Housekeeping

- All participants will be muted

- Enter **all questions** in the Zoom **Q&A** or **chat box** and send to All Panelists and Attendees

- Moderator will review questions from chat box and ask them at the end

- Want to continue the discussion? Look for the associated podcast released about 2 weeks after Grand Rounds.

- Visit impactcollaboratory.org

- Follow us on Twitter: **@IMPACTcollab1**

- **LinkedIn: https://www.linkedin.com/company/65346172   @IMPACT Collaboratory**
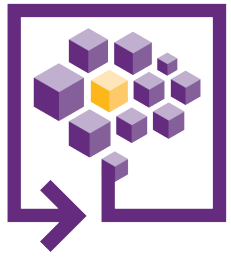
Use of Medicare Claims in Pragmatic Trials for Persons with Dementia

Joan M. Teno, MD, MS

Professor of Medicine, Oregon Health & Science University

Adjunct Professor of Health Services, Policy, & Research, Brown University School of Public Health

What will I cover?

- Pros and cons of administrative data for use in pragmatic trials
- Address potential limitations of using administrative data to infer the quality of care
  - E.g. burdensome transitions
- Discuss a controversial claim that pragmatic trials of decision-making for persons with dementia need to consider adding PCROs:
  - Addressing understanding, coercion
  - Addressing safety, "balance measures"

Potential Examples of Process and Outcome Measures

Measure	Measure Type/Use
Billing for advance care planning	Process measure
Health care reimbursement	Outcome measure
Hospice use less than 3 days	Potential outcome measure in that research shows differences in perceptions of quality of care among those with short hospice stays
Potentially burdensome transitions	Potential outcome measure in that multiple hospitalizations for expected complications of dementia have poor prognosis.

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Claims data

- Advantages
  - Readily available, national data on diagnoses, hospitalizations, post acute care, DME, Medications, etc. for Medicare beneficiaries in traditional Medicare, those in ACO
  - Data on hospitalization for persons in Medicare Advantage
  - Relatively low costs
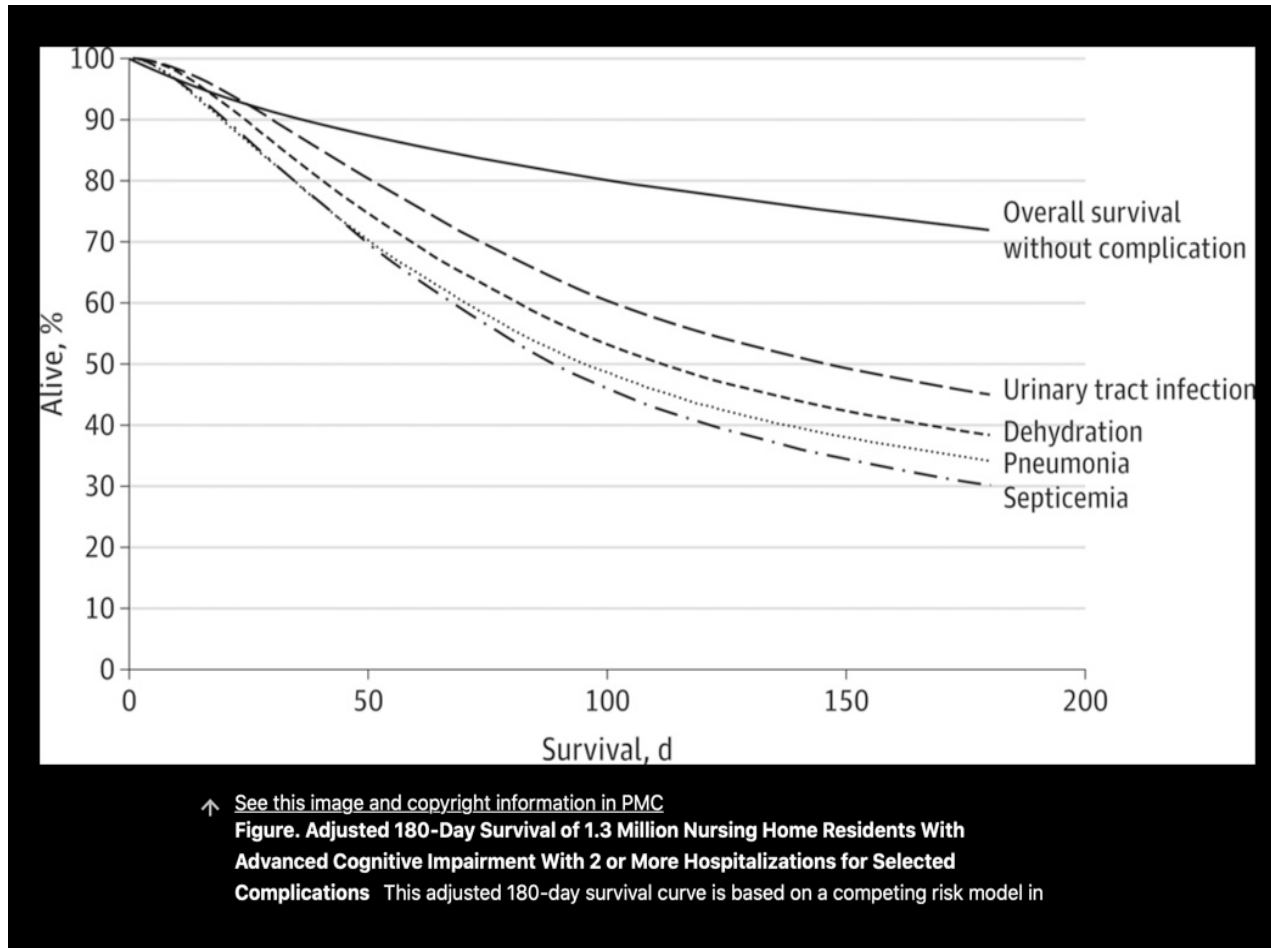 - Policy relevance – ½ of the value equation

- Concerns
  - May reflect financial incentives and not actual clinical care
  - Medicare Advantage lacks reliable data for DME and health care provider encounters
  - May reflect profit over actual disease severity (e.g., hospital billing for septicemia)
  - Historical changes (e.g., hospital bills increase secondary diagnosis with increase documentation of dementia…)
  - Any code that is not linked to reimbursements need careful thought about validity.

Potentially Burdensome Transition Index in Nursing Home Residents with Advanced Dementia

- Focus on two key types of transitions:
  - Transitions in the last 3 days of life
  - Multiple hospitalizations in the last 120 days of life for predictable disease that imply a lack of advance care planning in persons with advanced dementia

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Burdensome transitions: Repeat hospitalizations for expected complications in advanced dementia

Figure. Adjusted 180-Day Survival of 1.3 Million Nursing Home Residents With Advanced Cognitive Impairment With 2 or More Hospitalizations for Selected Complications This adjusted 180-day survival curve is based on a competing risk model in

- Expert opinion and competing risk models showing median life expectancy around 100 days

- But still, preferences → drive findings

- Clearly defined population of severe cognitive impairment with persons having 4 or more ADL impairments

Teno JM, Gozalo P, Mitchell SL, Tyler D, Mor V. Survival After Multiple Hospitalizations for Infections and Dehydration in Nursing Home Residents With Advanced Cognitive Impairment. *JAMA*. 2013;310(3):319–320. doi:10.1001/jama.2013.8392

Potentially Burdensome Transitions in Nursing Home Residents with Advanced Cognitive Impairment

Definition

- Institution base transition in the last 3 days of life
- Multiple hospitalizations for expected infectious complications of dementia
- 3 or more hospitalizations for any reason in the last 90 days of life.
- NH transition from NH A to Hospital to NH B

ABSTRACT

BACKGROUND
Health care transitions in the last months of life can be burdensome and potentially of limited clinical benefit for patients with advanced cognitive and functional impairment.

METHODS
To examine health care transitions among Medicare decedents with advanced cognitive and functional impairment who were nursing home residents 120 days before death, we linked nationwide data from the Medicare Minimum Data Set and claims files from 2000 through 2007. We defined patterns of transition as burdensome if they occurred in the last 3 days of life, if there was a lack of continuity in nursing homes after hospitalization in the last 90 days of life, or if there were multiple hospitalizations in the last 90 days of life. We also considered various factors explaining variation in these rates of burdensome transition. We examined whether there was an association between regional rates of burdensome transition and the likelihood of feeding-tube insertion, hospitalization in an intensive care unit (ICU) in the last month of life, the presence of a stage IV decubitus ulcer, and hospice enrollment in the last 3 days of life.

RESULTS
Among 474,829 nursing home decedents, 19.0% had at least one burdensome transition (range, 2.1% in Alaska to 37.5% in Louisiana). In adjusted analyses, blacks, Hispanics, and those without an advance directive were at increased risk. Nursing home residents in regions in the highest quintile of burdensome transitions (as compared with those in the lowest quintile) were significantly more likely to have a feeding tube (adjusted risk ratio, 3.38), have spent time in an ICU in the last month of life (adjusted risk ratio, 2.10), have a stage IV decubitus ulcer (adjusted risk ratio, 2.28), or have had a late enrollment in hospice (adjusted risk ratio, 1.17).

CONCLUSIONS
Burdensome transitions are common, vary according to state, and are associated with markers of poor quality in end-of-life care. (Funded by the National Institute on Aging.)

From Brown University Program in Public Health, Department of Health Services, Policy, and Practice, Brown University, Providence, RI (P.G., J.M.T., D.T., V.M.); Hebrew Senior Life, Institute for Aging Research, Boston (S.L.M.); and the Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth Medical School, Lebanon, NH (J.S., J.B.). Address reprint requests to Dr. Teno at the Center for Gerontology and Health Care Research, Warren Alpert Medical School of Brown University, 121 S. Main St., Providence, RI 02912, or at joan_teno@brown.edu.

