EVERYDAY IMPACT OF MEMORY CHANGES AMONG OLDER ADULTS

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Abstract

Many older adults report subjective memory complaints that can impact their everyday living. The extent to which such complaints impact daily functioning are important criteria to consider when diagnosing memory conditions. In addition, as most of the research identifying the impact of memory changes is qualitative in nature, there is a need for quantitative studies that examine the impact of memory changes across the cognitive aging spectrum and how this impact is related to subjective and objective cognition. Moreover, addressing the everyday impact of memory changes is a crucial goal of memory interventions due to its implications for later disease development, and as such there is a need for instruments with strong measurement properties that assess the everyday impact of memory changes. The goal of the present research was to address these issues. In Study 1, I examine neuropsychologists' practices in assessing functional abilities within the context of diagnosing memory conditions. A survey of 280 neuropsychologists revealed that neuropsychologists consider a variety of components that comprise everyday life and utilize several different instruments when assessing functioning. There was a lack of consensus among respondents when asked to diagnose individuals with different levels of impairment in daily functioning, underscoring the need for more measures that assess everyday functioning. In Study 2, I quantify the impact of memory changes across a cognitive aging spectrum ranging from normal cognition to mild cognitive impairment and describe associations between memory impact and both subjective and objective cognition. Results indicated that older adults with lower self-reported memory ability and poorer objective memory performance reported a greater burden of memory change on everyday living. In Study 3, I describe the responsiveness to intervention of a recently developed instrument that quantifies the impact of memory changes on everyday life. Results provided support for the clinical utility

of this instrument in evaluating changes in memory impact. Collectively, these studies explore the impact of memory changes on everyday functioning among older adults, particularly how functioning is assessed by clinicians, the cognitive correlates of everyday functioning, and tools that can be used to assess functioning within the context of memory interventions.

Dedication

This work is dedicated to my family.

Acknowledgements

In order to arrive at what you are not
You must go through the way in which you are not.
And what you do not know is the only thing you know
- T.S. Eliot

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CHAPTER 1

General Introduction

As they age, many individuals notice changes in their memory, and such changes are often referred to as subjective memory complaints (SMCs). Common SMCs reported by older adults include tip-of-the-tongue errors, failure to take one's medications, and forgetting various items and events, such as recently learned names, the location of everyday items (e.g., keys), or why one walked into a room (Farias et al., 2006; Ossher, Flegal & Lustig, 2013). These SMCs may or may not correspond to a decline in cognitive performance, with most studies identifying a significant but small correlation between SMCs and objective measures of performance (Burmester, Leathem, & Merrick, 2016). One explanation for this may be that self-appraisal of memory is more sensitive to subtle changes as compared to neuropsychological testing. Indeed, recent research identifies the presence of SMCs as an early sign of cognitive decline that predicts later development of clinically relevant conditions (Dardenne et al., 2017; Rabin, Smart, & Amariglio, 2017). In some cases, SMCs are accompanied by mild impairment on neuropsychological testing, and may by indicative of amnestic mild cognitive impairment (MCI). SMCs reported by individuals with MCI are similar in type but greater in degree than those reported by older adults with normal cognition (Niedźwieńska & Kvavilashvili, 2019).

SMCs can have important consequences for the daily lives of older adults. Although these memory errors may not be sufficient to impair functional independence, they can nonetheless affect activities of daily living (ADLs). Activities of daily living are everyday tasks that support independent living and can be subdivided into basic ADLs, such as grooming, feeding, and toileting, and instrumental ADLs (IADLs), such as managing finances and cooking (Lawton & Brody, 1969). Whereas it is widely accepted that basic ADLs remain intact until

advanced disease stages (Petersen et al., 2014), accumulating evidence indicates that even mild memory changes are associated with appreciable changes to IADLs (Lindbergh, Dishman, & Miller, 2016). Notably, changes in ability to perform ADLs have been observed even among individuals with SMCs who do not display an objective memory impairment (McAlister & Schmitter-Edgecombe, 2016). Such functional changes may be predictive of later decline among both older adults with normal cognition and those with MCI (Lau, Parikh, Harvey, Huang, & Farias, 2015), and therefore warrant further exploration as they may help identify individuals who would benefit most from therapeutic interventions.

In addition to affecting functional abilities, memory changes may also impact mental health. Indeed, several studies have reported associations between memory concerns and affective symptoms (i.e., depressive and anxiety symptoms) in older adults with normal cognition and those with MCI (see Hill et al., 2017, for review), though little is known about the temporality of this relationship, which makes it difficult to determine if such symptoms are a consequence of memory change. Similarly, memory changes are associated with reduced quality of life among older adults with normal cognition and those with MCI (Pusswald et al., 2015; Rotenberg Shpiegelman, Sternberg, & Maeir, 2019a). Also, such changes may negatively impact memory self-efficacy (Ramakers et al., 2009) and participation in positive health behaviours, such as compensatory strategy use (Hutchens et al., 2013).

Furthermore, qualitative research exploring the lived experience of memory change has identified unique aspects of daily life impacted by memory changes, with similar themes emerging in both cognitively normal older adults and those with amnestic MCI. Older adults with memory changes report changes to their relationships, restrictions to their lifestyle activities, changes in how they view themselves (e.g., feeling less capable), negative emotions

associated with memory change (e.g., feelings of embarrassment), and compensatory behaviours to address memory changes (De Vriendt et al., 2012; Meilak, Partridge, Willis, & Dhesi, 2016; Parikh, Troyer, Maione, & Murphy, 2016; Rotenberg, Sternberg, & Maeir, 2019b). Together, these qualitative studies demonstrate the impact of memory changes on more nuanced aspects of everyday life than have been explored through quantitative studies (e.g., quality of life, well-being).

In this body of work, I explore the everyday impact of memory changes among older adults with normal cognition and those with MCI. The everyday impact of memory changes is of clinical and scientific interest for many reasons. First, understanding the impact of memory changes on daily functioning is essential when ruling out dementia, as the diagnostic criteria for dementia require that cognitive changes contribute to significant disturbances in daily functioning (American Psychiatric Association, 2013). Second, although there is growing evidence from qualitative research identifying unique domains of everyday life impacted by memory changes, there is little quantitative research on this topic. Specifically, associations between these newly identified domains and both self-reported memory and objective cognitive performance have not been explored. As cognitive impairment in aging can be conceptualized as a continuum from healthy aging to dementia (Petersen, 2016), and dementia is characterized by marked functional deficits, mild changes in functional abilities may be present even in the earlier stages of the cognitive aging continuum (Lindbergh et al., 2016). Gaining a fuller understanding of the relationship between everyday functioning and age-related cognitive changes in these earlier stages of the cognitive aging continuum may help better identify older adults who can most benefit from clinical intervention. In addition, changes to functioning in everyday life may be predictive of later decline among both older adults with normal cognition and those with MCI

(Lau et al., 2015). As such, individuals who experience difficulties in everyday functioning may benefit from memory interventions that aim to delay onset of dementia.

In the following chapters, I explore these issues through three independent studies. First, I examine how neuropsychologists incorporate information about the impact of memory changes on daily functioning when diagnosing memory conditions, such as MCI and dementia, through a survey research approach. In the second study, I quantify the impact of memory changes across the cognitive aging continuum (from normal cognition to MCI) using a novel questionnaire, the Memory Impact Questionnaire (MIQ; Shaikh et al., 2018), that assesses the burden of memory changes on many of the domains of everyday living previously identified through qualitative research. I describe the associations between memory impact as measured by the MIQ and (a) self-reported memory, (b) strategy use, and (c) objective cognitive performance. In the third study, I describe the responsiveness to intervention of the MIQ in order to identify its clinical utility in evaluating the efficacy of memory interventions that target everyday functioning among older adults with normal cognition and those with MCI. Overall, my research aims to broaden and elucidate the memory change experience for older adults including how it is assessed by clinicians, its association with objective and subjective memory, and how its measurement can be used to gauge the efficacy of memory interventions aimed at improving the impact of such changes.

CHAPTER 2

Study 1: Evaluating functional abilities within the context of a memory assessment – A survey of neuropsychologists

Preface

Functioning in daily life is an important consideration when differentiating between normal aging, mild cognitive impairment and dementia. Despite this, there is no gold standard for assessing functional abilities and few guidelines on how to do so. The objective of this study was to examine neuropsychologists' practices regarding the assessment of functional abilities, within the context of memory conditions. A total of 280 psychologists who routinely conduct neuropsychological assessments completed an online survey querying their practices and perspectives with respect to the assessment of functional abilities. Respondents identified that changes to several components of daily functioning, including activities of daily living, were important when evaluating functional abilities. Respondents reported utilizing a variety of instruments to assess functioning, with an overwhelming majority indicating the use of semi-structured interviews. Most respondents indicated a need for more instruments of everyday functioning. Respondents further indicated that their recommendations to patients, particularly regarding compensatory strategies and follow-up with other professionals, were informed by results of their functional assessment. Finally, there was a lack of agreement among respondents on diagnoses of memory conditions based on presented vignettes that had varying depictions of cognitive and functional decline. Overall, our survey results indicate that neuropsychologists consider multiple factors when assessing functioning in daily life, use a variety of techniques to assess functioning, and perceive a need for improved measures of functional abilities. The lack of consensus on diagnoses of presented vignettes underscores this need.

A defining difference between mild cognitive impairment (MCI) and dementia is that functional independence is maintained in the former and compromised in the latter. Despite this, many people with MCI report mild but appreciable functional difficulties (Lindberg, Dishman, & Miller, 2016). Similarly, even those experiencing normal age-related memory changes report subtle changes in their everyday functioning (McAllister & Schmitter-Edgecombe, 2016; Parikh et al., 2016). Therefore, an important challenge in neuropsychology is how to incorporate functional information when distinguishing between normal age-related memory changes, MCI, and dementia.

Functional ability has been defined as an individual's capacity to independently participate in everyday activities, with a focus on social, occupational, and other important areas of functioning (Ustün & Kennedy, 2009). These nuanced, complex, and wide-spanning abilities are difficult to fully assess, though different aspects of functional abilities can be measured using participant-reported outcome measures (PROMs), informant measures, performance-based measures, and clinical interviews. At present, there is no gold standard for evaluating functional independence in neuropsychology (Burton, Strauss, Bunce, Hunter, & Hultsch, 2009; Gold, 2012). Functional assessments are further complicated by practical concerns such as whether a collateral informant is available and diagnostic concerns such as whether an individual has insight into their own abilities. In addition, it can be difficult to determine if there is an impairment in a functional ability when the individual has never participated in that activity. For example, some individuals may leave financial responsibilities to a spouse, which makes it difficult to determine whether they would be able to engage in those activities if needed. Functional abilities may also be compromised due to mood-related conditions or other physical conditions independent of memory processes and parsing out causation can be difficult.

In addition to informing diagnosis, assessment of functional abilities can inform recommendations offered to patients. Indeed, a discussion of how neurological conditions affect functioning in everyday life is appreciated by individuals and their families, and recommendations related to functional limitations are more likely to be followed than other types of recommendations (Westervelt, Brown, Tremont, Javorsky, & Stern, 2007). Documentation of functional limitations is also identified as an important role of neuropsychologists by physicians who make referrals to neuropsychological services (Temple, Cravalho, & Tremont, 2006). Together, these studies suggest that consumers of neuropsychological services value our profession's input on daily functioning, thereby underscoring the importance of assessing function within a neuropsychological evaluation.

Given the significance of this topic, it is important to understand neuropsychologists' beliefs and practices regarding the assessment of functional abilities within the context of memory diagnoses. We used a survey research approach to investigate this question, as survey research has a rich history in neuropsychology and has been used to understand a variety of professional activities, ethical beliefs, and assessment considerations (e.g., Rabin, Barr, & Burton, 2005; Rabin, Borgos, & Saykin, 2008; Sweet, Benson, Nelson, & Moberg, 2015). This type of research allows for sampling of a wide range of participants, and it is time and cost effective. We sought to determine instruments favored by neuropsychologists, the perceived importance of collecting information from these instruments, and the way in which functional information is used when diagnosing memory conditions or offering recommendations to individuals.

Method

Participants

Potential participants were recruited through email invitations. Emails were sent to randomly selected members of multiple professional organizations including the International Neuropsychological Society, the National Academy of Neuropsychology, and the College of Psychologists of Ontario. In addition, emails were distributed through professional electronic mailing lists, including the Neuropsychology Discussion List (NPSYCH)[1] and the Canadian Psychological Association – Neuropsychology Division[2]. Potential participants were contacted during a 3-month period from October 17, 2019, to January 17, 2020. To meet inclusion criteria, participants were required to be licensed psychologists who conduct neuropsychological assessments and regularly see adult patients with one of the following conditions: age-related cognitive changes, mild cognitive impairment, Alzheimer's disease, vascular disease, frontotemporal lobar degeneration, movement disorders (e.g., Parkinson's disease, Huntington's disease), traumatic brain injury, HIV infection, prion disease, or Lewy body disease. A total of 340 respondents initiated the survey, of which 60 individuals did not meet the inclusion criteria, which resulted in a final sample of 280 respondents. It is unknown how many total unique neuropsychologists were contacted for participation given that many neuropsychologists are members of more than one professional organization and were likely contacted both individually and via organization electronic mailing lists. However, 2762 emails were sent out (423 of which were returned as undeliverable), suggesting an estimated response rate of at least 15%.

[1] Information about the NPSYCH electronic mailing list can be retrieved at: https://jneuro.mrivner.com/index.php/2-uncategorised/85-nprequest

[2] Information about the Canadian Psychological Association – Neuropsychology Section can be retrieved at: https://cpa.ca/sections/clinicalneuropsychology/

Materials

Development of the Survey

An initial questionnaire containing 15 items with a combination of open- and close-ended questions divided into three main sections was developed. Part 1 queried basic demographic and practice-related information. Part 2 provided a description of functional ability and asked respondents to reflect on the importance of different components that make up this construct. This part also included questions about respondents' familiarity with various tools used to assess functional ability. Part 3 included three vignettes involving memory diagnoses, and asked respondents to describe their decision-making process when determining functional status.

To assess content and clarity, the initial draft of the survey was administered to four neuropsychologists who were known to the authors and who regularly assess functional status within the context of memory diagnoses. Based on their feedback, we specified the memory conditions of interest (e.g., MCI, dementia) within the survey questions, added an expanded description of our aims, and made a few changes to the wording of questions to improve readability and interpretation. To ensure that all participants met inclusion criteria, questions related to their neuropsychology practice were added to the survey, instead of being included in the description of the study only. One question about how functional assessments inform recommendations was also added. Finally, survey procedures were altered so that respondents would be randomly presented with two of three possible vignettes to reduce the length of the survey.

Pretest of the Survey

Following the expert review described above, emails were sent out to a subset of potential participants (n = 400) for pretesting the questionnaire and field procedures, as recommended by the American Association of Public Opinion Research (AAPOR; American

Association for Public Opinion Research, n.d.). Thirty-two neuropsychologists completed the questionnaire (8% response rate). Based on a review of responses, some wording changes were made in the questions, and the list of instruments was expanded.

Final Survey

The final survey consisted of 18 questions (see Appendix A). The informed consent section was followed by two questions regarding inclusion criteria. The remaining questions were divided into four parts. Part 1 consisted of five practice-related questions. Part 2 consisted of the following brief definition of (impaired) functional ability:

> Functional impairment refers to limitations in social functioning (e.g., participation in community and social life), occupational functioning (e.g., work or volunteer activities), and/or other major areas of functioning (e.g., basic or instrumental activities of daily living, learning, and communication).

This was followed by questions regarding the importance of different components that comprise functioning, the tools used to assess functioning, perceived importance of collecting information from these sources, additional functional assessment tools known to the respondent, and perceived need for the development of further measures that assess everyday functioning. Part 3 consisted of one question regarding various types of recommendations that the respondents offer to patients and whether such recommendations were impacted by their functional assessment. Recommendations in this section were derived from the authors' clinical knowledge as well as survey research that demonstrated recommendations most commonly provided by neuropsychologists (Meth, Bernstein, Calamia, & Tranel, 2018).

