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Prevalence of Behavioral Symptoms: Comparison of the Minimum Data Set Assessments with Research Instruments

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Abstract

Objective—To examine the total and domain-specific prevalence of verbally and physically abusive, socially inappropriate, and care-resistant behaviors according to the Minimum Data Set (MDS) compared with research instruments in nursing home residents with severe dementia.

Design, Setting, and Methods—As part of a longitudinal observational study, MDS behavioral symptoms data were compared with corresponding items from the Ryden Aggression Scale and the Cohen-Mansfield Agitation Inventory for 15 nursing home residents with severe dementia. McNemar's test was used to compare the difference in the proportion of subjects who experienced any symptoms, as well as specific symptoms in several domains, according to the MDS and the research instruments. Additionally, temporal fluctuations in behavioral symptoms were descriptively and graphically summarized.

Results—The MDS significantly underestimated both the total proportion of subjects experiencing any behavioral symptoms ($P = .016$), as well as the proportion of subjects experiencing verbally abusive symptoms ($P < .002$), physically abusive symptoms ($P = .008$), or socially inappropriate behaviors ($P = .016$) compared with corresponding items from the research instruments. Moreover, these behaviors exhibited considerable temporal instability, suggesting that the systematic daily collection of measures of behavioral disturbances is imperative during the week in which the MDS assessment is to be completed.

Discussion—Albeit from a small study sample, our findings call into question the validity of the MDS behavioral symptom items as they are currently recorded, and suggest that a simple intervention of twice daily completion of a behavioral symptoms checklist containing the MDS items during the week of the assessment may significantly improve the accuracy of the recorded data.

Keywords

Nursing home aggression; MDS validity; behavioral outcome measurement

Behavioral disturbances associated with dementia are prevalent and persistent clinical phenomena in long-term care (LTC) facilities.¹ They contribute to greater cognitive and functional decline, significant suffering, poorer quality of life for the residents and their professional caregivers, and a reciprocal cycle of resident-staff abuse, as well as increased staff turnover.²⁻⁵ The assessment and monitoring of behavioral disturbances in LTC facilities is mandated by the Centers for Medicare and Medicaid Services (CMS) under the statutory authority of the Omnibus Budget Reconciliation Act of 1987 (OBRA 1987).⁶ The Minimum Data Set (MDS), a component of the federally mandated Resident Assessment Instrument (RAI), contains a core set of screening, clinical, and functional status elements that form the foundation of the comprehensive assessment for all residents of LTC facilities licensed to participate in Medicaid.⁶ Assessments are required on admission, quarterly, annually, at discharge, and whenever there is a significant change in the resident's status. Since its implementation in nursing homes in 1991, the role of the MDS has expanded beyond scheduled assessments to identify care problems and tailor individualized care plans. It now also functions as a case-mix-based prospective reimbursement mechanism for Medicare and Medicaid, and as an indicator of the quality of care provided by LTC institutions.⁷ Thus, the reliability and validity of the MDS as an assessment instrument are of paramount importance.

Section E4 ("Behavioral Symptoms") of the MDS describes as its intent: "the assessment of the frequency, and alterability of behavioral symptoms in the last seven days that cause distress to the resident, or are distressing or disruptive to facility residents or staff members, even if staff and other residents appear to have adjusted to them."⁶ The coding for the 5 specific items comprising Section E4 focuses on the resident's actions rather than his or her intent. Sources of information may include a review of the resident's medical record, direct observation of the resident, and communication with the resident, family and all direct-care staff. In reality, registered nurses, who are the legislatively designated staff members responsible for coordinating the MDS assessment, often have little to no direct contact with the residents or their caregivers, and rely almost exclusively on documentation in the resident's medical record to complete the assessment. Thus, the validity of the behavioral data captured by the MDS are suspect in light of the fact that the medical record documentation is largely provided by direct-care staff who are overburdened and have limited training in the recognition and documentation of such behaviors.⁸

