

Relationships among Uncertainty, Coping, and Psychological Distress in Older Adults with Mild Cognitive Impairment

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RELATIONSHIPS AMONG UNCERTAINTY, COPING, AND
PSYCHOLOGICAL DISTRESS IN OLDER ADULTS
WITH MILD COGNITIVE IMPAIRMENT

by

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ABSTRACT
RELATIONSHIPS AMONG UNCERTAINTY, COPING, AND
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Jennifer Sjostedt Avery, MSN, RN, GNP-BC

Marquette University, 2014

Mild cognitive impairment (MCI) has an average prevalence of 18.9% and most often affects people 60 years of age or older. It is a cognitive stage between normal functioning and dementia (Petersen, 2003; Petersen, 2011; Petersen et al., 2014). MCI can be broken into two subtypes classified by the presence of memory impairment (amnestic MCI) or the lack thereof (nonamnestic MCI). Medical diagnostic criteria are commonly used to guide research with older adults with MCI. A theoretical framework that addresses the antecedents and consequences of MCI, specifically one examining the relationships among MCI, uncertainty, coping and psychological distress, is essential to guide the development of effective nursing interventions but is unapparent in published literature.

The aims of this quantitative, cross-sectional study are to: (1) test select components of a new conceptual framework for MCI by examining the relationships among uncertainty, coping, psychological distress, time since diagnosis, and level of cognitive impairment from MCI; (2) describe the levels of uncertainty, coping, and psychological distress in persons with MCI; (3) examine the differences in scores on uncertainty, coping, and psychological distress between the two subtypes of MCI; and (4) examine the strength and direction of relationships between scores on uncertainty, coping, and psychological distress within the subtypes of MCI.

The sample consisted of 91 primarily Caucasian (>85%) older adults receiving care at a neurology clinic, with a relatively even split between genders and MCI subtypes. Positive relationships were found between uncertainty, coping, and psychological distress, supporting the study framework. In addition, subjects reported low to moderate levels of uncertainty and psychological distress, and most often used emotion-focused coping strategies. Subjects with naMCI reported more somatic symptoms than those with aMCI ($p < 0.05$); however, there were no significant relationships between the MCI subtypes or level of cognitive impairment on the other psychological distress subscales, coping instrument, or uncertainty instrument. The long-term goal of this study is to provide a foundation for a program of research centered on the development and evaluation of interventions to assist older adults who have a diagnosis of MCI and their family members with coping and managing their condition.

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Jennifer Sjostedt Avery, MSN, RN, GNP-BC

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I. INTRODUCTION

Background and significance

The average lifespan in the United States is increasing; people can now expect to live to be approximately 78.5 years-old (Arias, 2014). Concurrently, advances in science have led to increases in quality of life through early identification of illnesses, impairments, and other age-related changes. One such condition, mild cognitive impairment (MCI), has become increasingly of concern as a potential pre-dementia condition, making it a new target for early diagnosis and interventions to help maintain quality of life through slowing or preventing the progression to dementia. MCI is currently defined as functional impairment affecting mental processes, such as memory or executive functioning, that is more than what is expected for normal aging and often precedes dementia (Petersen, 2003; Petersen et al., 2014). It is generally diagnosed starting around the age of 60 years (Petersen, 2011).

Diagnostically MCI can further be broken down into two subsets: Amnesic versus non-amnesic MCI (Petersen, 2014). The main difference between these subsets is the presence of memory impairment (amnesic or aMCI) or lack thereof (non-amnesic or naMCI). Despite fundamental differences between aMCI and naMCI, there is a significant lack of evidence for treating or screening one subset differently from the other (Gauthier & Touchon, 2005; Lin, Vance, Gleason, & Heidrich, 2012; Ross & Bell, 2014). In addition, older adults with either subtype of MCI are considered to be a vulnerable population, at risk for coercion or mistreatment directly relating to their level of impaired cognition, regardless of the nature of their impairment.

Unfortunately, the point at which it is determined that changes in cognition are being caused by MCI rather than normal age-associated changes or dementia is subjective and not completely clear cut. In general, the diagnosis of MCI typically starts with the patients' or family members' complaint of changes in cognition (Albert et al., 2011; Petersen et al., 2014; Portet et al., 2006). This complaint is accompanied by a significant difference in performance (within 1.5 standard deviations of what is normally expected for age) on a brief cognitive screening tool such as the Montreal Cognitive Assessment (Nasreddine et al., 2005) or Addenbrooke's Cognitive Examination revised (Mioshi, Dawson, Mitchell, Arnold, & Hodges, 2006).

Incidence and prevalence of MCI. Recently the average incidence rate and prevalence for all types of MCI, calculated from 16 large scale studies, is estimated to be 47.9/1000 person-years and 18.9% respectively (Petersen et al., 2014). For aMCI and naMCI separately, incidence rates are 3.8 and 3.9/100 person-years with prevalence of 11.6% and 9.9%, respectively (Katz et al., 2011). Comparatively, in the same study, for all types of dementia the incidence rate was 2.9/100 person-years and prevalence was 6.5% (Katz et al., 2011). Higher rates of naMCI have also been found in persons who identify as African American/Black compared to those who identify as Caucasian/White (Katz et al., 2011; Lee et al., 2012). African American/Black race was also found to be a significant risk factor for development of MCI in the Cardiovascular Health Study (Lopez et al., 2003). Other studies have found conflicting results, with incidence rates of MCI among Hispanic/Latino and African American/Black persons similar to the incidence rates of MCI among Caucasian/White persons (Manly et al., 2008; Unverzagt et al., 2011). These conflicting results suggest that the differences of MCI incidence by race

may be contributed to increased misclassification of MCI (Kennedy, 2011). In general, it has been estimated that MCI affects approximately up to one in five older adults globally (Laino, 2011).

The general rate of progression from those diagnosed with either subset of MCI to dementia is estimated to be between 5.9 to 10% per year (Gao et al., 2014; Petersen, 2011). However, the speed of progression (i.e. months versus years) from MCI to dementia is inconsistent and difficult to predict (Portet et al., 2006). In addition, there is little evidence to suggest which potential factors might influence or lead to one MCI subset over another, or which factors might influence an older adult's transition/speed from MCI to dementia (Alzheimer's Association, 2011). The higher incidence and prevalence of MCI versus dementia, and the potential progressive relationship between MCI and dementia highlights the possibility of a large portion of adults progressing from MCI to dementia in the not so distant future. It suggests a need for increased primary care visits to monitor potential progression from MCI to dementia, and increased use anti-dementive drugs at an earlier stage.

Potential costs related to MCI. Overall the potential direct/indirect costs, trajectory, and burden associated with MCI are not well understood and have only recently been estimated in the United States (Lin & Neumann, 2013). Compared to older adults without MCI or dementia in the US, those with MCI reported significantly ($p < 0.001$) higher rates of informal care use and substantially higher annual direct medical costs ($p < 0.001$) with a mean difference of \$3,530 (Zhu et al., 2013). Another US-based study also found that unspecified direct costs for older adults with MCI compared to those without impairment (adjusted for age and gender) were significantly higher by an

average difference of \$859 per year (Leibson et al., 2012). However, in Germany, Luppá et al. (2008) demonstrated a difference between the average direct costs from outpatient/inpatient care, pharmaceuticals, medical supplies, home care, assisted living and transportation for older adults with MCI at €4,443 (approximately \$5,710) compared to €3,814 (approximately \$4,902) for those without MCI. While the 14% (€629, or approximately \$808) difference in mean costs might be clinically significant, the difference was statistically insignificant ($n = 413$, $p = 0.34$).

Issues with MCI: Conceptualizations and definitions. Conceptualizations of MCI stem from its' evolving definitions branching from surrogate terms such as benign senescent forgetfulness and age-associated memory impairment. These conceptualizations of MCI are based on the assumption that a continuum of cognitive functioning exists between normal aging and dementia (Petersen et al., 2014; Portet et al., 2006). Originally, this continuum was based on diagnostic criteria with the assumption of memory loss as the only source of impairment, and Alzheimer's dementia reflecting greater cognitive impairment on the continuum. Later the diagnostic definition of MCI was broadened to include all types of cognitive impairment (aMCI and naMCI), thereby introducing more heterogeneity in the theoretical continuum and relating MCI to all types of dementia. Older adults transition along this continuum at differing, unpredictable rates; and, not all older adults diagnosed with MCI continue on to AD. Some older adults revert back towards normal functioning or stay stagnant within the scope of MCI (Anstey et al., 2008; Banningh, Vernooij-Dassen, Rikkert, & Teunisse, 2008; Chertkow, 2002; Costa et al., 2010; DeCarli, 2003; Diniz, Nunes, Yassuda, & Forlenza, 2009; Fisk & Rockwood, 2005; Gauthier & Touchon, 2005; Lingler et al., 2006; Portet et al., 2006;

Roach, 2005; Tuokko & Hultsch, 2006; Werner & Korczyn, 2008). For example, a recent study of older adults diagnosed with MCI in primary care practices ($n=357$) found that after 3 years, 41.5% of the sample reverted back to normal cognition, 21.3% fluctuated between normal cognition and MCI, 14.8% were stagnant within MCI, and only 22.4% had progressed to dementia (Kaduszkiewicz et al., 2014).

As a diagnostic entity, the definition of MCI has not always been straightforward and clear cut, and a specific conceptual framework that encompasses attributes, antecedents and consequences for MCI is nonexistent. Despite efforts to clearly and uniformly define MCI, it is only recently that a diagnosis for MCI was accepted within the *Diagnostic and Statistical Manual of Mental Disorders IV* (DSM-IV) (Matthews et al., 2007; Rosenberg, Johnston, & Lyketsos, 2006). In May 2013, the DSM-V included the diagnosis of “minor neurocognitive disorder” to encompass MCI, supporting it as its own diagnosable entity (American Psychiatric Association [APA], 2013). However, it is important to note that despite work towards the inclusion of MCI as a DSM-V diagnosis, national or international guidelines specific to the management of MCI have not been published (Bensadon & Odenheimer, 2013; Dean & Wilcock, 2012).

The historical lack of an accepted DSM diagnosis could be related to debates about MCI as its own entity rather than simply a new label for early dementia or memory loss associated with normal aging (Davis & Rockwood, 2004). Surrogate terms (including but not limited to benign senescent forgetfulness, age-associated memory loss, mild cognitive decline, and cognitive impairment, no dementia) have also added to the varying definitions of MCI as either a process of aging or a pathological decline (Matthews et al., 2007). Currently, the most widely accepted definition of MCI started to

arise in the early 1990's and is diagnostic: MCI represents a form of functional impairment affecting mental processes, more than what is normally expected with age, which often precedes dementia (Petersen et al., 2014; Petersen, 2003).

MCI is a useful concept to encompass the changes in cognition that are not the result of aging or dementia. Yet, other than the aforementioned theoretical continuum of cognitive impairment, a clear conceptual framework for MCI which addresses possible antecedents and consequences is not apparent in published literature. The existing theoretical continuum and diagnostic criteria only provide guidance about the trajectory and attributes of MCI, not the antecedents or consequences of MCI. These attributes contribute to understanding MCI but do not provide guidance for nursing interventions that might help older adults with MCI and their families cope with the illness. Other theories related to chronic illnesses have limitations for addressing the unique situation of older adults with MCI (Corbin & Strauss, 1991, 1992; Lazarus & Folkman, 1984; Levanthal, Meyer, & Nerenz, 1980; Mishel, 1988, 1990; Pearlin, Menaghan, Lieberman, & Mullan, 1981; Pearlin & Schooler, 1978). For example, chronic illness theories do not account for the unpredictable illness trajectory on consequences of having MCI or the impact of cognitive impairment on the older adult's appraisal of their situation. Consequently, a conceptual framework that addresses antecedents and consequences specific to MCI is needed in order to guide the development and evaluation of specific interventions and further legitimize MCI as a target for research.

Conceptual framework for MCI. This study proposes the Sjostedt framework for older adults with MCI (encompassing both aMCI and naMCI) that defines MCI as an unstable state of limbo weighted by heterogeneity between older adults' normal and

abnormal continuums (normal aging versus dementia). While the entirety of the framework is discussed in chapter two, the portion which will serve as the focus of this dissertation will be briefly introduced now.

In the Sjostedt framework, the main consequence of MCI is uncertainty, which then leads to the other consequences of coping and psychological distress. The uncertainty from MCI stems mainly from aforementioned inconsistencies in MCI diagnosis and variability in MCI trajectories. Uncertainty may then influence older adults' coping and psychological distress resulting from MCI. Coping and psychological distress from MCI result as responses to diagnosis and symptoms related to MCI. Coping may impact psychological distress, similar to the relationships between coping and psychological distress with other chronic illnesses where emotion-focused and dysfunctional coping have been positively correlated with psychological distress (Barron, 2000; Lauver, Kruse, & Baggot, 1999; Lynch, Kroencke, & Denney, 2001; Sanders-Dewey, Mullins, & Chaney, 2001) and problem-focused coping negatively correlated with psychological distress (Lynch et al., 2001; Sanders-Dewey et al., 2001). Finally, an older adult's progression with MCI or lack thereof over time may further shape the consequences of MCI. The potential relationships of MCI, time, uncertainty, coping, and psychological distress that will be tested in the Sjostedt framework are illustrated in figure 1.

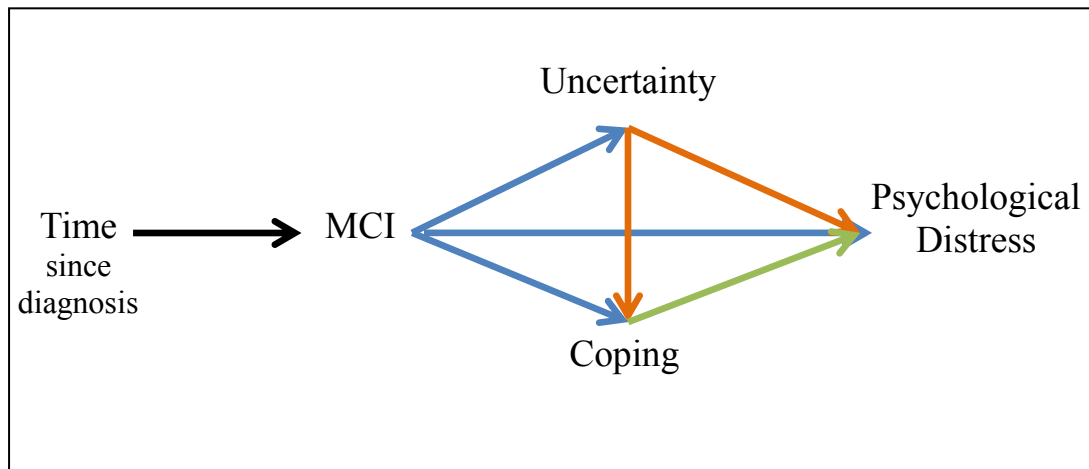


Figure 1. Conceptual framework for the consequences of MCI.

Uncertainty, coping, and psychological distress with MCI. Uncertainty is defined as an emotional state that occurs when a person is unable to assign definite value to events or objects and/or is unable to predict an outcome (Mishel, 1983). MCI is often referred to as an uncertain condition in qualitative studies of the experiences of older adults with MCI, and within attempts to conceptualize, diagnose, and define MCI (Bensadon & Odenheimer, 2013; Dean & Wilcock, 2012; Lu, Haase, & Farran, 2007; Portet et al., 2006; Werner & Korczyn, 2008; Yanhong, Chandra, & Venkatesh, 2013). Uncertainty can influence how older adults respond to any illnesses, treatments, and hospitalizations (Landis, 1996). Within any chronic illness, uncertainty can stem from a lack of clarity regarding symptoms, treatment options, disease etiology, and/or disease prognosis (Mishel, 1983, 1988, 1999). Unlike other chronic illnesses, uncertainty from MCI may stem from condition heterogeneity, varying trajectories, and inconsistencies in diagnosis. Despite evidence from qualitative studies, no studies have quantitatively assessed uncertainty from MCI.

Coping is defined as the intentional cognitive and/or behavioral efforts to manage internal or external demands appraised as exceeding the resources of or taxing the person (Lazarus, 2000; Lazarus & Folkman, 1984). In the conceptual framework, coping results as a response to MCI and uncertainty. Some older adults with MCI might use avoidance oriented (or dysfunctional) coping through attempts to improve memory performance, avoidance of activities to avoid making mistakes or masking of deficits (Banningh et al., 2008). Yet, older adults with MCI might also use emotion-focused or problem-focused coping through methods such as positive reframing, acceptance, religion, planning, and instrumental support (McIlvane, Popa, Robinson, Houseweart, & Haley, 2008). Uncertainty could affect an older adult's ability to define and relate to MCI, thus impairing their ability to cope effectively with it (Banningh et al., 2008; Blieszner, Roberto, Wilcox, Barham, & Winston, 2007; Lingler et al., 2006; Lu et al., 2007). Another result could be potential role and identity shifting, such as avoidance of independence (Blieszner et al., 2007).

Finally, psychological distress might result from the diagnosis of MCI and is likely influenced by uncertainty and coping. Psychological distress can be defined as the physical, psychosomatic, or emotional reactions to a stressor which negatively affect a person's well-being (Kellner, 1987). Psychological distress from MCI may present as emotions or reactions including anger, depression, anxiety, somatic symptoms, sadness, frustration, loss of self-confidence, discouragement, loneliness, rejection, inactivity, shame, self-blame, helplessness or loss of control (Banningh et al., 2008; Blieszner et al., 2007; Carpenter et al., 2008; Dean & Wilcock, 2012; Ellison, 2008; Lu et al., 2007; Pessin, Rosenfeld, Burton, & Breitbart, 2003; Petersen, 2003; Rosenberg et al., 2006).

One study found that older adults with MCI were unable to identify any positive consequences (Banningh et al., 2008). Yet, other studies have found positive emotions stemming from MCI such as happiness or relief that the diagnosis is not dementia, satisfaction from professional validation of their cognitive symptoms, optimism, and comfort through being able to reduce uncertainty by attaching a name to their cognitive symptoms (Dean & Wilcock, 2012; Lingler et al, 2006; McIlvane et al., 2008).

Uncertainty, coping and psychological distress with other conditions. To date, no correlational studies exploring the relationships between MCI, uncertainty, coping, and psychological distress exist. However, a variety of studies have examined these relationships pertaining to adults with other chronic conditions (Haisfield-Wolfe et al., 2012; Reich, Johnson, Zautra, & Davis, 2006; Landis, 1996; Lynch et al., 2001; Mullins et al., 2001; Sanders-Dewey et al., 2001) and non-chronic situations and provide support for the proposed hypotheses in the Sjostedt framework (Lauver et al., 1999; Taylor-Piliae & Molassiotis, 2001). Levels of uncertainty concerning a chronic illness (Haisfield-Wolfe et al., 2012; Landis, 1996; Lynch et al, 2011; Mullins et al., 2001) and emotion-focused coping strategies (Lynch et al., 2001; Sanders-Dewey et al., 2001) have been significantly and positively correlated with psychological distress. Problem-focused coping has been negatively correlated with psychological distress (Lynch et al., 2001; Sanders-Dewey et al., 2001), and while clinically significant, this relationship is not always statistically significant (Lynch et al., 2001).

In addition, another study found uncertainty to be positively and significantly related to perceived inability to cope, and both variables were significantly and positively correlated with increased levels of psychological distress among women receiving

abnormal papanicolaou results (Lauver et al., 1999). However, this result conflicts with that of Taylor-Piliae and Molassiotis (2001), who found no significant relationships between uncertainty and coping, and no significant relationships between uncertainty or coping and psychological distress among men receiving cardiac catheterization. Differences in relationships among uncertainty, coping, and psychological distress as demonstrated by Lauver et al. (1999) and Taylor-Piliae and Molassiotis (2001) may be attributable to gender, cultural, or illness differences.

Summary. Most previous studies focus on the diagnosis of MCI. Few studies focus on the consequences for older adults with MCI. Consequences of having MCI might include (1) uncertainty regarding diagnosis, condition trajectory, and treatment (Bensadon & Odenheimer, 2013; Dean & Wilcock, 2012; Lu et al., 2007; Portet et al., 2006; Werner & Korczyn, 2008); (2) coping with diagnosis and symptoms (Banningh et al., 2008; McIlvane et al., 2008); and (3) psychological distress (Banningh et al., 2008; Blieszner et al., 2007; Dean & Wilcock, 2012; Lu et al., 2007; Petersen, 2003). Older adults' responses to these consequences of having an MCI diagnosis are central to nursing's focus on holistic care. Understanding the consequences of having MCI is foundational to designing effective interventions that help to decrease uncertainty and facilitate coping with the condition.

Purpose of the study

This study is unique in quantitatively addressing consequences of MCI (uncertainty, coping, and psychological distress), which have been overlooked or equated with the consequences of dementia. This study will be foundational in validating a conceptual framework that can guide the development of nursing interventions and

further research for older adults with MCI. The purposes of this quantitative study are to: (1) test select components of a new conceptual framework for MCI by examining the relationships among uncertainty, coping, psychological distress, time since diagnosis, and level of cognitive impairment from MCI, (2) describe the levels of uncertainty, coping, and psychological distress in older adults with MCI; (3) examine the differences in scores on uncertainty, coping, and psychological distress between the two subtypes of MCI; and (4) examine the strength and direction of relationships between scores on uncertainty, coping, and psychological distress within the subtypes of MCI.

Specific aims and hypotheses. The specific aims and hypotheses of this study are:

Aim 1. Test select components of a conceptual framework for MCI by examining the relationships among uncertainty, coping, psychological distress, time since MCI diagnosis, and level of cognitive impairment from MCI.

H₁. There will be a significant negative relationship between time since diagnosis and level of cognitive impairment from MCI.

H₂. There will be significant positive relationships between uncertainty and coping.

H₃. There will be significant positive relationships between uncertainty and psychological distress.

H₄. There will be significant relationships between coping and psychological distress.

H₅. The relationships between level of cognitive impairment from MCI and coping will either be mediated or moderated by uncertainty.

H₆. The relationships between level of cognitive impairment from MCI and psychological distress will either be mediated or moderated by uncertainty and coping.

Aim 2. Describe the levels of uncertainty, coping, and psychological distress in older adults with MCI.

Aim 3. Examine the differences in scores on uncertainty, coping, and psychological distress between the subtypes of MCI.

Aim 4. Examine the strength and direction of relationships between scores on uncertainty, coping, and psychological distress within the subtypes of MCI.

H₇. There will be no significant differences between the subtypes of MCI in the strength and direction of uncertainty, coping, and psychological distress.

The hypotheses of this study in relation to the conceptual framework are summarized by figure 2 which displays the predicted relationships among variables within the conceptual framework.

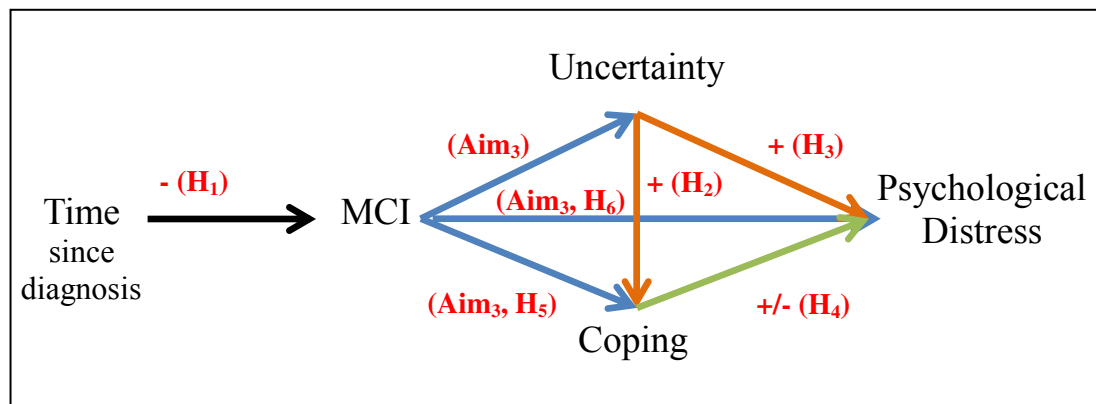


Figure 2. Predicted relationships between variables of the conceptual framework.

Summary of key variable definitions. The conceptual definitions for MCI, uncertainty, coping, and psychological distress can be summarized as follows:

MCI is an unstable state of limbo weighted by heterogeneity between older adults' normal and abnormal continuums (normal aging versus dementia).

Uncertainty is an emotional state that occurs when a person is unable to assign definite value to events or objects and/or is unable to predict an outcome (Mishel, 1983).

Coping is the intentional cognitive and/or behavioral efforts to manage internal or external demands appraised as exceeding the resources of or taxing the person (Lazarus, 2000; Lazarus & Folkman, 1984).

Psychological distress is the physical, psychosomatic, or emotional reactions to a stressor which negatively affect a person's well-being (Kellner, 1987).

Significance to nursing and contribution to knowledge

With the growing population of older adults, nurses will be caring for more older adults with MCI at various stages in a variety of environments. Specifically, the burden of providing education about MCI to patients and providing support and guidance for patients and family members is clearly within the scope of nursing. A validated conceptual framework will not only provide guidance to nurses involved in research with MCI, such a framework could also serve as a guide for designing patient and family interventions for the management of MCI. The consequences for older adults with MCI are central to nursing's focus on holistic care. Understanding the consequences of having MCI is foundational to designing appropriate interventions that help to decrease uncertainty and facilitate coping with the condition.

Potential for leading to future research. A validated conceptual framework for MCI will guide future research through identifying areas for interventions. Most published studies pertaining to MCI use only diagnostic criteria or do not specify a framework as the basis for their research. While the current practice of using diagnostic criteria to serve as a framework might help practitioners diagnose MCI, the current criteria do not address the possible antecedents or consequences of MCI which limits the potential scope of research and knowledge about how older adults with MCI respond to their diagnosis.

Dissertation chapters overview

This chapter has focused on the significance of MCI, presentation of a portion of a new conceptual framework for MCI, and introduction of the dissertation study's aims, and hypotheses. Chapter two will describe in more detail the historical shaping of MCI definitions and conceptualizations, analyze existing chronic illness theoretical frameworks and their limitations for MCI, then present the entirety of a new conceptual framework for MCI. Chapter three will explicate the methodology that will be used to accomplish testing of the new conceptual framework for MCI. Finally, chapters four and five will present two different data-based manuscripts associated with this dissertation. The first manuscript compared two commonly used instruments for the screening of MCI in older adults (the Montreal Cognitive Assessment and the Revised Addenbrooke's Cognitive Examination), in order to provide evidence for which instrument might be more appropriate for use in a primary care setting and this study. The second manuscript presents the main findings related to the specific aims of the dissertation.

II. REVIEW OF THE LITERATURE AND CONCEPTUAL-THEORETICAL FRAMEWORK

This chapter will review literature pertaining to the conceptualization and definition of MCI, limited applicability of theoretical frameworks related to chronic illnesses and MCI, and the current status of knowledge related to the relationships between MCI, time since diagnosis, uncertainty, coping, and psychological distress. This chapter begins with a brief description of the literature search, followed by an overview of the historical shaping of the definition and understanding of the concept of MCI. Next, frameworks that have been used to guide studies related to chronic illness are critiqued in relation to their applicability to older adults with MCI. The chapter then concludes with an examination of literature supporting the proposed theoretical framework for MCI, which will be tested in this study.

Literature search description

An extensive literature search was conducted using the CINAHL, Google-scholar, Web-of-Science, ProQuest dissertations, and PubMed databases, followed by ancestral searches of articles obtained from those databases. Initial searches were conducted primarily for performing a concept analysis of MCI between August and November 2010 using only the terms “mild cognitive impairment.” This search yielded over 34,000 possible articles and books. The search was then narrowed down by year (with a focus on literature from the last 10 years, aside from sentinel works), limited to English language, and the main search term, “mild cognitive impairment,” was combined with additional terms (or restricting terms) such as: MCI, pediatrics (to examine the use of

MCI in other populations), geriatrics, chemotherapy, alcohol, nursing, perception and concept. Surrogate terms for MCI were also searched to try to compile a comprehensive collection of studies. Articles were included if they specifically addressed the concept of MCI or the possible antecedents, attributes, and consequences of MCI. Articles were excluded if they focused only on dementia rather than MCI. The inability to exclude articles within the database searches (without accidentally excluding applicable articles) pertaining only to older adults with dementia or only to caregivers of older adults with MCI resulted in a lengthy search process and multiple duplicate articles or articles not meeting the inclusion criteria. This search process was repeated in 2011, 2012, 2013, and 2014 to update the collection of articles and books to include recently published works not present during initial searches.

The primary focus within the literature search was on MCI within the geriatric population. This was later followed by focusing on MCI outside of the geriatric population (i.e. pediatrics, or within patients suffering from “chemo-brain” or alcoholism) to broaden the overall view of the concept for the purposes of creating the conceptual framework. Articles were chosen based upon relevance to the concept and/or diagnosis of mild cognitive impairment. Literature for the historical overview of MCI came from articles used for the concept analysis of MCI.

Methods specified by Rodgers (Rodgers & Knafl, 2000) were used to guide the concept analysis and literature search, with literature collection that focused on the attributes, sociocultural, temporal, and discipline variations of MCI. The method can be summarized as: (1) selecting a concept of interest; (2) identifying surrogate terms and uses of the concept; (3) collecting relevant literature pertaining to all aspects of the

concept; (4) identifying attributes of the concept then identifying the antecedents, consequences, and other concepts related to the concept; and (5) drawing a conceptual model connecting the attributes, antecedents, and consequences (Rodgers & Knafel, 2000).

Outside of literature pertaining specifically to MCI, additional searches were conducted in the aforementioned databases to gather information on alternative theoretical frameworks that might be applicable to this study. Again, the search was not limited by year, but was limited to articles or books published in English. As MCI is considered to be a chronic illness, the search focused on the following chronic illness frameworks and their relation to MCI: (1) Pearlin and colleagues' theories of coping (Pearlin & Schooler, 1978) and stress (Pearlin et al., 1981), (2) Lazarus and Folkman's (1984) theory of Coping in Stress, (3) Corbin and Strauss' (1991, 1992) Chronic Illness Trajectory Framework, (4) Levanthal and colleagues' (1980) Common Sense Model of Illness Representations, and (5) Mishel's (1988, 1990) theory of Uncertainty in Illness. These frameworks were selected for their potential applicability to MCI and fit with study variables.

Related concepts to MCI. While searching for conceptualizations of MCI, several terms repeatedly arose within the literature search pertaining to memory. Specifically the concepts of memory loss, memory impairment, or forgetfulness were present in the majority of reviewed literature. The relationship of memory to MCI is likely due to aforementioned the early conceptualizations of MCI as a pre-AD condition, and hence only related to deficits in memory. There also appeared to be a major focus on what MCI is not. MCI can be presented as an absence rather than presence of certain

attributes, for instance the absence of functional impairment or absence of dementia rather than solely the presence of cognitive decline.

Brief historical overview of conceptualizing and defining MCI

Defining MCI. In the past, MCI was broadly identified as the increased risk but not definitive diagnosis of a neurodegenerative disease (Rosenberg et al., 2006). In this manner, MCI encompassed any of the possible conditions between normal aging and diagnosable cognitive decline (Diniz et al., 2009; Matthews et al., 2007; Roberts, Clare, & Woods, 2009). In younger adults (less than 65 years old), MCI has been tautologically defined as greater than normal cognitive impairment; seen as related to intelligence (rather than aging), function and developmental progression (Byrne et al., 1987; Chen et al., 2006; Hurria, Somio, & Ahles, 2007; Keefe, Easley, & Poe, 2005). These previous definitions of MCI resulted in several surrogate terms, including: Benign senescent forgetfulness, age-associated memory impairment, late-life forgetfulness, aging-associated cognitive decline, age-related cognitive decline, mild cognitive decline, questionable dementia, and mild neurocognitive decline (DeCarli, 2003; Ellison, 2008; Matthews et al., 2007; Norlund et al., 2005; Rosenberg et al., 2006; Visser, 2006; Werner & Korczyn, 2008). Cognitive impairment, no dementia (CIND) was also considered as a surrogate term. However, not all patients who meet the criteria for CIND also meet the criteria for MCI (Chertkow, 2002; Gauthier & Touchon, 2005). Surrogate terms have added to the multiple definitions of MCI as either a process of aging or a pathological decline (Matthews et al., 2007).

Starting around 1998 MCI began to be defined as a uniquely geriatric-condition, thought to be related to dementia (Golomb, Kluger, & Ferris, 2004; Reisberg et al.,

2008). Currently, the most widely accepted definition of MCI is diagnostic and comes from the work of Dr. Ronald Petersen and colleagues: MCI represents a form of functional impairment affecting mental processes, more than what is normally expected with age, which often precedes dementia (Petersen, 2011; Petersen, 2003; Petersen et al., 2014). Past efforts to define MCI were likely related to the desire to classify MCI as a useful/diagnostic entity; allowing for more definitive selections of subjects for treatment and research purposes. The philosophic underpinnings of MCI have also been largely shaped by pragmatic views, which are reflected, if not directly stated, in most studies (Fisk & Rockwood, 2005). Legitimization of MCI as a diagnosis (rather than broad concept) also provides justification for reimbursement from payers for care services and research funding for drug or other treatment studies (Werner & Korczyn, 2008).

Diagnostically MCI can further be broken down into two subsets: Amnesic versus non-amnesic (Petersen et al., 2014). The main difference between the subsets is the presence of memory impairment (amnesic or aMCI) or lack thereof (non-amnesic or naMCI). Evidence suggests that those with aMCI are the most likely to later progress to dementia, generally in the form of Alzheimer's dementia (Davis & Rockwood, 2004; Petersen & Morris, 2005). The general rate of progression from those diagnosed with either subset of MCI to dementia is estimated to be between 5.9 to 10% per year (Gao et al., 2014; Petersen, 2011). However, the speed of progression (i.e. months versus years) from MCI to dementia is inconsistent and difficult to predict (Portet et al., 2006). In addition, there has been little evidence to suggest which potential factors might influence or lead to one MCI subset over another, or which factors might cause an older adult to transition from MCI to dementia (Alzheimer's Association, 2011).

The presence of apolipoprotein (APOE) $\epsilon 4$ genotype, hippocampal atrophy (estimated by hippocampal volume), and some cerebrospinal fluid (CSF) biomarkers ($A\beta_{42}$, T-tau, and P-tau) have been suggested to possibly predict increased likelihood of transitioning from MCI to dementia (Farlow et al., 2004; Gomar, Bobes-Bascaran, Conejero-Goldberg, Davies, & Goldberg, 2011; Hansson et al., 2006; Jack et al., 1999; Mattsson et al., 2009; Okonkwo et al., 2011). Yet, studies evaluating the predictive values of APOE $\epsilon 4$, hippocampal atrophy, and CSF biomarkers have only focused predominately on older adults with aMCI (Ferreira et al., 2014). This focus on aMCI is related to the similarities between aMCI and Alzheimer's dementia (presence of a memory deficit), and aforementioned likelihood of progression from aMCI to Alzheimer's dementia. Given study sample biases towards aMCI (Ferreira et al., 2014), it is questionable if APOE $\epsilon 4$, hippocampal atrophy, and CSF biomarkers would also effectively predict transitioning to dementia in older adults with naMCI. It is possible that the predictive value of APOE $\epsilon 4$, hippocampal atrophy, and CSF biomarkers are not unique to older adults with aMCI. Currently within clinical practice, APOE $\epsilon 4$, hippocampal volume, and CSF biomarkers are not routinely being used to predict older adults' transitions from MCI to dementia given their low sensitivity and specificity as diagnostic tests, and subsequently do not influence the nursing care of older adults with MCI (Albert et al., 2011; Petersen & Trojanowski, 2009).

Conceptualizing MCI. Conceptualizations of MCI have been related to its' evolving definitions branching from surrogate terms such as benign senescent forgetfulness and age-associated memory impairment. Conceptualizing MCI is based on the assumption that a continuum of cognitive functioning exists between normal aging

and dementia (Portet et al., 2006). This continuum is best represented in a figure focused on the relations between normal aging, MCI, and a type of dementia, Alzheimer's dementia (AD) from Petersen et al. (2001):



Figure 3. Continuum of cognitive impairment (Petersen et al., 2001).

Figure 3 does not distinctly note a direction, but instead implies a unidirectional path from normal aging to AD. The progression of the path becomes more evident when another figure from the same publication is considered that proposes a theoretical negative relationship between age and cognitive functioning:

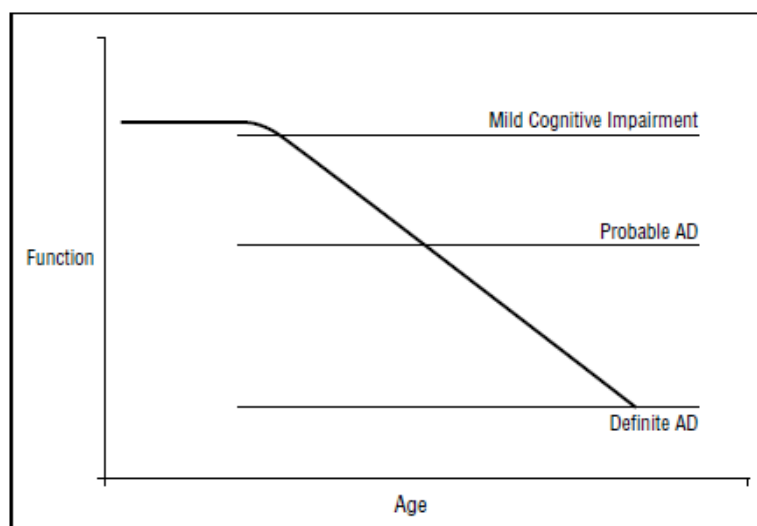


Figure 4. Theorized progression from MCI to AD (Petersen et al., 2001).

