Psychometric Evaluation of a Worry Scale for Dementia

A thesis presented to
the faculty of
the College of Arts and Sciences of Ohio University

In partial fulfillment
of the requirements for the degree
Master of Science

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December 2013

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This thesis titled
Psychometric Evaluation of a Worry Scale for Dementia

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ABSTRACT

KINZER, ADRIANNA J., M.S., December 2013, Clinical Psychology

Psychometric Evaluation of a Worry Scale for Dementia

Director of Thesis: Julie A. Suhr

Increased awareness of the signs of dementia can lead to early detection, but also to heightened levels of health anxiety, particularly among older individuals who may have difficulty distinguishing between normal symptoms of aging and pathological symptoms of dementia. Dementia worry results from ruminative anxiety associated with self-reported memory problems among older adults and likely reflects an overestimation of perceived risk for dementia. Individuals with high dementia worry, but who show no evidence of actual cognitive impairment, may still search for signs of dementia in their own behaviors and might be at risk for misdiagnosis.

The current study provided further validation data for a recently developed measure of dementia worry. Older adults (N=100) completed a packet of measures including the Dementia Worry Scale; psychometric characteristics of the scale were examined. Factor analysis suggested a revised shorter version of the scale was appropriate, and the revised scale demonstrated strong internal consistency and (interval) test-retest reliability. As expected, higher scores on the scale were related to higher memory complaints, more depressive symptoms, and higher general worry among older adults. Partially consistent with expectations, individuals with genetic dementia experience reported higher worry on average than those with either non-genetic experience or no experience.
Contrary to expectations, higher scores were not related to being female. Also contrary to expectations, age did not interact with worry to predict self-reported memory complaints. Supplemental analyses suggested that correlates of the Dementia Worry Scale differed depending on genetic experience with dementia, with the general patterns of correlations generally supportive of the construct validity of the scale. The scale appears to be a sound measure of dementia worry and a useful way to identify the “worried well” who present for evaluation and diagnosis. Future research should examine the properties of the scale in a clinical population.
DEDICATION

This thesis is dedicated to my parents, my grandmother, my sister and brother-in-law,
and my niece and nephew for their endless love and support.
ACKNOWLEDGMENTS

I would like to acknowledge my advisor, Julie Suhr, Ph.D. and the Department of Psychology at Ohio University for fostering this opportunity.
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INTRODUCTION

Over the past several decades, awareness of dementia among older adults has grown, due in part to the efforts of private foundations and public agencies to educate the public about its early symptoms (Cutler & Hodgson, 1996). According to the Alzheimer’s Association’s (2013) most recent report, 11% of people between the ages of 65 and 85 and 32% of people aged 85 and older are diagnosed with Alzheimer’s disease (AD), the most common type of dementia. Creating an informed public is a primary goal of health education campaigns because increased awareness is thought to lead to earlier detection and treatment of illness (Hodgson & Cutler, 2003). Although AD dementia cannot be reversed once it has begun, early detection and treatment might help to slow its progression and ease some of its symptoms. Further, distinguishing other causes of dementia, such as dementia with Lewy bodies and vascular dementia (e.g. McKhann, Knopman, Chertkow, Hyman, Jack, Kawas, et al., 2011), early in the course of decline may help doctors to establish the appropriate course of treatment.

Increased awareness of a disease can, however, be a double-edged sword. Consistent with models of health beliefs and illness representations (e.g. George, 2001; Leventhal, Meyer, and Nerenz, 1980; Rosenstock, 1974), increased attention and focus on the symptoms of disease can lead to increased health anxiety among those who pay heightened attention to their “symptoms” and who interpret their symptoms as signs of disease. Symptom attribution becomes increasingly complex with age due to the difficulty in separating the normal changes that result from healthy aging from the symptoms that result from disease (George, 2001). This can be the case for cognitive
symptoms as well as physical ones, as in the case of worry about developing dementia. According to health belief models such as the “common sense” model of illness representations (Leventhal, Meyer, & Nerenz, 1980), individuals differ in the ways they integrate various sources of information to create illness representations, which are used to guide coping behaviors and outcomes such as assessment- and treatment-seeking (e.g. Hagger & Orbell, 2003). One potential source of such information is a highly salient environmental event, such as the illness of a loved one.

The common sense model provides a framework within which to explain what a middle-aged or older adult might go through when he or she has a simple memory lapse, such as forgetting the name of an acquaintance. He or she might have a first-degree family member with dementia and may consider that this increases personal risk of dementia (Bondi et al., 2009, Schoenberg & Duff, 2011). He or she may be aware of other known risk factors for dementia that he or she has and understand that his or her increasing age is the most powerful predictor of increased risk for dementia (Schoenberg & Duff, 2011). If she or he has had any personal knowledge of dementia by watching a loved one experience the disorder, he or she understands that there are severe consequences associated with having dementia (which might result in excessive anxiety), that memory lapses are often the first signs of dementia (making a chronic illness attribution rather than an acute or benign one, which might increase the anxiety), and that the disease can progress rapidly (this might prompt the person to seek medical evaluation for his or her “symptoms”). If the individual has a strong illness identity, he or she is more likely to experience serious health anxiety and seek medical evaluation.
The term “worried well” refers to individuals who are concerned about declines in memory, but who show no evidence of actual cognitive impairment (e.g. Hodgson & Cutler, 2003; Suhr & Kinkela, 2007). These individuals are more likely to symptom seek, or to search for the signs of disease in their own behaviors (Hodgson & Cutler, 2003). Certainly, there are benefits of vigilance to one’s symptoms, such as early detection of disease. However, there are risks of hypervigilance to the overall health and well-being of symptom seekers.

Individuals who experience increased health anxiety and refer themselves for assessment may be at increased risk for misdiagnosis. Unfortunately, assessing older adults for the presence of dementia can be difficult, particularly because some decline in cognitive abilities is normal and expected with age. In 1984, the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) and the Alzheimer’s Disease and Related Disorders Association (ADRDA) assembled a workgroup to establish criteria for the diagnosis of dementia due to AD (McKhann et al., 2011); these criteria were recently revised based on increasing knowledge of the clinical manifestations and biology of dementia. The revised criteria emphasize that memory impairment is not always the primary cognitive deficit in patients with dementia and recognize that there are various nonamnestic presentations of the pathophysiological process of dementia. The revised criteria also acknowledge the heterogeneity of the “Possible” AD category, which includes patients who would now be diagnosed with Mild Cognitive Impairment (McKhann et al., 2011).
The implications of the updated diagnostic criteria are that the focus of diagnosis is still on the presence of self-reported cognitive symptoms and cognitive decline, even though the tendency to report these symptoms may be affected by a number of contextual factors. Additionally, consideration of the earliest cognitive decline as “Possible” AD has implications for diagnosing the worried well older adult population. Although a comprehensive neuropsychological evaluation is ideal for accurately diagnosing dementia (e.g. Schoenberg & Duff, 2011), clinicians frequently over-rely on patients’ self-reported cognitive symptoms, which may be influenced by many psychosocial factors and are not necessarily consistent with the pathophysiological process of AD or other dementias.

What is Dementia Worry?

A number of studies have examined the constructs broadly related to worry about developing dementia, although studies have used various terms to describe this worry. Some studies refer to perceived dementia threat (e.g. Cutler & Hodgson, 1996; 2001; Suhr & Kinkela, 2007), whereas others have discussed dementia worry specifically (e.g. Suhr & Isgrigg, 2011). Perceived dementia threat (e.g. Cutler & Hodgson 1996; 2001) refers to fear among middle-aged individuals who interpret normal declines in cognitive ability as early warning signs of the onset of dementia. These concerns appear to be particularly salient among family members of individuals diagnosed with dementia (Suhr & Kinkela, 2007), which is consistent with models of health beliefs and illness representations (e.g. Leventhal, Meyer, and Nerenz, 1980; Rosenstock, 1974). Although the constructs are related, there is a distinction between perceived dementia threat and inaccurate dementia worry: perceived threat refers to the perception that one is at
personal risk for dementia (e.g. Suhr & Kinkela, 2007), which may or may not be accurate; dementia worry differs from perceived dementia threat in that it results from the anxiety associated with self-reported memory problems among older adults (Suhr & Isgrigg, 2011) and likely reflects an inflated estimation of perceived personal dementia risk, coupled with ruminative thoughts about this risk in everyday life.

Perceived dementia threat can contribute to the development of dementia worry, though not all people who perceive themselves to be at risk for dementia will then worry about it. If an individual inaccurately perceives him or herself to be at high risk for personally developing dementia, then this individual might become more likely to worry about the typical memory lapses associated with aging (Suhr & Kinkela, 2007). Inaccurate perceived threat combined with high levels of worry can perpetuate a cycle of health anxiety and symptom seeking. Because diagnosis and treatment decisions are based partly upon the amount and severity of reported symptoms, as noted above, this process might ultimately lead to unnecessary evaluations and misdiagnoses. Thus, it is important that healthcare providers be aware of the implications of perceived dementia risk and dementia worry among the worried well older adult population (e.g. Suhr & Kinkela, 2007).

