al., 2006) are defined as "an area of occupation that includes activities oriented toward interacting with the environment such as shopping or using the telephone" (Bonder & Dal Bello-Haas, 2009, p. 659). Additional examples of IADLs include preparing meals, managing money, cleaning the house, doing laundry, driving, and completing simple home repairs. The Canadian Occupational Performance Measure (COPM) (Law et al., 2005) captures the distinction between ADLs and IADLs through the use of the headings self-care, productivity and leisure. Under the self-care section, the sub-heading of personal care (i.e., dressing, bathing, eating and hygiene) provides examples of ADLs. However, functional mobility and community management which are also headings under self-care represent examples of IADLs including getting around indoors and outdoors, driving, shopping and managing finances. An example of an IADL captured under the leisure section of the COPM is making a phone call.

Generally, ADLs are rote, over-learned tasks that persist much longer for people who have progressive cognitive impairment. At the MCI stage, ADLs are preserved and intact (Gitlin & Corocan, 2005; Goldberg, 2010) unless there are other co-morbid health conditions impacting the physical ability to care for oneself. IADLs on the other hand involve more complex problem-solving and executive function and performance in IADLs can decline when people are experiencing a transition from MCI to dementia. In fact, IADL performance is one of the criteria used in the distinction between MCI and Dementia of the Alzheimer's Type. The Diagnostic and Statistical Manual of Mental Disorders (DSM-4, 1994) presents diagnostic criteria that includes cognitive deficits that cause "significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning." Older adults commonly experience issues with their ADLs and IADLs for a variety of reasons related to both their health status and overall well-being, and to the environment in which they are living. While older adults living in institutions have significantly more difficulty with their ADLs and IADLs, 28% of adults aged 65 and older living in the community reported difficulty with one or more ADLs, and 12% reported difficulty with one or more IADLs (Administration on Aging, 2012). The next section of this thesis will discuss methods of IADL assessment.

Methods of Assessment

The methods available for the assessment or evaluation of IADLs include interviews (i.e., structured and unstructured), self-report, surrogate or proxy report and direct observation of activities including the use of standardized tests and performance-based measures (Gitlin, 2005; Kielhofner, 2006). What is generally agreed upon is that using multiple sources when collecting data is the best opportunity to provide the most accurate clinical picture in healthcare (Tisnado et al., 2006). While screening for the presence of IADL performance issues, self-reports are commonly used and involve asking a person to rate himself or herself on overall ability, level of difficulty and whether or not assistance is required with each IADL. Self-report measures can be administered face-to-face, over the telephone, via mail or by email and represent a time and resource efficient approach to data collection. Despite the benefits of this approach, it is worthwhile to discuss the issues inherent in using this method of assessment exclusively. The many limitations of self-report include those related to objectivity, insight, candor, memory lapses, understanding of the questions and interpretation of the rating scale and the possibility of an overestimation or underestimation of one's skills and abilities (Gitlin, 2005). Self-reporting can lead to halo effects and results that may be influenced by positive self-presentation. Furthermore, people may be reluctant to disclose the issues they are having related to coping and managing in their home environment (Applegate, Blass, & Williams, 1990). In addition, self-reports are more likely to be valid when used with people who have no cognitive impairment and when the reporting is on simple daily activities such as self-care (Wilkins, Letts & Richardson, 2009). Surrogate or proxy reports can be obtained in similar methods to those used for self-reports and this information can be particularly helpful for people who are unable to provide accurate information about their performance due to cognitive issues. Surrogate reports can lack objectivity and also rely on the surrogate or proxy having a good knowledge of a person's day to day functioning with regard to a variety of activities. Surrogate reports can introduce bias and either provide an over or underestimation of a person's abilities. Self and surrogate reports represent an inexpensive, time-efficient way to collect information about IADLs but caution is prudent regarding the interpretation of the information that is collected, and using alternate methods to corroborate the clinical information gathered is recommended (Tisnado et al., 2006).

Occupational therapists frequently use the direct observation of occupational performance as a method to assess IADLs. This method may or may not involve the use of an assessment or a framework to objectively document observations and the abilities of the person performing the activities. When completed informally, an occupational therapist is not able to use the information gathered to compare across individuals or across time (Doble, 2009). Direct observation may occur in a variety of settings, including clinic, hospital and home. When compared to self and/or surrogate reports, information gathered during the direct observation of occupational performance may be more objective, but also requires more resources (i.e., physical space and therapist time) and only captures a person's behaviours and abilities at one point in time, related to one or several specific activities (Goldberg, 2010). Another limitation of this assessment method relates to the environment in which the direct observation occurs as generalizability is an issue when the observation environment is anywhere other than the home (Brown, Moore, Hemman, & Yunek, 1996).

While standardized tests consist of artificial tasks related to cognition and/or motor abilities (Kielhofner, 2006), performance based measures provide the opportunity to evaluate people using a variety of functional, everyday tasks in a standardized format (Goldberg, 2010). Unlike a self or surrogate report, performance based evaluation affords the opportunity for real-time observation of IADLs, and an understanding of the issues that are either helping or hindering performance. There are both advantages and disadvantages to the use of performance based measures, but there is wide acceptance of their use because of the rigour that is introduced into the clinical assessment process (Kielhofner, 2006; Gitlin, 2005) when compared to use of informal checklists or questionnaires, and unstructured observations of performance. The use of this type of measure allows for comparison of performance within and between participants and may offer the ability to document change over a period of time. The disadvantages to the use of performance based measures can include issues related to cultural relevance and sensitivity, and the lack of ability to precisely answer more detailed research questions as information that is provided may be either too broad or too general in the context of a research project (Kielhofner, 2006). Furthermore, the use of performance based measures involves additional time, cost and availability of the assessment materials (e.g., manual and forms), the availability of a trained evaluator and the challenges associated with generalizability of findings from a clinic setting to a home environment (Gitlin, 2005). Environmental context related to the assessment of IADLs will be discussed in the next section of this paper.

Environmental Context

When completing clinical assessments, environmental context is an important factor for consideration, both when planning the assessment, and when interpreting the results. Occupational therapists have long recognized the value of, and have been funded for home visits, or "house calls" (Sinha, 2013). While much valuable clinical information can be collected in a traditional clinic setting, there is little research that has been done to date related to the generalizability of such findings to the home environment. It is important to note that impairments in IADLs may not be detected in routine clinical visits (Applegate, Blass, & Williams, 1990), and when assessments of IADLs are completed in a clinic setting there are many potential barriers to arriving at an accurate picture of how a person is functioning day to day in their home environment. Such barriers may include a brief length of visit, positive self-presentation and the differences between a simulated and a natural environment. With the ongoing financial pressures facing the health care system, clinic visits may be perceived as most cost effective. While this is true for issues that do not require an understanding of how a person functions day to day in their home environment, there is a risk of missing key information related to performance of IADLs, home safety and falls risk when information is gathered exclusively in a clinic environment. While not everyone who is assessed in a Memory Clinic Model necessarily requires a home visit to inform and/or enhance their plan of care, the question is how to decide with confidence who would benefit from an OT home visit and therefore maximize resources and provide this added layer of care for those who need it most. People have a tendency to be more relaxed when in a familiar home environment and may therefore be more forthcoming with information related to occupational performance issues and how they are managing with their IADLs. Furthermore, there may be challenges associated with attending additional assessments at the clinic including geography, weather conditions, confidence with and/or ability to drive and access to alternative methods of transportation if needed. If one goal of the Memory Clinic is to enable people with MCI to live well in their own homes and communities, it is imperative to evaluate their abilities and guide their plan of care with a solid knowledge and understanding of where and how they live. Bottari, Dutil, Dassa, & Rainville (2006) discuss the advantages of assessments occurring in home environments. The researchers note that performing tasks in a familiar and natural environment has been shown to result in a more accurate depiction of skills and deficits, and provide insight into the factors that help and hinder performance in this everyday environment. Furthermore, assessment in the home environment better informs intervention related to the specific equipment, adaptations and modifications that will contribute to enhanced occupational performance at home. Given the available information on the assessment of IADLs and the importance of environmental context, using a performance-based measure in the home environment was the method of choice by the researcher for use with older adults who had been diagnosed with MCI in the Memory Clinic. The following chapter of this thesis discusses and describes the process of developing a clinical assessment toolkit to be used during OT home visits with participants of the study under consideration.

Chapter 4: Development of a Clinical Assessment Toolkit

The development of clinical assessment toolkits using a critical appraisal process is of relevance to an array of occupational therapy practice areas and environments. The purpose of this chapter is to describe the process used to develop a clinical assessment toolkit used during home visits with participants diagnosed with MCI in a primary care Memory Clinic setting. A tool can be defined as "anything used to achieve some purpose or necessary to one's profession or occupation" (Gage Canadian Dictionary, 1997, p. 1542), whereas a toolkit is a "special set of tools that are kept together and that are often used for a particular purpose (Collins Cobuild English Dictionary, 1995, p. 1765), and "skills and knowledge that are useful for a particular purpose or activity, considered together" (Retrieved July 15, 2013 from http://www.dictionary.cambridge.org/dictionary/business-english/tool-kit).

In the context of this research project, the tools refer to the clinical measures that were selected for the OT home assessment through the use of a critical appraisal process. The toolkit included the clinical measures, the student researcher's skills and knowledge about client-centred, occupation-focused, community-based practice and the therapeutic use of self during interactions in participants' home environments. The purpose of assembling a toolkit of clinical measures and completing occupational therapy home assessments was to provide three Ontario primary care Memory Clinic teams with key clinical information about how people were functioning in their home environments following a diagnosis of MCI. A number of criteria were developed to guide the selection of clinical measures including a goal of completing home visits in a one-hour time frame, therefore developing an efficient model while easing the burden of measurement. Criteria specific to clinical measures included suitability for use in the home environment, good psychometric properties (i.e., reliability, validity and clinical utility), and an ability to capture a range of issues that may be impacting occupational performance in this population. With environment as a key consideration for occupational therapists, and in the context of this project, the ability to function in one's home environment, an assessment in a clinic setting was not deemed sufficient to answer the research question at hand. Technically, all clinical measures in the assessment toolkit could be completed in a clinic setting, but in the Memory Clinic model, the burden of measurement on clinic day is substantial with testing occurring over a two-hour timeframe and a team meeting to present findings and discuss a plan of care (S. Pritchard, personal communication, August 15, 2013). Based on the current assessment schedule, there is not additional time to administer other tools, and would involve additional stress for patients on clinic day. The Memory Clinic team had decided that a key missing piece of information was related to how patients were functioning in their home environment, and were looking to fill this gap.

Toolkits in the Occupational Therapy Literature

In occupational therapy research published in the last decade, there is a scarcity of information related to the development of clinical assessment toolkits for use during occupational therapy home visits. When searching the occupational therapy literature related to toolkits, two practice areas were represented, including an elderly population at risk of falls (Schryburt-Brown, Dixon, Paton, Connolly, & Craik, 2004) and most recently, older adults who have had a stroke (Poulin, Korner-Bitensky, & Dawson, 2013). Additional examples of toolkits were found online and included The Driving and Dementia Toolkit (Regional Geriatric Program of Eastern Ontario, 2009) (RGPEO), the Tools for Living Well Toolkit (www.caot.ca/PDF/ToolsforLivingWell.pdf), focused on community falls prevention and the Occupational Therapy Toolkit, a comprehensive resource designed for clinicians and educators. The toolkits aforementioned appear to have different objectives, are designed for a variety of audiences, and may focus on one or several areas such as assessment, development of a plan and/or provision of education. The following section will provide a brief summary of the toolkits as noted above.

Responding to a gap in the literature, an online working group conducted an extensive review and summarized best practice evidence related to the OT assessment of falls and associated risk factors in an elderly population (Schryburt-Brown et. al., 2004). The outcome was a comprehensive chart summarizing risk factors and corresponding clinical measures, within the framework of the Canadian Model of Occupational Performance (CMOP) (Law, Polatajko, Baptiste & Townsend, 1997). This assessment toolkit was designed to be used as a quick reference guide for occupational therapists involved in the assessment and intervention with older adults at risk of falls. Because the toolkit is not used as a whole, but instead therapists choose measures that best suit their client population and practice setting, it is difficult to report more recent information on how this project designed to promote expert practice has been utilized in clinical practice.

The Stroke-Specific Executive Function Toolkit (Poulin, Korner-Bitensky, & Dawson, 2013) was developed in response to a clinical concern that OTs rarely use assessments of executive functioning in the context of stroke assessment and rehabilitation. The purpose of this research and resulting toolkit was to increase clinician awareness about the importance of clinical measures evaluating executive function, and to develop a resource for clinicians to use across the continuum of stroke rehabilitation. The Stroke-Specific Executive Function Toolkit represents a resource for clinicians to use to facilitate the identification and utilization of appropriate assessment tools of executive functioning in a population of older adults who have experienced a stroke.

The Driving and Dementia Toolkit (3rd edition) was originally developed in 1997 and has evolved over time to include emerging clinical and research information related to this complex area of practice (RGPEO, 2009). Developed by an interdisciplinary team of health professionals, including OT, this resource includes tools related to assessment of fitness to drive and guidelines for discussing retirement from driving. This toolkit is freely available to health care professionals and represents an evidence-based toolkit focused on driving and dementia.

The Tools for Living Well Toolkit (CAOT, 2004) is a resource promoting falls prevention through the use of assistive devices. The intended audience is not only health professionals, but also community businesses such as hoteliers and retailers. The toolkit encourages the promotion of assistive devices as a means of preventing falls through the education of seniors and their caregivers about choosing and correctly using assistive devices. The Tools for Living Well Toolkit encourages a shift in thinking, promoting assistive devices as tools for living well, versus only for people with disabilities. This toolkit is freely available and includes reproducible handouts and brochures.

The last toolkit found online was the Occupational Therapy Toolkit (Hall, 2014) which has been developed by an OT for use by clinicians and educators. This toolkit represents a comprehensive and practical resource manual intended for use with an aging population and/or adults who have physical disabilities. Available for purchase as a book, or an e-book, the Occupational Therapy Toolkit includes reproducible patient education handouts, treatment guides and additional resources available on a blog. The resources have been designed to be relevant to a variety of educational and clinical environments.

Assembling clinical tools into a toolkit provides the opportunity to promote best practice in occupational therapy through the use of evidence-based and occupation-focused clinical measures, approaches and resources. Toolkits represented in the OT literature varied, and there did not appear to be existing literature about the development and use of toolkits of clinical measures designed for the assessment of multiple attributes for a specific population. What may be similar between exiting toolkits and the toolkit developed and used for this exploratory study is the identification of a clinical gap, related to assessment, knowledge and/or resources.

The Process of Toolkit Development

For the purpose of this research project, clinical measures were selected with the goal of building a toolkit, ensuring that the OT home assessment reflected an approach that was both evidence and performance-based, occupation-focused and administered in a timely manner. This approach to building a toolkit differed from the toolkits currently represented in the occupational therapy literature where the focus to date has been specific to one component or performance area only (e.g., arthritis and driving), or involved resources specific to one topic (e.g., use of assistive devices) or multiple topics (e.g., Occupational Therapy Toolkit). The toolkit developed as part of this research project involved starting with a gap in an existing model of care and tailoring the selection of clinical measures using the framework of the PEO and the ICF, as discussed earlier. The overall purpose of the toolkit was to evaluate performance of IADLs and how participants were functioning in their home environments. In addition to the consideration of IADLs, the OT assessment included the use of an interview-based tool encouraging participants to identify the key issues that were impacting their ability to participate safely and/or effectively in their everyday occupations, a home safety screening tool, and a tool that identified potential falls risk. When selecting clinical measures, the following broad criteria were applied: evidence of reliability and validity, good clinical utility, consideration of the burden of measurement, ability to use tools effectively and efficiently in a home setting and an overall toolkit of clinical measures that was reflective of the population being studied (i.e., older adults with MCI), both in terms of potential health challenges and occupational performance issues. Clinical measures were selected using a critical appraisal process involving various search strategies and levels of critique. For example, an initial list of potential measures of ADLs and IADLs was generated through an informal survey of occupational therapists working with adults and seniors providing community-based assessment and therapy in the Stratford and Guelph, Ontario areas and through this therapist’s involvement in a special interest group exploring cognitive assessments ('Grey Matters,' personal communication, September 13, 2011). The initial list included the following measures, used by OTs in this working group to assess ADLs and IADLs in the community: Barthel Index (BI) (Mahoney & Barthel, 1965), Functional Independence Measure (FIM) (Keith, Granger, Hamilton & Sherwin, 1987), Executive Function Performance Test (EFPT) (Baum, Morrison, Hahn, & Edwards, 2008), Cognitive Performance Test (CPT) (Burns, Mortimer, & Merchak, 1994), Arnadottir OT-ADL Neurobehavioural Evaluation (A-ONE) (Arnadottir, 1990), ADL Profile (Dutil, Bottari, Vanier, & Gaudreault, 1994) and the Independent Living Scales (ILS) (Loeb, 1996). With the exception of the CPT, the EFPT and the ILS all other measures were eliminated prior to additional critical appraisal because of a focus on ADLs and not on IADLs. The exception was the ADL Profile which was eliminated from further review due to a focus on ADLs and IADLs. A decision was made to eliminate measures that included both ADLs and IADLs and include measures of IADLs only. The rationale for this decision was based on the expectation that ADLs would be intact in a population of older adults with MCI.

