Standards of Care for Adults with Intellectual and Developmental Disabilities

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Closing the Gap: The Need for Standards of Care

“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.”

- Surgeon General: *Closing the Gap* was issued in 2002.
- *Developing credible standards of health care still needs to be done*
The Need for Standards of Care

- 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
- Patients with IDD - higher rates of HAEs than national averages

Agreed: Specific standards of care for this population
Case Study Example

Jean is a 30 year-old woman with IDD & admitted for cancer treatment. She has mild hearing loss and some difficulty speaking. She was accompanied by mother, her primary caretaker. Two teen-age brothers at home.

- Attempt at another institution did not go well
- First attempt at Rush did not go well
  - too distraught and anxious to receive chemotherapy
Adults with IDD Committee at Rush

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

How can hospitals and health care providers (HCPs) partner with Jean and her supports to provide the best quality of care?
Addressing the Need

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
Areas of Needs – Surveys Rush Staff and DD Nurses*

2008 Survey of Rush staff (N= 292)^4
- 30% Frequent or regular contact adult patient with IDD
- Areas of concern
  - Communication
  - Calming patient during procedures
  - Assessing pain levels
  - Discharge planning^2

2010 Survey of 63 RNs (from DDNA)^5
- Moderate/Major issues when their clients hospitalized
  - Communication - understanding communication pattern,
  - Environment - calming, frightening, overstimulation
  - Behaviors - understanding behaviors are communication
  - Caregiver role strain - family conferences when needed
**Goal:** The patient’s communication skills methods and skills will be assessed and maximized to facilitate nursing communication with patient.

<table>
<thead>
<tr>
<th>Action/Intervention</th>
<th>Rationale</th>
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<tbody>
<tr>
<td><strong>Ongoing Assessment:</strong></td>
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<tr>
<td>1) Assess expressive communication</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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|  • Presence of stereotypic behavior (repetitive behavior with lack of purpose and predictable feedback, i.e. hand-flapping, rocking back and forth) | Indicators of communicative intent include (Bunning, 2009):
|  • Indicators of communicative intent |  • *Alternating eye gaze:* Person looks at you, the at something or something else, then back at you again
| |  • *Clear waiting for a response:* Person appears to have suspended any ongoing activity in anticipation of reaction from someone
| |  • *Active seeking of proximity:* Person moves to follow or sit close to someone
| |  • *Systematic variation in behavior:* Where no response is forthcoming, the person will repeat, elaborate or change behavior
| |  • *Persistence and intensity of behavior:* Person emits behavior with a number of individuals in different situations and with apparent forcefulness
| | 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).
|  • Various dimensions of communication—linguistic as well as paralinguistic phenomena (i.e. changes in pitch, stress patterns and intonation) | |
Nursing Care Plan Topics

Specific Nursing Care Plans:
1. Enhancing Communication
2. Maintaining Safe, Accessible, and Comfortable Environment
3. Reducing Challenging Behaviors
4. Decreasing Caregiver Role Strain
Communication: Use of the "R" Word

- "Spread the Word To End the Word" Campaign
- Use "people first" language
Nursing Care Plan: Enhancing Communication

**Goal:** The patient’s communication 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
Communicating with Jean

Assessment:
- Mild hearing loss
- Some difficulty speaking
- Recognizes pictures/uses to communicate
- Able to read some words, brief sentences
- Relies heavily on her caretaker, who understands her speech fairly well

Intervention:
- Hearing aid, speak directly and clearly
- Give time for response
- Write out simple sentences
- Talk to Jean/Use caretaker to mediate when needed
- Use communication board with velcro pictures about what will happen
Nursing Care Plan Topics

Specific Nursing Care Plans:
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Nursing Care Plan: Environment

**Goal:** Maximize patient's skills in coping with environment of hospitalization

**Ongoing Assessment:**
1) Environmental conditions that would improve patient adaptation/cooperation
   - Ex. Routines, favorite items from home

