

RESEARCH ARTICLE

Two new positive psychosocial measures for persons living with dementia

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Abstract

INTRODUCTION: Differences in adaptive strategies used by individuals and families living with dementia have the potential to impact day-to-day well-being. The Living Well Inventory for Dementia (LWI-D) is a new measure to capture these strategies and to illuminate new options to support families living with dementia. The Quality of Day Scale (QODS) is a new measure to capture global well-being in persons based on a shorter temporal frame than traditional quality of life measures. This article summarizes the initial evaluation of the LWI-D and the QODS for face validity, content validity, and user acceptability.

METHODS: Initial acceptability and feasibility testing were conducted with a sample of 17 community-dwelling individuals with early-stage dementia (Montreal Cognitive Assessment [MoCA] scores of 12–30).

After revision and optimization of the two measures, a second pilot test was conducted with a sample of 30 dyads (persons living with dementia and family caregivers) in nursing home, assisted living, and community settings.

RESULTS: Data from both pilot studies are reported including item analysis and quantitative and qualitative results. Outcomes related to convergent validity between the LWI-D and the QODS with measures of positive affect-balance, quality of life, and well-being are presented. Within-dyad differences in ratings on both measures are discussed.

DISCUSSION: The LWI-D and the QODS are developing measures that warrant further testing and may enhance the ability to (1) identify strengths in living well with dementia, and (2) identify and test new interventions to bolster care and support.

KEYWORDS

Alzheimer's disease, dementia, instrument development, person-centered, well-being

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Highlights

- This article describes the process used to develop and test two new measures for research and clinical practice related to positive psychosocial approaches to dementia.
- The measures were developed with a team that included persons living with Alzheimer's disease as co-researchers in the process.
- A novel method of human-centered design was used to cultivate deep empathy, generate options, and conduct small, iterative tests of prototype measures.

Over 55 million people are currently living with Alzheimer's disease or related dementia (ADRD) worldwide, and another 10 million people are diagnosed every year.¹ Newly diagnosed individuals not only want information about their condition, but also resources that support living life to the fullest.² In the United States, the Alzheimer's Association National Early-Stage Advisory Group (ESAG), as well as other grass-roots organizations, has amplified the call to replace paradigms of deficit and debility, with strengths-based, person-centered approaches that empower individuals and families.

The concept of living well with dementia has emerged as a primary focus for scholarly inquiry.^{3–5} The Institute of Medicine defines living well with chronic illness as “the best achievable state of health that encompasses all dimensions of physical, mental, and social well-being.”⁶ Quality of life, subjective well-being, and life satisfaction have been studied as outcomes associated with living well.⁷ Psychological and social well-being have been identified as critical components.^{4,7,8} Psychological well-being includes positive affect, positive emotions, transcendence, sense of agency, purpose, and self-esteem.^{4,7–9} Experiences of support, connection, belonging, and social engagement contribute to social health and well-being.⁸ Persons living with dementia emphasize that the meaning of living well is highly individual and situational. Approaches to living well change as the illness progresses. A challenge for future research and practice is to develop measures that incorporate personal and situational meanings.⁴ There has been great progress in developing and testing interventions to support persons living with dementia and their care partners.^{10–15} To continue this progress, there is a need for strengths-based measures that are sensitive to personally meaningful dimensions of living well.¹⁶

A recent review of the literature identified 31 measures related to psychological and social well-being that were tested in samples of persons with cognitive impairment.¹⁷ Self-report measures often included complex questions and 7-point Likert-type response options.^{18,19} Some measures use anchors that ask persons with dementia to report on feelings, events, or thoughts over the past 2 to 4 weeks.^{20–22} These formats are not optimal over the broad range of cognitive abilities that characterize Alzheimer's disease and related dementias.

