SPECIAL TOPIC SECTION

Person-centered assessment of apathy and resistance to care in people living with dementia: Review of existing measures

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Abstract

Introduction: The review described in this paper builds upon the Dementia Care Practice Recommendations (DCPR) published by the Alzheimer's Association in 2018 and addresses behavior change and the need for targeted outcome measures that evolve from person-centered frameworks and help evaluate interventions. Apathy and resistance to care (RTC) are two specific behavioral expressions of unmet need or distress exhibited by people living with dementia, which are upsetting to formal and family caregivers and compromise quality of life for people living with dementia.

Methods: We conducted literature searches of major databases (PsycInfo, PubMed, EBSCO, CINAHL) for papers examining apathy and RTC constructs in samples of people living with dementia. Reliability and validity coefficients were reviewed and reported, along with examination of whether each measure facilitates contextual understanding of behavior.

Results: Three stand-alone measures of RTC and ten measures of apathy were identified and reviewed. The RTC measures demonstrated good psychometric properties but do not include the perspective of the person living with dementia or contextual aspects of the behavior. The identified apathy measures demonstrated fair to good psychometric properties, and although there is greater consideration of context, none adequately include the perspective of the person living with dementia.

Discussion: Although reliable and valid measures have been developed to measure apathy and RTC in people living with dementia, there is greater need for conceptually driven measurement of behavior context and for tools that elicit and include the perspective of the person living with dementia.

KEYWORDS
apathy, behavioral and psychological symptoms of dementia, challenging behavior, cognitive impairment, dementia, measurement, neuropsychiatric symptoms, resistance to care, unmet needs

1 | INTRODUCTION

Person-centered approaches to understanding dementia continue to transform research and care. This includes our understanding of behavioral changes. Agitation, apathy, delusions, depression, resistance to care (RTC), and wandering are relatively common and quite distressing to family caregivers, lead to poorer care, accelerate nursing home placement, and contribute to lower quality of life for the person living with dementia.[1,2] Although cognition has received more clinical attention and research funding than any other aspect of dementia assessment and care, research suggests that changes in behavior have a much greater impact on the person and their family support system.[3]

Historically many have assumed that behavioral changes are unpredictable expressions of brain pathology that are appropriate targets for antipsychotic medications. However, antipsychotic medications have limited efficacy in treating behavioral changes and carry a black box warning from the US Food and Drug Administration for use with people living with dementia. The American Psychiatric Association also does not recommend use of antipsychotic medication outside of acute emergencies, and even in this context, best practices require attempts to taper and discontinue.[4] Limited biomedical treatment options have further pressed the need for new approaches to treatment and care, and this requires better understanding of these behaviors, their causes, and measurement.

The confusion surrounding these behaviors is also reflected in that researchers and care providers no longer even agree as to what to call them. Neuropsychiatric symptoms (NPS) and behavioral and psychological symptoms of dementia (BPSD) are the most common labels, but challenging behaviors, behaviors that challenge, distressing behaviors, and unmet needs have also been used in the research literature. These various labels refer to a common experience: sometimes people living with dementia do things that are not fully understood by those providing care and who find this distressing. The lack of understanding extends to research as well and this rests at least partially on our limited operationalization and measurement of the behavior and its context.

Measurement efforts have largely followed a biomedical conceptualization that relies upon the application of global measures including the Neuropsychiatric Inventory,[5] the Cohen-Mansfield Agitation Inventory,[6] BEHAVE-AD scale,[7] the Revised Memory and Behavior Problem Checklist,[8] and the Challenging Behaviour Scale,[9] some of which have been reviewed elsewhere.[10] Most of these measures assume that the various behaviors contained therein cluster together and form a coherent, meaningful construct. Moreover, these measures take a global approach to screening for the frequency and severity of various behaviors, treating all as lying on a continuum, with little attention to context (e.g., antecedents and consequences), and meaning of the behavior.

Person-centered care conceptualizes behavioral changes as expressions of the person's distress or unmet needs. Rather than treating these behaviors as a reified construct driven primarily by the dementia syndrome or brain pathology, person-centered care treats these

RESEARCH IN CONTEXT

1. **Systematic Review**: The authors reviewed the literature using traditional sources including PsycInfo, PubMed, EBSCO, and CINAHL to identify measures of apathy and resistance to care (RTC) 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 three measures of RTC and ten measures of apathy that had been tested in samples of people living with dementia. Most demonstrated good psychometric properties but few evaluated context of behavior and none included the perspective of people living with dementia.

3. **Future Directions**: This article identifies several areas in which additional measure development is needed and highlights the need for greater attention to conceptually driven measurement of behavior and inclusion of the perspectives of people living with dementia.

as (1) purposeful expressions disrupted by the cognitive and communication changes associated with dementia, that are (2) experienced as challenging and stressful because they are not fully understood by those providing care. In this approach, the fundamental problem is our limited understanding of the person exhibiting them and their underlying needs. Although these behaviors become more common as neuropathology spreads and functioning declines, they remain fundamental, individualized expressions of human agency. For the purposes of this paper, we will abandon the term BPSD because the behavioral expressions are not necessarily symptoms of dementia, which only further implies that these are part of the disease, rather than meaningful expressions driven by antecedents such as unmet needs or inadequate care.

The review described in this paper builds upon the Dementia Care Practice Recommendations (DCPR) published by the Alzheimer's Association in 2018[11] and a review by Scales et al.[12] on nonpharmacological practices to address behavior change and the need for targeted outcome measures that evolve from person-centered frameworks and help evaluate care and interventions. Moreover, instead of treating behavioral expressions as part of a larger syndrome that is driven by dementia, we investigate specific behavioral expressions that are distressing to formal and family caregivers and compromise quality of life in people living with dementia. We selected apathy and RTC because they are highly prevalent and upsetting to caregivers and may be expressions of distress for people living with dementia.

Apathy is loss of motivation, initiative, and activity that is common in people living with dementia. Apathy has been linked to dementia

severity and to greater caregiver distress, but can also be decreased with psychosocial interventions.[1] Although a variety of apathy measures exist, the current paper examines standalone measures that were specifically designed to measure apathy in people living with dementia.

RTC occurs when a caregiver initiates an activity (e.g., personal care) and the person living with dementia does not cooperate, or when they "withstand or oppose the efforts of a caregiver."[10] Some have conceptualized RTC as expressions of unmet need,[13] suggesting that RTC behaviors are meaningful and purposeful, but compromised in their expression by dementia-related changes in cognition and communication.[14–16] RTC may occur when the caregiver fails to adequately communicate their intent before initiating the care process or when dementia-related changes diminish understanding by the person living with dementia.

Whereas apathy is expressed by declines in motivated behavior, RTC represents an increase in activity in response to care attempts. Both make care attempts more difficult by failing to elicit the desired response to the caregiver, but apathy elicits little response while RTC elicits an active, yet undesirable, response. Both are responses to engage a person living with dementia, and are disappointing and potentially challenging to family caregivers, yet they are distinct from one another in their expression and their consequences for the person with dementia. In paid care situations, apathy may put the person at risk for neglect, whereas RTC may put the person at risk for chemical/physical restraint. Examples of RTC and apathy are illustrated in the vignettes below.

> Henrik has been caring for Mina for 2 years. When he tries to help her get cleaned up, she often gets upset and slaps at his hands, particularly when he tries to help her undress for the bath. This continues as he runs the water for the tub, and as he tries to coax her to step in. Mina sometimes yells and uses words Henrik finds upsetting and hurtful.

> Bernadette has been caring for Linda who was diagnosed with Alzheimer's disease several years ago. When Bernadette attempts to engage Linda in personal care, she does not resist, but also does not take part. In fact, Bernadette has trouble engaging Linda at all. She simply doesn't seem to care. This is a significant and upsetting change, leaving Bernadette to feel like she is losing her best friend who just doesn't seem like herself anymore.

