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Running Head: Emotional Reaction to Dementia

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Chapter 1: Review of the Literature

Many older adults fear receiving a diagnosis of dementia. Individuals report that their fear of receiving a diagnosis of dementia is greater than their fear of death or other serious medical illness, like cancer (Corner & Bond, 2004; Kuhn, 2007). Receiving a diagnosis of dementia is often feared due to perceived consequent loss of identity, dignity, independence, and control over various aspects of their lives, including financial, social, relational, occupational, and emotional (Corner & Bond, 2004). It is estimated that 6% of the population over 65 years of age have severe dementia, and 10-15% have mild to moderate dementia (Bondi, Salmon, & Kaszniak, 2009). The proportion of those with dementia increases with age as reflected in the following prevalence rates: 3-7% of people between 70-79 years old, 20-30% of people aged 80-89 years old, and 25-50% of people over age 90 (Plassman et al., 2007). Given that the prevalence of dementia is age-related and that the older population in the United States is expected to increase in proportion from the current 13 percent to 20 percent by 2030 (Center for Disease Control, 2007), many more individuals will likely fear and receive this diagnosis.

The psychological impact of dementia on the diagnosed individual has been documented over the course of the disorder. In the early stages of dementia, individuals may exhibit co-existing emotional distress. Although an extreme reaction, suicide has occurred in individuals with early stage dementia, however this is rare (Carpenter et al., 2008). It is estimated that 11.5% of individuals in the mild stage and 10% of those in the
moderate stage of Alzheimer’s disease have major depression. The prevalence of major depression decreases to 4.5% in the advanced stages (Bierman, Comijs, Jonker, & Beekman, 2007). Although some individuals do not meet the criteria for a major depressive disorder, depressive symptoms are common among those with dementia with an averaging prevalence rate of 30% (Steffens & Potter, 2008; Teri et al., 1999). Furthermore, 25%-60% of patients with Alzheimer’s disease had anxiety symptoms (Teri et al., 1999). Particularly, individuals in early stages of dementia exhibit increased symptoms of anxiety (Bierman, Comijs, Jonker, & Beekman, 2007; Teri et al., 1999). Moreover, the occurrence of comorbid depressive and anxiety symptoms in an individual with dementia is more prevalent than an individual having only depressive or anxiety symptoms. Thus, if affective symptoms are displayed, one is more likely to exhibit comorbid symptoms than depression or anxiety alone (Teri et al., 1999). In summary, in the mild to moderate stages of dementia, a sizeable proportion of these demented individuals evidence varying degrees of depressive and anxious symptomatology, with some warranting a clinical diagnosis.

While affective distress has been documented over the course of dementia, only a few studies have investigated the psychological impact of this disorder immediately following the actual diagnosis. To date, only one prospective, quasi-experimental study has evaluated the emotional reaction to diagnostic disclosure of dementia (Carpenter et al., 2008). Of those diagnosed with dementia and their caregivers, Carpenter et al. (2008) found that there was little change in depressive symptoms, and a significant reduction in anxious symptoms following diagnostic disclosure, particularly for those who were highly anxious at baseline. The authors noted some limitations to their study insofar as
the participants were not asked to evaluate their mood in the context of diagnostic evaluation and disclosure. In descriptive research, case studies have described the emotional reactions categorically and in broad terms to the diagnostic disclosure of dementia (Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006; Derksen, Vernooij-Dassen, Gillissen, Rikkert, & Scheltens, 2006; Robinson, Clare, & Evans, 2005; Aminzadeh, Byszewski, Molnar, & Eisner, 2007). Taken together, these studies of dementia have not accounted for the demented individual’s cognitive appraisal and the degree of awareness of their deficits, which can affect emotional reaction.

Lazarus’ theory of emotion (1984, 1988, 1991, 1993) provides a lens to view how degree of awareness and cognitive appraisal can impact emotional reaction. Lazarus’ theory highlights the relevance of two types of cognition to emotion, namely, knowledge and appraisal. According to the theory, knowledge refers to individuals’ cognitions and beliefs about what is occurring, while appraisal refers to the personal significance of this knowledge in individuals’ encounters with their environment (Lazarus & Smith, 1988; Lazarus, 1991). Individuals with Alzheimer’s disease, as well as other forms of dementia, often have varied awareness of their own deficits (Green, Goldstein, Sirockman, & Green, 1993; Clare, Roth, & Pratt, 2005; Kashiwa, Kitabayashi, Narumoto, Nakamura, Ueda, & Fukad, 2005; Pia & Conway, 2008). For some, they may not fully comprehend that their memory is really impaired. Instead, they may believe that their “slips” in memory are age-appropriate and that there is no need for concern. Furthermore, the extent to which individuals know or comprehend what is occurring in the interaction between themselves and their environment can affect their appraisal of the situation (Lazarus & Smith, 1988; Lazarus, 1991). Individuals’ degrees of awareness of their
deficits will affect their ability to accurately appraise their personal resources to meet the
demands of a situation. Their cognitive appraisal involves not only interpreting the
degree of threat and challenge of the external situation, but also assessing their capacity
and resources to meet the identified threats (Lazarus & Folkman, 1984). Thus,
individuals may appraise a situation as highly threatening, but if they simultaneously
conclude that they have the resources needed to mediate the threat, then their perceived
stress of the event is reduced and distress is minimized. Investigating both the external
situation and internal resources of cognitive appraisal, with the degree of awareness will
provide a helpful framework for understanding factors that contribute to the
psychological impact of receiving a diagnosis of dementia. Recently-diagnosed demented
individuals’ degree of knowledge about their diagnosis, and their cognitive appraisals
likely contribute to the psychological impact of the diagnostic disclosure.

After the diagnosis has been communicated, it is important to determine the
presence of adverse psychological reactions such as depression and anxiety because these
symptoms often go unrecognized and untreated (Kasniak & Christenson, 1994). When
left undetected and untreated, negative consequences for the individual can result
including the exacerbation of cognitive problems, restlessness and agitation, impairment
in instrumental activities of daily living, poorer quality of life, and the increased
likelihood of premature nursing home placement (Pearson, Teri, Reifler, & Raskind,
1989; Reifler, Larson, & Teri, 1987; Seignourel, Kunik, Snow, Wilson, & Stanley, 2008;
Zarit & Zarit, 2006). Furthermore, untreated affective distress can also adversely affect
the caregiver by increasing the risk of caregiver stress (Bullock, 2004). The more
problem behaviors displayed by the affected individual, the greater the costs associated with caregiver burden (Bullock, 2004).

This research will examine the potential emotional impact of receiving a diagnosis of cognitive impairment on the affected individual, and the possible mediating role of the individual’s cognitive appraisals and insight within the framework of Lazarus’ theory of emotion. It is important to determine if cognitive appraisals and insight mediate the potential psychological impact following the diagnosis of cognitive impairment. Before a full complement of hypotheses is presented, the literature on Lazarus’ theory of emotion, deficit awareness in cognitive impairment, and prior studies investigating the emotional reaction to a diagnosis of cognitive impairment will be reviewed.

**Lazarus’ Theory of Emotion**

Lazarus’ theory of emotion is relational insofar as emotion involves a person-environment encounter (Lazarus, 1991). Emotions are generated from neither distinct personal nor environmental characteristics; rather, it is the interaction between the two at any given time. Individuals enter into this relationship with their personal goals, beliefs, characteristics, resources, knowledge, and ability to appraise characteristics about themselves and their environmental situation (Lazarus & Smith, 1988). These person-environment encounters can interfere with personal goals, inflict harm, and can result in negative emotions depending upon an individual’s knowledge and appraisals of the encounter. Then again, the person-environment encounter can be beneficial and congruent with personal goals, and result in positive emotions depending upon one’s appraisal and knowledge of the situation. Such a person-environment relationship can
change over time as circumstances change and consequently different emotions can surface (Lazarus & Smith, 1988). For instance, a person may have goals to lead an active and independent lifestyle but believe that a diagnosis of dementia interferes with that goal. These seemingly contradictory goals and beliefs would affect the person’s interaction with the environment in the context of a diagnostic disclosure. Thus, different types of emotions are produced based on the characteristics of the interaction between individuals and their environment. This person-environment dynamic is core to emotions, such that each emotion has its own reliable and identifiable person-environment dynamic (Lazarus, 1991).

Lazarus’ theory of emotion has several components. First is the cognitive component (Lazarus, 1988; Lazarus & Smith, 1988; Smith & Lazarus, 1993). One type of cognition is knowledge, which is the basic awareness of what is happening in the environment (Lazarus, 1988). Knowledge itself has two components, including general knowledge and contextual knowledge. General knowledge is our preconceived notions about ourselves and our environments whereas contextual knowledge is the “who, what, where, when, and how” of the situation (Lazarus, 1988). Contextual knowledge, that is the specifics about a situation, incorporates our general knowledge. Knowledge is a necessary component to emotions because an individual must first have knowledge about how things work generally, as well as in a particular situation, to be able to evaluate whether a situation or encounter has any personal significance (Lazarus & Smith, 1988). People with dementia may have varying degrees of knowledge about their diagnosis, disease, course, and prognosis. Individuals’ backgrounds, prior exposures to disease information, and personal histories with dementia will all affect their knowledge of the
present situation (i.e. diagnostic disclosure of dementia), and will also affect their appraisal of personal meaning.

The second component of cognition in Lazarus’ theory is called appraisal, which is the assessment of personal significance, or meaning, for the person (Lazarus, 1988; Lazarus & Smith, 1988; Smith & Lazarus, 1998). Knowledge and appraisal are presented as distinct, even though they are closely related. Only if individuals understand what occurred in a particular situation can they appropriately assess the importance of a particular encounter within their environment for their well-being, and therefore respond with specific emotions based upon the appraised significance for them. Lazarus asserts that knowledge is necessary to produce an emotion, but it is not sufficient (Lazarus 1988; Lazarus & Smith, 1988). Therefore, an understanding of the fundamentals of the situation is not sufficient by itself to produce emotion. Instead, the appraisal of the personal importance of an interaction with the environment, which is based on their knowledge, is both necessary and sufficient (Lazarus & Smith, 1988). A person’s knowledge affects how the situation is appraised; therefore both knowledge and appraisal are necessary in creating emotion. Without appraisal of the potential benefit or harm of the situation, it would be impossible to identify the situation as goal-relevant; thus, the situation would not likely produce strong emotion (Lazarus, 1991). If the person’s knowledge of the environment declines, as typically happens with the progression of dementia, then that person’s interaction with the environment also changes, along with their appraisal of potential harm or benefit.

Appraisals can be understood in the conceptual framework of Lazarus and Folkman’s (1984) primary and secondary appraisals. Primary appraisals classify the
external situation according to its threat or challenge to a person’s well-being (Lazarus & Folkman, 1984; Cavanaugh & Blanchard-Fields, 2006). Primary appraisal is ‘primary’ not because of sequence, but rather because it is what makes knowledge personal and potentially emotionally-charged (Lazarus & Smith, 1988). This classification is based upon the person’s subjective sense of the situation; therefore, two people may appraise the same situation differently. Primary appraisals consist of two components: motivational relevance and motivational congruence/incongruence (Lazarus, 1991; Lazarus & Folkman, 1987). Motivational relevance relates to how affected a person would be by the event or situation that they are facing. Thus, if the event is significant for a person’s own goals and motivations, then it has motivational relevance for that person. If an event has little or no motivational relevance, then it will not be appraised to significantly affect a person’s well-being; therefore, the event will not arouse emotion (Lazarus, 1991; Orbell, Hagger, Brown, & Tidy, 2004). Motivational congruence relates to whether the situation is consistent, or congruent with the attainment of personal desires and goals (Lazarus & Smith, 1988; Smith & Lazarus, 1993; Orbell, Hagger, Brown, & Tidy, 2004). Although primary appraisal evaluates the situation at hand, it alone is not sufficient to determine the emotional significance for a person; rather, an emotion also involves a secondary appraisal (Lazarus & Smith, 1988; Smith & Lazarus, 1993).