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Sample: Nursing Home Residents with Advanced Cognitive Impairment

Characteristic	Nursing home residents N= 474,829
Avg. Age	85.7
Gender (%F)	78.0%
Race (% Black)	12.0%
One or more burdensome transition	19.0%
Swallowing problems	54.1%
DNR	73.2%

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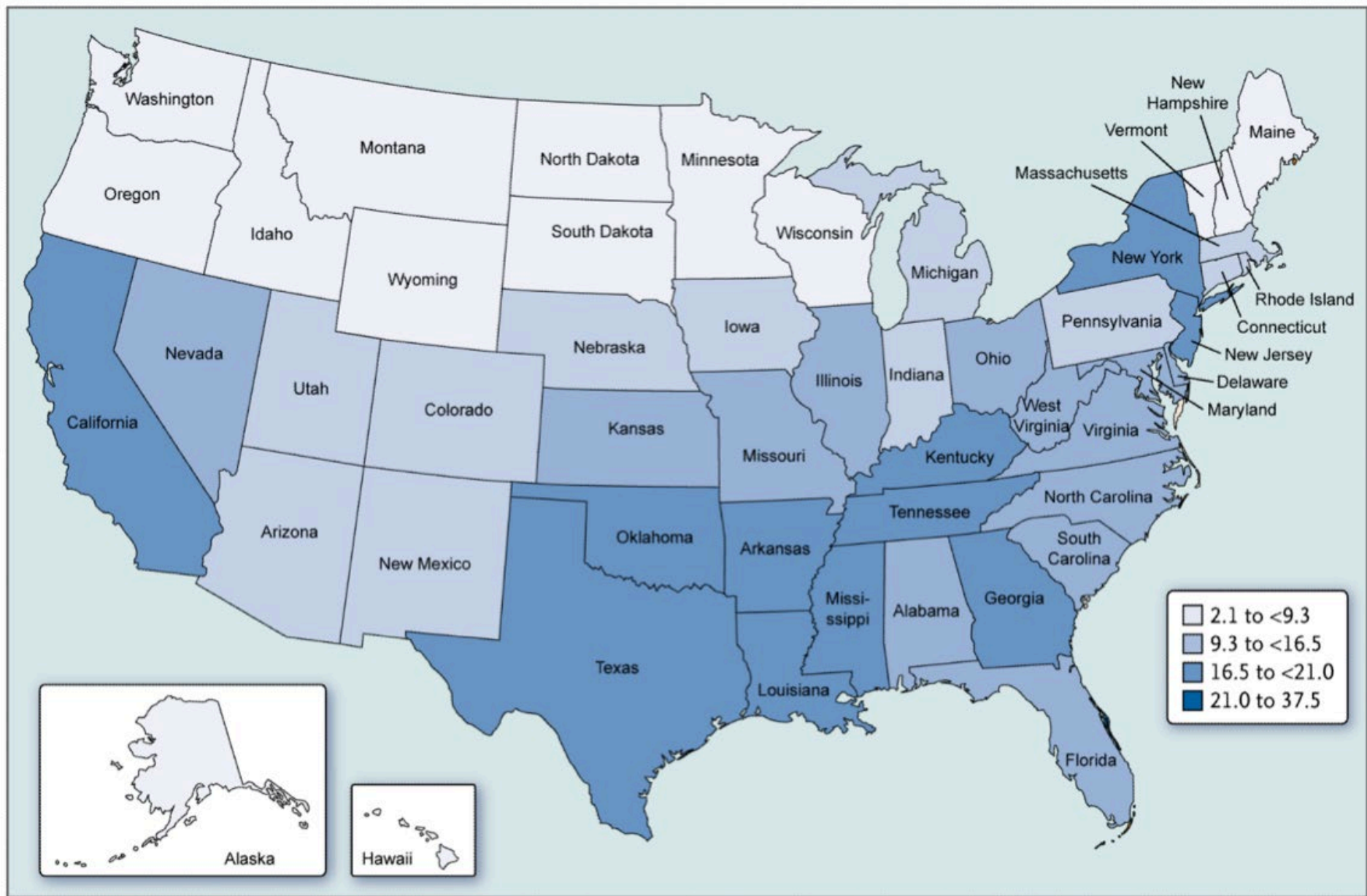
One or More Burdensome Transitions in NH residents with Advanced Dementia

Table of Two Cities…

Outcome	Grand Junction, CO	McAllen, TX	US
Multiple Hospitalizations for Pneumonia, UTI, dehydration	1.1%	25.8%	8.1%
PBTI None	89.0%	64.5%	81.0%
PBTI =1	11.0%	28.0%	16.0%
PBTI=2	0%	7.3%	3.1%

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Association of Burdensome Transitions and Adverse Outcomes

| Outcomes in 2006 and 2007	Lowest Quintile N=19,679 (ARR, 95% CI)	2nd Quintile N=21,141 (ARR, 95% CI)	3rd Quintile N=19,870 (ARR, 95% CI)	4th Quintile N=21,374 (ARR, 95% CI)	Highest Quintile N=20,556 (ARR, 95% CI)
Feeding Tube Insertion	Ref.	1.14 (0.81-1.62)	1.97 (1.43-2.70)	2.06 (1.51-2.81)	**3.38 (2.48-4.60)**
Stage IV DU	Ref	1.48 (1.31-1.66)	1.65 (1.48-1.85)	2.00 (1.79-2.23)	**2.28 (2.04-2.54)**
ICU use- last 30 days	Ref	1.47 (1.34-1.61)	1.85 (1.69-2.01)	1.86 (1.71-2.03)	**2.10 (1.93-2.29)**

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Justification for Claims-Based Measures to Infer Quality of Care of Hospice <= 3 days

Unadjusted and Adjusted Rates of Family Member-Rated End-of-Life Care as Excellent Quality

Wright AA, Keating NL, Ayanian JZ, et al. Family Perspectives on Aggressive Cancer Care Near the End of Life. *JAMA*. 2016;315(3):284–292. doi:10.1001/jama.2015.18604
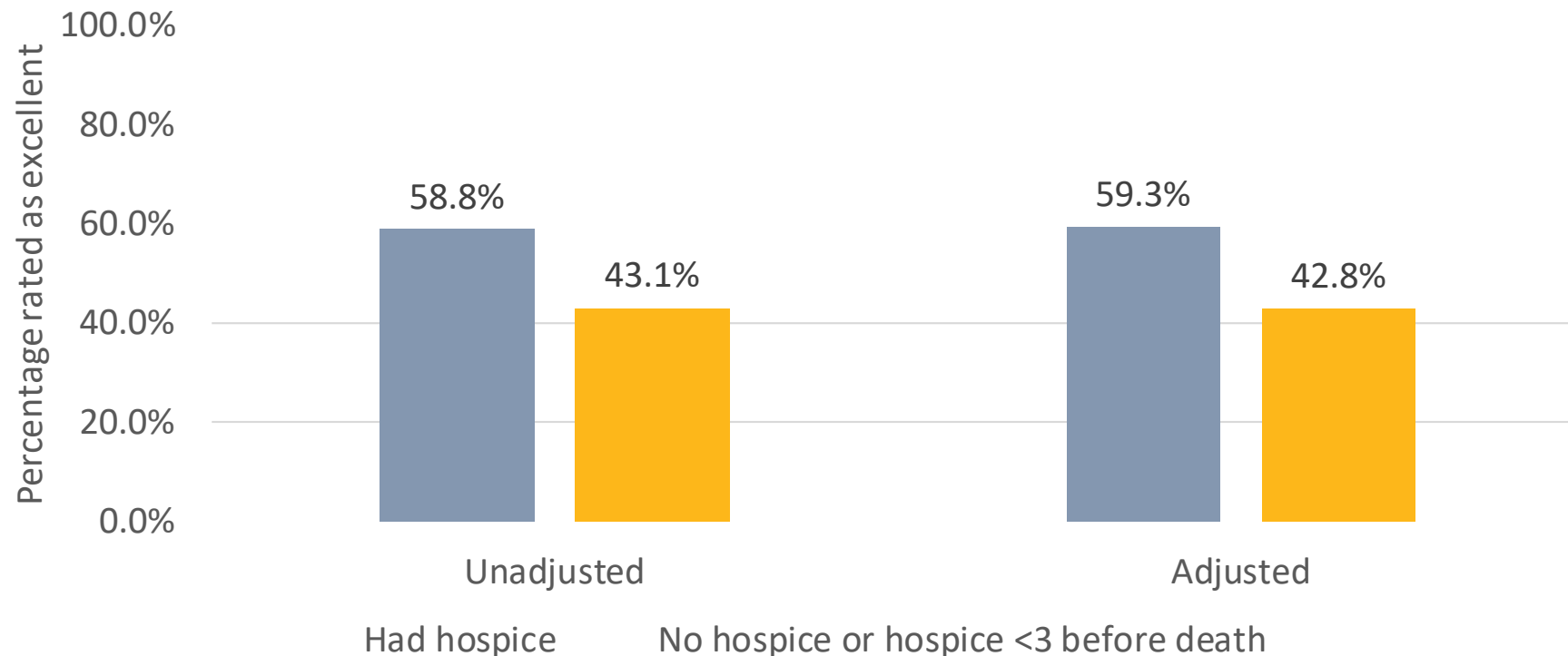
Justification for Claims-Based Measures

Respondent Reports of Quality of Care by Whether Decedent Had No Late Transition,
Any Late Transition or an Institution-to-Institution Late Transition

No LT   Non-institution LT   Institution-Institution LT

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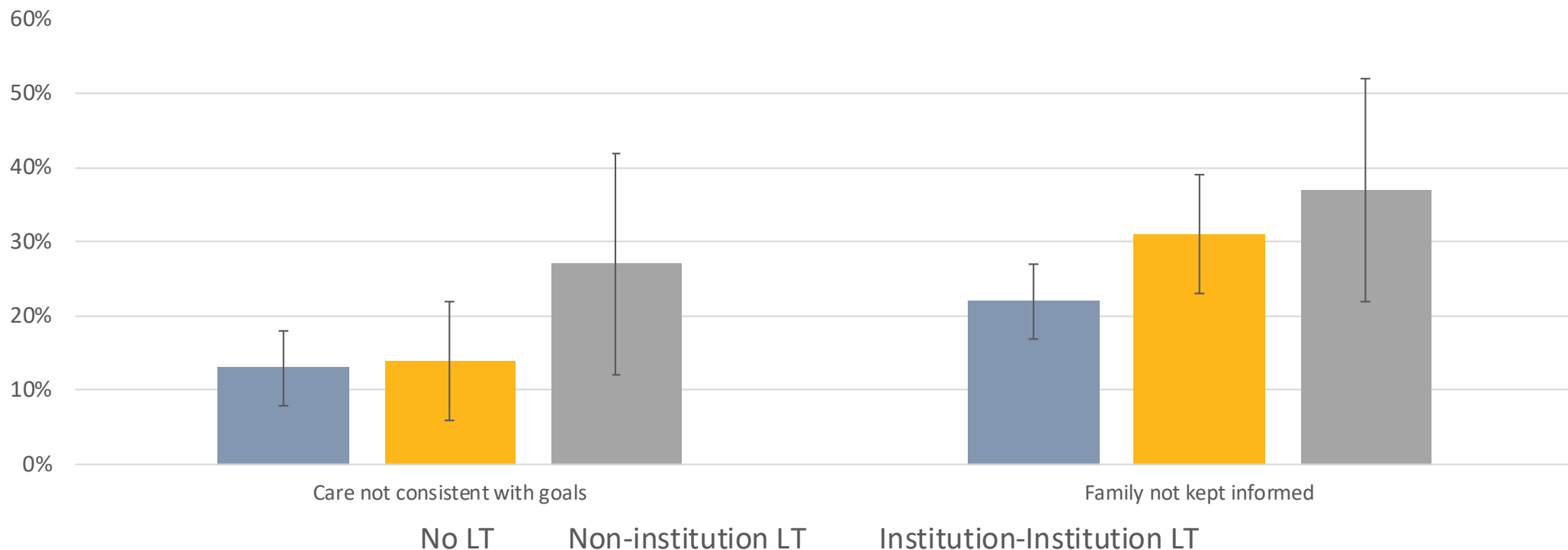
Concerns with use of measures to infer quality

- Important concerns when you are using claims to infer the quality

  - **Providing less care = high quality care**. This is not always true. For example, hip fracture and cancer patients on hospice with prognosis greater that 2-3 months.

