Received: 23 December 2022 | Revised: 15 March 2023 | Accepted: 27 March 2023

DOI: 10.1002/dad2.12432

Alzheimer's & Dementia
Diagnosis, Assessment & Disease Monitoring

RESEARCH ARTICLE

Validation of the Fear and Avoidance of Memory Loss scale in community-based older adults

Francesca R. Farina[1,2,3] | **Pavithra Pavithra**[4] | **Hosanna An**[1] | **Melissa Marquez**[1] | **Patricia O'Loughlin**[3] | **John Regan**[3] | **Michelle Taddeo**[1] | **Marc Bennett**[5] | **Bert Lenaert**[6,7] | **James W. Griffith**[1]

[1]Feinberg School of Medicine, Department of Medical Social Sciences, Northwestern University, Chicago, Illinois, USA

[2]Global Brain Health Institute, Trinity College Dublin, Dublin, Ireland

[3]School of Psychology, Trinity College Dublin, Dublin, Ireland

[4]School of Medicine, Trinity College Dublin, Dublin, Ireland

[5]School of Psychology, University College Dublin, Dublin, Ireland

[6]Faculty of Psychology, Open University, Heerlen, the Netherlands

[7]Faculty of Health, Medicine and Life Sciences, Limburg Brain Injury Centre, Maastricht University, Maastricht, the Netherlands

Correspondence
Francesca Farina, Feinberg School of Medicine, Department of Medical Social Sciences, Northwestern University, Floor 27, 625 N, Michigan Avenue, Chicago, IL 60611, USA.
Email: francesca.farina@northwestern.edu

Funding information
National Institutes of Health's National Center for Advancing Translational Sciences, Grant/Award Number: UL1TR001422; Irish Research Council; The Osher Center for Integrative Medicine

Abstract

Introduction: Alzheimer's disease and related dementias (ADRD) are among the most feared conditions. However, research around ADRD-specific fear and avoidance behaviors is lacking. Here, we validated a novel measure of fear and avoidance specific to memory loss, the Fear and Avoidance of Memory Loss (FAM) scale, and examined associations between fear avoidance and psychosocial functioning in older adults.

Methods: We assessed FAM Scale internal reliability and concurrent validity, and candidate subscales across two samples (total $N = 813$). We then examined associations between fear avoidance and memory performance, anxiety, depressive symptoms, sleep, social functioning, and quality of life.

Results: We identified two subscales: fear and avoidance, which yielded strong psychometric validity. Higher fear was associated with memory failures and sleep disturbance. Higher avoidance was associated with memory failures, poorer verbal memory, reduced social functioning, and quality of life.

Discussion: We present the first measure of fear avoidance specific to memory loss. We propose that targeting fear avoidance can promote ADRD risk reduction and resiliency.

KEYWORDS
Alzheimer's disease, avoidance, fear, memory loss, older adults

1 | BACKGROUND

Alzheimer's disease and related dementias (ADRD) are among the most feared age-related conditions.[1,2] Although some level of fear can be an effective motivator to engage in healthy behaviors, such as exercising more, intense fears can have the opposite effect, becoming a de-motivating factor. Experiencing heightened fears about ADRD is associated with psychological stress and lower psychological well-being, physical health, and life satisfaction in middle-aged and older adults.[1,3–7] ADRD-specific fear has also been linked to worse health outcomes in older adults over an 11-year period.[1] In this way, heightened fear of ADRD can be conceptualized as a type of health anxiety,

marked by feelings of worry and dread, attentional biases, and ruminative thoughts about perceived risk.[6,8] For example, an individual who experiences a memory lapse (e.g., forgetting someone's name) might start to worry there is something wrong with their memory, causing them to focus more attention on monitoring for ADRD symptoms. Self-monitoring in this way is cognitively fatiguing, which, in turn, can lead to increased experience of memory lapses, thus strengthening the initial fear. Over time, fears can also impact behavior; this is known as the fear-avoidance framework.[9,10] For example, an individual may start to withdraw from situations that provoke fear (e.g., cognitively demanding tasks or activities) as they attempt to prevent memory lapses. Withdrawal diminishes the quality and quantity of daily activities, ultimately reducing opportunities for cognitive stimulation and social engagement,[10,11] which, in turn, may increase ADRD risk.

Despite this potential to impact health and well-being outcomes, few studies have investigated fear-avoidance models in the context of ADRD. Research to date has focused primarily on psychological characteristics of fear, such as worries and beliefs about ADRD symptoms.[12–14] In contrast, behavioral components, like cognitive avoidance or withdrawal from social activities, have been largely ignored. Understanding avoidance is particularly important for risk-reduction efforts as maintaining healthy lifestyle behaviors is known to confer protection against ADRD.[15] To address this stark knowledge gap around avoidance, we developed and piloted the Fear and Avoidance of Memory Loss (FAM) Scale, focusing on memory loss as the most common and well-known symptom associated with ADRD.[16] Using this scale, we found evidence that higher fear-avoidance scores were associated with greater self-reported memory failures and lower quality of life in a pilot sample of older adults ($N = 67$).[5]

Building on our preliminary work, the aim of the current study was to validate the FAM scale in a large, community-based sample of older adults and examine associations between fear avoidance of memory loss and indices of psychosocial functioning. Specific objectives were to (1) assess the reliability and validity of the scale and identify candidate subscales and (2) determine the relationship between fear avoidance and memory functioning (self-report and performance-based), anxiety and depressive symptoms, sleep disturbance, social engagement, and quality of life. We hypothesized that our scale would demonstrate strong reliability and validity, and that a two-factor scale structure would be identified, corresponding to fear and avoidance constructs. We further hypothesized that fear-avoidance scores would be negatively associated with memory performance, social engagement, and quality of life, and positively associated with anxiety, depression, and sleep disturbance.