In the secondary appraisal, individuals assess whether they have the resources and abilities to meet the perceived challenge. Secondary appraisal pertains mostly to coping and determining plausible outcomes. According to Lazarus (1991), there are four secondary appraisal components. The first component is peoples’ accountability, or their attribution of blame. This attribution can be addressed internally if they perceive that they
are responsible, or externally if they perceive others, or factors outside themselves, are to blame. If a situation is consistent with a person’s goals, or motivationally congruent, then credit is attributed; whereas, if a situation is not consistent with a person’s goals, or motivationally incongruent, then blame is ascribed. If a person or object is assessed to deserve blame, then the person also identifies to whom coping efforts will be directed (Smith & Lazarus, 1993). The second component of secondary appraisal is problem-focused coping potential. Problem-focused coping is action toward a situation to make it congruent with one’s goals (Lazarus, 1991). The third component, emotion-focused coping potential, is the ability to attain psychological adjustment by altering one’s perception of situational aspects, or by modifying one’s own goals and desires (Smith & Lazarus, 1993). This coping potential pertains to the affective component of the situation. The final component is future expectation, which is one’s belief regarding the possibility of change to make the situation more or less motivationally congruent (Smith & Lazarus, 1993). For instance, individuals receiving a diagnosis of dementia may believe that there is hope for the future. By example, they may hope for a positive response to medication therapy, such that their situation may be more aligned with their goals and motivations. Although coping style is an important component when discussing the appraisal literature as a whole, this study will focus chiefly on the person’s emotional reaction and primary and secondary appraisal, which includes coping potential within the framework of Lazarus’ theory of emotion, but will not explicitly explore the person’s actual coping style.

The theory of emotion proposed by Lazarus attempts to define consistent relational, motivational, and cognitive patterns of emotion (Lazarus; 1988; Lazarus & Smith, 1988;
Smith & Lazarus, 1993). Emotion, then, is based upon evaluating several of the cognitive-relational components discussed above. In any situation, the event or stimulus must be considered motivationally relevant in order to produce emotion, either positive or negative. That is, there is no potential for emotion if the person does not appraise the situation to be important to them (Lazarus & Smith, 1988; Smith & Lazarus, 1993). As a result, a pattern of primary appraisals of personal significance (i.e. motivational relevance) and incongruence with one’s personal goals (i.e. motivational incongruence) categorize negative emotions. In this case the situation is appraised to be important to a person, but is incompatible with that person’s current goals. On the other hand, if a person assesses a situation to have motivational relevance and it is in agreement with that person’s goals, then the experience will result in positive emotions. These patterns underlying emotion are called “core-relational themes” and they represent the integration of all the individual appraisal components (Smith & Lazarus, 1993; Lazarus & Smith, 1988).

To determine specific emotions, the individual components of the appraisal must be evaluated in relation to one another. For example, one would experience anger if the primary appraisal of the situation was one of threat or potential harm (motivational relevance), and that this harm was perceived as inconsistent with a person’s goals (motivational incongruence), paired with the secondary appraisal that someone was to blame for this potential harm (Lazarus & Smith, 1988; Smith & Lazarus, 1993). Similarly, guilt is determined by a combination of motivational relevance (perceived harm) and motivational incongruence (inconsistent with personal goals); however, it is distinguished from anger by the attribution of accountability in that guilt is self-blame,
whereas anger is other-blame. Although these two emotions are similar, they represent
different patterns of appraisal and therefore are distinguishable from each other. Fear is
characterized by motivational relevance and incongruence, and a secondary appraisal of
poor or uncertain potential for emotional coping. That is, the person perceives a poor
ability to psychologically adjust to the situation or harm if it were to occur (Smith &
Lazarus, 1993). On the other hand, sadness remains motivationally relevant and
incongruent but has a low problem focus coping potential and a poor outlook for future
change that would improve the situation (Smith & Lazarus, 1993). A person
experiencing sadness believes that there is an “inability to restore the loss or eliminate the
harm” (Smith & Lazarus, 1993, pg. 239). The emotion of relief has been proposed by
Lazarus (1991) to represent a positive change in the person-environment interaction.
Relief is a positive emotion; thus, it is characterized by motivational relevance and
motivational congruence. According to Orbell, Hagger, Brown, and Tidy (2004), a
secondary appraisal is not necessary to produce the emotion of relief.

**Awareness of Deficits**

Anosognosia is defined as an unawareness of deficits and is commonly
experienced by people with dementia, stroke, and psychiatric illness (Pia & Conway,
2008, PDR, 1995). People with anosognosia often deny either their illness or the severity
of their illness; thus, they are at risk for overestimating their abilities. Among those with
dementia, it is most common in individuals with Alzheimer’s disease and Pick’s disease,
both of which are cortical dementias (Zec & Burkett, 2005).

Considerable variability is recorded in degree of anosognosia among those with
dementia (Zec & Burkett, 2005). Research is mixed regarding severity of anosognosia
over the course of Alzheimer’s disease. Some longitudinal research indicates that anosognosia worsens as the disease progresses (Derouesne, Thibault, Lagha-Pierucci, Baudouin-Madec, Ancri, & Lacomblez, 1999; Starkstein, Chemerinski, Sabge, Kuzis, Petracca, Teson, et al., 1997). On the other hand, in a sample of 406 patients, degree of awareness did not change for 60.8%, worsened for 26.6%, and improved for 12.6% (McDaniel, Edland, Heyman, & the CERAD clinical investigators, 1995). Further research by Weinstein, Friedland, and Wagner (1991) provides support for these findings. Given these contradictory findings, the progressive pattern of anosognosia in Alzheimer’s disease remains unclear. The variability found across studies suggests other factors may also contribute to individual differences in degree of awareness (Clare, 2004).

In addition to individual differences, anosognosia may also vary across domains of cognition within which individuals are unaware of their deficits. Research indicates that anosognosia is a multi-dimensional construct, and that a person may have awareness about one cognitive deficit but lack awareness of other types of cognitive deficits (Snow, Norris, Doody, Molinari, Orengo, & Kunik, 2004; Green, Goldstein, Sirockman, & Green, 1993; Clare, Markova, Verhey, & Kenny, 2005; Pia & Conway, 2008; Clare, Roth, & Pratt, 2005). For instance, a person with dementia may be aware of memory deficits, but lack awareness of other functional, cognitive, or behavioral deficits. This lack of knowledge may fluctuate over time. For example, there can be varying awareness of the deficit throughout the course of the day as well, as worsening during the disease progression. Thus, at any point in time, individuals may be aware of any number of their deficits. Particularly in Alzheimer’s disease, areas of cognition like recent memory
change relatively quickly. Therefore, persons with dementia are most likely to express anosognosia in this area because they lack updated knowledge of their changing abilities.

According to Lazarus’ theory, the ability to understand the interaction between a person and their environment is a critical piece of appraisal. Consequently, anosognosia will compromise people’s assessments of their own abilities, which in turn, will affect their appraisals of the person-environment dynamic. Individuals’ appraisals of the situation will in turn affect their emotional reactions. For instance, individuals with anosognosia may not respond emotionally to situations when they are unaware of their insufficient abilities. Therefore, this unawareness of their deficits may actually protect individuals from emotional distress by buffering the emotional impact of their cognitive loss (Zec & Burkett, 2005; Pia & Conway, 2008). Previous research regarding emotional reaction to diagnostic disclosure has not included anosognosia as a possible mediating variable.

**Prior Studies**

There is a paucity of literature regarding the emotional reaction to diagnostic disclosure of dementia. Much of the research regarding diagnostic disclosure of dementia has been qualitative. Vernooij-Dassen, Derksen, Scheltens, and Moniz-Cook (2006) conducted qualitative semi-structured interviews with eighteen pairs, each including a participant and caregiver present during diagnostic disclosure. Interviews were conducted at two weeks and ten weeks following disclosure. Researchers found that individuals who reported that they did not expect a diagnosis of dementia felt threatened and shocked by the news, whereas others perceived the diagnostic disclosure as confirmation of their suspicions of dementia. A potential weakness of this study is that the semi-structured interview design could have affected the responses given due to the
personal and relational element of interviews (Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006). Furthermore, the study was conducted with a small sample size; therefore, the results have limited generalizability.

In a following study using a similar design, Derksen, Vernooij-Dassen, Gillissen, Rikkert, and Scheltens (2006) analyzed qualitative semi-structured interviews for themes following diagnostic disclosure. Three key themes were identified. The first, a theme of “increased awareness of dementia,” was characterized by statements that reflected increased awareness of the diagnosis and awareness of its impact (Derksen, Vernooij-Dassen, Gillissen, Rikkert, & Scheltens, 2006). For some individuals, this increased awareness resulted in feelings of confusion, loss, and grief. “Partnership” was the second theme identified, and included statements that reflected changes in the partnership between caregiver and patient (Derksen, Vernooij-Dassen, Gillissen, Rikkert, & Scheltens, 2006). For some this resulted in a strengthening of the bond, whereas for others the changed dynamic represented an increased burden. The final theme of “social relationships” consisted of statements depicting changes in social roles, not only within immediate and extended family, but also among other sources of social relationships (Derksen, Vernooij-Dassen, Gillissen, Rikkert, & Scheltens, 2006). Weaknesses of this study also include small sample size and therefore limited generalizability.

In an exploratory study using a semi-structured interview design, Robinson, Clare, and Evans (2005) evaluated psychological reaction to the diagnosis of dementia in couples in which one person received a diagnosis of dementia within the last two years. These themes were considered within existing literature of reactions to diagnostic disclosure, systems theory, and theories of loss. Participants, ages 65 to 85 years old,
were recruited from memory centers and had received a diagnosis of probable Alzheimer’s disease or vascular dementia at some point throughout the course of the previous two years. To be included, participants must also have scored 18 or higher on the Mini-Mental Status Examination (Folstein, Folstein, & McHugh, 1975). The sample total included nine couples, with five women and four men having received a diagnosis of dementia. Results of this study indicate a cyclical process of realization, denial, and acceptance of the partner’s diagnosis of dementia (Robinson, Clare, & Evans, 2005). Participant reports indicate that this cycle was evident in their experiences before the diagnostic disclosure, as the couple decided to seek diagnostic clarification. Furthermore, diagnostic disclosure affected the couples in both positive and negative ways (Robinson et al., 2005). Positive responses included feelings of affirmation, relief, and increased feelings of acceptance. Negative responses included uncertainty about the future and feelings of loss (Robinson et al., 2005). Limitations of this study also include its small sample size and limited generalizability. Furthermore, the design may also have influenced the participant responses; for instance, a participant may have responded in a certain way to achieve other goals, such as not upsetting their partner or impressing the interviewer (Robinson et al., 2005). Therefore, future research may investigate reactions to diagnostic disclosure utilizing more objective measures and study designs to minimize this potential influence.

In the qualitative research on psychological reactions to diagnostic disclosure, most studies have utilized a retrospective design such that people are recruited within a time frame after they have received a diagnosis of dementia. In contrast, a study by Aminzadeh, Byszewski, Molnar, and Eisner (2007) used a qualitative, prospective design
that incorporated multiple informants, including views of people with dementia and their
caregivers, as well as recordings and observations from the disclosure meeting to
evaluate emotional reactions (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). Using a
sample size of twenty, the researchers found that the most common emotional response
immediately following diagnostic disclosure was that of shock and distress, or relief and
confirmation. These emotional reactions were at times an impediment to processing the
information being presented. After the immediate reaction, participants’ emotional
reactions could be organized into three broad categories which depend upon their
appraisal of the dementia diagnosis and its impact (Aminzadeh et al., 2007). These
categories included “denial/lack of insight,” illustrated by statements of denial,
minimization, and avoidance of the diagnostic label. The second category of emotion
was “grief reaction/emotional crisis” involving extreme sadness or sorrow, fear, guilt, and
hopelessness. Consistent with other research, the third category represented positive
reactions called “positive coping responses,” which included statements of optimism and
maximizing. Researchers observed these reactions through both verbal expressions and
in body language (Aminzadeh et al., 2007). Although these studies evaluated emotional
reaction to diagnostic disclosure, they are limited by small sample sizes and qualitative
designs. Furthermore, these studies did not take into account a person’s awareness of
his/her deficits, and how more or less awareness may affect an individual’s reaction to
diagnostic disclosure.