2) Environmental conditions that may decrease patient adaptation/cooperation
   - Ex. Lighting, noise levels, number of people in room
**A Healing Environment For Jean**

<table>
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<tr>
<th>Assessment:</th>
<th>Intervention:</th>
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<tr>
<td>Safety</td>
<td>Orient Jean &amp; her caretaker</td>
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<tr>
<td>Accessibility</td>
<td>Maintain routines such as medication times, takes meds with chocolate pudding</td>
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<tr>
<td>Security</td>
<td>Objects from home</td>
</tr>
<tr>
<td>Comfort</td>
<td>Use of touch</td>
</tr>
<tr>
<td>Distractors</td>
<td>Jean used pinwheels for distraction</td>
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Nursing Care Plan Topics

Specific Nursing Care Plans:
1. Enhancing Communication
2. Maintaining Safe, Accessible, and Comfortable Environment
3. Reducing Challenging Behaviors
4. Decreasing Caregiver Role Strain
Nursing Care Plan: Reducing Challenging Behavior

Goal: Maximize existing strategies to reduce behaviors interfering with patient care

Ongoing Assessment:
1) Behaviors may communicate unmet needs – pain, hunger, fear
2) Assess needs
3) History
   • Issues that may lead to behaviors
   • Behavior plan -Management strategies
   • Use of medications
     • Example: Will prn be needed for pre-medication before procedures
Decreasing Challenging Behaviors

Assess:

- Behavior interfering with care
- Use of medication
- Issues leading to challenging behaviors
  - Hearing impairment/IDD
  - Co-morbid illness

Examples of Interventions:

- Changes in environment, procedure handouts, support, foods
- Have medications readily available, routines
  - Earbuds, communication boards
  - Cancer diagnosis
Nursing Care Plan Topics

**Specific Nursing Care Plans:**
1. Enhancing Communication
2. Maintaining Safe, Accessible, and Comfortable Environment
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4. Decreasing Caregiver Role Strain
Nursing Care Plan: Decreasing Caregiver Role Strain

**Goal:** Communicate with appropriate caregivers regarding patient communication, reactions to environment, behaviors and plan of care

**Ongoing Assessment:**
1) Who are the caregivers
2) Guardianship status
3) Who patient/guardian wants communication to/from
4) Begin discharge planning with caregivers in mind
DECREASING ROLE STRAIN IN CAREGIVERS

Assess:

• Level of health care needs
  o Chemotherapy
  o IDD
  o Mild hearing loss
• Caregiver burnout

Examples of Interventions:

• Provide resources
  • May need resource information designed for low literacy, concrete thinking
• Stress relief, consultation, teach signs of depression/aggression, social work referral
• Discharge planning with caregiver in mind
Next Steps in the Care Plan Making Process

• Meetings with EPIC Committee
• Awaiting "Live Implementation" -- Tentative May 2012

• Ways to Determine Care Plan Implementation Success
• Usage, Satisfaction of nurses using care plan. Repeat chart review after in effect for period of time.
Patient/Family Education Resources

• Information for families on RUMC web page
• Additional information in electronic medical record
• Help Line 312 942-7806
  • Special Needs Buddies
  • Step-by-step pictorial preparation materials
  • Personalized communication boards
• Prehospitalization tours [http://www.rush.edu/rumc/page-1234554423845.html](http://www.rush.edu/rumc/page-1234554423845.html)
• Consultation patients not coping well

[http://www.rush.edu/rumc/page-1298329542406.html](http://www.rush.edu/rumc/page-1298329542406.html)
Conclusion

• Results support that health care providers need additional support in caring for people with ID
• Formalized nursing care plans
• Dissemination of nursing care plans

  Manuscript
  Publication/dissemination of care plans

• Standards of care related to many specific conditions/types of care needed such as:
  Protocols for ED
  End of life care
  Preventive care
Thank you for tuning in!