Yet, as previously stated, the path and speed of transition between normal aging and dementia is uncertain. Older adults transition along the continuum at differing,

unpredictable rates; and, not all older adults diagnosed with MCI continue on to AD, some revert back towards normal functioning or stay stagnant within the scope of MCI (Anstey et al., 2008; Bannings et al., 2008; Chertkow, 2002; Costa et al., 2010; DeCarli, 2003; Diniz et al., 2009; Fisk & Rockwood, 2005; Gauthier & Touchon, 2005; Lingler et al., 2006; Portet et al., 2006; Roach, 2005; Tuokko & Hultsch, 2006; Werner & Korczyn, 2008). Additionally, this initial continuum from normal aging to MCI to dementia was based on the assumption of cognitive impairment only affecting memory and thus only relating to AD. However, later conceptualizations widened the scope to include all types of cognitive impairment, and thus relating MCI to all types of dementia (Werner & Korczyn, 2008). Outside of memory, MCI can affect an older adult's executive functioning, attention, use of language, and visuospatial skills (Norlund et al., 2005; Petersen, 2011). In widening the scope of cognitive impairment, greater heterogeneity was introduced to the concept, adding more variance to the possible speeds and trajectory of the continuum and resulting in the subsets of aMCI and naMCI. Yet it is important to note, despite the variability in the subsets, there is a significant lack of evidence for treating or screening one subset differently from the other (Gauthier & Touchon, 2005; Lin et al., 2012). In addition, older adults with either subtype of MCI are considered to be a vulnerable population, at risk for coercion or mistreatment directly relating to their level of impaired cognition, regardless of the nature of their impairment.

Select chronic illness theoretical frameworks

Although there is not a specific theoretical framework for MCI, other chronic illness frameworks and theories exist that may be able to contribute to the understanding of MCI. In this section, five frameworks will be described and critiqued for their

relevance to MCI and this study. These frameworks include: (1) Pearlin and colleagues' theories of coping (Pearlin & Schooler, 1978) and stress (Pearlin et al., 1981), (2) Lazarus and Folkman's (1984) theory of Coping in Stress, (3) Corbin and Strauss' (1991, 1992) Chronic Illness Trajectory Framework, (4) Levanthal, Meyer, and Nerenz's (1980) Common Sense Model of Illness Representations, and (5) Mishel's (1988, 1990) theory of Uncertainty in Illness.

Theories of coping and stress. Theories of stress and coping are frequently used to guide research with older adults who have various types of chronic illnesses (Lazarus & Folkman, 1984; Pearlin et al., 1981; Pearlin & Schooler, 1978). Two theories of coping and stress developed by Pearlin and colleagues and one developed by Lazarus and Folkman share some similarities in their limitations related to their applicability of older adults with MCI. As such, these theories will be evaluated together, starting with a brief presentation of each theory.

Pearlin and colleagues: Two theories of coping and stress. Pearlin and colleagues provide two different yet connected theories pertaining to coping (Pearlin & Schooler, 1978) and stress (Pearlin et al., 1981). First, coping is defined as a behavior that serves to avoid being psychologically stressed or harmed by a problematic experience (Pearlin & Schooler, 1978). These behaviors are separated into three distinct categories: (1) behaviors that change a situation that is causing problems, (2) behaviors that control the meaning of the situation after it occurs but before it causes the person to experience stress, and (3) behaviors that serve to control stress after the situation has occurred (Pearlin & Schooler, 1978). Coping is influenced by the social and psychological resources available to the person, i.e. interpersonal networks with family

and friends, and personality characteristics such as self-esteem, self-denigration, and mastery (Pearlin & Schooler, 1978). The distinction between coping and psychological resources acknowledges that coping is an intentional action that is affected by predisposed or learned personality traits rather than being an unintentional personality trait.

The efficacy of coping is determined by how well the person is able to avoid stress (Pearlin & Schooler, 1978). Pearlin and Schooler (1978) suggest that using a variety and large number of coping responses may be the most effective way to avoid stress. This leads into Pearlin and colleagues' (1981) next theory on the stress process. Stress is defined as the multifaceted intentional and/or unintentional responses of a person to a stimulus perceived as noxious (Pearlin et al, 1981). Sources of stress are life events, life strains, and self-concepts (Pearlin et al., 1981). Coping and social supports are then seen as mediating resources which can happen at any point during the process to decrease stress (Pearlin et al., 1981). Stress can permeate the entire person resulting in outcomes that are biochemical, physiological, or emotional manifestations (i.e. increased blood pressure and depression). A simplified version of the stress version might look like Figure 5:

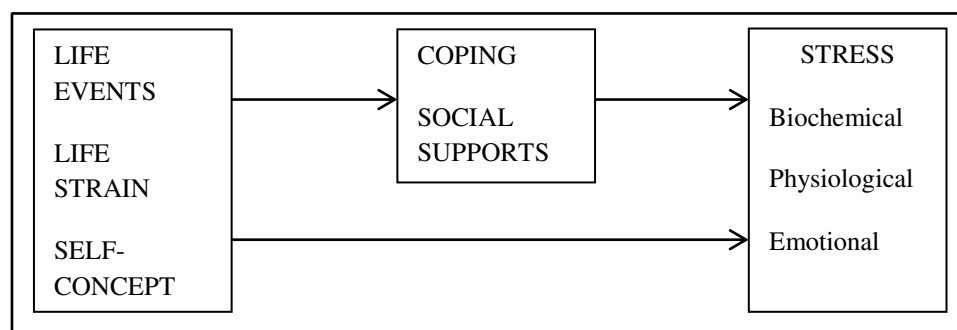


Figure 5. Potential model of the Stress Process adapted from Pearlin et al. (1981).

However, Pearlin and colleagues (1981) note from evaluating the connections between sources of stress and increases or decreases in depression as a manifestation of stress (or lack thereof), that the model is not simplistic as sources of stress may combine to influence one another (Figure 6):

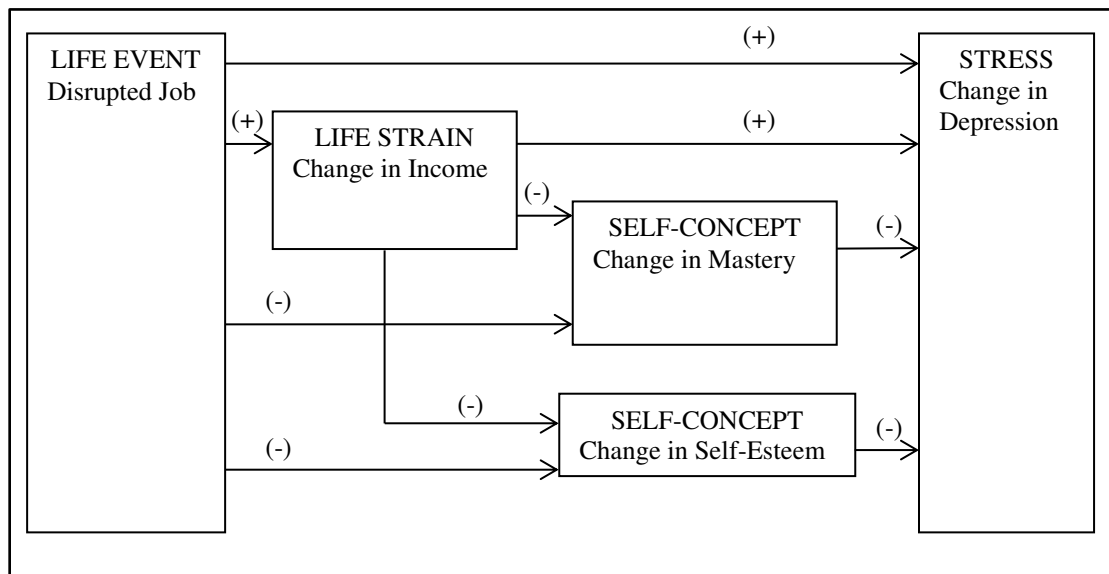


Figure 6. Path model of sources of stress (Pearlin et al., 1981).

In addition, Pearlin and Schooler (1978) noted that coping is influenced by social resources (i.e. social supports in the stress model). So finally, a more accurate representation of Pearlin et al.'s theories of coping and stress might be illustrated by Figure 7.

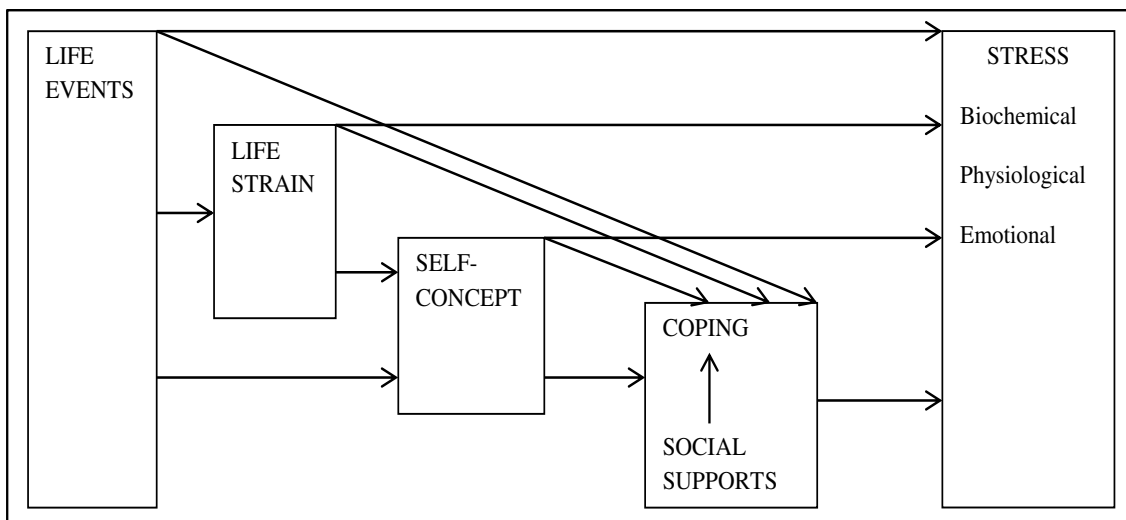


Figure 7. Revised model of stress and coping adapted from Pearlin et al. (1978, 1981).

Previous uses and populations. The general theories of coping and stress from Pearlin and colleagues (1978, 1981) have not been directly applied to research with older adults with MCI. However, the theories have been applied to other chronic illnesses such as cancer, (Dagan et al., 2011), diabetes mellitus (Bailey, 1996), depression (Penninx et al., 1998), and HIV (Linn, Anema, Hodess, Sharpe, & Cain, 1996).

Relation to MCI. MCI could be seen as a condition which either serves as a life event (receiving the diagnosis of MCI), life strain (adapting to cognitive impairments from MCI), or something that affects a person's self-concept, thus resulting in coping and stress. However, Pearlin and colleagues' theories assume that the life events or strains are perceived as noxious in order to precipitate coping and stress. While it can be assumed that older adults might perceive MCI as noxious, other research has suggested that it can alternatively be perceived in a more positive manner for being a lack of dementia (Lingler et al., 2006).

Lazarus and Folkman: Coping in stress. Coping is defined within the theory of Coping in Stress as the intentional cognitive and/or behavioral efforts to manage internal or external demands appraised as exceeding the resources of or taxing the person (Lazarus, 2000; Lazarus & Folkman, 1984). This view of coping obviously differs from aforementioned view provided by Pearlin and Schooler (1978), where coping is perceived as a method of avoidance rather than management of stress. Although it is not specified if stress is negative, positive, or neutral. With the term “management,” it is implied that stress is not uniquely positive, negative, or neutral. Always effective and always ineffective coping strategies do not exist (Lazarus, 2000). In response to a stressor, whether a coping strategy is effective or not depends on the person and the environment.

Figure 8 demonstrates these relationships:

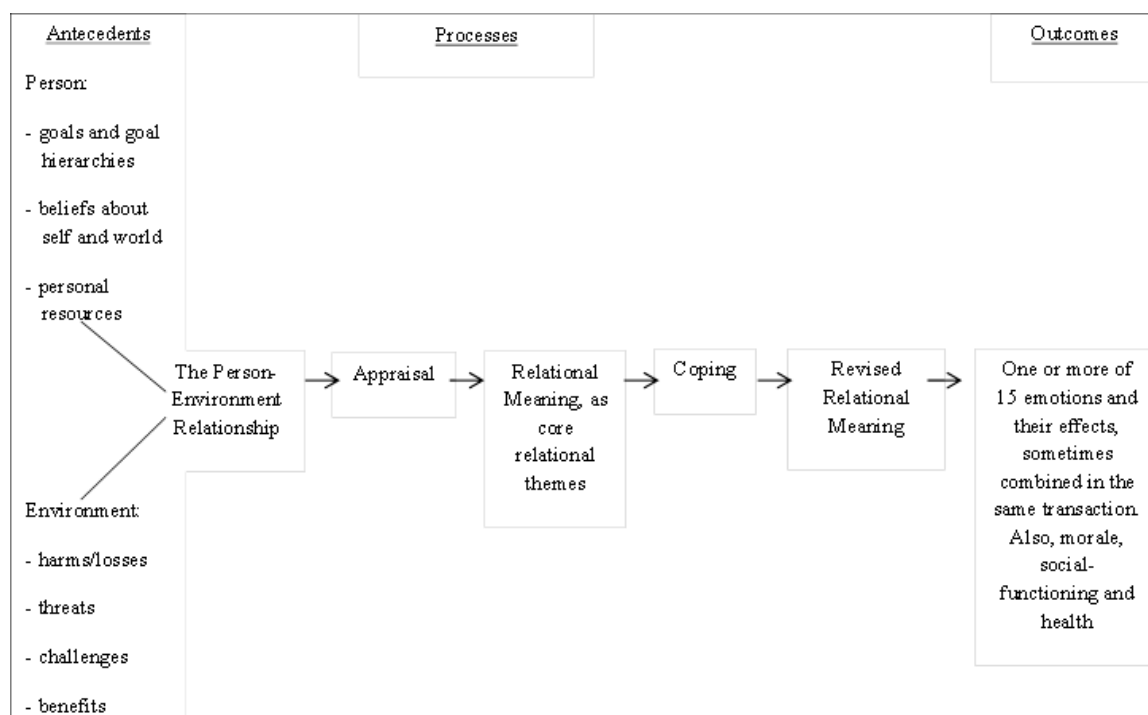


Figure 8. Revised model of coping and stress (Lazarus, 1999).

In the model, coping results in one or more of the following 15 categorical emotional responses: guilt, shame, jealousy, hope, fright, relief, pride, happiness, sadness, gratitude, compassion, anger, anxiety, envy, and love (Lazarus, 1999). In Lazarus' (1999) revised model, appraisal directs how a person copes with stress, hence impacting the outcome of emotional response(s). It also further supports the notion from Pearlin and Schooler (1978) that coping is an intentional action as it requires the person to take action in appraising the stressor.

Previous uses and populations. The framework provided by Lazarus and Folkman (1984) has been used to guide a multitude of studies related to coping with other chronic illnesses, including but not limited to: cancer (Felton & Revenson, 1984), depression (Penninx et al., 1998), diabetes mellitus (Felton & Revenson, 1984), hypertension (Felton & Revenson, 1984), psoriasis (Wahl, Hanestad, Wiklund, & Moum, 1999), and rheumatoid arthritis (Felton & Revenson, 1984; Walker, Jackson, & Littlejohn, 2004). However, the theory of Coping in Stress has not been used as the framework in research involving older adults with MCI.

Relation to MCI. In the theory of Coping in Stress, MCI could be seen as a source that affects the antecedents of coping, such as by role shifting which may alter the person's beliefs of self and the world (Blieszner et al., 2007). In addition, unlike the theories from Pearlin and colleagues, the framework provided by Lazarus and Folkman does not assume that the event which triggers coping is noxious. In this way, coping can also result from something that could be positive or neutral in nature rather than only negative.

Limitations of all three theories for this study. While somewhat different, all three of the theories are helpful in explaining the relationships between coping and stress. It is obvious with each framework that MCI may be seen as something that precipitates coping and stress. Specific to the theories by Pearlin and colleagues, coping is determined to be effective in the context of avoiding stress; whereas it might be more appropriate to consider the efficacy of coping, as it is in Lazarus and Folkman's framework, in its ability to manage rather than avoid stress (as not all stress is avoidable). Pearlin and colleagues' theories also do not specify stress as either a positive or negative; coping centers around the avoidance of stress, thereby suggesting that stress is only perceived as something negative. Consequently the theories do not account for the potential implications of positive stress (eustress) that could be experienced from receiving a diagnosis of MCI (as opposed to dementia) and may be inappropriate for use in evaluating stress and coping related to MCI.

A major limitation is that none of the three coping theories account for the effect of cognitive impairment on appraisal leading to coping and stress, and these theories do not consider the relationships between uncertainty, coping and stress. As previously mentioned, older adults with MCI may lack awareness of their cognitive impairment(s) (Tremont & Alosco, 2011), which could relate to a lack of awareness needed for appraisal of stress in coping. This is not to say that those with MCI would be incapable of appraisal, just that the appraisal may be impacted by MCI in a way that is unique from other chronic illnesses. In addition, although uncertainty could also be interpreted as a life event (Pearlin and colleagues) or related to personal resources (Lazarus and Folkman), there is the question of the neutral, positive, or negative nature of uncertainty

(and this relationship to stress and coping) which is not explicitly accounted for in the stress and coping theories.

Chronic Illness Trajectory Framework. Corbin and Strauss' chronic illness trajectory framework provides an understanding of problems unique to the course of chronic illnesses, and serves as a guide for the nursing management of chronic illnesses (Corbin, 1998; Corbin & Strauss, 1991, 1992; Glaser & Strauss, 1968). Corbin (1998) defines illness trajectory as the condition course and actions taken by participants (i.e. patient, nurses, caregivers) to direct and control that course. It is broken down into nine distinct phases which represent the different changes that occur within the course of chronic illnesses, demonstrated within Figure 9, starting with pre-trajectory:

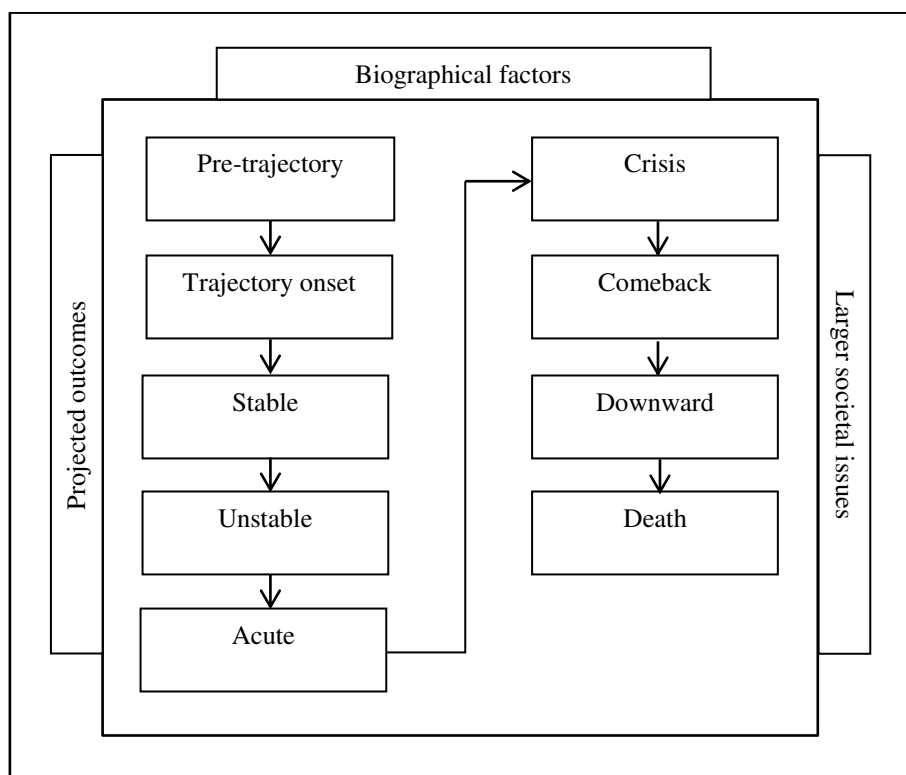


Figure 9. Trajectory phases of chronic illness adapted from Corbin (1998).

It is important to note that although arrows are drawn to connect the phases in Figure 9, a unidirectional path is not specified but implied through the numerical order listed (Corbin, 1998; Corbin & Strauss, 1991, 1992). The shaping of an illness trajectory is complex, requiring multiple resources and/or people. The trajectory phases (Figure 9) are shaped within the context of projected outcomes, biographical factors, and larger societal issues by management strategies (not in the Figure) that are not prescribed but instead evolve over time to meet the needs of each phase (Corbin, 1998). The goals of management strategies for each phase, and goal of definitions of the phases are explained by Table 1 from Corbin (1998):

Table 1. Trajectory phase definitions and management strategy goals from Corbin (1998).

Stage	Goal of definition	Goal of Management
Pre-trajectory	Genetic factors or lifestyle behaviors that place an individual or community at risk for the development of a chronic condition.	Prevent onset of chronic illness.
Trajectory onset	Appearance of noticeable symptoms, includes period of diagnostic workup and announcement of biographical limbo as person begins to discover and cope with implications of diagnosis.	Form appropriate trajectory projection and scheme.
Stable	Illness course and symptoms are under control. Biography and everyday life activities are being managed within limitations of illness. Illness management centers in the home.	Maintain stability of illness, biography, and everyday activities.
Unstable	Period of inability to keep symptoms under control or reactivation of illness. Biographical disruption and difficulty in carrying out everyday life activities. Adjustments being made in regimen with care usually taking place at home.	Return to stability.
Acute	Severe and unrelieved symptoms or the development of illness complications necessitating hospitalization or bed rest to bring illness course under control. Biography and everyday life activities temporarily placed on hold or drastically cut back.	Bring illness under control and resume normal biography and everyday activities.
Crisis	Critical or life-threatening situation requiring emergency treatment or care. Biography and everyday life activities suspended until crisis passes.	Remove life threat.
Comeback	A gradual return to an acceptable way of life within limits imposed by disability or illness. Involves physical healing, limitations stretching through rehabilitative procedures, psychosocial coming to terms, and biographical reengagement with adjustments in everyday activities.	Set in motion and keep going the trajectory projection and scheme.
Downward	Illness course characterized by rapid or gradual physical decline accompanied by increasing disability or difficulty in controlling symptoms. Requires biographical adjustment and alterations in everyday life activity with each major downward step.	To adapt to increasing disability with each major downward turn.
Dying	Final days or weeks before death. Characterized by gradual or rapid shutting down of body processes, biographical disengagement and closure, and relinquishment of everyday life interests and activities.	To bring closure, let go, and die peacefully.

The goals of management present a problem for the assumed unidirectional path of the model as they suggest that a person might be able to revert from certain stages (not necessarily all stages) back into the stage that came directly before it or even further back. For example, the goal of management for the unstable phase is to return to stability (the phase that came before it) but the goal of management for dying is not to return to the downward phase. Yet, in another example, the goal of management for the crisis phase is to remove the life threat (causing the crisis phase), which suggests, if successful, that person could possibly return directly to the stable or unstable phase, rather than simply returning to the acute phase below it (such that if the life threat is removed, symptoms might be resolved by its resolution, negating the acute phase).

Despite the question of a single or multidirectional path, it is a useful theory that clearly identifies important areas for nursing intervention within each phase of a chronic illness. Authors note that while the framework is general to all chronic illnesses, nurses need to be flexible and able to individualize how they approach the framework for each person (Corbin, 1998). This need for flexibility suggests that while a general path connecting the chronic illness phases could be assumed, the questionable theory path is not problematic as the path may be different dependent on the person, their condition(s), and other outside influences (i.e. culture).

Previous uses and populations. While the Chronic Illness Trajectory Framework has not been used in research involving older adults with MCI, it has been used in relation to describing the transitions of older adults coping with other chronic illnesses (Corbin, 1998). These conditions include, but are not limited to: AIDS/HIV

(Nokes, 1998), multiple sclerosis (Gulick, 1998), rheumatoid arthritis (Shaul, 2012), and stroke rehabilitation (Burton, 2001).

Relation to MCI. While MCI is a chronic illness whose trajectory may be somewhat similar to that assumed in the Chronic Illness Trajectory Framework, it is distinct from other chronic illnesses as it does not result in death, which completely negates the last phase of the framework. Additionally, MCI is also a condition that does not necessarily have a downward trend (necessary for phase progression in the Chronic Illness Trajectory Framework). As previously stated in chapter one, not all older adults with MCI have worsening cognitive impairment (or progress to dementia), some may have improved cognition or remain stagnant.

Limitations of theory for this study. The Chronic Illness Trajectory Framework has several aforementioned issues related to assumptions of MCI versus other chronic illnesses. Additionally, the framework does not account for all variables being assessed by this study. Specifically, the model does not account for the relationships of MCI to uncertainty, coping, and psychological distress. It could be argued that uncertainty, coping and psychological distress are projected outcomes which shape the MCI trajectory. However, even under that assumption, the relationships between uncertainty, coping, and psychological distress are not clearly defined.

Common Sense Model of Illness Representations. Levanthal's Common Sense Model dictates that people create mental representations of their illness through using information available to them (concrete and/or abstract) to help them make sense of and manage their illness (Levanthal et al., 1980). There are three sources for a person's available information: (1) lay sources, information provided through social contact and

cultural knowledge; (2) external sources, parents, significant others, or authoritative sources such as doctors; and (3) personal current experience with the illness (Hagger & Orbell, 2003).

The mental representations can be considered both cognitive and emotional representations and are generally composed of five themes: (1) Causes of the illness, (2) consequences from the illness, (3) the perceived ability to control/cure the illness, (4) identifying with the illness, and (5) the illness timeline (Hagger & Orbell, 2003). From the representation, the person copes with their representation of the illness, and the outcomes related to the illness. Emotional distress results from the emotional illness representation, and can contribute to illness outcomes in the form of psychological distress. These relationships are demonstrated by the graphical representation of the theory in Figure 10.

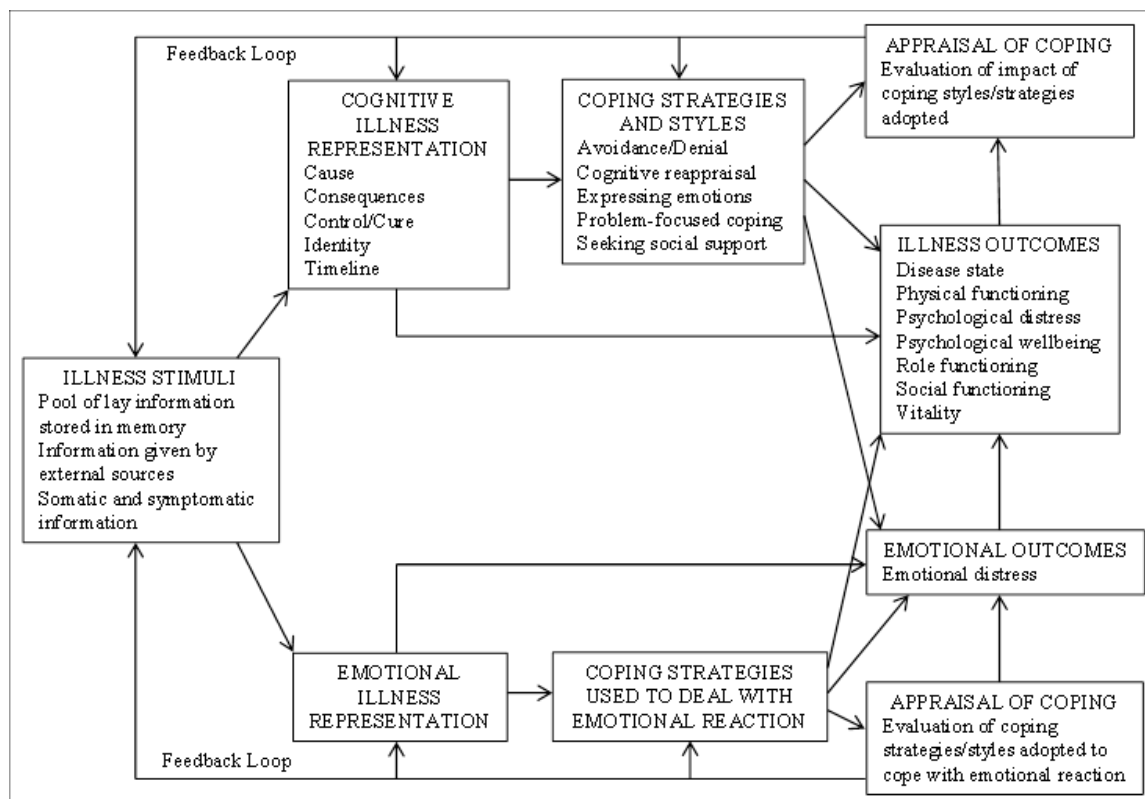


Figure 10. Graphical representation of Leventhal et al. (1980) Common Sense Model of Illness Representations (Hagger & Orbell, 2003).

Previous uses and populations. The Common Sense Model has been applied in three studies of older adults with MCI (Lin & Heidrich, 2012; Lin, Gleason, & Heidrich, 2012; Lingler et al., 2006). As demonstrated by a meta-analytic review of the Common Sense Model (Hagger & Orbell, 2003), the framework has also been applied to describe coping and psychological distress in multiple other studies including older adults with chronic conditions, including but not limited to: Alzheimer's dementia, chronic fatigue syndrome, diabetes, HIV, irritable bowel syndrome, osteoarthritis, psoriasis, and rheumatoid arthritis.

Relation to MCI. In a grounded theory study (Lingler et al., 2006), authors compared their results describing the process of making sense of a diagnosis of MCI to the Common Sense Model. Authors concluded that their findings were similar to the Common Sense Model in that assigning meaning to the diagnosis of MCI stems from the older adult's cognitive and emotional illness representations of MCI. However, the study did not evaluate the outcomes of created illness representations (coping strategies, illness outcomes, and psychological distress).

Lin and colleagues (2012) set out to describe the illness representations of MCI and evaluate the illness representations for their relationships to demographic variables and health history. Lin and Heidrich (2012) then took the application of the Common Sense Model one step further, focusing on evaluating illness representations *and* their impact on participant coping with MCI. Both studies included older adults with any subtype of MCI; however, neither study reported the distribution of subjects with aMCI versus naMCI, making it difficult to decipher if the results truly reflect both subtypes. Findings from the studies demonstrated support for the Common Sense Model, yet authors note that the directions of associations between illness representations differs from some previous studies with other chronic illnesses. For example, emotional representations of MCI varied greatly between individuals with many subjects having few to moderate MCI symptoms and positive beliefs about MCI, unlike emotional representations of other illnesses. This finding demonstrates a limitation of the Common Sense Model for MCI in that older adults' illness representations of MCI are unique from illness representations of other chronic illnesses.

Limitations of theory for this study. Aside from differences in the relationships of the Common Sense Model for older adults with MCI compared to those with other chronic illnesses, the main limitation of the Common Sense Model is the exclusion of uncertainty. If one is uncertain about the themes that comprise the illness representation, how does that affect coping and emotional distress? Uncertainty could be perceived as contributive to the model, affecting both the cognitive and emotional illness representations. Accounting for uncertainty in the common sense model may help with understanding the uniqueness of coping and illness representations with MCI.

Uncertainty in Illness. Mishel's (1988, 1990) theory of Uncertainty in Illness is perhaps the most well-known and widely used mid-range nursing theory related to the experience of uncertainty (Barron, 2000; Mast, 1995; Neville, 2003). The theory is not focused on one age-group or population but can be split into uncertainty as it applies in acute illness (Mishel, 1988, 1990, 1997) versus chronic illness (Mishel, 1990, 1999) situations. The overall purpose of the theory is to help explain how persons with acute or chronic illnesses cognitively process and construct meaning of their illness-related stimuli (Mishel, 1990). A graphic model of this theory is presented by Figure 11.

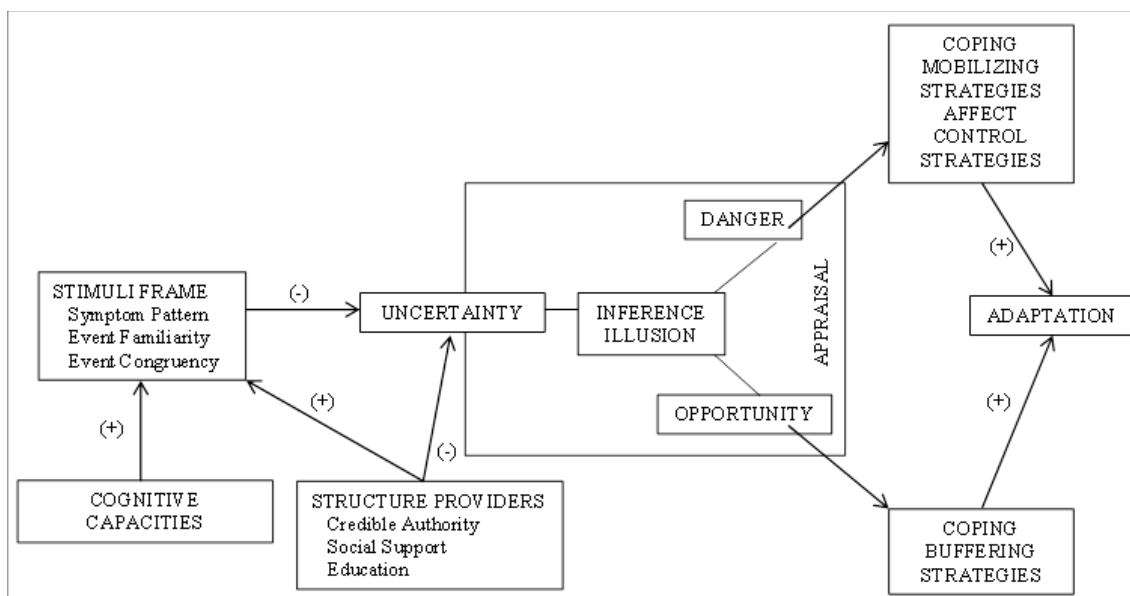


Figure 11. Mishel's model of perceived uncertainty in illness (Barron, 2000; Mishel, 1988, 1990; Neville, 2003).

In the theory, uncertainty is defined as the emotional state that occurs when a person is unable to assign definite value to events or objects and/or is unable to predict an outcome (Mishel, 1983). Within chronic illness, it is expected that uncertainty is not static but instead subject to change over time (Mishel, 1990). Additionally, with chronic illness, uncertainty is seen as something that happens slowly over time, rather than starting with one acute event (Mishel, 1999). Causes of uncertainty in chronic illness are not fully explicated by the model (Figure 5), but are multifactorial and include: the nature of illness (severity, erratic symptoms, and ambiguous symptoms), inability to predict the future, concept of self, insufficient information, social support, health providers, and personality disposition (Mishel, 1999).

Similar to appraisal for coping in the framework by Lazarus and Folkman (1984), uncertainty is perceived as a neutral state until it is appraised by one of two processes to

determine its value (demonstrated in Figure 5): inference and illusion (Mishel, 1990). It could be argued that uncertainty is not neutral but always negative and should be avoided or minimized whenever possible (Sheer & Cline, 1995). Yet, the view of uncertainty as neutral until appraised has been supported by other authors (Hilton, 1994), and highlighted in a concept analysis of uncertainty in illness by McCormick (2002).

Inference and illusion can be affected by the person, family, friends, and health care professionals, and with chronic illness are also subject to change over time (Mishel, 1990; Padilla, Mishel, & Grant, 1992). Inference is the evaluation of uncertainty as either a positive (opportunity) or negative (danger) state (Mishel, 1990). Illusion is the construction of beliefs in the event of a situation with a negative trajectory, which allows for uncertainty to be perceived as a potentially positive outcome (Mishel, 1990). If uncertainty is appraised as a danger, coping strategies are employed to reduce the presence of uncertainty. Similarly, if uncertainty is appraised as an opportunity, coping strategies are employed to maintain rather than reduce uncertainty (Mishel, 1990). In either event, if the coping strategies are successful, and uncertainty is reduced or maintained as desired, adaptation is said to occur (Mishel, 1990).

Previous uses and populations. The theory of Uncertainty in Illness has not been used in research involving older adults with MCI. However, the theory has been used with older adults that have other chronic conditions to guide the evaluation of levels of uncertainty, determine the effects of uncertainty, and guide development and evaluation of interventions to decrease uncertainty. These conditions include but are not limited to: atrial fibrillation (Kang, 2006; Kang, 2011), chronic hepatitis C (Bailey et al., 2010), fibromyalgia (Anema, Johnson, Zeller, Fogg, & Zetterlund, 2009; Reich et al.;

2006), human immunodeficiency virus (Brashers et al., 2003), Parkinson's disease (Sanders-Dewey et al., 2001), diabetes mellitus (Landis, 1996), rheumatoid arthritis (Landis, 1996), and multiple types of cancer (Clayton, Mishel, & Belyea, 2006; Kazer, Bailey, Sanda, Colbery, & Kelly, 2011; Lien, Lin, Kuo, & Chen, 2009; Padilla et al., 1992; Sammarco & Konecny, 2010; Wallace, 2005). It is important to note that all of the aforementioned conditions may involve the presence of physical pain or other outwardly obvious physical symptoms (i.e. shortness of breath, palpitations, etc.), whereas MCI is a condition that does not result in physical pain or involve outwardly obvious physical symptoms. In addition, many of the aforementioned conditions involve a downward trajectory with no chance of a return to normal functioning or stagnation, as may be seen with MCI.