To this author’s knowledge, only one empirical study has been completed to date
regarding the emotional reaction to diagnostic disclosure of dementia. Carpenter et al.
(2008) explored changes in depressive and anxious symptoms following diagnostic
detection. The study utilized a pre/post survey design of 110 participants and their companions who were recruited through the Memory and Aging Project (MAP) of the ADRC at Washington University in Saint Louis, Missouri. Anxiety was measured using the State-Trait Anxiety Inventory (STAI) and depressive symptoms evaluated using the 15-item Geriatric Depression Scale (GDS). Of the participants, 31% were given a diagnosis of no dementia, 46% were given a diagnosis of very mild dementia, and 23% were given a diagnosis of mild dementia (Carpenter et al., 2008). Results indicated that there was a decline in reported anxious symptoms following diagnostic disclosure, especially for those who had high levels of anxiety at baseline (Carpenter et al., 2008). Authors noted little change in depressive symptoms (Carpenter et al., 2008). The authors believe that the measures used may not have detected slight changes in depressive and anxious symptoms, or identified other types of emotional reactions. Furthermore, they did not include measures of appraisal nor more subtle measures of emotion. In particular, when participants completed the mood measures they were not asked to consider their mood in relation to diagnostic disclosure. Additionally, the authors did not include a measure of awareness, nor consideration of how degree of awareness of deficits could have affected appraisal and emotional reaction.

While previous qualitative research has categorically identified responses to diagnostic disclosure of dementia and Carpenter et al. (2008) found a decline in anxious symptoms following such diagnostic disclosure, none of these studies has explored the emotional reaction to the diagnosis of cognitive impairment, including dementia from the perspective of Lazarus’ theory of emotion. The purpose of this study is to investigate the
emotional reaction following diagnostic disclosure of cognitive impairment, based upon Lazarus’ theory of emotion.
Chapter II: Rationale and Hypotheses

The emotional reaction of individuals who have received a diagnosis of cognitive impairment, including dementia, has received little attention in the literature. Psychological reactions to receiving a diagnosis of cognitive impairment are critical to understand, because those reactions (and the factors that influence them) may predict how diagnostic information is understood and the ways in which health care professionals could customize disclosure for optimal benefit.

Lazarus’ theory of emotion will be used as a lens to understand emotional reaction to a diagnosis of cognitive impairment. There are three broad aspects to the theory. First it is relational, meaning that specific emotions are created based on consistent characteristics of the person-environment interaction. Therefore, there is the potential for changing emotional experiences as aspects of the person and/or the environment changes. Second, it is cognitive, meaning that the person brings to the interaction prior knowledge of how things work and personal experience. Deficit awareness, or lack of knowledge, is often present in cognitive impairment, particularly dementia, and will likely affect the person’s knowledge of aspects of the person-environment interaction. This lack of knowledge will affect the person’s appraisal of the severity of the situation (i.e. primary appraisal) and their ability to assess the resources available to them (i.e. secondary appraisal). The third aspect of the theory is that it involves appraisal. There are two types of appraisal, including primary and secondary appraisal. Primary appraisal broadly
answers the question of “is this a threat?” and pertains to how personally meaningful the situation is (i.e. motivational relevance) and how congruent or incongruent it is with one’s goals (i.e. motivational congruence). Secondary appraisal has four components (attribution of blame, problem-focused coping potential, emotion-focused coping potential, and future expectancy) and it represents the process of evaluating one’s personal resources.

Prior research has begun investigating emotional reaction to diagnoses of cognitive impairment, but emotional reaction has not been investigated in the context of an individual’s cognitive appraisal or degree of awareness.

The following hypotheses will be examined:

**Primary Analyses**

H1: There will be a significant difference in levels of depressive symptoms as measured by the Geriatric Depression Scale (GDS) at Time 1 and Time 2, and this difference will become nonsignificant when controlling for degree of awareness.

H2: There will be a significant difference in levels of anxiety symptoms as measured by the Geriatric Anxiety Inventory (GAI) at Time 1 and Time 2, and this difference will become nonsignificant when controlling for degree of awareness.

H3: There will be a significant difference in levels of anger as measured by the anger subscale of the emotional reaction measure by Orbell, Hagger, Brown, and Tidy (2004) at Time 1 and Time 2, and this difference will become nonsignificant when controlling for degree of awareness.

H4: There will be a significant difference in levels of sadness as measured by the sadness subscale of the emotional reaction measure by Orbell, Hagger, Brown, and Tidy (2004) at
Ho4: Awareness will not mediate the relationship between motivational relevance and guilt.

Ho5: Awareness will not mediate the relationship between motivational incongruence and guilt.

Ho6: Awareness will not mediate the relationship between self-accountability and guilt.

Fear/Anxiety

Ho7: Awareness will not mediate the relationship between motivational relevance and fear/anxiety.

Ho8: Awareness will not mediate the relationship between motivational incongruence and fear/anxiety.

Ho9: Awareness will not mediate the relationship between emotion-focused coping potential and fear/anxiety.

Sadness

Ho10: Awareness will not mediate the relationship between motivational relevance and sadness.

Ho11: Awareness will not mediate the relationship between motivational incongruence and sadness.

Ho12: Awareness will not mediate the relationship between problem-focused coping potential and sadness.

Ho13: Awareness will not mediate the relationship between future-expectancy and sadness.

Relief
Ho14: Awareness will not mediate the relationship between motivational relevance and relief.

Ho15: Awareness will not mediate the relationship between motivational congruence and relief.
Chapter III: Method

Power Analysis

Cohen (1992) has given guidelines for selecting sample size for multiple regression. According to Cohen, when using two predictors and a .05 significance level, 67 participants are needed to detect a medium effect size ($r^2=.15$). Given the availability of participants, it is estimated that a sample size of 40-60 participants will be obtained. Therefore, in consideration of this sample limitation, the analysis may not have sufficient power to detect a medium effect size. The model will have sufficient power to detect a large effect size. According to Cohen, using two predictors and a .05 significance level, only 30 participants are needed to detect a large effect size ($r^2=.35$). To maximize power, as many participants will be recruited as resources allow.

Participants

Participants will be individuals who are referred for services through a Neuropsychological clinic at a Midwestern Veterans Affairs Medical Center. More specifically, participants will be males and females sixty years of age or older who undergo neuropsychological examination due to concerns about memory impairment. Inclusion criteria will be a diagnosis of Cognitive Impairment, NOS, Mild Cognitive Impairment (any type), or dementia (any type). There will be no discrimination based on ethnicity, race, or religion.

Measures
Dementia Deficits Scale (Appendix A). The participant and clinician questionnaires will be utilized from the Dementia Deficit Scale (DDS) (Snow, Norris, Doody, Molinari, Orenge, & Kunik, 2004). The DDS is a standardized, multidimensional assessment of deficit awareness in those with dementia. The scale utilizes a yes/no format checklist of deficits that are commonly associated with dementia. Specifically, this scale assesses the patient’s awareness of illness as well as cognitive, emotional/behavioral, and functional deficits. This information is helpful as there is evidence that deficit awareness is multi-dimensional and persons may be aware of deficits in one area (i.e. cognition) but unaware of deficits in another area (i.e. functional abilities) (Snow et al., 2004; Snow et al., 2005).

For this study, the patient and clinician will be administered a self-report questionnaire assessing deficit awareness. To calculate scores for the scale, a one or zero point value was given to each yes or no answer. Some of the items were reversed scored, as defined by Snow et al. (2004). After the point value was determined for each item, a summation of points yields the total score for each completed version. In accordance with Snow et al. (2004), the sum scores were converted to z-scores to allow for direct comparison, given the different lengths of the patient and clinician questionnaires. Next, a deficit awareness score was calculated by subtracting the DDS patient z-score from the DDS clinician z-score. Larger scores reflect greater discrepancy between the patient and the clinician. Positive scores indicate that the patient endorsed fewer deficits than the clinician (underreporting), whereas negative scores indicate that the patient endorsed more deficits than did the clinician (overreporting; Snow et al., 2004).
The DDS has been shown to have good reliability and validity. The scale has demonstrated high internal consistency for both the clinician (Cronbach’s α = .87) and informant (Cronbach’s α = .88) versions (Snow, Norris, Doody, Molinari, Orenge, & Kunik, 2004). Not unexpectedly, the internal consistency was lower, but still acceptable, for the patients with dementia (Cronbach’s α = .69). Test retest reliability was also adequate (r = .78). Discriminate validity checks indicate that the Awareness Scores were affected by dementia but not by other factors, like depression. This means that deficit awareness is sufficiently discriminated from depression, even when depression coexists with dementia (Snow, Norris, Doody, Molinari, Orenge, & Kunik, 2004). Convergent validity was also demonstrated with high correlation between DDS-clinician and DDS-informant sum scores (r = 0.42, p < 0.001). Furthermore, sum scores between patient and informant were also significantly related (r = 0.42, p < 0.001) (Snow, Norris, Doody, Molinari, Orenge, & Kunik, 2004). Concurrent validity showed that dementia severity was significantly correlated with clinician and informant sum scores (r = 0.63, p < 0.0001; r = 0.62, p < 0.0001, respectively), meaning that as dementia severity worsened so did the awareness scores measured by the DDS. Concurrent validity was not demonstrated between the patient sum score and dementia severity (r = 0.21, p < 0.01) (Snow, Norris, Doody, Molinari, Orenge, & Kunik, 2004), indicating that there was not a significant relationship between the patient’s deficit awareness and dementia severity.

**Geriatric Depression Scale** (GDS; Yesavage et al., 1983) (*Appendix B*). The GDS is a widely used depression screener for use with geriatric population. The GDS is an instrument that has been widely used in clinical work and research since its first appearance over 20 years ago. It has the distinction of being the first screening scale for
depression specifically designed for use with older adults (Yesavage et al., 1983). The authors eliminated questions regarding age-related complaints (i.e. somatic and sexual complaints). The GDS utilizes yes/no format questions regarding how the individual has felt over the past week. There are multiple forms of the GDS, including a 30-item, 15-item, and 5-item questionnaire. The five-item version of the GDS will be used in this study and has demonstrated adequate reliability and validity as compared to the 15-item GDS (Hoyl et al., 1999; Rinaldi, et al., 2003). Rinaldi, et al. (2003) found the five-item GDS to have a sensitivity of 0.94 and a specificity of 0.81. Hoyl et al. (1999) found the five-item GDS to have sensitivity of 0.97, specificity of 0.85, and accuracy for predicting depression of 0.90. There was significant agreement with clinical diagnosis of depression among both the five-item GDS and the 15-item GDS (Hoyl, et al., 1999; Rinaldi, et al., 2003). Additionally, the five-item GDS has good interrater reliability (k= 0.88) and test-retest reliability (k= 0.84) (Rinaldi, et al., 2003).

**Geriatric Anxiety Inventory** (GAI; Pachana, Byrne, Siddle, Loloski, Harley, & Arnold, 2006) *(Appendix C)*. The Geriatric Anxiety Inventory (GAI) was developed to address the clinical shortcomings of other anxiety measures for use with older adults. The GAI is a 20-item self-report measure with an agree/disagree response format. The measure has minimal somatic symptoms to minimize endorsement of symptoms from general medical conditions. The measure is a screener; therefore, it is not appropriate for diagnosis of anxiety disorders in the elderly. The GAI has good concurrent validity, with high correlation with other measures including the GADS, STAI, BAI, Penn State Worry Questionnaire (PSWQ), and the Positive and Negative Affect Schedule (PANAS) (Pachana, Byrne, Siddle, Loloski, Harley, & Arnold, 2006). The optimum cut-point was
10-11 for distinguishing those with Generalized Anxiety Disorder (GAD) and those without GAD (Pachana, Byrne, Siddle, Loloski, Harley, & Arnold, 2006). This cut-point correctly classified 83 percent of patients with a sensitivity of 75 percent and specificity of 84 percent. Pachana, Byrne, Siddle, Loloski, Harley, and Arnold (2006) also recommended a cut point of 8-9 to identify individuals with any anxiety disorder, which correctly classified 78 percent of patients with a sensitivity of 73 percent and specificity of 80 percent.