These brief vignette's highlight the central features of RTC and apathy, respectively. The person living with dementia exhibits a behavior that is not understood and is upsetting. From a measurement perspective, neither of these care situations would be adequately captured by a global BPSD index, which may be better suited for screening for the presence and severity of these behaviors. Although well validated from a psychometric perspective, the global measures do not increase understanding of the behavior in context. They cannot help move research forward because they are not sufficiently detailed in terms of the social and context features, and do not provide an understanding of how these behaviors might be an expression of the person and their agency, rather than a symptom of dementia.

Measurement approaches must be expanded to provide a whole person conceptualization of these phenomena that seeks to understand the behavior as meaningful and purposeful to the person expressing it and that has individualized antecedents and consequences. Rather than reviewing global measures of behavior, the current review focuses exclusively on instruments designed to measure apathy and RTC. Global measures and their subscales were excluded, as were single items from the Minimum Data Set.

Where evidence was available, this review considered factors that promote or diminish these behavioral expressions. Person-centered processes and structures might promote better understanding of the antecedents of behavior, thereby reducing the person's need for behavioral expressions. Structures include a focus on contextual factors such as place (i.e., home, assisted living, long-term care, outpatient clinic), whereas processes for responding to behavior might include taking a functional analytic approach to behaviors, rather than medicating the behavior, may also reduce the frequency and reduce the negative consequences for the person with dementia and their family caregivers. For each measure reviewed, we investigate and report whether structures or processes are measured. It is worth noting here that structures and processes can be determinants and antecedents of behavior, or consequences and reactions to the behavior of others.

2 | METHODS

This review followed the COSMIN (Consensus-Based Standards for the Selection of Health Measurement Instruments) framework[17] guidelines. The constructs under study included apathy and RTC, and the population included people living with dementia. Eligibility criteria included peer-reviewed papers investigating the psychometric properties of self-report or observer ratings of RTC and apathy. MEDLINE, PsycInfo, and CINAHL were searched for eligible articles that (1) included measures of the identified constructs, (2) were collected on samples of people living with dementia, and (3) reported psychometric properties for the measures of interest. Studies with older adults without cognitive impairment or with mild cognitive impairment were excluded.

RTC was the primary search term, and was expanded to include aggressive resistance, care refusal, and resistiveness. Apathy was expanded to include passivity, lack of motivation, doing nothing, and engagement/disengagement. Only peer-reviewed papers published in English were included in this review. This search yielded 49 articles for RTC and 654 for apathy. All abstracts were reviewed to identify papers that included stand-alone measures of RTC or apathy. Of these abstracts, three RTC papers covering three measures and 16 apathy papers covering 10 measures were reviewed and included in Tables 1 and 2 (see Figures 1 and 2).

TABLE 1 Measures of resistance to care

Study authors	Year	Measure name	Sample/design	Reliability	Validity	Measurement of context	Who can use the scale, training, etc.
Mahoney et al.	1999	Resistance To Care in Dementia of the Alzheimer's Type (RTC-DAT)	Sample: Face and Content Validity established with 29 licensed and non-licensed nursing home staff. Reliability established with 68 nursing home residents. Design: Observational measure. 13 items not unidimensional.	Internal consistency: Cronbach's $\alpha = 0.87$. Item-total correlations ranged from 0.16–0.77. Lowest Kappa = 0.82	Construct validity: assessed by PCA, three factor solution accounted for 52.3% of total variance. Criterion-related validity: RTC-DAT correlated with the Discomfort Scale, $r = 0.5$, $P < .001$.	Not formally evaluated, but as an observational measure the RTC-DAT gives opportunity to gather information about the environment.	Scale is best used with video data because raters need to simultaneously capture individual behaviors and their duration. Training time not discussed.
Jablonski-Jaudon et al.	2016	Resistiveness To Care- revised (RTC-r)	Sample: 2328 observations of oral care with 83 nursing home residents with dementia to determine inter-rater reliability. Design: Observational measure. Duration categories removed and added a question on completion of oral care. Definition of care. Definition of "grab object" expanded to include "biting toothbrush."	Inter-rater reliability: ranged from 0.87 to 1.0.	Criterion-related validity: RCT-r scores correlated with a visual analogue scale that measures global restiveness (Spearman $r = 0.92$).	Not formally evaluated, but opportunity to gather information from the environment, same as above.	Revised RCT-DAT for direct observation in real-time clinical setting. Used in study of resistiveness to oral care. Training requires 9–15 hours depending on experience of rater. Raters included allied health, psychology, dentistry and nursing personnel.
Clifford et al.	2003	The Psychosocial Resistance to Activities of Daily Living Index (PRADLI)	Sample: 406 nursing home residents. Design: Caregiver subjective retrospective measure representing a scaling procedure to capture dependency due to resistiveness to care. Eight ADL items that include a rating for cooperation on a 7-point Likert type scale.	Internal consistency: Cronbach $\alpha = 0.88$. Median item-total correlation was $r = 0.56$. Test-retest: ($N = 22$) ranged from 0.83 (toileting) to 0.98 (medical compliance).	Composite PRADLI variable (PCA) correlated with FAST score ($r = -0.56$, $P < .0001$). All PRADLI items significantly correlated with Katz ADL scale ($r = 0.30$ to 0.98). Most items significantly correlated with the Geriatric Depression Scale ($r = -0.20$ to -0.12), the Neurobehavioral Cognitive Status Exam scales ($r = -0.01$ to 0.44), Dysfunctional behaviors ($r = -0.12$ to -0.18), and pain intensity ($r = -0.11$ to -0.17).	Not evaluated	Ratings on all scales done by licensed clinical geropsychologist.

Abbreviations: ADL, activities of daily living; PCA, principal components analysis.

TABLE 2 Measures of apathy

Study authors	Year	Measure name	Sample/design	Reliability	Validity	Measurement of context	Who can use the scale, training, etc.
Marin et al.	1991	Apathy Evaluation Scale (AES)	Sample: 123 adults, age 55–85. Healthy ($n = 31$), stroke ($n = 41$), probable AD ($n = 21$), depression ($n = 30$). Design: development, reliability, and validity of AES. Participants, clinicians, and informants completed AES-S, AES-C, and AES-I, respectively. To assess predictive validity, participants were placed in a waiting room and invited to interact with toys and games.	Internal consistency: AES-C $\alpha = 0.90$, AES-I $\alpha = 0.94$, AES-S $\alpha = 0.86$. Test-retest: AES-C $r = 0.88$, AES-I $r = 0.94$, AES-S $r = 0.76$. AD group AES-S $r = 0.44$. Interrater: Two raters-psychiatrist and master's level RA. ICC = 0.94.	Convergent validity: intercorrelations of AES-C, AES-I, AES-S, $r = 0.43-0.72$. Discriminant validity: clinician and self-rating of apathy correlated more strongly with other ratings of apathy than depression. Informant rating of apathy correlated almost the same or slightly better with measure of depression than with clinician and self-rating of apathy. Predictive validity: No significant correlation on number of games used. Percentage of total time interacting with the games correlated with AES-C ($r = -0.40$, $P \leq .001$) and AES-I ($r = -0.33$, $P = .004$). Average time per game correlated with AES-C ($r = -0.24$, $P \leq .001$) and AES-I ($r = -0.34$, $P = .003$). AES-S n.s.	Not evaluated	AES has three scales to be completed by the patient, an informant, and a clinician. A psychiatrist and master's level RA completed the clinician scale.
Clarke et al.	2007	Apathy Evaluation Scale (AES)	Sample: 121 adults (mean age 73.7, 52.9% female) strongly suspected to have dementia. Diagnosis for 105 participants; AD (55.2%), mixed dementia (20%), DLB (9.5%), vascular (5.7%), FTD (4.8%), other (4.8%). Design: Examines factor structure, suggests cutoff scores, and explores psychometric properties.	Factor analysis found two factors, apathy and interest, for AES-C and AES-I. AES-S has two factors: apathy and "other." Internal consistency: AES-C apathy factor $\alpha = 0.90$, interest factor $\alpha = 0.86$. AES-I apathy factor $\alpha = 0.90$, interest factor $\alpha = 0.88$. AES-S apathy factors $\alpha = 0.90$, other factor $\alpha = 0.41$.	Convergent validity: AES compared to NPI apathy subscale. AES-I ($r = 0.49$, $P < .01$), AES-C ($r = 0.27$, $P < .01$), AES-S ($r = 0.22$, $P < .05$) Discriminant validity: NPI depression subscale had low correlation with AES-I ($r = 0.22$, $P < .05$) and AES-S ($r = 0.23$, $P < .05$); no correlation with AES-C. Various other NPI subscales tended to correlate with AES-I but not AES-C or AES-S. Structure Clinical interview for DSM-IV not correlated with any scale. For all three forms: sensitivity (61.5%–92.9%), specificity (56.6%–65.2%), PPV (0.41–0.50), NPV (0.81–0.94).	Not evaluated	