Relation to MCI. The progression of uncertainty in chronic illness proposed by Mishel (1990, 1999) is similar to the theorized progression of MCI, where symptoms of cognitive impairment do not necessarily start with an acute event but rather are slowly progressive over time. As previously noted in chapter one, MCI is also a chronic condition, like many other chronic illnesses, where symptoms, disease trajectory, and treatment options can be extremely ambiguous and potentially resulting in uncertainty alike the causes of uncertainty noted by Mishel (1999). Additionally, in her reconceptualization of the theory of Uncertainty in Illness, Mishel notes that “when the alternative is negative certainty, uncertainty becomes a preferable state” (Mishel, 1990, 258). This anecdote is apparent in a qualitative study of the experiences of older adults with MCI where subjects noted being happy with the diagnosis of MCI as it is not the diagnosis of dementia (Lingler et al., 2006). In this manner, while being diagnosed with

MCI created uncertainty, older adults were able to use illusion to see this uncertainty as an opportunity rather than danger because it was perceived as certainty the diagnosis was not dementia.

Limitations of theory for this study. There are two main limitations of the Uncertainty in Illness theory for this study: (1) fit of the theory with study variables, and (2) theory assumptions. The Uncertainty in Illness theory would be a good fit for directing this study if the presence of uncertainty and its relationship to coping and psychological distress in older adults with MCI rather than the relationship of uncertainty, coping, and psychological distress as interrelated consequences of MCI was the only concern. While the theory of Uncertainty in Illness is useful to explain how an older adult might experience or respond to uncertainty, it does not account for the antecedents or consequences that may be unique to having a diagnosis of MCI. As noted by Figure 5, cognitive capacities are accounted for and might impact the older adult's stimulus frame, but do not serve as the stimulus frame. What does this mean for the older adult whose symptom pattern in the stimulus frame is from their cognitive capacities rather than affected by it? In other words, what is uncertainty for the older adult whose source of uncertainty might be their cognitive capacity rather than a more traditional chronic illness symptom such as pain?

In addition, Mishel's model assumes some level of awareness to be able to appraise uncertainty. Older adults with MCI may lack awareness of their cognitive impairment(s) (Tremont & Alosco, 2011), thus potentially lacking the awareness needed to be able to appraise uncertainty. Also, if there is no awareness of the stimulus frame, i.e. a lack of awareness resulting in an inability to recognize the symptom pattern, event

familiarity or congruence, it is entirely possible that there is no stimulus to produce uncertainty other than the stimulus provided by the introduction of being diagnosed with MCI. This later becomes a problem for other variables in this study as the model only accounts for coping and potentially psychological distress (from a lack of adaptation) resulting from the appraisal of uncertainty.

Grounded Theory and MCI

There have been a few recent attempts to establish theories pertaining to MCI which purported using grounded theory methodology from Corbin and Strauss (1990, 1998), and/or Glaser and Strauss (1967). These three qualitative studies (Banningh et al., 2008; Beard & Neary, 2012; Lingler et al., 2006) provide insight into how older adults experience, make sense of, or cope with their MCI diagnosis. Results of the studies highlighted coping with MCI as a reaction to both the attributes of MCI (cognitive impairment) and consequences from MCI (i.e. coping with negative emotions) (Banningh et al., 2008; Beard & Neary, 2012). Older adults with MCI also demonstrate a wide range of emotions (positive, negative, and neutral) in response to their diagnosis and symptoms (Banningh et al., 2008; Lingler et al., 2006); however, they may not identify with or fully understand their diagnosis (Beard & Neary, 2012; Lingler et al., 2006). Finally, rather than a clear conceptual framework for MCI, these three studies only provide themes to describe how older adults make sense of their diagnosis and cope with MCI. The only study that relates their findings to a framework (the Common Sense Model) was Lingler and colleagues (2006). In addition, all of the studies had small sample sizes (< 20 subjects), and two of the studies excluded older adults with naMCI (Banningh et al., 2008; Beard & Neary, 2012). Although the studies do not provide clear

conceptual frameworks and have sample limitations, they provide rich description of concepts central to the MCI experience and were influential on the development of a conceptual framework for MCI.

Sjostedt's conceptualization of MCI

The lack of a specific theoretical framework related to MCI and the limitations of existing alternative frameworks related to chronic illnesses necessitate a new conceptualization of MCI to provide support for research and the development of interventions specific for older adults with MCI. Sjostedt's new conceptualization of MCI encompasses both subtypes. In this model, MCI is defined as an unstable limbo weighted by heterogeneity between older adults' normal and abnormal continuums (normal aging versus dementia) rather than being solely linked to cognitive functioning. Older adults with MCI teeter between these continuums, and can eventually progress to dementia or revert back to normal functioning. Figure 12 demonstrates the complexity of this conceptualization with its accompanying antecedents and consequences. In Figure 12, the antecedents for MCI are highlighted in green, the attributes highlighted in blue, and the consequences highlighted in purple.

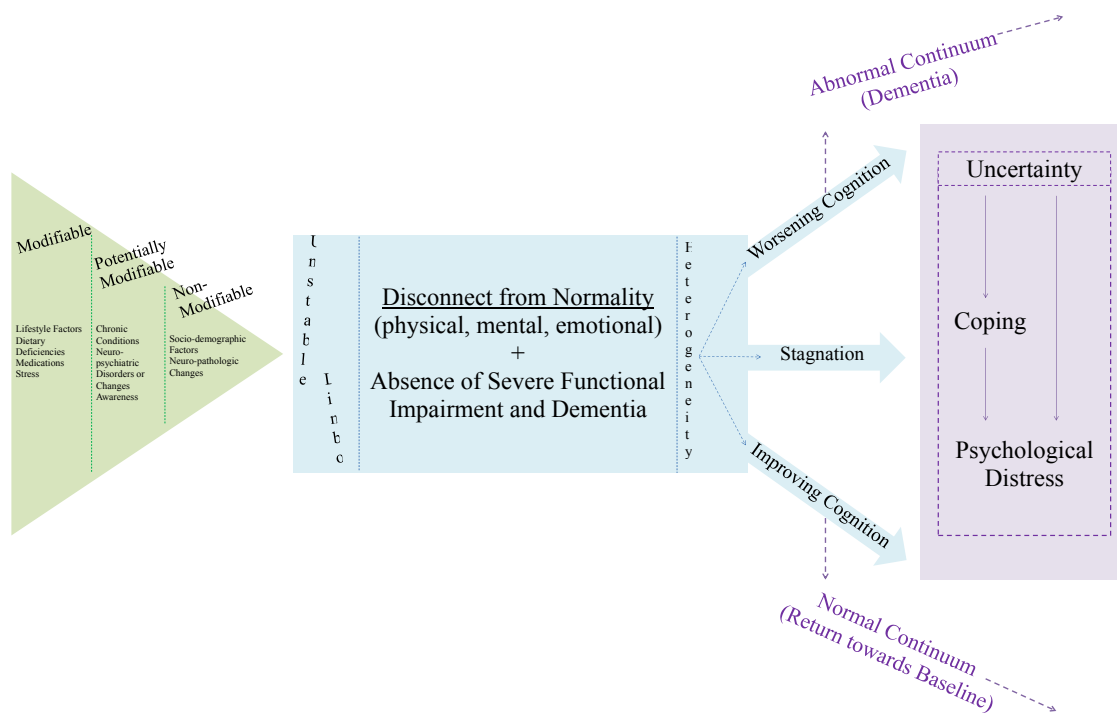


Figure 12. The Sjostedt framework for MCI.

It is important to understand that the model is pliable, subject to change over time and condition progression. As the unstable limbo implies, an older adult does not simply get MCI at one point and then it goes away or always stays at that point. Additionally, some antecedents, i.e. other chronic conditions, are subject to change over time which may result in changes related to MCI. The theoretical framework is presented in detail below, starting with the antecedents.

Antecedents. The antecedents for MCI are numerous—there is insufficient evidence to suggest which antecedents might have more of an influence than the others on the development or progression of MCI. Many of the reviewed studies assessed the correlation of antecedents to MCI rather than predictive values of antecedents for MCI. Hence the antecedents all may contribute in some way to MCI, but it is unclear how much of the variance in MCI can be explained by each antecedent. MCI’s antecedents

can be categorized into those that are modifiable, potentially-modifiable, or non-modifiable.

Modifiable. Modifiable antecedents were identified as lifestyle factors, dietary deficiencies, medications, and stress. With lifestyle factors and dietary deficiencies, increased levels of physical exercise and some dietary modifications or supplements to correct deficiencies have been shown to decrease symptoms of cognitive impairment associated with MCI (Lake, 2006; Rosenberg et al., 2006). Physical exercise in mid-life significantly reduces the risk of MCI later in life (Geda et al., 2010). Similarly, related to exercise, obesity has been correlated with increased cognitive impairment (Farr et al., 2008). Finally, dietary modifications such as strict adherence to the Mediterranean Diet and supplements such as vitamins D and E to correct dietary deficiencies have been correlated with lower incidences of MCI (Lake, 2006; Plassman, Williams, Burke, Holsinger, & Benjamin, 2010; Rosenberg et al., 2006; Scarmeas et al., 2009).

Previous studies have demonstrated a relationship between MCI and “vascular risk factors” such as midlife elevated serum cholesterol and blood pressure (Kivipelto et al., 2001), but the relationship is not consistent (Plassman et al., 2010). Smoking is one factor contributing to vascular risk that has been demonstrated to be predictive of cognitive impairment within sizable populations, and place older adults at increased risk for developing MCI (Cervilla, Prince, & Mann, 2000; Durazzo, Meyerhoff, & Nixon, 2010; Plassman et al., 2010). Another lifestyle factor, alcohol consumption, has also been demonstrated to potentially contribute to the progression or lack of progression with MCI (Anttila et al., 2004; Solfrizzi et al., 2007); but this result has been inconsistent (Plassman et al., 2010).

Similar to lifestyle factors and dietary deficiencies, regular medications and illicit or recreational drugs are also potential risk for MCI (Hurria et al., 2007; Rogers, Wiese, Rabheru, 2008; Shilling, Jenkins, & Trapala, 2006). NSAIDs and gonadal steroids have been shown to possibly decrease risk of developing MCI, whereas other medications such as statins and antihypertensives have no association or no consistent association with MCI (Plassman et al., 2010). In addition, cognitive impairment related to medications can be temporary, in which case an older adult may be inappropriately diagnosed with MCI or it may be inappropriately determined that the older adult has progressed completely from MCI to dementia. For instance, chemotherapy has been shown to increase cognitive impairment, known as “chemo brain” or “chemo fog,” but is oftentimes temporary (Hurria et al., 2007; Shilling et al., 2006).

Finally, stress is also a modifiable antecedent for MCI as it can be manifested as impaired attention which may contribute to the symptoms of MCI (Chertkow, 2002; Norlund et al., 2005). Stress reduction has been demonstrated to contribute to decreased MCI symptoms (Troyer, Murphy, Anderson, Moscovitch, & Craik; 2008). Stress may be present in many different forms, stemming from any aspect of an older adult’s life (i.e. accepting a new job, moving, or death of a loved one). However, stress can also result from the fear of cognitive impairment, likely associated with the stigmas surrounding the diagnosis of dementia (Corner & Bond, 2004).

Potentially-modifiable. Potentially-modifiable antecedents were identified as other chronic conditions, neuropsychiatric disorders or changes, and a lack of awareness of deficits. Neuropsychiatric disorders such as depression can potentially be reversible causes of MCI, where once treated, the older adult could return to normal cognition

(Rosenberg et al., 2006). Yet, depression in particular, has been linked to increased risk for MCI development (Plassman et al., 2010). There are also other chronic conditions which, while not necessarily reversible, may be controllable such as hypertension, diabetes, sleep apnea, schizophrenia, and other vascular diseases (DeCarli, 2003; Frisoni et al., 2000; Gauthier & Touchon, 2005; Keefe et al., 2005). Finally, a lack of awareness does not cause MCI, but it is seen as a precursor symptom to it, influencing how quickly an older adult seeks treatment for MCI. Awareness could be the realization that the older adult has become lost in a familiar place, personality changes, change in senses (such as olfactory changes) or has decreases in usual activities (Blieszner et al., 2007; Chung & Man, 2009; Devanand et al., 2000; Roberts et al., 2009). Increasing awareness of changes in cognition could lead to earlier identification of MCI and impact consequences related to MCI.

Non-modifiable. Finally, the non-modifiable antecedents could be categorized into sociodemographic factors and neuropathologic changes. Sociodemographic factors include but are not limited to educational level, age, race/ethnicity, and gender (Chertkow, 2002; Plassman et al., 2010). Neuropathologic changes could potentially be the result of Alzheimer's dementia or other insults such as strokes and as such are non-modifiable (DeCarli, 2003; Petersen et al., 2006; Visser, 2006).

Attributes. The first attribute of MCI is an "unstable limbo." The majority of articles refer to MCI in relation to dementia as a "transitional" state between normal aging and abnormal aging (dementia), an incipient stage to dementia or a pre-dementia stage. Many sources indicate that older adults with MCI are destined to have dementia (Anstey et al., 2008; Banningh et al., 2008; Blieszner et al., 2007; Carpenter et al., 2008;

Chertkow, 2002; Costa et al., 2010; DeCarli, 2003; Devanand et al., 2000; Diniz et al., 2009; Ellison, 2008; Ellison, Harper, Berlow, & Zeranski, 2008; Fisk & Rockwood, 2005; Frisoni et al., 2000; Gauthier & Touchon, 2005; Lee et al., 2009; Lingler et al., 2006; Matthews et al., 2007; Mattsson et al., 2009; Meyer, Xu, Thornby, Chowdhury, & Quach, 2002; Narasimhalu, et al., 2009; Norlund et al., 2005; Paulsen & Duff, 2009; Petersen, 2003; Petersen et al., 2006; Portet et al., 2006; Ready, Ott, & Grace, 2004; Roach, 2005; Roberts et al., 2009; Rosenberg et al., 2006; Solfrizzi et al., 2007; Tuokko & Hultsch, 2006; Visser, 2006; Visser, Scheltens, & Verhey, 2005; Werner & Korczyn, 2008). Yet, it is inaccurate to strictly refer to MCI as a “transitional” or other similar state, as it implies only one possible outcome. As previously stated, MCI is not always progressive; in many cases it can be stagnant or even revert back to “normal” cognition. In this way, MCI is better seen as an unstable limbo which is capable but not necessarily probable of tipping towards a normal or abnormal continuum but also possible to be stagnating. Through viewing MCI as an unstable limbo rather than something definitively progressive it is possible to reach new interventions; shifting the focus from the prevention of dementia back to treatment of MCI.

The second attribute is a disconnection from normality resulting from physical, mental, and emotional changes. This could be with regard to memory (Banningh et al., 2008; Chertkow, 2002; Chung & Man, 2009; Diniz et al., 2009; Ellison et al., 2008; Fisk & Rockwood, 2005; Gauthier & Touchon, 2005; Hurria et al., 2007; Matthews et al., 2007; Narasimhalu, et al., 2009; Petersen, 2003; Petersen et al., 2006; Portet et al., 2006; Rosenberg et al., 2006; Roberts et al., 2009; Shilling et al., 2006; Tuokko & Hultsch, 2006; Visser, 2006; Werheid et al., 2010), other functions of cognitive ability such as

intelligence (Byrne, Smith, and Backman, 1987; DeCarli, 2003), or expectations for how the older adult “should” be, such as how one should age (Banning et al., 2008; Blieszner et al., 2007). Acquiring subjects in memory clinics has led to increased emphasis on the memory disconnection as diagnostic criteria for MCI (Costa et al., 2010; Garand et al., 2005; Devanand et al., 2000; Diniz et al., 2009; Ellison et al., 2008; Gauthier & Touchon, 2005; Mattsson et al., 2009; Visser et al., 2005; Werheid et al., 2010). Opening the conceptualization to include other types of disconnect from normality highlights the need for MCI identification within primary care—outside of memory clinics. However, for the purposes of this study with the need to obtain a large sample of older adults diagnosed with MCI, the focus of MCI will be on the mental disconnect from normality, which will be assessed through subject performance on cognitive testing.

The third attribute is an absence of severe functional impairment and dementia which is determined by clinical judgment (Banning et al., 2008; Chertkow, 2002; Diniz et al., 2009; Ellison et al., 2008; Gauthier & Touchon, 2005; Lee et al., 2009; Matthews et al., 2007; Mattsson et al., 2009; Meyer et al., 2002; Petersen, 2003; Petersen et al., 2006; Rosenberg et al., 2006; Tuokko & Hultsch, 2006; Visser, 2006). The absence of severe functional impairment and dementia is evident through the presence of intact “normal” activities of daily living. Although intact, some studies have demonstrated minor impairments in “normal” activity areas of older adults with MCI such as geographical orientation, speed, and multitasking (Banning et al., 2008; Costa et al., 2010; Visser, 2006); but, the impairments were not “severe.”

The last attribute is heterogeneity, which results in the varied trajectory of the older adult with MCI to worsening cognition, stagnation, or improving cognition. Among

older adults, MCI is recognized as having several different forms with a wide variety of associated symptoms such as the differences mentioned between aMCI and naMCI, but also where one older adult may have multiple impaired cognitive domains whereas others may have only one (Anstey et al., 2008; Ellison et al., 2008; Fisk & Rockwood, 2005; Gauthier & Touchon, 2005; Lingler et al., 2006; Matthews et al., 2007; Norlund et al., 2005; Petersen, 2003; Petersen et al., 2006; Portet et al., 2006; Roach, 2005; Roberts et al., 2009; Rosenberg et al., 2006; Tuokko & Hultsch, 2006). Contributing to heterogeneity is the relationship of MCI to dementia, where some older adults with MCI progress to dementia (worsening cognition), others stay always with MCI (stagnation), and others still improve back towards normal cognitive functioning (improving cognition) (Anstey et al., 2005; Banningh et al., 2008; Blieszner et al., 2007; Chertkow, 2002; Costa et al., 2010; DeCarli, 2003; Diniz et al., 2009; Fisk & Rockwood, 2005; Frisoni et al., 2000; Garand, Dew, Eazor, DeKosky, & Reynolds, 2005; Gauthier et al., 2006; Gauthier & Touchon, 2005; Lingler et al., 2006; Narasimhalu, et al., 2009; Petersen et al., 2006; Portet et al., 2006; Roach, 2005; Roberts et al., 2009; Tuokko & Hultsch, 2006; Visser et al., 2005; Werner & Korczyn, 2008; Zaudig, 1992). There is the potential that the variability in MCI symptoms created by heterogeneity can also lead to a lack of information or misdiagnosis, such as an erroneous diagnosis of dementia, in turn causing increased stress for the patient and family (Banningh et al., 2008).

Some would argue that heterogeneity results in a need to treat each type of MCI on a case by case basis as opposed to treating all types the same (Gauthier & Touchon, 2005). For example, it is possible that older adults with aMCI versus those with naMCI may experience the consequences of MCI in different ways, given that those with aMCI

are more likely to lack an awareness of their deficits (Tremont & Alosco, 2011). However, there is opposition to this idea who believe that if treatment works for one type of MCI it might work for all types (Roach, 2005). Current recommendations for nursing care are consistent with this later view and do not vary based on MCI subtype (Lin et al., 2012).

Consequences. In the Sjostedt model, the main consequence of MCI is uncertainty, which leads to the other consequences of coping and psychological distress. Yet, it is important to note that most of the evidence to support the consequences of MCI comes from qualitative or limited descriptive studies. Therefore at this time, it cannot fully be determined how the trajectory of MCI (worsening cognition, stagnation, or improving cognition) impacts the consequences of MCI. In the model it is assumed that the trajectory does not cause the consequences of MCI to differ (aside from the progression towards a normal or abnormal continuum); that all older adults with MCI will experience (in some way) the consequences of uncertainty, coping, and psychological distress. In the future, longitudinal studies will be needed to determine the impact of the trajectory on the consequences of MCI.

Uncertainty. MCI is often referred to as an uncertain condition within attempts to both conceptualize and define it (Portet et al., 2006; Werner & Korczyn, 2008). The attribute of heterogeneity results directly in uncertainty stemming from ambiguity, confusion, and variability, impacting all of the consequences of MCI and leading to differing opinions on diagnosis and selections of MCI populations (Anstey et al., 2008; Banning et al., 2008; Blieszner et al., 2007; Chertkow, 2002; DeCarli, 2003; Frisoni et al., 2000; Gauthier & Touchon, 2005; Lee et al., 2009; Mattsson et al., 2009; Norlund et

al., 2005; Paulsen & Duff, 2009; Tuokko & Hultsch, 2006; Visser, 2006; Werner & Korczyn, 2008). Uncertainty can influence how older adults respond to illnesses, treatments, and hospitalizations (Landis, 1996). Yet, uncertainty is not a phenomenon unique to MCI. In general, uncertainty is said to occur when a person is unable to assign definite value to events or objects and/or is unable to predict an outcome (Mishel, 1983). Within any illness, uncertainty can stem from a lack of clarity regarding symptoms, treatment options, disease etiology, and/or disease prognosis (Mishel, 1983; Mishel, 1988).

Qualitative studies about the experiences of living with MCI have provided further evidence supporting the presence of uncertainty in MCI. Findings indicated that uncertainty can greatly affect an older adult's ability to define and relate to MCI (Banningh et al., 2008; Blieszner et al., 2007; Lingler et al., 2006; Lu et al., 2007). In addition, uncertainty about the nature of MCI was frequently identified, related to symptoms of MCI being dismissed as normal ageing or dementia (Banningh et al., 2008; Dean & Wilcock, 2010; Lu et al., 2007).

Nurses, physicians, and other practitioners can directly contribute to the presence of uncertainty with MCI through variance in practice and dissemination of information about MCI (Derksen, Graff, Visser, Vermooij-Dassen, & Rikkert, 2009). One study found inconsistencies from participant report in the frequency of clinicians informing them of their prognosis and likely condition trajectory (Derksen et al., 2009). Such variance with resulting uncertainty can cause unjustified stress or anxiety for older adults with MCI.

Coping. It is proposed that coping will result from MCI, similar to the result of coping with other chronic illnesses, but that coping may also result from or be shaped by uncertainty. Within Mishel's model of perceived uncertainty in illness, coping results from either the danger or opportunity appraised from uncertainty (Mishel, 1988), suggesting that coping might also result from or be shaped by the uncertainty resulting from MCI. Uncertainty could affect a older adult's ability to define and relate to MCI, thus impairing their ability to cope with it (Banningh et al., 2008; Blieszner et al., 2007; Lingler et al., 2006; Lu et al., 2007). An example would be avoidance oriented coping through attempts to improve memory performance, avoidance of activities to avoid making mistakes or masking of deficits (Banningh et al., 2008). Another result could be potential role and identity shifting, such as avoidance of independence (Blieszner et al., 2007).

Coping has been evaluated quantitatively in two studies involving older adults with MCI (Lin & Heidrich, 2012; McIlvane et al., 2008). Using the Brief COPE, findings from both studies indicated that older adults with MCI use significantly more emotion-focused coping and problem-focused coping strategies in comparison to dysfunctional coping strategies to manage with their MCI. Emotion-focused coping strategies included positive reframing and seeking emotional support; problem focused strategies included seeking out information or treatments; and dysfunctional strategies included substance use, self-blame or behavioral disengagement (McIlvane et al., 2008). Lin and Heidrich (2012) also found positive correlations between months since MCI diagnosis and problem-focused coping ($r = 0.31, p = 0.034$) and dysfunctional coping (r

= 0.64, $p < 0.001$). However, neither study evaluated the relationship between measured cognitive impairment or other demographic variables and coping strategies.

Psychological distress. Psychological distress is the final consequence of MCI in the Sjostedt framework and is influenced by uncertainty and coping. Psychological distress was commonly identified through reactions such as anger towards self or family members, sadness, loss of or low self-confidence or self-worth, loneliness, rejection, inactivity, shame, self-blame, helplessness or loss of control and exacerbation of existing relational problems (Banningh et al., 2008; Blieszner et al., 2007; Carpenter et al., 2008; Ellison et al., 2008; Pessin et al., 2003; Petersen, 2003; Rosenberg et al., 2006). These reactions are sometimes coupled with hypersensitive concerns of becoming a burden to others, needing to abandon complex activities, or becoming overly aware to how others react to the diagnosis (Banningh et al., 2008). Such responses can lead to increased hostility within the family system, future-oriented worry, or impede rational decision making (Pessin et al., 2003).

Although previous studies have not evaluated the relationships between psychological distress, uncertainty, and coping in older adults with MCI, these relationships have been examined in older adults with other types of chronic illness and lend support to the hypotheses proposed in the Sjostedt framework. Psychological distress has been demonstrated to be significantly and positively correlated with subjects' levels of uncertainty and coping strategies with other chronic illnesses such as fibromyalgia, diabetes mellitus, cancer, and multiple sclerosis (Anema et al., 2009; Landis, 1996; Lien et al., 2009; Lynch et al., 2001; Mullins et al., 2011; Reich et al., 2006). These relationships remained significant when controlled for subjects'

educational levels (Lynch et al, 2001). Among individuals with Parkinson's disease, one study reported no significant relationship between psychological distress and uncertainty; but a significant relationship between psychological distress and uncertainty for the caregivers of those individuals (Sanders-Dewey et al., 2001). Yet it has also been demonstrated that the relationship between uncertainty and psychological distress is affected by whether or not the uncertainty is appraised as a danger or opportunity. Kang (2006) demonstrated a significant negative relationship in patients with atrial fibrillation between uncertainty being appraised as an opportunity and depression; and, a significant positive relationship between uncertainty being appraised as a danger and depression.

Assumptions of the study

This study assumes that MCI is a diagnosable, and valid chronic condition that does not cause physical pain or result in death. As a chronic condition it is expected that the relationships demonstrated between psychological distress, uncertainty, and coping in older adults with MCI may be similar to what has already been demonstrated in other chronic conditions (Anema et al., 2009; Landis, 1996; Lien et al., 2009; Lynch et al, 2001; Mullins et al., 2011; Reich et al., 2006). Finally, consistent with current suggestions for care, this study also assumes that while the subtypes of MCI may be fundamentally different, nursing care related to MCI will not vary based on subtype (Lin et al., 2012).

Summary

The current status of knowledge about MCI indicates diagnostic criteria clearly delineate the attributes of MCI. However, a specific theoretical framework that addresses

the relationships of antecedents and consequences of MCI, in particular the relationships among uncertainty, coping, and psychological distress, is nonexistent. In addition, frameworks pertaining to other chronic illnesses are limited in their applicability to older adults with MCI as they do not account for the varying illness trajectory of MCI or impact of MCI on appraisal of their situation. A framework that addresses the relationships of antecedents and consequences of MCI is imperative to improve the care of older adults with MCI through the development of effective nursing interventions. This study will be foundational in quantitatively evaluating select components of the Sjostedt framework with the goal of providing a theoretical base for effective interventions and evidence-based practice specific to older adults with MCI.

III. RESEARCH DESIGN AND METHODS

This quantitative study used a descriptive correlational design. Data were collected using one-time in-person interviews. The advantages of this study's design are the ability to demonstrate relationships among variables in the model, reduce dropout rate related to single point data collection, and decrease missing data that might occur with other survey methodologies (Polit & Beck, 2008). The limitations of this study's design are the inability to track participant changes over time, and the inability to identify causal relationships among the variables (Polit & Beck, 2008).

Subjects and setting

Subjects. A convenience sample of 91 older adults from an outpatient neurology clinic comprised the sample. Subjects were included if they were over 54 years of age, had been given a diagnosis of MCI (either aMCI or naMCI) by their attending physician based on neuropsychological testing, and could understand, speak and write in English. Participants were excluded if they did not meet the above inclusion criteria, if their physician suspected that other neuropsychiatric disorders or chronic conditions might be complicating their diagnosis of MCI, or if they progressed from MCI to dementia.

Sample size. Analyses for aim 1 necessitate the largest sample, hence aim 1 was used to guide the sample size estimation. Sample size was initially estimated using a method from Cohen & Cohen (1983):

Effect size (f^2) = $R^2 / (1 - R^2)$ was calculated assuming a potential small squared multiple correlation (R^2) of 0.13

$$f^2 = 0.13 / (1 - 0.13) = 0.15 \text{ (medium effect size)}$$

L determined from tables in Cohen & Cohen (1983), assuming a maximum of 12 variables (given the number of instrument subscales) and $\alpha = 0.05$ for a power of 0.80

$$\text{Estimated sample size } (n^*) = L / f^2 + k \text{ (number of variables) } + 1$$

$$n^* = 17.34 / 0.15 + 12 + 1 = 128.6$$

In short, it was initially estimated that a sample of 129 older adults would yield a power of 0.80 at $\alpha = 0.05$. From experience in a previous study, it was estimated that the neurology clinic on Thursdays would see an average 3 older adults per week with MCI. From the clinic load, the resulting duration to achieve the desired sample size was estimated to be 43 weeks. Unfortunately, sample accrual did not occur as quickly for the main dissertation study as it was predicted from a previous study at the clinic. After 25% of the initial sample was collected ($n=33$), preliminary analysis was performed to assess the variables predicted for aim 1. It was determined from this analysis that the variables related to MCI type, duration, and level of cognitive impairment were not strongly related to the other main variables of uncertainty, coping, and psychological distress and should not be included in the analysis for aim 1. By removing those variables from the model, the sample size needed was recalculated. It was determined that only 91 people would be needed to yield a power of 0.80 at $\alpha = 0.05$.

Sampling procedure. Participant recruitment occurred over the course of 62 consecutive weeks (excluding federal-holidays or other weeks such as physician vacation when the clinic was not operational) starting immediately after IRB approval. Potential participants were identified prior to their scheduled appointment in the neurology clinic by clinic staff. After completing their scheduled appointment with their physician, all

potential participants were invited to participate and instructed to contact Jennifer Sjostedt, RN, GNP-BC if they had an interest in participating in the study.

If the potential subject expressed interest, Sjostedt discussed the study in detail with them and (when present) their family caregiver(s). After discussion of the study details, if the potential subject was willing to participate and met inclusion criteria, the informed consent process immediately followed. Data collection then began after written consent was obtained.

Setting. The sample for the study was recruited from a clinic in the area that specializes in the diagnosis of MCI (the Memory Disorders Clinic at Froedtert Hospital / Medical College of Wisconsin). The Memory Disorder Clinic (MDC) was chosen for its volume of patients with MCI. A preliminary cognitive screening instrument study by Sjostedt and Dr. Malgorzata Franczak at the MDC was able to recruit on average 3 subjects per week after a < 10% refusal rate (total of 49 subjects in 4.5 months) with a relatively equal amount of aMCI or naMCI diagnoses. The clinic is part of an academic facility focused on research located in Milwaukee, WI and serves Milwaukee, Waukesha, Ozaukee, Kenosha and Racine counties in Wisconsin. Between 30% to 75% of clinic's target population (dependent by county) are considered to be members of minority populations (Froedtert Hospital, 2011). It is expected that study participants from the clinic reside mainly in a diverse, urban, mid-western area of the United States, and the results of this study may not be applicable to other populations (such as those in rural communities).

Instruments

All instruments in this study were selected to be consistent with the conceptual definitions of the variables, and their reliability and validity (see summary of psychometrics and expected data in table 1). Instruments to assess the study variables by order of administration were: Montreal Cognitive Assessment (level of cognitive impairment from MCI), a Demographic Survey, Uncertainty Stress Scale (uncertainty), Brief COPE (coping), and Kellner Symptom Questionnaire (psychological distress). The demographic survey measured time since initial MCI diagnosis in months and years, and select antecedents which could potentially have an effect on uncertainty, coping, and psychological distress: subject gender, age, race/ethnicity, educational level, marital status, religious affiliation, and socioeconomic status. The demographic survey was administered as part of the in person interview; however, time since initial MCI diagnosis was obtained from the participant's electronic medical record by Sjostedt after completing the in person interview.

Table 2. Theoretical constructs, instruments, and reliability by order of administration.

Theoretical Construct	Instrument	Scale	α^*	Expected Data
Cognitive Impairment	Montreal Cognitive Assessment (MoCA)	11 items 0-30 points	0.83	Scale Level
Select MCI Antecedents	Demographic Survey	10 items N/A points	Not Available	Nominal and Ordinal Level
Uncertainty	Uncertainty Stress Scale (USS)	59 items 0-397 points	0.92-0.96	Scale Level
Coping	Brief COPE	28 items 0-84 points	0.50-0.90	Scale Level
Psychological Distress	Symptom Questionnaire (SQ)	92 items 0-92 points	0.76-0.95	Scale Level

*MoCA (Nasreddine et al., 2005), USS (Agretelis, 1999; Barron, 2000; Ford, 1989), Brief COPE (Carver, 1997; Lin & Heidrich, 2012; McIlvane et al., 2008), SQ (Bull, Luo, & Maruyama, 1994; Williams, 1993)

Montreal Cognitive Assessment (MoCA). MCI was operationalized by the level of cognitive impairment determined using the MoCA (Nasreddine, 2011). The MoCA was developed to be sensitive enough to detect subtle changes in cognition associated with MCI, easy to use/interpret, and could be administered within a short time

frame (Nasreddine et al., 2005). Outside of testing within memory clinics, the MoCA has been used to test for MCI in populations ranging from persons with subacute stroke or transient ischemic attacks (Dong et al., 2010; Pendlebury, Cuthbertson, Welch, Mehta, & Rothwell, 2010), to those with other cardiovascular diseases (McLennan, Mathias, Brennan, & Steward, 2011) or Parkinson's disease (Chou et al., 2010; Hoops et al., 2009; Nazem et al., 2009).

The initial instrument was tested with a sample of 46 patients with either MCI or AD and 46 healthy controls. After testing, the instrument was revised to the "final" version and retested with a larger sample of 94 older adults with MCI, 93 older adults with AD, and 90 health controls (Nasreddine et al., 2005). It does not appear that the final version of the MoCA was revised beyond the initial report revisions.

The first version of the MoCA assessed 10 different cognitive domains, but was later limited to 8 domains (11-items, 30-points) after it was concluded that 5 items did not discriminate well between MCI, dementia, and healthy controls (Nasreddine et al., 2005). The 8 domains included in the final version include: Short term memory, visuospatial abilities, executive functioning, attention, concentration, working memory, language, and orientation. The final version of the MoCA was first validated in both English and French (in Canada), and is now available in over 31 different languages (Nasreddine, 2011; Nasreddine et al., 2005); a copy of the English version and scoring instructions are included in the appendix.

Psychometrics. The sensitivity and specificity of the MoCA for identifying MCI with a cut-off score of 26 was reported as 90% and 87% respectively (Nasreddine et al., 2005), which has since been closely replicated in other studies (Smith, Gildeh, &

Holmes, 2007). Item analysis demonstrated differences between participants with dementia versus those with MCI and normal cognition; supporting the MoCA's ability to detect slight differences in cognition. Specifically, participants with dementia performed more poorly than those with MCI (and those with MCI more poorly than participants with normal cognition) on items assessing visuospatial abilities, executive functioning, short-term memory, and orientation (Nasreddine et al., 2005).

The resulting positive and negative predictive values for MCI with the MoCA were 89% and 91% respectively (Nasreddine et al., 2005). In a comparison between a widely used tool for dementia screening (the Mini-Mental State Exam, MMSE) and MoCA with a sample of 93 participants with MCI, 73% of participants scored within the "abnormal" range (<26 points) on the MoCA but in the normal range (≥ 26 points) on the MMSE (Nasreddine et al., 2005). A similar trend was found in other samples of people who had either an acute stroke, transient ischemic attacks or Parkinson's disease, where 32% to 58% of the subjects who had normal MMSE scores scored within the abnormal range on the MoCA (Dong et al., 2010; Nazem et al., 2009; Pendlebury et al., 2010). In addition to supporting the MoCA for identifying MCI, these results highlight the limitations of the MMSE for differentiating between MCI and normal cognition.

The MoCA appears to have good internal consistency, with a Cronbach's alpha of 0.83 (Nasreddine et al., 2005). Similar Cronbach's alpha levels ranging from 0.74 to 0.83 have also been reported for the Japanese and Arabic language translations of the MoCA (Fujiwara et al., 2010; Rahman & El Gaafary, 2009). Test-retest reliability also has been demonstrated with a small sample (15 older adults with MCI and 20 health controls), finding no significant differences in how either group scored on the MoCA between

initial testing and a 1-month follow up with the same test (Ahmed, de Jager, & Wilcock, 2012).

Construct validity of the MoCA was not reported by the instrument authors (Nasreddine et al., 2005). Only one study presented a factor analysis of the MoCA, and the results were unclear and difficult to interpret (Berstein, Lacritz, Barlow, Weiner, & DeFina, 2011). Despite the lack of factor analysis, several other studies have supported the face validity of the MoCA (Chou et al., 2010; Dong et al., 2010; Hoops et al., 2009; McLennan et al., 2011; Nazem et al., 2009; Smith et al., 2007); likely related to the high aforementioned predictive validity (sensitivity and specificity of the instrument for detecting MCI). The high sensitivity and specificity of the MoCA demonstrates its ability to correctly identify and rule-out MCI (to measure what it was made to measure); adequately providing evidence for its clinical validity.

