

SPECIAL TOPIC SECTION

Person-centered assessment of people living with dementia: Review of existing measures

Benjamin T. Mast¹ | Sheila L. Molony² | Nicholas Nicholson² | Caroline Kate Keefe³ | Diana DiGasbarro¹

¹ Psychological & Brain Sciences, University of Louisville, Louisville, Kentucky, USA

² Quinnipiac University School of Nursing, Hamden, Connecticut, USA

³ LiveWell Alliance, Inc., Plantsville, Connecticut, USA

Correspondence

Benjamin T. Mast, Psychological & Brain Sciences, University of Louisville, Louisville, KY 40292, USA.

E-mail: b.mast@louisville.edu

This research reviews existing studies and did not collect new data from human participants, therefore informed consent was not necessary.

Abstract

Introduction: Person-centered care and assessment calls for measurement tools that help researchers and providers understand people with dementia, their social relationships, and their experience of the care environment. This paper reviewed available measures and evaluated their psychometric properties.

Methods: Literature searches of major databases (PsycInfo, PubMed, EBSCO, CINAHL) for papers examining person-centered constructs in samples of people living with dementia or mild cognitive impairment. Reliability and validity coefficients were reviewed and reported.

Results: We identified 26 unique measures that had been tested in samples of people living with dementia. Twelve measures of hope, well-being, engagement, social relationships, meaning, resilience, stigma, spiritual beliefs and practices, values and preferences, and positive psychology constructs had strong psychometric properties in samples with dementia.

Discussion: A variety of reliability and valid measures were identified for use in person-centered care and research with people living with dementia. Additional measure development is needed for key person-centered concepts including dignity and strengths.

KEYWORDS

at-homeness, cognitive impairment, dementia, hope, measurement, positive psychology, social, stigma, values, well-being

1 | INTRODUCTION

Person-centered care principles are becoming more widely adopted across care contexts. As a result, there is a growing need for measurement tools that can evaluate intervention programs and help understand individuals living with dementia in terms of personhood. Kitwood¹ identified interpersonal care that conveys trust, respect,

and recognition as essential to person-centered care. Values most often associated with person-centered care in the literature include holistic, whole-person care, respect and value, choice, dignity, self-determination, and purposeful living that includes encouragement of continued social roles. There is an emphasis both on knowing the person and understanding their experiences, facilitating enriched relationships, and individualizing care to enhance and support autonomy.²

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2021 The Authors. *Alzheimer's & Dementia: Translational Research & Clinical Interventions* published by Wiley Periodicals, Inc. on behalf of Alzheimer's Association.

In 2018, the Alzheimer's Association published a special issue of *The Gerontologist* focusing on Dementia Care Practice Recommendations (DCPR), including recommendations for Person Centered Assessment and Care Planning.³ Key recommendations included prioritizing assessment of strengths and domains that support living well with dementia. In a cohort of persons living with mild-to-moderate dementia (n = 1547) in the "Improving the Experience of Dementia and Enhancing Active Life (IDEAL) study, self-esteem, optimism and self-efficacy predicted indices of wellbeing." To advance the science of person-centered care, measures of self-esteem, optimism, relationships, dignity, and meaningful engagement are needed. Measures of person-environment relationships are needed to understand the impact of physical (built and natural), social, spiritual, residential, and health-care environments on perceived person-centeredness and overall well-being. The current article responds to the DCPR recommendations by intentionally seeking and reviewing measures for supporting well-being and person-centered care. Because living with dementia is dynamic and situational, and "what matters" to the person and care partner will change over the course of the disease trajectory, this article considers instrument reliability, validity, and sensitivity to change over time.

Cognitive function and neuropsychiatric symptoms provide important insights into disabilities that may interfere with daily activities and quality of life, but a wider range of outcome measures will capture variations in psychosocial, interpersonal, and experiential aspects of personhood. Persons living with dementia and their care partners have highlighted the need for strengths-based measures to balance the emphasis on deficit, decline, and burden suggested by scales of medical and psychiatric symptomatology.

Adding new measures to those quantifying problem-focused outcomes will create opportunities for understanding and improving the daily lives and concerns of people living with dementia. Consistent with Dementia Care Practice Recommendations (DCPR), we draw upon person-centered principles,^{1,4} the notion of whole person dementia assessment,⁵ and the person's experience of the home and care environment.⁶ Such tools may help researchers and practitioners evaluate care practices and recommend changes to better meet the needs of people and families living with dementia.⁷

Whole-person dementia assessment is an expression of person-centered principles applied to assessment and diagnosis that rests on four principles.⁵

- Person-centered care argues that people are more than a diagnosis and that assessment practices should reflect this by measuring more than cognitive deficits (neuropsychological testing) and functional changes (instrumental activities of daily living [IADL] and basic ADL).
- Clinicians may be more comfortable assessing cognitive function than experiential outcomes that reflect the impact of the disease on selfhood.
- Person-centered approaches attempt to understand the person's experience and perspective, and take steps to invite their input on their daily life and care. The whole-person dementia assessment

RESEARCH IN CONTEXT

1. **Systematic review:** The authors reviewed the literature using traditional sources including PsycInfo, PubMed, EBSCO, and CINAHL to identify measures of person-centered constructs that have been evaluated in samples of people living with dementia. Measures were evaluated to determine their psychometric properties including reliability and validity in people living with dementia.
2. **Interpretation:** The review identified 26 measures of key constructs and 12 met criteria for good reliability and validity in samples of people living with dementia.
3. **Future directions:** This article identifies several areas where additional measure development is needed and highlights limitations in existing research, including limited attention to the role of culture and dementia type.

approach builds upon this principle by emphasizing the importance of developing and using self-report measures that can be completed in a reliable and valid way by people living with cognitive impairment.

- Finally, the focus of assessment determines intervention and care. Narrow assessment of cognition and function typically leads to symptomatic treatment and deficit management. Expanding assessment to include other aspects of the person and experience will create opportunities for tailored care planning and psychosocial and spiritual interventions.

Day-to-day living incorporates not only the social environment, but also the physical (built and natural) environment, care environment, and spiritual (meaning-making) milieu. Seamon⁸ first used the term "at-homeness" to convey the "usually unnoticed, taken-for-granted situation of being comfortable in, and familiar with, the everyday world in which one lives..." (p. 70). Molony⁶ conducted a qualitative meta-synthesis to identify key experiences of at-homeness: empowerment (choice and perceived self-efficacy), refuge (physical, spatial, and ontological security), relationships (social inclusion and connection to people, pets, places, cherished possessions, symbols, and values), and dynamic person-environment interactions that reconcile one's sense of self with one's past, present, and future.⁹ Persons living with dementia may lose the narrative thread connecting self to past or future, thus magnifying the importance of creating experiences and environments in the present that re-establish person-environment connection, restore ontological security, and rebuild at-homeness. Interventions such as therapeutic reminiscence, pet therapy, music therapy, family presence videos, and multi-sensory stimulation therapy are examples of approaches to enhancing at-homeness. These types of interventions need further testing using holistic, sensitive, valid measures.

In this article, we outline a range of measurement constructs that are relevant to assessment and care planning based on these concepts.

We focused our analysis on measures that help researchers and care providers better understand the person, their social relationships, and the care environment. These categories reflect three components of quality of life (QOL) proposed by Gitlin and Hodgson:¹⁰ psychological well-being, perceived valuation or appraisal of life (meaning and personal agency), and the physical and social environment. Behavioral competencies represent the fourth component (physical health, function, activities, behavioral and cognitive symptoms) in the Gitlin and Hodgson model. Other key constructs including cognition, decision-making capacity, health-related QOL, and functional measures are beyond the scope of this review and so are not considered here. It is however important to recognize that they influence the measures described here. For example, a person's level of cognitive functioning and decision-making capacity may determine their involvement in decision making; sense of agency; and in turn, psychological well-being. In this article, we focus on new emerging psychosocial constructs and measures that help people living with dementia and cognitive impairment to regain their voice and input into their own life and care.

