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RESEARCH ARTICLE

# The Dementia Literacy Assessment (DeLA): A novel measure of Alzheimer's disease and related disorders health literacy in diverse populations

James E. Galvin[1] | Deborah M. Germain[1] | Claudia P. Moore[1] | Jennifer A. Jeanty[1] | Vaatausili Tofaeono[2] | Lisa K. Wiese[3]

[1]Department of Neurology, Comprehensive Center for Brain Health, Miller School of Medicine, University of Miami, Boca Raton, Florida, USA

[2]American Samoa Community Cancer Coalition, Pago, American Samoa, USA

[3]Christine E. Lynn College of Nursing, Florida Atlantic University, Boca Raton, Florida, USA

**Correspondence**: James E. Galvin, Department of Neurology, Comprehensive Center for Brain Health, Miller School of Medicine, University of Miami, 7700 W Camino Real, Suite 200, Boca Raton, FL 33433, USA.
Email: jeg200@miami.edu

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## Abstract

**INTRODUCTION:** Low health literacy about Alzheimer's disease and related disorders (ADRD) may limit help-seeking, early detection, and enrollment in clinical trials, particularly in minoritized communities. We created the Dementia Literacy Assessment (DeLA) to improve ADRD health literacy.

**METHODS:** The DeLA, a storytelling method that included culturally adaptable vignettes embedded with important factoids about ADRD, was administered to 213 participants from urban and rural regions of Palm Beach and Broward County in Florida and 193 participants in American Samoa.

**RESULTS:** The DeLA increased dementia health literacy and performed well across different participant characteristics (age, sex, education, geographic locale, race, ethnicity, and cognitive performance). Gains in ADRD health literacy were associated with older age, more education, better socioeconomic status, greater resilience, and better cognitive performance.

**DISCUSSION:** Increasing ADRD health literacy could increase health-seeking behaviors in diverse populations for treatment, enrich recruitment into clinical trials, and may help reduce disparities in health outcomes.

KEYWORDS
Alzheimer's disease, dementia, health disparities, health literacy, vascular cognitive impairment

## Highlights

- Low health literacy about Alzheimer's disease and related disorders (ADRD) may limit help-seeking, early detection, and enrollment in clinical trials, particularly in minoritized communities.
- The Dementia Literacy Assessment (DeLA), a storytelling method that included culturally adaptable vignettes embedded with important factoids about ADRD, was

administered to 406 participants from urban and rural regions of Palm Beach and Broward County in Florida and American Samoa (11.8% White, 39.8% Black or African American, and 48.4% Pacific Islander [predominantly Samoan] individuals).
- The DeLA increased dementia health literacy and performed well across different participant characteristics (age, sex, education, geographic locale, race, and cognitive performance).
- Gains in ADRD health literacy were associated with older age, more education, better socioeconomic status, greater resilience, and better cognitive performance.
- Increasing ADRD health literacy could increase health-seeking behaviors in diverse populations for treatment, enrich recruitment into clinical trials, and help reduce disparities in health outcomes.

## 1 | BACKGROUND

Alzheimer's disease and related dementias (ADRD) affect nearly 7 million people in the United States and more than 55 million people worldwide.[1] Over the next 20 years, the number of people over 65 and 85 years old is expected to grow by 62% and 84%, respectively.[2] The older adult population in the United States is also becoming more diverse. By 2050, the proportion of older American adults from minoritized populations will increase to 39% with approximately 14 million Hispanic adults, 8.6 million African American adults, and 5.8 million adults from other ethnoracial groups.[3] African American and Hispanic individuals are estimated to have a 1.5–2 times increased risk[1,4]; two-thirds of persons living with ADRD are women[1]; and rural populations have a 1- to 2-fold increased risk.[5] Individuals with lower education and less economic resources (e.g., low socioeconomic status, rural populations) have poorer health outcomes.[1,4,5] Very little is known about ADRD in indigenous populations, including Pacific Islanders.[6]

Detection of the early stages of ADRD and its prodrome, mild cognitive impairment (MCI), is a clinical challenge,[1,4] with many people seeking medical attention and diagnosis at the moderate stage, particularly older adults from minoritized or underserved populations.[7] Early detection could inform people to start lifestyle changes that may slow cognitive decline, pursue appropriate current treatment protocols, and/or increase the pipeline of individuals willing to enroll in AD clinical trials.[8]

The ability of any audience to determine the value and credibility of health information depends on their educational and socioeconomic background.[9,10] Unfortunately, individuals from minoritized or underserved communities often have less years of education and, by association, lower health literacy,[11–13] which is a barrier to understanding the importance of early disease detection.[14]

Health literacy itself is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[15] Healthy People 2030 expanded the definition of health literacy to include an emphasis on the ability to use health information rather than just understand it and make "well-informed" decisions rather than "appropriate" ones.[16] Inadequate health literacy often goes unrecognized and increases perceived stigma associated with disease.[16–18] People with low health literacy are 1.5- to 3-times more likely to experience adverse health outcomes than their health-literate counterparts.[14] Such outcomes include less use of preventive services,[18] less adherence to medication regimens,[19] greater risk of hospitalization,[20] higher healthcare costs,[21] and worse overall health.[22] Low health literacy may also limit participation in ADRD research. Obstacles to ADRD health literacy may be related to knowledge deficits regarding ADRD risk and symptoms, mistrust of researchers and health systems, and a lack of culturally relevant information.[13]