RESEARCH IN CONTEXT

1. **Systematic review**: The authors reviewed the literature using traditional (e.g., PubMed) sources. While few studies have investigated fear and avoidance behaviors specific to Alzheimer's disease and related dementias, there are several publications in other chronic conditions. Relevant references are appropriately cited.
2. **Interpretation**: Our findings present the first measure of fear avoidance specific to memory loss. Higher fear of memory loss was associated with increased memory failures and sleep disturbance, while higher avoidance was associated with memory failures, poorer verbal memory recall, reduced social functioning, and quality of life.
3. **Future directions**: The article proposes a framework for the generation of new hypotheses and studies. Examples include further understanding: (a) the directional relationship between fear avoidance and psychosocial factors; (b) potential benefits of psychological interventions targeting fear avoidance (e.g., through the promotion of healthy lifestyle behaviors); and (c) identification of groups who may be particularly vulnerable to fear avoidance (e.g., family caregivers) and sensitive time windows (e.g., mid-life).

2 | METHODS

2.1 | Participants

We investigated the scale in two independent samples. The first sample comprised older adults living in the Chicago area of the United States, recruited through community-based outreach methods, digital and print advertising (e.g., flyers, postcards, e-mail outreach, web postings, and advertisements on transit lines, radio, and in newspapers), and official registries (e.g., ResearchMatch). The second sample comprised an international sample of older adults, recruited online through the Prolific Academic survey website (www.prolific.co/). Inclusion criteria for both samples were being aged ≥55 years, being able and willing to provide informed consent, being able to read and write in English, and having access to the internet for completion of study measures. Exclusion criteria were having a diagnosis of mild cognitive impairment, Alzheimer's disease (AD), or other dementia by a healthcare provider; having an unstable medical condition (characterized as hospitalization in the last 6 weeks or repeated emergency room visits); having inadequate vision or hearing to interact with study material; and having a current substance use disorder. As data were collected remotely, we obtained e-consent via REDCap[17] and Qualtrics XM. The study was approved by the institutional review boards at Northwestern University (US sample) and Trinity College Dublin, Ireland (international sample).

2.2 | Measures

All participants completed the FAM scale[18] and demographic questions. Some FAM items were reworded slightly from Farina et al.[5] to enhance clarity and simplicity; for example, "lapses in memory" for item 5 was rephrased as "memory lapses." The FAM scale comprises 23 items, with higher scores indicating higher levels of fear and

avoidance around memory loss. Preliminary psychometric analyses indicated good internal reliability (Cronbach's alpha = 0.82).[18]

Depressive symptoms were measured using the Patient-Reported Outcomes Measurement Information System (PROMIS-29; version 2) depression scale[19] in the international sample and the Geriatric Depression Scale (GDS-15)[20] in the US sample. The PROMIS-29 depression scale comprises four items, with higher scores indicating greater depressive symptoms. The scale has strong internal reliability (Cronbach's alpha = 0.80–0.93).[21] Raw scores are transformed to standardized T-score metrics, with a mean of 50 and standard deviation of 10. The GDS-15 comprises 15 items, with higher scores indicating greater depressive symptoms (Cronbach's alpha = 0.88).[22]

Participants in the international sample completed additional measures, including the Fear of Alzheimer's Disease Scale (FADS),[12] Geriatric Anxiety Inventory (GAI),[23] Memory Failures Scale (MFS),[24] Older People's Quality of Life brief questionnaire (OPQOL),[25] PROMIS-29 sleep disturbance and social functioning scales, and an online version of the Rey Auditory Verbal Learning Test (RAVLT).[26] The FADS comprises 30 items, with higher scores indicating higher levels of fear about AD (Cronbach's alpha = 0.94).[26] The GAI comprises 20 items, with higher scores indicating greater anxiety symptoms (Cronbach's alpha = 0.76).[27] The MFS comprises 12 items, with higher scores indicating greater frequency of memory failures in everyday life (Cronbach's alpha = 0.85).[24] The OPQOL comprises 35 items, with higher scores indicating greater quality of life (Cronbach's alpha = 0.75–0.88).[25]

PROMIS-29 sleep disturbance and social functioning scales comprise four items each, with higher scores indicating greater sleep disturbance (Cronbach's alpha = 0.77–0.88) and ability to participate in social activities, respectively (Cronbach's alpha = 0.90–0.96).[21] Raw scores are transformed to standardized T-score metrics, with a mean of 50 and standard deviation of 10. The online RAVLT comprises five presentations and recall attempts of a 15-word list (list A), a distractor task (list B), and post-distractor recall (list A). Memory performance was calculated as recall on learning trials of the original word list, with higher scores indicating more words recalled. Performance on the online-administered RAVLT has been shown to be equivalent to in-person administration.[26]

We also measured family history of ADRD, characterized as having a first-degree relative with a diagnosis of AD or another dementia. After e-consent, participants completed the study via REDCap or Qualtrics XM.