The first two assessments under consideration and included in the critical appraisal process were the CPT and the EFPT, both performance-based assessments of cognition. While the psychometrics of these measures were adequate, with input from committee members, this researcher recognized that additional assessment of cognition through the observation of IADL performance was not the information that would be most beneficial in the context of the Memory Clinic Model and the research question at hand. With this realization in mind, the CPT and EFPT were eliminated from further review and an extensive literature search was completed to

generate a list of performance-based measures used by occupational therapists to assess IADLs. The following section of this chapter will outline the selection process of the four attributes to be measured including: 1) self-perception of occupational performance; 2) IADLs; 3) home safety, and; 4) falls risk. While the rationale to use a performance-based measure of IADLs with patients who have been diagnosed with MCI was described within the Memory Clinic Model above, the use of clinical measures assessing the other attributes listed involves additional discussion. The summary in the next section is organized by attributes to be measured and include the psychometric properties of the tools that met the inclusion and exclusion criteria selected. The criteria headings utilized were developed based on the Outcome Measures Rating Form and Guidelines (Law, 1987) and those used by Donnelly (2013) during a presentation about clinical measures of relevance to primary care OTs. A selection of clinical measures will be organized in table format and included as appendices to this document.

Attributes to be Measured during Occupational Therapy Home Assessment

Self-Perception of Occupational Performance

Occupational therapists have had a long-standing interest in understanding how people perceive their ability to manage in their everyday occupations. While there is a body of literature related to occupational therapy and dementia (e.g., Dopp et al., 2013; Gitlin, 2005; Letts et al., 2011), understanding occupational performance in the context of MCI is a newer area of clinical and research interest. Within the current Memory Clinic Model, there is no specific method to gain a clear understanding of the patient’s self-perception of occupational performance. An emerging role for OT is the enablement of people with MCI to live their lives as fully and independently as possible despite cognitive changes, and potentially other co-morbid health issues. Historically, the model of care and focus of health care funding has been on disease and not on intervention at early stages of the process (e.g., in MCI). Intervention at the MCI stage could have major positive implications on participation and quality of life through an understanding of self-perception of occupational performance. Clinical measures of this attribute are discussed and summarized next.

When selecting a measure of self-perception of occupational performance, this researcher was looking for clinical measures that were evidence-based, client-centred, occupation-focused and a good fit for use in participants' home environments. In addition to the COPM, the Caregiver Assessment of Management Problems (CAMP) (Gitlin & Cocoran, 2005) was considered briefly but excluded as it is an assessment tool designed to be used with caregivers of individuals with dementia. As such, this tool focuses on ADLs only, and more specifically on those that become more difficult as the disease advances (e.g., bathing, dressing, eating and mobility). This tool was not a good fit for use with participants with MCI, as a way to develop rapport and to capture the issues that were experienced in performing everyday activities in the areas of self-care, productivity and leisure. When searching for other patient interview tools and questionnaires, the majority available appeared to be specific to particular health-care and rehabilitation settings and/or to the presenting health condition. Examples included The MACTAR Patient Preference Disability Questionnaire specific to arthritis (Tugwell et al., 1987), The Awareness Questionnaire for people who had experienced a brain injury (Sherer, Bergloff, Boake, High, & Levin, 1998), The Oswestry Disability Index (Fairbank & Pynsent, 2000) and The Roland-Morris Disability Questionnaire (Rowland & Morris, 1983) for low back pain and lumbar spine issues, respectively. In addition to the COPM, the Patient Specific Function Scale (PSFS) (Stratford, Gill, Westaway, & Binkley, 1995) was included for consideration as it was a generic tool designed to be used with any diagnosis, given client willingness and cognitive ability to participate. Although the PSFS was client-centred, this clinical measure was eliminated from further consideration as it would have required adaptation to ensure a comprehensive focus on occupation and occupational performance.

The COPM was chosen based on the following considerations: good clinical utility in capturing self-perception of occupational performance, evidence of good to excellent psychometrics, and ease of use in a variety of clinical environments, including a participant's home. Psychometric information for the COPM was reviewed and tabled (see Table 1). This researcher has previously used the COPM and found the measure to be very useful in providing a client-centred approach to occupational performance issue identification and goal-setting. As an occupation-based and client-centred clinical measure, the use of the COPM provides a summary of occupational performance issues within the context of MCI and provides a beneficial tool for educating others, including the Memory Clinic team about the role and scope of OT. Worth noting was the decision to use the COPM as a descriptive measure only, with participants identifying occupational performance issues and providing a score for importance at one point in time only, during the OT home visit and was not used as an outcome evaluation tool.

Instrumental Activities of Daily Living (IADLs)

When searching the literature for potential clinical measures assessing IADLs, inclusion and exclusion criteria were developed and utilized. Inclusion criteria included performance based measures focusing on activity/participation (ICF model), measures of IADLs only (i.e., not a mix of ADLs and IADLs), administration time of 30 minutes or less, a good fit for administration in home environments and evidence of reliability, validity and good to excellent clinical utility. Exclusion criteria included measures of IADLs that involved self and/or proxy reports because of previously discussed limitations, IADL and ADL items, administration time of 30 minutes or more, extensive training and/or cost related both to training and to assessment materials, and a lack of evidence of reliability and validity and/or poor clinical utility. The search for clinical measures assessing IADLs included use of health databases (i.e., CINAHL and PubMed) and occupational therapy textbooks published within the last 10 years.

Nine clinical measures were considered but eliminated based on the inclusion and exclusion criteria and therefore did not reach the next level of critical appraisal. These measures included: the Kohlman Evaluation of Living Skills (KELS) (Kohlman-Thompson, 1992); the Assessment of Living Skills and Resources (ALSAR-R2) (Clemson, Bundy, Unsworth, & Fiatarone Singh, 2008); The Direct Assessment of Functional Abilities (DAFA) (Karagiozis, Gray, Sacco, Shapiro, & Kawas, 1998); Structured Assessment of Independent Living Skills (SAILS)(Mahurin, DeBittignies, & Pirozzolo, 1991); ADL Situational Test (Skurla, Rogers, & Sunderland, 1988); Direct Assessment of Functional Status (DAFS); (Lowenstein et al., 1989), Extended Activities of Daily Living Scale (EADL) (Nouri & Lincoln, 1987); Refined ADL Scale (RADL) (Tappen, 1994), and; the OT Evaluation of Performance and Support (OTAPS) (Nadler, 1993). Measurement of both ADLs and IADLs was the most common reason for exclusion of clinical measures, followed by testing environment and length of administration. Clinical measures that were excluded based on the criteria described did not advance to the next level of critical appraisal which involved consideration of psychometric properties. Additionally, the Assessment of Motor and Process Skills (AMPS) (Fisher, 1995) was considered but eliminated because this assessment is not a measure of IADLs. Furthermore, this research had concerns about both the training costs involved, and the uptake of this tool by therapists working in the community. The requirements for clinicians include extensive training and involvement in a trial period for calibration. Despite a client-centred, occupation-focused approach to the assessment of IADLs and extensive psychometric testing (Gitlin, 2005) the costs and training involved may be prohibitive for facilities and for therapists, and therefore the AMPS was excluded from further consideration. The Independent Living Scales (ILS) (Loeb, 1996) was eliminated because many of the items require verbal responses as opposed to being performance based and the administration time was lengthier (i.e., 45 minutes to 1 hour) with the manual suggesting that two sessions may be required for completion. All of the aforementioned clinical measures have been tabled according to exclusion criteria applied (see Table 2). Finally, the Texas Functional Living Scale (TFLS) (Cullum, Weiner, & Saine) was considered for inclusion in the clinical assessment toolkit and is discussed in more detail in the next section.

The clinical measure that was considered and ultimately selected for inclusion in the assessment toolkit was the Texas Functional Living Scale (TFLS) (Cullum, Weiner, & Saine, 2009), a relatively new performance based measure designed to assess IADLs. A comprehensive summary is presented in Table 3, and the main strengths of the TFLS included an exclusive focus on a range of IADLs, a brief administration time (i.e., 15-20 minutes), adequate to good reliability and excellent clinical utility. While the authors note that more research is required to establish the validity of the TFLS (Cullum, Weiner & Saine, 2009) this measure has good face validity and appears to represent a high-quality fit with the existing Memory Clinic Model and a population of older adults with MCI. Originally developed for use in the context of Alzheimer’s disease (AD), the purpose of the TFLS is to provide relevant information related to an individual’s ability to function independently, in the context of IADLs. The measure was developed in response to some of the limitations inherent in the existing assessment processes used to evaluate functional abilities including self-report and caregiver report bias and lengthy tools that include both IADLs and ADLs. The TFLS includes 24 items assessing simulated IADLs within the following four functional domains: time (i.e., ability to use clocks and to tell time), money and calculation (i.e., ability to count money and to write cheques), communication (i.e., ability to make a snack and to use a phone book and phone) and memory (i.e., ability to remember simple information, and to remember to take medications). The authors of the TFLS report that the results of this IADL assessment can help to support diagnostic work-ups, placement decisions, treatment planning, evaluation of treatment outcomes and monitoring of disease progression. In summary, the TFLS is a brief assessment of IADLs with an administration time of 15-20 minutes. The TFLS is a performance-based measure that is oriented to cognitive tasks and can be administered in a variety of settings including clinics and homes. Within the framework of the ICF, the focus of the TFLS is at the level of activity/participation and includes the opportunity to record behavioural observations including those related to language, physical appearance, visual/auditory/motor problems, medications, attention and concentration, attitude towards testing, affect/mood, unusual behaviours/verbalizations and other. Home Safety & Falls Risk

Home safety and falls risk are two attributes that are interconnected and an area of expertise for occupational therapists. Falls pose a serious health risk to older adults and are the leading cause of nonfatal injuries and injurious death in adults 65 and older (Fabre, Ellis, Kosma, & Wood, 2010). While much of the falls literature has focused on older adults with dementia, an interest in the link between MCI and falls has been more recent. As previously discussed, there is a small body of literature to support the hypothesis that older women with MCI are at greater risk of falls (Liu-Ambrose et al., 2008) and that falls risk screening and prevention at the primary care level may be a very important factor in the medical management of older adults with MCI.

When considering home safety, the overall goal in the context of toolkit development was the inclusion of a screening tool of participants' home environments in the context of occupational performance to determine whether or not more in-depth home assessment and intervention related to home safety would be beneficial as part of the overall plan of care. With this goal in mind, The Safety Assessment of Function and the Environment for Rehabilitation (SAFER) tool (Oliver, Blathwayt, Brackley, & Tamaki, 1993) was briefly considered but excluded due to the length of the measure. While described in some OT literature as a screening tool, the Safer Tool is in fact a more in-depth and comprehensive assessment of the home environment. Likewise, the Westmead Home Safety Assessment (WeHSA) (Clemson, Fitzgerald, & Heard, 1999) has a lengthy administration time (i.e., 1.5 hours) and was excluded from consideration. The Safety Assessment Scale (SAS) (Poulin de Courval et al., 2006) which is available in both a shorter screening version and a longer, more comprehensive version, is a measure that captures activities and behaviours that pose significant risk to people living in the community, such as smoking, fires and burns, food poisoning and wandering. Based on the findings, the SAS is designed to lower the risk of accidents through the provision of recommendations and is a tool that can enhance case management. As a result, the SAS was excluded, but it is anticipated that this information would be more relevant to collect further into the disease process, and would be best used with a key informant.

The clinical measure that was considered and ultimately selected for inclusion in the assessment toolkit was the Home Falls and Accident Screening Tool (Home Fast) (Mackenzie, Byles & Higginbotham, 2002). This clinical measure is easily accessible to clinicians online and is available to download at no cost. Developed for older adults living in the community, the Home Fast can be administered in approximately 15-30 minutes and provides the opportunity for the early identification of home safety issues. A summary of the Home Fast is presented in Table 5.

While the Home Fast addresses falls risk at the level of the environment, an additional goal of the toolkit was to evaluate this attribute related to the physical function of participants. Based on a literature review and an informal survey of occupational therapists working with older adults in the community, several clinical measures were considered for inclusion. The Berg balance scale (Berg, Wood-Dauphinee, Williams & Maki, 1989) represents an in-depth measure of balance, involving a 14-item scale. Although this clinical measure requires little training and equipment, it was excluded due to an approximate administration time of 15-20 minutes. The Tinetti balance assessment (Tinetti, Williams, & Mayewsk, 1986) represents another example of a clinical measure that focuses on physical function related to falls risk, but the training required is extensive, the administration time is 20 minutes, and therefore this measure was excluded from further consideration.

The Timed Up and Go (TUG) (Podsiadlo & Richardson, 1991) was considered and ultimately selected for inclusion in the toolkit of clinical measures to be used during the OT home assessment. This tool met the criteria of evaluating physical function related to falls risk, had an administration time of less than five minutes, required little training and equipment and was easily used in home environments. A summary of the TUG is presented in Table 6.

The measures that were included in the toolkit to be used during the OT home assessment visits are the COPM, the TFLS, the Home Fast and the TUG. The researcher was confident that all clinical measures could be completed in a one-hour time frame, thus reducing the burden of measurement for participants, while gaining a comprehensive picture of how people with MCI were functioning in their home environments. The following timeframe for completion of clinical measures is estimated: COPM, 10-15 minutes, TFLS, 15-20 minutes, Home Fast, 15-25 minutes and the TUG, 5 minutes, with home visits ranging from 45 to 65 minutes in total. The next chapter of this thesis discusses the methods of this exploratory study.

Chapter Five: Methods

Overview

In this exploratory study, a toolkit of clinical measures was developed to be used during a one hour OT home assessment. The attributes that were measured included self-perception of occupational performance, IADLs, home safety and falls risk. This chapter describes the study design, the participants and setting, the procedure, the measures and reporting of OT home assessment findings.

Research Question

The following research question guided the study: To what extent does a standardized occupational therapy home assessment protocol [or toolkit] of self-perception of occupational performance, instrumental activities of daily living (IADLs) falls risk and home safety change the plan of care for patients with MCI in a Memory Clinic model in primary care? The plan of care includes the diagnostic process and health intervention plans including recommendations and referrals to community services and agencies. OT assessment findings that contribute to the overall plan of care may confirm what the team is recommending related to diagnosis and referrals to community agencies and services. A change in the overall plan of care based on the OT assessment findings may mean that the Memory Clinic team initiates additional referrals, changes existing referrals, considers a diagnosis change from MCI to dementia, initiates a discussion about medication options and/or makes a decision to reassess a patient earlier than originally anticipated. Through the examination of this research question, it may also be possible to identify which patients with MCI are more likely to benefit from an OT home assessment versus those that do not need and/or will not benefit from this additional service.