Our research team has conducted a suite of studies on health literacy, health beliefs, and dementia screening in older adults from diverse backgrounds.[8,23–26] We found that "how" we communicate is as important as "what" we communicate. Attempts to define ADRD health literacy[27] have generally been done in small samples through tests of knowledge or reading lists of words or labels,[27,28] with few studies including minoritized older adults.[11–13] An ADRD diagnosis can be highly stigmatizing, often due to fear of the unknown and poor understanding and awareness of the disease, delayed help-seeking, and limited research participation.[7] Improving health literacy could reduce the knowledge gap by helping people understand health vocabulary and concepts. Concerns about mistrust, or anticipation of loss of autonomy associated with dementia, coupled with a lack of ADRD health literacy could lead to delayed or missed diagnoses, and poor management of the disease. Better understanding can lead to better risk appraisals, which in turn may help older adults, particularly from disadvantaged groups such as ethnoracial minorities, rural populations, and low-income groups, access, and process information to maximize their engagement with the healthcare system as well as increase willingness to participate in research programs. To address this unmet need, we created and validated the Dementia Literacy Assessment (DeLA) as a storytelling-based method of measuring and improving ADRD health literacy.

## 2 | METHODS

### 2.1 | Study design and participants

Participants were recruited as part of two National Institutes of Health (NIH) studies: R01NS101483 to examine ADRD risk factors in urban and rural populations in South Florida, and RF1AG075904 to study the prevalence of ADRD in American Samoa. Both studies had common inclusion and exclusion criteria to permit representative recruitment from the community. Inclusion criteria were age 50+ years, English (US) or Samoan (American Samoa) speaking and community-dwelling. Exclusion criteria included cancer in the past 5 years, unstable medical conditions that would preclude participation, and an active Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) Axis I or Axis II diagnosis. Prior to any study procedures, informed consent was obtained from all study participants in American Samoa. The protocol was reviewed and approved by the Western Copernicus Group (WCG), a central institutional review board (Reference Number 20222217). The University of Miami institutional review board deemed this project exempt, and consent was waived for participants in Florida (Reference Number 20200279).

### 2.2 | Development of DeLA

The DeLA is a storytelling-based assessment of ADRD health literacy. Two stories are read independently by the participants. The vignettes were first designed by one of the co-creators (J.E.G.) based on 25 years of clinical experience, interviews, and stories from older adults and their caregivers, and then reviewed by the other co-creator (L.K.W.). The vignettes were then shared with community stakeholders which included a nurse from an ADRD community organization, staff members from health and social services organizations, and 12 community members (3 retired manual laborers, 2 retired teachers, 2 active nurses' aides, a retired registered nurse [RN], an active social worker, a nun, a grocery store clerk, and a police officer). All reviewers reported feeling the same type of frustration and helplessness dealing with family members or members of their community. The reviewers also helped revise, clarify, and simplify the pre- and post-test questions. In American Samoa, we translated the DeLA into Samoan and an independent party with a background in translation services created a consensus translation. A translation matrix was created for back translation to test contextual meaning and administered to five Samoan adults. Cognitive interviews were conducted with 20 Samoan-speaking older adults to ensure equivalence and cultural appropriateness. Cultural adaptation required changing names (e.g., "Tinamatua" for "Grandma") and items ("tea" for "coffee"). A pilot test was conducted with an additional 20 Samoan adults to inform feasibility, cultural appropriateness, and the need to make any design modifications. Participants were able to complete the DeLA without any further recommendations.

The first vignette (Grandma's Story) is told from the perspective of a loving granddaughter describing the changes she noted in her grandmother who was eventually diagnosed with Alzheimer's disease. The second vignette (Hank's Story) is told from the perspective of a recent widow regarding the challenges she faced recognizing the onset, progression, and eventual loss of her husband to vascular dementia. The stories are embedded with 25 factoids about ADRD presented at the 5th- to 6th-grade reading level (Table 1) and can be easily culturally adapted to names and relevant social situations. Pre- and post-tests contain 12 identical questions covering all 25 factoids. After completion of the post-test, participants are presented with an ADRD fact sheet discussing general knowledge, warning signs and symptoms, risk factors, and preventive behaviors that are contained within the story

**RESEARCH IN CONTEXT**

1. **Systematic review**: Low health literacy about Alzheimer's disease and related disorders (ADRD) may limit help-seeking, early detection, and enrollment in clinical trials, particularly in minoritized communities. The Dementia Literacy Assessment (DeLA) is a culturally adaptable storytelling-based measure of ADRD health literacy. Two vignettes were designed based on interviews and stories collected from the target population. Pre- and post-tests were reviewed by independent experts and community stakeholders.
2. **Interpretation**: The DeLA improved ADRD health literacy in diverse populations including African Americans in rural and urban settings and Pacific Islanders.
3. **Future directions**: With an increasing number of ADRD treatment and prevention trials, it is critical to raise awareness of ADRD across diverse communities. The DeLA can increase ADRD health literacy using culturally resonant storytelling. The DeLA may help clinicians and researchers better understand the role health literacy plays in health decision-making, including treatment choices and research participation.