2.3 | Statistical analysis approach

2.3.1 | Factor analysis

All data were analyzed in R software version 4.2.1. First, we performed exploratory factor analysis (EFA) to identify candidate FAM subscales using the Multidimensional Item Response Theory (mirt) R package version 1.33.2,[28] testing one-, two-, and three-factor models. Geomin oblique rotation allowed for correlations among factors. Scree plot and parallel analysis were used to guide the number of factors extracted. Loadings ≥0.4 were required for the inclusion of an item in a designated factor. We then performed confirmatory factor analysis (CFA) in our second, independent sample, using the mirt package. We hypothesized a two-factor structure, corresponding to fear and avoidance.

2.3.2 | Reliability and validity analysis

Internal reliability of the FAM scale and subscales was assessed by computing Cronbach's alpha. Concurrent validity was assessed by correlating FAM scores with FADS, GDS, and GAI scores. We hypothesized strong internal consistency and concurrent validity for the scale and subscales.

2.3.3 | Associations between fear-avoidance, demographics, and psychosocial factors

Associations between FAM scores and age were examined using Pearson product-moment correlations. Potential differences across sex, race, education, employment status, and family history of ADRD were examined using one-way analysis of variance (ANOVA) and independent samples *t* tests where appropriate. We hypothesized that FAM scores would be positively correlated with age and that individuals with a positive family history of ADRD would be more fearful and avoidant. We hypothesized no significant or substantive differences across sex, race, education, or employment status.

Associations between FAM scores and memory performance, anxiety and depressive symptoms, sleep disturbance, social functioning, and quality of life were examined using Pearson product-moment correlations. We also examined the association between FAM scores and psychosocial functioning above and beyond the effects of demographics and potential confounding variables using hierarchical linear regression analyses. Separate models were constructed for each outcome measure. Outcome measures included memory failures, verbal memory recall, depressive symptoms, sleep disturbance, social functioning, and quality of life. Demographic information (i.e., age, sex, and family history of ADRD), anxiety, and fear of AD were included as cofounders in all models. Predictors included the FAM subscales identified during the factor analysis stage. We hypothesized that fear avoidance would be positively associated with memory failures, depressive symptoms, and sleep disturbance, and negatively associated with memory recall, social functioning, and quality of life.

3 | RESULTS

3.1 | Participant characteristics

Our US-based sample included 583 participants. Of these, 70 individuals were excluded (6 who were < 55 years and 64 who did not complete

TABLE 1 Participant characteristics ($N = 813$).

	US sample ($n = 513$)	International sample ($n = 230$)
Sex, *N* (%)		
Female	348 (68%)	122 (53%)
Male	165 (32%)	108 (47%)
Age, mean (SD; range)	66.3 (7.2; 55.1–93.4)	61.3 (5.2; 55–76.1)
Race, *N* (%)		–
White	442 (87%)	
Black or African American	45 (9%)	
Other	19 (3.7%)	
More than one race	8 (2%)	
Education level, *N* (%)		–
High school or technical degree	162 (32%)	
College or advanced degree	349 (68%)	
Employment, *N* (%)		–
Employed or student	201 (39%)	
Unemployed, retired or on disability	295 (58%)	
Multiple	3 (< 1%)	
Family history of ADRD, *N* (%)	-	
No		171 (74%)
Yes		53 (23%)
Unsure		6 (3%)
Depressive symptoms, mean (SD; range)		
Depression scale (GDS-15)	3.6 (3.5; 0–15)	-
PROMIS-29 depression	-	50.5 (9.4, 41.0–79.4)
Fear of Alzheimer's disease, mean (SD; range)	-	60.9 (19.9, 30.0–128.0)
Verbal memory recall, mean (SD; range)	–	48.9 (11.2, 10.0–72.0)
Memory failures, mean (SD; range)	–	25.9 (7.3, 12.0–49.0)
Anxiety, mean (SD; range)	–	5.9 (6.7, 0–20.0)
Sleep disturbance, mean (SD; range)	–	57.8 (9.5, 38.8–79.1)
Social functioning, mean (SD; range)	–	55.4 (8.9, 27.5–64.2)
Quality of life, mean (SD; range)	–	53.9 (7.8, 25.0–65.0)

Notes: Missing values in the US sample were reported for age ($n = 6$), race ($n = 5$), education ($n = 8$), employment ($n = 23$), and GDS-15 ($n = 39$). No missing values were reported in the international sample. "Other" race category includes American Indian/Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander individuals.