Design

To answer the research question, a before and after study design was utilized. As an exploratory study of an occupational therapy assessment process in an area with very little knowledge, this design was an appropriate choice that was both simple and inexpensive. There are several limitations inherent in a before and after design: comparing the effects of the assessment process with another process or to a control group is not possible, and generalizability is limited (Kielhofner, 2006).

Participants

Participants eligible for this study included those who had been referred to and assessed at the primary care level in one of three Memory Clinics: The Centre for Family Medicine (Kitchener, Ontario), The Stratford Family Health Team (Stratford, Ontario) and the Grandview Medical Centre Family Health Team (Cambridge, Ontario). The inclusion criteria for the study for eligibility for occupational therapy assessment were the following:

* a new or ongoing stable diagnosis of Mild Cognitive Impairment (MCI) at an initial assessment or follow-up visit at the Memory Clinic
* ability to read, write and to speak English fluently

All participants with MCI were included, whatever the cause, to determine the impact of the occupational therapy home assessment findings on the plan of care. Exclusion criteria included:

* the inability to communicate in English as verbal responses were required to complete the COPM, the TFLS and the Home Fast
* the inability to provide informed consent to participate in the research study

For this exploratory project, a sample size of 30 was planned to allow the investigators to examine the feasibility of the intervention and the degree and magnitude of change in the outcomes in order to plan or future larger sample research using a more rigorous design. With recruitment happening among three teams, one additional participant was accepted for a total of 31 participants completing the OT home assessment.

Ethics

Ethics approval was granted by the Hamilton Health Sciences and McMaster University Research Ethics Board (REB). Following consideration of the initial application, clarification was requested by the REB related to the student researcher and the circle of care. An explanation was provided that the student researcher was not part of the circle of care because there was no assignment of ongoing care or clinical responsibility. The REB also recommended a modification to the consent form making explicit the provision of the OT assessment findings to Memory Clinic teams and this task was completed. At this point in time, a change was made to the study procedure related to the collection of personal health information. Based on feedback from the REB, the collection of personal health information shifted from the student researcher to a member of each Memory Clinic team. This change ensured the protection of personal health information that was unrelated to this research study. One final revision at the request of the REB involved the addition of a protocol for the student researcher to use should concern arise about a participants' ability to consent to assessment during the OT home visit (see Appendix A). Given a diagnosis of MCI this occurrence was not expected but provided the REB with assurance that a plan was in place for this possibility. Following final study of approval, recruitment of participants was underway.

Procedure

During their scheduled Memory Clinic visit, patients with MCI (i.e., new or ongoing stable diagnosis) were informed about the research study by either the physician lead, social worker, nurse or occupational therapist and given a handout summarizing this information (see Appendix B). The aforementioned team member then asked the patient if he or she would be willing to discuss their participation in more detail during a phone call with the student investigator. Verbal consent was obtained to provide the patient’s full name (i.e., first and last) and telephone number to the investigator and this consent was documented in the patient's Health Record or Electronic Medical Record (EMR).

As a final step in the recruitment process, the team member notified the investigator by telephone with the patient’s name and telephone number by leaving a voicemail message in a confidential and secure voicemail box. Voicemail messages were checked daily and participants were then contacted by telephone within three days of receipt of the message. Research related calls were made during the week, unless the purpose of the call was to confirm a home visit scheduled on either a Monday or a Tuesday of the following week and then a call would be placed over the weekend. The student investigator started the telephone conversation by asking to speak to the participant, using both first and last names. Following confirmation that the participant was on the phone, an introduction was made including student researcher name, role and designation (i.e., student researcher and occupational therapist), and affiliation (i.e., McMaster University). The student investigator then followed a telephone script (see Appendix C) to describe the research project in detail, to answer any questions the potential participant may have, and if verbal consent to participate was provided, to schedule a mutually agreed upon home visit to complete the OT assessment. A one-hour home visit was arranged and occurred within one to two weeks of the Memory Clinic appointment to avoid potential changes in the health and/or cognitive status of the participant. One to two days before the home visit, the investigator placed a reminder call to the participant to confirm the visit date and time. The participant was encouraged to have a spouse or other family member or support person present at the time of the home assessment.

When the OT home assessment visit was scheduled, the Memory Clinic was notified and either the social worker, nurse or occupational therapist on the team filled out Part One of the data collection form (see Appendix D) developed by the investigators, including site number, demographics (i.e., age, gender, current living arrangements, diagnosis, and current or past occupation), score on the Montreal Cognitive Assessment (MoCA), and current plan of care including Memory Clinic team members presently seeing the patient, referrals to community agencies, and family and other community supports. This information was collected from the participant’s Health Record or EMR.

When conducting home visits, the researcher wore photo identification and provided an introduction when greeted at the participant's door, asking for the person by first and last name to ensure arrival at the correct destination. All data collection occurred in the participant’s home during the course of the one hour visit. Prior to the administration of the clinical measures, the purpose of the research project was described using the letter of information and consent form (see Appendix E) and participants were encouraged to ask any questions that they have, which were then answered by the researcher. The researcher then informed the participant that with their consent, the assessment findings would be shared with the Memory Clinic team which may then result in a change in the original plan of care, with an overall goal of living well with MCI. The participant then signed the consent form prior to the completion of four clinical measures, to be introduced briefly in the next section of this paper. An in-depth discussion of the clinical measures utilized including psychometrics and clinical utility was previously discussed in the context of the development of the assessment toolkit for use during this research study.

# Measures

Canadian Occupational Performance Measure (COPM)

The first clinical measure that was used by the researcher was the COPM (Law et al., 2005) both as a tool to facilitate rapport with the participant and to gain an understanding of the participant's self-perception of his/her occupational performance in the areas of self-care, productivity and leisure, including IADLs such as driving, managing finances, shopping and preparing meals. The COPM is an occupation-based, semi-structured interview with excellent clinical utility, good reliability and is highly responsive to change (Law, Baum & Dunn, 2005). The COPM was used in an open-ended format as a descriptive tool and participants scored their performance out of ten at one point in time only, during the initial home visit. Completion of the COPM took between 10-15 minutes depending on the personality of the participant and the number and/or complexity of the issues that were being experienced and described. The rating scale was used to ensure that participants understood how to score the importance of identified occupational performance issues on a scale of 1 to 10, with 1 being not very important, and 10 being very important. Performance and satisfaction were not measured during the OT home assessment as ongoing intervention was not planned and the goal for the use of this tool was to capture the occupational performance issues identified by this population.

Texas Functional Living Scale (TFLS)

After finishing the COPM, participants completed the TFLS. The TFLS is a 24-item performance-based assessment of IADLs using a variety of simulated everyday activities. The psychometrics of this clinical measure include very high inter-rater reliability and strong evidence of validity based on response processes (Cullum, Weiner & Saine, 2009). Participants completed the TFLS while seated at a table in close proximity to the investigator. All stimulus materials were kept out of sight of the participant, with the exception of item-specific materials, including the scoring form. Completion of the TFLS took between 15-20 minutes and this time frame varied based on interruptions (e.g., a telephone call or someone arriving at the door) and/or participants requiring additional time and/or cueing to complete the tasks. The TFLS is an American assessment and the item related to counting money and making change was converted to Canadian currency, but otherwise remained unchanged. The items on the TFLS were scored on a rating scale i.e., 0-3 that varied between items. Raw scores for each subscale were calculated and then added to achieve an overall raw score out of 50. For each subscale, raw scores were converted to cumulative percentages, and a TFLS T-Score was derived.

Home Falls and Accident Screening Tool (Home Fast)

The Home Fast was used with the participant following the completion of the TFLS. The Home Fast is a 25-item questionnaire that is used to identify common functional and environmental home safety concerns. Items are scored as either present or absent in a yes/no format where a 'no' response indicates the need for further follow-up and/or intervention to reduce risk for the participant. The Home Fast has been found to be predictive of falls (Mackenzie at al., 2002), with acceptable agreement between raters (Mackenzie, 2009). The administration of this clinical measure was varied by encouraging participants to move around his or her home environment with the investigator, allowing for observation of the questionnaire items. Traditional completion of this measure involves discussion and self and/or proxy report only. Observation of participants' home environments while using the Home Fast was a useful addition to the assessment process, by providing additional information (e.g., style of bathtub or height of toilet) and verifying responses that were reported.

Timed Up and Go (TUG)

The final measure in the toolkit was the TUG, a brief screening tool used to predict participants' risk of falls that has been shown to be both reliable and valid (Podsiadlo & Richardson, 1991; Steffen et al., 2002). The TUG was completed within a 5 minute timeframe, including set-up, demonstration of walking task by OT assessor and participant involvement. While there is a small physical risk to the participant in the Timed Up and Go Test (TUG), this risk was managed by the student investigator (and registered OT) by encouraging the use of mobility devices when appropriate and/or staying in close proximity to the participant and exercising the same judgement utilized in clinical practice.

The administration of the four clinical measures in the toolkit followed the same order for all of the 31 participants in the study. After the completion of the clinical measures, the participant was thanked for being a part of the research project and asked if he or she had any questions or concerns about the home assessment. The researcher then provided answers to questions if appropriate, reminded participants that study results would be posted at their respective FHT and/or mailed directly to them based on their preference indicated on the consent form. The researcher then left the home, leaving only a copy of the information letter and consent form for the participants' reference.

# Reporting OT Home Assessment Findings

The results of the occupational therapy home assessment were summarized in a standardized reporting template developed by the investigator and included FHT site, participant number and initials, date of the OT home assessment visit, scores and clinical interpretation of the COPM, TFLS, Home Fast and TUG, and additional comments and observations (see Appendix F). The completed template was forwarded to the physician lead of the participant’s Memory Clinic by fax. After the results were shared and discussed with the team, the physician lead or other allied health professional on the Memory Clinic team in collaboration with the Physician Lead, completed part two of the data collection form (see Appendix G) which included participant name and initials, indication of whether or not there would be a diagnosis review because of the additional information provided by the OT home assessment, a checklist of potential ways that that plan of care for the patient may change (i.e., earlier follow-up appointment, discussion of medication options, referral to the Alzheimer's Society, referral to the Community Care Access Centre (CCAC) for OT or Physiotherapy (PT), further investigation and/or imaging, recommendation of long-term care planning, discussion of power of attorney, recommendation of assessment of driving ability and other), and a section to include any additional comments related to the plan of care and/or diagnosis. Part one and part two of the data collection forms were then faxed to, via private and secure fax line, or picked up by the student research for summary and analysis.

Analyses

Individual participant data including information collected from health records/EMRs by the FHT and feedback from the Memory Clinic Team were compared by the student investigator before and after the occupational therapy home visit to determine if the findings of the assessment resulted in any proposed changes to the overall plan of care and/or the diagnostic process. All data was collected using standardized forms as described in the previous section. This information was recorded for each individual participant using a yes/no format. If there were proposed changes to the plan of care, the number of changes (e.g., referrals to community agencies, referrals to other clinics within the Family Health Team such as the mobility clinic) was recorded. Data were analyzed using descriptive statistics by calculating the percentage of participants for whom changes to their plan of care and/or diagnosis was proposed, and how many changes were proposed following the sharing of additional information from the OT home assessment. Pearson product moment correlation was used to examine the relationship between several variables including: TFLS and the MoCA (the latter of which is used by the Memory Clinic as part of the initial and ongoing assessment process), age and number of proposed changes to plan of care, number of chronic conditions and number of proposed changes to plan of care and age and TUG score.

Dissemination Plan

The dissemination plan for this exploratory study includes multiple steps. The first step is the preparation of this thesis as the primary written document, completed according to

departmental guidelines. The second step involves the development of a one-page written summary using plain and easy to read language, to be mailed to study participants who indicated during the OT home assessment that they would be interested in receiving this information at study completion. The third step will be the provision of the one-page summary to be posted at the three FHT Memory Clinics that participated in the study. Finally, two scholarly papers will be written and submitted for consideration by peer-reviewed journals (i.e., one article outlining the development of a clinical assessment toolkit and one article summarizing this study) and presentations at relevant conferences will be pursued, such as those targeting occupational therapists, and for organizations and health settings with a focus on MCI and dementia.

The next chapter of this thesis will present the results of this exploratory study.

Chapter Six: Results

The results of this exploratory study are presented in the next section, including demographics and a broad overview. More specific findings related to the plan of care are included such as the of changes proposed to the plan of care following the communication of OT home assessment findings back to the Memory Clinic team. Findings are also summarized by clinical measure (i.e., COPM, TFLS, Home Fast & TUG) and correlational analyses follow. All relevant findings are presented in table format to further the reader's understanding of the impact of an occupational therapy home assessment on the overall plan of care for patients who have been diagnosed with MCI in a primary care Memory Clinic setting.

Demographics

Participants in this study included 31 older adults (i.e., 12 males and 19 females) with a mean age of 78. There was little difference in mean age between males and females (i.e., 77.9 and 78.4 respectively). The mean number of chronic conditions as reported by the FHT was 4, with heart disease, diabetes and arthritis most commonly reported. The MoCA was completed by the Memory Clinic teams for each participant and the mean score for participants in the study was 22.1 (SD=3.9) which was below the recommended cut-off score when screening for cognitive impairment (i.e., 26) (Nasreddine et al., 2005). Of the 31 participants, 21 lived with a spouse while 10 lived alone, and the majority (28 or 90%) lived independently at home, with three participants residing in an assisted living environment (i.e., retirement home).

Findings related to Plan of Care

A change in the plan of care was proposed by the Memory Clinic team for 24 of 31 participants (77%) who had completed an OT home assessment of clinical measures as previously described. Of the 12 male participants, changes to the plan of care were proposed for 7, or 58%, while for women participants, changes to the plan of care were proposed for 17, or 89%. Participants whose plan of care remained the same following the OT assessment all lived in the community with a spouse, had an average of 3.4 chronic conditions, and an average MoCA score of 24.4. In comparison, participants who had changes to their plan of care had an average of 4.4 chronic conditions and an average MoCA score of 21.4. There was little difference in the ages of participants who had changes to their plan of care versus those who did not (i.e., approximately one year).

The average number of proposed changes to the plan of care was 2.9 and 2.8 for men and women respectively, with a range of 0-6 changes for both men and women. The most commonly proposed changes to the plan of care included a diagnosis review (n=15), an earlier follow-up visit (n=17) and a medication review (n=13). Additionally, an occupational therapy follow-up home visit was proposed for 15 participants to address issues related to home safety and/or mobility. Proposed changes to the plan of care that were captured less frequently included referral to the Alzheimer Society (n=4), further investigation/imaging (n=3) and referral for assessment of driving ability (n=4). There were 5 females in the study who had no proposed changes to their plan of care related to diagnosis or management of MCI. In spite of this, these participants were flagged for follow-up by OT related to risks that were identified in the areas of home safety and/or mobility, and 3 of these 5 participants were living alone. Similarly, there were 5 men in the study who had no proposed changes to their plan of care related to diagnosis or management of MCI. However, none of these male participants were identified for follow-up by OT and all 5 men were living with a spouse. Of the 7 men who had proposed changes to their plan of care related to diagnosis or management of MCI, 5 were also flagged for OT follow-up. In summary, women were more likely than men to have changes proposed to their plan of care based on the findings of the OT home assessment. Women were also more likely than men to be flagged for OT follow-up in the absence of recommended changes to their plan of care related to diagnosis and management of MCI. However, when men and women had proposed changes to their plan of care, there was no difference in the average number. Participants who had no proposed changes to their plan of care included 2 females and 5 males, all of whom were living at home in the community, with a spouse, ranging in age from 60-82 (mean age=75). Interestingly, while their number of chronic conditions was similar to the mean number of chronic conditions for all participants (i.e., 3.4 versus 3.9 respectively), there were other differences worthy of noting. For participants who had no proposed changes to their plan of care, MoCA scores were an average of 2 points higher (i.e., 24.4 versus 22.1), average score on the TFLS was higher (i.e., 46/50 versus 41.3/50), and average score on the TUG was lower, indicating a lower risk of falls (i.e., 10.3 seconds versus 14.5 seconds). The average number of 'no' responses on the Home Fast was very similar for both groups (i.e., 3.8 versus 3.5 respectively). The full results related to proposed changes to the plan of care have been summarized in Table 6.