2 | METHODS

2.1 | Search guidelines

We searched PsycInfo, PubMed, EBSCO, CINAHL, and various reviews of psychosocial interventions to identify measures. The Appendix includes a list of terms and synonyms. Sample person terms included hope, resilience, gratitude, happiness, and optimism. Examples of relationship-focused search terms included loneliness, social isolation, social exclusion, and stigma. Experience of environment search terms included (for example) at-homeness, person-environment relationship, and person-environment integration. We limited our search to samples that had dementia or cognitive impairment. This included Alzheimer's disease (AD), other forms of dementia, mild cognitive impairment (MCI), and cognitively impaired no dementia (CIND). Only peer-reviewed papers published in English are included in this review. A recently published scoping review was also reviewed, but no unique measures were added based upon this review because (1) they did not fit the search categories, (2) had not clearly been tested in samples with dementia, or (3) did not report psychometric properties.¹¹

2.2 | Review criteria and evaluation

Tools were evaluated for evidence of reliability (internal consistency and test-retest for self-report measures, and inter-rater reliability for observer ratings) and validity. With regard to reliability, tools with Cronbach's alpha ≥ 0.80 were considered good and those with coefficients 0.60 to 0.79 were considered fair. For validity, correlation coefficients ≥ 0.60 were considered good and those 0.40 to 0.59 were fair. This is consistent with the approach taken by similar reviews¹² and the COSMIN framework.¹³ Studies on people with dementia were prioritized in the review process, but promising measures that have not yet

been used in dementia were also noted when appropriate. Finally, we recommend a series of measures based upon psychometric properties and evidence of person-centered focus.

3 | RESULTS

Twenty-six unique measures were identified, all of which have been tested in samples of people living with dementia. The results of this search are divided into three tables reflecting constructs relevant to the person and their experience (Table 1), their social relationships (Table 2), and the care environment (Table 3).

3.1 | Person and experience

The database search identified no measures of shame, embarrassment, guilt, hopelessness, or feeling like a burden. These are common themes in the qualitative literature on the dementia experience, but have not yet been operationalized into quantitative research measures. On the other hand, several constructs pertaining to positive psychological perspectives were identified and these measures are described below.

3.1.1 | Hope, resilience, meaning

More research has been conducted on hope in dementia than any of the other positive psychology constructs, with the exception of general psychological well-being. The Herth Hope Index (HHI)¹⁴ was the only measure of hope that appeared in database searches with dementia as a key term. The HHI was used in persons living with dementia in a secondary analysis of data from the Pittsburgh Alzheimer's Disease Research Center (ADRC).¹⁵ The sample included 45 individuals ranging from 43 to 91 years of age ($M = 74.27$, $SD = 10.15$) who had a diagnosis of MCI or early dementia and a Mini-Mental State Examination (MMSE) score of 16 or greater. The study found support for convergent and discriminant validity, good internal consistency, and a two-factor structure accounting to 51% of the variance. The HHI conceptualizes hope as a multidimensional, dynamic life force characterized by a confident expectation of achieving good, which is realistically possible and personally significant. The HHI domains include (1) temporality and future, (2) positive readiness and expectancy, and (3) interconnectedness.¹⁴ This conceptualization is consistent with the person-centered philosophy guiding this article. In a systematic review of Hope Scales tested in general populations, Redlich-Amirav et al.¹⁶ found 18 published instruments. Most had only one psychometric study. The two scales with the greatest evidence were Snyder et al.'s Adult Hope Scale (AHS)¹⁷ and the HHI. The AHS may prove useful for measuring hope in this population, as a recent study reported preliminary findings that the AHS is a reliable and valid measure of hope in recent nursing home residents with cognitive impairment.¹⁸

The Positive Psychology Outcome Measure is a 16-item scale that combines items related to hope and resilience. Reliability and convergent validity have been reported in one study with persons with

TABLE 1 Person and experience measures

Study authors	Year	Sample	Measure	Construct	Internal consistency reliability	Test-retest reliability	Convergent validity	Discriminant validity	Other Notes
Hunsaker et al. ¹⁵	2016	n = 45 with cognitive impairment and n = 41 care partners	Herth Hope Index (HHI)	Hope	$\alpha = 0.9$	NR	r = .37 with satisfaction with social support	Not correlated with HDRS, MMSE, or illness insight	
Cotter et al. ⁸⁵	2018	n = 57 early-stage dementia (diagnosis of dementia, MMSE > 18)	Herth Hope Index (HHI)	Hope	$\alpha = 0.71$	NR	r = .49 with self-esteem	Not significantly correlated with social support or social network size	Participants were recently admitted nursing home residents
DiGasbarro et al. ¹⁸	2019	n = 32 with cognitive impairment	Adult Hope Scale (AHS)	Hope	$\alpha = 0.85$	NR	Positive correlation with QoL-AD (r = .62) and optimism (r = -.56 with lower optimism scores signifying greater levels of optimism)	Not significantly correlated with medical burden or degree of cognitive impairment	
Stoner et al. ¹⁹	2017	n = 33; most within 3 years of dementia diagnosis	16-item Positive Psychology Outcome Measure (PPOM)	Hope and resilience	$\alpha = 0.85$	NR	Positive correlation with QoL-AD (r = 0.56)	Negative correlations with GDS-15 (r = -0.46)	
McGee et al. ²¹	2017	36 early-stage dementia (CDR 1)	Gratitude Questionnaire-6	Gratitude	$\alpha = 0.56$	NR	Positive correlation with life satisfaction r = .36 and resilience r = .39		
McGee et al. ²¹	2017	36 early-stage dementia (CDR 1)	Life Orientation Test - Revised (LOT-R; Carver)	Optimism	$\alpha = 0.63$	NR	Positive correlation with resilience (r = .38)	Negative correlation with depression (r = -.40)	
McGee et al. ²¹	2017	36 early-stage dementia (CDR 1)	Meaning in Life Questionnaire MLQ-Search - Steger	Meaning in life	$\alpha = 0.84$				
McGee et al. ²¹	2017	36 early-stage dementia (CDR 1)	Meaning in Life Questionnaire MLQ-Presence - Steger	Meaning in life	$\alpha = 0.77$		Positive correlation with optimism (r = .42) and resilience (r = .48)	Negative correlation with depression (r = -.45) and anxiety (r = -.56)	
McGee et al. ²¹	2017	36 early-stage dementia (CDR 1)	14-item Resilience Scale (RS-14)	Resilience	$\alpha = 0.81$		Positive correlation with meaning in life (r = .48), optimism (r = .38) and gratitude (r = .39)		

(Continues)

TABLE 1 (Continued)