Part 4 included three vignettes describing hypothetical individuals. To address common diagnostic challenges encountered by clinicians when assessing functioning, the vignettes varied

on several dimensions, including (a) occupational status and perceived changes to occupational functioning due to memory difficulties, (b) marital status and availability of informant insight into daily functioning, (c) lack of earlier involvement in certain functional domains (e.g., finances, social interactions etc.), (d) changes to activities of daily living, and (e) degree of memory impairment. Case 1 featured a single individual who was employed in a challenging job and perceived changes in the ability to perform work-related duties. This individual had a recent reduction in social interactions and normal memory performance, which may have been slightly decreased compared to a superior premorbid level. Case 2 featured a married individual who was partially retired and reported some difficulties in performing work-related duties. This individual had a few close social acquaintances and reported largely unchanged social relationships. A relative weakness ($z = -1.5$) in delayed recall and category fluency was also reported. Case 3 featured a married, retired individual with a large social network, mild to moderate ($z = -1.5$ to -2.5) memory impairment, and moderately impaired confrontation naming. This individual reported changes in social relationships and activities of daily living, which was corroborated by a spouse. All cases included self-reported memory complaints that are commonly reported by older adults, including misplacing items, forgetting names, and forgetting recent conversations. Respondents were asked to confer a diagnosis and ratings of functional impairment based on the presented information.

The gender of the individual featured in each vignette was counterbalanced such that approximately half of the respondents read vignettes with one gender and vice versa.

Procedure

Participants were asked to complete a brief (10-15 minute), web-based (Qualtrics), anonymous survey examining the practices and perspectives of neuropsychologists regarding

functional assessments during the diagnosis of memory conditions. A brief description of the study preceded the questionnaires, and informed consent was obtained through the web-based survey. In order to increase the response rate, potential participants received a reminder e-mail approximately 2 weeks after the initial contact. No incentives were offered for participation. All study procedures were approved by the Research Ethics Boards at Baycrest Health Sciences (Certificate Number: 18-47) and York University (Certificate Number: e2019-212).

Results

Practice-Related Characteristics

Practice-related characteristics of the sample are described in Table 2.1. Most respondents were located in North America, held PhD degrees, and reported completing more than 10 assessments per week. Approximately half of respondents reported carrying out their work in more than one setting (46%), with most respondents working in a hospital setting. Respondents were at various stages of their career, with most practicing for fewer than 5 years or more than 20 years. Approximately half of respondents regularly supervised students.

Assessing Functional Abilities

A large majority of respondents identified that changes to instrumental and basic activities of daily living were very important when evaluating functional abilities (Figure 1). Approximately half of the respondents also felt that changes in work and volunteer activities and changes in communication abilities were very important when evaluating functional abilities. Just under half of respondents indicated that changes in learning and applying knowledge, social activities, and relationships with others were very important, and a third of respondents indicated that sense of self was very important when evaluating functional abilities.

From a list of possible functional assessment tools, by far the most commonly utilized by respondents were semi-structured interviews with the client (85%) and with an informant (82%), as shown on Table 2.2. The next most frequently used tools, which were endorsed by a third of respondents, were Independent Living Scales (28%) and the collateral report of the Instrumental Activities of Daily Living (21%). All other listed tools were utilized by a low percentage (>20%) of respondents. Many respondents (39%) indicated use of a tool that was not listed. Respondents identified 59 unique instruments used to assess functional abilities that sampled a variety of constructs (see Supplementary Table B.1 for full list).

As shown in Figure 2.2, most respondents felt it was *very important* to collect information from the client and a collateral informant through a semi-structured interview and also from the collateral- and self-report versions of the Lawton-Brody Physical Self Maintenance scale. Other tools that were identified as *very important* sources of information by most respondents were the Direct Assessment of Functional Status tool, the Collateral-Report of the Instrumental Activities of Daily Living Scale, the Functional Assessment Questionnaire, and the WHO Disability Assessment Schedule.

Table 2.3 shows the recommendations respondents identified as being impacted by findings from their functional assessments. Recommendations relating to compensatory strategies and follow-up with other professionals (e.g., driving assessments, legal consultation, occupational therapists) were most commonly endorsed as being affected by results from a functional assessment. Respondents also identified a variety of other recommendations not provided within the survey that were influenced by their findings, including suggestions for cognitive interventions, limiting current activities (or increasing support when completing them),

planning for the future, recommendations for family members, and medical consultations (Supplementary Table B.2).

More than two-thirds of respondents indicated that there was *definitely* (26%) or *probably* (43%) a need for more measures. Eighteen percent of respondents indicated that *maybe* there was a need for more measures, 12% felt there was *probably not* a need for more measures, and 1% felt there was *definitely not* a need for more measures.

Diagnoses Based on Vignettes

A Kruskal-Wallis test indicated that the gender of the featured individual did not significantly affect the diagnoses conferred by respondents for Case 1, $H(1) = 0.70$, $p = .402$, Case 2, $H(1) = 0.08$, $p = .784$, or Case 3, $H(1) = 0.097$, $p = .756$. Therefore, results based on vignette questions are presented together regardless of the gender presented in the vignettes. Figure 2.3 shows the ratings of different components of functional ability for each case.

Case 1:

Diagnoses for Case 1 were almost evenly split between mild cognitive impairment (55%) and normal cognition (45%). Almost two-thirds of respondents indicated very mild changes to overall functioning (Figure 2.3a). Ability to perform basic activities of daily living (ADLs) and instrumental ADLs (IADLs) was thought to be intact by a large majority of respondents. Most respondents indicated very mild changes to social and occupational functioning, sense of self, and ability to learn and apply knowledge. Roughly half of respondents indicated intact communication ability, with the other half indicating very mild changes in this ability.

Case 2:

Most respondents conferred a diagnosis of mild cognitive impairment (74%), with some indicating that cognition was normal (25%). Approximately half of respondents indicated very

mild changes in overall functioning, whereas one-third of respondents rated overall functioning as intact (Figure 2.3b). Ability to perform basic ADLs was thought to be intact by a large majority of respondents; roughly half of respondents indicated that ability to perform IADLs was intact. Most respondents indicated intact sense of self and communication abilities. Very mild changes were indicated in occupational functioning and ability to learn and apply knowledge by most respondents. About half of respondents indicated intact social functioning, with the other half indicating very mild changes on this domain.

Case 3:

Diagnoses for Case 3 were almost evenly split between dementia (53%) and mild cognitive impairment (47%). Most respondents indicated a mild impairment in overall functioning (Figure 2.3c). Approximately half of respondents rated the ability to perform basic ADLs as intact, and half of respondents indicated a mild impairment on ability to perform IADLs. A little more than half of respondents identified mild impairments in occupational functioning and communication ability. Mild to moderate impairments in social functioning and ability to apply knowledge were identified by most respondents. Very mild to mild impairment in sense of self was indicated by most respondents.

Relationship Between Practice-Related Demographics and Vignette Questions

Multinomial regressions were calculated to determine if practice-related demographics predicted the diagnosis conferred in each case. The practice-related demographics included in each model were highest degree reported by respondents, number of years practicing as a licensed psychologist, and number of assessments conducted in a typical week.

For Case 1, the number of years practicing as a licensed psychologist significantly predicted diagnosis, $\chi^2(4) = 17.79$, $p = .001$. Less time in practice was associated with a greater

probability of a normal cognition diagnosis (as opposed to an MCI diagnosis). Relative to those with more than 20 years of experience, respondents with fewer than 5 years of experience had 4.75 times higher odds of indicating a diagnosis of normal cognition, Wald χ^2 (1) = 10.02, p = .002. Respondents with 5-10 years of experience had 7.48 times higher odds of indicating a diagnosis of normal cognition, Wald χ^2 (1) = 11.27, p = .001. Respondents with 10-15 years of experience had 4.62 times higher odds of indicating a diagnosis of normal cognition, Wald χ^2 (1) = 6.66, p = .010. Finally, the odds of respondents with 15-20 years of experience conferring a diagnosis of normal cognition did not significantly differ from those with 20+ years of experience, Wald χ^2 (1) = 1.88, p = .350. All other practice-related demographics, including highest degree reported by respondents, χ^2 (2) = .46, p = .794, and number of assessments completed in a typical week, χ^2 (3) = 2.41, p = .493, did not predict the diagnosis conferred by respondents.

For Case 2, practice-related demographics, including highest degree, χ^2 (4) = .80, p = .938, number of years practicing as a licensed psychologist, χ^2 (8) = 11.82, p = .160, and number of assessments completed in a typical week, χ^2 (4) = 2.56, p = .634, did not predict the diagnosis conferred. Similarly, for Case 3, practice-related demographics, including highest degree, χ^2 (2) = 3.08, p = .214, number of years practicing as a licensed psychologist, χ^2 (4) = 1.99, p = .738, and number of assessments completed in a typical week, χ^2 (3) = 2.21, p = .531, did not predict the diagnosis conferred.

Discussion

This study surveyed neuropsychologists' practices regarding the assessment of functional abilities within the context of differentiating normal aging, mild cognitive impairment, and dementia. Participants included 280 psychologists who routinely conduct neuropsychological

assessments in various settings (most commonly in hospitals and private practices). Results demonstrate the multifaceted nature of functional abilities. An overwhelming majority of respondents indicated that changes in activities of daily living (basic and instrumental) are very important when evaluating functional ability. Other components such as work and volunteer activities and changes in communication abilities were also rated as very important by a majority of respondents. Other domains including learning and applying knowledge, social activities, relationships with others, and sense of self were rated as very important or fairly important to consider when evaluating functional abilities by most respondents. Therefore, neuropsychologists seem to consider changes across several different domains when evaluating functioning, though changes in activities of daily living garnered the greatest agreement among respondents, which likely reflects the fact that such changes are an aspect of the diagnostic criteria.

Across respondents, there was a wide variety of instruments reported for assessing functional abilities, though the majority identified using interviews with clients and collateral informants and felt that it was very important to collect information from these sources. Scales that assessed activities of daily living (e.g., the Lawton-Brody Physical Self-Maintenance scale) were also identified as very important for collecting information, although the number of respondents who reported using such measures was relatively low. This suggests that although respondents identify the importance of ascertaining ADLs, they may use other approaches to assess this information (e.g., client or collateral informant interview), or there may be practical considerations (e.g., time to administer additional questionnaires) that restrict the use of such instruments. Notably, some respondents reported using instruments that sampled constructs other than functioning in their evaluation (e.g., dementia rating scales, general cognitive screens, self-

report measures of cognition). This may reflect the fact that daily functioning is dependent upon a variety of cognitive abilities, and associations have been demonstrated between many of the domains reported in this survey (e.g., global cognition, memory, executive functioning) and activities of daily living (Mlinac & Feng, 2016). Additionally, it is possible that the use of instruments that sample other constructs reflects a perceived lack of measures that adequately sample daily functioning. Indeed, more than two-thirds of respondents indicated that they perceived a probable or definite need for additional measures of everyday functioning.

Nearly all the clinicians in this study indicated that they incorporate information from functional assessments when making recommendations to patients, especially recommendations related to compensatory strategy use and follow-up with other professionals. Interestingly, in a recent survey of the types of recommendations neuropsychologists give to patients, Meth and colleagues (2019) found that elaboration strategies to improve memory encoding were one of the most inconsistently given recommendations (particularly in individuals diagnosed with dementia). One possible reason for this inconsistency is that neuropsychologists may choose to make this recommendation based on the results of their functional assessment. In addition, it makes sense that functional status influences recommendations regarding follow-up with other professions, as an important consideration in individuals with dementia is competency (Barbas & Wilde, 2001) and competency issues often require consultation with other professions (e.g., lawyers, driving instructors, occupational therapists).

When asked to consider diagnoses based on vignettes that reflected cases neuropsychologists may encounter in clinical practice, respondents were fairly divided. For Case 1, which featured no memory impairment and a mild functional decline, diagnoses conferred by respondents were split between normal cognition and mild cognitive impairment. Interestingly,

for this case, respondents with fewer years of experience were more likely to confer a diagnosis of normal cognition, and those with more experience were more likely to confer a diagnosis of MCI. This suggests that more experienced clinicians may be more inclined to perceive ambiguous symptoms as indicative of pathological processes than their less experienced peers. For Case 3, which featured objective memory impairment and functional deficits, diagnoses were split between mild cognitive impairment and dementia, and there was no relation between diagnosis and years of experience or other practice-related variables. The greatest agreement occurred for Case 2, which featured mild memory impairment and a deficit in occupational functioning; in this case, there was broad consensus for a diagnosis of MCI.

Overall, these results demonstrate diagnostic variability among our respondents. This may reflect the heterogenous nature of the cognitive aging spectrum (Petersen, 2016) and highlight the challenge of converting that information into discrete categories, particularly for borderline cases. However, it is important to note that in clinical practice, neuropsychologists would have access to more information than was presented in these vignettes, which could aid them in conferring a diagnosis. Despite the lack of consensus regarding diagnosis, there was agreement regarding the overall level of functional impairment. Therefore, it is possible that although clinicians broadly agree on functioning, they do not agree on what this means for diagnosis. These findings underscore the need for consensus criteria regarding functional decline in establishing a diagnostic threshold for memory disorders. Furthermore, our results suggest greater disagreement on more nuanced components of functioning, such as sense of self, communication ability, and ability to apply knowledge as compared to broader categories, such as overall functioning and ability to perform basic ADLs. In fact, despite identifying more

nuanced components as important to consider when evaluating functional abilities, respondents do not report utilizing instruments that assess these components.

A few limitations of this study may reduce the generalizability of our results. First, given concerns about respondent burden, we limited the number of questions relating to demographic characteristics and did not query variables such as age, gender, whether post-doctoral training was completed, or areas of specialization. As such, it is possible that the sample included in this study is not representative of the overall population of neuropsychologists. However, recruitment methods utilized in this study were similar to those used in other surveys (Hirst, Watson, Rosen, & Quittner, 2019; Meth et al., 2018; Rabin et al., 2008); therefore, it is likely that similar populations had access to the survey. In addition, practice-related demographics that were reported in this study, including highest degree and employment setting, are similar to those reported by others (Hirst et al., 2019; Meth et al., 2018; Rabin et al., 2008). Although an exact response rate could not be calculated for this study, due to overlap in electronic mailing lists and targeted emails used for recruitment, our estimated response rate is similar to those reported by other researchers utilizing web-based surveys (5-18%; Bortnik et al., 2013; Hirst et al., 2019; Rabin et al., 2008). Another limitation of our study is that respondents could not indicate their primary practice setting or rank-order their practice settings in cases where respondents reported practicing in more than one setting. As a result, we were unable to examine the relationship between practice setting and diagnoses made for the vignette cases. Finally, just over 10% of respondents were from outside the United States or Canada. It is likely that there are geographical and cultural differences in both conceptualization of functional abilities and in tools used to assess functioning; this would be an interesting avenue for future research to explore.

To our knowledge, this was the first study to survey neuropsychologists' approaches to functional assessments. Functional status is an important aspect of the decision-making process when differentiating between normal aging, MCI, and dementia. As such it is important to consider how we define functioning, what tools we use to measure these abilities, and how it influences the diagnoses we confer, as well as the recommendations we offer our patients. Our results indicate that respondents identify multiple components as important to consider when evaluating functioning but do not report utilizing instruments that seem to assess all these components. In addition, respondents demonstrate greater variability in evaluating more specific aspects of functioning than broader aspects, such as basic ADLs, based on the vignettes presented in this survey. As such, we recommend the development and utilization of measures that assess more nuanced aspects of everyday functioning to complement measures of ADLs. Few instruments exist that measure the impact of cognitive changes on everyday living; we are aware of two such measures. The first, developed through our own work, measures the impact of memory changes on nuanced aspects of everyday living, including restrictions to lifestyle activities (e.g., social relationships, work/leisure activities), negative emotions associated with memory change (e.g., self-identity, perceived judgment from others) and coping responses (Shaikh et al., 2018). The second evaluates self-reported cognitive changes and measures the impact of these changes on affect, skill loss, and social functioning (Frank et al., 2006). In addition, several instruments assess impact on quality of life (e.g., WHO Disability Assessment Schedule; Ustün et al., 2010; Illness Intrusiveness Ratings Scale; Devins, 2010; the Functional Assessment of Cancer Therapy-Cognition; Costa et al., 2018), and these may be useful for determining difficulties experienced due to health conditions.