**Emotional Reaction Measure** (Appendix D). Items to assess other emotions including anger, sadness, guilt, fear, and relief were derived and adapted from Orbell, Hagger, Brown, and Tidy (2004), which was based upon Smith, Haynes, Lazarus, & Pope (1993) and Lazarus (1991). Anger will be assessed using five statements of “I feel angry,” “I feel enraged,” “I feel irate,” “I feel mad at the world,” and “I feel furious.” Sadness will be assessed using three items including “I feel sorrowful,” “I feel downhearted,” and “I feel sad.” Guilt will be assessed using three items including “I feel sorry,” “I feel guilty,” and “I feel regretful.” Fear/Anxiety will be assessed with two items including “I feel anxious” and “I feel fearful.” Lastly, the emotion of relief will be assessed using two including “I feel relieved” and “I feel reassured.” All items will be assessed using a four-point Likert type scale (Not at all to Very Much So).

**Appraisal Measure** (Appendix E). The measure of primary and secondary appraisal used in this study will be adapted from Orbell, Hagger, Brown, and Tidy (2004), which were derived from Smith, Haynes, Lazarus, & Pope (1993). Specifically, primary appraisal will be assessed using a 4-point Likert-type scale which measures motivational relevance and motivational congruence/incongruence. Secondary appraisal
will assess accountability, problem-focused coping potential, emotional-focused coping potential, and future expectation.

**Perceived Social Support Survey** *(Appendix F).* The items to measure perceived social support will be taken from the MOS Social Support Survey (Shelbourne & Stewart, 1991), a reliable and valid measure. The measure was developed using a pool of 2,987 participants, aged 18 to 98 years of age, who responded to 19 items, which demonstrated good internal consistency (alpha = 0.97). The measure also demonstrated good convergent validity when correlated with loneliness (rs = -0.53 to -0.69), marital and family functioning (rs = 0.38 to 0.57), and mental health (rs = 0.36 to 0.45) (Maher, Mora, & Levanthal, 2006). The scale was developed to be short, simple, and easily understood making it an appropriate scale for use in an older adult population. The items used in this study will assess perceived social support (alpha = .83 and .79 for times 1 and 2), which measures the combination of emotional support (e.g. “How often is there someone you can count on to listen to you when you need to talk?” “How often is there someone to confide in or talk to about yourself and your problems?”), tangible support (e.g. “How often is there someone you can count on to help you with your daily chores if you are sick?” “How often is there someone who can take you to the doctor if needed?”), and friendship support (e.g. “How often is there someone with whom you can do enjoyable things?” “How often is there someone with whom you can get together for relaxation?”). All items use a 5-point Likert type scale (range 1 = never to 5 = always).

**Demographic Survey** *(Appendix G).* Information for the demographics survey will be obtained through chart review and will include patient’s age, sex, race, education, marital status, living situation, and prior diagnosis of cognitive impairment.
Procedure

Prior to any data collection, the study protocol will be approved by the Institutional Review Boards for the Cincinnati Veterans Affairs Medical Center and Xavier University to ensure compliance with human subjects standards. Participants for this study will be recruited through the Neuropsychology clinic at a Midwestern Veterans Affairs Medical Center. Participation in this research study will be completely voluntary and the decision to participate will not affect the individual’s care. All participants will be approached about opportunity to participate in the research project prior to their scheduled evaluation. If they choose to participate, informed consent will be obtained by the researcher. If the individual is unable to give informed consent, consent from guardian or power of attorney will be obtained as will participant assent, as is customary in other dementia research.

Once informed consent has been established, the researcher will administer the participant a packet of baseline measures (Time 1) including the patient version of the DDS, GDS, GAI, and emotion measure. The researcher will help the participant in the completion of these measures to the extent that the participant needs assistance. Completion of the participant surveys should take approximately fifteen to twenty minutes. Following the completion of these surveys, the participant will be seen by the neuropsychologist for their scheduled neuropsychological evaluation. After the evaluation is complete, the neuropsychologist will provide diagnostic feedback to the person as per customary procedure. The evaluating psychologist will complete the clinician version of the DDS and return the document to the researcher. At Time 1, participants will be notified that the researcher will contact them in twelve to thirty-six
hours for follow up data collection (Time 2), and on a separate form the participants’ first
name, phone number, and preferred contact time will be collected. At Time 2, the
participant will be contacted via telephone and administered a second packet of
questionnaires including the GDS, GAI, emotional reaction, appraisal, and perceived
social support. At Time 2, the participants will be asked to respond to all measures in the
context of their specific diagnosis (e.g. Dementia of the Alzheimer’s Type) and the
researcher will tailor this for each participant. The responses on all of the measures will
be confidential. Each measure will be coded with a participant identification number;
therefore, responses will not be tied to any individual person. Only necessary
demographic information will be collected. Any potentially identifying information
collected will be stored in a locked cabinet separate from the code-identified measures to
maximize security of participant information.
Chapter IV: Proposed Analysis

A correlation matrix for all of the demographic variables will be calculated to see how well correlated they are with each other and with the dependent variables (emotional reaction). To test primary hypotheses one through seven, a series of repeated measures ANCOVAs will be used. Each repeated measure ANCOVA will test whether a specific emotion (i.e., depression, anxiety, anger, sadness, fear/anxiety, guilt, and relief), changes significantly from Time 1 to Time 2, after removing the variance for which the covariate (degree of awareness) accounts.

Given that awareness is presumed to be necessary for emotional reaction, Baron and Kenny’s (1986) steps of mediational analysis will be followed to examine the relationship of cognitive appraisal, deficit awareness, and emotional reaction in the secondary analyses. According to the mediational model, the link between cognitive appraisal and emotional reaction is mediated, or explained, by deficit awareness. Without awareness of deficits, emotional reaction would not be possible. This will be tested using a series of multiple regression equations.

In the secondary analyses, three regression equations will be tested to evaluate the predictors of anger as an emotional reaction. In examination of the first of these secondary hypotheses, multiple regression will be performed using motivational relevance and deficit awareness as the predictor variables and anger as the criterion.
Motivational relevance will be entered in the first step, and deficit awareness in the second step. In order to support a mediational prediction, motivational relevance will significantly predict anger in step one. In step two, deficit awareness (the mediating variable) will significantly predict anger, but motivational relevance no longer will. In all further analyses, this two-step process will be utilized, with deficit awareness consistently serving as a mediator. In examination of the second secondary hypothesis, another multiple regression equation will use motivational incongruence and deficit awareness to predict anger. To test the third secondary hypothesis, other-accountability and deficit awareness will be used to predict anger using a multiple regression analysis.

In the secondary analyses, three equations will be tested to evaluate the predictors of guilt as an emotional reaction. To test secondary hypothesis four, multiple regression will test motivational relevance and deficit awareness as predictors of the emotional reaction of guilt. To test secondary hypothesis five, a regression equation will test motivational incongruence and deficit awareness as predictors of guilt. Finally, to test the sixth secondary hypothesis, a regression equation will test self-accountability and deficit awareness as predictors of guilt.

To evaluate the predictors of fear as an emotional reaction, three regression equations will be tested in the secondary analyses. To test the seventh secondary hypothesis, a regression equation will test motivational relevance and deficit awareness as predictors of fear. To test the eighth secondary hypothesis, a regression equation will test motivational incongruence and deficit awareness as predictors of fear. Finally, the ninth secondary hypothesis will be tested using a regression equation with emotion-focused coping potential and deficit awareness as predictors of fear.
To evaluate the predictors of sadness as an emotional reaction, four regression equations will be tested in secondary analyses. To test the tenth secondary hypothesis, motivational relevance and deficit awareness will be tested as predictors of sadness. To test the eleventh secondary hypothesis, motivational incongruence and deficit awareness will be tested as predictors of sadness. Problem-focused coping potential and deficit awareness will be tested as predictors of sadness for the twelfth hypothesis. Finally, future-expectancy and deficit awareness will be tested as predictors of sadness.

To evaluate the last emotional reaction of relief, two regression equations will be tested in secondary analyses. First, motivational relevance and deficit awareness will be tested as predictors of relief. Then, motivational congruence and deficit awareness will be tested as predictors of relief. Other emotional reactions will be evaluated in post-hoc analysis.
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Appendix A

Dementia Deficits Scale


This scale can be obtained by emailing Dr. A. Lynn Snow at asnow@bcm.tmc.edu.
Appendix B

5-item Geriatric Depression Scale (GDS)


This scale can be obtained in text in the above cited article.
Appendix C

Geriatric Anxiety Inventory (GAI)


This scale can be obtained by emailing Dr. Nancy A. Pachana at npachana@psy.uq.edu.au.
Appendix D

Emotion Measure

Time 1

Instructions: We are interested in knowing how you feel right now. Please answer each question by making a tick or mark in ONE box that best fits how YOU feel RIGHT NOW. There are no right or wrong answers.

<table>
<thead>
<tr>
<th>How do you feel at the moment?</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Moderately</th>
<th>Very Much</th>
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<tbody>
<tr>
<td>I feel angry</td>
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<td>I feel enraged</td>
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<td>I feel irate</td>
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<tr>
<td>I feel mad at the world</td>
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<tr>
<td>I feel furious</td>
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<tr>
<td>I feel sorrowful</td>
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<td>I feel downhearted</td>
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<tr>
<td>I feel sad</td>
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<td>I feel sorry</td>
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<td>I feel guilty</td>
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<td>I feel regretful</td>
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<tr>
<td>I feel anxious</td>
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<td>I feel fearful</td>
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<td>I feel relieved</td>
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<td>I feel reassured</td>
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**Emotional Reaction Measure**

**Time 2**

*Instructions: We are interested in how people FEEL after they hear a diagnosis of cognitive impairment. Please answer each question by indicating which ONE response best fits how YOU feel RIGHT NOW. You are to choose from “Not at All,” “Somewhat,” “Moderately So,” and “Very Much So.” There are no right or wrong answers.*

<table>
<thead>
<tr>
<th>How do you feel at the moment?</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Moderately So</th>
<th>Very Much So</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel angry</td>
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<td>I feel enraged</td>
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<td>I feel irate</td>
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<td>I feel mad at the world</td>
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<td>I feel furious</td>
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<td>I feel sorrowful</td>
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<td>I feel sad</td>
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<td>I feel sorry</td>
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<td>I feel guilty</td>
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<td>I feel regretful</td>
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<td>I feel anxious</td>
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<td>I feel fearful</td>
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<td>I feel relieved</td>
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<tr>
<td>I feel reassured</td>
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Appendix E

Appraisal Measure

Instructions: We are interested in how people think about their visit to the neuropsychology clinic. Please answer each question by circling the ONE response that best fits what YOU think. There are no right or wrong answers.

1. How important/unimportant to you was this visit to the neuropsychology clinic?

   1    2    3    4
   Extremely Unimportant Extremely Important

2. Thinking about what you didn't want to happen during your visit to the neuropsychology clinic, to what extent did these undesirable things happen?

   1    2    3    4
   Not At All     Very Much So

3. Thinking about what you did want to happen during your visit to the neuropsychology clinic, to what extent did these desirable things happen?

   1    2    3    4
   Not At All     Very Much So

4. During your visit to the neuropsychology clinic, how certain were you that you would be able to deal emotionally with what was happening, however it turned out?

   1    2    3    4
   Extremely unsure Extremely sure
   I would be able
   I would be able
5. During your visit to the neuropsychology clinic, how certain were you that you would be able to make things go the way you wanted them to during your visit?

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<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Extremely unsure</th>
<th>Extremely sure</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>I would be able</td>
<td>I would be able</td>
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</table>

6. To what extent did you consider yourself responsible for what happened during your visit to the neuropsychology clinic?