The National Institute on Aging convened a 2020 National Research Summit. One of the main recommendations from this summit was that persons living with dementia should be engaged as research partners

to enhance study design and relevance of outcomes.²³ This article describes the development of two new measures related to living well with dementia. We created a design team that included persons living with dementia and used principles of Human-Centered Design (HCD), guided by the philosophy and methods detailed in the IDEO Design Field Guide.^{24,25}

1 | PROCESS OF INSTRUMENT DEVELOPMENT

Design thinking is a human-centered, possibility-driven, iterative process of engaging in deep exploration into the lives of the people served, generating multiple options, and using small, real-world experiments to test those options prior to arriving at a solution.^{24,25} The three phases of the process are detailed in Figure 1.

Our design team represented potential end-users of new measures of well-being for persons living with dementia. The team included experienced researchers, members of the Alzheimer's Association National Early-Stage Advisory Group (or ESAG) living with Alzheimer's disease, two care partners of individuals living with dementia, and two biostatisticians. All members of the design team received training in the HCD philosophy and process. The coronavirus disease 2019 (COVID-19) pandemic resulted in an on-line, zoom-facilitated design process.

2 | INSPIRATION PHASE

The goal of the “Inspiration” phase of the design process is to gain deep empathy into the experience of the people who will be using the materials being designed. Members of the Steering Council with lived experience shared their own journeys, and additional strategies were used to deepen empathy including focus group interviews, observations, analogous experiences, and expert panel consultation. Six focus groups were conducted with a total of 40 participants living with dementia. The focus group findings are summarized in a separate article.²⁶

Many persons with lived experience described a grieving process after receiving the diagnosis, followed by a dawning realization that they were wasting precious time. Once they gradually absorbed the diagnosis and made the conscious decision to “get on with living,”

they became proactive agents in their own plan for living well. They described intentional engagement with life, seeking to maintain not only normalcy and independence, but also meaningful service to others. Persons living with dementia had a new sense of urgency to make every moment count and to do what they loved. People with dementia developed individualized coping strategies and adapted tasks and environments to facilitate success and build resilience.

Individuals stressed that although no two people with dementia are alike, even one person may experience wide variation in abilities, strengths, and needs for support, from day to day, or even from morning to afternoon. Conditions may range from a person being at their best to a day when cognitive reserve is depleted, or individuals are experiencing what many referred to as “brain fog.” Participants described having both good days and bad days.

3 | IDEATION

As the Steering Council moved from the inspiration to the ideation part of the design process, findings from the research literature were added to the discussion. In particular, the group noted key dimensions of living well such as seeking pleasure and enjoyment, keeping going, giving/receiving love and support, using humor, sustaining hope, giving thanks, and fostering identity and growth.⁵ Adaptation is a key process mediating the challenges encountered during the dementia journey. Access to and use of supports and services may facilitate or hinder adaptation and positive outcomes.⁷ Coping was defined as situational and focused on stress reduction and regaining control, whereas adapting included a set of strategies that build on personal assets and lead to longer-term positive growth.²⁷

Modified brainstorming and creative exercises were used to spark innovative thinking during the instrument design phase. The list of ideas was narrowed, and the Steering Council used HCD methods to brainstorm, innovate, and eventually narrow choices for the new measures. Two new measures were proposed including one process measure, the *Living Well with Dementia Inventory (LWDI)*, which identifies everyday efforts to live well, and one outcome measure, the *Quality of Day Scale (or QODS)*, which assesses self-reported well-being over a short time-frame.

RESEARCH IN CONTEXT

1. **Systematic review:** The authors conducted a review of the literature citing articles that support the need for new, positive psychosocial measures for persons living with dementia, including measures that incorporate personally meaningful dimensions and shorter temporal frames.
2. **Interpretation:** This research has the potential to provide person-centered measures that can inform the shaping of dementia-friendly environments, evaluate psychosocial interventions, and advance the science of humanistic dementia care.
3. **Future directions:** Future studies will be needed with larger sample sizes to provide additional assessment of the psychometric properties. The stability of the measures over time and the sensitivity to change and intervention will also need to be tested. Because of the short temporal frame of the Quality of Day Scale (QODS), it may be particularly useful for experiential sampling and ecological momentary assessment studies and enables triangulation with ratings of positive emotion, and simultaneous capture of social and physical environmental variables.