**What Factors Influence Perceived Dementia Threat?**

Perceived threat may be informed by many factors, including age, sex, race, education, and income (Hiraki, Chen, Roberts, Cupples, & Green, 2009). Interestingly, some of these variables are accurately perceived as risk factors for dementia, while others are not. For example, being female, being younger, and being more depressed have all
been found to be associated with higher perceived dementia threat (Suhr & Kinkela, 2007). Being female and being depressed are possible risk factors for dementia (e.g. Bondi et al., 2009; Schoenberg & Duff, 2011), but younger age is not; in fact, the relationship between age and risk for developing dementia is the reverse, with older age associated with increased risk (Bondi et al., 2009; Schoenberg & Duff, 2011).

Furthermore, research suggests that there may be an interaction between age and personal experience with dementia for predicting perceived dementia threat. Hodgson and Cutler (2003) found that among individuals with dementia experience, those who were younger perceived higher dementia threat relative to those who were older. In contrast, among individuals with no dementia experience, older adults perceived higher threat than did younger adults; because older age is actually a risk factor for dementia, perceived threat appears to be more accurate among individuals with no dementia experience. This finding is consistent with the common sense model of illness representations (Leventhal, Meyer, & Nerenz, 1980), which predicts that current perceptions of and previous experience with an illness guide illness representations; according to this model, individuals with personal dementia experience should be more likely to interpret a simple memory lapse as an insidious warning sign of dementia rather than make a situational attribution, such as a poor night’s sleep, for the lapse.

Even in the absence of personal experience with dementia, certain variables have been shown to predict higher perceived dementia threat. For example, personal perceptions of memory functioning are related to perceived dementia threat, regardless of personal dementia experience (Cutler & Hodgson, 1996). In addition to experience with
dementia and negative personal perceptions of memory functioning, preexisting health beliefs may be important factors in explaining health anxiety (Warwick & Salkovskis, 1990). Overall, the literature on perceived dementia threat suggests that factors such as dementia experience, depression, memory complaints, and gender can be influential in predicting the presence and severity of perceived dementia threat. Accordingly, these factors should be examined further in studies focusing on dementia worry.

**Validating a Dementia Worry Scale**

Because it can be difficult to distinguish the normal cognitive changes that occur with aging from the early symptoms of dementia, health practitioners should not base diagnostic decisions solely on self-reported cognitive concerns. However, it is far less expensive and time consuming to inquire about symptoms than to complete a full neuropsychological evaluation for every patient complaining of cognitive difficulties. As previously noted, some older adults inaccurately perceive an inflated personal risk of developing dementia and these individuals are likely to interpret normal behaviors as symptoms of dementia; this could lead to excessive anxiety, over-report of “symptoms” and possible misdiagnosis. A better understanding of factors that could relate to dementia worry and over-report of cognitive difficulties might improve our understanding of the accuracy of self-reported symptoms in the diagnostic process.

In previous research, concern about developing dementia has been assessed in various ways. For example, Cutler and Hodgson (1996, 2001) used a single-item measure to assess the degree of personal concern participants felt about developing dementia. Roberts (2000) assessed perceived AD threat using a 7-item scale consisting of
three subscales: perceived likelihood, concern, and consequences. Although previous
measures have assessed general concern about developing dementia, there are currently
no validated measures to assess dementia worry specifically. Thus, the purpose of the
present study was to further validate a recently developed scale for measuring dementia
worry (Suhr & Isgrigg, 2011). The aim was to establish the reliability and validity of this
instrument to gain confidence that it accurately measures the construct of dementia
worry.

Based upon prior findings, we expected high scores on the Dementia Worry Scale
(DWS) to be related to higher memory complaints, more depressive symptoms, and
higher general worry among older adults. Consistent with findings from previous
literature, dementia worry should also be higher among females and among individuals
with personal dementia experience. Consistent with prior findings, we expected that
among individuals with high dementia worry, younger age should be associated with
higher self-reported memory complaints, whereas among individuals with low dementia
worry, older age should be related to greater self-reported memory complaints.
METHOD

Participants & Procedure

Individuals who previously participated in studies on cognitive impairment in older adults were recruited for participation in the present study. Potential participants (N = 143) received packets containing study materials in the mail; one dollar was included in each study packet for recruited participants to keep as a token of appreciation. One hundred of these individuals (69.93% return rate) completed the measures and sent them back. Six of the 143 packets (4.2%) were returned by mail as undeliverable.

A subset of 50 participants received a second mailing approximately 20 days after the first. Of these, 37 participants (74% return rate) with usable data from the first mailing completed and returned the measures. Additionally, three packets were sent back as undeliverable, one was sent back missing the identification form needed to connect it to previous data, and one contained an identification form that did not match up with prior data.

For 89 of the 100 participants, data from the current study were merged with data from participation in previous studies on cognitive impairment; previous data included information about the demographic characteristics of the sample. For the subset of 89 participants whose data could be merged, 57 (64%) were female, participant age (as of 3/1/2013) ranged from 55 to 90 years (M = 69.22, SD = 8.50), and years of education ranged from 8 to 27 years (M = 18.13, SD = 3.19).

Participants also reported on physical health conditions. Nineteen participants (19%) reported a history of head injury involving loss of consciousness lasting between one minute and 120 minutes (M = 3.38, SD = 15.55), 7 (7%) reported history of seizures, 1 (1%) reported history of brain tumors, 3 (3%) reported history of stroke, and 9 (9.1%) reported history of
heart attack. Additionally, 45 participants (45%) reported a history of treatment for one or more mental health conditions, including adjustment disorders, anxiety disorders, depression, ADHD, Bipolar Disorder, and/or counseling to deal with divorce/marital issues. Participants reported how recently they received mental health counseling; responses ranged from 1951 to present. Three participants reported that they currently receive mental health counseling.

Based on prior cognitive performance, no participants met diagnostic criteria for dementia or Mild Cognitive Impairment (MCI) (Bondi et al., 2009; Schoenberg & Duff, 2011). MCI is characterized by both subjective and objective memory impairment that occurs within the context of relatively normal general cognition and functional abilities (Bondi et al., 2009). It is diagnosed when individuals experience subjective memory complaints and objective memory deficits relative to age-matched peers (defined as 1.5 or more standard deviations below average), while being otherwise cognitively intact and not demented (Schoenberg & Duff, 2011). Of the total sample of 100 participants, 28% reported having a genetic relative with dementia, 52% reported non-genetic experience with dementia (relative by marriage, spouse, close friend, or caregiver), and 20% reported no experience with dementia.

Materials

Copies of all noncopyrighted measures and more detailed psychometrics appear in Appendix A.

Participant Identification: This form allowed each participant to re-create their unique but deidentified ID number from their prior study participation so that data from the current study could be linked to the deidentified database. This allowed us to determine the age, gender, race, occupational status, and educational attainment of the participants.
**Medical History:** The medical history form was used to assess for past and current general health status. Participants provided self-reported history of head injuries, seizures, brain tumors, stroke, and heart attack, listed all medical diagnoses and current medications, and indicated the presence or absence of history of treatment for mental health conditions.

**Memory Controllability Inventory:** Perceptions of memory functioning and concerns about developing dementia were assessed with subscales of the Memory Controllability Inventory (MCI, Lachman et al., 1995). We examined scores on the Present Ability subscale, which assesses degree of confidence in current memory functioning, and the Alzheimer’s Likelihood subscale, which reflects fear of developing Alzheimer’s disease (Lachman et al., 1995). These subscales have shown adequate internal consistency and test-retest reliability in prior studies (e.g. Lachman et al., 1995); in the present study, internal consistency was questionable for the Present Ability scale ($\alpha = .67$) and acceptable for the Alzheimer’s Likelihood subscale ($\alpha = .70$). Prior studies have shown that these subscales relate in theoretically appropriate ways to the concepts of present memory beliefs and concern of personal risk for dementia (e.g. Lachman et al., 1995; Suhr & Kinkela, 2007).

