Bridging the Gap:
Improving Transitions in Care for People with Dementia

Andrea L. Gilmore-Bykovskyi, PhD, RN
William S. Middleton Memorial Veterans Hospital
Geriatric Research Education and Clinical Center (GRECC)
University of Wisconsin-Madison School of Nursing

Financial Disclosures

Funding:
- National Hartford Centers of Gerontological Nursing Excellence
- National Institute on Aging

Goals

- Identify health-system problems and outcomes associated with poor quality transitional care
- Understand why people with dementia are at increased risk for experiencing poor quality transitional care outcomes
- Identify components of effective transitions from hospital-to-home with dementia
- Solutions for improving transitions between hospitals and nursing facilities for people with dementia
What is Transitional Care?

- A set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care in the same location

Coleman. JAGS. 2003

Outcomes of Poor Quality Transitional Care

- Medication Errors
- Care delays
- Inappropriate care delivery
- Increased use of emergency and ambulatory services
- Increased care costs
- Increased staff work strain and burden
- Patient/caregiver dissatisfaction and stress
- Re-hospitalization

High Quality Transitional Care is Important for All Patients

- Anyone can have issues in the post-hospital setting, sometimes very serious
Certain Factors Increase Risk of Rehospitalization

- Prior Hospitalization
- Patient Disease, Comorbidities
  - CHF
  - Pneumonia
  - MI
  - COPD, Vascular or Orthopedic Procedures...
- Patient Cognition
- Social Situation
- Discharge Setting

30 Day Rehospitalizations: A Major Health System Problem

- Affect 1 in 5 hospitalized Medicare patients
- Account for over $17.4 billion annually
- Major target in health reform

Dementia Patients Experience with the Care Continuum

- Majority of dementia care provided by informal caregivers in community
- Majority of patients with dementia will utilize nursing facility services at some point
- Transitions across care continuum are not necessarily linear
  - About 21% of people with dementia experience frequent transitions across hospital, home (with or without home care), and into and out of skilled nursing facilities
  - Majority die in their homes

Nursing Facilities Play A Critical Role

- 5 million discharges to nursing homes annually
- 1 in 4 is rehospitalized within 30 days
- Costs >$4 billion each year
- In Wisconsin, rehospitalizations from nursing homes account for $30 million annually

* Mor et al, Health Affairs. 2010;29(1):57-6

Dementia and Hospital-to-Nursing Facility Transitions

- Nearly half of Nursing Facility residents have some form of dementia
- Dementia increases re-hospitalization risk by 40%*

*Callahan et al., JAGS. 2012; 60(5): 813-820
Major Points

- Health system fragmentation contributes to poor quality care transitions
- Evidence-based transitional care programs decrease re-hospitalization but are not appropriate for nursing facility patients or people with dementia
- Effective clinician-to-clinician communication lies at the core of safe transitions, especially for dementia patients

The Problem:
Health System Fragmentation

Contributors to
Health System Fragmentation

- Organization of the health system into distinct, independent institutions ("silos")
- Lack of formal relationships/information systems between care settings
- Communication between settings is often poor
- Nursing facility patients move frequently between care settings
- Transitional care given little emphasis in traditional clinical training programs

Dementia Patients Struggle to Overcome
Health System Fragmentation

- Little patient/caregiver empowerment in hospital
- Often can not advocate for themselves
- May not have family/caregiver to advocate for the patient during the transition
- Completely reliant on the system to “get it right”

* Coleman. JAGS. 2003;51: 549-555.

Major Points

- Health system fragmentation
- Education-based transitional care services decrease rehospitalizations in those going home, but are largely inappropriate for patients discharged to nursing facilities
- Effective clinician-to-clinician communication lies at the core of safe transitions, especially for dementia patients

Transitional Care Programs Combat System Fragmentation

- Post-hospital home visits to teach patients about their care and conditions
- Decrease rehospitalizations by 30%

….But they are not appropriate for most nursing facility patients or people with dementia

* Naylor, JAMA, 1996; Coleman, Archives, 2005.
VA Coordinated-Transitional Care Program (C-TraC)

- Phone-based program
- Specially-trained RN nurse case manager
- Protocolized encounters
- Teachings based on theory of Spaced Retrieval*
  - Method of learning information by practicing recalling that information over increasingly longer periods of time
  - Applicable in early stages of dementia
- Caregivers involved, activated at each step


C-TraC Goals

1. Educate and empower the veteran/caregiver in medication management
2. Ensure the veteran/caregiver has medical follow-up
3. Educate the veteran/caregiver regarding red flags
4. Ensure the veteran/caregiver knows whom to contact if questions arise