4 | PLANNING FOR IMPLEMENTATION

In HCD, prototyping is used to create low-tech versions of the product to be designed. The prototypes are tested and revised in rapid cycles of iteration prior to investing larger amounts of effort into one near-final product. This is the phase that builds on the design mindsets of “make it” and “learn from failure.” Initial items and measure formats were, therefore, developed and iterated using feedback from multiple stakeholder groups with lived experience with dementia.

QODS prototypes initially included a combination of faces, numbers, and bar-graph scales modeled after popular pain scales. A 33-item

Phase	Goal	Process	Questions
Inspiration (What is?) ^a	Hear	Develop deep empathy into the everyday lives, experiences, concerns and needs of individuals as the basis for design.	What is meaningful? What problems and opportunities exist?
Ideation What if?) ^a (What wows?) ^a	Create	Identify abstract themes, frameworks and opportunities followed by a concrete process of generating ideas and prototypes.	What are the possibilities? From the abundance of ideas generated, what stands out?
Implementation (What works?) ^a	Deliver	Perform iterative, small-scale testing and get feedback on what works.	Is the proposed solution feasible? Desirable? How does the idea perform in the real world?

Footnote ^a Adapted from: Liedtka, J., Salzman, R., Azer, D., 2017. Design Thinking for the Greater Good: Innovation in the Social Sector. Columbia University Press. <http://www.jstor.org/stable/10.7312/lie17952>.

FIGURE 1 Human-centered design process.

prototype LWDI was rated by researchers and persons with lived experience with dementia for clarity and relevance. The scale level content validity was calculated (S-CVI/Ave) using published methods.²⁸ The resulting questions had an S-CVI/Ave of 0.97 (Group 1) and 0.94 (Group 2).

The items on the LWDI were initially derived from feedback obtained in focus groups with individuals living with dementia, and revised in an iterative method consistent with HCD prototyping and rapid testing.²⁶ Each revision included feedback from persons with lived experience. Persons with dementia described personal habits and strategies for living well that included healthful practices, maintaining social relationships with friends and family, and coping strategies to manage stress and address specific challenges posed by dementia. Response choices included four Likert-type responses scored from 1 to 4, with 1 indicating a higher level of well-being. Yes and No responses were re-coded as 1.5 and 3.5, respectively.

Rules of thumb for pilot study samples have ranged from 20 to 70 participants.²⁹ Sample sizes were small in these initial pilot studies because the studies they were designed primarily to assess acceptability, usability, and feasibility of the new measures in preparation for a larger study to follow. Pragmatic considerations (identifying care partner dyads and scheduling multiple visits during the study period) influenced sample size for the second pilot.

5 | FIRST PILOT STUDY

After university institutional review board approval (Protocol # *anonymized*), feasibility, acceptability, and desirability were tested in a small initial pilot study with 15 individuals living with early-stage dementia or mild cognitive impairment (MCI) in community and assisted living settings. Inclusion and exclusion criteria are detailed in Supplement 1. Recruitment materials were posted on Alzheimer's Association websites in three New England states as well as to community support groups, memory care organizations, and advocacy groups in these states. After obtaining informed consent, the usability, acceptability, feasibility, and clarity of both measures were evaluated using the data-collection process described in Supplement 2.

6 | QODS PILOT 1 RESULTS

The QODS was feasible for all participants across a range of Montreal Cognitive Assessment (MoCA) scores, (13 to 28, indicating mild to moderate levels of cognitive impairment). Most participants ($n = 11$, 73%) preferred a version of the scale that used drawings with full body icons versus faces only ($n = 4$, 27%). Participants liked the colors, gender neutrality, and the simplicity of the full-body icon scale. Participants were also able to correctly interpret the ordinal progression of the pictures and to give examples of what each day might be like for them, corresponding to the rating on the ordinal scale. One person felt that the full body icons were a bit childish, but acceptable. Some changes to the graphic were recommended prior to the next pilot study as shown

in Figure 2. For example, one of the icons for level 2 was felt to look "angry" and the icon for level 5 was "too happy." Icons to represent persons of color were added.