Limitations. Authors reported that the initial instrument development was based on the “clinical intuition” of their initial study’s main author (Nasreddine et al., 2005). Given the lack of clarity or framework with MCI conceptualization, diagnosis, and language; clinical intuition might not have been the most appropriate initial method of development. In addition, low Cronbach’s alpha (0.55) was reported for the MoCA when used in a sample from a cardiac and diabetic/endocrine outpatient clinic in Australia; suggesting that it may be inappropriate to use the MoCA with that population (McLennan et al., 2011). Another study also reported lower standardized coefficient alphas ranging from 0.66 to 0.77 for the MoCA, after calculating a MoCA score for participants from other existing data from population or volunteer samples of health older adults or those with known or suspected brain pathology (Bernstein et al., 2011); although the alpha

levels could potentially be related to data collection methods. In addition, many other studies that have used the MoCA did not report reliability statistics (Dong et al., 2010; Hoops et al., 2009; Nazem et al., 2009; Pendlebury et al., 2010; Smith et al., 2007). Consequently, the lower alpha levels and lack of reliability statistics support the need for further in-depth evaluations of the reliability of the MoCA.

Uncertainty Stress Scale (USS). The USS was chosen to measure uncertainty from MCI as it does not contain items on uncertainty related to physical pain. The USS was developed based on a prior mixed methods study by Hilton using the community version of Mishel's Uncertainty in Illness Scale (MUIS) and qualitative interviews (Hilton, 1994). The USS was created to meet the needs specified within the qualitative interviews that were not addressed in the MUIS; specifically the USS measures uncertainty in illness-related situations and the stress, threat, or positive feelings generated by uncertainty. The USS has not been used in research involving older adults with MCI or any other type of cognitive impairment. However, the USS lends itself to research in uncertainty with MCI as it does not focus on uncertainty related to physical pain.

The USS can be separated into 2 sub-scales, one focused on uncertainty and the other focused on stress from uncertainty. Both scales were used in this study. The USS contains 54 items where subjects are asked to rate on a 0 to 4 (none to very high) or N/A Likert-scale their level of uncertainty related to a statement such as "I am uncertain whether changes in my mild cognitive impairment (MCI) will be detected early." After rating their uncertainty, the subject then rates their stress from that uncertainty on a 0 to 2 (none or very low to high or very high). After the 54 items, there are 4 additional items

that ask the subject to place an X on a line indicating their overall uncertainty, overall stress related to uncertainty, overall threat related to uncertainty, and overall positive feelings from uncertainty. There is also one yes/no question asking subjects if they have any positive feelings from their uncertainty. Higher numbers on the scale equate to higher levels of uncertainty and/or stress.

Psychometrics. Hilton's 1994 article discussed in detail the narrowing down of the USS to its current fourth version. Unfortunately, the only reported measure of internal consistency in Hilton (1994) comes from one of the previous iterations of the USS in Ford (1989), where the Cronbach's alpha was reported as acceptable, 0.92 for the total scale. The most recent version of the USS, used in this study, has been reported as having acceptable internal consistency of 0.95 on the uncertainty subscale and 0.97 on the stress subscale (Agretelis, 1999; A. Hilton, personal communication, October 15, 2012).

Limitations. The biggest limitations are the lack of published support for use of the USS and lack of studies involving older adults with MCI and the USS. The USS was originally designed for use in persons with cancer but has been adapted to fit other populations. The USS in this study was reworded with permission from the author (A. Hilton, personal communication, October 15, 2012) using the published cancer USS (Hilton, 1994), where MCI replaced the word cancer. This study may help to validate use of the USS in condition, such as MCI, where other uncertainty measures may be inappropriate because physical pain and medications or treatments resulting from the condition are near to non-existent.

Brief COPE. The Brief COPE is the only measure of coping that has been used in older adults with MCI. It is also shorter than other available instruments to measure coping, which will help to prevent test fatigue from the multiple instruments in this study. The Brief COPE contains 28 items which assess fourteen coping reactions (with two items for each for each reaction): active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, self-distraction, denial, venting, substance use, behavioral disengagement, and self-blame (Carver, 1997). The fourteen coping reactions can be reduced into three sub-scales of coping: (1) emotion-focused coping (acceptance, emotional support, positive reframing, religion, and humor), (2) problem-focused coping (active coping, planning, instrumental support), and (3) dysfunctional coping (self-distraction, venting, self-blame, behavioral disengagement, denial, and substance use) (McIlvane et al., 2008). Initially, items on the Brief COPE were scored on a 0-3 scale where 0 = I haven't been doing this at all and 3 = I've been doing this a lot (Carver, 1997). However, a 4-point scale where 1 = I haven't been doing this at all and 4 = I've been doing this a lot has also been used (McIlvane et al., 2008).

For this study, subjects were asked to complete the entirety of the Brief COPE by responding to the following with regard to each of the items: "The next set of questions asks you about ways that you have coped with your cognitive impairment over the past month. In the past month, how often have you done the following things to cope with your cognitive impairment?" Each item will then be graded by the subject on the aforementioned 3-point scale. The rationale for using the 3-point scale rather than alternative 4-point scale is to allow the study results to be comparable to recent research involving coping in older adults with MCI, where the 3-point scale was used (Lin &

Heidrich, 2012). With the Brief COPE both grading scales have demonstrated acceptable internal consistency, which is discussed below.

Psychometrics. The current version of the Brief COPE (Carver, 1997) resulted from a factor analysis and item reduction from the original COPE inventory by Carver et al. (1989). Carver (1997) demonstrated acceptable internal consistency with the Brief COPE in a convenience sample of 168 participants from a community affected by a hurricane. Cronbach's alpha was reported for each of the fourteen coping reactions (Carver, 1997) and ranged from 0.50 (venting) to 0.90 (substance use).

For older adults with MCI, McIlvane et al. (2008) found acceptable internal consistencies on the sub-scale measures of the Brief COPE: 0.80 (emotion-focused coping), 0.88 (problem-focused coping), and 0.62 (dysfunctional coping). Authors also reported reliability statistics for their comparison group of care partners for older adults with MCI, which also demonstrated acceptable internal consistencies: 0.84 (emotion-focused coping), 0.88 (problem focused coping), and 0.81 (dysfunctional coping). Another study of older adults with MCI (Lin & Heidrich, 2012) also found acceptable internal consistency on the sub-scales: 0.77 (emotion-focused coping), 0.88 (problem-focused coping), and 0.73 (dysfunctional coping). However, neither pre nor post power analyses were reported in either of the studies. Consequently, it is possible that the demonstrated Cronbach's alphas are related to the smaller sample sizes in McIlvane et al. 2008 ($n = 46$ older adults with MCI and 29 care partners) and Lin and Heidrich 2012 ($n = 63$ older adults with MCI).

Limitations. Only two studies have been published where the Brief COPE was used in older adults with MCI, and both studies used differing grading criteria for the

scale items. While this study will help to further validate the use of the Brief COPE with a larger sample of older adults with MCI using the original grading criteria, it is also considered a limitation. Another limitation is the instrument's ability to assess coping at one point in time rather than over time. To assess coping with MCI over time an additional study will need to be conducted which longitudinally evaluates coping.

Symptom Questionnaire (SQ). Kellner's (1987) SQ has been widely used since its initial publication to operationalize psychological distress in older adults. The SQ has not been used in research involving older adults with MCI; however, the SQ is brief and contains simple to follow yes/no or true/false items (Kellner, 1987). The SQ was used in its entirety in this study. The SQ was developed from the Symptom-Rating Test (SRT) (Kellner & Sheffield, 1973) to evaluate psychological distress. Unlike the questions on the SRT, the SQ contains brief items to which subjects respond yes/no or true/false. The items on the SQ were developed based on a review of literature on neuropsychological symptoms in normal controls and psychiatric patients, followed by statements selected from interview between investigators and neurotic patients or those with personality disorders (Kellner, 1987).

The SQ consists of 92 dichotomous items of which 68 items indicate symptoms of psychological distress and 24 items are antonyms indicating psychological well-being (Kellner, 1987). The items can be separated into four main subscales of depression, anxiety, anger-hostility, and somatic. These four subscales can then further be divided into symptom (depressive symptoms, anxiety symptoms, anger-hostility symptoms, or somatic symptoms) or wellbeing (contented, relaxed, friendly, somatic well-being) subscales for a total of eight possible subscales. For the symptom subscales, the items

are all either yes/no or true/false and scored as 0 = no or false, and 1 = yes or true with a maximum score of 17, with higher scores indicating more distress. On the well-being subscales, the items are reverse coded (0 = yes or true, and 1 = no or false) with a maximum score of 6, and again with higher scores indicating more distress.

Psychometrics. Criterion-related validity was established through using the SQ to differentiate between normal controls or people receiving treatment for their psychiatric condition to those with untreated psychiatric conditions, and through correlating the SQ scales to other existing instruments such as the Hopkins Symptom Checklist and the Hamilton Rating Scale for Depression (Kellner, 1987). Reliability of the SQ was demonstrated by Kellner (1987) using test-retest reliability, where after 2 weeks the split-half reliability of change in each scale for persons who were anxious and depressed ($n = 22$) was +0.92 (anxiety), +0.94 (depression), +0.91 anger-hostility, and +0.86 (somatic). Kellner (1987) also reported the conventional split-half reliability of the scales in other studies to be: +0.75 to +0.95 (anxiety), +0.74 to +0.93 (depression), +0.78 to +0.95 (anger-hostility), and +0.57 to +0.84 (somatic). Cronbach's alpha for the four main scales and total scale with adults were not reported by Kellner (1987) but has been reported elsewhere and found to be sufficient: ranging between 0.83-0.95 for depression, 0.76-0.92 for anxiety, 0.91-0.93 for anger-hostility, 0.90-0.92 for somatic, and 0.80 for the total scale (Bull, 2011; Bull et al., 1994; Lewis et al., 2009; Williams, 1993).

Limitations. Alike the instrument for uncertainty, the SQ has not been used in older adults with MCI. It is possible that the psychometrics of the SQ may be different in older adults with MCI compared to normal older adults. In addition, despite the simplicity of the instrument, it is a lengthy instrument and survey fatigue may be a factor

when giving this instrument last. This will be limited by providing subjects with breaks in between instruments, and frequently reminding subjects that they may stop the study at any point.

Procedure

Data collection. Sjostedt completed the Collaborative Institutional Training Initiative (CITI) program, institutional offered Health Insurance Portability and Accountability Act (HIPAA) training, and National Institute of Health (NIH) protecting human research participants training prior to beginning the study. Data were collected in person by Sjostedt as described within the above section on sampling procedure. Date of diagnosis of MCI was obtained from the participant's electronic medical record by Sjostedt after completing the in person interview. Data and consent forms was recorded using paper and pen. Caregivers when available were present during the informed consent process and study at the request of the participant. After informed consent, subjects completed the MoCA followed in order by the (1) demographic questionnaire, (2) USS, (3) Brief COPE, and (4) SQ.

As part of a normal clinic appointment, subjects received the Addenbrooke's Cognitive Exam revised (ACE-R). Consequently, only portions of the MoCA which are not repetitive of those in the ACE-R were completed for the study, and the subjects were asked for permission to obtain the results of the ACE-R from their clinic record. Repetitive sections in the MoCA that were excluded and instead obtained from the ACE-R include: cube copy, clock draw, serial 7's, and orientation (date, month, year, day, place, and city). When the ACE-R was not completed during the subjects' appointment, the MoCA was given in its entirety.

The responses were transferred into a password-protected electronic data file by Sjostedt and original papers filed in a locked file-box for the remainder of the study (after which time they will be shredded). Other than signatures required on the consent form, all remaining forms and electronic copies were assigned an arbitrary number to help protect subject confidentiality. This data management procedure is described in detail below.

Data management and analysis

Data management. Data were abstracted by Sjostedt directly from completed paper records of the participant interview into an Excel spreadsheet on an encrypted 4 Gb flash-drive dedicated solely to the research project. After paper records were entered into the electronic system, they were kept in a locked file-box until they can be destroyed. The Excel spread sheet had cell-parameters set to help minimize data entry errors; as data were entered, numbers which are outside of the cell parameters or are potentially outliers were highlighted and researcher prompted to recheck the data. Collected data did not include any participant-identifying information; subsequently, there will be no way to link collected data back to individual participants in the final data-set. In addition, all Microsoft Word and Excel files were assigned an additional password (different from that of the flash-drive) to provide further protection against any loss of confidentiality. After collection was completed, responses were entered into an Excel file and subsequently imported into SPSS for analysis. All paper data and consent forms will be destroyed after 3 years, and unidentifiable electronic files will be kept indefinitely.

Expected data. Aside from the demographic questionnaire, responses from each instrument were summed to result in scale level data as follows: (MoCA) the sum of

correct responses on the MoCA, (USS) the sum of item responses on the subscales of uncertainty and stress, (Brief COPE) the sum of item responses on the subscales of emotion-focused coping, problem-focused coping, and dysfunctional coping, and (SQ) the sum of item responses for each of the subscales: depression, anxiety, anger/hostility, and somatic.

Analysis. Data analysis was performed using SPSS statistical software. All data were assessed for frequencies, mean, median, mode, outliers (scatter plots), skewness and kurtosis. Prior to conducting data analysis to meet the study aims, differences related to demographic variables (i.e. gender) on the other variables of level of cognitive impairment from MCI, subtypes of MCI, time since initial diagnosis with MCI, uncertainty, coping, and psychological distress were examined using one-way analysis of variance or χ^2 tests as appropriate. Any differences related to demographic variables were considered as possible confounding variables within the remaining analyses to meet study aims. Below is a detailed description of the specific statistical analyses that were conducted to assess each study aim:

Aim 1 with related hypotheses. Test select components of a conceptual framework for MCI by examining the relationships among uncertainty, coping, psychological distress, time since MCI diagnosis, level of cognitive impairment from MCI, and (if determined appropriate in the analyses for aims 3 and 4) subtypes of MCI. Hypotheses 1 through 6 dictate the expected relationships within the Sjostedt framework, as demonstrated by Figure 2 in Chapter 1. Structural equation modeling (SEM) was considered as potential method for evaluating the fit of variables within the framework. However, SEM is unlikely to demonstrate the unique contributions of each of the

subscales, which is especially important when evaluating the variable of coping. Instead, to evaluate this aim and the associated hypotheses predicting relationships within the conceptual framework, multivariate hierarchical regression analyses were used with each psychological distress subscale as a separate dependent variable, and the scales associated with uncertainty (first block) and coping (second block) as the independent variables. The variables of time since diagnosis, level of cognitive impairment from MCI, and subtype of MCI were also considered as potential independent variables in the regression analyses predicting psychological distress. However, preliminary analyses demonstrated a lack of significant relationships between the outcome variables and time since diagnosis, level of cognitive impairment from MCI, and subtype of MCI. Given the lack of significant relationships, and concerns related to the speed of sample accrual, the variables of time since diagnosis, level of cognitive impairment from MCI, and subtype of MCI were excluded from the final regression analyses.

It was suspected that coping might act as either a moderating or mediating variable between uncertainty and psychological distress (anxiety, anger/hostility, depression, and somatic symptoms). An example of these potential relationships is demonstrated by figure 13:

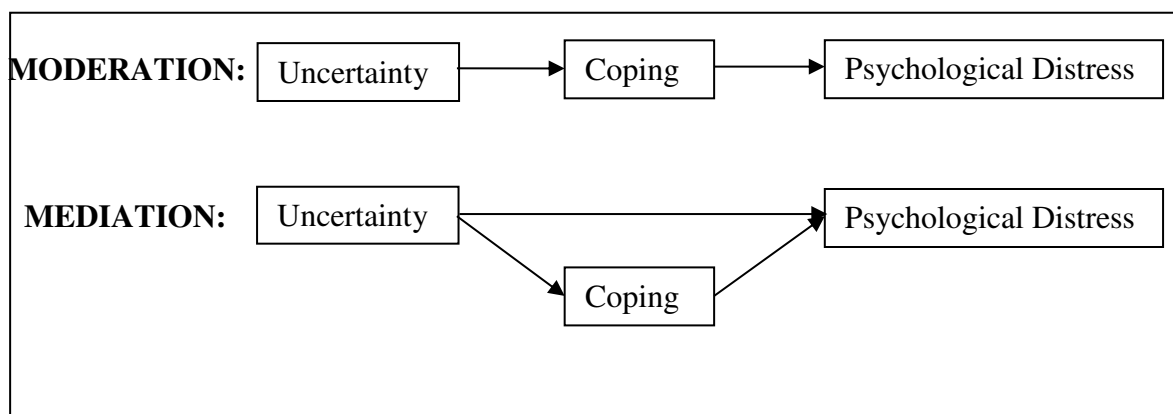


Figure 13. Moderation vs. mediation of coping between uncertainty and psychological distress.

Barron and Kenny's (1986) approach for assessing moderation/mediation was followed to determine if the relationships between uncertainty and psychological distress are moderated or mediated by coping.

Aim 2. Describe the levels of uncertainty, coping, and psychological distress in older adults with MCI. This aim was addressed by calculating response frequencies, means, and descriptive statistics. Following assessment of variable frequencies, outliers (scatter plots), skewness and kurtosis, reliability statistics were conducted for each of the instrument sub-scales and whole scales.

Aim 3. Examine the differences in scores on uncertainty, coping, and psychological distress between the subtypes of MCI. This aim was addressed by calculating *t*-tests or one way analysis of variance to evaluate the differences between group means (subtypes of MCI) on time since diagnosis, uncertainty, coping, and psychological distress.

Aim 4 with related hypothesis. Examine the strength and direction of relationships between scores on uncertainty, coping, and psychological distress within the subtypes of MCI. This aim was addressed by calculating Pearson's r or Spearman's ρ as determined appropriate by the scatter plots calculated in aim 2 to investigate the relationships between scores on uncertainty, coping, and psychological distress and the subtypes of MCI. It was hypothesized that there will be no significant differences between the subtypes of MCI in the strength and direction of uncertainty, coping, and psychological distress.

Limitations

The limitations of this study are (1) recruitment from one academic-focused clinic in the Midwest; (2) cross-sectional design; and (3) instrument limitations. Recruiting subjects from one academic-focused clinic in the Midwest and cross-sectional design limits generalizability of results. To address these concerns, further research is needed with other populations within different care settings and areas of the US or other countries. Specific to cross-sectional limitations, longitudinal studies will be needed to evaluate if the study variables change over time. Finally, two instruments have not been used in older adults with MCI (USS, SQ). It is possible that the psychometrics may be different in older adults with MCI compared to older adults with other chronic illnesses. Consequently, while this study may support the use of these instruments in older adults with MCI, future studies will still be needed to support the psychometrics demonstrated in this study.

Treatment of human subjects

IRB approval was obtained from Froedtert Hospital / Medical College of Wisconsin (FH/MCW) and Marquette University (MU) prior to the start of the study. Both the IRB at FH/MCW and MU provided approval for the study, including coordinated IRB form(s). Participants had the right to refuse participation, stop or withdraw from the study at any point. Decisional ability of the participants was assessed by their physician prior to consent (Simpson, 2010), and caregivers or other family members were requested to be present with the participant if available during the consent process to protect the rights of the participants. The caregivers and family members were not invited to participate in the interview of the participant unless the participant specifically requested that their caregiver or family member remain present for their comfort. The benefits to participants for being in the study included potential emotional benefits from discussing their experience, societal benefits from potential improvements in care designed based on the information that they provide, and compensation with a \$10 grocery store (Pick-n-Save) gift-card.

The risks posed to the participants included the potential for coercion, increased stress, fatigue, or distress from the lengthy interview process or interview content, and the potential loss of confidentiality. To prevent coercion, participants were recruited with the aid of a flier and only a researcher not affiliated with the clinic discussed the study, performed consent, and interviewed the participants. Additionally, to prevent potential coercion from caregivers or family members, participants were asked again prior to the start of the interview if they wished to proceed with the study and reminded of their right to refuse participation and their right for their caregiver or family not to know of their

refusal to participate. If participants decided to stop participating after consent, caregivers or family members who were present at the consent were simply informed (only if the researcher was asked) that it was decided that the participant was ineligible for the study and nothing more. Participants were also reminded that staff at the clinic would not be notified of their decision to participate in the study or not. To prevent increased stress, fatigue, or distress, subjects were reminded periodically that they could end the interview at any point and the researcher would end the interview if the participant appeared to become upset. Finally, to address the potential loss of confidentiality, several protection measures were in place including the use of numerical identification rather than participant names on study papers, and password-protections on files and hardware.

Vulnerable population. Older adults with either subset of MCI are considered to be vulnerable, and at risk for coercion or mistreatment directly relating to their level of impaired cognition, regardless of if the impairment is related to their memory. It is important to clarify that cognition does not simply refer to one's general knowledge or IQ, and is not a stagnant process. Instead, cognition can broadly be defined as the skill to organize thought and action towards obtaining goals (Miller & Wallis, 2009). To be able to organize thought and action, abilities such as memory and judgment are needed. These abilities are considered necessary for obtaining informed consent and subject to change over time. Vulnerability related to impaired cognition is an important ethical concern for clinicians, researchers, and institutional review boards, necessitating special protections for involving older adults with MCI in research.

The ethical concerns of research participant vulnerability and issues related to informed consent from impaired cognition are not new concepts. Informed consent processes and concerns in clinic and research settings for older adults with dementia have been well explored (Simpson, 2010). However, the level of cognitive impairment seen with dementia is greater than that with MCI (Petersen, 2003). Extra precautions or cognitive testing taken for determining informed consent in older adults with dementia may be inappropriate or excessive for older adults with MCI. Extra precautions or testing could potentially result in a loss or violation of dignity or autonomy, confusion, or emotional distress (Krohne, Slettebø, & Bergland, 2011). For researchers and clinicians, inappropriate or excessive testing could also translate to increased time and expenses, decreased retention or recruitment rates, or even impact study results through subjecting participants to multiple tools or procedures.

In order to provide informed consent, a person must be able to demonstrate a relatively high level of competence to ensure that their decision meets the ethical requirements for informed consent. These requirements for informed consent are that the decision is fully informed, voluntary, and given by a decisional person (Jefferson et al., 2008; Mittal et al., 2007). With MCI, competence appears to be most affected in varying degrees by deficits in abilities pertaining to memory, executive functioning, and information processing (Jefferson et al., 2008; Okonkwo et al., 2007; Okonkwo et al., 2008). Despite these deficits, MCI does not appear to greatly impact an older adult's ability to express choice.

Similar to determining the presence of MCI, the line at which someone determines a person's competence or capacity to give informed consent is not straight

and clear cut (Grebe, 2008; Simpson, 2010). Including family members or significant others on the informed consent process could be considered a loss of the participant's autonomy and a breach of confidentiality. Given the potential risks of coercion or loss of autonomy or confidentiality, potential participants were recruited using a flier and asked if they would like their caregiver present for the informed consent process and/or study. In addition, all possible efforts were made to maintain participant confidentiality through de-identifying and coding of the participant data.

Time frame

Months 1 - 11: Participant recruitment and data collection. Additional time included in the estimate to account for potential problems with participant recruitment/retention. Also during this time, the first manuscript (comparing the MoCA to ACE-R) was prepared for publication.

Months 9 – 15: Continued and finalized participant recruitment and data collection, performed preliminary data analysis and started drafting of the second manuscript (study results).

Months 15 – 16: Submission of first and second manuscript for publication and public dissertation defense.

IV. MANUSCRIPT 1: A COMPARISON OF THE MONTREAL COGNITIVE
ASSESSMENT TO THE REVISED ADDENBROOKE COGNITIVE EXAMINATION
FOR THE SCREENING OF MILD COGNITIVE IMPAIRMENT

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Abstract

Currently there is not a gold standard of screening for mild cognitive impairment (MCI). The purpose of this study was to compare two cognitive screening tools for persons with MCI: the Montreal Cognitive Assessment (MoCA) and revised Addenbrooke Cognitive Exam (ACE-R).

The sample consisted of 50 older adults (>54 years old) diagnosed with MCI, who, following a routine clinic appointment were administered the ACE-R and portions of the MoCA not included on the ACE-R.

As expected, Pearson's r indicated significant correlations between the instrument total scores ($r=0.80$, $p < 0.001$). A majority of the instrument subscales indicated a high degree of correlation, except the abstraction, fluency/naming, and language subscales. Gender and diagnosis differences were identified with both instruments.

These findings suggest using the MoCA for cognitive screening in primary care settings may be more sensitive for MCI with fewer items than and a high degree of consistency with the ACE-R.

Mild cognitive impairment (MCI) is becoming an increasing concern as a potential pre-dementia condition, making it a new target for early diagnosis and interventions to maintain quality of life through slowing or preventing the progression to dementia. From major population-based studies, the recently reported average prevalence of MCI in older adults is 18.9% (Petersen et al., 2014). MCI is generally diagnosed starting around the age 60 years and is defined as functional impairment affecting mental processes, such as memory or executive functioning, that is more than what is expected for normal aging and often precedes dementia (Petersen, 2003; Petersen, 2011). Diagnostically MCI can further be broken down into two subsets: Amnesic versus non-amnesic MCI (Petersen, 2011). The main difference between these subsets is the presence of memory impairment (amnesic or aMCI) or lack of significant memory impairment (non-amnesic or naMCI). However, despite fundamental differences between aMCI and naMCI, there is a significant lack of evidence for screening or treating one subset differently from the other (Lin, Vance, Gleason, & Heidrich, 2012).

In general, the diagnosis of MCI typically starts with the patients' or family members' observation of changes in the individual's cognition such as forgetting things or trouble with job performance (Albert et al., 2011; Petersen, 2011; Portet et al., 2006). These observations are accompanied by declines in cognitive functioning greater than 1.5 standard deviations of what is normally expected for age on a brief cognitive screening instrument. A variety of instruments that assess cognitive functioning are commonly administered in a primary care setting to indicate if further cognitive functioning testing is warranted. Further testing beyond the primary care setting consists of comprehensive

neuropsychological testing in combination with the health practitioner's assessment to assign the diagnosis of MCI (Smith & Bondi, 2013).

Presently there is no gold-standard instrument for screening for MCI in primary care settings. Historically, the majority of instruments used to screen for MCI were originally developed to screen for dementia and not the more subtle cognitive changes that accompany MCI (Smith & Bondi, 2013). Many of these screening instruments for dementia lack sensitivity and are unable to detect signs of MCI. Thus, persons with MCI are likely to be incorrectly screened as normal rather than MCI using such instruments. For example, Nasreddine and colleagues have demonstrated that the Mini-Mental State Examination [MMSE] can accurately identify dementia but is less specific in identifying MCI (Nasreddine et al., 2005). This has led to the creation of a number of instruments designed to detect MCI. Such instruments include but are not limited to the Montreal Cognitive Assessment [MoCA] (Nasreddine et al., 2005) and Addenbrooke's Cognitive Exam revised [ACE-R] (Mioshi, Dawson, Mitchell, Arnold, & Hodges, 2006). The MoCA and ACE-R have some similar items to the MMSE but have more items which test higher levels of cognitive functioning such as abstraction, language, and fluency. Thus, a need exists to identify an instrument that accurately detects MCI in the primary care setting.

Purpose

The purpose of this study was to compare two commonly used instruments for the screening of MCI in older adults (MoCA and the ACE-R), in order to provide evidence for which instrument might be more appropriate for use in a primary care setting. This purpose will be addressed through evaluating 3 research questions:

1. What is the internal consistency and correlation of total and subscale scores between the MoCA and ACE-R in a sample of older adults with MCI?
2. To what degree do the MoCA and ACE-R accurately identify older adults with MCI?
3. Are there any differences or relationships in total and subscale scores on the MoCA and ACE-R by demographic variables such as age, gender, and diagnosis subtype: aMCI vs. naMCI?

Methods

This cross-sectional study recruited a convenience sample of 50 older adults diagnosed with MCI from an out-patient neurology clinic at an academic medical center over a 5 month period while they attended routine follow-up appointments. Informed consent was obtained from all subjects and their care-partners as part of this institutional review board-approved study. Subjects were included in this study if they were over the age of 54 years old, had a diagnosis of MCI supported by neuropsychological testing and neurologist assessment, and could speak/write in English. Subjects were excluded if they did not meet the above inclusion criteria or if their neurologist documented in the patient record that a neuropsychiatric disorder(s) might be complicating their diagnosis of MCI.

As part of their clinical care, all subjects completed the ACE-R during their scheduled clinic appointment. Following the appointment, subjects were invited to participate by clinic staff and the study PI performed informed consent then administered a brief demographic questionnaire followed by the MoCA excluding portions which were repetitive of items in the ACE-R (which were then rescored from the ACE-R for a total

MoCA score). The items which were excluded from the MoCA included: (1) Cube copy, (2) clock draw, (3) serial 7's, and (4) orientation (date, month, year, etc.).

Instruments

Montreal Cognitive Assessment (MoCA). The MoCA was first presented in 2003 as one of the few available instruments specifically developed to screen for MCI (Nasreddine, 2011; Nasreddine et al., 2005). The target population for the MoCA is patients who present with “mild” cognitive complaints who might perform within the normal range on the MMSE (Nasreddine et al., 2005). The first draft of the MoCA assessed 10 different cognitive domains, but was later limited to 8 domains (11-items, 30-points) after it was concluded that 5 items did not discriminate well between MCI, dementia, and healthy controls (Nasreddine et al., 2005). The 8 domains addressed in the final version include: Short term memory, visuospatial abilities, executive functioning, attention, concentration, working memory, language, and orientation. Lower scores indicate higher levels of cognitive impairment. The MoCA exhibits acceptable internal consistency (Cronbach's alpha = .83) (Nasreddine et al., 2005).

Addenbrooke's Cognitive Assessment, revised edition (ACE-R). Unlike the MoCA, the ACE-R was not developed to screen solely for MCI but instead to screen for the early stages of dementia (including MCI) and differentiate between the many subtypes of dementia (Mioshi et al., 2006). The ACE-R contains 26 item components (over double the number of items on the MoCA) which can be combined to produce 5 subscales and produce the total score out of 100 points: (1) Attention/Orientation (18 points), (2) Memory (26 points), (3) Fluency (14 points), (4) Language (26 points), and (5) Visuospatial (16 points) (Mioshi et al., 2006). Again, lower scores equate to higher

levels of cognitive impairment. Similar to the MoCA, the ACE-R exhibits acceptable internal consistency (Cronbach's $\alpha = .80$) (Mioshi et al., 2006).

Data analyses

Data analyses were performed using SPSS statistical software. To describe participants in the study, frequencies and group differences on baseline demographics were examined using one-way analysis of variance or χ^2 tests where applicable. For research question one, total and subscale ranges were calculated for both instruments. In addition, bivariate correlations were calculated between the total and subscale scores on the two instruments. Cronbach's alpha was used to assess the internal consistency of both instruments. Research question two was addressed by comparing the percentage of participants identified as exhibiting normal cognition (false negative) rather than MCI in both instruments. The threshold score for MCI was previously identified by the instrument authors as 88 for the total ACE-R and 26 for the total MoCA score. Finally, for research question three, group differences between scores with regard to demographic variables (gender, and diagnosis) were assessed using *t*-tests and the relationship between scores and age was evaluated using bivariate correlation.

Results

A total of 50 people were recruited for the study with an average age of 75.88 ($SD=7.80$). The sample was largely Caucasian (98.0%) and highly educated with at least 98.0% having some college education. The sample included a similar number of males and females with either an aMCI (males $n=18$, females $n=10$) or naMCI (males $n=14$, females $n=8$) diagnoses ($\chi^2(1)=0.002, p=0.96$). There was also no significant difference

($t(48)=1.01, p=0.32$) in the mean age of participants by gender (male mean age=76.72, females mean age=74.39). However, there was a significant difference in mean age by diagnosis ($t(48)=2.56, p=0.01$) with aMCI subjects being older (mean age=78.25) than those with naMCI (mean age=72.86). 54.0% of subjects had their MCI diagnosis for less than one year, and there were no significant differences in the length of diagnosis by gender ($\chi^2(5)=4.73, p=0.45$) or diagnosis ($\chi^2(5)=3.60, p=0.61$).

Research question 1: What is the internal consistency and correlation of total and subscale scores between the MoCA and ACE-R in a sample of older adults with MCI?

Score distributions on the ACE-R and MoCA appear in table 1. As expected, the mean total score for both scales indicated the sample exhibited MCI with mean scores less than the threshold scores 88 (ACE-R) and 26 (MoCA). Internal consistency of both instruments was somewhat lower than expected ($\alpha \sim 0.60$), which may be related to sample homogeneity (Bernardi, 1994). For research question one, bivariate correlations were assessed on the total scales and subscale scores of the MoCA and ACE-R (table 2).

While the total scores of the ACE-R and MoCA were significantly positively correlated ($r=0.80, p<0.001$), the instrument subscales did not all positively correlate. Specifically, the abstraction and language subscales from the MoCA did not correlate with any of the ACE-R subscales.

Research question 2: To what degree do the MoCA and ACE-R accurately identify older adults with MCI?

For research question two, scores on the ACE-R and MoCA were examined using cut off scores of 88 (ACE-R) and 26 (MoCA) to determine the percentage of subjects who screened positive for cognitive impairment (figure 1). Of the 50 subjects, 20% ($n =$

10) screened within normal range on either one (MoCA $n=2$, ACE-R $n=5$) or both instruments ($n=3$). Of those, 90% were male, and 100% were college educated. The resulting sensitivity was 90.00% for the MoCA and 84.00% for the ACE-R. Specificity was not calculated as the study only included older adults with a diagnosis of MCI.

Research question 3: Are there any differences or relationships in total and subscale scores on the MoCA and ACE-R by demographic variables such as age, gender, and subtype of MCI?

Finally, to address research question three, total and subscale scores on the ACE-R and MoCA were compared by subject gender, MCI subtype, and age. The bivariate correlation indicated there was no significant relationship between scores and age. However, the t -tests demonstrated significant group differences in scores by MCI subtype and diagnosis (table 3). Males scored significantly higher than females on both instruments (indicating less impairment). Males scored significantly better than females ($p=0.003-0.04$) on the visuospatial ($MD=1.99$) and memory ($MD=2.43$) subscales of the ACE-R and the visuospatial ($MD=1.00$) and attention ($MD=0.83$) subscales of the MoCA. In addition, subjects with aMCI scored significantly lower than those with naMCI on both instruments (indicating more impairment). Subjects with aMCI scored lower than those with naMCI ($p=0.004-0.04$) on the attention/orientation ($MD=-0.76$) and memory ($MD=-2.67$) subscales of the ACE-R, and the orientation ($MD=-0.21$) and abstraction ($MD=-0.63$) subscales of the MoCA.

Discussion

The purpose of the study was to compare two commonly used instruments for the screening of MCI in older adults (MoCA and the ACE-R), in order to provide evidence

for which instrument might be more appropriate for use in a primary care setting. The results indicated that the ACE-R and MoCA are highly correlated (with the exception of a few subscales) with both instruments exhibiting a high degree of sensitivity for detecting MCI in older adults. The internal consistency of both instruments was lower than expected for both instruments which could be attributed to homogeneity of the relatively small sample (Bernardi, 1994). These findings must be considered within the framework of previous studies, clinical implications, instrument bias, and limitations of the study's design.

There have been two other studies which compared the ACE-R and MoCA directly, neither of which has reported differences in the instruments by diagnosis or gender. In one pilot study, the ACE-R and MoCA were compared with a very small sample of 15 persons with MCI versus 20 healthy controls (Ahmed et al., 2011). The results reported sensitivity and specificity for both instruments was 90% and 67% (respectively), using a cut off score of 88.5 for the ACE-R and 23.5 for the MoCA (as opposed to the recommended score of 26) (Ahmed et al., 2011). Researchers used a cut off of 23.5 as it was found to discriminate between controls and MCI in their sample (Ahmed et al., 2011). If the cut off score of 23.5 for the MoCA was used in this study, the sensitivity of the instrument would have dropped to 62.00%, supporting the need to use the instrument author's recommended cut off of 26 (Nasreddine et al., 2005).

Another study compared the two instruments in 91 patients with MCI greater than or equal to one year after a stroke or transient ischemic attack (Pendlebury, Mariz, Bull, Mehta, & Rothwell, 2012). Similar to the results of this study, total MoCA and ACE-R scores were significantly, positively correlated (Spearman $r^2=0.76$). Using a cut off score

of 26, the sensitivity and specificity of the MoCA were reported as 87% and 63% respectively. For the ACE-R, a cut off of 88 resulted in sensitivity and specificity rates of 56% and 100% respectively. The resulting sensitivity for the ACE-R was significantly different from this study (84%), but can likely be attributed to differences in sampling where Pendelbury and colleagues (2012) used participants whose MCI may be related to prior transient ischemic attacks or stroke.

Clinical implications

Both instruments have been validated in several languages and adapted cultural differences (Mioshi et al., 2006; Nasreddine, 2011; Nasreddine et al., 2005). Both contain some identical items: (1) cube copy, (2) naming animals, (3) serial 7 subtraction, and (4) orientation questions. However, while both instruments contain similar items (and similar subscales), there are some notable differences between the instrument subscales. For example, the MoCA contains the subscale “abstraction” which contains two items asking the participant to identify how two things are similar (e.g. banana and orange). The ACE-R does not contain an abstraction scale and does not have any similar items. In addition, the abstraction subscale from the MoCA was not correlated with any of the ACE-R subscales. Lack of significant correlations between the subscales suggests that the scales may not be measuring the same things. Clinically, abstraction is a higher form of cognitive functioning which is necessary for performing daily tasks and can be predictive of behavior such as medication adherence (Insel, Morrow, Brewer, & Figueredo, 2006; Jeste et al., 2003) and glycemic control in older adults with diabetes (Amer et al., 2014). The MoCA may be useful for identifying older adults in need of medication management interventions, however further research is needed.

