Toolbox for Improving Behavioral Health in Nursing Homes

Symposium presented at
The Gerontological Society of America's 66th Annual Scientific Meeting
New Orleans, LA November 24, 2013
Symposium Overview

- 8-8:10  Introduction- Kimberly Van Haitsma
- 8:10-8:25  Staff education & leadership programs- Ann Boseen
- 8:25-8:40  Process of assessment- Laura Gitlin
- 8:40-8:55  Implementation of feasible interventions - Rita Jablonski
- 8:55-9:10  Methods for system integration- Marie Boltz
- 9:10-9:25  Discussant- Alice Bonner
- 9:25-9:30  Q&A
• Reduce national prevalence of antipsychotic medication use in long-stay nursing home residents by 15% by end of 2012

• Baseline: national rate based on MDS data (Nursing Home Compare takes an average of previous three quarters) in December 2011
  – National rate in long-stay residents was 23.9%
  – Denominator includes all residents except those with schizophrenia, Tourette’s or Huntington’s disease
Acknowledgements

Ann Kolanowski, PhD & Kimberly VanHaitsma, PhD-Co-PIs on Commonwealth Foundation Toolbox for Improving Behavioral Health in Nursing Homes Project (Small Grant #20130170)

This work was supported by grants from the Commonwealth Foundation and the Hartford Foundation. The funding agencies had no role in the preparation of this presentation.
Goal of Project

Convene a national, interdisciplinary group of geriatric behavioral experts to collaborate on the development of a behavioral health Toolkit for staff in nursing homes.
Toolbox Concept

• Compendium of peer-reviewed/expert-endorsed resources that will assist staff in the implementation of non-pharmacological approaches for challenging behaviors.

• Readily accessible

• Components: staff educational and leadership development programs; methods for assessing behavior; non-pharmacological approaches (NPA) to challenging behaviors; system-wide methods for integrating approaches into the culture of care

• Plan for wide dissemination of the Toolbox.
Subgroups Who Worked on Toolbox

- **Philosophy** - Karen Love, Jackie Pinkowitz

- **Education & Leadership** - Judy Lucas, Cornelia Beck, Brenda Cleary, Ann Bossen

- **Assessment** - Laura Gitlin, K. Marx, B. Hansen, & Kimberly VanHaitsma (Linda Teri, Kitty Buckwalter & Chris Kovach reviewed draft)

- **Intervention** - Sharon Nichols, Rita Jablonski, Andrea Gilmore-Bykovskyi, Darina Molkina, Natalie Baker, Ann Bossen (Lois Evans & Kelly Carney reviewed draft)

- **System Integration** - Marie Boltz, Carmen Bowman & Pat Parmelee

- **Dissemination Plan** - Barb Resnick

- **Specific Behaviors** - Andrea Gilmore-Bykovskyi, Justine Sufcik
Other Players

Advancing Excellence
American Health Care Association
American Medical Director’s Association
Centers For Medicare and Medicaid Services (CMS)
Leading Age
National Dementia Care Initiative
Workgroup Agenda

• Face-to-face meeting in San Diego, Nov., 2012
• Multiple phone conferences
• Meeting with Mary Jane Koran (Commonwealth Foundation)
• Web design and dissemination with gift from Hartford Foundation
• Conducted eight focus groups with nursing home staff (CNAs, LPNs, RNs, Recreational Therapy) in Centre County and Philadelphia, Pa.
The Toolkit
www.nursinghometoolkit.com

Promoting Positive Behavioral Health:
A Non-pharmacologic Toolkit for Senior Living Communities
Tools to Integrate Non-pharmacologic Treatment of Behavioral Manifestations of Distress in Residents with Dementia

Marie Boltz, Patricia Parmelee, Carmen Bowman, G. Allen Power, Kimberly Van Haitsman, Ann Kolanowski
Our Goal

Identify best practices related to:

- implementation
- evaluation
- sustainability

_of systemic approaches that support safe and effective alternatives to antipsychotic use for behavioral symptoms of distress experienced by nursing home residents with dementia_
Methods