(Continues)

TABLE 2 (Continued)

Study authors	Year	Measure name	Sample/design	Reliability	Validity	Measurement of context	Who can use the scale, training, etc.
Hsieh et al.	2012	Apathy Evaluation Scale (AES) Taiwanese version	Sample: 144 participants (mean age 74.5, 52.1% male) with AD recruited from nursing homes and outpatient clinics in Taiwan Design: validate Taiwanese version of AES-C. AES-C translated to Taiwanese, then translated back to English by another individual who had not seen original English version. Process repeated until original and translated versions agreed.	Internal consistency: AES-C $\alpha = 0.85$ Test–retest: 3-day interval between assessments for 12 participants, $r = 0.89$	Criterion: AES-C correlated with NPI apathy subscale, $r = 0.61$, $P < .001$. Convergent: Positive correlation between AES-C and NPI anxiety subscale, $r = 0.35$, $P < .001$. Discriminant: AES-C did not correlate with NPI depression subscale. Negative correlation between AES-C and NPI euphoria subscale, $r = -0.46$, $P < .001$. Known-group validity: moderate AD participants had significantly higher AES-C scores than mild AD, $t = -2.98$, $P < .005$.	Not evaluated	Not evaluated
Koller et al.	2016	Apathy Evaluation Scale (AES) German Informant version	Sample: 100 community dwelling individuals with dementia (mean age 83.2, 71% female) and 80 caregivers Design: Participants assessed with German version AES-I and other cognitive, functional, and psychological measures.	Internal consistency: total scale German version AES-I $\alpha = 0.88$. Two items with low correlations were removed, improving Cronbach's α to 0.90. The shortened, 16-item version was used for further analyses.	16 item German AES-I correlated with the Barthel Index ($r_s = -0.43$, $P < .001$) and the Quality of Life-Alzheimer's Disease ($r_s = -0.70$, $P < .001$).	Not evaluated	Not evaluated
Lueken et al.	2007	Short version of the Apathy Evaluation Scale (AES-10) adapted for nursing home residents with dementia in Germany	Sample: Nursing home residents ($n = 356$, mean age 85.6, 82.9% female). AD (69%), vascular (7%), mixed dementia (4%), FTD (1%), non-classified (3%), MCI (8%), no signs of cognitive impairment (7%). dementia in PD (1%), Design: Development and psychometric properties of a brief version of the AES. Participants split into matched samples. Group A was used to develop the shortened scale. Group B was used to cross-validate shortened scale.	Correlation with original 18-item scale, $r = 0.97$ for both groups Internal consistency: Remained high for shortened version. Original AES, $\alpha = 0.94$; AES-10, $\alpha = 0.92$.	Convergent: NPI apathy subscale correlation with group A AES-10 ($r = 0.61$) and group B AES-10 ($r = 0.62$). Discriminant: NPI depression subscale correlation with group A AES-10 ($r = 0.07$) and group B AES-10 ($r = 0.09$). AES-10 correlation with MMSE and GDS decreased compared to AES-18.	Not evaluated	Developed specifically for use with nursing home residents with dementia.

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TABLE 2 (Continued)

Study authors	Year	Measure name	Sample/design	Reliability	Validity	Measurement of context	Who can use the scale, training, etc.
Leontjevas et al.	2012	Abbreviated Apathy Evaluation Scale (AES-10)	Sample: 100 nursing home residents (mean age 84.0, 66% female). No dementia (42%), AD (17%), vascular (11%), other (4%), mixed (8%), not specified (18%). Design: compare performance of NPI apathy subscale and AES-10 against the diagnostic criteria for apathy.	Internal consistency: AES-10, $\alpha = 0.95$.	Convergent: AES-10 and NPI apathy subscale correlated, $r_s = 0.62, P < .0001$. Discriminant: AES-10 correlated with Cornell Scale for Depression in Dementia, $r_s = 0.27, P = .024$. Concurrent: ROC curve analysis found AUC of 0.72 for AES-10 for all participants. In participants with dementia, AUC was not significant. Cut-off score of > 29 had sensitivity of 0.71, specificity of 0.70, and PPV of 0.28.	Not evaluated	Assessment through interview with a professional caregiver—no more details provided.
Agüera-Ortiz et al.	2015	APADEM – NH (apathy in dementia, nursing home)	Sample: Nursing home residents with different severities of dementia (n = 100). Design: Validation and psychometric properties of APADEM-NH.	Internal consistency: item total correlation was 0.43 to 0.72 for items; Cronbach's $\alpha = 0.83$–0.88 for overall domains. Test-retest: weighted kappa was 0.48 to 0.92 for items; ICC = 0.80 to 0.88 for domains. Inter-rater: weighted kappa was 0.84 to 1.00 for items; ICC = 0.97–0.99 for domains.	Convergent validity: APADEM-NH significantly correlated with AI ($r_s = 0.33$) and NPIa ($r_s = 0.31$), and with dementia severity, GDS ($r_s = 0.63$) and CDR ($r_s = 0.51$). No correlation with depression scales–Cornell Scale of Depression in Dementia and NPI depression. Known groups: APADEM-NH scores increased with dementia severity.	Not formally evaluated, but many items ask about behavior in specific situations.	Assessment through interview with a professional caregiver—no more details provided.
Robert et al.	2002	Apathy Inventory (AI)	Sample: 115 older adults: healthy controls (n = 19), MCI (n = 24), Parkinson's disease (n = 12), AD (n = 60). Design: Two versions of AI tested, Informant Report and Self-report	Internal consistency: Cronbach's α for Informant version = 0.84. Full sample not reported. Inter-rater: full sample (all items and global score) Kappa coefficient = 0.99. Test-retest: full sample emotional blunting (Kappa = 0.99); lack of initiative (Kappa = 0.97); lack of interest (kappa = 0.99); and global score 0.99); and global score (Kappa = 0.96).	Concurrent validity for full sample: lack of initiative ($r = 0.23$) and lack of interest ($r = 0.63$) correlated significantly with NPI apathy score. No concurrent validity for full sample self-report version. Concurrent validity for AD group: Informant version lack of initiative ($r = 0.22$) and lack of interest ($r = 0.66$) correlated significantly with NPI apathy score. No concurrent validity demonstrated for AD self-report version.	Not evaluated	Can be used by person with diagnosis (MCI, Parkinson's, AD) and knowledgeable informants.

