



Published in final edited form as:

*Am J Alzheimers Dis Other Demen.* 2021 ; 36: 1533317521995322. doi:10.1177/1533317521995322.

## A 2-Study Psychometric Evaluation of the Modified Dementia Worry Scale

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### Abstract

A modified version of the Dementia Worry Scale (DWS) used the terminology “Alzheimer’s disease and related dementias” (versus the DWS’ use of “dementia”). Two studies investigated psychometric properties of the modified DWS (MDWS). Study 1 compared the psychometric properties of the DWS and MDWS; both versions had single factor structures and exhibited excellent internal consistency ( $\alpha \geq .95$ ). The MDWS exhibited greater test-retest reliability after a 4-week interval (DWS  $r = .68$ ; MDWS  $r = .90$ ). In Study 2, the MDWS again displayed a single factor structure, excellent internal consistency ( $\alpha = .95$ ), and good test-retest reliability after an 8-week interval ( $r = .78$ ). Additionally, results support convergent validity between the MDWS and fear of dementia, subjective memory, general anxiety, health anxiety, and neuroticism. The MDWS is psychometrically consistent with the DWS, maintains strong test-retest reliability, and is appropriate for use in cross-sectional and longitudinal research.

### Keywords

dementia-related anxiety; dementia worry scale; psychometric; factor analysis

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Alzheimer’s disease and related dementias (ADRD) are prevalent diagnoses, and age is the greatest risk factor.<sup>1</sup> Approximately 5.8 million Americans have been diagnosed with Alzheimer’s disease (AD), which is the most common type of dementia. AD represents about 60 to 80% of dementia cases, and other dementia types include vascular dementia, dementia with Lewy bodies, frontotemporal dementia, mixed dementias, and dementias secondary to a medical condition (e.g., Parkinson’s disease or HIV).<sup>1</sup> Approximately 31% of US adults identify Alzheimer’s disease (AD) as their most feared diagnosis, yet 62% of

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Procedures for both studies were approved by the University of Colorado Colorado Springs Institutional Review Board (# 2020-014; #2020-023).

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

those adults acknowledge they know very little about AD.<sup>2</sup> ADRDs' prevalence and significant symptom profiles combined with a general lack of knowledge about those diagnoses likely contribute to dementia-related anxiety (DRA). DRA exists on a continuum, ranging from passing concern about difficulty recalling a name to preoccupation with having a neurodegenerative disorder. This anxiety can occur independently of cognitive function and therefore does not consistently reflect objective cognitive status,<sup>3</sup> yet DRA is associated with negative indicators of well-being, including lower life satisfaction,<sup>4</sup> greater state and trait anxiety,<sup>5</sup> and depression.<sup>6,7</sup>

Although ADRD receive significant attention in research, there is comparatively less research about DRA. Within the existing literature, various terms have been used: anticipatory dementia,<sup>8</sup> dementia worry,<sup>3</sup> and dementia-related anxiety.<sup>9</sup> Kessler et al<sup>3</sup> state that worry about ADRD may exist independently of objective cognitive status, may occur at any age, and is not just related to developing the disease. Rather, Kessler et al<sup>3</sup> suggest a person may worry about any biological (e.g., developing ADRD),<sup>8,10,11</sup> psychological (e.g., loss of identity or self-control),<sup>12</sup> or social aspects (e.g., caregiving).<sup>13</sup> As with other types of health-related concerns, dementia worry occurs on a spectrum from transient concern to more distress or preoccupation.

Though Kessler and colleagues<sup>3</sup> expanded the concept of fear related to ADRD to include a variety of biopsychosocial aspects, the label "worry" may not adequately describe the level or type of concern some people experience regarding ADRD. Because concern about ADRD is a disease specific worry with the potential to interfere with day-to-day functioning and mental health, this construct is better operationalized as a type of health anxiety. Health anxiety involves the misinterpretation and misattribution of disease-related symptoms as more severe than they are in reality,<sup>14,15</sup> may increase with exposure to personally significant health information, and is not only present during an illness.<sup>15</sup> The term DRA was selected over dementia worry based on the affective (e.g., fear, irritability, sadness), somatic (e.g., tension, heart racing, or fatigue), and cognitive (e.g., difficulty concentrating, sense of impending doom) components of anxiety, all of which may be experienced as part of fear of having or developing ADRD.<sup>15</sup>

Dementia terminology (e.g., dementia, neurocognitive disorders, ADRD, etc.) also differs in DRA research. The term "dementia" encompasses a broader range of ADRD than just Alzheimer's disease<sup>16</sup> and is used in some measures of DRA, but participants may not be familiar with the nuances of dementia as an "umbrella" term for a variety of neurodegenerative diseases, rather they may rely on common beliefs and understanding.<sup>17</sup> Depending on level of understanding, a person may have different internal conceptualizations and behavioral responses to the idea of developing dementia versus ADRD. For example, in a systematic review of studies evaluating the general public's understanding of Alzheimer's disease and dementia, Cahill and colleagues<sup>18</sup> reported that misunderstandings were common, including the belief that dementia was a typical part of the aging process. Cahill and colleagues'<sup>18</sup> review of the literature did not directly examine understanding of the differences and overlap between specific labels, such as ADRD, and broad labels, such as dementia. However, their review highlights the fact that general

knowledge is variable. Further, ADRD are more familiar and are anxiety provoking disease processes (e.g., second most feared disease after cancer).<sup>2</sup>

Although public awareness campaigns specific to ADRD exist, public misunderstanding about the term “dementia” continues.<sup>18</sup> In this study, we modified the language from dementia to ADRD for use in research involving participants with varying degrees of knowledge and understanding of dementia-related terminology. In addition to inconsistent nomenclature about the disease itself, as mentioned previously, various terms are used to describe worry or anxiety related to developing ADRD. The lack of clear operationalization may be related to the diverse ways in which DRA is felt or experienced by individuals.