Iterative:

- Literature review
- Website reviews
- Consultation with experts
- Committee discussions
Recognizing the complexity of the nursing home setting

Results: Social – ecological Factors

- Baseline and ongoing appraisal of the social and physical environment
- Educational methodology to support resident, family and staff interpersonal communication and relationship
- Intrapersonal tools to support evidence-based, individualized clinical interventions
- Performance improvement measures, tool, and initiatives to support adherence with regulatory policy
Step 1: Organizational evaluation

Appraisal of the social and physical environment
TESS -NH
(Therapeutic Environment Screening Survey)

A 37-item checklist consists of a range of environmental domains (safety / security, orientation, privacy/control), as well as staff interaction, resident involvement in activities, and physical environmental atmosphere.


Person-centered care assessment tool (P-CAT)

Person-directed Care Measure

50 items
- personhood
- autonomy/choice
- knowing the person
- comfort
- nurturing relationships
- physical environment
- organizational environment

Person-directed Care Measure

Step 2: Education: staff, residents, family

Project Management that supports uptake
Step 2
Use of an evidence-based educational program

P.I.E.C.E.S.:
Human resource development and project management tools to support changes in practice

STAR—Staff Training in Assisted-living Residences
Educational Methodology

Practices that support integration
- Mandatory inservices, scheduled as part of routine work time
- Incentives to participate (such as a meal) facilitate reach
- Ongoing educational opportunities at the bedside

Resident /family education
- Orientation to include philosophy, policy, and alternatives
- Revisit as needed at care planning

Rodwell et al. Supervisors are central to work characteristics affecting nurse outcomes J Nurs Scholarsh 2009; 41:310–319.
Step 3: Policy development

- Clinical protocol
- Interdisciplinary care planning processes
Clinical protocol (monitored by champion(s))

Preferences for Everyday Living Inventory

- **Assessment of**:
  - Social profile, coping measures, preferences, triggers.
  - Clinical presentation of cognition, mood, function

Clinical protocol

- A plan for:
  - family involvement as desired
  - a structured routine (24-hour) that reflects resident preference and capability
  - therapeutic communication

- Management of medical and psychiatric disorders
- If antipsychotics are used, conservative approach
- An individualized plan of care to avoid behavioral symptoms and manage acute behavioral episodes

Interdisciplinary care planning processes

that include:

- the resident and family with a copy of care plan provided to family
- nursing assistants in care planning
Step IV. Sustain the improvement

Quality assurance/ improvement activity
Evidence-based measures

- Pharmacist audit of psychoactive use (outcome measure) with feedback to staff
- Steering committee to develop process measures
- Include assessment of congruence to resident preference

Evidence-based approach to continuous performance improvement

- Include all levels of staff in QA/QI activity. Share results.
- Use of “QAPI at a Glance”


http://www.abramsoncenter.org/pri/projects/PELI.htm
Toolkits to achieve quality goals
Advancing Excellence in America’s Nursing Homes

Process Goals:
- Improving staff stability;
- Increasing use of consistent assignment
  - Increasing person-centered care planning and decision making;
- Safely reducing hospitalizations;

Clinical Goals
- Using medications appropriately;
- Increasing resident mobility;
- Preventing and managing infections safely;
- Reducing the prevalence of pressure ulcers; and
- Decreasing symptoms of pain.
In conclusion......

The social ecological view supports a systematic approach to promoting the well-being of persons with dementia, including alternatives to anti-psychotic medication.