  - **Information on preferences is missing**

  - **Disease Trajectory.** Sudden death and catastrophic events happen to seriously ill persons with dementia. Thus, hospice referral for greater than 3 days is not always possible.

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MCCM: Interim results on hospice transitions

- Among decedents, 83% of MCCM participants transitioned to the Medicare Hospice Benefit. Interim data found that transitions in the last 2 days of life increased from 6.7% to 11.7%
- 90% of bereaved family said the transition occurred at the right time
- Those who did not transition:
  - Sudden event, rapid health decline
  - Not wanting to "give up"; patient preferred continue curative treatment over hospice

Abt Associates. "Evaluation of the Medicare Care Choices Model: Annual Report 2". 2020. Accessed at https://downloads.cms.gov/files/mccm-secannrpt.pdf

Pragmatic Trials on Decision Making for Persons with Advanced Dementia that Only Examines $$

- Using the example of the failed UK Liverpool Pathway and POLST, there is need for safety or "balance measures" to avoid unintended consequences

Liverpool Pathway and POLST

Liverpool Pathway	POLST
Pathway to promote hospice practices in actively dying persons in acute care hospitals in UK	POLST form is not intended for healthy elderly persons, but for those with limited life expectancy
Proportion of person enrolled linked to financial incentives	Health care system implemented quality measure of POLST forms
Nationwide scandal based on misdiagnosis resulting in wrong person placed on the pathway and sedation → death	Health care system implemented quality measure of POLST forms with complaints and marked rise in full codes in Oregon POLST Registry

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Potential Pragmatic Approach

- MCCM added additional questions to routinely collected CAHPS Hospice Survey .

- CMS allows hospice to add up to 15 additional questions at the end of the survey.

- Separate survey for those MCCM participants that did not transition to hospice

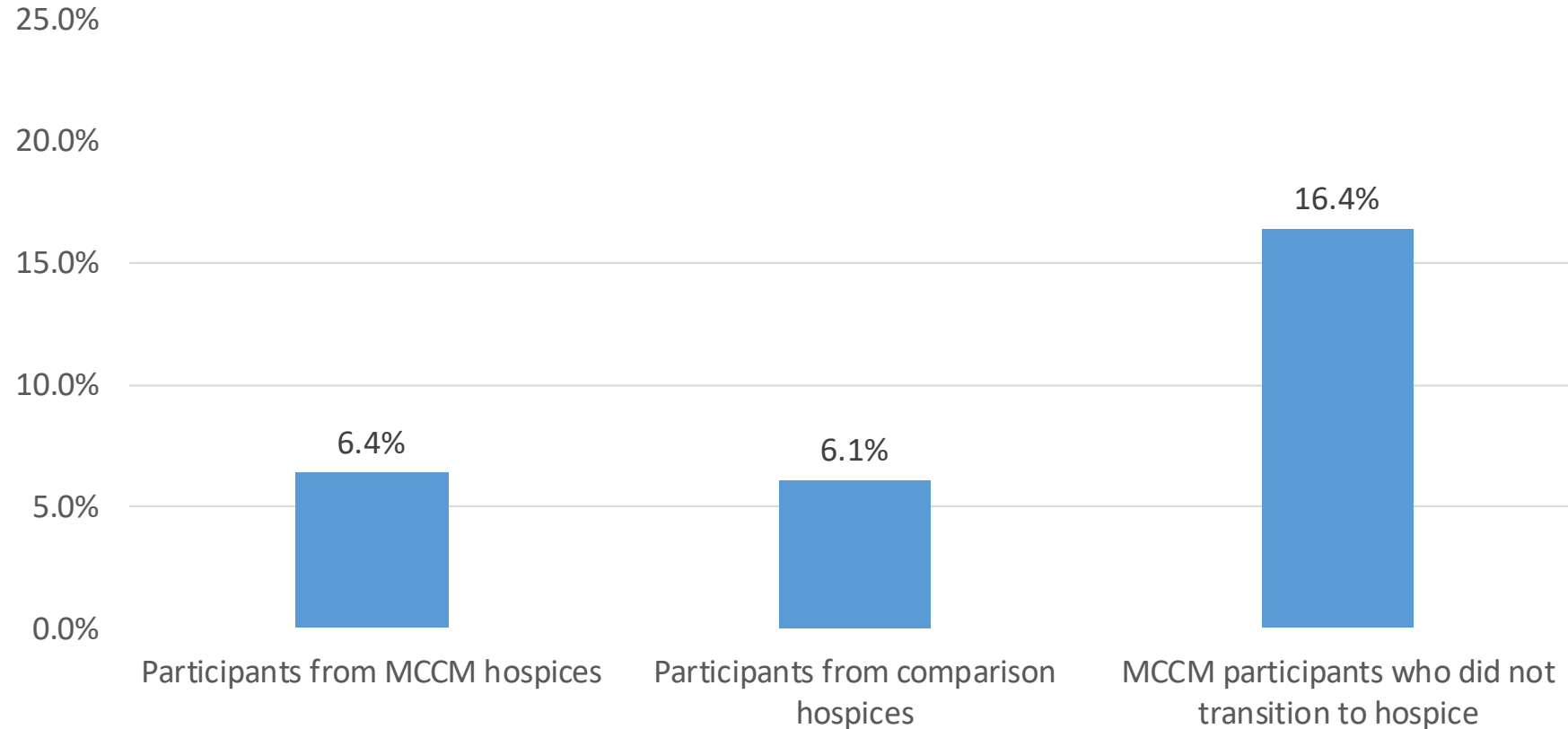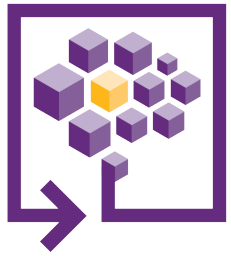| Survey Items Added to CAHPS Hospice Survey |
| --- |
| Was the decision about enrolling in full hospice care made free of pressure from anyone from the special program? |
| Did your family member continue to receive treatment for his or her terminal illness for as long as he or she wanted? |
| In your opinion, did the discussion about enrolling in full hospice care happen too early, at the right time, or too late? |
| Did the special program team do anything that went against your family member's wishes? |

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Conclusion

- Claims data provides cost effective outcome assessments

- Limitations include reflection of billing practices of providers; if a code is not linked to payment, there are concerns with validity

- Caution in inferring quality of care based on administrative data – not all 3-day hospice stays are poor quality of care, but key question if whether there is difference in units of randomization that are differential that result in difference in hospice referral

- Consider a risk-stratified approach to use of PCRO "balance" or "safety measures" in ADRD pragmatic trials of decision-making

Leveraging the Minimum Data Set (MDS) for Pragmatic Trials in Nursing Homes

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Anna and Harry Borun Endowed Chair in Geriatrics and Gerontology at UCLA

Director, UCLA/JH Borun Center for Gerontological Research

Physician Scientist, VA Los Angeles, GRECC and HSR&D COIN

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- Joan Teno, MD, MS
- Sheryl Zimmerman, PhD

Core Support:
- Stacey Gabriel
- Natalie Meeks
- Kathryn Wessell

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Example Clinical Outcome Measures for ePCTs

Outcome Domain	Clinical Outcome Tool	Measure Type	Methods for Data Capture
Detection and diagnosis	**Brief Interview for Mental Status (BIMS)**	**Person-reported outcome**	**Embedded in Minimum Data Set**
Assessment and care planning	**Preference Assessment Tool (PAT)**	**Person-reported outcome**	**Embedded in Minimum Data Set**
Medical management	Pain Assessment in Advanced Dementia (PAIN-AD)[57]	Clinician-reported outcome	Brief clinician observational tool with 5 items for pain behaviors; suitable for embedding in EHR
Information, education and support	Short-form Zarit Caregiver Burden Interview[58]	Caregiver-reported outcome	Brief survey in formats ranging from 1-6 items, suitable for embedding in EHR
Dementia-related behaviors	**Confusion Assessment Method (CAM)**	**Clinician-reported outcome**	**Embedded in Minimum Data Set[49]; suitable for embedding in EHR**
Activities of daily living	**Short Functional Survey**	**Clinician-reported outcome**	**Embedded in Minimum Data Set; suitable for embedding in EHR**
Workforce	Staff hours in direct caregiving	Utilization outcome	Administrative data sources
Supportive and therapeutic environment	Caregiver report of quality of hospice care	Caregiver-reported outcome	CAHPS Hospice survey
Transition and coordination of services	Hospital transfers	Utilization outcome	Administrative data sources or EHR
Person-centered	Dementia Quality of Life – Care Home (DEMQOL-CH)[59]	Clinician-reported outcome	Staff survey; items suitable for embedding in EHR; item subsets capture engagement, function, positive or negative emotion

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Learning Objectives

- Identify advantages & challenges of using Minimum Data Set (MDS) assessment items

- Describe some of the MDS data elements and their performance implications for persons with cognitive impairment

- Understand performance of resident self-report items

- Identify pragmatic skills for direct interviews

Promises of MDS Data

- Goal: improve detection & identification of needs

- All nursing home (NH) admissions

- Standardized items
  - Tested
  - Comparable across facilities
  - Instruction manual

- Many data elements based on direct interview
  - Resident Centered
  - More efficient
  - Open up discussions about important topics
  - Options for persons unable to express wants

- One form, multiple uses

- Trigger further evaluation & Care planning

Santa Monica, CA   2020

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Potential Pitfalls

CAUTION!

