PROMISES AND PITFALLS OF EXISTING DATA IN NURSING HOMES

THURSDAY, JUNE 17, 2021 @ 12:00 PM ET
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

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

- 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

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
Sample: Nursing Home Residents with Advanced Cognitive Impairment

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Nursing home residents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N= 474,829</td>
</tr>
<tr>
<td>Avg. Age</td>
<td>85.7</td>
</tr>
<tr>
<td>Gender (%F)</td>
<td>78.0%</td>
</tr>
<tr>
<td>Race (% Black)</td>
<td>12.0%</td>
</tr>
<tr>
<td>One or more burdensome transition</td>
<td>19.0%</td>
</tr>
<tr>
<td>Swallowing problems</td>
<td>54.1%</td>
</tr>
<tr>
<td>DNR</td>
<td>73.2%</td>
</tr>
</tbody>
</table>

One or More Burdensome Transitions in NH residents with Advanced Dementia

## Table of Two Cities…

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Grand Junction, CO</th>
<th>McAllen, TX</th>
<th>US</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple Hospitalizations for Pneumonia, UTI, dehydration</td>
<td>1.1%</td>
<td>25.8%</td>
<td>8.1%</td>
</tr>
<tr>
<td>PBTI None</td>
<td>89.0%</td>
<td>64.5%</td>
<td>81.0%</td>
</tr>
<tr>
<td>PBTI =1</td>
<td>11.0%</td>
<td>28.0%</td>
<td>16.0%</td>
</tr>
<tr>
<td>PBTI =2</td>
<td>0%</td>
<td>7.3%</td>
<td>3.1%</td>
</tr>
</tbody>
</table>
### Association of Burdensome Transitions and Adverse Outcomes

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

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

<table>
<thead>
<tr>
<th></th>
<th>Unadjusted</th>
<th>Adjusted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had hospice</td>
<td>58.8%</td>
<td>59.3%</td>
</tr>
<tr>
<td>No hospice or hospice &lt;3 before death</td>
<td>43.1%</td>
<td>42.8%</td>
</tr>
</tbody>
</table>
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

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 than 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.
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

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

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

<table>
<thead>
<tr>
<th>Survey Items Added to CAHPS Hospice Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was the decision about enrolling in full hospice care made free of pressure from anyone from the special program?</td>
</tr>
<tr>
<td>Did your family member continue to receive treatment for his or her terminal illness for as long as he or she wanted?</td>
</tr>
<tr>
<td>In your opinion, did the discussion about enrolling in full hospice care happen too early, at the right time, or too late?</td>
</tr>
<tr>
<td>Did the special program team do anything that went against your family member's wishes?</td>
</tr>
</tbody>
</table>
MCCM: Feeling Pressure on Hospice Transition

Persons whose families reported that decision to enroll in hospice was not free from pressure

- Participants from MCCM hospices: 6.4%
- Participants from comparison hospices: 6.1%
- MCCM participants who did not transition to hospice: 16.4%

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

Debra Saliba, MD, MPH

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
Senior Natural Scientist, RAND Corporation
IMPACT PCRO Core members

Core Lead: Laura C. Hanson, MD, MPH

Executive Committee:
– Antonia Bennett, PhD
– Amy Kelley, MD, MSHS
– Joshua Niznik, PharmD, PhD
– Christine Ritchie, MD, MSPH
– Debra Saliba, MD, MPH
– Joan Teno, MD, MS
– Sheryl Zimmerman, PhD

Core Support:
– Stacey Gabriel
– Natalie Meeks
– Kathryn Wessell
## Example Clinical Outcome Measures for ePCTs

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

<table>
<thead>
<tr>
<th>Detection of needs</th>
<th>Over 500 items</th>
</tr>
</thead>
</table>

**CAUTION!**
## Potential Pitfalls

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<td>Standardized items</td>
<td>Range of assessment &amp; documentation accuracy Detection bias</td>
</tr>
<tr>
<td>Comparable across NHs</td>
<td>No one reads instruction manuals</td>
</tr>
<tr>
<td>Instruction manual</td>
<td></td>
</tr>
</tbody>
</table>
## Potential Pitfalls

