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Measuring Problem Behaviors in Dementia: Developing a Methodological Agenda

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Abstract

As many as 90% of persons with dementing illness demonstrate problem behaviors that range from repetitive verbalizations, agitation, and wandering to verbal and physical aggression toward self and others.Reliable and accurate measurement of these behaviors is crucial for tracking illness progression; for monitoring the effects of pharmacologic and behavioral interventions; and for continued investigation into the correlates of caregiver stress, burden, and coping. However, there is no single, universally accepted measure or methodology for operationalizing problem behaviors, and variations in definition and measurement across studies complicate drawing meaningful conclusions about these behaviors. This article is an overview of five factors that have complicated accurate and dependable measurement of problem behaviors in dementia: the shifting domain of problem behaviors, slippage across research constructs, unexplored rater bias, scoring bias, and the absence of benchmarking studies. A methodological agenda is discussed for future investigations in this rapidly growing area of gerontological research.

Key words: aging research, behavioral assessment, dementia studies, problem behaviors

Alzheimer's disease is characterized by cognitive decline and loss of abstract thinking abilities as well as language and visuospatial difficulties. However, it is the disruptive behavioral changes associated with the illness that reduce quality of life for impaired individuals and their families and result in early institutionalization. [1-4] In addition to cognitive losses and psychiatric symptoms,

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at some point in the illness as many as 90% of the persons with dementing illness demonstrate problem behaviors that range from repetitive verbalizations, agitation, and wandering to verbal and physical aggression toward self and others. [5-9]

Reliable and accurate measurement of these problem behaviors is crucial for tracking illness progression; for monitoring the effects of pharmacologic and behavioral interventions; and for continued investigation into the correlates of caregiver stress, burden, and coping. However, there is no single, universally accepted measure or methodology for operationalizing problem behaviors, and variations in definition and measurement across studies have limited investigators' ability to draw meaningful conclusions about these behaviors. This article discusses five factors associated with measurement of problem behaviors in dementia and generates a methodological agenda for future studies. The article also includes an overview of 11 problem behavior measures frequently cited in the literature over the past decade.

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ORIGINS OF PROBLEM BEHAVIORS

Dementia of the Alzheimer's type (DAT) accounts for 80% of nonvascular dementing illnesses in the aged, [10] and there is no single causative agent for the behavioral manifestations associated with DAT. The current biological theory of DAT proposes that cognitive impairment results from neuron atrophy and loss in conjunction with the layering of protein-based (beta-amyloid) plaques and the development of neurofibrillary tangles in the frontal and parietal lobes of the brain. Extension of this cell atrophy and loss, plaque formation, and tangles in those parts of the brain involved with emotion and behavior (the hippocampus, amygdala, and olfactory cortex) is believed to result in affective and behavioral changes. [11-13]

Selected psychosocial factors also contribute to behavioral manifestations in DAT. For example, high levels of premorbid personality anxiety, depression, hostility, and openness to fantasy are correlated with similar-but heightened-behavioral characteristics in DAT patients. [14-16] In addition, situational stressors such as fatigue, acute illness or pain, changes in routine, or confusing stimuli can trigger the occurrence of problem behaviors. [17,18]

Finally, there is a growing awareness that behaviors change with illness progression. In early-stage DAT, vague personality changes, apathy, irritability, reduced ability to engage in social interaction, and lessened ability to manage the various instrumental activities of daily living (IADLs) characterize the illness. [19-21] As the illness progresses into the middle stage, disruptive behaviors and frank psychiatric symptoms such as verbal and physical aggression, screaming, wandering, and paranoid delusions and hallucinations appear. [22] However, in late-stage illness, patients often are bed bound and too debilitated to demonstrate many of the problem behaviors that previously upset and disrupted family life. [23] At this stage, the loss of basic activities of daily living (ADLs) such as eating, dressing, and continence occurs.

While the various biological, psychological, and social factors that trigger problem behaviors are not well understood, the disruptive effects of problem behaviors for DAT patients and their caregivers have generated considerable interest over the past two decades in interventions that reduce or ameliorate these behaviors. In turn, the search for effective interventions has stimulated rapid development of numerous outcome measures of behavioral problems associated with dementia.

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OPERATIONALIZING PROBLEM BEHAVIORS

There are obvious difficulties in operationalizing behaviors that are not consistently present across all subjects, are influenced by preexisting personality characteristics and concurrent situational factors, and vary according to the stage of the illness. The development of reliable and valid measures for operationalizing problem behaviors in dementia studies also has been complicated by several conceptual and methodological issues.