Although the visuospatial subscales of the ACE-R and MoCA were significantly correlated ($r=0.67$, $p<0.001$), the relationship is likely attributed to both instruments containing the cube copy and clock draw tasks. It is important to note that the ACE-R, unlike the MoCA, does not contain a trail-making or similar type of task. Trail-making tasks, specifically Trails B, are indicative of executive functioning (Sánchez-Cubillo et al., 2009), which is commonly impaired in persons with naMCI and necessary for complex tasks such as medication adherence (Insel et al., 2006) and driving (Richardson & Marottoli, 2003). Performance on trail-making tasks might aid practitioners in deciding what patients need to be referred for driving evaluations. The MoCA contains Trails B, making it more useful for primary care practitioners for the quick evaluation of executive functioning.

Finally, while the ACE-R and MoCA both contain the item “tell me all of the words that you can think of that begin with the letter p [ACE-R] or f [MoCA]” the subscales which contain the item were not correlated. There are several reasons why there may be no relationship between the subscales: (1) Test fatigue, (2) Other questions within the subscales could be measuring different things, (3) Item order could possibly cause more perseveration in one test than the other, and (4) Broader differences between the letter (p or f) in the item, e.g. participants having an easier time naming p words than f words.

Instrument bias?

The differences between genders and diagnoses on the ACE-R and MoCA scores noted in this study raise questions of possible instrument bias. With regard to gender, differences in performance could potentially be related to participants' educational

background and/or employment (e.g. more men than women employed in technical backgrounds necessitating the use of visuospatial skills more often), which were not widely explored in this study. In addition, gender differences on the instruments may be related to broader differences in brain anatomy, function, or chemistry between genders (Cahill, 2006). Differences in performance by diagnosis on the other hand are likely mostly related to memory tasks being weighted more heavily than other tasks in the total instrument scores or study limitations.

Limitations

The relationship of educational level to score on the ACE-R and MoCA could not be fully assessed in this study given the highly educated, homogeneous sample. Both instruments are affected by educational level, despite not being measures of general knowledge or IQ (Nasreddine et al., 2005). Consequently, the educational background of participants should be accounted for in any evaluation of instruments of cognitive functioning. However, educational level is only taken into account in scoring on the MoCA: those at a high school education or below receive one extra point.

Alike many previous studies on MCI, collecting data from only one clinic resulted in a very homogeneous sample which limits the generalizability of these results. In addition, the focus of the clinic is “memory disorders,” consequently; results may not be applicable to the other populations where the MoCA has been used (such as persons with cardiovascular disease, stroke, or Parkinson’s disease). Potentially impacting reliability, different test administrators (clinic staff vs. PI), the timing between instruments, and altered timing between questions on the MoCA through omission of repeated questions may have affected study results.

Finally, internal consistency (Cronbach's alpha) was surprisingly low in this study and may not be the best way to evaluate the reliability of cognitive examinations with this small, homogenous sample (n=50). Higher Cronbach's alphas have been reported in other literature with larger and more diverse samples ranging around 0.84 to 0.83 for both instruments (Fujiwara et al., 2010; Mioshi et al., 2006; Nasreddine et al., 2005; Rahman & Gaafary, 2009).

Recommendations for future research

Since the conclusion of this study, a new edition of the ACE-R (the ACE-III) has been published and has been validated in older adults with Alzheimer's disease and frontotemporal dementia (Hsieh et al., 2013). However, it is important to note that the ACE-III also does not contain items pertaining to abstraction or trail-making. Future studies will be needed to determine the reliability and validity of the ACE-III in comparison to the MoCA for the screening of MCI. Additionally, larger and more diverse sample sizes are needed to consider exploratory or confirmatory factor analysis to further assess the structure of each instruments' subscales (Pawlowski, Segabinazi, Wagner, & Bandeira, 2013). Finally, further studies are also needed to determine if group differences between aMCI vs. naMCI on the abstraction subscale of the MoCA are consistent. Such studies could support the clinical use of the MoCA for targeting older adults at risk for problems such as medication noncompliance or glycemic control issues.

Conclusions

The MoCA includes fewer items and requires less time to complete in comparison to the ACE-R. Both instruments appear to be reliable and valid for the screening of MCI

in a well educated sample. However, the recommendation of this study is to use the MoCA as a brief screening instrument for MCI for three reasons. (1) The MoCA is shorter than the ACE-R, which is an important consideration for primary care settings or other areas where assessment time may be limited or where subjects may be at risk for instrument fatigue. (2) The MoCA was slightly more sensitive than the ACE-R for detecting MCI in this sample. And (3) the MoCA contains a trail-making task and an abstraction subscale on which aMCI vs. naMCI subjects scored differently. Although future research is needed, the abstraction subscale may help clinicians to identify patients at risk for medication non-compliance or glycemic control issues.

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Tables and figures

Table 1

Instrument psychometrics

Variable	<i>M</i>	<i>SD</i>	Range	α
ACE-R	80.02	7.58	57 - 94	0.68
MoCA	22.10	3.00	14 - 28	0.64

Table 2

Correlations between instrument totals and subscales

		MoCA							
		<i>Total</i>	Attention	Orientation	Delayed Recall	Abstractio n	Naming	Language	Visuospati al
A	<i>Total</i>	.80**	.46**	.54**	.45**	.18	.27	.08	.52**
	Attention-Orientation	.53**	.29**	.70**	.28*	.02	.36*	.05	.10
E	Memory	.56**	.25	.43**	.57**	.10	.32*	-.14	.21
	Fluency	.26	.10	.13	-.09	.06	-.01	.26	.34*
R	Language	.46**	.15	.26	.28	.26	.26	.11	.24
	Visuospatia	.57**	.55**	.18	.14	.11	-.13	.11	.67**
1									

Note. Shaded areas represent subscales that should measure similar constructs.

* $p < 0.05$, ** $p < 0.001$

Table 3.

Significant differences in ACE-R and MoCA scores by demographic variables

Variable	Instrument	<i>t</i>	<i>df</i>	<i>p</i>	<i>MD</i>
Male vs. Female	ACE-R	3.29	48	0.002	6.72
	MoCA	2.46	48	0.018	2.07
aMCI vs. naMCI	ACE-R	-2.29	48	0.030	-4.75
	MoCA	-2.15	48	0.040	-1.77

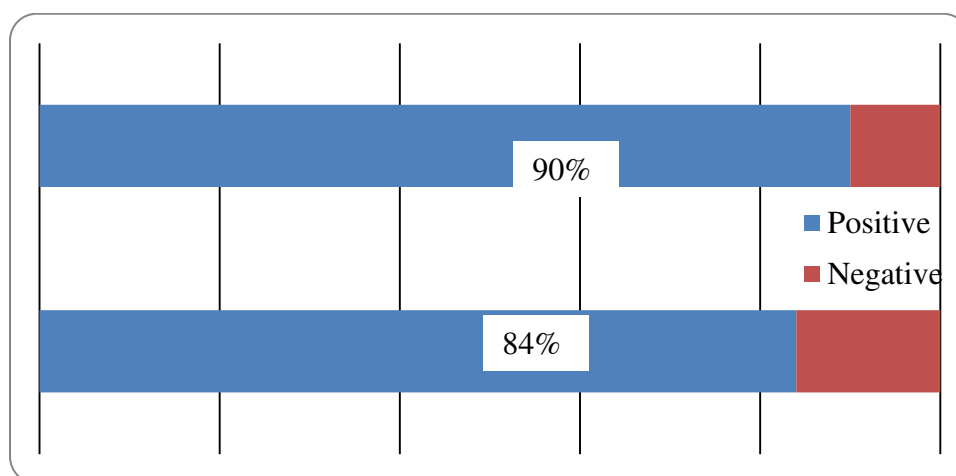


Figure 1. Percentage of subjects screening positive or negative for cognitive impairment.

V. MANUSCRIPT 2: RELATIONSHIPS AMONG UNCERTAINTY, COPING,
AND PSYCHOLOGICAL DISTRESS WITH MILD COGNITIVE IMPAIRMENT.

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Abstract

A diagnosis of mild cognitive impairment (MCI) can result in uncertainty, dysfunctional coping, and psychological distress; all potentially influenced by time and level of cognitive impairment. A conceptual framework that addresses these consequences of MCI could guide the development of nursing interventions. However, such a framework does not currently exist. The primary aim of this study was to test components of Sjostedt's conceptual framework for MCI by examining the relationships among uncertainty, coping, psychological distress, time since diagnosis, and level of cognitive impairment from MCI. A cross-sectional design was used with surveys completed by 91 older adults receiving care for MCI at a neurology clinic. Participants reported low to moderate levels of uncertainty and psychological distress, and often used emotion-focused coping strategies. However, 25.27% of the sample reported moderate/severe psychological distress. Significant relationships ($p < 0.05$) were found between uncertainty, coping, and psychological distress, providing support for the proposed conceptual framework.

Keywords: Mild cognitive impairment, uncertainty, coping, and psychological distress

Mild cognitive impairment (MCI) is considered a cognitive stage between normal functioning and dementia. MCI usually affects older adults starting around 60 years of age with an average prevalence of 18.9% (Petersen, 2003; Petersen, 2011; Petersen et al., 2014). Older adults with MCI report higher rates of indirect care use, such as informal assistance with activities of daily living, and annual direct medical costs (approximately \$808-3,530 more per year) compared to those without MCI (Leibson et al., 2012; Luppá et al., 2008; Zhu et al., 2013). MCI can be broken down into two main subtypes that include amnesic (aMCI) featuring predominately deficits in memory or nonamnesic (naMCI) with deficits outside of memory, such as executive functions, visuospatial ability or language (Petersen et al., 2014). Despite fundamental differences between aMCI and naMCI, there is a significant lack of evidence for treating or screening one subset differently from the other (Gauthier & Touchon, 2005; Lin, Vance, Gleason, & Heidrich, 2012). Both subtypes of MCI result in challenges from cognitive alterations and uncertainty that can contribute to psychological distress, resulting in anxiety, social withdrawal, anger, relationship disturbances, or depression (Banningh, Vernooij-Dassen, Rikkert, & Teunisse, 2008; Blieszner, Roberto, Wilcox, Barham, & Winston, 2007; Lyketsos et al., 2002; Petersen et al., 2014). Effective coping with MCI might help to decrease uncertainty and psychological distress; but the relationships between coping, uncertainty, and psychological distress have not been explored in older adults with MCI. Nurses are in a unique position to provide interventions to older adults to promote understanding and to help them overcome challenges associated with MCI (Lin et al., 2012). A framework to assist in addressing the consequences of MCI, specifically one that examines the relationships among MCI diagnosis, uncertainty, coping and

psychological distress, is essential to guide the development of nursing interventions that might help older adults with MCI cope effectively.

A conceptual framework for MCI

Diagnostic criteria for MCI and a theoretical progression of cognition from normal aging to dementia provide some justification for research and practice, but do not provide sufficient guidance for nursing interventions that might help older adults with MCI and their families cope. In addition, while the theoretical progression suggests that cognition will worsen over time, the path and speed of the progression is often uncertain; older adults with MCI transition along the continuum at differing and unpredictable rates where their cognition may improve, remain stagnant within the range of MCI, or progress to dementia (Banningh et al., 2008; Gauthier & Touchon, 2005; Lingler et al., 2006; Werner & Korczyn, 2008). Other theories that discuss coping with chronic illnesses, do not account for this sometimes unpredictable MCI trajectory on the older adult's ability to appreciate the appraisal of their situation or psychological distress. Consequently, a framework that addresses the relationships of antecedents and consequences of MCI is imperative to improve the nursing care for these older adults.

Development a framework

The lack of a specific theoretical framework describing the antecedents and consequences of MCI and limitations of existing frameworks related to other chronic illnesses necessitated the new conceptualization of MCI to provide support for research and the development of interventions specific for older adults with MCI. The Sjostedt framework for older adults with MCI (Figure 1) encompasses both aMCI and naMCI and

was developed to meet this need using concept analysis methods proposed by Rogers (Rodgers & Knafel, 2000). This framework evolved from a literature search that encompassed years 2000 to 2014 using the CINAHL, Google-scholar, Web-of-Science, Proquest dissertations, and PubMed databases, followed by ancestral searches of articles obtained. Search terms included “mild cognitive impairment,” and surrogate terms for MCI combined with terms such as: older adults, geriatrics, chemotherapy, alcohol, nursing, perception and concept.

Sjostedt framework for MCI

In the Sjostedt framework, MCI is defined as an unstable state of limbo weighted by heterogeneity between older adults’ normal and abnormal continuums (normal aging versus dementia). Figure 1 illustrates the antecedents, attributes, and consequences of MCI proposed within the framework. The main consequence of MCI is uncertainty, which then leads to the other consequences of coping and psychological distress. Uncertainty from MCI stems mainly from inconsistencies in MCI diagnosis and variability in MCI trajectories (Bensadon & Odenheimer, 2013; Dean & Wilcock, 2012; Lu, Haase, & Farran, 2007; Werner & Korczyn, 2008; Yanhong, Chandra, & Venkatesh, 2013). Uncertainty can influence how older adults respond and relate to any illness, treatments, or hospitalizations (Landis, 1996), thus potentially influencing the coping and psychological distress which result from MCI (Banningh et al., 2008; Blieszner et al., 2007; Lingler et al., 2006; Lu et al., 2007). Guided by the Uncertainty in Illness Theory (Mishel, 1988) or other modifications or proposed frameworks influenced by it, uncertainty has been quantitatively explored in chronic conditions such as cancer (Agretelis, 1999; Kazer, Bailey, Sanda, Colbery, & Kelly, 2011; Lien, Lin, Kuo, & Chen,

2009; Sammarco & Konecny, 2010), Parkinson's disease (Sanders-Dewey, Mullins, & Chaney, 2001), and fibromyalgia (Anema, Johnson, Zeller, Fogg, & Zetterlund, 2009; Reich et al.; 2006). The Uncertainty in Illness Theory's assumptions regarding the stimulus frame and appraisal do not account for the potential impact of MCI and lack of awareness of deficits in older adults with MCI; this limits the theory's applicability. In addition, uncertainty has not been quantitatively addressed in older adults with MCI.

The Sjostedt framework hypothesizes that coping and psychological distress from MCI result as responses to the diagnosis and symptoms related to MCI. Findings from one study suggest that some older adults with MCI might use avoidance oriented (or dysfunctional) coping through attempts to improve memory performance, avoidance of activities to keep from making mistakes or masking of deficits (Banningh et al., 2008). Yet, findings from other studies have indicated that older adults with MCI might also use emotion-focused or problem-focused coping through methods such as positive reframing, acceptance, religion, planning, and instrumental support (Lin & Heidrich, 2012; McIlvane, Popa, Robinson, Houseweart, & Haley, 2008). Emotional-focused and dysfunctional coping might increase psychological distress whereas problem-focused coping might reduce psychological distress, similar to the relationships demonstrated within other chronic illnesses (Barron, 2000; Lauver, Kruse, & Baggot, 1999; Lynch, Kroencke, & Denney, 2001; Sanders-Dewey et al., 2001).

Psychological distress from MCI may present as anger, depression, anxiety, somatic symptoms, sadness, frustration, loss of self-confidence, discouragement, loneliness, rejection, inactivity, shame, self-blame, helplessness or loss of control (Banningh et al., 2008; Blieszner et al., 2007; Carpenter et al., 2008; Dean & Wilcock,

2012; Ellison, 2008; Lu et al., 2007). One study found that older adults with MCI were unable to identify any positive consequences related to the condition (Banningh et al., 2008). Yet, other studies have found more positive emotions, such as happiness or relief that it is not dementia, satisfaction from professional validation of their cognitive symptoms, optimism, and comfort by being able to reduce uncertainty in naming their cognitive symptoms (Dean & Wilcock, 2012; Lingler et al, 2006; McIlvane et al., 2008).

Based upon the literature, MCI is a diagnosable and valid chronic condition that does not cause physical pain or result in death. As a chronic condition, it is expected that the relationships demonstrated between uncertainty, coping, and psychological distress in older adults with MCI may be similar to what has been observed among older adults with other types of chronic conditions. Finally, consistent with current recommendations for care (Lin et al., 2012), this study also assumes that while the subtypes of MCI may be fundamentally different, nursing care related to MCI will not vary greatly based upon the subtype of MCI.

Purpose

This study is unique in quantitatively addressing consequences of MCI and is foundational in validating aspects of a conceptual framework that can guide the development of nursing interventions and further research for older adults with MCI. The primary purpose of this study was to test select components of a new conceptual framework for MCI by examining the relationships among uncertainty, coping, psychological distress, time since diagnosis, and level of cognitive impairment from MCI. Secondary aims were to: (a) to describe the levels of uncertainty, coping, and psychological distress in older adults with MCI; (b) examine the differences in scores on

uncertainty, coping, and psychological distress between the two subtypes of MCI; and (c) examine the strength and direction of relationships between scores on uncertainty, coping, and psychological distress within the subtypes of MCI.

The hypotheses generated from the proposed framework that will be tested in this study are: (a) there will be a significant negative relationship between time since diagnosis and level of cognitive impairment from MCI, where longer time since diagnosis will be associated with lower scores of cognition; (b) there will be significant positive relationships between uncertainty and use of coping strategies (emotion focused, problem focused, or dysfunctional coping); (c) there will be significant positive relationships between uncertainty and psychological distress; (d) there will be significant positive or negative relationships between use of coping strategies and psychological distress; (e) the relationships between level of cognitive impairment from MCI and use of coping strategies will be mediated by uncertainty; (f) the relationships between level of cognitive impairment from MCI and psychological distress will be mediated by uncertainty and coping; and (g) there will be no significant differences between the subtypes of MCI in the strength and association of uncertainty, coping, and psychological distress.

Methods

Prior to approaching any subjects, institutional review board approval for the study was obtained from the study site. The study design used was descriptive, cross-sectional, and correlational. A convenience sample of 91 older adults was recruited from an outpatient neurology clinic. Subjects were included if they were over 54 years of age, had been given a diagnosis of MCI by their attending physician supported with

neuropsychological testing, and could understand and speak English. Participants were excluded if they did not meet the above inclusion criteria, if their physician suspected that other neuropsychiatric disorders or chronic conditions might be complicating or masking their diagnosis of MCI, or if they had progressed to dementia. Analyses for aim 1 necessitated the largest sample, hence aim 1 was used to guide the sample size estimation. Sample size was estimated using a method from Cohen & Cohen (1983), resulting in estimating a sample of 91 older adults to yield a power of 0.80 at $\alpha = 0.05$.

Participant recruitment occurred over the course of 62 consecutive weeks (excluding federal-holidays or weeks when the clinic was not operational) starting in July 2013. Potential participants were identified prior to their scheduled appointment in the neurology clinic by clinic staff. After completing their scheduled appointment, all potential participants were invited to participate in the study that same day. Consent and data collection then occurred as an in person interview with the study PI (unaffiliated with the clinic) in an available exam room at that clinic.

Instruments

All instruments in this study were selected to be consistent with the conceptual definitions of the variables, and their reliability and validity (see table 1). Instruments to assess the variables by order of administration were: Montreal Cognitive Assessment (lower scores equate to a higher level of cognitive impairment from MCI) (Nasreddine, 2011), a Demographic Survey, Uncertainty Stress Scale (higher scores indicate more uncertainty) (Hilton, 1996), Brief COPE (higher scores indicate more use of that coping strategy) (Carver, 1997), and Kellner Symptom Questionnaire (higher scores indicate more psychological distress) (Kellner, 1987). The demographic survey measured time

since initial MCI diagnosis in months and years, and select antecedents which could potentially have an effect on uncertainty, coping, and psychological distress: subject gender, age, race/ethnicity, educational level, marital status, religious affiliation, and socioeconomic status. The demographic survey was administered as part of the in person interview; however, time since initial MCI diagnosis was obtained from participants' electronic medical records after completing the in person interview.

Data analysis

Data analysis was performed using SPSS statistical software version 21.0 (IBM Corp, 2012). All data were assessed for frequencies, mean, median, mode, outliers (scatter plots), skewness and kurtosis. Prior to conducting data analysis to meet the study aims, differences related to demographic variables (i.e. gender) on the other variables of level of cognitive impairment from MCI, subtypes of MCI, time since initial diagnosis with MCI, uncertainty, coping, and psychological distress were examined using one-way analysis of variance (ANOVA) or χ^2 tests as appropriate. Any differences related to demographic variables were considered as possible confounding variables within the remaining analyses to meet study aims. Descriptive statistics were then calculated for each study instrument and assessed for group differences between MCI subtypes or other descriptive variables using t-tests and ANOVA. To evaluate the primary study purpose and associated hypotheses, first bivariate correlations were calculated to determine the relationship of study variables and continuous descriptive variables. Next hierarchical multivariate regression analyses were conducted with each psychological distress subscale as separate dependent variables. Differences in the strength or direction of study variables by MCI subtype were assessed using methods for determining the region of

significance in multiple linear regression 2-way interactions (Preacher, Curran, & Bauer, 2006); and Sobel tests were calculated to assess for potential mediating effects in the models (Preacher & Leonardelli, 2001).

Results

A total of 91 older adults were recruited for the study with a mean age of 75.22 (SD = 0.49, range 58-89 years). Participants were primarily Caucasian (94.5%), Christian (87.91%), married (76.9%), retired (85.7%) and had an average of 15.37 years of education (SD=3.52, range 4-27 years). The mean employment duration was 28.21 years (SD = 13.85, range 2-60 years) with professions split between office/law/sales (49.5%), health/education/service (27.5%), and engineering/manual (23.1%). The sample contained a relatively even split of aMCI (57.14%) and naMCI (42.86%) diagnoses, and participants had a mean MCI duration of 2.36 years (SD = 2.29, range <1-10 years). There were no significant differences ($p \leq 0.05$) between aMCI vs. naMCI subtypes on any of the demographic variables.

Table 2 describes the participants' responses on each of the study instruments by order of administration with group differences noted between the MCI subtypes. The only demographic group difference on study instrument means was with marital status; older adults who were divorced ($n=6$) reported significantly higher rates of depression, SQ-D ($F(4, 86) = 2.85, p = 0.03$), compared to those who were married ($MD = 5.52$). Bivariate correlation revealed only a few relationships between the continuous demographic variables and study instruments. Age was significantly negatively correlated with scores on the MoCA ($r = -0.23, p = 0.03$), emotion focused coping ($r = -0.45, p < 0.001$), problem focused coping ($r = -0.47, p < 0.001$), dysfunctional coping ($r =$

-0.34, $p = 0.001$), and anxiety ($r = -0.26$, $p = 0.01$). In addition, MCI duration was significantly positively correlated with somatic symptoms ($r = 0.35$, $p = 0.001$).

Participants indicated the least uncertainty (USS-U) and stress from uncertainty (USS-S) about whether they are being told the truth regarding their cognitive impairment (USS-U $M = 0.51 \pm 1.11$; USS-S $M = 0.33 \pm 0.63$) and if they will be well cared for by the nurses (USS-U $M = 0.57 \pm 1.17$; USS-S $M = 0.24 \pm 0.67$) or other hospital staff (USS-U $M = 0.59 \pm 1.12$; USS-S $M = 0.27 \pm 0.56$). Participants indicated the most uncertainty and stress about whether their MCI will be the same in 5 years (USS-U $M = 1.65 \pm 1.42$, USS-S $M = 0.87 \pm 0.79$), if their MCI will interfere with their ability to do their usual activities (USS-U $M = 1.49 \pm 1.41$, USS-S $M = 0.76 \pm 0.81$), and the stability of their MCI (USS-U $M = 1.43 \pm 1.10$, USS-S $M = 0.78 \pm 0.70$). Close to half of the sample (42%) indicated that they had no positive feelings, such as hope or optimism, about uncertainty from MCI. However, there were no significant differences between those who reported positive feelings vs. those who did not on the subscales of the USS, MoCA, Brief COPE, and Symptom Questionnaire or by subtype of MCI ($p = 0.08 - 0.77$).

Table 3 illustrates the bivariate correlations between the USS-U, USS-S, and other study variables. A strong significant positive correlation was noted between the USS-U and USS-S, indicating that the subscales likely measure the same concepts. In addition, when completing the instruments, some participants made comments about equating uncertainty with worry or stress accompanied by circling their response on the USS-U items to indicate that worry or stress rather than uncertainty. Consequently, only

the USS-S was considered as a variable for uncertainty within the testing of the conceptual framework.

The mean of average responses on the Brief Cope indicated that participants reported significantly higher ($p < 0.001$) use of emotion focused coping strategies ($M = 1.23 \pm 0.69$) and problem focused strategies ($M = 1.11 \pm 0.82$) in comparison to dysfunctional coping ($M = 0.48 \pm 0.41$). The most frequently reported strategies fell within the emotion focused coping subscale and were acceptance ($M = 1.81 \pm 0.90$), use of emotional support ($M = 1.42 \pm 0.94$), and religion ($M = 1.36 \pm 1.14$).

Mean responses on the psychological distress subscales (table 2) fell within the “normal range” for depression (≤ 6), anxiety (≤ 7), anger/hostility (≤ 8), and somatic symptoms (≤ 8) (Kellner, 1987). However, it is important to note that almost a quarter of the sample fell within the moderate to severe range for depression (20.88%), anxiety (25.27%), or somatic symptoms (21.98%). In addition, 9.89% of participants fell within the moderate to severe range for anger/hostility. Although a higher proportion of participants with naMCI versus aMCI scored within the moderate to severe range, a significant difference between the subtypes only existed for somatic symptoms ($\chi^2(2) = 5.98, p = 0.05$). Of participants with naMCI, 30.77% reported moderate ($n = 6$) to severe ($n = 6$) somatic symptoms versus 15.38% with aMCI ($n = 7$ moderate, $n = 1$ severe).

The first hypothesis, there will be a significant negative relationship between time since diagnosis and level of cognitive impairment from MCI, was not supported ($r = 0.03, p = 0.76$). In addition, although a significant difference was noted between aMCI and naMCI on the MoCA ($F(1,89) = 4.18, p = 0.04, MD = -1.46$), mean levels of cognitive impairment for both subtypes fell within the expected range for MCI on the MoCA (\leq

26). There were no significant relationships between the MoCA and other study instruments, and all of those relationships were < 0.20 (table 3); consequently, scores on the MoCA were excluded from further analyses.

The second study hypothesis, there will be significant positive relationships between uncertainty and coping, was partially supported. Both uncertainty (USS-U) and stress from uncertainty (USS-S) were significantly and positively correlated with problem focused coping (BC-P), and dysfunctional coping (BC-D). However, the positive relationship with emotion focused coping (BC-E) was not significant.

The third study hypothesis, there will be significant positive relationships between uncertainty and psychological distress, was also partially supported. There were significant positive relationships with both the USS-U and USS-S on depression (SQ-D), anxiety (SQ-A), and anger/hostility (AQ-AH). However, somatic symptoms (SQ-S) only had a significant positive correlation with the USS-S and not the USS-U.

The fourth study hypothesis, there will be significant positive and negative relationships between coping and psychological distress, was also only partially supported. Use of emotion focused coping strategies (BC-E) was positively correlated with the other measures of coping, but it was not significantly correlated with uncertainty or psychological distress (table 3). Given the significant relationships between the BC-E, BC-P, and BC-D, the decision was made not to exclude BC-E from coping step of testing the conceptual framework.

Four hierarchical multiple regression equations were constructed to assess the final hypotheses and determine the fit of variables to predict each of the four psychological distress variables in the conceptual model. MCI duration (Time) and

MoCA were excluded from the analysis as it was determined that they were not strongly related to psychological distress (see table 3); and these variables are not amenable to modification by nursing intervention. Consequently, the hypotheses, (a) the relationships between level of cognitive impairment from MCI and coping will be mediated by uncertainty; and (b) the relationships between level of cognitive impairment from MCI and psychological distress will be mediated by uncertainty and coping, were not supported as they could not be assessed with the exclusion of MoCA from the analyses.

Age and MCI subtype were included as control variables in step one of each analysis given their significant relationships between the variables in the models. The USS-S was inserted to represent uncertainty in step 2, and BC-E, BC-P, and BC-D were inserted in step 3 to represent coping. Finally, interaction terms for the subtypes of MCI by USS-S, BC-E, BC-P, and BC-D were added to step 4 in order to assess for possible differences by subtype of MCI in the strength and/or direction of the relationships between the dependent psychological distress variables and the independent variables of USS-S, BC-E, BC-P, BC-D.

All models significantly predicted psychological distress to some extent (table 4). The weakest model predicted somatic symptoms where MCI subtype was a significant predictor in each step, explaining approximately 9% of the variance in somatic symptoms. Stress from uncertainty (USS-S) was a significant positive predictor in every model indicating that as stress from uncertainty increases, psychological distress also increases. The USS-S accounted for 40% of the variance in anxiety, 19% in depression, 18% in anger/hostility, and 5% in somatic symptoms. With the addition of coping, USS-S remained a significant predictor in every model except somatic symptoms.

The addition of coping helped to explain an additional 13% of the variance in depression, 11% in anger/hostility, 7% in anxiety, and 4% in somatic symptoms. Problem focused coping was not a significant predictor in any model. Dysfunctional coping was a significant positive predictor in every model except somatic symptoms, indicating that as use of dysfunctional coping strategies increases, psychological distress also increases. Finally, emotion focused coping was a significant negative predictor only in the model for anger/hostility, indicating that use of emotion focused coping reduces anger/hostility. The significant predictive relationship between BC-E and SQ-AH was somewhat unexpected given their lack of significant correlation, which suggests that their relationship might be moderated by another variable. Considering that inclusion of coping variables occurred in step 3 of the regression models, variables in steps 1 (age, MCI subtype) and step 2 (USS-S) were investigated as potential moderating variables between BC-E and SQ-AH. The regression analysis for SQ-AH was repeated with only the interaction terms for BC-E and age, BC-E and USS-S, and BC-E and MCI subtype added as step 4. The resulting model demonstrated a significant change between step 3 and 4 ($F(3,81) = 2.95, p = 0.04, R^2 \text{ change} = 0.06$), and both USS-S ($\beta = -0.26, p = 0.01$) and age ($\beta = -0.18, p = 0.05$) were demonstrated to be significant moderating variables between the BC-E and SQ-AH.

A significant change in R^2 when interaction terms for MCI-subtypes were included was apparent only in the model predicting anger/hostility. Upon further exploration, a significant difference was detected in the strength but not direction of the relationship between USS-S and SQ-AH for those with aMCI ($r = 0.35, p = 0.01$) versus naMCI ($r = 0.62, p < 0.001$). Consequently, the final hypothesis, there will be no

significant differences between the subtypes of MCI in the strength and direction of uncertainty, coping, and psychological distress, was not supported given the difference in the relationship of USS-S and SQ-AH. This difference in the strength of relationship and possible clinical implications is demonstrated by figure 2.

Sobel tests demonstrated that BC-D was the only significant mediating variable in the regression models. BC-D provided significant partial mediation between the USS-S and SQ-D ($p < 0.01$), SQ-A ($p < 0.01$), and SQ-AH ($p < 0.03$). It is important to note that while the strength of the relationship between the USS-S and SQ-AH was significantly different between MCI subtypes, the relationship between BC-D and SQ-AH was not significantly different between the MCI subtypes.

Discussion

The results of this study support the hypothesized relationships between uncertainty, coping, and psychological distress within the conceptual framework. However, these results also suggested some possible areas for refining the framework. The regression models indicated that (a) increased uncertainty and dysfunctional coping resulted in increased psychological distress for older adults with MCI; (b) other than somatic symptoms, the relationships between uncertainty and psychological distress are mediated by dysfunctional coping; and (c) increased emotion focused coping resulted in decreased anger/hostility only when older adults' age and levels of uncertainty are accounted for. These relationships are demonstrated in Figure 3.

Responses on the Brief Cope were similar to those reported with the same instrument in other studies of persons with MCI in which participants also reported more emotional focused coping than problem focused or dysfunctional coping (Lin & Heidrich,

2012; McIlvane et al., 2008). The three coping subscales were all positively correlated with both uncertainty and psychological distress variables as predicted by the framework, but those relationships were not always significant as was found with the emotional coping subscale. Dysfunctional coping was the most significant coping variable predictive of psychological distress, and a significant mediating variable between uncertainty and psychological distress. This finding suggests that interventions to decrease uncertainty and psychological distress in persons with MCI might focus on decreasing dysfunctional coping behaviors such as self-distraction, venting, self-blame, denial, or behavioral disengagement.

Overall levels of uncertainty and stress from uncertainty were similar to findings from the USS in women with breast cancer (Agretelis, 1999). As expected, items which resulted in the most uncertainty were those that pertain to the unforeseeable future with MCI. Conversely, items that resulted in the least uncertainty pertained to trust in diagnosis (being told the truth), nurses and other health practitioners. This finding highlights the certainty in being able to trust nurses and other health practitioners which indicates the potential role they might provide to reduce uncertainty for older adults with MCI. Many participants talked about items on the USS or told a story about an item while completing the survey. In addition to making comments equating uncertainty with worry or stress, some participants indicated that if a loved one was filling out their form, or if they were receiving care at a different clinic, then they might indicate a higher degree of uncertainty. Others reflected that they had never thought about the items on the USS and had a desire to obtain more information about MCI. Such comments suggest there might be potential differences in uncertainty from MCI based upon trust of the

provider making the diagnosis of MCI, explanation of the diagnosis, and educational materials provided.

Although mean responses on the psychological distress subscales fell within the “normal range” for distress, 28.27% of the sample scored within the moderate to severe range of distress. This finding is supported by previous research which found greater levels of psychological distress, in particular depression and anxiety, in persons with MCI compared to those without MCI or dementia (Petersen et al., 2014; Shahnawaz et al., 2013). In addition, in this study, those with naMCI reported higher degrees of distress than those with aMCI; however, this finding is not well supported by previous literature. For example, one study found no significant differences in report of psychological distress by MCI subtype (Lee, Cho, Hong, Kim, & Oh, 2008); and yet, in another study, those with aMCI reported significantly more depression than those with naMCI (Shahnawaz et al., 2013). One confounding factor not explored in this study is differences in the amount and type of chronic conditions experienced between those with aMCI versus naMCI which may result in differences of reported somatic symptoms.

This study includes a number of limitations. Recruiting subjects from one academic-focused clinic in the Midwest and cross-sectional design resulted in a homogeneous sample and limits generalizability of results. To address these concerns, further research is needed with more diverse populations within different care settings and areas of the US or other countries. Specific to cross-sectional limitations, longitudinal studies will be needed to evaluate if the study variables change over time. Finally, two instruments had not been used in older adults with MCI (USS, SQ). While this study demonstrated acceptable alpha levels and may support the use of these

instruments in older adults with MCI, future studies will still be needed to support the psychometrics demonstrated and determine the appropriateness of these instruments over time.

Understanding the consequences of having MCI is foundational to designing appropriate interventions that help to decrease uncertainty and dysfunctional coping, and promote emotional focused coping in order to reduce psychological distress from MCI. The Sjostedt framework provides direction to nurses involved in research with MCI, and can also guide the development of interventions for the management of MCI. The findings of this study demonstrates the framework's proposed relationships between uncertainty, coping, and psychological distress as a consequence of MCI, independent of the level of one's cognitive impairment. Important clinical considerations from this study are the level of and differences in psychological distress between the subtypes of MCI and the sources of uncertainty. Psychological distress frequently presents as somatic symptoms in older adults but can be misattributed to chronic illnesses (National Ageing Research Institute, 2009). Persons with naMCI need to be assessed for interventions needed to address somatic symptoms of psychological distress. Interventions might include educational materials and support groups should address concerns about the future with MCI and offer guidance for future planning in order to reduce anxiety and uncertainty.

This study provides preliminary evidence to support the hypothesized relationships between the constructs in the Sjostedt framework for older adults with MCI. The next step in validating the framework will be to replicate the study results with more diverse samples over time and evaluate the potential interactions between the modifiable

antecedents and the consequences of MCI. Given the cross-sectional nature of this study, it is likely that if cognitive status were assessed over a given time rather than at one time point, a significant relationship between cognition and the study variables might be observed as it would allow for calculation of differences in cognition over time for each participant. Future studies will also need to contain cognitive comparison groups to further assess for the possible impact of cognitive impairment on uncertainty, coping, and psychological distress. Finally, while the design of this study was not mixed methods, several comments from participants were noted pertaining to the USS. It is important to consider those comments in planning future studies or interventions focused on uncertainty with MCI. For example, future studies might involve family members and/or paid caregivers in the assessment of uncertainty or explore differences in the uncertainty experienced between caregivers and older adults with MCI.

Notes

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Tables and figures

Table 1

Theoretical constructs, instruments, and reliability by order of administration

Theoretical Construct	Instrument with Subscales	Scale	α^*
Cognitive Impairment	Montreal Cognitive Assessment	11 items	
	Total Scale	0-30 points	0.66
Select MCI Antecedents	Demographic Survey	10 items	
		N/A points	N/A
Uncertainty	Uncertainty Stress Scale	59 items	
	Uncertainty	0-316 points	0.85
	Stress from Uncertainty	0-308 points	0.76
Coping	Brief COPE	28 items	
	Emotion Focused	0-30 points	0.85
	Problem Focused	0-18 points	0.86
	Dysfunctional	0-36 points	0.76
Psychological Distress	Symptom Questionnaire	92 items	
	Depression	0-23 points	0.89
	Anger/Hostility	0-23 points	0.83
	Anxiety	0-23 points	0.89
	Somatic	0-23 points	0.88
	Total Scale	0-92 points	0.95

*Observed in this study

Table 2.

Levels and differences of uncertainty, coping, and psychological distress for older adults with aMCI vs naMCI (mean \pm SD).