Detection of needs → Over 500 items

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Potential Pitfalls

Detection of needs	→	Over 500 items
All admissions	→	Required, mandated form

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Potential Pitfalls

CAUTION!

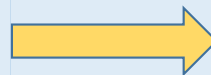|		
Detection of needs	→	Over 500 items
All admissions	→	Required, mandated form
Standardized items Comparable across NHs Instruction manual	→	Range of assessment & documentation accuracy Detection bias No one reads instruction manuals

Potential Pitfalls
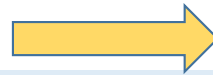
CAUTION!

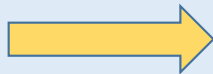|		
Detection of needs	→	Over 500 items
All admissions	→	Required, mandated form
Standardized items Comparable across NHs Instruction manual	→	Range of assessment & documentation accuracy Detection bias No one reads instruction manuals
Resident Voice through interview Open up discussions Observational items if unable to express	→	Skill not included in most training Requires recognize unmet needs Must reconcile self-report & observation Proxy differs from respondent.

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Potential Pitfalls

CAUTION!

|		
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Trigger evaluation & care planning	→	Only one step, need follow through

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Potential Pitfalls

CAUTION!

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Trigger evaluation & care planning	→	Only one step, need follow through
One form, Multiple uses	→	Clinical utility vs. $$$$ vs. ⭐⭐⭐⭐

JAMDA
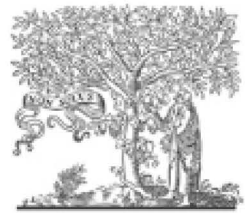
Original Study

Making the Investment Count: Revision of the Minimum Data Set for Nursing Homes, MDS 3.0

Debra Saliba MD, MPH [a,*], Joan Buchanan PhD [b]

[a] UCLA/Jewish Home Borun Center for Gerontological Research, Los Angeles, CA; Greater Los Angeles VA GRECC and HSR&D Center of Excellence; RAND, Santa Monica, CA
[b] Department of Health Care Policy (retired), Harvard Medical School, Boston, MA

MDS 3.0 Development Proceeded in 4 Phases

CMS Revised Draft MDS 3.0	

Phase 1: Stakeholder and Expert Feedback

Townhall Meeting & Open Comment	Expert Panel Meetings

Phase 2: MDS 3.0 Item Development

VA Validation Protocol Research	Integration of Phase 1 Feedback

Phase 3: MDS 3.0 Integration

Workgroup Review	Develop form & Instruction	National Pilot Testing

Phase 4: National Testing

Final Revisions	National Test of MDS 3.0	Data Analysis

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Behavioral Symptoms

E0200. Behavioral Symptom - Presence & Frequency		
Note presence of symptoms and their frequency		
Coding: 0. **Behavior not exhibited** 1. **Behavior of this type occurred 1 to 3 days** 2. **Behavior of this type occurred 4 to 6 days,** but less than daily 3. **Behavior of this type occurred daily**	↓ **Enter Codes in Boxes**	
	☐	**A.** **Physical behavioral symptoms directed toward others** (e.g., hitting, kicking, pushing, scratching, grabbing, abusing others sexually)
	☐	**B.** **Verbal behavioral symptoms directed toward others** (e.g., threatening others, screaming at others, cursing at others)
	☐	**C.** **Other behavioral symptoms not directed toward others** (e.g., physical symptoms such as hitting or scratching self, pacing, rummaging, public sexual acts, disrobing in public, throwing or smearing food or bodily wastes, or verbal/vocal symptoms like screaming, disruptive sounds)

MDS 3.0 vs 2.0 Behavior & Psychosis Items: Agreement with Gold Standard

Gold-Standard (CMAI / NPI)	MDS 3.0 Kappa (95% CI)	MDS 2.0 Kappa (95% CI)
Physical toward others	.86 (.74, .97)	.23 (.03, .43)
Verbal toward others	.73 (.61, .84)	.31 (.16, .45)
Other Behavior	.53 (.42, .66)	.22 (.12, .31)
Hallucinations	.92 (.81, 1.00)	.23 (.03, .43)
Delusions	.88 (.79, .98)	.31 (.16, .45)

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Severe Behavioral Health Manifestations in Nursing Homes: Associations with Service Availability
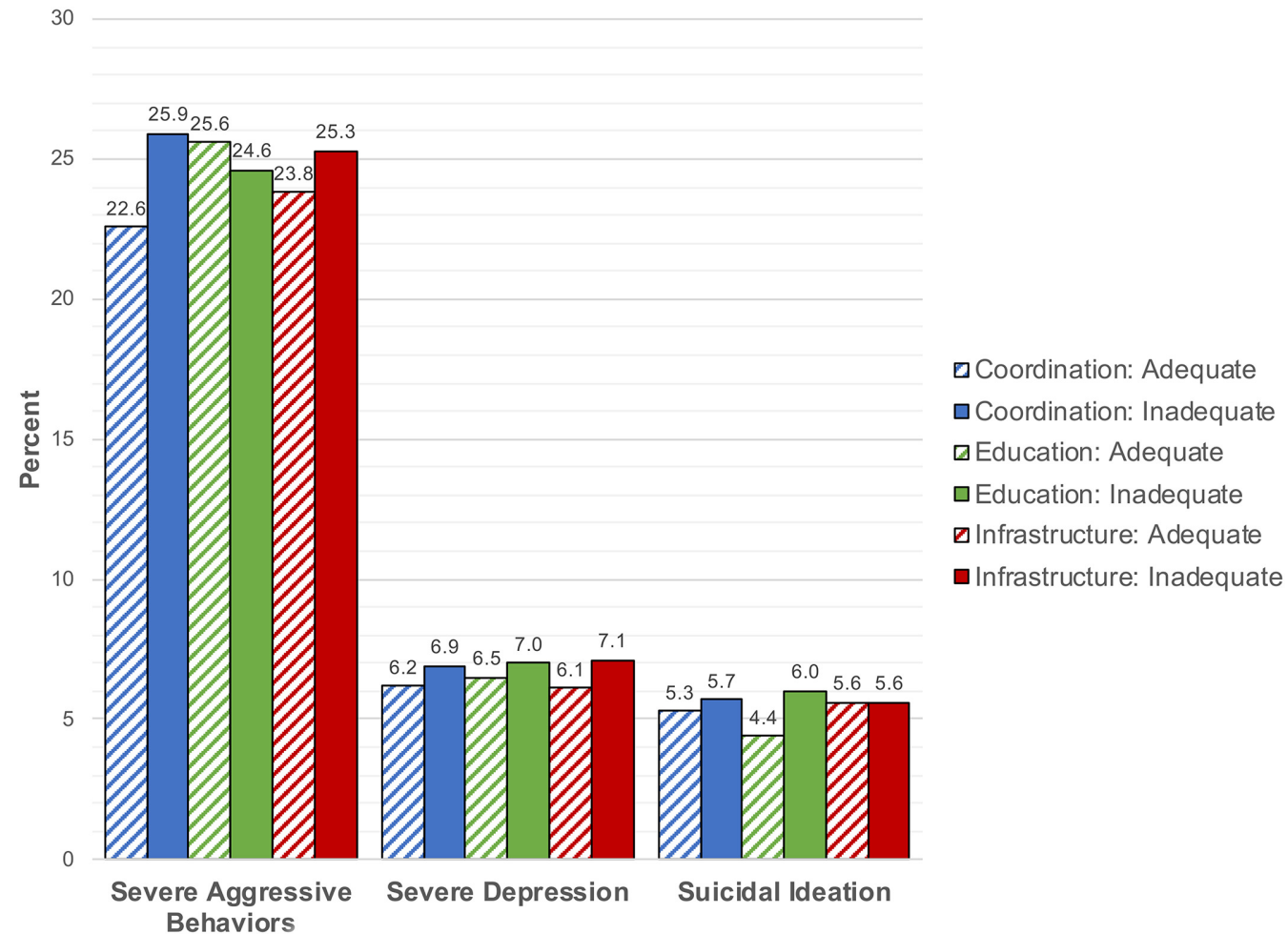
Symptom Impact

E0500. Impact on Resident

Did any of the identified symptom(s):

Enter Code [ ]
A. Put the resident at significant risk for physical illness or injury?
   0. **No**
   1. **Yes**

Enter Code [ ]
B. Significantly interfere with the resident's care?
   0. **No**
   1. **Yes**

Enter Code [ ]
C. Significantly interfere with the resident's participation in activities or social interactions?
   0. **No**
   1. **Yes**

E0600. Impact on Others

Did any of the identified symptom(s):

Enter Code [ ]
A. Put others at significant risk for physical injury?
   0. **No**
   1. **Yes**

Enter Code [ ]
B. Significantly intrude on the privacy or activity of others?
   0. **No**
   1. **Yes**

Enter Code [ ]
C. Significantly disrupt care or living environment?
   0. **No**
   1. **Yes**

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Wandering

E0900. Wandering - Presence & Frequency

Enter Code	Has the resident wandered?
☐	0. **Behavior not exhibited** → Skip to E1100, Change in Behavior or Other Symptoms 1. **Behavior of this type occurred 1 to 3 days** 2. **Behavior of this type occurred 4 to 6 days**, but less than daily 3. **Behavior of this type occurred daily**

E1000. Wandering - Impact

Enter Code	
☐	A. **Does the wandering place the resident at significant risk of getting to a potentially dangerous place** (e.g., stairs, outside of the facility)? 0. **No** 1. **Yes**
☐	B. **Does the wandering significantly intrude on the privacy or activities of others?** 0. **No** 1. **Yes**

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Type of Impact on Resident Varies