**Personal History of Dementia:** To assess personal experience with dementia, participants were asked whether they know or have known someone with dementia, and, if so, the nature of their relationship with that person (how frequently they see/saw them, how emotionally close they feel to them, how related to them they are genetically). Participants were also asked to report whether they have served as caregivers for family or friends with dementia. Experience was coded as genetic (must have reported having a first or second degree relative with dementia), non-genetic (any other personal experience with dementia), or no experience with dementia.
Depressed mood: Level of depressed mood was assessed using the Geriatric Depression Scale (GDS; Brink et al., 1983), a brief self-report depression scale designed for use with older adults. Prior studies show good test-retest reliability (e.g. Brink et al., 1983; Parmelee & Katz, 1989) and high internal consistency (e.g. Brink et al., 1983; Parmelee & Katz, 1989); in the present study the measure was internally consistent ($\alpha = .89$). Prior studies suggest it is an accurate measurement of depression in older adults (e.g. Brink et al., 1983; Parmelee & Katz, 1989).

General worry: General worry was assessed using an abbreviated version of the Penn State Worry Questionnaire (PSWQ-A; Hopko, Stanley, Reas, Wetherell, Beck, Novy, et al., 2003) and the Generalized Anxiety Disorders Questionnaire 4th Edition (GAD-Q-IV; Newman, Zuellig, Kachin, Constantino, & Cashman, 2002).

The PSWQ (Meyer et al., 1990) is a 16-item self-report questionnaire that measures general worry. The PSWQ appears to be a psychometrically sound self-report instrument with good reliability (e.g. Meyer et al., 1990) and validity (Meyer et al., 1990) for assessing the trait of worry. Crittendon and Hopko (2006) showed that the PSWQ can be effectively modified for use with older adults by excluding all five of the reverse coded items and three of the positively worded items. This modification results in the eight-item Penn State Worry Questionnaire-Abbreviated. The PSWQ-A has high internal consistency ($\alpha = .87$) and adequate test-retest reliability ($r = .63$) when used with older adults. The measure also demonstrates good convergent and divergent validity with other measures of anxiety and worry ($r = .39-.49$) (Crittendon & Hopko, 2006). Because the PSWQ-A appears to be more appropriate for assessing worry among older adults than the original
PSWQ, the PSWQ-A was used in the current study; within the present sample, the internal consistency was strong ($\alpha = .91$).

The GAD-Q-IV (Newman et al., 2002) is a revised self-report diagnostic measure of generalized anxiety disorder (GAD) based on the fourth edition of the Diagnostic and Statistical Manual (American Psychiatric Association, 2000). The measure has shown good internal consistency and test-retest reliability, as well as convergent validity and good sensitivity and specificity data when compared to diagnosis with GAD (e.g. Newman et al., 2002).

**Dementia worry:** Dementia worry was measured using the Dementia Worry Scale (Suhr & Isgrigg, 2011). This self-report measure contains 15 items rated on a 5-point scale, ranging from “not at all typical of me” (1) to “very typical of me” (5). Items assess aspects of AD worry such as dismissibility and controllability of thoughts about developing dementia. Items for the scale were initially selected based on a review of the literature on perceived dementia threat, as well as a review of literature on symptoms and manifestations of worry in older adult populations.

Preliminary analyses on the scale in a sample of 22 community-dwelling females aged 50-93 revealed that high dementia worry was associated with higher depression and higher perceived dementia threat and was higher among those with dementia experience than among those without (Suhr & Isgrigg, 2011). These results were consistent with the hypothesized relationships of worry to other psychological conditions and to self-reported experience with dementia posited by the health beliefs model. Dementia worry also moderated the relationship between subjective memory complaints and performance on a list recall task: among participants with low levels of dementia worry, memory
complaints were associated with worse performance on a list recall task when controlling for age. It was expected that memory complaints would be associated with poor list recall if those complaints were accurate. In contrast, among those who showed high dementia worry, memory complaints were related to better list recall performance when controlling for age; that is, among individuals with high dementia worry, more memory complaints were actually related to better recall for a list of words, suggesting that the worry was inaccurate (Suhr & Isgrigg, 2011).

Self-reported genetic vulnerability also interacted with dementia worry to predict belief in negative age stereotypes and performance on cognitive tasks (Suhr & Isgrigg, 2011). In those with no reported familial risk of dementia (defined as having no first-degree relative with the disease), high dementia worry was not related to age. It was, however, related to greater belief in negative aging stereotypes about cognition, and better cognitive performance. Among participants reporting familial risk, high dementia worry was associated with younger age and worse performance on cognitive tasks (Suhr & Isgrigg, 2011). These findings are consistent with previous findings regarding the idea that dementia experience moderates some of the variables associated with dementia worry, such as Hodgson and Cutler’s (2003) finding that younger age is related to dementia worry among those reporting dementia experience. Overall, these findings suggest that the Dementia Worry Scale might be tapping the construct of dementia worry.

**Analyses**

We first examined the basic characteristics of the Dementia Worry Scale, including the mean score, the range of scores, and the internal consistency (coefficient alpha) of the items. In addition, we examined the structure of the scale using factor analysis. To test the
first three hypotheses, we conducted correlations on the relationships between scores on the Dementia Worry Scale and scores on the Memory Controllability Inventory, Geriatric Depression Scale, and Penn State Worry Questionnaire - Abbreviated. The fourth and fifth hypotheses were analyzed using t-tests (to examine gender differences) and ANCOVA (to examine differences based on personal dementia experience). We also performed an ANCOVA to compare the differences among the subsamples that reported having genetic, non-genetic, and no dementia experience. The sixth hypothesis was examined using hierarchical linear regression analysis.
RESULTS

We first examined the items of the scale to determine the appropriateness of all items to a total score. Although the internal consistency of the items was high ($\alpha = .879$), further analysis of the appropriateness of all items for the final scale was applied. An examination of the correlation matrix of all items revealed that no items were positively correlated with some items but negatively correlated with others, suggesting no need to remove any of the items. To explore the possible existence of an underlying factor structure to the DWS and to potentially condense the scale to the items that most clearly loaded on the worry construct, we conducted a Principal Components Analysis (PCA) with a Varimax (orthogonal) rotation using all 15 items. Factors were selected if they had eigenvalues over 1. The first factor described 45.35% of the variance, the second factor contributed an additional 10.29%, and the third added 7.84%; thus in total, the first three factors explained 63.49% of the variability in the scores. Eight items loaded onto Factor 1, three items loaded onto Factor 2, and four items loaded onto Factor 3. All three of the reverse coded items (items 2, 7, and 12) loaded onto Factor 3; apart from this, no clear trend emerged among the item loadings and any underlying constructs that may be characterized by each of the factors is unclear. See Table 1 for factor loadings.

In the interest of making a scale that appears to reflect a unitary factor, we revised the DWS using only the items that clearly loaded on the first factor (items 1, 8, 9, 10, 11, 13, 14, and 15). Internal consistency was high ($\alpha = .865$). Scores ranged from 8 to 33, with an average score of 12.11 ($SD = 5.16$). Test-retest reliability over a three-week interval was strong, $r = .91$, $p < .001$. The distribution of the revised scale was non-normal, though this is
not uncommon in larger samples. An outlier analysis revealed that one case fell more than three standard deviations above the mean for the DWS. This case was removed from the dataset before running subsequent analyses; thus, further analyses included 99 participants in the overall sample and 88 whose data could be merged with prior data. Excluding the outlier, scores on the DWS ranged from 8 to 26, with a mean score of 11.899 ($SD = 4.73$). Internal consistency was good ($\alpha = .84$) and test-retest reliability over a three-week interval was high, $r = .86$, $p < .001$. The distribution of scores remained non-normal (see Appendix B for descriptive statistics on the DWS and all other scales in the present study).

Among the subset of 88 participants whose results could be merged with prior data, scores on the DWS did not correlate significantly with age, $r = -.08$, $p = .441$, years of education, $r = -.03$, $p = .774$, or cognitive performance on tasks of delayed list recall, $r = .05$, $p = .642$, delayed story recall, $r = .08$, $p = .459$, or delayed figure recall, $r = -.03$, $p = .775$.

**Hypothesized Correlates of the DWS: Memory Complaints, Depression, and General Worry**

To test the hypothesis that dementia worry would be positively correlated with memory complaints and estimations of dementia likelihood, we ran bivariate correlations between the revised DWS and the Present Ability and Alzheimer’s Likelihood subscales of the MCI. As expected, dementia worry was significantly negatively correlated with current perceptions of memory functioning, $p = .012$, and positively associated with belief that developing dementia was likely with age, $p < .001$.

DWS shared 6.5% of the variance with the Present Ability subscale and 25.9% of the variance with the Alzheimer’s Likelihood subscale. Also as expected, the Present Ability and
Alzheimer’s Likelihood subscales of the MCI were significantly negatively correlated with one another, \( p < .001 \). See Table 2.

To assess whether dementia worry was related to depressive symptoms and general worry we conducted bivariate correlations between the DWS and the GDS. As expected, dementia worry was significantly positively associated with depressive symptoms, \( p < .001 \); the DWS shared 22.6% of its variance with the GDS. The DWS was also positively related to general worry as measured by the PSWQ-A, \( p < .001 \), and the GAD-Q-IV, \( p < .001 \), as hypothesized. The DWS shared 21.1% of the variance with the PSWQ-A and 13.2% with the GAD-Q-IV. See Table 2.