**TABLE 1** Readability statistics of DeLA stories.

| Readability statistics | Grandma's story | Hank's story |
|---|---|---|
| Flesch Reading Ease score | 80.1 | 80.7 |
| Gunning Fog | 8.5 | 8.0 |
| Flesch–Kincaid Grade Level | 6.2 | 5.5 |
| The Coleman–Liau Index | 7.0 | 7.0 |
| The SMOG Index | 5.3 | 5.9 |
| Automated Readability Index | 6.4 | 5.2 |
| Linsear Write Formula | 8.1 | 7.0 |
| Consensus Grade Level | 5–6 | 5–6 |
| Reading Level | Easy to read | Easy to read |
| Reader's age | 10–11 years old | 10–11 years old |

and 25 factoids. Tailored information sharing can be completed based on the respondent's baseline knowledge and gain in ADRD health literacy. The complete DeLA package is provided in Supporting Information S1 and includes the two vignettes with marked sections for cultural adaptation, the pre/posttests, the answer key, the 25 factoids, and two resource/informational sheets to be used to facilitate discussion following completion of the DeLA

## 2.3 | Data collection

Participants were recruited through community announcements, referrals, and word-of-mouth recommendations into NIH-funded community dementia screening programs (R01NS101483 in South Florida, RF1AG075904 in American Samoa). The DeLA was incorporated into the screening visit occurring after informed consent and demographic data collection and before the other components of the screening visit. All participants received both vignettes. They were first administered the pre-test, then read the vignettes, and were immediately administered the post-test. They were then provided with the 25 factoids and additional tailored information. Demographic data including age, sex, race and ethnicity, education, geographic locale (e.g., rural, urban), occupational attainment, family, and medical history were collected. Socioeconomic status (SES) was calculated using the Hollingshead index of social status which combines the highest educational and occupational attainment of the household to develop an index from 11 (highest SES) to 77 (lowest SES).[25] Medical risk factors of vascular disease were assessed using the modified (mCAIDE)[29] with a range of scores from 0 to 14 (lower scores are better). Frailty was assessed using the Fried Frailty Score[30] with a range of scores from 0 to 5 (lower scores are better). Cognitive resilience was assessed using the Resilience Index (RI),[31] a summed total of six factors: Cognitive Reserve, Physical Activity, Cognitive Activity, Mindfulness, Diet, and Social Engagement with a range of scores from 0 to 378 (higher scores are better). Dementia risk factors were assessed using the Vulnerability Index (VI)[32] using a weighted score of age, biological sex, race and ethnicity, education, frailty, obesity, depression, and comorbid vascular medical conditions (diabetes, stroke, heart disease, hypertension, and hypercholesterolemia) with a range of scores from 2 to 20 (lower scores are better).

## 2.4 | Quick Dementia Rating System

The Quick Dementia Rating System (QDRS)[33] is a patient-reported outcome capturing subjective performance across 10 domains with a global score ranging from 0 to 30 (lower scores are better) and is highly correlated with the Clinical Dementia Rating (CDR).[34] The QDRS can be used to estimate the CDR Sum of Boxes (CDR-SB). QDRS scores greater than 1.5 are associated with cognitive impairment and biomarker abnormalities. Here, the QDRS is used to differentiate no subjective impairment versus subjective impairment.

## 2.5 | Cognivue clarity

Cognivue Clarity® (https://cognivue.com/videos/) is a 10-min, United States Food and Drug Adminiatration (FDA)-cleared, computerized cognitive battery that provides a global score ranging from 0 to 100 (higher scores are better). Cognivue *Clarity* scores have been cross-validated against the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) with age-normed scores from 18 to 85 years, and ethnoracial and education normative data.[35] Score interpretations are presented as no cognitive impairment or probable cognitive impairment.

## 2.6 | Statistical analyses

Statistical analyses were conducted using IBM SPSS v29 (Armonk, NY). Descriptive statistics were used to summarize overall sample characteristics. Student *t*-tests or one-way analysis of variance (ANOVA) with Tukey–Kramer post-hoc tests were used for continuous data, and chi-squared analyses were used for categorical data. Gains in dementia health literacy are captured with pre- and post-tests. In addition to absolute gains, we examined the percent change in DeLA scores calculated as ((Post-test score—Pre-test score)/Pre-test score) × 100 to represent net positive gains in dementia health literacy.

Given the discreet ordinal values of the DeLA with a limited range (0–12), non-parametric tests were used. Related-samples Wilcoxon signed rank test was used to compare differences in pre- and post-test performance on the overall DeLA score and changes in responses by individual DeLA questions. Stratified analyses were conducted to study subgroup differences in DeLA performance and gains in ADRD health literacy using Mann-Whitney U or Kruskal-Wallis tests. Kendall's Tau-b coefficients were used to assess the strength of association between DeLA pre- and post-test scores and % gain with sociodemographic variables and scores on rating scales.