<table>
<thead>
<tr>
<th>Potential Pitfalls</th>
<th>[ Conclusion ]</th>
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<td>Instruction manual</td>
<td>No one reads instruction manuals</td>
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<tr>
<td>Resident Voice through interview</td>
<td>Skill not included in most training</td>
</tr>
<tr>
<td>Open up discussions</td>
<td>Requires recognize unmet needs</td>
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<tr>
<td>Observational items if unable to express</td>
<td>Must reconcile self-report &amp; observation</td>
</tr>
<tr>
<td>Proxy differs from respondent.</td>
<td></td>
</tr>
</tbody>
</table>

**CAUTION!**
## Potential Pitfalls

<table>
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<td>Trigger evaluation &amp; care planning</td>
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</tr>
<tr>
<td>Trigger evaluation &amp; care planning</td>
<td>Only one step, need follow through</td>
</tr>
</tbody>
</table>
| One form, Multiple uses | Clinical utility vs. $$$$ vs. ★★★★★

**CAUTION!**
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 Bonin 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

- **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

- CMS Revised Draft MDS 3.0
### Behavioral Symptoms

#### E0200. Behavioral Symptom - Presence & Frequency

<table>
<thead>
<tr>
<th>Note presence of symptoms and their frequency</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Coding:</th>
<th>Enter Codes in Boxes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0. Behavior not exhibited</td>
<td><strong>A. Physical behavioral symptoms directed toward others</strong> (e.g., hitting, kicking, pushing, scratching, grabbing, abusing others sexually)</td>
</tr>
<tr>
<td>1. Behavior of this type occurred 1 to 3 days</td>
<td><strong>B. Verbal behavioral symptoms directed toward others</strong> (e.g., threatening others, screaming at others, cursing at others)</td>
</tr>
<tr>
<td>2. Behavior of this type occurred 4 to 6 days, but less than daily</td>
<td><strong>C. Other behavioral symptoms not directed toward others</strong> (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)</td>
</tr>
<tr>
<td>3. Behavior of this type occurred daily</td>
<td></td>
</tr>
</tbody>
</table>

---

**NIA IMPACT COLLABORATORY**

TRANSFORMING DEMENTIA CARE
## MDS 3.0 vs 2.0 Behavior & Psychosis Items: Agreement with Gold Standard

<table>
<thead>
<tr>
<th>Gold-Standard (CMAI / NPI)</th>
<th>MDS 3.0 Kappa (95% CI)</th>
<th>MDS 2.0 Kappa (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical toward others</td>
<td>.86 (.74, .97)</td>
<td>.23 (.03, .43)</td>
</tr>
<tr>
<td>Verbal toward others</td>
<td>.73 (.61, .84)</td>
<td>.31 (.16, .45)</td>
</tr>
<tr>
<td>Other Behavior</td>
<td>.53 (.42, .66)</td>
<td>.22 (.12, .31)</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>.92 (.81, 1.00)</td>
<td>.23 (.03, .43)</td>
</tr>
<tr>
<td>Delusions</td>
<td>.88 (.79, .98)</td>
<td>.31 (.16, .45)</td>
</tr>
</tbody>
</table>
Severe Behavioral Health Manifestations in Nursing Homes: Associations with Service Availability

### Symptom Impact

#### E0500. Impact on Resident

<table>
<thead>
<tr>
<th>Enter Code</th>
<th>Did any of the identified symptom(s):</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A. Put the resident at significant risk for physical illness or injury?</td>
</tr>
<tr>
<td></td>
<td>0. No</td>
</tr>
<tr>
<td></td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>B. Significantly interfere with the resident's care?</td>
</tr>
<tr>
<td></td>
<td>0. No</td>
</tr>
<tr>
<td></td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>C. Significantly interfere with the resident's participation in activities or social interactions?</td>
</tr>
<tr>
<td></td>
<td>0. No</td>
</tr>
<tr>
<td></td>
<td>1. Yes</td>
</tr>
</tbody>
</table>

#### E0600. Impact on Others

<table>
<thead>
<tr>
<th>Enter Code</th>
<th>Did any of the identified symptom(s):</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A. Put others at significant risk for physical injury?</td>
</tr>
<tr>
<td></td>
<td>0. No</td>
</tr>
<tr>
<td></td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>B. Significantly intrude on the privacy or activity of others?</td>
</tr>
<tr>
<td></td>
<td>0. No</td>
</tr>
<tr>
<td></td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>C. Significantly disrupt care or living environment?</td>
</tr>
<tr>
<td></td>
<td>0. No</td>
</tr>
<tr>
<td></td>
<td>1. Yes</td>
</tr>
</tbody>
</table>
# Wandering