**Dementia Worry as a Function of Self-Reported Genetic Experience with Dementia**

To test the hypothesis that self-reported experience with dementia would be related to dementia worry, dementia experience was coded as genetic, non-genetic, or no experience, based on responses to a questionnaire. Twenty-eight participants reported genetic experience with dementia, 51 reported non-genetic experience, and 20 reported having no personal experience with dementia.

First we examined potential covariates that would need to be considered, given that the DWS was significantly correlated with other potential confounding variables. Experience groups did not differ significantly in terms of perceptions of current memory ability, \( F(2, 95) = 1.774, p = .175 \), or general worry as measured by the GAD-Q-IV, \( F(2, 96) = 1.807, p = .170 \), nor did they differ in terms of depressed mood, \( F(2, 81) = .229, p = .796 \). See Table 3. For the subsample whose data included demographic characteristics, experience groups did not differ in age, \( F(2, 85) = 2.84, p = .064 \), or gender, \( \chi(2) = 0.68, p = .734 \).
<table>
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<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
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<tbody>
<tr>
<td>1. I know I shouldn’t worry about developing dementia, but I just cannot help it.</td>
<td><strong>.583</strong></td>
<td>.362</td>
<td>.512</td>
</tr>
<tr>
<td>2. I find it easy to dismiss thoughts that I might have dementia.</td>
<td>-.085</td>
<td>.337</td>
<td><strong>.584</strong></td>
</tr>
<tr>
<td>3. I find it difficult to control my worries about developing dementia.</td>
<td>.398</td>
<td><strong>.668</strong></td>
<td>.357</td>
</tr>
<tr>
<td>4. When I can’t remember something, I find myself wondering whether I have dementia.</td>
<td>.319</td>
<td>.492</td>
<td><strong>.560</strong></td>
</tr>
<tr>
<td>5. My worries about dementia overwhelm me.</td>
<td>.214</td>
<td><strong>.846</strong></td>
<td>.104</td>
</tr>
<tr>
<td>6. More often than not, I find my thoughts returning to concerns that I have dementia.</td>
<td>.224</td>
<td><strong>.885</strong></td>
<td>.219</td>
</tr>
<tr>
<td>7. I do not tend to worry about having dementia.</td>
<td>.091</td>
<td>.272</td>
<td><strong>.681</strong></td>
</tr>
<tr>
<td>8. When I hear about someone having dementia, I start to worry about having it myself.</td>
<td><strong>.634</strong></td>
<td>-.003</td>
<td>.314</td>
</tr>
<tr>
<td>9. When I am not distracted, I find my thoughts focusing on my own cognitive changes and concerns.</td>
<td><strong>.617</strong></td>
<td>.360</td>
<td>-.168</td>
</tr>
<tr>
<td>10. Even though I know it doesn’t help to focus on it, I can’t help thinking about whether or not I have dementia.</td>
<td><strong>.637</strong></td>
<td>.472</td>
<td>.299</td>
</tr>
<tr>
<td>11. Once I start worrying about dementia, I just cannot stop.</td>
<td><strong>.625</strong></td>
<td>.414</td>
<td>-.215</td>
</tr>
<tr>
<td>12. When I find myself making a mistake with my memory, I don’t tend to think about having dementia as the cause.</td>
<td>.150</td>
<td>-.105</td>
<td><strong>.663</strong></td>
</tr>
<tr>
<td>13. Sometimes when trying to go to sleep, I find my thoughts drift to concerns about having dementia.</td>
<td><strong>.774</strong></td>
<td>.123</td>
<td>.073</td>
</tr>
<tr>
<td>14. When I forget a word that I want to say, my thoughts immediately turn to dementia.</td>
<td><strong>.607</strong></td>
<td>.174</td>
<td>.423</td>
</tr>
</tbody>
</table>
However, genetic experience groups differed significantly from one another in terms of general worry as measured by the PSWQ-A, $F(2, 94) = 3.218, p = .044$, and belief in personal likelihood of developing dementia, $F(2, 96) = 7.206, p = .001$. For the PSWQ-A, follow-up Bonferroni corrected t-tests showed that those who reported genetic experience scored significantly higher than those with both non-genetic, $p = .019$, and no experience, $p = .049$, but those with non-genetic experience did not differ significantly from those with no experience, $p = .943$. Similarly, for scores on Alzheimer’s Likelihood, follow-up Bonferroni corrected t-tests showed that those who reported genetic experience were significantly higher than both those with non-genetic, $p = .008$, and no experience, $p = .002$, but those who reported non-genetic experience did not differ significantly from those with no experience, $p = .777$.

Because general worry as measured by the PSWQ-A and belief in developing dementia were both significantly related to the DWS, these variables were controlled for in a test of the main hypothesis.

As expected, the three groups were different in DWS scores, even after controlling for the effects of scores on the PSWQ-A and Alzheimer’s Likelihood scales, $F(2, 92) = 5.935, p = .004$. Both covariates were also significant: general worry, $F(1, 92) = 9.034, p = .003$, and belief in the likelihood of developing dementia, $F(1, 92) = 10.004, p = .002$. Follow-up Bonferroni corrected t-tests showed that those who reported genetic experience with dementia were significantly higher on the DWS than both non-genetic, $p = .022$, and no
experience, \( p = .004 \), groups, but individuals who reported non-genetic experience and those who reported no experience were not different from one another, \( p = .615 \). See Table 3.

Prior to testing the hypothesis, independent-samples t-tests were conducted to determine whether gender was related to age, years of education, perceptions of current memory capacity, belief in personal likelihood of developing dementia, depression, and general worry. Females did not differ significantly from males in age, \( t(86) = -1.32, p = .189 \), or years of education, \( t(86) = -1.35, p = .182 \). There were no significant gender differences for confidence in memory capacity, \( t(85) = -1.148, p = .883 \), belief in likelihood of developing dementia, \( t(86) = 1.058, p = .293 \), or depression, \( t(74) = .257, p = .798 \). Females did not differ from males in terms of general worry as measured by the GAD-Q-IV, \( t(86) = 1.230, p = .212 \), but females reported significantly higher levels of general worry than males on the PSWQ-A, \( t(84) = 2.000, p = .041 \).

Because gender differences were observed on the PSWQ-A, and the PSWQ-A was significantly related to the DWS, we conducted an analysis of covariance with gender and DWS using PSWQ-A as a covariate. The relationship between gender and DWS was insignificant when including PSWQ-A as a covariate, \( F(1, 83) = .431, p = .513 \); the covariate was significant, \( F(1, 83) = 18.119, p < .001 \). See Table 4.

**Interaction Between Age and Dementia Worry in Predicting Perceptions of Memory Capacity and Alzheimer’s Likelihood**

To test the hypothesis that dementia worry would interact with age to predict evaluations of current memory functioning and perceived likelihood of developing dementia, we conducted a linear regression analysis using age, DWS, and the mean centered interaction of these two variables for each of the MCI subscales.
Table 2

*Correlations of Dementia Worry Scale with Memory Complaints, Depression, and General Worry*

<table>
<thead>
<tr>
<th>Present Ability</th>
<th>Alzheimer’s Likelihood</th>
<th>Geriatric Depression Scale</th>
<th>Penn State Worry Questionnaire–Abbreviated</th>
<th>Generalized Anxiety Disorder–Questionnaire–IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia Worry Scale</td>
<td>-.25*</td>
<td>.51**</td>
<td>.48**</td>
<td>.46**</td>
</tr>
<tr>
<td>Present Ability</td>
<td>-.56**</td>
<td>-.30**</td>
<td>-.23*</td>
<td>-.22*</td>
</tr>
<tr>
<td>Alzheimer’s Likelihood</td>
<td></td>
<td>.45**</td>
<td>.42**</td>
<td>.40**</td>
</tr>
<tr>
<td>Geriatric Depression Scale</td>
<td></td>
<td></td>
<td>.49**</td>
<td>.69**</td>
</tr>
<tr>
<td>Penn State Worry Questionnaire–Abbreviated</td>
<td></td>
<td></td>
<td></td>
<td>.69**</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Before computing the interaction term, DWS and age were mean centered to minimize multicollinearity. For Present Ability, the DWS was a significant predictor, $t(86) = -2.375, p = .02$, but age, $t(86) = -.473, p = .638$, and the interaction between DWS and age, $t(86) = -.061, p = .952$, were not. For Alzheimer’s Likelihood, the DWS, $t(87) = 5.16, p <$
.001, was a significant predictor. Age, \( t(87) = -.28, p = .78 \), and the interaction between DWS and age, \( t(87) = -1.021, p = .31 \), were not significant.