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TABLE 2 (Continued)

Study authors	Year	Measure name	Sample/design	Reliability	Validity	Measurement of context	Who can use the scale, training, etc.
Stella	2013	Apathy Inventory (AI)	Sample: 175 older adults: AD (*n* = 55), Parkinson's disease (*n* = 30), depression (*n* = 32), MCI (*n* = 35), and healthy controls (*n* = 23). Design: Informant version used to establish the psychometric properties of AI in Brazilian population. AI translated into Portuguese and back translated into English.	Inter-rater reliability for full sample using intra-class correlations: AI emotional blunting (F = 0.805); AI lack of initiative (F = 0.881); lack of interest (F = 0.859); and total score (F = 0.965). Internal consistency using Cronbach's alpha coefficient and two raters: emotional blunting (0.930 and 0.962); lack of initiative (0.914 and 0.924); lack of interest (0.913 and 0.924); and total score (0.945 and 0.958).	Concurrent validity for full sample using NPI-C/Apathy domain (Spearman's correlation coefficient), and two raters: emotional blunting (rho = 0.849 and 0.852); lack of initiative (rho = 0.892 and 0.903); lack of interest (rho = 0.895 and 0.932); and total score (rho = 0.956 and 0.970).	Not evaluated	Healthcare clinicians (discipline not specified) were informants in this study. AI valid in Brazilian population.
Guidmaraes et al.	2009	Brazilian caregiver version of Apathy Scale (AS)	Sample: Initial translated version given to caregivers of people with AD or FTD (*n* = 11). Revised version then applied with individuals with AD or possible AD (*n* = 20). Design: Aim to create a Brazilian version of apathy scale and validate for use with carers.	Not assessed	Convergent: AS scores correlated with NPI apathy (*r* = 0.756, *P* = 0.001) and with DAD (*r* = −0.793, *P* = 0.0005).	Not evaluated	
Strauss & Sperry	2002	Dementia Apathy Interview and Rating (DAIR)	Sample: 50 men and 50 women (mean age 75.0) with probable or possible AD. Design: Development and psychometrics of DAIR. Caregivers completed DAIR either in person or over telephone.	Internal consistency: overall *α* = 0.89. In person 0.91, telephone 0.94. Test–retest: 20 caregivers interviewed twice, mean 56 days between administrations. *r* = 0.85, *P* < .001. Inter-rater: second rater scored 10 recorded interviews with 100% agreement.	Concurrent: DAIR ratings compared to subjective apathy ratings (1–10 scale) of physician, nurse, and neuropsychology technician. Correlation with physician (*r* = 0.31, *P* < .05) and technician (*r* = 0.46, *P* < .01) was significant, but nurse ratings did not significantly correlate. DAIR correlated at <0.001 level with MMSE (*r* = −0.36), CDR (*r* = 0.40), and BDRS ADL (*r* = 0.54). Discriminant: DAIR did not significantly correlate with BDRS depression subscale.	Not evaluated	Scale designed to be used for individuals with mild or moderate dementia. Assessment design is structured interview with caregivers. Not stated who is qualified to administer the scale.

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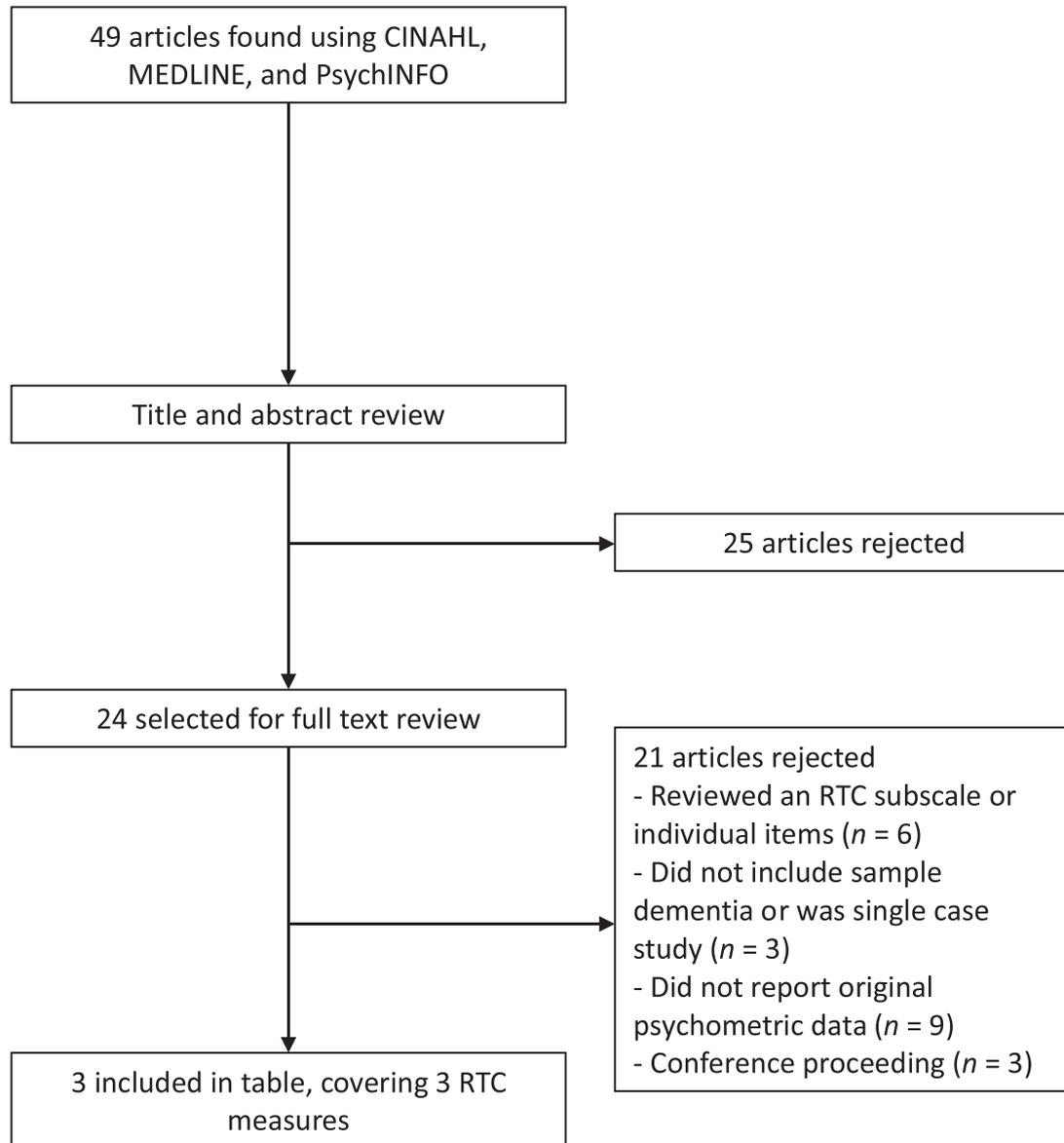| Study authors	Year	Measure name	Sample/design	Reliability	Validity	Measurement of context	Who can use the scale, training, etc.
Radakovic et al.	2017	Dimensional Apathy Scale (DAS)	Sample: people with self-reported AD diagnosis (n = 55, mean age 77.5, 28 male), carers (n = 102, mean age 78.2, 52 male), and control participants (n = 55, mean age 75, 28 male). Design: Cross-sectional study to investigate the psychometric properties of the DAS in dementia.	Internal consistency: Informant/caregiver version α = 0.93 and the self-rated version α = 0.85. Executive subscale (informant α = 0.89, self α = 0.86), Initiation subscale (informant α = 0.88, self α = 0.84), Emotional subscale (informant α = 0.73, self = 0.54).	People with dementia scored significantly higher on apathy relative to controls (P = .001). Convergent: informant rating correlated with AES (0.75) and GDS-15 (0.36), and self-ratings correlated with AES (0.75) and GDS-15 (0.52). Latent class analysis confirmed three subgroups based on apathy profile in dementia: Executive/initiation, global, minimal apathy.	Not evaluated	24-item scale for use in clinical and research settings. Informant and/or self-rated.
Radakovic et al.	2020	The Brief Dimensional Apathy Scale (b-DAS)	Sample: individuals with AD (n = 102, mean age 78.2, 52 male) and amyotrophic lateral sclerosis (n = 102, mean age 68, 71 male). Design: Secondary and cross-sectional analysis of responses to the DAS to create the brief DAS.	Not assessed	Convergent: all 9 items of b-DAS correlated with AES (0.5–0.8). Discriminant: items of b-DAS correlated with GDS-15 (0.12–0.43). Cut off scores on each sub-scale of the b-DAS were determined based on PPV/NPV scores and optimal sensitivity (ranged 94.4–98.8) and specificity (ranged 77.3–86.9).	Not evaluated	Suitable for use in clinical and research settings – no formal training required. Informant based.
Fernández-Matarrubia et al.	2016	Lille Apathy Rating Scale (LARS) adapted for people with mild to mod dementia	Sample: Individuals with cognitive impairment (n = 101), but 27 had questionable dementia and 7 had score of 0 on CDR. Comparison group of healthy controls (n = 50). Design: Original LARS measure translated, back translated and assessed for ICC and test–retest reliability.	Test–retest: ICC = 0.940, P < .001, n = 16. r = 0.943 P < .001. Inter-rater: ICC = 0.987 P < .001, r = 0.971 P < .001. Two scales with ICC of 0.5 (social life) and 0.6 (self-awareness). Internal consistency: Cronbach's α = 0.94. Item total correlations 0.63–0.84.	Concurrent: LARS and NPI apathy scores for the entire sample correlated (r_s = 0.834; P < .001). For individuals with cognitive impairment, the LARS correlated with NPI apathy (r = 0.800, P < .001) and with Frontal Behavioral Inventory apathy subscale (r = 0.777, P < .001). Sensitivity is 93.4 and specificity is 92.2 with −9 cut-off score.	Not formally evaluated, but the scale includes some open-ended questions that could be an opportunity to gather information about the context of behavior	Adapted to be used for individuals with mild to moderate dementia. Scale completed by a clinician, not specified what qualifies as clinician. In the study LARS applied by a neurologist and neuropsychologist