MDS 3.0 Behavioral Symptoms: Impact on Resident (N=317)
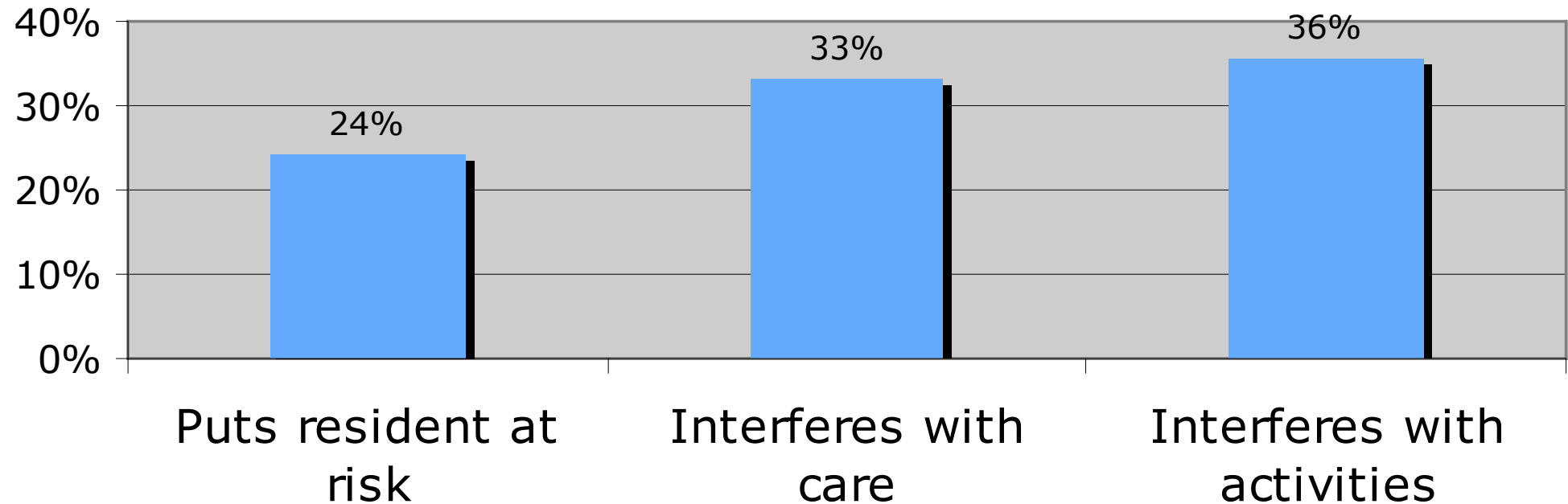
E0800. Rejection of Care - Presence & Frequency

Enter Code

Did the resident reject evaluation or care (e.g., bloodwork, taking medications, ADL assistance) **that is necessary to achieve the resident's goals for health and well-being?** Do not include behaviors that have already been addressed (e.g., by discussion or care planning with the resident or family), and determined to be consistent with resident values, preferences, or goals.

0. **Behavior not exhibited**
1. **Behavior of this type occurred 1 to 3 days**
2. **Behavior of this type occurred 4 to 6 days,** but less than daily
3. **Behavior of this type occurred daily**

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Review

A Conceptual Framework for Rejection of Care Behaviors: Review of Literature and Analysis of Role of Dementia Severity

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[b] Veterans Integrated Service Network 4 (VISN 4) Mental Illness Research Education and Clinical Center (MIRECC) Philadelphia Veterans Affairs (VA) Medical Center, Philadelphia, PA
[c] Geriatric Psychiatry Section, Department of Psychiatry, University of Pennsylvania, Philadelphia, PA
[d] VA HSR&D Center of Excellence for the Study of Healthcare Provider Behavior, Los Angeles, CA
[e] UCLA/JH Borun Center for Gerontological Research, Los Angeles, CA
[f] RAND, Santa Monica, CA

ABSTRACT

Keywords:
Rejection of care
challenging behavior
disruptive behavior
conceptual framework
meta-analysis

Rejection of care behaviors is common in the geriatric population, especially among patients with dementia. Nonetheless, the concept of rejection of care is not well defined and existing psychosocial theoretical models fall short of capturing complex relationships between factors associated with rejection of care. We propose a definition of rejection of care and develop a conceptual framework of rejection of care incorporating 7 components: intrinsic factors, match between needs and environmental resources, behavior state, antecedents, individual preferences, rejection of care behaviors, and consequences. A literature search yielded 55 studies that examined the associations between rejection of care and factors of the conceptual framework. We quantitatively synthesized studies focused on dementia severity and rejection of care. The literature review demonstrated that rejection of care is more prevalent among patients with dementia or functional impairment, associated with some mutable factors, and is triggered by specific antecedents in the context of daily personal care provision and associated with various adverse outcomes. The meta-analysis provided evidence that severe dementia is associated with higher likelihood of developing rejection of care behaviors compared with mild to moderate dementia. We also found that research on unmet needs, antecedents, and individual preferences has been scarce. The direction of further research is discussed.
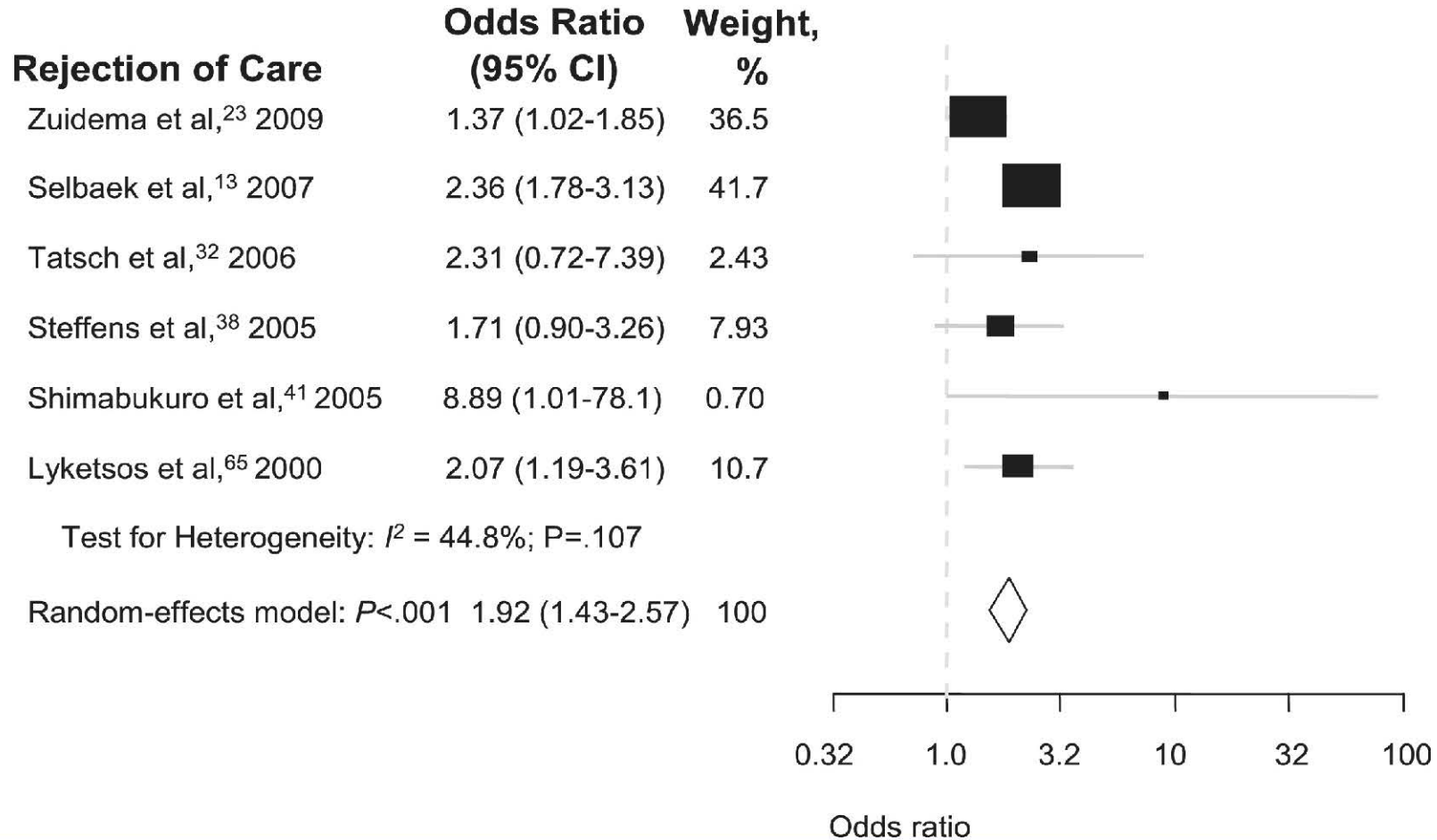
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1. Intrinsic Factors (Risk profile)
Health State
- General Medical Conditions
    (including neurological)
- Sensory (vision/hearing)
- Cognitive Factors
    (Attention, Memory, Language)
- Psychiatric Conditions
- Functional State
Psychosocial Factors
- Demographics
- Personality Traits (Response to stress)

2. Match between Needs and Environmental Resources

Needs
- Physiological Need State
    nutrition, hydration,
    comfort, sleep, rest
- Psychosocial Need State
    stimulus in social context,
    safety, security, affection
- Medical Needs (acute/chronic)

Environmental resources
- Physical Environment
    light level, sound level, heat,
    assistive devices
- Social Environment
    ward ambiance, staff stability
    staff attitude
- Activities
- Care Processes
    medical/nursing/
    rehabilitative treatment

3. Behavior State

4. Antecedents (Triggers)
Personal Care Processes (verbal, physical)
Physical Environment
Social Interaction (verbal, physical)

5. Individual Preferences

6. Behavioral Response
Rejection of care

7. Consequences

Fig. 1. Conceptual framework for rejection of care.*
*The numbers in the boxes are added for cross reference and do not imply linear relationships.

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Association with Dementia Severity

Rejection of Care	Odds Ratio (95% CI)	Weight, %
Zuidema et al,[23] 2009	1.37 (1.02-1.85)	36.5
Selbaek et al,[13] 2007	2.36 (1.78-3.13)	41.7
Tatsch et al,[32] 2006	2.31 (0.72-7.39)	2.43
Steffens et al,[38] 2005	1.71 (0.90-3.26)	7.93
Shimabukuro et al,[41] 2005	8.89 (1.01-78.1)	0.70
Lyketsos et al,[65] 2000	2.07 (1.19-3.61)	10.7
Test for Heterogeneity: I^2 = 44.8%; P=.107		
Random-effects model: P<.001	1.92 (1.43-2.57)	100

Odds ratio

Ishii et al, JAMDA 2012

Potentially Reversible Resident Factors Associated with Rejection of Care Behaviors

Shinya Ishii, MD,* Joel E. Streim, MD,†‡ and Debra Saliba, MD, MPH*§‖#

OBJECTIVES: To identify the potentially modifiable resident-level factors associated with rejection of care in nursing home (NH) residents.