**Does the Dementia Worry Scale Measure a Unique Construct?**

Several pieces of evidence presented above suggest that DWS measures a unique construct. Specifically, the DWS, although related to constructs such as depression, general worry, and beliefs about memory, did not share a large amount of variance with measures of these constructs.

Furthermore, the DWS demonstrates incremental validity over measures of similar constructs in that groups reporting dementia experience differ significantly from those reporting no experience even after controlling for scores on the PSWQ-A and Alzheimer’s Likelihood scale. However, in addition to these findings, demonstrating that the correlates of DWS may vary for groups with different self-reported dementia experience may help to demonstrate that the DWS is measuring a unique construct. Specifically, it might be expected that depression and general worry will be more strongly related to dementia worry among the groups reporting dementia experience relative to the group reporting no dementia experience.

To determine whether the correlates of DWS were different for different groups, we compared the correlates of DWS according to self-reported genetic experience with dementia. See Table 5.

Using the Fisher r-to-z transformation, we tested for differences between reported genetic experience groups based on correlations between DWS and GDS and DWS and PSWQ-A.
### Table 3

**Means and Standard Deviations of Dementia Worry, Alzheimer’s Likelihood Beliefs, Perceptions of Memory Ability, General Worry, and Depressed Mood as a Function of Genetic Experience with Dementia.**

<table>
<thead>
<tr>
<th></th>
<th>Genetic (N = 28)</th>
<th>Non-Genetic (N = 51)</th>
<th>None (N = 20)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M$ &amp; $SD$</td>
<td>$M$ &amp; $SD$</td>
<td>$M$ &amp; $SD$</td>
</tr>
<tr>
<td>Dementia Worry Scale *</td>
<td>14.04 &amp; .76</td>
<td>11.45 &amp; .53</td>
<td>10.18 &amp; .85</td>
</tr>
<tr>
<td>Alzheimer’s Likelihood*</td>
<td>3.59 &amp; 1.40</td>
<td>2.69 &amp; 1.21</td>
<td>2.31 &amp; 1.11</td>
</tr>
<tr>
<td>Present Ability</td>
<td>4.84 &amp; 1.14</td>
<td>5.29 &amp; 1.40</td>
<td>5.51 &amp; 1.13</td>
</tr>
<tr>
<td>Generalized Anxiety Disorder – Questionnaire – IV</td>
<td>2.52 &amp; 2.47</td>
<td>1.54 &amp; 1.87</td>
<td>2.00 &amp; 2.62</td>
</tr>
<tr>
<td>Geriatric Depression Scale</td>
<td>4.95 &amp; 6.04</td>
<td>4.16 &amp; 4.54</td>
<td>4.00 &amp; 4.79</td>
</tr>
</tbody>
</table>

* Denotes that genetic group scored significantly higher than the non-genetic and no experience groups, but the non-genetic and no experience groups did not differ significantly from one another.

The correlation between DWS and depression was significantly higher for the group with self-reported genetic experience compared to the group with no reported dementia experience, $z = 2.27, p = .02$, and for the group reporting non-genetic experience compared to the group reporting no experience, $z = 2.74, p < .01$. 


Table 4

Means and Standard Deviations of Demographic variables, Perceptions of Memory Ability, Alzheimer’s Likelihood Beliefs, Depressed Mood, and General Worry as a Function of Gender.

<table>
<thead>
<tr>
<th></th>
<th>Female (N = 54)</th>
<th>Male (N = 32)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Age</td>
<td>68.32</td>
<td>8.56</td>
</tr>
<tr>
<td>Education</td>
<td>15.77</td>
<td>3.26</td>
</tr>
<tr>
<td>Present Ability</td>
<td>5.17</td>
<td>1.31</td>
</tr>
<tr>
<td>Alzheimer’s Likelihood</td>
<td>2.98</td>
<td>1.37</td>
</tr>
<tr>
<td>Geriatric Depression Scale</td>
<td>39.61</td>
<td>2.46</td>
</tr>
<tr>
<td>Penn State Worry Questionnaire – Abbreviated*</td>
<td>17.74</td>
<td>7.92</td>
</tr>
<tr>
<td>Generalized Anxiety Disorder – Questionnaire – IV</td>
<td>1.85</td>
<td>2.00</td>
</tr>
<tr>
<td>Revised Dementia Worry Scale</td>
<td>12.71</td>
<td>4.94</td>
</tr>
</tbody>
</table>

* Denotes that females scored significantly higher than males.

The correlation between DWS and general worry was also significantly higher for the group reporting genetic experience than for the group reporting no dementia experience, \( z = 2.19, \ p = .03 \), and for the group reporting non-genetic experience compared to the group reporting no experience, \( z = 2.48, \ p < .01 \).
Table 5

*Correlates of Dementia Worry Scale*

<table>
<thead>
<tr>
<th></th>
<th>Genetic (N = 28)</th>
<th>Non-Genetic (N = 51)</th>
<th>None (N = 20)</th>
<th>Total (N = 99)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present Ability</td>
<td>-.16</td>
<td>-.29*</td>
<td>.05</td>
<td>-.25*</td>
</tr>
<tr>
<td>Alzheimer’s Likelihood</td>
<td>.63**</td>
<td>.28*</td>
<td>.07</td>
<td>.51**</td>
</tr>
<tr>
<td>Geriatric Depression Scale</td>
<td>.56**</td>
<td>.60**</td>
<td>-.08</td>
<td>.48**</td>
</tr>
<tr>
<td>Penn State Worry Questionnaire – Abbreviated</td>
<td>.49*</td>
<td>.50**</td>
<td>-.15</td>
<td>.46**</td>
</tr>
<tr>
<td>Generalized Anxiety Disorder - Questionnaire – IV</td>
<td>.48*</td>
<td>.29*</td>
<td>.17</td>
<td>.36**</td>
</tr>
<tr>
<td>Age</td>
<td>-.09</td>
<td>-.04</td>
<td>.02</td>
<td>-.08</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).
DISCUSSION

Overall, the present findings lend support to the validity of DWS as a measure of dementia-specific health worry. Examination of the underlying factor structure of the DWS indicated that a revised version of the DWS including only 8 of the original 15 items reflects a more unitary factor; thus, it seemed appropriate to condense the original scale to create a more parsimonious measure. Overall, the DWS demonstrated strong internal consistency and three-week test-retest reliability, suggesting that the scale has adequate reliability.

Correlates of the DWS

There were several variables that were not related to the DWS, which was not unexpected. The DWS was not correlated with age or years of education, indicating that scores on the scale are not influenced by either of these demographic variables. Findings regarding the effects of age and education on perceived dementia threat have been inconsistent in the existing literature. Some studies (e.g. Hodgson & Cutler, 2003; Suhr & Kinkela, 2007) have found that younger age is associated with greater perceived risk in some samples, particularly those with personal dementia experience; others (e.g. Cutler & Hodgson, 1996) have demonstrated an interaction between dementia experience and age in predicting concern about developing dementia. In the present study, there was no effect for age, regardless of dementia experience, which could indicate that dementia worry is a distinct construct from the perceived dementia threat measured in previous studies.

In a previous study, Suhr and Kinkela (2007) found a significant main effect of years of education on perceived dementia threat, with higher degrees of threat reported by
individuals with lower levels of education. Conversely, Cutler and Hodgson (2001) found that higher levels of education predicted greater concern about developing dementia among a subsample of participants with genetic dementia experience, although the opposite relationship emerged for the group with no dementia experience. Other studies (e.g. Hodgson & Cutler, 2003; Roberts, 2000) have found no relationship between educational level and perceived dementia threat. Our sample was highly educated, potentially limiting our ability to draw conclusions about the potential effects of educational attainment on levels of dementia worry.

DWS was also not significantly correlated with cognitive performance in our study. In other words, scores on DWS were independent of actual cognitive capacity (although participants in the present study were cognitively intact). This was also not unexpected, and supports the assertion that individuals who scored high on DWS may indeed represent the worried well population who exaggerate their personal risk of developing dementia. This finding is congruent with previous research (e.g. Suhr & Kinkela, 2007) demonstrating that inaccurate self-report of memory problems and concerns about developing dementia are common among older adults, especially for those with personal dementia experience or who are seeking evaluation or treatment.

On the other hand, the DWS was correlated with several variables that were consistent with study hypotheses. DWS demonstrated strong convergent validity in that it was correlated with memory complaints, depression, and general worry, as expected. Specifically, individuals who scored higher on dementia worry reported lower perceptions of current memory functioning, endorsed higher beliefs that developing
dementia was likely with age, reported higher levels of depressive symptoms, and scored higher on measures of general worry. These results are consistent with the extant literature on the correlates of perceived dementia threat, providing further support for the convergent validity of the DWS.