Abbreviations: ADRD, Alzheimer's disease and related dementias; GDS-15, Geriatric Depression Scale; SD, standard deviation.

the FAM scale), resulting in an analysis sample of 513 participants. Our international sample included 230 participants, none of whom were excluded from the analysis. Participants were predominantly European (74%), with some representation from North America (23%), Africa (1.7%), and Asia and South America (<1% each). Full details of participant characteristics are presented in Table 1. Both samples scored below the cutoffs for depression. For the US sample, the mean depressive symptom score was 3.6 (GDS-15 cutoff for depression ≥ 5).[20] For the international sample, the mean depressive symptom score was 50.5 (PROMIS-29 cutoff ≥ 55 for "mild" depression).[21]

3.2 | Factor analysis of the FAM scale

EFA in the US sample indicated that a three-factor solution was optimal (Table 2, left). Factor 1 comprised nine items relating to subjective feelings of fear, worry, and dread; for example, "I worry a lot about whether my memory will get worse." Factor 2 comprised nine items relating to cognitive fatigue and avoidance or restriction of activities; for example, "I have cut down on hobbies that are demanding on my brain." Factor 3 comprised two items relating to thought avoidance; for example, "I try not to think about whether my memory will get worse." Due to the

TABLE 2 Factor analysis of the FAM scale.

	3-factor model			2-factor model	
FAM item	F1	F2	F3	F1	F2
1. I worry a lot about whether my memory will get worse	0.71	0.10	0.01	0.73	0.06
2. I cannot do regular activities because it's too easy for me to forget things	0.16	0.72	−0.02	0.11	0.74
3. I am afraid that I might embarrass myself by forgetting something	0.51	0.37	−0.06	0.50	0.36
4. I try not to exert my brain too much as it might make my memory worse	−0.10	0.90	0.13	−0.15	0.93
5. Memory lapses tell me I should place fewer demands on my memory	−0.04	0.73	0.15	−0.07	0.75
6. I cannot be as social anymore because I forget things too easily	0.16	0.82	0.02	0.10	0.85
7. I hope people do not find out about my memory problems	0.39	0.47	−0.06	0.38	0.47
8. I try new things even though my memory might cause problems	−0.33	0.20	−0.09	−0.37	0.23
9. Memory problems tell me there is something seriously wrong	0.45	0.49	−0.04	0.43	0.49
10. I try not to think about whether I will lose my memory	−0.02	0.05	0.74	0.03	0.03
11. There is nothing I can do to improve my memory	0.01	0.45	0.16	−0.01	0.46
12. I try not to think about whether my memory will get worse	0.01	0.04	0.83	0.06	0.03
13. I am afraid that if my memory gets worse, my family, friends, or colleagues will treat me differently	0.68	−0.03	0.19	0.72	−0.06
14. It is not normal for me to forget simple everyday things	0.12	−0.25	0.29	0.16	−0.27
15. I think a lot about how memory loss will affect me	0.76	0.07	−0.04	0.79	0.03
16. I have cut down on hobbies that are demanding on my brain	0.14	0.75	0.01	0.09	0.78
17. I feel overwhelmed when I forget things	0.51	0.35	0.03	0.51	0.33
18. Whenever I forget something, I am afraid my memory is getting worse	0.70	0.15	0.04	0.72	0.12
19. My memory would be better if I engaged in more brain exercises	−0.18	0.15	−0.04	−0.20	0.17
20. I would still like to achieve things, but my memory limits me	0.41	0.51	0.00	0.38	0.51
21. I worry that something is seriously wrong with my memory	0.65	0.30	−0.11	0.65	0.28
22. I dread the day when I forget something important to me	0.76	−0.04	0.19	0.81	−0.08
23. If my memory gets worse, I will no longer be me	0.70	−0.06	0.20	0.71	−0.03

Note: Items 8, 10, 12, 14, and 19 were excluded from further analysis. Factor 1 ("Fear") = items 1, 3, 13, 15, 17, 18, 21, 22, and 23. Factor 2 ("Avoidance") = items 2, 4, 5, 6, 7, 9, 11, 16, and 20.
Abbreviation: FAM, Fear and Avoidance of Memory Loss.

small number of items associated with Factor 3, we decided to remove this factor from the scale for simplicity. We also removed three items whose factor loadings were below the cutoff (items 8, 14, and 19). This resulted in a final 18-item FAM scale with two factors: Fear (Factor 1) and Avoidance (Factor 2). Factor loadings from the two-factor model are shown in Table 2, right. The stability of this factor structure was supported by CFA in our second, independent sample of older adults. All factor loadings exceeded the 0.4 threshold for retention within this two-factor model (Table S1 in supporting information).

3.3 | Reliability and validity of FAM subscales

Cronbach's alpha indicated strong internal consistency reliability of both fear and avoidance subscales in the US sample (alphas = 0.8) and international sample (0.9 and 0.8, respectively). Fear and avoidance scores were significantly correlated with FADS scores ($rs > 0.4$, $Ps < 0.001$), GAI scores ($rs > 0.4$, $Ps < 0.001$), and depressive symptom scores ($r = 0.5$ and $r = 0.6$, $Ps < 0.001$), indicating good concurrent validity.