Consistent with the varying nomenclature for DRA, a number of approaches to measurement exist. DRA has been assessed using single-item measures (e.g., “How concerned are you about developing Alzheimer’s disease during your lifetime?”),<sup>19</sup> multi-item measures include single-factor questionnaires (e.g., 7-item perceived threat of ADRD,<sup>20</sup> Dementia Worry Scale,<sup>6</sup> a separate scale also titled the Dementia Worry Scale),<sup>21</sup> and multi-factor measures (e.g., a subset of items from the Metamemory in Adulthood Questionnaire,<sup>22</sup> and the Fear of Alzheimer’s Disease Scale<sup>5</sup> and Fear of Dementia Scale<sup>23</sup>). Single-item measures allow researchers to quickly assess the construct, which is advantageous when time spent in study is a concern. However, single-item measures do not provide information on the nuances of DRA. The use of multi-item and multi-factor measures may be more effective for assessing the many biopsychosocial aspects of DRA. For the purposes of this study, the Dementia Worry Scale<sup>6</sup> (DWS) was selected over other DRA measures for multiple reasons: 1) its conciseness minimizes participant burden, compared to the much longer Fear of Alzheimer’s Disease Scale,<sup>5</sup> 2) it has more reliable psychometrics compared to measures like the Fear of Dementia Scale,<sup>23</sup> and 3) the researchers were interested in whether changing the language from “dementia” to ADRD would affect the psychometric properties of the scale given greater awareness of and specific anxiety about Alzheimer’s disease.

The DWS<sup>6</sup> is a 12-item single factor measure of “dementia worry.” Kinzer and Suhr’s<sup>6</sup> initial sample included older adults previously enrolled in studies of cognitive impairment ( $N = 100$ ;  $M = 69.22$ ,  $SD = 8.50$ ; 64.0% female;  $M = 18.13$ ,  $SD = 3.19$ ; 95.0% White); the authors reported excellent internal consistency ( $\alpha = .91$ ) and good test-retest reliability ( $r = 0.89$ ). The DWS also displayed good convergent validity with general worry (Penn State Worry Questionnaire;<sup>24</sup>  $r = .53$ ,  $p < .001$ ), perceived memory function (Memory Controllability Inventory;<sup>25</sup>  $r = .37$ ,  $p < .001$ ), and depression (Geriatric Depression Scale;<sup>26</sup>  $r = .51$ ,  $p < .001$ ).<sup>6</sup>

Given the strong psychometric properties of the DWS, it was considered a viable option for use in research but was limited due to language referencing worry about “dementia.” The primary purpose of Study 1 was to evaluate the psychometric properties of the original DWS compared to a modified version with language including ADRD. The purpose of Study 2 was to confirm the psychometric properties of the modified DWS (MDWS) and establish convergent validity.

## Study 1: Original and Modified Measure Psychometric Comparison

Study 1 was designed to 1) establish the psychometric properties of the MDWS and 2) evaluate psychometric differences in the DWS compared to the modified version.

### Method

The Institutional Review Board (IRB) approved all study procedures. Study 1 was a 2-time point, repeated measures design used to evaluate and contrast the psychometric properties of the DWS and MDWS in an online sample of adults aged 18 years and older.

**Participants and Procedures**—Data collection for Study 1 occurred over a 5-week period in July and August 2019. A convenience sample of participants was recruited via Amazon’s Mechanical Turk (MTurk), an online crowdsourcing service. Participants were included if they were 18 years of age or older. Though young adults are not at immediate risk of ADRD diagnoses, prior research has shown that they do worry about neurodegenerative disorders (age range 18 to 58 years,  $M = 21.16$ ,  $SD = 4.85$ ).<sup>27</sup> Further, Anderson and colleagues<sup>12</sup> report that younger adults (age range 18 to 38 years) consider themselves at greater risk of ADRD compared to older adults (age range 58 to 89 years). At any age, a person can experience anxiety regarding the cause, timeline, consequences, and controllability of a disease. For this study, MTurk participation was restricted to those located in the United States and had a 95% or greater participation acceptance rate (an MTurk quality check suggesting prior researchers considered participant responses appropriate for use).

Prior researchers have suggested advantages to using MTurk, including cost effectiveness, demographic diversity, unique identifiers that limit duplicate responding to studies, and flexibility in limiting future participation.<sup>28,29</sup> However, the use of MTurk is not without limitations and outcomes are dependent on methods used to ensure quality data.<sup>28</sup> For this study, evaluation of data quality was conducted post-hoc. A common concern is that MTurk participants respond with low effort, contributing to measurement and systematic errors.<sup>28</sup> Participant effort was evaluated by examining irregular response patterns (e.g., using the same response option for all items), time it took to complete the surveys, and missing data greater than or equal to 80%. Three participants were excluded from data analysis for irregular response patterns and/or missing greater than 80% of the data. Six data sets came from the same IP address. Though the researchers cannot be completely certain that participant responses from the same IP address were from different people, after examining demographic responses it was determined that these were most likely to be participants living in the same home (i.e., different MTurk numbers provided, endorsement of different ages, genders, years of education, health status, and family history of dementia).