Our results indicate a fair amount of disunity among respondents when it comes to conferring a diagnosis on borderline cases. This lack of consensus is particularly notable when considering the relative agreement on overall functioning for these cases. Based on these findings, we recommend the establishment of criteria regarding the level of functional decline necessary for diagnosis of memory disorders. Although further research will likely be required to fully delineate the association between cognitive and functional decline, particularly given the fact that recent research has identified discrepancies between cognitive and functional trajectories in dementia progression (Wang et al., 2019), we recommend creating initial guidelines to aid clinicians in conferring diagnosis and updating as indicated by new evidence. Finally, although respondents in this survey had access to less information than would be available in a comprehensive neuropsychological assessment, it may be warranted for clinicians to make consumers of neuropsychological assessments (e.g., patients, family members, referring physicians) aware of the relative disagreement among neuropsychologists when it comes to diagnosing borderline cases. Receiving a memory diagnosis can have important consequences for patients (Lingler et al., 2006; Portacolone, Johnson, Covinsky, Halpern, & Rubinstein, 2018; Robinson et al., 2011), and as such it may be helpful for them to understand the divisive nature of such a diagnosis.

Table 2.1

Practice-Related Characteristics of Sample

Variable	Number of Respondents	Percentage of Respondents
Highest Degree		
PhD	205	73%
PsyD	67	24%
Other	8	3%
No. of Years Practicing		
0-5 years	84	30%
5-10 years	44	16%
10-15 years	38	14%
15-20 years	31	11%
20+ years	83	29%
No. of Assessments per week		
0	2	1%
1-5	72	26%
6-10	56	20%
>10	148	53%
Regularly supervise students		
Yes	148	53%
No	129	47%
Practice Setting		
Hospital	154	55%
Rehabilitation Facility	49	18%
Psychiatric Setting	22	1%
Community Clinic	30	11%
Private Practice	131	47%
University/Academic Setting	77	28%
Forensic Setting	19	7%
Other	14	5%
Location		
United States	208	74%
Canada	42	15%
Spain	6	2%
Australia	5	2%
United Kingdom	4	1%
Colombia	3	1%
Portugal	2	1%
China	1	0.4%
Czech Republic	1	0.4%
Denmark	1	0.4%
India	1	0.4%
New Zealand	1	0.4%
Nigeria	1	0.4%

Norway	1	0.4%
Saudi Arabia	1	0.4%
Sweden	1	0.4%
Switzerland	1	0.4%

Table 2.2

Instruments Used by Respondents to Assess Functional Abilities

Type of Instrument	Number of Respondents	Percentage of Respondents
Semi-structured interview questions – client interview	238	85%
Semi-structured interview questions – collateral informant interview	230	82%
Other	108	39%
Independent Living Scales	79	28%
Instrumental Activities of Daily Living Scale – collateral report	60	21%
Clinical Dementia Rating Scale	53	19%
Neuropsychological Assessment Battery - Daily Living Scale	46	16%
Functional Assessment Questionnaire	43	15%
Dementia Severity Rating Scale	42	15%
Instrumental Activities of Daily Living Scale - self-report	39	14%
Adaptive Behaviour Assessment Scale	30	11%
The World Health Organization Disability Assessment Schedule	26	9%
Katz Index of Independence in Activities of Daily Living	19	7%
Everyday Cognition	15	5%
The Global Assessment of Functioning Scale	14	5%
The Barthel Index of Daily Living	14	5%
Informant Questionnaire on Cognitive Decline in the Elderly	14	5%
Lawton - Brody Physical Self-Maintenance Scale - collateral-report	11	4%
Direct Assessment of Functional Status Tool	7	3%
Disability Assessment for Dementia	4	1%
Lawton-Brody Physical Self-Maintenance Scale - self-report	4	1%
Multiple Errands Test	3	1%

Table 2.3

Respondents' Ratings for Types of Recommendations Impacted by Functional Assessment

Type of Recommendation	Number of Respondents	Percentage of Respondents
Recommending compensatory strategies to manage everyday problems	231	83%
Recommending follow-up with other professionals	230	82%
Encouraging clients to seek support from family and friends	199	71%
Providing educational resources or supports	195	70%
Providing tips on improving lifestyle factors	193	69%
Recommending follow-up neuropsychological assessments	191	68%
Providing mood-related recommendations to individuals whose functioning may be affected by negative attitudes towards aging or anxiety about cognition	185	66%
Other	34	12%
None of the above - my recommendations are not impacted by my functional assessment	2	1%

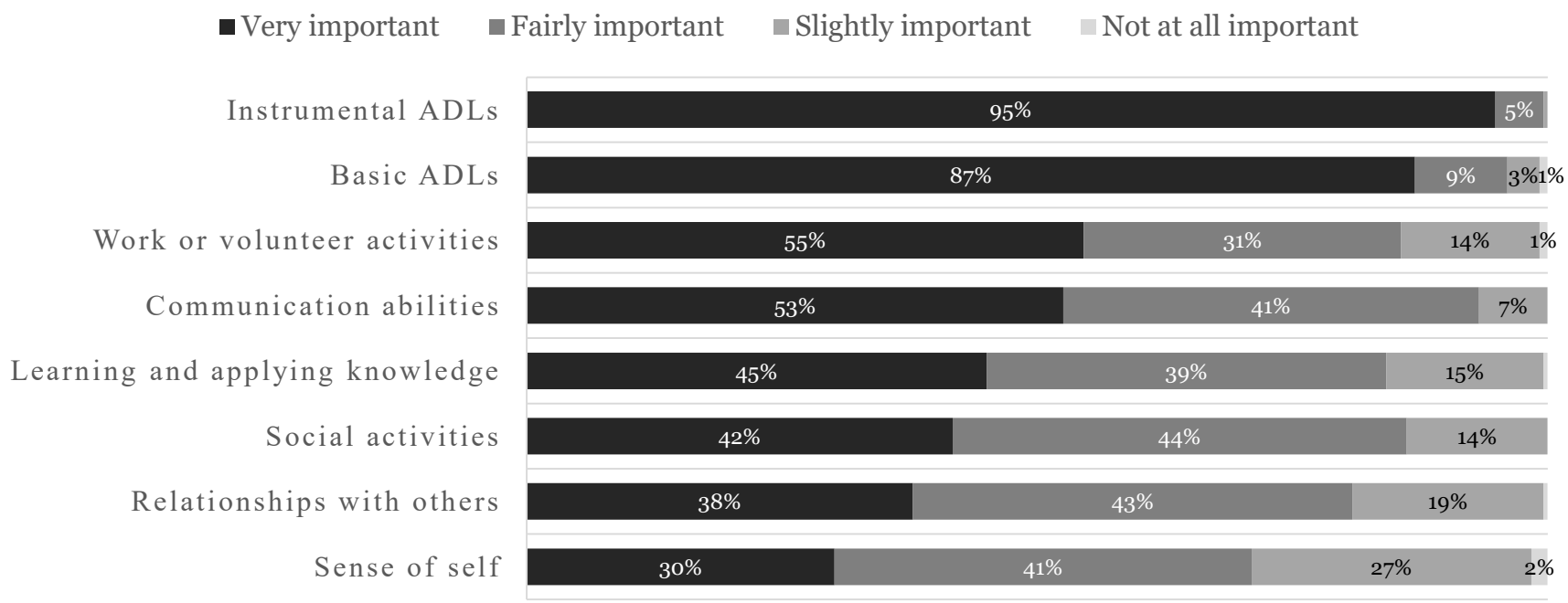

Figure 2.1. Respondents' Ratings of Importance of Components That Comprise Functional Ability. ADLs = activities of daily living

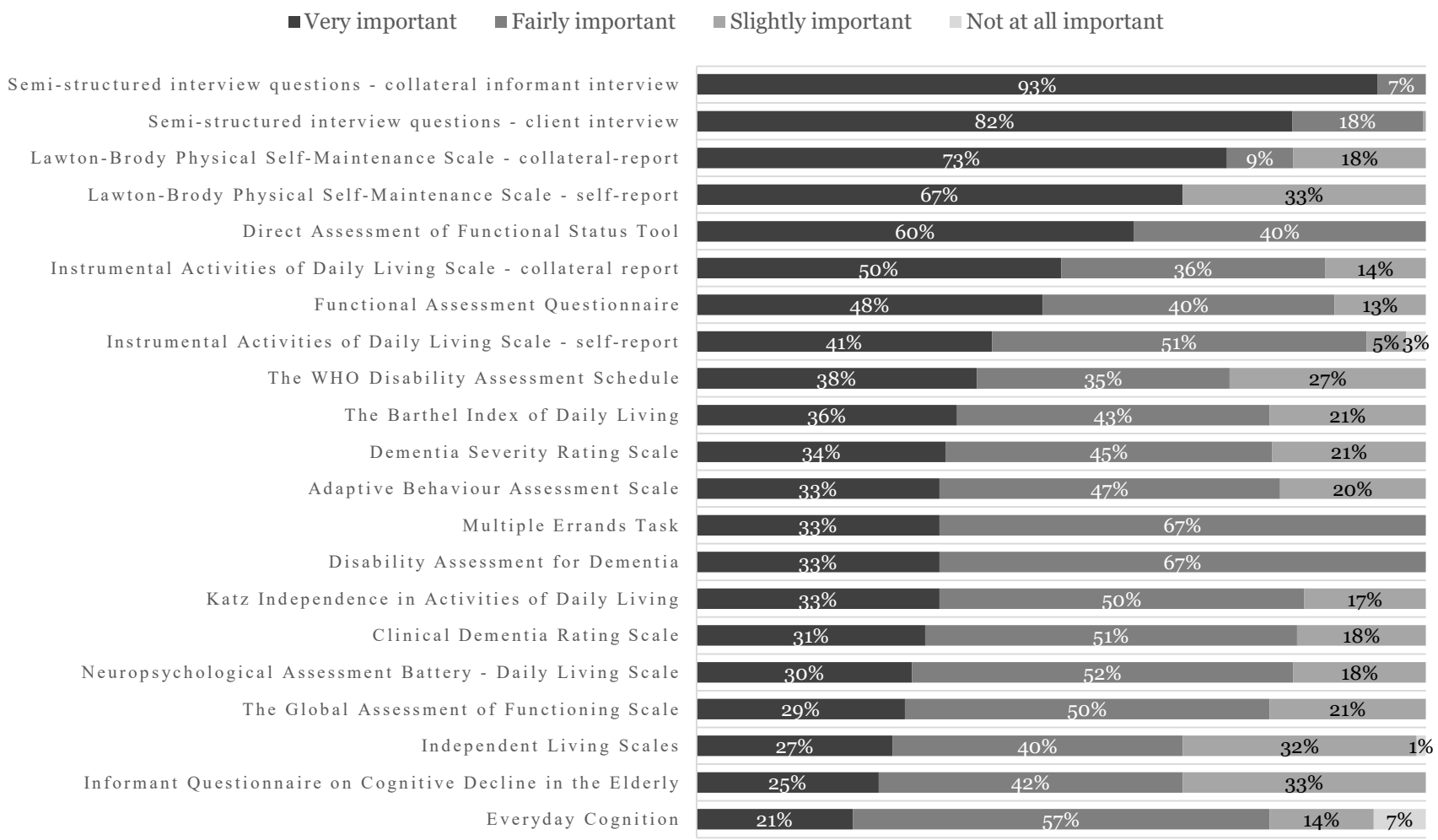

Figure 2.2. Respondents' Ratings of Importance of Collecting Data From Various Sources

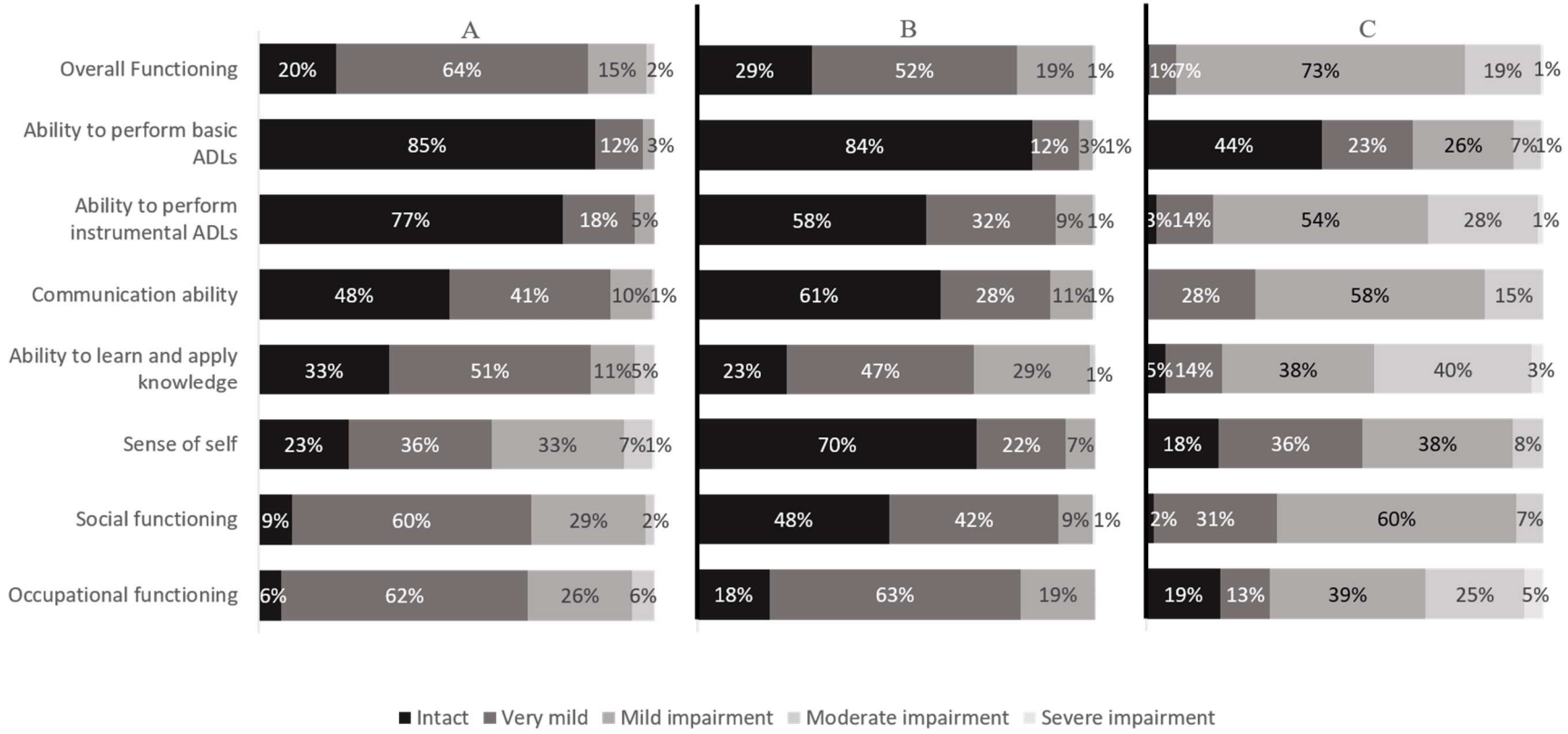

Figure 2.3. Respondents' Ratings of Functional Abilities for (a) Case 1, (b) Case 2, and (c) Case 3. ADLs = activities of daily living

CHAPTER 3

Study 2: The impact of memory change on everyday life among older adults – Association with cognition, self-reported memory, and strategy use

Preface

Many older adults experience memory changes that can have a meaningful impact on their everyday lives, such as restrictions to lifestyle activities and negative emotions. Older adults also report a variety of positive coping responses that help them manage these changes. The purpose of this study was to examine the associations between the impact of memory change and (a) objective cognitive performance, (b) self-reported memory, and (c) self-reported strategy use in a sample of 94 older adults (age 60 to 89, 52% female) along a cognitive ability continuum from normal cognition to mild cognitive impairment. Whole sample correlations revealed that greater restrictions to lifestyle activities , (|*rs*| = .36-.66), more negative emotion associated with memory change, (|*rs*| = .27-.76), and an overall greater burden of memory change on everyday living, (|*rs*| = .28-.61), were associated with poorer objective memory performance and lower self-reported memory ability and satisfaction. Performance on objective measures of executive attention was unrelated to the impact of memory change. Self-reported strategy use was positively related to adaptive coping with memory changes (|*r*| = .26), but the greater one's reported strategy use, the more negative emotions were reported regarding memory changes (|*r*| = .23). Given the prevalence of memory change among older adults, it is important to take an in-depth look at the experience of memory change and its impact on everyday functioning in order to develop services that target the specific needs of this population.