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Shifting domain of problem behaviors

Most behavioral measures are grounded in domain sampling models, a measurement approach in which a sample of items is drawn from a larger domain of items that represents the construct of interest. [24] Ideally, development of a new measure requires identification of the target population, definition of the domain of the construct to be measured, specification of the purpose of the measure, and construction of items that adequately represent the domain of the construct.

In the development of outcome measures, it is important to sample from all dimensions of the construct. Concern with changes in cognitive functioning and alterations in the capacity to independently perform routine activities of daily living have resulted in the use of measures that were either extremely diffuse or overly restrictive in the assessment of DAT problem behaviors.

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The diffuse measure

As a result of generating items from interviews and observations of heterogeneous dementia patient populations at varying stages of the illness, early measures often were a diffuse collection of items on cognitive losses, psychiatric symptoms, and aberant behaviors. While sum scores on such measures were intuitively appealing to researchers, they provided little information about changes in individual behaviors and were difficult to interpret.

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The restrictive measure

Some investigators attempted to classify into meaningful categories the various problem behaviors observed in dementia. For example, Rubin et al [21] specifically categorized problem behaviors in dementia as those involving passivity, self-centeredness, and agitation. Zarit and colleagues [25] grouped problem behaviors into memory losses, depressive symptoms, or disruptive behaviors. A recurring approach to classifying behavioral changes in dementing illness has been to differentiate behaviors according to whether they involve behavioral deficits or excesses. [26]

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Behavioral deficits

Progressive dementia is characterized by loss of functional independence in daily activities such as bathing, eating, walking, and social interaction with others. Thus, functional loss (behavioral deficits) in dementia often is measured through assessment of IADLs and ADLs. Failure to perform these work, social role, and self-care tasks is one of the diagnostic criteria listed for dementia in the DSM-IV. [27]

Measures of IADL and ADL deficits are predicated on whether an individual is dependent or requires some level of assistance to complete selected activities. Katz's Index of Independence in Activities of Daily Living, [28] the Philadelphia Geriatric Center Instrumental Activities of Daily Living, [29] and the Older

American Research and Services questionnaires [30] are examples of well-known measures frequently used to assess functional deficits in elder populations. While some investigators have attempted to adapt IADL-ADL measures for demented subjects, [31] the method of adaptation is seldom described in published reports.

Few ADL-IADL measures differentiate the need for physical assistance with a self-care task from the need for cueing and supervision of the impaired individual who then is able to complete the self-care task. [18] In that the incidence of dementia is higher among the aged, a complicating factor in focusing on ADL-IADL measures to assess behavior in demented elders is the difficulty of differentiating behavioral deficits associated with aging or coexisting chronic illness from those deficits associated with the dementia.

Exclusive dependence on IADL and ADL measures fails to provide a comprehensive behavioral picture. Critics of the focus on functional assessments in dementia also have noted that IADL measure scores "bottom out" (the "floor effect") early in dementing illness before measures of cognitive functioning show significant decline. [20] Thus, IADL measures are not sufficiently sensitive to behavioral change over time, and neither IADL nor ADL measures are specific to the complete range of problem behaviors in dementing illness (eg, the agitation, repetitive activities, and wandering that characterize midstage illness).

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Behavioral excesses

Although behavioral deficits are moderately stressful for families, behavioral excesses-the manifestation of disruptive behaviors-are far more stressful. [32,33] A few investigators have focused exclusively on these behavioral excesses. In her exploration of behavioral problems in nursing home patients with dementia, Cohen-Mansfield [22] concluded that agitation (patient aggressiveness toward self and others as well as nonaggressive agitative activities such as pacing, wandering, and screaming) was the criterion behavioral excess that distresses caregivers and ultimately results in institutionalization for a demented individual. Drachman and colleagues [34] explored behavioral excesses in dementia according to occurrence and severity of patient aggressiveness, idea or personality disturbances, aberrant motor behaviors (eg, wandering or repetitive actions), and vegetative activities (hyper- or hyposexuality). However, exclusive dependence on behavioral excess measures ignores behavioral problems that are present in early- and late-stage dementia.

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Slippage across research constructs

The less well defined a construct, the greater the likelihood of "slippage" between its theoretical definition and operationalizations subsequently selected to represent the construct. [35] In early dementia studies, the use of other constructs as proxies for problem behaviors, as well as the use of problem behaviors as a proxy for other constructs, resulted in theoretical-operational slippage that clouded the issue of construct validity in dementia behavior measurement.