3.4 | Associations between fear-avoidance, demographics, and psychosocial factors

Minimum and maximum scores possible on the FAM subscales are 9 and 45, respectively. In the US sample, mean scores for fear and avoidance were 27.2 (± 8.1) and 17.6 (± 6.5), respectively. In the international sample, fear and avoidance mean scores were 24.6 (± 7.1) and 17.3 (± 4.6), respectively. In the US sample, age was moderately negatively associated with fear and avoidance (see Table 3); however, this association was non-significant in the international sample. A small sex-based difference in fear scores was found in the US sample, with females being more fearful. No difference was found in the international sample. Avoidance scores were higher for US-based participants with fewer years of education (high school vs. advanced degree), though the effect size was small.

In the international sample, participants with a family history of ADRD reported higher fear and avoidance scores compared to those without. Fear and avoidance were positively correlated with all psychosocial measures, memory failures, and quality of life (Table 3). Avoidance was also negatively correlated with verbal memory recall.

TABLE 3 Associations between fear-avoidance, demographics, and psychosocial factors.

	US sample ($n = 513$)		International sample ($n = 230$)	
	Fear	Avoidance	Fear	Avoidance
Age	−0.3***	−0.2***	−0.1	0.1
Sex, female	0.2*	0.1	0.3	0.1
Race	<0.1	<0.1	–	–
Education	<0.1	<0.1**	–	–
Employment	<0.1	0.1	–	–
Family history of ADRD	–	–	0.4***	0.2*
Depressive symptoms			0.4***	0.3***
Fear of Alzheimer's disease	–	–	0.7***	0.4***
Verbal memory recall	–	–	0.1	−0.2**
Memory failures	–	–	0.6***	0.5***
Anxiety	–	–	0.5***	0.4***
Sleep disturbance	–	–	0.4***	0.3***
Social functioning	–	–	−0.3***	−0.2**
Quality of life			−0.3***	−0.4***

Note: Values for continuous measures represent *R* values and for categorical measures represent Cohen's *d*.
*$P < 0.05$;
**$P < 0.02$;
***$P < 0.001$
Abbreviation: ADRD, Alzheimer's disease and related dementias.

TABLE 4 Hierarchical regression models for fear and avoidance subscales

	Standardized coefficients					
	Age	Sex (male)	Fx (yes)	GAI	FADS	Factor 1 (fear)
Memory failures	−0.03	0.04	0.03	0.19**	0.01	0.47***
Depressive symptoms	−0.10*	0.04	−0.06	0.58***	0.15*	0.00
Sleep disturbance	−0.02	−0.02	−0.12	0.41***	0.02	0.18*
Social functioning	0.06	−0.03	0.04	−0.33***	0.03	−0.14
Verbal memory recall	−0.00	−0.28***	−0.08	−0.03	0.20*	−0.15
Quality of life	0.13*	−0.08	0.05	−0.39***	−0.04	−0.13
	Age	Sex (male)	Fx (yes)	GAI	FADS	Factor 2 (avoidance)
Memory failures	−0.03	−0.00	0.04	0.20**	0.21**	0.32***
Depressive symptoms	−0.10	0.03	−0.06	0.56***	0.12*	0.08
Sleep disturbance	−0.03	−0.03	−0.11	0.43***	0.11	0.07
Social functioning	0.05	0.02	0.05	−0.28***	−0.03	−0.29***
Verbal memory recall	−0.01	−0.24***	−0.08	0.01	0.18*	−0.24**
Quality of life	0.12*	−0.04	0.06	−0.36***	−0.05	−0.23***

Abbreviations: FADS = fear of Alzheimer's Disease scale; Fx, family history of Alzheimer's disease and related dementias; GAI, Geriatric Anxiety Index.
*$P < 0.05$;
**$P < 0.02$;
***$P < 0.001$

After adjusting for potential confounders (i.e., age, sex, family history of ADRD, anxiety, and fear of AD), fear scores significantly predicted self-reported memory failures and sleep disturbance (Table 4). The association was positive, such that as fear scores increased, so too did the frequency of memory failures and sleep disturbance. Avoidance scores also predicted self-reported memory failures, as well as social functioning, verbal memory recall, and quality of life. As avoidance scores increased, so too did the frequency of memory failures, while

social functioning, verbal memory recall, and quality of life decreased. Finally, avoidance scores were associated with reduced cognitive performance on the Montreal Cognitive Assessment (MoCA) in a subset of US-based participants ($N = 109$; Table S2 in supporting information).

4 | DISCUSSION

The aim of this study was to validate a novel measure of fear and avoidance specific to memory loss, the FAM scale, in community-based older adults and examine associations between fear avoidance of memory loss and indices of psychosocial functioning. We had two specific objectives. First, we aimed to determine reliability and validity of the FAM scale and identify candidate subscales. Across two samples of community-dwelling older adults ($N = 813$), we validated the 18-item FAM scale and identified two subscales, corresponding to fear and avoidance factors. We propose that that the fear subscale captures individuals' heightened attention toward memory lapses, while the avoidance subscale captures the impact of avoidant coping strategies on individuals' daily lives. Both subscales yielded strong internal reliability and concurrent validity across US and international samples, indicating suitability for use in community-based English-speaking older adult populations.