The study was advertised as a “test-retest validation of dementia-related anxiety measures.” Participants were informed that the study was intended to test the usefulness of questionnaires about dementia-related anxiety over time. Though the purpose of the study was not masked, risk of participants providing socially desirable responses was deemed minimal because they were informed that inclusion in the follow-up portion of the study would be based on random selection. Information describing the study was provided,

including payment arrangements and a statement that 100 participants would be randomly selected from the initial sample to complete the surveys again 4 weeks after baseline. All provided informed consent prior to completing the study measures. Participants were paid \$1.50 for each data collection time point, and those who completed both time points received a \$1.00 completion bonus. Payments were made directly to participants' MTurk worker accounts.

At baseline, 200 Human Intelligence Tasks (HIT; MTurk terminology for available tasks) were made available; all HITs were accepted. Participants were randomly assigned via Qualtrics software to complete the original measure or the modified measure. The final sample included 197 participants (original measure  $n = 99$ ; modified measure  $n = 98$ ). Four weeks after baseline, at time 2 (T2) a subset of 100 participants was randomly selected for participation in the retest portion of the study, 50 from each group. A total of 63 participants completed T2 measures (63.0% response rate; original measure  $n = 35$ ; modified measure  $n = 28$ ). Attrition from baseline to T2 was 37.0%. Study 1 demographic characteristics are provided in Table 1 for the full baseline sample ( $N = 197$ ) and the final T2 sample ( $N = 63$ ).

## Measures

**Dementia Worry Scale**—The DWS<sup>6</sup> is a 12-item measure of dementia-related anxiety. Participants rate how typical each statement is of them using a 5-point scale (1 = not at all typical of me to 5 = very typical of me). Scores were summed; higher scores indicate greater dementia-related anxiety. See Table 2 for original and modified items. For the present study, the DWS had excellent internal consistency at both time points (baseline  $\alpha = .97$ ; T2  $\alpha = .96$ ). At baseline, total scores ranged from 11 to 57 ( $M = 27.11$ ,  $SD = 13.33$ ). At T2 scores ranged from 12 to 54 ( $M = 25.69$ ,  $SD = 12.18$ ). Test-retest reliability at approximately 4 weeks was .68 ( $p < .001$ ).

**Modified Dementia Worry Scale**—The MDWS is a modified version of the DWS,<sup>6</sup> with references to dementia changed to Alzheimer's disease and related dementias. All other aspects of the measure are consistent with the original DWS. For the present study, the MDWS also exhibited excellent internal consistency (baseline  $\alpha = .95$ ; T2  $\alpha = .96$ ). At baseline total scores ranged from 12 to 54 ( $M = 29.36$ ,  $SD = 12.37$ ). At T2 scores ranged from 12 to 54 ( $M = 27.59$ ,  $SD = 12.45$ ). Test-retest reliability at approximately 4 weeks was .90 ( $p < .001$ ).

**Demographic Questionnaire**—The demographic questionnaire included items assessing age, gender, ethnicity, race, highest level of education completed, relationship status, annual household income, and genetic history of ADRD.

**Analysis Plan**—Data analyses were conducted using IBM SPSS v.26. Between-group demographic differences were evaluated using independent samples  $t$ -tests and chi-square tests. An independent samples  $t$ -test was used to determine whether scores differed on the DWS and the MDWS. Psychometric properties of each scale were also evaluated. Principal axis factoring was used to evaluate the factor structure of the original and modified measures at baseline.

## Results

Analysis of missing data was conducted to evaluate patterns of missingness and to test assumptions. Item/scale level missing data were deemed negligible (range 0.67% to 1.44%). The assumption of normality was met for the DWS and MDWS (skewness and kurtosis  $\pm 2.00$ ).

**Group Equivalence and Test-Retest Reliability**—Independent samples *t*-tests were used to establish group equivalence for those assigned to complete the DWS and MDWS. At both baseline and T2, no between-group differences were observed in age, years of education, gender, ethnicity, race, relationship status, annual household income, or family history of AD/DRD (all  $p$ s  $> .05$ ). An independent samples *t*-test was also used to assess mean differences at baseline and T2 between the DWS and MDWS. DRA scores were not different between the DWS and the MDWS at baseline [ $t(195) = -1.23, p = .22, 95\% \text{ CI} = -5.86 \text{ to } 1.37$ ] or T2 [ $t(62) = -0.62, p = .54, 95\% \text{ CI} = -8.07 \text{ to } 4.27$ ]. The MDWS ( $r = .90$ ) exhibited greater test-retest reliability after a 4-week interval compared to the DWS ( $r = .68$ ).

Additional analyses were conducted to evaluate group differences between those who completed both time points ( $n = 63$ ) and those who dropped out of the study after T1 ( $n = 37$ ). Participants who completed both time points were significantly older ( $M = 37.10, SD = 10.90$ ) compared to those who only completed time one ( $M = 32.73, SD = 9.04$ ),  $p = .04$ . No significant differences were observed between groups for any other demographic variable.