*Kind, Health Affairs, 2012; Gilmore-Bykovskyj et al. 2014

Protocol: In-Hospital Visit

- NCM meets with eligible veteran during their hospital stay for a brief educational intervention
  - Introduction
  - Medical follow-up
  - Red Flags
  - Contact information
- Contact reinforced by a brightly colored ½ page handout documenting 3 red flags, date/time of next NCM call, date of next f/u appointment and contact information for NCM and triage nurse
Protocol: Telephone Follow-up

- Initial call is 48-72 hours after discharge with caregiver/veteran to reinforce
  - Medication management
  - Medical follow-up
  - 3 Red flags
  - NCM contact information
- Medication discrepancies or red flags prompt additional action
- Average 36 min per call
- Coordination with PCP

Percent of Veterans with Medication Discrepancy Detected at 48-72h by C-TraC

<table>
<thead>
<tr>
<th>Medication Discrepancy?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>47%</td>
<td></td>
</tr>
</tbody>
</table>

Percent of Veterans with Medication Discrepancy Detected at 48-72h by C-TraC

30-Day Rehospitalization Rates for Veterans in VA C-TraC Program During Baseline and Intervention Periods, Overall

<table>
<thead>
<tr>
<th>Quarter</th>
<th>Baseline (N=103)</th>
<th>Intervention (N=605)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>22%</td>
<td>25%</td>
</tr>
<tr>
<td>Q2</td>
<td>22%</td>
<td>24%</td>
</tr>
<tr>
<td>Q3</td>
<td>23%</td>
<td>24%</td>
</tr>
<tr>
<td>Q4</td>
<td>22%</td>
<td>22%</td>
</tr>
<tr>
<td>Q5</td>
<td>22%</td>
<td>22%</td>
</tr>
<tr>
<td>Q6</td>
<td>22%</td>
<td>22%</td>
</tr>
<tr>
<td>Q7</td>
<td>24%</td>
<td>22%</td>
</tr>
<tr>
<td>Q8</td>
<td>24%</td>
<td>24%</td>
</tr>
</tbody>
</table>

Q = 3-month period, p-value = 0.013
Estimated Cost Avoidance

- Total up-front program cost = $250/veteran enrolled
- Gross direct cost avoidance of $966,167 over 18 months
- After accounting for all programmatic costs, net cost avoidance of $1,225/veteran enrolled

Major Points

- Health system fragmentation
- Education-based transitional care services decrease rehospitalizations in those going home, but are largely inappropriate for patients discharged to nursing facilities
- Effective clinician-to-clinician communication lies at the core of safe transitions, especially for dementia patients

Hospital Discharge Summary

- Primary post-hospital communication tool
- Can dictate patient’s care for up to 30 days
- Care plans for nursing home patients are copied directly from the discharge summary
  - Medications
  - Diet
  - Activity
- Accreditation groups set minimal standards which most transitional care experts feel are inadequate
- Discharge summaries are often inadequate, slow to arrive at next setting of care

* Kripalani, JAMA, 2007; Dimant, JAMDA, 2003
Inclusion of Care Plans in Hospital Discharge Summaries

<table>
<thead>
<tr>
<th>Component</th>
<th>0%</th>
<th>20%</th>
<th>40%</th>
<th>60%</th>
<th>80%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pending studies</td>
<td>5%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Code status</td>
<td>7%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prognosis/diagnosis</td>
<td>9%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discharge medication list</td>
<td>4%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disposition</td>
<td>6%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instructions for follow-up</td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td>9%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapy Orders</td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activity instructions</td>
<td>6%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication to patient/family</td>
<td>1%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Kind et al., JGIM, 2011

Nursing Facility Nurses Want Better Quality Discharge Communication

- Focus groups of nursing facility nurses:
  - How do they transition care of hospitalized patients?
  - What are the primary challenges they face?

- Nursing facility nurses could not identify a single example of a 'good quality' care transition from the hospital to the nursing home

*King, AGS Abstract, 2012

Nursing Facility Nurses Need Better Quality Discharge Communication

- Communication of information.
  - Discharge.
  - Incomplete discharge effect.
  - Necessary information.

- Gathering of information.

- Defining Plan of Care
  - Work sheet
  - Discharge planning

- Discharge planning

*King, AGS Abstract, 2012
Information: Missing/Incomplete

- Necessary information that is omitted from discharge paperwork
  - No wound care instructions
  - Medication orders missing important details
  - No signed prescription for opioids
  - No plans for medical follow-up
  - “... there was nothing about the femur fractures... we had no idea ... if she was weight bearing or not weight bearing... (or) what we were supposed to be doing with them.”

Information: Conflicting

- Discrepancies among written discharge documents
  - Multiple medication lists and order sets which vary in content
  - “… we have three discharge summaries with all these different medication lists... it is just like, how are we safely supposed to take care of this patient?”