For example, because cognitive losses lead to difficulties in performing IADLs, cognitive function tests have been used as a proxy for behavioral change in dementia. [20,36] Cognitive function measures assess the loss of memory and recall, language skills, abstract reasoning, object naming, calculation, and problem-solving behaviors. However, cognitive function tests seldom show appreciable decline until after IADL scores have dropped considerably. [37] Nor do tests of cognitive function measure or predict noncognitive behaviors that characterize dementia (eg, anger, agitation, wandering, and screaming).

Problem behaviors also have been used as indicators of other constructs in

dementia studies. This has happened most often around issues related to caregiving burden. Caregiving burden is usually conceptualized as a two-dimensional construct [38] consisting of an objective component (problems confronting the caregiver) and a subjective component (the affective reaction or response of the caregiver to objective burden). The use of problem behaviors as an indicator of objective burden in dementia caregiving studies often has confused explication of behaviors and burden as interrelated, but separate, constructs.

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Unexplored rater bias

Few dementia behavior studies report methods for rater training in the use of a measure to some criterion level, nor do they report ongoing monitoring to ensure continued adherence with rating directions. The omission in published reports of rater training and monitoring protocols makes it difficult to compare ratings across studies with confidence or to replicate caregiver rating procedures.

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Rater training

There are a few studies comparing caregiver ratings against those of clinicians. Fisher, Visintainer, and Schulz [39] reported caregiver ratings for cognitive function tests comparable with those of clinicians. Logsdon and Teri [40] had similar findings when they compared caregivers' and clinicians' ratings of depressive symptoms in demented individuals. From their pilot work in developing a measure of obstreperous behaviors, Drachman and colleagues [34] reported good intrarater reliability scores for family caregivers who rated the disruptive behaviors of a demented family member as well as good interrater reliability for two nurse aides who cared for the same patients in one nursing home.

Knowledge of a patient's cognitive deficits can influence a rater's assessment of a person's behavioral status. In their comparison of caregiver behavioral ratings (N = 49) of problem behaviors against those of trained clinicians, Auer, Monteiro, and Reisberg [41] found only moderate agreement. These investigators attributed their findings to differences in raters' interpretations of what constituted a problem behavior; rating time periods (the caregivers were asked about behaviors over the past two weeks; the clinicians made their ratings from 20-minute interviews with the demented individual); and the caregivers' focus on ADL behaviors (caregivers of late-stage dementia patients were believed to be most concerned with reporting behaviors that influenced ADL caregiving).

These studies are among the few published reports that scrutinized behavioral raters in dementia studies. Rater training reports are few in number and often depend on small samples of raters. Mixed findings from these studies justify future and further exploration of rater training procedures and the results of long-term monitoring of caregiving rating skills. Future studies also should develop and describe the use of a priori decision rules when there is score variance among behavioral raters.

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Caregivers as raters

There is intuitive logic in having the primary caregiver for an impaired individual be the judge of behavioral change. There is an obvious benefit in viewing an elder's functional and behavioral status through the eyes of those individuals who are intimately involved in daily interactions with the elder. In addition, unobtrusive observations by a familiar family member are often far less stressful for the demented elder than a clinical interview. Thus, many investigators rely exclusively on family members to assess behavioral change in an impaired member. Yet the moderating and mediating effects of caregiver variables on those proxy ratings of dementia behavior are seldom explored.

Moderator variables are those that either reduce the magnitude or reverse the direction of the relationship between a predictor and outcome variable in a causal model. Mediator variables are those that account for the relationship between predictor and outcome variable by either adding to or suppressing the relationship between the predictor and outcome variable. [42] Many of the causal models proposed in dementia studies acknowledge the influence of caregiver variables on patient outcomes, yet few studies have systematically explored the effects of caregiver variables as moderators or mediators in the measurement of dementia behaviors.

There is a growing body of descriptive literature indicating that while caregiver behavioral ratings of demented members are useful, they may be influenced by factors such as the nature of the preexisting relationship between the caregiver and impaired member, [43] the caregiver's sense of burden associated with caregiving, [44] and the caregiver's own emotional health and well-being. [45,46] Although caregiver ratings are an important adjunct to behavioral measurement in dementia, they should not be the sole deciding factor in patient behavior studies without some exploration of the moderating and mediating effects of rater characteristics on those ratings.