Findings by Clinical Measure

Canadian Occupational Performance Measure (COPM)

As previously discussed, the COPM was used as a descriptive measure at one point in time only during the occupational therapy home visit to capture participants' self-perception of occupational performance. Participants identified a variety of occupational performance issues in the areas of self-care, productivity and leisure. Following the identification of these issues, the importance of each item was scored from 1 to 10 referencing the visual scale as required. In summarizing these results, up to five occupational performance issues were captured for each participant, based on the issues that were scored as most important. While the results are summarized in Table 7, some interesting commonalities emerged. The most common occupational performance issues identified and rated high in importance included those related to self-care (i.e., dressing, bathing, mobility, managing finances and driving) and leisure. Identification of occupational performance issues differed for men and women both in terms of number and types of issues. For example, women identified on average, one more occupational performance issue than men, and more specifically issues in the areas of self-care related to dressing and mobility. However, men in this study were more likely than women to identify issues related to finances, driving and leisure.

Texas Functional Living Scale (TFLS)

On the TFLS, participant scores ranged from 28-50, with 50 being the maximum score attainable, representing no impairment in IADLs. The mean score on this clinical measure was 41.3, with no meaningful differences in mean score between male and female participants (M=41.33; F=41.32), with a standard deviation of 6.2. Separated into four subscales, the average score on time was 7.5 (max score=9) (M=7.67, F=7.32) with a standard deviation of 1.6, the average score on tasks related to money was 6.1 (max score=8) (M=5.75, F=6.26) with a standard deviation of 1.9, the average score on the communication subscale was 23.8 (max score=28) (M=23.75; F=23.79) with a standard deviation of 4.1 and the average score on the memory subscale was 4 (max score=5) (M=4.17, F=3.19) with a standard deviation of 1. The results related to the TFLS are summarized in Table 8.

Home Falls and Accident Screening Tool (Home Fast)

A score on the Home Fast is calculated by tallying the number of 'no' responses with a 'no' being an indication of home safety issues that may pose a potential fall hazard or accident risk. The range of 'no' responses were 1-10 (out of a maximum of 25) with a mean of 3.5 and a standard deviation of 1.85. When comparing the results by gender there was no meaningful difference (i.e., M=3.58, F=3.53). A wide variety of issues were identified and individual items are summarized in Table 9. Only 3 of 25 items did not receive a 'no' response by participants. The most commonly identified issues were slippery floor surfaces (n=18), loose floor mats (n=8), lack of grab bars in the shower/bath (n=12), lack of slip-resistant mats in the shower/tub (n=14), lack of a railing on outdoor steps (n=8), not wearing well-fitting shoes in the house (8 participants), having difficulty getting in and out of the bathtub or shower (n=18), an inability to climb stairs safely (n=7) and difficulty getting in and out of lounge chair (n=6). There were some interesting differences in responses between men and women on the Home Fast. Men in this study were more likely than women to wear well-fitting footwear while inside the house, indicate that walkways both inside and outside are clutter-free, have easy access to a bedside light, and were better able to perform all transfers including bed, lounge chair, toilet, bathtub and shower. All Home Fast findings are explored in the discussion section of this thesis.

Timed Up and Go (TUG)

The TUG is measured in seconds and a score of 13.5 seconds or longer is highly predictive of falls with a high degree of accuracy (Podsiadlo & Richardson, 1991). Participants ranged between 7.6-29.4 seconds when completing the TUG, with a mean score of 14.54 seconds and a standard deviation of 6.18 seconds. When comparing results by gender, men took an average of 11.93 seconds to complete the TUG, while women took an average of 16.19 seconds. Eleven of 17 female participants scored above 13.5 seconds in comparison to 5 of 12 male participants. The significance of this finding related to home safety and clinical practice is discussed in the next section of this thesis.

Correlational Analyses

In addition to summarizing proposed changes to the plan of care for participants and summarizing scores on the four clinical measures as described above, Pearson Product Moment correlation was used to measure the relationship between several pairs of variables. Correlations between the MoCA and the TFLS was r=.62, the number of chronic health conditions and number of proposed changes to the plan of care was r=.26, age and the number of proposed changes to the plan of care was r=.26, and age and TUG score was r=.27. The following and final chapter of this thesis explores and discusses the findings of this exploratory study, including recommendations related to next steps and future directions.

Chapter Seven: Discussion and Future Directions

The development and use of a toolkit of clinical measures during an OT home assessment offered key information about the functional performance of people who had been diagnosed with MCI in a primary care Memory Clinic. A summary of the OT findings provided information and understanding about how people with MCI manage in their home environments on a daily basis. Previously, Memory Clinics have been unable to capture this information related to functional performance in a reliable and meaningful way in the clinic environment. The next section of this paper discusses key findings from this exploratory study.

The Impact of OT on the Plan of Care

The purpose of this research study was to answer the following question:

To what extent does a standardized occupational therapy home assessment protocol [or toolkit] of self-perception of occupational performance, instrumental activities of daily living (IADLs), falls risk and home safety change the plan of care for patients with MCI in a primary care Memory Clinic model? Although the sample of 31 participants was small, the information from an OT home assessment resulted in proposed changes to the plan of care in over 3/4 of participants in the study. Specifically, Memory Clinic teams proposed changes to existing plans of care for 24 of 31 participants (i.e., 77%) based on the additional clinical information that was provided. Examples of the proposed changes captured more frequently during this study included an earlier follow-up appointment at the Memory Clinic, diagnosis review, medication review and further occupational therapy assessment and intervention related to home safety and/or mobility. While measuring IADL performance was identified as a key component to this study, the use of a comprehensive toolkit of clinical measures provided Memory Clinics with a broader view of the factors that were either supports or barriers to occupational performance at home. It is important to note and that some of the issues that were identified during the OT home assessment visit are significant in terms of potential impact to safety and overall health and well-being, including concerns about driving, moving around both in the home and/or community environments and managing finances. These issues will be explored in greater detail in an upcoming section that highlights and discusses results as categorized by clinical measure.

When a Memory Clinic team indicated proposed changes to the plan of care like an earlier follow-up appointment, diagnosis review or medication review, the study did not capture which pieces of clinical information led to a specific change, or changes to the existing plan. However, when a participant had difficulty on the TFLS, a performance-based measure of IADLs, it is reasonable to assume that concerns about functional abilities in the home could warrant a change to the plan of care related to one or more of the categories listed above. What is more straightforward however, is a change in the plan of care involving further OT assessment and intervention which related to issues identified with home safety and/or falls risk identified using the Home Fast and the TUG. Future research could involve follow-up with Memory Clinic teams to better understand which pieces of clinical information informed specific changes to the plan of care.

The proposed changes indicated less frequently by Memory Clinic teams included referral to the Alzheimer's Society, further investigation/imaging, and referral for assessment of driving ability. With regard to referrals to the Alzheimer Society, services and programs offered by this community organization have traditionally been geared to dementia, and healthcare professionals have not necessarily regarded the Society as a place to refer people who have been diagnosed with MCI. However, the Alzheimer Society offers individual support, support groups (i.e., when there are sufficient numbers of people with MCI), and education relevant to MCI such as learning about memory loss and reducing the risk of MCI developing into a progressive dementia. Another option currently being explored is an MCI support group via Ontario Telemedicine Network (OTN) for participants from six Alzheimer Society chapters in Southwestern Ontario (L. Hutton-Turner, personal communication, Feb. 17/14). As the demographics in Ontario shift to include increasing numbers of older adults, it is anticipated that MCI will be more prevalent too. Furthermore, it is important to recognize that not all people who are diagnosed with MCI go on to develop dementia. Providing services for people with MCI is a recent development for the Alzheimer Society and this, coupled with the stigma associated with dementia help to explain a reluctance to seek out the supports of this community agency in the context of MCI. Raising public awareness about MCI and promoting the Alzheimer Society as an organization focused on memory loss and not just dementia is an important next step for both the general public and for health professionals working with older adults. With regard to further investigation/imaging, it is possible that this change to the plan of care would more often be made for participants after their earlier follow-up appointment with the Memory Clinic.

The proposed changes that were listed on the form but not noted for any participant included care planning and discussion of a power of attorney (POA). Based on the discussion about the differences between MCI and dementia, these two plan of care items are more relevant to the latter. One physician lead did recommend 'financial and other safeguards' for a female participant but did not indicate a proposed change related to overall care planning or POA and reported that this participant had trusted family supports in place. While it is important to plan ahead related to a disease process, the trajectory of MCI is uncertain, and therefore, a conversation related to care planning and POA may be difficult and perhaps even inappropriate to have when someone receives a new diagnosis. When MCI progresses to dementia, it is anticipated that care planning and discussion of POA would be much more common and relevant, knowing the progressive nature of this disease, and the future need for care.

Additional proposed changes recorded by the Memory Clinics included referrals to one FHT's mobility clinic, referral to social work, and recommendations for other supports including housekeeping, a personal alert system (e.g., Lifeline) and the services of a professional organizer to address a cluttered home environment. A worthwhile next step would be consultation with the Memory Clinics who participated in this study to review the proposed changes to the plan of care that were captured in the reporting template and to make revisions and/or additions as appropriate. Involvement of the interdisciplinary team would be important as many of the categories included in the reporting template captured the medical aspects of the plan of care. With regard to community supports, a proposed change to the plan of care involving a referral to the Community Care Access Centre (CCAC) was recorded for two participants only, despite identifying the need for further OT assessment and intervention related to home safety and/or mobility. The referral criteria for OT through the CCAC can vary by geography but generally people who are at risk but not experiencing an acute health issue are not eligible for this community-based service. Two of the three FHTs (i.e., Kitchener and Stratford) had OTs as part of their allied health team and were planning to complete any follow-up required using their own clinic resources. However, the Cambridge team was planning on making referrals to OT through the CCAC.

While it was hypothesized that a large number of participants would benefit clinically from the OT home visit based on the recommended changes to plans of care, there were other participants who did not experience a change in their plan of care based on this additional information. For 7 participants (i.e., those who did not have proposed changes to their plan of care), several comments were made on the physician reporting template that the findings were helpful as they were a corroboration of the initial diagnoses and plans of care when patients attended the clinic without a spouse, friend or other family member present. These patterns have implications for identifying people with MCI who may benefit the most from an OT home assessment, and those who are likely managing well in their home environments.

The Impact of a Clinical Assessment Toolkit

A toolkit of clinical measures was assembled for the occupational therapy home assessment using a clinical reasoning and critical appraisal approach with several levels of critique. There has been no standardized protocol published for toolkit development to date. As previously discussed, the measures included the COPM, the TFLS, the Home Fast and the TUG. OT home visits took approximately one hour, and the results of each measure will now be discussed in the context of the current research study.

Canadian Occupational Performance Measure (COPM)

The COPM was the first clinical measure used with each participant and was an excellent tool for establishing rapport during occupational therapy home visits. The COPM was used in an unstructured interview format and following the description of the three broad categories of self-care, productivity and leisure, the researcher then encouraged participants to discuss occupational performance issues in the context of their day-to-day lives. Of particular interest was the broad range of occupational performance issues represented both related to MCI (e.g., forgetting appointments) and related to other chronic health conditions (e.g., having difficulty managing buttons and fasteners when getting dressed due to arthritis in hands). Many participants were insightful about the challenges they were facing and described making adjustments to the way that they were completing their occupations and/or to the environments in which they were living (e.g., moving to shared role for managing finances, self-limiting driving, renovating bathroom to include accessible shower in response to difficulties getting in and out of the bathtub). However, because the researcher was not more directive in use of COPM, participants may or may not have disclosed all occupational performance issues, and especially those of most interest to the Memory Clinic team (i.e., IADLs and other occupational performance issues related to cognition).

Despite a small sample size, several common occupational performance issues emerged through the use of the COPM and included self-care, driving, managing finances, mobility and loss of leisure occupations. With regard to self-care, participants most often discussed difficulty with dressing due to arthritis in their hands, challenges with reaching and mobility, and concerns about getting in and out of the bathtub safely and independently. These issues were largely unrelated to any cognitive changes inherent in MCI and demonstrate the complexity of the occupational performance issues experienced by this sample of older adults.

Driving

Related to driving, three issues were most commonly discussed including driving as an important occupation, self-limiting of driving and the need for a driver assessment. Not all participants discussed driving as important however, and one participant talked about that fact that she no longer cared for driving. In fact, she reported being quite willing to give up her license but needed support to come up with a feasible transportation plan for herself. The ways that people described self-limiting of their driving included only driving to familiar places, always having someone in the car and relying on that person to help them with directions and way-finding, not driving in particular conditions such as rain, snow, fog or darkness, and avoiding major highways and busy intersections. What was not explored was whether or not self-limiting of driving was impacting social interaction and connecting with friends and family members, other leisure activities and completion of community management tasks. When an older adult expresses concerns about their driving abilities but continues to drive in the absence of further assessment and/or intervention, it is quite possible that he or she is putting themselves and others at risk. The self-identification of driving as an occupational performance issue on the COPM allows for education and discussion of and/or planning of retirement from driving as appropriate, which may include a gradual plan of multiple steps. Providing choice and control related to a valued occupation such as driving is an important step in helping older adults to either adjust their current driving habits if necessary, consent to further assessment and come to terms with retirement from driving if this is a essential next step. While there is ongoing and emerging information related to dementia and driving , driving ability for people who have been diagnosed with MCI may be influenced by other factors including vision changes, peripheral neuropathy related to diabetes, and other chronic health issues. Retirement from driving is a commonly discussed topic in the Memory Clinic and the use of a tool like the COPM may encourage people to start talking about driving more generally, without a specific focus on cognition. While it is unclear what information led the Memory Clinic to make a referral for a driving assessment, OTs have the potential to play an important role in screening for driving ability in primary care, as is already the case in other clinical environments. An interesting next step in this research would be to better understand which pieces of clinical information from the OT home visit led the Memory Clinics to propose specific changes to the plan of care related to driving and other occupational performance issues.

Managing Finances

Managing finances, including writing cheques and paying bills was described as an important occupation and several participants made the connection between their ability to manage finances and living independently in the community, especially when they were living alone, or with a spouse who was no longer capable of assisting with this occupation. There were some participants who had either moved to sharing of the financial management with a spouse or family member and other participants were no longer involved in their finances at all. These findings are in keeping with literature that makes the link between MCI and a resulting decline in some money management abilities such as paying bills (Bierman et al., 2007; Gitlin, 2005). Having issues with money management poses a potential risk for fraud or financial abuse, indicating the need for further follow-up and intervention to minimize this risk.

Mobility

A wide variety of occupational performance issues related to mobility were described by participants including the use of equipment such as canes and walkers to assist with getting around home and community environments, concerns about walking outside on uneven ground, or on icy or snowy sidewalks and challenges and concerns related to walking on stairs. As previously discussed, falls are a common occurrence among older adults, and especially among women with MCI. Several participants indicated having previous falls and/or having a fear of falling that was limiting their participation in activities like bathing and walking outdoors. Preventing falls would be an important outcome of this OT home assessment, and an issue that should take priority in terms of follow-up and intervention. While risk was identified and some education provided as part of this study, the responsibility was then transferred back to the Memory Clinics to organize further support related to falls prevention and home safety.

Leisure

Finally, a large number of participants discussed the loss of valued leisure occupations which one participant described as activities that had "been and gone." Examples included travel, playing the piano, singing, gardening and needlepoint. Several participants talked openly about the reasons why they were no longer engaging in these occupations. A participant who frequently went on cruises and travelled with his wife noted that concerns about getting too far away from a hospital limited his travels. Another participant had changed the way he travelled as he previously enjoyed long driving trips but had switched to flying because of decreased confidence in his driving skills. One participant connected vision loss and arthritis in her hands to the need to give up needlepoint, and a participant who previously enjoyed watching television found this activity 'a nuisance' because of changes in her vision and hearing.