# 3 | RESULTS

## 3.1 | Sample characteristics

From May 2023 through July 2024, 213 participants were recruited from urban and rural regions of Palm Beach and Broward County in Florida and completed the DeLA. During this same period, 193 participants were recruited in American Samoa and completed the DeLA. The sample had a mean age of 66.5 ± 9.0 years (range 50–93), a mean education of 11.8 ± 2.8 years (range 0–20), and 15.7% reported a family history of AD or another dementia. The sample was 63.4% female and the ethnoracial make-up was 11.8% White, 39.8% Black or African American, and 48.4% Pacific Islander (predominantly Samoan). African American and Samoan participants were younger, less educated, had lower SES, lower resilience, lower cognitive performance, and more subjective memory complaints than White participants.

**TABLE 2** Sample characteristics.

| Variable | White | Black | Samoan | *p*-value |
|---|---|---|---|---|
| Age, y | 78.0 (7.5) | 68.8 (6.9) | 61.5 (7.2) | <.001[a] |
| Sex, % Female | 72.1 | 74.4 | 53.1 | <.001[b] |
| Education, y | 14.9 (2.6) | 12.2 (2.5) | 10.6 (2.4) | <.001[a] |
| Hollingshead Index Sum | 30.2 (11.6) | 50.4 (16.1) | 58.2 (10.8) | <.001[a] |
| Family history of dementia, % | 13.0 | 18.2 | 13.5 | .458 |
| Resilience Index | 169.4 (41.9) | 128.9 (44.4) | 138.8 (38.9) | <.001[a] |
| Vulnerability Index | 9.0 (2.7) | 10.4 (2.9) | 8.2 (2.3) | <.001[c] |
| QDRS | 1.7 (2.2) | 1.8 (2.5) | 2.6 (2.8) | .006[b] |
| QDRS-derived CDR-SB | 0.8 (1.1) | 1.2 (1.8) | 1.9 (2.0) | <.001[b] |
| mCAIDE | 6.5 (2.4) | 6.9 (2.6) | 5.6 (2.5) | <.001[b] |
| Fried Frailty Score | 1.5 (1.5) | 1.5 (1.6) | 0.8 (1.1) | <.001[b] |
| Cognivue Clarity | 64.3 (12.6) | 58.1 (15.7) | 51.0 (17.5) | <.001[a] |
| Subjective Memory Complaints, % | 29.5 | 34.1 | 48.9 | .007[a] |
| Probable Cognitive Impairment, % | 65.8 | 60.7 | 61.3 | .098 |

*Note*: Mean (SD) or %.
Abbreviations: CDR-SB, Clinical Dementia Rating Sum of Boxes; mCAIDE, modified cardiovascular risk factors, aging, and incidence of dementia; QDRS, Quick Dementia Rating System.
Post hoc comparisons.
[a]All groups different from each other.
[b]Samoan participants differed from White and Black participants.
[c]Black participants are differed from White and Samoan participants.

African American participants had the highest vulnerability index scores. Samoan participants had higher QDRS and QDRS-derived CDR-SB scores and lower mCAIDE and Fried Frailty scores than African American or White participants. Sample characteristics by ethnoracial groups are presented in Table 2. Pre-test scores on the DeLA were 6.4 ± 2.0 and after reading the two stories, the post-test scores improved to 7.4 ± 2.4 ($p < 0.001$). Pre- and post-test scores showed moderate correlation (Kendall's tau-b = 0.411, $p < 0.001$).

## 3.2 | DeLA performance by sociodemographic and performance variables

Pre-test, post-test, and %gain on the DeLA by participant characteristics and performance are shown in Table 3. There were differences in pre- and post-test performance by ethnoracial groups, sex, age, education, SES, geographic locale, and cognitive impairment. No differences in pre-test scores were seen by family history or subjective complaints. No differences in post-test scores were seen by family history but greater improvements in dementia health literacy were seen in participants without subjective cognitive complaints. When examining gains in dementia health literacy after completing the DeLA, there were no differences in the %gain by sex, SES, geographic locale, sub-