7 | LWDI PILOT 1 RESULTS

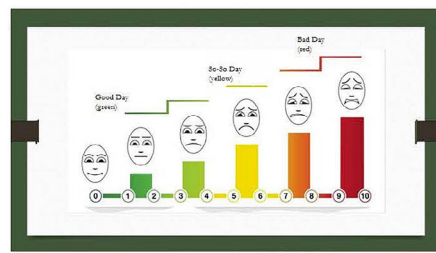
All participants in the first pilot study felt that the LWDI was acceptable and should be used in future studies. Three participants disliked the 4-point Likert-type response choices, preferring to respond with either yes/no answers or elaborating with narrative, qualitative data. Participants did not find the use of bar-graph depictions to improve response clarity. Eleven of the original items were felt to be clear and easy to use without any modifications. These items also elicited rich narrative data suggesting meaningfulness and relevance. Fifteen of the items were felt to be acceptable with minor revisions and/or participants needed examples to facilitate interpretation of the item. Based on this feedback and guided by the Steering Council members with lived experience, the most parsimonious items were selected for the next pilot study. Table 1 provides examples of item revisions with rationale. The response options were changed, and a modified two-step method of administration was developed. The Likert-type response choices were first dichotomized (such as "yes or no") and then in step 2, the remaining choices were given (e.g., very satisfied, satisfied, dissatisfied, very dissatisfied). A care partner version of the LWDI was also developed.

7.1 | Second pilot study

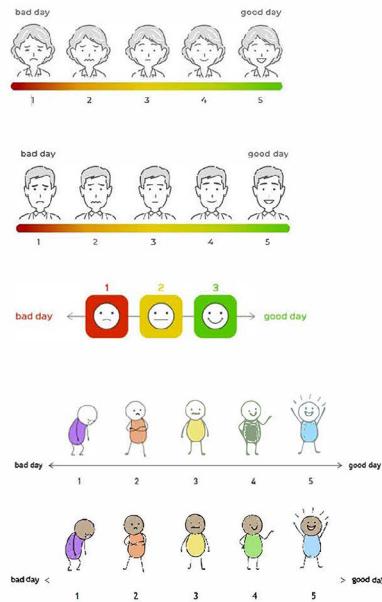
Participants in the second pilot study included 20 dyads of individuals living with Alzheimer's disease or related dementia and their care partners. Inclusion/exclusion criteria were similar to the first pilot. Participants in the second pilot also needed to have a care partner willing to participate in the study, and who spent at least 30 min per week with the person living with dementia. The data-collection process and methods of analysis are described in Supplement 3.

8 | SAMPLE

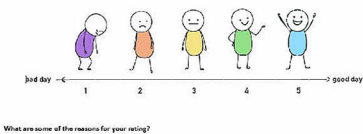
Participants included 10 male and 10 female participants with a diagnosis of Alzheimer's disease or related dementia and 20 care partners (Table 2). Participants lived in community ($n = 8$, 40%), assisted living ($n = 5$, 25%), or nursing home ($n = 7$, 35%) settings. Participants had mild ($n = 5$, 25%), moderate ($n = 5$, 25%), or severe ($n = 8$, 40%) levels of cognitive impairment based upon published norms for the Montreal Cognitive Assessment (MOCA). The average age of persons living with dementia was 80.8 (standard deviation [SD] = 6.4) and most had been living with their diagnosis for 5 to 6 years. Eight participants lived with their care partner. All participants had high school or college education. One participant in each of the two pilot studies identified as African American, non-Hispanic, and all others identified as White, non-Hispanic. Socioeconomic status was not reported.



QODS Pilot #1 Sample Prototypes:



Quality of Day Scale Version for Pilot #2:



Development Version: Comments

Feedback on this version: Lines above the faces are confusing; need to simplify – words, faces, numbers and colors are overwhelming; faces seem to express mood or pain rather than quality of day.