Previous studies have primarily focused on psychological characteristics of fear, such as worries and beliefs.[12–14] The current study extends this literature and provides an important contribution by presenting the first measure encompassing both psychological and behavioral components, that is, withdrawal from cognitive and social activities. Identification of separate fear and avoidance factors is consistent with our pilot validation.[5] Although the pilot study indicated a smaller, third factor, the two-factor solution identified here likely reflects a more stable, reliable structure, owing to the substantially larger sample size.[29] Items previously interpreted as "problematic beliefs" (e.g., "I would still like to achieve things, but my memory limits me"), were subsumed under the avoidance subscale in the current study. This supports the idea that negative beliefs about one's memory hinder motivation to participate in valued activities and may lead to disengagement and a sense of hopelessness.[30–32]

Our second objective was to determine the relationship between fear avoidance and memory function (self-report and performance-based), anxiety and depressive symptoms, sleep disturbance, social engagement, and quality of life. As hypothesized, we found significant associations with all variables. Follow-up regression analyses showed that fear scores were associated with increased memory failures and sleep disturbance, after adjusting for potential confounders (i.e., demographics, family history of ADRD, anxiety, and fear of AD). Avoidance scores were associated with increased memory failures, and decreased verbal memory recall, social functioning, and quality of life. Notably, these associations remained significant after adjusting for fears associated with AD. Thus, we suggest that our fear and avoidance scales represent a more-fine grained measure, which incorporates both psychological and behavior components of fear specific to the symptom of memory loss.

Growing evidence indicates that engaging in cognitively, socially, and physically stimulating activities confers neuroprotective effects against ADRD.[15] Though cross-sectional, our results raise the question of whether heightened levels of fear and avoidance could be a barrier to these risk-reducing activities. Longitudinal studies are required to test this theory directly. Here, we found that fear scores were more closely related to individuals' beliefs about their memory abilities and disturbance in sleep, perhaps reflecting ruminative tendencies. On the other hand, avoidance scores were more closely related to both perceived and actual memory ability, which could reflect a tendency to withdraw or disengage; for example, participants who endorsed more avoidance statements in Study 2 may have been more likely to disengage from the memory recall task earlier. Avoidance scores were also linked to reduced social engagement and quality of life, which could indicate the negative impact of avoidant coping behaviors.

Findings from the current study are consistent with the conceptualization of ADRD-specific fear and avoidance as a type of health anxiety.[6,8] Specifically, we propose that individuals who are more fearful may be more likely to self-monitor and misinterpret everyday memory lapses as early signs of ADRD, leading to a heightened experience of cognitive effort and failures, which strengthens their initial fear. Over time, these experiences can cause people to restrict their activities as they attempt to prevent future memory lapses, resulting in functional limitations. Withdrawal hampers individuals' ability to stay physically, cognitively, and socially engaged, thereby potentially increasing exposure to risk factors such as social isolation. As mentioned above, longitudinal studies are needed to determine causality and to account for possible reverse causality. However, it should be noted that the emotional processes highlighted here likely = interact with lifestyle risk factors recursively over time such that they mutually reinforce each other, making direct causality difficult to determine.

Regardless of the original direction of effect, the nature of fear-avoidance cycles implies that selectively targeting ADRD-specific fear and avoidance could accrue downstream improvements for health and well-being.[33] This is supported by evidence showing that addressing health anxiety about ADRD, particularly in individuals dismissed as the "worried well," can improve well-being and mitigate chronic stress, thereby reducing allostatic load.[15,31] Fear and avoidance can be allayed using a variety of well-established cognitive and behavioral therapies.[34–36] Addressing fear and avoidance may also lead to sustained or improved access to health-promoting resources and activities, which can limit the deterioration of cognitive function and risk of social withdrawal.[15,37] Further, for individuals who are experiencing measurable changes in cognitive functioning, managing fear and avoidance could encourage help-seeking behaviors, resulting in earlier access to treatment and supports.

Individuals with a family history of ADRD reported significantly higher fear and avoidance compared to those without a family history of ADRD in this study. The group difference was stronger for fear than for avoidance. This is consistent with some previous studies demonstrating higher levels of fear in adults with a positive family history[1,3] or family carers,[2] but not with others.[5,7] Varying results could be explained by differences in how family history was assessed;

specifically, Roberts and Maxfield reported any exposure to ADRD (e.g., sister-in-law) as opposed to genetically related family members.[7] Evidence for age and sex differences was mixed. In our larger, US-based sample, we found small but significant associations between fear avoidance and age; however, associations with age were non-significant in our international sample. This could be explained by the greater age range of the US sample (i.e., 55–93 years vs. 55–76 years). Fear scores were significantly higher in females compared to males in the US sample. While the difference failed to reach significance in the international sample, we observed the same trend; that is, higher fear scores in females than males. Avoidance scores were higher for participants with lower levels of education (i.e., high school only). Though speculative, this could be related to health literacy. Specifically, lower educational attainment is associated with limited health literacy—defined as the ability to find, access, and use health-related information—which, in turn, is associated with greater avoidance (e.g., of health-related information, behaviors, and services).[38,39] Further research is needed to directly test this theory.