**Factor Analysis**—Kinzer and Suhr used<sup>6</sup> principal axis factoring (PAF) with Promax rotation in their original psychometric analysis of the DWS. For this study, PAF with Oblimin rotation was used to evaluate the factor structure of the DWS and the MDWS. Oblimin rotation was selected over Promax because it accounts for correlation between items.<sup>30</sup>

**Original DWS Factor Analysis**—At baseline, the Bartlett's Test of Sphericity indicated that the observed correlation matrix was significantly different from the identity matrix,  $\chi^2(66) = 1120.25, p < .001$ . The Kaiser-Meyer-Olkin Measure of Sampling Adequacy value of .94 is considered "marvelous."<sup>31</sup> Extracted communalities ranged from .59 to .83. Using an *a priori* eigenvalue cut-off rule of greater than one,<sup>32</sup> a single-factor structure was observed, which explained 73.6% of the variance across all 12 items of the DWS. See Table 2 for factor loadings for both versions of the scale. A visual inspection of the scree plot<sup>33</sup> supported the single-factor structure.

**Modified DWS Factor Analysis**—At baseline, the Bartlett's Test of Sphericity indicated that the observed correlation matrix was significantly different from the identity matrix,  $\chi^2(66) = 943.45, p < .001$ . The Kaiser-Meyer-Olkin Measure of Sampling Adequacy value of .92 is considered "marvelous."<sup>31</sup> Extracted communalities ranged from .45 to .72. Using an *a priori* eigenvalue cut-off rule of greater than one,<sup>32</sup> a single-factor structure was observed, which explained 66.7% of the variance across all 12 items of the MDWS. A visual inspection of the scree plot<sup>32</sup> supported the single-factor structure.



**Study 1: Discussion**—For this sample of participants, the single-factor structure of the DWS and psychometric properties were similar to those reported by Kinzer and Suhr.<sup>6</sup> The DWS authors evaluated their original measure in a sample of adults over age 55 ( $M = 69.22$ ,  $SD = 8.50$ ). The sample of participants in this study was younger ( $M = 35.96$ ,  $SD = 10.64$ ), providing support for the use of DWS in samples with a wide age range. Bowen et al reported that levels of DRA follow a quadratic curve, increasing over adulthood, and peaking at age 65 followed by decline.<sup>34</sup> Given that DRA can be present at any age, use of a measure appropriate for a broad age range is important. This study provides support for the use of the DWS throughout the adult lifespan.

The study results also indicate the DWS<sup>6</sup> and MDWS are psychometrically similar despite differences in terminology (i.e., dementia versus ADRD); however, test-retest reliability was stronger for the MDWS than the original measure. Given the similarity between measures, the MDWS is appropriate for use in research, especially given its stronger test-retest reliability.

## Study 2: Modified DWS Psychometric Replication

Study 2 was designed to validate the results from Study 1, confirm the psychometric properties of the MDWS, and evaluate its construct validity with related factors. Due to the confirmatory purpose of Study 2, no a priori hypotheses were generated.

### Method

The IRB approved the Study 2 protocol. Data collected for this study were part of a separate 5-part longitudinal intervention study conducted with an online sample of adults aged 40 years and older who endorsed pre-existing dementia-related anxiety. Because the MDWS was used as the primary dependent variable in that study, it was deemed appropriate to replicate Study 1 outcomes specific to the MDWS and evaluate construct validity between the MDWS and other anxiety-specific factors.

**Participants and Procedures**—Data for Study 2 were collected as part of a larger 20-week longitudinal study evaluating change in DRA after an intervention intended to reduce this type of anxiety. A convenience sample of participants was recruited via MTurk. The same data quality measures were included in Study 2 as described in Study 1. All participants provided informed consent prior to completing the study measures. Participants were paid \$2.50 for each data collection time point, and for those who completed the full intervention study, a participation bonus of \$4.00 was awarded.

Participants first completed a pre-screen assessment. The purpose of the study was masked, but participants were informed that they may be invited to another study if they met qualification criteria, which were not disclosed. Participants were included in the intervention study if they were 40 years of age or older and endorsed at least a moderate level of pre-existing dementia-related anxiety (based on a single-item pre-screen question). At T1, 417 participants completed the study. Prior to conducting analyses, data were examined for quality. To control for the possibility that participants may have misrepresented themselves during the pre-screen, the demographic age question was

included again at T1. Twenty-two participants were excluded from analysis because they provided incomplete/inaccurate MTurk numbers ( $n = 6$ ), left all items blank ( $n = 4$ ), missed 2 or more attention checks embedded in other measures requesting that participants respond by selecting a predetermined item ( $n = 5$ ), or were younger than 40 years old ( $n = 7$ ; inconsistent with age reported at pre-screen). The remaining 395 T1 participants were included in Study 2 analyses specific to convergent validity; MDWS scores were collected prior to implementation of the intervention. At T1, participants ( $N = 395$ ) reported a mean age of 52.49 ( $SD = 8.71$ , range 40 – 78) and were mostly female (76.5%), not Hispanic, Latino, or Spanish origin (94.4%), and White or Caucasian (87.1%).