The validity of MDS Section E items specifically has been examined in at least 4 reports by comparing the MDS data with those collected via previously validated instruments in samples with varying levels of cognitive impairment.⁹⁻¹² Investigators have reported correlation coefficients of $r = 0.24$ (day shift) to 0.37 (evening shift) with the total scores on the Cohen-Mansfield Agitation Inventory (CMAI), $r = 0.54$ with the Psychogeriatric Dependency Rating Scale (PGDRS), and $r = 0.50$ with the Alzheimer's Disease Patient Registry Behavior Checklist as the comparative instruments. An additional report has documented significantly lower prevalence of behaviors as measured by the MDS compared with certified nursing assistants' ratings on the Revised Memory and Behavior Problem Checklist (RMBPC). Moreover, the reliability of the MDS behavioral and depression items decreased with worsening cognitive impairment.¹² Despite the modest to moderately strong correlations in these prior studies, however, the results must be understood within the limitations of their approach. These include (1) comparison of global MDS behavioral symptoms score with total scores on the comparative instruments, thus precluding analysis of correlation between the specific items (eg, verbally versus physically abusive behavior), (2) lack of clarity in some reports as to who completed the MDS and/or research instruments, and (3) significant time lags of 1 to 6 months between the completion of the MDS and the research instruments in most of the studies. Only Horgas and Margrett¹² completed all assessments within a 1-month timeframe. Unlike the present investigation,

however, Horgas and Margrett's¹² cohort examined items from both the mood and behavioral symptoms subscales of the MDS, and focused the data analysis only on global behavioral symptoms scores. In addition to the limitations of these investigator-initiated studies, federal agencies that have examined the reliability and validity of the MDS have relied on research nurses as assessors rather than the routine clinical staff, thus limiting the external validity, ie, generalizability, to actual clinical practice.¹³

As part of an ongoing direct observational study of the behavioral and social ecology of dementia units (CareMedia: Automated Video and Sensor Analysis for Geriatric Care, NSF IIS-0205219), we had the opportunity to compare consenting residents' MDS behavioral symptoms data with specific corresponding items from the Ryden Aggression Scale Version 2 (RAS2) and the Cohen-Mansfield Agitation Inventory (CMAI).¹⁴ To address limitations of some of the prior investigations, our MDS data were either collected during the study period or within 2 weeks before or after the study period by the facility's MDS coordinator. The primary certified nursing assistant responsible for each resident was the direct source of information for the RAS2 and CMAI (ie, the assessors were routine staff). Our primary aim was to determine the overall and domain-specific prevalence of behavioral symptoms in LTC residents with severe dementia based on the MDS versus a validated measure designed to optimally measure each domain. The specific hypotheses were (1) the MDS will significantly underestimate the total prevalence of behavioral disturbances, (2) MDS will significantly underestimate the prevalence of verbally and physically abusive behaviors as compared with corresponding items from the RAS2 (Section E4 items b and c), and (3) the MDS will significantly underestimate socially inappropriate/disruptive and care resistive behaviors compared with corresponding items from the CMAI (Section E4 items d and e).

METHODS

In October 2005, as part of a larger project examining the behavioral and social ecology of a dementia unit, we included instruments to measure cognition, activities of daily living, medical burden, aggression, agitation, and more general neuropsychiatric symptoms among nursing home residents of a nonprofit community LTC facility in suburban Pittsburgh, PA.¹⁴ Additionally, weekly changes in medications and medical problems, as well as MDS data most proximal in time to our study period were abstracted from the subjects' medical records. The study was approved by the Institutional Review Boards of the University of Pittsburgh, Carnegie Mellon University, and the Commonwealth of Pennsylvania Department of Health.

Comparative Assessment Instruments

These instruments represent the primary comparative outcome measures for the present analysis.