Despite the finding that perceived cognitive functioning, belief in the likelihood of developing dementia with age, depression, and general worry were correlated with DWS, these constructs did not actually share a large proportion of their variance with DWS. This suggests that the scale not only demonstrates convergent validity, but also discriminant validity. In other words, DWS appears to capture a phenomenon that is related to, yet distinct from, these similar constructs.

Most notably, the correlations between the DWS and the GAD-Q-IV were relatively low in our study, which is good evidence of discriminant validity. This suggests that the construct measured by DWS is not redundant with the symptoms of Generalized Anxiety Disorder.

**Hypothesized Age and Worry Interaction**

We hypothesized that age and DWS would interact to predict perceptions of current cognitive functioning and perceptions of dementia likelihood. This prediction was based on prior literature demonstrating a potential interaction effect for age and worry on perceived risk (e.g. Hodgson & Cutler, 2003; Suhr & Kinkela, 2007). Our hypothesis was not, however, supported. The DWS was related to both cognitive functioning and perceptions of dementia likelihood regardless of age. One possible explanation for this finding is that the nature of our sample differed in meaningful ways from those of
previous studies finding an interaction effect. For example, Hodgson and Cutler examined a sample of middle-aged adults, aged 40-60, whereas our sample ranged in age from 55-90. Also, the participants in Suhr and Kinkela’s study were self-referred for a free community memory screen, but our participants were not currently seeking evaluation for cognitive impairment. To address these inconsistencies, future research should explore this interaction effect further using different types of samples.

**Relation of DWS to Dementia Experience**

Partially consistent with our hypothesis, the subsample reporting genetic experience with dementia scored higher than the groups reporting non-genetic dementia experience and no dementia experience on DWS, even after controlling for the effects of general worry and dementia likelihood beliefs; however, the groups reporting non-genetic and no experience did not differ from one another on DWS scores. The same pattern held for the covariates of general worry and perceived dementia likelihood. This suggests that it may be self-reported genetic experience specifically that influences dementia worry, as opposed to dementia experience more generally. Perhaps, consistent with health belief models (e.g. Leventhal, Meyer, & Nerenz, 1980; Rosenstock, 1974), individuals reporting genetic experience are aware of family history as a risk factor, feel greater genetic vulnerability, and are more aware of the symptoms associated with dementia than individuals without genetic experience, leading them to experience greater perceived risk and higher levels of dementia worry.

Interestingly, supplemental analyses showed that type of reported dementia experience appeared to moderate the relationship of DWS to other constructs.
Specifically, depression and general worry were more strongly related to dementia worry among the groups reporting some type of dementia experience as opposed to the group reporting no dementia experience. Prior literature (e.g. Hodgson & Cutler, 2003; Suhr & Kinkela, 2007) has demonstrated that dementia experience is frequently associated with higher perceived dementia threat, and that perceived threat appears to be more accurate among individuals with no dementia experience. For individuals reporting dementia experience, depression and general worry should be correlated with dementia worry, consistent with prior literature and theoretical models of health worry. If DWS measures depression and worry more generally, the strength of these correlates should not vary according to dementia experience. If, however, rumination and worry specifically related to dementia represents a distinct construct, the strength of these correlates might depend on genetic experience; this is exactly what we found. These findings also suggest that DWS is distinct from measures of depression and general worry, given that these variables related to DWS only in some groups and not in others.

**Gender Differences**

Regarding gender differences, we expected that females would report higher levels of dementia worry than males, but this hypothesis was not supported; there was no difference between females and males on DWS. This is inconsistent with previous findings (e.g. Cutler & Hodgson, 1996; Suhr & Kinkela, 2007) in which females endorsed higher levels of perceived dementia threat relative to males. One possible explanation for this finding is that previous studies examined only the construct of perceived dementia threat rather than dementia worry specifically; perhaps females...
experience greater levels of perceived threat but perceived threat does not necessarily translate into higher worry.

Although we did not detect a gender difference for DWS, we did find that females reported significantly higher levels of general worry than males. This finding is consistent with previous research (e.g. Meyer et al., 1990) demonstrating that females tend to exhibit higher levels of general worry than males. This observation provides further support for the incremental validity of DWS in that the scale appears to measure a type of worry that is distinct from general worry.

Limitations

This study was characterized by several limitations, one being the nature of the sample. We utilized a sample of convenience; the individuals recruited for participation in our study were those who had completed previous studies conducted by our laboratory.

This sample might not have been representative of the general population of older adults for several reasons. First, our sample was composed of individuals who had previously requested feedback about their neuropsychological performance, although the point at which they received this feedback ranged from 2-5 years prior to participation in the current study. Because participants had sought feedback in the past, they may have been more inclined to think about their cognitive abilities in general. Further, because participants received feedback informing them that they did not demonstrate neuropsychological impairment, their anxiety about developing dementia may have been reduced and their current perceptions of their own cognitive ability may have been increased. If, however, receiving this information did nothing to reduce their levels of
dementia worry, this would suggest that providing neuropsychological feedback alone is an ineffective way to reduce dementia worry among the worried well. Unfortunately, the current study design did not allow us to examine this prospect, and future studies should utilize other samples to test the validity of the measure.

Our sample was also unrepresentative of the older adult population in terms of their demographic characteristics. For example, less than 2% of the sample was non-white, limiting our ability to draw conclusions regarding the potential effects of racial/ethnic status. Also, the sample was highly educated, reporting over 18 years of education on average. Previous findings on the effects of education and perceived dementia threat have been inconsistent, and education was not related to dementia worry in the current study. Examination of a more representative sample in this regard might have provided more conclusive information about the role of educational attainment in dementia worry. Future studies should address this limitation by recruiting a more diverse sample. A related limitation is that information about demographic characteristics was only available for a subset of our sample.

Further, although our sample sought out neuropsychological evaluation and feedback at one point in time, they did not receive evaluation or feedback for participating in the current study. Thus, our sample could not be considered an evaluation- or treatment-seeking sample. The nature of our sample might account for some of the inconsistencies between our findings and those of previous research. For example, Suhr and Kinkela (2007) found that dementia experience moderated the relationship between age and perceived dementia threat, but they examined these
variables in a sample of healthy older adults who were self-referred for a free community memory screen; conversely, the current study did not find an effect for age, regardless of dementia experience. Examination of the scale in an evaluation-seeking sample might provide further evidence that the scale accurately measures dementia worry among the worried well older adult population.

Another limitation is the possibility of response bias. Overall, our response rate was quite high, but it is possible that the individuals who responded to our surveys differed in some significant way from those who did not. Additionally, our method of administration (via the mail) might have impacted who actually received and who chose to return the packets.

Additionally, the way in which experience with dementia was coded in our study represents a limitation. Participants were asked to report on the nature of their experience (if any) with only one person who had dementia. Participants reporting both genetic and non-genetic dementia experience were coded as having genetic experience in all subsequent analyses, which did not allow us to evaluate the potential effects of having multiple types of experience with dementia.

Finally, because participants completed the measures at home and sent them back through the mail, we had no control over the order in which participants completed the measures. It is possible that answering questions about general worry might cause one to report more specific worry as well.
Implications and Directions for Future Research

The current study provides further evidence that revised DWS is a reliable and valid measure of dementia worry. More research is needed, however, before drawing stronger conclusions regarding the validity of this measure, as the present study design did not allow for a comprehensive psychometric validation of the DWS, and the current data available on this measure should still be considered in the preliminary stages. As previously detailed, the present evaluation suffered from numerous limitations, and findings from this sample cannot be generalized at this point. Thus, use of the DWS in a clinical healthcare setting is not recommended at this time.

Future studies should seek to address the limitations of the current study and evaluate use of the scale in a primary healthcare setting, using a more representative sample of evaluation- and treatment-seeking older adults. This would help to determine how accurately revised DWS can identify the worried well among individuals who refer themselves for cognitive evaluation. If revised DWS continues to demonstrate strong psychometric characteristics in a more diverse, treatment-seeking sample, future studies might examine the impact of a psychoeducational intervention upon the accuracy of individuals’ perceived dementia threat and levels of reported dementia worry. Previous research indicates that educational interventions have the potential to reduce dementia worry and increase the accuracy of appraisals of perceived risk. For example, Schmidt, Zwart, Berg, and Deelman (1999) examined an intervention designed to reduce negative stereotypes and worries about memory among adults over the age of 45 who were cognitively healthy but reported subjective memory complaints. The intervention
consisted of 6 one-hour sessions focused on challenging stereotypes about aging and emphasizing the cognitive competency of the participants. Participants were also educated about memory, including the ways in which memory typically changes with age and the potential impact of worry on cognitive performance. This intervention improved subjective memory reports, although actual performance on memory tasks did not improve (Schmidt et al., 1999). Given the difficulties in differentiating normal, age-related cognitive changes from the cognitive deficits associated with dementia, it is important to help older adults understand that memory complaints are not always indicative of dementia.