Many older adults experience mild memory changes as they age, such as tip-of-the tongue errors, forgetting to take medication, forgetting recently learned names and other information like the locations of items, or why one walked into a room (Farias et al., 2006). Such changes are common in both normal aging and amnestic mild cognitive impairment (aMCI), and although they are insufficient to impair functional independence, they can nonetheless have a meaningful impact on everyday living (Lindbergh et al, 2016). Recent qualitative work has characterized the lived experience of memory change and its consequences for daily life, with similar themes emerging in both cognitively normal older adults and those with aMCI. De Vriendt et al. (2012) reported that, in addition to functional changes, older adults with aMCI described emotional consequences of memory change (including feelings of discontent and greater uncertainty), activity disruptions due to feeling less capable, and difficulty adapting to memory changes. Our own work has identified an impact of memory change on several life domains including changes in feelings and view of the self, changes in relationships and social interactions, changes in work and leisure activities, and a deliberate increase in compensatory behaviours among cognitively normal older adults and those with aMCI (Parikh et al., 2016). Meilak and colleagues (2016) found that older adults with aMCI reported implementing both practical (e.g., creating lists) and emotional (e.g., normalizing memory changes) strategies to cope with memory change in their daily life. Similarly, Rotenberg and colleagues (2019b) reported negative emotional implications of memory change, including feelings of embarrassment, frustration, anger, and worry, as well as coping responses that focused on both active problem-solving behaviours (e.g., using external memory aids) and the practice of self-acceptance through reframing perceptions of memory problems among older adults seeking medical help for perceived memory problems.

Although there is accumulating evidence that there is, indeed, a meaningful impact of memory change on older adults' day-to-day lives, little is known about the correlates of this impact. In the current study, we investigate the relationship between the impact of memory change on everyday life and objective cognitive performance, self-reported memory, and strategy use. Specifically, we examined key aspects of the impact of memory changes on everyday life that have been previously identified through qualitative work, including restrictions to lifestyle activities due to memory change (de Vriendt et al., 2012; Parikh et al., 2016), coping with memory change (Meilak et al., 2016; Parikh et al., 2016; Rotenberg et al., 2019b), and negative emotions that emerge as a result of memory change (de Vriendt et al., 2012; Parikh et al., 2016; Rotenberg et al., 2019b).

Few studies have examined the association between the perceived everyday impact of memory change and objective cognitive performance. However, previous research examining the cognitive correlates of functional abilities provides some insight into the role of cognitive performance on daily life. For example, executive abilities and delayed memory are commonly studied as important predictors of functional status among community-dwelling older adults (e.g., Cahn-Weiner, Boyle, & Malloy, 2002; Hart & Bean, 2011; Schmitter-Edgecombe & Parsey, 2014). Given this, we explored relationships between these cognitive abilities and the impact of memory change on everyday living. In addition, previous research has demonstrated that engagement in lifestyle activities (i.e. physical, social, and cognitive activities) is protective of both memory (Small, Dixon, McArdle, & Grimm, 2012) and executive abilities (de Frias & Dixon, 2014); however, it is less clear to what extent lifestyle engagement is related to the experience of memory change. Similarly, the relationship between cognitive performance and

negative emotions associated with memory change on the one hand and cognitive performance and coping response to memory change on the other, have not been explored.

The aims of this study were to examine associations between the perceived impact of memory change on everyday life and objective cognitive performance, self-reported memory, and strategy use while controlling for affective symptoms. In the current study, we examined cognition using two methods. First, we examined cognition on a continuous scale because healthy aging and MCI can be conceptualized as overlapping categories (Palmer, Bäckman, Winblad, & Fratiglioni, 2008; Petersen, 2016). We hypothesized that greater impact of memory on everyday living would be associated with poorer performance on neuropsychological measures of memory and executive functioning and poorer self-appraisal of memory ability. While few studies have explored the relationship between self-reported memory complaints (SMCs) and impact on everyday life, prior research does demonstrate an association between SMCs and functional capacity (Montejo, Montenegro, Fernández, & Maestú, 2012; Ogata, Hayashi, Sugiura, & Hayakawa, 2015), suggesting that individuals with poorer self-appraisal of memory may face a greater burden of memory changes on daily life. We further hypothesized that self-reported strategy use would be associated with adaptive coping in response to memory change, as one way that older adults respond to perceived changes in their memory is by instituting strategies that compensate for memory change. Second, to enable comparison to other research, we examined categorical differences in the relationship between memory impact and self-reported memory and strategy use in older adults with and without aMCI.

Method

Participants

A community sample, consisting of 94 individuals, was recruited from an ambulatory memory clinic (n = 30) and a research participant database (n = 64) at a geriatric hospital. Participants were recruited to participate in a larger validation study of a novel online test battery. Inclusion criteria included age 60 and older and ability to understand and follow instructions in English. Exclusion criteria included diagnosis of dementia, history of brain tumour, clinical stroke, seizures, traumatic brain injury, current cancer in treatment, untreated sleep apnea, other neurological disorders, current attention-deficit hyperactivity disorder treatment, major depression, alcohol or drug abuse within the past 6 months and inability to use computers. An additional exclusion criterion included non-amnestic mild cognitive impairment, which was established after neuropsychological testing. Participants recruited from the research participant database were provided with compensation of $100 for neuropsychological testing; participants recruited from the ambulatory memory clinic were not compensated, as neuropsychological testing was part of their routine clinical care. As shown in Table 3.1, participants were well-educated with a roughly equal distribution of males and females.

Measures

Memory Impact. The impact of memory change on everyday living was assessed using the Memory Impact Questionnaire (MIQ; Shaikh et al., 2018). This measure consists of 51 items across three subscales: the Lifestyle Restrictions subscale (n = 19 items), the Positive Coping subscale (n = 19 items), and the Negative Emotions subscale (n = 13 items). The Lifestyle Restrictions subscale reflects changes in social relationships and work/leisure activities. For example, one item from this subscale states, “Because of my memory changes, I am less likely to get involved in my favourite hobbies.” The Positive Coping subscale reflects deliberate increases

in compensatory mechanisms and self-acceptance. For example, one item from this subscale states, “When I make memory mistakes, I tell myself, I can use a new strategy to get it next time.” The Negative Emotions subscale reflects changes in self-perception and perceived judgment from others. For example, one item from this subscale states, “My memory changes make me feel less capable.” A total score reflects the overall effect of memory changes on daily life, with higher scores reflecting a greater negative burden of memory changes. This is a psychometrically sound measure with good convergent validity (rs = 0.22-0.42), test-retest reliability (rs = 0.65-0.91) and internal consistency (αs = 0.87-0.93).

Cognitive Performance. A fixed battery of neuropsychological tests included Story B of the Logical Memory I and II subtests of the Wechsler Memory Scale-Revised (Wechsler, 1987); the Digit Symbol and Digit Span subtests of the Wechsler Adult Intelligence Scale-III (Wechsler, 1997); the Word List 1 and 2, Complex Figure 1 and 2, Clocks, Verbal Fluency, and Spatial Location Memory subtests of the Kaplan Baycrest Neurocognitive Assessment (KBNA; Leach, Kaplan, Rewilak, Richards, & Proulx, 2000); Trail Making Test, Forms A and B (Reitan, 1992); Boston Naming Test (split-half; Kaplan, Goodglass, & Weintraub, 1983); the Vocabulary (split-half protocol) and Matrix Reasoning subtests of the Wechsler Abbreviated Scale of Intelligence (Wechsler, 1999); and the Color-Word Interference subtest of the Delis-Kaplan Executive Function System test (Delis, Kaplan, & Kramer, 2001). Participants also underwent a semi-structured clinical interview and, wherever possible, collateral information was collected regarding their abilities to perform individual activities of daily living.

Self-Reported Memory. Self-appraisal of memory function was assessed using the Ability scale of the Multifactorial Memory Questionnaire (MMQ; Troyer & Rich, 2002). On this scale, respondents are asked to indicate how often they have made common memory mistakes in

the last two weeks. For example, one item asks respondents how frequently they "forget to pay a bill on time." Contentment with memory ability was assessed using the Satisfaction scale of the MMQ. For example, one item states, "I am generally pleased with my memory ability." A recent metanalysis of the measurement properties of these scales revealed strong convergent validity (*r*s = .52-.71), test-retest reliability (*r*s ≥ .90), and internal consistency (αs ≥ .91; Troyer, Leach, Vandermorris, & Rich, 2019).

Strategy Use. Strategy use was assessed using the Strategy scale of the MMQ (Troyer & Rich, 2002). In this scale, respondents are asked to indicate how frequently they use a given strategy. For example, one item asks respondents how frequently they "use a timer or alarm to remind you when to do something." This measure has strong convergent validity (*r* = .72), test-retest reliability (*r* = .88), and internal consistency (α = .86; Troyer et al., 2019).

Affective Symptoms. The Patient Health Questionnaire-9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001) was used as a measure of depression severity. This 9-item questionnaire is based on the Diagnostic and Statistical Manual of Mental Disorders (4th ed.; DSM-IV; American Psychiatric Association, 2000) diagnostic criteria for major depressive disorder. The measure has good internal consistency (α = .89) and test-retest reliability (*r* = .84). A recent meta-analysis of the psychometric properties of this measure found good sensitivity (.50-1.0) and specificity (.67-.95) among older adults (> 60 years of age; Levis, Benedetti, Thombs, & DEPRESSD Collaboration, 2019). The Generalized Anxiety Disorder Questionnaire Scale-7 (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006) was used to measure anxiety. This 7-item questionnaire is based on the DSM-IV diagnostic criteria for generalized anxiety disorder (American Psychiatric Association, 2000). Previous research suggests strong internal consistency (α = .92) and test-retest reliability (*r* = .83) among an adult population (Spitzer et al., 2006).

Procedure

A total of 301 participants were contacted for the study, of which 124 expressed interest and met initial criteria. Of these 124 participants, 30 were excluded for failing to meet study criteria (e.g., mood or medical criteria, presence of non-amnestic MCI), for a final sample of 94 participants. All participants underwent a semi-structured clinical interview and full neuropsychological assessment, which lasted approximately 4 hours. Administration order was as follows: neuropsychological measures of cognitive performance, measures of affective symptoms (i.e., PHQ-9 and GAD-7), self-reported memory and strategy use, and impact of memory changes. In addition to these tests, participants completed a brief screening measure (Montreal Cognitive Assessment; Nasreddine et al., 2005), an abbreviated assessment tool (the Toronto Cognitive Assessment; Freedman et al., 2018a; Freedman et al., 2018b), and an online test battery (Cogniciti's Brain Health Assessment; Troyer et al., 2014), as part of the larger validation study either before or after the neuropsychological assessment.

For the group-based analysis, consensus decisions were made by three neuropsychologists to determine group membership (i.e., cognitively normal or mild cognitive impairment) based on clinical information (e.g., estimated premorbid level) and performance on the complete neuropsychological assessments, as suggested by previously established criteria (Jak et al., 2005).

Of the 94 participants, 40 were considered cognitively normal and 53 were classified as aMCI. One participant could not be confidently classified to either group and therefore was excluded from group-based analysis, although she was included in the whole-sample correlational analysis. Of the 53 participants with aMCI, most had single domain aMCI (n = 39). All participants were functionally independent and therefore did not meet the criteria for dementia.

All study procedures were approved by the Research Ethics Boards at Baycrest Health Sciences (#09-02) and York University (#e2019-326).

Statistical Analyses

Five composite scores were calculated by averaging tests belonging to the same cognitive domain. The memory composite score was calculated by averaging the scaled scores of the Word List delayed recall score, the Complex Figure delayed recall score, and the Logical Memory Retention score. The executive attention composite score was calculated by averaging the scaled scores of the Color-Word Interference Inhibition score and Trail Making Test, Part B. The speed composite score was calculated by averaging the scaled scores of the Trail Making Test, Part A, Digit Symbol, and Color Naming and Word Reading scores of the Color-Word Interference test. The visuospatial composite score was the Visuospatial scaled score of the KBNA, which combines performance on the Clocks and Complex Figure subtests. The language composite score was calculated by averaging the scaled scores of semantic fluency, phonemic fluency, and the Boston Naming Test. Descriptive statistics of the neuropsychological profile of participants are displayed in Table 3.1.

Partial correlation coefficients that controlled for affective symptoms, as measured by the adjusted Pearson product-moment correlation, were calculated between measures of memory impact on the one hand and performance on memory and executive attention tasks as well as self-reported memory ability, satisfaction, and strategy use on the other.

An independent samples *t*-test was used to examine group differences on the impact of memory change and other self-report memory measures between cognitively normal older adults and those with aMCI. Effect sizes were calculated using Cohen's *d* (Cohen, 1988). In addition, the probability of superiority (Grissom & Kim, 2005) was calculated, as it provides a more

accessible estimate of effect size (Lakens, 2013) by providing the likelihood that a randomly selected member of one group performed better than a randomly selected member of the other group.

Results

Memory Impact and Cognitive Performance

Correlations between the three subscales of the MIQ and performance on memory and executive attention composite scores are shown in Table 3.2. The Positive Coping subscale of the MIQ and the memory composite were not correlated. Individuals with poorer memory abilities (as measured by the memory composite) reported greater lifestyle restrictions and greater negative emotions due to memory changes. Participants with poorer memory also reported a greater overall burden of memory changes on everyday living. MIQ subscale scores and the executive attention composite score were not correlated.

Memory Impact and Self-Reported Memory

Participants who rated their memory as poorer reported greater restrictions to their lifestyle, greater negative emotions, and a greater overall burden of memory changes (see Table 3.3). Similarly, participants who expressed greater satisfaction with their memory reported fewer restrictions to their lifestyle, fewer negative emotions and a lower negative impact of memory changes. Participants who reported greater satisfaction with their memory also reported utilizing fewer coping strategies.

Individuals who reported greater strategy use also reported greater positive coping with memory change. Finally, participants who reported more negative emotions associated with memory change reported using more strategies.

Group Differences in Memory Impact and Self-Reported Memory

As shown in Table 3.1, there were no significant differences between the cognitively normal older adults and those with aMCI in terms of age, education, gender, or IQ. Older adults with aMCI reported a greater burden of memory changes on their everyday living than did cognitively normal older adults (see Table 3.4). This effect size was medium, with a 62% probability that a participant with aMCI would report a greater impact of memory change compared to a cognitively normal older adult. Older adults with aMCI reported more restrictions to their lifestyle as compared to cognitively normal older adults. This effect size was medium, with a 64% probability that a participant with aMCI would have more restrictions to their lifestyle than would a cognitively normal older adult. Groups did not differ on adaptive coping in response to memory change or negative emotions due to memory.

Cognitively normal older adults reported greater satisfaction with their memory ability as compared to older adults with aMCI. This effect was medium in size, with a 61% probability that a cognitively normal participant would report greater satisfaction with their memory as compared to an individual with aMCI. There were no significant group differences on self-appraisal of memory ability or strategy use, with small effect sizes observed for both measures.

Affective Symptoms

In the full sample ($N = 94$), low endorsement of both depression ($M = 2.16$, $SD = 2.52$) and anxiety symptoms ($M = 2.22$, $SD = 2.50$) was observed, as expected given that presence of mood disorders (e.g., major depression) was an exclusion criterion. Overall, the relationship between memory impact and cognitive performance measures and memory impact and self-reported memory remained largely unchanged when affective symptoms were not controlled (see Supplementary Tables C.1 and C.2, respectively). There were no group differences in PHQ-9 scores, $t(91) = 0.14$, $p = .89$, or GAD-7 scores, $t(91) = -0.58$, $p = .57$.