Minimum Data Set (MDS), a component of the RAI Version 2.0, Section E4 ("Behavioral Symptoms")¹⁵—Section E4 contains the following specific items: (1) wandering, (2) verbally abusive behavioral symptoms, (3) physically abusive behavioral symptoms, (4) socially inappropriate/disruptive behavioral symptoms, and (5) resists care. The frequency of each behavior is coded as: 0 = no behavioral symptoms in the last 7 days, 1 = 1 to 3 days in the last 7 days, 2 = 4 to 6 days in the last 7 days, and 3 = daily in the last 7 days. The MDS was completed in routine fashion by the facility's MDS coordinator (registered nurse). The assessment most proximal in time to our study period was used, and all assessments were completed either during the study period, or within 2 weeks before or after the study period. The definitions offered for each specific behavioral symptom item by the MDS/RAI Manual are listed in Table 1 along with the corresponding items from the

RAS2 and CMAI that were selected for this analysis. A score of 1 or greater on any of the MDS domains E4b to E4e was considered an observed behavioral event for that category; in other words, a behavior(s) was documented as present on at least 1 day during the assessment week. We excluded domain E4a (wandering) from our analysis because of its nonspecific definition and unclear management implications.

Ryden Aggression Scale Version 2 (RAS2)¹⁶—The RAS2 is a 26-item scale, designed as a measure of the nature and frequency of aggressive behaviors. It includes 3 subscales: Physically Aggressive Behavior (PAB), Verbally Aggressive Behavior (VAB), and Sexually Aggressive Behavior (SAB). In contrast to the instrument developers, we asked the certified nursing assistants to simply check the presence or absence of specific behaviors rather than their actual frequency in order to minimize staff burden. The RAS2 was completed at approximately 2^{PM} and 11^{PM} daily, corresponding to the times of staff shift change, for 25 consecutive days. Because of the low frequency of agitation and aggression during the night shift (per staff), we chose to forego completing the RAS2 for the night shift. Certified nursing assistants had been trained in the use of the RAS2 by the principal author, and received additional education, clarification, and support as needed from the research associate who was present on the unit several times a week. The presence of one or more abusive behavior(s) on the RAS2 on at least 1 day during the week most proximal in time to the MDS assessment was considered an observed behavioral event. Additionally, we descriptively examined the temporal fluctuations in the behavioral symptoms over the entire 25-day study period.

We used only items from the verbally and physically abusive subscales of the RAS2 for comparison with corresponding items from the MDS, since the RAS2 does not contain items that correspond well to the socially inappropriate/disruptive behavioral symptoms (item E4d) and resists care (item E4e) categories of the MDS (see Table 1). Our goal was not a formal validation of the MDS with the subscales of the RAS2 or CMAI, or the instruments in their entirety, but rather an examination of the accuracy of MDS scores as recorded by routine clinical staff if a behavioral checklist of similar items was provided to certified nursing assistants to complete as verification of the MDS scores.

Cohen-Mansfield Agitation Inventory (CMAI)¹⁷—The CMAI, derived from empirical observations of nursing home residents, assesses the frequency of manifestations of agitation in the elderly. It consists of 29 items that address 3 major factors: physically aggressive behavior, verbally aggressive behavior, and nonaggressive behavior (verbal or physical). The items are rated according to frequency on a scale of 1 (never) to 7 (several times per hour), with the prior 2 weeks being the usual rating period. The CMAI was administered by a research associate to the certified nursing assistant most familiar with the subject at the end of weeks 1 and 3 of the study. The research associate reviewed the training materials provided by the instrument developer, and practiced administering the instrument with the principal author before application in the clinical setting.

For the purposes of the current analysis, we chose the CMAI score most proximal in time to the MDS assessment, and selected items from the CMAI that corresponded best to the socially inappropriate/disruptive behavioral symptoms (E4d) and resists care (E4e) categories of the MDS. For each CMAI domain, we determined whether any of the behaviors subsumed under that category occurred on at least 1 day during the week most proximal in time to the MDS assessment. Although the CMAI also includes verbally and physically aggressive domains as part of the instrument, we chose to include the RAS2 to evaluate these 2 domains because of its brevity and brief administration time that made twice daily administration possible.