The use of the COPM in the context of this study has helped to capture the complexity of the health issues facing older adults who have been diagnosed with MCI, and the range of occupational performance issues experienced, both related and unrelated to cognitive changes. A variety of issues were identified that could potentially be addressed by occupational therapy and therefore have an impact on a person's ability to participate in, and to enjoy their life to the fullest despite living with MCI and other chronic health conditions. For example, addressing mobility, safety and independence may impact community engagement and leisure, and promote overall health and fitness level. By addressing leisure issues, there may be a resulting positive impact on cognitive issues and caregiver stress. Finally, addressing self-care issues may impact safety, the ability to live independently and feelings of competence and increased privacy as people are more able to complete self-care activities independently.

While an average of 3.1 occupational performance issues were identified as important by each participant, the scope of this exploratory study did not include follow-up by the researcher. Although Memory Clinic teams were made aware of these occupational performance issues, occupational therapy follow-up was not a guarantee based on models of funding and prioritization of service. This finding indentifies a probable gap in existing service and a potential need for occupational therapists to provide intervention for older adults who have been diagnosed with MCI and have other chronic health issues that may impact their occupational performance. However, not all older adults with MCI and presenting occupational performance issues would be prioritized for OT based on how they were coping day to day, and what supports were in place. Evaluation of the outcomes from such services would be important to measure. The FHT model provides an excellent opportunity for OT to partner with allied team members such as social work and physiotherapy, in addition to other community agencies such as the Alzheimer Society to provide group coaching and consultation for this population with a goal of minimizing the impact of disease, avoiding or delaying further disability and enabling those with MCI to live well in the community.

Texas Functional Living Scale (TFLS)

The TFLS was chosen in part due to the brevity of the tool, and good clinical utility both in terms of portability and ability to assess performance of IADLs using simulated activities. It was the experience of the student researcher that the TFLS was straightforward in terms of administration and scoring and all participants completed the measure in its entirety. It would appear however, that several items may not be sensitive enough to detect a range of performance in this population of participants with MCI. For example, all 31 participants were able to complete the calendar items successfully, including indicating what day of the week it was after the researcher pointed to any Thursday in any month, identifying the date as the 17th after the researcher pointed to it and asked, "what date is this?", and indicating that it was the third Monday of the month, after the researcher pointed at it. A more challenging item such as remembering an upcoming appointment and then recording the details accurately on the calendar may have been a more sensitive and valid item. Items related to counting money and making change appeared particularly sensitive in this population to distinguish participants who were experiencing a decline in their functional abilities and those who were not. For example, while some participants managed all tasks with ease, there were others who experienced significant difficulty with either counting money and/or making change. The latter was more challenging and included three items that became progressively more difficult. It is possible however, that cognitive changes inherent in MCI are not sufficient to explain all of the variation in performance on these items.

Other variables such as cognitive reserve, overall intelligence, math skills and the influence of performance anxiety may have contributed to participants' ability to complete these tasks successfully. The researcher carefully managed other potential issues related to vision loss and hearing impairment by ensuring that participants were wearing hearing aids and glasses as appropriate, checking in to ensure that participants could see and read the items, and repeating instructions when requested and/or when it appeared that a participant may have missed hearing all or part of a message. The cheque writing task had an American context and it may have been more relevant to use a common household bill and a participant's own cheque (or similar item) but perhaps this item allowed consideration of generalizability of a skill, cognitive flexibility, and overall problem-solving ability.

Several other items on the TFLS warrant further discussion. The microwave task was simulated, using a printed recipe and a picture of the front of a microwave door. Several participants indicated that they had never used a microwave and this lack of familiarity may have had an impact on their performance. Furthermore, microwaves vary greatly in terms of their displays and buttons to use for various functions, and if the stimulus microwave was different than participants' actual appliance, completing this simulated task may have been more difficult. A next step for participants who had difficulty with this task would be the use of an additional assessment evaluating the use of a participant's microwave and potentially other home appliances to ensure safe use.

For the most part, participants were able to identify 911 as the number to call if they experienced an emergency, but it was striking when several participants were unable to provide this information spontaneously, even when provided with verbal and physical prompts. The most concerning example was a participant who was unable to verbalize the number 911 but proceeded to go into her kitchen and open a cabinet door with a list of numbers on the inside. Among a list of other numbers, 911 was posted in large red and white numerals. Despite this visual prompt, the participant indicated that she would call the health line, and proceeded to read off a 1-800 number from the inside of the cabinet. This example illustrates the importance of observations made in a home environment that would not have been captured in a clinic setting. Looking in the cabinet for the number demonstrated some problem-solving ability but also highlighted significant potential safety issues related to not knowing what to do in an emergency situation while living alone in the community.

While the use of the TFLS was a reasonably good fit for a population of community-dwelling older adults with MCI, future research looking at the specificity and sensitivity of this clinical measure would be valuable. The TFLS is a tool that allows OTs to complete a brief screening of IADLs that may be sensitive to the effects of cognitive change, and is easily administered in a home environment. One additional next step is to determine how best to assess IADLs in greater detail should there be concerns about functional ability following the completion of the TFLS.

Home Falls and Accident Screening Tool (Home Fast)

The Home Fast was used to identify common household issues that are related to falls risk and home safety, and appeared to be useful in raising participant awareness about these important issues facing older adults. When planning this research project, an initial decision was made to mail the Home Fast to participants in advance of their occupational therapy home visit but this was not done, in favour of completing this clinical measure as part of the OT home visit. A benefit of this approach that had not been anticipated was the opportunity to educate spouses, significant others and family members about falls risk and home safety when they observed the interaction of this researcher and participants completing the Home Fast. Using this clinical measure in the home environment gave the researcher the opportunity to walk through with the participant and others to see each area of the home and to provide education about falls prevention and home safety and/or flag the Memory Clinic team with specifics about issues that were identified. The items that were most likely to receive a 'no' and therefore required follow-up included those related to floor surfaces and scatter mats, transfers (i.e., lounge chair, toilet and bath), grab bars and non-slip mats in bathrooms and wearing of well-fitting footwear in the home. While it is not uncommon for homes to have floor surfaces that can be slippery, such as hardwood and ceramic tile, a simple solution to this issue is wearing well-fitting footwear. Another benefit of footwear is to protect the feet, especially when neuropathy is a presenting health issue. Several participants had renovated their bathrooms and utilized flooring that has a ceramic look but has non-slip features, even when wet.

Bathrooms are a common place where older adults experience falls (Tideiksaar, 2009). Transfers in to and out of the bathtub were very often cited as an activity that participants were unable to manage safely. While many participants indicated that they were opting for showers instead of baths, this was not always the case as a common theme involved enjoyment of baths, both for relaxation and to ease pain and other symptoms related to health conditions such as arthritis and low-back pain. There were two scenarios that were particularly concerning to the researcher involving one participant with mobility issues attempting to get in and out of a deep whirlpool tub unassisted, and another participant assisting his wife in and out of a whirlpool tub despite the significant mobility and cognitive issues that she was experiencing as the result of a stroke. A number of participants indicated an awareness about grab bars in the bathroom, but very few had this safety equipment in place. The reported barriers to use of grab bars included concern that installing this equipment was against the rules in situations where older adults were renting, and/or aesthetics (i.e., perception that grab bars are ugly, or make a person seem old). Comments related to non-slip mats included acknowledging the importance of using one, having a mat but not using it, and concerns about hygiene and keeping mats clean.

The patterns of responses on the Home Fast provide the Memory Clinic with a good starting place when thinking of education and coaching related to home safety and falls risk. What may be important however, is the approach that is taken. Promoting this education as a way that older adults can stay healthy, safe and strong while living in the community, versus labelling as falls or injury prevention will most likely result in a positive reaction to falls risk and home safety and therefore a greater likelihood of positive behaviour changes. There is a key occupational therapy role in primary care settings in assisting older adults to identify falls risks and hazards in their home and in the community, to navigate equipment choices available and assist people to find the best fit both in terms of safety and aesthetics, while addressing the barriers to behaviour change using a self-management approach. The use of the Home Fast in a clinic setting may be possible but environmental context becomes paramount when considering the prevention of falls and accidents in the home. Completing this questionnaire while accompanying a person through their home and encouraging demonstration of various tasks was ideal for this study and provided a more accurate and useful picture of the environmental barriers to occupational performance. Use of the Home Fast provides the opportunity to not only educate older adults about falls risk related to their home environment but can then provide a framework to guide intervention. Giving general recommendations about home safety and accident prevention is not as effective as pinpointing specific issues and providing education and optimal solutions that may include renovations, equipment and/or strategies to accomplish everyday tasks with greater safety and independence.

Timed Up and Go (TUG)

The TUG is a screening tool that has good psychometrics and identifies falls risk with a high degree of confidence. The TUG requires minimal set-up and equipment, and all 31 participants were able to complete this measure. Participants had a wide range of scores but the findings would indicate that many older adults who have been diagnosed with MCI in this primary care Memory Clinic model are at an increased risk of falls, and especially women in this sample. This finding is in keeping with a small body of literature suggesting that the falls risk is higher in older adult women who have been diagnosed with MCI (Liu-Ambrose et al., 2008). One physician lead expressed surprise at how much risk was identified in this population of older adults. The TUG is meant to be a screening tool only, and more investigation would be beneficial to better understand why a participant experienced a score on the TUG that predicted a higher risk of falls. There are other commonly used measures that would provide additional information about balance skills such as the Berg balance scale (Berg et al., 1995) and the Tinetti balance assessment (Tinetti, 1986) but it would be important to select an evidence-based measure with adequate psychometrics and is a good fit with this population of older adults who have been diagnosed with MCI. An additional measure focus on balance could be used as part of an in-depth follow-up for participants where risk of falls was identified during the OT home assessment. One option for the Memory Clinic team to consider is the use of the TUG in the clinic setting, following by a more in-depth balance assessment when an OT completes a home assessment.

Environmental Context and Assessment

One final topic of discussion prior to the consideration of implications and future directions is context as it relates to assessment. When planning this exploratory study, there was conversation about whether the OT assessment of functional performance would happen in the clinic setting or in the home setting. A decision was made to do the OT assessments at home to determine what additional clinical information could be gleaned from observing someone interact in their own familiar environment. The Memory Clinic had identified a gap in information related to how people who had been diagnosed with MCI were functioning in their home environments on a daily basis. As discussed by Bottari et al. (2006), there were several advantages to completing the OT assessment in a familiar home environment including the ability to walk through rooms with participants when completing the Home Fast allowing the researcher to pinpoint environmental factors that were helping and hindering occupational performance. There were several examples of participants disclosing more information about particular issues when completing the COPM than when in the clinic setting (i.e., driving ability and managing finances). When completing the TFLS, the researcher was able to observe participants reacting to real-life distractions in their home environments such as the telephone, door bell and pets. By completing the TUG in participants' homes, this researcher was able to observe how participants walk on the flooring in their home, and for some, compare scores when using a mobility aid and when walking independently. The use of the TUG and Home Fast in primary care settings such as FHTs promotes a culture of safety regardless of the outcome as there may or may not be risk identified. However, providing education about falls and the opportunity to mitigate common risks in the home environment is a worthwhile endeavour that is in keeping with a health promotion approach to client care. Use of the TUG may provide the opportunity for discussion and education about the importance of exercise in falls prevention and flag the need to complete further assessment of balance and other factors impacting mobility skills. The TUG could be used more broadly as a screening tool for older adults in primary care FHTs and not just those receiving care in the Memory Clinic Model.

In addition to evaluating the changes to plans of care based on additional information from OT home assessment visits, Pearson product moment correlation was used to examine the relationships between several variables. The correlations were small to modest and worth noting but with caution given the small sample size. Of note was the modest positive correlation between the MoCA and the TFLS (r=.62) suggesting that it is worthwhile to use both clinical measures when considering both the cognition and functional status of a population with MCI. Use of a paper-based assessment like the MoCA is an important first step but does not provide an adequate picture of functional ability related to IADLs and managing in a home environment. Further research with a larger sample using a longitudinal design would allow for the examination of multiple factors impacting the ability to live well in the community with a diagnosis of MCI. The following and final section of this thesis will discuss the implications of this exploratory study for occupational therapists, and future directions related both to toolkit development and to the OT role for people who have been diagnosed with MCI.

Implications and Future Directions

When considering the findings of this exploratory study, there appear to be several important implications for occupational therapists. Building standardized toolkits for specific populations and settings may be a useful approach to assessment and intervention planning and ensure the use of both evidence-based and occupation-focused measures. The use of standardized templates for reporting promote a simple and concise approach that has the potential to promote the understanding of the role and value of OT, and the usability of the findings. By understanding the unique needs and preferences of the audience receiving the OT assessment findings, reporting can be streamlined and tailored accordingly. In the context of this study, a one page reporting template was developed at the request of, and in collaboration with, a physician lead of a Memory Clinic. The resulting document was straightforward for this researcher to complete, easily shared in a team setting and scanned and included as part of participants' health records. In terms of next steps, the development of an algorithm or care pathway to assist with decision making in this Memory Clinic model (i.e., which clients would benefit from OT home visit as part of their plan of care given health care environment of fiscal challenges and limited resources) would be most beneficial and have application across Ontario, in this particular model. A common algorithm or care pathway would also facilitate the sharing of data and comparative research across settings.

Based on the experience of this researcher using the toolkit of clinical measures that was developed for this study, little revision is recommended. This specific toolkit can be used by OTs working in the community with older adults who have been diagnosed with MCI. One potential addition to the toolkit is The Activity-Specific Balance Confidence Scale (ABC Scale) (Powell & Meyers, 1995) for participants who are at greater risk of falls, as indicated by their results on the TUG. The ABC Scale is a 16-item self-report measure where people have the opportunity to rate their balance confidence in performing everyday activities while in their home, and in the community. Examples of activities that occur within the home include walking around, going up and down stairs and bending over to pick up a slipper from the floor. Community-based examples include walking around in a crowded mall, getting out of the car and walking in a parking lot, and using an escalator. Like the COPM, the ABC Scale measures self-perception of occupational performance but is directive in focusing only on home and community mobility skills. The ABC Scale could be completed outside of the home visit either independently, or in a clinic setting. The self-report nature of this measure may be problematic as previously discussed, but may also open the door to further discussion of more specific mobility issues. The ABC Scale would provide valuable additional information in terms of intervention planning and pinpointing areas of mobility where problem-solving and adaptations may be required. The ABC Scale appears to be a good fit with the existing toolkit of clinical measures developed for older adults who have been diagnosed with MCI.

An additional next step involves sharing findings of this exploratory study with OTs working as part of this Memory Clinic model, and more broadly with FHTs across Ontario to discuss the potential value of the OT role in assessment of the functional performance of older adults living in the community. Ongoing collaboration to develop guidelines and/or an algorithm for assessing functional abilities in home environments is important because OTs would benefit from an extension of the current toolkit to include evidence-based and occupation-focused options for use when more in-depth assessment and intervention is indicated. For some of the participants in this study, further OT assessment was recommended and it would be important to know which additional clinical measures therapists are currently using, and would be most beneficial when looking at IADLs, falls risk and home safety in this population.

Based on the findings of the current study, replication either as a research project or as ongoing program evaluation within this primary care Memory Clinic model would be a worthwhile next step. While this research project was exploratory in nature and represents a new area of study for occupational therapy, there are both strengths and limitations to be acknowledged. The generalizability of the findings of the study is limited by the small sample size of 31 participants and the use of a before and after design. To complete this project in a reasonable timeframe, the majority of changes measured were proposed changes to plans of care and not actual changes which typically occur when patients come back for a follow-up visit with the Memory Clinic team (e.g., diagnosis and medication review and resulting changes). Measuring actual changes to plans of care retrospectively would be an interesting and potentially informative extension of the current study.

Access to the participants' medical records was both a strength and a limitation of this study. The role of the Memory Clinic teams in accessing this information was supported by the REB at McMaster University as a method to limit student researcher access to sensitive personal and health information unrelated to the purpose of the study. However, this approach resulted in the researcher relying on others to extract most relevant clinical and demographic information from the health records. In future, more direction and guidelines for reporting of diagnoses would be beneficial to eliminate the inclusion of minor health issues and to ensure the documentation of common chronic conditions in an aging population using a framework like the International Classification of Diseases and Related Health Problems (ICD-10) (WHO, 1994).