**TABLE 3** DeLA performance by sociodemographic and performance variables.

| Parameter | Pre-test score | Post-test | %Gain |
|---|---|---|---|
| Race | | | |
| White | 7.8 (2.0) | 9.9 (1.5) | 31.9 |
| Black | 6.7 (2.1) | 7.9 (2.3) | 32.5 |
| Samoan | 5.8 (1.7) | 6.3 (1.9) | 18.0 |
| Kruskal–Wallis *p*-value | <.001 | <.001 | <.001 |
| Sex | | | |
| Men | 6.0 (2.1) | 6.9 (2.1) | 28.7 |
| Women | 6.6 (1.9) | 7.7 (2.4) | 23.3 |
| Mann–Whitney U *p*-value | .005 | <.002 | .480 |
| Age (years) | | | |
| <60 | 5.9 (1.7) | 6.4 (1.9) | 17.4 |
| 61–74 | 6.4 (2.1) | 7.3 (2.4) | 25.4 |
| 75+ | 6.9 (2.1) | 8.6 (2.2) | 36.2 |
| Kruskal–Wallis *p*-value | .003 | <.001 | .010 |
| Education (years) | | | |
| <12 y | 5.7 (1.9) | 6.4 (2.1) | 27.1 |
| 12–16 y | 6.6 (2.0) | 7.6 (2.3) | 24.5 |
| >16 y | 7.9 (1.9) | 9.8 (2.1) | 31.2 |
| Kruskal–Wallis *p*-value | <.001 | <.001 | .041 |
| SES | | | |
| Upper SES | 7.8 (2.1) | 9.6 (2.0) | 27.3 |
| Middle SES | 7.5 (1.9) | 8.7 (2.0) | 22.9 |
| Lower SES | 5.9 (1.9) | 6.8 (2.3) | 27.9 |
| Kruskal–Wallis *p*-value | <.001 | <.001 | .174 |
| Locale | | | |
| Urban | 7.8 (1.8) | 9.5 (1.5) | 26.4 |
| Rural | 6.4 (2.1) | 7.6 (2.4) | 36.2 |
| Mann-Whitney U *p*-value | <.001 | <.001 | .319 |
| Family history | | | |
| No family history of AD | 6.4 (2.0) | 7.4 (2.4) | 26.4 |
| Family history of AD | 6.7 (2.1) | 7.8 (2.4) | 27.5 |
| Mann–Whitney U *p*-value | .307 | .245 | .909 |
| Subjective memory complaints | | | |
| No subjective complaints | 6.4 (2.1) | 7.7 (2.3) | 28.9 |
| Subjective complaints | 6.4 (1.9) | 7.0 (2.4) | 21.3 |
| Mann–Whitney U *p*-value | .618 | .022 | .081 |
| Objective cognitive performance | | | |
| No cognitive impairment | 6.7 (2.1) | 6.1 (1.9) | 29.4 |
| Cognitive impairment | 8.0 (2.6) | 7.0 (2.1) | 26.2 |
| Mann–Whitney U *p*-value | .002 | <.001 | .177 |

*Note*: Mean (SD) or %. % Gain represents the absolute gain in health literacy as measured by DeLA.
Abbreviations: AD, Alzheimer's disease; DeLa, Dementia Literacy Assessment; SES, socioeconomic status.

jective complaints, or cognitive status, and marginal differences by age and education. The most notable differences were that Samoan older adults showed less gain in ADRD health literacy compared with White or Black older adults (Table 3).

### 3.3 | DeLA properties

We examined the percentage of correct answers for each of the 12 questions in the pre- and post-test, the difference and percent change in Table 4. For the cohort as a whole, the greatest gains in dementia health literacy were seen for question 1 (Forgetfulness is a normal part of aging—53.5% change), question 5 (Dementia usually runs in the genes of families—50.2% change), and question 8 (Which is the greatest risk factor for dementia—46.4% change). Question 12 (Getting an early diagnosis can help me, my doctor, and my family better plan for the future) was correctly answered by 96% of the respondents and showed no gain. Question 10 (Dementia is the same thing as Alzheimer's disease) declined following the completion of the stories suggesting more education is required regarding defining dementia and the differential diagnosis.

We then conducted a stratified analysis of individual DeLA questions by race (Table 4). White participants showed greatest gains for question 1 (Forgetfulness is a normal part of aging—67.6% change), question 5 (Dementia usually runs in the genes of families—169.5% change), and question 8 (Which is the greatest risk factor for dementia—95.6% change). Question 10 (Dementia is the same thing as Alzheimer's disease) declined by 5.9%. Black participants showed the greatest gains for question 8 (Which is the greatest risk factor for dementia—66.3% change), question 2 (Which is not a risk factor for dementia—49.2% change), and question 5 (Dementia usually runs in the genes of families—45.8% change). Question 10 (Dementia is the same thing as Alzheimer's disease) had the greatest decline (21.0%). Samoan participants showed the greatest gains in question 1 (Forgetfulness is a normal part of aging—83.3% change), question 2 (Which is not a risk factor for dementia—32.5% change), and question 6 (Which is not an early sign of dementia—30.9% change). Interesting, question 10 (Dementia is the same thing as Alzheimer's disease) increased by 22.6% although did not reach significance.

### 3.4 | Correlates of gains in dementia health literacy

Correlation coefficients (Kendall's tau-b) were used to examine strength of association between pre-test, post-test, and %Gain in DeLA compared to participant characteristics and performance (Table 5). There was no association between DeLA scores and family history, vulnerability index, mCAIDE, or frailty scores. Higher pre-test and post-test performance and percent gain was associated with older age, female sex, higher education, higher SES, urban dwelling, greater resilience, and better cognitive performance. High post-test performance was also associated with fewer subjective complaints.

We then conducted stratified analyses by race to examine for cross-group differences (Table 5). In White participants, DeLA scores and gain were associated with older age, higher education, higher SES, higher resilience, and better cognitive performance. In Black participants, DeLA scores and gain were associated with female sex, higher education, urban locale, higher SES, higher resilience, and better cognitive performance. In Samoan participants, DeLA scores and gain were associated with higher education, higher SES, higher resilience and better cognitive performance.