Discussion

In this study, we describe associations between the impact of memory change and objective cognitive performance, self-reported memory, and self-reported strategy use along a cognitive ability continuum from normal cognition to amnestic mild cognitive impairment. As hypothesized, we found that more negative impact of memory change on everyday living was associated with poorer memory performance, lower self-reported memory ability, and less satisfaction with one's memory.

Relationship Between Memory Impact and Cognitive Performance

Older adults with poorer memory performance reported less engagement in lifestyle activities (e.g., involvement in social relationships, hobbies and pastimes, volunteer and work) and more negative emotion due to memory change. Our findings are supported by earlier research showing an association between poor performance on memory tests and difficulty completing everyday tasks, such as evaluating nutrition labels, following recipes, and ordering household materials (Beaver & Schmitter-Edgecombe, 2017). These results may be important in identifying individuals at risk for developing dementia. Participation in lifestyle activities (including cognitive, social, and physical activities) during the lifespan is important for decreasing the risk of dementia in later life (Tortosa-Martinez, Zoerink, & Machado-Lopez, 2011), so it is crucial that barriers are identified and minimized to improve future outcomes. Similarly, identifying and mitigating negative emotions associated with memory change may have a positive impact on cognitive and emotional health as depressive symptoms in later life increase risk of progression to dementia (Singh-Manoux et al., 2017).

Contrary to study hypotheses, there were no significant relationships between performance on executive aspects of attention and memory impact. This may have been due to restricted variability in the executive attention domain observed in our sample, as most

participants scored in the average range. Although these findings warrant replication with a more cognitively diverse sample, other researchers have reported that older adults with memory impairments report different types of functional difficulties compared to those with executive impairments (Bangen et al., 2010), which suggests that cognitive correlates of everyday functioning may be specific to the aspects of daily life sampled.

Relationship of Memory Impact to Self-Reported Memory and Strategy Use

Our results indicate that older adults who report lower memory abilities and who are less satisfied with their memory also report a greater impact of memory changes on their everyday living (see Table 3.3). This is consistent with our previous work with cognitively normal older adults (Shaikh et al., 2018). In addition, older adults who reported more adaptive coping reported less satisfaction with their memory ability and greater frequency of strategy use. Older adults who are less content with their memory performance may be more motivated to employ coping strategies in a bid to reduce the negative impact of memory change. Similarly, an association between positive coping and strategy use is intuitive as compensatory strategy use is one practical way to cope with age-related memory change.

Group Differences in Memory Impact and Self-Reported Memory

Between-groups comparisons revealed that older adults with aMCI reported more restrictions to their lifestyle, greater burden of memory changes and less satisfaction with their memory than cognitively intact older adults. Considering that aMCI is conceptualized to be situated somewhere between healthy aging and dementia, it is reasonable that the everyday impact on lifestyle activities and overall burden should be higher in individuals with aMCI as compared to cognitively normal older adults. Notably, this finding is consistent with the results observed when memory was examined as a continuous variable, which showed that older adults

with weaker memory reported greater restrictions to lifestyle activities and a greater burden of memory changes. This provides further support for the notion of a cognitive aging spectrum rather than discrete diagnostic categories. Cognitively normal older adults reported greater satisfaction with their memory ability as compared to older adults with aMCI. Contrary to our hypothesis, self-appraisal of memory ability did not differ between cognitively normal older adults and those with aMCI. Other studies have reported a smaller effect size of this Ability subscale as compared to the Satisfaction subscale of the MMQ, which suggests that the latter is better able to distinguish between cognitively normal older adults and those who have aMCI (Troyer et al., 2019). In addition, previous research suggests that self-reported memory complaints in cognitively normal older adults may reflect mood-state and personality factors (Rönnlund, Vestergren, Mäntylä, & Nilsson, 2011), whereas in older adults with mild cognitive impairment, self-reported memory complaints reflect objective cognitive abilities (Bruce et al., 2011). Positive coping did not differ between cognitively normal older adults and those with aMCI. Prior research shows a relationship between type of coping responses utilized and personality traits (Connor-Smith & Flachsbart, 2007), which suggests that coping responses may depend on individualized factors more so than cognitive ability. Negative emotional reactions to memory change were also equivalent between groups. This is consistent with Linger and colleagues' (2006) finding that older adults with aMCI have a variety of emotional reactions to memory change, including but not limited to negative reactions. It is possible that older adults along the cognitive continuum from normal cognition to mild cognitive impairment have similarly negative emotions associated with memory change.

Study Limitations and Conclusion

In this study, we considered cognitive correlates of memory impact across a continuum of cognitive abilities ranging from cognitively normal older adults to aMCI. We chose this novel approach because of emerging evidence that there are no clear-cut boundaries between MCI and normal cognitive aging (Petersen et al., 2014); therefore, such diagnostic criteria may not fully capture individual differences. In addition to this approach, we explored group differences in the impact of memory changes, self-reported memory, and strategy use in order to enable comparisons with previous research. As two different recruitment sources were utilized in this study, it is possible that described group-based differences can be attributed to the fact that in one case, individuals presented to a clinic while in the other they were recruited from a research participant database. Indeed, while participants recruited from the memory clinic (n = 22) and participant database (n = 31) were represented roughly equally in the aMCI group, the cognitively normal group mostly included participants recruited from the participant database (n = 34). While this warrants further exploration in future studies, the fact that group-based differences were consistent with results observed when memory was examined as a continuous variable, suggests that cognitive differences between groups may better explain our results. Another limitation of our study is that our sample combined individuals with single and multiple domain aMCI, both of which are thought to represent prodromal stages of Alzheimer's disease. We did not conduct separate analyses for these two groups because of low power due to a small sample size for the multiple domain aMCI group and heterogeneity in the affected cognitive domains. It would be worthwhile for future research to explore differences in these two diagnostic categories with respect to the impact of memory changes, as individuals with multiple domain aMCI are thought to represent a more advanced prodromal stage of Alzheimer's disease (Backman, Jones, Berger, Laukka, & Small, 2004) and to have greater functional impairments

than single domain aMCI (Aretouli & Brandt, 2010). A final limitation is that self-report instruments were used to assess the constructs under examination. As such, it is possible that the observed relationship between memory impact and (a) self-reported memory, and (b) strategy use, may be partially attributable to response bias or a greater propensity to endorse symptoms.

Understanding the everyday impact of memory changes in older adults is an important goal for researchers and clinicians alike to help in the design and evaluation of interventions aimed at improving quality of life, functional ability, and coping with memory change. Although several studies have investigated functional abilities in individuals with aMCI, this is the first quantitative examination of nuanced aspects of memory impact, including restrictions to lifestyle activities, emotional reactions to memory change, and coping responses to this change in a sample of older adults with and without aMCI. Furthermore, this study provides information about the cognitive correlates of the impact of memory change on everyday living and the association between memory impact and self-reported memory. Our results indicate those who report a more negative impact of memory change have poorer performance on memory tasks, poorer self-reported memory ability, and less satisfaction with their memory. These findings add to the extant literature on broader functional abilities among older adults with varying degrees of memory impairment and provide insight into their everyday memory experience.

Table 3.1

Participant Characteristics by Group Membership

Variable	Full Sample (n = 94)	Normal Cognition (n = 40)	aMCI (n = 53)	*t*(df) (Normal Cognition vs. aMCI)	Effect Size (Normal Cognition vs. aMCI)
Age (M ± SD) Range	75.1 (6.4) 60 – 89	74.1 (7.0) 60 – 89	75.7 (6.0) 64 – 89	-1.2 (91)	0.25
Gender (M:F)	45:49	19:21	26:27	.02 (χ^2)	0.02
Education (M ± SD) Range	15.6 (2.7) 10 – 24	15.8 (2.6) 10 – 22	15.5 (2.9) 10 – 24	.52 (91)	0.11
IQ (M ± SD) Min-Max	124.5 (11.3) 84-145	124.8 (11.4) 100 – 145	124.2 (11.5) 84 – 143	-.05 (91)	0.05
Composite Scores:					
Memory (M ± SD)	10.7 (2.7)	12.6 (1.7)	9.2 (2.4)	7.8 (91)***	1.6
Executive attention (M ± SD)	11.7 (2.2)	12.2 (1.8)	11.4 (2.5)	1.6 (91)	0.37
Speed (M ± SD)	11.4 (1.8)	11.8 (1.2)	11.2 (2.0)	1.7 (91)	0.36
Visuospatial (M ± SD)	11.1 (1.7)	11.3 (1.6)	10.9 (1.8)	0.9 (91)	0.23
Language (M ± SD)	12.1 (2.1)	12.8 (2.0)	11.5 (2.1)	3.0 (91)**	0.63

Note. * $p < .05$, ** $p < .01$, *** $p < .001$. Effect sizes are Cohen's d for *t*-tests and Cramer's V for χ^2.

aMCI = amnestic mild cognitive impairment

Table 3.2

Partial Correlations Between Memory Impact and Measures of Cognitive Performance Controlling for Affective Symptoms

	Composite Scores of Cognitive Performance	
	Memory	Executive Attention
Lifestyle Restrictions	-.36***	-.18
Positive Coping	-.11	-.08
Negative Emotions	-.27*	-.11
MIQ Total Score	-.28**	-.12

Note. * $p < .05$, ** $p < .01$, *** $p < .001$
MIQ = Memory Impact Questionnaire

Table 3.3

Partial Correlations Between Memory Impact and Self-Reported Memory and Strategy Use Controlling for Affective Symptoms

	MMQ – Ability	MMQ – Satisfaction	MMQ – Strategy
Lifestyle Restrictions	-.46***	-.66***	.13
Positive Coping	-.13	-.27**	.26*
Negative Emotions	-.50***	-.76***	.23*
MIQ Total Score	-.44***	-.61***	-.02

Note. * $p < .05$, ** $p < .01$, *** $p < .001$
MMQ = Multifactorial Memory Questionnaire; MIQ = Memory Impact Questionnaire

Table 3.4

Group Comparisons of Memory Impact and Self-Reported Memory Scores

Outcome	Normal Cognition (n = 40)	aMCI (n = 53)	*t*(df)	Effect Sizes	
	Raw Score (M ± SD)	Raw Score (M ± SD)		Cohen's *d*	Probability of Superiority
Memory Impact					
Lifestyle Restrictions	8.38 (13.4)	15.3 (15.5)	-2.4 (91)*	.42	.64
Positive Coping	43.0 (14.6)	43.6 (11.8)	-.16 (91)	.02	.51
Negative Emotions	14.3 (13.5)	18.5 (13.7)	-1.4 (91)	.27	.51
MIQ Total Score	55.7 (25.0)	66.2 (27.2)	-2.1 (91)*	.45	.62
Self-Reported Memory					
MMQ – Satisfaction	49.6 (13.6)	43.9 (14.2)	1.9 (91)*	.42	.61
MMQ – Ability	53.7 (10.0)	52.3 (11.4)	.65 (91)	.14	.54
MMQ – Strategy	36.7 (11.6)	32.9 (11.2)	1.5 (91)	.32	.59

Note. * $p < .05$, ** $p < .01$, *** $p < .001$
aMCI = amnestic mild cognitive impairment; MIQ = Memory Impact Questionnaire; MMQ = Multifactorial Memory Questionnaire

CHAPTER 4

Study 3: Everyday Impact of Memory Change – Examining the Responsiveness of the Memory Impact Questionnaire

Preface

Cognitive interventions for older adults with memory concerns can play an important role in improving outcomes in everyday life. In order to evaluate the efficacy of such interventions, there is a need for valid instruments that assess the impact of memory changes on everyday life. The purpose of this study was to examine the responsiveness of the Memory Impact Questionnaire (MIQ) to memory interventions for older adults. A total of 59 individuals who enrolled in one of two well-established memory strategy training interventions for older adults with either normal age-related memory changes or mild cognitive impairment completed the MIQ prior to and after completion of their respective intervention program. Our results indicate changes in two scores reflecting increased positive coping responses and reduced overall burden of memory changes on everyday life following both interventions. However, no changes were observed in scores indicating restrictions to lifestyle activities and negative emotion associated with memory change. Overall, our results indicate moderate responsiveness (50 to 75% of hypotheses met) of the MIQ. Together with previous evidence for the reliability and validity of this tool, the current findings of scale responsiveness provide support for the clinical utility of the MIQ in evaluating the efficacy of memory interventions that target outcomes in everyday life for older adults.

Dementia is the leading cause of disability in older adults, and the prevalence of this condition is expected to increase significantly with greater longevity, which makes it a key public health priority (Prince, Wimo, Ali, Wu, & Prina, 2015). With a lack of effective pharmacological treatments currently available, behavioural interventions that may delay onset or slow progression are increasingly important. Given that subjective memory complaints (SMCs) may predict later development of dementia among healthy older adults and those with mild cognitive impairment (MCI; Dardenne et al., 2017; Rabin et al., 2017), individuals with SMCs may be the best candidates for cognitive interventions that aim to help maintain or increase functional independence and thereby forestall a diagnosis of dementia. In the past, studies evaluating the efficacy of such interventions have focused on objective cognitive abilities (e.g., Cooper, Li, Lyketsos, & Livingston, 2013; Gates, Sachdev, Fiatarone, & Valenzuela, 2011). However, it is equally important to consider the efficacy of cognitive interventions in improving everyday functioning. Indeed, individuals with SMCs identify maintaining everyday functioning, their sense of identity, and relationships and social connections as crucial outcomes of interest to them (Watson et al., 2019).

Recently, there has been increased interest in identifying the impact of cognitive interventions on everyday living, with studies reporting positive outcomes of such interventions on aspects of daily life, including metacognitive outcomes, mood, activities of daily living, and quality of life among cognitively normal older adults and those with MCI (Chandler, Parks, Marsiske, Rotblatt, & Smith, 2016; Hudes, Rich, Troyer, Yusupov, & Vandermorris, 2018). Although there is insufficient evidence to establish a gold standard for a successful intervention, most interventions that have been shown to improve aspects of everyday functioning share common features including therapist-led modules, memory skills training, psychoeducation,

focus on lifestyle factors (e.g., physical exercise, stress, diet), and peer support (Chandler et al., 2016; Hudes et al., 2018). Despite the burgeoning literature evaluating the everyday impact of cognitive interventions, an important hurdle is the lack of quantitative instruments that measure the impact of memory change on everyday living.

Recently, we developed the Memory Impact Questionnaire (MIQ; Shaikh et al., 2018), which quantifies the impact of memory change on key domains of everyday life identified through qualitative work, including restrictions to lifestyle activities (e.g., social relationships, work, and leisure activities) due to memory change (Buckley, Saling, Frommann, Wolfsgruber, & Wagner, 2015; Parikh et al., 2016), coping with memory change (Meilak et al., 2016; Parikh et al., 2016; Rotenberg et al., 2019b), and negative emotions (e.g., changes to self-identity) that emerge as a result of memory change (Buckley et al., 2015; Parikh et al., 2016; Rotenberg et al., 2019b). This measure allows a more nuanced exploration of aspects of everyday life that may be affected by memory change than extant measures of broader components such as mood, metacognition, quality of life, and functional status. Notably, these domains mirror the outcomes of interest (i.e., everyday functioning, self-identity, relationships) prioritized by older adults when considering the development of potential treatments for dementia (Watson et al., 2019). Many measurement properties of the MIQ have been previously established, including good convergent validity (|*rs*| = .22-.42), discriminant validity (|*rs*| = .08-.09), test-retest reliability (*r*s = .65-.91), and internal consistency (αs = .87-.93; Shaikh et al., 2018). However, the instrument's responsiveness, defined as "the ability of an instrument to detect change over time in the construct to be measured" (Mokkink et al., 2010, p. 743), has not yet been examined. An important goal in healthcare is to alleviate the burden of health conditions rather than merely identifying this burden at a given timepoint; therefore, it is important to assess the

responsiveness of this instrument before it can be effectively utilized in research and clinical practice.