Study authors	Year	Sample	Measure	Construct	Internal consistency reliability	Test-retest reliability	Convergent validity	Discriminant validity	Other Notes
McGee et al. ²¹	2017	36 early-stage dementia (CDR 1)	Satisfaction with Life Scale (SWLS; Diener)	Life Satisfaction	$\alpha = 0.72$		Positive correlation with gratitude ($r = .39$)	Negative correlation with depression ($r = -.41$) and positive association with anxiety ($r = .67$)	
Stoner et al. ²⁰	2018	$n = 129$; most within 3 years of dementia diagnosis	Control, Autonomy, Self-Realization and Pleasure Scale (CASP-19)	Well-being	$\alpha = 0.86$	ICC = 0.76-0.92	Positive correlation with PPOM ($r = 0.73$), EID-Q ($r = 0.75$), QoL-AD ($r = 0.71$)	Negative correlation with GDS-15 ($r = -0.71$)	CASP - 12-item version with 3 factors demonstrated best model fit in factor analysis
Burgener et al. ²²	2005	$n = 96$ persons with mild to moderate dementia	Psychological Well-being in Cognitively Impaired Persons Scale (PWB-CIP)	Wellbeing	$\alpha = 0.79 - 0.82$ (baseline and 18 months later)	NR	Significant relationship with Adult Personality Rating Scale (APRS; $r = 0.41$ to $r = 0.53$) and Functional Behavior Profile (FBP; $r = 0.36 - 0.51$)	Negative correlation with Cornell Scale for Depression in Dementia (CSD) ($r = -0.42$ to $r = -0.30$)	Factor analysis showed 2 subscales: positive affect/interaction and negative affect/interaction
Kerner et al. ²³	1998	$n = 159$ individuals with diagnosis of probable or possible Alzheimer's disease	Quality of Well-being Scale (QWB)	Well-being	NR	NR	Positive correlation with poorer cognitive function ($r = 0.52$) and lower QWB scores correlated with greater behavioral impairment ($r = 0.64$)	Negative correlation with self-reported psychiatric distress ($r = -0.26$)	
Chenoweth & Jeon ²⁹	2007	$n = 35$	Dementia Care Mapping (DCM)	Well-being	NR	NR	WIB compared to QOL ($r = 0.617$)	WIB compared to functional status ($r = -0.571$), WIB compared to memory ($r = -0.446$)	DCM did not appear to be a sensitive outcome measure of well-being. DCM observations impacted how staff interacted with and attended to the needs of the persons living with dementia

(Continues)

TABLE 1 (Continued)

Study authors	Year	Sample	Measure	Construct	Internal consistency reliability	Test-retest reliability	Convergent validity	Discriminant validity	Other Notes
Hall et al. ⁸⁶	2018	n = 14 persons with early-stage dementia in an adult day program	DCM	Well-being	NR	IRR 90–98%	NR	NR	77.42% of the time, elders were determined to be in a state of well-being 5.53% was determined to be a state of extreme ill-being
Fossey et al. ²⁸	2002	n = 123 (cohort A) assessed Internal Consistency n = 54 (cohort B) assessed test-retest reliability and concurrent validity	DCM	Well-being/QOL	NR	Test-retest reliability (r = 0.58). Well-ill being scores (r = 0.55); Activities (r = 0.40); Social withdrawal (r = 0.33).	WIB strongly correlated with QOL (r = 0.73), Activities and QOL demonstrated no significant relationship (r = 0.29).	NR	
Agli et al. ⁸⁷	2018	n = 31 with dementia, 30 with no cognitive impairment	Functional Assessment of Chronic Illness Therapy—Spiritual Well-being Scale (FACIT-sp)	Spiritual well-being	NR	NR	Positive correlation with quality of life (r = .37)	Negative correlation with depression (r = -.38)	
Katsuno ⁸⁸	2003	n = 23 people with dementia, MMSE 18–28	Systems of Belief Inventory (SBI-15R)	Spiritual and religious practices	$\alpha = 0.9$	NR	Positive correlation with quality of life (r = 0.44);		
Kaufman et al. ³²	2007	n = 70 people with probable AD, MMSE > 10	Duke University Religion Index (DUREL)	Religious practice and spirituality	NR	NR	Positive correlation with NIH/Fetzer Overall Self-Ranking r's range from 0.36 to 0.70		private religious activity associated with less cognitive decline
Kaufman et al. ³²	2007	n = 70 people with probable AD, MMSE > 10	Overall Self-Ranking subscale of the NIH/Fetzer Brief Multidimensional Measure of Religiousness/Spirituality	Self-rating of religiosity and spirituality	NR	NR	Positive correlation with DUREL attendance, private religious activity, intrinsic religiosity; r's range from 0.36 to 0.70		spiritual self-rating associated with less cognitive decline

Note: NR = not reported.

Abbreviations: AD, Alzheimer's disease; IRR, inter-rater reliability; MMSE, Mini-Mental State Examination; QOL, quality of life.

TABLE 2 Social relationship measures

Study authors	Year	Sample	Measure	Construct	Internal consistency reliability	Test-retest reliability	Convergent validity	Discriminant validity	Other notes
Nikmat et al. ³⁴	2015	n = 49 residents with dementia	Friendship Scale (FS)	Social isolation	$\alpha = 0.80$	NR	Correlation with SF-12 mental health (r = 0.37) and physical health scores (r = -0.12)	NR	
Casey et al. ³⁵	2016	n = 94	LSNS-6 friendship subscale Friendship scale	Social isolation/ social networks	LSNS-6 friendship subscale $\alpha = 0.89$ Friendship Scale $\alpha = 0.76$	NR	NR	NR	
Burgener & Berger ⁴⁶	2008	n = 40; 26 with Alzheimer's (AD) and 14 with Parkinson's disease (PD)	Stigma Impact Scale (SIS) and the Stigma Experience Scale (SES)	Stigma	SES overall $\alpha = 0.61$, for persons w AD is was $\alpha = 0.53$ and persons with PD $\alpha = 0.70$. SIS overall $\alpha = 0.89$	NR	Positively related to depression in the PD sample SIS correlation with depression (r = .64) and self-esteem (r = -.40)	Total SES scores were negatively related to mental status	

Note: NR = not reported.

dementia but further testing is needed before endorsing this questionnaire. The measure demonstrated good reliability and positive correlations with QOL.¹⁹⁻²⁰

A study by McGee et al.²¹ conducted a psychometric evaluation of several measures of positive psychological concepts, including gratitude, meaning in life, optimism, resilience, and life satisfaction. In a sample of 36 people with early-stage dementia (Clinical Dementia Rating = 1), the 14-item Resilience Scale (RS-14) and Steger's Meaning in Life Questionnaire (MLQ) demonstrated the highest reliability among these measures. The MLQ has 10 self-report items with two separate 5-item subscales, one measuring the search for meaning and the other the presence of meaning. The MLQ and RS-14 correlated positively with one another and with measures of optimism. Although the Gratitude Questionnaire and Life Orientation Test-Revised had low reliability, they showed significant, positive correlations with other positive constructs.

3.1.2 | Psychological well-being

Three instruments were identified with modest empirical support from studies conducted with persons living with dementia. The Control, Autonomy, Self-Realization and Pleasure Scale (CASP-19),²⁰ the Psychological Well-being in Cognitively Impaired Persons Scale (PWB-CIP),²² and the Quality of Well-being Scale²³ each demonstrated acceptable reliability and/or validity in at least one small single-site study with individuals with mild to moderate dementia. The CASP-19²⁴ is recommended for further study based upon the range of domains, the testing in more than one study that included persons living with dementia, and the clarity of interpretation. The 19-question Likert-type scale was originally developed as a needs satisfaction measure of QOL in early old age.²⁴ Although the reliability is good for the instrument as a whole, the autonomy subscale demonstrated poor reliability and problematic factor loadings in the only study conducted with individuals with dementia.²⁰ A shorter scale, the CASP-12, which combined control and autonomy in a single domain, demonstrated stronger support for factor validity.

The Visual Analog Scale (VAS)²⁵ and the Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWB)²⁶ were used in samples with dementia but did not report psychometric properties.