## 4 | DISCUSSION

We demonstrated that dementia health literacy could be increased using a storytelling method that included culturally adaptable vignettes embedded with important factoids about AD and related disorders. The DeLA performed well across different participant characteristics and performance with the greatest gains in awareness the memory loss is not part of the normal aging process and that age, rather than genetics/family history, is the most common risk factor. Gains in African American and Samoan participants reflected a better understanding of conditions that are not risk factors for ADRD (e.g., arthritis, vision loss). The DeLA stories were not sufficient to alleviate the common confusion about the differences between dementia and Alzheimer's disease in White and African American participants and were subsequently modified to enhance learning. Both baseline dementia health literacy and post-DeLA gains were associated with better education and socioeconomic status, greater resilience, and better cognitive performance. Individuals from urban regions had an overall greater gain in health literacy than participants living in rural regions. We had expected that younger age would be associated with higher dementia health literacy, but instead older age was associated with both higher baseline health literacy and greater gains. This could be attributed to greater exposure to spouses, family members and friends who are living with disease.

Health literacy can be influenced by social, economic, and cultural factors including access to healthcare services, language barriers, cultural beliefs and practices, peer influence, and practical knowledge related to medical conditions. Tests of dementia health literacy need to consider awareness and recognition of signs and symptoms, understanding different dementia etiologies, recognition of risk and prevention factors, and addressing social stigma related to ADRD diagnoses. Improving ADRD literacy should promote early diagnosis, augment clinical care, reduce stigma, and enhance overall quality of life for patients and caregivers. Most attempts to define health literacy have generally been done in small samples through tests of reading lists of words, numerical skills or interpreting labels,[27] with few studies including diverse study populations. Commonly used measures of health literacy include the Rapid Estimate of Adult Literacy in Medicine (REALM)[28] and its revised and short forms, the Test of Functional Health Literacy in Adults (TOFHLA),[36] and the Wide Range Achievement Test (WRAT).[37] The tests assess reading ability and pronunciation of medical terms (REALM), numerical skills related to health (TOFHLA),

**TABLE 4** Gains in ADRD health literacy by individual DeLA items stratified by race.

| | Entire cohort | | | White | | | Black | | | Samoan | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | %Correct | | | %Correct | | | %Correct | | | %Correct | | |
| DeLA question | Pre-test | Post-test | *p*-value[a] | Pre-test | Post-test | *p*-value[a] | Pre-test | Post-test | *p*-value[a] | Pre-test | Post-test | *p*-value[a] |
| Forgetfulness is a normal part of aging | 17.2 | 26.4 | <.001 | 24.4 | 40.9 | .013 | 25.7 | 35.0 | .016 | 9.0 | 16.5 | .018 |
| Which is not a risk factor for dementia | 34.3 | 46.4 | <.001 | 69.6 | 83.3 | .069 | 40.0 | 59.7 | <.001 | 19.7 | 26.1 | .077 |
| Changes in personality, behavior or mood may be an early sign of dementia | 86.8 | 89.3 | .108 | 95.6 | 100.0 | .157 | 86.4 | 88.7 | .317 | 85.1 | 87.2 | .596 |
| Which of the following may reduce the risk of dementia | 64.0 | 69.7 | <.001 | 81.8 | 95.6 | .039 | 74.7 | 87.3 | <.001 | 50.5 | 48.4 | .493 |
| Dementia usually runs in the genes of families | 39.0 | 58.6 | <.001 | 29.5 | 79.5 | <.001 | 40.4 | 58.9 | <.001 | 41.0 | 53.7 | .004 |
| Which is not an early sign of dementia | 47.0 | 50.5 | <.001 | 84.4 | 93.3 | .066 | 58.7 | 70.7 | .002 | 27.7 | 23.4 | .248 |
| Doctors can check for memory loss during an office visit | 81.2 | 91.1 | <.001 | 75.0 | 100.0 | <.001 | 82.5 | 90.2 | .002 | 81.4 | 89.9 | .010 |
| Which of the following is the greatest risk factor for dementia | 33.8 | 49.5 | <.001 | 34.1 | 66.7 | .001 | 32.9 | 54.7 | <.001 | 35.1 | 41.5 | .090 |
| There are treatments that can reduce the symptoms of dementia | 81.9 | 92.7 | <.001 | 82.2 | 95.6 | .014 | 72.5 | 89.0 | <.001 | 89.9 | 95.2 | .052 |
| Dementia is the same thing as Alzheimer's disease | 41.3 | 39.1 | .016 | 87.0 | 81.8 | .480 | 50.0 | 39.5 | .011 | 23.4 | 28.7 | .185 |
| Which of the following is not associated with dementia | 34.5 | 42.2 | <.001 | 57.8 | 70.5 | .403 | 42.6 | 54.7 | .003 | 23.4 | 25.0 | .639 |
| Getting an early diagnosis can help me, my doctor, and my family better plan for the future | 95.7 | 95.7 | .206 | 100.0 | 100.0 | 1.0 | 93.5 | 94.6 | .317 | 96.8 | 95.2 | .549 |

Abbreviations: ADRD, Alzheimer's disease and related dementias; DeLa, Dementia Literacy Assessment.

[a]Difference was determined by comparing scores in pre- and post-test performance with the Wilcoxon Signed Rank test.