In this study, we examine the responsiveness of the MIQ to two separate memory interventions that share many common features associated with improvement in everyday functioning: (a) a 5-week program for older adults with normal age-related memory changes (Memory and Aging Program; Troyer & Vandermorris, 2012), and (b) a 6-week program with a follow-up session 1-month later for individuals with mild cognitive impairment (MCI; Learning the Ropes for Living with MCI; Murphy, 2014). These programs provide psychoeducation about memory function, promote lifestyle factors (e.g., exercise, nutrition, stress management) that maximize cognitive health, and provide training in the use of compensatory memory strategies.

We tested *a priori* hypotheses regarding MIQ change scores as prescribed by a construct approach, rather than using the criterion approach, given that the latter requires a standard for assessing everyday functioning, currently lacking in the literature (de Vet, Terwee, Mokkink, & Knol, 2011). We selected traditional distribution-based measures of responsiveness (e.g., *t*-statistic, effect size), as these methods are considered acceptable when paired with a construct approach, and such methods facilitate comparison of the MIQ to other instruments (Angst, 2011; de Vet et al., 2011).

We hypothesized changes in all three subscales as well as the total score of the MIQ in the two intervention groups, as follows. The Lifestyle Restrictions subscale measures withdrawal from leisure participation and social relationships due to memory changes. Participation in both the aging program and the MCI program is associated with increases in healthy lifestyle behaviours (Murphy, 2016; Wiegand, Troyer, & Gojmerac, 2013), with a large effect size (η^2_p = 0.14) reported in the aging program (Wiegand et al., 2013); thus, we expected a moderate,

significant change in scores on this measure. The Positive Coping subscale measures adaptive coping following memory change including practicing self-acceptance, engaging in cognitively stimulating activities to maintain memory, and using compensatory strategies to improve memory performance. Given that our previous work demonstrates a small correlation between this subscale and strategy use (Shaikh et al., 2018) and that participants report increases in strategy use with a small-to-moderate effect size noted in the aging program (d = 0.43; η^2_p = 0.08; Troyer, 2001; Wiegand et al., 2013) and a small effect size reported in the MCI program (d = 0.20; Troyer et al., 2008), we expected a small (d = 0.20-0.49) significant change in Positive Coping scores. The Negative Emotions subscale assesses negative emotions that can arise as a result of memory change, including negative self-perceptions and perceived judgment from others, and is moderately related to satisfaction with one's memory (Shaikh et al., 2018). Because participants in the aging program report greater satisfaction with their memory, with small effect sizes reported in one study evaluating this program (d = 0.38; Troyer, 2001) and a large effect size reported in another study (η^2_p = 0.15; Wiegand et al., 2013), we hypothesized at least a small (Cohen's d values of 0.20-0.49), significant change in scores on the Negative Emotions subscale for participants of the aging program. As no change in memory-related affect (with negligible effect size) was reported after participation in the MCI program (Troyer et al., 2008), we did not expect a change in the Negative Emotions subscale for this group. Finally, the MIQ total score is an aggregate of subscale scores and reflects the overall burden of memory change in everyday life. We hypothesized a small to moderate (Cohen's d = 0.20-0.50) change in total scores, given the hypothesized changes in subscales that make up this score.

Method

Participants

A total of 59 individuals who had enrolled in the two interventions (aging program: n = 40; MCI program: n = 19) participated in this study. Although the MCI program is an intervention for both individuals with MCI and their family members, only individuals with MCI were included in this study. As shown in Table 4.1, most participants were well-educated, retired, and living with a spouse or life partner. Participants enrolled in the aging program were mostly female and reported minimal symptoms of depression (as measured by the Patient Health Questionnaire-8; Kroenke et al., 2001) and anxiety (as measured by the Generalized Anxiety Disorder Questionnaire Scale-7; Spitzer, Kroenke, Williams, & Lowe, 2006). There were roughly equal male and female participants enrolled in the MCI program, and these participants reported mild symptoms of depression and anxiety.

Materials

The Memory Impact Questionnaire (Shaikh et al., 2018) is a 51-item measure that examines the impact of memory changes across three subscales, (a) Lifestyle Restrictions (19 items), (b) Positive Coping (19 items), and (c) Negative Emotions (13 items; see Appendix D for full list of items). Scores on the Lifestyle Restrictions subscale range from 0-76, with higher scores reflecting more restrictions on leisure and social activities. Scores on the Positive Coping subscale range from 0-76, with high scores reflecting more adaptive coping responses. Scores on the Negative Emotions subscale range from 0-52, with higher scores indicating more negative emotions. A total score can be calculated using the following equation, with greater scores reflecting a greater burden of memory change on everyday life: $\sum$ Lifestyle Restrictions Items + (76 - $\sum$ Positive Coping Items) + $\sum$ Negative Emotions Items.

Procedure

Participants were recruited from six serial intervention groups of the aging program and five serial intervention groups of the MCI program from January 2019 to January 2020. Inclusion criteria included the ability to understand and follow instructions in English and sufficient visual acuity to complete a written questionnaire. Exclusion criteria included more than two missed group sessions. For the aging program, 83 participants enrolled in the program were approached for participation in this study, of which 59 expressed initial interest and were assessed for eligibility. Of the remaining participants, 5 declined to participate, 9 were lost to follow-up, and 5 were not included in the analyses due to missing more than 2 sessions (n = 3) or having invalid questionnaires (n = 2). For the MCI program, 52 individuals with MCI enrolled in the program were approached for participation in this study, of which 47 expressed initial interest and were assessed for eligibility. Of these, 15 declined to participate and 13 were lost to follow-up.

All participants were asked to complete study measures before the onset of the first session (T_1) and after the final session (T_2) of each intervention. We considered the 1-month follow-up session as the final session for the MCI program, as this session is a routine part of the program. Participants were given the option of completing the questionnaires online or using paper versions and could complete the questionnaires on site (at Baycrest Health Sciences) or at home. A demographic questionnaire was also administered to all participants. All study procedures were approved by the Research Ethics Board at Baycrest Health Sciences (Approval Number: 18-42) and York University (Approval Number: e2019-223).

Statistical Analyses

Paired samples *t*-tests were used to determine differences in MIQ scores before (T_1) and after (T_2) each intervention. Cohen's *d* was used as an estimate of effect size, with benchmarks of 0.20

for a small effect size, 0.50 for a moderate effect size, and 0.80 for a large effect size (Cohen, 1988). Following de Boer and colleagues (de Boer et al., 2004, 2006), we considered responsiveness to be high if fewer than 25% of the hypotheses were refuted, moderate if 25-50% of the hypotheses were refuted, and low if more than 50% of the hypotheses were refuted.

Results

Responsiveness of MIQ Subscales

Aging Program

Table 4.2 displays mean scores at T_1 and T_2 as well as difference scores between the two timepoints for each MIQ scale by group. Scores on the Positive Coping subscale were greater at T_2 as compared to T_1, with a small effect size, $t(39) = -3.02$, $p < .01$, $d = 0.45$. Scores on the MIQ total score were lower at T_2 as compared to T_1, with a small effect size, $t(39) = 2.39$, $p < .05$, $d = 0.32$. Scores on the Lifestyle Restrictions subscale, $t(39) = 0.75$, $p = .46$, $d = 0.11$, and the Negative Emotions subscale, $t(39) = 1.55$, $p = .13$, $d = 0.23$, did not differ from T_1 to T_2, with a negligible and small effect sizes, respectively.

MCI Program

Participants in the MCI program showed the same pattern of findings as those in the aging program, namely that scores changed from T_2 to T_1 on the Positive Coping subscale, $t(18) = -2.34$, $p < .05$, $d = 0.38$, and the MIQ total score, $t(18) = 2.41$, $p < .05$, $d = 0.25$, with small effect sizes, but not on the Lifestyle Restrictions subscale, $t(18) = 0.60$, $p = .56$, $d = 0.07$, or Negative Emotions subscale, $t(18) = 1.65$, $p = .12$, $d = 0.19$, with negligible effect sizes.

Overall, 62% of the *a priori* hypotheses about both the aging and MCI programs were confirmed, as shown in Table 4.3.

Discussion

Our results demonstrate responsiveness of the Positive Coping subscale and the total score of the Memory Impact Questionnaire to memory interventions designed for older adults with age-related memory concerns and those with mild cognitive impairment. Contrary to our hypotheses, the Lifestyle Restrictions subscale was not responsive to either intervention. With respect to the Negative Emotions subscale, scores before and after the aging program did not differ significantly, but there was a small effect size, as hypothesized. Overall, our results indicate moderate responsiveness of the MIQ based on previously established criteria.

Previous research with the aging program (Wiegand et al., 2013) and the MCI program (Murphy, 2016) indicates that participants report lifestyle changes (i.e., diet, exercise, relaxation and stress management, cognitive engagement) to improve their health or memory following participation in each intervention. As the Lifestyle Restrictions subscale measures reductions in both lifestyle activities (e.g., work, volunteer, and leisure activities) and social relationships, it is possible that this subscale is not responsive to changes in number of activities alone. Another consideration is that one-third of participants in the aging program (n = 14) reported low scores on the Lifestyle Restrictions subscale (i.e., scores lower than 10), and as such changes in this subscale may not have been observed due to scale attenuation. Furthermore, it is possible that there was insufficient time for participants of the aging program to implement lifestyle changes. Indeed, previous research in which participants completed follow-up testing one month after the intervention demonstrated that participants made further lifestyle changes during this period (Wiegand et al., 2013).

The Negative Emotions subscale measures negative affect due to unfavorable self-assessments and perceived criticisms from others, which an individual may experience as a result of memory change. Scores in this subscale were lower following participation in the aging

program, with a small effect size, though this effect was not statistically significant. It is plausible that changes in views of the self and perceived judgment from others require longer to institute than the period used in this study (5 weeks). However, given that previous RCTs with the aging program did demonstrate a significant change in memory-related affect over the same period (Troyer, 2001; Wiegand et al., 2013), the lack of responsiveness of this subscale is unclear.

An important concern in assessing the responsiveness of the MIQ is that there are no gold standard interventions for improving the impact of memory changes on everyday living. As a result, it is difficult to determine whether our results, namely no changes on the Lifestyle Restrictions and Negative Emotions subscales, are due to lack of responsiveness of the instrument or inefficacy of the interventions. Furthermore, we chose to use traditional distribution-based measures to assess responsiveness for many reasons, including that such an approach facilitates comparison of the MIQ to other instruments and may help researchers decide on the appropriateness of the MIQ as an outcome measure when designing intervention studies. However, one limitation of such methods is that it is difficult to distinguish between an instrument's inability to detect changes in a construct and the possibility that a given construct may be unaffected by the intervention. Therefore, it would be useful for future research to examine responsiveness using complementary anchor-based approaches, whereby changes to scores on the MIQ are compared to changes in scores on related measures. Such complementary approaches would provide stronger evidence for the responsiveness of the MIQ than that provided by any one approach alone.

A further limitation is that no control group was included in this study, and therefore it is possible that observed changes in MIQ scores were due to repeated administration rather than the

instrument's responsiveness to change. Future research with a non-intervention control group is needed to determine whether the magnitude of change observed here is greater than the magnitude of change observed as a result of multiple administrations of the instrument.

Finally, the sample size for the MCI program was relatively small, due to difficulty retaining participants after the cessation of the intervention. Although it will be necessary to evaluate the responsiveness of the MIQ using a larger sample, the sample size utilized in this study (n = 19) is similar to previous work evaluating the efficacy of the program (n = 24), which was able to detect changes in a variety of outcome measures (Troyer et al., 2008).

Overall, this research provides partial support for the responsiveness of the Memory Impact Questionnaire, which suggests that this instrument may be appropriate for evaluating the efficacy of memory interventions in targeting the everyday impact of memory change, particularly for interventions focused on improving positive coping in relation to memory changes among cognitively intact older adults or those with mild cognitive impairment. The validation of instruments that measure everyday functioning is an important goal as it may allow clinicians and researchers to measure the effectiveness of memory interventions in reducing the burden of memory changes on everyday life.

Table 4.1

Participant Characteristics

Variable	Aging program participants (n = 40)	MCI program participants (n = 19)
Age (in years)		
Mean (SD)	75.0 (6.7)	72.6 (9.6)
Min – Max	60-90	54-86
Education (in years)		
Mean (SD)	15.6 (2.2)	15.7 (2.2)
Min – Max	11-19	12-20
Gender (M:F)	14:26	10:9
Employment		
Full Time	5%	5%
Unemployed	-	5%
Part Time	10%	21%
Retired	77.5%	69%
Other	7.5%	-
Marital Status		
Married/Life Partner	60%	79%
Divorced/Separated	12.5%	5%
Single/Never Married	7.5%	5%
Widowed	20%	11%
Mood		
PHQ-8 (M±SD)	3.3 (3.5)	6.9 (7.0)
GAD-7 (M±SD)	2.8 (3.1)	5.6 (6.6)

Note. MCI = mild cognitive impairment; PHQ-8 = Patient Health Questionnaire; GAD-7 = Generalized Anxiety Disorder Scale-7

Table 4.2

Memory Impact Questionnaire Scores of Participants of the Intervention Programs

	Aging program (n = 40)			MCI program (n = 19)		
Memory Impact Questionnaire	T_1 M (SD)	T_2 M (SD)	T_2-T_1 M (SD)	T_1 M (SD)	T_2 M (SD)	T_2-T_1 M (SD)
Lifestyle Restrictions	17.8 (16.2)	16.1 (13.4)	-1.7 (14.4)	32.4 (19.7)	31.1 (19.1)	-1.3 (9.5)
Positive Coping	48.6 (8.6)	52.7 (9.6)	4.1 (8.6)**	43.9 (10.3)	47.9 (10.5)	4.0 (7.5)*
Negative Emotions	29.1 (11.2)	26.4 (12.0)	-2.6 (10.8)	32.8 (14.4)	30.2 (12.5)	-2.6 (6.8)
Total Score	74.3 (27.6)	65.8 (26.3)	-8.5 (22.4)*	97.3 (32.4)	89.4 (31.0)	-7.9 (14.3)*

Note. *$p < .05$, **$p < .01$. Positive outcomes are indicated by higher scores on the Positive Coping subscale and lower scores on the remaining subscales and the total score. MCI = mild cognitive impairment

Table 4.3

Hypotheses for Responsiveness of the Memory Impact Questionnaire

	Hypotheses	Cohen's *d*	Confirmed
	Aging program		
1.	A moderate significant change was expected on Lifestyle Restrictions subscale	.11	No
2.	A small significant change was expected on the Positive Coping subscale	.45**	Yes
3.	A small significant change was expected on the Negative Emotions subscale	.23	No
4.	A small-to-moderate significant change was expected on the MIQ total score	.32*	Yes
	MCI program		
5.	A moderate significant change was expected on the Lifestyle Restrictions subscale	.07	No
6.	A small significant change was expected on the Positive Coping subscale.	.38*	Yes
7.	No change was expected on the Negative Emotions subscale	.19	Yes
8.	A small-to-moderate significant change was expected on the MIQ total score	.25*	Yes

Note. *$p < .05$, **$p < .01$

MIQ = Memory Impact Questionnaire; MCI = mild cognitive impairment.

CHAPTER 5

General Discussion

General Summary

The overarching goal of the current set of studies was to examine everyday functioning in older adults. To that end, I conducted three studies, each focused on a different aspect of everyday functioning and aging. Below is a summary of each of the separate studies, followed by a more general discussion of how these findings fit into the larger literature. I then end with suggestions for future research.

In Study 1, I surveyed neuropsychologists' practices when assessing daily functioning within the context of diagnosing memory conditions. Respondents reportedly consider several components of everyday life, utilize a variety of techniques when evaluating functional abilities, and perceive a need for improved measures of everyday functioning. The variation in neuropsychologists' practices when assessing daily functioning is reflected in the lack of consensus among respondents when asked to diagnose memory conditions based on vignettes that depict cognitive and functional decline. Taken together, these results underscore the need for consensus guidelines for the assessment of daily functioning, particularly involving the development of criteria regarding the level of functional decline necessary for the diagnosis of clinically relevant conditions. Furthermore, these findings raise important questions about the association between everyday functioning and cognitive abilities.