Dementia Care Mapping (DCM) developed by Kitwood and Bredin in the early 1990s, is an observational assessment method designed to assess care processes from the perspective of the person living with dementia in formal care settings. Using a mixed methods approach, qualitative observations are gathered focusing on the behaviors of the person living with dementia, instances when they are ignored or infantilized, and moments when validation or empathic approaches are used to support the person with dementia. Quantitative data focus on service provision and quality of service interactions. Data are shared with the staff in the form of constructive feedback and can be used to measure subsequent changes in person-centered service delivery.^{1,27}

DCM is a valid tool for measuring QOL of persons living with dementia in residential care settings.²⁸ Chenoweth and Jeon²⁹ determined

TABLE 3 Experience of care environment

Study authors	Year	Sample	Measure	Construct	Internal consistency reliability	Test-retest reliability	Convergent validity	Discriminant validity	Other notes
Stoner et al. ¹⁹	2017	n = 33; most within 3 years of dementia diagnosis	Engagement and Independence in Dementia Questionnaire (EID-Q) 26-item	Engagement and independence	$\alpha = 0.907$	NR	No significant correlation with QoL-AD	Negative correlation with GDS-15 ($r = -0.562$)	
Stoner et al. ²⁰	2018	n = 225; most within 3 years of dementia diagnosis	Engagement and Independence in Dementia Questionnaire (EID-Q) 26-item	Engagement and Independence (social independence)	$\alpha = 0.921$	ICC = 0.768	Positive correlation with QoL-AD ($r = 0.682$)	Negative correlation with GDS-15 ($r = -0.741$)	Factor analysis showed 5 subscales nested within 2 higher-order factors that were highly correlated: sense of independence (activities of daily living, activity engagement and decision-making) and social engagement (support and reciprocity)
Cohen-Mansfield et al. ⁵²	2017	n = 104 people living with dementia	Group Observational Measurement of Engagement (GOME)	Group engagement (individual engagement and group-level engagement in group activity)	NR	ICC per item ranges 0.75 to 1.0	NR	NR	Construct validity demonstrated for individual engagement sub scale based on intercorrelations. Two distinct constructs emerged: engagement and attendance

Note: NR = not reported.

Abbreviation: ICC, intra-class correlation.

through a pilot study that DCM was not a sensitive outcome measure of well-being as other validated measures of function, behaviors, and QOL. However, DCM observations revealed ways in which the staff interacted and attended to the needs of the person living with dementia in a more person-centered approach.

In using DCM as a process improvement tool in long-term care (LTC), Griffiths et al.³⁰ discovered organization and cultural readiness to change are instrumental factors in determining how successful implementation of DCM and person-centered care approaches may be. Mansah et al.³¹ qualitatively assessed the impact of feedback from DCM coupled with reflective work practices of nurse's aides on care outcomes of persons living with dementia. Results indicate staff felt empowered to create/implement person-centered care plans and improved interpersonal interactions with persons living with dementia.

3.1.3 | Religion and spirituality

Five measures of religious participation and spirituality were identified, but only the Systems of Belief Inventory (SBI-15R) had reliability estimates ($\alpha = 0.9$), and also correlated positively with QOL. QOL was the most common domain these measures were validated against and most demonstrated positive and statistically significant correlations. The Duke University Religion Index (DUREL) and NIH/Fetzer Overall Self-Ranking subscale were the only two that were validated against other measures of the same construct, as they were positively correlated with one another in a sample of 70 people with probable AD.³²

3.2 | Social relationships

3.2.1 | Social isolation

The search revealed two instruments that measure social isolation including the Social Inclusion Scale (SIS)³³ and the Friendship Scale (FS).³⁴ The SIS has not been tested in populations with dementia. There has only been one study using the SIS, and it demonstrated good internal consistency (reliability 0.77). This instrument has potential for older adults living with dementia but needs further testing. The FS measures perceived social isolation and loneliness.³⁴ It is a 5-item scale and Cronbach's alpha was 0.80. The sample of 49 was small and the measure was tested in Malaysia with a sample of participants living with dementia. Casey et al.³⁵ used the FS in a sample of 94 older adults, some of whom had dementia. In that study the internal consistency of the FS was found to be 0.76.

3.2.2 | Social networks

There were two instruments found that measure social networks, the Patient Strain Measure PSM-4³⁶ and the Lubben Social Network Scale

(LSNS-6).³⁷ The LSNS-6 was tested in three specific sites with large samples ($n = 1964$, $n = 2870$, and $n = 2598$) in older adults without dementia.³⁷ The internal consistency for the 6-item scale was 0.83. The LSNS-6 has been used in numerous samples of older adults,^{35,38-40} but psychometrics have not been reported in samples with dementia. The PSM-4 has four items and was used in a sample of 294 veterans living with dementia, but did not report psychometrics.³⁶

3.2.3 | Loneliness

Three instruments that measure loneliness were identified, the UCLA Loneliness Scale Version 3,⁴¹ the Three-Item Loneliness Scale,⁴² and the 6-Item De Jong Gierveld Loneliness Scale.⁴³ The UCLA Loneliness Scale Version 3⁴¹ has 20 items and has been tested with older adults, but not specifically people living with dementia. Internal consistency was demonstrated to be between 0.89 and 0.94, and test-retest reliability of 0.73. The Three-Item Loneliness Scale,⁴² which takes its three items from the UCLA Loneliness Scale Version 3, was tested in a dementia population.⁴⁴ Other differences with the UCLA Loneliness Scale Version 3 is the Three-Item Loneliness scale reduced the number of response categories from four to three and the wording was changed from first to second person to adapt to telephone interviews.⁴² The 6-Item De Jong Gierveld Loneliness Scale⁴³ is a concise 6-item instrument with an internal consistency of 0.70 to 0.76. In total, the study had a large sample ($n = 14,491$) of older adults. Additionally, the 6-Item De Jong Gierveld Loneliness Scale was used in a population that included older adults living with dementia⁴⁵ and internal consistency was reported to be 0.77.

3.2.4 | Stigma

There was only one study that appeared in the search terms used which measures stigma as it relates to social relationships and connections. In this single study two measures, the Stigma Impact Scale (SIS) and the Stigma Experience Scale (SES), were evaluated.⁴⁶ These were tested in a sample ($n = 40$) of people living with dementia (26 AD participants and 14 Parkinson's disease). Internal consistency for the SES was below acceptable levels with a Cronbach's alpha score of 0.61. The SIS had an internal consistency of 0.89 and correlated with higher depression and lower self-esteem.

3.3 | Care environment and care planning

Two measures were found that assess the climate of the care environment or residential setting. The Sheltered Care Environment Scale⁴⁷ was designed to measure social climate. The measure is not an appropriate measure to identify individual experiential differences, however. The authors note that it was developed to maximize differences between facilities and minimize differences among individuals within a setting.⁴⁸

The Person-Centered Climate Questionnaire–Patient Version⁴⁹ was designed to identify individual perceptions of the health-care climate and has been tested in hospital and LTC settings.⁵⁰ The instrument has good reliability and construct validity, but the cognitive function of the 189 participants in the LTC psychometric study was not tested and it is unknown whether any had a diagnosis of dementia.

One measure was found that focused on the experiential, rather than physical, environment, as well as the degree of person–environment integration and fit. Molony et al.⁵¹ developed an instrument to measure the experience of home, defined as an existential experience created by dynamic transactions of physical and psychic energy that bond person to place. Their Experience of Home (EOH) Scale demonstrated strong support for reliability and validity in a sample of 200 older adults (without dementia) and demonstrated the ability to discriminate between known groups dwelling in the community versus residential LTC. The instrument demonstrated intra-individual sensitivity to change over time in one longitudinal study that included a small sample of cognitively impaired and cognitively healthy nursing home residents.⁹ The EOH scores corresponded strongly with concurrent qualitative data in this mixed-methods study. Further testing and development are needed to fully endorse this scale for use as an outcome measure for persons living with dementia.

The Engagement and Independence in Dementia Questionnaire (EID-Q) has strong support for reliability in moderately sized samples of persons living with dementia and appears to measure aspects that are distinct from QOL as measured by the Quality of Life in Alzheimer's Disease (QOL-AD).¹⁹

The Group Observational Measurement of Engagement (GOME) is assessment tool developed by Cohen-Mansfield et al.⁵² to evaluate individual and group engagement in group activities for people with dementia. This observational measure was developed based on Cohen-Mansfield et al.'s⁵² Comprehensive Process Model of Group Engagement, which posits that environmental, personal, and stimuli attributes affect group engagement, and that interactions among these constructs influence affect and behavior. The GOME has five items regarding individual engagement with the group, and three items regarding the overall engagement of the group itself; items are rated on a Likert scale ranging from 0 to 6. The initial psychometric analyses of this assessment tool show that the measure of individual engagement with the group has high inter-rater reliability and very good validity.