Descriptive Rating Instruments

The following rating instruments were collected to describe the baseline characteristics of our study cohort:

Severe Impairment Battery – Short Form (SIB)¹⁸—The SIB was developed to assess a range of cognitive functioning in patients who are unable to complete existing standard neuropsychological assessment scales. It was designed for the severely demented patient and takes into account the specific behavioral and cognitive deficits associated with severe dementia. It is divided into 6 subscales of attention, orientation, language, memory, visual perception, and construction. Additionally, there are brief assessments of social skills, praxis, and responding to name. The total score ranges from 0 to 100 with lower scores indicating greater cognitive impairment. The scale was administered to the study subjects by the research associate at baseline (week 0) after hands-on training with an experienced assessor.

Physical Self-Maintenance Scale (PSMS)¹⁹—The PSMS measures activities of daily living by rating the subject on competence in the activities of toileting, feeding, dressing, grooming, locomotion, and bathing. The PSMS employs a 5-point scale that evaluates each activity as requiring no assistance through varying degrees of requiring assistance, including total inability to perform activity without help. The scale was completed by the research associate by interviewing the primary certified nursing assistant for the subject, after receiving hands-on training from the principal author.

Cumulative Illness Rating Scale–Geriatric (CIRS-G)²⁰—The CIRS-G yields a global score representing medical status across 13 organ systems. The scale was completed by the principal author by reviewing the subject's medical record, and ratings were assigned on the basis of his judgment using a detailed, validated coding manual.²¹ The total scores range from 0 to 56 with higher scores indicating greater medical burden.

Data Analysis

Descriptive statistics were used to summarize the baseline demographic and clinical characteristics. The difference in the proportion of subjects exhibiting verbally and physically abusive symptoms according to the RAS2 and MDS, respectively, was tested using the McNemar's test. Likewise, McNemar's test was also used to compare the difference in the proportion of subjects who exhibited socially inappropriate or care resistive behaviors based on the CMAI and MDS, respectively.

We also descriptively examined the temporal fluctuations in behavioral symptoms over the 25-day study period by creating a graph of the mean daily number of behaviors endorsed across all subjects (with standard error bars) on the RAS2.

RESULTS

A total of 15 (of 16) dementia unit residents' legal proxies offered informed consent. Table 2 summarizes the baseline demographic and clinical characteristics of our subject cohort. In summary, they were "old-old," and two thirds were women. They had severe cognitive impairment, mild to moderate functional deficits, and relatively low level of medical burden.

The MDS identified 1 of 15 subjects as being verbally abusive while no subject was documented as physically abusive. Socially inappropriate and care-resistive behaviors were identified in 4 of 15 subjects each, respectively. Three of the 4 subjects who were reported to be socially inappropriate were also noted to resist care. In contrast to the MDS, a total of

13 (of 15) subjects were identified as experiencing behavioral symptoms by the composite RAS2 and CMAI scores (McNemar's Exact $P = .016$).

Within specific behavioral domains, in stark contrast to the MDS, 11 of 15 subjects experienced verbally abusive symptoms (McNemar's Exact $P < .002$), and 8 of 15 experienced physically abusive symptoms (McNemar's Exact $P = .008$) according to the RAS2 during the week most proximal in time to the MDS assessment. Eight of 11 subjects who were noted to be verbally abusive were also reported to be physically abusive.

The CMAI was the comparative measure for the MDS socially inappropriate/disruptive behaviors (E4d) and resists care (E4e) items. Eleven of 15 subjects experienced inappropriate/ disruptive behaviors on the CMAI versus 4 of 15 according to the MDS (McNemar's Exact $P = .016$). Care-resistive behaviors were documented for 8 of 15 subjects on the CMAI versus 4 of 15 on the MDS (McNemar's Exact $P = .220$). Seven of 11 subjects who were socially inappropriate also resisted care according to the CMAI.