Variable	aMCI (n=52)	naMCI (n=39)	Total (n=91)	Range
MoCA	21.52 \pm 2.80	22.97 \pm 3.99	22.14 \pm 3.42	12-30
Uncertainty Stress Scale:				
Uncertainty (USS-U)	90.49 \pm 80.11	77.78 \pm 53.16	85.04 \pm 69.79	0-291.00
Stress of Uncertainty (USS-S)	84.06 \pm 80.80	82.24 \pm 63.71	83.28 \pm 73.58	0-279.91
Brief COPE:				
Emotion Focused Coping (BC-E)	11.54 \pm 6.78	13.36 \pm 6.99	12.32 \pm 6.89	0-30
Problem Focused Coping (BC-P)	6.19 \pm 4.29	7.28 \pm 5.70	6.66 \pm 4.94	0-18
Dysfunctional Coping (BC-D)	5.15 \pm 4.62	6.44 \pm 5.17	5.70 \pm 4.88	0-20
Symptom Questionnaire:				
Depression (SQ-D)	3.38 \pm 4.22	3.69 \pm 4.50	3.52 \pm 4.32	0-17
Anxiety (SQ-A)	4.25 \pm 4.76	4.64 \pm 4.88	4.42 \pm 4.79	0-21
Anger-Hostility (SQ-AH)	2.23 \pm 2.69	3.54 \pm 3.65	2.79 \pm 3.19	0-13
*Somatic (SQ-S)	4.17 \pm 3.65	6.90 \pm 5.40	5.34 \pm 4.66	0-21
Total Scale (SQ-T)	14.04 \pm 12.37	18.77 \pm 15.64	16.07 \pm 13.99	0-52

*Denotes significant difference, t-test ($p = 0.005$), between aMCI and naMCI

Table 3.

Pearson's correlations between instrument scales (n = 91).

	Age	Time- MCI	MoCA	USS- U	USS-S	BC-E	BC-P	BC-D	SQ-D	SQ-A	SQ- AH	SQ-S
Age	1											
Time	0.06	1										
MoCA	-0.23*	0.03	1									
USS- U	-0.07	-0.08	-0.05	1								
USS-S	-0.20	-0.06	0.02	0.86**	1							
BC-E	-0.45**	-0.07	-0.05	0.13	0.21	1						
BC-P	-0.47**	-0.19	0.06	0.21*	0.34**	0.72**	1					
BC-D	-0.34**	-0.13	0.05	0.35**	0.46**	0.42**	0.59**	1				
SQ-D	-0.18	-0.02	0.08	0.36**	0.47**	0.08	0.26*	0.51**	1			
SQ-A	-0.26*	0.04	0.06	0.46**	0.67**	0.17	0.37**	0.55**	0.81**	1		
SQ- AH	-0.18	0.07	0.17	0.35**	0.44**	0.01	0.21*	0.44**	0.57**	0.62**	1	
SQ-S	-0.09	0.35**	0.16	0.08	0.23*	0.08	0.17	0.31**	0.44**	0.51**	0.46**	1

Significant relationships shaded: *p < 0.05, **p < 0.01

Table 4.

Testing of relationships between uncertainty, coping, and psychological distress (n = 91)

Variables ¹	Depression		Anxiety		Anger-Hostility		Somatic	
	<i>B (SE)</i>	β	<i>B (SE)</i>	β	<i>B (SE)</i>	β	<i>B (SE)</i>	β
Block 1: Control								
(Constant)	10.89 (4.21)		15.73 (4.59)		7.96 (3.06)		9.14 (4.42)	
Age	-0.10 (0.06)	-0.18	-0.15 (0.06)	-0.26*	-0.06 (0.04)	-0.15	-0.03 (0.06)	-0.05
MCI Type	-0.10 (0.92)	-0.01	-0.07 (1.00)	-0.01	-1.18 (0.67)	-0.19	-2.66 (0.96)	-0.28**
<i>R</i> ² Change	0.03		0.07		0.07		0.09	
<i>F</i> Ratio for								
<i>R</i> ² Change	1.56		3.08*		3.04*		4.21**	
Block 2: Uncertainty								
(Constant)	5.17 (3.98)		6.59 (3.66)		3.95 (2.91)		5.96 (4.53)	
Age	-0.05 (0.05)	-0.09	-0.07 (0.05)	-0.12	-0.03 (0.04)	-0.07	-0.01 (0.06)	-0.01
MCI Type	-0.25 (0.83)	-0.03	-0.31 (0.76)	-0.03	-1.29 (0.60)	-0.20*	-2.74 (0.94)	-0.29**
USS-S	0.03 (0.01)	0.45***	0.04 (0.01)	0.65***	0.02 (0.01)	0.43***	0.02 (0.01)	0.23*
<i>R</i> ² Change	0.19		0.40		0.18		0.05	
<i>F</i> Ratio for								
<i>R</i> ² Change	21.73***		65.72***		20.02***		5.18*	
<i>R</i> ² (Adjusted								
<i>R</i> ²)	0.23 (0.20)		0.47 (0.45)		0.24 (0.21)		0.14 (0.11)	
Block 3: Coping								
(Constant)	3.99 (4.51)		4.31 (4.23)		5.03 (3.36)		4.25 (5.50)	
Age	-0.04 (0.05)	-0.07	-0.05 (0.05)	-0.08	-0.03 (0.04)	-0.09	0.02 (0.07)	0.03
MCI Type	0.01 (0.77)	0.00	-0.09 (0.73)	-0.01	-1.19 (0.58)	-0.19*	-2.56 (0.94)	-0.27**
USS-S	0.02 (0.01)	0.29**	0.03 (0.01)	0.52***	0.01 (0.01)	0.31**	0.01 (0.01)	0.14
BC-E	-0.13 (0.08)	-0.21	-0.12 (0.08)	-0.18	-0.14 (0.06)	-0.28*	-0.06 (0.10)	-0.09
BC-P	0.02 (0.13)	0.02	0.12 (0.12)	0.12	0.04 (0.09)	0.06	0.03 (0.15)	0.03
BC-D	0.38 (0.10)	0.43***	0.28 (0.10)	0.28**	0.22 (0.08)	0.34**	0.23 (0.13)	0.24
<i>R</i> ² Change	0.13		0.07		0.11		0.04	

<i>F</i> Ratio for								
<i>R</i> ² Change	5.71***		4.42**		4.57**		1.39	
<i>R</i> ² (Adjusted								
<i>R</i> ²)	0.36 (0.31)		0.54 (0.51)		0.35 (0.30)		0.18 (0.12)	
Block 4: Interaction Terms (IT)								
(Constant)	4.37 (4.63)		4.05 (4.27)		4.74 (3.27)		3.49 (5.44)	
Age	-0.03 (0.06)	-0.06	-0.04 (0.05)	-0.08	-0.05 (0.04)	-0.13	0.01 (0.07)	0.01
MCI Type	0.01 (0.79)	0.01	-0.07 (0.73)	-0.01	-1.12 (0.56)	-0.18*	-2.52 (0.93)	-0.27**
USS-S	0.02 (0.01)	0.25	0.04 (0.01)	0.67***	0.03 (0.01)	0.66***	0.03 (0.01)	0.53**
BC-E	-0.19 (0.14)	-0.31	-0.12 (0.13)	-0.17	-0.05 (0.10)	-0.10	-0.02 (0.16)	-0.03
BC-P	0.01 (0.20)	0.01	0.05 (0.19)	0.05	-0.18 (0.14)	-0.27	-0.07 (0.24)	-0.08
BC-D	0.44 (0.17)	0.49**	0.23 (0.16)	0.23	0.33 (0.12)	0.50**	0.16 (0.21)	0.17
IT USS-S	0.01 (0.01)	0.02	-0.02 (0.01)	-0.23	-0.02 (0.10)	-0.43*	-0.04 (0.02)	-0.52**
IT BC-E	0.10 (0.17)	0.11	0.02 (0.16)	0.02	-0.11 (0.12)	-0.17	0.01 (0.20)	0.01
IT BC-P	0.05 (0.27)	0.04	0.17 (0.25)	0.11	0.31 (0.19)	0.31	0.16 (0.31)	0.11
IT BC-D	-0.06 (0.22)	-0.05	0.13 (0.20)	0.09	-0.17 (0.16)	-0.18	0.14 (0.26)	0.10
<i>R</i> ² Change	0.01		0.02		0.07		0.07	
<i>F</i> Ratio for								
<i>R</i> ² Change	0.22		0.92		2.46*		1.78	
<i>R</i> ² (Adjusted								
<i>R</i> ²)	0.37 (0.29)		0.56 (0.51)		0.42 (0.35)		0.25 (0.15)	

¹Note: MCI type coded as aMCI = 1, naMCI = 0

p* ≤ 0.05, *p* ≤ 0.01, ****p* ≤ 0.001

Figure 1. The Sjostedt framework for older adults with MCI.

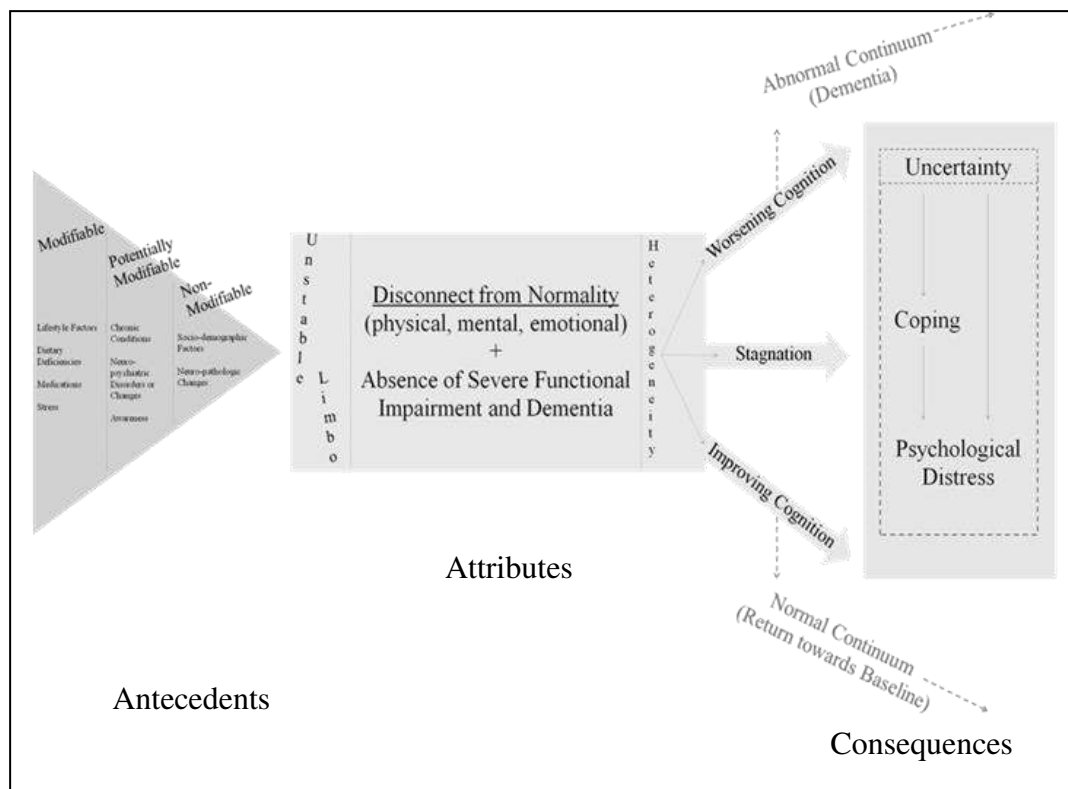
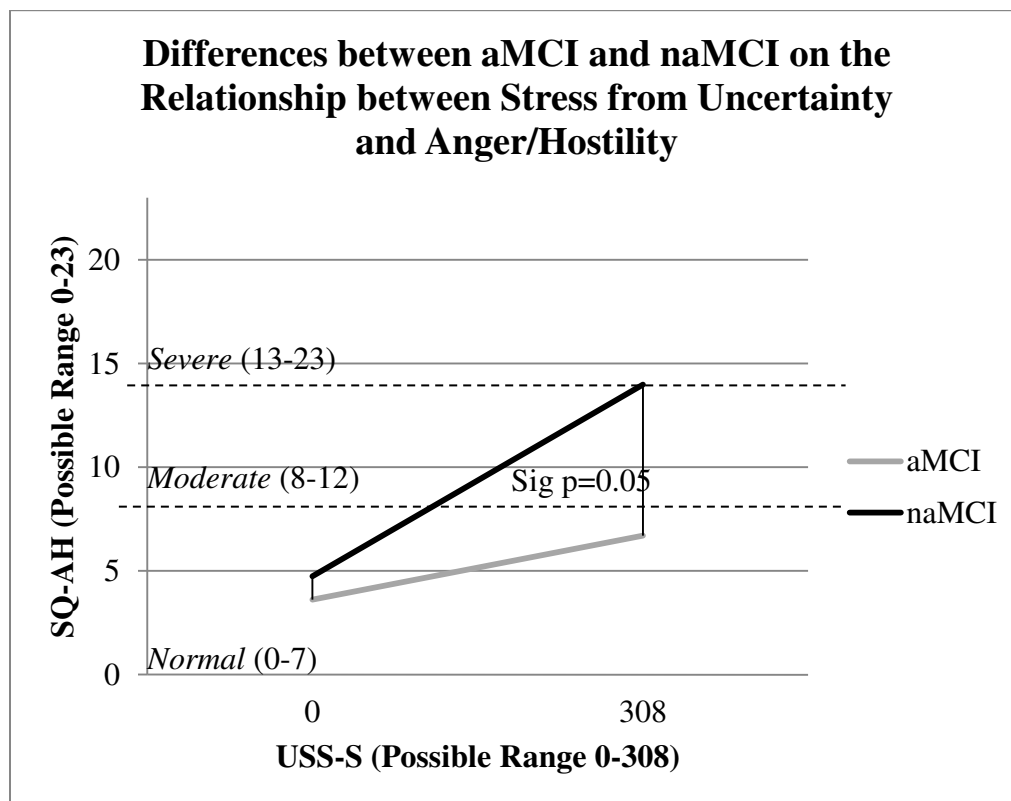
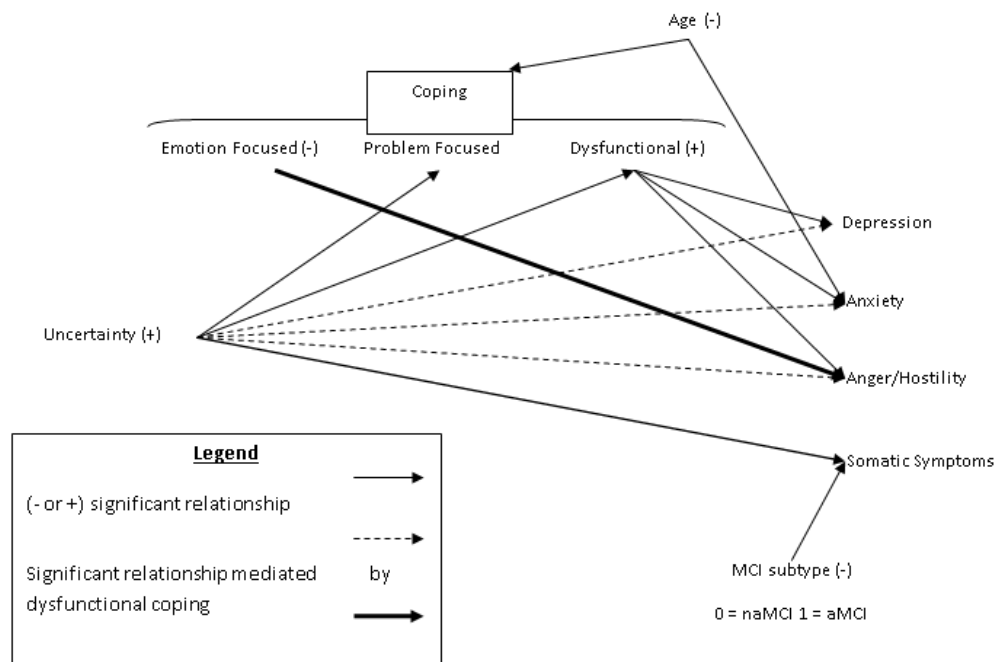


Figure 2. Demonstration of the differences between aMCI and naMCI on the relationship between stress from uncertainty and anger/hostility.



*Note: Dashed lines represent separation between clinical levels of anger/hostility.

Figure 3. Illustration of relationships within the conceptual framework.



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APPENDIX A: SUPPLEMENTAL TABLES FOR MANUSCRIPT 2

Table 3. Participant demographics (n=91).

Variable	aMCI (n=52)	naMCI (n=39)	Total (n=91)
Age (years), mean \pm SD	76.13 \pm 8.05	74.00 \pm 8.19	75.22 \pm 0.49
(Range)	(58-89)	(58-88)	(58-89)
MCI Duration (years), mean \pm SD	1.98 \pm 1.87	2.86 \pm 2.70	2.36 \pm 2.29
(Range)	(0-9.33)	(0-10)	(0-10)
Gender:			
Male, %	61.5%	61.5%	61.5%
Female, %	38.5%	38.5%	38.5%
Race/Ethnicity:			
Caucasian/White, %	94.2%	94.9%	94.5%
African American/Black, %	3.8%	5.1%	4.4%
Hispanic/Latino, %	1.9%	0%	1.1%
Marital Status:			
Married, %	76.9%	76.9%	76.9%
Widowed, %	5.8%	10.3%	7.7%
Divorced, %	7.7%	5.1%	6.6%
Single, %	7.7%	5.1%	6.6%
Dating/Engaged, %	1.9%	2.6%	2.2%
Religious Affiliation:			
Catholic, %	40.4%	61.5%	49.5%
Lutheran, %	21.2%	17.9%	19.8%
Other Christian Religions, %	25.0%	10.3%	18.7%
Non-Christian Religions, %	3.8%	5.1%	4.4%
No religion, %	9.6%	5.1%	7.7%

Education (years), mean \pm SD	15.16 \pm 3.71	15.65 \pm 3.28	15.37 \pm 3.52
(Range)	(4-25)	(12-27)	(4-27)
Currently Employed:			
No (Retired), %	88.5%	82.1%	85.7%
Yes, %	9.6%	7.7%	8.8%
No (Disabled), %	0%	7.7%	3.3%
No (Never Employed), %	1.9%	2.6%	2.2%
Employment (years), mean \pm SD	28.07 \pm 13.22	28.40 \pm 14.83	28.21 \pm 13.85
(Range)	(2-55)	(7-60)	(2-60)
Current/Former Professions:			
Office/Law/Sales, %	46.2%	53.8%	49.5%
Health/Education/Service, %	30.8%	23.1%	27.5%
Engineering/Manual, %	23.1%	23.1%	23.1%

*Denotes significant difference, One-way ANOVA or χ^2 ($p < 0.05$), between aMCI and naMCI

Table 4. Correlations and ANOVA: Relationships and group differences in instrument variables by demographic variables ($n = 91$).

Bivariate correlations	MoC a	USS- U	USS- S	BC-E	BC-P	BC- D	SQ- D	SQ- A	SQ- AH	SQ-S
Age	-0.23*	-0.68	-0.20	-0.45**	-0.47**	-0.34**	-0.18	-0.26*	-0.18	-0.09
MCI	0.03	-0.08	-0.06	-0.07	-0.19	-0.13	-0.02	0.04	0.07	0.35**
Duration										
Education	-0.03	-0.03	-0.01	0.19	0.11	-0.16	-0.16	-0.02	0.03	-0.10
Employment	0.03	-0.05	-0.08	-0.02	-0.18	-0.01	-0.09	-0.14	-0.16	-0.12
F-Statistic										
Gender	0.19	0.15	0.37	0.60	0.27	1.47	3.68	2.43	0.34	3.53
Marital Status	0.74	0.99	0.82	0.29	0.69	0.47	3.42**	1.51	1.12	0.94
Religion	0.38	0.19	0.47	2.44	0.98	1.92	0.24	0.36	0.70	1.18
Profession	0.50	0.23	0.18	0.48	2.73	1.77	0.57	0.54	1.66	0.20

Significant relationships shaded: * $p < 0.05$, ** $p < 0.01$

Table 5. Mean uncertainty and stress from uncertainty by items on the USS (n = 91)

Item	Mean	Mean Stress
“I am uncertain...”	Uncertainty	from Uncertainty
15. whether my MCI situation will be the same in 5 years	1.648	0.868
4. whether I will be able to maintain my present level of functioning	1.6	0.733
17. whether my MCI situation will interfere with my ability to do my usual activities	1.489	0.756
2. about the stability of my MCI	1.427	0.778
14. about my chances to be well	1.398	0.716
3. what caused my MCI	1.385	0.648
16. whether my symptoms can be controlled	1.371	0.798
5. about the present state of my MCI situation	1.352	0.659
35. about the unpredictability of my symptoms	1.296	0.679
38. how long my symptoms will last	1.263	0.638
45. about the cause of my symptoms	1.262	0.595
36. whether I will have difficulty coping	1.253	0.663

with my MCI situation		
10. whether my MCI condition is under control	1.23	0.58
33. about the seriousness of my condition	1.217	0.687
21. whether my MCI disorder will return	1.188	0.667
52. what to look for to check the state of my MCI situation	1.183	0.61
11. whether my MCI condition will cause me to have symptoms	1.178	0.611
50. about how to choose the treatments I should have	1.171	0.526
6. what questions to ask my doctors about my MCI situation	1.167	0.567
49. what symptoms I should be aware of	1.148	0.543
19. how to manage my symptoms	1.144	0.633
27. whether any changes brought about by my MCI affects my relationships	1.12	0.627
12. what to say to others about my MCI situation	1.101	0.449
7. whether changing my lifestyle will help my condition	1.1	0.511
53. whether treatments will eliminate the	1.099	0.556

MCI

41. what unusual symptoms mean in terms of my MCI situation	1.088	0.488
51. whether following the treatment plan recommended to me will help	1.088	0.55
30. whether I can depend on test results as an indicator of my condition	1.082	0.424
8. how to make sense of what I am told about my MCI	1.077	0.516
34. about my ability to handle my emotions related to the MCI	1.071	0.583
1. whether changes in my mild cognitive impairment (MCI) will be detected early	1.068	0.648
26. whether my treatments have corrected my condition	1.063	0.594
28. whether my MCI situation will affect my life goals	1.049	0.568
29. whether what I am doing about my MCI situation will help me	1.047	0.494
9. about the effectiveness of my treatments	1.038	0.526
23. about my understanding of the treatments I have received or am receiving	0.988	0.458

20. about choices made regarding my treatments	0.953	0.424
13. about differing explanations I have been given	0.952	0.422
54. how to manage my medical care	0.94	0.518
40. whether I would choose to have all the treatments recommended to me	0.936	0.462
32. whether delays in treatment will influence my chances of successful recovery	0.92	0.48
42. whether they might find something wrong when I go for a checkup	0.878	0.463
37. about the quality of information I have	0.867	0.427
24. how to approach health care workers about my care (for example, nurses, doctors, dietitians)	0.835	0.353
47. whether insurance can be obtained because of my condition	0.816	0.447
22. about the adequacy of the follow-up I am having	0.809	0.337
25. whether the MCI situation will be involved in my death	0.753	0.395

48. whether I can manage financially because of my condition	0.735	0.434
46. whether I can depend on people who are important to me to be there when I need them	0.729	0.4
18. about my doctor's(s') abilities	0.682	0.341
31. whether my MCI condition will affect my sex life	0.614	0.357
44. whether I will be well cared for by the health professionals other than the nurses	0.59	0.265
43. whether I will be well cared for by the nurses	0.573	0.244
39. whether I am being told the truth about my MCI situation	0.512	0.329

Table 6. Differences in bivariate correlations between instrument scales by MCI subtype ($n = 91$).

aMCI	1	2	3	4	5	6	7	8	9
naMCI									
1. USS-U	1								
2. USS-S	0.86**	1							
	0.87**								
3. BC-E	0.19	0.34*	1						
	0.05	-0.01							
4. BC-P	0.23	0.43**	0.68**	1					
	0.26	0.25	0.76**						
5. BC-D	0.32*	0.52**	0.31*	0.44**	1				
	0.50**	0.39*	0.52**	0.72**					
6. SQ-D	0.35*	0.51**	0.15	0.30**	0.57**	1			
	0.41*	0.41**	-0.02	0.22	0.45**				
7. SQ-A	0.41**	0.68**	0.29*	0.47**	0.64**	0.82**	1		
	0.62**	0.68**	0.02	0.28	0.44**	0.80**			
8. SQ-AH	0.26	0.35*	-0.01	0.23	0.41**	0.64**	0.61**	1	
	0.60**	0.62**	-0.02	0.17	0.45**	0.53**	0.64**		
9. SQ-S	-0.07	0.09	0.11	0.20	0.34*	0.34*	0.36**	0.31*	1
	0.39*	0.44**	-0.01	0.11	0.24	0.56**	0.67**	0.52**	

Significant relationships: * $p < 0.05$, ** $p < 0.01$

Shaded areas indicate a difference of 0.1 or greater between aMCI and naMCI

Table 7. Sobel Statistic (standard error) to test for mediation of coping variables between uncertainty and psychological distress ($n = 91$).

	Depression	Anxiety	Anger/Hostility	Somatic
BC-E	-0.64 (<0.01)	-0.28 (<0.01)	-1.03 (<0.01)	-0.08 (0.94)
BC-P	0.71 (<0.01)	1.29 (<0.01)	0.15 (<0.01)	0.64 (<0.01)
BC-D	2.84** (<0.01)	2.64** (<0.01)	2.56* (<0.01)	1.78 (<0.01)

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

APPENDIX B: SUPPLEMENTAL FIGURES FOR MANUSCRIPT 2

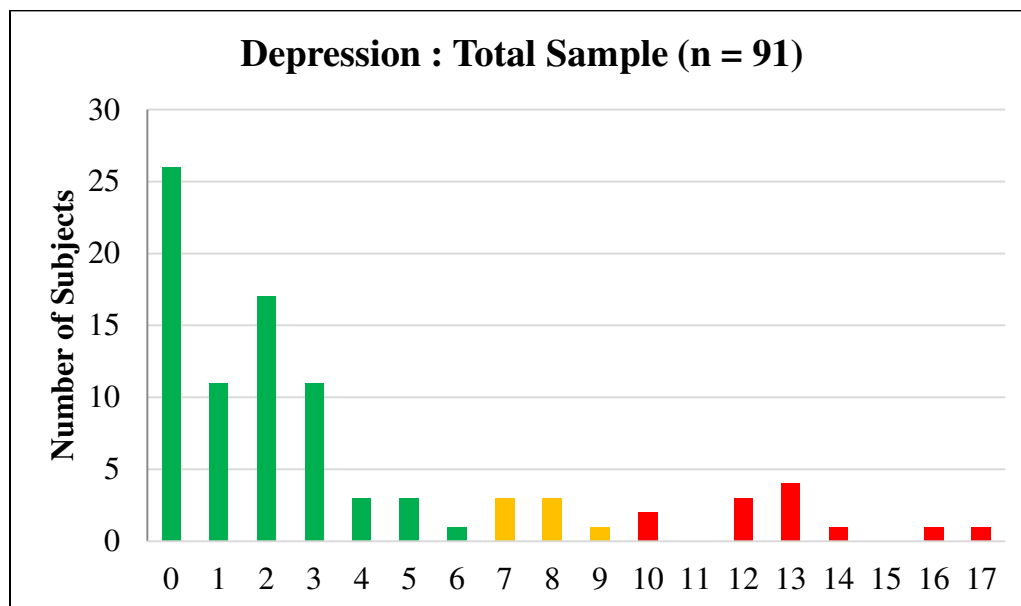


Figure 14. Clinical distribution of depression ($n = 91$)

*Note: Green = Normal, Yellow = Moderate, Red = Severe

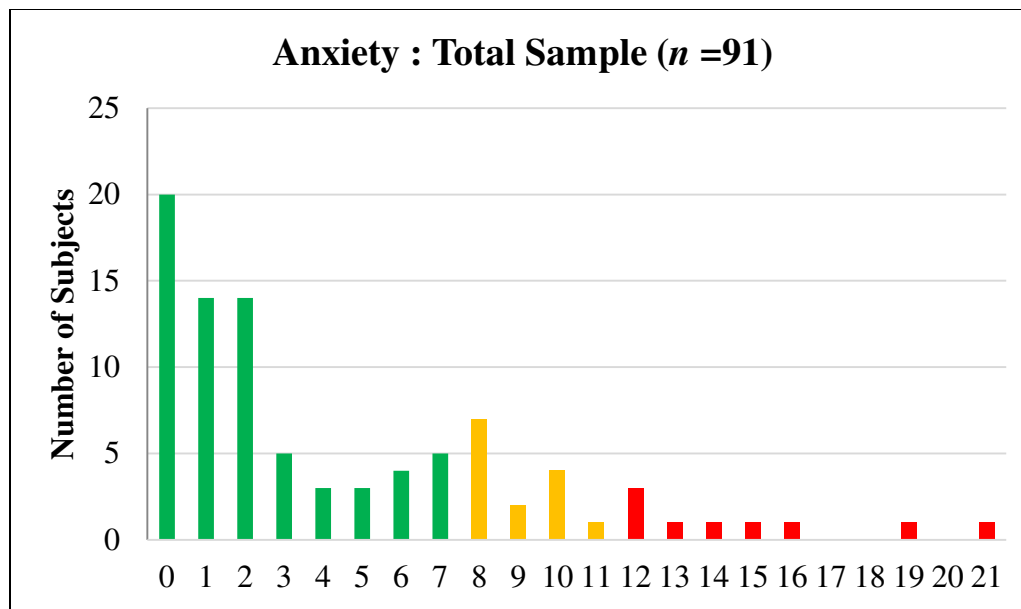


Figure 15. Clinical distribution of anxiety ($n = 91$).

*Note: Green = Normal, Yellow = Moderate, Red = Severe

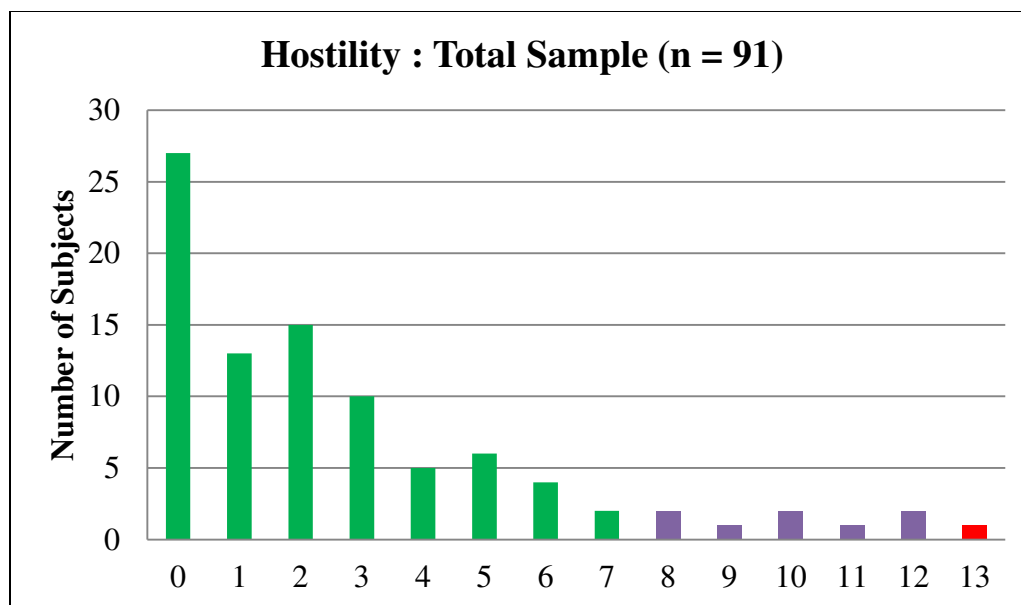


Figure 16. Clinical distribution of hostility ($n = 91$).

*Note: Green = Normal, Purple = Moderate, Red = Severe

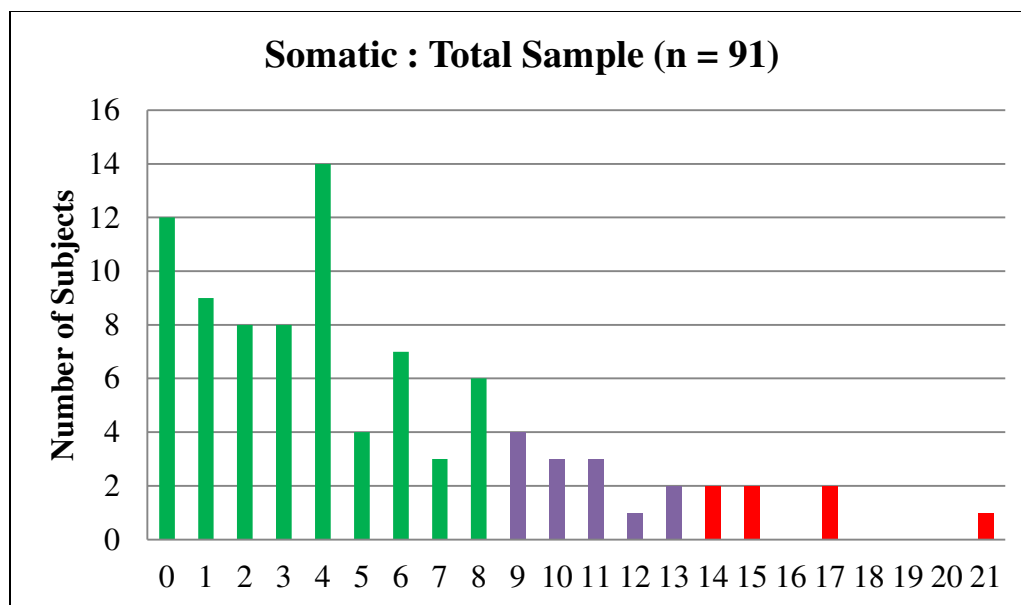


Figure 17. Clinical distribution of somatic symptoms ($n = 91$).

*Note: Green = Normal, Purple = Moderate, Red = Severe

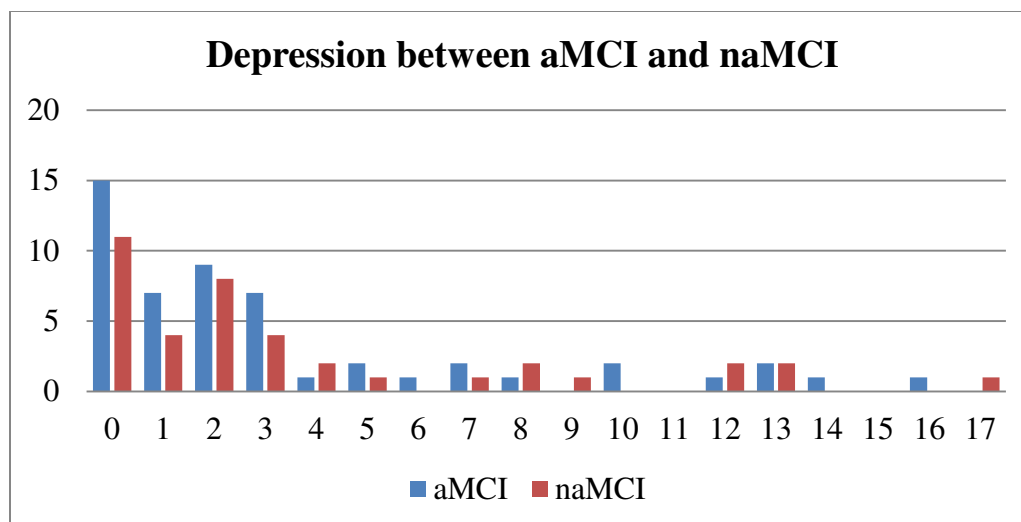


Figure 18. Distribution of depression by aMCI and naMCI ($n = 91$).

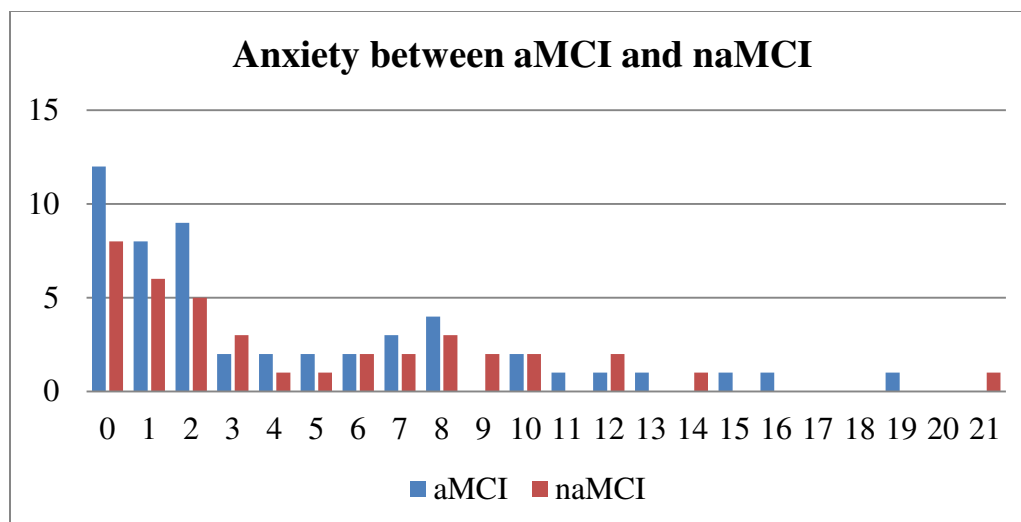


Figure 19. Distribution of anxiety by aMCI and naMCI (n = 91).