## E0900. Wandering - Presence & Frequency

<table>
<thead>
<tr>
<th>Enter Code</th>
<th>Has the resident wandered?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Behavior not exhibited ➔ Skip to E1100, Change in Behavior or Other Symptoms</td>
</tr>
<tr>
<td></td>
<td>Behavior of this type occurred 1 to 3 days</td>
</tr>
<tr>
<td></td>
<td>Behavior of this type occurred 4 to 6 days, but less than daily</td>
</tr>
<tr>
<td></td>
<td>Behavior of this type occurred daily</td>
</tr>
</tbody>
</table>

## E1000. Wandering - Impact

<table>
<thead>
<tr>
<th>Enter Code</th>
<th>A. Does the wandering place the resident at significant risk of getting to a potentially dangerous place (e.g., stairs, outside of the facility)?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Enter Code</th>
<th>B. Does the wandering significantly intrude on the privacy or activities of others?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
</tbody>
</table>
Type of Impact on Resident Varies

MDS 3.0 Behavioral Symptoms: Impact on Resident (N=317)

- Puts resident at risk: 24%
- Interferes with care: 33%
- Interferes with activities: 36%
**E0800. Rejection of Care - Presence & Frequency**

<table>
<thead>
<tr>
<th>Enter Code</th>
</tr>
</thead>
</table>

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

Shinya Ishii MD, Joel E. Streim MD, Debra Saliba MD, MPH

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

Abstract

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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Fig. 1. Conceptual framework for rejection of care.

*The numbers in the boxes are added for cross reference and do not imply linear relationships.*
Association with Dementia Severity

**Rejection of Care**

<table>
<thead>
<tr>
<th>Study</th>
<th>Odds Ratio (95% CI)</th>
<th>Weight, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zuidema et al, 2009</td>
<td>1.37 (1.02-1.85)</td>
<td>36.5</td>
</tr>
<tr>
<td>Selbaek et al, 2007</td>
<td>2.36 (1.78-3.13)</td>
<td>41.7</td>
</tr>
<tr>
<td>Tatsch et al, 2006</td>
<td>2.31 (0.72-7.39)</td>
<td>2.43</td>
</tr>
<tr>
<td>Steffens et al, 2005</td>
<td>1.71 (0.90-3.26)</td>
<td>7.93</td>
</tr>
<tr>
<td>Shimabukuro et al, 2005</td>
<td>8.89 (1.01-78.1)</td>
<td>0.70</td>
</tr>
<tr>
<td>Lyketsos et al, 2000</td>
<td>2.07 (1.19-3.61)</td>
<td>10.7</td>
</tr>
</tbody>
</table>

Test for Heterogeneity: $I^2 = 44.8\%$; $P=.107$

Random-effects model: $P<.001$ 1.92 (1.43-2.57) 100

Ishii et al, JAMDA 2012
Potentially Reversible Resident Factors Associated with Rejection of Care Behaviors
Shinya Iida, MD,* Joel E. Stein, MD,† and Debra Sibila, 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 assess 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 modifiable characteristics assessed were mood (Patient Health Questionnaire-9), delusions (Confusion Assessment Method), delusions, hallucinations or illusions, hearing impairment, vision impairment, pain severity, and infection diagnoses. Characteristic risks 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 = 4.6, 95% CI = 1.5-1.6), major depression (OR = 2.1, 95% CI = 1.5-2.8), and severe to horrible pain (OR = 1.6, 95% CI = 1.1-2.3). Depression 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. Am J 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. Interaction with caregivers or nursing home (NH) staff may trigger rejection-of-care behaviors, which are most frequently observed in the context of holding, rolling, groaning, or dressing or during attempts to reduce the patient. In NHs, rejection-of-care behaviors can include verbal refusal, argumentative behavior, and mild physical resistance but can escalate into physically combative behaviors of caregivers or NH staff persisting in attempting to provide the rejected care despite patient refusal. Rejection-of-care behaviors are often submerged under the rubric of agitation, which is commonly used as an all-encompassing term to describe disruptive behaviors but recent evidence suggests that rejection-of-care behavior and agitation may be different clinical entities, with different etiologies.