DESIGN: Secondary analysis of a 3.0 national field test to revise the Minimum Data Set (MDS).

SETTING: Seventy-one NHs in eight states.

PARTICIPANTS: Three thousand two hundred thirty NH residents scheduled for MDS assessments from September 2006 through February 2007.

MEASUREMENTS: The potentially mutable characteristics assessed were mood (Patient Health Questionnaire-9), delirium (Confusion Assessment Method), delusions, hallucinations or illusions, hearing impairment, vision impairment, pain severity, and infection diagnoses. Characteristics considered as covariates were cognition, communication abilities, and impairment in activities of daily living.

RESULTS: Of 3,230 residents assessed, 312 (9.7%) had demonstrated rejection of care in the preceding 5 days. In multiple regression analysis adjusted for covariates, rejection of care was associated with delusions (odds ratio (OR) = 3.9; 95% confidence interval (CI) = 2.5–6.0), delirium (OR = 1.8, 95% CI = 1.3–2.4), minor (OR = 2.1, 95% CI = 1.5–2.8) and major (OR = 2.3, 95% CI = 1.5–3.4) depression, and severe to horrible pain (OR = 1.6, 95% CI = 1.1–2.3). Infection diagnoses were not significant in bivariate analysis. Hallucinations or illusions, mild to moderate pain, and hearing and vision impairment were not significant in multiple regression analysis.

CONCLUSION: In this population, delirium, delusions, depression, and severe pain were associated with rejection of care, suggesting that some care rejection behaviors may resolve with appropriate interventions for the identified target conditions if the associations observed are causal. J Am Geriatr Soc 58:1693–1700, 2010.

Key words: rejection of care; nursing home; modifiable characteristics

Rejection of care has been noted to be a serious behavioral disturbance observed in patients with dementia.[1,2] Interaction with caregivers or nursing home (NH) staff may trigger rejection-of-care behaviors, which are most frequently observed in the context of bathing, toileting, grooming, or dressing or during attempts to redirect the patient.[3–6]

Rejection-of-care behaviors can include verbal refusal, argumentative behaviors, and mild physical resistance but can escalate into physically combative behaviors if caregivers or NH staff persist in attempting to provide the rejected care despite patient refusal.[3] Rejection-of-care behaviors are often subsumed under the rubric of agitation,[7] which is commonly used as an all-encompassing term to describe disruptive behaviors,[8] but recent evidence suggests that rejection-of-care behaviors and agitation may be different clinical entities, with different etiologies.[5,7,9]

Rejection-of-care behavior is commonly observed in patients with dementia. In a small community-based sample, caregivers reported that as many as 27% of patients with dementia rejected offered care.[10] In NHs, the reported prevalence of rejection of care in residents with dementia has been slightly lower. When limited to patients with a diagnosis of dementia, 18.6% of new admissions to NHs demonstrated behaviors designated as uncooperative.[11] Another report analyzing Minimum Data Set (MDS) 2.0 data found resistiveness to care in 9%.[7]

This disruptive behavior is considered significant not only because it is common, but also because its effects are

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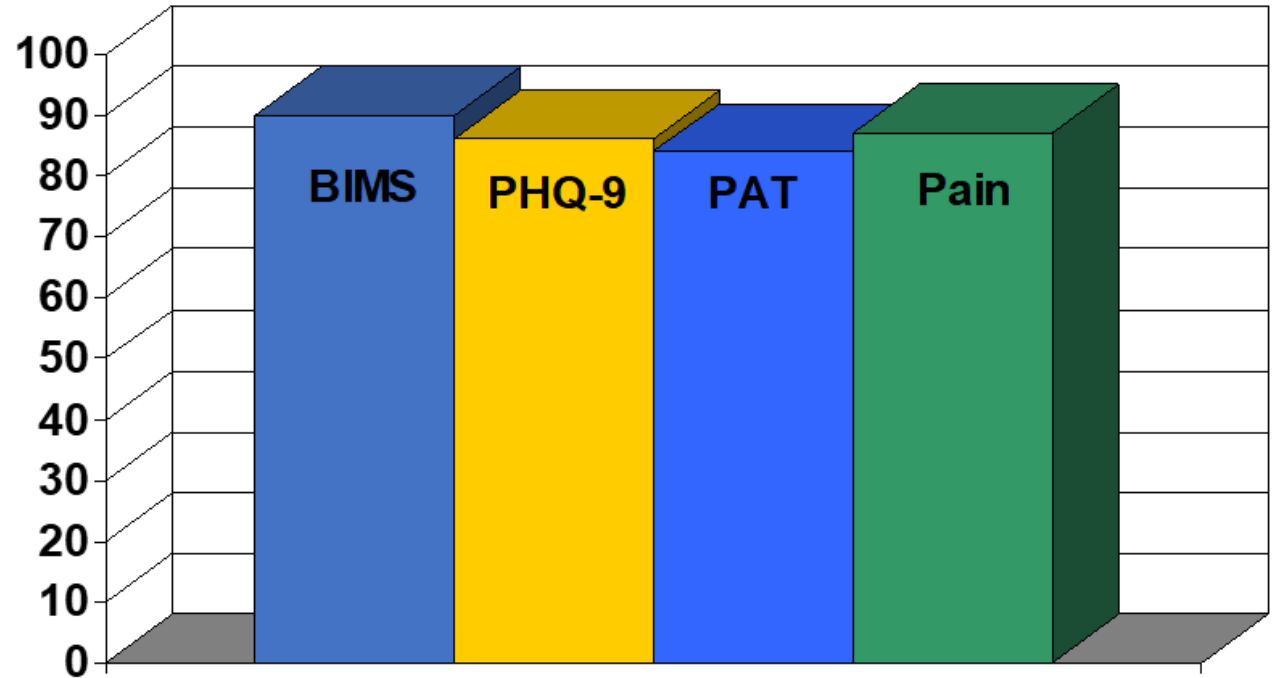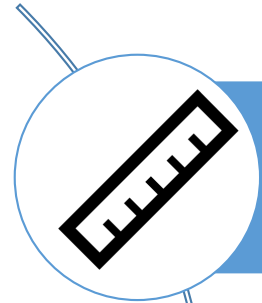
Percent Completing Interviews was High

Attempt with all residents able to be understood at least some of the time

- Cognition (BIMS)
- Mood (PHQ-9)
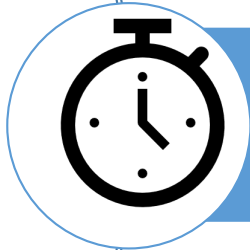- Preferences for customary routines & activities (PAT)
- Pain

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Resident Interview: Pragmatic Caution

◆ Pain as "fifth vital sign"

◆ Initial hesitancy, needed help acquiring skills

MDS 3.0 Cognitive Assessment

- Brief Interview for Mental Status (BIMS)[1, 2]
  - Structured test replaces staff assessment
  - Registration: *blue, bed, sock*
  - Temporal Orientation: *year, month, day*
  - Recall (prompted)

- MDS 2.0 observational items only completed for residents who cannot complete interview

- Confusion Assessment Method (CAM) [3]

[1] *Chodosh, et al 2008*

[2] *Saliba, et al 2012*

[3] *Inouye, SK et al 1990*

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BIMS Score

- Range 0-15

Score	Suggests
13 – 15	No or mild Impairment
8 - 12	Moderate Impairment
0 - 7	Severe Impairment

Distribution of Scores for Each Cognitive Assessment

Categories	% of Validation Sample in Each Category		
	BIMS	CPS	3MS
Intact or borderline/mild impairment	48	36	43
Moderate impairment	26	52	30
Severe impairment	27	12	26

BIMS: higher correlation with criterion measure
> MDS 3.0 BIMS = 0.91 (p< .0001)
> MDS 2.0 CPS = -0.74 (p<.0001)

Both had Excellent Performance

- BIMS
  - Reliability improved
  - More valid -- higher correlation with gold-standard (criterion) measure

- CAM
  - Reliability improved (MDS 3.0, kappa .75-.82)
  - Delirium prevalence approached that of independent research evaluations

Promise of BIMS & CAM

BIMS

- Highly correlated with 3MS
- Questions recognized by providers
- Helps identify residents who benefit from prompts
- Provides structure to observe CAM behaviors
- Bias reduction
- Helpful for case mix
- Same categories as CPS for observation

CAM

- Validated
- Used across settings
- Recognized by PCPs

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Cautions with BIMS & CAM

BIMS
- Language
- Does not diagnose dementia
- Does not replace in-depth assessment
- Does not capture executive function or distinguish mild CI

CAM
- Based on observation, requires assessment skill
- Must determine baseline
- Need protocols for f/u evaluation

Mood Assessment

PHQ-9©

- Resident interview preferred
  - PHQ-9[1] uses DSM criteria
  - Validated in multiple populations

Staff Assessment = PHQ-9 OV [2]

- Observational items
- only complete if resident cannot self-report
- Includes irritability item

Resident _____ Identifier _____ Date _____

Section D	Mood

D0100. Should Resident Mood Interview be Conducted? - Attempt to conduct interview with all residents

Enter Code [ ]

0. **No** (resident is rarely/never understood) → Skip to and complete D0500-D0600, Staff Assessment of Resident Mood (PHQ-9-OV)
1. **Yes** → Continue to D0200, Resident Mood Interview (PHQ-9©)

D0200. Resident Mood Interview (PHQ-9©)

Say to resident: *"Over the last 2 weeks, have you been bothered by any of the following problems?"*

If symptom is present, enter 1 (yes) in column 1, Symptom Presence.
If yes in column 1, then ask the resident: *"About how often have you been bothered by this?"*
Read and show the resident a card with the symptom frequency choices. Indicate response in column 2, Symptom Frequency.

1. Symptom Presence
0. **No** (enter 0 in column 2)
1. **Yes** (enter 0-3 in column 2)
9. **No response** (leave column 2 blank)

2. Symptom Frequency
0. **Never or 1 day**
1. **2-6 days** (several days)
2. **7-11 days** (half or more of the days)
3. **12-14 days** (nearly every day)

	1. Symptom Presence	2. Symptom Frequency
	↓ Enter Scores in Boxes ↓	
A. Little interest or pleasure in doing things	[ ]	[ ]
B. Feeling down, depressed, or hopeless	[ ]	[ ]
C. Trouble falling or staying asleep, or sleeping too much	[ ]	[ ]
D. Feeling tired or having little energy	[ ]	[ ]
E. Poor appetite or overeating	[ ]	[ ]
F. Feeling bad about yourself - or that you are a failure or have let yourself or your family down	[ ]	[ ]
G. Trouble concentrating on things, such as reading the newspaper or watching television	[ ]	[ ]
H. Moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	[ ]	[ ]
I. Thoughts that you would be better off dead, or of hurting yourself in some way	[ ]	[ ]

D0300. Total Severity Score

Enter Score [ ] Add scores for all frequency responses in Column 2, Symptom Frequency. Total score must be between 00 and 27. Enter 99 if unable to complete interview (i.e., Symptom Frequency is blank for 3 or more items).