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Scoring bias

Several investigators have noted the difficulties of comparing findings across studies when measures differ on the rating period. [41,47,48] Problem behavior items have been sampled in various ways: as a function of their current existence, their past existence, their progression over time, and their emotional impact on the caregiver. Some measures ask only about the current existence of behaviors. Other measures use retrospective rating time periods that range from currently present to present within the past several weeks or months. Despite studies indicating that sundowning (ie, the nocturnal occurrence of behaviors) happens with as many as 40% of dementia-impaired persons, [9,49,50] few measures ask about the diurnal occurrence of specific problem behaviors.

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Composite scores

In an effort to gain some quantitative sense of the severity of problem behaviors, some measures quantify the occurrence of each behavior on more than one scale. Several measures score behaviors on a frequency scale for behavioral occurrence (eg, "how often did [the behavior] happen in the past week?") as well as a severity scale to determine the caregiver's reaction to the behavior (eg, "how upsetting is this behavior for you?"). For example, in the development of the Memory and Behavior Problem Checklist, Zarit and colleagues [25] originally operationalized dementia behaviors with more than 60 items in three subscales on patient memory loss, depressive symptoms, and problem behaviors. These behaviors are scored on both frequency of occurrence and caregiver reaction. Despite the fact that in subsequent revision of the measures, the developers have recommended reporting separate scores for the three behavioral dimensions in dementia, [25,51] many investigators report only the sum of the two scales (ie, a single score for the cross products of the frequency and severity scale scores) in published reports. This score-reporting decision obscures the ability to draw conclusions about different behavioral dimensions.

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Unclear or missing measurement models

The choice of measurement model influences how reliability and validity are to be assessed and how scores on a measure should be interpreted. Dementia studies have been complicated by lack of clarity as to whether problem behaviors should be measured as norm or criterion referenced. Norm-referenced measures are those that compare subjects on the construct of interest. Norm-referenced

measures are global in nature and depend on score variability to discriminate among individuals on the construct. In contrast, criterion-referenced measures determine whether the individual demonstrates some critical amount of the construct, usually through the application of predetermined cutoff scores. [52]

Other screening tests used in dementia studies attempt to categorize the severity of the impaired person's problems through the use of cutoff scores. For example, measures used to screen for depressive symptoms in dementia such as the Beck Depression Inventory and the Geriatric Depression Scale classify the severity of subject depression as mild or moderate according to the score the subject receives on the measure.

Recommendations also have been published for the categorization of cognitive decline as mild, moderate, or severe in dementia subjects according to their score on a mental status exam. [53] In their comparison study of cognitive function tests, Galasko et al [20] were able to calculate and compare annual rates of change (ARCs) for various cognitive measures. Yet there are few published studies of either cutoff scores or ARCs for the various disruptive behavior measures.

Behavior research in dementia is handicapped by lack of guidelines for interpreting behavioral scores. Empirically based cutoff scores could be used to identify high-risk caregiving situations, to stratify and randomize dementia subjects to study groups on the basis of behavioral severity, and to create contrasting groups for various post hoc comparisons. Meaningful ARC scores could be used to report illness progression over time. The feasibility of problem-behavior ARC scores (a norm-referencing approach) and cutoff scores (a criterion-referenced perspective) with adequate predictive and concurrent validity is greatly in need of future study.

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Absence of benchmarking studies

Benchmarking studies are those that provide definitive data in an area. Several investigators have commented on the overdependence in the field on cross-sectional, small-sample, case studies of patients with heterogeneous dementia diagnoses (eg, DAT, multi-infarct dementia, Pick's disease) and at varied stages of the illness. [54-56] The sparsity of longitudinal benchmarking studies with dementia patients, as well as the absence of meaningful cohort studies with normal elders, has complicated determining whether select behaviors are unique to the dementias.

Some initial progress has been made in this area with institutionalized patients under the aegis of the federally mandated Minimum Data Set for nursing home residents. [57] Berg and colleagues' current cohort study (AG03991-12) of healthy and demented aged persons at St. Louis University offers benchmarking opportunities with community-dwelling subjects. However, such studies still are comparatively few in number. To ensure that measures are specific to behaviors associated with dementia and sensitive to change over time, there is a pressing need for more longitudinal studies of dementia patients as well as comparative studies with healthy elders.