Rejection of care behavior is commonly observed in patients with dementia. In a small community-based sample, caregivers reported that as many as 25% of patients with dementia rejected offered care. 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, 18-66% of new admissions to NHs demonstrated behaviors designated as uncooperative. Another report analyzing Minimum Data Set (MDS) data found increases in rejections to care in NHs, this disruptive behavior is considered significant not only because it is common, but also because its effects are
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
Resident Interviews: Pragmatic Promise

- Tested items for resident centered assessment
- 17 minutes
- 88% “improved understanding of resident”
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)\textsuperscript{1,2}
  \begin{itemize}
    \item Structured test replaces staff assessment
    \item Registration: \textit{blue, bed, sock}
    \item Temporal Orientation: \textit{year, month, day}
    \item Recall (prompted)
  \end{itemize}

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

– Confusion Assessment Method (CAM)\textsuperscript{3}

\begin{itemize}
  \item \textsuperscript{1} Chodosh, et al 2008
  \item \textsuperscript{2} Saliba, et al 2012
  \item \textsuperscript{3} Inouye, SK et al 1990
\end{itemize}
## BIMS Score

- Range 0-15

<table>
<thead>
<tr>
<th>Score</th>
<th>Suggests</th>
</tr>
</thead>
<tbody>
<tr>
<td>13 – 15</td>
<td>No or mild Impairment</td>
</tr>
<tr>
<td>8 - 12</td>
<td>Moderate Impairment</td>
</tr>
<tr>
<td>0 - 7</td>
<td>Severe Impairment</td>
</tr>
</tbody>
</table>
### Distribution of Scores for Each Cognitive Assessment

<table>
<thead>
<tr>
<th>Categories</th>
<th>% of Validation Sample in Each Category</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>BIMS</td>
</tr>
<tr>
<td>Intact or borderline/mild impairment</td>
<td>48</td>
</tr>
<tr>
<td>Moderate impairment</td>
<td>26</td>
</tr>
<tr>
<td>Severe impairment</td>
<td>27</td>
</tr>
</tbody>
</table>

- **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
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 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

1 Kroenke, et al JGIM 2001;
PHQ-9 interview had best agreement with mSADS

95% CI for kappas: for PHQ9 (.61-.76), for GDS (.44-.59), for MDS 2.0 (.16-.26)
<table>
<thead>
<tr>
<th>Candidate Item Compared to Cornell</th>
<th>Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHQ-9 OV (Staff Interview)</td>
<td>.84 (p &lt; .0001)</td>
</tr>
<tr>
<td>PHQ-9 Resident Interview</td>
<td>.63 (p &lt; .0001)</td>
</tr>
<tr>
<td>GDS Resident Interview</td>
<td>.41 (p = .019)</td>
</tr>
<tr>
<td>MDS 2.0 RUGs Definition</td>
<td>.28 (p = .203)</td>
</tr>
</tbody>
</table>
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
Pain Assessment

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

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

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

Maria Orlando Edelen,1 and Debra Saliba1,2,3

1Health Unit, RAND Corporation, Santa Monica, CA.
2VA Greater Los Angeles GRECC and HSR&D Center of Excellence, Los Angeles, CA.
3UCLA/Los Angeles Jewish Homes Bonn Center, Los Angeles, CA.

Address correspondence to Maria Orlando Edelen, PhD, RAND Corporation, Santa Monica, CA. Email: orlando@rand.org

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.

Received September 18, 2009; Accepted December 8, 2009

Decision Editor: Luigi Ferrucci, MD, PhD
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
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
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
Aspirate for "blood" return to ensure patency.
Building Pragmatic Skills

VIVE
Video on Interviewing Vulnerable Elders

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:

**Introduce**

Explain topic & that you are going to ask some questions.

**Normalize**

*We ask everyone these questions so we can be sure nothing is missed*

*Some may seem easy; some may seem hard*

**Explain**

that their answers will help the care team to work with them to develop a plan that fits their needs.
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
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
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
QUESTIONS?