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PHQ-9 interview had best agreement with mSADS

Agreement with mSADS
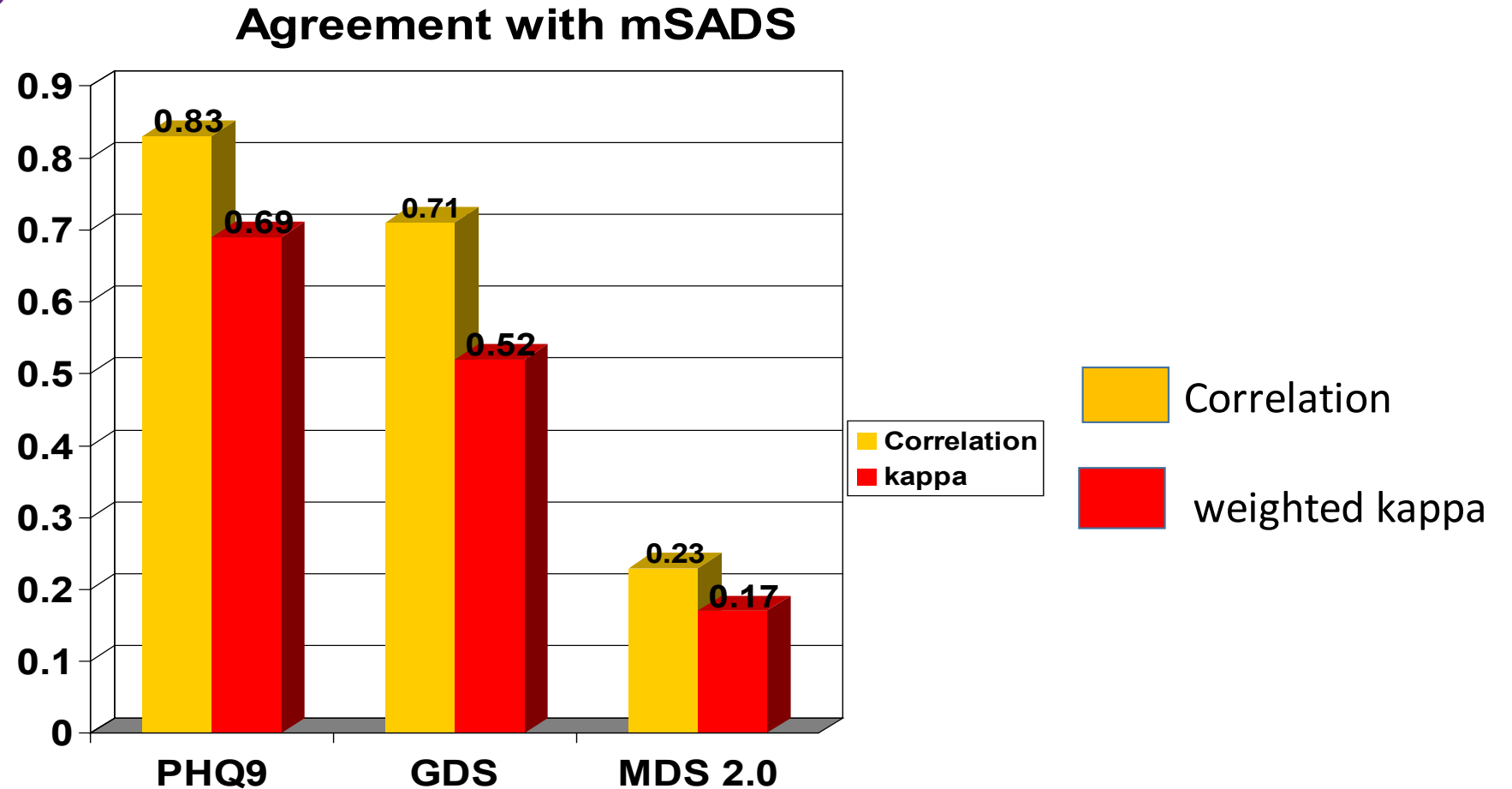
95% CI for kappas: for PHQ9 (.61-.76), for GDS (.44-.59), for MDS 2.0 (.16-.26)

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Severe Cognitive Impairment

Candidate Item Compared to Cornell	Correlation
PHQ-9 OV (Staff Interview)	.84 (p < .0001)
PHQ-9 Resident Interview	.63 (p < .0001)
GDS Resident Interview	.41 (p = .019)
MDS 2.0 RUGs Definition	.28 (p = .203)

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Promise of PHQ-9 & PHQ-9 OV

PHQ-9

- Validated in multiple populations
- Recognized by providers across settings
- Assesses symptoms in DSM IV and DSM V criteria
- Meet quality standard to document target symptoms
- Unfolding saves time & decreases burden
- Severity score (0-27; none-severe) sensitive to change

PHQ-9 OV

- Validated
- Inclusion of irritability
- Staff interview increases education about symptoms

Cautions with PHQ-9 & PHQ-9 OV

PHQ-9

- Does not diagnose depression
- Compound questions may require disentangle
- GDS canon
- Staff hesitation
- Need protocols for follow up

PHQ-9 OV

- Based on observation, requires assessment skill
- Not as sensitive or specific as direct interview
- Chart not sufficient; staff interview required
- Need protocols for follow up

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Pain Assessment

- Resident interview preferred for those who can make self understood
  - *Presence*
  - *Frequency*
  - *Effect on function [1]*
  - *Severity (0-10 or Verbal Descriptor Scale)*

- Staff pain assessment
  - Observational checklist of pain behaviors
  - Only complete for residents who cannot self-report

[1] Cadogan, et al J Gerontol A, 2008

Resident _____ Identifier _____ Date _____

Section J — **Health Conditions**

J0100. Pain Management - Complete for all residents, regardless of current pain level
At any time in the last **5** days, has the resident:

Enter Code [ ] A. Received scheduled pain medication regimen?
  0. No
  1. Yes

Enter Code [ ] B. Received PRN pain medications OR was offered and declined?
  0. No
  1. Yes

Enter Code [ ] C. Received non-medication intervention for pain?
  0. No
  1. Yes

J0200. Should Pain Assessment Interview be Conducted?
Attempt to conduct interview with all residents. If resident is comatose, skip to J1100, Shortness of Breath (dyspnea)

Enter Code [ ]
  0. No (resident is rarely/never understood) → Skip to and complete J0800, Indicators of Pain or Possible Pain
  1. Yes → Continue to J0300, Pain Presence

Pain Assessment Interview

J0300. Pain Presence

Enter Code [ ] Ask resident: "*Have you had pain or hurting at any time* in the last 5 days?"
  0. No → Skip to J1100, Shortness of Breath
  1. Yes → Continue to J0400, Pain Frequency
  9. Unable to answer → Skip to J0800, Indicators of Pain or Possible Pain

J0400. Pain Frequency

Enter Code [ ] Ask resident: "*How much of the time have you experienced pain or hurting* over the last 5 days?"
  1. Almost constantly
  2. Frequently
  3. Occasionally
  4. Rarely
  9. Unable to answer

J0500. Pain Effect on Function

Enter Code [ ] A. Ask resident: "*Over the past 5 days, has pain made it hard for you to sleep at night?*"
  0. No
  1. Yes
  9. Unable to answer

Enter Code [ ] B. Ask resident: "*Over the past 5 days, have you limited your day-to-day activities because of pain?*"
  0. No
  1. Yes
  9. Unable to answer

J0600. Pain Intensity - Administer **ONLY ONE** of the following pain intensity questions (A or B)

Enter Rating [ ][ ] A. Numeric Rating Scale (00-10)
  Ask resident: "*Please rate your worst pain over the last 5 days on a zero to ten scale, with zero being no pain and ten as the worst pain you can imagine.*" (Show resident 00 -10 pain scale)
  Enter two-digit response. Enter 99 if unable to answer.

Enter Code [ ] B. Verbal Descriptor Scale
  Ask resident: "*Please rate the intensity of your worst pain over the last 5 days.*" (Show resident verbal scale)
  1. Mild
  2. Moderate
  3. Severe
  4. Very severe, horrible
  9. Unable to answer

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Correspondence of Verbal Descriptor and Numeric Rating Scales for Pain Intensity: An Item Response Theory Calibration

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[3]UCLA/Los Angeles Jewish Homes Borun Center, Los Angeles, CA.

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Background. Assessing pain intensity in older adults is critical and challenging. There is debate about the most effective way to ask older adults to describe their pain severity, and clinicians vary in their preferred approaches, making comparison of pain intensity scores across settings difficult.

Methods. A total of 3,676 residents from 71 community nursing homes across eight states were asked about pain presence. The 1,960 residents who reported pain within the past 5 days (53% of total, 70% female; age: $M = 77.9$, $SD = 12.4$) were included in analyses. Those who reported pain were also asked to provide a rating of pain intensity using either a verbal descriptor scale (VDS; mild, moderate, severe, and very severe and horrible), a numeric rating scale (NRS; 0 = no pain to 10 = worst pain imaginable), or both. We used item response theory (IRT) methods to identify the correspondence between the VDS and the NRS response options by estimating item parameters for these and five additional pain items.

Results. The sample reported moderate amounts of pain on average. Examination of the IRT location parameters for the pain intensity items indicated the following approximate correspondence: VDS mild ≈ NRS 1–4, VDS moderate ≈ NRS 5–7, VDS severe ≈ NRS 8–9, and VDS very severe, horrible ≈ NRS 10.

Conclusion. This IRT calibration provides a crosswalk between the two response scales so that either can be used in practice depending on the preference of the clinician and respondent.

Key Words: Pain—IRT—Measurement.