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<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Not At All</th>
<th>Very Much So</th>
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<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Not At All</td>
<td>Very Much So</td>
</tr>
</tbody>
</table>

7. To what extent did you consider someone else responsible for what happened during your visit to the neuropsychology clinic?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Not At All</th>
<th>Very Much So</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Not At All</td>
<td>Very Much So</td>
</tr>
</tbody>
</table>

8. Think about how you wanted your visit to the neuropsychology clinic to be. When you were there, to what extent did you expect things to go (for any reason) the way you wanted?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Not At All</th>
<th>Very Much So</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Not At All</td>
<td>Very Much So</td>
</tr>
</tbody>
</table>
Appendix F

Perceived Social Support Survey

People sometimes look to others for companionship, assistance, or other types of support. How often is each of these kinds of support available to you if you need it?

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the Time</th>
<th>Most of the Time</th>
<th>All of the Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Someone you can count on to listen to you when you need to talk?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Someone to confide in or talk to about yourself and your problems?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Someone you can count on to help you with your daily chores when you are sick?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Someone who can take you to the doctor if needed?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Someone with whom you can do enjoyable things?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Someone with whom you can get together for relaxation?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G
Demographic Survey

What is the patient’s age? ______

What is the patient’s sex? Male Female

How many years of education did the patient complete? ______

With whom does the patient identify?
   ___ Arab
   ___ Asian/Pacific Islander
   ___ Black
   ___ Caucasian/White
   ___ Latino/Latina
   ___ Multiracial
   ___ Would rather not say
   ___ Other

What is the patient’s current marital status?
   ___ Married
   ___ Divorced
   ___ Separated
   ___ Widowed
   ___ Single

What is the patient’s current living situation?
   ___ Live alone
   ___ Live with someone (i.e. spouse, family, roommate)
   ___ Homeless
   ___ Live in a supervised environment or institution

Has the patient’s received any prior diagnosis of memory impairment?
   ___ Yes
   ___ No
Chapter V: Dissertation

Abstract

This research extends that of Carpenter et al. (2008) evaluating emotional reaction to receiving a diagnosis of cognitive impairment, by utilizing Lazarus’s theory of emotion to evaluate the roles of the covariate awareness of deficits and cognitive appraisal on emotional reaction. This study included 30 adults, age 65 years or older, undergoing neuropsychological evaluations at a VA hospital and a private geriatric practice. Data was collected at the time of neuropsychological assessment (Time 1) and 18-36 hours following diagnostic disclosure (Time 2). At Time 1, participants’ emotions and awareness of deficits were assessed. At Time 2, participants were asked to consider their recent diagnosis when responding to the emotion reaction, cognitive appraisal, and perceived social support measures. Although main effects revealed that participants experienced reductions in anxiety and depression, as well as an increase in feelings of relief, following diagnostic disclosure, these effects became nonsignificant in the presence of the covariate, awareness of deficits. Insufficient correlations between emotion reaction, appraisal, and awareness precluded further analysis of the potential mediating role of awareness between cognitive appraisal and emotional reaction. Clinical implications of the study are discussed.
Emotional Reactions to Diagnostic Disclosure of Cognitive Impairment

Many older adults fear receiving a diagnosis of dementia (Corner & Bond, 2004; Kuhn, 2007). Given that the prevalence of dementia increases with age and that the older adult population in the United States is expected to increase in proportion from the current 13% to 20% by 2030 (Center for Disease Control, 2007; Prince et al., 2013), many more individuals will likely fear receiving this diagnosis.

There is a high prevalence of psychological distress among those who have been diagnosed with dementia. Although some individuals do not meet the criteria for a major depressive disorder, depressive symptoms are common among those with dementia with an averaging prevalence rate of 30% (Steffens & Potter, 2008; Teri et al., 1999). Furthermore, an estimated 25%-60% of patients with Alzheimer’s disease have anxiety symptoms (Teri et al., 1999). It is critical for clinicians to understand and address affective distress among those diagnosed with cognitive impairments, as affective distress can further compromise a person’s cognitive abilities.

While affective distress has been documented over the course of dementia, only a few studies have investigated the psychological impact of this disorder immediately following the diagnosis. To date, only one prospective, quasi-experimental study has evaluated the emotional reaction to diagnostic disclosure of dementia (Carpenter et al., 2008). Of those diagnosed with dementia, Carpenter et al. (2008) found that there was little change in depressive symptoms. However a significant reduction in symptoms of anxiety was noted following diagnostic disclosure, particularly for those who were highly anxious at baseline. In descriptive research, case studies have described the emotional
reactions categorically and in broad terms to the diagnostic disclosure of dementia (Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006; Derksen, Vernooij-Dassen, Gillissen, Rikkert, & Scheltens, 2006; Robinson, Clare, & Evans, 2005; Aminzadeh, Byszewski, Molnar, & Eisner, 2007). Taken together, these studies of dementia have not accounted for the demented individual’s cognitive appraisal and the degree of awareness of their deficits, which can affect emotional reaction.

Lazarus’ theory of emotion (Lazraus & Folkman, 1984; Lazarus & Smith, 1988; Lazarus, 1991; Smith & Lazarus, 1993) provides a lens to view how degree of awareness and cognitive appraisal can impact emotional reaction to receiving a diagnosis of cognitive impairment. There are three broad aspects to his theory. First, emotion is relational, meaning that specific emotions are created based on consistent characteristics of the person-environment interaction. Therefore, there is the potential for changing emotional experiences as aspects of the person and/or the environment change. Second, emotion is cognitive, meaning that the person brings to the interaction prior knowledge of how things work and personal experience. The third aspect of the theory is that emotion involves appraisal. There are two types of appraisal, including primary and secondary appraisal. In primary appraisal, one assesses: 1) to what extent “is this a threat?”; 2) how personally meaningful the situation is (i.e. motivational relevance); and 3) how congruent or incongruent it is with one’s goals (i.e. motivational congruence). Secondary appraisal represents the process of evaluating one’s personal resources and has four components: attribution of blame, problem-focused coping potential, emotion-focused coping potential, and future expectancy.
Emotion, then, is based upon evaluating several of the cognitive-relational components discussed above. That is, there is no potential for emotion if the person does not appraise the situation to be important to them (Lazarus & Smith, 1988; Smith & Lazarus, 1993). As a result, a pattern of primary appraisals of personal significance (i.e. motivational relevance) and incongruence with one’s personal goals (i.e. motivational incongruence) result in negative emotions. In this case, the situation is appraised to be important to a person, but is incompatible with that person’s current goals. On the other hand, if a person assesses a situation to have motivational relevance and it is in agreement with that person’s goals, then positive emotions will be the consequence of this. These patterns underlying emotion are called “core-relational themes”, and represent the integration of all the individual appraisal components (Smith & Lazarus, 1993; Lazarus & Smith, 1988).

To determine specific emotions, the individual components of the appraisal must be evaluated in relation to one another. For example, one would experience anger if the primary appraisal of the situation was one of threat or potential harm (i.e., motivational relevance), and that this harm was perceived as inconsistent with a person’s goals (i.e., motivational incongruence), paired with the secondary appraisal that someone was to blame for this potential harm (Lazarus & Smith, 1988; Smith & Lazarus, 1993). Similarly, guilt is determined by a combination of motivational relevance (i.e., perceived harm) and motivational incongruence (i.e., inconsistent with personal goals). However, it is distinguished from anger by the attribution of accountability in that guilt is self-blame, whereas anger is other-blame. Although these two emotions are similar, they represent different patterns of appraisal, and therefore are distinguishable from each other. Fear is
characterized by motivational relevance and incongruence, and a secondary appraisal of poor or uncertain potential for emotional coping. That is, the person perceives a poor ability to psychologically adjust to the situation or harm if it were to occur (Smith & Lazarus, 1993). On the other hand, sadness remains motivationally relevant and incongruent but has a low problem focus coping potential and a poor outlook for future change that would improve the situation (Smith & Lazarus, 1993). Relief is a positive emotion. Thus, it is characterized by motivational relevance and motivational congruence. According to Orbell, Hagger, Brown, and Tidy (2004), a secondary appraisal is not necessary to produce the emotion of relief. The ability to understand the interaction between a person and their environment is a critical piece of appraisal according to Lazarus’ theory.

A lack of awareness of one’s deficits, also known as anosognosia, will adversely affect an individual’s knowledge of aspects of the person-environment interaction, including a person’s appraisal of the severity of the situation (i.e., primary appraisal) and their ability to assess the resources available to them (i.e., secondary appraisal). Individual’s appraisal of the situation will in turn affect their emotional reactions. This unawareness of their deficits may actually protect individuals from emotional distress by buffering the emotional impact of their cognitive loss (Zec & Burkett, 2005; Pia & Conway, 2008). Anosognosia is commonly experienced by people with dementia, stroke, and psychiatric illness (Pia & Conway, 2008; Physicians’ Desk Reference, 1995).

The purpose of this study is to investigate the emotional reaction following diagnostic disclosure of cognitive impairment, based upon Lazarus’ theory of emotion,
considering deficit awareness as a possible mediating variable. The following null hypotheses were examined:

**Primary Analyses**

H1: There will be a significant difference in levels of depressive symptoms as measured by the Geriatric Depression Scale (GDS) at Time 1 and Time 2, and this difference will become nonsignificant when controlling for degree of awareness.

H2: There will be a significant difference in levels of anxiety symptoms as measured by the Geriatric Anxiety Inventory (GAI) at Time 1 and Time 2, and this difference will become nonsignificant when controlling for degree of awareness.

H3: There will be a significant difference in levels of anger as measured by the anger subscale of the emotional reaction measure by Orbell, Hagger, Brown, and Tidy (2004) at Time 1 and Time 2, and this difference will become nonsignificant when controlling for degree of awareness.

H4: There will be a significant difference in levels of sadness as measured by the sadness subscale of the emotional reaction measure by Orbell, Hagger, Brown, and Tidy (2004) at Time 1 and Time 2, and this difference will become nonsignificant when controlling for degree of awareness.

H5: There will be a significant difference in levels of fear/anxiety as measured by the fear/anxiety subscale of the emotional reaction measure by Orbell, Hagger, Brown, and Tidy (2004) at Time 1 and Time 2, and this difference will become nonsignificant when controlling for degree of awareness.

H6: There will be a significant difference in levels of guilt as measured by the guilt subscale of the emotional reaction measure by Orbell, Hagger, Brown, and Tidy (2004) at
Time 1 and Time 2, and this difference will become nonsignificant when controlling for degree of awareness.

H7: There will be a significant difference in levels of relief as measured by the relief subscale of the emotional reaction measure by Orbell, Hagger, Brown, and Tidy (2004) at Time 1 and Time 2, and this difference will become nonsignificant when controlling for degree of awareness.

Secondary Analyses

Anger

Ho1: Awareness will not mediate the relationship between motivational relevance and anger.

Ho2: Awareness will not mediate the relationship between motivational incongruence and anger.

Ho3: Awareness will not mediate the relationship between other-accountability and anger.

Guilt

Ho4: Awareness will not mediate the relationship between motivational relevance and guilt.

Ho5: Awareness will not mediate the relationship between motivational incongruence and guilt.

Ho6: Awareness will not mediate the relationship between self-accountability and guilt.

Fear/Anxiety

Ho7: Awareness will not mediate the relationship between motivational relevance and fear/anxiety.
Ho8: Awareness will not mediate the relationship between motivational incongruence and fear/anxiety.

Ho9: Awareness will not mediate the relationship between emotion-focused coping potential and fear/anxiety.

**Sadness**

Ho10: Awareness will not mediate the relationship between motivational relevance and sadness.

Ho11: Awareness will not mediate the relationship between motivational incongruence and sadness.

Ho12: Awareness will not mediate the relationship between problem-focused coping potential and sadness.

Ho13: Awareness will not mediate the relationship between future-expectancy and sadness.

**Relief**

Ho14: Awareness will not mediate the relationship between motivational relevance and relief.

Ho15: Awareness will not mediate the relationship between motivational congruence and relief.