For 77% of participants in this exploratory study, an OT home assessment using a toolkit of clinical measures ensured the right care, in the right place, at the right time (Ontario's Action Plan for Health Care, 2012) as the findings influenced changes to existing plans of care. By providing a streamlined assessment of functional abilities in the home environment, the value and effectiveness of OT in an existing Memory Clinic model was demonstrated. Further research related to the OT role in the assessment of functional abilities and performance in the home setting would be beneficial, as would a clinical pathway to help Memory Clinics to decide who would benefit most from an OT home visit as an extension of the care provided in a clinic setting. Based on the findings of this exploratory study, OTs have an important role in assessing the functional performance of older adults who have been diagnosed with MCI in the context of a primary care Memory Clinic model.

Figures

Figure 1

Canadian Model of Occupational Performance and Engagement (CMOP-E)

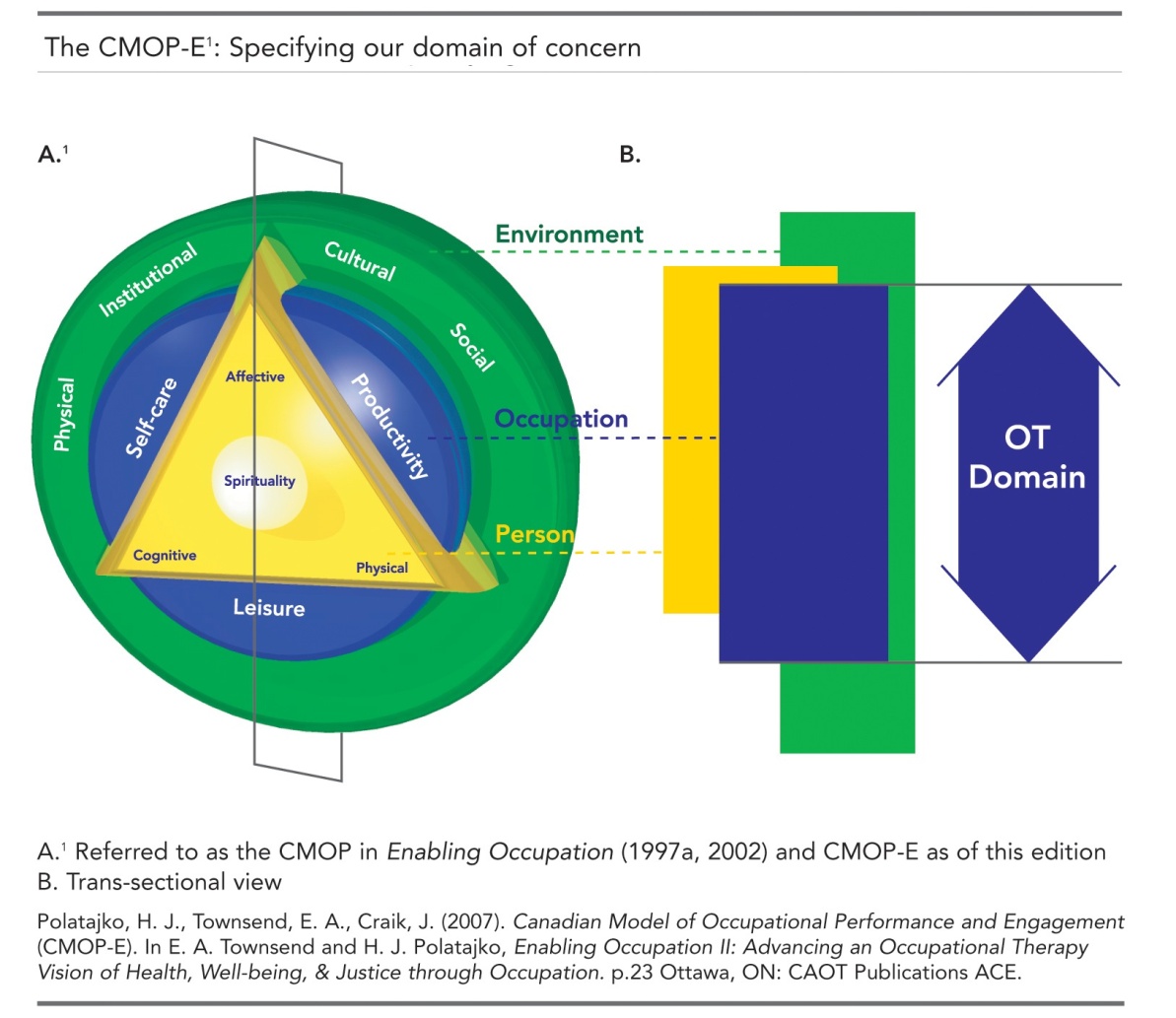


Figure 2

The Person Environment Occupation Model (PEO)



Figure 3

The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001)



Tables

Table 1

Attribute: Self-Perception of Occupational Performance

The Canadian Occupational Performance Measure (COPM)

|  |
| --- |
| Description: Client-centred, semi-structured interview used to determine client's self-perception of occupational performance in the areas of self-care, productivity and leisure. Five-step process includes issue identification, weighting, scoring, reassessment and follow-up. |
| Source: Law, M., Baptiste, S., Carswell, A., McColl, M. A., Polatajko, H., & Pollock, N. (2005). *Canadian Occupational Performance Measure Manual* (Fourth edition). Toronto, Ontario: CAOT Publications ACE. |
| **Psychometric Properties**  (Law, Baum & Dunn, 2005) |
| Reliability *Internal consistency:* 0.56 (performance); 0.71 (satisfaction) (Law et al.,  1998) *Test-Retest:* Good to excellent, in the range of 0.80 for performance  and satisfaction (Carswell et al., 2004) *Inter-rater:* Not established |
| Validity *Content:* Based on the process of development (Law et al., 1998); strong  evidence of discriminate validity, evidence of responsiveness  *Criterion and construct:* Based on relationships with a number ofconstructs and widely used measures (Carswell et al., 2004) |
| **Clinical Utility** |
| Availability Purchase of manual and forms required (www.caot.ca). |
| Ease of use Manual and forms are detailed and easy to follow; training DVD  available. |
| Time to administer 30-40 minutes |
| Type of client Suitable for any client with occupational performance issues |
| Scoring Client scores importance of occupational performance issue, and  performance and satisfaction on a scale from 1-10. |
| Strengths Client-centred, occupation-focused measure that facilitates rapport  between OT and client, and client understanding of occupational  therapy. |
| Weaknesses Administration requires good interviewing skills and measure can be  time-consuming depending on the extent of the occupational  performance issues identified. |
| Comments Designed as an outcome measure but will be used as a descriptive  measure in this research project; steps 1 & 2 completed with  participants. |

Table 2

Attribute: Functional Ability (i.e., IADLs)

Summary of Clinical Measures Eliminated Based on Exclusion Criteria

Exclusion Criteria

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Clinical Measure | Measures ADLs & IADLs | Admin time > 30 minutes | Not intended for home environment | Issues with clinical utility\* | Poor or limited psychometric  information | Self-report measure |
| ADL Situational Test | X |  |  |  | X |  |
| ALSAR-R2 |  | X |  |  |  | X |
| AMPS |  |  |  | X |  |  |
| DAFA |  | X | X |  | X |  |
| DAFS | X |  |  |  |  |  |
| EADL |  |  |  |  |  | X |
| OTAPS |  |  |  |  |  |  |
| RADL |  |  |  |  |  |  |
| SAILS | X | X |  |  |  |  |

\*Extensive training required

Table 3

Attribute: Instrumental Activities of Daily Living (IADLs)

The Texas Functional Living Scale (TFLS)

|  |
| --- |
| Description: Performance-based measure of simulated functional tasks designed to measure IADLs that may be more susceptible to cognitive decline. |
| Source: Cullum, C. M., Weiner, M. F., & Saine, K. C. (2009). *Texas Functional Living Scale.* San Antonio, TX: Pearson. |
| **Psychometric Properties**  (Cullum, Weiner & Saine, 2009) |
| Reliability *Inter-rater*: Excellent (97-99% agreement); *Test-Retest*: Good |
| Validity Internal Consistency: Adequate |
| **Clinical Utility** |
| Availability Purchase of manual and forms required (www.pearsonassess.ca) |
| Ease of use Detailed manual and scoring form; examiner required to provide some  additional assessment materials |
| Time to administer 15-20 minutes |
| Type of client Suitable for clients who are experiencing changes in cognition |
| Scoring Sum of four subscales (i.e., time, money and calculation, communication  and memory) raw score used to calculate t-score; guidelines for  interpretation included in manual |
| Strengths Brief, straight-forward administration with detailed manual |
| Weaknesses Lack of information about specificity and sensitivity for population of  older adults with MCI |
| Comments TFLS is American; some tasks required slight adaptation (i.e., using  Canadian currency instead of American currency |

Table 4

Attribute: Home Safety

The Home Falls and Accident Screening Tool (Home Fast)

|  |
| --- |
| Description: Screening tool of 25 items representing a wide range of safety concerns in the home, both functional and environmental. |
| Source: Mackenzie, L., Byles, J., & Higginbotham, N. (2000). Designing the Home Falls and Accidents Screening Tool (HOME FAST): Selecting the items. *British Journal of Occupational Therapy,* 63, 260-269. |
| **Psychometric Properties** |
| Reliability *Inter-Rater*: Acceptable (Mackenzie, 2009) |
| Validity *Content:* established through panel of expert judges (Mackenzie et al.,  2002); predictive of falls |
| **Clinical Utility** |
| Availability Available as a free download online (www.health.vic.gov.au) |
| Ease of use Definitions are provided for each item; items are clearly described and  measure is straightforward to administer |
| Time to administer 15-30 minutes |
| Type of client Suitable for most clients living in a home environment. |
| Scoring Simple yes/no scoring, or not applicable to home environment being  assessed |
| Strengths Free, quick administration as screening tool, psychometrics are  promising. |
| Weaknesses No manual available, no norms for the Home Fast. |
| Comments Use of Home Fast was altered to include participants showing researcher  different areas of their home and demonstrating functional tasks as  appropriate. |

Table 5

Attribute: Falls Risk

Timed Up and Go (TUG)

|  |
| --- |
| Description: Screening assessment of functional mobility. |
| Source: Podsiadlo, D., & Richardson, S. (1991). The timed "Up & Go": A test of basic functional mobility for frail elderly persons. Journal of the American Geriatric Society, 39, 142-148. |
| **Psychometric Properties** |
| Reliability Inter-Rater: Very high; 87% sensitivity and specificity (Shumway-Cook, et  al., 2000). |
| Validity Construct: Excellent |
| **Clinical Utility** |
| Availability Instructions available online at no cost. |
| Ease of use Very little training required; minimal equipment |
| Time to administer Approximately 5 minutes including set-up, demonstration and timing |
| Type of client Suitable for older adults with or without cognitive impairment |
| Scoring Time measured in seconds to complete walking task |
| Strengths Quick screening tool that can be administered in a variety of  environments including home and clinic. |
| Weaknesses Screening tool only that does not pinpoint specific issues with balance  and mobility. |
| Comments A cut-off score of 13.5 seconds or longer is predictive of falls  (Podsiadlo & Richardson, 1991). May be more relevant to those with MCI  due to increased executive function demands related to transfer and  turning aspects of the task as compared to the Berg Balance Scale and the  Dynamic Gait Index (Herman et al., 2011). |

Table 6

Summary of Proposed Changes to Plan of Care Following OT Home Assessment

Total Sample

(n=31)

# of participants % of participants

Proposed changes to plan of care 24 77

Diagnosis review 15 48

Earlier follow-up 17 55

Medication review 13 42

Referral to Alzheimer's Society 4 13

Referral to CCAC 2 6

Imaging 3 10

Care planning 0 0

Power of Attorney 0 0

Assessment of Driving 4 13

Occupational Therapy 15 48

Other\* 6 19

\*Includes other changes to plan of care: referral to social work, mobility clinic assessment, referral to neurology, Lifeline, blister pack medication, professional organizer, day program, housekeeping, and "financial and other safeguards"

Table 7

COPM Summary

OP Area Issues Identified Importance (M, SD) # Identifying

Self-care Personal Care 8.6 1.8 15

Mobility 9.5 0.7 14

Managing finances 8.4 1.7 14

Driving 8.3 1.7 20

Household management 8.7 1.7 7

Community management 10 0 3

Leisure 7.6 1.6 24

(e.g., gardening, playing piano, knitting, travelling)

Table 8

TFLS Summary

Total Sample

(n=31)

M SD Range

Time 7.5 1.6 3-9

Money & Calculation 6.0 1.9 3-8

Communication 23.7 4.1 14-28

Memory 4.0 1.0 1-5

TFLS Total Score 41.3 6.2 28-50

Table 9

Home Fast Summary

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | | # of 'no' responses per item | |
| Home Fast Items\* | Total | Male | | Female |
| Walkways clutter-free | 3 | 0 | | 3 |
| Floor coverings in good condition | 0 |  | |  |
| Non-slip floor surfaces | 18 | 9 | | 9 |
| Floors free on loose mats | 8 | 4 | | 4 |
| Able to perform bed transfers | 1 | 0 | | 1 |
| Able to perform lounge chair transfers | 6 | 0 | | 6 |
| Adequate indoor lighting | 1 | 0 | | 1 |
| Easy access to bedside light | 8 | 2 | | 6 |
| Adequate outdoor lighting | 3 | 2 | | 1 |
| Able to perform toilet transfers | 4 | 0 | | 4 |
| Able to perform bathtub transfers | 17 | 7 | | 10 |
| Able to perform shower transfers | 1 | 0 | | 1 |
| Grab rails in shower/bath | 12 | 4 | | 8 |
| Slip resistant mats in shower/bath | 14 | 8 | | 6 |
| Toilet in close proximity to bedroom | 2 | 1 | | 1 |
| Able to reach items in kitchen | 2 | 1 | | 1 |
| Able to carry meals from kitchen to dining area | 1 | 0 | | 1 |
| Full-length railing on indoor stairs | 1 | 0 | | 1 |
| Full-length railing on outdoor stairs | 8 | 5 | | 3 |
| Able to climb stairs safely indoors and out | 7 | 1 | | 6 |
| Edges of stairs clearly identified | 0 |  | |  |
| Able to use entrances safely and easily | 0 |  | |  |
| Outdoor paths in good repair | 2 | 0 | | 2 |
| Wearing well-fitting footwear | 8 | 2 | | 6 |
| Able to care for pets without risk of falling | 3 | 1 | | 2 |
| Total | 130 | 47 | | 83 |
|  |  |  | |  |
| \*Home Fast item names have been shortened for ease of reporting |  |  | |  |
|  |  |  | |  |
|  |  |  | |  |
|  |  |  | |  |
|  |  |  | |  |
|  |  |  | |  |

References

Albert, M. S., DeKosky, S. T., Dickson, D., Dubois, B., Feldman, H. H., Fox, N. C.,...

Phelps, C. H. (2011). The diagnosis of mild cognitive impairment due to Alzheimer's disease: Recommendations from the National Institute on Aging and Alzheimer's Association workgroup. *Alzheimer's & Dementia, 7*, 270-279.

Administration on Aging (2012). A profile of older Americans: Disability and activity limitations. Retrieved February 14, 2014 from http://www.aoa.gov/Aging\_Statistics/Profile/2012/16.aspx.

Applegate, W. B., Blass, J. P., & Williams, T. F. (1990). Instruments for the functional assessment of older patients. *New England Journal of Medicine,* 322 (17), 1207-1214.

Arnadottir, G. (1990). *The brain and behaviour: Assessing cortical dysfunction through activities of daily living.* St. Louis, MO: C. V. Mosby.

Barr, A., & Brandt, J. (1996). Word-list generation deficits in dementia. *Journal of Clinical and Experimental Neuropsychology, 18*, 810-822.