Information: Inaccurate

- Mismatch between the hospital’s report of the patient’s condition and the SNF nurse’s assessment on patient presentation
  - Mismatch between reported/observed cognitive status
  - Activity orders reflect a different level of assistance than needed by resident
  - Resident presents as physiologically unstable
  - “… a lot of the times we find when the person actually comes here they are a completely different picture than what we got in the pre-admission assessment.”
Consequences: Patient and Family

- Care delays, Inappropriate care
  - Pain medications delayed
  - Necessary equipment unavailable
  - Providing care without orders—wound care
- Patient safety compromised
- Increased rehospitalization risk
- Dissatisfaction with care during transition
  - “...we didn’t know what her mobility [was]. And we didn’t know if she was weight bearing... so we left her in bed for probably a week.”

Consequences: SNF Staff

- Increased work stress, frustration/inadequacy
- Guilt associated with patient harm
- Additional work effort
  - Delivering care ‘blindly’ while awaiting additional orders/clarifications
  - Unsuccessful attempts to clarify orders with multiple providers
    - “I had to talk to like 3 people just to find out who the doctor was... Well then I called that office... He wasn’t in. Nobody at the office could help me. It was like a week before we got some good information...”

Consequences: Facility

- Additional costs in staff time, wasted resources
- Decreased work satisfaction contributes to high turnover rates
- Patient/family dissatisfaction with care, perpetuating a negative facility image
  - “…It sends a terrible message to the patient and their family that we are ill prepared or that we are not capable of handling the acuity.”
The Gap for Dementia Patients

- Discharge communication in hospital-to-nursing facility transitions tends to be poor quality
- Transitional Care Programs improve the quality of transitions, but people with dementia are excluded from most of these interventions
- Transitional care needs of dementia patients not well understood

Goals

- Identify health-system problems and outcomes associated with poor quality transitional care
- Understand why people with dementia discharged to nursing facilities are at increased risk for experiencing poor transitional care outcomes
- Identify components of effective hospital-to-nursing facility transitions
- Discuss challenges and potential solutions for improving transitions between hospitals and nursing facilities for people with dementia

Challenges for Dementia Patients

- Individual/group interviews with nurses (N=33) employed at 8 SNFs in Wisconsin
- Goal: To identify factors that impact transitional care quality for people with dementia
Transitions for Persons with Dementia: Difficult, Resource-Intensive and Dominated by Behavioral Symptoms

- Successful transitions for persons with dementia required more time, more information and more resources
- Behavioral symptoms dominated the transition process for persons with dementia
- Behavioral symptoms were not consistently or accurately communicated, which put patients and the facility at risk for negative outcomes
  - “The more challenging the resident is…the more discrepancy we hear…it’s a big safety issue and the biggest struggle…we’ve learned the hard way—we just can’t, like we did in the hospital—we just call a doctor and get the Haldol…regulations are so different here…it’s chaotic for us, the people, this is their home—it upsets them too”

Facilitating High Quality Transitions for Persons with Dementia

- “Easing the Transition”
  - Engaged caregivers during transition
  - High quality discharge communication
  - Access to knowledgeable informants to establish personal/social history prior to admission
  - Additional time as social information is not readily available
    - “What makes it better (is) a lot of interaction with the family…personal history is extremely helpful. We never get that ahead of time.”
    - “…thing that helps with the transitions is that they come and set the room up ahead of time—and have the pictures hung—have the room set up—so that it looks like their room.”

Patients with Dementia Were Rarely Engaged or Prepared for the Transition Process

- Lack of engagement of the person with dementia worsens the quality of the transition
  - “Oftentimes they’ll just tell them ‘we’re going for a ride’ from the hospital…and unfortunately lie or fib to make the transition…cause the person with dementia…there is a lot of paraphrasing like that…. So unfortunately that (makes) some difficult transitions…the repeated questions, ‘can I go home now,’ ‘when’s my family coming’…trying to escape cause they probably thought they were going home”
Hospital Provider Perspectives

- Focus groups with 51 hospital providers
  - 11 MDs, 26 RNs, 5 discharge planners, 8 HUCs, 1 CNA

Challenges

- Sense of pressure to discharge
- Emphasis on acute care needs and placement criteria but little follow-through communication
  - “…I don’t think the social issues are really addressed... we always care for people with dementia as well as you know we should but I feel like there is a big push to like get them out of there and get them moving and do what we need to do. Its really systematic when they go to the nursing facility. I think sometimes a lot of the social aspects get pushed to the wayside.”
  - “…Nothing with, over a 24 hour period, they got to be completely chemical and mechanical free.”