**Method**

**Participants**

Participants were 30 individuals recruited through a Neuropsychological clinic at a Midwestern Veterans Affairs Medical Center and a local psychology private practice specializing in geriatric care. The study was approved by the Institutional Review Boards.
of the University of Cincinnati Medical Center, Cincinnati Veterans Affairs Medical Center (CVAMC), and Xavier University (see Appendix A). All individuals were diagnosed with Mild Cognitive Impairment (any type) or dementia (any type). A total of seven participants were collected through the Veterans Affairs Medical Center and 23 participants were collected through the private practice. Individuals collected through the Veterans Affairs Medical Center differed from those collected through the local private practice in that there were a greater proportion of individuals who had previously been informed of cognitive impairment. Specifically, six participants endorsed receiving prior diagnosis within the Veterans Affairs Medical Center whereas only one participant endorsed prior diagnosis through the private clinic. Of the total sample, 14 participants were female and 16 were male, with ages ranging from 65 years old to 89 years old. The mean age of the sample was 77 years ($SD = 5.9$). Mean years of education was 14.2 ($SD = 3.0$). The majority of the sample self identified as Caucasian (90%). Table 1 presents the percentages for demographic variables of the participants.

**Measures**

**Dementia Deficits Scale** (DDS; Snow et al., 2004; See Appendix B) The participant and clinician questionnaires were utilized from the Dementia Deficit Scale (DDS; Snow, Norris, Doody, Molinari, Orengo, & Kunik, 2004). The DDS is a standardized, multidimensional assessment of deficit awareness in those with dementia, which includes versions for the patient, informant, and clinician. For this study, the patient and clinician were completed as a self-report questionnaire assessing deficit awareness. The scale utilizes a yes/no format checklist of deficits that are commonly associated with cognitive impairment. Specifically, this scale assesses the patient’s
awareness of illness as well as cognitive, emotional/behavioral, and functional deficits. This information is helpful as there is evidence that deficit awareness is multidimensional and persons may be aware of deficits in one area (i.e. cognition) but unaware of deficits in another area (i.e. functional abilities; Snow et al., 2004; Snow et al., 2005). To calculate scores for the scale, a one or zero point value was given to each yes or no answer. Some of the items were reversed scored, as defined by Snow et al. (2004). After the point value was determined for each item, a summation of points yields the total score for each completed version. In accordance with Snow et al. (2004), the sum scores were converted to z-scores to allow for direct comparison, given the different lengths of the patient and clinician questionnaires. Next, a deficit awareness score was calculated by subtracting the DDS patient z-score from the DDS clinician z-score. Larger scores reflect greater discrepancy between the patient and the clinician. Positive scores indicate that the patient endorsed fewer deficits than the clinician (underreporting), whereas negative scores indicate that the patient endorsed more deficits than did the clinician (overreporting) (Snow et al., 2004).

Regarding the reliability and validity of the DDS, the scale has demonstrated high internal consistency for both the clinician (Cronbach’s $\alpha = .87$) and informant (Cronbach’s $\alpha = .88$) versions (Snow et al., 2004). However, the internal consistency for the patients with dementia (Cronbach’s $\alpha = .69$) was characterized as “questionable” according to George and Malory (2003) and Kline (1999). Test retest reliability was acceptable ($r = .78$). Discriminate validity checks indicate that the Awareness Scores were affected by dementia but not by other factors, like depression. This means that deficit awareness is sufficiently discriminated from depression, even when depression
coexists with dementia (Snow et al., 2004). Convergent validity was also demonstrated with high correlation between DDS-clinician and DDS-informant sum scores ($r = 0.42, p < 0.001$). Furthermore, sum scores between patient and informant were also significantly related ($r = 0.42, p < 0.001$; Snow et al., 2004). Concurrent validity showed that dementia severity was significantly correlated with clinician and informant sum scores ($r = 0.63, p < 0.0001$; $r = 0.62, p < 0.0001$, respectively), meaning that as dementia severity worsened so did the awareness scores measured by the DDS. Concurrent validity was not demonstrated between the patient sum score and dementia severity ($r = 0.21, p < 0.01$; Snow et al., 2004), indicating that there was not a significant relationship between the patient’s deficit awareness and dementia severity.

**Geriatric Depression Scale** (GDS; Yesavage et al., 1983; See Appendix C). The GDS is a widely used depression screener in the geriatric population. The GDS is an instrument that has been widely used in clinical work and research since its first appearance over 20 years ago. It has the distinction of being the first screening scale for depression specifically designed for use with older adults (Yesavage et al., 1983). The authors eliminated questions regarding age-related complaints (i.e. somatic and sexual complaints). The GDS utilizes yes/no format questions regarding how the individual has felt over the past week. There are multiple forms of the GDS, including a 30-item, 15-item, and 5-item questionnaire. The 5-item version of the GDS was used in this study and has demonstrated adequate reliability and validity as compared to the 15-item GDS (Hoyl, et al., 1999; Rinaldi, et al., 2003). Rinaldi, et al. (2003) found the five-item GDS to have a sensitivity of 0.94 and a specificity of 0.81. Hoyl et al. (1999) found the five-item GDS to have sensitivity of 0.97, specificity of 0.85, and accuracy for predicting
depression of 0.90. There was significant agreement with clinical diagnosis of depression among both the five-item GDS and the 15-item GDS (Hoyl, et al., 1999; Rinaldi, et al., 2003). Additionally, the five-item GDS has good interrater reliability ($k = 0.88$) and test-retest reliability ($k = 0.84$) (Rinaldi, et al., 2003). Two items on the five item version are reversed scored.

**Geriatric Anxiety Inventory** (GAI; Pachana et al., 2007; See Appendix D). The Geriatric Anxiety Inventory (GAI) was developed to address the clinical shortcomings of other anxiety measures for use with older adults. The GAI is a 20-item self-report measure with an agree/disagree response format. The measure has minimal somatic symptoms to minimize endorsement of symptoms from general medical conditions. The measure is a screener; therefore, it is not appropriate for diagnosis of anxiety disorders in the elderly. The GAI has good concurrent validity, with high correlation with other measures including the GADS, STA1, BAI, Penn State Worry Questionnaire (PSWQ), and the Positive and Negative Affect Schedule (PANAS; Pachana et al., 2007). The optimum cut-point was 10-11 for distinguishing those with Generalized Anxiety Disorder (GAD) and those without GAD (Pachana et al., 2007). This cut-point correctly classified 83 percent of patients with a sensitivity of .75 and specificity of .84. Pachana et al. (2007) also recommended a cut point of 8-9 to identify individuals with any anxiety disorder, which correctly classified 78 percent of patients with a sensitivity of .73 and specificity of .80.

**Emotional Reaction Measure** (See Appendix E). Items to assess other emotions including anger, sadness, guilt, fear, and relief were derived and adapted from Orbell, Hagger, Brown, and Tidy (2004), which was based upon Smith, Haynes,
Lazarus, & Pope (1993) and Lazarus (1991). Anger was assessed using five statements of “I feel angry,” “I feel enraged,” “I feel irate,” “I feel mad at the world,” and “I feel furious.” Sadness was assessed using three items including “I feel sorrowful,” “I feel downhearted,” and “I feel sad.” Guilt was assessed using three items including “I feel sorry,” “I feel guilty,” and “I feel regretful.” Fear/Anxiety was assessed with two items including “I feel anxious” and “I feel fearful.” Lastly, the emotion of relief was assessed using two including “I feel relieved” and “I feel reassured.” All items were assessed using a four-point Likert type scale where 1= “Not at all to 4 = “Very Much So”).

**Appraisal Measure** (See Appendix F). The measure of primary and secondary appraisal used in this study was adapted from Orbell, Hagger, Brown, and Tidy (2004), which were derived from Smith, Haynes, Lazarus, & Pope (1993). Specifically, primary appraisal was assessed using a 4-point Likert-type scale which measured motivational relevance and motivational congruence/incongruence. Secondary appraisal was also assessed using a 4-point Likert-type scale which measured accountability, problem-focused coping potential, emotional-focused coping potential, and future expectation.

**Perceived Social Support Survey** (See Appendix G). The items to measure perceived social support were taken from the MOS Social Support Survey (Shelbourne & Stewart, 1991), a reliable and valid measure. The items used in the original study assessed perceived social support (alpha = .83 and .79 for times 1 and 2), which measures the combination of emotional support (e.g. “How often is there someone you can count on to listen to you when you need to talk?” “How often is there someone to confide in or talk to about yourself and your problems?”), tangible support (e.g. “How often is there someone you can count on to help you with your daily chores if you are sick?” “How
often is there someone who can take you to the doctor if needed?”), and friendship support (e.g. “How often is there someone with whom you can do enjoyable things?” “How often is there someone with whom you can get together for relaxation?”). All items use a 5-point Likert type scale (range 1 = never to 5 = always). The measure was developed using a pool of 2,987 participants, aged 18 to 98 years of age, who responded to 19 items, which demonstrated good internal consistency (alpha = 0.97). The measure also demonstrated good convergent validity when correlated with loneliness (rs = -0.53 to -0.69), marital and family functioning (rs = 0.38 to 0.57), and mental health (rs = 0.36 to 0.45; Maher, Mora, & Levanthal, 2006). The scale was developed to be short, simple, and easily understood making it an appropriate scale for use in an older adult population.

Demographic Survey (See Appendix H). Information for the demographics survey was obtained through chart review and included patient’s age, sex, race, education, marital status, living situation, and prior diagnosis of cognitive impairment.

Procedure

All participants were approached about opportunity to participate in the research project prior to the start of the cognitive evaluation. Some individuals chose not to participant; therefore, no data were collected about them. Informed consent was obtained for each participant. Once informed consent had been established, the participant was administered a packet of baseline measures (Time 1) including the patient version of the DDS, GDS, GAI, and emotion measure. In each setting, there was one researcher to obtain informed consent and administer all Time 1 measures. The researcher helped the participant in the completion of these measures to the extent that the participant needed assistance (i.e., read questions to participant). Following the
completion of these surveys, the participant underwent the cognitive evaluation as scheduled with one of three psychologists. After the evaluation was complete, diagnostic feedback was provided to the person as per customary procedure of the evaluating clinician. The evaluating psychologist also completed the clinician version of the DDS. Participants were notified that the researcher would contact them for follow up data collection (Time 2). One researcher collected data for all of Time 2. The participants’ first name, phone number, diagnosis and preferred contact time was documented on a separate sheet of paper that was destroyed following collection of Time 2 data. At Time 2 (18-36 hours following diagnostic feedback), the participant was contacted via telephone and administered a second packet of questionnaires including the GDS, GAI, emotional reaction, appraisal, and perceived social support. At Time 2, each participant was asked to respond to all measures in the context of their specific diagnosis (e.g. Dementia of the Alzheimer’s Type). Each measure was coded with a participant identification number; therefore, responses were not tied to any individual person. The researcher at Time 2 was blind to the Time 1 data, including clinician rating on the DDS. There was no attrition from Time 1 to Time 2, such that all those who participated at Time 1 continued to participate at Time 2.

Results

Preliminary Analyses

The sample was drawn from two individual settings including a neuropsychological clinic at the Veterans Administration and an outpatient private practice. A total of seven participants were included from the VA and 24 participants were included from the private practice. Preliminary analyses were conducted to assess
group equivalence on demographic variables. Chi-square analyses were conducted to evaluate sex, race, marital status, living situation, and prior diagnosis. Independent sample t-tests were completed to assess for differences in age and years of education. Results of the chi-square and independent samples t-test are shown (see Table 2). The VA sample and the community groups were not significantly different on age, years of education, race, living situation, and perceived social support. Groups differed on whether they had a prior diagnosis of cognitive impairment, such that proportionally more individuals from the VA were previously diagnosed with cognitive impairment as compared to the community sample ($x^2 = 1, N=30 = 19.86, p = .00$). Specifically, six individuals from the VA were previously diagnosed with cognitive impairment whereas only one individual was previously diagnosed in the private practice sample. It is notable that prior diagnosis was gathered by chart review; therefore, it is uncertain whether the individual has previously been informed of this diagnosis. Also, groups statistically differed in sex ratio such that proportionally more men comprised the VA group as compared to the community sample ($t(28) = 2.03, p = .05$). Statistically, groups were collapsed because these variables were not significantly correlated with the dependent variables in the study.