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TABLE 2 (Continued)

Study authors	Year	Measure name	Sample/design	Reliability	Validity	Measurement of context	Who can use the scale, training, etc.
Jao et al.	2016	Person Environment Apathy Rating (PEAR)	Sample: For feasibility study: direct observation of residents ($n = 6$). For construct validity: individuals with dementia ($n = 24$), 96 videos comprised of 4 videos over 2 days per participant. Design: Aim is to distinguish two populations (truly apathetic or simply have fewer stimuli to which they can respond) through measurement of apathy and quality of environmental stimulation. Cross-sectional. Correlational design, videos, secondary data analysis (from repository).	Environment subscale- Intra-rater reliability: 79.2%–92.7% for agreement and 0.63–0.94 for weighted kappa. Internal consistency: Cronbach's alpha = 0.84. Inter-rater reliability of 48 videos: 74.0%–89.6% for agreement and 0.49–0.94 for weighted kappa. Apathy subscale-Intra- rater reliability was 75.0%–89.6% for agreement and 0.74–0.89 for weighted kappa. Internal consistency: Cronbach's alpha = 0.85. Inter-rater reliability of 48 videos: except for the facial expression and eye contact items, was 63.5%–85.4% for agreement and 0.66–0.86 for weighted kappa. Facial expression and eye contact had 51.0% and 56.3% agreement and 0.60 and 0.47 weighted kappa, respectively.	Concurrent validity: Environment subscale correlated with the Crowding Index ($r = 0.23$). No correlation with the Ambiance Scale. Convergent: Apathy subscale correlated with NPI-Apathy ($r = 0.710$) and the Passivity in Dementia Scale ($r = 0.814$). Discriminant: Apathy subscale correlated with NPI-Depression ($r = 0.462$).	Environment evaluated as integral aspect of apathetic behavior. Driven by goal-directed behavior model and environmental aspects. Environmental stimulation is an external determinant that triggers individuals' intentions and starts the cycle (goal-directed behavior).	Trained raters score videos of nursing home residents.
Jao et al.	2018	Person– Environment Apathy Rating (PEAR)	Sample: LTC residents with dementia ($n = 15$). Design: measure the inter-rater reliability of the PEAR scale for LTC residents with dementia using real-time observations.	Inter-rater reliability of Envir. Subscale: weighted kappa 0.5–0.82. 4 of six items > 0.6. Apathy Subscale: weighted kappa 0.5–0.8; five of six items > 0.6.		Environment evaluated as integral aspect of apathetic behavior (see above).	All research assistants reported having training in general research and experience in dementia research. Additional rating instruction and training for rater may improve the reliability.

Abbreviations: AD, Alzheimer's disease; ADL, activities of daily living; AUC, area under the curve; BDRS, Blessed Dementia Rating Scale; CDR, Clinical Dementia Rating; DAD, Disability Assessment for Dementia; DLB, dementia with Lewy bodies; DSM-IV, Diagnostic and Statistical Manual of Mental Disorders, 4th edition; FTD, frontotemporal dementia; GDS, Geriatric Depression Scale; ICC, intra-class correlation; MCI, mild cognitive impairment; MMSE, Mini-Mental State Examination; NPI, Neuropsychiatric Inventory; NPV, negative predictive value; PD, Parkinson's disease; PPV, positive predictive value; RA, research association; ROC, receiver operating characteristic.

FIGURE 1   Literature review flowchart—Resistance to care (RTC)

2.1 | Review criteria and evaluation

Instruments reported in the identified papers 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 reviews[18,19] and the COSMIN framework.[17] For measures included in intervention studies, we also review and report the extent to which the identified measures responded to intervention. Finally, consistent with the person-centered framework and prior reviews,[1,20] we also reviewed the articles and measures for identified

person, caregiver, and environmental determinants of the behavior. These are conceptualized as antecedents or risk factors for the behavior as identified in the study under review. We also sought to identify consequences of the behavior, as they were demonstrated empirically in the papers under study.