We are still on the journey....
Building a Toolkit for Improving Behavioral Health in Nursing Homes


Education Committee

- Cornelia Beck, PhD, RN, FAAN, University of Arkansas for Medical Sciences
- Ann Bossen, PhD, RN, University of Iowa
- Brenda Cleary, PhD, RN, FAAN, Healthcare Consultant
- Judith A. Lucas, EdD, RN, GCNS-BC, Seton Hall University
- Ann Kolanowski, PhD, RN, FAAN, Penn State School of Nursing
- Kimberly Van Haitsma, PhD, Polisher Research Institute
- Imani Baker, Rutgers University

Goal of education committee:

- To conduct a search to identify nursing education sources on existing non-pharmacological approaches to behavioral management in dementia care
Educational and Leadership Development Programs

- Educational Programs for Implementing Non-Pharmacological Approaches
- Leadership Opportunities for Professional Staff
- Educational Resources Available on the Portal of Geriatric Online Education (POGOe) Website
- Geriatric Certification Opportunities
Features identified

- Name of program
- Sponsoring agency
- Abstract/brief description
- Intended learning audience
- Peer reviewed
- Evidence-based
- Learning resource type & format
- CEUs available
- Duration
- Link
- Cost involved
Product formats included:

- 5 webinars
- 8 PowerPoint presentations
- 1 CD-ROM
- 6 videos
- 1 audio conference
- 3 continuing education presentations and modules
- Instructional materials
- 3 pocket cards
- 2 case studies
- Journal articles
- 1 book

Focus group input

- Direct care staff indicated that video and other types of demonstration were the most useful sorts of educational materials for helping them respond to behavioral symptoms.
Portal of Geriatric Online Education (POGOe)

- An existing database of educational materials supported by the Reynolds Foundation
- 20 resources identified
Leadership development programs

- 15 programs were identified with material specific for administrators and supervisory staff.
The Coalition of Geriatric Nursing Organizations

- 10 geriatric certification opportunities for management and professional staff were found
- These certification opportunities are designed for licensed practical nurses and registered nurses in long-term care and assisted living.
Challenges

- Finding products that were specifically for direct care staff. Limited to those products where the sponsoring organization did not charge a fee.

- Database itemized when there was a fee for use of the product.

- Costs for some products were higher for non-members of the organization, and may reduce access for facility use.
Thank you
Assessing Neuropsychiatric Symptoms in Persons with Dementia: A Review of Measures

Laura N. Gitlin, PhD
Professor, Director
Center for Innovative Care in Aging
The Johns Hopkins University

lgitlin1@jhu.edu
www.nursing.jhu.edu/agingcenter
Co-authors and Collaborators

- Katherine A. Marx, PhD, MPH
  - Center for Innovative Care in Aging, Johns Hopkins University

- Kimberly S. Van Haitsma, PhD
  - Director, Polisher Research Institute, Abramson Center for Jewish Life

- Bryan Hansen, MSN, RN
  - Doctoral candidate, Research Assistant, Center for Innovative Care in Aging, Johns Hopkins University, School of Nursing

- Ann M. Kolanowski, PhD, RN
  - Elouise Ross Eberly Professor, Director, Hartford Center of Geriatric Nursing Excellence School of Nursing, Penn State

- Assistance preparing GSA slides, Ian Stanley, Health Educator for Center for Innovative Care in Aging, Johns Hopkins University
Research Support and Disclosures

- Dr. Gitlin supported in part for work on this project from the:
  - NIA Grant #R01AG041781
  - Alzheimer’s Association Grant # NPSASA-10-174625
- Commonwealth funds awarded to Drs. Van Haitsma and Kolanowski

No relevant financial or conflict of interest disclosures
Objectives

- Why assess behavioral symptoms in persons with dementia?
- Summary of available tools
- Research and Clinical Implications
Why Assess Behavioral Symptoms?