Similarly, it is important for healthcare practitioners to be able to identify the worried well and to use this information to guide their decisions regarding evaluation, diagnosis, and treatment. As previously discussed, assessing older adults for the presence of dementia can be difficult. Those who experience increased health anxiety and refer themselves for assessment may be at increased risk for misdiagnosis, particularly because the focus of diagnosis is still on the presence of self-reported symptoms and cognitive decline, which may or may not be accurate.

To increase the chances of accurate diagnosis of dementia, it is important for healthcare providers to be aware of the implications of perceived dementia risk and dementia worry among the worried well older adult population. Our study revealed that dementia worry appears to differ in meaningful ways from general worry; healthcare practitioners could thus benefit from a psychometrically sound way to measure the type of worry associated with the possible over-report of cognitive symptoms. The present
The study provided preliminary evidence for the potential validity of such a measure, as well as a better understanding of factors that relate to dementia worry and over-report of cognitive difficulties. The study thus improves our understanding of the accuracy of self-reported symptoms in the diagnostic process and the need for objective testing of cognitive symptoms in older adults who present with concerns about dementia.
REFERENCES


APPENDIX A: MATERIALS

Participant Identification

This will re-create the identification number from your prior study participation. We wish to link the data from the questionnaires you are completing here with the prior data we collected from your previous participation in our laboratory. This identification number, although it is unique to you, cannot be used to identify you.

First initial of your mother’s first name _____

First initial of your father’s first name _____

Month you were born (circle) Jan Feb Mar Apr May June July Aug Sept Oct Nov Dec

Date of the month you were born ________ (for example, if you were born July 14th, put 14).

Medical History

Have you ever lost consciousness due to a blow to the head or other head injury?

YES  NO

IF YES…. For how long did you lose consciousness? ________

Did you see a doctor? ______________

Were you hospitalized? ______________

What was your diagnosis, if any? ______________

Did you have any form of treatment? __________________________

Have you ever had Seizures? YES NO

Have you ever had a Brain tumor? YES NO

Have you ever had a Stroke? YES NO

Have you ever had a Heart attack? YES NO

If YES, when?
Please list all of your medical diagnoses

Please list all of your current medications

Have you ever seen a mental health professional (psychiatrist, psychologist, counselor?)
YES  NO

If YES, For what diagnosis or purpose? ______________
When? __________________

Memory Controllability Inventory

This is a questionnaire about your memory. Please indicate the extent to which you agree or disagree with each statement. Provide the answer that is right for you by circling the number from 1 to 7 that best describes your beliefs. For example, if you strongly disagree with the statement, you would circle the number 1. If you strongly agree with the statement, you would circle the number 7. If you are neutral, you would circle the number 4.

<table>
<thead>
<tr>
<th>1.) There’s not much I can do to keep my memory from going downhill.</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.) I can remember the things I need to</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>3.) I can’t seem to figure out what to do to help me remember things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>4.) No matter how much I use my memory, it is bound to get worse as I get older.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
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<td></td>
</tr>
<tr>
<td>5.) Alzheimer’s disease is a common problem among the elderly.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>6.) As I get older I’ll need to rely on others to remember things for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>7.) If I work at it, I can improve my memory.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>8.) I’m not good at remembering things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>9.) If I use my memory a lot, it will stay in shape, just like my muscles do if I exercise.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>10.) I can find ways to improve my memory.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>11.) When I forget something I am apt to think I have Alzheimer’s disease.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>12.) I can’t remember things, even if I want to.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>13.) I think there’s a good chance I will get Alzheimer’s disease.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>14.) If I use my memory often I won’t lose it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>15.) As I get older I won’t have to rely on others to remember things for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>16.) If I really want to remember something I can.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>17.) I can think of strategies to help me keep up my memory.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>18.) If I want to have a good memory I need to have others to help me remember.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>
19.) I sometimes think that I have Alzheimer’s disease.

<p>| | | | | | | |</p>
<table>
<thead>
<tr>
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<td>1</td>
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<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

20.) When it comes to memory, there is no way I can make up for the losses that come with age.

<p>| | | | | | | |</p>
<table>
<thead>
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<th></th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

The MCI measures different conceptions of memory control and ability, and can be used to study these processes. In terms of reliability, the internal consistency coefficients ranged from .58 to .70 for the Present Ability scale across three studies (Lachman et al., 1995). Test-retest reliabilities for the Present Ability scale ranged from .65 at 9-day posttest to .53 at 3-month posttest. For the Alzheimer’s Likelihood scale, internal consistency coefficients ranged from .65 to .73 across three studies and test-retest reliability ranged from .67 at 9-day follow-up to .65 at three months (Lachman et al., 1995).

Results from tests of the validity of the scale (Lachman et al., 1995) indicated that high confidence in memory functioning (Present Ability) was associated with optimism for finding strategies for improvement, increased likelihood to view effort as a means to improve, and a lower belief in age-related memory stereotypes. There was a trend for age to be negatively related to perceived Present Ability; a similar trend was found with health. There were no consistent differences according to sex, educational attainment, or number of doctor visits per year (Lachman et al., 1995).

History of Dementia

Do you personally know anyone who currently has Alzheimer’s disease, or has had Alzheimer’s disease in the past? (Circle one)

Yes
No
If yes, what was/is the nature of your relationship with this person?

- How frequently did/do you see him or her? (Circle one)
  
  Daily
  Several times/week
  About once weekly
  Several times/month
  About once monthly
  Less often than once monthly

- How close did/do you feel to this person? (Circle one)
  
  Very close
  Close
  Somewhat close
  Not very close

- Are you genetically related to this person? If yes, circle one of the following:
  
  First degree relative (e.g. parent, sibling, child)
  Second Degree relative
  Not Sure (explain) ________________________________

- Have you ever been a caregiver for family or friends who had Alzheimer’s disease? (Circle one)
  
  Yes
  No

Geriatric Depression Scale

Instructions: Choose the best answer for how you felt over the past week.

1. Are you basically satisfied with your life?  
   
   YES  NO
2. Have you dropped many of your activities and interests? YES NO
3. Do you feel that your life is empty? YES NO
4. Do you often get bored? YES NO
5. Are you hopeful about the future? YES NO
6. Are you bothered by thoughts you can’t get out of your head? YES NO
7. Are you in good spirits most of the time? YES NO
8. Are you afraid that something bad is going to happen to you? YES NO
9. Do you feel happy most of the time? YES NO
10. Do you often feel helpless? YES NO
11. Do you often get restless and fidgety? YES NO
12. Do you prefer to stay at home, rather than going out and doing new thing? YES NO
13. Do you frequently worry about the future? YES NO
14. Do you feel you have more problems with memory than most? YES NO
15. Do you think it is wonderful to be alive now? YES NO
16. Do you often feel downhearted and blue? YES NO
17. Do you feel pretty worthless the way you are now? YES NO
18. Do you worry a lot about the past? YES NO
19. Do you find life very exciting? YES NO
20. Is it hard for you to get started on new projects? YES NO
21. Do you feel full of energy? YES NO
22. Do you feel that your situation is hopeless? YES NO
23. Do you think that most people are better off than you are? YES NO
24. Do you frequently get upset over little things?    YES  NO
25. Do you frequently feel like crying?    YES  NO
26. Do you have trouble concentrating?    YES  NO
27. Do you enjoy getting up in the morning?    YES  NO
28. Do you prefer to avoid social gatherings?    YES  NO
29. Is it easy for you to make decisions?    YES  NO
30. Is your mind as clear as it used to be?    YES  NO

The Geriatric Depression Scale (GDS) is a 30-item, yes-no format scale that ranges from 0 (no depression) to 30 (severe depression). The scale measures affective and behavioral symptoms of depression, but not vegetative symptoms (Parmelee & Katz, 1989). The current study used the total score from this measure.

The original validation of the scale (Brink et al., 1983) used two groups of geriatric participants. One group consisted of 40 healthy older adults, recruited from senior centers and housing projects, who had no history of mental illness and were functioning well in the community. The second group (N = 60) included older adults who were receiving treatment for depression. This group was further divided into those who were mildly depressed and those who were severely depressed. Twenty participants completed the measure twice, one week apart. Test-retest reliability was high (r = .85, p < 0.001), suggesting that scores on the GDS reflect stable individual differences. The GDS demonstrated high internal consistency among all participants (α = .94). An analysis of variance, in which the classification of participants as normal, mildly depressed, or severely depressed served as the between-subjects factor and the GDS total score served as the dependent variable, supported the
hypothesis that the healthy participants would receive the lowest GDS scores, and the severely depressed participants would receive the highest scores ($F(2, 97) = 99.48, p < 0.001$; Brink et al., 1983).