3 | RESULTS

Thirteen measures were reviewed for psychometric properties and whether they evaluated the context of behavior. Ten measures of apathy and three measures of RTC were reviewed. Measures with published psychometric properties are included in Tables 1 and 2 and results are presented below.
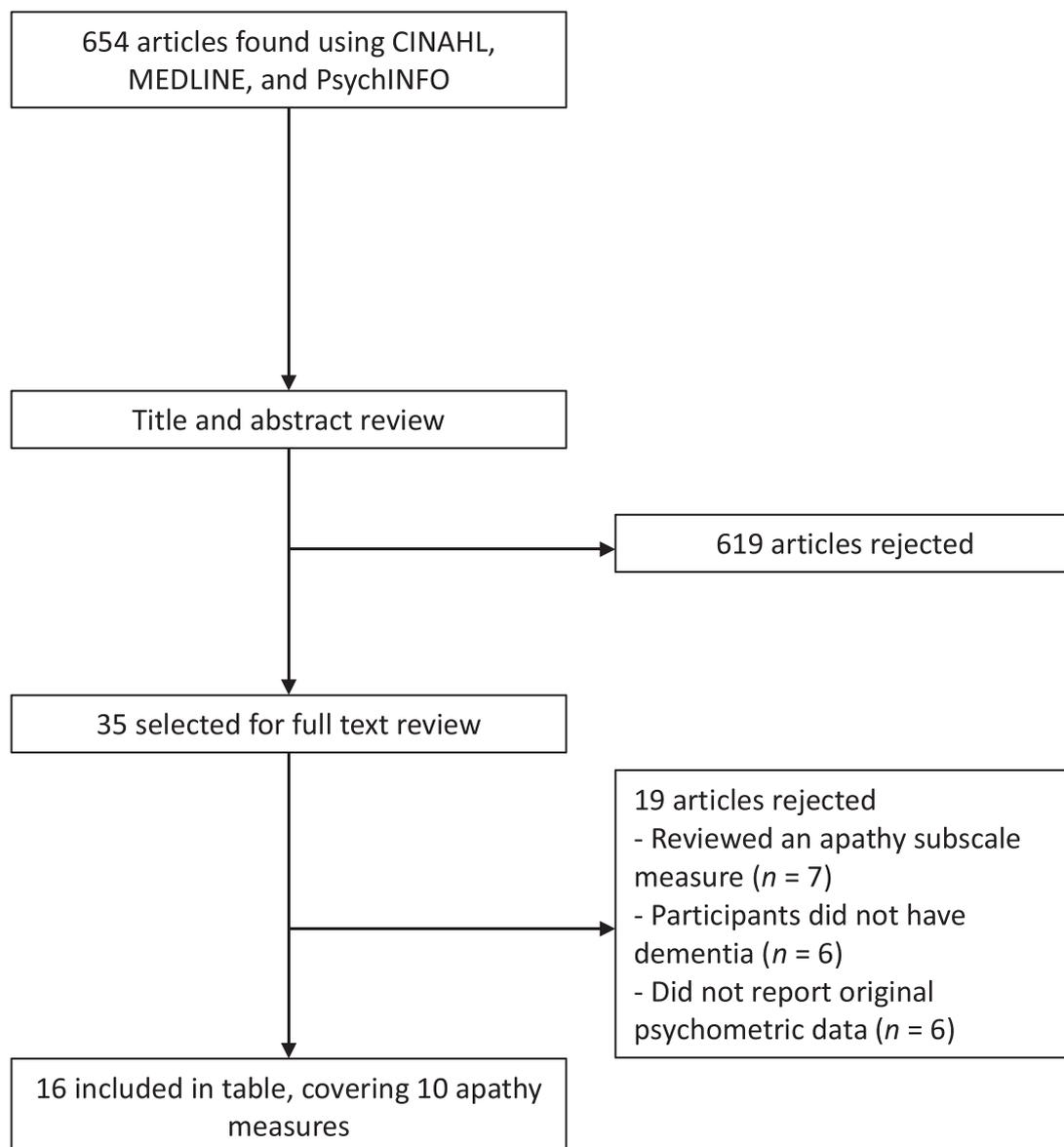
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┌─────────────────────────────────┐
│   654 articles found using CINAHL, │
│      MEDLINE, and PsychINFO        │
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└─────────────────────────────────┘          ▼
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                  │              │    619 articles rejected      │
                  │              └─────────────────────────────┘
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│   35 selected for full text review │──────────┐
└─────────────────────────────────┘          ▼
                  │              ┌─────────────────────────────┐
                  │              │ 19 articles rejected          │
                  │              │ - Reviewed an apathy subscale │
                  │              │ measure (n = 7)               │
                  │              │ - Participants did not have   │
                  │              │ dementia (n = 6)              │
                  │              │ - Did not report original     │
                  │              │ psychometric data (n = 6)     │
                  ▼              └─────────────────────────────┘
┌─────────────────────────────────┐
│ 16 included in table, covering 10 │
│      apathy measures               │
└─────────────────────────────────┘
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FIGURE 2 Literature review flowchart—Apathy

3.1 | Resistance to care

3.1.1 | Resistance to Care Scale for Dementia of the Alzheimer's Type

The Resistance to Care Scale for Dementia of the Alzheimer's Type (RTC-DAT) was developed by Mahoney et al. as the first domain-specific observational scale for measuring RTC in people living with dementia of the Alzheimer's type. Prior to the development of RTC-DAT only item-level measurement was available in the context of broader behavioral measures.[10] RTC-DAT has 13 specific behaviors that can serve as expressions of resistance. The scale achieved strong internal consistency reliability and agreement across raters as to the presence or absence of the 13 specific behaviors (see Table 1), as well as intensity and duration. Factor analyses supported three factors,

although the factors did not have adequate reliability and the authors recommend using a total score rather than factor scores. Observers can rate these behaviors using live observation or using video recordings. The RTC-DAT was developed with the intention of considering antecedents and consequences of resistance, recognizing that the 13 behaviors can be meaningful expression that are prompted by specific events and interactions, such as caregiver assistance with eating or bathing.

3.1.2 | Revision of RTC-DAT: RTC-r

The RTC-DAT was revised by Jablonski-Jaudon et al. for use in real time rather than video recordings.[21] Duration was removed from scoring, and a modified scoring with frequency and intensity of care

resistive behaviors was implemented. The RTC-r demonstrated strong interrater reliability and convergent validity.

3.1.3 | Psychosocial Resistance to Activities of Daily Living Index (PRADLI)

The PRADLI (Psychosocial Resistance to Activities of Daily Living Index) is an 8-item rating scale used to measure resistance in activities of daily living (ADL) care developed by Clifford et al.[22] Resistance in each ADL is rated by the caregiver on a 7-point Likert style response ranging from 1 (non-cooperative and independent) to 7 (motivated, oriented, and independent). Each response combines the person's level of dependence in each ADL and cooperation with care related to that ADL. In the validation sample, the PRADLI demonstrated strong internal consistency and test–retest reliability (see Table 1) and fair to good convergent validity with the Katz ADL scale. PRADLI scores were associated with Geriatric Depression Scale scores, although correlations were low ($r < –0.2$) across PRADLI items.

Although the PRADLI offers a rapid method for rating cooperation with care, it is confounded with independence and need for assistance in ADLs because each of the eight items reflects both ratings as one. Moreover, the PRADLI provides global ratings on each ADL but does not include a system for considering contextual factors or antecedents and consequences.

3.2 | Apathy

3.2.1 | Apathy Evaluation Scale

The Apathy Evaluation Scale (AES) developed by Marin et al. has three versions: a clinician (AES-C), informant (AES-I), and self-rated (AES-S) form.[23] The informant version is completed by a friend or family member familiar with the individual's daily activities. These forms consist of the same 18 items scored on a 4-point Likert scale. Of the apathy measures covered in this review, the AES has received the most attention. The AES has been translated into multiple languages, a shortened 10-item version has been developed, and it has been referred to as the gold standard for apathy measures.[24,25] The AES demonstrated good internal consistency, fair to good test–retest reliability, and good inter-rater reliability. Convergent validity with the Neuropsychiatric Inventory (NPI) apathy scale was generally good across studies, with the exception of the Clarke et al. study.[26] Table 2 provides a detailed description of the AES psychometrics. The AES was not designed specifically for people living with dementia, although all the subjects in Clarke et al.'s study were strongly suspected to have dementia.[26] This study found the AES-I to be more psychometrically sound than the AES-C or AES-S, and the authors concluded that the latter two scales are probably not needed in clinical settings.

Although the AES has strong psychometric properties, it fails to evaluate contextual factors related to apathetic behavior. The scale does not consider the environment of the individual with dementia.

Most of the items in the scale frame apathy as a trait, rather than a behavioral expression or reaction to the environment. (e.g., s/he is interested in things, s/he approaches life with intensity, s/he has motivation.) The respondent is instructed to answer according to behavior over the past 4 weeks, which does not allow for understanding of long-standing patterns in behavior or deviation from baseline. The AES also does not evaluate the caregiver's reaction or other consequences to apathetic behavior.

3.2.2 | Short version of the AES: AES-10

The AES-10, which consists solely of an interview with a caregiver, was developed for nursing home residents living with dementia. Yet, the study by Leontjevas et al. found that the AES-10 did not discriminate between apathetic and nonapathetic nursing home residents living with dementia.[27] It was only when the sample was considered as a whole, both individuals with and without dementia, that the AES-10 area under the curve was significant.

3.2.3 | Apathy Scale

The apathy Scale (AS) is a 14-item scale adapted from the AES. Guimaraães et al. sought to validate a Portuguese version of the AS.[28] The authors stated that the translated items were comprehendible, yet also described having to use extra explanation for some questions during administration. The measure was given to informal caregivers of 20 individuals with possible or probable Alzheimer's disease (AD). Reliability was not examined. Convergent validity was established using the NPI apathy subscale and Disability Assessment for Dementia (DAD), both of which had strong correlations with the AS. However, the authors did not sufficiently explain how the DAD demonstrates validity of the AS as a measure of apathy. The authors claim that the strong correlation between the AS scores and DAD scores reveal measurement of a behavioral disorder.