- Behavioral symptoms occur throughout disease progression
- Nearly universal - almost all persons with dementia will have one or more behavioral symptoms, regardless of dementia etiology
- Associated with poor patient outcomes:
  - Reduced quality of life
  - More rapid disease progression
  - Increased health care utilization and costs
  - Increased safety concerns
- Associated with poor caregiver outcomes:
  - Increased depression, burden and upset
  - Increased need for vigilance and time spent caregiving
  - Poor quality of life
  - Increased risk for placing person in nursing home care
  - Increased safety risk
- Under recognized and undertreated
<table>
<thead>
<tr>
<th>Behavioral Symptoms</th>
<th># (% of Caregivers Reporting Behavior Past Month)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Repetitive questioning</td>
<td>218 (80.1%)</td>
</tr>
<tr>
<td>Refusing care</td>
<td>147 (54.0%)</td>
</tr>
<tr>
<td>Argumentativeness</td>
<td>183 (67.3%)</td>
</tr>
<tr>
<td>Toileting issues</td>
<td>173 (63.6%)</td>
</tr>
<tr>
<td>Upset/agitated/restless</td>
<td>157 (57.7%)</td>
</tr>
<tr>
<td>Wakes up at night</td>
<td>145 (53.3%)</td>
</tr>
<tr>
<td>Verbal Aggression</td>
<td>145 (53.3%)</td>
</tr>
<tr>
<td>Wandering</td>
<td>52 (19.1%)</td>
</tr>
<tr>
<td>Inappropriate behaviors</td>
<td>20 (7.4%)</td>
</tr>
</tbody>
</table>

6-Steps for Identifying and Addressing Behavioral Symptoms

Gitlin, Kales, Lyketsos, JAMA 2012
Assessing Behaviors

- AMA Physician Consortium for Performance Improvement (PCPI) 2011 Dementia Performance Measurement Set suggests minimum yearly screen
  - Measure #4: Neuropsychiatric Symptom Assessment
    Percentage of patients, regardless of age, with a diagnosis of dementia and for whom an assessment of neuropsychiatric symptoms is performed and results reviewed at least once in a 12 month period.

- No widely agreed upon standard for screening for behavioral symptoms or one recommended tool
  - Behaviors typically brought to physician’s attention by concerned caregiver after occurrences or by staff in a facility

Odenheimer, et al., in press, Neurology; Marx et al., poster, AAIC, July 17th, 2013
Search Strategy

- A computerized search of:
  - Peer reviewed published studies of measures (1980 to present)
  - English

Search terms: neuropsychological tests, neuropsychological measurements, dementia, Alzheimer’s disease, behavior, delusions, hallucinations, agitation, aggression, depression, anxiety, eating, euphoria, apathy, disinhibition, irritability, motor disturbance, sleep, and vocalizations.

- Articles were further searched for additional measures.
Evaluation of Scales for:

- Number of Items
- Domains of Behavior
- How Administered
- Response Categories (domain and specific response)
- Target Population
- Reliability and Validity
RESULTS

2,260 articles identified

-2,233 articles from direct search
-27 additional articles

78 measures identified

44 (56%) measures With adequate psychometric properties

Fifteen (34%) broad-based measures

Twenty-nine (65.9%) behavior specific measures
General Behavior Scales (n=15)

1. Alzheimer’s disease assessment scale non-cog
2. Multi-dimensional observation scale for elderly subjects
3. Nurses’ observation scale for geriatric patients
4. The neurobehavioral rating scale
5. The nursing home behavior problem scale
6. **BEHAVE-AD**
7. Neuropsychiatric inventory (NPI-Q; NPI-C)
8. Revised memory and behavior problem checklist
9. Computer assisted behavioral observation scale
10. Clinical dementia rating scale
11. Behavioral syndromes scale for dementia
12. Dementia signs and symptoms scale
13. CERAD Behavior rating scale for dementia
14. Key behavior change inventory
15. Dementia Behavior disturbances scale
Specific Behavior Scales (n=29)

- **Agitation**
  1. Cohen-Mansfield agitation inventory
  2. Agitated behavior in dementia scale
  3. Pittsburgh agitation scale
  4. Brief agitation rating scale
  5. Overt agitation severity scale
  6. Disruptive behavior rating scales

- **Apathy**
  1. Dementia apathy interview and rating scale
  2. Apathy evaluation scale
  3. Lille apathy rating scale
  4. Irritability-apathy scale
  5. Frontal system behavior scale
  6. Apathy inventory

- **Aggression**
  1. Aggression behavior scale
  2. Overt aggression scale
  3. RAGE
  4. Ryden aggression scale

- **Depression**
  1. Cornell scale for depression in dementia
  2. Patient health questionnaire – 9
  3. The dementia mood assessment scale

- **Depression & Anxiety**
  1. Hospital anxiety and depression scale
  2. Depression anxiety stress scale