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EXISTING MEASURES OF PROBLEM BEHAVIOR


Table 1


Table 2


Table 3

There are numerous behavioral assessment scales but few that focus on problem behaviors in dementia. Some measures focus on functional losses (for an excellent review of functional assessment measures, see Kovar and Lawton's [58] 1994 review). Others focus on psychiatric symptoms (Teri and Logsdon's [48] recent review of behavioral measures that focus on psychopathology in dementia

is an excellent resource in this area). Table 1, Table 2, Table 3, Table 4 is an overview of 11 frequently cited measures that focus exclusively or in part on disruptive problem behaviors in dementia. [22,34,47,51,59-65] Most of these measures were developed independently of one another. Some focus on a narrow set of behavioral problems (eg, agitation), while others are multidimensional and span a range of cognitive, affective, and general problem behaviors. Some of these measures are direct patient observation measures to be completed by clinicians or trained raters. Others are interview measures that depend on patients and their family caregivers to assess behavioral change.

Table 4

Every measure has inherent advantages and disadvantages, and the measures shown in Table 1, Table 2, Table 3, Table 4 were chosen because of their frequent citation in dementia behavior studies over the past decade. Differences in behavioral dimensions, rating scales, and rating periods in these measures make it difficult to combine data sets and to compare findings across studies. An investigator's choice among these or other problem behavioral measures should be influenced by the study research questions, the stage of illness in the anticipated sample population, and the choice of behavioral rater as well as the psychometric strengths and limitations of the measure. Stewart and Archbold's [66,67] seven decision rules for selecting and evaluating outcome instruments can be helpful in choosing a problem behavior outcome measure.

1. Is the conceptual link between the intervention and outcome variable logical and empirically justified?

2. Is the outcome variable sensitive to change over time?

3. Is the content validity of the outcome measure adequate for detecting the effect of the intervention?

4. Does the reported construct validity of the measure indicate it will be able to detect change as a result of the intervention?

5. Do reports on the measure indicate it has a potential distribution of scores that will allow detection of change?

6. What type of reliability assessment is appropriate for this measure, and are data to support its reliability available?

7. Are there supporting data for correlational stability of the measure (ie, is there evidence that changes in scores can be attributed to the intervention)?

The ideal measure is reliable; valid across populations that are educationally, culturally, and gender diverse; comprehensive; easy to administer; and sensitive to change over time. All of the measures currently used for behavioral assessment in dementia have some limitations, and none has unequivocal support from investigators in the field. Selection of a specific measure requires careful scrutiny of those limitations and thoughtful consideration of the anticipated use of the measure.

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RECENT MEASUREMENT DEVELOPMENTS

Several recent developments in the field offer promise for improved behavioral measurement in the future. First, the current focus on developing heuristic models that attempt to correlate selected behaviors with illness stage

has sensitized investigators in the field to using measures that are content valid for the illness stages of the selected sample population.

Second, the acknowledged need for improved behavioral comparisons across dementia studies has generated interest in a central repository of standardized, core measures of behaviors in healthy as well as ill elders. In its recent report to the Institute of Medicine, [68] the Committee to Develop an Agenda for Health Outcomes Research for Elderly People included in its recommendations that a well-defined "toolbox" of outcome measures for elder assessment be developed and refined. The creation of the Consortium to Establish a Registry for Alzheimer's Disease (CERAD) and the recent reports by CERAD on development and preliminary testing of a standardized measure of psychopathology for patients with probable DAT indicate this may become a future reality. [47] Finally, the collaboration of national agencies such as the Agency for Health Care Policy and Research; the National Institutes of Aging, Mental Health, and Nursing Research; the Department of Veteran's Affairs; and the Alzheimer' Association in the 1996 Conference on Defining and Measuring Outcomes for Research in Alzheimer's Disease and Related Dementias, indicates greater future emphasis on methodological issues in problem behavior outcome measures for the future.

The five issues discussed in this article form the basis of a methodological agenda for improving the measurement of problem behaviors in dementia over the next decade. As such, the issues are meant to be illustrative, although not exhaustive, of measurement difficulties in this rapidly evolving area of gerontological research.

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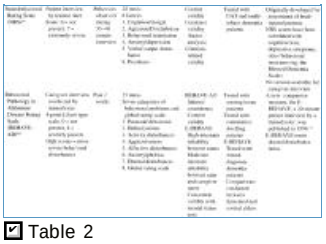
Table 1



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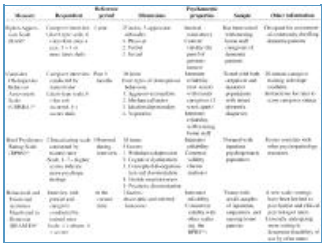

Table 3

Table 4

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