Four additional assessment tools that contribute potentially valuable data for care planning are: the Preferences for Everyday Living Inventory (PELI), the Values and Preferences Scale (VPS),⁵³ the Pleasant Events Schedule–Alzheimer's Disease (PES-AD),⁵⁴ and the Decision Making Involvement Scale (DMIS).⁵⁵ The PELI has been tested in both community and nursing home samples and has demonstrated good reliability and validity, as well as consistency across levels of cognitive function.⁵⁶ It is a useful tool to guide person-centered care planning and evaluate the effect of person-centered interventions. The VPS was found to have fair to good internal consistency for individuals living with dementia and their caregivers (alpha = 0.70–0.82). The responses to the VPS corresponded in the predicted manner to measures of depression, QOL, and involvement in decision making. This

tool may be particularly useful for discussions related to daily care decisions and plans for future care, and may illuminate congruence or disparity between individual and care-partner dyads.⁵³ The PES-AD has fair to good reliability and validity⁵⁷ but the longer 53-item version may be more valuable than the short form as a tool for activity planning. Caregiver assistance may be needed to complete the assessment. The DMIS has demonstrated good reliability (alpha = 0.85) in a sample of 217 people living with dementia.⁵⁵

4 | DISCUSSION

Table 4 provides a list of measures that are recommended because they demonstrate good reliability and validity in samples with dementia, along with sample items reflecting content consistent with person-centered principles. These 12 measures cover all three domains and a range of constructs that can be incorporated into person-centered research. A review of the *individual items* contained in the instruments recommended in this article reveals that many of them correspond to highly valued constructs for persons experiencing dementia. Hope, mastery or agency, giving and receiving love and emotional support, and being in an environment that supports continuity of self and identity, are addressed in the individual items populating many of these scales. This review also revealed a number of constructs that have received attention but need further development.

4.1 | Dignity

Dignity is often highlighted as a basic need for people living with dementia. The search criteria for dignity measures yielded numerous qualitative research studies, suggesting rich opportunity for additional instrument development and testing for this construct. Two measures emerged from this review. The Patient Dignity Inventory focuses on negative experiences and threats to dignity, and has not been tested in large enough samples to recommend use for persons living with dementia at this time. The Jacelon Attributed Dignity Scale^{58–59} has good psychometric properties but has not yet been evaluated in persons living with dementia.

4.2 | Well-being

The SWEMWB²⁶ is the only well-being scale that demonstrated sensitivity to change over time during pre–post intervention testing. It contains individual items consistent with valued constructs of person-centeredness with sample items including “I've been feeling useful” and “I've been feeling loved.” The scale is brief, easy to administer, and provides a potential outcome measure to identify positive sequelae of person-centered care. The scale was developed and tested in a population-based study in Scotland and demonstrated good internal consistency reliability in five population-based cohort studies⁶⁰ but has not yet been specifically evaluated for psychometric performance in older adults with dementia.

TABLE 4 Person-centered measures demonstrating good reliability and validity properties in samples with dementia

Measure	Construct	Person-centered content
Adult Hope Scale	Hope	Sample items: "I meet the goals that I set for myself." "There are lots of ways around any problem."
Control, Autonomy, Self-realization and Pleasure Scale (CASP-19)	Well-being	Sample items: "I can do the things that I want to do." "I feel that my life has meaning."
Psychological Well-being in Cognitively Impaired Persons Scale	Well-being	Observer report, no self-report version
Positive Psychology Outcome Measure	Positive psychology outcomes	Sample items: "I am able to adapt to things." "I am able to see the humorous side."
Engagement and Independence in Dementia Questionnaire (EID-Q)	Engagement and social independence	Sample items: "I have a role in my social circle." "I can make changes to my life to match my abilities."
Meaning in Life Questionnaire (MIL-Q)	Meaning	Sample items: "My life has a clear sense of purpose." "I understand my life's meaning."
14-item Resilience Scale (RS-14)	Resilience	Sample items: "I usually manage one way or another." "I am determined."
Systems of Belief Inventory (SBI-15R)	Spiritual beliefs, practices, support	Sample items: "I have experienced a sense of hope as a result of my religious or spiritual beliefs." "I pray for help during bad times."
Friendship Scale (FS)	Social support and isolation	Sample items: "I had someone to share my feelings with." "I felt lonely."
Stigma Impact Scale	Stigma	Sample items: "Some people act as though I am less competent than usual." "I feel others avoid me because of my impairment."
Preferences for Everyday Living–Nursing Home Version	Preferences	Sample items: "How important is it to you to do your favorite hobbies?" [followed by list of hobbies]
Values and Preferences Scale	Values and preferences	Sample items: "How important is it for you to: Be with family or friends? Come and go as you please? Feel useful?"

Note: all measures listed demonstrated good psychometric properties in samples with dementia or cognitive impairment.

4.2.1 | Thriving, flourishing, inner strength, and resilience

Thriving is a construct that is highly consistent with a whole-person framework, but the measures developed to quantify this construct have not yet been adequately studied in persons living with dementia. Strong conceptual work provides a promising foundation for future item development, instrument refinement, and testing. Flourishing is a related concept, but the one measure that has been developed and tested to measure this outcome thus far has focused on domains relevant to primary care, rather than broader person-centered care contexts for persons living with dementia. Measures that warrant further study include the Comprehensive Inventory of Thriving (CIT), the related Brief Inventory of Thriving (BIT), and the Thriving in Long-Term Care scales. Strong conceptual work provides a promising foundation

for future item development, instrument refinement, and testing. The one measure of flourishing that has been developed and tested thus far has focused on domains relevant to primary care, rather than broader person-centered care contexts for persons living with dementia.^{61–62} Lundman et al.⁶³ tested the Inner Strength Scale (ISS) in an age-diverse sample of cognitively healthy adults and later tested the Resilience Scale (RS-25), the Sense of Coherence Scale (SOC), the Purpose in Life Scale (PIL), and the Self-Transcendence Scale (STS).⁶⁴ These measures should be tested in samples living with dementia because these constructs are highly valued as indicated by qualitative studies.⁶⁵

Other positive attributes highlighted in qualitative work that were not found in the instrument-development literature include growth, humor, and coping. *Post-traumatic growth and coping* have been measured in a small study of stroke survivors but people with cognitive impairment were excluded.⁶⁶ Pleasure and enjoyment were not

found within research measures, but were included in questionnaires intended to improve person-centered care planning (e.g., PES-AD).

4.3 | Excess disability

Although there exists a multitude of assessments designed to measure disability and dependency in people with dementia, no formal measures were found when using “excess disability” as a search term. Excess disability can arise due to environmental, social, psychological, and pharmacological factors that prevent an individual from functioning at the level at which they are capable.^{67–68} While studies have been published examining excess disability in people with dementia, none have used a formal measure of the construct; instead, they have relied on coding schemes and comparing observed functioning to predictors of disability like the Charleston Comorbidity Index and the Global Deterioration Scale.^{67–68} Inherent in assessing excess disability is consideration of factors that lie outside the traditional biomedical model of dementia. In fact, a person-centered approach is necessary to identify and remediate social, environmental, psychological, or pharmacological factors that increase disability and dependency in a person with dementia. The creation of a standard assessment of this construct may facilitate development of interventions that target this concept.

4.4 | Strengths

It has become quite common for person-centered care to focus on integrating a person's strengths, yet no formal measure of strengths could be found. Many scholars have written about maintenance of the self and personhood throughout the course of dementia, and recently researchers have been expanding their study of people with dementia to include positive psychology constructs such as hope and resilience.^{1,19,69} There is a need for the conceptualization of dementia as a process that does not strip an individual of their personhood, which includes their strengths and virtues.^{70–71} Peterson and Seligman published *Character Strengths and Virtues*⁷² to systematically classify strengths and virtues that may be targeted for research and intervention to improve well-being in the general population. Yet, empirical research on people with dementia does not typically focus on identifying or targeting an individual's strengths, and indeed we could find no formal assessment of strengths of people with dementia. A bridging of positive psychology constructs, models of personhood, and care for people with dementia represents an emerging line of research that has the potential to improve the experiences of people with dementia and their caregivers, and society's perception of dementia.