- **Anxiety**
  1. Rating anxiety in dementia
  2. Geriatric anxiety inventory
  3. Beck anxiety inventory
  4. The worry scale

- **Sleep**
  1. Pittsburg sleep quality index
  2. The sleep disorders inventory
  3. Epworth sleepiness scale

- **Wandering**
  1. Algase wandering scale
No measures specific to:

- Euphoria
- Hallucinations
- Irritability apart from aggression or anxiety
- Motor and verbal disturbances
Observational tools (n=10)

- Multi-dimensional Observation Scale for Elderly Subjects (MOSES)
- Nurses’ Observation Scale for Geriatric Patients (NOSGER)
- The Nursing Home Behavior Problem Scale (NHBPS)
- Computer Assisted Behavioral Observation Systems (CABOS)
- Pittsburgh Agitation Scale (PAS)
- Overt Agitation Severity Scale (OASS)
- Disruptive Behavior Rating Scales (DBRS)
- Overt Aggression Scale (OAS)
- Rating Scale for Aggressive Behavior in the Elderly (RAGE)
- Algase Wandering Scale (AWS)
Characteristics of Assessment Tools

- 38 (86%) tools specific to settings
  - Nursing home
    - The Nursing Home Behavior Problem Scale (NHBPS)
    - Brief Agitation Rating Scale (BARS)
  - Assisted living
    - Algase Wandering Scale (AWS)
  - Home care
    - Dementia Behavior Disturbance Scale (DBD)
    - Agitated Behavior in Dementia Scale (ABID)
  - Hospital
    - Hospital Anxiety and Depression Scale (HADS)
    - Aggressive Behavior Scale (ABS)

- # of items across all 44 tools = range of 3 to 64

- 9 (20%) tools dependent upon specialized assessor (e.g., nurses/trained clinician)

Examples of response categories

- Frequency of occurrence using different time frames:
  - Dementia Signs and Symptoms Scale (DSS): 43 items, 8 subscales Over the past month: 0=absent, 3=daily
- A few examined severity to person with dementia
- A few examined level of upset to caregivers
Implications

- Assessing behavioral symptoms using reliable and valid measures should be part of routine and comprehensive care of persons with dementia.
- Good news - Measures exist with strong psychometric properties
- Choice of measure should depend upon:
  - Clinical setting or research context
  - Specific behaviors of concern
  - Method of ascertainment (clinician versus nonclinician; self-report versus observation).

 Recommendation:
- Use general measure that captures a broad spectrum of behavioral symptoms as screen
- For a behavioral occurrence, followup with specific measure to obtain more nuanced understanding.
- Existing measures represent an initial step for behavioral symptom detection
- Only a few evaluate severity to patient and level of upset to caregiver
Implications Con’t

- Existing measures represent an initial step for behavioral symptom detection but:
  - Only a few evaluate severity to patient and level of upset to caregiver
  - Do not capture phenotype of behaviors
  - Do not capture context in which behaviors occur
- These 44 assessments start the process only
- Most common measure used in research/clinical context is NPI (NPI-C; NPI-Q)
Measurement Development Needs

- Systematically characterize risk factors for behaviors
- Systematic measurement protocol for characterizing behavioral occurrences and contextual features
- Determine congruence between items and caregiver knowledge/understanding and own characterization of behavioral symptoms
- Determine whether self-report by proxies accurately captures behavioral occurrences
- Advance measurement protocols:
  - Quick screens for risk
  - Quick screens for behavioral symptoms
  - In-depth followup of context of occurrences
  - Link assessment tools to potential nonpharmacologic strategies
  - Cross train health professionals and caregivers in identifying/assessing for behavioral symptoms
Non-Pharmacological Interventions to Reduce Agitation in Persons with Dementia: Considerations for Feasibility and Future Research

Rita Jablonski, PhD, CRNP, FAAN1, Andrea L Gilmore-Bykovskyi, MS,RN2, Natalie Baker, DNP, CRNP,1 Ann Bossen, PhD, RN,3 Darina V. Molkina, MS, RN4

University of Alabama at Birmingham School of Nursing1
UW-Madison School of Nursing2
University of Iowa3
University of Pennsylvania4
Workgroup Objectives

1. Evaluate the efficacy and feasibility of various non-pharmacologic interventions for nursing home residents with dementia in reducing behavioral symptoms, primarily agitation.