Given the importance of the relationship both between the covariate, awareness, and the dependent measures in the primary hypotheses and the role of awareness as a potential mediator between the predictor and criterion variables in the secondary analyses, correlational analyses were completed to determine these relationships (See Tables 3 and 4). As a group, awareness scores were distributed with majority of scores within one standard deviation of the mean. Five individuals who underreported relative
(GAI) significantly differed from Time 1 to Time 2 after factoring out variance accounted for by degree of awareness. Although a main effect was found for scores on the GAI over time, such that there GAI scores decreased over time, $F (1, 28) = 5.29, p = .03$, this effect became nonsignificant in the presence of the awareness covariate, $F (1, 28) = 1.78, p = .19$.

In examination of the third hypothesis, a repeated measures analysis of covariance was conducted to determine if scores on the Anger Index significantly differed from Time 1 to Time 2 after factoring out variance accounted for by degree of awareness. The scores did not significantly differ on the Anger Index over time, $F (1, 28) = .13, p = .72$. The effect of awareness on anger was consistent across time, $F (1, 28) = 2.55, p = .12$.

In examination of the fourth hypothesis, a repeated measures analysis of covariance was conducted to determine if scores on the Sadness Index significantly differed from Time 1 to Time 2 after factoring out variance accounted for by degree of awareness. The scores did not significantly differ on the Sadness Index over time, $F (1, 28) = .72, p = .41$. The effect of awareness on sadness was consistent across time, $F (1, 28) = .14, p = .71$.

In examination of the fifth hypothesis, a repeated measures analysis of covariance was conducted to determine if scores on the Anxiety/Fear Index significantly differed from Time 1 to Time 2 after factoring out variance accounted for by degree of awareness. The scores did not significantly differ on the Anxiety/Fear Index over time, $F (1, 28) = .354, p = .07$. The effect of awareness on anxiety/fear was consistent across time, $F (1, 28) = .29, p = .59$. 
In examination of the sixth hypothesis, a repeated measures analysis of covariance was conducted to determine if scores on the Regret Index significantly differed from Time 1 to Time 2 after factoring out variance accounted for by degree of awareness. The scores did not significantly differ on the Regret Index over time, $F(1,28) = .01, p = .92$. The effect of awareness on regret was consistent across time, $F(1,28) = .34, p = .57$.

In examination of the seventh hypothesis, a repeated measures analysis of covariance was conducted to determine if scores on the Relief Index significantly differed from Time 1 to Time 2 after factoring out variance accounted for by degree of awareness. Although a main effect was found for scores on the Relief Index over time, such that Relief scores increased over time, $F(1,28) = 16.03, p < .001$, this effect became nonsignificant in the presence of the awareness covariate, $F(1,28) = .06, p = .80$.

**Secondary Analyses**

Because the degree of deficit awareness was considered to be a possible mediator of emotional reaction, mediational analysis was considered in the secondary analyses. According to the mediation model, the link between cognitive appraisal and emotional reaction is mediated, or explained, by deficit awareness. Without awareness of deficits, emotional reaction would not be possible. According to the mediational model as outlined by Baron and Kenny (1986), the first step is to establish that significant correlations exist between the mediator and the dependent variable (i.e., emotional reaction) and the predictor (i.e., cognitive appraisal). In order to evaluate possible mediation, significant correlations between these variables are necessary before proceeding to subsequent steps of the mediation model. In this study, significant correlations between awareness, appraisal and emotional reaction were not found;
therefore, further analysis of mediation was not conducted because the assumption of correlation between the three variables was not sufficiently met.

**Discussion**

When negative emotional reactions are undetected and untreated, an exacerbation of cognitive problems, restlessness and agitation, as well as increased likelihood of premature nursing home placement can occur (Pearson et al., 1989; Reifler et al., 1987; Seignourel et al., 2008; Zarit & Zarit, 2006). Therefore, research evaluating the emotional reactions to receiving such a diagnosis is much needed. Understanding emotional reactions to receiving a diagnosis of dementia or other cognitive impairment is critical to informing the clinicians who are diagnosing and disclosing this information to the patients. To date, one prospective, quasi-experimental study has been done to evaluate emotional reaction to receiving a diagnosis of dementia (Carpenter et al., 2008), which focused on emotional reactions of anxiety and depression. This prospective study extends the literature to evaluate and understand a number of potential emotional reactions, informed by Lazarus' theory of emotion (Lazarus & Folkman, 1984; Lazarus & Smith, 1988; Lazarus, 1991, and Smith & Lazarus, 1993), as well as consider the potential mediating effect of deficit awareness.

Inconsistent with primary hypothesis one, no significant decrease in depressive symptoms as measured by the GDS from Time 1 to Time 2 was observed. Carpenter et al. (2008) showed minimal change in depressive symptoms following diagnostic disclosure. Notably, the present study’s methodology is different from Carpenter et al. (2008). Specifically, Carpenter et al. (2008) methodology did not ask participants to consider the context of their recent diagnosis of cognitive impairment when responding to
the measures. The present study asked participants to consider their recent diagnosis of
cognitive impairment when responding to emotion reaction measures. This
methodological change was incorporated due to limitations discussed within the
Carpenter et al. (2008) study. Despite this methodological change, no significant change
in depressive symptoms was detected following diagnostic disclosure. The observed
power for the analyses was .45 and dropped to .34 with the inclusion of the covariate,
awareness. Thus, this lack of power due to small sample size may well have resulted in
accepting a false null hypothesis and committing a Type II error, namely that there may
be a true difference that is undetectable due to low power.

Consistent with primary hypothesis two, while a significant decrease in anxious
symptoms as measured by the GAI from Time 1 to Time 2 was noted, the effect became
nonsignificant in the presence of the awareness covariate. The main effect was consistent
with the finding by Carpenter et al. (2008) who also reported a decrease in anxious
symptoms following diagnostic disclosure. Interestingly, this finding is inconsistent with
results of primary hypothesis five, which assessed emotional reaction of fear/anxiety
using a two-question, likert-type scale format. This discrepancy between the two
measures assessing similar constructs may be explained in that the GAI was able to detect
more subtle changes from Time 1 to Time 2 due to the larger scope of questions as
compared to the two question format of the emotion reaction measure. However, when
the covariate awareness was included in this present analysis, the observed power was
.31. Thus, this lack of power due to small sample size may well have resulted in
accepting a false null hypothesis and committing a Type II error, namely that there may
be a true difference that is undetectable due to low power.
Consistent with primary hypothesis seven, while a significant increase in feelings of relief following diagnostic disclosure was observed, the effect became nonsignificant in the presence of the awareness covariate. The main effect finding is consistent with Robinson, Clare, and Evans (2005) finding that couples experienced relief following diagnosis of dementia in which one person of the couple received a diagnosis. This is also consistent with qualitative research that suggests that feelings of relief and confirmation are among the most prevalent immediate reactions to diagnostic disclosure of dementia (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). Despite consistency with some research, this finding is inconsistent with other research that has documented an intense fear of receiving a diagnosis of dementia (Corner & Bond, 2004; Kuhn, 2007). However, the fact that this main effect became nonsignificant when the covariate was included may be due to the low observed power (.08) for this analysis. Thus, this lack of power due to small sample size may well have resulted in accepting a false null hypothesis and committing a Type II error, namely that there may well be a change in relief scores after the diagnosis as indicated in the main effect.

With regard to primary hypotheses involving emotional reactions of anger, sadness, regret, and fear/anxiety, findings were inconsistent with the respective hypotheses insofar as none of these emotional reactions evidenced significant change from Time 1 to Time 2 on each respective measure. The effect of awareness on these respective emotions was consistent across time. In a study by Orbell, Hagger, Brown and Tidy (2004), which assessed emotional reaction to abnormal findings following colonoscopy using the same emotional reaction questionnaire, women endorsed sadness and anxiety following diagnosis, but not other negative emotions (i.e., anger, guilt). The
clinical implication of this finding is that in this sample, there was no significant change in negative emotions of anger, sadness, regret, or fear/anxiety, following diagnostic disclosure of cognitive impairment.

Through the correlation analyses, the appropriateness of awareness as a covariate is called into question. Although awareness was identified as a covariate based on theoretical understanding, statistically it is not recommended when correlation between the covariate and dependent variables are low. According to Huck, Cormier, and Bounds (1974) and Keppel and Zedeck (1989), ANCOVA analyses are generally not recommended when the correlation coefficient between the covariate and the dependent variable is less than $r = .2$ due to tendency to reduce power. When the correlation coefficient is less than .2, an ANOVA is recommended due to the increased power of the analysis when compared to the use of ANCOVA of the same data (Huck et al., 1974; Keppel & Zedeck, 1989). Specifically, for this study, the correlation between the covariate (awareness) and the dependent variables associated with the primary hypotheses (i.e., GDS, GAI, Anger, Sadness, Anxiety/Fear, Regret, and Relief) ranged from -.43 to .15 (see Table 3 for correlation matrix), which suggests that using awareness as a covariate may not only reduce power in the primary analyses but also not serve as an appropriate covariate.

Regarding secondary hypotheses, the role of awareness as a mediator between appraisal and emotional reaction was called into question due to the lack of significant correlation between awareness, appraisal and emotional reaction variables. Investigating awareness as a potential mediating variable in emotional reaction to receiving a diagnosis of cognitive impairment has not yet been done in research published to date. Therefore,
based on the nonsignificant findings of the present study, it is difficult to ascertain
whether this is due to theory or due to the nature of the sample in this study. Furthermore,
it is notable that the internal consistency on the DDS measure of awareness used for this
study was characterized as “questionable” for patients with dementia. In summary, the
lack of significant correlation between emotional reaction and awareness in this study
may be attributable to limitations of the DDS awareness measure and the inclusion of
additional emotion reaction measures. Although prior research has established
significant correlations with combinations of two of the three variables, to date no
research has yet included all three variables (deficit awareness, emotional reaction, and
cognitive appraisal). Future research is recommended to first establish correlations
between awareness using the DDS and emotion reactions, including anxiety, depression,
anger, sadness, fear, regret, and relief. Future research is then also indicated to correlate
these emotional reactions to appraisal theory.

Additional follow up analyses were completed to better understand if level of
awareness, specifically lack of awareness or underreporting, has an effect on each
emotion over time. Given that the awareness variable is inclusive of both overreporting
and underreporting relative to the clinician, the variable was dichotomized into positive
(overreporting) and negative (underreporting) scores by recoding into a new variable. A
total of 16 individuals were categorized as overreporting and 14 individuals were
categorized as underreporting. Then, a series of repeated measure analysis of variance
were completed to evaluate if the dichotomized awareness variable had an effect on each
emotion measure over time. Use of the dichotomized variable reflected no significant
change regarding the primary hypotheses that were nonsignificant with the aggregate
awareness variable (i.e., GDS, anger, sadness, guilt, and fear/anxiety); therefore, only the hypotheses reflecting statistical significance will be presented.

To further evaluate the second primary hypothesis, a repeated measures analysis of variance was completed to evaluate if dichotomized awareness had an effect on GAI scores over time. A significant main effect was found for scores on the GAI over time, $F(1,28) = 6.57, p = .02$. Comparison of mean GAI score indicate that scores at Time 2 ($M = 3.37, SD = 4.57$) on the GAI were significantly less than scores at Time 1 ($M = 4.60, SD = 5.30$). The interaction between GAI and the dichotomized awareness variable was significant, $F(1,28) = 5.38, p = .03$. Comparison of mean GAI scores indicate that scores for those who under-reported cognitive deficits at Time 1 ($M = 5.36, SD = 4.63$) evidenced a significant decrease in scores on the GAI at Time 2 ($M = 2.86, SD = 2.74$), whereas average GAI scores for those who over-reported at Time 1 ($M = 3.94, SD = 5.88$) evidenced only a modest decrease in scores on the GAI at Time 2 ($M = 3.81, SD = 5.78$). That means that individuals who under-reported cognitive impairment relative to clinician assessment of cognitive impairment showed a significant decrease in anxiety following diagnostic disclosure. In contrast, those who over-endorsed cognitive impairment relative to the clinician assessment experienced only a slight reduction in anxiety following diagnostic disclosure. This finding may be understood in that prior research has indicated that individuals with anosognosia tend to not only be unaware of deficits but also may hold an overly optimistic view of the medical condition and may overestimate their abilities to cope (Claire, 2004; Gainotti, 1997). Perhaps those who under-reported cognitive impairment relative to the clinician experienced a more significant reduction of distress due to optimism about their condition relative to those
who over-reported cognitive impairment relative to the clinician. It is notable that in this study, over-reporters and under-reporters did not significantly differ in perceived social support.