In Study 2, I explored the relationship between the everyday impact of memory changes and (a) self-reported memory, (b) strategy use, and (c) objective cognitive performance in order to gain an in-depth understanding of the experience of memory change for older adults along a cognitive aging continuum ranging from normal cognition to mild cognitive impairment. Greater

restrictions to lifestyle activities, more negative emotion associated with memory change, and an overall greater burden of memory change on everyday living were associated with poorer objective memory performance and lower self-reported memory ability and satisfaction. These findings provide the basis for a holistic understanding of the memory change experience that combines different perspectives (i.e., objective cognition and self-report measures). In addition, these findings demonstrate the impact of memory changes on the everyday life of older adults, thus underscoring the need for interventions that go beyond improving cognitive outcomes and target everyday outcomes. A crucial hurdle in developing such interventions is the lack of valid measures of everyday functioning.

To address the need identified in Study 2, Study 3 was designed to measure the responsiveness to intervention of a newly developed instrument that assesses the impact of memory change on everyday life. Results indicate moderate responsiveness of this tool to memory interventions for older adults with age-related memory changes and mild cognitive impairment. Specifically, increased positive coping responses and reduced overall burden of memory changes on everyday life were both observed following intervention.

Collectively, these studies were intended to advance our understanding of the everyday impact of memory change among older adults. In particular, these studies provide insight into how clinicians assess functioning within a neuropsychological assessment, characterize the cognitive correlates of different domains of everyday functioning, and provide evidence supporting the measurement properties of a tool used to assess impact on everyday life.

Implications and Future Directions

Everyday functioning is an elusive construct that comprises a variety of nuanced and complex abilities. Along with distress caused by clinical conditions, functioning in daily life informs the

clinical significance of a given condition and as such, it is an explicit part of the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) criteria for establishing a diagnosis. According to the DSM-5, functional impairment refers to limitations in social and occupational spheres of life, as well as other important areas of functioning. Similarly, the International Classification of Diseases (11th ed.; ICD; World Health Organization, 2018) considers a variety of domains of functioning, including understanding and communicating, as well as social, interpersonal, academic and occupational functioning. Despite these broad definitions of functioning, functional impairments are often equated with limitations to activities of daily living.

The present set of studies lends support to earlier qualitative research that characterizes the impact of memory change on more nuanced aspects of everyday life, such as self-identity, interpersonal relationships, and everyday activities (Buckley et al., 2015; Parikh et al., 2016; Rotenberg et al., 2019b). As such, this research broadens the perspective of everyday functioning by considering multiple areas of daily life affected by memory change, beyond just activities of daily living. Furthermore, this research characterizes an impact of memory change on everyday functioning well before the development of dementia; therefore, these subtle changes to everyday life might be a very early precursor to the functional disability that is a hallmark of dementia syndromes.

In keeping with previous research (e.g., Royall et al., 2007; Schmitter-Edgecombe & Parsey, 2014; Schmitter-Edgecombe, Parsey, & Cook, 2011), this work further supports the notion that different aspects of everyday functioning (assessed in the present studies using the Memory Impact Questionnaire) are differentially associated with specific cognitive domains (e.g., objective memory performance and self-reported memory). Taken together, this suggests a

complex relationship between cognition and functioning in daily life, where the cognitive contribution to everyday functioning varies depending on the domain of everyday life sampled.

Similarly, not all domains of everyday life assessed by the Memory Impact Questionnaire were equally mutable through clinical intervention. The Positive Coping subscale, which assesses coping responses including strategy use and practicing self-acceptance, was most responsive to memory interventions for older adults with age-related memory change and mild cognitive impairment. Although beyond the scope of the current work, it may be that an important avenue through which memory interventions achieve a positive therapeutic effect is by facilitating better coping among participants. Indeed, a recent review exploring active ingredients that drive the efficacy of nonpharmacological interventions identified many components that seem to target coping behaviours among participants (e.g., problem-solving, cognitive-behavioural therapy, education, environmental modifications; Wu et al., 2020).

Although the current body of work provides important insight into the everyday functioning of older adults, future research could be designed to address limitations of this work. One limitation is the exclusive use of self-report measures to assess the impact of memory changes on everyday living. Although there are several advantages to utilizing self-report measures, including ease of administration and time efficiency, such measures are susceptible to response bias. A recent study showed a moderate correlation between overreporting (as measured by response bias scales) and self-reported memory complaints (SMCs; Goldberg et al., 2020), which suggests that response bias may be a concern with instruments used to assess the memory change experience.

Furthermore, self-report measures may be influenced by a variety of reporter characteristics, such as psychopathology (e.g., anxiety, depression), personality, and level of

education. Indeed, a wealth of research identifies an association between self-reported memory complaints and mood (i.e., depression and anxiety), with some studies suggesting that mood rather than changes to cognition may better predict the presence of SMCs among older adults (see Hill et al., 2016, for review). To address this, in Study 2, I explored cognitive correlates of memory impact while controlling for affective symptoms. However, other reporter characteristics, such as personality factors, may still have influenced the obtained results. Personality features, such as neuroticism and conscientiousness in particular, are associated with SMCs (e.g., Merema, Speelman, Foster, & Kaczmarek, 2013; Slavin et al., 2010), and as a result these personality features may be similarly correlated to measures that identify the impact of such memory changes on everyday living.

Finally, prior research indicates that education modifies the type of SMCs in older adults (João et al., 2016). It is possible that the domains of everyday living impacted by memory change, or the extent of its impact, are also affected by educational level. Given that the participants described in Study 2 and 3 were highly educated, an interesting avenue for future research may be to explore the relationship between educational level and everyday functioning.

Other types of measures that are commonly used to assess everyday functioning include informant measures and performance-based measures. These measures may reduce response bias and are less influenced by the aforementioned reporter characteristics, but they have their own limitations. For example, informant measures may be affected by caregiver burden or a desire to protect their family member's feelings. In addition, an informant who has observed an individual's daily functioning may not be available or may not be privy to the aspect of daily functioning being queried. Similarly, performance-based measures offer a more objective indicator of functioning in daily life; however, such measures take time to administer and may

require extensive equipment or specific settings. For example, the Multiple Errands Test, a commonly used performance-based measure, requires access to shops in order to assess an individual's ability to purchase specific items (Knight, Alderman, & Burgess, 2002). Also, it is not clear to what extent performance on time-limited tasks in specific situations corresponds to performance in daily life, where tasks are conducted in a variety of environments and occur over longer periods of time (Schmitter-Edgecombe & Farias, 2018). An added consideration is that questionnaire and performance-based measures do not always correlate highly with each other and, as such, may not be measuring identical constructs (Schmitter-Edgecombe et al., 2011). Given that there are no gold standards for measuring everyday functioning, it is difficult to determine which of these types of measures is most effective as a proxy measure for functioning in daily life. It's likely that no one measurement type fully captures the complexity of everyday functioning among older adults. Therefore, future research would be needed to determine if the results described here are reproduced when different types of measures are used to assess daily functioning.

A further concern is that the generalizability of the present set of findings, and of this field of research, is limited by the lack of representation of cultural diversity. The quantitative exploration of the everyday impact of memory changes described in this body of work is informed by earlier qualitative studies. However, thus far, this work has been limited to Western countries (i.e., Belgium – De Vriendt et al., 2012; United Kingdom – Meilak et al., 2016; Canada – Parikh et al., 2016; Rotenberg et al., 2019b). Previous research has demonstrated differences in cultural representations of aging. Although in an individualistic context (often seen in Western countries), aging is defined by losses in cognition and autonomy, in a collectivist context, age is venerated, and more emphasis is placed on wisdom gained through age (Fastame, Penna, &

Rossetti, 2014). These differing attitudes about aging are associated with differences in cognitive abilities (Fastame et al., 2014; Medina et al., 2019) and may therefore also have a differential effect on everyday functioning. This will be an important area for future inquiry necessary for further development of this area of research.

Final Thoughts

Functioning in everyday life is a fundamental aspect of autonomy and as a result plays a crucial role in the well-being of older adults. There are several questions about everyday functioning that remain unanswered. It is vital that we determine to what extent neuropsychological and other relevant factors (e.g., mood) predict functioning in everyday life, in order to best identify individuals who may need support to maximize quality of life and safety at home. It is also important to determine whether clinical interventions are effective at improving everyday outcomes and what intervention features are most associated with an improvement to such outcomes (e.g., cognitive remediation, psychosocial), in order to better serve the needs of older adults. Finally, as more research becomes available, the development of clinical practice guidelines with respect to evaluating and addressing functional impairments will be needed in order to ensure agreement among clinicians who regularly work with older adults with impaired functioning.

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Appendices

Appendix A

Are you a licensed psychologist who conducts neuropsychological assessments?

- ○ Yes
- ○ No

Do you regularly see adult patients with at least one of the following conditions?

Age-related cognitive changes
Mild cognitive impairment
Alzheimer's disease
Vascular disease
Frontotemporal lobar degeneration
Movement disorders (e.g., Parkinson's disease, Huntington's disease)
Traumatic brain injury
HIV infection
Prion disease
Lewy body disease

- ○ Yes
- ○ No

If "No" is selected for either of the above items, participants receive the following message:
Unfortunately, you do not meet inclusion criteria to participate in this survey. Thank you for your interest in participating.

Tell Us About Yourself

What is your highest professional degree?

- ○ PsyD
- ○ PhD
- ○ Other: _____

How many years have you been practicing as a licensed psychologist?

- ○ 0-5 years
- ○ 5-10 years
- ○ 10-15 years
- ○ 15-20 years
- ○ 20+ years

What setting(s) do you work in? Check all that apply.

- ○ Hospital
- ○ Rehabilitation Facility
- ○ Psychiatric Setting
- ○ Community Clinic
- ○ Private Practice
- ○ University/Academic Setting
- ○ Forensic Setting
- ○ Other: _____

How many neuropsychological assessments do you conduct in a typical month?

- ○ 0
- ○ 1-5
- ○ 6-10
- ○ >10

Do you routinely supervise graduate student trainees in your clinical work?

- ○ Yes
- ○ No

Assessing Functional Abilities

Functional impairment refers to limitations in social functioning (e.g., participation in community and social life), occupational functioning (e.g., work or volunteer activities) and/or other major area of functioning (e.g., activities of daily living)

When evaluating functional ability in the context of differentiating normal aging, mild cognitive impairment, and dementia, how important do you think changes in the following components are:

	Not at all important	Slightly important	Fairly important	Very important
Social activities (e.g., changes to hobbies or past-times)	○	○	○	○
Relationships with others (e.g., initiating or maintaining friendships)	○	○	○	○
Work or volunteer activities	○	○	○	○
Basic activities of daily living (e.g., dressing oneself)	○	○	○	○
Instrumental activities of daily living (e.g., managing medications)	○	○	○	○
Communication abilities (e.g., starting and maintaining a conversation)	○	○	○	○
Learning and applying knowledge (e.g., learning a new skill)	○	○	○	○
Sense of self (e.g., feeling less capable of managing everyday tasks)	○	○	○	○
Other:	○	○	○	○

What tools do you use to assess functional impairment? Check all that apply.

- ○ Semi-structured interview questions - client interview
- ○ Semi-structured interview questions - collateral informant interview
- ○ The WHO Disability Assessment Schedule (Usten et al., 2010)
- ○ The Global Assessment of Functioning Scale (Goldman et al., 1992)
- ○ Functional Assessment Questionnaire (Pfeffer et al., 1982)
- ○ Instrumental Activities of Daily Living Scale - collateral-report (Lawton & Brody, 1969)
- ○ Instrumental Activities of Daily Living Scale - self-report (Lawton & Brody, 1969)
- ○ Katz Index of Independence in Activities of Daily Living (Katz & Akpom, 1976)
- ○ Disability Assessment for Dementia (Gauthier & Gelinas, 1994)
- ○ The Barthel Index of Daily Living (Collin et al., 1988)
- ○ Lawton - Brody Physical Self-Maintenance Scale - collateral-report (Lawton & Brody, 1969)
- ○ Lawton - Brody Physical Self-Maintenance Scale - self-report (Lawton & Brody, 1969)
- ○ Multiple Errands Task (Burgess, 2002)
- ○ Neuropsychological Assessment Battery - Daily Living Scale (Stern, 2003)
- ○ Direct Assessment of Functional Status (DAFS) Tool (Loewenstein et al., 1989)
- ○ Independent Living Scales (Loeb, 1996)
- ○ Adaptive Behaviour Assessment Scale (Harrison & Oakland, 2000)
- ○ Dementia Severity Rating Scale (Clark & Ewbank, 1996)

- ○ Clinical Dementia Rating Scale (Burke et al., 1988)
- ○ Everyday Cognition (Farias et al., 2008)
- ○ Informant Questionnaire on Cognitive Decline in the Elderly (Jorm, 1994)
- ○ Other: _____
- ○ Other: _____
- ○ Other: _____

When evaluating functional ability in the context of differentiating normal aging, mild cognitive impairment, and dementia, how important do you think it is to collect information from the following sources:

	Not at all important	Slightly important	Fairly important	Very important
Semi-structured interview questions - client interview	○	○	○	○
Semi-structured interview questions - collateral informant interview	○	○	○	○
The WHO Disability Assessment Schedule (Usten et al., 2010)	○	○	○	○
The Global Assessment of Functioning Scale (Goldman et al., 1992)	○	○	○	○
Functional Assessment Questionnaire (Pfeffer et al., 1982)	○	○	○	○
Instrumental Activities of Daily Living Scale - collateral-report (Lawton & Brody, 1969)	○	○	○	○
Instrumental Activities of Daily Living Scale - self-report (Lawton & Brody, 1969)	○	○	○	○
Katz Index of Independence in Activities of Daily Living (Katz & Akpom, 1976)	○	○	○	○

Disability Assessment for Dementia (Gauthier & Gelinas, 1994)	○	○	○	○
The Barthel Index of Daily Living (Collin et al., 1988)	○	○	○	○
Lawton - Brody Physical Self-Maintenance Scale - collateral-report (Lawton & Brody, 1969)	○	○	○	○
Lawton - Brody Physical Self-Maintenance Scale - self-report (Lawton & Brody, 1969)	○	○	○	○
Multiple Errands Task (Burgess, 2002)	○	○	○	○
Neuropsychological Assessment Battery - Daily Living Scale (Stern, 2003)	○	○	○	○
Direct Assessment of Functional Status (DAFS) Tool (Loewenstein et al., 1989)	○	○	○	○
Independent Living Scales (Loeb, 1996)	○	○	○	○
Adaptive Behaviour Assessment Scale (Harrison & Oakland, 2000)	○	○	○	○
Dementia Severity Rating Scale (Clark & Ewbank, 1996)	○	○	○	○
Clinical Dementia Rating Scale (Burke et al., 1988)	○	○	○	○
Everyday Cognition (Farias et al., 2008)	○	○	○	○
Informant Questionnaire on Cognitive Decline in the Elderly (Jorm, 1994)	○	○	○	○
Other:	○	○	○	○

List any additional functional ability instruments that you are aware of (even if you do not use them)

Previously listed tools include:
Clinical Interview
The WHO Disability Assessment Schedule
The Global Assessment of Functioning Scale

Functional Assessment Questionnaire
Lawton-Brody Instrumental Activities of Daily Living Scale
Katz Index of Independence in Activities of Daily Living
Disability Assessment for Dementia
The Barthel Index of Daily Living
Basic Activities of Daily Living Checklist
Multiple Errands Task
Neuropsychological Assessment Battery - Daily Living Scale
Direct Assessment of Functional Status (DAFS) Tool
Adaptive Behaviour Assessment Scales (Harrison & Oakland, 2000)Independent Living Scales (Loeb, 1996) Dementia Severity Rating Scale (Clark & Ewbank, 1996) Clinical Dementia Rating Scale (Burke et al., 1988) Everyday Cognition (Farias et al., 2008) Informant Questionnaire on Cognitive Decline in the Elderly (Jorm, 1994)

Do you believe there is a need for the development of additional measures of everyday functioning?

- ○ Definitely not
- ○ Probably not
- ○ Maybe
- ○ Probably yes
- ○ Definitely yes

The Impact of Functional Assessment on Recommendations

In the next survey question, we would like to understand how you use the information you collect from your functional assessment when formulating your recommendations for your patients.

Please indicate which (if any) of the following types of recommendations are influenced by the findings from your functional assessment. Check all that apply.