Baum, C. M., Morrison, T., Hahn, M., & Edwards, D. F. (2008). *Executive Function Performance Test.* St. Louis, MO: Washington University School of Medicine.

Berg, K.O., Wood-Dauphinee, S., Williams, J. L., & Maki, B. (1989). Measuring balance in the elderly: Validation of an instrument. *Physiotherapy Canada*, 41(6), 304-311.

Bierman, E. J. M., Comijs, H. C., Jonker, C., & Beekman, A. T. F. (2007). Symptoms of anxiety and depression in the course of cognitive decline. *Dementia and Geriatric Cognitive Disorders,* 24, 213-219.

Binegar, D. L., Hynan, L. S., Lacritz, L. H., Weiner, M. F., & Cullum, C. M. (2009). Can a direct

IADL measure detect deficits in persons with MCI? *Current Alzheimer Research, 6*, 48-

51.

Bonder, B. R., & Dal Bello-Haas, V. (2009). *Functional performance in older adults.* Philadelphia, PA: F. A. Davis Company.

Bottari, C., Dutil, E., Dassa, C., & Rainville, C. (2006). Choosing the most appropriate environment to evaluate independence in everyday activities: Home or clinic? *Australian Journal of Occupational Therapy, 53*, 98-106.

Brown, C., Moore, W. P., Hemman, D., & Yunek, A. (1996). Influence of instrumental activities of daily living assessment methods on judgements of independence. *American Journal of Occupational Therapy, 50*, 202-206.

Buckner, R. L. (2004). Memory and executive function in aging and AD: Multiple factors that cause decline and reserve factors that compensate. *Neuron, 44*, 195-208.

Burns, T., Mortimer, J. A., & Merchak, P. (1994). Cognitive Performance Test: A new approach to functional assessment in Alzheimer's Disease. *Journal of Geriatric Psychiatry and Neurology, 7*, 46-54.

Busse, A., Angermeyer, M. C., & Reidel-Heller, S. G. (2006). Progression of mild cognitive impairment to dementia: A challenge to current thinking. *British Journal of Psychiatry, 189,* 399-404.

Canadian Association of Occupational Therapists (CAOT). (2004). The tools for living well toolkit. Retrieved March 18, 2014 from http://www.caot.ca/pdfs/ToolsforLivingWell.pdf

Canadian Association of Occupational Therapists (CAOT). (2002). *Enabling occupation: An occupational therapy perspective* (Rev. ed.). Ottawa, ON: CAOT Publications ACE.

Canadian Association of Occupational Therapists (CAOT). (1997). *Enabling occupation: An occupational therapy perspective.* Ottawa, ON: CAOT Publications ACE.

Clemson, L., Bundy, A., Unsworth, C., & Fiatarone Singh, M. (2008). *ALSAR-R2: Assessment of Living Skills and Resources.* http://www.fhs.usyd.edu.au/ols/

Clemson, L., Fitzgerald, M., & Heard, R. (1999). Content validity of an assessment tool to identify home fall hazards: The Westmead Home Safety Assessment. *British Journal of Occupational Therapy,* *62*, 171-179.

Cullum, C. M., Weiner, M. F., & Saine, K. C. (2009). *Texas* *Functional Living Scale: Examiner’s Manual.* San Antonio, TX: Pearson.

Cullum, C. M., Saine, K., Chan, L. D., Martin-Cook, K., Gray, K. F., & Weiner, M. F. (2001).

Performance-based instrument to assess functional capacity in dementia: The Texas

Functional Living Scale. *Neuropsychiatry, Neuropsychology, and Behavioural*

*Neurology*, *14*, 103-108.

Doble, S. (2009). Dementia. In B. R. Bonder & V. Dal Bello-Haas (Eds.). *Functional*

*performance of older adults* (pp. 193-214). Philadelphia, PA: F.A. Davis Company.

Dopp, C., Graff, M. L., Rikkert, M. Nijhuis van der Sanden, M., & Vernooij-Dassen, M. (2013). Determinants for the effectiveness of implementing an occupational therapy intervention in routine dementia care. *Implementation Science, 8*: 131 doi:10.1186/1748-5908-8-131

Douglas, A., Letts, L., & Liu, L. (2007). Review of cognitive assessments for older adults. *Physical and Occupational Therapy in Geriatrics*, *26*, 13-43.

Dubois, B., Slachevsky, A., Litvan, I., & Pillon, B. (2000). The FAB: A frontal assessment battery at bedside. *Neurology, 55*, 161-166.

Dutil, E., Bottari, C., Vanier, M., & Gaudreault, C. (2005). *ADL profile: Performance-based assessment user's guide* (Version 5). Montreal, QC: Emersion.

Fabre, J. M., Ellis, R., Kosma, M., & Wood, R. (2010). Falls risk factors and a compendium of falls risk screening assessments. *Journal of Geriatric Physical Therapy, 33*, 184-197.

Fairbank, C. T., & Pynsent, M. D. (2000). *Spine, 25*, 2940-2953.

Findlay, L., Bernier, J., Tuokko, H., Kirkland, S., & Gilmour, H. (2010). Validation of cognitive functioning categories in the Canadian Community Health Survey - Healthy Aging. *Components of Statistics Canada Catalogue* (no. 82-003-X). Health Reports, 21 (4), 1- 16.

Fisher, A. (1995). *The Assessment of Motor and Process Skills (AMPS).* Fort Collins, CO: Three Star Press.

Gitlin, L. N. (2005). In M. Law, C. Baum, & W. Dunn (Eds.). *Measuring occupational performance: Supporting best practice in occupational therapy* (pp.227-248). Thorofare, NJ: SLACK Incorporated.

Gitlin, L. N., & Corcoran, M. A. (2005). *Occupational therapy and dementia care: The home environmental skill-building program for individuals and families.*  Bethesda, MD: AOTA Press.

Goldberg, T. E., Koppel, J., Keehlisen, L., Christen, E., Dreses-Werringloer, U.,

Conejero-Goldberg, C., Gordon, M. L., & Davies, P. (2010). Performance-based measures of everyday function in mild cognitive impairment. *American Journal of Psychiatry,* 167 (7), 845-853.

Hall, C. (2014). The occupational therapy toolkit. Retrieved March 18, 2014 from http://www.ottoolkit.com/

Healey, W. E. (2012). Mild cognitive impairment and aging. Topics *in Geriatric Rehabilitation, 3,* 157-162.

Herman, T., Giladi, N., & Hausdorff, J. M. (2011). Properties of the timed up and go test: More than meets the eye. *Gerontology, 57*, 203-210.

Karagiozis, H., Gray, S., Sacco, J., Shapiro, M., & Kawas, C. (1998). The Direct Assessment of Functional Abilities (DAFA): A comparison to an indirect measure of instrumental activities of daily living. *Gerontologist,* *38*, 113-121.

Kearney, P., Shaw, G., & Gitlin, L. N. (2005). Trajectory of dementia and impact on families. In L. N. Gitlin & M. A. Corcoran (Eds.). *Occupational therapy and dementia care: The home environmental skill-building program for individuals and families.* Bethesda, MD: American Occupational Therapy Association, Inc.

Keith, R. A., Granger, C. V., Hamilton, B. B., & Sherwin, F. S. (1987). The functional independence measure: A new tool for rehabilitation. *Advances in Clinical Rehabilitation*,*1*, 6-18.

Kielhofner, G. (2006). *Research in occupational therapy: Methods of inquiry for enhancing practice.* Philadelphia, PA: F. A. Davis Company.

Kohlman-Thompson, L. (1992). *The Kohlman Evaluation of Living Skills* (3rd ed.). Rockville, MD: American Occupational Therapy Association.

Law, M. (1987). Measurement in occupational therapy: Scientific criteria for evaluation. *Canadian Journal of Occupational Therapy*, *54*, 133-138.

Law, M., Baptiste, S., Carswell, A., McColl, M. A., Polatajko, H., & Pollock, N. (2005). *Canadian Occupational Performance Measure Manual* (Fourth edition). Toronto, Ontario: CAOT Publications ACE.

Law, M., Baum, C., & Dunn, W. (2005). *Measuring occupational performance: Supporting best*

*practice in occupational therapy.* Thorofare, NJ: Slack Incorporated.

Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist,* 9 (3), 179-186.

Lee, L., Weston, W. W., Heckman, G, Gagnon, M., Lee, F. J., & Sloka, S. (2013). Structured approach to patients with memory difficulties in family practice. *Canadian Family Physician, 59*, 249-254.

Lee, L., Weston, W. W., & Hillier, L. M. (2013). Developing Memory Clinics in primary care: An evidence-based interprofessional program of continuing professional development.

*Journal of Continuing Education in the Health Professions*, *33*, 24-32.

Lee, L., Hillier, L., Stolee, P., Heckman, G., Gagnon, M., McAiney, C., & Harvey, D. (2010). Enhancing dementia care: A primary care-based memory clinic. *Journal of the American Geriatric Society, 58*, 2197-2204.

Letts, L. (2011). Optimal positioning of occupational therapy. *Canadian Journal of*

*Occupational Therapy, 78(4), 209-217.* doi: 10.2182/cjot.2011.78.4.2.

Letts, L., Edwards, M., Berenyi, J., Moros, K., O'Neill, C., O'Toole, C., & McGrath, C. (2011). Using occupations to improve quality of life, health and wellness, and client and caregiver satisfaction for people with Alzheimer's disease and related dementias. *American Journal of Occupational Therapy, 65*, 497-504.

Liu-Ambrose, T. Y., Ashe, M. C., Graf, P., Beattie, B. L., & Khan, K. M. (2008). Increased risk of falling in older community-dwelling women with mild cognitive impairment. *Physical Therapy,* *88*, 1482-1491.

Loeb, P.A. (1996). *Independent Living Scales Manual.* San Antonio, TX: The Psychological

Corporation.

Loewenstein, D.A., Amigo, E., Duara, R., Guterman, A., Hurwitz, D., Berkowitz, N.,...Wilkie, F. (1989). A new scale for assessment of functional status in Alzheimer’s disease and related disorders. *Journal of Gerontology*, *44*, 114–121.

Lyketsos, C. G., Lopez, O., Jones, B., Fitzpatrick, A. L., Breitner, J., & Dekosky, S. (2002). Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment: Results from the cardiovascular health study. *The Journal of the American Medical Association,* *288*, 1475-1483.

Mackenzie, L., Byles, J., & Higginbotham, N. (2002). Reliability of the Home Falls and Accidents Screening Tool (Home Fast) for identifying older people at increased risk of falls. *Disability and Rehabilitation*, *24*, 266-274.

Mahoney, S. I., & Barthel, D. W. (1965). Functional evaluation: The Barthel Index. *Maryland*

*State Medical Journal, 14*, 61-65.

Mahurin, R. K., DeBittignies, B. H., & Pirozzolo, F. J. (1991). Structured assessment of independent living skills: Preliminary report of a performance measure of functional abilities in dementia*. Journal of Gerontology: Psychological Sciences,* *46,* 58-66. Malinowsky, C., Almkvist, O., Kottorp, A., & Nygard, L. (2010). Ability to manage everyday technology: A comparison of persons with dementia or mild cognitive impairment and older adults without cognitive impairment. *Disability and Rehabilitation: Assistive Technology, 5*, 464-469.

Mild cognitive impairment (2013). Retrieved January 27, 2014 from http://www.alzheimer.ca/en/About-dementia/Dementias/What-is-dementia/Mild- Cognitive-Impairment.

Nasreddine, Z. S., Phillips, N. A., Bedirian, V., Charbonneau, S., Whitehead, V., Collin, I.,...

Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatric Society*, *53*, 695-699.

Nouri, F. M., & Lincoln, N. B. (1987). An extended activities of daily living scale for stroke patients. *Clinical Rehabilitation*, *1 (4),* 301-305.

Novak, M., & Campbell, L. (2010). *Aging and society: A Canadian perspective* (Sixth Edition). Toronto, ON: Nelson Educational Ltd.

Ohman, A., Nygard, L., & Kottorp, A. (2011). Occupational performance and awareness of disability in mild cognitive impairment or dementia. Scandinavian Journal of Occupational Therapy, *18*, 133-142.

Oliver, R., Blathwayt, J., Brackley, C., & Tamaki, T. (1993). Development of the safety assessment of function and environment for rehabilitation (SAFER) tool. *Canadian Journal of Occupational Therapy,* *60*, 78-82.

Ontario Ministry of Health and Long-Term Care. (2012). *Ontario's action plan for health care* (ISBN 978-1-4435-8942-0). Toronto, ON: Queen's Printer for Ontario.

Patel, B. B., & Holland, N. W. (2012). Mild cognitive impairment: Hope for stability, plan for progression. *Cleveland Clinic Journal of Medicine*, *79*, 857-864.

Perneczky, R., Pohl, C., Sorg, C., Hartmann, J., Komossa, K., Alexopoulos, P.,...Kurz, A. (2006). Complex activities of daily living in mild cognitive impairment: Conceptual and diagnostic issues. *Age and Ageing, 35*, 240-245.

Pfeffer, R. L., Kurosaki, M. S., Harrah Jr., C. H., Chance, J. M., & Filos, S. (1982). Measurement of functional activities of older adults in the community. *Journal of Gerontology, 37*, 179-186.

Peterson, R. C. (2011). Mild cognitive impairment. *New England Journal of Medicine, 364*, 2227-2234.

Peterson, R. C., Roberts, R. O., Knopman, D. S., Boeve, B. F., Geda, Y. E., Invik, R. J., Smith, G. E., & Clifford, R. J. (2009). Mild cognitive impairment: Ten years later. *Archives of Neurology*, *66*, 1447-1455.

Podsiadlo, D., & Richardson, S. (1991). The timed “Up & Go”: A test of basic functional mobility for frail elderly persons. *Journal of the American Geriatric Society,* *39*, 142-148.

Poulin de Courval, L., Gelinas, I., Gauthier, S., Gayton, D., Liu, L., Rossignol, M.,...Dastoor, D. (2006). Reliability and validity of the Safety Assessment Scale (SAS) for people with dementia living at home. *Canadian Journal of Occupational Therapy, 73*, 67-73.

Poulin, V., Korner-Bitensky, N., & Dawson, D. R. (2013). Stroke-specific executive function assessment: A literature review of performance-based tools. *Australian Journal of Occupational Therapy,* *60*, 3-19.

Powell, L. E., & Myers, A. M. (1995). The Activities-specific Balance Confidence (ABC) Scale. *Journal of Gerontology Medical Science*, 50 (1), M28-34.

Public Health Agency of Canada (2005). Report on seniors' falls in Canada

(ISBN 0-662-41415-2). Ottawa, ON: Author.

Regional Geriatric Program of Eastern Ontario (2009). The Driving and dementia toolkit

(3rd ed.). Retrieved March 15, 2014 from

http://www.rgpeo.com/media/30422/d%20%20d%20toolkit%20pt%20crgvr%20eng%20

with%20hyperlinks.pdf

Reitan, R. M. (1958). Validity of the trail making test as an indicator of organic brain damage.

*Percept Motor Skills, 8*, 271-276.

Riley, K. P. (2009). Mental function. In B. R. Bonder & V. Dal Bello-Haas (Eds.), *Functional performance of older adults* (pp. 177-182). Philadelphia, PA: F.A. Davis Company.

Rowland, M. O., & Morris, R. W. (1983). A study of the natural history of back pain. Part 1: Development of a reliable and sensitive measure of disability in low back pain. *Spine, 8,* 141-144.

Royall, D. R., Cordes, J. A., & Polk, M. (1998). CLOX: An executive clock drawing task. *Journal of Neurology, Neurosurgery and Psychiatry, 64,* 588-594

doi: 10.1136/jnnp.64.5.588.

Schryburt-Brown, K, Dixon, C., Paton, D., Connolly, S., Craik, J., & Egan, M. (2004). Developing expert practice. Occupational therapy toolkit of fall risk in the elderly: A review of the literature. *Occupational Therapy Now*, *6*, 17-23.