2. Identify relevant barriers to disseminating information regarding non-pharmacologic approaches to long-term care facilities via the Behavioral Health Toolkit.
Identified Areas of Need

• Practical guidance for providers that integrates both **efficacy** and **feasibility** of various non-pharmacologic interventions

• Information about what **types** of non-pharmacologic interventions or basic care approaches are likely to be effective for which symptoms

• Reasonable expectations regarding the **effect** of different interventions and the **duration** of those effects
Challenges of Disseminating NPI to Nursing Home Care Providers

• Limitations of existing evidence-base for non-pharmacologic interventions
  • Methodological
  • Small to moderate effects for short durations

• Constraints of the nursing home environment
  ✓ Assessment of feasibility
  • Training
  • Time
  • Cost
  • Personnel
Effective Non-pharmacologic Interventions

- Systematic reviews and review of recent trials of clinical-decision support interventions
- Non-pharmacologic interventions that were most consistently found to be effective were sensory stimulation interventions
  - Music therapy, hand massage/gentle touch, aromatherapy
  - Medical/Nursing Interventions
    - Pain treatment
    - Clinical-decision support interventions
Feasibility Assessment

- Feasibility was defined as the overall resources required to successfully implement the intervention including: staff training, staff time, the need for specialized environments or equipment, changes in regulations, and resident/family time requirements.
Interventions with strongest evidence-base and high feasibility

- Music Therapy
- Massage/Touch Therapy
- Pain Management
Interventions with strongest evidence-base and moderate feasibility

- Clinical Decision-Support Interventions
  - Serial Trial Intervention (STI)
  - Treatment Routes for Exploring Agitation (TREA)
- Aromatherapy
### Approaches and Responses to Specific Behavioral Symptoms

<table>
<thead>
<tr>
<th>Apathy/Withdrawn</th>
</tr>
</thead>
<tbody>
<tr>
<td>A person who is withdrawn or apathetic is someone who is socially withdrawn and is experiencing a loss of interest and motivation. Behaviors that reflect being withdrawn or apathetic might include sitting alone in one’s room, avoiding contact with others and making limited eye contact with others.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Agitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agitation is a broad term that refers to a variety of verbal, vocal or physical behaviors that appear distressing to the person with dementia or are considered inappropriate or unusual or are disruptive to others.</td>
</tr>
<tr>
<td>Common behaviors observed in a person experiencing agitation are restlessness, complaining, repetitive statements or repetitive movements and constant requests for attention.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Inappropriate or Disruptive vocalizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disruptive vocalizations are any verbal noises (screaming, yelling, nonsense talking, cursing) which are generally considered unusual, inappropriate or are upsetting to others.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Aggressive behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aggressive behaviors are actions that are threatening or harmful and can be physical in nature (hitting, kicking, biting, grabbing people or things, throwing things) or verbal (screaming, cursing, making threats).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Wandering</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wandering or pacing is sometimes referred to as “aimless” walking. This can also refer to restlessness or excessive moving around during the day or evening.</td>
</tr>
</tbody>
</table>

**Please select the behaviors for details**
Identification of Barriers to Dissemination

• Getting the information “out there”
  • Passive versus active diffusion

• Identifying and effectively communicating potential risks associated with interventions.

• Limited understanding of knowledge base of direct care providers regarding behavioral symptoms.
  • Direct care staff (CNAs) often perceive behaviors as “normal”
Discussion

• Urgent need for emphasis on potential translatability of interventions into practice.

• Study designs that allow for assessment of singular impact of intervention components (i.e. social contact/music) and individualization are needed.

• Development/evaluation of implementation and dissemination methods for clinical decision-support interventions, which may make wide-scale translation of these interventions more feasible.