We also descriptively examined the daily fluctuation of the behavioral symptoms over the 25-day study period according to the RAS2 in order to examine the temporal instability of these behaviors that would argue for longitudinal measurement of these disturbances (Figure 1). This instrument recorded the presence of one or more behaviors during 147 of 750 assessments (15 subjects $\times$ 2 assessments per day $\times$ 25 days), with a total of 573 behaviors checked as present over the 147 assessments. This number represents the lower limit of the actual frequency of behaviors since certified nursing assistants were instructed only to record the presence or absence of behaviors and not their frequency. Of these, 448 (78%) notations of behavior present were during the afternoon shift (approximately 2 PM to 11 PM). Only 2 subjects did not experience any behavioral symptoms during the 25-day study period according to the RAS2.

DISCUSSION

The findings described herein strongly supported our hypothesis that the MDS would significantly underestimate the total and domain-specific prevalence of verbally and physically abusive and socially inappropriate behaviors when compared with corresponding items from the RAS2 and CMAI. However, our analysis failed to find a significant difference between the MDS scores recorded for the "resists care" (E4e) item compared with the CMAI. This may either reflect the psychometric limitations of a single item question to measure a particular construct adequately, or the fact that our sample size was small since there was an effect in the expected direction.

Our results are consistent with those of Horgas and Margrett¹² whose MDS data, analyzed as global scores, underestimated the prevalence of behavioral symptoms in their mixed cohort of cognitively intact and impaired nursing home residents. Unlike their analysis however our subject cohort was confined to those with severe dementia, and confirmed significant behavioral prevalence disparities within 3 of the 4 specific behavioral domains examined. Our findings suggest that twice daily administration of a behavioral checklist during the week of the MDS assessment, even when limited to the specific definitions of behavioral symptom items contained within the RAI Manual, may significantly improve the accuracy of the types and frequency of behaviors noted. In other words, the MDS would then be completed on the basis of the behavioral checklist data. This approach appears to address both the spirit of the MDS assessment as well as feasibility concerns arising out of the personnel, time, training, and cost constraints inherent in resource-poor LTC facilities. Ultimately, the "gold standard" would be automated continuous video monitoring that permits accurate detection and documentation of behavioral symptoms. Our group has

collected 13,800 camera-hours of video data in the nonprivate spaces of a dementia unit that are currently being annotated by human coders.¹⁴ Using the video data labeled by human coders as training materials, machine learning and computer vision techniques will be developed to move toward automated behavioral monitoring. At present, the project is in the early research phases and will require critical attention to ethical (ie, privacy) and regulatory concerns before actual clinical implementation.

Currently, a simpler intervention such as the one we propose in this manuscript has face validity and appears more feasible. An alternative approach would be to systematically address each of the previously reported concerns regarding the utility and validity of the MDS as a behavioral symptoms assessment and measurement tool.^{7,13} These include the retrospective nature of the documentation (recall bias), the effect of staff turnover and inadequate behavioral health training on the consistency and continuity of documentation, and propensity to rate behaviors based on inferred intent rather than actual action. Most importantly, however, the MDS coordinator often completes the instrument without any direct observation or interview of the resident. Moreover, specific process measures to determine adherence with MDS data collection protocols are needed to ensure the validity of the MDS behavioral symptoms data.

MDS 3.0, an updated version of the instrument, is currently undergoing field validation.²¹ MDS 3.0 aims to increase the accuracy of the assessments by interviewing the resident directly using psychometrically tested structured interview items whose content validity has been established by domain experts. The specific changes to Section E (Behavior) items include (1) shorter timeframe for the assessment period (last 5 days as opposed to last 7 days), (2) explication of a specific category for symptoms of psychosis (hallucinations and delusions), (3) specific identification of the target of the behavior (self versus others), (4) simplified scoring scheme, and (5) assessment of the impact of the behavior on self and others. Although the emphasis on a direct resident interview is laudable, those residents who are behaviorally disturbed likely will be more cognitively impaired, and will experience greater difficulties engaging in an interview. Thus, proxy observers and their poor medical record documentation will remain critical to the current assessment challenges. Moreover, it remains to be seen whether the MDS 3.0, in the absence of a behavioral checklist that is completed daily by direct care staff during the assessment period, improves the accuracy of the assessment.