Pilot 1 Prototypes: Comments

Of the 3 types shown here (faces, smileys, full body icons) the full body icons were preferred by all participants. Faces reflected skin colors other than just white per participant feedback. The icon over the number 2 was felt to look too angry and the icon over the number 5 was felt to look too joyous so both of these were modified prior to Pilot #2.

For Pilot #2, an open-ended question was added to the QODS to better understand reasons for ratings given.

FIGURE 2 Iterations and revisions of the Quality of Day Scale (QODS).

9 | QODS PILOT 2 RESULTS

All persons with diagnosis of mild cognitive impairment (MCI) or dementia were able to use the scale, including those with significant hearing impairment or expressive aphasia. Speaking loudly and clearly and repeating questions more than one time, as well as providing written, large print instructions, were successful strategies for one person with moderate to severe hearing impairment who declined an amplification device. All participants agreed that the scale was clear, easy to use, and should be used in future studies.

There was support for stability of the QODS measure with a Kappa of 0.40 ($p < 0.01$) for level of agreement between day 1 and day 2 ratings of the QODS. Inter-rater reliability was examined by having the care partner independently complete the QODS after spending at least 30 min visiting with their family member and comparing this rating to

the quality of day (QOD) using self-report. There was a statistically significant correlation between the QODS rating by the person living with cognitive impairment and the proxy rating completed by the care partner ($\rho = 0.51, p < 0.05$; Table 3). The correlation was stronger if the care partner was asked to rate based on how they felt their family member would respond ($\rho = 0.69, p < 0.05$).

There was support for content validity using triangulation (Figure 3) to compare qualitative and quantitative data. There was highly congruent agreement between narrative and measured ratings for persons with mild to moderate cognitive impairment, and a preponderance of agreement for individuals with severe impairment.

Individuals living with dementia gave reasons for their QOD ratings that were associated with social interactions, activities, environment, physical well-being, and psychosocial (mental clarity, self-talk, personal expectations). When care partners provided proxy ratings and gave

TABLE 1 Sample revisions of LWDI between pilot 1 and pilot 2.

Sample items used in pilot 1 and pilot 2:
Do you manage stress well?
Do you forgive yourself for your mistakes?
Do you feel gratitude for what is good in your life?
Overall, are you living well with dementia?
Sample items with minor revisions in pilot 2
Do you do things to keep your mind and brain as healthy as possible? [Pilot 1 wording: <i>How often do you do things to keep your mind as healthy as possible</i>]
Do you spend time doing things you really LOVE to do? [Pilot 1 wording: <i>How often do you spend time doing things that you enjoy?</i>]
Do you feel valued by others? [Pilot 1 wording: <i>How often do the people in your social circle make you feel valued?</i>]
Sample items eliminated after pilot 1 [rationale]
How often do you ask for help when you need it [Participants felt this was too general and/or relied on memory]
How much have you changed your environment to make living with dementia easier? [Participants had difficulty thinking of examples; some said that their children had done so]
How often do you receive the information you want about community resources and supports for people living with dementia? [Participants felt this was more relevant in the period soon after diagnosis]

their reasons, they most often cited physical well-being and social interaction, followed by activities and environment. Care partners did not provide any psychosocial factors.

Self-rated QOD was weakly associated with quality of life, and there was a moderate correlation between self-reported QOD and well-being ($\rho = 0.48$, $p < 0.05$; Table 3). Self-reported QOD did not correlate with affect-balance ($\rho = 0.01$, $p > 0.05$). In contrast, proxy ratings of QOD were significantly associated with the individual with dementia's self-report of quality of life ($\rho = 0.58$, $p < 0.01$) and self-reported affect-balance ($\rho = 0.52$, $p < 0.05$).

10 | LWDI PILOT 2 RESULTS

The LWDI was acceptable and feasible to administer across a range of living situations and levels of cognitive ability. All participants were able to respond to the inventory and reported that the measure was clear, easy to use, and should be used in future studies. Participants with MCI were able to use the 4-point Likert-type response options (with two-step administration), whereas those with severe impairment, as determined by MoCA scores, used a yes/no format.