An in-depth validation of the GDS with 806 nursing home and congregate apartment residents, 70% female with a mean age of 85 years, provided evidence that the scale is highly internally consistent and stable over a 1-month interval in an institutionalized sample (Parmelee & Katz, 1989). Among the 417 participants who completed all 30 items, the scale was highly internally consistent (standardized $\alpha = .91$). One-month test-retest reliability for a subgroup of 55 was also high, $r = .85, p < 0.001$ (Parmelee & Katz, 1989).

Penn State Worry Questionnaire – Abbreviated

Instructions: Rate each of the following statements on a scale of 1 (“not at all typical of me”) to 5 (“very typical of me”). Please do not leave any items blank.

<table>
<thead>
<tr>
<th></th>
<th>Not at all typical of me</th>
<th>Very typical of me</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My worries overwhelm me.</td>
<td>1 2 3</td>
<td>4 5</td>
</tr>
<tr>
<td>2. Many situations make me worry.</td>
<td>1 2 3</td>
<td>4 5</td>
</tr>
<tr>
<td>3. I know I should not worry about things, but I just cannot help it.</td>
<td>1 2 3</td>
<td>4 5</td>
</tr>
<tr>
<td>4. When I am under pressure I worry a lot.</td>
<td>1 2 3</td>
<td>4 5</td>
</tr>
<tr>
<td>5. I am always worrying about something.</td>
<td>1 2 3</td>
<td>4 5</td>
</tr>
</tbody>
</table>
6. As soon as I finish one task, I start to worry about everything else I must do.  1 2 3 4 5

7. I have been a worrier all my life.  1 2 3 4 5

8. I have been worrying about things.  1 2 3 4 5

Each item of the Penn State Sorry Questionnaire is rated on a scale of 1 (not at all typical of me) to 5 (very typical of me). Eleven of the items are positive for the presence of worry, and five are reverse coded, indicating an absence of worry (Knight, McMahon, Skeaff, & Green, 2008). Among the original normative sample (405 introductory psychology students), the mean score was 48.8 (SD = 13.8), with scores ranging from 16-80 (the entire range of possible scores). Females scored significantly higher than males, $t(404=) 3.24, P < 0.002$. The coefficient $\alpha$ was 0.93 for the total group. Test-retest reliability using a subset of the original sample over an 8-10 week interval was quite high, $r(45) = 0.92, P < 0.001$. In college samples, the measure correlated positively with other measures of emotional disturbance, assessments of other relevant psychological constructs such as perfectionism and self-esteem, and with specific maladaptive coping strategies. Responses did not seem to be influenced by social desirability. In clinical samples, the PSWQ distinguished levels of diagnosable Generalized Anxiety Disorder (GAD), and produced higher scores for those with GAD than for those with diagnosable Posttraumatic Stress Disorder (Meyer et al., 1990).

Although the PSWQ was shown to be a reliable and valid instrument in a normative sample, it was developed using younger to middle aged adults, and its psychometric properties appear to be inadequate for assessing worry in older adults (Crittendon & Hopko, 2006). However, there is some evidence that the PSWQ is reliable when used with older
adults: Knight et al. (2008) examined the psychometric properties of the PSWQ in a sample of 255 healthy older adults in New Zealand, and found an internal consistency of $\alpha = .89$. Crittendon and Hopko (2006) showed that the PSWQ can be effectively modified for use with older adults by excluding all five of the reverse coded items and three of the positively worded items. This modification results in the eight-item Penn State Worry Questionnaire-Abbreviated. The PSWQ-A has high internal consistency ($\alpha = .87$) and adequate test-retest reliability ($r = .63$) when used with older adults. The measure also demonstrates good convergent and divergent validity with other measures of anxiety and worry ($r = .39-.49$) (Crittendon & Hopko, 2006).

Generalized Anxiety Disorder – Questionnaire – IV

For each statement, please select the appropriate response to indicate the degree to which you feel the statement is characteristic of you.

1. Do you experience excessive worry?   Yes ___     No ___
2. Is your worry excessive in intensity, frequency, or amount of distress it causes?  
   Yes ___     No ___
3. Do you find it difficult to control the worry (or stop worrying) once it starts?  
   Yes ___     No ___
4. Do you worry excessively or uncontrollably about minor things such as being late for an appointment, minor repairs, etc.
   Yes ___     No ___
5. Please list the most frequent topics about which you worry excessively or uncontrollably:
   a. _______________________   d. _______________________
   b. _______________________   e. _______________________
   c. _______________________   f. _______________________
6. During the last six months, have you often been bothered by any of the following symptoms? Circle each symptom that you have had more days than not:
restlessness or feeling keyed up or on edge  
irritability

difficulty falling/staying asleep/unsatisfying sleep  
being easily fatigued

difficulty concentrating or mind going blank  
muscle tension

8. How much do worry and physical symptoms interfere with your life, work, social activities, family, etc.? Circle only one response:
none mild moderate severe very severe

9. How much are you bothered by worry and physical symptoms (how much distress does it cause you?) Circle only one response:
none mild moderate severe very severe

In a sample of 143 undergraduates, the GAD-Q-IV was found to have a sensitivity of 83% and a specificity of 89% when using a cutoff score of 5.7. A study using 391 undergraduates demonstrated that the GAD-Q-IV was correlated with the PSWQ ($r = .66$), indicating that the measure has good convergent validity with other measures of worry. A two-sample study comparing 148 undergraduates with 69 clinical community participants revealed adequate test-retest reliability over a two-week interval, with Kappa agreement between Time 1 and Time 2 equal to .64 (Newman et al., 2002).

Dementia Worry Scale

<table>
<thead>
<tr>
<th>I know I shouldn’t worry about developing dementia, but I just cannot help it.</th>
<th>Not at all typical of me</th>
<th>Very typical of me</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I find it easy to dismiss thoughts that I might have dementia.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>-------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>I find it difficult to control my worries about developing dementia.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>When I can’t remember something, I find myself wondering whether I have dementia.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>My worries about dementia overwhelm me.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>More often than not, I find my thoughts returning to concerns that I have dementia.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>I do not tend to worry about having dementia.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>When I hear about someone having dementia, I start to worry about having it myself.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>When I am not distracted, I find my thoughts focusing on my own cognitive changes and concerns.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Even though I know it doesn’t help to focus on it, I can’t help thinking about whether or not I have dementia.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Once I start worrying about dementia, I just cannot stop.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>When I find myself making a mistake with my memory, I don’t tend to think about having dementia as the cause.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Sometimes when trying to go to sleep, I find my thoughts drift to my concerns about having dementia.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>When I forget a word that I want to say, my thoughts immediately turn to dementia.</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
I think I probably worry more about dementia than other people my same age.
APPENDIX B: DESCRIPTIVE STATISTICS FOR STUDY MEASURES

<table>
<thead>
<tr>
<th>Measure</th>
<th>M</th>
<th>SD</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Skewness</th>
<th>Std. Error</th>
<th>Kurtosis</th>
<th>Std. Error</th>
</tr>
</thead>
<tbody>
<tr>
<td>DWS (N = 99)</td>
<td>11.90</td>
<td>4.73</td>
<td>8.00</td>
<td>26.00</td>
<td>1.62</td>
<td>.24</td>
<td>1.92</td>
<td>.48</td>
</tr>
<tr>
<td>Present Ability (N = 99)</td>
<td>5.19</td>
<td>1.30</td>
<td>1.25</td>
<td>7.00</td>
<td>-.48</td>
<td>.24</td>
<td>-.45</td>
<td>.48</td>
</tr>
<tr>
<td>Alzheimer’s Likelihood (N = 100)</td>
<td>2.90</td>
<td>1.35</td>
<td>1.00</td>
<td>7.00</td>
<td>.94</td>
<td>.24</td>
<td>.16</td>
<td>.48</td>
</tr>
<tr>
<td>GDS (N = 85)</td>
<td>4.40</td>
<td>4.98</td>
<td>0.00</td>
<td>23.00</td>
<td>1.86</td>
<td>.26</td>
<td>3.60</td>
<td>.52</td>
</tr>
<tr>
<td>PSWQ-A (N = 98)</td>
<td>16.36</td>
<td>7.85</td>
<td>8.00</td>
<td>40.00</td>
<td>.97</td>
<td>.24</td>
<td>.32</td>
<td>.48</td>
</tr>
<tr>
<td>GAD-Q-IV (N = 100)</td>
<td>1.98</td>
<td>2.33</td>
<td>0.00</td>
<td>10.42</td>
<td>1.86</td>
<td>.24</td>
<td>3.16</td>
<td>.48</td>
</tr>
</tbody>
</table>