Promise of Pain Interviews & Pain observations

Pain Interview

- Pain is a subjective experience, different reported experiences with same stimuli
- Commonly used pain scales, recognized in other settings
- Effect on function translates for providers
- Choice of severity scale

Pain Observation

- Observational items common to multiple scales

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Cautions with Pain Interview & Pain observation

Pain Interview

- Remember 5th vital sign
  - Did not/does not/will not match most charts
- Opioid epidemic confounding; need options
- Not full pain assessment (location, precipitant)
- Apply interview skills
- Follow instructions

Pain Observation

- Based on observation, requires assessment skill
- Chart not sufficient; staff interview required
- Follow instructions
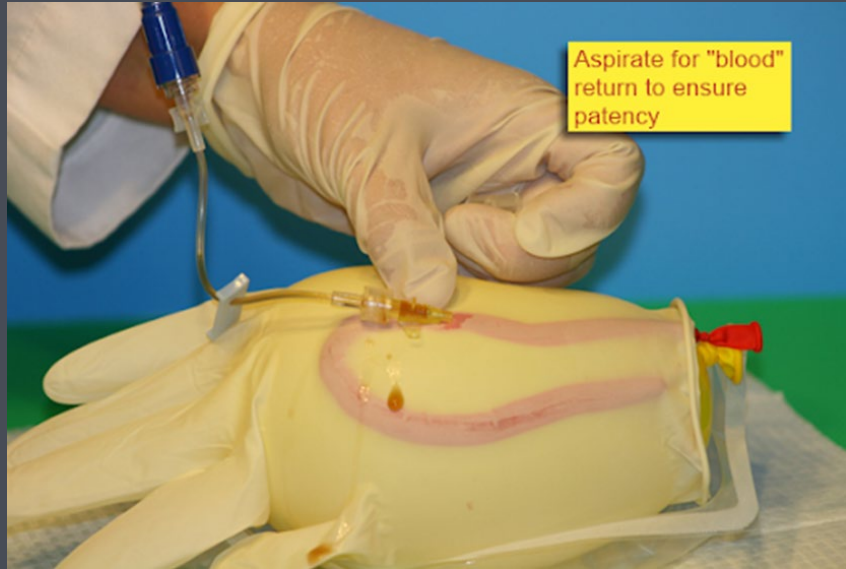
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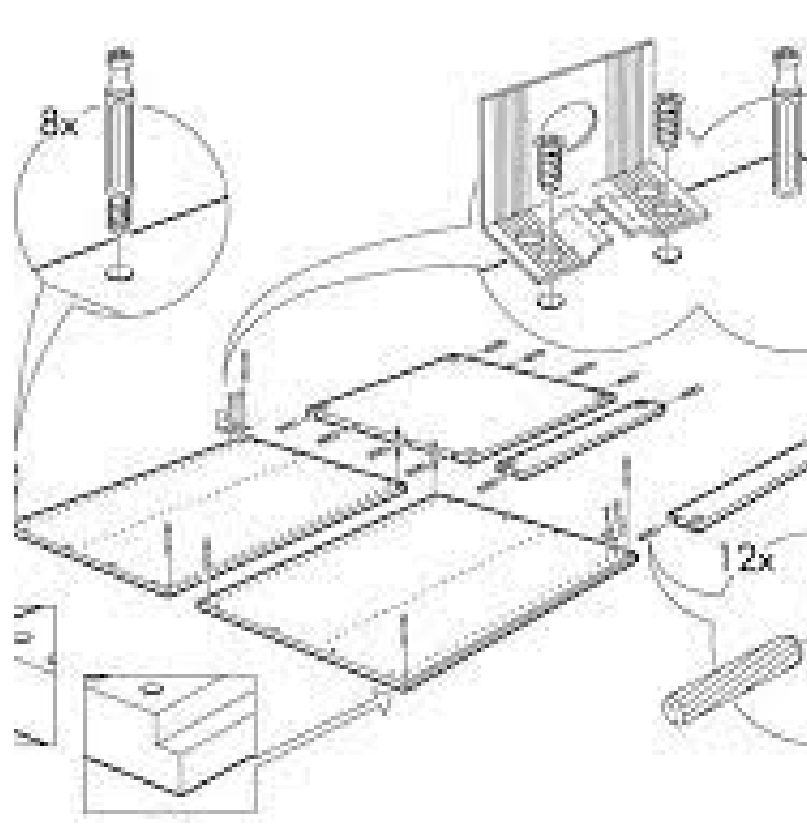
Instructions, pragmatic?

Instructions MDS –consistent map

- Intent (reason in MDS)
- Why is this important to assess?
  - Health-related Quality of Life
  - Planning for Care
- Steps for Assessment
- Definitions
- Coding Instructions
- Coding Tips & Special Populations
- Examples

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Aspirate for "blood" return to ensure patency

Building Pragmatic Skills

https://youtu.be/Ereawm4_F7k

How to Interview

- Can increase response rates & validity with the right approaches
- Introduce yourself
- Be sure they can hear what you say
  - Don't mumble or rush. Articulate
  - Ask about hearing and communication devices
  - Headphones
- Ask if they would like an interpreter
  - Language or signing

Interview Set up

- Quiet private area
  - Decrease interruptions & distraction
  - Eliminate background noise
  - Increase comfort in asking & reporting

- Sit where they can see you and you can see them
  - Lighting
  - Glare
  - Ask where they prefer you sit so they can see and hear you.
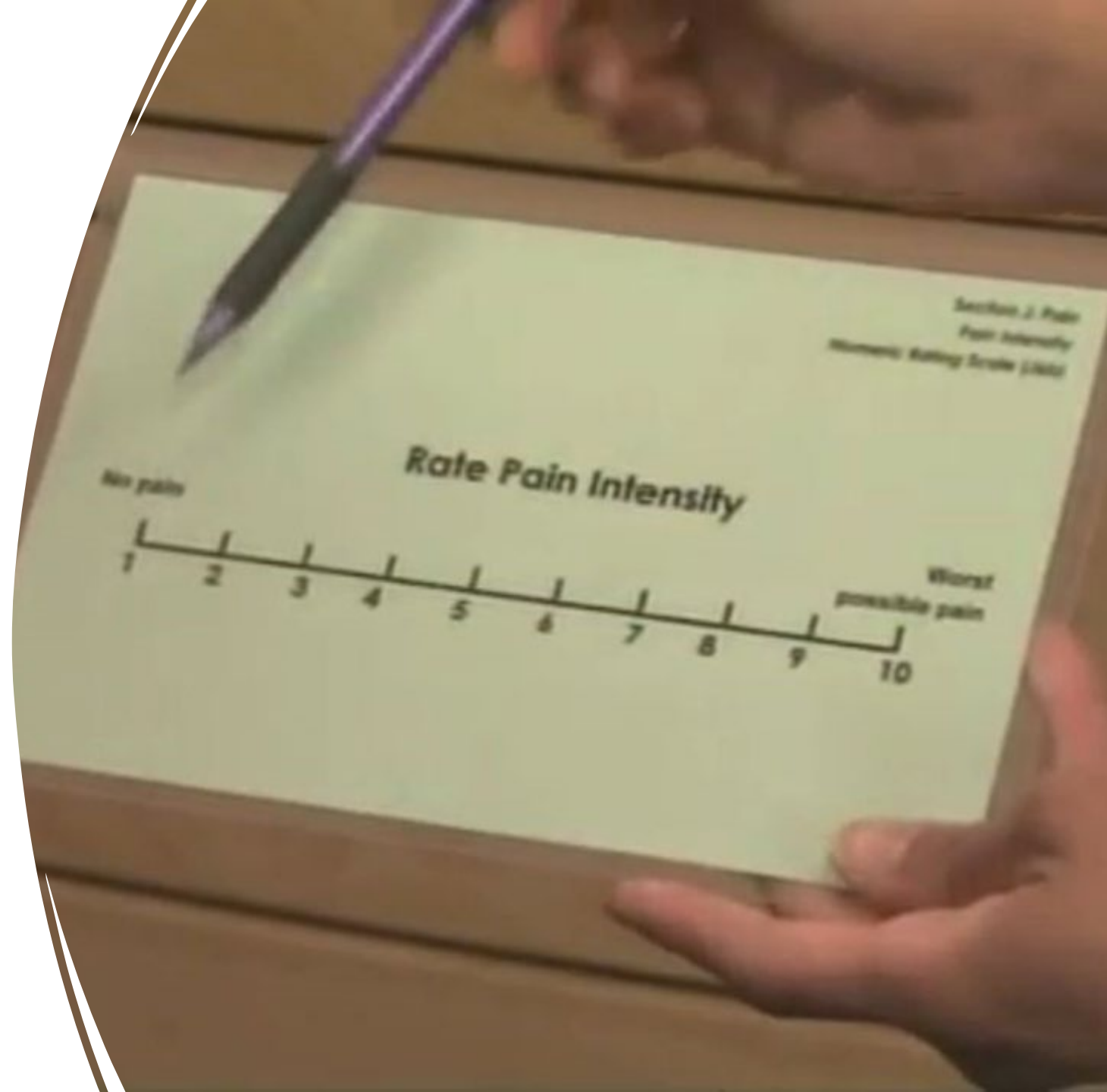
Interviewing: Show and Tell

Item Responses:
- Helpful for older adult to hear and see
- Verbally review and show written
  - Large clear print
- They can respond verbally, point to the answer or both

Rate Pain Intensity

No pain   1 2 3 4 5 6 7 8 9 10   Worst possible pain

Interviewing: Adapt

- Unfold:
  - Start with a general question, move on to more specific
    - Do you have this at all? Do you have it every day? Etc

- Disentangle
  - Separate item into manageable pieces
  - Useful for items in a list or items with "and" or "or"
    - Do you have trouble falling asleep? Trouble staying asleep?

- If resident understands item but has trouble selecting a response
  - Clarify and echo

Do not use unfolding, disentangling or echoing for cognitive testing

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Summary: MDS 3.0

- Consider including MDS assessment items in pragmatic trials
  - Tested & Standardized
  - Clinically relevant

- Like all data, items offer promises and pitfalls
  - Know what they are
  - Can minimize some pitfalls with basic pragmatic skills
  - Chart documentation, while important, is rarely sufficient for daily events
  - Skills and training can help leverage the investment already making in MDS and allow items to be helpful between assessments

- MDS = opportunity to improve NH quality of care processes and move from administrative burden to an assessment tool
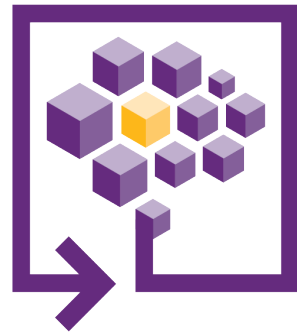
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QUESTIONS?