Eight weeks after baseline (T2), all participants were notified that a study link was available in their MTurk accounts for the next portion of the study. Because the intervention was intended to influence participants' DRA levels, only the data for participants assigned to the no-treatment condition (the control group) were used for the retest portion of this study ( $N = 120$ ). At T2, participants reported a mean age of 52.99 ( $SD = 8.84$ , range 40 – 75) and were mostly female (77.5%), not Hispanic, Latino, or Spanish origin (95.0%), and White or Caucasian (86.7%). Study 2 demographic characteristics are provided in Table 3 for the T1 and T2 samples.

Some attrition was observed between T1 and T2. At T1, 153 participants in the no-treatment group completed data and met data quality exclusion criteria (78.4% completion; 21.5% attrition). Additional analyses were conducted to evaluate group differences between those who completed both time points ( $n = 120$ ) and those who dropped out of the study after T1 ( $n = 33$ ). No significant differences were observed between groups for any demographic variable nor for the single-item DRA screen.

**Measures**—Measures were collected at T1 and T2 of the intervention study. For multifactor measures, details relating to the total score are reported because the primary interest was in relationships between the DWS and overall related constructs, rather than the subscale factors of each construct.

**Modified DWS**—In Study 2, the MDWS exhibited excellent internal consistency (T1  $\alpha = .95$ ; T2  $\alpha = .95$ ), and means (T1  $M = 22.58$ ,  $SD = 9.77$ ; T2  $M = 22.54$ ,  $SD = 9.43$ ) consistent with Study 1. Test-retest reliability after approximately 8 weeks was 0.78 ( $p < .001$ ). See Table 2 for Study 2 factor loadings for the MDWS items.

**Fear of Dementia Scale**—The Fear of Dementia Scale<sup>23</sup> (FDS) is a 35-item measure of DRA. The FDS was completed at T1 and included in this study to provide construct validity between 2 measures expected to assess the same construct. For the FDS, participants rate their level of agreement with statements using a 5-point scale (1 = not concerned to 5 = very concerned). Scores are summed and higher scores indicate greater fear of dementia on each of 3 dimensions: becoming a burden to others/personal loss, quality of life, and perceived social and cognitive loss. An example item from the FDS is “I will lose my identity or sense of who I am.” For the present study, the FDS had excellent internal consistency ( $\alpha = .96$ ). Total scores ranged from 38 to 171 ( $M = 115.09$ ,  $SD = 30.79$ ).



**Subjective Memory**—One of the more commonly reported predictors of DRA is a subjective sense of declining memory. Specifically, poor subjective memory has been associated with greater levels of DRA.<sup>25</sup> The Everyday Memory Questionnaire – Revised<sup>35</sup> (EMQ-R) was completed at T1 and used as a measure of subjective memory. The EMQ-R is a 13-item measure of common day-to-day lapses in memory. Participants rate how often events occurred in the last month using a 5-point scale (1 = once or less in the last month to 5 = once or more in a day). Scores are summed, with higher scores indicating greater frequency of memory difficulties on retrieval and attentional tracking. An example item from the EMQ-R is “forgetting that you were told something yesterday”). For the present study, the EMQ-R had excellent internal consistency ( $\alpha = .92$ ). Total scores ranged from 13 to 61 ( $M = 24.02$ ,  $SD = 10.09$ ).

**Mental Health Status**—The DSM-5 Self-Rated Level 1 Cross-Cutting Symptom Measure – Adult<sup>36</sup> (CCSM) was used to assess current mental health symptoms. The CCSM is a 23-item measure assessing the presence of mental health symptoms in 13 domains. For ethical reasons (i.e., inability to assess participant safety if suicidal ideation was endorsed), item number 11 “Thoughts of actually hurting yourself” was removed. For items on the CCSM, participants rate how often they have been bothered by each problem over the last 2 weeks using a 5-point scale (0 = not at all to 4 = severe). The CCSM clinical scoring method was used; for multi-item domains, the highest scale value endorsed is the domain score. Psychological domains used in this study include anxiety and memory. An example item from each domain is “feeling nervous, anxious, frightened, worried, or on edge” (anxiety) and “problems with memory (e.g., learning new information) or with location (e.g., finding your way home)” (memory). For the present study, items comprising the anxiety dimension had good internal consistency ( $\alpha = .83$ ;  $M = 1.72$ ,  $SD = 1.21$ ). The memory dimension ( $M = 0.73$ ,  $SD = 0.97$ ) is a single item, so internal consistency was not assessed.

**Health Anxiety**—The Short Health Anxiety Inventory<sup>37</sup> (SHAI) was given at T2 to assess health anxiety. For each of the 14 items, participants were asked to select which of 4 statements best describes their feelings over the last 6-months. The 4 options of an example item include “(a) As a rule I am not afraid that I have a serious illness, (b) I am sometimes afraid that I have a serious illness, (c) I am often afraid that I have a serious illness, (d) I am always afraid that I have a serious illness.” Items are scored (a = 0, b = 1, c = 2, d = 3) and summed; higher scores indicate greater levels of general health anxiety. For the present study, the SHAI had good internal consistency ( $\alpha = .89$ ;  $M = 12.37$ ,  $SD = 6.11$ ).