- ○ Providing educational resources or supports
- ○ Recommending follow-up neuropsychological assessments
- ○ Encouraging clients to seek support from family and friends
- ○ Providing tips on improving lifestyle factors (e.g., diet, exercise, sleep)
- ○ Recommending compensatory strategies (e.g., memory aids, circumlocution) to manage everyday problems
- ○ Providing mood-related recommendations (e.g., counselling, group programs) to individuals whose functioning may be affected by negative attitudes towards aging or anxiety about cognition
- ○ Recommending follow-up with other professionals (e.g., driving assessments, legal consultation, occupational therapists)
- ○ Other: _____
- ○ Other: _____
- ○ None of the above - my recommendations are not impacted by my functional assessment

Scenarios

Cognitive disorders (and their functional impact) exist on a continuum which can make it difficult to distinguish between them. The following two scenarios describe different degrees of cognitive and functional impairment. Please consider each scenario and answer the corresponding questions.

Respondents were randomly presented with 2 of the following 3 scenarios. Approximately half of respondents received scenarios that featured patients with the following gender; for the other half of respondents, gender of each patient in each scenario was reversed.

Mr. Mackenzie is a 73-year-old, right-handed, single man referred by his primary care physician for a neuropsychological evaluation due to concern regarding memory loss. The physician requests that you clarify the presence, nature, and extent of the memory loss. This is the first time you are evaluating Mr. Mackenzie. Mr. Mackenzie is a lawyer and has noticed changes in his ability to perform his job. These changes had a gradual onset and have progressively worsened over a course of two years. He describes requiring more time to finish his usual tasks and having difficulty recalling details of cases he is working on. Mr. Mackenzie has a family history of dementia and is concerned he is developing dementia like his mother. He does not report symptoms of clinical depression or anxiety but does describe being quite distressed by his cognitive symptoms. Mr. Mackenzie is in good physical health. Mr. Mackenzie has intact iADLs. Previously, he socialized often with other lawyers from his firm but he has recently reduced this social activity due to embarrassment about his memory changes. On occasion, he has forgotten details about conversations he has had with his colleagues, which further heightens his distress. Neuropsychological testing reveals that his memory is largely within normal limits, though it may be slightly decreased compared to his superior premorbid level. Imaging and blood tests did not reveal any remarkable findings.

Based on the information provided in the scenario, what diagnosis are you most likely to give this individual?

- ○ Normal cognition
- ○ Mild cognitive impairment or mild neurocognitive disorder
- ○ Dementia or major neurocognitive disorder

Using the key below, how would you rate this individual's functional abilities?

Key:
Intact - no change from previous levels
Very mild - able to complete tasks but require more time/effort
Mild - subtle difficulties in performing complex tasks
Moderate - difficulty performing everyday tasks
Severe - completely dependent on others

	Intact	Very mild	Mild impairment	Moderate impairment	Severe
Overall functioning	○	○	○	○	○
Ability to perform basic activities of daily living	○	○	○	○	○
Ability to perform instrumental activities of daily living	○	○	○	○	○
Social functioning	○	○	○	○	○
Occupational functioning	○	○	○	○	○
Sense of self	○	○	○	○	○
Communication abilities	○	○	○	○	○
Ability to learn and apply knowledge	○	○	○	○	○
Other:	○	○	○	○	○
Other:	○	○	○	○	○

Ms. Campbell is a 77-year-old, right-handed, married woman referred by her primary care physician for a neuropsychological evaluation due to concern regarding memory loss. The physician requests that you clarify the presence, nature, and extent of the memory loss. This is the first time you are evaluating Ms. Campbell. Ms. Campbell is a retired elementary school teacher, who volunteers at a tutoring academy two days a week. She has noticed difficulty recalling her students' names, despite working with some of these students over several weeks. In addition, Ms. Campbell's husband reports that she often forgets conversations she had a few days ago. These changes had a gradual onset and have progressively worsened over a course of two years. Ms. Campbell is generally in good health and does not report any symptoms of depression or anxiety. She has no family history of neurological conditions. Ms. Campbell has intact iADLs, except for finances which have always been handled by her husband. Ms. Campbell reports recently forgetting to attend a planned lunch with her friends because she did not write it down in her calendar. Other than this incident, she did not describe any changes to her social relationships. Neuropsychological testing reveals that Ms. Campbell's memory is largely within normal limits, and in keeping with her estimated premorbid level. However, a relative weakness was observed in a delayed recall of verbal information task ($z = -1.5$) and a category fluency task ($z = -1.5$). Imaging and blood tests did not reveal any remarkable findings.

Based on the information provided in the scenario, what diagnosis are you most likely to give this individual?

- ○ Normal cognition
- ○ Mild cognitive impairment or mild neurocognitive disorder
- ○ Dementia or major neurocognitive disorder

Using the key below, how would you rate this individual's functional abilities?

Key:
Intact - no change from previous levels
Very mild - able to complete tasks but require more time/effort
Mild - subtle difficulties in performing complex tasks
Moderate - difficulty performing everyday tasks
Severe - completely dependent on others

	Intact	Very mild	Mild impairment	Moderate impairment	Severe
Overall functioning	○	○	○	○	○
Ability to perform basic activities of daily living	○	○	○	○	○
Ability to perform instrumental activities of daily living	○	○	○	○	○
Social functioning	○	○	○	○	○
Occupational functioning	○	○	○	○	○
Sense of self	○	○	○	○	○
Communication abilities	○	○	○	○	○
Ability to learn and apply knowledge	○	○	○	○	○
Other:	○	○	○	○	○
Other:	○	○	○	○	○

Ms. Macphail is a 76-year-old, left-handed, married woman referred by her primary care physician for a neuropsychological evaluation due to concern regarding memory loss. The physician requests that you clarify the presence, nature, and extent of the memory loss. This is the first time you are evaluating Ms. Macphail. Ms. Macphail used to work as a sales associate for a local company and has been retired for 10 years. She did not notice any changes in her ability to perform work-related tasks before retirement. She and her husband have noticed a gradual onset of memory problems that have progressively worsened over two years. Her husband reports that she frequently misplaces items and often forgets to pick up necessary items when grocery shopping. Ms. Macphail was an avid reader but now finds she cannot do so as she forgets what she just read. She does not report any symptoms of depression or anxiety. She has a family history of dementia. Ms. Macphail has been having increasing difficulties performing household chores, particularly shopping. Her husband manages the finances, which he has always done. She continues to drive but has limited her driving to familiar local places. Ms. Macphail and her husband have an extensive circle of family and friends. She continues to be active in this circle, though her husband reports that she is less involved in the conversation than she used to be. She herself reports that she speaks in general terms when conversing with others in order to avoid making a memory mistake. Neuropsychological testing revealed mild to moderate ($z = -1.5$ to -2.5) memory impairments on both verbal and nonverbal tasks and moderately impaired confrontation naming. Imaging and blood tests did not reveal any remarkable findings.

Based on the information provided in the scenario, what diagnosis are you most likely to give this individual?

- ○ Normal cognition
- ○ Mild cognitive impairment or mild neurocognitive disorder
- ○ Dementia or major neurocognitive disorder

Using the key below, how would you rate this individual's functional abilities?

Key:
Intact - no change from previous levels
Very mild - able to complete tasks but require more time/effort
Mild - subtle difficulties in performing complex tasks
Moderate - difficulty performing everyday tasks
Severe - completely dependent on others

	Intact	Very mild	Mild impairment	Moderate impairment	Severe
Overall functioning	○	○	○	○	○
Ability to perform basic activities of daily living	○	○	○	○	○
Ability to perform instrumental activities of daily living	○	○	○	○	○
Social functioning	○	○	○	○	○
Occupational functioning	○	○	○	○	○
Sense of self	○	○	○	○	○
Communication abilities	○	○	○	○	○
Ability to learn and apply knowledge	○	○	○	○	○
Other:	○	○	○	○	○
Other:	○	○	○	○	○

Do you have any additional comments?

_____

If you would like hear the results of our survey, enter your email address here:

_____

Appendix B

Supplementary Table B.1

Other Tools Respondents Report Using When Evaluating Functional Abilities

Measure	Number of Respondents	Percentage of Respondents
Functional Ability Scales		
Texas Functional Living Scale	36	13%
Activities of Daily Living Questionnaire	7	3%
Rehabilitation Activities Daily Living Survey	2	1%
Amsterdam Instrumental Activities of Daily Living	2	1%
Bayer Activities of Daily Living Scale	1	0.5%
Karnofsky Performance Status Scale	1	0.5%
Patient's Assessment of Own Functioning Inventory	1	0.5%
Verbal Test of Practical Judgment	1	0.5%
Dementia Rating Scales		
Dementia Rating Scale	5	2%
Quick Dementia Rating System	3	1%
Blessed Dementia Scale	2	1%
AD8 Dementia Screening Interview	2	1%
Cognitive Screening Tests		
Mini-Mental State of Examination	1	0.5%
Montreal Cognitive Assessment	1	0.5%
Neuropsychological Assessment		
General or Multidimensional Measures		
Neuropsychological Testing	5	2%
Repeatable Battery for the Assessment of Neuropsychological Status	1	0.5%
Executive Abilities	1	0.5%
Delis Kaplan Executive Functions System	1	0.5%
The Pillbox Test		
Mood Symptom Inventories		
Hospital Anxiety & Depression Scale	1	0.5%
Self-Report Measures of Cognition		
General Cognition		
Cognitive Change Checklist	1	0.5%
Cognitive Function Index	1	0.5%
Memory		
Multifactorial Memory Questionnaire	1	0.5%
Behavioural Inventories (Self or Other)		
Behavioural Rating Inventory for Executive Functioning	3	1%
Adaptive Behaviour Assessment System	1	0.5%

Behavioural Assessment of Dysexecutive Syndrome	1	0.5%
Cambridge Behavioural Inventory	1	0.5%
Direct Observation Form – Achenbach System	1	0.5%
Frontal Systems Behaviour Scale	1	0.5%
Neurobehavioural Functioning Inventory	1	0.5%
Competency, Capacity, and Adaptability Measures		
Patient Competency Rating Scale	4	1%
Cognitive Competency Test	2	1%
Hopemont Capacity Assessment Inventory	1	0.5%
Mayo-Portland Adaptability Inventory	1	0.5%
Measure of Supervision Provided by Caregivers		
Supervision Rating Scale	1	0.5%
Screening Test for Health Literacy		
The Newest Vital Sign	1	0.5%
Information from Other Medical Professions		
Notes from Occupational Therapists	4	1%
Medical Information	2	1%

Supplementary Table B.2

Respondent-Reported Recommendations That are Influenced by Functional Assessments

Category	Specific Recommendations
Recommending limitation to current activities or increased support (n = 10)	Limitation or cessation of activities such as driving, managing medications and bills independently, or implementing supervision/consistent monitoring. Discussing risks due to cognitive errors (e.g., medication overdose, financial loss) Implementing appropriate services (e.g., visiting nurse, health aides, case manager) Workplace modifications, accommodations, assistive devices Work/volunteer placements and determine work capacity re prior/alternate work Discontinue certain activities (e.g., driving) Supervision (if functionally impaired and there are safety concerns) Potential notification of others regarding major safety concerns Increased supervision from family, friends, or living facilities Procedural checklist for medication management
Recommendations related to living arrangements (n = 7)	Recommending different level of care Nursing home placement or assisted living Make determination of safety at home and decisional capacity Determine capacity to live independently Begin future planning, such as need to consider change in residence
Recommendations regarding support from other medical professionals (n = 7)	Medication consult Coordination of care with other providers Recommending aides Recommending appropriate services (e.g., visiting nurse, health aides, case manager) Referral to social work for completion of Advanced Directive Formal Capacity Assessment (by psychology or other provider) Liaising with social work/care agencies
Recommendation related to future financial planning (n = 3)	Recommending establishing Durable Power of Attorney or guardian Determine financial capacity
Cognitive interventions (n = 2)	Neurocognitive programs Cognitive rehabilitation
Recommendations for family members (n = 2)	Recommendations for family and friends Caregiver support and classes

Appendix C

Supplementary Table C.1

Correlations Between Memory Impact and Measures of Cognitive Performance Without Controlling for Affective Symptoms

	Composite Scores of Cognitive Performance	
	Memory	Executive Attention
Lifestyle Restrictions	-.35**	-.20*
Positive Coping	-.11	-.08
Negative Emotions	-.26*	-.13
MIQ Total Score	-.27***	-.14

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

MIQ = Memory Impact Questionnaire

Supplementary Table C.2

Correlations Between Memory Impact, Self-Reported Memory and Strategy Use Without Controlling for Affective Symptoms

	MMQ – Ability	MMQ – Satisfaction	MMQ – Strategy
Lifestyle Restrictions	-.53**	-.69**	.11
Positive Coping	-.13	-.27**	.26*
Negative Emotions	-.59**	-.77**	.20
MIQ Total Score	-.54**	-.64**	-.01

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

MMQ = Multifactorial Memory Questionnaire; MIQ = Memory Impact Questionnaire

Appendix D

Memory Impact Questionnaire Items

1	Because of my memory changes, I sometimes feel left out of relationships.
2	When I make memory mistakes, I tell myself, “We’re all in the same boat.”
3	My memory changes make me feel scared.
4	Because of my memory changes, I have developed an interest in current memory research.
5	Because of my memory changes, I feel like I don’t have as much of a say in things that give me purpose for living.
6	My memory changes make me feel embarrassed.
7	Because of my memory changes, I don’t get out for social occasions as often as in the past.
8	When I make memory mistakes, I tell myself, “I can use a new strategy to get it next time.”
9	Because of my memory changes, I don’t contact old friends for fear of forgetting details about them.
10	My memory changes make me feel less capable.
11	I sign up for classes in order to maintain my memory.
12	Because of my memory changes, my family is less patient with me.
13	At times I am left out of discussions because of my memory changes.
14	Because of my memory changes, I am less likely to be involved in my previous volunteer activities.
15	To maintain my memory, I read a lot.
16	I can count on my family members as memory partners.
17	Because of my memory changes, I’m not as involved in what is happening when I’m in the company of others.
18	The things that I do to make up for my memory changes help me remember things better.
19	My memory changes make me feel less adequate.
20	My memory changes make me feel less confident in myself.
21	To maintain my memory, I do crossword or Sudoku puzzles regularly.
22	My memory changes make me feel upset.
23	Sometimes my memory changes make me feel stupid.
24	When I’m unsure about details, I can still participate in conversations by speaking in general terms.
25	Because of my memory changes, I tend to avoid being in the company of other people.
26	My life is easier because of the things that I do to make up for my memory changes.
27	Because of my memory changes, I don’t try to learn how to use new technologies.

28	My memory changes cause me stress.
29	Because of my memory changes, I am less involved in activities at my church, temple, or mosque.
30	I have learned to accept my memory changes.
31	I've come to the point where I can now laugh about my memory changes.
32	Because of my memory changes, I doubt myself more than I used to.
33	Because of my memory changes, I am less likely to get involved in my favourite hobbies and past-times.
34	My memory changes really bother me.
35	Because of my memory changes, I make a point of exercising my brain.
36	At times I am left out of decision-making because of my memory changes.
37	Because of my memory changes, I don't feel as close to my friends and family.
38	I don't get annoyed when other people remind me about things.
39	Because of my memory changes, I am less likely to sign up for formal educational courses.
40	I make a point of getting involved in hobbies and past-times in order to maintain my memory.
41	Because of my memory changes, I can't read the same types of materials that I used to.
42	Because of my memory changes, others have to check up on me more than they used to.
43	To maintain my memory, I make a point of socializing.
44	Because of my memory changes, I am less likely to try to create new friendships.
45	When I make memory mistakes, other people comfort me.
46	Because of my memory changes, I am less likely to get involved in conversations with people for fear that I might repeat myself, forget their names, or forget details.
47	My memory changes make me worry about how I would get by if my memory were to get worse in the future.
48	Because of my memory changes, I spend less time on my usual hobbies and past-times.
49	I've learned to adapt to my memory changes.
50	My friends and family have been supportive regarding my memory changes.
51	Changes in my ability to come up with words make it more difficult for me to communicate with others.