To further evaluate the seventh primary hypothesis, a repeated measure analysis of variance was completed to evaluate if dichotomized awareness had an effect on the Relief Index scores over time. A significant main effect was found for scores on the Relief Index over time, $F (1,28) = 15.81, p = .00$. Comparison of means indicate that scores at Time 2 ($M = 5.10, SD = 1.77$) on the Relief Index were significantly more than scores at Time 1 ($M = 3.57, SD = 2.01$). The interaction between Relief and dichotomized awareness was nonsignificant, $F (1,28) = .37, p = .55$. Overall, increased relief was experienced by both who over-reported and under-reported following diagnostic disclosure.

When considering results of this study, a few limitations should be noted. First, as mentioned above, the study is limited by a small sample size, which requires a large effect size for results to be statistically significant. Observed power for the main effects of most of the primary analyses was low, ranging from .05 (regret) to .71 (GDS), with the exception of relief with a high power of .97. Moreover, when the awareness covariate was included the observed power was reduced, ranging from .06 (i.e., regret) to .31 (i.e., GAI). Thus, the reduction in power may have resulted in committing a Type II error. Therefore, future research with a larger sample size should yield more power and more accurately determine real differences in emotional reaction to the diagnosis of cognitive impairment.
Another consideration is limited generalizability of the findings due to composition of the sample. The education distribution of the overall sample included in this study was not representative of the general public (United States Census Bureau, 2012). Specifically, the sample included in this study included proportionally more highly educated individuals, specifically 33% of the sample completed 12 years of education and 40% of the sample had 16 years or more education. No one included in this sample had less than 8 years of education. Furthermore, when considering the sample included in this study, it is possible that there was a selection bias because most people in the study were self-referred or were following through on medical advice provided by one of their medical providers (i.e., primary care physician). This suggests that the people who participate in a neuropsychological assessment are invested in knowing more about their cognitive functioning and are agreeable not only to undergoing further assessment but also agreeable to participate in research. This may represent a unique set of characteristics that differentiate those from individuals who experience cognitive decline but do not elect to have their cognition evaluated further or do not heed medical advice. Inclusion of a broader sample of the population experiencing cognitive decline is recommended for future research to further understand these characteristics and their potential relationships to deficit awareness, emotional reaction, and cognitive appraisal.

Furthermore, the combined sample potentially included diagnoses of both major (i.e., dementia) and minor (i.e., MCI) neurocognitive disorders. The instances of each disorder were destroyed following Time 2 data collection, consistent with the IRB protocol, which precluded further comparative analyses of severity of diagnosis, emotional reaction and awareness. Inclusion of this data in future research would allow
for further comparison among these groups, which would improve understanding of potentially different reactions among diagnostic severity categories.

An additional limitation is that the cognitive assessments utilized by clinicians to derive a diagnosis were not standardized, nor was the structure or style of feedback. Research has indicated that patient-centered communication by clinicians when giving diagnostic feedback reduces distress and enhances compliance (Zaleta & Carpenter, 2010). The absence of strong negative emotional reaction in this study may be in part due to the style and care of the individual clinicians to reduce distress through education, reassurance, and connection to resources prior to ending the diagnostic feedback session. Although this was not within the scope of this study, these factors may contribute to how the disclosure of diagnosis is conveyed and the reaction to that information (Zaleta & Carpenter, 2010). Future research may focus on process components of diagnostic feedback, including use of patient-centered communication, and its impact on emotional reaction to diagnostic disclosure of cognitive impairment. Further knowledge of these process components will help to inform clinicians on how to engage in diagnostic feedback to enhance patient's understanding and adjustment.

Overall, this study adds to the literature by extending the research of Carpenter et al., (2008) regarding emotional reaction to receiving a diagnosis of cognitive impairment by investigating awareness of deficits as a possible mediator of emotional reaction. While there was a reduction in anxiety and an increase in relief after receiving the diagnosis, these main effect became nonsignificant when the covariate, awareness of deficits, was included. However, this nonsignificant finding may be a Type II error owing to a reduction in power due to the present study's small sample size. This study also
highlights need for further research with larger sample size to understand the role of deficit awareness and cognitive appraisal in individual's emotional reaction to a diagnosis of cognitive impairment.
References


Derksen, E., Vernooij-Dassen, M., Gillissen, F., Rikkert, M. O., & Scheltens, P. (2006). Impact of diagnostic disclosure in dementia on patients and carers: Qualitative case
series analysis. *Aging and Mental Health, 10*, 525-531. doi:
10.1080/13607860600638024


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Table 2

*Chi Square & T-test Comparison of Demographic Variables of VA and Private Practice Groups*

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Table 3

Correlation between Awareness and Emotional Reaction for Primary Hypotheses

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Table 5

*Mean and Standard Deviations for Time 1 and Time 2 Dependent Variables*

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Appendix A

April 19, 2012

Amy Luitjohan,
5536 E. Galbraith Road Apt. 15
Cincinnati, OH 45236

Re: Protocol #1040, Emotional Reaction to a Diagnosis of Cognitive Impairment and the Role of Deficit Awareness

Dear Ms. Luitjohan:

The IRB has reviewed the request to modify your study, referenced above. We understand that you would like to include Legacy Psychological Services Outpatient Clinic as a collection site. The IRB office has a letter of support in your file. We are able to continue to approve your study based on the information you provided. Therefore, your above-referenced study, as modified, continues to be approved in the Full Board Review category under Federal Guidelines 45CFR46. Your approval expires on April 19, 2013 and a Progress Report is due by that date. The form can be found online at www.xavier.edu/irb/forms.

Please note that if you wish to further modify your study, it will be necessary to obtain IRB approval prior to implementing the modification. If any adverse events occur, please notify the IRB immediately.

We truly appreciate your efforts and attention to compliance within the spirit of human subject’s protection. We wish you great success with your research.

Sincerely,

[Signature]

Morell E. Mullins, Jr., Ph.D.
Chair, Institutional Review Board
Xavier University

MEM/sb

c: Jack Barrett, Advisor
Appendix B
Dementia Deficits Scale

Dementia Deficits Scale: Rating self-awareness of deficits. Alzheimer's Disease
Associated Disorders, 18, 22-31.

This scale can be obtained by emailing Dr. A. Lynn Snow at asnow@bcm.tmc.edu.
Appendix C

5-item Geriatric Depression Scale (GDS)


This scale can be obtained in text in the above cited article.
Appendix D

Geriatric Anxiety Inventory (GAI)


This scale can be obtained by emailing Dr. Nancy A. Pachana at npachana@psy.uq.edu.au.
Appendix E

Emotion Measure

Time 1

_Instructions:_ We are interested in knowing how you feel right now. Please answer each question by making a tick or mark in ONE box that best fits how YOU feel RIGHT NOW. There are no right or wrong answers.

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<th>Somewhat</th>
<th>Moderately So</th>
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<td>I feel enraged</td>
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<tr>
<td>I feel irate</td>
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<td>I feel mad at the world</td>
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<td>I feel furious</td>
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Emotional Reaction Measure

Time 2

*Instructions:* We are interested in how people FEEL after they hear a diagnosis of cognitive impairment. Please answer each question by indicating which ONE response best fits how YOU feel RIGHT NOW. You are to choose from “Not at All,” “Somewhat,” “Moderately So,” and “Very Much So.” There are no right or wrong answers.

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<tr>
<th>How do you feel at the moment?</th>
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<th>Somewhat</th>
<th>Moderately So</th>
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<td></td>
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<tr>
<td>I feel enraged</td>
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<tr>
<td>I feel irate</td>
<td></td>
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<tr>
<td>I feel mad at the world</td>
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<tr>
<td>I feel furious</td>
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<tr>
<td>I feel sorrowful</td>
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<tr>
<td>I feel downhearted</td>
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<tr>
<td>I feel sad</td>
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<tr>
<td>I feel sorry</td>
<td></td>
<td></td>
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<tr>
<td>I feel guilty</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>I feel regretful</td>
<td></td>
<td></td>
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<tr>
<td>I feel anxious</td>
<td></td>
<td></td>
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<tr>
<td>I feel fearful</td>
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<tr>
<td>I feel relieved</td>
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<tr>
<td>I feel reassured</td>
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Appendix F

Appraisal Measure

Instructions: We are interested in how people think about their visit to the neuropsychology clinic. Please answer each question by circling the ONE response that best fits what YOU think. There are no right or wrong answers.

1. How important/unimportant to you was this visit to the neuropsychology clinic?

   1                       2                       3                       4
   Extremely                Extremely                Important
   Unimportant

2. Thinking about what you didn’t want to happen during your visit to the neuropsychology clinic, to what extent did these undesirable things happen?

   1                       2                       3                       4
   Not At All              Very Much So

3. Thinking about what you did want to happen during your visit to the neuropsychology clinic, to what extent did these desirable things happen?

   1                       2                       3                       4
   Not At All              Very Much So

4. During your visit to the neuropsychology clinic, how certain were you that you would be able to deal emotionally with what was happening, however it turned out?

   1                       2                       3                       4
   Extremely unsure        Extremely sure
   I would be able         I would be able
5. During your visit to the neuropsychology clinic, how certain were you that you would be able to make things go the way you wanted them to during your visit?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely unsure</td>
<td></td>
<td></td>
<td>Extremely sure</td>
</tr>
<tr>
<td>I would be able</td>
<td></td>
<td></td>
<td>I would be able</td>
</tr>
</tbody>
</table>

6. To what extent did you consider yourself responsible for what happened during your visit to the neuropsychology clinic?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not At All</td>
<td></td>
<td></td>
<td>Very Much So</td>
</tr>
</tbody>
</table>

7. To what extent did you consider someone else responsible for what happened during your visit to the neuropsychology clinic?

<table>
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<tr>
<th>1</th>
<th>2</th>
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<th>4</th>
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</thead>
<tbody>
<tr>
<td>Not At All</td>
<td></td>
<td></td>
<td>Very Much So</td>
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</table>

8. Think about how you wanted your visit to the neuropsychology clinic to be. When you were there, to what extent did you expect things to go (for any reason) the way you wanted?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
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<th>4</th>
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</thead>
<tbody>
<tr>
<td>Not At All</td>
<td></td>
<td></td>
<td>Very Much So</td>
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</table>
Appendix G

Perceived Social Support Survey

People sometimes look to others for companionship, assistance, or other types of support. How often is each of these kinds of support available to you if you need it?

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the Time</th>
<th>Most of the Time</th>
<th>All of the Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Someone you can count on to listen to you when you need to talk?</td>
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<td></td>
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<tr>
<td>2</td>
<td>Someone to confide in or talk to about yourself and your problems?</td>
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<tr>
<td>3</td>
<td>Someone you can count on to help you with your daily chores when you are sick?</td>
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<tr>
<td>4</td>
<td>Someone who can take you to the doctor if needed?</td>
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<tr>
<td>5</td>
<td>Someone with whom you can do enjoyable things?</td>
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<tr>
<td>6</td>
<td>Someone with whom you can get together for relaxation?</td>
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</table>
Appendix H

Demographic Survey

What is the patient’s age? _______

What is the patient’s sex? Male Female

How many years of education did the patient complete? _______

With whom does the patient identify?
  ____ Arab
  ____ Asian/Pacific Islander
  ____ Black
  ____ Caucasian/White
  ____ Latino/Latina
  ____ Multiracial
  ____ Would rather not say
  ____ Other

What is the patient’s current marital status?
  ____ Married
  ____ Divorced
  ____ Separated
  ____ Widowed
  ____ Single

What is the patient’s current living situation?
  ____ Live alone
  ____ Live with someone (i.e. spouse, family, roommate)
  ____ Homeless
  ____ Live in a supervised environment or institution

Has the patient’s received any prior diagnosis of memory impairment?
  ____ Yes
  ____ No