**Neuroticism**—The Mini International Personality Item Pool<sup>38</sup> (IPIP) was completed at T2. Participants rate how accurate each of the 20 statements is of them as they are now in relation to others their same sex and age using a 5-point rating scale (1 = very inaccurate to 5 = very accurate). Scores for each domain are summed; higher scores indicate greater presence of the specific personality trait. The personality domain of interest for this study was neuroticism (“Get upset easily”); given its relationship with anxiety, it was expected to correlate positively with DRA, thus providing support for convergent validity. For the present study, the neuroticism dimension had adequate internal consistency ( $\alpha = .71$ ;  $M = 10.89$ ,  $SD = 3.67$ ).

**Demographic Questionnaire**—The demographic questionnaire included items assessing age, gender, ethnicity, race, highest level of education completed, relationship status, annual household income, and genetic history of ADRD.

**Analysis Plan**—Data analyses were conducted using IBM SPSS v.26. Principal axis factoring was used to replicate the factor structure of the MDWS at T1. Convergent validity between the MDWS and related constructs was evaluated using Pearson's Product Moment Correlations.

## Results

Analysis of missing data was conducted to evaluate patterns of missingness and to test assumptions. Item/scale level missing data were deemed negligible (range = 0.00% to 0.80%). The assumption of normality for all variables included in analysis was met (skewness and kurtosis within  $\pm 2.00$ ). Missing data were managed through listwise deletion. Test-retest reliability of the MDWS after an 8-week interval was good ( $r = .78$ ).

**MDWS Factor Analysis**—The Bartlett's Test of Sphericity indicated that the observed correlation matrix was significantly different from the identity matrix,  $\chi^2(66) = 3857.91$ ,  $p < .001$ . The Kaiser-Meyer-Olkin Measure of Sampling Adequacy value of .95 is considered "marvelous."<sup>31</sup> Extracted communalities ranged from .54 to .77. Using an *a priori* eigenvalue cut-off rule of greater than one,<sup>32</sup> a single-factor structure was observed, which explained 66.04% of the variance across all 12 items. A visual inspection of the scree plot<sup>33</sup> supported the single-factor structure.

**Construct Validity**—Correlations between the MDWS and related constructs are presented in Table 4. Greater MDWS scores were significantly correlated with greater fear of dementia (FDS;  $r = 0.47$ ,  $p < .001$ ), greater subjective memory problems (EMQ-R;  $r = 0.72$ ,  $p < .001$ ; CCSM,  $r = 0.60$ ,  $p < .001$ ), greater presence of general anxiety symptoms (CCSM;  $r = 0.45$ ,  $p < .001$ ), higher levels of health anxiety (SHAI;  $r = 0.51$ ,  $p < .001$ ), and higher levels of neuroticism (IPIP;  $r = 0.34$ ,  $p < .001$ ).

**Study 2: Discussion**—For this sample of participants, the single-factor structure and psychometric properties of the MDWS were consistent with Study 1. Further, the MDWS exhibited good test-retest reliability over an 8-week interval. The MDWS was also correlated with variables expected to relate to the concept of DRA. Specifically, participants endorsing greater levels of DRA on the MDWS also endorsed greater fear of dementia, greater subjective memory difficulties, greater levels of general anxiety and health anxiety, and greater levels of neuroticism. Results provide support for use of the MDWS in research, including longitudinal studies with test-retest intervals up to 8 weeks.

## General Discussion

Overall, these studies provide support for the use of the MDWS in research, including participants across the adult lifespan (18 years of age and older) and in longitudinal research with test-retest gaps at 4 weeks and 8 weeks. Results from 2 studies confirm the single factor structure, and Study 2 provides support for the convergent validity of the MDWS, which was

positively correlated with measures assessing fear of dementia, subjective memory difficulties, general anxiety, health anxiety, and neuroticism. Kinzer and Suhr<sup>6</sup> listed their small sample size as a study limitation (T1  $N=100$ ; T2  $N=37$ ). Results in Study 2 with a larger sample size (T1  $N=395$ ; T2  $N=120$ ) were consistent with Kinzer and Suhr's results.<sup>6</sup>

## Limitations and Future Research

In addition to the strengths of the presented studies, limitations were present. First, recruiting a convenience sample through MTurk introduced potential methodological limitations to the study. Though MTurk participants complete many studies and have been labeled as non-naïve,<sup>28</sup> the outcomes of this study were consistent with the original measure with data collected from a community dwelling sample. Further, the self-selective nature of MTurk studies<sup>28</sup> suggests that participants opting to complete the study may not be representative of the general population. Data quality measures were included to improve the reliability of information collected; however, it is acknowledged that there remain flaws in data collected on MTurk. Future research could evaluate the modified DWS in community samples to confirm the results of this study.

Importantly, samples for both studies were predominantly female and White, which raises questions about the generalizability of findings. Women are more likely to be diagnosed with ADRD,<sup>1</sup> sometimes found to report greater DRA,<sup>34</sup> and generally more likely to participate in studies; therefore, future studies should determine whether the psychometric properties of scales assessing DRA differ for men and women too. Likewise, Black or African American and Hispanic/Latino individuals have higher rates of ADRD per capita compared to White individuals,<sup>1</sup> and little is known about racial and ethnic differences in DRA. Therefore, additional studies of DRA in diverse groups, as well as determination of the psychometric properties of the MDWS in diverse groups are needed. Another potential limitation is the single-factor structure of the original DWS and MDWS, which may not capture the full spectrum of DRA. Though not assessed in this study, multi-factor DRA measures have been created (Fear of Alzheimer's Disease Scale<sup>5</sup> and Fear of Dementia Scale<sup>23</sup>) to address the complexity of concerns. Because DRA is a multi-faceted construct, a single-factor measure may not assess the nuances of DRA as well as multi-factor measures. Dementia knowledge is also of interest for future DRA research; including an assessment of dementia knowledge would help control for differences in participants' understanding of dementia pathologies and promote understanding of the relationship between ADRD knowledge and DRA.