Support for internal consistency reliability was found for the remaining scale as a whole, with Cronbach's alpha of 0.76. Five items were removed due to difficulty with interpretability after initial review of qualitative comments associated with those items, which improved the internal consistency ($\alpha = 0.83$). Items with item-to-total correla-

TABLE 2 Sociodemographic characteristics.

	Mean	Range
Age, y	64.3	44–8
	N	%
Gender		
Female	10	50
Male	10	50
Residence		
Community	8	40
Assisted living	5	25
Nursing home	7	35
Diagnosis		
Alzheimer's disease	8	40
Vascular	3	15
Mixed or other	9	45
Educational level		
High school	4	20
Two-year college	5	25
Four-year college	6	30
Graduate school	5	25
Cognitive impairment (MoCA score)		
Mild (18–25)	5	25
Moderate (10–17)	5	25
Severe (<10)	8	40
Missing/untestable	2	10

Abbreviation: MoCA, Montreal Cognitive Assessment

tions of <0.30 or >0.70 were removed, and the remaining items were examined for convergent validity. Support for content validity was found with statistically significant associations between the LWDI and quality of life ($\rho = -0.69$, $p < .01$), positive affect ($\rho = -0.55$, $p < 0.05$) and affect balance ($\rho = -0.62$, $p < 0.01$). Care partner proxy QODS ratings were also moderately associated with the LWDI total score ($\rho = -0.55$, $p < 0.05$). The care partner proxy LWDI and the self-reported LWDI were also moderately correlated ($\rho = 0.43$, $p = 0.08$).

Support for content validity was also provided by triangulation between quantitative and qualitative data. Even participants with lower MoCA scores were able to provide rich narrative description in response to questions that were most important to them.

11 | DISCUSSION

This study used HCD methods and co-researchers with lived experience with dementia to situate the instrument development in a person-centered framework. Rather than focusing on a single construct, the design team developed the LWDI, a questionnaire that explored holistic, proactive approaches to health promotion and coping, as well as proactive, adaptive strategies used by persons with

TABLE 3 QODS Correlations (Spearman's Rho).

	QODS - Same day	QOL-AD (Quality of life)	PANAS ratio (Affect- balance)	SWEMWBS Level (Well-being)	LWDI (Living Well Inventory)
QODS-PLWD	NA	0.377	0.012	0.481*	0.152
QODS-CP	0.505*	0.326	0.390	0.166	0.293
QODS-Proxy	0.692*	0.577**	0.523*	0.111	0.533*

LWDI lower score = higher level of living well; negative correlations shown as absolute values.

Abbreviations: CP, care partner; LWDI, Living Well with Dementia Inventory; PANAS, Positive and Negative Affect Schedule; PLWD, person living with dementia; Proxy, completed by care partner answering for person living with dementia; QODS, Quality of Day Scale; QOL-AD, Quality of Life in Alzheimer's Disease Scale; SWEMWBS, Short Warwick-Edinburgh Mental Wellbeing Scale.

*Significant at 0.05 level.

**Significant at 0.01 level.

Rating	Quote
5	I did painting. I love that. I'm learning a new medium for artwork. It was artfully simple. That's my rating for this half of the day. The first half was "blah." But I was excited you were coming.
4	I look at what I do instead of what others think. I'm more of being happy with what I'm doing today. I'm reasonably happy with what I'm doing. I was doing woodwork in the basement.
3	Because I'm not always happy here. I want to be home.
2	Well...here's a dummy here (that's me, not you)...they're trying to do something...use your brain to help other people. And I'm totally in favor of that. That's the only reason I'm doing it - I'm not doing it for myself. But still, it makes me...I'm on edge.
1	I didn't sleep all night. They brought someone in...she talked...she screamed.

FIGURE 3 Content validity: Triangulation between Quan/qual for Quality of Day Scale (QODS).

dementia who strive to live well and flourish. The designers also created the QODS, an outcome measure that was more relevant to living well “in the moment.”