ADRD are among the most feared conditions associated with aging. The current study contributes to the limited literature on ADRD-specific fear and avoidance through the introduction of a novel, open access tool to measure fear and avoidance specific to memory loss: the FAM scale (available at: https://doi.org/10.17605/OSF.IO/E9PWC). We also provide evidence for associations of fear and avoidance with psychosocial factors in community-dwelling older adults.

Strengths of our study include the large overall sample size and range of factors investigated. The main limitation is the cross-sectional nature of the study. Other limitations include the use of different depression scales, which limits direct comparison across samples; use of online data collection methods, which may have biased the sample (e.g., toward people with higher digital literacy); and the length of the survey, which may have led to lower levels of engagement. Future research should include longitudinal investigations of the relationship between fear avoidance and psychosocial functioning, as well as potential changes in fear and avoidance over time. Future research could also explore the inter-relationships between ADRD-specific fear and avoidance with modifiable and non-modifiable risk factors, including genetic and neuroimaging markers. Finally, future research could focus on fear and avoidance in specific subpopulations who may be more vulnerable (e.g., family caregivers of people who are living with an ADRD diagnosis[15]) and across different life stages (e.g., mid-life vs. later life). Continued research into fear avoidance will help to determine for whom, and at what stage, addressing fear and avoidance can be most beneficial in reducing ADRD risk and promoting resiliency.

ACKNOWLEDGMENTS

The authors thank the participants for contributing their time to this study. Research reported in this publication was supported, in part, by the National Institutes of Health's National Center for Advancing Translational Sciences (grant number UL1TR001422), the Osher Center for Integrative Medicine (Pilot grant scheme), and the Irish Research Council (Civic Engagement Fund). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts. Author disclosures are available in the supporting information.

CONSENT STATEMENT

All human subjects provided informed consent.

REFERENCES

1. Cutler SJ. Worries about getting Alzheimer's: who's concerned. *Am J Alzheimers Dis Other Demen*. 2015;30(6):591-598.
2. Tang W, Kannaley K, Friedman DB, et al. Concern about developing Alzheimer's disease or dementia and intention to be screened: an analysis of national survey data. *Arch Gerontol Geriatr*. 2017;71:43-49.
3. Cutler SJ, Brăgaru C. Do worries about cognitive functioning and concerns about developing Alzheimer's disease affect psychological well-being. *J Aging Health*. 2016;29(8):1271-1287.
4. Cutler SJ, Hodgson LG. Is health affected by dementia worries and concerns about cognitive functioning. *Revista de Asistenta Sociala*. 2014(3):7.
5. Farina FR, Bennett M, Griffith JW, Lenaert B. Fear of memory loss predicts increased memory failures and lower quality of life in older adults: preliminary findings from a fear-avoidance of memory loss (FAM) scale. *Aging Ment Health*. 2022;26(3):486-492.
6. Kinzer A, Suhr JA. Dementia worry and its relationship to dementia exposure, psychological factors, and subjective memory concerns. *Appl Neuropsychol Adult*. 2016;23(3):196-204.
7. Roberts JR, Maxfield M. Examining the relationship between religious and spiritual motivation and worry about Alzheimer's disease in later life. *J Relig Health*. 2018;57(6):2500-2514.
8. Kessler E-M, Bowen CE, Baer M, Froelich L, Wahl H-W. Dementia worry: a psychological examination of an unexplored phenomenon. *Eur J Ageing*. 2012;9(4):275-284.
9. Lynch C. World Alzheimer Report 2019: attitudes to dementia, a global survey: public health: engaging people in ADRD research. *Alzheimers Dement*. 2020;16:e038255.
10. Vlaeyen JWS, Crombez G, Linton SJ. The fear-avoidance model of pain. *Pain*. 2016;157(8):1588-1589.
11. Hofmann SG, Hay AC. Rethinking avoidance: toward a balanced approach to avoidance in treating anxiety disorders. *J Anxiety Disord*. 2018;55:14-21.
12. French SL, Floyd M, Wilkins S, Osato S. The fear of Alzheimer's disease scale: a new measure designed to assess anticipatory dementia in older adults. *Int J Geriatr Psychiatry*. 2012;27(5):521-528.
13. Page KS, Hayslip B, Wadsworth D, Allen PA. Development of a multidimensional measure to examine fear of dementia. *Int J Aging Hum Dev*. 2019;89(2):187-205.
14. Suhr J, Isgrigg A. Development and initial validation of an Alzheimer's disease worry scale. In Annual meeting of the International Neuropsychological Society, Boston, MA. 2011.
15. Fratiglioni L, Marseglia A, Dekhtyar S. Ageing without dementia: can stimulating psychosocial and lifestyle experiences make a difference. *Lancet Neurol*. 2020;19(6):533-543.
16. Burns A, Iliffe S. Dementia. *BMJ*. 2009;338(7691):b75.
17. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377-381.
18. Farina FR, Bennett M, Griffith JW, Lenaert B. Fear of memory loss predicts increased memory failures and lower quality of life in older