## Conclusion

Despite the limitations listed above, the MDWS displayed multiple strengths, and based on the outcomes of these studies, it is considered appropriate for research. Compared with the DWS, the MDWS has a stronger test-retest reliability after 4 weeks. It also has strong test-retest reliability after 8 weeks. Thus, the MDWS may be more appropriate for use in longitudinal research than the original DWS. Though slight variations in test-retest reliability and internal consistency were present, the DWS and MDWS were both

psychometrically sound. The causes of the slight differences cannot be definitively identified but may be attributed to differences in terminology (“dementia” versus “ADRD”). We view continued investigation of DRA to be an important part of understanding and promoting psychological health in middle-aged and older adults. In light of documented misperceptions that “dementia” is a part of typical aging processes,<sup>18</sup> we suggest that the MDWS is a viable and psychometrically sound option for simultaneously measuring anxiety about dementia and Alzheimer’s disease in samples of varying degrees of familiarity with this terminology.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was funded by a grant awarded to the second author from the National Institute on Aging (1R21AG052820-01A1).

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**Table 1.**

Study 1: Descriptive Statistics for Time 1 and Time 2 Respondents.

	Time 1: DWS (N = 99)	Time 1: MDWS (N = 98)	Time 1: Total (N = 197)	Time 2: DWS (N = 35)	Time 2: MDWS (N = 28)	Time 2: Total (N = 63)
Age in years (range: 40–78)	19–72	22–62	19–72	23–70	24–57	23–70
Mean (SD)	36.90 (11.74)	35.02 (9.34)	35.96 (10.64)	37.14 (12.13)	37.38 (9.37)	37.25 (10.88)
Gender						
Female	41 (41.4%)	36 (36.7%)	77 (39.1%)	15 (42.9%)	13 (44.8%)	28 (43.8%)
Male	57 (57.6%)	62 (63.3%)	119 (60.4%)	20 (57.1%)	16 (55.2%)	36 (56.3%)
Ethnicity						
Hispanic, Latino, or Spanish	16 (16.2%)	24 (24.5%)	40 (20.3%)	8 (22.9%)	7 (24.1%)	15 (23.4%)
Not Hispanic, Latino, or Spanish	82 (82.8%)	73 (74.5%)	155 (78.7%)	27 (77.1%)	22 (75.9%)	49 (76.6%)
Race						
American Indian or Alaska Native	1 (1.0%)	1 (1.0%)	2 (1.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Asian	5 (5.1%)	4 (4.1%)	9 (4.6%)	2 (5.7%)	1 (3.4%)	3 (4.7%)
Black or African American	16 (16.2%)	25 (25.5%)	41 (20.8%)	8 (22.9%)	9 (31.0%)	17 (26.6%)
Native Hawaiian/ Pacific Islander	0 (0.0%)	1 (1.0%)	1 (0.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
White or Caucasian	72 (72.7%)	62 (63.3%)	134 (68.0%)	23 (65.7%)	18 (62.1%)	41 (64.1%)
Multiple Races	3 (3.0%)	5 (5.1%)	8 (4.1%)	0 (0.0%)	1 (3.4%)	1 (1.6%)
Education (years)						
Mean (SD)	15.57 (2.02)	15.56 (1.93)	15.56 (1.97)	15.49 (2.12)	15.48 (2.05)	15.48 (2.07)
Relationship Status						
Single (never married)	34 (34.3%)	40 (40.8%)	74 (37.6%)	10 (28.6%)	9 (31.0%)	19 (29.7%)
Married/Partnered	56 (56.6%)	50 (51.0%)	106 (53.8%)	22 (62.9%)	16 (55.2%)	36 (56.3%)
Divorced	6 (6.1%)	6 (6.1%)	12 (6.1%)	3 (8.6%)	3 (10.3%)	6 (9.4%)
Widowed	3 (3.0%)	1 (1.0%)	4 (2.0%)	0 (0.0%)	1 (3.4%)	1 (1.6%)
Family ADRD						
No	59 (59.6%)	53 (54.1%)	112 (56.9%)	18 (51.4%)	14 (48.3%)	32 (50.0%)
Yes	34 (34.3%)	35 (33.7%)	69 (35.0%)	14 (40.0%)	14 (48.3%)	28 (43.8%)
Uncertain	6 (6.1%)	9 (9.2%)	15 (7.6%)	3 (8.6%)	1 (3.4%)	4 (6.3%)
DWS/MDWS						
Mean (SD)	27.11 (13.33)	29.36 (12.37)	—	25.69 (12.18)	27.59 (12.45)	—

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Note: ‘—’ indicates item not calculated. Where percentages do not add up to 100.0%, data is missing or participants selected “Other.” DWS = Dementia Worry Scale (Kinzer & Suhr, 2016). MDWS = Modified Dementia Worry Scale.