4.5 | Belonging

Two measures of belonging were identified: the Social Connectedness Scale (SCS) and the Social Assurance Scale (SAS). Although these tools

have excellent psychometrics among college students,⁷³ they have not been tested among older adults or people living with dementia. The person-centered approach for these scales is good, as they both attempt to seek input about the experience from the participant.

4.6 | Successful aging with dementia

In researching the topic of resilience, Harris⁷⁴ explored the concept of successful aging while living with a diagnosis of early-stage dementia. Informed by the biopsychosocial-cultural approach to dementia, Harris⁷⁴ applied the resilience framework most notably used with children who despite their social and psychological experiences, overcome adversity and have positive outcomes. Using the person-centered approach, two casestudies of persons living with dementia were identified from a larger study which examined living with the diagnosis of dementia⁷⁴ thus providing context, laying the groundwork to explore the observable behaviors of resilience through ethnographic, open-ended interviews. This study elucidates how a framework of resilience may be applied to persons living with adversity while demonstrating behaviors indicative of resilience. Williamson and Paslawski⁷⁵ conducted a qualitative study with seven persons living with dementia and five care partners, obtained via purposive sampling. Semi-structured interviews were conducted to elicit rich descriptions of the concept of *resilience and what it means to live with or care partner with someone diagnosed with dementia*. Thematic analysis was used with interview transcripts to generate themes and subthemes. Triangulation of interviews was completed with all participants. Three themes emerged related to resilience: (1) active and purposeful living, (2) perspective, and (3) resources. Subthemes of factors included: participation, physical activity, social interaction, attitudes/acceptance, openness, education, support, and strategies.

4.7 | Care planning

The process of care planning is predicated on the data that emerge from the assessment phase. Just as the ability to appropriately address pain management relies upon the assessment of location, intensity, context, meaning, and expression of pain, as well as previous experience with pain and pain relief, so does the ability to appropriately provide individualized psychosocial care rely on the assessment of experiences of social engagement, hope, spiritual connection, pleasure, resilience, and positive experiences of the person–environment relationship. While qualitative research typically sheds light on lived experience, and quantitative research identifies the correlates and predictors of desired outcomes, a mixed-methods study revealed that qualitative comments made while completing the EOH Scale illuminated values, preferences, and narrative clues to situations that supported or detracted from at-homeness, as defined by the individual.⁹ This suggests that mixed-methods studies and new innovative approaches may use these measures not only for evaluation of new interventions and

approaches in a particular population, but also for individualized care planning.

The need for measures applicable to everyday living has been emphasized in the call for pragmatic trials.⁷⁶ The National Institute on Aging (NIA) IMPACT Collaboratory is a nationwide organization that promotes the conduct of embedded pragmatic clinical trials (ePCTs) evaluating non-pharmacological approaches to care for people living with dementia and their care partners within health-care systems. To support these trials, robust measures are needed in domains of value to these stakeholders.

Key assessment questions to inform care planning include “What brings this person hope? What enables a sense of belonging or aloneness? Who provides social support?” The instruments listed above may provide key insights that enable care planning. Many other care planning tools were found in the literature that are recommended for future pragmatic trials including the Alzheimer’s Association Care Planning Toolkit,⁷⁷ the Person-Directed Dementia Care Assessment Tool,⁷⁸ Goal Attainment Scaling,⁷⁹ the WeCare Advisor™,⁸⁰ and the Process for Care Planning for Resident Choice Toolkit.⁸¹ Zimmerman et al.¹² conducted a comprehensive inventory of person-centered measures and instruments for quality improvement (QI) in assisted living. Many of these measures would be useful for QI in a range of environments providing care for persons with dementia.

Future studies need to focus not only on the content of psychosocial measures, but also on response formats, length, and presentation modality. Castle and Engberg⁸² noted differences in preference and response variability using diverse response formats to measure identical constructs in older adults. Safikhani et al.⁸³ identified differences in reliability, validity, and responsiveness to change across a variety of contexts of use for pain scales (e.g., numeric rating scales, visual analog scales, and verbal rating scales). Neither of these studies included persons with dementia.

This review has two key limitations, both of which related to sampling. First, this analysis did not differentiate between different types of dementia and their potential impact on person-centered measures. Even the most common dementias (e.g., AD vs. dementia with Lewy bodies vs. frontotemporal dementias) have important differences in the pattern of cognitive and behavioral change that likely impact experiences of living with dementia, as should responses on these measures and their psychometric properties. Second, there has been little analysis of cultural influences on experiential and person-centered measures in the context of dementia research. Future research should seek to better understand these key factors.

Gaugler et al.⁸⁴ proposed a new framework for research about life with AD. The framework requires methodologies that capture resilience and “positive milestones across the Alzheimer’s journey” (p. 394). Next steps in responding to the DCPR recommendations for reliable and valid measures that support personhood will require collaboration among teams of dementia experts (including persons living with dementia), psychometricians, and person-centered care researchers to advance the science by focusing on developing a range of tailored response formats that optimize measurement for specific subpopulations and contexts.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

REFERENCES

1. Kitwood T. *Dementia reconsidered: The person comes first*. Milton Keynes: Open University Press; 1997.
2. Kogan AC, Wilber K, Mosqueda L. Person-centered care for older adults with chronic conditions and functional impairment: a systematic literature review. *J Am Geriatr Soc*. 2016;64(1):e1-e7.
3. Molony SL, Kolanowski A, Van Haitsma K, Rooney KE. Person-centered assessment and care planning. *Gerontologist*. 2018;58(suppl_1):S32-S47.
4. Brooker D. What is person-centred care in dementia?. *Reviews in Clinical Gerontology*. 2003;13(3):215-222.
5. Mast BT. *Whole Person Dementia Assessment*. Baltimore, MD: Health Professions Press; 2011.
6. Molony SL. The meaning of home: a qualitative meta-synthesis. *Res Gerontol Nurs*. 2010;3(4):291-307.
7. Fazio S, Pace D, Flinner J, Kallmyer B. The fundamentals of person-centered care for individuals with dementia. *Gerontologist*. 2018;58(suppl_1):S10-S19.
8. Seamon D. Body-subject, time-space routines, and place-ballets. In: the human experience of space and place. 1st ed. Routledge. 1980:148-165.
9. Molony SL, Evans LK, Jeon S, Rabig J, Straka LA. Trajectories of aloneness and health in usual care and small house nursing homes. *Gerontologist*. 2011;51(4):504-515.
10. Gitlin LN, Hodgson NA. *Better Living with Dementia: implications for individuals, families, communities, and societies*. London, United Kingdom: Elsevier/Academic Press; 2018.
11. Clarke C, Woods B, Moniz-Cook E, et al. Measuring the well-being of people with dementia: a conceptual scoping review. *Health and Quality of Life Outcomes*. 2020;18(1).
12. Zimmerman S, Cohen LW, Washington T, Ward K. *Measures and instruments for quality improvement in assisted living*. 2016. https://www.theceal.org/images/Measures-and-Instruments-for-Quality-Improvement-in-Assisted-Living_Final-Report.pdf. Accessed December 15, 2020.
13. Prins CAC, Morkink LB, Bouter LM, et al. COSMIN guideline for systematic reviews of patient-reported outcome measures. *Qual Life Res*. 2018;27(5):1147-1157.
14. Herth K. Abbreviated instrument to measure hope: development and psychometric evaluation. *J Adv Nurs*. 1992;17(10):1251-1259.
15. Hunsaker AE, Terhorst L, Gentry A, Lingler JH. Measuring hope among families impacted by cognitive impairment. *Dementia (London)*. 2016;15(4):596-608.
16. Redlich-Amirav D, Ansell LJ, Harrison M, Norrena KL, Armijo-Olivo S. Psychometric properties of Hope Scales: a systematic review. *Int J Clin Pract*. 2018;72(7):e13213.
17. Snyder CR, Harris C, Anderson JR, et al. The will and the ways: development and validation of an individual-differences measure of hope. *J Pers Soc Psychol*. 1991;60(4):570-585.
18. DiGasbarro D, Midden A, Van Haitsma K, Meeks S, Mast B. Reliability and Validity of the Adult Hope Scale among nursing home residents with and without cognitive impairment. *Clin Gerontol*. 2020;43(3):340-349.
19. Stoner CR, Orrell M, Long M, Csipke E, Spector A. The development and preliminary psychometric properties of two positive psychology outcome measures for people with dementia: the PPOM and the EID-Q. *BMC Geriatrics*. 2017;17(1).
20. Stoner CR, Orrell M, Spector A. Psychometric properties and factor Analysis of the Engagement and Independence in Dementia Questionnaire (EID-Q). *Dementia and Geriatric Cognitive Disorders*. 2018;46(3-4):119-127.