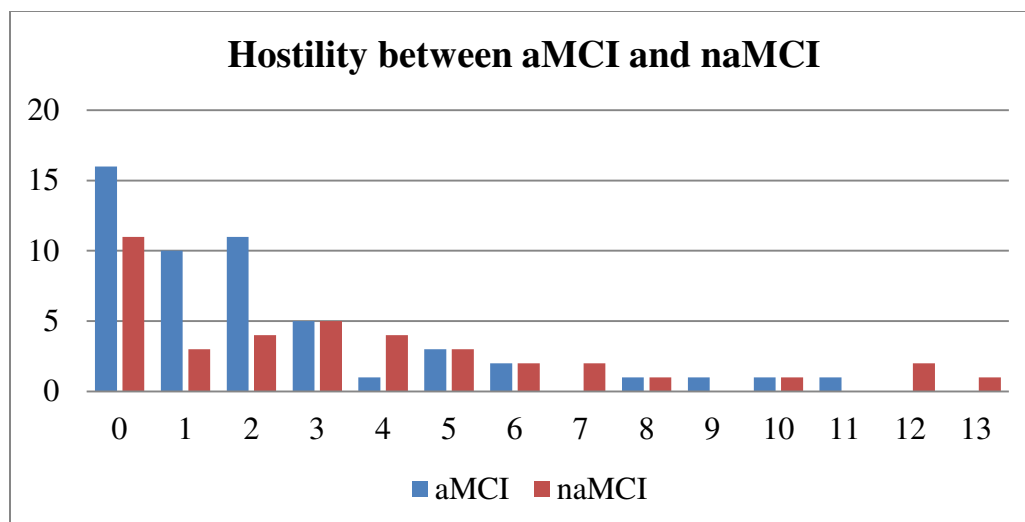


Figure 20. Distribution of hostility by aMCI and naMCI (n = 91).

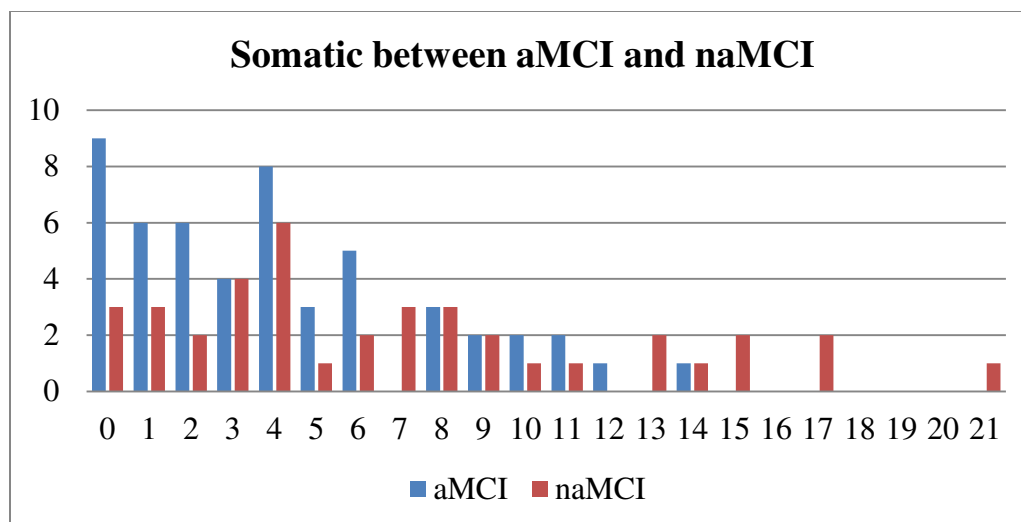


Figure 21. Distribution of somatic by aMCI and naMCI (n = 91).

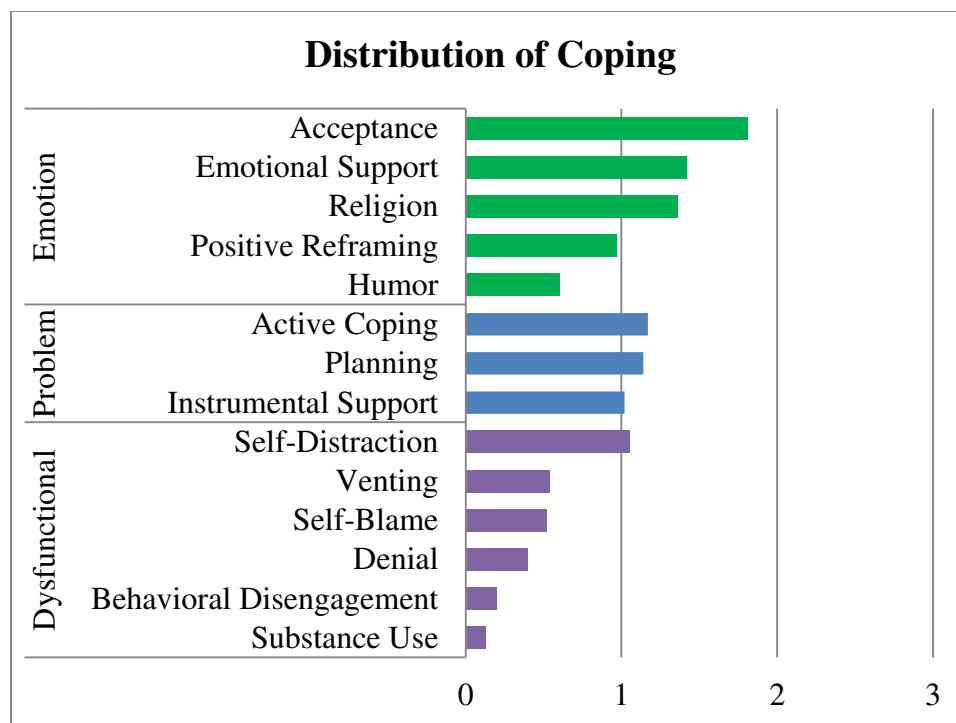


Figure 22. Distribution of coping behaviors ($n = 91$).

Note: 0 = Not at all, 1 = A little bit, 2 = A medium amount, and 3 = A lot.

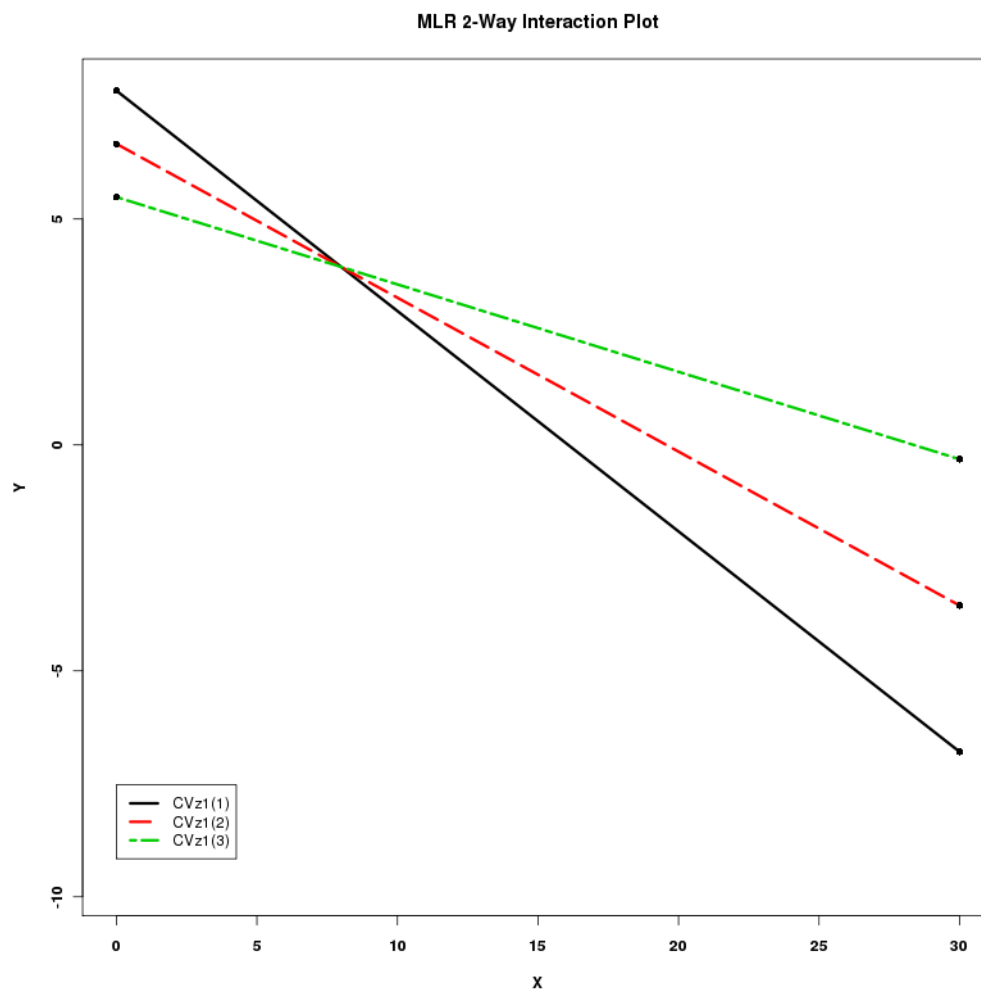


Figure 23. Interaction plot of USS-S on the relationship of BC-E and SQ-AH.

Note: $Y = \text{SQ=AH}$, $X = \text{BC=E}$, $\text{CVz}(1) = \text{USS-S Mean} + \text{SD}$, $\text{CVz}(2) = \text{USS-S Mean}$,
 $\text{CVz}(3) = \text{USS-S Mean} - \text{SD}$

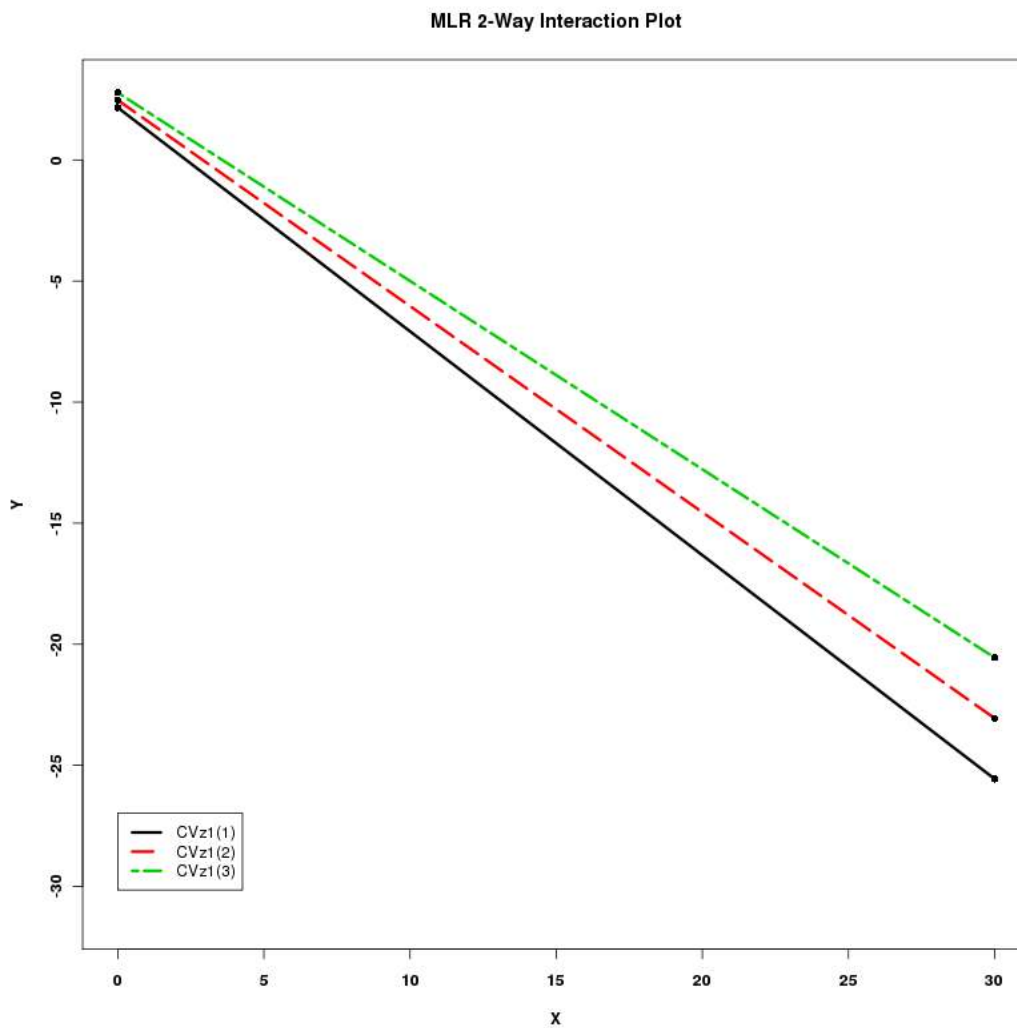


Figure 24. Interaction plot of age on the relationship of BC-E and SQ-AH.

Note: $Y = \text{SQ=AH}$, $X = \text{BC=E}$, $\text{CVz}(1) = \text{Age Mean} + \text{SD}$, $\text{CVz}(2) = \text{Age Mean}$, $\text{CVz}(3) = \text{Age Mean} - \text{SD}$

APPENDIX C: STUDY FORMS

The following appendix pages contain a copy of the consent form, recruitment flyer, and study instruments.

Human Subjects Consent Form

Please note, while the Institutional Review Board process has been started, approval has not yet been obtained for the following consent document.

CONSENT TO PARTICIPATE IN RESEARCH

Name of Study Subject: _____

Consequences of mild cognitive impairment.

Jennifer Sjostedt, Marquette University PhD-Student and Dr. Malgorzata Franczak Marquette University with the Department of Neurology

414-805-5224 Medical College of Wisconsin 8701 Watertown Plank Road

Milwaukee WI 53226

You are invited to take part in this research study. This form tells you why this research study is being done, what will happen in the research study, possible risks and benefits to you, your choices, and other important information. If there is anything that you do not understand, please ask questions. Then you can decide if you want to join this study or not.

A1. INTRODUCTION – WHY ARE WE ASKING YOU ABOUT THIS STUDY?

You are being invited to participate in this research study because you have been given a diagnosis of Mild Cognitive Impairment (MCI). Because of your diagnosis of MCI, you may be eligible for a research study which is investigating how people with MCI experience uncertainty, coping, and psychological distress (like depression).

A total of about 130 people are expected to participate in this study all at the Medical College of Wisconsin/Froedtert Hospital.

The Director of the study is Jennifer Sjostedt with Dr. Malgorzata Franczak in the Department of Neurology and at Marquette University. You can ask who these people are.

At this time, no funding has been received for this study.

A2. DO I HAVE TO BE IN THIS STUDY?

You can decide whether to take part in this study or not. You are free to say yes or no. Even if you join this study, you do not have to stay in it. You may stop at any time.

A3. WHY IS THIS RESEARCH STUDY BEING DONE?

In this study we want to find out more about the consequences of having MCI. The only way to find this out is to survey people with MCI about their levels of uncertainty, coping, and psychological distress from having a diagnosis of MCI.

B1. WHAT WILL HAPPEN IF I TAKE PART IN THE STUDY? Summary of study procedures:

To participate in this study, you will be asked to complete a number of directed paper and pencil surveys. Jennifer Sjostedt, a PhD student from Marquette University, or a hired research assistant from Marquette University will assist you with completing the surveys. Prior to starting the surveys, if you were not tested during your normal clinic visit using the Montreal Cognitive Assessment, you will first be screened using that instrument to make sure you fit the study's requirements. Next, you will be asked questions about your age, gender, educational level, marital status, religious beliefs, income, and profession. Finally, you will be given 3 surveys to complete regarding uncertainty, coping, and psychological distress. It is expected that participation in the

study will take up to 45 minutes. Data will be recorded for the study on an electronic password protected file with no identifying information such as your name, clinic visit date, or birthdate.

B2. HOW LONG WILL I BE IN THE STUDY?

Participation in this study will be a one-time commitment of up to 45 minutes.

B3. CAN I STOP BEING IN THE STUDY?

You are free to quit the study at any time. If you are thinking about quitting, please tell the study director.

The director can tell you about the effects of stopping, and you and the doctor can talk about what follow-up care would help you the most.

The study director may take you out of this study at any time. This would happen if:

- They think it is in your best interest.
- You do not follow the study rules.
- The whole study is stopped.

If this happens, the study director will tell you.

C1. WHAT RISKS OR PROBLEMS CAN I EXPECT FROM THE STUDY?

We watch everyone in the study for unexpected problems. You need to tell the study director or a member of the study team immediately if you experience any problems or become too upset.

C2. RISKS OF PARTICIPATION

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. You will also be asked some questions about psychological distress, which may tell us if you are potentially experiencing depression. If your responses suggest that you might be experiencing depression, we will request your permission to inform your physician in the Neurology Department that you may be experiencing depression, so that they might follow-up with you on treatment of depression.

C4. ARE THERE ANY BENEFITS TO TAKING PART IN THE STUDY?

This study will not help you, but we hope the information from this study will help us provide better health services for persons with MCI.

D1. ARE THERE ANY COSTS TO BEING IN THE STUDY?

There are no costs to you for participating in this study.

D2. WILL I BE PAID FOR PARTICIPATING IN THE STUDY?

If funding is received for this study, you will be compensated for participation with a \$10 Pick-n-Save gift card.

D3. WHAT OTHER CHOICES DO I HAVE?

You do not have to join this study. You are free to say yes or no.

If you do not join this study, your usual medical services will not change.

D4. WILL I BE GIVEN NEW INFORMATION ABOUT THE STUDY?

If we learn any important new information [about the intervention] that might change your mind about being in the study, we will tell you about it right away. You can then decide if you want to stay in the study.

D5. WHAT HAPPENS IF I AM HARMED BECAUSE I TOOK PART IN THE STUDY?

No funds have been set aside to pay any costs if you are harmed because of this study. If you think that you were harmed because of this study, let the study director, Jennifer Sjostedt know right away by calling (414)-810-2756. By signing this form, you do not give up your right to seek payment for harm you receive while participating in this study.

D6. WHO CAN ANSWER MY QUESTIONS ABOUT THE STUDY?

- If you have more questions about this study at any time, you can call Dr. Franczak at 414-805-5224.
- If you have questions about your rights as a study participant, want to report any problems or complaints, obtain information about the study, or offer input, you can call the MCW/Froedtert Hospital Research Subject Advocate at 414-456-8844.

E. PERMISSION TO COLLECT, USE AND SHARE HEALTH INFORMATION E1. What health information will be collected and used for this study?

To do this research study, we need your permission to collect and use some health information from you, or you cannot be in the study. This information may come from questions we ask, forms we ask you to fill out, or your medical record, as described below. We will only collect and use information needed for the study.

The health information we will collect and use for this study is:

Health information collected during this study such as questionnaires, and performance on cognitive testing.

Medical records dating from when you join this study until the end of the study.

E2. Who will see the health information collected for this study?

The only people allowed to handle your health information are those on the study team at the Medical College of Wisconsin/Froedtert Hospital and at Marquette University, those on the Institutional Review Board (IRB) and those who check on the research activities to make sure the hospital's rules are followed.

The study team may share your information with people who are not part of the study team because they planned, pay for, or work with us on this study. If this happens, the federal Privacy Rule may no longer protect your health information. For this study, we plan to share information with those doctors, researchers or government representatives working with us on this study at the institutions or companies listed here: Marquette University, Milwaukee, WI.

We may record your research information, including results of tests, procedures or questionnaires done for research, in your Froedtert Hospital and/or Medical College of Wisconsin medical record. As a result, this research information may be seen by people allowed to see your medical records for healthcare operations or treatment; by those you allow to see your medical records by giving written permission; and by others when required by law.

We will not use your personal health information for a different study without your permission or the permission of a hospital research review board (IRB). Once all personal identification is removed, the information might be used or released for other purposes without asking you.

Results of the study may be presented in public talks or written articles, but no information will be presented that identifies you.

E3. What are the risks of sharing this health information?

One risk of taking part in a research study is that more people will handle your personal health information collected for this study. The study team will make every effort to protect the information and keep it confidential, but it is possible that an unauthorized person might see it. Depending on the kind of information being collected, it might be used in a way that could embarrass you or affect your ability to get insurance. If you have questions, you can talk to the study director about whether this could apply to you.

E4. How long will you keep the health information for this study?

If you sign this form, we plan to keep your information for 3 years in case we need to check it again for this study.

E5. Can I cancel my permission to share this health information?

If you change your mind later and do not want us to collect or share your health information, you need to send a letter to Dr. Malgorzata Franczak at 9200 W. Wisconsin Avenue, Milwaukee, WI 53226. The letter must say that you have changed your mind and do not want the researcher to collect and share your health information. At that time, we may decide that you cannot continue to be part of the study. We may still use the information we have already collected. If your health information is no longer identified as yours, it is not possible to remove it from the study.

CONSENT TO PARTICIPATE IN THE STUDY

By signing my name below, I confirm the following:

- I have read (or had read to me) this entire consent document. All of my questions have been answered to my satisfaction.
- The study's purpose, procedures, risks and possible benefits have been explained to me.

- I agree to let the study team use and share the information gathered for this study.

- I voluntarily agree to participate in this research study. I agree to follow the study procedures as directed. I have been told that I can stop at any time.

IMPORTANT: You will receive a signed and dated copy of this Consent Form. Please keep it where you can find it easily. It will help you remember what we discussed today.

Recruitment Flyer

Have you been told that you have *mild cognitive impairment (MCI)*?
Are you willing to share some details of your experience with it?

After your normal clinic appointment today you will have the opportunity to talk with a student researcher from Marquette University who is interested in learning more about the consequences of having a diagnosis of mild cognitive impairment. The study involves a one-time guided interview using paper questionnaires, which may take up to 30 minutes total to complete. Please let your physician or nurse know if you would like to hear more about the study, and the student researcher will visit with you after your appointment today!

Instruments

Copies of all scoring instructions and study instruments are included in the order that they will be administered. Starting on the next page, you will find the scoring instructions (where applicable) followed by study instruments in this order:

- (1) Montreal Cognitive Assessment (Nasreddine, 2011)
Obtained from www.mocatest.org
- (2) Demographic Survey
- (3) Uncertainty Stress Scale (Hilton, 1994)
- (4) BriefCOPE (Carver, 1997)
Obtained from <http://www.psy.miami.edu/faculty/ccarver/sclBrCOPE.html>
- (5) Symptom Questionnaire (Kellner, 1987)

Montreal Cognitive Assessment (MoCA)

Administration and Scoring Instructions

The Montreal Cognitive Assessment (MoCA) was designed as a rapid screening instrument for mild cognitive dysfunction. It assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. Time to administer the MoCA is approximately 10 minutes. The total possible score is 30 points; a score of 26 or above is considered normal.

1. Alternating Trail Making:

Administration: The examiner instructs the subject: *"Please draw a line, going from a number to a letter in ascending order. Begin here [point to (1)] and draw a line from 1 then to A then to 2 and so on. End here [point to (F)]."*

Scoring: Allocate one point if the subject successfully draws the following pattern: 1 -A- 2- B- 3- C- 4- D- 5- E, without drawing any lines that cross. Any error that is not immediately self-corrected earns a score of 0.

2. Visuoconstructional Skills (Cube):

Administration: The examiner gives the following instructions, pointing to the cube: *"Copy this drawing as accurately as you can, in the space below"*.

Scoring: One point is allocated for a correctly executed drawing.

- Drawing must be three-dimensional
- All lines are drawn
- No line is added
- Lines are relatively parallel and their length is similar (rectangular prisms are accepted)

A point is not assigned if any of the above-criteria are not met.

3. Visuoconstructional Skills (Clock):

Administration: Indicate the right third of the space and give the following instructions: *"Draw a clock. Put in all the numbers and set the time to 10 past 11"*.

Scoring: One point is allocated for each of the following three criteria:

- Contour (1 pt.): the clock face must be a circle with only minor distortion acceptable (e.g., slight imperfection on closing the circle);
- Numbers (1 pt.): all clock numbers must be present with no additional numbers; numbers must be in the correct order and placed in the approximate quadrants on the clock face; Roman numerals are acceptable; numbers can be placed outside the circle contour;
- Hands (1 pt.): there must be two hands jointly indicating the correct time; the hour hand must be clearly shorter than the minute hand; hands must be centred within the clock face with their junction close to the clock centre.

A point is not assigned for a given element if any of the above-criteria are not met.

4. Naming:

Administration: Beginning on the left, point to each figure and say: *"Tell me the name of this animal"*.

Scoring: One point each is given for the following responses: (1) lion (2) rhinoceros or rhino (3) camel or dromedary.

5. Memory:

Administration: The examiner reads a list of 5 words at a rate of one per second, giving the following instructions: *"This is a memory test. I am going to read a list of words that you will have to remember now and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn't matter in what order you say them"*. Mark a check in the allocated space for each word the subject produces on this first trial. When the subject indicates that (s)he has finished (has recalled all words), or can recall no more words, read the list a second time with the following instructions: *"I am going to read the same list for a second time. Try to remember and tell me as many words as you can, including words you said the first time."* Put a check in the allocated space for each word the subject recalls after the second trial.

At the end of the second trial, inform the subject that (s)he will be asked to recall these words again by saying, *"I will ask you to recall those words again at the end of the test."*

Scoring: No points are given for Trials One and Two.

6. Attention:

Forward Digit Span: Administration: Give the following instruction: *"I am going to say some numbers and when I am through, repeat them to me exactly as I said them"*. Read the five number sequence at a rate of one digit per second.

Backward Digit Span: Administration: Give the following instruction: *"Now I am going to say some more numbers, but when I am through you must repeat them to me in the backwards order."* Read the three number sequence at a rate of one digit per second.

Scoring: Allocate one point for each sequence correctly repeated, (*N.B.:* the correct response for the backwards trial is 2-4-7).

Vigilance: Administration: The examiner reads the list of letters at a rate of one per second, after giving the following instruction: *"I am going to read a sequence of letters. Every time I say the letter A, tap your hand once. If I say a different letter, do not tap your hand"*.

Scoring: Give one point if there is zero to one errors (an error is a tap on a wrong letter or a failure to tap on letter A).

Serial 7s: Administration: The examiner gives the following instruction: "Now, I will ask you to count by subtracting seven from 100, and then, keep subtracting seven from your answer until I tell you to stop." Give this instruction twice if necessary.

Scoring: This item is scored out of 3 points. Give no (0) points for no correct subtractions, 1 point for one correction subtraction, 2 points for two-to-three correct subtractions, and 3 points if the participant successfully makes four or five correct subtractions. Count each correct subtraction of 7 beginning at 100. Each subtraction is evaluated independently; that is, if the participant responds with an incorrect number but continues to correctly subtract 7 from it, give a point for each correct subtraction. For example, a participant may respond "92 – 85 – 78 – 71 ... 64" where the "92" is incorrect, but all subsequent numbers are subtracted correctly. This is one error and the item would be given a score of 3.

7. Sentence repetition:

Administration: The examiner gives the following instructions: "I am going to read you a sentence. Repeat it after me, exactly as I say it [pause]; I only know that John is the one to help today." Following the response, say: "Now I am going to read you another sentence. Repeat it after me, exactly as I say it [pause]: The cat always hid under the couch when dogs were in the room."

Scoring: Allocate 1 point for each sentence correctly repeated. Repetition must be exact. Be alert for errors that are omissions (e.g., omitting "only", "always") and substitutions/additions (e.g., "John is the one who helped today;" substituting "hides" for "hid", altering plurals, etc.).

8. Verbal fluency:

Administration: The examiner gives the following instruction: "Tell me as many words as you can think of that begin with a certain letter of the alphabet that I will tell you in a moment. You can say any kind of word you want, except for proper nouns (like Bob or Boston), numbers, or words that begin with the same sound but have a different suffix, for example, love, lover, loving. I will tell you to stop after one minute. Are you ready? [Pause] Now, tell me as many words as you can think of that begin with the letter F. [time for 60 sec]. Stop."

Scoring: Allocate one point if the subject generates 11 words or more in 60 sec. Record the subject's response in the bottom or side margins.

9. Abstraction:

Administration: The examiner asks the subject to explain what each pair of words has in common, starting with the example: "Tell me how an orange and a banana are alike". If the subject answers in a concrete manner, then say only one additional time: "Tell me another way in which those items are alike". If the subject does not give the appropriate response (fruit), say, "Yes, and they are also both fruit." Do not give any additional instructions or clarification. After the practice trial, say: "Now, tell me how a train and a bicycle are alike". Following the response, administer the second trial, saying: "Now tell me how a ruler and a watch are alike". Do not give any additional instructions or prompts.

Scoring: Only the last two item pairs are scored. Give 1 point to each item pair correctly answered. The following responses are acceptable:

Train-bicycle = means of transportation, means of travelling, you take trips in both;

Ruler-watch = measuring instruments, used to measure.

The following responses are **not** acceptable: Train-bicycle = they have wheels; Ruler-watch = they have numbers.

10. **Delayed recall:**

Administration: The examiner gives the following instruction: "I read some words to you earlier, which I asked you to remember. Tell me as many of those words as you can remember." Make a check mark (✓) for each of the words correctly recalled spontaneously without any cues, in the allocated space.

Scoring: Allocate 1 point for each word recalled freely without any cues.

Optional:

Following the delayed free recall trial, prompt the subject with the semantic category cue provided below for any word not recalled. Make a check mark (✓) in the allocated space if the subject remembered the word with the help of a category or multiple-choice cue. Prompt all non-recalled words in this manner. If the subject does not recall the word after the category cue, give him/her a multiple choice trial, using the following example instruction, "Which of the following words do you think it was, NOSE, FACE, or HAND?"

Use the following category and/or multiple-choice cues for each word, when appropriate:

FACE: category cue: part of the body

multiple choice: nose, face, hand

VELVET: category cue: type of fabric

multiple choice: denim, cotton, velvet

CHURCH: category cue: type of building

multiple choice: church, school, hospital

DAISY: category cue: type of flower

multiple choice: rose, daisy, tulip

RED: category cue: a colour

multiple choice: red, blue, green

Scoring: No points are allocated for words recalled with a cue. A cue is used for clinical information purposes only and can give the test interpreter additional information about the type of memory disorder. For memory deficits due to retrieval failures, performance can be improved with a cue. For memory deficits due to encoding failures, performance does not improve with a cue.

11. **Orientation:**

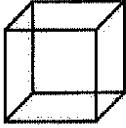
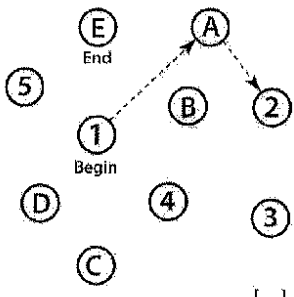
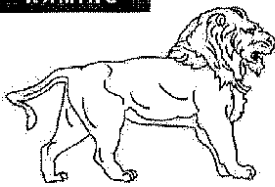
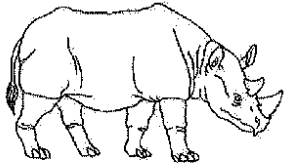
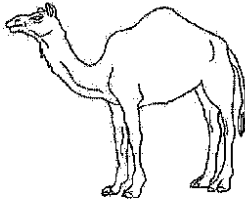
Administration: The examiner gives the following instructions: "Tell me the date today". If the subject does not give a complete answer, then prompt accordingly by saying: "Tell me the [year, month, exact date, and day of the week]." Then say: "Now, tell me the name of this place, and which city it is in."

Scoring: Give one point for each item correctly answered. The subject must tell the exact date and the exact place (name of hospital, clinic, office). No points are allocated if subject makes an error of one day for the day and date.

TOTAL SCORE: Sum all subscores listed on the right-hand side. Add one point for an individual who has 12 years or fewer of formal education, for a possible maximum of 30 points. A final total score of 26 and above is considered normal.

MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME: _____
Education: _____ Date of birth: _____
Sex: _____ DATE: _____

VISUOSPATIAL / EXECUTIVE		 Copy cube: []	Draw CLOCK (Ten past eleven) (3 points): []	POINTS																	
 []	[]	[]	[]	[]																	
NAMING		 []	 []	 []	___/3																
MEMORY	Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.	<table border="1" style="width:100%; border-collapse: collapse;"> <tr> <td></td> <td style="text-align: center;">FACE</td> <td style="text-align: center;">VELVET</td> <td style="text-align: center;">CHURCH</td> <td style="text-align: center;">DAISY</td> <td style="text-align: center;">RED</td> </tr> <tr> <td style="text-align: center;">1st trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td style="text-align: center;">2nd trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>		FACE	VELVET	CHURCH	DAISY	RED	1st trial						2nd trial						No points
	FACE	VELVET	CHURCH	DAISY	RED																
1st trial																					
2nd trial																					
ATTENTION	Read list of digits (1 digit/sec). Subject has to repeat them in the forward order [] 2 1 8 5 4 Subject has to repeat them in the backward order [] 7 4 2				___/2																
Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors.		[] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B			___/1																
Serial 7 subtraction starting at 100 [] 93 [] 86 [] 79 [] 72 [] 65		4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt			___/3																
LANGUAGE	Repeat: I only know that John is the one to help today. [] The cat always hid under the couch when dogs were in the room. []				___/2																
Fluency / Name maximum number of words in one minute that begin with the letter F [] _____ (N ≥ 11 words)					___/1																
ABSTRACTION	Similarity between e.g. banana - orange = fruit [] train - bicycle [] watch - ruler				___/2																
DELAYED RECALL	Has to recall words WITH NO CUE []	FACE []	VELVET []	CHURCH []	DAISY []	RED []	Points for UNCUED recall only	___/5													
Optional	Category cue: _____																				
	Multiple choice cue: _____																				
ORIENTATION	[] Date [] Month [] Year [] Day [] Place [] City				___/6																
© Z. Nasreddine MD www.mocatest.org Normal ≥ 26 / 30		TOTAL		___/30																	
Administered by: _____				Add 1 point if ≤ 12 y/edu																	

Demographic Questionnaire

Questions	Answers
1. What is your gender (Male, Female)?	
2. What is your age (Years)?	
3. What is your race/ethnicity (Caucasian/White, African American/Black, Hispanic/Latino, Asian, Other)?	
4. Are you single, married, divorced or widowed?	
5. How many years of school have you completed?	
6. What, if any, is your religious affiliation? (i.e. Catholic, Muslim, Methodist, etc)	
7. Are you currently employed? (Yes/No)	
8. What do you (<i>or did you</i>) do for work?	
9. How long have you been in (<i>or were in</i>) that profession?	
10. Which of the following best describes your annual income: Under \$25,000 \$25,001 – 49,999 \$50,000 – 74,999 \$75,000 – 99,999 \$100,000 – 149,999 Over \$150,000 Prefer not to say	
11. When were you diagnosed with MCI? (Month/Year)	

UNCERTAINTY STRESS SCALE
MILD COGNITIVE IMPAIRMENT VERSION
© A. Hilton, University of British Columbia, Vancouver, Canada

Scoring Instructions:

Degree of uncertainty rated for items 1 through 55 are totaled to give a cumulative score of uncertainty. Higher cumulative totals equate to higher uncertainty.
Degree of stress rated for items 1 through 54 and 56 through 57 are totaled to give a cumulative score of stress from uncertainty. Higher cumulative totals equate to higher stress from uncertainty.
Items 58 and 59 indicate positive feelings from uncertainty. Higher cumulative totals equate to more positive feelings regarding uncertainty.

Instrument:

Please read the following statements. To the right of each statement you will see columns labeled from 0 (No uncertainty) to 4 (Very high amount of uncertainty). Circle the number that most closely measures how you feel now about your uncertainties related to your diagnosis of mild cognitive impairment (MCI).

To the far right of each statement you will find three more columns of numbers. Circle the number in the column that most closely reflects the degree of stress you feel related to the uncertainty you identified.

Please respond to every statement. There are no 'right' or 'wrong' answers.