Scott, V., Wagar, L., & Elliott, S. (2010). Falls & Related Injuries among Older Canadians: Fall‐related Hospitalizations & Intervention Initiatives. Prepared on behalf of the Public Health Agency of Canada, Division of Aging and Seniors. Victoria BC: Victoria Scott Consulting. (accessed January 12/14)

Sherod, M. G., Griffith, H. R., Copeland, J., Belue, K., Krzywanski, S., Zamrini, E.,...

Marson, D. C. (2009). Neurocognitive predictors of financial capability across the dementia spectrum: Normal aging, mild cognitive impairment and Alzheimer's disease.

Journal of the International Neuropsychological Society, *15*,

DOI:<http://dx.doi.org/10.1017/S1355617709090365>.

Sherer, M., Bergloff, P., Boake, C., High, W., & Levin, E. (1998). The Awareness Questionnaire: Factor structure and internal consistency. *Brain Injury*, *12,* 63-68.

Sinha, S. (2013). Living longer, living well. Retrieved February 27, 2014 from

http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors\_strategy/

Shumway-Cook, A., Brauer, S., & Woollacott, M. (2000). Predicting the probability for falls in community-dwelling older adults using the timed up & go test. *Physical Therapy,* *80*, 896-903.

Soriano, T. A., DeCherrie, L. V., & Thomas, D. C. (2007). Falls in the community-dwelling older adult: A preview for primary care providers. *Clinical Interventions in Aging*, *2*, 545-553.

Skurla, E., Rogers, J. C., & Sunderland, T. (1988). Direct Assessment of Activities of Daily Living in Alzheimer's disease: A controlled study. Journal of the American Geriatrics Society, *36*, 97-103.

Stevens, M., Holman, C. D., & Bennett, N. (2001). Preventing falls in older people: Impact of an intervention to reduce environmental hazards in the home. *Journal of the American Geriatric Society,* *49*, 1442-1447.

Stratford, P., Gill, C., Westaway, M., & Binkley, J. (1995). Assessing disability and change on individual patients: A report of a patient specific measure. *Physiotherapy Canada*, *47*, 258-263.

Tappen, R. M. (1994). Development of the refined ADL assessment scale for patients with Alzheimer's and related disorders. *Journal of Gerontological Nursing*, 20 (6), 36-42.

The Canadian Population in 2011: Age and Sex (2011). Statistics Canada Analytical Document. Retrieved March 15, 2014 from http://www12.statcan.gc.ca/census- recensement/2011/as-sa/98-311-x/98-311-x2011001-eng.cfm

Tideiksaar, R. (2009). Falls. In B. R. Bonder & V. Dal Bello-Haas (Eds.). *Functional*

*performance of older adults* (pp. 193-214). Philadelphia, PA: F.A. Davis Company.

Tinetti, M. E., Williams, T. F., & Mayewsk, R. (1986). Fall Risk Index for elderly patients based on number of chronic disabilities. *American Journal of Medicine,* *80*, 429-434.

Townsend, E. A., & Polatajko, H. J. (2007). Enabling occupation II: Advancing an occupational therapy vision for health, well-being, & justice through occupation. Toronto, ON: CAOT Publications ACE.

Tisnado, D. M., Adams, J. L., Liu, H., Damberg, C. L., Chen, W. P., Hu, F. A.,...Kahn, K. L. (2006). What is the concordance between the medical record and patient self-report as data sources for ambulatory care? *Medical Care*, *44*, 132-140.

Tugwell, P., Bombardier, C., Buchanan, W. W., Goldsmith, C. H., Grace, E., & Hanna, B. The MACTAR Patient Preference Disability Questionnaire: An individualized functional priority approach for assessing improvement in physical disability in clinical trials in rheumatoid arthritis. *The Journal of Rheumatology, 14*, 446-451.

Wang, P.L. & Ennis, K.E. (1986). *The Cognitive Competency Test: Test handbook.*

Richmond Hill, ON: Assessment and Rehabilitation.

Ward, A., Arrighi, H. M., Michels, S., & Cedarbaum, J. M. (2012). Mild cognitive impairment: Disparity of incidence and prevalence estimates. *Alzheimer's & Dementia, 8*, 14-21.

Wilkins, S., Letts, L., & Richardson, J. (2009). In B. R. Bonder & V. Dal Bello-Haas (Eds.). *Functional performance of older adults* (pp. 429-448). Philadelphia, PA: F.A. Davis

Company.

WHO. (2007). *Global report on falls prevention in older age* (ISBN: 978-92-4-156353-6). Geneva, Switzerland: Author. http://www.who.int/ageing/publications/Falls\_prevention7March.pdf.

WHO. (2001). *International classification of functioning, disability and health*. Geneva, Switzerland: Author.

Appendices

Appendix A

Informed Consent Protocol

Step 1: A Memory Clinic team determines eligibility for participation (i.e., new and ongoing diagnoses of Mild Cognitive Impairment) and obtains consent from the patient for the researcher to call and provide more information about the study.

By definition, those with Mild Cognitive Impairment do not have functional impairment and therefore an assumption is made that they have capacity to give informed consent about participating.

Step 2: Researcher calls participant using telephone script.

Step 3: Researcher will do a home visit with the participant and review the information letter and consent form prior to starting any planned assessment activities. The researcher will ask the participant if he/she understands the purpose of the home visit, and ask the participant to describe the information that has been provided in their own words.

The researcher will be using clinical judgement as a registered Occupational Therapist and considering the following three questions when obtaining consent for research participation:

1. Is the participant able to repeat and explain the information that has been provided in his or her own words?
2. Does the participant demonstrate understanding of the potential consequences of participating in the study? (i.e., that information will be shared with the Memory Clinic and may result in changes to his/her plan of care)
3. Does the participant ask pertinent questions which reflect an understanding of the research activities?

If there are any indications that a participant may not be competent to provide consent, the home assessment will not proceed and the Memory Clinic team will be notified.

If the researcher is concerned about a participant’s ability to manage safely and competently in his/her home, the Memory Clinic will be notified immediately at which time follow-up by the Memory Clinic team social worker will be initiated, and a referral made to the CCAC for an OT home assessment.

Appendix B

Information Page for Participants

## PARTICIPANTS NEEDED FOR RESEARCH ABOUT PARTICIPATION IN EVERYDAY ACTIVITIES and MILD COGNITIVE IMPAIRMENT

We are looking for volunteers to take part in a study of whether an occupational therapy home assessment will assist the Memory Clinic to better understand how people with Mild Cognitive Impairment (MCI) participate in everyday activities.

You would be asked to complete four assessment activities: 1) a discussion about how you are managing with your everyday activities; 2) an assessment that looks at your ability to do everyday activities; 3) a questionnaire that focuses on home safety, and; 4) a timed 3-metre walking activity. Your participation would involve a one-hour occupational therapy assessment in your home, scheduled at your convenience.

For more information about this study, or to volunteer for this study,   
please contact:   
*Laura Turner, Occupational Therapist*McMaster University  
Email: [*lauraturner.ot@gmail.com*](mailto:lauraturner.ot@gmail.com)

**This study has been reviewed by, and received ethics clearance   
by the McMaster Research Ethics Board.**

Appendix C

Telephone Script for Participants

Hello, may I speak to Mr./Mrs. (insert last name of participant here)? Hi, Mr./Mrs. (insert last name of participant here), my name is Laura Turner and I an occupational therapist and a student researcher from McMaster University in Hamilton. I was given your name by (insert name of social worker here) from (insert Memory Clinic information here, including name and location).

I am calling you to tell you more about the research study that I am doing, and to ask you if you would be interested in participating. Is this a good time to speak? (if yes, continue; if no: Is there a time when it might be more convenient for me to call?) My study involves doing a one-hour home visit with people who have visited the Memory Clinic to see how they are managing with their everyday activities. We want to see if the information from this home assessment helps the Memory Clinic to plan your care.

There are four activities to complete during the one hour OT home assessment. The first activity that we will do is a brief 15 minute interview focusing on how you think that you are managing with everyday activities such as making meals, taking medications, paying bills and driving. I will then have you do some of the everyday activities that we talk about in the interview and this will take about 15 minutes. The final two activities are a questionnaire about home safety and a very brief walking task that is related to the risk of falling. The information that I gather during the visit will be shared with your Memory Clinic team to give them more information about how you are managing with everyday activities.

Do you have any questions about the information that I have given you? *(if so, investigator will answer questions).* I would encourage you to have your spouse or a family member or friend present during my home visit. Can we go ahead and schedule a one hour home visit?

*If yes, the investigator will schedule a mutually agreeable time, ask for a home address and let the participant know that the investigator will be calling one to two days prior to the visit as a reminder and to ensure that the time is still suitable.*

*If no, the investigator will thank the participant for their time and end the telephone conversation.*

Appendix D

Data Collection Form: Part 1

EXPLORING THE OCCUPATIONAL THERAPY ROLE IN A PRIMARY CARE MEMORY CLINIC MODEL: OCCUPATIONAL PERFORMANCE AND

MILD COGNITIVE IMPAIRMENT

|  |
| --- |
| Please complete this section of the form prior to the OT home assessment visit:  Site Number: (please circle your site number)  *The site number will correspond with the participant’s Family Health Team as follows:*  *1-Centre for Family Medicine*  *2-Stratford Family Health Team*  *3-Grandview Medical Centre Family Health Team*  Participant Number:  Initials:  **Demographics**  Age:\_\_\_\_\_\_\_\_\_\_ Gender: *(circle one)* M F  Current Living Arrangements: (e.g., Alone, With a spouse, With a family member)  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Diagnosis(please include all diagnoses): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Occupation (Current and/or Previous): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  MOCA score: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Current Plan of Care  Memory Clinic Team Members currently seeing patient:  Referrals to Community Agencies:  Family Supports:  Other Community Supports:  Completed by: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

Appendix E

Information Letter and Consent Form

**LETTER OF INFORMATION / CONSENT**

**A Study about Everyday Activities and Mild Cognitive Impairment**

I**nvestigators:**

**Student Investigator:** **Faculty Supervisor**:

Name: Laura Turner Dr. Mary Law

Department of Rehabilitation Science Professor, School of Rehabilitation Science

McMaster University McMaster University

Hamilton, Ontario, Canada Hamilton, Ontario, Canada

**(519) 273-6068, extension 327 (905) 525-9140, extension 27837**

[lauraturner.ot@gmail.com](mailto:lauraturner.ot@gmail.com) [lawm@mcmaster.ca](mailto:lawm@mcmaster.ca)

***What am I trying to discover?***

I am exploring whether information from an occupational therapy assessment about participation in everyday activities will assist the Memory Clinic to better understand how people with Mild Cognitive Impairment participate in everyday activities.

You are invited to take part in this study because you are a patient of a Memory Clinic.

I am doing this research for my thesis in the Masters of Rehabilitation Science Program at McMaster University.

**What will happen during the study?**

I will visit you in your home for about an hour and ask you to complete four assessment activities:

1. A discussion about the everyday activities that you are participating in, and how you think that you are managing with those activities. Some examples that we may talk about include meal preparation, taking medications, managing money and driving. You will be asked to use a scale from 1-10 to rate your performance and satisfaction in performing these everyday activities. This discussion will take approximately 15 minutes.
2. An assessment that looks at your ability to do everyday activities such as using a calendar, making change, paying a bill, and making a simple meal. Completing this scale will take about 15 minutes.
3. A questionnaire that we will use to take a look at your home environment to discuss things in your home that may place you at a greater risk for falls. We will be looking at six areas of your home including floors, furniture, lighting, bathroom(s), storage, and stairways/steps. Completing this questionnaire will take about 20 minutes.
4. A timed activity that involves rising from a chair, walking 3 metres, turning and walking back to the same chair. Completing this activity will take less than a minute.

With your permission, I will be taking handwritten notes during our visit.

With your permission, the Memory Clinic will be sharing information from your health records with me, including your age, diagnosis, education level, occupation, score on the Montreal Cognitive Assessment (MoCA) (collected as part of your Memory Clinic assessment), and your current plan of care.

With your permission, I will be sharing information from the OT assessment activities (as described above) with your Memory Clinic team. The overall goal of sharing this information with your Memory Clinic team is to help you to participate in your life as fully as possible. The Memory Clinic will also be sharing information with me, to let me know if your plan of care changes after your OT assessment.

**Are there any risks to doing this study?**

The risks involved in participating in this study are minimal. If you find the activities difficult you may feel uneasy but part of my job is to reassure you and to help you to understand the instructions and what I will be asking you to do. We may discover that there are features of your home that are putting you at greater risk of falling. If so, I will be sharing this information with your Memory Clinic so that a plan can be developed to address the issues that we have discovered. During the walking task, I will be watching you carefully and will stop the activity if either of us are concerned that you may lose your balance or are at risk of falling.

You do not need to answer questions or complete any activities that make you feel uncomfortable. You can also withdraw (stop taking part) at any time. I describe below the steps I am taking to protect your privacy.

**Are there any benefits to doing this study?**

The research may benefit you as the results of the occupational therapy home assessment will be shared with the Memory Clinic, and may lead to a change in your plan of care, with the goal of helping you to participate in your life as fully as possible.

I hope that what is learned as a result of this study will help us to better understand the impact of these assessments on the overall plan of care in a Memory Clinic.

**Who will know what I said or did in the study?**

The information that I gather during the occupational therapy home assessment will be shared with your Memory Clinic team and could contribute to decision-making about your ongoing plan of care.

The information that you provide will be kept in a locked cabinet where only I and my supervisor will have access to it. For the purpose of data analysis, your information will be assigned a number so that you will not be identified

in any way. Once the study is complete, an archive of the data will be kept in a locked cabinet at McMaster University and destroyed after 10 years.

**What if I change my mind about being in the study?**

Your participation in this study is voluntary and it is your choice to be a part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you and any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study. Your decision whether or not to be part of the study will not change or affect the way that you use the Memory Clinic.

**How do I find out what was learned in this study?**

I expect to have this study completed by approximately August 2012. If you would like a brief summary of the results, please let me know how you would like it sent to you. I will also be posting a copy of the results at your Memory Clinic.

**Questions about the Study**

If you have questions or need more information about the study itself, please contact me at:

(519) 273-6068, extension 327

lauraturner.ot@gmail.com

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

The Office of the Chair, HHS/FHS REB

905.521.2100 extension 42013

**CONSENT**

I have read the information presented in the information letter about a study being conducted by Mary Law and Laura Turner of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a copy of this form. I agree to participate in the study.

Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of Participant: (Printed) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Study Results

* Yes, I would like to receive a summary of the study’s results.

Please send them to this email address: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

or to this mailing address :\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

* No, I do not want to receive a summary of the study’s results.

Appendix F

OT Reporting Template

A Study of Everyday Activities and Mild Cognitive Impairment

OT Home Assessment Reporting Template

|  |
| --- |
| FHT Site:  Date of OT Home Assessment:  Participant Number:  Initials:  **Occupational Performance Issues Identified (COPM):**  **Texas Functional Living Scale (TFLS) score & summary:**  **HomeFast summary:**  **Timed Up and Go (TUG) score:**  **Additional Comments and Recommendations:**  Completed by: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

Appendix G

Data Collection Form: Part 2

EXPLORING THE OCCUPATIONAL THERAPY ROLE IN A PRIMARY CARE MEMORY CLINIC MODEL: OCCUPATIONAL PERFORMANCE AND

MILD COGNITIVE IMPAIRMENT

Data Collection Form: Part Two

Please complete this form after the OT assessment information has been provided to the Memory Clinic Team:

Participant #and initials: \_\_\_\_\_\_\_\_\_\_\_ (in top right corner of OT home assessment template)

1) Will there be a diagnosis review as a result of the information provided from the OT assessment?

(circle one) Yes No

2) Based on the information provided by the occupational therapy home assessment, please indicate how the plan of care may change:

* earlier follow-up appointment
* diagnosis
* medication
* referral to Alzheimer's Society
* referral to CCAC (for OT or PT)
* further investigation/imaging
* long-term care planning
* POA
* further assessment of driving ability
* other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Please add any additional comments related to the plan of care or diagnosis below.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Completed by: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_