adults: preliminary findings from a fear-avoidance of memory loss (FAM) scale. *Aging Ment Health*. 2022;26(3):486-492.
19. Cella D, Riley W, Stone A, et al. The patient-reported outcomes measurement information system (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. *J Clin Epidemiol*. 2010;63(11):1179-1194.
20. Yesavage JA. Geriatric depression scale. *Psychopharmacol Bull*. 1988;24(4):709-711.
21. Hays RD, Spritzer KL, Schalet BD, Cella D. PROMIS®-29 v2. 0 profile physical and mental health summary scores. *Qual Life Res*. 2018;27:1885-1891.
22. JUNG I-K, Kwak DI, Shin DK, et al. A reliability and validity study of geriatric depression scale. *J Korean Neuropsychiatr Assoc*. 1997:103-112.
23. Pachana NA, Byrne GJ, Siddle H, Koloski N, Harley E, Arnold E. Development and validation of the geriatric anxiety inventory. *Int Psychogeriatr*. 2007;19(1):103-114.
24. Carriere JSA, Cheyne JA, Smilek D. Everyday attention lapses and memory failures: the affective consequences of mindlessness. *Conscious Cogn*. 2008;17(3):835-847.
25. Bowling A, Hankins M, Windle G, Bilotta C, Grant R. A short measure of quality of life in older age: the performance of the brief older people's quality of life questionnaire (OPQOL-brief). *Arch Gerontol Geriatr*. 2013;56(1):181-187.
26. Morrison RL, Pei H, Novak G, et al. A computerized, self-administered test of verbal episodic memory in elderly patients with mild cognitive impairment and healthy participants: a randomized, crossover, validation study. *Alzheimer's Dement: Diagn Assess Dis Monitoring*. 2018;10:647-656.
27. Pachana NA, Woodward RM, Byrne GJ. Treatment of specific phobia in older adults. *Clin Interv Aging*. 2007;2(3):469-476.
28. Chalmers RP. mirt: a multidimensional item response theory package for the R environment. *J Stat Softw*. 2012;48:1-29.
29. Lingard HC, Rowlinson S. *Sample size in factor analysis: why size matters*. Hong Kong: University of Hong Kong; 2006.
30. Akyol MA, Zehirlioğlu L, Erünal M, et al. Determining middle-aged and older adults' health beliefs to change lifestyle and health behavior for dementia risk reduction. *Am J Alzheimers Dis Other Demen*. 2020;35:1533317519898996.
31. Cutler SJ, Brăgaru C. Long-term and short-term predictors of worries about getting Alzheimer's disease. *Eur J Ageing*. 2015;12(4):341-351.
32. Sutin AR, Stephan Y, Terracciano A. Psychological distress, self-beliefs, and risk of cognitive impairment and dementia. *Am J Alzheimer's Dis*. 2018;65(3):1041-1050.
33. O'loughlin P, Pavithra P, Regan J, et al. A randomized controlled trial investigating the feasibility of a low-intensity psychological intervention for fear of memory loss and quality of life in older adults: protocol for the reducing fear and avoidance of memory loss (REFRAME) study. *JMIR Res Protoc*. 2021;10(7):e30514.
34. Lenze EJ, Hickman S, Hershey T, et al. Mindfulness-based stress reduction for older adults with worry symptoms and co-occurring cognitive dysfunction. *Int J Geriatr Psychiatry*. 2014;29(10):991-1000.
35. Liu T-Wa, Ng GYF, Chung RCK, Ng SSM. Cognitive behavioural therapy for fear of falling and balance among older people: a systematic review and meta-analysis. *Age Ageing*. 2018;47(4):520-527.
36. Kaczkurkin AN, Foa EB. Cognitive-behavioral therapy for anxiety disorders: an update on the empirical evidence. *Dialogues Clin Neurosci*. 2022:337-346. https://www.tandfonline.com/doi/citedby/10.31887/DCNS.2015.17.3/akaczkurkin?scroll=top&needAccess=true&role=tab
37. Gow AJ. Opportunities for enhancing brain health across the lifespan. *BJPsych Advances*. 2021;28(2):1-10.
38. Geboers B, Reijneveld SA, Jansen CJM, De Winter AF. Health literacy is associated with health behaviors and social factors among older adults: results from the LifeLines Cohort Study. *J Health Commun*. 2016;21(2):45-53.
39. Orom H, Schofield E, Kiviniemi MT, et al. Low health literacy and health information avoidance but not satisficing help explain "don't know" responses to questions assessing perceived risk. *Med Decis Making*. 2018;38(8):1006-1017.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Farina FR, Pavithra P, An H, et al. Validation of the Fear and Avoidance of Memory Loss scale in community-based older adults. *Alzheimer's Dement*. 2023;15:e12432. https://doi.org/10.1002/dad2.12432