The QODS demonstrated acceptability and a robust psychometric profile in these initial studies. Additional testing will be needed in larger samples of individuals with mild to moderate dementia to understand the stability of the measure and the sensitivity to interventions to foster well-being. A strength of the measure is its usefulness across a wide range of cognitive abilities, including MoCA scores in the range of 9 to 12.³⁵ Supplementing the quantitative ratings with narrative comments about the reasons for the rating can provide insight to support individualized interventions and experiences to enhance well-being (e.g., as a care planning tool). If there is divergence between the quantitative rating and qualitative comments about the quality of day, this may be a warning sign of a short-term stressor that is tapping cognitive reserve and/or herald an impending delirium.

As expected, there was a significant correlation between the QODS and the measure of well-being conducted on the same day. However, there was only a weak association with quality of life as measured by the quality of life in Alzheimer's disease scale (QOL-AD), and no correlation with self-reported affect as measured by the positive and negative affect scale (PANAS). The QODS asks about the QOD “so far.” The QOL-AD ask about global items such as “marriage,” “memory,” “energy,” and “money,” or “ability to take care of oneself.” It may be unreasonable to expect a strong correlation between these two measures. It was surprising that there was a significant correlation

with proxy-rated affect balance, but not with the self-reported measures. Four individuals in the pilot study who had severe impairment were unable to complete the PANAS, and a larger sample size will be needed to understand this relationship more fully. In addition, some of the negative emotions mentioned most often by persons living with dementia such as anxiety, frustration, and anger, were not captured in the PANAS. Few participants endorsed PANAS negative emotions such as hostile or scared. In the current study, the QODS was administered once per day on two separate days. It is possible that averaging more frequent measures would have correlated more closely with comparison measures. It would be useful to analyze variability throughout the day, as well as sensitivity to change before/after positive/negative experiences. Affect-balance has been identified as a clinically useful indicator in persons with dementia.^{36,37}

Because of the short temporal frame of the QODS, it may be particularly useful for experiential sampling and ecological momentary assessment studies, and enables triangulation with ratings of positive emotion and simultaneous capture of social and physical environmental variables that have an important impact on persons with dementia.^{38,39}

The moderate correlation between caregiver proxy ratings and self-ratings indicates that the QODS may be useful as a proxy measure when self-report is no longer feasible. The utility would be strengthened by asking the caregiver how they believe the person living with dementia would respond.

The correlations between the LWDI and comparative measures of well-being were consistent with expected findings. The LWDI is

a process measure that taps into the person's adaptation, coping strategies, individual mindset, and participation in enjoyable activities. These are likely more stable and related to global measures of quality of life and well-being. The LWDI is useful not only as a process measure to understand components of adaptation that are most predictive of positive outcomes, but also as a care planning measure to engage the individual in a proactive process of adaptation and/or to guide and shape the types of services and supports to provide a fertile context for well-being.

12 | STRENGTHS AND LIMITATIONS

The QODS and LWDI represent strengths-based approaches to process and outcome measurement for persons living with dementia. They are person-centered and were developed with extensive input from persons with lived experience with Alzheimer's disease and related dementias. There was strong support for the acceptability and feasibility of both measures. The findings indicate initial support for reliability and validity, with several limitations. The small sample sizes in each pilot study preclude adequate assessment of the psychometric properties, and the mixture of Likert-type and yes/no scores may have blunted some of the results. The lack of diversity in the small pilot study samples also limits generalization of findings to a more representative population. Studies will be needed with a larger sample of diverse individuals living with cognitive impairment. Based on the results of the pilots, the LWDI will be revised and both instruments will be tested in a larger study.

With additional study to validate psychometric properties, these two measures offer new strengths-based assessments consistent with the person-centered philosophy essential to the newest dementia care practice guidelines.⁴⁰ These measures have the potential to advance the science of humanistic dementia care.

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CONFLICT OF INTEREST STATEMENT

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ETHICS STATEMENT

The protocol for this study was approved under expedited review by the Human Experimentation Committee/Institutional Review Board

(HEC/IRB), for the study entitled *Holistic Evaluation to Advance Research in Dementia (HEARD)* protocol #01321.

CONSENT STATEMENT

Written consent was provided.

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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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