Degree of Uncertainty	Degree of Stress
(0) None	(0) None or very low
(1) Low	(1) Moderate
(2) Moderate	(2) High to very high
(3) High	
(4) Very High	
(N/A) Not Applicable	

I am uncertain:

1. whether changes in my mild cognitive impairment (MCI) will be detected early	0	1	2	3	4	N/A	0	1	2
2. about the stability of my MCI	0	1	2	3	4	N/A	0	1	2
3. what caused my MCI	0	1	2	3	4	N/A	0	1	2
4. whether I will be able to maintain my present level of functioning	0	1	2	3	4	N/A	0	1	2
5. about the present state of my MCI situation	0	1	2	3	4	N/A	0	1	2

1. whether changes in my mild cognitive impairment (MCI) will be detected early	0	1	2	3	4	N/A	0	1	2
6. what questions to ask my doctors about my MCI situation	0	1	2	3	4	N/A	0	1	2
7. whether changing my lifestyle will help my condition	0	1	2	3	4	N/A	0	1	2
8. how to make sense of what I am told about my MCI	0	1	2	3	4	N/A	0	1	2
9. about the effectiveness of my treatments	0	1	2	3	4	N/A	0	1	2
10. whether my MCI condition is under control	0	1	2	3	4	N/A	0	1	2

Degree of Uncertainty
 (0) None
 (1) Low
 (2) Moderate
 (3) High
 (4) Very High
 (N/A) Not Applicable

Degree of Stress
 (0) None or very low
 (1) Moderate
 (2) High to very high

I am uncertain:

11. whether my MCI condition will cause me to have symptoms	0	1	2	3	4	N/A	0	1	2
12. what to say to others about my MCI situation	0	1	2	3	4	N/A	0	1	2
13. about differing explanations I have been given	0	1	2	3	4	N/A	0	1	2
14. about my chances to be well	0	1	2	3	4	N/A	0	1	2
15. whether my MCI situation will be the same in 5 years	0	1	2	3	4	N/A	0	1	2
16. whether my symptoms can be controlled	0	1	2	3	4	N/A	0	1	2
17. whether my MCI situation will interfere with my ability to do my usual activities	0	1	2	3	4	N/A	0	1	2
18. about my doctor(s)' abilities	0	1	2	3	4	N/A	0	1	2
19. how to manage my symptoms	0	1	2	3	4	N/A	0	1	2

20. about choices made regarding my treatments	0	1	2	3	4	N/A	0	1	2
21. whether my MCI disorder will return	0	1	2	3	4	N/A	0	1	2
22. about the adequacy of the follow-up I am having	0	1	2	3	4	N/A	0	1	2
23. about my understanding of the treatments I have received or am receiving	0	1	2	3	4	N/A	0	1	2
24. how to approach health care workers about my care (for example, nurses, doctors, dietitians)	0	1	2	3	4	N/A	0	1	2
25. whether the MCI situation will be involved in my death	0	1	2	3	4	N/A	0	1	2

Degree of Uncertainty **Degree of Stress**
 (0) None (0) None or very low
 (1) Low (1) Moderate
 (2) Moderate (2) High to very high
 (3) High
 (4) Very High
 (N/A) Not Applicable

I am uncertain:

26. whether my treatments have corrected my condition	0	1	2	3	4	N/A	0	1	2
27. whether any changes brought about by my MCI affects my relationships	0	1	2	3	4	N/A	0	1	2
28. whether my MCI situation will affect my life goals	0	1	2	3	4	N/A	0	1	2
29. whether what I am doing about my MCI situation will help me	0	1	2	3	4	N/A	0	1	2
30. whether I can depend on test results as an indicator of my condition	0	1	2	3	4	N/A	0	1	2
31. whether my MCI condition will affect my sex life	0	1	2	3	4	N/A	0	1	2
32. whether delays in treatment will influence my chances of successful recovery	0	1	2	3	4	N/A	0	1	2
33. about the seriousness of my condition	0	1	2	3	4	N/A	0	1	2
34. about my ability to handle my emotions related to the MCI	0	1	2	3	4	N/A	0	1	2

35. about the unpredictability of my symptoms	0	1	2	3	4	N/A	0	1	2
36. whether I will have difficulty coping with my MCI situation	0	1	2	3	4	N/A	0	1	2
37. about the quality of information I have	0	1	2	3	4	N/A	0	1	2
38. how long my symptoms will last	0	1	2	3	4	N/A	0	1	2
39. whether I am being told the truth about my MCI situation	0	1	2	3	4	N/A	0	1	2
40. whether I would choose to have all the treatments recommended to me	0	1	2	3	4	N/A	0	1	2

Degree of Uncertainty
 (0) None
 (1) Low
 (2) Moderate
 (3) High
 (4) Very High
 (N/A) Not Applicable

Degree of Stress
 (0) None or very low
 (1) Moderate
 (2) High to very high

I am uncertain:

41. what unusual symptoms mean in terms of my MCI situation	0	1	2	3	4	N/A	0	1	2
42. whether they might find something wrong when I go for a checkup	0	1	2	3	4	N/A	0	1	2
43. whether I will be well cared for by the nurses	0	1	2	3	4	N/A	0	1	2
44. whether I will be well cared for by the health professionals other than the nurses	0	1	2	3	4	N/A	0	1	2
45. about the cause of my symptoms	0	1	2	3	4	N/A	0	1	2
46. whether I can depend on people who are important to me to be there when I need them	0	1	2	3	4	N/A	0	1	2
47. whether insurance can be obtained because of my condition	0	1	2	3	4	N/A	0	1	2
48. whether I can manage financially because of my condition	0	1	2	3	4	N/A	0	1	2
49. what symptoms I should be aware of	0	1	2	3	4	N/A	0	1	2

50. about how to choose the treatments I should have	0	1	2	3	4	N/A	0	1	2
51. whether following the treatment plan recommended to me will help	0	1	2	3	4	N/A	0	1	2
52. what to look for to check the state of my MCI situation	0	1	2	3	4	N/A	0	1	2
53. whether treatments will eliminate the MCI	0	1	2	3	4	N/A	0	1	2
54. how to manage my medical care	0	1	2	3	4	N/A	0	1	2

The following five questions relate to levels of a particular feeling or perception. Please make a cross (X) on the line which best indicates your level right now.

55. Overall, my uncertainty level about my MCI situation is:



56. Overall, the stress I feel from my uncertainty is:



57. Overall, the threat I feel from my uncertainty is:



Some people find that uncertainty can have positive feelings (such as hope) associated with it because of the possibility that things will work out well.

58. Do you have any positive feelings because of your uncertainty?

Yes _____ No _____

59. If yes, the level of my positive feelings is:



BriefCOPE

Retrieved from: <http://www.psy.miami.edu/faculty/ccarver/sclBrCOPE.html>

Instructions:

The Brief COPE contains 28 items which assess fourteen coping reactions (with two items for each for each reaction): active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, self distraction, denial, venting, substance use, behavioral disengagement, and self-blame (Carver, 1997). The fourteen coping reactions can be reduced into three sub-scales of coping: (1) emotion-focused coping (acceptance, emotional support, positive reframing, religion, and humor); (2) problem-focused coping (active coping, planning, instrumental support); and (3) dysfunctional coping (self-distraction, venting, self-blame, behavioral disengagement, denial, and substance use) (McIlvane et al., 2008).

Scales are computed as follows by totaling participant responses (with no reversals of coding):

Sub-scales	Coping reactions and instrument items
Emotion-focused coping	Use of emotional support, items 5 and 15 Positive reframing, items 12 and 17 Humor, items 18 and 28 Acceptance, items 20 and 24 Religion, items 22 and 27
Problem-focused coping	Active coping, items 2 and 7 Use of instrumental support, items 10 and 23 Planning, items 14 and 25
Dysfunctional coping	Self-distraction, items 1 and 19 Denial, items 3 and 8 Substance use, items 4 and 11 Behavioral disengagement, items 6 and 16 Venting, items 9 and 21 Self-blame, items 13 and 26

Instrument:

These items deal with ways you've been coping with the stress in your life since you found out you have mild cognitive impairment. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how

frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

(Revised - January 1987)

MANUAL OF THE SYMPTOM QUESTIONNAIRE

Robert Kellner*

Abstract

The Symptom Questionnaire (SQ) is a yes/no questionnaire with brief and simple items. It contains self-rating scales of depression, anxiety, somatic symptoms and anger-hostility. Each symptom subscale has a corresponding well-being subscale which can serve as a check of internal consistency of the results. In several studies the scales were found to be valid and reliable. The psychometric properties of the SQ are somewhat different from those of similar scales. In double-blind crossover studies the scales tended to be somewhat more sensitive than other scales in discriminating between the effects of a psychotropic drug and placebo. The scales were found to be highly sensitive in discriminating between populations. In studies with small or moderately sized samples in which sensitivity of scales is important and in populations that include subjects with poor verbal skills such as in an average clinic population, the SQ appears to have advantages (19).

Description and Development

The items of the Symptom Questionnaire (SQ) are derived from the original list of symptoms from which the Symptom Rating Test (27) was constructed. The SQ differs from the checklist of the Symptom Rating Test in that it has brief items and that instead of questions it has a larger number of items (a total of 92). The research data on which the SQ is based are presented in a paper describing the development of the Symptom Rating Test (27). The principles of the design of distress scales have been discussed elsewhere (17,18). The SQ was developed and validated in conjunction with other self-rating scales as well as observer-rating scales (16). The SQ was developed because the yes-no section of the Symptom Rating Test (the SRT Checklist) was found to be more sensitive in discriminating between drug and placebo than the self-ratings of the severity and frequency of symptoms (28). Several of the studies referred to in this manual have been published; others are unpublished data or are awaiting publication.

The SQ consists of items which indicate symptoms and items constructed from antonyms which indicate well-being. For example, the depression scale contains items such as "no hope" and items such as "happy." If "no hope" is checked YES, the response scores one; if "happy" is checked NO, the response also scores one. In other words, the subject scores one for each symptom which he checks YES, and scores one for each statement of well-being which he checks NO. (In order to avoid double negatives, a few items have TRUE or FALSE responses.) The SQ contains four scales: anxiety, depression, somatic symptoms and anger-hostility; these scales were constructed from a review of the literature of factor analyses of symptoms of psychiatric patients and normals. There is evidence from recent studies that the total distress score (the sum of the four scale scores) tends to be a more sensitive measure of distress than the score of the individual scales.

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Item analyses were carried out for 114 symptoms and statements of well-being. Those items that discriminated between psychiatric patients and normals and that tended to discriminate between a psychotropic drug and placebo in three drug trials were retained in the final version for three of the scales. A previous version of the SQ contained a fourth scale, "feelings of inadequacy." This scale was deleted from subsequent versions because it consisted of more than one factor. The fourth scale--anger-hostility--was later constructed as follows: Statements were selected from interviews with neurotic patients and patients with personality disorders which the investigator judged to express anger or hostility. (Throughout this manual "anger-hostility" and hostility are used synonymously). Another psychiatrist made an independent judgement and the statements on which there was agreement were retained. In two studies the items which were answered "Yes" significantly more frequently by hostile patients than by others (normal subjects or patients judged to be not hostile) were retained. The literature on factor analysis of symptoms in psychiatric patients and normals was surveyed and only items which were part of a factor of anger, hostility and irritability were retained. In one subsequent study with psychiatric inpatients those who were judged to feel more angry and hostile scored significantly higher than other patients. Analyses revealed that the scales became more sensitive when the number of items was increased to about 16 to 20 and when the statements of well-being were included in the scales (25,28). This is in contrast to scales in which the subject rates severity or frequency of symptoms, when a smaller number of items is adequate (17,18,27).

Validity, Sensitivity and Study Results

Psychiatric Patients. The methods of validation of scales of distress have been discussed elsewhere (27). The SQ was administered to psychiatric patients and normals in eleven studies. All four scales significantly discriminated between the two populations. The means and standard deviations from one study are listed in Table I. In twelve studies with psychiatric patients, the scores changed with treatment in the expected direction and the changes were parallel with the changes in ratings by psychiatrists using standard psychiatric rating scales. The specificity of the Symptom Questionnaire is similar to that of the checklist of the Symptom Rating Test (SRT) (27).

Psychosomatic Disorders. In studies of patients with psychosomatic disorders and studies of psychophysiological relationships, the SQ sensitively discriminated between patients with different diseases or disorders (5,11) or changed in the expected direction. For example, in two studies all scales and subscales of the SQ discriminated between hyperprolactinemic women and women with normal prolactin levels (5,21). Postpartum women with high prolactin levels scored significantly higher on the anger-hostility scale than normal controls (33). In a double-blind placebo controlled study of bromocriptine in patients with hyperprolactinemia, the SQ scales of depression, anxiety and hostility discriminated significantly between the effects of the treatments, whereas the Beck Depression Inventory failed to do so (3). The SQ scores changed sensitively in a longitudinal study of women in various stages of their pregnancy undergoing amniocentesis (8,13). Similar changes were found in a subsequent study of amniocentesis (37). The SQ discriminated between amenorrheic and normal women, whereas the SRT score

did not discriminate at a significant level (32). In a prospective study of healthy elderly subjects, the total SQ score was significantly increased after crises, was positively correlated with serum cortisol levels and negatively correlated with caloric intake (38).

Physical Diseases. When the SQ was used in studies with patients with physical diseases, the scales discriminated between groups. In a walk-in clinic, the SQ was administered to consecutive patients during an influenza epidemic. Patients who had respiratory tract infection had higher scores on all SQ scales than other patients regardless of whether they had clinical influenza or another respiratory tract infection. The Eysenck Personality Inventory did not discriminate between any of the groups or subgroups (15). In a group of patients with cancer, undergoing chemotherapy and radiotherapy, the group was divided into those who stated they had no symptoms of depression (or no more than "normal"), those who stated they were depressed because of having cancer, and those who stated they were depressed for reasons other than having cancer. The last group had the highest depression, anxiety and somatic scores on the SQ. Their somatic symptoms were significantly more numerous than those in the two other groups, which suggests that a substantial proportion of somatic symptoms in cancer patients who are depressed are caused by the depression and not by cancer (35). In order to evaluate the relationship of anxiety to breathlessness in patients with chronic airflow obstruction, the SQ was administered together with the corresponding scales of the Hopkins Symptom Checklist to patients with chronic airflow obstruction. The patients rated various chest symptoms including breathlessness on several self-rating scales, and physicians also rated various forms of breathlessness and distress. The correlations of self-rated breathlessness with the scales of the HSCL and SQ were in a similar direction. In a stepwise regression the SQ Depression Scale and the HSCL Depression Scale were the only psychological measures predicting breathlessness (26).

Subgroups and Comparisons with Previous Studies. The SQ has been used to discriminate between subgroups of psychiatric patients. For example, in primary depressed patients, hostility scores were significantly lower in those who had experienced recent losses than in those who had no losses (10). In a later study with melancholic patients, those who had experienced losses rated themselves as significantly more friendly than other melancholics (6).

In a few studies, the mean score of the SQ differentiated between various groups of subjects, such as psychiatric patients and controls, whereas, in previous studies in which other scales were used, no significant differences were detected. For example, in a study of patients with bipolar disorder in remission and on lithium maintenance treatment, several psychological tests were administered and the patients rated with a modified form of the Brief Psychiatric Rating Scale; none of the scores discriminated significantly between patients and normal controls (31). In a subsequent study of patients also with bipolar disorder who were on lithium maintenance treatment and normal controls, three of the SQ symptom subscales were significantly higher and three well-being subscales significantly lower in patients than in controls; the differences on the two somatic subscales did not reach a significant level (12).

Drug Trials. The validation studies included tests of sensitivity in discriminating between the effects of an active psychotropic drug and placebo in double-blind drug trials--a validation against an external chemical criterion (4,17). The principle was that (for example) an anxiety scale

which discriminates significantly between the effects of an effective antianxiety drug and placebo in a double-blind trial with anxious patients is judged to be valid; it is also judged to be more sensitive in the measurement of changes in anxiety states than another scale which failed to discriminate in the same trial. In two crossover drug trials of antianxiety drugs and placebo (22,25), the SQ scales discriminated between the effects of the psychotropic drug and placebo more sensitively than observer ratings. In one of these studies with propranolol, the SQ was the only one of several observer rating and self-rating scales which discriminated significantly between drug and placebo. Moreover, only the anxiety and somatic scales discriminated at a significant level, which is in keeping with the known pharmacological effects of propranolol.

The SRT Symptom Checklist was the immediate precursor of the SQ. It shares many of the SQ items and also includes a yes/no questionnaire; the yes/no responses are simple and are apparently suitable for the majority of subjects. The checklist was administered in an early double-blind study (latin square design) of diazepam, hydroxyzine pamoate, and placebo. The checklist discriminated significantly between diazepam and the other treatments, whereas the Taylor Manifest Anxiety Scale failed to do so (23). In a placebo controlled multicenter double-blind drug trial of chlorazepote and placebo, the checklist was more sensitive than the self-ratings of the SRT (7). In a double-blind between subjects drug trial with depressed inpatients in which imipramine 150 mg daily was compared with 300 mg, there was a consistent trend on all measures for 300 mg to be more effective (36). The total score of the SRT symptom checklist was the only total self-rating scale score that discriminated significantly between the two doses (29). Normal Subjects. The SQ has been used to discriminate between groups of normal subjects. For example, law students were found to be more depressed and hostile than medical students (30) both on the SQ and the HSCL. Law students reported significantly less well-being on three of the four well-being subscales, a finding that suggests consistency in results. In another study, medical students attending traditional courses were compared longitudinally with students who attended a new practical curriculum. There were no differences in distress initially; at the end of the final semester the students in the traditional course had significantly higher total SQ scores, and this difference was maintained throughout four semesters of the study (34).

In a normal group, all four symptom subscales correlated positively, and all well-being scales negatively, with life events. The "Friendly" subscale was an exception in that the correlation was negative but did not reach a significant level (24). In a study of teachers, all four SQ scales were positively correlated with a self-rated external locus of control (2).

Some of the above studies were carried out with small samples, and subsequently the results were replicated with larger samples. Thus, in addition to conventional validation studies, new methods of scale construction and validation have been used with the aim of making the SQ more sensitive for clinical research.

Reliability

The principles of the testing of reliability of distress scales which purport to measure changes have been discussed elsewhere (17,27). The test-retest reliability of a personality inventory is evidence of its

temporal stability; a test which aims at measuring stable personality traits should have largely unaltered scores with the passage of time. Since the SQ measures distress--a changeable state--retest after a long time interval measures an altered state in a large proportion of patients. The function of the SQ is analogous to that of a clinical thermometer, rather than to that of a tape measure.

In all the studies described here the week form of the SQ was used. The split half reliability of changes (17) (the correlation of changes in the split halves of each scale) after two weeks in anxious and depressed neurotic outpatients (N22) was as follows: anxiety +0.92, depression +0.94, somatic symptoms +0.86, hostility +0.91. The findings suggest that the scales are reliable in that the changes of one half of each scale are highly correlated with the changes in the other half. In the same study, both halves discriminated between chlordiazepoxide and placebo (25).

The conventional split half reliability ranged in various studies from +0.75 to +0.95, median +0.83; for depression, +0.74 to +0.93, median +0.91; for somatic symptoms, +0.57 to +0.84, median +0.78; for hostility, +0.78 to +0.95, median +0.89.

The conventional test-retest reliability was carried out in spite of the reservation listed above. In a study with anxious outpatients, after four weeks (N18) the test-retest correlations were as follows: anxiety +0.71, depression +0.95, somatic +0.77 and hostility +0.82. With one exception, all correlation coefficients had $p < .001$. (The one exception was the conventional test-retest correlation of the somatic symptom scale, which was $p < .005$). These tests of reliability were similar to those of the Symptom Rating Test (27). The well-being subscales are unstable; particularly the contentment subscale seems to measure a fleeting mood (7). In a crossover drug trial with antianxiety drugs, the subscales of well-being tended to be more sensitive to treatment effects than the symptom subscales (25). Conversely, the test-retest correlation of the symptom subscales is high; in normal subjects (N 20) after one month it was +0.96 for anxiety and for depression also +0.96 (7). Although the SQ scales are state measures and sensitive to change, their conventional test-retest reliability compares favorably with other scales of psychopathology, such as the MMPI (14).

Response sets tend to make a scale more stable. Since the SQ scales discriminate sensitively between the effects of psychotropic drugs and placebo, it is unlikely that response bias or response set is responsible for the stability of the scores after a time interval (27). A likely explanation for the relatively high conventional test-retest reliability is a high consistency of responses in subjects whose state remains unchanged.

Administration

The time focus of the Symptom Questionnaire, like that of the original Symptom Rating Test (27), can be varied. For example, a patient can be asked to describe how he feels now (Now Form), how he has felt during the past hour (Hour Form) or today (Day Form), or how he felt during the past week (Week Form). For the self-rating of changes in distress in outcome research (for example, in drug trials) the "Week Form" appears to be most suitable. In some types of research the "Day Form" is more appropriate: for example, when changes from one day to the next are measured. When changes during the day are measured (such as diurnal variations), the "Hour Form" or the "Now Form" is more suitable.

The "Week Form" of the SQ is readied for administration by crossing out the word "today" in the first sentence; the "Day Form" is readied by crossing out the words "during the past week." The "Now Form" is constructed by changing the first sentence to "describe how you feel now." The "Hour Form" is constructed by changing the first sentence to "describe how you have felt during the past hour."

Scoring Stencils. Scoring can be carried out either by a computer program or with transparent scoring stencils. Stencils are available for the English version and for the Spanish version.

Insert the SQ form between the two transparent sheets of the stencil. The square on the stencil should be aligned with the margins of the items and the yes-no responses. The sum of the check marks within the circles of the same color is the score of the scale. The sum of the check marks of the "yes" columns is the score of the Symptom Subscale and the sum of the check mark in the "no" column is the score of the Well-being Subscale. A photocopy of a scored SQ is enclosed as an example.

Scoring of Subscales. Each scale can be subdivided into two subscales: a symptom subscale, which consists of items indicating symptoms, and a subscale of well-being, which consists of items indicating well-being.

The subscales are as follows:

Subscales of Symptoms	Subscales of Well-Being
AS (anxiety symptoms)	R (relaxed)
DS (depressive symptoms)	C (contented)
SS (somatic symptoms)	SW (somatic well-being)
HS (symptoms of anger-hostility)	F (friendly)

The subscales are identified on the stencils. In Table I the items of subscales of symptoms are identified by the letters "Y" and "T"; subscales of well-being by the letters "N" and "F". The maximum score for each subscale of symptoms is 17, and for the subscales of well-being it is 6.

Total Score. The total score is the sum of the scores of the four scale scores. The total score tends to discriminate more sensitively among populations (34) and tends to correlate more highly with physiologic measures (38) than individual scales do.

Cut-Off Points. Judging from comparisons of mean scores of various groups of patients and normals, a scale score between one and two standard deviations above the mean for normal subjects suggests moderate distress and above two standard deviations suggests substantial or severe distress or psychopathology.

Scale score	Normal Range	Moderate Range	Substantial to Severe Range
Anxiety	7 and below	8-11	12 and above
Depression	6 and below	7-9	10 and above
Somatic Scale	8 and below	9-13	14 and above
Hostility	7 and below	9-12	13 and above

The cut-off points are approximate; an SQ score alone cannot be regarded as adequate evidence in the assessment of an individual without further clinical evaluation. In addition, the somatic scale cannot be regarded as evidence of

somatization and must be interpreted with caution in the presence of physical disease.

On both sets of subscales (subscales of symptoms and subscales of well-being) a higher score indicates distress and a lower score indicates less distress or more well-being. If the well-being scales are scored separately, the well-being score can be converted by subtracting the raw score from 6. The conversion will lead to a higher score, indicating greater well-being, and not the reverse as it is with the raw score. For example, a raw score of 4.5 for a group on the friendly scale is converted into a "Friendly" score as follows: $6 - 4.5 = 1.5$.

Comments

In studies with small or moderately sized samples, it appears to be justified to administer more than one distress scale. It was an unexpected finding that scales which have a common content, are highly correlated and differ from each other only on a few features can yield different results. For example, the items in the SRT and SQ are similar, yet the psychometric properties of the two scales are somewhat different (7,9,25,28); the SQ misclassifies more patients and normals when both scales are administered to the two populations such as psychiatric outpatients and nonpatients (9). Yet the error in the SQ tends to be smaller; it tends to reveal significant differences between the means of two populations even when the differences are small and when other tests fail to do so; it also tends to discriminate more sensitively between the effects of psychotropic drugs and placebo in crossover trials. There is inadequate evidence at present to judge whether the SQ is also more sensitive in parallel (between subjects) drug trials; however, the results with the SRT checklist (the precursor of the SQ) suggest that the SQ may be more sensitive (36).

The sensitivity of the SQ scales seems to be due to the empirical selection of simple and sensitive items and the empirical choice of simple responses. In studies with small or moderately sized samples in which the sensitivity of the scales is important, or in populations that include subjects with poor verbal skills--such as found in an average clinic population--the SQ seems to have advantages.

SCALES AND SUBSCALES OF THE SYMPTOM QUESTIONNAIRE

The letters before the number indicate the response which scores (Y=Yes; N=No; T=True; F=False). For example, 1, 5, and 8 score (1) if the response is "YES"; 9, 16 and 50 score (1) if the response is "NO." Items with an asterisk are the well-being subscale scores.

<u>ANXIETY</u>		<u>SOMATIC</u>	
Y	1. Nervous	* N	10. Feeling healthy
Y	5. Tense, tensed up	T	12. Feeling of not enough air
Y	8. Frightened	* N	14. Feeling fit
- * N	9. Feeling calm	Y	15. Heavy arms or legs
- * N	16. Feeling confident	* F	19. No pains anywhere
Y	18. Shaky	* N	21. Arms and legs feel strong
- * N	23. Feeling peaceful	Y	22. Appetite poor
- * N	29. Relaxed	Y	28. Tight head or neck
Y	30. Restless	Y	33. Choking feeling
Y	34. Afraid	Y	41. Feeling of pressure in head or body
Y	36. Scared	Y	44. Weak arms or legs
Y	42. Worried	* F	46. No aches anywhere
Y	49. Terrified	Y	52. Breathing difficult
- * N	50. Feeling of courage	Y	53. Parts of the body feel numb or tingling
Y	54. Takes a long time to fall asleep	Y	57. Heart beating fast or pounding
Y	59. Jumpy	Y	65. Pressure on head
Y	62. Highly strung	Y	72. Nauseated, sick to stomach
T	63. Cannot relax	Y	74. Upset bowels or stomach
Y	64. Panicky	Y	77. Muscle pains
Y	68. Frightening thoughts	* F	78. No unpleasant feelings in head or body
Y	86. Feeling that something bad will happen	Y	79. Headaches
Y	87. Wound up, uptight	Y	85. Cramps
- * N	89. Self-confident	Y	92. Head pains
<u>DEPRESSION</u>		<u>HOSTILITY</u>	
Y	2. Weary	Y	3. Irritable
- * N	4. Cheerful	Y	11. Losing temper easily
Y	6. Sad, blue	* N	13. Feeling kind toward people
- * N	7. Happy	* N	17. Feeling warm toward people
Y	24. Feeling unworthy	Y	20. Angry
T	27. Cannot enjoy yourself	Y	25. Annoyed
Y	39. Feeling guilty	Y	26. Feeling of rage
* N	40. Feeling well	* N	31. Feeling friendly
* N	43. Contented	Y	32. Feeling of hate
Y	45. Feeling desperate, terrible	* N	35. Patient
Y	47. Thinking of death or dying	Y	37. Furious
* N	51. Enjoying yourself	* N	38. Feeling charitable, forgiving
Y	58. Depressed	Y	48. Hot tempered
Y	60. Feeling a failure	Y	55. Feeling hostile
T	61. Not interested in things	Y	56. Infuriated
Y	66. Blaming yourself	Y	69. Enraged
Y	67. Thoughts of ending your life	Y	70. Irritated by other people
* N	71. Looking forward to the future	Y	80. Feel like attacking people
Y	73. Feeling that life is bad	Y	81. Shaking with anger
Y	75. Feeling inferior to others	Y	82. Mad
Y	76. Feeling useless	* N	83. Feeling of goodwill
Y	84. Feel like crying	Y	88. Get angry quickly
Y	91. Feeling of hopelessness	Y	90. Resentful

9

Table I

Symptom Questionnaire Scores in Non-psychotic Psychiatric Outpatients, Family Practice Patients and Random Employees (20)

	Group I Random Employee N 50		Group II Family Practice N 44		Group III Psychiatric Patients N 44		Group I/II		Comparisons Group II/III		Group I/III	
	X	SD	X	SD	X	SD	q	Signifi- cance p<	q	Signifi- cance p<	q	Signifi- cance p<
Anxiety Scale	3.84	3.87	6.95	6.16	14.81	7.00	3.69	.025	8.92	.001	12.88	.001
Anxiety Symptoms Subscale	2.54	2.85	5.54	5.07	11.24	5.52	4.36	.005	8.30	.001	12.89	.001
Depression Scale	2.56	2.87	5.95	6.07	13.90	7.56	4.00	.005	8.99	.001	13.11	.001
Depression Symptom Subscale	1.77	2.16	4.37	4.65	10.60	5.90	3.96	.01	9.12	.001	13.20	.001
Somatic Scale	4.49	4.14	8.95	5.97	11.20	6.92	4.80	.001	2.57	NS	7.40	.001
Somatic Symptom Subscale	2.82	2.91	5.51	4.87	7.56	5.47	4.11	.005	2.99	NS	7.16	.001
Anger-Hostility Scale	3.90	3.79	5.50	4.66	9.63	6.91	2.12	NS	5.12	.005	7.34	.001
Hostility Symptom Subscale	3.43	3.32	4.77	4.24	8.00	5.88	2.04	NS	4.60	.005	6.71	.001
Well-being Subscales:												
Calm	4.70	1.47	4.50	2.03	2.53	1.95	.75	NS	7.45	.001	8.44	.001
Contented	5.21	1.11	4.42	1.96	2.70	2.16	3.00	.05	6.25	.001	9.33	.001
Somatic Well-being	3.88	1.76	2.56	1.75	2.27	1.97	4.94	.001	.68	NS	5.60	.001
Friendly	5.53	1.06	5.27	1.23	3.37	1.67	1.55	NS	4.37	.01	5.88	.001

SQ '83 rev.

NAME _____

DATE _____

Please describe how you have felt DURING THE PAST WEEK/TODAY and make a small check mark like this ✓. For example, the word NERVOUS is on the first line: if you have felt nervous, check YES like this: YES NO. If you have not felt nervous, check NO like this: YES NO.

A few times you have the choice of checking either TRUE or FALSE.
Do not think long before answering. Work quickly!

- | | | | | | |
|--------------------------------|------|-------|---|------|-------|
| 1. Nervous | YES | NO | 24. Feeling unworthy | YES | NO |
| 2. Weary | YES | NO | 25. Annoyed | YES | NO |
| 3. Irritable | YES | NO | 26. Feeling of rage | YES | NO |
| 4. Cheerful | YES | NO | 27. Cannot enjoy yourself | TRUE | FALSE |
| 5. Tense, tensed up | YES | NO | 28. Tight head or neck | YES | NO |
| 6. Sad, blue | YES | NO | 29. Relaxed | YES | NO |
| 7. Happy | YES | NO | 30. Restless | YES | NO |
| 8. Frightened | YES | NO | 31. Feeling friendly | YES | NO |
| 9. Feeling calm | YES | NO | 32. Feeling of hate | YES | NO |
| 10. Feeling healthy | YES | NO | 33. Choking feeling | YES | NO |
| 11. Losing temper easily | YES | NO | 34. Afraid | YES | NO |
| 12. Feeling of not enough air | TRUE | FALSE | 35. Patient | YES | NO |
| 13. Feeling kind toward people | YES | NO | 36. Scared | YES | NO |
| 14. Feeling fit | YES | NO | 37. Furious | YES | NO |
| 15. Heavy arms or legs | YES | NO | 38. Feeling charitable, forgiving | YES | NO |
| 16. Feeling confident | YES | NO | 39. Feeling guilty | YES | NO |
| 17. Feeling warm toward people | YES | NO | 40. Feeling well | YES | NO |
| 18. Shaky | YES | NO | 41. Feeling of pressure in head or body | YES | NO |
| 19. No pains anywhere | TRUE | FALSE | 42. Worried | YES | NO |
| 20. Angry | YES | NO | 43. Contented | YES | NO |
| 21. Arms and legs feel strong | YES | NO | 44. Weak arms or legs | YES | NO |
| 22. Appetite poor | YES | NO | 45. Feeling desperate, terrible | YES | NO |
| 23. Feeling peaceful | YES | NO | 46. No aches anywhere | TRUE | FALSE |

(OVER)

47. Thinking of death or dying	YES	NO	70. Irritated by other people	YES	NO
48. Hot tempered	YES	NO	71. Looking forward to the future	YES	NO
49. Terrified	YES	NO	72. Nauseated, sick to stomach	YES	NO
50. Feeling of courage	YES	NO	73. Feeling that life is bad	YES	NO
51. Enjoying yourself	YES	NO	74. Upset bowels or stomach	YES	NO
52. Breathing difficult	YES	NO	75. Feeling inferior to others	YES	NO
53. Parts of the body feel numb or tingling	YES	NO	76. Feeling useless	YES	NO
54. Takes a long time to fall asleep	YES	NO	77. Muscle pains	YES	NO
55. Feeling hostile	YES	NO	78. No unpleasant feelings in head or body	TRUE	FALSI
56. Infuriated	YES	NO	79. Headaches	YES	NO
57. Heart beating fast or pounding	YES	NO	80. Feel like attacking people	YES	NO
58. Depressed	YES	NO	81. Shaking with anger	YES	NO
59. Jumpy	YES	NO	82. Mad	YES	NO
60. Feeling a failure	YES	NO	83. Feeling of goodwill	YES	NO
61. Not interested in things	TRUE	FALSE	84. Feel like crying	YES	NO
62. Highly strung	YES	NO	85. Cramps	YES	NO
63. Cannot relax	TRUE	FALSE	86. Feeling that something bad will happen	YES	NO
64. Panicky	YES	NO	87. Wound up, uptight	YES	NO
65. Pressure on head	YES	NO	88. Got angry quickly	YES	NO
66. Blaming yourself	YES	NO	89. Self-confident	YES	NO
67. Thoughts of ending your life	YES	NO	90. Resentful	YES	NO
68. Frightening thoughts	YES	NO	91. Feeling of hopelessness	YES	NO
69. Enraged	YES	NO	92. Head pains	YES	NO

DO NOT WRITE BELOW THE LINE

A ___ B ___ G ___ H ___ T ___
AS ___ DS ___ SS ___ HS ___
R ___ C ___ SW ___ F ___

SYMPTOM QUESTIONNAIRE
University of New Mexico
C. R. Kellner, 1983

EXAMPLE OF SCORED FORM

SQ '83 rev.

NAME _____

DATE _____

Please describe how you have felt DURING THE PAST WEEK/TODAY and make a small check mark like this . For example, the word NERVOUS is on the first line: if you have felt nervous, check YES like this: YES NO. If you have not felt nervous, check NO like this: YES NO .

A few times you have the choice of checking either TRUE or FALSE.
Do not think long before answering. Work quickly!

- | | | | |
|--------------------------------|---|---|---|
| 1. Nervous | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> | 24. Feeling unworthy | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> |
| 2. Weary | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> | 25. Annoyed | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> |
| 3. Irritable | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> | 26. Feeling of rage | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> |
| 4. Cheerful | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> | 27. Cannot enjoy yourself | TRUE <input type="checkbox"/> FALSE <input checked="" type="checkbox"/> |
| 5. Tense, tensed up | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> | 28. Tight head or neck | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> |
| 6. Sad, blue | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> | 29. Relaxed | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> |
| 7. Happy | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> | 30. Restless | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> |
| 8. Frightened | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> | 31. Feeling friendly | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> |
| 9. Feeling calm | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> | 32. Feeling of hate | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> |
| 10. Feeling healthy | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> | 33. Choking feeling | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> |
| 11. Losing temper easily | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> | 34. Afraid | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> |
| 12. Feeling of not enough air | TRUE <input type="checkbox"/> FALSE <input checked="" type="checkbox"/> | 35. Patient | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> |
| 13. Feeling kind toward people | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> | 36. Scared | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> |
| 14. Feeling fit | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> | 37. Furious | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> |
| 15. Heavy arms or legs | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> | 38. Feeling charitable, forgiving | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> |
| 16. Feeling confident | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> | 39. Feeling guilty | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> |
| 17. Feeling warm toward people | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> | 40. Feeling well | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> |
| 18. Shaky | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> | 41. Feeling of pressure in head or body | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> |
| 19. No pains anywhere | TRUE <input checked="" type="checkbox"/> FALSE <input type="checkbox"/> | 42. Worried | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> |
| 20. Angry | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> | 43. Contented | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> |
| 21. Arms and legs feel strong | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> | 44. Weak arms or legs | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> |
| 22. Appetite poor | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> | 45. Feeling desperate, terrible | YES <input type="checkbox"/> NO <input checked="" type="checkbox"/> |
| 23. Feeling peaceful | YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> | 46. No aches anywhere | TRUE <input checked="" type="checkbox"/> FALSE <input type="checkbox"/> |

- | | | | | | |
|---|-----------------|------------------|--|----------------|------------------|
| 47. Thinking of death or dying | YES | NO | 70. Irritated by other people | YES | NO |
| 48. Hot tempered | YES | NO | 71. Looking forward to the future | YES | NO |
| 49. Terrified | YES | NO | 72. Nauseated, sick to stomach | YES | NO |
| 50. Feeling of courage | YES | NO | 73. Feeling that life is bad | YES | NO |
| 51. Enjoying yourself | YES | NO | 74. Upset bowels or stomach | YES | NO |
| 52. Breathing difficult | YES | NO | 75. Feeling inferior to others | YES | NO |
| 53. Parts of the body feel numb or tingling | YES | NO | 76. Feeling useless | YES | NO |
| 54. Takes a long time to fall asleep | YES | NO | 77. Muscle pains | YES | NO |
| 55. Feeling hostile | YES | NO | 78. No unpleasant feelings in head or body | TRUE | FALSE |
| 56. Infuriated | YES | NO | 79. Headaches | YES | NO |
| 57. Heart beating fast or pounding | YES | NO | 80. Feel like attacking people | YES | NO |
| 58. Depressed | YES | NO | 81. Shaking with anger | YES | NO |
| 59. Jumpy | YES | NO | 82. Mad | YES | NO |
| 60. Feeling a failure | YES | NO | 83. Feeling of goodwill | YES | NO |
| 61. Not interested in things | TRUE | FALSE | 84. Feel like crying | YES | NO |
| 62. Highly strung | YES | NO | 85. Cramps | YES | NO |
| 63. Cannot relax | TRUE | FALSE | 86. Feeling that something bad will happen | YES | NO |
| 64. Panicky | YES | NO | 87. Wound up, uptight | YES | NO |
| 65. Pressure on head | YES | NO | 88. Get angry quickly | YES | NO |
| 66. Blaming yourself | YES | NO | 89. Self-confident | YES | NO |
| 67. Thoughts of ending your life | YES | NO | 90. Resentful | YES | NO |
| 68. Frightening thoughts | YES | NO | 91. Feeling of hopelessness | YES | NO |
| 69. Enraged | YES | NO | 92. Head pains | YES | NO |

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*For abbreviations see page 6. T means total score.

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