**TABLE 5** Correlation of demographic and medical variables with DeLA scores stratified by race.

| | Entire cohort | | | White | | | Black | | | Samoan | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Variable | Pre-test | Post-test | %Gain | Pre-test | Post-test | %Gain | Pre-test | Post-test | %Gain | Pre-test | Post-test | %Gain |
| Age | .138 (<.001) | .223 (<.001) | .131 (.002) | −.116 (.287) | −.099 (.382) | .259 (.037) | .021 (.715) | .039 (.502) | .023 (.734) | −.022 (.689) | −.005 (.920) | .022 (.714) |
| Sex | .128 (.005) | .161 (<.001) | .047 (.366) | −.002 (.989) | .143 (.308) | .190 (.219) | .151 (.047) | .147 (.054) | .051 (.557) | .028 (.659) | .035 (.580) | −.058 (.426) |
| Education | .268 (<.001) | .384 (<.001) | .197 (<.001) | .132 (.258) | .509 (<.001) | .157 (.240) | .240 (<.001) | .293 (<.001) | .201 (.006) | .128 (.026) | .175 (.002) | .025 (.703) |
| Geographic locale | −.291 (<.001) | −.428 (<.001) | −.207 (<.001) | .087 (.501) | .060 (.653) | −.143 (.331) | −.299 (<.001) | −.289 (<.001) | −.090 (.258) | n/a | n/a | n/a |
| Family history of ADRD | .047 (.307) | .054 (.245) | −.044 (.404) | .291 (.025) | .135 (.320) | −.134 (.367) | .051 (.475) | .127 (.076) | .017 (.832) | −.007 (.923) | −.051 (.476) | −.079 (.327) |
| Socioeconomic Status | −.263 (<.001) | −.338 (<.001) | −.163 (<.001) | −.112 (.315) | −.267 (.021) | −.053 (.673) | −.171 (.004) | −.191 (.002) | −.145 (.037) | −.211 (<.001) | −.198 (.001) | .011 (.870) |
| Resilience Index | .154 (<.001) | .200 (<.001) | .116 (.004) | .152 (.154) | .292 (.009) | .207 (.088) | .174 (.002) | .224 (<.001) | .158 (.016) | .130 (.014) | .137 (.009) | .001 (.980) |
| Vulnerability Index | .057 (.187) | .051 (.232) | −.021 (.671) | .011 (.943) | −.156 (.331) | .027 (.878) | .038 (.645) | −.050 (.540) | −.159 (.091) | −.059 (.294) | −.070 (.204) | −.026 (.676) |
| Cognivue Clarity | .217 (<.001) | .312 (<.001) | .154 (<.001) | .221 (.070) | .332 (.008) | .036 (.795) | .201 (.001) | .291 (<.001) | .192 (.006) | .140 (.014) | .217 (<.001) | .035 (.592) |
| Quick Dementia Rating System | −.047 (.222) | −.104 (.007) | −.080 (.072) | .125 (.289) | −.018 (.883) | −.124 (.354) | −.016 (.806) | −.047 (.468) | −.093 (.212) | .012 (.832) | .004 (.935) | .022 (.723) |
| mCAIDE | .020 (.634) | −.008 (.860) | −.021 (.664) | .111 (.515) | −.065 (.708) | −.037 (.850) | −.037 (.640) | −.145 (.064) | −.117 (.191) | −.054 (.329) | −.075 (.177) | −.021 (.733) |
| Fried Frailty Score | .072 (.087) | .070 (.094) | −.018 (.708) | .130 (.276) | −.075 (.545) | −.284 (.036) | −.014 (.828) | .032 (.607) | −.026 (.717) | .013 (.850) | −.088 (.190) | −.070 (.358) |

*Note*: Kendall's tau-b (*p*-value).

Abbreviations: ADRD, Alzheimer's disease and related disorders; DeLa, Dementia Literacy Assessment; mCAIDE, modified cardiovascular risk factors, aging, and incidence of dementia.

n/a: Not applicable to American Samoan since all participants reside in different villages throughout the island.

or abilities in reading, spelling and arithmetic (WRAT). These tests do not specifically address literacy in ADRD, and it is unclear whether the ability to pronounce words such as "phlegm" or "gynecology" improves comprehension of the terms. The Newest Vital Sign[38] broadly assesses health literacy by asking individuals to read and interpret information on a nutritional label. This is a quick and practical tool for healthcare settings but provides no information regarding ADRD health literacy.

Most current ADRD tests of knowledge and attitudes include the Dementia Knowledge Questionnaire (DKQ),[39] the Alzheimer's Disease Knowledge Scale (ADKS),[40] and the Basic Knowledge Alzheimer's Disease (BKAD).[41] These tests include multiple choice items that assess ADRD knowledge and beliefs and may provide insight into deficits that could be addressed to improve a patient's or caregivers understanding of ADRD. These tests do not specifically address health literacy in ADRD but rather test baseline knowledge, and it is unclear whether baseline knowledge can be improved as a function of taking these tests.

The DeLA uses storytelling to provide the respondent with exposure to two of the most common forms of ADRD (Alzheimer's disease and vascular dementia) with embedded factoids (brief factual statements). Gains in ADRD health literacy are measured though pre- and post-tests with an information sheet reviewing the factoids provided after completion of the post-test. Storytelling is one of the oldest techniques of knowledge transfer,[42,43] and one of the most effective mediums to pass information to someone since many individuals tend to memorize stories better than dry facts and can easily link the stories to their personal experiences.[44–47] Storytelling shares information in a way that can create an emotional connection between data and reality for sharing a truth in a way data and facts cannot, especially when told in the first-person.[42–44] Storytelling may be a particularly effective way of health communication with minority and underserved populations, many of whom possess a rich tradition of storytelling,[48,49] and is a primary epistemological practice within the Samoan population.[50] As the DeLA can be easily culturally adapted, the same base stories can be used across diverse settings as was done in this study in a rural farming community, urban areas, and American Samoa.