The significant strengths of our analysis include the multiple repeated behavioral assessments using previously validated instruments, the use of routine clinical staff as sources of information for the assessments, and the temporal proximity of the MDS assessment with the research instruments. However, several important limitations merit acknowledgment. The small sample size of residents and restriction to a single facility limit the generalizability of the findings. We note that the results are statistically significant when using appropriate nonparametric statistical techniques. The lack of formal interrater reliability testing makes it impossible to disentangle 2 possible sources of error that could account for the underreporting on the MDS. Specifically, the difference in the rating scales being used and the different person doing the rating. We tried to reduce the difference due to the rating scales by recoding the data to a simple presence or absence of the target behavior. However, since the MDS coordinator used the standard response set, it is impossible to rule out response set bias. To rule out rater effects would require using the MDS coordinator to collect twice daily observation data, a requirement that is not feasible given their workload. Finally, although the time lag between our research instruments and MDS assessments is the smallest reported in the literature to date, some assessments were nevertheless not concurrent.

CONCLUSION

Our findings confirm significantly higher total and domain-specific prevalence of behavioral symptoms in older persons with severe dementia as measured by research instruments compared with the federally mandated MDS. Moreover, they document the temporal instability of these symptoms (both over days as well as over the morning and afternoon shifts). A simple protocol for certified nursing assistants to complete a behavioral checklist twice a day during the scheduled assessment period would dramatically improve the accuracy of the data recorded on the MDS.

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Figure 1.

Temporal fluctuations in frequency of behavioral symptoms (mean number of behaviors per day averaged across subjects $\pm$ standard error bars).

Table 1

Minimum Data Set Behavioral Symptoms Items and Corresponding Items from Research Instruments

Minimum Data Set (MDS) Section E4: Behavioral Symptoms	Ryden Aggression Scale (RAS2)	Cohen-Mansfield Agitation Inventory (CMAI)
4b: Verbally Abusive Symptoms	<ul style="list-style-type: none"> Q18 Makes verbal threats Q19 Curses at a person Q20 Hostile, accusatory language directed at a person 	
<ul style="list-style-type: none"> Others were threatened, screamed at, or cursed at 		
4c. Physically Abusive Symptoms	<ul style="list-style-type: none"> Q1 Pushes or shoves Q3 Hits or punches Q5 Pulls hair Q6 Scratches Q7 Bites Q9 Elbows Q10 Kicks Q11 Tackles Q12 Makes threatening physical gestures Q14 Strikes a person with an object 	
<ul style="list-style-type: none"> Others were hit, shoved, scratched, sexually abused 		
4d. Socially Inappropriate or Disruptive Behavioral Symptoms		<ul style="list-style-type: none"> Q4 Noises, strange laughter, moaning, crying Q12 Verbal sexual advances Q13 Physical sexual advances Q21 Hoards or collects objects Q33 Hurts him/herself using harmful object Q36 Eats or drinks nonfood substances
<ul style="list-style-type: none"> Makes disruptive sounds Noisy Screams Self-abusive acts Sexual behavior or disrobing in public Smears or throws food or feces Hoards Rummages through others' belongings 		
4e. Resists Care		<ul style="list-style-type: none"> Q8 Negative, uncooperative or unwilling to participate in activities
<ul style="list-style-type: none"> Resists taking medications, injections, ADL assistance or eating 		

Table 2

Demographic and Clinical Characteristics of Subject Cohort

Variable	Measure	N	Mean	SD	Median	Minimum	Maximum
Age, y		15	86.53	5.50	86.00	80.00	98.00
Gender, female		10					
Cognition	SIB-SF	15	13.53	16.83	3.00	0.00	43.00
ADL	PSMS	15	20.30	15.00	21.00	13.00	27.00
Medical Burden	CIRS-G	15	10.73	5.54	11.00	5.00	27.00

ADL, activities of daily living; CIRS-G, Cumulative Illness Rating Scale–Geriatrics; N, sample size; PSMS, Physical Self Maintenance Scale; SIB-SF, Severe Impairment Battery–Short Form.