The AS does not inquire about the context of apathetic behaviors. Furthermore, several items use the ambiguous term "things" (Portuguese translation "coisas"; e.g., Do you put much effort into things? Are you indifferent to things? Are you unconcerned with many things?) This may cause confusion for the caregiver and does not provide insight into possible antecedents or consequences of apathetic behavior.

3.2.4 | Apathy Inventory

Robert et al. operationalized apathy similarly to Marin et al.[23,29] The Apathy Inventory (AI) covers three domains: emotional blunting, lack of initiative, and lack of interest. This short measure has one question per domain and each question is ranked 1 to 4 for frequency and 1 to 3 for severity, with a maximum overall score of 36. The measure is intended to evaluate behavior changes, either since disease onset or over a specified period of time. Preexisting apathetic behavior is not

considered. The AI has self-report and caregiver forms. However, the self-report form did not demonstrate concurrent validity and reliability was not reported. Robert et al. do not specify whether professional or informal caregivers completed the AI.[29] The caregiver version of the AI demonstrated good internal consistency and inter-rater reliability. Test–retest reliability is also good, but was evaluated by having two different examiners administer the measure on the same day and using only 14 assessments. The NPI apathy subscale was used to assess concurrent validity. The lack of interest domain showed good validity in both the full sample and AD subgroup. The other two domains failed to show adequate validity; the lack of initiative domain failed to meet criteria ($r = 0.23$ for full sample and $r = 0.22$ for AD sample) and the emotional blunting domain did not reach statistical significance. Stella translated the measure into Portuguese and concluded it would be appropriate to use the AI in a Brazilian population.[30]

Because the AI measures apathy with three items (one per domain), it provides limited information. It does not assess the context or specific instances of apathetic behavior. The AI may be convenient due to its brevity, but does not provide a wholistic picture of the experience of the individual living with dementia.

3.2.5 | Apathy in Dementia, Nursing Home

The Apathy in Dementia, Nursing Home (APADEM-NH) created by Agüera-Ortiz et al. is a shortened version of the APADEM-NH-66.[31] The article with the original 66-item scale was not included in this review because it was not published in English. In contrast to other scales that conceptualize apathy as lack of motivation, the APADEM-NH is based on Levy and Dubois's model of apathy as a reduction in self-generated and purposeful behavior.[32] The APADEM-NH is completed by a professional caregiver and has 26 items covering three dimensions: deficit of thinking and self-generated behaviors, emotional blunting, and cognitive inertia. It was designed for individuals living with dementia, including severe stages, living in a care facility. The APADEM-NH demonstrated good internal consistency, test–retest, and inter-rater reliability for overall domains. The authors hypothesized that the APADEM-NH would have a strong correlation with other apathy scales and a moderate correlation with dementia severity. Yet they found a correlation of 0.33 with the apathy inventory and 0.31 with the apathy subscale of the NPI, which does not meet criteria for fair. Additionally, contrary to the authors' hypothesis, the APADEM-NH had a stronger correlation with the global deterioration scale and Clinical Dementia Rating scores.

The authors claim a significant limitation of other apathy scales is the low ceiling. Many people living with dementia obtain the maximum score on apathy scales, which does not provide useful care planning information. In contrast, participants earned total scores across the entire range possible on the APADEM-NH scale, without a notable skew in the distribution of scores. This indicates a lack of floor and ceiling effects, which provides a better indication of an individual's experience of apathy and could be useful in care planning. Many items on the scale ask about the individual's behavior in specific contexts (e.g.,

When I say his/her name, does s/he respond? When faced with different types of meals, does s/he show reaction to them?). This provides information about possible antecedents for the individual's apathetic behavior.

3.2.6 | Dementia Apathy Interview and Rating

The Dementia Apathy Interview and Rating (DAIR) scale is a 16-item scale that consists of a structured interview with a caregiver. The interview was completed by the primary caregiver, who had seen the individual with dementia at least two times each week for the previous month. The DAIR was created specifically for individuals living with dementia. Strauss and Sperry note that other apathy measures are inadequate for individuals with dementia, as they have items that capture symptoms of cognitive impairment, which inflates overall apathy scores.[33] Additionally, other apathy scales do not consistently discriminate between lifetime patterns of behavior and apathetic behavior that began after disease onset. The developers address both these issues in the DAIR by including items in the scale minimally related to cognitive ability (e.g., Are there things s/he is enthusiastic about? Does s/he show interest in news about friends and relatives?) and by having respondents record for each behavior whether it is a change from baseline. In a sample of 100 individuals with a diagnosis of probable or possible AD, the DAIR demonstrated good internal consistency, test–retest, and inter-rater reliability. To examine convergent validity, the scale was correlated with subjective ratings of apathy by a physician, neuropsychology technician, or nurse. The scale demonstrated fair validity with the technician's rating, but the correlation with the physician rating was low ($r = 0.31$) and did not reach significance with the nurse rating.

The DAIR does not directly measure context of behavior. The items inquire about behavior broadly (e.g., Does s/he seem less active? Is s/he concerned about how other people feel?). This does not provide insight into antecedents or consequences of apathetic behaviors.

3.2.7 | Dimensional Apathy Scale

The dimensional Apathy Scale (DAS) is a 24-item scale with informant and self-report versions. Radakovic et al. designed the DAS with three subscales to assess three subtypes of apathy: executive apathy, emotional apathy, and initiation apathy.[24] The authors mailed questionnaires to participants to investigate the reliability and validity of the DAS. Data from 102 informal caregivers and 55 individuals with AD demonstrated good internal consistency reliability. Convergent validity using the AES was also good for both the caregiver and self-report version.

3.2.8 | Brief Dimensional Apathy Scale

Radakovic et al. used data from earlier studies to create the Brief Dimensional Apathy Scale (b-DAS).[25] Data from 102 caregivers for

individuals with AD and 102 caregivers for individuals with amyotrophic lateral sclerosis was analyzed to create a 9-item caregiver version. Reliability for the b-DAS was not reported. Validity was examined with item-level correlation with the AES. Items correlated with the AES ranging from 0.5 to 0.8, indicating good convergent validity at the item level. Sensitivity and specificity of the b-DAS was examined to determine cutoff scores for each subscale. Subscale level sensitivity ranged from 94.4 to 98.8 and specificity ranged from 77.3 to 86.9.

Similar to the DAIR, the DAS and b-DAS items frame behavior broadly, rather than putting behavior in its context (e.g., S/he is able to focus on a task until it is finished; S/he is indifferent to what is going on around him/her; S/he tries new things). Antecedents and consequences of behavior are not measured.

3.2.9 | Lille Apathy Rating Scale

The Lille Apathy Rating Scale (LARS) was originally created in French and validated in a group of individuals with Parkinson's disease.[34] Fernández-Matarrubia explored the use of the LARS in a group of individuals living with dementia using a validated Spanish translation.[35,36] The LARS is administered to the patient; however, the informal caregiver or companion is present and when the informant disagrees with a patient's answer, the informant response is included. The LARS has 33 items across nine domains, which are classified into four factors: intellectual curiosity, emotion, action initiation, and self-awareness. In a sample of 101 individuals with dementia and 50 healthy controls, the LARS demonstrated good internal consistency, test–retest, and inter-rater reliability. The LARS also demonstrated good concurrent validity with the NPI apathy scale, both in the full sample and the subsample of individuals with dementia.

Although the authors state that the diagnostic criteria for apathy includes diminished motivation from baseline, patients are asked to only report their behavior from the last month. This does not allow for comparison of behavior from their previous level of functioning. The scale includes some open-ended questions (e.g., What are you interested in? What do you like doing to keep yourself occupied?). This could be an opportunity to gather information about the context of behavior.