21. McGee JS, Zhao HC, Myers DR, Kim SM. Positive psychological assessment and early-stage dementia. *Clin Gerontol*. 2017;40(4):307-319.
22. Burgener SC, Twigg P, Popovich A. Measuring psychological well-being in cognitively impaired persons. *Dementia*. 2005;4(4):463-485.
23. Kerner DN, Patterson TL, Grant I, Kaplan RM. Validity of the Quality of Well-Being Scale for patients with Alzheimer's disease. *J Aging Health*. 1998;10(1):44-61.
24. Hyde M, Wiggins RD, Higgs P, Blane DB. A measure of quality of life in early old age: the theory, development and properties of a needs satisfaction model (CASP-19). *Aging Ment Health*. 2003;7(3):186-194.
25. Johnson J, Culverwell A, Hulbert S, Robertson M, Camic PM. Museum activities in dementia care: using visual analog scales to measure subjective wellbeing. *Dementia (London)*. 2017;16(5):591-610.
26. Allward C, Dunn R, Forshaw G, Rewston C, Wass N. Mental wellbeing in people with dementia following cognitive stimulation therapy: innovative practice. *Dementia*. 2020;19(2):496-504.
27. Innes A. *Dementia Care Mapping Applications across Cultures*. Baltimore: Health Professions Press; 2003.
28. Fossey J, Lee L, Ballard C. Dementia Care Mapping as a research tool for measuring quality of life in care settings: psychometric properties. *Int J Geriatr Psychiatry*. 2002;17(11):1064-1070.
29. Chenoweth L, Jeon Y-H. Determining the efficacy of Dementia Care Mapping as an outcome measure and a process for change: a pilot study. *Aging Ment Health*. 2007;11(3):237-245.
30. Griffiths AW, Kelley R, Garrod L, et al. Barriers and facilitators to implementing dementia care mapping in care homes: results from the DCM™ EPIC trial process evaluation. *BMC Geriatr*. 2019;19(1):37. Published 2019 Feb 8.
31. Mansah M, Coulon L, Brown P, Reynolds H, Kisiwaa S. Tailoring dementia care mapping and reflective practice to empower assistants in nursing to provide quality care for residents with dementia. *Australian Journal of Advanced Nursing*. 2015;31(4):34-44.
32. Kaufman Y, Anaki D, Binns M, Freedman M. Cognitive decline in Alzheimer disease: impact of spirituality, religiosity, and QOL. *Neurology*. 2007;68(18):1509-1514.
33. Nicholson NR, Feinn R, Casey EA, Dixon J. Psychometric evaluation of the Social Isolation Scale in older adults. *Gerontologist*. 2020;60(7):e491-e501.
34. Nikmat AW, Hawthorne G, SH Al-Mashoor. The comparison of quality of life among people with mild dementia in nursing home and home care—a preliminary report. *Dementia (London)*. 2015;14(1):114-125.
35. Casey A-NS, Low L-F, Jeon Y-H, Brodaty H. Residents perceptions of friendship and positive social networks within a nursing home. *Gerontologist*. 2015;56(5):855-867.
36. Shub D, Bass DM, Morgan RO, et al. Irritability and social isolation in dementia patients with and without depression. *J Geriatr Psychiatry Neurol*. 2011;24(4):229-234.
37. Lubben J, Blozik E, Gillmann G, et al. Performance of an abbreviated version of the Lubben Social Network Scale Among Three European Community-Dwelling Older Adult Populations. *Gerontologist*. 2006;46(4):503-513.
38. Eshkoo SA, Hamid TA, Nudin SS, Mun CY. Importance of hypertension and social isolation in causing sleep disruption in dementia. *Am J Alzheimers Dis Other Demen*. 2014;29(1):61-66.
39. Crooks VC, Lubben J, Petitti DB, Little D, Chiu V. Social network, cognitive function, and dementia incidence among elderly women. *Am J Public Health*. 2008;98(7):1221-1227.
40. Yates JA, Clare L, RT; Woods. Cognitive function and ageing study: wales. "You've got a friend in me": can social networks mediate the relationship between mood and MCI?. *BMC Geriatr*. 2017;17(1):144. Published 2017 Jul 13.
41. Russell DW. UCLA Loneliness Scale (Version 3): reliability, validity, and factor structure. *J Pers Assess*. 1996;66(1):20-40.
42. Hughes ME, Waite LJ, Hawkey LC, Cacioppo JT. A Short Scale for Measuring Loneliness in Large Surveys: results From Two Population-Based Studies. *Res Aging*. 2004;26(6):655-672.
43. de Jong Gierveld J, Tilburg TV. A 6-Item Scale for Overall, Emotional, and Social Loneliness: confirmatory Tests on Survey Data. *Res Aging*. 2006;28(5):582-598.
44. Yin J, Lassale C, Steptoe A, Cadar D. Exploring the bidirectional associations between loneliness and cognitive functioning over 10 years: the English longitudinal study of ageing. *Int J Epidemiol*. 2019;48(6):1937-1948.
45. Burholt V, Windle G, Morgan DJ, on behalf of the CFAS Wales team. A social model of loneliness: the roles of disability, social resources, and cognitive impairment. *J Gerontol*. 2017;57(6):1020-1030.
46. Burgener SC, Berger B. Measuring perceived stigma in persons with progressive neurological disease: alzheimer's dementia and Parkinson's disease. *Dementia*. 2008;7(1):31-53.
47. Lemke S, Moos RH. Measuring the social climate of congregate residences for older people: sheltered Care Environment Scale. *Psychol Aging*. 1987;2(1):20-29.
48. Lemke S, Moos RH. Validity of the Sheltered Care Environment Scale: conceptual and methodological issues. *Psychol Aging*. 1990;5(4):569-571.
49. Edvardsson D, Koch S, Nay R. Psychometric evaluation of the English Language Person-Centered Climate Questionnaire—Patient version. *West J Nurs Res*. 2009;31(2):235-244.
50. Yoon JY, Roberts T, Grau B, Edvardsson D. Person-centered Climate Questionnaire-Patient in English: a psychometric evaluation study in long-term care settings. *Arch Gerontol Geriatr*. 2015;61(1):81-87.
51. Molony SL, McDonald DD, Palmisano-Mills C. Psychometric testing of an instrument to measure the experience of home. *Res Nurs Health*. 2007;30(5):518-530.
52. Cohen-Mansfield J, Hai T, Comishen M. Group engagement in persons with dementia: the concept and its measurement. *Psychiatry Research*. 2017;251:237-243.
53. Whitlatch CJ, Feinberg LF, Tucke SS. Measuring the values and Preferences for everyday care of persons with cognitive impairment and their family caregivers. *The Gerontologist*. 2005;45(3):370-380.
54. Logsdon RG, Teri L. The Pleasant Events Schedule-AD: psychometric properties and relationship to depression and cognition in Alzheimer's disease patients. *Gerontologist*. 1997;37(1):40-45.
55. Menne HL, Tucke SS, Whitlatch CJ, Feinberg LF. Decision-making involvement scale for individuals with dementia and family caregivers. *Am J Alzheimers Dis Other Demen*. 2008;23(1):23-29.
56. Van Haitsma K, Curyto K, Spector A, et al. The preferences for everyday living inventory: scale development and description of psychosocial preferences responses in community-dwelling elders. *Gerontologist*. 2013;53(4):582-595.
57. Amspoker AB, Hersch GL, Snow AO, et al. A Psychometric Evaluation of the Pleasant Events Schedule—Alzheimer's Disease (Short Version): among a veteran population. *Journal of Applied Gerontology*. 2019;38(5):673-693.
58. Jacelon CS, Dixon J, Knafel KA. Development of the Attributed Dignity Scale. *Res Gerontol Nurs*. 2009;2(3):202-213.
59. Jacelon CS, Choi J. Evaluating the psychometric properties of the Jacelon Attributed Dignity Scale. *J Adv Nurs*. 2014;70(9):2149-2161.
60. Cooper R, Stafford M, Hardy R, et al. Physical capability and subsequent positive mental wellbeing in older people: findings from five HALCYON cohorts. *Age (Dordr)*. 2014;36(1):445-456.
61. Su R, Tay L, Diener E. The development and validation of the Comprehensive Inventory of Thriving (CIT) and the Brief Inventory of Thriving (BIT). *Applied Psychology: Health and Well-Being*. 2014;6(3):251-279.
62. Bergland Å, Kirkevold M, Sandman PO, Hofoss D, Vassbø T, Edvardsson D. Thriving in long-term care facilities: instrument development, correspondence between proxy and residents' self-ratings and internal consistency in the Norwegian version. *J Adv Nurs*. 2014;70(7):1672-1681.
63. Lundman B, Viglund K, Aléx L, et al. Development and psychometric properties of the Inner Strength Scale. *Int J Nurs Stud*. 2011;48(10):1266-1274.

