Standards of Care for Adults with Intellectual and Developmental Disabilities

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With Acknowledgements to: Molly Miller and Kathleen Smulkstys
Introduction

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“At both the individual provider and health systems levels, credible standards of health care, based on scientific evidence, are essential to improving the quality of health care for people with intellectual disabilities.”1

Closing the Gap was issued in 2002. 

*Developing credible standards of health care still needs to be done*
Call to Action

The Joint Commission on Hospital Accreditation (2010) *Advancing Effective Communication, Cultural Competence, and Patient-and Family-Centered Care: A Roadmap for Hospitals*

- Patient-centered standards
- Clear patient-practitioner communication

The Institute of Medicine (IOM) issued *Envisioning the National Health Care Quality Report* (2001)
- Assess care received by people with specific health conditions
Chart review – Patients with IDD

• 217 adults with IDD (non-psychiatric) 2008-2009
• Identified through secondary diagnoses codes for IDD
• Intensive (by hand) chart reviews 70 cases
Hospital Adverse Events - our chart review

• Hospital-acquired infection - 7.1%,
• Hospital-acquired decubitus ulcer - 4.3%,
• Post-operative complications - 4.3%,
• Medication reactions - 5.7%,
• Falls - 2.9%.
• Overall rate of 21.4% compares to a Hospital Adverse Events rate of 13.5% among hospitalized patients with Medicare.
• Rate hospital-acquired infection 42% > than 5% estimated nationally.
The context

• Practice at medical center - specific precautions for patients at high risk falls, skin breakdown, other adverse events
• Patients with IDD were placed on precautions to prevent adverse events- on average more than matched controls
• Some specialized services already implemented at the medical center3
• Patients with IDD experienced higher rates of HAEs than national averages5
• Thought necessary to have specific standards of care at the hospital
Jean is a 30 year-old woman with IDD & hearing loss admitted for cancer treatment. Attempt at another institution did not go well. First attempt at Rush did not go well.

At Rush we have a consultative service for patients with IDD.
The consulting staff worked with Jean, her family, service providers and staff on the unit to determine:

- Best way to communicate – communication boards, pictures, gestures
- Changes in environment so more calming (use of pinwheels for distraction, items important to patient were brought)
- Who should be present during procedures

The work was successful
Specific Standards of Care

Currently, there is little information on national standards for hospital care treatment for people with IDD

Need for established standards through the development of:

• Specialized services
• Information in electronic medical records needed to enhance services
  • Specific standards of care
The need for standards of care

- High health care needs & high morbidity
- Small, but important group
  - In 2 regions of New York- Older adults (40-79 living in community housing 4-15 people)
  - 6% hospitalized in one year

- Use ED more than those without IDD
  - 44 per cent of those with IDD visited ED at least once in 2 yrs: 8.5 per cent at least 5 times
  - 30% of the older adults in NY visited ED at least once in 1 year
The need for standards of care

• Fear unfamiliar people/procedures
• Difficulty communicating needs
• Lack of medical and nursing staff training
• Limited research
  – characteristics
  – services receive
  – quality and safety of care
The need for standards of care - Staff Survey 63 IDD RNs*

Experiences when patients with IDD in hospital

• **Results based on whether issue is a problem:**
  - **Communication**
    - Proper consent obtained from Guardian – Moderate or major 36.5%
    - Understanding of living situation -Major-41.3%
    - Understanding communication pattern Major-50.8%
  - **Environment**
    - Environmental overstimulation  Moderate-54%

*Acknowledgement DDNA*
Staff Survey Results

**Results based on whether issue is a problem:**

- **Behaviors**
  - Understanding level of functioning - Major-52.4%
  - Understanding what is frightening - Major-49.2%
  - Understanding what is calming - Moderate-46%

- **Caregiver Role Strain**
  - Family conferences when needed Moderate-38%
Nursing Care Plans: Selected Topics

Absence of existing nursing care plans & concerns about Hospital Adverse Events:

• Met with leadership of care plan committee
• Came up with areas needing attention
• Worked with librarian on specific recommendations based on evidence

Team of 4 students developed drafts - assistance from nursing faculty, care plan committee, librarian
Nursing Care Plans: Selected Topics

4 Specific Nursing Care Plans:

1. Enhancing Communication
2. Maintaining Safe, Accessible, and Comfortable Environment
3. Reducing Challenging Behaviors
4. Decreasing Caregiver Role Strain*

* Note that this will be the first care plan to address needs of caregivers: Felt by nursing and social work to be important issue
NURSING CARE PLAN: Enhancing Communication

Goal: The patient’s communication skills methods and skills will be assessed and maximized to facilitate nursing communication with patient

Ongoing Assessment:
1) Receptive Communication
2) Expressive Communication
3) Use of Alternative Communication Methods
4) Nonverbal Communication methods that may improve patient adaptation and cooperation
NURSING CARE PLAN: Enhancing Communication: An example

**Use of alternative communication methods**
- Communication boards
- Gestures

**Assessment: Non-verbal communication**
- Facial expressions
- Behavioral responses
**Goal:** The patient’s communication skills methods and skills will be assessed and maximized to facilitate nursing communication with patient.

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<th>Action/Intervention</th>
<th>Rationale</th>
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<td><strong>Ongoing Assessment:</strong></td>
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<td>1) Assess expressive communication</td>
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<td>• Presence of stereotypic behavior</td>
<td>Frequency and intensity of such behaviors may interfere, disrupt or act as a barrier to communication flow (Bunning, 2009).</td>
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<td>(repetitive behavior with lack of</td>
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<td>purpose and predictable feedback, i.e.</td>
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<td>hand-flapping, rocking back and forth)</td>
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<td>• Indicators of communicative intent</td>
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<td>• Various dimensions of communication—linguistic as well as paralinguistic phenomena (i.e. changes in pitch, stress patterns and intonation)</td>
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<tr>
<td><strong>Ongoing Assessment:</strong></td>
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<td>Indicators of communicative intent include (Bunning, 2009):</td>
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<td>• <em>Alternating eye gaze:</em> Person looks at you, the at something or something else, then back at you again</td>
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<td>• <em>Clear waiting for a response:</em> Person appears to have suspended any ongoing activity in anticipation of reaction from someone</td>
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<td>• <em>Active seeking of proximity:</em> Person moves to follow or sit close to someone</td>
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<td>• <em>Systematic variation in behavior:</em> Where no response is forthcoming, the person will repeat, elaborate or change behavior</td>
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<td>• <em>Persistence and intensity of behavior:</em> Person emits behavior with a number of individuals in different situations and with apparent forcefulness</td>
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Communication is not just about exchange of words through linguistic code (i.e. speech, writing or sign) but includes paralinguistic phenomena. These add to the meaning being communicated (Bunning, 2009).
Nursing Care Plan: Case Study

A Care Plan for Jean:

- Assess how Jean best receives information
- Assess how Jean expresses what he wants her caregiver to know
- Assess Jean's uses for alternative communication methods
- Assess Jean's non-verbal communication methods
Conclusion

Mission:
“To foster awareness, sensitivity and skills related to individuals with intellectual and developmental disabilities in order to promote partnership in the healthcare experience.”
Thank you for tuning in!


4. Ailey SH, Johnson T, Fogg L, Friese TR. Hospital adverse events among adult patients with intellectual and developmental disabilities. *Unpublished data, manuscript in preparation, 2012*