3.2.10 | Person-Environment Apathy Rating

The Person-Environment Apathy Rating (PEAR) scale consists of an environment and apathy subscale. Both subscales consist of six items ranked 1 to 4. The environment subscale assesses stimulation clarity, stimulation strength, stimulation specificity, interaction involvement, physical accessibility, and environmental feedback, while the apathy items evaluate facial expression, eye contact, physical engagement, purposeful activity, verbal tone, and verbal expression. The PEAR psychometrics were examined using a sample of 24 participants with dementia in a long-term care facility. In contrast to other apathy measures in this review, the PEAR is completed through observations. Examiners watched video recordings of the participants taken at four different times and rated their behavior and environment. The PEAR

demonstrated good internal consistency reliability but variable inter-rater reliability. The kappa for inter-rater reliability ranged from 0.49 to 0.94 across items. In a follow-up study using in-person observations of 15 long term care residents with dementia, inter-rater reliability was similarly variable, ranging from 0.50 to 0.82 for the environment subscale and 0.50 to 0.80 for the apathy subscale.[37] The PEAR apathy subscale demonstrated good convergent validity with the NPI apathy subscale (rho = 0.710) and the Passivity in Dementia Scale (rho = 0.814). In contrast, the environment subscale demonstrated questionable convergent validity, having a low correlation with the Crowding Index and no correlation with the modified Ambience Scale. However, Jao et al. argue that construct validity is difficult to establish for the environmental subscale, given the lack of an adequate criterion measure.[38]

The PEAR evaluates context as integral to understanding apathetic behavior. Jao et al. state that environment is a vital component to consider when determining if an individual has apathy.[38] What may be considered apathetic behavior may simply be a natural lack of responsiveness due to an unstimulating environment. Jao et al. write that the PEAR is the first apathy scale to measure environmental stimulation and apathy simultaneously, which makes it uniquely suited to inform apathy interventions.[38]

4 | DISCUSSION

The research literature on behavior in people living with dementia has been dominated by research on global constructs such as BPSD. The current paper focused on domain specific, stand-alone measures of apathy and RTC, evaluating their psychometric properties and the extent to which they facilitate person-centered measurement. This is important for person-centered care research and the evaluation of a broad range of interventions designed to reduce the expression and impact of these behaviors on people living with dementia and their caregivers.

A systematic review of the literature identified three measures of RTC and ten measures of apathy. The RTC-DAT, RTC-r, and PRADLI demonstrated good reliability (above 0.8) and fair to good validity (0.4–0.59 fair; 0.6 and above good). These measures are completed by observers (RTC-DAT, RTC-r) or paid caregivers in long-term care (PRADLI) and include multiple items reflecting the RTC construct. However, neither include the perspective of the person living with dementia, nor do they include measurement of contextual factors such as antecedents or consequences of the behavior. On the one hand, these scales might be used with individuals who have difficulty articulating the reasons for their behaviors, which is likely the reason the test developers did not include this feature. On the other hand, these measurement tools also lack consideration of distress or unmet need–related questions that might prompt the rater or caregiver to consider whether these RTC behaviors are expressions of distress or unmet need.

The apathy measures generally demonstrated fair to good reliability and validity, although there was variability in the quality of their

psychometric properties. For instance, the LARS demonstrated good internal consistency, test–retest, and interrater reliability, as well as good convergent validity with the NPI apathy scale; however, some AI domains and the APADEM-NH correlated weakly with the NPI apathy scale, demonstrating questionable validity. Most apathy scales lack formal measurement of antecedents, and none examine consequences of apathetic behavior. The PEAR scale best captures the individual's behavior and environment, recognizing that level of stimulation in the environment influences apathetic behavior. The PEAR is limited to use in long-term care settings and administration by a trained rater, so there is a need for apathy measures that are easier to administer and evaluate contextual factors for individuals living with dementia at home. Without an understanding of unmet needs or circumstances of apathetic behavior, information gained from the apathy scales covered in this review has limited value in planning interventions to increase quality of life.

The existing apathy scales do not adequately consider the perspective of the individual living with dementia. The AS, APADEM-NH, and DAIR are completed by informal or professional caregivers. The AI, AES, and DAS have caregiver and self-report versions, but the AI self-report version did not demonstrate adequate validity and the shortened version of both the AES and DAS is completed only by the caregiver. The LARS is administered to the patient and the informal caregiver is present during administration to give input. For multiple scales, informal caregivers are asked to comment on the patient's internal state, such as whether the individual is motivated (DAS, AES, AS), indifferent (DAS, AS, DAIR), interested (AES, AS, APADEM-NH, DAIR) or concerned (AES, DAS, AS, DAIR). Caregivers may inaccurately make assumptions about patients' internal states based on behavior. For instance, perhaps the individual with dementia feels interested in an activity, but is challenged by physical or cognitive limitations. Such an individual may prefer not to engage with their environment rather than risk a failing attempt. As previously mentioned, it is understandable that scales fail to interview the individual with dementia considering the difficulty individuals may have providing insight into their behaviors in advanced stages of the disease. Yet this approach may cause family members, professional caregivers, and practitioners to miss valuable information about the experience of the individual with dementia. Perhaps the best approach is to include both a caregiver and patient version of behavior scales, as is done with the AI, AES, and DAS. However, decreased validity of the patient versions of the AI and AES relative to the caregiver version indicates that more research is needed to create effective self-report measures for individuals living with dementia.[26,29]

Although domain-specific measures of apathy and RTC have been developed and demonstrate promise from a psychometric perspective, additional research and development is needed to enhance person-centeredness. Person-centered perspectives on apathy and RTC suggest that these may be driven by several factors including expressions of distress or unmet needs, mismatches between the person's capacities and environmental supports or demands, or lack of understanding or unclear communication by their caregivers.[20]

There is currently a disconnect between measure development and person-centered perspectives. To bridge this gap, future measure development should be guided by strong theoretical frameworks to facilitate person-centered perspectives. These frameworks might inform a deeper understanding of specific behaviors by identifying the biomedical, psychosocial and environmental factors that explain their occurrence. Future research should also include people living with dementia to ensure that their voices and perspectives are reflected. Prior work highlights the usefulness of this methodological step such that measure development reflects the domains and behaviors that people living with dementia and their caregivers believe are most relevant.[39]

Most RTC behaviors occur in specific contexts, such as personal care initiated by a caregiver. Future measure development and revision should integrate context features including when, where, how often, as well as what happened immediately before the behavior and what happened after. RTC may also be triggered by elderspeak and other caregiver behavior.[40] The contextual features lend themselves to care interventions aimed at reducing the frequency and severity of these behaviors, and perhaps even improve understanding and empathy. This may lead to better care and lower burden among caregivers.[10,22]

Although apathy can result from damage to the brain, it also has psychological and environmental correlates.[20] Apathy may reflect an environment that is not sufficiently stimulating, is overly stimulating, or that does not provide meaningful opportunity to engage. New and revised apathy measures should include consideration of the environment and its role in promoting or diminishing apathetic behavior.

To enhance the practical care value of these measures, it would be useful to include measurement of the individual's needs and preferences that, if unmet, might be driving the behavior. Measures of care and social preferences, such as the Preferences for Everyday Living Inventory (PELI),[41–43] should be integrated to test conceptual models concerning the antecedents of apathy and RTC. It would also be useful to include possible mood states that could be considered in line with underlying distress that might be contributing to the behavior. These features would help caregivers connect behavioral expression with the person's experience.

In conclusion, although most of the measures reviewed were effective from a psychometric perspective, few were fully aligned with person-centered principles. Moreover, the measures evaluated in this paper were largely developed for research application, and additional work may be needed to help evaluate whether these tools enhance clinical care.

CONFLICTS OF INTEREST

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