### 4.1 | Study limitations and strengths

This study was cross-sectional so that no longitudinal predictions could be explored. Long-term retention of vignette content and ADRD factoids may benefit the participants and their families to enable recognition of risk factors and ADRD concepts in order to make informed decisions about care, treatment, or research involvement for themselves and their loved ones. This is a topic for future research. The DeLA performed equally well in White and Black participants with similar gains. Smaller gains were seen in Samoan older adults. Although the DeLA was translated and culturally adapted to the Samoan language, it is possible that the vignettes did not resonate with Samoan elders as well as with English-speaking individuals residing in the United States. Alternatively, Samoan elders may have started with cultural beliefs that will require more education about the differences between normal brain aging and ADRD. Further cultural adaptation may be necessary. This study also highlights the need for tailored information to be provided to the target audience. We did not test languages other than English or Samoan in this study. The DeLA has been translated into Spanish and Haitian Creole, but data collection is ongoing. This study was incorporated into two community screening programs for the detection of cognitive impairment; however, no formal diagnostic evaluations or biomarkers were completed at the time the DeLA was administered. The DeLA was able to be completed by respondents with a wide array of cognitive performance, supporting its use in varied clinical settings. Future studies may examine these relationships. The DeLA did not improve the respondent's understanding of the differences between "dementia" and "Alzheimer's disease." Revision of the text could improve this facet. Although the DeLa provides a measure gain in ADRD health literacy, it is not yet known whether gains in ADRD health literacy will likely translate into improved health outcomes. More research is needed to address this important question.

## 5 | CONCLUSIONS

With an increasing number of ADRD treatment and prevention trials, and the recent approval of two disease modifying medications, it is critical to raise awareness of ADRD across diverse communities. The DeLA can increase ADRD health literacy in a simple fashion using culturally resonant storytelling techniques and can help clinicians and researchers better understand the role health literacy plays in health decision-making. Such a strategy could increase the likelihood of health seeking behaviors in diverse populations for treatment or enriching recruitment into clinical trials. Early detection and better management of risk factors of dementia such as low health literacy may help reduce disparities in health outcomes.

### AUTHOR CONTRIBUTIONS

James E. Galvin was involved in the conceptualization, funding acquisition, methodology, formal statistical analysis, writing of the original draft, and review and editing of the final manuscript. He approves of the final version and ensures the accuracy and integrity of the work. He is a full-time employee of the University of Miami, Miller School of Medicine. He is the co-creator of the Dementia Literacy Assessment (DeLA). Deborah M. Germain was involved in recruitment, data collection, and review and editing of the final manuscript. She approves of the final version and ensures the accuracy and integrity of the work. She is a full-time employee of the University of Miami, Miller School of Medicine. Claudia P. Moore was involved in recruitment, data collection, and review and editing of the final manuscript. She approves of the final version and ensures the accuracy and integrity of the work. She is a full-time employee of the University of Miami, Miller School of Medicine. Jennifer A. Jeanty was involved in recruitment, data collection, and review and editing of the final manuscript. She approves of the final version and ensures the accuracy and integrity of the work. She is a full-time employee of the University of Miami, Miller School of Medicine. Vaatausili Tofaeono was involved in the funding acquisition, and review and editing of the final manuscript. He approves of the final

version and ensures the accuracy and integrity of the work. He is a full-time employee of the American Samoa Community Cancer Coalition. Lisa K. Wiese was involved in recruitment, data collection, and review and editing of the final manuscript. She approves of the final version and ensures the accuracy and integrity of the work. She is a full-time employee of Florida Atlantic University. She is the co-creator of the Dementia Literacy Assessment (DeLA).

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## CONFLICT OF INTEREST STATEMENT

James E. Galvin and Lisa K. Wiese are the co-creators of the Dementia Literacy Assessment (DeLA) and the copyright is issued to the University of Miami, Miller School of Medicine. James E. Galvin is the creator of the Quick Dementia Rating System, Resilience Index, Vulnerability Index, mCAIDE, and Number Symbol Coding Test used in this study. Cognivue *Clarity* is manufactured by Cognivue Inc. (Victor, NY). James E. Galvin is the Chief Scientific Officer for Cognivue, Inc. and receives consulting fees. The other authors (Deborah M. Germain, Claudia P. Moore, Jennifer A. Jeanty, and Vaatausili Tofaeono) have nothing to disclose. Author disclosures are available in the Supporting Information.

## CONSENT STATEMENT

Prior to any study procedures, an informed consent was obtained from all study participants in American Samoa. The protocol was reviewed and approved by the WCG, a central institutional review board (Reference Number 20222217). The University of Miami institutional review board deemed this project exempt and consent was waived for participants in Florida (Reference Number 20200279).

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## SUPPORTING INFORMATION

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

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