Challenges

- Difficulty identifying caregiving support
  - “…with people with dementia I really try to encourage to have somebody there. I am usually talking with the family members to see if somebody can be there... but sometimes it seems like those people are kind of you know, I don’t know if the family isn’t close or a spouse is at a nursing facility as well. So they can’t be involved.”
Communication Barriers

- Inconsistent hand-offs to the nursing facility
- Hesitancy to share information
  - “That's the challenge I've found is that when they call back, they're looking for information that I know is in there. Not to be rude to the person that's calling, but to say, the information is in the packet so that I don't have to duplicate work, could you please look a little further before I, you know, I'll be happy to answer your questions, but could you please look a little further before I repeat everything that I spent two hours on preparing to send this patient to you.”

Discharge Summary Communication of Dementia-Related Care Needs

- Dementia Diagnosis/Cognitive Status
  - Dementia Diagnosis
  - Cognitive Status/Delirium/Onset and Features
- Dementia-Related Care Needs
  - Behavioral Symptoms
  - Antipsychotic Medications
  - Direct, 1:1 Supervision
  - Fall-risk precautions
  - ACE/Geriatric Psychiatry Consultation
  - HCPOA/Activation Status and Contact Information
  - Family Involvement/Contact Information

Discharge Communication for Dementia Patients

In a sample of patients with Medicare-confirmed dementia diagnosis, only 68% had a diagnosis of dementia listed on their discharge summaries.
**Major Points**

- Discharge communication during hospital-to-nursing facility transitions in general is poor in quality.
- Preliminary research findings strongly suggest under-communication of behavioral symptoms for dementia patients and communication barriers between staff in hospitals and nursing facilities.
- Lack of detailed information about dementia-related care needs may limit the Nursing Facility's capacity to implement adequate care plans and respond to changes in conditions, potentially increasing rehospitalization risk.

**Emerging Interventions**

VA Care-cOordination and eMpowerment of PAintients in System-to-System Transitions (COMPASS) Protocol:

**COMPASS Team**

Amy JH Kind, MD, PhD
Laury Jensen, BSN, RN/BC
Marilyn Bazinski, BSN, RN/BC
Michele Pawlowsky, RN, BSN
Rachel Roiland, RN, PhD
Melissa Hovaness, RN, BSN

Korey Kennelly, PharmD, PhD
Alice Huang

Jacque Porter, BS
COMPASS Goals

1. Improve system-to-system communications
   - COMPASS nurse schedules medication review with SNF 4-24h post-transfer
   - Direct phone line to COMPASS nurse available to SNF at any time during business hours for questions
   - Confirmation of key information transfer (opioids, etc.)

2. Empower patients/caregivers in system-to-system transitions
   - Coach patients/caregivers regarding what to expect in SNF, what condition-related red flags to watch for and how to respond

COMPASS Enrollment

- Launch at William S. Middleton Veterans Hospital in April 2013
- 231 enrolled veterans over first 12 months
- No patient refusals
- Discharged to 78 Unique SNFs

Percent of Veterans with Medication Discrepancy Detected at 4-24h by COMPASS

Medication Discrepancy?

- Yes
- No

45%
Medication Discrepancies

Top 5 Medication Discrepancy Categories
1. Analgesics
2. Endocrine agents (i.e., insulin)
3. GI medications
4. Psychiatric medications
5. Anticoagulants

Range 0 – 15 medication discrepancies per patient

Other Outcomes

- Strong stories of clear impact
  - Post-hospital arrangements for serial paracentesis
  - Patient behavioral distress post-discharge → urgent VA psychiatry management → no readmission
  - Family rapport building/support → palliative care/hospice
  - Activated/coached local community members to medically support socially isolated veteran(s) post-discharge
  - Opioid prescription tracking, security

What You Can Do Now to Improve Transitions for Dementia Patients

- Warm hand-offs for all hospital-to-nursing facility transitions
- Encourage accountability for every patient hand-off
- Family activation/engagement
- Involve the persons with dementia in the transition whenever possible
- Transparency regarding behavioral care needs
### Collaborators
- Amy Kind
- Barbara Bowers
- Rachel Richaud
- Melissa Hovanes
- Kory Kenney

### Funding
- National Hartford Centers of Gerontological Nursing Excellence (Gilmore-Bykovsky PI) Madison VA GRECC
- NIA Beeson Career Development Award (1K23AG034551; Kind PI)
- VA T-21 Funding: Innovative Patient Centered Alternatives to Institutional Care (Kind PI)
- VA Office of Rural Health Funding
- Wisconsin Partnership Program New Investigator Award (Kind PI)
- Community Academic Partnerships UW ICTR (1UL1RR025011) from the Clinical and Translational Science

### Thank you
Michael Gehring, Alice Huang, Lydia Lemmenes, Michelle Burns, Madison VA Hospital; participating facilities and nurse participants.