64. Lundman B, Aléx L, Jonsén E, et al. Inner strength in relation to functional status, disease, living arrangements, and social relationships among people aged 85 years and older. *Geriatr Nurs*. 2012;33(3):167-176.
65. Wolverson EL, Clarke C, Moniz-Cook ED. Living positively with dementia: a systematic review and synthesis of the qualitative literature. *Aging Ment Health*. 2016;20(7):676-699.
66. Kelly G, Morris R, Shetty H. Predictors of post-traumatic growth in stroke survivors. *Disabil Rehabil*. 2018;40(24):2916-2924.
67. Rogers JC, Holm MB, Burgio LD, et al. Improving morning care routines of nursing home residents with dementia. *J Am Geriatr Soc*. 1999;47(9):1049-1057.
68. Slaughter SE, Eliasziw M, Morgan D, Drummond N. Incidence and predictors of excess disability in walking among nursing home residents with middle-stage dementia: a prospective cohort study. *Int Psychogeriatr*. 2011;23(1):54-64.
69. Sabat SR, Harré R. The construction and deconstruction of self in Alzheimer's disease. *Ageing Societ*. 1992;12(4):443-461.
70. de Vugt M, Dröes RM. Social health in dementia. Towards a positive dementia discourse. *Aging Ment Health*. 2017;21(1):1-3.
71. McGovern J. Living better with dementia: strengths-based social work practice and dementia care. *Soc Work Health Care*. 2015;54(5):408-421.
72. Peterson C, Seligman MEP. *Character strengths and virtues: A handbook and classification*. New York: Oxford University Press; 2004.
73. Lee RM, Robbins SB. Measuring belongingness: the Social Connectedness and the Social Assurance scales. *J Counsel Psychol*. 1995;42(2):232-241.
74. Harris PB. Another wrinkle in the debate about successful aging: the undervalued concept of resilience and the lived experience of dementia. *Int J Aging Hum Dev*. 2008;67(1):43-61.
75. Williamson T, Paslawski T. Resilience in dementia: perspectives of those living with dementia. *Canadian J Speech-Language PatholAudiol*. 2016;40(1).
76. Patsopoulos NA. A pragmatic view on pragmatic trials. *Dialogues Clin Neurosci*. 2011;13(2):217-224.
77. Care Planning. Alzheimer's Disease and Dementia. <https://alz.org/professionals/healthcare-professionals/care-planning>. Accessed December 15, 2020.
78. State of Wisconsin Department of Health Services. *Person-Directed Dementia Care Assessment Tool*. <https://www.dhs.wisconsin.gov/publications/p2/p20084.pdf>. Accessed December 15, 2020
79. Jennings LA, Ramirez KD, Hays RD, Wenger NS, Reuben DB. Personalized goal attainment in dementia care: measuring what persons with dementia and their caregivers want. *J Am Geriatr Soc*. 2018;66(11):2120-2127.
80. Kales HC, Gitlin LN, Stanislawski B, et al. WeCareAdvisor™: the development of a caregiver-focused, web-based program to assess and manage behavioral and psychological symptoms of dementia. *Alzheimer Dis Assoc Disord*. 2017;31(3):263-270.
81. Calkins M, Schoeneman K, Brush J, Mayer R. 2020. <https://www.pioneernetwork.net/wp-content/uploads/2016/10/Process-for-Care-Planning-for-Resident-Choice-.pdf>. Accessed December 15.
82. Castle NG, Engberg J. Response Formats and Satisfaction Surveys for Elders. *Gerontologist*. 2004;44(3):358-367.
83. Safikhani S, Gries KS, Trudeau JJ, et al. Response scale selection in adult pain measures: results from a literature review. *J Patient Rep Outcomes*. 2018;2:40. Published 2018 Sep 6.
84. Gaugler JE, Bain LJ, Mitchell L, et al. Reconsidering frameworks of Alzheimers dementia when assessing psychosocial outcomes. *Alzheimers Dement: Translat Res Clin Intervent*. 2019;5(1):388-397.
85. Cotter VT, Gonzalez EW, Fisher K, Richards KC. Influence of hope, social support, and self-esteem in early stage dementia. *Dementia (London)*. 2018;17(2):214-224.
86. Hall J, Mitchell G, Webber C, Johnson K. Effect of horticultural therapy on wellbeing among dementia day care programme participants: a mixed-methods study (Innovative Practice). *Dementia*. 2018;17(5):611-620.
87. Agli O, Bailly N, Ferrand C, Martinet G. Spirituality, quality of life, and depression in older people with dementia. *J Religion Spirituality Aging*. 2018;30(3):268-278.
88. Katsuno T. Personal spirituality of persons with early-stage dementia: is it related to perceived quality of life? *Dementia*. 2003;2(3):315-335.

How to cite this article: Mast BT, Molony SL, Nicholson N, Kate Keefe C, DiGasbarro D. Person-centered assessment of people living with dementia: Review of existing measures. *Alzheimer's Dement*. 2021;7:e12138. <https://doi.org/10.1002/trc2.12138>

Appendix: Literature search terms

Shame
Embarrassment
Guilt
Burden
Hopelessness
Helplessness
Excess disability

Hope
Gratitude
Happiness
Optimism
Meaning
Peace
Well-being

Resilience
Coping
Adaptation
Dementia
Alzheimer's
Outcomes measures
Outcomes assessments
Dementia Care Mapping

Religiosity/religion
Religious measures
Religious coping
Prayer
Meditation

Belonging

Belongingness

Social acceptance

Social distance

Social rejection

Social isolation

Loneliness

Social exclusion

Social connectedness

Social engagement

Social network

Stigma

Engagement

Meaningful activity

At-homeness

Person-environment relationship

Person-environment integration

Coherence

Place identity

Place therapy

Person centered OR person-centered

Personhood

Strength

Hardiness

Flourish*

Thrive OR thriving

Dignity

Respect

Self-esteem

Worthwhile