**Table 2.** Factor Loadings for DWS and MDWS at Study 1 Baseline and MDWS at Study 2 Baseline.

	Factor loading	
	Study 1	Study 2
<b>Original DWS items</b>		
1. I know I shouldn't worry about developing dementia, but I just cannot help it.	.77	
2. I find it difficult to control my worries about developing dementia.	.87	
3. When I can't remember something, I find myself wondering whether I have dementia.	.91	
4. My worries about dementia overwhelm me.	.82	
5. More often than not, I find my thoughts returning to concerns that I have dementia.	.87	
6. When I hear about someone having dementia, I start to worry about having it myself.	.80	
7. When I am not distracted, I find my thoughts focusing on my own cognitive changes and concerns.	.83	
8. Even though I know it doesn't help to focus on it, I can't help thinking about whether or not I have dementia.	.88	
9. Once I start worrying about dementia, I just cannot stop.	.85	
10. Sometimes when trying to go to sleep, I find my thoughts drift to my concerns about having dementia.	.83	
11. When I forget a word that I want to say, my thoughts immediately turn to dementia.	.82	
12. I think I probably worry more about dementia than other people my age.	.87	
<b>Modified DWS items</b>		
1. I know I shouldn't worry about developing Alzheimer's disease and related dementias, but I just cannot help it.	.67	.74
2. I find it difficult to control my worries about developing Alzheimer's disease and related dementias.	.81	.78
3. When I can't remember something, I find myself wondering whether I have Alzheimer's disease or a related dementia.	.78	.78
4. My worries about Alzheimer's disease and related dementias overwhelm me.	.82	.83
5. More often than not, I find my thoughts returning to concerns that I have Alzheimer's disease or a related dementia.	.85	.87
6. When I hear about someone having Alzheimer's disease or a related dementia, I start to worry about having it myself.	.72	.77
7. When I am not distracted, I find my thoughts focusing on my own cognitive changes and concerns.	.81	.74
8. Even though I know it doesn't help to focus on it, I can't help thinking about whether or not I have Alzheimer's disease or a related dementia.	.85	.88
9. Once I start worrying about Alzheimer's disease and related dementias, I just cannot stop.	.85	.84
10. Sometimes when trying to go to sleep, I find my thoughts drift to my concerns about having Alzheimer's disease or a related dementia.	.82	.77
11. When I forget a word that I want to say, my thoughts immediately turn to Alzheimer's disease and related dementias.	.80	.75
12. I think I probably worry more about Alzheimer's disease and related dementias than other people my same age.	.79	.76

Note: Oblimin rotation was used for analyses. A single factor was extracted for both versions of the measure, so no rotation was necessary. DWS Dementia Worry Scale (Kinzer & Suhr, 2016). MDWS = Modified Dementia Worry Scale. The original DWS was not administered in Study 2.

**Table 3.**

Study 2: Descriptive Statistics for Time 1 and Time 2 Respondents.

	<b>Time 1 (N = 395)</b>	<b>Time 2 (N = 120)</b>
	<b>M (SD)</b>	<b>M (SD)</b>
Age in years (range: 40–78)	52.49 (8.71)	52.99 (8.84)
Years of Education (range: 9–20)	15.20 (2.10)	15.04 (2.08)
MDWS (range: 11–55)	22.58 (9.77)	22.54 (9.43)
	n (%)	n (%)
<b>Gender</b>		
Female	302 (76.5%)	93 (77.5%)
Male	93 (23.5%)	27 (22.5%)
<b>Ethnicity</b>		
Hispanic, Latino, or Spanish origin	16 (4.1%)	3 (2.5%)
Not Hispanic, Latino, or Spanish origin	373 (94.4%)	114 (95.0%)
Unknown	3 (0.8%)	2 (1.7%)
<b>Race</b>		
American Indian or Alaska Native	3 (0.8%)	1 (0.8%)
Asian	15 (3.8%)	4 (3.3%)
Black or African American	17 (4.3%)	5 (4.2%)
White or Caucasian	344 (87.1%)	104 (86.7%)
Multiple Races	14 (3.5%)	6 (5.0%)
<b>Relationship Status</b>		
Single (never married)	67 (17.0%)	24 (20.0%)
Married/Partnered	229 (58.0%)	71 (59.2%)
Divorced	76 (19.2%)	19 (15.8%)
Widowed	19 (4.8%)	4 (3.3%)
<b>Family History of ADRD</b>		
No	236 (59.7%)	69 (57.5%)
Yes	124 (31.4%)	41 (34.2%)
Uncertain	35 (8.9%)	10 (8.3%)

Note: Where percentages do not add up to 100.0%, missing data is present. MDWS = Modified Dementia Worry Scale.

**Table 4.**

Study 2: Pearson's Product Moment Correlation.

Item/measure	1	2	3	4	5	6	7
1. MDWS	–						
2. DSM-5 Screen: Anxiety	.45**	–					
3. DSM-5 Screen: Memory	.60**	.44**	–				
4. Fear of Dementia Scale	.47**	.27*	.29**	–			
5. Everyday Memory Questionnaire	.72**	.55**	.71**	.31**	–		
6. Short Health Anxiety Inventory	.51**	.45**	.34**	.36**	.48**	–	
7. Mini IPIP: Neuroticism	.34**	.54**	.32**	.31*	.46**	.49**	–

Notes:

\*  
p < .01,\*\*  
p < .001.

MDWS = Modified Dementia Worry Scale.

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